Overview of Digital Health and My Health Record

Webinar, 23 August 2018

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Mark Metherell: Good afternoon, and welcome to this, the second of our series of Consumers Health Forum webinar series on the My Health Record. Today our panel with contributions and questions from you, the online participants, will explore the My Health Record from the perspective of an overview. My name is Mark Metherell and I'm Communications Director of the Consumers Health Forum. We're fortunate today to have on our panel a group of individuals with great experience and knowledge about the issues that we will be discussing today.

[00:00:30]

Mark Metherell: I first of all introduce Dr. Christine Slade who's a lecturer in higher education at the Institute of Teaching and Learning Innovation at the University of Queensland where her research includes digital health curriculum. Since 2004, Christine has undertaken her professional career while living with chronic illness. She is an active user of the My Health Record, and has experienced firsthand through the the Princess Alexandria Hospital in Brisbane the significant different digital health can make to a consumer's life. Christine is currently a member of the Australian Commission on Safety and Quality in Healthcare's My Health Record in Emergency Departments Oversight Committee.

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Mark Metherell: Next, Professor Ian Hickie, who has for many years been a leading national advocate for better services and policy for those living with mental health issues. Ian is Co-Director of the Brain and Mind Centre of the University of Sydney. He is an NHMRC Senior Principal Research Fellow, and until recently he was a Commissioner on the National Mental Health Commission, which he had been with since its establishment in 2012. He is internationally renowned as a researcher in various branches in clinical psychiatry, and important for us here has a deep interest in the development of the My Health Record.

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Mark Metherell: Also we're fortunate to have Garth McDonald, who is General Manager Service Delivery at the Australian Digital Health Agency which administers the My Health Record. Garth has an extensive public sector management experience before starting his journey with Digital Health more than 10 years ago with Medicare. He's helped deliver its Health Identifier system, and he has sense held senior positions in data operations at strategy with
the Department of Human Services. In his current position, Garth and his team are driving the future agenda of digital health to support a healthier Australia.

Mark Metherell: Of course we have you, our online participants, to offer your questions and perspective. I will deal with as many questions posed by you before and during this session as time permits. The webinar series has been designed and directed by the Consumers Health Forum and has been made possible with funding support from the Australian Digital Health Agency.

Mark Metherell: Thinking about My Health Record in terms of an overview is to open the door into a fairly vast world of current and potential developments of digital health including not just the widening scope for storage and communications of health records between patients and doctors, but also the way in which therapeutic and diagnostic technology is deployed to improve health outcomes.

Mark Metherell: To kick off, I'd like to ask each of our panelists to give a brief overview of how they see the My Health Record and the implications. We'll just keep this opening bit as brief as we can, but first of all like to ask Garth how do you see the My Health Record and what it will all mean to all of us.

Garth McDonald: Look, I really see the My Health Record as an opportunity to, I guess, improve the health of all Australians. That's one of the reason I work at the Digital Health Agency. Really the ability to share information securely and safely throughout Australia between clinicians, practices, hospitals, and so forth just gives us that opportunity to improve people’s lives, but also improve the quality of data and how we manage that throughout the Australian health ecosystem.

Mark Metherell: Ty, and Christine?

Christine Slade: I think the My Health Record gives consumers an opportunity to be more participatory in their health outcomes. Particularly for people like myself who have chronic illness or complex conditions, it enables them to have more understanding of different health avenues and be able to, I think, decide for themselves how much they actually want to be active in their own healthcare and decision making and self management, perhaps. It's opening a lot of opportunities for people to be more actively involved.

Mark Metherell: Thank you, Christine. Ian, what’s your view?

Ian Hickie: It's essential. If we're going to see any significant progress in health outcomes and the quality of healthcare delivery in Australia, we need this back end bit, Health Records, to be open, particularly to what Christine was saying. Where it needs to go is greater involvement of people themselves to be empowered to manage their own healthcare. This is the essential
back end bit before we get on with the real bit, which is how do you actually come to control your own health.

Mark Metherell: First of all we ask a question. Many people will be saying, "What is the difference between health and digital health?" What's your view on that? What would you say, Garth?

Garth McDonald: Look, I think really to me it's just health. The only reason we probably differentiate between health and digital health at the moment is there is legacy practices of paper files and faxes and so forth that you would probably deem to be more in an old school type health environment. The reality is every interaction now will have some digital part, whether it's your x-rays being sent electronically through to your doctor and retrieved online, whether it's using Telehealth and communicating across vast things. They're all digital health. It's going to evolve into virtual reality to treat mental health issues or whatever that may be. I think you'll find in 10 years, 5 years, it'll just be health. I think it'll really move from having a distinction that we probably have today.

Mark Metherell: You've been a big user already of it. What's your view? Do you think it'll be we won't distinguish in 5 years' time?

Christine Slade: I would say that's true. I think digital systems will be just come mainstream and probably the word "digital" will be dropped off. I think the benefit or the difference between health and digital health in my mind is that if it's digital it's online, but it integrates lots of different systems that we haven't been able to do on paper. Therefore because it's doing that, it's opening new opportunities across the individual consumer, but also cohorts of consumers and also the health system and clinicians, to be able to do a lot more things because of the flexibility and the richness of the data that they're collection.

Mark Metherell: Yes. Yes, indeed. Integration, what's your sense of this, Ian?

Ian Hickie: Integration, it’s the empowerment bit. I think what's really different. I had to sit in a doctor's surgery yesterday myself with the silly magazines left over from 15 years ago, no access to the records. Now I have to leave and go to the next doctor with the appropriate sets of records. In the future, you'll sit there, you'll be in control of what happens. You'll take the data with you so that healthcare is actually organized around you, not around the provider. Health has been a provider-centric, "We have the records. We do what needs to be done." In the future, it'll be exactly the opposite.

Ian Hickie: I think that's the really empowering, interesting bit. We aren't there yet. There are many sets of issues around privacy, confidentiality, the transfer. At the end of the day, can you imagine, and we can imagine. We all do it
with our banking now, with our other things now, with travel now, everything else. Health is back there in the mid-20th century. Everybody else is in the 21st century where you control your own journey through all those other systems, and we in health need to get there quickly to have better outcomes, particularly if you’ve got chronic and complex illness. At the moment you’re in a bad situation, you don’t know. When you’ve got it with you and it goes everywhere, we as providers will be much better at organizing care around your needs.

