Design and Implementation of FAIR principles in digital health data in Uganda, Africa

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Chapter 1

Introduction

1.1 General Introduction

In this research, we present the use of FAIR principles in digital health in Africa. To achieve the third Sustainable Development Goal, which is "to ensure the quality of life and prosperity for all at all ages", it is important to focus on health care in Africa [1]. In the broader context of this goal, improving digital health across the African continent has emerged as a key priority. The integration of digital health systems with seamless health care delivery is the key to data reuse [2, 145]. The delivery of integrated care that facilitates the exchange of patient information requires integrated solutions that are tailored to the unique healthcare system in Uganda and, more broadly, Africa. Moreover, a strong governance structure must be established. There should be ethical and legal considerations for digital health systems in order to protect patient privacy, support the integrity of data, and promote responsible use of data [4]. The digital health landscape is undergoing a transformation that will have a significant impact on healthcare systems. The integration of digital technologies into healthcare has become a global trend that has transformed the methods that are used to deliver, access, and manage medical services. Digital healthcare technology offers innovative solutions to the deficiencies in the structure of delivering healthcare through improvements such as enhancing stock-management systems and streamlining blood donations through GPS-equipped drones.

The adoption of digital health technologies is driven by a shared vision to improve access, quality, and efficiency [5] of healthcare. Governments, organizations, and innovators around the world are using digital tools to solve age-old challenges in healthcare. But this journey is not without its challenges, and the reuse of digital health information is a recurring concern [6, 7]. In response to the challenges posed by the rapid growth of digital health, the Ugandan government took prompt steps by launching the Centralized Center for Digital Health in 2016 [8]. The center aims to provide digital health solutions to facilitate and address the challenges within the delivery of national healthcare. The Ugandan experience reflects a global trend in which countries grapple with the dual task of harnessing the power of digital health and ensuring its long-term viability.

The global digital health landscape encompasses a range of sectors and services, each of which contributes to the goal of improving health outcomes through technology. In Uganda, 49 identified providers were involved in the Centralized Center for Digital Health [8]. Similar challenges are witnessed worldwide, necessitating an understanding of the dynamics at play in digital health ecosystems. Many initiatives around the world have focused on the applicability of digital health solutions, emphasizing the importance of understanding the unique challenges faced by these initiatives. The emergence of mobile health (mHealth) applications and digital health interventions underscores the transformative impact of even simple implementations [9]. The use of mobile phones to connect healthcare providers and people through voice, video, or messaging services has proven to be particularly impactful, transcending geographical barriers and improving healthcare access in both urban and rural settings. This is evident in 2013 statistics showing that nearly 54% of medical calls received by the center were resolved effectively by telephone consultation [10].

Countries such as Rwanda and Kenya have shown significant progress in prioritizing digital health in their regional strategies. However, Uganda does not have an equally focused ICT program with ICT-based infrastructure [145] provides a special case for examining the underlying components that support absence-data reuse. Globally, digital health experiences ongoing challenges despite the remarkable growth within this sector. The rapid growth in technology has led to innovative advancements that offer unprecedented opportunities, which have led to a transformation in healthcare delivery. Despite this, there are concerns regarding the existing problems of connectivity and data reuse. Uganda's experience is similar to the current global situation. Therefore, this highlights the need for comprehensive strategies to ensure that the success of digital health initiatives is lasting. To address that, this thesis explores possible solutions to overcome and control these challenges.

