COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS LEGISLATION COMMITTEE

Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011, Personally Controlled Electronic Health Records Bill 2011

MONDAY, 6 FEBRUARY 2012

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SENATE

COMMUNITY AFFAIRS LEGISLATION COMMITTEE

Monday, 6 February 2012

Senators in attendance: Senators Di Natale, Furner, McKenzie, Moore and Siewert

Terms of reference for the inquiry:

To inquire into and report on:

Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011, Personally Controlled Electronic Health Records Bill 2011

WITNESSES

HAMBLETON, Dr Steve, President, Australian Medical Association

Evidence was taken via teleconference—

Committee met at 08:06

CHAIR (Senator Moore): I declare open this public hearing and welcome everyone who is present today. The Senate Community Affairs Legislation Committee is inquiring into the Personally Controlled Electronic Health Records Bill 2011 and the related bill, the Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011. Today is the committee's first public hearing for this inquiry. These are public proceedings, although the committee may agree to a request to have any evidence heard in camera, or may determine that certain evidence should be heard in camera. I remind the witnesses that in giving evidence to the committee they are protected by parliamentary privilege. It is unlawful for anyone to threaten or disadvantage a witness on account of evidence given to the committee and such action may be treated by the Senate as contempt. It is also a contempt to give false or misleading evidence to any committee. If a witness objects to answering a question, the witness should state the ground upon which the objection is taken and the committee will determine whether it will insist on an answer, having regard to the ground which is claimed. If the committee determines to insist on an answer, a witness may request that the answer be given in camera. Such a request may also be made at any other time.

I welcome Dr Steve Hambleton from the Australian Medical Association, via teleconference, to today's hearing. Dr Hambleton will be talking from Brisbane.

I put on record that Senator Sue Boyce, who has had a great interest in this issue, has been unable to attend today due to illness. For all witnesses: we are expecting questions on notice from many people on the committee, but you will definitely be getting questions on notice from Senator Boyce. I thought I would put that on record at the opening of the proceedings.

In the room, Dr Hambleton, you have me—Claire Moore from Queensland; Senator Mark Furner from Queensland; Senator Rachel Siewert, the Deputy Chair, from Western Australia; and Senator Bridget McKenzie from Victoria. As a regular witness at our hearings you are aware of information on parliamentary privilege and the protection of witnesses. We have your AMA submission, which is No. 43. Please state the capacity in which you come to talk with us today and then open with any statement you would like to make, after which we will go to questions.

Dr Hambleton: I am the President of the Australian Medical Association and a specialist general practitioner in Brisbane. Thank you very much for the opportunity to appear before you today and for allowing me to give evidence over the phone from Brisbane. I start by saying that most AMA members are enthusiastic about using a shared electronic health record. They know that with the right system they can improve the patient's healthcare experience. The right sort of shared record system will help doctors deliver better care. They will have important information about their patients to help them to make good clinical decisions. Some of my elderly patients can tell me the strength and the name of their tablets and some can tell me the colour and the size of their tablets, but many others cannot. With new patients I have to question them about that and it takes longer to work out what medication they are on. With a good system I could confirm my assumptions by reading what the last doctor prescribed. This would be an improvement over the current situation. A good system will save extra costs for repeat tests. It will save time chasing down results and treatment can happen more quickly. This is why the AMA supports the long-term goals.

However, the proposed system could be improved to make it more useful to treating doctors. The reality of patients having to opt in means that when doctors look for a patient's record they will often find there is not one. Our submission highlights that we do not know what the opt-in rate will be, but we have given some examples in other areas where the opt-in rate is quite low. If doctors were to find that most of their patients had a personally controlled electronic health record, they would be more likely to keep using the system. They will quickly become reluctant users if they look for and cannot find a record for their patient. For better patient care, the AMA advocates an opt-out system that provides treating doctors with access to key clinical information to inform their clinical decisions.

We are also uncertain about how much of the system will be available on 1 July 2012 and how well the system will be connected to healthcare providers. The parliament may pass this legislation and some of the technical work might be finished, but there will not be a benefit for patients and medical practitioners until we get appropriate, interoperable, tested and affordable practice software that is available for providers to connect up to the system.

In terms of the legislation itself, the AMA is concerned about the administrative impact on medical practices. Medical practitioners who decide to use this system will have to adapt their clinical workflows and train their staff to work within the requirements of the legislation. Doctors will have to consider the impact of this additional workload and the changes to clinical workflow on the fees they charge their patients. The biggest impact will be on general practitioners. GPs will take on the role of the nominated healthcare providers and create and maintain the shared health summary. This is a key feature of a personally controlled electronic health record. This is a very specific clinical task and GPs will work with their patients to ensure that a complete and accurate summary is available to be used by other healthcare providers in their clinical decisions. That will take time. It is only reasonable that patients should receive a Medicare rebate for this very important clinical service. The personally controlled electronic health record system truly works to improve patient care and reduce waste and risk in health care. I am happy to take questions.

CHAIR: Thank you, Dr Hambleton.

Senator SIEWERT: Can I pick up on your last comment that patients should receive a rebate. How would you see that operating?

Dr Hambleton: We have to look at the extra tasks that are required because it is going to take doctors a bit of extra time. There are two kinds of extra time that are going to occur. One is searching for the record and sifting through the record to gather information that is going to be appropriate for the consultation at hand. That is part of the information we use to judge what to do with our patients now, but there is going to be another place to look so it is going to take us a bit longer. The second one, and the main one, is getting the information up in the first place. Taking the information that we have already got and cleansing that data—which means deleting information that is not up to date or current, perhaps even coding that data so it can be shared electronically—is going to take extra time. Unless we can incentivise that time in some way, or recognise that time as an expense in some way, it is going to take longer to get the momentum going in using this electronic record. As I said earlier, it is going to help us ultimately but getting it started is a problem.

Senator SIEWERT: So you are proposing two levels of rebate—one initially and one subsequently. Is that correct?

Dr Hambleton: I think that the AMA will come back with some more detailed analysis of what the workflow is going to look like. I guess we were a little bit in the dark about what the Wave 1 sites have found in terms of their extra workload to try and participate in this process. It is going to be a data-cleansing upload problem and I guess it is going to be a data search and utilisation problem. So there are two clear areas where there is going to be extra time spent.

Senator SIEWERT: I have a couple of follow-up questions. First, how many doctors would you say already have electronic records in their own clinics or practices? I know mine certainly does.

Dr Hambleton: Very, very large numbers of doctors have electronic records. I guess the problem is that all those systems are slightly different. The one I use in my practice, for example, records text copies of past history. It is not coded.

CHAIR: Could you just repeat that? I missed the word that came before 'records'. You said the one in your—

Dr Hambleton: The software in my practice does record past histories, which are actually not coded. So when we want to share that background information—for example, the fact that the patient has asthma, diabetes, heart disease or heart failure—we need the computer system to be able to code it so that it can interface with other systems and within prescribing software to assist doctors in their work. There are many systems set up differently, some with different coding systems, and all of which at the moment do not talk to each other well. I guess that is why we have a protocol, but unless those systems are able to be used electronically it is going to be very difficult to provide a health summary for other people to share that is meaningful.

Senator SIEWERT: You mentioned that there is the cost of setting it up and then you also mentioned additional funding support or a rebate for use of the system, if I understood what you said correctly. How does it differ from when you go in to see your doctor and your doctor looks up your records in the first place?

Dr Hambleton: It is yet another place where we should be looking for information. It has been described—I think we put it in our submission—as information chaos. There is a lot of accurate information—some of good quality and some of poor quality—that we need to sift through to try to make the decision for the patient. If there is an electronic health summary on a personally controlled electronic health record, it will be another place we need to look to make sure we are up to date. When our software can interface with the shared health summary and automatically update, those search times I am talking about will come down. But inside the personally controlled electronic health record there is going to be information potentially added by the patient—their allergies and

medications. We will have to analyse each one of those pieces of information to see whether they are more current or less current than what we have. There are going to be summaries of events where the patient has seen another practitioner that may have information that is relevant. So it is going to be another search location, often with very rich information, that at the end of the day we are going to have to search and make sure we are aware of. Software solutions are going to help us here, but at the moment they do not exist for much of general practice. We do have electronic records but, once again, we need them to be able to talk to each other properly.

Senator SIEWERT: Did you say that GP clinics do not have that software—that the software is not available?

Dr Hambleton: The communication between the personally controlled electronic health record health summary and what we have on our desktops. My software in my practice, for example, does not communicate externally. Unless I have a piece of software that can do it in a smooth way, it is going to take me extra time.

Senator SIEWERT: Okay, thank you. Can I ask about the definition of health care. You will be aware that some submissions have suggested that it is not comprehensive enough or it differs from private health insurance legislation. Do you have a view on that?

Dr Hambleton: We have not looked at that specifically. We could come back to you with a clearer answer to that question on notice, if you wish.

Senator SIEWERT: That would be helpful. The question is: do you think the definition is satisfactory and do you think the difference in definition between this legislation and private health legislation is going to be a problem?

Dr Hambleton: All right, I will undertake to do that.

Senator SIEWERT: Thank you. You also touched on the issue of the 1 July start date. Do you think that, if all goes according to plan, the start date is going to be significantly problematic?

Dr Hambleton: Yes, I certainly do. I think that we have a real problem with the level of expectation that is, I guess, set and out there and the actual ability for doctors to deliver on that day. It is very close now to 1 July this year. Even if the legislation is passed and the framework is available, there are many, many, many practices that will simply not be able to communicate with that piece of software. I guess many practices would also be very concerned about the risks to the practice, particularly in relation to recording who has access to the record and when, because our software does not do that. If patients come in on 1 July and say, 'I'd really like to have a personally controlled electronic record; I'd like you to upload a summary,' I really do not think we are going to be able to do it. In fact, I do not think very many practices at all will be able to do it. It will be a very slow start.

Again, the AMA is looking at the target, and it may be some years down the track. We really do believe this is worth supporting, but I think we need to reset expectations both in the profession and in the public so that we understand that there is not going to be a comprehensive personally controlled electronic health record available or indeed accessible by most software on that day.

Senator SIEWERT: Thank you.

Senator FURNER: Doctor, in your introduction you mentioned the time it takes you to identify medications and sometimes allergies of your patients, due to their lack of knowledge of what particular medication they might be on. On average, how long would it take you to identify the particular circumstances of someone's medication?

Dr Hambleton: That is a really good question. The broader answer is that, if we can share accurate, up-to-date medication lists, it will save lives. It is so important to get the medication and the allergies correct so that we do not prescribe things that people are allergic to and we do not prescribe things that people are sensitive to. Coming back to your question about how long it takes, with a new patient, particularly an elderly patient, this can be nearly half of the consultation. You can take up to 10 minutes to say to patients, 'Can you tell me what you are on at the moment?' They will say, 'Well, I'm on five medications.' 'All right. What's in the morning and what's in the afternoon?'

Our problem at the moment in Australia is that there are original drugs and generics, and often patients will know one or two or even three different names for the same medication. It is very difficult for them to say to you, 'This is exactly what I'm taking.' I would actually say to you that there are probably some doctors who do not know the generic names of some of the drugs. There are 12 or 13 different forms of simvastatin, for example. Sometimes patients say to me, 'I'm on this drug,' and I have to look it up to find out what it is and make sure it is not the same as something they have already told me. So the information search for medications can take us quite a bit of time. When even a regular patient goes to hospital there are often medication changes and, unless we have a piece of paper that they carry back with them, often from the pharmacist on discharge from hospital, piecing

together which medications were stopped, which ones were started and whether there is temporary medication that needs to run for two weeks and then stop again is very difficult. That can be a major part of the consultation, just getting the medication and even the allergies and potential side effects correct. On average? It is very hard to say. For a new patient it would be at least five minutes. In many cases, for elderly people on multiple medications, it is 10 minutes.

Senator FURNER: Therefore, if we had an e-health system in place currently, no doubt, if that patient opted in to be an applicant, they would not have that particular issue. Your time with them would be certainly a lot more efficiently spent on checking their current health as opposed to checking their history.

Dr Hambleton: I agree entirely. If we did one thing on 1 July and said, 'All right, we're going to start slowly; we're going to share allergies and medication lists,' we would both save lives and save time ultimately, once we get a sufficient number of records up and available. Most people are pretty happy to share their medication lists. If the pharmacist knew it was accurate, we knew it was accurate, the guy in the emergency department knew it was accurate and even some of the allied health professionals who see the patients knew it was accurate and up to date, it would be a huge benefit, and I think that is part of the reason why the AMA is so keen on making sure that, at the end of the day, we get something that is useful.

Senator FURNER: You also commented on the opt-out arrangement. How would you see that proposal operating, if that were suitable?

Dr Hambleton: The issue we have is the protection of patients' privacy and the setting of controls, and this legislation has numerous levels of control that individuals can set. But the people who are going to most benefit from this legislation are the ones who really want us to share their information—our elderly; Indigenous Australians, I guess; people with complex and chronic disease. They just want us to get the message shared between providers. There is a great trust between providers that they will treat that information with the sensitivity that it deserves. If it were an opt-out process, all of those people would not have to create themselves a record. They would not have to worry about the access controls. All of those people would benefit.

If there were persons with particular privacy concerns and they opted out, it would allow all those individuals who could most benefit from this process to have a record. It would mean that, when the doctor searched for a record for somebody who has a chronic disease, the chances would be that there would be a record there. We could certainly update and add information to those records to make sure it was accurate. The confidence that a record exists is going to be part of the reason that people get engaged in this process.

One of our concerns is that, when someone gets to a new doctor or an emergency department, the first few searches—which are going to be in the next year or so—are going to be fruitless and that there will not be a record, there will not be any summaries and there will not be any assistance. The problem is that extra time searching for something that does not exist is going to make people more reluctant to bother searching in the future. Until we get a critical mass of people who have accurate information, the value of this, the cost savings, the duplication savings and the concerns are going to take longer to realise.

Senator McKENZIE: My question primarily went to the opt in or opt out, which you have dealt with in your previous answers. My other issues are on the definitions in the bill and the AMA's perspective on the concept of health providers and defining what a health provider is. Obviously we are looking at a more holistic approach to health provision in Australia as we go forward. I would be interested in the AMA's perspective on the definition of health provider in the legislation.

Dr Hambleton: We certainly acknowledge that we need a modern approach to health care. We have burgeoning chronic disease. We need to have a team approach. I am not completely familiar with that particular sentence about what the definition of health providers is, but all registered health providers need to be able to access some summary information. They have different needs. They do not necessarily need the same depth of information that is available, but we need to be able to share that. You cannot treat a diabetic today properly without having a podiatrist, without having a dietician or without having even an endocrinologist sometimes involved in the patient's care, and all of those people need access to a record that is going to assist with that care. So we do embrace the modern approach to patient care. We certainly understand that there will be many more people accessing the information than just medical practitioners. Certainly nurses and Aboriginal healthcare workers form a key part of the health system, as do many, many allied health professionals, to the benefit of patients.

Do you want me to have a look at that particular issue about the definition? I can come back to you with that, Senator.

Senator McKENZIE: That would be fantastic. I would really appreciate that. Secondly, I hope you are able to flesh out for us a little more detail around the medicolegal concerns that you outlined on page 8 of your submission, specifically around the consultations that the AMA has had with the medical indemnity insurers and some of their concerns with the legislation.

Dr Hambleton: Yes. One thing the legislation does is significantly change, to some degree, how practices will operate. For example, at any one time on the front desk in my surgery, there are four or five different computers that are open and working. There are four or five different staff members. One of those staff members may have logged in and started up every one of those computers, so it might be one login but there are five individuals. As the day progresses, probably every one of those individuals uses every computer.

Under the way the PCEHR operates, the practice is expected to be able to supply to the system operator exactly who accessed the record at which particular time. Unless there is a software solution for that, it is going to cause us an enormous amount of extra work to manually write down who accessed what at what time. Some of those things might be just to access a record to check that a health summary has been uploaded or that there is a medication list available. It may not be an expert looking at it trying to analyse the information but someone looking just to establish that it actually exists. Patients will phone up and say, 'I'm going to come and see the doctor and I saw someone yesterday.' Is that record uploaded? There are lots of things that we are expected to do and, if you do not do that, then there are substantial penalties.

I think that is one of the keys. Until there is actually a piece of software to solve that problem, to enable the system to record who is accessing the record, I think that is going to be a problem. The definition of what 'inappropriate access' is, what 'storage' means—there are a whole lot of things about the way the system is written. We are not talking about hacking, because everybody agrees that hacking is illegal, that it should be tracked and that it is a problem. But, when you have a legitimate ability to access records, if you view, modify or access a record, that should be recorded. What are the differences between collection of information and use of information or between authorised downloads and unauthorised downloads? At the end of the day, I often sit in my surgery and read information from specialists. I will think, 'That's something that I want to keep in my health summary on my own records,' and I will access people's records. I might access another 10 or 12 records at the end of the day, and those patients are not even in the practice. But I am hoping that the information that I add or subtract or the reminders that I put in there are going to be useful to them next time they walk in the door.

So there are a whole lot of things that we do with records that we will now need to record—why we were there, when we were there—and the complexity of the penalty provisions and the severity of those are a concern. Really, we are saying that we have to put these in the background, put them on hold or wait until there are some software solutions to make that an easy process.

Senator McKENZIE: On the software solution, I presume you have given all that feedback to the development of the specifications of the software that is going to be used.

Dr Hambleton: Yes. There is a whole lot of clinical leads within the system at NEHTA which really need to be accessed appropriately. Recently, I have said that some of those clinical leads have been very concerned that even their suggestions inside the system are not being listened to. We are trying to provide as much constructive feedback as we can, and those doctors are as well. But when a software engineer designs something, there is going to be a clinical impact. We have got to make sure that it remains clinically driven and can fit in with the workflows as much as possible. Because changing the workflow, while it can happen and is sometimes for the better, often takes a bit of extra time in the beginning. It is the difference between are we reengineering what we are doing in medicine or are we just computerising it. If we are simply doing the same thing as we are doing now, but doing it with a computer, we may not get the benefit. If it leads to a reengineering and a simplification of what we are doing, I think we will see some benefits ultimately.

Senator McKENZIE: In their submission, the Australian Medical Students' Association suggests that the difference in the rights and responsibilities of medical students and registered medical practitioners is lost in the bill. I am just wondering if the AMA has a perspective on that.

Dr Hambleton: I think student access to records is really important. We now have a registration system for students as well. I think we have got to understand the place of students in our system, both for their own benefit and for the benefit of patients. They really do need to be recognised as healthcare providers in their own right and have access to records, and not be concerned about being caught by provisions of privacy. Clearly, when anyone else accesses a record they need to be there for a reason. But the place of students is very important, because they can often spend more time with patients. They can often have a different perspective, which can actually help with that team approach. I do believe students need to be recognised for their important place. I will actually have

a look at their submission and see what their concerns are. If you would like me to provide some further feedback, I would be happy to.

Senator McKENZIE: That would be fantastic.

CHAIR: Dr Hambleton, you know that in this inquiry we are looking at the role of NEHTA, generally, as well as the legislation. I am interested in whether the AMA has any statement you would like to make about the interaction with NEHTA and the engagement and, also, your comment in a previous answer that you try to give closer to an effective feedback. Would you like to put something on record about NEHTA as an organisation, and its future and its past?

Dr Hambleton: It would be fair to say that NEHTA had a slow start. The level of clinical engagement was a concern in the beginning. The level of clinical engagement has improved substantially. There are a number of clinical leads that work within NEHTA. There is certainly much more interface with those doctors. We absolutely have to see a solution that is clinically driven to make sure it can actually recognise the realities of practice, be it pathology practice, radiology practice, general practice or specialists. The fact that there is a whole series of clinical leads is very important. To allow those clinical leads to interface with their colleagues and with the colleges has been very good. The problem I see with NEHTA is that of the complexity of what we are trying to offer. They were expected to pick one system out of all the systems and develop communication protocols that we could all share. It is such a complex environment; we saw recently, for example, some of the wave one and wave type two sites had to be turned off for a short period of time. The quality of NEHTA is not so much that there was an error, it is how you respond to it. Recognising it now rather than when we were trying to roll something out was very good. Making a decision to stop the development is a good one. I am very pleased that NEHTA (1) had the systems in place to recognise it, (2) took action quickly and (3) is communicating with its clinical leads and also with the profession. We can see the benefits four or five years down the track, and I think it is going to be that long. We want to be engaged with the process and certainly the College of GPs, the AMA and the major specialist colleges all can see the benefits ultimately. We are thirsting for more interaction, more engagement, to make sure that the money we have spent is delivered well.

In terms of the future, the decrease in funding is very significant, from hundreds of millions of dollars to tens of millions. We are still looking at that interface time in the next couple of years where the protocols are set—the software that GPs, specialists and hospitals are using is going to have difficulty communicating. Somebody needs to be sitting there to keep driving that momentum.

CHAIR: And the role of Medicare Locals?

Dr Hambleton: The senators will be aware that the AMA has made some consistent statements about Medicare Locals. We need to make sure that those entities which support healthcare delivery in the non-public hospital environment actually recognise that the engine room of health care is the general practitioner, and they have to be focused on supporting GPs to engage with this process. When I have spoken to some Medicare local leads, they say: 'We're not divisions. We're not here to support GPs directly.' But, unless Medicare locals actually recognise that in fact they are there to support general practitioners and particularly to support this upgrade of IT, we are not going to get the outcomes as fast as we otherwise would.

What we have said is that we would like to see a majority of GPs on the boards of those Medicare locals because that will inherently make decisions they make sensitive to the needs of general practice. And certainly, at least initially, we cannot afford to have GPs disenfranchised from the Medicare local. So I think there is a great opportunity for the Medicare locals to be supportive in this area, but we have to make sure they are better defined. The public do not understand what they are. I think that the message needs to be sold a lot better. We have to make sure that whatever they do is actually responsive and sensitive to the needs of the general practitioners that are within their boundaries.

CHAIR: The last question, Dr Hambleton—and you will receive a number of questions on notice; you have already self-identified a couple—is about the issue that has been raised both by the AMA and by the consumer network about ownership of the records. You talked in your evidence about consumers having access and putting information up. In your submission from the AMA there was a little bit more detail about concern about the ownership of medical records, and certainly that was a key aspect of the consumers' submissions. Is there anything you want to add about that?

Dr Hambleton: I think that having the patient more involved in their care is a very good idea. This shared electronic health record is not going to be what the doctors keep on their desks or what the hospitals keep in their electronic systems—or paper or electronic systems, as it turns out. This is a piece of information that is going to be shared and completely available to the consumer, and I think that engaging them in their health care is actually

important. That is not such a problem. It is making sure that the information there is accurate and that all consumers—particularly those who want to access the controls which can turn on and off—understand the impact that is going to have.

As I say, if we step back a little and say, 'What are the pieces of information that would really make this work quickly?' it is very simple. It is medications, as we have said; allergies; diagnostic imaging; pathology results; hospital discharge summaries. If we share nothing but that—and there is probably not a lot of sensitivity in those things—we are going to have constructive outcomes.

Owning the records and having the ability to delete information is going to subtract from the benefits of the record. When patients and doctors sit together and agree to share something, it just decreases confidence in the next doctor that the information is accurate, if the patient subsequently decides to delete or remove information or decrease access to a particular practitioner about particular areas of information. Control and ownership are very important, but the impact that those decisions have on personal health care and, broader, confidence in the system entirely, I guess is the reason we have raised some concerns. We just have to get this up and running. It would be fair to say that the rest of the world is watching us to see whether we can do it, because other countries have not been able to do it. I guess the AMA and the colleges just want to make sure we get this thing working to benefit patients.

CHAIR: So the process is to get it working and work it out?

Dr Hambleton: Well, let us start with the simple things that everyone is comfortable with and then let us build on that.

CHAIR: Thank you very much, Dr Hambleton. Again, my apologies for keeping you waiting.

Dr Hambleton: Thank you.

MWAITELEKE, Dr Pendo, Principal Policy Officer, Aboriginal Health Council of Western Australia

PATEL, Mr Mitash, Information Technology Officer, Aboriginal Health Council of Western Australia

SCATES, Mr Simon, Information Technology Consultant, Aboriginal Health Council of Western Australia

LOWE, Ms Shelagh, Manager, Policy and Programs, Services for Australian Rural and Remote Allied Health

WELLINGTON, Mr Rod, Chief Executive Officer, Services for Australian Rural and Remote Allied Health

[08:46]

CHAIR: I welcome the next witnesses from Services for Australian Rural and Remote Allied Health and the Aboriginal Health Council of Western Australia. Good morning, everyone. Information on parliamentary privilege and the protection of witnesses and evidence has been provided. If you have any questions, someone from the secretariat will be able to help you through that.

We have SARRAH's submission, which is submission No. 8. Thank you very much. We also have AHCWA's submission, which is submission No. 13. Thank you very much for the work you have put into giving those to us. I will invite each of the organisations to make an opening statement and then we will go to questions.

Dr Mwaiteleke: I will make an opening statement. My colleagues, who are IT experts, will be able to answer some questions as required. If there are questions that involve policy clarification, I will be able to respond to that.

As the Aboriginal Health Council of Western Australia we are very thankful to the Senate Standing Committee on Community Affairs for the opportunity to present our response to this particular inquiry. We also want to make it very clear that AHCWA remains very interested in continuing engagement with the government and with NEHTA in fostering productive collaborative effort, ensuring that, hopefully, the personally controlled health electronic records needs of our Aboriginal people are taken into account so that when it comes to the implementation process hopefully we will be fully in there and that our sector will be able to participate.

We also very much see that the proposed legislation has great potential to enhance better patient outcomes in Aboriginal communities. Our sector also sees that this has a role to play in terms of Closing the Gap. It is also very clear from what the government is saying they are trying to do that this particular legislation and the proposal would support people who are in remote and regional centres. Just for reference, because I am going to be referring to quite a number of issues to do with our remoteness, I brought this along with me.

CHAIR: Thank you, very much, Doctor. We will table that document, with the agreement of the committee. I am sure Senator Siewert will be able to quote you kilometre distances.

Dr Mwaiteleke: Our member organisations and the Aboriginal population groups are spread across a very broad landmass. That has direct ramifications if you are talking about a PCEHR legislation. We are also talking about IT communications infrastructure, so issues of infrastructure cannot be avoided. They have got to be discussed, they have got to be explored, they have got to be addressed if the Aboriginal communities that live in regional and remote areas are going to be able to access these particular provisions as a universal service.

AHCWA takes this issue really seriously. In recent times AHCWA managed to procure some resources to get an auditor on board. This was not just specific to electronic records but it was in consideration that we live in contemporary times and e-health and issues of tele-health are quite important to us. AHCWA got Mr Scates to come in as an auditor to look at the statewide needs of Aboriginal medical services across the board. He is audit work is in progress. He has been auditing the infrastructure in the Aboriginal medical services.

What is also very clear from the sector and some of the preliminary information that is coming from the audit is the fact that the National Broadband Network is not going to reach some of our areas. It is also my understanding that even some of those areas that will be covered by broadband, unless we know the extent of that coverage, it cannot be taken for granted that the data demands of PCEHR are necessarily going to be catered to by the infrastructure that is going to be in place.

Also what is very clear to us is that, even given a best-case scenario, there are certain areas where the National Broadband Network will not be available. We are then of course going to continue to depend on satellite technology. The fact that we will depend on satellite technology does not mean that automatically we need to buy out of PCEHR. That is why we are saying we are really keen to engage and in terms of engagement there is work to be done there because we understand that there are some IT solutions. With the current level of technologies, there are certain interfacing technologies that can be used. That needs an upgrade and a whole range of things to operate at a level that is higher than what is operating now. The relevance of that really is that legislatively it

seems to us sensible that budgetary allocations be embedded in the legislation. Bs providers of Aboriginal medical services we do not have the funding for PCEHR. We do not have funding for IT. Even the funding, for example, to secure the services of an auditor, we had to work our way around. We are not getting any funding from NEHTA. We are not getting funding from anyone specifically to look at those issues. We are trying within our small budget to find ways ourselves to try to express the needs that we have. When you implement legislation of this nature—and the government and the parliament are talking about e-health and about engaging Aboriginal communities—we think it is sensible, really, that it should be supported with budgets.

Senators will probably be aware of a whole range of other areas of human services provision. The healthcare area is also moving towards activity based funding. So little of the funding is really focusing on a particular activity that the clinician or the provider, whoever it is, is providing, which means that as we shift much more away from co-funding, there is less funding for administration, less funding for training and less funding for management. We support PCR. We think it is going to be really useful but we think it is very important that there be some recognition with regard to funding. The funding that is there is not allocated to these activities, but funding is provided not just for implementation of PCR but also for preparation for the PCR legislation.

