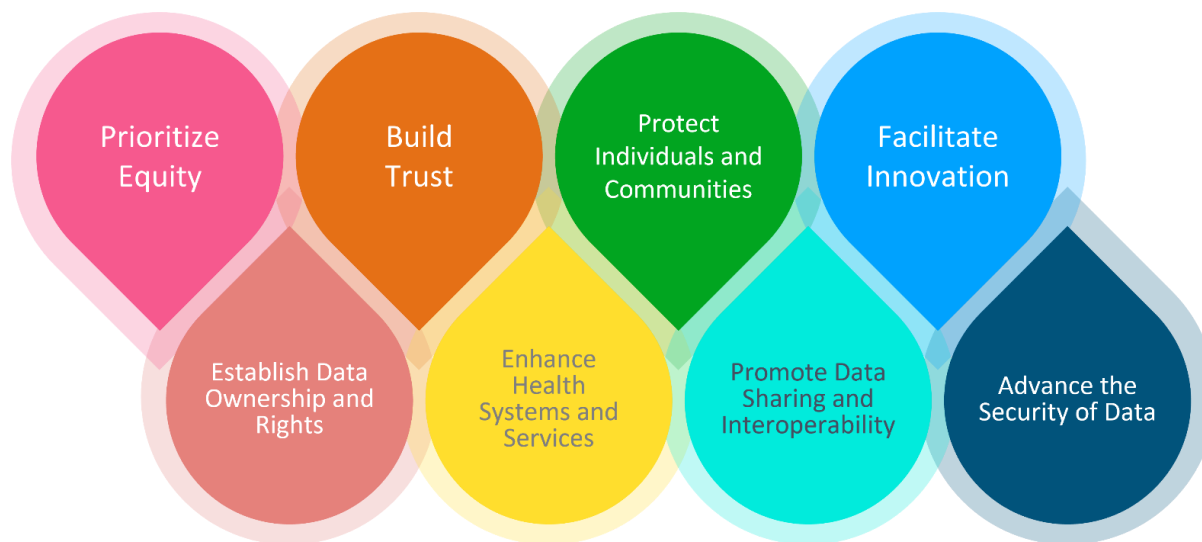# Developing Principles for Health Data Governance

Transform Health, together with partners, is stewarding the development of representative and human rights-based Health Data Governance Principles to inform, strengthen, and unify governance approaches across countries and regions. The Principles are designed to be an initial step and contribution towards the development of a global framework for health data governance, which would support the use of digital technologies and data for global public good.

Developed and driven by civil society, the Principles seek to align stakeholders around core tenets of data governance to create an environment where all people and communities can share, use, and benefit from health data. This includes governments, private sector, international organizations, research and academic institutions, foundations, civil society and global multi-stakeholder coalitions.

The draft Principles have been developed through an inclusive and consultative process with over 150 thought leaders, to gather perspectives and expertise from across geographies, sectors and stakeholders. At the end of October, Transform Health will launch an open, public consultation on the draft Principles, which will run until the end of Global Digital Health Week in early December. This will enable the principles to be refined, supported, and endorsed by an even wider audience.

Draft Health Data Governance Principles – complementary and reinforcing principles to guide behaviours, actions and policies

Principles	Core Tenets
Prioritize equity	• Represent all populations • Conder the unique needs of marginalised populations • Reduce and mitigate bias • Implement inclusive data feedback loops • Use accessible language and address knowledge gaps • Promote equitable impact
Build trust	• Align with data protection and privacy best practices • Prioritize transparent processes and systems

	• Require informed consent • Articulate the complexities of informed consent • Define concrete exceptions to informed consent requirements • Reinforce health data governance with evidence • Improve data quality, availability, and accessibility • Institute feedback and accountability mechanisms
Protect individuals and communities	• Collect data that are purpose-driven • Limit the collection of personally identifiable or sensitive data • Use secure data collection and storage mechanisms • Reduce individual risk • Define inappropriate uses of health data • Use de-identification and anonymization • Follow guidance specific to marginalized populations
Facilitate innovation	• Define common data structures across health systems • Address non-health data that may support public health equity • Support policy innovation • Apply health data governance to emerging technologies
Establish data ownership and rights	• Apply a human rights lens to health data governance • Codify data ownership and rights • Define clear roles and responsibilities • Connect to broader accountability mechanisms
Enhance health systems and services	• Elevate the benefits of health data • Enhance health services for individuals and communities • Consider all types of health benefits • Encourage data-led insights and action • Engage the general public around health impact • Reinforce health system resilience
Promote data sharing and interoperability	• Promote the interoperability of data systems • Establish data sharing policies • Support multi-sector partnerships • Validate informed consent before sharing data • Use common definitions • Use global data standards and coding • Define multiple levels of access to the data
Advance the security of data	• Require strong security measures for data collection, storage, and use technologies • Mitigate risks related to security breaches • Ensure transparency around data breaches

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