

My Data, Our Health
East Africa Benchmark Report
2023

SPIDER
INCLUSIVE DIGITALISATION THAT BENEFITS ALL



SPIDER is an independent centre of enablement for inclusive digitalisation that benefits all by contributing to the Sustainable Development Goals (SDGs). The center is based at the Department of Computer and Systems Sciences at Stockholm University (www.dsv.su.se).

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Table of Contents

Acronyms & Abbreviations **4**

Public Awareness of Health Data Governance in East Africa: Benchmark Report **5**

Introduction and background to the study 5

Definitions of Key Terms 6

Research Methodology **7**

Methods for data collection and analysis 7

Findings **9**

Policies, Laws, and Regulations on Health Data Governance in East Africa *9*

Analysis of Findings 18

Analysis of Online Discourse on Health Data Governance *18*

Analysis of Responses *20*

Perceptions and Understanding of Health Data Governance *21*

Public Awareness and Understanding of Health Data Collection; Purpose, Security and Use *22*

Health Data Protection and Privacy Practices *25*

Sociocultural Beliefs and Health Data Governance *29*

Health Data Management and Digital Systems' Utilisation *32*

Conclusions, Limitations & Indicators **33**

Limitations and Scope of the Benchmark Report *34*

Qualitative Indicators Proposed to Measure Campaign Results *34*

References **36**

Acronyms & Abbreviations

AI:	Artificial Intelligence
AIA:	Access to Information Acts
DPA:	Data Protection Act
FGDs:	Focus Group Discussions
EHR:	Electronic Health Records
EMR:	Electronic Medical Records
HIMS:	Health Information Management System
ICT:	Information and Communication Technologies
KeDPA:	Kenya Data Protection Act
KeMoH:	Kenyan Ministry of Health
MoH:	Ministry of Health
NGO:	Non – Governmental Organisation
NIHC:	National Insurance Health Cover
ODPC:	Office of the Data Protection Commissioner
PAHO:	Pan American Health Organization
PDPO:	Personal Data Protection Office
PDPC:	Personal Data Protection Commission
SPIDER:	Swedish Program on ICT in Developing Regions
TMA:	Total Market Approach
TzDPA:	Tanzania Data Protection Act
TzMoH:	Tanzanian Ministry of Health
UHC:	Universal Health Coverge
UgDPA:	Uganda Data Protection Act
UgMoH:	Ugandan Ministry of Health
USAID:	United States Aid for International Development
VHT:	Voluntary Health Teams
WHO:	World Health Organization
UAP:	Uganda Alcohol Policy

Public Awareness of Health Data Governance in East Africa: Benchmark Report

Introduction and background to the study

Transform Health has been working with partners to advocate for and strengthen health data governance, in particular regulatory aspects. Following the successful launch of the Health Data Governance Principles in 2022, which have gained wide recognition and endorsement by more than 150 organisations and governments, we have been focusing efforts to put the principles into practice through stronger regulation. In particular we are:

- Advocating for a **global health data governance regulatory framework to be endorsed by governments through a World Health Assembly resolution** and implemented through national legislation and regulation.
- Supporting the development of a global health data governance regulatory framework that contains **draft model legal and regulatory text articulating core elements for health data governance regulation, framed around equity and rights-based principles**.

Health data governance is shaped by attitudes, beliefs, practices and behaviours within societies. These factors are closely connected to how health data is viewed, gathered, organised and put to use. This report focuses on the East African Region and specifically Kenya, Tanzania and Uganda. Therefore, reference to East Africa or the region throughout the report is limited to these countries. There is a significant lack of knowledge when it comes to comprehending the governance of health data in East Africa. This is the very purpose of the “My Data: Our Health” campaign. It has initiated public dialogue about health data, advocating for heightened awareness and accountability with public authorities. The campaign seeks to address key questions regarding the collection and management of health data, its intended purposes, whether it serves public good, individuals’ access to their own health data, and the extent of individual control over this data.

When citizens understand the value of health data and the issues which guide its management there is a greater impact on public health and well-being as people are able to make more informed decisions about their health and care. Individuals may make more informed decisions and participate in community organisations that advocate for citizen involvement in shaping both current and future data policies. This is particularly significant concerning surveillance practices, as misuse of biometric data collection can potentially expose individuals to stigma and discrimination (Davis 2020). The *“My Data: Our Health”* campaign further sets out to grow and mobilise public awareness to reduce and eventually prevent misuse of health data and policies that have been hurried in the post-covid era. At

the same time citizens can contribute to public health efforts without sacrificing the individual control of their data.

Toro Development Network (ToroDev) conducted this baseline study in East Africa on behalf of the Swedish Program for ICT in Developing Regions (SPIDER). The main goal of the baseline study was to assess the effects of the campaign and monitor ongoing efforts. Sub goals derived from this objective are to:

1. Analyse past and current public debate, perspectives, norms and beliefs on health data governance and access in East Africa
2. Survey the perceptions or individuals giving credence to women and youth and their understanding as it relates to health data governance
3. Evaluate the public's relationship to and understanding of national policies, laws and regulations on health data governance in East Africa
4. Examine how public discourse is framing the narrative around health data governance the region

Definitions of Key Terms

Health data governance refers to the overall administration of health data, the processes deployed to collect, plan for, and effectively manage quality health data. This includes regulation around compliance to law and policies that affect the public's health data governance, who can access what level of health data, how data collection methods are improved and how data is used by the leadership of the country to make decisions to shape healthcare delivery.

Health data management/Health information management in this study refers to the planning, implementation and control of particular methods, tools, systems and other practices put in place by an institution, consistent with the existing legal framework (data governance), to gather, analyse, store, share and use health data resources to achieve operational and management objectives.

Interoperability within digital health systems pertains to the capacity of two or more systems to seamlessly exchange and utilise health data, thereby enabling the recipient system to employ this data for decision-making purposes and to facilitate or strategize healthcare provision within a connected clinical environment and to be able to share and use health data with one another. This data can then be used by the receiving system for decision making, to facilitate or plan for care at a linked clinic.

Privacy and security are central to a good data governance structure. Privacy ensures that individuals' rights to control their health information are respected. Security mechanisms

protect that information from unauthorised access or compromise. These principles are vital not only for legal and ethical reasons but also for maintaining trust in healthcare systems and facilitating the safe and efficient exchange of health data for patient care and research.

Data storage refers to retention of information using technology specifically developed to keep the data for use and access as necessary.

Healthcare data cleansing is the practice of quality assurance of accuracy of data, cleaning out bias and errors, avoiding duplication and ensuring up to date and complete data entries in the system.

Electronic Health Records (EHR) are comprehensive digital records of a patient's health information that can be shared across multiple healthcare providers and organisations and include information sources including Electronic Medical Records (EMRs). EHRs are designed for interoperable systems and play a crucial role in the improvement of care and access to the holistic history and status of a patient's health, ultimately leading to better health outcomes.

Electronic Medical Records (EMR) is a digital version of a person's paper chart within a single health care provider. They contain medical history, diagnoses, treatment plans, test results and immunisation records which are created and maintained by a particular healthcare provider.

Public narrative: the means through which people communicate their values and motivate one another to think, feel and act on a particular issue.

Research Methodology

This report relies on three data sources, namely a literature review, Focus Group Discussions (FGDs) and survey data from an online questionnaire developed by Transform Health. The literature review was carried out in February/March 2023. Focus group discussions and analysis extended from May to June 2023.

Methods for data collection and analysis

The literature review sought to establish existing knowledge on how the region is handling health data governance questions to increase value for data use, instil confidence in the public to participate in health data generation and use. The search was limited to google and google scholar search engines and therefore included grey and academic literature.

Google scholar provided peer-reviewed and/or academic publications and the search prompts were from each of the objectives mentioned in the introduction. For example, in

relation to the first objective, the search prompt was suffixed with country names along with “evaluating policies, laws and regulations on health data governance”. The search was filtered to remove publications that did not have Kenya, Tanzania and Uganda in the results. The filtering process similarly limited the search period to six years, in other words publications not later than 2017 are what were reviewed.

Google search provided grey literature in the form of country reports published by international agencies, local non-governmental organisations as well as debates and opinion pieces from the top three newspapers in each country. The google search also led to country health ministry URLs where different policies, laws and regulations on Health Data Governance were assessed. Policy documents earlier than 2017, but still operational in the region were considered in this literature category. The documents on each health ministry website were scoured for any mention of “data quality and timeliness”, “data protection and privacy” and “data integration and sharing”. The documents were examined based on the attributes outlined in this section to assess the degree to which access to and ownership of health data are facilitated for individuals, and also to determine if access to health data for public good is a factor.
Specifically; Kenya’s ministry of health has over 50 such documents in varying form (policy briefs, policies, strategic plans and action plans). Tanzania has four and Uganda seven also within the category of health policies and laws that govern the sector.

To broaden the search for public engagement on health data governance, social media platforms; X (formerly Twitter), Facebook, and YouTube provided public discourse view from the East African Region. The searches were country specific in examining what the public was discussing around the paradigm of health data governance at the same time to elicit from social media engagement what was being said about “My Data: Our Health " campaign. The search results indicate that Facebook is not as widely utilised as X and YouTube as a communication channel. There are fewer than 10 Facebook posts, all of which originate from Kenyan organisations. In contrast, YouTube videos discussing the role of data in health governance are mostly from international agencies, while X posts, which are mainly from international agencies as well, consist of concise statements that prompt additional discussion and commentary.

Also contributing to the data in this report are focus group discussions (FGDs) carried out in each country. Recruitment for participation was purposive targeting, health researchers, health professionals, health data governance advocates, organisation/associations supporting women and youth in health access questions, public institutions working with various issues on data protection, public health research agencies, policy makers in national ministries of health, members of parliament and others. FGDs were able to solicit from the participants their thoughts, experiences and perspectives around the notion of health data

governance. The FGDs also provided country specific situations and were particularly useful for exploring the nuances around beliefs, social attitudes as well as underlying motivations for health data sharing. The literature review provided the basis for some questions that fed into the FGDs and to similarly share insights on the growth/development of policies or programmes on health data governance in each country.

