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

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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 paper-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).

1. INTRODUCTION

Worldwide, cancer beats HIV, malaria and tuberculosis combined, as the leading cause of death. Mutinda J. (2019), estimates that 70% of the world's cancer burden is in Low- and Middle-Income Countries (LMICs). In Kenya as of 2019, 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, with an annual mortality rate of 28,000.

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 world population lacks quality cancer registration (Bray, *et al.,* 2015). Kenyatta National Hospital (KNH) and the University of Nairobi (UoN) Pathology Department 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. In order to effectively manage cancer, an evidence-based approach 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 objective information concerning the number of new cases of cancer, cancer-related mortalities, and 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 in the cancer burden within different populations and regions, thus implementing effective cancer control plans (Coebergh, *et al.*, 2015).

This study therefore purposed to digitize Kenyatta National Hospital (KNH) and University of Nairobi (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.

2. OBJECTIVES

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.

2.1 The 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.

3. METHODS

This research study involved three key phases: Phase 1 was the pre-study. This involved investigating the challenges and processes in the current cancer records management practices of the KNH/UoN Department of Pathology. Questionnaires and interviews were used to gather data during this exercise. During the second phase, the first step was to gather system requirements from the core users before proceeding to the ICT intervention development. A web application that stored detailed information about cancer patients (such as demographics) and the initial treatments they received (e.g. histopathology report form) was developed. Authorized users were allowed access to these records and retrieved information regarding a patient's medical history (e.g. lab results, screening information, and any history of a previous cancer).

The third phase was to evaluate the developed ICT intervention.

Scope of the study

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. The project aimed to provide an application prototype that facilitated digitized cancer record keeping in health institution.

3.1 Pre-study

This phase was conducted as the first objective of this research, in order to inform about the challenges and processes in in the current cancer records management practices of the KNH/UoN Department of Pathology. We did a thorough investigation through literature review and involvement of a significant number of participants who included health science professionals, record clerks, researchers, doctors, and medical student. Some of the data gathered from literature included a review of existing applications and documentation regarding cancer records .Some of the related work reviewed included:

3.1.1 Kenya Health Policy 2014–2030

The Kenya Health Policy, 2014–2030 gives directions to ensure significant improvement in overall status of health in Kenya in line with the Constitution of Kenya 2010, the country's long term development agenda, Vision 2030 and global commitments. The second objective of Kenya Health Policy 2014-2030 is to halt and reverse the rising burden of non- communicable conditions. Cancer disease is one of non-communicable condition. These non-communicable diseases represent an increasingly significant burden of ill health and death in the country.

These represented 50% to 70% of all hospital admissions and up to half of all inpatient mortality (Kenya Health Policy 2014–2030).

3.1.2 Medical Records at KNH

KNH receives a very large number of patients. According to (Cheruiyot 2013), 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.

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Figure 1: Histopathology Report Forms (Source: KNH/UoN Dept. of Pathology)

Figure 2: 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.

3.1.3 KNH's ICT Master Plan (2012)

KNH's ICT Master Plan was prepared in line with the Vision 2030 goal for the health sector to provide equitable and affordable health services to all Kenyans. Projects within The ICT Master Plan included digitizing all of KNH's manual records (approximately 40 Million paper documents) from the past 10 years onwards. A few areas were highlighted as priorities for automation including the patient registration and billing system. (Cheruiyot, 2013).

3.1.4 ICD-10 Coding system

The ICD is the international standard diagnostic classification for the entire general epidemiological, health management purposes and clinical use. This ICD-10 is used to classify and to record diseases and other health problems reported on many types of health and other records like death certificates. Also ICD-10 enables storing and retrieving diagnostic information for epidemiological, clinical and quality purposes (Valerie J et al 2012). However according to (Kiongo 2015) the coding and reporting of procedures and diseases in

Medicine at KNH is not satisfactorily done as per the WHO guidelines in their publication about ICD-10.

