Investigating the Impediments to Accessing Reliable, Timely and Integrated Electronic Patient Data in Healthcare Sites in Uganda

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Abstract: The purpose of collecting patient data is to support their care and wellbeing. Patient-centred care is attained by securely availing all records about the patient whenever it's necessary to the right persons and at the right time. However, healthcare providers have often failed to share integrated patient data on time due to limitations in accessing reliable patient data required to inform care/treatment decisions. This study aimed to investigate impediments to accessing reliable, timely and integrated patient data through investigating the processes for collection, analysis, and presentation of data across various healthcare sites in Uganda. A cross-sectional study design was followed, and data was collected from purposively selected National level (policymakers) and Sub-national level (health facilities). The field findings indicate various impediments to accessing patient data including but not limited to inadequate mechanisms for electronic health data collection, storage and access, non-standardised health data sharing mechanisms, inadequate Health Information System (HIS) and Information and Communication Technology (ICT) infrastructure, and inadequate skills, knowledge and training. Other impediments included; insufficient security and privacy measures, weak eHealth governance, and inadequate management support. Accordingly, these have negatively impacted on patient data use and quality of patient care in Uganda.

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1 INTRODUCTION

Governments in lower-middle and low-income countries like Uganda have adopted the use of ICT to improve the delivery of services including healthcare to all its citizens. Uganda's eHealth Policy and Strategy documents have identified unique pillars necessary to support the successful adoption of ICT to support healthcare (Ministry of Health, Uganda, 2016). However, reaping the benefits of ICT in healthcare have continued to face a lot of challenges including; lack of specific standards on electronic collection, data storage and sharing, noninteroperable ICT systems and technologies, resistance to using ICT to support healthcare, limited

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ICT skills and knowledge as well as weak governance structures (Ministry of Health, Uganda, 2016; Ross *et al.*, 2016; Sara, 2016).

These ICT challenges often impact the collection, sharing, storage, and use of patient data. Patient data is collected "to create holistic views of patients, personalize treatments, advance treatment methods, improve communication between doctors and patients, and enhance health outcomes" (Sakovich, 2019). To have a complete history of a patient, there is a need for all medical records/ data to be availed in an integrated and reliable manner. However, healthcare providers have often failed to access patient data on time, even though patient-centred care requires that all data about a patient is made available

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on time (Kuipers *et al.*, 2019). Any delay to access a patient's data resulting from technology, access rights or even lack of integration may lead to loss of life. Besides, patient data may be captured/stored on different geographically placed eHealth systems. Any lack of integration of patient data fetched from such systems may negatively impact healthcare.

Patient care involves the participation of various stakeholders including healthcare practitioners who provide care, healthcare organisations who participate in patient care, decision-makers in government, the patient's caretakers and the patients themselves. Patient data is required by any of them, anywhere, anytime; thus, the need for integration and timely access as any delay or lack of integration would hamper proper care of the patient.

To gain an insight into impediments to accessing reliable, timely and integrated electronic patient data in lower-middle and low-income countries. This study investigated Uganda's healthcare sites with a specific focus on the processes for collection, analysis, and presentation of patient data.

2 METHODS

The study followed a cross-sectional design. The cross-sectional design provides a snapshot of the prevalence of the study subjects in a single time point (Awaisu, *et al.*, 2019).

Sampling Method: Purposive sampling was used to select both study sites and participants of this study. The decision to use purposive sampling was motivated by its ability to support the identification of all cases that meet a predetermined criterion of importance (Palinkas *et al.*, 2015) as described below:

