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Data-Driven HIV Humanitarianism, Data Colonialism, and Data Ethics: A Sub-Saharan African (SSA) Perspective

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Abstract

This article examines how data-driven humanitarianism in the HIV/AIDS sector reproduces colonial patterns of extraction and inequality in sub-Saharan Africa (SSA). Drawing on case studies of AI-enabled health data systems, it analyses the ethical implications of large-scale data collection, storage, and transfer in contexts marked by poverty, weak regulatory capacity, and persistent stigma. While datafication and artificial intelligence promise efficiency and accountability in HIV response, they also risk coercive consent, exploitation, and surveillance. The article argues that these practices constitute a form of data colonialism, in which the informational resources of SSA are extracted for the benefit of actors in the Global North. It proposes that equitable data governance in health humanitarianism requires transparent agreements, enforceable benefit-sharing, and community accountability rooted in Ubuntu-based bioethics. The goal is not less data, but fairer data - secure, participatory, and oriented toward justice and sustainable health outcomes.

***Keywords**:* Digital health ethics; HIV; AIDS; data colonialism; humanitarianism.

Introduction

Digital data has been called 'the new oil'[1] of the 21st century[2] because of its potential to drive prosperity if optimally utilised. Our daily activities continuously generate huge volumes of data, including when we go to the hospital, shop, travel, or watch a video on our electronic gadgets. This data is often stored and processed using artificial intelligence (AI) and machine learning algorithms, and later utilised for several purposes, including marketing, surveillance, modelling, predictions, diagnosis, etc.[3] In the context of humanitarian aid - and, in particular, in healthcare - the intersection of large-scale data collection with advances in machine learning and AI offer opportunities for significant health benefits.[4] Further, with HIV/AIDS specifically, a better understanding of testing, treatment, support, and management facilitated by data collection can significantly improve the lives of those living with HIV/AIDS, reduce its spread, and potentially contribute to efforts to develop a cure.[5]

However, just as oil created stark global inequalities, the collection of data in the context of humanitarian aid - and support related to HIV/AIDS in particular - raises a concern that the rise of digital data will further entrench existing social, health and

[1] The term data is 'the new oil' is attributed to the British mathematician Clive Humby, who is said to have used it in 2006. However, it is not clear whether he was the first to coin this term.
[2] Lisdorf, "Demystifying Smart Cities."
[3] Chaudhary, "Real-world Applications of Data Analytics, Big Data."
[4] Yin, "Role of Artificial Intelligence Applications in Real-life Clinical Practice."
[5] Ngcobo, "Artificial Intelligence for HIV Care."

economic exclusion, particularly in Sub-Saharan Africa.[6] The process through which digital data related to HIV/AIDS is extracted, stored, processed, and utilised often reinforces existing unjust colonial relations, which have enriched the colonial empires at the expense of their colonies.[7] Mejias and Couldry have termed this process 'data colonialism,' which refers to 'a social order in which the continuous extraction of data from our lives generates massive wealth and inequality on a global scale.'[8]

The continuous extraction of data affects several facets of our lives, including in well-intended global health humanitarian interventions such as HIV testing, treatment, and support. In this article, we focus on data-driven HIV humanitarianism: humanitarian support that is characterised by the continuous generation of data evidence in HIV testing, treatment, support, and management. In particular, we consider how HIV humanitarianism in Sub-Saharan Africa (SSA) contributes to data colonialism. We offer an analysis of how HIV-related data is collected, stored, and shared by humanitarian organisations in SSA, drawing on *Ubuntu*-based bioethics.[9]

The remainder of the article is organised as follows. Section two provides some context to the ways that large-scale data collection, storage, and processing is carried out in healthcare. Section three then raises some *general* concerns about healthcare data collection, and section four considers *specific* problems that arise in the collection of HIV humanitarian data in SSA. In section five, we argue that the approaches taken in SSA amount to data colonialism and we further argue that avoiding data colonialism requires clear, transparent, and comprehensive data agreements, developed in the absence of coercion and with an understanding of existing colonial power asymmetries. Finally, section six concludes.

2. The Rise and Role of Data in Healthcare in SSA

The application of artificial intelligence and machine learning trained on healthcare data is on the increase, both globally and in many SSA countries.[10] The application of AI and machine learning in healthcare promises significant benefits, including efficiency, precision, and improved health outcomes.[11] In this article, we will not provide technical explanations of how these systems work. For our purposes, it is sufficient to follow Surden in characterising 'artificial intelligence' as 'using technology to automate tasks that normally require human intelligence.'[12] We understand 'machine learning' as an approach that enables computers to emulate human intelligence by learning from their surrounding environment without being programmed, just like human beings.[13] Finally, we take data mining to involve the algorithmic extraction of novel, sometimes unexpected information from large database systems.[14] Although these methods have been applied in a wide range of fields as diverse as finance, visual arts, and agriculture, our focus is on the use of AI in health and HIV humanitarianism. More specifically, we focus on the current use of these technologies in the response to the HIV pandemic in SSA.

Contemporary artificial intelligence systems employ methods such as machine learning, data mining, and probabilistic models for a variety of goals, including problem solving, facial and object recognition, and natural language processing. In many cases this technology can be used to generate novel insights or more efficient testing results. For example, in Lesotho and South Africa, Computer-aided detection systems (CAD4TB) based on artificial intelligence (AI) are used to screen for tuberculosis (TB) related abnormalities using X-rays.[15] In addition, deep learning algorithms were trained and used in South Africa to classify images of HIV lateral flow test results as either positive or negative, which significantly reduced the number of false results.[16]

In other cases, large datasets are used to administer, share and manage healthcare services and information. In Zambia, an Electronic Health Record system known as 'SmartCare' is used to collect, store, and process demographic and biomedical data of HIV patients, and AI algorithms are used to generate different types of insights from it.[17] Similarly, genomic data about the

[6] Gwagwa, "The Role of the African Value of Ubuntu in Global AI Inclusion Discourse."
[7] Nhemachena, "Relationality or Hospitality in Twenty-First Century Research?"
[8] Mejias, "Data Grab,"13.
[9] Mwinsa, "International Bioethics, Ubuntu and HIV Testing in Sub-Saharan Africa."
[10] Oladipo, "Impact and Challenges of Artificial Intelligence Integration in the African Health Sector."
[11] Lau, "Rewriting the Narrative of AI Bias."
[12] Surden, "Artificial Intelligence and Law."
[13] El Naqa, "What is Machine Learning?"
[14] Thuraisingham, "A Primer for Understanding and Applying Data Mining."
[15] Glaser, "Incidental Radiological Findings During Clinical Tuberculosis Screening."
[16] Turbé, "Deep Learning of HIV Field-based Rapid Tests."
[17] Kaumba, "Factors Affecting the Implementation of the SmartCare EHR System."

Omicron SARS-CoV-2 virus discovered in South Africa in 2021 was shared and stored on the Global Initiative on Sharing All Influenza Data (GISAID) sequence database for surveillance and scientific purposes[18].