Lastly an online survey designed by Transform Health was administered randomly to the general public in the region to gather data on the general population's understanding of what they know about their health data. The survey was launched on 23 January 2023 in French(1591 responses) and in English (467 responses). Most of the responses were made before the end of May 2023. The data from the survey yielded the quantitative data this report uses to identify trends, patterns and correlations. Responses are anonymous but required administering to assuage any data privacy concerns as survey respondents were cautious wondering how much of their personal information would go into the study. The data from the survey is objectively factual in so far as it gives insight into what the general population thinks about their health data.

Survey responses can be categorised by country. However, it's important to note that the data point for the countries was not initially available in the survey tool during the early stages of data collection. This category is included because the three countries under study also fall within this category. Other countries also fit within this grouping, and the survey results should be interpreted with this in mind.

Findings

Policies, Laws, and Regulations on Health Data Governance in East Africa

The baseline delved into an examination and analysis of various policies, laws and regulations pertaining to health data governance in East Africa. In Table 2 below, the outcomes of the evaluation of these policies are presented concerning four key attributes:

1. Attribute a: the recency of the document, specifically whether it was created or reviewed within the last five years
2. Attribute 2: whether the document addresses data quality and timeliness
3. Attribute 3: the document's focus on data protection and privacy
4. Attribute 4: whether the document discussed data integration and sharing.

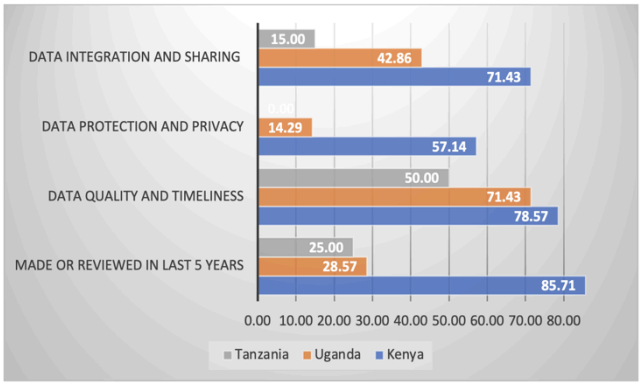
The results are presented alongside a reference name, serving as an identifier for the policy, with the initial letter signifying the respective country.

Table 1 *Evaluation of Ministry of Health Policies for Data Governance Attributes*

Policy	Ref Name	Attr 1	Attr 2	Attr 3	Attr 4
Infection Control and Waste Management Plan	KICWMP	✓	✓		✓
Kenya Cancer Policy 2019-2030	KCP	✓	✓		✓
Kenya Health Sector Monitoring and Evaluation Plan	KHMEP	✓	✓	✓	✓
Kenya National e-Health Policy	KNeHP		✓	✓	✓
Kenya National Oral Health Policy	KNOHP	✓	✓	✓	✓
Kenya National Non-Communicable Diseases Strategic Plan	KNCDSP	✓	✓	✓	✓
The Breast Milk Substitutes (Regulation and Control) Act	KTBMA	✓			
National Eye Health Strategic Plan	KNEHSP	✓	✓	✓	✓
National Nursing and Midwifery Policy	KNNMP	✓			
Peek Virus Periodic Screening Policy	KPPSP	✓			
National Policy on Patients, Health Worker Safety and Quality of Care	KNPPHS	✓	✓	✓	✓
Privacy Policy for e-Community Health Information System (eCHIS)	KeCHIS	✓	✓	✓	✓
National Pharmaceutical Policy	KNPP		✓		
The National Reproductive Health Policy	KNRHP	✓	✓	✓	✓
Uganda Alcohol Policy	UAP	✓	✓		
Uganda National Health Laboratory Services Strategic Plan	UNHLSSP		✓	✓	✓
Reproductive, Maternal, Neonatal, and Child Health Improvement Strategy/Policy	URMNCIP		✓		✓
National Oral Health Policy	UNOHP		✓		
Public Health Amendment Act 2021	UPHAB	✓			
National Medicines Policy	UNMP		✓		✓
National Integrated Early Childhood Development Policy	UNIECDP				
National Health Policy	TNHP				
Tanzania National Policy on HIV –AIDS	TPHivA		✓		
Tanzania Food and Nutrition Policy	TFNP				✓
Public Health Act	TPHA	✓	✓		

Note: Attr = Attribute

The remaining results were compiled from the discussions regarding health data governance within policies and regulations and are illustrated in percentages. See *Figure 1* below:



The findings revealed that Kenya's Ministry of Health (MoH) website hosts a greater number of health policies, and a significant portion of these policies have been either created or reviewed within the last 5 years. Kenya demonstrates a strong commitment to maintaining "updated policies," as reflected in higher percentages compared to other countries in the region. These policies explicitly outline how data governance aspects such as data quality and timeliness, data protection and privacy, and data integration and sharing will be addressed.

In fact, while the eHealth policy is accessible on the policy repository of Kenya's MoH website, it is notably absent from similar repositories in Uganda and Tanzania. However, it is

worth mentioning that the policy for Uganda can be found in an alternative repository on the MoH website.

The majority of these policies maintain consistency in their commitment to promoting gender equity, adopting a Human Rights-based approach, adhering to principles of transparency and accountability, and unequivocally opposing all forms of discrimination, as outlined in their provisions. (KCP, 2019; UNOP, 2007). However, it is not clear how this mandate in the policies can be achieved especially where mechanisms for data access by private individuals and researchers are not well elaborated in the same existing legal documents reviewed in this study.

We also observed that the data governance principles in the policies are more on the side of the policy makers and data managers. For instance, the Kenyan cancer policy aims at ensuring that the "*data collected is collated or aggregated to facilitate monitoring, evaluation and research and planning*". In addition, it aims to "*ensure that accurate data and characteristics of cancer patients are obtained in a timely manner and utilised for surveillance and planning.*" Evidently, the focus on research, accuracy, and planning in this context primarily serves the needs of data managers, with little consideration for the data owners or independent researchers who may also require access to such data.

In some policies, data access was explicitly mentioned. For example, the Uganda national alcohol policy of 2019 commits to "*ensure broad access to information and effective education and public awareness programs*". For such policies, the next step should be to create mechanisms for effecting such statements. Other policies, like the Uganda national medicines policy of 2015 reported that a "*pharmaceutical information portal was developed for users at all levels to easily access and analyse data from various data sources*". The portal's URL, https://pip.health.go.ug/, unfortunately, necessitates a username and password for access, and there is no evident process for obtaining these credentials. This evidently limits individuals' ability to access data, despite their role as contributors of the data featured on the portal.

Most of the existing legal frameworks, captured in *Table 1*, point out the need for adequate and timely data to effectively implement health policies. The Uganda Alcohol Policy (UAP, 2019), for example, states that: "*Government currently lacks a central point for documentation and collection of data to inform stakeholders. Inconsistent or inadequate data inhibits the development of effective responses. There is a need to scale-up alcohol related research and data collection*".

Kenya's National Policy on Patient Safety, Health Worker Safety and Quality of care (KNPPHS, 2022) notes that: "*Data collection, analysis, dissemination and publishing are not factored in routine health facility budgets. Data sources are in some instances incomplete,*

not comprehensive and not easily retrievable because of the lack of digitalization. In some cases, the hard copies are kept at home with patients. The formal structure for person's identification and civil registry makes population health research difficult."

The statement above suggests that the policy encourages the creation of unified metrics for patient and health worker safety within a coordinated and integrated system for collecting, analysing, storing, and sharing data.

Data protection and privacy was the least scored attribute of health data governance in all the three countries, as indicated in Table 1 and Figure 1. A few policies, like Kenya's eHealth Policy pointed to existing or upcoming data protection laws. The privacy policy for electronic Community Health Information System (KeCHIS) states that:
"*We will retain and use users' Personal Data to the extent necessary to comply with our legal obligations (for example, if we are required to retain your data to comply with applicable laws), resolve disputes, and enforce our legal agreements and policies"*

In addition to health policies, the decentralisation policy also exerts influence on health data governance, shaped by the management structure imposed within each country's health system. The three countries are positioned at different stages regarding decentralisation, national insurance policies, and legal frameworks. All three nations have decentralised health services, with the district or county health system responsible for delivering health services, planning, management, and policy implementation. At the national level, policy formulation, planning guidelines, coordination, and quality assurance are managed (Henriksson et al., 2019; Kigume & Maluka, 2018).

However, Kenya and Tanzania have embraced a more devolved system, including functional "intermediate level" governance structures such as provinces or counties, which Uganda lacks. This devolved system grants regional or county governments the authority to recruit their own staff and establish payroll systems tailored to their local needs. In contrast, Uganda's district-level system identifies staffing gaps at health units and submits lists to the national level, where decisions on recruitment are made. The absence of local units' autonomy in staff recruitment poses significant challenges to health data management systems in Uganda, directly impacting health data governance.

The implication for health data access, both for data providers (individuals/patients) and independent researchers, is that centralised data systems managed by public agencies like Ministries of Health in the East African countries tend to involve more bureaucratic steps for requesting data access by an individual. Requests for data access from such systems often encounter fewer positive responses and longer response times before feedback is provided.

Another emerging concern identified during the baseline study pertains to health data governance in the context of mental health and suicides (Iversen et al., 2021). There is a recognized need for data metrics and policies aimed at assessing individuals' mental well-being, particularly to provide guidance to young people and adolescents. This is crucial in helping them navigate the challenges they face during their formative years and preventing mental health issues from arising.

In a related context, it's worth noting that Kenya and Tanzania currently operate National Insurance Health Cover (NIHC) schemes, whereas Uganda does not have such a system in place. The objective of NIHC is to establish a healthcare system that is accessible, equitable, efficient, and sustainable, ultimately leading to the achievement of Universal Health Coverage (UHC).

Authors such as (Barasa et al., 2018; Mbau et al., 2020) have highlighted that Kenya and Tanzania, like other sub-Saharan African countries, have encountered challenges in implementing UHC. These challenges include "infrastructure gaps in public healthcare facilities and a distribution of contracted health facilities that tends to favour urban areas and the private sector, thereby compromising the delivery of and access to these new services."

