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A Framework to Enhance Patients Electronic Health Records Sharing.

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Abstract
In Uganda, the healthcare system experiences tremendous challenges during sharing patients' health information records. This is due to limited systems inter-connectivity and low technology penetration rate across the country. This study developed a framework for integrating referral hospitals with their associated community-based health facilities in Uganda into a centralized data scheme. The framework aims to provide an integrated and centralized platform that will sufficiently support the operations of health facilities in Uganda by creating a secure data transmission channel and enabling remote access to patients' electronic health records by patients and medical practitioners. The researchers reviewed literature about the existing framework used to share patients' electronic health records and collected data from participants to derive requirements that were used to design and develop the framework. We developed and deployed a web system that was used to test and validate the framework. Study contributions include a designed framework guiding tool for validating electronic health record systems before deployment in the health facility to improve information sharing. Secure Hash Algorithm (SHA1) and Message-Digest Algorithm 5 (MD5) encryption techniques were used to perform data encryption during information transfer to ensure confidentiality and data integrity

Key words
patients, electronic, health, records, systems

Introduction

In Uganda, the healthcare system experiences incredible challenges when sharing/exchanging patients' health information records due to limited interconnectivity and low technology penetration rate. Health records contain systematic documentation of a single patient's medical history and care across time within one particular health care provider's jurisdiction (Tang et al.,2006). Medical records contain a wide range of information, including clinical notice captured over time by the health practitioner, observation, drugs administered to the patient, laboratory tests results, medical reports, and other related demographic information (Archer et al., 2011). Medical workers are encouraged to access and review a patient's medical history to acquire prior knowledge about the patient's health status before administering drugs and therapies.

To ease access to patients' data, electronic health records (EHR) has been adopted, especially in middle income and developed world (Gunter & Terry, 2005), where medical practitioners share knowledge through consultations access patients' electronic records remotely, thereby boosting medical service delivery to patients especially during emergency cases where a patient needs quick medication. In developing countries like Uganda,the implementation of EHR is still limited, and this is evidenced by the paper-based storage of patients' medical records in many health facilities, especially in rural settings.

In some settings where EHR has been utilized, standalone computer-based systems (Kaundinya et al., 2009) are used, hindering remote access to patients' information, especially during referrals. In Uganda and other developing countries, the health sector has faced several challenges related to the exchange of knowledge in the form of consultations, sharing of patients' health records, which have resulted in a huge number of registered death cases and morbidity in Africa large.

There is a joint effort by the government of Uganda to digitize the economy by empowering different sectors such as the ICT sector, which aims to bridge the gaps in the health sector by addressing health issues that can be sold using technology innovations. However, the biggest concern is the three primary security goals, including Confidentiality, Integrity, and Availability (CIA) where confidentiality looks at keeping patients' data free from access by non-authorized individuals by empowering a patient to determine who, where and when to access their health data, integrity ensures that any modification to patients' data is done by only authorized individuals. At the same time, availability ensures that patients have full access to their information at any time (Tchernykh et al., 2019).

There is a lack of interconnectivity and interoperability amongst electronic health records systems used to store patients' health records in Uganda. This is caused by platform-dependent tools used by software developers while developing electronic health systems. This has hindered patients' record sharing amongst hospitals (Dalianis et al., 2015). Medical practitioners are encouraged to access and review patients' medical history to acquire prior knowledge about the patient's health status before administering drugs and therapies (Wu et al., 2012). However, access to patient information stored on different databases used in different hospitals is limited due to a lack of interconnectivity, thus hindering information sharing. Several algorithms and frameworks, such as Stockholm EPR Corpus-based data-sharing framework (Dubovitskaya et al., 2015)have been implemented to address this problem. However,none has been fully adopted due to a lack of systems interconnectivity functionalities and secure means of restrictions to data exchange. Many health facilities in Uganda have continued to use a paper-based record keeping approach, and semi-computerized systems as a result, information inflow and access to personal health records has been limited, thereby affecting timely medical service delivery

This study developed a framework for integrating referral hospitals with their associated community-based health facilities into a centralized data scheme. The framework aims at providing an integrated and centralized platform that sufficiently support the operations of health facilities in Uganda by securing medical records, enabling borderless access to patient's electronic health records bypatients and medical practitioners countrywide, and providing health information to guide stakeholders in the health sector and national policymakers during decision making.

III. RELATED WORK

Dalianis et al. (2015) defined the acquaintance for a data-sharing structure based on the Stockholm EPR Corpus, an EHR warehouse comprising more than two million patients. The structure is limited to accumulating data for academic research. The proposed framework illustrates the need for interoperability and access to health data systems beyond the research setting.