The issues of integration and consistency in software functionality, which I think we mentioned in our submission, are really key. A lot of our people would be ready to go; they are quite enthusiastic. We have transient populations—people moving from one region to another. If there is one sector that would be enthusiastic, ours would be one of those because we see the benefits. The software, though, is different. We have at least two major ones in our sector—Communicare and MMX—but our patients front up from time to time in emergency departments or wards when they are very sick or from time to time it could be that they front up in general practice. The software used by all the different providers is different. We do not know how the PCRS being put in place is going to work with the different software. It might seem quite straightforward but, because some of the software is different in terms of functionality, you may not be able to look up the same information. We are committed to information being shared but you have to have that information. Otherwise, you are investing but you need to make sure that the information coming out is consistent.

You might have software that uses a different coding system with medication. In terms of functionality, some software may have provision for medication and another software may be able to capture similar pharmaceutical records about what has been prescribed to the patient, but unless those codes speak to each other—that is the IT language—it is not going to work. It is really about how you are going to optimise the functioning. That is why we think that, in terms of how the government is going to be contracting the vendors, you have to have some specifications, and those specifications promote innovations not necessarily in one system—that could be counterproductive. You have to have systems that are interoperable, that deliver value for money for governments and that capture the clinical needs of the population groups. To us, it seems that the money being invested by the taxpayers is going to be well spent.

We also believe—and PCRS is a really good example of this but obviously this goes beyond PCR—that, given there are a lot of areas in regional and rural WA where we are not going to be covered by national broadband, yet we are moving forward with telehealth and e-health, when you are looking at government policies—and I am sure this is across this board, not one side or the other—different sides of politics will be focusing on how to move forward with telehealth and e-health. It seems to us that it may be a good case in the future to look at reviewing regional and remote internet services and how those areas could be better supported in WA.

Finally, there are issues of security. I want to be able to cover here, but some really need to be looked at closely. Where is the data going to be stored? The data is going to be massive. Is it going to be stored locally or is it going to be stored nationally? How can it be protected? Is it going to be stored outside Australia?

There are also key issues of engagement, and the sector asked me that we make sure we communicate this issue. If you want to engage Aboriginal communities issues of engagement are really important, and that means allocating budgets. Those budgets are not just about putting arts on telly. An example that was given to me was that you need the Aboriginal communities in remote and regional centres—maybe in metro areas as well—to be clear that they understand how beneficial the PCR system is. That means spending a bit of money, but it is money that in the longer term is well spent. You need them to have queried about use of names: if I go to an emergency department or I go to an Aboriginal medical service—an Aboriginal-controlled medical service—that I use the same name. It is the consistency in the name that is on a Medicare record, and whether everyone has a Medicare record.

I would like to finish there, and I am sure you might have quite a number of questions that my colleagues with IT expertise may be able to respond to.

CHAIR: We will move to SARRAH for their opening comments and then we will go to questions. SARRAH?

Mr Wellington: Thanks for the opportunity to attend today. I will make my opening statements as brief as possible.

As you know, SARRAH is nationally recognised as a peak organisation representing rural and remote allied health practitioners working both in the public and private sectors. I am sure you are also aware that about seven million people, or 32 per cent of the total Australian population, live outside major cities. Most of the seven million live in regional cities and country towns of various sizes. People in these areas have low levels of access to health and other services; almost all health professionals are less prevalent, some dramatically so. Allied health is no exception to that.

The need to travel to specialist services in capital cities, especially for ongoing treatment, can greatly disrupt work and family life. The situation is exacerbated further for people living in more remote communities. Aboriginal and Torres Strait Islander people make up a substantial proportion of the population in rural—especially remote—areas. On average, their health outcomes are substantially poorer than those of other Australians.

We see e-health as about providing the right health information to the right person at the right place and time in a secure electronic form. I will move on to some key issues shortly, but because of its potential for helping to overcome the effects of distance, people living in rural areas stand to benefit substantially from e-health in its various guises in our opinion. However, rural and remote communities have the poorest infrastructure and thus a limited capacity to access and make use of e-health applications.

In our opinion, there are five key issues. Health consumers must continue to be key stakeholders in the policy development stages of the initiative. In rural areas it is important that it is not just a GP tool. It was interesting listening to the AMA's comments this morning. A range of other health professionals must have access to the technology, including allied health professionals. We have some members in rural and remote Australia where there is no GP. We have some members that sleep in swags to service Indigenous communities. It takes 10 hours to get there, but those practitioners are poorly supported. Practical barriers to its uptake in rural areas include the physical broadband connectivity, reliable connections, compatibility between systems and clear information on what and how consumers and health professionals opt in to the technology. I must say I am not a technical expert in broadband and so forth. However, we wish to put those on the table as key issues, and AHCWA touched on those a couple of moments ago.

Provision of training, support and assistance to rural and remote consumers, as well as health professionals, will be important, including those in professions other than medicine. Other challenges will include rural and remote settings where a local health workforce is mobile and there is no lead GP clinic—health professionals fly or drive in and out from another location, so a consistent face or a common face providing a service over a period of time is somewhat difficult. And the local population is also itinerate.

From my perspective, I want to ensure that allied health gets a piece of this important activity. It is an important initiative. I did listen to some of the supplementary questions that you asked the AMA. Our concern is that we are not necessarily inside the tent at this stage, if I could use that term. However, upon saying that, NEHTA has been wonderful in consulting with and including rural and remote practitioners. But our concern is whether the infrastructure is going to be in place come 1 July. At the end of the day, you can have a fantastic tele-health or e-health record, but if there is no workforce out there—excuse the French—it is not worth a cold pie. That is our key issue. The key issue is workforce.

CHAIR: That was not really French, Mr Wellington. I thought you were going to go much further than that! You would be aware of the other inquiry that our references committee is looking at?

Mr Wellington: Indeed.

CHAIR: These things all work together.

Mr Wellington: Thank you for that.

Senator SIEWERT: We will start with AHCWA, given that it is my home organisation. First off, I specifically want to go to the issue you raised about actual records for Aboriginal people and how Aboriginal people can access support from this particular service. Many of the submissions mentioned opt out rather than opt in. Comments in your submission talk about needing resources for people to actually engage with the whole issue of electronic health records. I would suggest that many Aboriginal people have pretty poor health records to begin with. Would that be a fair assumption—actually having significant records in the first place?

Dr Mwaiteleke: There will be a fair bit of information in the Aboriginal-controlled medical services, because we at least maintain Aboriginal medical services. We know that Aboriginal people will attend emergency departments in the first instance, but also that we have a significant transient population comparable to the rest of

the Australian population perhaps. I think that there is information from the emergency departments, the from Aboriginal medical services and even from some of their GPs as well. In metro areas, let us say that perhaps close to 80 per cent of the population do not go to the emergency department if they are very sick. Some may front up at the GP or something like that. So we need that information, but by the very fact that people have been less likely to be engaged by the system in prevention, primary care has been limited.

We are now talking about primary care, and the concepts of primary care that are being pursued at the moment are looking at engaging people a bit more closely. For example, there have to be greater linkages in issues of chronic management, there has to be more liaising and there has to be a bit more interaction around educating patients around safe management and things like that. The way the healthcare agenda is moving, they seem to be for us a good reason to be embracing this concept.

Senator SIEWERT: Is your comment around additional resources to help people engage as an extension process to encourage people to opt in? There is a number of submissions that advocate having an opt-out system, so that you are in unless you say that you are out. What do you think would be the better way from a specific Aboriginal and Torres Strait Islander health perspective? Would it be better to have opt in or opt out?

Dr Mwaiteleke: It can be misleading if I say opt-in or opt-out, even though obviously we want people to opt in or encourage people to opt in. We still want people to have that choice. It is a basic choice if they are going to opt in or opt out. But we also want it to be promoting a situation where people are encouraged to opt in. I was the one to make the point that the issue is much more than opting in. We are interested in seeing that people are opting in to a system that is functioning, that is going to work. Say, for example, you want to encourage someone to opt in but then, with the example I used before, you have got to make sure that the name the person is using when they go to an emergency department is the same name that they are using when they go to an Aboriginal medical service and is the same name they are using if for some reason perhaps they have been seen by a clinical nurse somewhere. There has to be consistency in information.

Ways of communicating that information to the community are going to be done very differently. This is a big initiative. People need to understand why they have to share that information. It is not only why they have to be consistent even with names. Culturally, they say their names and understand that people may use or a person may be referred to by a particular name when there are reasons for it and it is okay. But, in the context of the PCEHR, using that name more or perhaps using one name and not the other can be quite disadvantaging. It seems to me that you could have a PCEHR system that you could design by taking account of diversity. If you design a PCEHR that perhaps assumes one size is going to fit all in terms of engagement then you are not going to capture the very population that you are seeking to reach. That means resources.

CHAIR: Doctor, I am just following up on that issue. Would not that same complexity exist with or without a PCEHR? We have been told that the issues about the appropriate name happens now. It is one of the confusions with paper records.

Dr Mwaiteleke: That the issue with names happens now?

CHAIR: The issue with names where the certainty about a name going from practitioner to practitioner, place to place, happens now.

Dr Mwaiteleke: It probably does, but I would assume that that was part of the reason that the PCEHR system was being brought in—so that information could be better integrated.

CHAIR: I just wanted to get on record that the issue of the confusion over names is not a PCEHR issue per se; it is an issue that needs to be right. It is an issue that we need to take into account with when dealing with clients, no matter who they are and it is an issue particularly important for the Aboriginal community.

Dr Mwaiteleke: It is an issue about the context.

CHAIR: Yes.

Dr Mwaiteleke: When you are implementing PCEHR, you have got to take account of context. The point I was making before is about diversity, managing this diverse context. With this particular context, engagement is going to require a bit of work and resourcing. I do not think it will be huge resources, but there has to be a bit of resourcing initially which I think will pay off handsomely in the long term.

Senator SIEWERT: I have got lots of questions but I think I am going to have put some on notice because we have got some for SARRAH as well. I specifically wanted to go to you, Mr Scates, as you have been doing the audit. In your opinion, what is the quantum of the additional resources that will be needed to address the specific issues that you are raising? It is not just in WA; it will be surely the same for essentially all Aboriginal health services, particularly the regional and remote ones.

Mr Scates: Yes. I found a lot of issues doing the audit. Most of them relate to items such as the reliability of communications. A lot of the areas in regional WA have very unreliable communications. They also have issues surrounding security of the information and compatibility of the systems, as the AMA touched on earlier. A lot of the infrastructure issues really relate to a lack of budgeting for IT. There is not any real budgeting for IT.

Senator SIEWERT: Has there been a commitment of additional resources specifically to assist Aboriginal health or—I will go broader—regional and remote? Your issues are going to be similar to a lot of other regional and remote health services, the broader allied health services. Are you aware of any additional commitment of resources specifically to meet your needs?

Dr Mwaiteleke: Not that we are aware of. A discussion paper has been issued for the funding guidelines for the regionally tailored funding for Medicare locals. One of the funding priorities, they say, among a whole range of things that the Medicare locals are going to be doing, is software technologies. But Medicare locals are privately constituted bodies. We do not know how they are going to operate. For Aboriginal groups and Aboriginal communities it has been difficult faring even with the universal systems that are in place. How easy, how complex or how difficult it is going to be to negotiate with each Medicare local, and whether each Medicare local in each region actually is going to prioritise that area, we think is going to be really difficult for us. Unless you can embed that in the legislation, unless you can also embed a provision that Aboriginal medical services and, significantly, Aboriginal population groups need to be catered for, then it is really difficult to get a look in. Alternatively, you can have, I think, funding provisions from DoHA, from the department, such that there is funding for the sorts of issues that my colleague Mr Scates just mentioned. So I think you can do it if you want to.

Ms Lowe: In terms of rural and remote in general, some medical services and medical centres are assisted to have IT support put in, but in terms of allied health there has been no funding available. In fact, many allied health professionals are still paper based and do not use electronic records at all. That whole issue of being ready on 1 July for integrated records is a major issue in terms of the infrastructure for allied health professionals because they are not part of any integrated records system currently and a lot of them are paper based, so the infrastructure does not exist for them to even have any communication.

Senator SIEWERT: Now that we have moved to you, Ms Lowe, I will just follow up with some of the questions I want to ask you—very quickly, because I know I am going to get pinged for time shortly. If I interpret your submission correctly, some of your members will be included under the definition of health providers and some will not. Is that correct?

Ms Lowe: The whole thing of who is in and who can access is very messy. The AMA alluded to registered professions and then talked about diabetes. When you look at a diabetic patient and the care that they require, a very key area of their involvement is dietitians. Dietitians are not a registered profession and are not likely to ever be a registered profession. So including just registered professions is going to leave a significant component of the allied health workforce not able to access records. Speech pathologists and social workers are two other key groups. They can get access if they are a member of their professional association, as per the current system with accessing MBS funding, but that generally applies to allied health professionals working within the private sector and not so much to those who are working within the public sector.

Senator SIEWERT: Do those professionals get access to patient records at the moment?

Ms Lowe: If you are working within the hospital and you are in an outpatient setting doing outpatient type services, the only records that you really have are your referrals from your doctor and whatever you create yourself. You are very dependent on the patient to provide you with what the AMA was talking about before, the allergies and the pharmaceuticals. You are dependent on the patient to tell you.

Senator SIEWERT: With this new system, it would be a sort of status quo for the professions that we are talking about that are excluded at the moment, so presumably your position is that, if we move into this new, you beaut system, surely the other professions should be able to access records?

Ms Lowe: On the whole access issue, there are a whole range of things relating to the actual access to the records. One is the education of the consumer to know who needs to have access to their records. They do not know what they do not know and they may not know why it is important that their dietitian can access what the medical specialist is writing up or things like that. That is the first point.

The second point is that allied health professionals, regardless of whether they are registered or where they are working, want enabled access to the system but also to be provided with the infrastructure necessary to access that system. As I said, the whole thing about whether a profession is registered or non-registered and whether they are a member of their professional association is that, when you look at rural and remote practitioners, the current evidence is that there are a lot of allied health professionals such that, the more remote you go, the more reliant

you are on public sector employees and the less likely they are to belong to their current professional association. It is also a lot more expensive to belong to your association than it is to be in a registered profession. If I am working in the public sector and I need to belong to my association, who is wearing the cost for me to become able to access that? Are we putting the costs back onto the practitioner, or are we going to be putting the costs onto the system?

Senator SIEWERT: I will sneak in one more question about IT. I saw you nodding when I was asking the question about IT. On the issues with IT in terms of remote access, the same applies for allied health professionals?

Ms Lowe: Everything that was said by our colleagues here applies to allied health professionals—and the fact that many of the services may be, as Rod said, fly in fly out or drive in drive out. They may not have paper based records. They do not have access, so access to the NBN or mechanisms to be able to access the electronic records are a major issue for allied health professionals.

Senator SIEWERT: How do they do it when they are doing fly in fly out? I am aware of the situation in our home state where there is no house for professionals or any people to live in, so they are having to travel in and out of the communities. Where do they access records?

Ms Lowe: Most of them would keep their records wherever it is they are based. For instance, if it is Tennant Creek or something like that in the Northern Territory and the service is being provided from Alice Springs, the record would be stored, paper based, back at their home base in Alice Springs.

Mr Scates: They use the remote access from their remote locations back into the centre. That is how they access the records electronically.

Senator FURNER: Just following on from that, Doctor, in the 19 communities you represent, would it be the case that all those medical records are on database, on paper or on a file system?

Dr Mwaiteleke: My understanding is that you have two major systems. In Communicare the information is stored locally, more less, because the technology is not web based, but, for users of MMX, that is web based. Now there are some interesting debates happening over that because also some of it links with security. We do not even know if MMX is going to be included in the final list or who is going to be included. But there are issues around security. I think that, once groups get more information, in the future there may be decisions that people are making about whether they opt for web based technology or not and also whether Communicare, in the future, goes on the Web as well.

Mr Patel: Ironically, in the Kimberley region all the nine AMSs are using MMX and all the rest in WA are using Communicare. I think one of them is using MD, Medical Director. MMX is a dot net version. It is using a fairly new technology and it is web based so, if the internet is connected and an MMX user is online, they can access all the data. But Communicare is built in Delphi technology, which is very old, so they are not online all the time and they are stored locally. The problem is that Communicare are in NEHTA's vendor list, and they are working with NEHTA to make an interface with PCEHR, but MMX is not in NEHTA's vendor list. I am not sure whether they have already been contacted or what the approach is from MMX. I am not sure right now.

Dr Mwaiteleke: To add to that, I think it is safe to say that there are some sensitivities that may have a bearing in the future on the choices made, because we are talking about Aboriginal communities. You want to be sure that the information that is going to be accessed by other stakeholders is going to be used ethically, is going to be used to promote the wellbeing of communities and is going to be used to promote notions of self-determination in the community and participation. So I think there is the relationship as well between how secure the information is going to be and the choices that are also going to be made in terms of some of the technologies. I think it might become a bit clearer, maybe, as the government engages much more with communities and also as the government provides more information about how it plans to address notions of security for the data.

Senator FURNER: You were in the room earlier when the evidence from the AMA was presented about concerns over administration efficiencies in inputting the data, correcting the data and so on. I imagine that would be an issue in your areas as well?

Dr Mwaiteleke: Without exception, our stakeholders—the supporters of the system—are saying that to make the system work you need your admin staff to get engaged. I think I mentioned earlier when I was making my opening statement that for the funding at the moment you do a procedure. Perhaps you are doing a care plan for a patient. You get funded for that particular care plan. We are a strong advocate of holistic medicine, holistic healthcare practices, but you also know that, the way we are funded, the shift is a bit more towards a bit of an individualistic focus. So, unless there is an alignment with the incentives for funding—the funding is actually funding admin staff, then you are going to employ admin to do that work. You need to be able to train people to

do that. You also need to be aware—for example, if you have Aboriginal health workers in the agency, then you also need to be able to engage them as well. The work is not all going to depend on the doctor, because perhaps another worker or another staff member may be able to spend more time engaging.

Senator FURNER: Notwithstanding that, according to the previous evidence provided, that generally relates to a new patient, and the efficiencies kick in once you have that data up and running, no doubt.

Dr Mwaiteleke: I think it is really just the initial phase. If you have an initial investment that takes account that administration expenses need to be taken care of, need to be factored in, then you have a better chance because you have kind of played a part in building the infrastructure and building the capacity. Then hopefully, over time—I am sure there are going to be other issues over time, like technologies, with innovation and licensing issues. Are the vendors going to be charging the same fees? Will the fees go up? We do not know that, but we want the government to take those issues into account.

Senator FURNER: One quick question for SARRAH: what is your current IT system? What do you presently have?

Mr Wellington: As you heard earlier from Ms Lowe, it ranges from nothing to a paper backed system. There is no consistent IT system throughout the allied health professional sector. It varies from profession to profession. I think optometry have a national system. What sort of coverage that has in rural and remote Australia I do not know. Really, when you are talking about allied health professionals and e-health, we are still in the sandpit. There will need to be an enormous amount of money provided to support the establishment of this infrastructure, not only to support consumers but to support the allied health professionals practicing in rural and remote Australia because there is not much out there, to put it bluntly.

Senator McKENZIE: I think most of my questions have been dealt with by my colleagues. The only issue I would like fleshed out a little more is the whole definition of a health provider. The registration to a professional body is one accountability mechanism within our health system, particularly as we move to an e-health model with our medical records online. How do you see an accountability measure like belonging to a professional body working in this proposed environment from the allied health professional's perspective for consumer concerns around privacy et cetera?

Mr Wellington: I will make a couple of comments and then hand over to my colleague. It is a common oversight in health as far as we are concerned. Health Workforce Australia has done it on a couple of occasions. They focus on registered professions for allied health. They do not focus on the self-regulated professions. So there is a significant number that fall through the gap. I am not suggesting Health Workforce Australia fall under this but the issue is that the government's concept is that they want to start from somewhere. It needs to be all in the tent or else it is not going to be an effective system. It cannot be a system whereby there is a whole-of-team care management approach to the consumer if half the people are outside the tent.

Senator McKENZIE: I understand what you are saying, Mr Wellington. My question then goes to what reassurances, structures or suggestions you have on how we can give consumers confidence that all of the people we put into the tent have an accountability structure.

Ms Lowe: The professional associations do have a significant role in accreditation and standards of practice. They may not necessarily set them, but they have a significant role. SARRAH has administered scholarships on behalf of the government for quite a number of years now and the stipulation that is usually involved is eligibility to be a member without actually forcing it. For many, particularly remote practitioners, they do not get any significant benefit out of belonging to their professional association, other than the fact that they can say they belong to it, because they are out of reach of a lot of the professional development and things like that that are provided and they need to access it in other ways. Having said that, the professional associations are getting better at recognising that need and trying to address it. Certainly for medical benefits scheme allied health item numbers, allied health professionals who are not registered have to belong to their associations. For a physiotherapist, for example, who works in a remote area it is $180 or so to register. It is $800 to belong to the professional association. That is my background. I do not get anything from my professional association in terms of professional development because of where I live. So it is a lot of money to spend for a system when other people are getting it for a lot less. That is why we have always used the criteria that if you can provide proof of evidence that if you applied to become a member of an association you would meet their criteria then you would be considered. Of course, the professional associations may have a differing view of that, but we are particularly interested in looking after our rural and remote colleagues. And that is what we would say—that they certainly need to be able to prove that they have the credentials. So if they meet the criteria to become a member, then they should be accessible.

Mr Wellington: In summary, I guess, there is no guarantee that we can give. We have a particular view that may not necessarily be shared by the individual professional associations, which is that the fundamental principle needs to be that if you reside in rural and remote Australia you are entitled to health services. However, as I touched on before in relation to infrastructure and workforce shortages, the option may well be that we are not really maximising the limited resources that are out there to their full capacity in terms of scope of practice. Some of the professional associations would fall off the back of their chairs to even consider that notion, but that is reality. That is the operating environment. So I suppose I cannot really give you a definitive answer, I am sorry.

Ms Lowe: The other potential approach to be taken would be, for those who are employed in the public sector, that if they meet the criteria to be employed in a public facility then they should be able to obtain an individual provider number.

CHAIR: Thank you very much. There will probably be questions on notice, which we will provide to your organisations. And if there is anything you wish to add, please be in contact. We will now move on to the next witnesses. Again, we thank you.

BENNETT, Ms Carol, Chief Executive Officer, Consumers Health Forum of Australia

MURBY, Mr Stephen, Chair, Consumers Health Forum of Australia

[09:37]

CHAIR: Good morning, Ms Bennett and Mr Murby, of the Consumers Health Forum of Australia, and thank you for coming to see us again. We welcome you. You well know the information about parliamentary privilege and the protection of witnesses, through your organisation and experience. We have your submission, which is submission 7. As always, thank you. Perhaps you would like to make an opening statement, and then we will go to questions.

Ms Bennett: Good morning, senators, and thank you for the opportunity to speak here today on this important issue. CHF is the peak body representing 200 members. Through those networks, we are directly connected to about two million health consumers around the country. While we represent those particular consumers, we believe that we also represent the interests of all Australian healthcare consumers on some of these issues. So we are particularly keen to talk to you today about what is one of the cornerstone issues in healthcare reform.

Let me begin with a very clear and definitive statement. CHF is strongly supportive of personally controlled electronic health records. Our members see PCEHRs as a fundamental step forward in health care that will, over time, significantly improve health outcomes, reduce medical mistakes, save lives, improve safety and confidentiality of health records, save time and money and give health consumers greater input into their own health care. They are all very significant advantages if we can achieve them.

It is important to note that this inquiry is occurring at a time when paper based personal health records are the basis of our health care systems. Current paper based health records, if created at all, are often not adequately or fully maintained. They lack confidentiality, they lack portability, they provide limited access or control to health consumers and they contribute to countless medical mishaps and poorer health outcomes.

The establishment of a fully functioning and effective PCEHR system is a no-brainer for anyone concerned about quality of health care. Our only concerns relate to how the PCEHR is implemented. The design and implementation of the system must be thought through from a consumer perspective if PCEHRs are to be effective and to realise their full potential. CHF's consultations have shown that, while our members recognise the benefits and support the introduction of PCEHRs, they are particularly interested in access controls for the PCEHR, transitional arrangements for young people, the functionality of the PCEHR and how the PCEHR is run or governed, and ensuring that the system will work for health consumers.

I will briefly outline some of these issues. On governance: CHF understands that the DoHA secretary will fill the role of the PCEHR system operator initially, with further discussions to be held with the states and territories around future governance options for longer term governance. We support the interim model but only for a period of two years of operation. The CHF submission calls for a transition away from the governance structures as proposed in the bill in favour of an independent system operator. This is based on the feedback that we have received in consultation with consumers, which called for the establishment of a statutory authority independent of the Department of Health and Aging, Medicare Australia or the states and territories.

In terms of young people, we support transitional arrangements for young people under 18 years of age. We know that has been the subject of significant discussions, certainly within our networks, and we welcome the arrangements outlined in the bill, which would enable minors to participate in the management of their PCEHR from the age of 14 and apply to take complete control of their record if they can demonstrate a need. Control of the PCEHR will be withdrawn from parents and guardians when the minor turns 18. This is entirely consistent with the arrangements currently in use by Medicare Australia. Minors, including those under 14 years, also will be able to apply to manage their own PCEHRs in certain exceptional circumstances, and CHF understands the need for the arrangements as outlined in the bill and supports these provisions.

On access controls: throughout our consultations on the PCEHR, there has been unanimous support for the reinstatement of the no access consumer control. A number of consumers have described the issue as a deal breaker in terms of their participation in the PCEHR system. The access controls have been significantly weakened since the release of the final concept-of-operations document in October 2011, with consumers no longer having the ability to mark a clinical document as 'no access'. Consumer representatives to the NEHTA have expressed concern to us that this decision to remove access control went against the advice of the NEHTA consumer reference forum. At CHF's recent consultation on the PCEHR legislation, consumers rejected the suggestion that documents could effectively be removed. CHF understands that consumers will now be able to see a list of deleted items from their PCEHR and will be able to apply to the system operator to restore access to

them. This approach is preferable to effective removal but it is likely to be complicated and time consuming and is not a life-long substitute for a no access feature.

No access is a feature crucial to the success and consumer centredness of the PCEHR. If it is not part of the PCEHR, consumers are likely to withdraw their participation, refuse to grant access, or simply withhold information. The removal of no access is contradictory to the principles of personally controlled, value, trust and confidence, which are all outlined in the concept-of-operations principles document.

In terms of functionality and consumer adoption, the full value of the PCEHR system will only be achieved if there is widespread adoption across the population to ensure there is sufficient data to make the system worthwhile to healthcare providers. Our research into the summary care record in the United Kingdom has shown that clinicians are unlikely to look for e-health records if there is not widespread utilisation of the system and that it is very difficult to establish confidence in the system if it fails to meet the needs of consumers. The literature also suggests that those most likely to benefit from a record are those who are least likely to sign into an opt-in system. Population groups including older Australians, rural and remote Australians, Aboriginal and Torres Strait Islander people, people with a disability and mental health issues, people who experience significant disadvantage and people from culturally and linguistically diverse backgrounds would all experience considerable benefit from the PCEHR system, but could also face significant barriers to signing up. In the context of an opt-in model, it is crucial that there is a targeted strategy to encourage consumers to register. Unfortunately, based on the capabilities described in the concept operations, the PCEHR will offer few benefits at the outset beyond those already provided by existing electronic health record systems in hospitals, general practice and other clinical settings. In many cases, there will be no immediate benefit associated with using the PCEHR. Momentum has also been lost as a result of features initially thought to be straightforward inclusions, such as the results of diagnostic tests not being included as originally planned.

The limited functionality of the system, coupled with the fact that there is no apparent strategy to drive consumer and clinician adoption through a national information and advertising campaign, mean that the system is likely to lack the critical mass required to function effectively. That raises questions for us about the viability of an opt-in model.

In conclusion, consumer adoption is critical to the success of the system, but consumers simply do not support electronic health records as an end in themselves. They must offer immediate clinical benefits to users in order to drive consumer adoption. I urge the committee in its reporting and recommendations to note the concerns of CHF and recognise the importance of consumer confidence and functionality to the long term success of the PCEHR.

CHAIR: Thank you very much. Mr Murby, have you got anything to add at this stage?

Mr Murby: No, thank you, Chair.

CHAIR: Senator Siewert.

Senator SIEWERT: Thank you. Can we go to the issue of no access. What is the reason that consumers have been given for changing the position on the no access issue?

Ms Bennett: Thank you for that question, Senator. I am not sure that we have actually received a particular answer in relation to that other than that it is part of the design functionality of the system and that it makes sense for consumers to be able to seal their documents in particular parts, but that sort of works in the context of the current design of the system. As I said, from our perspective, the current model is better than what we did have, where you would have the documents effectively removed, but it still is a long way from giving consumers really good control of their records.

