



HEALTH CONSUMERS'
COUNCIL

Can an EMR stitch up our Health System - transcript

Background – EMR vs EHR, WA’s EMR Program

- [PB] Welcome, everybody. This is Pip Brennan, Convenor of WA’s EMR Consumer Reference Group. This is our first in a series of conversations about the Electronic Medical Record and today we're diving into connectivity. We're going to have a conversation with:
Peter Sprivulis, from WA Health, he's WA’s Chief Health Information Officer
Harry Iles Mann who's a consumer leader and digital health expert.



Pip Brennan [PB]



Peter Sprivulis (PS)



Harry Iles-Man [HIM]

- [PB] But first, I wanted to take a moment to pause and to acknowledge the that we are all meeting both virtually and in person on Aboriginal and Torres Strait Islander land. I'm on Whadjuk Noongar Boodja and the Health Consumers’ Council office is as you probably know, is also situated there. So I’d just like to take a moment to acknowledge the Traditional Custodians of Whadjuk Noongar Boodja and pay respects to Elders past and present, but also importantly, to extend respect to all Aboriginal and Torres Strait Islander peoples. Always was and always will be the Aboriginal and Torres Strait Islander land.

Acknowledgement of Country

We acknowledge the traditional custodians of the lands we are meeting on today, both in person and virtually. HCC is situated on Whadjuk Noongar Boodja and we pay respects to Elders past and present.

We extend respect to all Aboriginal and Torres Strait Islander Peoples.

Always was, always will be.




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- [PB] Also, to take a moment to recognise the importance of the lived experience voice, this is obviously central to the Health Consumers' Council and all that we do. We recognise the importance of having the lived experience voice at all stages, and at all levels of health projects.

Recognition of Lived Experience


We recognise the importance and benefit of the lived experience voice in all aspects of health policy, services and research - at all stages, at all levels.





- [PB] So just before we get started with our guest speakers, I wanted to just go back a few steps and just make sure that we're all on the same journey together because it's easy to get confused. **What is the difference between My Health Record and the electronic medical record?**

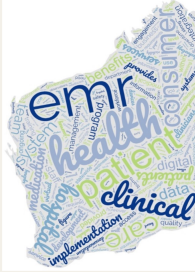
My Health Record



- Immunisations, test results, scripts, hospital discharge summaries
- Federal government
- National
- Primary care - GP, pharmacies, pathology

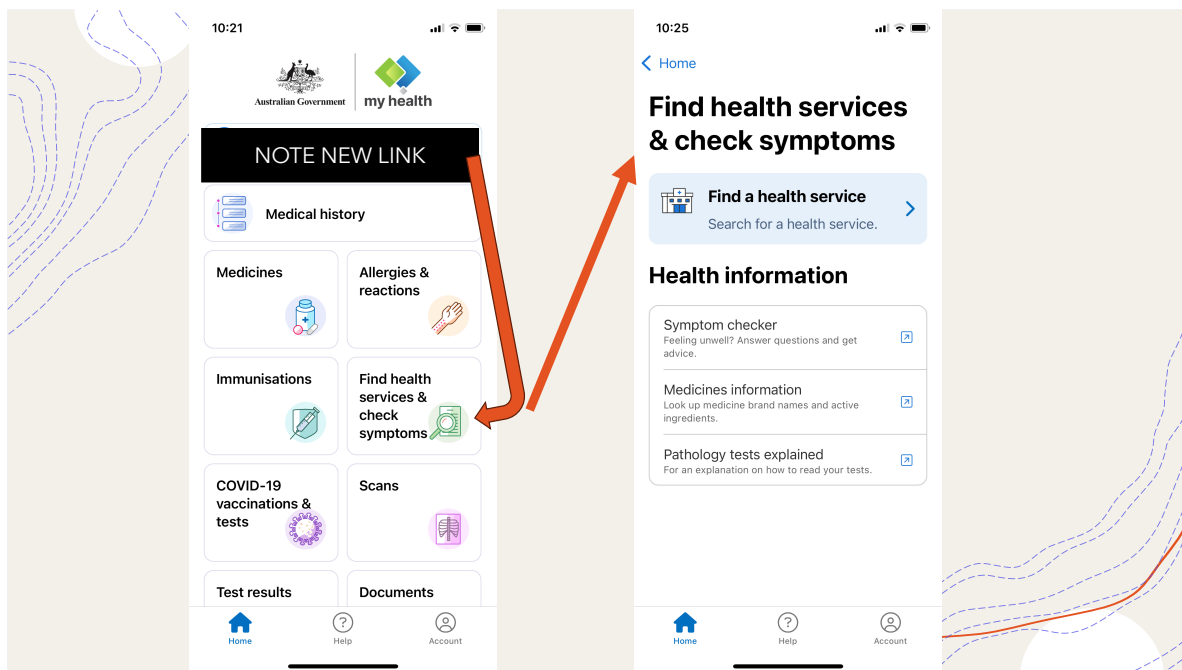
vs

Electronic Medical Record

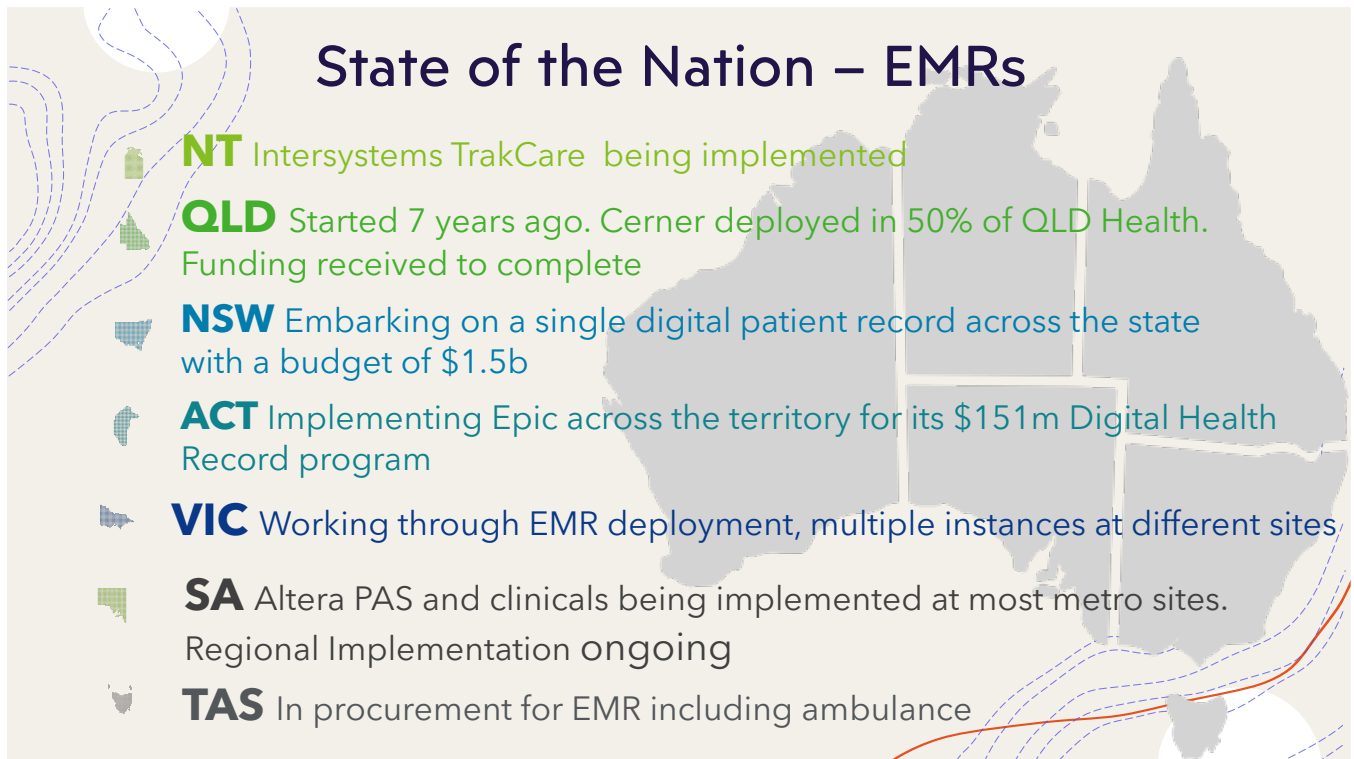


- Everything that happens within the walls of a West Australian public hospital - doctors, nurses, allied health etc.
- State Government
- State-based
- Hospital care

- [PB] **My Health Record**, as you're probably aware, is a federal initiative. And it has things like immunisations, test results, medication scripts, and so forth. It's primary care; your GP, your pharmacist, new pathology. It's called My Health Record, and it's about your health journey right across the system.
- [PB] On the right, the **Electronic Medical Record** covers everything that happens within the walls of our West Australian public hospitals.



- [PB] But just before we leave the topic of **My Health Record**, if you haven't looked at your health record for a while there is actually a new app called My Health to access you My Health record. So it's not a third party app like it used to be.
- [PB] On this new app you can see there is a Find health services & check symptoms. This is something that consumers advocated for with the Australian Digital Health Agency-how can we link with some excellent resources we've already got. For example, if you click on the find a health service it takes you to a page where you can search for a relevant health service in your area. If you click on the Symptom Checker or Medicines Information, it takes you to the Health Direct sites where you can run through the symptom checker list, or look up your medications. There is also a pathology tests explained button which takes you to that website, which used to be called Lab Tests Online. If you do find yourself suddenly having to face a barrage of tests, and you're really not sure you can actually go on to that website, and it tells you a lot the conditions, the tests, what to expect etc. But I digress. And I want to get us back on track. We are talking today about WA and the Electronic Medical Record.



