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

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Chapter 5

Possibility of Enhancing Digital Health Interoperability in Uganda through FAIR Data

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Abstract

This chapter examines the potential for improving digital health interoperability in Uganda through the adoption of FAIR (Findable, Accessible, Interoperable, and Reusable) data principles. Despite the increasing need for efficient data exchange in healthcare—especially highlighted during the COVID-19 pandemic—Uganda's health information systems remain largely paper-based and fragmented. These limitations hinder the ability of health facilities, researchers, and policy makers to access, share, and reuse clinical data effectively. The chapter explores existing data collection and reporting practices in Ugandan health facilities, identifies key barriers to digital interoperability, and evaluates how FAIR-aligned strategies could overcome these challenges. By mapping FAIR principles onto the current health data ecosystem, the chapter proposes practical pathways for achieving improved data interoperability, ultimately enabling more coordinated, data-driven decision-making across the country's healthcare system.This chapter also explores the interoperability assessment of two crucial digital health dashboards: the Digital Health Dashboard. Atlas Uganda (DHA-U) and the Uganda Digital Health Dashboard (UDHD), along with their associated vertical digital health tools within the Ugandan context. Efforts were made to enhance the FAIRness of the digital health hubs. To achieve this, a FAIR Data Point was used to facilitate integration and alignment with FAIR principles. The level of FAIRness was reassessed after the process of FAIRification, which was done using the FAIR Evaluation Services.

Keywords: FAIR, FAIRness level, Interoperability, Integration, Common standards, Health information exchange

5.1 Introduction

Interoperability has emerged as an indispensable element in the implementation of large-scale data management systems, particularly those intended for adoption by national health systems. This chapter analyses the potential augmentation of digital health interoperability through the FAIR (Findable, Accessible, Interoperable, Reusable) principles. We conduct an analysis that is centred on two digital health dashboards that were piloted in Uganda to scrutinize how sustainable they are. The value and potential scalability of an integrated system are significantly increased by the capability of a digital health product to easily and effectively exchange information with external systems.

Establishing interoperability with the National Health Management Information System (HMIS) enables seamless access to and utilization of the data that is collected by a digital health product by the country's Ministry of Health. This integration enhances the value of the health product as a tool that is being used to improve the administration of healthcare services. It also proves how critical it is for these health products that are employed to align with health system structures [84].

There has been significant progress in the evolution of digital health systems that were primarily constructed from Electronic Health Records (EHRs). In the early 2000s, medical records were confined to Microsoft (MS) Access spreadsheets within individual hospitals. This became insufficient shortly afterwards as the volume of data being managed continued to grow. Subsequently, a more efficient and robust system based on Java web applications and MySQL databases was created [85]. The Open Medical Record System (OpenMRS), which was introduced around 2005, was designed as a free and open-source system that could support healthcare delivery systems through a generalizable EHR, particularly in developing countries. Having been deployed in over 25 predominantly low-income countries, including Uganda, OpenMRS has proven to be effective, especially in recording the treatment of millions afflicted by HIV/AIDS and tuberculosis.

There has been an increase in initiatives that explore how digital health applications can offer solutions, which has been influenced by the potential of digital health to address structural challenges in African healthcare. This surge is evident in initiatives such as the Ghana Health Service telemedicine program, which is backed by the Novartis Foundation. This program leverages mobile phones to connect remote primary healthcare facilities and community health workers to a teleconsultation centre [86]. Despite these advancements, there are persistent concerns over the sustainability of digital health solutions, as discussed by the Broadband Commission Working Group [87]. The Commission emphasizes that there is a scarcity of policies and infrastructure that are necessary to embed these pilot solutions within a sustainable environment.

This apprehension aligns with findings from a systematic literature review [88], which covers mHealth for community health in Africa from 2005 to 2015. The review shows weak evidence regarding the sustainability of mHealth interventions, with technology-related issues and circumstantial complications being significant barriers to the expected impact. This classification of the challenges being faced explains the complexities that are associated with mHealth. Consequently, it validates the claims about its weak evidence base.

