

A Framework for Enhancing Health Information Sharing in

Public Health Facilities

Case study: Mulago and Jinja referral hospital

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DEDICATION

This work is dedicated to my parents for leading me into the classroom, my supervisor Richard Angole Okello, my lecturers and all those involved in my academic endeavors throughout the period of study at Uganda Martyrs University.

May the Lord bless them.

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LIST OF ABBREVIATIONS

HIPAA	Health Insurance Portability and Accountability Act
ICT	Information Communication Technology
SCDC	South Cambridgeshire District Council
PPI-EPR	Public Private Interface – Electronic Patient Record
HIS	Health Information System
PKI	Public Key Infrastructure
HILs	Health Information Librarians
NHITB	National Health IT Board
HIV/ AIDS	Human Immune Virus / Acquired Immune Deficiency Syndrome
TB	Tuberculosis
DDoS	Distributed Denial of Service
TSG	The Scottish Government
HIMSS	Healthcare Information and Management Systems Society
IOM	Institute of Medicine

ABSTRACT

Information sharing is the exchange of data between various organizations, people and technologies. This might be attributed to the presence of health information systems, standards for information sharing and information sharing frameworks. In Uganda, health information sharing is ineffectively done due to absence of a clear framework for information sharing in public health facilities- a factor in healthcare service delivery.

The focus of this research was to propose a framework to enhance health information sharing in public health facilities. To come up with an effective solution, a study was made on a number of policies, standards and frameworks putting emphasis on privacy and security of different information systems. Various frameworks that were partially offering possible solutions enhanced the development of the proposed framework.

Various information sharing frameworks were reviewed and eventually Kayondo's framework, Threat information sharing framework and Cambridgeshire information sharing framework are the lead frameworks for the study. Literature was used to guide the researcher in developing the concepts that are involved in the proposed framework. Considering Mulago and Jinja referral hospitals as the case study, qualitative and quantitative data were collected using questionnaires and interviews.

The framework was accepted by the users during validation.

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Health care is the largest service industry in the world (Salazar, 2001) composed of medical workers, patients, health policy administrators, and donor community who perform various activities such as accepting patients for care, administering medical services, discharging patients after services have been rendered, and follow-on services and care and providing bills to patients and/or insurers reflecting the services provided. It is in the interest of these players to have health information properly shared among themselves for the improvement of health care system while maintaining its security and privacy principles which is a constant balancing act worldwide (Tan, 1999). Today, there is a growing use of the internet for transfer of sensitive health information creating an additional complexity (Hsieh, 1998) for the health sector. Although the health sector is a highly regulated and closed system, public health facilities will need to consider information sharing as a key strand of their integrated service arrangements, and will need to work together with government, private sector where appropriate to maintain close relationships with patients and stakeholders in order to deliver health care services in this era of ICT.

In the developed world, this era has already been adopted and thus it has led to a paradigm shift in the way business activities are performed so as to enable collaborative computing, and sharing of information resources (Berman *et al.*, 2003). ICTs trends of improved computing power through increased network bandwidth, more powerful computers and the over whelming reception of the world wide web and its infrastructure continue to drive research efforts for better (Van Beijnum *et al.*, 2009; WITSA, 2004) health information sharing mechanisms. Health information sharing mechanism involves a multi-stakeholder arrangement in which information from patients and medical practitioners exchange and use health information in a secure manner, for the purpose of promoting the improvement of health services' quality, safety and efficiency (DCHS, 2006) resulting in heavy investment in the ICTs.

In Africa, a region with a number of developing nations, though there have been efforts to improve the process of sharing health information between health centers and statutory regulatory bodies, the current approach still faces a number of challenges due to resource limitations (Oludayo, *et al.*, 2011) resulting to poor quality of health service, lack of easy accessibility to service varieties and high costs of service management in the under resourced health facilities (Foster, and Tuecke, 2001; Oludayo, *et al.*, 2011). Grid computing if utilized will help create easy accessibility to service varieties by allowing distributing of health care resources to be massively reused to provide cost-effective services virtually (Oludayo, *et al.*, 2011; Berman *et al.*, 2003).

In Uganda, the current approach of health information sharing is based on a mechanism where medical information is transacted on physical paper and kept in filing cabinets at various medical offices and in boxes and paper folders in patients' homes (Fedorowicz *et al.*, 2004). This thus means that health information transfer and carriage by physical means whereby patients' themselves carry this information from appointment to appointments as demand may arise. Some of the challenges that can arise from this method of information management are; risk of distortion, loss or corruption of the information leading to poor patient-medical worker relationship management (Kulynych *et.al*, 2003).

Undertaking this research piece will offer significant benefits in managing the complex relationships of data and function in under resourced health facilities across the health domain. This research study thus aims at investigating state of art methods, tools and techniques that can facilitate information sharing amongst public health facilities in Uganda.

1.2 Statement of the Problem

Currently, Uganda lacks an effective framework that can facilitate sharing of health information amongst the public health facilities. This leads to high costs in terms of time, money and human ware incurred by government in storage and recording of the health information in individual health facilities. To the patients too, a lot of time, is wasted in providing background health information to the new health officer. The concept of asking patients for background health

information is further risky as most of them don't understand the technical jargons in health due to high illiteracy levels and given the fact that the respondents are sick, may not provide enough information. This may lead to acquisition of inadequate health information from the patient that could lead to wrong diagnosis hence wrong treatment. Also where information could have been stored in book files, the storage mechanisms of these files is very poor and many times books are lost or information is erased or blurred due to poor storage. Therefore the complexities in access of health information from patients may be disastrous. This study thus proposes a framework for health information sharing in public health facilities that would provide for information sharing amongst the health facilities.

1.3 Objectives of the Study

1.3.1 Main Objective

The main objective of this study was to propose a framework to enhance health information sharing in public health facilities.

1.3.2 Specific Objectives

- i. To analyze the existing health information sharing infrastructure and identify requirements for the framework.
- ii. To propose a framework that enables patients and medical practitioners to effectively share health information in health facilities.
- iii. To validate the proposed framework to assess its effectiveness.

1.4 Research questions

1. What are the basic requirements for proposing a framework for health information sharing among public health facilities?
2. What framework would enhance health information sharing among public health facilities?
3. What qualifies this framework to be more superior to the existing means of information sharing used in public health facilities?

1.5 Significance of the Study

In Uganda, health information sharing is ineffectively done due to absence of a clear framework for information sharing in public health facilities a factor in healthcare service delivery hence this study will specifically propose a framework to enhance information sharing in public health facilities.

The framework will provide guidance to public health organizations on how to share health information in the context of a developing country. This can also help local and international health policy makers and practitioner formulate and implement systems standards tailored to developing countries, this research is conducted as a partial fulfilment of a masters' award, the study once complete will help contribute to the literature in terms of health information sharing in public health facilities in under resourced environments, the study will also lead to decrease in costs incurred in the existing approach of information sharing among public health facilities, this study will thus focus on fixing the gap in lack of a common platform using the current state of art technologies in health information sharing amongst public health facilities.

1.6 Scope of the Study

A scope is defined as the parameters under which the study will be operating (Merilyn, 2013). It is realm in which the study is carried out for example; health, agriculture, education to mention but a few. This section will present the scope within which this study was done.

1.6.1 Geographical Scope

The study featured Mulago, a national regional referral hospital and the oldest hospital in the country and Jinja referral hospital found in Eastern Uganda as a case study. The study was limited to geographical location as obtained from Jinja and Mulago health facilities with a focus on doctors, nurses, patients and HILs. A total of 52 respondents participated in the study by providing responses accordingly. All the questions in both the questionnaires and the interview guides were limited to sharing of health information within the realm of public health facilities.

1.6.2 Time Scope

This study was conducted within a time frame of 8 months. This time included that of the proposal writing, framework development and testing and validation of the framework as required by the host institution of the research supervisor.

1.7 Definitions of terms

Information sharing: Is the exchange of data between various organizations, people and technologies.

Interoperability: Is the ability of two or more systems or systems components to exchange information and use the information that has been exchanged.

Health Facilities: Are places that provide health care.

Health Information: This is any information about the health of an identifiable consumer, or any health or disability services provided to him or her.

Access Management: A process control in which entities are granted or denied access to the resources of an organization ensuring that users can access only those resources for which the owner has given them approval.

Authentication: The process of establishing confidence in the identity of users or information systems. (Process to gain trust that a claimant is who he/she/it claims to be)

Authorization: The processes of granting or denying specific requests for obtaining and using information processing services or data and to enter specific physical facilities.

Framework: A layered structure indicating what kind of programs can or should be built and how they would interrelate.

1.8 Conclusion

In this chapter, a brief background about health information sharing in a context of a developing country has been provided. This chapter also presented the objectives that guided the researcher how to achieve the ultimate goal of developing a framework for sharing health information in public health facilities in Uganda. Factors, standards, theories, existing frameworks to back up this background is presented in chapter two below.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter explains state of the art and state of the process. It presents existing literature related to the research study. The chapter presents: section 2.1; Health Information Systems, 2.2; Inter-operability HIS, 2.3; Health Information Sharing, 2.4; Health Information Librarians, 2.5; Standards for Information Sharing, 2.6; Existing Information Sharing Frameworks and 2.7; Chapter Conclusion.

2.1 Health Information Systems

The wide spread use of Information and Communication Technologies (ICTs) has pervaded almost all aspects of life and healthcare sector has not been left behind. The intersection between business process in the healthcare and information systems technologies to provide better services is popularly known as Health Information Systems (HIS). This use of ICT in healthcare organizations has grown in the same pattern as compared to the large industry landscape. The use of web technology, database management systems and network infrastructure are part of ICT initiative that affects healthcare practice and administration. Its development and implementation in healthcare started in the 1960s and 1970s. This 21st century has witnessed a wide range of HIS implementation efforts in both developing and developed countries. Such rapid implementation is facilitated by the nature of healthcare industry of being dynamic. Healthcare industries dynamisms are influenced by economic, social, politics and technologies. Also healthcare is undergoing a paradigm shift, moving from industrial age medicine to information age healthcare (Smith, 1997), as result it is shaping public health systems (Haux *et al.*, 2002) and transforming the public health facility patient relationship (Ball, 2011) through information sharing thus forcing the countries to adopt HIS to keep improving the services. HIS is sought to be crucial for

addressing public health challenges associated with information sharing (Abouzer, 2010). Therefore, deployment of HIS to aid information sharing helps healthcare professionals to improve effectiveness, efficiency, and decision making in the public healthcare services sector.

In developing countries, HIS have in recent years received significant attention by both healthcare practitioners and the Information Systems (IS) research community. This attention has been from the increasing efforts by governments, international agencies, NGOs and other development partners seeking to improve public healthcare services through various interventions and approaches (Nyella, 2011).

Various developing countries are pursuing an integration strategy for the fragmented systems in order to fast track the process of information sharing (Dixon, 2016). While some countries are managing this process, some others like Uganda are still struggling to effectively adopt Health Information Systems causing inefficiency in health information sharing. Unfortunately, even for those developing countries that have tried to adopt HIS, they are still not able to enjoy full potential of HIS in information sharing to meet their people's demands despite tremendous efforts from different donors (such as Global fund, United Nations agencies, world bank, etc.) emphasizing on the importance of HIS integration to promote health information sharing in public health facilities.

Health related bodies in Uganda under the auspices of the ministry of health, have been struggling restlessly to advance health information sharing through integration of HIS but without much success. In a bid to create an environment for sharing quality health information among different stakeholders such as patients, many studies have been focused on the integration of multiple reporting channels within each program such as Malaria, TB, HIV/AIDS, etc but little research on guidelines in form of a framework on how to effectively share health information in public health facilities.

This therefore, forms an important foundation for this research to identify and address the major challenges and constraints of integrating Health Information Systems in a manner that fosters information sharing in public health facilities in Uganda.

2.2 Interoperability of Health Information Systems

Interoperability is the ability of two or more systems or systems components to exchange information and use the information that has been exchanged (Shah *et al.*, 2016). Public and private sector leaders alike have taken many actions to improve interoperability and information sharing, but more collaborative action is needed if developing nations are to reap the full benefits. However, the level of interoperability and meaningful electronic information sharing across different public or private health organizations is still fairly low. Therefore, to achieve effective health information sharing in public health facilities, there is need to have a framework to facilitate this interoperability (McGlynn, 2003). This is fundamental since critical to the success of health information sharing and the ultimate goal of a transformed health care system is real-time interoperable information systems among a variety of public health facilities stakeholders (clinicians, laboratories, hospital, pharmacy, health plans, payers and patients) regardless of the application or application vendor after all greater access to person-level health information is integral to improving the quality, efficiency, and safety of health care delivery in public health facilities.

2.2.1 Principles of Interoperability

There are four principles of interoperability of information systems. They include the ability to;- find information from outside sources, send information to other organizations, receive information from other organizations, use information from other organizations (Benson & Grahame, 2016).

2.2.2 Need for Interoperability of Health Information Systems

Today, the need for electronic information sharing and, therefore, interoperable systems, is driven by consumers who are using technology for nearly every other aspect of their lives and are demanding more from the health care system (Shah *et al.*, 2016). It is also being driven by a rapidly evolving health care system that increasingly rewards value and outcomes over volume, as well as advances in biomedical innovation that promise to deliver new cures and treatments to patients and herald a new age of digitally driven, personalized care as discussed below.

Increased Consumer Demands

Digitally driven people world over today, use online, electronic, and mobile tools for nearly every aspect of life, including shopping for consumer goods, banking, travel, and social interaction (Ricciardi, 2014). The Uganda health care system has been slow to move toward the information age when it comes to interacting with individuals about their health and health care despite the positive trends in digitalization of health information by government. A recent Nielsen survey released by the Council of Accountable Physician Practices and the Bipartisan Policy Center indicates that majority of people in the developed world for example in America would like to have better access to their health information (Farmer *et al.*, 2016). Achieving this important goal will require aggregation of an individual patient's health information from across the health care system in one single place, to support patients as they manage their health and health care- a processes that requires highly interoperable health information systems (Kaur, 2016).

New Models of Delivery and Payment

Billions of dollars are being invested by federal, state, and private sector organizations in new health care delivery and payment arrangements that reward better cost and quality outcomes (Akintoye, A. and Chinyio, E., 2005.). These arrangements will require greater information sharing and interoperable systems thus Clinicians and care teams will need to have access to information about the patient regardless of where care has been delivered as well as clinical decision support tools, to inform coordinated, clinical decision-making at the point of care and between visits by the patients to public health facilities (Friedberg *et al.*, 2015)

Therefore, new models of payment and delivery will require the aggregation and analysis of different types of data including but not limited to those derived from clinical systems, financial systems, administrative claims systems, medical devices, and consumer applications to be able to identify and predict where interventions are needed, monitor and provide feedback on progress, and measure outcomes and performance with an aim to support payment (Leider, 2016).

Given the critical role of the patient in improving cost and quality outcomes, clinicians and care teams will need to engage, inform, and support individuals in managing their health, making informed health care decisions, and navigating the healthcare system through effective sharing of

adequate health information among these stakeholders as long as there is high degree of interoperable health information systems (Shah, 2016). In order for this to happen, many types of data will need to be readily accessed from across the health care system, while effectively managing patient privacy and effectively aggregated, analyzed, and used.

The ability to effectively analyze and use data from multiple sources and disparate systems requires use of common standards for vocabulary; format, content, and structure; transport; security; and services (Schloeffel, 2002). It also requires common and accurate methods for both identifying providers and identifying and matching patient data from across multiple systems. Achieving broad-based electronic information sharing and interoperability will also require agreement on policies and basic “rules of the road” to assure trust.

