

## White Paper

# RESPONSIBLE DATA SHARING IN HEALTH AND HEALTHCARE





4	Preface
5	Executive Summary
6	Current State of Data Sharing in Health and Healthcare in Asia
9	A Framework for Trusted and Responsible Data Sharing
13	Data Classification and Tiering
16	Data Sharing Arrangements - How to Share Data?
22	Building Trust to Enable Data Sharing
25	Encouraging the Use of Shared Data to Draw Out the Value of Data
29	Conclusion: A Way Forward
30	Acknowledgements

# PREFACE

The rich sharing and discussions on the topic of data sharing in the health sector during the [Precision Public Health Asia Conference 2021](#) encouraged us to further explore this matter. Against the backdrop of the pandemic and the unprecedented sharing of data and information on all COVID-19 related matters, we held six roundtable sessions with more than [30 experts](#) representing different countries and professional groups to hear their views, insights and advice on this topic.

Across the world, the healthcare sector is facing the common challenges of an ageing population, increased healthcare needs and rising healthcare expenditure. In this setting, the growing prevalence of digital health is a key development that has the potential to disrupt the way governments, payers, providers and communities think about health and healthcare. Governments, ministries of health and international organisations recognise this trend and acknowledge that “*digital health is here to stay*”. In the 2018 World Health Assembly, Member States voted to adopt the [resolution on Digital Health](#). In 2021, WHO published a [Global Strategy on Digital Health](#), the Asian Development Bank launched a [Digital Health Implementation Guide for the Pacific](#) and the World Bank published its [Digital Health Assessment Toolkit Guide](#).

Digital services generate an enormous amount of healthcare data. Indeed, “*data is the new oil*” but how can we harness the value of health and healthcare data?

The insights and advice gleaned from the roundtables are succinctly captured in this White Paper on Responsible Data Sharing in Health and Healthcare. This White Paper provides useful and practical steps for readers who are working towards a more progressive future where health data are shared more openly, in a safe and responsible manner and in a way that value-adds to health systems around the world. Similar to how the roundtable sessions brought together stakeholders from different backgrounds - including policy makers, healthcare providers, technical experts in data sharing and technology systems, pharmaceutical companies, medical device manufacturers, researchers, academics, insurers and payers - we hope that this report will provide a useful starting point for conversations amongst stakeholders and serve as a scaffold for us to build a better future together.

## Dr Clive Tan

*On behalf of the teams at the Precision Public Health Asia Society  
and the Saw Swee Hock School of Public Health, National University of Singapore*

2022



# EXECUTIVE SUMMARY

Investments and spending in health and healthcare in Asia have grown. As healthcare becomes increasingly digital, countries and organisations have in their hands an increasing amount of health data. Sharing and integrating multiple data points can unravel unique insights that can improve population health. Three key factors influence whether countries can build a robust health and healthcare data sharing ecosystem: (i) the country's **level of familiarity** with managing data, data sharing arrangements and data sharing technology; (ii) the **prevalence of the use of electronic medical records** systems by healthcare providers and stakeholders in the healthcare ecosystem and (iii) the presence of a **national-level body** that is responsible for the development of the health and healthcare data sharing ecosystem.

To progressively build up the capabilities that are required to create a seamless data sharing ecosystem, a data sharing framework needs to be devised first. Establishing a data sharing framework must be a **joint effort involving multiple stakeholders** and collaborative dialogue among governments, the private sector, academia and the public. Such a framework would comprise of several key building blocks: (i) data sharing **strategy**, (ii) **technical and technological capacity**, (iii) **regulatory and legal capacity** and (iv) an approach to **operationalising data sharing**.

To build technical and technological capacity and to enable stakeholders to share health and healthcare data responsibly and safely, there must be an agreed way to classify and tier data into different categories. Within each category, there should be **different sensitivity tiers** for certain data fields. These tiers would then inform the optimal data sharing strategy – whether the data can be shared more openly or in a more restricted and controlled manner.

When deciding how to share data, it is useful to identify the roles of different stakeholders in the data sharing ecosystem: (i) **data generators**, (ii) **data users**, (iii) **data ecosystem regulator and governing agency** and (iv) **data exchange platform and IT service provider**. Understanding the roles, needs and responsibilities of the stakeholders in the system is an important starting point for conversations, and for building **different levels of control and access** to the data. For those starting out on this data sharing journey, it is important to **start small**, be conscious about the need to **build trust and confidence** and **collaborate with natural partners** first.

Meaningful data sharing can only take place in a trusted environment where there are clear measures to safeguard the confidentiality, integrity and availability of information. The key components of **trust-building** start with **transparency** of processes and common rules on how data are shared, used, managed and protected. Trusted data sharing for health and healthcare data must be built on the understanding that there is **consent** given for secondary uses of these datasets. In each trusted environment and data sharing ecosystem, the data ecosystem regulator and **governing entity** that is responsible for maintaining the integrity of data and managing its authorised use must show that it prioritises the **public's interest**. This agency must also have strong, clear and **timely communication** with members of the public on news and updates about the data sharing ecosystem, especially when it comes to dealing with negative events such as data leaks or cybersecurity incidents.

When the capabilities mentioned above have been set up, we can then **effectively harness the value** of shared data at three levels: (i) individuals, families and communities; (ii) companies and healthcare providers and (iii) governments and regulators. Data sharing is a means to an end, and we must not forget to harness the value of our efforts and investments in this endeavour. Now, let us prepare the grounds for responsible data sharing and sow the seeds for a better future.

# CURRENT STATE OF DATA SHARING IN HEALTH AND HEALTHCARE IN ASIA

The accelerating digital economy has led to an unprecedented advent of new technologies, generated high amounts of data and lowered costs of data storage and sharing. As Asia becomes more affluent and undergoes a demographic transition due to its ageing population, investments and spending in health and healthcare have grown. Health and healthcare are increasingly digital, resulting in greater access to services and a growing amount of health data.

The use and integration of health and healthcare data, coupled with artificial intelligence or machine learning, in identifying needs and offering personalised interventions present potentially significant benefits for public health. However, data are often fragmented and dispersed across multiple databases held by different stakeholders. 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.

## Countries are at different stages of maturity and development

Three factors were identified from the roundtable discussions as important considerations for assessing a country's level of development and maturity regarding data sharing in health and healthcare. A self-assessment based on these three factors can help identify and understand the country's current state and enable plans for progress towards a stronger health and healthcare data sharing ecosystem.

### The country's level of familiarity with managing data, data sharing arrangements and data sharing technology

Building data sharing expertise, capabilities and technology often do not start in the health and healthcare sector but rather in sectors such as finance, commerce, trade and law enforcement. A country's level of familiarity with managing data, data sharing arrangements and data sharing technology is often observable through its overall supporting IT infrastructure, the presence of relevant regulations and the strength of its national and sectoral data sharing frameworks. Advancements with data sharing in other sectors are positive developments for the sharing of health and healthcare data.

### The prevalence of the use of electronic medical records systems by healthcare providers and stakeholders in the healthcare ecosystem

Digitalisation of medical records is a good indicator of a country's readiness to adopt data sharing in health and healthcare. Several organisations have put in place tools to measure this, such as the [Healthcare Information and Management Systems Society's](#) (HIMSS) Electronic Medical Record Adoption Model (EMRAM). Hospitals and healthcare providers around the world can be evaluated by HIMSS to assess and understand their stage of digital maturity, on a scale of 1 to 7 with level 7 being the highest score. While it is encouraging for countries to have healthcare providers who have attained high levels of digitalisation and electronic medical records (EMR) usage, it is perhaps more important to look at the level of EMR usage across a range of healthcare providers in the country when assessing the country's readiness for data sharing.

### The presence of a national-level body that is responsible for the development of the health and healthcare data sharing ecosystem

Countries in the region with an agency or government body appointed to oversee health and healthcare data are well placed to convene stakeholders, set standards, assign responsibilities and promote best practices for the country. For example, [Australia's Digital Health Agency](#) established in 2016 has helped to fast-track greater use of electronic health records, electronic prescribing and shared health and immunisation records across the country.

Figure 1 highlights some examples of the current state of data sharing in health and healthcare relating to the aforementioned three factors in countries and territories in the Asia Pacific region, that were brought up by the roundtable experts.

