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Governance-by-Design as an Enabler of AI in Digital Health in Sub-Saharan Africa

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Abstract

To harness the benefits of artificial intelligence (AI)-enabled healthcare, access to data is a crucial component of AI in digital health technology development and adoption. This requires effective frameworks of digital and data governance. This paper highlights important digital, data, and data-related issues that present unique and pressing challenges to such adoption in sub-Saharan Africa (SSA). Specific non-exclusive challenges in SSA arise from issues around data integrity and quality, interoperability, and data provenance. Related emerging issues centre on surveillance capitalism, data commodification, and coloniality. Certain digital and data governance strategies and solutions in support of the public good are in place and include various legal rights, regulatory policies, and ethics frameworks. Building on these solutions, I advance an innovative and supplementary mechanism of grounding digital and data governance on the theoretical approach of human-centric design and on ideas of embedding ethics and law. As illustrated in India, this 'third way' of 'governance-by-design' practically embeds and operationalises rules as protocols within the infrastructure and architecture of the technology itself. Accordingly, an inclusive and augmented data and digital governance-by-design solution is offered as an enabler of AI in digital health in SSA.

***Keywords**:* Artificial intelligence; digital health technologies; data protection; governance-by-design; embedded ethics.

1. Introduction

Digital technology systems, driven by computational and data analytics, digital disease surveillance, and the power of Big Data and Artificial Intelligence (AI), are revolutionising modern medicine and healthcare.[1] Although of enormous potential benefit, these systems significantly impact society, raising important digital and data-related challenges. Specific challenges hinge on data integrity, the availability of complete, diverse, and representative datasets, data provenance, and interoperability. The purpose of identifying these important loci of concern is to articulate certain emerging, critical socio-legal issues for AI in digital health applications and, more generally, in health research, and the policies and ideologies that shape them. Situated within this context, it allows us to envisage, extended policy and governance interventions in several ways — by shaping the debate, framing issues, problematising the construction of concerns, and co-producing solutions by grounding implementable rules. This contribution seeks to Rethink Digital Health Data Regulation from the perspective of the South by conceptualising and offering a hybrid framework of transformative digital and data governance in sub-Saharan Africa (SSA). It draws on recent developments in other parts of the Global South, most notably, from India.

SSA faces many healthcare challenges including an increased burden of disease, a large proportion of the population living in rural areas, limited resources, and a lack of education and primary healthcare. AI in digital health is well positioned to play a significant role in healthcare in SSA by supporting access to medicine and treatment, facilitating early disease detection and prevention, improving diagnostic decision-making, enabling drug development and health research, monitoring public health

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[1] Zahlan, "Artificial Intelligence Innovation in Healthcare."

and disease surveillance, and in healthcare and disease management.[2] AI in digital health is increasingly adopted in SSA.[3][4] For example, AI-enabled deep learning modalities have been used to classify and interpret images of human immunodeficiency virus (HIV) tests acquired in rural South Africa. A further example is the electronic clinical decision support system for antenatal and intrapartum care implemented in Tanzania and Ghana.[5][6] Similarly, in Lesotho and South Africa, AI-supported computer-aided detection software has been used to screen digital chest radiographs for tuberculosis-related abnormalities and AI models, using local datasets, have enabled the detection and diagnosis of fetal abnormalities in Egypt, Algeria, Uganda, Ghana, and Malawi.[7][8]

While AI in digital health offers enormous promise to a region beset with healthcare challenges, these systems must be designed, developed, and deployed equitably and responsibly. Challenges around digital health in SSA have been well described in the literature, including the challenges posed by digital health technology use in primary health care,[9] to COVID-19 responses,[10] to healthcare workers and patients in Botswana,[11] to the effective scaling of these technologies,[12] and to critical rights issues in South Africa.[13]

Given the importance of data in the development of AI in digital health in SSA, the overall aim of this work is to focus on specific challenges brought about by digital, data, and data-related issues and the governance thereof. Accordingly, the contribution of this work is positioned in pursuit of three main objectives:

First, I highlight the role and availability of high-quality, representative data of known origin for use in training AI models: a necessary requirement if AI in digital health is to be utilised in the interests of the public good in SSA.

Second, I consider specific data and AI model challenges related to SSA. These challenges fall within the broader categories of dataset incompleteness (or the lack of cultural knowledge and representation of African languages); interoperability (or the inability of software systems within SSA to work together to exchange and make use of available data); and data provenance issues (or concerns around data extraction and sourcing). The latter leads to long-standing and well-documented problems of surveillance capitalism, data commodification, and coloniality.

Third, I more fully integrate and overcome certain of these data challenges by proposing a strengthened digital and data governance regime that coexists with extant governance approaches. The pressing issues of data ownership and related but distinct data-related rights are included for completeness. Although a careful conceptual and legal analysis is already well described in the literature, I believe that legal rights and data ownership are important aspects of a fully integrated multi-layered governance solution. By extending the theoretical focus to include aspects of human-centric design and by basing the approach on ideas of operationalising and embedding ethics and law, a ‘third way’ of ‘governance-by-design’ is considered, one where traditional approaches to digital and data governance are augmented and bolstered to further regulatory efforts. This method of ‘governance-by-design’ allows regulatory, ethics, and legal objectives, rights, and operational rules to be embedded within the code and architecture of the digital system itself and be used as part of a suite of effective digital and data governance measures.[14] In this way, I demonstrate how a multi-layered approach to digital and data governance can build on SSA efforts thereby framing a powerful foundation of accountability that reinforces collective public data and digital health priorities.