- [PB] WA is not on this list, because at this stage, we don't have an Electronic Medical Record. We are in the process of hopefully getting one—we are still waiting to hear whether or not this is going to happen to WA. But you know, hopefully this before too long, we will hear about the latest business case and whether it's been successful.
- [PB] But I think it's really important just to remind ourselves what's happening with Electronic Medical Records at a national level. So again, those records that sit within hospital walls within each state and territory, what's happening so you can see
 - Northern Territory has an EMR called InterSystems TrakCare.
 - Queensland has got Cerner so it's about half of Queensland Health.
 - New South Wales has had one attempt at implementing an EMR and they're having another go with a single digital patient record across the state.
 - ACT has implemented EPIC
 - Victoria, as some of you may be aware, Victoria has a lot of separate area health services and many things aren't centralized in their health system and they do have quite a few different EMRs at different sites; it isn't a statewide approach.
 - South Australia is working on implementing an EMR which is the Altera Patient Administration System.
 - Tasmania is in procurement for an EMR, it does also include ambulance services.
- [PB] So as you can see, we've got you've got a lot of different things going on state by state.

EMR – a 10-year journey

Paper record

- Not there when you need it
- Non-uniform
- Not with the patient



Digital record

- Immediately available
- Uniform and legible
- Works across many systems

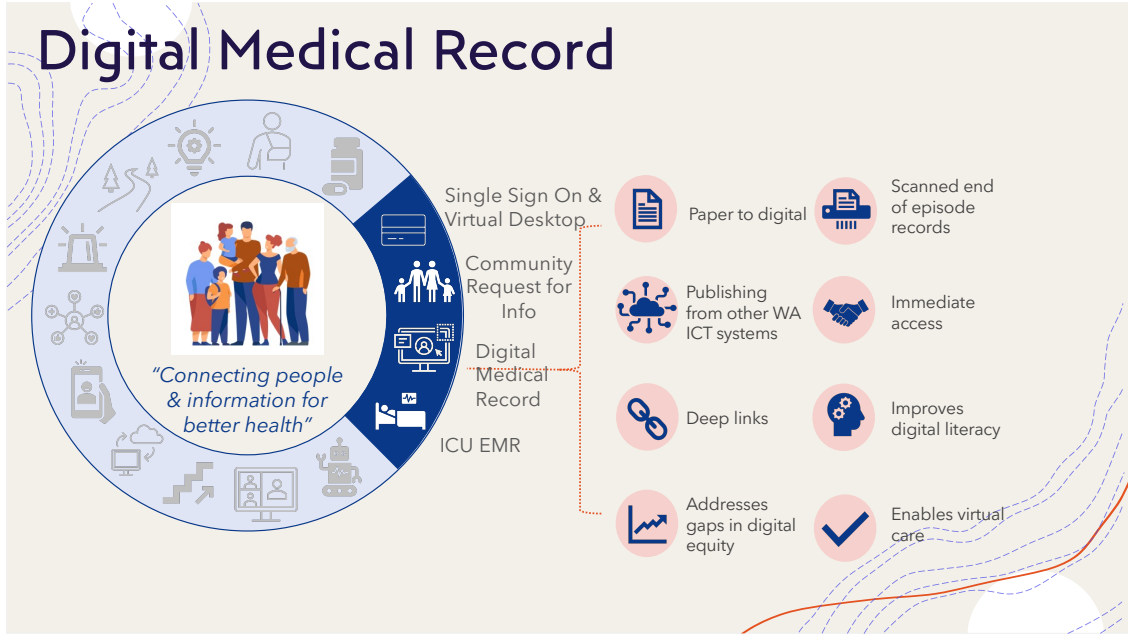


Electronic record

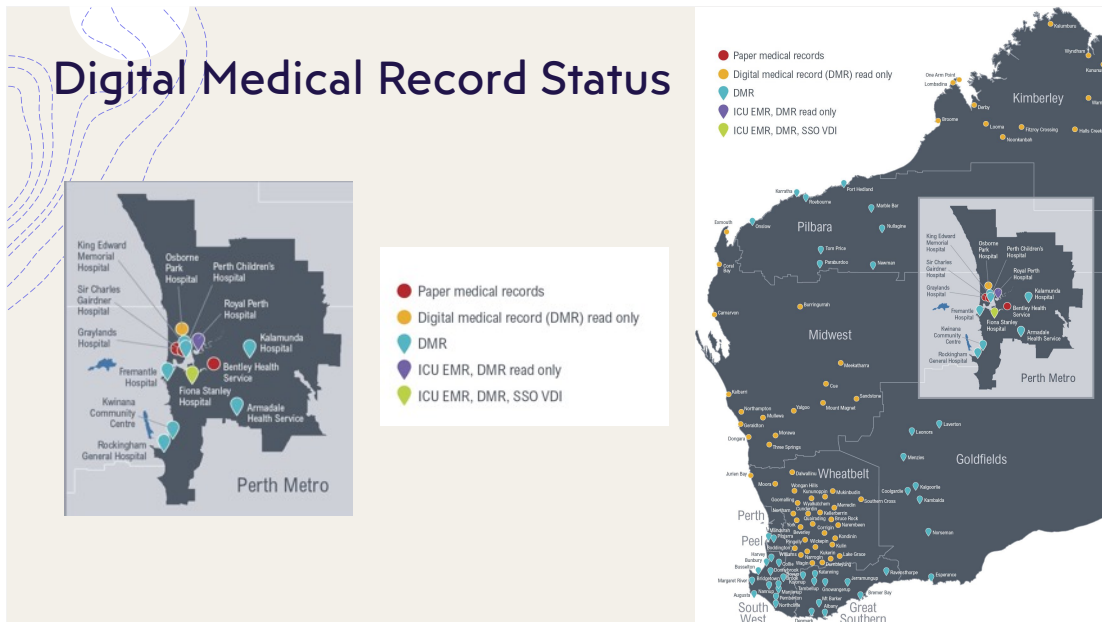
- Allows consumers to navigate pathway
- Clinical alerts to support decisions
- Links across all systems



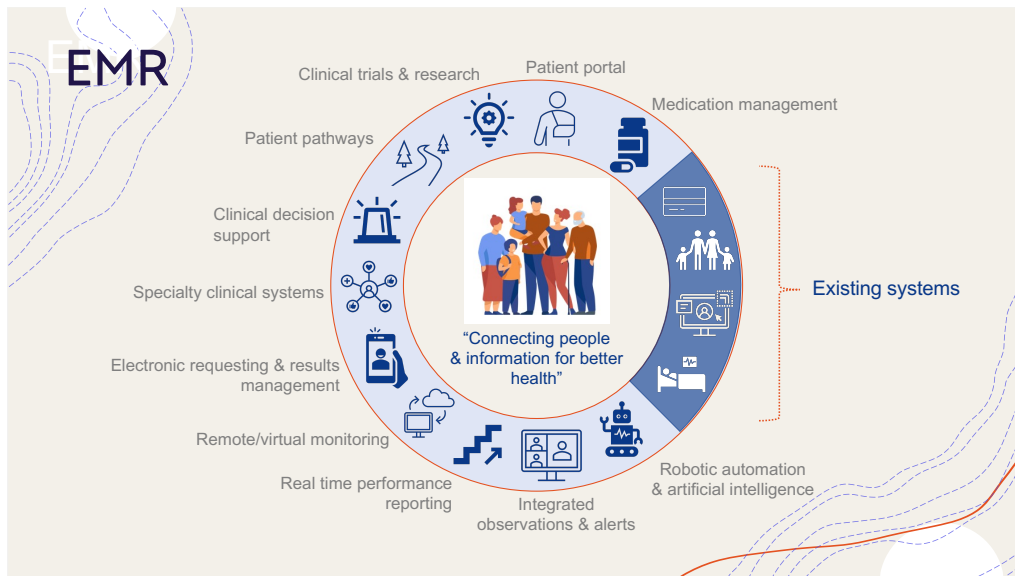
- [PB] **In WA we are looking at a 10 year journey**, I think it's really important for us as consumers to remind ourselves that this is a long journey. And we're not going to have any EMR in five seconds.
- [PB] Currently, if you need to go into hospital, generally speaking, there'll be a paper medical record. That's what you will see-people writing in paper records. We know all the issues around that – the information isn't always where you need it, there's no uniformity about it. It's not doesn't follow us along our health journey.
- [PB] What WA has been working really hard on is an interim solution, and that is digitising medical records. So some of you may if you've been to Fiona Stanley Hospital, you'll be aware when that hospital was set up, that they had a digital medical record. And so right now in WA Health are getting everybody up to the stage of having digital medical record. So obviously, it is digitized, but it's not particularly flexible.
- [PB] An Electronic Medical Record is another step again, and so it has a range of different things like “guard rails” where for example, optimal care path pathways can be hard-wired into the EMR itself. It's a safety and quality measure. An EMR can link across all public health systems and it provides many capabilities that a digital record can't.



- [PB] This next slide shows all the work that the WA Health Department's doing at the moment. Digital Medical Records are third on that list there but they've been implementing Single Sign On so that clinicians don't have to keep on signing on to the multiple web based applications. There is also an ICU EMR being implemented, and a Request for Information for community health services (i.e. those delivered by WA Health and HSPs)



- [PB] This slide shows all the work done digitizing our medical records over the whole state. And I just really wanted to flag that there is a statewide approach being taken with digitising medical records. In Queensland, 50% of the state have had an EMR implemented – many people who have missed out are regional.



