Transform Health

Health for all in the digital age

PATH

Strengthening governance of health data to realise benefits for all

Policy brief. November 2020.

The power of data

Digital health technologies, along with reliable high-quality data, have the power to accelerate health equity by making health systems stronger, more effective, and more responsive to the needs of the populations they serve. As innovation accelerates, the volume of accessible data that enables digital technologies and powers health decisions is growing exponentially. Responsible management of data sources and architectures are key to improving health, whether through successfully combating health emergencies or providing ongoing essential health services and primary health care. The way the world governs health data has never been more pivotal than it is in this digital age.

Health data governance

Health systems are awash with data. A shortage of data is often not the challenge; rather many policymakers are unable to collect, analyse, and make timely decisions based upon the data that is being generated. The global health community lacks policies to support effective data collection, storage, analysis, use and dissemination for the public good.

As dozens of stakeholders, alliances, and partnerships are working to achieve universal health coverage (UHC) by 2030, many are thinking about how health data should be used in the service of this goal.[1,2] Digital technologies and the data they generate can play an accelerating role towards UHC, but insufficient attention has been given to how the benefits of data-driven health care can be expanded to all people and communities of the world.

Health data is currently governed by a range of conflicting instruments, policies, and norms in different regions and jurisdictions that often fail to keep up with the pace of innovation.[3] There is no overarching international framework to guide the use and management of health data within and between countries in ways that support UHC and that do not undermine equity or threaten human rights violations.

Health data is any data that relate to the physical or mental health of an individual, or to the provision of health services to the individual. Any personal data that reveal information about an individual's health status, such as immunisation status, blood pressure readings, and diagnostic results.

Data for health is 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.

The COVID-19 pandemic has raised the profile of health data governance to new levels, particularly around issues of data privacy, ownership, sharing, and access.[4] Surveillance of the outbreak, and sharing of the data produced from that surveillance between countries and partners, has raised important questions about who governs data, and how.[5] These questions have generated renewed demand for the global health community to set international standards for data governance.[6] The pandemic has also brought attention to the importance of ensuring diverse voices are consulted on how data are collected, shared, and used so that all populations are represented in, and benefit from, health data, while also having their privacy protected.

Call for a global framework

To create an environment where all people and institutions can share, use, and benefit from health data, Transform Health believes that an inclusive and collaboratively developed global framework for governance of health data is urgently needed.

We are calling for an equitable and representative global governance framework that realises health data as a global public good whilst protecting individual rights.

To help determine where Transform Health can bring the most value in promoting a global health data governance framework, we commissioned PATH to undertake a landscape analysis of existing data governance regulations and approaches, and to identify gaps in ongoing efforts to strengthen health data governance.

The landscape included a review of 113 documents from across sectors, including national and regional governance policies, peer-reviewed journal articles, guidance documents, and reports on data governance topics. Experts from the multilateral, government, and non-profit sectors were also consulted through key informant interviews and an online survey.

Key findings

Below are key findings drawn from the landscape analysis that will inform Transform Health's work on health data governance.

1. Greater alignment in approaches to health data governance and data privacy is needed

Many policies have been created and launched to govern data at national, regional, and global levels, but these efforts often conflict and overlap, resulting in a global data governance landscape that can be simultaneously ineffective and overly complicated. 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 European Union (EU) members, as well as South Africa, India, and subnational 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 at the recent G20 meetings, a 'middle road' approach to data privacy that promotes building trust in technology.

Technology and health do not follow borders, and many important user populations are not defined by regional or state boundaries. To create an environment where all people, communities, stakeholders, partners, and institutions can share, use, and benefit from health data, a collaboratively developed global framework to build connections and trust between these approaches is needed.

Data privacy is a key component of the larger body of individual data rights which enable citizens to stipulate how their personal data are collected and used. Privacy is a right guaranteed in the United Nations International Bill of Human Rights, as contained in article 17 of the International Covenant on Civil and Political Rights (ICCPR).[7] In this light, data privacy also refers to the nature and scope of personal data collection and use, as well as aspects such as the right of people to be secure against unreasonable surveillance and the right to not be unfairly discriminated against because of data.[8]

Transform Health is calling for the development and adoption of a global framework to help overcome the existing challenges posed by having conflicting and overlapping policies and regulations. This framework does not have to be one-size-fits-all, but rather can offer a variety of components that can be adopted and adapted to meet specific national and regional needs, including humanitarian contexts and emergencies where non-state actors may also play a prominent role in collecting sensitive data.[9]

2. Data governance regulation should be human-centred and inclusive

The digital health technology development community often describes its ideal development process as 'designing with the user'.[10] The same approach should be used to design and implement the guidelines, policies, and regulations needed to govern health data and protect privacy.

