

Australian Medical Association Limited

ABN 37 008 426 793

42 Macquarie Street, Barton ACT 2600: PO Box 6090, Kingston ACT 2604
 Telephone: (02) 6270 5400 Facsimile (02) 6270 5499
 Website : <http://www.ama.com.au/>



Transcript: AMA President, Dr Tony Bartone, RN, *Breakfast with Fran Kelly*, Tuesday, 11 September 2018

Subject: My Health Record

FRAN KELLY: Well, the Federal Government's My Health system is back in the spotlight with a Senate inquiry into the database holding its first public hearing today. This comes just weeks after Health Minister Greg Hunt announced new privacy measures to restore public trust in the system.

[Excerpt]

GREG HUNT: No police or government agency will be able to access any records without a court order. That's the existing policy, but the legislation from 2012 under Labor will be strengthened to do that. Secondly, we will also ensure that if somebody seeks to cancel their record, it will be deleted from the system permanently.

[End of excerpt]

FRAN KELLY: Health Minister Greg Hunt speaking last month. But privacy advocates still say that greater protection of personal health information is needed, while private health insurers continue to lobby to get access to the data.

The AMA is appearing at today's public hearing. President of the AMA is Dr Tony Bartone. Dr Tony Bartone, welcome back to *Breakfast*.

TONY BARTONE: Good morning, Fran.

FRAN KELLY: Last month, the AMA said it was now happy with the privacy protections introduced by the Federal Government. So what are you presenting to this inquiry today? What concerns do you have? What more do you think can be done?

TONY BARTONE: The opportunity to present to the inquiry is a time to reflect on the implementation and the communication that's been affected during this opt-out period to stress the need why the opt-out period will assist in the maturation in the take-up of the record, but also to stress that the extra recommendations that we sought at the end of July - in terms of the deletion, the permanent deletion of the record opportunity, the extension to the opt-out period, the need for the warrant to access the records, and the increased communication - are to be implemented in the additional legislation, as well as the implementation.

But the other things that we will be stressing will be around the secondary use of the data, the de-identified data which is governed by really robust requirements and processes. Those processes are set and are, as I say, robust, but are set to be reviewed in 2020.

And what we're going to be also asking for, in addition to what is currently already achieved, is that those processes be enshrined further in perpetuity to allow the Parliament to have the opportunity to ensure that that case remains, the protection of that de-identified data remains ...

FRAN KELLY: [Interrupts] Let's talk about that, because it's a significant issue, I think, for people and their concerns about de-identified; who says it's de-identified, how foolproof is that and when might that be up for change. We've heard again from private health insurers: they are pushing for access to this secondary data from My Health Record. De-identified, that is without people's names attached. So they can use it, they say, to crunch the numbers and develop better services and treatments.

Now the model currently on the table does not give them that access. Do you believe private health insurers should be able to have access to that secondary de-identified data?

TONY BARTONE: Absolutely not. We're very, very happy with the current robust requirements that prevent the access to that de-identified data to private health insurers. We fear that if they were given the opportunity to access that data, they could reverse-identify the data, and that would be a serious threat to the community rating principle that is the cornerstone of equitable policies in the community. So, for many reasons, we do not support the ability of private health insurers to have access to that data.

FRAN KELLY: Has the Government done enough to ensure private health insurers never get access to the data? I mean, as you say, at 2020 this is being reviewed. What happens then?

TONY BARTONE: Well, our recommendation is that we would like to see the secondary use framework given the status of a regulated instrument, so that that ensures Parliamentary scrutiny to any future changes, because we're very happy with the current robust restrictions that prevent the access to private health insurers.

FRAN KELLY: Who does get access to the de-identified data?

TONY BARTONE: So it's accredited and appropriate educational and university bodies; people that will be using that data to benefit the development of health policies for government, for research purposes, to assist better outcomes for the Australian public.

FRAN KELLY: Okay, so there will be access to third parties to that de-identified data?

TONY BARTONE: And there are really strict guidelines to who can and who can't get access, and the people that will have that access need to go through extremely tight, robust processes to access that, and we're very comfortable with the guidelines that have been proposed and are in place.

FRAN KELLY: And it doesn't include private health insurers. And has the Government given you a guarantee it will not and never include public health insurers?

TONY BARTONE: Well, at this stage, on that review in 2020, one of the items up for discussion is the possible review of those guidelines, and we would like to see that that is taken off the table as an agenda item for 2020. And so ...

FRAN KELLY: So no review? To not be reviewable?