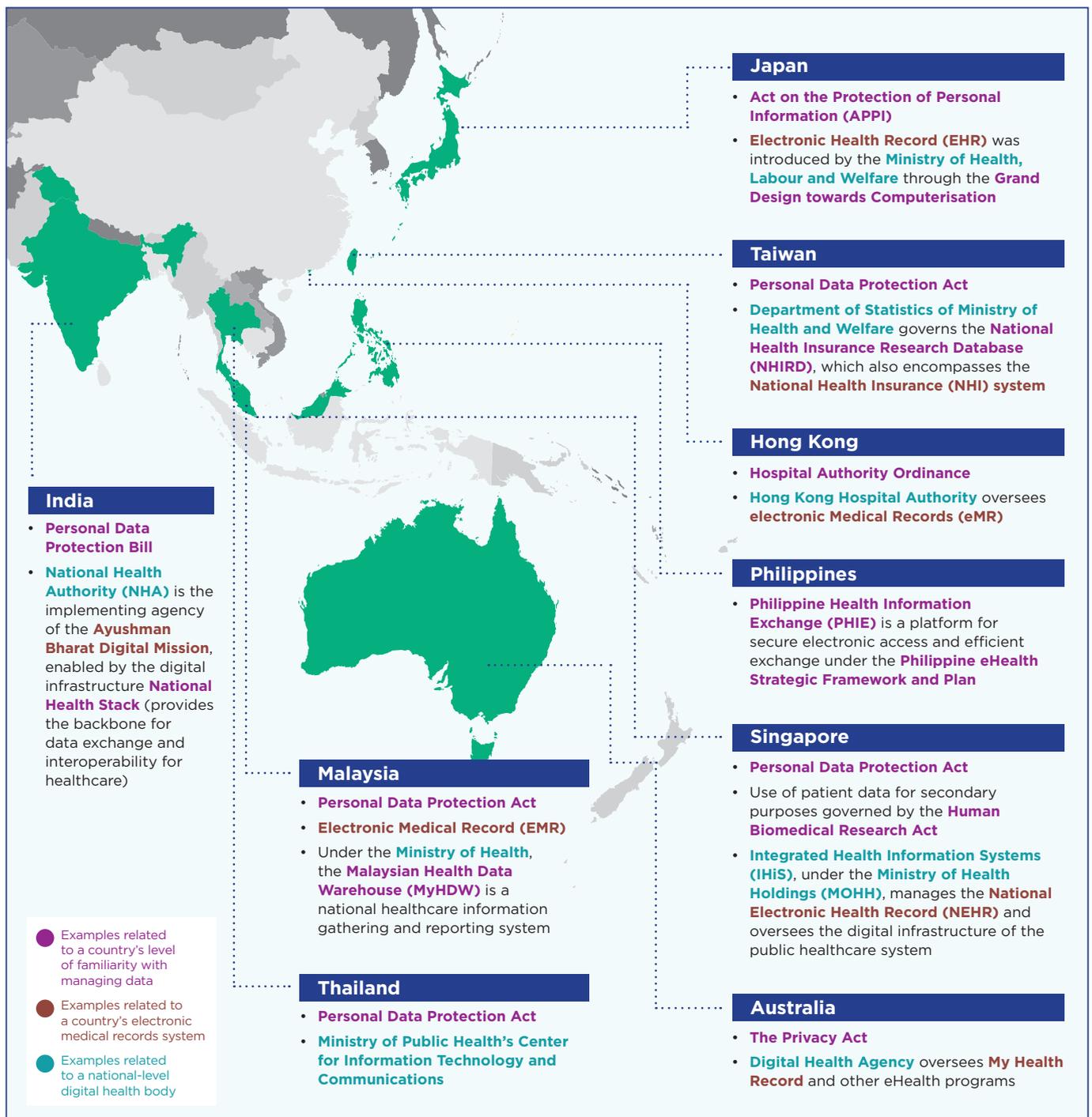


Figure 1: Data Sharing Initiatives in Health and Healthcare in the Asia Pacific

## Recognising the challenges and tangible actions for stakeholders

Countries in the region are at different stages of digital maturity. They will need to overcome their own unique set of challenges so that the region can move towards a more progressive, responsible and widespread data sharing ecosystem in the health sector.

Experts at the roundtable sessions shared on the challenge of fostering political will and the importance of vested stakeholders in creating momentum for data sharing initiatives at the outset. In circumstances where developments are progressing slowly, the root causes may trace back to national geopolitical issues or from conflicts between different stakeholders within the health and healthcare data sharing ecosystem. Stakeholders may also be held back by the belief that health and healthcare data are more sensitive than other types of data, and from a lack of technical know-how on the next steps to take. However, the COVID-19 pandemic is a great example of how progress can be rapidly made if there is a strong collective vision and a pressing need to share data. Against the backdrop of the pandemic, countries were able to come together to rapidly foster political will to share data about the virus genome, transmissibility and vaccination rates across borders.

For data sharing to take place, the data must first exist in digital form and be accessible. In certain settings, health and healthcare data are still paper-based and that is a major barrier to participating in the data sharing conversation. With the growing recognition of the value of data, many organisations have moved on to digitise their data. However, ensuring that the data are accessible remains a challenge as there is a tendency to protect data and layer on administrative red tape. Such challenges exist even within organisations where data sharing between departments may be suboptimal. The situation can be improved as stakeholders develop clear regulatory and legal frameworks that allow and encourage data sharing as the baseline default state. This can be done with clear rules, guidelines and measures in place to prevent abuse, ensure security and address privacy concerns.

The value and benefits of data sharing can be better optimised when more stakeholders can participate in and be part of the data sharing ecosystem. From a regional perspective, there is a need to increase investments to build technical capacity and interoperability in countries that are still developing their capabilities in this domain. To improve equity, it is crucial to ensure that the gap between countries does not widen further as technology continues to advance.

The differences in countries' developmental stages across the region also mean that best practices and recommendations will need to be contextualised according to respective countries' needs and development priorities. As a result, there cannot be a one-size-fits-all solution.

These political, regulatory, technological and cultural concerns must be identified and addressed to advance national-level data sharing and move towards cross-border data sharing in the longer run. The rest of this report will provide insights on several of these challenges and offer recommendations on tangible steps that stakeholders can take to realise this vision.

# A FRAMEWORK FOR TRUSTED AND RESPONSIBLE DATA SHARING

## Having a framework is the first step

Data sharing must be done in a safe and responsible manner. However, there is often no mandate or push to share data; if left alone, the healthcare sector will remain at the current status quo which can lead to huge opportunity costs. To enable the safe, trusted and responsible sharing of health and healthcare data, it is essential to have a data sharing framework and development roadmap to provide structure and continual guidance to the healthcare industry to progress towards a future proof data sharing system.

## Convening stakeholders and co-creating the framework

The creation of a data sharing framework should be a joint effort involving multiple stakeholders so that it is mutually agreed upon, standardised and harmonised. Collaborative dialogue is required to fuel the starting momentum required to shift the culture towards data sharing. Therefore, elements such as political will, convening power and trust among stakeholders are important to establish at the outset, even before more technical aspects, such as the framework itself, are discussed.

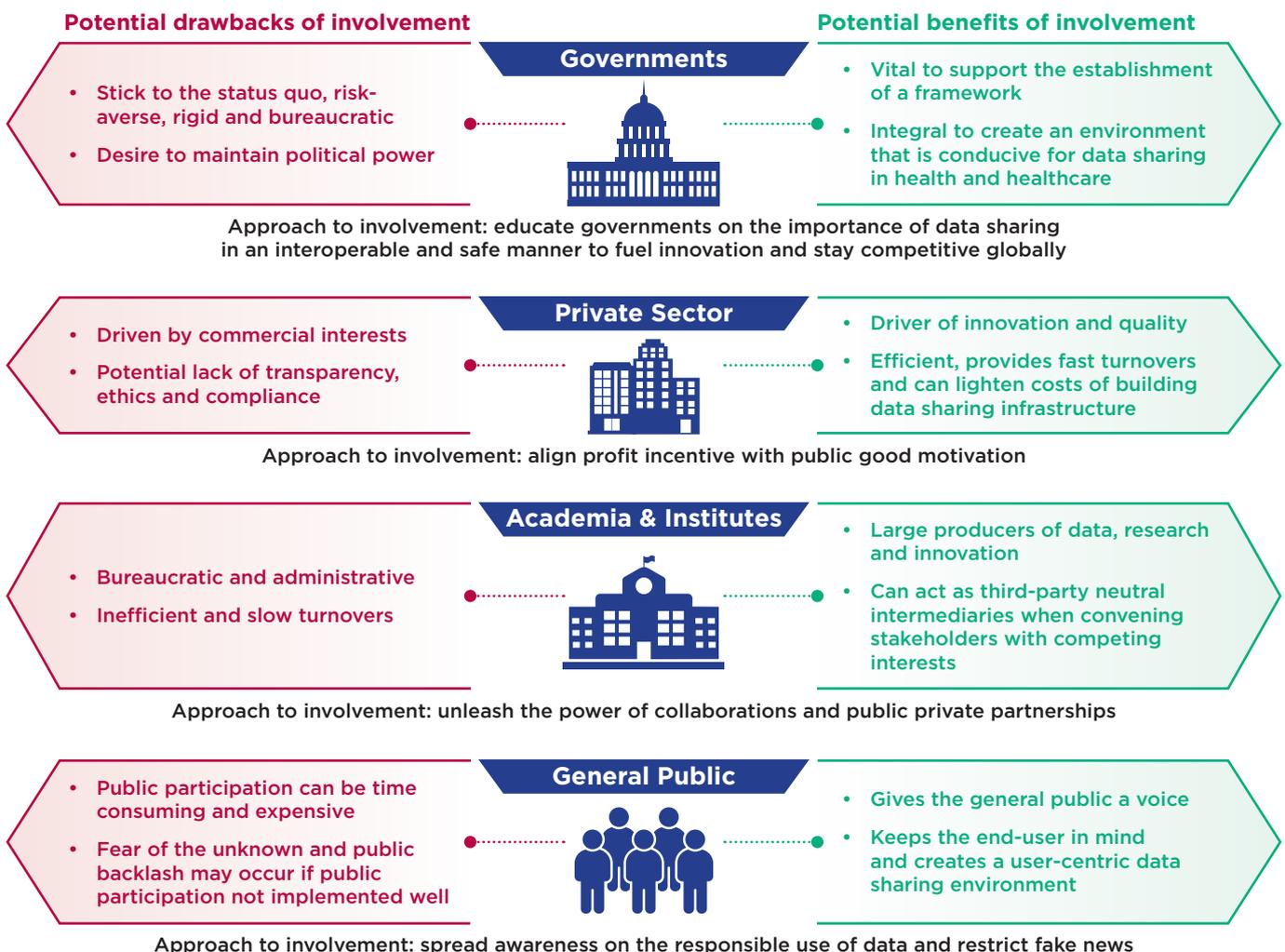


Figure 2: Understanding the Stakeholders in the Ecosystem

Multi-sectoral engagement of stakeholders such as the government, private sector, academia and public is required to create a framework that is common. Trusted and responsible data sharing is a joint responsibility among all parties, and therefore co-creation of the framework is a critical step.

### Building blocks of the framework

Having a standardised and harmonised regional data sharing framework that is comprehensive and widely applicable across Asian countries in varied states of development will help the region progress to a common desired end state. To help us envision how we can set up such a framework, the example of Singapore's Infocomm Media Development Authority's (IMDA) and Personal Data Protection Commission's (PDPC) [Trusted Data Sharing Framework](#) would be instructive. Given the perceived sensitivities surrounding health and healthcare data sharing, there should be a sharing framework (similar to IMDA and PDPC's) that is contextualised and specific to the health domain. This would then be similar to how the Association of Banks in Singapore (ABS) adapted the IMDA and PDPC model to create a [data sharing framework for the finance sector](#).

Figure 3 encapsulates a collection of best practices, framework building blocks and useful approaches collated from existing frameworks and shared by experts in this field. Stakeholders can consider these insights to build and adapt a framework that is feasible within and relevant to their local contexts.

