







Establishing the State of Practice about Data Standards in Monitoring Healthcare Interventions for HIV in Uganda's EMR-based Health Information Systems

Achilles Kiwanuka¹^a, Moses Bagyendera¹, Joseph Wamema¹^b, Andrew Alunyu¹^c,
Mercy Amiyo¹^d, Andrew Kambugu²^e and Josephine Nabukenya¹^f

¹Department of Information Systems, Makerere University, Kampala, Uganda

²Infectious Diseases Institute, Makerere University Kampala, Kampala, Uganda

Keywords: eHealth, Data and Interoperability Standards, Electronic Medical Records, Health Information Systems.

Abstract: Electronic Health Information Systems (EHIS) in Uganda are characterised by inaccessibility to reliable, timely and integrated data for effectively monitoring and tracking continuity of care for people living with HIV, exacerbated by disparate, fragmented EHIS in varying health system levels that are not interoperable and lack common data standards. In order for data to be comparable, there has to be uniformity in terms of standards that are employed in a uniform manner in all data management processes. In this study, we established the state of current practice regarding data and interoperability standards in monitoring and evaluating healthcare interventions for HIV in Uganda's EMR-based health information systems. The study findings indicate that there are scanty practices and/or implementation of the eHealth standards (data and interoperability), and limited to noncompliance of monitoring these standards in the implementation of the HIV healthcare interventions. Accordingly, our study recommendations point to the need of designing data and interoperability frameworks to provide for the specific set of standards, protocols, procedures, best practices and policies for eHealth standardisation in Uganda's health system.


1 INTRODUCTION


An estimate of 6.7% of Ugandan adult population have been diagnosed and are currently living with HIV (Ministry of Health, 2017). Given the magnitude of the disease, there is a need to use data-driven approaches to facilitate decision-making ensuring appropriate interventions are implemented in relevant populations in the right way (PEPFAR, 2011). In order for data to be comparable, there has to be uniformity in terms of standards that are employed in a uniform manner in all data management processes.


According to the Institute of Electrical and Electronics Engineers (IEEE), a *standard* is a


“document that defines the characteristics of a product, process or service, such as dimensions, safety aspects, and performance requirements” (IEEE, 2010). Standards facilitate the consistent and precise collection and exchange of information across different services of the health system (World Health Organization & International Telecommunication Union, 2012) and are a prerequisite for the smart healthcare (Chang et al., 2019).


Uganda's Ministry of Health has implemented numerous electronic-based Health Information Systems (EHIS) including OpenMRS/UgandaEMR, Integrated Clinic Enterprise (ICEA), and District Health Information Software 2 (DHIS2) that are used for reporting, documenting and managing HIV and


^a <https://orcid.org/0000-0003-3352-0312>

^b <https://orcid.org/0000-0001-6328-7801>

^c <https://orcid.org/0000-0003-2957-8423>

^d <https://orcid.org/0000-0002-8172-5382>

^e <https://orcid.org/0000-0002-3075-0211>

^f <https://orcid.org/0000-0002-4731-2496>

TB patients (Ministry of Health, 2017). Yet the country's health system is still challenged with translation of data into effective use for decision making and policy development (Henriksson et al., 2019). This situation is exacerbated by disparate, un-interoperable fragmented EHIS in varying health system levels and lack of common data standards to facilitate sharing data consistently across the health system (Ministry of Health, 2017; Alunyu and Nabukenya, 2018; Egwar et al., 2020).

To this end, this study aimed at investigating the current state of practice regarding data standards for monitoring healthcare interventions of HIV and TB in Uganda's EMR-based health information systems (EHIS). The choice of these diseases was remitted on the fact that several global and local efforts, that is, Uganda government and Health Development Partners (HDPs) implemented enormous EHIS investments to accelerate the achievement of the epidemics control of HIV and TB (Ministry of Health, 2010). Particularly, various duplicated and disintegrated EHIS have been developed to manage the HIV and TB epidemic; as such these require standardising in order to facilitate proper health information exchange across Uganda's health system.

2 METHODOLOGY

Study Design: We used the cross-sectional design since it provides a snapshot of the prevalence of the study subjects in a single time point (Awaisu & Banan Mukhalalati, 2019).

Study Area: The study covered four key regions in Uganda (Kampala, Wakiso, West Nile and Mid-Western) representing the full spectrum of HIV and TB prevalence (Ministry of Health, 2017). Kampala and Wakiso are mainly urban high-HIV prevalence regions, characterised by high mobility, slum-dwelling, and limited social support. Mid-Western comprises some urban/rural populations undergoing significant socio-economic transformation with an influx of high-risk groups for HIV transmission like sex workers). West Nile region is a low-prevalence, sparsely populated area but prone to the influx of refugees (currently standing at 1.4 million).

The structure of the health system in Uganda is decentralised in to six levels, which include: village health teams, health centre II, health centre III, health centre IV (district hospital), regional referral hospital, and national referral hospital. The health facilities that serve the various levels are referred to as health centres II, III, IV, and hospitals (district and regional)

(Ministry of Health, Health Systems 20/20 & Makerere University School of Public Health, 2012).

Data Collection Sites: A stakeholder analysis was done for all institutions affected by eHealth data and interoperability standards. The study engaged stakeholder groups at 4 different health system levels: national-referral, regional-referral, district hospitals and HCIVs. The focus on the top 4 levels was due to the existence of fairly mature but suboptimal EHIS for data collection and the clear links between those levels and data use for decision making processes.

Inclusion Criteria: The health facilities that were included in this study were selected based on the similarities of the healthcare system in the different regions in the country, coupled with analogous health services in health facilities in Uganda. The selected facilities were health centre IVs in the four key regions: Central (Kasangati, Namayumba, Ndejje, Wagagai, Wakiso, Kitebi), Western (Kigorobya, Emesco, Kibaale, Kakindo, Kakumiro, Kikuube), Northern (Atiak, Aboke, Amach, Awach) and West Nile (Adumi, Kuluva, Omugo, River Oli, Pakwach, Warr). Additionally, data as collected from hospitals (Kuluva, St Mary's Lacor, Nebbi and Mulago) and regional referral hospitals (Entebbe, Hoima, Lira, Gulu). The combination of health facilities increased heterogeneity, internal validity and thus generalizability of the study findings.

