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

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Chapter 3

Information Streams in VODAN-Africa Health Facilities: The Case of Uganda

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Abstract

In this chapter, we discuss the current challenges of health data management in Uganda, the limitations of paper-based systems, and the potential role of FAIR architecture in improving data accessibility and reuse. Amid the prevailing COVID-19 pandemic, the lack of digitally recorded and interconnected health data presents significant challenges for effective analysis. Virus outbreaks, such as the current pandemic, highlight the potential for optimizing and reusing data to enhance the management of future outbreaks. However, there is a general lack of knowledge about the actual flow of information in health facilities, which is also the case in Uganda. In Uganda, where this case study was conducted, comprehensive knowledge is lacking about the types of data collected and the methods used to collect it throughout a patient's journey in a health facility. This study investigates information flows of clinical patient data in health facilities in Uganda. The findings revealed that nearly all health facilities in Uganda store patient information in paper files, typically organized on shelves. Hospitals in Uganda rely on paper-based tools, including reporting forms, registers, and manuals, to collect district data in aggregate form, which are then submitted as digital reports to the Ministry of Health Resource Centre. These reporting forms are not digitised and are therefore not machine-actionable. Hence, it is not easy for health facilities, researchers, and others to find and access patient and research data. Additionally, reusing and integrating these data with global digital health datasets is difficult, often leading to the erroneous perception that health data in Uganda are scarce. Implementing a FAIR architecture offers the potential to address these challenges and support the transition from paper-based to digital records within Uganda's healthcare system.

Keywords: Data management, Information flow, FAIR principles, Hospital information system(HIS), Electronic medical record (EMR), Electronic health record (EHR), Patient health record (PHR)

3.1 Introduction

The crucial role of rapid data sharing in accurately diagnosing Coronavirus 2 (SARS-CoV-2), the causative agent of the ongoing new coronavirus disease (COVID-19) pandemic, has been underscored [57]. In response, the World Health Organization (WHO) called for global scientific cooperation and equitable sharing of knowledge, data, and intellectual property [58]. WHO's initiative to ensure that all COVID-19-related data is available immediately and is accessible with proper attribution is noteworthy [57]. Virus outbreaks such as the COVID-19 pandemic have made it necessary to optimize and reuse data so that future outbreaks can be effectively managed. However, there are persistent challenges in accessing and making data interoperable and reusable. This is demonstrated by the difficulties that have been encountered with data from past epidemics, such as Ebola [59].

The healthcare system in Uganda embodies a dynamic partnership between public healthcare and private healthcare providers, with the Ministry of Health serving as the authority [60]. The National Policy on Public-Private Partnerships in Health has formalized this collaboration. Various types of healthcare providers exist within the private sector. They are categorized into private-not-for-profit health providers (PNFPs), private health practitioners (PHPs), and traditional and complementary medicine practitioners (TCMPs). This categorization includes non-governmental and faith-based organizations, such as the Uganda Catholic Medical Bureau, Uganda Protestant Medical Bureau, Uganda Orthodox Medical Bureau, and Uganda Muslim Medical Bureau [60]. Beyond these recognized categories, there is an informal health sector, comprising individuals with limited or no formal health training engaged in treating patients and selling drugs in small pharmacy stores. Recognition within the private health sector requires registration with relevant regulatory bodies and obtaining the necessary licenses. Oversight is provided by entities such as the Uganda Medical and Dental Practitioners Council, Uganda Nurses and Midwives Council, Allied Health Professionals Council, and Pharmacy Council [17].

The Ugandan healthcare system functions across five distinct levels, each assigned a specific function (see figure 3.1). At the community or village level, the facilities of the Health Center I (HC I) and the Village Health Teams (VHTs) play an important role. Moving up, the parish and sub-county levels are served by HC II facilities (often referred to as dispensaries) and HC III facilities, respectively. HC IV facilities and general hospitals are located at the county or district level, while regional referral hospitals (RRHs) and national referral hospitals operate at the regional and national levels, respectively. In particular, HC I to HC IV facilities fall under the jurisdiction of the local government, while regional referral and national referral hospitals maintain a semi-autonomous status [145].

