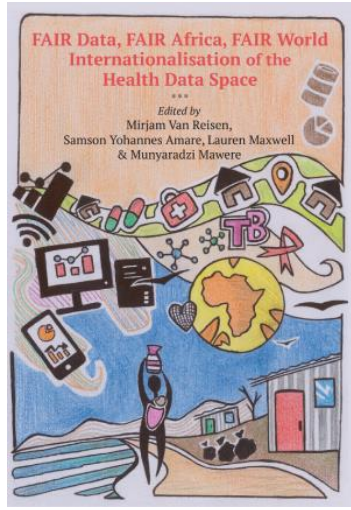
A Critical Incident Assessment of a FAIR Implementation Study on Patient Health Data in Africa

Abdullahi Abubakar Kawu, Putu Hadi Purnama Jati, Lars Schrijver, Mirjam van Reisen, Getu Tadele, Dympna O'Sullivan, & Lucy Hederman

Chapter in:
Fair Data Fair Africa Fair World:
Internationalisation of the Health Data Space



Cite as: Kawu, A. A., Jati, P. H., Schrijver, L., Van Reisen, M., Tadele, G., O'Sullivan, D., & Hederman, L. (2025). A critical incidence assessment of a FAIR implementation study on patient health data in Africa. https://doi.org/10.5281/zenodo.15382889. In Van Reisen, M., Amare, S. Y., Maxwell, L. & Mawere, M. (Eds.), FAIR data, FAIR Africa, FAIR world: Internationalisation of the Health Data Space. (pp. 241–276). Bamenda: Langaa. URL: https://www.researchgate.net/publication/391750151_FAIR_Data_FAIR_Africa_FAIR_World_The_Internationalisation_of_the_Health_Data_Space

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Chapter 8

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Abstract

This research investigates the critical incidents reported following a FAIR implementation aiming to enhance patient health data analytics, facilitate compliance with national regulations, and support point-of-care utilisation while ensuring that data remains within the respective countries' borders. Using a mixed-methods approach, the study involved interviews to identify facilitators and barriers to data production. The findings reveal that infrastructure deficits, particularly unreliable electricity and internet access, posed some challenges to system usability. Participants recognised notable benefits, including enhanced accuracy in health data reporting, automation of patient data records, and improved decision-making capabilities. The results underscore the need for investments in infrastructure, alternative power solutions, and enhanced system usability to unlock the full potential of FAIR-compliant health systems in resource-constrained settings. Capacity-building initiatives were instrumental in supporting stakeholders to adapt to the new technology. The research demonstrates the transformative potential of FAIR principles in advancing digital health initiatives in Africa. The success of such implementations is contingent on addressing infrastructural and operational barriers, refining system design, and fostering stakeholder collaboration.

Keywords: Critical incident theory, patient data, Africa, FAIR data

Introduction

The Digital Economy Report (2021) found that the literature on cross-border data flows in Low- and Middle-Income Countries (LMICs) is limited. An element missing in the literature is the lack of a 'commonly agreed definition' of 'data and cross-border flows' needs (United Nations Conference on Trade and Development, 2021, p. 73), because of which consensus and constructive discussion are missing. The report also observes that extant literature on cross-border data flows is 'ideological in character', meaning that it portrays interests (United Nations Conference on Trade and Development, 2021, p. 73).

As research on the development implications of cross-border data flows remains limited, it constrains policymakers' ability to formulate strategies that balance economic opportunities with data sovereignty concerns. Finally, it argues that cross-border research mainly concentrates on trade, overlooking multidimensional approaches that encompass both economic and non-economic dimensions (United Nations Conference on Trade and Development, 2021). This narrow perspective abandons how data flows impact sectors such as healthcare, where effective data management can be crucial for decision-making and public health outcomes.

Given these gaps, it is crucial to expand research on cross-border data governance beyond trade and into critical sectors such as healthcare. The report underscores the increasing importance of data in health, particularly its role in informing decision-making (United Nations Conference on Trade and Development, 2021). Digital health systems have become indispensable in addressing the global challenges of healthcare delivery and management, particularly in resource-limited settings. However, the effective utilisation of health data across health facilities, within regions, and across borders, often remains hindered by fragmented and inaccessible data systems.

To address these challenges, the semantic web-related FAIR (Findable, Accessible, Interoperable, and Reusable) principles (Wilkinson et al., 2016) have been proposed to improve federated data management globally, including across national borders.

Wilkinson et al. (2016) emphasise the role of the principles in fostering interoperability and data reuse.

Sinaci et al. (2020) further outline workflows for transforming raw health data into FAIR-compliant datasets, emphasising the need for standardisation and interoperability in the health sector. These principles offer a robust framework to enhance the usability and accessibility of health data for various stakeholders, including healthcare providers, policymakers, and researchers (Van Reisen, et al., 2021). Despite their increasing adoption in high-resource settings, the application of FAIR principles in low-resource healthcare environments, particularly in African contexts, remains limited (Van Reisen, Stokmans, Mawere et al., 2020). Existing research has not sufficiently addressed the contextual challenges of implementing FAIR-compliant digital health systems across borders. Llebot and Castillo (2023) argue that institutional policies are critical for their adoption. They highlight that while the principles are widely recognised in high-resource settings, their application in under-resourced environments, such as African healthcare systems, remains limited.

Sector-specific adaptations, such as FAIR for health services, demonstrate the principles' applicability in addressing privacy and regulatory concerns in medical research (Holub et al., 2018).The adaptation of FAIR principles for health data has spurred innovations like FAIR-Health and Personal Health Train which integrate privacy-preserving measures to address regulatory challenges in medical research (Holub et al., 2018). Despite these advancements, there is scant literature exploring the implementation of FAIR-compliant health systems in cross-border and resource-limited settings, creating a critical gap that this study seeks to address.

Studies have documented the feasibility of cross-border health data federated architectures (Van Reisen, et al., 2021; Van Reisen et al., 2022; Van Reisen et al., 2023; Van Reisen et al., 2024); and the feasibility of the realisation of these architectures in low-resource areas (Amare et al., 2023) and in situations of war and siege (Amare et al., 2024; Taye et al., 2024). Nevertheless, more work is needed to document the conditions for the integration of FAIR principles in low-resource settings, particularly in Africa. Conceptually focused

studies overlook unique contextual challenges. Significant obstacles to the exchange of cross-border health data may still exist (Richards, 2022). Limited empirical studies examine the practical implementation of FAIR-compliant systems in resource-constrained settings. This study aims to explore the contextual challenges associated with implementing a federated digital health system in low-resource environments. Specifically, it examines the key barriers to deploying a cross-border, federated patient data system in health facilities across four African countries.

