UNIVERSITY OF NAIROBI

COLLEGE OF BIOLOGICAL AND PHYSICAL SCIENCES

SCHOOL OF COMPUTING AND INFORMATICS.

Digital Archiving and Preservation of Cancer Records:
Case of KNH/UoN Department of Pathology.

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A project report submitted in partial fulfilment of the requirement for the award of Masters of Science degree in Distributed Computing Technology of the University of Nairobi.

SEPTEMBER 2020.

DECLARATION

This project is my original work and has not been submitted for any other award in any university.

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ABSTRACT

Cancer is considered to be 3rd leading killer and 2nd among non-communicable diseases in Kenya Mutinda J. (2019). Ferlay, *et al* (2013) noted there are about 37,000 new cases of cancer annually and annual mortality rate of 28,000. This indicates cancer records rapidly accumulate over time and more resources are needed to collect and manage cancer-related data. KNH/UoN Department of Pathology have for a long time kept their records using a paper-based system.

Objective of the study was to review current record keeping system including the process of preserving, storing and retrieving cancer records and the challenges faced, develop a model to guide the archival of locally available cancer-records and a web based prototype to preserve and avails this information to a wide range of stakeholders.

The study used descriptive research design involving 22 participants. Random sampling technique was used to select respondents among the sampled population. The intervention prototype was developed using the RAD methodology. It was noted that cancer patient data were captured through standard forms/books (86% of the respondents) and stored in standard forms/books (71% of the respondents). 57% stated that identification of record and documenting was done based on LAB number. ICD 10 Coding system was not fully implemented as many forms had old coding format. 77% of the participants stated that the inability to track patient records with ease as a challenge and lack of technology in records management as a potential security bleach and damage of records.

Findings presented a strong case for this research study where, upon prototype developed, there was concurrence among the respondents that the developed solution would be of significant to enhance cancer records management in the department and improving the healthcare service delivery process. This model can also be used to preserve other similar medical paper documents.

Keywords: Digital Preservation, Digital Archive, Digital Record, Electronic Medical Record (EMR).

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ABBREVIATIONS

CD-ROM	Compact Disk Read Only Memory
ECG	Electrocardiograms
GIS	Geographic Information Systems
HCRC	Hospital Cancer Registration Centre
HIS	Health Information System
HIPAA	Health Insurance Portability and Accountability Act
IARC	National Agency for Research on Cancer.
ICT	Information & Communication Technology
ID	Identification Document.
KEMRI	Kenya Medical Research Institute
KNH	Kenyatta National Hospital
LMICs	Low- and Middle-Income Countries.
NACOSTI	National Commission of Science Technology and Innovation
NCC	National Cancer Centre
RAM	Random Access Memory
SOA	Software Oriented Architecture
UCR	Unit Cancer Registration
UoN	University of Nairobi
WHO	World Health Organisation
WTO	World Trade Organization

CHAPTER 1: INTRODUCTION

1.1 Background.

Worldwide, cancer beats HIV, malaria and tuberculosis combined, as the main cause of deaths. Mutinda J. (2019) estimated that around 70% of the world's cancer problem is in Low and Middle Income Countries (LMICs). As of 2019 in Kenya, it was noted that cancer was the 3rd leading killer and 2nd among non-communicable diseases. This translates to roughly 7% of Kenya's overall mortality rate. Ferlay, *et al* (2013) reported that there are about 37,000 new cases of cancer annually and the annual mortality rate being 28,000. The numbers continue rising, with cancer patients and care-givers calling on the Kenyan government to declare cancer a national disaster. This means that cancer records rapidly accumulate over time, requiring more and more resources to collect and manage cancer-related data.

The mode of record keeping in a health institution could help advance or bring it down in equal measure (Muhaise, *et al.*, 2019). Roughly 85% of the total world population lacks quality and better cancer registrations (Bray, *et al.*, 2015). Kenyatta National Hospital (KNH) and the University of Nairobi (UoN) Department of Pathology have for a long time kept their records using a paper-based system. Any kind of paper records tends to be unreliable and tedious to maintain since they could be damaged or lost. A lot of time is lost digging into records which are probably missing and/or misfiled (Johnston, *et al.*, 2005), which is unconducive to the functioning of the health institution (Benfell, *et al.*, 2002). The gravity of the cancer problem in Kenya lacks adequate quality data to inform decision making. Thus, cancer patients experience ineffective care, while the health sector in general suffers a lack of the objective tools which would guide their efforts to properly and wisely manage their resources in the fight against cancer (Forsea, 2016).

Healthcare institutions need complete, integrated and readily available data to plan, monitor, and evaluate cancer cases (Hoyler, *et al.*, 1997). This improves the quality of information while ensuring timely retrieval of the information contained in the records (Bedrosian, 2006). In order to effectively manage cancer, an evidence based methodology is needed which can only be derived from the foundation of accurate and complete data provided by digital cancer records (Forsea, 2016). These digital registries become a crucial source of key data concerning the number of new cases reported, cancer-related mortalities, types of cancer, geographical spread of incidences, the number of people living with cancer, and the number

of cancer survivors in the populations they cover. Health institutions are then able to make informed assessments of the current cancer situation and estimate future trends and inclinations in relation to cancer within diverse population and regions, hence implementing effective cancer control plans (Coebergh, *et al.*, 2015).

This study therefore purposed to digitize KNH/UoN Department of Pathology cancer records as a way to secure the records and minimize the risk of loss or damage. This approach can also be replicated for other paper based health records such as x-ray reports, lab reports etc. The primary motivation for this initiative was to avail the cancer records on a digital platform thus opening up the possibilities of software-based data analysis and digital access to the records from various locations by healthcare researchers, practitioners and medical students.
The records were used in conjunction with other medical data sources to monitor and assess the attainment and effectiveness of new treatment procedures, compare patterns and trends of medical care with strategies and survival effects of different diagnostic and treatment practices to determine the best practice.

1.2 Problem Statement

In developing countries like Kenya, paper-based health record-keeping has been hardly successful in the care of chronic disease patients (Winkelman, *et al.*, 2004). Very few healthcare institutions have adopted the digital record keeping structure. The paper-based structure is not nearly optimal for recording multiple cancer cases, incidences, mortalities and survival rates, not to forget individual cancer patient demographics, and highly requires more and more physical space which may not be readily available. Paper records are also highly prone to physical damage, duplication, loss and may miss crucial patient information.

As a result, health institutions and practitioners lack comprehensive and accurate data on cancer patients and are thus unable to provide high quality medical care to these patients (Majeed, *et al.*, 2008). It is imperative for them to understand the advantages of advancing from paper records for them to gain positive outcomes while treating cancer cases.
One of the approaches that have been used to gather and collect cancer data has been the setting up of the population based Nairobi Cancer Registry that is located at KEMRI, as well as the KNH hospital-based cancer registry. The Nairobi Cancer registry was established in 2001.

However, KNH/UoN Department of Pathology have remained as the custodian of a rich historical paper-based cancer data records for the period 1969 to date. Up until early 1990's, the KNH/UoN Department of Pathology was the default lab for cancer diagnosis, supporting the majority of lab test for the country. There is data from 1969 to date that is available but with poor accessibility.

1.3 Research Objectives

1.3.1 Main Objective

To review the current record keeping system, develop a model that will guide in digital archival of locally available cancer paper-records and a web based prototype that preserves and avails this information to a wide range of stakeholder. For this study, we focused on the KNH/UoN Department of Pathology records.

1.3.2 Specific Objectives

1. To evaluate the current cancer records management practices of the KNH/UoN Department of Pathology.
2. To find out the challenges towards the digital archival of cancer records and assess the digital archival readiness of the KNH/UoN Department of Pathology.
3. To review related Models and Frameworks that aid in digital archival and preservation of health records.
4. To design, develop and implement a prototype for digital archival platform for cancer records. This platform will provide basic statistics and search functionality.

1.4 Research Questions

1. How are cancer records managed at the KNH/UoN Department of Pathology?
2. What are the Challenges for digital archival of the health records at the KNH/UoN Department of Pathology?
3. How can an ICT enabled platform for cancer record-keeping be implemented?

1.5 Justification

This study was justified in the health sector because it encouraged a more efficient facility to access and retrieve patient records thus helping reduce manual intervention during records management. The proposed solution aimed toward mitigating risks like records getting damaged, lost, mixed up and/or duplicated. The problem of storage space constraints would be resolved since everything was being stored digitally. Apparent benefits included improved efficiency, healthcare service delivery and productivity.

1.6 Scope

Geographically, the research was limited to the Kenyan context. The research was carried out at the KNH/UoN (Department of Human Pathology). The research mainly involved health science professionals, record clerks, researchers, doctors, and medical student's admin. These respondents were crucial to this study's main objective by helping us implement the proposed solution and apply it to improve practices. For the study's use case, we focused on cancer records. The project aimed to provide an application prototype that facilitated digitized cancer record keeping in health institutions.

1.7 Significance

The manner in which cancer data is kept and used can literally be a matter of life and death and that is why the transition to electronic records is so sensitive (Freudenheim, 2012). This study highly advocated for the adoption of a digitized mode of cancer records in the Kenyan healthcare system. For doctors, digitized cancer records could go beyond the contentment of delivering the best possible care. The appropriate setup provided researchers, doctors and records officers with an easier way to store and retrieve data. In addition to this, the potentiality of a user (e.g. doctors) to check in on the progress of a patient (e.g. has the patient undergone microscopy?) enabled the users to manage escalations and follow-up on patients more efficiently; for better patient-centric care, and also have immediate access to treatment documentation.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter explores literature on existing and previous digital health records system implementations, while also striving to establish the benefits and challenges of digital record solutions and how cancer record keeping practices can be improved.

2.2 Records Management in Health Institutions

According to Haux (2006), medical record is a confidential patient record and it is kept by a healthcare professional or organisation. The record contains patient's personal data, demographic data (name, address, date of birth), and medical history for the patient and a documentation of every event like symptoms, treatment and outcome. Pertinent documents and correspondences are also attached as well.

Medical records management is critical in any health institution. Good medical records management practices are key to ensuring quality health service delivery (Were, 2013). United States Department of Labour (2013) stated that the aim of medical record management is to guarantee quality, accuracy, accessibility, authenticity and security of information in both paper and electronic systems. Notable records managed in most health institutions include patient case notes, x-rays, pathological specimens and preparations, patient indexes and registries, pharmacy and drug records, nursing and ward records (Were, 2013).

Were (2013) noted that medical records mainly begin at the hospital's admissions office and then taken over by the attending physicians. Both the source of these records and their creation process are imperative since they determine value of those records and usability. Data entries are usually made at all care points by the healthcare provider for the patient during the time of observation, treatment or care. According to Department of the Army USA (2008) this documentation requirement is true to both paper and digital or electronic record.

In Kenya, the government stated that it is paramount for the medical records be created and preserved for use. Hospitals in Kenya are gradually conforming to electronic record keeping practices (Kola, *et al.*, 2003). However, it is still apparent that manual record keeping

practices still prevail even in those hospitals where digitization is in full effect (Were, 2013). Integrating ICT into health record management comes as a solution to the numerous shortcomings that accompany manual medical records management e.g. misfiling of patients' medical records, requirement for huge storage space, legibility of doctors' hand writing and transmission of medical records among the departments.

2.3 Kenya Health Policy 2014 - 2030

This policy provides a road map that will guarantee substantial improvement in the entire status of health in Kenya in relation to the Constitution of Kenya 2010, the long term development agenda for the country, vision 2030 and global commitments. The policy explains the health goals, objectives, principles, orientations and strategies aimed at achieving the best standard of healthcare in the country. Key objectives of the policy is to eradicate communicable conditions, Halt and reverse the increasing burden of non-communicable conditions, decrease the burden of injuries and violence, provide key and essential healthcare services, minimize exposure to health risk factors, strengthen collaboration with private and other health sectors.

The policy also focuses on stopping and reversing the rising burden of non-communicable diseases, Cancer being one of them. It was noted that non-communicated diseases represented an increasingly significant burden of ill health and deaths in Kenya. According to the policy they presented 50% to 70 % of all hospital admissions and up to half of most inpatient mortality (Kenya Health Policy 2014 - 2030).

Future projection indicated that annual mortality by disease domain would be as follows: 39% decline for communicable diseases and 47% increase for non-communicable and injuries conditions. This represented 48% reduction in absolute deaths due to communicable circumstances, but a 55% increase in deaths from non-communicable diseases.

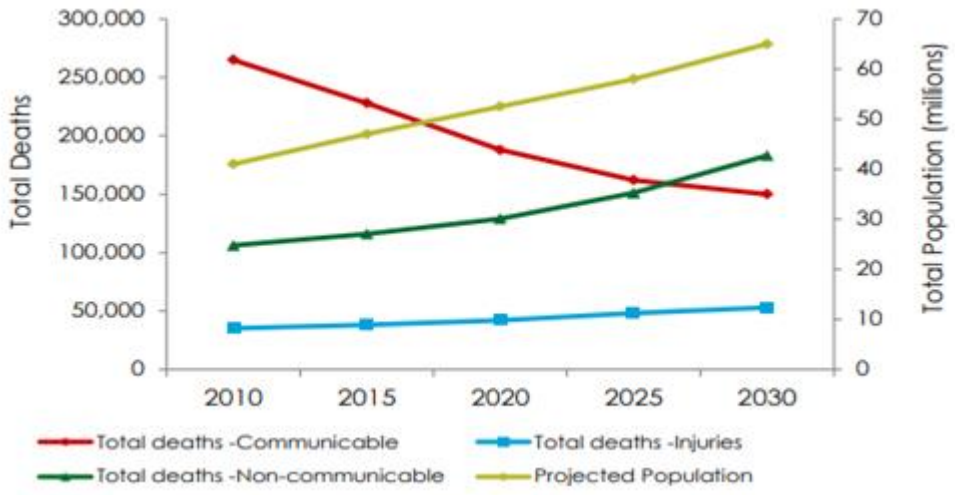


Figure 1: Kenya Health Policy 2014 – 2010 by disease domain (Source: Kenya Health Policy 2014 – 2030)

Specifically future projection also indicate mortality rate due to cancer cases will increases compared to other Communicable and non-communicable diseases as shown in the figure 2. The reason is because the efforts in place to deal with diseases such as malaria, TB and HIV are expected to bear fruits in the short and medium term.

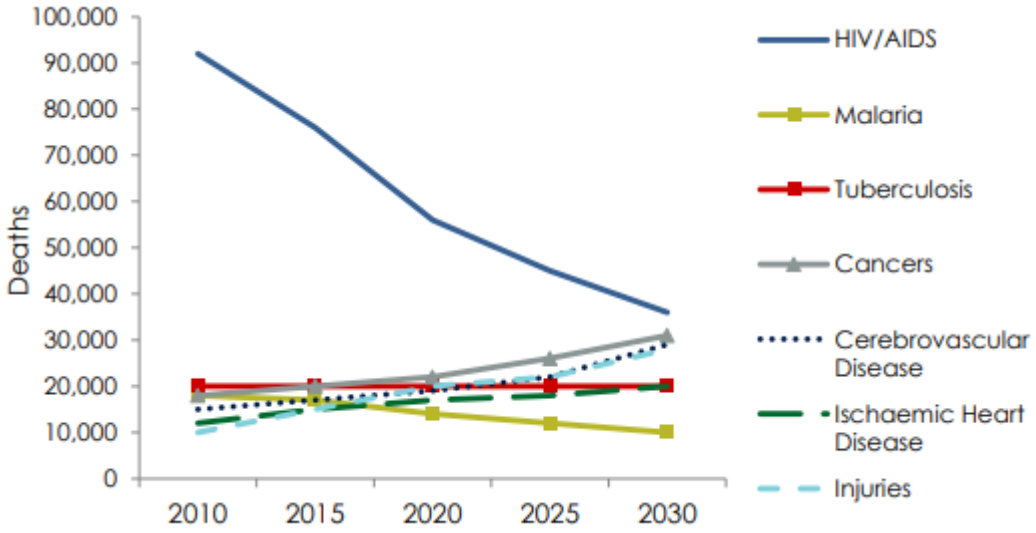


Figure 2: Health Projections: 2011 – 2030 by disease conditions (Source: Kenya Health Policy situation trends and distribution, 1994 – 2010, and projections to 2030.)

To achieve objective of this policy, one of the strategies indicated is to design and implement integrated health provision tools, mechanisms and processes with a view to enhance comprehensive control of non-communicable diseases and that is also in line with the aim of the researcher in this study.

2.4 Challenges in Paper Based Medical Records Management.

In relation to manual records, it is noted that the extreme issue is lack of space for the increasing number of patient records. Dollar (2002) stated that physical space for storage of paper records as a challenge many health institutions will keep combating with. Hospitals generating hundreds to thousands of records daily means that after a given duration of time the records automatically accumulate huge volumes of paper records. This will later bring about difficulty in locating some records and lack of enough space to store all these records. This becomes a key challenge for paper based records.

The paper based records are prone to physical damage meaning that over time, paper quality deteriorates. For instance, in cases of disasters (e.g. cyclones, floods, earth quakes, fires, storms, etc.) there are high chances of paper documents being damaged (Freudenheim, 2012). Manual paper-based record systems have no arrangements of backing up documents, meaning that if a document is lost it is gone for good.

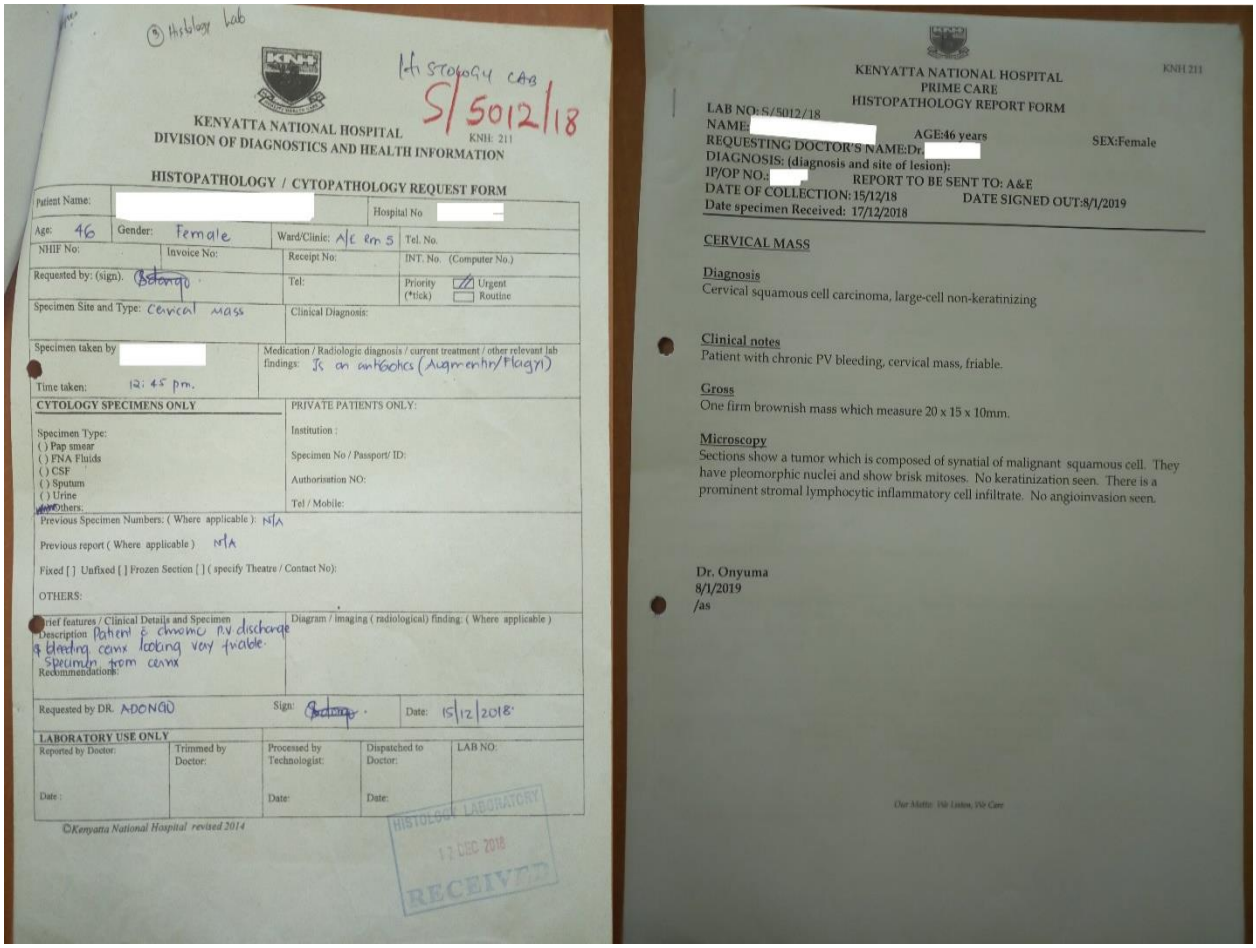
Medical records are very sensitive. Keeping them in paper form makes them vulnerable to breach of confidentiality by unauthorized persons. These malicious individuals may tamper with it or even steal it, culminating in grave effects on the patient(s), medical practitioners or the health institution as a whole (Winkelman, *et al.*, 2004). Paper documents suffer problematic document transportation (Muhaise, *et al.*, 2019) since even if it is possible to courier, or hand-deliver these documents in-person, it's always slow and inefficient.

Collaboration on paper documents is harder (Were, 2013). If different doctors need to access or use one record, they have to make multiple copies and different comments and notes on each paper will need to be consolidated. This makes working in parallel a headache.

2.5 Medical Records at KNH

KNH receives a very large number of patients. These patients stretch the hospital's capacity beyond the maximum. For instance, a patient that comes to the emergency unit may take between 7 and 9 hours to be admitted. It is therefore hardly surprising when patients die while in line receive medical attention (Cheruiyot, 2013).

According to Cheruiyot, patient records especially in the KNH Private Wing are maintained in manual files and stored in registries for as long as a patient remains admitted there. The records are later transferred to a section of the main registry after the patient has been cleared and discharged. The records can then be retrieved in case of the need for re-opening of treatment, analysis or data entry (e.g. for purposes of epidemiological reporting) and dissemination.



KENYATTA NATIONAL HOSPITAL
DIVISION OF DIAGNOSTICS AND HEALTH INFORMATION
KNH: 211

HISTOPATHOLOGY / CYTOPATHOLOGY REQUEST FORM

Histology Lab
Histology CAB
S/5012/18

Patient Name:
Hospital No
Age: 46 Gender: Female Ward/Clinic: A/E Rm 5 Tel. No.
NHIF No: Invoice No: Receipt No: INT. No. (Computer No.)
Requested by: (sign). Adongo Tel: Priority (*tick) Urgent Routine
Specimen Site and Type: Cervical mass Clinical Diagnosis:
Specimen taken by
Time taken: 12:45 pm.
Medication / Radiologic diagnosis / current treatment / other relevant lab findings: Is on antibiotics (Augmentin/Flagyl)

CYTOLOGY SPECIMENS ONLY
Specimen Type:
( ) Pap smear
( ) FNA Fluids
( ) CSF
( ) Sputum
( ) Urine
( ) Others:

PRIVATE PATIENTS ONLY:
Institution :
Specimen No / Passport/ ID:
Authorisation NO:
Tel / Mobile:

Previous Specimen Numbers: (Where applicable): N/A
Previous report (Where applicable) : N/A
Fixed [ ] Unfixed [ ] Frozen Section [ ] (specify Theatre / Contact No):
OTHERS:

Brief features / Clinical Details and Specimen Description: Patient c chronic P.V discharge & bleeding cervix looking very friable. Specimen from cervix
Recommendations:
Diagram / imaging (radiological) finding: (Where applicable)

Requested by DR. ADONGO Sign: Adongo Date: 15/12/2018

LABORATORY USE ONLY

Reported by Doctor:	Trimmed by Doctor:	Processed by Technologist:	Dispatched to Doctor:	LAB NO:
Date :		Date:	Date:	

©Kenyatta National Hospital revised 2014

HISTOLOGY LABORATORY
17 DEC 2018
RECEIVED

KENYATTA NATIONAL HOSPITAL
PRIME CARE
HISTOPATHOLOGY REPORT FORM
KNH 211

LAB NO: S/5012/18
NAME: AGE:46 years SEX:Female
REQUESTING DOCTOR'S NAME:Dr.
DIAGNOSIS: (diagnosis and site of lesion):
IP/OP NO.: REPORT TO BE SENT TO: A&E
DATE OF COLLECTION: 15/12/18 DATE SIGNED OUT:8/1/2019
Date specimen Received: 17/12/2018

CERVICAL MASS

Diagnosis
Cervical squamous cell carcinoma, large-cell non-keratinizing

Clinical notes
Patient with chronic PV bleeding, cervical mass, friable.

Gross
One firm brownish mass which measure 20 x 15 x 10mm.

Microscopy
Sections show a tumor which is composed of synatial of malignant squamous cell. They have pleomorphic nuclei and show brisk mitoses. No keratinization seen. There is a prominent stromal lymphocytic inflammatory cell infiltrate. No angioinvasion seen.

Dr. Onyuma
8/1/2019
/as

Our Motto: We Listen, We Care

Figure 3: Histopathology Report Forms (Source: KNH/UoN Dept. of Pathology)

Figure 3 shows a side-by-side capture of a couple of histopathology report forms from KNH. According to Muema (2014), in the recent past, medical records at KNH have been recorded on either paper, electronically or a combination of both and are typically held in various locations. In the case of cancer records, the KNH Department of Pathology has maintained a huge paper-based file system (See *Figure 4*).

Figure 4: A Snapshot of Record Folders at KNH (Source: KNH/UoN Dept. of Pathology)

Cheruiyot (2013) observed that the patient files are stored in lockable cabinets accessible only to serving medical staff. However, they noticed that a few current documents were mishandled e.g. left unattended on tables at the KNH service centres. This exposed the risks that come with manual record keeping, including people with malicious intent (e.g. untrustworthy staff) accessing and stealing patient documents, and dispersing this information to unauthorized third parties. Such incidents come about due to lapse in supervision and could have grave impacts on a patient's data with regard to security and confidentiality.