Inclusion Criteria for Study Sites: This study mainly focused on the HIV/TB disease domain of Uganda's healthcare system. The HIV/TB disease domain was adopted because of the heavy reliance on eHealth systems (i.e Integrated Clinic Enterprise Application (ICEA) and OpenMRS/UgandaEMR) to deliver services to clients (Castelnuovo et al., 2012). Both national and sub-national level health institutions were used in this study. At subnational level, 28 health facilities were chosen to participate in the study. A health facility was chosen as a study site if it was among the top four health system levels in Uganda, i.e., National Referral Hospital (NRH), Regional Referral Hospital (RRH), District Hospital (DH), and Health Center Fours (HC IVs); and also, if it was in the Northern, North-Western, Western or Central regions of Uganda. These regions were chosen on grounds that they have a high prevalence

of HIV/TB (Ministry of Health, Uganda, 2017) characterised by high mobility, slum-dwelling, and limited social support (Central Uganda), urban/rural populations undergoing significant socio-economic transformation with an influx of high-risk groups for HIV transmission (Mid-Western Uganda), lowprevalence, sparsely populated area but prone to the influx of refugees .and or internal displacement (West Nile and Northern regions of Uganda) Additionally, the sites were chosen if they had adopted and implemented eHealth systems of some nature. Lastly, if the site was an Infectious Disease Institute (IDI) site. Makerere University IDI is a major partner in the implementation of HIV in Uganda and possess experience in transitioning from paper-based to eHealth systems (Castelnuovo et al., 2012). Also, 11 government Ministries, Departments, and Agencies (MDAs), healthcare organisations, and eHealth like academia, developers stakeholders and implementers were included in the study. These were chosen on the basis that they participated in the development of the national eHealth strategy/policy for Uganda, undertaken research in eHealth, developed/invested in electronic health systems, implemented electronic health systems among others. Overall, the study sample size of this study was 196 possible responses from subnational level and 34 respondents from national level.

Inclusion Criteria for Participants: Participants at health facility level were chosen if they were officers-in-charge of a health facility, ICT/Data/Records/M&E Officers, or users of eHealth in the categories of Clinical Officers, Nurses, Pharmacist, and Laboratory Technologist. Participants at the national level were chosen if they were eHealth Policy Makers, standard/guideline developers, Health Implementation Partners, Health Systems and Health Informatics researchers. Only potential participants who consented to participate in the study were finally interviewed.

Ethical Consideration: The researchers obtained consent to assess the study sites from the Ministry of Health. Ethical clearance was also obtained from the Institutional Review Board (IRB) of the School of Public Health, Makerere University.

Data Collection Tools: To obtain representative views from facility-level and national-level participants, the study used both interviews and questionnaires to collect data. Whereas the questionnaires helped to discover what the eHealth stakeholders (the masses) think about timely, reliable and integrated access to patient data; follow-up interviews were conducted to further authenticate and/or corroborate their responses (Cohen, 2013).

Data Analysis: To analyse quantitative data (i.e. data collected at the facility level), the researchers used MS Excel software. Quantitative analysis was performed to explore the relationships in the collected data. The results of the quantitative analysis are presented either statistically or graphically to show the status quo regarding impediments to accessing reliable, timely and integrated patient data. The qualitative data (i.e. majorly collected at national level) was analysed following the framework method (Gale et al., 2013). The framework method allowed the researchers to develop codes, use and categorise the codes into themes. NVivo 12 was used to assist and aid the researchers to code and organise the qualitative data into themes and evidence on impediments to accessing reliable, timely and integrated patient data in Uganda.

3 RESULTS

Results of this study are based on 201 responses from obtained from sub-national and national levels. The sub-national level response was highest among nurses (26%) who are the majority users of the ICT, followed by medical officers (15%), laboratory (14%), pharmacy (13%), officers-in-charge of health facilities (11%). Response at the national level is represented by 6% being health systems and health informatics researchers, 4% were policymakers from Ministries, Departments and Agencies (MDAs), and 3% being the Healthcare Development Partners (HDPs) in Uganda.

Subsequent subsections present the findings categorized under the three broad themes of technology-related impediments, inadequate user skills, knowledge and training on eHealth, and healthcare organizational environment.

