

Transcript

Consumer Estimates on My Health Record

Webinar, 17 October 2018

Watch the webinar here: <https://www.youtube.com/watch?v=Ttz3eWx6BMU>

Find out more about the webinar: <https://chf.org.au/introduction-my-health-record-webinar-series/webinar-6-consumer-estimates>

Section 1 of 3 [00:00:00 - 00:30:04]

Jo Root: Good afternoon and welcome to our webinar today on the My Health Record. This is the last in the series of six webinars we've been doing, and today, we want to bring some questions that consumers have asked us about what is of concern to them. Issues that they don't think have been covered, either in our previous webinars or in the material that they've been saying. And some issues that have emerged during the time of opt-outs. We have three consumer panelists today with us. We have Paige Burton on my left and Paige is the 2017 Australian Youth Representative to the United Nations and is a health consumer.

Jo Root: We have Sharon Tonkin next to Paige, who is a consumer and carer with 40 plus years of rural health experience ... is a nurse and is a carer for somebody with significant disabilities. And then we have Marc Niemes, who is a consumer and a digital and E-learning business founder, and they're going to raise some questions that they have raised with us and also some issues that some of you have brought to us. From the other side of the table, we have our government panelists. Next to me, we have Michael Frost who's from the Australian Institute of Health and Welfare and he's the group head primary healthcare and veterans group. We have Karen Gallagher who's the general manager implementation My Health Record and who has done one of these webinars before, and we have Kim Webber, the general manager of strategy at the Australian Digital Health Agency, who has also done at least one webinar before.

Jo Root: Today, we're going to raise the questions. As you've seen on the video that played before this, you know how to ask questions. You type them in and they'll come through to us and we'll try to get through as many of those as possible. We have some questions already that we've shared with the panel so people can be prepared. I thought it would be useful to explain how we got Paige, Sharon, and Marc to come along. We did an expression of interest and we asked people to put up their hand who were interested in coming along to this consumer estimates, but we are making it friendlier than estimates. I'm just saying that. And we had a large number of people put up their hands to come along.

Jo Root: We asked people to say what were the key issues for them, and so then we went for people who we thought were asking questions that we hadn't

[00:03:00] covered in our previous webinars. We're trying to move the conversation along, but also getting a mix of views about the value of My Health Record to consumers. That's how these three people along. I want to thank them before we go any further for making the time to come today. It's a big time effort, particularly for Sharon, who's come from rural Victoria, and so we do appreciate it enormously. So, thank you. We might start off by asking each of the consumers, and we might start with Marc, about ... can you take a couple of minutes to tell us what your current attitude towards My Health Record.

[00:03:30] Marc Niemes: ... probably a lot of concern around, "Okay, is this being sort of thrust upon me or this is actually for my own [inaudible 00:03:45] benefit." I also come to that with where else would you really in the world would really like to get sick. Often people come to us and say, "Oh, they have complaints about the health system," you say, "Well, where else would you prefer to get sick and can you name a country that basically does this better of different?" There are quite a few places in the world that we probably wouldn't wanna get sick in.

[00:04:00] Marc Niemes: I start from the basis that my belief, having traveled, is that we have a fairly good health system, in the Australian context, but the service delivery is what I often refer to as tribes. You're dealing with a bunch of tribes and when you go to the GP and you're talking to the GP and they're spending some time with you, how much of that time is spent on administration, of talking with other tribes about your particular medical condition. I guess the question is from a health record perspective, if that's the first step in a common language between the tribes, fundamentally that has to be a good thing.

[00:04:30] Marc Niemes: I have concerns like everyone else around how that data is used, what access you can have to that after you use it within your tribes, but fundamentally we believe that it is a natural, good thing and more than happy to be involved in that and helping them basically formulate that. I fundamentally see the interoperability as a good thing because that's the way of moving the tribes forward into what I call, basically, a community.

Jo Root: So, have you got a record?

Marc Niemes: Yes, we do.

Jo Root: Okay. Okay.

Marc Niemes: And three children and [inaudible 00:05:15] else. I'm quite happy conceptually with that and the level of the ability to actually use that record. I'm very, very comfortable with that.

Jo Root: Oh, excellent. Thank you. Sharon, perhaps you'd like to tell us about your views.

[00:05:30]

Sharon Tonkin: Thank you, Jo. From my perspective, I've had several decades in the rural setting and communication for a health consumer into a major health setting where they're trying to access systems is fraught with difficult with information transfer. It's not uncommon for a rural person to be referred to a specialist. They get down there and they haven't received anything. They don't know why they're there. The referrals inappropriate. If there's a

[00:06:00] central repository for all that information, the consumer can access it, make sure they're on the right track. You've got hours of travel on difficult roads. Pain and suffering. We've got an elderly population who can't drive themselves, so they need reassurance with how to do it. With the IT, there needs to be some education. But I think it will be a major tool of reference and communication for rural Australians who are emotionally distraught when they enter the major health settings anyway, but to have that

[00:06:30] appropriate information there in a timely and accurate fashion, I think, has to be a real boon.

Jo Root: Thanks, Sharon. And you've got a record?

Sharon Tonkin: No, we haven't got one yet. Most of the people in the rural setting are concerned about what we said about the IT infrastructure. But as soon as that is certain, we will certainly access it and not [inaudible 00:06:45] that. We will certainly go ahead with the My Health Record.

Jo Root: And you're a carer for your husband, so when you say 'we', you'll be managing your his record as well as your own. Is that the expectation?

Sharon Tonkin: Yes, I will be. And the other side of that is, of course, my husband has a

[00:07:00] severe traumatic brain injury. If I predecease him, we need a central repository for everything that relates to his care and needs, medication, behaviors, signs of deterioration that other people can access because I'm off the scene now. Our adult children have moved away. He lives in a small community. All of that is very relevant ... The GP should be able to access what his intensive care stay was like, what his rehabilitation stay was like, and identified all those issues at the major discharge planning meeting. We really look at that as almost as a security blanket that the necessary information for his ongoing care will be in a place accessible by all involved.

[00:07:30] Jo Root: You're probably one of the groups of people that we all quote often as being the main beneficiaries of My Health Record.

Sharon Tonkin: Absolutely. Absolutely.

Jo Root: So, that's good. And Paige, what about you?

Paige Burton: [00:08:00] Yeah, definitely perspective entirely. I've spent the last five years kind of stumbling through appointment after appointment with lots of different doctors, specialists, with a large binder, basically, full of my medical history. So, when this was announced, I was really, really excited about it. I think it's a really good and important thing to make sure we can track records over time for all the reasons that have just been mentioned.

Paige Burton: [00:08:30] But I think this is a good idea that's been executed badly at a time where public trust in government data stewardship is at an all-time low. We've seen the census fail and other things like that, and I'm just not confident about the government's ability to make sure that privacy is maintained. I think that's a huge problem for people from marginalized communities, people experiencing chronic illness related to contraception and a bunch of other different stigmatized medical appointments, I guess. I'm concerned about the way that we've sort of taken it forward and looked at it and said, "We're gonna have all this data. It's gonna be really useful," instead of thinking back to that more individual based rights. I have a few sort of concerns about that.

[00:09:00] Paige Burton: And, also, for young people, young teenagers, who's parents have got them in the system at the moment. What does that look like for them when they turn 18 and they decide, "Actually, I didn't want that recorded"? I have a few concerns. But that's sort of my position is I want it to be good, but I'm not there.

Jo Root: When you went around talking to young people as part of your year of being the youth representative, did young people raise My Health Record with you as an issue?

Paige Burton: [00:09:30] My Health Record wasn't really sort of part of the public mainstream conversation at that time when I was traveling around. But I did ... so, I went to every federal electorate in the country and met about 50000 young people, and digital privacy is a huge concern for young Australians. They are worried about it. They were surprised by the census and how that went down, and concerns about ... as you've mentioned ... regional healthcare and all those things are really important to them as well. They want a system that works for them. They wanna make sure they have access to the same stuff that everyone else does. But specifically on this, it wasn't part of the conversation then.

[00:10:00] Jo Root: Okay. Well, you probably want to respond to some of that from any of these. We might see whether any of the government representatives want to respond. Perhaps before you ... when you do respond, can you just make it clear to people what the responsibility of your particular agency is?

Kim, did you want to respond at all to anything that's said or can you outline what the role of the agency is in My Health Record?

[00:10:30]

Kim Webber: Sure. The Australian Digital Health Agency has excited since 2016 and we are the system operator for the My Health Record. The Department of Health and the parliament have shepherded through some legislation in 2012 around the My Health Records Act, and I guess that's the legislative construct for how we operate the system. It's actually quite a readable piece of legislation and it does explain our responsibilities and the various rights of citizens and clinicians, et cetera. That's very much our role is to operate the system with that.

