

## Transcript

# Digital Inclusion, Health Literacy and My Health Record

Webinar, 13 September 2018

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### Section 1 of 3 [00:00:00 - 00:22:04]

Mark Metherell: Good afternoon and welcome to today's webinar, the fifth in our series of webinars on the My Health Record being presented by the Consumers Health Forum of Australia. Today's focus is digital inclusion and health literacy, and we welcome your online comments and questions during this next hour.

Mark Metherell: [00:00:30] We have, once again, a great panel of knowledgeable people offering a range of perspectives with us today. On my far right is Karen Gallagher she's the General Manager of Implementation of the My Health Record at the Australian Digital Health agency. Next is Dr. Chris Moy. He's a GP from Adelaide and chairs the Australian Medical Association's Ethics and Medico-Legal Committee. On my left, Louisa Walsh who's a consumer advocate and researcher at La Trobe University's Center for Health Communications and Participation, and Mohammad Al-Khafaji, Director of the Federation of Ethnic Community Councils of Australia. Welcome all. [00:01:00] I'm Mark Metherell. I'm Communications Director at the Consumers Health Forum.

Mark Metherell: [00:01:30] The Consumers Health Forum has designed and directed this series of webinars with the funding assistance from the Australian Digital Health Agency, which of course administers the My Health Record or MHR as we might refer to it. Today's topics, digital inclusion and health literacy, it seems to me, are linked in the sense that both go to people's capacity to interact and benefit from the health system, but they have effects in [00:02:00] different ways, so I propose for the start at least to look at each of these aspects separately.

Mark Metherell: [00:02:30] If we go to digital inclusion, that is the ability obviously for people to work with, to be involved in and benefit from the digital technology. According to one estimate though, there's two and a half million Australians who are still not online and not getting the benefits of education, health, social, and financial that you get from being connected. Digital inclusion is not just about computers, the internet, or even technology. It's about using the

technology as a channel to improve skills and in this case, to enhance quality of life obviously through healthcare.

Mark Metherell: [00:03:00] You could say that digital inclusion is really about social inclusion, and I'd like to start with raising this issue with all of them, all of our panelists here, that given the current practice and culture in healthcare, do we think the typical patient and particularly those with little digital school would get much support from health professionals, doctors, nurses, et cetera, to encourage them to use MHR to best advantages? Perhaps I should start with Chris Moy. He's the practicing doctor here. Chris, what's your view?

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Dr. Chris Moy: Yep. Look, what I'd say to you is My Health Record is not the panacea for everything, and it's not going to solve digital inclusion problem because that's a much wider problem, but what it does is really provide the information at the point of care not only for health providers to improve the care of an individual, but the other thing it does is allows, for the first-time, access of all that information to the individual. If the individual can't actually access this information, it could be for a nominated representative or an authorized representative because in many ways, what it's doing is providing information, which is so far not being transparent to individuals about what their doctors and their other health providers have been thinking about them.

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Dr. Chris Moy: Let me give you example. We know that, for example, 40 to 80% of all patients, when they walk out a room even if they've listened in, will actually forget what they've been told as they walk out of the consultation. This is obviously going to be a bigger problem, for example, if an individual has poor language skills or does not speak English, for example. They're going to go home with very little residual information about what's going on. In that situation, if they're able to access My Health Record for the first time, they're actually going to be able to look on their My Health Record and actually find out a little bit about what they've got.

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Dr. Chris Moy: In addition, say if it's a situation where they go home and they have somebody, again, if they're non-English speaking and they have somebody who actually is their nominated provider who can actually look in there, they may actually be able to interpret some of this information for them for the first time. In some ways, it reflects what happens normally. When a patient comes into my room, they're often going to come in with somebody who's a supporter, who's a carer, who will actually be doing that job. This time, they're going to be able to do it at another time and place.

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Dr. Chris Moy: Really, I think the main message I'd say to you is it is not the answer to digital inclusion, but having said that, I think there's a future that could enhance what we do with the information. I think the main thing is that for the first time, this information is not only going to be available to other doctors and other health providers to improve the care of an individual.

For the first time, it's going to be available and transparent to the individual or to the carers and representatives of that individual.

Mark Metherell: Thanks, Chris. What's the perspective of the ADHA on this, Karen? Where do we go in terms of reaching out to people who may not be technically knowledgeable in digital inclusion, et cetera?

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Karen Gallagher: Thanks, Mark. I think what Chris has really pointed out is that there is community, and then we are talking about inclusion within the community. I think it is important for us to look at the role of My Health Record within that community and that the key benefit of a digital system in this particular aspect is for the healthcare provider for that person, whatever digital barriers they may face themselves, to benefit them. The fact that their information is able to be shared between their providers gives them benefit even if they don't access their My Health Record for themselves.

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Karen Gallagher: I guess that that really is my view of that, but one of the important things that we are doing is we are working with a number of advocacy groups and stakeholders, and we're also doing community engagement because this is really the space we get a lot of questions about, how are people going to get access? What does this mean for people that don't speak English? What if someone has low vision, what if they open up a shared health summary and don't understand what it means? We get a lot of these questions, and I think that what the last few months has really done is raise an awareness around what it means to have access to your medical information and what it even means for healthcare providers to share that information.

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Karen Gallagher: We've opened the discussion, and this is part of that discussion to take those questions and start to be able to provide those answers, and then build the strategies and the tools to provide that support. That's one of the things that we are doing. We're ongoing. We're doing a lot of research in the health literacy space, and we've built over 40 organization partnerships, one of those being the Federation of Ethnic Community Councils who's been really supportive in helping us get out to ethnic communities and speak to them in language, which has been excellent.

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Karen Gallagher: We're creating a lot of self-help tools, and we're also continually doing product improvement. We do a couple of technical releases each year, but that's all driven by the sorts of questions and concerns that we get because we need to continue to look at how do we ensure access and equity in the use of My Health Record for the benefit of health outcomes. I think that's the real key here as well, is to continue to look at the value of this digital tool for health outcomes.

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Karen Gallagher: Probably, one other point that I would like to make just when I looked at that word literacy is that the information availability is really key to literacy.