Mark Metherell: Christine, you’ve been the one with the on-the-spot experience, if you like, using My Health Record with your condition. Would you agree with Ian? Is this the way you see it?

Christine Slade: I would. I think that at this stage it’s still very rudimentary, in my opinion. It’s really a repository of information. I’m anticipating that that will grow into a more like a portal idea where I can have interaction or there more interaction between care and people, but I appreciate that we’re in early stages of that. I think the perhaps dilemma might be for consumers is that they may not understand necessarily digital things very well, so we need to be able to help them understand would this be a benefit for me and how could it be a benefit. Some consumers may not want to actually pick up everything that is in there. Other consumers like myself are very highly motivated and do want this partnership and this empowerment. I guess it’s around choice for the consumers, but they need to understand what they’re making the choice on.

Mark Metherell: This all sounds ideal, Garth, but is it practical or possible with a national, highly technological regulated system like we have in health?

Garth McDonald: Look, I think the aim is to basically be an enabler. If you look at the national digital health strategy, it’s actually a paper that’s come together across state and territory governments and the commonwealth to actually look at the future for health. Now what we’re looking at is how do we provide the enablers so all these things that people are suggesting can occur? For me, it’s around how do I make that core bit of information safe and secure?

Garth McDonald: While the banking ideas and all that, we all want to embrace them and jump out, I think the public has to come on that journey of just because they put everything on Facebook may not mean they want the same with their health record. How do we get it to you have a choice of what is shown and shared is managed in a way that you feel safe and secure so you build that trust, and then hopefully we can get to that more innovative where we have phones and devices and watches and other things that can share, but in a way that people are managing that record as themselves. It’s their core data that they can choose how it’s shared.
Yes, indeed. Indeed. What would each of you ... A lot of people would say, "Health data, what does it mean to me?" Because of this idea we're moving from paper-based records the doctors kept to data which can mean all sorts of things. In one sentence, what would each of you, how would you describe health data?

Currently? 19th century. Hopeless. I'm trying to take care of someone with a complex manic depressive bipolar illness. Has a bit in a hospital. Patient was taken care of yesterday. She got immune data in one hospital. She got medication data in another hospital. She doesn't know herself what all the answers to all those questions are, some as unreported, I'm traveling. I'm supposed to be making decisions about medications descriptions now using a 19th century system. It's like paper tickets traveling in airlines we used to have. "Have you got a ticket?" It's your responsibility. When people are unwell, to assume that they are managing that situation or even understand what happened at the last hospital they were at or the last doctor they were at.

Australia is very complicated. Our health system is very hybrid. There are hundreds, thousands, of providers, each holding different bits. To me, the My Health Record is the national highway system. It's the connecting system. Could you imagine we all traveled on one lane roads around the country trying to get a service at the other end? I don't think people realize how much their health is put at risk by the current system, but as a provider, I'm aware every day of the week. I have to postpone decisions for a lack of information in real time to the person's real needs.

The moment you travel across systems, it barely works if you're in one of our hospitals, let anyone if you're in a hospital, out of a hospital, you've got a specialist, a GT, other care, a pharmacist, to organize. I think most people just in all of the discussion recently are just really not aware. A lot of those discussions being by people who are not really in the health system and not really facing the issues. Me as a prescriber, as a doctor, I am barely able to function effectively in complex disease areas on our current data systems.

Right. That was a long one sentence for data. What's your . . .

I'd just add to that. As a patient in a hospital that had paper and going across many different departments, I was always pleased to see the file arrive. I didn't realize at one point that it didn't have a summary page and that I was actually now the source of truth for my own care, which frightened me quite a lot.

I think also on another aspect of data, some consumers can be a bit frightened by that term because they think that that's going to invade their
privacy and could be used for things that they don't have control over. I guess data means different things to different people. To me, data would be what is recorded about me that I can access and have as a tool to help me be a partner in my care. I realize that clinicians and others are looking forward to having bigger systems of data because until now they haven't actually been able to know so many things because there's siloed paper or whatever. It's exciting in that way, but I guess it needs to assure consumers that it's safe for them to use this type of online data.

Mark Metherell: What about you? What's your perspective on this?

Garth McDonald: Look, I see it as an opportunity. From a consumer, probably put it simply, it's an opportunity to have a better and clearer involvement in managing their own health.

Mark Metherell: Yeah, okay, okay. How do you see the long term vision for digital health? Is there much we can learn from overseas, and how does Australian digital health arrangement so far compare with best overseas practice? Can you tell us?

Garth McDonald: Look, I think, to answer the first part, the long term view for digital health, and particularity for the My Health Record, is to continue to evolve to be that highway, to be that facilitator of information. As we've done a few times, we talked around there's going to be a public conversation on the way in how that works. If you look at how it works internationally, like for example, Israel has a national health record right now. What they don't have is any access to it by consumers. Therefore, they have a record that is put in place by the government, allows the information to be shared across the providers. They get all the benefits of the medicines and the data being exchanged freely.

Garth McDonald: What they don't have, which we have in Australia, is the ability to go in and access your own data, control which bit of data is shared. You can opt out of My Health Record. You can put a restriction on the record. You have to provide [inaudible 00:15:25] access it. You can remove documents you don't feel you want to share. That level of control and access is pretty much unique int he world in terms of these sort of health records.

Mark Metherell: Okay, okay. Have you looked at all assist overseas developments here, Christine?

Christine Slade: [inaudible 00:15:42] well, probably in the hospital system because I'm more connected with the Queensland Public Hospital system and their digital roll outs. I think one of the things I see here is the interoperability with the hospitals and the trying to connect even with the emergency departments across all of the hospitals that we're working hard to try and make this connection. Because that's one of the keys. If we can't use the My Health Record with other systems, then it's going to be very limited. I
think we're doing quite well at some of the roll outs in the hospitals and being able to ... compared to other countries in the world where perhaps some bits have been missing on some of their systems. We seem to be trying to tackle that quite well.

[00:16:30]
Mark Metherell: Right. Ian, is there much we can learn from overseas, in your experience?

