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Australian Digital Health Agency

INSPIRE

Interoperability and Standards in Practice: Innovation, Readiness, Education

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“Interoperability & Standards in Practice: Innovation, Readiness and Education – ***INSPIRE*** brought over 100 healthcare leaders and decision makers together headlining a week of digital health standards related activity.

*Influential speakers from across the globe spotlighted **key enablers** to success and acknowledged **contemporary challenges** and barriers impeding progress.*

*INSPIRE looked to promote a **mutual understanding** across the health ecosystem of what **strategic steps** are required to enable connected care, driven through the **adoption** and **implementation** of digital health standards.*

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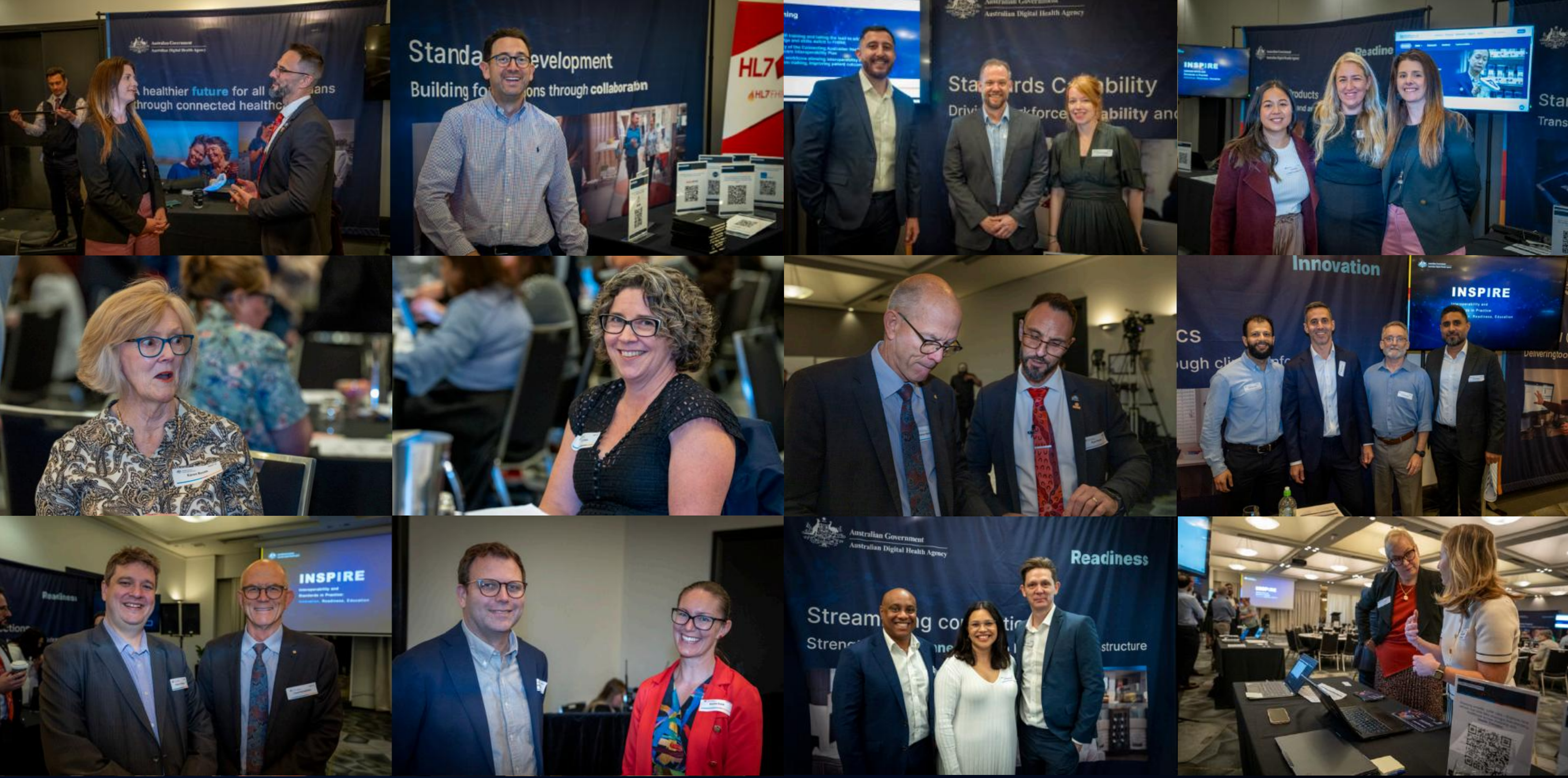

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Audience Snapshot

34%	28%	18%	20%
Government	Private Sector	Jurisdictions	Other (peak bodies, colleges, associations etc.)