1.1.1 The Sustainable Development Goals (SDGs) that Foster Uganda's Digital Health Agenda

Uganda's commitment to using technology to improve healthcare is aligned with the Sustainable Development Goals (SDGs). It specifically contributes to SDG 3, which focuses on Good health and well-being. Uganda is actively working towards ensuring healthy lives and well-being for all people of all ages by focusing on improving their access to healthcare services, promoting health education, and using technology to strengthen its healthcare systems [11]. Moreover, employing digital tools such as telemedicine addresses the shortage of healthcare workers, which is a significant barrier to achieving SDG 3. This action is also in harmony with SDG 9, which focuses on Industry, innovation, and infrastructure through aiming to build resilient infrastructure, promote sustainable industrialization, and foster innovation [12]. Uganda's Digital Health Program is expanding its impact on marginalized communities. This effort contributes to SDG 10, which focuses on reducing inequities. Reducing such disparities in healthcare is achieved through promoting the development of health services for underserved populations by using digital tools such as telemedicine [12, 13]. Since it acknowledges the need for action together internally and externally, Uganda's digital health strategy is in line with SDG 17, which focuses on sharing goals through creating and maintaining global partnerships on sustainable development [12]. In summary, Uganda's digital health agenda is linked with SDGs 3, 9, 10, and 17 because it promotes fostering innovation and global partnerships as well as adopting technological advancements to reduce inequalities within the healthcare systems, and promoting partnerships. Uganda is in a position to make significant contributions to these global goals. This is in line with the Ministry of Health's objective of "Building a Strong and Interoperable Digital Health Information System for Uganda" [12, 14].

1.1.2 Digital Structural Gaps in Primary Healthcare

Digital health emerges as a transformative force addressing crucial structural gaps within primary healthcare. This leads to improved health service delivery across various di-

mensions, as outlined in Table 1.1. A concrete solution to a structural gap has been implemented through the utilization of technologies such as drones for delivering HIV drugs to remote islands in Kalangala District, Uganda. This case serves as a testament to the efficacy of digital health in rectifying structural shortcomings by ensuring that essential healthcare requirements can be met through utilizing digital health in challenging areas [15].

1.1.3 Uganda's Digital Health Ecosystem Key Players

In guiding Uganda's dynamic digital health system, it is important to align with key stakeholders who have contributed significantly to improving healthcare. Understanding the specific roles of these organizations not only shapes digital health policy but also ensures alignment with global policies. The key players in Uganda's digital health ecosystem include government agencies such as the Ministry of Health (MoH), the National Information Technology Authority (NITA), and the Uganda Communications Commission (UCC). These agencies play a critical role in shaping policies, providing regulatory frameworks, and advocating for digital health solutions [22]. Using digital tools such as electronic health records (EHRs), healthcare providers contribute significantly to improving patient care and communication among professionals [85]. Private sector entities like Rocket Health actively contribute by offering services such as telemedicine, e-pharmacy, and health information systems development [24]. Non-governmental organizations like USAID, IntraHealth International, and Elizabeth Glaser Paediatric AIDS Foundation provide funding, expertise, and resources to support digital health solutions. Academic and Research Institutions like Kampala International University and Makerere University School of Public Health engage in research and training, thereby contributing to capacity building in the sector and for Patients. Patients, communities, and Community Health Workers (CHWs) also play a pivotal role in ensuring healthcare accessibility in remote areas, making them integral to Uganda's digital health ecosystem. While digital health research projects show great promise, they struggle with significant challenges, especially compliance with global policies. These challenges include navigating a complex regulatory framework, such as the Health Insurance Portability and Accountability Act (HIPAA) [25] and the European General Data Protection Regulation (GDPR) [26]. Although the GDPR is a European law, its impact extends beyond the EU, affecting digital health initiatives globally. Complex processes are required to comply with HIPAA and GDPR. This poses some challenges to digital healthcare design and implementation that are clear when trying to collaborate and navigate potential digital divides in the healthcare sector. The rapid deployment of digital tools to address the COVID-19 pandemic demonstrated the adaptability and resilience of Uganda's health systems. The country's journey in adopting and harmonizing digital health solutions is a reflection of the collaborative efforts of various stakeholders. While working towards overcoming challenges and aligning with global initiatives, Uganda's digital health transformation is at the crossroads of innovation, process, and collaboration. It is crucial to ensure that Uganda's digital health initiatives are locally inclusive and aligned with international standards and expecta-

tions. Such alignment ensures that these projects remain sustainable and successful in a global context. Uganda Industrial Research Institute (UIRI) serves as a center of excellence for the East African Community (EAC) in industrial research. The institution has evolved into a competence and capability centre which champions innovations, translates applied research results into practical applications, which include products and industrial processes, imparts technical skills, and deploys technology across Uganda. However, the existing research policies and guidelines are silent on research data management and data reuse [26]. This has resulted in limited accessibility, ownership, and data interoperability, leading to fragmented digital health data, disconnected research data, and over-reliance on manual analytics within Uganda's health facilities.

