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A Project Report for MRC Award MR S013164/1

Assessing the Potential for Transforming Health in Uganda through an Electronic Health Data Sharing Platform and Data Science

March 2022

This Project Report presents a description of the project deliverables as well as the preliminaries constituting the background, objectives, methodology, field findings, discussions and conclusion for the MRC Project Award MR/S013164/1



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LIST OF ACRONYMS

ART	Antiretroviral Therapy
AI	Artificial Intelligence
CHEW	Community Health Extension Worker
DOI	Diffusion of Innovation Theory
EHR	Electronic Health Record
eHTWG	eHealth Technical Working Group (<i>Nationally for Uganda</i>)
EHR	Electronic Health Record
EMR	Electronic Medical Record
FGD	Focus Group Discussion
GPS	Global Positioning System
HIIRE	Health Information, Innovation and Research
HIV	Human immunodeficiency virus
HMIS	Health Management Information System
HW	Healthcare Worker
ICT	Information and Communication Technology
IP	Implementing Partner
IRB	Institutional Review Board
KII	Key informant interviews
LMICs	Low- and Middle-Income Countries
MoH	Ministry of Health (<i>for Uganda</i>)
NGO	Non-governmental Organization
NITA-U	The National Information Technology Authority-Uganda
OPD	Out-Patient Department
PNFP	Private Not For Profit
PrEP	Pre-Exposure Prophylaxis
SDG	Sustainable Development Goal
SOPs	Standard Operating Procedures
TB	Tuberculosis
TOE	Technology Organisation Environment
UCC	Uganda Commissions Commission
UNAIDS	United Nations Programme on HIV/AIDS
UNCST	Uganda National Council for Science and Technology
VHT	Village Health Team
WHO	World Health Organization

EXECUTIVE SUMMARY

Worldwide most countries have recognized the value of integrating information and communication technology (ICT) into Healthcare and Public Health. The eHealth Technical Working Group (eHTWG) responsible for developing eHealth policy and strategy for Uganda working in concert with the United Nations SDGs and the country's health partner recognised that small, uncoordinated and pilot ICT initiatives in health abound in Uganda made it difficult to harness the data and information from these activities to provide more efficient and effective public health and healthcare services to the country nationally. This increased the risk of continued duplication, ineffective expenditure, and failure to harness what works for the whole of the country (Ministry of Health, Uganda, 2016). Therefore, there was need to evaluate the readiness of Uganda to support current and enabling new real-time electronic health record (EHR) systems that will feed into a central ICT framework providing automated data processing since implementation without evaluation of the setting in which the ICT 'intervention' would be initiated (i.e., performing a needs assessment) would be both premature and potentially a waste of precious and limited country resources.

The project overall aim was to assess the readiness of the health system across Uganda to successfully adopt an electronic health record (EHR) data capture system in an exemplar infectious disease area that can be used to support both care locally and interventions nationally. The study explored the readiness of malaria and HIV as potential demonstrator conditions for an EHR data capturing and processing system infrastructure. Additionally, the study investigated analytical methods that could support Uganda's Ministry of Health and related health institutions to provide responsive care and interventions based on real-time surveillance.

The study adopted a mixed-method research design where questionnaires, interviews, and focus groups were used to obtain responses from the study participants. This study was conducted in 13 districts in the four regions of Uganda, namely, Northern, Eastern, Western and Central regions. The activities included (a) surveys of healthcare professionals in selected healthcare facilities from the four regions of Uganda, (b) focus groups (13) each comprising of 8-10 participants and key informant interviews were held for participants drawn from governmental organizations (34), health partners/NGOs (36), commercial partner organizations (51), and health researchers (48). Interviews were conducted until saturation.

Our findings revealed that Electronic Health Records (EHRs) / Electronic Medical Records (EMRs) were perceived as being valuable and would enable sharing of information in real-time from different parts of the country. The collected data could be used to evaluate program impact, to determine appropriate public health interventions, to monitor progress, to determine which populations to target for an intervention, to determine barriers to care, and to influence public policy. However, the lack of importance given to data in decision making, corruption, insecurity, training and poor infrastructure were major challenges to implementing EHR/EMR systems; but that strong leadership and clear policy direction coupled with the financial support to acquire essential technology, improve the communication network, and provide training for staff could help to promote implementation. The role of health care workers (healthcare professionals, Community Health Extension Worker (CHEWs) / Village Health Teams (VHTs) was recognised as being very important in healthcare service provision.

The findings of this study further revealed that the major barriers to data access and use were poor governance and management, inadequate ICT equipment, poor network connectivity, insufficient funding, power shortage, use of paper-based formal, information security concerns, user resistance, and insufficient skills. However, there was lack of a sustainability plan to ensure smooth transition from Implementing Partners (Ips) support to facilitate governance and or continued financing of the system.

The study also explored technical, ethical/governance, workforce infrastructure, and cost factors for implementing a timely data capture system in Uganda. Several barriers to implementation of a data capture platform were identified and they included; poor governance and management, inadequate ICT equipment, poor network connectivity, insufficient funding, power shortage, use of paper-based forma, information security concerns, user resistance, and insufficient skills. Nonetheless, stakeholders in Uganda anticipate the benefits of having such a platform and have implemented some digital infrastructure which could be facilitators to the implementation of such a data capture platform. Though there is limited widespread existence of these facilitators across healthcare sites, they can still provide a launch pad for implementing the data capture platform in Uganda.

We argue that information is a very critical tool that can be used to benefit the community, facilitate accountability in healthcare, follow-up and planning purposes. We encourage continued use of existing systems/platforms to support health workers to do their work as the

country prepares to develop a national electronic routine health data capture, processing and dissemination platform.

The study concludes that this is a much-needed system as all healthcare stakeholders look forward to use community level information. However, what remains to be done is to (1) model the cost of an integrated data capture, processing and presentation platform for Uganda and to determine how much additional malaria and/or HIV control would be required to offset the cost of the system over various periods; and (2) establish structures and mechanisms to minimize barriers to its successful implementation.

1. INTRODUCTION

1.1. Background

Worldwide most countries have recognized the value of integrating information and communication technology (ICT) into Healthcare and Public Health. Within high-income settings, ICT in health is transitioning from solely supporting efficiency in recording and transferring health information between providers to near real-time surveillance for faster identification of public health problems (Gamache et al., 2018) and sophisticated decision support in healthcare settings based on sophisticated artificial intelligence (AI) algorithms (Buchlak et al., 2020; Contreras & Vehi, 2018; Hosny et al., 2018; Kim, 2018; Medic et al., 2019; Montani & Striani, 2019). For example, the Ugandan Government also embraced ICT as one of the critical tools to support the country's socio-economic transformation and improve the efficiency and effectiveness in delivering services to the Ugandan population. This is demonstrated in Ugandan national policy and planning framework documents, such as the “Uganda Vision 2040”(Uganda National Planning Authority, 2013) and the “National Development Plan III” (Uganda Ministry of Health, 2020). Similarly, the United Nations highlighted ICT in health as a key enabler of economic development and wellness globally in their Sustainable Development Goals (SDG) document entitled, “Transforming our world: the 2030 Agenda for Sustainable Development” (United Nations, 2016), emphasizing that utility of health ICT is not just for high-income settings. Moreover, low- and middle- income settings are more likely to receive greater benefit from ICT health interventions given the need for regular management of health conditions, such as infectious diseases (e.g., malaria and HIV).

To realize both the government agenda for ICT in health and to coordinate the abundance of health partner activities around eHealth in Uganda, the Ministry of Health (MoH) commissioned the national eHealth Technical Working Group (eHTWG) and currently known as the Health Information and Innovation Research Technical Working Group (HIIRE) in Uganda, which set forth the National eHealth Policy in 2013 and updated it in 2016. The eHTWG/HIIRE is responsible for developing the eHealth policy and strategy for Uganda working in concert with the United Nations SDGs and the country’s health partner. Of significant importance in eHTWG/HIIRE policy and strategy is the recognition that small, uncoordinated and pilot ICT initiatives in health abound in Uganda; one of the objectives of the eHTWG/HIIRE is to bring these together nationally (Ministry of Health, Uganda, 2016).

Thus, ensuring that the MoH and Ugandan health partners can harness the data and information from these activities to provide more efficient and effective public health and healthcare services to the country nationally. Without a national strategy for coordinating these activities, the eHTWG/HIIRE recognized the risk of continued duplication, ineffective expenditure, and failure to harness what works for the whole of the country (Ministry of Health, Uganda, 2016). In addition, it provides a system-level perspective to the Ministry and stakeholders on ICT and eHealth needs, priorities, and initiatives within the country.

To advance the eHTWG/HIIRE's agenda, support the MoH mission in health ICT, and create an inclusive and effective working solution for all eHealth stakeholders, we proposed to evaluate the readiness of Uganda to support current and enabling new real-time electronic health record (EHR) systems that will feed into a central ICT framework providing automated data processing. Implementation without evaluation of the setting in which the ICT 'intervention' would be initiated (i.e., performing a needs assessment) would be both premature and potentially a waste of precious and limited country resources. Therefore, this project report provides a comprehensive study on the needs assessment that focused on *“understanding the barriers and facilitators to national EHR and central data processing systems, identifies readiness of the health sector to participate, and provides a road map of potential models, plan and costs for the implementation of an electronic real-time data capture and processing platform to support public health and healthcare across Uganda.”*

1.2. Literature Review

As eHealth capability becomes an essential part of efficient and effective healthcare delivery worldwide, it has also become an important component of the World Health Organization (WHO) initiative to enable universal health coverage (WHO, 2017). At its centre is the electronic capture and near real-time processing of health data with the potential to support real-time and prospective action to effectively deliver care, interventions and treatment for a wide range of health conditions.

While health systems have mainly focused on eHealth use for patient flow, decision support and personalised medicine, it may also have significant application to population-level care and treatment, particularly in resource-limited settings. For example, simple data on the diagnosis of malaria or distribution of antimalarial medications in real-time could be used to alert public health officials to deliver effective interventions, e.g., insecticide-impregnated bed nets, to regions at need; thereby targeting resources where they will be most effective.

However, even very simple region- or nation-wide eHealth systems require a minimum of (a) a reliable information and communication technology (ICT) infrastructure that can support state-of-the-art security, data transfer, and automated analyses; (b) a workforce to support the ICT infrastructure; (c) a high-level of governmental, non-governmental organisation (NGO) and service provider coordination and regulation; (d) policies and procedures to support operation; (e) community acceptance for health data usage; and (f) front-line care provider engagement, training and cooperation in recording data. Nationally Uganda has begun to advance their ICT capacity for health systems delivery.

The Uganda Ministry of Health (MoH) recognized the value of eHealth and implemented a strategy to realise a national vision of eHealth adoption, including promoting significant leadership through the eHealth Technical Working Group (eHTWG). The 2016/2017-2020/2021 eHealth Strategy focuses on “...strengthening the national capacity to optimize the management and use of eHealth resources for better health outcomes” (Ministry of Health, Uganda, 2016). While there are several different eHealth data capture systems within Uganda, they are predominately based on proof-of-concept pilot projects with partner organisations and capture data retrospectively (Kiberu et al., 2017; Ministry of Health, Uganda, 2016). This is in part because the definition of eHealth is diffuse (Oh et al., 2005; Shaw et al., 2017), which can result in undermining the focus of national strategies, especially where resources are scarce, but also because the mobile data infrastructure for the country is well established, enabling even the simplest of eHealth applications in rural or urban settings. However, this has resulted in a breadth of disparate, diffuse and unlinked data managed by different data controllers, resulting in an inability to utilise the data for care provision. To advance the Uganda eHealth strategy, the MoH and eHTWG sought to consider the implementation of an exemplar EHR paired with a central data processing system that could support near-real-time analysis and dissemination of key information to support public health and healthcare.

The eHealth Strategy in Uganda clearly describes an “incremental approach” to building long-term national capacity, “focusing initial investment in those areas that deliver the greatest benefits”. As outlined in the Strategy and elsewhere, malaria, HIV, tuberculosis and maternal and child health continue to persist as major health concerns resulting in significant loss of healthy years in Uganda (Ministry of Health-Uganda, 2016). While malaria control programmes in Uganda have been estimated to be successful in lowering malaria incidence, consistent estimates of cases are not available (Talisuna et al., 2015), and malaria remains a

significant focus for the Ministry of Health (Ministry of Health-Uganda, 2014). Similarly, while the incidence and prevalence of HIV in Uganda have dramatically decreased over the past two decades, the prevalence is still 6.5% among adults (Ministry of Health, 2019) and HIV prevalence is known to significantly increase the incidence of malaria, (Flateau et al., 2011; Kanya et al., 2006; Patnaik et al., 2005) and potentially onward transmission due to increased parasitaemia (Patnaik et al., 2005; Whitworth et al., 2000). Both malaria and HIV have well-established diagnosis methods; effective treatment regimens; and well-defined interventional strategies, which, along with their national importance, makes them ideal exemplar conditions for an incremental real-time care delivery using an eHealth system.

1.2.1. Theoretical Frameworks that Informed the Study

While there is a clear interest in developing an exemplar national data capture platform for key infections in Uganda, it is critical to determine eHealth ‘readiness’ and costs before investing funds into its implementation. A small number of studies have looked at the cost return of EHRs, but these primarily focus on financial recovery through billing, which does not reflect the Uganda setting (Grieger et al., 2007; Wang et al., 2003); therefore it is important to conduct these analyses locally. There is a larger body of literature around eHealth readiness and technology adoption (Baker, 2011; Coleman & Coleman, 2013; DeLone & McLean, 1992; Jennett et al., 2005; Khoja et al., 2007; Légaré et al., 2010; Yusif et al., 2017). Though few focus on EHR adoption in low-income settings (Khoja et al., 2007), implementation success has been reported by contributing factors outside of theoretical frameworks in these settings (Fritz et al., 2015). Studies examining the adoption of eHealth in low- and middle-income settings suggest that a single model may not be sufficient (Zayyad & Toyman, 2018). Additionally, many studies that have assessed the quality of technology/EHR adoption models examine post-implementation data (Li et al., 2010), which provides different perspectives than pre-implementation information. We, therefore, planned to capture key information from a number of models to support greater understanding and did not chose to focus on models that lent themselves to post-implementation information, such as The Unified Theory of Acceptance and Use of Technology (Venkatesh et al., 2003) and Information Systems Success Model (DeLone & McLean, 1992, 2003). We selected three models to assess our data against. The Technology-Organisation-Environment (TOE) Framework (Baker, 2011) was used to provide a bigger picture of internal and external pressures, while the Diffusion of Innovation (DOI) Theory (Rogers, 2010) was used to support the understanding of driving factors in adoption. We also examined aspects described

in the Technology Acceptance Model (TAM)(Davis, 1985) including perceived usefulness and ease of use.

1.3. Problem statement

The MoH and its supporting committees / working groups, particularly the eHTWG/HIIRE, WHO-Uganda and other stakeholders, are keen to understand facilitators and barriers to feasibility and readiness for the implementation of electronic healthcare data capture and near-real-time processing to support healthcare and public health nationally. This required a thorough and formal assessment of various factors, including cost, infrastructure, ethical concerns and support at all system levels.

1.4. Research Questions and Objectives

1.4.1. Research Questions

The following three broad questions were explored in this study of Uganda's readiness for implementing a national electronic routine health data capture platform;

- (1). What is Uganda's readiness for implementing a national electronic routine health data capture, processing and dissemination platform that can function in near real-time?
- (2). What factors must be considered to increase readiness to the point of implementation?
- (3). What factors must be considered for sustainability over time?

The three broad questions were addressed through answering a number of sub-questions, including;

- (a). What are the barriers and facilitators of implementing a national electronic routine health data capture, processing and dissemination platform in Uganda?
- (b). What are the initial costs and potential models for cost recovery over time of a national electronic routine health data capture, processing and dissemination platform in Uganda?
- (c). What infrastructure (both technical and ethical) requirements are needed for a national electronic routine health data capture, processing and dissemination platform in Uganda?
- (d). Can the process function in a timely enough manner in order to effectively support more efficient public health and health care delivery across Uganda?

- (e). What features of this system are necessary for buy-in from all key stakeholders?
- (f). Will Ugandan health partners, including NGOs and research sites, have their needs appropriately supported through such a system?
- (g). Is use of personal healthcare data in this way considered ethically appropriate to the Ugandan people?

The above questions were summarized into the following question:

Given the answers to the above questions, what are the possible models for this system, is Uganda ready to adopt any of these, and are any sustainable?

1.4.2. General Objective

The study explored the readiness of malaria and HIV as potential demonstrator conditions for an EHR data capturing and processing system infrastructure, and analytical methods that could support Uganda's Ministry of Health and related health institutions to provide responsive care and interventions based on real-time surveillance.

1.4.3. Specific objectives

The study aimed to achieve the following specific objectives;

- Objective 1. To (a) develop a complete understanding of the routine care data currently captured, all surrounding dynamics including timing of capture by whom, how and what the current state of onward use is and (b) determine how these will influence data capture with electronic point of care capture systems.
- Objective 2. To determine what technical, ethical/governance and workforce infrastructure are required for a timely model data capture system that addresses stakeholders' medical, public health, and research needs.
- Objective 3. To determine readiness, we will (a) model the cost of each proposal/ model system and determine the ongoing cost and potential cost recovery, including the cost of all other components (i.e., Buy-in, Timeliness, Capability) and determine what would be required to eliminate key barriers; and (b) map our data to EHR data capture and processing readiness frameworks.
- Objective 4. To provide examples of cost-effectiveness by determining how much additional malaria and/or HIV control would be required to offset the cost of the system over various periods.

2. METHODOLOGY

2.1. Study Design

The study adopted a mixed-method research design. We employed questionnaires, interviews, and focus groups to obtain responses from the study participants. Such information was synthesized to indicate Uganda's readiness to adopt, implement, and use electronic data capture, analysis, and reporting platform that supports Uganda's public health and healthcare services and surveillance.

The study activities were designed as follows;

Part 1: Health Facility Questionnaire: We conducted an electronic questionnaire with registered healthcare providers registered at healthcare organizations in Uganda. The aim was to understand how, when, where, and by whom relevant information on patients is captured during care and the ICT infrastructure present within the clinical setting. This gave us an overall understanding of what happens in different types of clinics currently around routine healthcare data capture and what current ICT infrastructure exist for implementing a more rapid electronic system. The data informed the requirements and costs of implementing an automated electronic data capture, analysis and reporting platform. The platform supports public health and healthcare services and shaped focus group and qualitative interview discussions of possible barriers and facilitators of such a system.

Using the contact details in the healthcare master facilities list register, an email was sent out to all healthcare facilities in Uganda inviting them to complete the questionnaire. Where email contacts were missing, healthcare facilities were contacted by telephone, inviting them to participate in the study. We asked all facilities to complete the questionnaire electronically if they could or through interviewer-assisted telephone calls. Reminder emails were sent one week after the initial email for all healthcare facilities that had not responded to all email contacts. We also included a follow-up telephone call to establish initially if they had received the invitation. Finally, we contacted non-responding healthcare facilities by telephone to determine if we had the correct details and if their contact person were to participate by telephone or in-person assisted interviewing or decline.

Part 2: Qualitative interviews and ad hoc Focus Groups: We conducted qualitative interviews and/or ad hoc focus group sessions with healthcare professionals and CHEWs/VHT members. These interviews aimed to develop a deeper understanding of the challenges and opportunities of the proposed platform. Specifically, it was essential to

develop an in-depth understanding of why barriers exist and factors that would facilitate engagement with a platform if it were implemented.

