Strengthening health data governance: new equity and rights-based principles

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Abstract

Purpose – This paper introduces a new set of equity and rights-based principles for health data governance (HDG) and makes the case for their adoption into global, regional and national policy and practice.

Design/methodology/approach – This paper discusses the need for a unified approach to HDG that maximises the value of data for whole populations. It describes the unique process employed to develop a set of HDG principles. The paper highlights lessons learned from the principle development process and proposes steps to incorporate them into data governance policies and practice.

Findings – More than 200 individuals from 130 organisations contributed to the development of the HDG principles, which are clustered around three interconnected objectives of protecting people, promoting health value and prioritising equity. The principles build on existing norms and guidelines by bringing a human rights and equity lens to HDG.

Practical implications – The principles offer a strong vision for HDG that reaps the public good benefits of health data whilst safeguarding individual rights. They can be used by governments and other actors as a guide for the equitable collection and use of health data. The inclusive model used to develop the principles can be replicated to strengthen future data governance approaches.

Originality/value – The article describes the first bottom-up effort to develop a set of principles for HDG.

Introduction

Digitalised, data-driven healthcare is increasingly becoming the norm or aspiration for governments around the world (WHO, 2021a). Vast amounts of health data and data for health (see Box 1 for definitions) are being generated every day by digital technologies—within and outside of health systems—and by individuals themselves. Public health responses, service delivery, research and health system planning are increasingly reliant on this data. The extent to which the collection, processing and use of data contributes to health equity, strong and resilient health systems and accelerated progress towards universal health coverage (UHC) depends on how it is governed.

The growing availability of real-time data and enhanced data analytic tools offers significant benefits for health practitioners, policymakers, researchers and individuals. Large data sets can enhance different parts of a health system—from policymaking and budget allocations to epidemiological surveillance and clinical research—leading to improvements in prevention, diagnosis, treatment and care delivery. The availability of more accurate and representative data can reduce health inequities by allowing policymakers and health professionals to monitor the various underlying determinants of health as well as identifying population groups affected by different risk factors (Transform Health, 2021). The benefits of health data can be extended beyond geographical borders through data sharing and collaboration agreements (Wong *et al.*, 2022).

Despite the potential benefits of health data and data for health, ethical and human rights concerns arising from the actual, potential or perceived misuse of data—for example, for political and commercial gains, or to stigmatise individuals with health conditions—risk undermining public confidence and trust in data systems and in the opportunities that digital technologies and data offer (Transform Health, 2021; Davis and Williams, 2020). Along with data misuse, the challenges of missed use of data and missing data must also be addressed to reduce health inequities and to prevent artificial intelligence and other data-driven tools from perpetuating bias and discrimination towards marginalised communities (Gill and Germann, 2021).

The COVID-19 pandemic has raised the profile of health data governance (HDG), particularly concerning issues of data privacy, access, sharing, ownership and data deletion

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Box 1. Definitions

Health data – Any data that relate to the physical or mental health of an individual or to the provision of health services to the individuals.

Data for health – Data that do not specifically describe the health status of individuals but are used to support health decisions such as demographic data, telecommunications data and weather data.

Data governance – The process of managing and making decisions to guide the generation, collection, storage and management of data through normative, actionable and cross-cutting policies, practices, standards, benchmarks and regulations.

(Access Now, 2020). Many of the data governance challenges associated with COVID-19 are not new, but have highlighted important questions about who is involved in governing health data and how such governance should be performed in terms of privacy and security (European Commission, 2020). Whilst risks such as data breaches and patient identification can never be completely eliminated, Seastedt *et al.* argue that the costs of not sharing data are even greater and will curtail health advances. Rather than limiting data sharing, they call for robust and standardised governance frameworks for data sharing and investment in equitable data collection infrastructure (Seastedt *et al.*, 2022).

Growing momentum for health data governance
Support for stronger and more effective HDG has gained momentum across a wide range of stakeholders, particularly among those concerned with maximising the public value of health data (Ibragimova and Phagava, 2021). The report issued by *The Lancet* and *Financial Times* Commission on Governing Health Futures 2030 calls for globally agreed-upon rules and processes to unlock the public value of health data whilst safeguarding rights and building trust in the process of health data sharing. Specifically, the Commission argues for a solidarity-based approach to health data that gives people greater control over their data, ensures data is harnessed for the public good and counters extractive practices (Kickbusch *et al.*, 2021). The outcome statement of a World Health Organization (WHO) Health Data Governance Summit in 2021 also confirmed the interest of governments and other actors to work together to develop and adopt a common framework for HDG that is underpinned by a globally unifying set of principles (WHO, 2021b). Clear governance structures for data use, driven by a core set of equity and rights-based principles, have also been identified as a key element of policy maturity in virtual health and care (Broadband Commission, 2022).