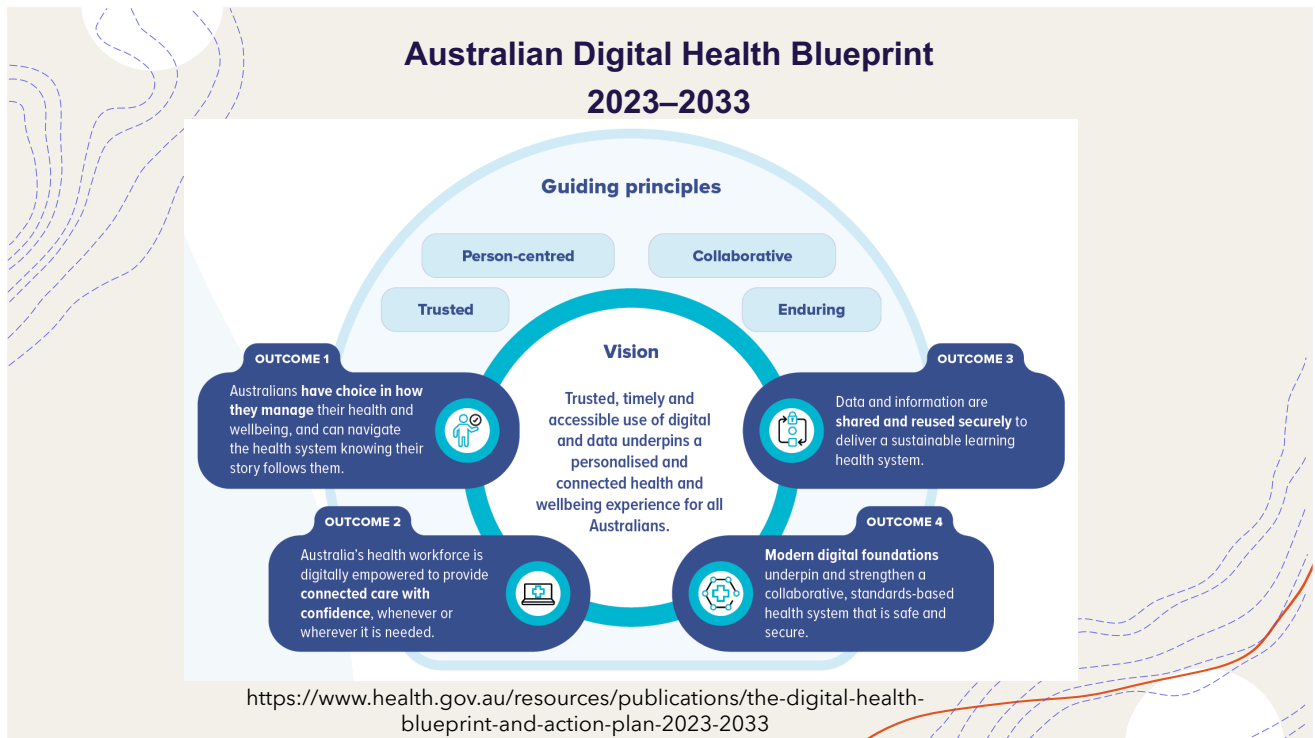
- [PB] So with an electronic medical record, as mentioned, aside from the dark blue circle showing digital medical records, and putting in an ICU EMR, single sign-on and the Community Care Request for Information, the light blue circle shows all the functions an EMR will bring to WA; Patient portals, clinical trials and research, patient pathways, clinical decision support, etc;
- [PB] In 2020 Health Consumers’ Council were funded to create an [EMR Consumer Charter](#), based on the [Queensland Health Digital Health Consumer Charter](#). When that business case was only partially accepted, the EMR work went into abeyance, but in 2023 we were funded to re-form an EMR Consumer Reference Group, and in 2024 we have been funded to run three webinars and convene four meetings of the EMR Consumer Reference Group. The goal of this work is to keep exploring how we can develop a well-resourced and well-informed digital health consumer network. There’s an [HCC webpage](#) for this project so you will find updates there.

NEXT WEBINARS

Date, Time	Title	
Fri 19 th April 2024 2-4pm	Patient Reported Outcome Measures - Opportunities and Challenges	How can and EMR make sure what matters most to consumers can be easily measured and tracked?
Wed 5 th June 2024 3.30-5pm	Data security and trust and the Electronic Medical Record	How data resources we have now could improve our healthcare and understanding what data security means to consumers

Check out the web page for updates:
<https://www.hconc.org.au/systemicadvocacy/digital-health-2/>

Stay in touch: p.brennan@hconc.org.au



- [PB] Nationally, there's a lot going on in digital health. And that's why I wanted to have Harry Iles Mann on today's session as he is a national digital consumer rep. Harry has mentioned that the Australian Digital Health Blueprint is quite a readable government document. And if you look at that vision in the centre, this is what really what we're talking about today, a trusted, timely, accessible use of digital and data underpins a personalised and connected health and wellbeing experience for all Australians. And that's what we would love to see.

National Healthcare Interoperability Plan 2023–2028

“outlines a national vision to share consumer health information in a safe, secure and seamless manner”

Council for Connected Care
Providing strategic advice on interoperability and supporting the implementation of the National Healthcare Interoperability Plan.

<https://www.digitalhealth.gov.au/about-us/strategies-and-plans/national-healthcare-interoperability-plan>

- [PB] The National Healthcare Interoperability plan. That slide I showed you earlier, and you could see each state and territory kind of doing its own thing with the EMR. We know where that's all going to go, don't wait, it's going to go with IT systems are not going to talk to each other. So there's actually a whole lot of work happening at a national level to really say that, that we need to be able to share, we need to be able to interoperate between this system.
- [PB] What people are constantly wanting to know, will an Electronic Medical Record, talk to My Health Record.

Panel Discussion – Transcript

Introductions to our speakers



Pip Brennan [PB]

Peter Sprivulis (PS)

Harry Iles-Man [HIM]

[PB] Harry, would like to introduce yourself to our audience and about your work in digital health?

- [HIM] Hello, everyone. First up, it's a bit later in Sydney here on Gadigal land so Good evening for me. I suppose the most important thing I start with is before anything else first and foremost, I am a patient. I'm a young person that's managing complex chronic illness and disability and have been since I was three years old, that's a journey that spanned four major operations, including both recently in the last three years two full liver transplants and about 50 weeks admitted to hospital. So, it's fair to say that in addition to the stuff that I do professionally, I very much live breathe, and unfortunately, for those of you that have spent time in hospital eat health, in terms of my professional roles, and my roles as a consumer, representative, and advocate.
- [HIM] I'm really fortunate to have spent some time a couple of years ago as National Youth Mental Health ambassador, with all our youth mental health peak organisations. I've been a digital health expert advisor to the Australian Digital Health Agency for the last eight years, I've run a lived experience engagement and collaborative design consultancy for a number of years now working to embed lived experience in consumer representation in design and decision making in health. I also have a role as the consumer representative advisor with the Department of Health and Aged Care Digital Health Branch, which gives me a fantastic level of visibility and access to design and decision making at a national level.
- [HIM] And just in terms of interoperability piece I also happen to be involved in-we'll probably chat about this a bit later-one of the main programs that is leading the work as far as collaboration of government on the national interoperability is something called the Sparked Program, which I am also fortunate enough to have been invited along as a Co-leader on the clinical design group for that.
- [HIM] So I'm, I suppose across the space in a number of ways, but fundamentally underpinning all of that is really the fact that I have been and lived in very literally our health system since near birth. It's something that I understand intimately and I'm incredibly keen to ensure that, you know, my experiences but more than that the experiences of all people with lived and living experience of complex chronic illness, disability, and so many areas of lived experience, that I don't have coverage of have capacity to have a seat at the table in design and decision making.
- [PB] Thank you so much, Harry.

[PB] Peter, I was wondering if you could introduce yourself to the audience and, you know, give some insight into your background in this area?

- [PS] Yes, well, I'm old enough to have had some experience with the healthcare system itself, but not quite at the level that Harry's describing. I'm an emergency physician with over 30 years of clinical experience, and I'm a digital health specialist and used to be a clinical academic. I'll probably write on my tombstone, that during my academic career, I crunched lots of amount of data to demonstrate the bleeding obvious, and that is that if you have overcrowded EDs with ambulance ramping and overcrowded hospitals isn't good for patient care.
- I've sort of stepped away from that space, and probably focus more on digital health over the last 20 years alongside my clinical career, starting with a Harkness fellowship in the US with the Institute for Healthcare Improvement, and Harvard. And following on from that had the privilege of leading one of the first iterations of National EHealth strategy for what was then NEHTA. And that really focused on interoperability and was replaced by the Australian Digital Health Agency.
- And at some point on the line, I focus more on state e-health strategy, and also, there are lots of digital health implementations, including putting together the jigsaw that we run at Fiona Stanley Hospital, the state imaging solution.
- One thing I'm really proud of is this small project, which was the E prescribing project where we did the QR code scripts, from WA Health facilities, off to community pharmacies, which other states seem to be struggling to do at the moment.
- I'm just in the process of retiring from clinical practice. I feel like I've had enough of that. I've got away with it long enough, but I'm continuing as a CCIO (Chief Clinical Information Officer) for the Department of Health as Pip says, and also doing a similar role for the South Metro Health Service for the next six months, just supporting them as well as someone stepped away from the role there.
- [PB] Thank you so much. And so I think, you know, you can see, I feel very lucky that we have Harry and Peter to speak to us tonight because they have such a broad range of areas that they're interested in.

National Initiatives – Digital Health Blueprint, Sparked Program

<https://www.digitalhealth.gov.au/about-us/strategies-and-plans/national-healthcare-interopability-plan>

<https://www.health.gov.au/resources/publications/the-digital-health-blueprint-and-action-plan-2023-2033>

<https://confluence.csiro.au/display/FHIR/SPARKED+-+AU+FHIR+Accelerator>

<https://confluence.csiro.au/display/FHIR/AUCDI+Release+1>

[PB] I was actually going to come to you next Harry. I wanted to talk a little bit about the some of the things that are happening on a national level. So I've briefly talked about the blueprint. And you also mentioned the Sparked Program. I was wondering if you could talk a little bit more about both of those.

