

Contextualizing Syntactic Interoperability Data Standards for Health Information Exchange in Uganda's Public Healthcare System

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Abstract: Syntactic interoperability data standards are crucial for effective collaboration in modern health systems, enabling seamless exchange of healthcare information. This paper aims to develop contextualized standards to support digital healthcare in Uganda within the WHO global strategic framework 2020-2025. The standards ensure patient data is collected, processed, shared, and stored in formats that facilitate interoperability. Validation was done by the Health Information Innovation Research and Evaluation Technical Working Group (HIIRETWG). A case study approach gathered primary data through questionnaires from Uganda's healthcare experts. Derived from landscape studies, these standards underwent expert verification and testing. Results show strong support (96%) for the developed standards, with 68% participation from digital health experts. These standards are poised to strengthen Uganda's digital health system and inform decision-making processes at various levels. The study underscores the importance of tailored standards to enhance healthcare information exchange in resource-limited settings.

1 INTRODUCTION

The World Health Organization (WHO) recognizes the crucial role of interoperability in health systems, promoting equitable access to quality health data and services globally (World Health Organization, 2020, 2021). This extends to various standards, including Semantic/Terminology, Syntactic/Content, Transport, Infrastructure, and Security/Privacy. This paper focuses on Syntactic interoperability data standards, emphasizing their significance in ensuring consistent data structure and formatting for seamless information exchange within healthcare systems.

Globally, three commonly used syntactic interoperability data standards are Health Level Seven (HL7), Fast Healthcare Interoperability Resources (FHIR), and Digital Imaging and Communications in Medicine (DICOM). These standards provide a common language for healthcare data exchange, facilitating electronic sharing to enhance future patient care (Lin et al., 2010; Umberfield et al., 2023).*

In Sub-Saharan Africa, limited interoperability within health systems impedes effective data collection and use (Verbeke et al., 2015). While some countries like Rwanda, South Africa, and Kenya have implemented standards to support seamless integration and patient information flow, there's a dearth of appropriate syntactic interoperability standards continent-wide. This challenge is not unique to Africa, as even European healthcare systems face difficulties in capturing uniform patient data (Pisana et al., 2022).

The barriers to interoperability and data utilization in public healthcare systems include limited knowledge of data analysis, poor attitudes toward data reporting, and cultural challenges (Jawhari et al., 2016; Kiberu et al., 2017; Kiwanuka & Nabukenya, 2023; Matovu & Ngo'ng' Ocholla, 2009; Okungu et al., 2019).

In Uganda, the Ministry of Health (MoH) has yet to officially adopt interoperability data standards for electronic data sharing, despite some health facilities implementing these standards independently (Kiwanuka et al., 2021; Wamema et al., 2023). The

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lack of comprehensive guidelines for sharing electronic patient data is a major barrier, hampering the realization of the WHO global strategic framework (Adeleke & Lawal, 2015; Ishijima et al., 2015; Kiberu et al., 2017; Kiwanuka et al., 2021). The existing Health Management Information System (HMIS) in Uganda, initiated in 1985 and evolved into DHIS 2 in 2012, aims to collect and manage epidemiological and administrative information at the district level.

Unfortunately, these systems lack customized syntactic interoperability standards, hindering reliable, timely, and integrated electronic health data sharing.

The study seeks to validate requirements and syntactic interoperability data standards for Uganda's healthcare system, aligning with the WHO Global Framework, 2020-2025, to provide guidance for future healthcare improvements (World Health Organization, 2021). As a result, provide guidance to all key stakeholders in Uganda to help improve the healthcare of its citizens in the future.

2 METHODOLOGY

2.1 Study Design

The study was conducted in three phases. First, a requirements analysis was undertaken, which is a descriptive cross-sectional survey to identify the requirements of interoperability data standards for HIE in Uganda (Peddireddy & Nidamanuri, 2021; Shah et al., 2014). The requirement analysis is seen as an important and key stage in Design Science Research (DSR) and artifact (Baskerville et al., 2018; Peffers et al., 2007). This analysis is typically performed using brainstorming, a systems review, and a literature review (Achampong & Dziondu, 2017). This approach identifies the requirements of the various actors and users of a system yet to be built. The outcome measures of the requirement analysis process are the purpose, scope, and objectives of any proposed solution.

