Speaker	Dr David Glance
Talk title	From health benefit to hazard. Where My Health Record went wrong.
Venue	The Stables Bar
Time	Tuesday 29 October 2019, 5:30pm

Anthony Fortina

Good Evening everyone.

You can start taking your seats please, we will be starting in about two minutes.

Good Evening, everyone, my name is Anthony Fortina and I represent UWA as your MC tonight.

I have been given the speech and I going to be a little bit Trumpesc and move away from the speech.

We started Raising the Bar Perth last year for the first time. We did ten bars and ten speakers, this year we have upped the ante and we are doing ten bars again, but twenty-two speakers so we can try and cram them all in. We will see how we go.

It was such a success last year that we thought we would give it a go again and people like you come to these events and make these events a success.

So, I hope you enjoy your dinner and your drinks and let's get into it.

The first thing I need to do is acknowledge the Whadjuk Noongar people as the traditional owners of the lands and the waters where we are meeting today and to pay our respects to their elders, past, present, and emerging.

At UWA, we are excited to make education a part of our cities popular culture and we want to do through coming into the city and in this particular instance transforming bars into learning spaces where you can enjoy a drink but also enjoy the impact of the research that we conduct at UWA. We do our events on campus but it's nice to get out every now and again. And the other thing, the difference from last year, I see so many faces I recognise, so welcome, everyone.

I have also been asked to make a particular mention of our UWA 2030 vision for the next decade, it is quite a big thing for the University and a significant part of that vision, is our focus on tackling the grand challenges for the wicked problems that face our societies and our environment.

Last few points, if you are wanting to use social media to help us advertise these events, the hashtag #rtbperth19 if you would like to use that hashtag and then obviously if put @UWAresearch we will be retweeting everything that you put on there.

The last point I have been asked to make is tonight's talks are being recorded and will be published as podcasts on our social media channels.

Okay, without further ado, Dr David Glance, who to many of you won't need much of an introduction but I am going to go through it anyway.

Dr David Glance is a director of the UWA Centre for Software Practice, a research and development centre. Dr Glance worked in the finance and software industry for over 20 years at companies such as the Royal Bank of Scotland, HSBC, Microsoft, Tibco and IONA Technologies before spending the last 18 years at UWA, some of these years, I have shared with him.

The UWA CSP provides training and research opportunities for students and has developed commercial software in the health and education sectors that are being used across Australia in hospitals, GP clinics and aboriginal medical services.

So, please welcome Dr David Glance.

[clapping]

Dr David Glance

Thank you very much and because Anthony has introduced me already before I start, I would just like to get a sense of who we have in the room.

How many people opted out of My Health Record?

How many people didn't know they had a My Health Record?

Any GP's in the room? That Okay, we will respect your privacy, unlike My Health Record. [laughing]

I promise I am going to try and be balanced about tonight. I know that we used a quite dramatic clickbaity for the talk, it was toned down by the marketing people, in fact, they were offering to re-write the talk in its entirety which I was almost prepared to do.

There are positive things about My Health Record and I want to emphasise those, there certainly was a potential and that's something that hopefully I will cover in the talk.

I hoping that I will leave some time at the end for questions or even comments from the audience, I have already been contacted by a couple of people relating their personal experiences with My Health Record and so I think these things are valuable to share.

So, as Anthony mentioned and I am using the English pronunciation of Anthony, so I am probably mispronouncing his name.

My original PhD was in Physiology, I did that at the Royal Post Graduate Medical School at the time, it is now Imperial College and then going into computing for a variety of commercial companies,

before coming to UWA, where thankfully, I was offered this opportunity of combining my interests in health and healthcare with computing and I am going to talk about this project and this is another conflict of interest that I have.

I have several, I am not an unbiased speaker, so that is important to remember, it's like when you listen to these shows, do not buy or any stocks or shares, because we may have in the stocks and shares that we talk about and in this case, my centre and UWA were heavily involved in a clinical system that is in use across the country, that did offer a particular vision of sharing clinical information but that sadly wasn't the model that was adopted by the Government. So I have, number one, that vested interest.

My research though has been based in the areas of *Health Infomatics*. I have done a lot of consulting with the OECD on eHealth strategies for countries, so in that process, I have actually looked at shared health systems from around the world, which ones worked, which ones didn't and we tried to develop, essentially a benchmarking to see how we could evaluate these systems and also, at the same time, avoid the pitfalls of around privacy, about negligence, about medical mistakes and errors, so sorts of things.

