ABAC
APEC Business Advisory Council

HEALTH
DATA SHARING

Public-Private Partnership Policies to Empower People and Health Systems in APEC Economies

August 2024

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Foreword

Under the ABAC 2024 theme of “People, Business, Prosperity”, we recognize the critical juncture for the global economy. Business and governments must come together now to act decisively for a sustainable future, including with respect to health and data. Data has played a critical role in the design and function of health systems for centuries, but the topic is evolving quickly as our digital technologies mature and capabilities develop.

Following what can only be described as a disruptive experience for all of us with the COVID-19 pandemic, we believe the timing of the topic of health data is more important than ever, especially when it comes to the deeper concept of health data sharing. Like the pandemic taught us, we should be proud of the resiliency of our health systems, though equally not complacent. The power of health data sharing is tremendous for citizens, government, and businesses, including on the cusp advancements like AI. And yet, there remain many challenges across public and private sectors alike which prevent maximum leverage of health data. We must raise our collective voice on the health data topic, to be more inclusive of the transition from informal to formal economies.

Taking a cue from our counterparts at APEC, who initiated the health data sharing topic in 2023, we embarked on this project at ABAC, under the Human Development Working Group and Digital & Innovation Task Force, to understand the latest health data sharing discussions, particularly with respect to its primary use, across different types of economies and stakeholders, including both large and small organizations. Indeed, what we found are a number of hurdles – inconsistent data standards, overly-restrictive or otherwise non-harmonized regulations, lacking ethical considerations, and implementation of change which, although commendable, leaves something to be desired by the way of insufficient governance and financing.

Fortunately, these challenges can be resolved with effective policy planning and public-private collaboration. In this report, we have outlined policy recommendations, best practices, and case studies, as well as articulating our view about how a bright, bold future for health data sharing can look. Importantly, this future goes beyond the data itself and empowers a vision of more integrated, personalized care through structured ecosystem collaborations.

The potential benefits of improved health data sharing are far-reaching – for governments to be able to better manage their economies and resources, for healthcare providers to gain a more realistic picture of interventions required, and for patients and citizens to take greater accountability of their own journeys. Beyond the economic gains, moreover, we can anticipate benefits of health data sharing to include greater social and equitable uplift.

Our populations expect and deserve greater well-being. We must strive to collaborate in public-private partnerships, and, for us, at ABAC, we think it is important to see health data sharing coming back to the human side of the conversation. The topic is not easy – it requires continued, collective discussion in order to refine our approaches to make progress ahead. We resonate with the positive yet also challenging experiences in our health systems, which we would like to see improved through better health data sharing.

Finally, we express our sincere gratitude to everyone who contributed to this report, and we are also deeply thankful for the support and guidance provided by our colleagues throughout the project. We look forward to hearing your feedback, in hopes that the discussion will help in moving our society forward to be better and healthier.

Julia Torreblanca
ABAC Chair, Peru

Jun Suzuki
ABAC Member, Japan

SECTION 3

Executive Summary & Methodology

Data, and digitalization more generally, of global societies, developed and developing alike, is no longer a new phenomenon, especially following the COVID-19 pandemic. We all experience the benefits, and challenges, of data and digital in our everyday lives, including related to essential activities such as securing shelter, food, and new models of employment. The digitalization journey has moreover been driven in large part by concerted policy efforts, such as the Asia-Pacific Economic Cooperation (APEC) Internet and Digital Economy Roadmap (AIDER).

Health data is unique, however, now constituting one-third of all data generated globally. Beyond the volume, health data is considered by many governments to be a public asset, the effective sharing of which is estimated to be worth up to 50 times more to economies. And yet, as much as 97% of health data is said to be under-utilized. Indeed, only 15 of 24 OECD economies have unified recordkeeping systems, with varying degrees of maturity around enabling data strategies such as universal health identifiers and sharing standards adoption. Expectations are high for data, especially as a prerequisite to the era of AI, to transform health systems into more personalized, integrated care models in anticipation of future population needs.

For these reasons, the Human Development Working Group and Digital & Innovation Task Force of the APEC Business Advisory Council (ABAC) undertook a focus on health data sharing, following a similar initiative launched by APEC in 2023, in order to better understand and propose policy strategies in the key economies. This inaugural report emphasizes the primary use of health data, defined as health data which is used to deliver healthcare and to make decisions about the care of the individual from whom it was collected. Leveraging existing APEC documentation to frame hypotheses for ABAC, an extensive literature review was conducted from domestic, regional, and supernational bodies. Thereafter, we spoke with more than 25 stakeholders across the APEC economies, coming from public and private sector, and ranging from policymakers to academia, healthcare providers, patient groups to tech firms. Lastly, the primary and secondary data was analyzed through ABAC consensus protocols.

A few consistent challenges with health data sharing emerged from the research. While perhaps the greatest progress has been made with adoption of data sharing standards (like HL7), APEC economies struggle with maintaining standards in decentralized care models, especially when attempting to construct health data repositories, within their borders and increasingly internationally. Beyond the standards, regulation is another common theme of discussion. While legislation for health data sharing is generally seen to be useful, often stakeholders feel the laws may be too restrictive, unharmonized, and leaving excess room to interpretation, which becomes sensitive in health data areas such as opt-out and ethical protocols. Lastly, and complementing the technicalities of health data sharing, is implementation strategy. Still too often, health data sharing implementation is misaligned when it comes to competing priorities, communication and education practices, and investment levels.

Fortunately, in this report, we provide solutions, recommendations, and best practice case studies for the identified challenge themes. The following table summarizes the recommendations accordingly:

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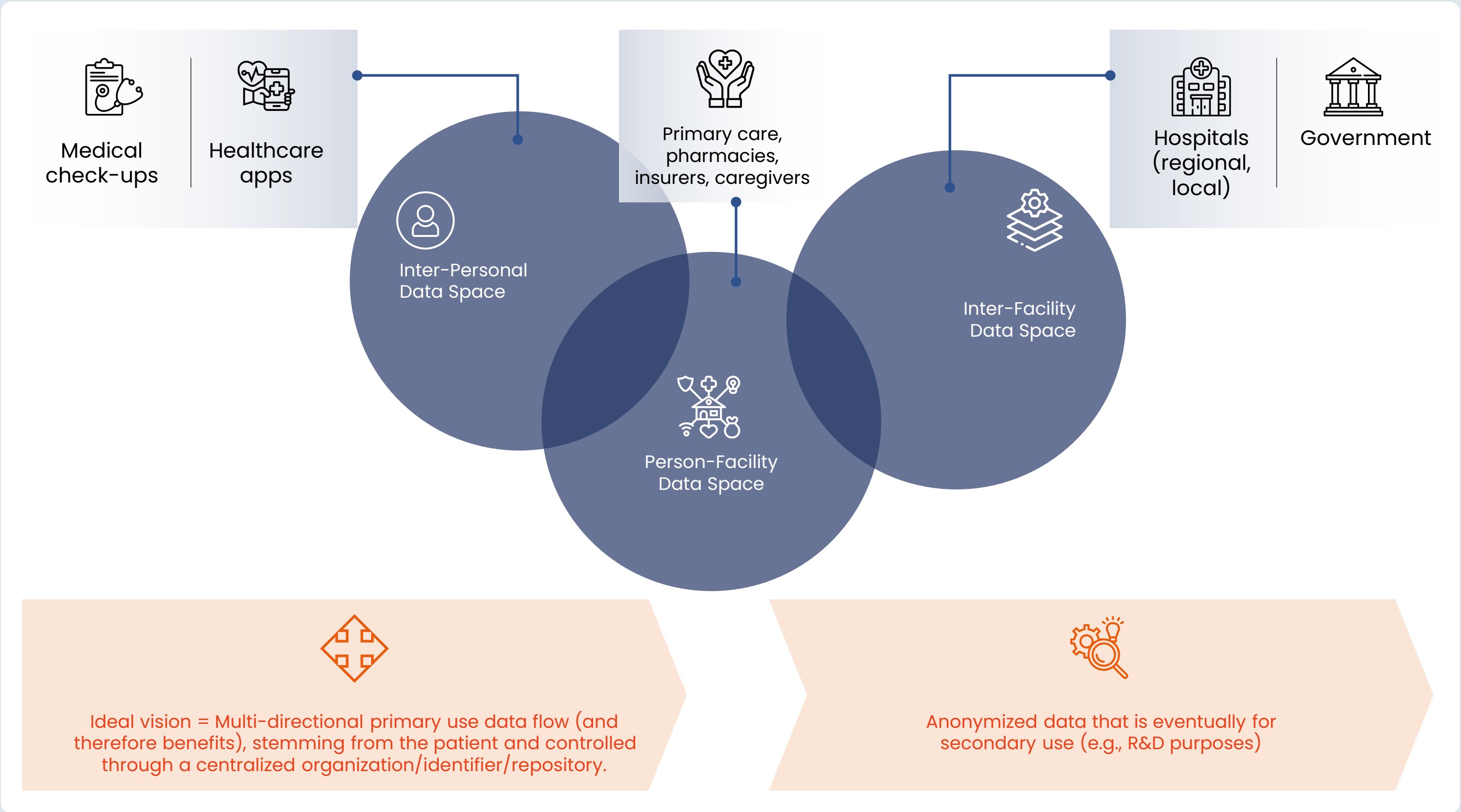
Executive Summary & Methodology

Challenge Themes	Recommended Strategies
Health Data Sharing Standards	01 Align on a common technical standard for data formats, identification numbers, and the interlinks therein (ideally following an international protocol like HL7).
	02 Also align on a common semantic coding standard in terms of ontologies and disease prediction models, across public and private sector, especially in anticipation of the adoption of AI.
	03 Establish a basis for formal licensing of the technical and semantic standards, including requisite training programs for the healthcare workforce and wider ecosystem of stakeholders.
	04 Beyond disease prediction models, aim increasingly for integrated care networks that follow the patient pathways and interlink data between primary care, specialty care, community care, and others such as pharmacies.
	05 Ensure that any health data networks which are created or developed are anonymized and harmonized, including in consideration of the emerging trend for such networks to effectively operate across international borders.
Health Data Sharing Regulations & Ethics	01 Foster an enabling environment of risk-based, flexible guidelines (rather than overly fixed regulations) which are safe yet adaptable, especially for fast-moving modern trends like AI.
	02 Support the harmonized adoption of data governance frameworks, like that of the OECD, which are specific to the healthcare sector and establish ready-made principles for privacy and security protocols.
	03 Shift from opt-in, consent-driven requirements into a collaborative, opt-out model, including with respect to relaxing data localization demands.
	04 Maintain multi-stakeholder ethical review boards along the way, including for addressing breaches, and in anticipation of greater secondary use requests for health data.
	05 Publish national blueprints for health data sharing, similar to the WHO's Global Initiative on Digital Health (GIDH), which are open to consultation across regulators, public and private sector, and patient voices.
Health Data Sharing Implementation	01 Beyond having a vision, establish a "Community of Practice" (a public-private partnership) for health data sharing and collaboration.
	02 Form an official Health Data Sharing Office within the government, complete with training, use case collection, and value capture, including down to a citizen level.
	03 Have a plan for ongoing capacity and capability development, leveraging best practice experience from the private sector and involving key stakeholders such as patients, caregivers, small enterprises, even other sectors.
	04 Right-size health data sharing investments, for the longer term and incentivizing sufficient data collection and sharing behaviors.
	05 Coalesce data sharing and case studies with the financial models to support the value-based healthcare journey, such as in the form of prioritizing outcomes data and ongoing ROI monitoring.

Executive Summary & Methodology

We conclude the report, taking in the challenges and opportunities which emerged from the primary and secondary research, by providing a to-be vision for health data sharing as a kind of APEC economy archetype. The vision encompasses inter-personal data (controlled and shared by patients and citizens), person-facility data (connectivity point between patients and healthcare facilities), and inter-facility data (sharing amongst healthcare facilities and government). Ultimately, we hope to see a centralized health data repository and authority, enabled by common health data platforms and identifiers, including, eventually, with proper security protocols, secondary use activities like R&D. Although each APEC economy is unique, our vision is for more common, rather than different, standards, regulations, ethical considerations, and implementation best practices.



Ideal vision = Multi-directional primary use data flow (and therefore benefits), stemming from the patient and controlled through a centralized organization/identifier/repository.

Anonymized data that is eventually for secondary use (e.g., R&D purposes)

More effective and efficient data sharing is estimated to generate economic benefits worth 2.5% or more of GDP. Beyond the economic benefits, we see improved health data sharing as a driver of population inclusiveness, too, especially for the more vulnerable communities. Indeed, investment will be required, including appropriate upskilling of our workforces, patients, and citizens. So, most importantly, health data sharing policies require a longer-term, public-private outlook, cultivated through continued open dialogue.

