



Speech

24 May 2018

Agency CEO Tim Kelsey's speech at the National Press Club:

Your health in your hands – the digital evolution of health and care in Australia

Acknowledgement

Thank you for welcoming me here today.

I would like to start by acknowledging the traditional owners of the land – the Ngunnawal people - on which we meet today, acknowledge their elders past, and present.

Collaboration

We are here to celebrate collaboration: between governments, consumers, clinicians, entrepreneurs and all of us, as people and sometimes patients, to make data and technology work better for modern health.

We have a common vision of the power of data to improve healthcare. We are here because we want to do more, and more quickly.

In Australia, harnessing the power of the modern information revolution is now – and resolutely - one of the first priorities for governments: improving the safety and efficiency of healthcare through better use of data and technology.

Australia has one of the best systems in the world – by any measure. We are at the forefront of medical research, we have world-class facilities, and the people that provide care are among the most highly skilled and committed professionals anywhere.

But the hum and whirr of the fax machine in the background of our care services reminds us that there is more to do: paper based healthcare means that clinicians do not always have the right information at the right time to make the best decision.

This has been exemplified all too tragically in a recent coronial inquiry in Melbourne into the death of a civil engineer that found a critical medical test had been sent to the wrong fax number.

Did you know in Australia more people will be hospitalised in a year due to medication misadventure than from car accidents? These errors occur in large part because health professionals don't have access to timely, accurate data about the medical history of their patients – and neither do the patients themselves.

That's one Australia - let me take you to another.

Berrigan

Recently, I had the great pleasure of visiting Berrigan, a rural town with 900 residents in the Riverina region of NSW. Like many rural towns, Berrigan has an ageing population, serviced by a local pharmacy, a small community hospital, a nursing home, and a local GP.

Also, like most community health services in Australia - despite literally being a few hundred meters away from each other - none of these services could securely share patient information between their computers.

So the proud town of Berrigan, with community spirit and the determination of its local clinicians got together to connect the town to the My Health Record so that all its services can now share key clinical information where appropriate, to improve health outcomes.

My Health Record is a consumer controlled, secure, electronic health record that can be accessed anywhere 24/7 by a patient and their care professional.



Every resident in the nursing home and over 60% of the town's population now have a My Health Record. They are using the system to share health information between all the health services in the community.

So as a community, they can care for each other. This is the power of people, rising up to take control of their health information and using safe and secure technology to make a difference.

This is why Michael Gannon, President of the AMA, has described My Health Record as the 'future of medicine'.

I was there on a sunny day a few weeks ago to mark this achievement: all clinical services connected. Two hundred or so local people gathered on the lawn outside the medical centre to celebrate; the local primary school children sang the National Anthem; and for afternoon tea a volunteer at the hospital had baked a special cake – a My Health Record cake – perhaps the first digital health cake in Australia; certainly the first I had seen.

Damien Taylor was standing next to me. He is principal of the Berrigan catholic primary school. He cannot imagine his life without My Health Record. Damien's baby daughter was diagnosed with two holes in her heart when she was born.

'That was the worst day of my life,' he said. She has now had successful surgery and is doing well. My Health Record is now critical for his family – it is the one safe place he keeps all his daughter's complex and lengthy clinical notes so that he can share it with her clinicians. 'It's invaluable,' he said. 'A key part of our lives.'

National Digital Health Strategy

Two years ago, all the governments of Australia decided to bring these benefits to all Australians and established the Australian Digital Health Agency to work in partnership with all in the community to put data and technology to work for patients and citizens and the care professionals who serve them.

Last August the Council of Australian Governments unanimously agreed a new National Digital Health Strategy.

I would like to thank all our partners – in the Commonwealth, states, and territories, among consumer and clinical peak bodies, industry and the community at large - for reaching a new consensus on our collective priorities in digital health.