Thus, to effectively access, use and share such data will require common standards for vocabulary; format, content, and structure; transport; security; and services (Libicki, 2016).

So, the actual exchange of health information needs to be both interoperable and electronic across a myriad of information systems for public health facilities to realize a patient-centered, value-driven health care system (Kaur, 2016). Effective communication and information sharing is essential to improving the quality of care, bettering health of communities, and lowering per capita costs through health information sharing (Campos, 2015). However, gaps and challenges still remain for the widespread use of interoperable systems and HIS across providers, settings of care, consumers and patients, and payers. Both providers and their vendors do not yet have a framework to electronically share person-level health information across providers and settings of care that exceeds the cost of doing so. It will take time to build a fully electronic interoperable system of coordinated care and communication across health care providers.

This research proposes a framework to facilitate better communication and enables more coordinated and connected care across the full continuum of health delivery and payment settings through a framework that facilitates interoperability of HIS as a major attribute for health information sharing in public health facilities.

2.2.3 Barriers of Interoperability

Barriers to interoperability and electronic information sharing are well-documented and discussed below (Shah, 2016).

Lack of a Business Case. The public health care system largely pays providers based on volume rather than value or outcomes, and therefore, to date, there has been little financial incentive to share information across settings to reduce costs or improve quality. This is expected to change, as new models of health care delivery and payment continue to proliferate.

Lack of a Technical Infrastructure. In 2015, 24 percent of provider organizations indicated that the lack of health information exchange infrastructure is a barrier to interoperability with 20 percent identifying incompatible solutions/technical limitations as an additional barrier.

Costs Associated With Exchange. According to a 2015 survey conducted by KLAS and CHIME, 28 percent of health care executives cited cost as a top barrier to exchange in 2015. Stakeholders have characterized the fees associated with health information exchange interfaces as “prohibitive,” while “set-up costs for the required hardware and internet links along with subsequent system maintenance” have also been described as a problem.

Need for Standards. Many stakeholders believe that more standards are needed, and that current standards need to be more explicitly defined. Providers also cite the lack of a common provider directory and lack of framework for accurately identifying and matching patient data as common barriers.

Table 2. 1 Interoperability Road Map Areas of Focus

DRIVERS	Supportive payment and regulatory environment
Policy And Technical Components	<p>Shared decision-making, rules of engagement, and accountability.</p> <ul style="list-style-type: none">• Ubiquitous, secure network infrastructure.• Verifiable identity and authentication of all participants.• Consistent representation of authorization to access electronic health information.

	<ul style="list-style-type: none"> • Consistent understanding and technical representations of permission to collect, share, and use identifiable electronic health information. • An industry-wide testing and certification infrastructure. • Consistent data semantics. • Consistent data formats. • Secure, standard services. • Consistent, secure transport techniques. • Accurate individual data matching. • Health care directories and resource location.
Outcomes	<p>Individuals have access to longitudinal electronic health information, can contribute to that information, and can direct it to any location.</p> <ul style="list-style-type: none"> • Provider workflows and practices include consistent sharing and use of patient information from all available and relevant sources.

Source: Hamilton Jr, J.A., Rosen, J.D. and Summers, P.A., 2002

2.2.4 Commitments of Interoperability

For any public health information systems to satisfy interoperability principles, three broad commitments must be defined and upheld (James, 2016). These are outlined below.

Helping consumers easily and securely access their electronic health information when and where they need it most, enabling individual health information to be shared with providers and implementing federally recognized national interoperability standards and policies.

2.3 Health Information Sharing

Health information of variable quality comes from a variety of sources including health professionals, media, family, social networks, religious leaders, educators, and the World Wide Web (Dutta, 2004). Much of the information about a patient's health and health care resides in the many settings in which care and services are delivered. This includes offices of primary care physicians and specialists, clinics, health plans, hospitals, laboratories, pharmacies, and radiology centers, as well as patients themselves (Moccia *et al.*, 2016). If this information is not shared effectively, proper and informed health decisions will not be made by both patients and the medical workers leading to poor health status (Marwa, Meshack & Godbolt, 2014).

The healthcare environment is generally perceived (Cheah & Abidi, 2002) as being 'data rich' and yet 'information poor'. This stems from the fact that much of the data collected has not been fully exploited due to the inadequacy of data and information management systems being in place. Much of the data and information generated is never processed and used. A joint effort of healthcare professionals, knowledge and data management experts is thus necessary to fully exploit the data generated for improving health care provision since the delivery of health services is increasingly becoming a function of the level of information possessed by health workers. (Wang *et al.*, 2003) asserts that electronic medical record systems improve the quality of patient care and decreases medical errors hence provide substantial benefits to physicians, clinics and health care organizations. Cheah *et al.*, (2002) argue that the role of information technology in healthcare is well established and its practice a time-honored tradition. There is growing demand from the healthcare systems to emphasize transformation of vast quantities of health care data and information into usable decision-quality knowledge. This position contradicts some critical aspects of the differences between countries with the capacity to transform vast quantities of data into usable information and those that do not possess such capabilities (Chase *et al.*, 2016). This is what is referred to as the digital divide. The digital divide is the persistent disparity between the rich and poor nations which determines the position of a health care system on the continuum. While well-advanced nations have in place Information Technology (IT) systems that foster the tapping of information for health care, poor nations characterized by rudimentary IT systems and lack of infrastructure in the sparse rural

areas struggle to effectively and efficiently provide sharing of health information despite the existence of health information sharing principles.

2.3.1 Health Information Sharing Principles

This section discusses four principles of information sharing (Bardram, 2010) as presented below:

Quality and Trust: High quality health information supports high quality health care therefore, consumers trust that the health system will keep their information safe, information held is as accurate, up-to-date and relevant as is necessary for the purposes of treatment and care.

Privacy and Transparency: On the collection of health information, health agencies will communicate the likely intended purpose and disclosures of the information to the consumer in a straightforward way. Therefore, a patient has a right to access and take a copy of their health information and to know who else has accessed it hence they do not need to give a reason for requesting that information. Secondly, a patient may withhold from sharing part, or all, of any of their health information that is not required to be disclosed by law.

Disclosure: A health agency may use or disclose a patient's health information if they have been granted authorized access to do so or for purposes that have been communicated to the patient. Likely purposes for disclosure include: delivery of care, referrals, research, teaching, audit and funding.

Security: Health agencies must establish reasonable safeguards to monitor and protect health information through clear identification of the parties involved in any healthcare transaction, including patients, providers and organizations. Data networks that handle health information must be resilient against intrusion, negligence and accidental damage including data corruption and loss. Health information is not held indefinitely and when it is deleted this must be done securely.

2.3.2 Barriers to health information sharing

This section presents twenty (20) barriers to information sharing (Willem *et. al.*, 2014) in a broad sense grouped into seven categories. Namely technical; motivational; economic; political; legal; ethical; language and culture. These are generic to any public health facility in the world.

Technical Barriers

These include barriers based on institutional information systems that hinder information sharing. Solutions for this group of barriers lie in building interoperable and secure health information systems.

Data not being collected. As long as severe limitations persist in public health data collection, data sharing will not be considered a priority. The WHO Health Metrics Network, the CDC/USAID Data for Decision Making project (DDM) and other agencies have found significant gaps in public health data systems, in particular in low- and middle income countries. Disease surveillance systems in many countries cannot meet data collection standards set by the 2005 International Health Regulations (Heymann, 2001). Civil registration systems in Uganda are lacking as well.

Data not preserved cannot be found. Public health data are often collected for short-term purposes such as outbreak detection. Data preservation or archiving is often not prioritized, especially in situations of limited capacity and resources (Byass, 2009) Even if data have been preserved, data retrieval systems may be lacking. This is amplified by relocation of offices, staff turnover, physical damage to paper or electronic files, computer viruses and computer theft.

Restrictive data format. Despite major advances in computational resources in public health, a large volume of public health data such as disease surveillance data and administrative data continue to be collected and preserved in hardcopy paper format or in electronic format that may be antiquated or incompatible with modern software systems

Technical solutions not available. Technical software solutions to collect, harmonize (transformation and recoding to enhance inter-operability), integrate (combining harmonized datasets), and share complex and heterogeneous data have been developed in the private or research sector, but have not become widely available to public health agencies (Rudolph, 2005, McNabb, 2010)

Lack of metadata and standards. In most cases, metadata describing data content, origin, methods, etc. are lacking for public health data and standards for data format, variables, and metadata are insufficiently used, limiting secondary data use and inter-operability (Nsubuga *et al.*, 2008) Some advances have been made through the development of the International Classification of Diseases (ICD), the Data Documentation Initiative (DDI) and the Standard Data and Metadata eXchange (SDMX) however, these standards are not always used efficiently. For example, between 1950 and 2010, up to 20% of deaths in African countries were attributed to ill-defined ICD codes (Mahapatra *et al.*, 2007).

Motivational Barriers

These include barriers based on personal or institutional motivations and beliefs that limit information sharing. Solutions for this group of barriers lie in building trust or developing transparent legal agreements.

No incentives. Data sharing requires time and resources that are chronically lacking in public health settings (Pisani, 2012) personal and institutional incentives are often required to prioritize data sharing over other pressing duties (Lopez, 2010), particularly if the benefit of data sharing is delayed and uncertain (e.g. possibly more efficient disease control programs) instead of immediately relevant to data providers (e.g. scientific credit or training).

Opportunity Cost. Public health officers who have invested time and effort in data collection could anticipate that scientific credit or other opportunities may be lost if data recipients with greater capacity for analysis could gain the majority of credit. This is a particular challenge in low resource settings (Pisani & AbouZahr , 2010)

Possible Criticism. Data providers could be discredited by errors found during secondary use of their data and disease control efforts may be criticized if data would reveal continued disease occurrence (Brest, 2007) In the worst case, data sharing could reveal data fabrication or manipulation. For example, studies have shown over-reporting of vaccine coverage by country statistics compared to independent surveys after introduction of GAVI incentive funding for vaccination programs.

Disagreement on Data use. Data providers may disagree with the intended secondary use of their data or may consider their data inappropriate for a certain use.

Economic Barriers

These barriers concern the potential and real cost of data sharing and solutions depend on the recognition of data value and on sustainable financing mechanisms. The solution to these problems lies on economic models and frameworks to guide expenditures.

Possible economic damage. Data sharing in public health facilities is challenged by the economic damage that this may cause to data providers. Public sharing of disease outbreak data, for example, can result in economic damage due to reduced tourism and trade (MARSH Inc, 2008) The global SARS outbreak led to estimated economic losses of 50 billion USD between 1998 and 2004 and Foot & Mouth Disease in the UK resulted in losses of 30 billion USD between 1998 and 2003 The possibility of such significant economic implications due to (over) reactive market forces could cause great reluctance among health agencies to rapidly release disease data.

Lack of resources. The process of data sharing requires human and technical resources for data preparation, annotation, communication with recipients, computer equipment, internet connectivity, etc. (Baldwin and Diers , 2009) These resources are frequently lacking in public sector agencies under economic pressure or in low income settings (Chretien *et.al.*, 2008, Fountain, 2004)

Political Barriers

These are fundamental structural barriers embedded in the public health governance system that are grounded in a political or socio-cultural context. Solutions for these barriers are not clear-cut and will require global and national processes to build consensus and political will for health information sharing.

Lack of Trust. Trust between a data provider and user greatly enables data sharing. In the absence of trust, providers could anticipate potential misinterpretation, misuse or intentional abuse of the data. For example the (El Emam, *et al.*, 2011), Indonesian government refused to share H5N1 influenza samples with the international community during the 2007 pandemic due to lack of trust on the potential use of these samples for financial gain (Fidler, 2008) Legal arrangements were required in the absence of a trust relationship which led to the development of the Pandemic Influenza Preparedness Framework.

Restrictive Policies. Agencies may have developed official policy guidelines that restrict data sharing, resulting from various possible underlying factors such as a general sense of distrust, negative prior experiences, or other factors.

Lack of Guidelines. Frequently, official guidelines on data sharing simply do not exist, are unclear or inconsistent (Heeks, 2000) The balance between making data accessible, safeguarding privacy, and protecting intellectual, time and financial investments by public health staff is often not well regulated or standardized, resulting in protective policies on sharing of public health data in general (Kephart, 2002).

Legal barriers

These barriers are legal instruments used to restrict data sharing, resulting from the underlying willingness (or not) to share data. Solutions to this group of barriers include legal instruments to facilitate data sharing and are highly dependent on solutions to underlying political barriers (Wu *et.al.* 2005). Ownership and copyright. Agencies that collect public health data are often

responsible for the protection of individual and community privacy and may feel that a guardianship or ownership role is bestowed on them by the public (Lungo,2004). This could result in a default of restricting access to most data copyright can be used to restrict rather than expand access to data. In practice, it is often not well documented or known who owns public health data, resulting in inconsistent ad-hoc guidelines (Kephart, 2002) For example a project in Canada to integrate National Population Health Survey data with provincial data required a different approval process in each province.

Protection of privacy. Public health agencies have the mandate and authority to collect private data from the population (Stansfield, 2008) governed by the Health Insurance Portability and Accountability Act (HIPAA) in the US or similar legislation in other countries. A clear distinction between data containing personal identifiers and fully anonymous (Safran *et.al.* 2007) data may not always be possible, leading to restrictive policies on all types of data due to privacy concerns. Aggregated data without personal identifiers may not be sufficiently detailed for certain applications (Gostin, 2013). Existing tools and standards for the de-identification of personal identifiers such as statistical data masking may not be known or available in many contexts.

Ethical Barriers

These are normative barriers (Baldwin & Diers, 2009) involving conflicts between moral principles and values. Solutions for these barriers will involve a global dialogue among all stakeholders on the ethical principles that should govern data sharing.

Lack of proportionality. The issue of proportionality (Chretien,2008), the careful deliberation in assessing the risks and benefits that derive from the amount and type of data requested compared to the potential impact of its secondary use, has been identified as a guiding ethical principle for public health data sharing. Public health facilities (Lang, 2009) may disagree with data

requestors about the proportional risks and benefits of the secondary use of data and its impact on public health.

Lack of reciprocity. Data sharing practices have not always been fair, and data producers have often felt exploited in transactions where they receive little credit or benefit from their work, while data users that can rapidly analyze data and publish results benefit from academic credit and career advancement (Willison *et al.*, 2012) as has happened in the past (Tangcharoensathien *et al.*, 2010)

Language and culture

These are barriers related to beliefs and communication of people across different nationalities. Given the background of African

Language barrier. (Wright,2010) routinely collected health data in public health facilities are often recorded in local languages, limiting the possibility to integrate and use such data together with other data sets, particularly in an international context.

Different Cultures. Culture is a critical determinant of the successful implementation of EMR systems in developing countries (Kephart, 2002). One particular issue is that of language. Since most EMR systems are designed in English, it becomes difficult to facilitate interaction between divergent cultural subsystems, preventing transfer of knowledge from one culture to another for instance, the Sub Saharan Africa region (Baldwin & Diers, 2009) is notable for its incredible language diversity. For example, Cameroon, with a population of about 14 million has 279 distinct languages, Nigeria has 515, Ghana has 79, and Senegal has 36. Furthermore, despite the role of English as the Lingua Franca of the Internet (Tangcharoensathien *et al.*, 2010), information presented in the users' native language, seems to be the most decisive factor for attracting website visitors thus, language becomes a significant factor in assessing usage of EMR systems in non-english speaking regions (Baldwin & Diers, 2009).