2.6 KNH's ICT Master Plan (2012)

A review of secondary literature revealed that KNH put together and launched an ICT Master Plan in August 2012. This Master Plan was prepared in compliance with vision 2030 aim for the health sector to provide equitable and affordable health services country wide. Projects within the ICT Master Plan include digitizing all of KNH's manual records (approximately 40 Million paper documents) from the past 10 years onwards. It had partnered with private sector and ICT Board to undertake this massive project. A few areas were highlighted as priorities for automation including the patient registration and billing system.

The Rockefeller Foundation through the ICT Board offered funding for the digitization of manual records. The project was implemented by Techno Brain, a local business process outsourcing firm. Techno Brain worked together with a Coseke, a Tanzanian IT company, which offered a web-based information management system (Cheruiyot, 2013).

2.7 Benefits and Challenges of Digitizing Paper Records

2.7.1 The Benefits

The foremost reason for digitizing paper records was so that institutions are able to cut back on how much physical storage space these records take up (Forsea, 2016). Digitization provides central data location, saves accessibility time for the various doctors involved in medical care, who also needs to consult this information so that they can prescribe suitable treatments and monitor the progress of the disease more effectively (Dollar, 2002).

The benefits of digital archival of cancer records are not limited to doctors alone. Records involving cancer patients (such as medical exam reports, blood test etc.) can become somewhat extensive overtime. As a bonus of digitization, patients also can have easy access to any kind of information they require and are not obliged to carry the records with them to every appointment. Once paper records are stored electronically, they can be quickly accessed and retrieved by different healthcare providers from different locations at different times (Bates, *et al.*, 2003). Providers can view a patient's medical history in full, track their treatment plans, and provide a more efficient course of care.

Bates, *et al.* (2003) commented that in the case of a life-threatening event, the accessibility of digital medical records could be lifesaving, meaning that the inherent ability of physicians and care-givers to view a patient's medical history (including allergies, blood type, past medical conditions) allows for treatment decisions to be made quickly.

Digital records also enhanced communication and engagement between doctors, and also between doctors and patients (Richards, *et al.*, 2012). Also, this mode of record keeping facilitated easier and more accurate ways to track care and treatment plans between doctors. Digitizing paper records also improved clinical outcomes which include improved quality of care, fewer medical errors, and numerous improvements in patient-centric service delivery that define the best possible care (Menachemi, *et al.*, 2011).

Last but not least, digital records eased the need for physical records storage, while also reducing records management costs. This ensured scalability and reliability of the records such that institutions were able to deploy new capabilities with minimal capital outlay (Forsea, 2016).

2.7.2 The Challenges

Data security could be compromised, which could possibly make the idea of digitizing paper records a much more complex issue than simply scanning pages and filing them away in some digital format (Menachemi, *et al.*, 2011). As it is, electronic information is directly prone to unauthorized access by computer hackers who could steal sensitive and private medical data. While a physical document may seem outdated, it is easier to secure it because its access is physical.

Secondly, Hospital Information Systems are highly split both across and within healthcare institutions, meaning that interoperability is highly undermined (Vest, *et al.*, 2010). This limitation of health institutions not yet realizing interoperability is characterized by isolated operations with no health data integration whatsoever (Chogi, 2002) e.g. patient records being stored on one form of database which is not be accessible to another form of database (such as that of patient referrals).

Importance is attached to adequateness of properly trained staff throughout a health institution's digitization efforts. As Vollmar, *et al.* (2010) emphasizes, people are key to successful digitization projects. Vollmar continued, stating that, "Staff is the paramount limitation for digitizing the collection. There is a steep learning curve for accuracy and speed of data entry." Staff must be familiarized with the use and possibilities of the data capture clients and/or whatever other technologies are being applied in the digitization process. Inexperienced staff may create doubt and uncertainty through erroneous data entry or classification of records. This therefore means that health institutions need to be ready to invest in hiring trained staff or training the current ones to avoid any consequences which may arise from negligent digitization of paper records.

Digitization is expensive (Amollo, 2011), specifically when unique materials are involved. Staffs have to work overtime; otherwise hiring additional staff is inevitable for this purpose. Some may perceive that digitization is simply photocopying or scanning of documents. No, this is not the case (Sharun, 2008). Sometimes, hard copy material is delicate. Prior to digitizing this material, it first needs to be prepared and conserved to minimize chances of damage during scanning.

Another challenge is that the digitization process is arduous and time consuming (Amollo, 2011). Hard copy material may be fragile and therefore difficult to scan. Great care must be taken when unfolding pages to avoid damage. Also, some items are bound in such a way that makes it hard to lay them flat for copying. Some have to undergo special treatment in order to harden them for scanning or copying. Others have pins and staples that have to be removed first. All this can be tedious and time-consuming.

Looking at the above challenges, digitization should not be seen as a replacement of paper records. The original documents are still precious and should be cared for even after digitization. This however, is not to say that digitization should not be considered since preservation is also a secondary benefit of moving from manual records to digital ones (Amollo, 2011).

2.8 ICD-10 Coding system

This is an international standard diagnostic classification for the epidemiological, health management purposes and clinical use as a whole. The standards used include analysis of the overall situation of health among groups' population and monitoring the prevalence and incidences of diseases and other complications concerning health matters related to other variables such as features and circumstances of the individual's reimbursement, affected, allocation of resources, guidelines and quality (Valerie J et al 2012).

The ICD-10 is applicable in classifying and recording diseases and other health problems reported on many types of health and related records such as death certificates. Similarly ICD-10 enables storage and retrieval of diagnostic information for epidemiological, clinical and quality purposes. Such records provide the basis for compiling of national morbidity and mortality statistics by WHO Member States (WHO 2009). However according to (Kiongo 2015) the coding and reporting of procedures and diseases in medicine at KNH was not satisfactorily done as per the guidelines from WHO guidelines in their publication ICD-10. Lack of training for the coders and lack of appropriate reporting by the clinicians and nurses working in the ward were the main problems. (Kiongo 2015).

2.9 National Cancer Institute (NCI)

NCI established that cancer is the 3rd leading cause of deaths after cardiovascular and infectious diseases in Kenya. It was estimated that the annual incidence of cancer was 47,887 new cancer cases, and annual mortality being 32,987 in 2018. The institute also noted that prostate, oesophageal and colorectal were the leading cancers in men. In women, the most cancer types were breast, cervical and oesophageal. Conspicuously oesophageal cancer was the main cause of cancer mortality in Kenya representing 13.2% (4,351 deaths). Following secondly was cervical cancer with 10% (3,266 deaths) while breast cancer comes in third at 7.7% (2,553 deaths) (GLOBOCAN, 2018).

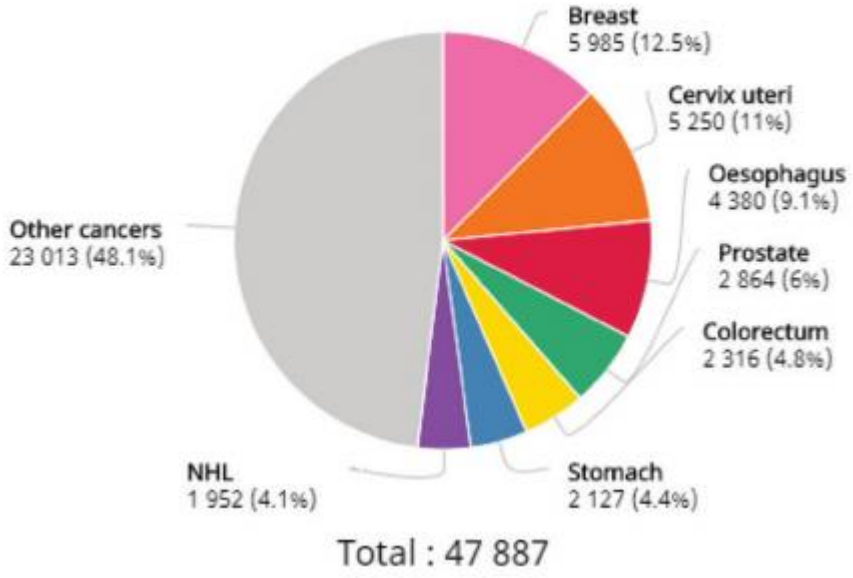


Figure 5: Estimated number of new cancer cases in Kenya among all ages, both males & females. (Source: GLOBOCAN 2018).

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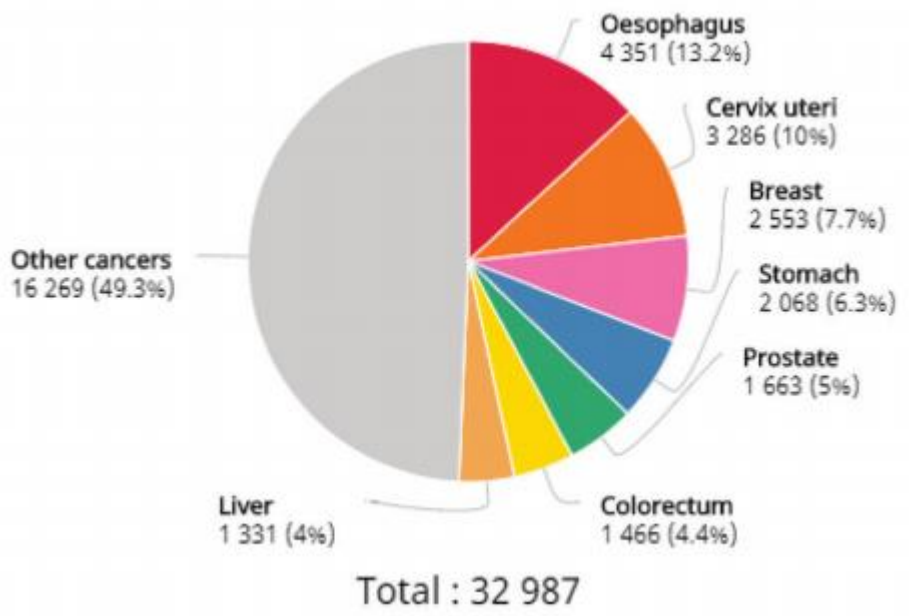


Figure 6: Estimated number of cancer deaths in Kenya among all ages, both males & females.(Source: GLOBOCAN, 2018)

A solid legal framework anchored on the Cancer Prevention and Control Act (No. 15 of 2012) had established the board that was mandated to coordinate and centralize all information relating to cancer screening. Available data was still insufficient to provide solid

scientific evidence to declare Cancer a national disaster. There has to be sufficient data built over time that is scientific, solid and comprehensive enough to back the declaration.
National Cancer Institute has a national cancer control strategy whose aim is to build the existing system in Kenya to enhance cancer control and prevention both in public and private sectors. This strategy also aimed to coordinate and harmonies cancer care, registration of nation cancer and sharing resources and information in health facilities. This strategy consolidate all the aspect concerning cancer prevention, screening, diagnosis, treatment and caring cancer patients and also the investments required to deliver these activities.

Kenya lacks a well all-inclusive national cancer registry that is comprehensive. The Kenya Research Institute Report (2008) noted that the cancer data in place needs a lot of enhancement since at there is no reliable National Cancer Registry. The one that is available is from Nairobi and its environment and even these slight information only dates back to the year 2000. The registry was established at the Kenya Medical Research Institute (KEMRI) and was sponsored by the International Agency for Research on cancer, National Cancer Institute of the United States, World Health Organization (WHO), among other stakeholders.

2.10 Legal and ethical Implications

Even though digitizing medical records could be considered a great step towards improving healthcare, it is encumbered by a number of legal and ethical issues which compromise their integrity. Koppel, *et al*., (2005) reported that any kind of digital medical records, while being lauded for the efficiency and effectiveness in greatly reducing medical errors, also results in small mistakes that can quickly morph into medical errors and malpractices. It is crucial to understand that the misuse of medical information found in medical records is not only apparent in paper-based records, but could also occur in electronic based records. Users need to be keener and more disciplined on how they manage medical records to avoid medical mistakes which could result in a chain of unintended, unwanted and grave consequences both to the patient and to the healthcare provider.

The Health Insurance Portability and Accountability Act of 1996 provided legislation for health data privacy and security (CDCP, 2003). Electronic information is also susceptible to breach or theft. HIPAA rules that while transmitting any confidential patient information

electronically, keenness should be attached to securing the privacy of this information, both in storage and transmission. Title II of HIPAA created criminal and civil penalties for privacy violations and a set of rules to govern the standards within which any form of digital medical record should be created. Security measures (e.g. firewalls and intrusion detection software) need to be applied to thwart any likelihood or attempts of patient information breach. Other workplace rules, (e.g. healthcare providers must not share their ID with anyone), serve to uphold patient confidentiality and privacy.

2.11 A Review of Related Work

2.11.1 Cancer Registry (CanReg)

CanReg is an open source software package for population-based cancer registries to enter, quality control, and store data, based on international standards (Ervik, *et al.*, 2014). As an IT system, CanReg has improved the processes of cancer registrations and eases in management of patient records, including the storage of the records, verification and analysis of cancer data. The system was established by National Agency for Research on Cancer (IARC) of WHO in a determination to assist nations implement their own cancer registrations (Pardamean, *et al.*, 2015). It sets the blueprint for how and why health institutions should move from paper-based cancer registries to digital ones, providing benefits such as better access, storage, retrieval and mining of data related to cancer. CanReg is used for both population based and hospital-based cancer registries as well (Ervik, *et al.*, 2014).

According to Pardamean (2015), the requirements for CanReg are as follows:

1. Unit Cancer Registration (UCR) – Needed to conduct data entries for cancer patients in specific unit e.g demographics, symptoms, diagnosis and treatment plans.
2. Hospital Cancer Registration Center (HCRC) – The recorded data from every unit is composed and validated. For instance since Kenyan health sector is devolved, then each county should have a single HCRC.
3. National Cancer Center (NCC) – It stores country-wide data by summing up data from each and every HCRC in a country.

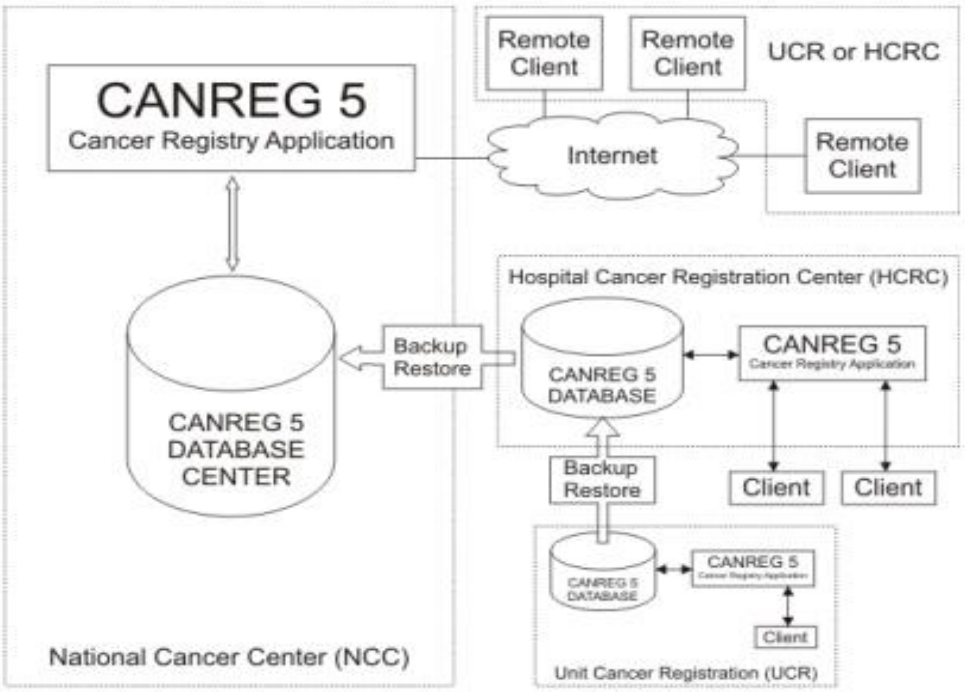


Figure 7: Implementation Model of CanReg5. (Source: CanReg5 Networks for Indonesia, 2015).

The model enables capturing of cancer records in hospitals which have limited computer and network support. Unit Cancer Registration (UCR) needs data entry staff and a personal computer to run this CANREG 5. After this data entry process, each Unit Cancer Registration (UCR) sends its back-up file database to the Hospital Cancer Registration Centre (HCRC). Then this Hospital Cancer Registration Centre (HCRC) now compiles and restores the back-up database from every Unit Cancer Registration (UCR) into one database. After Hospital Cancer Registration Centre (HCRC) creates its database, it would then back-up and direct the file to National Cancer Centre (NCC). Every personal computer that has Unit Cancer Registration (UCR) CANREG 5 application should be installed. From this model the researcher used Unit Cancer Registration (UCR) component that was used in data entry for cancer patients in a unit e.g. demographics, symptoms, diagnosis, treatment plans. It has also a browser based analysis to generate interactive and printable visualization of user data.

2.11.2 A Digital Transformation Business Model

Prem (2015) wrote a paper to find out the changes in business model innovation brought about by the transformation to digital technologies. They came up with a model reflecting the changes effected in business models as the industry turns digital.

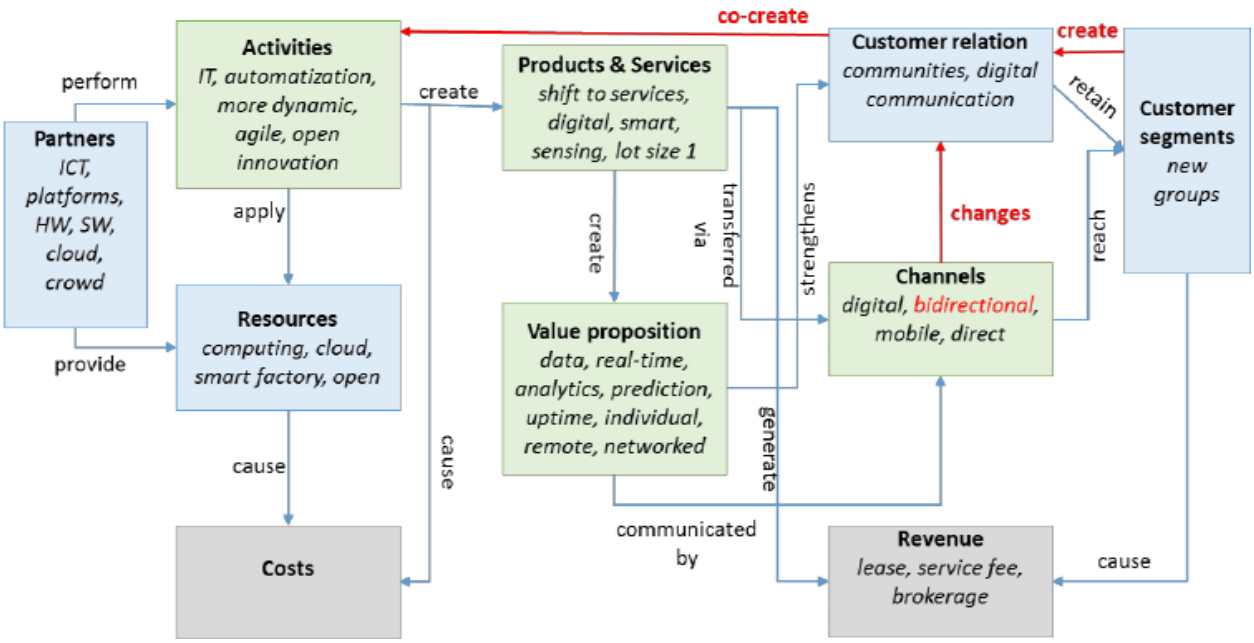


Figure 8: Prem's (2015) Model for Digital Transformation

This model interlinks changes within business model components and their connections with distinct characteristics of digital technologies. It is founded on a business model framework with causally interconnected components. Prem's objective for carrying out this study was to come up with testable, causal models of business model invention and comprehend the likely significances of digitization for a given business model.

The model focuses on representing empirical objects and empirical features of phenomena businesses know-how in the process of digitization. It simulates key components of business models and their connections with the defined characteristics of digital technologies and this was the basic component used from this model.

Key components derived from this model are:

- There should be linkage (connection) in business models with specific characteristics of digital technologies. Integration should be well implemented.
- Digital date should be collected, processed and analysed. This will enable networking of previously independent systems through internet of things, cloud computing and big data.
- There should be online interfaces in place to enable direct access of digital data and intermediaries using mobile internet and social networks.

2.11.3 Efficiency of Medical Records Automation (KNH)

Muchiri, *et al.* (2016) investigated the efficiency digitizing medical records in KNH. Specifically, their study sought to determine the level of computer-related staff training, the policies related to automation of medical records, and the cost and time effectiveness as a result of digitization. Results gathered showed that about 60% of 140 respondents thought that felt that automation would improve efficiency in terms of both time and financial resources. 90% of the respondents confirmed that there exists a policy on records automation at KNH. Based on their findings, Muchiri, *et al.* recommend that institutions conduct training on computer applications and make an elaborate presentation to the management illustrating to them how vital digitization could be to them, the hospital and also the Kenyan Ministry of Health at large.

2.11.4 E-Health readiness framework from electronic health records perspective.

The framework focuses on three key domains that are relevant to E-Health readiness practitioner, organisation and the general public. It brings out critical elements that are needed for successful E-Health initiatives. Wickramasinghe et al.'s framework gives a tool that enables analysis away from quantifiable data into a systematic synthesis of the major four impacts and four pre-requisites, implications of those pre-requisites and impacts to the objectives of E-Health including efficiency, evidence-based and preventive medicine.

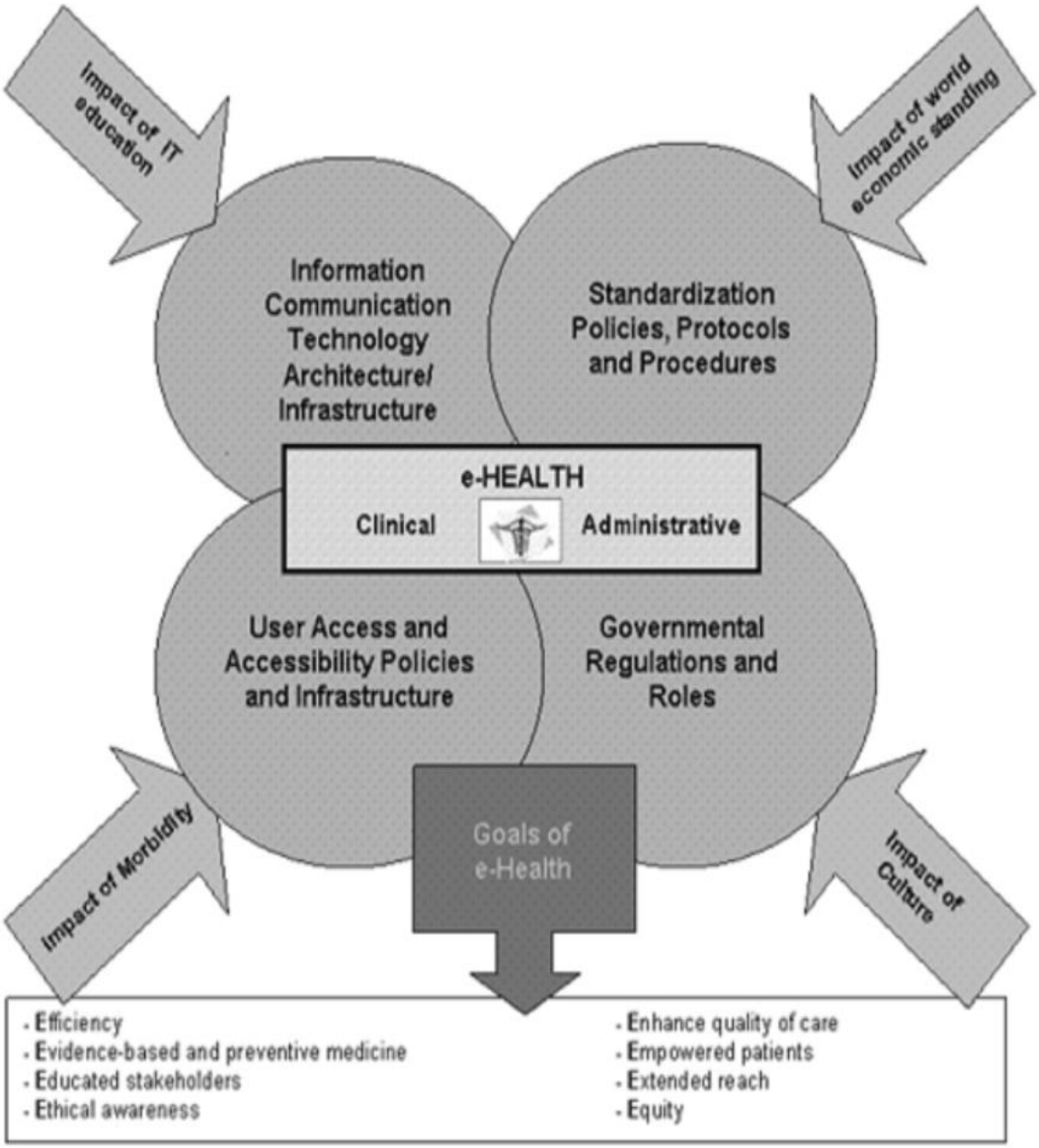


Figure 9: E-Health readiness framework from electronic health records perspective Wickramasinghe et al 2006

This framework has four key prerequisites.

i. Information Communication Technology (ICT) architecture / Infrastructure – This ia a sound technical infrastructure including phone lines, fiber trunks and submarine cables, telecommunication, electricity and access to computers. This is very vital ingredient to the undertaking of E-Health drive by any nation.

ii. Standardization protocols, policies and procedures – E-Health extends geographical dimensions since many parties are involved. To facilitate wide coverage a substantial amount of document exchange and information sharing and flow needs to be accommodated. Standardization plays a key role on this using widely and universally recognised protocol such as TCP/IP and HTTP.

iii. User access and accessibility policies and infrastructure – According to World Trade Organisation (WTO), accessibility to E-Commerce is consisting of two key components: Internet and E-Services access. Internet access focuses on user infrastructure and E-Services pertain to precise commitments to electronically accessible services.

iv. Governmental regulations and control – Key impact to E-Health use mainly is cost effectiveness, functionality and ease of use. This implies they should facilitate and allow many uses for physicians and other healthcare users by integrating different kind and forms of data on top of being easy to use and security enhancement.