In Kenya, open-source fingerprint technology is reported to efficiently identify HIV patients when accessing HIV services.[19] AI systems are also used to manage hospital inventories and to make medical supply chains more robust.[20]

AI is also widely used to discover new medicines, vaccines, and treatments. AI systems can sift through huge volumes of biomedical data to identify promising drug targets, design novel molecules, and even suggest potential vaccine components. This is not just theoretical: for example, the small-molecule drug Rentosertib, designed with generative AI, advanced into Phase 2a clinical trials for idiopathic pulmonary fibrosis in under 30 months - much faster than the traditional drug development timeline.[21] Reviews also highlight that AI is transforming early-stage drug discovery by improving target identification, lead compound selection, and pre-clinical testing.[22] In the vaccine sector, AI tools have been utilised to design candidate vaccines more efficiently, with systematic reviews documenting advances in both design and development.[23] Table 1 provides additional examples of the application of AI-powered healthcare and research in SSA.

Table 1: Examples of AI-powered healthcare and research in SSA

Country	AI-Powered Healthcare/Research	Description	Source/Reference
Ethiopia	National AI-powered Digital X-ray for TB screening	AI-powered digital X-ray machines that expedite the screening of tuberculosis (TB).[24]	WHO (2025)
Nigeria	Artificial intelligence-guided screening for cardiomyopathies among the obstetric population	A randomised clinical trial utilising Artificial Intelligence (AI)-guided screening in the diagnosis of left ventricular systolic dysfunction (LVSD) in pregnant and postpartum women.[25]	Adedinsewo et al. (2024)
Kenya	SIVQ/VIPR (Spatially Invariant Vector Quantisation/Vectorising Pattern Recognition) AI System	An AI-powered pre-processor system that enables subsequent machine learning algorithms to assess cancer likelihood with remarkable precision.[26]	University of Michigan (2025)
Uganda	Smartphone-based DNA malaria diagnostics	A study using a paper-based microfluidic diagnostic test, combined with deep learning algorithms and blockchain technology to diagnose malaria with 98% accuracy.[27]	Guo et al. (2021)
Rwanda	Rwanda Artificial Intelligence for Diabetic Retinopathy Screening (RAIDERS)	A study using AI to screen for diabetic retinopathy (DR) using retinal imaging.[28]	Mathenge et al. (2022)
Kenya	PROMPTS (Promoting Mothers through Pregnancy and Postpartum)-AI-Powered Maternal Messaging	A 'two-way AI-enabled SMS-based platform that sends messages to pregnant and postnatal mothers based on pregnancy stage, and connects mothers with a clinical help desk to respond and refer urgent cases in minute.'[29]	Ochieng' et al. (2024)
Zimbabwe	Nyamukuta: The AI 'Midwife'	An app helping at-risk mothers and mothers-to-be navigate pre- and post-birth risk.[30]	Manika, C. (2025)

[18] Viana, "Rapid Epidemic Expansion of the SARS-CoV-2 Omicron Variant."
[19] Jaafa, "Implementation of Fingerprint Technology for Unique Patient Matching and Identification."
[20] Maleki Varnosfaderani, "The Role of AI in Hospitals and Clinics."
[21] Xu, "A Generative AI-discovered TNIK Inhibitor for Idiopathic Pulmonary Fibrosis."
[22] Ocana, "Integrating Artificial Intelligence in Drug Discovery"; Kant, "Artificial Intelligence in Drug Discovery."
[23] El Arab, "Artificial Intelligence in Vaccine Research"; Villanueva-Flores, "AI-driven Epitope Prediction."
[24] WHO, "Ethiopia among Pioneers in Rolling Out AI-Powered Digital X-Ray."
[25] Adedinsewo, "Artificial Intelligence Guided Screening for Cardiomyopathies."
[26] University of Michigan, "Partnership Powers AI-Driven Cancer Diagnosis in Kenya."
[27] Guo, "Smartphone-based DNA Malaria Diagnostics."
[28] Mathenge, "Impact of Artificial Intelligence Assessment of Diabetic Retinopathy."
[29] Ochieng', "Exploring the Implementation of an SMS-based Digital Health Tool."
[30] Manika, "In Zimbabwe an AI 'Midwife' is Making Pregnancy Safer."

Two major global health funding bodies - the President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis, and Malaria - provided funding for antiretroviral therapy (ART) for over 25 million people living with HIV/AIDS in 2024 most of whom live in SSA.[31] PEPFAR administers around 64 million HIV tests annually and provides prevention support for 1.5 million pregnant women. Although international funding has decreased over the past decade, international funding bodies and agencies continue to fund 40% of HIV programming in low- and middle-income countries, with a significant share of this funding directed at SSA.[32] This means that decisions about the use, collection, and processing of patient data by PEPFAR and the Global Fund in particular are instrumental in shaping data policies that affect many millions of lives in SSA.

Machine Learning and AI can be - and is being - used in HIV humanitarianism in a variety of ways,[33] similar to those detailed above. Data can be collected and mined for patient risk stratification, to understand when visits might be missed or when patients might suspend treatment. It can be used to identify emerging hotspots for infections and to predict demand for testing and ART, and it can be used to send tailored messaging to patients and more generally to direct the initiatives carried out by community health workers.

3. General Ethical Concerns

While these technologies have resulted in transformative progress in healthcare, such as improving information management, service delivery, and treatment, they also give rise to serious ethical concerns. In particular, potential violations of patient rights and confidentiality, as well as potential biases, are ethically worrying. The ascent and consolidation of tech conglomerates - the so-called 'big five' compromising Apple, Amazon, Microsoft, Meta and Alphabet controlling nearly 50% of the NASDAQ stock exchange - also leads to worries about asymmetric power relations between those holding and processing data and the individuals that provide it.[34] This is coupled with the rising influence of China on the African continent, specifically through Chinese tech companies such as Huawei, TikTok, and others, which further reinforce these power asymmetries and ethical concerns.[35] Here, we outline each of these general concerns in turn, beginning with patient rights and confidentiality.

3.1 Patient Rights and Confidentiality

Perhaps the most common concern about the collection of data is how it will be processed. Often, individuals do not pay very careful attention to how they disclose data about themselves. Sometimes they hand over private information - telephone numbers, addresses, birth dates, financial information - to companies when signing up for their services. In other cases, often via social media, they voluntarily place private information in the public domain. However, they often fail to appreciate how the aggregation, processing and sharing of this information can reveal other facts that they may have wanted to keep private.
Charles Duhigg relates an anecdote about an angry father whose teenage daughter had received coupons for baby clothes and cribs from the US retailer *Target.*[36] The father said 'She's still in high school, and you're sending her coupons for baby clothes and cribs? Are you trying to encourage her to get pregnant?' A *Target* manager apologised and called a few days later to apologise again. However, on the phone the father said, 'I had a talk with my daughter… It turns out there's been some activities in my house I haven't been completely aware of. She's due in August. I owe you an apology.' *Target*'s coupon mailer was based on a pregnancy-prediction model, which identified 'about 25 products that, when analysed together, allowed him to assign each shopper a 'pregnancy prediction' score. More importantly, he could also estimate her due date to within a small window, so *Target* could send coupons timed to very specific stages of her pregnancy.'[37]

Duhigg's anecdote is now over a decade old and *predates* the rise of modern AIs and Large Language Models (LLMs), which have significantly increased the predictive power of data processing. The anecdote's lesson is that we must attend not only to what information is shared, but also to how it is *processed*, since intimate information can emerge from seemingly benign data. What matters here is not the retail setting itself, but that seemingly mundane consumer traces, once linked with clinical or demographic information, can reveal health states as sensitive as pregnancy, HIV status, or mental illness. In Duhigg's case, confidential *healthcare* information is revealed by data in an entirely different domain: the girl's consumer habits.

