Policy Brief

Advancing Health Data Governance for Societal Well-being

A Perspective on Health Digital Common Goods for the G20

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A Perspective on Health Digital Common Goods for the G20

Taskforce 1.4. Promoting Universal Health Coverage, Digital Health, and Open Innovation to Fight Health Inequalities

Authors:

Marina Fernandes de Siqueira, Lawyer of the Coordination of Telecommunication and Digital Rights Program, Idec (Brazil)

Vitor Ido, Program Officer, Health, Intellectual Property and Biodiversity Program, South Centre (Switzerland) & Professor of Commercial Law, University of São Paulo (Brazil)

Matheus Z. Falcão, Alex Trebek Visiting Doctoral Student Fellow, Centre for Law, Technology and Society - uOttawa (Canada)

Shreeja Sen, Research Associate, IT for Change (India)

Camila Leite Contri, Coordination of the Telecommunication and Digital Rights Program, Idec (Brazil)[1]

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[1] This policy brief was anchored by Idec, Brasil. To learn more about Idec's work please visit www.idec.org.br/

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Abstract

The apt use of data for health policies and innovation can enhance access and outcomes. However, the prevalent trend of exploiting personal data collected through digital technologies as economic assets poses risks of surveillance, discrimination, and exploitation.

This policy brief provides elements for a health data governance policy aimed at ensuring equitable distribution of economic and health benefits derived from the use of data, while also safeguarding the universal right to health. Complemented by previous G20/T20 intelligence and aligned with the SDG's 2030 Agenda, the focus is safeguards to individual and community rights and global health priorities. The paper draws on the authors' previous work (e.g., the 2022 international event "Right to Health and Personal Data Protection" (Idec 2022), co-organized by Idec and South Centre), and the WHO's works on "Health Data as Global Public Good" and "Report on Ethics and Governance of AI".

The concrete recommendations include: how to empower individuals and communities to control their health data; how to foster digital health strategies at the national level; avoiding the enclosure of data (e.g. by IP) by private entities; AI and lack of algorithmic transparency; how recognizing health data as public good can be translated into good policies; scope for data sharing for commercial purposes; and the issue of consent and secondary use of data in digital health.

Crucially, positioning health data as a public good within G20 and key international forums will ensure the imperative to safeguard against misuse and economic exploitation in commercial uses. This paradigm shift emphasizes the primary goal of utilizing health data – ensuring people's health as a fundamental human right.

Through collective efforts and responsible practices, the proposed health data governance policy aims to strike a balance: leveraging data for societal well-being while safeguarding individual and community rights and global health priorities.

Keywords

I. Diagnosis

Health data is the main driver of the digital transformation of health systems and health innovation. Data fuels artificial intelligence (AI), which can be used for administrative tasks, enhancing diagnostics, image processing, augmented reality for microsurgeries or teleconsultations, and bringing specialized care to remote areas. Digital health, therefore, is increasingly dependent on AI. While health data has historically been generated, developments in computational capacity and sensors have enabled its collection, processing, and application across various areas of healthcare.

Data is also essential for public health innovation. While the apt use of data for public health policies can enhance access and health outcomes, the prevalent trend of exploiting personal data collected through digital technologies as economic assets pose risks of surveillance, discrimination, and exploitation.

Economic exploitation can be observed in the use of health information to profile a person, enabling personalized marketing strategies, and in economic discrimination in access to services or goods based on the financial risk an individual poses to the healthcare system (Falcão et al. 2024). Regarding surveillance, there may be data sharing with government agencies for them to take punitive measures against individuals based on their health data (Illmer 2021). In all the situations mentioned, there is a repurpose (and secondary) use of personal data collected in the healthcare sector for uses that raise ethical, legal, and human rights concerns (WHO 2021a, 53).

