



Experience of Tanzania in Implementing Health Data Governance

Sosthenes Bagumhe

TAHIA President & HELINA General Secretary

Context: Digital Health Transformation

- Rapid growth of EHRs, DHIS2, telemedicine and AI
- Health data now central to planning, research & UHC
- Increased risks: privacy, misuse, inequity, weak accountability



Why do we need improved governance of health data?

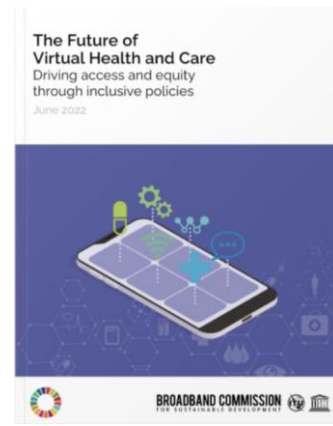
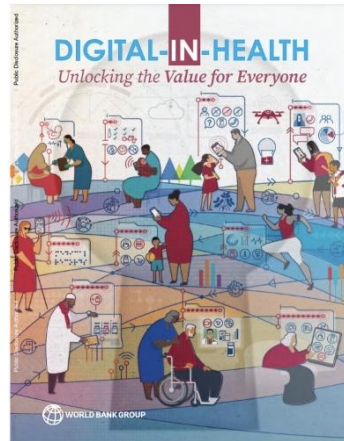


- To address issues of data privacy, ownership, sharing, and access
- To maximise public benefit of health (and health related) data, whilst managing risks and safeguarding individual rights

Improved governance of health data will:

- Reduce fragmentation, duplicative systems and wastage → increased efficiency and performance of public health investments
- Improve evidence-based decision making → stronger and more equitable health systems
- Strengthen health emergency response
- Advance research and innovation
- Help achieve UHC and SDG goals
- Build public trust → critical to fostering data use for public good!

Growing consensus on the need to strengthen **health data governance**



Why Health Data Governance Matters

- Protect rights and privacy
- Enable responsible data use for public benefit
- Build trust in digital health systems
- Support innovation, research, and UHC outcomes

Growing political and stakeholder support



Towards a global health data governance framework

Side event during the 76th World Health Assembly

24 May 2023 | Wed | 18:00 CET

Intercontinental Hotel, Geneva

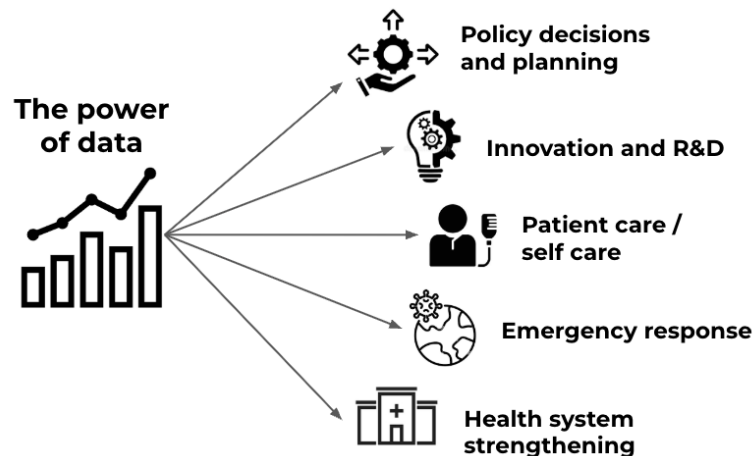
Supporting Organisations:



150+
organisations call for action on health data governance at the WHA76

A graphic featuring the number "150+" in large green font, followed by the text "organisations call for action on health data governance at the WHA76" in white text on a green background. To the right is a 3D illustration of a staircase with people climbing, symbolizing progress and action.

Harnessing data through robust governance



Urgent need for action

- AI changing the game
- Governance / Accountability gap
- Risks of inaction



Strong national legal and regulatory frameworks - clear rules around the collection and use of health data, balancing protection and ethical use - fit for the digital age and AI.



Health-specific legislation - responding to needs and elevated risks associated with sensitive health data.



Regional and global cooperation - consensus on essential legislative considerations; blueprint to strengthen national approaches; compatibility to foster legal coherence; cross-border data sharing.

