

## Transcript

# Privacy, Security and My Health Record

Webinar, 8 August 2018

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### Section 1 of 3 [00:00:00 - 00:21:04]

Mark Metherell: Good afternoon and thank you for joining us for today's Consumers Health Forum webinar on the My Health Record. Today, we're focusing on the issue of privacy and security of the MHR record in the first of our series of six webinars on the My Health Record which I'll refer to now as MHR. My name is Mark Metherell and I'm the Communications Director of Consumers Health Forum and I'll be facilitating today.

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Mark Metherell: We're very fortunate to have five people with us who'll be able to respond to the issues raised today. These are people well-informed and expert in the various different aspects affected by MHR. I'd like to introduce them.

Mark Metherell: First, we have Dr. Kim Webber who's the General Manager Strategy at the Australian Digital Health Agency which is administering the MHR. We have Dr. Charlotte Hesse who's a Sydney General Practitioner and also heads the General Practice and Primary Care Research at Notre Dame University. Have Karen Carey who's a former chair of the Consumers Health Forum and has been a consumer rep with on advisory councils with the National Health and Medical Research Council. Also, Dr. Bruce Baer Arnold who's Assistant Professor at the law school at Canberra University and he's an author and analyst on data and privacy.

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Mark Metherell: Thank you all for joining us. I think we're very fortunate to have this group of people with such in full knowledge. Of course, we thank you the attendee participants for participating today and for sitting in the questions which do help inform us as to the issues people are thinking about out there, so it's a very valuable thing that we have.

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Mark Metherell: The webinars have been designed and directed by the Consumers Health Forum and we also receive funding support from the Australian Digital Health Agency. Well, as we've seen in the past week security and privacy of the MHR has been something of a leading issue and we wanted to take this as an opportunity today to look at it more carefully.

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Mark Metherell: The Federal Government has taken measures to enshrine in legislation safeguards when it comes to confidentiality of medical information in announcement they made last week. We, at the Consumers Health Forum have strongly supported National Electronic Health Record system for

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some years because we believe it will do much to improve the effectiveness, safety and access to the health information for the benefit of both patients and clinicians.

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Mark Metherell: These latest measures that the government has introduced are in response to concerns about security and privacy safeguards. Now, the legislation that they've announced will enshrine in law to ensure that no health record can be released to police or government agencies for any purpose without a court order. As well, the new measures will also enable individuals to order permanent deletion of their health record from the system. Many of the topics we'll talk to today reflect the thrust of the questions and issues you've raised in your messages to us, and I'd like to start first with Kim to respond to some sort of fairly basic questions about MHR which have been raised in recent times. First of all, Kim, what information is in an MHR, and what is the timetable for any further development of that information on the MHR?

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Dr. Kim Webber: I'm sure my colleagues on the panel could also talk about this because particularly Charlotte uses it already in clinical practice, but at the moment we've had the My Health Record system operating for about six years and there are range of documents and information that are in My Health Record ranging from some of your billing information through Medicare and through pharmaceuticals that you might have had prescribed to you.

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Dr. Kim Webber: Event summaries from when you've been to visit a clinician or a hospital you might have discharge summaries, so some of that information that would have normally gone from your hospital back to your GP, well, it can also be in the My Health Record. Then also some other documents like an advanced care directive which is actually something that a consumer can put into their My Health Record to communicate to clinicians about how they want to be treated as part of end of life care.

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Dr. Kim Webber: It also has pathology and diagnostic imaging results and reports, so a range of information from pharmacies from general practices and from hospitals which comes together for someone's My Health Record. And of course, when My Health Record is created, that is the start of that process. There's no, I guess, place with those documents are stored at the moment.

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Dr. Kim Webber: When you create My Health Record, the first thing that goes in there is if you set your controls to that is MBS and PBS information, and it's really from then on that information starts to flow into your record. I've had a record since 2013 and it has my medical visits, some information about a surgery on my wrist and the medications that I'm on. I also have a shared health summary which is, I guess, my health history and information that was curated by my general practitioner and put it in there which is really a snapshot of my health at that time.

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Mark Metherell: Kim, can I ask who will have access to that record?

Dr. Kim Webber: [00:07:00] The people who care for you in your clinical team, the clinicians that you would see whether you go to the hospital, whether you go to an allied health provider, or a general practitioner as part of providing you with that care. Those are the people who can access your record.

Mark Metherell: How will last week's measures announced by the government fit the protections around release of your data?

Dr. Kim Webber: [00:07:30] The Australian Digital Health Agency is the system operator for the My Health Record system and we already had a policy in place that we wouldn't release data to third party site law enforcement unless there was a court order in place. The reason we had that policy in place is because first and foremost our role is to make sure that the public and clinicians have confidence and trust in this system, so that they will use it to improve their health care. We already had that policy in place.

Dr. Kim Webber: [00:08:00] What this change in the legislation done is doing is actually putting that within the legislative framework which guides us anyway. In terms of what our practice is, it doesn't actually change that but it does give that confidence and that trust to all Australians that it would require legislation change whoever change that.

Mark Metherell: For those who don't opt that the default will mean that the data on their record is in a sense open where can people find easy to understand instructions about how to access and control the data?

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Dr. Kim Webber: The My Health Record website which is myhealthrecord.gov.au has a lot of information about how you can set privacy and access controls. As you say, one of those is that you can actually opt out of having a record, so that's what this period of time is this is really taking a human rights approach, making sure that everybody understands that they can opt out of having a record and how they can do that quickly and easily.