2.3.3 Security in Health Information Sharing

All patients, their families, and service providers (Agaku, *et al.*, 2014) should expect to have consistent and timely access to standardized health information that can be securely shared between primary care providers, specialists, hospitals, mental health and substance abuse services, LTPAC, home and community-based services, other support and enabling services providers, care and case managers and coordinators, and other authorized individuals and institutions.

2.4 Health Information Librarians

Health librarians also termed as health information officers can also play an important role, as their purpose is to promote and enhance access to health information. Such groups can provide needed assistance through training and through the selection, repackaging, and dissemination of relevant materials (Eakin *et al.*, 1980; Colomb & Godbolt; Gathoni 2012). For information to be used, it must be available, accessible, and usable, and absorbed by the recipients of the information (Wagacha, 2007). In regions that lack adequate information systems, librarians can play a role facilitating access and use by information seekers, because they are (a) aware of the needs of users, (b) familiar with new information and communication technologies to meet local needs, and (c) skilled in techniques of information retrieval. Many librarians who support institutions working in health have access to at least some current sources of evidence-based information, and as information professionals they are committed to information sharing and to providing access to information for members of the health community (Coghlan, 1993).

These are at the center of the following questions below; how can greater availability of information that responds to the specific needs of health workers at multiple levels in the health sector be achieved across Africa? How can persistent barriers to access from infrastructure to language issues, information search and retrieval skills, and information literacy be addressed?

Health information professionals (D'Souza *et al.*, 2014) should take the lead in ensuring that health workers and the general population know how to retrieve the information and use it effectively and ethically. They have knowledge and skills in organization, retrieval, and dissemination of information and they can therefore take a central role in locating and filtering relevant information for personnel in the health sector, students at faculties of nursing and

medicine, and other health stakeholders. Associations of professional health librarians can also play an important role, as their purpose is to promote and enhance access to health information. Such groups can provide needed assistance through training; selection, repackaging, and dissemination of relevant materials; and other approaches known to improve information literacy (Tyner, 2014). The Association for Health Information and Libraries in Africa, for example, with members at information resources and libraries throughout the region, might be an ideal group.

The availability of information and communication technologies is important for the development of any nation. However, in developing countries, barriers such as language (Hodkinson et al., 2014), low literacy levels, and poor information literacy remain a challenge. Information literacy-the capacity to recognize when information is needed and to use the information effectively and in an ethical manner-is a critical component of information usage. If the population including librarians the technology is intended for cannot use and effectively manipulate the health information, then it does not serve the purpose it is intended for. Sometimes health information that is accessed and taken out of context is misinterpreted and can be detrimental. Basic literacy levels, information literacy, and the lack of comprehensible and usable information for health workers at every level need to be addressed for public health facilities to achieve the Millennium Development Goals by 2015.

2.5 Standards for Information Sharing

Information sharing is defined as the exchange, collection, use or disclosure of by one entity with another known entity for a number of purposes. This data exchange mechanism is enabled using a transmission mechanism deemed suitable (Cheung *et al.*, 2010; Dixon, 2016; Fung *et al.*, 2007). According to Dixon (2016) information sharing to meet the increasing demands of people, practitioners and organizations is essential to support governments' commitment to integrated and person-centered health care services.

Gottschalk (2008) defines inter-operability as a property of diverse systems and organizations enabling them to work together. In data exchange frameworks, standards are developed to support the seamless exchange of information amongst the stakeholders (TSG, 2015). There

should be a clear position on ownership and governance of stakeholder cross-sector standards so as to coordinate and generate standard approaches and supporting datasets for the required services (TSG, 2015).

Document sharing models which include direct push, centralized discovery-retrieve and federated discovery- retrieve models must be considered in developing data exchange standards (Witting and Moehrke, 2012). The direct-push model entails exchange of all medical content in form of documents and metadata directly to a known recipient or directly deployed on a media for end node delivery (Witting and Moehrke, 2012). In the centralized discovery and retrieve model, a centralized locator is used to discover locations for known documents which enables a retrieval of the document from an identified entity with registered existence of the document with the centralized locator (Witting and Moehrke, 2012). For the federated discovery and retrieve model a bunch of peer entities are enabled to query one another so as to discover documents of interest, followed by retrieval of specific documents (Witting and Moehrke, 2012). The document sharing models will be used in framing standards for information exchange in the proposed model.

The interoperability of medical information systems continues to gain attention given the need for cooperation in the growing health care domain (Stolba *et al.* (2002). Thus in order to overcome the challenge of institutional collaborative barrier, standardised interoperability data structures and corresponding underlying infrastructure must be implemented (Stolba *et al.*, 2002).

Duftschiem *et al.* (2003) and Stolba *et al.* (2002) recommends the basic baseline components of an electronic health framework to include; the message contents, models, standards; identification variables; data privacy and security and network and service providers. The message contents, models and standards component entails specified standard formats for health information exchange (Duftschiem *et al.*, 2003; Stolba *et al.*, 2002). Though the development of an electronic healthcare information model as a baseline standard for message exchanges is without policy barriers, there has been viable solutions to bypass that barrier with an example of the MAGDA-LENA framework that prescribes the use of existing standards both international

and national in relation to medical informatics and optimises their uniformity (Stolba *et al.*, 2002).

The identification variables component, is responsible for elimination of data abuse during data transmissions (Duftschmied *et al.*, 2003; Stolba *et al.*, 2002). According to Stolba *et al.*, (2002) the MAGDA-LENA framework enforces identification of communication parties, their roles and data to be shared via registered directories within the organization they are assigned to.

A health information sharing framework can be instrumental in support of patients interactions with health care services, including assessment information, notifications that can trigger actions, electronic messaging between organisations, practitioners and people, and business and operational information to support the day-to-day running and planning of health and social care services (COSFRSOCDT, BOHSP, and IOM, 2014; Dixon, 2016).

The construction of successful information sharing frameworks necessitates establishment a partnership among the information sharing entities (Cheung *et al.*, 2010). That is to say, clearly articulated partnership arrangements between delivery partners and co-ordinating bodies must be ensured (Cheung *et al.*, 2010). According to Sinha *et al.* (2013), the need for interoperability of health informatics applications, a number of health informatics standards have been developed and these include structural standards, data content standards, data exchange standards, and security standards.

2.5.1 Governance and Leadership Standard

The governance and control component is a diverse skill component which entails all key stakeholders in information sharing to undertake ownership and collective responsibility to steer the goal of information sharing (Cheung *et al.*, 2010). This component is responsible for legislation, policy and compliance to agreed baseline rules and standards in line with the goal of information sharing (Cheung *et al.*, 2010; Fung *et al.*, 2007). The Governance structure monitors the information sharing ecosystem and is the component critical for ensuring consistency and leadership, as is leadership that is risk tolerant and encourages information sharing (Cheung *et al.*, 2010; Sek *et al.*, 2007). According to Cheung *et al.* (2007), it is imperative that IT governance structures and processes are embraced with support from health sector personnel. The human ware in this component must entail a base line of experts, namely, project management

professionals, health informatics experts, electronic law experts, software engineers, enterprise architects and system administrators respectively (Cheung *et al.*, 2010). According to Cheung *et al.* (2007) it's imperative that humanware knows that information sharing is possible and thus a new problem solving and learning dimension invented. This component will be considered while planning and modeling of the management and control component of the proposed framework.

2.5.2 Development and Training Standard

This standard states that essential information sharing competencies must be constructed across the information sharing environment (Cheung *et al.*, 2010; HIMSS, 2010). Humanware must understand the exact information sharing parties so as to be able to construct and maintain sound collaborative and knowledgeable relationships (Cheung *et al.*, 2010; Dixon, 2016; Sek *et al.*, 2007). It is thus imperative that all personnel in information sharing environment be given mandatory trainings through a variety of training modalities that facilitate the development of essential information sharing competencies (Dixon, 2016; HIMSS, 2010). According to Fung *et al.* (2007) this component is responsible for capacity building to foster relationships that support information sharing and analysis. This component will be vital in scaling the training management module for the proposed framework.

2.5.3 Process and Technology Standard

The process and technology standard stands for application of consistent key information management practices and access control mechanisms to the classification and management of information supported by the underlying IT infrastructure (Cheung *et al.*, 2010; Fung *et al.*, 2007). It thus calls for transparent and consistent processes across the information sharing ecosystem, specifically in the area concerned with standardized consent and notification practices (Sek *et al.*, 2007). This component will be important while developing the proposed IT infrastructural module that supports sharing and managing information across the information sharing environment.

2.5.4 Legislation and Policy Standard

In policy and legal requirements patient privacy should be given consideration (Cheung *et al.*, 2010). Enterprise wide information sharing policies and standards are required for all collaborative faculties and service delivery partners (Fung *et al.*, 2007). Personal Data Ordinance could be adopted as a technique in addressing patient's privacy (Sek *et al.*, 2007). According to Cheung *et al.* (2010) in order to achieve the objectives of Personal Data Ordinance all personnel in control of the collection, holding, processing or use of patient's data must subscribe to the ordinance. In developing the legislation and policy standard, substantial information sharing barriers must be established (Cheung *et al.* 2007). To ensure observance of the ordinance the state or supreme authority in the region needs to regulate all medical personnel through the professional code of conduct in-line with management of patient's information (Cheung *et al.*, 2010; Sek *et al.* 2007).

This approach thus aims at developing a consistent approach to the application of legislative requirements (Cheung *et al.*, 2010; Sek *et al.*, 2007). This component will be essential in developing the legislation module entailing policy and legal requirements.

2.5.5 Change Management Standard

The change management standard entails the movement from the existing approach to the desired state of information sharing (Cheung *et al.*, 2010; HIMSS, 2010). This requires a strong vision and changes in culture, attitudes, relationships and business practices. According to Cheung *et al.* (2010), effective change would necessitate concerted effort from the entire human ware setup in the organization. To support consistency and capacity, a change management strategy should be engineered by the change management experts (Cheung *et al.*, 2007; HIMSS, 2010). In this research study, the interoperability components discussed in 2.2 will be used as a baseline standard in building of the proposed framework for Health Information Sharing in public health facilities in Uganda.

2.5.6 Infrastructure, Standards and Systems in Uganda

2.5.6.1 ICT infrastructure; hardware and connectivity

Currently data connectivity and networking in Uganda covers almost 100% of the whole country including; urban, district, rural and remote areas. This has been achieved through fibre for the major towns and wireless (mobile phone) connectivity for the district, rural and remote areas provided through the government National Data Transmission Backbone (NBI), and the private sector fibre and wireless networks. Mobile phone penetration is over 40%, and internet penetration of 3.2 users per 100 inhabitants. Operational TV stations are 44 while operational FM stations are 211.

ICT hardware is mainly comprised of desktop computers and mobile telephones. However the cost of internet is still high compounded by unreliable or unavailable power supply especially in lower health units and rural communities. In addition ICT hardware such as computers are few, poorly maintained and underutilized particularly in rural and remote health facilities.

Currently there is reliance on imported hardware and software in the face of fast changing technology. This has led to the proliferation of hardware, software and communication equipment used in the numerous fragmented donor-funded projects, which do not share information and provide limited information to healthcare professionals for managing patients effectively.

2.5.6.2 E-health Standards and systems

Currently there are no national standards for management of secure electronic health information and services for individuals. In addition, the security of personal information and access by unauthorized individuals are not adequately addressed (Shrivastava, *et al.*, 2016). This hinders the adoption of e-health and the realization of its benefits such as enhancement of health information sharing and effective management of the health system. Hence the framework am

proposing will include standards for information sharing as well as ensuring security of personal information.

Computer systems and network-based communications are available to a limited extent in the PNFP and the PFP health facilities. The Uganda Catholic Medical Bureau (UCMB) is to a large extent computerized with a high level of adoption across the country. This can be scaled up appropriately.

2.5.6.3 Legal and Regulatory Framework for e-health

Currently, in Uganda, the legislative and regulatory frameworks comprise of three cyber laws which address security and legal transactions, these are; The Computer Misuse Act 2011, the Electronic Signature Act 2011 and The Electronic Transactions Act 2011. These laws apply to all levels of government; national, district and community. The existing data protection, legislation and regulatory frameworks, do not ensure security, confidentiality and privacy of personal information. This may lead to access to personal information by unauthorized persons and mistrust in the health system by the intended users. Thus the proposed framework will ensure data protection and legislation to address security, confidentiality and privacy of personal information.

The national judicial system and the professional health councils are responsible for regulating compliance with data protection legislation. The health professional councils have an oversight function for legal and regulatory compliance in the health sector. However they do not have the competence in the area of e-health for effective enforcement.

2.6 Existing Information Sharing Frameworks

Existing studies (AHS, 2015; NHITB, 2012; Rashid, 2015) show that the study of information sharing concepts has been credited successful in developed governments with a number of benefits which include; information availability, privacy, ease of access, efficiency, among other advantages. Hence these concepts have been sighted relevant to the proposed framework. This section thus gives a descriptive account of existing information sharing frameworks.

2.6.1 Threat Information Sharing Framework

The threat information sharing framework is a security based information sharing framework developed by Microsoft to help provide guidance on effective information sharing and verifying the types of data that should be shared (Rashid, 2015). The framework entails all the parties which need to be involved in an information sharing exchange as well as the necessary types of information which should be included. These exchanges should include governments, private critical infrastructure firms, enterprises, information technology, security companies and security researchers (Rashid, 2015). This approach will be used in modeling the security component in the proposed framework.

In conclusion, this framework provides for guidance on effective information sharing and the types of data that should be shared hence it will act as a guiding tool in the proposed framework towards ensuring security of health information.

2.6.2 Cambridgeshire Information Sharing Framework

The Cambridgeshire Information Sharing Framework is a high level agreement involving a number of public organizations in Cambridgeshire (SCDC, 2015). The framework aims at providing the best effective data sharing approach across the Cambridgeshire region where there was need for improving service delivery to the public (SCDC, 2015). In this framework, data sharing can only be permitted only if it matches the legal standards (SCDC, 2015). The existence of the framework makes this process faster and also helps to ensure that each agreement is drawn up with advice from the organizations' Information Sharing Experts (SCDC, 2015). This framework will be used as an understudy for inter facility information sharing in the proposed framework.

In conclusion, this framework ensures that data sharing can only be permitted only if it matches the legal standards hence it will act as a guide in addressing legal issues in the proposed framework.

Challenges associated with health information sharing in developing countries

This section discusses challenges that can affect information sharing in public health facilities (Makedon *et al.*, 2015) with a context of developing countries like Uganda.

Poor Infrastructure: For HIS to run it requires technology infrastructure such as software, hardware, and network. It is equally important that the right infrastructure in terms of right sizing, the servers and PCs, with good bandwidth network connectivity and clean power supply will go a long way in ensuring smooth and satisfactory HIS implementation. But these infrastructures may not be available.

Inadequate Skills: There is a lack of knowledgeable personnel with capabilities of integrating and implementing HIS in the health institutions. Literature stated that without required expertise, implementing of HIS is most likely to fail. Due to complexities of HIS integration processes implementation integrated system requires IT skilled personnel to provide technical support and ongoing training issues and reengineering of system processes in case of business process changes.

Lack of Training: Most of health organizations merely spend money on HIS without investing in training and redesigning processes to take better advantage of the new technology. Usually these may also cause user resistances if no proper induction was provided.