[31] United States of America Department of State, "PEPFAR Latest Global Results"; Global Fund, "Results Report 2024."
[32] Yale Jackson School, "Financing the HIV/AIDS Response in Sub-Saharan Africa."
[33] Ngcobo, "Artificial Intelligence for HIV Care."
[34] Rong, "The Data-Based Power of Big-Tech Multinational Enterprises"
[35] Calzati, "'Data Sovereignty' or 'Data Colonialism.'"
[36] Duhigg, "How Companies Learn Your Secrets."
[37] Duhigg, "How Companies Learn Your Secrets."

This raises a second concern: the sharing, transfer and sale of data. In the anecdote, the data *Target* used to predict the pregnancy was all collected by *Target*. They knew some basic demographic information about the customer, some of her shopping habits, and then used this information to predict her pregnancy. However, a much more detailed picture could be painted if *Target* purchased data about the customer from outside sources. Data brokers and aggregators collect data from banks and credit agencies, consumer data from purchase histories and loyalty cards, location data from wearables and travel itineraries, online search behaviour and media streaming, and public civic and legal data. In aggregate, this information can reveal intimate and nuanced details about individuals' lives.

These concerns become even more worrying when healthcare data is included in the mix. Information about one's personal health is very intimate, and few wish for it to be in the public domain or to be used for the benefit of corporate interests. There are also often prudential reasons to keep this information private. In jurisdictions with employment-at-will laws (most notably the US), employment can be terminated 'at will.' Although many chronic conditions - diabetes, HIV/AIDS, cancer - are protected under the Americans with Disabilities Act (ADA), employers could, in principle, fire workers upon learning about the existence of other conditions.[38] More broadly, people can have prudential reasons to keep private diagnoses of stigmatised conditions such as leprosy, mental illness and STIs. HIV/AIDS is a particularly poignant example. Chambers et al. show that storing health data of persons living with HIV/AIDS could lead to misuse and violations that disadvantage patients.[39] HIV records held at healthcare centres could be misused to identify and discriminate against some patients based on their HIV status. Therefore, maintaining high standards of privacy is crucial in the case of persons living with HIV/AIDS to minimise the fear of discrimination, stigma, and surveillance.

The ethical issue that these concerns speak to is the violation of informed consent. Western approaches to bioethics make informed consent 'the core of bioethics.'[40] The specific requirements of informed consent - and the moral justification and grounds for the requirement are contested - but there is widespread agreement that informed consent requires: (a) provision of comprehensive information to the client, (b) the client has the capacity to comprehend the information and use it to make sound judgment. Further, giving informed consent requires (c) an act of authorisation that is made (d) voluntarily, without force, coercion, or pressure.[41]

To demonstrate how the above conditions for valid consent could be violated, in 2025, the Abuja High Court ordered Domino's Pizza to compensate three million naira to a customer by the name of Chukwunweike Araka Akosa for unsolicited direct marketing without his consent.[42] The customer had earlier shared his personal data with Jumia Foods, an e-commerce platform, when placing a food order. However, Jumia Foods unlawfully shared the customer's personal data with Domino's Pizza, which was later processed and used to send 16 unsolicited direct marketing phone messages without the client's consent after the food order was completed. The client argued that he had never previously provided personal data to Domino's Pizza nor consented to the use of his phone number for marketing purposes. The court ruled that sharing personal data and sending direct marketing messages without the consent of the customer was an infringement of the customer's right to privacy as provided for in Section 37 of Nigeria's Constitution and Sections 25 and 26 of the *Nigeria Data Protection Act*, 2023.

One lesson from this case is that informed consent is a continuous process that extends beyond providing information and obtaining voluntary authorisation, to disclosing how personal data will be subsequently used, shared with third parties and obtaining further authorisation. Even if consent to use personal data for food ordering purposes was obtained, this would not entail that the customer consented to sharing their personal data with third parties and later on to use it for marketing purposes. Western approaches in the Lockean and Kantian traditions recognise rights of self-ownership and autonomy that, by extension, include rights of individuals to control information about themselves and their lives.[43] These rights are best understood as a bundle of subsidiary ownership rights[44] that give individuals the power not only to keep certain information private, but also to consensually disclose and exchange information about themselves with other parties. Full ownership rights include use, control, and transfer rights over the property in question, along with full rights to the benefits generated by owning the property.[45]

When individuals have rights to control information about themselves, they have a say not only in *what* data they disclose, but also in how that data is used, whether it is transferred, how it is stored and so on. Informed consent requirements are not satisfied

[38] Kim, "Genetic Discrimination, Genetic Privacy."
[39] Chambers, "Stigma, HIV and Health."
[40] Eyal, "Informed Consent."
[41] Mwinsa, "International Bioethics, Ubuntu and HIV Testing."; Beauchamp, "Principles of Biomedical Ethics."
[42] Adepetun, "Court Orders Firm to Pay Customer for Data Privacy Breach."
[43] Locke, Two Treatises of Government.
[44] Hodgson, "Introduction to 'Ownership.'"
[45] Vallentyne, "Left Libertarianism and Its Critics."

simply by telling patients what data is going to be collected and then seeking authorisation for collection. The *informed* aspect of informed consent requires that they be notified about these other aspects of data collection: storage, processing, transfer and so on.

Encouragingly, there is growing recognition of these rights and increasingly jurisdictions are passing legislation to protect them, perhaps most notably in the EU and EEA by the *General Data Protection Regulation* (EU 2016/679) (*GDPR*), incorporated into and modified in the UK by the *Data Protection Act* 2018 (UK). The GDPR regulates the processing of data, which it defines as 'any operation or set of operations which is performed on personal data… such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination… alignment or combination, restriction, erasure or destruction' (Art. 4(2)) and requires that data be collected lawfully fairly and transparently, for necessary and limited purposes, and it must be kept up to date, stored securely and only as long as necessary. Further, data controllers must demonstrate that they are in compliance with the regulation (Art. 5).

