

Information Streams in Health Facilities: The Case of Uganda

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ABSTRACT

With the prevailing COVID-19 pandemic, the lack of digitally-recorded and connected health data poses a challenge for analysing the situation. Virus outbreaks, such as the current pandemic, allow for the optimisation and reuse of data, which can be beneficial in managing 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, there is no comprehensive knowledge about what type of data is collected or how it is collected along the journey of a patient through a health facility. This study investigates information flows of clinical patient data in health facilities in Uganda. The study found that almost all health facilities in Uganda store patient information in paper files on shelves. Hospitals in Uganda are provided with paper tools, such as reporting forms, registers and manuals, in which district data is collected as aggregate data and submitted in the form of digital reports to the Ministry of Health Resource Center. These reporting forms are not digitised and, thus, not machine-actionable. Hence, it is not easy for health facilities, researchers, and others to find and access patient and research data. It is also not easy to reuse and connect this data with other digital health data worldwide, leading to the incorrect conclusion that there is less health data in Uganda. The a FAIR architecture has the potential to solve such problems and facilitate the transition from paper to digital records in the Uganda health system.

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ACRONYMS

ART	antiretroviral therapy
BMI	body mass index
DHIS	Digital Health Information Software
EMR	electronic medical record
FAIR	Findable, Accessible, Interoperable, Reusable
FDP	FAIR Data Point
HC	health centre
HIS	hospital information system
HMIS	health management information system
KIU-TH	Kampala International University Teaching Hospital
LRRH	Lira Regional Referral Hospital
MF5	Medical Form Five
MUAC	mid-upper arm circumference
NIN	National Identification Number
PMTCT	prevention of mother to child transmission
PNFP	private-not-for-profit
RHITES	Regional Health Integration to Enhance Services
RRH	regional referral hospital
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
VHT	village health team
WHO	World Health Organization

1. INTRODUCTION

Rapid data sharing has proved crucial to accurately diagnosing severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which is causing the ongoing novel coronavirus disease (COVID-19) pandemic [1]. As a result, the World Health Organization (WHO) has called for international scientific cooperation and the equitable sharing of scientific knowledge, data and intellectual property [2]. WHO also moved to make all COVID-19 related data immediately available and accessible with proper attribution [1]. Virus outbreaks, such as the COVID 19 pandemic, call for the optimisation and reuse of data, which can be beneficial in managing future outbreaks. The immensely valuable data on past and current epidemics are not always equally accessible for different affected populations and countries. For instance, the data from past Ebola epidemics are very difficult to find and access and, if accessible at all, they are not interoperable, let alone reusable [3].

The healthcare system in Uganda is composed of public health and private health providers, with the Ministry of Health as the top overarching body. These two components are partners in healthcare delivery, as established in the National Policy on Public Private Partnerships in Health. The private sector has varied and diverse health providers, which have been categorised into private-not-for-profit health providers

(PNFPs), private health practitioners (PHPs), and traditional and complementary medicine practitioners (TCMPs). The PNFP category includes non-governmental organisations and faith-based organisations, such as the Uganda Catholic Medical Bureau, Uganda Protestant Medical Bureau, Uganda Orthodox Medical Bureau and Uganda Muslim Medical Bureau [4]. As well as the above recognised categories, there are informal health providers with very-limited to no-health training, who are also engaged in the treatment of patients and sale of drugs in small pharmacy shops. These health providers (the informal health sector) are not recognised as part of the private health sector, unless they register with the responsible regulatory body and acquire any necessary licences. The professional licensing bodies include the Uganda Medical and Dental Practitioners Council, Uganda Nurses and Midwives Council, Allied Health Professionals Council, and Pharmacy Council [5].

There are five levels of health care in the Ugandan healthcare system, as depicted in Figure 1. At the community/village level are health centre I (HC I) facilities and village health teams (VHTs). HC II facilities (sometimes referred to as dispensaries) and HC III facilities are at the parish and sub-county levels, respectively. HC IV facilities and general hospitals are at the county or district level. The regional referral hospitals (RRHs) and national referral hospitals are at the regional and national levels, respectively. HC I to HC IV facilities are controlled by the local government, whereas the regional referral and national referral hospitals are semi-autonomous [6].