Sampling Method and Size: Purposive strategies guided the sampling process by using individual judgement to select cases that answer the research questions (Saunders et al., 2012). The study population included respondents at health facilities and national level. The study respondents at health facilities included: clinicians (medical/clinical officers) – 32, pharmacists or their assistants – 20, laboratory technologists or their assistants – 28 and nurses or their assistants – 51. At the national level, respondents were from Uganda National Bureau of Standards (1), Ministry of ICT and National Guidance (1), National Information Technology Authority – Uganda (1), Ministry of Health (3), Central Public Health Laboratory (1), information system developers (2), research institution (1), telecommunications company (1) and HDPs (4).

Data Collection and Analysis: Primary data were collected using semi-structured interviews pre-programmed on a tablet using Open Data Kit (ODK) software. Secondary data were collected through document analysis of the existing data. Data were collected by 16 research assistants who were trained and piloted with the data collection tools before the actual data collection. The interviews were audio recorded in English, transcribed and then loaded into

NVIVO software version 12 for analysis. Quantitative data were analysed using descriptive statistics and presented using tables and figures. Qualitative data were analysed using thematic analysis methods (Maguire & Delahunt, 2017).

Ethical Clearance: Ethical clearance to conduct the study was obtained from the Makerere University School of Public Health Research Ethics Committee (REC) and/or Institutional Review Board (IRB); and the permission to conduct the research in the healthcare sites was sought from the Ministry of Health. Written informed consent was also obtained from study participants prior to being interviewed.

3 RESULTS

The results are presented in three subsections: existence and practice of eHealth standards, standardisation support provided to the Ministry of Health, and monitoring implementation of eHealth data and interoperability standards.

3.1 Existence and Current Practice of eHealth Standards

In this section, we report on the eHealth standards categorised as medical coding, data exchange and sharing, communication infrastructure and data security and privacy standards.

3.1.1 Medical Coding Standards

Medical classifications transform diagnoses or procedures into standardized codes. Regarding classification of diseases, 81% of the respondents mentioned that they classify data while providing services to clients as shown in figure 1. When providing HIV services, the data is coded using the Differentiated Service Delivery Models (DSDM) of HIV Services in Uganda as reported by respondent HSL2-06: “we do a lot of medical coding and we

always have somewhere where the codes are explained, for example under DSDM” – HSL2-06.

The International Classification of Diseases (ICD) standard has been adopted and integrated in the UgandaEMR, a system that is implemented in many Uganda health facilities, as mentioned by IP10. Respondent M01 also noted that the Ministry of Health had adopted the ICD11 standard for disease coding and the standard had been integrated in some of the systems that are used at the Ministry. The ICD10 standard was also found to be implemented in Mulago and St Mary’s Lacor hospitals.

In research institutions, it was found that the Medical Dictionary for Regulatory Activities (MedDRA) is one of the medical coding standard that was used in medical research databases.

Management is instrumental in the use of such standards in the health facilities as 70% of the respondents mentioned that management supports them to use classification of diseases and procedures while performing their duties. Insurance companies also did require health facilities to report medical diagnoses using the ICD standard.

3.1.2 Data Exchange and Sharing Standards

Majority (64%) of the respondents were aware of the presence of data sharing or exchange at the facilities. Only 16% mentioned that they were not aware while 20% were neutral. Although there were data sharing or exchange guidelines, 45% of the respondents disagreed that the existing ICT infrastructure was good enough to support healthcare processes. A lot of investments had been made in infrastructure including hardware, internet infrastructure, power availability and network infrastructure. At the time of the study, it was mentioned that the Ministry of Health was in liaison with Uganda’s National Information Technology Authority (NITA-U) to connect most of the healthcare facilities to the national backbone infrastructure.

It was also reported that the Government of Uganda had developed several interoperability

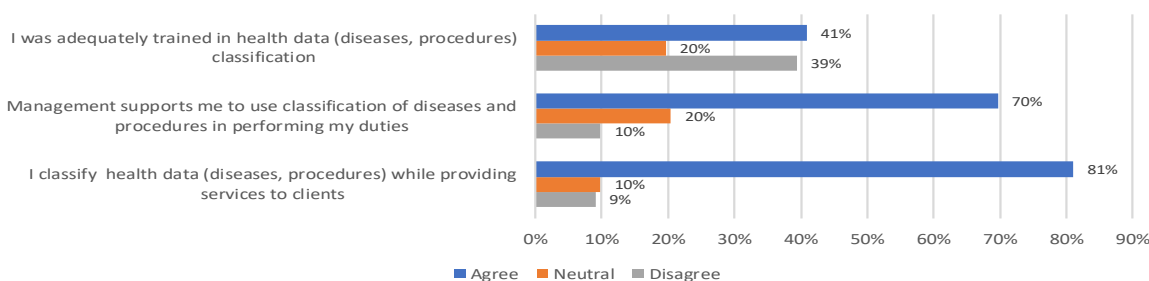


Figure 1: Perception of Coding Practices by Health Workers.

Respondent PM02 reported that *“the equipment that was used in the country was compatible with interoperability standards like HL7 for laboratories and DICOM for radiology services.”*

Additionally, Health Level Seven (HL7) had been adopted in the UgandaEMR as reported by respondent IP10. Another interoperability standard that had been tested is the Open Health Information Mediator (OpenHIM). *“The openHIM standard was tested and has worked for the exchange of some of the viral load data between the EMRs and the viral load systems”* respondent PM01.

Although the HL7, Digital Imaging and Communications in Medicine (DICOM) and OpenHIM interoperability standards did exist, only 35% of the respondents mentioned that the adopted EHS were compatible with each other.

The Ministry of Health had also developed systems that were interoperable like mTrac and DHIS2 which have been adopted at the national level to manage health information. These were communicating to each other as described by respondent IP01. *“We have data that is collected weekly on papers. We also have electronic components of data collection using SMS and Android application called mTrac. This data is hosted on DHIS2 server once it is collected. The data that is collected from SMS and android application ends up in DHIS2.”* – IP01

Although the Ministry had not explicitly adopted health information exchange standards, some interoperability standards were implemented in isolated EHS as reported by respondent IP01.