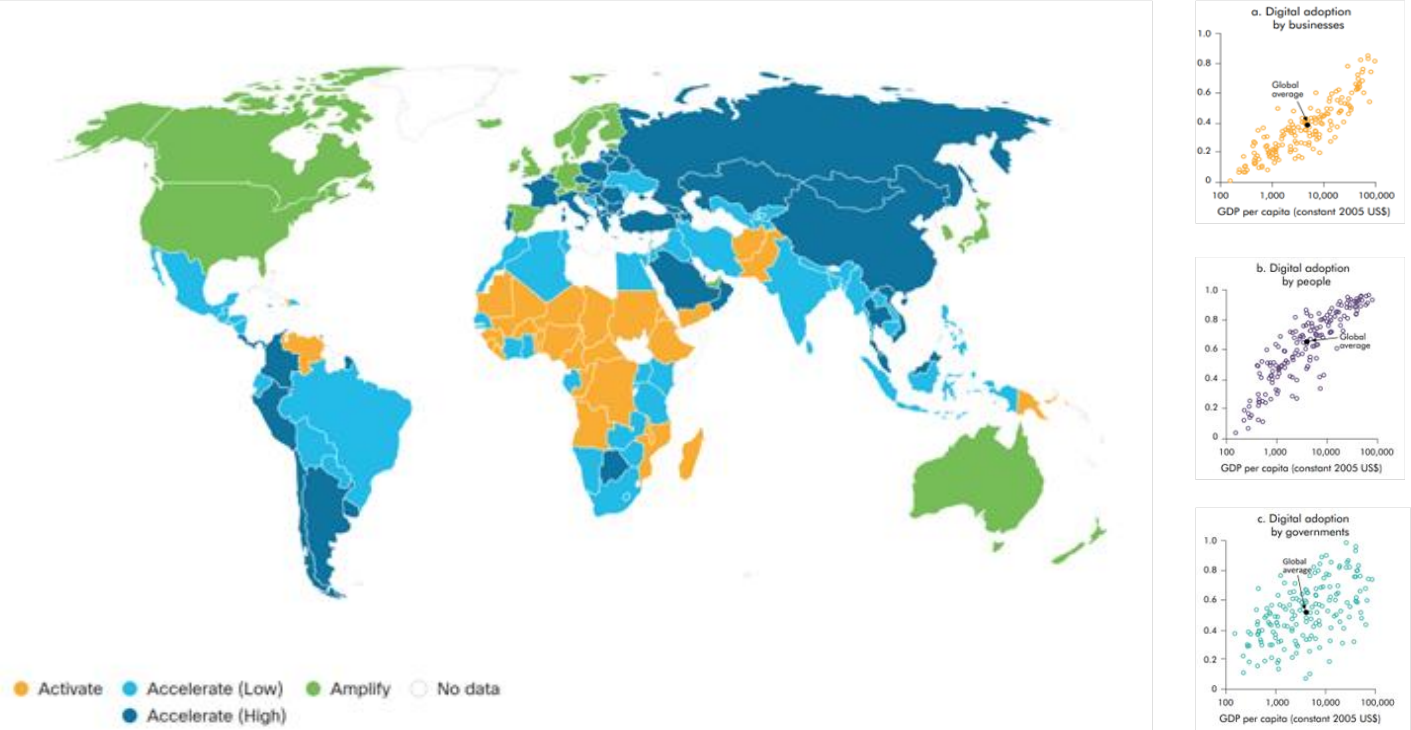
SECTION 4

Health Data Is the Topic of Our Time

Data, and digitalization more generally, of global societies, developed and developing alike, is no longer a new phenomenon, especially following the COVID-19 pandemic. We all experience the benefits, and challenges, of data and digital in our everyday lives, including related to essential activities such as securing shelter, food, and new models of employment. The digitalization journey has moreover been driven in large part by concerted policy efforts, such as the Asia-Pacific Economic Cooperation (APEC) Internet and Digital Economy Roadmap (AIDER)[1].

While there are no consistent, nor in some cases, even current, measures of digitalization of economies[2], according to the World Bank's Digital Adoption Index (DAI)[3], as of 2016 more households in developing economies had access to a mobile phone than clean water, and the number of internet users more than tripled from one billion in 2005 to 3.2 billion. According to CISCO, moreover, essentially all economies are in some stage of digitalization, as of 2021[4]. More recent rankings place the most well-developed digital infrastructure in geographies which are the key economies of APEC[5] – Japan, Korea, United States, China, and Western Europe round out the top five, with Singapore, Canada, Australia, New Zealand, and Russia also making honorable mentions.

Figure 1: Global Digital Adoption Indices from 2005 to 2021



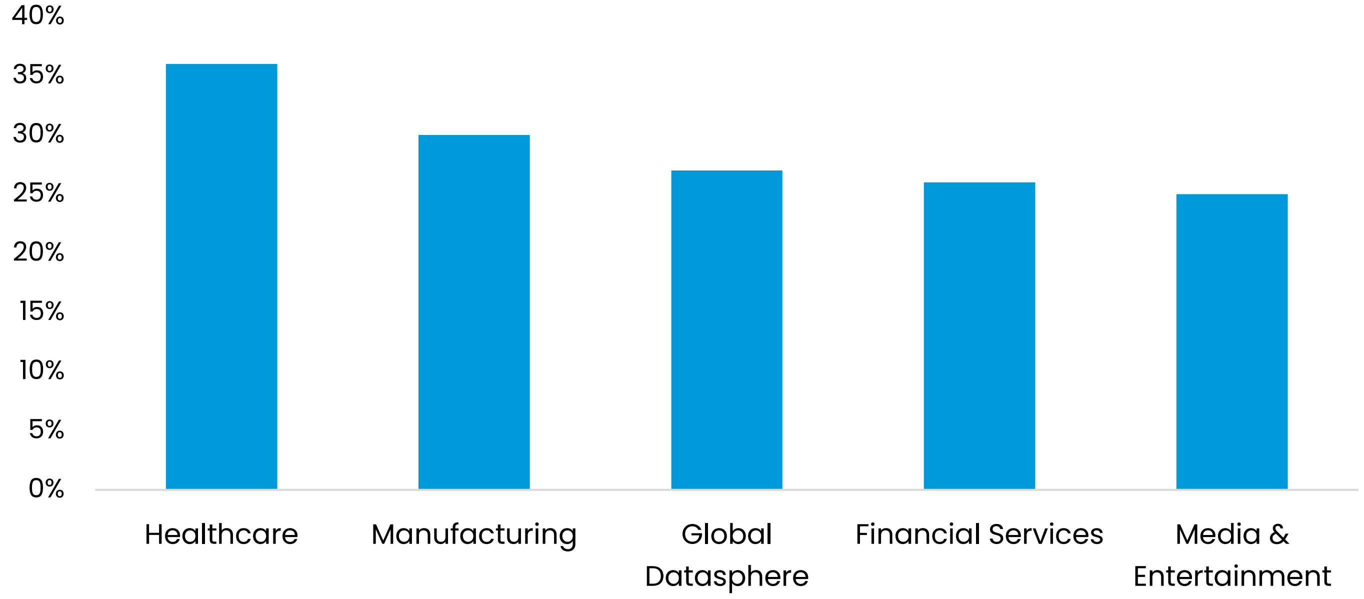
At top, CISCO's "Digital Readiness Index" 2021 which ranks economies from Activate (basic) to Amplify (advanced), based on factors such as government investment and technology infrastructure. At right, the World Bank's "Digital Adoption Index" 2016 (most recent edition), tracking progress since 2005 across 180 economies. Images inspired by CISCO and World Bank.

SECTION 4

Health Data Is the Topic of Our Time

Despite the wider digitalization trend, health data is unique. Health data now constitutes one-third of all data generated globally[6], which puts it in its own category in terms of volume, standards, regulation, and societal concerns like privacy. Beyond the volume, health data, particularly in terms of its primary use (defined as the health data used to deliver healthcare and to make decisions about the care of the individual from whom it was collected)[7], is considered by many governments to be a public asset, the effective sharing of which is estimated to be worth up to 50 times more to economies[8]. Expectations are extremely high that data can empower the much-needed transformation of healthcare access and delivery models. And yet, estimates put 97% of health data as under-utilized[9].

Figure 2: Projected Data Growth by Sector



Growth projections of data generated by leading sectors through 2025, with healthcare outpacing the rest and expected to represent one-third of all data being generated. Image inspired by IDC.

“Health data is a valuable public asset, accumulated by medical institutions and related organizations under the universal health insurance system”, said Naoko Ogawa, Director of the Industrial Technology Bureau at Keidanren (Japan Business Federation). “The utilization of health data can bring various public health benefits, such as promotion of self-health management, raising the quality of medical care, improvement of workflow efficiencies, and optimization of healthcare costs.” “Health data can be harnessed to reduce financial pressure on governments with competing priorities for public funds available,” agreed Anirudh Sen, Director at the Asia-Pacific Medical Technology Association (APACMed), an organization which published a whitepaper for health data policies in 2023[10]. “Health data, including concepts such as Real-World Data (RWD) and Real-World Evidence (RWE), should be better mobilized for its safe, effective use in order to benefit patient outcomes and resources.”

For these reasons, APEC announced in 2020 the Putrajaya Vision including, among other economic drivers, digital infrastructure, digital transformation, and data flow. Importantly, the APEC activities have emphasis on inclusive and sustainable growth, which target public services like healthcare[11]. To further illustrate the importance of the health data primary use topic, we will next look at emerging components of the conversation in terms of standards, Artificial Intelligence (AI), disease priorities, economic returns, and human development.

Most if not all APEC economies are already following a common data standard now

Standardized health data collection and sharing is essential for its efficient utilization, in particular from a health perspective in order to manage scarce resources most effectively. Fortunately, according to a recent study in the Asia Pacific region, many economies have already established such standards[12]. Most economies have implemented (or are in process of) electronic medical recordkeeping systems. These systems, albeit not always fully integrated, are offering an opportunity to maximize availability of patient information and to boost care provision quality and productivity.

These findings correspond with our stakeholder discussions, too. Health Level 7 (HL7) seems to be fairly commonplace across the economies, developed and developing, and, according to the tech firms we spoke to, active discussions are being held on key themes such as privacy by design, data minimization, and data anonymization. In Japan, for example, Akira Morita, Professor Emeritus at the University of Tokyo, describes the situation as "Health data infrastructure and legal frameworks are in place, driven by the Prime Minister to promote health data sharing nationwide" yet lingering challenges with social awareness, public-private collaboration, and databank integration. Hiroaki Hasegawa, Consulting Director at FINDEX Inc., agrees, saying that "In Japan, there are no significant obstacles to using medical data in clinical settings", looking forward to now being able to harness the data for insights, especially related to the cost-effectiveness of health system strategies. In Korea as well, according to Sang-soo Lee, Senior Director of Government Affairs & Market Access at Medtronic, what started as a consolidated healthcare claims database (under a single payer format) has led to the tagging of "data hospitals" in order to connect the claims data to the electronic medical record data, the latter of which has already achieved 90% coverage in the economy. Korea is building the "My Healthway" platform which aims to connect health insurance, clinical care, and even genomic data to offer better lifestyle guidance to citizens[13].

Australia, moreover, is a case study to learn from. The economy has made great strides in the sharing of health data, driven by demand from the population to have a more coherent, longer-term strategy around digital health[14]. Below are the databanks, services, and capabilities now available in Australia:

- Healthcare Identifiers Service for unique patient identification;
- SNOMED CT-AU standard vocabulary and clinical information exchange;
- My Health Record online summary of patient encounter information;
- Electronic prescribing for physicians, patients, and pharmacists;
- National Clinical Terminology Service for HL7 alignment, updated monthly;
- National Health Services Directory for patients and care providers to find each other;
- National Authentication Service for Health for data encryption; and
- Metadata Online Registry for the latest statistics about health, housing, and community.

We will further elaborate on healthcare digitalization and data sharing standards, including case studies therein, in Section 5.

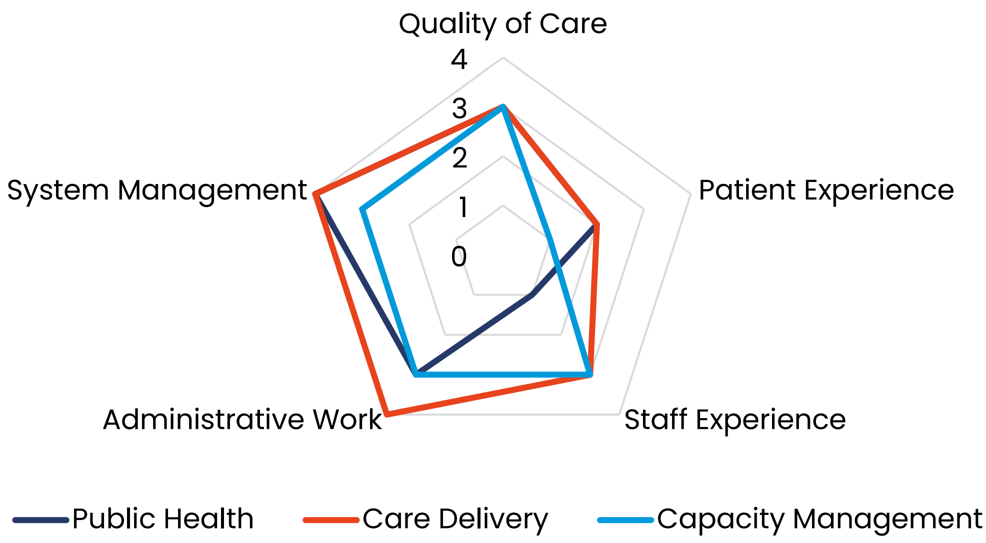
Health data, including its sharing, is a prerequisite to the AI revolution

A theme tied to health data which presents itself frequently in the literature and stakeholder discussions is the new era of AI and healthcare. While the focus of this whitepaper is more on the data sharing side than AI, we recognize the latter's importance and call attention to the sister work being conducted by the APEC Business Advisory Council (ABAC) to promote an enabling environment for AI, on the back of recent guidelines such as those issued by the Organization for Economic Cooperation and Development (OECD)[15]. ABAC is exploring use cases for AI such as precision health, smart medicine, telecare services, and ageing in place, as well as advocating for continued public-private dialogue, including in the face of potential future pandemics.