Conceptual framework

This study draws on two key conceptual frameworks: the FAIR Guiding Principles (Wilkinson, 2016) and Critical Incident Theory (CIT) (Flanagan, 1954), to investigate the challenges and facilitators encountered during the VODAN-Africa project.

FAIR Guiding Principles

The FAIR principles serve as the foundation for this study. Initially proposed by Wilkinson et al. (2016), these principles aim to enhance the utility of scientific data by ensuring it is machine-readable, reusable, and discoverable across diverse platforms. In the context of health data, the principles emphasise:

- Findability: Assigning globally unique and persistent identifiers to datasets, ensuring that data can be easily located by users and systems.
- Accessibility: Facilitating data retrieval through standardised protocols, while ensuring compliance with regulatory and privacy requirements.
- Interoperability: Enabling data exchange and integration through the adoption of standardised vocabularies and ontologies.
- Reusability: Ensuring data is well-described and available under clear licensing terms to maximise its future utility.

The FAIR principles provide a theoretical lens guiding the evaluation of system design, data workflows, and stakeholder engagement of the architecture deployed to study the adoption of FAIR based systems.

Critical Incident Theory

CIT introduced by Flanagan (1954), was utilised in this study to delve into the specific challenges and facilitators faced by project stakeholders. CIT is particularly valuable for exploring complex, context-dependent phenomena, as it encourages participants to recount significant incidents that shaped their experiences, and has its origin in industrial and organisational psychology, and did not come with a rigid framework (Butterfield, 2005). The overall concept it to ask observers who are directly involved in a situation to give concrete and factual reports on behaviours which can concern themselves or others that contributed to an outcome (Woolsey, 2011).

In the context of this study, CIT was applied to ask stakeholders directly involved with the implementation of the intervention (the installation of a FAIR-based system for patient data recording), to:

- Identify key moments that influenced the adoption and usability of the FAIR-compliant system.
- Elicit detailed narratives of barriers (e.g., infrastructural challenges) and facilitators (e.g., capacity-building initiatives) encountered during the project.
- Capture insights into the interplay between technical, organisational, and social factors affecting system implementation.

The integration of the FAIR principles and CIT provides a robust theoretical foundation for this study. While the FAIR principles establish the technical and operational objectives for data management, CIT serves as a methodological tool for capturing stakeholders' lived experiences. The combined application of these frameworks facilitates a comprehensive analysis, addressing both the intended outcomes and the practical challenges encountered during implementation.

The implementation of FAIR principles in healthcare data systems requires a robust understanding of the underlying system architecture, the context in which it operates, and the stakeholders involved. The FAIR principles serve as a foundational framework, aligning with the study objective to assess the feasibility of implementing a FAIR-compliant system. By establishing clear benchmarks for success, these

principles provide a structured approach to evaluating the system's effectiveness and compliance.

CIT is particularly suited to the exploratory nature of this research, as it captures context-specific insights that might not emerge through quantitative methods alone. By combining these frameworks, the study addresses the dual focus of the research question: understanding both the facilitators and barriers to FAIR-compliant data production in African healthcare systems.

Research design

The study adopts an explorative case study design.

Research team

The research team was organised in the Value-driven Ownership of Data and Accessibility Network-Africa (VODAN-Africa), formerly Virus Outbreak Network Africa (VODAN). VODAN Africa investigates the feasibility of FAIR and responsible cross-border digital health data production, access and use (Van Reisen, Stokmans, Basajja et al. 2020; Van Reisen, et al., 2022). Between 2019 and 2022, VODAN Africa developed its proof of concept and first Minimum Viable Product (MVP) for achieving this objective and deployed them in respective health facilities.

This study, which evaluates the perceptions on the deployment of the MVP by involved stakeholders, represents data from four countries: Ethiopia, Kenya, Nigeria and Uganda. These locations were selected from a larger group of countries in which the MVP was deployed. The overall MVP implementation comprised 88 health facilities in eight African countries: Uganda, Nigeria, Ethiopia, Kenya, Tanzania, Tunisia, Somalia, and Zimbabwe.

The four countries identified for the study were based on the following criteria:

- MVP was fully deployed in selected health facilities
- More than one health facility in the country participated in the study
- There was an active country coordinator throughout the study with insight in the entire process

- There was at least one active data steward throughout the study with insight in the entire process
- The data clerks who were responsible for the MVP could be reached.

The countries that were selected were Ethiopia, Kenya, Nigeria and Uganda. The study data consist of an evaluation of the deployment, conducted shortly after its implementation. Following the analysis of the evaluation data, in-depth interviews were conducted to further explore the findings in greater detail. Given the time lapse between the evaluation and the interviews, the latter also served as a means to assess how perceptions of critical incidents evolved over time.

Timeline

The overall research conducted on the deployment of the MVP took place from February 2021 to June 2023. The full deployment process included the following phases:

- Training and capacity-building
- Presentation of the MVP to Ministry/Bureaus of Health
- Identification of interested health facilities
- A survey on pre-implementation conditions in each site
- Technical deployment and instructions
- Assessment of problem and challenges
- Interviews to investigate post-implementation conditions

The timeline of these activities was as follows.

<u>February – June 2021</u>

- Training and information sessions. The deployment of the MVP included preparations in Uganda, Nigeria, Ethiopia, Kenya, Tanzania, Tunisia, Somalia, and Zimbabwe.

<u>January 2022 – August 2022</u>

- Survey administered to health staff in participating health facilities on the critical elements for adoption based on the Unified Theory of Acceptance and Use of Technology (UTAUT) methodology (Purnama Jati, et al., 2025)
- Data Use Agreement signed with the health facilities selected.
- Approach of Ministry/Bureau of Health for approval for the study.

May 2022 – December 2022

- Training and preparation of the data stewards for deployment.

September – October 2022

- Evaluation of the challenges encountered. The researchers created a feedback form to identify challenges from key areas including infrastructure status, system performance, and user experiences. March – May 2023

Semi-structured interviews were conducted by the researchers on critical incidents with the country coordinators and data stewards.

The data analysed in this study relate to the evaluation conducted from September – October 2022 and the semi-structured interviews, conducted from March – May 2023.

Participants

The participants of the study (the evaluation and the follow-up interviews) included:

- Data stewards: Individuals responsible for managing data entry and system operations at health facilities.
- Country coordinators: Project leads overseeing the implementation and support of VODAN-Africa systems at the country level.
- Data Clerks: Health facility staff responsible for data entry on the VODAN platform in the facility.

Participants were purposefully sampled based on their roles in the project and their ability to provide detailed insights into system implementation.

Data collection

The data collected for this study include the evaluation and the subsequent interviews.