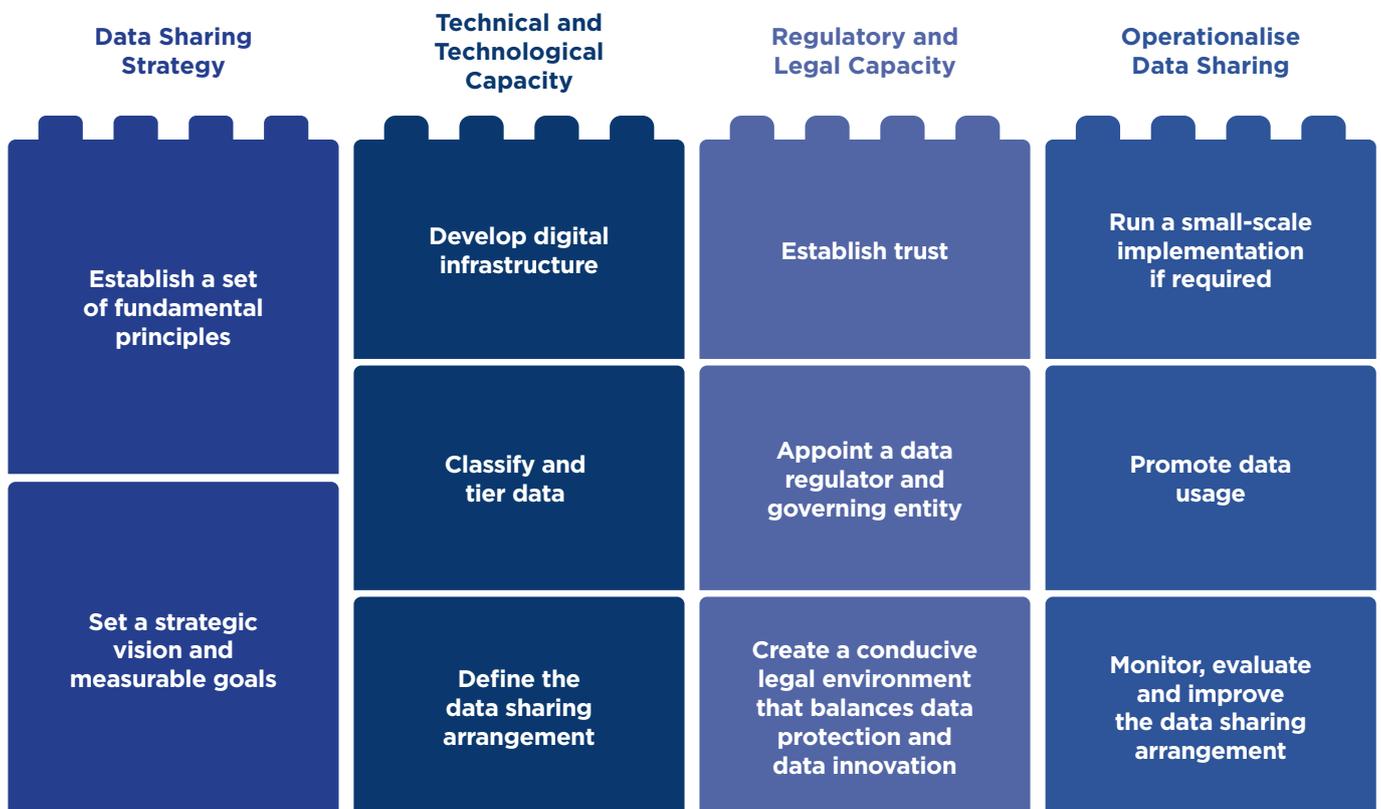


Figure 3: Building Blocks of a Data Sharing Framework for Health and Healthcare

Once the data sharing strategy is established, technical/technological and regulatory/legal capabilities need to be developed in tandem before data sharing can be operationalised and executed.

### Data sharing strategy

Establishing a set of fundamental and shared principles helps to define the values and standards that dictate how the data will flow and to align stakeholders on the ethos to follow going forward. When creating and agreeing on principles, it is helpful to categorise them into the three buckets of the [United Nation's Roadmap on Digital Cooperation: "Connect, Respect, Protect"](#).

"Connect" emphasises the capability to create governing and technological systems that facilitate easy "connection". Therefore, principles such as interoperability, alignment with e-health goals, agility, user experience and removal of unnecessary red tape become important.



***What is the capability of the government to actually create systems that are not bureaucratic, cumbersome and don't have red tape or multiple layers of approval? But one that can actually help everybody move towards - in health promotion terms, we would say the healthy choices are the easy choices - so how do we make sharing of health data a healthy choice AND make it easy?***



With regards to "respect", the framework should focus on values such as public good, trust, transparency, equity and digital inclusion. Lastly, "protect" includes protective features and measures for data systems and its users, including data privacy and data security. Examples of similar principles related to technology and data sharing include the [FAIR principles](#) and those by [WHO](#).

Next, creating a strategic vision and setting up specific and actionable goals can help to formulate the data sharing strategy.

### Technical and technological capacity

Given the different levels of technological maturity in Asia, it is important to first develop the digital infrastructure so that it can progress from a paper-based or siloed data ecosystem to a digital and integrated system. The digital infrastructure can be strengthened by having a strong baseline level of data protection and data security standards, and by incorporating best practices such as digital identifiers and privacy-preserving techniques like pseudonymisation and hashing. Investing in data digitalisation and training professionals to support the infrastructure can help to build up technical capacity.

Once the appropriate digital architecture is set up nationally and regionally, cross-border data flow can progress. When embarking on cross-border data sharing arrangements, data need to be classified and risk-tiered to determine the appropriate data sharing model and the underlying technology (e.g., cloud-based, blockchain, APIs etc). This White Paper further elaborates on data tiering and data sharing arrangements in later chapters.



### Regulatory and legal capacity

This building block of the framework relates to the responsibilities of regulators and governments. Cultivating trust is foundational to building a trusted and responsible data sharing ecosystem. The appointment of a governing entity responsible for health and healthcare data sharing that is cross-sectoral, supervisory and independent is of paramount importance for data governance. This engenders a sense of trust in the public that there is a trusted governing entity that exists to oversee data sharing and is responsible for managing negative incidents such as data leaks and cybersecurity breaches. In most situations, these digital health agencies are appointed and established at the state- and national-level. Potentially, these national bodies can then collaborate across the region to build a regional body for data governance and sharing.

Legislation is another key aspect. Rigid privacy laws, policies and standards that hinder and restrict data sharing, localise data and do not allow data to flow by default need to be carefully avoided. They could disadvantage the country or region and make them less competitive on the global stage. It could also limit opportunities for data exploration and analysis, and curtail innovation and discovery. Concurrently, we know that healthcare data can be sensitive, thereby justifying the need to prioritise cybersecurity, data privacy and integrity. Robust legislation is required to establish trust and define the allowable uses of data to protect data generators. Therefore, systems, laws and policies need to create an environment where the scales are balanced between the incentives for innovation and the need for protection.

In Asia, Brunei and Myanmar currently have no laws in place governing personal data while Malaysia, Thailand and Singapore have their versions of the [Personal Data Protection Act \(PDPA\)](#), which is similar to the European Union's General Data Protection Regulation (GDPR). While many of these laws are historically conservative, it would be useful to update them to align them with the latest technological and regulatory developments. To illustrate this progressive change, the [ASEAN Model Contractual Clauses](#) were derived from the [ASEAN Framework on Personal Data Protection](#) in 2021 to establish a modern, voluntary and legal basis for cross-border data flow within ASEAN. However, since the PDPA, GDPR and ASEAN Model Contractual Clauses pertain to personal data protection in general, a legal framework contextualised to digital health that supports the use of data as a medical asset may still be required.

Later sections of this White Paper cover how stakeholders can cultivate trust through regulatory and legal interventions.

### Operationalise data sharing

Once the first three building blocks help to establish the foundation of a data sharing ecosystem, the fourth block emphasises implementation. Before going live, consider running a small-scale implementation of the data sharing ecosystem as this allows for feedback, refining and validating the proof of concept. At the end of the day, the point of sharing data is to use the data. An OECD [Working Paper](#) showed that the widespread availability of datasets may not necessarily correlate with the usage of that data. The last section of this White Paper dives deep into how stakeholders can encourage the use of shared data to draw out the value of it, essentially unlocking the rich insights and utility that integrated data can unfold. Finally, it would be helpful to incorporate a process for continued and regular evaluation, monitoring and improvement so that the data sharing environment is adaptable and agile to new developments in the space.

In conclusion, creating a framework is of paramount importance to provide structural guidance for the region and the healthcare industry to progress towards a future-oriented data sharing environment. Cross-country and multi-sectoral engagement of stakeholders are required to co-create the foundational building blocks of a harmonised framework, so that stakeholders can align on the strategic, technical, regulatory and implementational aspects of their data sharing journey.

# DATA CLASSIFICATION AND TIERING

To enable stakeholders to responsibly and safely share health and healthcare data, there must be an agreed way to classify and tier the data into categories for the purpose of data sharing. While there can be many ways to categorise data in health and healthcare, two of the more commonly used parameters are: (i) data type and (ii) data sensitivity.

## Classification by data type

There are many sources and generators of data, such as data collected from health sensors, medical images, laboratory tests, electronic health records, patient registries, clinical and pharmaceutical claims, genome registries and clinical trials. One way for stakeholders to work towards a framework for data sharing is to start classifying data into common and agreed-upon data types. If there is no standardised taxonomy for the classification of health and healthcare data, it is difficult to talk about data sharing on a meaningful scale. Figure 4 provides a way for us to categorise and classify these data by data types.