I have a fair awareness of how E-Systems have worked in other countries and I will talk about that.

Before My Health Record, I just wanted to give you a little bit of a background and this is the liberal party who introduced this, there was a scheme that the governments came up with called Managed Health Networks and WA was fortunate in this regard, because we were given a lot of money to do a couple of them.

One of them was in the Goldfields, so basically Kalgoorlie and that was to implement a system that would allow for electronic health records but also sharing of information and Gold Health, as it was called, was quite a good example of where Government money went and a system of sharing information between, GP's, the hospitals, health care professionals generally, was put into effect and they implemented one of the very first shared health records via a company called Extensor which is based in Queensland. Again, reasonably successful. I got involved through UWA with a project through the Great Southern GP Network in Albany and this was based on money that the Government provided through the Department of Health and Ageing and it was a substantial amount of money, $4 million and we built a clinical system.

We built this system, it was web-based, but it was in conjunction with the Aboriginal Medical Services in the Kimberley, in fact, there are several people in the room who were in involved in that project, a couple of former people in the team and in fact, Anthony was a guiding light in all of this process as well, so a conflict of interest here.

So, we developed the system, it was called MMX, it's still available today and basically, because it was web-based, the Aboriginal Community Controlled Health Services that were using the system in the Kimberley and this is the one system that they use across the whole Kimberley for most of the

Indigenous patients up there, was able to be shared. We built with that explicit idea in mind, so, essentially a patient that was being treated in a clinic, going into a hospital, was able to be … basically, the doctors in the hospital were able to look at their clinical record and see everything about that patient but if they updated the record in the hospital, that record was immediately updated to the clinic as well.

That's an enormous benefit and we will see where My Health Record and Shared Health Records generally deviate from that process. When you have a single authoritative record, then it helps reduce errors, it helps reduce the fact that you are only getting a particular view of the record and a few other things.

The system that we developed has now been commercialised, so I have personally gained out of it, the University has gained out of it, so conflict number two or three, I have lost count now, in fact, I am so biased, you should really stop listening at this point.

It has been commercialised, we have somebody from the company that has now taken it over, it is used throughout Australia and actually, in Northern Queensland, it is going into all of the hospitals and clinics and even into the prisons.

In the part, the success was based on this premise that they could share records. A very good example is the Institute of Urban Indigenous Health in Brisbane, where they have used this as a pro-active health care measure.

The good thing about the platform and UWA's role in it, that it was very heavily researched-based, so we had research projects that were based on this platform. We consented to patients as they came through, we had Privacy by Design built-in, there were a whole range of different things that were put in place.

In WA, the Department Health WA bought the system and it does a range of things from, well in the past it has been involved in administrative Patient & Assisted Transportation through to a Cancer Registry to Wings West because not only was it shareable because it was web-based but we were able to do Telehealth and Remote Medicine based on this. So, we have done projects with the Lions Eye Project with Lions Eye Institute, with a whole range of other parties.

One of the things that, once we had finished this project, was that it was written up and this is how I got involved with the OECD as an exemplar of eHealth projects around the world that where government money had actually resulted in something successful and in that process, we actually looked at the problems and issues that were involved in sharing clinical information.

It wasn't all plain sailing. An immediate problem was the fact that the Aboriginal Community Controlled Health services are run by the communities. The WACS, the WA Country Health Service who run the hospitals is State Government organisation and there were immediately conflicts about who owns the record, who owns the information involved. If somebody changed something in a

hospital that the Community Health Services didn't agree with or contravened their processes and protocols, that raised issues as well.

It was by no means a straight forward, "we have this system, it's going to bring these benefits."

The other important thing about it was that gathering evidence and we will see that this is very important when looking at something like My Health Record, was difficult. It's very hard to actually test electronic health systems for their effectiveness and so, everybody resorts to anecdotes and I have plenty of them. We have anecdotes that the doctor shared about a patient coming in, in a coma into ER and they were able to look at their record that they have been prescribed a drug the previous day, that reacted negatively with another drug and that was cause of it, they were able to then treat that patient as a result of it. And you will hear these anecdotes given for My Health … for justifying My Health Record.