Recognizing the digital health agenda in the East African Community, particularly emphasized in the 2017 adoption of an action plan [290], some countries like Rwanda and Kenya have made substantial progress with active government support for ICT-led development. However,

Uganda, lacking a comparable focused ICT-policy orientation, provides an intriguing case study. The absence of central government focus often correlates with challenges to sustainability resulting from ICT-based infrastructure, making Uganda an apt subject for investigating the reasons behind this phenomenon and exploring potential remedies [89].

In this chapter, we scrutinize two digital health dashboards piloted in Uganda, evaluating their sustainability. Furthermore, we assess the extent to which the incorporation of FAIR data protocols could serve as a solution to structural challenges impeding the development and maintenance of sustainable digital health solutions in Uganda.

5.2 Research Questions and Objectives

To assess the level of interoperability and potential of enhancing digital health interoperability through FAIR in Uganda's eHealth sector, the following research questions were posed:

Research Questions

Main Research Questions:

Q1. What factors are currently hindering the interoperability of digital health solutions in Uganda?

Q2. Can the introduction of the systematic use of a FAIR data protocol through a FAIR Data Point help overcome structural challenges to the development and maintenance of sustainable digital health solutions in Uganda?

Sub-Research Questions:

Sub-Research Question 1:
What is the current level of FAIRness in Uganda's major digital health hubs, specifically the Digital Health Atlas Uganda and Uganda Digital Health Dashboard?

Sub-Research Question 2:
How do the FAIRness levels differ among various digital health interventions (DHIs) in Uganda?

Sub-Research Question 3:
What improvements in FAIRness can be achieved through the process of FAIRification for Uganda's digital health hubs?

Sub-Research Question 4:
How can enhancing the FAIRness of digital health hubs contribute to improved interoperability of digital health solutions in Uganda?

The main objectives of the study were:

To analyse the level of FAIRness of the two digital health dashboards piloted in Uganda before and after FAIRification.

To determine the level of the digital interventions in the two digital health dashboards

To examine the extent to which the introduction of FAIR data protocols would help overcome structural challenges to the development and maintenance of sustainable digital health solutions in Uganda

5.3 Two Digital Health Hubs

This section explores the interoperability assessment of two crucial digital health dashboards: the Digital Health Atlas Uganda (DHA-U) and the Uganda Digital Health Dashboard (UDHD), along with their associated vertical digital health tools within the Ugandan context. The primary objective of this assessment is to examine methods that can be used to enhance the sustainability of digital health interventions by improving the coordination between these digital hubs. In order to achieve this, this study investigated the existing situation in Uganda's healthcare system and suggested and then tested solutions that focus on improving how data is used and managed in the country's digital health centres. The step that followed was checking the effectiveness of the methods that were used to manage data within the specified digital health systems. This was done to ensure that the FAIR principles were implemented in those healthcare systems. Before discussing the results that were obtained from analyzing the DHA-U and the UDHD, this study will present an overview of these two digital health hubs.

5.3.1 Digital Health Atlas Uganda

The Digital Health Atlas (DHA), as mentioned earlier, is described as an open source that can be accessed from the web. It has a repository of digital health interventions (DHIs) and has records of similar interventions implemented globally. The primary purpose of the DHA is to support an efficient organization of the interventions that have been made within the fields associated with digital health systems, which are in line with the FAIR principles for data. It is worth noting the other supportive role of the DHA, which is to support the activities of advanced planning, timing, monitoring, and evaluation of digital health services. Some of the tools include mHealth Assessment and Planning for Scale (MAPS) that the DHA makes available to governments, service providers, and donors to determine the track of advancement of the digital health systems development [91]. DHA is considered a global public good as it has support from influential organizations, including the WHO's Division of Reproductive Health and Research, USAID, United Nations Foundation, UNFPA, Johns Hopkins University Global mHealth Initiative, and Digital Health and Interoperability Working Group.