Lack of Stakeholders Participation and Awareness: Stakeholders are all the people or organizations that will be affected by the system and who have a direct or indirect influence on the system requirements (Rogers *et al.*, 2002). The lack of participation and awareness also leads to unsuccessful introduction of the HIS. This can be attributed to the lack of capacity and training available in the organization but also with the social and cultural issues affecting the organization. This often tends to lead to stakeholders not willing to participate into this process. All stakeholders should be included in the awareness raising and training of the system (Gladwin *et al.*, 2003).

2.6.3 Security management of electronic health records

There are a number of frameworks developed for managing the security of health information such as Framework for Security Management of Electronic Health Records in Resource Limited Environments as shown in Figure below.

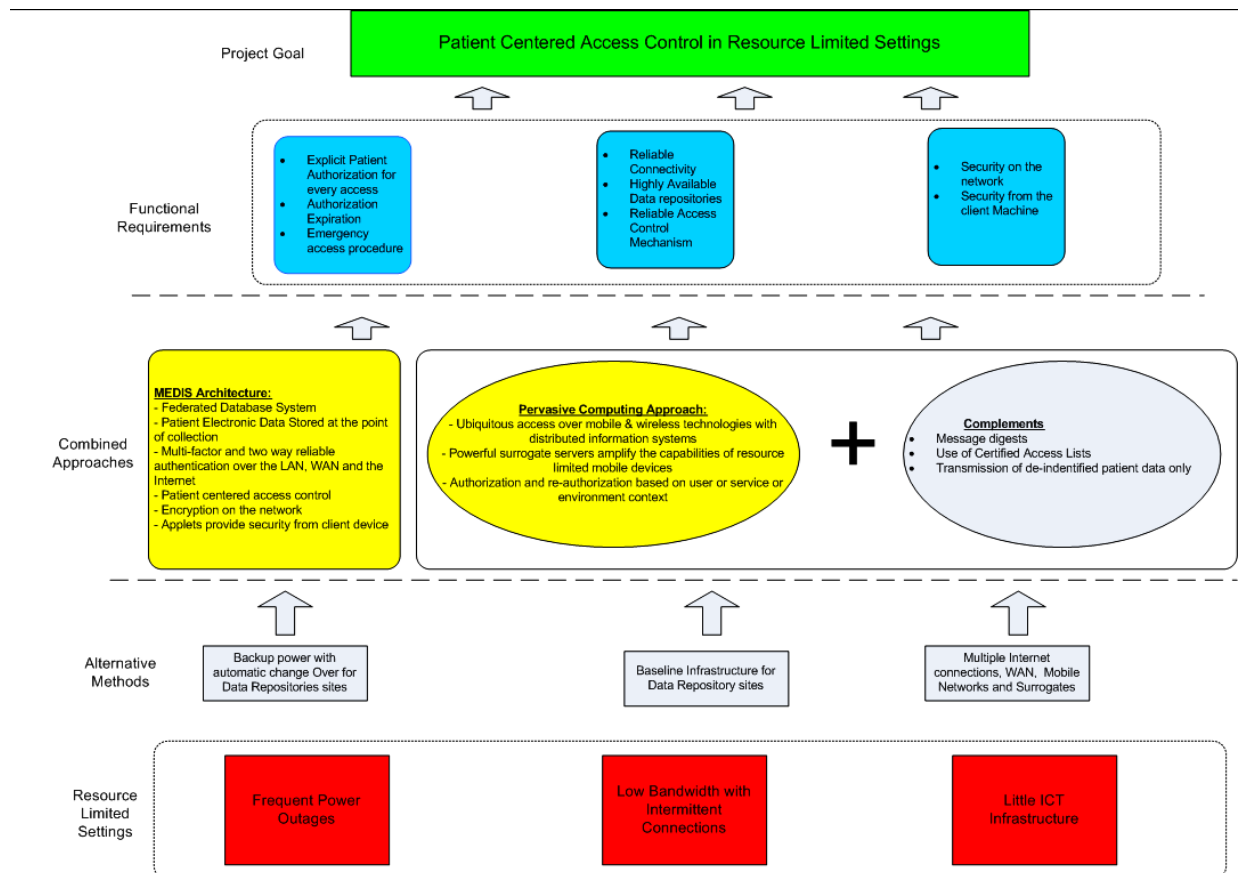


Figure 2. 1 Showing security Management of Electronic Health Records, source: (Lukanga Kayondo, 2009)

Strength of the Framework

According to this framework, the message digest or hash value of the access list changes every time the access list is modified (Ora, 2015). In this approach the patient can verify the integrity of the access list without using very high resources. The framework also provides a mechanism of override incase the patient is unreachable however this is used in cases only authorized by the patient.

One of the relevancy of this framework to this study lies in the fact that it was developed to serve in resource constrained environments like public health facilities in Uganda as a developing country.

Weaknesses of the Framework

Much as it includes most of the relevant authentication mechanisms to protect the security of the health information such as use of control access lists, message digests, certified access lists using PKI, it does not include mechanisms like biometrics technologies (Zhang, 2013) to strengthen authentication of health information users, medical verification of data and a legal verification framework.

Concepts of Interest to the proposed framework

Lukanga's report stresses the need for authentication and authorization mechanisms and this was adopted by the proposed framework as a crucial component with final permission to share information especially vital and sensitive information at the permission of the patient. This framework is much relevant and thus an appropriate benchmark for this study's proposed framework because of its links to the resource limited environment. And as such factors related to power, internet bandwidth and ICT infrastructure were implied.

Functional requirements according to Lukanga's framework, are regarded as the enabling environment for information sharing. This was considered a responsibility of health facility and government since the study was conducted within public health facilities. The gaps in this framework were used as a basis to formulate the theme of questions and tools to obtain information particular to health information sharing.

2.6.4 Biometrics Technology

Biometric technologies are defined as automated methods of identifying (Darrell Shawl, 2013) or verifying the identity of a living person based on unique biological (anatomical or physiological) or behavioral characteristics. Biometric technology is a type of recognition system which identifies an individual by analyzing anatomical and physiological characteristics (Perrin, 2002). An individual's fingerprint, face, iris, hand geometry, palm print, odor, voice, and signature are a few examples of characteristics used for scanning and identification (Zuniga, Win & Susilo, 2010). Biometric technology enrolls a person into a system by scanning and extracting the traits of the individual's characteristic, which is then stored as a template in the system's database.

Biometrics can provide very secure and convenient verification or identification of an individual since they cannot be stolen or forgotten and are very difficult to forge. (Smart Cards and Biometrics in Healthcare Identity Applications, 2012)

2.6.4.1 Need for Biometric in Public health facilities

The need for biometrics in the healthcare industry is growing at astronomical rates (Vaidya *et al.*, 2015) the worldwide market potential is currently estimated at \$1.9 billion. A significant driver in biometric market growth rates is the HIPAA Act; HIPAA imposes stringent new federal requirements to protect patient privacy and the confidentiality of patient information. This is causing all healthcare facilities to begin developing compliance procedures for meeting these new standards. As a result, public health institutions are beginning to embrace the deployment of biometrics. Institutionalizing biometrics does (Schneider, 2001) indeed compliment the strategy in assuring HIPAA compliance through user authentication to provide for, privacy of patient information, network security / PKI management, web security for e-business applications, internet authentication services, data storage and retrieval management.

Biometrics also creates operational efficiencies for all ID procedures (Zhang, 2013), it provides improvements to risk management programs by ensuring that accurate patient identification is tied into care or treatment plans or matched to medical records management systems for each individual patient (Ball, 2013). It also offers for the first time what many agencies have wanted the concept of a universal patient identification number that provides positive identification of an individual using a biometric tied to a unique number. And lastly, the overall quality of care is improved through accurate patient and/or staff identification. One of the types of biometric is multispectral biometrics.

2.6.4.2 Multispectral Biometrics

Multispectral biometrics plays an important role in healthcare applications, especially when there is a need to control access through positive identification of authorized users (Corroy *et al.*, 2014). HIPAA regulations mandate patient confidentiality and biometrics can help ensure that only authorized personnel gain access to those records. Biometrics help minimize insurance

fraud and theft of controlled inventories such as pharmaceuticals and they can secure against the unauthorized use of expensive medical equipment (Spence, 2011). In addition to controlling access, multispectral biometrics plays a role in facilitating operational efficiency in public health facilities. Most security solutions are designed to block rather than facilitate transactions. However, carefully designed biometric systems can streamline operations by providing quick and easy access to authorized users. Biometric systems can enforce and document compliance with hospital policies and procedures, enhancing patient and staff security (Zuniga *et al.*, 2014). Biometrics is only viable if the technology and solution can be made to work reliably for every user, every time. The cutting edge biometric technology multispectral fingerprint which has the unique ability to see beneath the surface layer of skin is having a dramatic impact on user performance and real world experience in the healthcare industry (Zhang, 2013). Not only can multispectral fingerprint handle the environmental factors that can affect fingerprints, but it is also the only technology on the market today that can extract a fingerprint image from a gloved hand (Spence, 2011). Biometric technology represents the future for positive healthcare identification and will enhance the secure use, storage, and exchange of personal health information. The lack of patient identity safeguards present many issues for patients and providers, patients are victims of medical identity theft so that their records may contain health data and claims that are not theirs, jeopardizing treatments in the future and health care financial limits (Porter *et al.*, 2014). Patients may have their medical records falsified to support fraudulent claims when they have not received care. Fraudsters can use providers and patients identities to falsify claims, all of these issues lead to less safe and efficient information sharing.

In order to achieve these benefits for a biometrics based authentication method, the particular biometric traits must be stored remotely in order to be available to multiple system (Ball, 2013). Remote storage raises concerns about what security measures are in place to protect the biometric information, what personnel have access to the stored information, and how the individual's privacy and civil liberties are protected. In order for multiple systems to have access to the database for authenticating individuals' identities, both an open application interface and tightly controlled and monitored access control mechanisms are required (Vaidya *et al.*, 2015). However, as a system becomes more widely available, there is greater risk of a system or

personnel security breach. Data breaches are a significant and growing problem for the healthcare industry (Smart Cards and Biometrics in Healthcare Identity Applications, 2012).

2.6.4.3 Need to combine biometric and smart cards

An ID system using the combination of smart card technology, Cryptographic functions and biometrics has significant security advantages (Smart Cards and Biometrics in Healthcare Identity Applications, 2012) including using digital signatures to ensure that the biometric template being used has not been altered, using encryption to protect the biometric template and other personal information stored on the smart card, using the smart card to compare the live biometric template (Nandakumar *et al.*, 2015) with the biometric template stored on the card. Since the biometric template never leaves the card, this protects the information from being accessed during transmission and helps to address users' privacy concerns, using a cryptographic challenge to authenticate the legitimacy of the card and the reader. This ensures a very high level of privacy for the cardholder, prevents inappropriate disclosure of sensitive data, and helps to prevent skimming of data that might be used to identity theft (Alliance, S.C., 2015)

2.7 Summary of the chapter

The literature reviewed gives insights into the study of the sharing of health information in public health facilities. A good number of frameworks have been reviewed giving guidance on the various strategies to be implemented to attain effective information sharing. Below the researcher presents a summary of the weaknesses and strengths of the literature.

First and foremost, most of the literature reviewed was obtained from studies done in developed countries like America creating a gap to understand the challenges and possible solutions in the context of a developing country. As for the frameworks, most of them put concentration on security and yet it is not the only barrier to information sharing. But even then, some of the security mechanisms like use of biometric technologies were not given consideration.

Secondly, the literature pointed out the importance of information sharing in economic developing countries through improvement of the health care system and identified the challenges affecting health information management in the world and those specific to

developing countries like Uganda. Through the literature review, the researcher was able to identify the key elements to achieve effective sharing of health information. These are health information librarians, interoperability of health information systems, and security of health information systems. The component of security was covered extensively as a major enabler of information sharing. These will compose the framework of health information sharing in public health facilities which is an output of this study.

Additionally, the researcher will adopt the strengths of the literature as an input to the study leading to the development of a framework for health information sharing in public health facilities in Uganda. The output of this study will be used to reduce or close the gap in the literature to benefit future researchers.

Finally, the following information was found relevant for proposing a framework which is translated into a conceptual framework namely;

1. Information capture – here patients are the major source of information.
 2. Medical verification – here medical workers ensure that the provided information is correct.
 3. Information storage – this is where the captured information is stored in the database.
 4. Legal verification framework – this is where the captured information is checked to ensure that it meets the required legal standards.
 5. Information sharing – it where the captured information is assembled for sharing.
 6. Health workers – these are the users of the captured and shared information.
- Security – these are authentic and authoritative mechanisms to access information.

Conceptual Framework for Health Information Sharing

This section presents the flow of ideas that led to the generation of the components of the proposed framework in a systematic manner. The researcher benchmarked key inputs to effective information sharing such as security and control of access to patient records on the framework for security management of health records (Lukanga Kayondo, 2009).

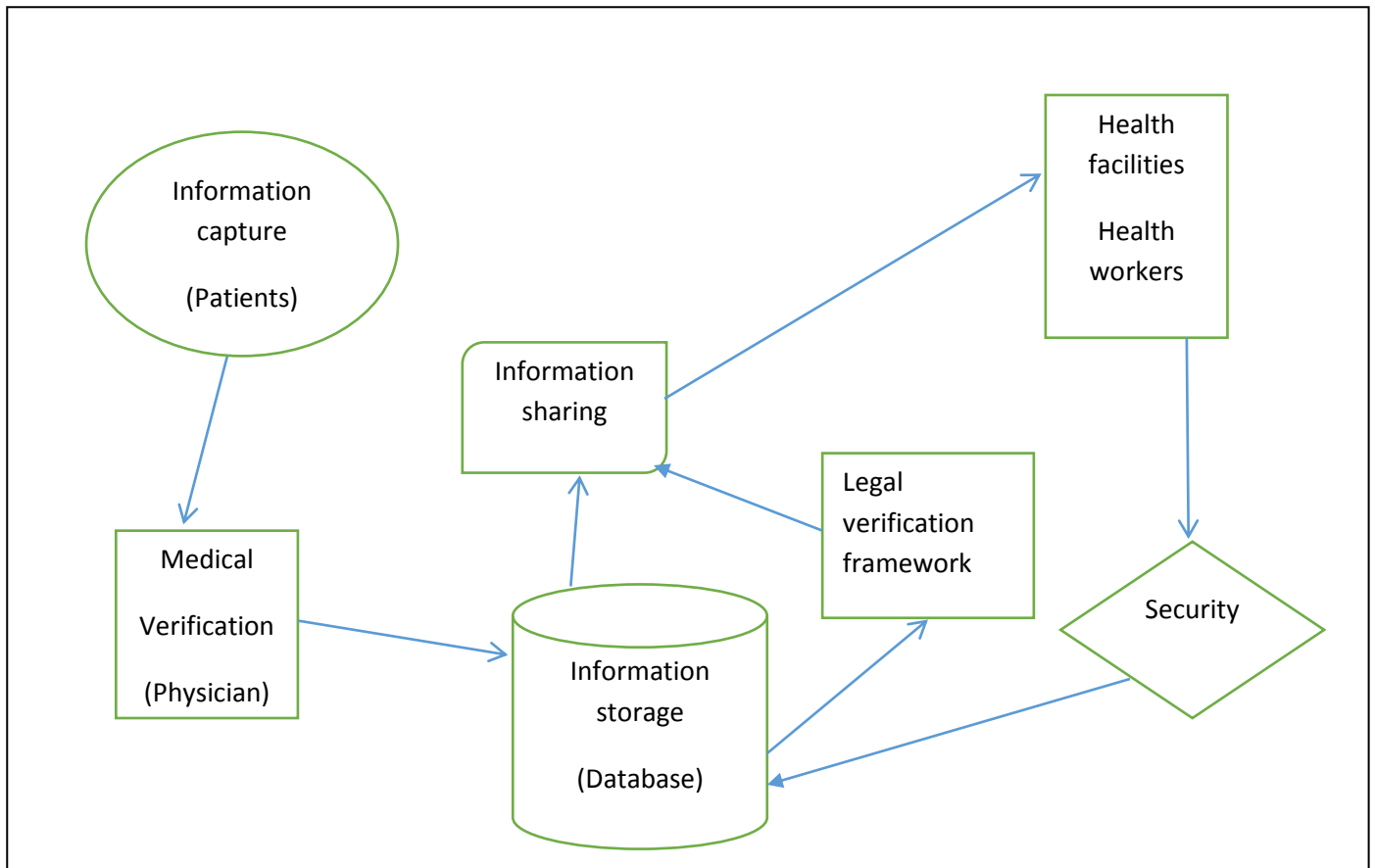


Figure 2. 2 Conceptual Framework

2.8 Research Methodology

2.8.1 Research Approaches

Trochim (2006) refers to two “broad methods of reasoning as the inductive and deductive approaches. Deductive research approach allows the research to establish a hypothesis by using theory. Variety of data and information is collected by the researcher to confirm or reject the hypothesis to resolve the issue (Gill and Johnson 2010). The deductive research approach is based on the general idea to reach at the specific situation and it is linked with the positivism paradigm and as such it has the advantage of objectivity and certainty though slow at obtaining a conclusion. On the other hand, Inductive research is a flexible approach because there is no requirement of pre-determined theory to collect data and information. The researcher uses

observed data and facts to reach at tentative hypothesis and define a theory as per the research problem. This helps the research to give inductive arguments (Mertens 2008). Inductive approach works over a specific idea to generalize the situation as per the research topic, which is linked with the inter-pretivism paradigm (Crowther and Lancaster 2009). As an advantage, Inductive approach works better in situations when information is incomplete. In addition inductive reasoning helps draw sometimes lifesaving conclusion very quickly. However, this approach cannot guarantee its conclusions, it assumes the uniformity of nature throughout the universe, and it relies on observation for information collection. This research adopted the deductive research approach in order to ably obtain the relevant requirements from both the literature and the field.