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Who was at INSPIRE?

- MedicAlert
- Department of Health, Disability & Ageing
- Australian College of Nursing
- Primary Health Networks
- Standards Australia
- HL7 Australia
- Cancer Australia
- Ramsay Health Care
- Telstra Health
- Ageing Australia
- CSIRO
- NACCHO
- Australian Digital Health Agency
- Heidi Health
- Australian Medical Association
- Australian Industry Information Association
- Jurisdictions
- Royal Australasian College of Physicians
- SNOMED
- Australian Institute of Health & Welfare
- MTAA
- Public Pathology Australia
- Adventist HealthCare
- GS1 Australia
- Kudos Paediatrics
- St Vincent's Health Australia
- Royal Australasian College of Surgeons
- Therapeutic Goods Administration
- NDIS Quality & Safeguards Commission
- ACSQHC
- SANE Australia
- Patients Australia
- National Mental Health Commission
- HIMAA
- Pharmaceutical Society of Australia

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Opening Vision

“*It was in a small room **20 years ago** that health ministers proposed a joint federal, state and territory body to develop the building blocks for a national e-health system.*

*Uptake and utilisation was hampered by several challenges...distrust, lack of complete integration, lack of useful information, concerns about privacy and security, impact of giving patient control and varying support from governments. **Now, that has all changed**!*

*We're seeing the mindset of developers change from my product will do everything to **my product will do my bit really well**.*

*There is **unambiguous support** from government. Governments have realised that to deal with the explosion of health care costs driven by chronic disease, ageing populations and the availability of better and more comprehensive care, we need a digital health system that can make the **right information** available at the **right time**, to the **right person**.*

*The Australian digital health market size reached **$11.7 billion in 2020** and is expected to **reach $43.7 billion** in the next ten years, exhibiting a combined annual growth rate of **15.7%** - You don't get that growth without market confidence in the opportunities available.*

*There were a **quarter of a million** hospital admissions annually as a result of medication related problems (**98% of aged care residents** have at least one medication related problem), at an annual cost of **$1.4 billion**. There were also **400,000** additional presentations to emergency departments, likely due to just medication related problems. Now, it's been estimated that perhaps **50%** of that harm is preventable, but I wonder if it's not **90%**.*

*We know that putting more hospitals at the bottom of the health cliff will not solve **health care cost explosion**, and that wellness, maintenance and better care of chronic disease will be an essential part of our future - that computer in your own hand can help to **change your health trajectory**.*

Dr Steve Hambleton

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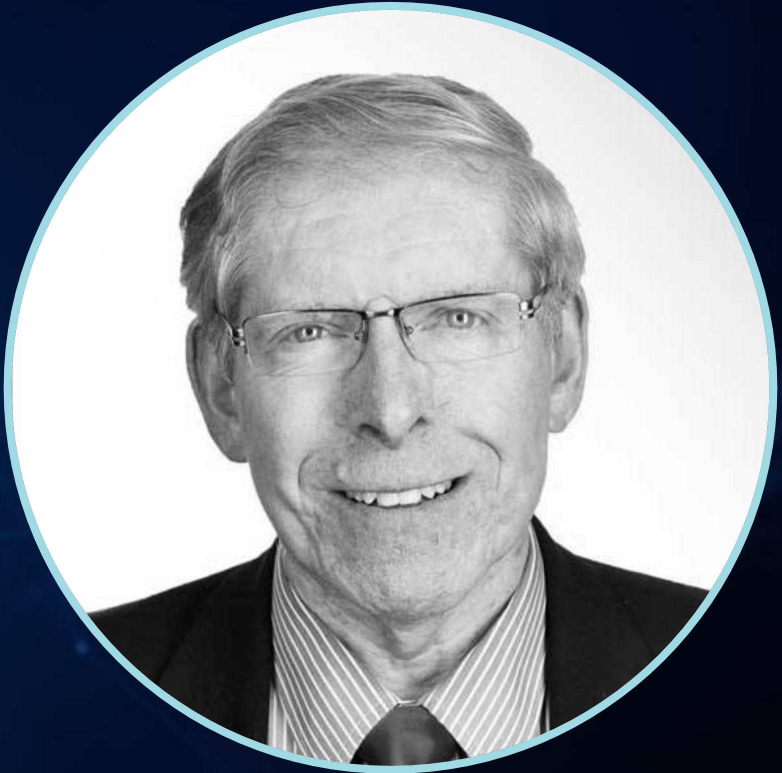
Consumer Keynote

