PS 3.2

STRENGTHENING HEALTH DATA GOVERNANCE: LEADERSHIP AND ACTION

| BACKGROUND

To fully harness the potential of health data for public benefit and improved health outcomes, while also managing risks, protecting individual rights, and ensuring people's data is protected from misuse, it is important to strengthen the governance of health data through more robust, effective and equitable legislation and regulation. While several countries and regions are taking steps to address this, approaches vary. By countries and other stakeholders coming together, this provides an opportunity to build on experiences and good practices, and establish a level of consensus around the essential elements that should be addressed through national legislation and regulation. There has been growing recognition of the need to strengthen health data governance approaches and increasing political will for action, with several governments exhibiting their leadership to drive this forward.

In support of this, Transform Health and partners, including AeHIN, HELINA, RECAINSA, OECD and Africa CDC, have been supporting the development of a draft model law on health data governance, articulating core elements, legislative guidance and reference legal text. The model law is underpinned by equity and rights-based principles (endorsed by more than 150 organisations and governments), and draws inspiration from the national legislative and regulatory landscape reviews of more than 30 countries, the OECD Recommendation on Health Data Governance (adhered to by 38 OECD member countries), among other national, regional and international instruments, commitments and best practice. It has been developed through a bottom up, consultative process, engaging nearly 1000 stakeholders from across the globe. This has included seven regional multi-stakeholder consultations (convened by AeHIN, HELINA and RECAINSA) engaging 500+ stakeholders from 65+ countries to inform an initial draft and a public consultation period on the draft, which included 16 national, regional and youth consultations, a widely disseminated survey and expert interviews to gather feedback.

The model law serves as a starting point to build consensus around core areas that should be addressed through national frameworks, while providing a blueprint and resource for a global framework and much needed data sharing agreements.

| OBJECTIVES

With the model law on health data governance as a starting point for discussion amongst governments and stakeholders in the Asia-Pacific region, contrasting with other regions including the EU and the AU, we see this session as having the following objectives:

- Help build consensus around core elements for health data governance legislation.

- Build political support for the endorsement of a global health data governance framework (containing a model law), looking ahead towards the WHO Executive Board meeting in January 2025 and the 78th World Health Assembly in May and ensuring health data governance is on the agenda.

- Discuss how a global framework, and the model law, can support countries in strengthening national health data governance approaches.

- Explore private sector perspectives on data governance (and a model law) in the age of digital advancements, including AI.

- Hear community perspectives and voices around health data governance for public benefit and expectations of governments and other actors.

Moderator

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Eric is a Senior Health Economist leading the OECD's work in Digitalisation of Health, bringing together policy guidance for digital tools, integrated data, and responsible analytics including artificial intelligence. In that role, he is accountable for measuring and evolving the OECD's Recommendation on Health Data Governance (2016) and supporting digitalisation of health policy that provides data protection (e.g. security and privacy) and timely access to quality data to optimize the use of data for information, insights, and impact among individuals, health workers, policy makers, researchers, and innovators. Eric's work has led to publications on the use of Artificial Intelligence in Health, the state of Digital Security in Health across the OECD, and a thematic chapter on digital health in the OECD's flagship Health-at-a-Glance 2023 report. Eric comes to the OECD by way of Canada where he led work associated with the Pan-Canadian Health Data Strategy and Health Data and Information Governance Framework and Toolkit.