The WHO's Global Strategy on Digital Health 2020–2025 stresses that digital health should be developed with a core set of principles including accessibility, privacy, security and confidentiality. It recognises the need for international agreements on the appropriate use of health data and guiding principles for equitable health data sharing and use and outlines WHO's commitment to develop principles over a medium-term period within two to four years (WHO, 2021a).

Transform Health, a global, multi-stakeholder coalition founded in 2020, in full understanding of the described scenario, identified weak data governance as a significant barrier to achieving health for all in the digital age (Transform Health, n.d.b). Coalition partners were concerned that whilst governments and international organisations had recognised the need to strengthen HDG, action was not being taken fast enough to maximise the value of health data for populations or to protect them from potential harm. Transform Health also favoured a more participatory approach to strengthening HDG that prioritised UHC and health for all values such as equity and human rights from the outset. To support the implementation of WHO's strategy and to accelerate progress towards a global framework for HDG, the coalition therefore initiated and led an inclusive and consultative multistakeholder effort to develop a set of equity and rights-based principles for HDG. This viewpoint article summarises the Health Data Governance Principles (hereon, the Principles) and how they were developed. It then discusses lessons learned from the principle development process and recommends how they can be incorporated into data governance policies and practices.

Methodology
The process to create the Health Data Governance Principles was as important for Transform Health as the outcome. The coalition's intention was for the principle development exercise to align different stakeholders behind a common vision for HDG and create a shared sense of

ownership of the resulting Principles. We therefore chose an iterative and inclusive methodology to develop the Principles from the bottom up over the course of almost two years. Governments, international organisations, civil society, youth, research institutions, regional digital health professional associations, and private-sector actors were all actively engaged in the creation process.

Landscape analysis

To strengthen the HDG ecosystem, Transform Health deemed it necessary from the outset to build on, rather than duplicate, existing data governance efforts. In 2020, the coalition commissioned PATH to conduct a landscape analysis of current policies and practices in data governance (Bennett *et al.*, 2020). The analysis sought to review the state of HDG in different contexts; identify strengths and weaknesses of existing approaches and establish where Transform Health could bring the most value in promoting a HDG framework.

The landscape analysis used a mixed methods approach to investigate data governance practices at global, regional and national levels. The authors reviewed 113 documents including data governance policies, peer-reviewed journal articles and a variety of grey literature including guidance documents and reports on data governance topics. The authors also conducted key informant interviews with ten experts from multilateral organisations, government and civil society.

The report found that health data are governed by a diverse range of regional, national and local legal and regulatory instruments, policies and norms. These practices are shaped by different ideas about privacy and data sovereignty (see Box 2). They also apply to different types of health data and levels of health systems.

At a global level, a number of guiding frameworks that were identified attempt to set an overarching context for HDG. For example: the OECD's Recommendation on Health Data Governance (OECD, 2017); the Council of Europe's Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (Council of Europe, 1985); and the WHO's Data Principles (WHO, 2020). The landscape analysis found that these frameworks had several limitations. For example, these frameworks have not been developed with core values such as equity and human rights at their centre. Furthermore, they were developed through top-down processes that excluded the perspectives and priorities of countries and communities with the most to gain—or lose—from the increased collection and processing of health data. As well as failing to reflect a truly unified approach to HDG, these frameworks are not legally binding and are difficult to enforce.

Box 2. Approaches to data governance

Source: (Bennett *et al.*, 2020)
There are broadly four global approaches to data governance and data privacy, each with powerful regional and national champions:
Stringent, individually centred: Best illustrated by the General Data Protection Regulation (GDPR) and championed by members of the European Union, as well as South Africa, India and sub-national regions such as the state of California in the United States.
Relaxed, commercially centred: Used, for example, by the United States. Promotes few regulations on the collection or use of data and privacy guidelines are more relaxed than the GDPR.
Stringent, government/state-centred: Embodied by China's current data sovereignty laws. Some components can also be found in other countries, such as Tanzania and India.
Relaxed, innovation-centred: Highlighted by Japan and the G20 as a middle road approach to data privacy that promotes building trust in technology.