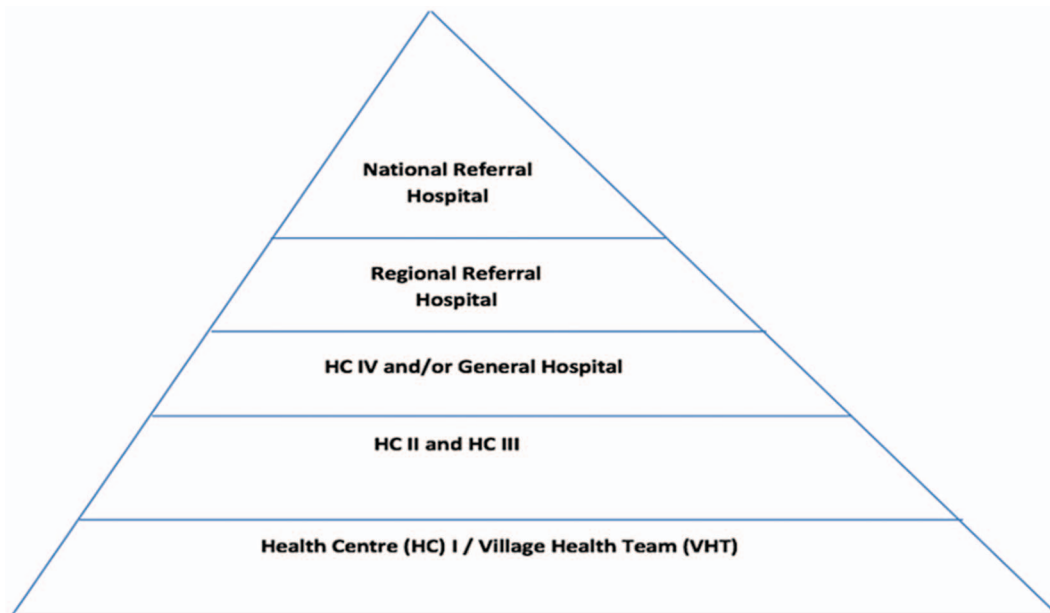


Figure 1. Ugandan Healthcare system [6].

The Uganda healthcare system is based on the District Health System, which was developed to deliver primary health care services [7]. The District Health System is a referral system that uses community-based services as the first point of delivery for primary health care, which includes preventive, curative and health

promotion programmes. 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 [8]. However, due to the rapid proliferation of political units (parishes, sub-counties, counties and districts), some do not have corresponding health facilities. For example, if the parish does not have a HC II, patients are referred to the next level of healthcare, e.g., a HC III.

Table 1. Health facilities (public and PNFP) by region [9].

Region	Clinic (HC I)	HC II	HC III	HC IV	GH	RRH	NRH	TOTAL
Central	645	1,065	318	51	53	3	2	2,137
Eastern	34	618	324	48	30	3	0	1,057
Northern	32	484	271	31	27	4	0	849
Western	120	774	376	67	34	4	0	1,375
TOTAL	831	2,941	1,289	197	144	14	2	5,418

Note: HC = health centre, GH = general hospital, RRH = regional referral hospital, NRH = national referral hospital

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, most of the reporting tools at the lower-level health facilities are still paper-based [10, 11]. 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. In addition, records personnel are sometimes asked to collect and capture information that is not in paper-based form. This tedious, time-consuming process, which involves the double entry of HMIS data on the online DHIS 2 platform and in paper-based versions, is not unique to Uganda and highly demotivating to health personnel [12]. Moreover, it is observed that such data does not benefit 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 [13].

In order 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 (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 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. Particular 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 or not the data is digitised and what tools are used to capture patient data at every point in the data flow, from health-facility level to national HMIS level.

