

**ACCESSIBILITY TO PATIENTS' OWN HEALTH INFORMATION: A CASE
IN RURAL EASTERN CAPE, SOUTH AFRICA**

by

SIMLINDILE ABONGILE BANTOM

Dissertation submitted in fulfilment of the requirements for the degree

Master of Technology Information Technology

In the Faculty of Informatics and Design

at the Cape Peninsula University of Technology

Supervisor: Prof Retha de la Harpe

Cape Town

September 2016

CPUT copyright information

The dissertation/thesis may not be published either in part (in scholarly, scientific or technical journals), or as a whole (as a monograph), unless permission has been obtained from the University

DECLARATION

I, Simlindile Abongile Bantom, declare that the contents of this dissertation/thesis represent my own unaided work, and that the dissertation/thesis has not previously been submitted for academic examination towards any qualification. Furthermore, it represents my own opinions and not necessarily those of the Cape Peninsula University of Technology.

Signed

Date

ABSTRACT

Access to healthcare is regarded as a basic and essential human right. It is widely known that ICT solutions have potential to improve access to healthcare, reduce healthcare cost, reduce medical errors, and bridge the digital divide between rural and urban healthcare centres. The access to personal healthcare records is, however, an astounding challenge for both patients and healthcare professionals alike, particularly within resource-restricted environments (such as rural communities). Most rural healthcare institutions have limited or non-existent access to electronic patient healthcare records. This study explored the accessibility of personal healthcare records by patients and healthcare professionals within a rural community hospital in the Eastern Cape Province of South Africa. The case study was conducted at the St. Barnabas Hospital with the support and permission from the Faculty of Informatics and Design, Cape Peninsula University of Technology and the Eastern Cape Department of Health. Semi-structured interviews, observations, and interactive co-design sessions and focus groups served as the main data collection methods used to determine the accessibility of personal healthcare records by the relevant stakeholders. The data was qualitatively interpreted using thematic analysis. The study highlighted the various challenges experienced by healthcare professionals and patients, including time-consuming manual processes, lack of infrastructure, illegible hand-written records, missing records and illiteracy. A number of recommendations for improved access to personal healthcare records are discussed. The significance of the study articulates the imperative need for seamless and secure access to personal healthcare records, not only within rural areas but within all communities.

Keywords

PHR, EHR, EMR, Accessibility, Healthcare centre, Eastern Cape

ACKNOWLEDGEMENT

- I give praise and honour to the almighty God for strength, protection, love, courage and wisdom, he has given me.
- To my late grandmother **Grace Thozama Bantom “Bhanqo”** whom we lost recently, thank you for everything you have done for me. With the little you had you made sure I got what I needed to get this far, thank you for believing in me. Most importantly for teaching me to believe and trust God all times. I am who I am today because of you. You have been there since the beginning of this study and kept motivating to finish this study, and you were looking forward to my graduation in September 2016. Thank you very much for the role you played in my life. You might not be here physically but I know you are my guardian angel and you are here in spirit. May Your Soul Rest in Peace **Mama wam, Mem wam, Gogo wam**. I will always love you and miss you. We hope to see you again when Jesus comes and take us home.
- To my aunt Busisiwe “D-Buh” and siblings Tembeleni, Akona, Tobile “Junior” and Sibulele Bantom and entire family thank you for the support and encouragement.
- Mr. Gaster Sharpley, thank you for being a son and good friend to my grandmother. Thank you for your support to my family, May God richly bless you.
- My father, brother, friend and mentor Prof. Nkqubela “Squ” Ruxwana, thank you motivating me to do this study and believing in me. You are always hard on me and criticise me constructively, I know you want the best for me. You have taught many things in my life and stressing that I should aim high. Your investment in my life is much appreciated. May God continue to bless you Tutu.
- To my older sister, and my best friend Dr. Sibongiseni Tunzelana (DJ Simply Sybz), you have taught me many profound things, and encouraged me to be the best at all times. Thank you for believing in me. Thank you for your unconditional love. May God Almighty protect and keep you.
- I would like to express my sincere gratitude and appreciation to my supervisor Prof. Retha de la Harpe, for her continual support, guidance, motivation and her supervision which has led to completion of this research study.
- Rubina Adam ooh my friend, thank you so much for all the sacrifices, criticism, and support for this study.
- My gratitude goes to my research family, Andile Koka, Siphokazi Tswane, and Odwa Gazana without your encouragement, criticism and support, I would be nowhere. A special thank you to all my research participants
- To Zinziswa Fikile Makopi and all my friends to thank you for walking with me in this journey.
- Cape Peninsula University of Technology, thank you for financial assistance.

DEDICATION

I dedicate this dissertation to **God** and My grandmother **Grace Thozama Bantom**, who passed away this year on the 12 June 2016.

TABLE OF CONTENTS

Contents

CHAPTER ONE : INTRODUCTION.....	1
1.1 Introduction	1
1.2 Problem Statement	3
1.3 Research Questions and Research objectives	5
1.4 Research Design.....	7
1.5 Significance and Potential contribution of the study	7
1.6 Ethical Considerations.....	8
1.7 Dissertation layout.....	9
CHAPTER TWO : LITERATURE REVIEW	11
2.1 Introduction	12
2.2 Healthcare	12
2.3 Healthcare in South Africa.....	14
2.3.1 Primary level of care	15
2.3.2 Secondary level of care.....	16
2.3.3 Tertiary level of care	16
2.4 Information in Healthcare	17
2.4.1 Information management in Healthcare	17
2.4.2 Protection of privacy and security of health information in South Africa	17
2.5 Medical Records.....	20
2.5.1 Paper-based records.....	21
2.5.2 Challenges and Limitations of Paper-based records	22
2.6 Electronic Records	24
2.6.1 Electronic Medical Records.....	24
2.6.2 Electronic Health Records	25
2.6.3 Benefits of Electronic Records Implementing.....	28
2.6.4 Barriers of implementing EHR	29
2.6.5 Current state towards Electronic Health Records in South Africa ..	30
2.7 Personal Health Records	31
2.7.1 Defining Personal Health Records (PHR)	31
2.7.2 Types of Personal Health Records	32
2.7.3 Benefits of using Personal Health Records	35
2.7.4 Barriers to the adoption of PHRs.....	35

2.8 Conclusion.....	37
CHAPTER THREE : RESEARCH METHODOLOGY	38
3.1 Introduction	39
3.2 Research Methodology	39
3.2.1 Research philosophy	41
3.2.2 Research Approach	42
3.2.3 Research strategy.....	43
3.2.4 Case Study research.....	43
3.3 Time Horizon.....	44
3.4 Data Collection.....	45
3.4.1 Literature Study.....	45
3.4.2 Interviews	46
3.4.3 Document analysis	46
3.4.4 Co-design sessions.....	46
3.4.5 Participant Observation	47
3.5 Research population and sampling.....	48
3.5.1 Sampling Techniques.....	48
3.6 Data Analysis.....	50
3.6.1 Thematic Analysis.....	50
3.7 Ethical Consideration	51
3.8 Delineation of the research	52
3.9 Conclusion.....	52
CHAPTER FOUR : DATA ANALYSIS	53
4.1 Introduction	54
4.1.1 Site Location.....	54
4.1.2 Site Description	56
4.2 The Participants.....	57
4.3 Data Collection.....	59
4.3.1 Data collection at St. Barnabas Hospital	59
4.3.2 Data Coding.....	61
4.4 Analysis	63
4.4.1 Health professionals' perspectives	63
Theme 1: Need for patient health records	63
Theme 2: Challenges of paper-based health records	64
Theme 3: Access to health records.....	66
Theme 4: Poor referral methods.....	67

4.4.2 Patients' perspectives.....	68
Theme 1: Data Elements relevant for patients	69
Theme 2: Empowerment of patients.....	70
Theme 3: Patient Information Privacy	72
4.5 Data from Observations.	74
4.6 Conclusion.....	75
CHAPTER FIVE : DISCUSSION OF FINDINGS.....	77
5.1 Introduction	78
5.2 Overview of the themes.....	78
5.3 Value of Health Records	80
5.3.1 Need for health records.....	80
5.3.2 Empowerment of patients	81
5.4 Data Elements and Privacy of patient information.....	82
5.4.1 Data Elements relevant for patients.....	83
5.4.2 Privacy concerns	84
5.5 Poor referral methods.....	86
5.6 Conclusion.....	87
CHAPTER SIX : CONCLUSION AND RECOMMENDATIONS	88
6.1 Introduction	89
6.2 Summary of Key chapters	89
6.3 Reflection of the key findings	90
6.4 Significance and contribution of the research	94
6.5 Limitations of the research	95
6.6 Recommendation for further research.....	95
6.7 Concluding statements.....	98
References.....	99
Appendix A: Referral letter used at St. Barnaba's hospital	109
Appendix B: Approval Letter from Eastern Cape Department Health.....	110
Appendix C: Letter of Informed Consent	111
Appendix D: Interview Schedule.....	112

LIST OF TABLES

Table 1-1 Research questions, sub-questions and objectives	6
Table 1-2 Ethical concerns	8
Table 2-1 Five levels of Electronic Health Records	28
Table 3-1 Phases of thematic analysis	51
Table 4-1 Demographic information of Patients	58
Table 4-2 Demographical information of Intuitional stakeholders	59
Table 4-3 Research Sub-Questions.....	61
Table 4-4 Identified themes from study.....	62
Table 4-5 Themes and categories from interview response from healthcare workers	63
Table 5-1 Key themes as cited in literature vs. identified themes from case study	79
Table 5-2 Data elements relevant for patient identified from different stakeholders involved in patient care.....	83

LIST OF FIGURES

Figure 1-1 Healthcare professionals and patient's interactions with health information	4
Figure 1-2 Dissertation Layout	9
Figure 2-1 Context for Information Security Management	19
Figure 2-2 Medical record department at St. Barnabas Hospital	24
Figure 2-3 : Elements entailing a basic electronic health record	27
Figure 2-4 PHR Range of Complex	33
Figure 2-5 Standalone PHR	33
Figure 2-6 Tethered PHR	34
Figure 2-7 Interconnected PHR	35
Figure 3-1 The research process onion	40
Figure 4-1 Provinces of South Africa	54
Figure 4-2 St. Barnabas Hospital	56
Figure 4-3 St. Barnabas Hospital	56
Figure 4-4 Patient folder cabinet of St. Barnabas hospital	57
Figure 4-5 Participants in Co-design session designing health records	69
Figure 4-6 Participants in Co-design session designing health records	69
Figure 4-7 Design and type of data elements participants would like to see in their health record	70
Figure 4-8 Patient process during their time at of appointment at hospital	75
Figure 6-1 Recommendation process that patient should follow at hospital	97

LIST OF ABBREVIATIONS

DoH:	Department of Health
CIA:	Confidentiality, Integrity and Availability
CHCF:	California HealthCare Foundation
eHealth:	Electronic Health
EHR:	Electronic Health Records
EMR:	Electronic Medical Records
HIT:	Health Information Technologies
HIV:	Human Immunodeficiency Virus
HIMSS:	Health information Management System Society
HPCSA:	Health Professions Council of South Africa
ICT:	Information and Communication Technology
ICU:	Intensive Care Unit
IS:	Information Systems
ISO:	International Organisation for Standardization
openEHR:	Open Electronic Health Records
openEMR:	Open Electronic Medical Records
IT:	Information Technology
NCVHS:	National Committee on Vital Health Statistics
PHC:	Primary Health Care
PHR:	Personal Health Records
SANS:	South African National Standards
TB:	Tuberculosis
TC:	Technical Committee
WHO:	World Health Organisation

CHAPTER ONE : INTRODUCTION

1.1 Introduction

Health is concerned with safeguarding and improving the health of people through healthcare services. The provision of quality healthcare services to a community or an individual requires good quality medical records, which are vital for providing safe and effective healthcare services. As part of healthcare services to treat patients, there is a need for information relating to the patient's condition and past healthcare services. Therefore reliable and accurate personal health information of the patients is vital for monitoring their health, evaluations, and improving the delivery of healthcare services and programmes (Ruxwana et al. 2010; Mphatswe et al. 2012) .

However, healthcare service providers have been experiencing several challenges in most developing countries and the developed world in general. Some of these challenges include lack of expertise and service, high mortality, lack of infrastructure, lack of implementation of health information technologies and this is especially the case in the rural settings (Sunyaev 2010; Ruxwana et al. 2010). Another challenge that healthcare services experience is the issue of lack of access to patient's personal health information and incomplete patient records that are stored in paper format and stored in different health institutions which affects the accessibility to the patient's health data for both the patient and the doctor (Mostert-Phipps 2011; Ruxwana et al. 2010; Liu, Shih, Hayes, 2011). This is because people are often moving from one place to another, and they receive many kinds of treatment and examinations from various healthcare service providers (Liu et al. 2011). In this way medical data and health information of a certain patient is stored and maintained by different healthcare service providers and in different places, which makes it difficult for a patient to obtain copies of his/her official health records from these providers (Liu et al. 2011; Mostert-hipps 2011).

This is likely the case for people who have chronic illnesses as they need to consult different healthcare specialists which include general practitioners, pharmacists, social workers, physiotherapists and social workers (Anderson, 2009) as cited in (Mostert-hipps 2011). Because patients are often moving from one place to another and consulting different kinds of healthcare providers resulting in multiple health records created for them, each and every healthcare provider that the patient has

ever consulted , and then most medical records are stored in paper based methods (Mostert-Phipps 2011).

Most healthcare providers still use paper-based systems to capture and store patient records (Mostert-Phipps, Pottas & Korpela 2012). However paper based health records influence both patient and healthcare providers, due to the fact that duplicate work that has to be done by healthcare providers such as doing tests because of previous test results or diagnosis that are not available to healthcare providers during consultation (Mostert-Phipps 2011). These paper-based patient records have a potential to negatively impact the quality of care that a patient receives and impact on the information continuity. Other issues that paper based health records present, include unclear handwriting, incomplete or inaccurate information and inaccessibility of health records from different locations which then expose patients to medical mistakes because healthcare providers would not be able to draw a connection between current and past medical history (Asangansi, Adejoro, Farri, & Makinde 2008; Liu et al. 2011; Al-nassar, Abdullah, Rozaini, & Osman 2011). There are also integrity problems where data reflects changes in one place and not in another healthcare service provider. These issues are discussed in more detail in Chapter 2, in section 2.2.

Patients do not always have the expertise to describe their full medical history accurately and in enough details and in fact most patients have to repeat their medical history every time they visit a new healthcare provider (Mostert-hipps 2011) .In addition in South Africa the Eastern Cape rural district has been perceived as one of the poorest rural settings in which public health system has been experiencing several challenges such as staff shortage, poor management and weak primary care together with high level of poverty and insufficient access to basic services such as piped water (Tom 2007) as cited in (Ruxwana et al. 2010).

Information and Communication Technology (ICT)'s strategies appear to be one of the vital core elements in operations and improving healthcare delivery throughout the world. As a result ICT has been used as a tool to deliver quality products, decision making and maintaining customer loyalty by many organizations (Ruxwana, Herselman, & Conradie, 2010) .

Resulting from the benefits that ICT shows in the healthcare sector, which include enhancing quality of care, reduce cost and medical errors, ICT has been adopted by many healthcare providers throughout the world. Accurate and detailed patient information is critical for healthcare professionals, medical researchers, health

administrators, policy makers, pharmacists and in families (Canada, 2000) as cited in (Ruxwana et al. 2010). Hence the adoption of ICT in the healthcare sector can facilitate the required sharing of information among healthcare stakeholders. In addition introduction of ICT assists in the potential shortage of skills, insufficient resources while improving productivities and reducing workload within public and private sectors.

This has resulted in the development of many ICT solutions within the healthcare sector, which include e-health, electronic health records (EHR), personal health records (PHR), and telemedicine. Of these issues stated above, ICT solutions have been introduced in most developing and developed country medical industries to assist in managing shortage of expertise, insufficient resources while enhancing efficiencies, improving access to basic healthcare services and health information, and reducing workload and increasing productivity and reducing workload (Ruxwana et al. 2010). This is a research initiative. The aim of this study is understand the needs of patients to access their health information in resource restricted areas and explore other means to transit medical history with patients.

This chapter servers as an introduction, the background to problems, and the problem statement to this study will be stated in the next section. In addition, objectives, methodology of this study is also stated.

1.2 Problem Statement

What is the problem driving the research?

Patients in rural areas of Umtata in the Eastern Cape lack access to their personal health Information. Their health information records are kept at the healthcare service provider and they not allowed to take their health information records home with them (Asangansi et al. 2008; Mitchell et al. 2009; Ruxwana et al. 2010).

How is this a problem?

Because patients do not get this information from the healthcare centers, when they visit another healthcare center in a different location, they do not have enough information or necessary skills to give a full history of their health conditions which

could be useful for healthcare professionals to diagnose and treat the patient (Chen et al. 2010; Kharrazi et al. 2012).

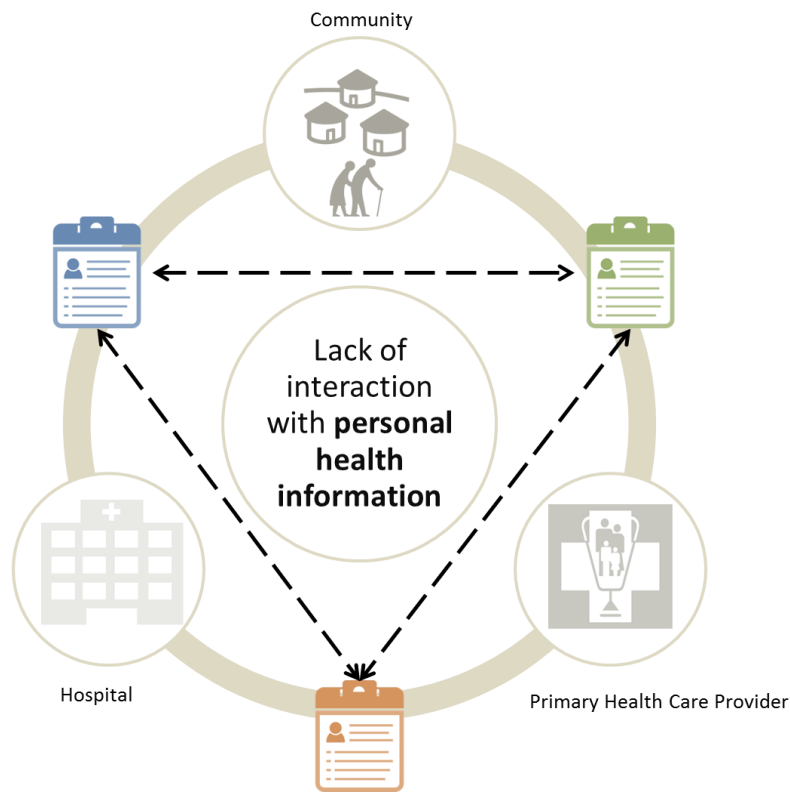


Figure 1-1 Healthcare professionals and patient's interactions with health information

Figure 1.1 above illustrates how patient healthcare information is currently being used from one healthcare provider to another and how this is a problem to patient and healthcare providers, as they are required to provide a history of their health each time they visit a healthcare provider. When patients feel ill, they either go to a doctor or go to a primary healthcare centre also known as a “clinic”, then depending on the complexity of their illness they may be referred to a hospital. This is a problem because each time they visit a new healthcare centre they are treated as a new person without any prior health information available to the healthcare professional who will treat the patient.

Why is this a problem

Unfortunately, one healthcare provider may not know what the other healthcare provider is doing to the patient at that point of care. This could lead to unnecessary duplication of tests or procedures, increased costs and inaccurate decision making which can result to death or severe health complications (Ruxwana et al. 2010; Sunyaev 2010; Liu et al. 2011) .

1.3 Research Questions and Research objectives

In order to solve the problem addressed in this study, the following questions should to be asked and the following objectives have to be met.

Table 1-1 Research questions, sub-questions and objectives

Research Problem	Patients in rural areas such as in Umtata in the Eastern Cape, lack access to their own health Information records, and if they have to visit another healthcare service provider in a different location these healthcare service providers will also not have the information of the patient's previous treatments and illnesses. This could lead to inaccurate decision making, which results in death or severe health complications.	
Research Questions	What are the considerations for patients to have access to their own personal health information in restricted resource settings?	
Research sub-questions	Research Method(s)	Objectives
Why may patients want access to their own personal health information?	Literature analysis, Interviews, co-design sessions	Identify the needs of patients to access their own personal health information in resource-restricted areas.
What data elements are relevant to patients' own personal health information to facilitate a healthcare service provision?	Literature Analysis, Interviews	Identify data elements relevant to patients' own personal health information to facilitate healthcare service provision
How is patients' personal information currently being used in the healthcare service provision?	Literature Analysis, Interviews	Determine and evaluate how patient's personal information is currently being used in the healthcare service provision.

In order to accomplish objectives of this study there are some methods that will be used, and these methods will be discussed in the next section.

1.4 Research Design

Research can be defined as a process that involves obtaining, analyzing, interpreting data or information and the investigation to discover factors, by means of using various methods and procedures to enhance our understanding about facts we are concerned about (Leedy & Ormrod 2001). In addition, research is about developing or creating new knowledge we do not initially know about. According to Welman, Kruger and Mitchelle (2005) approaches that are often used in research are qualitative and quantitative research approaches which are described below:

- **Qualitative research:** consists of multiple approaches and it studies social interaction in their natural settings. Welman et al. (2005) state that qualitative research involves exploration more in depth of attitudes, behavior, concerns and motivation of people and this research approach usually involves small numbers or small populations. The purpose of qualitative research is to understand in depth the characteristics of the situation and importance brought by participants and what is occurring to them at the moment. Methods which qualitative research approach normally use include in-depth interviews, observations, case studies and questions etc.
- **Quantitative research:** this approach was originally developed in the natural science to study natural phenomena. Quantitative research approach involves systematic empirical investigation of social phenomena through statistical, mathematical or computational techniques (Hunter & Leahey 2008). A research that follows the quantitative route tends to use surveys and questionnaires as data collection tools (Coombes 2001).

In this study, a quantitative approach was not a suitable technique because the objective of the study was to qualify rather than quantifying. An interpretive case study was adopted in one rural community of the Eastern Cape. Primary data was collected through qualitative methods; including interviews, and co-design sessions, secondary documents such as blank patient records were also used. The data will be analyzed and interpreted using thematic analysis.

1.5 Significance and Potential contribution of the study

The focus of this study is to understand and present consideration for patients to have access to their own personal health information in resource-restricted environments. Findings of this study may be useful for the community of information

technology research, particularly in the health informatics. The study may contribute an enhanced understanding of access to patients' health records which is contextually relevant to developing economies. Currently, there is limited understanding of relevance of patient health records infrastructure and resource-poor rural settings. The Information technology body of knowledge may benefit from the exploratory insights on varying dynamics and considerations that an environment can influence, in relation to usage and adoption of technology.

The findings of this study may contribute to a number of other bodies to act upon the significance of the considerations and needs for patients to have access to their health records; this includes the Department of Health, other healthcare providers, not merely primarily healthcare with resource-restricted environment.

1.6 Ethical Considerations

Ethical clearance was obtained from both Cape Peninsula University of technology and Eastern Cape Department of Health in order to conduct this study. All research participants were treated with respect in terms of time, human dignity, and position, information provided and willingness to participant in the study and it was made clear to participants if they felt uncomfortable at any point during the interview they could stop the interview (Myers, M.D, & Newman 2007). Table 1.2 lists the guidelines and guidelines that the researcher followed during the research process.

Table 1-2 Ethical concerns (Oates 2006)

Ethical Researcher	<ul style="list-style-type: none"> • Limit intrusion • Research with integrity and honesty • Follow the code of good research conduct • Do not plagiarise
Informed Participants	<ul style="list-style-type: none"> • Inform participant of the right not to participate • Inform participant the right to withdraw • Inform participants of the right to give informed consent • Inform participant of the right to anonymity • Inform participants of the right to confidentiality

Research participants were not forced to participate in the study, nor did the researcher reveal confidential information as per the request by the research participants. All research participant signed Informed Consent” (refer to Appendix C: Letter of Informed Consent), regarding participant’s involvement in the study.

Research participants personal information was not requested i.e. name and surname. Anonymity was kept at all times.

1.7 Dissertation layout

This study is organized in six chapters. Figure 1.1 illustrates the structure of this dissertation. At the beginning of each chapter, a dissertation map will indicate – in a blue shade – the stage in the dissertation.