2.8.2 Research strategies

It consists of case study, survey, empirical and experimental method.

Case study method

Case studies, in their true essence, explore and investigate contemporary real-life phenomenon through detailed contextual analysis of a limited number of events or conditions, and their relationships. Yin (1984:23) defines the case study research method “as an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used a reason for its application in most studies of similar nature. This study therefore, employed this strategy because of its ability to undertake an investigation into a phenomenon in its context and can be based on any mix of quantitative and qualitative approaches.

Survey method

The survey approach refers to a group of methods which emphasize quantitative analysis, where data for a large number of organizations are collected through methods such as mail questionnaires, telephone interviews, or from published statistics, and these data are analyzed using statistical techniques (Gable, 1994). By studying a representative sample of organizations, the survey approach seeks to discover relationships that are common across organizations and hence to provide generalizable statements about the object of study. However, often the survey

approach provides only a snapshot of the situation at a certain point in time, yielding little information on the underlying meaning of the data. Moreover, some variables of interest to a researcher may not be measurable by this method (e.g. cross-sectional studies offer weak evidence of cause and effect). The researcher employed survey research method in order to obtain information from large samples of the population of study and gathering demographic data that describe the composition of the sample.

Empirical research methods

Empirical research methods are a class of research methods in which empirical observations or data are collected in order to answer particular research questions (Daniel Moody, 2002). While primarily used in academic research, they can also be useful in answering practical questions.

Experimental research approach

The experimental research approach is a quantitative approach designed to discover the effects of presumed causes. The key feature of this approach is that one thing is deliberately varied to see what happens to something else, or to discover the effects of presumed causes.

This study adopted case study and survey research strategies because of their relevancy on the nature of the research.

2.8.3 Research design

This section presents the research design adopted by this study as discussed below (Creswell, 2003)

Quantitative

A quantitative approach is one in which the investigator primarily uses post positivist claims for developing knowledge (i.e., cause and effect thinking, reduction to specific variables and hypotheses and questions, use of measurement and observation, and the test of theories), employs strategies of inquiry such as experiments and surveys, and collects data on predetermined instruments that yield statistical data. The researcher will use the quantitative design to obtain data from respondents including the nurses, doctors, patients and HILs using

questionnaires as a typical quantitative data collection tool because it enables sampling of a large population.

Qualitative

A qualitative approach is one in which the inquirer often makes knowledge claims based primarily on constructivist perspectives (i.e., the multiple meanings of individual experiences, meanings socially and historically constructed. with an intent of developing a theory or pattern) or advocacy/participatory perspectives (i.e., political, issue-oriented, collaborative. or change oriented) or both. It also uses strategies of inquiry such as narratives, phenomenology, Ethnographies, grounded theory studies, or case studies. The researcher employed this design during an interaction with patients using interview as a tool to obtain views of patients about their health records' capturing and sharing within and out of the health facility. Also during the validation of the proposed framework in which interviews and semi structured questionnaires were employed to obtain the judgments of the experts about the relevancy, applicability and validity of the proposed framework.

Mixed methods

Mixed methods approach is one in which the researcher tends to base knowledge claims on pragmatic grounds (e.g., consequence- oriented, problem-centered, and pluralistic). It employs strategies of inquiry that involve collecting data either simultaneously or sequentially to best understand research problems. The data collection also involves gathering both numeric information (e.g., on instruments) as well as text information (e.g., on interviews) so that the final database represents both quantitative and qualitative information. The researcher will employ this method to verify or gain a better understanding of the requirements from the field. Some data collected using questionnaires acted as a basis to obtain the opinions and suggestions of respondents about certain issues in information sharing. This method indeed helped to answer the why and how questions in this study.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This section provides a discussion on the various approaches that were used to achieve the stated objectives of the research study. The section includes a discussion of the various tools and techniques to be used namely the research design used in the project study, the study population used, sample population and procedure, data collection methods and instruments, data analysis and validation of the framework.

This section presents a series of activities that will be performed to achieve the objectives of this study. These activities are summarized in Figure 3.1 below.

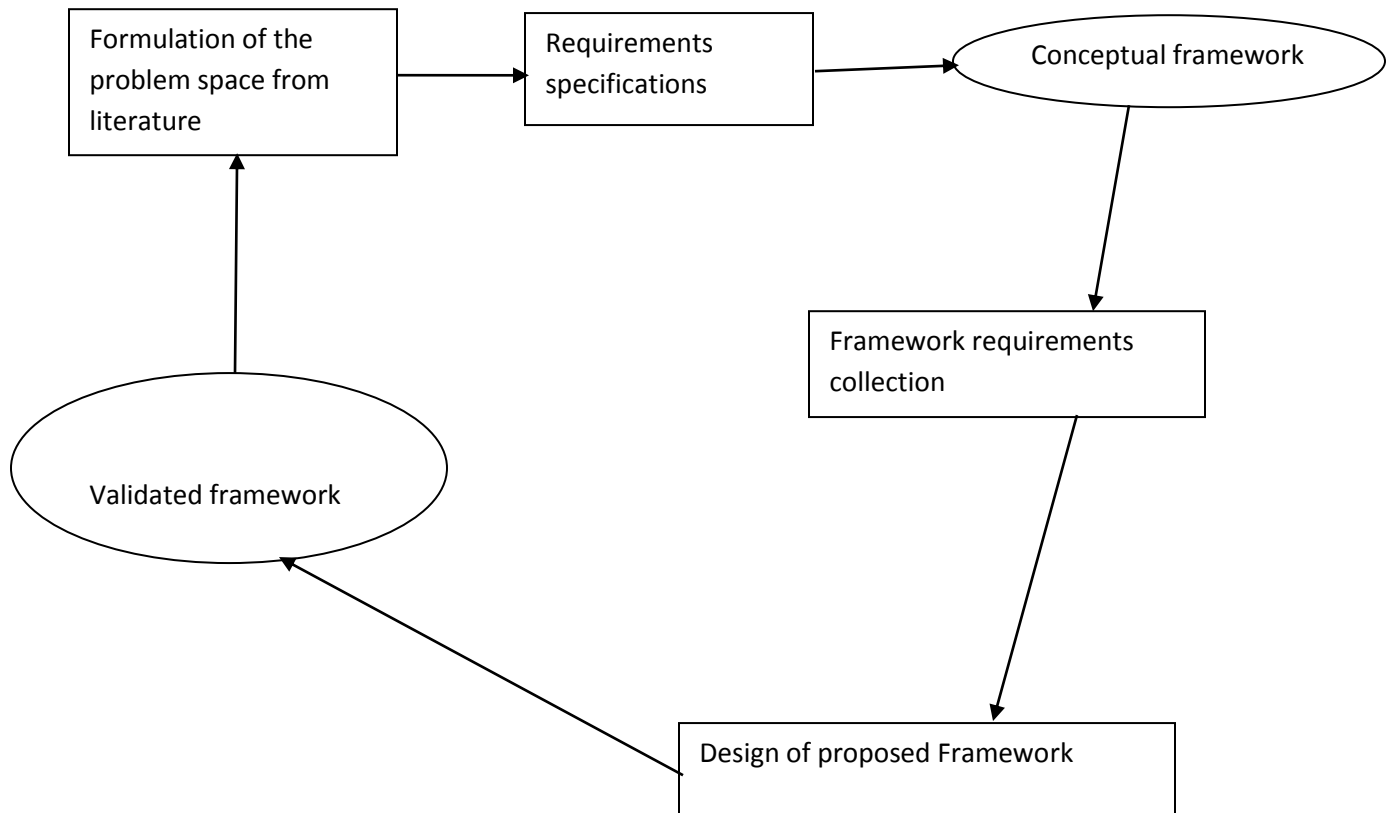


Figure 3. 1 Summary of the Methodology

3.1 Research Design

The research design refers to the overall strategy that the researcher chooses to integrate the different components of the study in a coherent and logical way, thereby ensuring effective addressing of the research problem; it constitutes the blueprint for the collection, measurement, and analysis of data.

This study was regarded as a descriptive research type. This rendered the study to be categorised under the mixed research approach and as such employed a case study and survey research approaches. The researcher used a case study to investigate (Bill, 2000) how HILs, doctors and nurses handle health information capture, processing and dissemination. This was studied or understood in context of public health facilities. Case studies were used to describe how patients provide health information and how they obtain it from the health facilities a task difficult to accomplish through surveying or experimentation strategies. Due to the need to obtain both numerical and text based information, the researcher employed mixed method approach by collecting data from respondents using both quantitative and qualitative approaches by interviewing 4 doctors, 5 nurses, 10 patients and 2 HILs whereas approximately twice the number of those interviewed were subjected to filling self-administered questionnaires. Results from these tools was descriptively analyzed using SPSS to form requirements of the proposed framework.

The researcher designed the framework using Microsoft office Word. The researcher considered a scenario of a typical patient and medical worker relationship in which a patient reports for treatment at the hospital. A patient is taken through the processes as prescribed according to the working of the hospital. This proposed framework was validated by a team of experts and the results presented in chapter four.

3.2 Study population

The target population to be used in this study entails respondents from Mulago national referral hospital and Jinja referral hospital. In the selected case studies three categories of respondents were considered, namely doctors, nurses, patients and HILs. A team of experts from ICT and the medical profession, will be drawn from different places to assist in validation of the proposed

framework, Mulago hospital will be selected because all serious cases are referred to it while Jinja referral hospital represents the many hospitals that refer serious cases to Mulago.

3.3 Sample Population and procedure

Sampling must be done by selecting representative of the given population in order to reduce the cost, after all the study of the sample attributes which is the specific part of the whole population can be used to get information about the whole population (Castillo, 2009). This study used Jinja and Mulago referral hospitals as a sample of the public health facilities in Uganda to participate in the study. The researcher employed a convenient and expert sampling technique (Forzano & Gravetter, 2011) to identify respondents that included patients, medical staff, information librarians, and ICT officers at these two referral hospitals. Results from this sample were used to generalize the target population described in table 3.1 below.

Table 3. 1 The Population Distribution of the respondents

	HEALTH FACILITY		
Category of respondents	MULAGO	JINJA	Totals
DOCTORS	5	6	11
NURSES	8	7	15
PATIENTS	12	10	22
HILs	3	2	5
Total	27	25	52

3.4 Data Collection Methods and Instruments

In this research study, data collection tools were used in identifying requirements for the study. The data collection tools that were used in the study include questionnaires, document reviews and interviews.

3.4.1 Questionnaires

The researcher employed a self- administered questionnaire as a research method to obtain requirements from the respondents. This questionnaire was categorized into background information of the respondents; interoperability of health information systems, security of the health information using biometrics and health information librarians. The questionnaire was comprised of pre-coded sections with lots of tick boxes for the respondents to fill in and structured section with lots of white space for people to make their responses in their own words. From this data, themes were collected and coded to obtain requirements. This data was grouped and analyzed descriptively using SPSS as presented in the following chapter.

3.4.2 Document Review

In this study, the researcher reviewed literature on international and national health information sharing standards, policies, theories and frameworks. This was done in the perspective of the developing country with a focus on the challenges and remedies to improve health information sharing as a driver to health care improvement in public health facilities.

The researcher reviewed literature on biometrics as a mechanism of security of health information, interoperability of health information systems, health information librarians. In fact the results of the literature review formed a basis for the development of questionnaires to ascertain the framework requirements from the users (patients and medical workers). The main objective was to determine what can and cannot work for public health facilities in developing countries regarding health information sharing.

3.4.3 Interview

The researcher conducted interviews with all the respondents that participated in the study as presented in table 3.1 above. The researcher developed an interview guide as presented in appendix IV below.

3.5 Data Analysis

After obtaining information from respondents using self-administered questionnaires and document review research methods, the researcher employed SPSS package to analyze the results. This analysis included running descriptive statistics and generation of graphical information on elements of the framework arising from themes obtained from the respondents backed by literature.

3.6 Validation of the framework

The researcher used health experts, civil society members and senior ICT officials from Mulago and Jinja referral hospitals to validate the proposed framework using a questionnaire. This tool gathered their expert's opinions about the framework as a validation mechanism. This was done with an objective to ascertain the relevancy and applicability of the framework in health information sharing in public health facilities in a developing country. Emphasis was put on interoperability of the health information systems as a strong pillar of information sharing among different information ecosystems.

CHAPTER FOUR

PRESENTATION, ANALYSIS AND DISCUSSION OF FINDINGS

4.0 Introduction

This chapter presents results obtained from the field. The conceptual framework arrived at after literature review of existing knowledge was tested in the field. The result were analyzed and presented in sections. Section 4.1; Presentation of results and discussion of findings, 4.2; Requirements for the Framework 4.3; Proposed framework, 4.4; Validation of the framework and 4.5; Chapter Conclusion.

4.1 Presentation of results and discussion of findings

Results in this section are presented into two parts i.e. demographic statistics of respondents and descriptive statistics. This study considered characteristics of resource limited environments to be the same as those presented by a study leading to the management of health information records of patients (Lukanga, 2009). As for the security mechanisms and requirements, results are presented below. These were obtained from the field using Lukanga's works as a benchmark as guided by the conceptual work.

4.1.1 Demographic results

Age of respondents

This study considers age as an important factor and the results is as shown below in the graph as figure 4.1.

