Transform Health

Strengthening Health Data Governance:

Leadership & Action

Session during

PMAC | PRINCE MAHIDOL AWARD CONFERENCE 2025

Sub-Theme 3: Governance, Policy and Stewardship

Harnessing Technologies in an Age of AI to Build A Healthier World

1 February 2025 | 15:00-17:00 ICT

World Ballroom C, FL. 23, Centara Grand & Bangkok Convention Centre at CentralWorld in Bangkok

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Opening remarks

ERIC SUTHERLAND

Senior Health Economist, OECD

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Setting the scene

MATHILDE FORSLUND

Executive Director, Transform Health

Strengthening Health Data Governance: Leadership & Action

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

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- Support digital transformation and artificial intelligence
- Advance research and innovation
- Improve data-driven decision-making
- Support health professionals
- Strengthen equitable and resilient health systems
- Improve health emergency and pandemic response
- Empower individuals

Enhance health outcomes and UHC

Consensus, commitments and political support

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Towards more robust health data governance

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A global and regional
Health Data Governance Framework

BUILDING COUNTRY CONSENSUS AND COMMITMENT

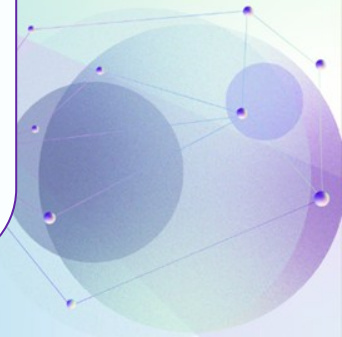
A global standard for health data governance and essential areas that should be addressed through national legislation - *based on countries experiences and good practice*.

ESTABLISHING COMPATIBILITY IN NATIONAL APPROACHES

Establishing a level of compatibility in national approaches to foster greater legal coherence across jurisdictions, which is important for cross-border data sharing.

A RESOURCES TO SUPPORT NATIONAL EFFORTS

Providing a blueprint and flexible framework that governments can use as a resource to strengthen national approaches.



Strengthening health data governance in the digital age

Health Data Governance

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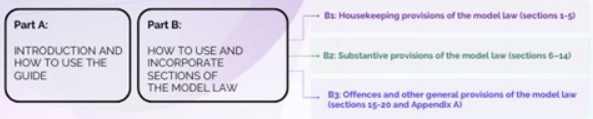
Resources and tools to advocate for and support more robust health data governance

Model Law

A blueprint for strengthening national legislation

+

Implementation Guide



National legislative and regulatory assessment tool

Equity and rights based Principles

National health data governance landscape reports

healthdatagovernance.org

#HealthDataGovernance #ModelHDGLaw

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Developing the Model Law on Health Data Governance

Informing the draft

500+
Stakeholders consulted

Health Data Governance *Principles*
Health Data Governance principles

65+
Countries engaged

30+
National legislative landscape reviews and reviews of national, regional and international instruments and best practices

Developing the draft

Drafting led by team of legal experts

Oversight and review by expert advisory group, Africa CDC Flagship Initiative, Transform Health's Policy circle and health data governance working group

Public consultation

550+
Stakeholders consulted

35+
Countries engaged

14
National and regional consultations

Youth consultation

Expert interviews

Transform Health's Community Forum

Aims and overview of the Model Law

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healthdatagovernance.org/modellaw

- Contains core elements, legislative guidance and reference legal text
- Blueprint and flexible framework - not prescriptive or imposing
- Strikes balance between protection of personal and community health data & facilitation of its use for public benefit
- Facilitates data use as a force for good
- Principles of equity, justice, and respect for human rights
- Addresses challenges/opportunities of emerging technologies
- Harmonised approach while respecting diverse legal, cultural, and societal contexts
- Assumes existence of a national data protection law

Government leadership and action

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We encourage governments to

Take Action on Health Data Governance

CHAMPION THE DEVELOPMENT OF A GLOBAL & REGIONAL FRAMEWORK

Prioritise health data governance on the World Health Assembly and regional agendas, calling for the development of a global/ regional framework.

PRIORITISE HEALTH DATA GOVERNANCE ON REGIONAL AND GLOBAL AGENDAS

Ensure health data governance prioritised as part of national, regional and global meetings and processes, to advance discussions and action.

ENDORSE THE HEALTH DATA GOVERNANCE PRINCIPLES

Endorse the equity and rights-based principles as a foundation for stronger national legislation and regulation and a global/ regional framework.

STRENGTHEN NATIONAL DATA GOVERNANCE FRAMEWORKS

Take steps to strengthen national health data governance legislation and regulation (the Model Law is a blueprint to support this).

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Thank you!

#HealthDataGovernance

#ModelHDGLaw

Panel discussion

ERIC SUTHERLAND

OECD [MODERATOR]

FAZILAH SHAIK ALLAUDIN

Ministry of Health, Malaysia

DR. PARK KIDONG

WHO Western Pacific Regional Office

SHELANI PALIHAWADANA

YET4H

NIRMAL RIJAL

Independent Consultant

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Closing Summary

ERIC SUTHERLAND

Senior Health Economist, OECD

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