This framework is founded on several perspectives including organizational for instance ICT infrastructure, Practitioner such as user accessibility and pubic such as government regulation. The perspectives are used to determine and assess readiness and capabilities of the country for E-Health and as well as the ability to maximize E-Health goals.

One of the pre-requisite of this framework is ICT architecture/Infrastructure and is one of the components that used by the researcher as a key idea to the undertaking of E-Health initiatives.

2.11.5 Informatics infrastructure framework to support data use. KEMRI.

Based on this framework, data capturing in health institutions occurs at the point of patient discharge where data from pediatric inpatient paper records are abstracted straight into a non-commercial electronic tool (REDCap). Minimum data set needed for the national reporting system (DHIS2) is composed from all patients admitted to the pediatric wards for all sites.

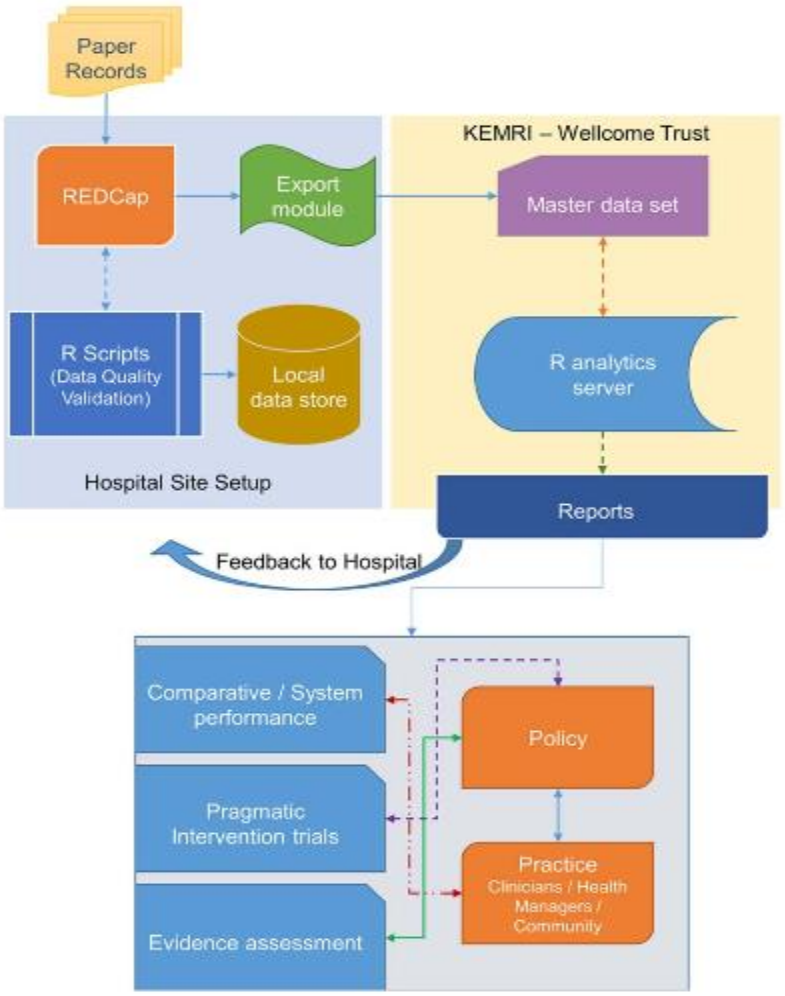


Figure 10: Informatics infrastructure framework to support data use. (KEMRI 2016)

In this Framework data are collected by competent clerks and pre-programmed filed validation guidelines in the REDCap are applied in checking data quality as it is entered. Then codes that are used for running on- site checks on daily basis are auto generated through Meta programming process and also using statistical software that is installed in hospital site's computers. Data is then shared with the central network analysis team is then shared with the central network analysis team and de-identified. It then as well cleans and recodes data to allow indicator measurement and reporting. The data are then used generate timely reports for health facilities that have traditionally had no access to daily routine information that consist of processes as well as outcomes for their patient. This framework enables availability of all these resources to be re-used in other projects. REDCap tool that was used by clerks to check data quality was one of the components that use in this study since it could also generate reports from the stored records.

2.12 Proposed Solution

A Model was developed for the digital preservation of cancer records in line with the objectives. The aim was to enable better way of organising, analysing and accessing those medical records which are rich with relevant information to assist all the stakeholders in medical field.

We envisioned an ICT intervention that improved record management for cancer cases at the KNH/UoN Department of Pathology. This means that for this study's scope, cancer records stored in paper form were scanned and uploaded as digital files onto a repository. Instead of manually maintaining records of cancer symptoms, diagnoses, and treatment outcomes on paper forms, we proposed an efficient record storage, quick search, access and retrieval mode which patients and medical personnel could be part of, guaranteeing more positive and timely care delivery.

The system basically stored detailed information about cancer patients (such as demographics) and the initial treatments they received (e.g. histopathology report form). Authorized users are allowed access to these records and retrieve information concerning patient's medical history (e.g lab information regarding a patient's medical history (e.g. lab results, screening information, and any history of a previous cancer).

2.12.1 Equipment for Digitization and Other Resources

Due to repeated physical handling by users over the years, hard copy material suffers wear and tear. It therefore becomes necessary to prepare and assess the degree to which these documents are worn out. Also, the documents will need to be categorically digitized since different resources may have different digitization requirements e.g. wide format scanners since some records are not in standard sizes.

Unless health institutions already have in place some degree of computerization, digitization is very equipment-intensive (Namande, 2012). Some of the equipment needs that digitization demands include:

1. **Computer Hardware and Software**

A few computers, if not one, will be required for the exercise. The computers will require having a practical size of RAM, disk space, and processor speed. They must be fast enough to

handle scanning and other digitization activities. Other equipment such as CD-ROM drives will be required for creating and copying CDs.

2. **Scanners**

Computers need to be fitted with good and quality flatbed scanners. These scanners are ideal to conduct standard scanning tasks. There may be need to also acquire a large bed scanner for oversize special records.

3. **Storage**

The proposed storage medium of the digitized information will be server-based, plus an offline CD backup.

2.12.2 Digitization Process Flow

Based on the literature reviewed, the proposed solution posed fair chances of addressing the concerns mentioned in the problem statement. Prem's (2015) model proved instrumental to coming up with this study's conceptual architecture. The model outlined four main levels of digitization:

1. Collection, processing and analysis of paper-based data.
2. Automating/digitizing value-adding activities and records.
3. Creation and networking of storage systems example cloud computing and digital storage devices.
4. Creation of direct user access for intermediaries using mobile or online interfaces such as mobile applications, social networks and collaborative tools.

Prem's model informed the creation of the digitization process flow in *Figure 11*.

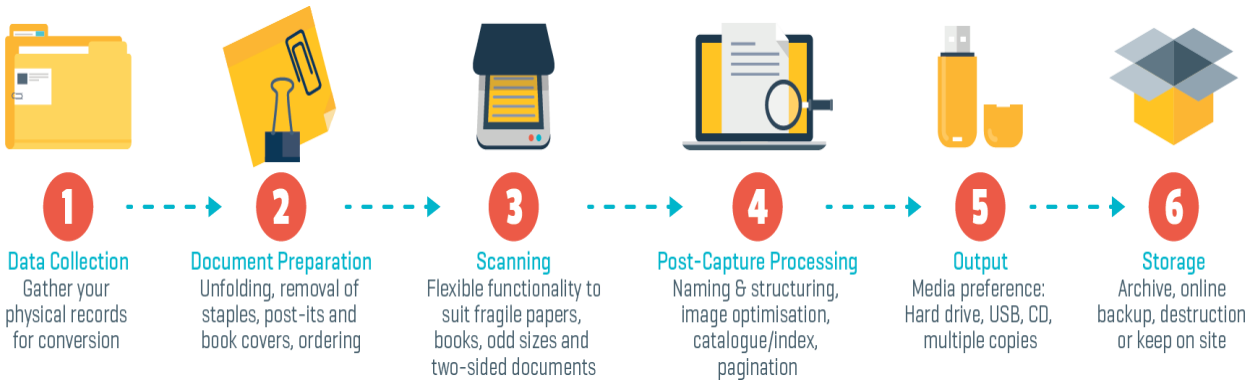


Figure 11: The Digitization Process

2.12.3 Components used from frameworks and models reviewed.

The researcher reviewed several frameworks and models and from these some of the components were used to come up with intervention. The table shows the frameworks and models reviewed and the components used from each.

	Framework/Model	Component used
1	Implementation model of CanReg5 – (Cancer Registry).	The National Agency for research on Cancer (IARC) of WHO applied CanReg model to come up with a system that assist nations in implementing their own cancer registrations (Pardamean, *et al.*, 2015). From this model the researcher used Unit Cancer Registration (UCR) component that was used in data entry for cancer patients in a unit e.g. demographics, symptoms, diagnosis, treatment plans.
2	Digital Transformation Business Model.	The model was suggested by Prem (2015) while studying the changes in business model invention brought about by the transformation to digital technologies. This model interlinks changes in business model components and their connections with the specific characteristics of digital technologies and this was the key component the researcher derived from this model.
3	E-health readiness framework from electronic health records perspective.	Wickramasinghe et al.'s framework offers a tool that enables analysis beyond quantifiable data into a systematic synthesis of the four key impacts and four pre-requisites. One of the pre-requisites: ICT architecture / Infrastructure was applied critical component to the undertaking of E-Health initiatives.
4	Informatics Infrastructure framework to support data use. KEMRI.	This framework enables data capturing in health facilities at the point of patient discharge where data from the pediatric inpatient paper records are channelled directly into a non-commercial electronic tool (REDCap). Data are collected by skilled clearks

		and programmed field validation guidelines in the REDCap tool are applied in checking data quality as it is entered. The researcher adopted REDCap tool component in this study.

Table 1: Components used from frameworks and models reviewed

We came up with a conceptual diagram to represent the problem area, the intended intervention, benefits and outcomes that aroused from digitizing cancer records. We found scoping the digital archival project for cancer records as a good start due to the continued prevalence of cancer in Kenya and the need to offer more efficient approaches to ameliorate oncological healthcare service delivery. *Figure 12* illustrates the conceptual Model perception of this study's objectives and outcomes.

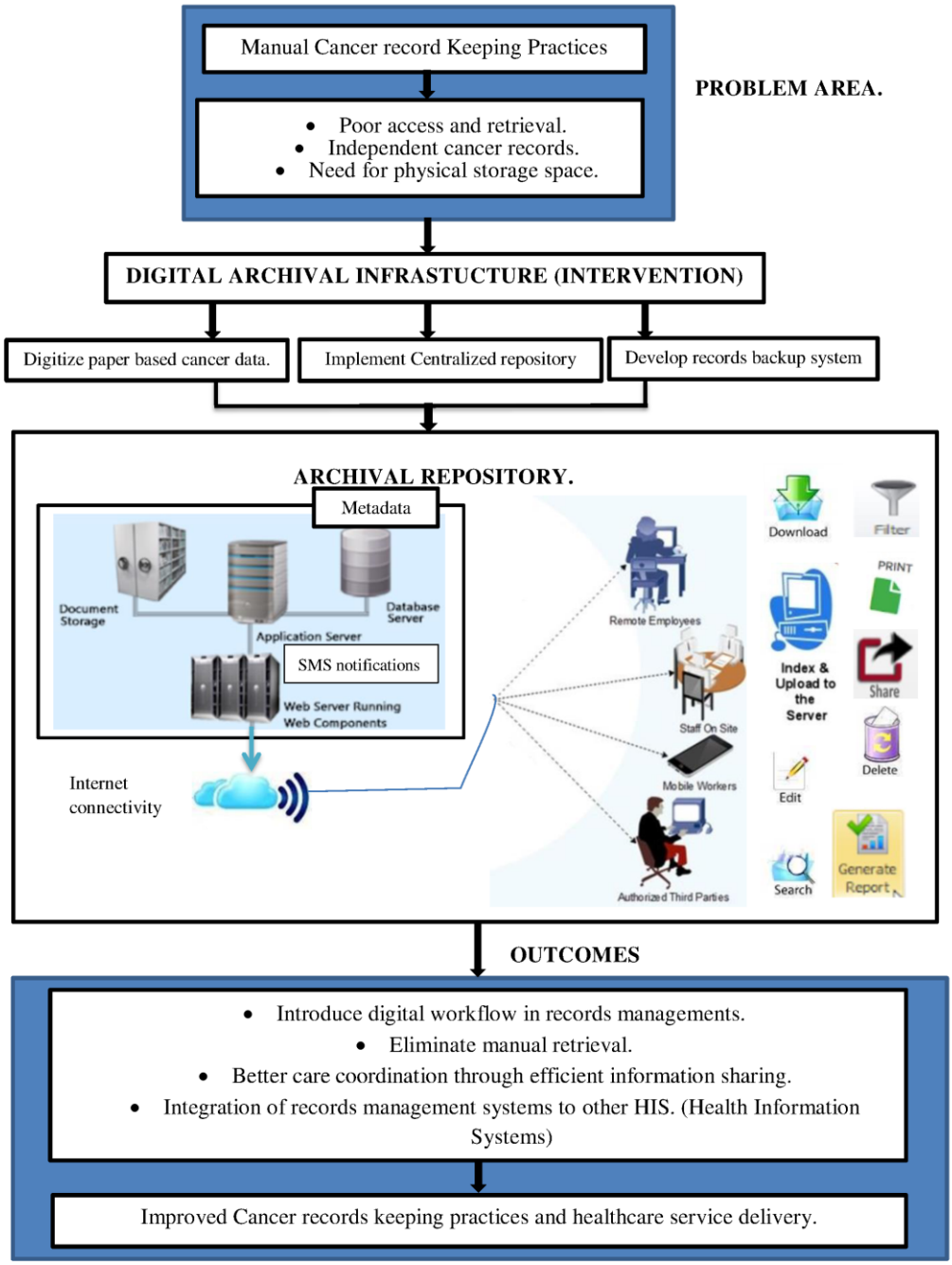


Figure 12: Conceptual Model.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter focuses on the methodologies used to digitize the paper records; the study's targeted population and sampling techniques; data collection and analysis methods; and ethical matters that were considered while conducting the research.

3.2 Research Design

This study revolved around both qualitative and quantitative approaches. The reason for this was so that we were able to generalize the proposed solution's practicality in health. The application was evaluated based on reviews and opinions granted by the core participants.
The table below shows a brief summary of how each research objective was achieved

Objective	**Research Methodology**
To evaluate the current cancer records management practices of the KNH/UoN Department of Pathology. To find out the challenges towards the digital archival of cancer records and assess the digital archival readiness of the KNH/UoN Department of Pathology.	Questionnaires were administered to participants drawn from the target population from KNH/UoN Department of Pathology. Also interviews were used where we had face to face interactions with these participants. These two types were used to get information about, various practises and activities carried out currently to manage cancer records and also the challenges faced when using the current practises used.
To review several related Models and Frameworks that aid in digital preservation of health records.	Different Models and frameworks were reviewed by the researcher in literature review. Also the researcher identified the model that was being used to manage cancer records in KNH / UoN department of the pathology currently. From this model the researcher came up with a model that was to aid the digitation of cancer records in this department (ICT inclusive).

To design, develop and to implement a prototype for digital archival platform for cancer records. This platform will provide basic statistics and search functionality	A web based platform (SOA) was developed using user-centered prototyping and Rapid Application Development design methodology. The platform stores detailed information about cancer patients and the initial treatments they received. Authorized users were allowed access to these records and retrieve information regarding a patient's medical history. This intervention provides basic statistics and search functionality.

Table 2: How Research objectives were achieved

3.3 Sample Size and Target Population

Before getting the sample size, we visited the KNH/UoN facilities to precisely know how many people dealt with records to enable access of both primary and secondary data including Clinical Officer, Histologist, Cryptologist, Pathologist, Policy Makers, Researchers, Lecturers, Medical Students and Record Clerks as to wholly include them as part of the target population before sampling them.

Random sampling was used to select respondents amongst the sampled individuals to avoid bias. The target population selected was of great importance to our research since they were directly involved with the cancer records.

3.4 The Digitization Methodology

The digitization process was as outlined below:

1. **Planning**

Materials to be digitized were identified, followed by assessment of resources required to facilitate the process. Decisions were then to be made on the standards and procedures to be applied during digitization. Finally, assessments of risks including current and future drawbacks were carried out before proceeding to pre-digitization.

2. **Pre-Digitization**

At this stage, the hard copy materials to be digitized were selected. A thorough assessment of their state and any treatment that may be required e.g. cleaning was done. Document

metadata – the contents and attributes of a digital item – was then captured, mainly descriptive and structural data.

3. **Digital Conversion**

The digitization process followed whereby the availability of professional equipment e.g. printers, scanners, compact disks, etc were very instrumental. Digital masters from which access copies are to be made were then created.

4. **Post-Digitization**

Information was submitted to delivery and repository systems, from where cancer records were to be managed. The digitized copies and metadata were then uploaded to servers and made available to authorized personnel e.g. Clinical Officer, Histologist, cryptologist and Pathologist. Back-up disks were burned and put in storage. An assessment and evaluation of the project was conducted to conclude the digitization process.

3.5 Data Collection

The study applied structured questionnaire and interview guide approaches to collect primary data. Questionnaires had both open ended and close ended questions and they enabled easier gathering of information from a large number of respondents. Secondary data was gathered from the records of office bearers in that institution. Informed consent was obtained from the participants to allow their data to be used in the analysis process of research results.

3.6 Data Analysis

Data collected were first scrutinized to identify the relevant information based on research questions and objectives. From there, the data was read and re read to take note to the repetitive ideas.

For this study, data analysis was both qualitative and quantitative. Quantitative analysis was done when studying closed-ended questions that had pre-set responses and can be assigned numerical values. It helped in acquiring definitive statistics and eventually informed conclusions and recommendations. Qualitative analysis involved data which was not quantifiable such as raw data collected through questionnaires.

Based on the type of data, it was coded and sorted according to apparent sets and themes. All the coded data under themes was placed was placed together to make a write-up.

3.7 Testing

After the implementation, the users were able to test the platform if it met their needs. The test checked the overall performance and functionalities of the entire system.

Beta testing

End users were given that opportunity to test the system and provide the feedback. The web application was hosted and users were requested (pathologists, record clerks, researchers / Medical students and policy makers) to use it and give any relevant feedback to enhance the system. The responses gotten were used in production of final intervention.

3.8 Research Ethics and Authorization

Primarily, relevant permission was sought from the school of Computing (UoN), sampled health institutions and the target population. Ethical concerns, such as confidentiality and avoidance of harm, were addressed since participants were assured on the same and they voluntary agreed to be part of this research. They were fully conversant of the intended purpose and the nature of the research. All responses and information collected from participants were considered as confidential and were solely used and applied in this research.

CHAPTER 4: SYSTEM ANALYSIS, DESIGN AND IMPLEMENTATION

4.1 Requirements Analysis

4.1.1 The Current System

After analysing questionnaires and literature review the following were confirmed:

- System in place was inefficient – it was mostly paper based
- Proposed solution from research carried would go a long way in aiding pathologists to store and retrieve cancer records efficiently and appropriately.
- Proposed solution would provide a more reliable means of documenting/recording and scanning cancer records that were existing in manual files.

4.1.2 Prototype's Functional Requirements

From the feedback given by the respondents, we were able to note the functional system requirements as follows:

i. Ability to register a new cancer patient.
ii. Ability to add, update or scan cancer patient record.
iii. Ability to provide reliable access to the cancer records based on pre-set permissions and roles by authorized users.
iv. Ability to ensure cancer patient data privacy and confidentiality was enforced.

4.1.3 Non-Functional Requirements

a) Reliability: System being able to perform the key tasks for which it was developed.
b) Integrity: Enabled by ensuring Data in the database was well structured and organized as a way of guaranteeing integrity.
c) Security: System should only allow authorized users to access it. OTP (One time password) was implemented. An activity log also was added to enable user sessions or access to systems put on audit trail.
d) Usability: Graphical user Interface should be designed in such a way that the user learns and use it in an easy way.

4.2 Overview of System Components

The ICT intervention was a web based application that improved record management for cancer cases at the KNH/UoN Department of Pathology. The Proposed system was a responsive SOA based web service hosted on Linux server. The system was deployed on a central server while being accessed and collected data from browsers (Client Side Programming) on different devices in distributed areas. All functionalities of the system were accessible over the internet using a web browser. The system was hosted live on SiteGround where a domain for the web application was set up. All functionalities of the system required an active data connection. The ideal methodology for the development of the prototype was Rapid Application Development (RAD).

Rapid Application Development

This methodology is intended to give much faster development and also to provide high quality and reliable results compared to traditional software development lifecycle. It involves gathering requirements using focus groups or workshops, prototyping and early user testing of design and reusability of software components.

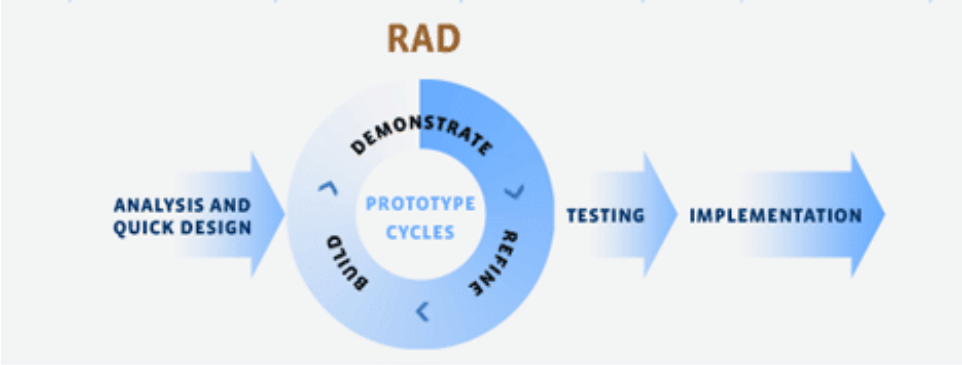


Figure 13: Rapid Application Development Model (Source: textingexcellence .com)

Stages of RAD

Analysis and Quick design-This stage involves requirements planning and designing the prototype

Prototype cycles – This stage is repetitive and it is where actual development of system take effect.

Testing and deployment – Here the complete prototype is tested and it is ready to be used.

Advantages of RAD.

i. It reduces the development time and reusability of components and this helps to speed up the development of the prototype.

ii. Large projects can be broken down to small manageable tasks hence easy to develop large systems

System Architecture

The system basically stored detailed information about cancer patients (such as demographics) and the initial treatments they received (e.g. histopathology report form). Authorized users were allowed access to these records and retrieve information concerning patient's medical history (For Example Lab results, screening information, and any history of a previous cancer testing clinical notes).

4.3 System Design

The prototype enforced coupling and cohesion by interlinking components (modules) where functional and non-functional requirements were key drivers in this particular phase. The system requirements were mapped onto the systems expected functionality.

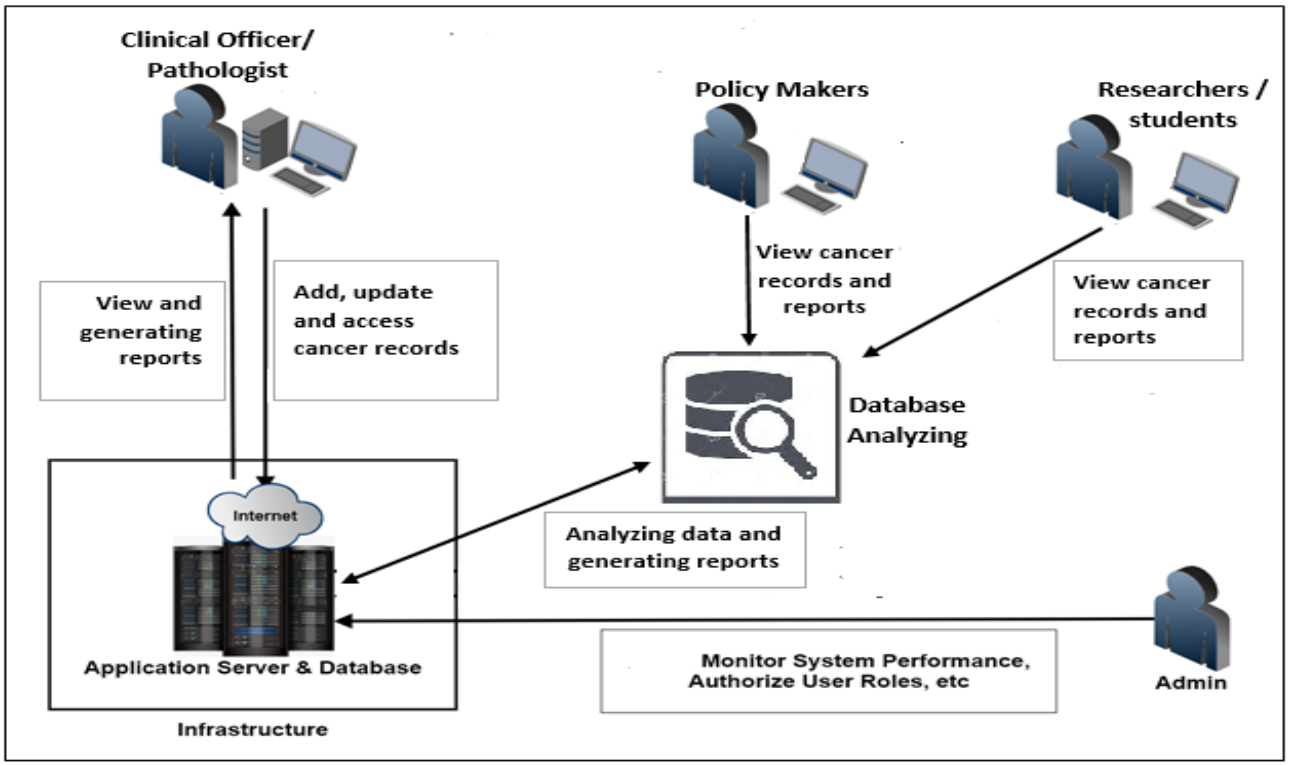


Figure 14: System Design.

