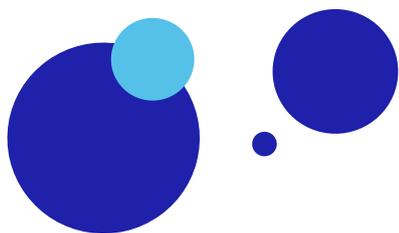


EXECUTIVE SUMMARY



This paper assesses the current state of cross-border health data sharing in a pandemic-influenced world, and the incentives and opportunities for APAC nations to resolve the many health data sharing challenges – strategic and operational.

It considers the role that frameworks proposed by global and regional consortia for financial and economic cross-border data flow might play in creating models that, with adaptation and policy-making input from all stakeholders, could enable sharing for the unique and specific aspects of health data. It also looks at the potential of the EU's EHDS proposal to provide a blueprint for the building of a regional health data space, with recommendations for governance and risk management to ensure the preservation of data privacy.

The paper shines a spotlight on the preparedness for health data sharing in a number of APAC countries: China, Taiwan, Australia, Hong Kong, South Korea, Singapore, New Zealand, Vietnam, and India.

It reveals how wide discrepancies in digital maturity, health systems interoperability, regulatory frameworks, privacy laws and specific responsibility for health data governance create a patchwork of inconsistency across the region. The paper categorises these countries as Advanced, Intermediate and Basic in their levels of preparedness.

It is notable that even in the most advanced digital health ecosystems, key challenges must still be resolved. Countries at the basic level have the most to do, but also the advantage of an opportunity to incorporate health data sharing as a central element of their evolving digital health systems. For all of them, the recommendation is for policymakers to focus on harmonising data sharing regulations and governance within their domestic health systems, in readiness for unleashing the potential benefits of cross-border data flows.

The paper outlines the long-term limitations and restrictions for collaborative research which are inevitable if the region does not rise to the challenge. This will be an opportunity for APAC nations to be an important influence on the evolution of global health data sharing frameworks, which will bring benefits to at every touchpoint across the digital health spectrum, from population health management policy to research and development, improved diagnostics and care models, patient outcomes and the ability of the individual to realise the value and take control of their own health data.

The paper concludes with a number of recommendations for policymakers to consider in order to continue the momentum generated by the pandemic, whatever stage of preparedness for sharing cross-border health data they have reached, including:

For countries at a basic level of preparedness:

addressing the challenges of digitalising health data and legacy manual systems, and accelerating regulatory development specifically to address the nature of health data.

For countries at an intermediate level of preparedness:

introduce specific consideration of health data within wider data sharing frameworks and policies, and consider the creation of a national level body to be responsible for the governance of all health data for primary and secondary use.

For countries at an advanced level of preparedness:

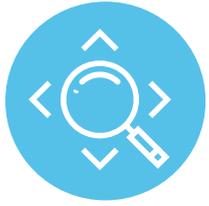
champion and lead the APAC region's ambitions to influence the development of global frameworks, and to address the significant interoperability challenges that health systems are facing in the long journey to digital maturity.

Cross-border health data flows in Asia-Pacific: breaking the ties that bind digital transformation

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OVERVIEW

Globally, there is a tension between more progressive approaches to enabling cross-border data flows and the caution of governments when it comes to the protection of data as an asset frequently dubbed “the new oil.” This tension is pulling in both directions.

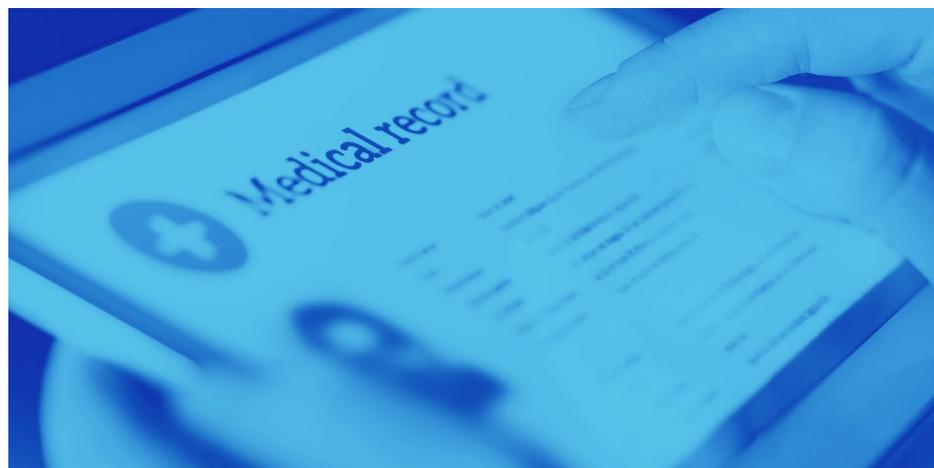
On the one hand, we have seen a rise in the number of frameworks proposed by global organisations such as the World Economic Forum (WEF) and the World Health Organization (WHO) for unlocking the collaborative power of cross-border data sharing. Many bilateral agreements are also being made between individual states, each of which offering its own model for creating a secure data-sharing route.

On the other, a complex combination of political, cultural, and practical challenges is causing some nations to build regulations that either inhibit data sharing or tacitly make it as difficult as possible to embrace the benefits that could be unleashed. The result is a growing trend toward data localisation rather than opening up to the possibilities that access to shared information can bring to stakeholders in every sector.

The challenges are particularly acute when it comes to health data. Largely from necessity, the Covid-19 pandemic triggered a major easing of data sharing restrictions, without which the speed of vaccine development and the management of population health in the face of such an aggressive new disease would have been considerably hindered. This temporary relaxation shone a fresh light on the potential for health information to play a key role in the wider global data economy.

In a paper published in 2020, The Global Data Alliance (GDA) noted the dependence of many remote health services on cloud-based platforms and technologies that might be hosted in another country.¹ “Countries can promote diverse healthcare delivery options for their citizens by ensuring that data transfer restrictions do not unduly interfere with the ability to offer secure and private remote healthcare services,” it said.

The rise of data-dependent digital health services in the wake of the pandemic could hit a major roadblock without the formation of policies that encourage and support their development. In this respect, patient populations tend to be ahead of their governments. They understand the importance of sharing their health data and its value to society. If governments are to capitalise on that, they will need to pursue policies that educate the general public about the benefits and advantages of personal information ownership, and making informed choices about how it is used.



¹ “Cross-border Data Transfers & Remote Health Services.” Global Data Alliance. September 2020. <https://globaldataalliance.org/wp-content/uploads/2020/09/09152020cbdtremotehealth.pdf>

Due to its complexity and sensitivity, many governments have been content to allow health data to fall under the broader regulation of data protection laws. Like the General Data Protection Regulation (GDPR) in Europe, these have been years in the making and can be slow to accommodate a change in perception of the unique value of health data – and its potential for advancing the quality of patient care, improving diagnosis, managing population health, developing better-informed health policies, and enabling collaborative research. But now, the rise of AI and machine learning in health research and care delivery is giving a new impetus to initiatives for opening up cross-border data flows.

The WEF recently observed that no country alone can hold the volume of data needed to help every patient with a rare disease.² Collaboration among countries with a similar sense of purpose to create transparent and interoperable health data-sharing frameworks that meet regulatory requirements and define good governance should be top of the policymaker's agenda.

This paper examines the complex picture across the Asia-Pacific (APAC) region, and places it in the global context of emerging frameworks and models for health data sharing. It considers the opportunities that can be realised in the region if major challenges are overcome: the wide disparity of digital maturity levels between APAC nations; lack of interoperability within national health systems; draconian data protection laws; and stringent data localisation trends. The paper will also make the case for policymakers in APAC to become champions for unlocking the power of cross-border health data flows for stakeholders at every touchpoint across the health sector.

Before we take a closer look at where APAC nations stand with regard to their readiness for cross-border health data sharing, however, it is important to understand two ideas that will frame the discussions in the rest of this paper: why cross-border health data flows are a necessity rather than a “good to have”, and how health data's standing in the global picture affects cross-border health data flows today.



² “Sharing Sensitive Health Data in a Federated Data Consortium Model, An Eight-Step Guide.” World Economic Forum. July 2020. https://www3.weforum.org/docs/WEF_Sharing_Sensitive_Health_Data_2020.pdf

IMPACT OF CROSS-BORDER HEALTH DATA FLOWS

There are largely three areas in which we can see the benefits of cross-border health data flows: research and development, patient access and outcomes, and the economy.



RESEARCH AND DEVELOPMENT

In some respects, the post-pandemic world of healthcare provision is defined by the rise of data-enabled services. And our ability to respond to pandemics and world public health crises depends on global cooperation. But without the creation of informed data-sharing policies, the opportunities these services create for digital health innovation will be stifled.

The pandemic also gave us a snapshot of how the easing of cross-border data transfer restrictions can accelerate research and development in every aspect of healthcare provision. The greater the range and quality of data, the more granular its use can be throughout the research, development, and post-marketing phases of new technologies and biopharmaceutical products.

In the area of drug discovery, the potential time and cost savings are significant. According to some estimates, AI-powered data analytics can accelerate drug discovery timelines by up to 50 percent in terms of time and save up to \$26 billion in costs annually.³



³ "Cross-border Data Transfers & Biopharmaceutical Research and Development." Global Data Alliance. September 2021. <https://globaldataalliance.org/wp-content/uploads/2021/09/09092021cbdtbiopharma.pdf>



PATIENT ACCESS AND OUTCOMES

As people travel across countries for professional or personal reasons, it is not uncommon for some to need emergency or non-emergency health services while they are abroad. In those situations, ensuring correct treatment often depends on the treating physician having access to patients' medical history. Operationalising cross-border health data flows can help address this gap by making medical histories portable and "consultable" without undue barriers.