[00:08:30] This is the first time that that's happening. To be able to actually read some information about yourself rather than to be looking around Google and doing research around Google rather than looking at it yourself, I think that makes a big ... It's a big change and a big shift in people being able to be more involved in their care or for their carers or their family to be involved in their care because they've got information about themselves. I hope that answers your question.

Mark Metherell: Okay. Thanks, Karen. Louisa, what's the perspective, do you think, from the consumers? I mean, is this sounding like the way to go?

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Louisa Walsh: Well, I think that there's a lot of benefit to the ability of health professionals to share information between each other more readily, and I think that continuity of care, that communication between health professionals is a massive issue in terms of patient care, but I also think we need to think about what the role of My Health Record is meant to be now and into the future and how that could evolve and change. I think there is capacity for consumers to input their own information. Some of that, health professionals can see. Some of it, they can't.

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Louisa Walsh: The consumer can then sort of decide which of the uploaded pieces of health information from the health professional side they sort of ... if they want to hide things or if they want to leave them open to their health professionals or which health professionals can see which pieces of information. There's a bit of capacity to sort of, I guess tailor the information, who sees what and have control in that way, but is this a true sort of tool that consumers can use as a personally controlled electronic health record where they can use this to build an equitable relationship with their health professional, or is this more a device and a way for health professionals to communicate more effectively with each other to have that continuity of care in the background?

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Louisa Walsh: I think that's a bit of a juggle, like is this a true kind of patient portal, or is this a way for health professionals communicate more effectively with each other? I think from my point of view, the fact that a lot of the kind of, I guess meaty information that the patients could input about themselves, things like there's all the personal health. Sorry. I get all the good terms confused. I've been reading a lot about it over the last three weeks. All the health information, the health note, the personal health note. The fact that health professionals can't see that unless it's actively shown, so a consumer can't choose to allow to share that with their GP, for example, really takes away some of those opportunities potentially, I think, for making this more about an equitable relationship and a collaborative relationship with the GP.

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Louisa Walsh: It is early days for the record. I think it's been around since 2012 but in this sort of iteration, in the opt-out period of getting a lot of people onto it, and

[00:11:30] it doesn't mean that these things can't happen in the future, but maybe that's where people are getting a little bit lost about whether there is actual ... what level of control consumers can have and what level of input they can have and how they can use this to enhance their communication with their health professionals or whether it is that kind of that information sharing for continuity of patient care and where the benefit sits at the moment.

Mark Metherell: Thanks, Louisa. Mohammad, digital inclusion, is this a more difficult challenge for people from non-English speaking backgrounds? Do you think it's allowing us with another technical step for them to go through? What do you think the experience has been so far in terms of accessing My Health Record?  
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Mohammad A.: Sure. That's a really good question. Thank you. Look, I think it's essentially, the question is about accessing equity for people of culturally and linguistically diverse backgrounds. When I think about my family and my parents, I didn't think that my mom would pick up a phone or know how to use a smartphone, but it's quite surprising that she is actually one of the heaviest users of technology. I think I would say [inaudible 00:12:45] communities are quite resilient when it comes to adopting to change and adopting to using technology to manage, for example, health records or Centrelink issues or whatever. They know how to work, I guess with the system if they're shown how to use it properly.  
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Mohammad A.: A good example of that is, I think there was a good case that beautiful design is important in terms of user experience because people get used to knowing exactly what buttons to press to do what they need to do, so you better not change that layout because if you do, they could put themselves in trouble because we need to acknowledge that not everyone speaks English or we can't also assume that everybody can read or write in their own language as well. I think people will adapt in those ways. I guess in terms of literacy, in technology literacy, I think people are quite resilient, but I think it's all about access and inclusion and equity for those people who can't read or write. A lot of them do need translators and interpreters.  
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Mark Metherell: Karen, could I ask, what has been the experience as far as MHR is concerned so far in terms of people coming from diverse cultural backgrounds?

Karen Gallagher: I'm actually unsure of the makeup. Do you mean of how many users are on My Health Record because that's not something that comes through as part of the system data as to ... Also, the system currently at the moment is English, so it's in English navigation. The website, we have translations on that, and it's also got an easy speaker, an easy read speaker, but the actual system is in English. Sorry. Unfortunately, I can't give you the data on that one, Mark.  
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Mark Metherell: Yeah. In the future, aren't there going to be a lot of people who don't read or speak English? What's going to happen about their access to MHR?

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Karen Gallagher: Yeah, so we're actually working with the Federation of Ethnic Community Councils and have recently actually been speaking with them about that, about the fact that currently, if someone went into a My Health Record, would they be able to use the tool because it's in English format? As I mentioned, we have a product improvement group, and we take a lot of feedback from stakeholders both from clinical consumers and different advocacy groups. We look at those in terms of, what barriers are there to use? What are the things that are maybe stopping people from using something effectively? Then, we look at the potential gain and benefit to the overall objective of My Health Record, which is to improve health outcomes.

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Karen Gallagher: Then, we put those improvements into technical releases. That is also something that we've already received feedback on, and we'll go through the evaluation process as to what changes in the future might be made to, as Mohammad said, to increase the equity of the ability to use My Health Record.

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Mark Metherell: Chris, could I ask you, have people looked or medical profession looked at any risks from digital exclusion if I can call it that where because everybody's gone towards the MHR model, there may be those who aren't digitally equipped who are going to be left behind? Is this an issue, do you think?

Dr. Chris Moy: I think quite the opposite in some ways because I think Karen has actually indicated previously that in fact, even individuals from a health point of view who are not going to access and have stayed in the system, as long as they know that they've got the right to opt out if privacy is more important for them, if they stay in the system, the health benefits will still be there because it will link ... When they go to see another doctor or another an health provider, for the first time, the information is going to be there at the point of care. We're going to avoid those, hopefully a lot of those 200,000 a year hospital admissions from medication mismanagement because of lack of information at the point of care. The benefit is already there irrespective.

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Dr. Chris Moy: Could I actually take one little point from Karen? Karen's made a really good point because I think the thing that I say, and I'm being involved in as well, is I think people misinterpret what the My Health Record is. They look at what it is like now. What we're trying to get along, what we're trying to get over the line is basically a digital Dropbox folder. I'll put it here. It's up

in the sky, and all it does is contain copies of the very same documents that a doctor might have like a summary and some results, and those sort of things.