Health data governance plays a pivotal role in facilitating the effective design and alignment of all sectors within the UHC framework. It is crucial for health authorities to establish robust data governance practices to develop an appropriate financing structure that accommodates the diverse categories of individuals found in most African nations. These categories encompass the extremely poor, who are unable to pay premiums; the large informal sector with a predominantly uninsured population; individuals who drop out of insurance schemes; the formal sector; and the affluent, who often opt for private insurance schemes (Pyone et al., 2017; Umeh, 2018).

Uganda's Total Market Approach (TMA) strategic plan for 2020-2025 envisions such categorization as it aims to achieve UHC through a sustainable resource mobilisation approach (TMA, 2020). The TMA segments the population based on their ability and willingness to pay for services and products, targeting different segments with free, subsidised, or fully priced commodities to enhance equitable access (TMA, 2020).

Health data protection and privacy practices in East Africa

The notion of privacy and confidentiality concerning health data is not a novel concept in the healthcare sector, with the Hippocratic Oath serving as a global benchmark ("Hippocratic Oath," 2023). Nevertheless, in today's digital era, characterised by heightened access and

mobility of personal data, coupled with the growing significance of such data for public benefit as well as potential political and commercial purposes, the legal and regulatory aspects governing the privacy and confidentiality of health data have assumed greater importance.

Through the constitutions and other enabling acts, Uganda, Kenya and Tanzania have clearly established the people's right to privacy. Acts such as Public Health Act (KePH, 2017; TzPH, 2010; UgPH, 2014), HIV-Aids Prevention and Control Act (KeHA, 2006; TzHA, 2008; UgHA, 2015), Access to Information Act (KeAI, 2016; TzAI, 2016; UgAI, 2005), Computer Misuse and Cybercrimes Act (KeCC, 2008; TzCC, 2015; UgCC, 2011), all penalise breaches of "medical confidentiality" and the unlawful disclosure of a person's health status' while also emphasising citizens' rights to access information for the exercise or protection of fundamental freedoms.

Despite the good intentions behind these laws, their effective implementation and harmonisation for robust data protection and privacy have been lacking (Kasanda et al., 2023; Malekela, 2022). In response to this challenge, each country has recently enacted a Data Protection Act (KeDPA, 2019; TzDPA, 2022; UgDPA, 2019) as a central enabling legislation to enforce the privacy and confidentiality of individuals' data.

A pivotal aspect of these Data Protection Acts (DPAs) is the requirement that any entity acting as a data controller or data processor for personal data must register with the respective data authorities of their respective countries. Furthermore, each institution handling personal data is mandated to appoint a data protection officer. These laws also permit the anonymisation of data, which involves removing all information that can be linked to an identified or identifiable individual.

A report from Strathmore University's Centre for Intellectual Property and Information Technology (CIPIT), authored by Ogonjo et al. (2022), has noted that the DPA, as a comprehensive legislation, encompasses many privacy and sensitivity regulations previously found in health acts. However, the report identifies certain gaps, including the need for more comprehensive policies and procedures regarding transparency and the anonymization of health data.

The rights of the data subjects need to be strengthened with regard to establishing and reaffirming the accuracy of the health data collected. Also identified, is a need to strengthen data transfer and sharing "in the context of cross-border data transfers, where the circumstances would merit, but also the transfer of data across the data collection systems, which would occur for instance in the case of referrals." The other gap identified is a need to streamline sharing of health data with private or third-party companies. In addition,

implementation of DPAs by appointing designated officers and funding activities to monitor and supervise proper health data governance is still inadequate in all three countries.

It is worth noting that the DPAs do not exist to limit access to data. The DPAs of the three countries clearly give rights to a data subject. A data subject has a right: “to be informed of the use to which their personal data is to be put; to access their personal data in custody of a data controller or data processor; to object to the processing of all or part of their personal data; to correction of false or misleading data; and to deletion of false or misleading data about them” (KDPA, 2019).

In addition, the East African region has related Access to Information Acts (AIA), which give citizens the right to access information subject to constitutional limits. For example, in both Kenya and Uganda, such acts give 21 days for an Information Officer to respond to a data access request, while it gives 30 days for Tanzania (KeAI, 2016; UgAI, 2005; TzAI, 2016). Despite the existence of these rights, access to health data by individuals and researchers in the three East African countries remains significantly limited. This underscores the necessity for public awareness and advocacy campaigns to empower people to confidently exercise these rights. Duty holders, too, should be encouraged to establish practical mechanisms aimed at enhancing actual access to data and information, especially in the healthcare sector, when lawful requests are made by data subjects, including individual patients and researchers.

With an uptake of digital health services in Uganda, Kenya and Tanzania, several authors (Basajja et al., 2022; Galvin & DeMuro, 2020) have pointed out areas that may not be adequately covered by existing data protection and privacy laws and implementation capabilities.

Galvin and DeMuro (2020), for example, stated; “*Recent literature demonstrates that the security of mHealth data storage and transmission remains of wide concern, and aggregated data that were previously considered de-identified have now been demonstrated to be re-identifiable*.”

Basajja et al. (2022) observed; “*An assessment of Uganda policy documents on eHealth based FAIR Guidelines— that data be Findable, Accessible, Interoperable, and Reusable (FAIR), found that 83% of the documents mentioned FAIR Equivalent efforts. The study recommended capacity-building efforts by international health bodies to promote adoption of FAIR practices.”*

These findings may have prompted the authorities to formulate new policies, such as the Kenya National eHealth Policy 2016-2030 and the Uganda National eHealth Strategy 2017-2021. The Kenya eHealth policy centres on three fundamental concepts: Interoperability, health data integration, and data protection.

Therefore, we recognise that health data integration plays a crucial role in incorporating private entities and non-governmental organisations operating in the healthcare sector into the national health data management infrastructure. As healthcare systems increasingly adopt technology, including biometrics and other electronic methods for data collection, storage, and analysis, it becomes imperative to develop and implement digital health transformation laws and regulations at both the national and decentralised levels by 2030 (KELIN, 2020; Shibah, 2022; Transform Health, 2023).

For instance, in Kenya and Uganda, the Data Protection Acts (DPAs) emphasise the registration and traceability of personal data collectors and controllers, along with measures to safeguard and anonymize data to prevent misuse. Simultaneously, the AIAs in both countries assert the citizens' right to lawfully access data and information held in the public trust without undue restrictions. However, practical efforts are still required to fully implement the provisions of these legislations.

Establishing a health data governance and management infrastructure or framework that prioritises these issues is essential to ensure complete ownership and easy access to health data for both legal data owners and researchers.

Sociocultural beliefs and health data governance in East Africa

Health data access, sharing and reuse is greatly affected by peoples' beliefs and gender dynamics. Hackett et al. (2018) observed that ***"Women's concerns regarding privacy aligned closely with a belief that pregnancies and expected delivery dates must be kept secret, reflecting fears that pregnancy renders women vulnerable to witchcraft by jealous neighbours."*** Furthermore, questions about health that significantly impact people's lives and health in the region are often considered "taboo." Public discourse surrounding topics such as sex education in schools, abortion rights, teenage pregnancies, female genital mutilation, and many more are frequently entangled in a clash between modern approaches and traditional beliefs held by the population (Moore et al., 2022; Ogolla & Ondia, 2019).

This presents a significant challenge: how can health data governance interventions be designed for issues that people consider taboo or are uncomfortable discussing publicly? This challenge results in several issues. Firstly, proper data collection regarding pregnancies, particularly among rural women, is hindered, leading to inadequate antenatal care. Secondly, conflicting ideas in society about how to educate youth on sexual matters contribute to a lack of confidence among young people in asserting their sexual rights. Additionally, there is often fear of seeking sex-related information, and sometimes even fear

among youth in openly purchasing contraceptives from stores (Moore et al., 2022; Ogolla & Ondia, 2019).
These factors can impede progress toward establishing a more effective healthcare management system in the region. Moreover, social taboos related to health matters also hinder the accurate diagnosis and treatment of certain diseases, ultimately resulting in suboptimal healthcare delivery by healthcare professionals. The absence of a contextually tailored and systematic data collection approach for these sensitive issues leads to the collection and dissemination of incomplete and inadequate data for decision-makers and donors.

Moore et al. (2022) advocates for interventions that build on peoples' cultural norms and values to find common ground between traditional beliefs and modern health methods. For example, in central Uganda culture, *Ssengas* (paternal aunties) are traditionally tasked with preparing young women, who are about to get married, in matters of sex and home etiquette. In Uganda, authorities need to find ways of merging the traditional and socially accepted *Ssengas*' sex education for health data governance for reproductive health issues among youth and women. Uganda has used this approach in the past with appreciable success. The early HIV-AIDS and Ebola awareness campaigns were met with scepticism but were gradually welcomed and adhered to in large part due to authorities including socially acceptable people like traditional rulers, religious leaders and celebrities (Abbo et al., 2019; Perehudoff et al., 2022).

Effective strategies for health data governance need to take the social cultural contexts into account, and accommodate social beliefs that may impede rural women from revealing their pregnancy data due fears of being bewitched. Merely informing individuals that their data will be anonymized or de-identified is insufficient. There is a critical need for robust community engagement and public awareness efforts to elucidate the advantages of health data access and sharing, all while addressing deeply rooted traditional beliefs. These engagements should enlist community leaders who possess an intimate understanding of the local culture and have the capacity to foster public trust (Graamans et al., 2019; Mbuthia et al., 2019).