If I was to crystallise this consensus into important, realistic human outcomes it would be that:

- First, by the end of 2018 Australia will be the first country of its size to provide a mobile My Health Record to every citizen unless they choose to opt out – putting health in the palm of everybody's hand;
- Second, by 2019, it will have provided every registered clinician with a secure means of communicating digitally with their colleagues, without resort to paper or a fax machine;
- Third, by 2022, the first regions in Australia will have connected all care services so that all clinicians in and out of hospital have access to the right information at the right time – seamlessly across all their borders – administrative, organisational, and clinical.

There are other key benefits:

- parents will soon, for example, have access to secure digital baby books and related services – the last Budget announced a significant investment in this program, building on the work of the Children's Digital Health Collaborative which the Agency established in partnership with NSW Health in 2018



- at the other end of life, people will be empowered: individuals can already upload an advance care plan into My Health Record – but this will now become part of more integrated palliative and end of life care management

We called the Strategy: *Safe, seamless and secure: evolving health and care to meet the needs of modern Australia.*

This is not a technology strategy but a human imperative – to improve the health and wellbeing of every person in Australia.

Besides the skill and commitment of its extraordinary clinical workforce – digital technology will be the most important enabler of high quality, sustainable health and care in Australia.

There are three overriding principles the community has told us that will underpin success in modernising health and care:

1. **Participation:** empower people to take more control of their health and care
2. **Collaboration:** co-design services with care professionals and the community – so that they serve real need. Always be evidence-based and always listen
3. **Innovation:** create platforms for industry, developers, entrepreneurs, and researchers so that their creativity and businesses can flourish and health outcomes in Australia benefit.

In July, we will publish the Framework for Action (FFA), which will describe the detailed roadmap for delivery of our shared priorities so that we can collectively be accountable to the people of Australia for their delivery.

I should say now that we are at the start of a journey: the history of technology in healthcare has been mixed.

We must manage our expectations: technology has transformed other industries – airlines, finance – and it will change the experience of healthcare. But this will take time and patience. This is an evolution much more than a revolution.

My Health Record

The first priority of the Strategy is My Health Record -- something simple yet essential in the information age in which we live – an offer to every Australian to take control of their health information whenever they want to and decide who else sees it.

Their care professionals can also access it – meaning that in an emergency, or when you are away from home, a doctor you don't normally see will have instant sight of your medical history, your allergies, your medicines; or if they are supporting you to manage a chronic illness at home, that the same key information is shared between relevant members of the care team.

This means – just to give two examples:

- a reduction in the number of diagnostic tests that are duplicated (some research suggests that this is as high as 14%),
- and a reduction in the number of adverse medication events that cause avoidable admission into hospital (research says this is around 2-3%).

My Health Record means safer, more effective care. My Health Record has the potential to be a global innovation in consumer empowerment in health and wellbeing. Today more than 5.7m Australians have a My Health Record.



In May last year, the Australian government went further – on the overwhelming evidence from two opt out trials – and announced in the Budget that My Health Record would move to an opt-out registration, meaning that every Australian will have a record by the end of 2018 unless they choose not to do so.

We announced last week that the opt-out period will start on July 16 and run for three months. If people want to cancel their record after the end of that period, they can do so at any time – or, of course, they can opt back in if they choose to.

It is essential that everyone is able to make their own decision on participation.

So the Australian Digital Health Agency is implementing a comprehensive communication strategy to inform the Australian public about My Health Record, its security controls and benefits and their rights to opt out – building on learning from the opt out trials, which involved around 1m people.

We are working with many partner organisations across the community to ensure that all Australians are aware of their rights to opt out of My Health Record – and of its benefits. I am very grateful to the support of partners as diverse as the National Farmer’s Federation, the Federation of Ethnic Communities Councils of Australia, and Australia Post in this initiative.

Information will be made available in over 15,000 health care locations including general practices, pharmacies, public and private hospitals, and Aboriginal health Services.