Mr Murby: Yes, it is an extremely astute question. We have not been given a clear answer to the question. There have been allusions to medico-legal issues; there have been allusions to the break glass phenomena, where someone is admitted into a hospital and is incapable of giving permission to access their record. There have been a range of scenarios played out, but there has been no clear statement, certainly from the consumer perspective, as to why they have removed the no access. It is fundamentally important that the PCEHR is introduced so that it does not change—if you like, it does no harm, if I can steal the Hippocratic line—that it does no harm to the system we operate now. It is fundamentally our right as individuals, each and every one of us, to go to a medical practitioner for a particular condition, to have that particular condition dealt with and then return to our mainstream regular general practitioner and decide whether or not to disclose that we have had that particular procedure taken care of. That no access is within our control today and that no access must be preserved in the PCEHR.

Senator SIEWERT: I have already heard you say that the consumers will withdraw support; they feel that strongly about it. If this legislation went through and the no access issue was not resolved, in your opinion, would it stop people opting in?

Ms Bennett: I guess that remains to be seen ultimately, Senator, but that is our concern. Obviously we need a critical mass to ensure that the system is functional and gets off the ground. That is the first thing. But, secondly, consumers have to have confidence that the system safeguards their information, that it works well for them and that it offers benefits and features that will assist them with their healthcare management. Those things are really vital to people who feel they want to opt into this system. For us, and certainly for the people with whom we have consulted around the country, that has been one of those critical deal-breaker issues for them in terms of their interest in signing up. So it is our concern that that may well be the result. We certainly hope that that issue will be addressed in the design of the system before it is implemented.

CHAIR: The 'no access' stuff has sprinkled through some of the submissions. My understanding from the consumer's point of view is that it is the consumer saying 'no access'. There is also the 'no access' from the practitioner's point of view. That is a further question but, from the consumer's point of view, the position you have given us in evidence is that in the discussions we had eight months ago, when we talked about consumers being able to have that privacy and no access to things—after those two rounds of consultations that happened later in the year— the two papers that went out—then you were advised that that was the process that happened.

Mr Murby: 'No access' was referred to as 'document suppression,' I think in the original ConOps 1. It was a position we supported, it was a position after consultation that also gained support and then the position was changed. And 'no access' was removed.

CHAIR: It was in ConOps 1 for discussion and it was not in ConOps 2?

Mr Murby: It was removed.

CHAIR: That was the whole sequence to get the process going. Regarding the process you spelt out that, in your situation, you could still, through the proposed committees and the position that will be held by the DoHA secretary, apply to have things done under the arrangement that you now have on record. That is the kind of compromise position you have been given. That is accurate?

Ms Bennett: Absolutely.

CHAIR: Because of the amount of stuff that is before us, I just had to get that really clear in my brain as to how it worked.

Mr Murby: Clearly, PCEHR is a workaround. You can imagine that, in an instance, it does not sound so difficult but, over a lifetime of keeping track of records that you have decided to remove from your record and archive and then have to go through the archive of a lifetime of records and say, 'I want that one reinstated, but I do not want it reinstated for a small period of time because someone else can see it whilst it is reinstated.' It is a kludge—I think that is the technical expression. It is a workaround that really does not work.

CHAIR: The final situation is everything is on the board in something defined as an emergency situation? We are not clear what the definition of 'emergency' is, either.

Mr Murby: 'Break the glass.'

CHAIR: How I read it at the moment is that, if you go around and do the workaround and get something that is private—and we have had discussions previously about things that could be private—in an emergency situation that still could be wiped out because of the definition of 'emergency'. Do I have that right?

Mr Murby: Yes. It is unclear. It is actually unclear in the emergency or the 'break glass' situation whether that would give you access to 'no access' documents or whether it would just give you access to all other documents. There are reasons here. There is a shift, fundamentally, in the philosophy of the model of whether this is a medically driven implementation or a consumer driven implementation. One can understand that practitioners are very keen to ensure they have access to absolutely everything that they could possibly imagine they could have access to. I think we can also understand that, as consumers, we are responsible for managing our own health moving forward and we ought to have the right to decide what we do or do not disclose.

Ms Bennett: As we do now.

Senator McKENZIE: With respect to the medicos saying 'no access'; that is not to consumers, though.

Ms Bennett: The issue of medicos saying 'no access' and wanting access to absolutely everything is a real concern and certainly has been for the people we have consulted. Currently, you can choose what information you give your various health providers. Many consumers have told us, for instance, they do not want their physio knowing about their mental health problems or their dentist knowing about their sexually transmitted infections

and so forth. Currently, there is that option. The PCEHR has to offer some kind of value and benefit that extends beyond what is currently on offer. People need to know and it is fundamental to their confidence in the system that they know that they can seal off parts of their information that they do not want particular providers to have access to.

Senator McKENZIE: I understand that. I guess I went to that when Senator Moore was outlining that there are two no access issues.

CHAIR: That is a clarification I have to make with NEHTA, because under the current provisions there is information that practitioners do not provide to the patient; they actually provide it in a go-around way because it could be 'too dangerous' to the patient, and I want to know how that works. That is a question I have to put to NEHTA and the department. From your perspective I wanted to know whether that was part of the discussions you have had as well.

Mr Murby: We have not had the practitioner's perspective as part of what we have consulted on with our members specifically in terms of practitioners being able to deny access to information about our own personal health, largely because that was a latter day request rather than an earlier request from practitioners or health providers. It was not part of the original ConOps, as I recall. However, speaking, as you would not be too surprised to hear, as a consumer, I imagine everybody in this room would be slightly concerned if there were concerns about your health condition that were being kept from you because it was considered to be in your best interest—

CHAIR: Which happens now.

Mr Murby: Yes—well, I do believe 1984 has come and gone. Really, that is an appropriate course of action. If it cannot be framed in the context that informs us as consumers in a language that we can understand without causing undue stress and anxiety and undesirable outcomes then it probably should not be on the record in the first place.

Senator SIEWERT: Can I go to the issue that was raised by SARRAH—I think you were in the room at the time, and it has been raised in submissions—relating to the definition of 'health provider' and who is covered. Can you quickly outline your position on who is covered by a health provider and who you see as being in and out?

Ms Bennett: Currently we understand that the GP, the Aboriginal health workers and nurse practitioners will be covered under the legislation as the nominated providers but that other providers will have access to that information if the consumer chooses for them to do so. Firstly, it is probably a good thing that the provider would be a registered provider of some sort. We would not see that as particularly concerning. The second thing would be that it must be somebody that the consumer has confidence in as their provider and somebody that the consumer wants to have access to their information and believes is a critical part of their healthcare management team. I guess they are the two parts that satisfy us within the legislation, and I imagine it will evolve over time to expand to the number of nominated providers. Ideally it is about what the consumer thinks is in their interests.

Senator SIEWERT: SARRAH, for example, use social workers and dietitians as two examples of practitioners who are not included. Your position, if I interpret it correctly, is that if I as a consumer say, yes, I want my social worker—this particular one—and this particular dietitian to have access, they should be able to have access?

Mr Murby: There are two issues. There is the health provider and the nominated health provider. Health providers do have access to the record if the consumer allows it. The nominated health provider, as you would well know, I realise—but just for the record—is the one that the consumer trusts to be able to take event based records and load them into the summary record and to manage the summary record of the total health care. So health providers will be able to load up their event data, going to a particular consultation. It is the person that we actually trust who is going to help us co-manage our record. The key thing for us in our consultations is that we recognise two elements. This health provider, as the nominated health provider, needs to be trusted by the consumer and needs to be regulated to ensure system integrity—some form of registration that will ensure system integrity in the way in which people are assisted in managing their summary level record. But it certainly does not affect any health provider being able to load information or indeed access information at the consumer's behest in the system. They are the two elements: trusted by the consumer and regulated by the system.

Senator SIEWERT: Thank you. Can I go to the issue that you raised at the beginning of your comments going to the independence of the system. I think I understand what you said correctly. Do you think that the bill needs to be amended to say, 'This is for two years and then we will move to an independent body'?

Ms Bennett: Yes. That was very clear in our consultations with consumers. They did want an independent system operator in place that was not the Department of Health and Ageing, that was not Medicare and that was

not a state or territory body. It needs to be an independent body, and that is a critical factor in generating consumer confidence in the system.

Senator SIEWERT: Thank you. I just wanted to be clear that you wanted to see the legislation amended. We have already discussed the no access, but that would require amendments as well.

Ms Bennett: Absolutely.

Senator SIEWERT: Then the issue that is coming up all the time—and you have mentioned it as well—is the opt-out model. You believe that we should move to an opt-out model rather than an opt-in?

Ms Bennett: Yes. Ideally we think that it should be an opt-out model. We have arrived at that position over quite a long period of consultation, looking at the literature—particularly the international literature—on the models that have worked and have not worked, talking with other stakeholder groups and obviously talking with a wide range of health consumers around the country. I guess there is that issue of critical mass, which we are concerned about with the system not achieving. That is the first point. We need that for it to get off the ground and to work effectively. We want to see it work effectively.

The second point is that the groups that we are talking about who are effectively the groups that will benefit the most from a personally controlled electronic health record are the groups that are least likely to be opting in in the current model. It concerns us that they will not be getting access to a system that would benefit them. The third thing, I think, is informed consent. It is absolutely critical in this whole system, as is consumer control. What you are registering for and what you are opting into has to be made absolutely clear. You have to know what the benefits and the limits of that system are. It needs to be really clear. I think with an opt in system we still have questions about exactly how that informed consent will occur. Consumer control, which we think in many instances would be provided better if they had particular points at which they could opt out of some of the system functionality, would be a better approach. Stephen might pick up on that.

Mr Murby: Thank you. The question of opt in and opt out, whilst it is a really critical question and, I think, fundamental, is in fact clouding the reality of the situation. We have been looking for parallel models. I am on the record as saying that the introduction of the PCEHR is akin to the move to decimal currency. I meant that in the context of the reach that it would have for every single person living in Australia. It would change the way we transact our health business. But in fact the parallel model is more like superannuation. It is one that does not yield immediate benefits, but it is one that we are—

CHAIR: You just picked a really easy one, Mr Murby.

Mr Murby: Yes, I thought I would pick something pretty straightforward. It is one that is actually for the benefit of the nation well into the future. It does not yield results on day 1. When we introduced compulsory superannuation for the country, we understood it was better for the nation in the longer term. It did not yield benefits on day 1, but we were all participants in that. I suppose if we chose not to work, we were not participants. But we were all participants in that system. The question about opt in and opt out is focusing on the question of how we fundamentally participate in the PCEHR. We all—or 99.9 per cent of Australians—now have a unique individual health identifier. Whether we operate with six names, two names or one name, we actually have spent a lot of time—it still has to be right—matching the one IHI with the one physical person irrespective of the number of names. Given that that happens, in that sense we have all entered into the system. There is no opt in; we have actually got that. It is now a question of whether we choose to activate that as part of our PCEHR.

This comes to critical mass and this comes to a really important point, which is why we have been pushing for opt out, because it would focus people on: 'How do I activate my record' or 'How do I choose not to activate my record?' That leads us to then making an informed activation of the record. At the moment, there are lots of controls and levers. We can do the settings as we activate our record. We can set it at a variety of levels of access, discretion and so forth. It is quite complicated. It is a bit like saying to someone in superannuation, 'Look, we have got 16 different investment portfolio possibilities, and you can choose where you want to place the settings'—or people can take the balanced, the conservative balanced, the aggressive or whatever. That is a key part of the system. If we actually have a way in which people can meaningfully activate their PCEHR with confidence, knowing that they can provide the sort of level of access to the people they believe they trust in the way that they run their health today, then we have got a system that is going to reach critical mass and work. If we have got a system where people go to their health provider and their health provider says, 'This is going to make it a whole lot easier for us if we sign you up to this system and we tick these boxes and it works this way,' that is a real concern for consumers. They really want to know that they are making an informed activation of their record. So the notion of opt out—we all have a record and we have to think about how we activate it—is a much more powerful one for achieving critical mass and will lead to a better outcome for the PCEHR system than one that

you can chose to be in or out of and one where we can always let the health provider do it for us because it will be so much more convenient.

Senator FURNER: Ms Bennett, about this consent proposal: currently you go along to a doctor and a doctor places on record your name, your address, your contact details and all the medication you are on. There is really no consent process now, is there? It is a case of data being collected as a result of having the opportunity and with safeguards for the patient in mind to make sure that, whatever happens to them in future, the records can be easily accessed. That is the case currently, isn't it?

Ms Bennett: It is the case in terms of that individual practitioner, but where we are talking about potential access to summary records or event summaries that are basically delivered by a different provider the necessary level of consent suddenly rises because you have got a range of different information sources potentially feeding into that record. It is about ensuring that the person who is signing up knows what they are actually signing up to and what that will provide to them as a benefit, not just to the practitioner, and what some of the limitations might be around that system. That is what people need to know.

Mr Murby: Senator, your question goes right to the point. What is called the event record is that one-on-one exchange with a practitioner. The question is what of that event, if any, we put in our summary record that others can see. At the event level record, it remains between the consumer and the practitioner. It is only at the summary record level that the information is shareable with a variety of people. Our nominated health provider is the one that helps us decide which part of that event record we will put up into the summary record and make more accessible to a larger number of health providers.

Senator FURNER: What are the general concerns that consumers are raising in terms of exposure of that information beyond the doctor-patient relationship?

Mr Murby: It cuts back to the no access. There are some events that you do not necessarily want to share with your nominated health provider. One of the concerns about no access is that when we go to the event we have that summary and we can say to that particular practitioner that we do not want this to actually be made available to our nominated health provider; we want to say this record is a no access record. Our nominated health provider does not get access to it. We can still see it and the provider that we went to see can still see it, but nobody else can. That is really important for us. It cuts back to the no access record.

In terms of us deciding what we put at the summary level, there are less concerns because clearly we have a say with our nominated health provider—'So you went to see somebody about the bunion. This is what happened as a result of the bunion procedure, so what do you think we will put on the record: this part of it, that part of it, your reaction to a particular drug or whatever it may be?' Then it is decided and that goes on the summary record. That causes us less concern. It is actually when we want to suppress the record and not have it available to the nominated health provider that is of the greatest concern to consumers.

Senator FURNER: Do you hold any concerns about the implementation date at all?

Ms Bennett: This is an evolving system, so what we will have is the opportunity to sign up, opt in, register or whatever you would like to call it on 1 July and there will be the capacity to have a summary record populated. Then your choice to sign up will enable that to happen. We are not so concerned about 1 July being the date at which this system has to be ideally operational and provide all of the bells and whistles and all the things that everybody wants. There is the balance between achieving critical mass and the system working but there is also accepting that there are some limitations to what the system will be able to deliver on 1 July. I guess that is where we want consumers to know that, firstly, this system is coming into existence on 1 July and that they can sign up to it and, secondly, what its limitations are, what its features are and how it will benefit them so that they can make that choice to sign on. I think it is then a process of getting all the elements right. Certainly the ones we have outlined in our introductory statements are those that we think are really critical to getting the critical mass and uptake which is essential to ensuring that the system does not fall over too soon and that we have a system that will evolve into something that is really functional and be the glue of the health system if it works really well down the track.

Mr Murby: Being able to make an informed activation of a record is far more important than achieving a date. If we are not confident that consumers in Australia are able to make an informed activation of their record, then the date is immaterial.

Senator FURNER: Thank you.

Senator McKENZIE: My question goes to one of the recommendations that you make which I think goes to 'break glass' scenario. I wondered whether you have any comments from a consumer's perspective on those people

who because of their religious beliefs might have certain perspectives around how they want their health care to be provided in certain situations and how you see this working in that sort of scenario.

Ms Bennett: I suppose it again comes to the issue of consumer control. Our concern about information being able to be accessed in emergency situations, I think, needs further clarification. What are those emergency situations and in what situations will consumers actually have control over information, for whatever reason, whether it be for religious reasons or for other reasons which they would not want that information accessed? Certainly in the consultations we have had people who have expressed concerns about that, and they do want to have some level of control, ideally, that would surpass the need for 'break glass in emergency' situations. We think that is quite important. It is the consumer control that is the critical key to ensuring that people have confidence in the system.

Senator McKENZIE: Could you envisage a scenario where we access the record in an emergency and the record has information saying, 'Do not do X, Y or Z in this scenario' and that that would be followed as advice to the doctor from a consumer perspective?

Ms Bennett: Yes.

Mr Murby: The PCEHR specifically provides for the storage of care directives and end-of-life directives. From the consumer point of view, we would clearly believe that they are the directives that ought to be followed. Again, the introduction of the PCEHR is not to change the way in which we as consumers manage our health care; it is to actually improve the way we manage our health care. In that particular scenario, end-of-life or care directives are indeed incredibly important and it is very valuable to consumers to have them on the PCEHR.

Senator McKENZIE: Yes.

CHAIR: I have two questions and there will be questions on notice. Senator Boyce, who has been handling this issue for the opposition, is not able to be here today, and you know her interest. We have agreed that questions on notice will be coming out so be ready. On the first question, can you explain to me whether there is any crossover between the Consumers eHealth Alliance and the consumers group that you represent?

Ms Bennett: My understanding is that the Consumers eHealth Alliance are members of the Consumers Health Forum. I am not sure which range of groups they represent—I think they represent a number of civil liberties groups.

CHAIR: They do.

Ms Bennett: I understand they are speaking later this morning.

CHAIR: Yes. We have not had a situation in the committee before where we have had two formal consumers networks. It is good, but I just wanted to find that out. On the second question, we do have significant evidence this afternoon with people who have privacy concerns about the legislation. I know that you have consulted widely with your members. Can you let us know about the level and issues about privacy that came up in your conversations?

Ms Bennett: I guess privacy really is a codeword for us that has been around consumer control. The privacy issues are largely taken care of if people feel as though they have control over what goes in the record—that is, who gets access to it and so forth. The other aspect of that, of course, is the governance arrangements and the legislation in making sure that there is independence and that arrangements are in place that will cover any concerns around breaches of privacy. There have been some issues, which we have outlined in our submission. Of course, consumers expect that those issues will be addressed, and it is a critical part of the confidence that consumers will have in the system.

There is also a counterbalance to that—and it does not negate the need for those proper privacy controls: the people who are most interested in having their health care managed in a way that means they will have reduced medical misadventure will have their medical information in one place. They will not have to recount their medical history, their treatments, their prescriptions—all of their medical issues—every single time they see a different provider. Those people are fundamentally concerned about getting a system in place like this, one that will help them manage their health better. The privacy issues are really critical and important but should not be a reason not to have this kind of system in place, because there are a lot more concerns around the paper based system we have at the moment in terms of privacy breaches. When you have information sitting on fax machines and in paper records on people's desks, then there is not a secure information exchange that we could potentially have with this system if we get it right.

CHAIR: You may want to take this on notice, Ms Bennett: you know that we are looking at NEHTA through this process as well, and we would like your views about the engagement process and the operations of NEHTA in the past and into the future. It might be easier for me to put that on notice.

Ms Bennett: Sure.

CHAIR: You have been engaging with your organisation for a while but I would just like some indication, because as you know we are looking at the role of NEHTA into the future with that process, as the funding is only until July this year.

Ms Bennett: I will be happy to do that.

CHAIR: Thank you very much for your time.

Proceedings suspended from 10:17 to 10:31

HOSSACK, Miss Emma Jane, Board Member, Medical Software Industry Association

HUGHES, Mr Jon, President, Medical Software Industry Association

McCAULEY, Dr Vincent, Medical Software Industry Association

CHAIR: I welcome representatives of the Medical Software Industry Association to today's hearing. Information on parliamentary privilege and the protection of witnesses and evidence has been provided. If you have any questions please ask us or the secretariat.

Mr Hughes: I am a partner and a director of an Australian health software company. My company is participating in two of the PCEHR lead site programs. I am also on the Standards Australia IT14committee and am the current president of the Medical Software Industry Association.

CHAIR: Mr Hughes, is it possible for you to tell us the name of your company.

Mr Hughes: Smart Health Solutions.

CHAIR: I just think it is easier to have it on record, because I know you are all in that business.

Dr McCauley: I am a clinician. I have worked for 20 years in health departments, principally emergency departments, in New South Wales. I am also the CEO of a small health company, McCauley Software. I am the chair of IHE Australia, which is the Australian outreach of the global IHE standards organisation. I represent MSIA on IT14 committees. A am the treasurer of MSIA as well. I am appearing here today as the national e-health implementation coordinator for MSIA.

Miss Hossack: I also wear the hat of a CEO of a small Australian software company called Extensia Health Solutions, which is not involved in any of the ways that we are going to be talking about. I am a board member of the International Association of Privacy Professionals—Australia and New Zealand. A am also a lawyer with a keen interest in privacy.

CHAIR: I take it, Mr Hughes, that you will be leading off with an opening statement and then we will go to questions.

Mr Hughes: The Medical Software Industry Association welcomes this opportunity to contribute to a review of the personally controlled electronic health records program. The MSIA has 120 members and has operated for more than 10 years. It provides a forum for the health information technology industry to collaborate outside its normal competitive environment. Our members range from small and medium enterprises, like Emma's and mine, to the very big end of town, including companies like IBM, HCN and Sirna. We include clinicians, informaticians, health care administrators and health industry businessmen and women. Our clients represent all clinical domains and practice types, including hospitals, GPs, specialists, diagnostic services, aged care, allied health and pharmacies.

Our association is strongly supportive of the national e-health program and has contributed extensively to it over many years. The government's National E-Health Strategy and the recommendations from the National Health and Hospital Reform Commission report were warmly welcomed by industry. Our members have participated in countless reference groups, tiger teams, working groups, Standards Australia committees and other industry standards groups to try to ensure that the PCEHR program will be a success. In our submission to this review we focused on key issues that we are convinced must be addressed if the national PCEHR program is to be a long-term success. I would like to summarise those issues for you now as simply and as briefly as possible. First, the PCEHR program is characterised by risks to patient safety even before development has been completed. The MSIA has previously requested access to NEHTA safety assessments, which NEHTA has consistently refused. The MSIA has also recommended several months ago that the PCEHR program should be paused or significantly reduced in scope until safety and other implementation issues have been addressed. NEHTA has in fact now paused PCEHR development across the lead site programs to address safety issues.

Second, with less than six months before the PCEHR program is scheduled to go live, the Department of Health and Ageing has not provided a sustainable, commercial model that will support the national e-health program in the long term. The program risks falling into disuse from the very first day of live operation. This has actually been a theme that we have heard in the previous sessions this morning.

Our third issue is NEHTA's project management. The PCEHR program has been characterised by ineffective project management, unrealistic deadlines, inadequate review processes for specifications and a lack of progress to Australian Standards. These have had a significant impact on the introduction of risk, particularly patient safety, and will result in significant continuing high costs to the sector.

Finally, our fourth key issue is that industry has lost confidence in NEHTA's ability to deliver this program. There is evidence of a lack of probity, ineffective governance and an inability to deliver targeted programs. One senior NEHTA manager has said in a public forum that NEHTA could stand for 'never ever having to achieve'.

We can speak to each of these issues in more detail during the remainder of the session. I would like to complete his introduction by describing the outcomes that the association would like to see from this inquiry—outcomes that are essential in our view to ensuring that the PCEHR program is to have any chance of being successful. First and most importantly, reduce the complexity and scope of the PCEHR release 1 program—the 1 July 2012 program—effective immediately. A much simpler release 1 program could still deliver an effective, valuable solution to the health sector on 1 July but only if the scope of that program is reduced significantly—that is, if it is completed without many of the components that are currently included in that program. An essential element of that strategy would be a new 12-month timetable for the development of outstanding functionality as release 2 of the PCEHR program, with supporting funding and with the delivery schedule for 1 July 2013.

The second key outcome that we are seeking is the provision of certainty for the health sector by requiring the Department of Health and Ageing to develop a sustainable business model for e-health that pays healthcare professionals and their technology providers fair fees for helping to deliver better health outcomes through the use of e-health technologies. The national PCEHR program is being projected to save the Commonwealth several billions of dollars in a full year of operation when it is fully implemented. It is reasonable to expect the Commonwealth to return a portion of those benefits to the sector that achieves the savings to ensure continued development of the solution. Given that the major beneficiaries of a successful PCEHR program will be Medicare and the PBS, forward estimates for these programs should take into account PCEHR savings. Some of the savings should be applied to the building and delivery of PCEHR capability by providers and practices, which is where the majority of the activity and data collection takes place.

The food outcome we are seeking lies at the very root of the patient safety issues that were acknowledged by NEHTA just a few weeks ago. This committee should subpoena all NEHTA documents that relate to the assessment of the NEHTA work program in relation to patient safety. Patient safety and is impact on consumer confidence is the most important concern that our association has with the development of the PCEHR to date. NEHTA has refused to make these safety assessments available for external review. The fourth outcome that we are seeking is for the Commonwealth to take steps to restore industry's confidence in the implementation of the national PCEHR program. There needs to be a formal inquiry into why things have gone so badly wrong. Replace, restructure or supplement NEHTA with an e-health management team that has a proven record in the successful implementation of e-health programs. MSIA proposes that an industry-led task force could provide this capability. Finally, investigate the procurement and funding processes within NEHTA. Thank you for the opportunity to present this opening statement. If the chair is agreeable, we would like to request a few minutes at the end of the session to sum up any issues that emerge from your questions.

CHAIR: Thank you. Dr McCauley and Miss Hossack, anything at this stage?

Dr McCauley: I think we will wait for questions.

CHAIR: Senator Siewert?

Senator SIEWERT: Can we go to the issues around patient safety and the comments that you are raising. Could you just explain your concerns about the potential impact on patient safety and also your interactions with NEHTA about access to the assessment?

Dr McCauley: As a clinician, I lead the patient safety agenda for MSIA. We have had concerns about the underpinnings of the PCEHR—the health identifier services—safety for some time. We initially believed that over time those issues could be addressed. However, it has become apparent only in recent months, when finally the full specification has been released to industry, that in fact those safety concerns cannot be addressed without a significant change in the specification. An independent technology assessment committee looking at the issues of organisational and provider identifiers came to the conclusion that, in its current form, the service could not be operated safely. Subsequently NEHTA's clinical safety unit was also asked for an assessment. After some time, they also endorsed that conclusion. Perhaps it is happenstance but within days the manager of the clinical safety unit had left NEHTA, as we understand in a very distressed condition. That has meant that access to organisational and provider identifiers is not possible electronically in the current state. The committee charged with this has put forward recommendations for changes to the health identifier service for it to be modified. However, the committee has been provided with no information as to how those recommendations are being addressed or any time frame in which the health identifier service specification may be changed and implemented to address those concerns.

There is a further issue with the patient identifiers that has again only emerged recently as the detail of how you may use them has come to light. It is outlined in our submission. A patient's identifier can in fact change under a number of defined circumstances. When that change happens, there is no mechanism for Medicare notifying practices or practitioners of that change in identifier. Consequently, it becomes impossible to validate that identifier electronically against the service. Both the new identifier and the old identifier will fail validation. It means that any PCEHR record that is based on that IHI as a key to the patient record will no longer be useable and hence any information within the PCEHR will effectively disappear. That has significant consequences for patient management.

Senator SIEWERT: There is so much in what you have just said. I imagine it is very technical. It seems to me that one of the key things there is the identifier changing. Is it a technical glitch that it changes?

Dr McCauley: No, it was part of the original specification. Medicare have implemented it as specified by NEHTA. I do not know if you remember, but I appeared at the Senate committee two years ago that was inquiring into the identifier service. At that time we expressed concerns that the health identifier service was not based on applicable standards but rather had been made up. The problems inherent with that have come home to roost in that the specification has been shown to be inadequate, poorly designed and unsafe.

Senator SIEWERT: It was in the fundamental specifications that that enables the number to change?

Dr McCauley: Yes. And we should be clear that Medicare have faithfully implemented the specifications, so this is not something that is Medicare's problem. They have implemented the specification that was handed to them by NEHTA and their implementation meets those specification requirements. Unfortunately the specification is fundamentally flawed in a number of areas.

Senator SIEWERT: You have specific examples of where identifiers have changed?

Dr McCauley: Yes.

Senator SIEWERT: Okay.

Dr McCauley: Medicare in fact have produced the numbers of occasions on which that has already occurred but have not been willing to release that information either to the technical committee considering these issues or to the industry more generally.

CHAIR: That is the technical committee of NEHTA?

Dr McCauley: No, this is an independent technical committee that is looking at the conformance and compliance requirements for the Healthcare Identifiers Service.

CHAIR: I am sorry; I just want to check that bit. There is a proliferation of committees in this process. When you say 'independent committee', who set that up, under what auspices, and to whom does it report?

Dr McCauley: It is a committee of the conformance, compliance and accreditation governance group which has been established by DoHA to oversee conformance and compliance across the e-health sector. It contains representatives from Medicare, jurisdictions, the three industry associations—AIIA, MSIA and ACIVA, the aged care association—as well as DoHA and NEHTA and representatives from Standards Australia and NATA, the National Association of Testing Authorities. A technical subcommittee of that group was established to put together and approve tests for conformance and compliance of the health identifiers service and in particular has been looking at the organisational and provider identifiers.