Ian Hickie: Yes. Not only that, overseas are going to solve the problem, I mean internationally. At the moment, every health system in the world is constrained by health. Health is so controlling. It's so [inaudible 00:16:41] in Australia. We think we're acting in behalf of people. In fact, you don't own your own health record at all. It's owned by the organizations that have collected it. You don't have access now to that information. People say things, they collect things, they're accurate, they're inaccurate, they're out of date.

Ian Hickie: What's happening here is actually the big innovations are not in health. They're actually in Apple, Google, elsewhere, and they're personally controlled. The model is fact that you control, and this is what was alluded to where we're actually going. You decide how that record works. Until health gets it in its head that the consumer has to be at the center of it, and most health organizations still don't. Most hospitals, most other institutions, most professional organizations still think it's about them and information they trade about you with somebody else.

[00:17:30]
Ian Hickie: All the people that come from the personal technology information industry see it the other way around. You put consumers in charge of their own world. Guess what, health changes. It'll change like finance. It'll change like airlines. It'll change like everything else we do, because it has to work at the consumer end, and in this case to improve your health.

Ian Hickie: This is about trust. Do you trust your bank or not? Do you think your bank gives your information away every day or not? In your own health, your own data is precious to your own care. I would say your health is in danger now through the current system. If you get sick, for God's sake, you want the data not to have to report it yourself as you go for operating theatre to recovery. You want the data to be available to clinicians now in real time. You really only see it, I think, in intensive cares now is about the only place the data's really at the bedside in real time. That should be there all the time.

Ian Hickie: The innovations are coming, but I wouldn't be looking in health. They're actually happening internationally through consumer controlled device and systems. The issue is do we have a highway to connect to when they arrive?
Mark Metherell: Do we have a highway to connect to when we arrive?

Garth McDonald: We do, and that's what we are continuing to improve. The My Health Record has been in place for six years, has worked extremely well. The opportunity of having a national ... having all the public connected, all those that are not now, really gets us to become embedded into actual work on processes between the hospitals and practices and so forth so that actually becomes mainstream activity. I think that will then give the opportunity that, "Well, if I connect this information, it'll be shared readily," whereas at the moment you connect it to one hospital but isn't being used by your practice or your specialist that you attend and so forth.

Ian Hickie: Can I say, if we don't do that, we'll be left out. People want to bring those innovations here. If there's no highway ... It's like the airplanes. If there's nowhere to land, why go there?

Ian Hickie: One of the things is we've got to have a national system for all these other innovations to arrive and connect to. Some of the stuff that's going on at the moment, "We may do this within another five years." This is happening internationality. The question is which countries are up to connecting their health systems to the innovations in information technologies. I think the really good aspect of this and the opt out aspect is get organized now for the revolution that is coming in consumer controlled healthcare.

Mark Metherell: What do you think, Christine? Isn't there a tension here? We say we're giving ... empowering the patient, but will a lot of the people seeing the amount of data that the system can collect and be held by providers or whatever will be nervous about this, do you think, or not?

Christine Slade: I think that's true. I think that a lot of people would ...

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Christine Slade: I think that's true. I think a lot of people would be excited but because innovation can be threatening because we may not be able to keep up with it. For example, cyber security now is a big hot topic where we have seen breeches of different important systems and so that can cause some people to go "I don't want to do that."

Well I think that's okay but I think that shouldn't be the barrier that stops us moving forward with innovation, integration, making sure. I think one of the key things is making sure that systems do talk to each other so we have the Maya health record than we need to work hard at not sprouting other little systems in other places for convenience. We need to be able to have those conversations to say "We need to all connect. Otherwise it falls down because the consumer cannot travel from one place to the other."
Christine Slade: So that is quite a big issue I see.

[00:21:00] Mark Metherell: As far as integrated care, for instance, that we are in the health groups like the consumer health forum is wanting more in the way of integrated, coordinated primary health care and that would one presumes be helped by an integrated information system so different specialists and allied health professionals and the like can see that patient's data all at the same time.

Christine Slade: Yes. I was just going to say that's different to banking and that because banks have their own systems. In health, we are actually asking for more. We're asking for the whole lot of things in health to be connected as much as possible so we can see a cross different services and I think that's quite a massive task because I know in every state things are different, done differently, different systems.

Christine Slade: One of the big ones is, and you be able to answer more to this Garth, is that a lot of the IT systems hospitals have don't talk to each other and across states they don't talk to each other.

Garth McDonald: Even within hospitals.

[00:22:00] Christine Slade: Well yes. And so when you ask it, it will all sort of line up. It what you might think is a very small thing to achieve, is actually a big thing.

Ian Hickie: But this is the, when you say banks just talk to themselves, they don't they talk to retail, they talk to your credit card, they transfer money. So we have systems reserved bank and others across this.

Ian Hickie: I mean, we are finally on the road to having a governing system and as, what the national digitalize is doing is talking to all of those things so eventually, and hope we're not too far in the future, it becomes as efficient as you tagging your credit card, and tapping it, or transferring it and that go into your bank account.

Ian Hickie: There are many other people who see that data.

Christine Slade: I was thinking more across the banks themselves aren't talking to each other necessarily with their competitors...

Ian Hickie: Well they do, they trade...

Christine Slade: Yeah.
Ian Hickie: But they trade. So they're both competitive but they also have to trade information so there are regulatory frameworks in many other areas that have dealt with how we secure data, I would expect my bank account not to be hacked by somebody else.

Ian Hickie: So I think in health, we are very protective, we're very careful for good reasons and there are very good reasons and you always have the option of opting out. You know, if you really don't want anyone to see anything, if you don't want to have a credit card, you don't want to have a bank account, you know but really, if you've got a chronic health problem, do you realize the risk you're actually currently at by the non sharing of information that's critical to decision making?

Christine Slade: I think that's very true. I don't think consumer do really understand one, what it's like for clinicians to actually have to address things, for example if I want results of some test and they're not onsite, what they have to go through to actually get those to then deliver them to me so there's a lot of work involved.

Christine Slade: The fact they can't necessarily see everything and you know, as I said the paper file and I'm the source of truth about medications or whatever, that was actually a real eye opener to me when I discovered that and it was quite, I didn't realize it before that that the system was that fragile.