We selected up to 4 healthcare facilities (3 public health facilities and 1 Private Not For Profit (PNFP)) across 13 districts of Uganda with a representation of 3 districts from each region, including Kampala Capital City for discussion about barriers and facilitators to implementation and use of an EHR, how they could benefit locally, support and infrastructure required, and to collect in-depth measures of readiness on components of our theoretical models. These were mainly healthcare providers who recorded information on patients during care as we selected a representative sample of clinic types. We also conducted 26 Focus Group Discussion (FGD)s with CHEWs and VHTs, with each FGD comprising between 8-10 participants to learn about their potential role in helping support early syndromic reporting, including methods, feasibility, barriers, facilitators and how it might support the work that they do. All interviews were conducted on the telephone and those that lasted for 30-45 minutes were tape-recorded and transcribed. Participants were only eligible if they had completed informed consent for the interview and recording.

Part 3: Key Informant Interviews and formal Focus Groups: We conducted key informant interviews with key stakeholders from a range of groups. These were conducted to ensure that we (a) had a thorough understanding of key stakeholder needs, support and concerns; (b) developed a deeper understanding of partnership opportunities with key stakeholders; (c) identified any cost-sharing or contribution opportunities, and (d) determined interest and support for the proposed models. The key stakeholder groups included the general public; governmental, non-governmental, (NGOs); commercial organisations, e.g., telecommunication; researchers; and front-line care providers, and VHTs/CHEWs.

Key informant interviews with non-governmental organisations (NGOs) and health partners operating in Uganda, such as Centres for Diseases Control and Prevention, United Nations Children's Fund (UNICEF), WHO, Infectious Diseases Institute, were conducted to determine if the proposed system would support their needs in data capture and processing. As with governmental organisations, we predominantly focused on key informant interviews. Interviews were completed on the telephone and/or zoom call at the time that was convenient with the participants.

Discussions with commercial organisations, e.g., telecommunications, cloud data provision, etc. to identify possible commercial support and/or products to enable ICT infrastructure,

were conducted using key informant interviews; the goal for this population was to identify services and costs in order to establish estimated costs for required services and the best methods for securing these.

Key informant interviews involving health researchers were conducted to determine the value of the potential data captured for research purposes and discover innovative methods in ICT and data analytics to deliver a model system.

Part 4: Data analysis and Information Synthesis: Data collected from the questionnaire, interviews, and focus groups were analysed. By triangulating information from all these data sources and using the thematic analysis procedure, the study identified emerging issues. The results presented are based on anticipated themes emerging from the data itself.

2.2. Study Site Selection

This study was conducted across districts in the four regions of Uganda, namely, Northern, Eastern, Western and Central regions. Activities included (a) surveys of healthcare professionals in selected healthcare facilities from the four regions of Uganda, (b) focus groups and key informant interviews of different populations and professional groups in both rural and urban settings that were representative of Uganda's four regions, and (c) qualitative interviews with key informants from commercial partner organisations/NGOs, Research Institutions, Government entities, and ICT professional organizations.

2.3. Study Population and Sampling

2.3.1. Study Population

This project focused on a range of study populations as described below;

- (1). **Adult members of the general Uganda population:** We conducted focus groups with members of the general population to discuss the appropriate use of individuals' health data on the proposed platform. We recruited people residing within administrative districts where the official authority member provided permission to do so. The study population represented rural and urban settings across all four regions of Uganda to illicit a broad set of population views.
- (2). **Government officials who work in a health-related capacity:** We conducted key informant interviews with purposively selected government officials from established organizations, such as; Ministry of Health, National Information Technology Authority-Uganda (NITA-U), National Identification and Registration Authority,

National HIV Programme etc. while at the district level 2 participants were selected from each of the 12 districts from the District Health Department. We used an online survey questionnaire to collect background information about the participant. This was followed by a telephone and/or zoom interview to understand the health information needs, potential impacts of near real-time reporting, and challenges of near real-time reporting.

- (3). ***Representatives of commercial ICT***: Related companies that serve Uganda: In order to understand costs and partnership, we held key informant interviews with ICT providers within Uganda, including; Telecommunications, Cloud data provision, Commercial support and /or products for ICT infrastructure etc.
- (4). ***Health Partners and NGO partners who are involved in health provision and public health in Uganda***: In order to understand electronic health data capture systems already in place, needs of the Country's partners in health and interests/vision for future data capture, we held key informant interviews with the Ugandan health partner organisations, as well as NGOs working to support health across Uganda.
- (5). ***Health researchers from Uganda universities and those from other countries who have a significant presence in Uganda***: Participants included Ugandan researchers who work on human health/public health research for example, the Rakai Health Sciences Program to discuss what electronic data they already capture, how these might fit into the system that we are developing, and what data and/or services they might find as beneficial for their work.
- (6). ***Healthcare providers across Uganda, including CHEWs and VHTs***: We held qualitative interviews with healthcare professionals and both interviews and ad hoc focus groups with VHT members and CHEWs to understand facilitators and barriers to near real time data capture and determine what information they would like in what form to support their work, should such a system become available. The healthcare providers included nurses, Doctors / Pharmacists, / Lab technicians per region.

2.3.2. Sampling

This was a mixed-methods study; therefore, we employed several sampling designs. First, for the electronic healthcare questionnaire, we purposively identified three public healthcare facilities and one PNFP from each of the 12 districts selected, representing three districts per region inclusive of Kampala.

For key informant interviews, we used convenience sampling by contacting key informants for the government, health partner organization, commercial partners, and researchers. They were asked to confirm their willingness to participate in interviews or refer us to a colleague(s) who could participate. A similar convenience sampling strategy was used for healthcare providers and CHEWs/VHT members. These were stratified by types of care providers to ensure representation from a wide range of providers as shown in Table 1.

Table 1: Table showing Respondent Categories

Respondent/Participant Category	No. of Responses
Healthcare professionals (<i>questionnaires</i>)	195
CHEWs/VHTs focus groups	20
Community focus groups	13
Governmental Organizations	34
Health Partners/NGOs	36
Commercial Partner Organizations	51
Researchers	48

Healthcare facilities were selected in each of the regions of Uganda to ensure a good representation. We aimed to recruit up to 200 healthcare professionals from 200 different healthcare facilities for qualitative interviews. For the qualitative interviews, 20 Ad hoc focus groups were conducted with CHEWs and VHT members. Interviews were conducted until saturation. For the formal focus groups with the general public (drawn from the local council and church leaders), a total of 13 FGDs each comprising 8-10 participants were conducted, representing 01 FGD in each of the 13 districts identified including Kampala. Finally, key informant interviews were held for participants drawn from governmental organizations (34), health partners/NGOs (36), commercial partner organizations (51), and health researchers (48).

2.4. Ethical considerations

This study involved participation of humans, and thus required an ethical review. All study documents and tools were submitted to Makerere University, School of Public Health Institutional Review Board (IRB) and the Uganda National Council for Science and Technology (UNCST) who approved the study in Uganda after following the due process. It

was also submitted to the Cambridge Human Biology Research Ethics Committee at the University of Cambridge with the Makerere approval to ensure that the University of Cambridge was pleased with their participation in this study.

All participants completed an informed consent form before participating in the study activity. Filling in and submitting the electronic questionnaire was considered consent by those that participated via electronic means. Participants were free to opt-out of answering any question and could withdraw from the study. All researchers were trained in appropriate, non-coercive recruitment procedures and appropriate informed consent procedures, including ensuring that all questions were considered, that the study had been appropriately described and that participants understood the study before agreeing to participate.

While this study held no personally sensitive information, confidentiality was considered important. All data gathered from this study were stored confidentially. Only the study team had access to these data or those they hired (i.e., the transcribers) qualified professionals to work on the study. All data were stored as unidentifiably as possible, and all identifiers were removed.

Finally, there were no identifiable personal risks to individuals for participating in this study. The only burden was the use of the participants' time. Therefore, none of the information gathered was likely to have any bearing on the individuals' wellbeing, and participants were unlikely to benefit from participation directly. However, the value of the information collected has the potential to support infrastructure for healthcare and public health across Uganda. This study, therefore, has an excellent risk-benefit ratio with extremely low risk and very high potential benefit to society.

3. RESEARCH FINDINGS

3.1. Demographics

In this section, we present the background characteristics of participants. Information provided covers the distribution of participants by a health facility, government or organization, level of education, position held, and duration served in the same place. We believe that these participant characteristics depict- the expertise and experience that make them eligible data sources for reliable and credible information.

3.1.1. Respondents' distribution by Health facility, government or organisation

Figure 1 shows that most of the participants in this study responded to the questionnaires (49%) from healthcare professionals drawn from health facilities. In addition, 5% were CHEWs/VHTs focus groups, 3% were community focus groups, 9% were government organisations, 9% were Health partners/NGOs, 13% were commercial partner organisations, and 12% were researchers.

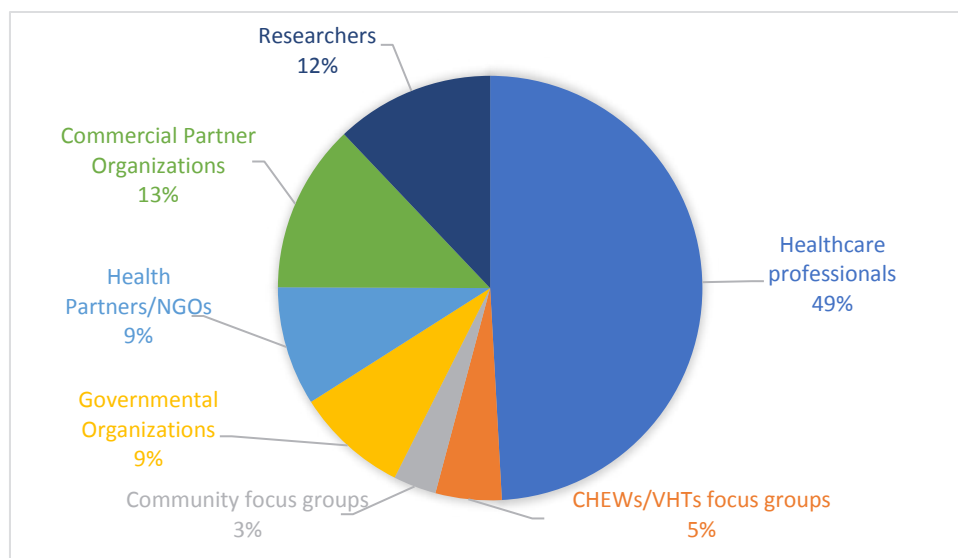


Figure 1. Respondents distributed by Health facility, government or organization

3.1.2. Highest level of education

In regard to the type of education or professional training received, Table 2 shows that the highest percentage of healthcare professionals had received other professional training (45.2%), while 23.4% and 17.1% had Certificate and Diploma training respectively; only 12.3% of them had obtained bachelor degrees. For CHEW/VHTs, less than half of the

respondents had attained some secondary level of education (46.9%). 22.6% of the CHEWs/VHTs had gone past secondary education, while 1.8% had no formal education.

Table 2. Participant distribution by Highest Level of Education

Respondent	Level of Education								Total
	Doctorate degree	Masters	Bachelors	Diploma	Certificate	Secondary	Other professional training	Declined/No formal Education	
Healthcare professionals			31 (12.3%)	43 (17.1%)	59 (23.4%)		114 (45.2%)	5 (2.0%)	252
CHEWs/ VHTs			38 (22.6%)			109 (46.9%)	18 (10.7%)	3 (1.8%)	168
Community focus groups									-
Governmental Organizations	24 (70.6%)		10 (29.4%)						34
Health Partners/NGOs	28 (77.8%)		8 (22.2%)						36
Commercial Partner Organizations			26 (51.0%)		7 (13.7%)		8 (15.7%)	10 (19.6%)	51
Researchers	23 (47.9%)	25 (52.1%)							48

For government officials, the majority (70.6%) were graduates with master's / professional degree/Doctorate degrees, and only 29.4% had a bachelor's degree. Responses from healthcare partners/NGOs show that the majority (77.8%) of healthcare partner/NGO participants had masters or doctorate degrees, and the remaining 22.2% had bachelor's degrees in respective fields. For commercial partners, 51.0% had completed a Bachelor's degree as their highest level of education, 13.7% and 15.7% had at least a certificate and other training, respectively. Whereas 52.1% of the researchers had master's degrees, 47.9% held doctorate degrees. Participating researchers were those that were actively involved in health-related projects in Uganda.

3.1.3. Position of the Respondents at the Health facility, Government and or Partner Organizations

Table 3: Table showing the positions of the respondents

Respondent	Position/ role	No. (%)
Healthcare professionals	Health Facility Administration & Management	15(9.3%)
	Maternal and Child Healthcare Services	24(14.8%)
	Health Education	11(6.8%)
	Nutrition & Immunization Services	40(24.7%)
	General Healthcare and Patients' management	16(9.9%)
	Patients Records Management	8(4.9%)
	Pharmacy services	14(8.6%)
	Laboratory Services	10(6.2%)
	Other	24(14.8%)
CHEWs/VHTs	Two focus groups per 10 districts	20
Community focus groups	One community focus group per 11 districts	11
Governmental Organizations	Mid-level management	19(60.0%)
	Senior management	11(32.0%)
	Other	4(12.0%)
Health Partners/NGOs	One officer per Partner organisation	4
Commercial Partner Organizations	Director	27(54.0%)
	Manager	12(24.0%)
	Other	11(22.0%)
Researchers	Director, Head or another senior leader	10(21.3%)
	Associate professor, Lecturer or equivalent	18(38.3%)
	Researcher	8(17.0%)
	Other	11(23.4%)

24.7% of healthcare professionals were engaged in general healthcare and patient management, 14.8% were involved in maternal and child healthcare services and health education as shown in Table 3. The remaining healthcare professionals were involved in health facility administration (9.3%), nutrition and immunization (6.8%), patient record management (9.9%), pharmacy services (4.9%), and laboratory services (8.6%). As for governmental organisations, 60% were mid-level managers, 32% were senior managers and others (12%). Participants from commercial partner organisations included directors (54%), Managers (24%), and other staff (22%). For the researchers, most of the respondents were either lecturers (38.3%) or heads of departments (21.3%) in their respective institutions.

3.1.4. Years worked at the organization/position

Regarding years of work at the organisation and/or in the position, Table 4 shows that most of the participants had worked at their current places/positions for five to ten years. The majority of the remaining number of participants/respondents even worked for over ten years than those who had worked for less than five years. About 30.0% of healthcare professionals had worked professionally for 2-5 years, with the least percentage working for one year or less (6.7%). About 78.3 % of CHEWs had worked for ≤ 5 years while only 21.7% had worked for >5 years. The biggest percentage of VHTs (41.8%) had worked for 6-10 years, and only 12.4% had worked for 21 years and above.

Table 4. Work Experience

Respondent	Years worked - (years worked) No. of participants					
Healthcare professionals	(>1) 17	(2-5) 75	(6-9) 61	(10-13) 45	(14-17) 23	(18+) 29
CHEWs/VHTs	(1-5) 23		(6-10) 64	(11-15) 18	(16-20) 29	(21+) 19
Community focus groups						
Governmental Organizations	(>5) 4	(5-10) 25		(11+) 5		
Health Partners/NGOs	(1-5) 7		(6-10) 15		(11+) 10	
Commercial Partner Organizations	(>5) 12		(5-10) 28		10	
Researchers	-	-	-	-	-	-

The majority of the agencies, departments or divisions had worked for 5-10 years (73.5%), and only 11.8% had worked for less than 5 years. Additionally, most of the government officials, 62.0% had majorly worked for 5-10 years within the Ugandan government, with the least having worked for less than 5 years (6.0%). Less than a half (42.9%) of the healthcare partners/NGOs had worked in their respective organizations between 6 and 10 years, and only 8.6% had worked for less than one year. Most of the healthcare partners (60.6%) also revealed that their organizations were first established before year 2000. These organizations (61.7%) had worked in Uganda for 21 years and above, while 8.8% had worked in Uganda for 11-15 years. The majority of the commercial partner organisations had worked in Uganda for 5-10 years, and only 17.0% had worked in Uganda for less than 5 years.

3.2. Current Health Data Capture and Use Processes

To gain an insight in the current state of data capture and use processes within Uganda's healthcare system, the study sought to investigate the roles of the different healthcare workers, what data they captured in the execution of those roles, how this data was captured, used as well as the barriers and facilitators to data capture and use processes.

3.2.1. Role of health care workers

In this sub-section, we present the roles of the healthcare workers at the health facilities with a special focus on those roles where data capture and use are involved.

(i). Roles of healthcare professionals at a health facility

This section presents the roles of the different healthcare professionals where data capture, processing and use may be involved. The different roles presented here relate to their weekly activities at the health facilities. Key informant interviews (KIIs) were conducted with 195 healthcare workers (HWs) across the four regions of Uganda. Respondents were asked to give their opinion on the activities they get involved in per week involving data capture and use, whether most people in their role perform the same duties, and how many patients each of them sees per week. Figure 2 below presents the percentages of healthcare professionals who perform roles that involve data capture, processing and use.

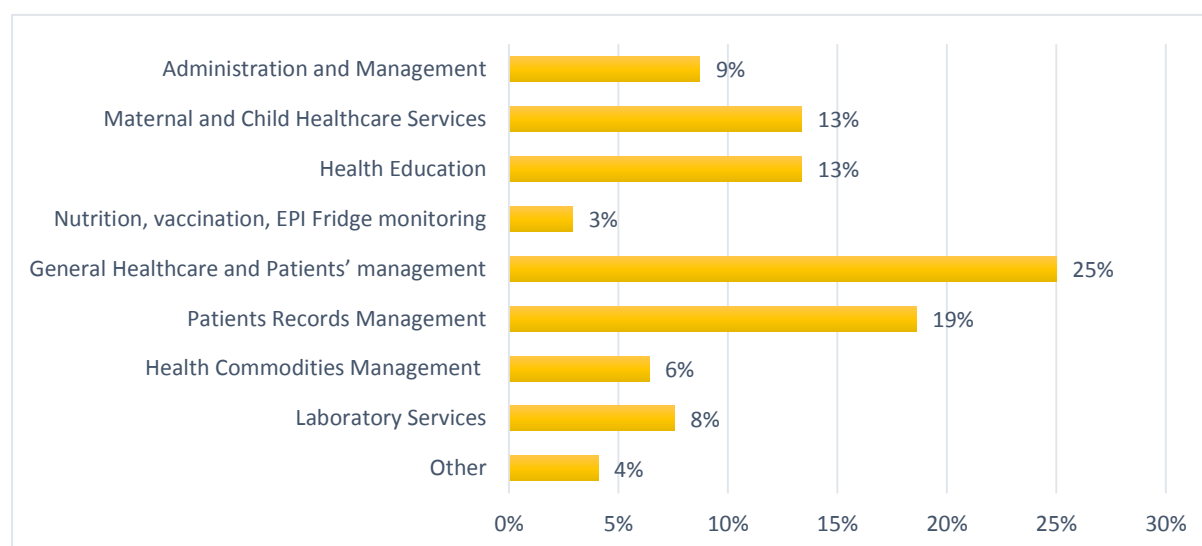


Figure 2. Healthcare professionals involved in roles requiring data capture and use

25% of respondents indicated that they provided general healthcare to patients. The scope of general healthcare included diagnosis and treatment, clerking of patients, laboratory investigations, testing and recording results, collection of samples, and operations. 19% of

respondents reported that they support patients' records management. 13% of respondents said they provided Maternal Healthcare services, and another 13% agreed that they provided health education. While 9% reported that they were involved in administration and management, 8% provided laboratory services.

The remaining 6% of the respondents provide Health Commodities Management; 3% provide Nutrition Immunization Services, Expanded Programme on Immunisation Fridge monitoring; and 4% provide other services.