You have to be a little bit careful because they're emotive, they are certainly compelling but they don't constitute scientific evidence that this system is effective or that the costs involved for the people that it's potentially bringing benefit to are justified.

One of the … there was a number of benefits of this system that, basically, as I said, an authoritative single source of information so that reduced errors, it was a very effective platform for communication, in fact we ran the system where you could do electronic referrals from, the Royal Perth, for example to rural practices and a whole range of different things that the benefits had. It had a fully, electronic medical record and that was very important.

In the Kimberley, we have one of the few examples in the world of an entirely electronic medication system. From ordering drugs to handling scripts to the dispensing of those drugs in these remote areas, so lots of benefits.

Ironically, it was the Government, who recognised this, so that when the personally controlled Electronic Health Record, which was the name that was originally given to My Health Record, was … came into existence.

There was a launch of that system in Melbourne and at that launch, the showed various films, showing the potential for this record and they filmed one of the clinics that was used, saying MMX our clinical system which was at Beagle Bay in the Kimberley.

There was a slight irony in this, that you will later come to hear about because they were actually showing the benefits through a record that was developed in WA and when they launched the PCHR or MY Health Record, there was a wave of pilot studies and WA was essentially not included in any of those studies, despite the fact that at the time we got together with the Department of Health WA, with the Royal Flying Doctor Service with the Aboriginal Community Controlled Health Services, with pretty much everybody in WA and said, "Yes, we would like to run a trial for this Record."

One of the things about PCHR was that the context of it was this was at the time of Kevin Rudd, the Labor Government, it was one of his grand ideas, so you have got to put this into context, this was along with Pink Batts, with one laptop per child.

My daughter is here in the room and I remember her carrying this three-kilogram laptop off to school every day. It sat on the desk and she brought it home.

These were grand gestures, there was a reason for them, but it wasn't like this was a particularly evidence-based idea of producing a system.

So, PCHR came out of that, the original budget was about eight hundred to nine hundred million dollars and it was launched in around 2011 to 2012 and in 2015, it got rebranded as My Health Record.

As part of that process, there was some legislation that came into effect. There was the My Health Record Act, which renamed from the personally controlled PCHR Act and that brought around, some more legislation around things like Health Identifiers.

Does anybody know this thirty-two digit Health Identifier?

There was a long history of the fact that we had our Medicare ID's and they were not able to be used to identify patients, they were simply being used for billing purposes and that's the only thing that you could use them for, because the public and the Government were paranoid about it being labelled as an identifier to track people to be the essentially the Australia Card.

The legislation came in with the PCH that allowed a Health Identifier.

This is a good thing, because, to date, when you go and have pathology or radiology done, the way that you identified to a GP practice is by your name, your date of birth and your address and all sorts of errors happen, as a consequence of that.

It becomes a string, text matching problem.

With the Health Identifier, if everybody is using it properly which we are still not using it, then potentially you can reduce those sorts of errors.

So, that legislation came into effect.

The original legislation was problematic for My Heath Record. It had some things that people got quite upset about. It was an opt-in system, so there were low rates of adoption. That was problem number one. The second problem was that basically, children or young adults or young teenagers between fourteen and eighteen had their parents as being the authorised representative on their Record, so basically if you were a fifteen year old and you had gone to see your GP about your mental health issues or issues about sexuality or gender, potentially your parents could just look in your Record and find out. They had no control.

There were other problems. There were problems about the potential of abusive partners and other family members, to get access to records and to be notified about a child. So if the father was still on the record and being responsible for a child, the mother had gone with the child to live elsewhere, then the father could potentially track them down through My Health Record and that was another issue.

So, lots of problems, the main one being that they spent a billion dollars and nobody was using the system.

It wasn't just patients, it was hospitals, GP's, everybody.

So, they then thought, "Let's change it, let's change it to 'Opt-Out'."

This is a sensible idea, we know from things like organ donation that if you change from "Opt-In" to "Opt-Out" the adoption is pretty much close to 100%.

They had to change the legislation, they changed the name to get away from PCHR, the went to My Health Record and they changed things. There were various amendments by various political parties that they essentially argued against. Teenagers having to have their parents on, so they changed that, so now, if you are between the ages of fourteen and eighteen, you are the representative, you can basically contact the System Operator as it's called, officially called and you can say, "I want my parents or some other person to be the authorisation person on this record," but it's basically an "Opt-In" for that and if they have put in some protections against the scenarios for potentially abusive partners, notifications don't happen.