As we mentioned previously, the Covid-19 pandemic accelerated the acceptance and adoption of digital health services. An area where these services improve the accessibility of care for patients is in seeking a second medical opinion which for various reasons they may wish to obtain internationally. From a technology perspective, broadband connectivity and a telehealth software license are all that is needed to enable the provision of second opinions on services across borders.

With respect to patient outcomes, in a paper considering the importance of transatlantic data flow and the need for clear legal frameworks to enable it, the Information Technology & Innovation Foundation (ITIF) emphasised the importance of data and better analytical tools in transforming healthcare and drug development.⁴ New treatments, improved patient outcomes, and lower development costs are the fruits of cross-border data sharing. Stifling the flow in ways that disrupt or prevent research could damage prospects on all three fronts.

The ITIF suggests that the GDPR is already having a negative impact on the digital transformation of life sciences, despite the success of cross-border collaboration during the pandemic.

It cites two specific examples of how this is happening. In 2018, a joint diabetes research project between the US National Institutes of Health (NIH) and Finland's National Institution for Health and Welfare was undermined because the NIH could not give assurances that would satisfy the Finnish institution's interpretation of GDPR requirements. Data sharing for the International Genomics of Alzheimer's project has also been severely disrupted. Some EU institutions have restricted data sharing, meaning that the consortium must now run separate analyses on either side of the Atlantic.

"Restrictions on the transatlantic transfer of data for health research would ultimately detract from the potential to use that data for the greatest public good," write the authors of the paper. "Data localization and data sovereignty would hurt everyone on both sides of the Atlantic, given it would inevitably lead to less health-related innovation and poorer health outcomes."

Genomics research organisations have been particularly vocal in making the case for data sharing frameworks that do not restrict collaborative projects. In 2017, the Global Alliance for Genomics and Health (GA4GH), which advocates for a global federated architecture, drew attention to research's dependence on data access mechanisms that are both appropriate to research applications and respectful of the rights of the owner of personal health data.⁵ The global Pan-Cancer Analysis of Genomes (PCAG) consortium has also published a call for an international code of conduct for genomic data sharing⁶.

⁴ How to Build Back Better the Transatlantic Data Relationship. ITIF. March 25, 2021.

<https://itif.org/publications/2021/03/25/how-build-back-better-transatlantic-data-relationship/>

⁵ Birney, E., Vamathevan, J., Goodhand, P. (2017). Genomics in healthcare: GA4GH looks to 2022. bioRxiv, 203554. <https://doi.org/10.1101/203554>

⁶ Genomics: data sharing needs an international code of conduct." Nature. February 5, 2020. <https://www.nature.com/articles/d41586-020-00082-9>



THE ECONOMY

The Covid-19 pandemic demonstrated the benefits of sharing the expertise of different skill sets to develop treatments and vaccines at speed – successes that could not have been achieved if barriers were not removed to enable the minds of researchers to come together. Beyond the obvious reason of safeguarding the health of global populations, the boons of accelerated vaccine development potentially include economic benefits – in a paper titled *A Proposal to End the COVID-19 Pandemic*, it was found that while “vaccinating 40 percent of the world’s population by 2021 could cost around \$50 billion, its engendered benefits could reach about \$9 trillion in economic gains.”⁷

Another example of how cross-border health data flows can benefit the economy is the European Health Data Space (EHDS) – which we will explore in greater detail in a later segment of this paper. Simply put, the EHDS will enable the secure collection, storage, and use of health data to advance care access and health research. It is expected to save for the EU around €11 billion over ten years: €5.5 billion will be saved from better access and exchange of health data in healthcare, and another €5.4 billion will be saved from better use of health data for research, innovation, and policy making.⁸



⁷ Agarwal, R., & Gita G. (2021). [A proposal to end the COVID-19 pandemic](#). IMF Staff Discussion Notes 2021, no. 004.

⁸ Questions and answers - EU Health: European Health Data Space (EHDS). https://ec.europa.eu/commission/presscorner/detail/en/qanda_22_2712

WHERE DOES HEALTH DATA SIT IN THE GLOBAL PICTURE?

An increased focus on localisation suggests that governments and regions recognise the value of data as a resource – but also that they do not necessarily understand the nature of that value. Seeing this value through the prisms of commercial protection and data privacy distorts and limits the vision when it comes to the benefits of sharing health data.

In healthcare, the value of data increases with re-use. It is an infinitely renewable resource, which makes the much-used analogy of data as “the new oil” inaccurate and unhelpful. Its value is not enhanced by controlling supply. If anything, the opposite is the case. Policymakers need a different focus: protecting data privacy while enabling it to be used in collaborative models. The creation of effective data privacy regulation should actually liberate health data for reuse in ways that the public understands and supports.

At present, the reality is that policy is largely being set outside healthcare. With global attention focused on cross-border data flows for trade and finance, health data is passing somewhat under the radar. That said, policymakers may find strong parallels between the challenges that have been widely identified around enabling economic global data sharing and the evolution of a global health data ecosystem.

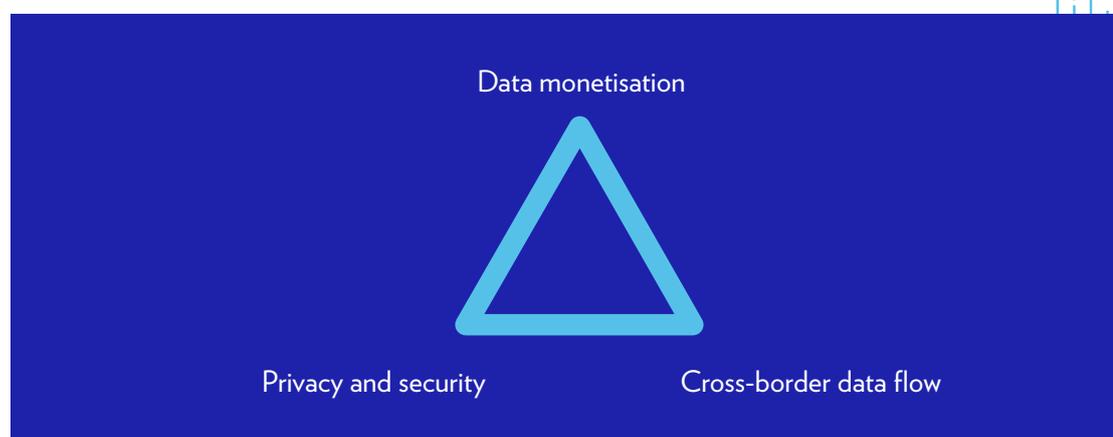
These challenges were recently highlighted in an Economic Bulletin from the Indonesia Financial Group (IFG), which drew on the Mundell-Fleming Impossible Trilemma concept to explain how governments face important policy decisions when it comes to cross-border data flows.⁹



⁹ Cross-border Data Flow: A Trilemma of Mobility, Monetization, and Privacy. Indonesia Financial Group. Published 8 June 2022. https://ifgprogress.id/wp-content/uploads/2022/06/Econ.-Bulletin-Issue-9-Cross-Border-Data-Flow_7-June-2022.pdf

The cross-border data flow trilemma

Figure 1. Cross-border data flow management



In data flow, the trilemma pitches data mobility, personal privacy and security, and data monetisation into the equation.

Over-emphasis on one area may have an impact on the other two. A swing towards data localisation in some APAC countries might appear to reinforce data security and privacy, for example. But it also restricts the economic advantages that could be realised by those countries with a more flexible approach to data exchange. Good privacy regulation is essential in healthcare. But it can be enacted in ways that liberate data for appropriate use and reuse rather than stifling innovation.



At the same time, giving too much weight to free data flow might incur a higher risk of breach if it is accompanied by weak security.

In any case, the wrong balance could have a negative impact on a country's GDP growth. In the health arena, that impact might be reflected in the performance of a country's health systems, its population health management, and even in its capacity to participate in international health research and innovation and the contribution they make to global health.

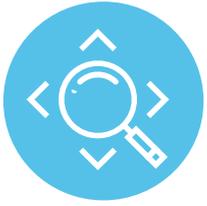


The ideal, suggests the IFG, is to combine an openness to data flows with robust privacy protections. This will require an open and inclusive national data strategy, an interoperability strategy, global cooperation in expanding consumer choices and benefits, and maintaining trade openness through cross-border data flows.

As previously stated, most data flow policy is being set outside of healthcare. However, each of these cornerstones could apply equally to a cross-border health data flow model, with research and development replacing trade per se as a major driver. Interoperability will be an important challenge of health data sharing, but it is something that policymakers will have to prioritise.

What the IFG describes as “the ability for any sector information systems to flexibly exchange, transform, and interpret shared data across multiple systems and devices to increase productivity and efficiency, to reduce cost, and to reduce errors,” might be a desired outcome for stakeholders at any level in a national health system. Equally, more data enablement will require the engagement of non-technical leaders, who will need to use it as a lever to show and build trust in the mechanisms around data protection and the use of private data. Stakeholders at every level, from the general public upwards, must be able to understand how those security parameters work, and who gets access to what data within them.





THE ASIA-PACIFIC PICTURE

Showing the world the benefits of cross-border health data flows

In some ways, the APAC region is at least an exemplar for the ideals of cross-border health data sharing. Even before the Covid-19 pandemic, the region had a progressive track record of collaboration – specifically around the control and prevention of infectious disease – which evolved through the epidemics of avian influenza and SARS, both of which had a significant impact on population health management during the first two decades of the 21st century.