3.1.5 Benefits of Digitizing Paper Records

Enables all data to be stored in a single location (Dollar, 2002). They can be quickly accessed and retrieved (Bates, *et al.*, 2003). , Enhance communication and engagement between doctors. (Richards, *et al.*, 2012). Improved quality of health care. (Menachemi, *et al.*, 2011). Ensures scalability and reliability of the records (Forsea, 2016).

3.1.6 National Cancer Institute

National Cancer Institute (NCI) had noted that in Kenya in Kenya, cancer is the 3rd leading cause of death after cardiovascular and infectious diseases. The annual incidence of cancer was estimated at 47,887 new cancer cases, with an annual mortality 32,987 in 2018. NCI also noted that prostate, Oesophageal and colorectal are the leading cancers on Men, while breast, cervical and oesophageal cancers are most common women. Oesophageal cancer is the leading cause of cancer mortality in the country Kenya contributing 13.2 % (4,351 deaths). Cervical cancer is the second leading cause of cancer death contributing 10% (3,266 deaths) while breast cancer comes in third at 7.7% (2,553 deaths). (GLOBOCAN, 2018)

3.1.7 Frameworks and models reviewed

3.1.7.1 Implementation model of CanReg5 – (Cancer Registry

National Agency for Research on Cancer (IARC) of WHO used CanReg model to develop a system that help nations implement their own cancer registration (Pardamean, *et al.*, 2015).

The model enables capturing of cancer records in hospitals with limited computer and network support. Unit Cancer Registration (UCR) requires data entry staff and a personal computer to run this CANREG 5.

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.

3.1.7.1 A Digital Transformation Business Model.

Prem (2015) wrote a paper to study the changes in business model innovation brought about by the transformation to

digital technologies. This model aims to represent empirical objects and empirical characteristics of phenomena businesses experience in the process of digitization. It models particular components of business models and assumes underlying causality in the gap between components following changes in any given component. The model connects changes in business model components and their linkages with the precise characteristics of digital technologies and this was the basic component used from this model.

3.1.7.3 E-health readiness framework from electronic health records perspective.

This framework is concerned with three domains relevant to E-Health readiness practitioner, organization and public. It highlights the key elements that are required for successful E-Health initiatives. This framework is based on multiple perspectives which includes organizational such as ICT infrastructure, Practitioner such as user access and public such as government regulation. One of the pre-requisite of this framework is Information communication technology (ICT) architecture/ infrastructure and is one of the components that was used by the researcher as an essential ingredient to the undertaking of E-Health initiatives.

3.1.7.4 Informatics infrastructure framework to support data use KEMRI

In this Framework data are collected by trained clerks and pre-programmed field validation rules in the REDCap tool are used to check data quality as it is entered. Then codes that are used for running on- site checks on daily basis are auto generated through metaprogramming process and also using statistical software that is installed in hospital site's computers. It then also cleans and recodes data to enable indicator measurement and reporting. These data are used also to create timely reports for health facilities that have traditionally had no access to daily routine information that includes process as well as outcomes for their patient. REDCap tool that was used by clerks to check data quality, was one of the component that use in this study since it could also generate reports from the stored records.

Data collection

The data was gathered using open ended and closed questionnaires and interviews. 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 in the 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. The participants include 12 researchers (medical students), 3 Policy makers, 5 pathologists and 2 Record clerks from KNH/UoN facilities.