In this chapter, the intricate details of information flow within health facilities in Uganda were delved into. The practices and tools used to manage the data within these facilities were explored through interviews conducted in prominent health facilities, including Lira Regional Referral Hospital, Case Clinic Hospital, and Kampala International University Teaching Hospital. Furthermore, data flow from health facility levels to the national Health Management Information System (HMIS) was analyzed. As these as-

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pects were studied, the insights of the current literature were integrated. This provided a comprehensive understanding of the challenges and opportunities in healthcare data management within Uganda’s healthcare system.

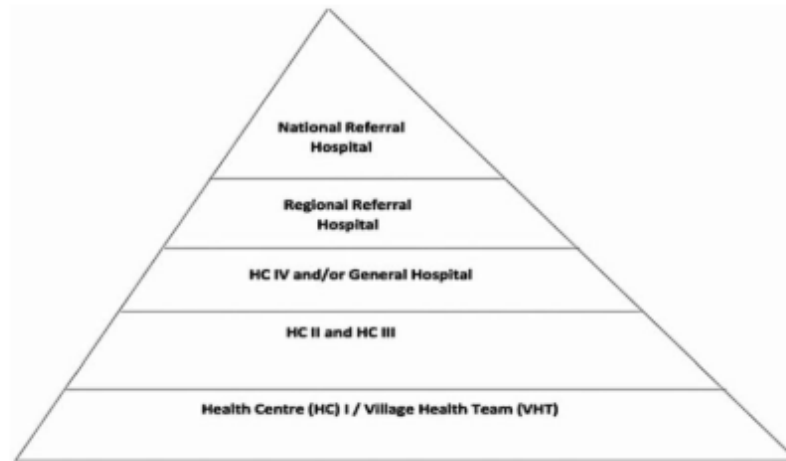


Figure 3.1: Pyramid diagram depicting the hierarchical levels of the Uganda’s Healthcare system including community health services, health centres, general hospitals, regional hospitals and national referral hospitals

Uganda’s healthcare system operates on the District Health System, a referral system that uses community-based services as the first point of delivery for primary healthcare. In this context, primary healthcare includes preventive, curative, and health promotion programmes. The District Health System [61]. In Uganda, VHTs, also known as community health workers, are the first point of contact between community members and the healthcare system. VHTs then refer patients to parish and sub-county-level health units (HC I and II), respectively. These lower-level health workers can then refer patients for more specialised treatment to the HC IVs and general hospitals at the county and district level, respectively [62]. However, the rapid proliferation of political units (parishes, sub-counties, counties, and districts) has resulted in some areas lacking corresponding health facilities. For example, if the parish does not have an HC II, patients are referred to the next level of healthcare, e.g., an HC III.

Adding another layer to the context, Uganda boasts a total of 6,937 health facilities, encompassing public, private, and not-for-profit entities. Government-owned facilities constitute 45.16% (3,133), Private and Not for Profit (PNFP) establishments make up 14.44% (1,002), and Private for Profit (PFP) facilities contribute 40.29% (2,795), with a minimal 0.10% (7) representing community-owned facilities. Notably, Government and PNFPs predominantly operate higher levels of health facilities, while Private For-Profit establishments are primarily involved in lower levels, such as HC IIs and clinics.

Even though the adoption of the District Health Information Software (DHIS) 2 as part of Uganda’s core Health Management Information System (HMIS) has facilitated the transition from paper-based reporting and storage to an electronic web-based system,



Figure 3.2: Piechart illustrating the distribution of Health Facilities in Uganda by ownership category including government-owned, private not-for-profit, private for-profit and community owned facilities

most of the reporting tools at the lower-level health facilities are still paper-based [64, 65]. Some of the data captured on the paper-based HMIS forms are not incorporated in the online DHIS2. This exacerbates the general lack of knowledge of the actual flow of information in health facilities in Uganda. Additionally, records personnel are often tasked with collecting and capturing information that exists outside the paper-based system. This labor-intensive process, requiring double entry of HMIS data into both the online DHIS2 platform and paper-based versions, is not unique to Uganda and significantly demotivates health personnel [309]. Furthermore, such data offers little value for data analytics at the point of care. The burden of data entry is, therefore, of no benefit to the health facility that produces the data [290].