"AI is a very important technology," said Fuji Nagami, Professor at the Tohoku University's Medical Megabank Organization (ToMMo). "That said, high quality data will be important for AI, so our focus now is on preparing the primary data, including as derived from biobanking, for useful clinical analysis." "AI is an emerging enabler for the healthcare industry," agreed Yean Cheong, Executive Director at SGTech. "Similar to the data sharing conversation, for AI we must be transparent about its consent, usage, and accountability. This also means managing different stakeholder interests for more seamless data exchanges."

The health data sharing + AI spotlight is on Canada, for example, an economy whose robust healthcare system has led to inflationary medical expenses which are growing faster than Gross Domestic Product (GDP)[16]. Canada established its National Task Force on Health Information in 1991 followed by the Canadian Institute for Health Information in 1994 and Canada Health Infoway in 2001, all working jointly together to facilitate pan-Canadian collaboration on digital health and health data, including the sharing of health, social, and genetic factors of citizens. More recently, the conversation has shifted into the potential of AI, with Canada being the first economy to have a domestic AI strategy, under the leadership of its Canadian Institute for Advanced Research. As the Canadian example shows, AI, powered by health data, offers health systems a more personalized approach to patient care.

Figure 3: AI Impact Areas to Healthcare by Technology Purpose and Value Chain Step



AI offers opportunities across public health, care delivery, and capacity management. While each technology purpose has different levels of impact, system management and administrative work are particularly noteworthy. Image inspired by McKinsey.

Health Data Is the Topic of Our Time

APEC economies have priority disease themes for data, especially the integration therein

When it comes to the data journey, especially in a complicated sector like health, there is a tricky balance between driving change at the system level while also making tangible progress through niche, more tactical initiatives. This notion rings true from a disease prioritization perspective for health data as well, according to our stakeholder conversations (which were diverse in terms of type of economy).

On one hand, following the COVID-19 pandemic which remains top-of-mind for many, health data is a focus for preparations of the anticipated "Disease X"[17]. "We must prioritize health data for diseases with the highest transmissibility, morbidity, and mortality, such as respiratory infections," said Robe Yang, Senior Director at Quanta Computer in Chinese Taipei. "Health data allows us to analyze disease patterns and associations, and to identify the emerging risk factors."

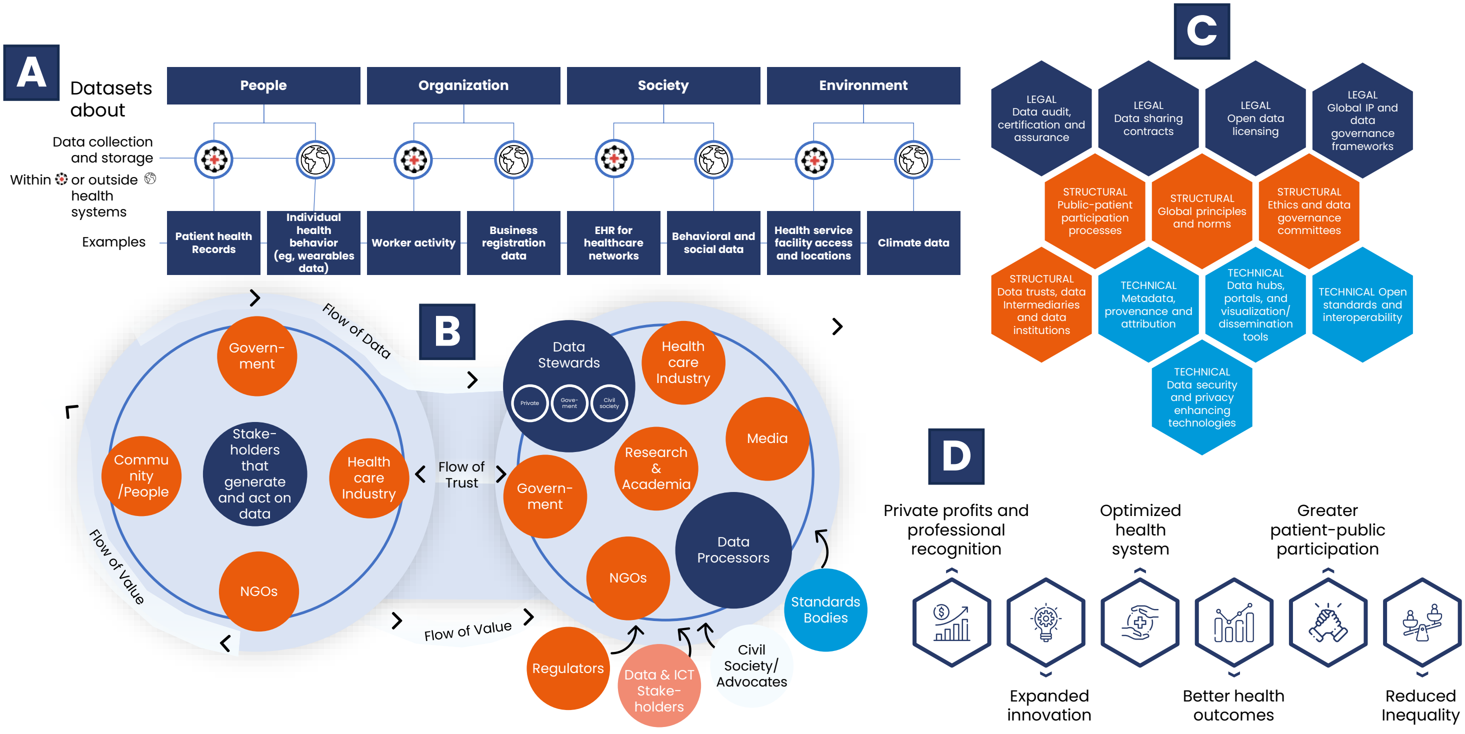
On the other hand, modern societies are focused on tackling the rise of Non-Communicable Diseases (NCDs) too, utilizing health data for preventative action such as earlier detection, treatment, and management. "We are analyzing registries and electronic medical record systems to better understand public health challenges like metabolic, cardiovascular, and cancer diseases," said Clive Tan, a Senior Consultant in the Population Medicine Department of Singapore's National Healthcare Group. "We are also starting to analyze opportunities to do more in mental health, though this subject remains sensitive in terms of data sharing."

Perhaps most resoundingly, however, is the desire from APEC economies to utilize health data for transforming into more integrated care models (i.e., across both communicable and non-communicable diseases, even prevention). Health data has the potential for health systems to be more personalized to individual patient needs, such as, for example, in the case of aged care. "Our current priorities are now around the transition of care, rather than any specific disease," said Mike Lau, Chief Data & Analytics Officer of the Australia Digital Health Agency. From the patient perspective, Aparna Mittal (Founder of PatientsEngage in the Asia Pacific), said that the "Driving force behind healthcare digitalization has traditionally been process efficiency", and instead that we need to shift our mentality to being more about integrated, population health outcomes for patients. Birgit Bauer, likewise, Founder and Project Manager at DataSavesLives in Germany, said that "The more we know about a patient through primary health data, the more we can help while also avoiding unnecessary medical steps." However, Bauer also warned that at the moment there are major gaps in digital health literacy, calling on governments to do more to clearly explain the "'do's and don'ts" of health data to average citizens, void of too much jargon, including by collaborating directly with patient organizations.

An integrated approach for health data seems to resonate with the care provider community, too. Eduardo Gotuzzo, Emeritus Professor of Medicine at Universidad Peruana Cayetano Heredia in Peru, said that "Public health is strengthened when we have solid data sources", a lesson learned with the mining community (who tend to work in close proximity) during COVID-19 in which health data, such as vaccination records, were more efficiently shared and, therefore, disease controlled, saving an estimated USD 2-3 million per day if otherwise mining work had to be stopped. Matthias Keilen, CEO and Board Member at the Bezirkskliniken Mittelfranken hospitals in Germany, added that the physician community is now more aware about the power of health data, which is elevating their role from "a detective to a communicator" based on more reliable insights to guide the patient journeys.

Health Data Is the Topic of Our Time

Figure 4: Key Elements of a Health Data Sharing Ecosystem



Visual representation of an entire health data sharing ecosystem, including the types of health data (A), the value flows (B), the governance mechanisms (C), and the benefits categories (D). Workshops and case studies are available for each component. Image inspired WHO.

In terms of health data sharing policies with respect to these priorities, the trend seems to be a framework which is flexible enough to accommodate both systems- and disease-level efforts. Here we can take learnings from the European Union, whose European Health Data Space (EHDS) provides a policy framework, technical infrastructure, and guidelines for data sharing, including as citizens move across border lines in the region[18]. While perhaps not a perfect solution, including for application to unique APEC economies, the EHDS offers principles for a balanced approach to health data sharing, especially in the face of very stringent General Data Protection Regulation (GDPR) rules. Other economies have started to follow suit too, such as the signing of a Memorandum of Understanding (MOU) between Singapore's Personal Data Protection Commission (PDPC) and Mexico's National Institute for Transparency, Access to Information, and Personal Data Protection (INAI)[19]. In recent years the United States government removed info-blocking[20], Peru passed legislation to govern telehealth integration (for data sharing)[21], New Zealand announced a domestic platform to connect 28 sub-regions under a core data model[22], and there is a big push in Southeast Asian economies like Thailand and Indonesia to mandate unified electronic medical records[23].

While there are varying stages of maturity with health data sharing, including related themes like digitalization and AI, and still improvements which need to be made, the progress is promising. Data sharing can empower people to be informed about their health and to make better health-seeking behavioral choices, be it at the system level or along disease-specific tracks. "The outcome, if we are able to do this right, is to drive improved health data collaboration around the world," said Eric Sutherland, Senior Health Economist for the OECD. "Which effectively means activating 8+ billion people to be advocates for their own health and care, adding quality years to all of our lives."

There are both cost avoidances as well as economic gains associated with sharing health data

As has already been alluded, there is economic potential awaiting improved health data sharing, too. These economic benefits can come in the form of cost avoidances, such as enhancing the efficiency of precious resource deployment, as well as in the form of actual developmental gains through better health outcomes and quality of life.

“Health data can detail a clear blueprint to costs with the view toward improved decisions that are more holistic and less siloed, including for a preventative rather than reactionary focus,” said Lisa Foster, CEO of the New Zealand Home & Community Health Association. “This is especially true for those who are often missed by traditional data capture, such as rare disorders or under the disability radar. We learned the hard way during COVID-19 that, sometimes, people who are most vulnerable are invisible.”

Indeed, data sharing is estimated to generate social and economic benefits worth up to 1.5% of GDP, and, in the case of public sector data, as high as 2.5%; further, when combining public and private sector data, the figure reaches 4%[24]. In a study in Europe, “open data societies” across nine economies were estimated to have created more than 100,000 jobs and EUR 1.7 billion in efficiency gains[25]. “The strategic use of health data holds immense potential to fortify health systems and catalyze economic development,” said Daniel Otzoy, CEO of the Central American Health Informatics Network (RECAINSA). “In essence, health data sharing can transform care delivery, elevate public health standards, and drive economic prosperity, underscoring the critical role of data in achieving health and economic goals.”

The good news from an economic benefit perspective – health data is already, for the most part, becoming available, with many global examples of best practices about its successful sharing[26]. “Health data, electronic medical records but also data personally collected, is valuable as a source of evidence to improve the quality-of-care services,” said Dipak Kalra, President of the European Institute for Innovation Through Health Data (i-HD), commenting that, in Europe, patients are increasingly able to benefit from accessing healthcare services across borders due to the sharing of records. “If health data could be better shared across borders by following a regional or even global standard,” said representatives of ERIA (Economic Research Institute for ASEAN and East Asia), “we could improve the health economic environment by driving costs down without sacrificing the quality of services.”

We mustn't overlook the human development factor of health data sharing

A repeated finding from the literature and stakeholder conversations, in line with the priorities of the ABAC Human Development Working Group, is the "people factor" of health data. Healthcare is inherently a human-centric industry, an industry which is severely challenged by insufficient resources, including in terms of workforce. What's more, care providers and patients alike require greater training in order to improve their digital health and data literacy.