More broadly, the region's efforts to build a common approach to data regulation have attracted global attention: in a 2021 report on the rise of barriers to cross-border data flows, ITIF recommended that the Asia-Pacific Economic Cooperation (APEC) Cross-Border Privacy Rules (CBPR) be opened up to non-APEC members and adopted as a global model for data governance.¹⁰ The report also noted the work of the late Japanese prime minister Shinzo Abe in putting data governance and localisation on the global agenda with his concept of Data Free Flow with Trust (DFFT).

In a speech at the WEF annual meeting in Davos in 2019, Abe said: “We have yet to catch up with the new reality, in which data drives everything, where the DFFT should top the agenda in our new economy.”

This theme was given further impetus by the Leaders Declaration at the 2019 G20 summit in Osaka, which stated: “By continuing to address challenges related to privacy, data protection, intellectual property rights and security, we can further facilitate data free flow and strengthen consumer and business trust. Such data free flow with trust will harness the opportunities of the digital economy.”

The Japanese government has subsequently indicated its intent to continue to work on the basis of this declaration on DFFT, ahead of its G7 presidency in 2023, including promoting regulatory cooperation through round table discussions of data protection and privacy authorities.

In April 2021, the Center for Strategic & International Studies (CSIS) published a brief, *Governing Data in the Asia-Pacific*, which noted “several promising strands of work on data governance [in the region] that could be pulled together to help drive efforts toward global consensus in this critical area.”¹¹ The brief went on to assert that no region of the world has done more to establish data principles, standards and rules than the Asia-Pacific.

¹⁰ “How Barriers to Cross-Border Data Flows Are Spreading Globally, What They Cost, and How to Address Them.” Information Technology & Innovation Foundation. July 2021. <https://www2.itif.org/2021-data-localization.pdf>

¹¹ “Governing Data in the Asia-Pacific Information.” Center for Strategic & International Studies. April 2021. https://csis-website-prod.s3.amazonaws.com/s3fs-public/publication/210420_Goodman_Governing_Data_Asia-Pacific_1.pdf?pq39nLltpU646BwZOHGlm9K_l2HAE2Fj

THE CURSE OF FRAGMENTATION

However, while these assessments give the perception of a region with a relatively proactive approach to building frameworks that enable cross-border data flows, the reality is that APAC largely reflects a fragmented global picture in which national attitudes and reservations around data governance tend to be at odds with multilateral initiatives to establish standardised mechanisms.

The region itself tends to be more market-oriented: if a collaborative initiative enables innovation, it has shown itself to be more open to data flow. Singapore is a case in point: it has been a regular participant in cross-border collaborations, such as Project Orbis, a US Food & Drug Administration (FDA) Oncology Center of Excellence Initiative to share information in regulatory reviews.

However, individual countries that are less willing to cooperate can actually have a negative impact on what is, essentially, a healthcare data economy. China, for example, appears to have doubled-down on its data localisation strategy, with patient data being treated in the same way as any other kind of personal information, the storage of which is prohibited beyond the national border. At the same time, it has a reasonable track record of participating in regional public health programmes.

Nowhere was this apparently conflicted approach to the sharing of health data clearer than during the Covid-19 pandemic. The restriction of information during the early stages of the pandemic, particularly around its origins in Wuhan, would have a significant impact on the rest of the world's initial ability to respond to and prepare for the spread of the virus. Ultimately, China may need to decide how it wants to share data globally if it is not going to rely solely on its own data sets for healthcare innovation.

Despite such specific examples that demonstrate the wider potential benefits of cross-border health data flows, there is little evidence to suggest that the APAC region is about to take its lead from the European Union's pursuit of harmonisation through initiatives such as the eHealth Digital Service Infrastructure (eHDSI) and the EHDS.



POSITIVE SIGNS OF COLLABORATION

There have been isolated examples of collaboration. For instance, between 2018 and 2020, the Australian Genomics Health Alliance participated in the World Economic Forum's Breaking Barriers to Health Data project. This was set up to discover how to maximise the benefits and minimise the risks of federating genomic data to diagnose rare diseases. A 2019 OECD survey on health data governance revealed Singapore to be something of a pioneer among countries, reporting that de-identified data could be shared from six or more key national health data sets for approved research work.¹²

Additionally, the IFG noted in its Economic Bulletin a Bangladesh/US project led by Augmedix, which allows Bangladeshi clinicians to help practitioners in the US by remotely attending patient consultations and releasing prescription.¹³

For the most part however – as is the case internationally – much of the focus at a national level tends to be on the creation of economic and trade data-sharing models, and reveals the complexity of the disparities between every nation's approach to the sharing of every kind of data. It also exposes how security concerns and caution are driving many countries towards increased data localisation rather than embracing cross-border flows.

According to a 2022 report from Zurich, “Countries seem to be doubling down on data localisation at a time when increasing cross-border data flows would benefit population health and innovation. An international architecture for managing cross-border flows would help to secure the benefits of digitalisation.”¹⁴



¹² OECD (2019), Health in the 21st Century: Putting Data to Work for Stronger Health Systems, OECD Health Policy Studies, OECD Publishing, Paris, <https://doi.org/10.1787/e3b23f8e-en>.

¹³ Cross-border Data Flow: A Trilemma of Mobility, Monetization, and Privacy. Indonesia Financial Group. Published 8 June 2022. https://ifgprogress.id/wp-content/uploads/2022/06/Econ.-Bulletin-Issue-9-Cross-Border-Data-Flow_7-June-2022.pdf

¹⁴ “Risks and opportunities: why cross-border data flows matter.” Zurich. June 2022. <https://www.zurich.com/en/knowledge/topics/digital-data-and-cyber/why-cross-border-data-flows-matter>

CHALLENGES

The region's challenges can largely be categorised under two areas: strategic and operational.

Strategic challenges

Health data, whether for research, population health management or the improvement of diagnostics and patient care, is unique in its volume, range and complexity, not to mention its dependence on privacy and the extent of its vulnerability to security breaches across health systems. The rise of AI in data modelling and the drive for digital inclusivity while preserving patient privacy – so important to the digital maturity of a country's health systems – create further layers of complication.

Frameworks for the cross-border sharing of financial and international data will need to undergo considerable modification – for example, by taking into account the global server distribution of cloud-based digital health tools – in order to support the degree of interoperability required for effective health data sharing. They will also struggle to accommodate the disparity in digital maturity among APAC nations, and the fragmented nature of internal health systems among which even basic standardisation and interoperability remain a significant obstacle.

These are also the most important challenges for national health policymakers and health system leaders to address if they are to realise the widely recognised benefits of enabling cross-border health data flows. In 2018, before the Covid-19 pandemic, the problems created by a lack of data comparability and discrepancies in data collection systems were noted by the

authors of a paper published in *Globalization and Health, Sharing public health data and information across borders: lessons from Southeast Asia*.

Fundamentally, they observed that countries which have weaker information systems themselves tend to have less confidence in their own data.¹⁵ And gaps in IT infrastructure means that data is often still collected in paper form at a community level, where the use of technology is less advanced. At a national level, a readiness to strike bilateral and multilateral public health agreements has tended to work against the creation of an overarching framework.

“Best practices require significant involvement of an independent third-party brokering organisation or office to redress gaps between country partners at different levels in the data sharing process and generate the benefits,” they wrote.

The acceleration of digitalised healthcare unleashed by the pandemic was yet to happen when this paper was written, but even with the advances that have since taken place, there is not a great deal of evidence to suggest that the overall picture has changed when it comes to cross-border data flows within APAC. At the same time, the insights gained have provided compelling arguments to pursue collaborative data sharing in the interests of population health management as well as the diagnosis and deeper understanding of both chronic and infectious diseases.

¹⁵ Liverani, M., Teng, S., Le, M.S. et al. Sharing public health data and information across borders: lessons from Southeast Asia. *Global Health* 14, 94 (2018). <https://doi.org/10.1186/s12992-018-0415-0>

Operational challenges

Precision Public Health Asia Society and the National University of Singapore recently noted the operational challenges for the APAC region: “With a wide range of data privacy laws, data sharing infrastructures, digital expertise and financing across the region, there is no established nor clear way of how to move forward to encourage cross-border data sharing in health and healthcare.”¹⁶ By implication, it will be difficult to make significant progress until individual countries have addressed health data governance comprehensively, including their readiness to participate in cross-border data sharing. This will require a rigorous examination of the gaps in their own digital maturity.

A few countries in the region certainly show relatively advanced states of digital maturity, and a familiarity with the challenges of managing data in general and health data in particular. However, the obstacles are considerably greater in other nations. This can partly be attributed to a lack of political will to realise the benefits of data sharing for health systems and value-based patient care – a challenge for policymakers, who are in a position to prioritise sharing as a baseline principle of governance frameworks. Some countries, for example, do not have a national-level body that can take responsibility for the development of a health and healthcare data sharing ecosystem.

More fundamentally, there are also substantial silos of paper-based health data in some health systems. In these circumstances, data accessibility will clearly be as substantial a barrier as wider issues of interoperability between systems.



¹⁶ “Responsible Data Sharing in Health and Healthcare.” Precision Public Health Asia Society and NUS Saw Swee Hock School of Public Health. May 2022. <https://pphasia.com/publications/papers-reports/whitepaper-responsible-data-sharing-in-health-and-healthcare/>

APAC AT THE CROSSROADS



In APAC as in the rest of the world, governments are at a crossroads. Even as they are in the process of developing their own frameworks for national health data governance, they have an important choice to make between entrenching their strategies in data localisation and potentially stifling cross-border collaboration or acknowledging their potential role in building models that are beneficial to global healthcare.

