Health and Human Rights Journal

VIEWPOINT

From Information to Valuable Asset: The Commercialization of Health Data as a Human Rights Issue

AMY DICKENS

Health data is a valuable source of knowledge that states can use to advance or undermine the right to health. But the sources and use of health data are changing in our emerging global data economy. Novel forms of digitized health information are fueling a booming industry for algorithmic technologies in health care, rendering it a huge source of scientific and commercial value. To date, the tech giants—Google, Apple, Microsoft, Facebook, and Amazon—are way ahead of public health systems in capitalizing on this value. There is an urgent need for states to recognize the value of health data and use it to advance human rights. Failing to do so risks private actors gaining ever more expansive monopoly powers that threaten patients' social and economic rights.

Health data as a valuable asset

Health data—that is, "information related to health conditions, reproductive outcomes, causes of death, and quality of life"—has long been at the core of efforts to improve health through its use in epidemiology, public health, and health informatics.[1] Human rights advocates have also utilized health data as a tool to identify vulnerable populations and monitor states' progress toward the realization of the right to health.[2] Conversely, repressive states such as China, Venezuela, and Turkmenistan have undermined the right to health through the censorship of public health data.[3] These uses of health data point to a longstanding recognition of its value as a source of knowledge and power.

More recently, the increasing production of digitized health data through the widespread use of electronic patient records, new health applications, and wearable technologies—coupled with advancements in computational power—have enabled the development of novel algorithmic and machine learning tools to improve diagnostics, treatment, and administration in health care. Training these algorithmic technologies requires access to huge datasets, resulting in increased demand for health data and fueling the emergence of a burgeoning global health data economy. With the booming AI health care market set to be worth US$6.6

Amy Dickens is a doctoral researcher for the Human Rights, Big Data and Technology project at the University of Essex, UK.

Please address correspondence to the author. Email: amyvdickens@btinternet.com.

Competing interests: None declared.

This work was supported by the UK's Economic and Social Research Council [grant number ES/M010236/1].

billion by 2021, health data is no longer simply a source of information but a valuable asset used to generate intellectual property and economic profit.[4]

The commercialization of health data: A problem for human rights

Today, the scientific and commercial value of health data is captured predominantly by the tech giants, whose first-mover advantage, technical expertise, and wealth of resources enable them to dominate the market for data-driven innovation in health. In recent years, these companies have sought to extract the commercial value of health data by collaborating with health care providers to develop new algorithmic technologies. This business model is exemplified by the controversial partnership between Google's DeepMind and the UK's National Health Service, in which DeepMind was given free access to 1.6 million patient records in exchange for developing a new clinical application to detect acute kidney injury.[5]

The deal raised serious concerns around patient privacy, highlighting how the tech giants' access to health data risks infringing on civil and political rights, such as the right to privacy.[6] It also granted DeepMind exclusive property rights to any technologies developed through the collaboration, enabling the company to determine the price of such technologies and to control access to their health benefits. Commercial capture of the scientific and financial value of health data through partnerships such as these may restrict equitable access to data-driven technologies and their health benefits, thus infringing on the rights to science and health.

Unlike the tech giants, states are currently ill equipped to realize the value of patient data. Most health systems, particularly those in low- and middle-income states, do not have the financial or technological capacity to develop algorithmic technologies themselves. The private sector thus has an indispensable role to play in facilitating data-driven innovation. Yet the public sector also lacks the necessary commercial expertise to strike up effective deals with the tech giants. This is compounded by the difficulty of quantifying the true "value" of data, which makes it unclear as to whether states (and patients) are getting a fair return for providing access to patient records.

The commercialization of health data is thus a double-edged sword for human rights: while the development of data-driven technologies that could advance socioeconomic rights depends on the capabilities of tech giants, human rights are also threatened by these companies' involvement.