3.2 Prototype development

3.2.1 Proposed solution

Figure 2 illustrates the researcher's conceptual perception of the system design. The design was based on literature reviewed, and the researcher's understanding of the stipulated current process of capturing, storing, retrieving and disseminating cancer records

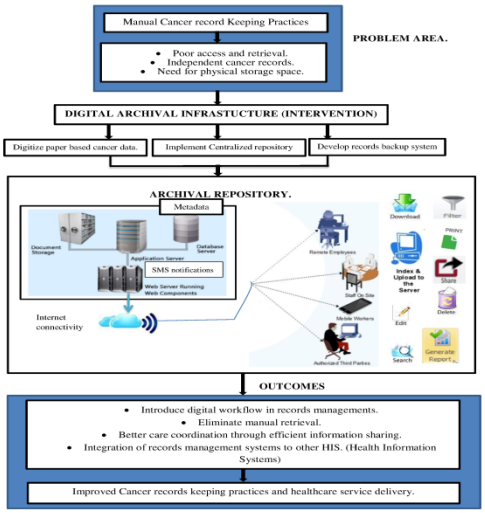

Figure 3: Conceptual Model.

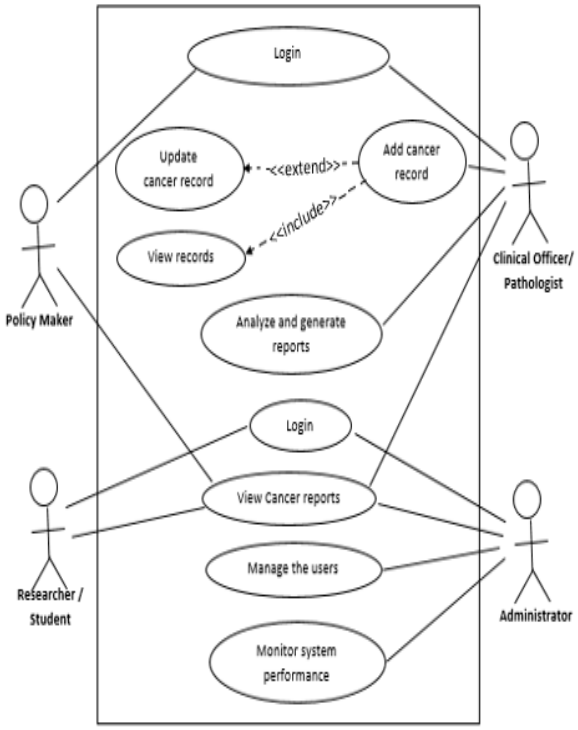

Figure 4: UML Diagram

3.2.2 Overview of the system developed

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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 retrieved information regarding a patient's medical history (e.g. lab results, screening information, and any history of a previous cancer). The ICT intervention was a web based application that improved records management for cancer cases at the KNH/UoN Department of Pathology. The Proposed system was a responsive website hosted and on Linux server.
The preferred methodology for the development of the prototype was Rapid Application Development (RAD).

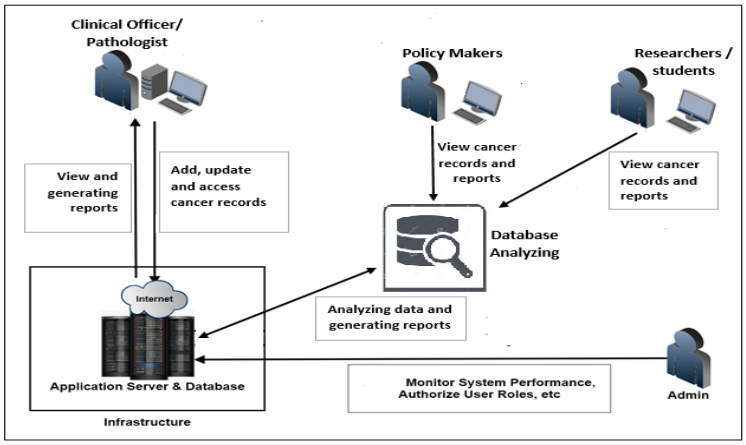

Figure 5: System Design

3.2.3 System design

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

3.2.4 Design Decision and implementation

Based on the intervention functional and non-functional requirements, technology design decisions were made and the system was implemented using the following technologies. (See table 1)

Table 1: Development Platform

Development Platform	
User Interface (UI)	HTML5 and CSS
Backend (Database Management System)	Microsoft SQL (Structured Query Language) Server
Hosting	Linux server
Sending password to the users through SMS	Africa's Talking API Messaging
Scripting	Laravel 5.3 a PHP framework and bootstrap 3
Generating graphs and charts	Chart Java Script (JS)

3.3: Prototype Evaluation

This was to assess whether or not intervention / system developed worked the way it was intended to and if the user requirements were met.