2. RESEARCH QUESTION AND OBJECTIVES

In order to assess the general flow of information within the health facilities in Uganda and explore the possibility of implementing the FAIR Guidelines in Uganda's e-health sector, the main research question was: *What are the data management practices and information systems used in Uganda?*

The study objectives were:

- To document the data management processes in select health facilities in Uganda and assess the findability, accessibility, interoperability and reusability of such data
- To discover ways to transform the data into FAIR data and establish a FAIR Data Point, specifically, whether or not the data is digitised and what tools are used to capture patient data at every point in the data flow, from health-facility level to national HMIS level
- To assess the feasibility of mapping the HMIS reporting forms used in Ugandan health facilities to the machine-readable format (RDF) so that the resulting data consists of machine actionable (FAIR) digital objects and, towards this, to assess the feasibility of creating user-friendly web-based data input forms (data entry/data capture system) that contain FAIR data and that are interoperable

3. METHODS AND MATERIALS

3.1 Study Design

This article is based on a set of qualitative study data collection methods, including observations and interviews, in order to understand and document the flow of information and data management practices. Three health facilities in different regions of Uganda were selected for the study. Observation provided context and an understanding of how patient information flows play out in the health facilities. Face-to-face as well as follow-up interviews, were also carried out to probe for the meaning behind the events observed. These interviews gave the researcher an insight into the motivation, preference and events that led up to the current behaviour and practices. The interviews were held in English and followed a semi-structured format using a questionnaire (see Supplementary Material). The follow-up interviews consisted of phone and email conversations that sought clarification on issues discussed during the initial interview. The findings were used to develop graphic representations of the flow of patient data at the hospital. This data was collected to assess what kind of data is collected from a patient and how.

3.2 Sampling Procedure

The selection of health facilities was based on ease of obtaining authorisation from the respective district local government authorities and district health officers. However, all health facilities in Uganda follow similar standardised guidelines, as stipulated by the Ministry of Health [10]. The maximum variation sampling approach [14, 15] was also considered in order to reasonably account for the wide range of data management practices. Two facilities from the private sector and one from the public sector in different parts and regions of the country were selected. 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. The inclusion of study participants was based on their knowledge and experience with Uganda's HMIS. Participants were informed that the information provided would be used to understand the data management practices in the hospitals/clinics as part of the Virus Outbreak Data Network (VODAN) research project. They were also informed that there was no obligation to participate in the research or answer any question. Their participation was entirely voluntary, with room to withdraw any time. For the initial interviews, verbal consent was obtained, while for the follow-up interviews, the participants gave written consent. The respondents were assured that their identity would be kept anonymous and their personal data would not be used or published.

3.3 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) (Table 2). 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 officer, data clerks, data officers, monitoring and evaluation officer, data statisticians, IT specialist and bioinformatics officer.

Table 2. Interview details.

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

The interviews were conducted by Mariam Basajja in person at the selected hospitals/clinics. A questionnaire (see Supplementary Materia) was used to conduct the interviews and collect data from the participants. Three main questions were posed to the study participants:

- How does patient data flow from the time a patient arrives at the hospital to when he/she is discharged?
- What patient data is collected?
- How is patient data collected and where is it stored?

The interviews were conducted in English, the official national language of Uganda. Each interview lasted approximately 120 minutes. During the sessions, the interviewer listened intently to the participants and made notes while seeking any necessary clarification on their responses. Follow-up discussions via phone and email were also conducted.

4. RESULTS

4.1 Face-to-Face and Follow Up Interviews

Figure 2 shows the flow of information and processes at Kampala International University Teaching Hospital.