The important thing was the "Opt-Out" part and so, we were all given the opportunity to "Opt-Out" and out of the twenty-five million people in Australia, about 10% have opted out, two and a half million.

Now, that's a big problem, because it means that every person that walks in through the door, is basically, you have a one in ten chance of them not having a record, so if you rely on that information then that's going to be a particular issue, already.

My Health Record came into existence, it became an "Opt-Out" system but what is it exactly.

The idea is that they thought that they would … you couldn't really have a completely blank record when you signed in, so they thought, "What can we populate it with?" So, they took Medicare data.

Now, every time you go to see your GP or a specialist and you make a Medicare claim, that is recorded by Medicare. Every time a script is issued, that's recorded by the Pharmaceuticals Benefits Scheme. So there is PBS and MBS as it's called, Medicare Benefits Scheme data that records, basically, that you went to an appointment, it was this type of appointment and it was with this doctor and that information was all sucked in and pre-populates your record.

Now, they are increasing it. In fact, just recently, there are pathology and radiology results that are going in there.

There is information about scripts, so when you go to the pharmacy and you essentially get a medication dispensed, that information can go into your Record.

Then, you can go into your GP and you can ask, or they will do it, potentially automatically, to have a Shared Health Summary put on.

What's in that Summary is up to the GP and in part to you.

It's a bit complicated but essentially there are things like your current medications, your medical history, current medical condition and other relevant information.

GP's have been incentivised to essentially do this, because it is quite an overhead and we will go into a little about what the AMA, the Medical Association, the Royal College of GP's have to say about this, because bear in mind that the average GP session is around about seven minutes and that's just coming in, listening to you, already interacting with our system and putting all of this information and so, actually having the burden of putting up a Record, which the GP themselves, don't benefit from, GP's are the one person who has the most information about your healthcare. They act, in this country, as essentially the single authoritative source of your medical information.

There are problems when you start seeing specialists as well and we will see that's an issue with My Health Record but the GP has the curated, essentially, if you want a particular view of what your problems are, your history, it's you GP that will know.

You are asking the GP to do a lot of work to actually put up a Record that will benefit, not the GP but potentially you, in a situation that may or may not happen ad so, that, in terms of benefits and costs, you are asking the GP's to wear the costs for potential benefits to other people.

Now, of course, they care about your health and they don't want you to die from something that's preventable if there is a Record, so they will do that.

GP's generally don't do anything unless they are paid for it and so there is a ... what's called a Practice Incentive Payment and in this particular case, it's called an ePractice Incentive Payment or an ePIP and the ePIP has been used to incentivise GP' to get Clinical Record Systems, Electronic Systems to send messages to various people electronically to do a variety of things. So, the incentivised, they are paid, depending on how many patients they have in the Practice to actually send Shared Health Summaries up to the "Cloud" to My Health Record.

It's quite a lot of money but they only have to do twenty-five of those, every claiming period. So, it's a tiny, tiny responsibility forgiven the number of patients that they see and they can fulfil that pretty easily without having any impact necessarily, on the system. And it's only GP's that get incentivised, so specialists don't, your Allied Health Professionals don't, nurses don't, any of the community

health workers or community services that you might use, don't get incentivised either. They have to bear all the cost.

It's worth also bearing in mind that when you think about My Health Record and you have got this Record, it may or may not have information with it, but it is shared and potentially accessible with close to a million people in Australia.

Just think about that. One million people in Australia have access to your Health Record.

That is very different from your GP and potentially the administrators in a practice having access to your Health Record.

When there are a million people and you are trying to guarantee that your access has been, your Record has been accessed appropriately, it becomes very, very difficult.

There are safeguards that have been put in place around this, but there are a lot of problems with that.

Some other stats, there are about sixteen and a half thousand healthcare organisations, so seven thousand GP practices, about five thousand pharmacies and the lowest state participation in My Health Record, anybody care to guess where that is?

If you have seen Utopia, you know the answer to this.

Canberra! And why is Canberra the lowest participation because they know all about the problems and in fact, there is an episode of Utopia that I strongly urge you to watch it, where they stop a project by saying, "Let's share the record with … we will start with the politicians first" and then they quickly scrap the record.