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Dr. Kim Webber: You can also, once you have a record you can set a record access code which is a four-digit number that you can put on your record and then a clinician needs to have you in the room to ask you that code in order to access your record. You can also put a code on specific documents within your record so you might want to put in some certain set of documents and then put a code on those so the rest can be accessed, as a clinician would when they're treating you but those specific documents they need to ask your permission and get that code.

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Dr. Kim Webber: Also, you can delete documents from within your My Health Record if you want to do that and restrict the access as I said. So there are a range of those privacy and access controls that you can put in place.

Mark Metherell: Can researchers access MHR data for research purposes?

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Dr. Kim Webber: What you're talking about there is actually called secondary use of My Health Record data and the Department of Health last year and this year did a broad consultation around secondary use of My Health Record data. A whole range of policies and processes are being put in place by the Australian Institute of Health and Welfare, which is a very trusted data analytics agency that's been doing data analysis for many, many years. They are going to be the data custodian for this secondary use.

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Dr. Kim Webber: It's going to take quite a bit of time to set that up, so no data will be released to them until at least 2020, and importantly only the identified data is actually going to be released from the agency to the Institute of Health and Welfare, so that that won't include any information that would identify a person within that data set and that will allow the institute to then have a rigorous governance and ethical framework, which they're currently putting in place which researchers will be able to then have a look at the data.

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Mark Metherell: What about access by insurance and other companies to the identified data?

Dr. Kim Webber: Insurers are specifically excluded from being able to access any information for secondary use, and importantly to note as part of the My Health Record's Act and the act that goes with it which is the Health Care Identifiers Act it's already prohibited for the My Health Record System and health care identifier system to be used by insurers for setting premiums or anything like that or employers for any employment purposes.

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Dr. Kim Webber: Those things are already prohibited in the Healthcare Identifiers Act and you cannot access in My Health Record System without using a health care identifier, so those safeguards are already in place for that.

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Mark Metherell: Thanks, Kim. I'd like to go broader now and ask each of our panelists their perspective on what the key issues of privacy and security are that we need to explore when looking at MHR, what the people need to consider about the safeguards and regulatory oversight of MHR data, and I'd like to start with Charlotte.

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Dr. Charlotte: Thank you. I suppose I need a little bit more direction in terms of domain as a GP, things will-

Mark Metherell: Well as a GP from your perspective, what are the sorts of issues when it comes to privacy and confidentiality that strike you when we're talking about MHR?

Dr. Charlotte: Look, from my perspective I don't think there's anything different about MY HR from the way in which I think we should be thinking about a whole  
[00:13:00] medical records. At the moment, we have sort of a whole lot of individual records, if you go to a hospital you have a health record created for you which is got information there and the people at that hospital have access to that data, but nobody else and not you once you've left there.

Dr. Charlotte: You can ask for certain summaries and with your permission they might release information, and the same thing with your GP who's got a record if you go to another GP they've got a record. At the moment, we've got lots  
[00:13:30] of different places that have your information stored, and so there were issues about the privacy for you and access and those around it, which at the moment is very much about the person who's got the custodial rights of that particular record.

Dr. Charlotte: The difference from My Health Record is that it is going to be a sort of as a repository of the summation of visits. So it doesn't have the richness of the data that is in your record. For me, as a GP I've got really quite  
[00:14:00] complete notes about someone but the summary that I put can put up onto the My Health Record in consultation with my patient. I never put anything up on there without actually making sure that the person who I'm uploading it about is comfortable with the information that goes up. I think that's an important part of this whole process.

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Dr. Charlotte: That now means that someone else can have a look at that summary document as well as the person who owns it, so that it might help in directing care or being safe about it. For me, that's about what medications you might be on, what things have happened in the past that are important medically that mean that ongoing care is affected by that. What allergies do you have, what immunizations if you had? Those are the key things that are in that summary, and those are the things there.

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Dr. Charlotte: It's a one page document, we're not talking like a health file that most of us think about can sometimes if you've got a lot of things happening can be files and files, that is not accessible through My Health Record and it's never going to be. The point of the My Health Record is really a conduit of the important facts that need to be able to be access between the points.

Dr. Charlotte: The privacy is really important because I don't want that summary  
[00:15:30] accessed by people who shouldn't be able to access it and it needs to be very much with the permissions and the security and I'm certainly confident from my perspective the hoops I've had to go through to be able

to put up a record have a really very, very secure. It's very different from then having someone actually accessing the file that I keep about somebody that's behind the generation of that summary.

Dr. Charlotte:  
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I think sometimes we get that gets lost in this conversation that because we're calling it a health record people think that it's their health record and that's the really rich file that talks about the everything. Remembering too, that in that summary conversation so I'll talk to someone and say, "Okay, I've been seeing you for the last 20 years and you've had arthritis, you've had an operation for your gallbladder. You've seen me a few times about anxiety. What are the things that we think need to go on to that summary that are important for somebody else?" Now, we might say the anxiety doesn't need to go there, nobody else needs to know about that, that's being managed and it's not an important thing. But yes I think it's important that people know you go blood has come out, and I think it's important that we know which joints are affected for arthritis in terms of ongoing care for other issues and the medicines that you're taking for those are really important.

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Dr. Charlotte:  
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It's about understanding what's important, what needs to be there, and then you can go home and go, "Actually I don't want that there after all." You can actually lock that one down exactly as Kim was talking about, or you can come back to me and go, "Can we do that again and put up a document that actually reflects the things that I want, because actually I do want the anxiety to go up." I've thought about it and I realize that I really do want someone to know that I do get anxious about things and I need you to actually be able to have conversations that a mindful of that and respectful of that.