On whether most professionals performed the same duties at the health facility, the majority of the respondents reported that they performed similar duties. This is evidenced by respondents *HPMSK_01* and *HPH_04*, who said., *"In my section as laboratory we all perform the same duties in terms of professionalism"* and *"I think most people perform the same duties but it would be better if some duties would be given to someone else, an addition person would help to ease the work"*.

However, some respondents indicated that the roles sometimes differed, as evidenced by a respondent who in an interview said: *'No! I don't think so, like I told you, I do many duties that I am not meant to be doing because of shortage of staff, like in the OPD, this forces me to do their work too, I think this should relieve me of some duties so that I can concentrate on my Paediatrics Ward.'*- *HPKY_08*.

Concerning the number of patients each of the health professionals see per week, most respondents indicated that they saw between 100-200 patients per week as evidenced by the following responses; *"In a day I see average 100 patients"* -*HPMF_02*, *"Okay like 150 in a week"* -*HPNP_05*, *"120-200 in a week"* -*HPNP_09*. However, in some health facilities, respondents see more than 250 patients per week as reported by respondent *HPH_13* who in an interview said *"I see about 300 patients per week and in some weeks, it even goes higher"*.

(ii) Role of CHEWs/VHTs

To further understand the role of health workers in data capture, processing, and use, we investigated the roles of CHEWs/VHTs, focusing on duties that they perform in a typical week. In addition, 20 *ad hoc* focus group discussions (FGDs) of 2-5 members were employed from 10 districts. Respondents were asked to explain their role that relates to capturing, processing and use of health data, as well as their interaction with health professionals and clients. Figure 3 below presents the percentages of CHEWs/VHTs who perform roles that involve data capture and use.

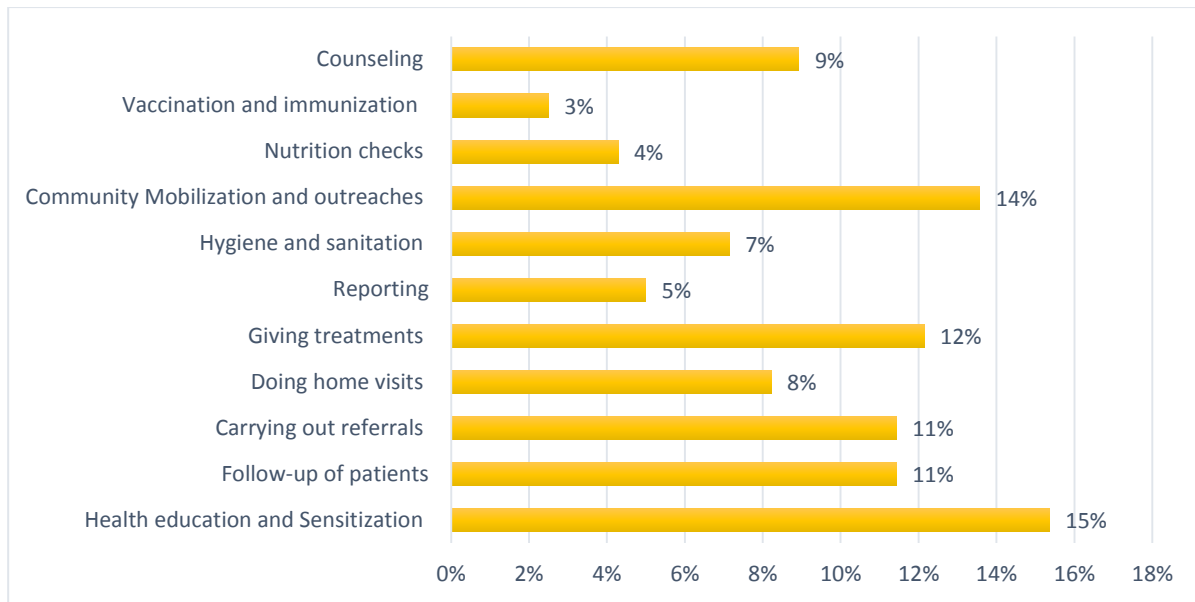


Figure 3. CHEWs/VHTs involved in roles requiring data capture and use

15% of respondents indicated that they provide health education and sensitization to patients, 14% reported that they do community mobilization and outreach, 12% said that they give treatment to patients including malaria, flue and cough mostly, 11% said that they follow-up patients and another 11% carryout referrals. The remaining 9%, 8%, 7%, 5%, 4% and 3% carry out counselling, home visits, hygiene and sanitation, reporting, nutrition checks, and vaccination and sanitation, respectively.

On whether most professionals perform the same duties, the majority of the respondents reported that they do similar responsibilities. This is evidenced by respondents who, in an interview, said. *“Yes, all VHTs perform the same duties”*- HFG_01, *“yes, we all perform the same duties”*- NeFG_02.

However, some respondents indicated that the roles sometimes differed, as evidenced by respondents who said in an interview: *“Most of them are the same, but we hear some districts like Kamwenge are different, those VHTs test for malaria and even give medication to the sick. Some VHTs are ahead of us in what they do. Some of us were trained on how to test for malaria, but that is where we stop”*- KFG_02

With regard to the number of patients each of the VHTs see per week, most respondents indicated that they see between 15-30 patients per week, as evidenced by the following responses; *“it depends on the services offered, but it is between 15-20 people, some are always sick and don’t know where to go for services”* -KyFG_02, *“Between 15-25 people and by the time we identify them they are very sick”* -MFG_01, *“Between 15 and 30. Some*

come saying that my child has been feeling pain since yesterday, others come looking for family planning methods, and others come with side effects of family planning, and we explain to them.” -HFG_01.

3.2.2. Routine care data currently captured in Uganda

(i). Type of data collected

To understand what care data is captured, processed and used at the health facilities/clinics, healthcare workers were asked what type of data each one of them collected in the course of performing their respective roles. Respondents indicated that the data they collected depended on the institution's mandate where they are employed. They reported that some institutions collected health data directly, while others collected non-health data that supports the various health systems running in the different entities in Uganda. Figure 4 below shows the different types of data that the health workers collect in performing their duties.

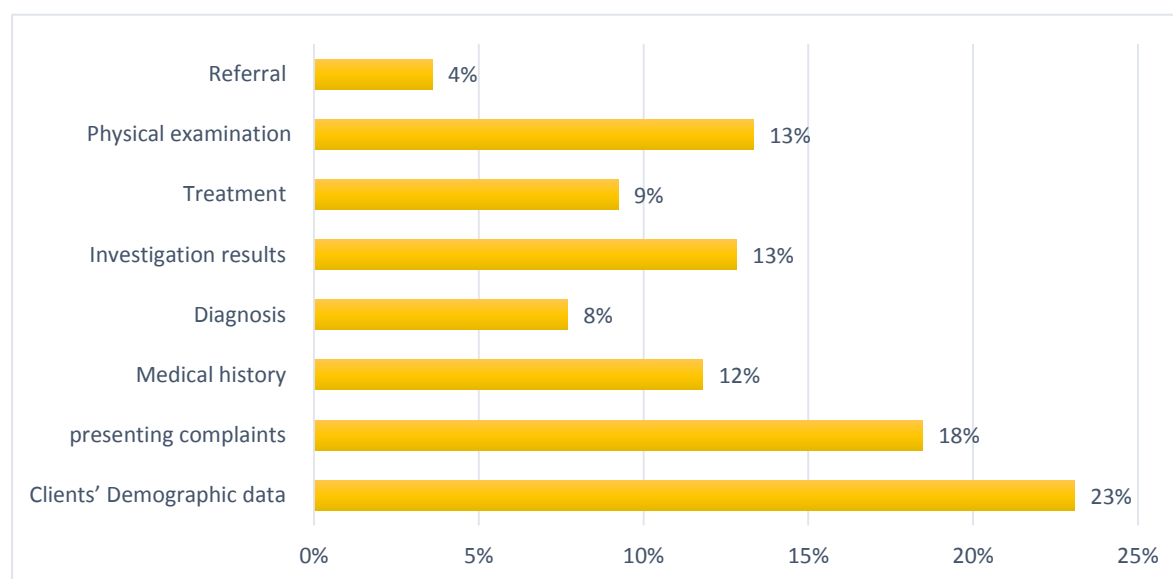


Figure 4. Types of Health Data Collected

23% of health workers reported that they gather demographic data, 18% reported presenting complaints, 13% physical examination, 13% reported investigation results, 12% medical history, 9% treatment, and 8% reported diagnosis while referrals information was reported to be the least gathered with 4%. This is evidenced by responses from several respondents who said that; *“Bio data: the name, age, sex, symptoms and signs, treatments, and referral information; we also keep the number of households in the community and the community population; then the household head and the household members’ basic details.” -HPG_06,* *“We collect bio data like name, age, sex, we also record the symptoms, diagnosis, treatment,*

prescription, referrals, statistics of mothers that have given birth, new-borne, pregnant mothers, HIV clients, and their locations, the conditions, household size, household head, population of the village, number of children in schools, death in the community (cause, time, name).” -HPS_07

(ii). Methods for Health Data Collection

To gain an insight into the health data collection mechanisms, health workers were further asked how they collected the data that they use to perform their roles. Respondents revealed various ways of how information was recorded. These included; health workers manually taking the lead using plain books and well-formatted registers and forms for specific programs and other hospital units. This was evidenced by respondents who reported that:

“We just have registers, at the triaging point. When the patient comes, that’s when you take the demographic data-outside, now when the patient sees the clinician, then the clinician sends the patient to the lab, the lab people also record theirs using the lab registers, then the book comes back to the clinician, then he prescribes the medicine, if the patient is taken to the ward, there is an inpatient register, we also capture, if the patient is an ART patient, we also take them to the ART register, and if the patient is having other conditions like Tuberculosis (TB), we have the TB register, if it is the side of maternity, they also have their register there. We do not use electronic recording.” -HPH_12,” We use exercise books to record patient treatment and the registers and records when the patient is there” -HPJ_03

However, some respondents further stated they used electronic devices to collect data especially for the HIV patients as evidenced by one respondent who said; *“in ART Clinic, they use EMR, which is managed by a data officer; the staff there, send the files to the officer to be updated. For us in the OPD, the registers are taken to the records officer to enter the data” HPJ_12, “We don’t use electronic methods to record data apart from ART clinic.” HPH_04*

As much as data was collected either manually using books, forms and registers or electronically using computing devices, some respondents reported recording data manually and electronically. This was confirmed by a respondent who said that: *“So, the bio-data is normally taken at the Triage table from outside, then from inside it is now the real condition the patient is now presenting and are recorded in different registers that we are having. OPD uses paper work but in ART Clinic, they use EMR, which is managed by a data officer; the*

staff there, send the files to the officer to be updated. For us in the OPD, the registers are taken to the records officer to enter the data”-HPNB_01

Some respondents also indicated that the health data was obtained from studies conducted by researchers. It was reported that the data was usually cleaned, and as such was not in its raw state due to the many quality checks that are done. As reflected by a respondent who in an interview said: *“Sometimes we commission studies and to help us get interventions and it depends on data and we normally get it in a raw form and we are able to make sense out of it but our kind of desire would be getting data in a more usable performance like when I go to the system and simply look at the data where a lot of cleaning has been done. A lot of processes have been done. In other words, it’s not raw data. There is a lot of quality checks that have been undertaken in the kind of data. So maybe the other additional data because you asked about format is that we always need more data around Global Positioning System (GPS) coordinates for communities that we are serving and we kind of make geo social analysis. Then about formats, picture data makes a lot of sense in programming where you simply make a purpose visit then we shall have that data coming in. Then its further used for collaboration especially when making reports of progress such data in that format is used in making a case or sense of whatever we are reporting about.”-HPO_01*

3.2.3. Data use in the Healthcare System

The study also investigated how health data was used to deliver value for different actors in the healthcare system. The questions asked were related to the relevance of data collected to support healthcare work-routines and characteristics that make the data suitable to support access to services in a reliable and timely manner.

Respondents indicated that health data collected is used in continuous monitoring and evaluation processes, understanding to what extent the intended objectives have been implemented and also assessing how the mortality is being reduced as a result of the implemented programs.

Respondents also reported that data was analysed to give insight into the kind of courses health workers register for, which cadres are more likely to finish a course, and which region and district have more of those health workers. The data was also analysed to inform decision-making and know where more efforts/interventions should be put. On the other hand, health data is used to write manuscripts and then reports which are shared with local partners like the Ministry of Health and the funders.

The non-health data collected was used to find gaps in the country's communication sector from an infrastructure perspective and from the demand side. The non-health data collected includes; network coverage data from telecommunication companies, the number of computers in different institutions, internet connectivity, human resource capacity, specifically ICT staff that deliver services, location details of the health facilities and medical personnel licensed to operate e.g., doctors, nurses, surgeons, location of the infrastructure, etc.

Other respondents reported that health data was useful for planning and budgeting analysis of the number of diseases reported in a particular period, resulting in proper management of the health facility. It was also reported that medical data was normally summarized in charts and graphs at the primary source health facility. Reports were submitted to the district and then to the national office at the Ministry of Health on a monthly basis. In an interview, two respondents had this to say: *“This information is used to identify problems of particular patients, sometimes also, our problems too! So, the complaints of the patients help us to identify our weaknesses but also in planning. At my level, Nursing Officer, I make a summary which I report to the health facility in-charge on a daily basis. The In-Charge then reports to the district and the diocese and then finally to the national office, Ministry of Health.”*- HPNB_08

In addition, it was also noted that the findings are used to inform the decision-makers in the health sector in coming up with the proper decisions that would affect the health service delivery. This is because the findings might directly impact the lives of the people and help the government make informed decisions on how to prevent disease breakouts. This was evidenced by respondents who said that: *“Research findings are useful and from an experience, I have had studies or been part of studies that have been translated and improved health or changed the way healthcare has been provided in the different parts of the country. For example, one time we did a study of where we were testing men in betting centres, testing them for HIV, and those results kind of became pertinent because at some point then the United Nations Programme on HIV/AIDS (UNAIDS) asked for the findings from us and this led to another campaign called “KICK HIV out of the country” so you can have these small projects that can be translated into research, yeah!”* - HIR_08.

“Once the research findings are good, they are used to make amendments to policies or create new policies that are then implemented and tried out to healthcare professionals. I can give you an example of some policies we have been involved with; we did a Pre-Exposure

Prophylaxis (PrEP) implementation study that eventually informed PREP roll-out. So, ultimately, we need to get the policies written to support implementation. We inform the commissioner about our findings and publish so that other people can learn from us. The health units that we work with give them like leaflets that kind of tell them about the outcome, but even posters so that they can learn from it.” - HIR_05

Collected data was also used to provide researchers with datasets that they could easily tap into to develop further research questions. Researchers were able to quickly pick up burning or low hanging questions that impact health care in the country. Sometimes, researchers did not need to go to the field to collect the data since they were able to use the existing data in the database. From a research perspective, many research organizations are currently doing research in silos, funded by different people and following different mechanisms. So, if one had a system that would enable one to know what was going on in different parts of the research organizations and in real-time, that would be helpful. This was evidenced by a respondent who said that: *“If people can get data from one place, then it will help a lot before they collect their own baseline data. If someone already has existing baseline data, then they can use the data and identify a gap followed by the intervention. They don’t need to like go through the whole process of cleaning the data, making sure it is accurate before they start using it for an intervention, so it impacts on the process of research. On the other hand, we spend a lot of money collecting data and yet we can use existing data to answer some of the research questions. However, the challenges of existing data, the data collectors do not have in mind the researchers who may use the data. Therefore, the quality is not to the level of what the researcher may need. So, if we have such a system that can collect high-quality data, then we shouldn’t be spending money on data collection. We just use existing data that is already collected to answer such questions and that would bring down the cost of conducting research in the country.” – HIR_03.*

Further still, researchers hoped that the intervention would help get quick responses on issues that were coming up, such as epidemics. The intervention would also be good for data quality, especially if there are checkpoints. This was evidenced by respondents who said that: *“For example, even with electronically transferred data, there is sometimes a need to be very careful. If somebody, does it wrongly, everything goes wrong. However, if there are proper checks, then they can be reported in good time, which will be very fruitful on the research side. In addition, the issues that need emphasis are easily and quickly revealed. Therefore,*

action is taken as soon as possible, and probably more research is generated without wasting too much time.”- HIR_09

“Data access for any researcher is critical because one can develop so many research questions once the data is available. So, this platform will significantly impact the research portfolio, research capacity and outcome. It will also be possible to provide feedback to the community from research findings and even better if data is disaggregated, say by district or region, making it even more informative. The feedback will also encourage people to participate more. Any innovation integrating health and technology to generate reports from the community to the national level is what is needed at the moment.”-HIR_07

“This platform will be of much help, if I can find a database with data that can answer certain key research questions. For example, the demographic health survey data has been used often to answer very key research questions and this is routinely collected data from survey, so I think it will be really super helpful and it will push my work forward. Besides, with this intervention, results will be coming out even much faster and we will get to know what every other person is doing, even in health itself which has so many subsections, sub departments and whatever, one can easily know where issues are and what to pick from where” - HIR_06.

3.3.4. Data and Information Sharing

Both data and information can either be shared on paper or electronically. Participants were asked about the differences in paper or electronic health data/information sharing with the locals or national health officials. The responses from almost every FGD conducted indicated that they preferred paper-based information instead of electronic format. This could be attributed to the illiteracy levels in many rural communities and the lack of technology gadgets for use. On the other hand, just a few FGDs had community leaders who felt they needed the electronic version of information sharing. These quotes can summarize views of focus group discussions: *“It would be better for me when the information is just written on paper because as long as you put it on electronic, that means it is now publicized all over the world and it's not going to be secret. It should be on paper because paper can easily be hidden. It may also depend on the type of people, there are some of those who are current, but like some of us who are old it is better on paper. I would prefer paper because we cannot afford phones and those electronics but if we had them, it would be better electronically. It should be on a gadget but restricted where it should be sent, not on social media but email*

because it is more secure on email. You may put it on electronic when you need help from the people who may be far away from you” – NeCL

The same group further said: *“We prefer electronic because it is faster and also messages that are "flagged red" can easily be deleted and the information kept to yourself in the heart. Generally, when it comes to privacy, easy access and durability, we prefer electronic sharing because paper can easily get destroyed. Paperwork can easily be destroyed or lost compared to electronic data which can easily be retrieved. Paperwork is slow, so easy sharing of data compared to the long process of paperwork.”*

Considering sharing information at the individual level, the respondents perceive that; people willingly share information about their conditions freely, knowing that their privacy is kept confidential. Then, this information is quickly shared with the community during the exchange of ideas for the proper handling of the problem. When names are attached or shared, tracing the patients would be more accessible when the interventions have come. Such people can be followed up, counselled and treated appropriately. A participant said, *“It is okay to share name, age, sex, village of person with a contagious disease across different healthcare providers for easy follow up. When it comes to HIV, it would be okay to share information without unique identifiers to protect the privacy of an individual” – ACL.* However, the interview findings showed that; some people in the community are rooted in superstitions, limiting them from treatment. On the other hand, privacy and confidentiality must be maintained for cancer, HIV and sexually transmitted infections.

Community leaders further emphasized that it's good to collect most of this information like age, sex, names on almost all cases, because it helps with the planning to know the different conditions and sometimes draw reasons for why these conditions happened. Specifically, persons' names are important since if one is talking about age, sex and district name, there might be people of the same sex, age and from the same district, so the name can act as an identifier. However, if patients' data is going to be shared, patients' names should be removed to cater for confidentiality issues and avoid sharing people's health conditions. Specifically, for certain conditions such as HIV and cancer, the number and not the name should be maintained.