3.1 Technology-related Impediments

a) Mechanisms for Data Handling

Figure 1 shows the views of respondents regarding the handling (i.e., collection, storage and access) of patient data at various health facilities across the four regions that were studied. The responses relate to how patient data handling processes at health facilities affect its timely access, reliability and integration.

Limited Training in Electronic Health Data Classification: On the classification of health data, 81.1% of the respondents agreed that they do classify the health data during its collection. Much as the majority of the respondents agreed to classifying health data during collection, only 40.9% reported that they had been trained on health data classification, an indication that they had limited training in health data classification as expressed by respondent HSL4-25 ... "For me, I was not trained in coding but I had to learn from a colleague who was trained by ministry officials." Lack of proper training in the classification of health data can affect its reliability and integration since data collectors are likely to use different classification codes. When respondents were asked what challenges were faced in classifying the health data during its collection, changing of indicator definitions was mentioned as the key challenge. In an interview, a respondent said: "The challenge that we have is that the indicators are usually changing. You find even the indicators that are national keep on changing. For example, the HMIS tools have been revised. We have to be so adaptive to all the new changes and train people again. When the staff have just learnt how to capture the data, new indicators are put in place and so more training is needed on the new indicators" - HSL2-06. While another respondent felt the impact of changing indicators' definitions as expressed: "Since many of the tools we use are routinely revised. You find that the data that was stored five years ago is different from the data that is currently stored because of the new indicators. If they add new indictors, they bring along new registers. Therefore, I am asked to train the staff on the new registers"- HSL3-01.



Figure 1: Views on Health Data Handling.

Use of Paper-based Data Storage Mechanisms: To gain an insight into how health data was stored at respective health facilities, majority of the respondents (84.8%) reported that this was done. Our findings indicate that most of the health data was stored manually (paper-based files), and most times were incomplete as reported by one respondent: "Most of our data is in manual files so we keep the files in the records office that you see there. Some are incomplete, others are misplaced. They always present it to us as senior management on every Thursday but you see a lot of gaps in them when they are presenting"- HSL2-02.

On how to access the data stored in manual files, a respondent indicated that it was a tedious exercise requiring one to go through all the shelves to locate a file that had a record of interest. A respondent had this to say: *"Filing is one of the trick works. Sometimes, once in a while someone can interchange the position of the file and you want to retrieve and you cannot see it. Maybe by mistake it has been twisted and it has missed its position. That can make the file a little bit difficult to be traced.*."-HSL4-25. Such a response evidenced use of poor mechanisms to store health data, impacting its timely access as well as reliability.

Untimely Access to Health Data: To understand how well health data is managed at the health facilities, respondents were asked whether they had timely access to patients' data. 78.8% agreed they do. However, some complained about delay in accessing patient data as commented by this respondent: "The only challenge to data access is the workload of the person who has the data that you need. You may find that that person has too much work and cannot give you the data at the time that you need it. You go and find someone doing other things and may postpone the time you may access data" – HSL2-04.

b) Non-standardised Health Data Sharing Mechanisms

To gain an insight into the data-sharing challenges, this study investigated issues on the guidelines/SOPs for sharing health data, and how this data was shared both within and with other health facilities (Figure 2).



Figure 2: Mechanisms for Health Data Sharing.

Existence of Guidelines/SOPs for Sharing Electronic Health Data: On the existence of guidelines and/or Standard Operating Procedures (SOPs) for sharing health data, 64.4% agreed to existence of guidelines/SOPs for data sharing. The majority of the respondents who agreed to the existence of guidelines/SOPs for sharing health data

might not have referred specifically to the use of ICT to share data, rather to the general guidelines for health data sharing and exchange such as the data protection policy, as evidenced by some respondents who said; as an institution, we have a data protection policy that guides all staff that are accessing data and other records" - IP06; "what I know is that data is confidential and if you are sharing you need to share with only health workers" - HSL4-26; "There is no comprehensive SOP" - HSL3-02. However, some respondents indicated that though their facilities had SOPs for data sharing, these were not comprehensive enough and that some had been locally made as reported by respondents: "There is no comprehensive SOP" - HSL3-02; "the health sector is sensitive and you cannot come up with your own SOP and yet "some of them are locally made"- HSL2-06.