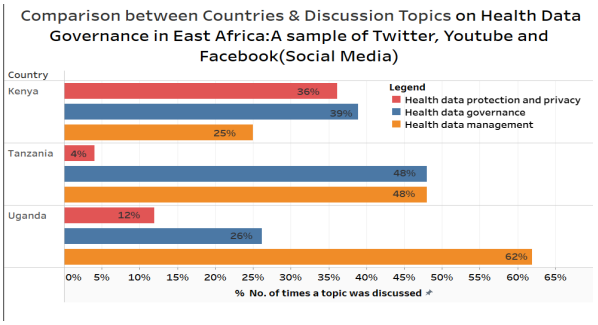
The relationship between health workers and those who seek care from hospitals is a matter of concern in East Africa. Disrespectful treatment of health care seekers, especially pregnant women, is still prevalent in the region (Lewis et al., 2018; Lusambili et al., 2020; Mwanga-Amumpaire et al., 2021). Healthcare seekers, particularly those without the means to "expedite the process," through bribes often experience subpar treatment and are treated as second-class citizens. This unfavourable treatment of healthcare seekers undermines the conducive environment necessary for data generation, access, and sharing. It also compels some individuals to seek alternative healthcare options from traditional healers or spiritual practitioners. Moreover, there is a pressing need for enhancements in palliative

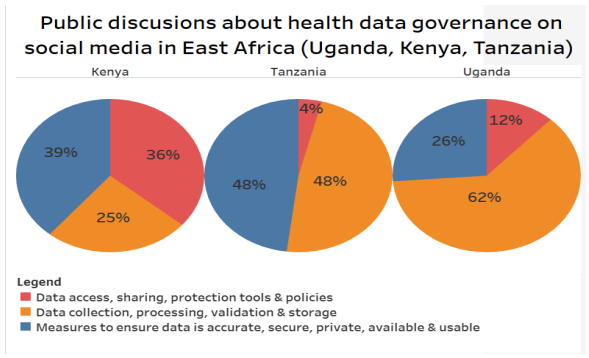
care for patients with conditions like cancer and other debilitating illnesses (Lewis et al., 2018; Mulemi, 2008). Efforts to improve the situation must include substantial technical capacity-building for healthcare providers to ensure that pregnant women, cancer patients, and other healthcare seekers receive more compassionate care. Such improvements will contribute to the creation of a hospitable environment for the flow and accessibility of health data.

Analysis of Findings

Analysis of Online Discourse on Health Data Governance

Online content and discussion forums were scrutinised to examine and observe the ongoing discourse concerning health data governance in Kenya, Tanzania, and Uganda. The analysis spanned from 2018 to April 2023. The social media data, as detailed in the methodology section, underwent thematic analysis, and the predominant themes for the three countries are visually represented in the pie chart shown in *Figure 2*.





As outlined in the methodology section, most of the social media posts originated from international and public agencies. Commentary primarily surfaced after various events centred around health data governance. Public engagement by individuals was largely centred on reinforcing the responsibility of governments or public authorities in ensuring a healthy data environment for the sector. Individual posts were minimal and mainly comprised of likes, or in the case of YouTube, dislikes, accompanied by comments suggesting that such initiatives were aimed at surveillance or spying on individuals.

Similarly, a noteworthy observation is that the few individual commentaries or posts on social media appear to be predominantly from men, a conclusion drawn based on first names. Furthermore, while the content presented strives for inclusivity, with women providing background commentary or presenting material in YouTube clips, there is a notable pattern where men often take the lead in addressing specific health inquiries requiring expert input. Consequently, despite media efforts to disseminate content on health data governance, public engagement and consumption appear to lean towards a male audience. This observation may shed light on why women in the survey data express a desire for greater control and comprehension regarding their health data. It's possible that they either find it challenging to relate to the online content, face limitations or lack access to the internet, or lack the necessary devices to support their information-seeking efforts.

Figure 2 illustrates the prevailing topics of discussion and their specific focus in each respective country. Upon delving deeper into these media discourses, there is a unanimous recognition of the significance of health data governance and its associated benefits. Various quotations emphasise the value of health data governance, with a significant focus on attributes like accessibility, timeliness, actionability, and reliability of data. For instance, a post from the World Health Organization (WHO) on September 30, 2021, underscores the role of a robust data governance foundation in enhancing evidence-based health outcomes.

Furthermore, YouTube channels provide both overviews and, in some instances, detailed discussions regarding gatherings related to health data governance and the resulting conclusions. From the media discourse on health data governance, it becomes evident that this paradigm is highly regarded but is still in its early stages of development. Other posts corroborate this perception, highlighting that efforts are being made to engage research consultants who can assist in fact-finding missions related to health data governance. Some missions seek to explore opportunities for greater interoperability, as exemplified by a post from July 8, 2019, which sought a consultant to conduct a case study on PEPFAR DREAMS Partnership programs' data systems in Kenya, Uganda, and Zimbabwe, aiming to identify best practices in health data interoperability.

Additional posts disseminate findings from research studies, such as one conducted in 2022 that uncovered the link between inadequate Health Data Governance and the apprehension experienced by people living with HIV when seeking care and treatment; a post from January 28, 2023. Moreover, there are posts announcing the publication of the Health Baraza Data Governance by the Imara Leadership Initiative in Tanzania. This publication serves to provide insights to the Ministry of Health regarding crucial policy interventions and programming aspects in the realm of Health Data Governance, with the announcement posted October 14, 2022.

Additional commentary provides updates on collaborations between regional governments and international organisations in pursuit of their health data governance objectives. For example, one post reports that the government has joined forces with the Rakai Health Sciences Program to implement an electronic data entry system across 144 health facilities, aimed at enhancing the efficiency and promptness of HIV health service delivery.

Analysis of the media discourse reveals that the state of health data governance remains a subject of ongoing debate. While policies and strategies for its management continue to evolve, discussions surrounding the practical implementation of these policies appear to be limited. Public awareness, as previously mentioned, appears to be at a surface level. Notably, statements such as "Health data in Kenya is considered sensitive data and is subject to particularly strict rules and can only be processed by health professionals who are bound by the obligation of professional secrecy," dated February 8, 2022, underscore the prevailing focus of governments and data management experts on the professional and strategic utilisation of health data. However, there seems to be insufficient consideration given to the interests of the individuals who provide this data, including whether they have an interest in understanding how their data is governed. Given this state of affairs, it is not surprising that survey data reflects limited public engagement. The prevailing narrative surrounding health data governance appears to be skewed towards health professionals and other data management experts, which may contribute to the observed lack of broader public involvement in the discourse.

Analysis of Responses

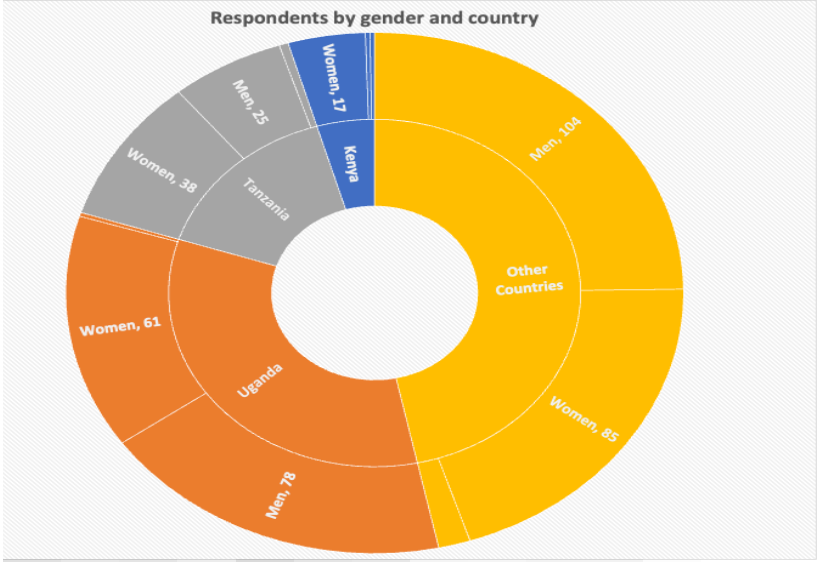
In this report section, we analyse data from the FGDs and the online survey to establish a baseline. This baseline provides valuable insights for ongoing and future advocacy campaigns aimed at enhancing health data governance in the Eastern Africa region. The discussion is organised in **five key themes,** and in line with the four specific objectives that were pursued by the study. The themes are; *1) Perceptions and Understanding of Health Data Governance, 2) Public Awareness and Understanding of Health Data Collection Purpose, Security and Use, 3) Health Data Protection and Privacy Practices, 4) Sociocultural Beliefs and Health Data Governance 5) Health Data Management and Digital Systems' Utilisation.*

Table 2. Profile of Focus Group Discussion Participants in Kenya, Uganda and Tanzania

Kenya		**Uganda**		**Tanzania**	
Participant K1	*Data Equity & Inclusion Policy Manager*	Participant U1	*MoH, Data Systems Analyst*	Participant T1	*Program Officer, Women CSO*
Participant K2	*Lawyer of Data Governance*	Participant U2	*Data Governance Project Manager*	Participant T2	*Program Officer, Human Rights CSO*
Participant K3	*Lawyer/Data Governance Researcher*	Participant U3	*Feminist Data Governance Advocate*	Participant T3	*Advocate of Court*
Participant K4	*PhD Holder & Research Manager Health Data in Kenya.*	Participant U4	*Data Governance Researcher*	Participant T4	Lawyer/*Attorney on Digital Rights Law*
Participant K5	*Health Data Advocate at KELIN*	Participant U5	*Advocate of the High Court*	Participant T5	*PhD Researcher*
Participant K6	*Public Health Specialist & HIV/AIDS Network Director*	Participant U6	*Digital Rights Advocate/Researcher*	Participant T6	*PWD/University Student of Law*
Participant K7	*Program Officer, Health & Governance*	Participant U7	*Data Systems Engineer*	Participant T7	*Human Rights CSO Director*
Participant K8	*Program Manager, HIV & TB*	Participant U8	*Data Protection Manager*	Participant T8	*Medical Practitioner/Lecturer*
Participants K9	*PhD Researcher in Data Governance*	Participant U9		Participant T9	*Medical Health Researcher*

Perceptions and Understanding of Health Data Governance

The profile of the participants of the FGDs is summarised in *Table 2*. The study respondents who participated in the online survey were disaggregated according to population age groups and gender identity as shown in *Figure 3*.



Kenya, where the digital health system has matured more rapidly than its neighbours, has as shown in *Table 1* more policies relating to health data governance than Uganda and Tanzania. The connection between public awareness and the presence of these laws and policies appears to be symbiotic, each bolstering the other.