In 2019, the OECD published its *Health in the 21st Century: Putting Data to Work for Stronger Health Systems* report. The authors of Chapter Six suggested that isolated, national health data resources are not able to fulfil the needs of a world in which global collaboration for the improvement and

delivery of patient- and population-centric healthcare is only growing in importance.¹⁷

“It is becoming clear that breakthroughs in biomedical research will increasingly rely on using large, high-quality datasets that describe a range of determinants of health and disease,” they wrote. “Datasets of sufficient size can only be created by cross-border collaboration. Indeed, private pharmaceutical studies are often multi-country.”

It is useful at this point to look at the broader data governance status of APAC countries and more specifically, the extent to which current regulations incorporate health data – and potentially erect barriers to cross-border data flows.

¹⁷ OECD (2019), *Health in the 21st Century: Putting Data to Work for Stronger Health Systems*, OECD Health Policy Studies, OECD Publishing, Paris, <https://doi.org/10.1787/e3b23f8e-en>



China

According to an ITIF report, China's focus on data localisation makes it the most data-restrictive country in the world. Throughout the last decade, a steady flow of policy and regulation, best practice recommendations and standards have narrowed the opportunities for international collaboration.¹⁸

China includes population health and genetic information in its opaque definition of sensitive data, but as DLA Piper reports, there is currently no specific regulation or legislation governing telehealth data. This means that any cross-border transfer of telehealth data comes under the applicable law and regulation instituted for healthcare data in general.¹⁹

In 2014, it published Administrative Measures for Population Health Information, which decreed that population health data must only be stored in China. In 2019, the Regulations of the People's Republic of China on Administration of Human Genetic Resources prevented foreign organisations from collecting or preserving Chinese genetic data, either domestically or abroad. In the same year, Draft Critical Information Infrastructure Regulations were expanded to include government agencies and entities in healthcare, science and technology businesses.

China is working on a privacy-specific law, which is expected to focus on the protection of biometric data – tying in with the country's rapid adoption of AI technology, as well as its widespread use of digital surveillance and facial recognition.

China was also one of 15 Asia-Pacific countries which joined the Regional Comprehensive Economic Partnership (RCEP) in 2020. However, while the agreement theoretically offers an opportunity to create a standardised framework for data flows and localisation, it also allows individual nations to decide when data localisation requirements are necessary.

How progressive are China's data sharing policies?

On the face of it, China's approach to cross-border health data sharing remains relatively conservative. But despite its reticence at the start of the pandemic, there are signs of a more progressive national strategy – for example, in the expanding scope of internet diagnosis and treatment services, and an anticipated standard for approving them. This suggests that interoperability issues might be addressed internally – and externally, in the long run. While the government has implemented measures to control data transfers and enforce data protection regulations, it is also encouraging collaboration between domestic and international institutions. Ultimately, any data flow enablement will primarily support the development of the country's own healthcare and diagnostic industries.

¹⁸ "How Barriers to Cross-Border Data Flows Are Spreading Globally, What They Cost, and How to Address Them." Information Technology & Innovation Foundation. July 2021. <https://www2.itif.org/2021-data-localization.pdf>

¹⁹ Telehealth around the world – DLA Piper. <https://www.dlapiperintelligence.com/telehealth/index.html>



Taiwan

Taiwan is a participant in the US's Trans-Atlantic Data Privacy Framework, which has been set up to create a Global Cross-Border Privacy Rules forum. This is just one of several multilateral efforts to make cross-border data governance compliance more straightforward.

The Personal Information and Protection Act (PIPA) covers medical records, medical treatment, genetic information and health examination. These also fall into a special category of personal information that must not be collected, processed or used except by consent. The Department of Statistics of Ministry of Health and Welfare governs the National Health Insurance Research Database (NHIRD). This also encompasses the National Health Insurance (NHI) system.

How progressive are Taiwan's data sharing policies?

The country has implemented strict data protection regulations and provides a secure platform for the exchange of health data. Taiwan also encourages cross-border collaboration in research and has made significant investments in healthcare technology. However, data localisation policies require foreign companies to store data locally, which may limit international collaboration and hinder progress.



Australia

As we have already seen, Australia has participated in projects based on cross-border data sharing, including the WEF's Breaking Barriers initiative to test how a distributed, federated data system could be built and run sustainably across countries with clear governance, optimised for operational efficiency, patient privacy and data security. However, the country's general approach to international health data flows has generally been cautious.

Since 2012, its Personally Controlled Electronic Health Records Act has required that personal health records are only stored in Australia. The Privacy Act stipulates that personal information can only be transferred to another country where reasonable steps have been taken to ensure compliance with APP 8. This is essentially a consent-based model which governs, for example, the transfer by a telehealth business of a patient's information to an overseas location.

As far as the secondary use of health data is concerned, the OECD's 2019 survey on health data governance reported that while the possibility of sharing exists in Australia, a complex approval process to ensure the secure and appropriate use of data could be a barrier to accessing and using it.²⁰

Australia's Digital Health Agency oversees My Health Record – the country's national digital health record – and various other eHealth programs.

How progressive are Australia's data sharing policies?

The country has a strong focus on privacy and security while allowing for the sharing of medical data across borders for improved diagnosis and research. While the government supports international collaborations and has established data sharing agreements with other countries, there are still some challenges in balancing privacy protection with data access for research purposes. Ultimately, the rate of progress will depend on how they are resolved.

²⁰ OECD (2019), Health in the 21st Century: Putting Data to Work for Stronger Health Systems, OECD Health Policy Studies, OECD Publishing, Paris, <https://doi.org/10.1787/e3b23f8e-en>



Hong Kong

While Hong Kong's Personal Data (Privacy) Ordinance (PDPO) does not define personal information specifically, there are codes of practice that regulate certain data including patient numbers. There is also no current definition of 'telehealth data', meaning that data generated during a consultation for example, would fall under the general umbrella of "personal data". The PDPO prohibits the cross-border transfer of personal data without certain conditions being met, including a whitelist of jurisdictions, voluntary consent and an enforceable data transfer agreement. The Office of the Privacy Commissioner of Personal Data (PCPD) has also issued specific guidance for consent-based collection of biometric data as well as model clauses for organisations to use for compliance with cross-border transfer restrictions.

Hong Kong's government hospitals and healthcare institutions are overseen by the Hospital Authority, which is also responsible for electronic medical records.

How progressive are Hong Kong's data sharing policies?

Hong Kong's cross-border data flow and data localisation policies for healthcare, diagnostics and collaborative research appear relatively progressive. The government has established a legal framework for protecting personal data and ensuring the free flow of information, while also encouraging international collaboration in the healthcare sector. But there are still some limitations on the cross-border flow of sensitive medical data.



South Korea

Since 2019, Korea's Cloud Security Assurance Program (CSAP) has required that any cloud service used by public sector agencies is physically located in the country, and that these services should be physically separated from the cloud service area for private institutions.

In 2020, the country amended its Personal Information Protection Act (PIPA) to address the concept and use of pseudonymised data. The legislation also stipulates that the cross-border transfer of any personal information must be consent-based and comply with specific technical, managerial and physical protection measures.

How progressive are South Korea's data sharing policies?

Overall, South Korea's policies are relatively progressive. Established data protection laws and regulations ensure the privacy and security of personal health information. However, there are limitations, particularly when it comes to cross-border data sharing for research purposes, which could restrict progress.



Singapore

Singapore has been among the most pro-active participants in multilateral cross-border data flow initiatives for the development of frameworks. This paper has already referenced its response to the OECD's 2019 survey on health data governance, which suggested that de-identified data could be shared from at least six national health data sets for approved research work.²¹

However, in general, the nation shares a more conservative approach to cross-border data flows with other APAC countries. Personal data, including telehealth data, can only be transferred across borders in compliance with the Personal Data Protection Act (PDPA), and the recipient of the data is bound by legally enforceable obligations to provide the equivalent standard of protection. It is the responsibility of any telehealth service provider to ensure that these conditions are met by any recipient.

The use of patient data for secondary purposes is governed by the Human Biomedical Research Act. Integrated Health Information Systems (IHIS), under the Ministry of Health Holdings (MOHH), manages the National Electronic Health Record (NEHR). It also oversees the digital infrastructure of the public healthcare system.

How progressive are Singapore's data sharing policies?

Despite its digital maturity, Singapore's cross-border data flow policies are something of a balancing act between realising the benefits of sharing health data and data protection requirements. The country shows strong leadership in the promotion of data sharing and integration to enhance healthcare services – a good indicator of progressive goals - while also implementing data protection measures to ensure privacy and security.

²¹ OECD (2019), Health in the 21st Century: Putting Data to Work for Stronger Health Systems, OECD Health Policy Studies, OECD Publishing, Paris, <https://doi.org/10.1787/e3b23f8e-en>



New Zealand

New Zealand's Privacy Act 2020 includes specific measures for safeguarding health data due to its sensitivity: the Health Information Privacy Code 2020 is a code of practice issued by the privacy commissioner, giving extra protection to health information. All health agencies are covered, and the code protects all personal health information relating to an identifiable individual. The Ministry of Health is responsible for ensuring that it complies with the code in managing all health data entrusted to it.

The Ministry also provides Health Information Governance Guidelines, which give health providers guidance for the collection and sharing of personal health information in a legal, secure, efficient and effective way.