4.4 Use Case Diagram

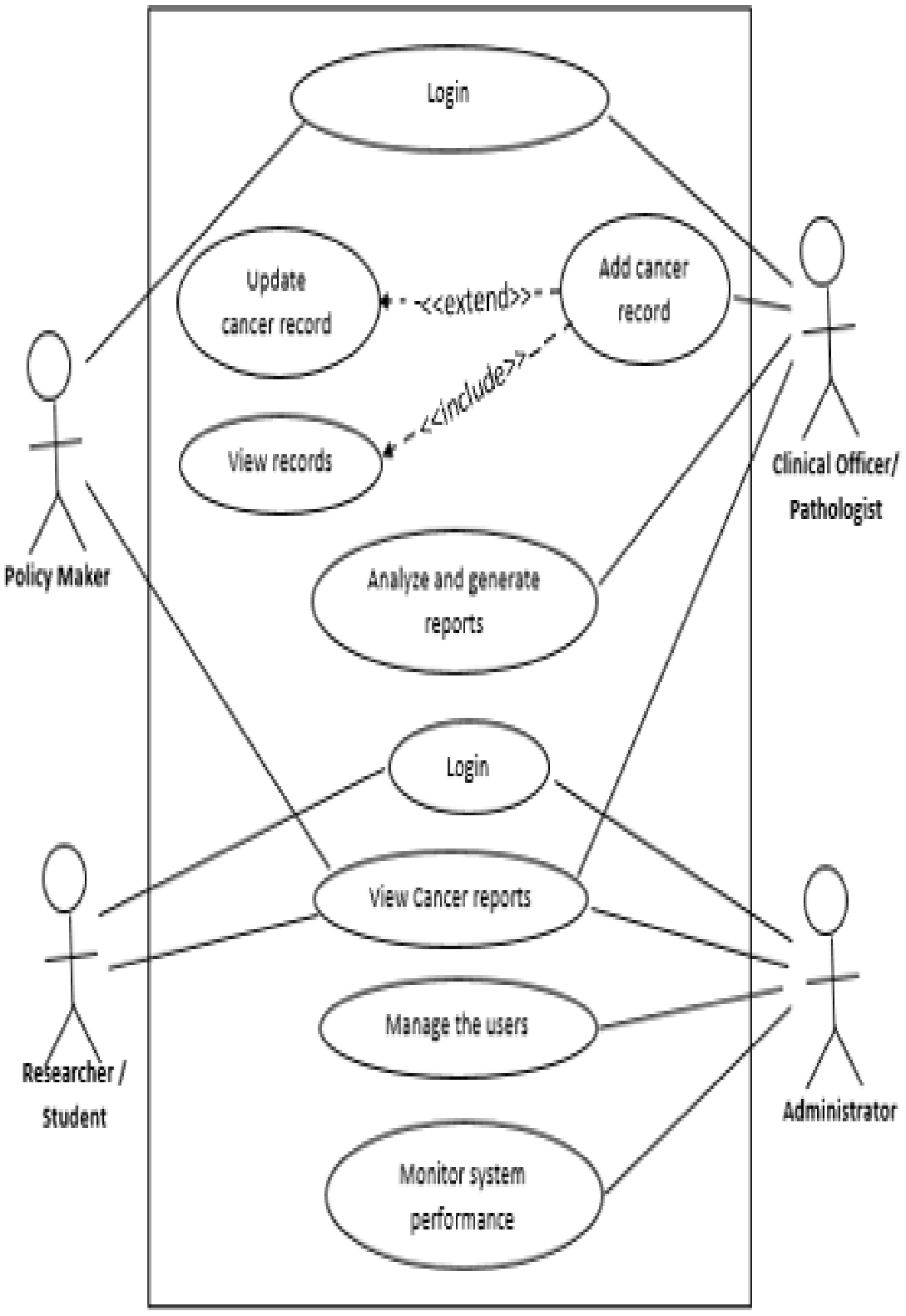


Figure 15: UML Diagram

4.5 Design Decision and implementation

Based on the intervention functional and non-functional requirements, technology design decision were made and the ICT intervention was implemented using the following technologies

-HTML5 and CSS for designing the web interface of the web application - these tools were used to code the system user interface (UI).

-Microsoft SQL (Structured Query Language) Server for database design – MYSQL was used because it guarantees data security and integrity. MySQL database use primary keys hence avoiding redundancies. The foreign keys in MySQL database aided in creating relationships between entities.

-Linux server for hosting the application – Linux web server made the system readily available to all users of the system. Also modification can be made to suit system users' needs

-Africa's Talking API Messaging – This was used to send the requested OTP (One Time Password) to the users.

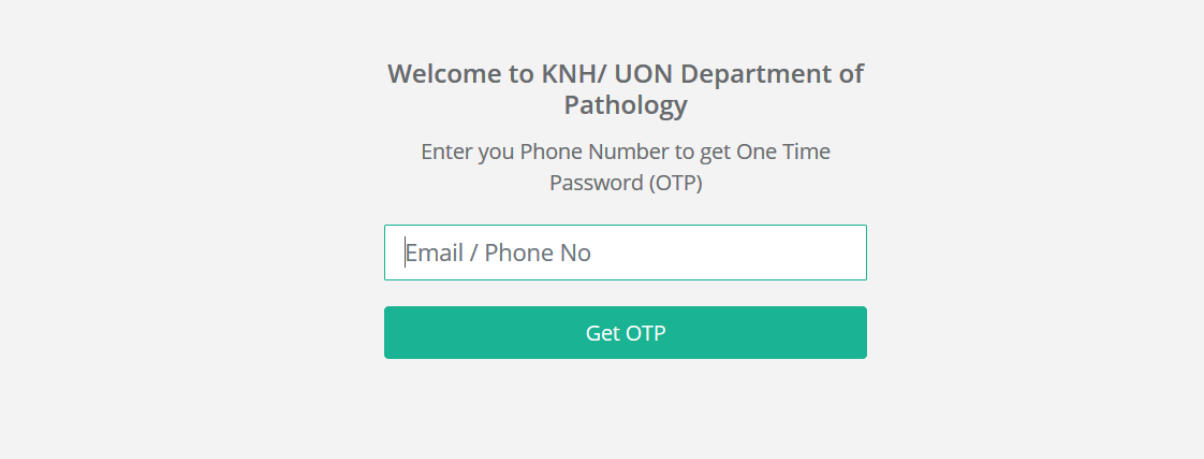


Figure 16: Login page before getting OTP Password

In the login page, the user should enter his or her phone number and the password is sent to his or her phone number through Africa's talking API.

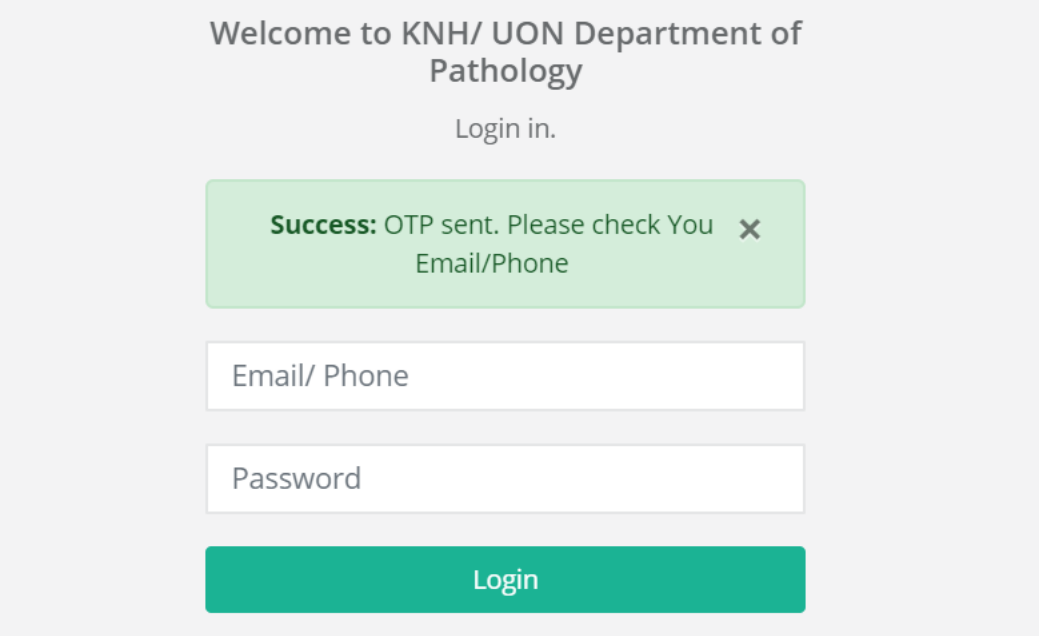


Figure 17: Login page before after OTP Password

After the user receives the one time password (OTP), he/she can now enter the phone number (or email address) and the password to log in to the system.

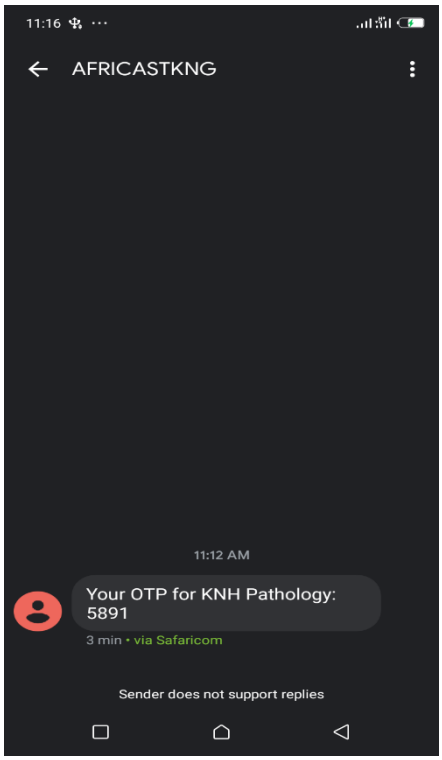


Figure 18: OTP Password sent to phone number

-Laravel 5.3 a PHP framework and bootstrap 3 for developing server-side scripting codes front end – Laravel was used to enhance security and spped up database migration without any data loss. Tables were created to store, display, manipulate and delete database

records. Forms were also created to allow for user input and retrieval of data from the database. Figure 19 shows the form from the system that captures cancer test details. Pathologists and record clerks capture patient's cancer test details using this form.

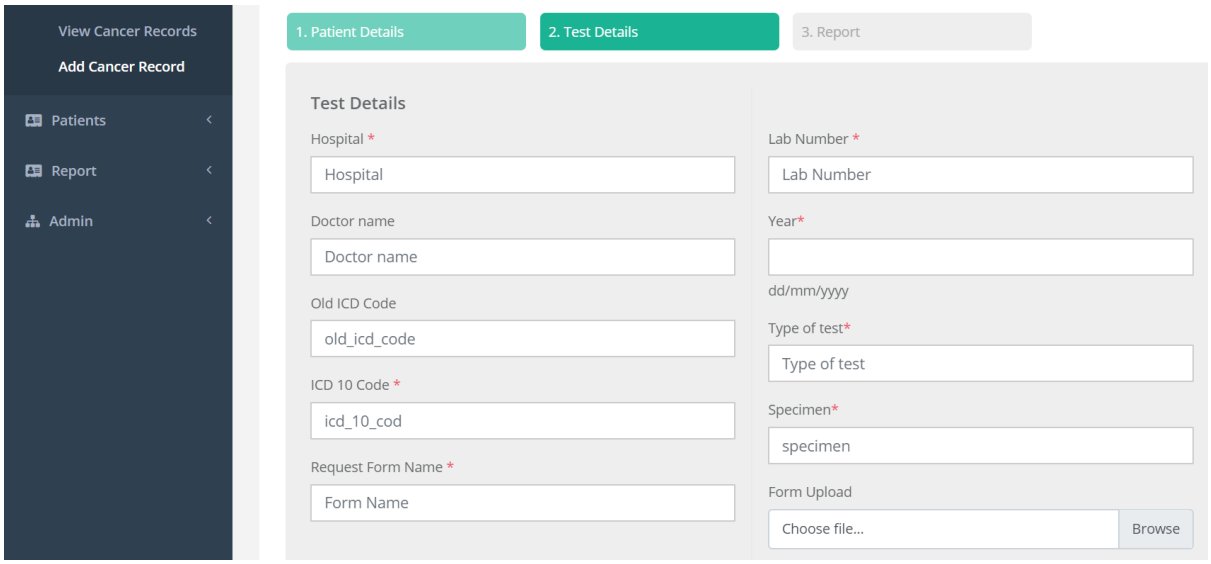


Figure 19: A form from the system that captures patient's cancer test details

Forms also were used to display the captured cancer records to the system users. His enabled the users to view all the captured cancer records as shown in the figure 20.

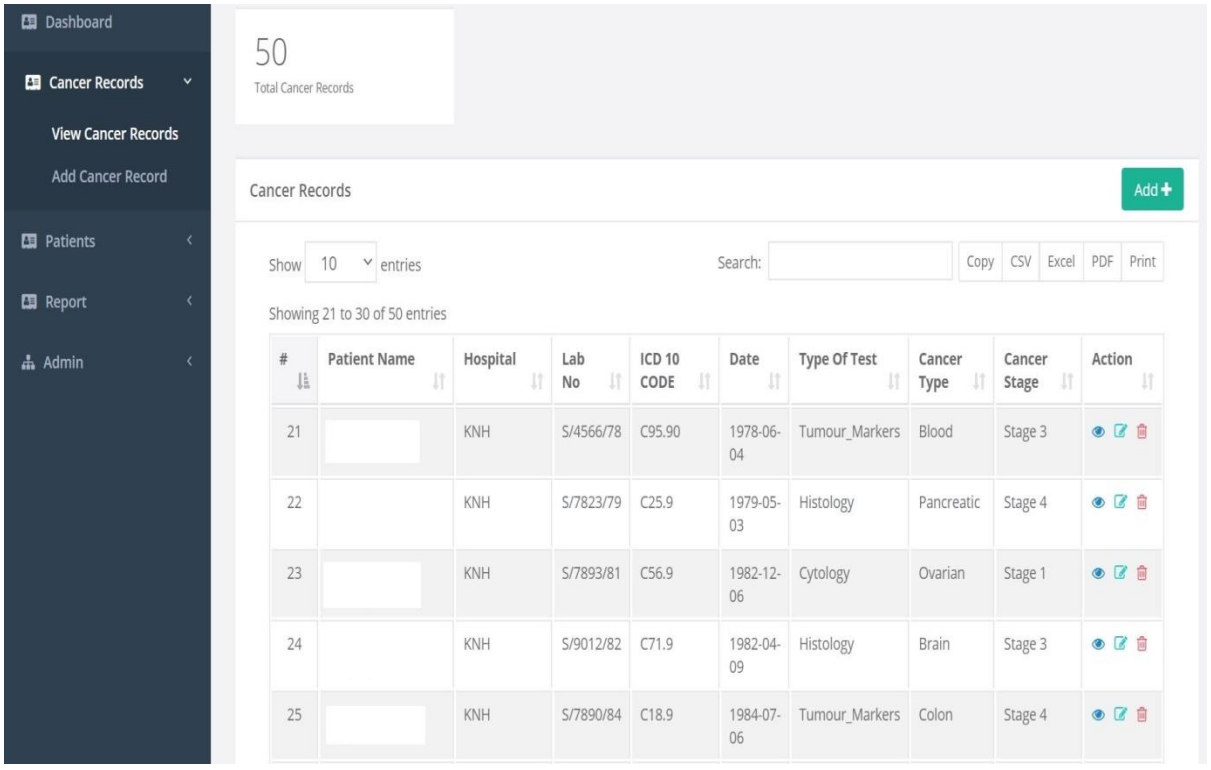


Figure 20: A form from the system displaying all the cancer patients captured in the system

The users were also able to view captured cancer details of a single cancer patient as shown below.

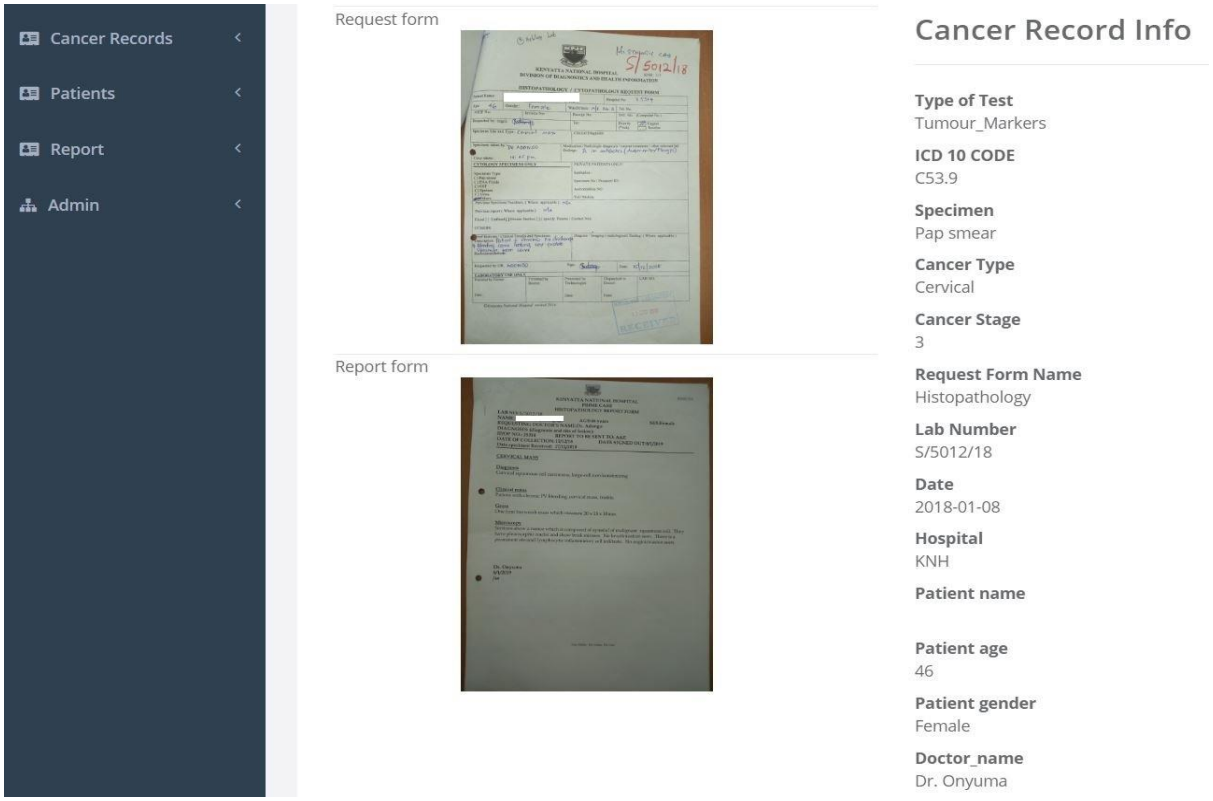


Figure 21: A form from the system displaying captured cancer details of a single cancer patient

-Chart Java Script (JS) – This software was used to analyse the captured and stored cancer records in the system and generate the graphs and charts. This was to aid report generation to people who wanted to use cancer records to do research or to make certain decisions.

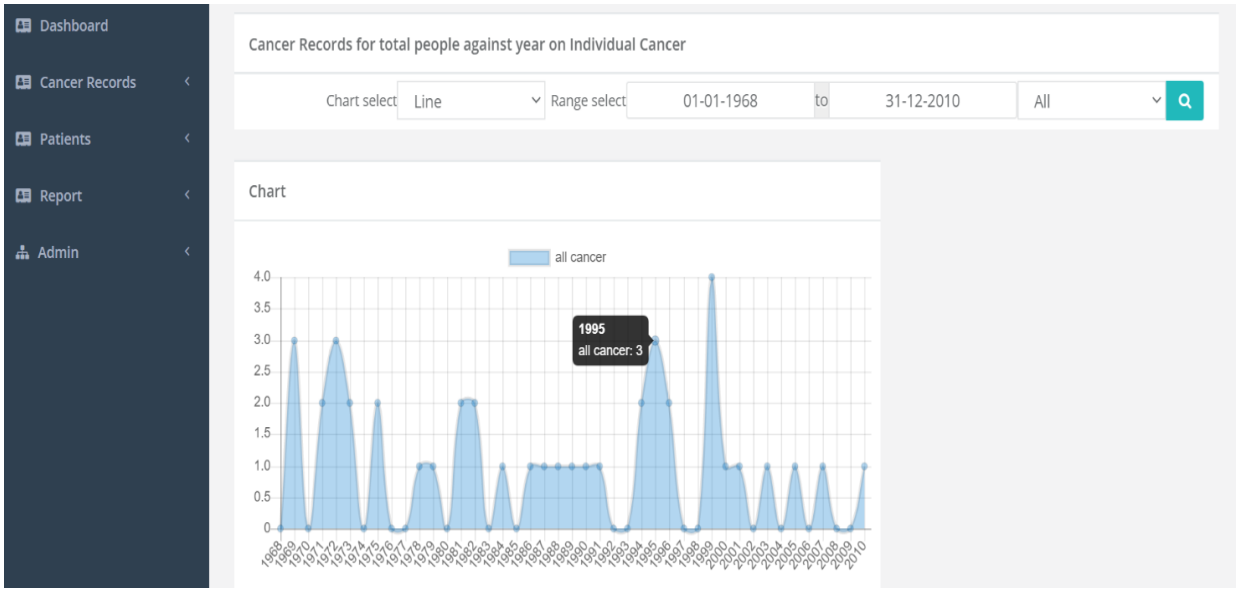


Figure 22:A line graph showing cancer cases reported against year.

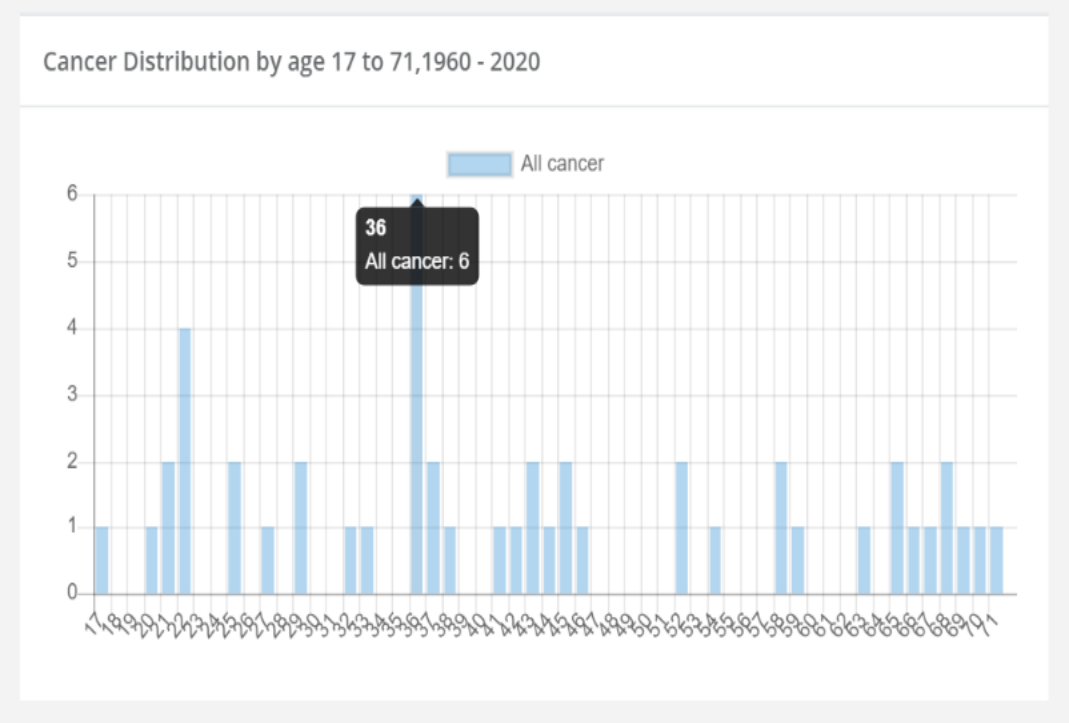


Figure 23: A bar graph showing cancer cases reported against age.

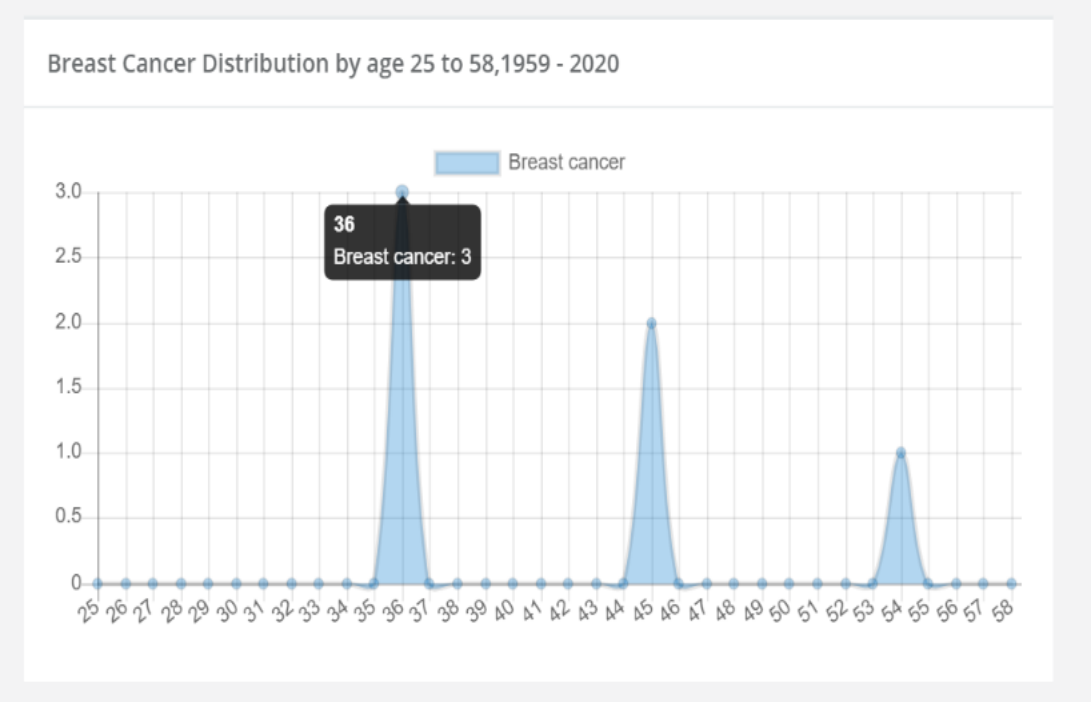


Figure 24: A line graph showing breast cancer patients against age.