Its mission includes enabling service providers to list their digital healthcare business globally. In this way, DHA acts as an inventory of digital health products. It helps to create a comprehensive understanding of the global digital health landscape, working towards minimizing duplication, enhancing cooperation, and promoting integration among software projects. This aligns with the FAIR Guidelines' emphasis on interoperability. The DHA facilitates strategic alignment and reduces redundancy in the efforts being made to improve healthcare systems by allowing investors access to crucial information on DHIs, such as geographic scope, health focus areas, project duration, implementation phase, readiness for scale, and financial support details [91].

In Uganda, the DHA-U consists of 38 DHIs, 25 of which receive government investment, while 13 of them are funded by other stakeholders. These digital health solutions address various health focuses such as HIV/AIDS, malaria, maternal health, tuberculosis, surveillance,

and adolescent and sexual reproduction as they operate across various health facilities in Uganda [91].

5.3.2 Uganda Digital Health Dashboard

The Uganda Digital Health Dashboard (UDHD), also known as the Health Enabled Dashboard, was established in 2016. It is regarded as a pivotal hub for digital health initiatives in Uganda. The dashboard was created by the Government of Uganda to address various challenges within the country's healthcare provision, with a focus on coordinating digital health solutions. The dashboard has a catalogue of 57 providers of Digital Health Interventions (DHIs). In this way, it exhibits the diverse actors who are engaged in digital health in Uganda and the existing fragmentation in service delivery [92].

Comprising four national digital health systems and 53 organizations implementing digital health projects, the UDHD plays a crucial role in consolidating and streamlining digital health efforts in the country. The four national digital health systems featured on the dashboard include:

District Health Information System 2 (DHIS2): Adopted in 2010 as a national tool for collecting and reporting health data.

Human Resource for Health Information Software 3 (HRHIS3): Utilized for data collection, storage, analysis, reporting, and the dissemination of human resource information for evidence-based decision-making.

mTRAC: An mHealth solution designed to track essential medicines and enhance health service delivery. The mTRAC Stop Malaria Program, a component of mTRAC, enables health workers to input data on essential malaria drug stock levels.

Stop Malaria Program: Collaborating with districts to procure supplies.

However, a notable limitation of the 57 DHIs on the UDHD is the absence of a data export function. The health focus areas of these digital health solutions span diverse domains, including HIV/AIDS, malaria, maternal health, tuberculosis, surveillance, adolescent and sexual reproduction, clinical decision support, virtual health education, m-health, eHealth, Health Management Information System (HMIS), and preventable diseases. The UDHD, like the DHA-U, has identified instances of DHI duplication, indicating a need for streamlined coordination [92].

5.4 Methods

This case study employed a comprehensive methodology to evaluate the FAIRness of two digital health hubs and the associated vertical digital health solutions within these hubs. The study, conducted as a desk study based on documents related to digital health solutions in Uganda, encompassed the following key steps:

- Step 1: FAIRness Assessment Using the FAIR Evaluation Services Tool [93]: The initial phase involved assessing the level of FAIRness of the Digital Health Atlas Uganda

(DHA-U), the Uganda Digital Health Dashboard (UDHD), and the vertical digital health solutions within these hubs using the FAIR Evaluation Services tool, which is a web-based automated service. This tool offers a structured evaluation of digital resources as it checks and validates metadata based on the FAIRMetrics and FAIRSharing groups. It also uses a collection of maturity indicator tests in order to ensure compliance with the FAIR Guidelines of Findability, Accessibility, Interoperability, and Reusability.

- Step 2: FAIRification and Integration of the Hubs: Based on the findings from Step 1, some efforts were made to enhance the FAIRness of the digital health hubs. The FAIRification process involved making the hubs more Findable, Accessible, Interoperable, and Reusable. To achieve this, a FAIR Data Point was used. This facilitated integration and alignment with FAIR principles. Subsequently, the level of FAIRness was reassessed after the process of FAIRification, which used the FAIR Evaluation Services Tool.