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Mark Metherell:

Thanks Charlotte. Karen, if I can ask you what sort of issues do you think as a long time health consumer advocate we need to be thinking about in terms of privacy and security with MHR.

Karen Carey:  
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Sure, Mark. I think that generally overall people are best taking the attitude that the data may be made public by a mistake, by someone criminal activities, by something. Let's just assume that the data might become public, so then for people, for individuals, the issue is to identify their personal risk is that about it becomes public, to minimize the risk and to mitigate it.

Karen Carey:  
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At the moment, the discussion certainly the social media discussion things has been about either having a record or not having a record but there is this really important third option which is to have a record but to manage it quite closely so that it only has the information in it that you consider to be appropriate and not put you at risk.

Karen Carey: That really means that for an individual, each piece of data that's considered to be put on it to the record you need to say, what is the risk if this information becomes public, becomes known by my employer, becomes known by my husband or family.

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Karen Carey: All of those things that we've managed to identify that are real risks and then mitigate them, manage your record tightly, lock them up in the code, ask your good doctors to not have them. They're always of ensuring that you get the benefits from having My Health Record without necessarily the risks, so it's about minimizing the risk.

Karen Carey: [00:19:30] There's a few things that I think people need to be aware of, we talk about having the MBS, MPB started there as really an accounting record. It may be possible looking at MBS item numbers to identify a service that you've had, it may be possible looking at the PBS data to identify drugs that you've had for a specific condition.

Karen Carey: [00:20:00] People with mental health conditions are particularly sensitive to having My Health Record for very good reason, so we know that people with mental health issues do suffer by it. You need to check whether or not that MBS data and PBS data contains information that might identify the fact that you have a mental health issue, if you are taking a drug for psychosis.

Karen Carey: [00:20:30] Those are the things that you need to look at, that's about risk identification and then minimize and mitigate that risk for you as an individual. I really think that that's the way that people will get the most benefit out of the My Health Record, I think it would be a great disappointment for individuals and for Australia generally if people simply opt out because they don't feel they have control. The controls are there, they are reasonable but we should not in any way minimize the risk that that data might get out.

Mark Metherell: Thanks, Karen. Bruce what's your sense?

Dr. Bruce: [00:21:00] Well, I think I'm probably the bad boy on this panel. Basically, we've heard what's effectively an advertisement from the people who are going to run the system. We've been told that the policy will protect you. Policies can change within five ...

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Dr. Bruce: [00:21:30] The policy will protect you. Policies can change within five minutes. We've been told that the legislation will change to give you meaningful protection. At the moment, that's simply a vague promise. And again, legislation can change, doesn't take very much. And what we've seen historically in Australia over the last 30 years in a range of sectors is that we start off with fairly robust protection, at least in terms of law. And over

time, that protection is eroded, drip by drip, drip by drip, so that ultimately you have very little protection.

Dr. Bruce: We've heard that, oh, all right. There will be accountability. There will be a strong framework. The main regulator in Australia for privacy was on death row for a couple of years. The attorney general who really cares about consumers, the Attorney General said, "Really, we don't need this body." There was a bit of pushback. We currently have the Office of the Australian Information Commission. It's grossly under resourced. It doesn't have expertise, it doesn't have bodies, and has a culture that ... It's a toothless tiger, when you can actually get it out of its cage, it tends to lick the hand of the health department and the Attorney General's department, and any other department in the calm of Government.

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Dr. Bruce: We need to be conscious if we're talking about risk. We need to be conscious about what's happening out there in the real world. If we look at Singapore, a model for Australia, that's the equivalent database, equivalent system in Singapore was hacked only a few weeks ago. We've heard about protection for medical records. What's happened in New South Wales in the last two weeks? Thousands of patient records were basically abandoned by the New South Wales Government, an agency that we would expect to care for consumers. And if we look at overseas, the My Health Record system is based on a flawed failed system in the UK where among other things, the policy planners quite explicitly plan to sell off bulk health data.

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Dr. Bruce: Hospital incident records, we heard a moment ago, in the UK Hospital incident records for basically most people in London, was sold to insurance companies. The government made an express commitment. It was busy planning to sell bulk health records for the whole of the UK population to drug companies, insurers, and basically anyone else who could pay. Why am I saying this? Because ultimately, we have to be sensible about risk. We have to be wary about assurances that we're getting. All right, the government cares for you and the government will look after you. And we have policies, and law, and regulators. Those things can all change. We need to look a bit beyond what we're hearing, and be I think hard headed, and think about what are the implications, discrimination perhaps, stigma, care, and ultimately respect for individuals. If the government was so concerned about privacy, why does it have to wait till five minutes to 12? Why are we getting a promise, and simply a promise at this stage, a promise at this stage, that you can opt out. Sorry, a fix that you can opt out, and a promise that in future, well, the legislation will be changed so that basically anyone in government can't get access to records simply by asking, why did we have to wait so long? This tells us something fundamental about the government's policy fundamental about how government views consumers.

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Mark Metherell: Thanks, Bruce. What about the benefits of the system? We're talking, you've raised those points about this in it. It does seem as though since the legislation was first promulgated five or six years ago, community sensitivity knowledge awareness of data risks, data threat, has certainly increased.

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Dr. Bruce: Yeah.

Mark Metherell: But don't you have to put the benefits of such a system of having comprehensive health records for easy access by both the consumer and the [inaudible 00:25:14]. How much is that worth?