4 DATA ANALYSIS

This study's main objective was to develop a model that was to guide the digitization and archival of locally available cancer paper-records and a web based prototype that preserved and availed this information to a wide range of stakeholder. As such, both quantitative and qualitative data analysis methods were perceived as the most suitable approaches for this study. Qualitative data analysis was conducted on interviews and open-ended questionnaires, while quantitative analysis was done on close-ended questionnaires. 22 participants from KNH/UoN Department of Pathology (12 Researchers, 3 Policy makers, 5 Pathologists and 2 Record clerks) were involved.

4.1 Socio-Demographics

Age of most of researchers was ranging 25-35 years (7/12), Policy makers was ranging 35-44 years (2/3) ,which was the same range to the pathologists(3/5). The level of education of most researchers was postgraduate (6/12), same to pathologists (3/5) .Most of the pathologist had served in the

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department for 6- 10 years (3/10) meaning they understood very well the challenges affecting that department.

4.2 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.

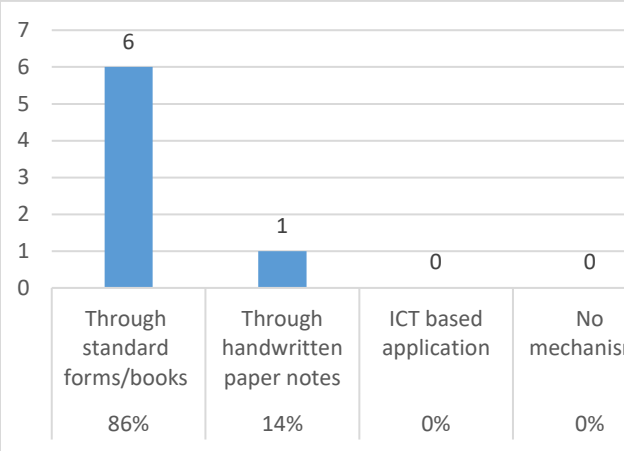
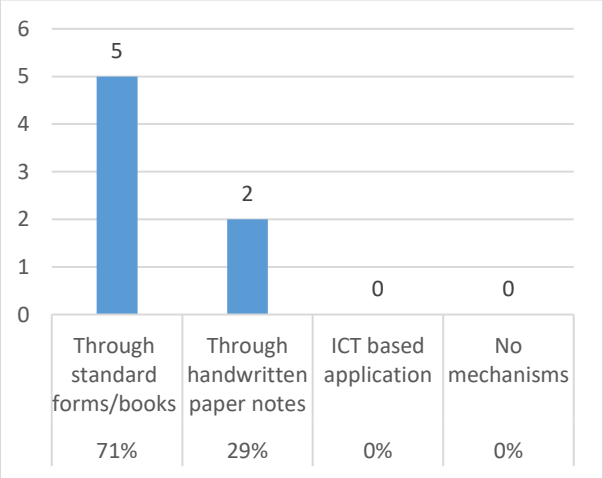


Figure 6: Capturing patient's personal data

This clearly showed that cancer records are captured manually.

4.3 Storing of the captured cancer records

This was aiming to know how the data is stored after it had been captured from the cancer patient. It was also responded by the record clerks and the pathologists.



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. Crucial patient information may as well miss when needed.

4.4 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.

Majority of the responses 57% (4/7) reported that Identification of patient record and documenting lab report was done based on LAB number. The LAB number contained the slide number, the report number and the year that record was stored, example of LAB number was S/5012/18. 14% of the respondents (2/7) reported that this was done using record index number, hospital number and based on Inpatient and Outpatient number.

