Universiteit Leiden
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Design and implementation of FAIR principles in digital health data in Uganda, Africa

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Citation

Basajja, M. (2026, September 8). *Design and implementation of FAIR principles in digital health data in Uganda, Africa*. Retrieved from https://hdl.handle.net/1887/4309278

Version:	Publisher's Version
License:	Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden
Downloaded from:	https://hdl.handle.net/1887/4309278

Note: To cite this publication please use the final published version (if applicable).

Chapter 4

FAIR Equivalency with Regulatory Framework for Digital Health in Uganda

This chapter is based on the following publication:

Basajja, M., Van Reisen, M., Oladipo, F.: FAIR Equivalency with regulatory frameworks for digital health in Uganda. Data Intelligence 4(4) (2022). doi: https://doi.org/10.1162/dint_a_00170

Abstract

This chapter explores the intersection between the FAIR (Findable, Accessible, Interoperable, and Reusable) data principles and Uganda's existing regulatory framework for digital health. It highlights the critical challenges paper-based data systems pose in Ugandan health facilities, especially amid health crises such as the COVID-19 pandemic. The study examines the flow of clinical patient data and reveals a significant reliance on non-digitized reporting tools, which hinders timely data access, sharing, and reuse. As a result, national and international health stakeholders face difficulties in integrating Ugandan health data into broader global datasets, often misinterpreting the country's data landscape as sparse. The chapter argues that aligning Uganda's digital health strategy with FAIR principles could significantly improve data governance, interoperability, and reusability. By examining the current gaps and drawing parallels between FAIR standards and Uganda's health data regulations, the chapter proposes a roadmap to transition from fragmented paper records to a cohesive, machine-actionable digital health infrastructure.

Keywords: eHealth, Digital health, GAIR Guidelines, FAIR Equivalency, Findable, Accessible, Interoperable, Reusable, HMIS

4.1 Introduction

Within the introduction, we present the background, main objectives, specific research questions, and objectives.

4.1.1 Background

In the era of digitization, data serves as the cornerstone of modern healthcare systems worldwide. The exponential growth of data, coupled with advancements in technology, has revolutionized the methods used in managing, accessing, and utilizing healthcare information [70, 71]. However, amidst this data deluge, ensuring that information is Findable, Accessible, Interoperable, and Reusable (FAIR) remains a persistent challenge, particularly in the context of Uganda's digital health landscape.

Uganda, like many nations, faces significant challenges in managing vast amounts of health-related data. Although FAIR principles have gained global recognition, their implementation within Uganda's digital health regulatory framework presents unique challenges and considerations. It is important that the health data policies, regulations, and existing frameworks within Uganda's digital health ecosystem are examined. Integrating FAIR principles into Uganda's digital health governance holds potential to unlock new avenues for data-driven decision-making, research, and innovation in healthcare delivery.

As global perspectives on FAIR principles evolve, Uganda is uniquely positioned to leverage these principles to enhance the interoperability of its digital health infrastructure. Through a systematic evaluation of Uganda's regulatory framework and the existing digital health policies, this study aims to explore the feasibility of integrating FAIR principles and the implications of this integration on the country's healthcare ecosystem. This research aims to foster equitable digital health frameworks in Uganda by bridging the gap between theoretical concepts and practical implementation. Collaborative efforts within the Virus Outbreak Data Network (VODAN) [56] offer Uganda an opportunity to align with global best practices while tailoring FAIR principles to its socio-economic and healthcare contexts.

This chapter examines the alignment between FAIR principles and Uganda's regulatory framework for digital health. Through analyzing Uganda's digital health policies, research objectives, and theoretical considerations, this study aims to develop a roadmap for seamlessly integrating FAIR principles into Uganda's digital health governance.

4.1.2 Main Objective

This study was conducted within the Virus Outbreak Data Network (VODAN) [56] as part of a project that focuses on developing a FAIR Data Point for Uganda [73]. The primary aim was to assess the conditions of Uganda's digital health ecosystem, focusing on health data policies and documents, to evaluate the feasibility of initiating a policy window for adopting and implementing FAIR principles. The study specifically explores how these guidelines could address challenges confronted by Uganda's e-health sector.

4.1.3 Specific Research Questions and Objectives

The primary research question aimed to evaluate the governance framework for digital health policies in Uganda and explore the feasibility of creating a policy window to adopt FAIR principles in the e-health sector.

The following are the objectives of the study: **To examine the governance framework for digital health in Uganda and the standards employed in managing digital health data:** This objective entailed analyzing Uganda's governance framework for digital health policies, focusing on health policies and managing digital health data within the context of information and communication technology (ICT).

To investigate the conditions within the digital health ecosystem in Uganda and assess the feasibility of opening a policy window for adopting and implementing FAIR principles: This required a comprehensive review of key policy documents related to digital health governance in Uganda. The review aimed to identify factors influencing the introduction of FAIR principles and to evaluate strategies for maximizing their adoption.

Research Questions

Main Research Question: To what extent does the absence of policies on data management, sharing, and analytics contribute to interoperability and information flow challenges within Uganda's digital health solutions? **Sub-Research Questions:**

Sub-Research Question 1:
To what extent are FAIR (Findable, Accessible, Interoperable, Reusable) principles referenced and implemented in Uganda's digital health policy documents?