> “Health care cannot achieve its **potential** unless information is available at the **point of need** - nobody can perform to the top of their **potential** if they don't have the facts, the data and the relevant information.
>
> You see, standardisation is a lot of work, right. But it's **compassion for the suffering at scale**.
>
> We need longitudinal health records with the data from all the providers - different hospitals can see each other’s individual lab reports but none of them can see a **composite picture**.
>
> A scan showed signs of potentially fatal toxicity. The report was **faxed to a wrong number** because they didn't have interop [interoperability].
>
> Pain, suffering and medical errors and **even death** can happen when the facts are not at **the point of need**.

PATIENT IMPACT REPRESENTATIVE STORIES

1. *Her records are across **23 portals**, and no single provider anywhere has the full picture. She herself, told of how she had to spend hours **requesting her records from 12 doctors** while she was sick enough to be in the hospital. You understand how senseless our even cruel that is. **We can do better**.*
2. *She had **treatment delayed three days and four nights** while doctors tried to retrieve her records.*
3. *She has had **three patients die** while awaiting records so that she could seek second opinions for them.*
4. *His case involved **extra suffering**. When they transferred him to a new hospital, they wouldn't give him pain medication or food until they went and got the medical record from the old place, which in 2009 would cost **$0.73 per page**, which was outrageous.*



Dave deBronkart

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The Human Standard

> "So what do we mean by the human standard? It's a standard that ensures that health care puts **people first**. It's the healthcare that knows that you're more than a person. You're more than a diagnosis, more than a bed number, and certainly **more than a line of code** and someone's algorithm.
>
> As technology is rapidly reshaping health care, implementing standards isn't just about today. It's about how we **prepare for the future**.
>
> We know what keeps planes in the air. It's fuel, navigation and expert decision making. A plane falling from the sky is unacceptable. In healthcare, what keeps us airborne is **information that is accurate, timely and shared**. When the information is available but not accessible, the **consequences can be devastating**.
>
> The Civil Aviation Safety Authority provides the science behind fuel calculations - **they don't guess they use standards**. In healthcare, we shouldn't be guessing either. We can't rely on goodwill and hope that information will flow safely. We need clear **technical and clinical standards** to help us calculate what's needed to keep the system running.
>
> If we can't see, share and trust the data, then we are flying blind. It's like having a **broken fuel gauge** in an aircraft.
>
> We know we fill the tank, but we can't see how much is left, how fast it's being used, or whether it's even reaching the engines until it's too late. In health, that uncertainty translates to **delayed decisions, duplicated effort, unmanaged risk, financial** and **human cost**. For governments and healthcare leaders, this is not just a technical issue, It's a **strategic imperative**.
>
> So, as with preparing a flight for takeoff, every healthcare decision, whether it's surgery or issuing a prescription, depends on **how much** information we have, **where** it came from, and **whether it's fit for purpose**.
>
> Unified governance is our **cockpit** and where we navigate. Our **leadership decisions** determine whether we stay level, change altitude or switch course. The human standard, that's our purpose, our flight plan. Information is how we keep **25 million Australians** travelling safely [on their health journey].

