

Health Data Governance Principles:

User Guide

ABOUT

The Health Data Governance Principles were developed for governments, technology companies and other stakeholders involved in the collection and use of health data at national, regional and global levels. To have a positive impact on the future governance of health data, the Principles should ultimately be incorporated into national standards and legislation and to organisational policies related to health data. They should also be used to inform the development of health data governance frameworks and guidance, and can be used as an advocacy and accountability tool.

Below are just some examples of the ways that different stakeholder groups can use the Health Data Governance Principles to support the improved and equitable governance of health data.

STAKEHOLDERS



Governments

Publicly endorse the equity and human rights-based Health Data Governance Principles to guide the collection and use of data, at national, regional and international levels.

Update (or develop) national and sub-national legislation, regulation, policy frameworks and practices on data governance to incorporate the Health Data Governance Principles.

Call on WHO to lead the development of a global health data governance framework, which incorporates the Health Data Governance Principles, for Member State adoption at the World Health Assembly.



Communities and civil society organisations

Publicly endorse the equity and human rights-based Health Data Governance Principles to guide the collection and use of data, national, regional and international levels.

Raise public awareness in your community about the Principles and the importance of equitable and rights-based governance of health data so that the public value of health data can be maximised whilst protecting individual rights.

Advocate for your government, technology companies and other stakeholders to endorse the Principles and incorporate them into legislation, regulation and policy frameworks, and to support a global health data governance framework.

Hold governments and other stakeholders accountable for their commitments to health data governance and progress in implementing the Principles.



Youth and youth-led organisations

Publicly endorse the equity and human rights-based Health Data Governance Principles to guide the collection and use of data, at national, regional and international levels.

Raise public awareness in your community about the Principles and the importance of equitable and rights-based governance of health data.

Advocate for your government, technology companies and other stakeholders to endorse the Principles and incorporate them into legislation, regulation and policy frameworks, and to support a global health data governance framework.

Hold governments and other stakeholders accountable for their commitments to health data governance and progress in implementing the Principles.



Research institutes / academia / think tanks

Publicly endorse the equity and human rights-based Health Data Governance Principles to guide the collection and use of data, at national, regional and international levels.

Generate evidence on the positive and negative impacts of different approaches to health data governance, including how the Principles can be applied across different contexts.

Monitor the data collection and use practices of public and private health service providers, government agencies and technology companies to assess whether they are aligned with the Health Data Governance Principles.



Technology companies and the private sector

Publicly endorse the equity and human rights-based Health Data Governance Principles to guide the collection and use of data, at national, regional and international levels.

Update organisational policies and practices on data governance to incorporate the Health Data Governance Principles.



Donors

Publicly endorse the equity and human rights-based Health Data Governance Principles to guide the collection and use of data, at national, regional and international levels.

Update (or develop) policies and practices on data governance—including funding guidance and monitoring and evaluation frameworks—to incorporate the Health Data Governance Principles.

Provide technical and financial assistance to governments wanting to incorporate the Health Data Governance Principles into their data governance policies and practices.

Increase support to communities and civil society, particularly youth and women-led organisations, to advocate for more equitable and rights-based approaches to health data governance and to be able to hold stakeholders accountable.



International organisations and UN agencies

Publicly endorse the equity and human rights-based Health Data Governance Principles to guide the collection and use of data, both nationally and internationally.

Provide technical and financial assistance to governments wanting to incorporate the Health Data Governance Principles into their data governance policies and practices.

Increase support to communities and civil society, particularly youth and women-led organisations, to advocate for more equitable and rights-based approaches to health data governance and to be able to hold stakeholders accountable.

Support the development of a global health data governance framework, to provide a shared vision and guidance for stronger and more equitable governance of health data. Ensure such a framework is underpinned by equity and human rights-based and developed through an inclusive and intergenerational approach, including civil society and youth-led organisations.

Further questions

If you have any questions or would like to get involved, please send us an email at info@transformhealthcoalition.org.