Dr. Bruce: I think it's incredibly valuable, both in term both in terms of the national economy, in terms of for the taxpayer, for individual patients, and the people that we all love. I have people out there who I love. I just love some of my friends and relatives to pieces. As someone who teaches law, who teaches health law in particular, who's worked in the IT sector. I'm really keen on an effective, comprehensive, national health system. I'm really keen on a comprehensive, effective, national health system. But unfortunately, My Health Record is not it, and simply plastering lipstick on this pig will not make it a good system.

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Dr. Bruce: We need to think as a community about what we want to do. We need effective regulation. We need effective resourcing, and we need a meaningful commitment on the part of all the stakeholders, government, [inaudible 00:26:13], clinicians, even people like me to make the system work. At the moment, it is a flawed system, and it needs to be fixed. We can't simply rely on some tensile ... "All right, I'm the minister. Don't worry, I will fix it." Because the next minister could well change his mind.

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Mark Metherell: Karen, you wanted to say something?

Karen Carey: Yes. I just think that we should look at this issue of the benefits of the system. I absolutely agree with you. It's about individuals looking at the benefits for them against the risks. What we know about the healthcare system and we have all worked hard towards for many decades, is that there are some things in the healthcare system that have really let patients down and we find them readmitted to hospital. Those things are discharge summary, so we talk about the Valley of Death of leaving the hospital. We don't get to discuss charged summary, and then our GP doesn't know the medication changes that we've had, they don't know the tests that we've had, and we're getting all sorts of trouble.

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Karen Carey: Medication safety. It's estimated that one out of every 10 people in hospital are there because of an adverse incident with their medication, because we don't have a comprehensive medication record. People, when you go out and you speak to patients, quite often, they say that in the

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[00:28:00] hospital, they instigated a new medication rating, when in actual fact it's the same drug they had before, but it's a different name. The My Health Record should deal with things like that. And then there's the duplication of tests. And this is an issue of the patients. It's an issue for the public economically because we waste a lot of money in the healthcare system duplicating tests, but it's also a problem for individual patients. When you are in serious strife with your health, you need something to happen quickly. Not being able to access your blood tests that you've had just three days ago is a real problem. It compromises your health.

[00:28:30] Karen Carey: Those things are all benefits of the system. Individuals will all get different types of benefits, there are additional benefits. But what we've looked to the eHealth record to solve for us is really those big problems. As a consumer representative, we've been highly critical of the system for saying, "Why on earth haven't you solved this problem? I can go to my hairdresser, and they can tell me what I've had done to my hair for eight years. Why can't you tell me what medications I'm on?" I think it's important for people to understand that the development of the eHealth record has been very consumer driven because there are these problems in the system that each should solve, and it would be great to solve them.

[00:29:00] Karen Carey: The research benefits is another issue. There is an argument that if the public is paying for services shouldn't it have access to the data to be able to do research to make sure that the services work? That's also a big benefit for patients, but it is about every individual assessing their own risk for that data and then either managing that risk or choosing to walk off until they feel the system is more safe.

Mark Metherell: Kim, could you come in here? What do you think about this issue that in the end, as Karen says, it's for the consumer to balance their beliefs, their needs, from the health system to balance the risk? These sorts of more personalized decisions. What do you think?

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[00:30:00] Dr. Kim Webber: I think it absolutely is an individual decision, and that's really what this opt out period is about. The public debate has been really interesting and is absolutely beneficial because this is exactly how we want people to think about their own healthcare. I personally registered for My Health Record. It was known as the personally controlled electronic health record back in 2013, before I ever worked in digital health. I'd worked in health equity and in rural health policy for my whole career, but I read I registered myself for record because I know about the golden hour, which is, when something happens to you, a stroke or a heart attack, this is kind of golden hour where treatment can be provided.

[00:30:30] Dr. Kim Webber: I'm currently pretty healthy and I'm not on any medications, but I want clinicians in an emergency department to know that, I want them to know that they can immediately give me whatever the best medication is

[00:31:00] because I don't have any medications that are going to [inaudible 00:30:36] with that. I want them to have that information directly at hand. My personal reason for actually registering was safeguarding my health for an emergency situation. Because I don't have a chronic illness, I don't have records that I need to keep track of, but I do want those decisions made in an instant which will be of most benefit to me. That was personally for me, why I registered for a record, but I think the issues around having to take time off work for repeated tests and the cost and expense to consumers, I think is absolutely a benefit, but the medication safety is the number one issue.

Dr. Kim Webber: [00:31:30] The fact that so many people are harmed through medication misadventure, I think that is a huge area of work for the not only digital health agency but the broader health system consumers and in our national digital health strategy which is our four year plan for the future. Medication safety is right at the center of that. It has a whole pillar of attention to it because it's where we can save the most lives, improve and improve healthcare. And if I just add even when my grandparents, I remember when towards the end of their life, when they would go into hospital and then their medications would be changed, it with the best intentions, but we knew those medications that are already been tried and they didn't react well within my grandparents. Now, I think the training physicians would have much more information to be able to make decisions about changing medications than they did from when my grandparents were around. And that's why I've joined digital health to be part of that, to be part of the way that we really are going to make that difference particularly around medication.

[00:32:30] Mark Metherell: Charlotte, on a related issue, some of the medical profession have been critical of the fact that if patients have a choice of what goes on and off their record, this may in fact endanger clinicians treatment decisions down the track. What's your feeling about this?