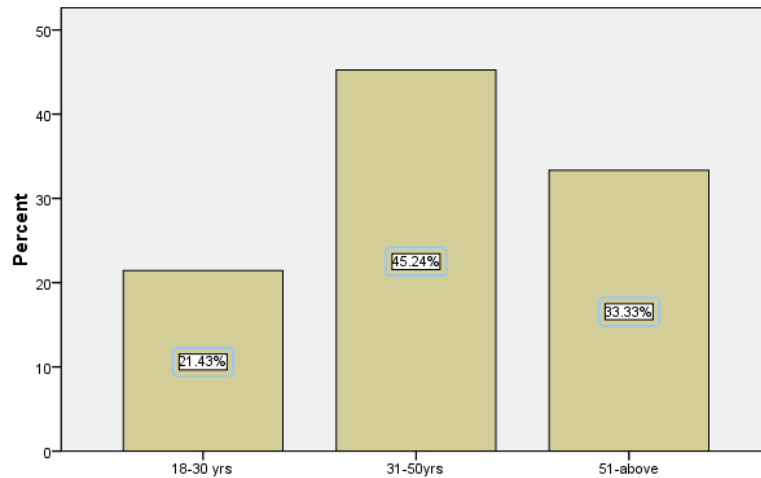


Figure 4. 1 Age of the respondents

The result in the figure shows that 21% were of age 18-30years; 45% are of age 31-50years and 33% are above 51years.

This shows that many young professionals are being prepared to take up management of health that implies good planning.

Gender of respondents

This study considers gender of respondents as an important factor and the results is as shown below in the graph as figure 4.2.

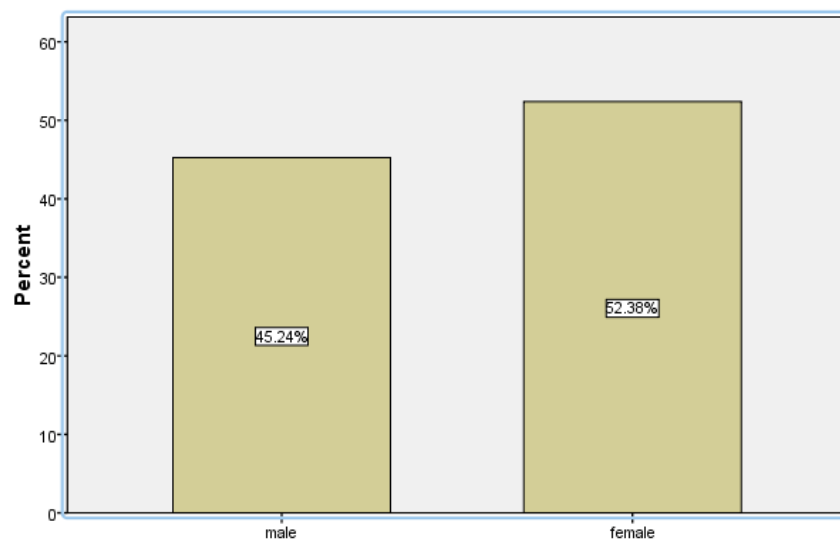


Figure 4. 2 Gender of respondents

The result in the figure shows that 45% were male and 52% were female.

This shows that the number of male and female workers is almost the same hence the results will be objective enough thus no bias because they will easily be distributed.

Level of education

This study considers level of education as an important factor and the results is as shown below in the graph as figure 4.3.

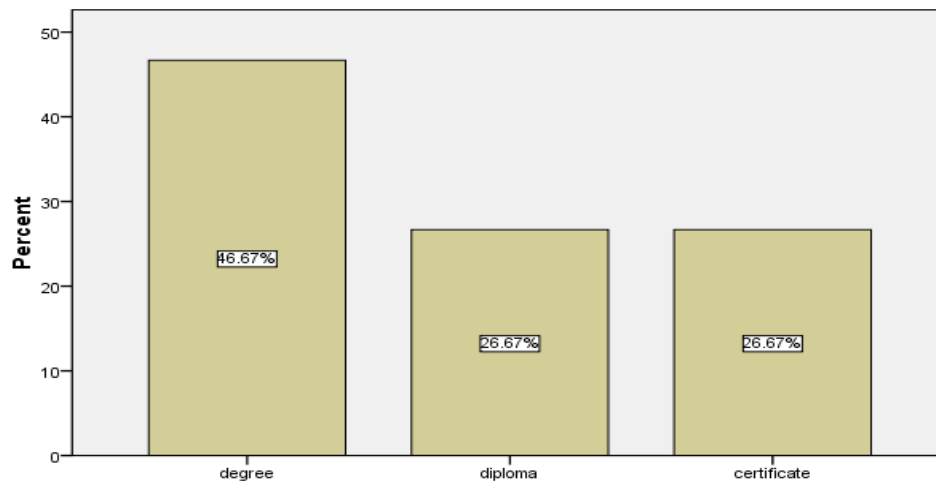


Figure 4. 3 Level of education

The result in the figure shows that 47% are degree holders; 27% are diploma holders and 27% are certificate holders.

This shows that most of the workers are degree holders hence they can easily adapt to the new framework due to their high level of education.

4.1.2 Descriptive statistics

Information Capture

The capturing process is done manually and all the information is filled in the form provided to the patient by the health worker. During inquiries, a patient is given a form to fill in after which he/she is sent to the physician for action. All the information captured from patient by the doctor and the receptionist/front desk officers is later entered in the computer by the data clerks also known as health information librarians.

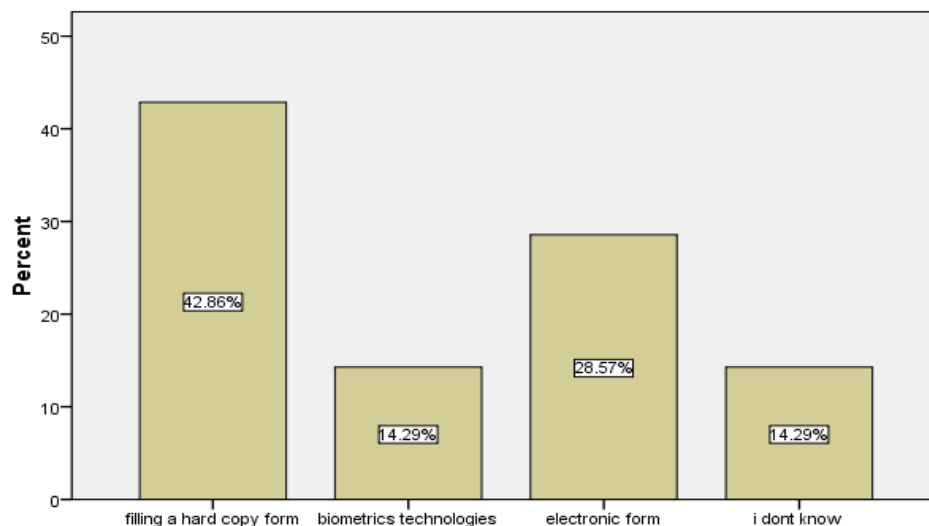


Figure 4. 4 Information capture

The result in the figure shows that 43% was filling hardcopies; 14% was biometrics technologies; 29% was electronic form and 14% didn't know how their information was captured.

This shows that most of the health records are manually captured using papers and stored in filling cabinets making records erased or blurred due to poor storage.

Verification of the captured information

Information is manually captured on a form and this involves steps like data cleaning and summarization to eliminate incomplete and inconsistent data about the patients.

The verification of health information is crucial and since this information is needed to achieve information sharing, quality information needs to be entered in the system hence data cleaning.

Results from the field show that this verification exercise is manual. Hence requiring better improved technologies to aid the process in order to safeguard the integrity principle of the data captured from the patients.

Storage of Health Information

This is both the manual and automatic database, although most patients would prefer manual storage due to challenges associated with electronic method as discussed in literature review. All the filled in forms are placed in the folder files and the folder files are kept in the filing cabinet. At a later date some of this information is transformed into the computer, this work is done by the HILs as part of back up.

Storage is fundamental for a health facility which deals with large volumes of information on a daily basis. According to this study, once the information has been captured from the patients, it is verified and later stored in the database. The database is a major component of the Health Information System at the public health facility.

Need for electronic data capture

Results reveal that the use of electronic means is highly recommended by both staff and the patients who responded to this question as evidenced in Fig 4.5 below. The obvious reasons were associated with speed and accuracy as key attributes of electronic devices like the computers.

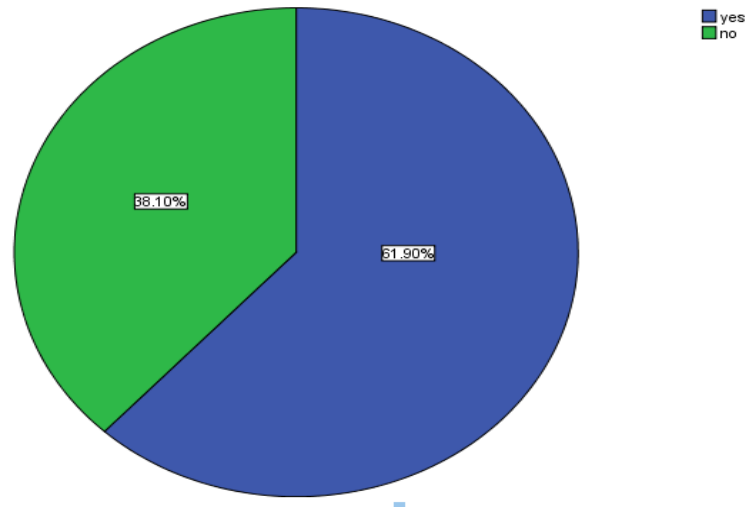


Figure 4. 5 Supporting the use of electronic means to capture and/or store health information

The result in figure shows that 62% of the respondents support electronic capture while 38% do not support it.

This shows that the use of electronic means to obtain health information from patients is a requirement to improve health information sharing thus it should be included in the proposed framework.

Legal Verification

Currently, legal verification of patient's data is based on personal conduct of the patient or medical worker hence there is no recommended legal framework in place.

From the literature above, legal verification framework was deemed fundamental in handling of health information especially when that information is delicate and so personal such as HIV/AIDS related results of the patients.

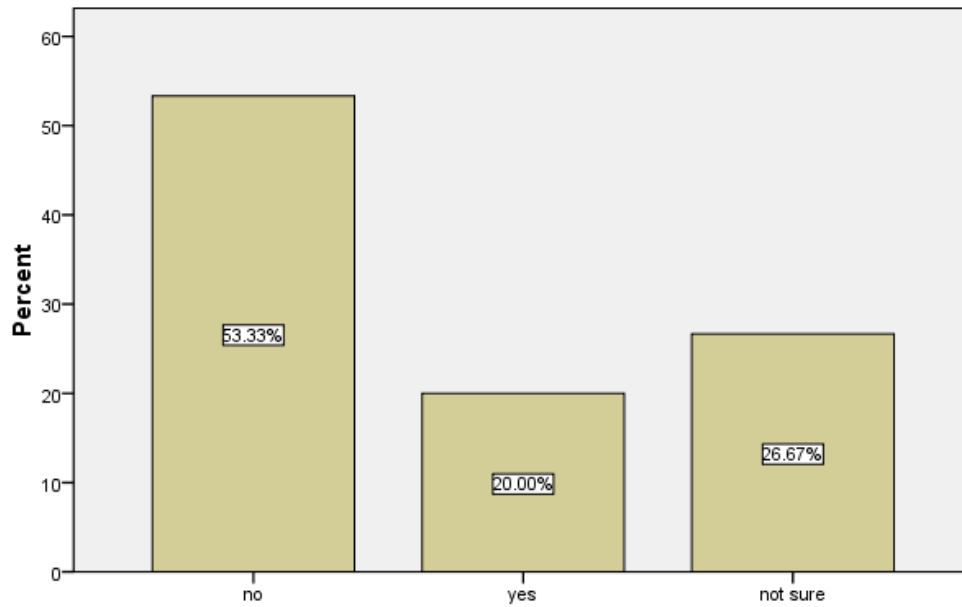


Figure 4. 6 Legal Framework verification procedure

The result in the figure shows that 53% say there is no framework; 20% say there is a framework and 27% are not sure whether there is a framework.

This shows that there is a great need of a legal verification framework in the developed framework.

Security of Health Information Sharing

Respondents were skeptical with the process of sharing health information. Most of the respondents pointed out security concerns as the leading source of their skeptical behavior. However other concerns like privacy, cost and perception were also significant.

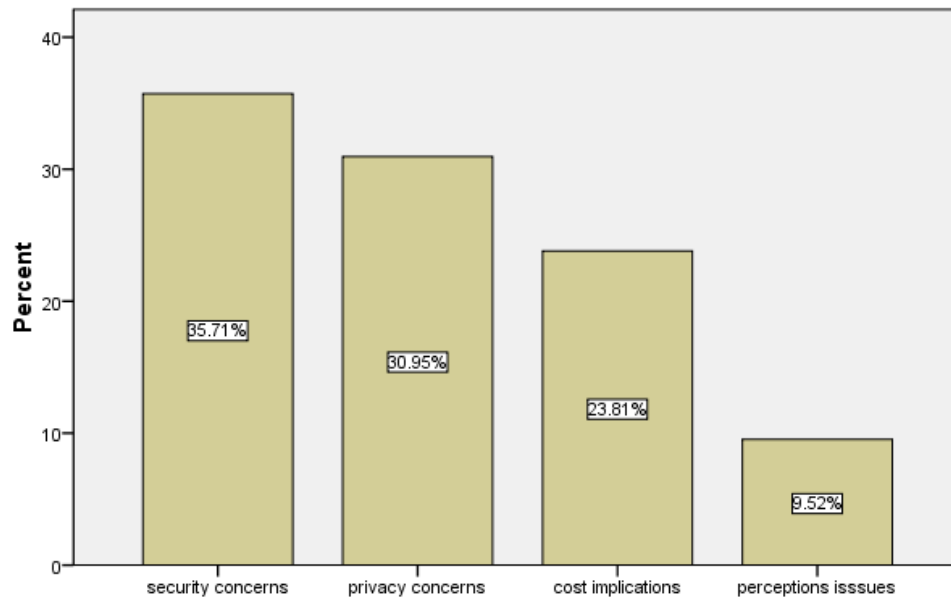


Figure 4. 7 Supporting Adoption of Health Information

The result in the figure shows security concerns with 38%; privacy concerns with 31%; cost implications with 24% and perception issues with 10%.

This shows that security concerns are the great threat to information sharing.

Required measures

Because of the relevancy of security and privacy components of information sharing, this research adopts them as key components and suggests improvements for the proposed framework in form of mechanisms to be undertaken to guarantee the security and privacy of the health information of the patients during and after information capture. These mechanisms are the use of biometrics, firewall, PKI and passwords.