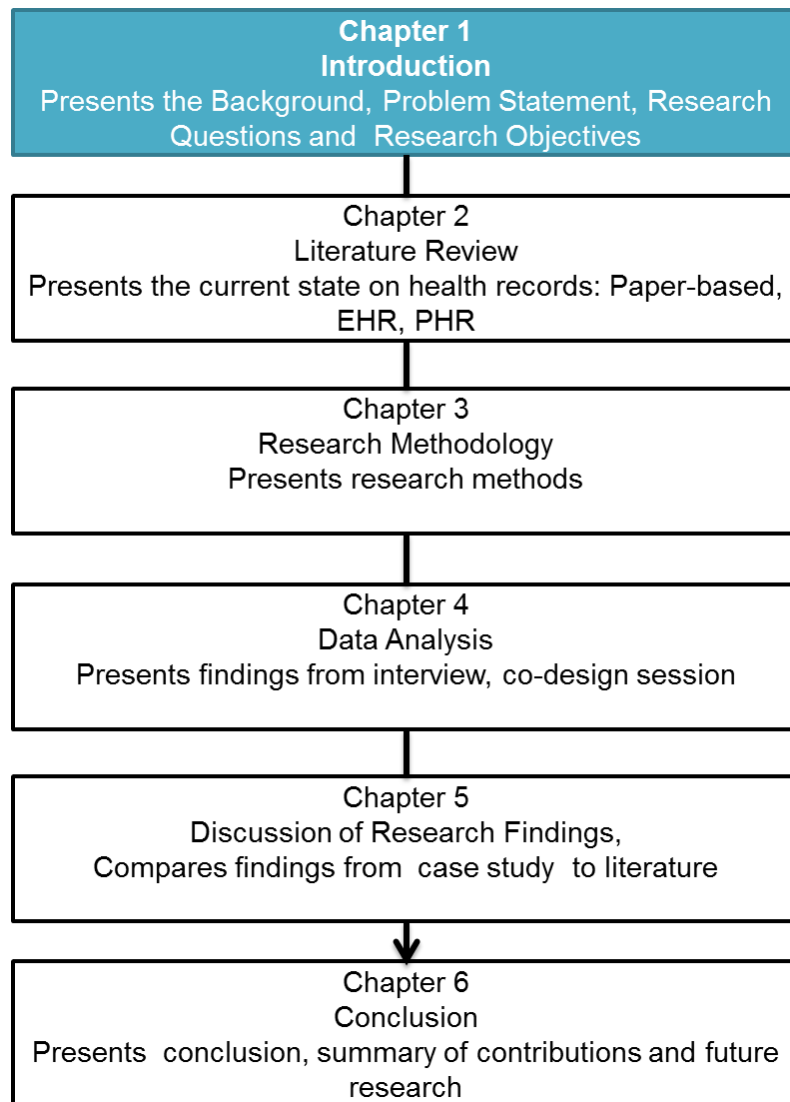
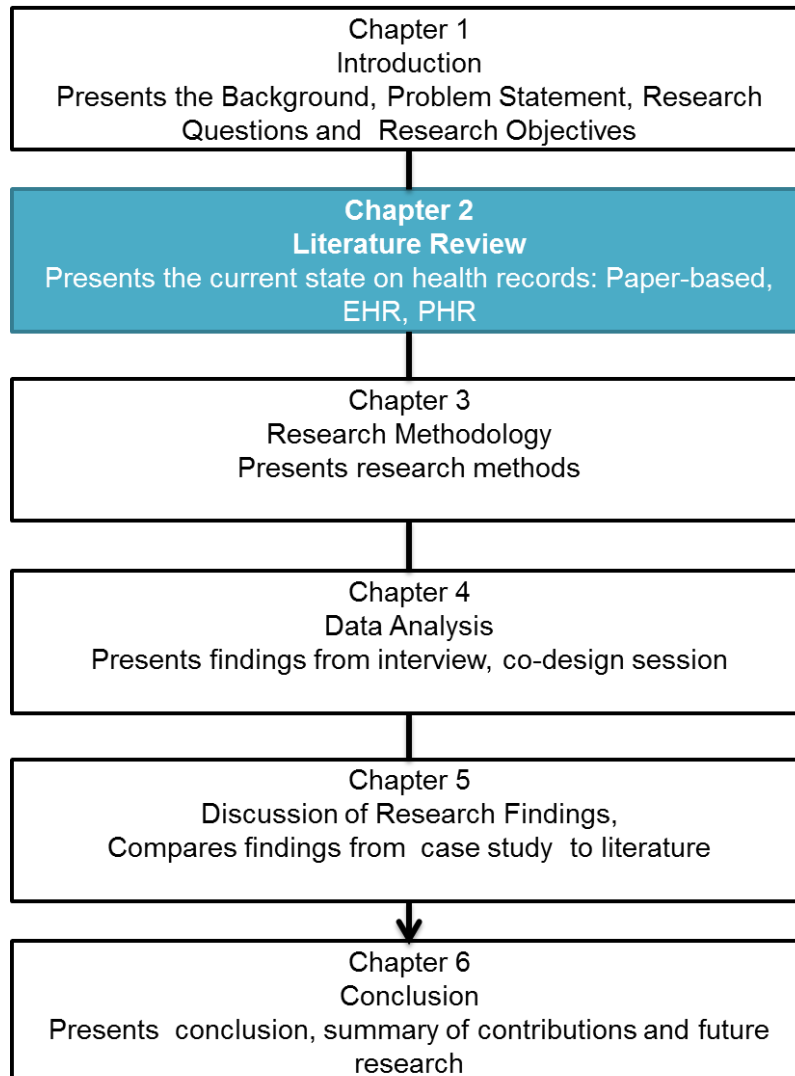


Figure 1-2 Dissertation Layout

- **Chapter 1:** provides an overview of the proposed research study by stating the background, the problem statement, research questions and research objective, methods that will be used to achieve each research objective and chapter outline.
- **Chapter 2:** will focus on the literature review and what other researchers have done in the research area.
- **Chapter 3:** This chapter presents research methods and approaches used in the study, including the research strategy, design, data collection techniques and why they are appropriate in this study.
- **Chapter 4:** Presents the results from the interviews, co-design sessions, and co-design sessions. This chapter also represents the analysis process for the research using thematic analysis.
- **Chapter 5:** Presents a discussion of all the research findings, by comparing findings collected from literature.
- **Chapter 6:** Concludes the study and presents a set of recommendations according to the findings.

CHAPTER TWO : LITERATURE REVIEW



2.1 Introduction

Chapter 1 introduced the research study by stating the problem statement, research objectives and research questions. Medical industries, in most developing and developed countries have taken advantage of ICT innovation in improving healthcare delivery systems (Ruxwana 2010; Coleman 2010; Lewis et al. 2012; Chen et al. 2010). As a result, many government hospitals, clinics, mobile clinics and private hospitals have produced ICT solutions to improve quality of life, reduce medical errors and improve service delivery. Although using ICT has benefits in most developed countries and developing countries, some developing countries have not taken this opportunity especially in accessing healthcare records and delivery of healthcare services which are vital to health.

This chapter contains a literature review. Fink (2005:3) as cited in (Coleman 2010) defines literature review as a systematic, explicit and reproducible method of identifying, evaluating, synthesizing the existing body of completed and recorded work produced by researchers, scholars and practitioners. Literature in this chapter was reviewed to identify issues which are relevant to this study. Different concepts are derived from literature and will be presented later in this chapter.

In this chapter healthcare, healthcare in South Africa, Information in healthcare, Medical records, Electronic records, Personal health records and conclusion are discussed. The chapter begins with discussion on health.

2.2 Healthcare

Healthcare varies from around the world and is a concern for all the developing and developed countries. Developed countries are regarded as the countries that are well resourced and with good infrastructures. Developing countries on the other hand are those countries which are less industrialized and characterized than the developed countries by having high levels of premature mortality, poor healthcare and illiteracy for a large part of their populations (Anand 2000). Healthcare is generally a very costly industry for both the healthcare providers and payers of service in both the public and private setting (Adão 2013; Ambali Mugabe & Mutero. 2009). Furthermore, countries around the globe are facing difficult challenges to manage rapid increasing cost of healthcare. With the cost of healthcare service being

expensive, the number of people who suffer from chronic conditions is also increasing (Adão 2013).

Looking at most of the African countries for example, the healthcare services are challenged by the fact of healthcare professionals who are migrating to wealthier countries which offer them better remuneration (Couper & Worley 2006). Furthermore, Ambali et al. (2009) state in the Sub-Saharan Africa life expectancy has fallen considerably in last decades due to rapid spread of HIV/AIDS and chronic diseases which has proven to be catastrophic. Chronic disease is the leading cause of death and has been recognized as a growing worldwide epidemic with economic and social implications (Shine 2001; Dohan, Abouzahra & Tan 2014). Life expectancy has fallen to 46.1 year as compared to the North African countries with the average of 71.5 years (Ambali et al. 2009; Neuman 2011; Salomon et al. 2012). Among other challenges that cause a burden to healthy life style of individuals in the continent include unemployment, lowest human development high poverty rate and lack of access to basic healthcare (Ambali et al. 2009).

Another challenge that health care sectors around the world is facing, is missing or inappropriate medical records. For example in 2006, in the United States of America, the US Department of health and Human Services reported that for most cases, 80% of the problems in Health care institutions are caused by inaccurate information, inaccessible charts, mislabeled specimens and inaccurate records. The report shows that in healthcare institutions in the U.S the ratio for missing records is 1:7 (US Department of health and Human Services 2006). This means that for every seven patients that have been served by that particular health institution, one health record would be missing (US Department of health and Human Services 2006). Similarly in South Africa a number of missing health record cases have been reported which are discussed in section 2.3.2.1. With a lack of access to basic health care services, individuals in rural communities constantly receive care from many different health care providers and consequently their health data is dispersed over many facilities.

With these challenges that healthcare industry are facing, information technology in the last few decades has played a significant role in making access to information and communication easier (West, 2012). The healthcare sector is no exception to this innovation, even though some countries are still behind when it comes to implementing them. It is with no doubt that ICT utilized in healthcare can improve the way in healthcare delivery is administered to patients and with providing information to patients (Party, Morris & Leatherman 2010).

2.3 Healthcare in South Africa

In South Africa, healthcare is provided by a well-developed, resource intensive and highly specialised formal private healthcare sector and resource-restricted public healthcare sector (Mostert-hipps 2011). The public sector in South Africa is founded and owned by the government and is used mostly by those individuals who cannot afford to pay their medical expenses, due to the high poverty rate and high unemployment rate (Musango 2008). The private healthcare sector is owned by private healthcare groups and provides costly services to individuals who are able to pay their healthcare expenses.

After the change of government in 1994 the new government reformed the largely inequitable and fragmented health system with a new focus on primary healthcare and preventative measures (Allan et al. 2004; Harris et al. 2011; Burger et al. 2013). However, the public healthcare sector servicing 80% of the total population is still under-resourced and suffering from the burden of diseases such as HIV/AIDS, TB, etc. (Maillacheruvu & McDuff, 2014). A disparity exists in healthcare services across geographical areas between provinces; urban versus rural with a higher concentration of facilities in urban areas remains (Ataguba & McIntyre, 2012).

The public health sector is faced with a number of challenges which include the lack of or insufficient facilities which leads to overcrowding of healthcare facilities and healthcare personnel shortages. The public sector is also often criticized for poor service delivery to patients (Mostert-hipps 2011). There are still access barriers such as vast distances; high travel costs; difficulty with out-of-pocket payments; long queues and waiting time at health facilities; and disempowered patients (Harris et al. 2011). Other barriers are linked to a combination of demographic factors such as age, sex, population numbers and density; geographic such as distance and topography; and socio-economic such as poverty levels (Eagar et al. 2015). It was also found that vulnerable groups tend to under report ill-health; they ignore diseases resulting in the illness being unattended (Burger et al. 2013). This could be because of having to travel a large distance to the health facility; long queues and waiting times at the facilities; problems with rude staff; and lack of medicine (Harris et al. 2011; Burger et al. 2013).

There are more access barriers specific to rural areas because the population is usually less condensed; there are more elderly people and children resulting in a demand for basic social and healthcare services; and the people tend to be poorer and more vulnerable to social determinants whilst less likely to have the means to access these services (Eagar et al. 2015).

The Eastern Cape Province is one of the poor provinces in South Africa and has many rural communities relying on public health services. Cullinan (2006) reported in her study that the following issues were found at the Cecilia Makiwane hospital in East London: Poor hygiene and infection control; abuse and neglect of patients; crowding of patients at the points of care; understaffing and poor working conditions; malfunctioning of equipment; role of trade unions; and theft of linen, medicine and other stock. It is not clear to what extent these issues were addressed and to what extent these problems were also experienced at the other facilities. Allan et al. (2004) also reported on the leadership crisis; staffing and financial management issues; and oversight and lack of accountability.

Although patients can choose which sector they prefer, the majority of them receive healthcare services from the public health sector. This is due to the fact that many South Africans cannot afford to pay for the services of the private health sector.

The public healthcare sector is composed of three broad levels of care namely: primary level of care, secondary level of care and tertiary level of care (Van Rensburg 2004). These levels are discussed next.

2.3.1 Primary level of care

The primary health care (PHC) level is based on a mechanism that brings healthcare to as close as possible to the people (Dookie & Singh 2012). Healthcare here is provided as entry level of care to the public health system, which offers free services to previously disadvantaged individuals, women and children (South African Government 2013) and is graded into four sub-levels of care:

- Grade I PHC: clinics which include mobile satellite and fixed clinics which offer services up to 8 hours per day, 5 days per week. This is the biggest group of healthcare service providers as they need to care for a large group of healthcare users and are entry level of care.
- Grade II PHC: these are the clinics, which operate on 24-hour services 7 days per week and include maternal, obstetric services and sometimes referred to as day hospitals.
- Grade III PHC: consists of psychiatric trained nurses and provide psychiatric mental clinics in community healthcare centers.
- Grade IV or District hospital.

The PHC level of care may include preventative, promotive, curative and rehabilitative care (Dookie & Singh 2012). PHC, especially those in the rural areas in South Africa, face numerous challenges. These challenges include shortage of healthcare workers, transport challenges, long waiting times, lack of resources, poor infrastructure (Visagie & Schneider 2014). This results in people going to hospitals, far from their homes, causing overcrowding in those hospitals.

2.3.2 Secondary level of care

Secondary level of care provides healthcare services at hospitals for more complicated healthcare conditions that cannot be treated at district hospitals, include 24 hour casualty services, Intensive Care Unit (ICU), 72 hour assessment/care admission ward and may provide a specialised psychiatric inpatient care unit.

2.3.3 Tertiary level of care

The healthcare that is serviced within the province include specialised healthcare for specific healthcare needs, rehabilitation, and psychiatric care.

All these levels of healthcare are available for both public and private healthcare sectors. However the demand in the public healthcare sector is high as services are highly utilised, while resources and equipment are scarce. Furthermore the public healthcare centres are overcrowded by a number of patients with HIV/AIDS, TB and poverty related illnesses as South Africa has a high rate of these mentioned issues. This results in patients with other illnesses not being able to access healthcare services. Commonly cited problems by individuals with accessing public healthcare services include: long waiting times; missing healthcare records; drug stock-outs; staff attitudes; poor infrastructure; poor infection controls; safety and security of staff and cleanliness (Department of Health 2002; Grebe 2013).

The private healthcare sector provides high quality and improved services, clean facilities, less waiting times, better infection control, advanced health technologies in hospitals, clinics and specialised units such as optometry, pediatric, surgery, dentistry, cardiology, laboratory and surgery (Mostert-Phillips 2011). The problem with private healthcare sector primarily relates to high cost of services. The private sector caters for middle to high earners mainly belonging to medical aid schemes. These services are unaffordable to most of the people in South Africa.

For both the public and private healthcare sectors, which provide healthcare services nationally, there is a need for information. This is discussed in the next section.

2.4 Information in Healthcare

Information is the lifeblood and a vital core element of any healthcare organisation throughout the world. It is used by healthcare professionals, medical researchers, health administrators, policy makers, patients and families for several reasons ranging from making informed decisions regarding diverse issues at point of care, to health policies. Information can be recorded, presented, evaluated and analysed in several ways and using various tools (Blaya, Fraser, & Holt, 2010; Tang et al. 2006; Nair 2011). Information is central to all aspects of healthcare and the success of its service delivery (Blaya et al. 2010; Nair 2011). This section defines terms such as data, information and various forms in which information is recorded, presented in healthcare. Health Information technologies used in healthcare will be also be discussed.

2.4.1 Information management in Healthcare

Data is raw unprocessed facts such as text, numbers, symbols and video (Tswane 2012). Data can be any number 0/1 or letter without actual context meaning (Uriarte 2008). Information is defined as relationship between data that is dependent on context for it to have meaning (Uriarte 2008). Tswane (2012) further states that data without context is meaningless and data users need to create meaningful information by interpreting the context around data. Information is an important asset for any organisation irrespective of its size (Von Solms 1998) and nature. Information serves as the lifeblood for most organisations (Von Solms & Von Solms 2006) and its protection must be maintained at all times using proper information security measures. For doctors to diagnose and treat a patient, they need reliable and accurate information. This information includes: patient's identity, the nature and cause of illness, x-rays, scans, information as to how the patient can be assisted and medication patients are on, if the is any (Puckree, Threethambal, Mkhize, Melody & Mgbobhozi, 2002). This information is stored in patient health records, such as paper-based records and electronic records discussed further in (Sections 2.5.1 & 2.6). When healthcare workers have access to a single, unified copy of the patient's medical history, they are able to give quality care and make informed decisions on the patient's needs. However, it is clear that paper-based patient records are failing in all regards when it comes to that (section 2.5.1 discuss that in more detail). The sections below discuss components that ensure protection of information.

2.4.2 Protection of privacy and security of health information in South Africa

The International Information Security Management Standard, ISO 27799 (SANS 27799 in South Africa), was adopted by the South African public health care sector in

2008. This standard was published by the ISO technical committee, TC215, which is responsible for the health informatics (Coleman 2010). SANS 27799 is based on the ISO 27001 and ISO 27002 standard which ensure that an appropriate level of information security management are in place. The ISO 27799 is a comprehensive guideline for both security and privacy in the healthcare facilities. ISO 27799:2008 “specifies a set of detailed controls for managing health information security and provides health information security best practice guidelines”. By implementing these international standards, healthcare organisations’ and other custodians of health information will be able to ensure a minimum requisite level of security is appropriate to organization’s circumstances. This is to ensure that confidentiality, integrity and availability (CIA) of personal health information both in printed and digital format is maintained at all times (Coleman 2010). Components of information security (CIA) will be discussed below:

Confidentiality

Humphreys et al. (1998) state that confidentiality involves “protecting sensitive information from unauthorized disclosure or intelligible interception”. This means that organisations such as healthcare centres must make sure that information is kept secret. Only parties who have been given authorization to access information should be allowed access to it. However, unauthorised access to information should be restricted. In healthcare patients communicate sensitive personal health information to healthcare professionals (i.e. nurse and doctors) to explain what they are suffering from and to ensure that they are treated appropriately. This information is perceived and seen confidentially and it is a responsibility of those parties receiving it, to keep it as a secret.

Integrity

The general principle of integrity around health records implies that no unauthorized personnel are able to add, change or remove any data in health records. Integrity includes concept of “data integrity” and ensures validity of data. According to Humphreys et al. (1998) integrity ensures correctness and comprehensiveness of information. Integrity is a critical aspect in health environment, as it can guide healthcare professionals as to which parts of information can be amended. Furthermore, information integrity is important because information is the lifeblood of any organisation or individual and it plays a critical role in decision making (Ritchie & Brindley 2001). For personal health records, this will ensure that original accuracy

and authenticity of patient's data is stored or exchanged whenever it is accessed and used.

Availability

This refers to data being available and accessible, whenever it is needed and in a correct format. It ensures that the data is only available to authorised individuals. Therefore a patient's health record should be accessible for retrieval and usage to both healthcare providers and patient at all times, otherwise if the health record is not available this could put the patient's life in danger. According to Gerber and von Solms (2001) it is important to maintain availability of information at all times, because without timely information an organisation would be incapable of continuing normal operations. In the case of patients, if their health information and their records are not available when needed by authorized person, it puts their life at danger, and can cause serious complications.

If any of the three pillars of information security (CIA) are not in place or breached this could lead to errors that can endanger patients' safety, decrease the quality of care and in worse case cause patient to die. Below Fraser (2006) graphically presents ISO 27799:2008 and components of information security in the Figure 2.1.

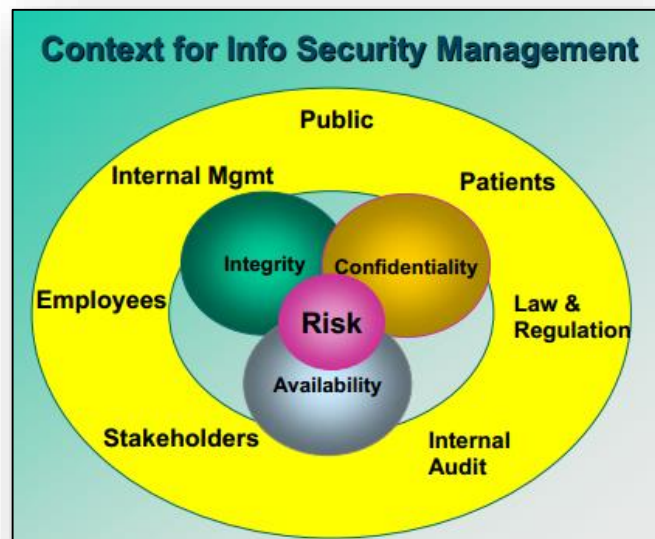


Figure 2-1 Context for Information Security Management (Source: (Fraser, 2006))

The above figure shows that health information must maintain its confidentiality, integrity and availability, whenever health information is transmitted, stored, shown on printed or spoken in a conversation.

This information together complied with medical records which are discussed in the next section.

2.5 Medical Records

Patient data is any form of data collected about the patient at point of care and is stored in a record called medical record. The World Health Organisation (WHO) (2006) defines a medical record as “a collection of facts about a patient’s history, including past and present illness(es) and treatment(s) written by the healthcare professional treating the patient”. These records can be paper-based or in electronic format. Medical record typically is a combination of test results, referral letters, (doctor’s past and present), immunizations notes, medication, medical procedures, all together bundled into one folder with patient’s identification on the front i.e. with the name, surname, age and I.D number or folder number (Tang et al. 2006; WHO 2006; Health Professions Council of South Africa 2008). The Health Profession Council of South Africa (2008) states that healthcare professionals should capture and maintain at least the following information for each patient they examine:

- Personal particulars of the patient i.e. name, surname, age and I.D number or folder number, contact numbers and address.
- Date, time and place of consultation
- Bio-psychosocial history of the patient, including allergies and idiosyncrasies
- Medication and dosages prescribed
- Written proof of informed consent, where applicable
- Information on the times that the patient was booked off from work and the relevant reasons
- Next appointment date
- Proposed clinical management of the patient
- Details of referrals to specialist
- Test results
- Imaging investigations results
- Any reactions to medications or treatment including adverse effects

Medical records serve a primary purpose to support patient care in a way that assists healthcare professional with the past and present medical history of the patient and facilitate information continuity (Medical Protection Society 2011; Nair 2011). Other

secondary purposes of medical records listed in literature include (World Health Organisation 2006; Nair 2011):

- For later clinical audits
- Medical research
- Production of healthcare statistics
- Epidemiology
- Resource allocations
- For medico-legal purposes
- Communicating with other healthcare providers for the patient
- For quality assurance activities
- Management and planning of healthcare facilities and services

In a healthcare patient data is collected mainly by healthcare professionals' i.e. doctors or dentists, and nurses who play a vital role in data and information continuity and information flow (Mostert-Phillips 2011; Tswane 2012). Patient data is captured in patient records either in paper-based or electronic records, which will be discussed in the next section.

2.5.1 Paper-based records

Patient information is created by a healthcare worker such as a doctor/nurse based on his/her interpretation of medical condition as of direct interaction with a patient (Tange 1995; De la Harpe 2008). Paper-based medical records are locked securely in the medical record storage rooms located within the healthcare institution to ensure that the records are kept safe (National Archives and Records Service of South Africa Department of Arts and Culture 2004). These patient records have been traditionally loosely structured, handwritten documents used to record relevant medical information and facts about a specific patient at point of care (Tsai & Bond 2008). It is very important that this information is legible, accurate, accessible, updated and adequate (Tsai & Bond 2008).

Paper-based patient records have the following advantages associated with using them (Tange 1995; Ayatollahi et al. 2009):

- **Flexibility:** allow healthcare professionals to decide which patient data to record, the level of detail, which words to use to describe the content and the order in which to record data. In concurrent to that these records allow easy modification of information as information can be easily be added on the patient record (Mikkelsen & Aasly 2001).
- **Compatibility:** they fit in the daily routine of the healthcare provider

- **Simplicity:** Information sharing is also simplified (van Dyk 2002), as the files are light weight and are easy to carry.
- **Stability** – since using the records does not need electricity

However a number of issues arise with using of paper-based patient records, but these are discussed in more detail in the next section.

2.5.2 Challenges and Limitations of Paper-based records

The disadvantages of paper-based patient records are records are often incorrectly filled or incomplete, and unclear hand writing. Furthermore if these records are exposed to bad weather conditions such as rain, sunlight and wind (Sanbar 2007), they can be destroyed making the data not being easily readable.

The medical record can be lost or stolen easily. Paper-based records make data access to be more complicated since the records can be viewed in one location at one time (Kharrazi et al. 2012) and since patient can have different health records for every medical practice they visit. This makes their health information to be dispersed residing in different locations in different medical practices. This can cause inconvenience for the patient and for healthcare workers, from making informed decisions as a result of missing healthcare information.

Based on a study that was conducted by De La Harpe in 2008, who visited general practices, the following were some the findings related to the paper-based records:

- Data is sometimes incomplete
- Time is wasted when a patient has to complete an identical form again when consulting with another unit in the same center
- It is sometimes difficult to read handwritten notes
- Paper-based patient folders are misplaced
- Record keeping is a problem due to litigation problems, regardless whether a paper-based system or electronic based system is used.