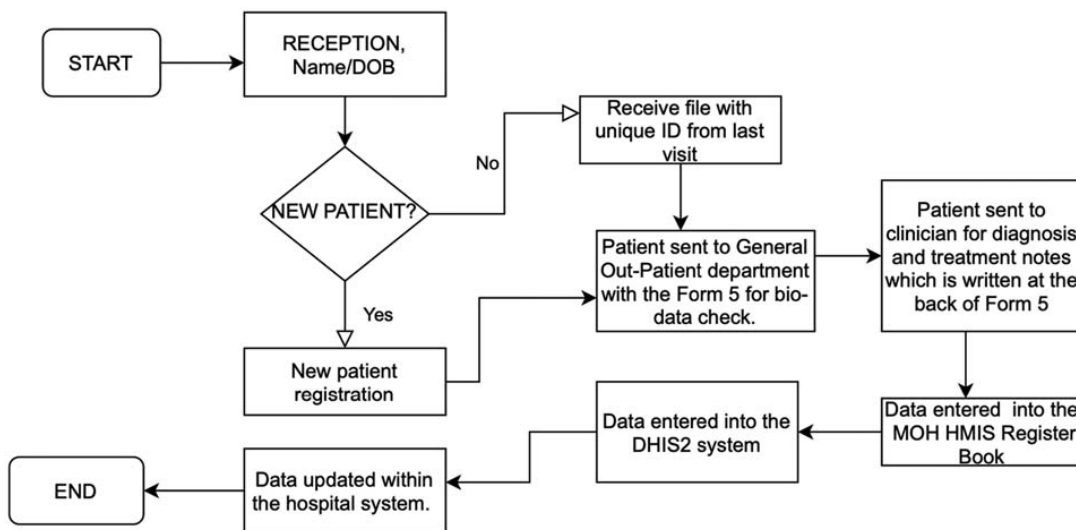


Figure 2. KIU-TH information flow chart (Source: Created by Basajja, 2021).

Upon arrival at the reception, patient biodata is recorded in the Medical Form Five (MF5) and Outpatient Register (HMIS Form 031). This information includes name, age, weight, height, body mass index (BMI), blood pressure, blood sugar, mid-upper arm circumference (MUAC), Z-score, next of kin, and contact info, etc. Then the records assistant enters the information in the Outpatient Register into the KIU-TH HIS and assigns a file number, which acts as the patient ID. The patient takes the MF5 to the doctor who performs a clinical examination, fills out a Lab Request Form and sends it to the lab. After performing the required tests, the lab personnel fill in the results on the Lab Request Form, which is then sent to the doctor. The lab personnel enter the data on the Lab Request Form into the Laboratory Register.

The doctor completes the MF5 with the diagnosis and treatment notes. The doctor fills out another form for prescriptions, which is taken to the pharmacy. The pharmacy uses it to complete the Pharmacy Register. The medical records assistants collect the MF5s from the doctors twice a day (afternoon and evening) and use them to complete the Outpatient Register or the Inpatient Register (for patients who are admitted to the wards). Every department/lab has different registers and they are all hard copies (paper forms). The registers (Outpatient Register, Inpatient Register, Pharmacy Register, Lab Register, etc.) are used to enter data into the KIU-TH HIS. They are also used to aggregate the data that is entered in the DHIS2 and the Regional Health Integration to Enhance Services (RHITES) system weekly, monthly, and quarterly, as required.

The duplication of patient records is avoided by assigning the same patient ID/file number to the patient upon registration in the Outpatient/Inpatient Registers and the KIU-TH HIS. Therefore, the patient ID in the KIU-TH HIS can be used to retrieve the patient's file stored in the shelves. However, the patient files have more details than the KIU-TH HIS, because x-rays, clinical letters and photographs are not entered in the HIS.

In order to reliably access a patient's past medical records and investigations, the same file number is given for new attendance (new month) and re-attendance (same month). In this way, the KIU-TH HIS keeps the medical history of all the patients for a long time. According to the interview participants, the patient records from when the system was first installed can still be retrieved.

The KIU-TH HIS facilitates the proper and thorough identification of patients, because patients have one unique identifier (patient ID) across all departments, which is assigned upon patient registration and is the same for both the Outpatient/Inpatient Registers and the HIS database. However, the KIU-TH-HIS does not use information from the national identification database, such as the National Identification Number (NIN), biometric details or contact information. The interview participants revealed that this is because at the time the KIU-TH HIS was designed, the National Identification system was not in place. There is a possibility and opportunity to make both the National Identification system and KIU-TH HIS interoperable. Some of the immediate benefits of this integration would be having a unique identifier (i.e., NIN) across multiple healthcare providers, thereby facilitating the sharing of electronic health records.

When asked in the interview about whether or not there is a written document that lays down the KIU-TH regulations regarding data management practices to be followed in the management of patient data/information, the KIU-TH statistician (the head of the data management team at KIU-TH) said:

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

Whereas the HMIS Health Unit and Community Procedure Manual (known as the HMIS Manual) requires that copies of some HMIS forms are sent to the Health Sub-District for entry into the DHIS2 (see Table 3 for HMIS forms used at KIU-TH), the interview participants revealed that KIU-TH sends its reports directly to the district for both the DHIS2 and the RHITES information system.