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Dr. Chris Moy: The difference is, now, it's accessible at another time and place for other health providers where they never might have seen this before to benefit the patient, but also, it's accessible to the patient or in a situation where this person is not actually health literate or may be culturally and linguistically diverse. In those situations, the nominated provider, for example, or authorized provider that's appointed can actually access it for them. The difference is, now, what will happen is that if they turn up into an emergency department over, their family member, for example, who's got access could actually punch it up. I can show you a map. You can just show it. They can actually, instead of turning up cold when they have no information, the hospital have no information, you show them the history.

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Dr. Chris Moy: I think the other important thing that's really important is the reason why I got involved in this was actually not about the medical history. It was actually about the fact that when patients are actually in situations of medical care and there's no information, they're in incredibly vulnerable situation. The power differential is great. If you don't know your history but also, if for example very often, you're going to end up in hospital when you've lost decision-making capacity, actually unconscious or actually delirious or something like that.

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Dr. Chris Moy: The advanced care directives and advanced care plans that patients can upload but also the ability to actually put their emergency contact numbers are incredibly important. Particularly more beneficial, say an individual has, I would say dementia. Unfortunately, when a patient ends up from a hospital, from a nursing home for example, with dementia, quite often, there's no information about medical history. There's no information about the advanced care directive, what their wishes are. There's no information that contact details, but also ... I think Louisa put up a really good point. I think that the record needs to be more than just about medical history. It's got to be about what that person is.

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Mark Metherell: Louisa mentioned the personal note, which is now there.

Dr. Chris Moy: Exactly. I think the thing is, well, I'm going to get back to Karen's point. I think Karen's point is exactly right. We're at the beginning of this. This is a folder, and I think that consumers need to start taking control of this and actually start making this instead of half empty, make it half full because they can build it the way they want because that patient who comes with dementia into an emergency department, I'm going to frankly say to you that quite often, their care is sub-optimal, and they're not treated with the sort of respect that they should because people view that person as a diagnosis with dementia. Instead, that person was somebody who, he's a

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very important person, did a good job, is a great husband, a great father. That sort of information about that person can actually be added to the My Health Record over time.

Dr. Chris Moy: I think that's the way we have a chance to evolve this thing, and I think consumers need to be part of journey. Instead of a person coming into a hospital emergency department or seeing their doctor when they're vulnerable, just being a diagnosis or a problem, they can be a person now when they can't actually convey that information.

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Mark Metherell: Mohammad, is that point coming through to your communities that in fact for people who don't speak English, this may be a plus in that this record, patient record is available, say if they end up in the hospital or at some other place?

Mohammad A.: Absolutely. Look, I think My Health Record is I think it's revolutionary especially for older Australians with cultural linguistically diverse backgrounds because of exactly that case, What happens if you do land in an emergency situation and you don't have your children or siblings or whoever that to translate for you? Having those records right there for you right at the start in that critical time when they need to know quite a lot of information about you, that could save lives.

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Mohammad A.: Also, My Health Record could say, "Well, does this person need an interpreter? What kind of language, what dialect?" because it's quite diverse. It's not just Arabic or Farsi. There's different dialects within that. With those dialects, there are a different cultural baggage that comes with it, if that makes sense. I mean, people come here as refugees, and they might be, for example, North Sudan, South Sudan. Sometimes, they don't want to be translating for someone or they don't want someone translating for them who was from the other side of the fence, so there's quite lots that My Health Record could have that information in there to select the appropriate-

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Mohammad A.: ... Health Record could have that information in there to select the appropriate translator or interpreter at the right time when they need it, but just in terms of, I guess knowing about My Health Record and actually the usability of it, I don't think our communities actually know about it.

Mark Metherell: Really?

Mohammad A.: I mean I've lived here for 15 years and up until a few months ago, I've never heard of My Health Record before, and it's been going for a while. I mean I could be wrong, but I think a lot of Australians don't actually know about My Health Record and the benefits that it could bring to them. I think if that

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message is conveyed and if people know that, wow, I can actually be in control of my information, and to give access to and what all sorts of information, I think they would actually sign up to it.

Mohammad A.:  
[00:23:00] For consumers, we manage to get them to opt out rather than opt in, so we've got a pretty critical mass there. For this to work, and I think this is part of expectation management, is to make sure that the practitioners also take it up in a large scale to make sure that it is worthwhile their time to actually go in there and update their records and actually manage to do that, because if it doesn't, people will use it once, and if it's not up to their standard or if it doesn't meet their expectation, they won't go back in there and use it again.

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Mark Metherell: What do you think, Louisa? You've sort of looked into this.

Louisa Walsh: Yeah. Well, I'll talk about my personal experience first and just pick up on a few points in the matter on the table. Number one, with this increasing desire for consumers to be able to input more information, then obviously, there's increasing need for digital literacy and health literacy to be able to do that. This is what the point I was making before about, what is this record for? As it becomes more interactive, as it becomes more person controlled and person centered, then there's this increased need to address the barriers of digital and health literacy.

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Louisa Walsh: Secondly, my own experience really comes ... We talked about digital literacy from the consumer point of view, but also, we need to acknowledge from a health professional point of view and maybe not GPs who already have the systems in place that mean ease of access into the record and ease of transferring information from one electronic record to another. For my own experience, I'm a transplant recipient and most of my care happens in a specialist environment. Then, the GP, I see for very simple things, so vaccinations, stitches out, that sort of stuff.

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Louisa Walsh: My GP has no interest has ever spoken to me about My Health Record even though I have one. My specialist, I know that the hospital that I go to has finally got on board but there's never been anything inputted from there. Actually, My Health Record has the stuff that I've put in in terms of my medications, it has my Medicare data, my PBS data, and from that, you could make an inference that I've had a transplant if you understood the medications that I was on, but there's nothing that actually says any of my diagnoses.