Ian Hickie: You're taking the blue one or the red one. You know, it's not a really good system.

Christine Slade: Yeah, what name is that?

[00:24:00] Mark Metherell: Garth, can I ask you, somebody mentioned tapping, could we get to a state with My Health Record where we can tap our card when we go to see the doctor or whatever and that's going to immediately tell the doctor the latest side of planned terms of our medical history.

Garth McDonald: It's been years since, Countryside, Germany actually as a model where they have a smart card where they allow you to actually do tap into that sort of thing.

Garth McDonald: What's the advantage of that? It's carrying information more secure than having it in a record. You have that as access or security to get into your system so those things are possible, but it's actually really asking the question is what is the outcome you're trying to achieve which is really having the right information in front of the doctor at the time of service and so whether that's having the card that brings it in whether it's us having it in the My Health Record System so people can pull it down or even throughout work on interoperability and so forth just having the train lines of disconnect that we might have between hospitals and practices.
line up so that the data that comes across is recognizable in all the systems.

Garth McDonald: There's a whole bunch of ways I think to get there. But I don't know if the card. Yes, if you wanted to, you could do that. Banking is showing you can do tap and go but does that get the outcome we want? I think the outcome is getting the right data securely in front of the clinician at the time you need it.

Ian Hickie: But don't you think, I mean the data is a bit of a problem I think in the dialogue. It's always about the clinician. It's actually not whether the clinician can see the data, it's also whether you can check whether it's accurate.

Garth McDonald: Sure.

[00:25:30]
Ian Hickie: So the active participation here about whether the data is accurate and is relevant to the particular thing, so I think where we haven't got yet, what people are not seeing yet is where records go where the consumer, the patient is actually much more active in that particular process and how they can see the decision making happening in which they're a partner to things.

Ian Hickie: So I think one of the problems we had in this [inaudible 00:25:52] is a lot of these discussions have been behind closed doors, behind providers, "Trust us it's good for you."

Garth McDonald: Yep.

Ian Hickie: And people are going "Hang on a second, I can't see this. How's this good for me?"

Garth McDonald: Yeah.

[00:26:00]
Ian Hickie: Unless you've been in the situation.

Garth McDonald: And I think that's the advantage of having the My Health Record and having it so citizens entering it, you'll be able to look at it yourself is to add that value and I suppose that...

Ian Hickie: You still can't interact with it yourself. There's a way to go [inaudible 00:26:15] tools.

Christine Slade: Yes.
Garth McDonald: Yeah. And I mean look, at the moment what is uploaded to My Health Record is what you can see and I guess there is a broader ecosystem of stuff that isn't and I mean, we've got to have that discussion of is that something that will come into the record in the future or not?

[00:26:30]
Garth McDonald: As you said, hospitals might collect information and then they may not see that relevant to a summary document that's shared and that's a separate conversation to the My Health Record function is "Where does the broader health terms of state based or nationally based ERs and hospitals and how private and public work and interact between each other" which is broader.

Christine Slade: As part of that, we've had a question from one of our viewers, Tonya asks "Does this mean clinicians have to updated the certain records as requested by patients?" No I'm guessing at the extent to which clinicians must follow the patient's request for updating, what's your?

Ian Hickie: Aren't clinicians funny people. I mean it's [inaudible 00:27:16] partnerships in key, I love those kinds of questions, you know "I'm going to have to do whatever that the patient wants."Or this idea that it'll change the record or whatever else.

Ian Hickie: I mean, we have an issue about what's actually going into the records now. In some sense, the sort of privacy I might have written something about you and I don't want you, or whatever else, may contain material that clinicians can see that should be kept confidential. I'd say "What exactly are you putting in those records that you are not sharing with the person?" And you if you want to record that person's perspective about that particular thing, you can do that in particular ways.

Ian Hickie: There are issues about at the moment what is directly shared. So I think what you have, and what we find a lot of we're in, a lot of the resistance is actually at the clinician level from a misunderstanding of these issues.

Ian Hickie: You made a comment about people not understanding digital health, I suggest people understand digital consumer things very strongly. My 91 year old mom banks by personal computer. Actually we expect a very high level of consumer interaction. Conditions are kind of going "I'm not really used to this. I used to write records for me. Am I really working with you on this shared health plan?"

Ian Hickie: So, it's a different kind of record in the future if you have a partnership in care.

[00:28:30]
Mark Metherell: This person seems to be raising the question that maybe the clinician may not record everything the patient wants even where it may be wanted. To what extent can the patient say "No, I want you to put that down."

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Christine Slade: Well, I can say something to that. I think, obviously you get [inaudible 00:28:50] some reason that as well so I have seen that coming through. At the moment, I think one limitation of the My Health Record is that I could write myself notes as the patient but nobody else gets to see them and I think that’s one thing I would really like to see change.

[00:29:00]

Christine Slade: Now I know there’s the argument to say "I might not get it right, but I have a subjective, lived experience of my illness, which I can be quite an expert at over time." and the health systems objective and it writes it fair enough but I think we should be able to write the lived experience in there as long as we’re on the same page of partnership to be effective about our health, and people should be able to see that. The patient should be able to see what I’m writing.

[00:29:30]

Ian Hickie: Isn’t it great. That’s new, right? This whole electronic record is about the providers. Now you can have health care where you can put your actual experience in or even more importantly, we’re working with families like a parent of a child can put accurate information in or the child of a parent with dementia can put accurate information in so that that very important care information subjective information, actually becomes part of the record. Not in competition to the clinician but in addition to the condition because it often has critical information that is never recorded or recorded inaccurately in the current records.

[00:30:00]

Christine Slade: Garth, can, is that right, the patient can put something in but it will not be seen by other clinicians?

Garth McDonald: So we do have some people like we have Our Health Improvement Group and one of our patient advocates was on that actually uses that quite actively record information and he then shares that with his clinician.

[00:30:30]

Garth McDonald: Now it’s not naturally that it goes through and becomes a document in the system that is sent around between the doctors but I guess it’s a way of, if people work well with their doctor and they have built that relationship trust, even now you would possibly turn up with, whether it’s paper based or on a USB or use all the information I’ve collected all around.

