



HEALTH DATA GOVERNANCE PRINCIPLES

Universalising the benefits
of health digitalisation

PROTECT PEOPLE | PROMOTE HEALTH VALUE | PRIORITISE EQUITY

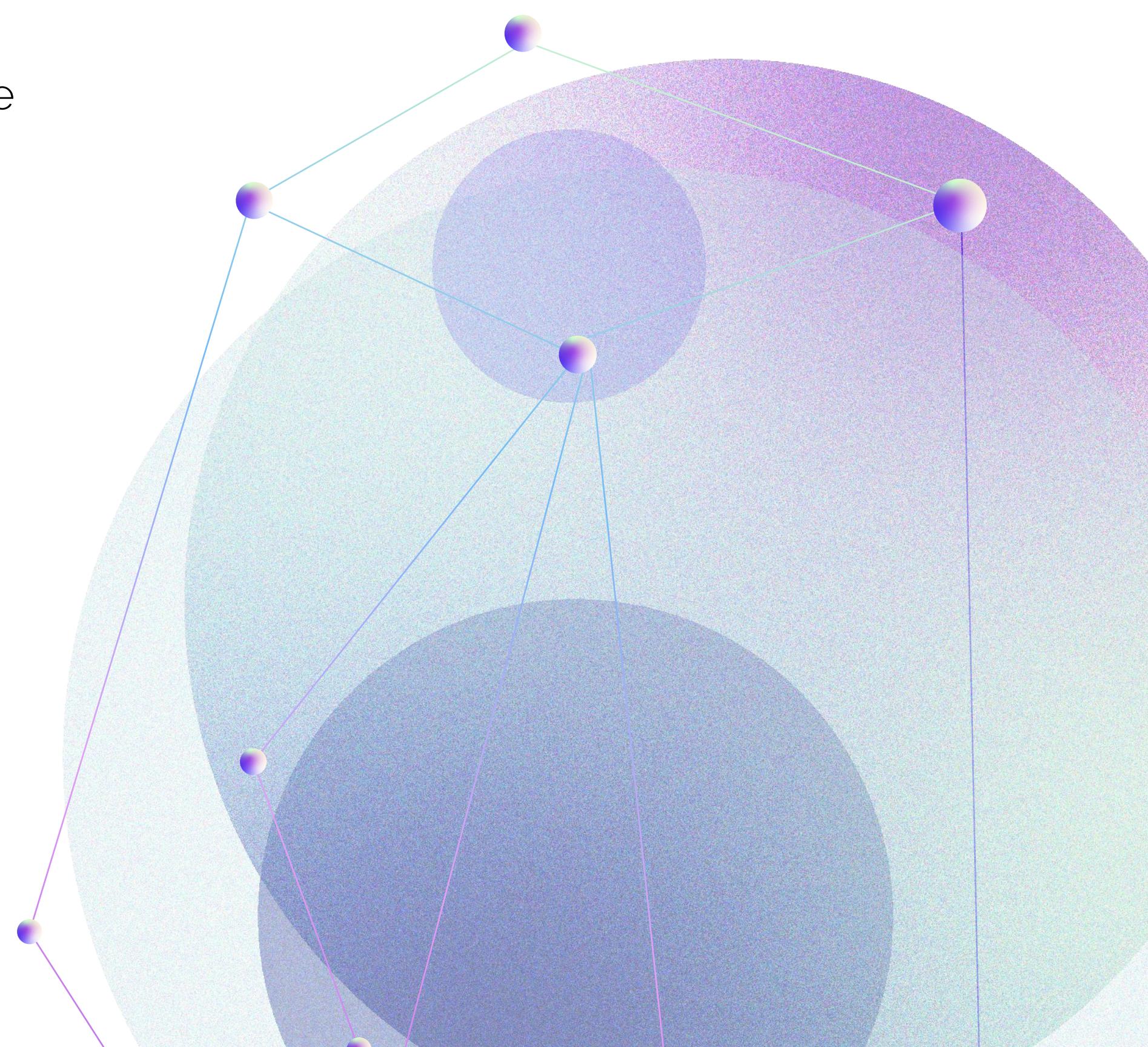
Introduction

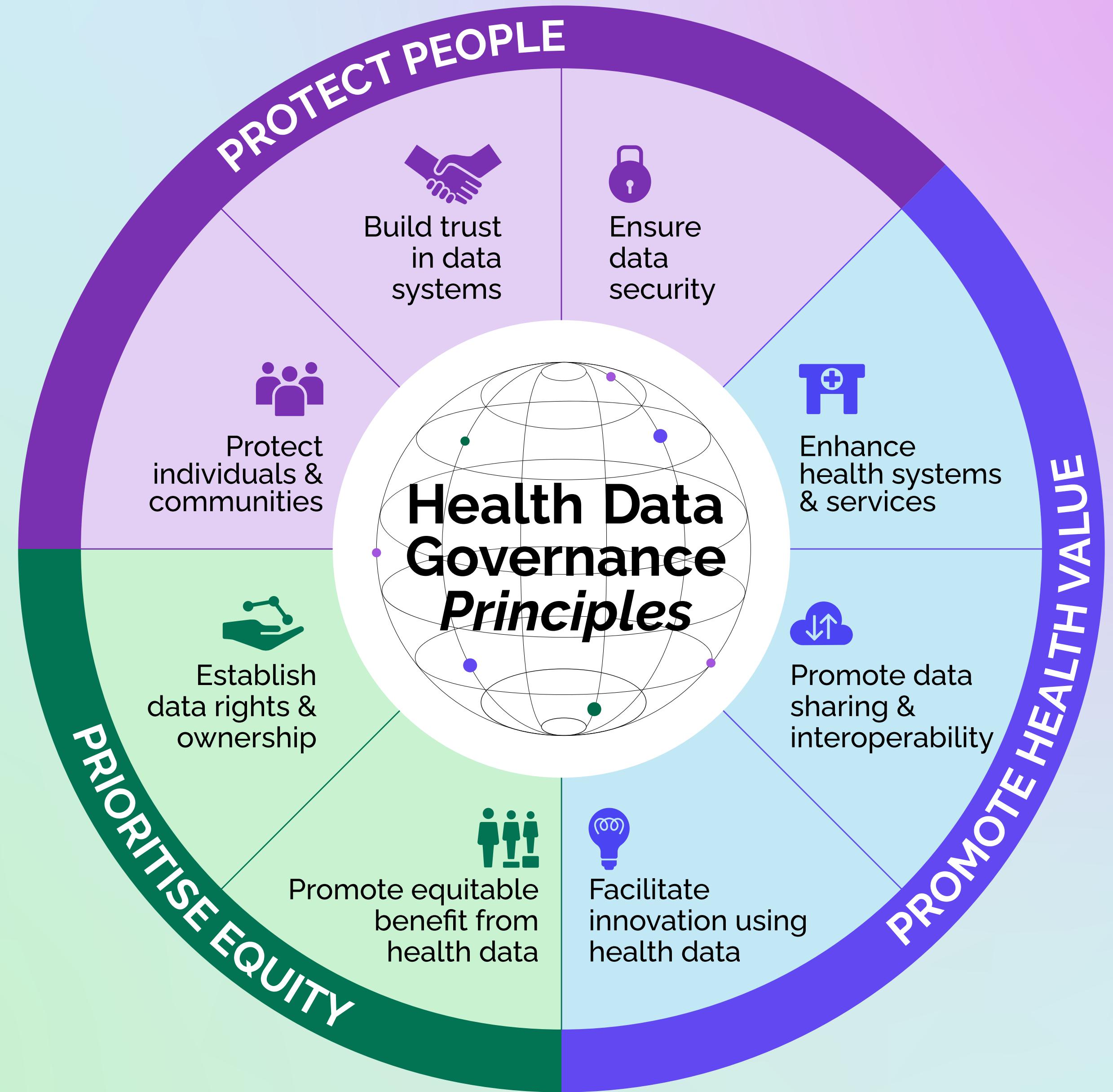
The Health Data Governance Principles bring a human rights and equity lens to the use of data within and across health systems. They are oriented towards supporting sustainable and resilient public health systems that can deliver Universal Health Coverage (UHC).

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.





Protect People

as individuals, as groups, and as communities



PROTECT PEOPLE PROTECT INDIVIDUALS AND COMMUNITIES

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.