Sub-Research Question 2:
How has the evolution of ICT and health-related policies shaped the current state of digital health solutions in Uganda??

Sub-Research Question 3:
What is the level of FAIR equivalency in Uganda's existing policy documents related to digital health?

Sub-Research Question 4:
How can FAIR principles address the challenges in Uganda's e-health sector, particularly regarding standardized communication protocols and unique identifiers?

4.2 Materials and Methods

We address the theoretical considerations, study design, and historical perspective on the Evolution of ICT and Health-Related Policies in Uganda, Identification of Relevant

Documents, Mention of the FAIR principles in Policy Document, and Level of FAIR Equivalency in Policy Documents.

4.2.1 Theoretical Considerations

Kingdon's model finds the connection between a problem, potential policy solutions, and political relevance, and creates a policy window that enables the introduction of new ideas into the policy agenda [49]. This dynamic process, involving the interaction between policy changes and the roles of policymakers and policy entrepreneurs within specific domains, was explored to understand how policy evolves [49, 74]. Van Reisen and others introduced the concept of cultural entropy to explain the reasons for the acceptance of FAIR principles potentially being hindered. If there is a significant cultural entropy — that is, the discrepancies between the guidelines in a framework and the beliefs of practitioners implementing the framework - the adoption of the FAIR principles may be impeded [30, 31].

In the context of this study, the awareness of cultural entropy is crucial as significant misalignment between the FAIR principles and the practices of stakeholders may lead to substantial obstacles to the successful adoption of FAIR principles. Therefore, exploring cultural entropy is an integral theoretical consideration that offers insights into the factors influencing policy acceptance and the implementation of FAIR principles within the digital health sector in Uganda.

4.2.2 Study Design

This cross-sectional study analyzed policy documents related to ICT and health that were published by the Government of Uganda between 2009 and 2019.

4.2.3 Historical Perspective on the Evolution of ICT and Health-Related Policies in Uganda

The historical evolution of ICT and health-related policies was explored to identify the foundational policy documents and legislation shaping digital health/e-health policy in Uganda. In this section, the study focused on understanding the steps leading to the establishment of e-health reforms in Uganda by looking into the key reforms that were initiated in 2000 in both sectors. In the early 2000s, the Ugandan Government recognized emerging issues due to the Internet and technological advancements. Responding to these trends, the National ICT Policy Framework was approved in 2003 to guide the developments experienced in the ICT sector. The creation of the Ministry of ICT in 2006 aimed to consolidate ICT responsibilities under one entity [75]. Several policies were implemented to guide the evolving ICT sector, leading to the formulation of e-health reforms in Uganda.

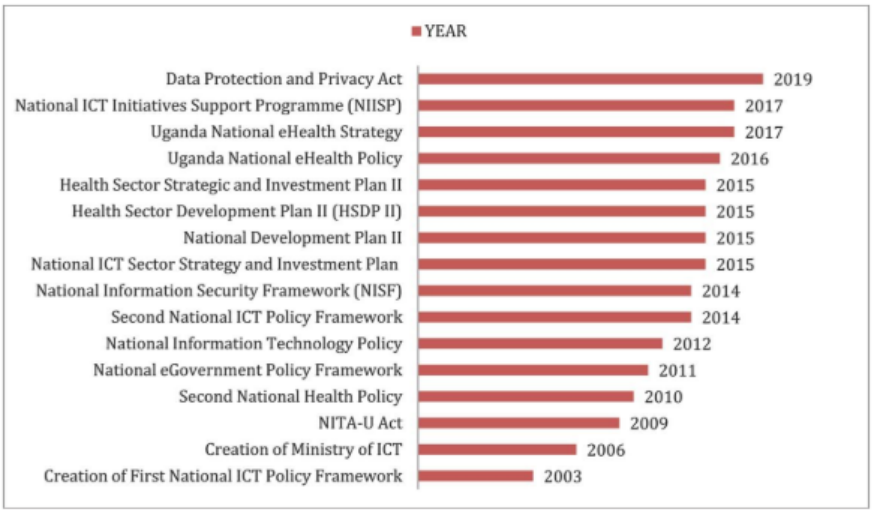

Figure 4.1: Bar chart illustrating the timeline of major ICT, eHealth, and health-sector policy reforms in Uganda between 2000 and 2019

These policies include the following:

1. **National Information Technology Authority Act (2009):**
   Establishment of the National Information Technology Authority-Uganda (NITA-U).

2. **National e-Government Policy Framework (2011):**
   Framework for advancing e-government initiatives across sectors.

3. **National Information Technology Policy (2012):**
   Policy addressing key aspects of information technology.

4. **National ICT Policy Framework (2014):**
   Policy acknowledging emerging areas, including e-health [75]..

5. **National Information Security Framework (2014):**
   Framework focusing on information security.

6. **National ICT Sector Strategy and Investment Plan (2015):**
   Strategic plan for the ICT sector's development and investments.

7. **National ICT Initiatives Support Program (2017):**
   Support program fostering ICT initiatives.

8. **Data Protection and Privacy Act (2019):**
   Legislation addressing data protection and privacy.