Engaging, convening, collaborating to galvanise action



ENGAGING DECISION MAKERS

Building political support and action

Supporting more robust national legislation

Urging and supporting progress towards global and regional frameworks (*through the World Health Assembly and regional mechanisms*)



CONVENING DISCUSSIONS

Building consensus and action during key events:

- World Health Assembly, UNGA, Africa HealthTech Summit, Global Digital Health Forum, AU Summit



STRENGTHENING COLLABORATION

WHO, Health Data Collaborative, Africa CDC, AUDA-NEPAD, OECD, AeHIN, HELINA, etc.



REGIONAL ENGAGEMENT

Africa CDC - Continental Framework
WHO WPRO - Regional guidance.



#MyDataOurHealth

Campaign engaging communities, politicians and media to raise public and political awareness

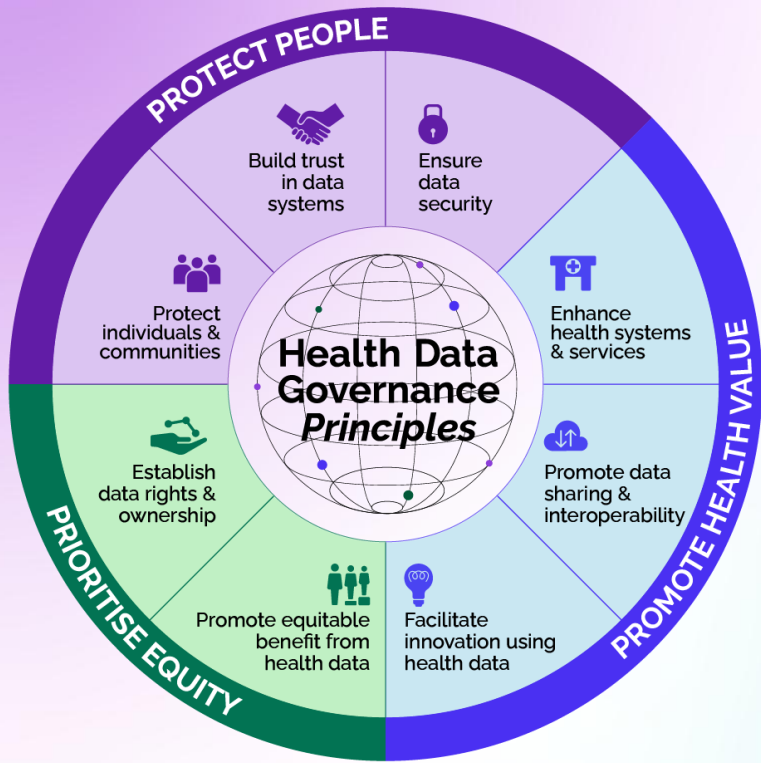
Action at the World Health Assembly (18-23 May) - Agenda 12.10

We encourage Member States to:

- A. Support a **WHA resolution on health data governance**, ensuring it includes commitments on a **global standard that harmonises essential legislative provisions and protocols for responsible cross-border data sharing**.
- B. Commit to strengthening **national health data legislation** and regulation.
- C. Ensure national and global health data governance frameworks are grounded in **equity and rights-based principles and developed through an inclusive process**.
- D. Establish **reporting and accountability mechanisms** to track progress on commitments (through the World Health Assembly and the next Global Digital Health Strategy).
- E. **Support an official Member State side event** on health data governance.

Transform Health Support to Tanzania

- Technical support using HDG Principles and Model Law
- Legislative landscape assessment
- Multi-stakeholder consultations
- Development of a national HDG roadmap






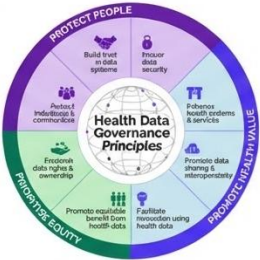



healthdataprinciples.org

150+ endorsers

| | | | | |
|--|---|---|---|---|
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |

Resources and tools to strengthen frameworks

| | |
|--|--|
|  <h3>National legislative and regulatory assessment tool</h3>  |  <h3>National health data governance landscape reports</h3>  |
|  <h3>Equity and rights based Principles</h3> <p>175+ endorsers</p>  |  <h3>Legislative Blueprint + Implementation Guide</h3> <p>A blueprint for strengthening national legislation</p> <div style="display: flex; justify-content: space-around;"> <div data-bbox="946 963 1072 1063"> <p>Part A: INTRODUCTION AND HOW TO USE THE GUIDE</p> </div> <div data-bbox="1072 963 1226 1063"> <p>Part B: HOW TO USE AND INCORPORATE SECTIONS OF THE MODEL LAW</p> </div> </div> <p>1000+ stakeholders engaged</p> |



healthdatagovernance.org

Approach & Process

- Landscape review of laws and policies
- Benchmarking against global & regional frameworks
- National stakeholder workshops (Oct & Dec 2025)
- Validation of HDG Roadmap (2025–2028)