- [HIM] The Blueprint is sort of the outline, I guess of sort of the government's vision. And look, one of the first things I'll say, as a caveat is I'm here this evening as a consumer leader, not as the representative of department or the or the strategy or Digital Health Agency so I won't presume to speak on their behalf. But this is all information that's publicly available, and I really do encourage you to go and have a look of it.
- [HIM] So the Digital Health Blueprint, which is really establishing the vision for what we'd like Australia to look like from a digital health point of view, and where our health systems are communicating.
- [HIM] The interoperability plan obviously sits as a core part of informing how all of that information exchange actually happens.
- [HIM] Accompanying a Digital Health Blueprint is another document called the Digital Health Action Plan, which actually sets out some far more granular, more easily identified and actual sort of tangible things that we need to be doing beyond just this is a nice vision.
- [HIM] So those two documents, the Blueprint, and the Action Plan in combination is a really, really powerful set of documents to be released. And it's the first time least in my memory that government has gone about approaching reform of this scale in a way where they have established a clear and transparent vision and then actually identified what's necessary as the steps to take towards that.
- [HIM] The National interoperability plan is sort of, I suppose the nitty gritty sort of gears and architecture that will sit beneath everything, ideally, it's a lot of the system that you don't see, if you are seeing it, it's usually because something's going wrong, or we're building it in the first place.
- Brilliantly, a lot of the design of that, well all of the design of that so far, has been incredibly transparent in the way that both government and the sector have gone about having these conversations.
- [HIM] I'd say we're probably still not at a point yet where there's as many consumer representatives involved, as I'd like to see. But one of the natural challenges in this space is obviously that, to understand a lot of what sits beneath and behind, the way these systems communicate and share information is technically really complicated. So it's a really high bar of entry as far as our own literacy goes.
- [HIM] And this is something that you know, people spend entire careers devoted to trying to figure out, so one of the tricks and I guess one of the sort of key challenges that's shared amongst government in

the health system and us as a community of consumer representatives and advocates in health is how do we both partner with one another, and uplift one another in terms of our understanding and our literacy to the point that we can have a dialogue about what needs to change what decisions need to be made?

- [HIM] Part of that interoperability at a national level is I suppose at this point, and I will say intention, because the government has been very clear that it is not committing necessarily, to a declarative plan. This is something that they really want to be informed, I suppose, as an organic evolution of discussion and decision making amongst the sector.
- [HIM] But the intention is to have a effectively a common language that sits below all of the technology architecture, that allows all of these different systems to communicate with one another. The Sparked Program is a really important part of that. If you speak to anyone in Sparked, you'll hear them calling it "the core of the core". So the core of everything being connected, is the interoperability. But the core of the interoperability is a consistent terminology set and language that all the different systems speaks.
- [HIM] And Sparked as a program is the collaboration of the Department of Health and Aged Care, the CSIRO, HL7, which is the organisation responsible for developing something called the FHIR Standard (Fast Healthcare Interoperability Resources), which is the language model standard that is used internationally as the highest benchmark of language standard, and the Australian Digital Health Agency to come together to define what goes what information goes into that language set.
- [HIM] And then from a technical perspective, how do those different parts of the system or those different dots actually exchange information with one another and that's effectively what that what the Sparked Program is responsible for. I'm happy to drop some links and share some stuff after all of this because the Sparked website is all publicly accessible as well. They're in the middle of a website revamp I will base I will say those so give them a couple of weeks and I promise you you'll have something much better looking at it currently is in terms of being able to navigate.
- [HIM] But the Digital Blueprint, the Action Plan, the Interoperability Plan, and the Sparked Program are all at this stage publicly accessible, which is a really fantastic thing, because it signals to us that government is taking very seriously the traditional approach of all the different parts not talking and kind of building their own little four walls and kingdoms has not worked.
- [HIM] It's the reason this system looks the way that it does. And it's this much of a pain in the backside for us as patients to navigate. So we're taking a different approach.
- [PB] I just wanted to share some reflections. So this what in simplistic terms, if things are going to interoperate, then we have to use the same thing to mean the same thing. So you know, name has to be the same name. And, you know, medication has to be the same field and so forth. And as you said, that Sparked website is worth having a look at. And actually, there was a the first release seeking feedback on the Australian Core Data for Interoperability. I had a go at providing a submission, which was basically I abstained from all decisions, but I just said, "you need more consumers". And then I got an invitation to the next meeting. So I just think I would agree that there is there is quite an openness [in Sparked].

Aged care Data and Digital Strategy

<https://www.health.gov.au/resources/publications/aged-care-data-and-digital-strategy>

[PB] There was a comment in the chat about the Aged Care Data and Digital Strategy. And with that fits in, Peter, because I was going to pick on you next.

- [PS] I don't mind just mentioning the point that clearly, it's the Department of Commonwealth of Health and Ageing, and so they're very, very keen on supporting to the Aged Care System uplift its standards, not only for its internal purposes, so that they can understand better the quality of aged care, but a real focus is trying to share information between the aged care sector and in the state healthcare sector, because obviously, a lot of people in aged care, end up washing up on the shores of the state care system. And what we really want to do is, make sure that we have the right information shared, both when aged care residents come to see us. But also really importantly, when we either look after people in a virtual care capacity in their aged care facility and or when we send people back out at whatever time of the day or night, we tend to do that with the right information to enable ongoing care.
- [PB] So it's yes. And I just want to acknowledge that question from one of our finest our state's finest aged care advocates, you know, it's such an important area, this is something that she constantly reminds us of. And as somebody who's the carer of a frail aged person, myself, I've experienced my mother transitioning from hospital into aged care, and the delay in any information appearing on her My Health Record-I would still love for her aged care stuff to also appear on My Health Record-but I recognise that that's a bigger conversation.

Council for Connected Care, Interoperability and WA's EMR

<https://www.digitalhealth.gov.au/healthcare-providers/initiatives-and-programs/interoperability-and-digital-health-standards/council-for-connected-care>

But I wanted to move to you, Peter, and I wanted to ask you, you've been doing a lot of work, you're sitting on the Council for Connected Care, and that Council for Connected Care is really providing strategic advice about implementing the Interoperability Plan. What does that mean for us in Western Australia as we are on the brink of -hopefully, everything crossed that we do get funding and we can actually proceed to a full EMR - will we be required as the state to pay more attention than other states have to think about interoperability of GP records and our EMR, and maybe even our Aged care?

- [PS] Well, Western Australia's in a somewhat unusual position that I was at a meeting earlier today where we've got various representatives trying to work out what sort of expectations we will have in our Healthcare Agreement Schedule, (<https://www.health.gov.au/our-work/2020-25-national-health-reform-agreement-nhra>) which was which is how we get money from the Commonwealth, about what the expectations will be about. How each state or territory is going to adopt standards to share information interoperably and it is really important, interoperability because really, you know, how do we share information so it's accurate? It's got the same meaning and can be used the same way with whoever's sharing it?
- [PS] Because I had a lot to do with developing the National Strategy, you know, 18 years ago, it's been at the front of my mind in every leadership role I've had in Western Australia for WA Health.
- We've (WA) probably been earlier adopters than the other jurisdictions in terms of the kinds of things that the Federal Government wants from us, like we upload a lot of information already, to My Health Record, probably the best state for doing that. I feel like I'm bragging, but I wish I wasn't bragging, I wish I could say we weren't the best, that everyone was at least as good or better than us.
- [PS] But we've also been quite lucky in WA, because at a state level, at a state health level, we've done a lot of work making sure we're using these tools, we've actually been effective in negotiating with the private sector in WA Health, to lift their game as well, because particularly things like pathology services, imaging services, they compete with our State Health Services.
- [PS] And being able to say that as a state system, "well, we're uploading all our pathology, why aren't you?" and letting health consumers know that we've seen really a high level of adoption in WA Health noting, we've got fairly concentrated markets that pathology and imaging, in addition.
- The people who are a bit left out, I think the private specialists, we still have a long way to go to get some people who are very focused on their self-optimised small businesses to engage with sharing information.
- [PS] They're also very fearful of losing referrals, if they move away from whatever is the easiest way for a GP to send them information, which is a fax in actual fact.

- [PS] So although at a state level, we're doing some work with a Smart referral solution. Other states have done smart referral solutions where a GP, from within their system can send us electronically, an accurate, appropriate referral that'll get sent to the right people and you as a health consumer, and the GP can be confident that it'll go to the right place, you'll get information about that.
- [PS] The GP can actually have conversations online with the specialist about it. We sort of need to do more work, I think in the in the private space as well, to bring those into the picture a bit more. And I think that's more of a challenge.
- [PS] But hopefully, we'll see some effective incentives, shall I say? Certainly, in the minds in terms of the way things like Medicare schedules are used as a way of providing some incentives for a bit better engagement with our interoperability ecosystem that we have.

Incentives

[PB] When you say that, what you're saying is, would you pay a GP to more effectively interact with our Electronic Medical Record, for example? Or would you pay a hospital specialist a fee, so that so that they will do the same? Is that what I'm hearing?

- [PS] No, I'd actually revert it. We've thrown incentives at my clinical brethren for a long, long time, and it hasn't really resulted in much. I suppose. The way I'd like to describe it, and this is my opinion, it's not, I'm not speaking for the state government or the federal government. I don't know why we pay people for a service if they don't provide the information to those who need to see it downstream and provide it to your health record if you have enrolled in health record, and you want access to that information. So I would actually flip it around the other way.