To meet the needs of everyone, a health data governance framework should be developed through a participatory, human-centred process that includes diverse groups of end users. A regulatory framework that is designed without such an approach will fail to meet the needs of all population groups, particularly those who are traditionally marginalised and excluded. Getting feedback from various stakeholders and iterating on the regulation with their support will lead to regulation that is more likely to be accepted by all parties, leading to better compliance and overall outcomes.

Transform Health is working to address the unequal voice that has historically been given to local communities in the digital development process by advocating for design approaches that value local knowledge and allow for deeply engaging with and listening to end users.[11] Transform Health has a specific focus on working with youth, women and marginalised groups to ensure their full involvement in the design, use and governance of digital health and data.

3. Foundational principles of health data governance must be defined

Starting with principles that communicate the value of an equitable and just approach to health data governance provides a baseline of commitment for national governments, global partners, and stakeholders from across all sectors. Although localisation and adaptation will always be needed, global alignment on the basics will promote a common understanding of what health data governance should accomplish. For example, potential principles may be centred around ethical responsibility, transparent governance, accountability, and equity, and should build on the existing body of literature on data ethics and management.

Transform Health will facilitate an inclusive process to develop a set of principles for health data governance. We will work with the Digital Impact Alliance (DIAL), the World Health Organization (WHO), Health Data Collaborative, and other national and regional organisations and entities that are undertaking similar efforts to define common ground for health data governance practices. These principles will learn from initiatives such as the Principles for Digital Development,[2] the Principles of Donor Alignment for Digital Health,[12] and the

Organisation for Economic Co-operation and Development (OECD) Recommendation on Health Data Governance.[13]

4. Transform Health is well positioned to mobilise support for a global health data governance framework

Health data governance needs to keep up with digital innovation. Current normative structures, such as the International Health Regulations (IHR) coordinated by WHO, often take almost a decade to be ratified and are developed through non-inclusive processes that don't engage those who are most impacted by the resulting policies. **A more inclusive and agile process is needed to develop a global health data governance framework that can better respond to today's rapidly changing and often disparate technology landscape.**

Transform Health will use its growing platform to raise awareness among the public and policymakers about the need for stronger governance of health data. We will convene diverse stakeholders at national, regional and global levels – including typically underrepresented groups such as young people, women, and marginalised groups – to agree on the steps needed to bring a health data governance framework into existence that is adaptable to different contexts but based on a set of agreed principles that promote health data as a public good and health for all in the digital age.

Acknowledgements

This policy brief summarises the findings of an internal landscape analysis report written by PATH on behalf of Transform Health. The work was funded by Fondation Botnar.

Bennett A, Deelstra J, & Goertz H. Protecting data privacy while ensuring health data benefits for all: Recommendations for building a global data governance framework. Basel, Switzerland: Fondation Botnar, August 2020.

Endnotes

1. Joint Learning Network for Universal Health Coverage (JLN). Using Health Data to Improve Universal Health Coverage: Three Case Studies. Arlington, VA: JLN; 2018.
2. Wyber R, Vaillancourt S, Perry W, et al. Big data in global health: Improving health in low- and middle-income countries. *Bulletin of the World Health Organization.* 2015;93:203–208.
3. Organisation for Economic Co-operation and Development (OECD). *Health Data Governance: Privacy, Monitoring and Research*. Paris: OECD; 2015.
4. Access Now. *Recommendations on Privacy and Data Protection in the Fight Against COVID-19*. March 2020.
5. Commission Recommendation (EU) 2020/518 on a common Union toolbox for the use of technology and data to combat and exit from the COVID-19 crisis, in particular concerning mobile applications and the use of anonymised mobility data. European Commission.
6. Cory N, Stevens P. *Building a Global Framework for Digital Health Services in the Era of COVID-19*. Information Technology & Innovation Foundation (ITIF). May 26, 2020.
7. UN Human Rights Committee. CCPR General Comment No. 16: Article 17 (Right to Privacy), The Right to Respect of Privacy, Family, Home and Correspondence, and Protection of Honour and Reputation. 1988.
8. Tisne M. It's time for a Bill of Data Rights. *MIT Technology Review.* December 14, 2018.
9. Greenwood F, Howarth C, Escudero Poole D, Raymond NA, Scarnecchia DP. *The Signal Code: A Human Rights Approach to Information During Crisis*. Cambridge, MA: Harvard Humanitarian Initiative; January 2017.
10. Principles for Digital Development website. Design with the user web page. Accessed August 2, 2020.
11. White SC. Relational wellbeing: A theoretical and operational approach. *Bath Papers in International Development and Wellbeing*. Centre for Development Studies, University of Bath; 2015.
12. The Principles of Donor Alignment for Digital Health website. The Principles web page. Accessed August 6, 2020.
13. Organisation for Economic Co-operation and Development (OECD). *OECD Recommendation on Health Data Governance.* Paris: OECD; 2017.