The community leaders are rather concerned with the people with whom information is shared due to variations in their education, training, accessibility and professionalism. This has been emphasized in the quote from the FGD community leaders as; *“Yes, it matters a lot*

not everyone in the facility should have every information concerning our conditions and well-being. If am seen by a doctor for instance I expect some of our private information to be accessible by the doctor and not a cashier in the facility. Also, some information on some conditions like HIV status should not be shared across all facility staff.” - HCL

When it comes to other specific groups, including identifiable, anonymized, aggregated data and examples of obvious problems (e.g., injury), non-obvious/mildly personal (e.g., malaria, cancer), very private (e.g., HIV), community leaders reported that; specific groups should only get access to certain kind of data, for example, most of the information shared outside the facility should be anonymized and identifiable information should only be shared with health providers who are to give the primary care to the people. Specific groups should have access to certain data/information. For example, identifiable data should be accessed by the health workers working on the patients, anonymized and aggregated data can be accessed by the leaders such as district health leaders and the Ministry of Health. *“For injuries, all the healthcare providers both in and out the community can receive the information, the VHTs as well should receive such information because they can educate and give first aid or make referral to healthcare facilities. Although, the VHTs may not receive the information in full proportion because they have limited experience with injuries, they are trained on mild and specific diseases like malaria, cough, diarrhoea and cannot handle some of these diseases; more so they are limited to children under five.” - HPO_02*

“For mild diseases such as malaria, information can be shared with the VHTs because they have basic training, then to all the healthcare providers both in and out of the community. Others should be the public health people who can educate on preventive measures and also who can carry out investigations of the healthcare problem, and everyone in the community because from the community is where support and help are found.” - KyCL

“For the very private diseases, information cannot be shared with the VHTs because they know us personally, and they are reckless and cannot keep information confidential. Although, sometimes it depends on the person: they are some who are trustworthy have high integrity and can advise you or refer you to the healthcare facility for help”. - ICL

The respondents affirmed to sharing health data however little it may be and intimated that they are already doing so with the MOH while observing the output. According to the respondents, protection and control of individualized health data are a priority, and they try as much as possible not to share individualized data within organizations. The respondents

intimated that the data could be shared based on the data-sharing policies in place and if it will not be misused as elaborated in the quotes; *“So long as these ethics are followed. In reality we wouldn’t want it to be misused.”*- SCL *“Definitely it can be agreed upon because as an organization we have a data sharing policy, data governance policy and we are guided by those policies. If partnership comes in, then we can put it in that policy on how the sharing can be done.”*- HPO_02

When it comes to other specific groups, including identifiable, anonymized, aggregated data and examples of obvious problems (e.g., injury), non-obvious/mildly personal (e.g., malaria, cancer), very private (e.g., HIV), community leaders reported that; specific groups should only get access to certain kind of data for example most of the information shared outside the facility should be anonymized and identifiable information should only be shared with health providers who are to give the primary care to the people. Specific groups should have access to certain data/information. For example, identifiable data should be accessed by the health workers working on the patients, anonymized and aggregated data can be accessed by the leaders such as district health leaders and Ministry of Health. *“For injuries, all the healthcare providers both in and out the community can receive the information, the VHTs as well should receive such information because they can educate and give first aid or make referral to healthcare facilities. Although, the VHTs may not receive the information in full proportion because they have limited experience with injuries, they are trained on mild and specific diseases like malaria, cough, diarrhoea and cannot handle some of these diseases; more so they are limited to children under five.”* - PTC_01

Furthermore, these participants said; *“For mild diseases such as malaria, information can be shared with the VHTs because they have basic training, then to all the healthcare providers both in and out of the community. Others should be the public health people who can educate on preventive measures and also who can carry out investigations of the healthcare problem, and everyone in the community because from the community is where support and help are found.”*- PTC_01

Respondents felt that such information should be shared with only ID numbers when it comes to individual level data shared at the local, district and national levels. But in some instances, both ID numbers and names can be used for easy access during follow-up to avoid a loss-to follow-up. Information on family members or next of kin is needed by the healthcare providers in-cases when one is in a state of an emergency and for psychological support. A quote from an FGD by community leaders: *“For example, when its malaria, the local facility*

should have all the information like names, age, sex because they need to give out treatment and sometimes this treatment is dependent of age and sex especially for pregnant mothers. But district and national level can get summaries like age, sex, condition treated, medicine given and residence because they are enough to make them plan for the population. On the other hand, personal health number should be shared instead of the name, not everyone should know you are sick especially with these deadly diseases like HIV. Even if it's a small child/ a baby, everyone's privacy should be observed. Maybe age, sex and disease can also be used for accountability and planning purposes, this too still makes the patient safe.”- MCL

3.2.5. Perception and Attitude to use of Technology in Data Collection

When healthcare professionals were asked to provide their views regarding the use of technology in information gathering, they had the following to say regarding;

1. How electronic medical records can help or hinder the delivery of patient care

A respondent had the following to say; *“Of course it would help. Like in a laboratory we have a part of following up these TB patients, giving them drugs following them from the first month up to the sixth month. So, it becomes easier for you to open the side of that patient and see how far”* (HPI_01). This assertion was confirmed by several respondents who said, *“It will be easy to record and retrieve patient information”* (HPA_02, HPA_03, HPJ_13, HPJ_14) and being *“fast and time saving ... will ease my work of delivering care”* (HPH_11). Its *“helpful in identifying the needs of the clients”* (HPJ_02) and with existence of an EMR, it will be *“easy to retrieve information and you don't need to write everything when the same patient comes back”* (HPH_12). Also, *“If I have the information in a medical record, it will make my interaction with the patient easy because I just be asking to confirm”* (HPI_12). Finally, another respondent said, *“I think the electronic records will ease our work because they are organized. I would use a computer to feed in the required information of the patient and I prefer using a computer. I would enter data when the patient is in the room because it can help not to forget anything”* (HPH_02).

Hindrances include no-accessibility to required patient information like when electric power is off (HPH_16) or there is a system crash (HPJ_01), inability to fully use the EMR,

2. How electronic medical records can help or hinder understanding the needs of your patients

“When someone comes back, you review the previous history before you make another treatment” (HPI_09). *“Helps to track the patients' medical history even if the patient does not*

want to disclose that information” (HPJ_08). “It will help me because the records will be there and will be easy to retrieve, also would use it to analyse the data and know which help my patients most need” (HPH_04). “Helps to review patient treatment outcomes” (HPJ_09), like of a given treatment. It can help identify out breaks and improve client services (HPH_10). “I would use them to review patient’s previous information to make sure I make informed decisions” (HPH_13).

Cited hindrances to how EMR can hinder understanding the needs of your patients include, failure to access the records in the event of a power blackout (HPH_15, HPKD_12), as expressed by a respondent who said *“When for example electricity has gone and I can’t access the information this will hinder me”* (HPH_15); failure to use features of the EMR because of a knowledge gap (HPJ_06); distracting of healthcare professional by being preoccupied with typing than paying full attention to the patients’ history (HPKD_12);

3. How electronic medical records can help or hinder assessing quality of provided to patients

“Data can be aggregated and put in a chart to see if this one is okay or needs attention. You can also put in percentages to know which ones are high or low” (HPI_03) or “we generate a data summary to evaluate our performance. This helps us to know the quality we give” (HPKD_15). One respondent argued that the EMR can help understand “how many patients have we treated, what conditions do they have, what drugs have we given them. What do we need to do? Why are these patients coming back? It will help us to know if we have drug resistance and whether our drugs are not working or if we need to change the services” (HPI_06). Another argued that “by going through and I see how I was able to manage the patients” (HPH_03).

Hindrances include difficulty in using the system to access quality of care – like express by a respondent who requested that *“I will need training on how best I can be able to analyse data to get the best out of it”* (HPH_13), and *“It will need more time for me to understand how to use it so this will be an hinderance to me”* (HPH_14).

4. How electronic medical records can help or hinder reporting to other authorities (e.g., MoH, WHO, etc.).

According to respondents, the EMR will lessen work, easier, faster, make reporting faster and near real-time reporting and feedback, and accurate reporting. Several respondents alluded to these facts as follows; *“It will actually help to reduce on the time taken while generating data*

to make reports. I also think it can quicken the communication that we can send reports and get timely feedback” (HPH_01). “It will actually help quicken the flow of data and it will be more less work and it will allow real-time flow of information back and forth.” (HPH_02). “it’s very easy to make electronic reports especially when handling many patients. Also, easy to distribute reports to different authority at once. This will save a lot of time” (HPJ_08). Specifically, “It will make reporting to MoH easier (HPA). “It will help us send accurate information and get timely feedback and it will be less work with such systems” (HPH_13). “Reporting will bring less work. If I already have computerised work, then at the end of the month, I will just extract the numbers and put in the template. or if it's organised well, you easily command the data I entered in a month directly to a reporting template” (HPI_01). Overall, it will improve on the way we report and enhance accurate reporting.

Hindrances include inaccessibility to medical records/reports in case *“the stored data is crushed or lost” (HPJ_01).*

3.2.6. Barriers and Facilitators to Data Collection, Sharing and Use

(1) Barriers to Health Data Collection and Sharing

Figure 5 shows barriers to data collection and sharing. When asked about the barriers to data collection and use, 83% of respondents indicated that there is insufficient funding, as evidenced by *“Well, funding is definitely part of every man’s problem, if you have the funds, you’d always want to have data but sometimes we don’t have the funds so that’s the given. Sometimes even when you get the funds, the red tape around data in Uganda is just too much due to lack of awareness in things like data sharing which becomes a hindrance to accessing good quality data.”- HIR_02*

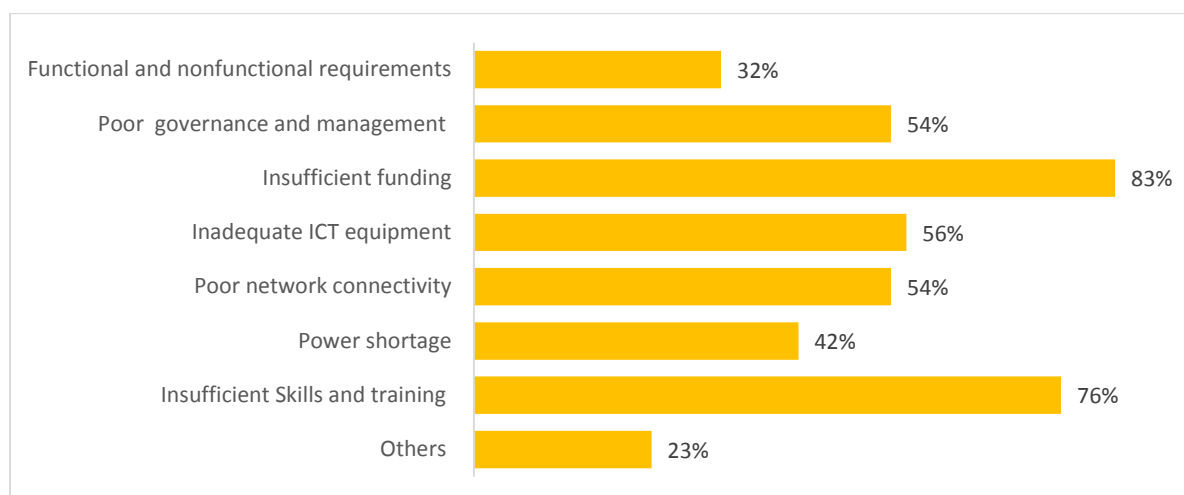


Figure 5. Barriers to Health Data Collection and Sharing

76% said that insufficient skills and training, as evidenced by a respondent who said that; *“The time lapse between training and the implementation! We expected that after training the technical officers immediately implement the system but due to certain challenges this took longer than expected. At this point, the skills and knowledge that had been impacted had already been forgotten and everything looked like something new because of lack of practice.”*- HPH

56% said it was inadequate ICT equipment as evidenced by a respondent who said that; *“these days the rate of life expectancy of ICT equipment is short and people easily get absolute, also physical damage or theft of the equipment from health facilities, success of eHealth relies on the extent to which the related technology, such as the electronic device,”*- MICT_02

54% cited poor network connectivity and governance and management, as evidenced by several respondents who reported that; *“Not every health official had the computers and knew how to use them. Also, the poor network system as well as the few computers in the hospital; some of the HWs didn't know how to use the system so we had to teach them.”*- UCC_03

42% of the respondents said that power shortage was a barrier, as evidenced by a respondent who reported that, *“The knowledge gap in ICT is also a barrier; some people are not IT literate. The network is very poor and often times there is no electricity. When the computers break down there is no contact person to repair them, leaving them unutilised for a long time. The work on supplying the HMS forms was left to IPs whose agenda is different and they are also interested in collecting different data e.g., HIV data. Sometimes they also indicate that they are not in position to print the tools because they lack the capacity to due to the large*

volume tools used. Also, the tools for data generation keep on changing due to emerging conditions, but when they supply us with old tools, we end up not capturing some information which is important. The irregular supply of tools leads to improvising and some data is not captured because health workers depend on their memory to capture data, leaving out some indicators.”- DHO_7

23% reported that functional and non-functional requirements was a barrier to data collection and use as evidenced by a respondent who said that; *“I think it is possible, right now people are getting used to collecting data on phones, tablets, I think it is picking up, it is convenient, it is quick of course, the challenge is when the data is sent to the central system, can they be able to retrieve it or access it? It looks like you enter the data into the system then the data collector may not be able to access it, can they be able to download it and use it for their local health facility for programming, I haven’t heard that in the system which I think is a very good way to improve data use.”- MOH_02*

23% of the respondents said that there were other barriers of data use and sharing including, continuous use of old manual forms, information security concerns, user resistance, stigma as evidenced by several respondents who reported that; *“It would be better for me when the information is just written on paper because as long as you put it on electronic, that means it is now publicized all over the world and it's not going to be secret. It should be on paper because paper can easily be hidden. It may also depend on the type of people, there are some of those who are current, but like some of us who are old it is better on paper. I would prefer paper because we cannot afford phones and those electronics but if we had them, it would be better electronically. It should be on a gadget but restricted where it should be sent, not on social media but email because it is more secure on email. You may put it on electronic when you need help from the people who may be far away from you.”- NCL* *“Cancer or HIV, the patients are treated as "living dead" by the population and in the healthcare facilities they involve a lot of counselling to help the psychologically stressed people to ease their worry and anxiety. These days, cancer scares people more than HIV in the community, and also fear diseases that kill very fast like; Ebola, COVID-19. Although we think HIV status must remain confidential not the same because different ailments have different medications. Different ailments give different shock to patients, i.e., some need special attention.”- KyCL*

(2) Facilitators to Health Data Collection and Sharing

Figure 6 shows enablers to data collection and sharing. When asked about the facilitators of data use and sharing, 86% of respondents indicated that education and training is the major facilitator of data collection and sharing, 82% reported availability of internet as evidenced by one respondent who said; *“Okay! For the paper records, some of the information can easily be missed or lost unlike for information which is digitized which can be accessed from anywhere any time. For instance, if the entire health facility is connected to the internet, then can be linked to the Ministry of Health and information can easily be shared. Sometimes when we are for meetings with officials from MoH, I always hear people talking about dashboards, so we can also use those dashboards, to see how we are performing directly.”*- NeFG_01

75% said that increased resource allocation would facilitate data use and sharing as evidenced by a respondent who reported that; *“One, at a health center III there is a Health Management Committee which is formed by members from the community itself. Their meetings are normally every quarter, so they come with the views of the community. Then, in the community there are outreaches we normally carry out and community dialogues we do carry out every once in a while, when the funds are available. So that's how we get the perspectives from the community. In addition, the meetings at the town council level where the Parish chiefs can air out the facility stuffs of what the community is thinking about.”* - HIV_02

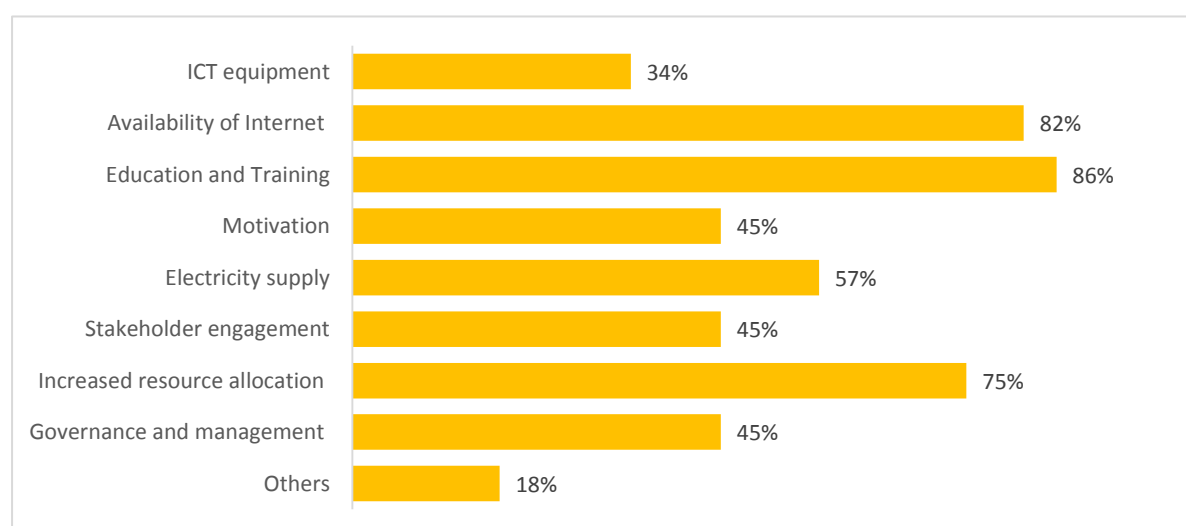


Figure 6. Facilitators to Health Data Collection and Sharing

57% reported electricity supply as evidenced by a respondent who said that, *“Currently implementation of systems is possible in Uganda because there is electricity in many parts of the country, I can give you an example not necessarily under research but I know that under the PEPFA programming there are lots of systems that they’re using such as electronic medical records. We now have a good ICT capacity as a country, so developing such a system would not be a big challenge because we already have the technical skills developed within and from within the country.”*- HIV_01

Motivation, stakeholder engagement, governance and management were also cited as facilitators each with 45% of the respondents as evidenced by a respondent who said that: *“Most of our findings have been translated into real policy, we publish our findings in peer review journals and we get really wide audience out there, and we also publish through international and national conferences. Most of our findings have caught the eyes of policy makers at the international stage including the WHO, UNICEF and UNAIDS who have really used them to formulate policies around HIV. Further still, our findings have guided so much the prevention efforts internationally and nationally and have showed people that the major driver of HIV transmission is the viral load and how much virus people have in their blood. For example, there’s now the use of treatment of HIV using ART not simply as treatment for someone but also to serve as a preventive tool, now that is a big policy worldwide whereby WHO and UNAIDS is called test and start on treatment as prevention, but that work came from us. We have carried trials on prevention such as male circumcision and showed that male circumcision prevents/reduces male acquisition of HIV by over 50% and that has already gotten into policy. Our findings on ART are also already used by the MOH of Uganda as policy, we have contributed a lot to diagnostics, before the HIV treatment eligibility in Uganda was based on symptoms. However, we did the research that showed that staging alone would miss a lot of people/patients that were meant for treatment and it would miss about 50% of people on treatment so that has also gotten into policy already scrapping symptoms alone as criteria to use of CD4 counts and we really also showed that CD4 counts are not as useful so we went to viral load and that has also gotten into the policy.”*- HIR_06

34% reported that ICT equipment was a facilitator to data use and sharing as evidenced by a respondent who said that: *“Largely we are still at paper-based data collection at the health facility. Some few computers exist which are used to track commodities, drugs that have been given out, consumables, HIV and OPD. We therefore believe that having more computers can improve data sharing.”*- HPJ

18% of the respondents reported that there were other facilitators of sharing including, continuous M&E, disease outbreaks, sensitization and user commitment. Overall, data sharing is permissible. In fact, a participant said that, “There *would only be a problem if you don't follow the laws and restrictions related to data. But sharing wouldn't be a problem as long as you consent and use it for the same reason you asked for it*” – MICT_01.