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)

During a follow-up phone interview, one of the research team members explained that the health sub-district under whose jurisdiction KIU-TH falls is Bushenyi Health Centre IV, Ishaka Municipality, Bushenyi District.

One of the participants also explained that the KIU-TH HIS uses a local area network (intranet) that consists of three computers; one at reception, several in the medical records office, and the server, which is located in the office of the hospital executive director. When asked whether the computers have back-up power devices that guarantee uninterrupted power supply, the participant responded:

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)

When asked about the risk of data loss in case of Internet or power outages happening while the data is being entered or in case of a fire outbreak damaging paper-based records, one of the participants responded:

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 where you stopped when restarted after power blackout. However, if there was a fire outbreak, we would lose 90% of our records. (Participant 2, face-to-face interview, 20-01-2020)

The participants also explained that data is backed up at the server in the office of the hospital executive director. The RHITES information system and the DHIS2 are online so there is no need to install software. However, the KIU-TH HIS database software was installed by a third party and is upgraded from time to time upon request of the hospital management.

When asked whether the Internet speed is sufficient, the participant responded as follows:

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)

The different departments (e.g., pharmacy, laboratory, radiology, etc.) in KIU-TH have different paper registers that are used in the day-to-day collection of data. The physicians/clinicians, nurses, radiologists, pharmacists, and laboratory personnel fill in the paper registers as they go about their daily routines. Forms are used to fill paper registers or registers are filled in directly. The Admissions Register is used to record patients admitted in the wards. Medical records assistants collect the data every morning and enter it into the KIU-TH HIS.

Both the KIU-TH HIS and the DHIS2 can only take data in text format, not images. With the DHIS2, one can download data in pdf or text/Excel format.

4.2 Security and Authentication

The KIU-TH HIS requires all data management personnel to have individual usernames and passwords for the database, which they use to login and enter data. The DHIS2 has a requirement to have data entry done using the medical records officer and hospital statistician accountants, who have a username and password. For access control purposes (restrictions on changes to information), the DHIS2 system gives an alert to the administrator that 'so and so' (username, institution) has made this change in the system.

The participants revealed that there is training for using new HMIS forms. It was further revealed that DHIS2 training is done using the HMIS Manual. However, there are no training materials for using the KIU-TH HIS.

With regard to the quality of the data (accuracy and completeness) entered into the DHIS2, one respondent answered:

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)

The respondents also explained that the KIU-TH HIS was created as a standalone and does not communicate with any other system and is, therefore, not interoperable with the DHIS2 system.

4.3 Interviews at Lira Regional Referral Hospital

Figure 3 shows the flow of processes and information within Lira Regional Referral Hospital, which is located in the district of Lira.

On 24 January 2020, an approval from the Principal Assistant Secretary of the District Local Government Headquarters Lira was obtained to carry out interviews with the data management personnel of HC III and IV. The Assistant District Officer also gave written permission in order for the researchers to access all health facility data in the district, including data from the LRRH and ART Clinic. The tools used to record and report the data in the LRRH (Northern Uganda) and KIU-TH (Western Uganda) are the same.