A noteworthy challenge lies in the tedious and time-consuming data entry process, where records personnel are tasked with collecting and capturing information that exists solely in paper-based form. This cumbersome double-entry process, both on the online DHIS 2 platform and in paper-based versions, proves demotivating to health personnel [273, 64]. Moreover, the observed data entry practices often fall short in delivering tangible benefits to the originating health facility, particularly in terms of facilitating data analytics at the point of care.

To understand the actual flow of health information in Uganda's Health Management Information System (what data is collected, how it is stored, transferred and accessed in hospitals and/or clinics in Uganda), interviews were conducted at three major health facilities: Lira Regional Referral Hospital (LRRH) (Lira District, Northern Uganda), which is a public health facility; Case Clinic Hospital (Kampala District, Central Uganda), which is a private health facility; and Kampala International University Teaching Hospital

Research Question and Objectives

(KIU-TH) (Bushenyi District, Western Uganda), which is also a private health facility. LRRH is the only regional referral facility in the sub-region offering both specialised clinical care, including care for HIV/AIDS, and general clinical services. The hospital is a free hospital serving numerous districts (all eight districts in the Lango sub-region in Northern Uganda).

The overall goal of this study was to understand the data management practices and information systems used at selected healthcare facilities (hospitals/clinics) in Uganda. Emphasis was put on documenting the tools used and data collected at every step along the patient's journey/care timeline (e.g., registration → history and physical examination → laboratory testing → diagnosis → prescription), discovering ways to transform the data into FAIR data and establish a FAIR Data Point. This study specifically looked at whether the data is digitised and what tools are used to capture patient data at every point in the data flow, from the health facility level to the national HMIS level.

3.2 Research Question and Objectives

To evaluate the general flow of information within Ugandan health facilities and examine the potential for implementing FAIR Guidelines in the country's e-health sector, the following research questions and sub-research questions are proposed.

Research Questions

Main Research Question: What are the current data management practices and information systems employed in Uganda?

Sub-Research Questions:

Sub-Research Question 1:

How does the ideal state health information management in Uganda compare to its actual implementation in various healthcare facilities?

Sub-Research Question 2:

What perspectives and experiences do different stakeholders hold regarding Uganda's healthcare information management system?

Sub-Research Question 3:

How do health information management practices differ among various types of healthcare facilities in Uganda?

The objectives of this study are as follows:

To document the data management processes in selected Ugandan health facilities and evaluate the findability, accessibility, interoperability, and reusability (FAIR) of the collected data.

To assess the readiness of Uganda's current health data management system for implementing FAIR principles, specifically examining whether data are digitized

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and the tools used to capture patient information at each point in the data flow from health facilities to the national HMIS level.

To evaluate the feasibility of mapping the HMIS reporting forms used in Ugandan health facilities to machine-readable formats (RDF), enabling the creation of machine-actionable (FAIR) digital objects. Additionally, to explore the potential for developing user-friendly, web-based data input forms that support FAIR data and interoperability.

3.3 Methods and Materials

In this section, we present the study design and sampling procedure of the research.

3.3.1 Study Design

This study employs qualitative data collection methods, including observations and interviews, to understand and document the flow of information and data management practices. The study was conducted at three health facilities located in different regions of Uganda. Observation provided context and an understanding of how patient information flows play out in the health facilities. Face-to-face and follow-up interviews were conducted to investigate the underlying meaning behind the observed events. These interviews provided insights into the motivations, preferences, and events that shaped current behaviors and practices. The interviews were held in English and followed a semi-structured format using a questionnaire (see Supplementary Material). Follow-up interviews were conducted via phone and email to clarify issues raised during the initial interviews. The findings informed the development of graphical representations illustrating the flow of patient data within the hospitals. The data collection aimed to evaluate the types of data gathered from patients and the methods employed for data capture.