The SSA region is used to illustrate how governance-by-design may be used as an enabler of AI in digital health as SSA mirrors many of the issues found throughout the African region. This, however, is not an attempt to provide a complete solution or a ‘one-size-fits-all’ approach throughout the SSA region itself or within the African continent. Neither is it an attempt to conflate Africa with SSA or to suggest an overly simplistic generalisation about Africa or the independent sovereign jurisdictions that comprise it. Solutions conceptualised in one jurisdiction may or may not be applicable to other African jurisdictions each with

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[2] Topol, “High-Performance Medicine.”
[3] Owoyemi, “Artificial Intelligence for Healthcare in Africa.”
[4] Ephraim, “Application of Medical AI Technology.”
[5] Turbé, “Deep Learning of HIV Field-based Rapid Tests.”
[6] Sukums, “Promising Adoption of an Electronic Clinical Decision Support.”
[7] Glaser, “Clinical Tuberculosis Screening in Lesotho and South Africa.”
[8] Sendra-Balcells, “Fetal Ultrasound Deep Learning Models.”
[9] O'Brien, “Analysis of the Use of Digital Health Technologies.”
[10] Bakibinga-Gaswaga, “Digital Technologies in COVID-19 Responses.”
[11] Ncube, “Perceptions and Attitudes Towards Telemedicine Use in Botswana.”
[12] Motiwala, “Barriers to Scaling Health Technologies.”
[13] Townsend, “Software as a Medical Device.”
[14] Matthan, The Third Way.

its own data protection and privacy laws. Although many of the challenges described here are far-reaching, they are of particular concern to SSA where health inequality and access to healthcare often run parallel to existing forms of social exclusion, inequity, and marginalisation in the region. The suggestion is that SSA can draw on digital, data, and AI protection mechanisms offered by the African Union (AU) Malabo Convention,[15] the AU Data Policy framework,[16] and the AU Continental AI Strategy,[17] and from domestic data protection legislation and their philosophical underpinnings. Yet, with novel development in AI, additional emerging challenges are seen, especially, but not exclusively, by the introduction of machine learning and generative AI models and their increasing data dependence. Whereas data governance and privacy law offer protection, because of the fast pace of AI in digital health development and the novel unfolding challenges, issues persist. Specific challenges that centre around data integrity and quality, data provenance, and the lack of interoperability are worthy of scrutiny and stand potentially to fall between the cracks of current data protection and other laws in SSA. In doing so and encouraged by digital and data governance advances across the region,[18] I emphasise the need for greater accountability and extended practices of practical data governance.

2. Data Imperative and Data Integrity

While the development of AI in digital health applications can make healthcare accessible to many, acquiring robust, quality, representative datasets for such purposes is problematic in many low- and middle-income countries, including those in SSA.[19] Data unavailability is likely a consequence of limitations elsewhere in the healthcare ecosystem, such as access to medical diagnosis and treatment. However, inroads are being made, for example, by the efforts proposed in Africa CDC's future datasets initiative for digital disease surveillance to monitor cholera, Ebola, and yellow fever. This initiative is aimed at developing digital surveillance indicators and online disease dashboards to strengthen real-time infectious disease surveillance across participating countries, including Ghana, Liberia, Madagascar, Nigeria, Sierra Leone, and South Africa.[20] Indeed, it is not only in SSA where a lack of data accessibility is experienced. Albeit for different reasons, a so-called 'data winter' is restricting the availability and use of data across web domains with an ongoing decline in consent to use open web data.[21]

AI in digital health solutions uses data to facilitate learning, adaptation, and model improvement with the understanding that with higher quality data comes better model performance and increased predictive accuracy.[22] However, for the development of certain models, training datasets are frequently selected using unspecified or unclear principles with a lack of transparency regarding the quality, nature, origin, and acquisition of the training datasets.[23] Data integrity is a driver of safe and responsible AI adoption and refers to data completeness, data consistency, and data accuracy over the entire data lifecycle.[24] The concern is that AI in digital health may not be accurate *for everyone* as the composition and quality of input data, used in many devices as test, training, and validation data, may not be representative of the target population. Concerns about the diversity, size, completeness, and comprehensiveness of the data have long been identified as pressing ethical issues.[25] Predictive accuracy may be compromised where algorithmic models are trained on a restricted demographic cohort, or a homogenous population, or where certain ethnicities are under-represented, without dataset transparency and clearly stated inclusion and exclusion criteria in the compilation of the dataset.