From the perspective of the care provider community, a resounding topic of interest from stakeholders is investment into workforce upskilling. According to Christine Sham, Director of Information Management for the Ontario Ministry of Health in Canada, "data stewardship" is only emerging as a formal discipline. Moreover, the discipline is cross-functional in nature, requiring medical data education to go further upstream through channels such as universities, certificate programs, and continuing professional development. Otzoy of RECAINSA agrees, stating that it's time for medical education to "modernize", especially if the care provider workforce wishes to guide, rather than be consumed by, the ongoing digital transformation. From the perspective of a tech firm like Amazon Web Services (AWS), not only can digital and data help to reduce care provider workforce burnout through, for example, mixed-reality consultations, but there should also be better pairing of a digitally skilled care provider workforce with technology developers. "There are now several universities in the Asia Pacific region offering advanced programs in health informatics," said Alvin Marcelo, Director of the Asia eHealth Information Network (AeHIN), "however skills training for the general public and frontline healthcare workers remains limited. Educational opportunities for digital health literacy are sparse."

There is similar motivation to upskill patients and citizens too, especially along the lines of an ambition for more self-empowerment of health management. Perspectives shared by stakeholders in New Zealand, for example, say that proper training about data integrity, monitoring, and usage is critical for the adoption of new technologies to succeed. Importantly, these approaches should leverage international best practices but be locally tailored, with the flexibility to adapt to evolving societal priorities especially in health systems which remain decentralized. Such efforts would serve to improve the quality of the data being captured; in other words, small yet usable data sets are increasingly of more value than large, complicated ones. Looking further to East Asia, there is emphasis on the user interfaces and training related to data entry for citizens, a step which increasingly falls onto patients under remote care monitoring. "The crucial movement comes from individuals capable of identifying where and what kind of data is stored," said Hasegawa of FINDEX. "Education occurs through daily interactions between patients, clinicians, and wider communities."

To achieve the above will require systems-level thinking, too. This includes according to stakeholders, continuing to build capacity and capability around data standards, such as HL7, adopting the right cultural mentality for digital health ecosystems, and combining skillsets across care provision and data strategy in a way that, rather than one trying to replace the other, operates in tandem. An example comes from the United States, which has established its Office of Public Health Data, Surveillance, and Technology, built around domestic databanks and data sharing protocols through a centralized platform which gained momentum on the back of COVID-19[27]. "The lack of human development with specialized knowledge about health data will continue to be an issue until it is formally incorporated into policy," said Morita of University of Tokyo.

SECTION 5

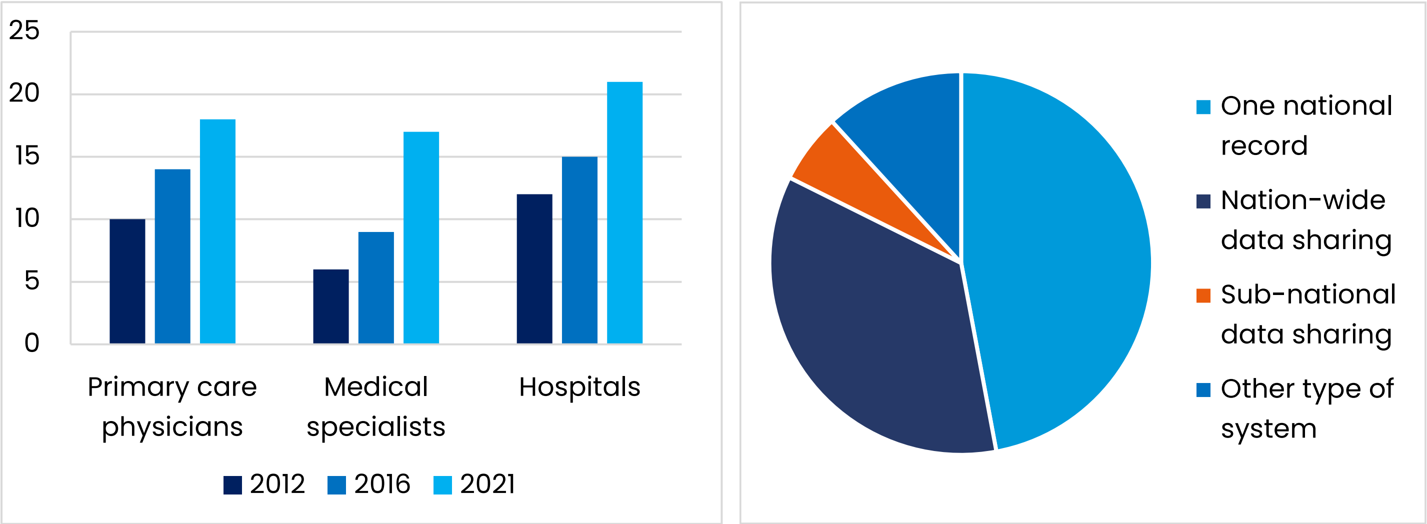
Progress Made, Yet Lingering Challenges with Health Data Sharing

The importance of the health data sharing topic, as highlighted in Section 4, has led to tremendous progress over the past few years. That said, there remain a number of lingering issues to overcome if the ultimate vision is to be achieved. We will cover both angles in Section 5.

To frame the context for APEC economies, as compared to the broader digitalization journey described previously, the penetration of health data sharing strategies remains more fragmented. On one hand, there has been noticeable progress with the implementation of electronic patient recordkeeping – a 2021 survey by OECD found that 24 of 27 economies have the basic infrastructure in place now, with Japan showing the greatest improvement of all[28]. Japan established its public health information network in 2020, enabled by interlinked medical and social security identifiers[29]. Singapore is another featured case study, an economy which, since 2011, has had an integrated medical record across public and private sectors covering more than 1,300 institutions, the record of which is owned by the government under a program called "One Patient, One Health Record."[29] That said, only 15 of 24 OECD economies are considered to have unified recordkeeping systems, due to both technical and legal hurdles[28]. The United States is one such example of the hurdles because, despite electric patient record penetration reaching a remarkable 90%+ of hospitals and 60% of clinic practices as a result of the 21st Century Cures Act, the systems are not typically interlinked[29].

According to the Canadian Digital Health Survey 2023, similarly, even at 87% electronic patient record adoption, only 39% of Canadians have accessed their data. "Lack of connected care is harming the health and safety of Canadians who experience increased risk of treatment delays, medication errors, or misdiagnosis, and is adding to the strain of our health system. Fragmented data makes it difficult to understand how our health system is performing or to respond effectively to public health events," said Elizabeth Toller, Executive Director of Digital Health at Health Canada. "Which is why federal, provincial, and territorial governments are collaborating to modernize the health system with standardized health data and digital tools through the 'Working Together to Improve Health Care for Canadians Plan'."

Figure 5: Electronic Patient Record Usage Patterns and Platform Types in OECD Economies



There is a noticeable uptick in electronic patient record adoption across healthcare facilities, especially among hospitals. While many economies claim a single national record (e.g., Australia, Japan, and Europe), quite a few economies operate on a data sharing basis. Images inspired by OECD and HL7.

On the other hand, and more from a data rather than systems perspective, a major inhibitor to progress is the inconsistency regarding unique patient identifiers. Unique patient identifiers are particularly important, and therefore a sign of health data sharing maturity, in order to achieve Universal Health Coverage (UHC) ambitions, in terms of connecting the legal identities of citizens to vital health information but also wider social and financing needs. As it stands currently, there are varying models of unique (or universal) patient identifier efforts and purposes, which makes the consistency around sharing protocols, particularly across borders, much more difficult. Thailand is an example to learn from here, with its integrated civil registration and patient identifier system covering nearly 70 million citizens. Thailand, one of the early UHC economies of Asia, moved from a paper-based to computerized, centralized registration system in 1982, with vital health statistics being incorporated as of 1996. Known in whole as the Personal Identification Number (PID), the identifier obtains details such as citizenship, public health insurance enrollment, tracking of services at the hospital level, and, more recently, e-referrals[30].

Figure 6: Types of Health Identifiers and Their Key Purposes

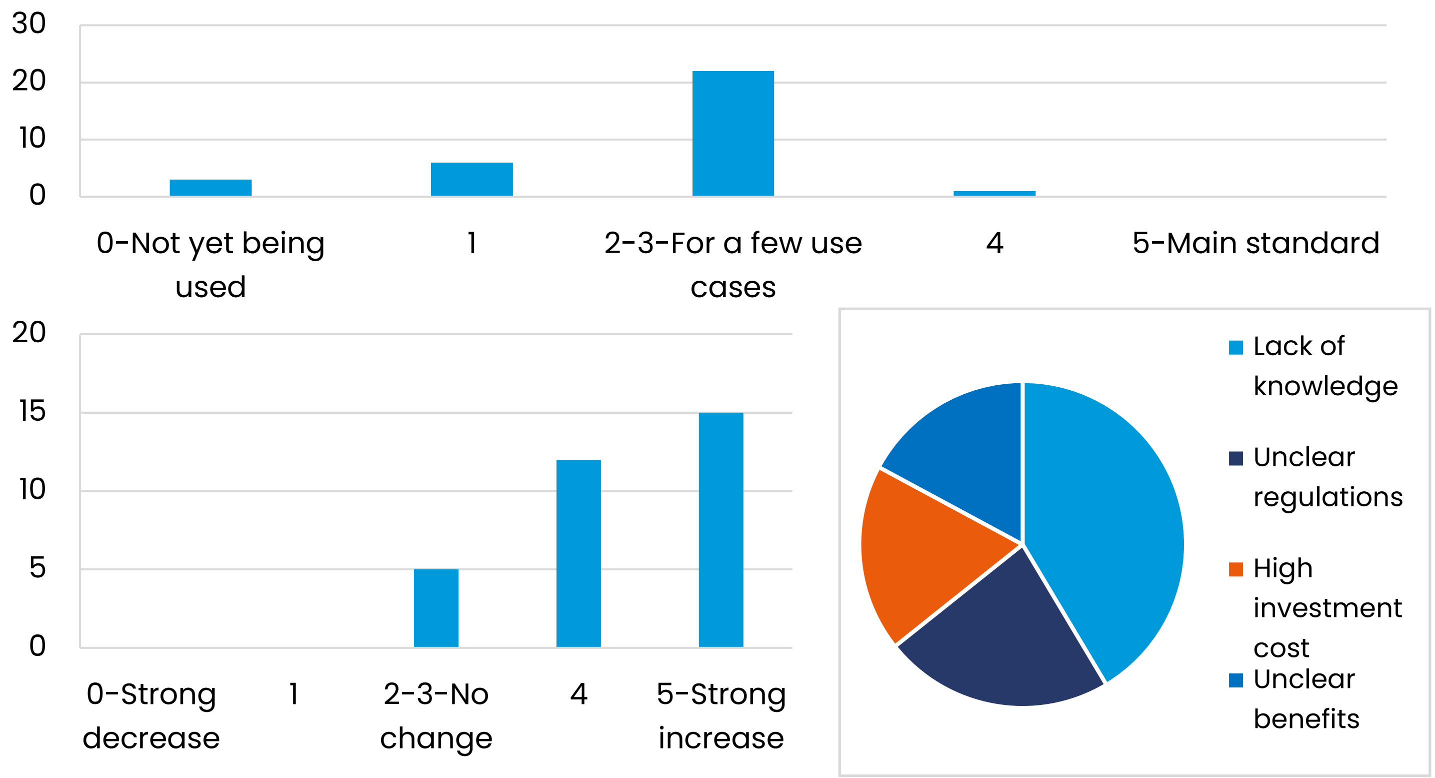
Economies with universal citizen identifier same as universal health identifier	India, Israel, Japan, Korea, Netherlands, Norway, Slovenia, Thailand
Economies with separate yet linked identifiers	China, Denmark, France, New Zealand, Singapore, Sweden, Chinese Taipei

Unique Health Identifier Use	**Canada**	**Denmark**	**New Zealand**	**Korea**	**Switzerland**
Output measurement	🟦	🟦	🟦		🟦
Reimbursement	🟦			🟦	🟦
Quality monitoring		🟦			
Accounting	🟦				
Staff performance		🟦			
Benchmarking		🟦			

While quite a few economies claim a unique or universal health identifier which is integrated into the overall citizen identifier, other economies have separated or even un-linked identifiers. Denmark is perhaps the most advanced in terms of use of identifiers for both clinical and administrative purposes. Images inspired by World Bank and Garcia-Armesto et al.

Lastly, in terms of context about health data sharing progress, is the adoption of standards. According to HL7's most recent survey in 2023[31], and in line with our key stakeholder conversations, there has been an uptick in Fast Healthcare Interoperability Resources (FHIR) adoption, though the use cases are still emerging. Canada, a leading example, estimates more than 45 FHIR projects are already underway, in areas such as patient summaries across provincial jurisdictions as well as community risk stratification. At the same time, challenges with standards adoption do still exist, with lacking knowledge, unclear regulation, and high investment costs ranking among the top.

Figure 7: FHIR Current Usage, Adoption Rates, and Challenges (2023)



At top, moderate use of FHIR, with Canada, United States, Europe, and Chile leading the way. At bottom, however, a strong upward trajectory of FHIR adoption. Many of the lingering challenges are non-technical, especially capabilities, messaging, and investment/benefit. Images inspired by HL7.

With this context in mind, we will review the progress and challenges of health data sharing around three key themes: standards, regulations and ethics, and implementation considerations.