Phase 1: Evaluation assessment

A structured questionnaire to assess problems with the deployment of the MVP was administered to data stewards in participating health facilities to evaluate the extent of technical challenges encountered. The questionnaire comprised 42 questions, targeting infrastructure

status, system performance, and user experiences. Participants were asked to provide detailed responses and supporting evidence, such as system screenshots and operational logs which could be studied by the technical team who were responsible for the deployment of the MVP.

Phase 2: Interviews

The data collection second phase involved 20 semi-structured interviews with country coordinators, data stewards, and data clerks. The participants were selected because they were closely involved in the training, deployment, and test of the MVP and had insights into the functioning of the MVP.

The interviews were conducted via Zoom. They lasted 45 to 60 minutes each. The content of the semi-structured interviews was structured through a topic list to explore whether barriers and facilitators were identified in the evaluation assessment of the deployment. The content of the semi-structured had open questions to explore whether participants identified critical incidents that were not anticipated before the deployment of the MVP in the survey that was conducted. Overall, the topic list focused on identifying critical incidents based on Flanagan (1954).

Data analysis

For the first phase, the questionnaire on the evaluation assessment, descriptive and content analysis was used for the analysis to identify patterns and issues. These were categorised into main barriers and obstacles, which were included as topics in the interview topic list.

For the second phase (interviews), thematic analysis was employed to identify patterns and themes across the collected data. The analysis followed Clarke and Braun's (2017) six-step process:

1. Familiarisation: Transcriptions of interviews were reviewed using Otter.ai and validated by replaying audio recordings for accuracy.
2. Generating initial codes: Data was systematically coded in NVivo 12 based on the research questions and emerging patterns.

3. Searching for themes: Codes were clustered into overarching themes representing facilitators and barriers to FAIR implementation.
4. Reviewing themes: The themes were cross validated against raw data and refined to ensure consistency.
5. Defining themes: Each theme was clearly defined, and sub-themes were identified where applicable.
6. Producing the report: Findings were synthesised into actionable insights, supported by anonymised direct quotes from participants.

To enhance the validity of the findings, data from the evaluation assessment and interviews were triangulated. Responses from the evaluation assessment were compared against interview insights to identify areas of convergence and divergence. Additionally, contextual data, such as country-specific infrastructural challenges, were identified and findings were discussed with the research leadership team, to arrive at a contextual relevant interpretation. This was particularly relevant to understanding the impact of the situations of war that emerged in Ethiopia.

Ethical and regulatory compliance

- Ethical approvals: the study is covered based on ethical approval.
- Data protection: all personal and sensitive data were anonymised during collection, analysis, and reporting to ensure participant confidentiality and compliance with local regulations.
- Informed consent: participants provided informed consent before participating in surveys and interviews, and were assured of their right to withdraw at any time.

Ethical and regulatory compliance is a recurring theme in the literature on digital health. The data handling did not include any personal data, but only consisted of data aggregates, already reported in existing District Health Information System 2 (DHIS2) reporting systems in the health facilities. The study followed the specifications and requirements reported by Van Reisen et al. (2021) and Amare et al. (2024), which emphasise the importance of data sovereignty, particularly in African contexts where health data governance frameworks often vary across countries. Ensuring that data remains

within national borders, complies with local regulations, and is stored where it is handled is critical for fostering trust and enabling the broader adoption of digital health technologies. This principle formed the basis for the study's data handling approach.

The MVP architecture

The MVP is based on a De Novo FAIRification architecture, also referred to as a FAIR architecture by design (Lin, 2025). The design was based on the Center for Expanded Data Annotation and Retrieval (CEDAR) metadata platform, which was re-engineered into locally run microservices (Amare et al., 2025).

A data entry application is installed in each health facility where data is generated. This enables a single entry of patient data, ensuring its availability in multiple formats for various purposes. The data is stored in AllegroGraph with semantic metadata, structured using a template based on VODANA Portal (OntoPortal-based) vocabulary (Aktau et al., 2025).

Additionally, the data supports multiple concurrent use cases, including an external dashboard that displays aggregated statistics from various locations and an internal dashboard for patient-level data. Furthermore, the system includes an export function for integration with other health information systems, such as DHIS2, as well as an AllegroGraph repository accessible via Query Language and Resource Description Framework (SPARQL) queries for advanced data retrieval and analysis. The architecture of the MVP is shown in Figure 1.

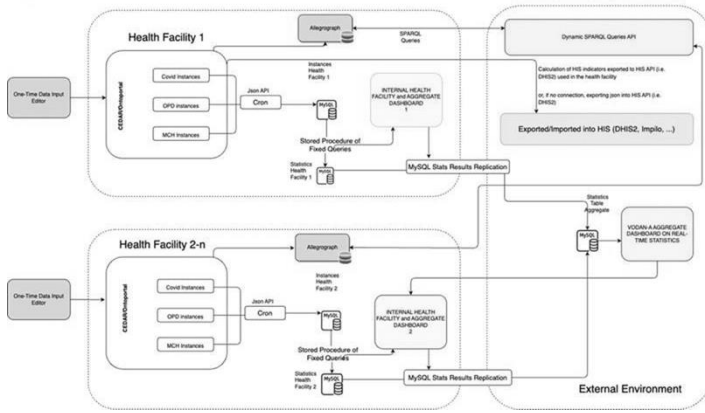

Figure 1. The VODAN MVP Architecture

Source: Van Reisen, et al., 2022

The architecture presents a federated setup, presenting insights from the data within each of the health facilities based on the data produced in the facility. The architecture also includes a dashboard with insights generated from across the community.

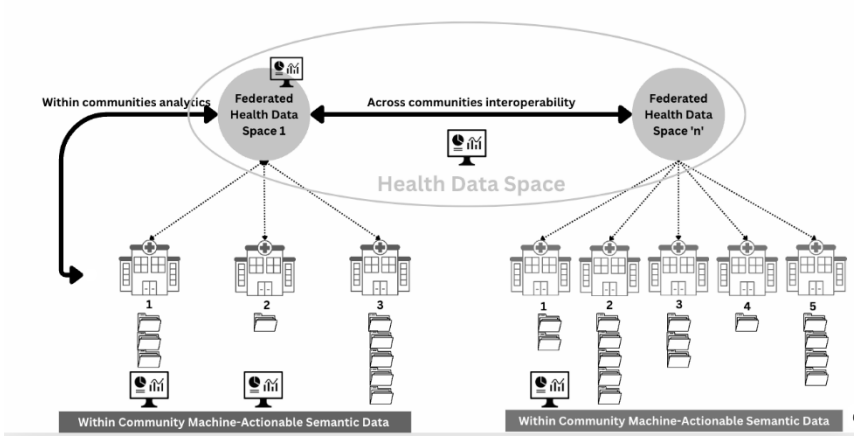

Figure 2. FAIR-OLR federated analysis and learning

The insights generated from across the community are aggregate data, which show trends on key indicators. The queries can generate real-time insights, as the algorithms can run across the repositories in real time.