While local datasets exist, such as those stored in the repositories of government ministries, NGOs, and university and research institutions, there are limited Africa-specific, accessible datasets to train AI digital health models.[26] Dataset acquisition is a costly undertaking, with many local datasets not collected with machine learning purposes in mind. Thus, datasets typically used at scale to test, train, and validate AI models are over-represented from geographical regions outside of SSA. Most widely used datasets in AI research emanate from a handful of institutions, predominantly sourced, and housed in the Global North and within a small number of elite institutions.[27] Over- or under-representation of certain population groups and sub-types can reduce the predictive accuracy for those groups. Here, too, persons with low economic status typically have less available health

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[15] African Union, African Union Convention on Cybersecurity and Personal Data Protection.
[16] African Union, AU Data Policy Framework.
[17] African Union, Continental AI Strategy.
[18] Centers for Disease Control and Prevention, "Digital Disease Surveillance."
[19] World Health Organisation, Regulatory Considerations on Artificial Intelligence for Health.
[20] Centers for Disease Control and Prevention, "Digital Disease Surveillance."
[21] Roose, "Data that Powers AI."
[22] Schwabe, "The METRIC-Framework." Bommasani, "Opportunities and Risks of Foundation Models."
[23] Bommasani, "Opportunities and Risks of Foundation Models."
[24] World Health Organisation, Regulatory Considerations on Artificial Intelligence for Health.
[25] Vayena, "Machine Learning in Medicine."
[26] Ojenge, "Africa-specific Datasets Challenge AI in Education."
[27] Koch, "Reduced, Reused and Recycled."

data with data availability on race, ethnicity, and language largely incomplete or missing.[28] Datasets are often biased towards those population subtypes for which there is the most data, excluding ethnic minorities, elderly people, women, rural communities, and marginalised groups. Fewer young women in low- to middle-income countries, for example, own a mobile phone and are connected to the Internet compared to young men thus contributing less to the data ecosystem.[29] With lowered data availability, limited representative datasets are available for AI model training, which in turn informs model quality and ultimately inequitable AI adoption.[30] As universal data protection principles (such as consent, data minimisation, data security and the like) contained in many of the data protection laws around the world, and indeed in SSA, set necessary compliance standards for data protection, in their current form they provide only a partial solution to many new emerging challenges. These data-related challenges, it is proposed, require a rethinking of the way in which novel forms of data and digital governance should be supported in SSA.

3. Data Challenges to AI in Digital Health Adoption in SSA

In this section, I briefly describe emerging challenges associated with data and its role in AI in digital health technology development. These challenges, it is argued, require further direct and novel governance and mitigation measures.

3.1 Cultural and Knowledge Challenges

As technologies function within a social and cultural setting, technological outcomes are informed by human interaction with the technology itself within an environment or context. These contexts differ across locations, cultures, and historical times. Considerations of appropriate integration within established practices and environments are important if the technology is to meet a necessary condition of fairness and global equitable adoption. Resolving these problems requires a full range of representative datasets that are responsive and adaptive to the nuances of linguistically and culturally varied groups.

This speaks to the far wider problem of language and cultural integration. AI is often designed based on the intuition, knowledge, and values of people who can be described as Western, educated, industrialised, wealthy, and democratic.[31] Certain cultures, languages, regions of the world, education levels, and age groups are largely excluded or underrepresented in datasets. As of 2024, English accounted for 52% of website content on the Internet.[32] While English, French, and Portuguese are spoken in Africa, the diversity of traditional African languages is rarely represented. Curating data from English websites only is to risk excluding other languages and cultures, and large language models (LLM), have shown limited effectiveness in processing, and specialisation for languages other than English, particularly for languages and dialects that are not well represented online.[33] The implications of failures in linguistic diversity, data quality, and relevance of the training data, serve to exclude cultural appropriateness and sensitivities in local contexts and may dissuade user groups from using the technology thereby deepening the digital and data divide. This is also true of LLMs that have not been fine-tuned for local user groups, where certain contextual aspects prevalent within localised groups or group types are not considered or prioritised. For instance, performance disparities have been shown to present in models that have not been trained and evaluated on data from communities affected with blindness or low vision.[34] It can also present problems where an annotation framework does not consider multilingualism, and the linguistic diversity prevalent in SSA, placing certain traditions, cultures, religious groups, and other perspectives at risk of being excluded or misrepresented within the system. Under-resourced, underrepresented training data, and not fine-tuning diverse local contexts at the design stage, means that the model may significantly underperform, or not perform at all, for certain individuals and user group communities.

In tandem, it is important to address the ‘knowledge’ problem in AI and the poor representation of African indigenous traditions, history, and cultural narratives in datasets. Failure to do so can serve as a form of alienation where a culture, society, or group identity, or the lived experience of being a member of such a group is not recognised or diminished. It also extends to instances where the gravitas of certain aspects of cultural or social identity are ignored or not respected and is most harmful when past injustices go unacknowledged or underrepresented, for example, by tagging a sacred site as a ‘field’ or an ancient African relic as a ‘stick’.[35] This is particularly problematic with generative models, already prone to hallucinations and confabulations.[36] But

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[28] Arpey, “Socioeconomic Status Affects Patient Perceptions of Health Care.” Ng, “Data on Race, Ethnicity, and Language.”

[29] United Nations Children’s Fund, Bridging the Gender Digital Divide.

[30] Hacker, “A Legal Framework for AI Training Data.”

[31] Linxen, “How Weird is CHI?”

[32] Statista, “Languages Used for Web Content.”

[33] Truong, “Crossing Linguistic Horizons.”

[34] Massiceti, “Explaining CLIP’s Performance Disparities.”

[35] Katzman, “Taxonomizing Representational Harms.”