(c). Barriers to Health Data Access and Use

On data access, there is a general view that data should be accessible to the right persons, especially when it comes to meeting national interests (MAL_02). Government participants were then specifically asked to state what they perceive as potential risks to the different types of health data, i.e., aggregated data, non-identifiable data, and identifiable data. Their responses showed that most of the participants perceive low risk when dealing with aggregated data. The following responses express their views; “*The risks are lower with aggregated data than with the EMR records at the health facility*” -NITAU_02, “*There is no risk in sharing aggregated data*” - NITAU_04, “*There is no risk because no one will be able to identify whose data it is.*” - HIV_02, and that “*aggregate data wouldn't be harmful as such because it doesn't identify specific individuals, as long as the person requesting for the data is going to put it to its rightful use*” – DHO_7. “*Overall, when aggregated data is shared, it is used to improve programs, so I can hardly think of a risk to this.*” - HIV_03. These respondents believe that if responsible people can access the information, it will help the decision-making process, planning, and even accountability. Therefore, they think that the benefits outweigh any potential risks (HIV_03, DHO_6, DHO_7).

On non-identifiable data, many of the participants confirmed that if properly used, there are no risks. For example, participants who said, “*There is no known risk unless the people who anonymise it tries to expose it*” – NITAU_03, and “*I wouldn't see any problem because the individuals cannot easily be identified*” – DHO_08. However, some alluded to the fact that if used to support patient care/referrals, it can hinder continuity of care as expressed by a respondent who said, “*It is hard to verify who the actual clients are and the details of their sickness which can bar continuity of help and support. This also affects decision making because some questions cannot be answered, especially the 'why' questions*” – HIV_01. Another respondent said, “*With this kind of data it is hard to trace the person who is sick, and leads to wastage of resources in case this patient needs to be followed up*” – DHO_12. Overall, the common view is that anonymizing health data had more benefits than the potential risk that sharing such data might pose.

Regarding identifiable data, all respondents rejected the notion of sharing identifiable health data. They argued that it is quite risky as it may expose patient data to the wrong people, which is against Uganda's data-sharing policies. A series of responses evidence this: *"It is very dangerous to share identifiable data. You can compromise the confidentiality of that person. The harm may not be to Uganda but to the individual person whose data can be shared"* - DHO_07, and *"There is exposure to people who are not supposed to access it which creates a risk"* – NITAU_02. One concludes that *"Sharing this data is unacceptable based on the data sharing policies"* – NITAU_01. However, some respondents retaliate that identifiable data can be useful, like in patient care and national security. For example, respondent HIV_03 argued that identifiable data can be shared if the right policies are in place and followed. *"This data can only be used under the standard good clinical data sharing principles. People need to be able to sign agreements that they are not going to do wrong stuff with data. Those principles cannot be compromised. As long as the right procedures and standards are used the benefits outweigh the risks. However, there is a risk of people not knowing the ethical rules or choosing to ignore them concerning this kind of data. Here then the risks outweigh the benefits, and thus it's a two-sided argument"* – HIV_03. Another respondent pointed to the potential benefit of sharing identifiable data but cautioned that users be mindful of the context in which they are sharing the data. *"The benefits depend on the context within which the data is shared e.g., Classified categories like national security"* – NITAU_02.

(d). Barriers and Facilitators to obtaining high-quality research data

Researchers identified several barriers to obtaining high-quality research data in Uganda. Several issues were cross-cutting but more pronounced were issues to do with funding, incompetent research teams, the attitude of the respondents etc. Indeed, the respondents reported as below: *"Well, funding is definitely part of every man's problem; if you have the funds, you would always want to have data but sometimes we don't have the funds so that's the given. Sometimes even when you get the funds, the red tape around data in Uganda is just too much due to lack of awareness in things like data sharing which becomes a hindrance to accessing good quality data.... So, there those steps and policies that need to be dealt with to make data custodians aware of the need to share data. There is the issue of workforce, if you don't train your data collectors well, they don't have the right ethics. Somebody will sit down under a tree and make data; yeah, it's a mix of so many things. Yes, I think it directly impacts; first speaking from a statistical standpoint if you have poor quality data the results*

are going to be as good as the data that you put in. Poor quality data “garbage in garbage out” you don’t have what you really wanted to have but it does affect career growth because there are so many students who can come in and say can I use your dataset; can I have access to this data set and use it for my masters’ projects and you don’t have the right to give that dataset, so in a way you are curtailing a career growth.”- HIR_03

“So, collection of high-quality data is expensive, so cost is a very big barrier that you need to have very well-trained team but even beyond the team the people collecting the data, you need people to do quality control and quality assurance. If you don’t do that you could easily sleep into a situation where people just collect the data for the sake of earning income and in so doing you can have very poor-quality data, so to have the real scientific rigor that ensures high quality data, cost is a very big issue. The other barrier has to do with community engagement so with a low community engagement in research your participation rates are usually going to be low. If communities do not perceive research as useful, you end up getting low participation rates that biases your results and that reduces your generalizability of the findings. For us in Rakai our success has been built over time, building community trust in research and engagement, and now we don’t have any big challenges with getting people to participate because people have now seen the value of the research and then they know why they should participate. Another very big barrier has been well trained personnel, research scientists who are trained to a degree that can be perceived to support research fully. Also, the challenge of getting the funding to do the research, leave alone the cost of data collection but actually the action people in Uganda here having access to research grants as principal investigators requires you to have much better ground in research and the more you do it the more experience you get so if we don’t have so many people in our country engaging as primary applicants of these research grants, that’s really big barrier to founding research in the country. Obviously if you don’t have people engaging at a high level of being primary applicants, the career progression say for Ugandan scientists would slow down a lot because there would be much dependency on international investigators coming in here and then Ugandans at their very best being investigators or co-investigators so that does not really help with career progression it impacts a lot.”- HIR_07

Almost all researchers believe that issues related to research are about high-quality research data and appropriately using those data. They further assert that one can’t use poor quality data for high-quality research output. For instance, if one is researching family planning and the only data available is about men, one will only write about condoms and will miss out on other methods. So, it’s both the tools used and the people who will use the data. Therefore,

one needs to gather high-quality data if they are to use it appropriately; otherwise, if one collects poor quality data, then it will not speak. Indeed, the quote from the respondents who reported that: *“I think, it’s both. I have seen people with the right data but not using it effectively and not using it the way it should be done for example, I can give an example of the data that are collected by these partners as long as they have the few of the indicators that they want the data sits there and it’s not used sometimes the data use, the issues around correctly using it stand but the bigger parties, what was the second part of the question? Using it? and the other bit was what? Obtaining yes obtaining, I think for me I think personally, where I am obtaining because there are so many questions, we want to address, but access to the data is such a challenge, yeah!”*- HIR_04

“I think you need both. If you have high quality data which never gets used, that is even unethical you know spending people’s useful dollars and you don’t actually use the research for any purpose to benefit humanity would be unethical but also poor-quality data you know if its poor-quality data, then you use it for research translation, you are really going to be giving the wrong guidance, wrong recommendations of what should be done so really you cannot take one from the other. High quality data is extremely important but equally important is translating that data into policies that really helps humanity.” HIR_03

To obtain high-quality data, researchers think the right connections and collaborations are key because one can get the funds, but one needs to build systems that will enable one to get access to the data that one wants. When designing a project, one needs to know where one is going to get the data from the start. Sometimes researchers blindly assume that they will get this data and then later hit a wall, so the right connections are needed.

The other key facilitators might be skilled human resources, and the finances to facilitate data collection are relevant. In addition, respondents involved in the data collection process need motivation; for example, there are cases when printed questionnaires are distributed, and the respondents end up not even filling these questionnaires, hence the need for motivation. There also needs to be proper training and collaboration between various departments, for example, the data management and statistics departments, to support each other because people’s specialization differs. This collaboration makes follow up easy up to the time when results are released in an organized manner. The respondents stated that: *“I would think it is the experience. Let’s say it is the knowledge someone has in that field where they are getting that data. Yeah! Many people are into those different areas of the fields where they are being relied on to get the data yet they are really not the best at that moment to be able to give you*

the data. I also think obtaining high quality research data is really a matter of people who are collecting the data being conversant with the protocol or standard operating procedures. If you have qualified people trained to do the job they tend to do well and accurately. Experienced interviewers, who know how to get people to give the right information, experienced researchers and who can extract the right information.” - HIR_08

3.2.7. Barriers and Facilitators to Implementing an EMR/EHR

Both participants who had some form of understanding of the electronic data collection system and those who did not have were all asked to respond with regards to the barriers and facilitators to implementing an EMR/EHR.

(1) Barriers to Implementing an EMR/EHR

Several health facilities haven’t yet implemented an EHR. Respondents who indicated that their facilities did not have near real-time EMR/EHR, provided several views on what they foresee would be the greatest barriers to implementing an electronic medical/health record in their respective healthcare facilities. Figure 7 provides a summary of their responses.

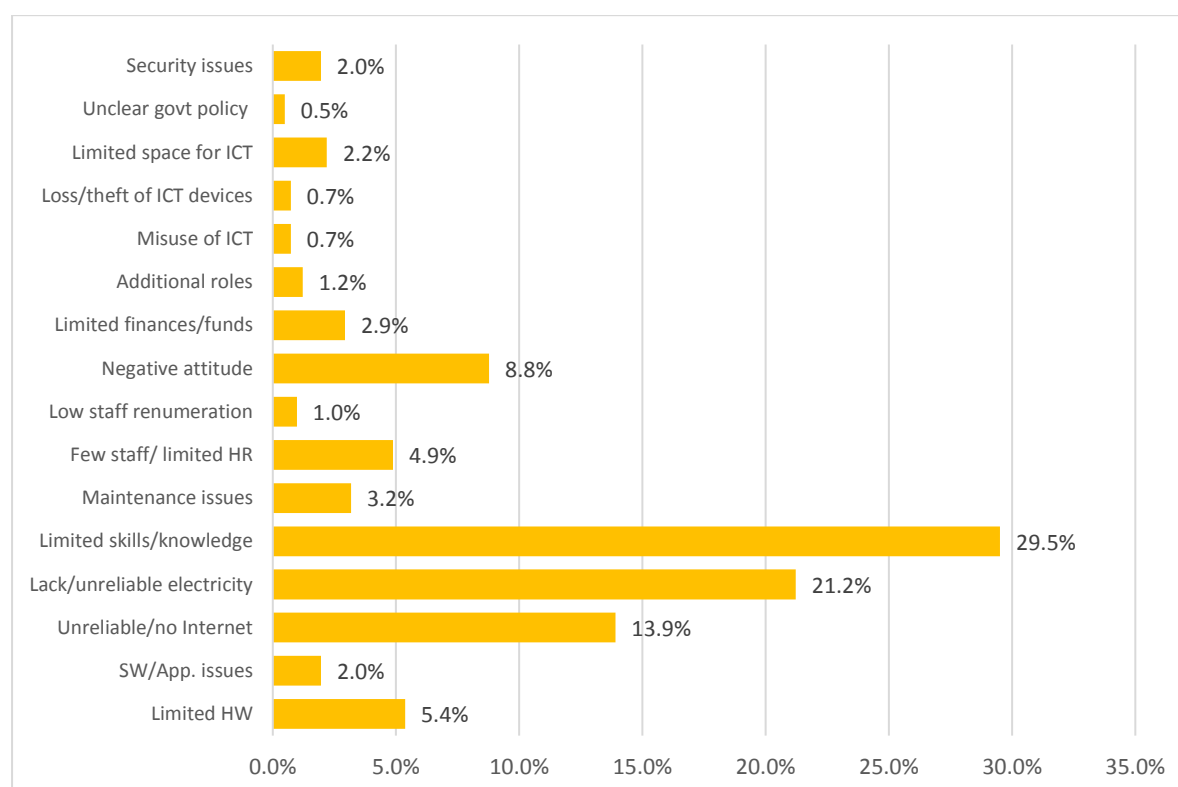


Figure 7. Potential Barriers to implementing a Near Real-Time EMR

Most of the participants (29.5%) identified limited skills/knowledge as a possible significant barrier to implementing the near real-time electronic medical/health record. Respondents said, “*we lack the computer skills*” (Hoima), and therefore would require “*more training*

about the system. How to use it” (Ibanda). According to some of them, *“the greatest barrier would be knowledge deficit but of course after training, it will not be an issue”* (Ibanda).

Regarding the reliability of electricity to power the devices and communication system, 21.2% of the participants said it is unreliable. On network/Internet connectivity, 13.9% said it was inconsistent. A government participant reported that most of the barriers are infrastructure based (NITA-U). He further asserted that Internet connectivity is also a problem.

Other barriers included negative perception/attitude to the adoption of electronic systems in health (8.8%), limited computing devices/hardware (5.4%), few technical staff (4.9%), challenges in maintaining existing ICT devices/network (3.2%), and limited funds to finance implementation. The rest of the barriers received low records from participants, including limited space for ICT (2.2%), software/application issues (2.0%), security issues (2.0%), data entry being added roles of already over-stretched healthcare professionals (1.2%), misuse of ICT devices/networks (0.7%), loss of the devices (0.7%), and unclear government policy (0.5%).

Respondents who indicated that they had already had a real-time EMR/EHR, identified seven challenges/difficulties that they experienced in adopting the new electronic medical/health record. Figure 8 shows the distribution of their responses regards the identified problems.

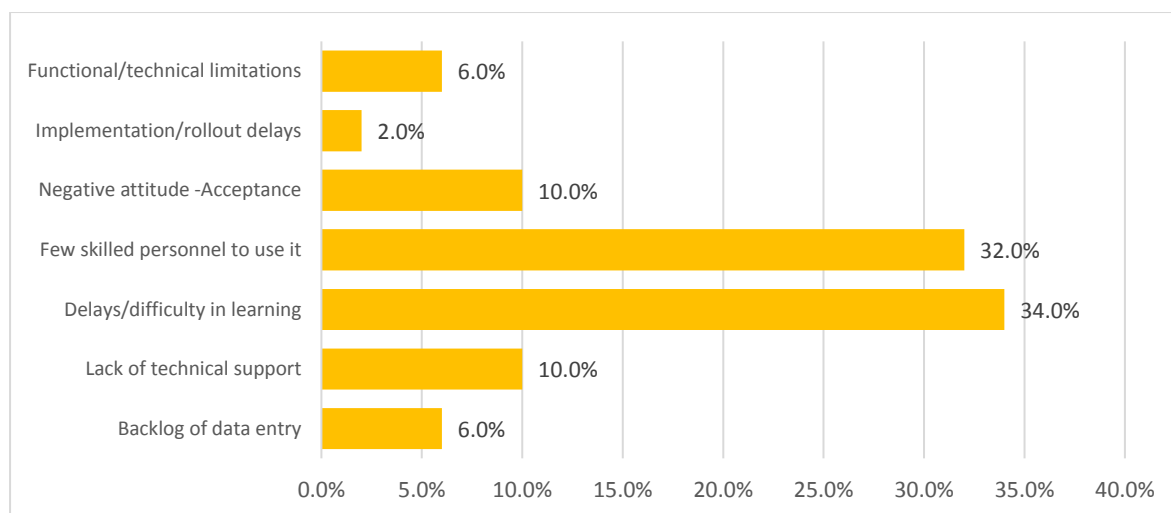


Figure 8. Barriers Experienced by those Implementing an EMR/EHR

(34.0%) of those who said they have implemented EMRs/EHRs highlighted finding difficulty/delays in the training/learning process as a barrier. Participants raised several issues related to training, including the fact that there was *“low turn up by staff in training as some wanted training allowances in order for them to attend”* (Manafwa), *“learning the system took a lot time”* (Ibanda), and *“The time lapse between training and the implementation we*

expected that after training that the officers come and then they hit the ground running but then due to challenges with computers it took a lot of time, people lost knowledge and then when we introduced it, it looked like something new since they haven't practiced" (Nebbi) among others.

Despite these efforts, some participants (32%) said that only a few personnel could use existing EMRs. In addition, some of the participants claimed that at first, they didn't know how to use the system and had to learn by themselves, which was very hard because there was no technical support and it took them a lot of time to learn the technology (Kayunga, Nebbi).

In addition, 10% of the participants agreed that negative attitude to the adoption of EMRs in their health facilities, another 10% of the respondents said that there was lack of technical support implementation of existing EMRs. Another 6% pointed to the backlog created by the introduction of EMR and functional/ technical limitations of the system as barriers to their adoption and use by healthcare professionals.

Comparing similar barriers as expressed by both those who have and those who do not have EMRs revealed that skills set to use electronic systems and perception/attitude to adopt/ use such systems topped respondents' list of concerns as evidenced by respondents who said that: *"The time lapse between training and the implementation! We expected that after training the technical officers immediately implement the system but due to certain challenges this took longer than expected. At this point, the skills and knowledge that had been impacted had already been forgotten and everything looked like something new because of lack of practice."* *"Not every health official had the computers and knew how to use them. Also, the poor network system as well as the few computers in the hospital; some of the HWs didn't know how to use the system so we had to teach them."*

When asked to compare experiences in the implementation and use of the EMR among the health facilities, respondents noted that the experiences are often the same in most government health facilities but differ for the privately owned. Some facilities have enough human resources, devices, good motivation, good working conditions, especially privately-owned facilities and PNFPs. Finally, the study showed that the challenges (except complaints about rollout delays) were crosscutting among several health facilities.

3.3. Readiness Factors (Requirements) for Implementing Health Data Capture, Processing and Dissemination Platform for Uganda

Considering the barriers to implementing a health data capture, processing and dissemination platform for Uganda, participants suggested several readiness factors for implementation. Their suggestions may be considered as requirements for implementing Uganda's health data capture, processing, and dissemination platform. The suggestions can be broadly categorized into technical infrastructure, governance, workforce, functional and data requirements.

3.3.1. Technical Infrastructure required for a timely model data capture system

The study further showed that the culture of data use in the country is still poor. The Ministry of Health needs to put governance issues in place as far as health data is concerned. This is well articulated in the current national eHealth policy. People make decisions politically without paying attention to what the data is saying. However, for example, data needs to be classified into public and private data to ease access, ICT infrastructure and internet challenges need to be fixed, such infrastructure should be availed at all levels e.g., computers, internet, LANs, electricity, power back up, etc. at the most basic of levels. In addition, system security should be improved to create trust in data sharing across health facilities. Hence, electronic data collection should also be adopted because of the many data elements that are collected.