The National ICT Policy, launched in 2014, recognized the dynamic nature of the ICT sector and highlighted emerging areas that required policy attention, including e-health [75]. Consequently, the Ministry of Health formulated policies specific to e-health. This included the drafting of the National e-health Policy (2013) and the National e-health Strategy (2013), leading to the final versions: National e-health Policy (2016) [76] and National e-health Strategy (2017) [77]. These policies aimed to guide on leveraging ICT for healthcare transformation, emphasizing information access, operational support, and decision-making within the healthcare sector [76].

4.2.4 Uganda's National e-health Vision

An investigation was conducted to evaluate the conditions within Uganda's digital health/e-health ecosystem, aiming to determine the feasibility of initiating a policy window for the adoption and implementation of the FAIR principles. The governance framework for the digital health/e-health sector in Uganda was shaped by the publication of the National e-health Policy (2016) [76] and the subsequent National e-health Strategy (2017) [77]. This strategic initiative was spearheaded by the Ministry of Health, laying the foundation for the National e-health Vision.

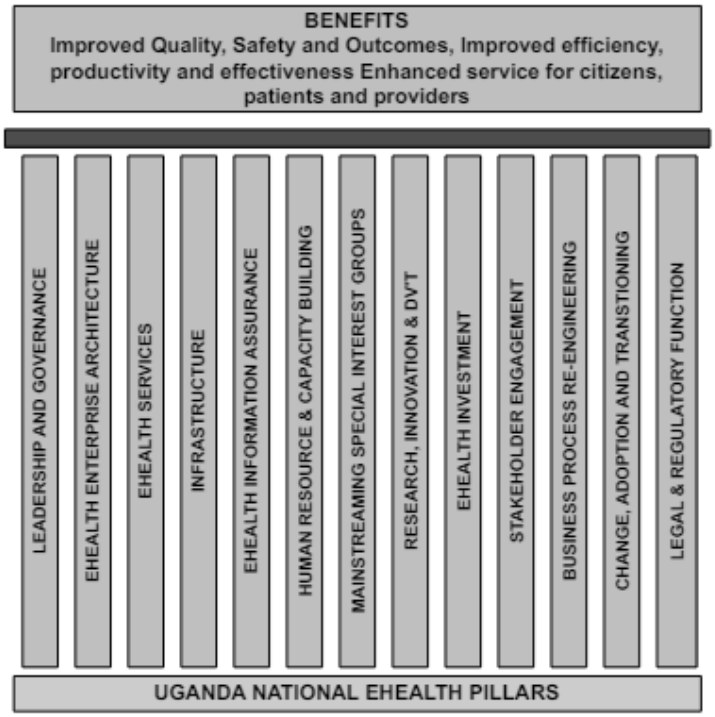

Figure 4.2: Conceptual framework illustrating Uganda's National e-health Vision that constitutes the thirteen strategic e-health Pillars that support digital health governance, implementation and service delivery

The National e-health Vision identified 13 priority areas, referred to as pillars, that are crucial for realizing advancements in digital health. Each of these pillars is supported by a specific leadership and governance structure. They are also associated with an action plan of five years that is stated in the National e-health Policy and the National e-health Strategy [77].

Implementation Phases (2016/17-2020/21)
For effective execution, each pillar underwent detailed planning, including budget allocation and action plans spanning three phases: phase I (2016/17-2017/18), phase II (2018/19-2019/20), and phase III (2020/21). This phased approach aimed to systematically implement the strategic objectives and associated initiatives, ensuring the gradual realization of the National e-health Vision over the stipulated five-year period.

4.2.5 Identification of Relevant Documents

A set of 14 policy documents, encompassing plans, policy frameworks, acts, strategies, and programs, was identified for analysis in alignment with the study's research objectives (refer to Table 4.1). These documents, published by the Government of Uganda and pertinent to both ICT and health, constitute the focal point of the investigation. The selection process involved obtaining documents from ICT personnel in the Ministry of Health and extracting others from the websites of relevant government institutions.

SN	Title	Type of Document	Year	Publisher	Source of Document
1	National Information Technology Authority-Uganda (NITA-U) Act	Act	2009	National Information Technology Authority	National Information Technology Authority-Uganda (NITA-U) Act NITA-U Act (Act No. 4 of 2009)
2	Second National Health Policy	Policy	2010	Ministry of Health	Second National Health Policy 2010
3	National eGovernment Policy Framework	Framework	2011	Ministry of ICT	National e-Government Policy Framework 2011
4	National Information Technology Policy	Policy	2012	Ministry of ICT	National IT Policy 2012
5	National ICT Policy Framework	Framework	2014	Ministry of ICT	ICT Policy 2014

6	National Information Security Framework	Framework	2014	National Information Technology Authority	National Information Security Framework
7	Second National Development Plan	Plan	2015	National Planning Authority	NDPII Final
8	Second Health Sector Development Plan	Plan	2015	Ministry of Health	Health Sector Development Plan 2015-16_2019-20
9	Uganda National e-health Policy	Policy	2016	Ministry of Health	Uganda National e-health Policy
10	Uganda National e-health Strategy	Strategy	2017	Ministry of Health	National e_Health Strategy
11	National ICT Initiatives Support Program	Program	2017	Ministry of ICT	NIISP Program
12	Data Protection and Privacy Act	Act	2019	Ministry of ICT	Data Protection and Privacy Act 2019

Table 4.1: Policy Documents Analyzed

Source: Compiled from various sources by M. Basajja, 2021.