[36] Gekhman, “Fine-Tuning LLMs on New Knowledge.”

creating datasets that portray the subtle nuances of cultural and societal traditions requires a shared, collective, often costly, effort - one that cannot be offloaded and outsourced exclusively to model designers and developers. These are not merely technical problems, but also moral and political ones. Accordingly, we should think more carefully about the nature, accuracy, and completeness of the datasets used, about how AI models work (or do not work) for certain communities, and the limitations and constraints of the data on model building and model accuracy.

3.2 Interoperability

AI in digital health development faces the critical and practical challenge of interoperability across Africa. Interoperability refers to the ability of software systems to work together to exchange and make use of available data. Increased interoperability provides a means of data interchange between healthcare organisations and AI developers, improving the accessibility of data for AI in digital health development and adoption. Thus, better AI in digital health in SSA development and implementation requires interoperable and integrated health system solutions and an architecture of robust health information exchange policies and standards. Interoperable digital health ecosystems and policy and standards on health information exchange and interoperability between heterogeneous systems facilitate secure, seamless, and timely data use and transfer within and between SSA countries, organisations, and digital health developers.[37] However, difficulties are experienced in SSA settings, where challenges of clinical and administration acceptance and the provision of user training and ongoing technical support were demonstrated in the implementation of an open-source health record system in Kenya.[38] And while, for example, Ndlovu et al. describe Botswana's interoperability landscape for connecting mHealth applications to eRecord systems as an exemplar in SSA, fragmentation and disintegration of technologies and the inability to link digital health applications and health records remain unresolved challenges across SSA.[39]

Certain countries within SSA, such as South Africa, Tanzania, and Malawi, have digital health strategies that include as key priorities frameworks to support digital health interoperability by, inter alia, publishing artefacts that allow users to easily adopt and implement standards and to strengthen data exchanges between health systems.[40] Moreover, data protection legislation, such as that evidenced in South Africa's South African Protection of Personal Information Act (POPIA), has enabling provisions that stipulate the conditions under which data transfers can lawfully be achieved.[41] Interoperability and data transfer standards have been identified throughout Africa, including in South Africa's National 2021 Normative Standards Framework for Interoperability in Digital Health and the IGAD's Regional Health Data Sharing and Protection Policy to which countries such as Kenya and Uganda belong.[42] However, comprehensive technical standards and the establishment of interoperability frameworks at a national and regional level, and at the level of the Africa Union (AU), can greatly serve in supporting the implementation of harmonised interoperable technical standards and technical security guidelines across SSA.[43]

3.3 Data Provenance

A further challenge is one of 'data provenance'. This refers to the origin, derivation, or source of data, including how it is collected or curated using data-capturing technologies. Certain data collecting technologies such as health surveillance, facial recognition technologies, and drones – may be multiple-use – that is, for health and disease monitoring, legitimate counter-terrorism initiatives, and for purposes of law enforcement.[44] However, limited or no policy protection risks creating de facto data havens and opportunities for data misuse and rights violations. Concerns also centre around unfair and inequitable methods of data acquisition and the increasing use of data scraping, data mining, web crawls, and data capturing technologies to harvest and create composite datasets. These are not isolated incidents but are symptomatic of more pervasive power asymmetries around data extraction, capture, processing, repurposing, and data sharing. Ideas such as 'data grabbing', 'data commodification', and 'surveillance capitalism' are foreboding challenges on the sub-Saharan digital-, data-, and AI-governance horizon.

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[37] Mamuye, "Health information Exchange Standards for Digital Health."

[38] Muinga, "Implementing Open-source Electronic Health Record Systems."

[39] Ndlovu, "Interoperability Opportunities in Linking mHealth Applications."

[40] Republic of South Africa, National Digital Health Strategy for South Africa 2019–2024; Republic of South Africa, National Health Normative Standards Framework for Interoperability in eHealth in South Africa; United Republic of Tanzania, The National Digital Health Strategy 2019– 2024; Republic of Zambia, Digital Health Strategy 2022 -2026.

[41] Republic of South Africa, *Protection of Personal Information Act 4 of 2013;* Townsend, "Lawful Sharing of Health Research Data."

[42] Mamuye, "Health Information Exchange Policy for Digital Health Systems;" Republic of South Africa, *2021* Health Normative Standards Framework for Digital Health Interoperability in South Africa*;* Intergovernmental Authority on Development. Regional Health Data Sharing and Protection Policy 2022.

[43] Mamuye, "Health Information Exchange Policy for Digital Health Systems."

[44] Bu, "Global Governance on Automated Facial Recognition (AFR)."

Advancing fair and responsible data collection is crucial. Generative models are trained on text, art, and image data often scraped from the Internet and content distribution platforms, non-consensually and without compensation, and stand to destabilise the very knowledge ecosystem upon which they rely.[45] Indeed, AI-supported technologies can plagiarise the style and content of human work at far greater speed and efficiency than human copyists.[46] Notwithstanding knowledge ecosystem issues, data mining activities in Africa can also amplify existing societal tensions by excluding African subpopulations that are perceived to represent 'low value' data. The prevalence of web-scraped datasets for use in training AI generative and foundational models, and how such data will be governed, remains unanswered.[47] Although certain regulatory authorities may impose fines for data privacy infringements, this is not a protection necessarily afforded to those jurisdictions where data is less strictly regulated, or under-enforced.[48] The concern is that as the utility and value increase for accessing and producing large datasets, this might encourage actors to pursue aggressive data collection practices, despite these activities being legally questionable or contrary to user expectations.[49] If data subjects including those from SSA communities were encouraged and incentivised to contribute to self-representational and diverse training datasets this could address some of the unwanted bias currently represented within certain AI models potentially reducing the dominance of a narrow range of homogenous data, content, and perspectives.