Core Elements:

- 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





PROTECT PEOPLE

BUILD TRUST IN DATA SYSTEMS



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



ENHANCE HEALTH SYSTEMS AND SERVICES

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

Core Elements:

- 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





PROMOTE HEALTH VALUE

PROMOTE DATA SHARING AND INTEROPERABILITY

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





PROMOTE HEALTH VALUE

FACILITATE INNOVATION USING HEALTH DATA

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



PROMOTE EQUITABLE BENEFITS FROM HEALTH DATA

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



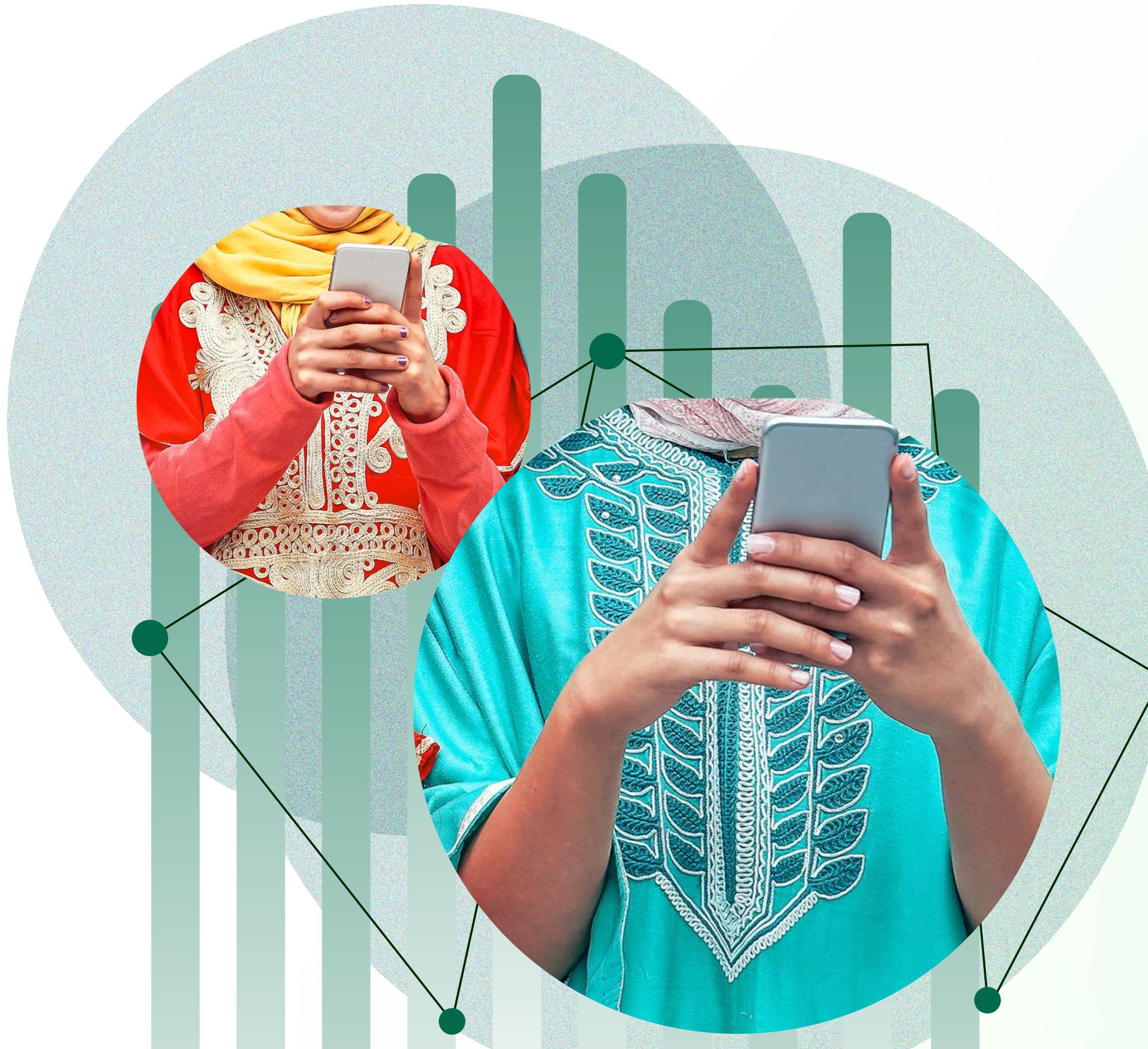


ESTABLISH DATA RIGHTS & OWNERSHIP

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





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