3.1.3 Communication Infrastructure / Technologies Standards

Regards communication infrastructure/technologies standards, 46% of the respondents mentioned that the facility could afford to establish and maintain the required ICTs, while 39% disagreed. On internet connectivity, only 11% of the respondents mentioned that the internet connectivity was very good at the health facilities, 22% mentioned that it was stable but slow, whereas over 43% mentioned that they had variable connectivity (on and off). Besides, only 32% of the respondents agreed that the facility had guidelines for communication and access to electronic health records. The standards for electronic communication infrastructure, as adopted from international standards are shown in table 1.

The existing ICT and communication networks in health facilities were mostly used to support healthcare processes as mentioned by 53% of the respondents. The quality of the infrastructure was in question as only 41% reported that it was good enough to support healthcare processes. Respondent HSL4-15 reported a constant problem of power and internet challenges to be affecting the quality of the infrastructure. Respondent HSL4-07 also mentioned that they still had limitations in accessing the internet in their health facility. Adequacy of the hardware and application technologies was poorly ranked as only 38% agreed that the facility had adequate hardware and application technologies to support healthcare processes. Whereas the adequacy of ICT infrastructure was 38%, more respondents (46%) mentioned that the facility could afford to establish and maintain required ICTs.

Table 1: Electronic Communication Infrastructure Standards.

Category	Standard
Health Informatics	US ISO 17090-1:2013 - Public key infrastructure - Part 1: Overview of digital certificate services
	US ISO 17090-2:2008 Public key infrastructure - Part 2: Certificate Profile
	US ISO 17090- 3:2008 - Public key infrastructure - Part 3: Policy management of certification authority
Data Management and Interchange	US ISO IEC 9075-2: 2011 - Information Technology – Database Languages - SQL - Part 2: Foundation (SQL/Foundation)
	US ISO IEC 9075-11: 2011 - Information Technology – Database Languages - SQL - Part 11: Information and Definition Schemas (SQL/Schemata)
	US ISO IEC 9075-14: 2011 Information Technology – Database Languages - SQL - Part 14: XML –Related Specifications (SQL/XML)
Telecommunications and Information Exchange between Systems	US ISO IEC 9594-8:2008 - Information Technology - Open Systems Interconnection - The Directory: Public-key and Attribute Certificate Frameworks
Information and Documentation	US ISO IEC 15489-1:2016 - Records Management - Part 1: General
	US ISO 13008:2012 - Digital Records Conversion and Migration Process
	US 1717:2017 - Implementation Guidelines for Digitization of Records
Information Technology Service Management	US ISO IEC 20000-1: 2018 - Information Technology – Service Management - Part 1: Service Management System Requirements
	Guidelines and Standards for Acquisition of Information Technology Hardware & Software for Government Ministries, Departments and Agencies

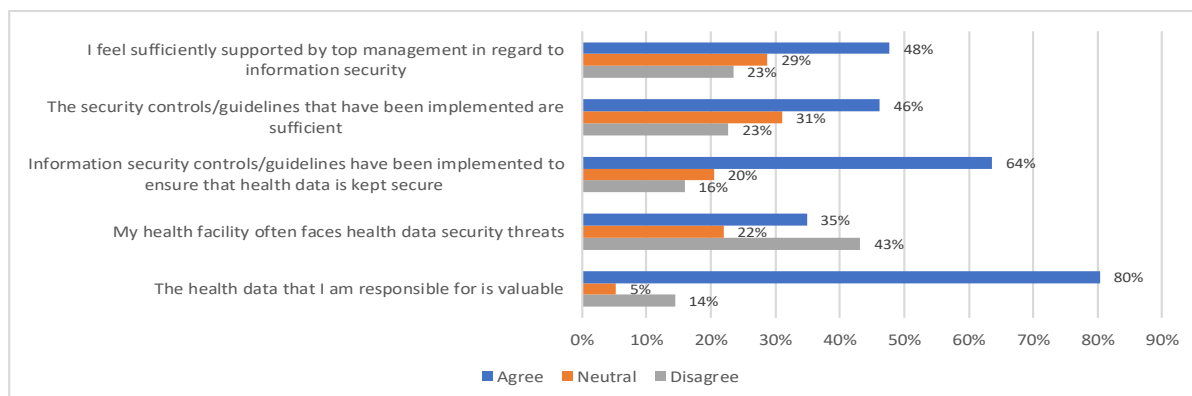


Figure 2: Perception of eHealth Security at Health Facilities.

3.1.4 eHealth Data Security and Privacy

71% of the respondents agreed that they were aware of the guidelines for privacy and personal identifiable data in their settings whereas only 8% disagreed. Two information security standards were adopted by NITA-U: US ISO IEC 27007: 2011 and US ISO IEC 27032: 2012.

The perception of health workers towards eHealth security was assessed as shown in figure 2. Over 80% of the respondents noted that the health data that they were responsible for was valuable, and 64% mentioned that information security controls/guidelines were implemented to ensure that health data were kept secure. Only 35% of the respondents mentioned that their health facilities often faced health data security threats, 46% felt that the security controls/guidelines implemented were sufficient. 63% of the respondents reported that the existing ICTs were secure and protected the client’s privacy and information, and that the available guidelines fully addressed security issues, access privileges and or privacy concerns.

53% of the respondents disagreed that there was a sense of insecurity in using ICT in health. Some of the security measures that had been implemented were: each authorised operator had a secret password that was updated every 3 months and they were held responsible in case it was used by someone unauthorized in case they did not report this prior; various levels of security were deployed, including authenticating users who attempted to access these resources, firewalls; some HDPs had their own security policies and all new staff had to be trained on them as mentioned by respondent PM07.

3.2 eHealth Standardization Process

The eHealth standardisation process refers to the process of utilising best practices and principles for managing eHealth data and processes in a uniform manner across various levels of the health system (Kimaro and Twakyondo, 2005). In this sub-section, we present: eHealth standards adoption, adaptation and contextualization process; standardisation support provided to the Ministry of Health; and challenges affecting the standardisation process.

3.2.1 eHealth Standards Adoption, Adaptation and Contextualization Process

Regarding facility assessment for ICTs, only 38% of the respondents agreed that an assessment was done for readiness to adopt ICT for healthcare processes. At the time of study, the Ministry had adopted eHealth guidelines for provision of its health services. However, only 35% of the respondents agreed that the ICT adoption and implementation decision processes were properly streamlined. The guidelines for eHealth were specific for health information exchange, telemedicine and digital health implementation as mentioned by respondent PM01.