CHAIR: It reports to DoHA?

Dr McCauley: It reports to CCAGG, the conformance, compliance and accreditation governance group, on which DoHA is represented.

CHAIR: Is there a feed-in mechanism to NEHTA from that group?

Dr McCauley: NEHTA is on that group, but NEHTA actually provides the secretariat for that group.

CHAIR: Thank you. I need a whiteboard!

Senator SIEWERT: Can we go back to the issues of the recommendations that came out of the previous process. You have access to those recommendations but not the safety audit itself; is that correct?

Dr McCauley: Sorry, the recommendations for which group?

Senator SIEWERT: You said that we should be asking for the information from NEHTA around the—

Dr McCauley: The safety report.

Senator SIEWERT: The safety report, yes.

Dr McCauley: Starting back with the health identifiers service, we were assured by NEHTA that a full safety assessment had been made and we assumed that there was a report available of that. We have asked for that consistently for over two years and it has not been provided.

More recently we have been asking for safety reports on the PCEHR implementation strategy and specifications, and again such safety reports have not been available. A freedom of information application by the *Australian* to the Department of Health and Aging, looking for safety documents related to the PCEHR, was returned with no records found. So our assumption is that they are within NEHTA and have not been shared with the department and that NEHTA is not subject to any discovery mechanism, as outlined in our document. It is not subject to FOI; it is not subject to any of the usual government controls as a private corporation.

Senator SIEWERT: Thank you.

CHAIR: In terms of the safety—and the term 'safety' is important to define—this is the accuracy of the records and then the implications of not having them accurate; is that right?

Dr McCauley: It is not so much the accuracy of the records as the ability to access them, the audit control around who can access and the audit trail of how that access has occurred. Fundamental to the PCEHR is the ability to control access, which is based on the organisational identifier and the provider identifier, and also to audit access, which again is based on those two identifiers, to actually identify who has accessed the system from where. Without those numbers being verifiable and validated, there is no actual control over who is auditing or accessing the system. Any number could be put into the system, and there is no way of determining whether that number is correct or has been allocated to the right practitioner or organisation.

CHAIR: Your submission does not spell that out in detail. Can we get exactly what you have just said in terms of your understanding with your background? As you would expect, we will be asking NEHTA and the department these questions as well. Could we get what you have just said to us as a definition of safety? I think it is a really important thing to have defined for our issue.

Dr McCauley: I am happy to do that. We were actually concerned about what level of detail we should go into in the submission, but we are certainly happy to enlarge on areas.

CHAIR: That would be useful for the committee's purposes.

Senator SIEWERT: Can I follow up on that point? Your submission talks about clinical safety impacts, which I then take to mean—and maybe it is just my understanding—the safety of the patients. So there are two aspects here. There is the issue of access and privacy—that sort of safety—and then there is the clinical safety aspect as well. Is that correct?

Dr McCauley: Sure. If the patients personally controlled electronic record can suddenly disappear because their individual health identifier has changed then that will have potentially significant impact on patient safety.

Senator SIEWERT: That is what I was interpreting as the safety domain. I had not then made that leap to the other thing. I now understand, so thanks for that.

The proposal that you touched on at the end talks about reducing the scope of the program. Can you articulate which elements you think could be in this process and which should be taken out for the next phase?

Mr Hughes: Certainly. The current implementation program that is being targeted for 1 July is extremely complex with a lot of very complex data defined in the clinical documents that we are all expected to exchange and share through this personally controlled electronic health record. A feasible solution for 1 July could simply contain images of the reports that are currently generated by various health systems: the discharge summaries, the event summaries, referrals. They are currently generated electronically in a lot of systems as letters or the visual equivalent of a letter—a PDF document—and those documents would work fine in a simple initial personally controlled electronic health record without needing to get to the stage of detailed, atomic, discrete individual bits of data which have to be consumed electronically and understood and interpreted by computer systems. It is the use of that detailed data that introduces the risk, and that is where there are complexities that have not yet been solved and could well wait for the next iteration of the solution.

Senator SIEWERT: Okay. You think that those safety issues could be fixed up along with implementing the first phase.

Mr Hughes: Leaving aside the health identifier service, which Dr McCauley has just talked about, the risk exercise that is just being conducted now by NEHTA as part of the pause that we are currently experiencing would largely be obviated by a move to a simpler, document based health record in the short term. These are documents the clinicians share now. They share them sometimes via email, sometimes via fax and sometimes within electronic systems. They would work perfectly well in a PCHR, but they would be a document that a

clinician would read rather than a re-presentation of that data in a structured document that depends on being able to interpret that electronically.

CHAIR: Can you give me an example of the second? My head is working through this. The first one is a simple exchange of information: 'I went to hospital. I had this test.' Give me an example of the second one, which actually needs the complex.

Mr Hughes: The examples of the documents which we are currently working on in this space are things like a discharge summary from a hospital. That is a familiar one. It might contain detailed information about the medications that the patient was on at the time the patient left hospital, details about some of the diagnostic tests that the patient had whilst the patient was in hospital as well as the results, information about the conditions the patient was diagnosed with, and the procedures that the patient underwent. All are potentially coded using coding systems, structured terminology and very detailed data—for the medication, for example, the name of the drug in our new *Australian Medicine* terminology name with details of the dose as discrete data and the route as discrete data. This is information which can theoretically be interpreted by the PCHR system or by other systems and re-presented in a summary format or a structured way, but that interpretation is dependent on a high degree of standardisation, conforming with that standard and all the various systems, effectively, talking the same language.

All that information can also be encapsulated in an image of a report—the same page that you might get now on a piece of paper when you leave hospital. It can still appear electronically within a health record, but the doctor would read the report online on his computer just like he would read a fax. He can read the medication details without having to have it presented individually as dose, route, frequency and so forth.

Dr McCauley: It would also remove one of the safety issues of the actual PCHR content itself. Where you are pushing information together from multiple sources—let's look at medications as a discrete example that has been discussed here previously—you need to be able to identify that a medication with different names coming from different sources is in fact the same substance so that you do not end up with the same medication in a medical record multiple times. To do that effectively you have to have what is called medicines terminology, which is basically a number that is assigned to a substance and which contains a list of all the names of that substance that it might turn up as so that, when you get the same drug by multiple names pushed into an electronic record on the PCHR, you can say, 'Okay, we've already got that one; we can take that one out or mark it as a duplicate.' To have that working effectively you have to have what is called a medicines terminology—that list of what each substances is called by, which at routes it is produced in, what dosage forms it comes in. That is called the Australian medicines terminology.

That has been a work item for NEHTA for many years from when it was first set up. I was actually part of the group that put together the initial work that was put into NEHTA. However, that medicines terminology still has serious issues due to changes that have occurred whilst it was in the NEHTA process that are to do with its correctness and its utility. We already have medicines terminologies in use in the system. They are provided by companies like MIMS, HCM and others. They have said, 'Why would we change from using a medicines terminology that we understand and has proven safety and quality for another that is of unknown quality, unknown safety and introduces a whole range of new issues. The Australian medicines terminology, which is a NEHTA work item, has been implemented in a trial in one system. It is not used across the sector. It is not generally available. The transition from the current usage of diverse terminology to a single terminology is a very substantial piece of work that is not going to occur before 1 July. So we are in a situation where potentially you have this complex data format that is being pushed in from multiple different sources and you will end up with it being multiply represented and misunderstandings occurring about which medications the patient is actually on. Even in the NEHTA specification as it is there is no intention to audit or manage that medication list, so until the terminology is in place it is going to mean that that medication list is going to become a major mish-mash of information from different people and different places and description of medication using different names.

It is going to be extremely confusing. By going to a representation of the actual report from a prescription or the pharmacy dispensed record—by putting those into the PCHR—you are actually presenting the information in a readable format that the commissions can understand, and it gets around those problems with terminology that we can move to at a later time. But in that initial phase, if we have that simplified format, we have safety risks that might not be involved otherwise.

Mr Hughes: It is a laudable goal. It is a desirable endpoint. But it is not for 1 July 2012.

Senator SIEWERT: I have a question about resources. You made a point in your opening statement about sustainable, recurrent funding that supports long-time viability across the health sector. We heard earlier this morning—I am not sure if you were here—from AHCWA and others about the need for resources.

CHAIR: And SARRAH.

Senator SIEWERT: And SARRAH. Can you put a quantum on how much you think would be required to be allocated?

Mr Hughes: The short answer is no. It is a very difficult question. I think the key point of our opening statement was that the Commonwealth needs to reinvest a portion of what it gains to sustain the solution on an end-to-end basis. At the moment we have clinicians saying they are going to be faced with additional work items and doing more work to support their patients and requests from that AMA—for example, that that extra work should attract NBS claim items. There is a desire by all of those healthcare providers that their technology providers give them the tools to support these various activities. A sustainable outcome in the long term depends on healthcare providers, whoever they are in any setting, in our view, being paid a fair, reasonable fee for helping to develop the nation's e-health resource; and for that fee to be spent partly on the technology that makes it happen. Without that, the solution will wither and die.

Senator FURNER: What is that fee?

Mr Hughes: It should be relate to be fair. It should relate to the effort that goes into management of the data. There are currently scheduled fees—in fact, there was a very good email from a doctor in South Australia recently—for five- to 20-minute consultations, for sub-five-minute consultations, for long consultations and for other activities that take place in healthcare practices. It is reasonable for there to be a fee or an enhancement to those fees where the data that is managed as a result of those consultations is managed in the context of a PCHR. Where the output of a consultation, referral or whatever it is ends up contributing data to the PCHR or to interoperability with other practices, I think it is reasonable for that to attract an extra rebate NBS payment.

Senator FURNER: In terms of your concerns expressed around the safety of patients and the example of an incorrect prescription being put in the database, I think that is relevant and a reasonable matter to put forward. However, several years ago, when this discussion about e-health commenced, we had evidence before this committee about the savings of misdiagnosis and those sorts of issues amounting to the saving of thousands of people's lives.

Mr Hughes: And they can be realised. The issue is that those terminologies that will lead to those improvements in care and reductions in cost are not in place. NEHTA has failed to roll those out across the sector. They are still in a situation where they are being externally reviewed. Ernst & Young have recently been asked to review the AMT again to assess whether it is fit for purpose. Despite five years of work, those terminologies are still not ready for prime time and certainly are not available in any clinical system that is meaningful in Australia. To expect those terminologies to be used to populate a PCHR is not possible. Those savings and improvements in care can be realised down the track, and the current proposal for the PCHR system allows for that to occur over time, but it does not need to be there at day 1.

Senator FURNER: Even if you took NEHTA out of the picture, there was evidence provided first up this morning from the AMA indicating that there are doctors out there who cannot readily identify generic prescriptions on drugs currently. So if you take NEHTA out of the picture altogether you still have an existing problem on the ground, where those sorts of records need to be identified and maintain and people need to be educated about what sort of education you are on, the dosage and all those sorts of things. There is a huge area out there that needs to be resolved irrespective of the issues that you have with NEHTA.

Dr McCauley: Absolutely. That is an area of current work. There are a number of works like NPS that are working to provide that education and improvement in quality. But pushing all the data together into a central store is not going to improve that.

Senator McKENZIE: The final paragraph of page 10 of your submission has an example of overstatement before substance or delivery. There are numerous other examples. I wonder if you could provide a few more on notice.

Dr McCauley: Sorry—overstatement on delivery by NEHTA?

Senator McKENZIE: Yes. There is a whole list: 'poor planning, failure to complete to deadlines and a range of other unacceptable behaviour that contravene normal Australian business practices.'

Dr McCauley: We would be happy to do that.

Senator McKENZIE: Thank you. I want to quickly talk about one of the issues you raised: how to make NEHTA accountable for its services and activities. I wonder if you could flesh out some suggestions on how we could do that.

Dr McCauley: I think that question really comes to the central core of NEHTA's ability to deliver and function: if it cannot actually do things, making it accountable will be extremely difficult. NEHTA has become what I would classify as a toxic workplace. In evidence before this committee the CEO of NEHTA admitted that their turnover rate for staff is close to 30 per cent per annum, which is extraordinary. Our information is that in the current financial year this climbed to closer to 40 per cent. There is no published organisational chart of NEHTA; the joke in the industry is that it would take too much time to keep it up to date.

There have been losses from NEHTA's management structure in very significant areas over the last six months. I classify the four pillars of e-health as standards, security, terminology and safety, and in each of those areas the managers have disappeared from NEHTA under extraordinary circumstances. The standards manger, whilst at an overseas standards meeting representing NEHTA, came home to find that her job no longer existed. The National Authentication Service for Health manager—NASH is used to authenticate and create access control—was dismissed summarily a few months ago. I do not think reasons were ever provided, though there were rumours of bullying involved. The terminology manager suffered a similar fate a few months before Christmas. As I have already described, the manager of the clinical safety unit left NEHTA a few weeks ago. When we inquired after her because we were concerned that she had left the premises in a distressed state, she said that she was not—

CHAIR: I should remind you of parliamentary privilege. So far you are just putting forward, but you have to be very careful with opinion as opposed to fact—as you know. It is public. I know you know that, but I feel I had to step in and put that out there.

Dr McCauley: I understand. We cannot know what the reasons are for these people leaving. They are constrained by agreements that they have signed with NEHTA. But we can observe the effect of their loss from the NEHTA workplace. There are many excellent people that work within NEHTA at the technical level, but the management has been of great concern to us. The technicians are starting to become concerned as well. The area that looks after what is called the clinical document architecture—the actual core delivery that NEHTA is providing to the wave 2 PCHR sites—has had three out of five technicians leave in the last four months. The last is leaving tomorrow. here have been serious concerns about how NEHTA is functioning internally. There have been allegations that have been aired in front of this committee about bullying in the workplace at NEHTA. We believe there is an active and ongoing investigation into that, which is actually more extensive than appears to have been agreed to by the CEO in his testimony here. There are concerns about the competence of the NEHTA personnel. The people in charge of the rollout of the IT implementations have no experience in either IT or health. I can tell you from my interactions with many of the staff that the morale within NEHTA, which again the CEO of NEHTA was asked to comment on, is at an all time low. The fact that he was unable to answer that question is in itself an issue. The fact that you have not received answers to your questions on many issues also reflects some of those problems.

Senator McKENZIE: Thank you, Dr McCauley. My question went to suggestions you might have on how we can make NEHTA accountable for its services and activities. Do you have any suggestions on the how rather than the why?

Dr McCauley: Without removing the cloak of secrecy and lack of accountability that currently covers NEHTA's activities, I believe that is almost impossible.

Senator McKENZIE: Thank you.

CHAIR: Dr McCauley, do you see that as a structural issue?

Dr McCauley: It is totally a structural issue. It really comes back to the way the board is constituted.

Senator McKENZIE: You recommend a review of the government furnished data liability issues. I am just wondering about a recommendation around how that might be achieved in terms of the incorrect IHIs, PBS and NBS information et cetera.

Miss Hossack: I think one of the submissions refers to clouds of confusion around this whole area. To be honest, the legislation is really grappling to put in place a framework which will work around something which has not fully been specified to date. Certainly it has not been tested in the field. There are just too many opportunities for omission or error in relation to data going into the record and then subsequently being found to be incorrect or in fact not being there when it should be and so forth. On the whole issue of pause, do not just stop work but also look at what work has been done to get the specifications for the PCEHR right. Get them tested first and then look at how you are going to legally put the framework in place.

CHAIR: Thank you very much. Mr Hughes, we have run out of time. There will be a number of questions on notice, as you heard earlier, and certainly I will be putting some on notice as well. Perhaps the time for pulling together that you asked for, if you do not mind, can be used in that way and you can focus in on some of the

questions we will have. We do appreciate your time and the effort you put into your submissions and we will be in contact.

Mr Hughes: Thank you very much.

CHAIR: Hansard will be available within a couple days for you to review and see where that goes. Thank you very much.

BROWN, Mr Peter Michael, Convenor, Consumers eHealth Alliance

BROWNE, Dr Eric Donald, Member, Steering Committee, Consumers eHealth Alliance

McGOWAN, Mr Russell, Member, Steering Committee, Consumers eHealth Alliance

WALE, Dr Janet Louise, Member, Steering Committee, Consumers eHealth Alliance

[11:14]

CHAIR: I welcome representatives of the Consumers eHealth Alliance. I apologise for keeping you waiting. We are, in the normal way with this committee, running slightly late, as you would know from your interactions with us over the years. Information on parliamentary privilege and the protection of witness and evidence is available. I know most of you have got that in the past. We have received your submission as No. 37. I invite any or all of you to make an opening statement and then we will go to questions.

Mr Brown: We as consumer representatives have raised a number of concerns relating to the PCEHR. We note that others have too and many of these concerns are paraphrased in the recent Parliamentary Library research paper, *The e health revolution: easier said than done*. However, we contend that most of these concerns can only be addressed through an improved governance framework. The material I am now presenting is not a summary of our submission but an expansion of our assessment of why e-health is not reaching its targets. This has been our developing view and it fits in with the excellent Parliamentary Library paper. It is not generally understood that the implementation of e-health requires an independent community wide body that can oversee the provision of the electronic networking infrastructure needed for the interoperable interchange of data which, in turn, is needed to support the increasingly complex clinical services being provided to consumers.

There is a widely accepted global understanding about the ability of an e-health system to effectively and safely interchange a person's health status and healthcare experiences and so help to improve the quality of clinical services and health advice supplied to consumers. We are also aware that this function cannot be effectively done manually; we need to employ computers.

We are advised by the IT software fraternity that they have the requisite knowledge and capability, together with the development of appropriate standards ready for when the various technology players decide to collaborate. The evidence abounds that in no small measure most industries have operational systems that are able to do this. Sure they might have operational glitches but, for the most part, these are manageable. In effect, we have an environment that is not so much limited by technology but by organisational policies and practices and overall governance. There have been several disasters with, for example, the NASA spacecraft. But, in the end, in spite of valiant attempts at management cover-up they were put down to human error. So we have the rationale that e-health infrastructure networking is relatively simple, just like doing our banking. This was the analogy that seemed to have been the prime business judgment that led the National Health and Hospital Reform Commission to recommend that we introduce the world's first national policy for a personally controlled electronic health record.

No reason has been provided as to why a decade of work associated with the so-called shared electronic health record and belatedly name-changed by NEHTA to the individual electronic health record and being prepared for introduction and approval by the end of 2008 should have been unceremoniously dumped. Not that it was likely to have been anymore operationally successful without authentic engagement with all industry sectors regarding their own specific requirements. However, the PCEHR was given priority over getting viable access to clinical records and the required information flows established first and, in that sense, it was putting the cart before the horse, which is what the NHHRC recommendations seem to be doing.

NEHTA also now seems to have regarded this as an error of judgment; hence its latter-day accession to the clinicians who demanded that their key local clinical but still unshared record be maintained as the primary record. NEHTA's marketing material now clearly states this. NEHTA has still adhered to the globally held view that has accepted that clinicians are unlikely to sign up to the PCEHR unless this is agreed. We are not aware of how the NHHRC became convinced to make this flawed recommendation and we are not aware that it was ever put to any form of authentic public discussion before its public release and official endorsement.

Of course, it was contended that the consumers would have a prominent role in the EHR, by whatever name, and it has been strongly recommended in the parliamentary and advisers health online reports of 2001, which emerged from a parliamentary inquiry at that time. The prime issue was how to best achieve that with a solely government owned management structure. We submit that this is the main issue to be resolved within the legislation. We have drafted our governance proposal in the form of an amendment to the legislation within the body of our submission and it can be referred to on pages 8 and 14.

It is our considered contention that the principal factor which has been and still is inhibiting the introduction of an e-health system that meets its key targets anywhere globally is that there has been no grasp of what business e-health implementation actually is in. Its operational development has been organisationally given over for management as though it was in the health business or alternatively the information technology business. In fact, it is neither of these. It needs to be an efficient infrastructure provider of an electronic network service suitably set up to enable the interchange of health data related to the wellbeing of each individual. The people promoting collaborative, scientific research seemingly understood this when they decided to build their own infrastructure, the Australian Academic Research Network, which has been successful and is now, in association with the NBN, extending its service to the greater challenges within telemedicine.

There is another major issue that has probably been a significant contributor to this global misunderstanding. The health industry is different from most others. We are aware that all industries think this about themselves. This is true to some extent, but a major difference with health is quite critical to the mistake made not only by Australia but in our view universally. In an IT sense, e-health has been lined up with the normal one-to-many type networking, like a bank, gas company et cetera, where there are only two parties directly involved in each data transfer, usually the central operator and the supplier and/or the customer. The central operator is the main beneficiary and so develops the product and runs the show. That is also the case with paying health bills, buying in supplies et cetera. But when a data transfer, like multidisciplinary care, involves more than one other party in the same transaction or even a series of them and in a teamwork environment, this becomes what is termed a many-to-many situation. This is not unique, but in the case of e-health, each such situation requires detailed data for a series of disparate functional situations. These detailed data must also be disparately usable when diagnosing and treating a diverse range of problems experienced differently by each individual—so a very complex situation in that sense, but not necessarily complex for the infrastructure that needs to relate that data.

The aim of our submission is to clearly establish what the actual e-health business scenario is. We then need to find a suitable way of providing the necessary support infrastructure. We suggest that dealing with this is relatively simple infrastructure wise and needs to be kept that way. We have summarised the key issues within our summary in bold. The principal issue in the limited consultation we have had with NEHTA is to keep it simple. That assessment was agreed to by the chairman of NEHTA Mukesh Haikerwal, but how to do it has not seeped through to the various levels of people that were there. We simply say that all of this depends on the four Cs, as we refer to them—communication, cooperation, collaboration and coordination—within that principle I have mentioned of keeping it simple.

CHAIR: As no-one else wishes to make an opening comment, we will move to questions.

Senator SIEWERT: I want to go to the issue of governance. I appreciate your keeping it simple because, I must admit, I am finding some of your diagrams really hard to follow.

Dr Wale: I think they are there to demonstrate the point and not to be studied in detail.

Senator SIEWERT: In terms of governance, the Consumers Health Forum this morning made some comments around the need for independence, and I notice that you have your PCEHR Independent Advisory Council. They this morning were suggesting that the current arrangements should be in place for no more than two years, that there should be, essentially, a sunset clause put in and then an independent body emerge from that process. They made other recommendations as well but, in terms of some of the governance models, would you support that the current arrangements, albeit with some amendments, be put in place for two years with an independent body then being put in place?

Mr Brown: When you say the current arrangements, I take it you are talking about the arrangements proposed in the legislation?

Senator SIEWERT: Yes.

Mr Brown: No. We would agree with the principle of that, obviously, in what we have said. But we think a two-year interregnum would be quite dangerous for the process because, as one of our graphs shows—there is a big question mark in the middle of it—there is no governance there at the moment, and there has not been governance for some time. The most urgent need we have is for a channel to bring the whole community together. As I think the AMA said this morning, we need to bring everybody together at the same time, to the same place and in the same way. That has not happened really in this process at any time. There was some pretence of it happening at a four corners roundtable sort of thing earlier last the year. That was very welcome in the way of it, but in terms of the outcomes reported from that meeting there really was no substance in saying, 'Here's what the community have had to say and here's how we have reacted to it.' The meeting had an agenda and the outcome of the meeting did not really move beyond that agenda.

That has been the process right through this event. We were interested to hear MSIA people talking about their experiences of being involved. We know from the feedback that that is not practical. To some extent they are lucky, because we have not been at the table of all as consumers in an authentic way. All the players need to be there. The complexities of these issues need to be understood by everybody and answers sorted out in a definitive way, not filtered through a multilevel bureaucratic process, which has been the experience.

Senator SIEWERT: From that I take it then that some amendments need to be made to the current arrangements while the process moves to being independent?

Mr Brown: Yes. To suggest that we have an independent body, which probably would meet irregularly, made up of representatives of a very small number of people representing 23 million people is really not an adequate way of dealing with this complexity at all. If that body is independent it should not be reporting to the operators of the system and going into that maze of activity; it should have a direct line to the minister.

In the terms of what the Consumer Health Forum was saying, and what we have been saying for two or three years, we think there should ultimately be a quite separate and independent body that becomes expert in the running of the infrastructure and the contents of the system that will flow from that, content that will never flow unless you get the basic system working. That has been the global experience. Everybody agrees with the benefit of all this, but they have not yet found the way to actually operate it properly.

Senator SIEWERT: Do you think this process will be ready by 1 July? Taking from what you have just said, I think that answer is actually no, it will not be.

Mr Brown: We have not been at the table, so we have no means of judging that situation. We hear what other people are saying. We note the doubts about it and we see that the systems, between themselves, have broken down. Somebody said that they will be fixed shortly but nothing else has been 'fixed shortly' so we really cannot answer it. The doubts are growing, obviously, in people. The general community really do not have those concerns, because they do not actually know what it is all about.

Dr Wale: Obviously Peter is expressing our views very clearly and they are unanimous. I think it is really important that it is understood that this is with us and not for us. That is why it is really important that consumers and the public have a strong voice within the governance. Obviously not all of us can comment on the operation level or the technical details, but certainly there are a lot of policy issues and values and beliefs that need to be addressed here. Often in the present situation it is the people with the loudest voice, which is usually from professional people and organisations, and that is why it is really important and we are asking for a governance structure that clearly has a consumer role within it.

This is not an IT business or a health business personally controlled electronic health record; it is more like health technology and needs to be treated in the same way, where you start with a basic model and there are quality improvements as you go along and incremental developments. That is how we work with medical devices and drugs—whatever treatments we use within the health system. We do not start with the perfect item. It is really important that our values, beliefs and needs are within this electronic health record, because it can make a lot of difference for us and actually improve patient safety and help us on the patient journey.

Mr McGowan: I will respond to the specific question as well. Perhaps the question is not: will it be ready? We do not know. It is more: what will be ready? If it is not sufficient then people will lose faith in the system. If it is overambitious then it will fall over and people will lose faith in the system. That is our concern.

CHAIR: Dr Browne, before I put my last question, is there anything you want to add?

Dr Browne: To follow on from that, it is clearly very complex. It is a lot more complex than a lot of the systems that exist at the moment. I also want to clarify a misconception that appears to be around—and I do not know whether any of you have that misconception; you probably do not. We have a lot of trouble explaining what PCEHR is to our constituency; the concept of operations itself is quite complex. It is couched in terms of simple messages like, 'E-health is here to replace the existing paper based system.' I think we even heard that this morning: 'We have a paper based system and the PCEHR is going to move us to an electronic system, a sort of utopia.' We currently have a whole lot of silos, and those silos are developed inside each individual practice for business reasons to meet the needs of that practice, and they are closed for those practices, those organisations. A hospital has a different system from a GP system. There is still a lot of paper used in hospital systems, but they are silos. The PCEHR is not a replacement for those. The PCEHR is yet another silo, and it is a silo which allows a different level of access to people. That access is open to people controlled mainly by the consumer; that is the model that is being put up in the legislation at the moment. What ends up in that silo is a copy of information from all the other silos, and we do not know what information is going to go into those silos yet. It is not just an opt-in by the patient or the consumer; it is an opt-in by each and every provider that is involved as well. I do not

think people realise the complexity of that. Not only do we have the complexity of the extra silo that providers have to now interact with in various ways; we have all these different access controls around that and we have a completely new technology. We have documents having to be sent up to the silo which currently are not capable of being produced by any of the systems now because that is not how they operate. So all the existing systems have to change to be able to provide these documents. We see the whole thing as very, very complex. We will need to have a way to manage that complexity to prioritise what we can achieve.

Dr Browne: I might just add a little piece of philosophy rather than provide a direct answer. In the consumer field the hope of e-health was in fact that it would act to break down the silo situation, which we see as the main problem of the overall health system itself. By bringing people together and forming a new form of collaboration and cooperation and communication between all of them in that way, we can start to bring that about. It will not happen in five minutes, because it did not take five minutes to get there. That is the key beyond e-health and if we just repeat the mistakes in e-health, God help us.

Dr Wale: We also do not want to repeat the paper silos on the e-health record by having a whole lot of PDFs that nobody will take the time to actually open. A consolidated view is crucial to the PCEHR.

Senator McKENZIE: I am interested in the notion of informed consent arrangements and that citizens are not being advised by federal authorities about the breadth and depth of data that the government holds and uses. You have just touched on that. How do you propose that the bills be amended to specifically address these concerns?

Dr Wale: I think, firstly, keep it simple.

Senator McKENZIE: You can maybe take that on notice.

Dr Wale: Yes.

Senator McKENZIE: I have asked a couple of other witnesses today about the definition of 'health provider' and allied health professionals specifically. I wonder whether you have views on that or whether the chair would also like that question put on notice.

