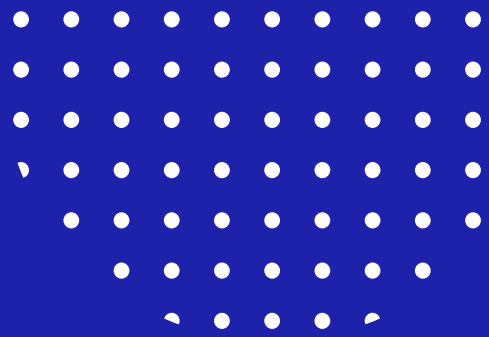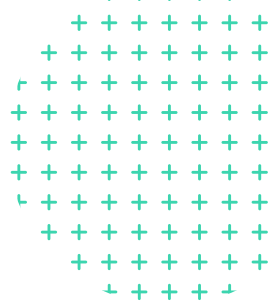# HIMSS

Laying the foundations for health data-based collaboration in Asia-Pacific

Building a framework for Asia-Pacific countries to realise the benefits of a shared health data space

Is there a need to share health data across borders? And if so, is this the right time to take stock of the health data landscape across the Asia-Pacific region, and consider the potential benefits of a common approach to data sharing – a framework in which key dependencies, challenges, opportunities, and strategies can be identified, pooled and learned from, leading to the implementation of an Asia-Pacific Health Data Space?

These fundamental questions provided the starting point for a multinational APAC Health Data Space Summit, held on 18 September 2023 as part of the HIMSS23 APAC Conference and Exhibition at Jakarta. The summit was attended by representatives from regional ministries and multinational healthcare organisations – all of them in a position to influence direction and thought leadership, and many of them reflecting experiences close to the front line of digital health provision. Countries represented included Australia, Hong Kong, India, Malaysia, New Zealand, Singapore and South Korea. The event was held under the Chatham House Rule, and participants quoted in this report have been anonymised.

TOWARDS A COMMON APPROACH

The summit was led by HIMSS President and CEO Hal Wolf, who set the scene for the discussion by suggesting that despite the variations in progress in healthcare systems throughout the region, there is more in the collective experience to unite rather than divide APAC nations in their quest for the benefits of sharing health data.

Wolf stressed that this was not about taking a one-size-fits-all approach. He reflected on a similar event held in earlier in the year at the HIMSS Conference and Exhibition in Chicago, which revealed that regions have many common challenges when it comes to health data sharing, but each one is also unique in its needs and complexities. "As we know in healthcare, when you've seen one hospital, you've seen one hospital, and when you've seen one country, you've seen one country. And if you've seen one region, you've seen one region," he said.

He suggested that there are three levels of experience among the region's hospitals:

- "Gems" – well-performing exemplars that have benefited from advancement and investment;

- A large middle group that has started to make progress but are yet to define the ability, financing and expertise to drive a digital health strategy; and

- Those with the greatest need – hospitals that have not yet begun a significant digital health journey, particularly at a clinical level.

Kickstarting the discussion, Wolf posed some key questions. "If all this is true, then what can we do together in a common framework that can help us all advance?" he asked. "Where can we go to share our stories, our outcomes – not just the victories, but also where the troubles have been, so we can learn from our mistakes? And is this a good time to think about a common approach with the region?"

Wolf acknowledged that by looking at the potential value of a health data space from a public health point of view, the spectrum is necessarily broad. Dealing with high-level public health targets speaks to the exchange of data and information, especially during the time of a pandemic. But he suggested the crossover is to recognise that all the way down to an individual level, what used to be a broad separation between public health data and data gathered in clinical settings and apps is no longer there. Data is all now coming from the same place.

"We should recognise what a short journey it is from public health to the individual," said Wolf, adding, "But pandemics reveal the just-in-time nature of the need for health data sharing, particularly on a regional basis. And that's why it's important to identify the building blocks of a common approach."

A participant from Australia agreed that this is a good time and said there are exciting initiatives happening in some Asia-Pacific countries that are looking to invest in their health services and digital health technology. This would be an opportunity to transfer some of the learnings from countries that have been making this investment, including the United States. They said that the combined impact of significant spending on technology, the 21st Century Cures Act, and associated regulations are creating some great examples of standardisation in the exchange of information and interoperability.