Data Type	Definition	Examples	Possible Applications
<b>Demographic</b>	Attributes of the population under study	Age, race, sex, education, occupation, income, etc.	Population stratification, bias prevention, etc.
<b>Medical</b>	Data collected through the course of medical treatment at healthcare units	Vital parameters, medication, medical tests, imaging, electronic health records, etc.	Medical diagnosis, treatment, continuity of care, etc.
<b>Consumer Generated Health Data</b>	Information on the health and behaviour of individuals collected through personal smart devices	Smart personal devices data such as sleep patterns, heart rate, physical activity, etc.	Health self-management, behaviour and social habits assessment, etc.
<b>Financial</b>	Information related to the financing of healthcare	Claims and reimbursements, out-of-pocket costs, hospital financial statements, etc.	Cost-effective analyses, health technology assessments, health economic models, etc.
<b>Environmental</b>	Information gathered from the context in which people live	Air, food and water quality; safety; infrastructure etc.	Impact of social determinants of health, etc.
<b>Research</b>	Data collected through healthcare research and clinical trials	Genomics, observational studies, etc.	Pharmacogenomics, clinical trials improvement, advancements and innovation in healthcare, etc.

Figure 4: Data Types in Health and Healthcare

## Tiering by data sensitivity

Tiering health and healthcare data based on sensitivity provides a useful framework for stakeholders and regulators to identify the level of protection required and the potential rules and processes to put in place for responsible, ethical and legal sharing of these data.

Figure 5 presents a way for us to risk-tier health and healthcare data, in a format that can be easily adapted to address one's organisational needs.

	Data Tier	Data Sensitivity	Data Sharing Arrangement	
Data Spectrum ↑ ↓	Tier 1	Low	Open Access	Degree of Openness ↑ ↓
	Tier 2	Moderate	Controlled Access: Restricted	
	Tier 3	High	Controlled Access: Closed	

<b>Data Spectrum</b>	Spectrum of data ranging across tiers that are less sensitive to tiers that are more sensitive.
<b>Data Sensitivity</b>	Relates to the risk of re-identification and the impact of loss of the data.
<b>Degree of Openness</b>	Relates to the appropriate data sharing arrangement. Degree of openness reduces as one goes down the data spectrum; less sensitive tiers can be shared via open access while more sensitive tiers must be shared via controlled access.

Figure 5: Data Tiering Framework for Health and Healthcare

In Figure 5, we consider that the sensitivity of the data will determine the optimal data dissemination strategy, i.e., whether the data can be shared openly or in a more restricted and closed arrangement. Data sensitivity considers the risk of re-identification and the impact of loss, i.e., the financial, operational, reputational and legal impacts of a data leak on operations, organisations and individuals.

Data in tier 1 would be less sensitive, have a limited impact of loss and have low value. For example, anonymised data could fit into tier 1 since it is almost impossible to identify individuals from such data and is not of much value thereby having a minimal impact of loss. Such data can be shared easily in a less costly and more accessible way on an open access basis. One such example is the EU's GDPR, which stipulates that [anonymised data can be exempted from privacy regulations](#).

Tier 2 data could include data such as aggregated or de-identified data. Aggregated data combines and summarises many data points to highlight macro-level or population-level trends. Though raw data and individual information are not accessed, there is a moderate risk of re-identification if the correct scientific analysis is performed on aggregated data. Deidentified data is a common privacy safeguard since it removes the identifiers from protected health information; however, due to technological advances and the ability to combine de-identified data with other data sources, there is a moderate risk of re-identification and impact of loss. Consequently, tier 2 data should be shared in a more restricted manner with higher technical and legal safeguards.

Lastly, tier 3 data, which would include data like sensitive health information and genomic data, are usually shared in a more controlled and closed manner due to the potentially sensitive risk of data re-identification and the high impact of loss. Therefore, risk-tiering data is important to determine the required level of gatekeeping and the most appropriate arrangement to share the data.

## Taking action for data classification and tiering

Classifying and risk-tiering data into a common codified framework allows for a more nuanced understanding of the data in order to ensure seamless compatible data exchange. When stakeholders come together to establish this data classification and sensitivity tiering framework, they need to consider the following:

### Convene stakeholders to agree on the need for standardisation and common definitions

Different organisations within the ecosystem will likely have different ways of classifying and categorising their data types and differing definitions – this is to be expected. Identifying the differences is the first step towards building an agreement and consensus. Agreeing on the need for standardisation and common definitions is the next step towards creating a data classification and tiering system that is generalisable and widely applicable.

### Keep it simple

When creating this framework and ecosystem for a wide range of stakeholders, there is a tendency for rules to be gradually added on and processes to grow in complexity. However, when the system gets too complex and the processes get too complicated, stakeholders and users will find it too cumbersome to want to use the system. At the convergence phase of the process, the stakeholders must have a healthy obsession to keep the system, in the words of Einstein, “as simple as possible (but no simpler)”.

### Make it user centric

Keeping the end-user of the data sharing ecosystem in mind is important. To prevent public confusion about data types, the framework must have clear definitions and be easy to understand and use.

In addition to Figures 4 and 5, existing international standards, such as those developed by the [National Institute of Standards and Technology \(NIST\)](#) or the [International Standards Organisation \(ISO\)](#), can also be used as helpful references for organisations to classify and tier their data. These are small tangible steps that stakeholders can take to lay the foundation for building a strong data sharing ecosystem.

# DATA SHARING ARRANGEMENTS - HOW TO SHARE DATA?

## Roles in a health data sharing ecosystem

In an optimised data sharing ecosystem for health and healthcare data, stakeholders can view themselves as having one or more of these roles: data generator, data user, data regulator & governing entity and/or data exchange platform & IT service provider.

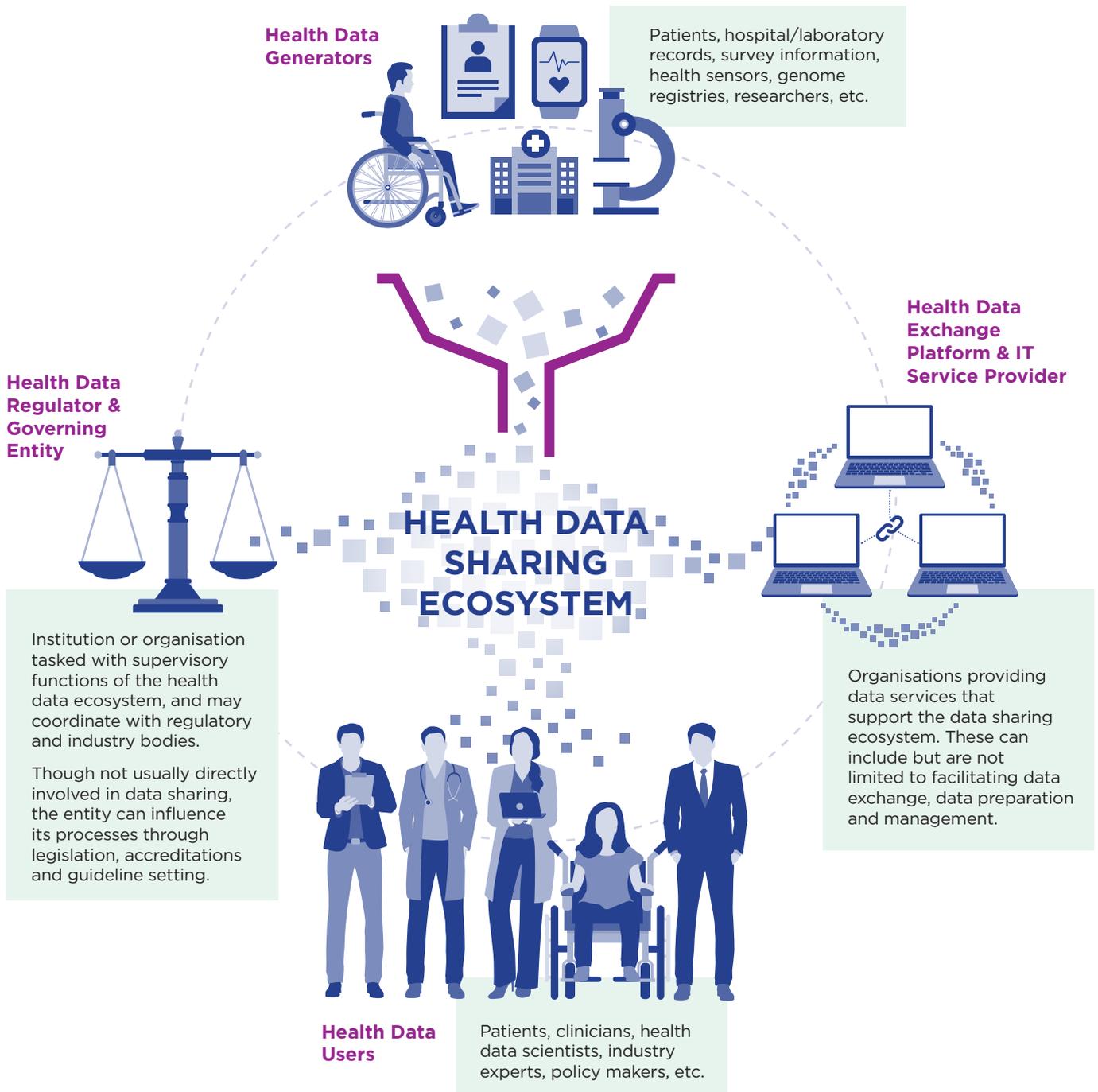


Figure 6: Roles in a Health Data Sharing Ecosystem

Depending on their level of involvement and access, different stakeholders will require different levels of onboarding and clearance. This helps ensure that each stakeholder in the ecosystem is familiar with the rules, processes and responsibilities of sharing and using data.

### Moving from data owners to data stewards

Data ownership was extensively discussed at the roundtable sessions, where experts concurred that ideally the data generators should be the data owners. However, in practice, information from data generators may be perceived to be simultaneously owned by different individuals, organisations, governments and various stakeholders. Data generators share their health and healthcare data with various stakeholders in the ecosystem through many avenues. This information is generally obtained and held with consent from data generators. Yet once the data are shared, the original data generators often do not have much control over their data subsequently. In these situations where the rights and responsibilities of safeguarding and managing the data are shared across several stakeholders, the term 'data owner' becomes less relevant. Instead, it might be more progressive to think of stakeholders who hold these data as 'data stewards', with certain rights and responsibilities associated with the privilege of access to these data.