1.2 FAIR Data and Digital Health

In 2014, a collective of academics, industry leaders, funding agencies, and scholarly publishers collaborated to introduce the FAIR principles [27]. These guidelines, designed to enhance data management practices, aim to make both data and metadata easily discoverable by both humans and machines. The four foundational principles of FAIR are 'Findable', 'Accessible', 'Interoperable', and 'Reusable' [28]. The absence of FAIR attributes makes deep and integrative data analysis challenging, often requiring significant time for data aggregation. Given the constant evolution of data types and formats, ensuring data is machine-actionable becomes increasingly critical. Harmonizing and integrating data across general-purpose and special-purpose repositories, thereby making data FAIR, holds the key to extracting maximal benefits, saving time, and reducing research costs [29].

Originating in Europe, the FAIR principles gained momentum in 2014 with support from stakeholders in life sciences. Major entities, including the European Union, G7, G20, and the US-based Big Data to Knowledge (BD2K), endorsed these guidelines. In 2017, the European Union established the European Open Science Cloud (EOSC), mandating FAIR-based data stewardship for all publicly funded scientific research from 2020 onward [119, 30]. Although adoption of FAIR has progressed in some regions around the world since 2014, its implementation in Africa, particularly in the realm of digital healthcare, has been gradual. Scholars, such as Van Reisen and others, have emphasized the potential of FAIR principles to address systemic issues in African healthcare, highlighting the need for contextual awareness in implementation [31]. Despite its clear benefits, FAIR uptake in Africa has been limited and slow [31].

Semantic web technologies can be leveraged to make data interoperable by machines. Several platforms aligned with the FAIR principles have been developed. For example, FAIRDOM combines SEEK [32], a web-based resource for sharing heterogeneous scientific research datasets, models, or simulations, processes, and research results, and openBIS, a system for managing biological data. Both systems implement a semantic representation of data using the Resource Description Framework (RDF) data model. Resources such as UniProt have converted the entire database into this semantic representation, allowing both humans and machines to mine these resources efficiently [33].

Furthermore, various efforts have been performed on the FAIRification of existing datasets, making them more fair [34]. FAIRification refers to the process of enhancing existing datasets to meet FAIR standards, ensuring that both resource data and metadata are machine-readable. This involves making metadata clearly describing how data can be accessed and reproduced while ensuring metadata is Findable by machines. The data FAIRification process includes original data retrieval, dataset identification and analysis, the definition of the semantic model, data transformation, license assignment, metadata definition, and FAIR data resource development (data, metadata, license), which involves datasets being generated directly according to FAIR principles, in which data and metadata are in a linked format. This is achieved through the development and use of computational applications and workflows in which data can be consistently appended with metadata.

A noteworthy milestone in FAIR implementation in Africa was the establishment of the East Africa Open Science Cloud for Health (EAOSCH) in 2019 by the East African Community (EAC) [31]. This regional initiative aims to facilitate the sharing of health data among EAC member states, showcasing the advantages of data reuse and interoperability across borders. The East African Health Research Commission (EAHRC) endeavours to set common standards for digital health, emphasizing regional principles for data sharing, system interoperability, and digital tool design, aligned with FAIR principles [35, 31].

1.3 VODAN Africa

The VODAN-Africa architecture is designed to support the principles of Findable, Accessible, Interoperable, and Reusable (FAIR) research data. This research became part of the VODAN-Africa and Asia implementation network in March 2020, which aims to address current and immediate challenges in the use and connectivity of digital health data [290]. The VODAN-Africa and Asia initiative is central to an expanding network of equal partnerships between African and European universities. These partnerships produce or utilize high-quality, high-volume, machine-actionable data, bringing African health insights into the global medical knowledge base to improve health and healthcare in Africa. It is integrated with repositories where datasets are stored and made available for discovery, access, and use under clearly defined terms. This study is driven by the need to bridge gaps in digital health in Africa by exploring the transformative potential of FAIR data principles. It aims to leverage FAIR data support design to overcome the prevalent concerns about the interoperability and reusability of digital health data for quality treatment at the point of care in Uganda. This is achieved by implementing remote querying facilities across Uganda and other VODAN-Africa member countries, ensuring that data remains within health facilities while enhancing the quality of care. Understanding the need for FAIR data requires recognizing its potential to transform the current data landscape. Adherence to FAIR principles ensures that data becomes more findable, accessible, interoperable, and reusable. The research questions outlined below guide the exploration of how FAIR data impacts overcoming interoperability challenges,

enhancing data accessibility, and contributing to a more cohesive and usable digital health ecosystem in Uganda.