The key architectural features include:

- Local data hosting: all health data generated within a country is stored locally to comply with data sovereignty requirements.
- Interoperable design: the system used standardised vocabularies and ontologies to facilitate seamless data sharing and integration.
- Privacy by design: security features such as encryption and role-based access control were embedded into the architecture to ensure data privacy and compliance with local regulations.

The deployment of the MVP was designed around the principles of FAIR-data with Ownership, Localisation, and Regulatory Framework (Van Reisen et al., 2023). The MVP architecture also integrated components for real-time data capture, analytics, and reporting, enabling healthcare providers to make informed decisions at the point of care.

Results

The results of the evaluation of the MVP are based on an assessment and follow-up interviews. The findings are organised into four main thematic areas: (1) infrastructural challenges, (2) system performance issues, (3) user interface and functionality, and (4) capacity building and communication support. Each section draws on both quantitative data based on the feedback form and qualitative interview insights to provide a comprehensive overview of the barriers and facilitators met during the implementation of the MVP.

Infrastructural challenges

Access to electricity

Many participants in several health facilities reported unreliable electricity and limited internet connectivity, which directly impacted system functionality. The result from the first assessment shows a significant challenge highlighted by the survey respondents relating to infrastructural issues, particularly the lack of adequate power supply and reliable internet access. The diagram below shows how many hours of uninterrupted electricity per day in the Facility.

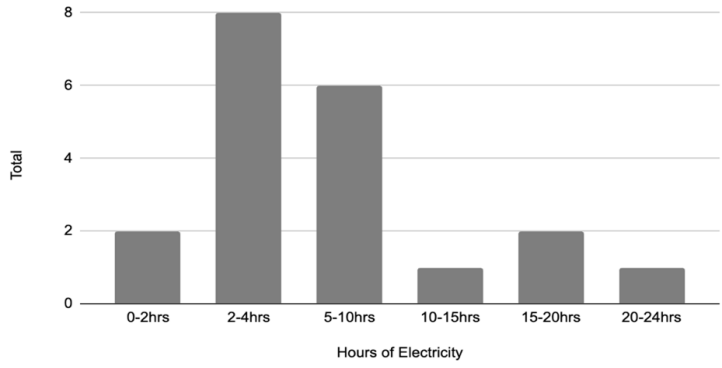

Figure 3. Hours of uninterrupted electricity per day in the facility

The diagram illustrates that electricity remains a significant challenge for most health facilities in operating the system. Specifically, eight health facilities have access to uninterrupted electricity for only 2 to 4 hours per day, while six facilities operate with uninterrupted electricity for 5 to 10 hours. Notably, only one health facility has continuous electricity availability for 20 to 24 hours.

Many regions face infrastructural challenges related to electricity shortages that disrupt data collection. One country coordinator (P1) described the situation, noting that an unstable power supply forced health facilities to revert to paper-based data collection before the digital entry:

> *Yeah, so there was a complete, I mean, a very difficult situation in regard to electricity and charging the computers. So, what we were doing was that first, they collect the data in papers and then it is after getting the data in papers that they were entering them into the platform. So yes, always we like electricity. Could be a challenge but, not in the sense that what happened in other countries, like in Nigeria or Uganda, where you have the VODAN MVP and he provided this VODAN MVP along with all accessories to the health facility, anywhere, collecting the data.* (Interviewee #KQOD89, March 23, 2023, online interview, Leiden, interviewed by Abdullahi A. Kawu)

Interestingly the participant explained how the MVP was still operational despite the challenge of electricity. The interviewee underscores the critical role of infrastructure - especially electricity and charging facilities to computers, in the successful deployment of digital health systems. The interviewee suggests that the lack of electricity hindered direct digital data entry, necessitating a hybrid approach (paper-based first, then digital). The comparison to Nigeria and Uganda implies that providing comprehensive solutions (such as power backups and necessary accessories) can improve system adoption and efficiency in low-resource settings.

Indicating that health facilities reverted to the solution of installing an uninterruptible power supply (UPS) to create greater reliability with regard to electricity availability, a data steward (P12) reported that while some facilities managed to partially address the electricity issue, these measures were only temporary:

> *To some certain degree. I would tell you in some of the facilities, the issues were resolved, but it was not a permanent resolution. It being all these health facilities rely on the national grid and the national grid in Nigeria, is epileptic. It is not for you to*

> *see electricity. It's actually a bit of a challenge. At some of these facilities. So, part of the systems that were deployed in the facility. We had a UPS but UPS cannot go above 30 minutes.* (Interviewee #VFID79, April 17, 2023, direct interview, Leiden, interviewed by Abdullahi A. Kawu)

Another data steward (P17) emphasised that regular power interruptions frequently led to complete internet shutdowns, critically hindering communication and operational efficiency:

> *There was a regular interruption with the electricity and the more severe one was that the Internet was completely shut down. A phone call was a complete shutdown so we can't we couldn't reach the data clerks by phone. If we have to reach them, even to call for training and we have to go to their office in person to the health facilities, and inform them and you can imagine how difficult it could be.* (Interviewee #TSMN15, April 29, 2024, online interview, Leiden, interviewed by Abdullahi A. Kawu)

These findings illustrate that unreliable electricity and resultant low internet connectivity not only complicate data collection and digital system implementation but also significantly weaken communication, thereby affecting the overall effectiveness of digital health initiatives.

Internet access

The diagram in Figure 4 presents the percentage of health facilities with internet access as part of the institutional setup. This further highlights the severity of the infrastructural limitations that impact system reliability. As seen from the result of the survey below, it was reported that only 5 out of the 20 health facilities report having some access to the Internet.

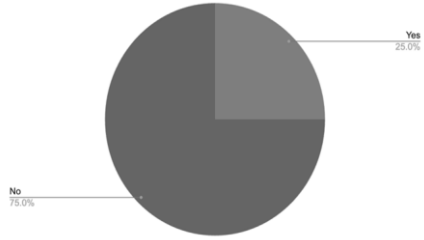

Figure 4. Percentage of the health facilities that had internet

The diagram illustrates that 75% of the 20 health facilities lack internet access, while only 25% have internet connectivity as part of their facility policy. Furthermore, respondents highlighted that the effectiveness of the MVP is significantly hindered by infrastructural

limitations, particularly the lack of a reliable power supply and internet service, both of which are somewhat essential for ensuring the system's functionality.