Dr. Charlotte: [00:33:00] Oh well, I would agree that if people are withholding really important pieces of information, that that can make a difference to what then gets communicated. The conversations that I have with my patients about what goes on and what doesn't go on is about that safety issue. It's like, well, what things do matter? What is it that needs to be communicated to somebody else that really does affect your healthcare? And I think that goes back to the setting of the risk mitigation and what are the things that do or don't need to be safely communicated. We make a choice, and it's an informed choice, about understanding the importance of having the medications there, so that there is this record of what is being taken and not taken so that errors don't happen.

Dr. Charlotte: I'm excited about the fact that on a daily basis, there are issues that arise because of poor communication between systems about the not knowing

[00:34:00] the name exactly, what Karen was talking about. I have got patients who go and see a specialist, they can't necessarily remember the conversation that happened with the specialist, but they know that they will put on a new medication. They come to me and they go, "Look, I really don't know that I want to be on it and I don't understand it, but I can't remember the name of it." I haven't got the letter yet from the specialist because some specialists aren't very good at sending letters in a timely manner, and I've already found that My Health Record has been a really good way of being able to go, because you can open it up and see what was actually dispensed by the pharmacy at that time.

Dr. Charlotte: They go, "Okay, this is what it is, this is what it's supposed to do, and this is how we can make ... These are the choices about whether it's a good option for you or not." Same thing with changes in medication, being on the same thing, being able to chase up what did or didn't happen. I've got some elderly patients who went up to the North Coast, ended up in hospital, had to have some investigations done and were put on stuff, came back to me, and had lost all the documentation somewhere. Couldn't remember what the details were, and so ... Now, normally that can take me several hours of phone calls to try and chase up. What was really nice was I was with their permission, I would have access to my health record, and on there, there was actually ... Although there wasn't a discharge summary from the hospital, that would have been really nice, and hopefully down the track.

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Dr. Charlotte: There was some investigation results, and I was able to, through that, safely figure out what had actually happened and figure out where we needed to go, which goes back to the things that go on. It is about that being able to communicate safely things. And I really understand why you might be not wanting certain bits of information to go on. I have these conversations with my patients say with a psychotic illness, about whether that the diagnosis goes on to the record or not. And it's like, well, what happens if you get hit by a bus? Nothing, a minor injury. Maybe, we're talking about a little bus and you get knocked over, but you hit your head and you're a bit delirious, you get into hospital and they don't know what you're on, what you're not on, et cetera. Do you actually want them to know the important medications that you're on? I think you should. Those are the times when it's really, really important.

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Dr. Charlotte: I get that we need to be really mindful of what I know is the prejudice and bias around certain things. But for me as a practitioner, if you're experiencing that, then you probably need to go to another practitioner anyway. Maybe that's a good red flag that it's not the right person, but it should never get in the way of me being able to care for you properly and make sure that it's always the best care for that condition at that time. I'm a complete advocate for it. I totally get that it's not the best, it's not what I

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[00:37:30] want yet. But can I tell you, I've worked with it right from the very beginning while I was an early adopter trying to get it to be what I thought was really the best thing for patient care, and it's improved so much over that time. We can only improve by using it and going, "This is not doing this. There are these gaps." Or, "Do you not realize that you need to be able to protect your safety that way? It's an evolution, and yep, I get you that there might be a risk that happens when something bad happens.

Dr. Charlotte: So far, we've been really good. There hasn't been any breaches in the data. It's been, I think, well managed, and there's a really good system in place to try and pick up where those happen. For instance, if you open up your My Health Record, you can actually see who's opened it and you can then go back and interrogate well, that that person shouldn't have.

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Dr. Charlotte: From my understanding, all the other systems around the world, no where has got such a good ability for you as the owner of that health record to actually understand who might be accessing it, why, and what the informations are actually accessible.

Mark Metherell: Thanks. Karen, you had a thought.

Karen Carey: Just two things. On that issue of access, some consumers have raised with me, and I don't have the expertise to answer it, but it seems to be a relevant issue. And that is that quite often when you walk around hospitals, you'll notice that their computer terminals are open, because doctors open them up to work on patients, and because of their workflow, it makes sense to leave them open. There is a concern that the system is only as secure as all of those terminals are secure. And that's why I think it's important to take a view, for individuals to take a view that their information may get out in the future. Not definitely, and if it did, it might not actually have any effect.

[00:38:30]

Karen Carey: A lot of these sets of information haven't actually had serious consequences for the people whose information has been released. I think there's that. I think there's vulnerability in the system. There has to be vulnerability. We can't close off that vulnerability because we'd make the system unworkable for doctors. Doctors have to be able to link in and use their normal workflow in a hospital, but I think that you can manage, and minimize, and mitigate that risk. I just also wanted to comment on your point about the medication safety.

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Karen Carey: The example that you were giving of the older couple, that to me is a good scenario. I myself have had a heart transplant, so I'm on more than 20 medications. On a good day, I can tell you exactly what they are and exactly what dosage I'm on. But on a bad day, when I've lost consciousness and I've recovered and I'm in hospital, I could not string

[00:40:00] two words together. And I think that eHealth record is a bit of an insurance policy for when things go wrong. It is valuable for us in our day to day chronic illness sort of lives, but it's much more valuable at pointy end and it's the pointy end that can save your life.

Dr. Charlotte: Can I say, you got me on my ... That's my big passion. It is about. Things change, and so being able to upload the changes so that that there is an up to date record at all times, and that's one of the really nice things about the My Health Record. When someone like myself opens it with a patient in front of me, the system is able to give me a list of what would appear to be the current, all the current medications.