This methodological approach aimed to evaluate the FAIRness of digital health data in Uganda comprehensively while focusing on improving interoperability and accessibility through the process of FAIRification. The subsequent sections provide the details of the outcomes of these assessments and the implications of those results for sustainable digital health solutions in Uganda.

5.5 Results: Level of FAIRness of Digital Health Hubs in Uganda

The FAIR Evaluation Service was used to assess the level of FAIRness of the Uganda Digital Health Dashboard (UDHD) and Digital Health Atlas Uganda (DHA-U). A globally unique identifier (GUID) was used for the evaluation, and the results are summarized in Table 5.1.

Table 5.1: Results of Maturity Indicator Tests for UDHD and DHA-U [13, 14]

Principle	Metric Test Description	UDHD	DHA-U	FAIR Data Point
F1	Unique identifier presence	1	1	1
F1	Identifier persistence	0	0	0
F1	Data identifier persistence	0	0	0
F2	Machine-findable metadata	1	1	1
F2	'Grounded' metadata	1	1	1
F3	Unique identifier in data	0	0	1
F3	Unique identifier in metadata	0	0	1
F4	Machine-discoverable resource	1	0	0
A1.1	Open and free data protocol	0	0	1
A1.1	Open and free metadata protocol	1	1	1
A1.2	Authentication capability	0	0	1
A1.2	Metadata authentication capability	0	1	1
A2	Persistence policy presence	0	0	0
I1	Broadly applicable language	1	1	1
I1	Semantically-grounded language	1	1	1
I2	Resolvable linked data terms	0	0	1
I2	Linked data terms resolve to FAIR data	0	0	1
I3	Links outward to third-party resources	1	0	1
R1.1	Explicit pointer to license	0	0	1
R1.1	Metadata pointer to license	0	0	1

5.5.1 Uganda Digital Health Dashboard (UDHD) Results

The UDHD was evaluated using the FAIR Evaluation Services based on its unique identifier [1]

. The results that are illustrated in Figure 5.1 demonstrate a varying level of FAIRness across different principles.

[1]Source: `http://healthenabled.org/wordpress/uganda-digital-health-dashboard/`

Figure 5.1: Pie chart illustrating the FAIR Evaluation results for DUganda Digital Health Dashbord showing the distribution of successful and unsuccessful maturity indicator tests

Source: [95]

Upon detailed analysis, the UDHD showed the lowest FAIR metrics test pass percentage in the 'Reusable' category at a score of 0%. This is because an explicit pointer to the license was absent in the linked data metadata. Conversely, the 'Interoperable' category achieved the highest FAIR metrics test pass percentage of 60%. The reason for this successful result is that interoperability is positively impacted by the use of a formal language that is broadly applicable for knowledge representation and the presence of links to third-party resources.

5.5.2 Digital Health Dashboard Uganda (UDHD) Results

After evaluating the DHA-U, conducting the FAIR metrics evaluation using the FAIR Evaluation Services and maturity indicator tests, the results show that out of 20 tests, 9 succeeded, and 11 failed. The detailed results are shown in Figure 5.2.

