



Why is Data Accessibility a Human Rights Issue?

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Abstract: the COVID-19 pandemic revealed a gap between existing technical capabilities in data analytics and the ability of public authorities to use them. While some societies were able to implement solutions based on data analytics, others, due to low mobile internet penetration, lack of appropriate legal frameworks or limited digital literacy in the population, were forced to rely on traditional forms of response to the spread of SARS-CoV-2.

The potential of digital data in preventing and combating the COVID-19 pandemic has been recognised by both international organisations and national governments. For example, in June 2020, the World Health Organization [created](#) a global [database](#) of technologies to combat COVID-19, including data, intellectual property and knowledge on COVID-19 health products. At the country level, public authorities across the world publicly shared detailed pandemic [data](#). Some countries, such as [Italy](#), adopted new regulations to streamline data sharing between healthcare facilities, research entities and public authorities. The largest digital corporations, including [Baidu](#), [IBM](#) and [Twitter](#), also facilitated access to data and algorithms. Why is accessibility of data so important? There are at least

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three reasons. First, access allows organizational, financial and human resources to be allocated to data analysis instead of data collection. This translates into quicker and more robust responses as various researchers can address different challenges at the same time. Secondly, as Gutierrez and Li have [pointed](#) out, access facilitates cross-validation of scientific results, which makes new discoveries more reliable. Thirdly, it improves data quality because more people are proactively monitoring data integrity and reporting issues. We could observe these effects during the COVID-19 pandemic, which was characterised by the unprecedented mobilisation of [citizen science](#).

Although data accessibility has recently been much discussed in the context of COVID-19, we should not miss the bigger picture. Large data sets can be used to develop data analytics-based diagnostics or predict the spread of *any virus*. The need to establish principles for responsible data sharing in epidemics was [highlighted](#), for instance, during the Ebola outbreak in 2015. And as Hatch [notes](#), text mining of scientific publications is used in drug discovery as it improves the process of selecting drugs for clinical trials and thus shortens the time that elapses before they reach the market. At the same time, however, these trends also contribute to the perception of data as an economic asset. Thus, momentum must be maintained, and action taken, in order to prevent the potentially adverse effects of data concentration and, consequently, innovation and market concentration. In this regard, it is encouraging that in responding to COVID-19, some governments introduced or amended laws [regulating](#) the scope of compulsory licenses (e.g., Canada, Chile, Germany and Israel). International and regional organisations also adopted instruments on Open Data (e.g., [European Union](#), [UNESCO](#)). The response to COVID-19 shows that the facilitation of data access is a human rights issue. Moreover, the UN treaty system provides solid ground for the development of normative standards. These should be derived primarily from the rights in the field of science promulgated in the Universal Declaration of Human Rights ([Article 27](#)) and established in the International Covenant on Economic, Social and Cultural Rights ([Article 15\(1\)\(b\)](#)), including the right of everyone to benefit from scientific progress and its applications.

Data-related obligations of states

The normative clarification of the right to benefit from scientific progress and its applications has been recently taken up by the UN Committee on Economic, Social and Cultural Rights. In 2020, the Committee adopted [General Comment no. 25](#) on science and economic, social and cultural rights, which was discussed on this blog by experts and commentators including [Mikel Mancisidor](#) and [George Ulrich](#). In line with UNESCO's approach, the General Comment emphasises the need to ensure data availability for research activities and identifies data as a primary means of the scientific enterprise. The text expressly formulates the obligation of states as regards the promotion of open science, including data, in the following way:

States should promote open science and open source publication of research. Research findings and research data funded by States should be accessible to the public (para. 16).

The General Comment also [addresses](#) data exclusivity, which hinders the advancement of science. It calls on states to ensure that any intellectual property restrictions on data are consistent with the public interest, reasonable and proportionate. This also means that states should not include data exclusivity clauses in '[TRIPS-plus](#)' agreements which are signed by EFTA, the European Union and the US with developing countries.

General Comment no. 25 also includes a brief overview of human rights issues posed by emerging technologies, including Big Data. In this context, the Committee indicates that 'emerging inequalities are strongly linked to the capacity of some business entities to access, store and exploit massive data' (para 76). Therefore, states should regulate the ownership and control of data according to human rights principles. The UN Office of the High Commissioner for Human Rights has [provided](#) comprehensive guidance in this matter

Looking into the future

COVID-19 has magnified the issue of data accessibility and the need for changes in the data governance framework. Future frameworks should adequately strike a balance between intellectual property rights and the right to benefit from scientific progress and its applications. To achieve this, the legislative toolkit already includes instruments such as compulsory licenses, the right to data portability and the principle of re-use of publicly funded data. Policymakers and legislators should thoroughly review the existing data governance framework and ensure that everyone can benefit from the digital revolution.

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