On the issue of guidelines for accessing EMRs, the respondents had mixed opinions. While 31.8% of the respondents agreed to the existence of guidelines for EMR, 42.4% were neutral and 25.8% disagreed. The respondents who agreed to the existence of the standards to access EMRs could not provide copies of such standards as we observed: "*It's not documented but we know about them*"-HSL4-26.

On data sharing within a health facility, 84.8% agreed that health data was shared. The respondents who agreed to share data intra-facility referred to the paper-based mechanism to share health records. For example, when asked whether they used ICTs to share health data with another ward or physician within the health facility, a respondent said: "currently we have not been using ICT, but we are hoping that it will be there" – HSL3-06.

On data sharing with other health facilities, 56.1% of respondents agreed that they do. However, from the interviews, it was noted that the current nature of shared data mainly constituted national, monthly and quarterly reports as evidenced by one respondent who said: "The information we generate from here is entered into the District Health Information System and from there it is transmitted to the ministry. The partners also use the same system to get their share, their part of the information. But, at the same time like for the partners, they come up to the primary source of the data, they pick it also and then they compare with what the facility has sent" – HSL4-11.

As much as patient data was shared both within and outside the health facility, there seemed to be no agreed mechanism for sharing this health data as indicated by a respondent in an interview: "We *have* to use other things. So, you have to use like WhatsApp and Facebook, those others, not the government systems, not the Uganda health system" – HSL4-20.

c) Insufficient Electronic Health Data Security and Privacy Measures

The study also investigated the existence of measures for security and privacy of health data at the health facilities (that is, safeguards to health data as well as personally identifiable data as seen in Figure 3). On the issue of safeguards to health data, 63.6% of respondents agreed that security measures/controls had been implemented at the health facilities. This high percentage could have referred to physical access to health data storage facilities including ICTs. In an interview, respondents had this to say: "Physical security is key, the server environment is secured, locked with only fingerprint access" - IP03. "specific people who are using this machine. It's not everybody who accesses it and even we lock also the computers and even as I told you we have the security guards we have two that makes our information safe" - HSL4-18. "Not everyone enters the records room. All the cabinets are lockable" - HSL4-22.



Figure 3: Data Security and Privacy Measures.

On whether security controls had been implemented in the ICTs that are used at the health facilities, 62.9% agreed that this had been done. Respondents could have interpreted security to mean the presence of passwords that are used to access computers as evidenced by the interview responses:

"There is a password in this EMR. A person who is logging in is given account so you log in using their account. And the account is not given to all. And the access right is not given to all the people"-HSL4-13; "Here like on my computer, we have password that not everyone has access to"-HSL3-03; and "In softcopies there is passwords which I normally put there and people cannot access the data"-HSF4-18.

However, only 46.2% agreed that information security controls were sufficient. Those who disagreed (22.7%) or were neutral (31.1%) could have represented respondents from health facilities where security breaches had been experienced. From the interviews, respondents said; "we have experienced theft of computers like regional referral in October they lost about ten computers." - HSL4-25; "Yes, some thieves have ever broken in the facility, although the computers were recovered. if his place can be faced maybe the issue of security would be solved and also we might need more security guards to guard the facility"-HSL4-30.

Concerning personally identifiable data, 71.2% of respondents agreed that this data is hidden which is an indication that measures to ensure the privacy of personally identifiable data had been implemented. This high percentage of respondents who agreed could be attributed to the need to protect information as confirmed by 80.3% of respondents who said that the health data they collect is valuable.

d) Inadequate HIS and ICT Infrastructure

Respondents were asked to give their views on the suitability of existing HISs and supporting infrastructure in Uganda's top four health system levels to deliver access to quality and timely health data. The questions asked related to the relevance of the applications to support healthcare work routines, use of eHealth applications and/or technologies, characteristics that make the application suitable, and technology infrastructure to support access to patients' data in a reliable, timely, and integrated manner (Figure 4).