[PB] Sounds good to me! But I guess the question is, given that there is this Interoperability Plan nationally, is there something as Western Australia does this piece of work, for example, where we have to more clearly prioritise how the Electronic Medical Record interfaces with the GPs in West Australia?

- [PS] I think it's going to be really helpful for us. We've got very clunky processes for gathering the information we need to put into those summaries to share with either an aged care facility or a GP. And so in the case of your mother, or my mother-in-law has been hospitalised recently, the fact that the information in Western Australia systems is sitting in a range of disparate systems, it's a lot of time and effort on a junior doctor to sort of synthesise that information. Patients are in and out so quickly, often the doctor doing the summaries is not even a doctor who's familiar with the case information. So it's, it's a hard task.
- [PS] So the great thing about sticking Electronic Medical Record system or one of the many, many benefits, is it's a one stop shop for the information. And a lot of them now have tools which really assist supporting and can have analytics done to draw out in an automated way using modern, either AI or

things similar to AI, the important features of what happened when a person was in hospital or what their most important problems are. So that that can be summarised quickly and made available more quickly. And there's also much, much better tools for making information available to you in your hand through your smart device. And then to the GP via portal, not just having to wait for a document to sort of belch its way out of our healthcare system in your direction.

- [PB] The idea of a **patient portal** is something that we explored a with the EMR Consumer Reference group, and we are in the process of socialising a presentation on it - we're just still getting our tech organised. But that does have some interesting things. So I just wanted to be clear. So until we get an Electronic Medical Record, it is going to be difficult to have that interface. I heard that right?
- [PS] We've got pretty good interfaces, but they're not as good as they'll be when we get an Electronic Medical Record.

[PB] And a Digital Medical Record won't fix it either?

- [PS] Well, no, a Digital Medical record is just another source of information that a Junior Doc needs to summarise along with all the other bits and pieces. So yes, so we've got a lot of the railway tracks is what I would say, but the carriages are sort of spread on different parts of the rails, and they need to be joined up to be sent off, down the track. So our issue is more the gathering of the information to stick on the rails rather than us not having the rails that diverse property states in terms of the rails to share the information.

Legislation, Incentives vs Mandating

[PB] And certainly in terms of your comment earlier, I think a few of us are in furious agreement that no doctor or health professional should be paid for a service until the records are uploaded. So we're definitely behind you there. Harry, I saw you come off mute. I was wondering, is this something you had wanted to chip in on?

- [HIM] Yeah, there was just a few ideas. I mean, look, I think first to that to that question of incentives. Peter, while you were talking in the back of my mind was echoing “it's time for a bit more stick”. Really. We've taken we've taken an approach of an abundance and generous use of carrots over the last numerous decades. And it is time for a bit more stick in my personal opinion.
- [HIM] I did see a question pop up that was asking “What level of support is there from each of the State Governments for a national strategy?” The level of support from state governments is a really critical question to be asking.
- [HIM] One of the levers that we haven't actually talked about so far, but is an integral lever to this national interoperability, and integration piece is the legislative level, Sharing By Default, Australia following suit, and taking lead from the United States, 21st Century Cures Act

<https://www.congress.gov/bill/114th-congress/house-bill/34>) to legislate the mandatory uploading of information is a very, very key step.

- [HIM] One of the challenges that has existed predominantly, in that sort of public pathology as an incidence of that public private divide, has been that it's more a matter of boasting rights to try and get one another to improve their service provision, not someone coming in and saying, "Hey, everyone, it's actually just good practice that you should be doing this, the bar should be here, because we know the bar should be here". Not have them competing with one another to say, "Well, look, we upload 90%, now is your opportunity to come and beat us."
- [HIM] So something like a national in this case, the introduction of national legislation mandate uploading of information, completely removes and negates this argumentative sort of, I suppose culture that we see on the ground that permeates all states into all state and territory health systems and all divides in health. It's there in the divides between local health districts. It's there in the divides between hospitals themselves, it's there and the divides between public and private. It's there in the divides between states and territories, and it's there the divide between states and territories, and federal and Commonwealth. So something like this is a was also a really important mechanism.
- [HIM] We've recognised that actually we've reached a point where it's not appropriate to say anymore, "you need to be incentivised more to do some really fundamental aspects of your job", that should just be part of that job. There are elements of a duty of care. There are elements of, you know, administrative burden that if we're being honest, come with the job and are well known upfront.
- [HIM] And I suppose one of the things to caution and something else on the side is, that's not to say that there isn't 100% an opportunity and a need to better support our workforce to deal with these challenges and these burdens, because on one hand, if we are going to be saying, "Look, you need to meet this bar now, because we mandate it to be so". And we know that our service providers are sitting down here, understaffed, overworked, struggling to keep their businesses afloat, because, you know, in large part, a number of these entities are operating as businesses, it is also incumbent upon us at a national and state and territory level, to seriously and thoroughly investigate how we most appropriately support this transition.
- [HIM] Because I personally don't think it's at all appropriate to say that we must require a change from state A to state B, but that we're not going to support you to achieve that change. That's already preparing ourselves for failure. And that's already preparing ourselves for a situation where the only people that will cross the finish line are the ones that are already resourced and doing well enough to actually make it that far, and the rest will flounder. And we'll end up with a system that has exactly the same disparity of service provision, and quality of data entry and interconnectedness as we have now.
- [HIM] But that is also one of the things that I have seen personally, in my time as a health consumer representative over the last decade or so. There is kind of something in the air that has changed both at a state and territory level. It's there on the ground at a hospital and district and health service and health regional level as well. And it's there at a federal level. There's a change in the air that as if to say everyone recognises that we have an opportunity, probably a once in not just a single generation, but multi generation opportunity to fundamentally transform the way our health system equips and works.

- [HIM] And more importantly than that, that by transforming that, that underlying infrastructure, how we can completely reform and change the way that we provide high quality, safe, timely, accessible, and exemplary care to the Australian public.
- [HIM] And that's something that there is 100% a role for us as consumers and community to play in terms of the design decision making implementation and evaluation. I will say, we're not quite there yet.
- [HIM] I'm delighted to hear that it took less than a week for Sparked to come back to you and say, "let's roll you into it." That in itself, I think speaks to what I'm perceiving as a really significant cultural shift in the health sector towards involving us in that design and decision making.
- [HIM] And on behalf of government in the sector, actually offering up a lot more vulnerability and transparency in the way they make decisions and what they're thinking about by bringing us to the table and showing us stuff and letting us into conversations that honestly probably would have stayed behind closed doors for another 12 to 18 months before we heard a whisper about them.
- [HIM] That cultural change, I think that that for me is probably one of the most important aspects to any discussion about digital transformation is that the technology is not really the thing that we haven't figured out. The technology exists. The language and interoperability standards exist by US standards, which is that that national and international standard. They've been used in the US since the 21st Century Cures Act got introduced over five years ago, they're used in other parts of the world.
- [HIM] The technology's not the bit that we haven't figured out. The bit that we haven't figured out is the cultural change in the workforce management, and also the upskilling, uplifting and empowerment of consumers and community as part of that partnership with decision making.
- [HIM] Where we're headed, as far as a success state, relies way more on culture and a positive shift in our culture in health than it does on the technology. I think to be quite honest with you the technology is probably the easiest piece of the puzzle at this stage.

[PB] I'm going to ask you, Peter, if you agree with it, and it's great Harry how you anticipated my next question. "what we're embarking on in WA, it's not really a IT project. It's a culture change project. How do you How much do you agree with that, Peter, and how are we sitting in WA?"

- [PS] Well, when Amanda Cattermole came on as head of the Australian Digital Health Agency, I disclosed to her my framework that I always look at for these issues of solving complex issues in our healthcare sector. We can't really call it a system because we just have this community of actors who operate in a strange set of ways. And in the chat, I'm seeing a lot of comments about how challenging it is.

Comment from the chat: There is also frustration regarding the lack of communication between Centrelink and health and aged care and the need to actually obtain paper documents e.g. income statement from Centrelink in order to access aged care - and the risk of missing out on a bed available while the document comes by SNAIL mail and while a hospital bed is occupied unnecessarily.

- [PS] And I actually read a book chapter about healing, fractured healthcare, and some of the things we need to do 15 years ago now.
- [PS] But as Harry's pointed out the technical level is usually trivial to solve, we know what we're doing there. Sparked is an illustration of how you can get a community engaged around sorting out the technical issues, no problem.
- [PS] The next level up, I like to think about the workflow. Because if you don't have the workflows, the same on both sides of a transaction, then information can mean quite different things. We even see this with sharing with our public private partners in Western Australia, where the way they manage allergies in their system is a bit different from the way we do. And this took three or four very painful years to iron out the differences in workflows so that when we send them some allergy information, it doesn't come back as scrambled information about you and your allergies when it comes back.
- [PS] The level above that is a legal and regulatory thing. And it took a pandemic for us to get over the hurdle of needing a paper script in the hands of a community pharmacist so we could implement the scripts, the QR code script solution. So the legal regulatory stuff does need sorting out. It's a bit of water on stone. But usually, if you thought through what those legal and regulatory barriers are, you can usually migrate through them.
- [PS] And probably the most interesting thing I heard at in terms of legal and regulatory thinking from the Feds is beginning to mutter out loud things like broadening the scope of the My Health Record Act, which provides a lot of safety for health consumers, and puts very clear obligations on us providers to a My Health Information Act.
- [PS] Now, that's not going to happen in five seconds, there'd be a whole bunch of consultation, a whole bunch of stuff that needs to go through. But if you think about it, we've got something that works for part of our healthcare is your healthcare information, if we could sort of work out a way of making that a level playing field for other forms of health information that's sitting in other silos, like within a radiology practice or within a state health system, then that could be really quite beneficial if we could iron out those, those wrinkles.
- [PS] And then above that, is the financial and cultural piece. And in the words of Paul Keating, between self interest in the public good, always back self-interest, because at least you know, it's trying. And as I say, you know, we tend to treat a lot of actors in our healthcare sector, as small businessmen, who are fee for service paid, they're looking at throughput. They're trying to do the right thing.
- [PS] But also, I was having a conversation with a general surgeon at PCH just recently, and, and he says, "you know, look, I'm trying to do the right thing, but my incentives are over here." We need to deal with it.
- [PS] A classic example where the incentives are all wrong is that if your GP without you in the room rings up one of our specialists, no one gets paid. So we can't pay for our specialist time that we've made available to that GP, the GP can't get paid for contacting the specialist on behalf of you. Yet, a short phone call might be exactly what's needed to solve problems for you rather than you having to make your way to an outpatient clinic. So there are really important issues in the financial sphere that we need to have.