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Louisa Walsh: For me, in an emergency situation, if someone opens up My Health Record, hopefully, the fact that there's no health summary in there makes them go, "Aha, this isn't a complete record," but actually, the incompleteness of the record makes my care potentially more dangerous and in a situation where I can't advocate for myself. I think that's a really

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[00:26:00] important point that you've made, Mohammed, about yes, we can get consumers on and we can put them into an opt-out situation, but if we don't have those concurrent systems at the provider end, then you end up with a situation where potentially, an incomplete record that people think is complete is more dangerous than having no record at all and going off information like having to start from scratch with that information.

Louisa Walsh: That's the point. Then, yes, so I work for the Centre for Health Communication and Participation at La Trobe as you said, and part of my work there has been to look into the health literacy demands of My Health Record. I started that back in 2016-17. I'll just have a drink. We actually did a lot of analysis back when the health record changed from the personally controlled electronic health record to the much more kind of snappier My Health Record. That analysis looked into a couple of things.

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Louisa Walsh: The first thing that we looked into, we did a big content analysis of all the consumer facing information that was available online for My Health Record, both from, it wasn't the ADHA then but what was prior to the ADHA, and also from other agencies around. We had a look, and we did things like readability, looking at currency, looking at the author, looking at how things linked to each other online, just to get a good sort of understanding of, from a health literacy perspective and from some of those things that people use to judge information quality, sort of just a map of how things were at that time.

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Louisa Walsh: We also looked into usability, using some previously developed by other researchers' usability checklists that had a real focus on health information and health literacy. Through those two pieces of work, we sort of found at that time that My Health Record and the information surrounding it almost globally, not just from the government information perspective, didn't really meet the information needs or the usability needs of someone with low digital health literacy or low digital literacy or low health literacy. That was obviously back in 2016. There's been a lot that's happened since then.

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Louisa Walsh: We've sort of repeated that study at the moment, and the analysis isn't complete, but we're seeing some improvements from the consumer information side with the My Health Record website in terms of usability, but probably content wise and obviously, there's also been an explosion in content around opt-out, so as an explosion information but probably information content wise and also the usability of the record itself, probably still is lacking when it comes to meeting the needs of people with low health literacy and low digital literacy.

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Louisa Walsh: Again, I come back to the point of, if this record, especially moving into the future, is going to become more person controlled, more consumer controlled with the ability to input more information to control what is seen

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and what is not seen, to try and use this as a more collaborative tool between health professionals and consumers, then those things really need to be addressed because actually, to use the record at the moment and even to get to understand the information that's provided to then get on and use the record is very reliant on consumers having very high levels of health literacy and digital literacy. That's just something that really needs to be considered when we think about how the record is going to be and what it is going to do moving forward. I think all of these things that you've mentioned, Mohammad, are great potentials. I think that's sort of what consumers want it to be able to do, but at the moment, those barriers are probably going to be very significant for a lot of users.

Mark Metherell: Karen, can we expect to see the continued developments that meet some of the issues that Louisa raises?

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Karen Gallagher: Yes. We are working with, as I said ... I guess one of the things that I think is really important throughout this program, because I come from a communication background, is to not assume the best and to listen to the audience. I think that that's one of the really, I think quite amazing things about what is happening, has happened since the agency has been started, is how many people were working with and listening to and getting feedback from consumers? That is informing what we're doing moving forward.

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Karen Gallagher: For example, we have worked with the Council of Intellectual Disability to recently develop easy read materials. We've received feedback on our indigenous materials and as a result, we've then developed those into audio versions in 13 different indigenous languages. We've modified our messaging so that it made sense, not just in the language but in the meaning of the language. We're going to, I believe from a communications perspective, almost extraordinary lengths to try to ensure that we're able to meet the needs of the user.

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Karen Gallagher: From the website perspective, I'm glad that there's been an increase in the usability of that because as you know, the website was relaunched this year. We've gone through a process of re-evaluating our communication. The team continued to do that. One of the things that continues to inform that has come off the back of this increased, hugely increased interest in digital health. We've now had over a million people visit our website. We have people email us all the time if they have a problem. They call our helpline, so we're starting to really understand where people are finding problems.

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Karen Gallagher: What that's allowing us to do is to then get those problems and start to say, "Right, where do we solve these problems?" For instance, we've developed a number of how-to videos. Those videos might sit on our website. It might also be on YouTube, but then we've also provided them

[00:32:00] on a micro-site that's accessible by, I think it's probably about 500 different organizations now can get that link to that website. If they wanted to, they can download that video and show it to someone. We're trying to make sure that those materials are available, but I think we definitely have work to do in terms of continuing to make sure people understand that those tools are available and having them available in the right place.

Karen Gallagher: We definitely need to continue to do that because right now, we have six million registered accounts, and at the end of the year, we're going to have way more than that, so we really are going to move from a focus on awareness and providing enough information for people to make an informed choice. Should I be in or out? Then, we're going to start to move to enablement. How do we help people use this tool? To your point, Louisa, why would people want to use this tool? What's the role for that? I was looking at the webinar and what we're going to be speaking about today. It said a tool for everyday life, and I thought, "I'm not sure for me, that's the role of this. I think it's going to be important for me and my family and my children when I have a health interaction."

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Karen Gallagher: That's what I think is important for me, is to understand what the utilization is for me and that as an agency, we consider our role with My Health Record in a broader digital context. We're not Apple. We're not going to be counting steps anytime soon, I don't think, but I think it's important for us to understand that. What is this for me? To that point as well about, can the doctor see my notes? For that personal health note, no, but does the information, because I can see it, allow me to ask better questions when I go in to have a conversation with the GP? I don't understand what this means, and you've put it on my child's record. Now, you're sending me off to see a specialist, and they're going to talk to me about stuff I don't understand.

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Karen Gallagher: I think as a tool, there is ability to use it in its current state, but the best information we're going to get about the utility is when we have a lot more people using it, and that's the point of, I guess moving from opt-in to opt-out. We're going to continue to learn and listen.

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Mark Metherell: Okay. Well, that's the digital inclusion aspect of our discussion today. Perhaps, now, we should move to health literacy, which has been defined as the cognitive and social skills, which determine the capacity of individuals to access, understand, and use information in ways, which promote and maintain good health. Do each of you want to just give a quick idea of how you think health literacy will be affected with the rollout of MHR? Perhaps, I should start with the consumer. Louisa.