The process of developing and/or reviewing standards in Uganda is inter-sectorial and involves various Ministries, Departments and Agencies (MDAs). This was well elaborated by respondent PM05, and can be summarised into seven stages as identification, preparatory, committee discussing draft, public enquiry, confirmation, approval and declaration of mandatory standards.

The Ministry of Health developed the eHealth Policy to guide eHealth standards implementation as mentioned by respondent PM03: “the Ministry had a participatory way in which it developed standards,

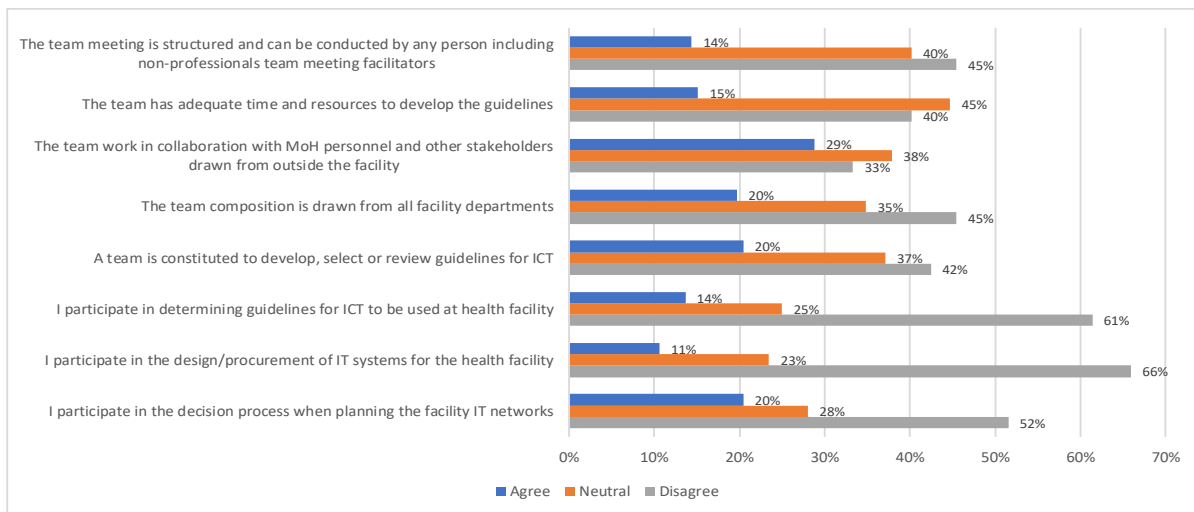


Figure 3: Perception of eHealth Adoption and Standardisation.

guidelines and Standard Operating Procedures. There were consultative meetings in the beginning, development process and a validation process that took place before adaptation. The guideline had to go through the bureaucracy of the Ministry. We have technical working groups that must approve it for use. It must be presented to the monitoring, evaluation and budget technical working groups to understand what the implication will be in terms of resources. Then it is pushed forward to the HIPA, which is one of the approving bodies and then to senior management for final clearance. Once senior management has cleared it, it can then be put into standard use” – PM03

Only 29% of the respondents at health facilities agreed that there was team work and collaboration with the Ministry of Health personnel and stakeholders drawn from outside the health facility when developing standards, and only 20% agreed that the team composition was drawn from all facility departments as shown in figure 3.

45% of respondents disagreed that the meeting was structured and could be conducted by any person. Over 61% mentioned that they did not participate in determining guidelines for ICT to be used at health facility. For some who were involved, the participation was about assessing and acknowledging draft documents as mentioned by respondent HSL2-06: “Recently, I was part of the team that came up with the M&E health plan for the country.....we basically gave technically support..... They first make the draft and we come in to assess and acknowledge what they have done” – HSL2-06

Although the participation at the facility level was low (14%), a respondent from the Ministry of Health

elaborated that health workers were involved in consultations and validation of the documents.

3.2.2 Standardisation Support Provided to the Ministry of Health

Resources for developing guidelines were not sufficient as mentioned by 40% of the respondents. HDPs like United Nations Children's Fund and World Health Organisation (WHO), provided funding directly to the Ministry of Health to support the standardisation process. The catalytic funds were used to facilitate initial scoping to know the extent of need and make a case for development of standards.

43% of the respondents disagreed that health workers have the required level of literacy to use ICT in health. HDPs provided technical support to the Ministry of Health during the standardisation process including the provision of standards and guidance documents as mentioned by respondent IP02: “provide standards from other settings/countries, that can be used for benchmarking and best practice.” – IP02.

Some HDPs had well-established systems that the Ministry of Health used for benchmarking as reported by respondent IP07: “Ministry of Health and other stakeholders already picked interest in Infectious Diseases Institute's in-house developed eHealth platforms - ICEA... The Ministry of Health has on several occasions engaged Infectious Diseases Institute teams in discussions aimed at understanding and possibility adopting some of our eHealth platforms for nationwide use” – IP07.

3.2.3 Challenges of the Standardisation Process

Insufficient Participation of Key Stakeholders: Only 14% of the respondents at health facilities mentioned that they participated in determining the guidelines for ICT to be used at health facility level. Similarly, at national level, respondent PM05 reported that there was insufficient participation of key stakeholders while conducting review meetings or workshops and proposed vigilance by the Ministry of Health.

Inadequate Technical Expertise: Uganda did not have adequate technical expertise in the field of public health informatics. Only 35% of the respondents agreed that healthcare workers had the required level of literacy to use ICT in health. Further, only 47% of the respondents agreed that management at the health facility was aware of the complexity of the changes that would result from the adoption of eHealth in their work practices.

Financial Constraints: Only 15% of the respondents at health facility level agreed that standards development or review team had adequate resources to develop the eHealth guidelines. The same was echoed by respondent PM05 at national level that a significant amount of money was needed for implementing the standards.

Weak Leadership: There was a challenge in the leadership structure of deciding which innovations were to be considered or not as mentioned by respondent IP01. The complexity of multiple innovations led to having multiple systems with different standards that could not be interoperable. There were challenges of individuals or agencies with interests of moving their agenda forward and not abiding to the implementation of standards. The weak leadership resulted into siloed applications as mentioned by M01: *“Our biggest challenge has been siloed implemented applications at disease level that are not even speaking to each other.... most of these solutions are not also sustainable.....this is because*

HDPs implement systems without following the structures put in place for approval.” – M01. The siloed systems were also facilitated by lack of monitoring systems in place as noted by respondent R101. This finding aligns with the fact that only 33% of the respondents agreed that implementers adhered to guidelines when implementing ICT in healthcare.