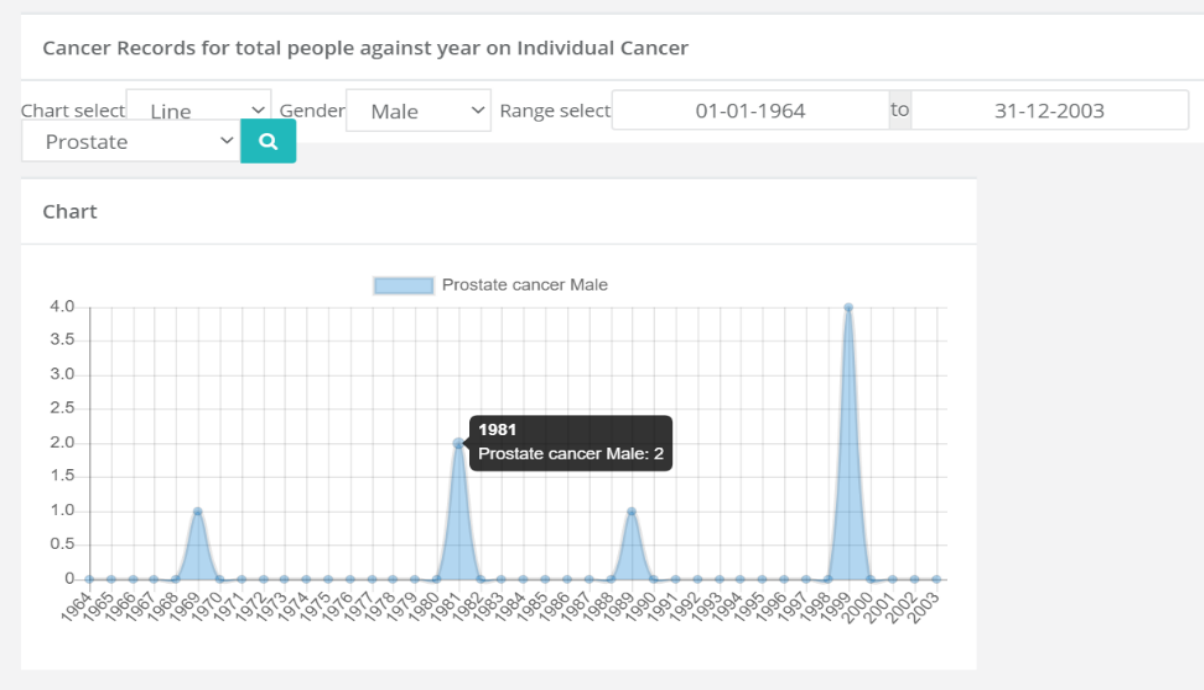
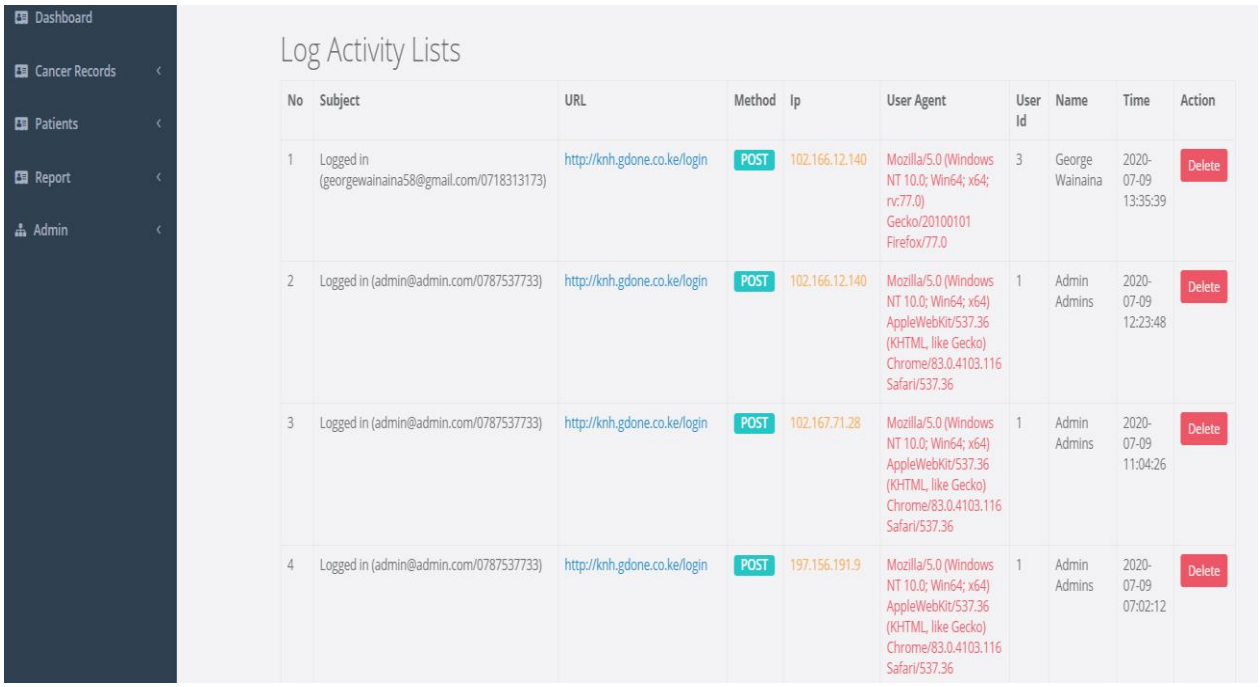


Figure 25: A line graph showing cancer cases for a specific gender against year.

To ensure the system security was enforced due to the nature of data it holds, activity log was added. This is the administration metric page that included user activity. It had the capability to log key data regarding specific user activity or even events that took place within the system as a repository that can later be viewed and analysed to monitor trends or issuing alerts.



No	Subject	URL	Method	Ip	User Agent	User Id	Name	Time	Action
1	Logged in (georgewainaina58@gmail.com/0718313173)	http://knh.gdone.co.ke/login	POST	102.166.12.140	Mozilla/5.0 (Windows NT 10.0; Win64; x64; rv:77.0) Gecko/20100101 Firefox/77.0	3	George Wainaina	2020-07-09 13:35:39	Delete
2	Logged in (admin@admin.com/0787537733)	http://knh.gdone.co.ke/login	POST	102.166.12.140	Mozilla/5.0 (Windows NT 10.0; Win64; x64) AppleWebKit/537.36 (KHTML, like Gecko) Chrome/83.0.4103.116 Safari/537.36	1	Admin Admins	2020-07-09 12:23:48	Delete
3	Logged in (admin@admin.com/0787537733)	http://knh.gdone.co.ke/login	POST	102.167.71.28	Mozilla/5.0 (Windows NT 10.0; Win64; x64) AppleWebKit/537.36 (KHTML, like Gecko) Chrome/83.0.4103.116 Safari/537.36	1	Admin Admins	2020-07-09 11:04:26	Delete
4	Logged in (admin@admin.com/0787537733)	http://knh.gdone.co.ke/login	POST	197.156.191.9	Mozilla/5.0 (Windows NT 10.0; Win64; x64) AppleWebKit/537.36 (KHTML, like Gecko) Chrome/83.0.4103.116 Safari/537.36	1	Admin Admins	2020-07-09 07:02:12	Delete

Figure 26: Log Activity List from the system

CHAPTER 5: DATA ANALYSIS, PRESENTATION AND DISCUSSIONS

5.1 Introduction

The chapter focuses on results, data analysis, presentation and discussion from the research conducted. The data was gathered using open ended and closed questionnaires and interviews. The analysis and interpretation was made based on research objectives and research questions. The findings presented on this study were on the basis of data collected from researchers (medical students), Policy makers, pathologists and Record clerks from KNH/UoN facilities.

5.2 Response rate

The study targeted 28 respondents drawn from KNH/UoN facilities. The targeted population of 28 people was the actual number of people in KNH/UoN unit that was the main focus for this study. According to research findings 22 participants responded to the researcher whereas 6 targeted participants did not respond to the researcher.

	TARGET POPULATION	SAMPLE POPULATION
Researchers (Medical Students)	15	12
Policy Makers	4	3
Clinical Officer / Histologist / Cryptologist / Pathologist (DOCTORS)	7	5
Record Clerks	2	2
TOTAL	**28**	**22**

Table 3: Target population and the sample population

This represented a response rate of 79% which was well considered since according to Mugenda and Mugenda (2003) the response rate of above 75% is adequate for academic research.

	Frequency	Response rate
Responded	22	79
Not responded	6	21
Total	28	100

Table 4: Response rate

5.3 Findings

5.3.1 Socio – Demographic

This section documents the response inputs from the study population relative to the research objectives. The total sample population reached 22 participants from KNH/UoN facilities.

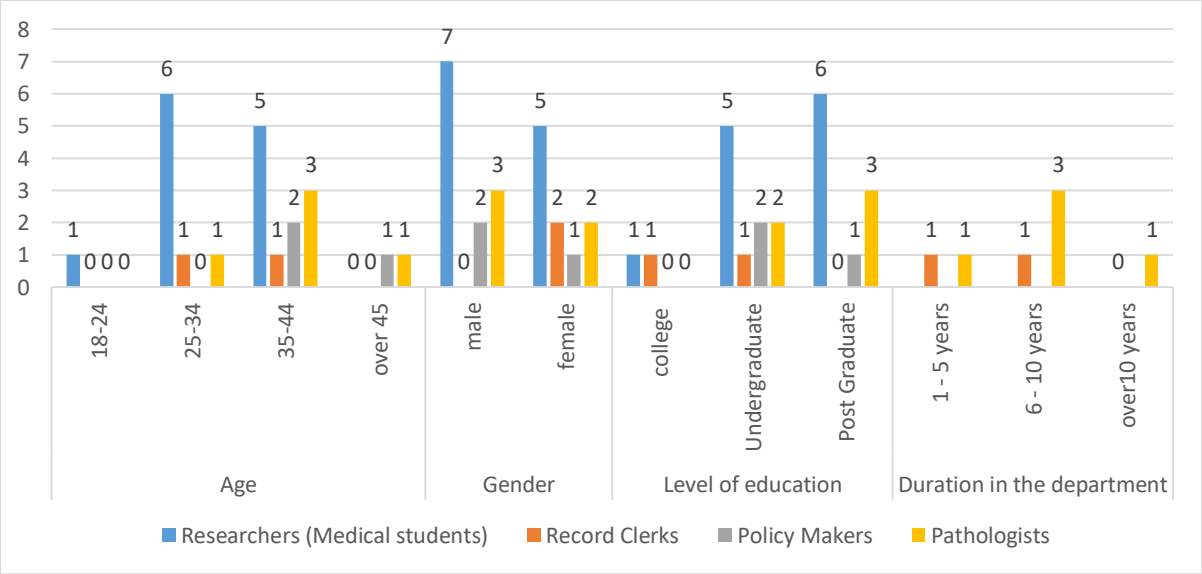


Figure 27: Socio - Demographic

Age of most of researchers was ranging 25-34 years (6/12), Policy makers age was ranging between 35-44 years (2/3), which was the same range as that of the pathologists (3/5). The level of education of most researchers was postgraduate (6/12), same to pathologists (3/5). Most of the pathologist and data clerks had served in the department for 6- 10 years (4/7) meaning they understood very well the challenges affecting that department.

5.3.2 Capturing patient's personal data

Record clerks and pathologists were the respondents to these questions. Record clerks were 2 in number and pathologists were 5, resulting to 7 in total. 86% of the respondents (6/7) reported that cancer patient's personal data was captured through standard forms and books. This clearly showed that cancer records were captured manually using a form (Template).

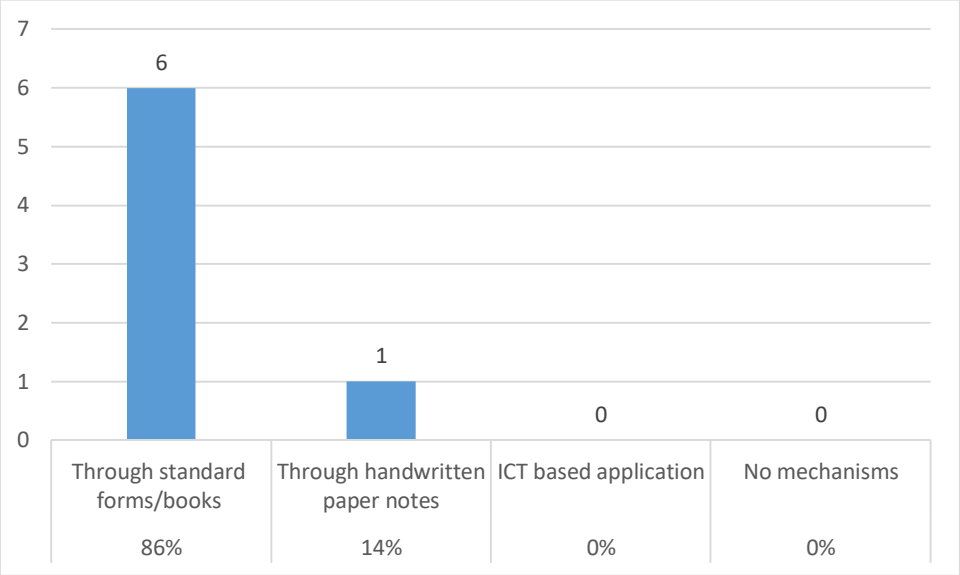


Figure 28: Capturing patient's personal data

5.3.3 Storing of the captured cancer records

This was aiming to know how the data was stored after it had been captured from the cancer patient. It was also responded by the record clerks and the pathologist. 71% of the respondents (5/7) reported that the captured data was stored using standard forms and books. Having majority of the respondents reporting that data was stored using forms and books showed that cancer records still were stored manually in files and these paper records were highly prone to physical damage, duplication, and loss and may miss crucial patient information.

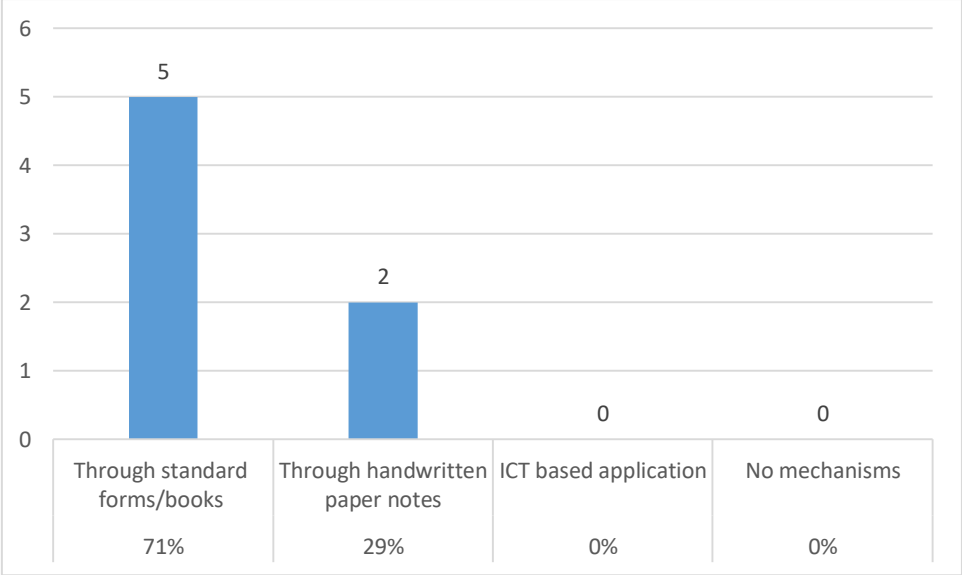


Figure 29: Storing the captured cancer records

5.3.4 Identifying particular patient record and documenting lab reports

This helped the researcher to know the unique ways of identifying a particular patient record and how the lab reports for histology and cytology were documented. This was responded by the pathologists and the record clerks. Majority of the responses 57% (4/7) reported that Identification of patient record and documenting lab report was done basing on LAB number, 14% of the respondents (2/7) reported that this was done using record index number, hospital number and based on Inpatient and Outpatient number. The LAB number contained the slide number, the report number and the specific year when that record was stored, example of LAB number: S/5012/18.

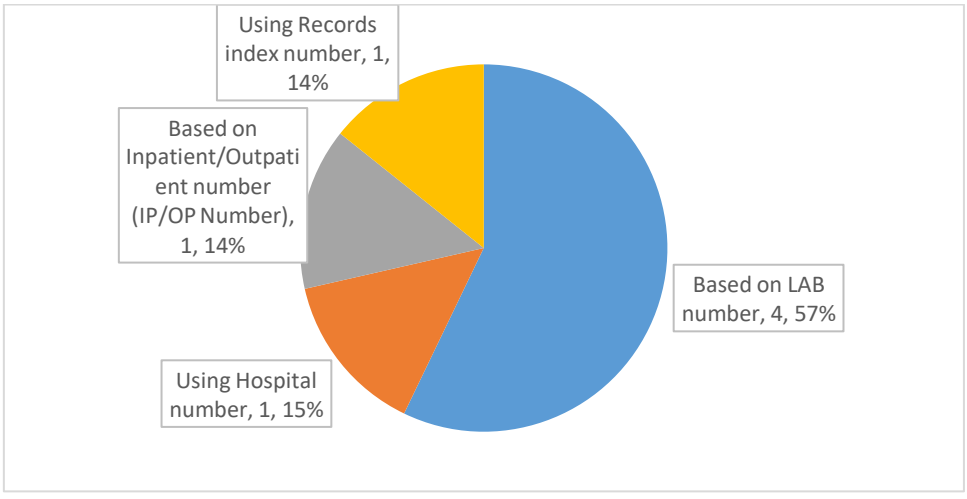


Figure 30: Identifying particular patient record and documenting lab reports

5.3.5 Cancer record accessibility

This was to find out how frequently cancer records were accessed by researcher/medical students and policy makers. Researchers / medical students were 12 in number and policy makers were 3, resulting to 15 in total. 54% of the respondents (8/15) reported that they accessed the cancer records frequently while 33% (5/15) of the respondents stated that they accessed cancer records sometimes. The kind of information that was accessed by researchers/ medical students was patient records history and lab results that helped them in their studies and in research while the policy makers had interests in information relating to cancer incidences and prevalence

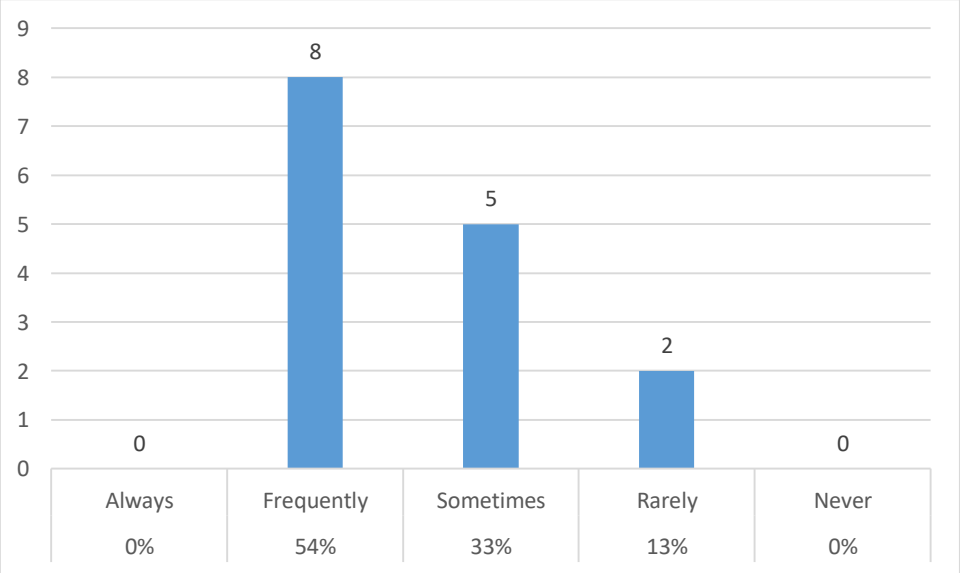


Figure 31: Cancer record accessibility

5.3.6 Challenges with the current cancer record keeping practices

This was responded by all the participants in the study (22). Adding onto the challenges discovered in literature review, a big number of participants (77%) noted inability to track patient records with ease was the main problem in the current processes of storing and retrieving cancer records in KNH/UoN facilities. Healthcare institutions need complete, integrated and readily available data to plan, monitor, and evaluate cancer cases, but when there is a problem of tracking patient records due to manual processes, then institution would not be able to monitor and evaluate cancer cases. 64% of the respondents reported that the main challenge faced was Loss or damage of patient records. Paper records that were in use

were highly prone to physical damage, duplication, loss and others missed crucial patient information. The above two key challenges were caused by lack of technology in record management as stated by 73% of respondents. All record clerks and pathologists also indicated that another challenge they faced was poor communication and data sharing between the different departments.

Challenge	**Researchers (N = 12)**	**Policy Makers (N = 3)**	**Pathologists (N = 5)**	**Record clerks (N = 2)**	**Total responses (N = 22)**	**Per cent (%)**
Lack of clear record keeping guidelines or protocols	2	2	3	1	8	36%
Poor communication and data sharing between the different departments	0	0	5	2	7	32%
Inability to track patient records with ease	8	3	4	2	17	77%
Loss or damage of patient records	6	2	5	1	14	64%
Lack of technology in records management	8	2	4	2	16	73%

Table 5: Challenges with the current cancer record keeping practices

5.3.7 Rating of the current means of cancer record keeping

This was responded by all the participants (22). Most of the respondents reported that the means of cancer record keeping were not efficient at all (54%, which represent 12/22). 32% of the respondents reported that means used by then were not so efficient. This showed that participants were never satisfied with the manner in which KNH/UoN Department of Pathology kept the cancer records.

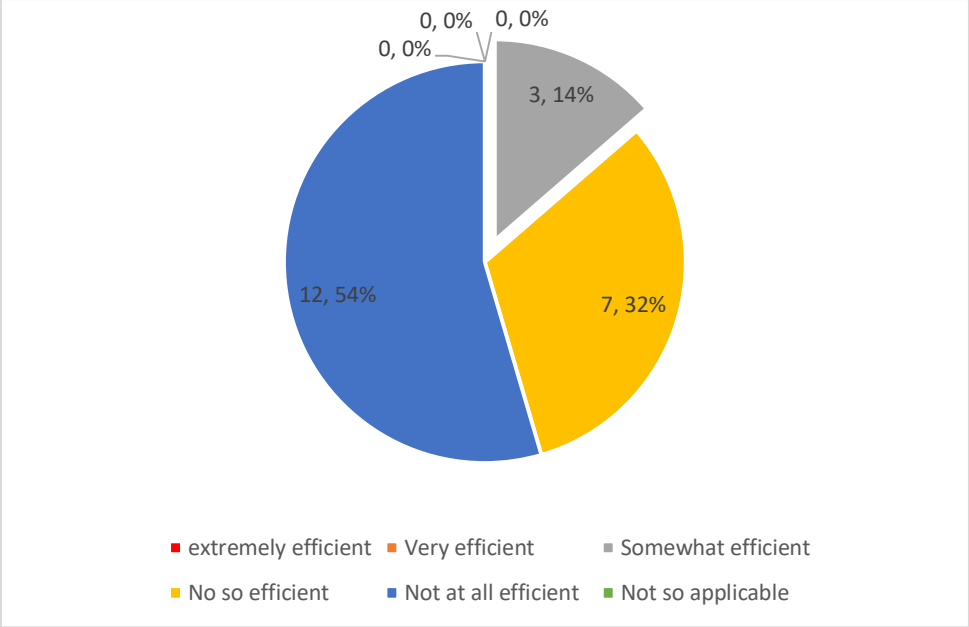


Figure 32: Rating of the current means of cancer record keeping

5.3.8 ICT Usage levels

This was to determine the rate or level of ICT usage in the whole process of cancer data / Information record keeping**.** Evaluation of the use of ICT in this process indicated that ICT usage was poor (0-25%), this was reported by most of the respondents 77.27% which represented 17 out of 22 responses given. 5 out of 22 respondents reported that the level of ICT usage ranged between 26-50%. This indicated how manual processes were used in KNH/UoN Department of Pathology.

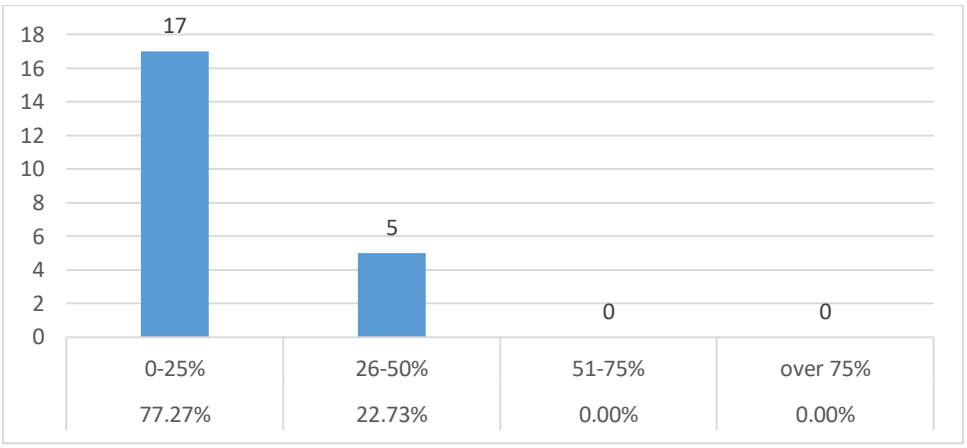


Figure 33: ICT Usage levels

5.3.9 Challenges that hinder the implementation of digital preservation of cancer record.

The intention was to determine the key challenges that delay or hinder the implementation of digital preservation of cancer record to enable distributed form of accessibility. Most of the respondents (36% - 8/22) reported that the department had not deployed any advanced Technology to be used while 23% (5/22) of the respondents reported lack of innovation that had led to lots of manual data (paper records) accumulating over time as a challenge. This showed that ICT usage in the department remained to be low.