Figure 4: Characteristics of eHealth applications/ technologies used in healthcare facilities.

Apprehension to using ICT in Healthcare: Results show that although a majority of the respondents agreed on the compatibility of existing technologies with work routines (40.9%) and ability of eHealth applications to enhance productivity (41%); they disagreed or remained neutral on the rest of the characteristics indicative of existing apprehension/challenges to using ICT in healthcare.

Insufficient Training in the use of eHealth Applications/Technologies: On the question of whether the eHealth applications that they used were easy to learn, respondents had mixed reactions with 34.8% in agreement, 28% neutral and 37.1% disagreed. The negative responses concerning the ease of use of the eHealth applications could have been a result of the varied training capacities, that is, while some were trained by the funders/investors, others did not receive any training as evidenced from the interview responses; "We are given the system with the database and they are national. We are trained on how to use it" - HSL4-24; on the contrary, a respondent said: "No I just trained myself" - HSL4-08; while another respondent said: "All those who work on these computers struggle with some few days of training, say like in Uganda EMR" – HSL3-05.

Characteristics of the HIS Applications that are used: Respondents were asked to give their opinions on the characteristics of the eHealth applications that they use. On whether the applications were error-free, only 18.8% agreed. This meant that the reliability of the applications' data could be queried. This could be the reason 37.1% disagreed with the relevancy of data provided by these eHealth / HIS applications.

When asked whether the eHealth applications used within the health facilities can integrate with other eHealth applications outside of the health facilities, there were mixed responses; 37.9% of respondents disagreed, 35.6% remained neutral, and 26.5% agreed. Those who remained neutral and disagreed may represent respondents that had a limited understanding of the functionalities of the eHealth applications that were being used at the health facilities. Generally, the respondents did not commit to the suitability of the eHealth applications that they used to access health data on time. In one of the respondents' own words he said: "I would actually recommend that if there is need to introduce any other system, it should be a system that is safe, effective, fast which can help us access what we need in a timely manner. If we can at least get a system which is quick, effective and convenient with no interruptions, it would be better" – HSL2-04.

Poor eHealth Infrastructure: On whether the health facilities had adequate eHealth infrastructure to support timely access to patient data, 48.5% of respondents reported that hardware and application technologies that support eHealth were not sufficient to support healthcare processes that relate to collection and analysis of health data. The respondents' views ranged from inadequate ICT

devices e.g. "lack of enough systems in place like the workstations. You find you may have like 3 computers to serve all this large number of 12000 clients." -HSL2-04); poor electric power e.g. "we have power challenges. we find that at times there is power fluctuation and our backups at times are not so reliable. We have a backup generator but at times there is no fuel." - HSL2-06); poor maintenance e.g. "The few gadgets around have a challenge of maintenance costs and so maintenance being a problem" -HSL4-32); and intermittent network connectivity and/or lack of mobile data e.g., "The challenge I have experienced for a while has been internet connectivity. Sometimes you are supposed to send reports when there is no data on the modem" -HSL2-01) among others.

3.2 Inadequate Skills, Knowledge and Training on eHealth

This study also sought for respondents' views on the expertise, confidence and training on using eHealth (Figure 5). On confidence and control when using eHealth, only 31.1% of respondents agreed that they were confident when using eHealth applications. The low percentage of respondents who agreed to be confident when using eHealth may be attributed to limited experience and expertise in eHealth usage. Less than half (42.4%) of respondents agreed that they had experience and expertise in using eHealth. The low percentage of those who agreed that they had experience and expertise in the use of eHealth may also be attributed to insufficient training (52.3%), as evidenced by some respondents: "... challenge is the human resource. They are yet to train our people to know how to use it" – HSL2-02; "it is a new system which has come up. You know it comes with some challenges if one is having a knowledge gap" -HSL2-05; and "ICT skills are inadequate/lacking among healthcare workers"- RI01.