The ICT infrastructure in the health facilities is below the minimum required level to support a national electronic health data capture, processing and dissemination platform. For example, the Internet in some hospitals may be found in particular offices like the laboratories and administrators' offices. This follows earlier drives made, 20 or 30 years ago, to digitise health services, which realised suboptimal results, hence leading to both donor and government fatigue at the health facility level. There's always a minimum or typical level of investment needed to be able to benefit from ICTs. At the moment, there are no computers, no electricity, no stable power, no network coverage, no alternative power source, no data coverage, one or two solar panels in some health facilities. However, there is a new drive, the government and the IPs are willing to invest in ICTs again and hopefully, the results will be better: *"Largely we are still at paper-based data collection at the health facility. Some few computers exist which are used to track commodities, drugs that have been given out, consumables, HIV and OPD."* - HPMF

The Uganda EMR is currently being used to manage HIV and TB clients, and it's not spread across all health facilities. The District Health Information System version 2 (DHIS2) is the main software that is used to manage health data from all the health facilities. There is also mobile tracking (mTRAC), a phone-based software system, which is used for weekly surveillance reports where facilities submit these weekly reports by SMS, and the biostatistician's office receives the records on a dashboard. Some health workers use their personal laptops, which might pose a risk in terms of data security: *"We don't have computers or modems; I actually use my laptop to do my work. The district data is stored on my laptop and I use my modem to access internet."* - HPKD

The shortage of materials and equipment also extends to paper-based systems. While recording patients' data, CHEWs and VHTs sometimes buy the books they use for recording purposes. The kind of data they mostly collect is family planning: *"We used to have books but now they all got finished.... only those who do outreaches and family planning buy books for themselves."* - IFG_01

Internet Connectivity: Health facilities need to be connected to the national internet grid to harness from a national electronic routine health data capture, processing and dissemination platform. This was observed by a health partner as he identified the challenge. *"A number of facilities are still out of network reach with poor internet connectivity to foster reporting"* - HPO_04

3.3.2. Ethical / Governance Infrastructure

Absence of Documented Standard Operating Procedures (SOPs) and Guidelines

The Ministry of Health should develop documented guidelines and procedures to access data and information systems through its governance structures, including the Division of Health Information and Steering Committees. Currently, the challenge is that the procedures are not documented. Similarly, the frameworks in place, such as the data process framework, are not clear enough to be operationalised. *"We have guidelines for example data process framework but the kind of understanding in the operationalization of this is not very clear"* - HPO_01

Health respondent HPO_04 proposed some of the contents to be considered in the SOPs, and respondent HPO_01 added that any identifying information should not be granted to anyone requesting access to the data. *"They should state their variables that they really want so that they can answer their objectives and those responsible for giving data should make sure that*

the data they are giving should ensure that the data is not easily identified so that they cannot trace the data to the given individual who has health issues.” - HPO_04

The MoH should also be supported in regulating health service points at the lower levels since the health industry is complex and large. “... supporting the ministries role in regulating these organizations and ensuring that systems that are contributing to patient data at whatever service point end up at Ministry of health coordination.” - HPO_01

Political Will

Health Development Partners support health data services in the country financially to a larger extent and are uncoordinated. Yet the resources to facilitate evidence-based kind programming and decision making are a hindrance, as mentioned by a health development partner. “At national level we have the aspect of resources to create the environment that allows evidence-based kind of programming. So, the budget is very minimal to support this and its largely supported by partners therefore a hindrance.” - HPO_01

Uncoordinated donor efforts

Fragmented information systems are a result of uncoordinated donor efforts. The silos result from many pilot projects that donors implement without standards, as one health partner mentioned. “We have a challenge of fragmentation of systems that are not even interoperable. You have these many donors coming on board, but government finds itself in a position where every donor is contributing but they are not well coordinated in efforts of steering committees. We still have a gap because we don’t have standards yet. Everyone develops a system and this piloted system happening a lot of fragmented system.” – HPO_01

Capacity building of Health Workers on Ethics

Health workers need to be trained on the ethics of data collection to maintain the integrity of collected data and the quality of the analysed data. One researcher mentioned that, “There is an issue of workforce, if you don’t train your data collectors well, they don’t have the right ethics. Somebody will sit down under a tree and make data ... from a statistical stand point if you have poor quality data the results are going to be as good as the data that you put in” - HIR_08

Data Sharing Guidelines

Well-documented SOPs can assist with ethical data access. In addition, the people requesting for data need to state their objectives and the required variables clearly. The required data

also needs to be anonymized so that it cannot be traced back to the owners. There should be guidelines for sharing clinical data with agreements that can be enforced. Under all circumstances, the benefits should outweigh the risks as mentioned by a respondent working in a government HIV programme. *“People need to be able to sign agreements that they are not going to do wrong stuff with data. Those principles cannot be compromised.”* HIV_03

Responsibility for Data Access and Regulation

Respondents agreed that the Ministry of Health should be responsible for providing oversight for data *collected in real-time from healthcare* and public health providers in Uganda. Specifically, the respondents from health partner institutions mentioned that; *“Access is primarily supposed to be Ministry of Health”* -HPO_01. *“There can be a body or a department somewhere in the ministry of health where it could be responsible for the data or trust and confidentiality issues”* - HPO_04

To be specific, one health partner respondent mentioned that the Division of Health Information should regulate the access and have clear SOPs that document the process one must go through to access national health data.

3.3.3. Workforce Infrastructure

Inadequate staffing at Health Facilities

Health facilities should have data collection responsibilities as core to their functions. For example, health workers collect data in real-time, with the health facility responsible for the data collected.

However, health facilities are understaffed, and thus health workers cannot simultaneously perform dual roles of data collection and service provision. Digitization could partly solve the under-staffing challenge as mentioned by Health partner HPO_03 that; *“many clinicians do administrative work ideally needing some support. But if the system is digitalized, they don’t have to run a lot of administrative data because it would give them summary reports and everything automatically. So, collection at the time of input, the health facility which is headed by in charge would be responsible.”* The Ministry should digitise hospital information systems to reduce the burden of making summaries and lessen administrative work on clinicians.

Quality of Human Resources

The human resources handling data at health facility and community levels are not skilled enough to manage data in its rightful dimensions. One health partner mentioned that the situation is even worsened at community level by VHTs and CHEWs. *“Even before we brought in technology, their capacity in terms of paying attention, recording the right data, dimensions of quality were a challenge. It’s even worse at the community level. You find a community health worker who is supposed to be reporting quarterly but are not able to write. Then when you bring in technology it becomes worse”* HPO_01

3.3.4. Functional requirements

Processed data: Data that is normally available in systems is not processed. This gives health partners an additional duty of cleaning it before being used. In an interview with one health partner, he mentioned the need to get data in a more usable format. *“We normally get it in a raw form and we are able to make sense out of it but our kind of desire would be getting data in a more usable format like when I go to the system and simply look at the data where a lot of cleaning has been done., a lot of processes have been done.”* HPO_01

Data with GPS Coordinates: Data received from communities with GPS coordinates enables geospatial analysis. It also enables health workers to locate patients who need health interventions. *“We always need more data around GPS coordinates for communities that we are serving and we kind of make geo social analysis.”* HPO_01

3.3.5. Data Requirements/Needs

Bidirectional Information Flow in the Health Sector

VHTs raised concerns about the unidirectional flow of information for the referrals to health facilities and summaries to districts. Responses from FGDs and KIIs highlighted the need to get feedback from higher authorities. *“We have counts of diseases in our registers which we summarize in our reports and help us to track the causes of such big numbers and the possible interventions that we can do locally and jointly after reporting to the healthcare facility, we also use these studies to compare with other fellow VHTs in other communities and copy each other on the best practices they are using.”* - NeFG_01. *“We need statistics of health happenings in our communities”*- HFG_02

An avenue that was produced through which the information could be disseminated is through workshops that collate VHTs within the same locality to ease data comparisons and

collectively explore approaches to tackle community problems. *"We would like to receive this information through training workshops and presenting summaries of the information collected so that we could do community mobilization, sensitization, and health education."*- IFG_01

Format of data

During an FGD, CHEWs and VHTs mentioned that they need information about various health issues including TB prevention, indoor residual spraying, gender-based violence, family planning and safe male circumcision. They suggested that the information could be provided in pie-charts, simple words or pictures. The same was supported by a VHT in Kayunga who mentioned that; *"In a pictorial form but in a language, I understand, they can draw graphs or charts or summarise them this would help me to teach it to the community"* KyFG_02.

The need for a pictorial format of data presentation was also echoed by health partners and also emphasized collaborations when making reports. *"...picture data makes a lot of sense in programming where you simply make a purpose visit then we shall have that data coming in. Then its further used for collaboration especially when making reports of progress such data in that format is used in making a case or sense of whatever we are reporting about."* HPO_01

VHTs proposed that the information include the patient's location for easy follow up. Additionally, in an FGD, one respondent added that they need information on community population, household numbers, and number of children. In the same FGD, the importance of comparing the data was mentioned by another respondent. *".... comparisons, we need to know if our work is helping our community or not"* - AFG_01.

3.4. Perceived Use and Features of the Electronic Data Capture Platform

Also, the study investigated opinion on features of a data capture system that would encourage stakeholder buy-in and usefulness of such a system to support timely and efficient public health and health care delivery across Uganda.

3.4.1. Features that Promote Stakeholder Buy-In

In light of these readiness factors, healthcare professionals were asked to suggest features of an electronic medical record system for capture that would make stakeholders buy-in. Respondents provided limited views including, easy to use, easy to navigate and simple

interface, always available, reliable storage, multiple functionalities, support data aggregation, and security feature to preserves patient privacy and confidentiality. Some of the views are summarised in this response from Ibanda; *“It's good to have a system and learning to use it is part of the process. Let's say if I want the information from the ministry or from the side on the line of my department, just search and get it. Or send the information from our side to where it is supposed to go. I want that type of system. To get information from maternity. A person from maternity should just click to get information from the lab. Another thing, the best thing, for example, we do send Bio samples, Gene expert samples to other hubs. And we first call them to print the results and bring them through the hub Rider. So, it would become easier for us to key in and get the information from there”* -HPI. The system should be *“one that is user friendly”* – HPI.

3.4.2. Usefulness of the Proposed Data Capture Platform

Regarding the potential usefulness of the proposed data capture platform, most health workers believe that the system will be useful and applicable to healthcare. This is evidenced by several respondents who said; *“Data will be easily accessible by those who need it. It's better when the patient has left to enter the data. I would prefer using a computer”*. -HPH-07, *“Electronic will improve on time of reporting by quickly generating summaries but will require technical skills. Am not sure how I would record information on it, but I would use a computer and I think it's better to record when the patient is still in the laboratory”*. -HPJ_03, *“It is fast and time saving so it will ease my work of delivering care”*-HPA_03.

In terms of research, respondents indicated that this intervention will enhance research capacity and enable answering of certain research questions without collecting more data. Some respondent had this to say; -

“I believe such a system is really wonderful for our setup because, we have a lot of data generated from these patients due to the many existing disease conditions but we don't know the relevance of the data. Most of such data ends up getting wasted because it's not properly stored, and when one wants to use the data, some of which you can't find such records. Therefore, when there's such an organized system, data will easily be collected and stored electronically. So, this intervention will be a wonderful facility for the researchers for example, with big data and analytics, this helps researchers who may want to do a given study, to use this kind of central database. So, it would help much in research with this kind

of data being now available where we have over a number of researchers working with it. - HIR_01”

However, they indicated that the platform has to be disease specific where each module of the system deals with a specific disease domain. A respondent said; *“I think this would be extremely valuable, but also, I need to say that there could be some challenges, and I don’t know if you have looked at them, should I mention? You see, there is the existing EMR and this is I think by METS and its focus is on HIV data. One time I wanted data on maternal and child health and this system could not provide. The new system should provide for all diseases”-HIR_02*

As evidenced above, most respondents agreed that such a system is worth an investment in Uganda. This platform will collect data in near real time at the different facilities of the healthcare, the data will automatically be analysed, presented, and dashboards will be used to show the trends and indicators of interest. Such an investment could do very well for notifiable diseases, like tetanus cases where people need real-time information so that they can intervene. A limitation of electronic systems indicates that they target mostly residents in the urban settings while those in rural areas that have limited access to smart phones are left out.

However, despite the usefulness of the anticipated intervention, respondents had some reservations to do with the cost, who the primary users were and who was responsible for collecting data on vital signs at the point of care. The respondents were also concerned about the training required specifically in rural areas, and generally what works for urban areas and how to adjust it to suit the rural settings. But as far as advancing technology is concerned, respondents felt the research team was on the right path and that such technologies would go a long way in saving time.

3.5. Requirements for Sustainability of a Health Data Capture, Processing and Dissemination Platform for Uganda

IFAD (2006) defines *sustainability* as a means of “ensuring that the institutions supported through projects and the benefits realized are maintained and continue after the end of the project.” In a way, it focuses on resource flows with the aim of the continued viability of the project beyond the initial funding period and prevents burdening of the beneficiaries. Sustainability may be understood to mean the continued use of programme components and activities beyond their initial funding period (Walugembe et al., 2019).

The literature presents five dimensions of sustainability, i.e., Financial/ Economical, Social and Cultural, Institutional, Technological, and Environmental (Kisan et al., 2013). Several factors influence these dimensions of sustainability in the healthcare domain. However, this study only focused on those technological, financial, institutional, and environmental factors of sustainability that relate to the implementation and maintenance of a health data capture, processing and dissemination platform for Uganda. In addition, while one participant explained the scope of sustainability as “*extending beyond project implementation to include how the platform will remain functional and require resources*” (GC_04), another said; “*Sustainability depends on people managing the system and the structure being set because not every system being developed has a future of running. Sometimes people are just after the money and will mess-up everything*”- GC_02.

3.5.1. Critical Factors for Sustainability

The reasons mentioned for readiness for implementing EMRs in Uganda were availability of electricity in many parts of Uganda (HIR_01), continual improvement in ICT technical skills in Uganda (HIR_04), the existing range of data capture and access methods (HIR_05), and familiarity with using ICT (HIR_05). Some reservations were dependence of implementation on funding availability. For example, HIR_06 said that sustainable implementation “*is possible as long as there is funding for it*”. However, another respondent said; “*Sustainability is where my worry comes in because most government projects have always started very well but there is a serious problem with sustainability. I would recommend once the system is implemented, there is need for training the health personnel on how to use this system. There is also need to have strict laws and sensitize the stakeholders on the values of the system. Because, whenever there is a change, there is always resistance to accept change because some may be worried of their jobs*” – GC-04

Overall, in the word of one participant, “*Depending on who is implementing, everything is possible*” (HIR_07). Therefore, the study identified factors that facilitate or hinder Uganda's implementation of a health data capture platform as detailed below;

Factors that increase or decrease feasibility of a near real-time data collection and analytics platform

- (i). **ICT infrastructure**– Limited ICT infrastructure, including intermittent internet connectivity, would decrease the feasibility of implementing the system. Availability of the internet will affect how readily the collected data is uploaded to the shared

platform, and hence a factor of the near real-time that the system intends to achieve. Several respondents alluded to the fact that there is a considerable lack of ICT infrastructure to support electronic data capture, processing and presentation. Participants made statements such as “*We don’t have the ICT infrastructure but can use what is available to transfer information to data centre*” (CP_01); there is “*Limited ICT infrastructure*” (CP_02); “*Our infrastructure is still poor such as poor network and power outages*” (GC_04); there is “*Limitation in internet access country wide*” (CP05); and “*There’s still low internet penetration*” (CP_06). These remain technological hindrances to the implementation of data capture, processing and presentation platform. To this end, participants suggested that ICT infrastructure for health be extended to cover the entire country, electrical power be extended to the last mile of a health facility, respective healthcare personnel should have devices for data capture and access, each district or health centre should have internet connection, adequate computers and that the developed system/procured applications are compatible with both mobile and desktop computing devices.

Furthermore, to ensure sustainable platform implementation, there should be a plan for continued improvement and maintenance of Uganda's ICT infrastructure. An *ICT infrastructure must be put in place for such a system to be feasible or for the project to be a success* (HIR_04). For example, there is a need for electricity, Internet connectivity, working computer devices, software applications and networks (PTC_01, KTC_02, NB_02). Like it was expressed by one of the participants that “*You need to have access to power and internet. They said you can have an offline one but at the end of the day, you still need to have internet connection*” (HIR_08). “*But the only challenge is that we have failed to reach the last mile*” (HIR_10). Despite improvements in ICT infrastructure like the extension of the internet backbone, internet remains a challenge in hard-to-reach health facilities in rural areas. However, some respondents agree that the internet challenge is common in rural areas, with most hospitals in urban areas better equipped with computers and connected to the Internet (Gc_05).

- (ii). ***Human resources with requisite technology skills*** – availability of skilled human resources is an enabler of successful data capture and analytic platform implementation. There is need for necessary workforce/labour force to develop, implement, use and maintain the system. To support “*real timework we do definitely need enough human resource and we don’t have, we don’t really have enough*” –

HIR_02. In addition, there is need to train the people who will man and use the data capture, processing and dissemination platform – HIR_08. To avert the human resources limitations, participants suggested that the training of staff on ICT and use of such platforms should continue, that more healthcare professionals with required ICT skills be recruited, and the employment of ICT knowledge persons to deploy, maintain and manage the system. It should be noted that *“health personnel have undergone training in ICT skills and believe they have positive attitudes”* (GC_05) towards ICT projects for health.

Also, lack of familiarity with the data capture platform or limited competency in using such a platform often causes healthcare professionals to choose between spending time in data capture and serving the patient. A participant argued that *“if these things are going to increase the time spent by healthcare professionals and reduce the amount of time they’re spending on patients, then what choice do they have to make, is it in completing the data or attending to the patient?”* (HIR_02). A dilemma often causes healthcare professionals to choose between spending time in data capture and serving the patient. Then, *“Government or MoH should educate people on how to operate the system because it will ease the work in the hospitals”* (KTC_02).

- (iii). **Funds** – Limitation of funds decrease the feasibility of implementing the system. According to HIR_02, funding comes at the top of the list of factors that facilitate the sustainable implementation of the data capture platform. A participant argued that *“It’s expensive to implement and sustain such a system because technology is still low.”* (CP_01). For example, it may require meeting the cost of building a connected computer network across all healthcare sites in Uganda, the initial cost of procuring required computing devices and of installing them, cost of maintaining the computing systems, updating device software and applications, cost of internet connectivity, repair and maintenance cost, and salary/wage for respective human resources. In order to finance the entire project and sustain it over a long period of time, funds must be available. Several participants alluded to the funding need. HIR_04 said, *“available funding for such a system must be there”*. In fact, implementers like the government require finances to run the project (GC_02).
- (iv). **Stakeholder buy-ins** – getting stakeholders to adopt a new system is not easy, often characterized by a slow process of buy-ins and adoption. HIR_03 argued that *“the challenge is getting them on board. It requires talking to partners and political leaders”*. That in addition, stakeholders have to be convinced about the importance of

the system, and also, they often require training on how to use the system. Similarly, improved health stakeholder engagement/involvement in the system design process enables them to better understand the system and appreciate its relevance in supporting healthcare.

- (v). **Data sharing, ownership and access rights** – Fears of data sharing, ownership, and access rights decrease the system's adoption and implementation feasibility. In fact, study participants expressed concerns about ownership of the technology that holds data and data sharing issues. *“Who owns the technology at the end of the day; is it ministry or somebody else hosting these data bases? Data sharing issues”* (HIR_02). Health data ownership access and use in Uganda should be stipulated to aver these fears.
- (vi). **Organizational management** – Often, negative organizational/managerial vices hamper Uganda's deployment, use, and maintenance of ICT interventions. Some participants mentioned corruption as one of those vices that may hamper Uganda's implementation and proper maintenance of the data capture platform. Participants argued that MOH would not be able to sustain the system because of corruption (CP_03). That if corruption can be dealt with, then it will improve finances. But as long as we are in the same mess, there is nothing to improve (NB_01). Corruption is a vice that negatively impacts any project implementation. *“Corruption should be avoided”* (CP_04). In fact, to assure sustainability, leaders/managers should make an effort to flush it out of a project completely. A respondent asserted that *“Poor leadership affects sustainability”* (NB_01).
- (vii). **Sustainability plan** – The lack of a well-thought-out implementation plan decreases the feasibility of the sustainable implementation of the system. A participant said, *“that is where my worry comes in because most government projects have always started very well and there is a serious problem with sustainability”* (GC_04). The participant recommends that any sustainability plan should include training of the health personnel on how to use this system, strict laws/policies/SOPs on use, sensitization of the stakeholders on the values of the system.