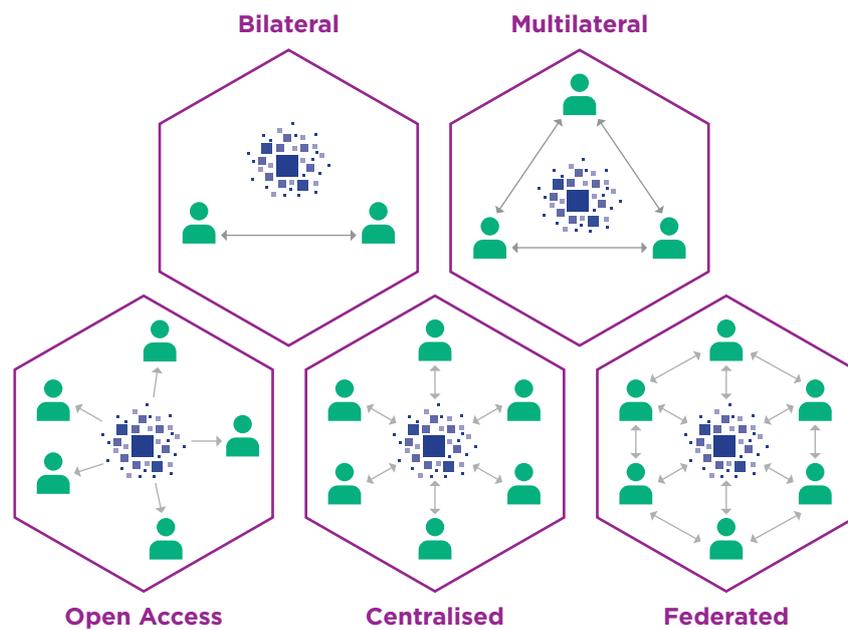


*We [a company that collects health data] don't view ownership of data as being transferred to us; we do not consider that we own and can decide what to use the data for. Typically, our consideration is more of being a custodian or steward of the data because we serve our customers: the patients. We hold custody or stewardship of their data so that we can provide better care. However, in the world today, it is seen that organisations hold the data and they use the data for whatever purposes that they deem fit; I think that in itself is wrong.*



## Modes of sharing data

Different data sharing arrangements provide different stakeholders with different levels of control and access. Therefore, it is important to choose the most appropriate data sharing arrangement that meets the aims and goals of the data sharing ecosystem.



Some examples of data sharing arrangements that were brought up by the roundtable experts and are prevalent in the literature are listed below.

### Bilateral

Bilateral data sharing, that is between 2 parties, is the simplest form of data sharing. Usually, an exchange of data between a data generator and a data user. For example, with a personal medical device that measures heart rate.

### Multilateral

In a more complex multilateral arrangement, 3 or more parties that may hold one or both data generator and data user roles pool their data to work towards a common objective. For example, sharing data within a hospital among doctors, nurses, pharmacy and diagnostics.

### Open Access

Open access data sharing arrangements are useful for sharing data that are insensitive enough to be shared in a public domain. These systems are easy to establish, relatively fuss-free to maintain and more common in the research and academia space. These data can be readily accessible to data generators and users with minimal gatekeeping mechanisms. One example is [SpringerOpen](#), where their journal portfolio of more than 200 peer-reviewed journals includes American Association of Pharmaceutical Scientists (AAPS), Journal of Anaesthesia (JA) Clinical Reports and European Journal of Nuclear Medicine and Molecular Imaging (EJNMMI) Research. In this way, SpringerOpen democratises knowledge by removing access barriers.

### Controlled Access

Controlled access data sharing models are more common and the default, as most of these data have some levels of sensitivity. Examples of such models include the centralised and federated models, which rely on a third-party gatekeeper who de-identifies data and/or enhances the security of data shared.

### Centralised

A centralised approach runs all of the functions from a single division that coordinates them. For example, [C-CAT](#) is a centralised database; it coordinates several independent/autonomous platforms (e.g., Cancer Genomics Repository, Genome Analysis Platform, Liaison for Cancer Genomic Medicine Hospitals, etc.), aggregates them under a centralised database and makes it available to other academia/industries under appropriate rules.

### Federated

Within a federated approach, a single goal is set and the individual divisions take their own initiatives to reach it. For example, the [Genomics England](#) project analyses clinical and genomic data across England in association with NHS England and over 85 NHS Trusts and hospitals, utilising a federated system under Amazon Web Services (AWS) to power their cloud platform.

Figure 7: Examples of Data Sharing Arrangements

When deciding on a data sharing arrangement, a major challenge is managing the differing perspectives and goals of providers and users. Hence, all stakeholders should have a voice in the creation of the regulations that govern such a system. Ultimately, the objective is to draw value from such an arrangement for all involved. Several other sectors, such as finance and security, have managed to develop systems that benefit both them and their consumers. There is much potential for the health sector to adapt these best practices and contextualise them to the health setting.

## Data architecture spectrum

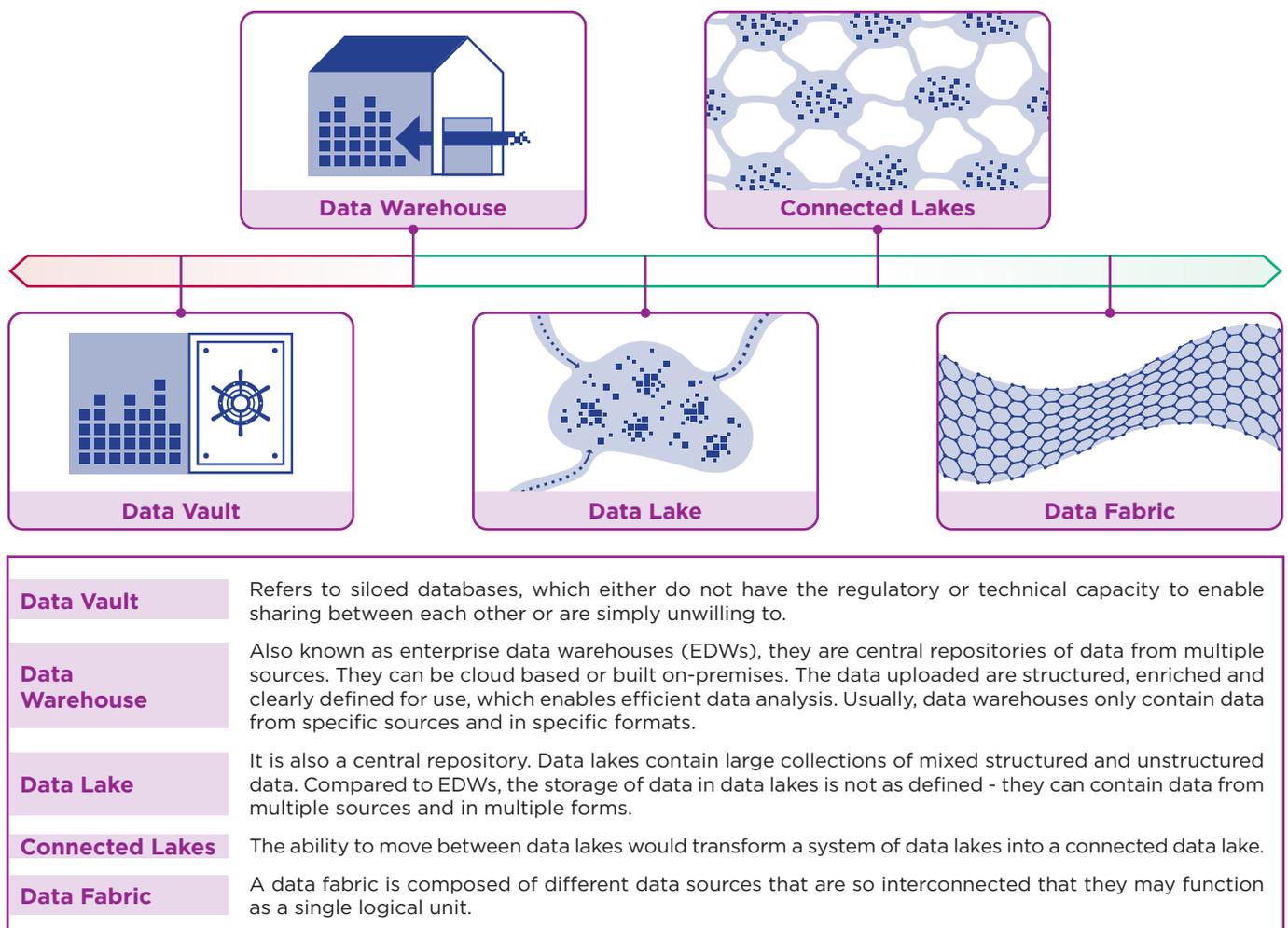


Figure 8: Data Architecture Spectrum

Many stakeholders holding a significant amount of data would have a data warehouse, which is in some ways the baseline structure for storing and accessing datasets safely and efficiently. However, some of these data warehouses end up becoming data vaults when more and more security and protection requirements get layered on over time. This may occur when organisations become reluctant to allow access to these datasets on the premise that much of the data are considered sensitive or proprietary. In this climate where cybersecurity incidents are prevalent and the populace is increasingly sensitive about personal data protection, it does take considerable effort to prevent data warehouses from becoming data vaults.

Instead, our collective investments and efforts towards building a stronger and robust data sharing ecosystem and framework should help all stakeholders to move towards a more progressive data sharing architecture. In such situations, we will see a transition from data warehouses to data lakes, to connected data lakes and perhaps eventually to data fabrics in certain areas where there is high trust and high efficiency.

## Importance of interoperability and common data standards

### Human to human

Experts acknowledge that there is a need for uniformity and standardisation to enable data sharing. This would involve defining a set of common technical terms and sharing data in a common language. Such classification systems are widespread throughout every specialty and field. For example, within a disease context, the Systematized Nomenclature of Medicine- Clinical Terms (SNOMED-CT) is a set of medical terminologies created by the College of American Pathologists (CAP) designed specifically as inputs into electronic medical records. Another example is the International Statistical Classification of Diseases (ICD), which are classifications designed for outputs or reports and are compatible worldwide.

With increasing globalisation, it becomes more vital to design processes with cross-border data sharing in mind. As individuals move across the globe, the use of international standards would enable better communication among stakeholders, improve interoperability and increase patient access to their own data.