The increase in public awareness about other peoples' [perceived] understanding of health data governance and data protection seems to, in itself, be stimulating public debate on health data governance. A majority of the respondents admit that they are not well informed about the key technical and legal implications within the concept of health data governance.

> ***"Briefly, generally, I have not specifically talked about health but this is what we look at as being data governance. So, it must start from where it is generated from the lowest level up to the level where it is being used. And data governance, the challenge I have which we may discuss later in Uganda is that there are very many issues which affect it, basically, that is my understanding of data governance." (U1-11)***

The Focus Group discussions also surfaced the significance of national maturity models and developmental stages in the context of health data governance. The maturity levels of countries in terms of their readiness to introduce and effectively govern health data were a central point of discussion. While discussions in all three countries touched on the question of whether the national capacity was sufficiently mature to govern health data credibly, Tanzanian respondents expressed profound frustration. They raised concerns about individuals' rights to provide and withdraw consent, vulnerabilities in the healthcare pathway leading to potential data breaches, and doubts about the government's ability to uphold and adhere to the policies and guidelines it has put in place.

Institutional capacity building has consistently emerged as a noteworthy deficiency in all three countries across various subject areas. The public expresses a strong desire for a transition from individual-driven decision-making within ministries to the development of institutional capabilities that effectively oversee health data governance, while upholding citizens Human Rights. The COVID-19 pandemic has greatly impacted the public opinion on the value, but also the dangers digital systems bring to nations. Several focus group discussions centre around siloes in both how data is used but also how communicable and

non-communicable diseases are managed differently with varying priority and funding contributing to inequity of priorities.

Focus group participants displayed, to a higher degree than online survey respondents, knowledge about their individual right to obtain their health data and how this relates to Health Data Governance. A substantial proportion of the individuals surveyed online demonstrated a notable interest in acquiring further insights into the realm of health data governance. Furthermore, they exhibited a pronounced willingness to partake in the sharing of their health data under the condition that it is anonymised and harnessed for the advancement of public health through research and the establishment of evidence-based practices.

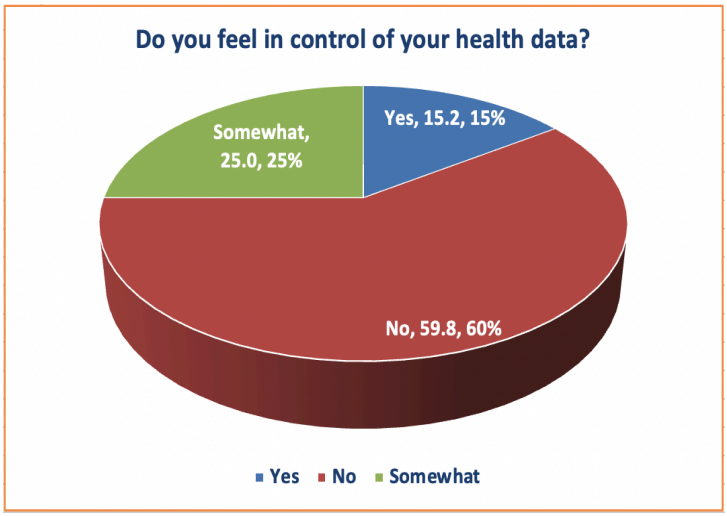
The online survey yielded valuable key insights into the experiences of marginalised groups, especially those with diverse abilities such as people who are deaf or hard of hearing who are often denied agency in a predominantly hearing community to influence or benefit from current policies, campaigns and awareness efforts.

> ***"Deaf people are vulnerable, powerless and isolated. Decisions are made on [our] behalf without [our] consent when it comes to health issues!"***

Public Awareness and Understanding of Health Data Collection; Purpose, Security and Use

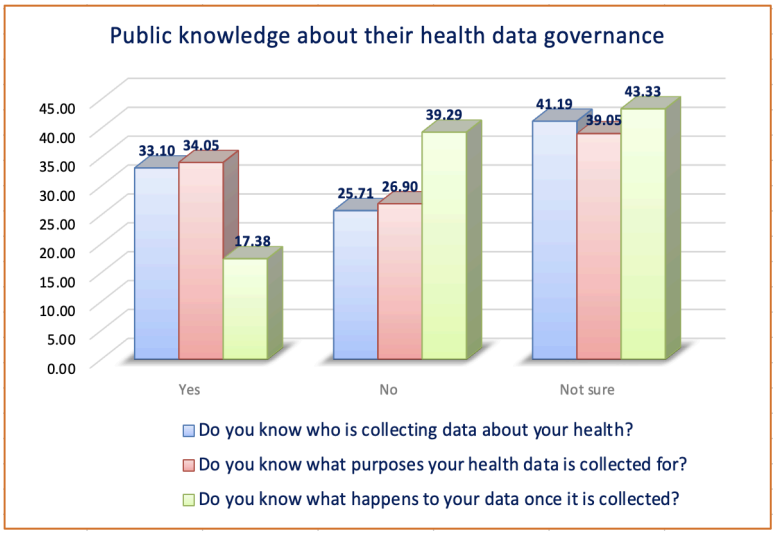
One of the study aims was to explore the extent of public awareness regarding the management of health data, aligning with the goals of the "My Data: Our Health" campaign led by Transform Health. Participants in the online survey for this research were queried about their familiarity with various aspects, including (1) their control over health data, (2) the reasons for data collection, (3) the entities responsible for gathering their health information, and (4) the security measures in place to safeguard the health data collected from them.

The findings related to the general public's feelings about the control of their data are visualised in *Figure 4*. A significant proportion of respondents (85%) from the online survey indicated that they do not feel in control of their health data collected by healthcare institutions. Conversely, only 15% of the total respondents affirmed having a positive feeling of controlling their health data.



A deeper analysis of the raw data revealed that the majority of those who

feel in control of their collected health data are those working in the healthcare sector themselves. In light of these statistics, it becomes evident that a substantial portion of the general public lacks confidence in their ability to control their health data. This prevailing sentiment could potentially foster a negative attitude when patients interact with and seek healthcare services from institutions. The study further explores the level of public understanding of how their health data is governed by health institutions. The findings in Figure 5 show the responses from the online survey on health data governance and indicate that 33% of the respondents know who collects their health data. This number is relatively low compared to those who express having no such knowledge. In total, 41% are uncertain and 26% do not entirely know who collects their health data.1 As also observed in the analysis of the social media discourse, the lack of understanding or engagement from the public on health data governance also has to do with how the narrative around this debate is framed. It is not surprising that survey results show a lack of confidence among the majority when health data governance at least according to the assessment of policies illustrate design processes that do not prioritise individual interests.



Furthermore, it is evident that a significant number of respondents are uncertain regarding the purposes for which their health data is collected (39%) and nearly one third do not know why their data is collected (*Figure 5*). A similar pattern is observed concerning their understanding of subsequent steps taken with their data once collected, with 43% expressing uncertainty and 39% indicating a lack of knowledge regarding the handling of their health data.

Findings from the online survey prompted further exploration of what the general public knows about the security and privacy of their collected health data depicted in *Figure 6.*

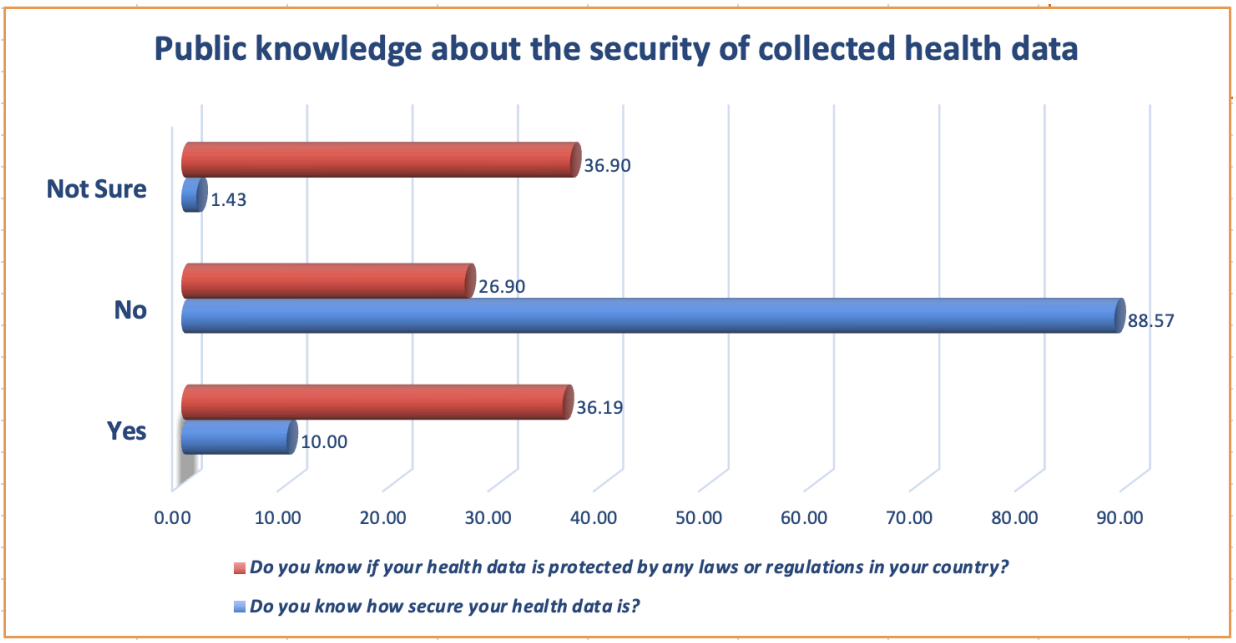


Figure 6. Public knowledge about health data security (in percentage among the respondents)

Perceptions regarding the security of collected health data indicate a lack of public awareness about data protection laws and strategies. When we aggregate the "no" and "not sure" responses, they outnumber the positive responses. As discussed earlier, the design of health data governance in each country primarily favours public authorities over individuals, which may also contribute to the limited knowledge about the security of one's health data. Figure 7 below extends this discussion, highlighting that data transparency is essential to foster greater public engagement with health data governance.