Of course, the influence of GDPR and related regulations extends far beyond Europe through what Bradford (2020) terms the Brussels Effect: the EU's capacity to externalise its regulatory standards globally through markets, and, to a lesser extent diplomacy, and normative emulation.[46] Data protection regimes in much of the Global South - including many African and South Asian countries - have adopted GDPR-style provisions on consent, purpose limitation, and data subject rights.[47] For example, the African Union (AU) *Convention on Cybersecurity and Personal Data Protection* (the Malabo Convention) reflects similar data protection laws as GDPR.[48] Yet, such transplantation is often partial and uneven. In Africa, for instance, a growing number of states have enacted national data protection statutes inspired by the GDPR, but enforcement remains limited by resource constraints and weak institutional capacity.[49] The result is a patchy landscape in which formal legal convergence coexists with variable implementation, raising questions about whether GDPR-derived norms genuinely enhance data subjects' autonomy in humanitarian contexts or merely reproduce compliance without protection.

In short, many jurisdictions do not, or do not adequately protect personal data. As Beck et al. note, efforts to protect confidentiality in low- and middle-income countries are often constrained by resource scarcity, weak digital infrastructure, and competing public-health imperatives. This risk is magnified in HIV-related contexts where stigma and discrimination remain widespread, and disclosure can carry severe social consequences.[50]

Moreover, new forms of humanitarian data collection - such as genomic sequencing for surveillance and personalised medicine - raise further privacy and equity concerns in African settings. Munung et al. highlight a tension in African genomics between inclusion and vulnerability: as African populations become more visible in global genomic research, they also face heightened risks of re-identification and exploitation, particularly where consent and benefit-sharing frameworks remain underdeveloped. These risks are acute for smaller or marginalised populations, whose over-representation in disease-specific datasets can make them more easily identifiable.[51]

Together, these factors underscore that data use in humanitarian health contexts requires adaptation to account for structural inequalities, limited institutional capacity, and the heightened vulnerability of individuals whose data are collected in SSA.

3.2 Biases

Davis and Williams caution that the data used to train models is sometimes inaccurate, biased against women and minoritised populations, and is often laced with faulty assumptions by designers.[52] In such cases, using it as a basis for AI-determined decisions and information might be fundamentally flawed. Relying on faulty data to make automated decisions on HIV services might deprive minority groups of their right to healthcare and privilege certain populations. In line with this argument, the UN Special Rapporteur shared concerns that 'digital technologies can perpetuate racism, sexism, ableism or discrimination based on sexual orientation or gender identity, among others.'[53]

[46] Bradford, "The Brussels Effect."
[47] Bentotahewa, "The Normative Power of the GDPR."
[48] ALT Advisory, "Mapping the Progress (and Delays) for Data Protection."
[49] Gwagwa, "The Role of the African Value of Ubuntu in Global AI Inclusion Discourse."
[50] Beck, "Protecting the Confidentiality and Security of Personal Health Information."
[51] Munung, "Genomics and Health Data Governance in Africa."
[52] Davis, "Enter the Cyborgs."
[53] United Nations, "Digital Innovation, Technologies and the Right to Health," 1.

For example, of the most widely cited cases of bias in healthcare AI involves an algorithm developed by Optum, a subsidiary of UnitedHealth Group. The Optum 'Impact Pro' algorithm, used by insurers and major U.S. health systems to manage care for more than 200 million patients annually, was found to systematically underestimate the needs of Black patients.[54] The model used past healthcare costs as a proxy for medical need, on the assumption that sicker patients tend to generate higher costs. However, research published in *Science* found that, because Black patients historically spend less on healthcare due to structural barriers to access, the algorithm systematically underestimated their illness burden compared to white patients with similar conditions. As a result, Black patients were far less likely to be flagged as eligible for additional care, despite having equal or greater need.

Additionally, bias has also been documented in predictive models for maternal health. In the United States, Black women experience maternal mortality rates more than three times higher than white women, yet algorithmic risk scores often fail to reflect these disparities. For example, common obstetric prediction tools - such as those estimating the risk of postpartum complications - have been shown to under-predict risks for Black women, in part because they are calibrated to average population data that does not adequately account for racialised differences in access, treatment, and outcomes.[55] When hospitals and insurers rely on such tools to allocate resources or design interventions, they risk reinforcing existing inequities, leaving those most vulnerable to maternal morbidity and mortality systematically underserved.[56]

These cases highlight the danger of assuming that datasets capture 'neutral' medical reality, when in fact they often reproduce the social and structural inequities present in the health system. Biases that can be detrimental to minoritised populations emerge even from models developed by well-intentioned practitioners.

3.3 Power Asymmetries

A final concern, distinct from worries about rights, confidentiality, or bias, is the huge, concentrated power that a relatively small number of large technology firms now exert over the healthcare sector. Patients who disagree with the data collection terms and practices of a particular service often have few meaningful alternatives, leaving them effectively pressured into participation. Scholars of data justice have warned that this imbalance is not incidental but structural: digital infrastructures are designed in ways that consolidate corporate control over information flows and reinforce existing social hierarchies.[57] In this sense, healthcare AI does not merely inherit bias from training data but also reflects the broader political economy of 'surveillance capitalism,' in which individuals' capacity to exercise meaningful choice or control is sharply constrained.

The 2016-2017 collaboration between Google DeepMind and the UK's National Health Service illustrates the problem. Under the arrangement, the Royal Free London NHS Foundation Trust shared the identifiable health records of 1.6 million patients with DeepMind to develop the Streams app, intended for kidney injury detection. The UK Information Commissioner's Office later ruled that the Trust had failed to comply with data protection law because patients had not been adequately informed that their medical information was being used in this way. Critics noted that while the project promised clinical innovation, it also demonstrated how asymmetries of expertise and infrastructural capacity allowed a private technology firm to gain access to vast troves of sensitive patient data without meaningful public debate or consent.[58]

A similar pattern is evident in the United States, where major health systems have entered into data-sharing agreements with large technology companies. For example, Project Nightingale, a collaboration between Ascension Health and Google, involved the transfer of millions of patient records to Google for the development of predictive analytics tools.[59] Around the same time, Mayo Clinic struck high-profile partnerships with both Amazon and Microsoft to migrate sensitive clinical data to cloud services and enable AI-driven research. In each case, questions were raised about whether patients were adequately informed or able to opt out, and whether entrusting core healthcare infrastructures to profit-driven firms risked prioritising shareholder value over patient welfare. These examples highlight how the concentration of technological expertise and infrastructural capacity in a handful of corporations generates profound power asymmetries:[60] those most affected by healthcare AI systems often have the least voice in shaping how they are built and deployed. These asymmetries play out along the entire data value chain: from collection at clinics, to hosting on servers abroad, to training models in universities or tech firms, and finally to the commercialisation of tools from which local systems rarely benefit.