Building consensus on **minimum standards** for health data governance regulation



- Agreement between countries around minimum standards / considerations
- Political commitment, alignment and consensus
- Guiding resources / benchmark for countries to strengthen regulation
- Improved harmonisation for data sharing across countries
- Focus on the regulatory environment to hold all actors accountable nationally
- Foundation for improved public trust in health data systems

Existing Legal Framework

- Constitution (Right to Privacy)
- Personal Data Protection Act (2022)
- Public Health Act, Cyber laws
- Digital Health Strategy & HIS Guidelines

Supporting national efforts

Working with governments and stakeholders to **strengthen national health data governance legislative and regulatory frameworks** through the development and implementation of actionable roadmaps. Process is supported through our technical support approach and tools.



Engaging stakeholders

Engaging the government and key stakeholders to build buy-in and ownership from the outset, and to ensure an inclusive multi-stakeholder process.



Reviewing laws & regulations

Reviewing current national laws and regulations related to health data governance

Tools: Legislative Assessment Tool; Health data governance Principles



Assessing gaps & mapping needs

Assessing gaps in national legislation and regulations, identifying areas to be strengthened (through existing or new laws) and mapping what is needed for this.

Tools: Model law (Blueprint) and implementation guide



Convening national workshop(s)

Convening national stakeholders through workshops to validate gaps and needs and align on a way forward to strengthen the national framework.



Developing a national roadmap

Developing a national roadmap outlining actions, roles, timelines, resources, and structures needed to update or develop health data governance laws and regulations.



Implementing the roadmap

Drafting and enacting new or updated laws and regulations. Implementing structures and allocating resources to support this.

**Countries so far: Cameroon, Côte d'Ivoire, Malawi, Rwanda, Senegal, Tanzania, Uganda, Zambia; Mongolia, Nepal and Vietnam; Ecuador and Mexico.*

Key Strengths

- Existence of PDPA and regulator (PDPC)
- Strong digital health investments
- Political commitment to interoperability
- Growing multi-sectoral engagement

Key Gaps Identified

- No health-specific data governance regulations
- Fragmented institutional mandates
- Weak consent and rights frameworks
- Limited enforcement capacity

Emerging Risks

- AI, genomics, and advanced analytics unregulated
- Cross-border data sharing unclear
- Risk of data misuse and inequity
- Innovation outpacing governance

A Rare Moment of Alignment

- Government, regulators, CSOs, researchers aligned
- Shared understanding of HDG principles
- Validated national roadmap
- Strong foundation for reform

The HDG Roadmap (2025–2028)

- Policy & regulatory development
- Institutional coordination
- Standards & interoperability
- Capacity building
- Resource mobilisation
- Monitoring & accountability

Priority Reform Actions

- Develop health-specific regulations under PDPA
- Establish national HDG coordination mechanism
- Strengthen consent, rights & accountability
- Regulate AI, genomics & cross-border data

Key Lessons Learned

- General data protection is not enough
- Governance must be coordinated
- Trust is essential for digital health
- Governance enables innovation

Strategic Opportunity

- Translate roadmap into implementation
- Leverage Transform Health support
- Align with global & African frameworks
- Position Tanzania as regional leader

Call to Action

- Political commitment and financing required
- Operationalise the roadmap urgently
- Strengthen institutions and coordination
- Ensure equitable and rights-based data governance

Government leadership to drive this agenda



- Prioritise health data governance and support the development of a set of minimum standards
- Support consultations around their development (including a Member State consultation)
- Sponsor a resolution on a the minimum standards at the World Health Assembly
- Prioritise this at the AU Summit, including the endorsement of an African Common Position

Closing Message

- Health data governance is not a barrier
- It is the foundation for trust, innovation and UHC
- Tanzania is ready for implementation



transformhealthcoalition.org/



@Transform Health



@trans4m_health



@transformhealth.bsky.social



**Transform
Health**

HEALTH FOR ALL IN THE DIGITAL AGE



Thank you !