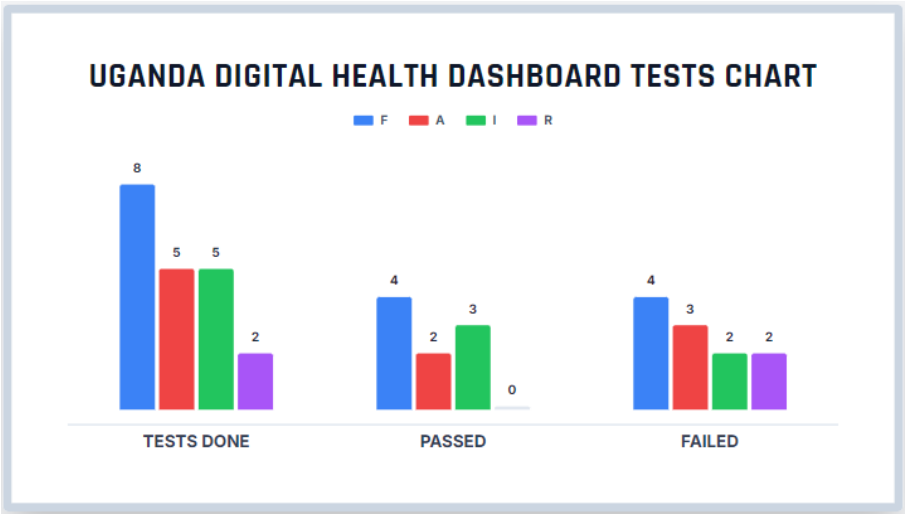

Figure 5.2: Bar chart illustrating the results of FAIR maturity indicator assessments conducted for the Uganda Digital Health Dashboard(UDHD) across the four FAIR principles

The study showed that the performance of DHA-U in different formulations varied. The results indicated that the 'Interoperable' and 'Findable' categories were more successful compared to the other two categories. The reason for the success of the 'Interoperable' category is that the language that was used is formal and common, leading to knowledge representation. However, the 'Findable' category faced challenges because of the complexity of the machine-discovery resources that are used in search engines.

These results illustrate the current state of FAIRness for UDHD and DHA-U. The insights from this study form the basis for further discussion on how to improve the integration and sustainability of digital health solutions in Uganda.

5.5.3 Digital Health Atlas Uganda (DHA-U) Results

The Digital Health Atlas Uganda (DHA-U) was evaluated using its unique identifier [2] through the FAIR Evaluation Services.

Figure 5.3: Pie chart illustrating the FAIR Evaluation results for Digital Health Atlas Uganda showing the distribution of successful and unsuccessful maturity indicator tests

Source: [96]

The maturity indicator test results for the DHA-U show that out of the 20 tests that were conducted during the assessment, 7 succeeded, and 13 failed. More detailed results are exhibited below.

[2]Source: `https://www.digitalhealthatlas.org/en/ug/`

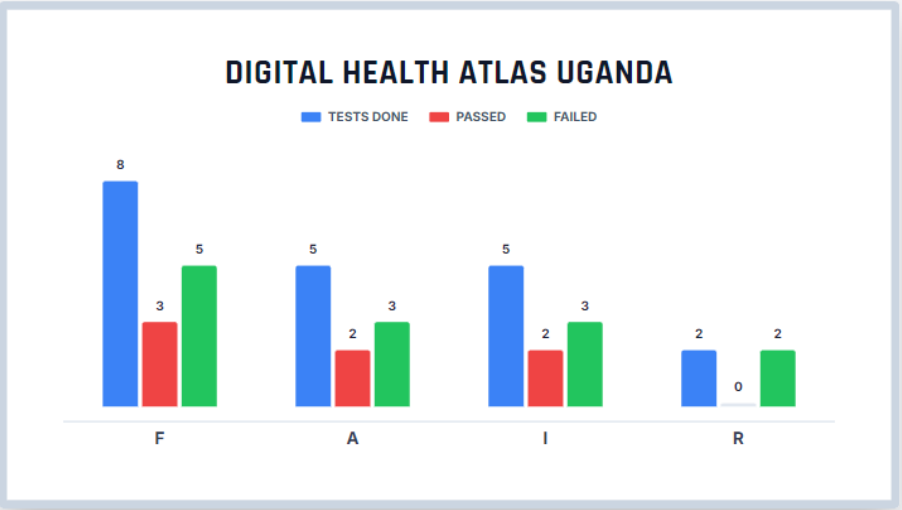

Figure 5.4: Bar chart illustrating the results of FAIR maturity indicator assessments conducted for the Digital Health Atlas(DHA-U) across the four FAIR principles

The analysis showed that DHA-U scored the lowest in the 'recyclable' category, receiving a 0% FAIR metrics test pass. This deficiency was attributed to the absence of an explicit pointer to the license in both linked data metadata and metadata. On the other hand, DHA-U excelled in the 'Findable' category by achieving a 50% FAIR metrics test pass. This success is because the unique indicators for metadata processing are available. Additionally, this success was due to the ability of devices to search through structured geographic metadata.