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Kim Webber: Our focus is very much on ensuring that ... at the moment ... that consumers are aware of opt-out, aware that records are going to be created later in the year and how they could go about opting out if they want to do that. That's our obligation and our focus at the moment.

Jo Root: Thank you. Did you want to add anything, Karen?

Karen Gallagher: I just wanted to pick up on what Paige was talking about and I think that ... there's a lot of people in the healthcare system that do think about this as a health program, and it is. The outcome is to improve patient care. I guess one of the perspectives in that ... And that's why I wanted to be part of this program because I see the potential benefit.

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Karen Gallagher: One of the perspectives it brought home to me very quickly was ... particularly this year ... is about human rights. It's about making sure people understand what this means for them and allowing them to make an informed choice about whether they participate. As we've gone through the last few years, I think this is probably a really an interesting ... it's been an interesting insight for me watching the government listen and having the different groups, and particularly the individuals but also the people that represent individuals, whether that's a carer or a member body, bring those concerns through us a system operator and have ... or directly to the minister or to the Department of Health, and to really scrutinize the legislation and to raise concerns. And also then to begin to work collaboratively with us in the agency to say, "Well, what does this mean for us and how are we going to make sure that people continue to know, if they are gonna be part of the system, how to set their privacy controls, how to talk to their doctor, how to choose when not to upload information."

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Karen Gallagher: That's obviously ... we're sort of just on the forefront of this concept of you've got a record and you can participate in choosing who sees your information and we have a long way to go, I think, in making people understand what they can do. For those that choose to opt out, obviously, that's not even a discussion we need to have. I definitely think the future is

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now to begin to make sure that we understand the concerns, continue to listen, and continue to then create the education and the forums within which people can learn how to control their record.

Jo Root: Thanks. Michael, did you want to say anything about or perhaps explain why AIHW is involved in this discussion?

[00:13:30]

Michael Frost: Yeah, thank you, Jo. The Australian Institute of Health and Welfare is a national statistical agency formed to produce relevant information and statistics on Australia's health and welfare. We were set up in 1987 as the Australian Institute of Health and expanded about 10 years after that into welfare area. We have recently been identified as the agency to be the custodian of the data for secondary uses from the My Health Record for public health and resource purposes, and so that's where our interest comes in in that role where we'll have probably mainly two roles. One of which is to establish and administer the governance arrangements that are set out in that secondary use framework, relating to the data governance board and so on.

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Michael Frost: And the other will be into prepare and provide or make publicly available data for those research purposes, where people have successfully gone through those governance processes and sought and received access to the data. We're interested in it from that point of view. Obviously, we've got a long history working with sensitive health and welfare information, strong governance arrangements of our own that help us to understand the issues that we need to think through in doing those roles and to, obviously, preserve privacy and act in accord with the privacy act and the My Health Records Act and the Institute of Health and Welfare act in doing so.

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Jo Root: Yes, and I think privacy and people's control of their data has been one of the themes that has come out ever since we started the opt- out, when people have concentrated on it. I guess one of the questions that came through from people who sent us questions who aren't represented here today ... and I'm going to pass to Marc in a minute ... to Sharon. Sorry. But there's a feeling from some consumers that maybe My Health Record is more for health professionals than health consumers. What would you say to people who are saying that a lot of the marketing, a lot of the emphasis has been on health professionals rather than the consumers who it's supposed to ... I mean, some of us are old enough in things to remember when it was called the Personally Controlled Electronic Health Record, which slides off the tongue so easily. My Health Record makes it my, but people aren't feeling it's my. What would you say to that.

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Kim Webber: I think that what was really good from the three stories from the three consumers is really how you're looking at your own situation and you're making a decision for yourself. That's where I think the My Health Record

[00:16:00] ... and I will make a decision for myself as well, and potentially for my family. It's the privacy controls that I think are where the consumer has the control. You can ask your clinician to not upload information and that is paramount. You have that control over what information goes into your record, about how you might hide away parts of it, almost lock them in a safe within your record and give a clinician a code to access those particular documents.

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Kim Webber: Or you can lock down your entire record. Put an access code on that, and the clinician can only access that when you give them the actual codes. That's where I guess the consumer controlled and it being about your record, but who is the record for? I think it's definitely both, but focused on the consumer. It's about your conversation with your clinician, your various clinicians, whether they be specialists, nurses, a general practitioner. It's our very difficult and challenging role is to support consumers through their journey, to understand best practice, how to manage their diabetes and what the information in their record is. And I think as Karen said, we're just as the start of that.

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Kim Webber: At the moment, we have a lot of clinicians who are uploading information in, but we have a lot who aren't. At the moment, the record is reflective of that, and I'm sure if you've had a look, you've got some of your pharmacy scripts, maybe some visits to the doctor, but then maybe not some hospital visits. Over time, that will build up and you will have more and more of a holistic view of your healthcare, be able to discuss that with your families, with peers, et cetera. It really is a health literacy tool as well, but I think it's about the expectations that as Australians we're on the start of that journey. The start of the consumer empowerment journey, which is, for me, what it's all about, why it's so interesting. But also giving those clinicians access to that information when you want them to have it as well. So, I wanna say both. But you're right, it's the My Health Record and this is a tool for really empowering consumers.

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Marc Niemes: If you have lots of data that doesn't really relate to each other ... say you have your pharmacy scripts, something from a GP, something from your fitness tracker ... what seems to be the value moving forward is the actual analytics and the insight into that. On its own, it doesn't actually mean anything, right? Well, it means something as a snapshot in time. I guess my question is, as a record, is it ... version one, it's a document store of everything for you, if you need to go emergency, it's there, which, hopefully, none of us ever have to go to emergency so we don't wanna be in that situation but at least a record's there.

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Marc Niemes: But I fully get what you're saying is if you're no longer available ... in my own situation, I know my wife has a little post-it note of stuff to ask when you to go a GP for her mother, or whatever. I mean, that happens now. That's the daily reality now. I see it's really, really important. But what you

sort of decided to talk about was, okay, you've got this data ... is there any analytics or moving from basically healthcare into basically preventative healthcare? Is that being sold or at the moment, just saying, "No, no. It's a single site. A single repository for you so everything's there for you if you actually need it"?

Kim Webber: [00:19:30] In the National Digital Health Strategy, which I guess is the four-year plan agreed by all governments around digital health ... So, that's from this year, 2018, to 2022. One of the key pillars there is around innovation and it's how we actually enable mobile apps and the data analytics at an individual level and, as Michael will talk about it, at a population level. But that kind of insight and analysis of your own data is definitely the journey that we're about to embark on and how we actually do that is a conversation we have to have with the Australian community, which is how do you wanna share your data? Not only with clinicians, but potentially people who can provide you with that individual advise, that individualized medicine.

Marc Niemes: Yep. Cool.

Jo Root: Do any of you want to add anything to that question? Sharon, we might go to one of the questions that you said that you would like to ask.

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Sharon Tonkin: One of the things that interested me was do we have the possibility that, basically, an E-conversation can happen between medical disciplines and the consumer is left out? How do we ensure the involvement of the consumer at all times? I acknowledge I have limited knowledge of how the system will work, so there might be safeguards for this but I was concerned. I had visions of two clinicians and the consumer out there on the wings.

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Karen Gallagher: So, I guess that ... I'll take that question, but jump in. I guess that the key point, and I think Marc talked quite really nicely about this ... I like analogies ... is this concept about tribes. At the moment, you say that the hospital group would be a tribe and the GPs would be a tribe and the pharmacies might be a tribe. Well, I guess that the whole Australian population is a tribe and part of what My Health Record will do is connect those tribes, but it also, I believe, will give a consumer the opportunity, by logging into their record, to actually involve themselves in the conversation in a different way for the first time with their treating clinicians.

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Karen Gallagher: It gives the consumer, if they don't want to get into their record, the knowledge that those clinicians are talking to each other about a piece of information that might currently not be available to either of them. There's that sense of security that you were talking about. But more so, at the moment, we know that a lot of people go to Google before they go to the doctor, and a lot of people go to Google after they go to the doctor. They're

[00:22:00] already asking questions about what that doctor said, but it's not actually about necessarily their information. You don't get that record. They don't print it and give it to you. They might give you a script, but they don't print you a shared out summary and give it to you.

Karen Gallagher: If you or a patient, as a carer or a patient, decides to go home, log in, and has a question, the information will be there upon which for you to involve in the conversation. I think it depends on what the benefit is that you see and what role you wanna take in your own healthcare as to how much you'll participate in using the information that will now be available to you to then have that conversation and be part of your own healthcare experience.

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Jo Root: Does anybody else want to chime in on that one?

Paige Burton: No.

Marc Niemes: Are you talking about trust? So, if you ... we're very willing to put a hell of a lot of our personal data up in return for some sort of benefit. Lots of free websites for this. We put our own information up. We put our own kids' photos up on various social media sites, et cetera. I guess my question is, in that context, once the information is out, if that bit of information you didn't want out is out, what level of control or what recourse actually is there? Because once it's out, it's out, right? Once the photo's out, it's out. Is there any level of recourse ...