In Practice, the system has gone live, there are a lot of … the information that has been provided. Once the system went live, as I mentioned previously, the Government decided … The Department of Health and Ageing decided to fund some "test beds" and this was to test whether they should move to an "Opt-Out" system and also to gather evidence.

It is important to note that when they gathering evidence, they only wanted to gather positive evidence. They didn't want to know if it didn't work, how effective it was, they just wanted to get evidence to say, "It's effective." Because no Government, Liberal or Labour has deviated from this, despite the cost and we are now out about two billion dollars that has been spent on this system.

So, there were "test beds" that were set up, as I said, WA was excluded from that process and you will find that most of the activity around My Health Record is where those "test beds" were set up. Money was given to people, to companies to essentially put this into practice to get it working and to produce case studies that justified its use.

When you look at participation from things like pathology providers, from radiology, from private hospitals, you see that it's more prevalent in the areas where there were "test beds" and they were paid to do this, than in areas like WA.

One of the principal problems of My Health Record is that GP's are fully electronic and that was a process of incentives and Government policy dating back twenty to thirty years. But hospitals aren't, so even with our new hospitals in WA with Fiona Stanley and The Perth Children's Hospital, they have the opportunity of putting a fully electronic health record in, they went for a compromise and in fact the build Fiona Stanley without the facility to store paper records and then, as they decided to backtrack from having a fully electronic health record, they went into a panic about, what the hell they were going to do with all the paper records.

So, the implemented a system which was essentially a compromise.

It was scanned paper. So, PDF's that were launched and a lot of the benefits of electronic health records, structured data, things that you can do analytics on and decision support disappeared and essentially doctors then get into the situation where they are just trolling through, essentially PDF's which are not necessarily searchable, which have all of these … they may be scanned, so low quality … all of these problems that occur as a result.

They can't [inaudible 33:57] that information in and so what the hospitals do with My Health Record, is that they have access in the Emergency Departments to read the records, potentially, but they contribute by the way of Discharge Summaries.

So, every time you go into a hospital and as you come out, a junior doctor, usually one of our medical students or a medical student or an intern will be charged with writing up a summary of what you did in the hospital and that will be sent to My Health Record. So there are Discharge Summaries in there but an awful lot of information about what happened in the hospital, how you were treated, any problems is lost in that process. It is just a summary again.

GP's don't tend to use Discharge Summaries very much. There has been lots of research looking at that. What they want is essentially a handover from the GP at the hospital to say this is what we have prescribed them, this is how we want you to essentially treat the patient going forward.

That's problem number one, that hospitals in this State and most of Australia are not using the Electronic Health Record System. They can't take data from My Health Record directly. They can view it but it's very passive.

The other aspect is Specialists. If you have been to a Specialist recently, you will see that they do have systems, but they mainly use it for billing and booking appointments, they, on the whole, do not use it, in the same way, GP's use it.

[comment from the audience]

Really? [laughing] Okay.

I knew this was going to happen, so they are not electronic?

We get to My Health Record, we get this information then the benefits are clear that if you have information that is being collected that you can potentially use it for secondary health use. You can use it for research and as researchers we have linked data, we could use it along with machine learning, AI, big data, all of these techniques to essentially do things like manage health care better, more efficiently, you are going to come up with new treatments and a whole range of different things.

That's the potential benefit.

There are some benefits about having access to this information and certainly, the Digital Health Authority who have a responsibility for My Health Record will say, "that people's lives have been saved because they have turned up at a hospital and have been prescribed a medication and you then know what the problem is."

Those things are true.

What we don't have is any particularly clear scientific evidence of any other benefits and when you look at what benefits they are looking at, they are looking at mostly administrative ones.

They are looking at things like reducing duplication of pathology and radiology which is great for the Government, they don't want to spend money needlessly.

Not so much of a problem for the patient or for doctors.

Medication errors and here I would contest that actually in our practice and in our experience, that electronic health records, generally, cause just different errors to the ones that they solve.

So, you don't get rid of the errors, you essentially just transfer them to a different place.

There are records, they are information and the problem … the main problems that occur with My Health Record is that it is based on this premise that everybody has an electronic health system that can basically provide information into the Record and consume it, and that's not the case in Australia.