4.5 Cancer record accessibility

This was aiming 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. 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.

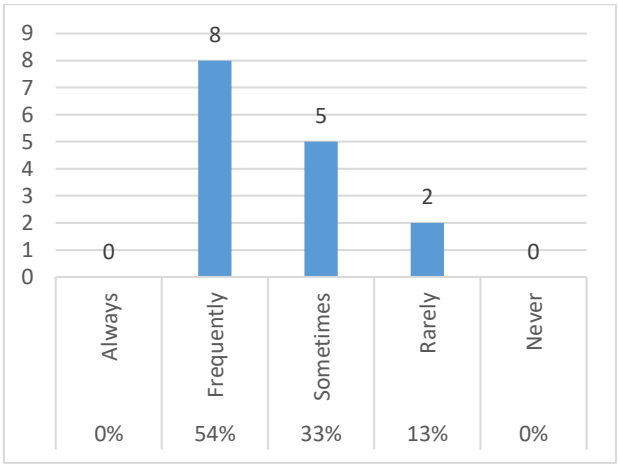


Figure 7: Cancer record accessibility

4.6 Rating of the current means of cancer record keeping.

This was responded by all the participants (22). 54 % of the respondents stated that the current processes of cancer record keeping were not at all efficient.

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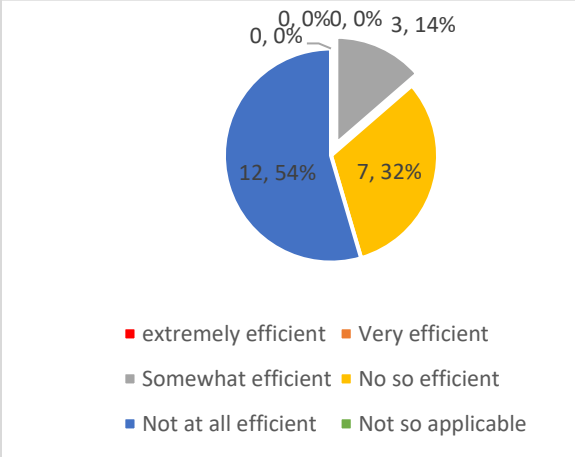

Figure 8: Rating of the current means of cancer record keeping

4.7 Challenges with the current cancer record keeping practices

This was responded by all the participants in the study (22). 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.

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 2: Challenges with the current cancer record keeping practices

4.8 ICT Usage levels

This was to determine rate the level of ICT usage in the whole process of cancer data / Information record keeping.

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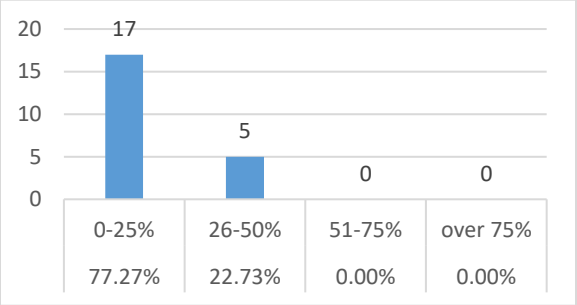

Figure 9: ICT usage levels

This indicated how manual processes were used in KNH/UoN Department of Pathology.