Liz Keen

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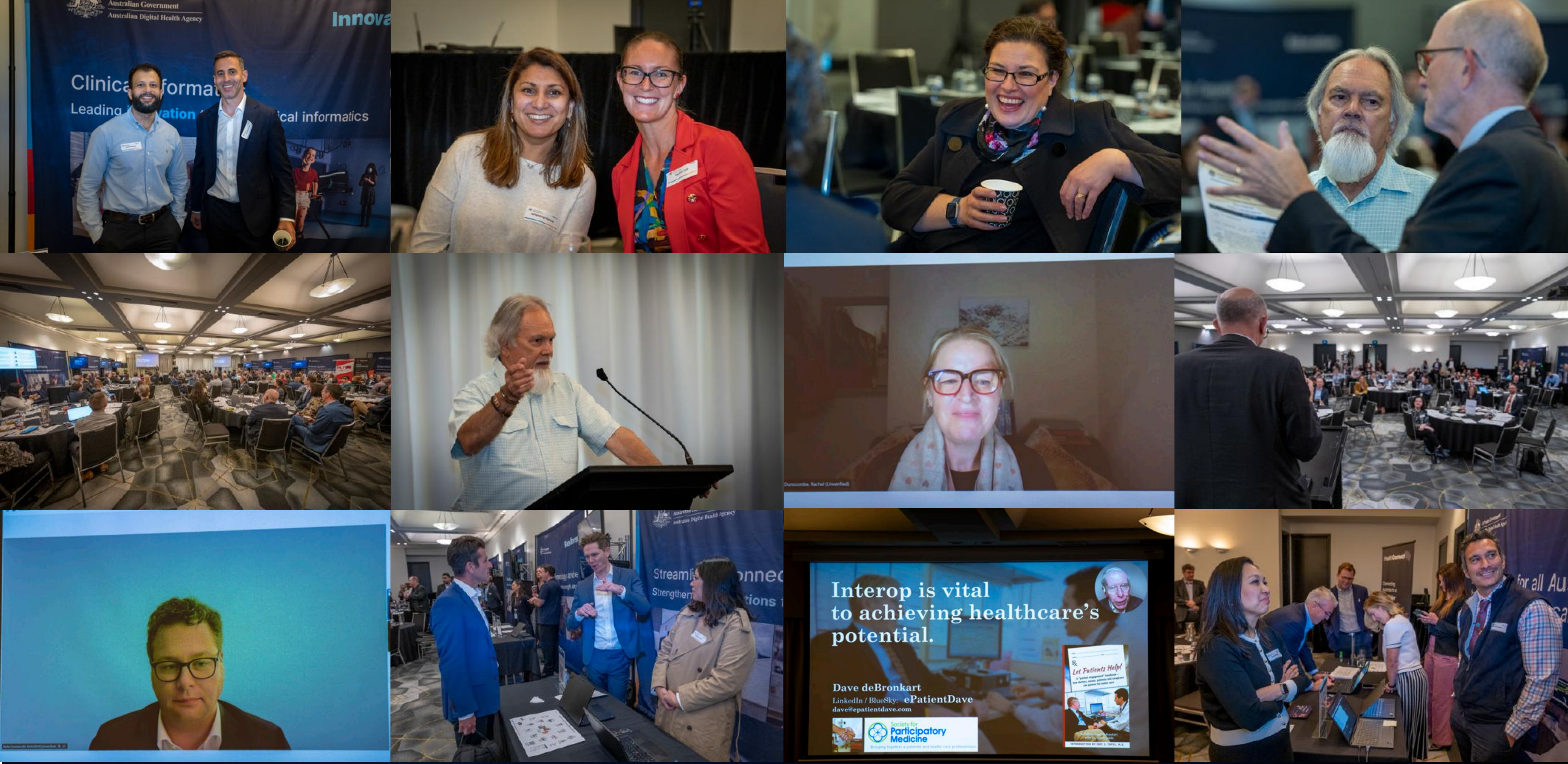

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Power of Collaboration

“*Digital health is inherently international, because **every country is facing the same health challenges.***

*We are at a crossroads where either technology shapes society, which is what we can see every day now with AI generated fake news, attacks on science and democracy, polarising debates and things like that OR **we can have society shape technology** and we do this by using standards because standards are not about the technology - they are about **codifying and translating our societal values** into the rules by which the technology can work within our society. Values like, autonomy and freedom and privacy and solidarity. So very core human and societal values and by using standards, we shape the technology into tools for the society that we want.*

*Half of our country [Netherlands] is below sea level and we learned a vital lesson early on that **you cannot fight the sea alone** - so we were forced to work together, and we created a **system of radical collaboration** where even competing groups must agree on common rules and shared infrastructure.*

***Australia is defined by distance**. From your earliest days, your challenge has been connecting a population across the vast and sometimes harsh continent. You needed visionary, collaborative solutions like the Royal Flying Doctor Service, connecting remote patients with critical care.*