SECTION 5

Progress Made, Yet Lingering Challenges with Health Data Sharing

5.1 Progress and challenges related to standards for health data sharing

According to the statistics and in speaking to stakeholders, perhaps the most progress in APEC economies, developed and developing alike, has been in the adoption of health data sharing standards. Standards tend to be a fairly technical subject, entailing data sharing terminologies, formats, and methodologies. Readers can reference APEC's 2024 report about health data sharing standards[32] for further details, particularly regarding the technical configurations of the sharing networks.

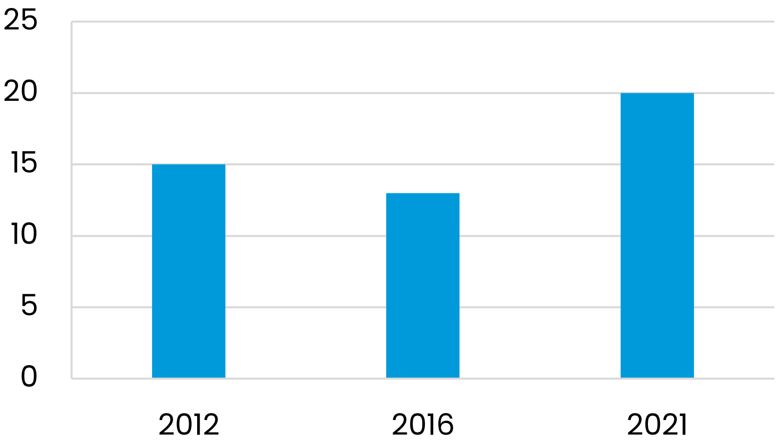
Of the various health (and wider) data standards available, HL7 seems to be the most commonplace, and growing. In particular, FHIR, the standard developed by HL7 designed to enable the electronic sharing of health data between disparate platforms, now covers some 80% of typical system requirements. According to Charles Jaffe, CEO of HL7 who has contributed to the APEC work, global standards for health data sharing will serve to improve the timeliness of patient diagnosis and treatment, and thereby outcomes overall. And, while HL7 continues to evolve, including related to new trends like AI, Jaffe stressed the need for further dialogue about the standards. "We are seeing a strong push toward the use of HL7/FHIR standards," observed Rowland Illing, Global Chief Medical Officer at AWS. "In Japan, where for many years we shared health data using proprietary methods, we are now utilizing HL7 in daily service provision," said Hasegawa of FINDEX. "We are following stricter procedures now with HL7 to interconnect systems through identification numbers, albeit anonymized," agreed Nagami of ToMMo. "The health data network in Korea follows international standards," said Lee of Medtronic. "In part this is driven by the desire of Korean companies to expand abroad, too."

It is likely for the standards adoption reason, according to OECD surveys, that health data sharing across care providers has increased dramatically in recent years. Chinese Taipei is one example, in which citizens carry an electronic card with encoded personal information, insurance data, medical visit notes, diagnoses, drug prescriptions and allergies, immunization records, organ donation consent, palliative care directives, and more. The "Medicloud" system then integrates the records across different hospitals and clinics, which, when required to use in order to receive reimbursement, has led to an estimated savings of USD 264 million in drug spending and USD 93 million in lab exams since 2018[33].

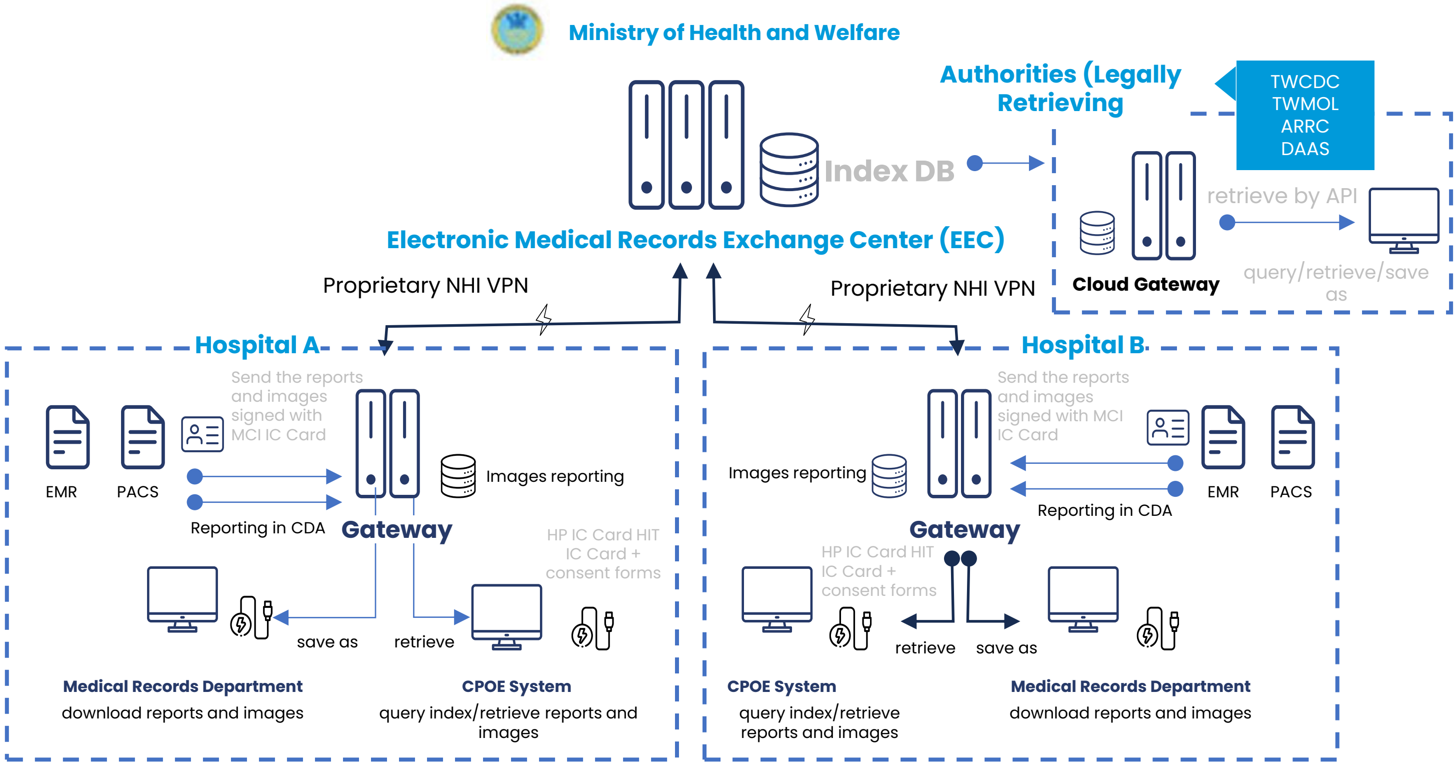
There are still some issues to sort out, however, with respect to health data sharing standards adoption. We spoke to several hospitals as part of the research that often lack the capacity and/or capability to collect and anonymize the data at the point of primary use. In addition, when it comes to health systems which are decentralized, consistency with the data methods across federal and local levels is a concern, as was pointed out by Lau of the Australia Digital Health Agency. Standards adoption is even lighter in the stepped-down care segments of the pathway, such as community pharmacies (41%) and long-term nursing homes (27%)[34]. Partnerships with the private sector, moreover, seem limited, according to our stakeholder conversations.

Building upon the standards is a bigger ambition of establishing functional health data repositories. In Singapore, for example, according to Tan of the National Healthcare Group, there is effort underway to link socio-economic with behavioral with genomic data under a program known as "TRUST". The secure and anonymized repository is meant to help the government better understand the health of its population, current and future needs, and to develop relevant, data-driven solutions. Several economies are also aiming for regional or even global health data repositories.

Figure 8: Inter-Facility Health Data Sharing, FHIR Status, and Example Architecture



Australia	FHIR is base for National Healthcare Interoperability Plan.
China	FHIR "Connectathon" held by own HL7 affiliate.
Japan	FHIR core implementation guide published by own HL7 affiliate.
Singapore	FHIR-based certification by own HL7 affiliate for cross-border travel.



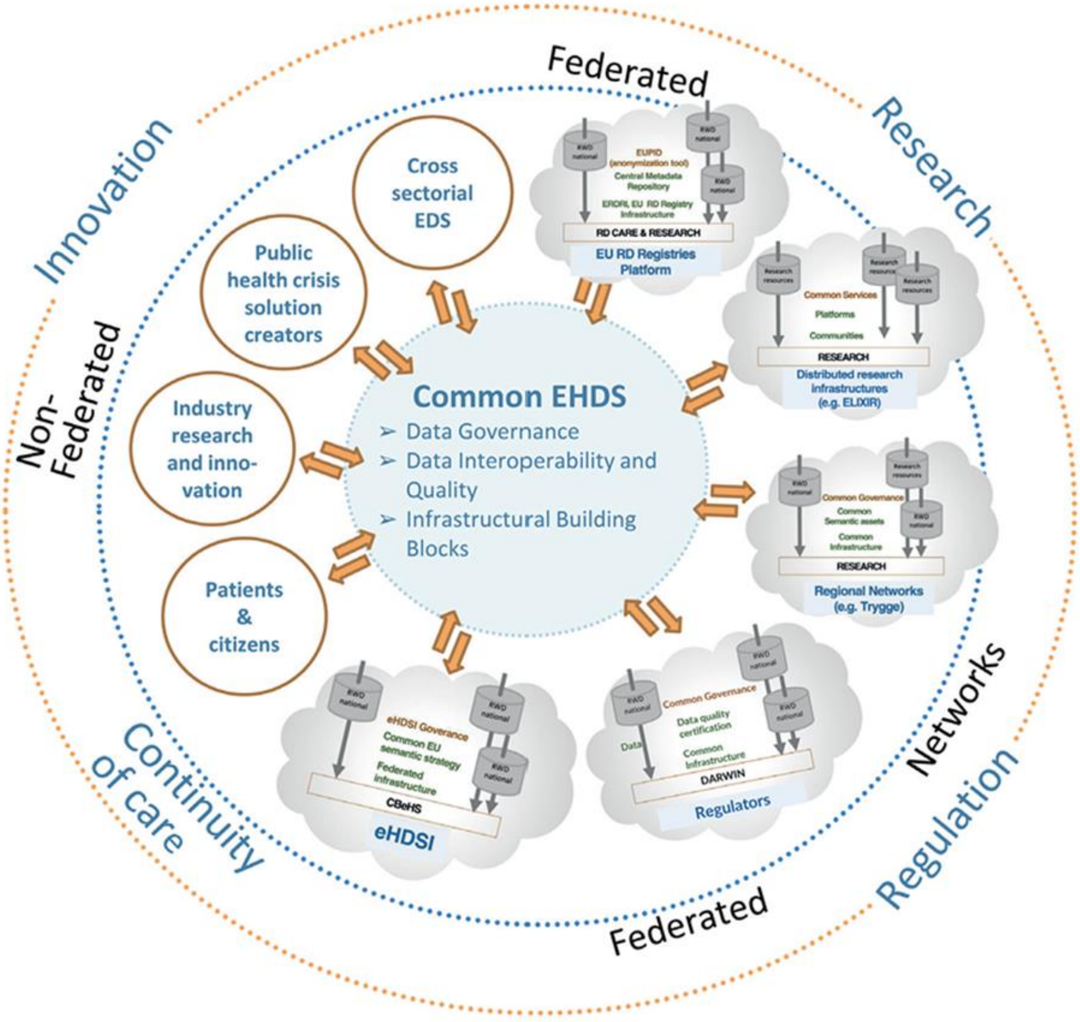
HP* Card: Healthcare Professional IC Card **HI[1] Card: NHI IC Card** **MCI[2] Card: Medical Care Institutions IC Card**

Although there was a slight dip in 2016, 20 major economies are now sharing data amongst healthcare facilities, with localized HL7 efforts highlighted. At bottom is an example health data sharing architecture from Chinese Taipei. Images inspired by HL7 and Hsyien-Chia et al.

Progress Made, Yet Lingering Challenges with Health Data Sharing

Drivers may include medical tourism, multinational healthcare companies, and AI (all data stewards which tend to move seamlessly across borders). According to Otzoy of RECAINSA, a multi-country HL7 affiliation is underway, which would be a new milestone for the standard. The most recognizable health data repository, however, is the EHDS touched on in Section 4. Adopted into law by policy directive 2011/24/EU, citizens are able to exchange health data across borders as a kind of personal health record, with the EHDS functioning like a hub-and-spoke model out to the participating economies. Uptake has perhaps been slower than desired, though, due to the voluntary nature of the directive as well as lingering concerns around access controls[35]. So, while similar concepts are being discussed in other regions, including a proposal put forth in Japan to mimic the EHDS[36], APEC economies may want to consider the balance between harmonization and fit.

Figure 9: Additional Example from Europe of Health Data Sharing Architecture



The health data sharing architecture behind the EHDS (in Europe), interconnecting the member economies and empowering patients. Image inspired by the European Commission.