5.5.4 Digital Health Interventions (DHIs) FAIRness

To assess the quality of each digital health intervention (DHI) in the two digital dashboards, UDHD and DHA-U, the unique identifier for each DHI was examined. The data that was assessed was obtained and evaluated using the FAIR Evaluation Services comprised 98 digital health interventions from both dashboards. The results are presented in the table below.

The results in this table show that the majority of DHIs had a score of under 10, which is below the average success score. Only one DHI attained the score of 12, which is the highest success score out of all the other digital health interventions. Considering these low scores in the digital health interventions that were assessed, it is clear that there is a need to enhance the FAIRness of DHIs in Uganda. This can be done in various ways that include improving the Findability of each DHI through assigning persistent unique identifiers (PIDs) to metadata and data resources.

5.5.5 After FAIRification

A FAIR Data Point, which serves as a distributed data repository that hosts machine-actionable data and metadata that is aligned with the FAIR Guidelines, was implemented at Kampala International University, Uganda. This was done to improve the FAIRness of the Uganda Digital Health Dashboard (UDHD) and the Digital Health Atlas Uganda (DHA-U). Metadata

Table 5.2: Level of FAIRness of Digital Health Interventions

Group	Success Score	Failure Score	Number of DHIs
1	3	17	19
2	7	13	15
3	8	12	11
4	9	11	7
5	10	10	6
6	11	9	3
7	5	15	1
8	12	8	1
9	0	20	1
10	4	16	1

configuration for the FAIR Data Point included a catalogue, layer, dataset layer, and distribution layer, with a specific catalogue created for the digital health hubs in Uganda.

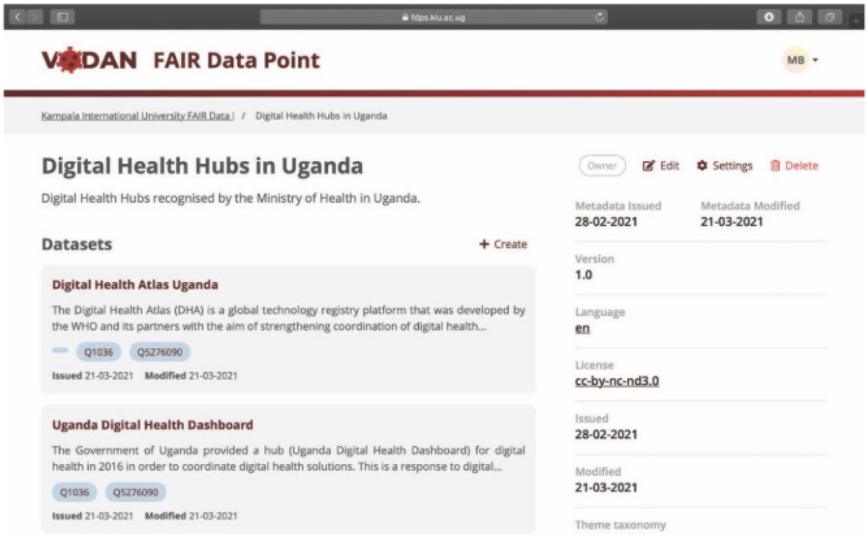

Figure 5.5: Screenshot of the FAIR Data Point catalogue for Ugandan digital health hubs, illustrating the organisation and publication of machine-actionable metadata in accordance to the FAIR Principles

Source: Screenshot taken by M. Basajja, 2021

A subsequent FAIR metrics evaluation was performed on the FAIR Data Point Catalog to assess the new level of FAIRness. The results of this evaluation are presented in Figure 6.