Internet connectivity is one of the major challenges faced by data clerks and professionals working in remote areas. Participants emphasised the difficulties in maintaining a stable internet connection, which significantly affected their work. One of the data stewards in the study (P17) stated that:

> *internet is always a problem in most of the places except the advanced countries where you always have access, because most of those places are remote areas so I can say if I was given one thousand dollars from maybe, I would like you to do this analysis for me, if I was given one thousand dollars from VODAN, I can tell you that I spent like 700 to 800 Dollar on internet connectivity because it's really bad I had to connect through my Wi-Fi through my hotspot and others, so it was really really bad and it goes together with electricity but electricity can be overcome easily for that of data you have to spend more money and you download a lot of things you install a lot of things and before you know you are out of data and everyone is tired because sometimes they also told me, are we going to use our data we are data clerks, you should provide everything for us so those are the kind of examples that was how I was able to resolve lots of them I connected with my own internet, and we were able to do some things from time to time.* (Interviewee #TSMN15, April 29, 2024, online interview, Leiden, interviewed by Abdullahi A. Kawu)

This statement highlights the significant financial burden and infrastructural limitations that professionals in low-resource settings face when accessing the Internet. The reliance on personal hotspots and costly data packages not only hinders efficiency but also creates barriers to data management and collaboration. Furthermore, while electricity challenges can sometimes be mitigated, the persistent lack of affordable and stable internet access remains a critical obstacle.

System performance issues

System's memory limitation

In our interview with the participants, they pointed out the issues of memory space. They face issues with data lost when the memory is down. The participants P9 states:

> *I think that this system doesn't have the, we will call him some temporary local memory, for storing data when the Internet goes down and when the system has run for some time, you realise that you cannot do entries on it again until you, you clear,*

the memory of the computer. (Interviewee #EBLT17, April 13, 2024, online interview, Leiden, interviewed by Abdullahi A. Kawu)

This observation indicates that the system lacks a buffering mechanism to temporarily store data during internet outages. With a current design that operates on a 16GB memory limit, the rapid consumption of available resources leads to system glitches and interruptions in data entry, thereby undermining data continuity and operational efficiency.

Documentation

In addition to memory limitations, participants highlighted the critical need for comprehensive documentation. The absence of centralised and accessible documentation was underscored by one participant (P9):

Also, the system doesn't have proper documentation where you can get your like these other systems have. Something called there's central user documentation. Then there's also a technical definition for developers so there for the VODAN and I have not been able to find these documents. It is something we just learned by looking at the system. (Interviewee #EBLT17, April 13, 2024, online interview, Leiden, interviewed by Abdullahi A. Kawu)

The lack of documentation creates barriers for both end-users and technical staff, hindering effective system utilisation and troubleshooting. Without clear user manuals and technical guidelines, users must rely on informal learning, which can delay the adoption of best practices and inhibit system scalability.

Speed

Another recurring issue raised by participants is the system's slow performance, particularly during startup. A data steward (P12) remarked:

This system actually goes slow, sometimes. It all depends on how the system starts up when the system starts open. A very good day after you. Wait like, 20, 20 minutes for it to boot. And discover I started you can impute record heat free for days, which the system is inconsistent. (Interviewee #VFID79, April 17, 2023, online interview, Leiden, interviewed by Abdullahi A. Kawu)

These delays not only frustrate users but also compromise timely data entry and system responsiveness. The slow boot times and overall inconsistency in performance show fundamental inefficiencies that

need to be addressed to ensure that the system meets the demands of data-intensive environments.

User interface and functionality

User interface

Participants consistently emphasised the need to improve the system's user interface. One participant (P12) remarked:

> *It has been a good system and it's coming out well, it's working progress. They need to work more on the user interface and should be friendlier than it is, but not right now. Right now, it doesn't have some of the Buttons, Links menus which are clearly not easy, or understandable, unless you are somebody who has worked with the system. So they need to make it more user-friendly.* (Interviewee #VFID79, April 17, 2023, direct interview, Leiden, interviewed by Abdullahi A. Kawu)

The respondent reflects a generally positive perception of the system's progress while also highlighting critical usability challenges that need to be addressed. The speaker acknowledges that the system is functional and evolving, describing it as "a good system" and "a work in progress". This suggests that the core components are operational but require further refinements. The main concern is the user interface, which is described as not user-friendly in its current state. Specific issues include buttons, links, and menus that are difficult to navigate or understand.

The interviewee also suggests that using the system requires a steep learning curve, where only users familiar with the system can effectively operate it. The respondent emphasises the necessity of making the system more intuitive and user-friendly for a broader range of users. The underlying concern is that poor user interface design hinders adoption and usability, particularly for new users.

The essence of what the interviewee states highlights a usability gap that could impact the system's effectiveness and adoption. While the system is progressing, improvements in interface design, navigation, and accessibility are necessary to enhance its user experience and inclusivity. The feedback suggests a need for user interface optimisation to ensure that users, even those unfamiliar with the system, can navigate it easily and efficiently.

This observation indicates that while the system shows promise, its current interface poses usability challenges that may delay adoption among new users.

Modules

In addition to the interface, several participants suggested the incorporation of additional modules to enhance system functionality. For example, one participant (P12) stated:

> *There should be some additional modules, like the module for patient contacts, As you're able to see (..) there's an option of putting the patient contact details such that when you share the visit can remind a patient through text messages through email automatically that the patient is said you (came) for a visit or something like that. So they VODAN are supposed to implement such things.* (Interviewee #VFID79, April 17, 2023, online interview, Leiden, interviewed by Abdullahi A. Kawu)

This recommendation highlights the potential benefits of expanding system capabilities to include features that support proactive patient engagement and communication.

Ease of use

The ease of use of the system remains a critical objective for the VODAN project. Many participants expressed a desire for an intuitive system that facilitates efficient data entry. One participant (P8) commented:

> *As a facility, they want the system to be easy and even the health department technologies want to see the report on this because they are collecting the data from each department, if the system is upgraded and can collect the data from individual level. The facility can use the data for decision making.* (Interviewee # TFTT76, March 30, 2023, online interview, Leiden, interviewed by Abdullahi A. Kawu)

The interviewee highlights the need for an improved, user-friendly system that enhances data collection, reporting, and decision-making at the facility level. The principal issues raised by the respondent is the desire for greater system usability. The MVP is too complex and not well integrated into existing workflows.

The health facility's team wants access to reports generated from the collected data. This underscores the requirement underlying the MVP that real-time or structured reporting capabilities are essential for the health facility. The respondent also suggests that if the system is

upgraded to collect data at the individual level, the facility could use this data for informed decision-making, as the data become more relevant to decision-making support for patient care.

This indicates a gap in the system's current functionality, where aggregated data collection is prioritised over patient-level data that supports patient care. Individual-level data collection would enhance precision in health interventions, resource allocation, and policy planning.

The respondent's comments underscore the need for a more user-friendly system to improve adoption and efficiency. The interviewee also points to the need for better data integration and reporting functionalities for the health department's oversight. There is a need for enhancements in individual-level data collection to enable evidence-based decision-making at the facility level.