Progress Made, Yet Lingering Challenges with Health Data Sharing

Herein lies additional lingering issues to overcome. For one thing, as compared to a common data standard like HL7, economies are going their own ways when it comes to the repositories. “Many economies are still at a nascent stage in policy formulation on health data, so, as they move ahead with their own frameworks, there are major questions around harmonization, localization, and further data fragmentation, especially across borders,” said Sen of APACMed. “There may not be a near-term, one-sizes-fits-all solution, so it is important for governments to signal their policy intentions for open discussion among diverse stakeholders.”

Another issue relates to consent protocols for the health data repositories. Many stakeholders we spoke to lamented the “opt-out” sharing default which ultimately had to be adopted in order to gain political and population support, thereby rendering many repositories incomplete. Japan, for example, passed a law in 2020 that requires companies to obtain informed consent for any cross-border transfer of personal information[37]. Stakeholders are calling for better standards like a “permission ecosystem”, including with clear, appropriate privacy and security principles (the focus of 5.2, next). That said, there is optimism. “We are making progress as average digital health literacy has improved,” said Lau of the Australia Digital Health Agency. “I believe that the benefits and convenience factor for patients and care providers of sharing data will overcome, including perception-wise, the barriers.” The United Kingdom, for example, shifted their policy to allow for opt-out exemptions and to invest in better educational materials for patients to understand health data sharing[38]. In Chinese Taipei, patients can create a password to override the opt-out health data sharing default in their My Health Bank account[39].

5.2 Progress and challenges related to regulations and ethics for health data sharing

Beyond health data sharing standards, where significant strides have been made, regulation, including the ethical considerations therein, remains a sticking point. Most of the stakeholders we spoke to find the existing sharing regulations to be "overdone", in attempting to apply wider data restrictions to healthcare. In this section, we will look at the balance of "carrot" versus "stick" regulations, the difficulties in lacking harmonization, and the latest discussions from a privacy perspective, including the trend toward data localization.

To be fair, much of the health data sharing progress discussed already in this whitepaper was a result of economies which adopted a regulatory-driven approach. The EHDS, for example, is an explicit directive – part of the 2021-2027 EU4Health program which passed in 2022 including EUR 400 million earmarked for a patient portal and back-end cloud infrastructure[40]. As part of the directive, both public and private organizations are obliged to make data available for use, backed by strong GDPR rules. In the United States, similarly, the Cures Act was signed into law in 2016 and Final Rule in 2020, mandating, among other aspects, the removal of info-blocking and a health IT certification program[20], including a FHIR adoption requirement added in 2022[41].

Figure 10: Common Examples of Info Blocking

Disabling or restricting the use of a capability that enables users to share electronic health information with users of other systems

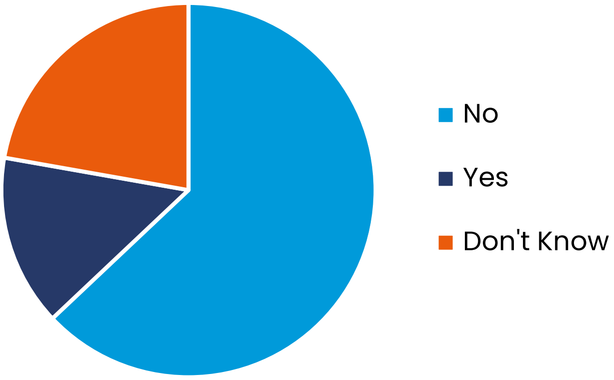
Placing excessive fees on consumers for creating unique patient record interfaces or for connecting with other health registries

Configuring technology in a way that limits the types of data that can be exported, such as non-standard implementation methods

Info blocking interferes with, prevents, and/or discourages the sharing of health data, a practice which new policies, particularly in the United States, are seeking to deter. Image inspired by the American College of Surgeons.

Elsewhere, however, governments have been more hesitant to enforce health data sharing. In Australia, for example, the Data Availability and Transparency Act of 2022 is more of an agreement between the Commonwealth, State, and Territory governments[42]. That said, recent policy movements there have suggested a "sharing by default" mandate, on the back of FHIR standards, starting with lab reports through the MyHealth Record[43]. Such a shift is a trend we observe in which governments will increasingly use "sticks" rather than "carrots" to improve health data sharing regulatory enforcement.

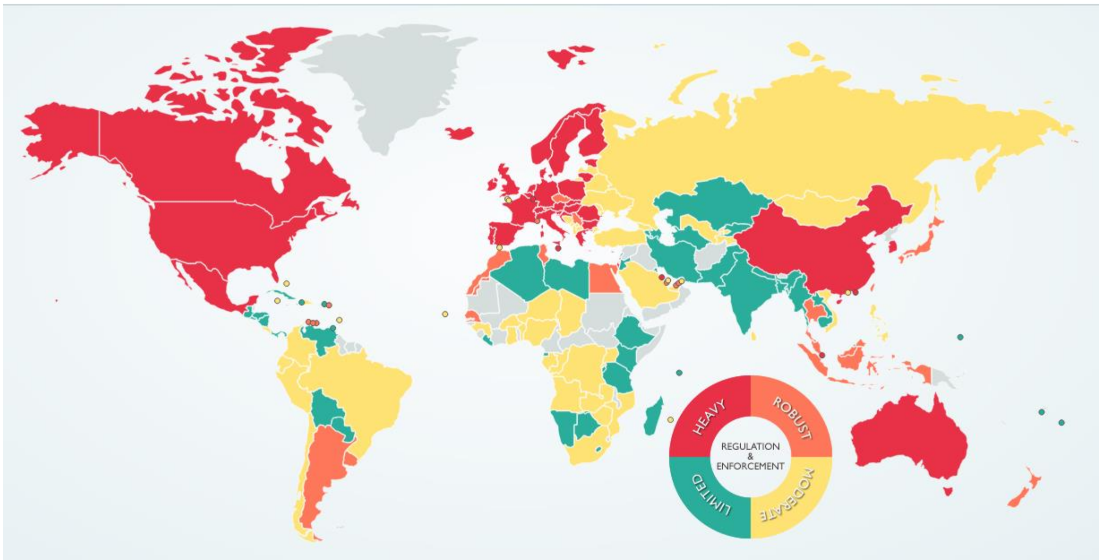
Figure 11: Regulatory Fines Accompanying FHIR Implementation Deadlines



Even though more economies are moving into the “sticks” approach of health data sharing standards implementation, still the majority are not yet pushing regulatory fines (with the exception of Chile, Germany, and a handful of others). Image inspired by HL7.

Harmonization of these rulings then, as alluded to during the discussion about domestic and international health data repositories, is a concern which emerges from stakeholders. The ambiguity hanging over sharing regulations, jurisdiction-by-jurisdiction, complicates efforts for such a diverse stakeholder ecosystem, much less for the vision of an integrated record.

Figure 12: Assessment of Global Data Protection Legislation



As of 2023, approximately 65% of the global population is covered by some type of data protection law. While many APEC economies have heavy or robust such legislation, still many other geographies are lacking. Image inspired by Databasix.

"Japan has stricter regulations than other developed economies, with consent required each time data is collected, used, or transferred," said Morita of the University of Tokyo. "For this reason, sharing has become more regulated than necessary, which has placed a burden on patient data for primary use." Morita also commented on the complications of the health data sharing topic falling across multiple government agencies, including the Ministries of Health, Economy, Trade & Industry, Internal Affairs & Communications, and, more recently, the Digital Agency. "Health data sharing regulation has always been challenging to harmonize," agreed Yang of Quanta Computer. "Especially now with the onset of AI, we need to find more common grounds." According to Health Canada, aligning of domestic agendas is important in order for data sharing policies to harmonize. Canada Health Infoway, for example, is utilizing the Global Health Data Partnership (GHDP) for best practices in areas such as international patient summaries. Canada has also been monitoring how to harmonize its approach to policies by looking at the legislative and regulatory actions of other economies, such as the United States' 21st Century Cures Act; in June 2024, the Government of Canada introduced Bill C-72, the "Connected Care for Canadians Act", which would require the adoption of common technical and data standards and prohibit data blocking by health IT vendors in order to enable the secure exchange of health information across health IT systems.

The other challenge with regulatory harmonization lies in interpretation. According to Kalra of i-HD, interpretation is the hanging balance between governments attempting to use regulation to safeguard health data while at the same time encouraging innovation and valuing efforts in the sharing activities. "A huge barrier is establishing a health data sharing ecosystem that wins public confidence as well as decision-maker acceptance," said Kalra. "At the moment, there is inherent risk in the interpretation activities taking place across economies."

All of which feeds into the final challenge, and more on the ethical side of health data sharing, in terms of individual privacy and protection demands that have fuelled heavy regulation. In short, there is no single, magical answer. Continued discussions will need to be had, within the health sector but also wider best practices, in order to find the appropriate common ground. Perhaps most important is to avoid over-regulating, such as in the trend toward data localization requirements. Rather than driving protection through data sharing, the fragmentation of efforts is creating vulnerabilities. "While we need integrated data systems, including across health and social care, much more needs to be done in terms of privacy and security," said Mittal of PatientsEngage. "Health data is extremely valuable, so we are seeing increasing incidences of hacking." "There was a serious health data breach in Singapore in 2018 that led to a slew of reviews and enhanced security measures," said Tan of the National Healthcare Group. "The result has been a strong cybersecurity system and process for the health sector."

Some economies are striking the right balance. The Data Availability and Transparency Act (DATA) of Australia, mentioned above, enables sharing by incorporating the Privacy Act for security safeguards, for example[44]. The DATA scheme accredits users, with the government taking ultimate responsibility as the data custodian[45]. In 2023, the United States, moreover, established the National Strategy to Advance Privacy-Preserving Data Sharing, to improve data governance and responsibility in line with privacy best practices[46].

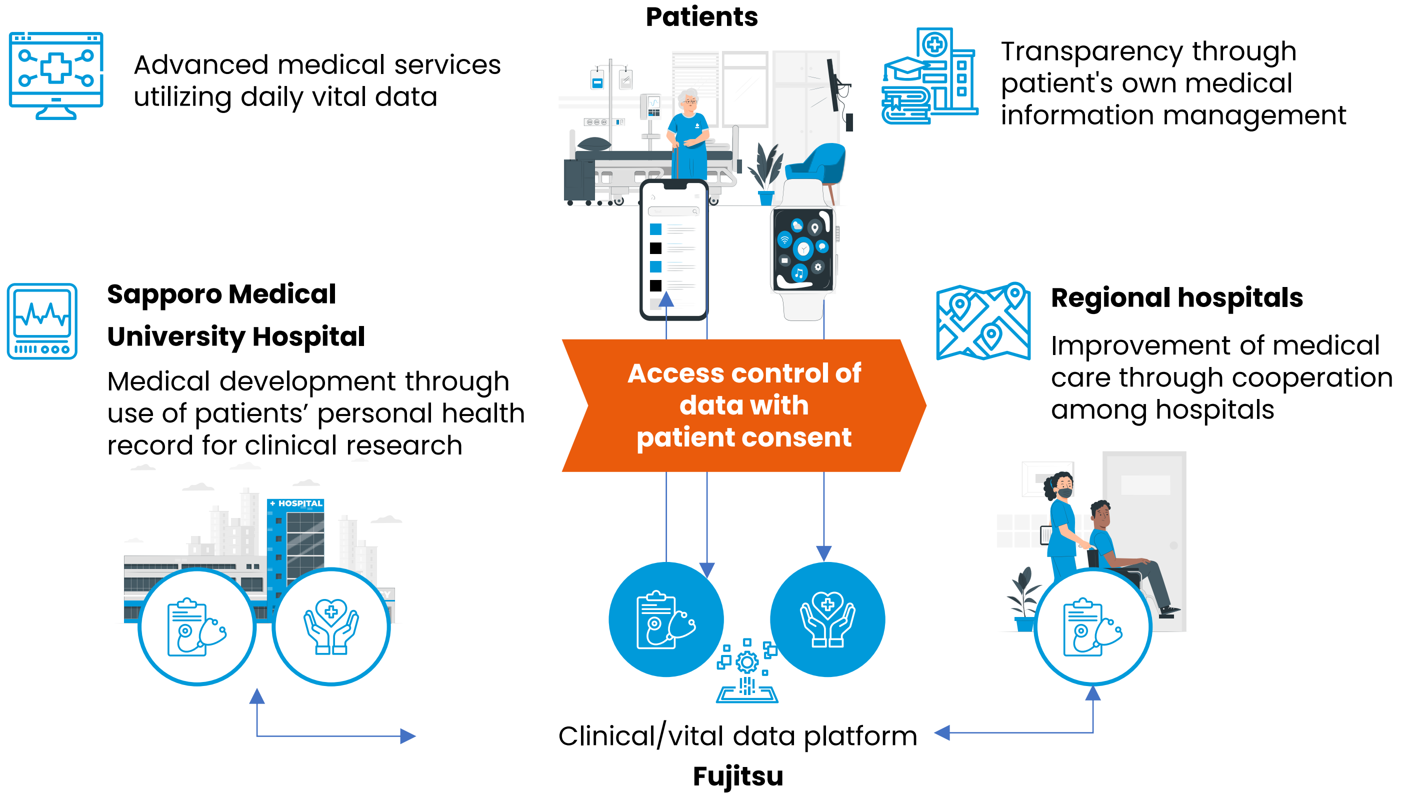
5.3 Progress and challenges related to implementation considerations for health data sharing

In fact, a large bulk of the lingering challenges about health data sharing aren't technical at all. Instead, they tend to be more along the softer lines of competing priorities, lack of clarity in communications, and insufficient financing for change.