[00:31:00]

Garth McDonald: I took my own hat right, or did xyz, or here’s my exercise. So this gives you a way of capturing that electronically but I suppose it’s that, hopefully we’re impairing the consumer or patient to actually be able to have a conversation with their doctor. Just say I want to contribute more to my health. How do I get you that information? And then it’s really up to the two of them to work on what is the best approach.

[00:31:30]

Ian Hickie: Or perhaps just use other information. The area that I work in, mental health, at the same advance, I want you to involve my wife in this when I’m
on will and to put that in there and to be known in a particular, in a forward way, and to be used in real time in a particular critical situation.

Ian Hickie: When things haven't been expressed views about particular, that should influence the decision making but they won't necessarily be known by all the people along that path and they need to know and often a critical an acute point, or serious points along the way and that's the kind of thing that has been missing from our records.

Ian Hickie: So I think this much more empowered person in care, in partnership starts to become possible.

Mark Metherell: Presumably lots of GPs would already sort of record that information. "I want my partner to be in on the decision making or whatever." They already do that don't they?

Ian Hickie: But if you turn up at the local hospital acutely and it's in the GP thing...

Mark Metherell: Okay.

Ian Hickie: I recently at an acute hospital and I asked the doctor to ring me to ring the GP to ask them what they had in their record that was sent by the hospital. I went "What?"

Ian Hickie: Because they had no access to that but often in a hospital, in an emergency department in another city, that acute thing, something really important, might well have been in the GP record but it's not shared with the hospital. It's not there at the point of care where a critical decision is actually being made. And I think that some of these personal preference things, human preference things are really important. And some bits of information might be lost.

Ian Hickie: Others may previous had bad experience with opiates for example, and whatever I really prefer that you do not give me opiates for my pain relief and you know. So there can be various levels of information which can improve the journey of care and the experience of care if they're available at critical decision making points along that journey.

Mark Metherell: What about mental health care, that's your specialty. What can you tell us about the impact and influence of My Health Record in that sphere?

Ian Hickie: Well there are divided opinions this would surprise you. So there's one of those areas not the [inaudible 00:33:05] and sexual health and other areas where people coming in for the first time are often worried that some information will go into a record they might have shared confidentially...
previously with a GP or a psychologist or a psychiatrist. But they wouldn't want it to be widely available.

Ian Hickie: So often people entering new care are a bit worried about the confidentiality of their privacy. At the other end, those with complex problems and what many mental health advocates in this area, consumer advocates, like "For God sake, would you get all the information there, because I have complex mental health, physical health..."

[00:33:30]

Ian Hickie: We previously had different parts of the hospital where records were locked up differently and kept separate. The person with a mental health problem turns up in the emergency department, couldn't access their records, couldn't access medications.

Ian Hickie: So the more complex and ongoing in [inaudible 00:33:46] other areas of chronic illness, the patients in that area and their families are saying "For God sake, would you get on with this so I can get effective care at the right point."

Ian Hickie: So I think there's a bit of a division I think here about the trade off between confidentiality and concerns about privacy. People don't want all things to be available versus actually I'm getting very poor care under the current systems for those with established illness.

Mark Metherell: Garth, what sort of safeguards do you have in the system to protect confidentiality where it needs to be particularly in the small sensitive and complex area of mental health for instance?

Garth McDonald: So there's a couple of ways within the system. So you can actually put a restriction access code on your record which means no one in the health ecosystem can have a look at your record unless you expressly give them that code.

[00:34:30]

Garth McDonald: If it's, you want to restrict say mental health or sexual health or something, you can actually go through and put documents under restricted and you can then go to the different organizations you work with and actually say "Well this one can look at my restricted documents because it's my mental health GP or specialist but these ones can not.

Garth McDonald: So you can set that granular filtering within the system. What we found is that people also may have immolated or authorized [inaudible 00:34:59]. So somebody who will often not be able to manage their own health care can actually have another party who can either look at their record and make decision within that record or just look at it as a read only but it does give you that option that if there is somebody that comes in that is incapacitated or is unable to communicate clearly, that there is other channels to get in and validate that information and to perhaps review it.
Garth McDonald: It'll be something that will continue to be involved. I think with what is going through legislation and the moment and the changes we've got that balance on making sure the content is, people are comfortable, that it's safe and secure and they really have that option of getting rid of it or deleting it.

Mark Metherell: Christine, what's your sense of the evolution, particularly the confidentiality safeguards? Do you have a feeling that for your experience things are evolving, or likely to evolve?

Christine Slade: Well I'm quite comfortable with the security on my health records. I can appreciate other people may not. But you do have power to open it as much as you want to do that. I guess my, and I appreciate it's early days, and value the fact that we had it, but I would be looking to more interaction or interactive features in it as time goes by.

Christine Slade: I've been very fortunate because since 2010 I've had clinicians that allow me to talk to them by virtual means and so I kind of look for that now.

Mark Metherell: When you say by virtual, you mean by email or...

Christine Slade: Yeah, so my first my collection at[inaudible 00:36:39] gave me her mobile number when I first came to her in 2010 and we used to do virtual consultations and SOS and email and all that so it got me into that partnership mode I guess, which I really appreciate it.

Christine Slade: And even now, with some clinicians if I have email or something it does give me an opportunity to say something if I really want. I'm careful about it but I do have that partnership arrangement so I can appreciate even more features and all that.

Christine Slade: So there's a few things that I would like to see. I would like to see obviously being able to have an opinion about some of the things that go on so as you see, information floating through there, one is you could verify it, yes? Which some consumers say is wrong. That discharge thing doesn't have the right things. I should be able to see that.

Christine Slade: I've had to make decision in my health care that have been very difficult so being able to talk to someone or do something with that in some way to sort of help me, perhaps educational resources, so I'm a Googler expert, but you have to learn which are credible sites and which aren't credible sites. What you can believe and what you can't but I think it would be nice to have dedicated educational resources of some kind so it would help people build up their understanding...

Ian Hickie: But let's be clear, they're not going to come from My Health Record. There's an explosion world wide in all these assistive technologies. I mean,
I would argue they're all the government enthusiasts, going back to the airline analogy, is create great runways so that much better vehicles can arrive or around the world so you access information from all around the world...