The Privacy Act includes various safeguards for the cross-border transfer of personal data to ensure that it is not compromised by a lack of equivalent frameworks in the receiving country. New Zealand's law has been recognised as providing adequate protection by the European Commission since 2012, meaning that data can be transferred between it and the 27 member states of the EU for processing without the need for further safeguards.

New Zealand's National Data Infrastructure (NDI) is governed by NZStats, which manages access to health data for secondary use.

How progressive are New Zealand's data sharing policies?

Generally, New Zealand's data flow policies are among the APAC region's most progressive – particularly with regard to cross-border sharing and collaboration for research. At the same time, the country's data localisation policy requires certain sensitive health data to be stored within its borders, which could potentially limit collaboration in some cases.



Vietnam

While there are no specific restrictions on cross-border data transfer in Vietnam, the framework of the country's Law on Network Information Security (NIS) places constraints on data storage and flows that can also restrict any cross-border movement.

ITIF cites Vietnam as an example of a nation pursuing increased data localisation: "Recent laws... highlight how data localization does not lead to greater data privacy – but rather the exact opposite in making it easier for governments to access a small number of servers."²²

There is no independent data protection agency; responsibility lies with the Ministry of Public Security – effectively allowing the government to control access to and storage of all personal data.

One example of the potential restriction on cross-border health data exchange is the way in which the NIS Law imposes stringent requirements on foreign service providers operating in Vietnam. Any business that collects and processes personal data must maintain a physical office and store the data in Vietnam.

That said, Vietnam has a robust history of participation in regional health programmes that are dependent on the cross-border transfer of health data.²³

How progressive are Vietnam's data sharing policies?

Vietnam has implemented measures to ensure the privacy and security of healthcare data, while also allowing for cross-border data exchange for the purpose of research and collaboration. One sign of more progressive ambitions is its growing investment in healthcare technology, which could make it an increasingly attractive focus for international collaboration.

²² "How Barriers to Cross-Border Data Flows Are Spreading Globally, What They Cost, and How to Address Them." Information Technology & Innovation Foundation. July 2021. <https://www2.itif.org/2021-data-localization.pdf>

²³ Liverani, M., Teng, S., Le, M.S. et al. Sharing public health data and information across borders: lessons from Southeast Asia. *Global Health* 14, 94 (2018). <https://doi.org/10.1186/s12992-018-0415-0>



India

The evolution of India's data protection law continues to be a work in progress, with new bills replacing previous iterations almost on an annual basis. A fourth, simplified version of the proposed law – The Digital Personal Data Protection Bill 2022 – is out for public consultation at the time of writing. There are no indications of when it might be passed, although it was expected to be introduced in Parliament in the Budget session of 2023. The draft does not appear to include previously signalled government intentions for the creation of a digital health ecosystem, in the form of the Draft Information Security in Healthcare Act. According to Deloitte, this is focused on regulating the process of collecting, storing and transmitting digital health data.²⁴

The cross-border transfer of sensitive data is currently permitted, dependent on the meeting of equivalent data protection standards. However, the prevailing trend is considered by many observers to be heading in the direction of more stringent localisation measures. For example, in 2018, draft rules for online pharmacies were published, specifying that any data generated must be localised and not shared outside India.

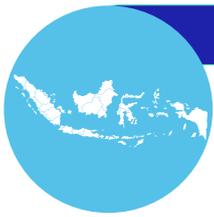
The National Health Authority (NHA) is the implementing agency of the Ayushman Bharat Digital Mission, enabled by the digital infrastructure National Health Stack. This provides the framework for data exchange and interoperability in healthcare.

How progressive are India's data sharing policies?

India's cross-border data flow and data localisation policies are a work in somewhat slow progress. While the government has proposed data localisation for sensitive personal data, there is limited regulation for healthcare and research data. Collaborative research could also be limited by conflicting data protection laws. On the plus side, India's digital infrastructure and growing healthcare sector will naturally create opportunities for progress in data management and sharing.

²⁴ "Unity in Diversity – The Asia Pacific Privacy Guide." Deloitte. July 2019.

<https://www2.deloitte.com/content/dam/Deloitte/nz/Documents/risk/apac-privacy-guide-interactive.pdf>



Indonesia

after China.²⁵

Indonesia is also in a long process of passing its first data protection law. However, the vagueness and opacity of its current policies allow for the restriction of cross-border data flows to the extent that ITIF describes it as the second most data-restrictive country in the world

In 2020, the Ministry of Communications and Information Technology published its Regulation on Governance of Private Scope Electronic System Administrators, which specified healthcare among those sectors stipulated as Holders of Electronic Data. Under these regulations, archive servers must be connected to a specific data centre – but there is no guidance about how to get approval for storage outside the country.

As things stand, there are stringent compliance controls and requirements for the cross-border transfer of any data. An electronic system operator providing services to a public body must establish a data centre and disaster recovery centre in the country. However, in 2021 DLA Piper noted that the Ministry's infrastructure was not yet in place to handle the coordination of cross-border data flows, and that no officer had been appointed to oversee it.²⁶

How progressive are Indonesia's data sharing policies?

While the government has implemented measures to ensure the protection of personal data, there is still room for improvement in terms of data sharing between healthcare providers and regulatory compliance for data storage and protection. However, Indonesia is an active participant in regional and international efforts to promote cross-border data sharing and collaboration in healthcare research.

²⁵ "How Barriers to Cross-Border Data Flows Are Spreading Globally, What They Cost, and How to Address Them." Information Technology & Innovation Foundation. July 2021. <https://www2.itif.org/2021-data-localization.pdf>

²⁶ Telehealth around the world – DLA Piper. <https://www.dlapiperintelligence.com/telehealth/index.html>

The summaries above reveal that while there are many similarities in national data security and privacy policies among APAC countries, the variation and status of regulations and legislation is considerable. There is also little sign of commonality or consistency when it comes to integrating cross-border data flow frameworks with national data policy.

Some nations look to the models being advanced by the EU, and seek to reflect the conditions and requirements for data protection generally and for health data protection specifically. Others are more focused on their participation in the development of regional and multilateral frameworks for cross-border data sharing, although these tend to be concentrated on financial and trade data, and make no allowance for the unique aspects of health data, and its role in research and diagnostic advances.

As many of them continue to work on national data laws that reflect the challenges and manage the threats of global connectivity, there is an important opportunity for APAC governments to develop policies that prioritise the benefits of cross-border data flows for the health of their own populations and the improvement of their health systems. This opportunity could be exploited by making cross-border data sharing a central plank of their healthcare digitalisation strategies – particularly when it comes to enabling secondary use.

In 2020, the WEF published an eight-step guide, *Sharing Sensitive Health Data in a Federated Data Consortium Model*. It acknowledged that many of the challenges and obstacles must be addressed by individual countries in their own systems before global frameworks can be established. But the growing importance of doing so is helping to make a strong case for a more proactive approach: “Each country in

the world simply cannot hold the volume of data needed to help every patient with a rare disease.”²⁷

The WEF said that while it could take longer to establish trust with institutions that are geographically and culturally different, effort must be made for genomics and personalised medicine to realise the long-term value of sharing data. In other words, APAC nations – as with other regions around the world – should also be looking beyond the concept of simply sharing data with their neighbours, a strategy which could simply lead to the creation of niche consortiums rather than contribute to global population health.

Over the course of the paper so far, we have discussed several enablers for countries to participate in cross-border health data sharing: whether an advanced health data governance framework is in place; whether there is a national body for health data; a country’s approach to cross-border health data sharing (e.g., participating in the development of international standards and frameworks); where a country appears to be headed with its data sharing policies; and a country’s level of digital maturity.

Using these enablers as a guide, we have benchmarked where APAC nations stand with respect to their readiness for cross-border health data sharing in the table that follows. Based on available information, we have assessed their readiness on a scale from Advanced (highly prepared and proactive) to Intermediate (some key building blocks in place but with significant gaps remaining) and Basic (very much in the early stages of building a health data ecosystem). In the conclusion of this paper, we have provided some recommendations for countries at each stage of readiness to enable the region to unlock the power of cross-border health data flows.

²⁷ “Sharing Sensitive Health Data in a Federated Data Consortium Model An Eight-Step Guide.” World Economic Forum. July 2020. https://www3.weforum.org/docs/WEF_Sharing_Sensitive_Health_Data_2020.pdf

Figure 2: Countries' preparedness for cross-border health data sharing

| | ADVANCED: Countries at this stage scored positively in all the enablers above. They are ready to participate in cross-border health data sharing and to lead the charge for the region. | | INTERMEDIATE: Countries at this stage scored positively in three to four of the enablers above. They are lacking some of the building blocks (e.g., an advanced data governance framework) to be fully ready for cross-border health data sharing. | | | | BASIC: Countries in this stage scored positively two or less of the enablers above. Work has to be done on many fronts to be ready for cross-border health data sharing. | | | |
|--|---|--|--|--|---|--|--|--|--|--|
| ENABLERS |  New Zealand |  Singapore |  South Korea |  Australia |  Taiwan |  Hong Kong |  Vietnam |  China |  India |  Indonesia |
| Advanced health data governance framework in place | Yes | Yes | Yes | No | No | No | No | No | No | No |
| Stage of building a national level body for health data | Advanced | Advanced | Nascent | Nascent | Nascent | Nascent | Nascent | Nascent | Nascent | Nascent |
| Approach to cross-border health data sharing | Progressive | Progressive | Progressive | Progressive | Progressive | Progressive | Progressive | Restrictive | Restrictive | Restrictive |
| Where do countries appear to be headed with data-sharing policies? | Progressive | Progressive | Progressive | Progressive | Progressive | Progressive | Progressive | Progressive | Restrictive | Restrictive |
| Stage of digital maturity | Advanced | Advanced | Advanced | Advanced | Advanced | Advanced | Nascent | Advanced | Nascent | Nascent |

Sources: Based on data obtained from [DLA Piper's Data Protection Laws of the World](#), [IMD World Digital Competitiveness Ranking 2022](#) and other sources (see country summaries on pages 18-26 for further context)



THE GLOBAL PICTURE

The influence of emerging cross-border data sharing models

Collaboration on cross-border data models is gathering space both globally and within the APAC region. However, the primary focus of projects and initiatives is economic; a broad consensus is emerging on the need for frameworks that facilitate international trade without compromising national data security.