4.2.6 Mention of the FAIR principles in Policy Documents

An analysis of the policy documents (Table 4.1) related to the e-health sector in Uganda was conducted to determine their explicit or implicit references to the FAIR principles—Findable, Accessible, Interoperable, and Reusable. None of the examined documents explicitly mentioned the FAIR principles [29]. However, semantic equivalents, denoted as 'FAIR Equivalent,' were identified within the documents. The determination of whether a statement found in the policy documents was equivalent to FAIR principles hinged on assessing its intent, purpose, or meaning concerning the original FAIR article [29]. For instance, if a document advocated for the use of standards to facilitate data exchange, it was labelled as equivalent to 'Reusability', a FAIR Guideline emphasizing the necessity for data and metadata to conform to domain-relevant community standards. Keywords and phrases such as common language/vocabulary, harmonise, incorporate, common systems, alignment, collaborate, common infrastructure, coordinate, integrate, open-source, information exchange, one-stop centre, and shared services were associated with the concept of 'Interoperability.' To signify this similarity in policy direction, the term 'FAIR Equivalent' was coined.

A binary code system was employed for tabulating annotations, with '1' signifying the presence of either a 'FAIR Mention' or 'FAIR Equivalent,' and '0' indicating the

absence of both (refer to Table 4.2 in Results). This structured approach parallels the framework method, widely employed in health research for qualitative data management and analysis.

Policy Document	FAIR Mention	FAIR-Equivalent
NITA-U Act (2009)	0	0
Second National Health Policy (2010)	0	1
National eGovernment Policy Framework (2011)	0	1
National Information Technology Policy (2012)	0	0
National ICT Policy Framework (2014)	0	1
National Information Security Framework (2014)	0	1
Second National Development Plan (2015)	0	1
Second Health Sector Development Plan (2015)	0	1
Uganda National e-health Policy (2016)	0	1
Uganda National e-health Strategy (2017)	0	1
National ICT Initiatives Support Program (2017)	0	1
Data Protection and Privacy Act (2019)	0	1
Average	0	0.833333333
Percent	0%	83%
Sum of FAIR-Equivalent (n)	0	10

Table 4.2: FAIR Mentions and FAIR-Equivalents in Policy Documents

4.2.7 Level of FAIR Equivalency in Policy Documents

To gauge the level of FAIR Equivalency in the examined policy documents, an analysis was extended to identify the presence of the equivalent of the 15 sub-criteria, termed 'FAIR facets,' that constitute the FAIR principles. These facets encompass four main categories: 'Findability' (F1, F2, F3, F4); 'Accessibility' (A1, A1.1, A1.2, A2); 'Interoperability' (I1, I2, I3), and 'Reusability' (R1, R1.1, R1.2, R1.3) [29].

Policy Document	F1	F2	F3	F4	A1	A1.1	A1.2	A2	I1	I2	I3	R1	FE-Score
NITA-U Act (2009)	0	0	0	0	0	0	0	0	0	0	0	0	0
Second National Health Policy (2010)	0	0	0	0	0	0	0	0	1	0	0	0	1
National eGovernment Policy Framework (2011)	1	0	0	1	1	1	1	0	1	0	0	0	7
National Information Technology Policy (2012)	0	0	0	0	0	0	0	0	0	0	0	0	0
National ICT Policy Framework (2014)	1	1	0	0	1	1	1	0	1	1	0	1	11
National Information Security Framework (2014)	0	0	0	0	1	0	1	0	0	0	0	0	2
Second National Development Plan (2015)	1	0	0	0	1	1	1	0	1	0	1	0	6
Second Health Sector Development Plan (2015)	0	0	0	0	1	0	0	0	1	0	1	1	5
Uganda National e-health Policy (2016)	1	1	0	1	1	1	1	0	1	0	1	0	11
Uganda National e-health Strategy (2017)	1	1	0	1	1	1	1	0	1	0	1	1	12

National ICT Initiatives Support Program (2017)	0	0	0	0	1	1	1	0	1	0	0	0	6
Data Protection and Privacy Act (2019)	0	0	0	1	1	0	0	0	0	0	0	1	4
Average	0.41	0.25	0	0.33	0.75	0.5	0.58	0	0.66	0.08	0.33	0.33	4.25
Percentage	41.7	25	0	33.3	75	50	58.3	0	66.7	8	33.3	33.3	4.25
Sum of FAIR-Equivalent (n)	5	3	0	4	9	6	7	0	8	1	4	4	51

Table 4.3: Summary of FAIR Equivalency assessment results for the analysed Policy Documents, indicating the presence and frequency of FAIR-related facets

A systematic review was conducted on the policy documents with the mention of the equivalent of each FAIR facet labeled by appending the respective FAIR facet code (e.g., F1, A1.2) to the corresponding statements. Using a binary code system ('1' for presence and '0' for absence), a Microsoft Excel spreadsheet (refer to Table 4.3 in Results) was utilized to compute the FAIR Equivalency Score (FE-Score) for each policy document. The FE-Score, representing the sum across all 15 facets, provides insight into the alignment of each document with the FAIR principles. The highest attainable FE-Score per document is 15 (refer to Supplementary Material 3, Basajja, 2021).