There has been a particular focus in our communications research on developing appropriate support for people with limited digital literacy or access, and other groups including people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal and Torres Strait Islanders, and people living in rural and remote communities.

If you have not opted out, then a My Health Record will be automatically created for you. Once a clinical professional or you activate it, it will start to populate with data – including the last two years of your Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data.

Other information sources will only upload into your record as they happen, for example, when you see a GP or have a blood test. You can upload information yourself at any time, for example, an advance care plan or your emergency contact details.

Over time, your My Health Record will contain copies of your key clinical documents – private and public pathology and radiology reports, discharge summaries from public and private hospitals, information on medicines dispensed in the community and hospital pharmacy, shared health summaries from the GP.

I’d like to thank all our healthcare provider partners for their commitment to improving the quality of clinical content in My Health Record.

Improvements in the availability of clinical content – and in the user design of the service - are being welcomed in the clinical community.

I was sent this email by a leading clinician:

*“I just found this new document on a patient’s MyHR called Medicines View.
A single document with everything I need to know about my patient’s medications, easy to read, easy to download and incredibly useful.
Absolutely brilliant - too good to be true but it is!
Please pass on my thanks to the team who developed it.
Along with pathology and radiology this will be a game changer.”*



That's Dr Danny Byrne, former president of RACGP in South Australia.

We will be introducing a series of ongoing design improvements so that, for example, aged care services will start to be connected across the country and information about implanted medical devices will be uploaded.

The Agency, together with governments, Primary Health Networks and clinical and consumer peaks – including the AMA, RACGP, ACRRM, the National Aboriginal Community Controlled Health Organisation (NACCHO), the College of Nursing, the Pharmacy Guild, PSA, CHF and the Association of Allied Health Professionals and many others - have been working with care professionals for the last six months ensuring they are aware of My Health Record and of the forthcoming opt out period.

There have been more than 900 events across the country and training provided in both online and offline formats.

This month, every registered health practitioner in the country will receive correspondence from their registration authority alerting them to the opt out period and providing them with links to relevant information.

Security and Privacy

I am often asked about the ways in which My Health Record safeguards privacy and manages the threat of cyber crime.

In 2012, the Australian Parliament legislated that the recipient of a My Health Record has a series of rights to safeguard their privacy.

A person can set an access code on their account, for example, and can see a real time audit log of those who have viewed it – and set an SMS or email alert. They can even withhold a document from the view of their clinician. Imagine that you would rather your allied health professional did not need to have knowledge of your mental health condition: My Health Record gives you that control.

My Health Record has a range of protocols, which mean that all instances of access by a clinician are attributable directly to them and recorded in real time.

Unauthorised access — is subject to a custodial prison sentence of up to two years.

Trust is the essence of medicine – digital services can support confidentiality rather than undermine it.

My Health Record operates to the highest cyber security standards and is independently audited on that basis by a number of organisations, including the Australian Signals Directorate.

The Agency has set up a National Cyber Security Centre to ensure constant multi-layered surveillance of My Health Record – and since the system was launched, there has been no breach. Real time vigilance remains our highest priority.

People are quite rightly concerned about the security of their clinical information but they are also concerned about how it might be used beyond their direct clinical care by governments and health researchers.

Two weeks ago, the federal Government released its Framework for this kind of 'secondary use' of data held in the My Health Record system. This followed a public consultation in which there was a widespread



consensus that analysis of clinical data was in the public interest when it helped support public health improvement and clinical research.

The framework defines how data on the My Health Record system can be used for these purposes while preserving privacy and security of data in the system.

From the outset, the Government has ruled out the solely commercial use of this information – for example, by the insurance industry to set premiums.

The Agency has welcomed the decision by Government to allow every person with a My Health Record to choose if they do not want their information to be used for secondary use purposes.

All those with a My Health Record will as a result be able to choose if they want their data shared for research or healthcare improvement by switching on or off a ‘Withdraw Consent’ button in their record.