One non-technical challenge observed by a number of stakeholders pertains to competing priorities, in the sense of stakeholder layers. In the public sector, health data sharing discussions can be complex and even inconsistent between federal, regional, and local directives. Other governments are approaching the health data sharing topic using terminologies such as macro- (inter-organizational), meso- (intra-organizational), and micro-level (point of care) tiers[39]. In any sense, such layers tend to be misaligned with the patient value chain, and therefore stakeholder ecosystem, creating more siloes than solutions.

"There are both formal and informal consortia efforts," said Marcelo of AeHIN. "However, the lack of coordination among various agencies results in unclear vision and leadership." "Differing domestic agendas when it comes to health data sharing affects progress," agreed ERIA representatives, "which actually leads to duplication and unnecessary costs."

Figure 13: Example of Multi-Stakeholder Health Data Sharing in Japan



Partnerships across diverse stakeholders and also between public and private sector are key to enable robust health data sharing, as this case study from Japan demonstrates. Image inspired by Fujitsu.

SECTION 5

Progress Made, Yet Lingering Challenges with Health Data Sharing

According to one report, as many as 205 government initiatives for data sharing were identified in only 37 economies[8]. What's more, it's estimated that fewer than 15% of these initiatives involve the private sector, feeding into another challenge of competing priorities – lacking use of Public-Private Partnerships (PPPs), according to various stakeholders we spoke to who see the potential of the private sector in health data sharing yet recognize the barriers to full leverage of PPPs. There are models to learn from, however. The Chilean government, for example, partnered with Google to build an information network for healthcare institutions[48], and hospital clusters of 25+ sites are following suit in Mexico with such sharing infrastructure (albeit with different partners)[49]. In Japan, moreover, Sapporo Medical University partnered with Fujitsu to link patient medical records through the Apple Health app, with all parties working hand-in-hand together[50].

A second non-technical challenge lies in communications. As has already been alluded to, many stakeholders, particularly the care provider workforce and average citizens (and patients), seem confused by the data standards and regulation. According to our stakeholder discussions, the challenge is multifaceted in terms of clear and transparent governance over the data, single points of contact and accountability, data literacy, and storytelling, particularly about the benefits of sharing. Australia, for example, refers to the "Foundational Four" in their data guidelines – leadership, strategy, governance, and asset discovery – with the ultimate aim of improving the "data culture."[51] Meanwhile, in a post-pandemic review of data transformation status in Southeast Asia, despite progress in areas such as data infrastructure, access, and governance, lower scores are observed in data culture and competency[52].

One idea suggested by stakeholders, in order to avoid getting hung up on "data sharing" (which implies a technical connotation), is to start thinking more in terms of "data collaborations." Rather than treating data like a scarce resource, to consider data as a shared capability between two or more organizations, working toward a common vision yet operating in their own, ethical methods[53]. An example is the United States' Trusted Exchange Framework and Common Agreement (TEFCA), which functions more like a central node for onward data collaborations across the network[54]. "We are wasting time and money by needlessly duplicating data assets," said Sutherland of the OECD. "Under a collaboration model, we upgrade from a position of linear to exponential value by unlocking the power of networks."

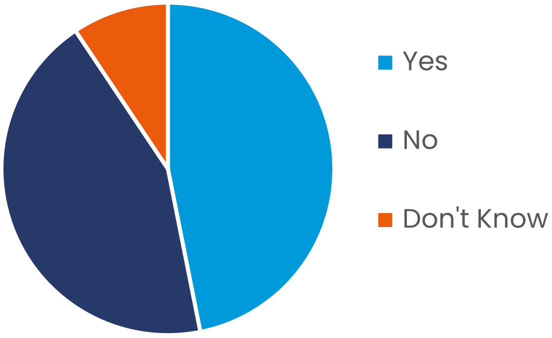
SECTION 5

Progress Made, Yet Lingering Challenges with Health Data Sharing

A third and final non-technical challenge is funding. While, generally-speaking, we recognize the huge investments which have gone into health data (and health systems more broadly), the varied allotments are also a cause of progress barriers in many APEC economies. In other words, health data sharing policies, as progressive as they may be, without right-sized funding, are not very useful. The EU4Health program, which led to the EHDS, as a frame of reference, represents a total government investment of EUR 400 million over a four-year period, leading to an estimated EUR 5.4 billion in revenue opportunities and EUR 5.5 billion in savings by cutting down on excess health information networks[35,55]. As compared to USD 86 million in Australia over the same time period for health data sharing (albeit part of a much larger investment in digital health infrastructure)[56] or Thailand's USD 3 million for its national medical data sharing strategy[57].

Another aspect of the financials tied to health data sharing are incentives (or penalties) to stimulate adoption. In terms of standards, for example, Australia and New Zealand governments are driving FHIR with committed budgets. In Chinese Taipei, organizations are only eligible to receive incentive payments once they have uploaded >60% of the requisite health data for sharing[33]. We expect to see continued financial attachments to health data sharing priorities under concepts such as Value-Based Payment (VBP), especially as these mechanisms also rely on access to the data for decision-making[58].

Figure 14: Availability of Funds to Stimulate FHIR Adoption



Around 50% of economies are now using funds to stimulate FHIR adoption, as of 2023. Examples include Australia, Canada, much of Europe, New Zealand, Peru, Chinese Taipei, and the United States. Image inspired by HL7.

Fortunately, despite the identified challenges pertaining to the standards, regulations and ethics, and implementation of health data sharing, progress has been made with many case studies to learn from. In Section 6, we will summarize the recommendations from stakeholders, while also providing a vision for how health data sharing can continue to empower our people and economies ahead.

Progress Made, Yet Lingering Challenges with Health Data Sharing

MSMEs play a critical role in the health data sharing ecosystem, too

While perhaps much of the health data policy discussion happens amongst large public and private sector organizations, the role of Micro, Small, and Medium Enterprises (MSMEs) is growing in prominence too, especially in line with broader socioeconomic development goals.

For one thing, MSMEs are often the pioneering innovations trying to "break" the system.
This is both empowering, in ushering in much-needed disruptive change, but also concerning, in that appropriate guiderails must apply to all parties, large or small, especially given the implications of error in an industry like healthcare. According to AWS, a driver of MSME influence over digital health and data is their speed and lower cost base, enabled by, among other lacking technologies deployed to the wider healthcare ecosystem, cloud-native capabilities which are already regulatory-compliant. In Korea, moreover, given the advancements in digital health/AI regulatory and reimbursement pathways, use cases are emerging around imaging, diagnosis, biomarkers, and clinical decision-making support for MSMEs to work directly with hospitals. Going a step further, in New Zealand, stakeholders mentioned that the larger organizations actually lean on MSMEs to be able to provide data which is otherwise hard for the traditional systems to capture. There are even structural efforts to put MSMEs into the heart of the discussion, such as designing their access to health data under the EHDS in Europe, and in Japan, which offers services for their solution approval and scale-up, a policy function which became critical during the pandemic for COVID-19 test kits innovation.

In addition to the innovation, MSMEs offer new opportunities for partnerships, highlighted as a key challenge above to health data sharing progress. A point raised by stakeholders is that, in reality, many organizations along the patient value chain, such as primary care, home care, labs, community services, are also MSMEs. Support for, rather than resistance to, these value chain steps to plug into the shared networks will only serve to further enrich the data. RECAINSA, for example, in Central America, convenes clustered groups of innovators via the local chambers of commerce. Similarly, in Japan, Keidanren (the Japan Business Federation) brings together organizations of various sizes in order to engage in training, such as for HL7, as well as to openly discuss ideas, like in the case of regulatory reform.

Lastly and importantly, MSMEs are a core driver of growth for just about any APEC economy, developed and developing alike. It is estimated that 90% or more of healthcare innovator organizations are in the MSME category, promoting economic priorities around entrepreneurship, talent, and prosperity. In Canada, for example, stakeholders informed us of a domestic priority to support the scale-up of ideas even just from one province to another. In Singapore as well, there are efforts underway to ensure robust regulatory, security, and privacy certifications for health data such that the MSMEs are well-positioned to bring their solutions to global scale.

SECTION 6

Policy Recommendations to Take Forward

By now we have discussed the importance of the health data topic as well as both challenges and opportunities therein with respect to its sharing policies. Section 6 aims to coalesce these findings into concrete recommendations for public and private sector stakeholders to take forward, hand-in-hand. These recommendations are based on existing efforts as defined through prevailing literature, complemented by direct suggestions given to us during the interview process. The health data sharing recommendations, then, are divided into three categories:

A call for continued implementation of policy efforts, particularly in the APEC context

Resolution concepts for the standards, regulation & ethics, and implementation challenges highlighted in Section 5

Go-forward health data sharing archetypes, for APEC economies to lean in to

6.1: Recommendations about existing policy efforts for health data sharing

Fortunately, when it comes to health data sharing, we are at a moment in time in which much progress has been made and momentum exists by stakeholders to continue policy adoption. As mentioned already in this report, broader digital economic efforts such as AIDER, combined with health-specific initiatives occurring at the supernational, regional, and local levels, are promising. We recommend for these efforts to continue, evolving with modern needs as we go (e.g., on the topic of AI) and being sure to consult public and private sector organizations alike for best practice input.

APEC, moreover, has launched its own health data sharing dialogues as of 2023-2024, culminating in their health data standardization report[32]. We, at ABAC, are supportive of these policy efforts, too. The following are our reflections for APEC to consider in driving forward the implementation of its own recommendations:

What's already been done	APEC has laid excellent foundation about health data standards with its educational materials and awareness campaigns. The materials strike the balance between technical yet informative, based on real case studies.
What's in motion and should continue	ABAC supports the call for establishment of a Working Group specific to health data standards within APEC. It would be further ideal for this Working Group to represent a mix of APEC and ABAC organizations.
What could still be improved	ABAC suggests for APEC to drive a common standard (e.g., HL7), and to ensure robust capability development activities, including moving into real pilots. In addition, ABAC calls for attention to nuances such as human development and MSMEs when considering implementation of health data sharing standards.

Lastly, while much of the ABAC (and, indeed, APEC) work has thus far focused on the primary use of health data sharing, certainly there is enormous potential in secondary use. Examples include public health monitoring, research, innovation activities, quality certification, even payment reform. A suggestion, then, for future APEC-ABAC policy research, is to establish a workstream more specific to the challenges and opportunities of health data sharing secondary use.

6.2: Recommendations about resolutions to highlighted challenges for health data sharing

Section 5 highlighted the potential yet challenges of health data sharing in three main areas – standards, regulations and ethics, and implementation. The following, then, are policy suggestions across each area, as primarily derived by direct stakeholder conversations and supported by real-world case studies to consider as best practices. These recommendations are provided in a stepwise manner (for practical adoption), yet may be considered non-exhaustive; rather, starting points for the needed health data sharing improvements on the continued journey ahead.

Policy Area	Policy Suggestions	Case Studies
Standards	1. Align on a common technical standard for data formats, identification numbers, and the interlinks therein (ideally following an international protocol like HL7). 2. Also align on a common semantic coding standard in terms of ontologies and disease prediction models, across public and private sector, especially in anticipation of the adoption of AI. 3. Establish a basis for formal licensing of the technical and semantic standards, including requisite training programs for the healthcare workforce and wider ecosystem of stakeholders. 4. Beyond disease prediction models, aim increasingly for integrated care networks that follow the patient pathways and interlink data between primary care, specialty care, community care, and others such as pharmacies. 5. Ensure that any health data networks which are created or developed are anonymized and harmonized, including in consideration of the emerging trend for such networks to effectively operate across international borders. “We need standard formats and identification systems to more seamlessly and reliably link health data,” said Morita of the University of Tokyo. “There remain too many silos, creating duplication and difficulty in health data sharing, rather than a robust health data utilization infrastructure.” “This notion of ‘my data’ needs to be re-framed toward a more collaborative sharing ecosystem,” said Rossana Rivas Tarazona, Co-Chair and Founder of HL7 Peru. “We need more open data,” said Lee of Medtronic. “This means following prevailing standards to share data across public and private sector as well as the various stewards of the healthcare ecosystem, most importantly to improve the lives of patients.”	• Consolidated electronic patient record adoption in Korea and Singapore, including the tagging of “data hospitals” and data sharing platforms. • Citizen identification numbers in Thailand and Chinese Taipei, which encompass healthcare needs including for insurance and digital cards. • Health data sharing networks in Japan and Canada, driven top-down on international standards like Bill C-72 (Connected Care for Canadians Act to require common exchange standards for health IT vendors), and with appropriate training at the localized workforce levels. • Taking a more integrated view of health data along the patient pathways in Australia, especially with respect toward the increasing needs of aged care. • Hub-and-spoke (yet on common standards) health data sharing across borders, of particular advancement in the European Union but under development in Latin America too.