At the same time, data localisation continues to rise. This does at least suggest a recognition by governments and regions that data is a valuable resource – and that the analogy of data as ‘the new oil’ has substantial currency. However, the analogy is not necessarily helpful if it is applied to health data. In the oil industry, suppliers retain the power of ownership. In healthcare, the value of data grows the more widely it is shared and used. It is a renewable resource which does not deplete. Countries that adopt a de facto localisation policy to health data are missing out on the value it can generate through collaboration and the contribution of insights to the healthcare ecosystems of individual countries – and those of the world.

The Global Cross-Border Privacy Rules (CBPR) is one notable data flow project which could serve as a launchpad for essential conversations around health data sharing in the region. The seven participating countries signed a declaration in April 2022 to promote trusted cross-border data transfers and establish The Global Cross Border Privacy Rules and Privacy Recognition for Processors (PRP) Systems. These will be international certifications that ensure member countries adhere to the level of data protection and

privacy standards of the Asia Pacific Economic Cooperation CBPR and PRP systems.

Figure 3. Countries participating in the CBPR



However, while its purpose is to create a standardised governance model for cross-border data transfer, the lack of a sector-specific focus will not necessarily make it fit for purpose if applied to health data. The fact also remains that a regional patchwork of non-binding principle for sharing economic data will not be able to provide a more universal framework for the sharing of health data. As the CSIS noted, “The most coherence we are likely to see in this system over time is a collection of different but interoperable regimes.”²⁷

As with the EU’s GDPR regulations, there could also come a point when it becomes clear that such models are actually impeding progress towards a harmonious framework for cross-border health data flows. Precision Public Health Asia Society and the National University of Singapore noted the specific challenge for the APAC region.²⁸

²⁷ “Governing Data in the Asia-Pacific Information.” Center for Strategic & International Studies. April 2021. https://csis-website-prod.s3.amazonaws.com/s3fs-public/publication/210420_Goodman_Governing_Data_Asia-Pacific_1.pdf?pq39nLtpU646BwZOHGlm9K_l2HAE2Fj

²⁸ “Responsible Data Sharing in Health and Healthcare.” Precision Public Health Asia Society and NUS Saw Swee Hock School of Public Health. May 2022. <https://pphasia.com/publications/papers-reports/whitepaper-responsible-data-sharing-in-health-and-healthcare/>

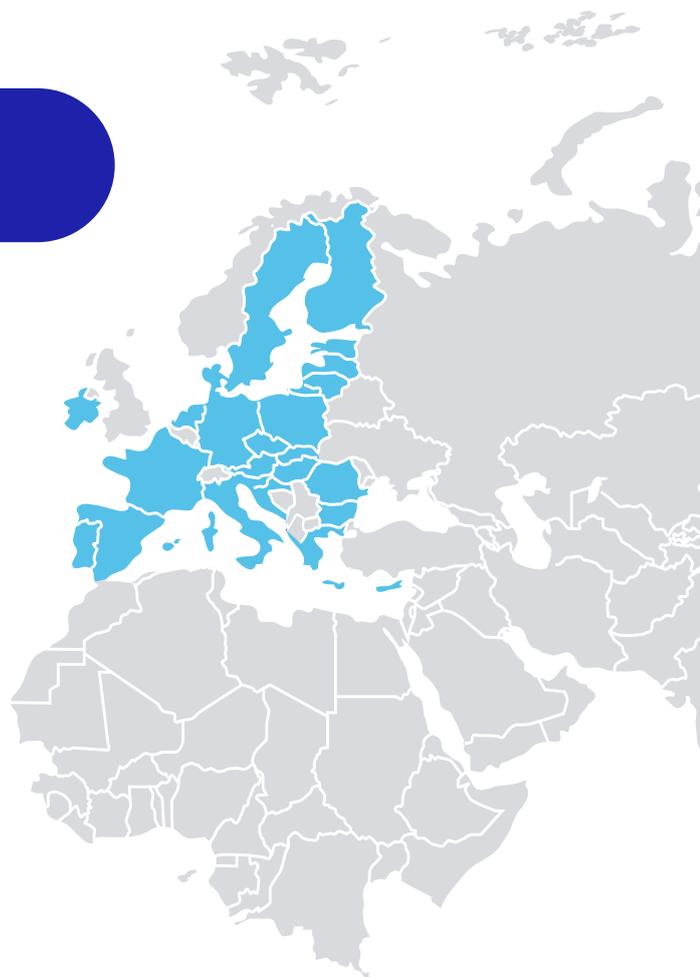
EUROPE PROVIDES A BEACON

While a number of multilateral and bilateral health data initiatives exist – many of which involve collaboration among APAC countries – the most advanced proposition, and the one that could provide a model for a regional consortium, is the EU’s European Health Data Space (EHDS).



The EHDS

- **The EHDS sets out specific intentions and nuances for the use and re-use of health data within the big picture of EU data governance.** It recognises that the future of personalised healthcare delivery will depend on data held by multiple jurisdictions and ministries, all of which will inform the nature and type of care that populations receive.
- **It is an initiative that could give governments a lever to address cultural inhibitions and fears around the sharing of personal data** – and embrace the progressive visions of disruptors such as Apple, Google and Amazon for which the concept of global data sharing is a challenge to be embraced rather than restricted. In short, it proposes a safe space for cross-border sharing – the opposite of the hoarding approach which can accompany localisation policies.
- **With its aim to provide federated access to important health data among member countries and with countries that meet appropriate data governance standards, EHDS is the first time such a concept has been set out specifically for health data.** It seeks to provide a framework that clarifies and simplifies primary and secondary use of health data, as well as harmonising rules on health data processing. It also proposes a Code of Conduct that would explain how GDPR works in relation to health data, and ensure a consistent approach to health data exchange.





In its paper, *A European Health Data Space: harnessing the power of health data for people, patients and innovation*, the European Commission set out the objectives of the EHDS while addressing the significant challenges that will need to be overcome at a national level before they can be achieved. “Healthcare delivery and innovation are hampered by widely varying digital health solutions (often incompatible with each other between Member States and sometimes even within Member States), fragmented standards and specifications and various legal and administrative rules,” the authors wrote.²⁹

One of the biggest hurdles, which the EHDS seeks to address by creating a regulatory framework, is the disparate and fragmented implementation of GDPR by individual member states which can act as a brake on cross-border research and restrict the secondary use of data in developing public health policy. According to the Commission, more than half of member states lack specific legislation on the reuse of health data for research, policy-making or regularly purposes, and simply revert to non-sector

specific GDPR provisions for guidance. Some member states also lack a competent body for health data access, despite the increase in requests to use it for research or policy-making.

Interoperability between health systems is also a major challenge. Indeed, it would not be an exaggeration to describe it as a headache for stakeholders for which there is no rapid cure. One important outcome from the development of the EHDS will be decisions on how a common infrastructure would facilitate access and collaboration for disparate systems – and if such an infrastructure should be centrally operated.

These challenges are hardly unique to the EU and will be recognisable to APAC countries facing a similar demand for frameworks that will allow them to reap the benefits of cross-border health data flows. The underlying premise of the EHDS is that however advanced a national health system might be on its journey to digitalisation, that journey cannot be considered truly complete until the system is able to take advantage of cross-border data sharing at every level.

²⁹ “A European Health Data Space: harnessing the power of health data for people, patients and innovation.” European Commission. May 2022. <https://health.ec.europa.eu/publications/communication-commission-european-health-data-space-harnessing-power-health-data-people-patients-and-en>

STEWARDSHIP OVER OWNERSHIP

The EHDS vision of a data exchange “system” that enables national health systems to ‘learn’ from a shared resource is a long-term goal, which will require cooperation among all stakeholders if it is to be realised. This distinction between an overarching system and a data lake will perhaps help to clarify some interpretations of the proposition as data localisation on a grand scale. It also mirrors the need for a progressive shift, identified in a recent Asia Society paper for stakeholders.³⁰ Rather than seeing themselves as data ‘owners’, they might embrace a new role as ‘data stewards’ who are responsible for the governance and accessibility of data within their domain.

The EHDS targets three layers of health data sharing³¹:

- Empowering individuals to take control of their own health data
- Supporting the use of health data for improved healthcare, research, innovation and policy-making
- Enabling the EU to maximise the potential of a safe, secure exchange and the use/reuse of health data

Combined in a single ecosystem, they will bring the benefits of cross-border data flows to all stakeholders – from the individual citizen through to clinicians, healthcare system decision-makers, policymakers and governments, and researchers, and will create a single market for digital innovation and development.

The European Commission has established five main objectives covering the primary and secondary use of health data:



The empowerment of individuals to control their own health data and share it with healthcare professionals and third-parties such as wellbeing apps on their own terms.