3.3 Compliance to Monitoring Implementation

3.3.1 Governance Structures

As shown in figure 4, 46% of the respondents mentioned that there was a strong eHealth governance at health facility level whereas 29% disagreed.

Regarding eHealth expertise at health facilities, 42% of the respondents mentioned that there is adequate expertise while 34% disagreed. The expertise matches with the finding that only 28% of the respondents reported that they were trained on how to use the eHealth applications that they used. The skills gaps are covered by HDPs through training and mentoring.

Only 36% of the respondents agreed that they were involved in decision making of eHealth development whereas over 43% disagreed. In line with the same issue, only 32% mentioned that the facility had guidelines for communication and access to electronic health records. Some facilities had implemented their own measures as described by one of the respondents: *“We have something which is quite brief, mainly for guiding the workers on guarding against misuse of the ICT. We even have a security system whereby you cannot go to other websites....”* – HSL3-02.

Majority (63%) of the respondents agreed that the existing ICTs were secure and protected clients’ privacy and information. Physically, there were security personnel to guard the equipment as

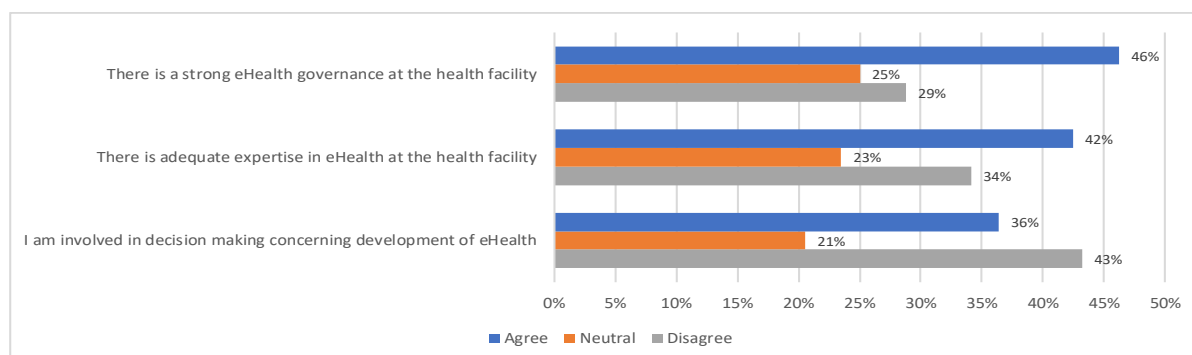


Figure 4: Governance Structure of eHealth at Health Facilities.

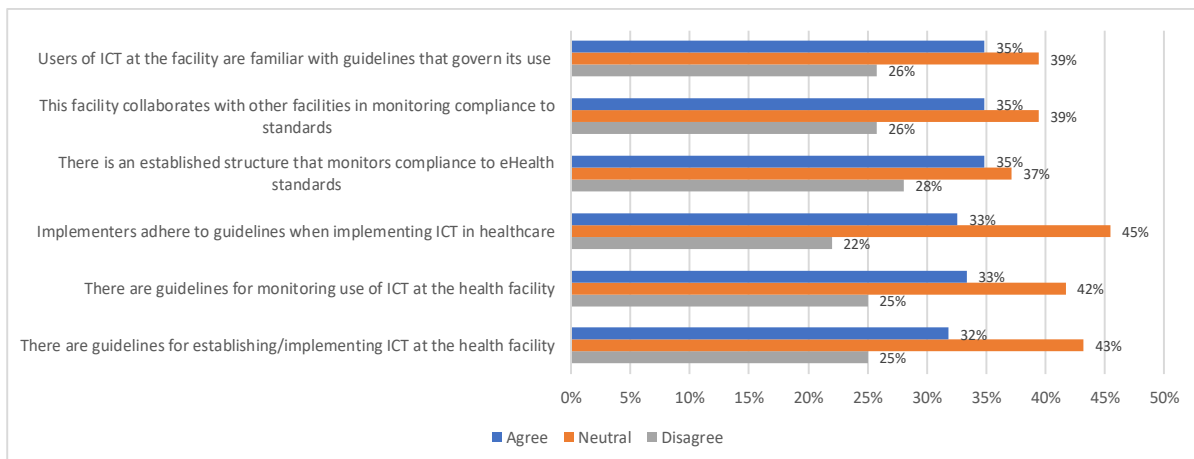


Figure 5: Compliance to eHealth Standards at Health Facilities.

mentioned by respondent HSL4-24 and M09 respectively: “we have security personnel who are responsible for guarding the facilities, the rooms are lockable and access is limited to a few people”- HSL4-24, “the server environment is securely locked with only finger print access” – M09. The security measures that had been put in place were adopted from the Ministry of ICT. The government also had a role in ensuring that there was secure exchange of information by providing a public key infrastructure.

3.3.2 Compliance to eHealth Standards and Guidelines at the Health Facility and National Levels

Familiarity of the guidelines that govern ICT was at 39% among respondents as shown in figure 5. Similarly, only 39% mentioned that there was an established structure that monitored compliance to eHealth standards. This showed non-awareness of the compliance structures as there were monitoring and evaluation plans in every guideline as mentioned by respondent PM01: “For each of those guidelines, we have a monitoring and evaluation plan on how we are going to implement and monitor compliance with those guidelines” – PM01.

Only 36% agreed that they were involved in eHealth planning and decision making. Respondent HSL4-10 mentioned that no consultations were done before bringing systems to the facility: “they have to come to the facility and do an assessment of what is specifically needed. Most times we find everything just brought without consulting the facility on what is needed.” – HSL4-10.

Only 32% of the respondents agreed that there were guidelines for establishing and implementing ICT at health facilities. Similarly, only 33% agreed

that there were guidelines for monitoring the use of ICT and that implementers adhered to the guidelines when implementing ICT in healthcare. The same challenge of non-adherence to guidelines when implementing ICT was reported at national level by respondent, PM03: “someone goes and develops a system without consulting us and knowing what problem we have and then tries to force us to use the system” – PM03. Some measures for monitoring compliance had been devised by health institutions. Access to some sites were blocked as mentioned by HSL3-02; “...you are blocked if you try to access certain sites which you are not supposed to.” – HSL3-02. The effectiveness of the measures in place can be backed up by the fact that 64% of the respondents agreed that information security controls/guidelines had been implemented to ensure that health data were kept secure.

