Health Data Governance Principles FAQs:

Data-driven approaches are increasingly the norm or aspiration in the operation of health systems. The collection, processing, storage, analysis, use, sharing and disposal of health data has grown in complexity. This exponential increase in data use necessitates robust and equitable governance of health data. Countries and regions around the world are instituting health data governance policies and legislation. However, there is not yet a comprehensive, global set of principles to guide the governance of health data across public health systems and policies. The Health Data Governance Principles respond to that need.

The Principles are intended as a resource for, and have applicability to, a range of stakeholders involved in the collection and use of health data, including governments, the private sector, international organisations, civil society, among others. We encourage all stakeholders to endorse the Principles.

We want to see the Principles adopted by governments, technology companies, and other institutions responsible for collecting and managing health data.

FAQs

1. Why do we need principles on health data governance?

Digitisation has allowed an exponential increase in the production and use of health data and data for health. This increased availability of timely data offers huge benefits for practitioners, policymakers, and individuals seeking to improve personal and public health. At the same time, weak governance of health data risks exacerbating health inequities, perpetuating bias and discrimination towards marginalised communities, and undermining individual health and human rights.

The need for stronger health data governance has never been greater. A set of globally accepted principles for health data governance that are regionally and sectorally representative is urgently required to redress the uneven distribution of benefits and harms that we currently see arising from the collection, analysis and use of health data. Consensus on high-level principles is an important step towards the creation of a global health data governance framework that could support the use of digital technologies and data for the public good.

2. Who are the Principles for?

The Principles target governments, technology companies, and other stakeholders that collect and use health data. The Principles should ultimately be applied in the domestication of national and organisational policies related to health data governance and inform a global health data governance framework. The Principles will also be a tool for organisations advocating for equitable, human-rights-based governance of health data and can eventually be used as an accountability mechanism.

3. Who developed the Principles?

Transform Health stewarded the process to develop the Principles, under the leadership of its Policy Circle, which includes digital health and data governance experts from: Asia eHealth Information Network (AeHIN), FIND, Fondation Botnar, the Health Data Collaborative's Digital and Data Governance Working Group, I-DAIR, IT for Change, Jhpiego, PATH, Philips Foundation / Digital Connected Care Coalition, Red Centroamericana de Informática en Salud (RECAINSA), and Young Experts: Tech 4 Health (YET4H). The following partners were instrumental in supporting the global and regional consultations: PATH, AeHIN, the BID Learning Network, Mwan Events, RECAINSA, Wilton Park, Governing Health Futures 2030 and YET4H. This work was funded by Fondation Botnar.

4. How were the draft principles developed?

The process of developing the Health Data Governance Principles was designed to be inclusive and collaborative. To ensure the legitimacy and ownership of the final Principles, Transform Health actively engaged governments, international organisations, civil society, research institutions, and private-sector actors in the co-creation process.

To ensure diversity of perspectives, Transform Health, alongside partners such as PATH, RECAINSA, AeHIN, Governing Health Futures 2030 and Young Experts: Tech 4 Health, has hosted a series of consultations in different regions and with different audiences throughout 2021.

Eight consultations took place:

- Regional workshop: Latin America and the Caribbean – conducted by Red Centroamericana de Informática en Salud (RECAINSA) on 11 March 2021, facilitated by PATH.
- Regional workshop: Sub-Saharan Africa – conducted by the BID Learning Network on 16 March 2021, facilitated by PATH.
- Regional workshop: South and East Asia – conducted by the Asia eHealth Information Network (AeHIN) on 19 March 2021, facilitated by PATH.
- Regional workshop: Middle East and North Africa – conducted by Mwan Events on 31 March 2021, facilitated by PATH.
- Global workshop – conducted by PATH on 29 April 2021.
- Global workshop by Wilton Park – co-organised with Governing Health Futures 2030 – 7 July 2021.
- Youth workshop (global) by Wilton Park – co-organised with Governing Health Futures 2030 and Young Experts: Tech 4 Health – 14 July 2021.
- Global workshop – conducted by Transform Health on 27th September 2021.

The first five workshops – four regional and one global – facilitated by PATH for Transform Health, collected insights that fed into the first draft of the Principles. Once the draft principles were ready, the second set of Wilton Park consultations collected further feedback and input from experts and young experts in two separate workshops in July. A third draft of the Principles was shared with stakeholders in advance of a virtual workshop in September. This was followed by a one-month public consultation on a draft set of Principles.

5. How will the Principles be used?

The Principles are a tool and conceptual framework for civil society organisations and other stakeholders to advocate for equitable, human rights-based approaches to health data governance at national, regional, and global levels.

As an initial step, Transform Health and partners will seek endorsement of the Principles from all actors involved in digital health and data including civil society, private sector, and governments. Ultimately, we want to see the Principles adopted by governments, technology companies, and other institutions responsible for collecting and managing health data.

6. What does it mean to endorse the Principles?

The Health Data Governance Principles are a normative tool to guide the equitable and rights-based collection, processing, storage, analysis, use, sharing and disposal of health data. The Principles are forward looking, representing a common vision for health data governance and the direction an organisation or governments strives to go, in alignment with global best practice. Application of the Principles will vary according to the stakeholder and context(s) in which they are working.

By endorsing the Principles, a government or organisation is demonstrating their commitment to the Principles and intention to use and incorporate them into their policy, programmatic and advocacy work. Endorsing the Principles does not create any legally binding obligations upon organisations or States.

7. Who will ‘own’ the Principles?

The Principles will be a public good, available for everyone to use and incorporate into their policy, programmatic, and advocacy work with health data. To encourage wide community ownership, they are hosted on their own website, together with resources to support stakeholders to use and champion them.

8. How do these Principles relate to the work by other organisations to strengthen health data governance?

Other important principles exist, such as the WHO’s data principles (which provide a framework for data governance for WHO) and their ethical principles for the use of AI for health; the Principles for Digital Development and Digital Investment Principles stewarded by the Digital Impact Alliance; as well as OECD’s Recommendation on Health Data Governance and their Principles on Artificial Intelligence. Key normative and technical partners involved in health data governance, such as the WHO and Health Data Collaborative, have been involved in the co-creation of the Health Data Governance Principles.

However, what is distinct about the Health Data Governance Principles is that they are being developed and driven by civil society. The inclusive and consultative process has brought in diverse perspectives and expertise from across geographies, sectors, and stakeholders.

Another key characteristic of the Health Data Governance Principles is that they are grounded in Universal Health Coverage (UHC); take an equity and rights-based approach; and support sustainable and resilient health systems. They include core principles aimed at protecting people and creating public health value, while going beyond this to include forward-looking principles around equitably distributing health benefits, towards delivering UHC.

9. Will the Principles be revised in the future?

To remain relevant in the fast-evolving domain of digital health, the Principles will need to be periodically reviewed and updated where necessary. Any future exercises to revise the Principles will need to follow the same spirit of co-creation that shaped the development of the original Principles.

Further questions

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