- [PS] And it needs to be a joined up conversation between the private providers, the state health providers, and the Commonwealth as a funding agency to resolve some really important issues there if we want to really get proper rubber hitting the road in terms of digital care models.

[PB] There's something else I wanted to talk about around financial incentives, and it's hard for me to see the financial incentive for IT companies, for us to all work together. If you look at that map of Australia with that dreadful jigsaw of all the different Electronic Medical Record systems that are being implemented. Number one, I feel like that is a failure of leadership at a national level. But number two, am I right in thinking that in America it was actually legislated that IT companies were not able to create electronic medical records that couldn't talk to each other? I know that's a bit simplistic, but is that also an area that needs addressing?

- [PS] What we know is that the big players are actually on ancient code, some of that code was written in the 1960s, like the best solution on the planet from the point of view of a clinician, literally is written in a programming language that was started writing that EMR in the 1960s.
- [PS] So they're very old. And so adding the pieces to allow them to talk to each other, which was the Health Information Exchange requirements that the Americans brought in, absolutely, it was important, but the bulk on components, they're not the underlying structure of the records themselves. And the conversations we're having, between the jurisdictions, and as we speak, I was in a meeting today. And, the Feds is along the same lines, you know, we accept that these solutions will do what they do internally
- [PS] But just like the banking system, you know, you've got your BSB and account number, every bank has got a different system behind that. But that's the key and the interoperability key, that and processes and workflows that they have to support moving money between bank accounts.
- [PS] It's the sharing piece that we really need to do, to really make sure that we get all the ducks lined up. And we did it so well with the QR code descriptions, nationally, and at a state level, and territory level across Australia. So that's an exemplar of how we can all work together to do it well. And we need to learn kind of example, and do more of that kind of thing.

[PB] I just want to acknowledge that comment around just how helpful the QR codes have been for their health journey. And just to acknowledge that that's made a big difference. And also their comments that there's a range of different comments that I see fit under that space of something similar, like open notes, which is, if I get this right, it's a facility whereby the consumer can see what is written about them. So that there's that partnership and what's written because there's a range of different examples that they've given where there's that lack of ability to actually say, "this is what needs to be discussed", and a lack of ability to be sure that the right, for example, pronouns are being used at the right diagnosis are being used. So. So that's another piece of consumer empowerment. That's possible, am I right?

Comments from the chat:

- *"I love e-scripts! Specifically, before the QR codes, I consistently struggled to have my specialists not expect me to travel to their offices to collect scripts, even though we do Telehealth due to my limited mobility. QR codes have been magic and 90% of my scripts are able to be done with them now."*
- *None of my family have used the federal health record as yet. One of the concerns is around what is written in it if it isn't accurate. For example, we had our autistic son in at emergency ... a few years ago for a physical health need. His autism was relevant because the doctor wished him to swallow a medication that he was unable to do because of sensory needs. Overall the visit was not useful for his needs. When I read the ED discharge letter later it contained sentences that were inaccurate and unhelpful, such as a query as to whether he was actually autistic.*
- [PS] I think so. And one of the great things you can get with a portal is access to that information. If you think about the ACT with their EMR they've implemented. Despite my comments about the antique architecture and encoding language that it's written in, it's got a brilliant consumer portal, and they've got over half the residents of the ICT have signed up for it.
- [PS] Now, if you take out all the people who have no interaction with the state health care system, you've probably got almost everybody who needs to have access to their state health information, have signed up for the portal, and they can see not only what's going on with their care, but they can see the records.
- [PS] And I heard just yesterday, on another national meeting I was on it someone who was saying they got their lab results before the GP, you know, onto this smartphone.
- [PS] So I think the [OpenNotes](#) is really important. I think it's important at a number of levels. One is that from a clinical point of view, I think puts a bit of discipline on us in terms of the quality of what we write and how we write. I think there's no harm in that at all.
- [PS] The other side of it is making sure that the information is right. I've had situations where I've had to sit on video conferences with my mother in law to correct information that I know is wrong about diagnoses of her that will result in wrong decisions being made by clinical colleagues. And so that I saw that information because I happened to be a doctor and could read his summary and see it was wrong but if you see yourself you know it's important that you can correct that information and because you can have really important implications for how you cared for.

- [PB] Yes, I just wanted to before we leave this topic, I just wanted to just go back to the previous one, just there was a comment about the understanding of one of the listeners is that until very recently, the large intimate EMR vendors were able to lock in the data, and external parties had to pay to access and that was what the legislative changes in the US outlawed. And so I guess, you know, so that's something that we don't want in Australia.

[PB] And the other thing that I don't want is I don't want a patient portal to be an either or with the Electronic Medical Record. It needs to interoperate.

- [HIM] I might just jump in to say, this is where there's a recognition that an ongoing investment in the My Health Record as a platform is an important one. Although I'm sure everyone that's joining us today, it's probably a variable level and mixed opinions about the usefulness of people's My Health Record. And you know, as someone that's previously co-chaired the My Health Record Improvement Committee that advises the Board on the product itself, I'm obviously a little bit biased to it. And I will be one of the first people to acknowledge that one of the really big challenges that we had there was that we had expectations that were set here (high) and we had a product that was delivered here (low). That in itself is not necessarily a reflection of technology, it speaks to the importance of how we actually talk about, conduct dialogue and set expectations for change.
- [HIM] But one of the important reasons for the ongoing investment in something like the My Health Record, is so that regardless of what independent actors states and territories different vendors do, you can be assured that there will be something that is sitting within the domain of government and the custodianship of government that is a point of access for you and your health information.
- [HIM] My Health Record probably initially had a value proposition as sort of the central repository into which all the information goes. I think that that value proposition is probably departed us a little bit now as we look about how the systems can actually just talk to one another.
- [HIM] But the My Health Record as a point of accessing information in terms of patient portal and visibility or a window into information about you and your health, never before has that value proposition been as strong as it is now. And that's one of the driving motivators behind the continued investment in My Health Record as a product.
- [PB] I've always tried to have my pom poms out for My Health Record. And as I say, I have been using it a bit more with a new app.

EMR and a more joined up health system

[PB] Harry, my next question is for you. Do you actually think an EMR could facilitate a more joined up health system?

- [HIM] I mean, fundamentally, yes. I mean, it's one of the one of the big problems that that we have is that we - and this is a problem I speak to a lot in conversations about digital, and I particularly like to make this point, probably rather provocatively, and audiences of mostly digital and health sector representatives is-
- [HIM] Your problem is that you don't collect enough data. Your problem is that you collect really bad quality data, and you don't do anything useful with it. We collect so much information.
- [HIM] The thing that actually supports us being able to provide care is the way that we're able to connect, share, validate, in some cases, update and verify the credibility of that information or correct it when it's when it's not right.
- [HIM] I mean, I've had examples, you know, I won't name places, but, you know, top performing hospitals in the country where four days prior to an emergency admission, I went to an outpatient clinic appointment, and we updated my medications list, and I just happened to end up in emergency at the same hospital four days later. And lo and behold, they turned around and said, "Are you on X, X, Y, Z medications?" And I went, "gosh, no, what are you talking about? That sounds months out of date. And that's it. How far back does that go?" No, go go. All that goes back to your last admission to emergency six months ago." And I went, "Hang on a second. I was in this hospital four days ago. Three levels up, we updated all this and you're telling me that down here in emergency that doesn't speak to a couple of levels up?" And that's the reality of the world that we live in.
- [HIM] So at that point, if it hadn't been for the fact that and something I encourage to do not as a not as a brand thing -and I say this completely independently that I have, for example, with my iPhone, I've set up my medical ID because it's a consistent point of reliable health information. I've used it a number of times. A couple of months ago had to call an ambulance for some pain related stuff effectively was in too much pain to communicate my preferences and information about myself, I unlocked my medical ID held it up and went, "read this." They looked at it, and it was so useful to them as a repository of information that they actually kind of broke the rules, and instead of taking me to their local base, they took me to the hospital, where all of my care is at. Because they recognised that I was complex enough that I needed to be where people knew who I was, what I'd been through, and where they can access that information that was necessary to support the highest quality and safest provision of my care. We have an ability to make that the standard.
- [HIM] I think one of the things that's really important to acknowledge and I you know, ahead of any conversation about sort of my own history and my own journey and health, I'll be the first person to

acknowledge the layers of privilege that I have experienced in accessing care. You know, I am, I am a white, straight, middle class, privately educated male, right, that comes with a package of probably some of the best fringing privileges you can have. But even I have fallen through numerous cracks in our system, hit walls of frustration and received care and being treated in a way that is unacceptable.