Figure 5.6: Shows FAIR Data Point (UDHD and DHA-U catalogue) test results using FAIR Evaluation Services

Source: [97]

The maturity indicator tests, out of 20, demonstrated a substantial improvement in FAIRness after FAIRification, with 16 tests succeeding and 4 failing. A detailed breakdown of the tests per FAIR Guideline is illustrated in Figure 5.7.

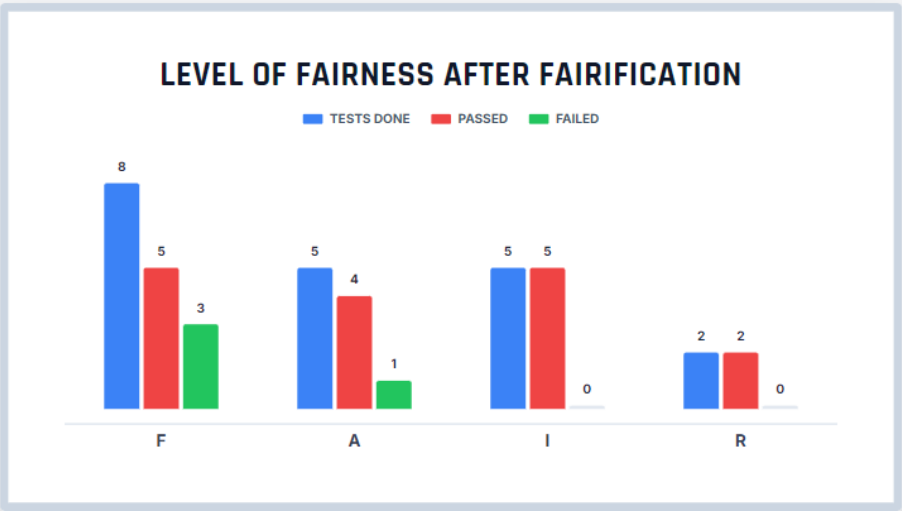

Figure 5.7: Bar chart illustrating the results of FAIR maturity indicator assessments conducted, passed and failed by the digital health hubs in Uganda after FAIRification.

Following FAIRification, the digital health hubs in Uganda exhibited a noteworthy improvement in FAIRness. The 'Reusability' and 'Interoperability' aspects reached 100%, a considerable enhancement from the initial 0%. While 'Findability' and 'Accessibility' experienced slight challenges, with 3 and 1 failed tests, respectively, due to the absence of a persistent identifier and a defined persistence policy, improvements in the number of passed tests were observed. In summary, the introduction of FAIR data protocols, as demonstrated by the FAIR Data Point implementation, significantly addressed structural challenges in the development and maintenance of sustainable digital health solutions in Uganda. This improvement showcases the effectiveness of FAIR principles in enabling Findability, Accessibility, Interoperability, and Reusability.

5.6 Conclusion

The FAIR Guidelines have been emphasized as a general framework for achieving FAIRness in data rather than a rigid standard since they were first developed and implemented. For this reason, the guidelines should be implemented responsibly to make technical decisions that are aligned with the principles of making data Findable, Accessible, Interoperable, and Reusable (FAIR). A detailed FAIR metrics evaluation that used the FAIR Evaluation Services revealed distinct FAIRness characteristics between the Uganda Digital Health Dashboard (UDHD) and the Digital Health Atlas Uganda (DHA-U).

Surprisingly, the UDHD demonstrated higher FAIRness compared to the DHA-U, particularly excelling in 'Findability' and 'Interoperability.' Both hubs achieved equal scores for 'Accessibility' and 'Reusability,' with 'Reusability' scoring the lowest due to inadequate metadata and data description, limiting indexation in searchable repositories. The absence of well-described licenses further restricted data readability to human users.

In particular, none of the digital health interventions assessed exceeded half of the FAIR maturity tests conducted. These interventions operated independently, lacking inherent support for FAIR principles. Data collected by the District Health Information System (DHIS) faced challenges in terms of Findability, Accessibility, Interoperability, and Reusability, hindering easy retrieval, access, and reuse.