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Marc Niemes: Some of the stats I've read is that up to sort of, what, 900000 medical practitioners will potentially have access to your particular data if you want them to. What level of security do we have as consumers that that's been taken care of, and if that does get out in some way ... it's out, it's out ... what can we do? Is it worth something to somebody? Don't know. But the flip side is the fact that we're sharing seems to ... the benefit seems to be better than it accidentally getting out, in my view, than not sharing. But sharing with whom?

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Karen Gallagher: Yeah. I'm actually going to pass to Kim on this one because what you're talking about there is essentially two concepts. One's around privacy and who's allowed to access the system and then the other is about security.

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Marc Niemes: Yep.

Karen Gallagher: Because getting out beyond ... like you're talking about a photo getting out onto the internet ... is definitely around security, but for the most part, what you're talking about is who can see my information? And I'll pass to Kim to give you what are the rules.

Kim Webber: Yeah, because I think it relates to what you were saying before, which is the data analytics for a consumer and how they interpret the record. What clinicians have is they have that in their own practices. They have clinical information systems in a hospital or in a practice or at a specialist's office, et cetera. It's those clinical informational systems that can view the My Health Record as part of your overall care. In order for a GP, for example, to access your My Health Record, they already have to have set up a record in their local system and saying, "Okay, Kim Webber is a patient of mine. Here's her Medicare card, date of birth, a few things like that," before that system can even go to the My Health Record system and look and access your information.

Kim Webber: They need to know quite a few personal details about you already. I think there's no mass downloads. There's no kind of opening up the My Health Record system and flicking through all the Kim Webbers to find the right person. You actually have to know my date of birth, my Medicare card, my first name, my surname, and ... so, there's some certain demographics that you need to know to actually find the right Kim Webber, and if you don't have those right, you can't find my file. I think that's a real safeguard in terms of having to already be a patient within that clinician's practice.

Kim Webber: There are actually both civil and criminal penalties in the My Health Records Act for inappropriately accessing a person's record or distributing the data or anything like that. It's a very well regulated environment and clinicians already have access to records in hospital and general practices, et cetera. Another safeguard is in your My Health Record, you have an audit log. You can actually go in there and it will tell you which organization has accessed on which date, et cetera. That's quite a safeguard, and you can also set up an SMS alert. I have that on my record and when I was sitting in the waiting room waiting to go into hospital for an operation, I got an SMS alert that the hospital had looked at my record. So, A, it's a safeguard that I know who's looking at my record and, B, it was actually a bit of record to know that they had looked at my record when I was about to go in for an operation.

Kim Webber: It's those kind of safeguards, which protect the system. Clinicians are aware of them and consumers are aware of them too.

Marc Niemes: I find that quite interesting because when we go to a health provider now, who goes and asks them, "Oh, do you have a disaster recovery plan? Can you tell me where my record's gonna end up?" Where in most cases, it's a folio on the end of a bed. Right? Nobody asks where that record actually goes. Well, where does it go? Does it sit in a compactor somewhere? No one actually asks that. But as soon as you go electronic, it tends to be, "Oh, it's gonna be everywhere. Everyone can basically access it."

Marc Niemes: Just as a question about your SMS notifications. In your scenario where you're looking after somebody else, can that notification be the designated carer or the designated care provider or ... ?

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Kim Webber: Absolutely. You can be an authorized representative for either a child's record or someone who's incapacitated can also have an authorized representative. That means that you basically get to do everything that that person could within their record, including putting the SMS alert. And we don't ask whose phone number is this SMS alert going to, so whoever owns the record can put that phone number in.

Marc Niemes: A potential side benefit in that scenario would actually be ... so, if you didn't know, if you weren't around, and your record was being accessed by a health provider in a rural, your first question would be, "Hold on, why is this being accessed at 3:00 in the morning?" Or wherever. At midday. So, okay. Cool.

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Paige Burton: Yeah, I mean, I guess my concern is like why send that text message after you've accessed the record and not before. There are simple switches that can be done in this system that set it up so the individual is in more control. It's great to know that someone's accessed my record if they shouldn't have, but it would've been a lot easier if I had have known before they did that because, like you said, once it's seen, it's seen. If that's the wrong person, I find out the wrong person accessed it, well, that's great. I can go back, but that's already been seen by the wrong person. That's quite annoying to me.

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Karen Gallagher: I guess the other thing that you can do is you can set a PIN code across your entire record, and what that will mean is when that healthcare provider organization does their search on you and says ... as you were saying, you were talking about a scenario where they shouldn't be doing it. I guess that's probably one thing that I often think about is do I trust healthcare provider organizations ... do I trust people that provide care in Australia?

Karen Gallagher: I often think about that just in the first instance because that's really what a lot of people are making a decision on. Do I trust healthcare providers to access correctly and will they do their duty of care? If I'm concerned about a healthcare organization accessing my record for any reason, then you can set a PIN code across your entire record. That means that when they'll do a search on you, they'll see that there's a PIN code and they'll have to have that PIN code to be able to access your record and you can set that from within your record yourself.

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Karen Gallagher: There's an emergency break glass facility, which then says, "Have you ..." In certain scenarios, this person might be unconscious in an emergency, for example, that they can break the glass and they can access your

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record. Again, as you said that would be happening afterwards but there's very few cases of that happening and every one of them is essentially asked for the reason and has to be in accordance with the reason as to why they would've used that mechanism to access the record. Again, I think there's that point that Kim made before, which is the information is already sitting within a lot of different places, potentially, if you have gone to a lot of different places for care. And you're not currently aware of what they're doing with your record. So ...

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Karen Gallagher: ... currently aware of what they're doing with your record. The system, in itself, actually has a layer of scrutiny on it, that it's being checked. It has an audit log. There are rules around who can use your record. It's legislated. You're able to look and watch, and as health care providers, themselves, responsible to act in accordance with the legislation.

Karen Gallagher: [00:30:30] Again, now, if that's something that concerns you to the point where you felt that was something that would put you at risk, either from healthcare or from stigmatization, then that would be a reason why you would consider not being part of the system. That's what's great about these sort of discussions, to actually have an hour talking with people interested about communications, in various formats. Some people just want to look at the password, or not at all.

Jo Root: I think, Paige, you had a question around ...

Paige Burton: Documentation.

Jo Root: ... about documentation.

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Paige Burton: Yeah, so like putting aside this security stuff, because I know we're going to get to it quite a bit. My GP, my family GP until maybe five years ago used a typewriter to take notes, and is not the most computer literate person. There's no, as I'm aware, incentive for GPs, medical practitioners, to take extensive notes, and that the system relies on that. What incentives are there for GPs to do that?

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Paige Burton: Particularly, when I take notes, I take them for myself. How are we going to make sure that people are taking notes in a way that is clear, that allows for nuance, and when someone else looks at that record they can say, "Actually, I know what was happening here"? It wasn't just a couple of little notes to myself.

Kim Webber: I might answer that one, because there's a few things there. Firstly, Australia has one of the most computerized general practitioner

[00:32:00] populations. A lot of effort was put into investing in general practitioners, making sure they have computers and are computerize, probably quite a while ago, probably before the My Health Record system. That might have been, actually, why your GP finally gave up the typewriter.

Kim Webber: The My Health Record system is not going to have all of the notes. When you go see your general practitioner, you know, when they take a range of notes, those don't automatically go up into the system. What will go up is a shared health summary. That's something the GP would provide a summary of your medications and illnesses, and things like that. Something that would be easy for you and another clinician to read. An event summary, so it might be a summary of what happened.

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Kim Webber: Still, the general practitioner will keep quite detailed notes within their system that don't go into the My Health Record system. That's just to make that distinction that not every single record is going to up into the My Health Record system.

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Marc Niemes: How did they do that in the GP clinic? Like 15 minute consult, nine minutes. How's a GP realistically going to separate that out?

Kim Webber: Yeah, most of that is automated in the clerical automation systems. The agency works very closely with the clinical information system vendors. We have a roadmap with them. We let them know what's coming up, because it takes a long time, with technology, for it to get from our system.

Kim Webber: For example, one of the big revolutions was we, in our system, we created a medicines view, which was kind of a one page, all the medicines that you're on. Incredible useful for clinicians to be able to see that. It actually takes a bit of time for that to be reflected in the clinical information systems. They need to be able to read that, because clinicians tend to not go in and open the My Health Record system. They use it side-by-side with their own record systems.

[00:33:30]

Kim Webber: In the past, there was a lot of work around digitizing and computerizing general practice. They still have practice incentive payments, they're called, which are around uploading shared health summaries and informing people around the My Health Record system, etc. Those still exist and we still work closely with the Department of Health about the future of those, and what has to be done to get those payments. But it's still a priority for [crosstalk 00:34:20].