3.5.2. Risk factors for Sustainability

Among the risks are bad leadership, corruption and lack of sustainable maintenance program (NB_01). Other risk factors include the following: -

- (i). **Lack of sustainability plan** - One participant expressed the following views regards the plan for sustainability of electronic data capture platform, saying that their only issue is always with maintenance and sustainability. The participant emphasized that until we have really thought about maintenance and sustainability, information systems will continue to come and then die off very quickly (HIR_03).
- (ii). **Poor system maintenance:** GC_01 suggested that Uganda has the challenge of maintenance of systems after deployment. In fact, theft of computing devices, network challenges, servicing of these data communication systems are major risks to the sustainability of the data capture platform (GC_02, GC_04).
- (iii). **Poor management systems.** Lack of inbuilt checks and balances for its long-term impact and sustainability. In line with finance, corruption can be the greatest risk but can be avoided by establishing a system where everybody is accountable (GC_01). A participant claimed that “*corruption and mismanagement of funds are the main causes for setbacks*” (GC_02). In addition, “*if you have wrong guys, they will do for you dirty work. The project has to hire people of value not everyone*” (GC_02).

3.5.3. Finances and Project Costs

Finance is key in every project and cannot be isolated (GC_03, GC_04). Mobilizing adequate funds to sustain the project can be a challenge that may require lobbying financial support from donors to supplement government resources (GC_05). Figure 9 shows the number of respondents from commercial organizations who indicated cost implications for the data capture analysis and presentation platform.

Participants indicated that most project costs 27% goes to healthcare professionals' training to use ICT and deployed applications and 24% to the procurement and installation of the ICT devices and network components. This is followed by costs for internet access and network services at 16%, cost of recruitment and salaries for ICT human resources at 11%, the cost for maintenance and repair of the computing devices and network at 8%, software applications at 5%, lastly the costs for data translation, sensitization and meetings/workshops each at 3%, respectively. These costs can be grouped into initial/upfront costs and ongoing/maintenance costs.

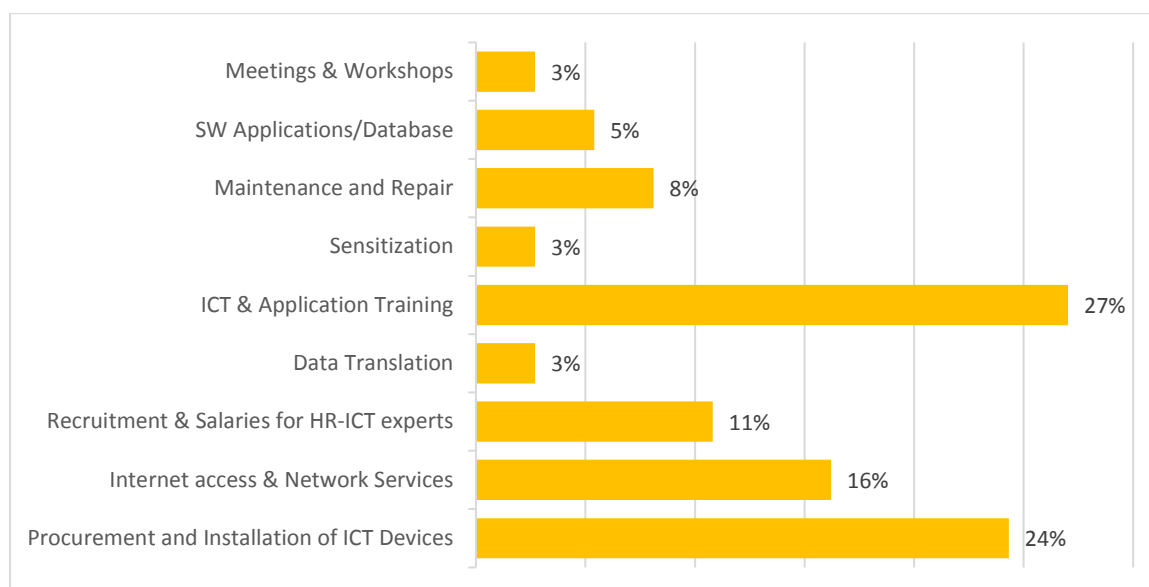


Figure 9. Cost Implications for the Data Capture, Analysis, and Presentation Platform

(i). Initial/Upfront costs

The highest upfront cost for developing and implementing data capture platform goes to procuring and implementing high-end computer systems, cloud-based and physical storage and data capture analysis, and presentation platform to share this information, initial training of the human resources to deploy, use and maintain the system (GC_01, GC_05). *The initial stages of the project require some source of funds to be available (GC_02) to finance these activities.* The cost includes the acquisition of the platform, payment of technical staff to install the platform and provide initial training on the use and installing/establishing the data communication network.

(ii) Ongoing costs

There are several ongoing costs. They include costs for network services, salaries for ICT staff, ongoing training, maintenance and repair, software updates, meetings and workshops. A participant pointed out that money is needed to have the system well managed (CP_03). In addition, it may include *“facilitation of the human resources and material costs. ... costs to mitigate or deal with risks that have already occurred requires budget”* (GC_04). In addition, costs related to training and workshops have to be factored in (KTC_01).

There is *“need for heavy investment”* (CP_06) in the ICT infrastructure and human resources to support sustainable implementation, maintenance of the data capture and analytics platform. The participant further suggested that *“the system will not be sustainable in the short run, but will be in the long run”*. Therefore, to ensure the sustainability of the health

data capture and analytic project, there is a need to ensure skilled personnel to run the system, money for servicing the system and discourage corruption at all costs (NB_02). In fact, a general perception regards a realistic cost for the implementation and continued sustainability of the platform is summarized in this view from participants who believe that this realistic cost is achievable only if there is proper planning and execution of the plans (GC_01, GC_03). That is, putting money to the right use and making use of available resources is key to the successful implementation of the platform.

3.5.4. Reinvestments as a partial sustainability plan for ICT Infrastructure

Participants from government organisations were asked how reinvestment as a partial sustainability plan for ICT infrastructure of a near real-time electronic health data capture system would look like. Respondents' views included cost sharing, collaboration/partnerships and sharing of the existing technical expertise in ICT.

Cost sharing – One respondent said, *“Attracting more people to use the system will make maintenance more bearable because of cost sharing since there are many users on board”* – NITAU_01. *“Government entities e.g., UMEME can provide subsidized rates”* - HIV_03.

Collaboration and sharing of technical expertise – establish partnerships to share ICT expertise in the repair and maintain the equipment and systems. *“Any private IT company can also come on board to provide maintenance services”* – HIV_03. *“Some of these companies have Corporate Social Responsibility projects”* – UCC_04 that when approached can be explored to benefit the eHealth programs.

Overall, participants agreed that several stakeholders are willing to support eHealth initiatives in Uganda. In fact, a participant from Uganda Commissions Commission (UCC) pointed out that they *“have supported a number of eHealth initiatives in the past”* and that *“several partners would also be interested in providing resources and maintaining the platform. Even telecoms like MTN and Airtel have come out to support such initiatives especially with the coming of Covid”* – UCC_02.

Participants went ahead to suggest stakeholders who could contribute to the sustainability of the ICT infrastructure. Identified stakeholders include health facilities, NITA-U, MoICT, UCC, MoH, local government, private IT companies, Development partners, Implementing Partners, and CBOs/NGOs

Despite the proposed contributions that the different stakeholders could make to sustaining ICT infrastructure for health, some respondents still doubted the efficacy of existing

measures. A case in point is the view of one respondent who said, “UCC can support in the infrastructure. However, our fingers have been burnt before because after 3 or 4 years you realise that the investment you put in is worth nothing at the moment because the ministry has failed to take it up. But this is largely because projects are not generated within the MOH itself, I would rather they originated from the ministry and the ministry then asking how UCC can come on board to support. There they would be a bigger sort of ownership than us just coming in and initiating the project. But we also haven't had requests from the ministry of late probably they are occupied by other things now” – UCC_01.

4. DISCUSSION

4.1. Current Health Data Capture and Use Processes

Routine care data currently captured in Uganda

The respondents indicated sources such as the Health Management Information System (HMIS) registers, OPD turn-up, community outreaches, interaction with patients with VHTs and co-workers gathering the information. In addition, Mayston et al., (2020) indicated the use of several new technologies to facilitate health data collection, such as portable document scanners, smartphones, and web-based data collection. On the contrary, Mutale et al., (2013) observed that the iterative process of health data use to monitor and assess the health system has been heavily communication dependent, with challenges due to poor feedback loops. Implementation to date has highlighted the importance of engaging frontline staff and managers in improving data collection and its use for informing system improvement. Other approaches have focused on technological interventions such as information communication technologies (ICT) designed to reduce errors through reducing data bulkiness and automating data collection, validation, and analysis. In principle, this health information can be acquired through numerous avenues, such as surveys, electronic financial transactions for health insurance claims, computer-based patient records (CPRs), and disease registries. In practice, no one system will suit every need or produce information appropriate for every question.

With regards to how health information is used, participants specified that these medical records were used to determine health care issues, auditing in planning like in surveillance of the different sub-divisions of the district in-case of any communicable disease, in stock refills, drug replacements and in-drug requisitions. Similarly, Alotaibi & Federico, (2017) state that health data is also used for the implementation of policies in order to better treat and prevent the spread of diseases. Thus, the use of health IT improves the quality of healthcare delivery, increases patient safety, decreases medical errors, and strengthens the interaction between patients and healthcare providers (Alolayyan et al., 2020).

Our findings further revealed that the collected health data can be used to; evaluate program impact, determine appropriate public health interventions, monitor progress, determine which populations to target for an intervention, determine barriers to care, and influence public policy. However, the lack of importance given to health data in decision making, corruption and insecurity, lack of training and poor infrastructure were major challenges to implementing Health Information Exchange (HIE); but that strong leadership and clear policy



direction coupled with the financial support to acquire essential technology, improve the communication network, and provide training for staff could help to promote implementation. According to Meystre et al., (2017), secondary databases facilitate reuse of data that have been gathered for another purpose (e.g., patient care, billing, or research) because that data, may generate new knowledge in new applications.

Concerning understanding of HCP's perspectives on the use of technology in information gathering, Rose et al., (2015) noted that, success of eHealth relies on the extent to which the related technology, such as the electronic device, is accepted by its users. Patients (highly) prefer to have digital contact with a health professional, to have digital access to their personal record in which both the patient and the health professional can make notes, and finally to digitally schedule appointments with the health professional. The study by Wentink et al., (2018) showed that more than 90% of the respondents who were patients used at least one ICT device, either a computer/laptop most frequently, followed by a smartphone and then a tablet. Younger patients were found to use more devices than older patients, but older patients used their ICT devices with the same frequency as younger patients. Their study further showed that patients used their devices for e-mail, finding information, support (e.g., scheduling, banking, route planning), social media and physical and mental exercises. Patients' usage preferences of ICT devices in rehabilitation included; having contact with health professionals (telecommunication), having access to their health record and scheduling appointments with health professionals. Similarly, Barnor-Ahiaku, (2016) and Blok et al., (2020) confirmed that most patients in reintegration with a registered email address used one or more ICT devices every day of the week (younger patients more often than older patients). Hence, the most frequently used devices were a computer/laptop, smartphone and tablet, and according to patients, eHealth in rehabilitation needed to include online access to their health record, communication with peers and scheduling of appointments with health professionals.

The role of health care workers (healthcare professionals and CHEWs/VHTs)

This study clearly shows that for many patients the most basic elements of care were emphasized. All health service staff have a duty to care for patients, colleagues and themselves. That means, while a healthcare professional does not have to be the best nurse, midwife, scientist, technician, therapist, paramedic or doctor, they must practice at the standard of a "reasonably competent" practitioner. The relevant service should be closed or suspended until such standard can be achieved. Health professionals are trained to exercise specific skills and provide care, support, advice and treatment to a safe and effective standard

(Knebel & Greiner, 2003). Indeed, their job description allows for disciplinary action if their work falls below the required standard or breaches their professional code; whether as a doctor, dentist, nurse, midwife or in a profession related to medicine. Although there is no conclusive evidence concerning the relationship between health outcomes and the number of human resources (HR) available for health care, it is clear that qualified and motivated human resources are essential for adequate health service provision, but also that HR shortages have now reached critical levels in certain areas (Kabene et al., 2006).

Our study has confirmed that CHEWs/VHTs play a very important role in the community. Among the key roles identified were; checking on the nutrition status of young children, making referrals to health facilities, visiting new born children to monitor their progress and visiting of new born children still undergoing immunization to ensure they are being immunized. Developing countries use CHEWs to fill the human resource gaps and to improve community health.

In Uganda, CHEWs close the gap between communities and the formal Health system (Ministry of Health-Uganda, 2018). They play an important role in referral, health promotion and disease prevention at community level and their effective involvement leads to better health outcomes. A number of countries are already investing in community health workers (CHEWs) as one of the strategies to promote public health as well as achieve the health-related SDGs. Such countries have made remarkable progress in addressing the high burden of preventable diseases. Ethiopia, for example, has trained 38,000 (female) community health extension workers (CHEWs) to focus on maternal, new-born and child health, nutrition, hygiene and sanitation malaria, tuberculosis and HIV interventions. Tanzania continues to train health extension workers as part of the formal health system (Ministry of Health-Uganda, 2018). Other examples include Malawi and Rwanda.

Musoke et al., (2020) report that the main roles of the VHTs include carrying out health education at household and community levels, conducting house-to-house visits for health improvement participating in integrated community case management of childhood illnesses of pneumonia, malaria and diarrhoea, referral of patients to health facilities, as well as mobilization of communities for public health interventions such as immunization of children and distribution of mosquito nets. According to Kimbugwe et al., (2014), VHTs have additional roles which include; distribution of health commodities, community information management, disease surveillance, identification of health problems in the community, immunization activities, provision of basic healthcare messages for behaviour change,

children growth monitoring and community work such as school cleaning and linking of the community members to the health centres.

Similarly, according to Kimbugwe et al., (2014), home visiting of individuals is one of the major roles executed by the VHT members. They routinely go door-to-door on specific days of the week visiting households they oversee. The aims of these visits include; finding out the health statuses of individuals in these households, delivery of health education and promotion services with much emphasis on sanitation, delivery of medications as well as identification of sick individuals, who are then referred to health facilities. It is through these home visits that information concerning households and individuals in the community is obtained and recorded in the health management information systems report forms. They termed these visits “community walks”.

Barriers and Facilitators to routine healthcare data capture, processing, sharing and use

The findings of this study revealed that the major barriers to data access and use were poor governance and management, inadequate ICT equipment, poor network connectivity, insufficient funding, power shortage, use of paper-based forms, information security concerns, user resistance, and insufficient skills. These results corroborates the findings of another study of impediments to accessing reliable, timely and integrated electronic patient data in healthcare sites in Uganda (Alunyu et al., 2021). Sometimes data is captured differently across health facilities and the data collectors do not understand some of the indicators they are collecting (Alunyu et al., 2021; Seid et al., 2021). Therefore, data is not being utilised because some of the people who are supposed to be using it do not understand it or are not interested, while others lack the skills or culture of data use.

In fact, the study shows that the culture of health data use in the country is still poor. The Ministry of Health needs to put **governance** issues in place as far as health data is concerned as articulated in the current national eHealth policy (Ministry of Health, Uganda, 2016) to prevent health managers making decisions politically without paying attention to what the data is saying. In addition, information systems security should be improved to create trust in health data sharing and exchange across health facilities.

More so, the study identified challenges of **governance structures** for data access. The various stakeholders are uncertain about the means to access data in case it is needed for use. Data governance requires companies to achieve data transparency. Information such as the

kind of data the organization has, where this data resides, who has access and how this data is used, need to be accounted for; Gregory (2011) believes that without strong data governance, organizations will fail to provide effective corporate governance and compliance, and will open organizations to significant risk of failure in both, which certainly may lead to failure of the projects (Gregory, 2011).

In this study, participants also reported barriers to electronic data collection such as power shortage, lack of adequately trained personnel and internet blackout in most parts of the country especially in the rural settings. This aligns with the study by Jawhari et al., (2016) that sought practical insights about facilitators and barriers to EMR implementation in urban slum environments. Therefore, our findings are consistent with what other researchers have reported, especially with regards to the practical barriers to EMR deployments in resource-constrained settings. Although many reported systems (e.g., power, network, Internet, hardware, interoperability) and software (e.g., data integrity, confidentiality, function) challenges, social factors (e.g., identity management, training, use incentives) appeared to be the most important impediments to sustainability. These barriers to data quality have also been reported by Ni et al., (2019) including heavy workload, staff rotations, lack of detailed information for specific research, variations in terminology, limited retrieval capabilities, large amounts of unstructured data, challenges with patient identification and matching, as well as problems with data extraction and unfamiliarity with data quality assessment.

Nonetheless, the study reported some facilitators for implementing the EHR/EMR including the benefits that come with using an electronic system such as reduction in workload and training of users. Therefore, to improve data quality, suggestions from participants included the need for better staff training, provision of monetary incentives, performance of daily data verification, improvement of software functionality and coding structures as well as enhancement of multidisciplinary cooperation which aligns well with findings in the study by (Ni et al., 2019).

The research findings revealed that the greatest barrier to translation of research findings into action is the lack of a technical body at the level of MOH that is focused on research translation. However, (Grimshaw et al., 2012) cited common barriers across target groups some of which include issues relating to knowledge management, such as the sheer volume of research evidence currently produced, access to research evidence sources, time to read evidence sources and skills to appraise and understand research evidence.

Interest in Electronic Health/Medical Records Collection

In this study, participants' responses indicated several benefits for the EHR/EMR implemented including helping in summarizing of the data coupled with reviewing and identifying of the needs of the patients so as to provide appropriate healthcare. The EHRs/EMRs have also eased the transfer of data from hard copy to digital format which has quickened data analysis. In addition, the needs of the patients are easily accessed through summaries, reviews and outbreaks in communities. This agrees with a study by Ruiz Morilla et al., (2017) that technology has significantly changed the way health organizations operate. However, the success of technology depends on the end-users; that is the physicians and patients using it, which in turn largely depends on how it is implemented. Thus, physicians must be involved, and their needs considered to implement this change.

4.2. Requirements for Implementing Health Data Capture, Processing, and Dissemination Platform for Uganda

Despite the development of ICT and the Internet that has provided access as a platform for data sharing and reuse among interested stakeholders, the study findings have shown that there are still some challenges in implementing health data capture, processing, and dissemination. Some of the challenges to data use may include; integrating data from various sources, lack of data professionals, lack of proper understanding of the data, and many others (Pastorino et al., 2019). In addition, to making meaningful judgments about data presentation practices that don't work, there must be clear principles about the purpose of data presentation and what identifies it. For example, health facilities collect and send data, but they don't utilize that data, and yet they may be reporting a considerable problem, but they never do anything about it. However, in developing countries, data sharing offers numerous benefits because the costs and challenges of data reuse and sharing seem to outweigh costs incurred during their initial collection. Some respondents in this study argued that, there is a need for data sharing for sustainable development. Pastorino et al., (2019) concur that data sharing can improve patient outcomes and evidence-based healthcare decision-making. Respondents to this study indicated that additional information that data collectors must capture on a patient includes; patient location, education level, information on alternative places where people get care, the kind of foods they eat, their employment, and water sources. It is also essential to

collect household-level data that link individuals to their respective households, communities, parishes, and districts.

Respondents reported that they would need good internet connection, devices to use, proper training on using those devices, and adequate maintenance to decide whether to use an EHE/EMR. In their study, Austin et al.(2015) suggest that collecting research data requires considerable coordination to ensure completeness, accuracy, and timely data transmission. Therefore, electronic data collection, particularly at the point of care, offers some potential solutions, including; the ability to monitor patient progress, provision of patient-centered healthcare care, and proper management of referrals (Bosse et al.,2018).