Mr Brown: One of the graphs on our sheet there illustrates our first simplistic interconnection between all the health providers and consumers. As far as I have noticed, that simple graph we have shown is the only one that has health providers listed in their place, on Figure 1 in our submission—

Senator McKENZIE: Do you define 'health providers' as somebody who is registered with their professional body or is it the dietician or social worker that we might have heard about earlier this morning? How would you define the 'health provider'?

Mr Brown: He is the one who is actually giving the service to the patient and sending the patient a bill in the end for that service. If they organise an association that is to do with the carrying on of their business in a more orderly way. That has a place—it is an essential place. But we are actually dealing with a person-to-person thing, not with associations and that sort of business and, we hope, not with bureaucracies.

Dr Wale: I think the important point at the moment is that, with a lot of referrals and treatment between different providers—and I am using the term in a general sense—a lot of crucial clinical information is not given to the other provider, whereas within this system they will actually know they have got something that will affect how that provider treats the patient. So allied health is an important component of this.

Mr McGowan: So it is the patient who decides who the carers are that they want this information to be accessible to. In my case, certainly, it would include allied health, as well as medical practitioners.

CHAIR: I am going to put on notice two questions and there will be many more because, as you know, different senators have not been able to be here today. One is to do with the issues around privacy. Your particular submission did not go into great detail about that, whereas I know it is always a big issue for consumer networks. I would like to get some more information, on notice, from your perspective about that.

There was another issue, as to whether your group has the same view on the nominated provider as the consumer forum that gave evidence earlier. You said, Mr McGowan, that you wanted to determine who got the information. I would like to get some information back, if you are willing, from your group about the whole thing of access and who should have access and all those things. I want to flesh that out. We will get those questions to you as soon as possible.

Thank you very much for attending, and thank you very much for your extensive submission.

CLARKE, Dr Roger, Chair, Australian Privacy Foundation

FERNANDO, Dr Juanita, Chair, Health Sub Committee, Australian Privacy Foundation

[11:39]

CHAIR: Welcome. Information on parliamentary privilege and the protection of witnesses is available. You have both given evidence before, so you know that. But, if you have any questions, the secretariat is available to you.

Do you have any comments to make on the capacity in which you appear?

Dr Clarke: I have a 40-year background in the IT industry, in particular in the e-business, security, consumer rights and privacy arenas. I am a visiting professor at two universities in computer science and law, but I am appearing in my role as Chair of the Australian Privacy Foundation.

Dr Fernando: I am a lecturer at the Faculty of Medicine, Nursing and Health Sciences at Monash University. I am also a health informatics researcher and I convene the honours degree for medical students. I am here today in my capacity as Chair of the Health Sub Committee of the Australian Privacy Foundation.

CHAIR: We have your submission; thank you very much. I now invite both of you or each of you to make an opening statement and then we will go to questions.

Dr Fernando: I want to congratulate the Australian government more generally about the focus on e-health. I think it is a timely and an appropriate focus—that is, the focus on e-health and the way that e-health can benefit patients. Essentially, we have three fairly deep concerns. The first one relates to governance in the sense that there does not appear to be any accountability. In terms of freedom of information and so forth, I would point to NEHTA. The second point relates to the retrofitting of governance policies and protocols. The third point relates to the fact that e-health is now coming under the auspices of the DoHA secretary as the services operator, which means that there is no independence between the governance of the PCEHR system and the government interests that are involved in it.

I am also concerned about ongoing project failure. Our point of view is that there has been project failure after project failure. I will give you an example: the declared outcome for the IHI, the individual health identifier, was that we would be able to identify the right patient at the right time in the right place. That in fact has not been able to be validated. Standards are a mishmash. There is not a single international or national standard that applies across the e-health sector; rather, we have borrowed from standards all over the place.

There are issues in terms of informed consent, because nobody knows precisely what the roles, rights and responsibilities are of all the players—patients, administrators, clinicians and so on. There is no workforce training so that, when I talk to my medical students and my colleagues, nobody knows what a personally controlled electronic health record is, let alone some of the nomenclature that goes around the personally controlled electronic health record.

Finally, I am really concerned about safety. There seems to be no focus on ongoing patient safety concerns. I am now talking about, for instance, bridging software to link the personally controlled electronic health record to practice software. We are talking about NASH. I do not know what has happened with NASH. Again, in terms of the individual health identifier and the validity of data stored on an individual health identifier, there does not seem to be a very reliable way of ensuring that the IHI that you are dealing with is in fact the IHI of the patient in front of you.

CHAIR: Dr Clarke, do you have some opening comments?

Dr Clarke: No, thank you.

Senator SIEWERT: You raised a wealth of issues just then and also in your submission. Can I go to your proposals regarding how we resolve the governance issue. We have heard a number of proposals. To start with, can you quickly outline how you see us resolving those issues.

Dr Fernando: I do not think they can be quickly resolved, but I think the key issue here is transparency. One issue that the Australian Privacy Foundation has been grappling with over several years is transparency. Various reports are released at various stages, quite often too late to actually be included in the submission. Everything seems to be arriving at the 11th hour. Nobody seems to be held to account for the project failure that I referred to in my opening statement. So it seems that, while there might be one set of goals, aims or accomplishments that are publicly released or publicly available when NEHTA starts to investigate a particular avenue of implementing the PCEHR, in fact that ends with a whimper. The goal is never completely achieved. In fact, quite often, it is

either not achieved at all for just slips off the agenda like NASH. I have not heard anybody talk about NASH for ages from NEHTA.

I do not think there is a simple answer to the question, to be perfectly honest, but I think transparency is a really good start. I also think that it is really important to engage with civil society in a way that NEHTA has not done thus far.

Senator SIEWERT: Dr Clarke, did you want to add something?

Dr Clarke: Can I just add a few things to that, please. We submitted many, many times to NEHTA and DoHA over the last three years trying to achieve engagement and failing, because NEHTA and DoHA have both refused to engage effectively and have excluded privacy and consumer advocates from any meaningful consultation processes. We submitted quite specifically a document about a year ago to NEHTA and DoHA, which perhaps we did not include in the batch that we submitted to you. Perhaps we should include that as a follow-on the evidence.

CHAIR: That would be useful.

Dr Clarke: In addition to the transparency issue, there is the representation issue. Our perspective has always of course being from the consumer and privacy as subset of consumer concerns. So this orientation is towards that. We did not feel we needed to fight the battle on behalf of the clinicians, because although they were excluded until about two years ago, once the change finally came and one CEO was removed and a replacement CEO came, the recognition did arrive that clinicians needed to be engaged. Unfortunately, that appreciation and understanding did not extend to consumers and privacy advocates. So we have had to battle for consistency of process.

One of the obvious things is to ensure that there is corporate memory—that all of the developments are cumulative ones, that conclusions reached and undertakings given at the end of one round carry through to the next round. It has been refused and declined on every occasion that we have attempted to achieve consistency. There is no coherence and no integration. There has been one occasion when the consumer groups have met in conjunction with clinicians. We have being excluded from that kind of an arrangement. We have been held off to one side throughout. So fixing each of these blunders that have been made serially by DoHA and NEHTA is very important as part of the fixing of governance.

But another facet that now matters, which did not matter back then so much, is that now that we are reaching the point where something may or may not come into existence if not on 1 July then at some point later than that, we have a merely advisory role for these organisations, for these interest groups. Governance is not just about advice; governance is about actually being able to influence and cause change and cause changes in direction. Now we are trying to cause change in direction, it appears, for the super bureaucrat, because the super bureaucrat has been put in charge of the entire undertaking. The purchaser-provider arrangement seems to have gone out the window. All control is now vested in an entirely inappropriate governance arrangement. So switching back to the principles of governance and actually applying them is what we would recommend. We believe the current arrangements are simply inappropriate.

Senator SIEWERT: I hear what you are saying. What we have got to do is write a report making recommendations about what amendments or changes should or could be made. The Consumer Health Forum this morning, for example, said that looking at what is in the current bill there may need to be some changes there but definitely write in a sunset clause under the current arrangements and move to an independent body. What I am looking for is what recommendations we can make to deal with the issues that you have raised. What would you say would be the things that we could recommend to deal with some of the issues raising, bearing in mind I realise that they cannot all necessarily be fixed by the suggested date of July 2012.

Dr Clarke: We do not believe there should be a commencement of operation with the current governance arrangements. Therefore, we believe you should recommend a completely different set of governance, an orthodox governance arrangement, which does not just have an advisory arrangement with consumers and possibly—although we do not think there are any—privacy arrangements. There is at least some consumer representation in the advisory panel, but advisory is not sufficient. It has got to be a board which includes representation which has responsibilities. So I believe you have to rewrite it. That is the only way I believe that governance can be fixed.

Senator SIEWERT: In other words, to a truly independent body?

Dr Clarke: Yes, absolutely.

Dr Fernando: Yes.

Senator SIEWERT: The point that was made this morning is that these changes are going to take some time, so you put a sunset clause in. Do you see the potential for that sort of, essentially, compromise—that you go with some of the arrangements that articulate in the bill, perhaps with amendments, with a sunset clause with the shift to then an independent body being put in place in, say, two years?

Dr Clarke: 'Compromise' is the relevant word. It would compromise the public interest to do that. If you permit the bureaucracy to build it the way it wants it, it will be set in stone. There will be so many things that will be unable to be reversed, because they would be designed to be unable to be reversed. So it is not appropriate to commence that way. The bridging notion to me is caving in and permitting the government agencies to do what they wish.

Dr Fernando: And quite apart from that, the roles and responsibilities of the services operator are not defined in any case at the moment. So you could not leave the legislation as it is. I would not support leaving the legislation as it is now with a services operator who has a completely open job description. I mean, the job description of the services operator presently, as far as I am aware anyway, does not exist in the public domain. What are the roles of the services operator? What information can the services operator ask for? How can the services operator use information? How can the services operator disclose information? No-one understands the role of the services operator. So whilst a sunset clause might be a useful compromise, before you could implement or even look at a sunset clause, you would have to look at the rights, responsibilities, the role and responsibilities, and the role and the limitations of that role, of the services operator.

Senator SIEWERT: All right. So you would need to make other amendments to articulate that first.

Dr Fernando: Yes.

Senator SIEWERT: Okay. Thank you. That is the sort of thing that is extremely helpful for me.

I know that time is short. I did have a specific question. You talk about the minimum terms, rights and responsibilities for individuals and healthcare providers' participation in the context of the system specified in the bills, and you talk about the fact that there is no complaints mechanism embedded in the bills. That would all need to be part of the governance arrangements—that, surely, is all part of that, isn't it?

Dr Fernando: Yes, that is precisely right. I had a look on the web a couple of days ago—I think, Thursday or Friday—to look at the complaints mechanisms for patients who are enrolled in the personally controlled electronic health records system. There are huge gaps. You could drive a truck through some of the gaps in the responses. The simple question: 'How can I find out about who has accessed my record?' And so on and so forth. From our point of view and from the number of consumers that are contacting the Australian Privacy Foundation we know that that in fact that mechanism is urgently required; it is not something that can be deferred, it is not something that can be gate kept, and it is not something that you can empower a third-party to organise. Consumers want direct involvement in their personally controlled electronic health record.

Senator SIEWERT: In terms of access we talked this morning about the access and the no access and the changes. There was a very strong message that this is a deal breaker—that if the legislation does not include a no-access provision, consumer support for this process would be withdrawn.

Dr Fernando: Yes.

Senator SIEWERT: I am presuming from your comments just then that you feel similarly.

Dr Fernando: I feel similarly. I am not speaking to the foundation now; I am speaking for me, because it is something that I have not had a chance to in fact discuss with the rest of the foundation. But, yes, I think that would be a deal breaker. Certainly based on the day-to-day correspondence and communication that we have had with patients, I think you are correct in that that would be a deal breaker.

Dr Clarke: Yes, the tenor of discussions on the board have been entirely consistent with that. So I think we can do policy on the run on that one. Can I just add to that that if we are extending the governance scope to include the complaints handling, we have been submitting from the beginning that the Privacy Commissioner—who seems to have been swallowed and now we talk about the Information Commissioner—the federal commissioner, is not an appropriate repository for all of the responsibilities. There are a number of reasons for that. Some of them are jurisdictional. Some of them have to do with the very limited powers that the Privacy Commissioner has and the very limited additional powers that would be granted. Others of them have to do with the fact that, for the last seven years, the Privacy Commissioner has not been protective of privacy and does not enjoy the trust of the privacy advocacy community. So, for all of those reasons, the Information Commissioner's office is not an appropriate organisation to be doing this.

We submitted from the beginning that there had to be a specialist arrangement developed here for complaints handling. We have not seen that. DOHA has ignored those proposals, as it has done with so many of the submissions put to it. It is completely unclear to us quite how the mechanisms could work right now, because there are a great many state government and territory government organisations that are involved in healthcare provision. The whole of the private sector is involved. There are many instances where an individual may be subject to, at different times, each of the private sector provisions of the Privacy Act, several privacy provisions within state acts, acting as individuals—self-employed, shall we say, or employed by their own companies—and may also be subject to state acts by virtue of their working as contractors in hospitals, surgeons. Then heaven only knows what happens when the surgeon hires time in a state government operating theatre—whether he or she is subject to state law, private sector law and whether it is of the state or of the Commonwealth. I am sure the surgeon does not know. It is not our job to give advice, but I am sure we do not know.

There is enormous complexity. That is not DOHA's fault; that is a constitutional matter. But those sorts of things have got to be clarified. I think there are enormous gaps in the process at the moment. Bear in mind that this is all in the context where we have enormous gaps that are identifiable in the offences and sanctions provisions. Despite all the submissions and despite what we thought were undertakings, it is not a matter of civil responsibility and liabilities backed up by criminal liabilities. There are no criminal offences that have been built into the healthcare component. Yes, there are these bits and pieces lying around of official secrets acts and God knows what, which have never have had a great deal of impact.

We have submitted—and we thought we had an understanding—that there would be civil and then criminal for the more serious instances. It is not there. We do not have the assurance that complaints processes will be conformant with standards and expectations of how complaints processes should be handled. We are not quite clear as to whether there is a single port of call, a single portal through which complaints can be submitted. The sanctions are very light. Enforcement depends upon resources. We are not clear that there are going to be sufficient resources for whoever is going to handle this. The basic situation that we reach is that, even if there are some quite serious instances in the early stages, we do not know whether they can be dealt with. So it is a completely unsatisfactory arrangement—on the complaints, that small portion down the bottom end of the governance structures.

Dr Fernando: Attached to that confusion is the confusion of the clinicians themselves. If you talk to clinicians about e-health tools and you talk to them about devices and you talk to them about various applications, there is so much misinformation as well as noninformation out there. That misinformation and that noninformation is actually preventing clinicians from using the tools that are legitimately useful, in terms of proof of purpose having already occurred. This is preventing clinicians from legitimately using equipment because they are so confused and they are so concerned. The entire area of medico-legal liability is so grey that there is a really urgent need to start addressing some of those legitimate concerns about the legislative parameters of e-health. It needs to be done now, not in two years. It needs to be done quickly. Clinicians need to feel confident. They need to know what they are using and why they are using it. And patients need their clinicians to feel confident in what they are using, in terms of getting a good diagnosis. At the moment, what we have is a vacuum.

Senator McKENZIE: Dr Fernando, I was interested in your comments about medical students. We heard some comments earlier this morning about the Australian Medical Students Association and their role in access, no access et cetera. It would be interesting, given your other role, if you would like to make some comments around that.

Dr Fernando: I am assuming that the feedback that you heard this morning was about medical students requesting access when they were on rotation and so on.

Senator McKENZIE: Yes.

Dr Fernando: From my point of view, so long as authorisation is appropriate—and I believe that there is an appropriate authorisation mechanism in place—then I would support medical student access. Getting back to the issue of transparency, I also believe that patients need to understand that medical students will have access to their health records once they have been appropriately authorised. My primary concern about medical students—because that is more a nuts and bolts thing that is really easy to sort out—is that out of all the students in the five-year bachelor of medicine or bachelor of surgery there are two to three students who are aware of the personally controlled electronic health record and that is because they were working with the clinical lead from NEHTA. When I talk to surgeons, heads of huge hospital departments and other clinicians such as general practitioners or medical students in first year, second year or third year, I find that they have not got the remotest idea about this. Last year, we ran a class on the use of mobile devices for health care. I was fascinated to have to spend the first three hours of the class going through the nomenclature and explaining what an electronic health record was. I

was explaining to these students, who are going to be future practitioners, what a personally controlled electronic health record is.

Senator McKENZIE: From your experience, there has been no engagement at that level.

Dr Fernando: Absolutely no engagement.

Senator McKENZIE: I might flesh that out further in some questions on notice. The other question that I have goes to definitions of health providers. I am interested in the accountability mechanisms, from registration to the more typical definition of what a health provider is and how that plays into accountability and protection for consumers and also notions of holistic health delivery through this.

Dr Fernando: That is a really interesting debate in terms of medicos. You have hit the nail on the head. There is no simple answer. Someone answered earlier on that they would like to write an in depth response to that question. But, in short, basically you need to involve patients in what the definition of a healthcare provider is. You need to involve universities and training organisations. You need to involve the royal colleges. You need to involve all of the professional associations and bodies. You have to ensure that practitioners involved in alternative healthcare practices are also involved. I do not know a great deal about alternative health care, so I do not know if there is a professional body for alternative health—I cannot comment on that. But all of those stakeholders have a vital role to play in defining what a healthcare provider is. I have heard 'healthcare provider' defined differently in different locations—for instance, I have heard Meals on Wheels staff defined as healthcare providers. Speaking for myself, I do not think that I would be particularly comfortable if a Meals on Wheels staff member was able to look at my personally controlled electronic health record and look back over my medical history. That information made be germane to my general practitioner. I might have had an episode of depression 30 years ago. I would not be comfortable with my Meals on Wheels provider knowing that I was clinically depressed 30 years ago.

The truth is, I do not think that there is a simple answer. I wish that there was. The whole industry wishes there was, to be completely frank. But it is something that we can come to together. I have made this point several times to NEHTA and DoHA before. People have rights and responsibilities. That does not mean that everything goes your way and it does not mean that every conclusion reached is the conclusion that you wanted reached. We all have rights and responsibilities. It is really important to bring all those people to the table. Maybe we need to articulate their rights and responsibilities. But I think that you could define 'health practitioner' for the purposes of a personally controlled electronic health record quite quickly. I do not think that that would necessarily take a long time. It is an undertaking that is quite important and it would be a very positive step for the government to take.

Dr Clarke: To me, this strikes at one of the major problems in the project. Up until now, we have been fairly clear as individual health consumers about the localised nature of our dealings with a healthcare provider. This system moves to a generalised and centralised record, with all of that stuff poured into one record which is then readily available to our healthcare provide. So instead of it being situational and localised—with everyone knowing what they need to tell the dietician, what questions were fair questions and what things I was not going to them—and an environment in which the consumer had a fair bit of control and understanding, we are moving into we are not sure what.

Bear in mind that this links to one of the major problem with the whole conception of a PCEHR. If we were going to target the real issues and concerns of people who suffer significantly from health conditions, we would pick an array of chronic conditions and complex conditions, or co-morbidities, which is what my nurse daughter tells me I should say. We would look at those sorts of things where people have real problems and really want healthcare treatment teams to have access to quite a significant amount of data because of the complexity of what they are dealing with and its long-term nature. We would focus on those things. Then we would get enormous payback for individuals and we would also get enormous payback for taxpayers' dollars, because we would be focusing on the kinds of things where we can save money and still come up with better treatment.

What does the PCEHR do? None of that. It is totally vanilla flavoured. It is, in effect, targeted at largely the healthy people, because the stuff that is going to be on there is only going to be of so much interest. It will only get so far. It will not be getting to the point of actually helping to deal with chronic conditions. You link all of those things together and you think: 'Well, why are we here? Why are we investing these sums of money in this kind of a vanilla flavoured thing?' It could be of great value to administration. It could be of great value if the insurers are allowed into this. It could be a lovely source of data for research. But what has it got to do with patient care? Far, far less than it should have.

Senator DI NATALE: I have got a question about informed consent and point number 12, where you refer to the various databases and the question of merging the databases and then go on to talk about one of the options for providing informed consent around that and publicising the details of the centralisation. The tricky thing is that it is hard enough for somebody who is engaged with this issue to some degree to understand. How would you actually practically provide informed consent around a really technical question like that in a meaningful way to the average consumer?

Dr Fernando: Actually, the role of drawing should not be underestimated.

Senator DI NATALE: Sorry, the role of—?

Dr Fernando: The role of drawings or illustrations should not be underestimated. I think that it is quite a simple thing to devise a diagram of co-located data. That is really not as problematic as it sounds. I am not a technician, so I am not someone who can do technical drawing. But I am sure for instance that, if you spoke to someone from the MSIA, they would have people who are very well skilled and very well qualified to simplify that data in a meaningful way so that the community was able to look at where information had been co-located or where information had been integrated and harmonised. It is quite a simple matter then to draw a diagram that shows how that information is accessed. It is not a terribly complex undertaking. It is not something that I feel qualified to do, but it would be something that a technical person could certainly do. There is a word for them; I cannot think of the terminology. But there is a word for people who do technical design, technical specs. That would be quite a simple thing for someone who was accustomed to devising technical specifications.

CHAIR: We will put that question on notice with all the other questions on notice that we have put to them. Senator Furner had to go to another meeting, but he was particularly interested in asking a question about the opt in, opt out process. We have had a number of witnesses today who were very keen on the opt out model. Your submission actually strongly argues for the opt in model. So, he wanted to get something on record from you as to why you prefer that.

Dr Fernando: Essentially, the first thing is that the PCEHR system as it is presently designed—and I know that there are all sorts of holes—basically cannot cope with an opt out system. In order for an opt out system you would need to register not just all the patients but all the health practitioners and health providers. I imagine there would be a whole range of other health professionals that we would register as well. As present, we have something like one per cent of health practitioners registered for an individual health identifier. If we were looking at a release date of sometime in the middle of this year, I do not believe that we would be able to recruit the other 99 per cent and do the system redesign that is required to populate the databases that would support an opt out system. The other issue with an opt out system is the issue that Dr Clarke was talking about, in terms of whether this system is designed to support and care for people who need healthcare or devised for healthy people. Healthy people basically do not look at the issue of opting in or opting out until they are sick. When I say 'until they are sick', I am talking about until they have got the flu or until they have broken an arm or until they have broken a leg. People have complex illnesses, people have chronic illnesses. They look at the issue of their health care. But, essentially, in the New South Wales experiment, which was two or three years ago, I was absolutely blown away by the number of patients who only discovered that they had been opted into an electronic health record system when they tried to opt out. They had gone to receive some health care, realised that they were part of an electronic health record system, that they had no consent role in terms of registering them or their children, then tried to opt out, unsuccessfully, I might add.

CHAIR: Because they were already in? It was too tough to get them out in that sense?

Dr Fernando: It was too tough to get them out. The hospitals could not get them out. Once they were in, the hospitals could not get them out.

CHAIR: We will be asking the same question to NEHTA and DoHA.

Dr Fernando: So the answer is twofold: one is that it is capacity.

Dr Clarke: If I can just add to that: the whole of this arrangement in health care data, let alone e-health records, has to do with trust. Up until now it has been a case of trust and credibility between the healthcare professionals in various settings and the patient. Now we have the state interposing more and more in these environments. We are now building in a question: do we have sufficient trust and are we earning sufficient trust by the patient of the state which is interposing, taking control of data, building infrastructure and then doing I am not sure what with all the data? I think the scope for cynicism and distrust to work against honest and open information flows from patients is enormous and that is extraordinary against the interests of consumers and indeed against the interests of the whole healthcare system.

Dr Fernando: In fact, there is research from New Zealand and also from the United States that actually backs up the point Roger has just made in terms of the importance of trust, the intention of patients and the actual act of patients to provide misinformation in wanting to protect their privacy and a lack of trust between the patient concerned and the healthcare provider.

Dr Clarke: The HealthConnect case in New South Wales is a trail of disaster, because they began by creating an exemption for the key element of the Information Privacy Act in New South Wales in order to enable it to be an opt-out arrangement. Not only did they then shove everybody into the system that were in the geographical areas that were subject to the trial but they also made it extremely difficult, partly by accident and partly by design to ever actually effectively opt-out. The credibility was zero and it is no surprise that it was a failure of a project. We do not want that. We are both in IT, we are both pro technology and pro appropriate applications of technology. We want to see e-health be effective. We believe that forcing people to opt out of something like this—enrolling them by force will work seriously against effective application of IT in health.

Dr Fernando: Again, if I can add: there are two pieces of research, one imminent, one already published, which show that the majority of Australians do not want to be involved in an opt-out personally controlled electronic health record. One piece of research shows 56 per cent of Australians—this is multistate research—and the other one shows 84 per cent.

CHAIR: Who is going to publish that? You said it was imminent.

Dr Fernando: One is imminent. I can get that to you. I do not have that information at hand. I am really happy to pass on the information.

CHAIR: Thank you for your evidence. There will be questions on notice and the secretariat will get that to you. If you think of anything you want to add, please get it to us.

Dr Fernando: Thank you.

Proceedings suspended from 12:13 to 13:14

ANDERSON, Ms Abbe, Chief Executive Officer, Metro North Brisbane Medicare Local

GIBSON, Mr Mark, eHealth Manager, Health Industry Exchange

McLEOD, Mr Adam, Director, Strategy and eHealth, Inner Melbourne East Medicare Local

CHAIR: I welcome witnesses from Medicare Local. Thank you very much for your patience. Information on parliamentary privilege and the protection of witnesses is available to you, but you can always get more from the secretariat if you need it.

We have your submission—submission 47. I ask any of you, or all of you, to make an opening statement and then we will go to questions.

Ms Anderson: Thank you. I will make an opening statement on behalf of the three of us, if that is all right?

CHAIR: Sure.

Ms Anderson: Firstly, I would just like to take a few moments to thank you for inviting us to come and speak today about our experiences. I will be sharing about our role as the lead primary care implementation sites. I assume many of you are familiar with the work that we are doing, but I am going to give a brief summary of what we have been up to so you understand our role. Then we are happy to take any questions that you have, both about our role or other things that you have already been speaking about earlier today.

For the past 12 months we have been testing systems and processes in our local regions to prepare for the introduction of the national PCEHR in July of this year. In a little bit more detail, that has included things like recruiting and training approximately 300 general practices across our collective regions. We have been assisting those practices to obtain patient IHIs, or individual healthcare identifiers, from Medicare Australia and to incorporate those into their clinical software. We have been assisting general practices and providers to enrol and register, and to gain access to the HPIIs and the HPIOs, which you know as the health provider identifiers for the organisations and the individuals. We have been establishing local secure data repositories. We have been developing patient information consent materials and documents, and assisted registration processes. In fact, we are on the cusp of recruiting the first patients into our local projects. Our projects are meant to run until the end of June, and we are in discussions with NEHTA at the moment about transition over to the national PCEHR.

The main point of our local implementations through all of those processes that I have described though has been to discover, feedback and resolve the inevitable problems that there are with those various systems and processes. As you would understand, most of those are brand new and have never been tried or tested in a real world setting before. We have been working very closely with NEHTA, with DoHA, with Medicare Australia, with the software vendors and others to try and make sure that everything is tested and ready to go in time for the national implementation in July.

The question arises: why do we do that at a local level ahead of the national implementation? From my point of view, it is a very easy answer. That is, that it is not really sensible to implement such a complex system across the whole of the nation without having tested it somewhere first. In a nutshell, that is really what we have been trying to do. As I say, we are very happy to answer questions about each of those things or the projects overall.

I do not particularly have comments on the legislation itself other than to say that we do hope the passage of that legislation does not get held up, because it is obviously a very important part in order for all of us to continue and to be able to meet the deadlines that we would like to see happen. We are quite prepared to explain how we could see those deadlines being met in our local areas at the very least.

I might end there and invite my colleagues to make any further comments if they would like, and/or if the panel would like to ask us questions. Gentlemen?

Mr Gibson: No.

Mr McLeod: No.

Senator SIEWERT: Thank you. Maybe we could start where you just left off? There has been a lot of criticism about the time lines for the beginning in July this year, 2012. If you could go further from where you just left off about how you think—and do you think—that those timelines can be met?

Ms Anderson: We are working closely with NEHTA at the moment to work out the plan for transition. My understanding of how things are at the moment is that there will be components of the national system that we will be able to start implementing, certainly in our local areas, where we already have systems in place and where we already have momentum, people on the ground and practices that are already trained. We will be able to start implementing those parts of the system that are ready. We will be able to do that from the end of our project, which is 30 June. I really could not comment on the rest of the country and how ready other places will be. But in

our case, with a number of things falling into place, like legislation being passed et cetera, we are ready to implement those things.