There is no question that the time is right, a participant from Singapore also agreed. But they also said it was important to ask 'Why?' and 'How?'. "Is the reason for sharing because patients are very mobile and they're moving across different countries, or is it a need to share anonymised data for the purpose of understanding disease patterns or policy needs?" they asked. "From there, you can probably then think about the how."

Another Singaporean participant observed that most countries represented at the summit would probably have legislation that supports data sharing in one way or another. But for some others who were absent, the challenge would be having the legislation to support health data sharing domestically before contemplating a common approach. A separate challenge would be landing on common terms, concepts and terminology, as well as the supporting domestic legislation. "How do we even find the middle ground for a lot of different countries, what they can subscribe to, and what is acceptable in terms of borrowing some of these good ideas or practices and bringing it into their countries?" they asked.

A representative from New Zealand said the desire to move forward with data sharing is strong. But the lack of political will is an obstacle. "Do we actually have the political will to say, people who are not doing data sharing – can you consider doing some data sharing? Do we have to have a legal platform in order to enforce that you will share?" they asked.

"That's controversial, even within New Zealand. So, the idea of international data sharing might be even more broadly politically controversial. But that just makes the idea of starting from a collaboration standpoint even more appealing because it sets the right tone from the ground up."

A participant from India offered an example of the benefits of a common approach – the development of an mRNA vaccine within 100 days of the first sequence of the latest coronavirus. They said that the experience of people outside health ministries has provided the opportunity to use common data models, learn insights and use the data for commercial interests, and that decision makers should build on that.

"It was only possible [to have the mRNA vaccine] because there was an established mechanism under a proper data sharing, global coordination mechanism that countries could submit the data to," they said. "Do we want to be caught unaware when the next pandemic or threat hits us? Because in the middle of the pandemic is when we were sorting out how to share information about vaccine certification."

A participant from Malaysia endorsed this point but said that one of the major challenges to a common approach is the willingness of countries to participate – particularly when it comes to public health. They referenced IHR 2005, which requires countries to submit data for infectious disease, and said it is struggling to get all countries to report on certain illnesses. "It [a common approach] is a must," they said. "But we need a methodology of how we are going to do it."
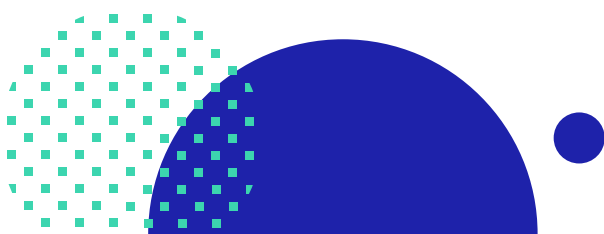
KEY BUILDING BLOCKS

Following this conversation around the timeliness and challenges of implementing a shared health data space for Asia-Pacific, the summit focused on the specific elements that could form the foundation of this space. Six areas were defined for further discussion:

1 Governance

2 Data access and use

3 Standards and frameworks

4 Workforce

5 Sharing innovation

6 Technology, technological capability, and maturity

An informal poll was held among participants to determine the hierarchy of and relationship between these areas. It quickly became clear that the diversity in perspectives and experiences made a consensus unlikely, even among representatives from the same country, and this was a useful reflection of the granular challenges faced across the region. A number of significant observations were made during the conversations.

Governance

Data governance emerged as a major theme, particularly in a cloud-based world, and in APAC where there is a lot of cross-fertilisation between countries. A Malaysian participant noted that people still subscribe to data being "in the country" and this is fundamentally one of the greatest challenges. Wolf agreed that rules around "data can never leave my country" don't work that way anymore, particularly in a cloud-oriented world.

He said that a good starting point might be to look at governance with a 'small g'. "If we can talk about how we're doing things at the country level and then share, it can help to create some backbone for the political will," he said.

An Australian participant suggested it might be helpful to look at ways in which other initiatives are benefiting from shared data, including the Global Digital Health Partnership and the International Patient Summary. Wolf suggested that some of these collaborative partnerships had struggled when it came to regionalisation, and it was important not to lose sight of the regional aspect. "There's something unique [in APAC] in the challenges, especially around workforce and especially around the data sharing on a 'small g' governance standpoint, the how and creating the frameworks of standardisation," he said.