Several challenges emerged from the landscape analysis that a global HDG framework could address. Significantly, data governance efforts were found to conflict and overlap, resulting in a policy and regulatory environment that is complex and fragmented for policymakers, health workers and communities. Furthermore, rules to govern the collection and use of data have not kept pace with digital innovations and the growing potential for data to support better health and well-being, or the potential harms arising from data misuse.

Key informants and the literature review revealed that levels of trust in data collection and use are low, in part due to the lack of strong feedback loops. Lack of trust is common when data—or insights from that data—are not shared back with the population from which they were collected, particularly for data collection conducted through digital tools. Communities that see no clear benefit to adopting data-sharing models will be reluctant to participate in them. Lack of transparency and trust in data sharing between countries also undermines the potential for the benefits of health data to transcend boundaries.

Drawing on the findings of the landscape analysis, the report recommended that Transform Health could take several actions to improve HDG. These included defining a set of foundational principles for HDG that promote a common understanding of what HDG should accomplish whilst being adaptable for different contexts, health systems and priorities.

Principles development process
In December 2020, Transform Health organised a stakeholder meeting to discuss the findings of the landscape analysis and consult partners on the merits of developing a set of principles to underpin a future HDG framework. Participants included key normative and technical partners involved in HDG, such as the WHO and Health Data Collaborative as well as representatives from global organisations, coalitions, commissions and collaboratives working on digital health transformation. Participants reached a consensus on the added value of such a set of principles, agreeing that the Principles must be relevant for different regions and contexts and complement national governance efforts. They supported Transform Health's proposal to facilitate their development under the guidance of the coalition's Policy Circle, a working group comprising a dozen digital health and data governance experts.

For many Transform Health partners, it was critical that the Principles were rooted in the realities of low and middle-income countries (LMICs) with lower levels of digital maturity but with great potential to leverage digital technologies and data to strengthen health systems. To encourage a diversity of perspectives and to ensure that the priorities of LMICs were central to the Principles, their development began with a round of consultative workshops with regional and national level organisations. In March 2021, four organisations—AeHIN, RECAINSA, BID Learning Network and Mwan Events— organised regional workshops in Asia, Latin America, Africa and the Middle East/North Africa (MENA) respectively. Between 17 and 30 people took part in each of the workshops with attention paid to achieving a balance of participants from different countries. Participants represented a range of stakeholders including governments, international organisations, civil society, research institutions, regional networks, health financers and private-sector organisations. Women, young people and representatives from marginalised communities were part of each workshop.

The objectives of the regional workshops were to identify key topics and areas of focus for the Principles and validate some key definitions. The workshops were also an opportunity to gather examples and perspectives on current data governance practices in each region. The main themes arising from the regional workshops were national and community data governance mechanisms; data privacy and security; infrastructure and applications; human resources; technology and data standards; public engagement; and financial resources.

Participants agreed that digital health solutions would not work to their full potential without increasing trust in HDG. Many wanted the Principles to help resolve tensions

between data access and data privacy, with one participant asking: "How do we find the balance between individual data rights and public rights?" It was important to many participants that the Principles help to increase data transparency and accountability and are mindful of the need to protect the rights of marginalised communities.

Major recurrent challenges that participants wanted stronger data governance to address included the lack of interoperable data standards and fragmented and siloed approaches to digital health and HDG. In addition to the need for clear protocols for sharing health data and data for health within national health systems, participants also wanted to see common protocols and standards for cross-departmental and cross-border data sharing associated with clinical research, telemedicine and artificial intelligence.

The outcomes of the regional workshops were presented at a global workshop in April 2021 which brought together 29 participants including representatives from each of the regional workshops. During this workshop, participants discussed the themes that arose from the regional workshops, identified gaps and began to elaborate on how the different topics of concern could be translated into HDG principles. Participants also considered the potential audiences for the Principles.

Based on these collective inputs from the five workshops, Transform Health developed the first draft of the Principles. This draft was then presented and refined at two Wilton Park meetings in July 2021 organised in partnership with the Governing Health Futures 2030 Commission. The first meeting brought together 27 global thought leaders and experts who highlighted additional considerations that must be taken into account to ensure the Principles are inclusive and sustainable. During this meeting, participants reinforced the need for the Principles to support more inclusive and sustainable data governance and to maximise public health and equity goals. In order for the Principles to have impact, participants noted they would need to be implemented across sectors and government departments.