3.4 Surveillance Capitalism and Coloniality

Following increased undesirable data acquisition practices, the well-established problem of data extraction and the commodification of data arises, as does the new relationships that emerge from using one's social life and the surveillance thereof as a capital resource or 'surveillance capitalism'.[50] In an ever-increasing desire to modify our behaviour, ubiquitous computational architecture in conjunction with data use, births a new type of asymmetrical power – one Zuboff refers to as 'instrumentarianism' or the operational and instrumental power that knows, informs, and shapes human behaviour for the benefit of others. Zuboff denounces data appropriation and the commodification of data, and cautions that data is used to not only know our behaviour but also to shape our behaviour, directing how we understand the world and relate to it.[51] While not unique to SSA, sustained surveillance capitalism, which claims human experience as free raw material, and the novel ways of commodifying data, we see a global shift that runs contrary to entrenched information privacy rights unfold rapidly and alarmingly.

This is of particular concern in SSA where data protection safeguards are underenforced. These activities strip away the illusion of connectedness as being positive and good to a far more sinister and dark attribution of connection for commercial ends. Such forms of commodification can devalue and diminish the individual and the community, with strong associations to both inequality and subordination. Notions of 'data vampires' – or entities feeding upon the data of others for their ends – are not accidental and concentrate power outside of data subjects and into the hands of big technology companies and other actors.[52] Similarly, Mejias and Couldry speak about a new form of colonialism, that of 'data grabbing', drawing parallels with colonialism and the consequential harmful impact on global equity.[53] The danger is that in the acquisition and control of data, power asymmetries are created, which stand to usurp personal data sovereignty, exert an unhealthy level of social control, and seize the world's data resources for the benefit of a few. Without extended, enforceable privacy and data protection, privacy protection is used merely as an epithet, designed for rhetorical and political value, with little actual value or realisable protection afforded to the data subject or their data.

4. Strengthening Equitable AI in Digital Health Adoption in SSA

How do we address the important legal, ethical, social, and cultural consequences of AI-supported digital health technology adoption in SSA and provide a means of making these technologies work for the good of individuals and societies while preventing harm? It is proposed that data-related challenges and neglected sociotechnical aspects of AI in digital health adoption require an increased focus on human-centric discourse and accountability and novel governance responses.

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[45] Pasquale, "Consent and Compensation."
[46] Knibbs, "AI-Generated Books."
[47] Wajert, "Scraping Public Websites."
[48] Coleman, "Digital Colonialism."
[49] Nissenbaum, Privacy in Context.
[50] Zuboff, The Age of Surveillance Capitalism.
[51] Zuboff, The Age of Surveillance Capitalism.
[52] Véliz, Privacy is Power.
[53] Mejias, Data Grab.

4.1 Human-Centric AI and Increased Accountability

Human-centric AI adoption positions human values, thoughts, and experiences as central to the enquiry. It is the integration, more fully, of the technology with individuals and human aspects, and allows us to establish, first and foremost, what technically works best for humans and society.[54] A key aspect of human-centric involvement is the ability to orient efforts towards human outputs and human values. It seeks to understand what stakeholders value and supports them in delivering this value.[55] Placing people at the forefront of the conversation, and rooted in humanistic values and cooperation, a human-centric approach to AI design and development resonates deeply with the cultural diversity and community values of the SSA region. It crafts AI in digital health and data practices locally and keeps algorithmic and data governance and control responsible and agile. Following a human-centred design approach, humans and human values are positioned at the very core of the development and the local adoption process.

Encouragingly, we see a growing body of work exploring ideas of human-centric AI for optimising healthcare within the SSA context. Okolo, for example, calls for digital health technologies to be deployed to empower front-line users in the Global South by considering the unique requirements of marginalised communities if the existing issues of algorithmic bias and imposed additional work burdens are to be avoided.[56] Moreover, Odero et al. propose a framework for AI value alignment and value integration based on the African philosophical tradition of Ubuntu, and Grancia advocates for AI ethics to be understood within the context and value-system of the people of Africa.[57] Yet, value alignment in data governance and AI in digital health adoption remains a challenge with high-level normative framing often abstracting away from the unique particularities inherent in local contexts and specific AI applications. The complexities of the context within which these technologies are to be adopted often demand that we resolve and reconcile plural, competing normative claims. That is, for instance, to privilege ideas of individualism (dominant paradigms in most data protection law around the world including in POPIA) or to support collectivism (that is, giving legal recognition to communal, familial, or ethnic group interests). This is especially salient in contexts using genomic data. But, in recognising a context of cultural and social variability, the ensuing values adopted depend, at least in some part, on unique local particularities and the articulation of these values. These particularities also allow us to better consider the relevant questions to ask in the first place. Accordingly, to speak of 'responsible' use of AI in digital health adoption and 'good' digital and data governance is to recognise the complexity of the historical and present context and the people for whom these technologies are to be designed and ultimately to serve.[58]

Accountability is crucial in any attempt to provide good data governance and digital health technology development. It requires a chain of accountability, that is delineated and permits verification and compliance with a set of substantive normative standards. 'Accountability' can thus tell us something about what accountability standards to account 'for' even in situations where the standards themselves are contested, still emerging, or unsettled.[59] A governance approach for AI in digital health design, deployment, and evaluation should both optimise performance *and* prevent sociotechnical harm. It should, therefore, consist of a multi-layered model of digital and data governance combining 'top-down' solutions, such as international and national regulatory policy and data rights and laws, as well as 'bottom-up' forms of self-regulation, ex-post regulation, and embedded ethics.[60] It is here that governance-by-design plays a key role (discussed in detail below). A wider range of governance solutions would more practically demand inclusive, ethical, and equitable data availability and transparency. It would also enable mechanisms and measures to increase interoperability.