From a rights-based perspective, data has two dimensions. On an individual level, data is considered an extension of the self. So, data protection is a fundamental right for the formation of individuals' personalities and for the exercise of citizenship. Data also has a collective dimension, as they are produced collectively as a cyber cultural memory and heritage of a society (Moraes 1998). For example, an AI tool produced in the Global North may represent the unilateral appropriation of data from Global South populations without benefits sharing. With this, we observe that although health data also have both personal and collective nature, there is a tendency in the private sector to appropriate and misuse them for economic purposes.

Data capture is led by private companies because the healthcare sector is dependent on large technology companies to handle data and develop new technologies - making the Global South more vulnerable to data extraction. Health data are essential for promoting and protecting the right to health, and their appropriation represents risks related to personal data protection, access to healthcare, and the national sovereignty of countries.

Even though the right to data protection and health is regulated in most G20 countries, current frameworks are insufficient. In Brazil, for example, there are no regulations related to data processing

by health apps (Idec 2018), the use of artificial intelligence, or even the specific application of the data protection law in the health sector.

This policy brief provides elements for a health data governance policy aimed at ensuring the equitable distribution of economic and health benefits derived from the use of data and safeguarding the universal right to health. The responsible development of health technologies must also correspond to the needs of the Global South (Singh 2023). Digital health should therefore be tailored to promote the right to health through governance that places healthcare users at the center of the discussion.

II. Recommendations

1. Empowering individuals and communities to control their health data; and fostering digital health strategies at the national level.

Data protection: Digital health strategies must prioritize personal data protection, emphasizing non-discrimination, transparency, and autonomy as fundamental elements. The degree of protection afforded to personal data should empower individuals and communities to comprehensively comprehend how their data may potentially be utilized.

Ensuring transparency and limitations in the secondary use of health data is central, going well beyond the general privacy policies typically placed by companies. It is imperative that stringent enforcement mechanisms are in place to ensure personal data protection.

Incorporating social markers into health surveillance: It is imperative to incorporate social markers such as race, ethnicity, gender, and income into health information, extending beyond clinical settings. This holistic approach is essential for accurately assessing social contexts, mitigating biases, and acknowledging the social determinants of health.

Policy coordination and multistakeholder collaboration: Collaborative efforts across various governmental entities, including statistics bureaus, universities, and health authorities, are crucial to ensure cohesive policymaking that aligns with broader societal goals and effectively addresses the multifaceted challenges posed by the evolving landscape of health data usage.

Adequacy of policies with the Declaration of Alma-Ata: The relation between national health data strategies should be guided by the principles enshrined in the Declaration of Alma-Ata, that conveys the idea of social acceptability of technologies and strong public support to ensure the realization of right to health accordingly to community values (WHO 1978).

 Accountability: Data controllers (whether public or private) should be able to demonstrate that the services they offer adequately protect individuals' data, meeting their expectations. Responsible parties must adopt technical and organizational measures capable of mitigating the risk to the rights

and freedoms of individuals. Tools such as (i) Algorithmic Impact Assessment (AIA), (ii) Data protection impact assessments, and especially (iii) external data protection audits, can contribute to the explainability and transparency of these algorithms.

2. Avoiding the enclosure of data by private entities.

Access to health data and governance issues: A key issue around health data, which is a public welfare good, is to ensure that it is available for public authorities to address health emergencies – like the COVID-19 pandemic. However, without adequate governance mechanisms, tech companies enclose publicly available data within their proprietary algorithms, which restricts accessibility to them. As seen during the pandemic, it is only through state-led health measures that accessibility to health services is ensured. The governance mechanisms also fail to protect traditional knowledge of Indigenous peoples, which is then open to being extracted and exploited by large corporations.

Intellectual property enclosures of health data: The issue of intellectual property in digital health is another concern for access to health technologies – through quasi-IP systems like trade secrets protections, corporations continue to enclose information in a way that is detrimental to public welfare outcomes. The restriction on source code disclosure in many trade agreements only enables Big Tech to continue holding on to their dominant positions and misuse health data for advertisement purposes.