[54] Obermeyer, "Dissecting Racial Bias in an Algorithm Used to Manage the Health of Populations."
[55] Vyas, "Hidden in Plain Sight."
[56] Birhane, "Algorithmic Colonisation of Africa."
[57] Noble, "Algorithms of Oppression"; Zuboff, The Age of Surveillance Capitalism.
[58] Powles, "Google DeepMind and Healthcare."
[59] Schneble, "Google's Project Nightingale Highlights the Necessity of Data Science Ethics Review."
[60] Sharon, "The Googlization of Health Research."

In sum, the collection, aggregation, transfer and processing of individual data - and especially individual *healthcare* data - raises concerns about the violation of patient rights and confidentiality (via violations of informed consent), bias, and asymmetric power. These ethical concerns are general. They arise for *any* patients whose data may be collected, whether they are relatively wealthy patients living in Western countries with private healthcare systems, or in countries with nationalised healthcare systems or in comparatively poorer countries with limited healthcare resourcing. However, as we will argue in the following section, some specific moral problems arise in the context of HIV humanitarianism in SSA.

4. HIV Humanitarianism in Sub-Saharan Africa and Special Ethical Concerns

4.1 Background Context

To begin, it is important to note that Africa has unique historical experiences, including colonialism, whose effects still live on even today. Colonialism relegated occupied Sub-Saharan African colonies to mere sources of raw materials, which were then processed in the Global North, a pattern that the current digital world order appears to follow.[61] European colonialism of Africa began in the early 15th century, but as van der Linden writes, '(b)between 1880 and 1914, the whole of Africa was divided between rival European powers, leaving only Liberia and Ethiopia independent of foreign rule. The speed of the process was unprecedented: most of Africa's landmass and most of its peoples were parcelled out in about ten years after 1880.'[62] Major colonial powers in SSA were Britain, France, Germany, Belgium, Portugal and Italy. Colonial administration involved conducting colonial censuses to gather crucial population data for planning, extraction and administrative purposes. This enabled the imperial governments to map African societies in ways that facilitated the extraction of labour, the enforcement of taxation, and the planning of infrastructure necessary for the extraction of raw materials.[63] The ultimate goal was the subjugation, oppression, and exploitation of natural resources, with administrators imposing economic systems that benefited the colonial countries rather than the colonies. Colonies became dependent on imported goods and services after their indigenous economic, political, and social systems were brutally disrupted, such as in the case of the former Belgian Congo by King Leopold II.[64] Most African countries have not recovered from the effects of colonialism, and they remain tied, to varying degrees, to their former colonial metropoles, making it easier to be controlled, manipulated, and exploited.[65]

SSA countries continue to face various socioeconomic challenges as most of their economies are small and fragile, resulting in low investments in technological advances such as AI technology and electronic health records (EHRs).[66] The threats of poverty and underdevelopment are ubiquitous throughout the region, and SSA countries are significant beneficiaries of development and humanitarian aid. For example, in 2024 net bilateral Official Development Assistance from OECD countries to SSA was $36 billion, representing 22% of disbursements from OECD development assistance committee members.[67] While countries in the region are working hard to catch up with the rest of the world, they often lack financial resources to fund developmental activities without the support of international humanitarian and developmental organisations. Modern humanitarianism is data-driven, and therefore HIV projects collect huge volumes of personal data of patients, which is sometimes stored on transboundary databases and shared with other collaborators and partners, who may mine and process it.

Significant complications to growth and development have been introduced by the HIV pandemic, which disproportionately affects SSA countries. HIV/AIDS remains a serious public health threat in the Sub-Saharan African region, attracting different local and foreign humanitarian organisations that provide and support various HIV services such as testing and treatment. As demonstrated by Crane, the HIV/AIDS pandemic has attracted industrial-scale humanitarianism since the continent lacks the capacity to fight this disease on its own. HIV humanitarian organisations, such as the Global Fund and Gates Foundation, continuously collect programme data from their beneficiaries for accountability, transparency, funding, measurement, and scientific purposes.[68]

Andanda et al. have argued that historically, such data have favoured and benefited the Global North countries at the expense of data subjects in SSA.[69] Furthermore, Everill has shown that humanitarian organisations often influence policies and

[61] Mejias, Data Grab.
[62] van der Linden, "The Acquisition of Africa."
[63] Gervais. "How to Count the Subjects of the Empire?"
[64] van der Linden, "The Acquisition of Africa."
[65] Ypi, "What's Wrong with Colonialism?"; Ferguson, "Territorial Rights and Colonial Wrongs."
[66] Ephraim, "Application of Medical Artificial Intelligence Technology in Sub-Saharan Africa."
[67] OECD, "Preliminary Official Development Assistance (ODA) Levels in 2024."
[68] Crane, "Scrambling for Africa."
[69] Andanda, "Equitable Data Sharing in Collaborative Health Research."

agreements to the detriment of recipient countries.[70] Similarly, Madianou argues that humanitarian organisations are agents of technocolonialism, which entrenches power asymmetries and inequalities between the Global North and Global South countries, often resulting in various harms and structural violence.[71] HIV humanitarianism has resulted in unequal power relations between foreign humanitarian agencies and recipient governments or local communities.[72] The financial and technological power makes it easier for humanitarian organisations to influence and control how data is collected, processed, stored, and shared. As Crane argued, global health survives on the very health inequalities it seeks to end. HIV humanitarian organisations often introduce technologies that are too advanced to be managed and maintained by host governments, in the end creating dependence on the support of those organisations.[73]

4.2 Data-Driven HIV Humanitarianism in SSA: An Overview

HIV remains a major public health threat and causes the highest disease burden in Sub-Saharan African Countries, accounting for 25.6 million out of the total 39 million people living with the disease globally.[74] The transition from paper-based systems to electronic health records has made automation - and increasingly AI - central to HIV service delivery, because digital tools capture, store, and analyse clinical data far more efficiently.[75]

The earliest attempt to implement data-driven HIV humanitarianism in Sub-Saharan Africa is chronicled by Crane.[76] Early HIV researchers and healthcare providers in Uganda developed a standardised way of collecting and storing social, behavioural, and biological information from the African HIV patients so that data could be pooled into a large dataset to be used in research and HIV programming. This was started by a young Ugandan doctor by the name of Atuhaire, who systematically recorded all the HIV patients on antiretroviral therapy in a ledger book, which later transformed into a computerised and automated database with donor funding and technical support from PEPFAR.[77] The advent of this electronic database transformed analogue medical records to digital clinical data, a valuable resource in research, teaching, publication, etc, and in the name of good science, this resource was shared with other foreign collaborators, and it became a critical resource in securing further HIV grants to implement projects in Uganda. This is because humanitarian organisations are under increasing pressure to demonstrate accountability and value for money to donors. They need to provide evidence that funds are being used appropriately, efficiently, and target the circumstances for which they were earmarked.