Wu et al. (2012) designed a broker-based control method for sharing patients' data, this method aimed at solving the problems coupled with using the patient-centric authorization framework at every healthcare center. The broker-based method contains three steps: creating an ontology mark for every EHR node basing on ISO EHR standards, a combined EHR schema for integrating all the EHR nodes, and an intradomain aggregation of the EHR data schema to form a virtual composite EHR shared over the internet. This method is limited because the issue of data confidentiality and integrity during data transmission is not covered anywhere in the three processes. Furthermore, installing independent nodes for every healthcare is expensive, especially in remote places (rural Uganda) where technology infrastructure is still lagging.

Dubovitskaya et al. (2015) presented a framework to create an infrastructure for medical data management to enable medical professionals to share patients' information while observing patients' privacy. They used generalization represented inform of binary trees and a pseudonym created by multiple key searchable encryptions to achieve this. The architectural design contains a database at the client and server-side, a cryptographic component that executes a multi-key searchable encryption process, encrypts the EHRs, and generates signatures to perform data authentication.

The anonymization module permits healthcare workers to upload patients' medical information for research purposes while preserving the anonymity of the research database. Lastly, a standalone certification authority issues public key certificates and smartcards that store private keys and have PINs known only to their owners.

To share and access patients' data stored at the server-side database, the patient generates a key and shares it with the care provider using a card reader device located at the patient's care provider's office. The EHR is encrypted using that shared key and is signed using the care provider's secret key.

Although it is not easy to guess the PIN, the card is protected only with that PIN. If the PIN is found, the patient's private key will be disclosed, limiting the security of this framework. Secondly, this framework becomes limited in case a patient is in critical condition where they cannot generate a key using the card, and in a situation where a patient forgets the card at home or loses access to their information becomes tricky

IV. METHODOLOGY

A. The design science approach

Design science research approach focuses on the development and performance of the designed artifact with the explicit intention of improving the functional performance of the artifact (Hevner&Chatterjee, 2010). It is typically applied to categories of artifacts, including algorithms/models, frameworks, human/computer interfaces, and systems on which this study is centered. It follows the following steps: -awareness of the problem, Suggestion, development, validation, and conclusion, as shown in the diagram below.

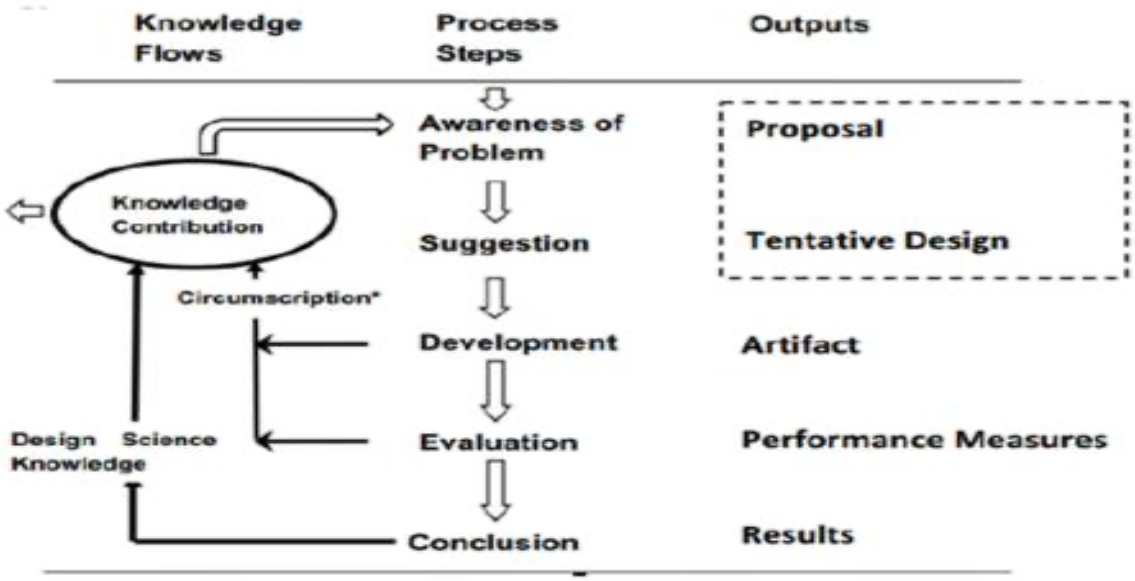


Fig. 1. Illustration of design science methodology adopted from (Havner& Chatterjee, 2010)

B. Why design science methodology

Design science theory applies a similar iteration process during the development and evaluation of the artifact.Therefore, the refinement of the design artifact is aligned with the development theory making it suitable for user-centered design upon which our framework design is based. The outcome of this framework design was customer-oriented, aiming at offering an artifact that solves the identified problem while focusing on user needs.Thus, design science approach was considered since it offered a step-by-step approach for achieving the study objectives elaborated below.