Figure 5: Capacity in using eHealth Applications/ Technologies in Healthcare Processes.

The limitations of user skills and knowledge by health practitioners may be a result of failure to incorporate ICT skills in most of the curriculum of healthcare professionals as mentioned by some respondents who said: "inadequate integration of eHealth skills into existing health professional training curricula"-IP04; and "Not everyone in the ART clinic is computer literate. It is only the health information assistant who is well trained in computer skills" - HSL4-15. Some universities and tertiary institutions have however started training healthcare professionals in ICTs skills as mentioned by a respondent: "ICT skills related to eHealth are inadequate, both in terms of the numbers and skills mix/set. However, situation though is much better now than it was 5 years or more ago. Some training institutions has trained healthcare professionals who understand ICT" - IP04.

3.3 Healthcare Organizational Environment

To further understand how the healthcare environment can impact on access to reliable, timely, and integrated data, this study also investigated the governance factors including governance of ICT for healthcare and management support for the implementation and operation of eHealth (Figure 6).



Figure 6: eHealth governance factors that affect eHealth data management.

Weak eHealth Governance - On the governance of eHealth, this study mainly focused on planning for eHealth, coordination of eHealth implementation and compliance monitoring. The majority of the respondents (52.3%) reported that management is involved the preparation in of eHealth implementation plans and that there is coordination with implementation agencies (60.6%). These findings indicate that there is some kind of framework that is followed to govern the implementation of eHealth in Uganda. However, our findings indicate that the framework has not yet been documented as

evidenced by one respondent: "let's say there is a framework but at the time we developed ICEA, it wasn't necessarily written down. It's just that we all knew that the system we wanted to develop would address the institutions need, the funders need, and the MOH requirement. So that was the framework, but that framework was in our mind, I don't think it was explicitly laid down somewhere at that time"-IP05. Lack of a well-documented implementation framework was further echoed by respondents: "There are insufficient governance structures to guide the development of eHealth across the health sector" -R101; and that "There is insufficient coordination and participation of partners in publicprivate-partnerships in promoting ICT in the health sector"-PM04.

On the existence of monitoring structures, 34.8% agreed, 37.1% remained neutral and 28% disagreed. Also, on monitoring compliance with ICT guidelines, 30.3% agreed that this is done, 35.6% remained neutral, while 34.1% disagreed. These results show that a higher number of respondents remained neutral on the existence of monitoring structures as well as compliance with ICT guidelines. This may signify the lack of awareness of eHealth governance structures at the health facilities level. It is evident by the fact that despite more respondents agreeing on the existence of monitoring structure (34.8%), a significant number said it is not monitored (34.1%). Most users of eHealth comply because it is mandatory; however, with "limited/lack of a monitoring system in place" -RI01, the compliance is compromised.

Inadequate Management Support - Results from this study (Figure 7) show that management at the health facilities provides resources and support for use of the eHealth (50.7%). This may be attributed to the management's awareness of the benefits of eHealth (69.7%). Support for eHealth by management was echoed by some respondents as evidenced in their own words: "Management, their level has done best to ensure that possible request has been met in terms of the ICT tools. The computers and these all come through them" - HSL2-01; "Management has always been supportive in the use of electronic systems, electronic data. How are they supportive? Right now, if you can see there is a lot of investment being done in purchase of these electronic systems" - HSL3-01; and "The management has helped us in funding our trainings, when we have been called for training because the training focus on the use of the software system or the software we have been using for the medical management"-HSL2-01.



Figure 7: Role of Management to Support Implementation and Use of eHealth Applications.

These responses could mean that there is suitable eHealth implementation and its use; however, gaps remain as only 42.4% agreed that management effectively address eHealth applications challenges.