Figure 4.3: Process flow diagram showing the steps undertaken to assess FAIR equivalency within Ugandan policy documents.

4.3 Results

The results of this study are addressed in this section.

4.3.1 Mention of FAIR principles in Policy Documents

The investigation into whether the policy documents explicitly mention the FAIR principles revealed that the principles are not specifically mentioned in any of the documents. However, 10 of the 12 documents mention principles that are equivalent to the FAIR principles, which is a significant majority, see Table 4.2. This indicates that 80% of the documents are connected to the FAIR principles to some extent. Notably, the other two documents, which are relatively early policy documents from 2009 and 2012, do not contain any elements related to the FAIR principles.

4.3.2 FAIR Equivalency in Policy Documents

The FAIR principles consist of 15 FAIR facets. An examination of the presence of each facet in the documents is presented in descending order based on frequency:

1.Most Mentioned:

A1 (75%, n=9):
Accessibility facets are frequently mentioned, indicating the importance placed on data retrievability using a standardized protocol.

I1 (66.7%, n=8):
Interoperability shows emphasis on using a formal, accessible, and commonly shared language to provide knowledge representation is well-represented.

A1.2 (58.3%, n=7):
The protocol allowing for authentication and authorization procedures is also present.

2.Moderately Mentioned:

A1.1, R1.3 (50%, n=6):
Both the Authentication Protocol openness and Reusability aspects are moderately present.

F1 (41.7%, n=5):
Findability, including assigning a globally unique identifier, is relatively less mentioned but still present.

3.Less Frequently Mentioned:

F4, I3, R1, R1.1, R1.2 (33.3%, n=4):
These facets, including metadata registration and using qualified references, are less commonly found.

4.Rarely Mentioned:

F2 (25%, n=3):
Rich metadata description is less emphasized in the documents.

I2 (8%, n=1):
The use of vocabulary is the least mentioned facet.

5.Not Mentioned:

A2, F3 (0%, n=0):
Accessibility of metadata when data is unavailable, and metadata explicitly including data identifiers are not mentioned in any document.

These results are visually represented in a heatmap (Figure 4.5). To assess the potential improvement in FAIR Equivalent representation over time, the FAIR Equivalent Score (FE-Score) was calculated, providing an aggregate score across all documents and facets (Table 4.3 and Figure 4.4).

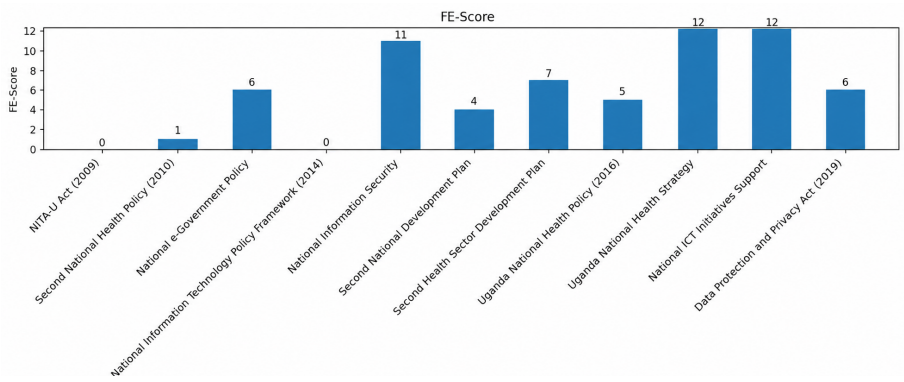

Figure 4.4: Bar chart illustrating the FAIR Equivalency(FE) scores across the analysed Ugandan Digital Health policydocuments published between 2009 and 2019.