Policy Recommendations to Take Forward

Policy Area	Policy Suggestions	Case Studies
Regulations and Ethics	1. Foster an enabling environment of risk-based, flexible guidelines (rather than overly fixed regulations) which are safe yet adaptable, especially for fast-moving modern trends like AI. 2. Support the harmonized adoption of data governance frameworks, like that of the OECD, which are specific to the healthcare sector and establish ready-made principles for privacy and security protocols. 3. Shift from opt-in, consent-driven requirements into a collaborative, opt-out model, including with respect to relaxing data localization demands. 4. Maintain multi-stakeholder ethical review boards along the way, including for addressing breaches, and in anticipation of greater secondary use requests for health data. 5. Publish domestic blueprints for health data sharing, similar to the WHO's Global Initiative on Digital Health (GIDH), which are open to consultation across regulators, public and private sector, and patient voices. "Most current legislative approaches center accountabilities with individual care provider organizations, and these localized approaches to policy interpretation and decision-making result in fragmentation," said Sham of the Ontario Ministry of Health. "System-level approaches to health data governance are needed to support and enable innovation." "Governments should consider enacting specialized laws for healthcare, separate from the more generalized data protection rules," said Ogawa from Keidanren. "Governments need to have a well thought out, formal strategy for health data sharing," said Illing of AWS. "The strategy should be risk-based rather than 'knee-jerk', and flexible rather than stifling."	• European Union's approach to flexible, cross-border legislation rather than hard-line policies, a model being tested for harmonization (yet agility) in the likes of Singapore/Southeast Asia, New Zealand, United States, and Latin America. • The Canadian Institute for Health Information, which follows OECD and GHDP recommendations for health data governance including regarding AI, as well as Canada's new health data stewardship framework for consistency in health data sharing approaches across jurisdictions. • "Sharing by default" health data policy of the United Kingdom, now under adoption in Australia and Chinese Taipei. • Data privacy and security rigor of the United States and Latin America, which is aligned with non-healthcare standards yet also flexible to accommodate sector-specific needs.

Policy Recommendations to Take Forward

Policy Area	Policy Suggestions	Case Studies
Implementation	1. Beyond having a vision, establish a "Community of Practice" (a public-private partnership) for health data sharing and collaboration. 2. Form an official Health Data Sharing Office within the government, complete with training, use case collection, and value capture, including down to a citizen level. 3. Have a plan for ongoing capacity and capability development, leveraging best practice experience from the private sector and involving key stakeholders such as patients, caregivers, small enterprises, even other sectors. 4. Right-size health data sharing investments, for the longer term and incentivizing sufficient data collection and sharing behaviors. 5. Coalesce data sharing and case studies with the financial models to support the value-based healthcare journey, such as in the form of prioritizing outcomes data and ongoing ROI monitoring. "Health data and digital tools, including AI, have significant potential to transform healthcare," said Toller of Health Canada. "Collaboration at all levels is therefore key to align priorities, strengthen our health data foundation, and improve digital health literacy." "We need a more participative approach to health system design," echoed Mittal of PatientsEngage and Bauer of DataSavesLives. "Health data sharing policies should be built with empathy, easily understood, and return benefits full circle." "The opportunities to make better use of health data are tremendous, but will require investment," said Kalra of i-HD. "And while the return on these investments is likely to be substantial yet a few years away, the 'pump priming' needs to occur now, calling for strong, committed leadership."	• Office of Public Health Data, Surveillance, and Technology in the United States, aligned to HL7 standards, with a similar "Foundational Leadership" pillar in Australian policy. • Data collaboration (beyond sharing) models such as the United States' TEFCA, which tend to be more open and inclusive yet still centrally controlled. • Innovative public-private partnerships, including with tech firms, like those observed in Chile, Mexico, and Japan. • Inclusion of MSMEs in the health data sharing conversation in New Zealand, Japan, and Latin America, as well as services to support MSMEs with standards and regulatory compliance. • Investment levels (and ROI) of Europe, coupled with health data sharing incentives (or penalty) schemes such as those in Australia and Chinese Taipei.

6.3: Recommendations about a to-be APEC archetype for health data sharing

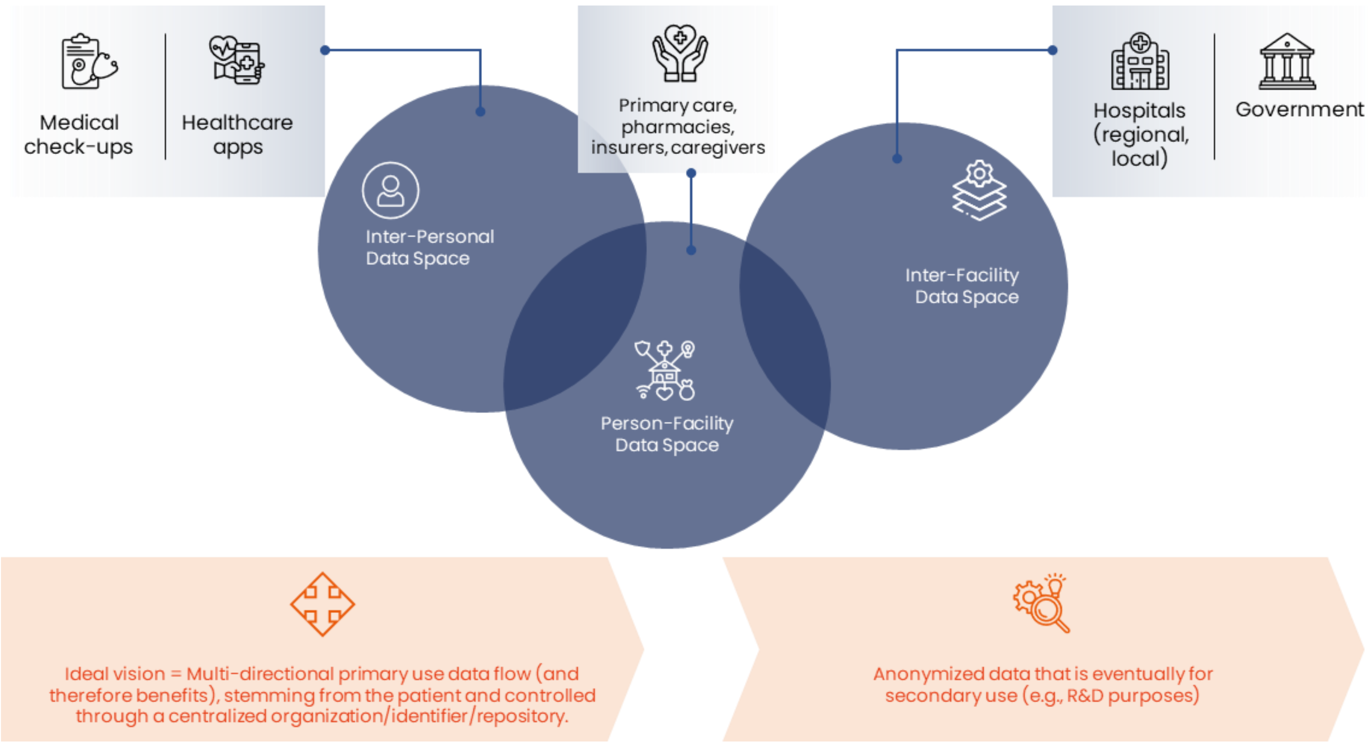
Taking in the above (importance of health data sharing, challenges, ongoing efforts and best practices, thematic recommendations) brings us to a final concluding point – a vision for the to-be future of healthcare, data, and empowerment. We present this vision for APEC economy consideration, realizing that of course every economy is in different stages of development and, therefore, different needs for bespoke conversation around appropriateness of change. That said, we aim for bold progress and greater harmonization above all.

In this vision, we look at the APEC to-be archetype across three layers:

- Inter-Personal Data Space – Where patients and citizens share data through personal devices;
- Person-Facility Data Space – Where patients and citizens share data with healthcare facilities; and
- Inter-Facility Data Space – Where healthcare facilities and government share data with each other.

And while we expect data to flow forward and backward, including associated benefits to all parties therein, we recognize the conceptual hurdles of such a vision. We see an initial focus on the Person-Facility Data Space, where much of the primary use activity happens today. Whereas patients/citizens and centralized authorities (including government) may have the most to gain from the health data sharing, others, especially in the Inter-Facility Data Space, may only be indirect beneficiaries. Nevertheless, it is a vision worth pursuing, as this report has described.

Figure 15: To-Be Vision for a Health Data Sharing Archetype in APEC Economies



Ideal vision = Multi-directional primary use data flow (and therefore benefits), stemming from the patient and controlled through a centralized organization/identifier/repository.

Anonymized data that is eventually for secondary use (e.g., R&D purposes)

Bringing together insights from our research produces a full vision for a health data sharing archetype in APEC economies. While this report focuses on primary use, with data and benefits flowing across the specified data space layers, there is a future in secondary use, too. Image inspired by ABAC.

Policy Recommendations to Take Forward

We, as ABAC, advocate for APEC economies to move in the direction of a centralized health data repository, ideally managed by a centralized authority through a common identifier and platform. Such a repository could more seamlessly work across the data space layers, even across borders (e.g., in the case of another pandemic). For example, as patients move through the Person-Facility Data Space, the common identifier would serve to interlink the data flow. Another example is better leverage of intelligence from the Inter-Personal Data Space, including for patients' own empowerment. With proper security protocols, like anonymization, health data can eventually be used for secondary purposes too, such as innovation activities like R&D. Although each APEC economy is unique, our vision is for more common, rather than different, standards, regulations, ethical considerations, and implementation best practices.

In closing, to reiterate, there is significant economic benefit to be gained from forward-looking investment into better health data sharing policies. An APEC economy equipped with a fully functioning health data repository enables, through primary use, its patients and citizens, healthcare facilities, and government to empower health systems, not to mention the potential secondary use benefits by industry developments in the form of R&D activities. As has been experienced in the European Union, the economic gains alone stand in the billions of dollars. Beyond the economic benefits, we see improved health data sharing as a driver of population inclusiveness, too, especially for the more vulnerable communities. Indeed, data that spans health (demographic and genetic) and social dimensions stands to be better utilized as we anticipate pressing needs ahead in areas like AI, pandemic preparedness, and aged care. Most importantly, health data sharing policies require a longer-term, public-private outlook, cultivated through continued open dialogue.

> **"Each life, regardless of its health condition or stage of disability, is worth the investment."**
>
> ***-- Keilen of Bezirkskliniken Mittelfranken***

Authors & Contributors

Dr. Chris L. Hardesty, Visiting Professor at UCL Global Business School for Health (Singapore)
Navi Boparai, Senior Project Manager at Centre for Addiction & Mental Health (Canada)
Dr. Jun Suzuki, Senior Advisor at Teijin Limited (Japan)
Additional Teijin authoring members include Shinya Kukita, Hiroko Kosaka, Toshihiko Sakaguchi

We appreciate the gracious support provided by the diverse of panel of stakeholder contributors:

- Professor Akira Morita, Professor Emeritus at University of Tokyo (Japan)
- Dr. Alvin Marcelo, Director at Asia eHealth Information Network (Philippines)
- Anirudh Sen, Head of Market Access at APACMed (Singapore)
- Aparna Mittal, Founder & CEO at PatientsEngage (Singapore)
- Birgit Bauer, Founder & Project Manager at DataSavesLives Germany (Germany)
- Christine Sham, Director of Information Management Strategy & Policy at Ontario Ministry of Health and Long-Term Care (Canada)
- Dr. Clive Tan, Senior Consultant at Tan Tock Seng Hospital (Singapore)
- Daniel Otzoy, Executive Director at Central American Health Informatics Network (Guatemala)
- Dr. Dipak Kalra, President at European Institute for Innovation Through Health Data (United Kingdom)
- Dr. Eduardo Gotuzzo, Emeritus Professor of Medicine at Universidad Peruana Cayetano Heredia (Peru)
- Elizabeth Toller, Executive Director of Digital Health & Primary Care at Health Canada (Canada)
- Eric Sutherland, Senior Health Economist at OECD (France)
- Professor Fuji Nagami, Tohoku Medical Megabank Organization (Japan)
- Hiroaki Hasegawa, Director & Department Manager of Consulting at FINDEX Inc. (Japan)
- Dr. Jonathan Lumen Chua, Principal Advisor at Ministry of Health (New Zealand)
- Dr. Keren Priyadarshini, General Manager of Healthcare at Microsoft Asia (Singapore)
- Lisa Foster, CEO at Home & Community Health Association (New Zealand)
- Dr. Matthias Keilen, CEO & Board Member at Bezirkskliniken Mittelfranken (Germany)
- Mike Lau, Chief Data & Analytics Officer at Digital Health Agency (Australia)
- Noriko Ogawa, Director of Industrial Technology Bureau at Keidanren (Japan)
- Representative from a health futures lab (Korea)
- Dr. Robe Yang, Digital Health Senior Director at Quanta Computer (Chinese Taipei)
- Rossana Rivas Tarazona, Co-Chair & Founder at HL7 Peru (Peru)
- Dr. Rowland Illing, Chief Medical Officer and Director, Global Healthcare and Nonprofits at Amazon Web Services (United States)
- Dr. Sang-Soo Lee, Senior Director of Government Affairs & Market Access at Medtronic (Korea)
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- Yean Cheong, Executive Director at SGTech (Singapore)

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