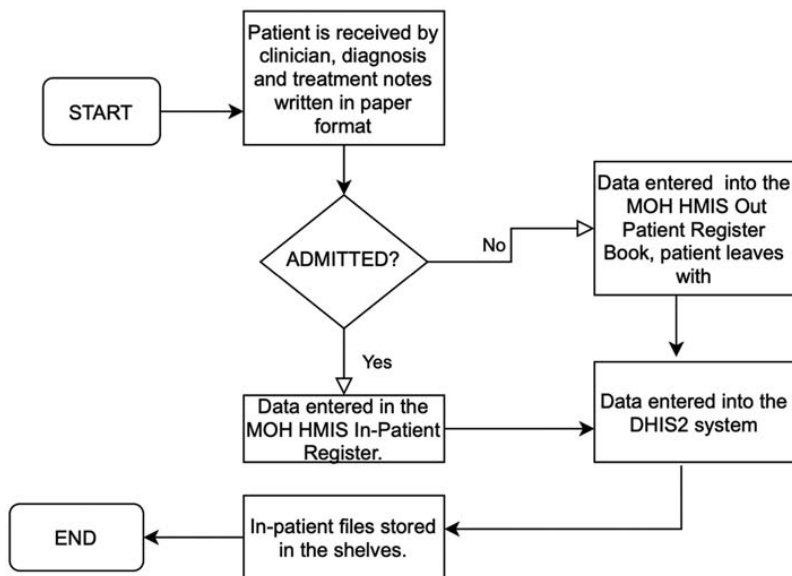


Figure 3. Lira Regional Referral Hospital information flow chart (Source: Created by Basajja, 2021).

With regard to how patient data is managed at the LRRH, the medical records officer narrated the following:

On arrival at the hospital, patients are immediately directed to see the clinician. A label ('male', 'female', or 'child') is put on the Outpatient Register, depending on whether the patient is male, female or a child. After manually entering the 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)

The medical records officer continued to explain about the digital flow of information about patients in the hospital:

However, there is a separate system run and owned by the Ministry of Health to capture the personalised information of the children so that they can acquire a birth certificate. Apart from the Ministry of Health systems, the hospital has no digital system. Apart from the data entered into the Ministry of Health registers, the hospital does not keep records of patients who are not admitted (outpatients) in the hospital. The outpatients receive a form, while those who are admitted (inpatients) have files stored in the shelves of the hospital. 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 is in sync with the data from the HMIS register. (Participant 3, face-to-face interview, 24-01-2020)

Health workers at the LRRH face several challenges while managing patient data. These include having no database to store patient information, requiring cumbersome paperwork. The hospital has no Internet connectivity, therefore, health workers have to use their personal funds to buy data bundles in order to submit patient data to the Ministry of Health on time.

4.4 Interview with Data Clerk at ART Clinic

On 24 January 2020, an interview with the data clerk volunteer of the Antiretroviral Therapy (ART) Clinic (part of the Lira Regional Referral Hospital) was conducted. The clerk mentioned that the hospital uses the electronic medical records (EMR) system run and owned by the Ministry of Health, which is used countrywide by all HIV clinics. This system captures all patient personal information and, therefore, cannot be accessed online, but can only be accessed while at the hospital to protect the patients' data. Patient information is stored for as long as possible, even after death. The data is stored on a central processing unit (CPU), interconnected with five other computers due to absence of a server. This slows down the system. There is a lot of paperwork involved, even when entering the data into the EMR system. The patient data is inputted into the EMR and the DHIS2 systems, which are independent of each other.

The bio-statistician at HC III and IV level facilities in Lira District further explained that the Ministry of Health paper tools (reporting forms, registers, databases, manuals) are used according to the level of facility. He said that the sub-district level is led by health information assistants, district level by a bio-statistician, and national level by the Ministry of Health. Each facility has a box-file stored at the Directorate of District Health Services. Besides the data entered into the DHIS2, which is run and owned by the Ministry of Health in Uganda, the data is only available in paper format.

4.5 Interviews at Case Clinic Hospital in Kampala District

Figure 4 shows the flow of information and processes at Case Clinic located in Kampala, the capital city of Uganda.

On 4 February 2020, two interviews with the public health specialist in charge of statistics and the IT specialist from the Case Clinic, a private hospital in Kampala, were conducted. The public health specialist said that on arrival at the hospital, the patient data is entered directly into the local hospital system (Med360) and DHIS2. This system can be accessed by the hospital data management personnel, who have different access rights, while at the hospital. The system is mainly for data storage and does not do any analysis. The patients have access to their information through reports from health attendants. Insurance, antenatal and delivery data are also collected in paper format. According to the data management personnel, the hospital owns the patient data. The patient data is stored off-site using remote servers for as long as possible and backups are run on a monthly basis.