1.4 Research Questions and Contributions

The specific focus of our research was to examine the adoption of FAIR data in the digital health landscape in Uganda. Understanding the complexities of digital health challenges, particularly in the context of Africa and Uganda, is essential to formulate meaningful research questions.

1.4.1 Main Research Question

How can data integration, supported by the FAIR data principles, address the challenges of data interoperability and reuse within the African digital health sector?

1.4.2 Specific Research Questions

How does the lack of policies on data management, data sharing, and data analysis contribute to the under-utilization of digital health data in Uganda?

How can the systematic application of FAIR principles address the challenges related to interoperability and reusability in the development and maintenance of digital health data systems in Uganda?

How can data analytics of health data be effectively propagated, integrated, and maintained within health facilities in Uganda through the application of FAIR data principles?

Can the adoption of FAIR principles support and strengthen privacy-preserving access to diverse health data types, particularly for applications in machine learning?

1.5 Thesis Outline

This thesis explores the application of the FAIR principles to digital health data in Africa, with a specific focus on Uganda. It is structured into nine chapters, beginning with an introduction in Chapter 1, which outlines the research problem, the objectives, and the significance of the principles of FAIR data. Chapter 2 reviews the VODAN Africa and Asia initiative and the global implementation of FAIR principles. Chapter 3 investigates data management practices and information flow in Ugandan health facilities through focus group discussions and interviews. Chapter 4 assesses Uganda's regulatory framework for digital health and examines the feasibility of adopting FAIR principles. Chapter 5 explores how FAIR principles can enhance interoperability in Uganda's digital health initiatives. Chapter 6 demonstrates a proof of concept using the VODAN-in-a-Box (ViaB) system for COVID-19 data transformation and exchange. Chapter 7 compares

FAIR data with DHIS2 for privacy-preserving health analytics. Chapter 8 examines the integration of machine learning models with FAIR health data for enhanced analytics and decision-making. Finally, Chapter 9 presents conclusions and recommendations for the further application of FAIR principles in Uganda's digital health ecosystem.

Table 1.1: Roles, Benefits, and Challenges of Digital Health in Addressing Structural Gaps in Primary Healthcare

Service	**Role of Digital Health**	**Benefits**	**Challenges**
Human Resources for Health (HRH) / Integrated Human Resources Information System (iHRIS) [16, 17]	iHRIS stands at the forefront of addressing HRH challenges. It ensures efficient workforce deployment and management, optimizing the availability of experts and consultants in the healthcare sector.	Improved staffing decisions, streamlined HR processes, and enhanced workforce efficiency contribute to robust healthcare provision.	Resistance to digitalization, data privacy concerns, and the need for extensive training pose challenges to the seamless implementation of iHRIS.
Community Health Workers (CHWs) / Village Health Teams (VHTs) [18]	Digital Health empowers CHWs/VHTs in administering crucial services like family planning, antenatal care, vaccinations, and Integrated Community Case Management (iCCM).	Digital tools facilitate the coordination and effectiveness of frontline healthcare workers, bridging gaps in service delivery in remote and underserved areas.	Limited digital literacy among CHWs, connectivity issues, and the need for ongoing technical support can hinder the effective use of digital tools.
Health Service Delivery in Remote Areas [19, 20]	Digital health interventions in telemedicine break geographical barriers, extending healthcare services to remote or underserved areas.	Telemedicine ensures that individuals in distant locations have access to healthcare expertise and services, reducing disparities in health service delivery.	Limited infrastructure, poor connectivity, and the need for investment in digital infrastructure can pose challenges to the widespread implementation of telemedicine.
Supply Chain Management and Stock Availability[21]	Digital health interventions in supply chain management ensure the availability of essential health supplies such as blood and drugs.	Innovations like drone delivery (e.g., Zipline) provide efficient and timely transportation of crucial medical resources, addressing logistical challenges in remote or isolated regions.	Regulatory hurdles, and the initial cost of implementing health technology, pose challenges to the scalability of such solutions.