[00:40:30]

Dr. Charlotte: Well, I actually did a little exercise to see how good at was, and it's actually from my perspective as a GP is really keen to make sure that my medication lists are always up to date. It actually reconciled really well. It was fantastic.

Dr. Charlotte: Going back to the issue of the access of records in the hospital, though. That's really a different issue in many respects, because that's the whole of the hospital record, which is, like I was talking about the richness of my record in my GP file, which is quite different from what gets uploaded onto the My Health Record. To get into the My Health Record is another couple of security steps from the terminal that's open good or bad, and that's really about again I think looking after the data that is in our hospitals records and who can access it, which although is completely relevant to the My Health Record, is really another conversation again about how we manage those, yes.

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Dr. Bruce: It's a human problem about the technology problem which is one of the reasons that regulatory capacity, the ability ... No. Meaningful law, meaningful rules follow up by regulators is really important and we do not have that at the moment. People have been talking about change improvements. Yes, the system isn't perfect, but don't worry over time, time will improve. Great appeared in today's Sunday Morning Herald and I suspect in the age from Wendy [BenNathan 00:42:00], who is a molecular geneticists, what we see-

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**Section 2 of 3** [00:21:00 - 00:42:04]

**Section 3 of 3** [00:42:00 - 01:02:51]

Dr. Bruce: Wendy [Beniten 00:42:00] who's molecular geneticist, what we see at the moment, again, one minute to 12 the government's acknowledging that in claims of future proofing the system we're building an extra capacity. We're heading towards building a national genomic data repository with this system.

Dr. Bruce: Now, that may will be really useful for public health and for the taxpayers, but we need to think about it and simply claiming as has been done by the

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[00:43:00] Minister and by other, for some time that, 'Look don't worry you can trust us, it will be okay', I think is deeply disingenuous. Why hasn't this consultation taken place with ordinary people and with specialists in the past? Why at this five minutes to 12 do we now have scope for opt out? Why was an opt out brought in right at the front? And a system that would respect consumers people who have rights, people who have autonomy.

Mark Metherell: Bruce, it's also a matter of balance the same paper that you're quoting from as an idiot editorialized in recent days that in support of MHR, so it is a-

Dr. Bruce: Yeah, it's disagreement about this.

Mark Metherell: We've had one of the email messages that's come through who says, "I assume that the comments by the gentleman on privacy apply equally to all clinical records."

Dr. Bruce: Yes.

[00:43:30]

Mark Metherell: So you're saying any clinical record is the system currently isn't, what do you think?

Dr. Bruce: We have real concerns we need stronger protection there.

Mark Metherell: Okay, going to more focused element, if I could ask Charlotte for the 14 to 17-year-olds who can apparently take control of their records, what does one do about educating both them and their parents about this if it comes to this?

[00:44:00]

Dr. Charlotte: Look, I think that 14, 17-year-old is as the person that we need to be educating anyway. From my perspective, all GP's we all know that at 14, if you're an intelligent understanding young person that you actually need to understand your rights as a health literate person, and that's all about privacy being able to do things on your own without your parents that you don't need to have parental consent for doing things as long as you do understand, and that's what is sort of like the intelligence.

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Dr. Charlotte: The time between 14 and 16, there are some who are very young and may not actually be able to make decisions that don't require a parent, and there are others who absolutely can make decisions and informed consent. I, very much see my role and I see GP's role is about that educating. It's about educating the parent who might not be ready to let go of overseeing and oversight of their children's health, and educating the children to say, "This is time you're now of an age where you actually have a right to sit in a room on your own without your parents and understand and have a discussion about your health care."

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Dr. Charlotte: Now, that also then blows falls over into, you have a health record that is electronic. You now can access that yourself and you can put permissions on it so that you can actually say, "You know, I'm ready for mom and dad not to have access to My Health Record anymore," or on the other hand you go, "I want mom and dad to still be accessing My Health Record because I want them to there." We have that sort of relationship that I don't mind if they know that I've had been already been sexually active and I'm on the pill and whatever whereas there might be another 14-year-old who there is no way that they want them here just to know that.

[00:45:30]

Dr. Charlotte: Again, it's about an individual discussion but it's about informing them, that informing the children and it's about informing the parents, it's about saying that, "Okay they're 14 and you actually need to be respectful that you cannot just go and look at their whole file without letting them know, and actually letting them know that they can actually keep it private." Actually a really good opportunity because I think it's bringing into focus that this age group is an age group that we really need to be both upskilling and educating, empowering, being respectful in terms of their rights and I think really being able to bring them up into the ability to be managing their health into the future as well.

[00:46:00]

Mark Metherell: Kim ...

Dr. Bruce: Seniors like me as well, it's [crosstalk 00:46:49].

Dr. Charlotte: I understand that, but I think that what happens that gray area particularly the 14 to 16-year-olds is that people don't appreciate that they actually have a right to health care without a parent in the room, and it's sort of like, I'll often explain that when they're in the room that whatever happens in the room is in the room and doesn't go anywhere else.

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Dr. Charlotte: Again, that there might well be conversations that would never go onto My Health Record and shouldn't go onto a health records versus actually that's something that's really important that we've now made this diagnosis or you know et cetera, should go on. What is shared isn't shared, it all needs to be talked about.

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Mark Metherell: I think that I'll ask, are there age available for that sort of a situation to protect younger people and older people who want to ensure their information doesn't exist by near and dear one.

