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Ethics and governance challenges related to genomic data sharing in southern Africa: the case of SARS-CoV-2

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Abstract

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We declare no competing interests.

Data sharing in research is fraught with controversy. Academic success is premised on competitive advantage, with research teams protecting their research findings until publication. Research funders, by contrast, often require data sharing. Beyond traditional research and funding requirements, surveillance data have become contentious. Public health emergencies involving pathogens require intense genomic surveillance efforts and call for the rapid sharing of data on the basis of public interest. Under these circumstances, timely sharing of data becomes a matter of scientific integrity. During the COVID-19 pandemic, the transformative potential of genomic pathogen data sharing became obvious and advanced the debate on data sharing. However, when the genomic sequencing data of the omicron (B.1.1.529) variant was shared and announced by scientists in southern Africa, various challenges arose, including travel bans. The scientific, economic, and moral impact was catastrophic. Yet, travel restrictions failed to mitigate the spread of the variant already present in countries outside Africa. Public perceptions of the negative effect of data sharing are detrimental to the willingness of research participants to consent to sharing data in postpandemic research and future pandemics. Global health governance organisations have an important role in developing guidance on responsible sharing of genomic pathogen data in public health emergencies.

Introduction

Africa has been home to exploitative research practices for decades. The terms safari research and parachute research arose out of this culture of exploitation.¹ Public health crises have exposed the continent's vulnerability to such research practices, most starkly during previous Ebola virus outbreaks.² The current COVID-19 pandemic is no exception. Genomic data for pathogens with epidemic and pandemic potential have proven invaluable in diagnostics, therapeutics, vaccine development, and public health planning. Consequently, the promotion and encouragement of the sharing of pathogen genomic sequence data has been pivotal. Before the pandemic, global research teams carefully guarded their research findings for months until data analysis and publication had occurred.³ However, this practice is incompatible with public health emergencies during which the health and lives of the global population are at risk.⁴ Open data sharing with scientists and governments allows for rapid assessment of the extent of the public health threat, development and initiation of diagnostic test kits, development of vaccines, and innovative response measures.⁴ At the same time, surveillance and research teams require credit for the work they do. This credit is particularly relevant in low-income and middle-income countries (LMICs) because the resources and skills needed for data analysis are unevenly distributed such that high-income countries (HICs) usually have more capacity to analyse data that are openly accessible.² Although this concern applies to the sharing of samples and data, the sharing of pathogen genomic sequence data is used in this Viewpoint to highlight that striking a balance between advancing science through data sharing, preventing exploitation, and maintaining scientific integrity creates an ethical dilemma for LMIC researchers.¹

The COVID-19 pandemic saw many research teams supporting national public health institutes that are usually responsible for public health surveillance. To some extent, this pandemic opened debate on different legal and ethical frameworks surrounding public health surveillance and research. The WHO guidelines on ethical issues in public health

surveillance includes guideline 15, which states: “During a public health emergency, it is imperative that all parties involved in surveillance share data in a timely fashion.”⁵

Data sharing options currently occupy a spectrum that ranges from open access databases without any restrictions (US GenBank and European Nucleotide Archive) to databases with restricted access, such as the Global Initiative on Sharing Asian Influenza Data (GISAID). The different options have caused controversy, with prominent scientists in North America and Europe appealing for unrestricted access⁶ and scientists from Africa requiring sufficient protections for those who generate and share data as per the GISAID terms and conditions.⁷

In September, 2021, UNESCO published a Draft Recommendation on Open Science, recommending global data sharing of science, technology, and innovation.⁸ Likewise, several funding bodies require unrestricted data sharing. Policy makers have promoted open science for decades to discourage a reluctance to share data.⁹ Hence various research groups, policy makers, and funders are in disagreement over preferences.