*We [globally] have a narrowing **window of opportunity**, because what I see is that there's a lot of **political will** to leverage the power of data and digital solutions to improve health and care. Every country is now looking into how it can **relieve** some of the **pressures** on the health workforce. We see a lot of funding in **large investment programs**, **implementation schemes**, and **private investment** into capacity building worldwide.*

*If everyone is facing the same problems then the solutions are mostly **globally applicable solutions**. The best way to leverage our resources is to leverage the **economy of scale** and this is why global collaboration is key. GDP is a collaboration of now **42 countries** and the World Health Organisation. Together we have **more than 40% of the world's population**. It means that if we create aligned policies on interoperability or cybersecurity, we can push the needle, of the global markets, together.*

Herko Coomans

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Clinical Value and the Power of Standards

*“The faster we can get data in research, **the faster we can continue to change practice.***

*It's an important lens to appreciate some of the challenges of doing clinical research, particularly in a world like intensive care where there's **a whole lot of data**. We've got the information coming from the ventilator screen, all the settings of what's happening in terms of breathing pressures. Of course, all the observations from all the bedside monitoring, it's a lot, and that's just where we start, not to mention the other things that we like to measure along the way.*

*Access to data to data drives our research design. So basically, if we don't think we're going to be able to access it, we're probably not going to measure it. And we are struggling to find ways to make it faster and easier. Honestly, **electronic medical records are not designed for research** output at this point, and I get it - But I guess I'm begging that we really need to have the energy put into them so that we can now access that data that is dutifully inputted so that we can make meaningful change as a result of that [data].*

*We didn't have access to data to inform that guidance. It was based on sensible decisions, middle of the night conversations over zoom, trying to figure out what was going to be reasonable, to make sure patients still got treated and progressed. But it was made in a **vortex of data** and in an ideal world, what if we could have actually justified our decisions based on data*

*I would just like to talk about what I would like with a **magic wand**. In my imaginary world, researchers would be able to run reports on selected patient data from electronic medical records across the country. Wouldn't that be amazing for these patients? Without any manual entry, we could skip straight to the data cleaning phase at that point, and then the icing on the cake would be to integrate that with patient based health data from the apps, where they have consented to share this.*

*What the consumers are telling us is also what's good for research. There's a **beautiful synergy** there.*

Bernie Bissett

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Power of Getting the Data Right

"*It's taken* ***22 years to get this global consensus*** *that we've got to date, we've got over* ***4000 clinicians globally****, in a sort of Delphi like process that agree what needs to be recorded to* ***globally have consistency in the underlying data****.*

So why is the data so important? Why are we doing all of this work on the data? Well, ***data is now capital asset*** *and what do I mean by a capital asset – It's something that's* ***worth investing in long term****.*

Data that you collect from day one and indeed, even before you're born is really important and it needs to be person centric. OpenEHR is a completely person and citizen centric technology, and the aim is to ***allow you to carry your entire record throughout your entire life*** *and gift it to your family for research.*

The interesting thing with openEHR is it's completely ***language agnostic****. So it, does not deal with a single language – it can* ***overlay any language*** *on top of it. Which means we don't have to do translating and that's been one of the actual benefits and one of the reasons that they're looking at it because it reduces that load of ensuring that people receiving the record understand what was meant by the senders. It separates the identity of the individual from the record, and it allows the granularity to enable* ***privacy by design****.*

The data is the key to ***unlocking a lot of the initiatives*** *that we need to undertake and is the new infrastructure for healthcare systems, be it for improvement, be it for enabling the patient, be it for the new models of care that we want to deliver in a sort of distributed way.*

Quite interestingly, if it unlocks that ability for us to ***deliver care in the community*** *or near the home or in the home, then we can* ***reduce hospital sizes*** *and deliver care in more suitable places that happen to be* ***lower cost*** *for the whole system.*

It [openEHR] allows you to collect the data once in an ***optimally engineered format*** *and* ***use thousands*** *of times across a person's life for health care.*