4.2 Digital and Data Governance in SSA

To be effective digital and data governance as an enabler of digital health technologies in the SSA must better integrate value alignment, sustainability goals, and sovereignty. The positive influence of the African Union Convention on Cybersecurity and Personal Data Protection (the Malabo Convention) and the AU Data Policy Framework provides an enabling environment in SSA by elevating the rhetoric of the protection of personal data to an international level. [61][62] Establishing a normative framework consistent with African legal, cultural, economic, and social perspectives, the Malabo Convention represents a shared, coordinated African position embedding human rights of privacy, dignity, and autonomy. In recognising the interdependence of African states, and the obstacles presented by the development of electronic commerce in Africa related to

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[54] Ystgaard, "Requirements of Human-Centric Internet of Things."

[55] Cockton, "Value-Centered HCI."

[56] Okolo, "Optimizing Human-Centered AI."

[57] Odero, "The Ubuntu Way;" Grancia, "Decolonizing AI Ethics in Africa's Healthcare."

[58] Townsend, "Multiculturalism and AI Value Alignment."

[59] Lechterman, "Accountability in AI Ethics and Governance."

[60] Pagallo, "The Middle-Out Approach."

[61] African Union, African Union Convention on Cybersecurity and Personal Data Protection.

[62] African Union, Data Policy Framework.

security issues, it calls for concerted action to protect the rights of individuals in 'the establishment of an appropriate normative framework'.[63] Aligning member states with a required predetermined minimum standard of data protection, it seeks to accelerate relevant reforms around data protection and cyber security in African member states. Such conventions can greatly assist in integrating and reimagining novel AI solutions within the rich philosophical tradition of indigenous African law. However, these instruments are limited in one crucial sense: the changing nature of AI in digital health development in SSA demands a rapid and nimble approach to governance. This is a global challenge that acquires a new sense of urgency as AI in digital health is increasingly positioned as a transformative solution to healthcare in SSA.

Further initiatives have been shown to work at a continental level, and existing collaborations at a regional level can play a role in strengthening and harmonising legal instruments across regions in Africa, (be it the East African Community 'EAC', Economic Community of Central African States 'ECCAS', Economic Community of West African State 'ECOWAS' or the Southern African Development Community 'SADC'). This is achieved by improving cooperation between member states and in the coordination and support of regional policies, examples of this include past efforts involving cyber law and data protection.[64] Examples include the development of a SADC model law to guide Member States on the drafting of data protection laws, e-transactions, and cybercrime.[65][66][67]

In other Global South regions frameworks for data governance include those advanced by the Caribbean Community (CARICOM) countries that promote digital transformation in the Caribbean and the Association of Southeast Asian Nations (ASEAN) that shapes regional data standards and cross border collaboration in Southeast Asia.[68][69] In response to aspects of data ownership, China has developed a sophisticated alternative data governance model that offers categories of legal rights in data namely, the privacy rights of data subjects and the proprietary rights of data processors or generators. Data protection developments in Brazil, China, and India that introduce a high level of novelty and challenge dominant data protection models have redefined the borders of what Belli describes as a new post-Western Model of Data Governance. [70] These policy choices are likely to inform wider Global South data governance frameworks because of the considerable geopolitical and economic weight these countries have at both a regional and international level. Similarly, Global South efforts involving aspects of AI-related regulation are not being overlooked. Brazil has implemented an AI Strategy that supports its progress towards AI development and pursuit of AI sovereignty and India is developing national frameworks to manage data and govern various aspects of AI regulation.[71][72] Moreover, an AU AI Strategy was published in 2024 to encourage inclusive AI development across AU member states by adopting a unified and strengthened approach to navigate the complexities of AI. [73]

Despite the existence of common difficulties across the SSA region, policy responses at a regional level face the challenge of a diverse and fragmented policy landscape.[74] On a national level certain legal guardrails are already in place, such as in South Africa's POPIA and Kenya's Data Protection Act.[75][76] While concepts may vary across the domestic legal instruments, the substance of the salient normative features is frequently similar. Commonalities and uniformity within the region exist and facilitating greater harmonisation and standardisation across and between African borders has benefit to the SSA region thereby preventing regulatory fragmentation. However, better harmonisation and integration of policy require cooperation and coordination between states, not a quick or straightforward solution. As recently seen, responses by member states, required to accede to and ratify the Malabo Convention and provide a national legal framework based on its provisions, have taken time.[77] The Convention required the ratification of 15 member countries for it to come into effect. Mauritania was the 15th member country to ratify the Convention on 9 May 2023, bringing the convention into effect on 8 June 2023.[78] This Convention demands a commitment to core regulatory principles based on transparency, flexibility, proportionality, and legal certainty.