It is also based on the premise that everybody is health literate and when they talk about the fact that they were expecting a 10% attrition rate, what they failed to mention is that … is 10% of the overall population. They don't mention how many people actually know about My Health Record.

Just as I was walking out the door of the University, I asked somebody, one of my colleagues, "Do you have a My Health Record?" He said, "I don't know."

So, this is, for an educated person, the fact that they don't have any interest.

There was estimates around about the fact that 60% of people in Australia knew who should know, did know about the My Health Record so if 10% of the entire population then "Opted Out" that's a much larger number, so we are essentially using a system where there is still a high degree of the lack of knowledge about this system.

The problem with that is, that being "Opt-Out" we have never consented. We have never given informed consent about this being part of this system.

All sorts of information can go into that record and that can include information that may not explicitly say that you have a mental health issue or that you have had problems or you have had a sexually transmittable disease or anything like that, that you don't want to share but that information will be there nonetheless.

If you do not know about the record, you do not have health literacy or even literacy generally, then the most disadvantaged population is the most at risk, are the ones that potentially, are going to have their privacy abused.

There is another issue which is the secondary use of data and we have seen this with Facebook but our Government is quite keen on third-parties getting access to our records. The My Health Records Act does stipulate that insurance providers are not supposed to access this information, so they can't give it to insurance providers. They can, to insurance providers for GP's for indemnity purposes, so they do have access to the records, but the insurers can come to you and say, "Give us access to your Record and if you do, we will reduce your premiums." When they have got information at that access then you have no control over what then happens to it.

There are protections, there's Court, fines and there is potential prison sentences but with one million people having access, hackers in … and I won't name any countries that have an interest in exploiting this … and remember My Health Records are the number one things that get hacked.

Singapore has had all its Records hacked. The US ransomware attacks. All of these things.

This is a potential "front-page headlines" waiting to happen.

They keep saying, "Well we have got security and ....." but given that, it's not necessarily the fact that you have to be particularly sophisticated to get into these Records.

We are running out of time and this is something that could go on for a long time.

There are benefits to this system.

There are a range of problems and the thing that we lack is concrete evidence.

Just as an aside, just to think that we are not alone in this, the US has spent USD$50 billion since Obama's time on trying to introduce Electronic Health Records and it is then essentially a bit of a disaster.

The average GP has to click four thousand times in a session in the Emergency Department, that being attributed for the burn out of doctors and GP's.

It hasn't led to any significant decrease in errors, in fact, errors have gone up as a consequence and because they all use disparate systems, it hasn't necessarily succeeded.

Where the systems do succeed is when you have a centralised single record.

Some of the Scandinavian countries, who do everything well, especially when it comes to social policy, and so that makes sense, that's not the case in Australia.

What is sort of, puzzling with all of this and what I don't know is why Governments seem absolutely intent on carrying on with this system, whatever the cost.

That may change when we see a breach of significant proportions, which is really largely inevitable.

Anyway, I am going to have to end there because Anthony is giving me glares.

Thank you very much for listening.

[clapping]

Anthony Fortina

You did that without prompting, well done!

I just didn't want us to eat into question time, which we have done, so we have got about fifteen minutes for questions, so please stick up your hands and I will come to you with the mic and you can ask a question unless you can shout?

First one I saw.

Audience

Thank you.

I just wanted to clarify something you mentioned about the hospitals and My Health. So, they are able to access that information in all hospitals in Western Australia, or they can't?

Dr David Glance

Public hospitals have signed up to it and they can access the Record. What I didn't mention is that the original name was "Personally Controlled Electronic Health Record" which means that individuals can go in there and they can basically deny access to any and all clinicians. They can also go in and amend and edit information and I haven't talked about the general liabilities that doctors face, so if you have any friends that are GP's or doctors, there is a medical-legal cases just waiting to happen around this but yes, they have a "read" access.

They contribute to information through the Discharge Summaries and they potentially have access.

Audience

Thank you.

Audience

Brilliant presentation.

I just want to jump on the comment you made at the end there, where you said that Governments continue to want to throw money at this regardless of cost. Reading between the lines does that mean you would recommend a different system [inaudible 44:28] [laughing]?