Christine Slade: Well I guess what I'm saying there is that you know that it's trustworthy, where it comes from, whether it's connected from somewhere else because that is a real challenge to know, just reading I've been reading about a certain thing and honestly a lot of it was not credible. But I have to work my way through all that information to learn what is and what isn't. So it's quite a journey for people to understand so in some way that they can have credible sources to know at least a start or what they want to do.

Christine Slade: And the other one is, and it may go out from somewhere else, is a very lonely journey. I am a patient in a very big hospital system. In all of those years, 16 years of being in and out of, I have not really talked to another patient about my own, that sort of concerns. We just sort of sit there in waiting rooms and I think, obviously there are support groups, but being able to hear some of the stories of people and just what they approve, and what's safe for them to say, but being able to read or interact with other consumers to say "This is my story." Would be really supportive to people when they're tackling things and they feel quite alone in a big system.

Christine Slade: So I think there's a lot of different ways we can enhance the system over time to help people become more empowered.

Mark Metherell: Give me an example, how would you enhance it? What are these better highways?

Ian Hickie: Well, if you've got the highways in place, facilitating self help groups, facilitating information, facilitating access to the world's best information in certain areas, bringing that back to the particular thing so you're not, I've been in many great hospitals in Australia, but you might prefer to see what the Mayo Clinic's doing or John Hopkins is doing or how they manage that situation.

Ian Hickie: In fact, you may prefer to bring their system into your hospital. You know, in particular way. You may prefer to join their...

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Ian Hickie: Their system into your hospital. In particular, you may prefer to join their patient group for that rare disease in a particular way. So, I think the digital enablers are already growing very quickly. What they've not been able to connect to is our actual health system.
Christine Slade: Yeah.

Ian Hickie: So they resisting this isolation [inaudible 00:40:16], most, many patients have become very active in those worlds. But they can't connect it with their own personal experience. So I think this is happening worldwide, the challenge for us is to have a national infrastructure, that is actually enabling, and allows that to come back to your hospital, your clinic, your providers, so that we're all sharing the same information, and you'll be able to ask the doctor, "Why aren't we doing things the way they do it at the [inaudible 00:40:43] Clinic" or, "John Hopkins?" or somewhere else.

Ian Hickie: And there may be very good reasons as to why we are what we aren't, or other people had experiences, they've benefited from this type of thing or not. When you're [inaudible 00:40:54], I think many people, many providers have been using obvious digital technologies to increase the efficiency and the responsiveness of people they take care of with chronic disease. It's much easier for me. I prescribe a medication yesterday for a patient that tell me they had a side effect to die, then not know, and wait four weeks, and find they never took the drug because they had a problem on day two, which is the current kind of [crosstalk 00:41:16], in a non-digital world.

Mark Metherell: But the problem is Medicare, and they fee for service system, which is designed,

Ian Hickie: Which it dumb.

Mark Metherell: But are not designed to pay the doctor to give time to respond to emails.

[00:41:30]

Ian Hickie: So the National Infrastructure includes the National Broadband Network, it includes the National Financing Systems, it isn't just a tech issue.

Mark Metherell: But isn't this a problem? I mean increasingly, people, [inaudible 00:41:40], you can communicate with your doctor outside the surgery. This ain't that common yet, because doctors who resisted it for not being paid for.

Christine Slade: Well as far as I understand, doctors have been saying that message for quite a long time.

Ian Hickie: But hang on, hang on, we do stuff everyday that we don't get paid for. I really resent that kind of argument. Doctors do all sorts of things I think in partnership with people they care for, everyday, to try and make better care. And since we had these things, lots of doctors, lots of doctors I know, use digital technology everyday.

Mark Metherell: Sure.
Ian Hickie: Now there may be restrictions, in fact it’s the other way around. Some public authorities, some hospitals, some others prevent their doctors using technology. That’s even more interesting. So it’s not the doctors, you can get paid for it. The organization you work for says, "You’re not to do it."

Mark Metherell: I suppose anything more that the GP’s media [crosstalk 00:42:27] relying on a [inaudible 00:42:28] income, needing volume of patient, services. It is difficult for them.

Christine Slade: I agree, I think it should be addressed. That issue has been around for quite a long time, and it’s probably one of those institutional-type things things that does need to be addressed, that would encourage more people to feel free to do that. But you’re right, a lot of people that I know do use it. I mean clinicians give their time very freely to [crosstalk 00:42:52].

Ian Hickie: Of course they do. We got an MBS reform, committee’s going somewhere in the country. We need the payment systems to line up with the healthcare delivery systems of the 21st century.

Mark Metherell: Garth, to what extent is my health record and the digital health agency able to, or expose to overseas international developments that may provide advances for what can be offered here?

Garth McDonald: Well we actually have a global digital health partnership that was created last year, which actually has about 17-member countries [crosstalk 00:43:24], Canada, US, Israel, Singapore, and so forth. That’s actually been quite good cause we actually been able to have some policy discussions at what would be considered a global level, around how some of those things would work.

Garth McDonald: Now, as Ian’s pointed out, the conversation though, their needs, obviously if you talking things around [inaudible 00:43:42] or, whether you pay MBS based on an outcome versus based on a service, a lot of those will actually be more health department-type things. So what will be involved in the conversation? It really comes down to probably a government policy on how they wanna do that.

Garth McDonald: But I think the discussion will become more informed with this global partnership, and the people raising issues, and really want an outcome, rather than a bunch of service events.

Mark Metherell: In the mental health sphere, there’s a growing number of, online apps, helping people, with their condition. Are there concerns that this is loading too much onto the patient, and is this a wider concern with digital health? People sure can access more information, but at the same time perhaps, don’t get to consult or see the doctor or whatever when they should.
Ian Hickie: Well in one of those areas of healthcare, would demand far exceed supply? So actually we're gonna have something different happen. We're gonna have the uberization of mental health. We have so failed to develop a health system to respond to the actual community demand, that private providers and digital health options, the apps you talked about, are already out there. Cause in the US, you watch television ads, telling you, "You gotta see a psychologist online." And people are, because it's affordable, and it's accessible, and they're not getting it under current arrangements.

