

Against data individualism: Why a pandemic accord needs to commit to data solidarity

Ilona Kickbusch¹ | Barbara Prainsack² 

¹Global Health Centre, Graduate Institute of International and Development Studies, Geneva, Switzerland

²Department of Political Science, University of Vienna, Vienna, Austria

Correspondence

Barbara Prainsack, Department of Political Science, University of Vienna, Universitätsstraße 7, 1010 Vienna, Austria.
Email: barbara.prainsack@univie.ac.at

Abstract

An accord to increase global pandemic preparedness is currently negotiated at the World Health Organisation (WHO). One aspect is conspicuously missing from the draft version: data governance. As the COVID-19 pandemic has shown, the availability of good quality data, and prudent ways of using this data while preventing other forms of data use that is harmful to people and communities, is literally a matter of life and death. It is of utmost importance for the pandemic accord to include a data governance strategy. We argue that data solidarity provides a suitable foundation for such a data governance strategy in the context of pandemics. It includes instruments to facilitate data use in cases where data use is likely to create benefits for many people without entailing high risks for individuals or communities. Data solidarity also calls to refrain from data use in cases where it would pose unacceptable risks. Finally, data solidarity helps to mitigate harm where it occurs. In sum, data solidarity helps to enhance the benefits from digital practices in health crises without playing out collective interests against the rights and needs of individuals.

INTRODUCTION

Based on lessons learned from the ongoing COVID-19 pandemic, an accord (WHO CA+) is currently being negotiated at the World Health Organisation (WHO) with the goal overcoming obstacles to global cooperation in pandemic preparedness. In particular, the pandemic accord aims to address current inequities in the monitoring of early signs, in the sharing of information, and in access to medical supplies, vaccines and treatment. These inequities are not only an ethical problem; they have also significantly hindered the effectiveness of pandemic measures. The exact legal nature of the accord has not yet been decided. Its next version is expected to be ready for the next step in negotiations in June 2023.

At present, one topic is conspicuously missing: health data governance. The draft document refers to the importance of 'early, safe, transparent and rapid sharing' of genetic samples and data as well as to the value

of building digital health and data science capacities (WHO, 2023). However, not only does it lack substance on an overarching health data governance framework, it does not even acknowledge the need for one. The WHO-CA+ also fails to address the fact that the digital divide reinforces—and can worsen—the health divide. In a pandemic, this is a matter of life and death.

Given the strong demand for data-driven decision-making during the COVID-19 pandemic, this lack of attention to health data governance is concerning. During health crises, a strong data infrastructure and reliable access to information is crucial. Health data governance includes important questions about collecting, opening, organising, storing, sharing and using data. It also highlights the challenges associated with data use (Holly et al., 2023).¹

In the COVID-19 pandemic, reliable and relevant data have often been missing or not available in near real time. For example, grave racial and socio-economic disparities remained unaddressed for too long because

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of missing data on the ethnic background of those who became critically ill (Dace, 2021; Maybank, 2020). Moreover, the lack of harmonised data collection standards made it impossible to compare epidemiological and other information between countries. Access to and re-usability of data left much to be desired. The experiences and needs of certain vulnerable groups remained entirely invisible (Steventon, 2021). The absence of health data governance frameworks, alongside that of meaningful norms and laws around digital platform governance, has unfortunately facilitated to the spread of mis- and disinformation across the globe. The human and financial costs of fake news around COVID-19 are estimated to be higher than those of natural disasters or terrorism (Bruns et al., 2021; EPP Group, 2022; London Economics, 2020).

Many of these governance challenges need to be resolved within regional, national or supranational health data governance frameworks and infrastructures. These must be a key feature of post-pandemic action and investments. But in the case of a pandemic, the sharing of data and information—and the counteracting of mis- and disinformation as well as otherwise harmful information—across borders becomes critical. International Health Regulations and the WHO CA+ must set the framework for the sharing of health data as global public goods to inform global policy responses. The data provided must be of good quality, and there must be no negative repercussions for the people and countries sharing these.

If the pandemic accord is to be effective in enhancing pandemic preparedness and response, it needs to include health data governance that is fit for the digital era. Part of the solution is technical; to some extent, privacy-protecting features can be designed into the formats and software of data sharing. But a large part is also normative, built around concepts of trust in how and by whom technologies are developed, made available to others, and for whose benefit.

BEYOND DATA INDIVIDUALISM

During the COVID-19 pandemic, it has been falsely suggested that there is a zero-sum game between the protection of people's health and respect for people's right to freedom and privacy. In reality, the two are connected: we cannot meaningfully exercise our freedoms if our health is under threat (EGE, 2022). Regarding data privacy, research has shown that people's concerns about privacy in connection with contact-tracing apps, for example, have pertained as much to concerns about over-surveillance and other societal issues as to individual privacy (Lucivero et al., 2022). In short, the pitting of individual privacy and freedom against public health during the COVID-19 pandemic has missed the point that individual freedoms require collective goods

to be realised and vice versa. It has fuelled atomistic individualism and enabled the hijacking of values such as freedom and liberty by agitators at one end of the political spectrum, and their divorcing from any links to obligations of citizens and the common good.