Although 60.6% of respondents agreed that there were good communication and coordination among eHealth implementing agencies, 18.9% disagreed. The few who disagreed argued that there is still "insufficient coordination and participation of partners in public-private-partnerships in promoting ICT in the health sector"-PM04. The limitation in communication and or coordination may be attributed to governance factors including structures to oversee implementation and compliance to standards as reported by some respondents: "Insufficient governance structures to guide the development of eHealth across the health sector" - PM04; "Limited/lack of monitoring system in place" – RI01; and "I believe the regulatory framework is still in its infancy stage and therefore generally still lacking; it needs to become better developed, coordinated and enforced" – IP07.

4 DISCUSSION

In Uganda, we observed that numerous EMR-based electronic Health Information Systems(eHIS) initiatives including OpenMRS/ UgandaEMR, ICEA, DHIS2, OptionB+ were being used in the management of HIV and TB patients (Ministry of Health, Uganda, 2016). Despite their existence, our findings evidence various impediments to accessing reliable, timely and integrated patient data from existing eHIS as discussed below:

Insufficient Mechanisms for the Collection, Storage and Access to Electronic Health Data -Collecting healthcare data generated across a variety of sources encourages efficient communication between doctors and patients, and increases the overall quality of patient care providing deeper insights into specific conditions. The way health data is collected and stored has a bearing on its access, reliability and ability to integrate. For example, "during the move from a paper record or from one computerized system to another, records can be misplaced or incorrectly added to a patient's record" (Rodziewicz & Hipskind, 2020) affecting the reliability of the patient data. The study identified limited training in electronic health data classification and use of paper-based data storage mechanisms as specific impediments to the process of electronic data handling in Uganda's health system affecting integrated and timely access to patient data across health facilities. Therefore, first-line eHealth technology users (data collectors) and the eHISs/applications or technologies need to capture, process and present accurate data.

Inadequate and Unsuitable HIS and ICT Infrastructure - eHealth has been recognized to have tremendous potential for managing patient health data (Barello et al., 2016). eHIS and/or applications allow the development of reliable and integrated patient data and promote effective exchanges among the actors involved in the healthcare process (Khubone et al., 2020). However, existing eHealth applications have errors, lack useful data, and cannot be easily integrated with data from other applications. This is a design-reality gap. eHealth success or failure largely depends on the size of the gap that exists between current realities and the design of the application (Anthopoulos et al., 2016; Ishijima et al., 2015) which user-centred participatory design can remedy (Williams & Coles-Kemp, 2014).

Also, facilitating infrastructure should be adequate to support capture, analysis, storage, sharing and presentation of health data (Aanestad *et al.*, 2017). However, findings revealed few and poorly maintained infrastructural resources that may be slow and unable to support the timely and integrated sharing of health data. Current modes of health data communication include the sharing of text, images, audio, and video (Al-Safadi, 2016) requiring the supporting eHealth infrastructure to be fast, flexible, large, reliable and with appropriate security and privacy measures (Aanestad *et al.*, 2017). The poor state of the eHealth applications and infrastructure could have led to apprehension among some of the target users of eHealth in Uganda to use ICT in support of healthcare processes contributing additional challenges to timely access to patient data (Ministry of Health, Uganda, 2016).

Inadequate eHealth Skills and Knowledge although eHealth has become an integrated part of modern healthcare (Bedeley & Palvia, 2014; Gregory & Tembo, 2017), a range of individuals within healthcare experience challenges of using and benefiting from the technology (Furstrand & Kayser, 2015). For eHealth to be valuable in providing timely, accessible and integrated health data, users must have the necessary skills and understanding (Standing & Cripps, 2015). However, this study showed that there was a lack of sufficient skills and knowledge to use eHealth applications as represented by 52.3 % who claimed that they were not trained in the use of eHealth. Without proper skills and knowledge, healthcare providers are likely to find difficulty in accessing healthcare information to make good medical decisions (Hoque et al., 2014). Availability of a skilled workforce that understands healthcare and ICT is a critical success factor (Standing & Cripps, 2015). That can be achieved through training and demonstrating the benefits of eHealth (Alunyu et al., 2020; Hoque et al., 2014; Were et al., 2015).