TONY BARTONE: In that respect. In the respect of the private health insurers' access to that data. We'd would like to see the framework given the status of a regulated instrument so that any changes have to go before Parliament, and that would give the Parliament the opportunity to see any changes and ensure that the Australian public is protected from that possibility.

FRAN KELLY: What about the actual access to the data itself? Who gets access to that, the frontline data?

TONY BARTONE: The frontline data - let's be very clear about that. There are a couple of steps that you need to access the data, you need to be providing health care to that healthcare recipient. So ...

FRAN KELLY: And what is that- what's the definition of health care?

TONY BARTONE: So providing normal, day-to-day health services. Not enquiries, not research, not any other purposes but the delivery ...

FRAN KELLY: But what's the definition of day-to-day health services? Is it only GPs and specialists? Is it health practitioners? Is it laser clinics? Is it physiotherapists? What is it?

TONY BARTONE: So anyone that- okay so let's just step it out here. Anyone that you give access to that data who is a registered Australian health professional that has a compliance software and a registration to access data in the first place, and plus the ...

FRAN KELLY: [Interrupts] Yeah, I'm just wondering who that is. Who's a registered Australian health professional that has access to the data? What's the definition of that?

TONY BARTONE: So you need to be an AHPRA professional, and you need to also then have a secondary process of being registered as an organisation to access that data. So you need to have an organisational permit to have that; and you need - as a professional - need to be registered to access that data so there's three ...

FRAN KELLY: [Interrupts] I'm sorry to be pushing on this but I'm trying to understand who gets to do that. Is it just GP clinics and hospitals and specialists or is it, as I said, is it laser clinics or is it sports medicine clinics or?

TONY BARTONE: Any of the 14 registered AHPRA organisations governing - which make up the AHPRA - the Australian Health Practitioner Regulatory...

FRAN KELLY: [Interrupts] And what do they include?

TONY BARTONE: So doctors, nurses, pharmacists, physios, and the list goes on, but it certainly doesn't include laser operators or beauty therapists or any people of that ilk.

FRAN KELLY: Okay. But it's quite a lot of people.

TONY BARTONE: And the list is- I'm sorry, I don't have the list in front of me of the 14 ...

FRAN KELLY: No, no. That's fair enough. I'm sorry. I didn't give you warning of this, that's fine.

TONY BARTONE: [Talks over] But they are registered and they are governed by significant legislation as to who those 14 domains are, and they all have their own regulatory body that oversees their registration and regulations.

FRAN KELLY: Is this sort of information- do you think the public needs details on this sort of information in order to restore trust in this list? Because a lot of people go to a health practitioner of some kind and they're asked: do you want to go to My Health, and they're not really sure. But do you think this- we talked earlier about the Government mishandling the narrative - what's that done to the trust and what needs to be done to restore trust, do you think?

TONY BARTONE: And that's an important point. Trust forms the cornerstone of our relationship with our patients. If that trust isn't there, it does circumvent the exchange of information and the confidence.

So we really would- and one of those things we did seek is an extension of the opt-out period, but also a significant ramping up of the communications and the information and education in this, because it is called My Health Record, because it gives the patient the ability to review, reflect, and be in control of their own summary of medical data.

It's not their every piece of medical data that they have in the system, because that's in many different places, be it hospitals, be it GPs, be it pathology or diagnostic imaging results, all over the system.

But it does give them access to their summary of the repository of their information; gives them control; and gives them additional engagement in their health journey; and improves health literacy. All of these things will improve their health journey and their health outcomes.

FRAN KELLY: Can I just ask you finally and briefly because, in terms of restoring trust, is it true as reported that many GPs haven't signed onto My Health or have pulled out of My Health because of all of this? And what does it say? Just briefly.

TONY BARTONE: So you make the point about trust and trust is a very, very important part, and that it really also reflects the fear from some GPs who have been consumed by the negative media reporting and thought: well, you know, this is just something perhaps that I'm just going to wait and see how it pans out.

FRAN KELLY: [Interrupts] It's not much of an ad for it, is it, if some of the doctors themselves don't think it's worth signing on to, or that valuable.

TONY BARTONE: And this is why we're calling for a significant ramping up and robust communication commitment to the Australian public, so everyone can have confidence in the system.

FRAN KELLY: Tony Bartone, thank you very much for joining us.

TONY BARTONE: My pleasure. Thank you.

FRAN KELLY: Dr Tony Bartone is the President of the AMA, appearing at today's Senate Inquiry into My Health Record.

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CONTACT: John Flannery 02 6270 5477 / 0419 494 761
 Maria Hawthorne 02 6270 5478 / 0427 209 753

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