Next to ethical and trustworthy data use, regulatory frameworks need to change to increase not only individual but also the collective control of societies over data use. In digital societies, people can become the target of discrimination and other problematic practices based on other people's data. Informed consent alone cannot reduce these risks. Neither can it alone prevent any of the problems mentioned above, from the absence of good and relevant datasets during the pandemic to the spread of mis- and disinformation. Multiple societal harms can emerge from the concentration of data and power in the hands of a few dominant actors, whether commercial businesses or public authorities. The apparent powerlessness of governments in the face of the rapid spread of COVID-19 misinformation has been one consequence.

Data individualism, as well-intentioned and as helpful as it may have been in the past, is no longer fit for purpose, particularly when managing data in a pandemic age. Also public health approaches require a different mindset. While individual-level control over data remains important, it needs to be complemented by instruments of collaborative control and oversight over the production of data and its use. Only such collective instruments can address the power asymmetries of the digital age and support a global and public-health-based approach to disease outbreaks and pandemics.

We propose data solidarity as the conceptual framework to get us closer to this goal (Praisack et al., 2022; Kickbusch et al., 2021). Data solidarity is based on the principle of data sharing for the common good and seeks to increase collective control over data governance in three ways.

First, data solidarity seeks to ensure that data collection and data use that yield high public value receive strong public support and data infrastructure investment. In such cases, significant public funds need to be dedicated to building digital health and data science capacities, including infrastructures for data storage. Comprehensive legal action is required to ensure that health data are collected in a standardised, interoperable and re-usable form, and that human rights and equity considerations are respected. The WHO CA+ needs to address both of these issues.

Second, data solidarity seeks to prevent and to mitigate harm. It resonates with Health for All values (Ganten et al., 2018; Ghebreyesus, 2023) and a public health approach. During the COVID-19 pandemic, for example, lives could have been saved if disadvantaged groups had had better access to protective equipment and treatment or if social media platforms had been obliged to remove obvious dis- and misinformation. In the context of pandemic prevention and response

specifically, the involvement of stakeholders in the various stages of the policy cycle will be essential—it is necessary to develop collaborative governance models in advance as part of resilience and preparedness. In the case that individuals or groups are harmed by data extraction, it is of key importance that they have access to support, independent of their social and financial means (McMahon et al., 2019).

Third, data solidarity aims to ensure benefit sharing, meaning that some of the profits that emerge from commercial data use come back to the public domain, in an acknowledgement that people, communities and public infrastructures have enabled the creation and collection of this data. While the requirement of (genuine) informed consent of people to the use of their data by corporations remains of utmost importance, more needs to be done to benefit people and communities. Whenever people's health or behavioural data are used for commercial purposes, digital taxes or benefit-sharing agreements need to ensure that some of the profits generated are invested for public purpose. The benefit-sharing rules addressed in the WHO CA+ must also apply to data. This is essential not only in low- and middle-income countries but also with regard to disadvantaged regions and groups in high-income countries. Overall, data governance needs to deserve public trust, which, in turn, requires that the increasing involvement of big tech in data policies must be curbed.

The pandemic accord that will eventually be adopted must be a strong one fit for the digital age—at present, this is not the case.

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CONFLICT OF INTEREST STATEMENT

Both authors have no conflicts of interest to declare. They note their relevant memberships of advisory bodies in the author biography.

DATA AVAILABILITY STATEMENT

This is a comment on policy making that does not use datasets. We refer to academic publications, as well as to policy documents that are all in the public domain.

ORCID

Barbara Prainsack  <https://orcid.org/0000-0002-6335-1532>

ENDNOTE

¹ Open Data Watch has structured these needs according to the stages of the data value chain: availability, openness, dissemination, and use and uptake. It also requires a strong grounding in ethics and equity as driving principles.

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AUTHOR BIOGRAPHIES

Ilona Kickbusch is the founding director and chair of the Global Health Centre at the Graduate Institute of International and Development Studies in Geneva. She advises international organisations, national governments, NGOs and the private sector on new directions and innovations in global health, pandemic preparedness and governance for health. She was co-chair of the Lancet/FT Commission on Governing Health Futures - Growing up in a Digital World.

Barbara Prainsack is a professor at the Department of Political Science at the University Vienna, where she also directs the interdisciplinary Research Platform 'Governance of Digital Practices'. She is also the Chair of the European Group on Ethics in Science and New Technologies which advises the European Commission.