A striking contemporary example of the use of data for accountability and efficiency is the Global Fund. To optimise rational decision-making, efficiency, accountability, and evidence, it has invested heavily in the generation of programme data. The Global Fund is structured as a public-private organisation, meaning it collaborates and receives funding from the public, private, and philanthropic entities.[78] It has a financing share of 28% in the total global financing of HIV programmes, and since its inception in 2002, up to June 2024, it spent over US$26.6 billion on HIV programming.[79] Such a huge investment creates a moral imperative for accountability, measuring impact, and demonstrating value for money, and data is the means for providing such evidence. For this reason, the Global Fund publishes the annual 'Results Reports,' where it estimates the 'Lives Saved' from HIV/AIDS, TB, and Malaria[80]. For example, in 2024, the Global Fund reported that in its supported countries, HIV mortality rate declined by 81%, HIV incidence rate by 73%, and new infections by 61% between 2002 and 2024. The same report indicated that 84% of people living with HIV knew their status, as compared to 68% in 2015, 78% of people diagnosed with HIV were commenced on antiretroviral therapy (ART), increasing from 22% in 2010, and 72% of people on ART had suppressed viral load, in comparison to only 15% in 2015. To produce such quantitative programme reports, there is a need for huge volumes of data, especially from programme beneficiaries. Yet, in addition to the familiar ethical concerns, there are some key features of the HIV/AIDS pandemic in SSA that raise special concerns for data collected by humanitarian organisations targeting HIV.

[70] Everill, "Humanitarianism in Africa."
[71] Madianou, "Technocolonialism."
[72] Reith, "Money, Power, and Donor–NGO Partnerships."
[73] Crane, "Scrambling for Africa."
[74] UNAIDS, "Fact Sheet."
[75] Norman, " Ethics and Electronic Health Information Technology"; Mweebo, "Security of Electronic Health Records in a Resource-limited Setting."
[76] Crane, "Scrambling for Africa."
[77] Crane, "Scrambling for Africa."
[78] Global Fund, "Partnerships."
[79] Global Fund, "Results Report 2024."
[80] Global Fund, "Results Report 2024."

4.3 Ethically Distinctive Features of the SSA Context

Here we outline features of HIV/AIDS in SSA that raise special ethical concerns about the collection of healthcare data.

Individual and Institutional Resource Constraints. Recipients of HIV/AIDS healthcare provided by humanitarian groups are typically vulnerable individuals.[81] The direct impacts of colonialism in the region have left many significantly impoverished and the indirect effects - via colonialism's weakening of state power and sovereignty and an increase in regional conflict fuelled by interests in the Global North - have further impoverished the population[82]. The addition of an HIV/AIDS diagnosis to this existing poverty makes those who seek humanitarian healthcare to treat HIV/AIDS doubly vulnerable.

Not only are individuals impoverished, but healthcare institutions in SSA also face serious resource constraints. Even the wealthiest country in SSA, South Africa, must cope with a significantly under-resourced healthcare system. For example, despite having the world's largest HIV treatment programme, it continues to face chronic shortages of healthcare workers, with the estimated 'shortage of skilled health professionals in South Africa… projected to be 97,000 by 2025.'[83] Reports from the South African Human Rights Commission have also documented overcrowding, long waiting times, and equipment shortages in public clinics - problems that compromise both patient care and the secure management of sensitive health data.[84] The situation is typically much worse in other SSA countries, where resource constraints are even more severe. These gaps mean that health systems in many SSA countries struggle to provide even basic clinical services, let alone implement robust protocols for managing the sensitive digital data generated by HIV programmes.

These factors jointly create intersectional vulnerabilities that confront persons living with HIV/AIDS in SSA. While all healthcare practitioners ought to act in patients' interests, those in wealthy countries with well-provisioned health systems have additional instrumental reasons to act in patients' interests. First, in the Global North, patients often have some degree of choice over their healthcare provider. If a clinic, trust, or hospital treats patients poorly, they can go elsewhere. Second, if patients are severely mistreated, they often have recourse to legal remedy, either via a tort claim or by pursuing criminal charges. These twin threats of an outside treatment option and litigation empower patients in wealthy countries and reduce their vulnerability. Contrast these options with those confronting an impoverished person living with HIV/AIDS in a country such as Lesotho, with a population of 2 million and only 228 ART sites - about 11 per 100,000 people.[85] Persons living with HIV/AIDS in Lesotho have few treatment options and their alternative to treatment offered by humanitarian organisations is often no treatment. They also will have less (or no) access to legal counsel. Consequently, they are far more likely to accept whatever terms they are offered in exchange for treatment. So, while it is true that all persons living with HIV/AIDS are, to some degree, vulnerable and in serious need of treatment, the vulnerability of recipients of HIV humanitarianism in SSA is greater in degree. The ethical upshot is that the increased vulnerability of persons living with HIV/AIDS in SSA raises concerns that any authorisation for data collection that they provide will arise out of conditions that undermine the voluntariness of the authorisation. Consequently, it will not qualify as valid informed consent. Of course, in some wealthier regions, extreme vulnerability can also undermine the validity of consent. But our point here is that consent-undermining vulnerability is *widespread* in SSA to such an extent that few, if any, authorisations of data collection given to HIV humanitarian organisations will involve valid informed consent.

Weak State Regulation. The continuous generation of digital data in various sectors has necessitated the passing of data protection laws in several SSA countries. By January 2024, 36 (65%) out of 55 SSA countries had national data protection laws.[86] However, the implementation and enforcement of these laws remain a challenge due to, among other problems, the lack of independence of regulatory authorities from political control, low investments in data protection activities, and a shortage of equipment, technology, and trained staff to enforce the data protection regulations.[87] We are, however, aware that some SSA countries have robust legal frameworks and systems capable of preventing data extractivism. For example, in 2025, the Kenyan court suspended the execution of the U.S. health cooperative agreement with the Kenyan government over data privacy and data sharing concerns.[88] Similarly, the Zambia *Cyber Security Act No.3 of 2025* and the Zambia Health Data Governance Framework of 2024 prohibit unlawful extraction, sharing and processing of personal data, while in South Africa, the *Protection of Personal Information Act 4 of 2013* provides legal guidance on the collection, processing, storage and sharing of personal

[81] Wabiri, "Socio-economic Inequality and HIV."
[82] Acemoglu, "The Economic Impact of Colonialism."
[83] Matseke, "Taking Stock of the Healthcare Workforce."
[84] South African Human Rights Commission, "Annual Report 2020/21."
[85] Global Health Supply Chain, "Procurement and Supply Management;" Isavwa, "Notes from the Field."
[86] Munung, "Data Protection Legislation in Africa."
[87] ALT Advisory, "Mapping the Progress (and Delays) for Data Protection."
[88] Burkybile. "US-Kenya Health Agreement Suspended Over Patient Data Concerns."

information. Furthermore, health workers and researchers in many SSA maintain strict data protection, as health data in many countries is categorised as sensitive.[89]

However, in some SSA countries, especially in weak states characterised by poor governance systems and institutions, there is a laxity in applying stringent data control measures on humanitarian and development organisations concerning data sharing and data exportation because they are regarded as partners in development. This is because authorities often believe that the data collected by such organisations is for the public good of the people in their countries, and without such data, it would be difficult to implement such humanitarian and developmental projects and to raise funds for future projects.[90] Furthermore, host governments also benefit from the data collected by humanitarian organisations, which they would not otherwise collect due to competing needs and a lack of capacity to do so. Host governments understand the need for comprehensive and accurate data but usually lack the capacity to collect it. Therefore, when humanitarian and developmental organisations collect the data on their behalf and share it with them, they find it hard to impose restrictions.