### IT to IT

IT interoperability is an important topic, and HIMSS has defined four different [interoperability levels](#): Foundational, Structural, Semantic and Organisational. Foundational interoperability relates to the ability to transfer data between systems without changing it. Organisational interoperability refers to the regulations that enable this exchange; for example, policies between organisations. Structural interoperability refers to the standardisation/structuring of data that can be interpreted across systems, such that a receiving system is able to recognise and perform specific functions, such as detecting specific data fields. One commonly utilised framework for this is the Fast Healthcare Interoperability Resources (FHIR), an open-source standards framework for healthcare data that builds off a previous standards framework called Health Level 7 (HL7). FHIR was created to move healthcare data across systems. It can organise healthcare data, provide a standardised structure for data analysis and structure financial data and workflow data. Other well-known examples include Consolidated Clinical Document Architecture (C-CDA) and HL7v2. Semantic interoperability elevates this concept by enabling data exchange whilst retaining the same level of information; for example, DICOM and non-DICOM formats for images.

With the foundations for a strong data sharing arrangement in place, stakeholders can progress to maximise interoperability. There are numerous strategies that can be undertaken to achieve different interoperability levels simultaneously. The Observational Health Data Sciences and Informatics (OHDSI) approach converts data from different sources into a common format, which they call the [Observational Medical Outcomes Partnership \(OMOP\) CDM \(Common Data Model\)](#). A slightly different approach is to set clear standards for data format and data types from the very beginning of the research process to drive automation, which the [Clinical Data Interchange Standards Consortium \(CDISC\)](#) has endeavoured to do.

## How to start

### Start small

Rather than rushing into building a costly data arrangement, it would be advisable to first come up with a strategy and a framework that lines up with the organisation's aims and long-term goals. Even before designing the technical framework, engagement with stakeholders is essential. Having conversations about the requirements and expectations of the system will better future-proof and therefore reduce the cost whilst increasing the versatility of it.

### Build trust and confidence

Reinforcing trust and empowering users through proactive stakeholder engagement and community building is important to facilitate data sharing and help maximise the value of data re-use. [Genomics England](#) sets an excellent precedent with their Patient and Public Involvement (PPI) Networks that provide feedback on patient information literature and consent processes; and public engagement events which hold several events, debates and talks around the country.

### Collaborate with natural partners first

Making the decision to share data is straightforward; there is a myriad of evidence showcasing the benefits of doing so. However, determining whom to share that data with can be daunting. The most sensible approach would be to start with entities and organisations you know, where relationships have already been formed due to natural interactions in the field of work, i.e., natural partners.

# BUILDING TRUST TO ENABLE DATA SHARING

Meaningful data sharing can only take place in a trusted environment where there are clear measures to safeguard the confidentiality, integrity and availability of information. The key components of trust-building start with transparency of processes and common rules on how data are shared, used, managed and protected. In each trusted environment and data sharing ecosystem, there must be a data regulator and governing entity that is responsible for maintaining the integrity of data and managing their authorised use. The work of this authority involves having clear communication with members of the public on news and updates about the data sharing ecosystem, and timely communication when it comes to negative events such as data leaks or cybersecurity incidents. The governing authority and stakeholders must commit to building a trusted data sharing environment that prioritises the public's interests - that is a key component of building trust with the public.

## Transparency

[Transparency](#) refers to the openness of all stakeholders involved in data sharing to make available all information that is necessary for a successful data sharing partnership. This includes providing clear and publicly accessible information on how data are shared, managed and protected. For companies and institutions that are data users, clear procedures and guidelines on data access help them to retrieve the data easily and promptly. This in turn can incentivise them to peruse and use as much data as possible, thus maximising the value of shared data. In addition, transparency includes disclosure of the intent of how the data are going to be used by various stakeholders. The governing entity and data regulator needs to be consistent in the authorised use of data to prevent miscommunication with data generators or patients whose data are shared. This helps to maintain the confidence of the individuals in the data sharing system.

## Consent

Trusted data sharing for health and healthcare data must be built on the understanding that there is consent given for secondary uses of these datasets. Consent means awareness and acknowledgement by data generators that the shared data can be used for a wider range of ascribed purposes, other than for their personal healthcare services. The governing entity has an important role to obtain consent and establish a clear and consistent consent protocol. The process of obtaining consent should allow the individuals to exercise a range of control over the sharing of their data - to decide what they want to share, what they do not want to share and be clear that the shared data are used only insofar as their authorisation allows. In the most ideal circumstance, individuals can choose ways in which their data can benefit others or the healthcare services at large.

According to a [Eurohealth report](#), patients ideally have to be informed of all the options available with regard to the use of their data at the point of registering to any primary care facility or referral to secondary care. In addition, when the technology allows for it, individuals should also be allowed to opt out from the data sharing environment at any point in time.

## Having a governing entity with good governance and processes

A reliable, principled and impartial governing entity is a cornerstone of a trusted data sharing environment and would encourage the participation and support of both the private and public sectors for data sharing projects.

The governing entity would be responsible for consent related protocols, regulate the secondary uses of shared data and mitigate any form of risks that can jeopardise the shared data or the trusted data sharing environment, which includes the potential risks of re-identification of originally anonymised and/or pseudonymised data. In so doing, it would build long term trust with the public and stakeholders of the health and healthcare data sharing ecosystem.

As data sharing expands in terms of scope and size, there are risks of exposing the identities of data generators. For instance, if healthcare data are merged with insurance data and public sources data, the re-identification becomes a real risk. The governing entity must strike a delicate balance between sharing large amounts of data and reducing the risk of re-identification. While such risks cannot be eliminated entirely, a governing entity should focus on the *management* of these risks.

The de-identification mechanism in Germany would be a good example. The German Institute for Medical Documentation and Information ([DIMDI](#)) performs double-pseudonymisation to all claims data received from the National Association of Statutory Health Insurances and the Federal Office for Social Security. DIMDI provides anonymised data to all recipients legally entitled to receive routine data for fulfilling their responsibilities and can provide pseudonymised data upon a separate application.

When established and mature, the governing entity should be leading at the forefront of data sharing initiatives and encouraging the participation of more non-governmental stakeholders such as private companies and the academic community to foster a more progressive health and healthcare data sharing ecosystem. As the ecosystem matures and with more data sharing between a wide range of stakeholders, the trust among stakeholders may become more tenuous and they may be concerned about the use of their shared data by other entities. As the system becomes more complex, the governing entity's role as an intermediary, an honest broker and at times a mediator becomes more important.



### **An ideal governing entity: learning from Finland and New Zealand**

Based on our discussion thus far, an ideal governing entity would embody the role of the administrator of data sharing mechanisms, the technical expert who can safeguard and guarantee the integrity and quality of data shared as well as the leader of data sharing initiatives who can establish connections and collaborations necessary to encourage better participation from various stakeholders.

We can find examples in Finland and New Zealand as the closest approximation to our ideal entity.

In Finland, [Findata](#) exists as a one-stop portal that manages the secondary uses of social and health data. Findata collects and safekeeps all sensitive data from various registries in Finland and restricts access to authorised users. It also anonymises the data collected, and in doing so, it maintains a secure environment for data sharing in the country. In addition, it becomes the only entry point to access data for secondary purposes, which centralises and speeds up the process to obtain data use permits for any parties interested.

In New Zealand, [NZStats](#) serves as the governing entity over the country's Integrated Data Infrastructure (IDI). The IDI contains de-identified health and social data collected from non-profit organisations, government agencies and surveys. Upon integrating the data collected, NZStats de-identifies the data and makes that available for secondary uses by researchers.

## Liaising with stakeholders to establish and maintain a trusted data sharing environment

At the inception stage of a data sharing initiative, the lack of trust among relevant stakeholders may be present due to the lack of information about the potential benefits that healthcare data sharing may bring. Thus, one way to build trust is through involving as many stakeholders as possible in the creation of a trusted data sharing environment, so that everyone has their interests represented in data sharing endeavours. This is once again to drive the point that the main beneficiaries of the shared data are the stakeholders in the data sharing ecosystem and members of the public.

In addition, a governing entity needs to communicate measures in the case of disruption and other unexpected issues that may jeopardise the shared data. The guarantee that there are mechanisms set in place to mitigate security risks serves as a reassurance to all stakeholders, especially the individual data generators, that their data are handled wisely and with utmost discretion.



*How you manage your data security breach says a lot about whether you're going to earn trust or lose trust.*



The governing entity must also seize opportunities during events, such as the COVID-19 pandemic, to strategically advocate for the value of sharing data, and showcase not only the need but also the capacity and readiness to expand or kickstart data sharing initiatives. This would be useful especially in countries and communities that are still sceptical or lukewarm about the possibility of establishing a trusted data sharing environment. Seeing how consequential health and healthcare data sharing has been in the process of managing and reducing the spread of COVID-19, there can be a strong case to be made on how data sharing is no longer good to have but an imperative if we want to bolster our healthcare services, especially in the face of events like a pandemic.



*We also need to be savvy enough to have opportunistic communication in situations where we capitalise on the kind of public health emergency situation and use that to strengthen [data sharing initiatives].*



Finally, once the governing entity and relevant regulations have been set up, clarity in terms of the purpose and value of data sharing must be established with members of the public. Thus, governing entities need to engage members of the public right from the beginning of the data sharing initiative to improve public awareness of the architecture and mechanisms of the system. With time, governing entities would need to maintain and upkeep communication and engagement efforts with members of the public on the latest news and updates about the data sharing ecosystem. This is especially important against the backdrop of incidents that may negatively impact public perceptions and trust in data sharing, such as data leaks or hacks.

In conclusion, a trusted environment is built upon the values of transparency and consented use of data. A governing entity is needed to uphold these values and has to be established from the earliest stage of data sharing endeavours as an impartial body that seeks to balance the interests of different stakeholders.

# ENCOURAGING THE USE OF SHARED DATA TO DRAW OUT THE VALUE OF DATA

It is important for those who are responsible for putting in place a more progressive model of data sharing to understand the incentives that can help to drive stakeholder utilisation of shared health and healthcare data so that value can be harnessed. To understand and communicate the needs and aspirations of various stakeholders, it is useful to think in terms of stakeholder groups - individuals, companies and governments/regulators.

