**Prince Mahidol Award Conference (PMAC) 2025**

| **Session:** PS 3.2 "Strengthening Health Data Governance: Leadership and Action"  **Date:** Saturday 1 February 2025 Time 15:00 - 17:00 hrs  **Keynote:** Mathilde Forslund  **Background paper on the topic/presentation (below; slides available** [**here**](https://docs.google.com/presentation/d/1tldYiBuqe5nc-nzJjDv9grm888UFHFn16ezFD0tcn74/edit?usp=sharing)**):** |
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**Strengthening Health Data Governance - Towards a global framework**

***The power of health data - and the need for more robust governance***

Digitalisation and the use of digital tools have become an integral part of health systems and health service delivery. If implemented in an equitable and sustainable way, the digital transformation of health systems offers a huge opportunity to scale up access to primary health care services, strengthen resilient health systems, close equity gaps, and accelerate progress towards UHC goals.

This digitalisation has also exponentially increased the generation of health data, a vital asset that can further enhance healthcare delivery and outcomes. It can help: enable digital transformation and artificial intelligence; advance research and innovation; improve data-driven decision-making; support health care professionals; strengthen equitable and resilient health systems; improve health emergency and pandemic response; and empower individuals to achieve their personal health goals. Ultimately this will help enhance healthcare delivery and outcomes, towards UHC goals.

While this offers a huge opportunity, it doesn’t come without its challenges and risks. Health data needs to be effectively and equitably governed - including through a robust legislative and regulatory environment – to ensure the right protections are in place to safeguard data privacy and rights, and mitigate risks of data misuse; while also supporting responsible data use for public benefit. This is important to build public trust in health data systems; and to fully harness the value of health data as both an individual and public good.

As discussions advance around the opportunities (and regulation) of Artificial Intelligence (AI) for health, data governance must be central to this. Data governance is pivotal to AI governance; and responsible AI in health is unattainable without robust health data governance. This was highlighted by the expert panel during the recent Strategic Roundtable on Artificial Intelligence at the 77th World Health Assembly, as well as in the report of the High-level Advisory Body on Artificial Intelligence, which recommends the creation of a global AI data framework.

***Growing consensus, commitments and political support***

There is a strong case for more robust legislation and regulation to govern the collection and use of health data. There is also growing consensus and wide political and stakeholder support on the issue. During the last two World Health Assemblies, several Ministries of Health have co-hosted and spoke at sessions on health data governance, and expressed strong support for action (including Cameroon, India, Indonesia, Maldives, Philippines, Sri Lanka and the Council of Ministers of Health of Central America).

Many reports, strategies and initiatives also recognise the need for action, including most recently the adoption of the Global Digital Compact at the Summit of the Future during the UN General Assembly, which sets out a commitment from governments on data governance. Moreover, the 2025 G20 Health Ministers’ declaration recognises “the importance of building robust data protection frameworks” and “the importance of the alignment of legal and regulatory frameworks between countries… ensuring data privacy and personal data protection, and to further explore health data exchange across borders”. These represent critical opportunities to take forward action on this important issue.

***Towards more robust health data governance and a global framework***

It is against this backdrop that Transform Health and many other partners are calling for a global (and regional) health data governance framework to be developed and endorsed by governments, as a step towards more robust and equitable national legislation and regulation - to maximise the public value of health data whilst protecting individual rights.

Towards this end, and among other global, regional and national initiatives, Transform Health and partners have been supporting efforts to improve health data governance, including:

* Stewarding the development of equity and rights-based principles
* Supporting the development of a model law on health data governance.
* Raising public and political awareness and galvanising action on the issue, health data governance Working with community-based organisations through the My Data Our Health campaign.
* Engaging with governments to build support for the development and endorsement of a global (and regional) health data governance framework through a World Health Assembly resolution and regional processes.

We see a global health data governance framework as a key step towards more robust national legislation and regulations by:

* Building country consensus and commitment around a global standard for health data governance and essential areas that should be addressed through national legislation - *based on countries experiences and good practice*.
* Establishing a level of compatibility in national approaches to foster greater legal coherence across jurisdictions, which is important for cross-border data sharing;
* Providing a blueprint and flexible framework that governments can use as a resource to strengthen national approaches.

***Equity and rights-based health data governance principles***

The Health Data Governance Principles were launched in April 2022 and have been endorsed by more than 170 organisations and governments. They aim to align policymakers and other stakeholders around a shared vision of equitable health data governance, where all people and communities can share, use and benefit from health data. The eight principles are clustered around objectives of: Protecting people; promoting health values; and prioritising equity.

They were developed through a participatory and inclusive multistakeholder process, designed to gather perspectives and expertise, and to ensure meaningful engagement of diverse stakeholders from across geographies and sectors. This brought together over 200 contributors from more than 130 organisations, including governments, international organisations, civil society, private sector, and youth, among others. We encourage governments and other organisations to endorse the Principles and for them to be integrated across policies and programmes.

***A model law on health data governance***

Transform Health, AeHIN, and other national, regional and global partners - including Africa CDC, the Health Data Collaborative, OECD, HELINA, RECAINSA, and Young Experts Tech for Health - have been supporting the development of a model law on health data governance, as a tool for governments, and a step towards a regional and global framework.

A team of legal experts have been engaged to support the drafting of the model law, together with the oversight of an expert advisory group, and review from the Africa CDC Flagship Initiative working group and other regional and global partners. It has been informed by equity and rights-based health data governance principles and a review of national, regional and international legislative frameworks. It has been developed through a consultative process, engaging nearly 1000 stakeholders from across the globe, including several national consultations hosted by Ministries of Health, many of which across the region.

The draft model law contains core elements, guidance and reference legal text to support more effective and equitable health data governance. It provides a blueprint and flexible framework, serving as a resource to assist countries with their efforts to strengthen national laws and frameworks dealing with health data governance. It is not meant to be prescriptive or imposing, but rather can be adapted to suit the legal systems of different countries. It seeks to foster a harmonised approach to health data governance, while respecting the diverse legal, cultural, and societal landscapes of different nations. As such, different parts of the model law can be inserted into different existing laws within a country, or support the development of new laws. It does not need to be implemented as a single health data governance law.

It aims to strike a delicate balance between the protection of personal and community health data and the facilitation of its use for greater public benefit. It facilitates the use of health data as a force for good, driving improvements in healthcare, research, and public health policies, while ensuring that progress in health data use is anchored in principles of equity, justice, and respect for human rights.

It addresses challenges and opportunities presented by emerging technologies, ensuring that innovation in health data use does not come at the expense of fundamental human rights.

***Government leadership and action***

Government leadership is critical to move towards a global and regional framework for the governance of health data, and more robust national legislation and regulation, while ensuring diverse stakeholders, including civil society, remain meaningfully engaged. We encourage governments and other stakeholders to prioritise this at upcoming moments, in order to advance discussions and turn recent commitments into action.

In particular, we encourage governments to: ensure health data governance is on the agenda of the WHO Executive Board meeting (Jan 2025), looking towards the World Health Assembly (May 2025); champion the development of a regional / global framework (informed by the model law); endorse the health data governance principles as a foundation for stronger legislation/regulation and a regional / global framework; champion health data governance as part of other regional and national gatherings; consider how provisions from the model law can be adopted into existing national legislation, to ensure health specific data is protected.