"I think what's interesting from a regional perspective is we've got a lot of focus in Australia and New Zealand – and I expect other countries within the region – around primary and community care," said the Australian participant. **"And a lot of our interoperability strategies are around the community, the community care, and the primary care and how we support that interoperability to the tertiary care and not just being focused on interoperability within the tertiary care system."**

They added that there's a lot of work happening throughout the region which would be useful to share and collaborate upon.

One of Hong Kong's representatives questioned the value of shared governance, given the unique political scenarios in each country.

A representative from India suggested one approach could be for governments to adopt a more directional role – as was the case with the development of their country's unified payment gateway, for which it outlined the architecture, created a reference architecture and a number of 'sandboxes' for innovation.

"Similarly, currently in our national digital health implementation roadmap, we've created a national reference architecture and created a sandbox," they said. "If you want to be part of the ecosystem that is going to contribute to development of an electronic or maintaining electronic health record or interoperative, all of that, you have to comply through the sandbox and get certified. So, can the government's role be a little more of giving directional indications, setting these broad rules of the game, and facilitating innovation rather than getting into who really needs to annotate the EHR? Because when it gets too granular, you get lost in the details and are not really be able to do the governance with a capital G."

Data access and use

The conversation around data access and use centred on data ownership and the tension between, for example, a patient being able to alter their health record to avoid sensitive information being made available, and the consequences for clinicians and institutions – the challenge posed by alteration versus annotation.

"It's a core element," said Wolf. "Because regardless of who may own something, access to it from a public health standpoint is extremely important to know what's occurring, and then the protection of it on a use standpoint at the individual level, from a security and privacy standpoint, that's where it becomes incredibly important to the individual as well. If you have trust on usage, access becomes much less of an issue."

Standards and frameworks

A Singaporean representative, who considered the list of building blocks from a regulatory perspective, placed both governance and standards and frameworks at the top of their list, and qualified this by saying, "We do have to assess the capabilities of the countries before we can share standards because we need something that everybody can participate in."

For Hong Kong's participants, standards and frameworks emerged as priorities, supporting data access and best practice, with the sharing of expertise and innovation also important.

Malaysian participants were united on their top three priorities – governance, standards and frameworks, and technological capability – but not on their order of importance. These priorities were also voted for by the South Korean representative.

This was a notable contrast with the Indian participant, who ranked data access, workforce and sharing innovation as the most significant.

An Australian representative suggested that time constraints and political requirements are one of the biggest challenges to having a roadmap and realising benefits – at a hospital, regional and national level. "The first thing to go is always standards and frameworks," they said. If something takes too long, and a solution is available now or appeals to the clinician, that's the short-cut path which gets taken – at the expense of benefit realisation.

Workforce

Wolf said that the WHO and other spaces are reporting significant workforce challenges – not just in terms of a shortage of clinicians, but also a lack of technical expertise at the CIO level. "We heard that very clearly from our own adviser group last year that in many situations, we have CMOs who are doing the job of what we would traditionally think of as CIOs or CMIOs," he said. Wolf suggested that some of these incumbents may not have the strategic view of technologies like cloud which may be required to drive digital health forward.

A second participant from Australia said the issue is not limited to the clinical workforce of informatics specialists, but also extends into the tech industries. Graduate developers go into other areas than health. "I think it's the most exciting time to be in health," they said. "But you've got a hospital that wants to move forward but they can't get developers to work with them. The [tech] company wants to support the hospital, but they can't get developers to work with them."

New Zealand's representative placed workforce second in importance after governance. "If you don't have a well-enabled workforce, then your development of standards and frameworks won't make sense," they said. "We've had a lot of experiments and failed attempts at developing standards and frameworks that just haven't been appropriate because of this."

Sharing innovation

One representative from Singapore identified workforce as the most pressing issue, followed by sharing innovation and technological capability. "If it is done properly, sharing innovation is a way of building confidence – showing that you're willing to share good practice – whether it's in the area of efficiency improvement, patient care or patient experience," they said.

"So, all these innovations become the catalyst for people being willing to say – hey, I think I can use that too. And that starts the trend to be able to trust each other and go beyond innovation to data. And of course, the technology capability is the basis on which all this can happen. So, an amount of maturity is needed too."

New Zealand's participant put sharing innovation in third place, and said it had to be done in a meaningful way. Ideas are easy to share, they added, but the challenge is implementing the solution that comes out of it.