[00:34:00]

Marc Niemes: So does the GP see it as an admin layer, or an actual benefit?

Kim Webber: That's a very good question. Unfortunately, you can probably chat to Sharon on this. It'd be great to get your view from the clinician side.

[00:34:30]

Kim Webber: At the moment, it's part of the visit. I think what you were saying, "Is there a specific payment for putting things in the My Health Record system?" There isn't. It's part of just a layer of care, is how it's seen.

Sharon Tonkin: I think, from a general practitioner point of view, and I speak specifically knowing the attitude of our local GP, it is so hard in the rural setting, to get information back once someone's referred off. If they can immediately go in and, especially in the aging population, say.

[00:35:00]

Sharon Tonkin: For example, we look at an orthopedic referral. You know, you've got someone in chronic pain. "I did send you off to an orthopedic surgeon, what did they say? They're replacing your knee." The older person's not real sure. The daughter that went to the appointment's gone.

Sharon Tonkin: If a GP can, in a timely fashion, access, the orthopod said, "This has got to happen and you're on the theater list for December," immediately, you manage the pain differently, because you know there's a light at the end of the tunnel. Or is it chronic because they're no longer a surgical candidate?

[00:35:30]

Sharon Tonkin: The timely transfer of information to the rural setting, from major health centers, is poor. I think the rural GPs would see this as a plus.

Sharon Tonkin: My caution around it is we're all used to work until 12 months ago, we had five GP practices in five towns. There was two IT systems. Very well known ones, but they didn't talk to one another. We're holding our breath, "Will they talk to My Health Record?"

[00:36:00]

Kim Webber: That is a challenge for us. We have a very strong relationship with vendors in industry, exactly for that reason, to make sure that no matter ... For a consumer, it shouldn't matter which clinician they go and see. We do a lot of work around interoperability, which as you had talked about before, which is making sure all the systems work together. It's an ongoing area of work.

[00:36:30]

Kim Webber: We've had a lot of success with getting more pathology and diagnostic imaging, those kind of really important documents into the My Health Record system. It seems every month we've got new announcements of Queensland coming on board, or WA coming on board. It's getting more and more integrated with the various elements of the health system.

Jo Root: So, we're moving away from the fax machine?

Kim Webber: We are moving away from the fax machine.

Paige Burton: Good riddance.

Karen Gallagher: I think the fax machine is moving away from us as well.

Paige Burton: Yeah, it's gone.

Karen Gallagher: I guess that they can stop producing it at some point.

Jo Root:
[00:37:00] I thought the medical profession had been keeping the fax machine makers in business for some time, now. Marc, you had a question around why we've gone with a particular structure of My Health Record we've gone with.

Marc Niemes:
[00:37:30] Yeah, I guess the question was why not just use a digital wallet, or a token, or something of that nature? When you talk about personally controlled electronic health record, then I'm quite happy to have a digital wallet with my data on it. Then it's my responsibility if it goes somewhere it shouldn't be. It's kind of my responsibility, that was sort of in that line.

Kim Webber:
[00:38:00] I'm happy to talk on that one. Having a system like this, I think, the most important elements to ensure its use, it has to be reliable and it has to be quick to access. This is, I guess, the question about government versus industry, and what is government's role in this? At the moment, our role is to ensure that this data is available to every clinician and consumer who wants to access it, when they want to access it, and in the form they want to access it. That's our priority.

Kim Webber:
[00:38:30] Having a card or something at the local, which you carry around with you, I think, – and this would, again, be great to hear Sharon, because I think it's so important to hear from clinicians – but actually some of the work around looking at your records and what has happened since your last visit happens when you're not in the room. It actually happens before. "Okay, Marc's coming in," so they might have a look through your record to see if you've had any tests or etc., before you come in the room. I guess it would interrupt the workflow, to actually have to sit and do that in front of you. It's a potential solution. There are a range of ways that you can deliver something like the My Health Record system. That is definitely one of them.

[00:39:00]
Kim Webber: It's almost, that system, is almost like having the record access code. That means you have to be in the room with the clinician, say, "Okay, now you can have a look at my record." Which does mean it might interfere with the normal way they would look at your health records, before you came into the room. Sure, Sharon has more insights.

Jo Root: Did either of you want to comment on that, at all?

Paige Burton: I'm fine.

Sharon Tonkin: [00:39:30] No, no. Look, just on my next point, though, and I hope I'm not flogging an issue, but I think we need to remember that there's a lot of people in the rural setting in the age bracket who can't even get money from the bank anymore, because they can't use an ATM and the bank's no longer in town. I think people with polypharmacy and comorbidities have got a huge gap in their IT abilities. We're going to have people who desperately need a centralized record not able to do any of this, and that worries me considerably.

[00:40:00]

Karen Gallagher: There is a model overseas that does have a digital wallet. One of the concerns, or what they've experienced, is that people lose them. Also, data storage capacity. They're actually currently looking at our model, to review what might work.

Karen Gallagher: I think that every system is going to have inherent issues that some people might say, "There's a better way of doing this." I think that that's also, from a world perspective in terms of digital transformation in healthcare, that there's a lot of people looking at what we're doing with My Health Record, and vice versa. That's part of what Australia and that agency's doing, as well, is collaborating with world leaders in this space.

[00:40:30]

Karen Gallagher: I think that's good to know. I think, from the perspective of knowing that what we're doing is perceived to be best practice, at this point in time.

Marc Niemes: If we're an aging population, and I have to deal with it even in my own parents, that record responsibility, what else would they use? There is nothing. Your only other option is a post-it note, a book, a notebook that they carry with them. So there's literally nothing there.

[00:41:00]

Sharon Tonkin: Look, even now, it's not uncommon for an older person to turn up with a very ragged and torn little notebook that said, "Look, I've fallen over three times within the last week, so I thought I'd better come. I didn't want to trouble anybody, but my hips not too good."

Sharon Tonkin: There's such fear around it. We all know that you can't kill a computer with a stick. They don't want to touch them for fear of what they want to do. They see a nice big file at the nurse's station, take great comfort in the fact that that's all there. The fact that the holes are torn and pages are falling out, and that record is not ideal bypasses them.

[00:41:30]

Jo Root: That was one of the questions that came through to us online. "How will people access their health record, if they're unable to access through myGov?" There is this whole, both digital literacy, which I think is what Sharon is talking about, and also access to the technology. We have a very patchy infrastructure of IT in this country, called the NBN. How are those people going to be included in the benefits of this?

[00:42:00]

Kim Webber: Do you want to go?

Karen Gallagher: Yeah. Unfortunately, we can't solve the NBN, though I would like to. So, I guess this also comes back to this question that was asked before, is who is this more for? Is it for the healthcare provider or is it for the consumer?

Karen Gallagher: I actually have experience in talking to people that there's a lot of people, actually, that feel a sense of great responsibility and fear that they are now going to have to control their own information and log in and do something. From my perspective, one of the great benefits for the patient is that the people involved in your care have information available to them when they need it, in a way that has been researched and co-designed with them, so that it's a benefit to you by being a benefit to them. That will apply to everyone that has a My Health Record, whether they access their record, or whether they have digital literacy skills, or whether they set up a myGov account.

Karen Gallagher: I think that's, in the first place, an important thing for people to understand. You can choose to get a My Health Record, and then you can continue to do nothing. It's not what I would like to see people do. I would like them to all activate their record and start to get more involved in their own healthcare by understanding their information.

Karen Gallagher: From that perspective, that really does come back to that consumer education piece. We've not had this system before, so there's not been a need for us to say, "How do we increase digital health literacy, specific to this tool?" Obviously it's been in existence from 2012, but not to this degree. That's what we need to work forward with. We are doing that at this point in time, in terms of asking questions and getting feedback from stakeholders and consumers. "What support are we going to give you, in what forums, to be able to access My Health Record via myGov?"

[00:44:00]

Karen Gallagher: Then, also, we do have the help line. People can't necessarily view their information through the helpline, but they at least can call and ask questions and find out information as to what might have been added to their record, for example, as a type of document type.

Kim Webber: And activate some of the privacy controls. That can be done through the helpline recognizing that not everyone wants to get on a computer.

Sharon Tonkin: Not everyone has one.

Kim Webber: Or can get on a computer.

Jo Root: [00:44:30] That's right. We might take a bit of a change of pace, because quite a lot of the concerns and quite a bit of work last year was done around secondary use of data. This is one of the privacy concerns, I suppose, is, "What happens to my data? It's fine. I use this bit. My doctor and I have a conversation about me. But who else can access that data?"

Jo Root: I guess that's the AHW's role, responsibility. Michael, can you tell us about who can access data and for what purposes?

[00:45:00]
Michael Frost: Well, the secondary use framework sets out the arrangements by which a person can get access. In terms of who can, it doesn't specify who can, directly, in that sense. But you know that it's for public health and research purposes, under that framework. There's some prescriptions in there, on insurance companies having access to the information, for example.