Another critical requirement for consideration in implementing the Health Data Capture, Processing, and Dissemination Platform for Uganda is data governance. **Data governance** provides healthcare organizations with a standardized and structured method of sharing medical data to provide the highest quality of care to every patient. Although the in-charge is responsible for the data at the health facility, the challenge with the storage facilities remains. The registers are usually scattered and not easily accessible, which contributes to compromise in data confidentiality. However, respondents suggested that health facilities in Uganda should ensure the availability of HMIS forms at health facilities.

Furthermore, respondents also recommended training all staff involved in HMIS data reporting. In their study, Beck et al. (2016) affirm that electronic modalities for data collection address the issues related to confidentiality and security of the health data at the health facility. This is mainly true in low and middle-income countries where increasing health information is being collected to monitor and evaluate the use, cost, outcome, and impact of health services at the facility, sub-national, and national levels (Beck et al. 2016).

Our findings further showed challenges to do with capacity gaps at the health facility and community level in terms of even using the paper-based system to collect quality data. This is similar to a study conducted by Miseda et al. (2017) in Kenya that showed the overall skills gaps in 46 counties and that focusing on training was the major remedy. The authors also suggested more innovative approaches, including the use of technology plus the need to consider addressing this challenge in the immediate, medium, and long terms. In addition, efforts are needed to ensure harmonized skills gaps amongst healthcare workers. The study findings further revealed that some health workers could not even write correctly, which may worsen the situation when the use of technology commences. In addressing such a challenge,

(Ash et al., 2004) in their study, considered the implementation of automated reminder systems that can reduce errors by eliminating illegible orders, improving communication, improving the tracking of orders, checking for inappropriate orders, and reminding professionals of actions to be undertaken. Besides, study findings revealed that the low literacy levels sometimes negatively affect the health workers' attitude towards using electronic platforms to collect health data. According to Dapaah (2016), dealing well with clients during interactions in the health centres and clinics is crucial for reducing the perceived stigma associated with the use of services; this increases uptake. However, based on the studies conducted in Sub-Saharan Africa, most health workers have shown that nurses rarely show positive attitudes and behaviours towards clients who access healthcare services (Etafa et al., 2018; Rayner et al., 2019). Although the MOH encourages electronic-based data collection and reporting at all health facilities, the norm in private facilities and some lower-level and rural facilities is to still use paper-based forms due to shortages of computers, power, and internet connectivity (Wandera et al., 2019). All health facilities (i.e., public, private for-profit, and private not-for-profit) are required to use the MOH's standardized forms to avoid duplication of data and reduce the overload of reporting to the HMIS.

Findings from the respondents indicated that EMRs are valuable and will enable sharing of information in real-time from different parts of the country. Manca (2015) highlights the benefits of electronic health records as a platform that will secure the sharing of electronic information with patients and other clinicians, helping provide diagnoses to patients more effectively, reduce medical errors, and provide safer care. In addition, the platform improves patient and provider interaction and communication and health care convenience, thus enabling safer and more reliable prescriptions (Austin et al., 2015). The researchers further believe that this platform shall support research activities in Uganda. This will create a good platform that will provide electronic access to health data. In addition, it will provide researchers with the availability of datasets that they can easily tap into to develop further research questions. According to (Cowie et al., 2017), EHRs provide opportunities to enhance patient care, embed performance measures in clinical practice, and also facilitate clinical research.

4.3. Features and Perceived usefulness of the proposed data capture platform

According to authors features that influence stakeholder buy-in cover operability (ease of use), self-management and usefulness in supporting secure data collection, processing, sharing and use (Torbjørnsen et al., 2019; Zaidi et al., 2020). This study identified similar

features that may promote stakeholder buy-in to include, easy to use, easy to navigate and simple interface, always available, reliable storage, multiple functionalities, support data aggregation, and security feature to preserves patient privacy and confidentiality. Therefore, if such a system will have to be developed for Uganda, it should provide such capabilities to improve acceptance among stakeholders.

Concerning usefulness of the proposed health data capture platform, the study found out that respondents believe it will be useful and applicable to Uganda. By linking data/healthcare information from multiple healthcare points, the platform is expected to support near real-time health information sharing and exchange about patients, healthcare, disease surveillance, and research (Medeiros et al., 2014; Schreiweis et al., 2021). In addition, such a health data capture platform would support effective health data/information sharing that informs and improves public health actions, eventually incurring benefits including collaboration, capacity strengthening, insight into public health system performance, and better risk management and control of infectious diseases among others (Schreiweis et al., 2021; The Royal Institute of International Affairs, 2017). However, concerns remain over costs, required skills/training, who the primary users and beneficiaries are, data rights and potential misuse of health data (The Royal Institute of International Affairs, 2017). There is hope that the health data capture platform/system will be useful to the urban as well as rural settings in Uganda.

4.4. Requirements for Sustainability of a Health Data Capture, Processing and Dissemination Platform for Uganda

According to Kisan et al., (2013), sustainability factors encompass Financial/Economical, Social and Cultural, Institutional, Technological, and Environmental. In addition, Walugembe et al., (2019) argued that a focus on *sustainability* requires due consideration to be made of the potential loss of investments for organisations and people in the event that interventions with perceived or actual benefits are not sustained. However, the responses from the study only covered financial, technological, and institutional dimensions with a little discussion on possible reinvestments as a partial sustainability plan for ICT Infrastructure. Just like other ICT and health intervention studies, this study found out that; there remains a problem of financial resources/funds to support continued maintenance, staffing and use of the system. That whenever the key funders of eHealth interventions in Uganda (the IPs) pull out, the system eventually collapses. It was also found that there is a lack of technical personnel to support repair, maintenance and use of ICT devices and systems in health. It is

challenging to obtain technical support from government often resulting in prolonged system downtime. Lastly, there was lack of a sustainability plan to ensure smooth transition from IP support to facility governance and / or continued financing of the system.

These issues highlight several critical factors of sustainability including; limited ICT infrastructure and intermittent internet connectivity would decrease the feasibility of implementing the system; availability of skilled human resources is an enabler of successful data capture and analytic platform implementation; availability of funds; stakeholder buy-ins – getting stakeholders to adopt a new system is not easy, often characterized by a slow process of buy-ins and adoption; fears of data sharing, ownership, and access rights decrease the system's adoption and implementation feasibility; organizational management; and lack of a sustainability plan.

On the issue of reinvestments as a partial sustainability plan, it should be noted that several interventions require substantial investment in terms of human, fiscal and technical resources and any form of inadequate attention to such investments could be considered careless and inefficacious (Walugembe et al., 2019). The need to maximise limited resources continues to be a crosscutting discussion of system sustainability (Walugembe et al., 2019). It is impossible to make progress without resources including financial, competent human and ICT infrastructural resources (Kimaro, 2006). Whereas, finances are needed to pay for the initial or upfront cost of investment; sustainability would require additional finances to fund the cost of running the system, train and facilitate competent human resources who use the system, and maintain ICT infrastructure. Despite the existence of funds, it may still be difficult to sustain the system implementations over time without a proper sustainability plan, management and maintenance plan. A good sustainability plan could include aspects of reinvestments. When the study explored this concept only two issues emerged, i.e., cost sharing and partnerships with aim to share available resources and technical expertise.

Finally, regarding the cost implications of developing and deploying a data capture platform for Uganda, the study found out that there are initial costs of investing in the system and ongoing costs incurred in ensuring that the system remains operational and viable. These costs are kin to the findings of other earlier studies, for example in their study of the costs of implementing an EMR, (Wang et al., 2003) include metrics of the system and induced costs. To measure system costs, they explored the annual software license, implementation, support and maintenance, and hardware (computers and network). The induced costs only focused on the temporary productivity loss as a consequence of using the system. All these costs must be

covered to ensure success and continued operation of such an implementation of a data capture platform.

5. CONCLUSION

The study explored Uganda's readiness for an EHR data capturing and processing system infrastructure to support responsive care and interventions based on real-time surveillance. We were able to develop a complete understanding of the routine care data currently captured and all surrounding dynamics. The study also explored technical, ethical/governance, workforce infrastructure, and cost factors for implementing a timely health data capture platform/ system in Uganda. Several barriers to implementation of a health data capture platform were identified and they include poor governance and management, inadequate ICT equipment, poor network connectivity, insufficient funding, power shortage, use of paper-based forms, information security concerns, user resistance, and insufficient skills. Nonetheless, stakeholders in Uganda anticipate the benefits of having such a platform and have implemented some digital infrastructure which could be facilitators to the implementation of the health data capture platform. Though there is limited widespread existence of these facilitators across healthcare sites, they can still provide a launch pad for implementing the data capture platform in Uganda.

We argue that health information is a very critical tool that can be used to benefit the community, facilitate accountability in healthcare, follow-up and planning purposes. We encourage continued use of existing eHIS systems/platforms to support health workers to do their work as the country prepares to develop a national electronic routine health data capture, processing and dissemination platform.

The study concludes that EMR/EMR is a much-needed system as all healthcare stakeholders look forward to use community level health information. However, what remains to be done is to; (1) model the cost of an integrated data capture, processing and presentation platform for Uganda, and to determine how much additional malaria and/or HIV control would be required to offset the cost of the system over various periods, and (2) establish structures and mechanisms to minimize barriers to its successful implementation.

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APPENDICES

Appendix A: Coding of Focused Groups and Interview Respondents

Participant/Respondent	Code
CHEW/VHTs	
Agago – first focus group	AFG_01
Second focus group	AFG_02
Ibanda – first focus group	IFG_01
– Second focus group	IFG_02
Hoima – first focus group	HFG_01
Second focus group	HFG_02
Jinja – first focus group	JFG_01
Second focus group	JFG_02
Kassanda – first focus group	KFG_01
Second focus group	KFG_02
Kayunga – first focus group	KyFG_01
Second focus group	KyFG_02
Masaka – first focus group	MFG_01
Second focus group	MFG_02
Napak – first focus group	NFG_01
Second focus group	NFG_02
Nebbi – first focus group	NeFG_01
Second focus group	NeFG_02
Serere – first focus group	SFG_01
Second focus group	SFG_02
Community Leaders	
Agago	ACL
Hoima	HCL
Ibanda	ICL
Kassanda	KCL
Kayunga	KyCL
Manafwa	MaCL
Masaka	MCL
Napak	NCL
Nebbi	NeCL
Ntungamo	NtCL

Serere	SCL
Government Organisations	
Respondent 1 (NITA U)	NITAU_01
Respondent 2 (NITA U)	NITAU_02
Respondent 3 (NITA U)	NITAU_03
Respondent 4 (NITA U)	NITAU_04
Respondent 5 (HIV)	HIV_01
Respondent 6 (HIV)	HIV_02
Respondent 7 (DHO)	DHO_01
Respondent 8 (DHO)	DHO_02
Respondent 9 (HIV)	HIV_03
Respondent 10 (DHO)	DHO_3
Respondent 11 (DHO)	DHO_4
Respondent 12 (DHO)	DHO_5
Respondent 13 (DHO)	DHO_6
Respondent 14 (DHO)	DHO_7
Respondent 15 (DHO)	DHO_8
Respondent 16 (DHO)	DHO_9
Respondent 17 (DHO)	DHO_10
Respondent 18 (DHO)	DHO_11
Respondent 19 (DHO)	DHO_12
Respondent 20 (DHO)	DHO_13
Respondent 21 (MOH)	MOH_01
Respondent 22 (Min of ICT)	MICT_01
Respondent 23 (Min of ICT)	MICT_02
Respondent 24 (Min of ICT)	MICT_03
Respondent 25 (Malaria)	MAL_01
Respondent 26 (UCC)	UCC_01
Respondent 27 (UCC)	UCC_02
Respondent 28 (UCC)	UCC_03
Respondent 29 (UCC)	UCC_04
Respondent 30 (MOH)	MOH_02
Respondent 31 (Malaria)	MAL_02
Respondent 32	DHO_14
Respondent 33 (DHO)	DHO_15

Respondent 34 (DHO)	DHO_16
Health Partner/NGOs	
Health Partner/Organization	HPO_01
Health Partner/Organization	HPO_02
Health Partner/Organization	HPO_03
Health Partner/Organization	HPO_04
Commercial Partners	
Respondent 3 GC – 01	GC_01
Respondent 3 GC – 02	GC_02
Respondent 3 GC – 03	GC_03
Respondent 4 - GC – 04	GC_04
Respondent 5 - GC – 05	GC_05
Respondent 6 - PTC – 01	PTC_01
Respondent 7 - PTC – 02	PTC_02
Respondent 8 - KTC – 01	KTC_01
Respondent 9 - KTC – 02	KTC_02
Respondent 10 - NB -01	NB_01
Respondent 11 - NB -02	NB_02
<i>Commercial organisations' engagement with health sector in both Mbarara and Ibanda districts</i>	
ID 1	CP_01
ID 2	CP_02
ID 3	CP_03
ID 4	CP_04
ID 5	CP_05
ID 6	CP_06
ID 7	CP_07
ID 8	CP_08
ID 9	CP_09
ID 10	CP_10
ID 11	CP_11
ID 12	CP_12
ID 13	CP_13
ID 14	CP_14
ID 15	CP_15

Researchers	
Health Informatics Researcher	HIR_01
Health Informatics Researcher	HIR_02
Health Informatics Researcher	HIR_03
Health Informatics Researcher	HIR_04
Health Informatics Researcher	HIR_05
Health Informatics Researcher	HIR_06
Health Informatics Researcher	HIR_07
Health Informatics Researcher	HIR_08
Health Informatics Researcher	HIR_09
Health Informatics Researcher	HIR_10
Health Professionals	
Agago	HPA_ ...
Hoima	HPH_ ...
Ibanda	HPI_ ...
Jinja	HPJ_ ...
Kassanda	HPKD_ ...
Kayunga	HPKY_ ...
Manafwa	HPMF_ ...
Masaka	HPMSK_ ...
Napak	HPNP_ ...
Nebii	HPNB_ ...
Ntungamo	HPNT_ ...
Serere	HPS_ ...

Appendix B: PROPOSED PUBLICATIONS

This research study generated three manuscripts that have been submitted to three specialised digital health / health informatics international journals for review as detailed below:

1. Critical Risk and Success Factors for Sustainability of an Electronic Health Data Capture, Processing and Dissemination Platform for Uganda. *Health Informatics Journal* (submitted for review)
2. Electronic Health Initiatives and Interventions for Data Capture against Public Health, Social, or Clinical care in Low- and Middle- Income Countries: A Systematic Review. *Journal for Health Informatics in Africa* (submitted for review)
3. Feasibility and Utility of Point-of-Care Electronic Clinical Data Capture in Uganda's Healthcare System: A Qualitative Study. *Journal of American Medical Informatics Association* (submitted for review)

Appendix C: ACKNOWLEDGEMENTS

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Appendix D: THE RESEARCH TEAM

The research study was conducted by a team of several researchers as described below;

Principal Investigator



Dr. Josephine Nabukenya is a Professor of Information Systems & Health Informatics at the School of Computing and Informatics Technology, Makerere University. She is the Founder and Chair of the Health Informatics Research Group. She is a member of the Uganda Health Information & Research (eHealth) Technical Working Group, and Digital Health and Interoperability Working Group of Health Data Collaborative. She was part of the 10-member Core Team that developed the Uganda eHealth Policy and Strategy, and collaborating with the Ministry of Health (MoH) for its implementation. Josephine has over 19 years of research experience in Information Systems with a focus on health informatics and data science; and currently leading research on: 1) Potential for Transforming Health in Uganda through an Electronic Health Data Sharing Platform and Data Science; 2) Development of an Evaluation Framework to Measure Performance Outcomes and Impact of Digital Health Interventions on Healthcare in Uganda; 3) Designing and Piloting of a Mobile-based Technology linking Mothers to Health Providers and Health Facilities to Reduce Maternal and New-born Deaths in Uganda during- and post-COVID-19 Pandemic; and 4) Implementing and Evaluation of a low-resource digital infrastructure in Uganda: Visualization and Interpretation of Radiographic Images to improve access to imaging services in regional referral hospitals. 5) Feasibility for Strengthening Uganda's Health System through Standardizing Digital Health: Enterprise Architecture, Standards and eRegistries. She is also a Co-Investigator on two International Digital Health research projects including 1) mHEALTH-INNOVATE: Exploring how healthcare workers' informal and innovative uses of mobile phone messaging apps are shaping service delivery and governance in LMICs; 2) Development and Evaluation of an Information Management and Communication System for Population-wide Point-of-Care Infant Sickle Cell Disease Screening. Josephine has published widely in Information Systems and Health Informatics. She is an Editorial Board member of various International Digital / Health Informatics and journals.

Co-Investigators



Dr Lydia Drumright is a University Lecturer of Clinical Informatics in the Department of Medicine at the University of Cambridge. Within Cambridge Clinical Informatics, she directs the science and research activities, and facilitates expansion of the Centre through collaborations and securing external funding.



Dr. Agnes Rwashana Semwanga is an Associate Professor of Information Systems at the School of Computing and Informatics Technology, and Senior Researcher in the Health Informatics Research Group, Makerere University. Her research interests focus on systems modeling, health informatics and information systems. She has extensive experience with System Dynamics Modeling and have done extensive research, published and developed system dynamics models of health issues such as maternal health, neonatal health and food security.



Dr. Simon Kasasa is a Senior Lecturer at the School of Public Health and Researcher in the Health Informatics Research Group, Makerere University. His teaching areas include; research methods, Epidemiology, Biostatistics and M&E. As a research scientist, Dr. Kasasa has been involved in a number of research activities in areas of HIV/AIDS, Malaria, pneumonia, and TB.

Researchers



Alunyu Egwar Andrew is a PhD student in the Health Informatics Research Group, School of Computing & Informatics Technology, Makerere University. His research focuses on computer and data communications, standardization of the digital health environment particularly the communication infrastructure that supports patient data sharing and health information exchange, securing patient data / health information to ease Health Information Exchange (HIE) in Uganda's Health System; as well as Collaboration Engineering for collaborative problem solving.



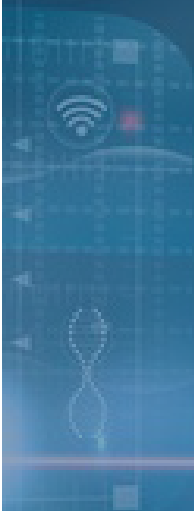
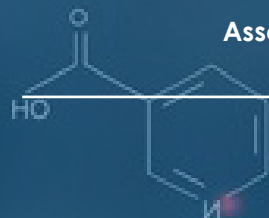
Dr. Vincent M. Kiberu is a lecturer at the School of Public Health and Researcher in the Health Informatics Research Group, Makerere University. His primary research interests are in ICT project management and evaluation; mobile technologies, Telehealth and Electronic Health Information Systems; Data analytics; systems interoperability and standards frameworks.



Achilles Kiwanuka is a PhD student in the Health Informatics Research Group, School of Computing & Informatics Technology, Makerere University. He has carried out research on the adoption and standardization of digital health technologies and systems. Currently, he is researching about how international eHealth medical coding standards can be contextualized to improve semantic interoperability in Uganda's eHIS, focusing on the three standards: Systemized Nomenclature of Medicine – Clinical Terms (SNOMED), Logical Observation Identifiers Names and Codes (LOINC) and International Classification of Diseases (ICD).



Joseph Wamema is a PhD student in the Health Informatics Research Group, School of Computing & Informatics Technology, Makerere University. His research is aimed at developing a digital health Enterprise Architecture Framework to streamline the digitalization of Uganda's healthcare system. He is particularly interested in research studies that focus on the interoperability of digital health Systems, barriers to successful adoption of digital health and the technology-fit of digital health in the African context. He has hands-on practical experience with Enterprise Architecture Frameworks such as The Open Group Architecture Framework (TOGAF) and Zachman framework.





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