An effort at data sharing occurred during the COVID-19 pandemic. However, this scientific goodwill left southern African countries unjustly ostracised and the global scientific community polarised. Negative consequences associated with data sharing, whether real or perceived, discourage transparency as Africa is often considered last for all interventions required to manage a pandemic—diagnostics, therapeutics, and vaccines—yet first in line for travel bans.¹⁰

Omicron reports in South Africa and Botswana

On Nov 25, 2021, the South African health minister and a team of scientists announced the identification of a new variant of the SARS-CoV-2 pathogen.¹¹ The announcement was made in the interest of transparency and to build public trust. The Network for Genomic Surveillance South Africa, working with scientists from Botswana, uploaded the new genetic sequence data to the GISAID database to rapidly share genome sequences. Following an urgent meeting with WHO, omicron (B.1.1.529) was formally designated a variant of concern.¹¹ A disappointing surge in unscientific travel bans were immediately imposed upon southern African countries. The travel bans were unscientific because the variant was already present in other countries before the announcement and the time advantage was already lost. Furthermore, blanket travel bans were not the least restrictive way of preventing viral spread given the availability of vaccines and improved treatment and prevention measures by December, 2021.¹² One of the authors of this Viewpoint (TdO), a bioinformatics expert at Stellenbosch University (Stellenbosch, South Africa) who led the team credited with identifying the omicron variant, implored authorities to transform the way pandemics are dealt with. Calling for a collectivist approach in data sharing during pandemics, he cautioned that more harmful pathogens could emerge if nationalist attitudes endure.¹¹ The South African team similarly identified the beta variant (B.1.351) in October, 2020, and helped in the identification of the alpha variant (B.1.1.7) in December, 2020, serving as a testament to South Africa’s adept genomic surveillance capabilities. At the time of the discovery of omicron, many travel bans were still in place resulting from the detection of beta—long after beta had been displaced by delta (B.1.617.2) throughout Africa

and globally. Local communities, journalists, and researchers expressed concerns that data sharing had caused more harm than good.¹³ Parallels were drawn with previous exploitative practices.¹⁴

Challenges with data sharing

A history of exploitation

Past events in research practices have led to the exploitation and misuse of viral samples, resulting in the erosion of trust within the existing global surveillance system. In 2007, Indonesia declined to share samples of the H5N1 virus with WHO on the basis of their previous unjust experience when data were freely and publicly provided to WHO's Global Influenza Surveillance Network. The refusal to share the samples came after a journalist informed Indonesian officials of plans for the samples to be used by an Australian pharmaceutical company to develop a vaccine. There were also no benefit-sharing plans in place to ensure vaccine access for LMICs.¹⁵ Indonesia's act of resistance generated international concern regarding open data sharing, disrupting a tradition of gratis distribution of influenza viruses, as other nations contended patents on vaccines and medicines developed from data sourced freely.¹⁵ The discovery of the Ebola virus is another example of the pillaging of research data and biological samples involving Africa. In 1976, Belgian microbiologist, Dr Peter Piot, was unduly given sole credit for the discovery of the Ebola virus that had been identified in partnership with Congolese microbiologist, Dr Jean-Jacques Muyembe-Tamfum, who sent blood samples from the Democratic Republic of Congo to Belgium for virus isolation. Piot later acknowledged that he should have been more proactive in correcting misconceptions that he was the sole discoverer of the virus, as this could have drawn more or equal attention to the contribution of the African scientific team.¹⁶ During the 2013–14 Ebola virus outbreak in west Africa, approximately 50 000 samples left the continent without consent or export permits. Similar incidents in which local researchers or communities have not benefited from research have surfaced where there has been a viral outbreak in Africa.¹⁷

Benefit sharing

Given the history of disproportionate distribution of benefits derived from data sharing, researchers understandably fear appropriation of data without equitable recognition, and so the hesitancy to openly share data outside the country of origin persists. The predatory nature of some HICs and pharmaceutical companies reveals the inequities of global health systems,¹⁸ which magnify the discrepancies in access as patented vaccines and medicines become financially inaccessible to developing nations.¹⁸ The status quo of restricted access to vaccines, medicines, and medical apparatus only to nations that can afford them is rightly contended.