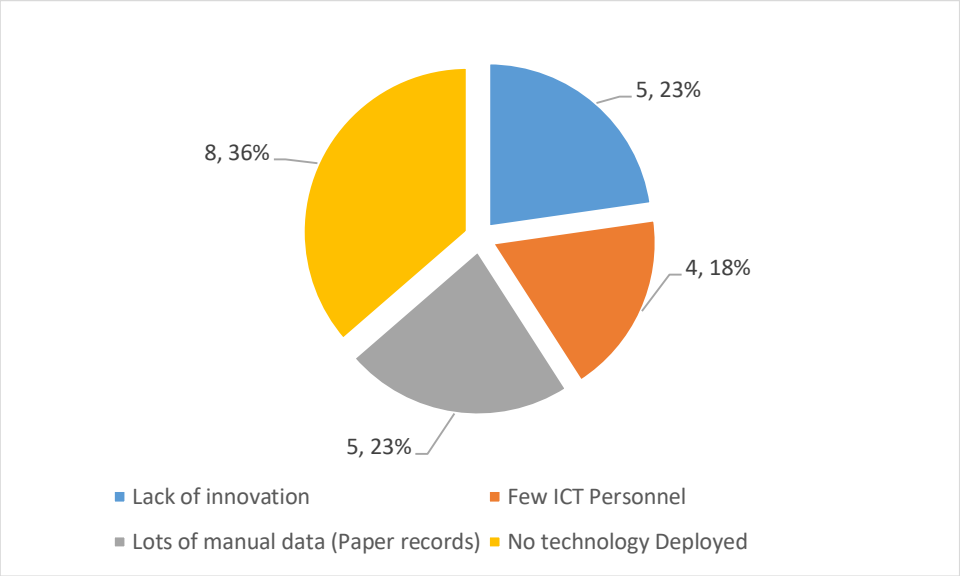


Figure 34: Challenges that hinder the implementation of digital preservation of cancer record

5.3.10 Dealing with the challenges mention in 5.3.9

To determine the measures KNH/UoN department of pathology could apply to deal with challenge mention in 5.3.9, respondents were allowed to give their views and concerns. 41% (9/22) of the respondents reported that the department should deploy ICT Infrastructure and the existing one to be upgraded. 32% of the respondents reported that processes of cancer records management should be automated. It was also noted that the department should benchmark with existing cancer registries such as Nairobi Cancer registry to implement ICT enabled infrastructure and this was supported by 18% of the respondents.

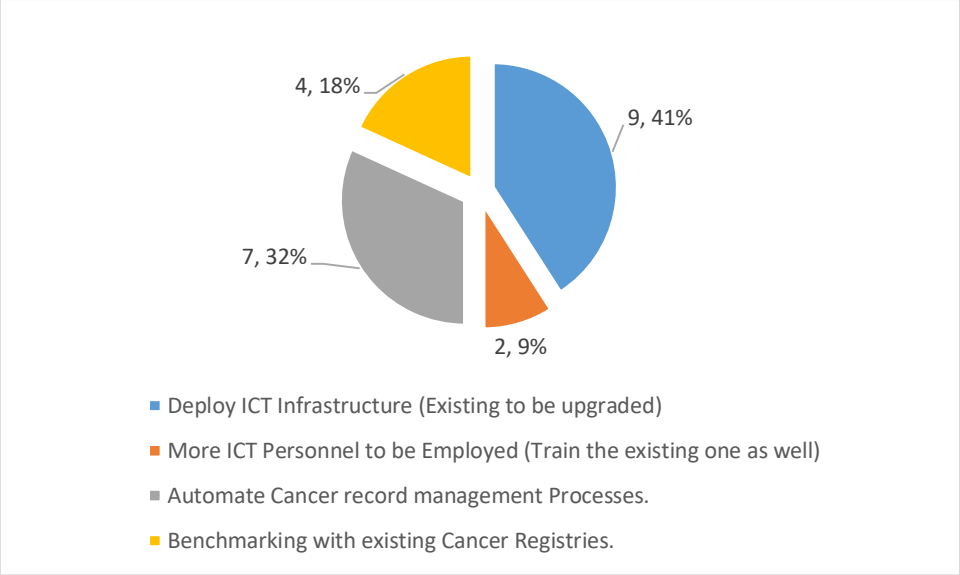


Figure 35: Dealing with the challenges mention in 5.3.9

5.3.11 Suggestions from participants on what should be done to improve cancer record keeping.

The participants of the study were required to give their suggestions on what should be done to improve the whole process of cancer record keeping in KNH/UoN Department of Pathology. Majority of the respondents (63% - 14/22) reported that the department should have ICT systems and ICT resources , 23% representing 5/22 reported that the department should separate cancer cases from other patient cases for easy access and retrieval of cancer records.

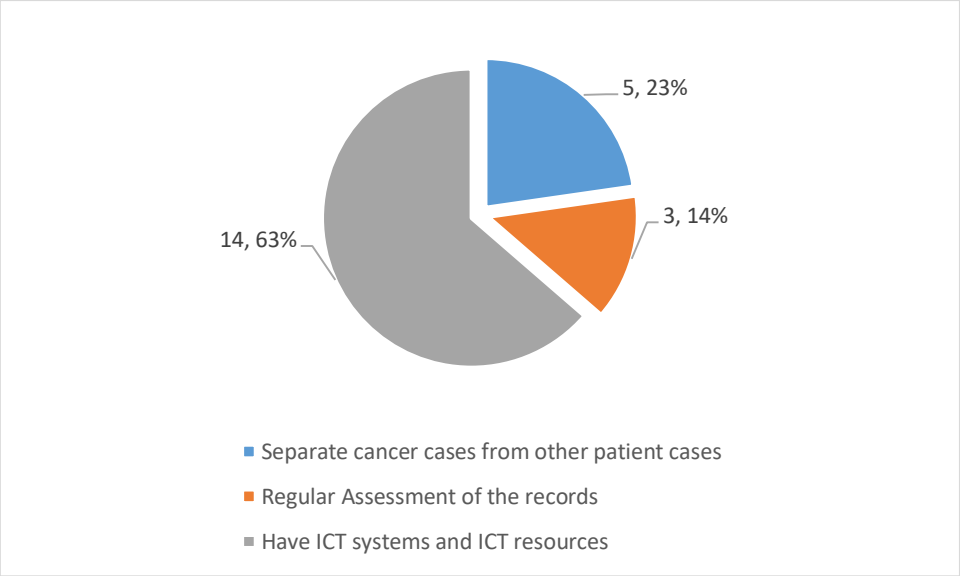


Figure 36: Opinions on what should be done to improve cancer record keeping

5.3.12 Recommendations of using the digital platform for capturing, storing, retrieving and preservation of cancer records

This was to determine some of the recommendation from the participants that should be incorporated to the ICT intervention to improve the process of capturing, storing, retrieving and preservation of cancer records. 50% of the respondents (11/22) recommended that the ICT intervention should provide basic statistics and search functionality, 41% of the respondents (9/22) recommended that the ICT intervention should archive the records to maintain the rich information about cancer while 9% (2/22) recommended that benchmark with KEMRI and Africa Cancer Organization Registries should be done.

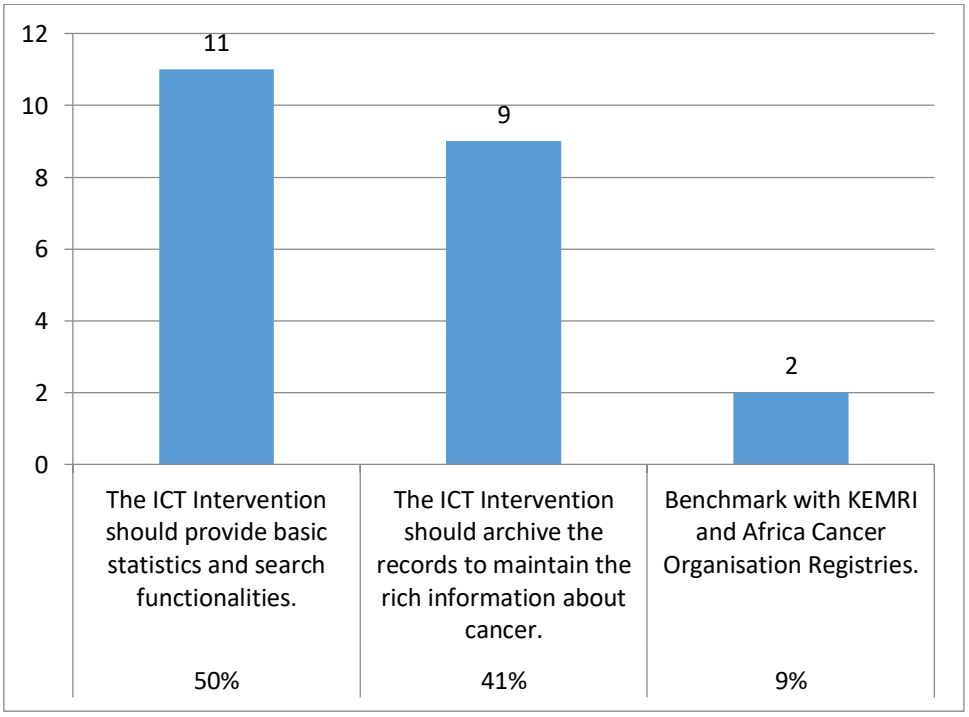


Figure 37: Recommendations of using the digital platform for capturing, storing, retrieving and preservation of cancer records

5.3.13 Cancer records management process model in KNH/UoN Department of Pathology

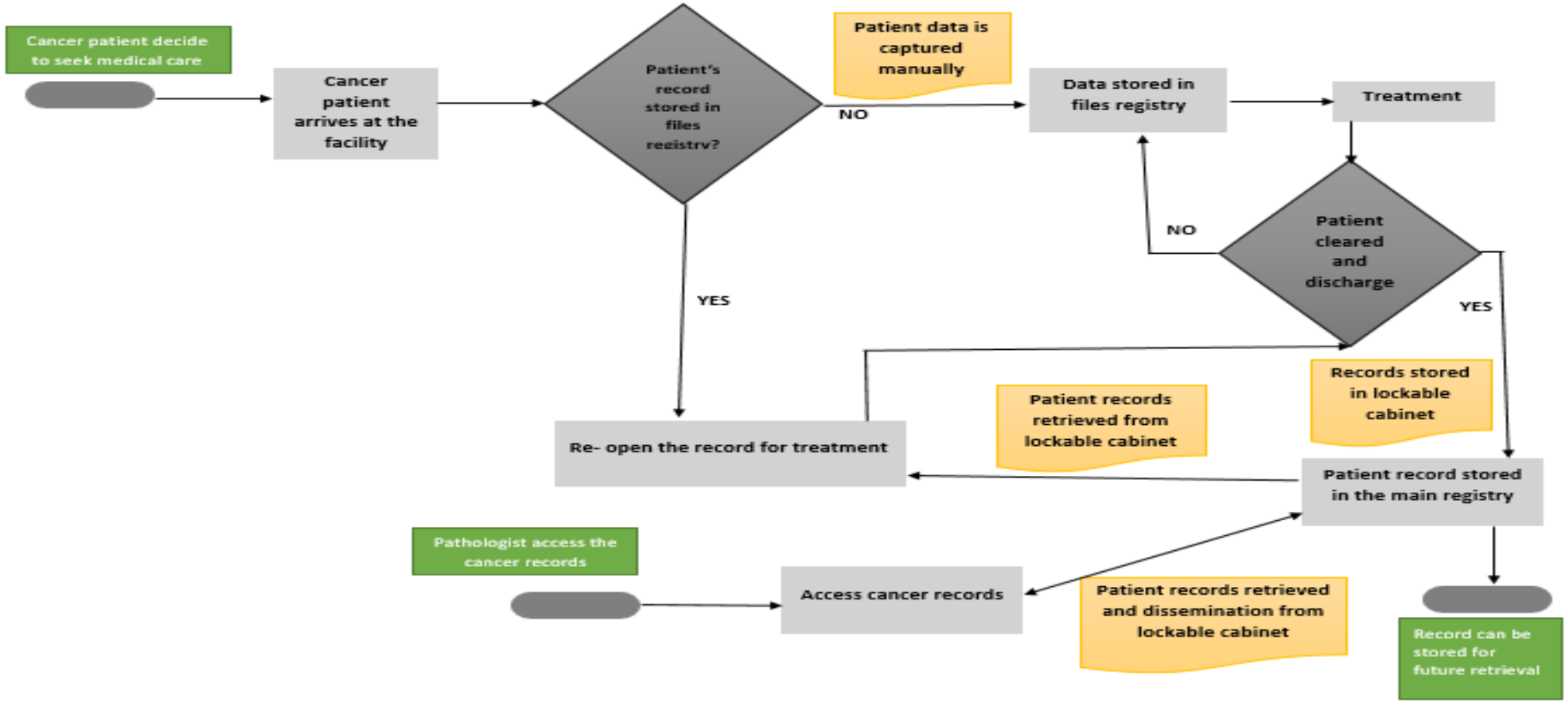


Figure 38: Cancer records management process model in KNH/UoN Department of Pathology

Based on the data gathered from the questionnaires and interview, we were able to understand the whole Cancer records management processes in KNH/UoN Department of Pathology and map it onto a flow chart. This was done to accomplish part of this study's objective. It also assisted us in learning where to inject the proposed solution into the cancer record management processes in our area of study. Figure 38 shows the standard process that KNH/UoN Department of Pathology followed at the time of this study.

At the beginning, cancer patient record was captured manually given that the details were not stored in the main registry. When the cancer patient had been treated and discharged then the records were stored in main registry in a lockable cabinet. These paper records tend to be unreliable and tedious to maintain since they could be damaged or lost. A lot of time also was lost digging into records which were probably missing and/or misfiled. The records from the main registry could be retrieved when the patient visit that facility several times for check-ups. This clearly showed that pathologists and practitioners may lack comprehensive and accurate data on cancer patients and thus unable to provide high quality medical care to the patients. Similarly the records could be retrieved manually from the main registry when requested by other pathologists / clinical officers or researchers.

Looking at these processes, we came up with a process model that showed where the ICT intervention of digitizing the cancer records would be applicable. The process is illustrated in Figure 39.

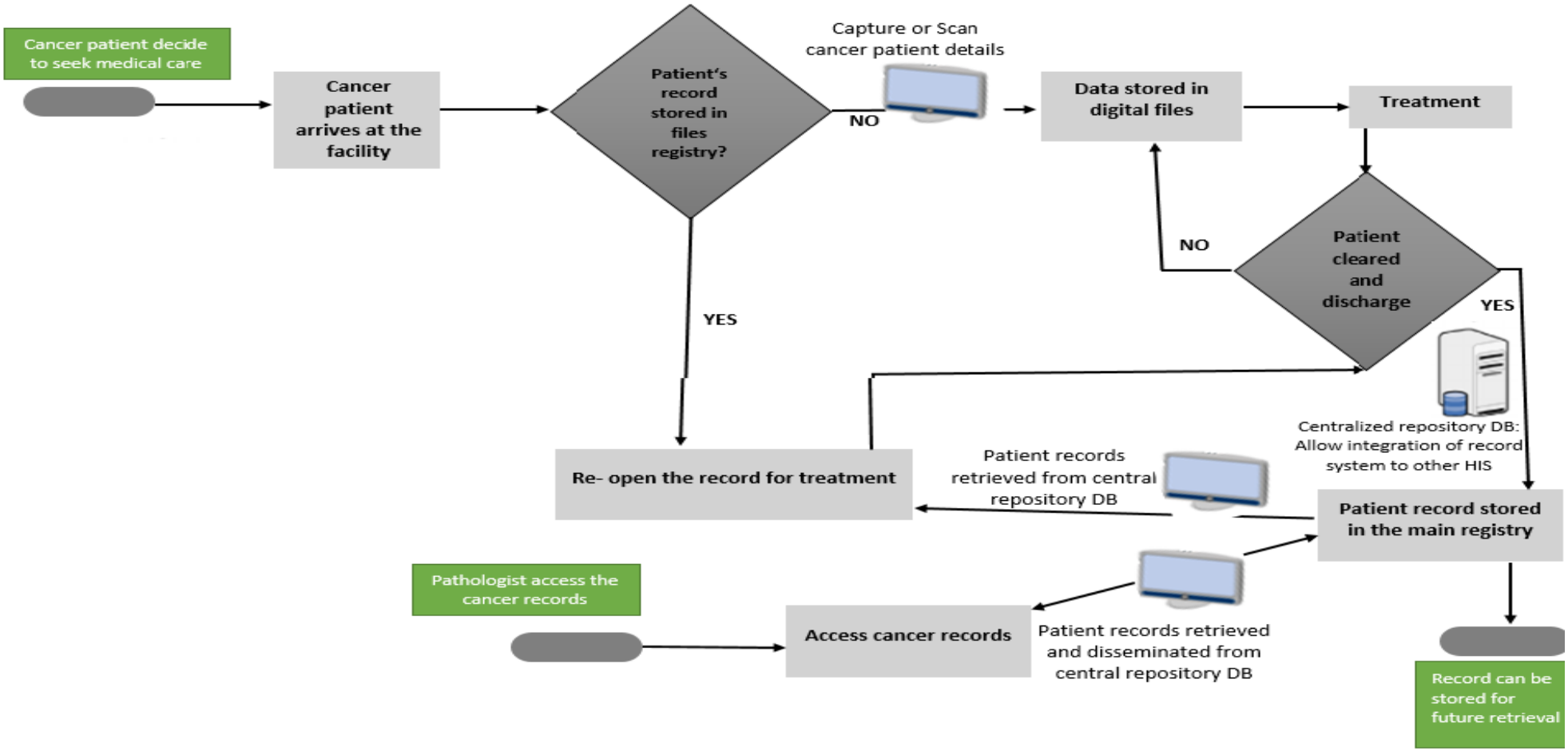


Figure 39: Cancer records management process model in KNH/UoN Department of Pathology: ICT Inclusive

5.4 System evaluation

Following development of the prototype, we went on to conduct an evaluation on the system with a number of respondents. We targeted seven participants to the evaluation questionnaires (two pathologists, one record clerk, three researcher/ medical student and one policy maker). Once the respondents had interacted with the system and had a feel of what it does, they were administered with the evaluation questionnaire.

The responses from the participants were positive about the proposed ICT intervention. The participants strongly agreed that the system would improve and enhance cancer record management practices. Majority of the respondents (86%) strongly agreed that cancer records could be identified and accessed quickly in the system and they were satisfied with the overall navigation experience of the system. 71% of the respondents strongly agreed tha cancer information from the system was well captured and represented since the platform provided basic statistics by analyzing data and search functionality as intended.

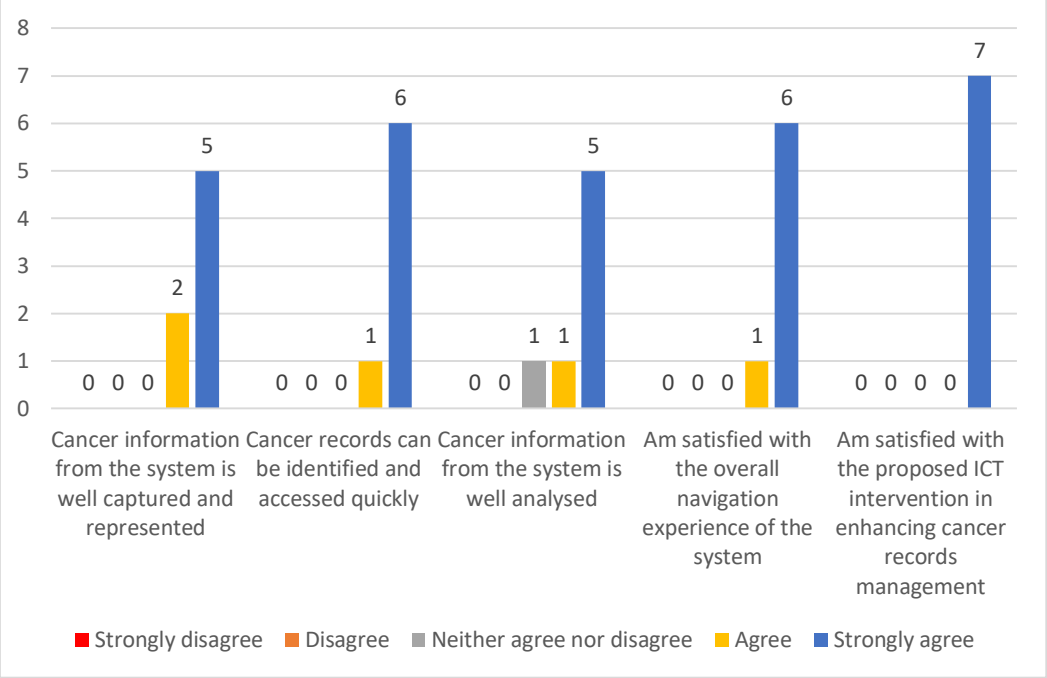


Figure 40: System evaluation

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

In KNH/UoN Department of Pathology all processes concerning cancer records remain to be done manually. The process of capturing and storing the cancer records were just keyed in forms (Microsoft Word Template) that were later printed and filled. Identification of the stored patient records including LAB test reports were done mainly using the LAB number instead of more advanced ways like ICD10 format which is currently used by physicians and healthcare providers. As far as capturing, storing and retrieving cancer records was concern, inability to track patient records with ease and loss or damage of patient records were the main challenges, since almost all these processes were done manually. The evaluation of the ICT usage in these processes was rated poor (0-25%), this was reported by most of the respondents 77.27% (17/ 22).

The study further concludes that cancer records stored in KNH/UoN Department of Pathology remained to be relevant to the researchers / medical students in their studies and for research purposes. Policy makers as well needed a platform that would provide basic statistics and search functionalities about cancer incidences and prevalence to assist and guide in decision making.

The developed system enabled digitization and archival of locally available cancer paper-records in a way that preserved and availed this information to a wide range of stakeholder thus improving overall cancer records management practices in the department under study. The system stored detailed information about cancer patients (such as demographics) and the initial treatments they had received (documented in histopathology report form). Applicability is more apparent in the transfer of medical related records or files from one department to another and it supported health organisations access old records instantly. Also all cancer records stored in paper form were scanned and uploaded as digital files onto a repository. Authorized users were allowed access to these records and retrieved information regarding a patient's medical history. The researcher also considered the system transitions to being used for new/current cancer test cases reports and a template was added in the system.

6.2 Limitation of the study

Access to personal medical reports from KNH/UoN Department of Pathology was a challenge since records were private and confidential and were archived in a place that was

only accessed by authorized persons. Relevant research permit letters were sorted to assist in data collection. The state in which some records were in, was also a challenge, they needed to be handled with care to ensure the rich information in those records were maintained.

Also the research participants were recruited from one of the four units and thus the generalizability of the findings may be limited because of the sample size. The unit involved was selected carefully based on the researcher objectives. Time constraint was also a limitation worthy of mention to get participants at their own convenient time to fill the questionnaires and respond to interview questions.

6.3 Recommendations for future works

Respondents suggested interoperability of Health Management Information systems in different health facilities need to be improved. This would enable cancer records stored on one form of database to be accessible in another form of database. GIS and comprehensive cancer surveillance system should be incorporated in the system to locate areas where many people with a different cancer cases are.

Also, from the study it was recommended that public health institutions need to allocate a significant budget to cater for technological development in their operations. This approach can also be replicated for other paper based health records such as x-ray reports, lab reports etc. Adequate ICT Infrastructure should be supplied and put in place since it was noted from the research carried out that there was no enough technology deployed and the one existing needed to be upgraded.

ICD10 coding system should be implemented fully to enable medical personnel track healthcare statistics. Periodic staff training should be planned for the medical staff to advance their ICT skills and make them relevant in the present day technological driven health care delivery and make them embrace and apply digital platforms.

Population based cancer registry should be in place in most counties country wide since the available cancer data is wanting and it could assist in monitoring incidences and prevalence of cancer cases. Capturing and storage of cancer records in central database will enable distributed sharing of this information. With cloud hosting in place, these records can be encrypted and stored on offsite servers where they can only be accessed with a unique login that will decrypt them. ID user sessions or access to systems must also be put on audit trail since any medical records have personal information on them that is a great legal risk and needs to be protected.

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APPENDICES

Appendix 1: User Guide for KNH/UoN Department of pathology cancer records management System. (http://knh.gdone.co.ke/)

Description

This system intends to store the cancer records in KNH on a digital platform. Data for the period 1969 to date would be captured and saved into the system. This would help in predicting future cancer cases by analysing the trends of the previous cases.

One Time Password (OTP) request

All users of the system must request a one-time password. A four digit random number will be sent to their phone with which they are registered with. The number is the password. Every time a user wants to login to the system they must request for a new password.

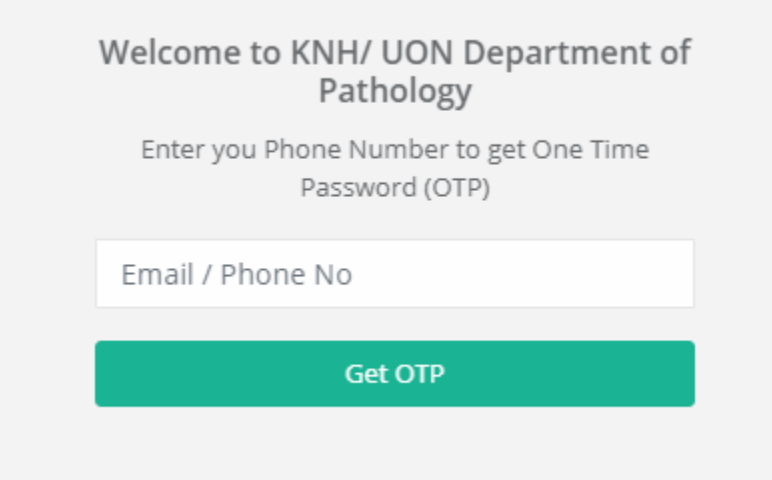


Figure 1: Login interface

A user must have been created by the administrator who will give user the rights of using the system. The user will be assigned roles in the system.

Login Page

A user will get a success message and the login page appears. They will be required to enter their phone number and the new password that has just been sent to their phone.