1) **Awareness of the problem:** At this stage, the challenge of the problem was identified to drive a formulation of a better approach of a solution. We used metadata search to find several scientific studies

carried out by other researchers, and through a meta-analysis, we were able to acquire statistical results, which helped us know how big the problem was.

2) **Suggestion:** Having obtained insights on strengths and weaknesses within existing frameworks, we suggested designing a framework for integrating large general hospitals with their associated community-based health facilities to foster patients' electronic health records sharing while addressing the identified lope holes.

3) **Framework design and development:** Three different system development languages, including PHP, HTML, JavaScript, and Cascading Styling Sheet (CSS), were used to develop the web system to answer the research question. Unified modeling language (UML) diagrams such as Use Case Diagram were designed to present the framework's logical actions, services, and functions. Entity Relationship Diagrams, including class and activity diagrams, were designed to help visualize data relationships in a relational database.

4) **Validation and conclusion:** A Likert method was used to validate the framework. Likert scale is a rating scale of five categories commonly used to measure attitude, and the categories may include; Strongly Agree (SA), Agree (A), Undecided (U), Disagree (D) and Strongly Disagree (SD), where the scale value 5= Strongly Agree, 4= Agree, 3 = Undecided, 2 = Disagree and 1 = strongly disagree.

The framework was deployed in a web application/system and five (5) medical workers were recruited to assess the framework performance, relevancy, and potentials of improving patients' record sharing. A testing and validation guide was used to guide participants on what to focus on while conducting the evaluation process. Framework validation by medical experts was based system usability in terms of system interface appearance and ease to use, information security, and relevancy to ease information access.

IV. RESULTS

As illustrated below, a framework for integrating large general hospitals (referral hospitals) with their associated community-based health facilities to foster patients' electronic health records sharing was implemented.

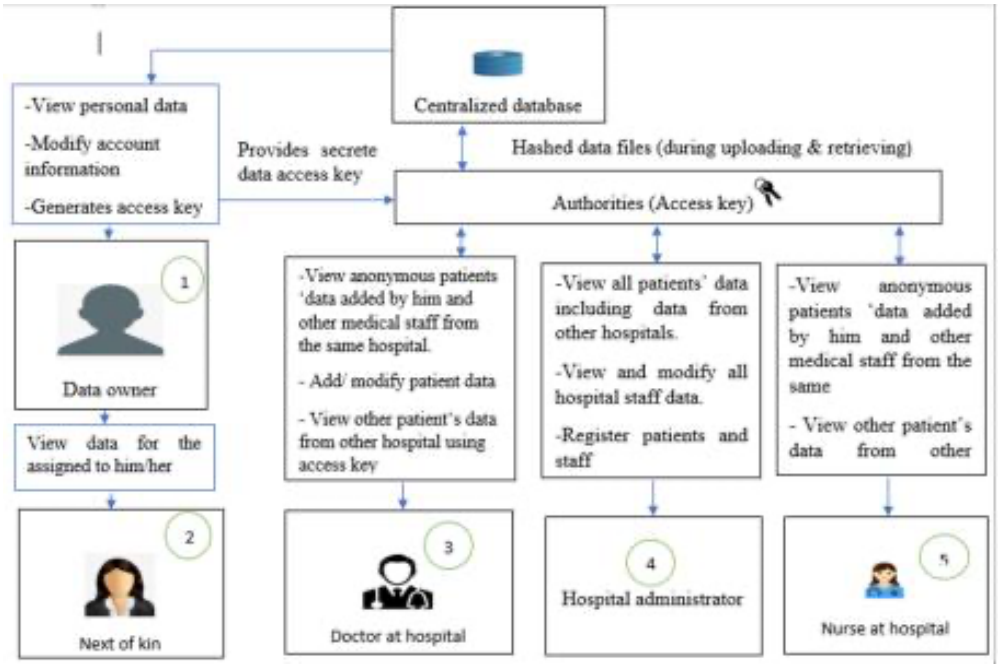


Fig. 2. A framework for patient electronic data sharing

A. Description of the framework

When a patient visits a hospital for the first time, a health worker registers the patient by capturing their biodata, login credentials, and the next of kin details. Upon successful registration, patient's details reflect across all nodes (1,2,3,4, and 5)with access to the hospital system resources.

