Health Data Governance Principles: FAQs

About the health data governance principles

1. Why is Transform Health developing health data governance principles?

Realising Transform Health's vision of health for all in a digital age depends greatly on how we collect, analyse, and use the health data that is being generated both within health systems and more widely. Stronger governance frameworks are needed to maximise the public health benefits of health data and health-related data, whilst protecting individuals from harm and human rights violations.

Whatever form global, regional, or national health data governance frameworks take, Transform Health believes that they should be grounded in a set of core values and principles such as equity, human rights, and inclusion. Health data governance frameworks also need to reflect the views and needs of communities and groups of people who have least access to health services and who are often excluded from discussions around data and health governance.

That is why Transform Health has been facilitating a process to co-create a set of health data governance principles. The principles seek to align stakeholders around a shared vision for health data governance and to create an environment where all people and communities can benefit from health data.

2. 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.

3. 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. 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.

4. How were the draft principles developed?

The process of developing the Health Data Governance Principles has been designed to be inclusive and collaborative. To ensure the legitimacy and ownership of the final principles, Transform Health is actively engaging 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.

To date, eight consultations have taken place:

1. Regional workshop: Latin America and the Caribbean – conducted by Red Centroamericana de Informática en Salud (RECAINSA) on 11 March 2021, facilitated by PATH.
2. Regional workshop: Sub-Saharan Africa – conducted by the BID Learning Network on 16 March 2021, facilitated by PATH.
3. Regional workshop: South and East Asia – conducted by the Asia eHealth Information Network (AeHIN) on 19 March 2021, facilitated by PATH.
4. Regional workshop: Middle East and North Africa – conducted by Mwan Events on 31 March 2021, facilitated by PATH.
5. Global workshop – conducted by PATH on 29 April 2021.
6. Global workshop by Wilton Park – co-organised with Governing Health Futures 2030 – 7 July 2021.
7. Youth workshop (global) by Wilton Park – co-organised with Governing Health Futures 2030 and Young Experts: Tech 4 Health – 14 July 2021.
8. 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 were shared with stakeholders in advance of a virtual workshop in September. This meeting was an important opportunity to not only present the latest draft of the principles but also to discuss plans to finalise and launch them in early 2022. The meeting also sought to build consensus around opportunities to ensure the principles are widely endorsed and used, including in support of a global health data governance framework.

5. **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 proposed 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.

About the public consultation process

6. **What is the objective of the public consultation process?**

For all people to benefit equally from the use of health data, it is important that the principles upon which health data governance is based are reflective of diverse groups' needs and priorities, especially those who are traditionally left behind. The purpose of the public consultation process is therefore to allow the principles to be further refined, supported, and endorsed by as wide an audience as possible. Legitimacy and ownership of the principles will in part be derived from the inclusive processes of consultation.

7. **Who can take part in the consultation?**

Any individual or organisation with an interest in health data and how it should be governed is encouraged to take part in the consultation. People from low and middle-income countries, youth, women, and key and marginalised populations are particularly encouraged to participate in the consultation.

8. **How can people contribute to the public consultation?**

Feedback on the draft principles can be submitted through an online form. Networks, coalitions, and organisations working with communities are encouraged to gather insights from diverse stakeholder groups. Transform Health has provided some resources to support local consultations on the principles.

9. How long will the public consultation process last for?

On 27th October 2021, Transform Health will launch an open public consultation to gather further inputs on the draft principles. The consultation will run until the end of Digital Health Week on December 3rd.

What will happen next?

10. When will the principles be finalised?

The Principles will be finalised in December 2021 ready to be launched at global and regional events in the first quarter of 2022.

11. How will the principles be used?

With the proliferation of digital health, and expansion of data linked to this, It is crucial that health data governance principles are adopted by governments. The principles must also underpin and contribute to the development of a framework to ensure participatory, equitable, and efficient health data governance so that all people benefit equally from the use of health data, in support of UHC.

The principles will become 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.

12. 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 will be hosted on their own website, together with resources to support stakeholders to use and champion them.

13. 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.