Michael Frost: [00:45:30] The information wouldn't be able to be granted access where it's for a solely commercial benefit. There must be a demonstrated public health benefit of the work. The other coverage in there is that at moment, the way the framework is laid out is that identified information is only available where the person involved has provided explicit consent for that to be available. Where we're talking about public health and research purposes, it's mainly referring to de-identified data, and releasing that data where people have also not opted out from secondary use in the system.

[00:46:00]
Michael Frost: So in the My Health Record, there's the current opt-out arrangements, for the My Health Record, per se. But there's also, within the consumer portal, there, the opportunity to opt out of secondary use. You can opt out of secondary use and still have a My Health Record to get the direct benefits for you, as an information store, and the benefits it provides to your clinicians, in terms of tracking your health information and enabling them to understand your health history when you present to them.

Jo Root: [00:46:30] So people can have a My Health Record, but they can still make sure that it's not used for any other purpose, other than just their, basically, their own ...

Michael Frost: Yeah, you can opt out of the secondary use arrangements within the My Health Record.

Karen Gallagher: We call it withdraw participation.

Jo Root: Is that reassuring to consumers, that people could actually do that if they knew how to do it?

Sharon Tonkin: [00:47:00] I think so, absolutely. Mike, I have one small query. What about compensatory bodies? I can only speak for Victoria, where I'm from. We have the Work Safe Authority and the Traffic Accident Commission. In

discussions around injury, say for example, in a workplace event, do compensatory bodies, is that, again, through commission of the consumer? Or do they have a statutory right to unlimited access?

Michael Frost: I guess it would depend on the legislation that they operate under.

Sharon Tonkin: Right.

Michael Frost: The legislation for the My Health Records Act, is currently, there's amendments before the parliament to require, in certain circumstances, and I'm not sure if it would cover this particular one, but would require a court order or a warrant to get access to that information. The secondary-use framework just says no to insurance companies, and also to any uses that are primarily or only for commercial benefit. It doesn't touch on those issues, but there are current amendments before the parliament that probably deal with that.

[00:47:30]

Sharon Tonkin: Thank you.

Jo Root: So what checks and balances are there? Somebody says that they're going to use the ... they come and they want to use the de-identified data. Then they use it for a different purpose. What happens then?

[00:48:00]

Michael Frost: We're still in the process, now, of setting up the governance arrangements that will apply to the secondary-use arrangements. There would be the need for the Data Governance Board to who makes the decisions about access to be assured of the purposes that are required. There would then need to be confidentiality undertakings made by researchers who are seeking access, which would also potentially contain, then, conditions of use. Then there would be liability for breaches of those conditions, as defined under the act.

[00:48:30]

Jo Root: Some people have raised concerns about, we talk about de-identified, and maybe you and I understand that, and maybe everybody around the table. A lot of people don't understand it, and there are concerns that actually, if you go down to small enough cells, you can actually identify people. What's the process for de-identifying?

Michael Frost: That's a really great question. De-identification is really just the removal of the identifying information from the records. We, actually, at AHW, but also many people covered by the privacy act, but our Act itself is a bit stricter, need to consider whether or not information, before it can be publicly released, is potentially re-identifiable, which is a different question, then. That, then, therefore, does mean that we have a whole lot of principles about small cell suppression and so on, that mean that, say for example, there's a cell that has fewer than five people in it; we wouldn't actually release that information. Then, also, just to make sure that it can't be

[00:49:30]

recalculated, you wouldn't release information from at least one other cell in each row and each column that intersects with that cell.

Michael Frost: There are systems like that that can help to prevent the re-identification of information. Our ethics committee, the AHW Ethics Committee, oversees our processes through, and then our data governance committee, internally, oversee the rules that we apply to those.

Michael Frost: [00:50:00] Separately, in regard to My Health Record, I understand the ADHAs doing work, as well, in regard to de-identification, and ensuring as best possible that that information can't be re-identified.

Jo Root: Do any of you have any questions?

Marc Niemes: Is it too simplistic to say if you are receiving the public benefit of a medical service, then you should, by rights, because you're in the health system, be willing to basically give them your de-identified data, anyway? To basically help do it as a better service in the first place? Is that not the structure of the government?

[00:50:30]

Marc Niemes: For me, if you're doing a medical procedure, and in order to make that medical procedure better for the population, you actually need the data sets to do it. If it's a de-identified, granted what de-identified means, to me, makes a hell of a lot of sense. If you're going to take this new treatment, this new treatment relies on the data about its efficacy, so we need that data. For me, at least on the surface, it creates an incredible opportunity in which to actually get better clinical outcomes.

[00:51:00]

Marc Niemes: The flip side to that, I think as you articulated, is if only five people have that condition and you release that data, then it's very clear who those five people are. It's good to know that you've already got safeguards that say, "No, we can't release that, because that condition only ... It's clear you can still reverse engineer who those actually people are."

Karen Gallagher: I think one thing that's happened this year is that we've had the secondary-use framework come out, just before the opt-out period. We've had this rise in public awareness as to their information and what that might mean. [00:51:30] There's been some confusion around access to My Health Record, as a primary source of information. That's what the legislation changes are bringing in line with what the system operator policy already is. Which is, government agencies or law enforcement cannot get access to the My Health Record system without a court order.

Karen Gallagher: [00:52:00] That would be in a case, for instance, where you'd be, for instance, the Federation of Ethnic Community Councils Australia, would be concerned, for example, that it would be used for immigration purposes. That's sort of

a primary use. The primary use of the My Health Record system is for the provision of care, of healthcare. Employment checks is also something that the system cannot be used for.

Karen Gallagher: Whereas, the secondary use of data, it very much is about the use of a whole lot of data together to look for trends, and to look for learnings and for insights that might inform how things are done in the future. That is back to your point, Marc. It's to say that there probably hasn't been a public awareness of what secondary use of data, or even for the purpose of research and health outcomes, what that even means to them, to us as population; and why we might chose to say, "Great, if I get a My Health Record, happy to participate in that. I do want the health system to get better. I do want more money put into rural areas if we're seeing more chronic disease there than should there be." I'm just coming up with scenarios. I don't know, of course, whether or not that's going to get approved. But that's the thing I think that we've all ... Again, there's so much education that's happening around what we've got to learn, new concepts that just aren't really even in our sphere of understanding. We haven't been able to make this choice before, and I guess that's a good thing, to be able to have that conversation and learn.

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Marc Niemes: I guess the analogy often is, you know how you go to a newspaper website, or you go to a shopping site and you look at a particular object. Then you go to a newspaper website and suddenly, the cookies that have been used in the background have suddenly, you're looking at fishing equipment and then suddenly you're readying a newspaper and there's an ad for fishing equipment. You go, "Okay."

[00:53:30]

Marc Niemes: Then the secondary use of data in that scenario goes, "Well, actually the policy of that particular newspaper was that, 'Okay, we have these security in place. We don't share your data.'" But then, by the way, they served up ads from 15 different companies, and then it's taken away from you. Again, that's effectively de-identified data in the sense of it's just you visiting a particular website.

[00:54:00]

Marc Niemes: Here, I guess the concern is, as you articulated as well, "Are you going to be taking my stuff to insurance companies and they're not going to insure me now, because they know that I've had this predisposition to this medical condition? When I do my application, they're going to say, 'Person XYZ's not going to get their insurance?'" I guess that's the ... I don't know, that's something that always resonates-

Karen Gallagher: That's definitely a major concern that I've heard this year.

[00:54:30]

Michael Frost: That's why that's in the framework as specifically proscribed. I mean, it is a good issue to discuss, because it does go to how the system works and why people might want to participate in it. If you take the example that

Sharon raised, before, about the person who's gone to the orthoped. The doctor wants to know what happened and the person can't remember, but the doctor can now, at least, see. That might help them decide on different types of pain amelioration treatment.

Michael Frost:
[00:55:00] Now, that's something that, in time, as the data becomes rich enough, that could be a research question to ask someone to say, "Well, what are the best courses in these different types of patterns you can see in the data?" That would be de-identified, aggregated information that people can study and work out. "Did that, then, subsequently lead to the people coming back and saying, 'Well, actually that didn't work and I'm still sore?'" Then you know different treatments.

Michael Frost:
[00:55:30] It can get to very practical questions that improve the model of care for conditions. In the case of very rare conditions, this will be quite a rich data source, potentially, with a lot of records in it that might mean you pick up a lot of people in rare conditions and can do research that otherwise wouldn't be possible because of privacy and suppression concerns. That's very important for people to participate, and to enable those kinds of researches that have to demonstrate a public health benefit to occur. That, then, feeds back into how people can use the system to help you.

Paige Burton:
[00:56:00] Sure. I think it's pretty flippant the way we're talking about, "Oh, people haven't been educated about it," or whatever. When we just see that like eight thousand Brits in the NHS got their record and the health records leaked to the immigration system in the UK. That meant that people's lives were at risk.