The fostering of a single market for digital health services and products.



Ensuring interoperability, health data security and a level playing field for manufacturers.



Unleashing the power of the health data economy.



Ensuring a consistent and efficient framework for the reuse of health data for research, innovation policy-making and regulatory activities.

³⁰ “Responsible Data Sharing in Health and Healthcare.” Precision Public Health Asia Society and NUS Saw Swee Hock School of Public Health. May 2022. <https://pphasia.com/publications/papers-reports/whitepaper-responsible-data-sharing-in-health-and-healthcare/>

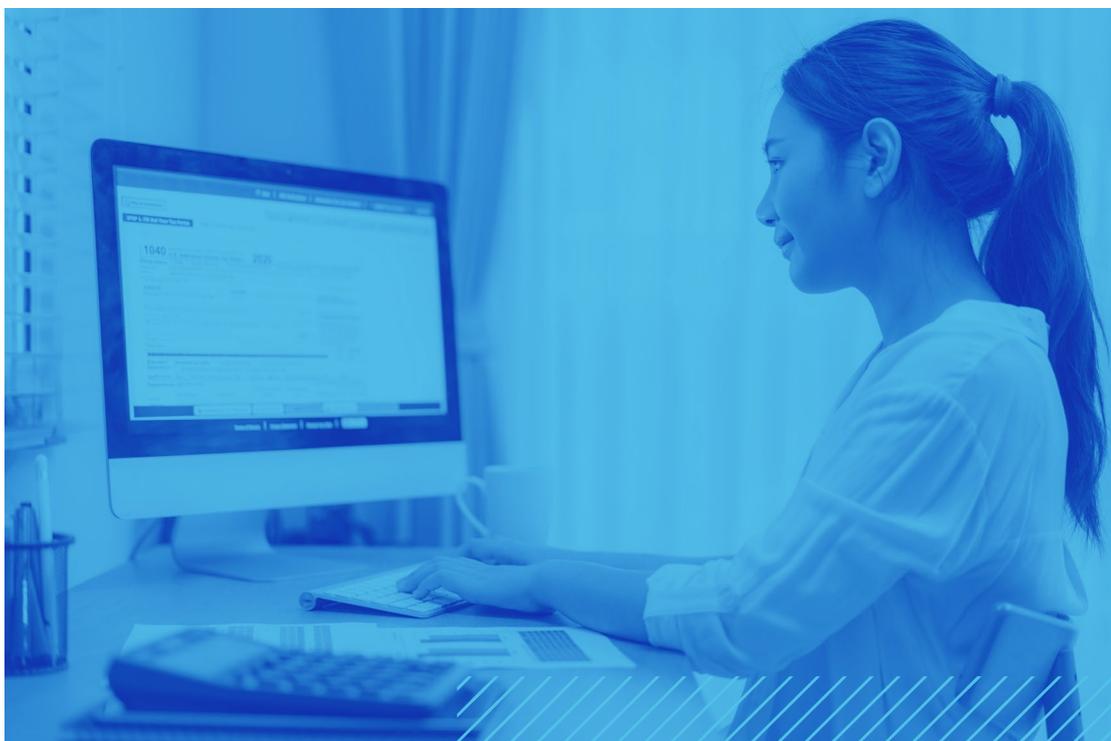
³¹ “A European Health Data Space: harnessing the power of health data for people, patients and innovation.” European Commission. May 2022. https://health.ec.europa.eu/publications/communication-commission-european-health-data-space-harnessing-power-health-data-people-patients-and_en

The ultimate outcome will be two infrastructures that enable cross-border data flows for primary and secondary use. These will build on the data protection and cyber security mechanisms of existing regulations including GDPR, helping to generate trust in the concept from individuals, and create secure processing environments for the secondary use of health data. The Commission has also suggested that the EHDS will provide access to datasets that enable the use of “emerging responsible, human centred artificial intelligence and machine learning techniques” that are expected to drive innovation in healthcare.

It should be noted that the EHDS is not without its critics. In 2022, the GDA published a white paper expressing concern that some articles of the draft proposal

might be counter-productive on the global stage.³² It suggested that the creation of a regional data localisation policy, with the potential to impede international research and development, would be to the detriment of healthcare in both the EU and the rest of the world.

The GDA paid particular attention to the definition of “highly sensitive” personal data, which could be applied to anonymised data if there is deemed to be a risk of re-identification when transferred to a third country. “Without the ability to exchange such non-personal data, representation and broad populace profiles from Europe could be excluded from the scope of ongoing multi-regional efforts to find treatments for emerging healthcare challenges,” it observed.



³² “Data Transfers Under the EU Proposal on the European Health Data Space.” Global Data Alliance. 2022. <https://globaldataalliance.org/wp-content/uploads/2022/08/07282022gdaehealthdataspace.pdf>

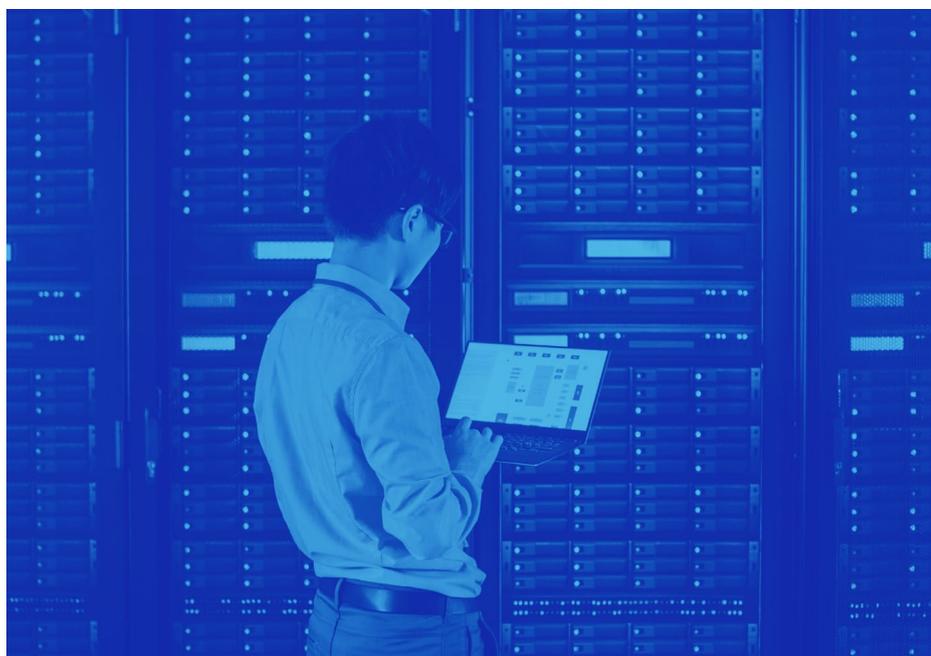
SECONDARY DATA-USE PRINCIPLES

Much of the groundwork in developing the principles for the secondary use of health data in the EHDS that will inform policy and regulation is being undertaken by the joint action Towards the European Data Space (TEHDAS). This is a project carried out by 25 countries with the aim to create a European governance model for the use of health data, led by Finnish innovation fund Sitra as the competent body. In March 2022, TEHDAS published its guidelines for a peer-to-peer and cross-border partnership for the secondary use of health data.³⁵ An early example of such a partnership is a Memorandum of Understanding for a collaboration between Europe's first two national centralised health data platforms, the French National Data Hub and Findata, Finland's social and health data permit authority.

As noted by the Precision Public Health Asia Society and the National University of Singapore, Findata has emerged as something of a standard bearer for the model governance of health data. It collects and safeguards all sensitive data from Finnish registries and restricts access to authorised users via a one-stop portal. Data is anonymised, creating a secure environment for sharing within the country. Findata is the sole entry point for data access for secondary use, which makes the process of obtaining a permit more efficient.

A similar example exists in New Zealand, where NZStats is the governing entity over the national Integrated Data Infrastructure (NDI). Health and social data are collected from government agencies, surveys and not-for-profit organisations, de-identified and made available for secondary use by researchers.

TEHDAS has identified the main obstacles to cross-border data flows, which again are not exclusive to Europe and will need to be addressed by stakeholders at every level of healthcare provision in the APAC region, from government down to the individual.



³⁵ "TEHDAS establishes European guidelines for data partnerships." Towards European Health Data Space. March 31, 2022. <https://tehdas.eu/results/tehdas-establishes-european-guidelines-for-data-partnerships/>



Obstacles to cross-border health data flows

- Among these obstacles, the **impact of complex regulatory procedures and pricing models among different countries** – particularly for use cases that require the cross-referencing health data – has an impact on the development of digital health solutions. There is no common European interpretation of “sufficient anonymisation” in the transformation of data from personal to non-personal. Equally, there is no common interpretation of what ‘secondary use’ actually constitutes.
- The **harmonisation of cybersecurity and ethics requirements is another challenge**. So, too, is funding and being able to define a sustainable economic model before the start of a data sharing project. There are also key issues to be resolved about the data itself, in terms of interoperability – the fragmentation of information systems in healthcare institutions and lack of standards, and in terms of quality.
- Finally, there is **the trust and transparency on which any successful cross-border data sharing project must be based** – at political, social and organisational level. Citizens must be engaged and understand the contribution their data can make – with their consent – to improving national and global standards of research, public health management and patient-focused care.