4.9 Challenges that hinder the implementation of digital preservation of cancer record

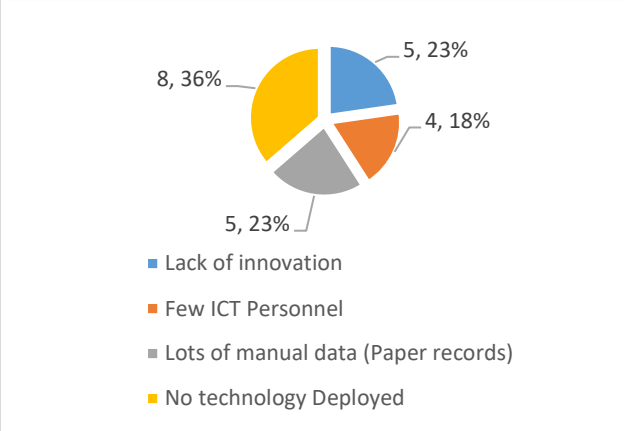

Figure 10: Challenges that hinder the implementation of digital preservation of cancer record

The aim was to determine the challenges that hinder the implementation of digital preservation of cancer record to enable distributed form of accessibility.

4.10 Opinions on what should be done to improve cancer record keeping

The participants of the study were required to give their opinions on what should be done to improve the whole process of cancer record keeping in KNH/UoN Department of Pathology.

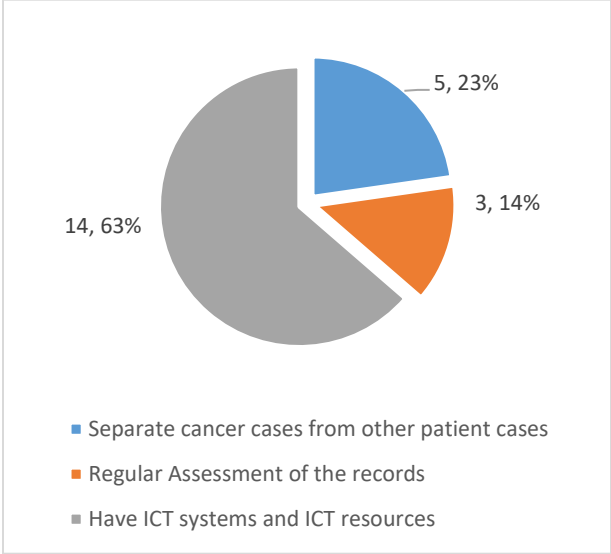

Figure 11: Opinions on what should be done to improve cancer record keeping

4.11 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.

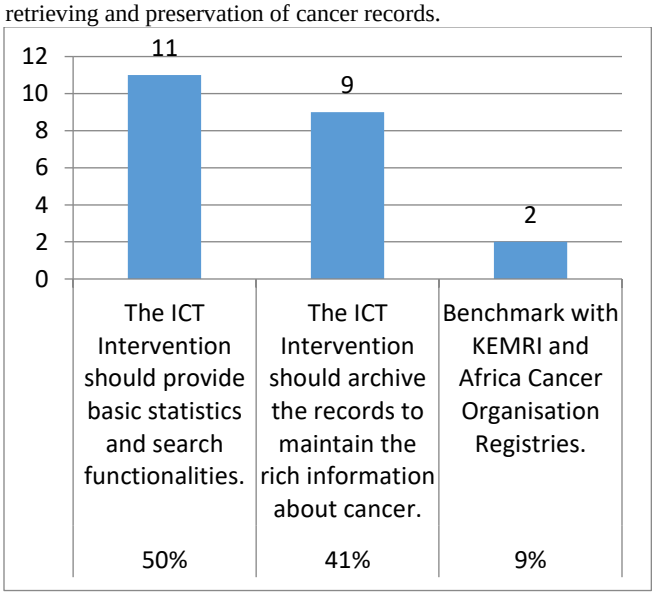

Figure 12: Recommendations using the digital platform for capturing, storing, retrieving and preservation of cancer records

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5 CANCER RECORDS MANAGEMENT PROCESS MODEL

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. 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.

At the beginning, cancer patient record was captured manually given that is 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.

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 13.