A medical doctor in hospital (3) can only access the patient's datarecorded byhospital 3. In an attempt to access patients' data recorded from hospital 4 and 5, the system will require data access key for a particular patient whose data is being requested. This key is automatically generated whenever a patient loginto the system using his\her login credentials provided at patient registration. This key is a one-time access key that expires immediately once the patient logs out of the system.

Upon request for patient's data residing in different systems used at hospitals 4 and 5, system integration engines create virtual storage, which acts as a buffer where patient's health records from multiple systems are pooled, making it available for access by the authorized requester. Before data transfer from a centralized database (residing on the cloud) to the virtual storage, data ishashed using SHA1 hashing algorithms to protect it from non-authorized access. SHA1 hashes data files to ensure that even when there is non-authorized accessto the data files either during transmission or when residing in the virtual storage, the intruder cannot decrepit the meaning, hence protecting data against violating confidentiality and data integrity. This virtual storage serves the purpose of storing a copy of a patient's health records from multiple

hospital databases, making it available for access and this virtual storage is immediately demolished once a patient logs out of the system, making it unavailable for access

1. **Framework flow chat**

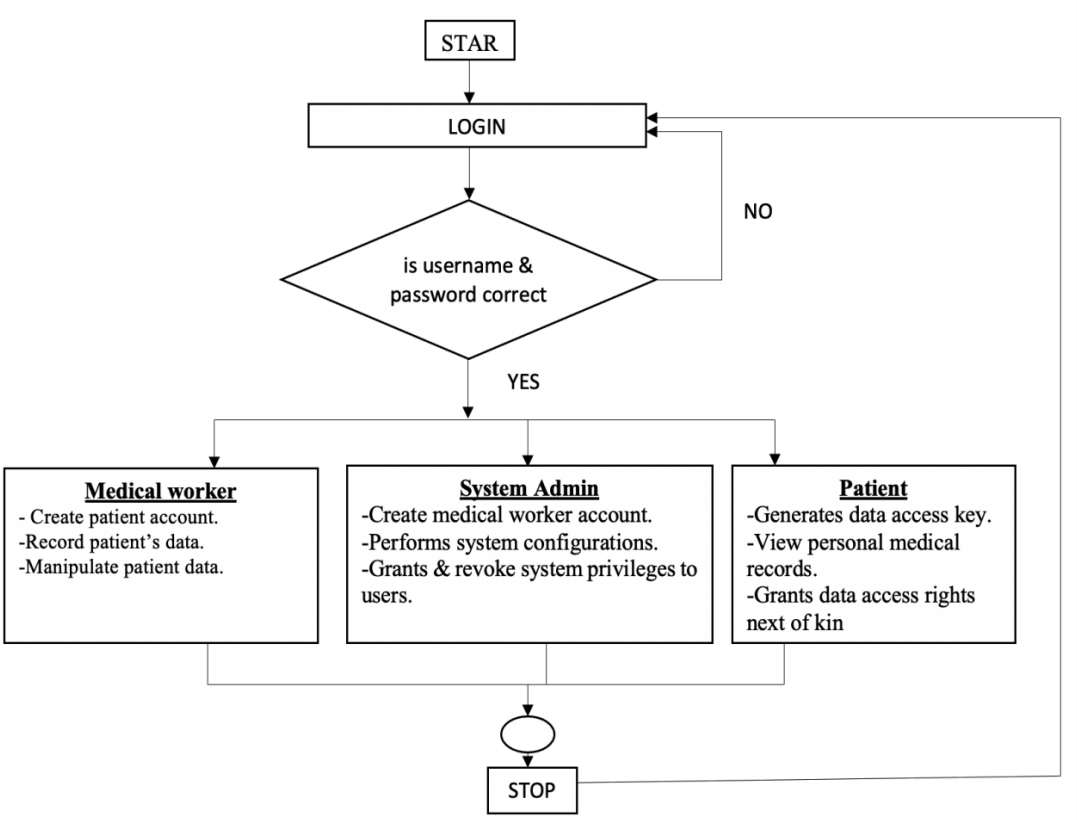


Fig 3 Illustration of the framework flowchart

B. Validation of the framework

Participants in framework validation included medical experts (nurse, midwives and doctors) and non-medical experts (patients and ICT experts).

i) Framework validation by medical experts

The framework was integrated with a websystem to provide an interactive user interface for testing. Five (5) medical workers were recruited to assess the framework performance, relevancy, and potentials of improving patients' record sharing. We designed a testing and validation guidetool to guide participants on what to consider while evaluating the framework. Framework validation by medical experts was based on; system usability in terms of system interface appearance and ease to use, information security, and relevancy of the framework towards easing information patients' record sharing. Results from this survey presented by frequency, mean and mode of the responses is as shown below.

