

# ACT-Accelerator data governance framework: Balancing individual rights with the public interest in responding to COVID-19

COVID-19 is a global pandemic, and the world's first 'digital pandemic'. The response to the disease has seen the development of digital tools to track, trace and analyse the virus, and we have seen a rapid scale-up in the use of digital health.<sup>[1]</sup> An effective COVID-19 response is contingent on timely access to personal data.<sup>[2]</sup> These data can be used to identify COVID-19 hotspots and guide national and localised responses, but importantly, can also be used in the development of tests, treatments and vaccines. The use of these personal data in responding to COVID-19 is essential, but their use impacts the right to privacy and risks stigmatising and discriminating against individual, group and minority populations. Other risks can also arise depending on the context in which the personal data are used, and the vulnerabilities of the individual or population.<sup>[3]</sup> There is a clear public interest in enabling access to, sharing and use of personal data to respond to COVID-19, but there is an equally clear public interest in ensuring that the use of these personal data is rooted in human rights, including the right to privacy, the right to health and life and the right to economic and social development. Thus the use of personal data during COVID-19 brings to the fore a critical question in access to and use of personal data: how do we balance individual rights with collective interests in the use of personal data to respond to a public health crisis?

The Access to COVID-19 Tools Accelerator (ACT-Accelerator) was launched in April 2020, bringing together governments, scientists, businesses, civil society, philanthropists and global health organisations.<sup>[4]</sup> Its purpose is to end the COVID-19 pandemic by scaling up the development and equitable distribution of tests, treatments and vaccines. It comprises four pillars: the diagnostics pillar; the vaccines pillar (also called COVAX); the therapeutics pillar; and the health systems pillar. Early in its work, the research and development (R&D) and digital working group of the ACT-Accelerator diagnostics pillar realised that initiatives funded under its pillar would involve the use of personal data. To ensure that initiatives funded under ACT-Accelerator respect human rights and that the use of personal data is appropriately governed, the Framework for the Governance of Personal Data for the Access to COVID-19 Tools Accelerator was initiated.<sup>[5]</sup>

The framework is grounded in the substantive principles of solidarity, respect for persons and communities, equity, non-exploitation, privacy and data stewardship, as well as the procedural principles of transparency, accountability and engagement. These principles are implemented in a procedural guideline on the collection, retention and management of personal data. In recognition of the importance of public trust and public involvement, the framework requires that initiatives funded under the ACT-Accelerator develop a public engagement strategy to identify potential risks involved in the processing of personal information, and provide a mechanism to feed back to the data subjects and wider public on the progress of their work.

There has historically been inequitable access to tests, treatments and vaccines, and the delayed procurement of COVID-19 vaccines in many African countries demonstrates that this persists. The framework requires that all initiatives funded under ACT-Accelerator have a duty to ensure that there is equitable distribution of tests, treatments and vaccines. However, inequity can also pertain to access and sharing of personal data. To help ensure equity of access to personal data, any initiative funded under ACT-Accelerator must share data at no cost or at cost-recovery only, collaborations must consider community, individual researcher and organisational benefits as part of benefit-sharing and capacity development, the primary data collectors and anyone involved in knowledge production must be afforded appropriate recognition, and while access to COVID-19 tests, treatments and vaccines will be the clear benefit to local communities, other benefit-sharing arrangements must be discussed and agreed upon as part of community engagement.

Governments equally have a responsibility to ensure that they are transparent and accountable in their use of personal data during the COVID-19 pandemic. In an effort to achieve this, the framework recommends the establishment of national independent data stewardship oversight committees. Each committee should be interdisciplinary and include experts in public health, law (particularly privacy), ethics, technology and security, as well as people who have or have had COVID-19, and representatives from marginalised groups, with a specific emphasis on those facing intersectional discrimination. It should, at a minimum, monitor the collection, use and sharing of COVID-19 personal data, provide further guidance where necessary and engage with the public on their expectations and the wider implications of the use of COVID-19 personal data.

Looking to a post-pandemic world, there will be an immense amount of COVID-19 personal data available. Processes need to be put in place to ensure the long-term management of these data. The clear public interest that currently justifies its use will have passed, but there is real value in using these personal data to inform our pandemic preparedness, as well as other research. The emergency situation will have ended: thus the rules and procedures on access to and use of these data may differ. The framework states that it is the Data Stewardship Oversight Committee that should be tasked with deciding on future access to COVID-19 personal data, and ensuring that this access and use is in line with public expectations.

The framework aims to promote best practice and the responsible use of personal data in responding to COVID-19, both now and in the future. It seeks to safeguard privacy interests and mitigate risks associated with the use of personal data. It applies to all initiatives funded under ACT-Accelerator, and is intended to complement data protection regulations (where they exist). However, it is also intended to guide the development of national regulations on the governance

of personal data for COVID-19-related activities, where these are lacking. ACT-Accelerator welcomes and actively encourages COVID-19-related consortia, COVID-19 research projects and other initiatives that are using COVID-19 personal data to adopt this framework. The framework is a living document and should be updated and refined based on recommendations and experiences with its implementation. Feedback should be sent to the ACT-Accelerator diagnostics pillar (ACTAdiagnostics@finddx.org). In addition, the R&D and Digital Working Group of the ACT-Accelerator diagnostics pillar must evaluate and update this framework every 6 months. Through this sharing of experiences in the use and implementation of the framework during this pandemic, it can be used to guide the use of personal data in future pandemics.

**Acknowledgements.** I would like to acknowledge the R&D and Digital Working Group of the ACT-Accelerator diagnostics pillar, who initiated the development of this framework, and the ACT-Accelerator ethics and governance working group, who provided substantive feedback throughout the process. We would like to thank the other groups and individuals who provided feedback on earlier drafts of the framework. A full list of the acknowledgements can be found in the framework.

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*S Afr J Bioethics Law* 2021;14(1):4-5. <https://doi.org/10.7196/SAJBL.2021.v14i1.756>