## Helping individuals to share data

It is often assumed that people are naturally reluctant to share their health data for secondary uses. However, this assumption appears to stem from the lack of engagement with members of the public. In Australia, a [study](#) reveals that half of the respondents thought that their healthcare data are already used for medical research without their explicit consent. Another [study](#) reveals that most respondents agree that their data should be used for health services research. This shows that individuals are more generous and willing to share their data for secondary purposes than previously expected.

Furthermore, people are keen to see tangible rewards and benefits for their participation in certain initiatives, including data sharing projects. Direct incentives, especially those that come in the form of monetary benefits, help people to put a value to their data sharing. If individuals see that their data are highly valued and beneficial for them, they are more likely to share their data.

AIA Vitality






**Making positive behavioural changes to #LiveWithVitality**

[AIA Vitality](#) is a health and wellness programme that encourages members to know their health, improve their health and get rewarded with an extensive suite of partner rewards and benefits. Members earn Vitality points for every healthy choice they make, such as going for a basic health screening and submitting their results, clocking steps and tracking runs with supported fitness devices/apps and going to partner gyms for workouts.

For example, members are encouraged to go for a basic health screening every year to track four key health metrics - body mass index, blood pressure, cholesterol and glucose. By submitting the results for these four metrics, members will earn 2,000 Vitality points. If the results are in the healthy range, members will earn up to an additional 4,000 Vitality points. Members can also opt for advanced health screenings such as mammograms and colon cancer screenings to keep their health in check and submit their results to earn more Vitality points.

The more Vitality points they earn, the higher the Vitality status and the more rewards they can unlock with AIA Vitality.

There are also indirect benefits of data sharing that individuals receive when they share their data to integrated healthcare data portals like [HealthHub](#) and [Health Buddy](#) in Singapore, where they benefit from the seamless and integrated repository of their health data that includes test results, vaccination and medication records, doctor's appointments as well as hospital bills. These healthcare portals help to make healthcare services more accessible to individuals and make it more convenient for them to make appointments at different hospitals. In addition, the shared healthcare data also enables continuity of care by healthcare providers from different institutions, bringing value to the individual patients.

### Encouraging companies and healthcare providers to share data

Organisations - for-profits and non-profits alike - also stand to benefit from data sharing in healthcare in several ways. Firstly, the wealth of data available via data sharing initiatives allows healthcare providers to provide good continuity of care for patients across various care settings. Secondly, shared health and healthcare data enable companies and regulators to conduct more rapid and efficient Health Technology Assessments (HTA) to determine which medical devices, medications and treatment modalities are most cost-effective and efficacious for the needs of the community. Health and healthcare data sharing in basic science research also promotes and hastens the advancement of medical science and research to combat diseases.

When healthcare providers share patient data with one another, physicians are better able to make a more complete assessment of the patient's conditions and more quickly determine the most appropriate treatments at the earliest possible juncture. Scaled up across the health system, this will allow our limited healthcare resources to be spent and allocated more efficiently. When data sharing across healthcare providers becomes more widespread and starts to include outcomes data, that is where the health system can better understand which treatments and interventions are the most cost-effective.



***Clinical outcomes are really useful to help improve cost-effectiveness of interventions. That's something that real-world data can really drive, not only better use of facilities but also specific interventions, [especially] the right mix of interventions.***



On top of that, data sharing is also essential to help companies understand the state of the diseases and the needs of each country and community. An example would be [EUnetHTA](#) which has pioneered data sharing in HTA within the EU. EUnetHTA has the EVIDENT Database which houses information on requests or recommendations for Post-Launch Evidence Generation (PLEG) made by EUnetHTA partners after the initial HTA. In its pilot project, health regulatory agencies from various EU member states collaborated to share post-launch data that each collected at national-level to identify gaps in the currently approved treatments. Companies benefit because the wider base of data lessens the costs of acquiring information. Sharing data also reduces the duplication of similar research being conducted by different companies, and helps companies be more efficient when conducting literature searches and preparing regulatory paperwork needed to launch healthcare products in any given jurisdiction. At a systems level, this would translate to more affordable treatment alternatives that are available in a timely manner.

Finally, academic research institutions would greatly benefit from embarking on a large-scale data sharing initiative to gain insights on topics affecting large populations and requiring swift responses. An example would be the joint effort to monitor clinical data of patients infected with tuberculosis (TB) and the genetic sequences of the mycobacterium strain that the person has. The real-time data sharing between research institutes in the Southeast Asian region Comprehensive Resistance Prediction for Tuberculosis: an International Consortium ([CRyPTIC](#)) has enabled the research on TB advances in five different areas: the identification of new strains, especially those that are resistant to antibiotics; the creation of diagnostic tools that are more savvy and accessible, which ideally can diagnose the specific type of infecting strain and thus help to narrow down the treatments at disposal; the mapping of TB, in terms of its geographical and demographical spread to quantify and make sense of the scale of the issue; the evaluation of strategies implemented in different countries to detect and respond to TB cases; and finally the establishment of a database for improving TB care. This collectively shared repository of data allows for a more focused and concerted effort to fight against TB cases in the region, and enables prioritisation of a research agenda to fight certain strains of TB or outbreaks that occur in certain localities. Researchers in other areas should consider emulating this model of data sharing so that research efforts can be more targeted and collaborative in nature, and better meet the needs of the patients and their communities.

## Structural adaptations within government bodies to allow easier data sharing

Governments play an important role to serve the public good. One of the biggest value propositions of data sharing for government bodies is to improve the quality and cost-efficiency of healthcare services. To allow data-driven policymaking to guide the provision of trustworthy, quality and cost-efficient healthcare services, governments must first have comprehensive, timely and high-quality health and healthcare data.

Firstly, governments should handle and use healthcare data in a manner that is open to inquiry and use by members of the public. Naturally, there is hesitancy in making healthcare data open to access due to uncertainties and concerns related to how the data are going to be used and analysed by members of the public. However, a transparent and accessible repository of healthcare data enables faster and trusted decision making especially during a public health emergency like the COVID-19 pandemic, as members of the public become cognizant of the steps that the government has undertaken and how the resources have been allocated thus far. Likewise, for government bodies, open data is a strategic way to bolster communication efforts with members of the public. Thus, government bodies need to establish a system whereby health and healthcare data, at an anonymised/de-identified state, should be pooled and publicly shared as much as possible.

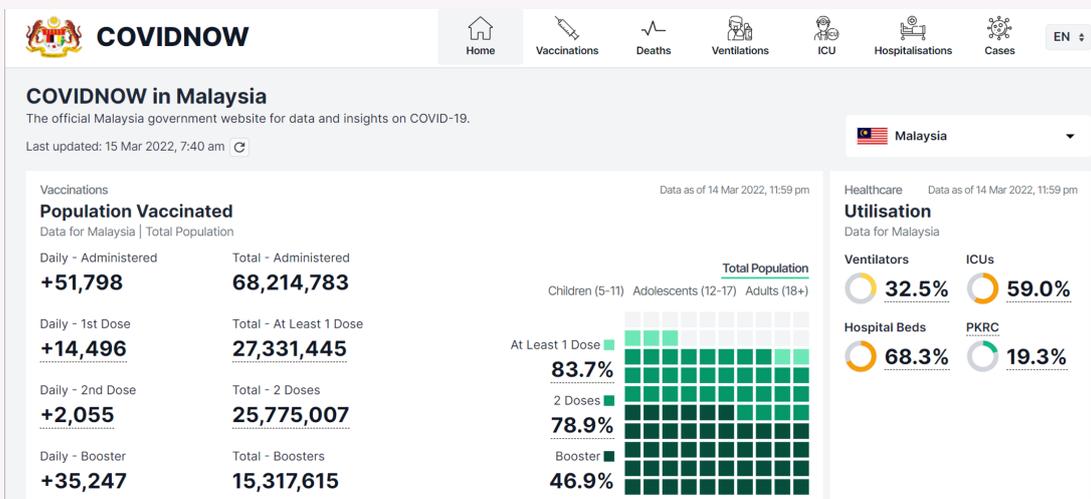


### Enabling informed decision-making with Malaysia's COVID-19 GitHub

In Malaysia, the shared data on bed occupancy rate and the number of COVID-19 active cases have helped government officials and healthcare providers to map out the trends and the spread of the disease in different parts of the country more easily.

The data are pooled from various contributors including the Crisis Preparedness and Response Centre (CPRC) and CPRC Hospital System, Makmal Kesihatan Awam Kebangsaan (MKAK, or the National Public Health Laboratory) as well as MySejahtera, a mobile app developed as a COVID-19 surveillance tool. The aggregated data allow for a bird's eye view of how each state fares against the disease, and thus it helps the decision makers at the national-level strategise on how resources should be allocated.

In addition, the open data repository on GitHub also becomes the basis for a one-stop informative website that communicates how the government handles the pandemic. The [COVIDNOW](#) website by the Malaysia Ministry of Health and COVID-19 Immunisation Taskforce presents neat and intuitive infographics that inform Malaysians and the international audience alike on the rate of healthcare services utilisation, number of active cases and most recently, vaccination rate.



In addition, data sharing by healthcare providers allows stakeholders and resource owners to ascertain the levels of utilisation and consumption of healthcare services by the public. This allows stakeholders to identify segments of the population that may have underutilised healthcare services – these could be economically or geographically vulnerable groups that have not been able to access healthcare services easily. These groups are at risk of suboptimal health conditions due to their under-utilisation of healthcare services. Government entities and healthcare providers can harness the power of shared health and healthcare data beyond the conventional electronic health records to glean greater insights on patterns of inequity that exist in the society.

Thus, an important step at the inception of a trusted data sharing environment is ascertaining the interests and aspirations that stakeholders plan to fulfil through their participation in the data sharing project. This would allow the governing entity to communicate the value and benefits of data sharing strategically. Finally, when stakeholders realise the value of data sharing, they will be more likely to be active participants in the data sharing initiative.

# CONCLUSION: A WAY FORWARD

The steps outlined in this White Paper - such as establishing a framework for data sharing and setting up a national digital health agency - are some of the practical actions that stakeholders can take to progress towards a more progressive and responsible data sharing ecosystem for health and healthcare data. Moving forward, there are several guiding principles and key considerations for stakeholders to keep in mind when implementing these recommendations in order to foster cross-border data sharing that is premised on the values of equity, trust and public good.