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Louisa Walsh: It's an interesting question because at our research center, we very much take the view that health literacy is a skill that can be built over time. It's not a sort of a kind of reductive thing or a problem. It is something that develops and grows and changes as people kind of get more involved in

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[00:35:30] their health and learn more. The involvement, the ability to see information about yourself like you say is great. I think there's capacity or opportunity to go beyond that because like you said, what does someone do if they then find something about themselves that they don't understand? Where do they then go? How do they then judge that the information that they're searching for and finding is good information?

Louisa Walsh: Again, where there's capacity in the system to help people understand how to judge good information to direct people to websites that are trusted, that sort of thing because if someone is right there on their computer looking at something about themselves, they are going to then do a search about themselves. That's not a bad thing, but it's understanding and judging that information if that information is available and right there because very few people are going to then make an appointment to go and see their doctor to ask them, what does this word mean?

[00:36:00]

Louisa Walsh: I think like you say, it's good that people can look and see information about themselves, and hopefully, that will then prompt further investigation, which can help grow health literacy, but I think that there is possibly capacity within the system to help guide searches and information finding.

[00:36:30]

Mark Metherell: Yeah. Mohammad, do you think the My Health Record will help with health literacy and people learning more about healthcare how best to keep good health, et cetera?

Mohammad A.: Yeah, I think so. I think so. Absolutely, I mean exactly what Louisa said there. I mean some of those fancy words might come up, and the first thing I'll do is put on Google and see what Dr. Google says. God forbid, one of these causes down the track might be cancer, and I think we need to manage that. We need to make sure that, hey, just because you saw this, it doesn't mean it will lead to XYZ. I think this might actually frustrate the GPs later on because they'll make an appointment and say, "Hey, I Googled this and it says this. Tell me about it." "All right, I'll be patient with you, and I'll explain this." Then, they might turn around and say, "But it said it might also lead to XYZ."

[00:37:00]

[00:37:30]

Mohammad A.: You might have this beautiful discussion instead of actually, "Just trust me. I am your GP, and I'm telling you what this is and what this is not." It can only be a good thing because people will actually be interested in their own health, and we'll find out more, but I think the GPs might find it frustrating.

Mark Metherell: Chris, all this, "Trust me. I'm a doctor," sort of angle-

[00:38:00]

Dr. Chris Moy: I love that. I love what some of you have said.

Mark Metherell: One of our online-

Dr. Chris Moy: Made my job easier.

Mark Metherell: One of our online questions is from Jane who asks, "The discussion's all about the use of the consumer portal as a tool and how it's not so easy to navigate. Third-party apps can provide a more user-friendly experience for people. What's happening in this space?" What do you think of that?  
[inaudible 00:38:24]

Dr. Chris Moy: Okay. I'm going to take the question back a bit. The whole issue about health literacy, I got ask this question. "Oh, we need to talk about My Health Record." The consumer stood up and said, "Hey, it's not going to solve my health literacy." I said, "No, it isn't actually," but I said to him, "At the moment, what information do you have about yourself? Zero." I said, really, at the end of the day, the issue on the question to health literacy, it gives you the first step only, which it gives you some information that you've never had before, okay? Previously, this information is kind of zinging around. I'm faxing it to people, and it's in my notes, but you've never seen it before.  
[00:39:00]

Dr. Chris Moy: This doesn't fix your health literacy problem, but I think the thing that happens now in terms of being able to take it from here is to understand ... The reason why I gave this example is understand ... What Karen's been trying to say is that the My Health Record is the sandbox right now in terms of how we develop. We're at the beginning of it, so don't judge it on what it is now. Judge it on what it can be in the future.

Dr. Chris Moy: Really, I think as consumers, instead of actually looking at something, "Well, somebody else should build it," actually understand become a part of building this properly because this is something that could make ... The way the third-party app side of things isn't I'm going to say, "I could show you My Health Record," but what would happen then is, I think the way it should go and the way I [inaudible 00:39:40] is that you have your My Health Record. You can open up your file, and you can actually see your diagnosis, which is a scary thing because you have all these medical terms, but you might see type 2 diabetes, for example, and you go, "What's the type 2 diabetes mean?"  
[00:39:30]

Dr. Chris Moy: Well, there is the potential with these third-party apps to actually be able to launch off that into a reputable information source such as Diabetes Australian, which might actually be able to give you information about the differences between the diabetes. I mean, this is the sort of way I think we need to go, but understand that the way it is at the moment isn't the way it has to be, but I think all of us, doctors, consumers, need to take ownership of this and actually ... I mean, I have this principle because I think it's a lot easy to criticize than to create. I very much take the view that you actually  
[00:40:00]  
[00:40:30]

... the Kennedy, don't ask what we can do for you, but what you can do for this.

Dr. Chris Moy: I think that in some ways, this is something you can finally own, and that's why I think it's very important. I'm talking that as a doctor, and it may make my job a bit harder sometimes. It has actually because people have come in and said, "Hey, Chris, you got it wrong. It was my left arm that I actually had an operation on." I go, "Oh, no, no, no," but in fact, it was good because what it did is it made me correct the data and I made the data better. It was good for me, but also, I think in terms of actually the consumers in the future, I think the way to understand, it's the first step, it gives you information you've never had before. Build it from there. That's really up to the consumer group, not the doctors' group to do this.

[00:41:00]

Mark Metherell: Do you think, Karen, that people, we're in the middle now of the opt-out season if you like to call it that, I mean do you think people have the health literacy as a rule to make the best judgment on whether or not to stay with My Health Record?

[00:41:30]

Karen Gallagher: From my experience, the more interested you are in this and the more concern you have as to what it might mean for you, the more likely you are to go looking for more information and to ask more questions. I think that probably goes beyond health literacy. That goes to people's reaction to the media. That concerned me. I don't know what that's about. What we are finding is that people are asking a lot of questions. I do think as well, there are a lot of people out there including the AMA and the RACGP, Consumer Health Forum, and a number of other advocacy groups that are advocating for people that they may be concerned that may not have the health literacy to make an informed choice. They're doing everything they can to provide the information and ask questions. We have hundreds of questions asked so far that are being asked on behalf of people that may have low health literacy.