A clear dependence exists between innovative technology and improving processes for the workforce, said a participant from Singapore. "Those go hand-in-hand as important functional requirements," they said. "At the end of the day the patient will benefit. If you have a happy workforce and they have good support and they're efficient, the patient will be happy as well. It isn't just that care quality is improved – the whole experience is improved. And that's where innovation comes in – successful integration between the workforce and improved technology. If that is shared, it will improve a lot of the things we're trying to solve today."

India's representative suggested that innovation could stem from a process, or the way data is used rather than simply from developing a 'shiny new digital app'.

A participant from Hong Kong noted that people working on technical projects and innovation are usually happy to share. They also suggested that sharing how an individual solution has adopted a 'supernational' innovative technology from, for example, Google or Apple, might mean it could be copied across the region.

The significance of this point was acknowledged by Wolf, who suggested that too often, market suppliers are kept at arm's length during these conversations when they should be heard and encouraged to participate in digital health discussions.

"If the cloud suppliers don't want to go there, we need to understand why and collectively, potentially have a point of view as to why we would want to persuade them to do so," he said. "I do think that's really important because if we had a view of governance that allows access or use of data for informational purposes at a population health level, how they develop that infrastructure is important in terms of the sharing at a data governance level."

Technology capability and maturity

A participant from New Zealand suggested that there are two aspects to technological capability and maturity. The first is solutions themselves – how well the tech workforce can interface with the technology and craft usable solutions. The second is the technological capability of the workforce. "Having an assessment framework of each of those levels could potentially be helpful for targeting resource allocation, the division of time and effort, and figuring out what's falling downside so you can prop it up a bit more," they said.

Wolf welcomed this idea. "We're talking about technological capability and maturity in terms of the measurements of where facilities, systems, regions or countries are. And we're also using it in terms of the individual and the maturity of our workforce," he said.

One Singaporean representative said: "Technology capability is the basis on which all of this this can happen. So an amount of maturity needs to be there in order for this framework [we are discussing] to happen."

Several participants felt that the overlapping and inter-dependence between the categories meant they should be grouped together.

"I think governance and data access overlap, and probably standards and frameworks, and technology capability and maturity, overlap enough that you could address them all in the one category," an Australian participant said. "And then I think workforce and sharing innovation… Because I think that sharing innovation builds on the other things. If you don't do the other things, it's much harder to have meaningful sharing of innovation."

The inter-dependence of many of these building blocks was also picked up by another participant from Australia, who suggested that innovative digital health projects can fail to realise benefits because of the design trade-off decisions that are made along the way. "If your goal is around interoperability and your benefits are based around the goal of interoperability and use of data, then there's certain capability maturity and technical maturity you need around standards that are going to enable that," they said. "If you make a design decision and throw that out, you may actually not ever get and realise those benefits."

NEXT STEPS

Following this extensive discussion about the key building blocks of a regional framework for sharing health data – and their inter-dependence – Wolf placed them in 'buckets' that complemented their dependencies:

1 Governance, data access/use, standards and frameworks

2 Workforce and technical capabilities (acknowledging that there is a dependency on the workforce in order to do the measurements)

3 Sharing innovation

"The question then becomes how do we take this forward and what does it look like?" he said.

Wolf suggested that following the summit, summaries of the three 'buckets' should be circulated to interested individuals – including those from countries who were not represented at the event – as a way of building momentum for a collaborative regional approach to the creation of a shared health data space. He also suggested the formation of workgroups focused on each bucket to exchange ideas and identify potential areas for sharing experiences and expertise.

On governance and data access, for example, there was agreement that studying those countries with relatively advanced models and compiling a best-practice document would be valuable. With workforce identified as a longer-term aim, the other main focus should be technology capability and maturity.

Wolf concluded the summit with a request for participants to consider the importance of trust in building any kind of framework for health data sharing, and in their responses to the ideas pulled out of the conversation for further development.

"I would ask you all to think about what would qualify as trust, or barriers to trust, in terms of adopting [a framework]," he said. "At the individual or governmental level, there's a feeling that if data usage, for example, is left to anyone, you erode trust. If data is held in the hands of big conglomerates, that should be called out. Is there an element of trust if data has to be held regionally versus internationally? That could be at citizen or government level. So, I would just ask you all to put that filter in place when it comes to thinking about your responses."

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