Dr. Kim Webber: Excuse me, I'm just following up from what Charlotte said. So from 14 years young people can go onto our website and take control of their My Health Record if they have one that's a process that can be done or they can either call our help line either way that they can do that. Part of the I

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guess the communications that we're doing around the My Health Record, I'm not only for those 14 to 17 year olds but also their parents because we just want to give them some advice and support about how those conversations can happen, and there will be other organizations like the National Children's Commissioner who will also give some advice and support.

Dr. Kim Webber: I think it's a part of growing up like getting your license, your own  
[00:48:30] potentially, your Medicare card, all of those things into my gov account and even when you start to get a job that you need to register with the Tax Office. So part of that period of time we're all of that online, the online world opens up for you as a young person.

Mark Metherell: We also have a question from James who asks, "What sort of billing information is included on the MHR and how secure is this information?"

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Dr. Kim Webber: The Medicare Benefits Scheme and the Pharmaceutical Benefits Scheme repositories are part of the My Health Records or the information in there, which you can even get by logging into your Medicare account. So it's similar information which is an item number, the provider, who provided that service and it's only just a very small amount of information, it's an administrative piece of information it can give clues to a clinician about what has been done for that, but it's an administrative dataset that already exists.

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Karen Carey: But an item number can disclose the service, so it does item numbers, and particularly with the MBS review they're actually going to be more tightly identified with the service and therefore ...

Dr. Charlotte: You can cut them out. So one of the things with your My Health Record is you can actually say, "I don't want any of that information on my My Health Record."

Karen Carey: Can you say you want some of it but not other bits, so you can take an individual with that or you have to take it all that?  
[00:50:00]

Dr. Charlotte: Well, I mean, yes, I was going to say you can do the deleting like you can delete her health records, you can delete bits. It's like I sort of say to people have it all there and then decide if you think that you don't want it you can get rid of it or shut it down as you go.

Mark Metherell: If you delete information, does your GP made aware of it? Automatically no?

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Dr. Charlotte: No, so the only interaction that your GP has with the My Health Record is when I actively open it and there is no reason for me to actively open it

[00:51:00] unless I have you there with me, and we're about updating it or getting something down because quite honestly my record is a richer fuller record. Again, I would only be opening a particular electronic file if I have reason to. For instance, if you ring me up and asked me a question, or if I'm sending off a referral, or if I'm dealing with results that have come in, or if I've actually got you there for a consultation.

Dr. Charlotte: In My Health Record there is far less reason for me to open up and deal with it because again it's just a summary document and/or and mechanism for me to be able to retrieve information that has not otherwise come to me.

Dr. Bruce: In summary at this stage and I would love to believe. Sorry, I would love to believe that everyone out there in the world is as honorable and trustworthy as you, but the reality tells us that they're not. We've heard reference to Medicare data. Remember, roughly a year ago or more than a million, million people's Medicare data was leaked, million people. This is what we're told is a state of the art, state of the art system. Constant claims that don't worry I mean Minister Hans referred to military grade security which my IT contacts just sort of fall on the floor laughing at this notion.

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Dr. Bruce: We're ignoring the human factor, we need to think seriously about risk, about autonomy and about respect.

Mark Metherell: Karen, can I ask you what factors should patients who have the diagnosis of a stigmatizing illness mental health, HIV/AIDS, what are the sorts of things they need to think of when it comes to My Health Record?

[00:52:30]  
Karen Carey: Look, I think what they need to ask themselves is for each of these events that they're concerned about is how will my life be affected if that information gets out? If it gets out to women having terminations are particularly sensitive, if it gets out to a husband, they haven't told or it related to a time when they were 16, but they don't want their husband to know. Now, people with mental illness we know that there is bias. Certainly, I've spoken to some very well-educated people who are very concerned, they're homosexual, very concerned that they might suffer bias.

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Karen Carey: People need to look at their individual situation and say, what would have a negative impact on my life? And for me I simply decide not to have that information there because I believe that we have to go forward on the basis that the information may get out. It's just about individual, I think there's a very special case for genetic information. Genetic information is different because it gives a future risk that a disease might happen but it doesn't tell you you've got that disease, but also it affects your siblings,

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your offspring, your parents, your offspring's offspring. It's very important information that involves third parties.

Karen Carey: My big concern about genetic information is that if I decide to have a genetic test, having the results of that test actually affects my sister, it affects my children and it might affect their children. Therefore, it's a third party consent process and my understanding is that you can't get third party consent, I can't consent to something on behalf of my sister. I think that storing this information where it may lead could become available is a very special circumstance.

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Karen Carey: I think it needs its own legislation, we do have non-discrimination against for genetic information under the Anti-discrimination Act, however, I don't believe it's strong enough. In America, they have an act called GINA which is the Genetic Information Non-Discrimination Act. It is solid, it is specific, it calls it out loud and wide and I think I would urge the Government to consider having some very specific legislation about that.

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Mark Metherell: Kim, what's the status of the genetic genomic information issues as [inaudible 00:54:58]?

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Dr. Kim Webber: Pathology reports can be uploaded to the My Health Record now and of course you can ask that it's not uploaded to your GP or to your pathology provider and they must go along with your wishes. I think some of the reports that are in the media at the moment is that genetic reports can be uploaded like any other report into the My Health Record, but your actual genetic makeup can't be uploaded to the My Health Record.

[00:55:30]

Mark Metherell: Yet?

Dr. Kim Webber: Yeah.

Mark Metherell: Yet.

Dr. Bruce: The road to hell is paved with good intentions.

Mark Metherell: Indeed.

Dr. Bruce: What we will see is creep.