Cases of missing records

In Middelburg hospital, in South Africa in the Mpumalanga Province it was reported in 2008 that missing patient data (Nkombua 2008) which resulted in many problems for healthcare professionals as they could not draw conclusions from previous diagnosis done on patient at point of care and delays in the delivery of good quality and reliable healthcare services.

The Eastern Cape Department of Health (2011) reported a nurse at St. Elizabeth hospital in Lusikisiki in the Eastern Cape Province, South Africa, and a healthcare professional was caught red-handed trying to steal a patient medical record. The nurse was said to scheme with lawyers to take the department of health to court. "They hand potential damaging records to these lawyers they are in cahoots with and they taunt families to start litigations against the department" (Eastern Cape Department of Health 2011).

Nene (2015) reported that at King Edward VIII Hospital a patient suffering from diarrhea had to spend more than eight hours searching for his medical record in the file room before the doctors would treat him. "When he got to the file room a staff member asked him to search for his own medical record from a heap of folders on the floor and another piled on the shelves". According to Nene (2015) the hospital issues between 750 – 1000 cards a day between Monday and Friday. The filing department experience challenges in locating medical records from time to time due to among other things, misfiling and missing records (Nene 2015).

In some cases these records may not be really lost but just be misplaced by healthcare professionals and maybe later on found, in the healthcare professional's office and by the time found a replacement record would have been already been created and therefore causing duplicate record.

For example in a study that was conducted by Marutha (2011) it was found that at Nkhesani Hospital in Limpopo Province, South Africa where doctors could not operate a patient because of missing health records of the patient. The patient's leg was paralyzed partially due to a motor vehicle accident that happened in 2005. According to the report the doctors needed the missing file, which contained information about the patient's accident and health problems and sickness in order to trace the history of the injuries before they could operate on the patient. Unfortunately the only available health record of the patient was of the patient's diabetic illness. The Limpopo Department of Health and Social Development intervened and clarified in this matter that the hospital had a slight mix-up with files.

It is evident from the above cases that missing patient health records in paper format cause huge problems for patients and puts their lives in danger, which can lead to death. This can also cause damage to the health organization. According to Moore (2007) duplicated data is a problem for many organizations and systems and is considered as poor and unreliable data of the patient (Cline & Luiz 2013). Another disadvantage of paper-based medical records is that they are generally viewed in one location, where the physical document is present, so the information cannot be

shared by many users (JobQna 2008). Below figure 2.2 an example of how paper-based records are currently stored in medical record department is illustrated



Figure 2-2 Medical record department at St. Barnabas Hospital

It can be concluded that paper-based patient records have numerous disadvantages. This has resulted in a shift to health information technologies (HITs) in most developing world and developed world and which are discussed in the next section.

2.6 Electronic Records

The use of Health Information Technologies in healthcare industry is currently supported in many developing and developed countries in the world. These include various HIT such as electronic records, which ensures that information of patient is up to date and available at point of care when needed. Various HIT including Electronic Medical Records, Electronic Health Records, Personal Health Records and Health Information Exchange will be discussed next.

2.6.1 Electronic Medical Records

Electronic Medical Records (EMR) are digital versions of paper-based health related records created by the healthcare provider (Garrett & Seidman 2011; Kidwai 2014).

EMRs are created, managed and kept by the healthcare provider by who saw the patient. Healthcare providers create EMRs and use them for diagnosis and to determine the relevant treatment for the patient. An EMR can also provide the healthcare provider with underlying patient information such as symptoms, drug-to-drug interactions; recommended care practices; interpretation of data to support clinical decision (Garrett & Seidman 2011; Kidwai 2014). With an EMR a patient may get paper copies of the EMR information however, they cannot alter it (Siek, Khan, Ross, Meyers, Cali 2011). According to Garrett et al. (2014) an EMR allow health care provides to:

- Improve data tracking.
- Provide complete and accurate information
- Timely access to a patient's health information in one location.
- Identify which patients are due for checkups or preventative screening.
- Manage patient's parameters (blood pressures, vaccinations).
- Monitor and improve overall quality of care within the practice.

However, not all EMRs are interoperable, and information stored on it is not easily shared with other healthcare providers outside of a practice (Garrett & Seidman 2011; Kidwai 2014). The difference between EMR and EHR is that EMR contains medical information and treatment history of a patient that is collected and kept in a single practice while EHR contains data collected from more than one practice and with the history of care (Garrett & Seidman 2011). Electronic Health Records (EHR) will be discussed further in the next section.

2.6.2 Electronic Health Records

The medical industries in some developing and developed countries have taken advantage of the ICT innovations of improving healthcare delivery systems. Countries such as the United States and Europe have implemented and have many years of experience of ICT in the health industry, and have achieved a lot of success through the implementation of ICT (Brown 2008).

ICT in the health industry includes e-health which comprises of many areas such electronic health records and Health Information Systems (HIS). Eysenbach (2001) defines e-health as: "an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of

thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology” (Ruxwana et al. 2010). These e-health technologies are viewed to have great potential in bridging the digital divide between rural and urban communities, improving decisions made by health professionals and as well as patients by providing access to medical and health information (Ruxwana et al. 2010). The focus of this study is on electronic health records.

EHRs were introduced during the 1960s. Back then EHR projects had significant technical and programmatic issues, such as non-standard vocabularies and system interfaces, which still remain some of the implementation challenges to date (National Institutes of Health National Center for Research Resources 2006).

The extent and type of electronic health records vary from country to country, and what each country calls it. The WHO, (2006) defines EHR as: “an evolving concept defined as a systematic collection of electronic health information about individual patients or populations. It is a record in digital format that is capable of being shared across different health care settings, by being embedded in network-connected enterprise-wide information systems. Such records may include a whole range of data in comprehensive or summary form, including demographics, medical history, medication and allergies, immunization status, laboratory test results, radiology images, and billing information.” However, the Institute of Medicine 2006 asserts that an EHR is a collection of information about a person in an electronic format, which contains health information about individual or health care provided to the individual, and it is only accessed by an authorized person. Al-nassar et al. (2011) state that electronic health record is an electronic middleman that allows healthcare providers to access retrieve and review a patient’s health information and medical history to facilitate the activation between patients and medical users. Tang et al. (2006), also define EHR as a computerized health history of an individual that can be viewed as a collection of electronic medical records and other health-related information that can be used and made available to caregivers. Information included in EHRs are a patient’s demographics, diagnosis, past medical history, immunization, laboratory results, progress notes, radiology reports, vital signs and medication of a patient.

From the above definitions it is clear that EHRs are the enabler of achieving effectiveness, efficiency and providing lifelong summary of patient data to the healthcare provider. However EHR patients do not have the ability to manage control over their information. For the purpose of this study we is define EHR as repository of information regarding the healthcare about a patient in a computerized form (ISO

Technical Report 2007). Its purpose can be clearly understood as a record that comprises of health-related information of patients that they encounter every time they visit a health facility, and only accessed by authorized persons.

The WHO (2006) illustrates a simple basic electronic health record showing the typical sources of information for the EHR from different departments within a hospital.



Figure 2-3 : Elements entailing a basic electronic health record, adapted from (World Health Organisation 2006)

According to the Medical Records Institution as cited in Luo (2006), an Electronic Health Records can be distinguished in five levels which are listed in the table 2.1.

Table 2-1 Five levels of Electronic Health Records (Source Luo (2006))

<ul style="list-style-type: none"> • Level 1: The automated medical record is a paper-based with some computer-generated documents
<ul style="list-style-type: none"> • Level 2: The computerised medical record makes the documents of level 1 electronically available.
<ul style="list-style-type: none"> • Level 3: The EMR restructures and optimizes the documents of previous levels, ensuring inter-operability of all documentation systems.
<ul style="list-style-type: none"> • Level 4: The electronic patient record is a patient-centred record with information from multiple institutions.
<ul style="list-style-type: none"> • Level 5: The electronic health records add generated health-related information to EPR that is not necessarily related to a disease.

Luo (2006) also states that these levels are theoretically helpful in determining what type of EHR is necessary for different kinds of healthcare settings. Solo practitioners may only need a level one record system, but integration with a local hospital for continuity of information transfer, more sophisticated systems may be needed. Several clinical systems and electronic record system in healthcare struggle integrating systems from departments such as laboratory, pharmacy and scheduling in terms of managing patient flow across all these platforms (Luo 2006).

2.6.3 Benefits of Electronic Health Records Implementing

EHR present tremendous benefits for the health care industry. The most cited benefits of EHR by (Coleman 2010; Ruxwana et al. 2010; Al-nassar et al. 2011; Kleynhans 2011) are: (a) is that of enabling better communication about the patient referred for consultation and that of the health record being available any time when it is needed by an authorized person, (b) shared and easily communicated information among all healthcare providers and patients, (c) accuracy and completeness of patients' health information.

Other benefits include (a) reducing medical errors, supporting clinical decision support; (b) an EHR plays a significant role in maintaining privacy and security of patient information. Electronic records also play a significant role in maintaining confidential, integrity and availability (CIA) of patient's information, as unauthorized access can reveal a history of drug abuse, psychiatric notes, life-threatening illness, and sexual activities etc., compared to traditional paper health records, therefore if

anyone can easily access patient private information, it could cause problems for patients on daily basis (Al-nassar et al. 2011).

The Health information Management System Society (HIMSS), 2003 as cited in Kleynhans (2011) also states other benefits that EHRs bring that include reduced lengths of time stay (in acute care settings), improved continuity of care, increased efficiency and timeless care and effective disease management by gathering and improving treatment protocol. An EHR does not present benefits to patients since it benefits the main users by assisting and improving the duties and routines of physicians and healthcare institutions.

However, there are some issues associated in implementing electronic health records, which are discussed in the next section.

2.6.4 Barriers of implementing EHR

The barriers to the implementation of EHR can be many; some can be consistent from country to country when comparing the implementation and the impact of which these barriers may differ from. Below are some possible barriers listed in the WHO (2006) report:

- The lack of standard terminology and clinical data entry issues
- Resistance to computer to computer technology and the lack of computer literacy
- Strong resistance to change by healthcare providers
- Funding limitations and high cost of computers
- Concern by providers as to whether information will be available on request
- Concern raised by stakeholders of healthcare i.e. healthcare professionals, patients, and general community about confidentiality, privacy and the quality of electronically generated information.
- Accuracy of data entries and quality of electronic healthcare information
- Lack of staff with required knowledge of disease classification systems
- The issue of manpower – lack of staff with adequate skills
- Involvement of clinicians and hospital administrators
- Environmental concerns – supply of electricity, and electrical wiring and amount of adequate space needed for computers etc.

Other most cited barriers of EHR in most developing and developed countries include: (a) Interoperability among systems with the ability to extract relevant patient's relevant data and to share information among healthcare providers across multiple location is also one of the major recognized challenges to benefit fully from

electronic health records, (b) cost of implementation and maintaining the EHR systems (Luo 2006; Ruxwana et al. 2010; Coleman 2010). Difficult implementation process, training concerns and resistance from medical staff to divert from paper records to electronic records which limits the implementation and to fully benefit from Health Information technologies such as EHR (Kleynhans 2011).

2.6.5 Current state towards Electronic Health Records in South Africa

In South Africa, at Inkosi Albert Luthuli Hospital Central Manor near Durban, Kwa Zulu Natal Province is an example of a paperless hospital that has implemented EHR and are successfully used (Kahn 2011). The hospital has been developed as a private public partnership and is regarded as a state-of-the-art, paperless hospital (Mars & Seebregts 2008).

Open Electronic Health Record (openEHR), is an application managing, structuring and storing patients' information. It also helps in facilitating the sharing of patient information among healthcare providers (Pishev, 2006) as cited in (Mchunu 2013). OpenMRS is an open source electronic medical record system that has been designed for use in the developing countries to help with delivery of health care in some of the resource restricted settings (Mars & Seebregts 2008).

However, according to Kahn (2011), the majority of public hospitals in South Africa have implemented HITs which are limited to the streamlining of administrative tasks such as billing and patient demographic information. For example some of these systems that have been implemented in different provinces are:

- Clinicom, Delta 9, Meditech, Medicom, PAAB (which caters for entry and maintenance of demographic information of a patient, printing of labels and tracking patient visit to the hospital) (Mars & Seebregts 2008). These systems are currently deployed in the public health care sector in South Africa and are not integrated to each other due to the lack of bandwidth (Kahn 2011) and in some hospitals like the St. Barnabas Hospital where this study is conducted do not have any form of these systems nor do they have internet connectivity.

A solution that is promising and has a great potential in terms of complete and longitudinal patient health information are personal health records which is discussed in the next.

2.7 Personal Health Records

Natural disasters like floods, earthquakes, Tsunami, and economic conditions that cause great damage to life and information, call for the need of having a commonly accessible, longitudinal and comprehensive electronic personal health records. Personal Health Records (PHR) is an evolving and burning concept in healthcare globally. According to Tang et al. (2006), PHR offers great potential to prevent medical errors, and improve quality of healthcare by providing complete medical information of a patient.

With growing the potential that electronic health records and personal health records show in the medical industry, patients have shown significant interest in having access to their health records (and been increasingly asking for access to their health records) (Schneider 2008; Nazi 2013; Cassel & Guest 2012). For example a survey that was conducted in the United States of America indicated that participants would prefer their healthcare providers to use Health Information Systems such as Electronic Health Records and Personal Health Records as these HITs are more efficient and effective as compared to the paper-based records (Kaiser Permanente 2007) . However, in South Africa, patients are interested in having access to their health records, but they are not aware of HIT such PHR and EHR. This is was revealed by a survey that was conducted by Pottas and Mostert-Phipps in (2013) at the Nelson Mandela Bay, which showed that 84 % participants that were interviewed were not aware of the existence of PHR tools prior to participating in the survey (Pottas & Mostert-Phipps 2013). The next section gives detailed definition of personal health records.

2.7.1 Defining Personal Health Records (PHR)

Personal Health Records (PHR) can be defined as patient-oriented electronic records, which are usually web-based that allow an individual to manage his/her own healthcare and contain his/her health related information that has been gathered from various sources (Tang et al. 2006).

However Markle Foundation (2003) defines PHR as computer-based tools that allow individuals to have access and co-ordinate their life long information and making appropriate that part of that information available to those who need it. A patient's PHR is initiated by the patient who request medical attention and then store details of the diagnoses and treatment. PHRs should typically contain information on patients past and current illnesses, allergies, immunizations, medication, tests and more (Tang et al. 2006).

PHRs are typically owned and managed by individuals and allow them to have a lifelong summary on his/her health information in one convenient place (Mostert-Phipps 2011). PHRs are typically useful for individuals who have chronic illnesses such as HIV, diabetes, cancer and Hypertension, as with these illnesses the medical professional or doctor needs to review their past and current health history before they draw a conclusion on the individual (Markle Foundation 2003).

PHRs empower individuals to manage their own health information, and help them to actively participate in their healthcare while assisting them in informed decision making (NCVHS 2006). Furthermore PHRs allow sharing health information, increasing understanding and help to transform patients into better-educated consumers and being empowered (Siek et al. 2011).

It is evident from the above definitions that the key elements of PHR are to provide lifelong information of an individual from various sources to be kept in one convenient place electronically; it empowers individuals on managing their health information and helping them in active decision making. As a result to these promising benefits that PHR show for patients, large technology companies such as Google and Microsoft have entered in the PHR space for example Microsoft with their PHR product of HealthVault and Google with Google Health product. PHRs can be classified into three diverse types, which will be discussed in the next section.

2.7.2 Types of Personal Health Records

PHR can be distinguished into three types namely Standalone, Tethered and Interconnected PHRs (Tang et al. 2006; Kaelber & Pan 2008; Alberta Health Services 2009). Figure 2.5 illustrates the complexity between these PHRs. Tethered and standalone PHRs are less complex, with interconnected PHRs being the most complex (Tang et al. 2006), but they will be discussed in detail below.

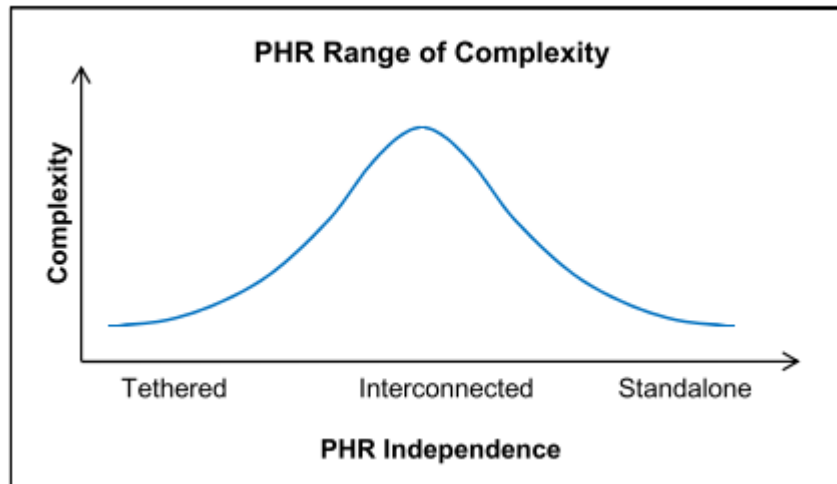


Figure 2-4 PHR Range of Complex (Tang et al., 2006)

Standalone PHRs do not integrate with any other systems and are also commercially available web-based systems (Tang et al. 2006; Kaelber & Pan 2008) . Certain standalone PHRs may allow an individual to give their healthcare provider access to the PHR to help in populating information for the PHR. The individuals are usually responsible for entering into the PHR (Jeong, Kim & Bae, 2009) as cited in (Mostert-hipps 2011). With standalone PHRs, information can be downloaded from other sources into the PHR. Some standalone PHRs can have a number of features such as social media, decision support, disease/health management which can help patients to engage with their own health information and health (Alberta Health Services 2009). A limitation of these PHRs is the fact that the patient needs to enter and update their own health information themselves. This could be a problem for patients who are illiterate in terms of medical terminology and technology. Furthermore, with standalone PHRs, the health record becomes an information island that contains different subsets of patient’s data, which is isolated from other health information about the patient (Tang et al. 2006). Figure 2.6 shows standalone PHR (Eysenbach 2008)

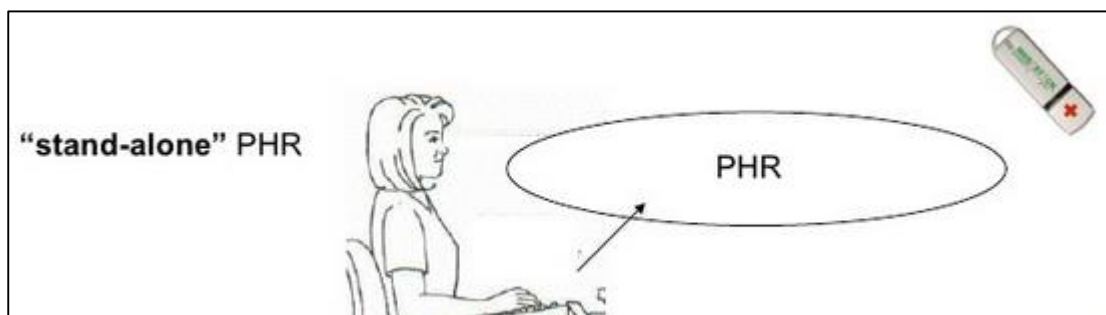


Figure 2-5 Standalone PHR (Eysenbach 2008)

Tethered PHRs provide a patient-oriented view integrated with other electronic health information of a certain organization (Kaelber & Pan 2008). These PHRs comprise of data which is compiled by the healthcare provider or healthcare payer and such PHR systems are known as provider-tethered or payer-tethered (Mostert-hipps 2011). Because tethered PHRs are linked to particular health systems they are not portable (Alberta Health Services 2009). With Tethered PHRs patients can have access to their information through a secured portal. Typically patients can view information such as such lab results, immunization history or next appointments. These PHR have limited ability to support specialized search to assist patients with access to health education (Alberta Health Services 2009) . Figure 2.7 shows Tethered PHR (Eysenbach 2008).

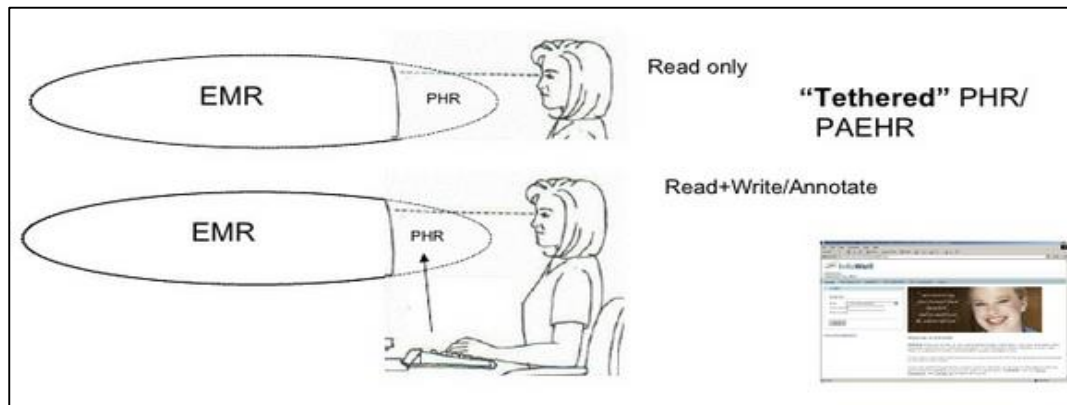


Figure 2-6 Tethered PHR (Eysenbach, 2008)

Interconnected PHRs provide a more complete view of health information related to the individual and they consist of data which is obtained from several sources including Electronic Medical Record (EMR) of the provider, pharmacy data, medical aid claims and information entered by patient himself/herself (Tang et al. 2006). In addition Mostert-Phipps (2011) states that interconnected PHRs that allow data from various PHRs to be uploaded to an EMR of numerous healthcare providers and vice versa, can play a vital role in improving information continuity of care

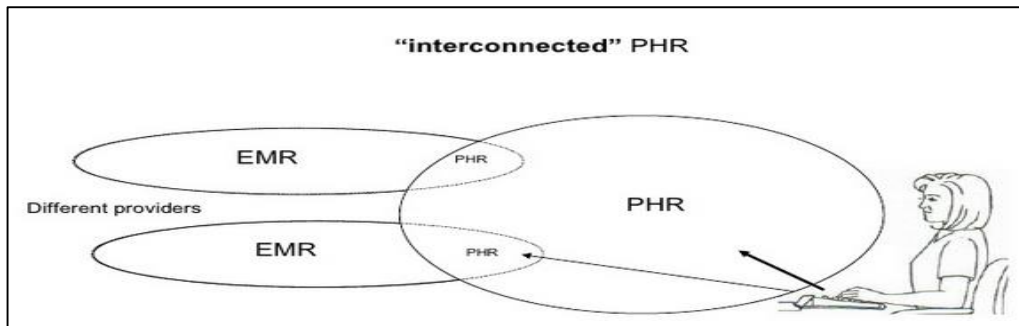


Figure 2-7 Interconnected PHR (Eysenbach 2008)

2.7.3 Benefits of using Personal Health Records

Personal Health Records have numerous benefits associated with using them (Markle Foundation 2003; Tang et al. 2006; Nagykaladi et al. 2012; Mostert-Phillips 2011; Cline & Luiz 2013; Liu et al. 2011; Chen et al. 2010; Kharrazi et al. 2012; Nazi 2013). Some of the benefits are:

- Empower patients and their relatives to become more involved in the patient's care.
- Allow patients to better manage their decision regarding their medical conditions.
- Allow patients to share decision making with their providers and eventually leading to better health results.
- Allow patients to verify accuracy of their medical records kept by their health care provider.
- Improve care by encouraging collaborative disease tracking between patients and their healthcare providers.
- Enhance communication between patients and their doctors and caretakers.
- PHRs can improve the quality and empower both the patient and doctor with access to accurate health information about the patient.

In the next section the barriers to the adoption of PHRs are discussed.

2.7.4 Barriers to the adoption of PHRs

Despite many of benefits that PHRs show to the patients, doctors, and health institution, the rate of their adoption is low, this especially in developing countries (Dohan, Abouzahra, & Tan, 2014).

- **Digital divide and literacy related issue.** This is one of the rising major issues affecting the effective use of PHRs by consumers who have low computer and health literacy in particular in resource restricted areas (Archer et al. 2011; Kim & Nahm 2012) . According to a study that was conducted by Kim and Nahm (2012), it was found that the PHRs were less likely to be adopted by most of users in resource restricted areas because of poor computer & technical skills and Internet skills, limited physical and cognitive abilities, low health literacy and technophobia. Furthermore divide a between people who have higher annual income who are more likely to adopt than those with less annual income.
- **Privacy and Security concerns.** In a survey that was conducted in California it was found that about 75 % of adults who did not have PHR would be concerned about the privacy of their health information, if their health information was in a PHR (CHCF, 2010). Furthermore Tang et al. (2006) assert that while consumers of health desire protection of their personal health information, aggressive protection measures might hamper PHR access by patients and doctors and delay optimal care.
- **Limited standards.** There are limited standards that exist for the implementation and use of health information technologies and other related record-keeping systems like PHRS as results could create systematic issues of interoperability (Liu et al. 2011; Chen et al. 2010; Marshall n.d.).
- **Individual barriers.** Developers and users of PHRs must understand both the patients' and doctors' mental model within the health care process and in their related work follow (Tang et al. 2006). PHRs can be useful and of value to an individual only if the person understands the purpose, use of PHR and how it fits into their flow of day-to-day activities.