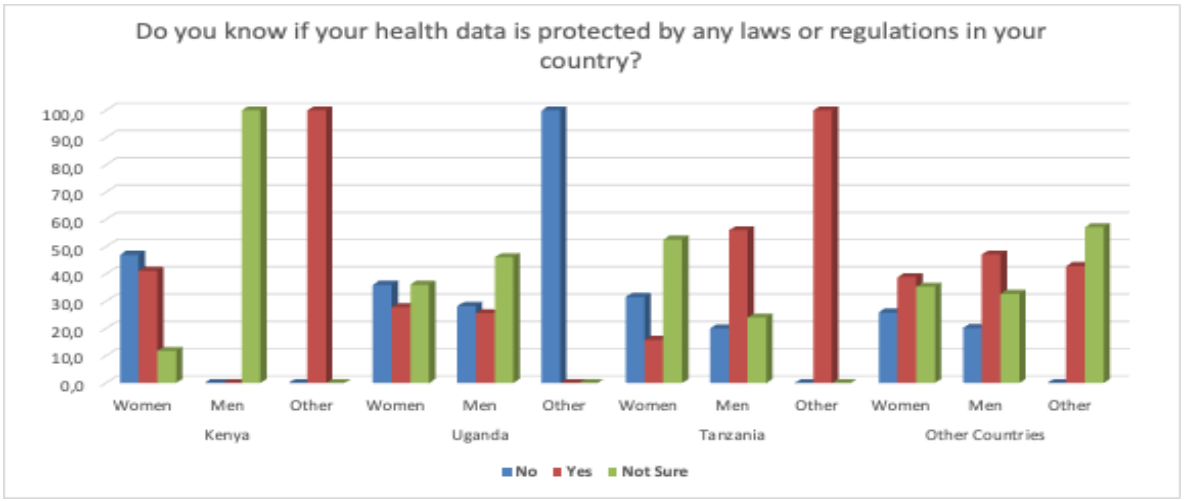


Figure 7. Knowledge of the public about health data governance laws and regulations in the region

Expanding upon the preceding discussion, as demonstrated in Figures 6 and 7, Figure 8 below offers detailed insights into the subject of data transparency. The majority of survey respondents are inclined to share their health data and grant permission for its usage as long as they comprehend its intended purpose. This willingness remains consistent across gender, age, and marginalised groups. However, they emphasise the importance of receiving transparent information about how their data will be utilised while safeguarding

their privacy. This willingness is driven by their desire to contribute to the enhancement of healthcare systems in their respective countries.

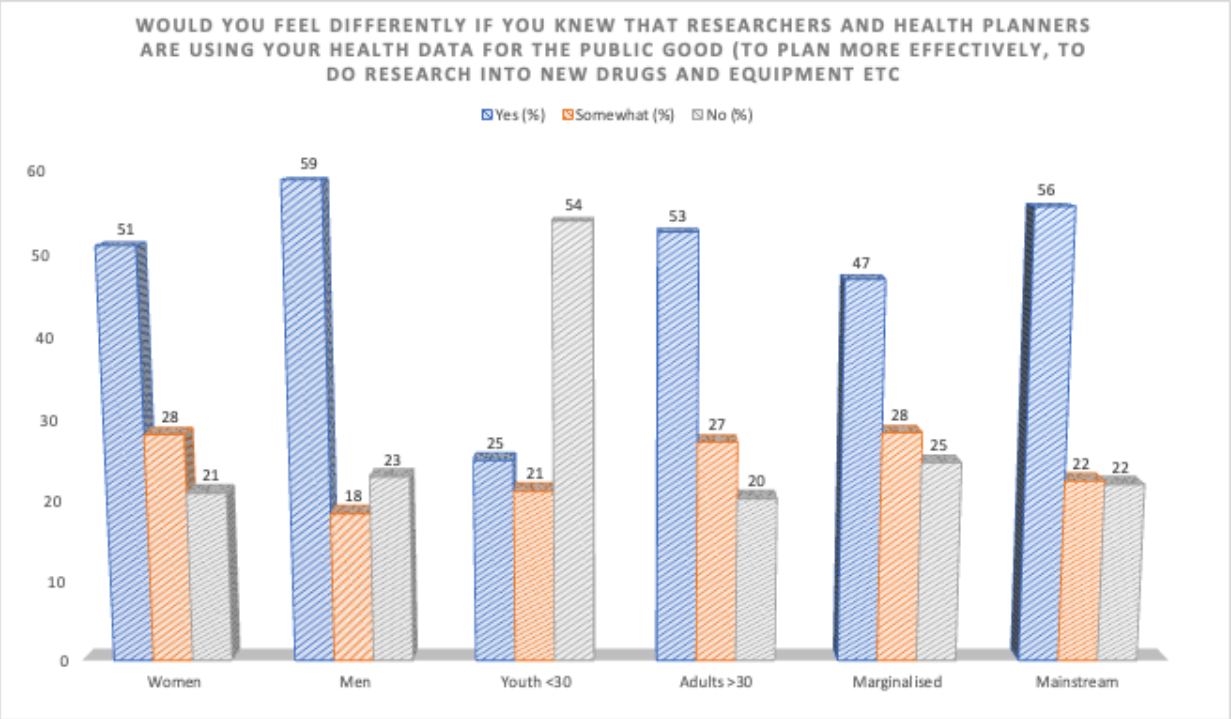


Figure 8. Online Survey Respondents' Perspective on Personal Data Use by Authorities

Notably, inadequate budgeting by MoHs in each country to support an improved health data management system (accurate and timely collection, analysis, and storage) was also found to be a key challenge affecting health data governance. This was largely mentioned in the FGDs and corroborated by the literature review, with evidence of national health funding per GDP at less than 5% in all the studied Eastern Africa countries (World Bank, 2022; to Nyawira et al., 2022).

The sustainability of digital health systems and the significance of data governance raise concerns regarding the reliance on donor funding to support Ministries of Health. This dependency on external funding questions whether there should be a sustainable model in place to ensure the continued functioning and eventual independence of the healthcare system.

Health Data Protection and Privacy Practices

In Uganda, respondents in the FGDs expressed optimism regarding the establishment of the Personal Data Protection Office (PDPO) in 2021, as a means of operationalising the DPA of 2019. They believed that this development would provide a mechanism for healthcare patients to seek redress if their personal health data was compromised or misused by any party. Additionally, respondents noted a growing trend in' registration of data holders with the PDPO, surpassing 1,900 institutions registered by April 2023 (PDPO, 2023). This steady increase created some level of confidence among the public to share

their personal data, including health related information. However, the majority of respondents expressed concern about the need for closer supervision by PDPO over institutions involved in data processing and control.

FGD participants made clear their understanding of the fact that the mere introduction of digitalised health systems would not automatically mean that sensitive data was more, or indeed less, secure. The records within the systems can still be printed and leaked as previously. There was even testimony that inappropriate handling of documents at health facilities mean that classified documents can end up as paper wrapping for street food vendors.

> **"*Like if you buy mandazi or chapati on the roadside, you find for example people wrapping chapati with very sensitive information… sometimes it is academic information from pupils or even clinical notes; because people simply dump papers [even when] they contain important private information.*" (U1-83)**

The rapid global digital transformation trends may contribute to the worry around identifiable records being stolen, especially seen as respondents' trust in government and health facilities' ability to safeguard data is extremely low.

Although the legal framework was generally perceived as better in Kenya by respondents in FGDs, with slightly over 2,000 registered data processing institutions (ODPC, 2023), the analysis of public discourse on social media platforms such as X (formerly known as Twitter), YouTube and Facebook as depicted in Figure 2 above, reveals a different narrative. More than 70% of citizens expressed concern about insufficient practical compliance of health service providers and other stakeholders in protecting personal data. This apprehension acts as a deterrent, hindering individuals from wanting to share health data. Ultimately, the situation endangers efforts of generating and processing enough relevant data resources required to plan for better health care support in Kenya.

The concerns outlined above were corroborated by the analysed online survey data that suggest that over 85% of respondents in the region share similar worry. Additionally, the review of existing literature (Kasanda et al., 2023; Malekela, 2022) highlights a pervasive concern about the security of their personal health data.

For instance, Figure *9* clearly illustrates the prevalent negative perceptions regarding the use of individuals' health data. Furthermore, it underscores the limited knowledge among members of the public regarding the storage and security protocols for their health data.