Realizing the potential of health data resources

State signatories to the International Covenant on Economic, Social and Cultural Rights have an obligation to take steps to progressively realize the rights to science and health to the maximum of their available resources and to protect these rights from violations by third parties.[7] Furthermore, according to the Committee on Economic, Social and Cultural Rights' General Comment 25, states are required to "promote scientific research … to create new medical applications and make them accessible and affordable to everyone."[8]

If states are to harness the true value of health data to advance human rights, they must first recognize its potential to deliver scientific and economic benefits. To this end, they should strive to improve the availability of health data while ensuring appropriate protections. This requires that states invest in efforts to develop and maintain high-quality health data systems. Where resource-scarce countries face barriers to digitization, other states should provide international assistance.[9]

States must also ensure that research collaborations with technology companies do not allow commercial actors to infringe on human rights, including the rights to science and health. To do so, they must challenge tech giants' monopoly ownership of algorithmic technologies and demand equitable benefits for the use of rights-holders' data. This requires that states consider alternative means to advance data-driven innovation, such as commercial models like profit- or IP-sharing agreements or more innovative data governance solutions like data trusts. In order to determine what constitutes a fair return for rights-holders, states should support efforts to develop novel methods of quantifying the value of health data and actively promote the participation of patients in data governance efforts.[10]

For the commercialization of health data to advance human rights, states must use patient data to generate new innovations, while pushing back against the encroaching powers of the tech giants by laying claim to rights-holders' legitimate stake in the ownership of algorithmic technologies and protecting patient privacy. This urgent task reinforces the Committee on Economic, Social and Cultural Rights' call for states "to regulate the ownership and control of data according to human rights principles."[11]

References

1. Free Dictionary, *"Health data" definition*. Available at https://medical-dictionary.thefreedictionary.com/health+-data.

2. See S. Glowa-Kollisch, K. Andrade, R. Stazesky, et al., "Data-driven human rights: Using the electronic health record to promote human rights in jail," *Health and Human Rights Journal* 16/1 (2014); C. Williams, D. Exeter, S. Gibb, and P. Hunt, "Using big data to demonstrate indivisibility of rights and promote cross-sectoral responses to the Sustainable Development Goals," *Journal of Human Rights Practice* 11/1 (2019), pp. 239–250; Center for Economic and Social Rights, *Egypt social progress indicators: Health* (2018). Available at https://www.cesr.org/sites/default/files/espi_health_factsheet_2018_web.pdf.

3. J. J. Amon and M. Wurth, "A virtual roundtable on COVID-19 and human rights with Human Rights Watch researchers," *Health and Human Rights Journal* 22/1 (2020); A. Yaylymova, "COVID-19 in Turkmenistan: No data, no health rights," *Health and Human Rights Journal* (October 5, 2020).

4. Accenture, *AI: An engine for growth*. Available at https://www.accenture.com/sg-en/insight-artificial-intelligence-healthcare.

5. See A. Dickens and L. McGoey, "Beyond privacy: The right to health implications of data sharing Partnerships in healthcare," *Human Rights, Big Data and Technology Project blog*. Available at https://www.hrbdt.ac.uk/beyond-privacy-the-right-to-health-implications-of-data-sharing-partnerships-in-healthcare.

6. See J. Powles and H. Hodson, "Google DeepMind and healthcare in an age of algorithms," *Health and Technology* 7 (2017), pp. 351–367.

7. International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966), art. 2(1); Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health, UN Doc. E/C.12/2000/4 (2000), para. 33.

8. Committee on Economic, Social and Cultural Rights, General Comment No. 25, Science and Economic, Social and Cultural Rights, UN Doc. E/C.12/GC/25 (2020), para. 67.

9. Committee on Economic, Social and Cultural Rights, General Comment No. 3, The Nature of States Parties' Obligations, UN Doc. E/1991/23 (1990), art. 13.

10. See, for example, Open Data Institute, Data's value: How and why should we measure it? (August 9, 2018). Available at https://theodi.org/article/datas-value-how-and-why-should-we-measure-it; Ernst and Young, *Realising the value of health care data: A framework for the future* (London: Ernst and Young, 2019).

11. Committee on Economic, Social and Cultural Rights (2020, see note 8), para. 76.