

## Case on YET4H, Transform Health and Data Governance

Young Experts: Tech 4 Health (YET4H) is a youth organization that brings attention to young people's needs on health policy and the digital health agenda. YET4H works with a wide variety of organizations, with the goal of making digital health accessible to and usable for young people. It also focuses on creating awareness for issues in digital health, for example through the [“My data, our Health”](#) campaign together with [Transform Health](#) or the project on [“Digital Health Rights for Youth”](#) together with other youth-focused and youth-led organizations. Both campaigns raise important issues that come with connectivity in a digital age, they showcase the significant gaps in health data governance as well as make sure (young) people know their rights (e.g., through digital literacy courses or webinars and workshops) and are able to demand compliance.

Further, Transform Health, YET4H's mother organization, is currently working on establishing a [framework for health data governance](#) (see fig. 1) in collaboration with experts, other organizations and institutions and community stakeholders. This framework is centered around three key issues: Protecting people, promoting health (data) value and prioritizing equity. In April 2024, Transform Health conducted a series of public consultations to get input from civil society.

Transform Health is advocating and lobbying for this framework to be adopted in a World Health Assembly Resolution and thereby endorsed by different national governments, thereby moving from principles to practice. This is a critical phase of the Health Data Governance Principles, as transitioning into practice and being adopted by governments and governing bodies is a critical step to implementation.

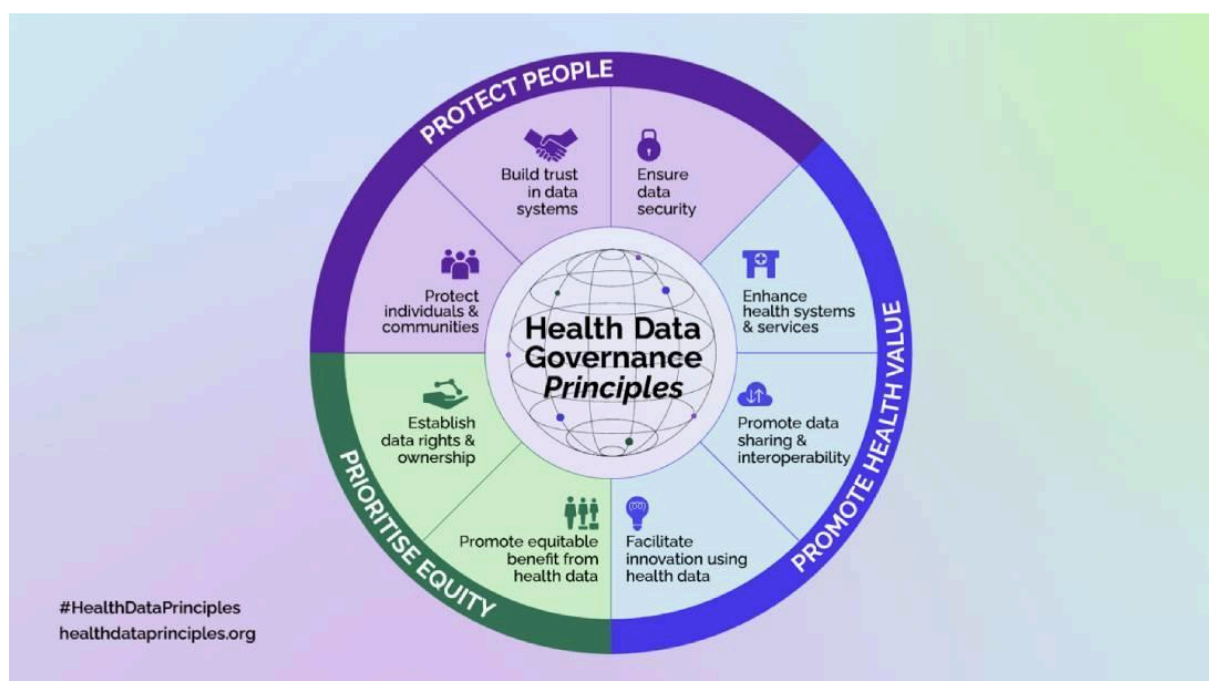


Figure 1: Global Health Data Governance Principles

Within the coming year, YET4H aims to conduct youth-led and youth-focused consultations to assess the different national health data governance landscapes in the six WHO regions (Africa, Americas, Eastern Mediterranean, Europe, South-East Asia, and Western Pacific) and to explore youth perspectives on data governance on regional or national level. These consultations will be used to draft a model health data governance law that encompasses the views and needs of young people.

In the past, YET4H has led youth-led consultations on for example “digital first health systems” using foresight methodologies such as flip the future and scenario planning. Additionally, our members have moderated youth roundtables guided by overarching questions which were less focused on using certain methods. We are currently in the pre-planning and scoping phase for conducting the youth consultations on the health data governance framework. Here, it would be useful to learn more about the different theories and frameworks used in academic research to guide such an endeavor in practice and ensure meaningful participation of young people in decision-making processes as well as to produce tangible outputs that can be used for drafting a model law on data governance.