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Saw Swee Hock  
School of Public Health

# RESPONSIBLE DATA SHARING IN HEALTH AND HEALTHCARE

**Event Report**

5 SEPTEMBER 2022



The [Precision Public Health Asia Society](#) and the [NUS Saw Swee Hock School of Public Health](#) launched the Whitepaper on Responsible Data Sharing in Health and Healthcare on 22 July 2022. The event was supported by Novartis and Becton Dickinson.



The Whitepaper distils the knowledge, expertise and inputs from roundtable discussions with more than 30 experts in the field, with insights and recommendations summarised and presented under five broad categories:

- A Framework for Trusted and Responsible Data Sharing
- Data Classification and Tiering
- Data Sharing Arrangements
- Building Trust to Enable Data Sharing
- Drawing out the Value of Shared Data

This event was attended by up to 50 stakeholders from diverse domains, including government bodies, healthcare companies, healthcare providers, consultancy firms, technology companies and research institutes.



The event started with a fireside chat segment with expert panellists who shared their insights on advancing data sharing in resource-poor settings, overcoming technical barriers to data sharing, establishing trust and proliferating purpose-driven data sharing. The panellists included:

- **Dr Clive Tan** (moderator) — Asst Chief, Integrated Care (Population Health), National Healthcare Group
- **Prof Teo Yik Ying** — Dean, Saw Swee Hock School of Public Health, National University of Singapore
- **Mr Paul Chua** — Associate Director, Information Security, Greater Asia, Becton Dickinson
- **Dr Dhesi Raja** — Board of Directors, Malaysia Digital Economy Corporation (MDEC)
- **Dr Jonathan Tan** — Head of Disruptive Access, APAC & Middle East, Novartis

Following the fireside chat, the participants came together to discuss the next steps to take to advance data sharing in their organisations and settings. They also collectively brainstormed about how they could address some of the impediments to data sharing that were raised during the fireside chat.



Some of the key findings and topics discussed during the event are summarised below.

### **Building Blocks of Data Sharing**

There is a need for better frameworks around data sharing and innovation. This would enable better solutions for sharing and data design protocols. The framework should consider stakeholder engagement, data tiering, data privacy measures and data standards to use. Setting common and unanimous goals for the short and long term is also an essential and initial aspect of the framework that needs to be decided upon before data sharing commences. At the outset of operationalising the data sharing ecosystem, it is helpful to start small, collaborate with natural partners first, rally around shared interests and focus on getting some small initial successes. As the ecosystem expands, it is important to identify the right use cases from other countries for Singapore to learn from and customise.

### **Barriers to Data Sharing**

While there are several reasons why data sharing is not taking place on a large scale, the main barriers discussed revolved around the lack of political will and concerns over data privacy.

Participants shared that policymakers need to come together and mutually scope the data sharing system. They need to clearly define the stakeholders involved (data generators, data users, data regulators, IT providers etc) in the ecosystem and their roles. Policymakers should also be upfront about who will bear the costs and where the benefits will accrue.



In terms of data privacy, the most appropriate technology (e.g. blockchain, homomorphic encryption etc) needs to be identified and enforced to minimise cybersecurity breaches. Data classification and risk-tiering of data are also important to determine the extent to which regulatory and technical safeguards are required. While the technology may already exist for this, there could be substantial challenges in terms of implementation and execution.

### **Data Sharing to Improve Health Equity**

In the Asia Pacific region, there exist significant disparities among countries in terms of governance, ethics and data infrastructure (security, confidentiality and interoperability). It is important to keep in mind this differential capability among countries in ASEAN when creating regional frameworks. Data sharing in health and healthcare should not exacerbate existing health inequities but rather be used as a means to improve equity.

Similarly, the capabilities of countries to share, analyse and harness the value of data also vary significantly. It appears that most of the benefits of data sharing tend to accrue in well-resourced settings where people are able to use the data that is shared to generate insights and take action. Resource-poor countries may not always be able to harness the value of shared data – even if they participate in the data sharing endeavour – as they may not have the resources to tap into the new insights or carry out interventions based on the new insights. The global community should think about what steps need to be taken to ensure the playing field is fair and equitable for all countries.

### **Establishing Trust**

Building trust among all stakeholders in the data sharing ecosystem is foundational to the ecosystem's success. Fostering trust can be challenging since it is extremely difficult and time-consuming to build but can be easily fractured. The government can play a crucial role in establishing trust among the public by being transparent and clearly communicating how data will be used, stored and dealt with in the event of a breach. Those in charge of the data sharing ecosystem should also be explicit about who owns the data – the growing consensus seems to indicate that the data generators should be empowered to share their data. To incentivise data generators to participate in data sharing, it may be helpful to educate them about the benefits of data sharing or better yet, allow them to experience the benefits of shared data, so they associate the process of data sharing with reward and gratification. Finally, all data sharing stakeholders should be consulted at each stage of the data sharing lifecycle to create a trusted, reliable and sustainable ecosystem.



Many important concepts and shared experiences were brought up during the session that added to the richness of the frameworks and themes proposed in the Whitepaper. Participants agreed that the Whitepaper provides a good frame for policymakers and other stakeholders to consider when planning to progress towards trusted and responsible health data sharing in the region.

If you wish to download a copy of the Whitepaper, you may visit the link [here](#).

Stay tuned for more updates on data sharing, digital health, population health and precision medicine at the upcoming Precision Public Health Asia Conference to be held in July 2023.

Note: This event was held under the Chatham House Rule. The facts and ideas described in this report reflect the authors' interpretation of the discussion and should not be directly attributed to any specific speaker.

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