Mr McCleod: Just to be clear, in terms of readiness, are we talking about our local system as opposed to all of the components of the national system going live prior to that date?

Senator SIEWERT: Yes.

Mr McCleod: Okay.

Senator SIEWERT: You obviously feel that you are on top of your IT requirements for setup. Is that correct?

Mr McCleod: We have repositories set up in each of our jurisdictions. We have basically been testing the software to a point where we feel it is ready to go. There are some specification changes that we know NEHTA is looking at. Barring significant changes that come out of those we think we have something that is ready to go.

Senator SIEWERT: Is the Queensland Aboriginal medical service—QAIHC—part of your Medicare local?

Ms Anderson: No. We have the Institute for Urban Indigenous Health as a member of our Medicare local, and one of their members is QAIHC.

Senator SIEWERT: One of the issues that came up very strongly this morning was Aboriginal medical services. The point was about particularly remote areas. I know you are not remote, but how prepared do you think the Aboriginal medical services you are involved with are? Do they have the IT requirements and the resources to effectively implement the system?

Ms Anderson: We are targeting a number of different specific cohorts of patients to enrol in our initial project. We call them use case cohorts. Certainly the Aboriginal medical services in our region are one of those groups. In terms of their software readiness, I might ask Mark whether he has a comment on that. But as far as I am aware, like all of the other general practices we are working with, they use a particular software package that many of our other practices use. So they can be involved just like all the rest of our general practices can be, and they are certainly one of the groups we are working with to recruit early on.

Senator SIEWERT: So you think that the Aboriginal medical services in your area will be ready to start the process in July.

Mr Gibson: From a technical perspective they use similar systems to other general practices in the area. I am not up to date on the very latest from the working team in that area. But, having been exposed to that for a number of years, I can say that they have very similar systems. The issue with each of the cohorts is getting them ready to transition their members and their groups. Different groups are going at different paces. Aged care, Indigenous, allied health and chronic disease areas are moving at different paces. Maybe it is something we could take on notice if there are any specifics there that we can come back to you on.

Senator SIEWERT: That would be appreciated. Thank you.

CHAIR: Is there anything in Melbourne, Mr McCleod?

Mr McCleod: In the inner eastern suburbs of Melbourne there is a relatively low Aboriginal population. There is an Aboriginal service there, but we are not particularly targeting them as one of our use case cohorts.

Senator SIEWERT: Why is that?

Mr McCleod: Because of the low Aboriginal population we have in that area, not because we were moving away from them or anything like that.

Senator SIEWERT: I do not know whether this is a question that you can answer. We have had a lot of discussion this morning about opt in versus opt out. How are you targeting your patients? Are you proactively encouraging them to opt in? And do you have a preference for opt in or opt out?

Ms Anderson: I'll start with the second half of that question. Opt out would be easier. Opt in is the model that we are all following. I think opt in is quite good from the point of view that, for people who do have a serious concern about sharing their information and do not want that to happen, they do not need to opt in to the system. With respect to the first part of your question in terms of how we are targeting patients, we have a very specific targeting methodology, which is mainly based around our general practices. We are ready, but we are just waiting for the go-ahead to start sending out letters from our practices. We are helping the practices that are participating to put out letters to all their patients, to invite them to consent to and register for a shared record, should they want one.

It is an assisted process where we assist with that. Once that record is prepared and is ready, a placeholder is put on the system and the next time they visit their general practice that GP can upload a shared health summary, in conjunction with the patient, in that consultation. That is the main methodology that we are using to recruit

patients. We do have these specific use cases around after hours, aged care, Aboriginal medical services et cetera. Some of those follow a slightly different pattern—for example, with after hours. Adam may want to speak to this, but there is a slightly different model there.

Mr McCleod: Because the after-hours model that we run basically uses GPs from the surrounding area and they all give up their time to form a collaborative that runs the after-hours service, the patients who go there are not regular patients of the after-hours clinic. They are patients who have gone there because they have a particular after-hours need at that time.

In those kinds of areas a mail-out or something like that will not work. So we are looking at basically using things like tablets or kiosks where people can actually go up and fill in their details and register or just use a pen and paper. That is our least favourite option because it is the most complicated in terms of getting it through the system, processed and registered et cetera. To be honest, we do not know which of those will be the most effective. There are various levels of how difficult it is on our side to administer each of those and the costs associated with them. Part of what we are doing is trying to put out various methods of doing it so that we can feed back to the national body and to others, to say, 'These are the four or five things we have tried. These two worked really well; these ones did not work so well. We thought using a pen and paper was a great idea at the start, but it turned out that pen and paper does not go so well.' We do not yet know the answers to those questions, but that is part of what we are trying to find out.

Ms Anderson: One of the things we will know in the next few weeks and months is the response from patients so, as letters go out to literally tens of thousands of patients, we will be very interested to see how quickly and how many people reply and actually want to participate in the system.

Senator SIEWERT: When you are sending out the letters, you obviously explain what it is but do you explain the pros and cons: these are some of the frequently asked questions and things like that?

Ms Anderson: Yes, and we have websites and all sorts of brochures, posters and other materials to back up all of that—all of the consent documentation et cetera and all the approved versions that have gone through NEHTA and DoHA to ensure that we are using information that is agreed across all of the different providers who are involved. I have not personally seen all of the Q&As that are up there, but my understanding is that we are trying to cover off all the different issues so that people genuinely have informed consent about what they are doing. We expect, though, that GPs will end up having to answer a lot of those questions. Patients will receive the letter, some will fill it out and send it back. Others will probably take it with them when they see their GP and ask quite a few questions about it. We are trying to make sure that the GPs and the other practice staff are very well informed to be able to pass that information along to the people.

Mr McCleod: And the better that we can communicate that information in those letters et cetera, the fewer questions that will come back to the GP and the more open to participating the GPs will be.

Senator SIEWERT: Did you say that they are just about to go out?

Ms Anderson: That is right. That is the other thing that we are monitoring—the amount of extra workload that would happen for the GPs on account of people coming back in with either questions or wanting to be assisted with the registration of the practice.

Senator SIEWERT: That leads me to my next question, which was about the resources. I do not know if you have seen the AMA submission—

Ms Anderson: Yes.

Senator SIEWERT: The AMA have made recommendations around additional funding for establishing the system in the first place, but then the rebate, if I understand it correctly, for each patient basically because of the increased need for time spent uploading information et cetera. Are you also monitoring how much those costs are going to be as part of the process?

Ms Anderson: That is what we are trying to do. Once we get to the next stages of the project we will see what the response rates are like, how many people come back to their practices for help and the number of people who show up for their shared health summary to be uploaded. That is part of what we are trying to actually ascertain: is there a dramatic impact or a significant impact on the GP's time? It is part of the information we help build.

Mr McCleod: I think it is fair to say that we are fairly confident that our GPs will let us know if it is becoming too much or a burden et cetera.

Mr Gibson: And the GPs are on the committees and, Adam, I know there is some work done in Melbourne in terms of estimating activity and time, and having a close look at both the processes and the time involved. It is an

important topic and it is something that is being discussed through the committees and is part of the focus of the work that we are doing.

Mr McCleod: From the feedback from our GPs so far, with our system it is not so much the process of how they upload a record that they are concerned about; it is predominantly the consent and the questions they are going to get around that from patients, and what they are going to have to do to data cleanse their own records so that the antibiotics they were on three years ago when they had the flu have been removed from their system, so it is not a thing that is being uploaded to PCEHR. For them to cleanse their records prior to doing that, that is the bit that started them thinking: 'Hang on, how are we going to that? How do we account for our time to do that?'

Senator SIEWERT: Yes, thank you. As you know, there have been numerous issues. Another one is the no access issue. As we said earlier, consumers say this is deal breaker, that people need to be able to say, 'no access on certain records', and that they are feeling fairly strongly about it. Have you dealt with that issue at all or how are you intending to deal with that issue of people saying, 'I want no access on this particular part of my record'?

Ms Anderson: In terms of the patients that we have had involved in the past, we have not actually had that come up as an issue. Having said that, we are aware that that is a very important issue for the general public and will no doubt be for many patients as the PCEHR is rolled out. My understanding is that the system is certainly built in such a way—and certainly what we are working with is built in such a way—that patients have those options, so they can limit the care team providers, the people who can access the record overall. I believe they can also limit access to certain portions or ask the GP, for example, not to upload certain things as part of that shared health summary.

Senator SIEWERT: The consumers are not happy with the way the bill stands at the moment.

Ms Anderson: The consumers who we are working with, yes.

Senator SIEWERT: No, the consumers we heard from this morning are not happy with the way the bill is structured at the moment in terms of the controls over access.

Mr Gibson: The national PCEHR has a set slightly different controls in terms of consumer access. In terms of the projects that we are doing locally, there are controls over whether your record is uploaded and who can see your record. That can be totally blocked or it can be enabled on a selective basis. Those choices are made by the consumer. It is a model that is done in conjunction with the GP in the first instance, so we are testing and validating those different types of tools for the consumer to say what they like and what they do not like, what works and does not work. To some degree there is a lot of learning that needs to go on there. We can have lots of options and lots of choices and lots of websites can go through and configure privacy options; at some point we need to learn what actually happens on the street with consumers and with GPs and what works best and what is going to be most practical. To some degree the options we put in place are quite varied, and there are lots of choices there, so that we can get different feedback from clinicians and consumers about what sorts of options are going to work. But there is a slight difference in that because we have put our consent model together, with NEHTA and DoHA approval, in terms of what we are covering. But the national one does go a little further in terms of some of the codes and the enabling. So I am not too sure what the issues are that were raised earlier, but there are some slight differences in the control mechanisms over their data.

Senator SIEWERT: We heard from SARRAH this morning, Services for Australian Rural and Remote Allied Health, and a number of other people have raised the issue of who a health provider is. In your process, how far are you going in terms of access and providers in terms of allied health? Who is on and how have you made that decision?

Mr McCleod: It is probably a bit different between each of the sites and our specific use cases. To be part of the system their organisation has to have an HPIO. The individual provider has to have an HPII. They have to have signed an agreement to be part of the system that we have got, and that has a range of things that outline the correct use of the system, privacy et cetera. For us, in terms of allied health, if you can meet those criteria—aged care would be a good example—we have had a few where we have said, 'Exactly how is that going to work? We are not too sure.' For example, the director of nursing or a registered nurse who works there would have access to that. If you are a visiting OT and you are not part of that organisation, exactly how would that work when you go in there? For some it is very clear. For some it is still a bit grey.

Senator SIEWERT: That is the issue that is coming up this morning. I think almost those exact circumstances were articulated and concern was expressed that people will not have access to the system.

Mr McCleod: When we go live we are only going to look at people who do meet that criteria. It may limit some of those others—the visiting OT et cetera, but that is our starting point.

Senator SIEWERT: I understand you are putting it in place now. Do you have a process in place that will look at whether we should have included those people?

Mr McCleod: I think we probably should. Without a way for us to link the identifiers, we would not be able to properly track that back in our audit logs et cetera. It would be difficult to do. There is no doubt that if I were a relative of someone in a nursing home, I would say, yes, it is pretty relevant that if an OT is going to come in and do something that they should have access to that record.

Senator SIEWERT: I am wondering if you were going to be undertaking a survey of some of those organisations and facilities to see if there are some problems and if you are looking at ways that that can be dealt with.

Mr McCleod: We are providing lessons learned documents to NEHTA and DoHA. When we commence I am sure that will be captured as part of that.

Senator FURNER: Should the implementation date be delayed, what will that mean to Metro North Local?

Ms Anderson: If it is delayed, that depends on whether we would be allowed to continue working with the local system that we have. We are ready to implement the local system. If we were able to continue doing the local system until the national one is ready—if it is not ready by 1 July or the necessary component is not ready by 1 July—there would not be too much of a problem from my point of view. If we had to completely stop what we were doing and there was a gap between then and the implementation of the national, that would be a problem for a range of reasons, from the teams that we have in place who have the expertise to do this and more so from the point of view of the patients and the clinicians, who would have gone to a lot of trouble and effort to get everything signed up and happening and then possibly be put on hold. That would be problematic from my point of view.

Senator FURNER: Would there be a likelihood of any job losses?

Ms Anderson: Again that would depend on whether we would be able to carry on with our local program or not. I would have to discuss that with our funders—DoHA in particular.

Senator FURNER: So it all hinges around possibilities of continuing or maintaining the status quo?

Ms Anderson: That is right.

Senator FURNER: You did mention that you had a close working relationship with NEHTA. Can you explain that relationship a bit more and how it has been developing?

Ms Anderson: There are three wave 1 sites: Metro North Brisbane, Inner East Melbourne and Hunter Urban. We each individually have a contract with DoHA as the funder. DoHA in that contract uses NEHTA, who are a tripartite signatory to those contracts as the managing agency on behalf of DoHA. Therefore our regular program board meetings et cetera are held with NEHTA. DoHA is involved in those as well but NEHTA is the driving force behind making sure we are keeping on track with the project and supplying the essential elements into it that we need, such as specifications et cetera. Mark has an even bigger role in corresponding constantly with NEHTA to make sure that supporting technologies that we need in our projects are ready in time. So it is an extremely close working relationship and a very positive one, I would like to add.

Senator FURNER: Just going back to the questions regarding the letters that are about to be sent out to patients, will you be sending those out? It is not the role of the GPs?

Mr McCleod: Each of us are looking at doing a mail-out. I cannot put an exact number on it, because it depends on what each individual GP clinic would like to do. When I go to one of my GP clinics they might say to me, 'We can see what you are trying to do and we really want to focus on diabetic patients, so we would like you to send a letter to these particular people who are involved in that.' For a big clinic that has 40,000 or 50,000 people on the books that might turn out to be a large number. Another clinic might say, 'I want to target a certain age group' et cetera. It really depends on what a particular GP practice wants to do and how they want to target that. In some cases they may say, 'We are pretty happy to get all our patients registered with this,' in which case that would obviously be a very large number.

Ms Anderson: So tens of thousands.

Senator FURNER: And that will be sent in the next few weeks?

Ms Anderson: We certainly hope so. We are ready to go.

Mr McCleod: We are waiting on that advice from DoHA and NEHTA about the specification changes et cetera before we are proceeding with that.

Senator FURNER: With respect to the consent arrangements applicable to your current requirements and as opposed to the particular bill, will there be any impediments where you need to seek further consent?

Ms Anderson: I would not call it an impediment, but, yes, we are informing the patients and the practices now that one of the benefits of us being lead sites is that the people who are enrolling now will, we hope, be given the first opportunity to be involved with the national system. But we will be needing to make sure that those patients at that time who do want to switch over to the national system are given that opportunity to opt in at that point.

Mr McCleod: The privacy framework we are working to is as per the current myriad of legislation that is there. It is not dependent on the national one coming through. But obviously when that does happen that will hopefully make life easier.

Senator FURNER: In conclusion, can you give a bit of a snapshot of what this will mean to the general population?

Ms Anderson: Hopefully it will mean better health care at the end of the day. Many patients who have been involved with our programs in the past have needed their information when they have shown up at an emergency department, for example. We have had elderly patients on a number of medications and their adult children, who are their carers, have not known for certain all of the medications they are on. They have been grateful to find out that their parent has a shared record, because the information is all captured there. Hopefully we will streamline and make more safe the provision of health care. We are hoping that as things progress to a national level it makes these records all the more pertinent and important, because if you travel across Australia or you are not within your same local area for health care then those records will be available at that point in time as well.

Senator McKENZIE: My question goes to the key learnings. You said that you were reporting back to NEHTA. How regularly does that happen? How does that all feed into the process to be more than just you guys who are ready to go on 1 July?

Mr McCleod: We provide a monthly report back to NEHTA, which then goes to DoHA, which is about the project and where we are up to. Every three months we provide a more comprehensive 'lessons learned' document that talks about what we have found and recommends changes or tweaks that could happen—two things. For example, when the original HPIO applications forms came out, we suggested a range of changes to those and some of them have been taken up, which has been good. It showed that the loop was working. We now have forms that are not perfect but they are a lot easier than they were, which is good. So there is a definite loop there that happens with that.

Ms Anderson: Can I just add to that. Flowing on from those lessons learned, we have had a number of occasions where we have been brought together with key players such as Medicare Australia to discuss some of the issues that we have discovered and to try and rectify those. We are also meeting both formally and informally with our fellow Medicare Locals to talk about what they can do and need to do in the hope that when the national system is ready it will be able to be assisted by the Medicare Locals to roll those out. My personal plug for Medicare Locals is that the implementation at a national level still needs to be assisted in a similar way to how we have been doing it in our local region. Medicare Locals are the obvious choice for doing that.

Mr Gibson: There are also weekly reviews for the lessons feedback. We meet every week with NEHTA. I can say that at times there is almost daily feedback in terms of experience of specifications, deployment, processes and policy. It is a very active interaction. It gets rolled up in open time into the monthly- and three-monthly reports. There is now also an increase in workshops with the new change in adoption agent partner coming in and that is starting to be a source for us in which to feed some of our experiences. So there is a lot of richness being created as part of these three projects in terms of local experience and a lot of it is being fed back into Medicare, NEHTA and DoHA.

Senator McKENZIE: And the loop is being closed. I have a quick question on consumer consultation. I am interested in the group of people who do not have a regular GP in the community. How do you consult with those people within your Medicare Local?

Ms Anderson: In terms of their involvement in having a shared record, again, our model is quite clearly directed at people who are in a general practice setting. It does not mean that, in the future, that is the only method, but for the purposes of our project that is what we have been targeting. Obviously, we feel it is very important to encourage people to have a regular GP, if they do not have one. Our plan for the future is to have methods for the national system whereby people can sign up without their GP. I am not the right person to comment on how that will work, but certainly the shared health summary generally comes from the GP's system and from the information that they are keeping on the person. That is partly why we have been targeting that cohort in particular.

Senator DI NATALE: I have a very general question: what is your view of the response from GPs? How enthusiastically are they taking this up, or are you meeting with a lot of resistance?

Ms Anderson: With our projects, we are targeting about 50 per cent of general practices. We have had absolutely no trouble at all in reaching those targets. This is partly because we have very good relationships with those practices and partly because the model that we use to implement this and other projects is a highly supported model. Our staff spend a lot of time in those practices trying to help them set up their systems and make sure that it is as easy as possible to use. Part of the learnings that we are sharing are about how to do these systems in a way that fits in with the workflows of how providers and practitioners already work.

Mr McCleod: It is probably fair to say that there are a group of GPs who say: 'No way. Don't want to know.' But then there are other groups. I spoke to a new GP the other day who basically said: 'Yes. Sign me up. Where do we go? This is fantastic. I've been waiting for this for years. This is something we should go forward with.' And there is another group that is cautious but happy to be involved. They want someone else to go first. They want to have a look at their friend down the road to see how it has gone with him. When things go all right with him and the sky has not fallen and everything is all right then they have said yes; they are happy to jump in.

Ms Anderson: One of the important things with implementing these sorts of systems through organisations like ours, who do understand and work so closely with the providers, is that where there are issues and problems we are feeding them back into the system and trying to get those issues resolved before we get to a stage of going live across the nation.

CHAIR: Ms Anderson, you made a comment on 23 January about trials being stopped. Was that something being fed back through the NEHTA network so that you knew exactly what was going on and how it would impact on you?

Ms Anderson: Yes. In fact, prior to that coming out in the media we received a conference call that we participated in prior to that from NEHTA to let us know that there had been an issue discovered with the specifications. A request was made at that time from NEHTA for us to pause our projects until they could determine the significance of the issue that had arisen. We have subsequently met with NEHTA and have a reasonable idea, I think, of where those specifications are at, at the moment. As far as I am aware, unless there have been new developments since I last spoke with NEHTA, I do not think there should be a very long pause before we are able to get going. I would say it is in the range of about six weeks in order to have assurance that what we have been doing is aligned with the final version of the specifications. So I do not think it is actually a big impact on us at the end of the day.

CHAIR: The pause did impact on what you were doing in your trials.

Ms Anderson: Certainly. We would have started sending those letters out and doing the patient recruitment on 30 January, I believe.

CHAIR: So that is the delay; it is nothing do with the legislation?

Ms Anderson: No.

CHAIR: We will find out from NEHTA the reason why this happened. Did the stuff that came out in the media pause what you were doing?

Mr McCleod: That is correct.

CHAIR: Because that was not clear. That is why the letters have not gone out; it was to do with that. There was a great deal of evidence earlier in the day about safety aspects and safety committees within NEHTA. At your level in the trials that you are operating, do you get involved in things like safety of access to the system, safety of information in the system and resultant safety for patients? Is that the kind of thing that you have to feed into? If so, how then do you find out whether it is working? There were specific questions raised about safety within the system and an inability to find out whether safety trials had been done and things were safe. I would like to know from your perspective within the process what you know about that.

Mr Gibson: It probably operates at a couple of levels. Clearly, inside NEHTA there are a set of processes that we may not fully understand and see or go through all the steps that oversee the development of the specifications and the suitability of those specifications. A lot of clinical advisers are part of those processes. So, to a large degree, we rely on the material that does come out. It is the specifications and processes and the compliance with those specifications that we go through that says: if those processes are overseen and supported and managed by NEHTA, then we are relying to a large degree on that. Separately, though, there are specifications and there is implementation. So, on our side from an implementation perspective, we certainly have our own committees and GPs who look at what is being done to see that it makes sense in their terms. Whereas NEHTA might have a top-

down oversight of clinical and technical specifications and processes, we are certainly working at the grassroots level with our GPs, who say: 'This is my job now. How does my job change? What are the issues I am being asked to do? What are the interactions?' It probably operates at those two levels. It is a challenging area because there are a lot of different dimensions to that. In terms of specific things they would be the broad processes that we would follow.

In order to exchange clinical information we are required to go through a conformance process to those specifications. So it is important that those conformance processes are clear and visible and the things that we have to do because not only do they need to be safe they also need to be seen to be part of a process that is starting to assert that there is compliance with specifications and those specifications have clinical oversight and are meeting what is required. We are all part of that. I know that is evolving and changing as the complexity and the various processes around this are evolving. They need to be focused on. There has been a bit in the press on that of late.

CHAIR: Do people in the trials, such as your organisation, get feedback about what is happening in those clinical areas?

Mr Gibson: We do at some level. It does not necessarily come to the technical people. It probably comes through in different ways to the project managers or their clinical leads. Is there a formal report or a formal document given to us? No. But in terms of the intermingling of all the different participations on committees and processes, yes, there is. If you are asking: is it sufficient; does it cover everything? I cannot say, because I am not in all those places.

CHAIR: Can you tell me when the phone hook-up was held with the stakeholders?

Ms Anderson: It was 19 January. It was a Thursday.

CHAIR: And the media coverage was the 23? I do not know. It was in one of submissions. The people involved in the trials across NEHTA were advised of the issues around the 19th in a phone hook-up.

Ms Anderson: The Wave 1 sites were informed on the 19th—should that be the Thursday.

CHAIR: We might put this next question on notice because of time. It is to do with issues around privacy. You know that there has been a lot of discussion in some groups and in some areas about privacy. It is absolutely true that privacy is something that raises concern. Would you, from your perspective of the trials you have been working on up until now—which has been over a significant period of time—be able to give us some information on anything that has come up about privacy concerns or anything else that you think the committee should know about the people who are working on the ground and the concerns about privacy .

Ms Anderson: I am very happy to take that on notice. In summary, in the previous work that we have done there really have not been big issues that have come up with that but we are happy to provide any further information on notice.

CHAIR: That would be very useful. There will be a number of other questions on notice as well, but we would like to thank you for your time and your evidence.

BUNKER, Mr David, Head of Architecture, National eHealth Transition Authority

FLEMING, Mr Peter, Chief Executive, National eHealth Transition Authority

HALE, Mr Christopher, Chief Financial Officer and Company Secretary, National eHealth Transition Authority

MITCHELL, Dr Chris, Change and Adoption Lead, National eHealth Transition Authority13.59

[13:59]

CHAIR: Welcome. You have information on parliamentary privilege and protection of witnesses. If you wish any more information on that, the secretariat can provide it to you. Dr Mitchell, where are you from.

Dr Mitchell: Northern New South Wales. Ballina is my hospital.

CHAIR: Are you flooded?

Dr Mitchell: A little.

CHAIR: I hope it works out for you. We have NEHTA's submission, No. 2, thank you. I invite any or all of you to make an opening statement and then we will go to questions.

Mr Fleming: Thank you, Chair, and good afternoon, senators. I welcome the opportunity to update you on the progress of the personally controlled electronic health record and to respond to some of the statements that have been made today. We are in the midst of introducing very significant change into Australia's health system. We are all familiar with the pressures our health system is under with an ageing population and booming incidence of chronic disease placing increased strains on our hospitals, general practice and aged-care sectors.

Australians want greater control over the management of their health care. None of us want to be stuck in hospitals or GP surgeries any longer than we need to be. We do not want to have to remember every blood test, the name of every medication being taken, or to carry around X-rays with us. A report produced by Booz & Co. in 2010 estimated annual savings of more than $7.6 billion and 5,000 lives by 2020 by introducing a comprehensive e-health system. That is why Australia's governments believe in e-health and why they have invested in e-health. HEHTA began this journey back in 2005, and on 1 July the personally controlled electronic health record will be available for consumers to register.

The PCEHR will provide a secure way for information currently locked away in clinical systems to be shared with the consumers and people providing health care. Healthcare providers will of course continue to use their own self-ware systems that are designed for a specific context and will continue to communicate directly and in some detail with other healthcare providers. However there is a core set of information in the personally controlled electronic health record that is valuable to both consumers and other providers such as current medications, adverse reactions, immunisations, and discharge summaries from any hospital.

Building and implementing e-health and the PCEHR is very complex. Some have compared it to the rail gauge problem where we are trying to lay national tracks for a system that currently has eight different state and territory tracks. Changes to the health system—to general practice, the pharmacy sector, pathology, aged care and so on—fall into a similar category. There are many stakeholders involved in this program, some of whom you have heard from today. NEHTA takes its role as managing agent for the PCEHR very seriously and we endeavour to consult with, and accommodate, the views of interested parties.

However, as is the nature of reform and introducing a change of this magnitude, there will always be points of contention. I can assure you that NEHTA consults extensively with clinicians, healthcare consumers and industry. Consultation is part of our core business. Nothing happens in NEHTA without a clinician's approval. No products or specifications are produced without industry input.

Last month NEHTA had to pause implementation of new self-ware standards in the lead e-health sites around the country. This is a temporary setback not uncommon in large infrastructure projects of this nature. This is not an excuse. We are fixing the problem. We will get back on track and we will ensure that it does not happen again. We have already learned much from the lead e-health sites. Almost 1.4 million healthcare identifiers have been downloaded to the sites. GP and consumer recruitment has commenced in some locations, and solutions such as e-discharge summaries are being used. More than 47,000 patients are now using the Northern Territory EMR. This work and these learnings will continue.

E-health is being implemented in other areas nationally. Australian Medicines Terminology is starting to be used in Victorian hospitals. The National Product Catalogue is being used in New South Wales, Western Australia, South Australia and Queensland. The Northern Territory is using the secure messaging delivered through the Australian Standards. and NEHTA is closely supporting these projects. As chief executive officer of

NEHTA I am proud of our skilled and dedicated staff, some of whom are the world's leading experts in their field, working very hard to make the e-health vision a reality. I acknowledge that we have detractors whose concerns are valid, and we are listening to them. I believe strongly in our work program and in our staff, and I believe Australians will benefit enormously from this opportunity to take control of their healthcare information from 1 July this year. Thank you.

CHAIR: Thank you, Mr Fleming. When you started giving your evidence you made the comment that you were aware of questions that have been raised and statements made during the day.

Mr Fleming: Some of them, yes.

CHAIR: And we expect that. We will run out of time, and a lot of this will go to questions on notice.

Mr Fleming: That is fine.

CHAIR: This committee has a chequered history with your organisation regarding questions on notice and getting them back on time, and I think it is important to put that on the record. We need to establish a process this time so that, as much as we can, we can get things back in time so we can draw our report together. I understand the industry constraints and the time frames. But you would be aware that there was some concern by some of the other people submitting to this inquiry that they were waiting for answers to questions on notice from the previous Senate estimates before they could write their submissions, and we had some concern about that. You know that, but I thought it was important to put that on the record.

Mr Fleming: Thank you.

CHAIR: We will now go to questions from the senators. Senator Boyce has not been able to be with us today because of ill health, and she has a considerable number of questions, as you would expect. They will be given on notice.

Senator SIEWERT: I thought maybe we would start with the issues around safety, the identifier numbers and the problem that was identified this morning during the discussion of medical software. We were talking about safety but also the fact that there are problems with the identifiers—numbers changing for specific people. Have you seen all the submissions to the inquiry?

Mr Fleming: Yes.