In the second phase, the Syntactic Interoperability data standards were generated based on the ascertained requirements from the first phase. Syntactic interoperability Data standards encompass regulations for exchanging and sharing data within a standardized framework. A number of standards should be applied to ensure that the patient (health) data collected as well as the information processed, shared, and stored, are in formats that support syntactic interoperability. These include; Patient

Identification, Health Information Exchange Registries, Compliance, Management and Communication of Medical Imaging Data, Health Information Systems, Digitization of Health Information, Security and Privacy for Data and Training and capacity building Standards.

In the final phase, the standards were face-validated through technical expert opinion selected by ministry of health digital health technical working group. Candidate standards were passed through the process which helped to filter suitable standards for possible adaption or contextualization for the Ugandan health system. The process helped to eliminate candidate standards that were not relevant to the needs of the environment. Only standards that survived this elimination stage were subsequently considered for adaption/contextualization.

2.2 Study Population and Sample

Expert opinion was obtained from the 17 respondents. The selection criteria for inclusion of the respondents required that they had been actively involved in the digital health sphere of Uganda for at least 5 years and/or had participated in the stakeholder validation workshop to understand the challenges of digital health in Uganda. The stakeholder validation meeting enabled respondents to have a background of the derived requirements and validate them from an informed perspective, with the respondents chosen to represent the full spectrum of digital health stakeholders in Uganda to increase the heterogeneity of the study findings.

2.3 Data Collection

Data for both phases were collected using an interviewer-administered questionnaire that was subsequently adapted to requirement validation techniques (Peddireddy & Nidamanuri, 2021). The questionnaire included standards contextualization development syntactic interoperability data standards criteria. These were the syntactic interoperability data standards development process, standards implementation, M&E, and the interoperability data standard determination process.

Respondents used a 5-point Likert scale of either Yes (agreed) or No (disagreed) regarding the suitability of the Syntactic Interoperability data standards validated based on five evaluation metrics, i.e., completeness, clarity, applicability, usefulness, and efficacy. The rating statements used a scale of 1 to 5, where 1 = strongly agree, 2 = agree, 3 = neutral, 4 = disagree and 5 = strongly disagree (Altillo et al.,

2021; Dackus et al., 2012; Gupta et al., 2019; Mbonane et al., 2023).

Regarding the requirements for syntactic interoperability data standards development, respondents selected either Yes, No, or Not applicable to the proposed contextualized standards well-specified.

2.4 Data Management and Analysis

The collected quantitative data was analyzed using MS Excel. This included data on current challenges in light of the various challenges to the standardization of digital health in Uganda's health system (Alunyu et al., 2021; Kiwanuka et al., 2021).

We subsequently derived and validated requirements to guide the development of the syntactic interoperability data standards for Uganda. These requirements were also informed by the literature and success stories in other countries (Ameller et al., 2012; Tun & Madanian, 2023).

The interoperability data and the standards were adapted and subsequently presented to Digital Health stakeholders in Uganda for their consultation and validation. The Ministry of Health Information, Innovation and Research Technical Working Group (HIIRETWG) developed a validation tool/set of criteria for validating the standards. Standards validation and testing focused on completeness, usability, applicability, and perceived usefulness. This led to consensus building that resulted in the approval of documented standards.

2.5 Ethics

The ethical clearance to conduct this research was approved by both the Makerere University School of Public Health Research ethics committee (REC) and the Ministry of Health.

3 RESULTS

3.1 Characteristics of Respondents

A total of 17 respondents were recruited giving a response rate of 68% (n=17/25). Respondents included, Digital Health professionals, ICT officers, Systems Developers, Biostatisticians, Monitoring and Evaluation specialists, and epidemiologists (Figure 1).