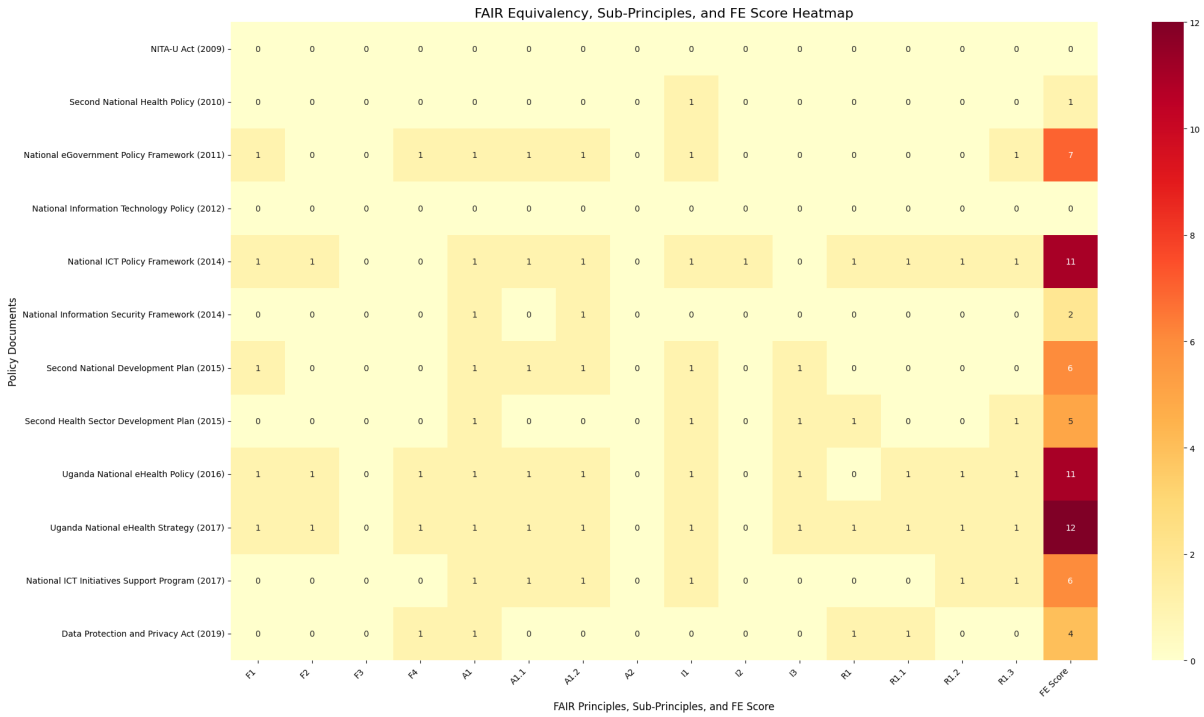

Figure 4.5: Heatmap illustrating the frequency of the FAIR equivivalent concepts identified across Ugandan digital health policy documents mapped against the FAIR priciples and their corresponding sub-priciples 'Findability' (F1, F2, F3, F4), 'Accessibility' (A1, A1.1, A1.2, A2), Interoperability' (I1, I2, I3) and 'Reusability' (R1, R1.1, R1.2, R1.3) per policy document

Figure 4.4 shows the FE-Score for each document by the year of its publication. The figure shows that the National e-health Policy (2016) and the National e-health Strategy (2017) have the highest FE-Scores, followed by the National ICT Policy Framework (2014). The charts show that FAIR Equivalency does not consistently increase over time. Instead, the highest FAIR Equivalency is observed for the National e-health Policy (2016), and the National e-health Strategy (2017), both have an FE-Score of 12, while the National ICT Policy Framework (2014) has an FE-Score of 11. The three documents that exhibit the highest FAIR Equivalency form the core of the framework of governance for Uganda's e-health sector and the foundation of Uganda's digital health policies.

4.4 Conclusion

Applying the FAIR principles to Africa's digital health services presents a transformational opportunity to address critical issues within the health sector on the continent. Such issues include: sustainability challenges and fragmentation of health service solutions. This study aimed to evaluate Uganda's framework of governance for digital health policies. It also investigated the feasibility of opening a policy window for adopting and implementing the FAIR principles in the country's e-health sector.

Key policy documents that are central to the emerging e-health sector, encompassing information, communication, and technology (ICT) and health, were identified and analyzed. A binary coding system using keywords and phrases was employed to assess whether these documents explicitly mention the FAIR principles or their equivalent, spanning 15 FAIR sub-criteria or facets. The resulting FAIR Equivalency Score (FE-Score), representing a total of 15 facets, was calculated for each document. Despite none of the documents directly referencing the FAIR principles, 83% of them acknowledged efforts equivalent to FAIR principles.

The highest FE scores were associated with Uganda's National e-health Policy, National e-health Strategy, and National ICT Policy Framework, indicating a higher alignment with FAIR principles. Notably, these three documents were among the most recently drafted of the selected policy documents. While the explicit mention of the FAIR principles was absent, the prevalent mention of FAIR Equivalency efforts, such as the adoption of the National Identification Number and planned integration of information systems, suggests a favourable environment for FAIR adoption in Uganda's Health sector within e-health.

In conclusion, the study indicates that the necessary conditions are favourable for advocating the adoption and implementation of the FAIR principles in Uganda's e-health sector. The FAIR Equivalency efforts reflected in policy documents demonstrate a foundational alignment with FAIR principles, paving the way for the potential acceptance and integration of these guidelines into Uganda's digital health policies.

4.5 Discussion

Although the analyzed documents do not explicitly reference the FAIR principles, the use of FAIR Equivalent terminology indicates a relatively small cultural entropy. This suggests that stakeholders in the e-health sector may not strongly resist the acceptance of FAIR principles, as the foundational principles align closely with existing policy language and objectives.

4.5.1 FAIR Equivalency

The FAIR Equivalency analysis was conducted using a systematic approach to identify terms and concepts in policy documents that align with the FAIR principles. The analysis revealed that in all examined policy documents, the facets of 'Accessibility' and 'Reusability' were most frequently referenced, with frequencies of 22 and 18, respectively. In contrast, the facets of 'Findability' and 'Interoperability' appeared less frequently, with frequencies of 12 and 13, respectively. The most frequently referenced FAIR Equivalent facets include:

> A1: "(meta)data are retrievable by their identifier using a standardised communications protocol."
>
> I1: "(meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation."