Senator SIEWERT: I will take you to the Medical Software Industry Association's submission and the comments they made this morning, which I am sure you or members of your staff at the table were listening to. The issue around the identifiers was raised, including the fact that some of the identifiers changed when they were being used. In other words, as I understand it, you cannot guarantee that a patient will have an identifier that stays the same. There will be accuracy problems.

Mr Fleming: The Medical Software Industry Association produced a white paper raising those issues, and we have responded. Certainly the individual health identifier is a unique number. Occasionally—very occasionally—there may be a duplicate whereby someone may, for instance, have two numbers. Medicare has a process for identifying that and rectifying it with the individual involved. I stress that that is only caused by an occasional manual area. Certainly there is no systemic issue attached to the individual health identifier. The reason it is being introduced is so that we can have an accurate identifier.

Senator SIEWERT: Yes, that is what I understood from the previous inquiry we had. You are saying it is a manual error, not a systemic error.

Mr Fleming: There is a small possibility that something may be keyed in incorrectly. Medicare, the IHI system operator, has very advanced processes to identify that, detect it and rectify it.

CHAIR: Is your response written in language that we could understand?

Mr Fleming: I can go back and look at that response and make sure that it is.

CHAIR: I am just wondering if you have already made a response to the specific question. I know that the medical people are going to give us a copy of the document they have done. If you have done that, I am just worried that none of us have the technical expertise to understand it if it is written in the language Mr Bunker would probably write it in.

Senator SIEWERT: We are not being rude or anything!

CHAIR: We just need to know the issues that were raised and the answers.

Mr Fleming: It would be a pleasure.

CHAIR: Perhaps you could have a look at what you have, and that will be one of the questions.

Senator SIEWERT: The same applies to the provider numbers as well. I understand there has been an issue there as well.

Mr Fleming: The provider numbers come to us from AHPRA, which is the group that is responsible for going through the registration process. Once again, with AHPRA we have processes in place to identify and rectify if something were to occur.

Senator SIEWERT: The issue that was raised following that was guaranteeing patient safety. If there is a problem with the numbers not identifying people properly, what implications does that have for safety? We were told that you had done several analyses of the issues around safety and that members of the community have been trying to get copies of that and have been denied access. Is that correct?

Mr Fleming: There have been a number of analyses done and a lot of that has been fed through to the community as part of the processes we have gone through. For example, as we have worked through it with the jurisdictions in implementing it in Tasmania and the ACT et cetera, we have done detailed analysis of match rates and so on and have published the implications of that. However, beside me I have Dr Chris Mitchell, who can probably answer that from a medical perspective.

Dr Mitchell: Clinical safety is not my field within NEHTA but there is an extensive team involved with clinical safety. The point I would really like to make is that we would all love to work in an environment that is safe and we would all love to work in an environment where we can guarantee patient safety. We have misidentification occurring all the time in our current system and the health identifier process has actually minimised that risk significantly. In terms of a technical answer, I am not the man for that. In terms of making sure that the language is intelligible to somebody who is not technical, I am certainly happy to work with that document and make sure it makes sense. Really the point is: we are trying to create a system where that identity is more secure than what we have at the moment. We do not have that right now.

Senator SIEWERT: I think you indicated you would take it on notice. That would appreciated. The other point that was included as part of this question is the issue of how many safety reports have been done. You indicated that some of them have been released to the community. I infer from that answer that not all have been. My question is: why not and can we see them?

Mr Fleming: Clinical safety is actually embedded into everything that we do. We have a specific clinical safety team, but we also have a group of clinicians who work closely with us, in fact 60, who represent all the different areas of the medical community. They get involved right from the early specifications of what is required in the system. That does not mean that they are just inputting into us. They are representing clinical peak bodies, colleges et cetera, and they are working through that within their own teams. So right from the very beginning of what we do, flowing through into the concept of operations, it reflects heavy clinical input in terms of what is required. Quite often, even in our own teams, we have one clinician saying one thing or another, so everything that we do here needs to be balanced against different perspectives on how we move forward.

Following on from that, as you would expect with the number of standards and specifications we are dealing with, there is a huge amount of paperwork generated. The clinical process firstly analyses what components of those are appropriate from a clinical context and what are purely technical. In the clinical context they then go through and check, dot the i's and cross the t's, and sign off. In fact, before we progress through each of our stages internally, we receive sign-offs from each of our key areas—architecture, clinical et cetera—that it meets the requirements. Those sign-offs are attached to very detailed documents and, as such, are an embedded component.

It is our intention that, once we have been through each of those individual components and we are doing the end-to-end work around this, we will produce a high-level report that reflects all of the clinical safety components and we will make that available for public distribution before 1 July. Releasing the individual components raises the issue of being taken out of context and also, as you would expect with these things, when we identify a problem and we fix it, that is reflected in our change control.

Senator SIEWERT: With all due respect, that was a long answer to say, 'No, we're not going to give it to you.'

Mr Fleming: No, we will release that. Now, over and above that, Senator, we implemented a methodology some time ago, an international one from BT, whereby BT come in and audit us on a six-monthly basis. That is what we are doing with that. We also have—and this is getting medical checks in terms of what we do—the Commission on Safety and Quality in Health Care auditing us at the moment as part of that process. We have also invited the AMA and the RACGP—and I believe they are taking up the invitation—to come in and review what is being done internally from a quality and safety perspective. I am very happy then to look at what we can do to try to consolidate the thousands of documents into a report that can be issued.

Senator SIEWERT: My concern is that we are due to report on this legislation and to consider this legislation in the Senate in the not-too-distant future in the absence of the information in that overall report. My inclination is to ask, 'How can we be guaranteed that this is clinically safe if we have not had access to that information and that information is due to be reported only after the legislation goes through parliament?'

Mr Fleming: I understand. I will take on notice to see what we can do to take all of those documents and produce them in a context that is usable.

Senator SIEWERT: I want to go back to the issue around the identifiers and the mistakes that have been made with the identifiers. The point that was made to us this morning, and I forget the proper name—essentially the implication was that rather than human mistakes it is a more systemic mistake with the platform. Is that the correct terminology for the software?

Mr Fleming: Yes.

Senator SIEWERT: The implication was that it is the platform that is the problem rather than human error.

Mr Fleming: There is no evidence of that. We have responded to that. As I have said, I am very happy to make that response available along with maybe a plain English summary.

Senator SIEWERT: Thank you, I just wanted to make sure that is clarified. That is the end of my questions for identifiers.

CHAIR: Where do you want to go next?

Senator SIEWERT: There are some issues that have come up that I think are more for the department than for you. The issue around access and opt-in versus opt-out: I know that is an issue that we really need to raise with the department.

CHAIR: It is a policy issue rather than an implementation one. Is that right?

Mr Fleming: It is a policy decision. There are obviously strengths and weaknesses on both sides of the argument.

Senator SIEWERT: Did you provide any feedback to government around opt-in or opt-out?

Mr Fleming: There has been a huge amount of work, with NEHTA inputting into that dialogue, as you would expect. The reality is that when you look at the various components that have been built in and the discussions around privacy and control, the decision that has been made very much puts this in the control of the consumer and says upfront 'You have a choice as to whether you want that or not.' And so, yes, we did input very strongly into that discussion.

Senator SIEWERT: So you are happy with the opt-in?

Mr Fleming: I believe very strongly it is our job to make sure that this is a good enough system that people will want to opt in.

Dr Mitchell: Fundamentally that is exactly the point. We have to create a system that meets the needs of consumers and also a whole lot of different clinicians for them to play. Breaking it down to say whether it is opt-in or opt-off actually misses the point. In the UK in May 2010, I believe, a whole lot of letters went out telling people that they were going to be having access to a summary health record within 12 weeks unless they chose to opt out. The reality is that that envelope is empty unless clinicians are filling it with information. So, whatever happens, clinicians and consumers have to be engaged and want to play, whether it is opt in or opt out. That decision does not resolve that problem. Our focus is on making sure that it meets the needs of consumers and clinicians and a whole range of other different groups.

Senator SIEWERT: I want to go to an issue that was raised this morning. You would have seen the submission from AHCWA. Some health services—for example, Aboriginal health services—and particularly the regional and remote AMSs are not going to be ready to participate and are going to need more support because of the distances, inadequate access to the internet and also their particular client and patient basis. How are you dealing with that?

Mr Fleming: Chris is the immediate past president of the RACGP. I am reminded of a discussion that I had with them two years ago in which the CEO of the RACGP used an analogy in dialogue. He said that this is a big relay race. It is up to the GPs to pick up the baton first and so on. I have on my desk a baton. The reality is that there is a huge amount of change happening here. The infrastructure is being updated to reflect all these things. But there is a change management program for each of the individual groups that we need to go through. Clearly, when you look at the Northern Territory and their update of the electronic health record, my recollection is that they there are now 47,000 members of the Indigenous population in the Northern Territory on that record. That is

something in the order of 85 per cent of the population. It will be a long-term journey, but they have done a good job of getting that change model right. It is being used and it is making a difference. For groups like our Indigenous population we will absolutely be working with the Northern Territory and taking into account what they have learned. I will pass over to Chris now.

Dr Mitchell: One of the points that we all need to make is that this is a really important area and we need to focus on it. In terms of the gap between Aboriginal life expectancy and that of other Australians, this is the single most important thing that we need to do. We need to ensure that the system meets those needs. I have gone to a lot of stakeholder meetings in rural and remote areas and also for Aboriginal and Torres Strait Islander health. The Northern Territory is a shining light. They have shown what can be achieved. Those results that have just been mentioned are amazing. They have targeted the most difficult to reach population. They have focused on rural and remote Aboriginal and Torres Strait Islanders, and they have achieved amazing results. We can all work to try and match that achievement. They are currently connecting through Communicare, which covers about 50 per cent of Aboriginal and Torres Strait Islander community controlled workplaces. We need to work to bring all of the vendors on board. But it is a journey. The fact is, it will take time to get all of the different vendors on board. They have made a remarkable start in the Northern Territory and we want to follow that up nationally.

Senator SIEWERT: What additional resources were made available to the NT to ensure that that happened?

Dr Mitchell: The NT has a really strong process on the ground. It is engaged with the communities. It has elders involved. It is resourced to do really meaningful engagement with the community. That is how they have achieved those amazing results in the Northern Territory

Senator SIEWERT: Has AMSANT been involved in that process?

Dr Mitchell: Yes.

Senator SIEWERT: Were they given additional resources to ensure that that happened?

Dr Mitchell: I cannot comment on that. That should be taken directly to them.

Mr Fleming: We will take that on notice and come back. Certainly NEHTA has staff on board working with the Northern Territory to assist them. But we are happy to come back with specifics.

Senator SIEWERT: The point is that AHCWA this morning did not say that they did not want to do this. They are supportive of the process—I am pretty certain I am not putting words in their mouth. I have the map here. They identified that we are slightly bigger—and I am being a bit parochial now—than the NT. The different services have different software systems for a start. The point that they were making is that they need additional resources to make this happen.

Mr Fleming: Absolutely.

Senator SIEWERT: They need more resources for the organisations but also to encourage patient engagement. Has that been happening in the NT?

Mr Fleming: Yes. Indeed, part of our work with the Northern Territory is about how we take advantage of it in South Australia and Western Australia and ultimately in Queensland, who are also participating in those discussions. We absolutely understand that it goes beyond the Northern Territory.

Senator SIEWERT: Could you take on notice what support services have been provided to the NT and the quantum.

Mr Fleming: Absolutely.

Senator McKENZIE: I have a general question about the people in rural and regional Australia and their health outcomes and the potential of something like this to assist them. What work has been done and resources committed to assisting rural and regional communities and health providers to be ready to go on 1 July?

Mr Fleming: I will ask Chris to comment on this, as it is his area of expertise. However, when we look at 1 July, there is a journey from there. As we said before, there is a lot of work happening to put in place the infrastructure. One of the reasons why we are working with all of the wave sites is to understand the local lessons and how they can roll through. But we know that it will take time from the moment when people can register to when there will be an impact on health outcomes. Clearly, as we look at the target areas, whereas we will support the ability of every Australian to register, there are groups that are going to derive specific benefits from this. Rural and remote communities, our Indigenous population, mothers with new born babies, the elderly and those with chronic disease are groups that we know will get maximum benefit from this. From a Commonwealth and a jurisdictional perspective, they will have a better return on their investment. Chris, as a rural and remote doctor and the man who drives our program, would like to make a few comments.

Dr Mitchell: I do not claim to be a remote GP, but I am a rural GP. I have worked in the public hospital system as a VMO and in general practice. My wife, Sue Page, is a past president of the Rural Doctors Association of Australia and works down the road in a community controlled centre. I get what the challenges. I have had the great opportunity of going to a lot of the rural and remote consultations and hearing firsthand where the issues are going to be—and not just from doctors but from allied health professionals, nurses, midwives and Aboriginal community controlled health workers. NEHTA has a very extensive engagement process so that we can find out what the issues are across Australia. You have heard mention of the clinical leads. A number of the clinical leads are rural GPs.

I was introduced as a past president of the Royal Australian College of General Practitioners, which I am. I am also the immediate past chair of the RACGP's National Rural Faculty. The gap that you are talking about—the big black hole in the middle of Australia—in terms of preventative mortality is of significant concern. The personally controlled electronic health record is not, I am sorry, going to fix that. There is a lot of other things that we need to do. There is a whole lot of resourcing that we need to do to better meet the needs of rural and remote Australians. But better communications is going to help.

In terms of the change support that is going to be needed on the ground, our rural and remote operations identified this as an area of priority. We have also had Aboriginal and Torres Strait Islander people identified as a priority group. When we have been formulating a strategy for the change involved in taking on the personally controlled electronic health records, those areas have been specifically looked at.

In terms of the resources that are going to be deployed, the resources for that program are delivered through a portal electronically. They will be available from the end of February, rolling out until June. Our intent is for that to provide the information that people need to become engaged with the personally controlled electronic health record.

But your questions goes to a whole lot of other stuff. We need the software integrated into people's clinical systems. That is a little beyond the scope of the change and adoption role. That is about professionalism. That is about organisations like the RACGP, the Australian College of Rural and Remote Medicine—and I am a fellow of both of those—the Rural Doctors Association, the midwifery organisations and SARRAH talking with their members to get them ready. We have a lot of work to do to get ready for the personally controlled electronic health record. The first step is to make sure that we are recording clinical information electronically. We cannot share it unless we are doing that. The second thing that we have to do is make sure that we have health identifiers incorporated into our software. That means advocating to the vendors who are producing that software so that it meets our needs going forward. And, obviously, we need to address training as well. It is not just as simple as all that. There is a whole push-pull that needs to happen.

CHAIR: There are a lot of questions that we will have to put on notice, as well as policy issues for the department. I want to ask a couple of questions about NEHTA specifically. We had a number of witnesses today talking about a veil of silence. You have put on record that you have an open and consultative process. Witnesses from the Australian Privacy Foundation have put on record that they have written to you many times wanting to engage in a discussion around privacy and have not been able to do so. They raised that concern. Do your records indicate that they have been involved? If so, it could just be that people have different views. But you will see the *Hansard*. They said that they have tried to talk with NEHTA and have not been able to.

We also had evidence from people that through the consultative process they have not been able to get responses. There may well be meetings, but they say that the outcomes of the meetings are predetermined and it is a matter of having people round 'a four-cornered round table'—and I have never heard that term. They say that people do meet but there is no engagement. It is just coming in, spending some time, having some morning tea and then leaving. If things they want are not able to be made policy, they are not told why. That is quite a large question. I would be interested in hearing from you about that, probably on notice. When you take about engagement and consultation, what is the process?

There is another issue that we have discussed before. I am particular interested to get on record the accountability mechanisms in the organisation. There have been a number of claims that, because you are not subject to the standard government FOI processes or the standard government accountability processes, there is no link. That has led on to statements about the proposed new structure, with the advisory committees and the strategic systems person, not being accountability. That is more for the department. They know that those questions will go to them. What I am trying to get on record are your responses to the proposals that have been put forward that NEHTA has not been open and transparent. You claim that you have been open and transparent. Can we get some evidence of that to counterbalance the claims that you have not?

Mr Fleming: Absolutely. We will provide a detailed report. Would you like it to be verbal?

CHAIR: No, it is too big an issue. You will have a chance to review the *Hansard* and see the submissions. When people have been prepared to put their concerns on record, it is important that you get a chance to response.

Mr Fleming: Terrific. We will.

CHAIR: I have a question regarding the media statement on 24 January. On notice, can you give us any indication of whether a NEHTA media release led to the story?

Mr Fleming: No, it did not.

CHAIR: We know that a couple of journalists have a particular interest in NEHTA and are following this issue very closely. I am interested to know how it was determined that the appropriate thing was to call a halt and how the public found out about. You heard my question to the people in wave 1 and their response that they were told two days before. I want to get some sense of how the communication operates from the microcosm of that significant issue and how people found out.

Mr Fleming: We will do that.

CHAIR: Thank you very much. There could well be further hearings. We will put any other questions on notice. We look forward to seeing you at Senate estimates.

BAGGOLEY, Prof. Chris, Chief Medical Officer, Department of Health and Ageing

GOLIGHTLY, Ms Malisa, Deputy Secretary, Health and Service Delivery Reform, Department of Human Services

GRANGER, Ms Fionna, First Assistant Secretary, eHealth Division, Department of Health and Ageing

HUXTABLE, Ms Rosemary, Deputy Secretary, Department of Health and Ageing

KRUSE, Ms Sue Margaret, General Manager, Health eBusiness, Department of Human Services

MADDEN, Mr Paul, Chief Information and Knowledge Officer, Department of Health and Ageing

ROE, Ms Jennie, Assistant Secretary, Medicare Locals Implementation and Transition Branch, Department of Health and Ageing

[14:35]

CHAIR: Welcome to the officers from the Department of Health and Ageing and the Department of Human Services. You all know the information on parliamentary privilege and protection of witnesses, and if you need to get any more information the secretariat can provide that. I will put the standard paragraph on record, even though people will try to breach it all the way through.

I remind witnesses that the Senate has resolved that an officer of a department of the Commonwealth or of a state shall not be asked to give opinions on matters of policy and shall be given reasonable opportunity to refer questions asked of the officer to superior officers or to a minister. This resolution prohibits only questions asking for opinions on matters of policy and does not preclude questions asking for explanations of policies or factual questions about when and how policies were adopted.

The officers all know the process. If anyone has an opening statement we would be happy to hear it, and then we will go to questions. There will be a number of questions on notice because, as I have said, Senator Boyce is not with us today and, as you know, this is an area that she has been following very closely. Ms Huxtable, I presume you will be kicking off.

Ms Huxtable: Thank you for the opportunity to address the committee. This legislation is the next critical step in realising the aims of the national e-health strategy, which was agreed by governments in 2008 and which sought to enable a safer, more equitable and sustainable health system for all Australians by transforming the way information is used to plan, manage and deliver healthcare services.

The approach to developing e-health solutions as set out in that strategy represents a shared direction of Commonwealth, state and territory governments, recognising the interconnected nature of the health system as patients cross healthcare settings, and the value of improving access to up-to-date health information for the quality of health care and its efficient management. The strategy was prefaced by the creation of the National E-Health Transition Authority in 2006; again, a shared initiative of all governments.

Currently in Australia the health information of individuals is fragmented across a range of locations rather than being attached to a patient. Every year the average person has approximately 22 interactions with the health system, including four visits to a GP, 12 prescriptions and three visits to a specialist, amongst others. Patients with chronic and complex conditions experience more interactions, often including periods in an acute care setting. Each time a person goes to a new clinician they must remember their medications, allergies and past medical history, and the clinician may order further tests where information already gathered is not readily available. The result can be unnecessary testing, delays and medical errors.

In seeking to improve access to information, governments have been mindful of the level of preventable medication errors that occur, resulting in an estimated 190,000 hospital admissions each year. Research suggests that up to 10 per cent of hospital admissions are due to adverse drug events and that up to 18 per cent of medical errors are due to insufficient patient information.

By putting in place a means of sharing health information between providers, including access to information about allergies and reactions, medication lists and past medical history, the personally controlled electronic health record is a key enabler of improved health outcomes. At the centre of the PCEHR is the concept of personal control, with the intention of putting consumers at the heart of the system as the ones who are able to exercise control of their information and who accesses that information, and in doing so creates an environment for patient centred care and personal responsibility. As is appropriate for a personally controlled record, the system is designed to be opt in to enable consumers to exercise a choice as to whether to participate and to support a

gradual implementation, focused first on those groups most likely to benefit: those with chronic disease, Indigenous Australians, mothers, newborns and the elderly.

The bills before you establish the essential characteristics of the PCHR, its infrastructure, access controls and governance. The Commonwealth is developing the national infrastructure in close consultation with states and territories and stakeholders, and building on the foundation solutions that NEHTA has been developing since 2006. We are not building every technology solution but providing infrastructure for registers of participants and patient control, indexes and national repositories. Construction of the national infrastructure is proceeding to plan, with patients able to register for a record from 1 July 2012. The PCHR will have the capacity to contain summary health information such as medical conditions, medications, allergies and medical events. It will also include discharge summaries from hospitals and information from Medicare systems should the patient choose to include it in their record. Registered consumers can also be represented by authorised and/or nominated representatives. This allows minors and persons with limited capacity to have a PCHR.

A patient's PCHR, particularly in the early days, may not be a complete record, just as current patient records are not complete records. Patients already have a choice about what information they disclose to their healthcare provider. Providers will continue to seek relevant information from the patient as part of the consultation, just as they do today. Patients will be able to remove documents from their records but will not be able to edit clinical records. Consumers will be able to add their own notes and information. The system is designed to be as easy to use as possible so that accessing the PCHR is streamlined into normal clinical workflow. The action of uploading clinical documents can be part of the health provider's usual clinical practice. The system balances security and access, and ensures that consumers have the same protections over digital records as they do with paper based records.

Privacy is a critical element of the system's build and of the proposed legislation. There are additional consent settings and audit trails that do not usually exist for paper based records. The legislation has been developed to work together with existing Australian legislation and clarifies how state and territory privacy laws will apply. Additionally, it includes a range of remedies and civil penalties. The PCHR builds on achievements to date with e-health, including the implementation of health identifiers service in 2010. These provide the foundation for the PCHR, with almost 1.5 million identifiers currently downloaded across jurisdictions and lead health sites.

The first release of the national infrastructure includes all the functionality required for healthcare professionals to connect to the national system via their IT vendors as well as direct access through the PCHR portals. The core build for this has been completed and is now being tested. The second release provides the functionality for consumers to register for the PCHR. Design for this release has been substantially completed and is scheduled to be completed prior to 1 July 2012. Once the system is ready for patient registration, the department, as the system operator, will have strong governance support through both the independent advisory council and the jurisdictional advisory committee. The Australian Information Commissioner will be the key regulator of the system and will have the capacity to conduct audits, investigate complaints and impose a range of sanctions. Transparency is ensured by annual reports from both the system operator and the Information Commissioner to the minister and the ministerial council.

Extensive consultation with consumers, clinicians and the health IT industry has and continues to be an essential element in the development of both this legislation and the concept of operations for the PCHR and will continue to guide safe and secure implementation.

Senator SIEWERT: I will start with the access issue and the comment you made about documents being able to be removed.

CHAIR: Or edited.

Senator SIEWERT: I expect you have been listening to or are aware of the evidence that was given today by the Consumer Health Forum and others saying that the no access issue is a deal breaker. I am wondering why the decision was made to be able to remove documents but not have 'no access' on records?

Ms Huxtable: There was a lot of discussion in the consultation process around the various ways in which those issues could be addressed.

Ms Granger: There are three levels of access for documents. There is general access, where you choose to share with all your clinicians. Then there is limited access to a range of documents that can be then only seen in an emergency situation or by a clinician nominating to have access to them. Then there is either choosing not to upload a document or removing it from the record with no access in emergency. It went to the heart of the desire by clinicians to be able to see everything that was on the record in all circumstances and the desire of consumers to be able to control access and consultations as to the depth of the medico-legal issues where the best balance

situation seemed to be having the consumer being able to remove their document—the equivalent of choosing not to tell a practitioner that information—rather than have essentially a locked box on the record that people then had to decide what to do with in an emergency. But the original healthcare provider who gave the service would still have a record of that and the consumer would still have whatever they kept privately as a record if they chose not to load it. So it is just saying that a record that you do not want to share with anyone is not on a shared record. Does that make sense?

Senator SIEWERT: Yes. The argument that was being put this morning is that those records should still be there with just a 'no access' on them.

Ms Granger: That makes it more complicated for the clinicians and for the medico-legal issues if that is the case. But the consumer still could keep a copy of their record if they chose, and so would the doctor who provided the treatment.

Senator SIEWERT: So the reason you cannot do that is legal issues, is it?

Ms Granger: It was a balance of those three things.

Ms Huxtable: It was a negotiated outcome at the end of the day.

Senator SIEWERT: Because the medical profession are too scared of legal implications if they do not look at a document having been told not to.

Ms Huxtable: The medical clinicians had issues and the consumers had issues—

Ms Granger: and the insurers had issues—

Ms Huxtable: and this was a sort of reasonable blend.

Senator SIEWERT: The feedback that we got this morning was that consumers want those there with 'no access' on it. That was really clear this morning.

Ms Granger: The other thing is that it then gives consumers four different sets of access controls to consider and we would have lots of feedback about 'if you can you simplify how we're controlling access' as well.

Senator McKENZIE: Was that feedback that you got, Ms Granger, from consumer advocacy groups?

Ms Granger: It was through the many consultation processes on the concept of operations including consumer advocacy groups. There is not a clear and passionate line one way or the other at all the groups that I have spoken to. Some have very strong views in one direction and others have very strong views in another direction.

Ms Huxtable: In that part of the consultation work on the concept of operations I think a lot of people commented in regard to that specific issue. So the views were very mixed. I do not know whether you can say it has just come from one group or another group as many groups have views and they have all been taken into account in the process of developing policy responses.

I think the other part of this is what is the sort of engagement with consumers around the process of registration and setting access controls. We would hope, and based on international experience we would expect, that many people will be very comfortable about having a default setting of 'any provider involved in the provision of my health care can access my PCHR' and they will be comfortable with having all the appropriate records available to be part of the PCHR. Certainly there is the change in adoption strategies and the way in which our work practices are reviewed and in the process of assisting consumers to register we will be focusing on ensuring that they are fully aware of the benefits of clinicians having access to all the information as they are caring for them.

Senator SIEWERT: Presumably, as people get more familiar with the system they will probably consider changing access.

Ms Granger: That is certainly available. It is quite interesting to look at the experience in the Northern Territory, and I know that you have spoken a little about that earlier. One of the things that are coming through very strongly with the Northern Territory experience is that each year the shared health record is being used more and more in everyday consolations, so there is the level of familiarity that not just consumers but also providers have with the concept of a shared health record and with how that shared health record is used. We would expect with the PCHR too that would drive take-up and also drive the richness of the information that is available within the record.

Senator SIEWERT: This morning we heard evidence around the New South Wales experience where, we were told, there was a trust issue and people put false information on their records. Have you looked at that issue?

Ms Huxtable: Which people? Consumers?

Senator SIEWERT: The consumers.

Ms Huxtable: Consumers put false information on their record?

Senator SIEWERT: Yes.

Ms Huxtable: I think it is important to understand that, as to the information that has been put into the record, the clinical information is clinical information and it cannot be edited by a nonclinician. There is a place in the record for the consumer to write notes or to have a diary. In fact, one of the e-health sites is looking at the consumer health diary issue. But, in terms of the clinical content, that is not content that can be edited by a consumer. A consumer can decide to remove something from the record but that is different from them changing the information on the record.

Senator SIEWERT: Or they can tell their clinician false information.

Ms Huxtable: They could, and they can do that now.

CHAIR: Given that and that there is no agreement on that, and you have the two sides and they are not going to agree—so that is fine—what is the process then for telling the people on both sides the background and the reasons for the decision? We have just heard what the current decision is, and that is fine. We have certainly heard that consumer networks are unhappy with that. What we have heard is that they did not feel that the explanation was fulsome to them as to the reason that their views were not picked up and they felt there was a power imbalance. In fact, from the doctors, as we had read in a submission, there was also a power imbalance, that a small number of rowdy consumers had actually got their way for a switch and they had now been overturned. But I think one of the core issues is how the explanations are given once a decision is made. So can we find out how that was given and in what way and then it is knowing how we move forward.