The second Wilton Park meeting was co-organised by the Governing Health Futures 2030 Commission and Young Experts: Tech 4 Health with a focus on capturing the feedback and inputs of youth. Priorities highlighted at this meeting included meaningful, ongoing inclusion of youth as a non-homogeneous group in all stages of data governance; protecting children's and adolescents' health data; addressing power imbalances in the data ecosystem; and ensuring explicit references to issues like cybersecurity and informed consent in the Principles. Youth also highlighted the importance of education, training and mentorship in digital health and data to enable more young people to participate in data governance and accountability efforts.

Following a further round of inputs and written feedback from Transform Health partners, a global workshop was held in September 2021 to finalise a draft set of principles for public consultation. The draft Principles, along with supporting background materials, were posted on the Transform Health website for one month and various listservs, direct outreach and social media channels were used to encourage partners to submit their feedback through an online form.

As a result of the public consultation, many elements of the draft Principles were validated and several refinements were suggested. Transform Health incorporated the inputs from the public consultation into a final set of eight Health Data Governance Principles at the end of 2021 and they were publicly launched on World Health Day in April 2022 (Transform Health, n.d.a). Overall, more than 200 individuals from over 130 organisations, representing diverse geographies and stakeholder groups, contributed to the Principles' development.

The Health Data Governance Principles
The Health Data Governance Principles are the first comprehensive, globally-applicable set of principles to guide the governance (and decision-making about governance) of health data

across health systems. The overarching goal of the Principles is to align policymakers and other interested parties around a shared vision of equitable HDG, where all people and communities can share, use and benefit from health data.

Overview of the principles

The Principles are clustered around three interconnected objectives, which aim to balance both individual and collective perspectives: protect people; promote health value; and prioritise equity. Visually, the Principles are arranged into a circle since they are designed to complement and reinforce one another and are not weighted or listed in any priority order (see Figure 1). Each principle has a number of core elements that further describe it and how it can be put into practice (see Table 1).

The first cluster of principles, focused on protecting people, highlights the need for HDG to ensure protection against various kinds of individual and collective harm at every stage of the data lifecycle, including data-driven exploitation, discrimination, surveillance capitalism and neocolonialism. This work requires rigorous evaluation and risk assessment of data practices to identify and mitigate any potential harm through meaningful participation of civil society, communities and individuals. Due to the highly personal and potentially sensitive nature of health data, this cluster also emphasises the need for additional specialised protections in law and data use practices. Sustained security and conscientious governance of health data are essential components in building trust in data systems over time.

Under the second objective of promoting health value, the three associated principles seek to maximise the value obtained from the meaningful use of data to improve health outcomes and advance equity through a whole health system approach. Data sharing, facilitating
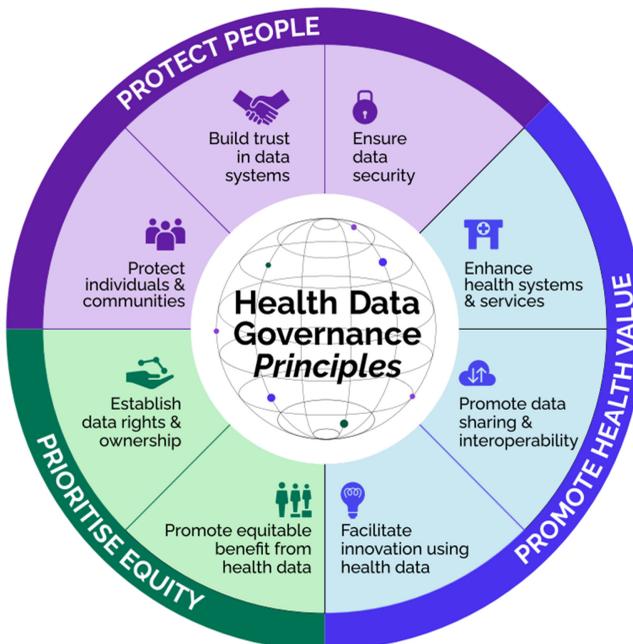