The above barriers need to be overcome and be addressed for PHRs to be implemented especially in resource restricted areas and for general community to start experiencing the positive benefits of PHRs and to be effectively used.

2.8 Conclusion

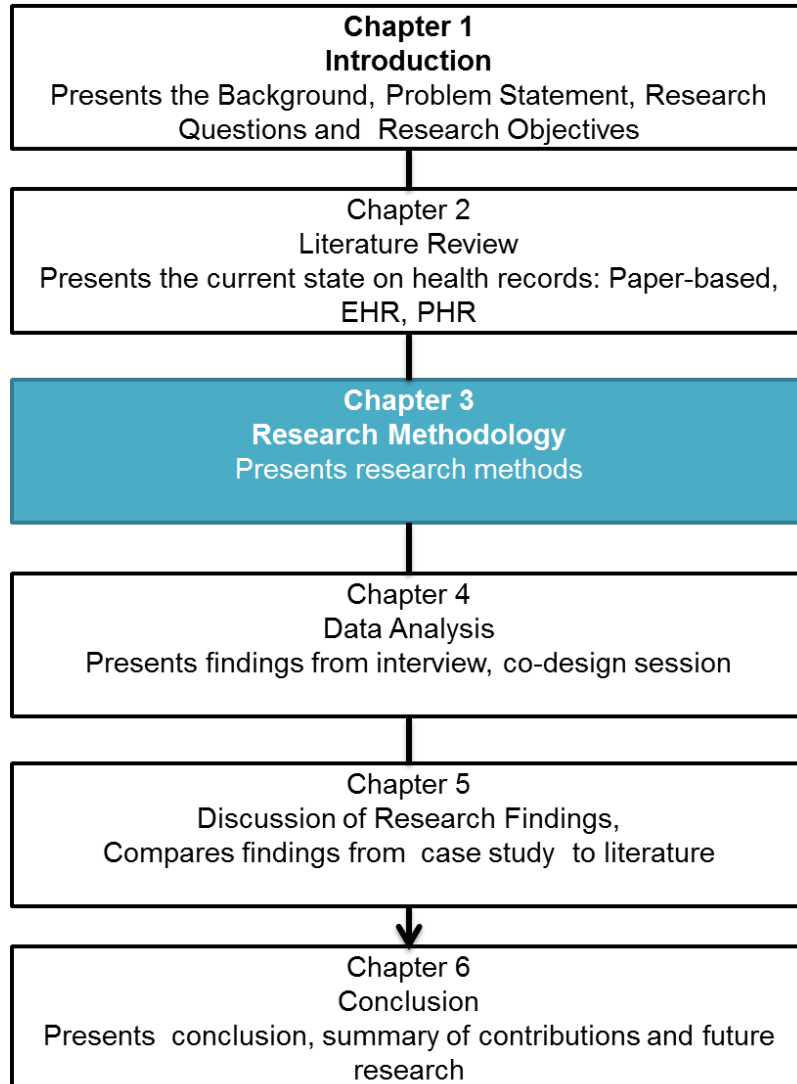
This chapter explored various healthcare sectors in the South African landscape. This chapter also explored paper-based health records with their advantages and disadvantages. It explained various HITs such as electronic records which can play a role in improving quality care by ensuring that up to date information about patient at point of care when need (Mostert-Phipps 2011).

There are limited studies that explored the concept of a patient's access to their health records within a rural setting, particularly in South Africa and other developing economies particularly studies that involve community-based research. In South Africa, very few living labs studies were published with regard to the adoption of specific technologies, more specifically in reference to electronic health care technologies implemented within communities. It is also evident that most studies focused on determining perceived adoption of electronic health medical records from the perspective of health care professionals and not necessarily the patients, who can be regarded as the main initiators for the patient health records. There are currently very few studies that focus on determining the considerations for patients to have access to their personal health records.

There is a considerable need for more research to be conducted to address the gaps and contribute to the larger Information Technology body of knowledge.

The next chapter will discuss in detail the research methodology undertaken for this study.

CHAPTER THREE : RESEARCH METHODOLOGY



3.1 Introduction

The previous chapter introduced healthcare and different types of health records (paper-based health records; electronic medical, and health records; and personal health records) used in healthcare. These records play a critical role in a patient's health information continuity and for a healthcare provider to make an informed decision about patient's health as part of continuous care. The research problem emphasizes the need to investigate the lack of access to patient's own health information in the case of rural setting and the consideration for them to have that access. To ensure that the objectives of this study are met, the selected research methodology must be clear and aligned to the aim of the study.

This chapter covers an overview of the methodology used in this study. The sections that follow, present a discussion which is structured around the research process, research philosophy, research approach, data collection and data analysis. Ethical considerations are discussed before the conclusion of the chapter.

3.2 Research Methodology

Research is defined as a process of collecting, analyzing and interpreting information to answer a question, a solution to a problem, or greater understanding of a phenomenon (Leedy 1997). Ryan et al. (2002) define research as a process of intellectual discovery to transform peoples' knowledge and understanding of the world. As an opposing view Kumar (2005) states that research is an unbiased and objective process of finding answers to enquiry which is carried within the framework of a set of philosophies or approaches. It is clear from the above definitions that research enhances our knowledge of the facts we are concerned about. There is however a difference between a subjective or objective view of the investigation that is influenced by the nature of the research problem and aim of the research study.

Research methodology on the other hand is defined as a process followed to conduct a research study (Khothari 2005). In concurrence Welman et al. (2005) define methodology as an organized way, consisting of sequences, procedures and systems to manage and execute a research process. The main aim of the research methodology is to highlight the methods and tools that are applied during the research process (Leedy & Ormord 2001). Lindsay (1995) recommends that research methodology should "provide enough details to knowledgeable colleagues to repeat the same study in a different environment and obtaining almost similar results". In this study that has been taken in consideration. However, according to

Tswane (2012) as part of her research reflection states that “Deciding on which methodology to use in research is of the most difficult and daunting task for researchers, particularly novice researchers”.

An overview of the research design model from Saunders et al. (2011) in the study is shown in Figure 3.1 where a research onion is used to illustrate the different aspects of the research process.

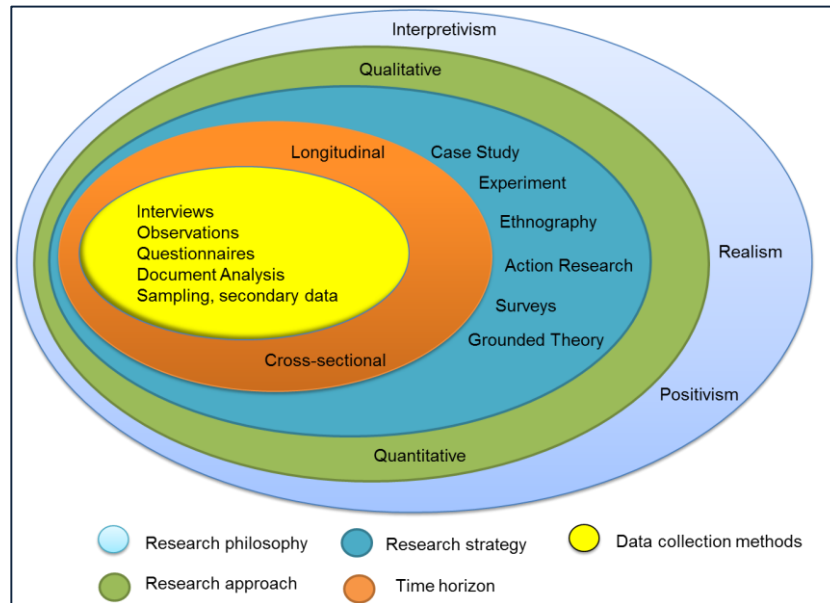


Figure 3-1 The research process onion, adapted (Saunders et al. 2011)

The research onion presented above compares the research process to peeling the different layers of the onion until the center has been reached (Saunders et al. 2011). The research process as depicted in the research onion consists of the outer “onion” layer research philosophy, followed by the research approach. The third layer refers to research strategies, followed by the time horizon and at the core are the data collection methods. The layers are peeled off in the order precedence. The process starts with the outermost (research philosophy) and proceeds inwards until the core of the onion is reached (data collection methods). The researcher selects one of the options indicated in the layer based on the research study. The next section discusses the layers of the onion starting with the outer layer (research philosophy).

3.2.1 Research philosophy

This section describes the suitable research paradigmatic view appropriate for this study. All research are based on an underlying philosophical paradigm (Oates 2006), about what constitutes 'valid' research and which methods are appropriate for that particular study, so that it can add to the development of knowledge. A paradigm is an accepted model or pattern that "proved able to guide the whole group's research" Kuhn (1999) as cited in (Olivier 2009). There are many different types of philosophical paradigms, but the most prominent are interpretivism, realism, and positivism as illustrated in Figure 3.1. Below each philosophical paradigm will be explained.

- **Interpretivist philosophy** – is concerned with understanding phenomena through the meaning people assigned to them (Deetz 1996). The focus in this paradigm is to seek to understand the phenomena from the subjective interpretation of the investigation and of the researcher, mostly by observing the society's behavior in a specific environment (Voce 2004). This means in this paradigm, concern is observing participants while in action. Methodological Interpretivism focuses on the qualitative data methods (Denzin & Lincoln 2005) and not to test theory, but build theory (Henn et al. 2005).
- **Realist philosophy** – This paradigm holds a subjective and value-mediated view of co-created findings (Denzin & Lincoln 2005). The focus on this paradigm is to transform society and to bring about change in a situation by clearing way all myths and coming out reality (Burke 2007). Researchers in this paradigm believe that what we perceive as reality now can be different later. Methodologically, the emphasis on the critical paradigm is on qualitative data through "dialogic dialectical approach" (Denzin & Lincoln 2005; Guba et al. 2011) but again quantitative data approaches cannot be excluded (Creswell & Clark 2007).
- **Positivist philosophy** – Positivism paradigm holds an objective view which sees findings as true, based upon verification of a hypothesis to establish facts or laws (Denzin & Lincoln 2005; Guba et al. 2011). Positivism is also referred to as a scientific method (Oates 2008), and views the world as structured and ordered. This paradigm is mostly aligned with natural sciences and is based on quantitative methods such as (statistical analysis, surveys, and experiments) (Voce 2004).

Philosophical paradigms were presented above, considering the research question and objectives. Interpretive paradigm was identified as suitable framework for this study, since it gives the research greater scope to address issues of influences and impact and to ask questions such as 'why' and 'how' in the process (Deetz 1996). Furthermore, the interpretive paradigm was suitable because it provided deeper understanding to considerations for patients to have access to their own personal health information in resource restricted settings such as rural Eastern Cape, South Africa.

The next section discusses research approach.

3.2.2 Research Approach

The research approach affects how the research is carried out, that is from general or from a more specific standpoint. Research can be either Quantitative or Qualitative, as shown on second layer of the research process onion.

- **Quantitative Research Approach.** Studies focus on numerical data and involve some kind of measuring (Walsh 2001). This methodology was strictly associated with the natural and pure science disciplines its history can be traced back in the 19th century (Creswell 2009). Creswell, (2003) defines quantitative methodology as where "the investigator primarily uses post-positivist claims for developing knowledge (such as cause and effect thing, reduction to specific variables and hypotheses questions, the use of measurements and observations and testing of theories), employs strategies of inquiry such as experiments and surveys, and collects data on predetermined instruments that yield statistical data". Analysis of quantitative data is normally predetermined prior to the research process (Struwig & Stead 2001).

This methodology is more appropriate for a study that involves quantitative data i.e. statistics, measurements, experiments and figures. This approach will not be applicable for this study, as this study explores accessibility to patient's own health information in a rural setting based on the healthcare professionals' and patients' own views.

- **Qualitative Research Approach.** According to Creswell, (2007) qualitative research involves an inquiring process of understanding based on a distinct methodological tradition of inquiring that explores a social or human problem. Furthermore Mack et al. (2005) justified the strengths of a qualitative research, as

its ability is to provide a complex textual description of how people experience a given research issue. It provides information about “human” side of the issue that is often the contradictory behaviours, beliefs, opinions, emotions and relationships of individuals. The research builds a complex, holistic picture, analyses words, reports the detailed views of informants and conducts the study in a natural setting (Coleman 2010). In addition Maree (2007) also states “rich descriptive data” is gathered regarding a specific phenomenon or context of what is being studied to attach meaning to the observations to gain an understanding of the phenomena. Qualitative methods are often effective in identifying intangible factors such as status, gender roles, religions, social norms, ethnicity, and socio-economic whose role is in the research.

As stated earlier in the introduction this study is qualitative and seeks to explore considerations for patients to have access to their own personal health information in resource restricted settings such as in rural Eastern Cape, South Africa.

The following section discusses the research strategy.

3.2.3 Research strategy

According to Yin, (2003) research strategy provides pre-specified procedures that should be followed to address research questions and fulfill research objectives. Furthermore Marshall and Rossman (2011) state that research strategy helps researchers to achieve the goals and objectives of their study. This study adopted case study as a strategy that will help in achieving the goals of this research. In this study, the data was collected from a rural hospital and at a rural community which formed the case. This was done to make sense of the participants’ view on relating to patients accessing their health records. The research strategy of case study research used literature review, interviews and co-design sessions methods.

Case study as a research strategy is discussed in the subsection that follows

3.2.4 Case Study research

Creswell, (2007) defines case study as the study of an issue through one or more cases within a bounded system. According to Yin (2003) case study is an empirical inquiry that investigates a phenomenon within its real-life context, especially when the boundaries between the phenomenon and context are not clearly evident. In concurrent Welman et al. (2005) state that case study “pertains to facts that a limited

number of units of analysis is studied intensively". Furthermore Leedy and Ormrod (2005) define case study as the type of qualitative research in which in-depth data is gathered relative to a single individual, program or event for the purpose of learning more about an unknown or poorly understood situation. It was found that case study is the most important and commonly used qualitative method in Information Systems (IS) research, as its findings can be applied in practice (Shakir 2002; De Vries 2005). Case Studies tend to be based on qualitative data, as this provides a richer and deeper description.

Within case study research, the researcher has limited control and often focuses on life cycles. Yin (2003) further states that case study is also considered a suitable research strategy when the proposed research deals with contemporary phenomenon, which the researcher has no control over, as boundaries are not clear between the phenomenon and context. The research is mostly exploratory and addresses the "how" and "why" questions (Rowley 2002). Case Study research strategies are used in many situations to contribute knowledge of individuals, groups, organizational, social, political and related phenomena (Yin 2008).

Case Study research can be done on either single or multiple cases (Yin 1994):

- **Single case** is either holistic or embedded. Single case is useful where it characterizes a critical case or where it is an extreme or unique case.
- **Multiple case** "allow cross- case analysis and comparison and investigation of a particular phenomenon in diverse settings" (Yin 1994). This also allows a large amount of data or information to be collected from diverse locations

This research has adopted a single case for the study because it uses multiple sources of evidence and aims to provide answers to the "how" of the research associated with the single hospital in the Eastern Cape. This is aimed at understanding considerations for patients to have access to their own personal health information. This study does not attempt to generalize the results and by studying a single case it is possible to consider the context of the hospital and gain deeper insights in the health professionals' and patients' perceptions of patient information.

3.3 Time Horizon

Time horizon is the time framework within which the research study is intended to complete (Saunders et al. 2007). There are two types of time horizons namely: Longitudinal and cross-sectional as shown in the research process onion Figure 3.1 (Bryman 2012).

- **Cross sectional time horizon**, refers to the collection of data undertaken only once and in a short period of time (Saunders et al. 2007).
- **Longitudinal time horizon**, on the other hand refers to the collection of data undertaken repeatedly over an extended period of time, with several interventions (Goddard & Melville 2004; Saunders et al. 2007). According to Saunders et al. (2007) the strength of longitudinal time horizon, is ability to study change and development.

This study was conducted from 2013 to 2015, with all the interviews conducted in 2013. Below section discusses data collection methods that were used in this study. It can therefore be regarded as a cross sectional time horizon study for the period 2013 to 2015. It did not consider the collection over a longitudinal time horizon because the aim of the study was not to observe changing patterns of health professionals' and patients' views of patient information. It was not possible to collect all the data in a single visit due to the long distance to the site of the study and the different data collections took part during a number of visits.

3.4 Data Collection

There are several sources for data collections, but the method of data collection must always be appropriate to the particular research project, and collection must gather evidence for improvements of practice. For the purpose of this study, more than one method of gathering data has been chosen. Oates (2008) explains that using more than one data collection method enables the researcher to look at the phenomenon of interest in different ways. Therefore, the researcher will use document analysis, interviews, co-design sessions and observations.

3.4.1 Literature Study

A literature study gives understanding of the background and history of a specific phenomenon under investigation as it is possible to have been studied before. According to Zakaria (2004) a literature study involves the process of finding, collecting and reading some documents, journals and books which are relevant to the study. A literature study is regarded as the main data collection method since most of the important information is found on previous written and published documents (Marrelli 2005) to identify the issues that need to be considered for the research topic but also to identify the gap in the literature. For this research a literature study was done to research the background of the research topic of this thesis which involved reading journals, books to find detailed information on the

current status of health records and personal health records. Keywords were used to search through the relevant databases to identify suitable literature sources.

3.4.2 Interviews

Interviews is a data gathering method with communication between the research and the participants, with the objective of trying to obtain information from the participants (Fox 2009). An interview allows a researcher to obtain information that cannot be obtained from observations alone. There are three forms of interviews in qualitative research, namely: unstructured (no pre-defined set of standards), semi-structured (responses from the research participants can change the standard structure of the predefined questions) and the structured (pre-defined set of standard questions only) (Oates 2006).

Semi-structured interviews were decided to be suitable for this study because of its flexibility to allow the researcher to divert slightly from the pre-arranged structure of the interview, thereby allowing the researcher to dig deeper into the emergent issues during the interview process. For this study semi-structured interviews were conducted at St. Barnabas hospital. The semi-structured interviews included questions about paper-based patient health records; challenges with current methods used to keep patient health records; methods used to refer patients to another hospital; and healthcare workers' knowledge about emerging technologies such personal health records.

3.4.3 Document analysis

Document analysis is one of the qualitative data gathering methods which were used. All documents that provide information about the problem were gathered and analyzed. Such documents include both published and unpublished documents, patient records, hospital reports and any document that will add value to the research. Care was taken to not consult documents with actual patient data since the study was interested in the data elements rather than the actual values.

3.4.4 Co-design sessions

Co-design is a research development process and philosophy where a researcher guides, encourages and empowers users to develop a service or product solution themselves (Ylirisku et al. 2007). This method promotes the user contribution to developing ideas and solutions together with designers and researchers, rather than

being mere participants in someone else's product (Ylirisku et al. 2007). One of the benefits of this method is that it can leverage local knowledge since the team of design solution is composed of people from the local community and local value chain actors. Co-design can lead to innovations that may be better adapted to the context and be more likely to be adopted, since local people have invested resources in their creation of the solution (Halloran et al. 2009). Since personal health records are already well adopted in countries with advanced healthcare systems it was important to establish the views of the local people to identify potential different needs and uses of personal health records. This was an important consideration for this research since the selected case forms part of a severely under-sourced healthcare system and furthermore, the patients may not have the same literacy levels as patients of sophisticated systems.

The study constituted of two co-design sessions which included people who had at least visited a healthcare center within the last 5 years.

3.4.5 Participant Observation

Participant Observation is a qualitative method that aims to assist the researcher to the basic human experiences, discovering through involvement and participation of the how and whys of human behavior in a particular context. Kumar (2005) states that observation can be useful in determining how the program is implemented and provides opportunities for identifying unanticipated outcomes. Participant observation also helps the researcher to discover important elements for detailed understanding of the research problem that were unclear or unknown when the study was designed. This method can be used when there is a need for direct information and can lead to deeper understandings than interviews alone, because it provides knowledge in which events occur and may enable the researcher to see things that participants themselves are not aware of or not willing to discuss (Kumar 2005). The benefit of participant observation is that it can help the researcher not only to understand data collected through other methods, but also to plan questions that will give the researcher's best understanding of the phenomenon being studied (Maree 2007).

In the case of this study observations were not one of the main data collection methods but rather to compliment the other methods to obtain insights that can be missed from a focus only on the answers of the respondents. Examples could be to note frustrations, confusion, etc. as the respondents interact with the patient information.

3.5 Research population and sampling

The researcher, after formulating the research questions, identified the sources of the phenomenon being studied. Welman et al. (2005) define a population as a group of potential participants to whom the researcher wants to generalize the results of the study or make a conclusion. Population is also defined as a collection of individuals, events or objects which share common behavior or characteristics to be studied by the researcher (Mouton, JS & Marais 1996). In addition Babbie (2006) refers to a study population as the entire aggregation of components from which a sample is actually selected. When a population is too big to include in a study, a representative sample from the population is selected. The population covered in this study is in the Umtata area within the Eastern Cape in a specific region of healthcare professionals working at the St Barnabas hospital and persons who can be served as patients by the hospital.

3.5.1 Sampling Techniques

Individuals who are willing to describe their experiences in terms of phenomenon in questions are identified as research samples. Cormack (2000) refers to a sample as a group of people that the researcher selects from a defined population. Neuman (2011) defines sampling as a process of selecting a small and workable representative number of a large research population. Copper and Schindler (2003) state that a sample is a carefully selected representative part of the target population. According to Goodwin (2002) in order for results to be valid, a sample must be representative. This means that a sample must have the exact properties in the exact proportion as the population from which it is selected. These are the individuals who will provide information for research. Sampling strategies in qualitative research are guided by the principle of gaining in-depth information. Sampling is grouped into two categories; probability and non-probability sampling. Both methods are discussed below.

- **Probability sampling**

The sample is statistically chosen at random, which gives elements of the population the same chance to be selected for participation in the study (Oates 2008). In probability sampling the exact quantity and location of the elements are identifiable and reachable by the researcher (Mouton & Babbie 2001). Probability sampling includes systematic sampling and simple random sample, which are briefly discussed next:

- **Systematic sampling.** In this sampling method elements or units are chosen at regular intervals from the sampling frame
- **Simple random sampling.** The method in which each element of the population has an equal chance of inclusion independent of any other event in the selection process. This is the simplest and easiest to apply, form of probability sampling

This sampling method is not concerned with in-depth analysis and will not be suitable for this study.

- **Non-probability sampling**

Non-probability sampling refers to selecting participants from a population whereby the exact number and location of the population is not certain to the researcher (Mouton & Babbie 2001; Cooper & Schindler 2008) . This sampling method is more subjective in nature as the researcher has more control over selection of the elements (De Vos et al. 2002). Non-probability includes Snowball sampling, Quota sampling, self-selection and purposive sampling:

Snowball. In this sampling method the researcher must find participants that meet the exact criteria and participants may be asked to suggest additional participants that meet the criteria (Mouton & Babbie 2001).

- **Quota.** A sampling technique which chooses categories of the population and identifies the number to be used based on the judgment of the researcher (Babbie 2010). Specific characteristics that are outlined must be met based on the investigation being done on the study (Neuman 2011).
- **Self-selection.** Self-selection sampling is useful when the research allows units or individuals to choose to take part in the research “voluntary” (Mouton & Babbie 2001). For example the researcher may put a questionnaire online and invite anyone to take part (Neuman 2011).
- **Purposive.** In purposive sampling the researcher has a preconception that the sample is a true representative of the behavior, characteristics, and attributes of the population (Babbie 2006). These units are selected on the basis of the researcher’s own judgment about which will be useful. Purposive sampling is also referred to as Judgmental sampling.

For the purpose of this study, purposive sampling was applied to obtain particular participants for this study. Research participants involved patients who had visited a healthcare center at least in the last 5 years.

3.6 Data Analysis

Neuman (2011) defines data analysis as a process of transforming raw data which has been collected through surveys, interviews and observation into meaningful information. This process starts only after the research has fully finished data collection, tried finding meaning and understanding on the data which was collected. Data analysis is dividing categories into two categories namely quantitative and qualitative data analysis. For the basis of this study data collected will be analyzed using qualitative data analysis since this study is qualitative (Babbie 2006). Qualitative data analysis includes the following methods namely: Thematic analysis, narrative analysis, discourse analysis and grounded theory. Yin (2003) notes that one important practice during the analysis stage of any study is to return to the proposition. The purpose of data analysis is to identify themes emerging from data collected (Brink 1994). Data analysis requires the development of categories, making comparison and forming contracts. It requires openness to possibilities and seeing contradictions or findings. Other qualitative analysis methods in literature include narrative analysis, grounded theory and discourse analysis.

In this study, the researcher will employ thematic analysis to analyze data, as discussed in the next section.

3.6.1 Thematic Analysis

Thematic analysis is a widely qualitative method used for “identifying, analyzing, and reporting patterns (themes) with data” (Braun & Clarke 2006). It goes beyond counting explicit words or phrases and focuses on identifying and describing both implicit and explicit ideas (Braun & Clarke 2006). This research will further be guided by six stages of thematic analysis shown in Table 3:2 (Braun & Clarke 2006).

Table 3-1 Phases of thematic analysis (Braun & Clarke 2006)

Phases	Description
Familiarizing yourself with your data	Reading and rereading of the data, noting down initial ideas
Generating initial codes	Coding interesting features of the data
Searching for themes	Collating codes into potential themes, gathering all relevant to each potential theme
Reviewing themes	Checking in the themes work in relation to the coded extracts (level 1) and entire data set (level 2)
Defining and naming themes	On-going analysis to refine the specifics of each theme and overall story the analysis tells; generating clear definitions and names for each theme.
Producing the report	Selecting of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature.