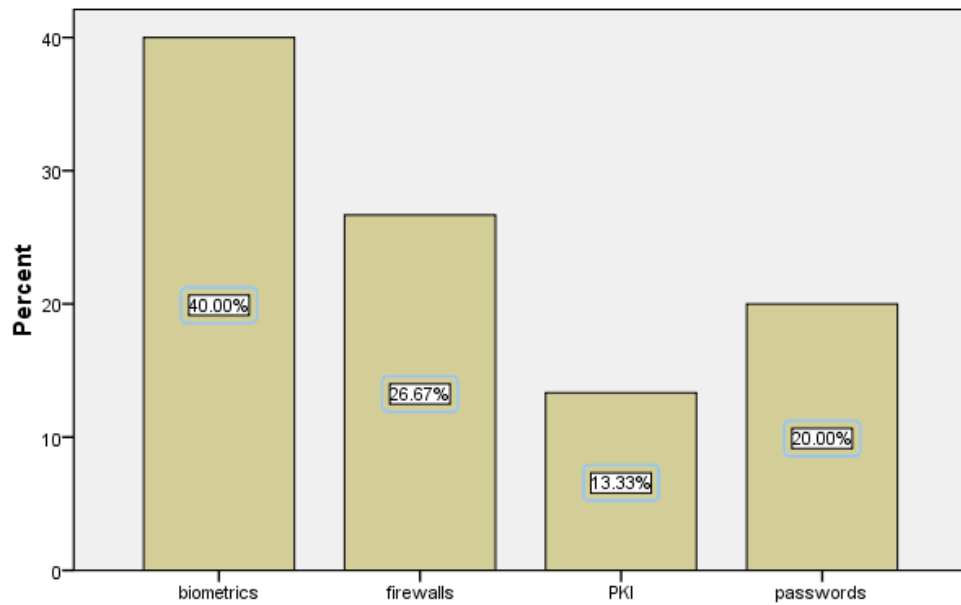


Figure 4. 8 Required Authentications and security mechanism

The result in the figure shows biometrics with 40%; firewalls with 27%; PKI with 13% and passwords with 20%.

This shows that biometrics is the most required authentication and security mechanism during information sharing.

Interoperability

Referral cases have been found to suffer most from limited or poor health information sharing processes. Patients are found from time and again carrying with them all the hard copy files that contain forms and prescription information from one health facility to the next.

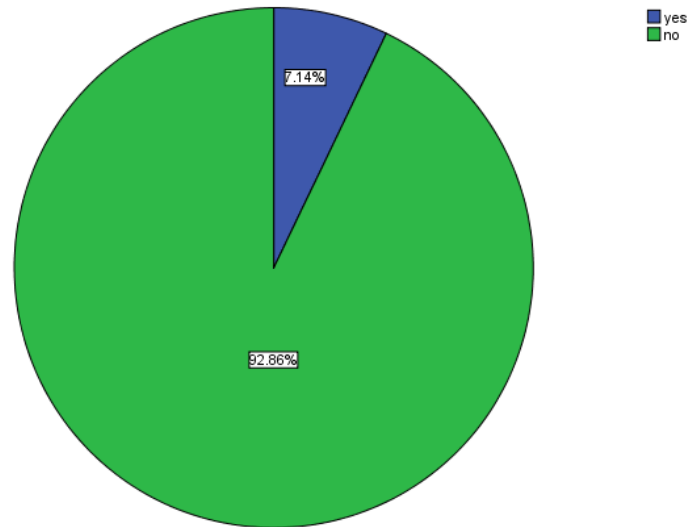


Figure 4. 9 Interoperability of Health Information Systems

The result in the figure shows no remote access to health information with 93% and yes to remote access with 7%.

This shows that access to health information is too poor hence need for an interoperability framework for health information sharing.

Challenges of mode of information sharing

Ranking most was privacy and security at a point of sending and receiving/sharing health information. There are other challenges ranging from business operation models, organizational and technical standards, institutional structures to facilitate data exchange and diffusion issues.

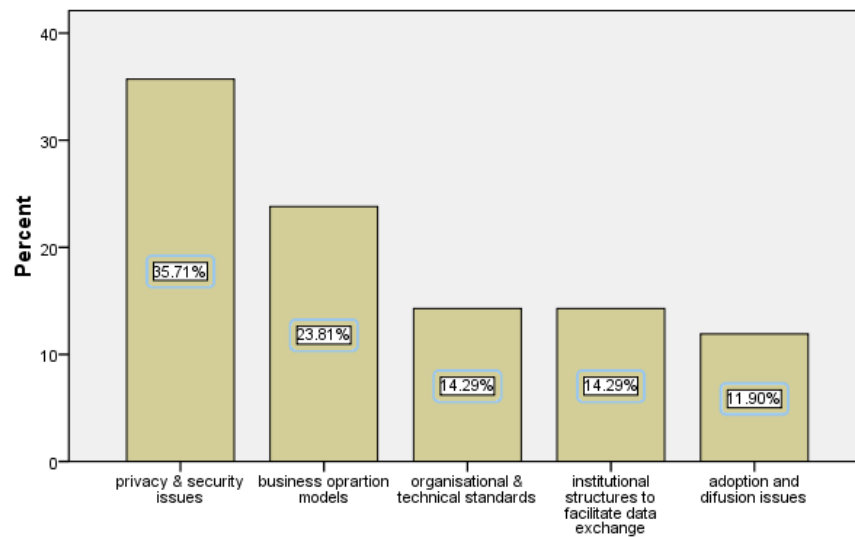


Figure 4. 10 Challenges of Health Information sharing

The result in the figure shows privacy and security issues with 36%; business operation models with 24%; organizational and technical standards with 14%; institutional structures to facilitate data exchange with 14% and diffusion issues with 11%.

This shows that privacy and security concerns is the greatest challenge to information sharing.

How referral information is shared

Information is manually transferred on hard copies from one health facility to the other exposing it to risks of distortion. The responses from both patients and health workers regarding how the referrals are conducted are presented in the figure 4.11 below.

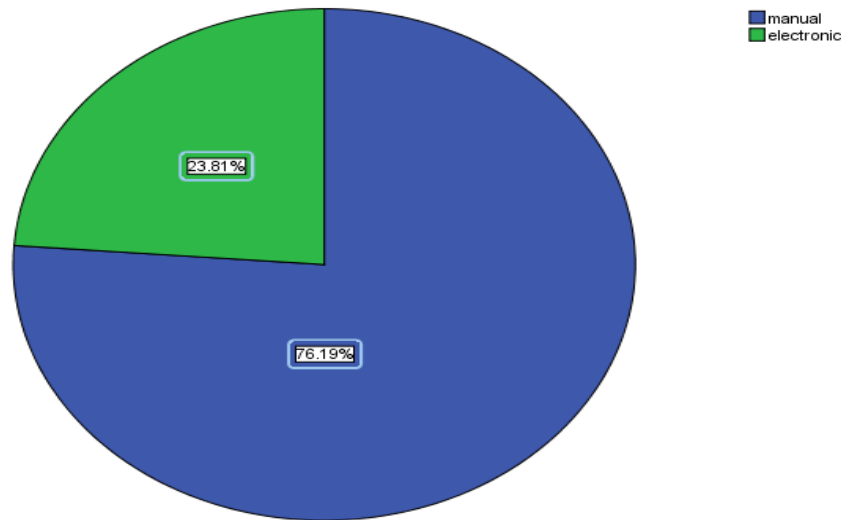


Figure 4. 11 Sharing of health information during referral cases

The result in the figure shows manual information transfer with 76% and electronic information transfer with 24%.

This shows that most of the information is manually transferred on hard copies hence need for electronic means in information sharing.

Suggestions to improve health information sharing

Respondents pointed out suggestions on how to improve the situation of health information sharing in public health facilities in Uganda.

Key to note was the issue of the right policy formulation, adoption of pervasive computing and public standards for data exchange. However there are others like the use of private and public networks, implementing privacy and security mechanisms and highly available data repositories.

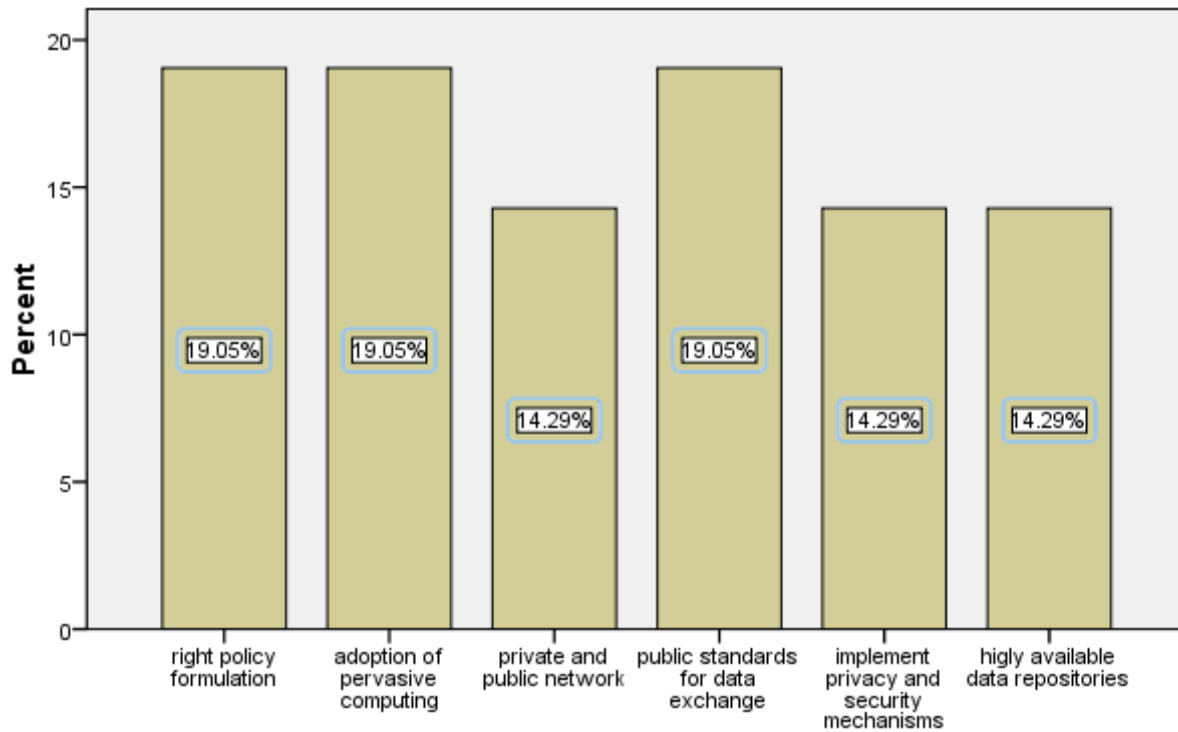


Figure 4. 12 Measures to improve health information challenges

The result in the figure shows right policy formulation with 19%; adoption of pervasive computing with 19%; private and public network with 14%; public standards for data exchange with 19%; implement privacy and security mechanisms with 14% and highly available data repositories with 14%.

This shows that all measures with 19% were suggested to improve health information sharing in public health facilities.

Summary of requirements from the field study

From the information gathered from the field, the following was found necessary to aid information sharing.

Table 4. 1 Showing the requirements as obtained from the field

No	Item	Requirement	Intervention
1	Patients	Authorize information capture	Password
		Explicit authorization for use or disclose	Biometrics
		Expiry of the authorization	Password policy
		Emergency access procedure	Policy
		Demand accountability	Policy
2	Medical worker(s)	Captures information from patients	Software/computer and biometric gadgets
		Verifying information	Biometrics
		Forward health information to HILs	Electronic and print
		query for health information from repository	Pervasive computing
3	Health Information Librarians (HILs)	Electronic population of the database	Computer/Phone training
		Remote retrieval of health records	Computer/Phone
		Access control of health records from unauthorized users	Biometrics
		Updating the database electronically	Tele service/ pervasive computing
4	Health information	Interoperability with sister systems	Remote data repositories/

	systems		Internet
		Reliable repositories	Firewalls
		Authentication and authorization procedures	PKI
5	Security and privacy challenges	Confidentiality of the telecommunication network	Composite security Mechanisms
		Reliability of the telecommunication network	Firewalls
		Health information integrity	PKI
6	Background challenges (Demographic)	Issues related to <ul style="list-style-type: none"> • Level Of Education • Age • Gender 	Standards Policies Frameworks Training and mentorship

4.2 Requirements for the framework

Requirements from literature

Computerization of information system

Ensuring that all the information systems are interoperable

Recruitment of Health information librarians

Improving information privacy and security

Adoption of policies, standards and legal framework

Requirements from the field

Computerization of patients' health records

Improving the interoperability of all the systems in the health information sharing ecosystems

Requirement and training of health information librarians

Use of firewalls and biometrics to address security and privacy concern surrounding health information sharing.

Use of legal framework and relevant standard and policies of sharing information in public health facilities.

4.3 Proposed framework

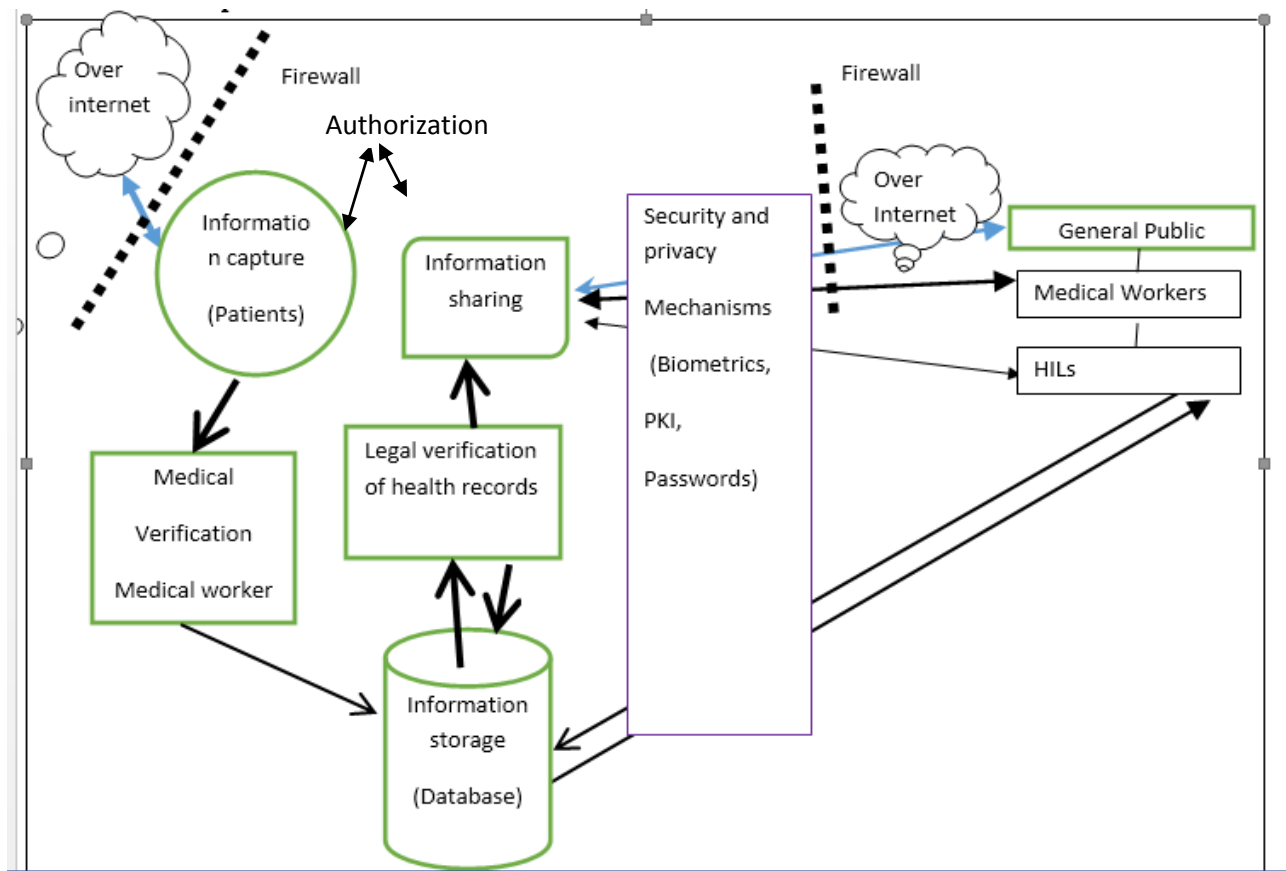


Figure 4. 13 Proposed framework

Explanation of the framework

The framework above is presented diagrammatically. It is composed of a number of components each with its own function.