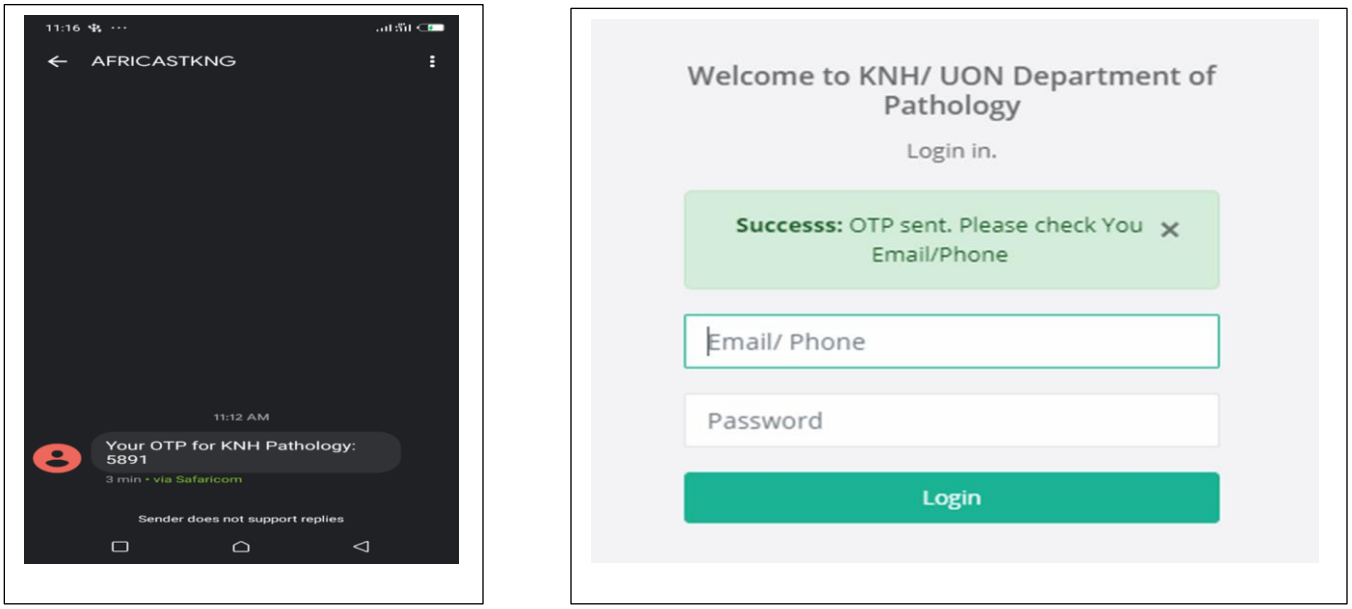


Figure 2: Login interface after OTP has been sent to the user via SMS.

Dashboard

The dashboard shows the count of all patients, records and all the users of the system.

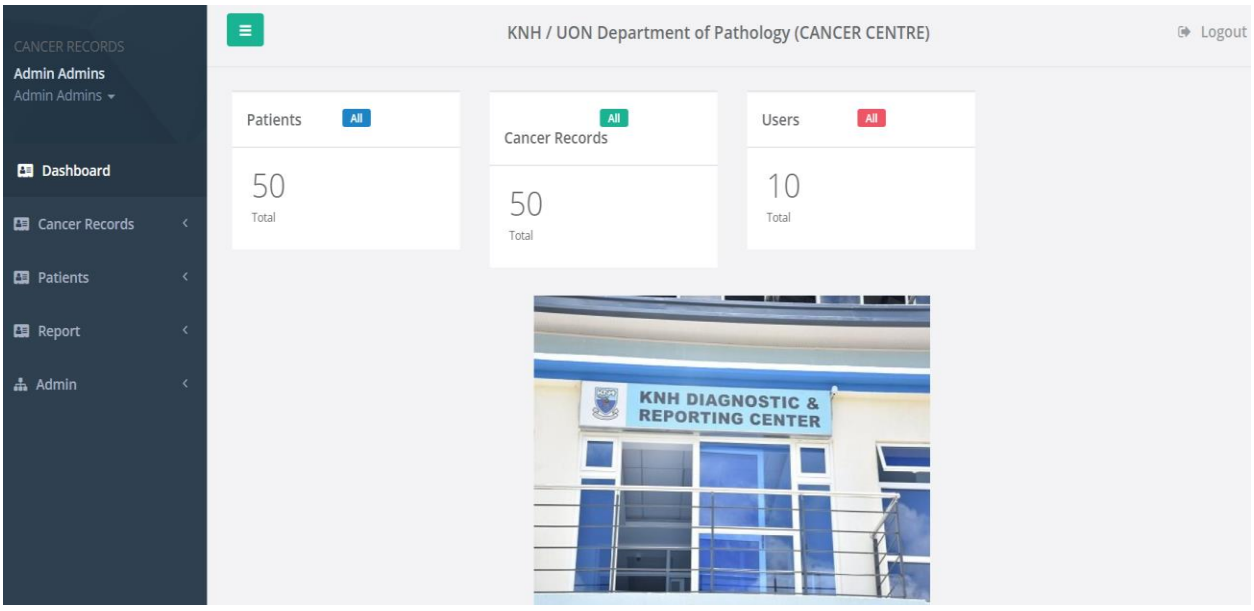


Figure 3: Main Dashboard after the user successfully logs in.

Menu

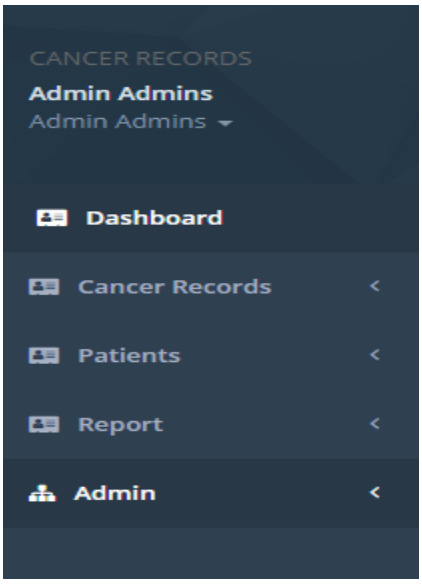


Figure 4: Navigational menus in the system.

View all cancers

One can see all cancers cases that are in the system.

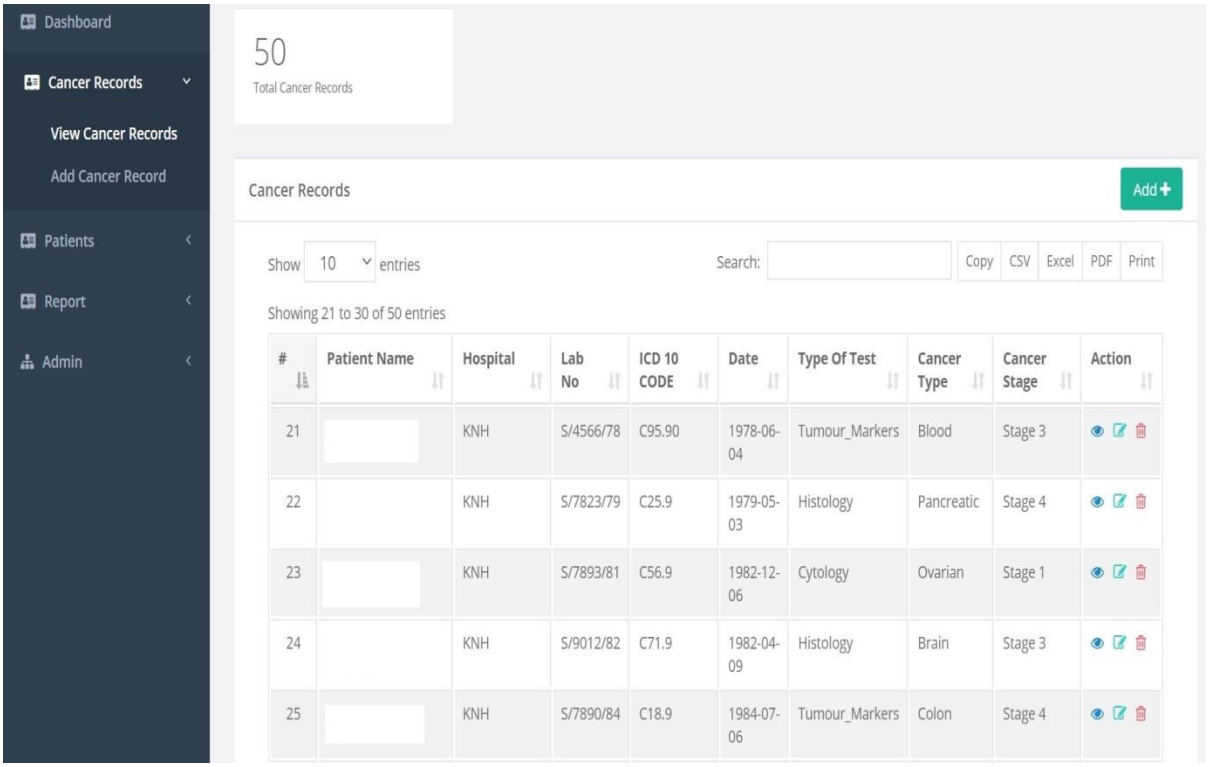


Figure 5: A view of cancer records in the system.

We have a row with action. It has three buttons (see figure 5- Action).

- Eye Icon – Click to view individual cancer details
- Editor Icon – Click to modify each cancer record
- Trash Icon – click to delete a cancer record

View Individual Cancer Record

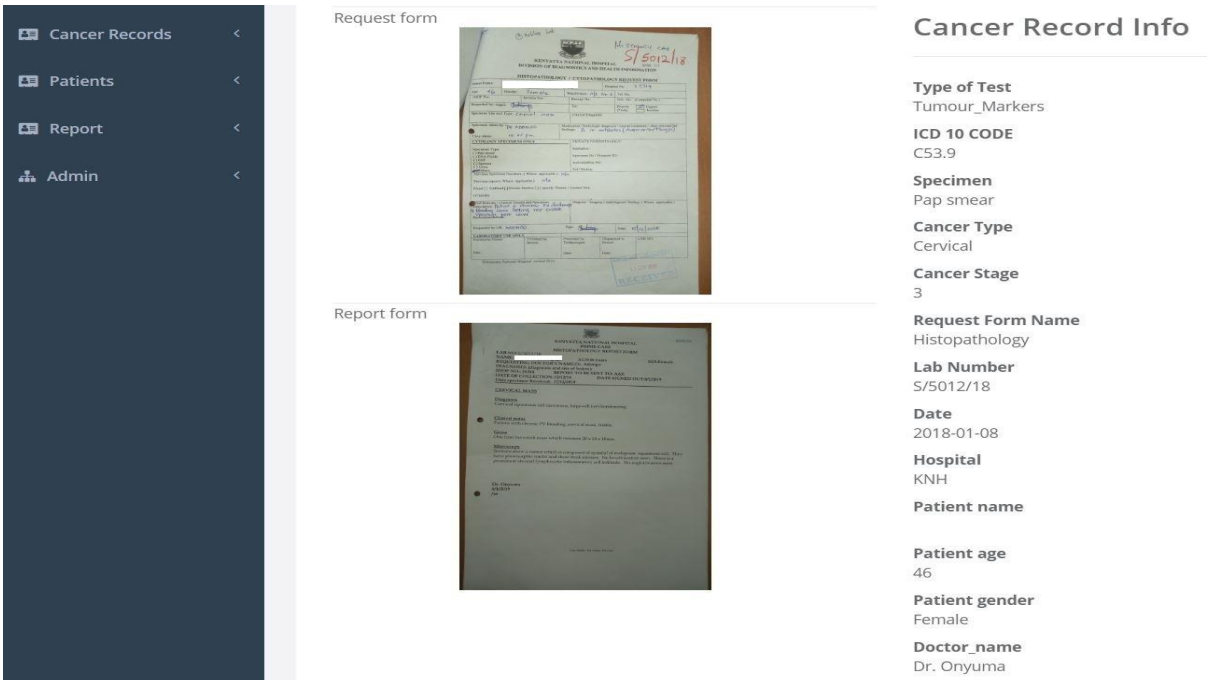


Figure 6: A comprehensive view of a single record in the system.

Add Cancer Record

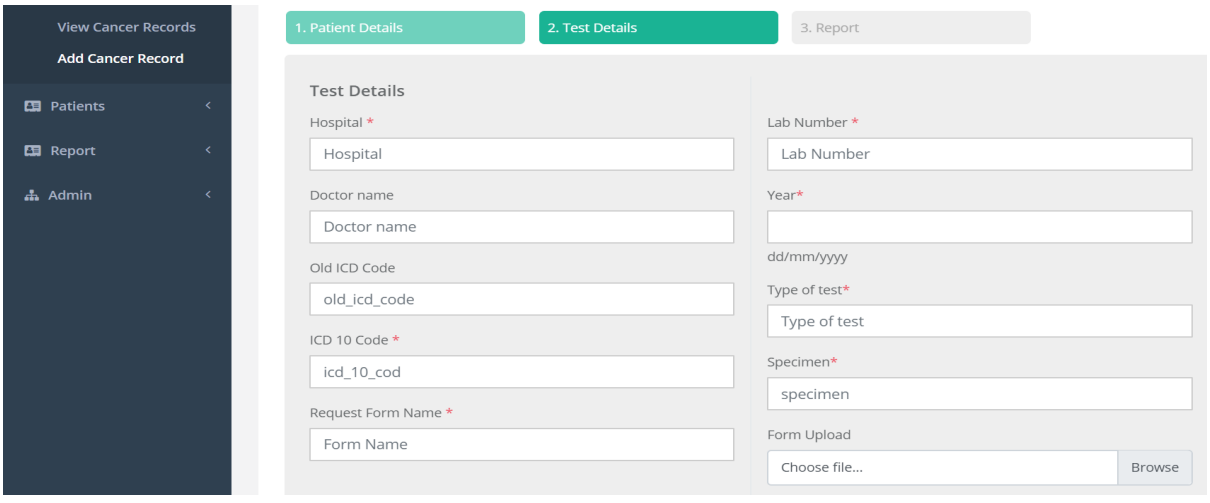


Figure 7: A form used to capture Cancer patient Test Details.

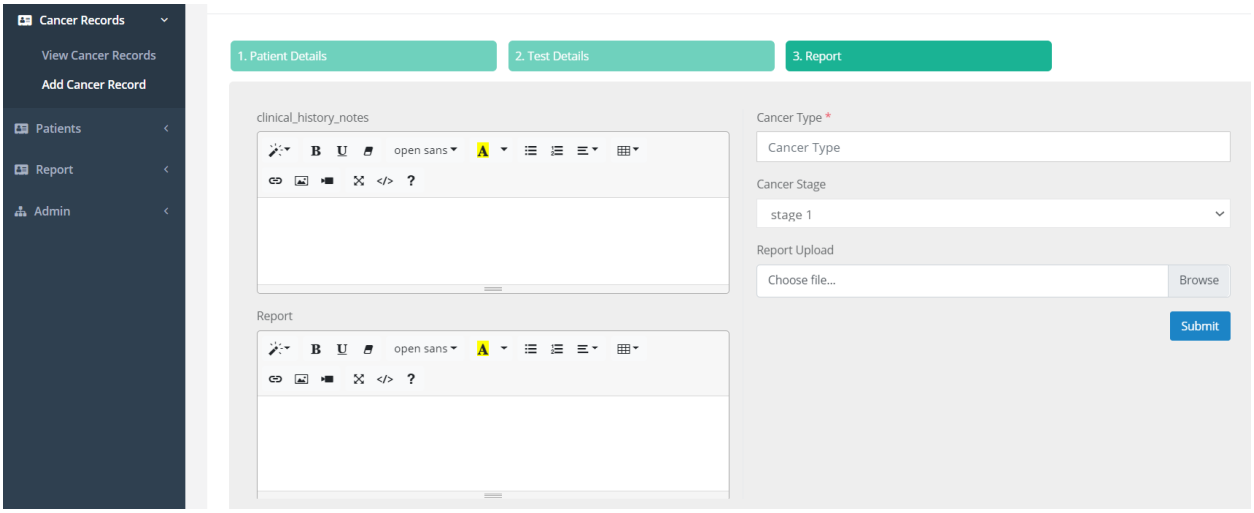


Figure 8: A form used to capture patient cancer report.

Report.

The system uses bar and line charts to display reports for them to be easily read and analysed.

We have three types of report.

- General report.
- Cancer distributions by gender and year.
- Cancer distributions by age and year.

Line Chart

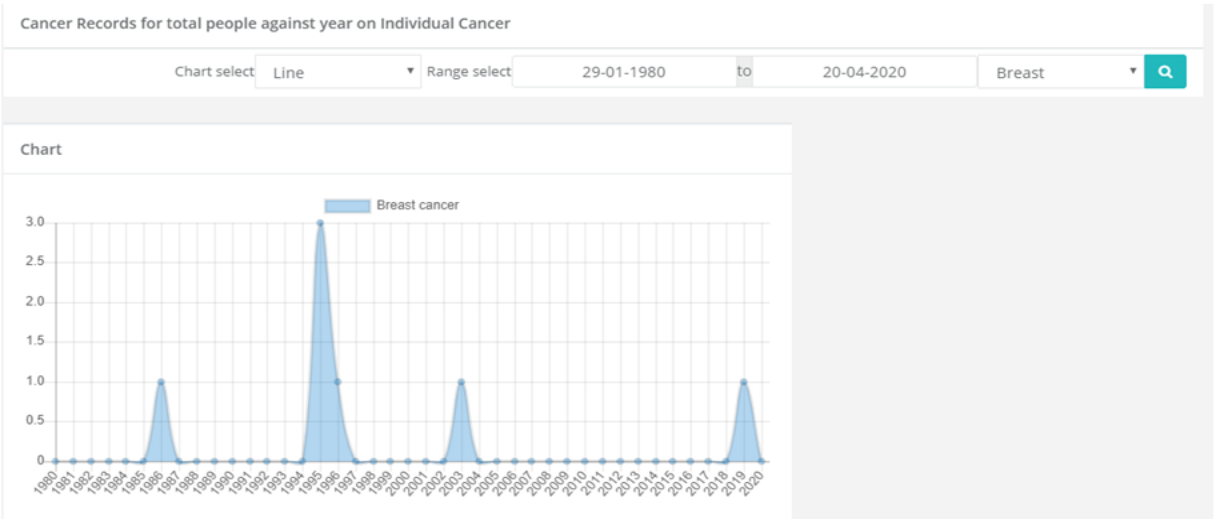


Figure 9: A line chart showing total patients against year on individual cancer.

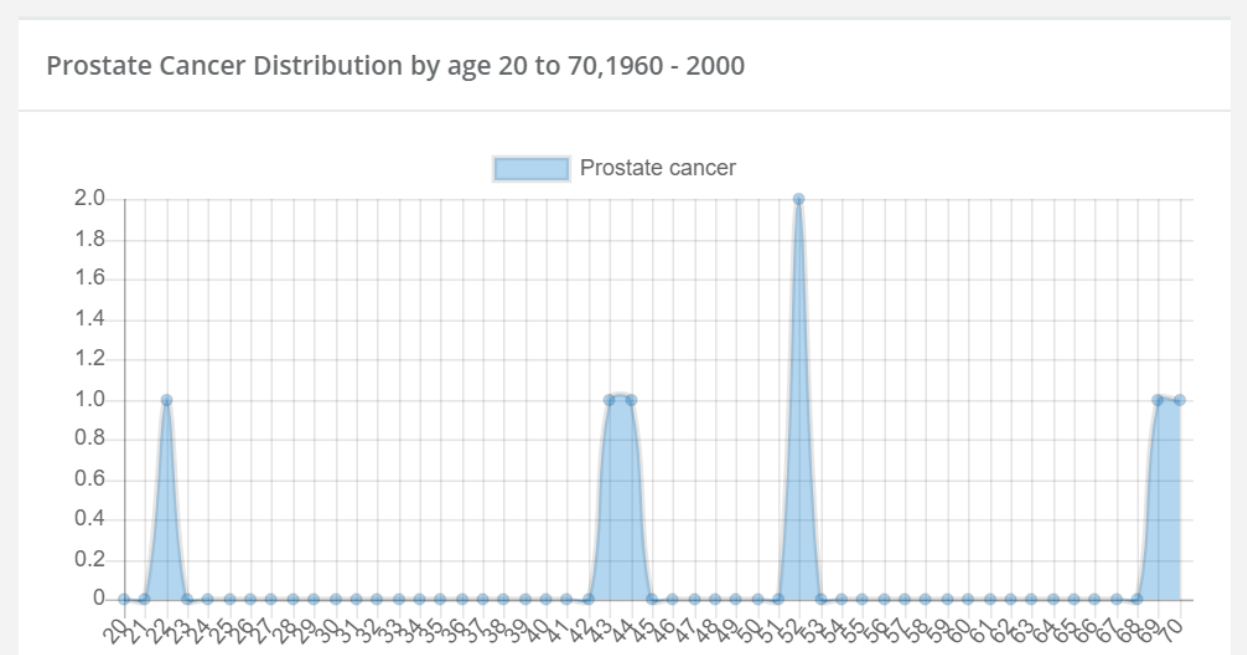


Figure 10: A line chart showing individual cancer distribution by age.

Bar Chart

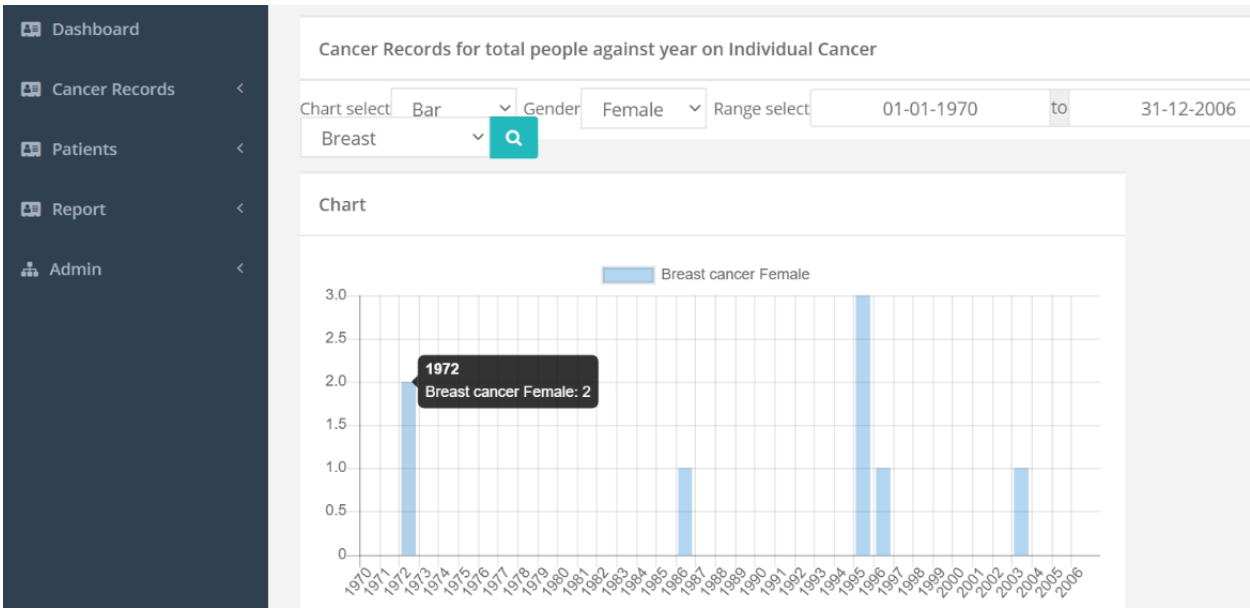


Figure 11: A bar chart showing cancer cases for a specific gender against year.

Specific Doctors reports and test types

Search functionality was also included to filter specific doctor reports as shown below.

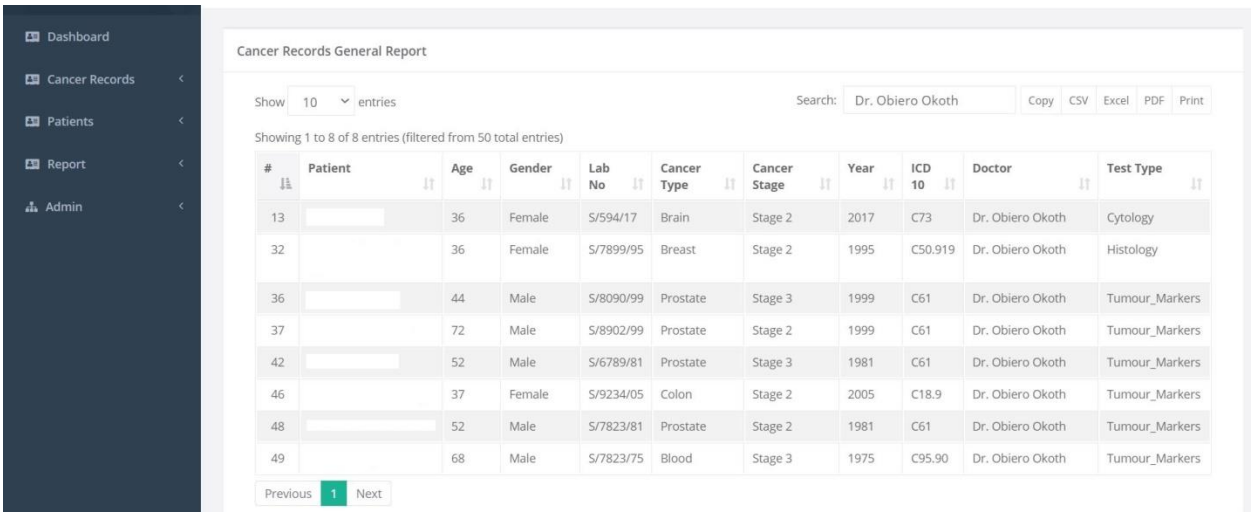


Figure 12: A report for specific doctor test cases.

The report can be printed or be downloaded in CSV, excel or PDF format as shown.