Some researchers refer to the response of HICs to data sharing during the pandemic as data imperialism, cautioning researchers of the Global South that they should not allow a repeat of history.¹⁹ Systemic change is necessary to address existing barriers and ameliorate inequality by promoting an enabling research culture that allows greater participation from African researchers.²⁰ The recent call from *The Lancet*²¹ for inclusion of African

researchers as authors on papers emanating from research in Africa is an example of how benefit sharing needs to occur more explicitly. Likewise, research collaborations and networks need to include those who generate and share data.²¹

Although SARS-CoV-2 genetic sequence data have been shared on both public and private online databases, a struggle continues regarding open data sharing via public domain data-science repositories and regulated sharing initiatives, such as GISAID. Ideally, collectivist principles, including solidarity and social justice, that highlight population-based benefits should be honoured to produce the appropriate balance of individual and shared values, rights, and interests. Open data sharing is a key element of research integrity, yet must have governance mechanisms built in to prevent further inequity.

A specific benefit arising from the detection and early sharing of information about variants of concern is that the genomic data have allowed vaccine companies to modify their vaccines. The omicron-adapted COVID-19 vaccine has been rolled out across parts of Europe and North America as of September, 2022, in time for a likely rise in infections. Speed is important, so the vaccine companies started working on updating the vaccines as soon as the sequence data were shared and omicron was designated a variant of concern. But the expectation and likelihood is that countries where omicron was first detected and characterised will again be at the back of the queue for these modified vaccines. This expectation is not unfounded, considering the current global monkeypox outbreak in which HICs are making stockpiled smallpox vaccines available to their vulnerable populations, whereas African countries have been desperate to access these resources for decades.²²

Towards more equitable data sharing

The first genomic data of the novel coronavirus was released on Jan 10, 2020. This collaboration enabled the globe to develop the first diagnostic tests and to work toward the first vaccines. Following the first genome, within weeks, thousands of genomes were shared in GISAID. Many described the utilisation of GISAID as revolutionary, and almost all African countries have shared coronavirus data through it.¹⁹

Developed in 2008, with the intent of mitigating the challenge of data sharing hesitancy, GISAID aims to protect the rights and interests of researchers, thereby preventing exploitation.⁶ This platform allows authorised users of the data repository to have open access to all data stored within the system, both published and unpublished genomic data of influenza viruses and the coronavirus responsible for the COVID-19 pandemic. Authorised users need to identify themselves, acknowledge both the originating and submitting laboratories that provide specimens and generate sequencing data (should they use that data), and have no restrictions attached to any data submitted. However, they do need to provide proper attributions and acknowledgments when using data from GISAID in publications, manuscripts, and any other analyses, and make efforts to collaborate with those researchers.⁶ Authorised users must also agree not to distribute data made available through GISAID with others who have not agreed to the GISAID terms of use.

GISAID's activities are governed by several independent organisational bodies. It is concerning that there are no representatives from Africa and other LMICs apart from Indonesia and China. Authorised users agree to the terms of use by accepting that their use of all GISAID data will comply with all applicable laws and regulations, including, but not limited to, laws relating to the export and import of technology, personal privacy, and human use of any product, material, or substance derived from the GISAID database.²³

Critics of GISAID propose that the protections for data contributors are too cumbersome and that public-domain repositories (without contributor protection) are preferable.¹⁹ They argue that GISAID restricts the public resharing of genetic sequence data, which hampers efforts to understand SARS-CoV-2 by adding to the rapid increase of new variants and delays prompt and calculated action against the pandemic. SARS-CoV-2 genetic sequence data from Africa are vital in identifying different genomic–environmental interactions and interpreting the effect of pathogen genome sequence data.¹⁹ However, it is also important to recognise the consequences South Africa faced upon alerting the globe to omicron and to question what benefit South Africa received from doing so.