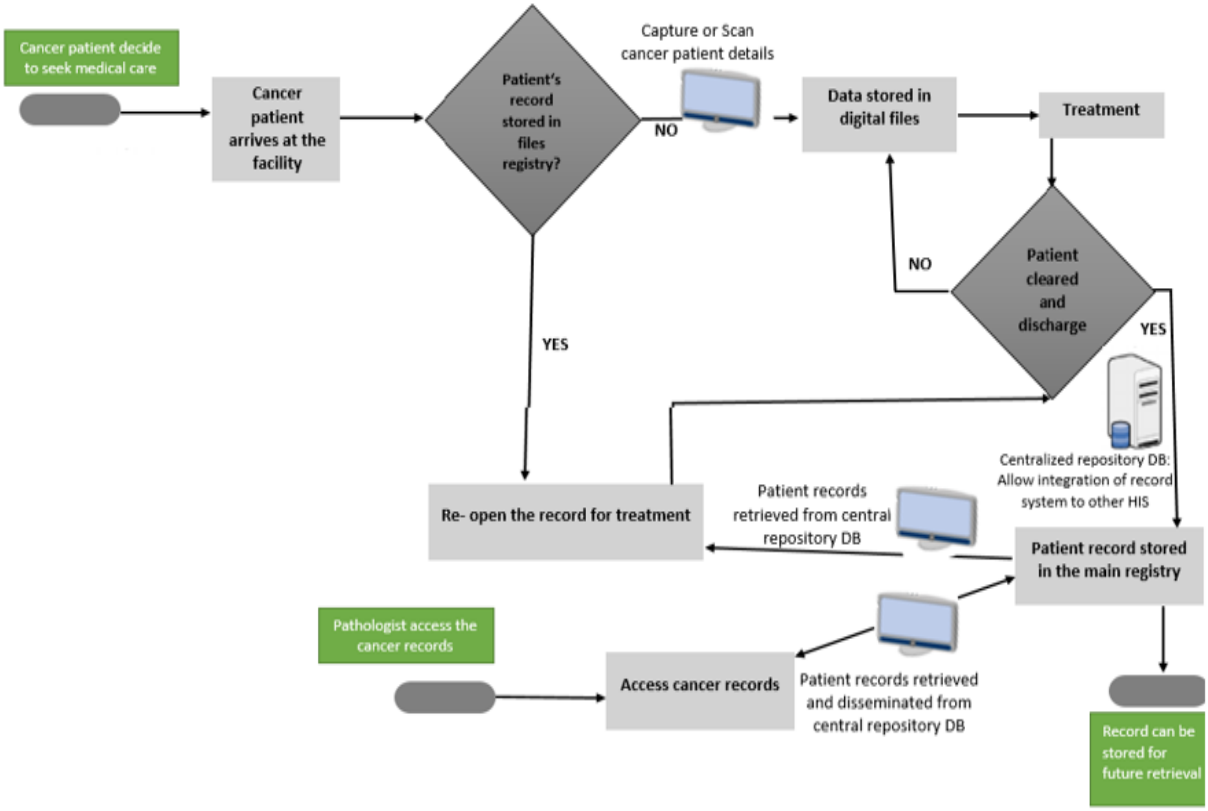

Figure 13: Cancer records management process model in KNH/UoN Department of Pathology: ICT Inclusive

6 System Evaluation results

Seven participants were used to evaluate the proposed ICT intervention: two pathologists, one record clerk, three researcher/ medical students 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.