[00:45:00]

Mark Metherell: But does it work?

Ian Hickie: Yes. It works a little bit, short-term.

Ian Hickie: So, most of the digital health I'm interested in, is not an alternative to the rest of the health systems. But we have a major problem, that the health systems have been so slow to develop quality mental healthcare, that other options, digitally-based, and they won't just be based in a sense. You can now access overseas. Very close colleague and friend of mine, previous commissioner Jackie Crow sadly died last year. She was accessing great health care from the UK online, for her mental health condition, which she was paying for, cause it was so much better, and responsive. Medication changes respond overnight, things happen overnight. Condition interaction, based in the UK.

[00:45:30]

Ian Hickie: So this issue of where is best care, now it's not the goal of mental health apps or digital health to replace, or simply compete with. But with a real problem, in extent to our traditional healthcare system, is responding to the volume. So I am quite skeptical about apps on their own and systems on their own, but they are filling a void [inaudible 00:46:08], that is not being met by traditional healthcare.

[00:46:00]

Ian Hickie: So the ideal medical healthcare integrates both.

Mark Metherell: What about the [inaudible 00:46:16] safety and quality in healthcare issues at all? Christine, you're part of the Health Quality and Safety Commissions, work in this area. Does the digital health raise new, fresh, different challenges in terms of safety and quality?

[00:46:30]

Christine Slade: I think actually there's a lot more benefits than challenges. I think that there's more accuracy in the data if it's digital. And the quality of healthcare, depending on what level you're thinking of. I think consumers sure have their own needs from the digital health system, but they need to think widely, that it's not just about us and our own care, it's also about better improved care for cohorts of people.

[00:47:00]

Christine Slade: For example, in Queensland hospitals, where they have the diabetes dashboards and things like that, that can look at whole cohorts. Or it could be around research and around healthcare systems generally that I would
[00:47:30] expect that we would have, because of the increased data and the richer data that they can get, that consumers generally will be better off, because they can then make informed decisions on empirical data.

Christine Slade: On the other hand, if you're the consumer, and you are expected to make some more decisions perhaps around, we're being pushed to say, "How much do you wanna be involved in your healthcare?" And I think that's something that we have to feel comfortable about. I have at times felt overwhelmed by data, and stopped looking at things, because it was actually complicating it. So I make choices not to, and perhaps I talk to a clinician then if I'm confused. I think it's around trust, really. I think the clinicians and the patients, they have to trust each other, and they have to work at that, so that they can make judgment calls and accept each other's opinion.

Christine Slade: So if I raced off and wanted to look at an app, it would have to be informed and think, "Is this gonna really help?" And then maybe I would talk to somebody. So I think we are asking a lot more of consumers in what their digital literacy, in their health literacy. But obviously, it still comes down to the fact that you have people that are in your care, that are looking after your care as well, and so therefore those communication with them as well, which you have to be quite skilled sometimes to actually navigate your way around, and sometimes you feel like your own case manager, which can be challenging, I accept that.

Christine Slade: So I think, we need to have self-advocacy when we can, and when we can't, we need to be free to ask that this isn't working. So, that's a protection I guess.

Mark Metherell: Garth, do you think there's a question of balance here? I think between the extent to which my health record and digital health is there to help clinicians consult other clinicians, or to help patients with their clinicians. Is there sort of a challenge here in terms of getting the balance right, or is your plan one case at a time, or?

Garth McDonald: Look I think, in terms of my health record, there probably is a balance, and I think putting the citizen at the core of their own record is really important, and having the ability to control it as we talked about today is important. But, I think some of what we're talking about here, if we put the my health record aside, if you look at the generation coming through, everything they do is online. They don't go to shops anymore, they order online. They buy food online, it's delivered to their house. It's very much a self-service, "I want it now." type mentality.

Garth McDonald: So, [inaudible 00:50:07] of my health record, there will be a shift for, "I've got a 12 and 14 year old," you know, 14 year old daughter. So you can mention all sorts of fun things coming through her life, and every time I build a system, I think, "Oh my god, she's gonna be in that," you know. "As a
Ian Hickie: Guess what? I want a more responsive health system! [crosstalk 00:50:36] to their needs. So this is a big challenge, to the more [crosstalk 00:50:42].

Mark Metherell: But the uberization of health, this instant drive thru healthcare, or whatever it is going to be, is it really [inaudible 00:50:51]?

Ian Hickie: Fundamental, there are two issues here, and I think Christine is right, it’s important ones. I actually think the accountability of systems improve considerably. We learn what is not right in the current systems. And we just this week seen reports about accidents and injuries and they’re enormous. People don’t realize in the current system, the risks they’re actually taking.

Mark Metherell: But if we’re moving it faster, does the risk increase?

Ian Hickie: Well, we’ve been slow. Health has been a terrible industry from an information, technology point of view to respond to the digital age. Only health could’ve survived this long without doing this. Cause people are so trusting of the health system and doctors and hospitals, they got no idea the risks they currently at. Some idea the inconvenience of waiting and waiting lists and com.

Ian Hickie: So the expectation be more responsive, and I think we see this also with the National Disability Insurance Scheme has shift to, "Hang on, I have complex needs, not simple needs." I really don’t like the primary care idea where everything’s simple. Most things are complicated, and we’re gonna get more personalized. And the future of healthcare needs to be more personalized. So your needs go in, and you get the right response the first time, and the level of need gets responded to.

Ian Hickie: So, what we should end up with is smarter systems, that more efficiently triage what you get, to get the right level sooner, not to have to go through a whole lot of steps where you file and cue-up and waste my time and money, ‘till you finally see someone that’s right for your problem.

Ian Hickie: So I think you have the modern, young consumer, hopefully that’ll be all of us, as it is in many of the other things we now do digitally. So it’s a big challenge to the existing system, you bet.

Mark Metherell: This triage system, do you think my health record is really moving towards that sort of triaging if you like the virtual triaging, so that a patient’s going
to more likely get the coordinated care, because of my health record, is that your sense of it?

Christine Slade: I think, if you just let it sit there, that may be the case, but probably not. As I was saying before, it does require consumers to take a role. And they may be very happy about doing that. But, you do have to drive that, you do have to have some part in that. So, otherwise, I think it would just sit there and just be the repository-type idea.