Figure 1.
Health Data
Governance Principles

Overarching objective	Principle	Core elements
Protect people	Protect individuals and communities	• Address individual and collective risk • Collect data with a defined purposes • Collect personal or sensitive data only when necessary and with informed consent • Use secure data collection and storage mechanisms • Use de-identification and anonymisation • Define inappropriate uses of health data • Institute safeguards against discrimination, stigma, harassment and bias • Provide guidance specific to marginalised groups and populations
	Build trust in data systems	• Align with best practices for data protection and privacy • Ensure consent is informed and understood in all its complexities • Obtain collective consent where appropriate • Define concrete exceptions to informed consent • Ensure data quality, availability and accessibility • Reinforce HDG with evidence • Establish transparent and accessible processes and systems • Institute feedback and accountability mechanisms
	Ensure data security	• Require strong technical security measures for data processing • Mitigate risks related to security threats • Ensure transparency around data breaches • Consider federated data systems
Promote health value	Enhance health systems and services	• Evaluate the benefits of health data • Use data to enhance health services for individuals and communities • Encourage a culture of data-led insights and action • Address health system efficiency, effectiveness and resilience • Strengthen community ownership of health data • Enable and empower frontline health workers
	Promote data sharing and interoperability	• Establish data sharing rules and guidelines • Validate informed consent before sharing data • Promote interoperability of data systems • Define common data structures across health systems • Define multiple levels of data access • Use common definitions and global standards • Support multi-sector partnerships
	Facilitate innovation using health data	• Apply HDG to emerging technologies • Address the use of non-health data in health contexts • Build public health data infrastructure • Employ policy innovation

Table 1.
Health data
governance principles
and their core elements

Overarching objective	Principle	Core elements
Prioritise equity	Promote equitable benefits from health data	• Represent all groups and populations equitably in data • Consider the unique needs of marginalised groups and populations • Mitigate data bias • Use accessible language and plug knowledge gaps • Implement inclusive data feedback mechanisms • Promote equitable impact and benefit
	Establish data rights and ownership	• Apply a human rights lens to HDG • Define clear governance roles and responsibilities • Codify data rights and ownership • Extend data rights and ownership to products and services • Develop health data trusts and health data cooperatives • Employ participatory data governance mechanisms • Connect to broader accountability mechanisms

Table 1.

innovation and collaborations are prerequisites for creating value from health data. However, aggregating and sharing health data must be done in a manner that protects individual, group and community rights. Lastly, the two principles categorised under prioritising equity affirm that equity must be embedded within HDG and should extend beyond policies, processes and outcomes to include public engagement, education and meaningful participation of all groups in relevant decision-making about health data systems. These principles focus on the critical need for all people to have an equitable stake in the health value that their data generates, both in terms of ownership and in terms of derived benefits. This should include mitigating data bias, considering the unique needs of marginalised groups and applying a human rights-based approach to HDG.

Added value of the principles
The Health Data Governance Principles recognise and build upon existing norms, principles and guidelines, adding value in three different ways. Firstly, in terms of content and focus, the Principles bring an important, but often overlooked, human rights and equity lens to the use of data within and across health systems. Centring such a perspective encourages stakeholders to always consider who stands to benefit from health data practices and who is at risk of being left behind or even harmed. The Principles also have UHC at their core and focus on maximising the public value of health data and supporting more sustainable, resilient public health systems.

A second benefit of the Principles is that they are applicable to a wide range of stakeholders, including governments, technology companies, donors and other bodies that collect and use health data, as well as organisations advocating for stronger HDG. They are intended to serve as guiding principles that can be adapted to diverse contexts and stages of readiness across regions.

Finally, what is particularly unique about the Health Data Governance Principles is that they have been driven by civil society and developed together with a diverse set of partners and organisations. The comprehensiveness and applicability of the Health Data

Governance Principles are the result of the inclusive, consultative and bottom-up process used to develop them. The principles build upon the foundation of knowledge that already exists for this work, while bringing in a wider set of stakeholders across the global population, including stakeholders that are not experts in digital health. This process was intentionally designed to incorporate diverse perspectives and expertise while ensuring the meaningful engagement of stakeholders from across geographies and sectors in terms of justice and equity.

To encourage wider community ownership and adoption at individual country level the Principles are hosted on their own website, together with resources to support their use and promotion. Alongside the published Health Data Governance Principles, the website provides additional details, context and implementation guidance for different types of stakeholders (e.g. governments, research institutes, private sector) to advance HDG within their particular context. It also includes space for stakeholders to share case studies and insights on the implementation of the Principles to foster further dialogue and knowledge-sharing.