Rachel Dunscombe

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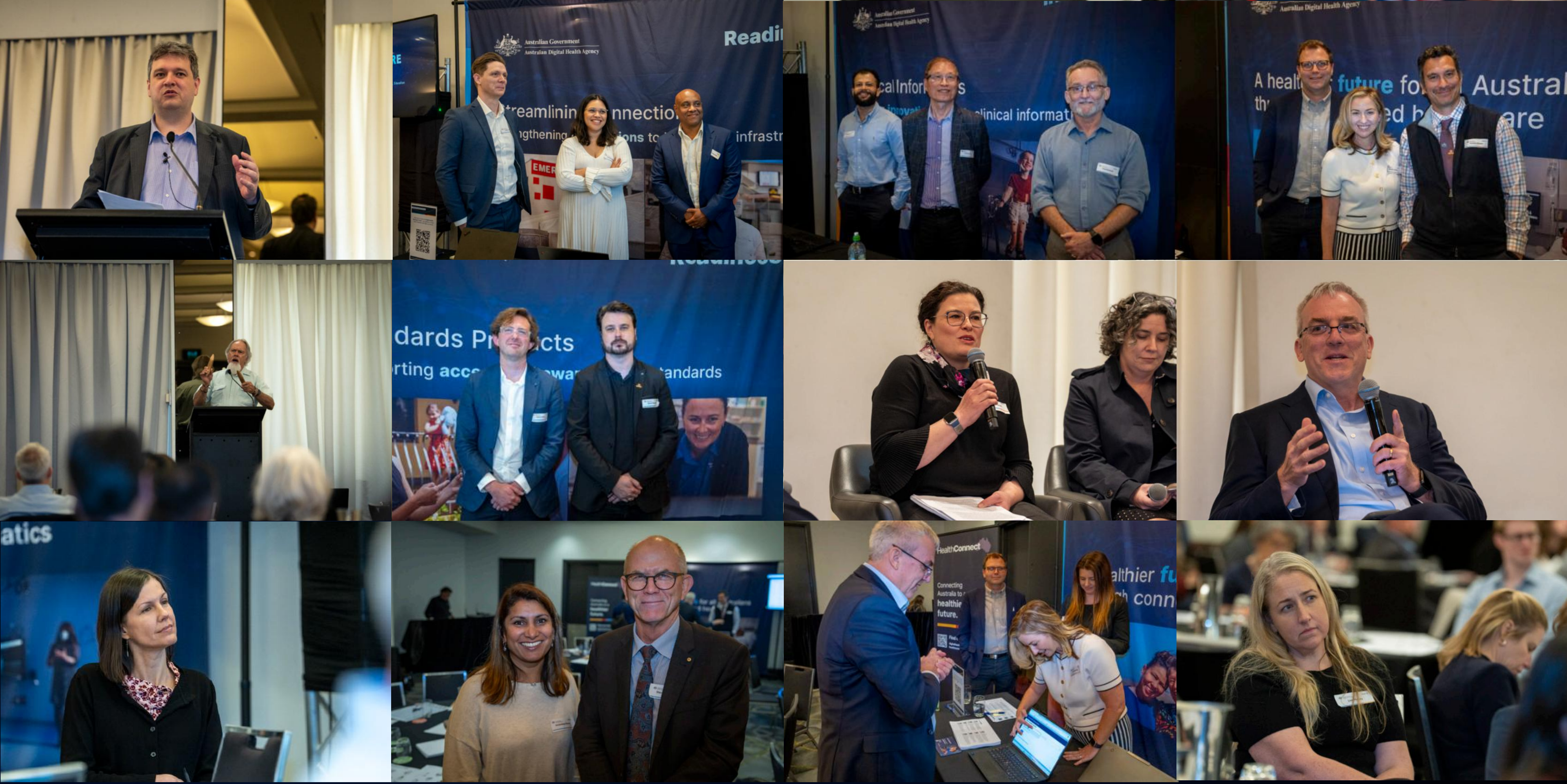

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Panel: Reflections from our CDO

> “What we're all focused on is interoperability within a healthcare environment, which covers a critical area, but it's a **small part of someone's life**, as you know.
>
> Over the next three to five years, I think that's where we see all those different barriers breaking down and the Agency is already doing more work with the National Disability Insurance Agency, with Services Australia, with Veterans Affairs, looking at some of these type of things, of **how do we bridge across that divide**.
>
> The next conversation we need to have with Australians is if this information is being **collected for healthcare**, are you happy to share it with the Department of Veterans’ Affairs or with Services Australia, or with an aged care provider to enable that care?
>
> Would I be happy for it? Yes, but I think that's one of those **conversations we need to have with the public** and it can get shared with their **control and consent**.
>
> That has to be **nirvana** of where we're heading. So, it's on the roadmap and we are working every single week with a number of other agencies across the government to look at how could we do this? What could be the next steps?
>
> I think it's probably still a few years away. **Moving into the care community** with disability care and aged care, I think **that's a lot quicker, a lot easier**.
>
> Moving beyond that to how does that data get shared with Services Australia and how does that data get shared with someone else is probably another few steps and requires a whole lot of both the **social licence** but also the **legislation change**.