In this study qualitative thematic analysis was used to allow the researcher to report experiences of the study participants which were captured during the interview process. Furthermore, thematic analysis was regarded befitting for analyzing issues related to patient's access to their personal health record in a rural area.

3.7 Ethical Consideration

The study did not involve any unethical behavior and did not involve participants who were unable to give informed consent. All the interviews were carried out in a sensitive manner to ensure dignity of the participants. Participants were free to refuse participation at any stage of data collection. Privacy and confidentiality were assured and no identity of names and addresses of the participants will be disclosed. The research did not look at patient's information such as past diagnosis and current diagnosis and no actual data values were considered since the issues around the data elements and not their values are considered in this research. Patient records that were investigated were the empty forms and cards with no data filled in. The research did not involve environmental studies which could be contentious, and the outcome will not damage the environment. The research method that was used in

collecting data was appropriate to the participants and will not have any negative impact on their health. A brief explanation on the topic, methods for data collection, data analysis and presentation of findings were discussed with the participants for them to better understand the purpose of the research. The research proposal for this study was reviewed and approved by the Cape Peninsula University of Technology Research Ethics committee to ensure that ethical issues are considered before the research process continues. Permission was obtained from the Department of Health in the Eastern Cape.

3.8 Delineation of the research

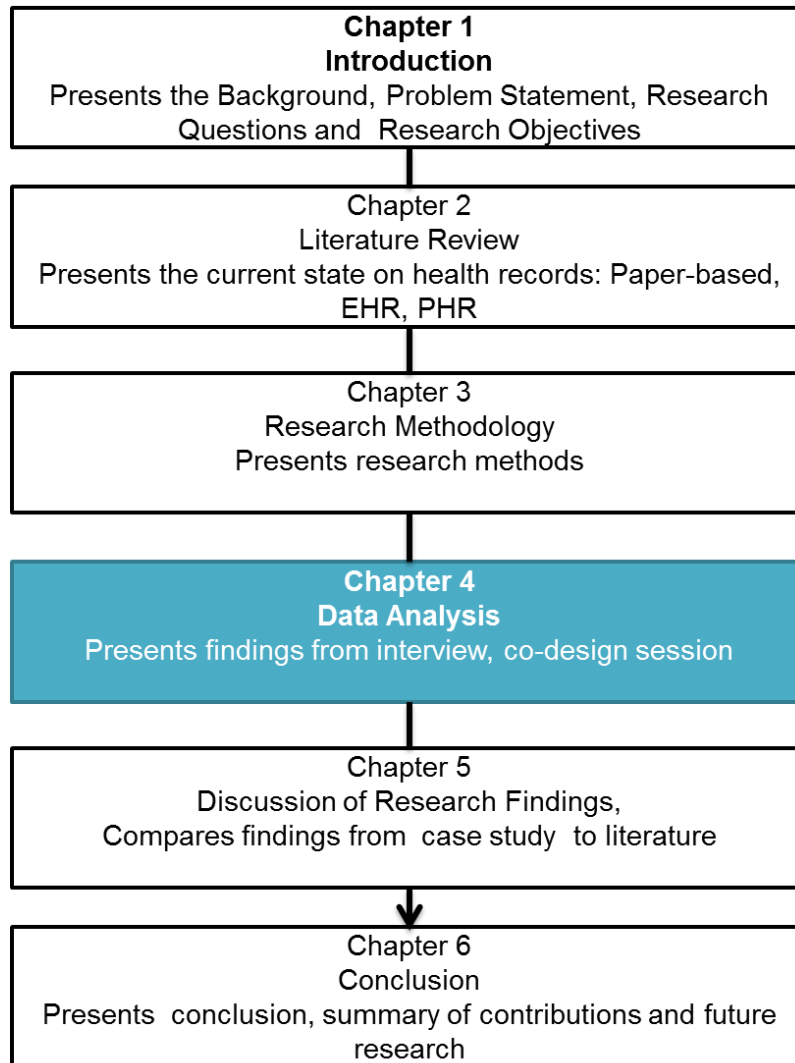
This study only covered one clinic that patients visit and one hospital that patients are referred to by clinics in the Eastern Cape rural areas. Other South African provinces were not covered, due to time and financial constraints. Respondents' focus was on Healthcare providers' i.e. doctors, nurses, clerks, pharmacist and patients i.e. youth or students and elderly people. The focus is on the point of care at the primary level, i.e. where healthcare services are provided at the clinic or hospital. Only referrals from the clinic to the hospital in the geographical area of the study were considered and not referrals for specialised care.

3.9 Conclusion

This chapter presented motives for adopting a specific methodology.

A cross-sectional, interpretive case study was adopted because it was considered vital to interpret the multiple research participants' perceptions regarding giving patient's access to their own personal health records within a resource restricted environment. The primary data collected from the St. Barnabas hospital is presented in Chapters 4, and 5. Qualitative methods assisted in obtaining valuable insights and perceptions regarding patients accessing their health records.

CHAPTER FOUR : DATA ANALYSIS



4.1 Introduction

In the previous chapter the research methodology for this study is discussed. This chapter provides detailed information describing how data was collected from the research community. Qualitative methods were used for capturing data. Step-by-step accounts will be provided about the research activities in the natural context. Interviews, co-design sessions, and participant observation provided valuable data for analysis and interpretation. The researcher analyzed the data into meaningful categories in order to make sense of each relevant theme. South Africa is divided into nine provinces (see Figure 4.1). The research was conducted in one of the Province of South Africa, the Eastern Cape Province. Figure 4.1 provides context of the province in which the study was conducted, but further descriptions of the province will be discussed in the next section.



Figure 4-1 Provinces of South Africa (Explore South Africa n.d.)

4.1.1 Site Location

The study was conducted in one of the IsiXhosa speaking communities of the Eastern Cape. The Eastern Cape is the second largest province in South Africa by surface and the third largest population with 6,916,200 people (South Africa has a population of 54,956,900) (Day & Gray 2015). The province is one of the poorest in

South Africa, with the majority of its population living in the rural areas. It consists of six district municipalities and 38 local municipalities. IsiXhosa is one of the 11 official languages in South Africa and the most commonly spoken language in Eastern Cape. The Eastern Cape health system is faced with a number of socio-economic issues such as: poor management, high crime rate, weak primary care, staff shortage, high level of poverty and unsatisfactory access to basic services such as piped water (Ruxwana et al. 2010). The Eastern Cape Province has 5 regional hospitals; 3 provincial tertiary hospitals; 17 private hospitals; 1 national central hospital; 65 district hospitals; 41 community health clinics and 731 public clinics (Day & Gray 2015).

Data was collected at Nyandeni district municipality which is situated in the Eastern Cape Province. Nyandeni with a population of 290 389 is one of five municipalities of the OR Tambo district. The other four municipalities are: Ngquza Hill (278 481), Port St Johns (156 140), Mhlontlo (199 229) and King Sabata (451 710). The hospital in which the study was conducted is St. Barnabas hospital. The hospital is a district hospital serving the Nyandeni district including Port St Johns, Libode district, Ntlaza and some parts of Ngqeleni (see Figure 4.2). Complex medical cases are referred to more equipped hospitals which are situated in Umtata. Critical patients' issues that cannot be treated at St. Barnabas are either transferred to Umtata General Hospital or Nelson Mandela Academic Hospital.

This site was selected as an example of a typical resource restricted setting in a rural environment.



4.1.2 Site Description

Background of the St. Barnabas hospital

The research site is situated in the Eastern Cape in Ntlaza, which is 45 kilometers away from Mthatha (former Transkei). Figure 4.3 shows a photograph of the hospital. The hospital was selected because of its geographical location. This is a “rural” area and is disadvantaged with many incidents of patient’s health records which are missing and incomplete. The hospital serves about 300 patients per week. The hospital provides the following services:

- Accidents and Emergency services
- Maternity services
- National Health Laboratory Services
- Operating theatre
- Out-patient pharmaceutical services
- X-Ray services
- Dental services
- Post trauma counseling Services



Figure 4-3 St. Barnabas Hospital

Hospital Infrastructure

St. Barnabas Hospital has a well-constructed building. The hospital comprises of 6 wards and 4 consultation rooms. In total the hospital has 250 beds. The hospital has about 7 medical doctors and 2 dentists. In terms of ICT availability and accessibility at St. Barnabas hospital there are: a few desktop computers, a telephone line, a fax machine and limited internet connectivity. There were no computers in consulting rooms at the time the research was conducted; the nurses and doctors do not use computers for work-related duties. Patient health records at the hospital are stored inside the cabinets which are not lockable and placed on top of the filing cabinets (refer Figure 4.4) in the record room at the hospital. This method of keeping patient records is slow, time-consuming and ineffective. Patient data elements like their names, ID numbers, and folder numbers (format: **date/number on the queue**) are created manually and handwritten by clerks.



Figure 4-4 Patient folder cabinet of St. Barnabas hospital

4.2 The Participants

As stated in chapter 3, purposive sampling was applied to select the participants from rural hospitals to meet the objective of the study. A total number of 11 participants were selected from the rural hospitals and rural communities. The

selected participants consisted of doctors, a nurse, an admin-clerk, a pharmacist and patients. Participants were informed prior to the interviews as well as after the completion of a session, that participation in the research was completely voluntary and information provided would be treated strictly confidential. All 11 participants who were selected voluntarily agreed to participate in the research. Table 4.2 shows the demographic information of the patients who were interviewed. No incentives were offered to the participants. One male participant from the patient segment dropped out at the beginning of the session, since he was not comfortable being the only male in the participating group.

Table 4-1 Demographic information of Patients

Demographics	Patients
Gender	Females (5)
Age	30 – 39 (2) 40 – 49 (1) 50 – 59 (1) 60 – 69 (2)
Race	Black (4) Coloured (4)
Educational Level	Completed Standard 7 or less (4) Completed Matric (1) Completed University Degree (1)

In order for the researcher to fulfil the research objective, the researcher had to understand the different perspectives from different stakeholders. This included doctors, nurses, and pharmacists. This was necessary as the researcher wanted a holistic understanding of considerations for patients to have access to their own personal health information in a restricted resource setting. This was conducted to collect information with regard to access and relevant data elements on the patient's

own personal records. Table 4.2 shows demographic information of intuitional stakeholders.

Table 4-2 Demographical information of Intuitional stakeholders

Demographics	Healthcare professionals and Administrators
Gender	Males (2) Female (3)
Age	25-29 (2) 30-39 (3)
Education Level	Completed Matric (1) Completed University Degree (4)
Occupation	Admin Clerk (1) Nurse (1) Doctor (2) Pharmacist (1)

4.3 Data Collection

In this section the data collection methods and coding of the data are discussed.

4.3.1 Data collection at St. Barnabas Hospital

Permission was granted by the Eastern Cape Department of Health to conduct interviews at the hospital (refer to Appendix B). An open-ended, semi structured interview schedule was used to gain insights from the participants. The interview schedule served a guide to obtain responses from research participants. The interview schedule was used to get understanding of considerations for patients to have access to their own personal health information in a restricted resource setting.

The interview schedule consisted of 20 questions, (refer to Appendix D: Interview Schedule). The questions were categorised into the following sections: access, patient record storage and patient record sharing.

The duration for the interview was approximately 45 minutes per participant. The following people were interviewed: 2 doctors, 1 nurse, 1 clerk and 1 pharmacist.

As alluded in Section 3.5.1, the researcher used the *purposive sampling technique* which entailed the selection of specific participants from the population. These participants were purposely selected because of their domain knowledge that was pertinent to the context of the study. The participants were recruited by the chief executive officer (CEO) of St. Barnabas hospital and participation was voluntary.

Interviews were conducted at the hospital boardroom which was booked by the CEO of the hospital. In terms of the arrangement of the room in which the interviews were conducted, a standard table and two chairs were positioned to face each other. A cellphone was used to record the session.

Upon the arrival of the participant, the researcher was introduced. The researcher gave a brief explanation of the study to the participant. The participants were made aware that their participation in the interview was completely voluntary and informed consent was requested (a copy of the informed consent form can be found in Appendix C). They were also told that they were allowed to withdraw at any point and that everything discussed during the session was confidential and that their identity would not be revealed to anyone.

Below is the main research question, which was addressed by the study:

What are the considerations for patients to have access to their own personal health information in a restricted resource setting?

The main research question was broken down into four sub questions. The sub research questions in turn were broken into specific questions or design activities to obtain the data needed for the study. Multiple data collection methods were applied to make sure that the data collection was effective. Oates (2008) stresses that using multiple measuring methods assists the researcher to obtain more detailed information about the phenomenon under investigation. Data collection instruments such as interviews, co-design sessions, and observation were used to elicit answers to the research sub-question found in Table 4.3.

Table 4-3 Research Sub-Questions

Sub-questions	Interviews	Co-design sessions	Observations
Why may patients want to access their own personal health information?	√	√	√
What data elements are relevant for patients' own personal health information to facilitate a healthcare service provision?	√	√	√
How is patients' personal information currently being used in the healthcare service provision?	√		
What are the factors that should be considered for accessing patients' personal health information?	√		√

4.3.2 Data Coding

As mentioned earlier on, the data collection methods that were used to collect data were interviews, observation and co-design sessions. Interviews were recorded using a smart phone and later transcribed. Observational data was used to identify the facial expression, gestures, body language and overall process that patients have to undergo when they visit the hospital from start to end. Co-design sessions were used to elicit and to understand a patient's mental model when it comes to a health record, the type of health record they would like to see or use; their terminology when it comes to health related issues. There was a need to create the design probes in IsiXhosa because most of the participants were IsiXhosa speaking and could not read or understand English. Since the researcher is an IsiXhosa speaking person, translation of the design probes to IsiXhosa was done by him. Co-design sessions helped the researcher and participants to come together and

contribute effectively in designing a health record. This helped to identify the type of data elements that participants thought were relevant for them to see.

The researcher analyzed the interview transcripts using thematic analysis to identify themes, and sub-themes and categories as stated in Chapter 03 (see Section 3.6.1). The process of coding started with reducing raw data by drawing lines on each unit of text. For interviews the researcher cross checked and amended the transcripts. During the analysis when a new theme emerged, the researcher changed the coding frame and re-read the data according to the new structure. The data was re-read to ensure that there were no new themes that emerged. To make analysis simple and manageable the data was broken down into units of codes. The identified codes were: **need to know, awareness about HIT, Information on records, data sharing, patient data fields**. At the end of the analysis, six key themes were identified. Table 4-4 tabulates a list of all identified themes.

Table 4-4 Identified themes from study

<p style="text-align: center;">Themes from Healthcare Professionals</p>	<p style="text-align: center;">Themes from Patients</p>
1. Need for patient health records	1. Empowerment of patients' through data elements
2. Challenges of paper-based health records	2. Patient information privacy
3. Access to health records	
4. Information sharing for healthcare workers	

4.4 Analysis

All the data for each data collection method was analyzed separately. Each theme is discussed next with a summary of different participants' responses. Analysis of information from healthcare professionals and patients will be discussed separately in the next section. Table 4.5 shows themes that emerged from the iterative thematic analysis of the raw data that emerged from interview responses from healthcare workers

Table 4-5 Themes and categories from interview response from healthcare workers

Themes	Categories	Sub-categories
Need for patient health records	Functions of patient health records	Communication media with healthcare workers
		Patient health records are used as reference point by healthcare workers for a particular patient.
Challenges of paper-based health records	Challenges	Missing or Misplaced patient health records
		Data loss
		Limited storage space within the hospital's records room to store patient health records.
		Effort in creating folder number
Access to health records	Data elements Benefits of giving patient access to the health records	Giving patients access to their health records
		Privacy
		Information relevant for patient to see on the health records
Information sharing by healthcare works	Types of referrals	Referrals with other healthcare providers

4.4.1 Health professionals' perspectives

Each theme is discussed next.

Theme 1: Need for patient health records

The following responses of the healthcare professionals about the need of paper-based health records in their work were recorded:

“These records are very important ... we communicate with others who are involved in patient care... help whoever is consulting with patient at point of care to draw conclusion on previous notes...us to see what medication that patient is on” **doctor 1**

“... Where the doctor’s write orders, and ... we communicate between the two shifts night and day as we cannot rely on human mind. Doctor’s write for example amount of dosage we should give to a particular patient... help us to track any changes on the patients’ health” **Nurse**

“Patient records are very important because this is where we get a full view of the patient, especially for us pharmacists the records show us what they doctor has prescribed for the patient” **pharmacist**

“Yes, patient records are very important in our field. We write diagnosis we get well when we consult with patient... we write progress about the patient, refer to when the patient has similar issue in future, they help us to see what they previous doctor note about the patient... most of the times they are missing, or writing is not clear” **doctor2**

This theme is in general on the importance of patient health records by healthcare workers. The responses reveal that patient health records are very important communication media between different healthcare workers involved in a particular patient care. Also the responses reveal that these records provide healthcare workers a complete overview of the patient’s history. The doctors and nurses use these records to write clinical diagnosis information about a particular patient and they use them as a reference point later if the patient becomes ill with a similar illness.

Theme 2: Challenges of paper-based health records

The following answers by healthcare workers disclose the challenges they face using paper-based health records:

“Sometimes folder will be missing, and then new health record for patient has to be created. In some cases the record is misplaced which is not found or sometimes found” **doctor1**

“We store patient health records in filing cabinets which are not lockable, storing them using their surname, name and folder number for example (2014-10-17) (year-month- number in queue) number, which is a number, we create for a patient visiting hospital for the first time, however this is not effective and we can make mistakes and this is very strenuous.” clerk

“Method is not good, most of the time; records are missing from the storage. And sometimes these records are incomplete.” doctor2

“It’s a very long and tiring process. For example patient folder gets missing and patient has to be admitted we have to go to the record department and manually go to each every folder and search for it and if not found we have to create another which is also another long process itself.” nurse

Challenges of paper-based records findings indicate that:

- St. Barnabas hospital uses paper-based health records
- Patient records get lost or misplaced in the hospital with valuable information of the patient, resulting in a new patient record being created even though there is already a record for the patient.
- At St. Barnabas hospital patient records are not securely kept and they are placed on top of cabinets since there is no space and lockable cabinets are full as shown on (Figure 4.4). This results in patients’ personal health information being at risk as anyone who walks in the record room can steal the patient’s health record.
- Paper-based records cause strain to healthcare workers, for instance to the clerks as they have to create folder numbers using this format (*year-month-number on queue: (2014-10-17)*) using their head, for every new patient that comes to the hospital for the first time and for regular patients if their folder happened to be missing.

These challenges create poor information continuity, duplicity and unnecessary tests to done on the patient, when their records get lost or misplaced. As for “folder number” that clerks create for patient this can likely result in different patients having the same folder numbers.

Theme 3: Access to health records

The discussion below demonstrates the perceived benefits that healthcare professionals and administrators gain from giving patients access to their healthcare records. It also shows which data elements that they think would be relevant for patient to see:

“By giving patients access to their records makes them to be more informed and empowered about their illness. However there is a responsibility on the patient to keep their health information safe in case in future they would be given permission to keep them. Information on health records relevant to be seen: Diagnosis, procedures done to them if any, full background history of their health and medication they use”

doctor1

“I think patients should have complete access to Health records, so that they can know what is happening to their lives. Diagnosis, treatment and laboratory tests and results, actually everything that concerns their health status, even though it would not make sense to them i.e. It's like speaking French to a Xhosa person” **doctor2**

“We should not give them access to take their folders at home because it might get missing. It would be great if we can have an electronic system that we can use to register their demographic information, and all their health related issues stored in it. Surname, Name, ID and Address, Next hospital appointment and date they were seen” **nurse**

“Patients must be given access to everything in their health records, but then privacy and confidential should be maintained all times. Medication, and full medical history, so they can explain it to a doctor maybe in another province are important for them to know” **pharmacist**

“We should not give them access to take their folders home because it might get missing. Relevant information for patient to see on their health records: Diagnosis, treatment and laboratory test and results, actually everything that concerns their health status, however patient might be very ill and might be travelling with their relative and would not want them to see details about their illness or status” **clerk**

Out of the five healthcare workers that were interviewed, three of them saw the need to give patient access to their health records. Furthermore concerns about privacy

and confidentiality of patient's health information were mentioned should patient lose their health records. The responses reveal that by giving patients access to their health records would empower them and inform about their health. On the other hand, even though most of the healthcare workers said that patients should be given access to their health records, some participants' i.e. the nurse and record clerk were against the idea of giving patients access to their health records. This is due to the fact that patients might lose their health records, and their privacy, and confidentiality of their health information could then become compromised. These participants indicated that patients should be only given access when they are in the hospital premises. One participant indicated that patients should have access to their health records, also said that even if a patient is given access the information on the health records this would not make sense to patients - "*It's like speaking French to a Xhosa person*". In terms of which data elements are relevant for patient to see, the following are indicated by the participants:

- Medication,
- Full medical history
- Laboratory test and results
- All procedures done on the patient
- Demographic information (Name, Surname, Date of Birth and Address)
- Next hospital appointment

Theme 4: Poor referral methods

The following responses by healthcare workers on how they share health information about patients within the hospital and with other hospitals are discussed next.

"We only share records and patient's information when it's clinically relevant, that is when decisions must be made regarding patient's health in order to help patient as a team. This includes all the doctors in direct contact/ involved with the patient's management. Patient's identification, together with working diagnosis, interventions done as used as prospective future management is shared. Even though the referral letter we use has limited space. We do down referrals i.e. (clinics & health centres) and referrals to higher institutions i.e. (Tertiary Hospitals)" doctor1

"It is very important so that there can be a follow up information. However if I have referred patients within the hospital, they are just given their folder to that department or call that department informing them about the patient. It is very important for a colleague in other hospitals too. We use referral letters for up (provincial hospitals) and down referrals (to clinics)" doctor2

“Doctors refer patients to our dispensary for medication, however the writing on the prescription is poor and for someone junior like me this can result in incorrect medication dispense to patient” **pharmacist**

“Clinics when they refer patients to us, they do not give detailed information about the patient’s condition and this requires us to build the history again with the patient”
Nurse

Findings relating to poor referral method are:

- Healthcare workers at St. Barnabas hospital do referrals both down referrals (to clinics) and up referrals (other hospital).
- The referral letter (refer Appendix A) which is used to share patient health information, has limited space for healthcare professionals to fully state patient clinical diagnosis and interventions. This results in the receiving doctor having to do a duplicate test so that he/she can have a full view of the patient.
- Healthcare professionals sometimes call the other doctor to whom they are referring patients, to inform them about the details of the patient.
- There is no form of follow up on patients referred to other hospital.

The above findings result in a negative impact on the patients’ care as some of their critical information may be missed; this could result in incorrect diagnosis and in a worse case could lead to fatality.

4.4.2 Patients’ perspectives

The researcher planned the co-design session. A few meetings with the relevant participants were held to encourage them to participate in the sessions. No specific incentives were used and it was observed that the participants enjoyed the participation process and they felt valued. The participants felt part of the design team and that they appreciated that their suggestions could be taken in to consideration in designing a personal health record. Possible data elements and pictures were made available to participants. Participants were encouraged to cut the pictures, data elements and paste them on an A4 paper in the way they would want to see them. This was to get participants to design a personal health record, and get them to give suggestions as to which data elements they want to see in a health record (see Figure 4.3). The researcher would then probe as to why participants choose a particular item, and why they arranged them in a certain way. The duration for the co-design session was approximately 1 hour 30 minutes.

This section provides themes that emerged from co-design and focus group sessions that the researcher had with patients.

Theme 1: Data Elements relevant for patients

The below image shows the participants during co-design sessions (see Figure 4.5 & Figure 4.6)



Figure 4-5 Participants in Co-design session designing health records



Figure 4-6 Participants in Co-design session designing health records

During this session participants were given possible data elements that the health records would have. They were given examples of data elements to make sure they understood the meaning of a data element and the purpose and format of a health record. Participants were asked to cut out those elements that they would like to see on their health records and place them in the order they would prefer to see on their health record. Figure 4.7 illustrates the design. During the session and as part of the conversations the researcher noted that participants want to be involved in decision making about their health, self-care and shared decision making and they felt that they do not have an open relationship with the healthcare professionals they receive care from.