Implications for policy and practice

The Health Data Governance Principles offer a strong vision for HDG that reaps the public good benefits of health data whilst safeguarding individual rights. They are part of a larger movement to push HDG into the collective consciousness and begin to illustrate tangible, actionable approaches to equitable and responsible HDG at multiple levels.

Since their launch, the Principles have been endorsed by more than 130 national, regional and international organisations representing different sectors (Transform Health, n.d.c). The high level of engagement during the development of the Principles and the rapid show of public support following their publication are a clear sign that organisations, communities and civil society want to see health data used to its full potential but without undermining their rights or driving further inequities.

To have the greatest impact, the Principles should be swiftly incorporated into national and organisational policies and programmes relevant to HDG, as well as advocacy work on HDG and wider health agendas. Governments and other stakeholders should use the Principles to update, strengthen or create governance models, instruments, compliance rules, treaties, regulations and standards within and across countries and regions. Healthcare professionals, technology companies, and other actors involved in the collection, processing and regulation of health data and data for health are encouraged to use the Principles as an ongoing guide. The Principles can be incorporated into academic curricula and guidelines for ethics committees to ensure that future data practices are equitable and rights-based. Finally, the Principles can be used as an assessment and accountability tool to track progress on the equitable and human-rights-based governance of health data.

Translating the principles into a global health data governance framework

Whilst localisation and adaptation of the Principles will be critical, international alignment on fundamental principles for HDG will promote a common understanding of what data governance should accomplish and help to maximise the public health benefits of data even further. This alignment could be achieved through establishing a global HDG framework which could support both the immediate and sustained long-term incorporation of the Principles into practice, as well as to overcome the existing challenges posed by conflicting and overlapping policies and regulations between countries.

A global HDG framework cannot be a one-size-fits-all model for data governance, but rather can offer a variety of components that can be adopted and adapted to meet specific

national and regional contexts, health systems models and priorities. Starting with principles that communicate the value of an equitable and just approach to data governance provides a baseline of commitment for national governments, global partners and stakeholders from across all sectors.

Transform Health's vision for a global framework on HDG is a multinational agreement among nations, negotiated by the WHO and adopted by Member States at the World Health Assembly (WHA). A framework should go beyond a set of technical guidelines and focus on the regulatory environment needed to ensure political commitment and the elements necessary to enable countries to develop laws and regulations to govern the collection, ownership and use of health data. The framework should draw on the Principles as well as other existing norms and standards, which outline countries' obligations to respect, protect and uphold basic rights.

The WHO, along with other UN agencies, has recently outlined an intention to develop an international data governance framework (MacFeely *et al.*, 2022). While these moves to strengthen data governance are welcomed, the specific sensitivities around health data and the importance of data for both individual and population health merits specific governance structures for health data. Ahead of the next meeting of the WHA in May 2023, governments should endorse the Principles and mandate the WHO to develop a global HDG framework, through a transparent and inclusive multistakeholder process, that builds on the eight Principles for adoption through a future WHA resolution.

Making inclusive processes the norm in digital health

Increasing public trust and understanding of digital health and data is important for increasing implementation of more equitable health data practices, as well as for building individual agency over personal health data. That is why Transform Health was committed to following an inclusive, participatory and ethically-grounded methodology throughout the development of the Health Data Governance Principles. To increase the legitimacy and ownership of the Principles, it was important that they were developed not just by traditional digital health and data experts but by representatives of groups who are directly affected by HDG, including youth, women and marginalised communities. Including diverse groups also considerably enriched the Principles, ensuring that they were built up from UHC values and informed by the priorities and lived experiences of people living in LMICs.

As one participant of the youth consultation remarked, "The Principles are needed in these times of uncertainty and shifting mindsets. We are going towards universality, but it must be rooted in local ownership. This is good for the nexus of youth, technology and movement building".

We propose that the same inclusive model employed for the development of the Principles be replicated in the creation of other similar health, digital and data governance processes, including the development of any global HDG framework. Such processes empower people, increase trust and ownership and also greatly enhance the final outputs. We envision that all digital health stakeholders can embed a culture of more equitable and inclusive governance, through consistent use of this proposed model and mindset.

Through more aligned approaches to HDG that prioritise equity, protect people and promote health values, we can create an environment where all people and communities can trust that data systems are being governed with their health and wellbeing at the centre. The Health Data Governance Principles offer governments and other data users a clear roadmap towards achieving this vision. Now is the time to move from principles to action and universalise the benefits of health data.

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