Conversely, the least-referenced FAIR Equivalent facets are F3, A2, and I2. These frequencies may be attributed to several factors:

> **Policy focus**: The higher frequency of Accessibility and Reusability facets likely reflects a policy emphasis on making data easily accessible and reusable for multiple purposes.
>
> **Technical complexity**: The lower frequency of Findability and Interoperability facets might reflect the technical challenges associated with implementing these principles, or a lack of awareness about their importance.
>
> **Historical context**: The emphasis on certain facets may be influenced by historical data management practices and an evolving understanding of data-sharing needs.
>
> **Stakeholder influence**: The frequencies could reflect the priorities of key stakeholders involved in policy development.

Regarding the least-mentioned FAIR Equivalent facets, Wilkinson and colleagues [29] described these facets as follows: F3—' metadata clearly and explicitly include the identifier of the data it describes'; A2—' metadata are accessible, even when the data are no longer available; I2—' meta(data) use vocabularies that follow FAIR principles'. The reason why these FAIR Equivalent facets (F3, A2, and I2) are the least referenced in the policy documents is that they are data-centric, meaning that they specifically deal with details about data and metadata, which is beyond the scope of the documents analyzed. As they are policy-level documents, they do not explicitly mention such things. Therefore, it is only after the policies or guidelines in the documents have been implemented in a particular context that one can ascertain whether or not the particular implementation conforms to these facets. serves

4.5.2 Facet A1: Standardized Communications Protocol for Accessibility

Facet A1 of the FAIR principles emphasizes the need for a standardized communications protocol, ensuring both human and automated users can easily retrieve data and metadata through identifiers. While acknowledging exceptions for highly sensitive data, maintaining accessibility through contact details is considered FAIR.

Examples of Mention in Policy Documents:

1. **Uganda National e-health Policy (2016):**
   Highlights the Ministry of Health's Knowledge Management Portal serving as a single access point for health-related information, supporting evidence-based decision-making.

2. **National e-Government Policy Framework and National ICT Policy Framework:**
   Emphasizes implementing an open data system for the government to streamline how citizens access information on the government, aligning with the priority of e-government applications.

3. **National Development Plan (NDP) II Public Investment Plan:**
   Outlines the development of a Monitoring and Evaluation Web Portal with a database, acting as a centralized information hub for government program monitoring.

4. **Health Sector Development Plan (HSDP) II:**
   Focuses on establishing a functional community information system, emphasizing the development of a National Health Information System Framework (NHISF) for reliable and accessible health data management.

These examples demonstrate a commitment to standardized communication protocols, reflecting a broader strategy to enhance accessibility and data retrieval. The incorporation of technology, portals, and frameworks aligns with the FAIR principle of A1, ensuring data and metadata accessibility through standardized protocols.

4.5.3 Facet I1: Formal, Accessible, Standardized Controlled Vocabularies

In terms of the FAIR principles, this is reflected in the first aspect I1: the use of formal, understandable, and broadly accepted language for knowledge representation; this is achieved by adopting standardised vocabularies, ontologies, and clear data models. This requirement can be met by taking up the Enterprise Architecture and Interoperability Framework for e-government and e-health implementations, which has been mentioned in policy documents such as the National e-health Policy, National e-health Strategy, and the National e-Government Policy Framework.

The National e-health Policy (2016) endorses the use of the Enterprise Architecture and Interoperability Framework for the development of e-health systems. They highlight the need to integrate systems for interoperability and avoid the lack of standards in managing health information.

In the National e-health Strategy published in 2017, it was also mentioned that an e-health Enterprise Architecture(EA) and Interoperability Framework should be created that would govern all investments in e-health. This emphasizes the role of EA in avoiding fragmentation and duplication and promoting integration in digital health solution architectures. The National e-Government Policy Framework also discusses the adoption of the Enterprise Architecture and Interoperability Framework for e-government and e-health, underlining the ability to use the simplified structures to enhance interoperability.

The importance of integration work in this context depicts the value of integrating information systems with various health information systems, such as HRHIS, CIS, and LSMIS. The intended integration of such systems complies with the 'Interoperability' principle of FAIR.

These examples show an adherence to the outlined frameworks and languages for knowledge representation to structure the FAIR interoperability component of I1 with reference to a common language. That having been said, the emphasis on integrated systems can be seen as corresponding with efforts that have been made in the development of the e-health system toward improving the availability and usefulness of health information.

4.5.4 Facet F1: Globally Unique and Persistent Identifiers for Findability

Facet F1 of the FAIR principles emphasizes the importance of assigning globally unique and persistent identifiers to data and metadata, ensuring their findability. This facet is foundational for the subsequent principles of Accessibility, Interoperability, and Reusability within the FAIR framework. Here are examples from the policy documents highlighting initiatives aligned with FAIR's 'Findability'. Both the National e-health Policy and National e-health Strategy recognize the crucial role of a unique health identifier in e-health systems. Acknowledging the absence of a unique identifier for health records and the issue of record duplication, the policies propose the use of the National Identification Number (NIN) as a unique identifier [76, 77].

The National Identification and Population Databank Project, represented by the NIN, provides a unique identification number for every individual in Uganda. The policies advocate for reusing the NIN as the unique health identifier for electronic medical records, electronic health records, and personal health records [76, 77]. The National e-health Strategy outlines the strategic objective of adopting the NIN as the unique identifier for patients/clients. It also emphasizes the enforcement of its use in electronic medical records systems. Additionally, there are existing plans that include the adoption and enforcement of unique identifiers for health facilities and providers.