Peter O’Halloran

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Panel: How can we be more ambitious?

David Hansen

*“The genomics initiatives that are around is a great space for it because there is so much, rare disease – so none of them have clinical trials. So, trying to find the best treatments for kids is a great example of where we need to **combine lots of patient data with the world of literature** and other things.*

Kathryn Briant

*“being able to really access enough information to, **prepare you as a consumer** for that next step in your care. Be able to look at a more complete data set and trends over time...dig deeper and be able to look at things like pathology tests explained to **better understand the data**.*

Rachel Dunscombe

*“it's about **falling in love with the problems** and deeply understanding the clinicians’ answers to some problems that we have. It's **getting close** to the **people at the problem** and understanding what tools you've got and what you should be using them for - not using a hammer for everything.*

Herko Coomans

*“if you want my practical advice, I would start with **giving patients control not just access over their own data** - the ability to share, to add their own data and to do things with their data. If you want ambition, then give it to the patients and, see what happens.*

Liz Keen

*“every opportunity I get, I'm lobbying for **policy change** around **clinical governance**. Why do I do that? Because that is the way that we focus on everything covered today – making sure we're looking at health outcomes and experiences. If we can get that part right, then the rest of it will **drive the innovation**.*

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Turning Standards into Action

"Patients and providers and indeed carers need access to quality, structured, harmonised information to be able to ***avoid harm*** *and to be able to do the best they can to work at their peak*

Most importantly, we have a ***limited window to act****. We've got the right ingredients to actually bring this together right now and ready or not,* ***AI is coming****. If we don't move, if we don't* ***get in front of this wave*** *and harmonise data with the appropriate standards, we may not be happy with what AI does and how it solves the problem for us.*

Let's take a look at ***why we need to decide to use standards****. If we look across the health system today we see bespoke terminology being used. We see free text persistent across all the clinical information systems, whether it's a practice management system, whether it's an EMR. Proprietary data sets are all across the place. We see* ***manual coding*** *for billing. We see* ***manual extraction*** *and massaging of data for research and for government reporting. So, all of this translates to suboptimal research and* ***disconnection of care****. What we see is, either standards being adopted in name only or ignored altogether. We see the health system connecting dots in bespoke, weird and wonderful ways to try to solve immediate problems because they're too busy, because they didn't know about the standards, or because they didn't understand the information that they were being given.*

What that essentially means is a health system disconnected from standards is a health system that is disconnected from care and that's ***what we're all here to solve****.*

We're building a ***community platform*** *where people with comparable roles across the health sector can come together and* ***network with peers****, as well as looking at access to all of those, standards, products and assets and artefacts that we've already talked through. So, think about being able to solve a particular problem in an ICU or with paediatrics, being able to talk to your colleagues, being able to think about what tools are there and being able to link in to the standards that are applicable, all in a* ***consistent space****.*

Ryan Mavin

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Agency Showcase

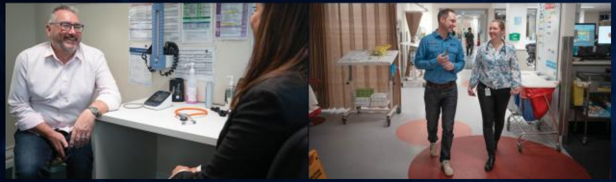
A healthier **future** for all Australians through connected healthcare

Standards Capability

Driving workforce **capability** and industry **uplift**

Standards Development

Building foundations through **collaboration**

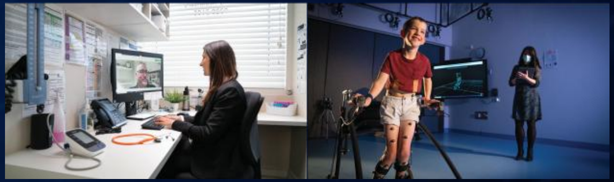


National Clinical Terminology Service

Delivering tools for **consistent** and meaningful **data**

Clinical Informatics

Leading **innovation** through clinical informatics



Standards Products

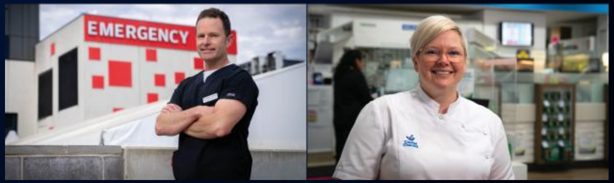
Supporting **access** and **awareness** of standards