The interviewee reflects a broader demand for system upgrades that prioritise usability, interoperability, and data-driven decision-making in healthcare management. Such feedback highlights that streamlining user interaction is essential for improving data collection processes and enhancing overall decision-making.

Capacity building

Capacity building through training and technical support also emerged as a crucial theme. One data steward (DS17) reflected on the positive impact of training provided by the VODAN research team:

> *I think VODAN actually helped me because sometimes I browse and say, what is the meaning of all these codes sometimes I check the terminals, I check what a virtual box actually entails even if I know what a virtual box is, I say okay what and what can it do what are the major things that the VirtualBox can do, so I had a lot of training on VirtualBox. I really benefited from the Ubuntu Linux operating system and I also learned how to work with a medical facility based on some ontologies and some vocabularies, yeah so it was okay. I've increased and I know yes I can do something on it now even if I didn't know it before.* (Interviewee #TSMN15, April 29, 2024, online interview, Leiden, interviewed by Abdullahi A. Kawu)

In this quote, the data steward mentioned training on technical skills received from working with the VODAN-Africa MVP system. The quote reflects personal learning and skill development gained through

the VODAN project, particularly in technical and medical informatics domains. The interviewee highlights several key areas of growth:

(i) Technical knowledge enhancement: the interviewee gained a deeper understanding of coding systems and technical terminologies; the interviewee explored the functionalities of a VirtualBox, beyond basic familiarity, to understand its broader applications; the interviewee benefited from training on Ubuntu Linux, which improved their ability to work within a Linux-based environment.

(ii) Application in medical informatics: the interviewee learned how to engage with healthcare facilities using ontologies and controlled vocabularies relevant to medical data management.

(iii) Increased confidence and capability: the interviewee expresses a sense of progress and achievement, noting that they can now perform tasks that were previously unfamiliar.

The interviewee underscored the impact of the VODAN MVP implementation in building technical expertise, bridging the gap between technology and healthcare, and empowering individuals with new digital skills essential for handling medical data effectively.

Country coordinators also highlighted the benefits of targeted training. One coordinator mentioned:

> *We assist to the training, we access to the training on how to create the templates with K(..) on CEDAR.* (Interviewee #KQOD89, March 23, 2023, online interview, Leiden, interviewed by Abdullahi A. Kawu, name anonymised)

'K' [anonymised name] introduced CEDAR to the MVP implementation team; he was a trainer who helped data stewards understand semantic data and machine-actionable FAIR data. This training was important for data stewards to understand the underlying foundational logic of what the MVP was aiming to introduce.

Moreover, comprehensive support extended to medical doctors. As one coordinator (P3) explained:

> *…The doctors in Nigeria, particularly we have supported them, we have given them a lot of support in terms of the technical know-how, what they need to do, how do you need to do it. Particularly we have organised. a workshop, we've had meetings with them where we can enhance their skill sets, particularly as regards the VODAN project and we have been able to do so also tactically. Mobilise them in*

> *terms of, mobile data so that they can input records into our dashboard in the VODAN project.* (Interviewee #KRMY66, April 27, 2023, online interview, Leiden, interviewed by Abdullahi A. Kawu)

The quote highlights capacity-building efforts and strategic support provided to doctors in Nigeria, particularly within the context of the VODAN project. The support primarily focused on technical skill development, ensuring that medical professionals acquired the necessary expertise to effectively engage with the system. Key elements of this support included:

- Training and workshops: sessions to enhance doctors' technical competencies related to the VODAN project.
- Guidance on implementation: detailed instructions on what needs to be done and how to do it, ensuring proper system use.
- Tactical support: assistance in mobilising resources, particularly mobile data, to enable doctors to input patient records into the VODAN dashboard effectively.

The participant underscores a structured and proactive approach to training and resource allocation, ensuring that Nigerian doctors could successfully engage with the MVP system while overcoming connectivity and infrastructure challenges.

The participants were asked to rate the level of support given to them in the range of 1 being the lowest and 10 being the highest. Most of them rate it above 5. For instance, Data steward, Participant 2 (P2) mentioned that:

> *..If I am allowed to use a range of 1 to 10, 1 as one being the lowest and 10 being the highest I would say the support is around seven, a strong seven…* (Interviewee #TSMN15, April 29, 2023, online interview, Leiden, interviewed by Abdullahi A. Kawu)

One participant indicated the constraints resulting from resource issues:

> *… because we couldn't receive the funds for training for providing orientation because of the complicity and blackout of the banks. So, we were trying our best like, to use the existing system in the health facilities instead of identifying six people or six health professionals in the facility or health system. Health information system experts can take care of these six roles like privacy officer technical development or quality or access permission. So rather, we were supporting them like the technical expertise, taking these roles and in the health facility, if we get, if there is one health information technician, we work with this one existing health technician instead of*

looking for six people who can take care all these roles. (Interviewee #TSMN15, April 29, 2024, online interview, Leiden, interviewed by Abdullahi A. Kawu)

The interviewee reflected on taking a pragmatic approach to resource constraints in health facilities by optimising existing personnel rather than recruiting multiple specialists. Instead of identifying six distinct professionals to handle various roles—such as privacy officer, technical development, quality assurance, and access permissions—the approach focuses on leveraging a single health information technician within the facility.

The technical support team provided external expertise to cover these roles, reducing the burden on health facilities while ensuring that essential functions are still maintained. This adaptive strategy acknowledges the limited availability of specialised personnel and promotes efficiency and sustainability by integrating external technical support with existing health facility staff.

Overall, the interviewee highlighted a resource-conscious, capacity-building approach that enhances health information system implementation without overwhelming local institutions.

This interviewee pointed out that challenges remain, particularly regarding funding for training, which sometimes forces facilities to rely on a single technician to fulfil multiple roles. This points to a situation that underscores the need for increased investment in training and support.

Communication support

Effective communication among stakeholders was another recurring theme. Participants described the establishment of direct communication channels between country coordinators and data stewards. For instance, one participant (P2) observed:

…there was a very good direct channel of communication between the country coordinators and the data stewards… the participant further stated that: we select the 10 health facilities and deployed that we, we made sure that we received their consent and they signed the contract agreement for the testing phase that we have done so far. So they are very supportive.... So, that indicates that there was transparency between the coordinators and the data stewards. (Interviewee #URNE42, March 17, 2023, online interview, Leiden, interviewed by Abdullahi A. Kawu)

The quote highlights the effective communication and transparency between country coordinators and data stewards in the deployment process. It suggests that there was a well-established, direct communication channel between these stakeholders, facilitating smooth collaboration. The participant emphasised that during the selection and deployment of the health facilities, informed consent was obtained, and formal agreements were signed, ensuring all parties were aware of and supported the testing phase. This structured approach reflected trust, cooperation, and accountability, reinforcing the notion that the process was conducted transparently and with mutual understanding. The interviewee underscored the importance of transparency and stakeholder engagement in successful system implementation, particularly in contexts involving data management and institutional coordination.