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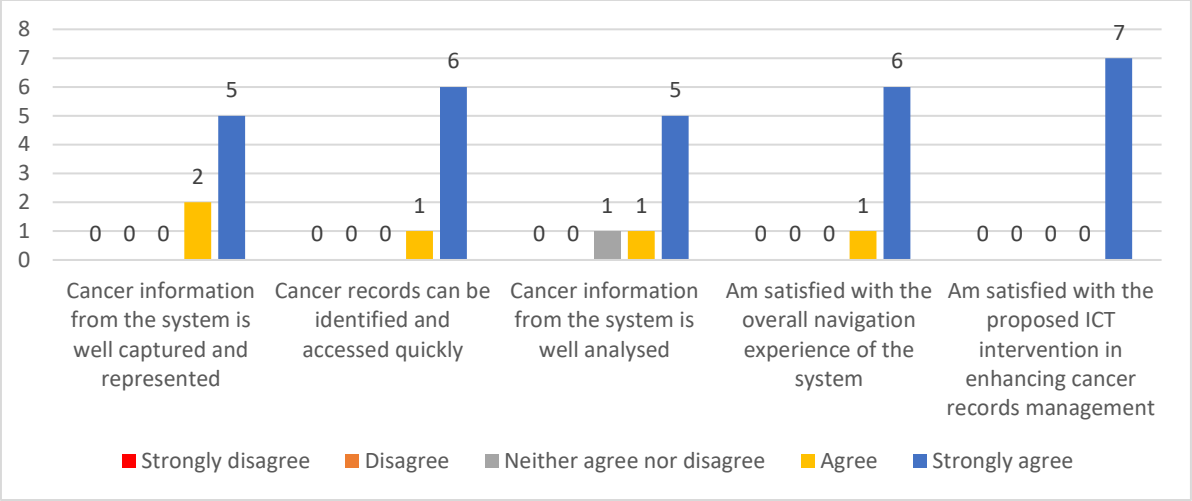

Figure 14: System evaluation

7 Strengths of the system

a. It would enable managing of escalations and follow-up on patients more efficiently; for better patient-centric care, and also have immediate access to treatment documentation.
b. It would help in reducing manual intervention during records management
c. It would help toward mitigating risks like records getting damaged, lost, mixed up and/or duplicated.
d. The problem of storage space constraints would be resolved since everything was being stored digitally.
e. It would improve efficiency in healthcare service delivery and productivity.

8 Conclusion

a) 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 are just keyed in forms (Microsoft Word) that are 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.
   - Evaluation of the use of ICT in this process indicated that ICT usage was poor (0-25%).

b) Inability to track patient records with ease and loss or damage of patient records are the main challenges as far as capturing, storing and retrieving cancer records is concern
c) Cancer records stored in KNH/UoN Department of Pathology remain to be relevant to the researchers/ medical students and the policy makers.
d) The developed system enables digitization and archival of locally available cancer paper-records in a way that preserves and avails this information to a wide range of stakeholder and provides basic statistics and search functionality. thus improving record management for cancer cases at the KNH/UoN Department of Pathology.

9 Limitation of the study

a) Access to personal medical reports from KNH/UoN Department of Pathology was a challenge.
   - Records are private and confidential and are archived in place that is and can only be accessed by authorized persons.
   - The state in which some records were in, was a challenge, they needed to be handled with care to ensure the rich information in those records were maintained.

b) 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.
c) Time constraint was also a limitation worthy of mention to get participants at their own convenient time to fill the questionnaire and respond to interview questions.

10 Recommendations for future works

a) This approach can also be replicated for other paper based health records such as x-ray reports, lab reports etc. ICD10 coding system should be implemented fully to enable medical personnel track healthcare statistics.
b) Respondents suggested interoperability of health information system in different health facilities should be enhanced.
   - To enable cancer records being stored on one form of database to be accessible in another form of database.

c) GIS and comprehensive cancer surveillance system should be put in place to locate areas where

many people with a different cancer cases are located.

d) Public Health institutions should devote a substantial budget to enable technological development.

- ICT Infrastructure should be supplied and put in place and the existing ones to be upgraded.
- Constantly train their medical practitioner to improve their technological-driven health care delivery.

e) Population based cancer registry should be in place in most counties country wide since the available cancer data is wanting and if is preserved and distributed virtually it could assist in monitoring of the prevalence and incidence of cancer cases.

- 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.

- Tracking exactly who logged on with their unique ID will be in place and what they did to keep out unauthorized individuals since the records have personal information on them that is a great legal risk and needs to be protected.

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