3.3.2 Sampling Procedure

The selection of health facilities was based on the ease of obtaining authorisation from the respective district local government authorities and district health officers. Nevertheless, all health facilities in Uganda adhere to standardized guidelines set by the Ministry of Health [64]. The maximum variation sampling approach [67, 68] was employed to account for the diverse range of data management practices. Two private-sector facilities and one public-sector facility, located in different regions of Uganda, were selected for the study. The participants who took part in the study consisted of nine data management personnel at the respective health facilities (i.e., data clerks, records officers, and statisticians), which is a relatively modest sample. Participants were included based on their knowledge and experience with Uganda’s Health Management Information System (HMIS). Participants were informed that their responses would contribute to understanding data management practices in health facilities as part of the Virus Outbreak Data Network (VODAN) research project. Participants were also informed that their participation was

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voluntary, and they were under no obligation to answer any questions. Participation was entirely voluntary, and participants could withdraw at any time. Verbal consent was obtained for the initial interviews, while written consent was provided for the follow-up interviews. Respondents were assured that their identities would remain anonymous and that their data would not be published or disclosed.

Interviews

Face-to-face interviews were conducted with data management personnel at four health facilities in different geographic regions in Uganda: KIU Teaching Hospital (Western region), Lira Regional Referral Hospital (LRRH) (Northern Region), the Antiretroviral Therapy (ART) Clinic Lira (Northern region) which is part of Lira Regional Referral Hospital, and Case Clinic Kampala (Central region). With the aim of understanding what data is collected and how it is collected at the level of hospitals and clinics, a questionnaire was designed (see Supplementary Material) to collect information from the data management personnel at the respective health facilities. The first step was to document the actual data practices at the health unit, without interfering with decisions on how the data is managed. The overall goal was to enable the semantic interoperability of clinical data at the hospital or clinic with other datasets available elsewhere. The questionnaire also aimed at obtaining information regarding the regulations and policies governing data at the participating hospital/clinic.

The purpose of the interviews was to discover whether the patient data is recorded in digital or paper form; what templates are used for data collection (if any); who has access to, owns, and makes use or reuse of the data; whether or not an electronic health record system is in place; whether or not an information system for computer-based data storage, retrieval, and analysis is used; whether or not the different data systems in place are interoperable; what security and authorisation is needed to access the data; how digital data is stored; and, finally, the challenges faced in all the above data handling procedures.

The interviews were conducted with 9 participants in the period January - February 2020. The participants were associated with five health facilities. The participants were working as records management personnel, medical records officers, data clerks, data officers, monitoring and evaluation officers, data statisticians, IT specialists, and bioinformatics officers.

Table 3.1: Interview Details

# of Participants	Position
5	Records management personnel
1	Monitoring & evaluation officer
2	Statistician
1	IT specialist

Mariam Basajja conducted the interviews in person at the selected hospitals and clin-

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ics. A questionnaire (see Supplementary Material) was used to facilitate the interviews and collect participant data. Three primary questions were posed to the study participants:

How does patient data flow from the moment a patient arrives at the hospital to their discharge?

What types of patient data are collected?

How is patient data collected, and where is it stored?

The questionnaire used in this study was carefully designed to ensure its relevance and effectiveness in capturing comprehensive insights into the complexities of information flow within Ugandan health facilities. Informed by a synthesis of current literature, the research team identified key themes and critical areas for investigation. Subsequently, a draft questionnaire was crafted, incorporating open-ended and closed-ended questions to solicit detailed responses from participants. The draft underwent a rigorous review process involving experts in public health, Ministry of Health officials, data management professionals, and healthcare administrators to improve its clarity, comprehensiveness, and cultural sensitivity..

After refinement, the questionnaire was evaluated for appropriateness and effectiveness through a pilot study. Data from pilot study participants, along with observations and insights from the research team, played a central role in further refining the questionnaire. Ethical approval for the study was subsequently secured from the Kampala International University Ethics Review Committee, ensuring compliance with established research ethics guidelines.

The interviews were conducted in English, the official language of Uganda. This was done to facilitate clear communication with participants. Each interview lasted approximately 120 minutes, allowing participants to elaborate on their experiences and perspectives regarding challenges facing healthcare facilities. The interviewer listened attentively, took notes during the interview sessions, and sought clarification as needed. To deepen understanding, follow-up discussions were conducted via phone and email, enabling participants to elaborate on specific points and ensuring a thorough exploration of the topics covered in the questionnaire. This systematic approach to designing and approving the questionnaire strengthens the robustness and validity of the study's findings.

3.4 Results

This section outlines the findings on health information systems and data management practices within healthcare facilities in Uganda. It begins with an overview of the ideal scenario for health information management and an analysis of the actual state of affairs in each facility study, and concludes with insights from individual stakeholders.