[00:42:00]

[00:42:30]

Karen Gallagher: As a country, our health literacy is, as you were saying, Louisa, it's pretty good, but there's a whole group of people that aren't. I think you said as well, there's 2.5 million people that aren't on digital. I think there's a lot of learning that's occurred over the last couple of months. I think it will continue, and I believe that the opportunity here is for people to make an informed choice. There's definitely enough information out there now to allow them to either feel comfortable that they're comfortable with the benefits or to say, "No, I still don't know enough. I don't trust this," and to opt out.

[00:43:00]

Karen Gallagher: That's really what this period, as you call it, the opt-out season is about, is giving people enough time and enough information to be able to make a choice. At the end of the day, if they don't want to be part of it, they can opt

[00:43:30] out. Then, they can watch and see as well. I think that's the other thing as well. If they wanted to watch and see, they can opt back in later. I'm sure there'll be some people that make that choice as well because there will be an ongoing learning about this.

Karen Gallagher: That's what I guess I'm probably the most pleased to have been part of this program for because it started this year when I said to some friends, "I'm going to work on My Health Record," and I'm going to be unavailable pretty much to my family for the next eight months. They were like, "I don't really know what you're talking about," and now, everyone knows. I just think it's fantastic that there is this national conversation going on about digital health and that we're sitting here talking about how we can improve health literacy. I think that's fantastic, but-

[00:44:00]

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**Section 3 of 3** [00:44:00 - 01:04:23]

Karen Gallagher: And improve health literacy, I think that's fantastic. But if people are concerned they don't have enough information, the key is to ask. We've got community engagement officers and events, there's over 1,300 events that have already been attended where there's someone to talk to. We have a helpline that's open 24/7 a day. We have a website. There's heaps of videos on YouTube on our MyHealthRecord channel and we have easy read materials and low-literacy materials as well that people can access to find out more.

[00:44:30]  
Mohammad A.: If I can just add, I think it's really important to get that information out there but I think it's also really important to correct the record on some of the issues that have been raised in the past, one of them being privacy and security of MyHealthRecord because, obviously, for example, people saying that this data could be accessed by other agencies, for example immigration or health providers. And rumors go around the community very quickly, especially, for example, for cold communities, they use WhatsApp very effectively. And the information goes like wildfire.

[00:45:00]

Mark Metherell: Yes, indeed.

Mohammad A.: Surprisingly, actually, my sister actually posted something, you should opt out, to the family line and said and this could potentially be ... your information could be shared with other agencies, blah, blah, blah, everybody should opt out. It was pleasant to see that they know about it now but I think now we need to go back and actually say, "No, the security aspect of it had been addressed, and the privacy aspect of it, you have full control over now and it is protected by a legislation." So, I think some of those myths and misconceptions need to be addressed because, otherwise, you won't have buy in or a lot of people have already opted out without actually knowing the benefits for them, with added that level of misunderstanding, I think.

[00:45:30]

[00:46:00]

Mark Metherell: Thanks. Louisa, do you have any idea of just how many or what proportion of the population has a clear idea about risks as against benefits of MyHealthRecord, do you think?

Louisa Walsh: I have absolutely no idea, no.

Mark Metherell: Oh, that's a great [crosstalk 00:46:24].

Louisa Walsh: [00:46:30] I have absolutely no idea about the proportion of the population who knows about MyHealthRecord. I have no idea about the proportion of the population who is judging those risks and benefits. I think, possibly, the opt-out trials that happened up in Queensland and in New South Wales, where we are. Maybe that data was collected by them, but that isn't data that I've seen about people who had a record without knowing that they had a record. I don't know.

Louisa Walsh: [00:47:00] And I think there's a couple of things that I wanna pick up on. Number one, this idea that consumers should be the ones who are responsible for growing and developing and embracing the record, but we're only one part of it. We're only one half, and the other half is really health professionals. And it's only very recently that my main, very large tertiary hospital in Melbourne actually got on board the record, and I have no idea about how to get my specialist to upload any of my health information onto the record because they're extraordinarily busy. I think if I ask them, any of the specialists that I see, they will give me a blank stare because I don't know how much it's filtered down from the executive. [00:47:30]

Louisa Walsh: [00:48:00] So, this idea that consumers somehow have greater responsibility for what happens in the record, that we opt out but there's no opt-out equivalent for health professionals. That's an issue, and it's an issue of power because there's been ... The whole time, since the inception, there's kind of been this idea that consumers coming onto the record will be the driver to talk to their doctors to get the doctors on board to using the record.

Louisa Walsh: [00:48:30] I think that doesn't take into full account the power differentials that naturally exist in that relationship, and also, how much ... it's unavoidable that having this type of record increases the administrative burden for consumers as well. So, something that we previously couldn't access, yes, we now can but there's also things that we have to consider about opting in, opting out, weighing out benefits, risks.

Louisa Walsh: [00:49:00] You know, whether we want to carve off some parts of our records and say, "Not all health professionals can see them," these are all sorts of things that we didn't have to think about before. That doesn't mean that it's a bad thing that we're thinking about them now, but it's just ... I think that this kind of ... there is a little bit of falsehood in this idea that

consumers are the ones who are railing against it and that health professionals are the ones that don't seem to have to have that place as strongly in building it.

Louisa Walsh: So, I think, I just wanted to pick up that point because I think that was a [crosstalk 00:49:22].

Dr. Chris Moy: Can I just say that I think ... you were supposed to ask me a question about what the medical profession were doing about this.

[00:49:30]

Louisa Walsh: Yes.

Mark Metherell: Well, I was hoping-

Dr. Chris Moy: Yeah, yeah, we gotta go straight for that one. Look, the bottom line is that frankly, doctors, by nature, are skeptics. We do not wanna be people that actually take the first medicine and make you the guinea pig. It's important to have doctors, skeptics. There have been a lot of concerns, and to be frank, a lot of the issues that have happened has been because there's been nothing to [inaudible 00:49:47] on for them so far to actually work with. It's a chicken and the egg situation.