To establish an electronic medical records system, the Ministry of Health has adopted the Open Medical Records Systems (OpenMRS), an open-source electronic health record system. OpenMRS facilitates the sharing of an individual's medical record electronically across different medical departments, aiding in patient tracking and addressing specific health concerns [81, 82]. The Ministry of Health's plan includes rolling out OpenMRS in a significant number of health facilities to contribute to the findability and accessibility of medical records. This initiative aligns with FAIR's 'Findability' principle by establishing a system with globally unique and persistent identifiers [83]. These examples demonstrate the commitment to creating globally unique and persistent identifiers for health records. This improves their findability and lays the foundation for achieving the FAIR principles comprehensively. Additionally, the emphasis on using the already established identification systems, such as the NIN, reflects a strategic approach to aligning e-health initiatives with FAIR principles.

4.5.5 FAIR as a Solution to Challenges in Uganda's e-health Sector

The FAIR principles are rooted in the belief that publicly funded data is for the public good. Therefore, the principles emerge as a solution to the challenges facing Uganda's e-health sector. An essential step towards adopting FAIR principles involves aligning them with Uganda's National e-Health Vision. This alignment aims to address existing barriers while strategically leveraging opportunities within key e-health pillars.

In Leadership and Governance, the FAIR principles must be represented as a solution to challenges in e-health implementation. The GO CHANGE Pillar plays an essential role in this by engaging stakeholders to align the 'eHealth Information Assurance' pillar with FAIR principles. A key initiative involves the formulation and enforcement of the information security guidelines for e-health and the privacy guidelines [77].

The e-health Enterprise Architecture pillar provides an avenue for adopting FAIR by applying its principles in areas such as data, information, knowledge sharing agreements, as well as data standards. Collaboration with digital health providers through the GO BUILD Pillar is necessary to develop mobile software that adheres to FAIR principles when establishing an e-health data, information, and knowledge management system [77].

FAIR integration in developing mHealth infrastructure must be explored so that the services can be aligned with the emerging technologies within e-health Services. Collaborative efforts by the GO BUILD and GO TRAIN Pillars are needed to ensure the development of mobile software that complies with FAIR principles. A strategic initiative involves developing guidelines for data ownership, data quality, and data analysis [77].

The infrastructure pillar emphasizes the continuous assessment of mature and emerging technologies for supporting e-health. The GO CHANGE Pillar should advocate for the adoption of FAIR principles by aligning them with both mature and emerging technologies, considering those that alter the business and social environment substantially [77].

Addressing e-health Information Assurance involves including FAIR principles in the review of information security frameworks and data protection laws. The GO CHANGE and GO TRAIN Pillars should work collectively with stakeholders to embed FAIR within data handling procedures and protocols, especially in scenarios where data accessibility is restricted due to privacy concerns [77].

The Human Resources and Capacity Building pillar presents a unique opportunity for FAIR adoption by proposing its inclusion in the e-health curriculum for workforce development. The GO TRAIN Pillar should engage stakeholders to advocate for the inclusion of FAIR principles in training programs. Strategic goals include developing accredited courses, providing ICT training, and establishing e-health centres of excellence [77].

In the context of change, adoption, business process re-engineering, and transitioning, aligning the digital health transitioning strategy with FAIR principles for standardization and interoperability is essential. Collaboration with the Ministry of Health Resource Centre is necessary for motivating FAIR adoption, especially considering the objective of managing rapid technological changes through adherence to e-health 'Enterprise Architecture' [77].

In order to effectively engage stakeholders, it is required that FAIR principles are incorporated into mass campaigns alongside e-health services. Additionally, it is critical to establish a framework for measuring the level of effectiveness in engagement and awareness of FAIR to ensure the adoption of the FAIR principles [77]. Positioning FAIR as an international best

practice is a vital step to further open the policy window. With entities like the World Health Organization backing it, FAIR can become an integral part of e-health governance, aligning with global standards.

Health authorities globally benchmarking their e-health systems against international best practices will lead to the rapid adoption of FAIR principles in ways that reflect a commitment to data management excellence. This strategy leverages existing benchmarks used in adopting e-health Enterprise Architecture to promote harmonization with international standards and practices. Establishing a regional FAIR Center of Excellence that could reinforce FAIR principles' visibility and offer a collaborative space for stakeholders in East Africa will lead to enhanced understanding and application of FAIR principles.

4.5.6 Challenges of the Study

The study faced challenges in obtaining two potentially relevant documents. Despite extensive searches on relevant NGO and government institution websites and formal requests submitted to key personnel, these documents remained inaccessible, as they were neither available online nor provided upon request. This limitation may have affected the comprehensiveness of the governance overview. The research focused exclusively on national-level documents published by Uganda's Government. This selection criterion comprised policies, frameworks, strategies, plans, legislation, and programs, and was applied to obtain a governance overview that aligns with the research objectives. However, the exclusion of annual health sector performance reports, evaluation reports, survey reports, and program reports may limit the depth of the analysis. These limitations should be considered when interpreting the study's findings, as they may affect the generalisability and depth of the governance framework overview in Uganda's digital health sector.