Mark Metherell: Well-

Dr. Charlotte: I think the conversation that we're having now though are really useful for that, because by putting up the sort of the red flag and go, "This is where we're happy to go to but no further," is a really important conversation to

[00:56:00] have. Whereas it may well be that people go, no actually we do want further and these are the protections we're going to put in place.

Dr. Charlotte: I agree with you that we have to be aware of creep and what happens, but I also say that we need to have those conversations that each step.

Dr. Bruce: We need a national discourse and so academics such as myself have been calling this writing about this for at least five years. One of the great disappointments with the current health minister, his predecessor and without her is that this conversation has not been fostered. It's been a technocratic approach. Okay, we're going to do it. At the very last moment when people start to get a sense of problems, it's all right, look we'll let you opt out reluctantly possibly we'll make it a bit difficult, and then people scream a bit more legitimately.

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Dr. Bruce: Don't worry we're going to fix the legislation, this conversation should have been taking place a couple of years ago, and it raises real questions about the legitimacy, the effectiveness of policymaking and of administration.

Mark Metherell: But we are having the conversation right here right now.

[00:57:00]

Dr. Bruce: Yes, but with a fairly restricted audience.

Karen Carey: You have to say-

Dr. Bruce: That's obviously leaked.

Karen Carey: It's a bit leaked, it would have been nice until we've had this conversation earlier and I think that it is a disservice to consumers when governments come out and say, "We have this fabulous software, it is never going to get out there. It's military grade."

Dr. Bruce: It's military grade.

Karen Carey: All of those things. Why don't we have a conversation that says, "Look, we know there's a risk it's happened in the U.K., it's happened in America, it happened in their medical records. Let's just assume that it's going to get out there. Let's minimize and mitigate the risks," and that means having that legislation that protects people down the track.

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Mark Metherell: Some people have suggested that say, "Women who live with chronic pain or have a history of anxiety should opt out as they risk their diagnosis being used as a reason to not investigate something further." How is the medical profession dealing with that sort of issue where anxiety on your record might mean the doctor would say, "Oh, I won't go down that track?"

[00:58:00]

Dr. Charlotte: Okay, so you've said that if a diagnosis is there it's a prejudice against you?

Mark Metherell: Yes.

Dr. Charlotte: Look, yeah, I mean I think that's really difficult. As a doctor I would like to say that that should never be the case and it is all about, from my perspective, it is about full disclosure. I appreciate that I'm not the person sitting on the other side of the desk when I'm saying that. But certainly if you think that a doctor is not listening to you and is being disrespectful of your current health concerns because of another diagnosis on your record then you need to go to another doctor, because a good doctor will listen to you and take everything into account and make sure that what he's actually needing to be investigated and managed appropriately does happen.

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Dr. Charlotte: I suppose I would say it might be a red flag if you actually breach that barrier rather than saying don't put it there, use it as a conduit. I mean I'd look after a number of vulnerable populations, so for instance transgender population I have a number of patients and I'm always astonished when they tell me the stories of terrible care because they have felt prejudiced against et cetera. I'm hopeful that we can educate doctors better as we go forward and that's part of my role in being involved in teaching students, but there are people that I know we're never going to change. Quite honestly it's about then making sure there are doctors there who are really good and mindful of all of that.

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Dr. Charlotte: Just go and find in these networks to be able to help you find the right person who's going to look after you particularly for that condition if you feel you're not being listened to properly.

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Karen Carey: Well you know Mark, that when women present in emergency departments women are significantly less likely to get investigated for cardiac purposes rather than men, so we know that that bias is just there and it's inherent. There is a chance that the e-health record will actually make it better because doctors will be aware that their action or non-action, non-investigation is going to be recorded into a record. Therefore, I think the doctors will be more careful about making those assumptions.

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Karen Carey: I, myself, have had five open heart surgeries and yet I still sometimes and the emergency department people say to me, "Do you suffer from anxiety attacks?" So I know that that actually is real and it's real at emergency times when people don't want it to be so I understand why people are sensitive, but having that in their record. But there is this chance that the e-health record might actually improve it or they will make it worse.

[01:01:00]

Mark Metherell: Look we're now overtime, I should just say, "Is anybody want to take literally a few seconds to make any final point in second rather than minutes?"

Dr. Charlotte: Look, My Health Record is a fantastic opportunity to actually really improve the way that as a patient we can navigate a very complex health system that we have in Australia. I'm extremely mindful that it is not the best yet, but it's an evolving document and it is only by finding the gaps that we can get better, but let's hold the opportunity that we've got and use it and go forward and really make sure that the patient consumer is at the center, so every improvement that they got is always got that at the heart of it.

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Dr. Kim Webber: I have to say that everyone is going to make a choice and that the conversations that we're having here and elsewhere and in the future webinars are critically important. To enable people to make the choice that this is right for them.

Karen Carey: From my point of view it's a fabulous resource, it's a tool that we've wanted for a decade, there is ways of using it safely and that is identifying your own personal risk and then stopping those records that you're worried about going into the record. Please don't abandon it altogether when you can actually be safe.

[01:02:00]

Dr. Bruce: If you're listening to this webinar, you're an adult, use your agency, use your dignity, hold your government to account, required the government to come up with a system that does indeed produce all the benefits that we expect and that we deserve from a national e-health system.

[01:02:30]

Mark Metherell: Well, I think we'll have to wrap it up there. Thank you for joining us and thank you very much to our panel Charlotte, Kim, Karen and Bruce. I think you've heard of diversity of views here and I believe it is very helpful in our getting a better grasp of the issues involved. Thank you and good afternoon.

**Section 3 of 3** [00:42:00 - 01:02:51]