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[63] Preamble to the Malabo Convention.
[64] African Union, Convention on Cyber Security and Personal Data Protection.
[65] Southern African Development Community, *Data Protection.*
[66] Southern African Development Community, *Electronic Transactions and Electronic Commerce.*
[67] Southern African Development Community, *Computer Crime and Cybercrime.*
[68] CARICOM, "From Dialogue to Action: Advancing Digital Transformation in the Caribbean."
[69] Association of Southeast Asian Nations, Data Management Framework.
[70] Belli, "Data Sovereignty as Elements of Digital Transformation."
[71] Brazil, Artificial Intelligence Plan.
[72] India, National Program on Artificial Intelligence.
[73] African Union, Continental Artificial Intelligence Strategy.
[74] Townsend, "Regulatory Landscape of AI in Africa."
[75] Republic of South Africa, *Protection of Personal Information Act 4 of 2013.*
[76] Republic of Kenya, *Data Protection Act No. 24 of 2019.*
[77] Townsend, "Regulatory Landscape of AI in Africa."
[78] African Union, African Union Convention on Cyber Security and Personal Data Protection Status List.

Yet current practices of digital and data exclusion, data exploitation, and data commodification would benefit from the introduction of better policy responses and digital and data governance mechanisms to ameliorate some of the worst socio-technical harms.[79] As governance spans layers and disciplines including law, philosophy, ethics, and cultural traditions so mechanisms of governance should not be divorced from important socio-political and philosophical implications. Certainly, integration into a wider governance landscape can address difficulties that are shared across the region offering solutions that are sensitive to local conditions and challenges. Solutions that are more carefully aligned to issues around health data availability, data sharing, and exchange, for example.

Moreover, digital technologies present new sociotechnical and policy concerns requiring a review of existing regulatory frameworks.[80] Although AI in digital health is regulated in SSA, a policy window of opportunity exists to facilitate data accessibility and digital health adoption.[81] Private and state research organisations can greatly assist by creating a network of accessible regulatory grade and sustainable databases that adhere to legal and ethical standards for accuracy and representativeness. Along with formal policy regulation, we have seen a proliferation of ideas about *ethical*, *responsible*, and *inclusive* AI development and what this might mean in the governance of AI. This is with the view to orienting design and development practice towards socially desirable outcomes. Strong digital and data governance is foundational for effective AI adoption. Accordingly, it is proposed that a governance solution should take the form of a powerful triumvirate of legal principles and policy; ethical constraints and embedded rights and values; and operational necessities such as system testing, evaluation, and assurance case building. Ultimately, the solution lies in bringing together existing local knowledge at all levels with technological expediency in the form of a new data architecture, amalgamated within a formalised multi-layered governance framework: that is, the merging of a meaningful, coordinated, extended, and overlaid practice of data and digital health governance.

4.4 Data Ownership, Solidarity, and the Public Good

One crucial part of the solution to counter challenges of data colonialism is to recognise and assert proprietary rights over data by sub-Saharan research institutions. Of late, in South Africa, there has been a growing corpus of legal literature that supports the multi-faceted nature of data arguing that, based on common-law property principles, the entity or institution that generates data - often a research institution or healthcare provider - has a moral right to claim ownership of such data and is the lawful owner of that data.[82] Understanding key aspects of data ownership, informational privacy law, and personality rights, and their respective dimensions and interrelationships within a jurisdiction allows us to more carefully view data in terms of a bundle of rights.[83] Stressing the distinction between various legal rights such as ownership rights over data, as distinct from other rights in data, such as privacy, personality, and intellectual property rights, is an important informant of data governance helping to ground the legal governance of data and the respective parties' rights.[84] While these rights may coexist or conflict; rights are qualified, rather than extinguished. Such data-related rights also have significant, although often overlooked, implications for inferential data. Inferential data arises from an analysis of the project data, often used to draw conclusions, or make predictions about people from whom the data samples have been drawn. In these instances, the data may well fall beyond the ambit of typical data protection laws while full ownership nevertheless persists.

Aligned with this is the important role public institutions play as data owners and custodians of data in SSA. Public hospitals, clinics, and universities are vast collectors, generators, and holders of health data across SSA. As such, they are under a legal duty to manage this data in the public interest positioning data ownership with solidarity and the public good. Data ownership as understood as a legal foundation for institutional control and accountability can be used to reinforce public priorities providing a commitment to broader collective digital health goals. In the recent past, various model laws, tools, and frameworks have served to accelerate these commitments. To this end, a Model Law on Health Data Governance, launched in 2024, offers a tool for governments, and the foundation for a global and regional framework, to support efforts to strengthen national laws and frameworks on health data governance.[85] A further advance to better support data governance in South Africa is the provision of clear and adaptable guidelines for data rights in a data transfer template drafted for use by the research community

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[79] Here, regulation refers to the legally binding rules that govern the sector, while oversight refers to the processes of monitoring and enforcing compliance with such rules.

[80] Meinhardt, "Pathways to Governing AI Technologies."

[81] The regulatory authorities of South Africa, Kenya, and Tanzania are affiliate members of the International Medical Device Regulator Forum (IMDRF) with regional harmonisation initiatives with the African Medical Devices Forum.