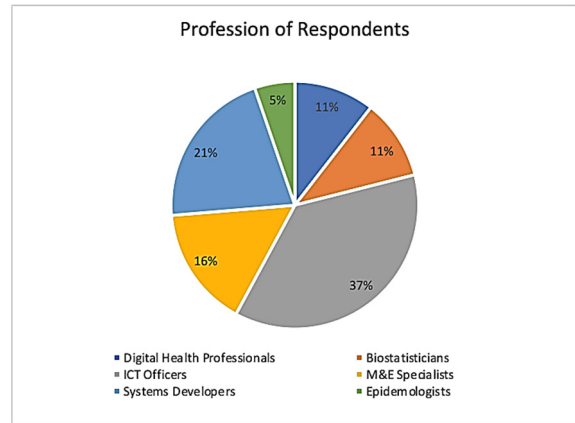


Figure 1: Distribution of respondents by category.

3.2 Challenges Facing Standardization of Interoperability of Health Data and Requirements for Interoperability Data Standardization

Table 1 contains details of the challenges facing the standardization of Health Information Exchange in Uganda based on Phase 1 of the research project.

Table 2 contains the derived and validated requirements to guide the development of the syntactic interoperability data standards for Uganda based on the identified challenges facing the standardization of Health Information Exchange in Uganda (Table 1).

3.3 Syntactic Interoperability Data Standards

Table 3 contains details of the Syntactic Interoperability data standards generated from the designated requirements. These include data exchange and sharing standards. The contextualized syntactic interoperability data standards should be applied to ensure that the patient (health) data collected, information processed, shared, and stored are in formats that support syntactic interoperability.

Table 1: Challenges facing standardization of Health Information Exchange.

Theme	Sub-themes	Challenge
Limited guidelines for standardization	Policy development	Limited guidelines for collecting, storing, sharing, and exchanging electronic patient data to inform decision-making and efficient service delivery.
	Policy adoption	Despite some health facilities implementing or having adopted electronic sharing and exchange of patient data guidelines, the Ministry of Health is yet to officially adopt them.
Inadequate capacity	Monitor compliance	There is an inadequate capacity to monitor compliance with Interoperability Data Standards and or guidelines for data use and management across the Health sector
	Interoperate images	Lack of reliable mechanism for managing health images information/data collection, storage, and sharing among health providers
	Coordination	Uncoordinated process guidelines for capturing paper-based patient records into digital formats suitable for Electronic Medical Records (EMR), Electronic Health Records (EHR), and Personal health records (PHR).
	Training	Healthcare workers have inadequate training, and experience in data management skills including; data collection, analysis, reporting, and use to inform the decision-making process at different levels of the continuum of care.
Data safety	Data privacy	Data Security and Privacy Standards have not been officially adopted.
	Security	Health facilities do implement and/or use insufficient security and privacy measures for electronic health data; which may compromise/put at risk the privacy and confidentiality of patients' data.

Table 2: Requirements for interoperability data standardization.

Theme	Sub-theme	Challenge addressed
Interoperation data framework	Procedure	Develop data interoperability standards/ SOPs/Guidelines for collecting, storing, sharing, and exchanging electronic patient data.
	International benchmarks	These should be based on the international standards for Health Information Exchange (syntactic) - HL7, FHIR, DICOM, and the Uganda Data Protection and Privacy Act, 2019. An adoption mechanism should be put in place for data interoperability standards for the electronic sharing and exchange of patient data across the health sector
	Security	The MoH should develop guidelines to support the core data security elements of confidentiality, integrity, and availability across the health sector to roll out data Interoperability Data Security Standards/guidelines for health information management.
	Images and media	Develop Data Standards for Images, Multimedia, Waveform, and documents for exchanging images across the continuum of patient care based on the international standards for Health Image Information Exchange (DICOM), and the Uganda Data Protection and Privacy Act, 2019).
	Migration of paper data to electronic forms	Formulate a strategy to migrate paper-based health records into electronic formats to enhance data sharing and use.
Compliance mechanism	Enforcement	The MoH should enhance the compliance mechanism of all users to adhere to Interoperability Data standards.
	Privacy and security	Deploy security and privacy measures that protect the privacy and confidentiality of electronic patient data at all levels.
Capacity building	Monitor process	MoH should build the capacity of data custodians and owners to monitor the implementation and compliance of data management including data cleaning and adherence to standards at all levels of the continuum of care.
	Awareness / Advocacy	The MoH should create data use and utilization awareness campaigns to monitor compliance requirements and structures for health Information/data management. The MoH should advocate for digital health courses including data analysis, monitoring, and evaluation to be incorporated into health workers' training curricula.
	Access	Data security guidelines should be well disseminated to all relevant stakeholders.
	Capability	The MoH should develop training guidelines for health workers on basic ICT Skills, analysis, and data management