- [HIM] What that says to me, is if even the 1% even those with the most privilege, cannot access the care that they need, when they need it in a way that is safe and high quality and be listened to and respected as a patient. If we can't make that happen, what are we doing for everyone else? And the privilege that I have experienced in the way that people in individuals, mostly not the system, the system has often been the thing that we've tried to overcome or had to work around the off the beaten path that we have followed, where I have been guided by people, not systems, that has allowed for me to receive exemplary care should not be the exception to the rule. It should be how our system is fundamentally geared to support the provision of care. That should be our baseline.
- [HIM] And one of the most important ways of securing that is ensuring that underneath all of it, and working behind the scenes and being exchanged is the ability for me as a patient, my exercise physiologist, my clinical psychologist, for my GP, for my surgeons, my liver doctors, my gastroenterologist, my endocrinologist, etc, to be able to access the right information at the right time to inform the right decision making that is in the interests of me as a patient aligns with my values and my goals of care, and happens in a relationship which fundamentally respects and trusts me as a source of information about my own health that can be accessed and validated and is transparent to me.
- [HIM] And this is this is this is the really exciting thing about the opportunity that we have in front of us today is we really do you know, I often say, "it'd be great if we could just rip the whole thing down and start again". But in reality, the time and expense that that would incur is just beyond conceivable. This is the closest we've got to transforming and reforming down to the very core of our health system that we will have in probably mine and you know, a number of generations beyond that. So it's incumbent upon us to really come together as a sector and assist them.
- [HIM] And a conglomerate of, not homogenous communities of practice and belief and understanding and make these decisions in lockstep with one another in a way that is understood by and is present and is transparent to one another that such that the outcomes and the decisions that we reach are ones that we accept that we trust that align with our values, because at the end of the day, it's going to be us that rely on them to support our health and well-being.

[PB] Peter, do you think we can use digital health in a way to stitch up our health system?

- [PS] For sure. Look, I'm thinking of two slides I produced either years ago when I mentioned at that meeting in Sydney (Connected Care Community) that you were at a couple of weeks ago. One is

describing, summarising what you said about the quality and what we do with it. “Isolated islands in an ocean of opportunity” is how I describe our healthcare information.

- [PS] And My Health Record, which you [Pip] described as a Dropbox for PDFs, is part of the maturity journey, we need to get on to it where Harry's talking about, obviously, the digital health agencies working on making information more discoverable and federating. That is, joining up together a range of other isolated islands.
- [PS] So that someone like myself, if I see someone wash into an emergency department, I don't know where their last CT scan was held, I can go to the what they're going to turn My Health Record into, as a place to identify “Well, that's right, this person actually had that scan, their report's here”. And through that information exchange, I can pull those images to compare to the ones that I've done today. So that's the kind of thing the [Australian Digital Health] Agency's working on in terms of improving discovery and federating information across the sector, which is really useful.
- [PS] The other thing is the issues of the fact that we're not talking about a one big bucket solution here, and Harry also mentioned the point that it's in terms of the privilege of looking at information, not everybody needs to see everything all the time. They need the information that's relevant to them for the kind of role they play in your healthcare.
- [HIM] And so that there's an important piece here, around getting the consent workflows correct. There's an important piece here about that being informed and the right sorts of regulatory and legal frameworks around who's doing the searching for what to make sure that you can see who's doing what and you're comfortable with who's accessing your information. That it's for the reasons that that you're comfortable with.
- [PS] So there's some pieces there that I think, as I say, the Feds are beginning to make some noises about there's nothing formal yet, but I wouldn't be at all surprised to hear if they do open that conversation about sorting out whose eyes when and how. In addition to the work they're doing in terms of improving discoverability and federating their health information.
- [PS] And obviously, state EMRs are just a behemoth source of information around an individual. And within that is absolutely important gold that needs to be discoverable by others who sit outside of the health system.
- [PS] A concept that we developed when I was back at NEHTA was a thing that I called a Summary, a Shared Health Profile. People liked that word, so it got transitioned into Australian standard as a Shared Health Summary, which is what GPs are supposed to be providing up to My Health Record.
- [PS] I've had several GPs since My Health Record came about. None have sent up to My Health Record my Shared Health Summary. I go into My Health Record, in the consumer portal part of the solution,

because what it does is, it tells me just how ineffective our incentives are. For someone who's old enough and clapped out enough to be on more than a handful of drugs and has had a bunch of procedures that people probably need to know about, you know, we obviously haven't got the framework right yet. If it's something that I conceived of 18 years ago, my GPs aren't voluntarily and automatically doing for me, it motivates me is what I would say to keep working on it.

Comment from the chat:

On a similar note - I have difficulty having my health needs met by specialists across all domains. One reason I've narrowed it down to is that what my GP writes on the referral isn't necessarily aligned with what I actually want from the specialist appointment. That's despite my having a very good relationship with my GP. For a recent neurology appointment my GP told me that the diary I'd been keeping for many months was key for the neurologist to review. I emailed it to the neurologist in advance but they did not review it. I would find it very effective if I could upload my own notes, along with my access needs and so forth.

- [PB] Exactly. Very interesting. Yes, I was just having a quick look at my own Shared Health Record. I've been following these things; I jump on My Health Record horse quite a lot. My GP is actually not too bad.
- [PB] I just wanted to flag when you mentioned NEHTA [National Electronic Health Transition Authority], the that was the precursor of the Australian Digital Health Agency [ADHA]. Have I got that right?
- [PS] Yes, [NEHTA], the first attempt at a national coordinating agency didn't quite have the level of strong backing from the Commonwealth I don't think that the ADHA has nowadays. So it was sort of my feeling is, it was trying to please a lot of different stakeholders without a lot of aligning principles to support the work that that came out of it. But we got there in terms of a My Health Record solution, but it was the new agency, [ADHA] that delivered it not NEHTA itself.
- [PB] That sort of thinking, I think that's what Harry has been talking about, that he can feel that there's something shifting, I'm really hoping that's right.

Education and Culture Change

[PB] I just want to shift topic slightly, because this is one of the questions that came through from one of our people who registered for today, and that's the issue of education. We've talked about that it's not just an IT, project, it's a culture change piece, and a culture change piece, very often, as also has been reiterated in the chat in the conversation now, is driven by education. So I guess I'm seeing two different things. One of them is education, as in workforce education, and upskilling staff, and the other I see is education as in upskilling consumer reps. I wanted to talk first about upskilling the workforce. And this is really a question for either, but what do you see the role of consumer reps in education for the workforce to make sure they're more digitally up to speed?

- [PS] I'd like to hear from Harry first.

Consumer movement and education

- [HIM] And I think it's incredibly important. Look, to be honest, at this point in certain in certain areas, I think it's entirely appropriate. And it's something that I know, amongst our own community, does cause a stir because it raises the question of, well, if I work for [government], then do I really serve the purpose that I am here to serve?
- [HIM] But one of the things that we also really do need to understand is that change happens from inside the building, working with the teams. So if we build our tents on the street, and we refuse to move from there, honestly, there's a part of us that can't be surprised that we don't get let in the door, and we don't get to work with those teams to make this change.
- [HIM] I think there is I suppose there's a level of nuance and a level of maturity that it's necessary in navigating that relationship, and that's not something that you can just go and do a course in.
- [HIM] And I think one of the challenges we have in the consumer space is that for the most part, the point of inception for us, and our interest is that something went wrong for us. And we went “Gosh, this is crap, I've got to fix this”. And as a result, we've each taken our own very unique parts, you know, we may have found groups of people similar to us with similar, you know, similar or even the same motivations. But ultimately, if you zoom out in a weird way, as much as we might bemoan how siloed our health system in our health sector is we, as a community are siloed too. And that's something that we need to acknowledge and confront, if we seriously do want to be a part of this dialogue and decision making.

- [HIM] Because ultimately, I suppose, for me, that's sort of, it always come back to this question of, and I've carried it for years, this sense of credibility and impostor syndrome. And the question of, you know, "Am I relevant to the conversation that's happening here?" But it gets raised in in instances where, you know, I might be in a position of leadership in a project or working in a team working on a project or I'm sitting in a committee, and I'm the only consumer representative that just through chance and circumstance happens to have the intersectionality and right overlap of knowledge sets, in addition to my lived experience lens, that means I can contribute.
- [HIM] But as much as I can speak for, you know, arguably, probably a lot more wheel barrows of experience than any one person really should have to sort of lug around behind them in their life, I by no means speak for all.
- [HIM] And the challenge has been that in those situations, it has been my ability to speak the same language as the system and to work, not on their terms, but in a way that is amenable and trustworthy, credible to them, that has been my opportunity to get a seat at the table.
- [HIM] But the problem once there is that I become the only person and the one that everyone goes to. And that leads to really challenging situations where, you know, you might have a committee so one of the big challenges of committees with you know, with the token consumer on it is I've had instances where I've been in a committee meeting and we've turned to discussion on you know, how this particular issue or change that we're considering is going to affect indigenous and Torres Strait Islander communities. And everyone looks at me and goes, "Well, Harry, you're the consumer representative, what do you think?" And I go "Um, I don't know if you can tell, but I am 100% not the right person to be making representations on behalf of that community, I can't tell you any more, or offer any more insight than you could pick up off of a book, or a library shelf, or figure out from a Google search. You need to speak to and engage at a grassroots level with those communities.
- [HIM] So one of the challenges that we have in digital, and I think this is, you know, this was granted, one that I haven't got completely figured out yet, but I think the key is not so much the what it's, more of the how. And the how is the part is the active partnerships is that we work with the change makers. And we are less rigid in the way that we say, "I will refuse to sit under a hierarchy or bureaucracy." And sometimes recognise that in actual fact, you know, and this was a point of personal reconciliation for me, coming out the other end of that journey of two liver transplants, I had a really firm rule three years ago, before all this happened, that I will always work with, and never for. Obviously, now, having a role working half my week, advising federal department, obviously, that shifted for me.
- [HIM] And the key thing that motivated that shift was a recognition that in engaging with this team and this group of people, it was a recognition that our missions are actually the same. And if our missions are the same, it's not inappropriate, that we sit a little bit closer, or we sit at some tables that we previously might have gone, "that's a bit too close for comfort". So I think on both sides, there's a little bit of a necessary sort of cultural maturity and a growth aspect to it.