[82] Thaldar, "Claiming Ownership of Human Genomic Data."

[83] Thaldar, "Multidimensional Nature of Genomic Sequence Data."

[84] Thaldar, "Ownership of Personal Information."

[85] Health Data Governance. Model Law on Health Data Governance.

in South Africa.[86] These legal constructs and mechanisms have important implications for digital and data governance and control, enhancing data-sharing and resisting data colonialism in SSA. While significant, this work further illustrates a novel way of practically operationalising embedded ethics and law with a view to inform a complementary strategy for increased AI in digital health adoption in SSA.

4.5 A Third Way of Governance-by-Design

We are, thus, called to reimagine data and digital governance with a view to addressing specific challenges in SSA. One way is to offer the innovative approach of governance-by-design. Governance-by-design allows legal and ethical principles, values, and standards (such as, amongst others, transparency, privacy, fairness, and equity rights and interests) to be incorporated and embedded directly, as practical operational rules and protocols, into the architecture of the technology itself. To this end, Matthan suggests for example that questions around data governance can be resolved by, in combination, a 'third way' consisting of a framework of platforms and protocols to build digital ecosystems atop open, interoperable architecture for the public good. Accordingly, in the pursuit of greater accountability and compliance, the approach allows legal and regulatory objectives (such as data protection laws) to be embedded and operationalised within the fabric of the infrastructure and within the digital architecture itself.[87]

Thus, the refinement of high-level ideas, such as around data privacy and transparency requirements, is supported by lower-level evaluative standards and operational rules that are integrated and built within the system architecture. This, in turn, tells us something about these normative values as design requirements and their practical application, context appropriateness, and application within a particular domain or sector for a specific target user audience. In a similar vein, it might be possible for rules and protocols around data integrity and accuracy to be written into the data architecture, creating the opportunity to incorporate principles of 'privacy by design' and 'AI ethics by design'.[88] Pragmatically then the technology itself is used as a tool and enforcer of digital and data laws, norms, and standards; not as a replacement for regulation and other governance measures, but as an adjunct informer of it.

An expanded notion of governance-by-design is to include other normative requirements – such as social and cultural requirements - into the non-technical design infrastructure.[89] However, to be realisable these valued normative principles and rules, and the protocols they underpin, must be articulated, and carefully delineated. The framing of normative imperatives and legal, social, and ethical values and principles that guide the conduct of people in SSA society, already well-documented in the literature, can be extended to the governance-by-design space.[90] Indeed, the practical operationalisation of certain ethical framings – such as privileging collective interests or respecting human autonomy - can benefit from elements of technical novelty. It can allow, for example, for data subject empowerment as it provides greater opportunities for nuanced consent, control over data use and transfer, and public benefit.[91] A good illustration of this third way governance-by-design mechanism emanates from India and is embodied within the Indian Data Empowerment and Protection Architecture (DEPA) policy framework. This is a digital consent management system incorporating privacy-by-design principles that allow for securing control over user data and assists in data sharing.[92] In essence, it amounts to the creation of open-source protocols and software to translate legal rules into practical, technical tools and allows regulators direct control over the management of the protocols and the ability to influence policy outcomes in real-time.[93] These mechanisms can form a core component of a wider Digital Public Infrastructure (DPI) initiative designed to foster digital and data innovation and interoperability, track data provenance, protect rights, and drive inclusive growth at scale.

Although it does not negate the need for philosophical underpinnings and legal safeguards, governance-by-design has the potential to provide both a supplementary and complementary vehicle for transformative governance.[94] Certainly, policy choices in progressive digital economies with a high level of technological expertise and the data architecture to support it - such as India - provide a persuasive and aspirational model for adaptation to SSA requirements. This can act as a practical framework and a model for fellow Global South neighbours and data partners across the African continent. While the

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[86] Thaldar, "Enhancing Data Governance."
[87] Matthan, The Third Way.
[88] Cavoukian, "Privacy by Design," 2.
[89] Townsend, "From Pluralistic Normative Principles to Autonomous-agent Rules."
[90] Gyekye, "African Ethics;" Metz, "African Reasons Why AI Should Not Maximize Utility."
[91] Matthan, The Third Way, 4.
[92] IndiaStack "Data."
[93] Matthan, The Third Way, 2.
[94] Belli, "New Data Architectures."

opportunity to create sovereign, inclusive systems is encouraging, practically, we need to understand the constraints imposed by a lack of infrastructure to introduce these measures in the region.[95]

5. Conclusion

A multi-layered approach to digital and data governance is mindful of the complex realities of AI in digital health systems in SSA and is consistent with a construct that is supportive of data availability as well as with much-needed, afforded data protection. Motivated by human-centric AI adoption and the idea of operationalising law and ethics, this contribution reimagines and extends data and digital governance as it relates to AI in digital health development and adoption. If AI in digital health is to provide the many benefits promised to SSA, we should address certain data-related challenges and augment existing digital and data frameworks with novel governance mechanisms. Drawing on an example from India, a third way of governance by design allows regulatory, ethics, and legal objectives, rights, standards, and operational rules to be embedded within the code and architecture of the digital system itself. The incorporation of these is offered as a novel and progressive data and digital governance measure to address ever-evolving digital, data, and data-related challenges in SSA.

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[95] Belli, “New Data Architectures,” 145.

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