Paige Burton:
It's not an abstract thought, when we think about this data going to people. It does happen; it has happened. There's been breaches of hundreds of thousands of people's data in Singapore. This isn't just like, people didn't know stuff and they're suddenly angry and scared about it. It is happening, it has happened around the world. I think it's really important to remember that when we talk about privacy.

Paige Burton:
[00:56:30] It's not just like, if the data was like, "These procedures that you have will be improved by this data," absolutely! Sure, of course. Everyone wants that. People want to know what they're doing with that data, even if it's disaggregated. What is the point of that data? What is it being used for?

Paige Burton:
People just want a bit more transparency around it. I don't think that's unreasonable. We can't just say, "People have suddenly learnt something and they're angry about it," when actually we've seen time and time again things like this happen across the world.

Karen Gallagher:
[00:57:00] I definitely wasn't saying that we're suddenly, that that's the ... I guess, the information is available, in that you can go and read the secondary use of data framework. You can read our entire website.

Karen Gallagher: The reality is, most people don't do that. Most people have never heard of secondary use of data framework before this year, in regards to their healthcare. It is a big thing for them to come into, and that's part of what we've had feedback about as well. This like, "Wow, wait a second. This is completely new for us."

Karen Gallagher: At the same time, we've been working with stakeholder bodies, and it is absolutely the concern, for instances, of [FICA 00:57:29], who's the ethnic community council, because of the experience in the UK, to say, "We want to prosecute this legislation to make sure that this can't happen here." The AMA, RACGP, organizations like CHF, and many other organizations, we're very clear in saying that law enforcement and government bodies should not be able to access this data, access this system, other than with a court order. That's the legislation that's currently in parliament.

[00:58:00]

Karen Gallagher: The reality of that, as well, is that's actually been in the legislation. That hasn't been picked up or hasn't been something that's been brought to the fore, even though the legislation's been in place since 2012. I do think it is that the awareness and the raising of awareness right now, and people going, "Wait a second, I didn't understand it like that," or, "I didn't even know about that," that has created this change.

[00:58:30]

Karen Gallagher: With those concerns, and some of which are quite real, has resulted in scrutiny around this program and around the system. I perceived it to be of benefit, because people should only want to be in the system if they've got the confidence in the system. That's the key part of that.

Marc Niemes: But it does happen, already. If you go get a scan, an MRI scan or you go get a scan for your broken bone, that data, if any clinical researcher wants to do, you know, past ten years worth of study, can actually apply to get that de-identified scan data. It happens all the time, from a research perspective.

[00:59:00]

Marc Niemes: I guess from what you're saying is the advantage of this is you actually have an audit trail. You have a committee making some decisions around it. Yes, what's your digital record actually worth? From the research I've done, it depends. It could be worth \$2, it could be worth \$50 to people, literally, on the dark web. On its own it doesn't really ... They're using it for other purposes.

Marc Niemes: Here, at least it seems to me you have some control over what's actually going on. You do actually have committees making those decisions.

[00:59:30] Someone's going to hack you, they're going to hack you, right? If they really want to do something, they're going to get it. In this scenario, the way

you've articulated it, that sharing of de-identified data already happens in a research context. Here, now, though, everything's in one lovely little honey pot that you can get access to.

Paige Burton: Yeah. I guess I just don't see like what public health benefit there is in insurance companies having access to sensitive information [inaudible 00:59:50].

Karen Gallagher: I don't.

Paige Burton: Yeah, but that was the example you've given before. Those conversations, it's not just about hackers. I'm not concerned about hackers in that way.

[01:00:00]

Jo Root: CHF did some work on how consumers ...

Section 2 of 3 [00:30:00 - 01:00:04]

Section 3 of 3 [01:00:00 - 01:28:46]

Jo Root: ... work on what ... on how consumer's feel about their data being used and it was clear from that work that we did that they were happy for a ... many consumer's were happy for their data to be used for research purposes. They actually wanted to consent each time, so I guess ticking the box for a blanket yes to research or no to research isn't quite

[01:00:30] consistent with what we found when we talked to consumers. We have raised this before with the secondary use that we think people want to know each time their data is used for research. They actually want to know about it. So I guess that's part of the issue. I mean, related to this is a question that Sharon raised with us around informed consent. Sharon did you want to ...

Sharon Tonkin: Yeah, we have touched on it a bit, but I was wondering how we're going to protect the concept of informed consent? We've talked a bit today about people can say yes or no and opt out and things. How do we know an individual has informed consent? It's one thing to give consent, but it's another thing to really know what you're consenting to, and that could be to do with your clinical care, or it could be to do with what our health records going to do with your data.

Kim Webber: So, there's a few defaults that are built into the system so a clinician doesn't have to ask for your consent each time they upload to the system. The consumer can say "No I don't want you to upload that report" or that pathology report or this event or that prescription, but otherwise there is a default ability for a clinicians to do that's in the My Health Records Act, and part of the work that we're doing at the moment is to make sure that people are informed about opting out, and that they are aware of the privacy controls and what controls they have in the system.

[01:02:00]

Kim Webber: So I think it's a little bit different to the informed consent but as we move towards an opt out model, our obligation is still to make sure that everyone understands that they can say no, but it's not an active consent model each time that the clinician will ask and that's important that consumers understand that.

Jo Root: And related to that there's a question comes through from Russell online saying "Why is it have to be 100% opt in or 100% opt out?" And I guess what I'm hearing from you is people can in fact opt to not have things go on their record. So although you can have a record, you can stop things going onto your record is that correct?
[01:02:30]

Kim Webber: That's right. And Russell might've been talking about secondary use 'cause we were talking-

Jo Root: No, no. He was talking ... it was earlier, it was more generally, but I think it was about whether you could just ... so you can have a record so you can pick what data goes on it, and what doesn't go on it. So what pieces of information go on the consumer can control that.

Kim Webber: That's fair, and we are a little bit half-half because even within the system you can opt out of the secondary use, which is actually a stronger control than the Privacy Act because we're actually allowing people to opt out of-
[01:03:00]

Michael Frost: Deidentified data.

Kim Webber: Data that doesn't even identify them, so quite a control and I think as the system develops and we do think about consent for identified data, which I think is the report and the consumer survey that you did was around identified data. We will get to a much more dynamic consent model with the Institute of Health and Welfare, but that's a long way down the track.
[01:03:30]

Kim Webber: 'Cause I think it's really important that we talked about the trust and confidence, so all of these decisions and all of these discussions are ongoing debates with the community, and as Paige says, one perspective [inaudible 01:03:47] another that we actually have to have the debate with all Australians about their doubts and what their concerns are and make sure that we respond to that. All of those voices are really important because for us we don't have a system if there's no trust and confidence. If we are hacked, if the data is used against people, anything like that, we lose trust and confidence, and then we lose all the health benefits and that's just what we think about as the agency.
[01:04:00]

Jo Root: And I think that was another question that Sharon had around education. Did you want to-?

Sharon Tonkin: Yeah. How're we going to teach the population how to use it?

[01:04:30]

Karen Gallagher: That's a good one for me, but I did actually want to come back to Russell's question just in case he might've meant ... you currently can opt out, but you can also currently opt in if you wanted to, you can go and set up and account, and if you choose to opt out because you wanna take a wait and see approach, later you can opt in. So you can choose to have a My Health Record pretty much at any point in time. Also with the legislations coming through, if you decided to get a My Health Record and in the future you decided that you didn't want to be part of the system anymore, you can cancel your record at any time, which is already the case, and the legislation will mean that that record is deleted rather than archived.

[01:05:00]

Karen Gallagher: So, it is an opt in and an opt out system in a way, it's just that this opt out year is doing is it's accelerating us to that point where we've got the majority of Australians, hopefully, on the system.

Karen Gallagher:

[01:05:30]

So back to how are we going to educate consumers. We have received a fair degree of criticism this year as to how we're communicating with consumers, and so that's been a really great bit of insight as to what we can do better, which is excellent and we've been actually evolving some of our communication as we've moved through this program and one of the things that we have been doing is we've been doing consumer engagement in every area of Australia so we've run about two thousand local events and people ... and those avatars on our website, on social media [inaudible 01:05:55] local organizations as well within their regions. We've found those being very effective in terms of people being able to come along and learn about My Health Record and that's really, I guess, without the same degree of scale because people are not going to be as interested in us as we would like them to be every day of the week for the next year or so.

[01:06:00]

Karen Gallagher:

[01:06:30]

We are looking at how we develop a scalable model for both the people that require offline help and potentially who go to their community center or have help from a hospital once they leave. Then we're also looking at online help, so how do we ... once they get on to, even when they hit My Gov or when they hit My Health Record or even when they're reading a blog about health, how do we make sure the information's available so they can utilize the system where they need it, and that includes in healthcare provider situations as well. We're very aware that people will ask their GP, and whilst we cannot make them do our job for them, that's going to be a place where people look for information.