Dr David Glance

And then again, I just happen to have one with me actually, I prepared earlier! [laughing]

Yes, interestingly … I think that, regardless of what I think, there were better ways of spending the money and I think that actually getting the hospitals better equipped to use electronic systems would probably have been my starting point. I think that there were a number of projects in Australia at the time that this came in. I didn't mention the Northern Territory, for example, which has its Shared Health System as well that was in place and essentially a small enough area of population and that was working effectively.

We have these systems and rather than a centralised Government system, it probably would have been better to have essentially funded a number of different systems that were more focused at the State or even Regional level and allowed more control at that level, than spending all of this money on a centralised system.

What we have seen with the Digital Health Authority, which is a little bit like the NBA, Nation Building Australia in Utopia and it as called something different as well. They went through a rebranding and various people associated with it, learned that they have so much of a vested interest in keeping this going, producing evidence that basically supports their argument and not denies that they will keep going as long as it takes, so I don't know what the upper limit is, there are probably better of spending that money.

Anthony Fortina

Questions down the back?

Audience

Thank you very much for your presentation.

I realise my question is going to ask you to hypothesise to some extent but from within the industry there is a big push for access to My Health Records from an aged care perspective, which in a lot of ways could be beneficial but how would see that playing out in the current My Health Record world.

Dr David Glance

In aged care?

Audience

Yes, aged care.

Dr David Glance

There are residential aged care facilities that are using My Health Record and there was an argument as well, as I said in Queensland and we were going to do this in WA in the prison system as well.

The big problem in prisons is that prisoners come in, they are treated by a health service that the prison service provides and then when they go out, they don't have access to any of the information that was in the prison as such, should really have been shared.

In aged residential facilities, that is certainly the case that there is a benefit because one of the biggest problems is residents going into hospital. When they are discharged, then there is a continuity of care problem there, and so, having that information shared is important.

The thing is though, is that there are a number of different ways of actually tackling this and then the essence of that is the problem of handover and sharing of proper new structured information.

That can be handled in a number of different ways, it doesn't have to have a Shared Health System to do that.

Ultimately what you are trying to do is, essentially give the person that's taking over the care, some explicit instructions.

So, there are all sorts of other things that you can do with co-ordinating care, dare I say it, blockchain and new technologies that come in, that could potentially have been used and I came up with this idea of using blockchain as a way of patients being able to dictate who could access information for a period of time and discovered that IBM had already patented this, ten years ago and so that wasn't going to be my next "get rich scheme" [laughing] so, all claimed to fame.

Ultimately, yes, there are scenarios that, where this potentially could help across the board in healthcare, it just doesn't have to be done in this way.

Anthony Fortina

I must confess David, that I am one of those people that just hasn't quite got around to looking at My Health Record.

I would be curious to know, this is obviously a completely different audience, people who understand the issues around privacy etc., etc.

I would be interested in a show of hands, who actually has gone into My Health Record.

Okay, that's pretty good.

Dr David Glance

Did anybody adjust the privacy settings?

A few people!

Anthony Fortina

It certainly made me realise that I need to go in and adjust my privacy settings.

Any other questions?

Audience

GDPR, would that be a solution?

Dr David Glance

There are two bits of legislation and I have to say, I am not a lawyer and I have been involved in these discussions, both at the Federal level and at the State level to bring into effect legislation that would essentially make it easier and have laws around the sharing of data and that includes health data.

One of the biggest challenges that we have as researchers in the research community is getting access to linked data.

WA has had unique legislation for a long time, that allows the collection of, pretty much every bit of information that you may have in hospitals and that has provided a very rich data source, that we can get in the de-identified form, but it takes a very long time to do that.

We went to the Attorney General, the Universities, this is. So, essentially UWA and all the other universities and health institutes and the Department of Health, signed a letter to the Attorney General asking that the legislation that they were thinking of bringing in in WA should match GDPR.

GDPR is the General Data Protection Regulation and its privacy law that has come into effect in Europe is generally acknowledged essentially.

The leading example of privacy legislation, are the Europeans and not just Scandinavians this time. Basically, have got strong protections for the individual about how you can use data and what it can be used for and what protections you have to get rid of it.

Yes GDPR would a part of that.

The legislation they are planning for, would be potentially an answer and there is in the My Health Records Act, there are protections, that's clear, so you can be sent to jail for five years for illegally accessing somebodies record and whether that actually happens, we haven't seen the case law that is going to back that up or put it into Court because we don't know potentially what the defences are or how the law is going to come into effect.