Standards Program

Transforming the **vision** of digital health into **action**

Streamlining connections

Strengthening **connections** to healthcare infrastructure



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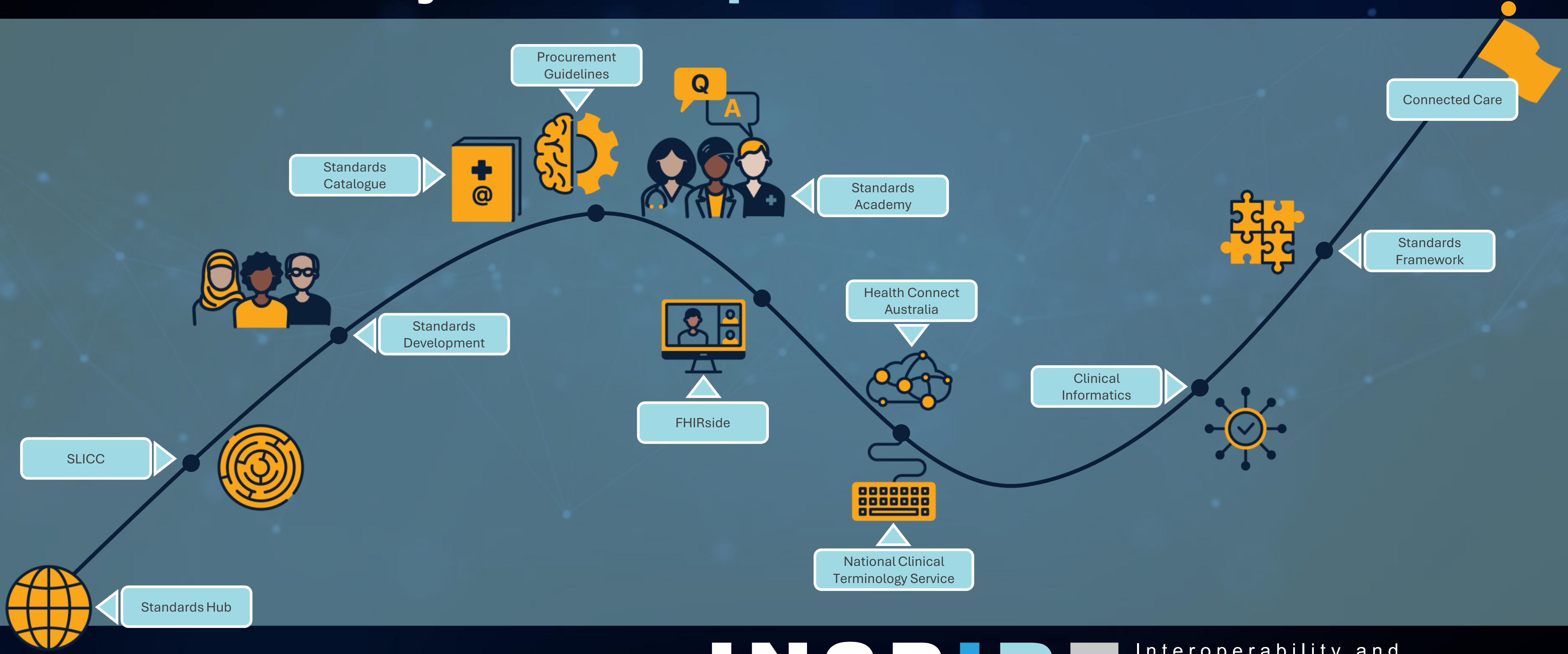
INSPIRE Day Roadmap



- Standards Hub
- SLICC
- Standards Development
- Standards Catalogue
- Procurement Guidelines
- Standards Academy
- FHIRside
- Health Connect Australia
- National Clinical Terminology Service
- Clinical Informatics
- Standards Framework
- Connected Care

Contact standards@digitalhealth.gov.au for more information.

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