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Transcript: AMA President Dr Tony Bartone, *Kenny on Sunday*, Sky News, Sunday, 22 July 2018

Subject: My Health Record

CHRIS KENNY: Look, sticking with the health scheme, of course, there's been an emerging controversy over the past week about the Government's My Health scheme; this is a scheme where the Government collates all your personal health information in one place. It's been running for a long while but what's brought this into a new focus is the fact that now we're all going to have these records, this little cache of information created on our behalf, unless we opt out over the next three months. A lot of people are opting out; a lot of people are urging others to opt out.

I want to hear from both sides of this debate. We're going to have both sides represented in this little exchange. I'm joined, from Melbourne, by the President of the Australian Medical Association, Dr Tony Bartone - and he's in favour of this Government plan. And against the Government plan - an opter-out, if you like - is the former advisor to then Health Minister, Tony Abbott, way back, and health policy consultant, Terry Barnes. Thank you both for joining us, gentlemen.

TERRY BARNES: Good evening, Chris, thank you.

CHRIS KENNY: Let me go to you first, Tony. It surprised me to learn that there are six million people who already have these My Health accounts. Presumably these are people who have gone out of their way to put up their hand and say, "yes, thanks, I want this electronic record of all my health details".

TONY BARTONE: And that's right, Chris. So, this My Health Record in one way, shape or form, has been in operation now for nearly six years or more. And over that time a number of people have made the positive step of enrolling and becoming part of that system which will allow their records to be summarised and kept on an online portal. The opt-out trials, which were done in two particular districts in 2016, did also then create almost another million files in that exchange. So, basically we've got nearly six million records on the system now.

The more records that we get on the system, of course, that will drive more utility both to the clinicians, and, in terms of other opportunities, to ensure that we have that communication portal between the various health care providers, ensuring more up to date information and more complete synopsis of the patient's record.

CHRIS KENNY: So, the scheme's in place and that's happening, and anybody who wants to be part of it can be part of it. Why should the Government come in, Big Brother style, and say that everybody's going to be a part of it unless they find out about it and opt out?

TONY BARTONE: As I was trying to sort of describe, the more people on the system, the more utility will be in the system. And that's really...

CHRIS KENNY: [Interrupts] But that's my personal information.

TONY BARTONE: But in terms of - it's not so much personal information, it's about ensuring that when you go looking for a record, you know you're going to find a record. And then, the more people that are using the system, the more it becomes second nature. It's more like everybody's doing online banking, whereas before it was "did you have the app" or "did you have the provider at the bank" - now it's just a common day occurrence. And we need to ensure that we've got that kind of robustness in the system to allow that ease of access and that'll facilitate the exchange in an efficient manner, one that also respects and protects the patient's privacy and becomes a second nature in that consultation.

CHRIS KENNY: Terry, what's wrong with this being an opt-out situation now? Surely people should just be able to opt-in. Why is it forced? There must be millions of Australians who right now don't even know that they have the option to actually opt-out.

TERRY BARNES: Well, that's exactly right, Chris. And I think it's important to be able to choose where your information goes. And I think the Government - and I'm not criticising Greg Hunt specifically for this - I think the Government, and actually whoever is in Government for that matter, seem to have this presumption that it's better to err on the side of Government having too much of your personal information rather than too little.

And I think the best - and certainly the Minister himself talks about people having an absolute right to have access to their health records - and I don't disagree with him, but what I do disagree with him on is that the Government doesn't have an absolute right to get hold of them as well. And when it comes to their usefulness and their relevance, I think it's actually important that health practitioners do get access to the information they need to treat you for a given thing. But to have your health records online, open slather, in this very cyber attack tendency world that we now live in- we're talking- it's very timely actually that in Singapore just the other day, a data hack of their equivalent of My Health Record has actually exposed the records of 1.5 million Singaporeans, including the Prime Minister, to cyber attack. And while some of the...

CHRIS KENNY: [Interrupts] But Terry, we've always had health records, there's always been filing cabinets full of them. And for, of course, many years now there's been digital records. What is wrong, what's the problem with someone having access to them, why would we be so worried, especially given that this scheme's supposed to have privacy protections?

TERRY BARNES: Well, look, I think that our personal health records - a record of our illnesses, the drugs we take, the diagnoses that are given - are probably the most intimate personal information that we have. And I, frankly, don't want to sort of just lie back and let Government have open slather on controlling access on it. I want to ensure that my records are actually as private as possible because I do value my privacy.