- [HIM] But I do also agree that that as a sector, and this is something that's a responsibility that goes both ways, it's unreasonable of government and the health sector to turn around and invite us to the table and expect that somehow we understand everything we need to understand in order to make an informed contribution and contribute value to the greatest extent possible.
- [HIM] But at the same time, it's not fair of us to sit here and go, "well, the government or the health sector, by inviting us should be the ones that offer all of it to us". We've got to find a hybrid and a middle ground of collaboration and partnership, where we both recognise that we're actually both really important to making this work. And we need to figure out how we support one another to grow and learn and integrate the ways that we work and represent and contribute insight and impact and value to achieve a common mission. That would be sort of, I suppose, my thinking around it.

Comment from the chat:

"There can never be a single 'representative' consumer or survivor who can speak authentically to all our needs. Consumers/survivors, like any cross-section of a population, are a heterogeneous group. In some policy circumstances, it is understood that our experiences vary in terms of demographics, identity, and culture, for example engaging with youth. However, independent of differences in demographics, identity, and culture, consumers/survivors also have differing experiences of mental health treatment and care. These experiences inform our views about what makes for a safe and helpful service. In practice, this means that engaging with just one consumer/survivor, or limiting engagement only with groups of people whose views are similar, can never result in an authentic, respectful, or effective engagement process."

Consumer co-design

- [PB] So what I'm hearing is that mixture of the importance of how we do it like that codesign approach and also that consideration around diversity of voice, and Vee I know you put a really useful and thought-provoking link in the chat. (<https://onlinelibrary.wiley.com/doi/full/10.1111/inm.12653> - I find this model quite helpful for considering how our experiences with care might inform our perspectives as L[ived] E[xperience] workers) There's that ongoing issue that we have as consumer reps around how we how we navigate that space. And certainly for this piece of work that the Health Consumers' Council is doing this period of time, we are looking find out what we don't know, and try to upskill so that we can be sitting around the table, hopefully with some diversity, hopefully with some understanding.

PB: Peter, do you have any thoughts about education for staff that involves consumers? Can you see an interest an opportunity?

- [PS] If I reflect on what's helpful from consumers, I think what's really important it is probably three levels for me. I think about that stories about what's working for you and what isn't a really powerful and have much more interest to policymakers and funders, then facts and figures.
- [PB] Okay, so, like some of the comments we've had today, I think it'd been super valuable that have really sparked that. Sorry, I interrupted.

- [PS] So begin with the story. I think that's really important. Like even I've been sharing stories of the experiences I've been having with my mother in law with people to help them understand things we're trying to solve.
- [PS] And I'd like to point out that our funders and policymakers don't really care about us clinicians, but they do care about people who might get sick and who vote. And so the more that you can give them stories that assist them to understand why digital health investments need to happen, and how they might help, based on lived experience is really important.
- [PS] The next piece is obviously the codesign piece, you know. If we're going to sort of build a workflow that's going to be centred around the interests of the patient, rather than a self optimising self businessman, which is what we tend to have otherwise, you've got to be in the room in those design things. And again, it's the user story is the important piece to centre the conversation around the outcome for the patient rather than the outcome for me.
- [PS] Because one of the huge challenges, information isn't captured and shared for free. There's a law of physics, it's the second law of thermodynamics that says you don't actually get information in an organised high quality way, share between people for free, it costs time, money, effort, and energy. So, so that we need to be around the table when we're designing solutions and workflows.
- [PS] And then of course, we always need you there, around the change management stuff. First, make sure that we use the tools in a way that helps you.
- [PS] I think that's what's one of the huge issues you have in terms of education is not that the education materials aren't fantastic, not that the staff know they shouldn't do those education materials. But what they don't do is think about the fact that their shoddy adoption of that training, is going to impact on their ability to use those tools to help you. And I think, having a consumer in in the room around that.
- [PS] Because Harry, I'm sure that there was a portal that that ED doc could have looked at, for your meds, or there was a specialist letter in the clinical record that he could have looked at that your meds, and the fact that they don't even think of doing that says something about us, and we need the story to remind us to do these things as well.
- [PS] So and obviously change management, when you're going to be the person using the tools yourself, obviously, you got a right in the middle of the room for that. So that's sort of my perspective on it.

[PB] Harry I can see that you wanted to say something. Also, can you think of maybe one or two or three things that we must we must focus on as consumer reps as we take this journey in Western Australia?

- [HIM] Yeah, on the education front as well, I think we've also got to look at education, not just in the sense of areas that that we don't know. It's a fantastic point that's been made about the fact that a clinician might not be aware that there's actually an opportunity for access.
- [HIM] A really important part that needs to fill a gap of education right now is, in our new generations of clinicians, is something like cyber security for example. But we now live in a world where there are, you know, substantial risks around, you know, information access, security and privacy. And that needs to be a core component of what they actually learn in their practising of medicine so that they have a

cognizance of how to safeguard and protect that in whatever format or organisation they happen to work. So there are a number of layers to I think, to the education piece. There's stuff that we know, for certain needs to be modules.

- [HIM] And then there's some other stuff that we've got to figure out. Because we've kind of all grown and got to this point organically and inherently in that, in in that organic process of growth, there is some chaos, and it's going to take some untangling to try and figure out what those common and consistent and really key threads are that actually need to be shared by all of us.
- [HIM] In terms of, I guess, sort of parting thoughts. Look, I would say the one thing I see so often that discourages people from getting involved in conversations about all things digital, they feel that they don't know enough or understand enough. And I really want to reinforce that you know, far more than you think you do.
- [HIM] But also I want to reinforce and validate the value of not knowing, because by asking simple questions, and by asking what admittedly to you might seem like stupid questions, you can reveal significant gaps and redundancies and inefficiencies in the way that we do things that no one else has been able to identify, because they think up here and they have never just stopped to actually examine a base assumption that they have been working. And by actually forcing the system and the people in it just stop and examine the assumption, by asking that silly question is an incredibly powerful, incredibly powerful tool and point of leverage that we have. So I'd really encourage you, regardless of whether or not you think you understand, obviously go out, seek and learn to the best of your ability. But don't be afraid to challenge assumptions and ask what you feel might be those silly questions, because more often than not, you're actually going to reveal that we're working on some pretty flawed assumptions. And it's an opportunity for the system as a whole to reexamine those assumptions.
- [HIM] Because I won't, for the purposes of the recording and language, I won't, I won't use the same words, but effectively crap in crap out. If our assumptions are crap, and we continue to work with crap assumptions, then our outcomes are going to continue to be crap as well. So you're actually doing us a favour by asking what you might think are simple or silly or stupid questions and challenging those assumptions. That's probably the first thing that I really want to encourage people to do and get engaged with.
- [HIM] The second I would say is, you look, I know, we're all really fatigued, as a sector and a space and a community. COVID was a really rough ride for us. It reinforced, I think, through a number of political mechanisms, the perception that we aren't worthy, we aren't as valuable, we're not considered to be as equal or important. It's a real shame that at a higher system level, those ways of thinking are what were left behind as a legacy.
- [HIM] But I really also think that we do need to give credit, and I suppose separate our thinking that very often we find frustration with the system, but there are incredible people working to support us every day. I don't personally, and I know we all have varied experiences, and yes, there are culturally things to work on. We don't all have good experiences with doctors and nurses and health workers. But generally speaking, no one turns up to work going, "I'm gonna do a crap job today." So we also need to give an incredibly strained, resource confined, overworked and burnt out workforce and opportunity to breathe a little bit and recognise that, rather than being another point of friction, in a pursuit of something bigger, we can actually offer ourselves as an ally to them in achieving that vision.

- [HIM] That for me, going back to the point about workforce, that's why I think seeing consumer representation as part of our help with workforce is so important, because all of a sudden, we're not two different actors, trying to find common ground from across the chasm, we're actually allies working towards a common goal.
- [HIM] Those I think would be would be the two things, ask the questions that you think are silly, I encourage you wholeheartedly to do so. And also, you know, as much as we ask, and we ask, just be mindful of, of what's happening on the other end of the spectrum in terms of the service provision, and the restrictions that they're working with.
- [HIM] And always ask yourself the question, is it a problem with the person? Or is there something around the process or a protocol or rule or funding, that's not allowing them to do their job and support you to the best of their ability? And if that is the case, congratulations, the two of you have just joined, just buddied up, and you know where to direct your frustration and anger and energy for change at.

[PB] Agreed. So that idea of being allies for change. And, Peter, any final thoughts from you?

- [PS] Just one thing, I don't think there is a stupid question you can ask, and feel confident that what you can share about your experience is more than valuable, than you spending time understanding a whole bunch of geek language.
- [PS] And so I would also insist on answers in plain English. If the geeks can't explain to you what they're trying to do in plain English, then then you've probably got a program that's not really set up for success anyway, because there is an art to that. One does have to be bilingual, but there have to be bilingual people in the room. Otherwise it geeks will be off and do whatever they're going to do, and it will not connect with you and meet your needs.
- [PB] Now on that wonderful note, we're actually slight just over the hour here and Kieran has put in the chat a link - we'd love to have your feedback on this session. And also a reminder that there's two more webinars in this series coming out. We've got one on Patient Reported Outcomes which is coming out on the 10th of May, and we've also got the really important one on data, use of data and trust, and that's coming up in June in early June, so we really hope you'll join us for that. And thank you for your presence today, Peter and Harry, thank you so much. It's been a really thought provoking conversation and very motivating. Thank you so much.
- [HIM] Always a pleasure. Thanks for joining us, everyone.