[01:07:00]

Karen Gallagher:

So we're going to continue to look at that point of when people are interested, and when they are engaged with ... they say "I've got a need now, I want to learn about this," we need to make sure that they're able to get that help in the way that works for them because we've got to go to a model that's consumer focused.

[01:07:30]

Sharon Tonkin: I suppose part of me, from a clinician's perspective, when we moved across to digital records of residents in aged care for example, we had a particular system that was going in. Prior to that going in there was basically a fictional one, a training platform you could go into and create a record for a resident coming in to residential aged care that impacted nowhere, but taught the user how to put a document in, take a document out, communicate in that system, and then they would shut down, do it in their own time with no worries that they were crashing or fiddling with the system. Because I think people who are unfamiliar with IT think "If I put a full stop there and it's wrong, the whole thing will come to a full stop." There's a few modules but the play areas were great using tools when they knew they couldn't do harm to the actual proper system.

[01:08:00]

Karen Gallagher: It's a good idea.

[01:08:30]

Jo Root: I think because we're vastly running out of time and it's amazing how quick it goes, Paige you had a question about ... and you mentioned it in your introduction about under 18, do you want to ...

Paige Burton: Yeah, so what kind of assurance is there for the privacy of people ... like young teenagers who still have their guardians there, but they're accessing GP's ... are guardians going to be able to access that information? And also what does that mean when they turn 18 when they get old enough to access their own and deal with their own medical records?

[01:09:00]

Kim Webber: So, at the moment, I'll start at 18. So when a person turns 18, their authorized reps, that's usually their parents, no longer have access to their record. The young person doesn't need to do anything, the parents are automatically removed. So that's at 18. At 14, the young person can call our help line or online take control of their record and when they do that the parents are automatically removed unless the young person says "No, no I'd like to keep them on." So that's between 14 and 18, but it does require an action on the young person from 14. Under 14 there is a process that you can go to to get yourself accredited as a mature minor, and also take control of your record.

[01:09:30]

Kim Webber: So our obligation is to make sure that the young people between 14 and 18 understand that. We're really trying to encourage young people to take control of their record, come and register for their record and that's our challenge over the next three months.

[01:10:00]

Paige Burton: Is that also true if they have their own Medicare cards separate from their family? They're 14, they go and get their own Medicare card, do they still have to go and opt out separately?

Kim Webber: They do. Yeah. So it's separate ... and you're right, sorry and I forgot about opting out. Of course. So from 14, a young person can opt out as well or their parents can opt them out from 14 and from 18 the person's an adult.

[01:10:30]

Jo Root: So the family could be opted in ... the family could've chosen to be in but the person 14 to 18 could opt out.

Kim Webber: Absolutely.

Jo Root: And then if they did then they're-

Kim Webber: They can cancel their record if they [crosstalk 01:10:35]

Jo Root: ... the record would need to be canceled though wouldn't it if the family had opted in, they would then have to go through the cancel and until the legislation passes, cancel doesn't mean delete.

Kim Webber: Yeah, it means archiving, which means no clinicians and no one else has access to the record, but it is in an archive, but it's not available to you.

[01:11:00]

Jo Root: That was one of the reasons why CHF pushed for cancel to mean delete not to just archive, and I think it's why a lot of people make a conscious decision not to have a record. They don't want it anywhere ... existing in any shape or form, so I think ...

Kim Webber: It is separate to the Medicare card issue though, and that's an important communication for us to communicate to young people that, just because you've got your own Medicare card or that you can be on your parent's Medicare card and still take control of your record. They're not connected.

[01:11:30]

Marc Niemes: So if a parent wants ... between the ages of 14 and 18, if a parent wants their child to have a record and it's set that up, and a 14 or a 15 year old says "No, I don't wanna have a record," the child's ... will override the parents and delete or not delete, but or archive or delete, but the 15 year old says "No, I don't wanna-"

Karen Gallagher: As has always been the case with Medicare.

Marc Niemes: Yeah, okay.

Kim Webber: That's right. If you choose to take control of your health record than anytime from the age of-

[01:12:00]

Marc Niemes:

But if they both choose to want a record ... so the parent says "Yes I want you to have a record" and the 15 year old says "Yes I want to have one, but I don't want you to see it."

Kim Webber: They kick you off.

Marc Niemes: They kick you off. Cool, that's a rebellious ... kids would love that.

Kim Webber: But it'll be part of growing up. It'll be part of as we get further along in the system you can imagine young people will start to learn about health care and taking control of their record ... in school it'll be starting to think about anything ... having a My Gov account, getting your first job, all of those things-

[01:12:30]

Marc Niemes: But it's no different than a 15 year old going to a GP or a pharmacy now saying "This is what I want, but ..." no discussion ... if you call up a pharmacy now often they say "No, no, I can't, even if you're the parent, you can't ... if they're not that age no we can't talk about that case." In theory.

Paige Burton: As it should be, really.

Sharon Tonkin: So, could I ask if a record is archived and the person has a change of heart can they unarchive, or do they start a fresh?

[01:13:00]

Kim Webber: So they can archive. At the moment, so the legislation's about to be changed so that that's it, when you cancel a record it'll be completely destroyed, but at the moment yes if you call up and you want to reinstate your record it will be as it was, but you can choose to say "No, no I don't want to ... I just wanna start fresh." So that's a conversation you can have with us, and we can delete the old documents or reinstate them, it's up to the consumer.

[01:13:30]

Sharon Tonkin: And are there ... sorry, Jo, are the schedules the same as they are with the Office of Public Records for death and all the ... at seven years if someone is deceased, or do they go as soon as the date of death is put in?

Kim Webber: It's different, but it is about archiving, but it's actually 30 years from the date of death, or a 130 years from the date of birth that retains at the moment in the legislation.

Jo Root: That's pretty amazing.

Michael Frost: People might soon live that long.

[01:14:00]

Jo Root: Paige you had a question about penalties of not having a My Health Record in a sense.

Paige Burton: Yeah, so there were reports of the federal government's home care health-

Kim Webber: Health Care Homes.

Paige Burton: ...homes of people having to have to have a record to get access to that, so they work across 200 GP's across the country and they deal with complex chronic illness stuff. Is that going to be the case for ... are there any other instances of where people will have to have a record to access that kind of care and those kind of trials?

Kim Webber: I think the principle is that the My Health Record ... having one, not having one, opting out, etc, should not lead to any discrimination and the Health Care Homes ... I think the decision was that you didn't have to have a record, and I'm not sure whether that's enshrined in legislation or just a principle of the health department and it certainly of us. So we don't advise a clinician that the patient has opted out, we don't say they've got hidden parts of their My Health Record. We don't let the clinician know that.

Jo Root: I mean, I guess that raises the question that somebody here has said, what is the point of ... in a sense this is probably better answered by the health department who unfortunately not able to be here today, so if you want to answer this fine, otherwise you can just say we'll refer it off. But one of the questions from column was why make people have a record who don't want it? What is the point of having all these empty records sitting on the system?

[01:15:30]

Kim Webber: You're talking about the opt out participation model?

Jo Root: Yeah.

Kim Webber: So a lot of the opt out participation model is based on two things. Firstly clinicians will use the system if there are a lot of people ... more than half of the population have a record, so it becomes part of normal clinical care. Otherwise most of the people who walk through the door don't have one, and they don't particularly think about it, so there's that clinical engagement part. The other part was the opt out trials and the work that was done before that ... actually the people who most need the records, older people and people with disabilities, people with multiple morbidities that probably the least able to register for a My Health Record and actually get one. So the benefits for opt out are about benefiting that particular population. So that was the rationale, but with that comes obligation to make sure that everyone knows that that's happening and they can make that free choice to opt out, and then they won't be discriminated against in the future, etc.

[01:16:00]

[01:16:30]

Jo Root: So it's up to people ... consumers are having to opt out, doctors can still opt in, and that's really comes to a question from Rosemary about "My GP's not currently set up for MHR, and he's reluctant to get involved, what rights do I have as a consumer? How can I insist?" I mean how are we going to ... so the consumer wants one and their doctor doesn't want to do it, you can't do it without your doctor playing in a sense, 'cause nothing will go on. So what's the process there?

[01:17:00]

Karen Gallagher: So I was actually presenting with Dr. Mike Bainbridge the other day, and it was interesting because we've been through ... this is our fourth month of opt out, we've seen people start to ask this question, which is really interesting because it's sort of going from that thing of going "Okay well I've chosen to be in it now, why aren't they in it?" And Dr. Mike said "Well, people are going to start voting with their feet," and I guess that's absolutely a given. Your information will not be on My Health Record if the healthcare provider you see is not connected to My Health Record.