And look, the other side of it is. given the experience we've had with cyber attacks - and I only have to think of the 2016 Census, I mean they told us that was un-hackable, that was un-attackable and what happened? It was hacked and attacked. There have been data breaches in Medicare; there have been data breaches in the Tax Office. In the UK, even, similar systems in the National Health Service. And, of course, Singapore. I mean, I don't feel particularly confident in trusting Government with my most intimate personal information.

CHRIS KENNY: Tony, this seems to be the problem. How can you trust any agency - including Government - to keep this information secure? And there are downsides - possible

downsides? You might have an HIV background and be worried about potential employers finding out about that or people discriminating against you. Likewise, you might be worried about some of your health records from previous problems counting you out of job opportunities or a life insurance policy you want to get hold of. How can we ever be confident that Government is either not going to be hacked, there's not going to be some sort of illegal breach or also that the Government agencies mightn't either share this information or sell it?

TONY BARTONE: Well, you make a number of points there, Chris, and so let's take them one by one. First of all, you've always got people of ill intent who try to do the wrong thing and try to access records or other information through hacking. And that's always going to exist as a risk. You can make the system so secure that it becomes so inoperable, so unachievable that it becomes of little benefit to anybody. So, it's a balance of the two sides, and you try and strike the right balance that ensures both usefulness and overall security and privacy.

But let's remember, it's called My Health Record for a reason. You, as the patient, will be able to control what goes up there and what stays up there. So, you can - through your interaction with your doctor, the nominated curator - you can say, "no, I don't want that up there", or you can, even later on in the comfort of your own room or study, you can just go on there and completely remove or mask certain bits so that it never becomes visible to anybody. In terms of...

CHRIS KENNY: [Interrupts] Do you have an account, yourself, Tony?

TONY BARTONE: Not as yet because basically I've probably been too inefficient managing my own time...

CHRIS KENNY: [Talks over] You haven't opted-in, you're not one of the six million Australians who's opted-in, you're just going to wait for the Government to do it?

TONY BARTONE: It will be - 15 October, it will be created there and I don't have to do anything...

CHRIS KENNY: [Laughs]

TONY BARTONE: ...So, it's as simple as that. But, Chris, look, we digress. The important thing here is about maintaining that exchange, that usefulness to both the clinician but also remembering that the patient ultimately has control of the system, control of who can see it when. So, in terms of insurers, they're specifically prohibited. If someone who doesn't have an authority to view the system does view the system, there's going to be an audit trail that can be traced back. So, there's so many layers of security built in to the system. You won't stop the most nefarious of operators trying to hack in but, at the end of the day, it's that balance, it's striking that useful utility versus ultimate security and privacy.

CHRIS KENNY: Terry, very briefly, you've opted out, why, what was your greatest fear in terms of being left on that system?

TERRY BARNES: Well, I opted out, and urge you too to opt out, Chris...

CHRIS KENNY: [Interrupts] Yeah, my wife's urging me to opt out as well. I'm trying to come to a landing here.

TERRY BARNES: She actually asked me to put the pressure on you...

CHRIS KENNY: [Laughs]

TERRY BARNES: But look, I think it is data security...

CHRIS KENNY: [Talks over] [Indistinct]

TERRY BARNES: ...I think it is the fact that data can be retained for a heck of a long time. It can be up to 130 years, 130 years from the date you're born. But what really bugs me - and besides the fact that you could lie back and think of England and [indistinct] on 15 October - is that third parties who are not doctors, who are not professionals like Tony, who I respect, can get access to it, and that includes law enforcement agencies, that includes the Tax Office. If you listen to some health insurance CEOs out today, they've been urging people to share their health records with them to help improve their care, but I distrust that as well. Look, I think if third parties weren't able to get access to it, with or without accord or as a Minister says, I'd probably be more comfortable with it.

CHRIS KENNY: Look, we are out of time but just briefly, an issue - one point that I wonder if you both might agree on, and that is don't you think the Government should have done a lot more to tell people in this country that this is happening, to advise us of our rights and to make us aware of this choice? Because it's kind of come out of nowhere over the past week or so. You first, Tony.

TONY BARTONE: Look, we've had a communication campaign for our practices throughout the country basically alluding to the fact that it was coming. But still, all the possible communication that could be done, should have been done in this case. It's a case where for many Australians it has seemed that it's crept up on them, they haven't been aware. And from that point of view, yes, information is always better than finding out about by...

CHRIS KENNY: [Interrupts] Terry.

TERRY BARNES: Yeah, look, we healthy people who don't go to the doctor very often, I mean it came out of the blue and it barely came on the radar last week as a news story, I think the Government and the Minister needed to do a lot more to actually give people a heads up that this was happening.

CHRIS KENNY: Yeah, I think you're spot on there. Thanks so much for joining us. Terry Barnes and Dr Tony Bartone.

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