To address these challenges, the Ugandan government is being asked to instill a degree of Fairness in all digital health tools. While acknowledging the diverse software and technology used by different Digital Health Interventions (DHIs) due to varied health focus areas and implementation challenges, standardizing data formats and adopting Application Programming Interfaces (APIs) could enhance interoperability. A systematic incorporation of FAIR data protocols through the implementation of a FAIR Data Point is proposed as a solution to overcome structural barriers and promote sustainable digital health solutions in Uganda. This strategic shift towards FAIRness has the potential to foster collaboration, reduce duplication of efforts, and improve the overall effectiveness of digital health initiatives in the country.

5.7 Discussion

The Uganda Digital Health Dashboard (UDHD) and Digital Health Atlas Uganda (DHA-U) both aim to serve as comprehensive repositories of digital health solutions. UDHD and DHA-U can promote collaboration and address the challenges facing sustainability in Uganda's healthcare system. The DHA-U is recognized for its contributions to providing information on interoperability and best practices within the healthcare field. Surprisingly, the UDHD showed higher levels of FAIRness compared to the DHA-U in terms of 'Findability' and 'Interoperability.' However, the results on both hubs showed that they had equal levels of accessibility and reusability, with 'Reusability' scoring the lowest out of all the other categories.

Despite the DHA's aim of encouraging reusability and interoperability, the FAIR metrics evaluation underscored the need for improvements to be made. Only seven of 20 tests passed. This indicated specific areas that require attention. It should be noted that DHA offers valuable information on interoperability and standards for each registered digital health project, including compatibility with various systems. However, there are persistent challenges, with many projects indicating 'N/A' for interoperability. This raises concerns about the transparency of

the details of the implementation of this repository.

To be registered, a digital health project in the DHA is required to complete global and country-specific fields that cover project overview, implementation details, technology, and interoperability. Although DHA encourages comprehensive information sharing, the completeness of the data that is collected is dependent on the diligence of the project team. The lack of details of interoperability may stem from a lack of awareness or understanding of the technology architecture and software used in other systems.

The metaphorical description of the current wave of mHealth interventions as 'black boxes,' indicating a lack of documentation on implementation details, resonates with the findings in Uganda. Despite efforts by the DHA-U, many projects lacked interoperability information, pointing to a broader issue in the documentation of implementation specifics. To address this, governments could play a pivotal role by mandating policies requiring digital solutions to provide comprehensive information, thereby incentivizing adherence to standards, formats, and ontologies in common use.

It is essential to note that FAIR principles emphasize machine-actionable data and metadata without explicitly prescribing specific frameworks. While RDF and linked data represent popular solutions, achieving FAIRness is viable using diverse frameworks. The FAIR Guidelines, however, underscore the importance of machine-readability for comprehensive application.

In line with the principles advocated by Tomlinson et al.[98], there is a critical need for concerted efforts by governments, funders, and private enterprises to establish standards for interoperable platforms, ensuring the scalability and sustainability of mHealth initiatives. Open mHealth architectures that are based on robust platforms with application development standards are recommended, as this aligns with the core of the FAIR Guidelines that promote interoperability and scalability.

Guidance tools such as the mHealth Assessment and Planning for Scale (MAPS) Toolkit focus on using best practices to scale up mHealth innovation and advocate for standardization and interoperability. The lack of specified standards and communication protocols in mHealth systems can lead to competing and duplicated datasets that hinder the integration and improvement of these systems.

In a 2011 paper, Lemaire reiterates the importance of data standardization and communication infrastructure to successfully scale mHealth systems [99]. Suggestions in this regard include developing a framework type, reference systems, and the use of specific data and technical standards will be encouraged. Governments are encouraged to be more efficient in implementing these policies and standards to align with the objectives of the FAIR Directive.

Thus, promoting data standardization and collaboration is important as this has an impact on the implementation of projects that are aimed at scaling up mHealth systems in developing countries. These principles are consistent with the WHO's recommended integrated approaches based on standards expected within the sector.