Unanticipated consequences of the announcement of the omicron variant

The immediate travel bans imposed by many HICs following the announcement of omicron greatly affected not only the South African economy but also the country's ability to make further progress in research. Access to COVID-19 technological equipment and science diagnostics were delayed. This equipment was needed for critical early variant analysis. Scientists at the University of Cape Town (Cape Town, South Africa) announced that their collaborators from the La Jolla Institute for Immunology (San Diego, CA, USA) were unable to send them omicron laboratory reagents due to the travel bans.²⁴ Furthermore, delivery of medical supplies was interrupted, academic conferences and exchanges were cancelled, unreasonable quarantine requirements were imposed globally if travel had occurred to and from southern Africa, and some scientists in the region faced death threats and abuse on social media.^{25,26} Others were chastised by local communities both for sharing the genomic data and announcing its presence in southern Africa. On Nov 28, 2021, South African President, Cyril Ramaphosa, called on countries to urgently reverse scientifically unjustified travel restrictions.¹² The profound economic effect of the travel ban was largely detrimental to the country's tourism sector, which is responsible for 18% of the country's employment.¹⁰ Botswana also faced detrimental economic effects. Regrettably, swift action was taken by global nations that imposed travel sanctions on southern Africa, which could not afford to have its economy penalised, whereas efforts are stagnant in assisting with vaccine accessibility in Africa.¹⁰ This element is merely one of the inequities revealed by the pandemic. By October, 2022, 75% of the population belonging to HICs have been fully vaccinated against COVID-19, whereas only 23% of Africans and 33% of South Africans have been fully vaccinated.²⁷

Recommendations

How do we build a more sustainable culture that values research and surveillance data globally and especially in Africa? Empowerment of researchers in Africa is imperative.

Given the widespread trust in GISAID, this initiative could have an essential stakeholder role by confirming and monitoring the international race between researchers to be the first to provide the genetic sequence data of new variants to secure some national benefit. Global governance of surveillance and research efforts in genomic research could be substantially improved.²⁰ The purpose of genomic data sharing is to support the human right of all to benefit from science and its applications. It is important to remember that international scientific initiatives are based on good faith and mutual trust, with the underlying belief being that genomic databases are a global public good. Communities need to be convinced that data sharing is beneficial for the public. Open science holds the capacity to further nurture research conduct that promotes standard processes for protocol sharing and study registration; reporting and dissemination of findings; and sharing data, biospecimens, and code. We recommend that GISAID makes an effort to incorporate African researchers into its board of members for improved diversity representation. The concept of data authorship is another recommendation to ensure that those involved in primary data collection are acknowledged in publications.²⁸ Data generators could also be credited via a virtuous cycle that links those who collected primary data using ORCID identification and persistent identifiers with all future use.

Travel bans ought to be based on scientific justification and public health ethics. Consideration must be given to the principles of solidarity, social justice, efficiency, and proportionality. The principle of proportionality requires that civil liberties can be restricted provided that the risk to public health is serious and that there are no less restrictive measures available.²⁹ At the time of the detection and announcement of omicron there were options other than travel bans at our disposal. These included mandatory vaccination of people at high risk of severe COVID-19, promotion of booster vaccine doses, and selective lockdown measures. These less restrictive measures could have been implemented. It is also imperative that genomic sequencing technology is equitably developed and available globally, and that capacity development is accelerated to ensure that all countries are able to sequence human and pathogen genomic data contemporaneously.³⁰

Conclusion

Data sharing in health research and surveillance is undoubtedly a scientific and ethical necessity. Genomics research has reaffirmed this especially during the COVID-19 pandemic. However, such communal scientific practices must be embedded within a moral context of solidarity and social justice that serves to reduce, rather than exacerbate, global health inequities. Public perceptions are important in regards to data sharing. Among local communities, travel bans were associated with the sharing of the omicron sequencing data and the announcement of the variant. Such perceptions will negatively affect data sharing in research outside public health emergencies. Announcement of the detection of the omicron variant via genome sequencing paradoxically disadvantaged many countries in southern Africa and raised concerns about future variants and disclosure. In response to these concerns, WHO is engaging in several initiatives to promote sharing of human and pathogen genomic data in an ethically sensitive, responsible, equitable, and sustainable manner. We hope these efforts will produce a unifying approach to genomic surveillance efforts in the face of future public health threats.

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