In our interview with one of the country coordinators, Participant five (P5), P5 mentioned that:

> *Very importantly, also, the data clerks have formed another step of communication, that makes it easy for us in Nigeria to have a good communication regime. Or what we call a new communication approach where the data clerk is to answer directly to the data steward, which in turn gets back to the country coordinator….* (Interviewee #XZPQ87, April 12, 2023, online interview, Leiden, interviewed by Abdullahi A. Kawu)

The interviewee highlights the establishment of a structured communication framework within the data management process in Nigeria. It emphasises how the role of data clerks has evolved to create a more efficient communication system by introducing a clear reporting hierarchy. The data clerks play a crucial role in facilitating communication between different levels of data management.

This structured approach is referred to as a "new communication approach", suggesting an improvement over previous, less coordinated methods. Data clerks report directly to the data steward, ensuring that data-related issues are addressed efficiently. The data steward then relays relevant information to the country coordinator, ensuring central oversight and strategic decision-making.

This clear chain of communication helps streamline data management, reducing misunderstandings and ensuring that information flows efficiently. The reference to a 'good

communication regime' implies that this structured approach fosters accountability and responsiveness in data handling. The interviewee emphasises the importance of vertical and direct communication structures in data governance and coordination, particularly within health data management systems. By creating direct communication pathways, this approach enhances efficiency, accountability, and collaboration among the stakeholders involved. The interviewee underscores that a well-structured communication framework is essential for ensuring transparency, coordination, and effective problem-solving across all levels of system implementation.

Discussion

The findings of this study reveal both the opportunities and persistent challenges in implementing the cross-border, federated patient data system in low-resource healthcare environments within the FAIR-based MVP installation. This discussion examines the strengths of the results, their alignment with existing literature, and their implications for advancing FAIR-compliant health systems in resource-constrained settings.

Respondents provided several suggestions for improvement, focusing on system deployment capabilities, internet accessibility, and functional updates to the application. Some respondents recommended enabling system deployment on local servers to mitigate challenges related to internet connectivity, while others advocated for the provision of internet infrastructure to facilitate seamless data synchronisation. Additionally, there was a clear emphasis on enhancing user experience, with suggestions for implementing a single sign-on (SSO) system and refining the interface to improve overall usability.

The suggestions bear witness to the keen interest of participants. The participants reported that they were learning from the introduction of new modalities and showed eagerness to understand the logic and implementation ideas of the innovation. They also engaged in training colleagues, facilitating the doctors in the health facilities, and offering solutions. The engagement in critical reflection demonstrates a real eagerness to engage and see how, in the given context and circumstances, the MVP could be made to work better.

The perceived benefits of the MVP system among the respondents are aligned with the core objectives of digital health systems. Improvements in the accuracy and quality of data reporting, automation of patient data records, and enhancements in patient data collection and reporting were cited as significant advantages of using the MVP system. These benefits highlight the potential of digital health systems to transform healthcare delivery and data management, provided the infrastructural and usability challenges are adequately addressed.

The survey's findings underscore the critical need for stakeholders, including healthcare providers, system developers, and policymakers, to address the highlighted challenges to maximise the benefits of digital health systems like the FAIR-based MVP. It is critical to address infrastructural challenges such as power and internet access through alternative power solutions (e.g., solar power systems) and more reliable internet service provisions could significantly enhance the system's usability and effectiveness. Also, use of paper and digital approaches, may be helpful in resource-challenged environments (Moreover, continuous improvement in the MVP system's deployment, functionality, and user support is essential to meet the users' needs efficiently and leverage the system's full potential.

The deployment of the MVP system in healthcare facilities presents a promising opportunity for improving healthcare delivery and data management. However, the optimisation of its full potential is dependent on how to overcome the infrastructural challenges and the continuous process of improving the system's usability and functionality. Stakeholders must collaborate to address these challenges, ensuring that digital health systems can effectively support healthcare providers and ultimately improve patient care.

Capacity building has also facilitated the availability of data within the pipeline. In contrast, a lack of intrinsic motivation, a lack of sufficient electricity and internet connection, and a lack of a mechanism to evaluate data quality timeliness appear to be common barriers that affect the data production in the studied MVP digital health system. For the next phase, our findings indicate that opportunities for enhancing quality data production have been leveraged, including users' existing technology orientation and organisational policies.

Limitations of the study

While the study successfully identified critical insights, it was constrained by limited access to study participants in some regions, due to unreliable internet and electricity. Future research may benefit from expanded participant pools and broader regional representation.

While the findings provide valuable insights, the study has certain limitations:

- Geographical scope: the study focuses on four countries, which may not fully capture the diversity of challenges and opportunities across the African continent.
- Sample size: although the study included 20 stakeholders, a larger sample may have provided a more comprehensive understanding of the barriers and facilitators.
- Time constraints: the limited timeframe of the study may have constrained the depth of analysis, particularly for longitudinal trends in system adoption.

Strength of the results

The study demonstrates that the MVP, established based on FAIR guidelines, has the potential to transform health data management in African healthcare facilities through its adherence to FAIR principles. Key strengths include:

- Enhanced data accuracy and usability: stakeholders consistently reported improvements in the quality and reliability of health data collected, a core objective of FAIR-compliant systems.
- Effective capacity building: training programs were well-received, with most participants rating their effectiveness as above average. This highlights the importance of investing in technical skill development to ensure the successful adoption of digital health systems.
- Scalable insights: the study provides actionable recommendations, such as deploying local servers and integrating new modules, which could inform the implementation of FAIR-compliant systems in other low-resource settings.

However, the results also underscore critical challenges, particularly related to infrastructure, system design, and user support. These

findings point to the need for multi-faceted strategies that address both technical and human factors.

Relation to existing literature

This study contributes to the literature in that it provides empirical insights into the barriers and facilitators of FAIR-compliant health data systems in African contexts. It highlights the importance of infrastructure, capacity building, and stakeholder collaboration in achieving successful implementation. The study offers actionable recommendations for scaling FAIR-compliant systems in similar low-resource settings.

The findings align with and expand upon key themes in the literature on FAIR principles and digital health systems.

Infrastructure challenges

The findings of Van Reisen et al. (2022) highlight that infrastructural deficiencies are among the most significant barriers to the adoption of digital health technologies in African contexts. Consistent with this work, this study highlights the significant impact of unreliable electricity and internet access on the functionality of digital health systems in Africa. The study reaffirms the importance of addressing these infrastructural barriers through investments in alternative power solutions and improved connectivity. Several studies underscore the importance of reliable infrastructure—such as electricity and internet connectivity—for the successful deployment of digital health systems (Chukwu et al., 2022).