Mark Metherell: Sure.

Ian Hickie: But do you think Christine, some chronic issues in the area, this is happening in mental health and other chronic diseases, certain kind of consumer will drive the system faster? Cause they're the ones who get us. You don't have to have everyone to [inaudible 00:53:22] or whatever. When certain kinds of problems are pressing the system to respond faster and smarter, that'll actually drive a good deal of the improvement, which the rest of us, lazy, we'll be the beneficiaries of.

Christine Slade: So I think there is a shift to having more consumer voice. How much that actually drives the complete institutional systems, I'm not sure. I guess it's variant.

Mark Metherell: We had a question, how will the quality of inputs be insured? My wife went from the emergency department to intensive care unit, to a cardiac ward, then to a general ward. When she left the hospital, her discharge report was full of inconsistent statements about medication, and confusing information about what had happened, and what it was thought had happened. Isn't this the problem? We get information overload as a result of my health record. Could I ask Garth, you're the data manager. How do you deal with this?

Garth McDonald: Look from that sort of point of view, it's actually quite beneficial, because what normally would occur is you would get a [inaudible 00:54:27] arrived ten days after you've left the hospital to your practitioner. In this case, it's uploaded, if they're connected, straight away. Now, as a consumer, I would go in and look at that, and then I would immediately go back to the hospital and say, "Look, I believe this or this didn't occur." And you can get it updated or [inaudible 00:54:43].

Garth McDonald: That opportunity didn't exist on a completely paper-based process. I don't think people would wait two or three weeks, go back to their doctor, and then go, "I think that's wrong." And then I'm not sure how that would feed backwards. If you've got that opportunity to do that the 48 hours after you've left, and you've got that relevant information, it gives you that opportunity to go back, and that'll just improve the quality, which means two years down the track when somebody's referring to those documents, they're actually going to make more informed decision. It might be as
simple as, "Well it was a left knee, right knee that I grazed or cut." or whatever. But, it's relevant in the bigger picture, and I think having the citizen access to that quickly, [crosstalk 00:55:20].

Mark Metherell: Quite often, people will have complex conditions, which are involving complex and sophisticated treatment, they won't understand the chemistry or whatever is involved when they look at what's happened to different hospital, will they?

Christine Slade: Oh I think consumers have a pretty good idea.

Mark Metherell: Do they?

Christine Slade: Yes!

Mark Metherell: But if I was being treated for some complication of diabetes and high blood pressure, and different medications had been used, I wouldn't know, would I?

Christine Slade: I think if you have a complex condition, you start learning about that. You would maybe even sense there's something wrong, whether you understand completely what every medication does, maybe you do, maybe you don't. But I've heard these stories before around discharge summaries, and I think it pretty vigilant at that point, or someone in your family is your carer, to know there is something wrong with that.

Ian Hickie: I mean the example given's fabulous, the current record's incredibly inaccurate. Wrong things are written down all the time. Here's a chance to correct, and often I think it's often the person themselves or a carer [inaudible 00:56:18]. "That didn't happen." Or that stopped because the side effect, which is not in the traditional summary. So actually this transparency of records, corrects problems, but also allows the interaction. It highlights at the moment that we get inaccurate information all the time. A discharge summary I get from the hospital doesn't tell me about the four other things that were tried, that caused problems, but was chosen not to put in the discharge summary. I can't see! And the patient themself doesn't know necessarily those things.

Ian Hickie: So, the increased transparency, where someone who cares, guess who cares? The patient themselves and the family. They really care to get it right. There is a certain kind of consumer, it won't be everyone, but it drives quality improvement in the system. Even within hospitals at the moment, the transfer information from one department to another, contains these kind of inaccuracies. But we in the healthcare system, we just sorta let it go. Someone who cares suddenly starts to interact with that. And I think people's expectations at the moment for my health record, it isn't doing all this at the moment. There's a whole lotta levels of developments of the
system. But once you've got a system that can allow that to develop, we're a whole other world.

[00:57:30]
Mark Metherell: Okay, are there things we need to watch, then? The way he paints it, it looks as though along the verge of a wonderful new era of perfect healthcare. Are there things that you think we need to watch as this rolls out, Christine?

Christine Slade: Well in summary, I think people need to feel comfortable about the privacy of their information, which I know is already having some work done on that, cause that's been a concern for quite a long time. And I think the other one is probably to feel confident that they can use that system and know how to use it.

[00:58:00]
Christine Slade: So some sort of education to help people understand digital and what that means for health, and then what they can do with it, I think there's still some work there, to make sure we give each consumer an understanding of perhaps what they want to do with it.

Mark Metherell: Okay. Garth, is there any final points you'd like to make about [crosstalk 00:58:19] to wrap up?

Garth McDonald: Pretty much on the same vein as what Christine's saying. It's really, as things of all, we just need to look at what the outcomes that people are looking for, and how do we safe and securely deliver those outcomes, so we can keep confidence in the system, and keep people trusting it. It's great to share information, but it needs to be done in a way that it's secure, and is accurate as possible in having these abilities of people to interact with it, as the owner of their own data.

Mark Metherell: Ian?

Ian Hickie: So obviously security really matters, and it will be challenging. It's challenging in every other industry, and it will be challenging here. So that's gotta be at the top. But beyond that, I want a country that actually has the capacity import the world’s best technology here, so Australians can use the world’s best evolving technology in personal healthcare, as soon as possible. And link the consumer reel active bit, with sensible, smart, actual valuable information.

Mark Metherell: Thanks. Any last word from you, Christine?

Christine Slade: I guess my last word would be to each consumer that you need to feel comfortable with your decision about how you use My Health Record, and to think broadly about what it could do for you before you may quickly feel anxious to opt out, I think. And if you need to explore new information,
then go ahead and try and find out what are the benefits and, [inaudible 00:59:36] to come, that will also talk about those issues so to be informed.

Mark Metherell: Thank you Christine, Garth and, Ian. As Christine says, there's more formal webinars to come. Thank you for your participation today, and look forward to having you back for the next four series. Thank you.

Section 3 of 3 [00:40:00 - 00:59:57]