Table 3: Contextualized Syntactic Interoperability Data Standards.

Syntactic Interoperability Data Standards		
Standard		Statement
UG_DHS_DS01_P1: Patient Identification	Patient	<i>Establish a unique, standardized, comprehensive, and comprehensible Electronic Medical Record (EMR), Electronic Health Records (EHR), and Personal Health Record (PHR)</i>
UG_DHS_DS02. _ NHIE: Health Information Exchange Registries Standard	Health	<i>Developing and maintaining comprehensive interoperable master lists of health facilities, providers, and patients/clients is a necessary step toward monitoring health infrastructure and services that form a core component of the National Health Management Information System (HMIS).</i>
UG_DHS_DS03. _CP: Compliance		<i>Establish an Intelligent and Integrated monitoring mechanism to ensure compliance across the health sector. Generate data for observation and clinically relevant events and encounters. This requires having a common semantic and syntactic logical information model and structural composition.</i>
UG_DHS_DS4. -_MI: Management and Communication of Medical Imaging Data		<i>All health record management complies with the DCOM/ PACS Standards in terms of imaging modalities including radiography, magnetic resonance imaging (MRI), nuclear medicine, ultrasound, tomography, echocardiography, X-ray, CT, and other modalities used in radiology, cardiology, radiotherapy, ophthalmology, and dentistry.</i>
UG_DHS_DS5 HIS: Health Information Systems Standard		<i>Establish mechanisms for implementing and adhering to set guidelines for all HIS solutions in the health sector</i>
UG_DHS_DS6_DHI: Digitization of Health Information Standard	Digitization of Health Information Standard	<i>Establish an ICT infrastructure that forms the foundations for electronic communication and information/data sharing across geographical and health-sector boundaries. This includes the computing infrastructure, databases, directory services, network connectivity, and storage that underpin a national eHealth environment.</i>
UG_DHS_DS7_SP: Security and Privacy for Data Standards		<i>The Ministry of Health shall ensure adherence to the National Information Security Policy and Strategy, the Uganda e-Government interoperability framework, and other relevant global standards.</i>
UG_DHS_DS8_TCB: Training and capacity building Standard	Training and capacity building Standard	<i>Build health workforce skills in data management and use through training, mentorship, and coaching.</i>

3.4 Validation of Syntactic Interoperability Data Standards

Figure 2 depicts respondents' views regarding the standards contextualization development of Syntactic Interoperability Data Standards. 94% of participants agreed that the framework supports interoperability data standards suitable to support HIE, 68% agreed that the framework encompasses all stakeholders involved in the syntactic interoperability data standards development, and 88% agreed that the framework facilitates members to set standards that satisfy the principles of clarity, well-defined and precise, that is required for standards. In addition, 88% of the respondents agreed that development process was systematic enough to guide the interoperability data standards development for the MoH. However, 31% of respondents were neutral on whether the framework encompasses all stakeholders involved in the Syntactic Interoperability data standards development.