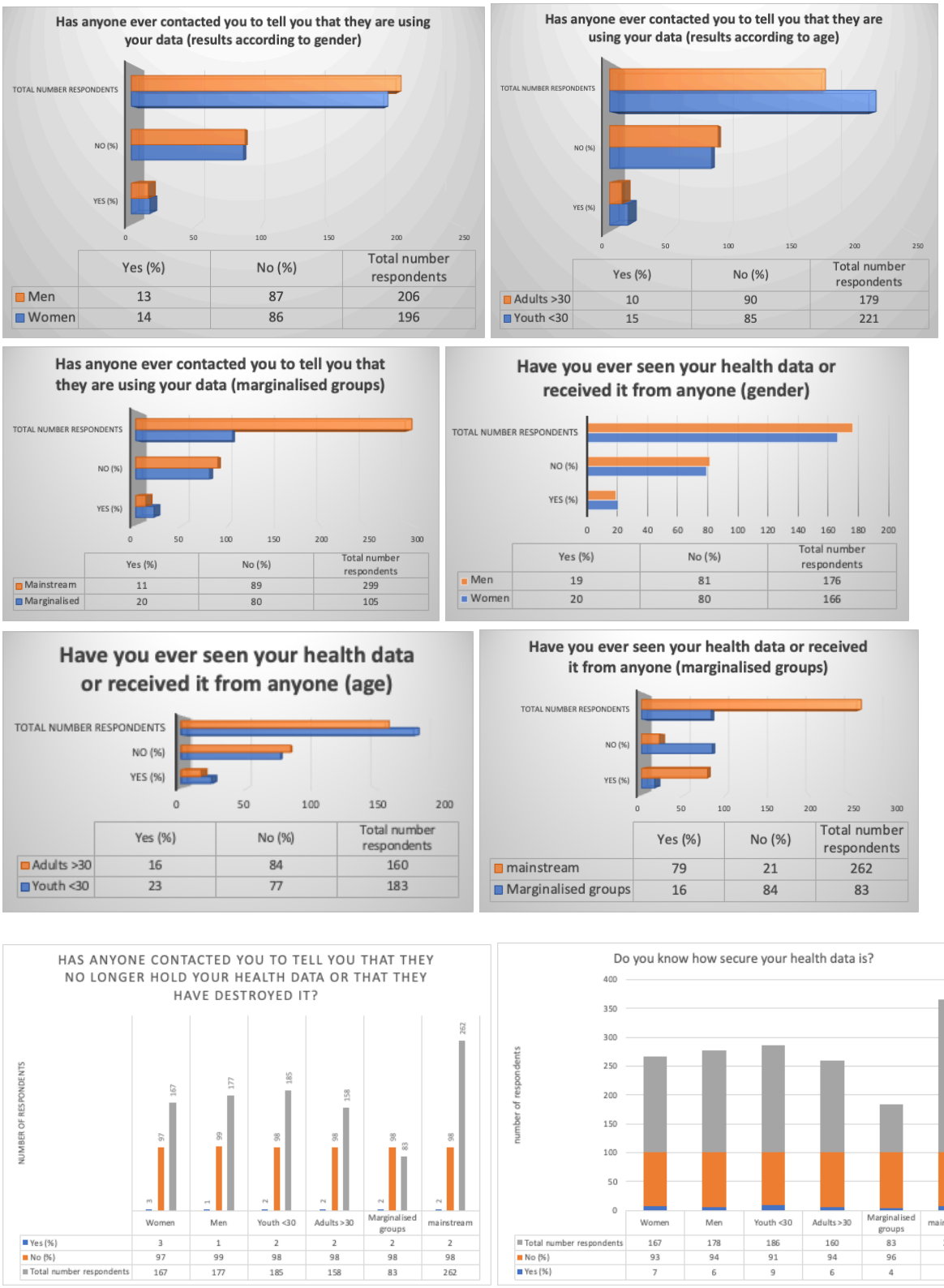


Figure 9. Eight graphs - Online Survey Respondents' concerns about personal data protection and security

The responses to this question are categorised by gender, age, and communities that mention some form of marginalisation. The results indicate that those who have been contacted regarding their health data and its usage are significantly fewer than those who have never been consulted. The majority lack awareness of how their health data is utilised, possibly due to the channels used for establishing contact, which may not be easily

accessible to said individuals. It's worth noting that a higher percentage of marginalised individuals seem to possess more access or knowledge about their health data compared to those who did not mention being in a marginalised category. This could be attributed to people seeking private healthcare services perceived to be more accommodating for marginalised groups or the involvement of international agencies and national NGOs in collecting data for advocacy and health support. In summary, there is a widespread lack of knowledge and understanding of health data governance in the region.

Survey respondents were also questioned about whether they had ever come across or received their health data. The patterns observed among gender and age categories mirror those of the previous question regarding contact about their health data. Responses from marginalised communities raise concerns, as these communities exhibit a similar lack of access to seeing how their data is used. Conversely, the category labelled as "mainstream" shows a higher percentage of positive responses to this question.

Furthermore, there are even fewer survey participants who possess an understanding or knowledge of the security measures in place for their health data. Additionally, there are fewer individuals who are uncertain whether their health data is still stored, in use, or has been deleted, primarily because they have never been contacted regarding it.
This challenge was reiterated in the literature review. Moreover, even those health stakeholders and/or practitioners who were aware of availability of some health data governance policies, were not compliant with them in practice. Some excerpts from the FGDs were;

> **"But when you go to the facility, some of them are not aware that the [health data] policy is in place. Some will ask you why you ask for your data, and what happened. But you simply tell them that I want my data for my personal use because I am the one who gave you my data."** (T2-58).

> **"…… that people are not aware of their rights, and they are not aware of what the laws say so, in addition to what everyone else suggested."** (K3-75).

> **"For me, I think my main concern is about compliance, on top of availability of regulations. The laws are there, but are the relevant people compliant with them and what you have mentioned?"** (U1-77)

Generally, participants in all three FDGs confirmed that the public and health stakeholders in the three East African countries (Kenya, Uganda, and Tanzania) had limited awareness about the existing legal framework that governs health data in their respective countries.

The survey also revealed that public awareness of health data laws in their respective countries was generally low (see Figure 7). This observation becomes more evident when

we combine the "no" and "not sure" responses and compare them to those who responded positively. This trend aligns with findings from some of the Focus Group Discussions (FGDs) conducted during the study. The scenario was different with participants of the FGD held in Tanzania. One of the concerns was that the DPA (2022) was very new in the country and the Personal Data Protection Commission (PDPC) was not yet established, as prescribed in the country's DPA (2022). This largely inhibited the public's willingness to share their personal health data. This finding was also corroborated by the systematic literature review on Figures 1 and 2. It underscores the serious concerns regarding the security and privacy of personal data in Tanzania, particularly in the operational practices and compliance of health data generators and custodians.

The above implies that increased lobbying and advocacy by Transform Health's "*My Data: Our Health*" campaign and others, might motivate the government in Tanzania and the rest of the region to fast-track the establishment of the PDPC and raise awareness of the new DPA (2022) among the public. Relatedly, advocacy in Kenya might be a priority for the "My Data: Our Health" campaign, in the areas targeting improved compliance to DPA (2019), and resourcing the Kenyan OPDC, not only to register all personal data handling institutions in the country, but also to conduct routine and an announced spot-checks on registered institutions to evaluate practical compliance. In Uganda, more awareness and partnerships are needed with campaigns in mainstream media, targeted knowledge sharing sessions and capacity building in personal data protection, could see more organisations register with PDPO and increase assurance among citizens that their personal data is secured and protected by the law. Transform Health and partners may also consider engagements with the data protection office, to collaborate in the design and delivery of such awareness campaigns.

Sociocultural Beliefs and Health Data Governance

It was evident in all cases of analysed data that was collected for this study; literature review (Moore et al., 2022; Ogolla & Ondia, 2019), FGDs, and the survey that cultural norms and beliefs influence debates and perspectives about health data governance in the region. Exploring options like collaborating with cultural structures within communities to promote awareness of citizen rights to their data could serve as an alternative to addressing the lack of knowledge among the population in the region. Therefore, as advised by Perehudoff et al., (2022) and others like Mbuthia (2019), any future and/or existing campaigns should factor in consideration of community's beliefs in order to improve data management (accurate collection, analysis, storage, sharing, and usage).

A notable example can be drawn from the data related to sexual reproductive health, which emerged from the literature review and focus group discussions, particularly in Uganda and Tanzania. Patients in these regions were found to be culturally hesitant to share such

sensitive data. This cultural inhibition presented a significant obstacle to health data generation throughout the region, as it introduced a contextual challenge.

This reluctance also poses a substantial hurdle to health data management, as it has the potential to lead to the collection of inaccurate and biased data regarding sexual and reproductive health. Consequently, this may result in the dissemination of poorly informed data, undermining the effectiveness of health systems in addressing these critical issues. Furthermore, it was observed that public health practitioners tended to be more stringent compared to their counterparts in private healthcare facilities. However, the services provided by private facilities were often unaffordable for the majority of patients compared to those offered by public facilities when seeking sexual reproductive health services in the region. Similarly, health data related to HIV testing and treatment for youth was considered sensitive, and the sharing of such data by health facilities with patients was influenced by cultural norms surrounding the stigmatisation of patients in all three countries.

The increase in biometric identifiers worries some respondents, especially as certain health conditions may be linked to state surveillance and/or societal stigma. The criminalisation of same-sex relationships and sexual minorities deter key populations from accessing health facilities due to the risk of prosecution and imprisonment, should their sexual orientation become known. The strong link between understanding how central digitalisation of health data is and how it may be misused by governments is obvious from the discussions. Many respondents make the connection that it is the existence of other laws that have an impact on health data governance, and not simply regulation that applies to the health sector.

Since digital technologies have been acknowledged to play a central role in streamlining data management, in rural communities in Eastern Africa, patients still face challenges of adequately accessing such technologies, let alone trusting them to handle gathering and exchanging of their sensitive health data. Some excerpts below demonstrated such perspectives and cultural undertones;

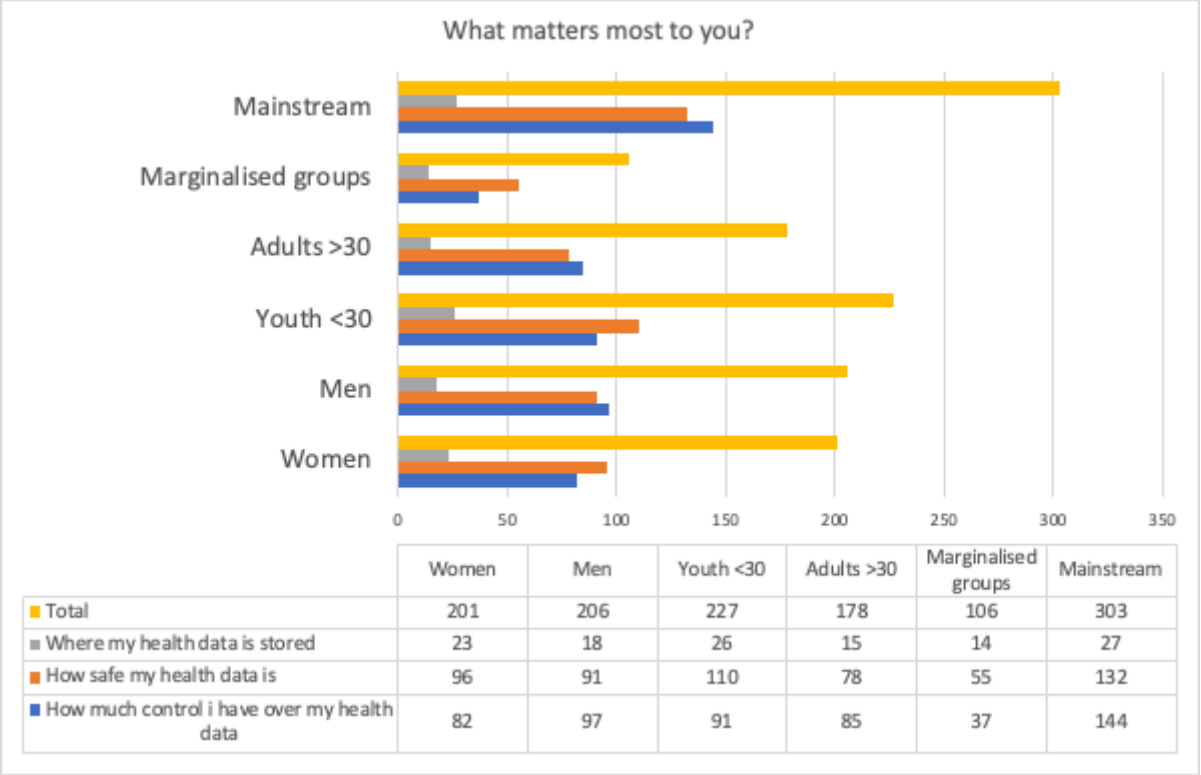
> **“General work/practice ethics of health workers is also wanting. They exhibit a lot of carelessness and negligence when handling patients, shouting at them and asking them for their health data/history without any privacy.” (T2-16).**