Ms Huxtable: The concept of operations has been a fairly critical document in the development process. There was an addendum to the concept of operations that was released quite recently but I could not tell you the exact date. The addendum went to all the issues. In the original concept of operations, as you might be familiar with, there were various boxes that said what the status of things was, and some things were still under consideration. There was a number of views. So the final addendum to the concept of operations set out the thinking behind the decision that was finally taken and then that was part of the final design of the document. So, in terms of the development of documents, I think there is a great deal of documentation that has underpinned the policy settings for the PCHR. But what that has done is really reflect a very strong level of engagement that has occurred not only through the NEHTA processes and their various roundtables et cetera but also the legislative consultation process and the concept of operations consultation processes as well. So all those things have been brought together. In the process of doing that we have had, and I personally have had, meetings with many of the key groups. Ms Granger has met with more than I have. For example, I have had a face-to-face with the Consumers Health Forum going to their issues. We are going back a bit, to about mid-last year probably. So I do not feel personally that this has been hidden away. In fact, there has been quite a lot of discussion around these issues. As to whether or not as it ripples out everyone has got access to all that information, maybe there are some people who do not have the same visibility as to the final decision.

Senator SIEWERT: Can we go to the issue of the systems operator and the position that has been put by several submissions and that we have discussed quite a bit this morning—that is, the level of independence, either immediately or into the future, of the operator. The position that was put, again, by the forum and, I am pretty certain, was then supported by the Consumers e-Health Alliance is that the body should be independent. There are differences of opinion over how soon, ranging from a suggestion that, for example, there be a sunset clause of two years on the current arrangements and then a move to an independent body. Others are saying that it needs to be more independent straightaway. Can you take us through the thinking on why you came up with this particular structure and the level of independence that is there and that is not there. Does that make sense?

Ms Huxtable: Sure. We are really looking at what the governance options were in the immediate term, when you have a system that hopefully will be operating from 1 July. There are probably three main options. The first was to establish governance through a company like NEHTA—a company that is established under the Corporations Act. That is on one side. On the other end of that spectrum is probably to move more down an interjurisdictional statutory-authority-type road. The middle option is to vest the system operation within the Commonwealth at this time.

In terms of the thinking around where we have got to, which is clearly that middle option, there were fairly strong views—and I think this has come through in consultation, including on the healthcare identifiers—that where there is the capacity to hold and provide governance over health information, including private health information, that responsibility should be vested in the protections of government rather than in a company-type structure. So that puts on the option 2 or 3 side of the table. The reality is that to move to a more

interjurisdictional statutory authority is probably a fairly time-consuming development process where you are looking at the legislative requirements that cover not only the Commonwealth but also the states and territories. So the legislation certainly does not rule out the possibility of moving more to an interjurisdictional statutory-authority-type governance structure, and it does in fact require a review of the functions et cetera within two years, but the value of this responsibility being vested within the Commonwealth and within the department is that it is subject to all the requirements of Commonwealth law in terms of an FMA agency. It is not a function that is unknown.

I know that there has been some speculation in the media about why the Secretary of the Department of Health and Ageing is named as the PCHR system operator. The reality is that the secretary has vested in her a whole range of powers: she is the regulator of therapeutic goods, she has roles and responsibilities in terms of the operation of nursing homes, she has the capacity to delegate these powers et cetera. It is not a strange thing that the secretary would have these powers vested in her. On top of that, by having in legislation the requirements around the jurisdictional advisory committee and the consumer advisory committee, there are mechanisms being put in place to ensure the openness and transparency of the governance process. On top of that, there are also the requirements for annual reports to be made and processes through ministerial councils. I think we have a governance structure that does cover off a lot of the expected concerns that people would have about a body such as this. Implicit in that is that it is very difficult to have effective e-health solutions without full engagement, particularly of the states and territories. We have certainly had that through the NEHTA processes and we continue to have that in the governance that we have proposed for the PCHR, and the states were certainly a part of the process and very much consulted in the development of the legislation.

Senator McKENZIE: A lot of grey areas have been raised today, one of which is around definitions of what a health practitioner is and looks like in this context. How do you see that definition being decided come 1 July?

Ms Granger: There seems to have been some confusion. There are two types of healthcare practitioners that are involved in the record. One is the nominated representative who, over time, can prepare your summary and is likely to be involved in your ongoing care. The other is accredited practitioners who can put an event summary on the record. For details of registration I may need to call on one of the other officers. Anyone who is a registered healthcare practitioner can access a record with your permission and can load an event summary. This was one that there was very long consultation about, trying to balance the views of clinicians and consumers. We came to the definition of medical practitioners, nurses and Aboriginal health workers as those practitioners that were most likely to be engaged in ongoing care and most likely to be trusted by their colleagues to be able to put the summarised information into a shared health summary.

Ms Huxtable: And particularly most likely to be at the centre of the coordination of a person's care.

Ms Granger: That is right. That was the key criterion.

Senator McKENZIE: What about people in Medibank suggesting the definitions around health care, illness and disability being problematic?

Senator SIEWERT: They are different. The Medicare definition is different from—

Senator McKENZIE: Rather than having consistent definitions across the system, I guess, of these things.

Ms Huxtable: Sorry, I am not sure I understand what that issue is. I cannot say that I have read the Medibank submission, I am sorry.

Senator McKENZIE: But their suggestion is that the definitions are the same as the private health insurance definitions of those things.

Ms Granger: I would have to take a look into that, but it is the same as the healthcare identifier service definition.

Senator McKENZIE: Okay. A definition is a definition.

Ms Huxtable: But is this about who is able to import information into the record? My understanding is that it is those providers who are registered under AHPRA who can input to the record. So I am not sure what the differences would be.

Senator SIEWERT: So there are issues around the definition of health care. Medicare says that it is limited through this legislation to illness and disability, whereas they are saying the private health insurance legislation refers to disease, injury or condition. Have you looked at those two issues and at whether there is going to be a problem or whether it is simply, "She says 'potato'; I say 'potarto'"?

CHAIR: And surely this is not the only area where this comes about.

Ms Huxtable: And, 'What is the material impact?' is the other part.

Senator SIEWERT: Is there a potential issue through the definition and what is in and what is out or is it purely nomenclature?

Ms Huxtable: I would have to say it does not immediately come to mind that that would be a huge issue.

Senator SIEWERT: Could you take it on notice?

Ms Huxtable: We are happy to take it on notice and have a look at it.

Senator SIEWERT: Can we go back to the provider issue and those professions. The issue that SARRAH raised this morning—they did not raise OTs but someone else did—was that social workers and dieticians that are not registered are not necessarily going to have access to records, and they are central to—

Ms Huxtable: We are certainly aware of that issue, if that is the issue you are raising.

Senator SIEWERT: That is another issue that has been raised separately.

Ms Huxtable: One of the responses to that, which I think Ms Granger mentioned before, is that there are circumstances where an individual can provide someone with access to their record as a nominated representative, which is different to being a nominated provider. So they are someone who can view their record. They can provide them with that access. If your provider is outside the capacity to receive AHPRA registration, you could give your provider that nominated representative status so that they could view your record. I know that does not go as high as they might want, but that is one way that they can view the record.

Ms Huxtable: The employees of an organisation that provides healthcare service can also access it that way, just not in their own individual right.

Senator SIEWERT: There are a couple of issues I would like to follow up there. One is that when we were talking to the people from the Medicare Locals they were saying that in the first wave they are going to be receiving feedback. For example, we talked about the issues around OTs and aged-care facilities. They are going to be providing feedback. If this is seen as a problem, is there then the capacity to enable OTs, for example, to be more widely recognised rather than just being nominated?

Ms Huxtable: I am not sure. We might have to take that one on notice. That depends on the degree to which things are in the rules and regulations and the degree to which they are in the primary legislation.

Senator SIEWERT: It would be appreciated if you could take that on notice. The other issue that was raised by SARRAH is that if they are regional and remote they do not actually get any support from their organisation they would be registered with. So, although they have the capacity to be registered, they do not necessarily do it. I think the example of it costing $800 was raised and that they get no service and support because they are regional and remote and it is too far, so they choose not to be registered. Will that then affect them being able to access or upload?

Ms Huxtable: I get your drift. If we can wrap all of those issues up to take them on notice that would be good.

Senator SIEWERT: If you can take that on notice it would be appreciated.

Senator McKENZIE: It sounds like there is going to be a great need for educating both clinicians and consumers come 1 July and similarly medical students as this will be modus operandi when they enter the profession after they graduate next year. I am just wondering what work the department has done or plans to do and has budgeted for, given where we are in the cycle, around educating those three groups. Also, what conversations have you had? So I want to know about the costs and the conversations.

Ms Huxtable: As part of the investment in the two years leading up to 1 July there has been a significant investment in both change and adoption strategies and in understanding the benefits and the benefit evaluation side of things. On the change and adoption side, there is certainly work that has been occurring already in preparation for 1 July. So it is not something that you have to do come 1 July; it is work that you need to be doing now. There is an online learning centre that will be established to support providers and consumers on PCHR issues. We have a change and adoption partner who has been appointed. NEHTA is the managing agent for the change and adoption partner. I think PwC and McKinsey are doing that work. There is a consortium doing that work, and there is a whole range of activities that they are involved in, including the creation of information and support. They are focused very strongly on the key target groups for the PCHR.

You would have heard from others during the day, I am sure—and I think I said this in my opening statement too—that the initial focus is very much on those who are most likely to benefit, such as the elderly, Indigenous Australians, people with chronic disease, mothers and newborns. Clearly there are also a range of health communities that include provider communities that also need to be part of those change and adoption strategies. So there is a whole variety of work.

We could give you much more detail to talk about on notice about the various things that are happening. We are looking to leverage the investment that is available at this stage to produce materials that have a lasting life, that can be continue to be used beyond 1 July.

Senator McKENZIE: What component of the funding that has been made available has been dedicated to education and the interaction with medical students and allied health students?

Ms Huxtable: We can take that on notice and come back to you.

Senator SIEWERT: Can we roll that over into the broader issues around funding. I am sure you have read the AMA's submission around suggestions of, firstly, the need for an MBS number for implementation of this—in other words, to convert all their records and do all that for the GPs—and, secondly, the claim that there will be a cost to each consultation to access and check all the records and then upload records. Have you (a) heard that argument before and (b) what is your response?

Ms Huxtable: I think there is a range of issues there. Part of it is around how the system is designed and part of it is around how health financing operates now.

Senator SIEWERT: We have been through these sorts of things before.

Ms Huxtable: And we have talked about this before in estimates, I know. Certainly one of the objectives of setting up the e-health lead sites was to better understand what the practical implications for PCHR would be for practitioner communities. I am sure the person from the relevant e-health site who was here just before would have talked a bit about that. One of the important things is what exactly is the requirement on providers in a practical sense. In terms of the design of the infrastructure, what we are seeking to achieve is ease of use as far as possible and having the software within practice management systems that enable a very easy upload and download of information so that it is not at all an onerous task and in fact is probably no different from what occurs now in the recording of notes et cetera. Part of it is about what exactly is the work practice and understanding that better. Their helpful insights are certainly helping us get information around what that might be.

The second thing is that there is a range of investments that are already made into general practice. I think there is capacity to see them in the context of changing the healthcare delivery environment, including e-health. Clearly, there has been a lot of investment already in computerisation, particularly of GPs. We have very high rates of computerisation, so that has supported people in that regard.

The other thing is the practice incentive payments, PIPs. There has been an e-health PIP for some time. If you access certain thresholds, you can access the e-health PIP and the payments are up to $50,000 per year for a practice. We are in active discussion with the sector now about how those requirements may change in the future to take account of the PCHR. The PIP becomes a potential financing flow-in for practices around e-health.

The other thing is to understand where the Medicare Benefits Schedule itself fits. The consultation already imagines that the taking of notes, the recording of notes and the creation of information around the patient, including some items that go specifically to care coordination, is in play. We would see in a world where the PCHR becomes part of the practice of medicine that the MBS would also cover the practice of recording notes and putting them into the practice management system, uploading documents et cetera.

The other thing I should say is that where Medicare Locals fit and the sort of support that potentially can be provided to practices through Medicare Locals are important too. There are e-health support officers that we have funded for some time within Medicare Locals that can support practices.

Senator SIEWERT: Yes, but does each Medicare Local that is already established have one and, supplementary to that, where we do not yet have Medicare Locals do the GP divisions have them?

Ms Huxtable: They are actually in divisions. They have been in divisions. That is my understanding. I am sorry, they are in state based organisations. I was told that about five minutes ago and I had forgotten.

Senator SIEWERT: So where the division is not appropriate or where there is not a Medicare Local, they are in the state based organisations?

Ms Huxtable: They have been in state based organisations. Jenny can probably answer the question better than me.

Senator SIEWERT: And can you explain what is meant by state based organisations? I am going to come to AMSs in a minute.

Ms Roe: I am sorry, I missed the last question.

Senator SIEWERT: What do we mean by state based organisations?

CHAIR: Where are the e-health support people?

Ms Roe: Can I give a bit of a history lesson. As Ms Huxtable talked about, there has been a long history of support through divisions and now through Medicare Locals, particularly in the IT space. Previously, there have been IT support officers and funding throughout most of the Divisions of General Practice. In recent years that has been through the state based organisations. As the name implies, every state has an organisation that is a representative organisation of all the Divisions of General Practice in that state, so they are the SBOs. Then through the Wave sites there have also been significant resources put in through those Medicare Locals in terms of practice support and e-health support.

Senator SIEWERT: I have been trying to get my head around many of the issues you have just touched on, but one in particular is the issue around what an MBS item number already covers. What I can recall from our previous conversations, most recently about better access, is that these things are expected—that access to records, writing up notes et cetera are part of item numbers already. Has any work been done to look at the fact that this is going to take a bit of extra work, I would have thought, just for the beginning?

Ms Huxtable: They are time based items. So if it takes extra time then potentially it has become a longer consult, and it depends on what extra time. What we are trying to achieve here is a mechanism that, if anything, is more streamlined than what occurs now—maybe that is not feasible, but as streamlined, because basically you are still using the practice management software and you are uploading or downloading, so it is not a particularly onerous task. The other side of it, which I have talked about before and maybe was not hugely popular for saying it, is that there are business benefits and practice benefits from having easy access to shared health information. That means that you do not have to run around trying to find the discharge summary that may not be readily available, or the fax machine has run out of paper, or whatever.

What we are trying to address through the PCEHR and through e-health generally is actually overcoming those inefficiencies in the system that mean that things are done more than once or you cannot attach the right bit of information to the right patient. Part of the issue with the e-health sites is actually better understanding what the whole picture is, not just the additional but the less than. You have to put it in the whole picture here.

Senator SIEWERT: Thank you. I want to move on to specifically address Aboriginal Medical Service issues and the issues that were raised this morning—and I am not allowed to show the map again!

Ms Huxtable: I was in a meeting this morning.

Senator SIEWERT: Okay. So, without showing a map, what AHCWA raised this morning—and I am sure these issues are relevant for other states' Aboriginal medical organisations as well—is that there is a lack of resources, a range of different software or IT systems and basic issues of access to the internet. I know Aboriginal health organisations are supportive in general of e-health, but how do you overcome some of those practical barriers that are above and beyond what we have just been talking about in terms of additional resources for GP clinics?

Ms Huxtable: Certainly as part of the change in adoption work there is some very focused and specific work happening in terms of the benefits for Indigenous Australians. While I know that many Indigenous Australians are not in rural and remote communities, clearly that is an issue in rural and remote communities as well. That is a very strong focus. We have had a lead site in the Northern Territory, and I think the experience in the Northern Territory is interesting. I heard Chris say before that they are sort of a shining light. They have been successful in enrolling large numbers of people, including in rural and remote communities, and having that shared health summary being accessed at the time of the visit. That may mean that here we have consumers who are in another place where they can have access, where there is access to the internet. I do not know. But I think we have got a very strong base in the Northern Territory that we are building off, and the work that we are doing with that lead site—and obviously there is funding that has gone into that lead site in the Northern Territory—is again going to help us in terms of 'How do you make this of benefit to those communities?' It is hard to overcome every barrier. It is about what the workaround is, I suppose.

Ms Roe: Part of the core functions for Medicare Locals, amongst other things, is about integrated care across the primary healthcare sector and between the sectors. One of the priorities for funding under their core funding from next year will be supporting the rollout of e-technologies and the rollout of the PCHR and telemedicine. Another key priority is to focus on special target groups. Indigenous is clearly one of them. Another one is rural and remote communities. Their role is not just to work with GPs; it is also general practice and primary healthcare organisations. Part of what they will need to be doing is engaging with the right people in the right organisations in their communities but also looking at needs based requirements. Those needs will differ from one community to the next.

Ms Huxtable: We should not divorce the e-health stuff from what is happening on the telehealth side of things, because there is significant investment going into infrastructure around telehealth as well.

Senator SIEWERT: Could you perhaps take notice what additional resources were made available to the NT? I think NEHTA took that on notice as well, but I am sure you have got additional resources that have also been made available for telehealth et cetera which NEHTA—

Ms Huxtable: That is right. You could take a wider view and bring together the variety of things that are available.

Senator SIEWERT: It would be appreciated if you could take on notice what resources are already available and are being made available. The other point that was made to us is that there need to be resources made available to facilitate access and understanding for patients to engage with the system, particularly as we have got the opt-in system rather than an opt-out system. Could you take that on notice as well, or can you tell me now?

Ms Huxtable: That is a really critical part of both the change in adoption strategy but also the e-health sites. One of the purposes of the e-health sites is to understand the process of engaging consumers. I think the evidence that we have, and partly the international evidence, is that provider interest and engagement is a key factor in consumers being interested and engaged and wanting to have a PCHR. So it is part of a broader picture.

Senator SIEWERT: Is that assistance also being made available in terms of the different IT systems that are operating? I understand, from evidence this morning, that there are at least three different systems just in WA. I imagine that is the same in other states as well.

Ms Huxtable: We might have to take that one on notice. We are well familiar with the GP software but, as to other software we are not so sure.

Senator SIEWERT: There were names of software systems being rattled off this morning that went like this for me, but it was obvious there were different systems operating. As I said, I expect that is going to be happening in other states as well.

Ms Huxtable: Okay.

Senator McKENZIE: How confident are we that 1 July is going to be the kick-off?

Ms Huxtable: The intention is that people will be able to register for a PCHR from 1 July. The national infrastructure is the part of the roll-out that is required for that and that is on track.

Senator McKENZIE: So is the change in adoption work that NEHTA is doing at the moment due to finish up or is that ongoing?

Ms Huxtable: The money that has been made available finishes on 30 June. So the money we are working with is the two-year envelope of $467 million. Everything that we are talking about is included within that envelope including national infrastructure.

Senator McKENZIE: So when 1 July comes the two-year bucket of funding will be finished. That is only 4½ months away. What is the plan for after 1 July?

CHAIR: The committee can handle it if you cannot answer that.

Senator McKENZIE: I hope you are planning for it, but you might not be able to answer that question today.

Ms Huxtable: There is consideration both within government and between governments being given to future funding, but I cannot really comment further than that. But yes, we are planning and discussing it.

Senator McKENZIE: I would like to ask a final question: There are four or five target cohorts that this project is specifically focusing on, and I know you have explained the change from the opt-in to the opt-out model, but I am wondering when we are so targeted in terms of the people that we want—and we have heard all day about the difficulties of getting everybody up and running on 1 July—why we are not trialling or encouraging just certain target groups to opt in. A person with chronic disease, for instance, would be regularly engaging with their medical professional and so that conversation could be had with them.

Ms Huxtable: That is what we are doing. We are seeking to begin by focusing implementation on those cohorts of the population who we know will most benefit. They are the ones who have more than one healthcare provider and who regularly have engagement across different health settings. The groups of people that will be the early adopters during the roll-out are those who will gain a material benefit from the exchange of health information between their providers.

So it is an opt in. If it were an opt out, then you would be preparing for a whole-of-population implementation from day one. That is not the system that is envisaged for a number of reasons that have probably been discussed at length. Once you are talking about a personally controlled record, it is hard to blend that idea with an opt-out

system. It does not quite gel to say on the one hand that people should have choice and control and on the other that everyone is going to have one unless you specifically say you do not want one. The reality is that this is a way to effect a staged implementation where you can get the benefits without all of the risks that come with a wholesale cross-population implementation from day one.

Senator McKENZIE: Who will be in charge of that implementation?

Ms Huxtable: The system operator, the Commonwealth, will be the one that is responsible for the PCHR itself, but there will be a number of partners including our colleagues in Medicare. NEHTA still has a body of work to do around foundation solutions and the expectation from discussion between the states and territories and the Commonwealth is that NEHTA will continue for a period. There is still some very significant development work to be done on the PCHR functionality. The early focus has been on a certain functionality where you get the maximum benefits, like medication management and discharge summaries, but the business case for PCHR anticipates functionality growing over time with the gradual incorporation of more and more information. It will continue to be a coordinated effort across governments including, one anticipates, investment across governments. But this is not just about governments; this is a partnership across the broader community, whether it be the provider community—for example, private hospitals—the software vendors, the consumers and the consumer organisations. It has been a very broad partnership and that will be the approach to implementation.

Senator SIEWERT: I want to go to the issues that were raised about safety assessments and the broader issue about NEHTA. In the submissions and today, there has been criticism of the way NEHTA has carried out certain functions. Has that criticism also been raised with the department?

Mr Madden: The question of clinical safety of all of the systems is absolutely critical to everything we are trying to do around getting success and credibility around the PCEHR. The clinical safety angles and the clinical safety assessments for all of the specifications and standards for the system are systemically in all of the development processes. The clinical safety people are involved all the way from the concept of operations and the creation of specifications, through to the publication and the compliance, conformance and accreditation process, so that is all there. The reports and the risks that are found in any of those processes we expect to be published within the specifications. To date we have processes to identify and understand the risks that come with these things, and if there are particular clinical risks that we are aware of then we will certainly take steps to remedy them. That stems right across the system from the system specifications, the national infrastructure, the specifications for particular documents and behaviours that might be built into software that some of our software vendors create, all the way through to the HI Service, which is operated by Medicare, and the ongoing operational aspects for the national infrastructure.

Senator SIEWERT: Were you aware before today of the criticisms that were raised about the potential risks to safety and some of the problems with issues of identification numbers?

Mr Madden: Through the CCA processes and development, we have certainly worked hard to understand what some of those clinical risks and things might be. The notion that there could be misidentification and how that system works is certainly being worked through the processes that exist with Medicare. I will hand over to Medicare to talk about the description of the HI Service and how we take those risks and issues out of the system.

Ms Golightly: Certainly there has been a very lengthy process with NEHTA, Health and all of the other stakeholders to work out specific processes on how we might deal with an issue should there be a duplicate or some other issue found, and they are fully documented. There is quite a formal and official process whereby we would work through and investigate whether indeed there was a duplicate or some other issue, then work through who we would need to notify if that were the case, link those records and so on and so forth to make sure that that number was indeed unique.

Senator SIEWERT: It was reported to us today that there have been problems.

Ms Golightly: Yes, I heard about that evidence and I am not aware of what the MSIA was referring to. We do monthly reports for NEHTA on the data quality issues, and there have been none identified to us.

Senator SIEWERT: From a patient perspective, with the health identifier number and/or the provider number, there have been no problems with either?

Ms Golightly: Not that we are aware of.

Senator SIEWERT: Could you take on notice to see if in fact there have been?

Ms Golightly: Certainly.

CHAIR: In DoHA, an independent committee, a technical subcommittee, was looking specifically at these issues.

Mr Madden: I think the reference in that piece of evidence was—there is a group called the compliance, conformance and accreditation governance group, which—

CHAIR: Yes, and a technical subcommittee of that group.

Mr Madden: There is a technical subcommittee within that. But, again, I attend the CCA governance group and have not been aware of any of these particular issues. I know that there has certainly been the necessity to make sure that our tests and processes are able to detect these, but, again, I am not aware of any particular notion of report or incidences of this occurring. I will take that on notice.

CHAIR: We may come back on that, yes.

Senator FURNER: Would you inform the committee of how many public consultations were held by the department in respect of the formation of the bills and how many public consultations may be held, if any, before the implementation date?

Ms Huxtable: You always ask really easy questions! Somewhere we have a list, but I think it only goes to our consultations. Consultations occur on a few levels. There are consultations which we, the department, have specifically involved in.

I beg your pardon—I have a list here. It might be easier to table it, because it goes on for a few pages, although I am not sure it covers every workshop that has every occurred.

Senator FURNER: That is okay.

Ms Huxtable: What I was going to say is that we, the department, had consultations around the concept of operations and the legislation, but NEHTA has also had very many consultations across its reference groups—it has had four-cornered roundtables and workshops and the like. There have also been 50 consultations held by the national change and adoption partner. I will table this. It sets out the various things which have occurred.

In terms of what we have left—

Ms Granger: It is rules and regulations.

Ms Huxtable: You can speak to that.

Ms Granger: We plan to have a draft of the rules and regulations soon—they are nearly complete—and to hold consultations on those.

Senator FURNER: During those consultations, were there stages where the community was advised of informed consent arrangements—how they would be conducted and to what depth and level those consent arrangements would be applicable?

Ms Granger: Yes, certainly we went through the consent problems.

Senator FURNER: The Australian Privacy Foundation indicates that that is where there has been some neglect in respect to providing 'the users, the disseminators and the data mines without consent'. Can you explain how the bills will enforce those informed consents around those issues?

Ms Granger: I think we have taken them through those, but we can provide details of the consultation.

Ms Huxtable: The legislation basically goes through that in a degree of detail and the rules and regulations will go through that in greater detail. But there was a lot of direct engagement, including with specific consumer subgroups. For example, I know that, in discussions around the nominated or authorised representative issue, there were some significant changes in the design around that issue. Those changes in part came from discussions with groups of people who have mental health needs or intellectual disabilities or people who move in and out of having the capacity to care for themselves—discussions about how you might put in place arrangements where they could enable someone to act on their behalf at times but at other times not be able to. That was a long toing and froing discussion with many of the affected and interested consumer groups. They were incredibly generous in giving their time and working through potential solutions. I think the solution which has been adopted in the legislation, which is to allow for more fine-grained access controls and to have a bit of a drop-down menu to allow selection of the level of control you want to enable someone to have, was worked through and pretty much accepted. People were happy with the outcome. As far as I am concerned, it has been a pretty open process.

Senator FURNER: The AMA indicated in their evidence this morning that this would lead to administrative issues in dealing with the consultation of a patient. I listened carefully to your opening comments where you used the words 'the normal workload' consultation process. That is your view on how the process will—

Ms Huxtable: As I said, what we were trying to do in terms of the design was to enable ease of use by incorporating the capacity to upload and download into the existing practice management system.

The intention is for that to be a simple process for clinicians. The evidence, including from international areas, is that in a couple of ways providers will encourage consumers and that is an important part of registration. If your provider says that this is a useful thing for you to have, then you are more likely to be open to the idea but also providers will take advantage of the benefits of this if it is an easy thing for them to use. Certainly that is what we have been focusing on.

Senator SIEWERT: Some of the submitters have raised issues around liability. Medibank, for example in their submissions, raised issues around liability. What happens if a practitioner relies on the information that is in the records? What does that mean for liability?

Ms Huxtable: We have worked through this quite a lot with the professions at the time.

Senator SIEWERT: I presume that you would have. Maybe if you could take that on notice, it would be appreciated rather than taking up time now; it is easier if it is all laid out. Thanks.

CHAIR: I am deeply concerned that there is a lot of legislation and the detail of the legislation that is going to be reliant on regulation as happens in so much of the stuff that comes before this committee. There is a lot of detail around how it will run and operate, who will be affected, timing and those things. The way I read it it will be subject to regulation. Is there any indication when we will have the regulations so we will be able to look at a the whole package?

Ms Huxtable: They are in an advanced stage of drafting, and we expect to be in a position to be able to release them quite soon for public consultation. I could not give you an exact date but quite soon.

CHAIR: Just to put on record clearly: there will be a format of public consultation on those regulations as well.

Ms Huxtable: Yes.

CHAIR: It is an ongoing complaint that we do not get the package beforehand.

Senator SIEWERT: I really appreciate you cannot give us an exact date. Are we talking about months or weeks?

Ms Huxtable: No, weeks—not months.

Senator SIEWERT: Less than months.

Ms Huxtable: We do not have months to be honest. We want it to start on 1 July.

CHAIR: There will be significant numbers of questions on notice and that is what we expect. We are aware that, particularly for your group, it also leads into this Senate estimates period, which is very difficult because--

Ms Huxtable: I see I will be excused next week.

CHAIR: I do not have that delegation, Ms Huxtable, but in terms of process, we are aware of that. With the process under which we are operating, it has at this stage a date of completion of the end of this month. We will go and have a talk about that as well ,but at this stage what we publicly got is a date of the 29 February. I am just reinforcing the need for turnaround on those things. We will be in contact all the way through. Thank you.

Ms Huxtable: The sooner we can get them—

CHAIR: I am looking desperately at the people from Hansard who are looking down as I am looking at them. We will be relying on the *Hansard* to go through and then individual senators will have their own questions on a number of things we have highlighted during the day that will be put on notice. Any witnesses that are still in the room, we will be contacting you formally with those as quickly as we can. Thank you very much. That concludes today's public hearing and the committee now stands adjourned.

Committee adjourned at 15:43