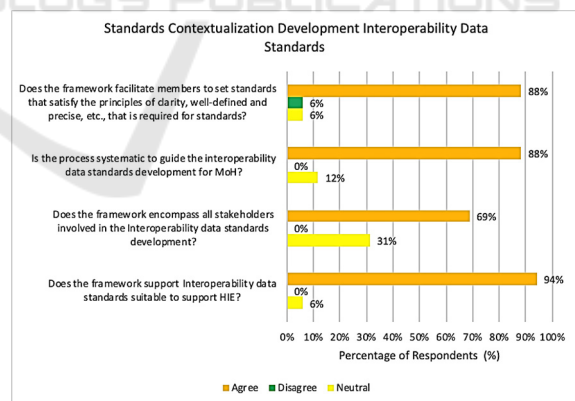


Figure 2: Validation of Syntactic Interoperability Data Standards.

4 DISCUSSION

We believe this is the first study in Uganda to assess the requirements and validate the syntactic interoperability data standards for Uganda following initial activities. Our study found that the main

requirements for standardization should be explicit about data sharing and exchange across the four domains, i.e., business, data, applications, security, and technology, and users should extract, analyze, and use them. The main challenges were limited guidelines for the standardization process, inadequate capacity, and data safety. Encouragingly, the level of validation by expert opinion was high regarding the proposed framework.

As far as we know, we believe this is also the first study in a resource-limited country to validate the interoperability data standard for healthy ecosystems. The study identified that the key challenges to the implementation of interoperability standards for health in Uganda is the current heterogeneity of health information systems, with the heterogeneity of health information systems posing a significant challenge to the implementation of interoperability standards for health in the country. Current health information systems in Uganda differ in terms of their data structure, data format, data definitions, and data exchange protocols. This heterogeneity makes it difficult to establish a common language for sharing and exchanging health information.

Over the years, Uganda similar to other LMICs has seen a general transformation of the Health Information System and specifically, a rapid growth in eHealth solutions (Ndabarora & Chipps, 2014). The recognition of ICT as having great potential to improve the delivery of healthcare services, and therefore an aid to the delivery of public health services to Ugandans, has resulted in the development and execution of many eHealth interventions that have mainly stayed at the pilot stage commonly known as the “Uganda eHealth Pilotitis Disease”. In other words, these initiatives have not been successful in further scaling and implementation across the entire country due to several impediments in four key categories: governance, financial and human resources, standards, and infrastructure availability (Huang et al., 2017). Worse still, these interventions address individual health programs and are largely parallel and/or uncoordinated centrally by the Ministry of Health. This has hindered seamless health data flow across both the public and private sectors in Uganda coupled with stretched human resource to support data collection, transformation, presentation, and archiving, among others (Ndabarora & Chipps, 2014).

To address this challenge, Uganda needs to invest in standardizing its health information systems. This will involve developing a common data model for health information, adopting common data standards, and implementing interoperability standards

including FHIR (Fast Healthcare Interoperability Resources), HL7 (Health Level Seven International), and DICOM (Digital Imaging and Communications in Medicine). In this regard, investment is required in terms of standards-compliant systems development and implementation. Alongside this, considerable effort is required in terms of change management to achieve interoperability. The investment required by early standards adopters at the leading edge of new initiatives is typically significantly higher and the benefits are slower to accrue than that required by implementing standards-based systems that are already widely in use. The late adopter benefits from the investment and efforts of early adopters in terms of time and money needed to ensure any failures and barriers to success are dealt with. This means that vendors and providers in particular may be hesitant to bear the cost of progressing with the implementation of interoperability standards until Government takes the lead in advocating and implementing interoperability data standards (Brailer & Blumenthal, 2010a).

As mentioned, one of the key challenges to the implementation of interoperability standards for health in Uganda is the current heterogeneity of health information systems, similar to other countries (Katehakis & A Kouroubali, 2019). Most large hospitals will use many different ICT systems from different suppliers, each supporting different functions. There is no single health information system that could facilitate all administrative, clinical, technical, and laboratory ICT requirements of a large healthcare organization. In such a fragmented environment, the requirement to achieve interoperability is critical and the need for interoperability standards becomes evident (Brailer & Blumenthal, 2010a; Jama, 2016; Perlin et al., 2016). This needs to be borne in mind by all key stakeholders in Uganda going forward.