3. Promoting safe and equitable ai and algorithmic transparency.

Transparency and explainability in data automated processing: The automated decision must be explainable to users and professionals. This transparency requires that information be available using clear and plain language. The data protection impact assessment and the algorithmic impact report should be public so that the risks and mitigations in AI systems are transparent to all society, including public authorities, regulators, civil society, healthcare professionals, and users.

Equity and diversity: The training data used in AI systems should effectively represent society, especially age, gender, income, ability, or other sensible characteristics. Equitably AI for the entire population should not contain biases or risks of discrimination against minority groups.

Human oversight: Ensure human supervision and effective intervention in decision-making involving AI. AI systems should assist health professionals in making informed decisions. Health professionals should have control over healthcare systems and medical decisions.

Measures against discrimination: During the development and utilization of such systems, safeguard individuals from the use of these technologies to make decisions concerning economic, social, and cultural rights, such as housing, employment, and social benefits. Health data carries discriminatory potential, so this technology should be limited to healthcare purposes.

4. Translating health data as public good into good policies.

Benefit sharing from health data: Addressing the urgent imperative for collective ownership of data demands moving beyond the prevailing paradigm that predominantly privileges the primary use of health data within an individual consent-based framework. Community-driven ownership models should be further studied and considered, ensuring that groups such as patients, local communities, and mobile app users can tangibly benefit from the utilization of their health data.

Drawing inspiration from the World Health Organization's (WHO) framework for Global Public Good is a starting point, however it is important that member states seek a model that ensures equitable benefits from health data utilization, particularly for underserved regions like the Global South (WHO 2021b). This necessitates guarding against a scenario where the South merely serves as a data source while the North holds the economic rewards of innovation.

Existing frameworks such as the WHO's Pandemic Influenza Preparedness (PIP) Framework offer viable alternatives and should be considered. However, it's imperative that these models prioritize country-led initiatives on the international stage (WHO 2023). The notion of public good must transcend rhetoric and be translated into concrete, binding structures rather than remaining an empty category confined to soft law. This is essential for fostering genuine equity and ensuring that the benefits of AI innovation derived from health data are shared equitably across communities and regions worldwide.

5. Clarifying the scope for data sharing for commercial purposes: ensuring consent and clarifying secondary use of data in digital health.

Mandatory sharing of health data: Health data as a public welfare imperative has to be made available through mandatory data sharing. Secondary and downstream uses of health data are an important consideration, which require adequate consent frameworks and patient data stewardship models to ensure they have a voice in how their data is being shared. An example of a mandatory health data sharing model is the EU Health Data Space, where the EU Parliament and EU Council agreed on a provisional text of the law to make health data accessible and available at the EU level. However, civil society actors have raised concerns about failure to incorporate the right kinds of safeguards to ensure that Big Tech monopolies do not become further entrenched even in the tech sector.

Safeguarding rights in downstream uses of health data: When health data is used for secondary purposes, like research, it is imperative to ensure that rights of data subjects are protected. There have to be clear data sharing guidelines, including the right for participants to not be part of any secondary data sharing. This includes providing adequate information to patients (or their families) about potential uses of their data when data is collected.

III. Scenario of Outcomes

The deepening exploration of health data represents risks to personal data protection and a potential increase in equity imbalances. The current regulatory landscape may be inadequate to address global needs, especially those related to the fragmentation of forums, trade, human rights, and development issues treated separately. A human rights-based framework by countries is essential to ensure protection against misuse and economic exploitation in commercial uses. This paradigm shift emphasizes the primary goal of utilizing health data – guaranteeing people's health as a fundamental human right.

By adhering to the proposed recommendations, digital health can promote greater accountability and transparency, empowering individuals and communities to manage their health data. The availability of health data as a common good can also enable sustainable innovation in developing countries – this furthers health imperatives and strengthens digital health outcomes.

As health data takes a key place in innovation and on the promotion of an important fundamental and human rights, G20 plays a pivotal role in taking the lead on creating an inclusive framework of it.

With that, it is also expected data protection legal frameworks to be enhanced, alongside with specific regulation related to health.

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