Figure 4-7 Design and type of data elements participants would like to see in their health record

Theme 2: Empowerment of patients

The following discussion illustrates reasons as to why patients want access to their own personal health records. The answers of the respondents for the question led to identification of this theme: *“What are the reasons that make you to want access to your personal health record?”*

The key theme that emerged was *“Empowerment”*. This theme emerged during the co-design session that the researcher conducted with patients. Respondents felt as if they were disempowered due to the number of reason stated below:

“I want to have complete access to my folder because it belongs to me and I do not understand why I should leave it behind even though that information belongs to me. If I have my record with me it will save me time and memory

effort from explaining my full medical history and treatment I take. In the past 3 years I have been going to hospital, the clerks have created about 3 to 4 new folders for me, reason being that my previous one was nowhere to be found”.~ **patient 1**

“I want to know everything that is helping to me, and medication I am taking because doctors write medication on my folder then after seeing him, I have to go straight to dispensary, they do not even explain how this medication will help me with my health condition. When I am waiting in the queue outside the consultation room to see the doctor I sometimes try to read what is written on my folder just out of curiosity but however I cannot make sense out of it and the writing on the folder is not clear at all”.~ **patient 2**

“I always have a problem when I have to go to Durban to visit my daughter and need to go hospital for my treatment; I have to explain to doctor the type of treatment I am taking for my diabetes and those doctors always ask me the type of diabetes I have and that is difficult for to remember that. Then blood tests are redone again and again. It was going to be easy for me if I had the folder with me everywhere I go so that if I forget I can always go refer to it.” ~

Patient 3

“... know everything happening to me, ... know how to take care of myself and not always go to the doctor or hospital spending the whole day to be examined, like for instance when I have flue I know what to do. I just go in my garden and take “Umhlonyane”, boil it and steam myself under the “mhlonyane. Giving access to my folder will make things easy for me, when I go to another doctor in Umtata I do not have to explain the full history to them. What I found out is that I am asked to state my full history to every time I go to a new doctor, since I change doctors now and again because of their cheaper price from the other”. ~ **patient 4**

“If I have my folder with me, the good thing is that I do not have to stand in three queues when come on my appointment day. Queues I am talking about are the one to clerks to get the my folder, one to see the doctor and the one at the dispensary for my medication” ~ **patient 5**

The co-design sessions gave a good overview of the research questions. The responses indicate the respondents' views as to why they want access to their personal health records and are summarized as follows:

- Reduces memory load on them since they will not have to explain the full history of their condition
- They want to have complete access to folders since sometimes their records get missing at the hospital and then duplicate test have to be performed
- Patient want to be in control and want to know ways in which they can take care of themselves without going to a doctor
- Patients wants to be informed of everything relating to their health status
- Patients want access to their folders so that when they want to change doctors, they do not have to explain the full history to the new doctor
- Reduce the waiting time by not having to stand in a number of queues that at hospital.

Theme 3: Patient Information Privacy

The following discussion shows the responses that were raised by patients when asked “how safe do they think your health information is at the hospital?” This question was posed to the patients after the co-design session. The researcher conducted semi structured interviews after the co-design session, with participants to gain insights about safety of their records at hospital.

*“My personal health information is not safe at all at the hospital reason being if my folder gets misplaced or missing anyone can see what I am suffering from and can judge me... when doctor has finished with writing all his notes on my health record that goes to dispensary, and to the record department. Who know what the clerks do with my information, because they full access to it and they can see whatever I am suffering from e.g. if I were HIV positive clerks would know that. ” ~ **patient 1***

*“ I do not think my information is safe there because any one can steal it even that nurse, what I heard on radio same time last year who was caught red handed stealing patients folders at Lusikisiki. ~ **patient 2***

*“I do not think my information is safe at the hospital because when I collect my folder at the folder room it is not locked inside a cabinet and I can see when I have my appointment with doctor and like I said earlier on sometimes my folder get missing when I need it. And by the look of things anyone who works at the hospital be it a cleaner or potter or clerks can access my folder”~ **patient 3***

“I do not trust ... the fact that my folder is kept by the hospital and the clinic for that matter, reason being for example ... clerks that work at hospital are these children we stay with them here in our community. Who knows what they see and who they

tell my private information after they have been sent to their department for record keep. You can never trust people. I would be very comfortable if my health information was only seen by the doctor and nurse” ~ patient 4

“My information is not safe with the hospital ... everyone that work at hospital has access to this folder even those that does not need them. The nurses, and doctor, ... only people who should have access to the folder its myself... great if the folder was kept that way.... see the need of taking my whole folder to dispensary for medication where they will just see only the medication that the doctor just prescribed for me... what I am suffering from and what the doctor performed on me they do not need to see that ... go to dispensary and take my folder there, and have to wait about 1 – 2 hours to be called, who knows what those people see in my folder, while am sitting in the waiting room. ~ patient 5

The findings relating to privacy of patients information are:

- It is clear that patients are not comfortable with their patient records being kept by the hospital. This is because patients are not sure as to who else sees their personal health information besides doctors and nurses.
- Patients were not comfortable with records being set to record department, since they think clerks have full access rights to their patient records, and felt that information in their patient records should be seen only by the doctor or nurse.
- Patients feel that the clerks can see all their health information and might tell people what a particular patient is suffering from in the community.
- Patient were concerned to be discriminated by the community if privacy of their health information is lost
- Participants were also informed of various cases of theft of patient folders at other hospitals in the Eastern Cape, which makes them more uncomfortable having their folders at the hospital.
- Patients were concerned with safety of their health information at hospital.

The above can be summarized as follows: Patients are concerned about their health records being kept at the hospital since anyone can easily access it that then compromise their privacy. Details about their condition can then become known to anyone in their community.

If privacy of patient's health information is not maintained this could result in patient not being open about their condition to doctor. In the next section the findings from observations are discussed.

4.5 Data from Observations.

Figure 4.8 illustrates the process and different departments that a patient has to encounter with during their visit at the hospital. Most of their time is spent when they have to request for their folder from the clerks and at the last stage when they have to wait for the pharmacist to dispense their medication.

When patients are feeling ill or have a checkup date at the hospital, they have to travel a long distance from their home to a clinic hospital. When arriving at the hospital they have to wait in a long queue to request their patient record, which in most of the cases is missing or lost, which results in clerks creating a new folder for them, giving them a new folder number ((2014-10-17) (year-month- number on queue)). More information is asked from the patient and more tests need to be performed on them. If the patient is lucky enough to get his patient record, then he/she still has to stand in a long queue to see the doctor.

When it is their turn to see the doctor, they then go and consult with the doctor who then diagnose the patient and prescribes medication to the patient. When patients require medication they are instructed to go to the dispensary to collect the medication.

At the dispensary the patient gives his/her patient record to the pharmacist and has to wait again for hours to get the dispensed medication. Lastly, the patient's name is called to collect his/her medication, and his/her folder is left at the dispensary. Around 17:30 pm the clerk has to go to the dispensary and collect all the folders that are left at the dispensary and puts them at the record room for storage (see figure 4.8).

Findings from the observation data:

- Patients spend unnecessary time requesting their folders
- Patients spend unnecessary time waiting to see the doctor
- Patient spend unnecessary time waiting for medication at dispensary
- The hospital does not have any form of system to create unique patient folder ID, other than the one clerks creates ((2014-10-17) (year-month- number on queue)) manually.

- Patient records are not secure and safe at hospital, they get lost most of the time

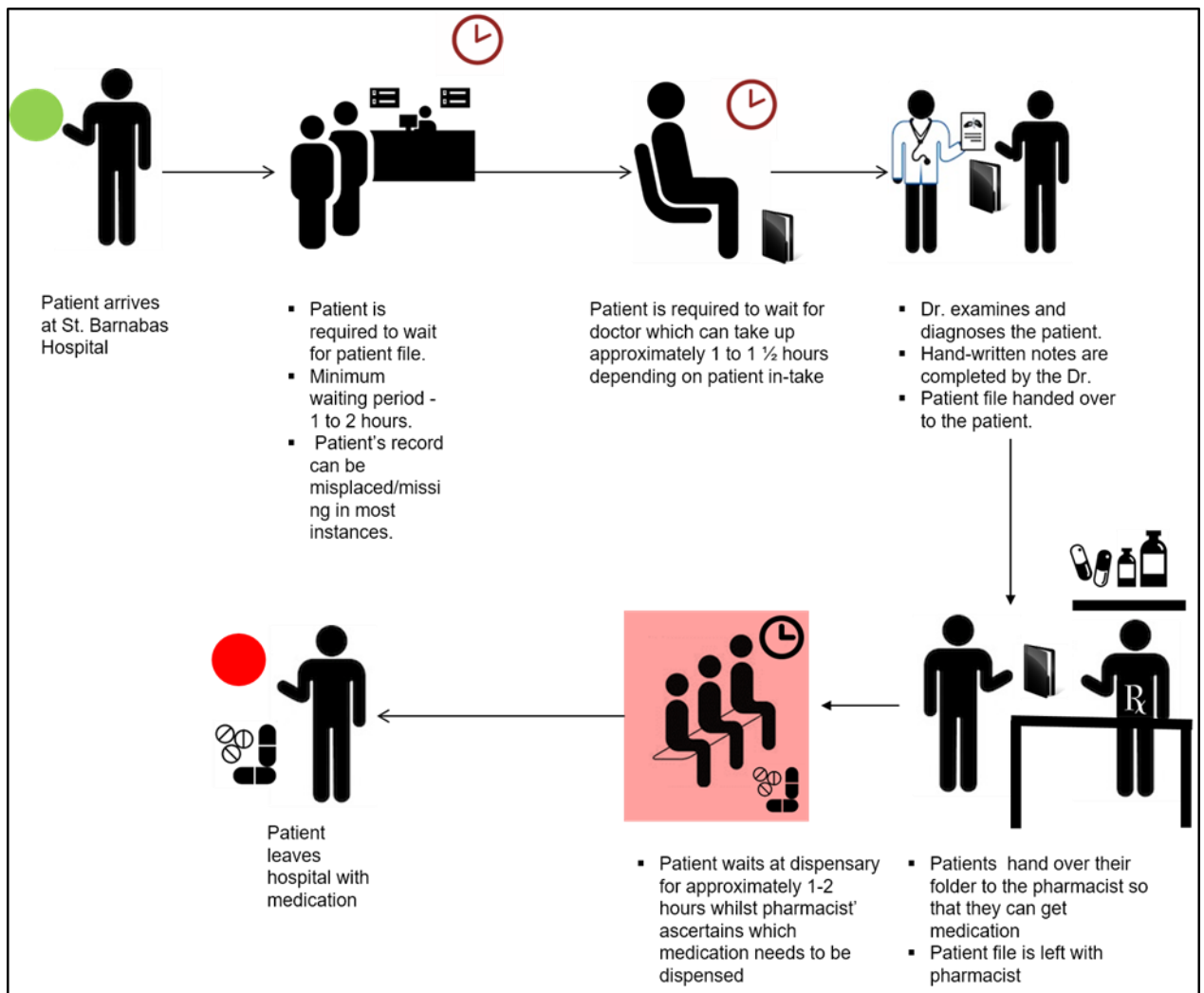


Figure 4-8 Patient process during their time at of appointment at hospital

4.6 Conclusion

In this chapter the findings derived from data collection instruments such as the interviews, co-design sessions, observations and interviews are presented. The aim of this chapter was to understand considerations for patients to have access to their own personal health information in a restricted resource setting. The researcher examined the findings as stated above and various themes emerged from the respective interview transcripts.

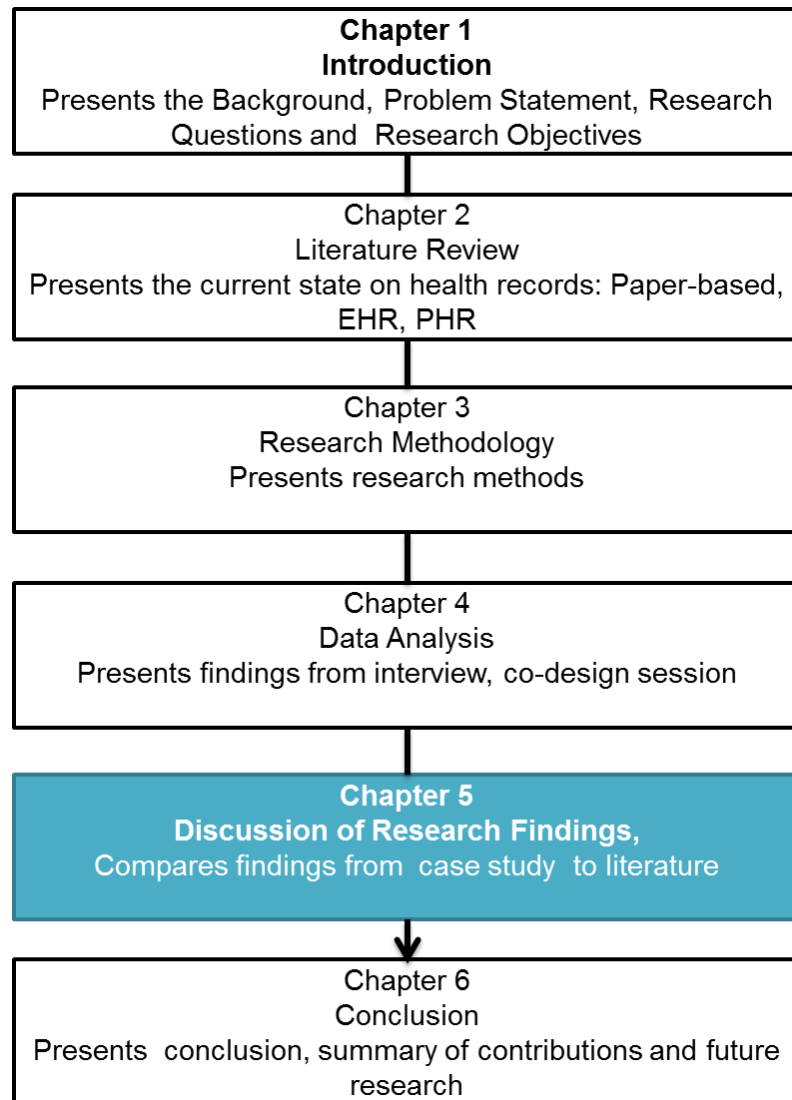
The findings indicated a number of challenges with regards to patients' health records being kept at the hospital records room. This inconveniences both patients

and healthcare professionals. However, even though there are these challenges, some healthcare professionals like nurses and clerks did not see the need for giving patients access to their health records, due to the fact of protecting hospital's and patient's confidentiality. Furthermore, participants raised the issue of patient's education literacy levels and even if patients are given access to health records they would not understand what is written in it. Doctors stated that if safety and confidentiality of patient's health information would be maintained at all times, they did not see any issues of giving patients access to their health records, but did not trust patients since they might lose their health records.

The findings revealed that patients want access to their health records due to the fact that they want to be involved in decision making, they want self-care, shared decision making and by giving the access to their health records would make them feel empowered. In addition findings reveal that if patients are given access to their health records, they would be able to go to any healthcare centre and receive immediate care without the patient going through the process of stating their clinical history, which sometimes is a challenge since in many cases they forget what they are suffering from. Furthermore, patients did not feel comfortable with the fact that their health records are being kept at the hospital because sometimes their health records get lost and they have to do blood tests again, and have to go through the same process of stating their full medical history.

In the next chapter the findings of this case study are discussed to attach meaning.

CHAPTER FIVE : DISCUSSION OF FINDINGS



5.1 Introduction

The goal of this study was to determine and interpret the factors that support the access of a patient's personal health record by key stakeholders, within a resource-restricted setting, in order to maintain medical records and information continuity for the specific-patient. This chapter juxtaposes findings presented in Chapter 4 with findings identified from the literature review presented in Chapter 2. The following sections discuss the three key themes that resulted from the case study. An overview of the themes is presented in Section 5.2. The value for patient health records is discussed in detail in Section 5.3. The challenges related to the retrieval of personal health records are discussed in Section 5.4. The distribution of patient health records between and amongst the stakeholders is discussed in Section 5.5

5.2 Overview of the themes

An overview of the identified themes is presented in Table 5.1. The table cites studies that have identified and explored the themes in various contexts. A detailed comparison of the findings that were presented in the cited studies and identified themes from this study will be discussed in the sub-sections to follow.

Table 5-1 Key themes as cited in literature vs. identified themes from case study

Themes	Evidence in Literature	Research Findings			
		Value of Health Records			
		Doctor	Nurse	Patient	Pharmacist
Need for health records	(Cline & Luiz 2013; Liu et al. 2011; Chen et al. 2010; Kharrazi et al. 2012; Cassel & Guest 2012)	"...write progress about patient, refer to when the patient previous notes,""	"follow doctor's instructions, and ..communicate between the two shifts night and day about a patients"	"... know everything that is happening to me .medication I am taking because doctors"	"...are very important because this where we get a full view of the patient, ... records show us what doctor has prescribed "
Empowerment of patients	(Siek et al. 2011; Cassel & Guest 2012; Chen et al. 2010; Nazi et al., 2013)	"giving patients access to their records makes them to be more informed and empowered about their illness"	"even if patients are given full access to patient records, they would understand information there"	... "know how to take care of myself and not always go to the doctor or hospital spending the whole day to be examined...when I have flu I know what to do"	"I think patients should have complete access to Health records, so that they can know what is happening in their lives"
Data Elements and Privacy					
Data Elements relevant for patients	(Mostert-Phipps et al. 2012; Nazi 2013; Cline & Luiz 2013)	"Diagnosis, procedures done, medical history, medication"	"Surname, Name, ID and Address, Next hospital appointment and date they were seen"	Name & Surname, DOB, Age, Next appointment, Dr.'s contact details, medical history and medication.	"Diagnosis, Treatment and Laboratory test and results, actually everything that concerns patient,"
Privacy concerns	(De Bord et al. 2013; Fetter 2009)	"responsibility on the patient to keep their health information"	"We should not give them access to take their folders home because it might get missing"	"My health information is not safe at the hospital reason being if my folder gets lost, anyone can see what I am suffering from and can judge me"	"Patients must be given access to everything to in their health records, but then privacy and confidential should be maintained all times"
Referrals					
Poor Referrals method	(Mostert-Phipps et al. 2012; Mabuza et al. 2011)	"Referral letter we use has limited space"	"...refer patients to us, they do not give detailed information about the patient's condition"	"Do not like to say asked what I am suffering from over and again when I go to another doctor"	"the writing on the prescription is poor and for someone junior like me this can result in incorrect medication dispensed to patient"

5.3 Value of Health Records

This theme is divided into two different sub-themes namely: need for health records and empowerment as shown by Table 5.1. It became evident that patient records play a significant role for both healthcare workers and patients, since healthcare professionals use these records to write their clinical notes about a patient and to draw a conclusion on previous clinical notes.

5.3.1 Need for health records

The study revealed that these records help healthcare professionals to have a clear view about the patient. It was clear during observations in this study that communication of information about patient is essential in order to provide quality care to patients. At St. Barnabas hospital the means of communication is done through the use of health records and verbal communication between different stakeholders within the same health organisation; however, these patient records can only be seen at a single point in time. In the note of communication Van Bekkum and Hillton (2013) highlight the importance of communication practice and role of healthcare workers to patient's health outcomes. Furthermore Edwards et al. (2012) state that effective communication between healthcare workers is essential for successful collaboration on patient's care and decision making. Without effective means of communication in healthcare can result in serious medical errors and could lead to mortality cases. As stated earlier on at St. Barnabas hospital, paper-based patient health records are used as means of communication. This study and literature review on (section 2.5.2) show that paper-based records have numerous disadvantages.

Furthermore this study showed that patients are not allowed to obtain copies of their health records, this however makes it difficult for them to seek a second opinion from other healthcare providers other than the St. Barnabas hospital. Chen et al. (2010) state the importance of patient health records, that they help healthcare providers in that doctors can have a prompt response to patient's condition without running the same test again if the same record is available to the different healthcare professionals involved in the patient's care.

Another need for personal health records is to reduce the waiting time at the different points of care due to difficulties in locating the patient's record. It is important to have all the patient details in a single health record that is accessible to the relevant healthcare professional when needed. This will provide a single source with the entire patient health history for healthcare purposes. The need for a personal health

record provides the patient with the ability to provide information for care purposes when needed.

5.3.2 Empowerment of patients

Findings relating empowerment of patients indicate:

- Most healthcare workers think by giving patient access to their health records will empower them and informed about their health conditions. However, the clerk and nurse thought that if patients are given access to their health records they would not understand medical terminology in their patient records.
- The hospital uses paper-based health records which have several advantages and disadvantages for both healthcare workers and patients.
- Patients are not comfortable and find it difficult to explain their condition to another healthcare provider if they did not have access to their health records.
- Patients want access to their health records and believe that it would empower them.

The study revealed that if patients can be given access to their health records, this can empower them and they can then be more informed about their health condition. However, nurses and clerks may not support giving patients' full access to their patient records since they may not understand the medical terminology on the records. They feel that some patients may lack the skills to read and write and in such cases their information may not make sense to them. It was clear that healthcare professionals at St. Barnabas hospital still relied on paper-based health records that record a patient's history and their own memory and that of the patients to recount their various encounters. Most patients indicated that they had to recount their medical histories repeatedly every time when visiting different healthcare providers.

Apart from that some of the patients stated that they were not able to recount their medical history accurately and in sufficient details, however they showed interest being given access to their patient records. This could lead to duplicate test to be done on patient, since insufficient information about patient's condition, can also negatively impact the quality care they receive. Patients showed a huge interest to access their own records and some healthcare professionals supported that giving a

patient access to health records would empower the patient, though someone did not agree with that due to concerns about patient's education literacy. According Nazi et al. (2013), when patients are given access to their healthcare data, this enables them to become "stewards" of their own information. In addition literature shows that by giving patients access to their patient records using electronic records such a PHR, it could enable patients to provide their healthcare providers with a detailed summary of their medical history, medication they are taking (Chen et al. 2010; Siek et al. 2011; Mostert-Phipps et al. 2012; Cassel & Guest 2012; Nazi 2013). This can aid in enabling patients to be better manage their care (Mostert-Phipps et al. 2012). According Mostert-Phipps (2012), by giving patients access to their patient records using PHR, it could educate and empower patients about their medical conditions, engage patients in medical decision.

The findings of this study are similar to findings reported in the literature. However, giving patients access to their personal health data needs to be considered in terms of their literacy level. Furthermore the design of such a record needs to also consider its purpose and how it will be incorporated in the hospital processes, especially for referrals within and between hospital facilities.

5.4 Data Elements and Privacy of patient information

The section below shows which data elements that healthcare workers and patients thought were relevant for patients to see and know in their patient records

5.4.1 Data Elements relevant for patients

Table 5.2 as shown below tabulates the data element that all the stakeholders in patient care thought are relevant for patient to see and know in their health records. These data elements are divided in two categories: the patient demographics and clinical data. The ticks in the table indicate the responses from Chapter 4 that healthcare professionals and patients think are relevant for patients to see. Findings for data elements indicate that:

Table 5-2 Data elements relevant for patient identified from different stakeholders involved in patient care

	Data Elements	Stakeholders				
		Patient	Clerk	Nurse	Doctor	Pharmacist
Patient Demographics	Patient ID	✓	✓	✓	✓	✓
	Name & Surname	✓	✓	✓	✓	✓
	ID Number	✓	✓	✓	✓	✓
	Next Appointment	✓	✓	✓	✓	✓
	Contact Details	✓		✓		
	Next appointment	✓	✓	✓	✓	✓
Clinical Data	Medical History	✓			✓	✓
	Medication	✓			✓	✓
	Lab results	✓			✓	✓

- Data elements are currently recorded on paper-based patient records, and most of the patients do not have understanding of what some of these fields mean i.e. “past and current medical history, and medication”
- These data elements are collected and captured by doctors, nurses and clerks. For instance clerks capture the (demographic information and create folder number, next appointment date), while doctors records (clinical diagnosis, prescribe medication) and nurses capture (body temperature,

glucose level, note medication they give patient as per doctors instruction), and lastly pharmacists (record medication they have dispensed to patient).

- Nurses and clerks did not see the point of patients knowing everything in their health records.
- Doctors, patients and pharmacist felt strongly that patients should see, and know what their data elements are about. However, nurses and clerks disagreed with that, since they thought it would not make sense for patients to know what their data elements were about, because most of the patients are illiterate.

This means that it is essential for patients to be aware and informed of every data element on their patient record. For instance if patients know what the data elements in their patient record mean, this will empower them and make them active participants of their healthcare. Investigating to what the patient are suffering, involves doctors and nurses asking patients what they are suffering from, which part of their body they are experiencing pain and when did they start experiencing the pain and what medication the patient taking etc. Patients being informed about what their data elements means, would prevent difficulties from explaining what they are suffering to another doctor in a different hospital, since most patients see different doctors. When patients do not know how to explain to another doctor what they are suffering from and what medication they are taking, it can result in duplicate test being done, prolonged quality care, incorrect diagnosis which can result in serious medical complications and a death case. This implies that it is essential that patients are aware of what is happening when it comes to their health and patients' records.

There seems to be a consensus between all the stakeholders about the data elements mentioned. The only difference is with clinical data where the clerk and nurse felt that the patients may not understand the clinical data in spite of the patients indicating that they would like to see their clinical data.

The next section discusses privacy relating to patient information.

5.4.2 Privacy concerns

The findings relating to privacy of patient information are:

- Paper-based patient records are not a secure method of keeping patient information.

- Patient information can be viewed by anyone who has access to the records. For example patient records at St. Barnabas hospital are currently placed on top of cabinets and not locked.
- Patients were not comfortable that their patient records are left unsecurely at the hospital (see figure 4.4). The patients felt that clerks at the record department have full access to their records and can view their sensitive medical information and then may share this with others.
- Healthcare professionals are concerned with the privacy risk that paper-based records pose.
- Both patients and healthcare workers have privacy concerns from different perspectives.

The findings suggest that patients are aware of the privacy risks posed by paper-based patient records and were not comfortable with merely leaving the health records at hospital. Both patients and healthcare professionals indicate that they have privacy concerns about the patients' health information. If patients lose their health records, their privacy might be lost, while patients did not feel comfortable with records left at the hospital because they felt that clerks have access to their personal information and might judge them. It is also evident that patients do not want to divulge their diagnosis and treatment and are afraid that the clerks might leak their personal information to the community. Most of the clerks that work at St. Barnabas Hospital reside in the same community as the patients.