No	Question	1's	2's	3's	4's	5's	n	Mean	Mode
1	Integrating all hospital patients' electronic data management systems is necessary to allow			1	1	3	5	4.4	5

	information sharing amongst hospitals and patients.								
2	The required inputs for data access authentication are necessary				1	4	5	4.8	5
3	The system is bug/error-free, and all functionalities are working smoothly					5	5	5	5
4	The framework will provide adequate patients information flow amongst hospitals				1	4	5	4.8	5
5	System interfaces are user friendly				3	2	5	4.4	4
6	The system flow is understandable to the user with minimal ICT skills				1	4	5	4.8	5
7	The framework/system provides the minimum required security to ensure patients' data privacy			1	2	2	5	4.2	4.5
8	Would you recommend this model?				1	4	5	4.8	5

Figure 1 show model validation results

From the results collected, we discovered that the designed framework for improving patients' electronic record sharing is relevant and essential to the health sector of Uganda.

We calculated the MEAN using the formula below.

$$\overline{X} = \frac{\sum fx}{n}$$

Where: $\overline{X}$ is the mean?

f is the number of correspondences

x is Likert scale value

n is the total frequency (Total number of questions)

∑fx = Sum of the product of the number of the correspondence and the Likert scale value

$$\overline{X} = \frac{4.4 + 4.8 + 4.4 + 4.8 + 4.2 + 4.8}{6} = 4.57$$

Framework validation results obtained from medical professionals indicated that the framework is user-friendly, relevant and it will help to improve patients' records sharing.

ii) Framework validation by non-medical experts

We recruited five participants we purposively selected from the community. Two of these were hospital systems administrators and three patients. We followed the selection criteria below;

a) Possession of basic ICT skills by the participant, i.e., using either a desktop computer, laptop, orsmartphone.
b) Participants must be fully registered and enrolled under a given hospital with an active account.
c) Participants accepted to participate in the validation survey voluntarily.
d) Participants agreed to create enough time to interact with the system and provide assessment feedback.

The main aim of this was to assess the framework's relevancy, usability security, and acceptability to both hospital systems administrators and the patients. Responses from theparticipants are as shown below:

No	Question	1's	2's	3's	4's	5's	n	Mean	Mode
1	Integrating all hospital patients' electronic data management systems is necessary to allow information sharing amongst hospitals and patients.			1		4	5	4.6	5
2	The framework will provide adequate patients information flow amongst hospitals			1	1	3	5	4.2	5
3	System interfaces are user friendly					5	5	5	5
4	The system flow is understandable to the user with minimal ICT skills			1	1	3	5	4.4	5
5	The framework/system provides the minimum required security to ensure patients' data privacy				2	3	5	4.6	5
6	Would you recommend this model?				1	4	5	4.8	5

Results obtained from non-medical participants (hospital systems administrators and patients) indicatedthat the framework and its web system are user-friendly and acceptable to hospitals andpatients.

V. CONTRIBUTION TO KNOWLEDGE

Literature: This research contributes to a state of art survey about patients' electronic records sharing in Uganda, which other researchers can use to research the same area. The reviewed literature has an in-depth grasp of patients' electronic records management hence adding to an existing body of agreed knowledge by providing a synthesis of issues, trends and concepts surrounding the topic at hand.

Algorithm development: This research has produced a frameworkthat helps in securely exchange patients' electronic records among stakeholders by offering systems integration and interoperability engines to enable medical systems to communicate and exchange data seamlessly.The framework design and implementation focused on addressing the loopholes within the existing frameworks and systems. This framework relates to real-world challenges where the researcher aligns scientific knowledge with concrete societal problems, contributing to sustainable development. Future scholars can use the designed framework as a stepping stone to improve it by addressing the suggested areas of future work.

VII. Future Work

Future work should also focus on integrating biometric authentication mechanisms such as thumbprint scanning to enable medical workers to access patients' data in emergencies where the patient is too ill to log in to the system and a next of kin is very hard to access.

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