Capacity building

The importance of training programs aligns with findings from Aktau (2020) who found that training was essential for the adoption of FAIR-based health data integration. The findings also align with Thompson et al. (2020), who emphasise that capacity building is essential for ensuring the sustainability of digital health innovations. The findings confirm the results of the FAIR-based implementation study by Zhang (2022) on rare diseases data, which highlights that a dedicated team of FAIR data stewards is essential for harmonising the processes of making data FAIR in large organisations with multiple stakeholders. The study also emphasises the need for multi-level training of the teams to address diverse requirements and

suggests that insights from the FAIRification steward team's experience can enhance FAIR awareness and provide solutions to FAIRification challenges.

The positive feedback from stakeholders following their engagement in capacity building, reinforces the understanding that capacity building is essential for the introduction of FAIR-based initiatives in health. Prior research by Thompson et al. (2020) shows that technical training and stakeholder engagement are pivotal to improving the adoption and utilisation of digital health platforms. The findings regarding the relevance of training data stewards and healthcare professionals align with these findings, addressing the need for technical and operational expertise in managing FAIR-compliant systems. Capacity building is critical for ensuring the sustainability of FAIR digital health systems.

System design and usability

The study corroborates Holub et al. (2018), who emphasise the importance of user-centred design in FAIR-compliant health systems. Stakeholders' suggestions for enhanced user interfaces and additional modules echo broader calls in the literature for systems that are both functional and user-friendly.

Data sovereignty and privacy

The study supports the findings of Van Reisen et al. (2021), which emphasise the importance of data sovereignty in Africa. Van Reisen proposes Ownership of data (handling), Localisation of Data repositing, and Regulatory Compliance with the jurisdiction as essential additional guidelines of the FAIR principles, referred to as FAIR-OLR (Van Reisen et al., 2023). By ensuring that health data remains within national borders and complies with local regulations, the VODAN-Africa project addresses key ethical and regulatory concerns and proves cross-border data insights are possible when the system complies with FAIR-OLR criteria.

Implications for practice

The results suggest several practical steps for improving the implementation of FAIR principles in African healthcare:

- Infrastructure investments: provide health facilities with alternative power solutions, such as solar energy, and reliable internet connectivity is critical for ensuring system functionality.
- Enhanced system design: address issues such as temporary local memory, startup times, and documentation gaps would improve system usability and user satisfaction.
- Expanded capacity building: provide ongoing training and support programs which are tailored to the needs of data stewards and healthcare providers, ensuring they have the skills necessary to effectively use the system.
- Stakeholder collaboration: reinforce interaction with policymakers, system developers, and healthcare providers must work together to address the multifaceted challenges identified in this study.

Future directions

Building on these findings, future research should explore:

- the long-term impact of infrastructure improvements on system adoption and functionality.
- strategies for enhancing system interoperability with other health information systems, such as DHIS2 or Kenya Health Information System (KHIS).
- the role of government policies and international collaborations in supporting FAIR-OLR compliant health systems.

This will have the potential to advance privacy preserving and secure cross border patient data sharing. This study contributes to identifying future directions on how cross border patient data sharing may be fostered.

Conclusion

Research on cross-border data flows is essential due to ideological leanings that shape existing studies, reflecting specific interests and policy priorities. Research on the development implications of cross-

border data flows remains limited, constraining policymakers' ability to formulate strategies that balance economic opportunities with data sovereignty concerns. A mixed-methods study addressing cross-border patient data management through a FAIR-based federated system highlighted opportunities of and barriers to implementation in low-resource healthcare environments. The study employed a survey of data stewards to assess technical challenges and interviews with 20 stakeholders from four countries to explore the facilitators and barriers to data production.

The major barriers to cross-border federated data systems included infrastructural deficiencies, system limitations, and resource constraints. Infrastructure challenges such as unreliable electricity and internet connectivity significantly delayed system deployment and usability. System limitations - including the absence of temporary local data storage, sluggish performance, and inadequate user documentation, hindered efficient data management. Additionally, resource constraints forced reliance on personal resources such as mobile data, underscoring the need for improved operational funding and institutional support.

Despite these challenges, several facilitators contributed to the system's success. Capacity building through structured training initiatives effectively equipped data stewards and healthcare workers with the technical skills necessary for system adoption and use. Moreover, collaborative support within a community of practice - particularly through robust communication channels between country coordinators and stakeholders, enhanced transparency and expedited system troubleshooting and engagement by multidisciplinary teams.

The study concludes that while the FAIR-based patient data recording system demonstrates significant potential in health data management, its success is contingent on addressing key infrastructural and operational challenges. Investments in alternative power solutions, reliable internet connectivity, and user-friendly system design are essential for realising the full benefits of FAIR-compliant systems in resource-constrained settings.

The findings reinforce the importance of sustained capacity building, stakeholder collaboration, and context-specific adaptations of the FAIR principles. A multifaceted approach that integrates technical, infrastructural, and human-centred solutions is necessary to overcome implementation barriers and advance FAIR-based digital health initiatives in Africa.

The FAIR-based patient data recording system offers a valuable model for implementing FAIR-compliant systems for interoperability in the health domain in low-resource environments. The findings reinforced the importance of sustained capacity building, stakeholder collaboration, and context-specific adaptations of the FAIR principles.

Acknowledgements

This work was conducted as part of the PhD internship of the first author, with the financial support of the Research Ireland Centre for Research Training in Digitally-Enhanced Reality (d-real) under Grant No. 18/CRT/6224 and at the ADAPT Research Centre for AI-Driven Digital Content Technology under Grant No. 13/RC/2106_P2 at Technological University Dublin. For Open Access, the author has applied a CC BY public copyright licence to any Author Accepted Manuscript version arising from this submission.

The study was jointly conducted by Abdullahi Abubakar Kawu and Putu Hadi Purnama Jati, both in the framework of their PhD studies and they are both first authors.

Author's Contributions

Abdullahi Abubakar Kawu and **Putu Hadi Purnama Jati** conceptualised the research and carried it out together. **Lars Schrijver** assisted as a research assistant. **Mirjam van Reisen** assisted in the supervision of the research and provided overview over the write-up. **Getu Tadele** assisted in the technical implementation. **Dympna O'Sullivan** and **Lucy Hederman** provided supervision on the theoretical framework.

Ethical Considerations

Tilburg University, Research Ethics and Data Management Committee of Tilburg School of Humanities and Digital Sciences REDC#2020/013, June 1, 2020-May 31, 2024, on Social Dynamics of Digital Innovation in remote non-western communities. Uganda National Council for Science and Technology, Reference IS18ES, July 23, 2019-July 23, 2023.

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