This could lead to stigma issues and the patient fearing discrimination within the community. Furthermore, a patient's personal health record can be exposed to anyone who has access to the record at St. Barnabas hospital. In the instance of St. Barnabas, the clerks have full access rights to what the patient has been diagnosed with and what treatment was prescribed to the patient. It can therefore be said that paper-based records are not an adequate method for keeping patient health information securely, as evident from this case study. If the patient's record gets lost and lands in the wrong person hands, it can result in a loss of privacy and confidentiality of a patient. As supported by literature, privacy of medical information of patient is a major concern among patients and healthcare providers (Fetter 2009). According to De Bord et al. (2013) creating a trusting environment by respecting patient's privacy encourages the patient to seek care and to be as honest as possible during care. If patients feels that their privacy is not protected in any form, be it either *spoken, written, or transferred*, it would make them uncomfortable and less likely to share any sensitive information with the doctor or nurse, which could negatively impact their care (De Bord et al. 2013).

The perceived lack of privacy of the paper-based patient records results in a sense of mistrust between the patients and the persons working at the health facility.

The next section discusses the poor referral methods used at St. Barnabas hospital.

5.5 Poor referral methods

Findings relating to referrals

- Referring a patient to another hospital or clinic is done using paper-based referral letters (refer to Appendix A).
- Referral letters used at the hospital only capture brief information and a summary of the patient's health condition.
- Lack of ability to follow up on referrals to other hospitals or clinics.

Referrals at St. Barnabas hospital are done using paper-based referral letters. These referral letters have several limitations and have a negative impact on the patient's condition. For example, when a patient has to be referred to another hospital or clinic, the doctor typically gives the patient a referral letter with few notes, which do not capture all the necessary information about the patient's health condition. The receiving doctor then finds that the patient arrives with the referral letter with less information and the doctor has to rebuilt the clinical history and ask patient questions and in most case the patients do not know how to explain the condition to the doctor. This influences the quality of care the patient receives and results in duplicate tests that have to be done to patient again, which delays the healing process for the patient. Mostert-Phipps et al. (2012) indicate that with patient referrals between healthcare providers, the referral letter is often used at the hospital as the only source of information about the patient's condition since there is no access to the complete health record of the patient. This results in inadequate information for the doctor to treat the patient. This is still the case today as indicated by the findings of this study. Poor referral communication is an important quality and safety issue, hence improving communication can lead to improved clinical quality and patient care experiences (Ramanayake et al. 2014; Mabuza et al. 2011).

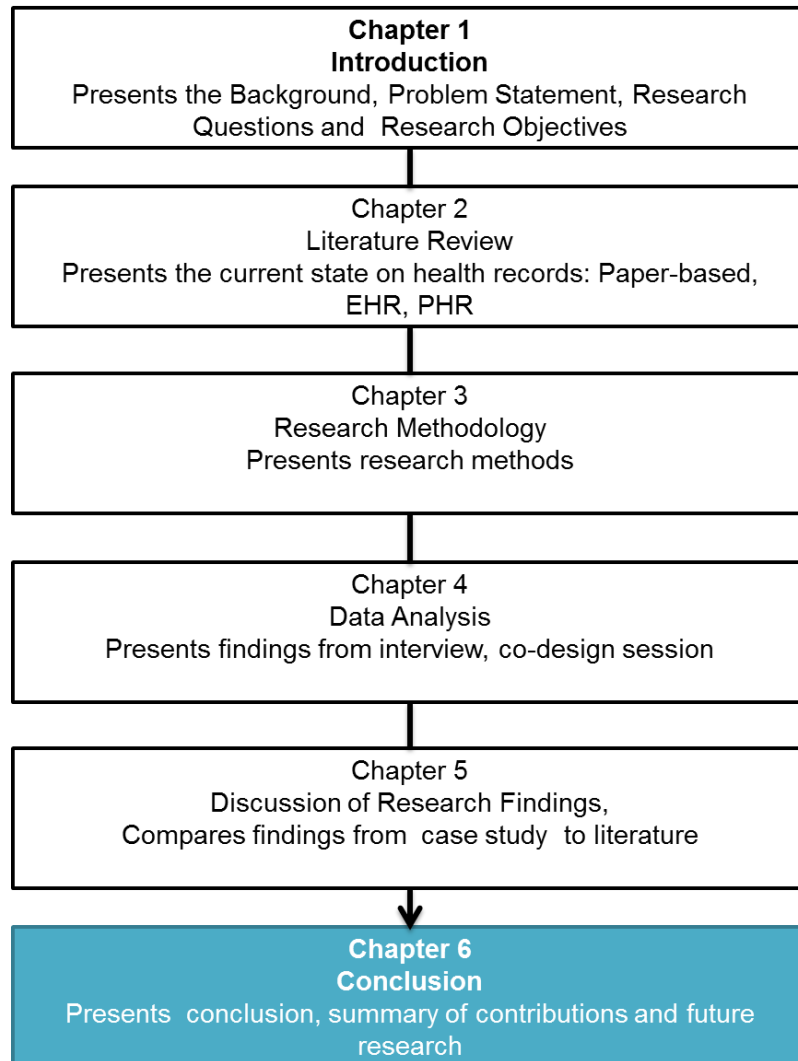
Referrals have inadequate information about the patient because the only data is what is provided on the referral letter. Personal health records have the potential to supplement the referral data with more comprehensive details about the patient's health history.

5.6 Conclusion

This chapter discussed the key research findings and interpreted the findings of study. Both findings from case study and literature show that paper-based patient records have several challenges and have negative impact to both patient and healthcare workers. The key findings that emerged include: need for patient records, empowerment of patient and the benefits of giving patients access to their patient records. Data elements relevant for patients to see in their health records and privacy of patient's information was also discussed and it was clear that it plays an important role in patient care and should be maintained at all times. Failure to maintain privacy of patients may result in patients not being open about their illness. The referral method used at St. Barnabas hospital is seen as inadequate and could put the patient's life in danger. These findings seem to concur with findings from the literature analysis.

The next chapter entails conclusion, recommendations and possibilities for further research.

CHAPTER SIX : CONCLUSION AND RECOMMENDATIONS



6.1 Introduction

The intention of the study was to identify the need for patients to have access to their personal health information within a resource-restricted environment. In the final chapter of this dissertation, a summary of preceding chapters is presented in Section 6.2. The key research findings are reflected upon in Section 6.3. The research findings are beneficial to varying audiences and the significance of the findings is highlighted in Section 6.4. The limitations of the study are discussed in Section 6.5. A number of recommendations are posed in Section 6.6, for further research inquiry. A final reflection of the study is presented in Section 6.7.

6.2 Summary of Key chapters

This dissertation comprised of 6 Chapters. The structure of the thesis and the focus of each chapter were presented. A brief summary highlighting the focal points of each chapter is presented below:

- **Chapter 1:** This chapter introduced the research rationale and necessity for conducting the study. There is an urgent need to assist patients residing within rural areas. The patients in these communities do not have access to their personal health information records. Furthermore, due to a lack of maintainable records, inaccurate capturing of patient diagnosis and treatment, this could result in overwhelming time delays and unintended consequences in the treatment and care of patients. The main objective of the study was to determine the current need and considerations to allow access to patient health records; the type of information required by different stakeholders and factors to consider enabling access to different stakeholders, particularly health care professionals and patients.
- **Chapter 2:** An extensive review of literature was conducted and emphasized in this chapter. The literature review focused on the key healthcare challenges faced in developing and developed countries, particularly with regards to access to patient health records. The different methods used to record patient information were discussed. It was established that paper-based records pose a number of challenges to a patient's on-going and chronic health care. The paper-based records could also affect the healthcare workers' ability to diagnose and treat patients, particularly with follow-up or referral patients. Several health information technologies that are generally employed in most developing countries to overcome the identified challenges of paper-based records were highlighted in the chapter, including HITs (EMR,

EHR, and PHR). The main gap is that there are limited studies exploring patient's access to their own personal health records in rural settings and that there is few research studies in South Africa that employed a community-based research approach to conduct further inquiry.

- **Chapter 3:** The research methodology employed for this study was encapsulated in the form of an adapted research process onion (Saunders et al. 2011) depicted in Figure 3.2. The methods were specifically selected for this interpretive field case study, in order to gather, analyse, interpret and appreciate a holistic understanding of the varying meanings attributed to the importance of access to a patient's personal health record. The co-design approach was an appropriate and informative approach to gather information from patients regarding the access to their personal health records. The interviews provided a detailed understanding, from the perspective of the health care workers, that otherwise would be difficult to obtain for purposes of this study.
- **Chapter 4:** An analysis of the findings was presented in this chapter. A background of St. Barnabas Hospital was provided to depict the context of the case study. The case study was discussed in detail and included a description of why and how specific research participants were recruited for participation.
- **Chapter 5:** The findings from the case study are discussed in this chapter. The key findings will be reflected in Section 6.3 to follow.

6.3 Reflection of the key findings

The findings derived from literature, interviews with healthcare workers and patients, co-design sessions with patients, and observation allowed for the research questions to be addressed.

<p>Sub-question 1: Why may patients want to have access to their personal health information?</p>
--

Chapter 5 addressed sub-question 1. Chapter 5 showed why patients want to have access to their own personal health information. There are a number of reasons. Firstly, patients want to be empowered and want to be involved in decision making about their healthcare. Patients raised their frustration about the issues when it comes to them going to another healthcare provider in a different location, where

they are expected to re-explain their full medical history, with which most of them had problems having to reaffirm what they are suffering from. Every time they visit a new healthcare provider they are a new patient and have to start everything all over. Secondly, patients were concerned about privacy of their health information, and feared to be discriminated by healthcare workers i.e. clerks since they have full access to their health records. A concern was also around stigma issues since most of the clerks that work at hospital reside in the same community as the patient. Thirdly, issues around missing health records was a concern, and patients did not like the fact that they have to do duplicate tests because of health records that have been lost at the hospital.

Sub-question 2: What data elements are relevant for a patient's own health information to facilitate a healthcare service provision?

Chapters 2 and 5 addressed sub-question 2, it was recognised that if patients are given access to their patient health records and are informed about every data field in their patient's records, it would empower them to be informed about their health and treatment thereof. There were, however, significant concerns about the patient's privacy and literacy level when it comes to reading and interpreting the medical information contained in the records. There were also concerns related to issues surrounding illegible handwriting on the patient records. Chapter 2 gave a description of various HIT (i.e. EMR, EHR, & PHR), and it was evident that PHR could empower patients with regards to their health and well-being. A list of demographic and clinical data elements were proposed by the participants although cannot be regarded as a complete list.

Sub-questions 3: How is patients' personal information currently been used in healthcare service provision?

Chapter 5 addressed sub-question 3 and it was recognised that a patient's personal health information are used to as a reference point, a medium of communication between healthcare workers about the patient. It was evident that the hospital in which the study was conducted uses paper-based health records, which presents many challenges to patients and health care professionals. The hospital is required to communicate with other hospitals in the form of referral letters, should they have to refer critical patient conditions to another hospital, and these referral letters have many problems associated with them. Chapter 2 also discussed the problems associated with using paper-based patient records.

Main Research question

Main Research Question: What are the **considerations for patients** to have access to their own personal health information in a restricted resource setting?

The main research question aimed to address the considerations for patients to have access to their personal health information within in a resource-restricted setting. The sub-research questions assisted in addressing the main research question and objective of the study. The findings culminating from the literature reviews and case study, as discussed in detail in Chapter 5, suggest that the following need to be considered:

- **Relevant data elements for Personal Health Records for patients in rural resource-restricted settings:** It is important to reach consensus about the data elements that should be included in a personal health record. Patients in such settings may not have the same needs as patients in advanced settings with a consumer-oriented patient healthcare service focus. The biggest need for these patients is around basic healthcare that is typical of a primary healthcare setting and the personal health record in such a case should be designed to overcome the challenges of such a setting. It is important to obtain the input from all the relevant stakeholders in providing such a service and the personal health record should also specifically consider the preferences of the patients rather than the other stakeholders deciding what data elements the patients should see.
- **Education and technology literacy:** Most patients within the community are not educated, with a limited understanding of English. They use mobile feature phones and some do not have any form of mobile technology. Though patients showed huge interest in having access to their health records, there is a need for them to understand more about their respective conditions especially those who suffer from chronic and life-long illnesses. The potential for technology to be exploited to educate and empower the patients is there, however, patients need to be consulted in the process. It is only through a deep appreciation and understanding of the patients themselves that appropriate electronic patient health records can be designed, tested and used sustainably to educate patients within communities. The introduction of

personal health records can be seen as an opportunity to educate patients about healthcare to involve them more in taking care of their own health through preventative measures.

- **Privacy:** Ideally, giving patients access to their health records would support transparency and inform patients about the status of the health, however, this can also impact the privacy and confidentiality of sharing health information. A breach in privacy could create unintended consequences such as undue discrimination within the community. It is imperative that all healthcare stakeholders should be aware of the importance of securing all personal health information, electronically or otherwise.
- **Lack of infrastructure:** There is a current lack of infrastructure within rural communities. This lack of infrastructure limits the maintenance of and access to electronic patient health records. There is an opportunity for infrastructure providers and other key stakeholders to consider. This is a great need for better basic health care to be provided to assist patients within these communities. If infrastructure can enable the provision of access to information, communities can be uplifted and citizens can be informed about the importance of good health and well-being.
- **Context of use:** There are specific contextual aspects that influences healthcare services for a particular setting and these same aspects need to be considered for the design of electronic patient health records, including personal health records. The manner in which these records are used may differ from one setting to another and from one country to another. Each country has their own policies and legislation that governs the healthcare services and that will influence the use of patient health records. It is therefore important to consider contextual factors for designing health records to provide for their actual use in practice. Other contextual factors are language (in the case of this study the patients speak Xhosa and will probably not understand English terminology on the health record); literacy levels; distance to health facilities; and especially the community norms and values. The findings of this study also confirmed that rural settings have their own unique challenges that need to be considered as well.

6.4 Significance and contribution of the research

The outcome of this study provides a holistic and richer understanding of patient health records within a rural resource-restricted environment. This study contributes an enhanced understanding of access to patient health records which are contextually-relevant within developing economies. Currently, there is limited understanding of the relevance of electronic patient health records in infrastructure and resource-restricted rural settings. It is, therefore, important for the Information Technology body of knowledge to be aware of the varying dynamics and considerations that an environment can influence, in relation to the usage and adoption of technology. The usage of electronic patient health records can be influenced not only by the environment but also by the many different stakeholders, including the main initiator of personal patient health records that is the patient. It is therefore an important aspect to consider in the provision of these technologies and services, and should therefore be studied more widely to improve access to these services.

In addition to the academic contribution, a number of other bodies can also act upon the significance of the considerations and needs, including the Department of Health and other health care providers, not merely primary health care providers within a resource-restricted environment. It is only through a consensual understanding of these considerations that more suitable and novel solutions can be explored to assist in the implementation and maintenance of electronic health records. Furthermore, electronic patient health records have the potential to draw upon more informed health analytics with regards to patient, disease, and treatment and medication usage for different periods and regions. These health care service improvements can ultimately promote improved health care decision-making and service-provision to all patients.

Lastly, these findings can stimulate the need for infrastructure providers such as telecommunication service providers, to improve access to and delivery of information technology services such as, Internet and Cloud services for maintaining and securely storing electronic patient health records. This should be done in engagement with community leaders, citizens and other stakeholders, in order to co-design solutions that will help alleviate technology access concerns, within resource-restricted environments.

6.5 Limitations of the research

Although a number of considerations for access to patient health records were identified through the case study at St. Barnabas, a number of limitations were identified. These limitations are discussed below:

- **Single Case.** This first limitation showed by this study is the setting; only one rural hospital was selected. This could constitute a major limitation in terms of generalisation of the research findings. Other hospitals in private healthcare sectors could also have been considered, but due to time and the process of getting permission they could not be considered.
- **Translation and Transcription.** Translation and transcription from Xhosa to English was problematic. The researcher understands and speaks Xhosa, however, some words and nuances of meaning were difficult to comprehend and translate due to the varied complexity between the two languages.
- **Permission from Department of Health.** Obtaining permission from the Eastern Cape Department of Health took a very long time (6 months); this resulted in the researcher having to wait for permission before he could start data collection.
- **Distance and Time constraints.** Data collection could not be done over long period of time due to distance and time. The research had to travel from Johannesburg to Ntlaza to collect the data. Transport was also challenge for researcher.
- **Gender inequalities.** On the data collection day more female participants availed themselves and participated in the collection. Because of this one male participant showed interested and later dropped out because of feeling uncomfortable being the only male participant.

6.6 Recommendation for further research

A number of recommendations for further research can be made. These recommendations need to be considered for improving access to electronic patient health records.

Figure 4.8 illustrated the current process that patients undergo through on their appointment day, which results in unnecessary time being wasted at the hospital. This study suggests that when patients are given access to their health records using health information technologies such electronic personal health records, this can reduce the amount of time patients spend at the hospitals. This can also reduce the

number of challenges that traditional paper-based records pose to patients and healthcare workers. In addition giving patients access to their health records can empower and inform patients about their health, provided that information in the healthcare records is communicated in a meaningful form.

Figure 6.1 illustrates the process that patients could follow when they have an appointment at the hospital. There is a need for more training and different translation mechanisms in electronic personal health records as more people do not understand English. For example personal health records can functionality that translates (English to Xhosa) and vice versa. In addition to training, healthcare workers and patients need to be trained about the importance of maintaining the privacy and confidentiality of personal health information.

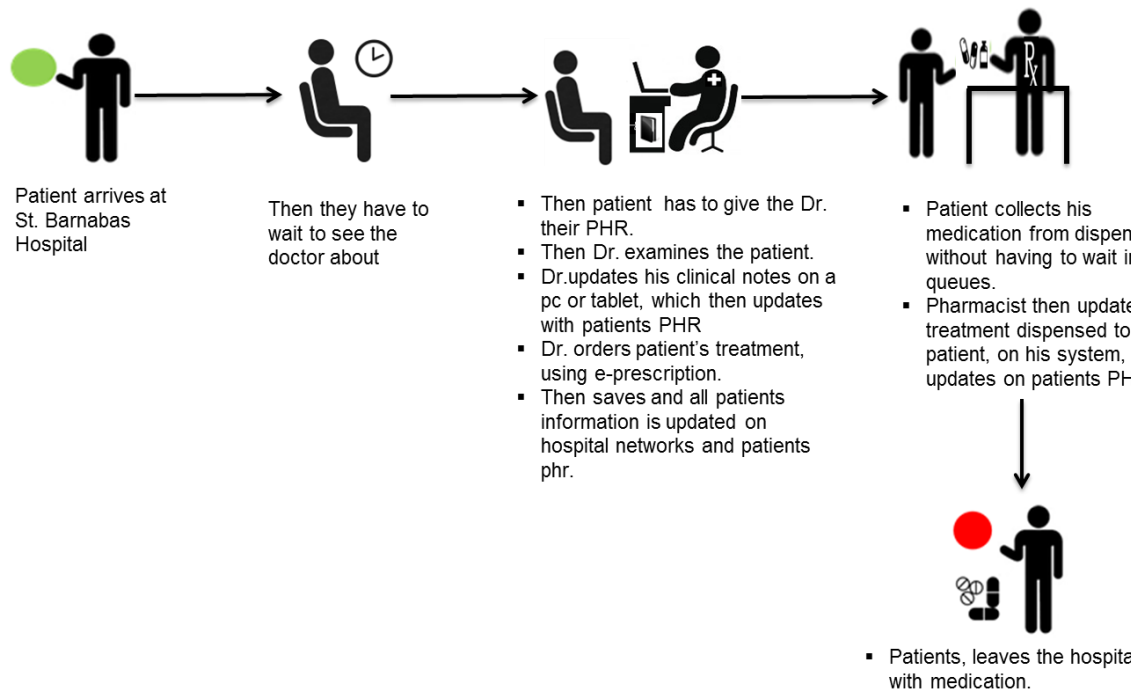


Figure 6-1 Recommendation process that patient should follow at hospital

It is imperative that communities are involved in the process of developing personal health records. As this could be done through community based research and living labs, it could result in more deep and rich information.

Other research recommendations can include:

- Determining the main motivators for adopting personal health records within resource-restricted settings
- Understanding what would be regarded as the meaningful use of personal health records in resource-restricted settings
- Investigating the appropriateness of giving illiterate patients access to their health records and how patient health records could be used to empower technologically- illiterate people.

6.7 Concluding statements

The findings of this study address the research questions and objectives set for this study. The findings not only support current literature in terms of the imperative of electronic patient health records, but also provide invaluable insights in terms of considerations of access to electronic patient health records, within resource-restricted environments. As discussed, a number of profound considerations need to be taken into account, including the literacy surrounding the interpretation of patient health information, privacy of access to patient health records and the lack of infrastructure to support access to patient health records.

Although the circumstances with regards to the access of patient health records, at St. Barnabas is stressed in this study, it is one example too many. The problem surrounding the access of patient health records affect healthcare service delivery for the entire community and could affect health care service delivery to other resource-restricted communities alike.

It is vital that key stakeholders progressively collaborate to implement real-solutions that will make a realizable impact in the delivery of improved health services within communities.

This study serves as a foundation for further studies, as alluded to in Section 6.6. The provision of improved health care cannot be ignored any longer. In times when technology is not only emerging but has already emerged, time is of the essence to understand how people, technology and services can work in harmony. The challenges are many, but the potential for improved health care is innumerable.

“Of all the form of inequality, injustice in healthcare is the most shocking and inhumane.”

- Martin Luther King, Jr.

References

- Adão, W., 2013 Technology enabled self-care to overhaul healthcare industry. Available at: Deloitte: <http://www.cover.co.za/healthcare/technology-enabled-self-care-to-overhaul-healthcare-industry> [Accessed May 20, 2014].
- Al-nassar, B., Abdullah, M. & Osman, S., 2011. Overcoming challenges to use Electronic Medical Records System (EMRs) in Jordan Hospitals. , 11(8), pp.51–58.
- Alavi, M. & Carlson, P., 1992. A review of MIS research and disciplinary development. *Journal of Management Information Systems*, pp.45–62.
- Alberta Health Services, 2009. *Engaging thE patiEnt in hEalthcarE: an ovErviEw of pErsonal hEalth rEcord systEms and implications for albErta*,
- Ambali, A., J. M. & Mutero, C., 2009. *Public health in Africa*,
- Anand, S., 2000. Human Development and enconomic Sustainability. *World Development*, 29(12), pp.2029 – 2049.
- Archer, N. et al., 2011. Personal health records: a scoping review. *Journal of the American Medical Informatics Association : JAMIA*, 18(4), pp.515–522.
- Asangansi, I.E. et al., 2008. Computer use among doctors in Africa : Survey of trainees in a Nigerian teaching hospital. , 2(1), pp.10–14.
- Ayatollahi, H., Bath, P.A. & Goodacre, S., 2009. Paper-based versus computer-based records in the emergency department: Staff preferences, expectations, and concerns. *Health Informatics Journal*, 15(3), pp.199–211.
- Babbie, E., 2006. *The basics of social research*, Belmont: California: Thamson Wadsworth.
- Babbie, E., 2010. *The Practice of Social Research Internatio.*, Wadsworth: Cengage Learning.
- Blaya, J.A., Fraser, H.S.F. & Holt, B., 2010. E-health technologies show promise in developing countries. *Health Affairs*, 29(2), pp.244–251.
- Braun, V. & Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), pp.77–101.
- Brink, H., 1994. Basic issues in clinical nursing research. *Nursing RSA= Verpleging RSA*, 9(8), pp.14–15.
- Brown, K., 2008. Developing countries must plan road map for e-health. In *Conference Interview by Africa. Bellagio, Italy.[Online] www. allfrica.com.[Accessed: 20/10/2010]*.
- Bryman, A., 2012. *Social research methods*, Oxford university press.
- Burke, M.E., 2007. Making choices: research paradigms and information management: Practical applications of philosophy in IM research. *Library review*, 56(6), pp.476–484.
- Cassel, C.. & Guest, J., 2012. Helping Physicians and Patients Make Smart

- Decisions About Their Care. *Jama*, 307(17), p.1801. Available at: <http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.2012.476>.
- Chen, R. et al., 2010. Management of personal health information sharing for long term care services. *Service Systems and Service Management (ICSSSM), 2010 7th International Conference on*, pp.1–6.
- Cline, G.B. & Luiz, J.M., 2013. Information technology systems in public sector health facilities in developing countries: the case of South Africa. *BMC medical informatics and decision making*, 13, p.13.
- Coleman, A., 2010. *Developing an E-Health Framework Electronic Health Readiness Assessment*.
- Coombes, H., 2001. *Research using IT*, UK: Basingtoke: Palgrave.
- Cooper, D. & Schindler, P., 2008. *Business research methods: second European edition* 2nd Europe., Maidenhead: McGraw-Hill Higher Education.
- Cooper, D. & Schindler, P., 2003. *Business Research Methods* 8th ed., New York: McGraw-Hill/Irwin.
- Cormack, D., 2000. *The research process in nursing*, Blackwell Publishing.
- Couper, I. & Worley, P., 2006. Health and information in Africa: the role of the journal Rural and Remote Health. *International Journal of Rural and Remote Health Research, Education, Practice and Policy*, 6(644). Available at: www.rrh.org.au/publishedarticles/article_print_644.pdf.
- Creswell, J., 2009. *Research design: Qualitative, quantitative, and mixed methods approaches*, SAGE Publications, Incorporated.
- Creswell, J.W., 2003. *Creswell, J.W. (2003). Chapter One, "A Framework for Design."* London: Sage Publications.
- Creswell, J.W., 2007. *Qualitative enquiry and research design: Choosing among five approaches*.
- Creswell, J.W. & Clark, V.L.P., 2007. *Designing and conducting mixed methods research*.
- De Bord, J., Burke, J. & Dudzinski, D., 2013. *ETHICS IN MEDICINE* University of Washington School of Medicine. Available at: <https://depts.washington.edu/bioethx/topics/confiden.html> [Accessed October 15, 2015].
- Deetz, S., 1996. Crossroads-describing differences in approaches to organization science: Rethinking Burrell and Morgan and their legacy. *Organization science*, 7(2), pp.191–207.
- De la Harpe, R., 2008. *Organizational Implications of Data Quality: A Social Perspective*. Cape Peninsular University of Technology, South Africa.
- Denzin, N.K. & Lincoln, Y.S., 2005. *Qualitative research The Discipline and Practice of Qualitative Research* 3rd ed. Thousand Oakes, ed., London: Sage.