3.4.1 Ideal Health Information Management in Uganda

In an ideal scenario, Ugandan healthcare facilities would implement a unified electronic Health Information System (HIS) to streamline patient data management. This system would incorporate standardized data collection and reporting procedures across all facilities and include robust security measures to safeguard patient data. Seamless integration between local HIS and national systems such as DHIS2 would be essential, supported by reliable infrastructure, including consistent power supply and internet connectivity. Well-trained personnel would oversee data management, adhering to clear guidelines on data ownership, storage, and sharing. The system would be interoperable with national identification systems and support diverse data formats, including multimedia files such as images. Regular audits and data quality assessments would uphold the integrity and reliability of the information.

3.4.2 Actual State of Health Information Management

Kampala International University Teaching Hospital (KIU-TH)

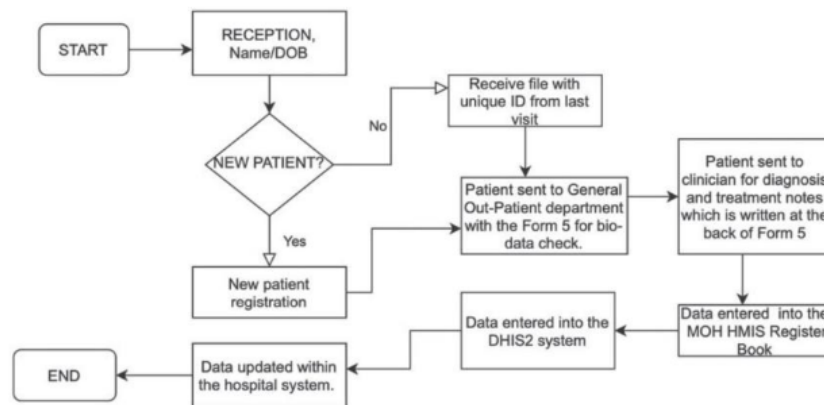


Figure 3.3: Workflow illustrating the flow of patient data through clinical, administrative and reporting processes atKampala International University Teaching Hospital.

KIU-TH operates a hybrid system that combines paper-based and electronic data management. Patient biodata is first recorded on paper forms (MF5 and HMIS Form 031) and later entered into the KIU-TH Health Information System (HIS). Each patient is assigned a unique ID for tracking purposes across departments. Departments maintain separate registers, all of which are in hard copy format. These registers are used to input data into the KIU-TH HIS and to aggregate data for the DHIS2 and RHITES systems on a weekly, monthly, and quarterly basis.

The KIU-TH HIS operates on a local area network, with data backed up on a server in the executive director’s office. While there’s no uninterruptible power supply (UPS) for computers, a generator provides backup power during outages. The system uses

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individual usernames and passwords for database access, enhancing security. However, the risk of significant data loss in case of a fire outbreak remains a concern.

Data reporting and integration at KIU-TH face several challenges. The KIU-TH HIS lacks interoperability with DHIS2 or the national identification system, significantly limiting its data-sharing capabilities.. Patient files contain more details than the KIU-TH HIS, including x-rays, clinical letters, and photographs, none of which are captured in the electronic system. Internet speed issues, particularly near reporting deadlines, further complicate the data management process.

Lira Regional Referral Hospital (LRRH)

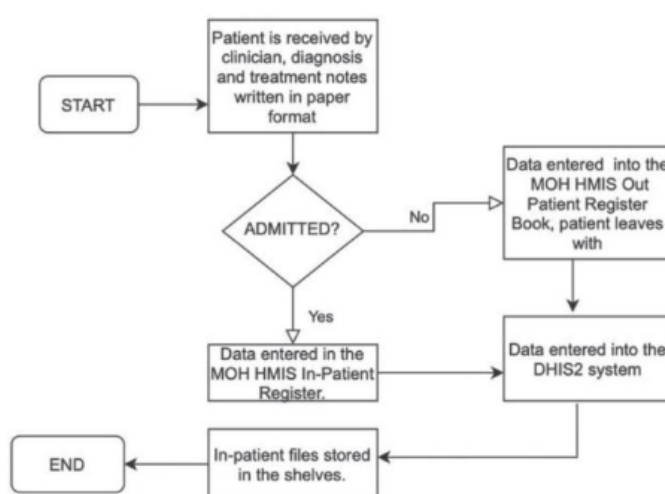


Figure 3.4: Workflow illustrating the flow of patient data through clinical, administrative and reporting processes at Lira Regional Referral Hospital

LRRH relies predominantly on a paper-based system for data collection and management. The hospital uses an outpatient registry for general patient data, with a separate Ministry of Health system to record information from the birth certificate of children. The lack of a comprehensive digital system results in limited storage space for outpatient records, with only inpatient files stored on shelves.