Dr. Chris Moy: But the thing I would say to you is, to what you said, is the experience in Northern Territory in the opt-out areas. See, the problem is, we're looking at it from where there's nothing there that [inaudible 00:50:01] on at the moment. It's a theoretical exercise for us, at the moment. But, in the Northern Territory, for example, when they did take it, what actually happened is, yes, at the start, it was very slow, but when they hit 50% connectivity between the providers but also the users, it took off. Because at the moment, the problem is it's chicken and the egg. It's kind of like, not enough people connected so I've got a 25% chance of actually having a patient on there and then not much data on there because nobody bothers 'cause it's only a 25% chance on there.

[00:50:30]

Dr. Chris Moy: That's the whole point of opt out, to tip it over into a critical mass situation where you actually have a majority people on there, and a situation where the majority are ... then what happens is people are gonna go ... the first time they look in there and go, "Oh, God, does that patient have an allergy? What medications are they?" They're gonna look at it once, and they're gonna go, "I get it. Now I know where to get all ... I couldn't reach that pathology result 'cause I know which lab they [crosstalk 00:50:55]-"

Mark Metherell: Can I ask [inaudible 00:50:56], are the specialists now on MHR?

[00:51:00]

Dr. Chris Moy:

[00:51:30] I don't know whether it's [inaudible 00:51:00], but I think it was actually in a certain area in Northern Territory, but there was actually a [inaudible 00:51:04] report, which you can actually read about. I suppose that's ... the chicken and egg situation, which we haven't hit, and to some degree, it's kind of like saying, "Well, okay, what user," and I'm gonna say Victoria's been one of the worst places so far in terms of penetration. In Sydney, for example, one of doctor friends just received ... he had a patient who had—and I can say this 'cause he gave permission—had a major neurological condition, turned up, no notes. He looked at MyHealthRecord, had all the specialist letters and the results and didn't have to put the patient through this. There already was. We can't get this from our local hospital; it's Australia, but he had it and it made such a difference in this person 'cause he didn't put him through the nightmare of the full investigation again.

[00:52:00] Dr. Chris Moy: So, the point is, it's kind of like chicken and the egg. You can't see the future 'cause you haven't been through it yet, and it isn't reaching that critical mass. So, I accept what you said there because I think, in some ways, it's like there hasn't been this compulsion to do this, but the flip side is, and I actually don't say the consumers are the ones that actually riled against it. In fact, I actually think the health providers have been, to some degree, in the same boat. But understand their role. They had this role of being the skeptics and protectors, and they should be skeptical about most things.

[00:52:30] Dr. Chris Moy: But the experience in certain areas, such as [inaudible 00:52:19] areas where people have found much more new models of care to look after homeless people who actually haven't had records because it's not continuous or situations where you are dealing with disconnected communities that move around. You can see, by the trajectory, that's what we need to get to.

Mark Metherell: Karen, can I ask is the MyHealthRecord administration relying just on rising critical mass? Say, if we take the hospital specialists' involvement, is there anything ADHA doing to drive that?

Karen Gallagher: Yeah.

Mark Metherell: Or are you just relying on natural-

Karen Gallagher: No, we're not.

Mark Metherell: No? So, what's happening?

[00:53:00] Karen Gallagher: So, I guess you could say, behind the scenes, we have been working very, very fast, very collaboratively with all of the state governments who are all part of the funding model for MyHealthRecord expansion program to bring on board public hospital systems. That has progressed rapidly this year,

[00:53:30] and I think Chris was saying that Victoria and South Australia will come on board a little bit later, but they're got strategies in both of those states, but all other states will have MyHealthRecord in public hospitals.

Karen Gallagher: One of the biggest focuses for us to add value to the record for GPs and for other healthcare providers has been pharmacists. So, we've been working with the Pharmacy Guild and also directly with pharmacists and Community Pharmacy to get them connected to the system. So, we'll have [00:54:00] the majority of pharmacists connected by the end of the year. Also, pathology labs. That's another area where we see there's about 15% duplication in blood tests, and so we, by having pathology and blood tests be able to be uploaded to MyHealthRecord means that people can see that they've had a blood test, versus reordering it.

Karen Gallagher: So, definitely that the agency and also healthcare providers have been very aware that it's the content within the system that will ultimately be of [00:54:30] value, and you don't have content unless you have those people connected. So, it's been a very strong program of work to bring all of those connections on board. Also, a program with the software vendors that run the clinical software systems, the Confirmat systems, to ensure that the use of MyHealthRecord is simpler than what it has been in the past, so that's made it a difference as well. That's the evidence that we're hearing that stories coming back saying, "Oh, it's easier to use." So, that's good 'cause we've reduced the barrier of use there.

[00:55:00] Karen Gallagher: Definitely there is the reality of the fact that some people before haven't been that impressed. So, part of that is we've had a training program in place, our CGPs working with us on this, plus also all of the primary health networks around the country, and we've been out training healthcare providers now in OTPs and pharmacists this year, and also GP practices and pharmacists and also the jurisdictions of the state government, so [00:55:30] working with us to do training within the public hospital environment 'cause we're quite aware that one of the biggest benefit areas is gonna be in the emergency department, and so it's important that emergency department staff know that's somewhere to look for information and that there's information there, and then also that the discharge summary from the hospital goes back to the GP via this system. So, massive piece of work there in terms of providers, both in connections and then in education and that will go through continue.

[00:56:00] Karen Gallagher: In terms of specialists, I think that continues to be a focus for us, as does the allied health, so physiotherapists and psychologists. With specialists, I think that within the public hospital environment or the private hospital environment, that's a way for us to reach them and for that information to go up because they're connected. Obviously, some specialists don't use digital systems the same way, and so there's an addition step for us. But I

[00:56:30] think that, as we move forward, that all of the healthcare providers, like the Northern Territory example, are going to see that's the easier way to get this information, or this complements what I have already on my system, and it's faster. I can look here, see if it's there, and it saves time with you don't have to call the pharmacy, you don't have to call back to the doctor. So, that's a lot of the education as well to make sure that the healthcare providers see the benefit in it.