Another approach to overcoming this challenge is to use data integration platforms that can harmonize data from different systems, and convert them into a common format. These platforms can help facilitate the exchange of health information between different health information systems.

In addition, capacity building and training programs can be implemented to improve the skills and knowledge of health practitioners on health information systems and interoperability standards. This can help ensure that the health workforce in Uganda is equipped with the necessary skills to effectively use and exchange health information across different systems as they seek to improve the care of patients including access to and the use of

medicines (Kiggundu et al., 2022). Based on our findings in the study, implementation initiatives were generated to solve the problems of fragmented implementations of eHealth systems, a lack of integrated data sharing, and a lack of reliable, timely, and lack of integrated access to patient data (GÅRDSTEDT et al., 2013; Huang et al., 2017). Similar to other LMICs, Uganda needs to adopt, contextualize interoperability data standards to facilitate health Information Exchange in the Uganda health system.

The validated requirements should lead to the development or contextualization of syntactic interoperability data standards for data use and aid the decision-making processes, and offer an efficient continuum of care, as stipulated by the WHO (World Health Organisation, 2012). In addition, most respondents agreed on all the requirements indicating the need to fast-track standardization activity in Uganda's healthcare system as previously suggested by Alunyu et al. (2021)(Alunyu et al., 2021). Whereas a few respondents had concerns that some of the requirements are over-ambitious, others pointed out that some of the standards were too prescriptive. These few concerns could be solved by producing detailed guidelines on the implementation of the standards. The Ministry of Health and its partners should also take advantage of these initiatives that have not been successful in other countries when developing and integrating syntactic interoperability data standards. These include addressing four key areas namely: governance, financial and human resources, standards, and infrastructure availability. These interventions should holistically address all health programs coordinated centrally by the Ministry of Health. This will enable seamless health data to flow in the future across both the public and private sectors in Uganda along with the necessary human resource to support data collection, transformation and reporting.

Cultural changes within the health sector are also required to ensure independent healthcare organizations are willing to share health information beyond the confines of their systems. Standardization removes an element of local autonomy for providers and the perception may exist that independent control of health information systems by providers is compromised (Kim, 2005; World Health Organization, 2013). The changes required in processes and operations at the local level also act as a barrier to implementation as providers and local ICT professionals must be educated about new processes and methods of recording health information with the introduction of standardized

terminologies (Umberfield et al., 2023). This will change with developments in health data flow in Uganda in the future.

Overall, whilst the benefits of interoperability in healthcare are considerable, they may be difficult to realize as the benefits are dispersed across many stakeholders including vendors, providers, policymakers, and the individual. Some vendors use a lack of interoperability to their advantage as a customer retention strategy by building systems that can only interoperate with their own products (Brailer & Blumenthal, 2010a). This also needs to be addressed.

5 CONCLUSION

In conclusion, while the majority of respondents have endorsed the derived interoperability data standards artifact, it's important to recognize that selection criteria may evolve over time to accommodate changing needs. The successful implementation of the validated syntactic interoperability data standards promises to enhance service delivery, improve patient outcomes, and ensure equity and safety in healthcare. However, numerous barriers and challenges must be addressed, including the availability of skilled personnel, motivation, and adequate resources. Continuous monitoring of the situation is imperative.

Therefore, significant investment is warranted in the development and implementation of standards-compliant systems. Additionally, substantial effort is needed in terms of change management to achieve seamless interoperability. Early adopters of standards-based systems typically incur higher investment costs and experience slower benefits compared to those implementing established standards. Late adopters benefit from the groundwork laid by early adopters, saving time and resources required to overcome obstacles and failures. Consequently, vendors and providers may hesitate to invest in interoperability standards until government-led advocacy and implementation efforts gain momentum (Brailer & Blumenthal, 2010b).

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