Data reporting at LRRH involves manual entry into DHIS2 from paper registers. Ministry of Health officials periodically verify the DHIS2 data against HMIS registers to ensure accuracy. The hospital faces significant infrastructure challenges, particularly in terms of internet connectivity. Health workers often resort to using personal funds for bundles of internet data to submit patient data to the Ministry of Health on time.

ART Clinic at Lira Regional Referral Hospital

The LRRH ART Clinic uses an electronic medical record (EMR) system run by the Ministry of Health. The system captures comprehensive patient information and retains

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it indefinitely, even posthumously.. However, the EMR system faces technical limitations, running on interconnected computers without a dedicated server, which slows down its functionality.. Despite the electronic system, paperwork is still involved when entering data into the EMR, adding to the workload of clinic staff.

Case Clinic Hospital, Kampala

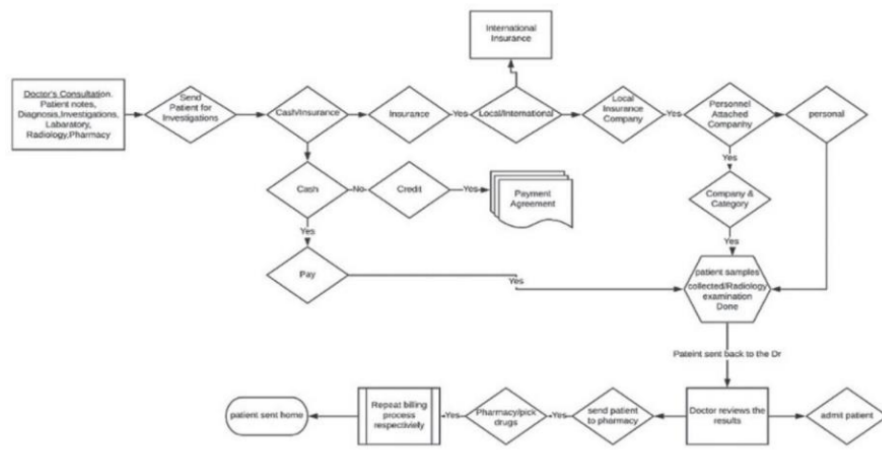


Figure 3.5: Workflow illustrating the flow of patient data through clinical, administrative and reporting processes at Case Clinic Hospital

Case Clinic Hospital in Kampala employs a more advanced electronic system for data management. The hospital uses a local system (Med360) alongside DHIS2 for direct entry of patient data. Certain types of data, including insurance, antenatal, and delivery information, are still collected on paper. The Med360 system primarily serves as a data storage mechanism without analysis capabilities.

Case Clinic boasts a more robust infrastructure and security measures compared to the other facilities included in this study. Patient data is stored off-site using remote servers, with monthly backups conducted. The hospital implements varying access rights for personnel to enhance data security. Notably, the hospital claims ownership of patient data, with patients able to access their information through reports provided by health attendants.

3.4.3 General Observations

Across all facilities, the Health Management Information System (HMIS) established by the Ministry of Health is the common thread. Most facilities use a combination of paper-based and electronic systems, with DHIS2 software mandated for use by all health facilities in Uganda. Standardized HMIS forms facilitate routine reporting, with health information assistants overseeing operations at the sub-district level and biostatisticians

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managing processes at the district level. Each facility maintains a box file stored in the District Health Services Directorate, serving as a physical backup of critical information.