- De Vos, A., Strydom, H. & Fouche, C., 2002. *Research at Grass Roots: For the social sciences and human service professions*. 2nd ed., South Africa: Pretoria: Van Schaik Publishers.
- Department of Health, 2002. The Primary Health Care Package for South Africa – a set of norms and standards.
- DeVries, E.J., 2005. Episyemology and Methodology in Case Research: A Comparison Between European and American IS Journals. *ECIS 2005 Proceedings*, p.145. Available at: <http://aisel.aisnet.org/ecis2005/145>.
- Dohan, M.S., Abouzahra, M. & Tan, J., 2014. Mobile Personal Health Records: Research Agenda for Applications in the Global Health. In IEEE, ed. *47th International Conference on Systems Science*. Hawaii, pp. 2576 –2585.
- Dookie, S. & Singh, S., 2012. Primary health services at district level in South Africa: a critique of the primary health care approach. *BMC Family Practice*, 13(1), p.67. Available at: <http://www.biomedcentral.com/1471-2296/13/67>.
- Eastern Cape Department of Health, 2011. Patient files missing, nurse arrested. Available at: <http://www.gov.za/patient-files-missing-nurse-arrested> [Accessed June 5, 2014].
- Edwards, R. et al., 2012. Communication strategies in acute health care: evaluation within the context of infection prevention and control. *Journal of Hospital Infection*, 82(1), pp.25–29.
- Explore South Africa, Map of South Africa. Available at: <http://www.exploresouthafrica.net/accommodation/provincemap.htm> [Accessed March 20, 2015].
- Eysenbach, G., 2008. Personal Health Records 2.0. , pp.1– 17. Available at: <http://www.slideshare.net/eysen/eysenbach-phr-20-personal-health-records-20-vancouver>.
- Eysenbach, G., 2001. What is e-health? *Journal of Medical Internet Research*, 3(2).
- Fetter, M., 2009. Personal Health Records: Protecting Behavioral Health Consumers' Rights. *Issues in mental health nursing*, 30(11), pp.720 – 722.
- Fox, 2009. Using Interviews in Research Project. *National Institute for Health Research*, p.4.
- Fraser, R., 2006. ISO 27799 : Security management in health using ISO / IEC 17799. , pp.1–41.
- Garrett, P. & Seidman, J., 2011. EMR vs. EHR—What is the Difference? Available at: <http://www.healthit.gov/buzz-blog/electronic-health-and-medical-records/emr-vs-ehr-difference/> [Accessed June 1, 2014].
- Gerber, M. & Von Solms, R., 2001. From risk analysis to security requirements. *Computers & Security*, 20(7), pp.577–584.
- Goddard, W. & Melville, S., 2004. *Research methodology: An introduction*, Juta and Company Ltd.

- Goodwin, R., 2002. Conducting cross-cultural psychological research in changing cultures: Some ethical and logistical considerations. *Online readings in psychology and culture*.
- Grebe, E., 2013. Minister acts on Eastern Cape crisis. Available at: <http://ehealthcrisis.org/news/2013/09/minister-acts-on-eastern-cape-crisis/> [Accessed May 1, 2014].
- Guba, E.G., Lincoln, Y.S. & Lynham, S.A., 2011. Paradigmatic controversies, contradictions, and emerging confluences, revisited. *The Sage handbook of qualitative research*, 4, pp.97–128.
- Halloran, J. et al., 2009. The value of values: Resourcing co-design of ubiquitous computing. *CoDesign*, 5(4), pp.245–273.
- Health Professions Council of South Africa, 2008. *Guidelines on Keeping Patient Records*, Pretoria. Available at: <http://www.hpcs.co.za>.
- Henn, M., Weinstein, M. & Foard, N., 2005. *A short introduction to social research*, Sage.
- Humphreys, E.J., Moses, R.H. & Plate, E.A., 1998. *Guide to BS7799 Risk Assessment and Management*, Britin: British Standards Institution.
- Hunter, L. & Leahey, E., 2008. Collaborative Research in Sociology: Trends and Contributing Factors. *American Sociologist*, 39, pp.290–306.
- ISO Technical Report, 2007. New ISO technical report to help ensure patient safety of health software. No Title. Available at: http://www.iso.org/iso/home/news_index/news_archive/news.htm?refid=Ref1068 [Accessed June 20, 2014].
- JobQna, 2008. Discuss advantages and disadvantages of computer versus paper-based medical library? Available at: http://www.jobqna.com/health-care/discuss_advantages_and_disadvantages_of_comp.html.
- Kaelber, D. & Pan, E., 2008. The value of personal health record (PHR) systems. In *AMIA Annual Symposium Proceedings*. p. 343.
- Kahn, T., 2011. Government paves the way for move to paperless hospitals. *Health Systems Trust*. Available at: <http://www.hst.org.za/news/government-paves-way-move-paperless-hospitals> [Accessed May 14, 2014].
- Kaiser Permanente, 2007. Americans Prefer Electronic Health Records. *Information Management Journal*, 41(4), pp.8–8.
- Kharrazi, H. et al., 2012. Mobile personal health records: an evaluation of features and functionality. *International journal of medical informatics*, 81(9), pp.579–93. Available at: <http://www.sciencedirect.com/science/article/pii/S1386505612000743>.
- Khothari, C., 2005. *Research Methodology Methods and Techniques*, India: New Age Publications.
- Kidwai, S., 2014. EMR vs. EHR – What is the Difference? Available at: <https://drchrono.com/blog/emr-vs-ehr/> [Accessed October 1, 2014].
- Kim, K. & Nahm, E., 2012. Benefits of and barriers to the use of personal health records (PHR) for health management among adults. *Journal of*

- Nursing Informatics*, 16(3). Available at: <http://ojnni.org/issues/?p=1995>.
- Kleynhans, A., 2011. *Is South Africa ready for a national Electronic Health Record (EHR)?*
- Kumar, R., 2005. *Research Methodology: A Step-by-Step Guide for Beginners* Sage, ed., London.
- Leedy, P. & Ormrod, J., 2001. *Practical research: planning and design* 7th ed. Prentice Hall, ed., New Jersey.
- Leedy, P.D., 1997. *Practical research: planning and design* 6th ed., Columbus: Prentice hall.
- Leedy, P.D. & Ormrod, J.E., 2001. No Title. In *Practical research: Planning and design*. Upper Saddle River: Merrill Prentice Hall.
- Leedy, P.D. & Ormrod, J.E., 2005. *Practical research. Planning and design*, 8.
- Lewis, D. et al., 2012. Understanding the role of technology in health information systems. *Pacific health dialog*, 18(1), pp.144–54. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/23240349>.
- Lindsay, D., 1995. *A guide to scientific writing*, Longman Melbourne.
- Liu, S., Shih, P. & Hayes, G.R., 2011. Barriers to the adoption and use of personal health record systems. *Proceedings of the 2011 iConference on - iConference '11*, pp.363–370. Available at: <http://portal.acm.org/citation.cfm?doid=1940761.1940811>.
- Luo, J., 2006. *Electronic Medical Records*. , 13(February), pp.20–23.
- Mabuza, L. et al., 2011. Quality of general practitioner referral letters to a South African tertiary hospital: determinants of quality content and good practice. *Journal of Public Health and Epidemiology*, 3(11), pp.482–488. Available at: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=cagh&AN=20123025058\nhttp://lshtmsfx.hosted.exlibrisgroup.com/lshtm?sid=OVID:caghdb&id=pmid:&id=doi:&issn=21412316&isbn=&volume=3&issue=11&spage=482&pages=482-488&date=2011&title=Journal>.
- Mack, N. et al., 2005. *Qualitative research methods: a data collectors field guide*.
- Maree, K., 2007. *First steps in research*, Van Schaik Publishers.
- Markle Foundation, 2003. *Personal Health Working Group Final Report. Markle Connecting for Health*. Available at: <http://www.markle.org/publications/1429-personal-health-working-group-final-report> [Accessed May 9, 2015].
- Marrelli, A., 2005. Literature reviews. *Ultrasound quarterly*, 30(1), pp.81–7. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24905994>.
- Mars, M. & Seebregts, C., 2008. Country Case Study for e-Health: South Africa. *e-Health Connections: Country Case Study Reports*, pp.1–46. Available at: <http://ehealth-connection.org/files/resources/County Case Study for eHealth South Africa.pdf>.
- Marshall, C. & Rossman, G., 2011. *Designing qualitative research* 5th ed. Thousand Oakes, ed., California: Sage.
- Marshall, P., *Personal Health Records: Their Benefits and the Role of*

Standards.pdf.

- Marutha, S., 2011. *RECORDS MANAGEMENT IN SUPPORT OF SERVICE DELIVERY IN THE PUBLIC HEALTH SECTOR OF THE LIMPOPO PROVINCE IN SOUTH AFRICA*. University of South Africa.
- Mchunu, 2013. *Adequacy of healthcare information systems to support data quality in the public healthcare sector , in the Western Cape , South Africa by Nokubalela Ntombiyethu Mchunu Thesis submitted in fulfilment of the requirements for the degree Master of Technology*. Cape Peninsula University of Technology.
- Medical Protection Society, 2011. *Medical Records in South Africa An MPS Guide*, Pretoria. Available at: www.medicalprotection.org/southafrica.
- Mikkelsen, G. & Aasly, J., 2001. Concordance of information in parallel electronic and paper based patient records. *International journal of medical informatics*, 63(3), pp.123–131.
- Mitchell, M. et al., 2009. Improving care – improving access: the use of electronic decision support with AIDS patients in South Africa. *International Journal of Healthcare Technology and Management*, 10(3), p.156. Available at: <http://www.inderscience.com/link.php?id=25819>.
- Moore, S., 2007. *“Dirty Data” is a Business Problem, Not an IT Problem, Says Gartner*, Sydney, Australia. Available at: <http://www.gartner.com/newsroom/id/501733>.
- Mostert-hipps, N., 2011. HEALTH INFORMATION TECHNOLOGIES FOR IMPROVED CONTINUITY OF CARE : A SOUTH AFRICAN PERSPECTIVE by by.
- Mostert-Phipps, N., Pottas, D. & Korpela, M., 2012. Improving continuity of care through the use of electronic records: A South African perspective. *South African Family Practice*, 54(4), pp.326–331. Available at: <http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L366042483> \n http://www.journals.co.za/WebZ/images/ejour/mp_safp/mp_safp_v54_n4_a11.pdf?sessionid=01-55738-89496325&format=F \n http://sfx.hul.harvard.edu/sfx_local?sid=EMBASE&issn=1726.
- Mouton, J. & Babbie, E., 2001. *The practice of social research*. Cape Town: Wadsworth.
- Mouton, JS & Marais, H., 1996. *Basic concepts in the methodology of Social Sciences* 5th ed. H. S. R. Council, ed., Pretoria.
- Mphatswe, W. et al., 2012. Improving public health information: a data quality intervention in KwaZulu-Natal, South Africa. *Bulletin of the World Health Organization*, 90(3), pp.176–182.
- Musango, L., 2008. Social health insurance: how feasible is it in the African Region? *Development ISSues*, 10(November), pp.7–9.
- Myers, M.D. & Newman, M., 2007. The Qualitative interview in IS research: Examining the craft. *Informationnnnn and Organisation*, 17(1), pp.2 –26.
- Nagykaldi, Z. et al., 2012. Impact of a Wellness Portal on the delivery of patient-centered preventive care. *Journal of the American Board of*

- Family Medicine : JABFM*, 25(2), pp.158–167.
- Nair, B.K.R., 2011. *Clinical examination: a problem based approach*, World Scientific.
- National Archives and Records Service of South Africa Department of Arts and Culture, 2004. RECORDS MANAGEMENT POLICY MANUAL. , (April).
- National Institutes of Health National Center for Research Resources, 2006. Electronic Health Records Overview. , (April).
- Nazi, K.M., 2013. The personal health record paradox: health care professionals' perspectives and the information ecology of personal health record systems in organizational and clinical settings. *Journal of medical Internet research*, 15(4).
- NCVHS, 2006. Personal Health Records and Personal Health Records Systems. Available at: <http://www.ncvhs.hhs.gov/050909lt.htm> [Accessed May 7, 2014].
- Nene, N., 2015. Find your file, sick man told. *IOL News*. Available at: <http://www.iol.co.za/dailynews/news/find-your-file-sick-man-told-1.1812123#.Vd8KKGKuDIU> [Accessed March 1, 2015].
- Neuman, W., 2011. *Social Research Methods: Qualitative and Quantitative Approaches* 7th ed., Boston: Pearson Education, Inc.
- Nkombua, L., 2008. The practice of medicine at a district hospital emergency room: Middelburg Hospital, Mpumalanga Province. *South African Family Practice*, 50(1), p.65.
- Oates, B.J., 2006. *Researching Information Systems and Computing*.
- Oates, B.J., 2008. *Researching Information Systems and Computing* 2nd ed., London: Sage Publications Ltd.
- Olivier, M., 2009. *Information Technology Research: A practical for Computer Science and Informatics* 3rd ed., Pretoria: Van Schaik Publishers.
- Party, J., Morris, K. & Leatherman, J., 2010. The Importance of the Health Care Sector to the Economy of Cheyenne County Kansas Rural Health Options Project. Available at: <http://krhw.net/assets/docs/Economic Impact Reports/Cheyenne County Health Care Impact Report.pdf>.
- Pottas, D. & Mostert-Phillips, N., 2013. Citizens and Personal Health Records – the Case of Nelson Mandela Bay. , pp.3–7.
- Puckree, T. et al., 2002. African traditional healers: what health care professionals need to know. *International Journal of Rehabilitation Research*, 25(4), pp.247–251.
- Ramanayake, R. et al., 2014. Why are specialists reluctant to reply to referral letters - exploring the views of specialists in Sri Lanka. , 5(3), pp.44–48.
- Van Rensburg, H.C.J., 2004. *Health and health care in South Africa*, Van Schaik Publishers.
- Ritchie, B. & Brindley, C., 2001. The information-risk conundrum. *Marketing Intelligence & Planning*, 19(1), pp.29–37.
- Rowley, J., 2002. Using case studies in research. *Management research*

- news*, 25(1), pp.16–27.
- Ruxwana, N., 2010. *The Adoption of Quality Assurance in e-Health Acquisition for Rural Hospitals in the Eastern Cape Province by Nkqubela Ruxwana*.
- Ruxwana, N.L., Herselman, M.E. & Conradie, D.P., 2010. ICT applications as e-health solutions in rural healthcare in the Eastern Cape Province of South Africa. *The HIM journal*, 39(1), pp.17–26. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/20335646>.
- Ryan, B., Scapens, R.W. & Theobald, M., 2002. *Research methods and methodology in accounting and finance*, Thomson Learning.
- Salomon, J. et al., 2012. Healthy life expectancy for 187 countries, 1990–2010: a systematic analysis for the Global Burden Disease Study 2010. *The Lancet*, pp.2144–2162.
- Sanbar, S., 2007. *Legal Medicine* Seventh Ed. C. U. Press, ed., New York.
- Saunders, M., Lewis, P. & Thornhill, A., 2007. *Methods for Business Students* 6th ed., London: Pearson.
- Saunders, M., Lewis, P. & Thornhill, A., 2011. *Research methods for business students*, London: Pearson Education London.
- Schneider, J.M., 2008. My Health e Vet: Fighting for Health with Information. *Journal of Consumer Health on the Internet*, 12(1), pp.13–21.
- Services, U.. D. of H. and H., 2006. Consumer Awareness, Addressing Healthcare Connectivity as a Matter of Life and Death. Available at: <http://www.hhs.gov/healthinformationtechnology/consumerAwareness.html>.
- Shakir, M., 2002. The selection of case studies: strategies and their applications to IS implementation case studies. Available at: <http://hdl.handle.net/10179/4373>.
- Shine, K., 2001. A critique on complementary and alternative medicine. *The Journal of Alternative and Complementary medicine*, 78(2), pp.258–266.
- Siek, K. et al., 2011. Designing a personal health application for older adults to manage medications: a comprehensive case study. *Journal of medical systems*, 35(5), pp.1099–121. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/21562730> [Accessed March 21, 2013].
- van Bekkum, J.. & Hilton, S., 2013. The challenges of communicating research evidence in practice: perspectives from UK health visitors and practice nurses. *BMC nursing*, 12(1), p.17.
- Von Solms, R., 1998. Information security management (1): why information security is so important. *Information management & computer security*, 6(4), pp.174–177.
- Von Solms & Von Solms, 2006. Information security governance: A model based on the direct-control cycle. *Computers & Security*, 25(6), pp.408–412.

- South African Government, 2013. Health. Available at:
<http://www.gov.za/about-SA/health> [Accessed April 1, 2014].
- Struwig, F.W. & Stead, G.B., 2001. *Planning, reporting & designing research*, Pearson South Africa.
- Sunyaev, A., 2010. Evaluation Framework for Personal Health Records :
 Microsoft HealthVault vs . Google Health. , pp.1–10.
- Tang, P. et al., 2006. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. *Journal of the American Medical Information Association*, 13(2), pp.121 –126. Available at:
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1447551/>.
- Tange, H.J., 1995. The paper-based patient record: Is it really so bad?
Computer Methods and Programs in Biomedicine, 48(1), pp.127–131.
- The Guardian, 2014. Why you should be angry about changes to NHS patient data policy. Available at:
<http://www.theguardian.com/commentisfree/2014/jan/20/nhs-patient-care-data-policy-medical-information>.
- To South Africa, Ultimate Guide to South Africa. Available at:
<http://www.tosouthafrica.co.za/> [Accessed March 21, 2015].
- Tsai, J. & Bond, G., 2008. A comparison of electronic records to paper records in mental health centers. *International journal for quality in health care : journal of the International Society for Quality in Health Care / ISQua*, 20(2), pp.136–143.
- Tswane, S., 2012. *Indigenous Knowledge and Caregivers' Use of Data Elements in Home-based Healthcare*.
- Uriarte, F.A., 2008. Introduction to Knowledge Management, the ASEAN Foundation. *Jakarta, Indonesia*.
- van Dyk, P., 2002. Information sharing and information archiving-are they at odds? *SA Journal of Information Management*, 4(1).
- Visagie, S. & Schneider, M., 2014. Implementation of the principles of primary health care in a rural area of South Africa. *African Journal of Primary Health Care & Family Medicine*, 6(1), pp.1–10. Available at:
<http://www.phcfm.org/index.php/phcfm/article/view/562>.
- Voce, A., 2004. Introduction to research paradigms Handout for the Qualitative Research Module. *Retrieved*, 10(25), p.2011.
- Walsh, M., 2001. *Research made real: A guide for students*, Nelson Thornes.
- Welman, C., Kruger, F. & Mitchell, B., 2005. *Research Methodology* 3rd ed. Oxford University Press Southern Africa, ed., South Africa.
- West, D. et al., 2012. How Mobile Devices are Transforming Healthcare. *Brookings.Edu*, 18(16), pp.1–38. Available at:
http://www.brookings.edu/~media/research/files/papers/2012/5/22_mobile_health_west/22_mobile_health_west.pdf
 \file:///Users/felasfa/Dropbox/Papers2/Articles/Unknown/West/West.pdf ER -\nhttp://vge-mktg.vodafone.com/content/GatedFormSuccess-newDocId?doc.

- World Health Organisation, 2006. Electronic health records: manual for developing countries.
- Yin, R., 1994. *Case study research: Design and methods* (2 nd. Newbury Park, ed., California: Sage Publications.
- Yin, R., 2008. *Case Study Research: Design and Methods: Design and Methods*, Sage Publications.
- Yin, R.K., 2003. Case study research design and methods third edition. *Applied social research methods series*, 5.
- Ylirisku, B. et al., 2007. Framing innovation in co-design sessions with everyday people. *Design*, pp.1–10.
- Zakaria, O., 2004. Understanding Challenges of Information Security Culture: A Methodological Issue. In *A/SM*. pp. 83–93.

Appendix B: Approval Letter from Eastern Cape Department Health



Eastern Cape Department of Health

Enquiries: Zonwabele Merile

Tel No: 040 608 0830

Date: 16th September 2014

Fax No: 043 642 1409

e-mail address: zonwabele.merile@impilo.ecprov.gov.za

Dear Mr A. Bantom

Re: Accessibility to patients' own health information: a case in rural Eastern Cape, South Africa

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT



ikamva eliqambileyo!

Appendix C: Letter of Informed Consent



Letter of informed consent

In this study, the focus is on Health Informatics which is a program available in the Information Technology department at CPUT for continuing research and adding to body of knowledge to students for life improvement.

The researcher will conduct face to face interviews with Doctors, Nurse, Pharmacists, and Clerks to gather sufficient information. The interviews will be audio recorded. All the mentioned healthcare professionals are taking active role in this role and developing new knowledge. It is important to make a potential participant comfortable as possible about discussing the research, so that you can be able to give more information in this research and feel confident enough and comfortable to ask questions. All of your information and interview responses will be kept confidential.

A major role is your voluntary participation in this study. It is up to you to decide whether or not to take part in this study but you will need to sign a consent form. If you decide to take part in this study, you are still free to withdraw at any time without giving a reason. You are to answer any question if you choose. This will not affect the relationship with the researcher. Also there are no potential risks, no harms as well.

Only researcher will have access to the study data and information gathered during this project. There will not be any identifying names on the interviews transcripts, they will be coded and the key to the code will be kept locked away. Your names and other details will never be revealed in any publications of the study results. The audio recorded will be destroyed at completion of the study. The results of the research will be published in a professional journal or presented at professional meetings. It may also be published in a book form.

If you have any questions or concerns, please contact the researcher or his supervisor

My signing this consent form below, I acknowledge that I have read and understand the above information. I am aware that I can discontinue my participant in the study at any time.

Participant

Date

Signature

Researcher

Date

Signature

Appendix D: Interview Schedule

INTERVIEW QUESTION FOR HEALTH CARE PROFFESIONALS i.e. Nurses, Doctors and Clerks

The researchers from Cape Peninsula University of the Technology (CPUT) would like to request your participation on in this study research on accessibility to patient's own health record a case in the rural Eastern Cape. You are asked to participate in this study by completing this interview. Please note participation is voluntary and all participants will remain anonymous. No participants under the age of 18 are allowed to complete this questionnaire.

You may direct your queries research this study to main researcher:
Simindile Abongile Bantom: 076 862 9222 / 078 5888 467

About the interview

All information will be treated as confidential. Interview will be record for analysis. Participation is voluntary

Purpose of the interview

- To investigate the current retrieval, storage, and share process of patient record at the hospital or Surgery.
- To compare paper-based patient record system and PHR and assess its impact on improving information flow at the hospital.

Background

1. What is position at the hospital?

2. What is your typical day and week here?

3. How long have you been working at this hospital?

4. How did you get where you are?

5. What is your education level?

Access

6. Do you have access to computer system at this hospital? Please elaborate on the kind of access if relevant

7. Do you have access the internet? Please elaborate...

Computer training

8. What training did you receive have you been trained on using a computer?

9. What do you know about Personal Health Records or PHR? Please explain your understanding of a PHR and how it can benefit your work (or not) ?

Patient Record Storage

10. What form of identification does your organisation use to retrieve record in the storage?

11. How effective is this retrieval effective?

12. How do you experience with this method present (challenges)?

13. What would you find most **difficult** about giving access to patient to their own records?

14. What do you think about patients having access to their own records? For example PHR?

15. What information on a PHR do you think would be relevant for them to see or know?

16. What information should patients not have access to? (and why?)

17. How does this health facility, e.g. hospital/clinic store and process patient records? (electronically, if so which parts?)

18. What are some challenges do you face with keeping patient records?

19. How difficult is it to identify patients who arrive at the health facility unconscious with no form of identification in place?

20. Which method of storage do you think is safer and more reliable? Please comment on electronic records versus paper-based?

Patient Record Share

21. How important do you think it is to share patient records with
- a. other colleagues in the same facility?
 - b. Other health professionals in other health facilities?

22. To what extent does your facility share patient records within or for referral purposes to other facilities?

23. To what extent does your organisation share patient records **electronically** within or for referral purposes to other health facilities?

24. Please comment on the following media of communication for patient information:

- Email Photocopy Carbon Copy
- Phone call SMS

25. Who do you share patient records with e.g. clinics or other hospital?