## Data sharing is a means to an end

Progressing towards a responsible data sharing ecosystem, while important, is not the ultimate end goal. The goal is to help everyone receive quality, accessible and timely healthcare services as well as optimise everyone's health. This means that the architecture and the goals of the data sharing environment must be user-centric, equitable and geared towards addressing the healthcare issues and needs on the ground. Having a shared understanding that data sharing is one of the means to the end gives clarity to stakeholders on the need to establish a common vision and value-proposition for this joint effort.



## Build trust and safeguard the public's interest

Trust is hard to earn but easy to lose. Trust can be built among stakeholders by building a common framework, showing early successes, maintaining clear lines of communication and being transparent. In addition, ensuring equitable use of the data sharing ecosystem, generating value for vulnerable populations in the society and constantly safeguarding the system with the public's interest at heart are actions that help to provide the moral compass and add to the longevity of the data sharing ecosystem.



## Ensure that everyone at the table has a stake in the success of the ecosystem

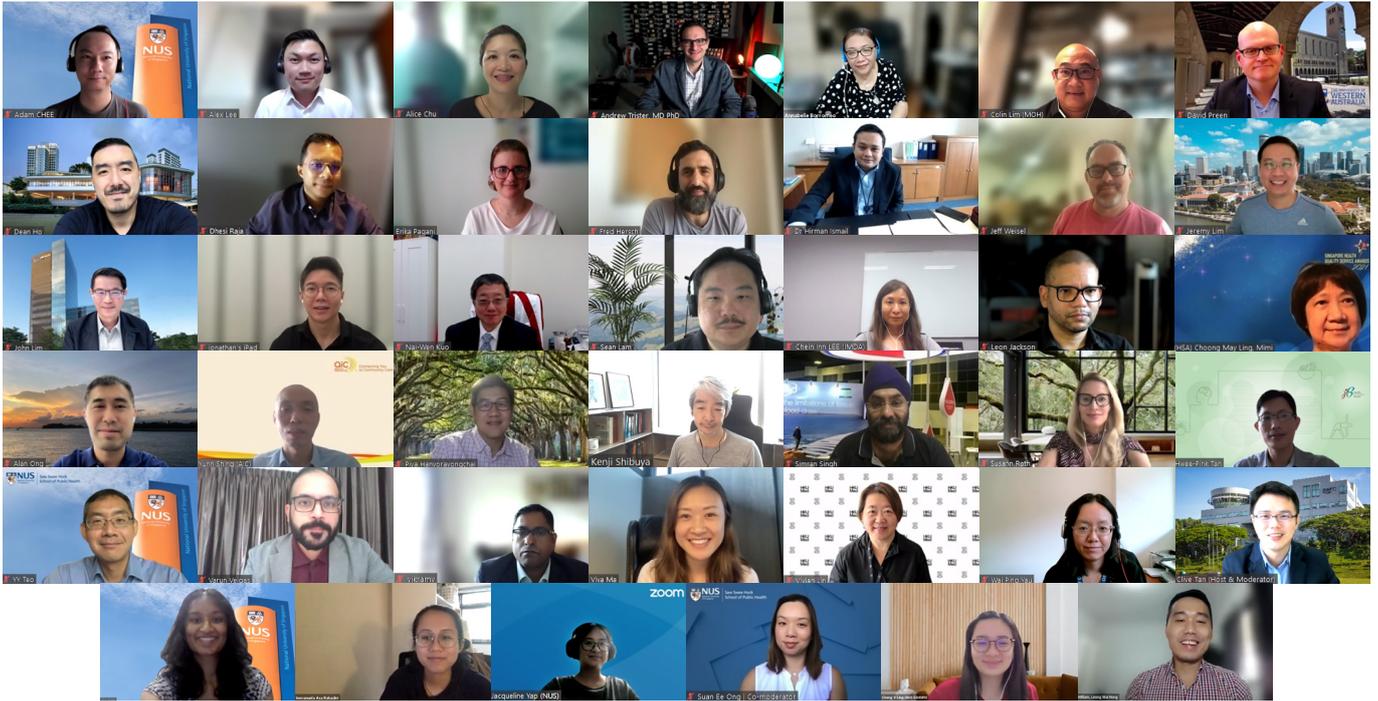
An important aspect of every stage of this journey to create a trusted data sharing ecosystem is active involvement from all stakeholders to ensure that the framework created is accessible and useful for all. It is important that all stakeholders at the table are vested in the ecosystem's success, contribute meaningfully to the process and hold the view that the success of the data sharing ecosystem will create value for them.



## Take action

A journey of a thousand miles begins with a single step. Distilling the wisdom from our roundtable experts who gave their advice so generously and freely: start small, focus on building trust and collaborate with the natural partners that you are already working closely with first.

## ACKNOWLEDGEMENTS



### Roundtable Experts

#### Dr Adam Chee

Chief, Smart Health Leadership Centre, Institute of Systems Science, National University of Singapore  
[Singapore](#)

#### Mr Alex Lee

Director, APAC Strategic Planning & Partnerships, Abbott  
[Singapore](#)

#### Dr Alice Chu

Director, Market Access and Medical Marketing, APAC, Glaukos  
[Singapore](#)

#### Dr Andrew Trister

Deputy Director, Digital Health and Innovation, Bill & Melinda Gates Foundation  
[USA](#)

#### Dr Annabelle Borromeo

Professorial Lecturer, Trinity University of Asia  
[Philippines](#)

#### Mr Colin Lim

Chief Information Officer, Ministry of Health, Singapore  
[Singapore](#)

#### Professor David Preen

Chair in Public Health, School of Population and Global Health, The University of Western Australia  
[Australia](#)

#### Professor Dean Ho

Head, Department of Biomedical Engineering, National University of Singapore  
[Singapore](#)

#### Dr Dhesi Raja

Chief Medical Innovation Officer, AINQA  
[Malaysia](#)

#### Ms Erika Pagani

Country Manager, Pfizer  
[Singapore](#)

#### Dr Fred Hersch

Senior Program Manager, Google Health  
[Singapore](#)

#### Dr Hirman Ismail

Deputy Director of the Medical Development Division, Ministry of Health, Malaysia  
[Malaysia](#)

#### Mr Jeff Weisel

Managing Director, APAC, PRMA Consulting  
[Singapore](#)

#### Associate Professor Jeremy Lim

Director, Leadership Institute for Global Health Transformation, Saw Swee Hock School of Public Health, National University of Singapore  
[Singapore](#)

#### Professor John CW Lim

Executive Director of the Centre of Regulatory Excellence (CoRE), Duke-NUS Medical School  
[Singapore](#)

#### Dr Jonathan Tan

Head of Disruptive Access, APAC & Middle East, Africa, Novartis  
[Singapore](#)

#### Professor Kuo Nai-Wen

Professor, School of Health Care Administration, Taipei Medical University  
[Taiwan](#)

#### Dr Lam Shao Wei, Sean

Head of Data Science, SingHealth Duke-NUS Academic Medical Centre  
[Singapore](#)

#### Ms Lee Chein Inn

Deputy Director (Data Innovation Programme Office), Infocomm Media Development Authority  
[Singapore](#)

#### Mr Leon Jackson

Healthcare Chief Technologist, Asia Pacific and Japan, Amazon Web Services  
[Singapore](#)

#### Dr Mimi Choong

CEO, Health Sciences Authority  
[Singapore](#)

#### Dr Ong Eng Seng, Alan

Medical Director, AIA  
[Singapore](#)

#### Mr Ong Yunn Shing

Chief of Corporate Services, Agency for Integrated Care  
[Singapore](#)

#### Dr Piya Hanvoravongchai

Lecturer, Chulalongkorn University  
[Thailand](#)

#### Professor Shibuya Kenji

Director, Tokyo Foundation for Policy Research  
[Japan](#)

#### Mr Simranjit Singh

CEO, Guardant Health AMEA  
[Singapore](#)

#### Dr Susann Roth

Advisor and Chief of Knowledge Advisory Services Center, Asian Development Bank  
[Philippines](#)

#### Dr Tan Hwee Pink

Director of Research Collaborations and Analytics, Health Promotion Board  
[Singapore](#)

#### Professor Teo Yik Ying

Dean, Saw Swee Hock School of Public Health, National University of Singapore  
[Singapore](#)

#### Mr Varun Veigas

Regional Regulatory Affairs & Policy Lead APAC, Roche Diagnostics  
[Singapore](#)

#### Dr Vikram Venkateswaran

Founder, Healthcare India  
[India](#)

#### Dr Viva Ma Yan

Director, Strategic Access, Public Affairs, Greater Asia, Becton Dickinson  
[Singapore](#)

#### Professor Vivian Lin

Executive Associate Dean, Li Ka Shing Faculty of Medicine, The University of Hong Kong  
[Hong Kong](#)

#### Dr Yau Wai Ping

Senior Lecturer, Department of Pharmacy, National University of Singapore  
[Singapore](#)

### Authors

#### Dr Clive Tan

Founding Member, Precision Public Health Asia Society Adjunct Faculty, Saw Swee Hock School of Public Health, National University of Singapore

#### Ms Nikita Kanumooru Mandyam

Research Assistant, Saw Swee Hock School of Public Health, National University of Singapore

#### Ms Immanuela Asa Rahadini

Research Intern, Saw Swee Hock School of Public Health, National University of Singapore

#### Ms Jacqueline Yap

Research Intern, Saw Swee Hock School of Public Health, National University of Singapore

### With Support From

#### Dr Ong Suan Ee

Ordinary Committee Member, Precision Public Health Asia Society Adjunct Research Fellow, Saw Swee Hock School of Public Health, National University of Singapore

#### Ms Cheng Yi Ling

Secretariat, Precision Public Health Asia Society Senior Executive, Executive Programmes Office, Saw Swee Hock School of Public Health, National University of Singapore

#### Mr Leong Wai Hong, William

Secretariat, Precision Public Health Asia Society Assistant Manager, Executive Programmes Office, Saw Swee Hock School of Public Health, National University of Singapore