We don’t expect any data to flow for these analytic purposes for a year or two – as detailed work is undertaken to develop appropriate approvals processes.

Equity

Digital health offers many benefits to improving clinical outcomes. Liz Jackson, an Obstetrician and Gynaecologist practising in Cairns where the opt-out trials took place, reports that: “It has been a game changer because everyone is in it.”

When Professor Jackson’s patients call the hospital, the midwife looks up their most recent updated pregnancy information on My Health Record and plans what services they need. In a potential emergency, it allows for rapid planning of theatre time and staffing.

My Health Record is now the main tool Liz uses for managing pregnancy records between her rooms, the hospital, her patients, and their GPs.

These benefits must, of course, be accessible to all Australians – and that is why we are working so closely with partners in remote and rural Australia and with other communities who may be less familiar with computers or simply not able to access them - so that everybody will be supported to access digital health services, like My Health Record, when they wish to.

I met with an Aboriginal Care worker in Melbourne recently who works providing drug and alcohol rehabilitation services to her local community. She worries deeply about the way in which her clients do not always receive co-ordinated care from the agencies and medical services they encounter because nobody shares information, other than on paper, which the clients lose or forget – and then they don’t get follow up and end up back in rehab.

She has a My Health Record and uses it regularly: ‘For me it is great because I don’t have to explain stuff. I try to explain to my people that rather than having to explain their story or forget stuff, this could be a good option for them. It will be great when we have opt out.’

My Health Record is not the only summary care record system – but it is unprecedented for the way in which it provides the consumer with complete control of their medical information.

The legislators should be applauded: these rights will future proof Australian health care. It is one of the reasons why Australia is widely regarded as a global leader in digital health.

And in that capacity, Australia recently initiated and took on chairmanship of a new international initiative called the Global Digital Health Partnership involving 16 countries and the World Health Organisation.



The more we can learn from other countries, the faster we will be able to realise the benefits of digital health for Australians.

Conclusion

Last week one of my team was setting up for a presentation on the My Health Record in a hotel. A hotel employee managing the AV equipment noticed the My Health Record logo scrolling across our laptop and said – “I just signed up for one of those”.

His employer had sent him information about the My Health Record. That night, his family signed up to My Health Record and he and his wife have already used it to manage his children’s vaccinations. He’s just getting on with it. Like many other people.

Let’s imagine every town and city in Australia just like the pioneering community of Berrigan. Sources of innovation and energy – putting technology to work for better health and care.

I think every Australian should be very proud that their Government, with the support of the whole Parliament, has backed the power of people and technology to improve our health system.

Of course, some people will be apprehensive about My Health Record – the move to a digitally empowered health service. But let’s reflect on the status quo: I saw a GP right at the start of my work with the Agency who showed me a single paper record of a new patient that he was treating that was literally three foot high – and he was taking it home that night to try and identify the key clinical data.

Paper based healthcare is not just inconvenient and threatening for people who have to remember their history in the Emergency room when they are at their most vulnerable – how many times have I heard that - it is also dangerous.

My Health Record is a part of the solution – it is not everything; it will not solve all the information challenges of modern Australian healthcare but it is an important step forward on our collective journey, one of the digital health basics.

The story of technology in healthcare over the last 10 years has not always been a good one – but it is the fastest growing social investment in most countries in the world, probably the most innovative, and – from the perspective of our children, let alone ourselves – perhaps the most important.

Artificial Intelligence, Machine Learning, Genomics – new technologies will change our world quickly but they will only flourish if the digital basics are in place in our health services. If the world is full of faxes, it will not be full of precision medicines.

My message is: let’s get the digital basics right. We have the momentum; we have a consensus on our priorities for action. Let’s get this job done - as a community – government, industry, clinicians, and citizens.

This is a clinical, and economic – but above all human - imperative.

Thank you for inviting me here today.