So, in contrast to countries governed by relatively stringent data protection regulations like the GDPR, data protection regulation enforcement is comparatively weak in SSA.[91] The obvious explanation is that countries in the region have become reliant on the resources provided by HIV humanitarian organisations to combat the HIV pandemic. Consequently, they are reticent to pass and enforce regulations that meaningfully constrain the organisations' data collection abilities. In short, just as desperate individuals have an incentive to accept unfavourable terms in an attempt to find a treatment option, states reliant on external funding are also incentivised to accept help on terms they would otherwise reject, as was the case in Kenya with the suspended health agreement. Therefore, although many countries in SSA may officially prohibit trans-border sharing of personal data, it is still transferred if it meets the grounds for trans-border sharing, such as:

> sharing of data with a country that has an adequate level of protection (adequacy); Standard contractual clauses that provide a similar level of protection; Binding corporate agreements that provide a similar level of protection; The transfer is necessary for the performance of a contract between the data subject and the controller or measures prior to the conclusion of such a contract; Data subject consents to the transfer; The transfer is necessary to safeguard the vital interests of the data subject; The transfer is necessary or made legally binding for the protection of an important public interest, or for the establishment, exercise or defence of legal claims.[92]

This has created a legal pathway for data extractivism from many SSA countries, which in some circumstances might be unethical.

HIV/AIDS Stigmatisation. A third ethical concern relates to the stigma that continues to surround HIV/AIDS in many SSA countries. HIV remains a stigmatised health condition leading to stigma and discrimination.[93] Fear of social exclusion, discrimination in employment or education, and even violence has historically discouraged people from seeking testing and treatment. Studies show that stigma remains one of the strongest predictors of poor adherence to antiretroviral therapy and of reluctance to disclose HIV status to partners or healthcare providers.[94] When humanitarian organisations collect and store sensitive health data in such settings, the risks of unintended disclosure are magnified: breaches of confidentiality can carry consequences far more severe than in less stigmatised contexts. Even where South Africa has made progress in normalising HIV treatment, research still reports persistent stigma at the community level. In many other SSA countries, the situation is worse. Pooled data from 15[95] SSA countries show approximately 47% of the general population endorsing discriminatory attitudes toward persons living with HIV/AIDS.[96] The Stigma Index survey found that in 12 months, stigma in HIV healthcare settings was experienced by 43% of respondents in Cameroon and 38% in Uganda, showing that a hostile social environment can spill into clinical encounters.[97] To address HIV discrimination, the United Nations (UN) Commission on Human Rights developed The Protection of Human Rights in the Context of Human Immunodeficiency Virus (HIV) and Acquired

[89] Munung, "Data Protection Legislation in Africa."
[90] Brand, "Data Sharing Governance in Sub-Saharan Africa."
[91] Munung, "Data Protection Legislation in Africa."
[92] Munung, "Data Protection Legislation in Africa," 6.
[93] Bond, "The Local Dynamics of Sociostructural Features and HIV Stigma."
[94] Chambers, "Stigma, HIV and Health."
[95] The 15 were: Burundi, Ethiopia, Uganda, Zambia, Zimbabwe, Malawi, Benin, Sierra Leone, Gambia, Guinea, Liberia, Mali, Nigeria, Angola, and Cameroon.
[96] Teshale, "Discriminatory Attitude Towards People Living with HIV/AIDS."
[97] Friedland, "The People Living with HIV Stigma," 514.

Immunodeficiency Syndrome Framework,[98] and many countries have since followed suit to develop similar national policies, such as the Zambia National HIV/AIDS/STI/TB Policy of 2005.[99]

By contrast, in the United States, where legal protections are stronger, stigma persists, but at generally lower levels. A recent survey of HIV/AIDS stigma in the United States found that 'discrimination was experienced more frequently by Hispanic men (23%) than by Hispanic women (18%) and by Black or African American (Black) Hispanic persons (28%) than by White Hispanic persons (21%),'[100] and systematic reviews confirm the ongoing presence of HIV-related stigma among U.S. healthcare providers.[101] While the American stigma survey still reports concerning levels, the rates of discrimination in healthcare settings are nearly half of those found in Cameroon.

Stigma in SSA is relatively more significant than in America, amplifying the consequences of data breaches that undermine patient confidentiality. So, not only are persons living with HIV/AIDS in SSA under greater pressure to accept unfavourable data collection terms, they also are at greater risk from the consequences of poorly managed data.

5. Data Colonialism

Sub-Saharan Africa was under European Colonialism specifically for raw material extraction and exploitation. While colonialism officially ended, vestiges of it still exist today, including *digital coloniality* (Benyera, 2021). Sekalala and Chatikobo define *digital coloniality* as 'the systemic and structural violence of human life through technological systems and designs to exploit the everyday socialities, localities and temporalities of individuals.'[102] It involves the quantification and datafication of human life as a commodity and raw material for exploitation.

Mejias and Couldry have likened the seizure of land in Zimbabwe during colonialism to the current grab of data by tech-giants. They argue that this data grab is necessitated by the same colonial logic, which is that data 'is potentially as valuable as land' and argue that 'today's data grab really is a continuation of the colonial land grab.'[103] Similarly, Birhane argues that while traditional colonialism is driven by political and governmental forces and applies brute force, data colonialism is driven by corporate agendas disguised as state-of-the-art AI solutions, meant to perpetuate the same colonial-era exploitation.[104] Furthermore, Benyera also contends that the looting of Africa that began with slavery and later colonialism has now morphed into digital data looting.[105] Therefore, data colonialism is a sequel of imperial colonialism whose goal remains the same: to *extract*.

This data extraction generates massive wealth and inequalities on a global scale, just as imperial colonialism did.[106] Data colonialism has metastasised into different sectors, including in global health, such as HIV humanitarianism. Following this old colonial framework, today's global health is characterised by knowledge extraction and power asymmetries between the Global North and the Global South countries. The coloniality agenda is also built in digital technology infrastructure, including software, hardware, and cloud technology, which are mainly dominated by tech companies in the Global North.

