Universalising the benefits of health digitalisation

PROTECT PEOPLE | PROMOTE HEALTH VALUE | PRIORITISE EQUITY
Introduction

The Health Data Governance Principles bring a human rights and equity lens to the use of data within and across health systems. They are oriented towards supporting sustainable and resilient public health systems that can deliver Universal Health Coverage (UHC).

The Principles have been developed to strengthen national and regional health data governance approaches so that the public value of health data can be maximised whilst protecting individual rights. By incorporating the Principles into data governance frameworks, instruments, treaties, regulations, standards and guidance, policymakers and other stakeholders can align around a shared vision where all people and communities are able to share, use and benefit from health data.

The 8 Principles

The Health Data Governance Principles are clustered around three overarching objectives: protect people, promote health value and prioritise equity. The Principles are designed to complement and reinforce one another. They are not weighted or listed in any order of priority. Each Principle has core elements that describe how it can be put into practice.
Health Data Governance Principles

- Protect individuals & communities
- Establish data rights & ownership
- Build trust in data systems
- Ensure data security
- Promote equitable benefit from health data
- Facilitate innovation using health data
- Enhance health systems & services
- Promote data sharing & interoperability

PROMOTE HEALTH VALUE

PROTECT PEOPLE

PRIORITISE EQUITY

PROMOTE HEALTH VALUE
Protect People
as individuals, as groups, and as communities
Address individual and collective risk
Collect data with a defined purposes
Collect personal or sensitive data only when necessary and with informed consent
Use secure data collection and storage mechanisms
Use de-identification and anonymization
Define inappropriate uses of health data
Institute safeguards against discrimination, stigma, harassment and bias
Provide guidance specific to marginalised groups and populations

Core Elements:

Health data governance must protect individuals, groups and communities against harm and violations at every stage of the data lifecycle. It should balance protection and rights with the societal value of data use for health.
Health data governance should reinforce trust in data systems and practices.

Core Elements:

- Align with best practices for data protection and privacy
- Ensure consent is informed and understood in all its complexities
- Obtain collective consent where appropriate
- Define concrete exceptions to informed consent
- Ensure data quality, availability, and accessibility
- Reinforce health data governance with evidence
- Establish transparent and accessible processes and systems
- Institute feedback and accountability mechanisms
PROTECT PEOPLE
ENSURE DATA SECURITY

Processes for collecting, processing, storing, using, sharing and disposing data should all employ robust security mechanisms.

Core Elements:
- Require strong technical security measures for data processing
- Mitigate risks related to security threats
- Ensure transparency around data breaches
- Consider federated data systems
PROMOTE HEALTH VALUE

through data sharing and innovation
Evaluate the benefits of health data
Use data to enhance health services for individuals and communities
Encourage a culture of data-led insights and action
Address health system efficiency, effectiveness, and resilience
Strengthen community ownership of health data
Enable and empower frontline health workers

Health data governance should enhance health system efficiency and resilience, improve health access, and advance health equity towards UHC.

Core Elements:
Data collection and sharing is a prerequisite for creating value from health data but must be done in ways that support equity and human rights.

Core Elements:
- Establish data sharing rules and guidelines
- Validate informed consent before sharing data
- Promote interoperability of data systems
- Define common data structures across health systems
- Define multiple levels of data access
- Use common definitions and global standards
- Support multi-sector partnerships
Governance approaches must enable innovation and flexibly accommodate new technologies and uses of data.

Core Elements:

- Apply health data governance to emerging technologies
- Address the use of non-health data in health contexts
- Build public health data infrastructure
- Employ policy innovation
PRIORITISE EQUITY

by ensuring equitable distribution of benefits that arise from the use of data in health systems
Equity in health data governance must ensure equitable representation in data of all individuals, groups and communities; extend to include meaningful participation of all groups in decision-making; and equitable access to data-generated health value about health data systems.

**Core Elements:**

- Represent all groups and populations equitably in data
- Consider the unique needs of marginalised groups and populations
- Mitigate data bias
- Use accessible language and plug knowledge gaps
- Implement inclusive data feedback mechanisms
- Promote equitable impact and benefit
Health data governance should be rooted in strong and clear data-related rights.

**Core Elements:**
- Apply a human rights lens to health data governance
- Define clear governance roles and responsibilities
- Codify data rights and ownership
- Extend data rights and ownership to products and services
- Develop health data trusts and health data cooperatives
- Employ participatory data governance mechanisms
- Connect to broader accountability mechanisms