It is observed that the information systems used in hospitals in Uganda consist of the HMIS established by the Ministry of Health and the in-house HISs of health facilities. Both of these systems are paper-based and electronic record systems. The Ministry-managed electronic record system is comprised mostly of the

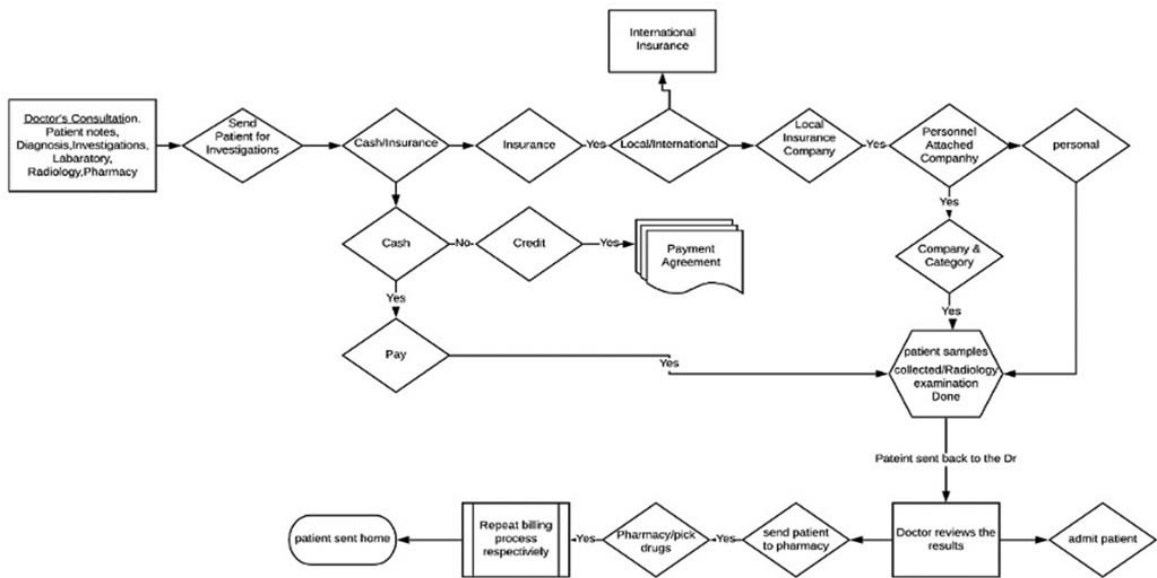


Figure 4. Case clinic information flow.

DHIS2 software. This is used by all health facilities in Uganda, as required by law. The Ministry-managed HMIS requires each health facility to conduct mandatory routine reporting using the standardised HMIS forms. Some of the most frequently used DHIS2 reporting forms are given in Table 3.

The MF5 is specific to HC I facilities and is used to capture the patient’s details, while the rest of the HMIS forms are used by all facilities in Uganda. The above registers are used to collect data within the hospitals and clinics regularly.

5. DISCUSSION

According to information obtained from the data management personnel at the selected hospitals through interviews and follow-up interviews, it was discovered that the information systems used consist of the HMIS established by the Ministry of Health and various in-house HISs of health facilities. Both of these systems are paper-based and electronic record systems. The Ministry-managed electronic record system uses mostly the DHIS2 software.

The Ministry-managed HMIS requires each health facility to conduct mandatory routine reporting using standardised HMIS forms. The policies and regulations that govern the management of patient data collected by both public and private health facilities under Uganda’s Ministry-controlled HMIS are enshrined in the HMIS Manual, which is revised approximately every five years, as discovered during the interview with participant 3. These regulations include: mandatory HMIS forms to be completed by the health facility and to which higher administrative level they should be submitted (e.g., health sub-district or Ministry of Health

Table 3. HMIS data collection and reporting forms [16].

HMIS form	Reporting frequency	Information on form
Medical Form Five (MF5)	Daily	Captures patient's personal 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	Outpatient department, monthly reporting tool	Used to report on: depersonalised outpatient department attendance, referrals and diagnoses, maternal and child health, HIV/AIDS counselling and testing, safe male circumcision, essential medicines and health supplies, outpatient laboratory tests
HMIS Form 108	Inpatient department, monthly reporting tool	Used to report on: depersonalised data of the inpatients, including: census information, referrals, major surgical procedures, minor surgical procedures, utilisation of special services, number of admissions and deaths by diagnosis, maternal conditions
HMIS Form 107 HMIS Form 033B	Annual report Surveillance form (weekly reporting)	Captures depersonalised data on: disease surveillance of patients, notifiable diseases/epidemics at outpatient department, maternal health, drug balances
HMIS Form 031	Outpatient register (daily reporting)	Records: patient name, residence, age, sex, next of kin, MUAC, BMI, blood pressure, malaria test, tuberculosis, new diagnosis, drugs and treatment
HMIS Form 071 HMIS Form 106a	Antenatal Health unit quarterly report	Captures depersonalised data on: HIV/ART services, nutrition quarterly cross-sectional report, tuberculosis/leprosy services, comments by health facility in charge
HMIS Form 009	Nutrition addendum (monthly reporting)	Captures: nutrition addendum details