3.4.4 Stakeholder Insights

KIU-TH Statistician

“We currently do not have written guidelines or regulations regarding patient data handling, but I am working on developing such guidelines.” (Participant 1, face-to-face interview, 20-01-2020)

KIU-TH Data Management Team Member

“We send our reports directly to the district because we have access to the system (DHIS2 or RHITES system). For health facilities that do not have access to the system, they send their reports to the health sub-district for entry into the system.” (Participant 2, face-to-face interview, 20-01-2020)

“The computers do not have UPS for power back-up, but there is a generator that comes on in case of power outage, although there may be a short period before the generator starts operation.” (Participant 1, face-to-face interview, 20-01-2020)

“The DHIS2 and RHITES databases are online, and they capture the data entered automatically. As for the KIU-TH HIS, it also saves the data entered and will take you back to where you stopped when restarted after a power blackout. However, if there were a fire outbreak, we would lose 90% of our records.” (Participant 2, face-to-face interview, 20-01-2020)

“Sending reports to the district through the DHIS2 system is slow, especially towards the deadline, because that is when most people are sending reports.” (Participant 2, face-to-face interview, 20-01-2020)

LRRH Medical Records Officer

Upon arrival at the hospital, patients are immediately directed to see the clinician. A label (‘male’, ‘female’, or ‘child’) is placed on the Outpatient Register, depending on the patient’s gender or age. After manually entering patient data into the Outpatient Register and Outpatient weekly, monthly, and quarterly reports, the data is then entered into the DHIS2 system.” (Participant 3, face-to-face interview, 24-01-2020)

“However, there is a separate system run and owned by the Ministry of Health to capture the personalized information of children so that they can obtain a birth certificate. Apart from the Ministry of Health systems, the hospital

Conclusion

has no digital system. Apart from the data entered into the Ministry of Health registers, the hospital does not maintain records of patients who are not admitted (outpatients) in the hospital. Outpatients receive a form, while inpatients have files stored in the hospital's shelves. This is due to a lack of space to store all patient files. The Ministry of Health officials then come to verify whether or not the information entered into the DHIS2 system aligns with the data from the HMIS register.” (Participant 3, face-to-face interview, 24-01-2020)

KIU-TH Data Management Team Member on Data Quality

“A team from the Ministry of Health comes twice a year to perform a data quality assessment by checking whether the data entered in the registers is the same as the one in DHIS2. There is also a team from the district that comes quarterly to do supervision and review.” (Participant 8, face-to-face interview, 04-02-2020)

These findings highlight the disparities between the ideal scenario and the current state of health information management in Ugandan healthcare facilities, revealing challenges in infrastructure, integration, and standardization at different levels of healthcare provision. The reliance on paper and electronic systems, coupled with issues of connectivity and data security, presents significant obstacles to achieving a unified and efficient health information system.

3.5 Conclusion

This study explored the dynamics of health information flow across the patient's care trajectory within the selected health facilities in Uganda. The study focused on documenting the tools used and data collected at each stage of the patient journey, including registration, history taking, physical examination, laboratory testing, diagnosis, and prescription. Insights derived from face-to-face and follow-up interviews with data management personnel underscored the dual reliance on the Health Management Information System (HMIS), predominantly the DHIS2 managed by the Ministry of Health, and diverse in-house Health Information Systems (HISs) tailored by health facilities.

These information systems are hybrid as they integrate both paper-based and electronic record systems. The DHIS2 is utilized for routine reporting under the Ministry's purview. Conversely, individual health facilities make use of their HISs to cater to specific operational needs such as patient record management, inventory oversight, and billing. With the use of the different systems, there is a significant hurdle in the lack of interoperability between these individualized systems and the Ministry of Health's DHIS2. This lack of interoperability is hindering seamless communication and data exchange.

Digitizing paper-based systems has the potential to transform the healthcare system, not only by improving resource efficiency but also by significantly enhancing patient care quality across Ugandan hospitals and clinics. Additionally, this change towards the

digitization of managing data within the healthcare system is pivotal for advancing the FAIRification process. This process fosters data that is Findable, Accessible under well-defined conditions, Interoperable, and Reusable (FAIR). Such a transformation addresses limitations on data sharing and reuse attributed to the structural non-uniformity and semantic heterogeneity prevalent in existing information systems. Consequently, this lays the groundwork for the development and establishment of a FAIR Data Point (FDP) in Uganda, enabling machine-assisted querying across diverse datasets, thereby unlocking insights from disparate sources.