Participants of the FGD in Tanzania also revealed to the research team that it was largely seen as a sign of disrespect against health service providers and by the public if a patient or an aggrieved party opened charges against a health facility as a result of any personal data breach. There was a strong likelihood for the health facility to withdraw services or ostracise concerned patients, if it was taken to courts of law over such issues. Such revelation was corroborated by earlier findings in existing literature (Lusambili et al., 2020; Mwanga-Amumpaire et al., 2021).

The FDG in Tanzania also explained that patients usually do not come back to the health providers to ask for their health data unless initially requested by the former. Additionally, respondents, especially in Tanzania and Kenya revealed that many questions could be asked or frustrating delays could be experienced if an individual went back to a health facility to request their data about a previous diagnosis and treatment/prescriptions. This individual and societal perspective needed to be addressed through increased sensitizations and other awareness campaigns like the “My Data: Our Health”.

Another prevalent perspective voiced by respondents across all the three countries was the perception that external donors had greater influence over indigenous citizens’ health data than their own health authorities, such as MoHs. This perception created hesitancy among citizens and health service providers to freely share their health data. This caused uncertainty among data subjects about who was responsible for their health data, and if there was any breach, who to hold accountable.

Therefore, the results of the online survey, as depicted in Figure 10, indicate that respondents are primarily concerned about the level of control they have over their data and its safety, rather than the specific storage location of the data.



	Women	Men	Youth <30	Adults >30	Marginalised groups	Mainstream
Total	201	206	227	178	106	303
Where my health data is stored	23	18	26	15	14	27
How safe my health data is	96	91	110	78	55	132
How much control i have over my health data	82	97	91	85	37	144

Figure 10. Aspects of Data Control

Statements from the FGDs echoed the sentiments expressed in the survey data, with one participant making a noteworthy comment:

> **"But also, in terms of the [data] management aspect, for me when it comes to health data, there is a huge component of donors taking more lead than the ministries. So that is why I would push for more involvement of the ministry, when it comes to the management of health data." (U1-19).**

The same concern of donor-dependency was raised by previous researchers, as observed in the systematic review of extant literature (TMA, 2020).

Health Data Management and Digital Systems' Utilisation

When it comes to ensuring equitable and secure access to health data, during FGDs, findings from the Kenya study revealed that there was no predictable standard for recording health data, which endangered data protection and privacy practices. This made it difficult for people to seek, receive, understand or make sense of their health data – a concern that was also emphasised by a significant number of online survey respondents in the Eastern Africa region (75%).

The tools for collecting health data and data variables collected depended on the collector and varied from facility to facility. This posed a big problem of uniformity and completeness of the health data collected. The standardisation of health data management tools, platforms and systems also depended on the availability of adequate funding/budget resources, which were still meager in all three countries.

> **"I think another challenge is the way this data is recorded. We don't have standards for how health data should be recorded. If you walked into the hospital today and you asked for your medical file and someone pulls it out for you, you will probably not even understand what has been written in that file because it is either written in a medical language that you don't understand, incomplete and/or scattered." (K3-72).**

In terms of managing the data collection from subjects, FGDs participants were also concerned about the stigmatisation and persecution of some population groups who accessed health facilities and the generation of data from such groups was problematic. Examples of vulnerable patients included sex workers, youths, and LGBTQIs. There were also reported cases of corruption to manipulate health data in some health facilities, including at management levels to inflate numbers for inappropriate resource gains for some practitioners and health managers.

Findings from FGDs and literature review further revealed the capacity gaps in digital health data management in East Africa, affecting the state of health data governance. For example, Voluntary Health Teams (VHTs) in Uganda exhibited limited knowledge and proficiency in utilising available digital systems. This limitation was attributed, among other factors, to the infrequent use of digital equipment and limited skills. Data gathered by them

was inputted by registrars working at healthcare facilities, which increased the likelihood of inaccuracies.

Participants from the Kenya and Uganda FGDs revealed that the courts and other law enforcement agencies in their countries, had limited capacity to support the implementation of the existing policies, laws and regulations on health data.

Respondents emphasised the importance of mobilising, sensitising and training efforts targeting key stakeholders, including officials of judicature, the police and Human Rights commissions' officials. Such initiatives could substantially enhance their capacity in areas related to litigation, apprehension, and a deeper understanding of the health data governance and management (access, ownership, sharing, protection, etc) rights of individuals, also enable the use of the same data resources by researchers to improve health care systems and health care service delivery in the region.

Conclusions, Limitations & Indicators

Responses to the survey and the limited public engagement in social media on the subject at hand highlight a lack of public awareness concerning health data governance. There is a notable absence of understanding of the entire process involved in health data management, including aspects such as collection, storage, ownership, security, privacy, and dissemination. Many survey respondents and participants in the focus group discussions expressed their lack of knowledge regarding why their health data is collected. Additionally, a significant majority of respondents expressed deep concerns regarding the security of their collected health data. This study also underscores that most of the general public lacks sufficient knowledge about what happens to their data once it is collected.

In light of these research findings, it is evident that further advocacy efforts, such as the "My Data: Our Health" campaign or similar initiatives, could provide solutions to increase awareness and understanding of how health data is managed. Such campaigns could offer information about mechanisms supporting citizen engagement and advocacy groups in influencing relevant policies and regulations, all while assessing the level of public understanding of health data governance and its various components, ranging from data collection and storage to usage and related security measures, to be implemented by healthcare institutions in the East African region.

This study also reveals that health data governance is still in its early stages of development in the region. This phenomenon heavily relies on a robust legal and policy framework, best practices, highly trained professionals, and dedicated agencies. Effective leadership in health data governance is necessary to provide guidance aimed at improving public attitudes and understanding of their health data's significance and the importance of

sustainable health data governance for effective healthcare service delivery. Furthermore, this baseline identifies a lack of a harmonised legislative structure within the current legal landscape nationally and regionally, which hinders the progress of health data governance and may contribute to a less favourable public attitude towards health data sharing. From the findings, it is evident that these foundational elements are still largely absent in the assessed three countries.

Additionally, budget prioritisation for the health sector remains below average in all three countries, resulting in the neglect of health data governance interventions. This leaves such initiatives largely dependent on donors, who may not fully comprehend the context-specific dynamics of indigenous communities. Consequently, this reliance on external funding can lead to non-compliance and inhibitions, such as a low willingness among the public to freely share health data to support healthcare service planning and delivery.

Limitations and Scope of the Benchmark Report

This study was intended to appraise, on behalf of Transform Health, the current level of public awareness of health data governance in three countries of Eastern Africa (Uganda, Kenya and Tanzania) to set a benchmark in order to measure the impact of *My Data, Our Health* campaign stewarded by Transform Health. Primarily, the study focused on assessing the existing legal frameworks and related enforcement and how they are impacted or impact public attitudes and understanding of health data governance. Since the study was mainly aimed at informing a Health Data Campaign in practice, it was not necessary to subject it to strict orthodox academic or scholarly theoretical frameworks. Secondly, given the need to generate the baseline situation of the health data governance awareness as quickly as possible, the study was conducted using rapid data collection tools and techniques in a short period of time stretching, between February and April 2023.

Qualitative Indicators Proposed to Measure Campaign Results

The following qualitative indicators are proposed to measure the parameters of impact of the “My Data, Our Health” campaign within Kenya, Tanzania and Uganda, and the East Africa region. The below indicators can be used to measure the impact of the My Data, Our Health campaign

1. Analyse past and current public debate, perspectives, norms and beliefs on health data governance and access in East Africa

Indicator 1A: Media coverage change; measuring pre-campaign volumes with post campaign volumes over time.

Indicator 1B: Social media discourse; track how data governance discourse shifts and reveals changes in attitude, opinion and awareness

Indicator 1C: Website statistics; observe if traffic to the campaign site, or Transform Health pages on health data governance attract more traffic

2. Survey the perceptions or individuals giving credence to women and youth and their understanding as it relates to health data governance

Indicator 2A: Demographic reach; assess whether the campaign has been effective in reaching youth, women, and marginalised groups as intended.

Indicator 2B: Focus group discussions on issues specific to youth, women or specific marginalised groups and whether the awareness within the groups differ. Contrast this to data on access to digital tools and public decision-making forums.

3. Evaluate the public's relationship to and understanding of national policies, laws and regulations on health data governance in East Africa

Indicator 3A; Public engagement metrics; measure public engagement with national health data governance policies, this includes measuring increase or demographic shift within citizen advocacy forums, how data breaches are reported, and different laws implemented as a result of public demand.

Indicator 3B; Follow up surveys measuring increase in public awareness about the specific laws and regulations in place in the specific countries.

4. Examine how public discourse is framing the narrative around health data governance in the region

Indicator 4A: Tracking key messages of the campaign; monitor how key messages are adopted and used in public discourse on health data governance

Indicator 4B: Discourse monitoring; continuously track and document changes in public discourse, noting emerging trends, cultural and societal themes and contextual language use.

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