Mark Metherell:  
[00:57:00] Thanks, Karen. One of the big ongoing claims made in support of the Electronic Health Record is that it should bring more knowledge and information towards the consumer, because they have already access to what their doctors prescribed, et cetera. Now, I was interested ... I think Chris said the doctor/patient power differential would be moderated, but you seem to have a different story. What do you think? Does this have the potential to, if you like, equal up the power imbalance at all?

[00:57:30]

Louisa Walsh:  
[00:58:00] I think, as Mohammad has talked about, if it's a prompt for people to learn more about their conditions, bring that learning back to their doctor, do their own research and come back and ask between different treatment types or screening decisions, that sort of thing. There are opportunities there, and I think those relationships grow and change as someone's health literacy grows and changes as well. There's potential that I think that's a larger cultural shift in medicine and person-centered care and person-centered practice, and maybe this will be a part of that, but again, as it can't be the solution to digital inclusion, it also can't be the solution to person-centered care. It is just another tool, and the people who are most likely to benefit most from that relationship change are the people who are most likely to be able to use and tailor their health records, so the people with higher health literacy anyway and the people with higher digital literacy anyway. So, again, it's about how do we support people to develop those skills who are maybe starting from a bit of a lower base and not starting with those skills already?

[00:58:30]

[00:59:00]  
Dr. Chris Moy: I'd actually just take another tack on this, and I'll actually take a different situation. I'd take it much more to a daily situation. I had a patient the other day, she came in and she complained about her treatment in hospital. They didn't believe that her husband had allergies when he was unwell, and so she actually pulled out a [inaudible 00:59:19] and said, "There." And then so funnily, the doctor had been adamant about that stage, was gonna give this patient something, and the power differential changed at that point.

[00:59:30]  
Dr. Chris Moy: I'll give you another example, and I'll actually say to you, in a situation where individuals are culture and linguistic diverse and they come into the room for the first time and even if they have an interpreter there, the time taken to get a history and examination in a 15-minute appointment is

[01:00:00] gonna be much higher. You know that. In the consultation, everybody's getting pretty frustrated and the care of the individual drops off pretty quickly and the frustration level goes up. You do wonder, you probably understand from the group that you had ... but the ways that doctors maybe sometimes appear to be frustrated when treating certain patients.

Dr. Chris Moy: Well, how about if I go in, I see the history, and I actually spend more time with the patient and dealing with the problem. You see what I mean? This is what I mean by powered individual. I'm not talking about this big issue. I'm talking about this daily grind issue where it's actually right in front of you every time where your odds are stacked against you 'cause the information isn't there and the balance of communication is actually really against the individual in front of you.

[01:00:30]  
Mark Metherell: Well, Chris ... Sorry, the consultation is almost over with. We've run out of time but last words, Louisa.

Louisa Walsh: I was just going to make the point that ... it's probably getting a bit into it in the last ... now we've gone three minutes over. Yes, it's true that the information is there, but if we're coming to situations where a patient isn't being listened to and they need to pull out their MyHealthRecord as evidence, the information that's in the MyHealthRecord that they can show as evidence is stiff information that's curated from their doctor, rather than being a full record of their health. I come back to the issue that, if something goes wrong with my health and I need to make a complaint, I still need to get an FOI to actually access my full record because this isn't a full record.

[01:01:00]

Louisa Walsh: So, again, it's a tool that can be utilized and can probably be utilized best by people who have high levels of digital literacy, high levels of health literacy, and already have some strength in their relationships with their doctors, but it isn't a full health record, either, to consult when there's complaints or if there's actual issues with health. So, I think it's one of the many tools, but it's not the solution to person-centered care, as it's not the solution to health literacy, as it's not the solution to digital inclusion.

[01:01:30]

Karen Gallagher: I think that's a really good point to end on, which is MyHealthRecord has its role within care provision, and it will improve the access to information, both for doctors and for consumers. That's a really good start point for us to have when we're looking at digital health, and that's a system we don't have currently. So, if everyone can work together from here to say, "This is my interest in this, and this is what I'd like to see," then I think that's a pretty good outcome. Again, it's still everyone's choice to be part of it.

[01:02:00]

Mark Metherell: Mohammad, do you want a last word?

[01:02:30]

Mohammad A.: I don't know about the last word, but I just wanted to mention that, obviously back to your point, I think for the new doctors, I think there needs to be a lot more training as part of the studies or the continuous development, but just wanted to kind of pick up on just the issue of new migrants coming to the country because they will automatically have a MyHealthRecord, and I think ... no, that's not correct?

[01:03:00]

Karen Gallagher: No. So, newborns and new migrants get an opportunity when they apply for their Medicare card to choose whether or not they wanna be part of the system.

Mohammad A.: Great. Thanks for correcting me, but I think it's really important for us to-

Karen Gallagher: Obviously parents on behalf of the newborn. That's worth clarifying.

Mohammad A.: Of course. But I think it's really important to continue to support new migrants in understanding actually what MyHealthRecord is, just like getting your Medicare card. But also, this system is evolving all the time, and I think MyHealthRecord wasn't what it is today, and that's because, for example, Fair Care have advocated for a lot of changes for it to be where we are today, and I think it's important to keep an eye on it and make sure that we .. kudos to you guys. Well done where you're at today, but yeah, we'll tell you if we [inaudible 01:03:48].

[01:03:30]

Karen Gallagher: Keep us honest. Thanks, Mohammad

Mark Metherell: Thanks, Mohammad; thanks, Louisa; thanks, Chris; and thanks, Karen.

Karen Gallagher: Thanks, Mark.

Mark Metherell: Well, that just shows there's still lots more questions, lots more issues to be discussed with MyHealthRecord, and we will be having a wrap up MyHealthRecord estimate session, we're calling it, next month. I think it's October 4th, so watch that space on the Consumers Health Forum website. Thanks for joining us today and thank you very much to our panel. Thanks and good afternoon.

[01:04:00]

Karen Gallagher: Thank you.

Louisa Walsh: Thank you.

Mohammad A.: Thank you.

**Section 3 of 3** [00:44:00 - 01:04:23]