It suggests that every patient who comes to the health facility must provide all the necessary information to the medical worker during consultation, diagnosis and prescription processes. This can be done when the patient is either physical or virtual online. All the information captured from the patient is subjected to medical verification before it is fed into the database either manually or electronically which is a central repository for all online and offline health information of patients in the public health facility. As a requirement, because of the sensitivity of some of the information from patients with cases like HIV/AIDS, all the health information must be verified against the legal framework before it is made available for sharing. The framework categorizes stakeholders who can share information into three HILs, medical workers and general public.

All these groups are free to share information as long as it is in a sharable mode. However, the framework puts much emphasis on multiple authentication mechanisms such as biometrics, PKI and the use of passwords as a measure to guarantee security of the health information. As for the privacy, the framework provides for authorization of access of the health information by the patient. That way patient's records are safeguarded from unauthorized users.

The framework, recommends the use of firewall to filter all traffic that enters and leaves the health information systems. Lastly the framework suggests that in order to effectively exchange information with the outside world especially during referrals, the health information ecosystems should satisfy the principle of interoperability of information systems.

4.4 Validation of the Framework

The major 15 key stakeholders were walked through the framework. The researcher consulted seven medical workers who contributed 62%, six ICT Experts who contributed 35% and two senior members of the civil society who represented the general public contributing 3% to the exercise.

Following the results of the validation process, the proposed framework was deemed necessary, important and relevant to the needs of the population in the developing country like Uganda.

From the validation process, 93% strongly agreed that a framework for effective information sharing is important, 67% strongly agreed that this framework would contribute to healthcare service delivery, 60% strongly agreed that the security concerns are fully addressed by the framework, 67% of the ICT experts strongly agreed that interoperability as suggested by the framework is a crucial element in health information sharing especially in referrals, 47% strongly agreed that use of biometrics, internet firewalls, passwords and PKI is relevant for the kind of health information sharing, 93% strongly agreed that legal framework suggested in the framework is important, 69% of medical workers and ICT experts strongly agreed that electronic capture and storage of health information is important in information sharing, 80% strongly agreed that this framework addresses issues surrounding information sharing in developing countries, 87% strongly agreed that they are willing to implement this framework.

4.5 Conclusion

This chapter focused on mainly identifying the requirements from two perspectives i.e. literature and the field.

The following were requirements as identified from reading existing literature;- The health information systems, interoperability of information systems, health information librarians, issues in information sharing, health information sharing standards, legal and policy framework of information sharing plus privacy and security concerns of information sharing. All these are considered in terms of their role in information sharing.

After carrying out the research, all these were confirmed to be requirements for the proposed framework from the perspective of the respondents. Except that emphasis was put on the firewalls and use of biometrics as a means to further entrench privacy and security of the health information. In addition, training of health information librarians to learn local languages as an avenue to facilitate effective communication

The framework components were validated by a team of experts from medical, ICT fields and members of the civil society and the results were in favor of the proposed framework.

CHAPTER 5

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.0 Introduction

This chapter presents the summary, conclusion, recommendations, limitations and future research based on the information presented in the entire research.

5.1 Summary

This section presents a summary of the results obtained from the research according to the objectives of the study.

From objective one that stated; to analyze the existing health information sharing infrastructure and identifying the requirements for the proposed framework, the researcher reviewed a number of frameworks, policies, standards with a focus on the challenges, opportunities and gaps of information sharing in public health facilities from the existing literature using document review technique of data collection. Some of the documents reviewed include research papers, reports and books. This helped to identify the requirements for effective health information sharing from the perspective of the literature. All the essential requirements to effectively share information were analyzed and compared to those obtained from the field. The merger of the two sources gave rise to the requirements of the proposed framework as presented in chapter 4 above. Document review and literature can help obtain secondary data (Abdirizak, 2013) from diverse sources. The need for: a computerised information system; interoperability of information systems; health information librarians; standards, policies and legal framework; privacy and security mechanisms.

To propose a framework that enables patients and medical practitioners to effectively share health information in public health facilities in Uganda. Following literature review a conceptual framework was constructed from which a questionnaire was developed as an instrument to collect requirements from the field of study. These results were descriptively analyzed using

SPSS technique. A collection of requirements from literature were confirmed by this analysis and others like firewall emerged from the field.

To validate the proposed framework to assess its effectiveness. After proposing the framework, a team of 15 experts were walked through this framework in order to assess its effectiveness. This team was composed of 7 medical workers, 6 ICT experts and 2 senior members of the civil society and overall 80% of the respondents strongly agreed that the proposed framework addresses issues surrounding health information sharing and 87% are willing to implement the proposed framework.

5.2 Conclusion

After implementing the methodology as outlined in chapter 3 above, the researcher came up with a new framework which was validated against user's needs. This framework was accepted by the users enabling the researcher to achieve the major objective of the study which was to propose a framework for health information sharing in public health facilities in Uganda.

5.3 Recommendations

Following the proposed framework presented in 4.13 above using the stated methodology the researcher presents the following recommendations;-

Deployment of the framework should follow the top down approach i.e. senior and top management should be targeted as key drivers of the diffusion process. All efforts should be focused towards building buy-in by top management of health facilities, civil society organizations and key health and ICT policy developers, implementers and beneficiaries.

Government should provide an enabling environment to create standards, policies and laws that facilitate the adoption of the framework through sensitization, training human resources and providing financial support.

5.4 Limitations and Future research

Due to limited time and financial resources, the researcher used questionnaires to collect qualitative data that was coded as quantitative using the linkert scale.

The researcher limited the scope of the study to only two public health facilities and therefore, I would recommend for future research involving a more elaborate scope including a mixture of public and private health facilities to be done to increase the validity of the results.

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Appendix I (Research Introductory Letter)



making a difference

OFFICE OF THE DEAN, FACULTY OF SCIENCE
deanscience@umu.ac.ug

3rd October 2016

Ref: Assistance for Research

The Director,
Mulago National Referral Hospital,
Kampala

Dear Sir/Madam,

Greetings from Uganda Martyrs University.

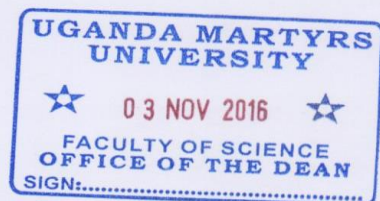
This is to introduce to you **MUGULUMA Erasto** registration Number: 2013-M142-20023. He is a student of Master of Science in Information Communication Technology, Management and Architectural Design. He is carrying out a research on the topic; A FRAMEWORK FOR HEALTH INFORMATION SHARING IN PUBLIC HEALTH FACILITIES IN UGANDA, as part of the curriculum requirements for the award of Master of Science Degree of this University, for the submission of a dissertation paper.

I kindly, request you to render the student such assistance as may be necessary for the research.

Thanking you in anticipation.

Yours sincerely,

Dr Richard Awichi (PhD)
Dean



Appendix II (Research Introductory Letter)



making a difference

OFFICE OF THE DEAN, FACULTY OF SCIENCE
deanscience@umu.ac.ug

3rd October 2016

Ref: Assistance for Research

The Director,
Jinja Regional Referral Hospital,
Kampala

Dear Sir/Madam,

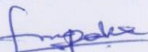
Greetings from Uganda Martyrs University.

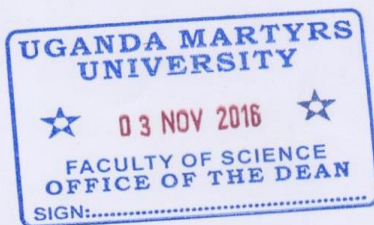
This is to introduce to you **MUGULUMA Erasto** registration Number: 2013-M142-20023. He is a student of Master of Science in Information Communication Technology, Management and Architectural Design. He is carrying out a research on the topic; A FRAMEWORK FOR HEALTH INFORMATION SHARING IN PUBLIC HEALTH FACILITIES IN UGANDA, as part of the curriculum requirements for the award of Master of Science Degree of this University, for the submission of a dissertation paper.

I kindly, request you to render the student such assistance as may be necessary for the research.

Thanking you in anticipation.

Yours sincerely,


Dr Richard Awichi (PhD)
Dean



Appendix III (Questionnaire)

Faculty of Science, Uganda Martyrs University-Nkozi

**Questionnaire to be filled in by patients, medical practitioners, information librarians and
ICT officers at Mulago or Jinja referral hospital**

Dear Respondent,

This questionnaire is designed for an academic research project towards developing a framework for health information sharing in public health facilities in Uganda. This project is carried out at Mulago and Jinja national referral hospitals as a case study as a partial fulfillment for the award of a Master's degree in ICT Management, Policy and Architectural Design of Uganda Martyrs University-Nkozi. The objective of collecting this data using this tool is to analyze the existing situation regarding information sharing and obtaining requirements for the framework.

Therefore, as a respondent, your input is of great value to the success of this study and shall be used only for the purpose of this project and shall remain confidential during and after the research process.

Thank you for your co-operation.

Section A- (Background Information)

A.1 In this hospital, I am a *(Please Tick appropriate)*

- ☐ Patient
- ☐ Medical worker
- ☐ Information librarian
- ☐ ICT officer

A.2 What is your age group?

- ☐ 18-30 years
- ☐ 31-40 Years
- ☐ 41-60 years
- ☐ 61- Above Years

A.3 What is your level of Education?

- ☐ Primary
- ☐ Secondary
- ☐ Tertiary Institution

A.4 What is your Gender?

- ☐ Male
- ☐ Female

A.5 Does your organization have a health information system?

☐ Yes

☐ No

SECTION B – Patient Information *(Fill this section only if you are a patient)*

B.3 Is this information collected through a form or a computer?

☐ Form

☐ Computer

☐ Mobile Phone

B.4 Have you ever been referred to another hospital for further treatment or check up or diagnosis?

☐ Yes

☐ No

B.5 During a referral, how do you transfer your health information from one health facility to the next?

☐ Manually

☐ Electronically

☐ Not sure

B.6 Which mechanism would you prefer to transfer your health information between health facilities and other service providers?

☐ Electronic copies

☐ Hard copies

☐ Not sure

B.7 Would you state why you choose the method

.....

.....

B.8 How do you receive information from other health facilities?

.....

.....

B.9 If an ICT framework is proposed to you to support your healthcare services, would you adopt it?

☐ Yes

☐ No

B.10 If No, can you explain why

.....
.....

SECTION C. Security and privacy

C.1 Do you have consent on what kind of information to share with another health facility during a referral case?

☐ Yes

☐ No

C.2 Do you have control over when and what information can be shared among health service providers?

☐ Yes

☐ No

C.3 Have you ever received or sent your health information to the health facility electronically using the hospital health information system?

☐ Yes

☐ No

C.4 Did you provide your identification before that transaction took place?

☐ Yes

☐ No

C.5 Which mechanism did you use?

Passwords ☐

Biometrics ☐

Access control lists ☐

C.6 What would you prefer?

.....
.....

C.7 Why would you prefer that mechanism?

.....

.....

C.8 Do you trust the confidentiality of the information you leave in the hospital?

☐ Yes

☐ No

C.8 If No, why do you doubt?

.....

.....

SECTION D. Interoperability

D.1 Would you like your health information to be shared electronically across all service providers that may need it?

☐ Yes

☐ No

D.2 How easy is it for you to share your medical records with other health service providers?

☐ Very easy

☐ Easy

☐ Hard

☐ Very hard

D.3 Is it easy to access patients' health information anywhere any time?

☐ Yes

☐ No

SECTION E. For Librarians

D.4 As a health information librarian, are you involved in sharing of health information of patients with other health facilities or departments within this hospital?

☐ Yes

☐ No

D.5 How do you transfer health information of patients among service providers?

.....

.....

D.6 What recommendations would you make to improve the process of information exchange?

.....

.....

THANK YOU FOR YOUR RESPONSE

Appendix IV (Interview Guide)

Faculty of Science, Uganda Martyrs University

Guide to be used to Interview medical practitioners, patients and information librarians and ICT officers at Mulago or Jinja Referral hospitals to determine their requirements

Dear Respondent,

This interview guide is designed for an academic research project towards developing a framework for health information sharing in public health facilities in Uganda. This project is carried out at Jinja and Mulago national referral hospitals as a case study as a partial fulfillment for the award of a Master's degree in ICT Management, Policy and Architectural Design of Uganda Martyrs University-Nkozi. The objective of collecting this data using this tool is to analyze the existing situation regarding information sharing and obtaining requirements for the framework.

Therefore, as a respondent, your input is of great value to the success of this study and shall be used only for the purpose of this project and shall remain confidential during and after the research process.

Thank you for your co-operation.

Section A- (Background Information)

1.1 Age

☐ 18-30 ☐ 31-40

☐ 41-50 ☐ 51-above

1.2 Gender

☐ Male ☐ female

1.3 Education

☐ None ☐ Primary level

☐ Secondary

☐ Tertiary/University

2. Patient information

2.1 How often do you visit the public health facility?

2.2 Does the public health facility collect health information from you?

2.3 Does the health facility collect the same information from you the next time you go back?

2.4 Do you access your records from other health facilities?

2.5 Would you like other health facilities to access your health records without your authorization?

3. Medical Practitioner

3.1 How do you capture information from patients?

3.2 In cases of referrals how do you send/receive patient information?

3.3 Would you like to send/receive information directly to the referral health facility?

4. Librarians

4.1 Do you share health information with the public/research organizations?

4.2 Do you seek permission from the patients?

4.3 Do you operate within the legal framework while sharing this information?

4.4 How do you share this information?

What kind of security mechanisms are implemented in the health facility information systems?

- 1) Firewalls
- 2) Biometrics
- 3) Token ring
- 4) Passwords

4.5 What would you suggest?

Thank you

Appendix V (Validation Questionnaire)

Questionnaire to be filled in by senior medical workers, civil society members and ICT experts

Dear Respondent,

This questionnaire is designed for an academic research project towards developing a framework for health information sharing in public health facilities in Uganda. This project is carried out as a partial fulfillment for the award of a Master's degree in ICT Management, Policy and Architectural Design of Uganda Martyrs University-Nkozi. The objective of collecting this data using this instrument is to validate the results obtained in this study that culminating into a tool to champion effective health information sharing.

In that regard, as a respondent, your input is of great value to the success of this project and shall be used only for the purpose of this project and shall remain confidential during and after the research process.

Thank you for co-operation.

No.	Item	RATING (Linkert Scale)				
		1 Strongly agree	2 agree	3 disagree	4 Strongly disagree	5 Not sure
1	A framework for effective health information sharing is important.	93%	7%			
2	This framework would contribute to healthcare service delivery	67%	33%			
3	The security and privacy concerns are fully addressed by the framework	60%	34%	6%		

4	Interoperability as suggested by the framework is a crucial element in health information sharing especially in referrals	67%	33%			
5	Use of biometrics, internet firewalls, passwords and PKI is relevant for the kind of health information sharing.	47%	27%	20%	6%	
6	Legal framework suggested in the framework is important	93%	7%			
7	Electronic capture and storage of health information is important in information sharing	69%	31%			
8	This framework addresses issues surrounding information sharing in developing countries	80%	13%	7%		
9	Am willing to implement this framework and I can recommend it to my colleagues to do the same.	87%	13%			