KNH-UON-DEPT-Pathology

#	Patient	Age	Gender	Lab No	Cancer Type	Cancer Stage	Year	ICD 10	Doctor	Test Type
13		36	Female	S/594/17	Brain	Stage 2	2017	C73	Dr. Obiero Okoth	Cytology
32		36	Female	S/7899/95	Breast	Stage 2	1995	C50.919	Dr. Obiero Okoth	Histology
36		44	Male	S/8090/99	Prostate	Stage 3	1999	C61	Dr. Obiero Okoth	Tumour_Markers
37		72	Male	S/8902/99	Prostate	Stage 2	1999	C61	Dr. Obiero Okoth	Tumour_Markers
42		52	Male	S/6789/81	Prostate	Stage 3	1981	C61	Dr. Obiero Okoth	Tumour_Markers
46		37	Female	S/9234/05	Colon	Stage 2	2005	C18.9	Dr. Obiero Okoth	Tumour_Markers
48		52	Male	S/7823/81	Prostate	Stage 2	1981	C61	Dr. Obiero Okoth	Tumour_Markers
49		68	Male	S/7823/75	Blood	Stage 3	1975	C95.90	Dr. Obiero Okoth	Tumour_Markers

Figure 13: A report for specific doctor test cases (PDF Format downloaded from the system).

Admin

In the Main menu, there is admin with three sub menus.

- Manage users
- Manage roles
- Activity Logs

Roles

View roles that are in the system. These are the permissions that each role has in the system.

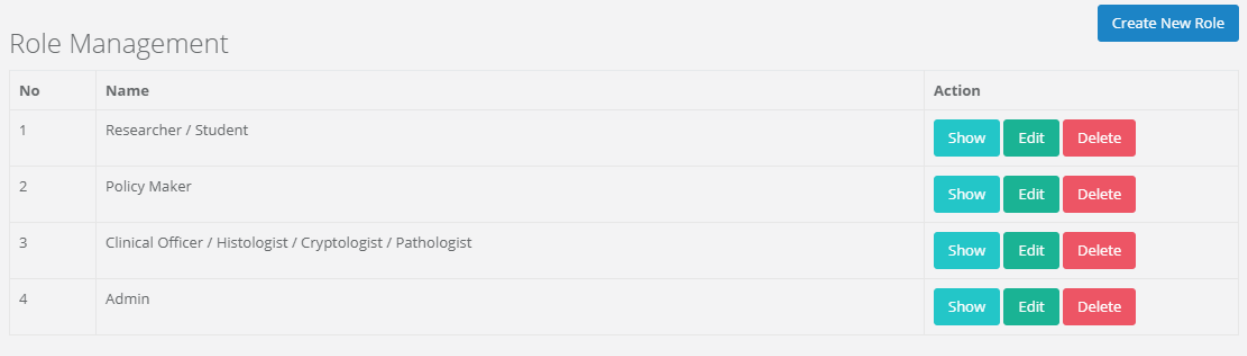


Figure 14: Role management panel to assign roles to various system users.

New Role

Give role name and select the checkbox to give permission to that role. Once checked, that permission will be granted to that role.

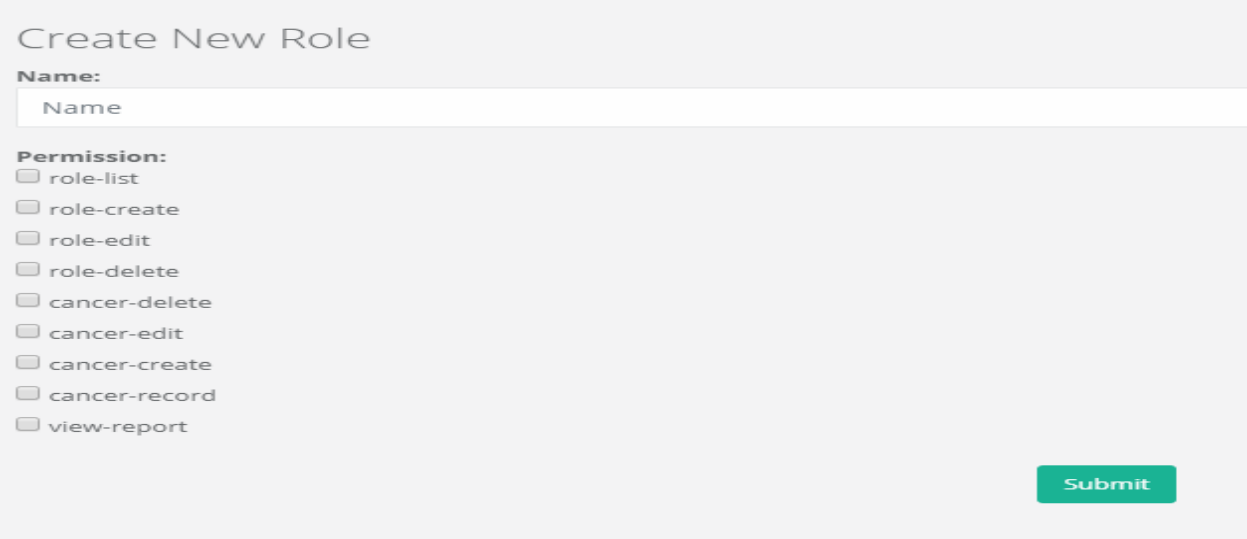


Figure 15: A form used to create a new role and grant permissions for respective system users.

Users

These are system users. They are created by the admin. Once a user is created, he/she is given a role. The role will define what that user will be able to access in the system.

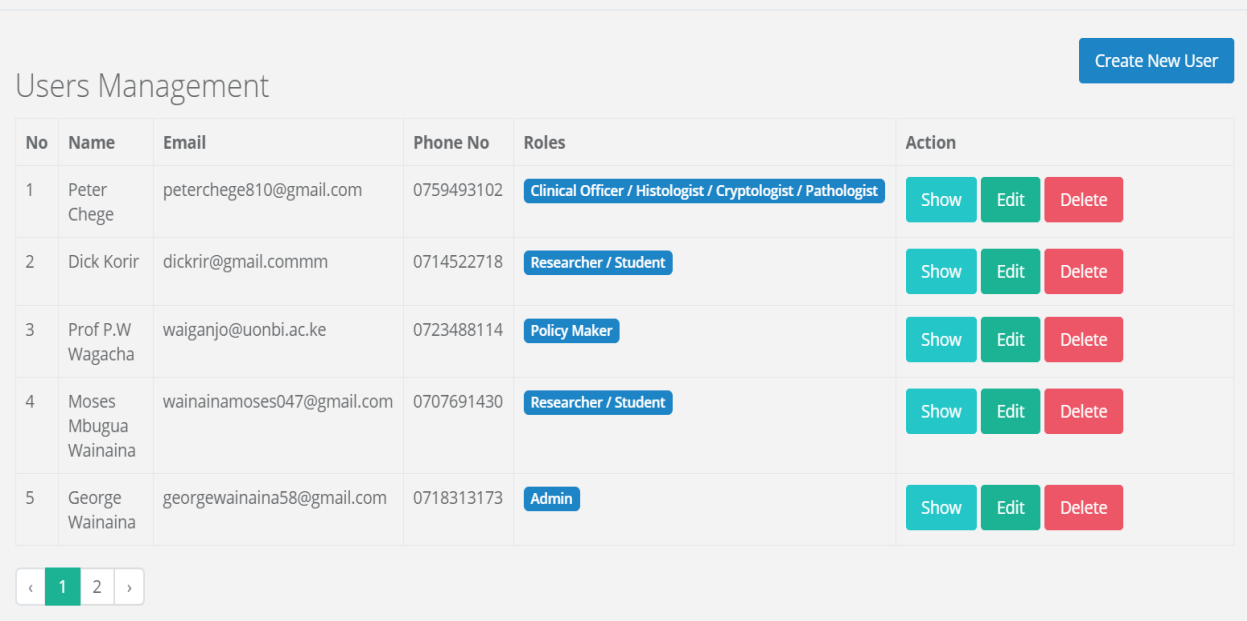


Figure 16: Users in the system with their roles.

New User

Create a user and assign a role

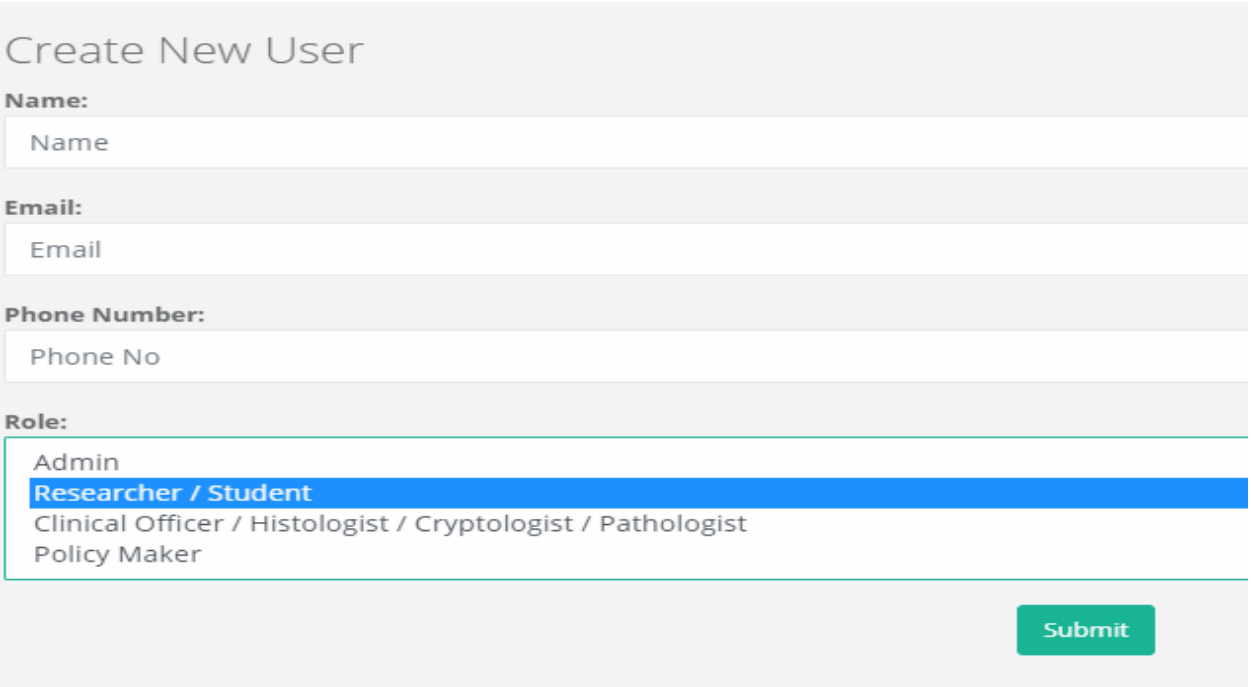


Figure 17: A form to add new user in the system.

The system transitions to being used for new/current records.

System also considered the future contributions and implications after all records have been digitized. Future cancer cases needs to be captured as well and no manual records will be there. To capture Report data such as diagnosis, Clinical note, Gross and Microscopy, the following template was included in the system.

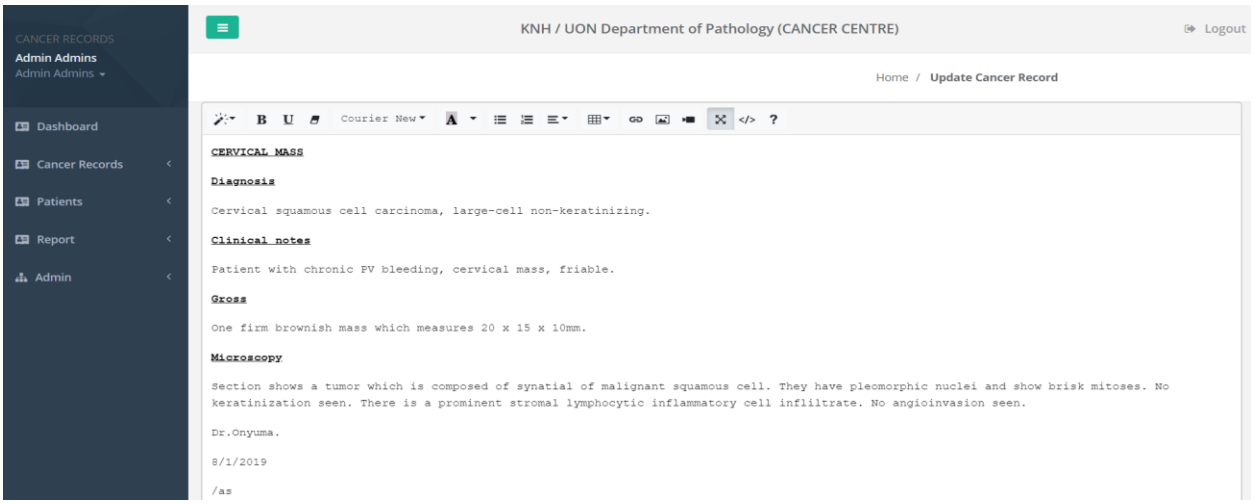


Figure 18:A template to capture current and future cancer test reports (No documents uploading).

Activity Logs

This was to ensure all user sessions or access to systems were put on audit trail.

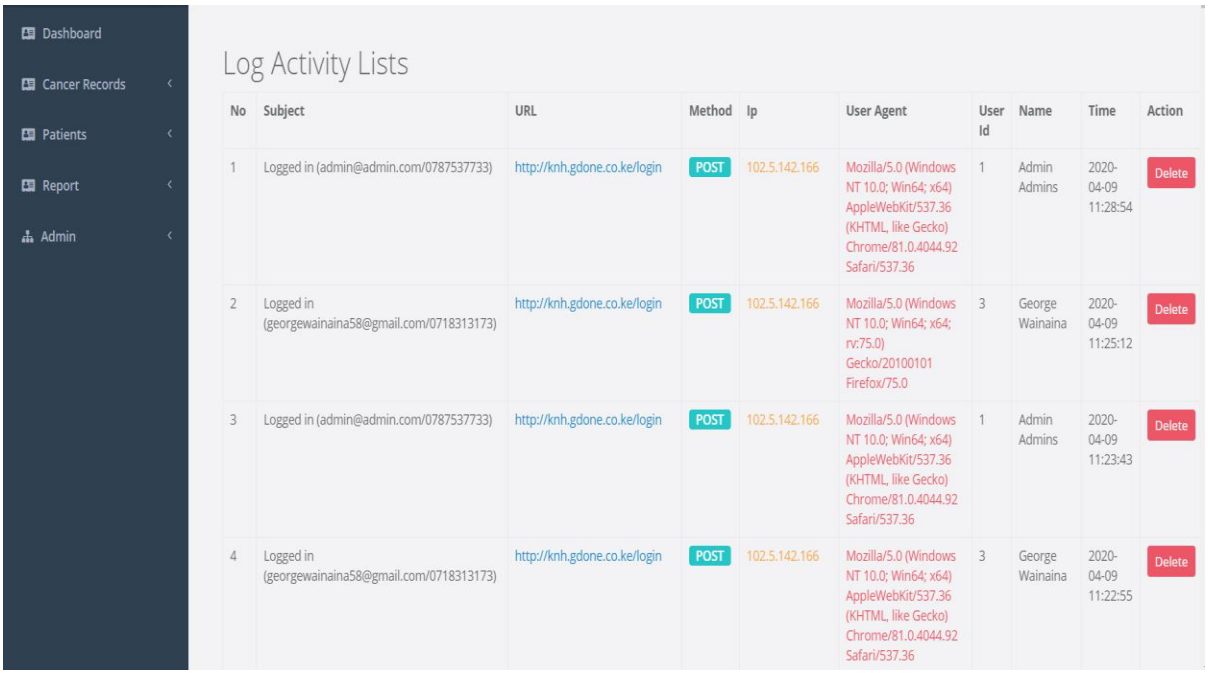


Figure 19: Activity log that tracks and record the users who accessed the system.

Appendix 2: Data Collection: Introduction.

Thank you for kindly participating in this questionnaire. Your opinions are important for the accuracy and preciseness of this research. It may be used to support recommendations proposed in conclusion to my dissertation project.

The aim is to identify and collect data about leveraging ICT towards digital preservation of Cancer records; Case KNH/UoN Department of Pathology. This questionnaire is for the purpose of Post-Graduate studies only by the researcher and the University of Nairobi – School of Computing and Informatics (Distributed Computing Technology Programme). Your responses will remain confidential and anonymous.

Data from this research will be reported only as a collective combined total. If you have any questions about this project, feel free to contact George Wainaina (Researcher) at georgewainaina58@gmail.com (0718313173).

Appendix 3: Clinical Officer / Histologist / Cryptologist / Pathologist Questionnaire

Section A: Socio-Demographic Characteristics.	
Please indicate your age group	○ 18 – 24
	○ 25 – 34
	○ 35 – 44
	○ Over 45 years
Gender	○ Male
	○ Female
Highest level of education	○ College (certificate/diploma)
	○ Undergraduate
	○ Postgraduate (masters/PhD)
Years served / Years you have been in that department.	○ 1 - 5 years
	○ 6 – 10 years
	○ More than 10 years
Section B: Cancer data / Information Record Management.	

How are the patient's personal data captured?	○ Through standard forms/books ○ Through handwritten paper notes ○ ICT based application ○ No mechanisms ○ Other. Please specify
How are the information stored after it is captured?	○ Through standard forms/books ○ Through handwritten paper notes ○ ICT based application ○ No mechanisms ○ Other. Please specify
What are the unique ways of identifying a particular patient record?	
How are the lab reports for Histology and cytology documented? (Is there a standard used e.g ICD10)	
How do you rate the current means of cancer record management?	○ Extremely efficient
	○ Very efficient
	○ Somewhat efficient
	○ Not so efficient
	○ Not at all efficient
	○ Not so applicable
Please rate in your own evaluation the level of ICT usage in the whole process of cancer data / Information capturing and documenting.	○ 0-25%
	○ 26-50%
	○ 51-75%
	○ Over 75%
	○ I don't know
What are the main challenge that hinders the implementation of digital capturing, documentation and preservation of cancer records?	

How do you think KNH can deal with the challenges mention above?	
Section C: Recommendations.	
In your opinion, what do you think would help improve cancer record management?	
What if a digital platform was to be introduced to enhance cancer records management in KNH, how would you rate it in improving the community healthcare service delivery process?	○ Extremely useful ○ Very useful ○ Somewhat useful ○ Not so useful ○ Not at all useful
What are your recommendations of using the digital platform for capturing, storing, retrieving and preservation of cancer records?	

Appendix 4: Policy Makers Questionnaire

Section A: Socio-Demographic Characteristics.	
Please specify your Age group	○ 18 – 24 ○ 25 – 34 ○ 35 – 44 ○ Over 45 years
Gender	○ Male ○ Female
Highest level of education	○ College (certificate/diploma) ○ Undergraduate ○ Postgraduate (masters/PhD)

Section B: Cancer data / Information Record Accessibility.	
How often do you access and use the cancer records in KNH?	○ Very infrequently
	○ Infrequently
	○ Frequently
	○ Very frequently
	○ Do not use
	○ Was not aware of
What kind of information do you access?	
What is your level of satisfaction with the information you get?	○ Very Unsatisfied
	○ Neutral
	○ Satisfied
What are the major challenges with the current cancer record keeping practices?	▪ Lack of clear record keeping guidelines or protocols
	▪ Poor communication and data sharing between the different departments
	▪ Inability to track patient records with ease
	▪ Loss or damage of patient records
	▪ Lack of technology in records management
	▪ Other. Please specify
How do you rate the current means of record keeping?	○ Extremely efficient
	○ Very efficient
	○ Somewhat efficient
	○ Not so efficient
	○ Not at all efficient
	○ Not so applicable
Please rate in your own evaluation the level of ICT usage in the whole process of	○ 0-25%
	○ 26-50%

cancer data / Information record management.	○ 51-75% ○ Over 75% ○ I don't know
What are the main challenge that hinders the implementation of digital preservation of cancer record?	
How do you think KNH can deal with the challenges mention above?	
Section C: Recommendations.	
What do you think KNH can do to improve cancer records management?	
What if a digital preservation platform was to be introduced to enhance cancer records management in KNH, how would you rate it in improving the community healthcare service delivery process?	○ Extremely useful ○ Very useful ○ Somewhat useful ○ Not so useful ○ Not at all useful
What are the recommendations of using the digital platform for capturing, storing, retrieving and preservation of cancer records?	

Appendix 5: Researchers / Lecturers / Medical Students Questionnaire.

Section A: Socio-Demographic Characteristics.	
Please Specify your Age group	○ 18 – 24 ○ 25 – 34 ○ 35 – 44 ○ Over 45 years
Gender	○ Male ○ Female
Highest level of education	○ College (certificate/diploma)

	○ Undergraduate
	○ Postgraduate (masters/PhD)
	○ 6 – 10 years
	○ More than 10 years
Section B: Cancer data / Information Accessibility.	
In your own knowledge, how are the cancer records kept?	○ Manually
	○ Digitally
How does it work?	
Have you ever wanted to retrieve a patient record but were unable to do so?	○ Yes
	○ No
	If you answered 'Yes', why?
Which kind of Information do you access?	
How often do you access cancer related data.	○ Always
	○ Frequently
	○ Sometimes
	○ Rarely
	○ Never
What are the major challenges with the current cancer record keeping practices?	▪ Lack of clear record keeping guidelines or protocols
	▪ Poor communication and data sharing between the different departments
	▪ Inability to track patient records with ease
	▪ Loss or damage of patient records
	▪ Lack of technology in records management
	▪ Other. Please specify

How do you rate the current means of record keeping?	○ Extremely efficient
	○ Very efficient
	○ Somewhat efficient
	○ Not so efficient
	○ Not at all efficient
	○ Not so applicable
Please rate in your own evaluation the level of ICT usage in the whole process of cancer data / Information record keeping.	○ 0-25%
	○ 26-50%
	○ 51-75%
	○ Over 75%
	○ I don't know
What are the main challenges that hinder the implementation of digital preservation of cancer record to enable distributed form of accessibility?	
How do you think KNH can deal with the challenges mention above?	
Section C: Recommendations.	
In your opinion, what do you think would help improve cancer record keeping and accessibility?	
What if a digital preservation platform was to be introduced to enhance cancer records management in KNH, how would you rate it in improving the community healthcare service delivery process?	○ Extremely useful
	○ Very useful
	○ Somewhat useful
	○ Not so useful
	○ Not at all useful
What are the recommendations of using the digital platform for capturing, storing, retrieving and preservation of cancer records?	

Appendix 6: Record Clerks Questionnaire.

Section A: Socio-Demographic Characteristics.	
Please indicate your Age group	○ 18 – 24
	○ 25 – 34
	○ 35 – 44
	○ Over 45 years
Gender	○ Male
	○ Female
Years served / Years you have been in that department.	○ 1 - 5 years
	○ 6 – 10 years
	○ More than 10 years
Section B: Cancer data / Information Record Keeping.	
In your own knowledge, how are the cancer records kept?	○ Manually
	○ Digitally
Which standard way of filling do you use?	
How does it work?	
How are the patient's personal data captured?	○ Through standard forms/books ○ Through handwritten paper notes ○ ICT based application ○ No mechanisms ○ Other. Please specify
How are the information stored after it is captured?	○ Through standard forms/books ○ Through handwritten paper notes ○ ICT based application ○ No mechanisms ○ Other. Please specify
What are the unique ways of identifying a particular patient record?	
What challenges do you face when collecting and retrieving data from the	

current system of the cancer record keeping?	
Have you ever wanted to retrieve a patient record but were unable to do so?	○ Yes
	○ No
	If you answered 'Yes', why?
What are the major challenges with the current cancer record keeping practices?	▪ Lack of clear record keeping guidelines or protocols
	▪ Poor communication and data sharing between the different departments
	▪ Inability to track patient records with ease
	▪ Loss or damage of patient records
	▪ Lack of technology in records management
	▪ Other. Please specify
How do you rate the current means of record keeping?	○ Extremely efficient
	○ Very efficient
	○ Somewhat efficient
	○ Not so efficient
	○ Not at all efficient
	○ Not so applicable
Please rate in your own evaluation the level of ICT usage in the whole process of cancer data / Information record keeping.	○ 0-25%
	○ 26-50%
	○ 51-75%
	○ Over 75%

	○ I don't know
What are the main challenges that hinder the implementation of digital preservation of cancer record?	
How do you think KNH can deal with the challenges mention above?	
Section C: Recommendations.	
In your opinion, what do you think would help improve cancer record keeping?	
What if a digital preservation platform was to be introduced to enhance cancer records management in KNH, how would you rate it in improving the community healthcare service delivery process?	○ Extremely useful ○ Very useful ○ Somewhat useful ○ Not so useful ○ Not at all useful
What are the recommendations of using the digital platform for capturing, storing, retrieving and preservation of cancer records?	

Appendix 7. Interview Guide.

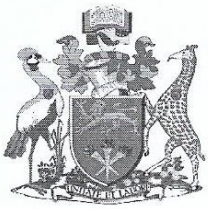
i. What is your role in this department?
ii. Tell me about the whole process of capturing, storing and retrieving stored cancer records.
iii. What are major challenges that are faced when using processes displayed above?
iv. What do you think should be done to address the challenges?

Appendix 8: System Evaluation questionnaire

Tick where appropriate

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
Cancer information from the system is well captured and represented.					
Cancer records can be identified and accessed quickly.					
Cancer information from the system is well analysed.					
Am satisfied with the overall navigation experience of the system.					
Am satisfied with the proposed ICT intervention in enhancing cancer records management.					

Appendix 9: Research Permit Letter.



UNIVERSITY OF NAIROBI
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P. O. Box 30197
00100 GPO
Nairobi, Kenya

Our Ref: UON/CBPS/SCI/ MSC/DCT/2016

14th February 2020

To Whom it May Concern

Dear Sir/Madam

RE: RESEARCH PERMIT – GEORGE NDUNG'U WAINAINA REG.NO. P53/85611/2016

The above named is a bona fide student pursuing an MSc course in Distributed Computing Technology at the School of Computing and Informatics, University of Nairobi. He is currently carrying out his research on the project entitled ***"Leveraging ICT Towards Digital Preservation of Cancer Records: Case of Kenyatta National Hospital; University of Nairobi, Department of Pathology.***". He is under supervision of Prof. Peter w. Wagacha.

The project involves gathering relevant information from various institutions and he has informed the office that he would wish to carry his research in your organization.

We would be grateful if you could assist Wainaina as he gathers data for his research.

If you have any queries about the exercise please do not hesitate to contact us.

Yours sincerely

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PROF. ROBERT O. OBOKO
DIRECTOR
SCHOOL OF COMPUTING AND INFORMATICS

ROO/jsn