Health Development Partners had played a crucial role in monitoring compliance to standards. In the absence of an independent arm of monitoring and evaluation in the government, HDPs support the Ministry of Health as mentioned by respondent HSL2-06: “The government does not have an independent arm attached to monitoring and evaluation. The health development partners bring in their M&E systems.” – HSL2-06.

Generally, each of the Ministry guidelines had a section of monitoring and evaluation, particularly on implementing and monitoring compliance as mentioned by respondent PM01: “For each of the guidelines, we have a monitoring and evaluation plan on how we are going to implement and monitor compliance.” – PM01.

Additionally, technical working groups approve information systems in Uganda before they are deployed: “The technical working group of the

Ministry of Health has sub-committees that sit and evaluate these systems before they (systems) are approved and implemented for the case of monitoring ICD-11” – PM01.

The NITA-U conducts assessments of implemented systems as part of monitoring to ensure that they complied with standards as mentioned by respondent PM04: *“NITA-U also conducts assessment to compliance to standards once systems have been implemented.”* PM04.

3.3.3 Challenges of Monitoring Compliance

Inadequate Resources: Only 15% of the respondents agreed that the standards development team had adequate time and resources to develop standards or guidelines. Besides, only 35% of the respondents agreed that health service providers had the required level of literacy to use ICT in health. Respondent IP02 supplemented by saying that ICT skills related to eHealth are inadequate, both in terms of the numbers and skills mix/set. Respondent PM04 also commented about the eHealth skills of the health workers and mentioned that there was inadequate integration of eHealth skills into existing health professional training curricula. Moreover, only 41% of health workers mentioned that they were adequately trained in health data classification.

Financial Constraints: Only 38% agreed that health facilities and Ministry of Health had adequate financial capacity to support ICT, yet it was expensive to hire consultants as mentioned by respondent M05.

Non-Involvement of Stakeholders: At the health facility level, only 36% of the respondents agreed that they were involved in eHealth decision making. At the national level, the technical MDAs would only provide support; however, the Ministry of Health had not taken the lead in enforcing compliance as reported by respondent PM04. Moreover, only 52% agreed that management takes an active role in preparing plans for implementing eHealth.

Non-operational Regulatory Frameworks: Although health facilities had guidelines with quality parameters to regulate implementation as mentioned by 76% of the respondents, implementation was a challenge because of the lack of regulatory frameworks as mentioned by respondent PM05: *“once the National Standards Council has declared a Ugandan Standard, at that stage, it is still voluntary to use the standard because of the regulatory framework that we have in this country.”* PM05. Respondent R101 also noted the inability to operationalise the regulatory framework currently in place.

4 DISCUSSION

4.1 Existence and Current Practice of eHealth Standards

In health facilities, it has been reported that the ICD standard has been used to a lesser extent to record morbidity and mortality statistics (Ministry of Health, 2014). In our study, 81% of the respondents noted that they classified health data while providing services to clients. The ICD standard is the foundation for the identification of health trends and statistics globally, and the international standard for reporting diseases and health conditions (WHO, 2020).

One of the standards that is used to code health research data is MedDRA). This is a clinically validated international terminology for medical products used by regulatory authorities (MedDRA, 2015). One advantage of the MedDRA standard is that it can be mapped to SNOMED (Banda et al., 2016; Bousquet et al., 2019; Yuksel et al., 2016).

Inefficient EHIS for public health surveillance are partly as a result of inability of lack of interoperability (Celi et al., 2017; Greenwell and Salentine, 2018). Yet poor coding processes can damage also information quality (Teixeira et al., 2013). Information systems in public health should ensure greater quality and efficiency, not only in the management of health institutions, but also in patients' treatment (Carvalho et al., 2016). Efforts are in place to have a comprehensive approach to an integrated and efficient data collection process important to public health (Health Enabled, 2017; Kuperman et al., 2013; WHO, 2015).

Data is a major challenge in the information security (Aggarwal et al., 2013). Data security refers to the assurance of data and its important assets like tools and equipment for its gathering, data storage and the transmission process (Whitman & Mattord 2009). Standards decrease health workers' concerns over patient data safety and professional liability (Benavides-Vaello et al., 2013; Jennett et al., 2004) and thus enabling ease of work.

Although many of the electronic communication infrastructure standards are not direct for public health informatics, they can still be adopted or customised for the health sector. This is exemplified by NITA-U in Uganda adopting international ICT standards. NITA-U also has national guidelines and standards for acquisition of information technology hardware and software for government MDAs that can be readily adopted for the health sector and most especially HIV services.

Interoperability of national information systems ensures sharing of valuable information across the government systems (Mandl & Kohane., 2012; Terhune et al., 2009) to collectively support online improved service delivery (McDonnell, 2012). A number of international certification and standards bodies work towards developing standards to address interoperability issues including; International Standards Organization (ISO), European Committee for Standardization (CEN), HL7, OpenEHR and IEEE 11073-20601-2008 (Trigo et al., 2013). Opportunities to improve healthcare by reusing data are often missed due to the limited interoperability of eHealth solutions (Berenwinkel et al., 2018). An interoperability framework provides for the specific set of standards, protocols, procedures, best practices and policies to improve digital solutions (Barbabella et al., 2017; Lamine, 2017).

In order for information management to have meaning across health systems, there has to be a common language and format across all facilities (Braa et al., 2017). For health facilities transitioning from paper to electronic systems, the common format provides an opportunity to move from errors in paper-based record-keeping that can affect the delivery of safe quality care (The Joint Commission, 2011).

Standards have to be implemented in health information systems to achieve interoperability, portability and data exchange. Yet, systems that conform to different standards cannot communicate with one another (Hammond & Cimino, 2006). Oderkirk (2017) also noted multiple standards as a challenge to standardisation. This can be caused by siloed systems having different standards. Information technology standards, including standards for messaging, content and coding, networks, electronic data interchange, and electronic health records, are important to healthcare information systems.

4.2 eHealth Standardization Process and Compliance to Monitoring Implementation

Uganda made advancement in utilizing information technology to report aggregated data at national level in 1997 through the introduction of electronic Health Management Information System (MoH, 2017). Consequently, the eHealth framework was put in place including the ICT Policy (Ministry of ICT, 2011), eHealth Policy (MoH, 2016) and the five-year eHealth Strategic Plan. These policies are instrumental in shaping the eHealth governance in Uganda's health system.