But, Privacy Law in Australia, not so good.

And that's the next talk, by the way, I don't know if you are staying for that and Julia is far more knowledgeable about these things, those I would raise those questions is you are with her.

Audience

So can you Opt-Out at any stage or have we missed that opportunity?

Dr David Glance

No, you can Opt-Out and one of the other things about the Act that was changed was the fact that, again through politicians bringing in amendments that your Record will be deleted and that was the thing that if you don't delete you Record it will stay in existence up until thirty years after your death so that may or may not be a good thing.

If they don't essentially have a date of birth, then it will be when you are 130 years old. How they are working that I don't know?

So, yes, it will be deleted so you can Opt-Out at any stage.

Anthony Fortina

Any more questions?

Alright, I am getting confused.

Audience

From a public policy perspective, what went wrong? [laughing]

Dr David Glance

Well, I think Kevin Rudd was probably partly responsible. I think we are going to be paying for my daughter's chiropractic bills into the future from the laptops!

I think again, with health and with IT generally, Governments really find it hard to understand and I think that this is potentially something that they can argue, eventually will be a benefit and so they are pushing it all the time.

As I said there is … what's needed really and I would be the first to agree, if they can get some scientific evidence and when I had this argument with the GP on radio, in fact, the GP who was responsible at the Digital Health Authority for spruiking this, and she said, "I said, you said" type of argument where … it was very Trumpian, it's you said there was … I said there was no evidence of support, she said, "Yes there was!" and actually I would qualify my response, there is evidence that says, "If you have a patient record that you can do things, like, increase medical adherence, so medication adherence. You can improve the level at which people will take their drugs. There is motivational and engagement issues if there is a patient record but they are for systems that don't equate to the system that we have got."

It's a bit of a stretch to take research that has been done and apply it as evidence first.

What we need is proper scientific evidence that really means randomising controlled trials and we are not necessarily going to see that.

From a policy level, that's what I would be asking to fund.

Anthony Fortina

So we need to start winding it up. If there are any more questions we can get one or two last questions in?

Audience

Sorry if you have already answered this but I keep coming back to your thing about there is a million people who can access this Record and the hacking of this Record, but you obviously think that some electronic records are really valuable and have very valuable information, but wouldn't all records susceptible to hacking and if you are sharing information, aren't you always going to have quite a large pool of people in the medical system who can access it?

Dr David Glance

Absolutely, yes.

I can give another talk about cybersecurity and how many times everybody has been hacked in this room but if you want to go, there are plenty of websites you can put your email address in … there is a site called "Have you been pwned?" My data has been breached about seventeen times, so far.

Systems like Adobe etc.

A year or so ago, there was an incident where Medicare details were being sold on the "dark web". If I want 100 points of ID I can spend $30 to get anybody's ID in this room. I can set up a bank account

with those 100 points of data which will be a perfectly replicated version of your Medicare Card, your Driving Licence and with that, I can get access to other information.

The fact that there are a million people who have access to this Record, means that I don't have to do anything, I just have to essentially get details, their log on details, get into a GP system and essentially retrieve that information.

The Medicare system detected that there was unusual activity or you as a patient went into your Record and reviewed, because I know that's what you do every night [laughing] and see who has actually accessed your information, then potentially you could report it and say, "this is somebody I don't know who has done this?"

People have done this, they have gone into their Records after a hospital visit and seen that twenty-four different people accessed that Record but that's a long stretch from proving that one of them wasn't a hacker in a hoodie in a basement of his mother's house in Uzbekistan and I apologise to the Uzbekistanis here, because I am sure they are not all hackers.

That's the fundamental problem.

We can get targeted information about politicians, about … I can guarantee you that politicians won't have My Health Records for that very reason because it is so easily compromised.

Anthony Fortina

That brings us to the end of this session, please thank David for his talk.

[clapping]

And again, I would like you all for attending this talk, its once again been a great success, packed house again and a nice environment.

I haven't had my beer yet but I certainly will be having it.

The next talk starts at 7:00 pm so could you please, if you are not coming to the next talk, make your way out to the main bar and if you want to keep talking to David he will probably be heading down for a well-deserved glass of wine.

If you do have a ticket to the next talk, unfortunately, you have to scan in again, so you have to go out and come back in.

So thank you again for coming.