Resource Center); obligatory reporting deadlines and required reporting frequency; personnel responsible for each HMIS form; procedures to be followed in filling out the HMIS forms and summarising the information into weekly, monthly, quarterly and annual summary tables; and the format of the information to be entered in each column of the HMIS forms (e.g., the codes and abbreviations to be used). In addition, the diagnosis must be written clearly in the diagnosis column, according to the standard case definitions and Uganda Clinical Guidelines provided by the Ministry of Health.

6. CONCLUSION

This study explored the flow of health information along the patient's care timeline in the selected health facilities. Particular emphasis was placed 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). According to information obtained from the data management personnel

at the selected health facilities through face-to-face and follow up interviews, health facilities in Uganda use both the HMIS established by the Ministry of Health (mostly the DHIS2) and their own in-house HISs for managing data. These two systems are a combination of paper-based and electronic record systems. The DHIS2 software is managed by the Ministry of Health and used for routine reporting. Health facilities also use their own HISs, which are tailored to serve their respective individual operations, including patient record management, stock/inventory management, and billing etc. Unfortunately, it is not possible for the individual information systems to communicate with each other and there is no interoperability with the Ministry of Health DHIS2.

The digitisation of the paper-based systems would play a big role in enabling the efficient utilisation of resources like time and labour, as well as improving the quality of patient care in hospitals and clinics in Uganda. This would also support the FAIRification process, as it would make patient health data Findable, Accessible under well-defined conditions, Interoperable and Reusable (FAIR), thereby addressing the limitations on data sharing and reuse caused by lack of structural uniformity and semantic heterogeneity of these information systems. As a result, the information obtained could be used in the development and establishment of FAIR Data Point (FDP) in Uganda. This FDP would allow for the machine-assisted querying of more than one dataset in different locations so as to generate insights from multiple datasets.

7. LIMITATIONS

This study was conducted in one regional referral hospital (LRRH), one district general hospital (KIU-TH) and two clinics (the Case Clinic and ART Clinic), with a relatively modest sample of nine participants. However, given that all health facilities in Uganda follow the same standardised guidelines for health data collection and processing, as stipulated by the Ministry of Health, it is believed to represent the data management practices of all the health facilities in Uganda.

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AUTHORS' CONTRIBUTIONS

Mariam Basajja (m.basajja@liacs.leidenuniv.nl, 0000-0001-7710-8843) guided the conception and design of the work, carried out the data collection, data analysis and interpretation, drafted the article, and contributed to the critical revision of the article and approval of the final version to be published. Mutwalibi Nambobi Nambobi (amnambobi@gmail.com, 0000-0001-6822-616X) contributed to the critical revision of the article and the approval of the final version to be published.

CONFLICT OF INTEREST

Both of the authors declare that they have no competing interests.

ETHICS STATEMENT

The study was approved by the KIU Research Ethics committee. Permission to conduct interviews in the health facilities was also obtained from the Ministry of Health, district local government authorities and the respective district health officers. All participants provided voluntary informed consent before each interview. The privacy of the participants was ensured by conducting the interviews in private and not including identifiable information. Individual autonomy to participate in the study was guaranteed, as participants were free to decline to participate. All who consented to participate were informed about their freedom to withdraw from the study at any time. No participant withdrew from the study. Permission to tape record the data was similarly obtained. All the audio recorded material and transcripts were safely stored by the lead author, Mariam Basajja.

SUPPLEMENTARY MATERIAL

https://docs.google.com/document/d/1KHFgRX6LIN_al6T6g-zp4ANfpXsZw5ip/edit

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