Successful EHS interoperability depends on the presence and use of widely adopted data exchange, security, and messaging standards (Measure Evaluation, 2019). A standard should be approved by a recognized standards development organization, or it should have been accepted by the industry like International Telecommunications Union (ITU), ISO, WHO or a national standards body (Celi, et al., 2017). True data interoperability requires the development and implementation of standards and clinical-content models and frameworks (Begoyan, 2007; Goossen et al., 2010) for the unambiguous representation and exchange of clinical meaning (Knaup et al., 2007).

The findings indicate that there are scanty practices and/or implementation of the eHealth standards. The same was also found out in Tanzania where Mukasa et al (2017) noted absence of health information system standards control mechanisms to be the cardinal challenge of standardizing information systems for integrated TB/HIV services. Insufficient participation of key stakeholders and inadequate resources as reported in this study were also identified as challenges to the standardisation process by Mukasa et al., (2017). During the design of EHS, a holistic service perspective can leverage the full potential to health information systems.

5 CONCLUSIONS

This study investigated the state of current practices and challenges to data and interoperability standards in monitoring HIV healthcare interventions in Uganda's EMR-based health information systems. The key data standards practices included MedDRA, DSDM, ICD and HL7 which positively impacted on the monitoring of HIV data management and exchange among healthcare interventions in various EHS. The study also identified challenges to data and interoperability standards compliance monitoring that included insufficient participation of key stakeholders, inadequate technical expertise, financial constraints and weak leadership or governance. These challenges are barriers that adversely affect successful eHealth standards implementation in EHS. As such our future work is to progress with designing of contextual data and interoperability frameworks to provide for the specific set of standards, protocols, procedures, best practices and policies that can be used to improve monitoring of HIV healthcare interventions for Uganda's EMR-based health information systems.

ACKNOWLEDGEMENTS

The authors acknowledge the Government of the Republic of Uganda through Makerere University Research and Innovation Fund for sponsoring the study; as well as the study participants at national and sub-national level in Uganda's health system.

REFERENCES

- Aggarwal, N., Tyagi, P., Dubey, B.P., Pilli, E.S.: Cloud computing: data storage security analysis and its challenges. *Int. J. Comput. Appl.* **70**, 33–37 (2013)
- Alunyu, A., and Nabukenya, J. (2018). A Conceptual Model for Adaptation of eHealth Standards by Low and Middle-Income Countries. *Journal of Health Informatics in Africa*, Vol. 5(2), 10-16
- Awaisu, A., & Banan Mukhalalati, M. I. M. I. (2019). Research designs and methodologies related to pharmacy practice. *Encyclopedia of Pharmacy Practice and Clinical Pharmacy*, 7.
- Banda, J. M., Evans, L., Vanguri, R. S., Tatonetti, N. P., Ryan, P. B., & Shah, N. H. (2016). A curated and standardized adverse drug event resource to accelerate drug safety research. *Scientific data*, 3(1), 1-11.
- Barbabella, F., Melchiorre, M. G., Quattrini, S., Papa, R., Lamura, G (2017): How can eHealth improve care for people with multimorbidity in Europe? World Health Organization, Regional Office for Europe (2017).
- Beerenwinkel, N., Fröhlich, H., Murphy, S., A.: (2018) Addressing the Computational Challenges of Personalized Medicine (Dagstuhl Seminar 17472). In Dagstuhl Reports (Vol. 7, No. 11).
- Begoyan, A. (2007). An overview of interoperability standards for electronic health records. *USA: society for design and process science*.
- Benavides-Vaello, S., Strode, A., & Sheeran, B. C. (2013). Using technology in the delivery of mental health and substance abuse treatment in rural communities: A review. *The Journal of Behavioral Health Services & Research*, 40(1), 111-120.
- Bousquet, C., Souvignet, J., Sadou, E., Jaulent, M. C., & Declerck, G. (2019). Ontological and non-ontological resources for associating MedDRA terms to SNOMED CT concepts with semantic properties. *Frontiers in Pharmacology*, 10, 975.
- Braa, J., Sahay, S., Lewis, J., & Senyoni, W. (2017). Health information systems in Indonesia: Understanding and addressing complexity. *IFIP Advances in Information and Communication Technology*. ISSN 1868-4238. 504, s 59- 70
- Carvalho, J.V., Rocha, A., & Abreu, A. (2016). Maturity models of healthcare information systems and technologies: A literature review. *Journal of Medical Systems*, 40 (6), 131.
- Celi, L. A., Fraser, H. S., Nikore, V., Osorio, J. S., & Paik, K. (Eds.). (2017). *Global health informatics: Principles of eHealth and mHealth to improve quality of care*. Cambridge, MA: The MIT Press. Available from <https://mitpress.mit.edu/books/global-health-informatics>.
- Chang, V., Cao, Y., Li, T., Shi, Y., & Baudier, P. (2019, May). Smart healthcare and ethical issues. In *1st International Conference on Finance, Economics, Management and IT Business* (pp. 53-59). SciTePress.
- Egwar, A., Ssekibuule, R. and Nabukenya, J. (2020). Status of Resources for Information Technology to Support Health Information Exchange in Resource-constrained Settings: Case study of Uganda. 13th International Joint Conference on Biomedical Engineering Systems and Technologies, HEALTHINF, Vol 5: 463-471, ISBN: 978-989-758-398-8
- Goossen, W., Goossen-Baremans, A., & Van Der Zel, M. (2010). Detailed clinical models: a review. *Healthcare informatics research*, 16(4), 201-214.
- Greenwell, F., & Salentine, S. (2018). Health information system strengthening: Standards and best practices for data sources. *Chapel Hill: MEASURE Evaluation, University of North Carolina*, 58-63.
- Hammond, W., & Cimino, J. (2006). Biomedical informatics. In E. Shortliffe & J. Cimino (Eds.), *Standards in biomedical informatics* (pp. 265–311). New York: Springer-Verlag.
- Health Enabled. (2017). The global health digital health index. Available at <http://healthenabled.org/wordpress/the-global-digital-health-index/>. Accessed on September 25, 2020
- Henriksson, D. K., Peterson, S. S., Waiswa, P., & Fredriksson, M. (2019). Decision-making in district health planning in Uganda: does use of district-specific evidence matter? *Health research policy and systems*, 17(1), 57.
- Institute of Electrical and Electronics Engineers (2010). *IEEE Standard Computer Dictionary: A Compilation of IEEE Standard Computer Glossaries*. New York: The Institute of Electrical and Electronics Engineers.
- Jennett, P. A., Scott, R. E., Affleck Hall, L., Hailey, D., Ohinmaa, A., Anderson, C., ... & Lorenzetti, D. (2004). Policy implications associated with the socioeconomic and health system impact of telehealth: a case study from Canada. *Telemedicine Journal and E-health*, 10(1), 77-83.
- Kimaro, H.C. and Twaakyondo, H.M. (2005). Analyzing the Hindrance to the Use of Information and Technology for Improving Efficiency of Health Care Delivery Systems in Tanzania. *Tanzania Health Research Bulletin* 7, 189-197.
- Knaup, P., Bott, O., Kohl, C., Lovis, C., & Garde, S. (2007). Electronic patient records: moving from islands and bridges towards electronic health records for continuity of care. *Yearb Med Inform*, 2007, 34-46.
- Kuperman, G. J., Gardner, R. M., & Pryor, T. A. (2013). *HELP: a dynamic hospital information system*. Springer Science & Business Media.
- Lamine, E., Guédria, W., Rius Soler, A., Ayza Graells, J., Fontanili, F., Janer-García, L., Pingaud, H. (2017). An Inventory of Interoperability in Healthcare Ecosystems:

- Characterization and Challenges. *Enterprise Interoperability: INTEROP-PGSO Vision*, 1, 167-198 (2017).
- Maguire, M. & Delahunt, B. (2017). Doing a Thematic Analysis: A Practical, Step-by-Step Guide for Learning and Teaching Scholars. *AISHE-J*, 3, 3351. Accessed at <http://ojs.aishe.org/index.php/aishe-j/article/viewFile/335/553> on 25th January 2019.
- Mandl, K. D., & Kohane, I. S. (2012). Escaping the EHR trap—the future of health IT. *N Engl J Med*, 366(24), 2240-2242.
- McDonnell, B. (2012) ACCF 2012 Health Policy Statement on Patient-Centered Care in Cardiovascular Medicine. A Report of the American College of Cardiology Foundation Clinical Quality Committee
- Measure Evaluation, (2019). Health Information Systems Interoperability Maturity Toolkit: Users' Guide Version 1.0. Available at: <https://www.measureevaluation.org/resources/tools/health-information-systems-interoperability-toolkit> . Accessed August 15, 2020
- MedDRA, M. S. S. O. (2015). MedDRA. Medical Dictionary for Regulatory Activities.
- Ministry of Health Uganda, (2014). The Health Management Information System: Health Unit and Community Procedure Manual 2014. 2014;1. Available from: <https://nutrition.opm.go.ug/wpcontent/>
- Ministry of Health, (2010). Uganda, The Second National Health Policy: Promoting People's Health to Enhance Socio-Economic Development, 2010.
- Ministry of Health, (2016). Uganda, Uganda National eHealth Strategy 2016/2017-2020/202
- Ministry of Health, (2017). Uganda, Uganda Population-Based HIV Impact Assessment UPHIA 2016–2017, 2017.
- Ministry of Health, Health Systems 20/20, Makerere University School of Public Health. (2012) Uganda Health System Assessment 2011. Kampala, Uganda and Bethesda: MD: Health Systems 20/20 project, Abt Associates Inc.
- Ministry of Health, Uganda. (2017). Uganda National eHealth Strategy 2016/2017—2020/2021.
- Ministry of Health. (2016) Uganda eHealth Policy, Kampala, Uganda.
- Ministry of ICT (2011). Uganda ICT Policy. Uganda
- Mukasa, E., Kimaro, H., Kiwanuka, A., & Igira, F. (2017). Challenges and strategies for standardizing information systems for integrated TB/HIV services in Tanzania: a case study of Kinondoni municipality. *The Electronic Journal of Information Systems in Developing Countries*, 79(1), 1-11.
- Oderkirk, J. (2017), "Readiness of electronic health record systems to contribute to national health information and research", *OECD Health Working Papers*, No. 99, OECD Publishing, Paris, <https://doi.org/10.1787/9e296bf3-en>.
- PEPFAR, Data for Impact, 07-Jan-2011. Available: <https://www.pepfar.gov/priorities/data/index.htm> . [Accessed: 10-September 10, -2019].
- Saunders, M., Lewis, P. & Thornhill, A. (2012). *Research Methods for Business Students*. 6th edition. Pearson Education Limited
- Teixeira, J. G., Patrício, L., Nóbrega, L., Constantine, L., & Fisk, R. P. (2013, October). Healthcare professionals as customers: A service perspective on Portuguese primary care health information systems. In *2013 IEEE 15th International Conference on e-Health Networking, Applications and Services (Healthcom 2013)* (pp. 377-381). IEEE.
- Terhune, C., Epstein, K., & Arnst, C. (2009). The dubious promise of digital medicine. *Business week*.
- The Joint Commission. (2011). Comprehensive accreditation manual for hospitals (updated September 2011). Oakbrook Terrace, IL: Author.
- Trigo, J. D., Kohl, C. D., Eguzkiza, A., Martínez-Espronedá, M., Alesanco, A., Serrano, L., ... & Knaup, P. (2013). On the seamless, harmonized use of ISO/IEEE11073 and openEHR. *IEEE journal of biomedical and health informatics*, 18(3), 872-884.
- Whitman, M. and Mattord, H. (2009), Principles of Information Security, 3rd ed., Course Technology, Boston, MA.
- WHO, (2015) Measurement and Accountability for Results in Health Summit, 9–11 June 2015. World Bank Headquarters, Washington DC, USA
- WHO, 2020. As accessed from <https://www.who.int/classifications/icd/en/>. Accessed on 21st August 21, 2020.
- World Health Organization & International Telecommunication Union (2012). *National eHealth Strategy Toolkit*. Geneva: WHO Press.
- Yuksel, M., Gonul, S., Laleci Erturkmen, G. B., Sinaci, A. A., Invernizzi, P., Facchinetti, S., ... & De Roo, J. (2016). An interoperability platform enabling reuse of electronic health records for signal verification studies. *BioMed Research International*, 2016.