# TRANSCRIPT

*Health Consumers Queensland Annual Forum 2018*

## Day 1

### Q&A: Let's get digital: My Health Record

- **James Wilson, Director, Community Partnerships and Insights, Australian Digital Health Agency**
- **Matthew Ames, Co-chair, Australian Digital Health Agency**
- **Christine Bain, Gold Coast Primary Health Network**
- **Facilitated by Anne Curtis, Health Consumers Queensland**

**Anne Curtis:** We have just under ten minutes for questions, so are there questions - lots of questions, I thought there might be. That's why I did say before that if we go to lunch you can meet with Christine, James, will you be out there too, Matthew - and talk to them.

**Audience member:** I'm just raising this because a consumer in my area which is a rural area, had an issue where the allergies were listed on the viewer and they were incorrect and I tried numerous ways to get it back, allergies, incorrect, removed from the viewer, the impact of having that on meant that they couldn't get the medications every time they went to hospital, it meant they led to withdrawals and it meant that - people still... With a very complex needs package. To this day, this person still cannot get that off the viewer because there's no Government or no input to get that done and the person who put it down was in a big punt, put on the Administration and just uploaded and they haven't got any way to get it back or get that National documentation removed and it is just a big concern because if it comes up on my My Health Records through systems that are already dumped out in, adds to their distress as an ordinary person. Is there a Government or something that can override what is already happening and being dumped in the system?

**Panel member:** That's a good question. I think what you've brought out here around a system for clinicians that is state-based and the My Health Record is a patient-based system that is national so the agency engages with stakeholders at many levels including State Government, and so there are detailed conversations to ensure that this type of situation doesn't happen with the My Health Record, in saying, with the My Health Record there is a national contact centre that is a health based centre that people can contact if they have when think do have the opportunity to opt out they can contact the centre but challenges with their My Health Record they can call the contact centre and they can help problem solve some of those challenges.

**Anne Curtis:** Thank you. A reviewer of the Queensland health system, so we have five minutes. Suzanne?

**Audience member:** My question is around Google doctor. You were saying we can open up PDFs to look at the results of different tests and that type of thing. As a medical person who can go in and have a look at their script and maybe also a diagnosis, what are the I suppose constraints or what can we do to ensure that people aren't doing that self-diagnosis, something they that could be a concern?

**Panel member:** Thank you for the question. The concern I'm hearing is about what consumers self-diagnosing. So the information in the My Health Record is the summary of the clinical conversations, whether they're in a mental health context, with GPs whether a discharge summary there's no diagnostic information per se, however, sorry from the consumer, so it's a clinician diagnosis, as a summary and that as Matthew called out it's a PDF that's uploaded. There is a space for patient notes where people can write their own hotel notes however it doesn't undercut any clinical conversation or process that you might have as a clinician.

**Panel member:** The results are uploaded to my panel. Having gone to see the doctor to access the blood results, before the doctors have that conversation with people.

**Panel member:** So there's a rule that is put in place that when there is something uploaded that's clinical, that the consumer does not see that for seven days, with the idea that if particularly if it's critical I would hope it's much earlier than seven days but that it's very important that this record is not seen as a way of communicating information to the consumer, that the current processes around conversations between consumers and their various clinicians or therapists is the manner to do that and that this is basically a way of collating that information after the fact so if if you do see that information, you should have had a conversation already with your doctor about that information.

**Anne Curtis:** Time for two more questions. Michael?

**Audience member:** Are we in a way in a communication process putting the cart before the horse in that one thing we're trying to do is improve the stand and quality as we're seeing in other parts of the overall Australian standards we're relying on a process that we're in the process of improving, what I mine by that as people have said, if the relationship between clinicians and consumers and their advocates are still in the process of ensuring we're not getting garbage in, we're not going to get garbage out and I support that view, in terms of sitting on the panel at the PA Hospital where members of our panel with complex needs report that it's like a Chinese whisper where information passing forward from one admittance and one clinician to another often ends up with all the best of intentions distorted and consequently the concern being that we're ending up with is information under a PDF system that may or may not adequately and accurately reflect not just what's wrong with the person but the nature of the tired overworked best intentioned clinician who may or may not have listened as adequately as what we may have liked?
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>>: So my perspective around that is that I have experienced exactly what you mentioned. So trying to get information across to people in many different scenarios and I really don't see the My Health Record as a replacement of trying to do that.

The best person is the consumer or the patient. If I have a knowledge of those things being available then I can refer people to it so I think - I think - I don't think it should replace or try and reinvent those other processes that are flawed, I think almost the opposite that it can assist those and is effectively a double check and ensuring that we as consumers have more visible and that it's connected as well.

**Anne Curtis:** Thank you. One last very quick question, we're almost out of time. Suzanne?

**Audience member:** Hello. I think it makes perfect sense to digitalise the health record, but the one area of concern is the secondary use of patient data. And I read that from 2020 identifiable medical into will be available to third parties and although it should be in the public interest it also said it can't be used solely for commercial purposes, I found the word 'solely' a bit worrying, also it should be identifiable when for most research purposes it doesn't need to be and I also understand that arch two years it will be up for review with the possibility of wider uses including provision of data to insurance agencies, after the opt out date, especially after two years have gone by and all the launch fanfare will die down, how will people fully understand where the information might be used, especially if it changes after the review? Thanks.

**Panel member:** I'll respond to that. It's a good question. Prior to the announcement of the opt out there was also an announcement of the secondary use framework and that's the secondary use data framework for My Health Record data. First call out, all information used for secretary use is deidentified so it's deidentified and also a person can have the ability to have a My Health Record and then opt out of their data being used for secondary use purposes so that's the important thing to kind of specify, it's not I'd official, it's de-identifiable data. Secondly, it will come in in two years and there's a clear governance process around requests for that information. Insurance companies cannot access that information, that's been called out in the framework from the Department of Health and any requests for information ie medical research will go through a committee that will include consumers on the committee, representatives from a range of different groups in the community and ensure that there is a clear and transparent robust process on why they want to use the information.

In relation to the consumer opting into the secondary use of data if you choose I don't want my information to be used and you change your mind in the future you can then include your information into the future, as Matthew called out around personal choice and control, it's the same with the secondary use framework. We'll be here if there's any other questions we can address those, but I think we need to wrap up for lunch.

**Anne Curtis:** Thank you to James, Christine and Matthew and yes, they will be outside. Hopefully they'll have some lunch first before you get to them but it's a start of a really amazing conversation that we all need to have so thank you very much.
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