The exploitation of digital data benefits the tech companies, organisations, and governments located in the Global South more than countries in the Global South, where data is extracted[107], and the core agenda is to reproduce the colonial logic of extractivism under the veil of modernity, rationality, efficiency and accountability.[108] In support of this argument, Andanda et al. also argue that 'historically, data-sharing agreements have favoured high-income countries (HICs), granting them access to, and control over, data collected in the Global South, often without ensuring commensurate benefits for the data-originating countries in terms of capacity-building, authorship, or policy influence.'[109]

[98] UN Commission on Human Rights, "The Protection of Human Rights in the Context of Immunodeficiency Virus (HIV)."
[99] Ministry of Health, "National HIV/AIDS/STI/TB Policy."
[100] Padilla, "Discrimination and HIV-related Stigma," 1293.
[101] Geter, "HIV-related Stigma by Healthcare Providers."
[102] Sekalala, "Colonialism in the New Digital Health Agenda," 2.
[103] Mejias, "Data Grab," 10-15.
[104] Birhane, "Algorithmic Colonisation of Africa."
[105] Benyera, "The Fourth Industrial Revolution."
[106] Benyera, "The Fourth Industrial Revolution."
[107] Gwagwa, "The Role of the African Value of Ubuntu in Global AI Inclusion Discourse."
[108] Sekalala, "Colonialism in the New Digital Health Agenda."
[109] Andanda, "Equitable Data Sharing in Collaborative Health Research." 42.

Further, Sekalala and Chatikobo also argue that under the veil of data evidence, 'multinational corporations, global institutional financers and philanthropic foundations are compelling governments in the Global South to develop neoliberal policies and regulatory frameworks in ways that inevitably lead to the financialisation and assetisation of development, which also includes areas such as digital health.'[110] Similarly, Nhemachena et al. also argue that in the new scramble and recolonisation by global corporations, the African continent is being denied genuine data sovereignty.[111] These data agreements feed into the already existing colonial loop of data extraction and exploitation.[112] Table 2 provides further examples of modern data colonialism pathways in SSA.

Table 2: Selected examples of modern data colonialism pathways in SSA

Country	Data Colonialism Pathways	Identified ethical risks	Source/Reference
Kenya	**Maisha Namba Digital ID Card:**[113] a unique identifier assigned at birth to be used throughout one's life to access services and for identification purposes. Shaped by Powerful global entities such as the UN and Gates Foundation, it feeds into the global digital infrastructure, where African data is commodified, analysed and leveraged by external actors.[114]	- Data security - Exclusion of marginalised groups - Unconsented sharing with external entities	Motshweni (2025) Aratek (2024)
30 African countries	**US Health Agreements with African countries**[115] contain provisions granting the United States Sweeping access to national health data and pathogen samples. In total, 30 African countries have already signed the US health agreements, except for Kenya, Zambia and Zimbabwe, which raised concerns regarding access to health data.	- Unauthorised access and processing of health data	Nwosu (2026) KFF (2026)
Ethiopia and Kenya	**M-Pesa and Telebirr Super Apps.**[116] The most dominant super apps in East Africa, M-Pesa (with 30 million subscribers) and Telebirr (with 36 million subscribers) are supported by external entities such as Huawei, raising concerns about unauthorised data access.	- Data protection concerns - Data sovereignty concerns	Shen and Itumbiri (2025)
South Africa	**Global Initiative on Sharing All Influenza Data (GISAID) sequence database**. In 2021, the South African government shared genomic data about the newly discovered Omicron SARS-CoV-2 virus on the Global Initiative on Sharing All Influenza Data (GISAID) sequence database for surveillance and scientific purposes.[117]	- Unauthorised data processing - Data was used by some European Countries to impose travel bans on some African countries.	Viana et al. (2022)

[110] Sekalala, "Colonialism in the New Digital Health Agenda."
[111] Nhemachena, "Relationality or Hospitality in Twenty-First Century Research?"
[112] Munung, "Genomics and Health Data Governance in Africa."
[113] Motshweni, "New Colonialism: The Digital ID Dilemma in Kenya."
[114] Aratek, "The New Kenyan ID Card."
[115] Nwosu, "Journalist Critiques US Health Agreements"; KFF, "America First MOU Bilateral Global Health Agreements."
[116] Shen, "Comparative Analysis of the Emerging Super App Model in East Africa."
[117] Viana, "Rapid Epidemic Expansion of the SARS-CoV-2 Omicron Variant."

Finally, and in some ways most fundamentally, cultural groups in SSA do not all fully endorse Western, rights-based bioethical approaches. The ethical framework predominant in Bantu-speaking communities of sub-Saharan Africa is *Ubuntu*, a communitarian ethic that emphasises living harmoniously within one's community. While those working in African Ethics have debated the particulars of this moral imperative, all standard approaches recognise that individual rights can sometimes be superseded by community needs.[118] Such an approach means that data collection should be to the benefit of the community, rather than to the benefit of corporations or institutions collecting and using the data.

6. Conclusion

There is an urgent need to decolonise the digital data sector by promoting the development of locally driven technologies for data collection and management. Sekalala and Chatikobo propose creating a South-to-South Movement that involves 'developing collective ownership and control of digital health data and data infrastructures for equitable benefit sharing, and public good.'[119] Alongside this, Sub-Saharan African countries must strengthen enforcement of data protection laws and ensure that transparency and fairness are embedded in data-sharing agreements with humanitarian agencies. Yet too often, the governance of data generated through humanitarian support remains an afterthought, leaving unanswered questions about how such data will ultimately be managed and shared.

The collection of data in HIV humanitarianism in SSA therefore faces a profound dilemma. The same infrastructures that make care more efficient, enable accountability, and accelerate discoveries can also reinscribe extractive relations, compromise consent, and amplify structural vulnerabilities. Material scarcity among patients and providers, weak or uneven regulatory enforcement, and persistent HIV-related stigma create environments in which nominal authorisation of data collection often lacks meaningful voluntariness. Moreover, the political economy of aid and technology procurement concentrates power in extraterritorial actors, leaving data subjects and local institutions with little control over storage, analysis, and secondary use. These dynamics exemplify what has been called data colonialism: the organised capture and commodification of health information that generates value elsewhere while exposing SSA communities to heightened risk.

Avoiding data colonialism requires more than conventional privacy compliance. It calls for substantive governance commitments that rebalance control and benefit. Consent must be relational and longitudinal: not a one-time signature but an ongoing authorisation that explicitly covers cross-border transfer, linkage, and downstream analytics. Agreements should incorporate data sovereignty, local hosting or mirrored repositories, and capacity-building obligations tied to authorship, infrastructure, and durable technical skills. Benefit-sharing must be specified and enforceable, ensuring that clinical tools, analytic dashboards, and model updates return to the systems that originate the data.

Drawing on Ubuntu-based bioethics, governance should prioritise community accountability and the preservation of person-in-community, rather than treating data subjects as isolated choosers. This is not an argument against data-intensive care or innovation, which can be highly beneficial when appropriately governed. It is a call to re-engineer the terms on which data are produced, moved, and monetised: with transparent contracts, genuine opt-outs, independent oversight, and co-ownership arrangements that align incentives with public health. In short, the path to ethical, effective HIV data work in SSA is not *necessarily* less data, but fairer data - technically secure, legally grounded, socially legitimate, and oriented toward equitable health outcomes.

[118] Olinger, "Western Privacy and/or Ubuntu."
[119] Sekalala, "Colonialism in the New Digital Health Agenda."

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