3.6 Discussion

To document the data management processes in select health facilities in Uganda and assess the FAIRness and feasibility to transform the data into FAIR data, interviews and follow-up discussions with data management personnel at the selected hospitals shed light on the prevailing information systems, primarily comprising the Health Management Information System (HMIS) established by the Ministry of Health and diverse in-house Health Information Systems (HISs) employed by health facilities. These systems exhibit a dual nature, incorporating both paper-based and electronic record systems, with the Ministry-managed electronic record system predominantly relying on the DHIS2 software. Within the framework of the Ministry-managed HMIS, each health facility is mandated to undertake mandatory routine reporting utilizing standardized HMIS forms. The governance of patient data management, whether collected by public or private health facilities under Uganda's Ministry-controlled HMIS, is encapsulated in the HMIS Manual. This manual undergoes revision approximately every five years, as disclosed during the interview with participant 3. The regulations encompass critical components, including the stipulation of mandatory HMIS forms for completion by health facilities, the designated higher administrative level for form submission (e.g., health sub-district or Ministry of Health Resource Center), obligatory reporting deadlines, required reporting frequency, personnel responsibilities for each HMIS form, prescribed procedures for form completion, summarization protocols into weekly, monthly, quarterly, and annual tables, and the designated format for information entry in each column of the HMIS forms. Notably, the diagnosis must be articulated clearly in the diagnosis column, aligning with standard case definitions and Uganda Clinical Guidelines provided by the Ministry of Health. The structured nature of data management practices under the Ministry-controlled HMIS is underscored by the reliance on standardized forms, reporting protocols, and adherence to comprehensive guidelines. This approach ensures consistency and facilitates the systematic collection of data at various levels of administration. The periodic revision of the HMIS Manual shows a commitment to adaptability in order to stay aligned with healthcare needs as they evolve and the advancements in technology. Overall, the active involvement of the Ministry in overseeing the HMIS has established a cohesive and standardized approach to the management of health data in the health care systems in Uganda.

Table 3.2: HMIS Data Collection and Reporting Forms

HMIS Form	Reporting Frequency	Information on Form
Medical Form Five (MF5)	Daily	Captures patient's details and biodata including: name, outpatient number, age, sex, tribe, village, parish, sub-county, district, telephone contact, next of kin, blood pressure, weight, height, BMI, blood sugar, Z-score, MUAC, diagnosis, and treatment notes.
HMIS Form 105	Monthly (Outpatient Department)	Reports depersonalised outpatient attendance, referrals, diagnoses, maternal and child health, HIV/AIDS counselling and testing, safe male circumcision, essential medicines and health supplies, and outpatient laboratory tests.
HMIS Form 108	Monthly (Inpatient Department)	Reports depersonalised inpatient data including: census information, referrals, major and minor surgical procedures, special service utilisation, admissions and deaths by diagnosis, and maternal conditions.
HMIS Form 107	Annual	Captures depersonalised data on disease surveillance, notifiable diseases, and epidemics at the outpatient level, maternal health, and drug balances.
HMIS Form 033B	Weekly (Surveillance)	Captures depersonalised data on disease surveillance, notifiable diseases, and epidemics at the outpatient level, maternal health, and drug balances.
HMIS Form 031	Daily (Outpatient Register)	Records patient name, residence, age, sex, next of kin, MUAC, BMI, blood pressure, malaria test, tuberculosis, new diagnoses, drugs, and treatment.
HMIS Form 071	Antenatal	N/A
HMIS Form 106a	Quarterly	Captures depersonalised data on HIV/ART services, nutrition (cross-sectional), tuberculosis/leprosy services, and includes comments by the health facility in charge.
HMIS Form 009	Monthly (Nutrition Addendum)	Captures detailed nutrition-related data to supplement routine reporting.

This study was limited in scope, focusing on one regional referral hospital (LRRH), one

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district general hospital (KIU-TH), and two clinics (Case Clinic and the ART Clinic), with a modest sample size of nine participants. Despite this limitation, it is important to note that all health facilities in Uganda adhere to the same standardized guidelines for health data collection and processing, as mandated by the Ministry of Health. Consequently, the findings of this study are believed to be representative of data management practices across all health facilities in Uganda.