Full stakeholder engagement required

- **Part of the solution will come from well-informed data governance and transparency about how health data is aggregated, and how and with whom it may be shared.** Stakeholders will need to become better acquainted with the terminology of data privacy and how it defines permission for data to be used or re-used to build clinical research models and address population health issues, as well as improving patient care.
- **The increase in data enabled services requires non-technical health leaders to engage with data governance** so that they can use it as a lever to show how the mechanisms around protection and the use of private data work in the interests of patients and health systems. This is a way in which health data flows can be demystified.
- Parameters determine who gets access to what data. **Setting up those parameters is a discussion to be led by policymakers at all levels** – and those conversations should involve non-technical leaders. If the health and life sciences sector is engaged in these discussions, their considerations can be incorporated with the unique intentions and nuances that set health data apart from the wider economy – making for better and more specific governance.
- **A key step forward would be the creation of a national independent health data governance body**, different versions of which have already been noted in Finland and New Zealand. This would create a foundation for accessibility and standardisation. It would need to be government-led, but health leaders have a clear opportunity to drive discussion and build confidence in the concept by advocating the benefits of enabling cross-border data flows and unlocking the value of health data.
- By **making the case for enabling global data flows at every level** – enhanced patient care, greater health system efficiency, and more advanced research models – health policymakers can start to build momentum around well-formed national campaigns that touch every stakeholder.
- **The scale and pace of a change in approach should not be underestimated.** Interoperability and technological challenges are well-understood by digital health leaders, and standards-based systems and technologies are constantly evolving to address them. But the need for a shift in perception about the value of health data sharing among some stakeholders – and even the wider community of citizens whose trust and consent will be essential – could be an even greater challenge.

- The data silo remains commonplace in healthcare. Joining up unconnected repositories of fragmented locally aggregated information remains a challenge – often between faculties or facility departments, let alone across borders. This inaccessibility is hindering innovation within health systems and research on a global scale. **If policymakers can persuade resistant stakeholders that enabling data to flow freely across their own health systems and beyond will not only drive higher standards of patient care but also enhance the quality of information that is used to manage population health and streamline healthcare provision, they will begin to overcome this considerable hurdle.** The arguments are powerful. From more streamlined care delivery to the elimination of redundant testing, from enabling access to richer, globally gathered information that enables faster and more accurate diagnosis to complete patient profiles that are updated in real time as they move through the care journey, the potential impact on patient-centric, value-based care is potentially limitless.

But it will also be felt beyond the clinical setting. Throughout the healthcare system, data collected from global experience can be used to enable more efficient use of resources and allocate budgets with better-informed targeting, removing vulnerabilities in processes. And in research, diagnostic and pharmaceutical product development will be liberated from a reliance on retrospective analysis, allowing for a greater emphasis on innovation, a quicker speed to market and lower development costs.

- In some ways, the **policymaker's role is educational – and they have persuasive messages at their disposal.** Stakeholders at every level have heard the generalised cliché of data as the oil that lubricates the modern economy. This can tend to encourage an insular approach to its use as a resource, which must be kept within and remain only for the eyes of their domain. **A progressive health data ecosystem would bring stakeholders together with a new vision of data as a resource that increases in value the more widely it is shared and used.** It would also encourage a new perspective on data as a high-value commodity rather than an overhead that must be managed and stored within limited pathways – usually at considerable cost.



CONCLUSION

It would be difficult to overstate the importance of the role policymakers will need to play in effecting the significant cultural and attitudinal changes that must be addressed in order to enable cross-border health data flows among APAC countries. The EHDS offers a framework of intent which will almost certainly be a significant influence on any regional efforts to coalesce around a common strategy. Global organisations including the WHO and WEF have also published broad recommendations for action in the health data space.

Any such efforts will need champions at a health policy-making level who can influence the incorporation of cross-border data sharing as an integral pillar of healthcare digitalisation. In its widest form, this influence will be about promoting the benefits for each layer of stakeholder: governments, health system decision makers, healthcare and research institution leaders, clinicians and citizens. In short, success will depend on individual nations getting their own health data sharing houses in order, in preparation for cross-border data flows. Unless they do this, population health will be inhibited by missed opportunities for innovation and research.



Recommendations for APAC nations with respect to stage of readiness

| STAGE | RECOMMENDATIONS |
|--|---|
| <p>BASIC:</p> <p>China </p> <p>Vietnam </p> <p>India </p> <p>Indonesia </p> | <p>Countries that have been assessed to be at a basic stage of readiness for cross-border health data sharing have much work to do. In the cases of India, Vietnam and Indonesia – which are playing digital catch-up in healthcare – this is the time for policymakers to address the challenges of predominantly paper-based health data and devise migration strategies for the digitalisation of EMRs. These strategies should be proactive – again, based on the long-term view that the capacity to share health data across borders can make every country an important player in the global health ecosystem.</p> <p>At the same time as building the foundations for internal data sharing, there is a need to accelerate the making and passing of regulations that provide a comprehensive framework for the governance of health data. This recommendation also applies to China – an outlier in this stage with its advanced level of digital maturity – but with similar restrictive approaches to cross-border health data sharing to India and Indonesia. Countries at this stage should also be setting their sights on accelerating the development of a model that enables and encourages the sharing of data nationally (noting that Vietnam is quite progressive in this regard) and takes a long-term view on the value of cross-border sharing. They can look to many of the currently evolving international initiatives for guidance and examples.</p> |
| <p>INTERMEDIATE:</p> <p>South Korea </p> <p>Australia </p> <p>Hong Kong </p> <p>Taiwan </p> | <p>Countries at an intermediate stage of readiness – South Korea, Australia, Taiwan and Hong Kong – share many similarities. These digitally mature nations have approaches and policies related to cross-border health border data sharing that are generally progressive, but there are also gaps in frameworks and policies which suggest a lack of focus on the unique aspects of health data. In the cases of Australia, Taiwan and Hong Kong, there is a need to accelerate the making and passing of regulations that provide a comprehensive framework for the governance of health data.</p> <p>For all the countries at this stage, a national level body specifically for the governance of health data should be an integral part of their vision for cross-border health data sharing. We have seen notable progressive examples of this in Finland and New Zealand, but globally such initiatives are slow to emerge. This is a golden opportunity for APAC countries to set a regional agenda for granular health data governance.</p> |

| STAGE | RECOMMENDATIONS |
|---|--|
| <p>ADVANCED:</p> <p>New Zealand </p> <p>Singapore </p> | <p>Countries at an advanced stage of readiness – New Zealand and Singapore – have all the enablers in place to facilitate cross-border health data sharing. They are already demonstrating a concerted effort to engage in cross-border health data sharing in many key areas, such as research and development. Even here, there is more work to be done on consolidation. But we should expect these countries to lead the APAC region’s ambitions to be a key global player and influence on frameworks and standards as the drive to share data for the benefit of health systems and research picks up speed. Along with their digitally mature cousins in the intermediate stage, these countries should also be building the foundations for the levels of interoperability that will be needed to underpin comprehensive cross-border data sharing; it will not be enough to consider accessibility on a case-by-case basis, which will simply enable the current piecemeal approach to continue indefinitely.</p> |

Government focus is likely to be strongest on trade and economic data sharing frameworks, which will naturally inform sector-specific national models. Policymakers for health will need to stake their claim to a seat at the development table; the same issues that demand attention for trade-based models – regulatory and operational – will need to be resolved for healthcare.

The fundamental challenges have been identified consistently by almost every proposed framework or statement of intent for driving cross-border data flows:

- A lack of legal and regulatory transparency;
- A lack of understanding among regulators about the technology challenges of data sharing;
- Overlapping regulations that are often in place within a single country; and
- A lack of common understanding of standards and specifications for data communication.

Many of these challenges manifest themselves particularly in the fragmented health systems of less digitally mature nations. But even in those countries where digital health infrastructure is more advanced and better connected, the lack of a consistent data sharing strategy will complicate further evolution. Regulations will need to be developed that accommodate the future advent of new technologies without imposing restrictions that will hamper the use of data in machine learning and AI technologies – both increasingly important in the evolution of healthcare and diagnosis.

Some of the pressure for change will come from within health systems. The pandemic response demanded the sharing of health data on an unprecedented scale. Clinicians and healthcare professionals have experienced the value of digital health systems in new ways and will be less tolerant of legacy information-sharing models that do not provide the same access.

Patients have also shared in this accelerated voyage of discovery and have a much greater knowledge of the value of their own data and how they want it to be used.

Healthcare is on the brink of a new era of data-enabled collaboration and data as an asset whose value has hardly begun to be realised. Frameworks that enable comprehensive cross-border data flow, and define its use in accessible and meaningful ways, will only emerge at the speed with which APAC governments are able to move.

In conclusion, this is a matter of taking steps now to ensure that the APAC region is in a strong position to drive the cross-border health data sharing agenda as it evolves rapidly. Policymakers can seize the opportunity to put health data at the heart of regulatory and governance development. And they can turn their attention to the health systems within their domain and drive change with data-aware allies to ensure that those systems are ready to embrace cross-border data flows when frameworks eventually arrive that are fit for their purpose. Ultimately, building diversity in data is in all our interests – but this cannot happen without global data flows.





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Cross-border health data flows in Asia-Pacific: breaking the ties that bind digital transformation

Authors:

Thiru Gunasegaran
Managing Editor, HIMSS

Piers Ford
Writer

Contributors:

Varun Veigas
Leader - Policy and Strategic Partnerships, Health Policy and Patient Access Value Stream, Roche

Hang Le
APAC Policy and Health System Shaping Lead, Roche

Afua van Haasteren
Manager, Health Policy & External Affairs, Roche

Acknowledgements:

Jennifer Pougnet
Global Data Policy Strategy Lead, Roche

Graphic Designer:

Anna Galang