Insufficient Electronic Health Data Security and Privacy Measures - The study findings show three broad security and privacy concerns, i.e., limited understanding of ICT security and privacy measures, lack of policies specific to security and privacy of health data, and full implementation and enforcement of security and privacy measures to include both physical and electronic security. The right of individual patients to nondisclosure of their health information (privacy) and mechanisms in place to protect privacy (security) may directly or indirectly contribute to reliable, timely and integrated access to patient's health data/information (Sahama et al., 2013). Privacy in healthcare settings refers to people's right to control access to their personal information (Kumar & Wambugu, 2016). Security, on the other hand, refers to the mechanisms put in place to safeguard health information and health information systems from unauthorised access, modification and denial of service to authorised users (Kumar & Wambugu, 2016). For providers and individuals to adopt eHealth, they must trust the security and privacy of their electronic health information (Sahama et al., 2013). If patients feel that the eHealth systems are not secure, they may not use them to share their health information with healthcare providers. This has a negative bearing on timely access to patient information for decision making by providers.

Non-standardised Health Data Sharing Mechanisms – Mukasa et al., (2017) recommends that organisations who intend to share data should deploy standards as part of their integration efforts. The purposes of the standards are; to ensure proper and integratable data formats are captured, those participating in sharing of health data/information adhere to a set of rules that govern exchange, only the right persons have access to a patient's data, and security and privacy of patient information are protected (Adebesin et al., 2013; ITU-T, 2012; Mukasa et al., 2017). However, our study findings show that although there are SOPs for sharing of health information, they are not comprehensive enough to guide patient data sharing; and procedures for accessing EMRs are not documented or documentation is not widely shared. These shortcomings are a hindrance to timely access or electronic sharing of patient data. This study suggests that future development or review of standards for eHealth should include health facility level users as part of the stakeholders involved in the development and/or review of the standards. Furthermore, the standards for eHealth should be widely provided and disseminated among all eHealth implementing agencies and developers.

Organizational Healthcare Environment - in this study, eHealth governance and leadership, legal and regulatory frameworks as well as standards have been reported as key to successful utilization of eHealth (Hoque et al., 2014; Ishijima et al., 2015; Ross et al., 2016). Without an enabling organization healthcare environment, it may be difficult to successfully utilize eHealth to realize timely, reliable and integrated health data (Palabindala et al., 2016). However, our study findings indicate that there are insufficient governance structures within Uganda's health system to monitor the implementation of eHealth as well as compliance to standards. Healthcare is a sensitive domain. If some eHealth application is going to be used to handle data, proper governance, as well as procedures and rules, need to be devised and followed to ensure safe practices of healthcare services; otherwise, it could lead to serious consequences. Although the Government of Uganda has some guidelines and policies in place, the regulatory and legal framework has not yet been modernized and or operationalised at health facility level. This study, therefore, recommends that the Ministry of Health creates structures at facility level to oversee the implementation and use of eHealth.

Investigating the Impediments to Accessing Reliable, Timely and Integrated Electronic Patient Data in Healthcare Sites in Uganda

5 CONCLUSIONS

This study investigated the impediments to accessing reliable, timely, and integrated electronic patient data in healthcare sites in Uganda's health system. Findings show the key impediments ranging from unsuitable mechanisms for electronic health data collection, storage and access; non-standardised health data sharing mechanisms; inadequate HIS and ICT infrastructure; inadequate skills, knowledge and training; to insufficient security and privacy measures. Other impediments include weak eHealth governance and inadequate management support for eHealth. To mitigate these challenges and attain the full benefits of eHealth, our future work will generate requirements that must be met to improve access to reliable, timely and integrated patient data in the healthcare sites. The requirements will act as inputs to the development of contextualised eHealth standards and an eHealth Enterprise Architecture to digitally-enable, standardize, implement and use eHealth in healthcare and service in Uganda.

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