[01:17:30]

Karen Gallagher: So, we have a fairly high connection rate to My Health Record at the moment and as we move forward with, as Kim just said, once 50% or more of the population's on board, we've got pathology connected, increasing levels of pharmacy connected ... that the evidence base will be that this is the new normal and the people that are not connected, it'll be up to their patients to see whether or not they choose to continue to use that doctor if the information's not going up to the system.

[01:18:00]

Karen Gallagher: I guess it's hard to agree with why you would be part of a system based on the benefits, but then be okay with not receiving any of those benefits. So I think it'll be an interesting thing to watch as we move forward.

[01:18:30]

Jo Root: What work are you doing with specialists has come up a number of times. We all talk about GPs as though they're the only doctors. We have a huge number of specialists out there. I don't know, some of you may have access to specialists, I have the misfortune to do that. I don't think my specialist would even know how to turn on a computer. So how do we get specialists on board. They're renowned for still having medical secretaries who type up their notes and still love the fax machines and everything else. What are you doing with specialists to get them on board?

[01:19:00]

Kim Webber: That is absolutely our next challenge because the work that was done with general practitioners about computerizing GPs, yes it did a lot of good for that area, but specialists, as you say, sometimes still writing notes, still having paper files and what we're already starting to see is GPs who put all of this work into doing a shared health summary, explaining really well what they've done. Then they get a phone call from the hospital asking about the patient, and they think "Well, hang on, I just did all of that work. Why is the hospital ... why is the specialist not looking at the record?" So that's where we really need to invest a lot into specialists.

Kim Webber: Unfortunately, you know how I talked before about dealing with the software and the vendors and the clinic information systems, they're really diverse for specialists. So specialists do rely on GPs to refer patients to them of course, and if GPs are more and more involved and demanding communications and information back from the specialists and into the My Health Record system, I think that will be additional layer for specialists to be involved with the system but that is really our next big challenge, working with the colleges, working with the peak bodies, but giving them a good reason to actually engage with the system.

[01:20:00]

Kim Webber: So we're looking at some really innovative models of care, so we've actually got these test bed projects which are available on our website. Some really interesting models of care, even around things like pancreatic cancer, and this is where we have specialists and general practitioners, nurses and whole teams working together with My Health Record with how they can support those patients with pancreatic cancer to understand their care better. Once we get into more of those models of care around diabetes, we're looking at diabetes in western Sydney, even looking at some prison populations, etc, that get specialists excited about getting involved and being part of the team.

[01:20:30]

[01:21:00]

Kim Webber: So I think that's really gonna start taking off. There's a number of ways that we're doing that, but it is a big focus for us over the next few years.

Jo Root: Just as we're going down, I'll give each of the consumers an opportunity to make final comment or raise any things, burning question that either has come up through what people have said or that we haven't covered yet. Paige did you wanna go first?

[01:21:30]

Paige Burton: Yeah, I mean I still think the same thing. I think it's a really valuable and important idea and I think it could be a really valuable thing. I just want that power back in the hands of consumers. I want people be able to opt out ... to opt in instead of opt out, and I think that at so many points in the system if that was changed then that power's given to the consumers, it would be a much better system for everyone involved.

Jo Root: And you're not convinced by the fact that people, whilst you might have a record, you still can make conscious decisions about what information goes on and who can have it.

[01:22:00]

Paige Burton: I think that, when we were talking before of the reason the system is opt out is because otherwise people won't opt in. I think that concern is the same the other way. I think people are gonna not opt out and not realize what they're getting themselves in to and that's gonna be ... that power shouldn't be in the reverse, the burden shouldn't be on the average

consumer, the general public to opt out of that. The system should be able to opt in and take control of their care and all of those things.

Jo Root: Okay. Sharon?

Sharon Tonkin: I've been reassured by some of the things I've heard today, but unfortunately I need to be naysayer on one thing and that's IT infrastructure. In the rural setting we've still got massive black spots where mobile phones won't work. If you want your communities to get on to My Health Record it's gotta be there. The NBN rollout is not happening in large patches when we're not on it. We've all got landlines because we need a modem to try and get to the internet.

Sharon Tonkin: So, I'm very cautious about the infrastructure that exists for the consumers to use it. I think they'll willingly grab it because the rural person has so many incidences of miscommunication. They'll be thrilled to do it, I just say please look at the IT in anywhere outside the suburbs.

Jo Root: That's to government, not just to you.

Sharon Tonkin: Yes, that's right. [crosstalk 01:23:15]

Karen Gallagher: ... you're giving me a challenge to go take the [inaudible 01:23:18].

Sharon Tonkin: I'll talk to whoever you like.

Marc Niemes: [inaudible 01:23:20] same door don't they? They're in the same building? [crosstalk 01:23:23]

[01:23:30]

Marc Niemes: I think everyone has a very, very unique perspective and it's usually in a "What's in it for me?" And that's how I think it's actually ... personally looking at it as an outsider looking in, there's obviously the personal things with my own family, etc, that you look at, but coming back to the tribal nature and sense of community. I think your sense of community should be "This is good for the country to basically have this data." Personally, I'm probably a little bit more almost dictatorial I would think that if you're receiving the benefit from the country in the sense of healthcare, then the return of that is we're going to use ... we need some information regards to that so we can actually improve the care for you, right?

Marc Niemes: But absolutely granted that if this isn't the care, what would be the case? So if not this what? If not now, when? Right, so it's all right to say "No, no, no we don't want to do this," I say "Absolutely fine," but I also ... granted the benefits of being able to see this in a environment where you don't have access to technology, I think you've reassured me a little bit on the "Okay, well you can call someone up if you need to to say okay we can't talk about your individual record, but we can say that yes something has

been created, or something hasn't been created or something's been accessed." I think that's basically absolutely reassuring.

Marc Niemes: By all means, it's something to ... I mean, we live in a democracy, and I think it's great that you're taking all these other considerations on board, personally and certainly brought it to my attention all these other things where the individual is the key here. So, good luck.

[01:25:00]

Karen Gallagher: That's for all of us.

Marc Niemes: That's all of us.

Jo Root: Did any of you want to make a final comment, a final plea?

Kim Webber: Probably I think for a long time in the health system we've been trying to have clinicians work together, provide more integrated care for consumers, particularly when they travel ... people who travel and don't go to a normal practitioner, and I think this is the reason I got into digital health was because I could see that we're gonna change the conversation.

[01:25:30]

We're gonna bring the consumer in. We're gonna allow clinicians to be able to change information, almost give you more choice because you can take your ... you almost have a record that can be seen by various clinicians so it's just the start. It feels like it's been such a lot of publicity, but it really is just the start, and I hope we don't all lose interest, that all of your voices and everything that we're saying actually is really important and the government continues to respond, and that you continue to say "This doesn't work, this does, etc." I think it'll be a really good five years.

[01:26:00]

Jo Root: Karen?

Karen Gallagher: I'm really hopeful that people do remain engaged and continue to ... it's just amazing that there's been this many consumers want to talk about their health and their record. Whether they want to be part of it or not. I think that's really exciting stuff and I really hope that continues and our next goal is to ensure that it doesn't drop from the consciousness again, and that we say "Right, this is when you use it. This is when it gives you benefit," and that's really going to be what makes it successful, and that's both the consumers and for health care providers. So that is absolutely the next challenge.

[01:26:30]

Jo Root: And Michael from a data and research point of view?

Michael Frost: Well, I would support both of those comments, and I hope that that discussion continues as we move through implementation of the circular use framework and making the data available for public health and research purposes by 2020. As set out in the framework that at that time I hope that, obviously, people don't overwhelmingly opt out of the My Health

[01:27:00]

[01:27:30]

Record and that, of those who do, they don't overwhelmingly opt out of the second reuse because that's a big part of the benefit. I mean, there's a lot of benefits in the face to face treatment and in how it works in the system, but there's a lot of the benefit that comes from identifying models of care that work based on the system information that we'll be able to see. I think that a lot of times we have good tangible example of the things that can go wrong, but we'll be looking, hopefully, to have some tangible examples of the things that can go right.

Jo Root:

[01:28:00]

Excellent, and on that I'd just like to say that if consumers out there are interested and want to know more, then they can contact Dean Hewson at Consumer's Health Forum of Australia who are funded to do some of this ... to do some work and to help people understand it. We all look forward to the legislation finally passing if the Senate can get on with it, that would be good. And the report from the inquiry is due to come down soon, and I think I'd echo the comments from Karen and Kim that this is the beginning and people who are deciding that they don't want one now may choose, as the system gets better, as the benefits become more obvious, as we do find the loopholes, find the problems and solve them, I don't think any of us are saying there won't be problems, but we're going to find solutions and put safeguards in place.

[01:28:30]

Jo Root:

So hopefully more people will come on board and it will actually do what we hope it will do, which is improve health outcome. So thank you all for participating, thank you to the panelists. Thanks very much.

Marc Niemes:

Thank you.

Section 3 of 3 [01:00:00 - 01:28:46]