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THE USE OF ELECTRONIC NARRATIVES RECORDS TO SUPPORT THE DECISION-MAKING PROCESS IN ONCOLOGY CARE AT PRIVATE HOSPITALS IN CAPE TOWN

by

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DECLARATION

I, Musimwa Chantal Kalorho declare the contents of this thesis represent my own work.

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ABSTRACT

Electronic narratives are recognised for their significant contribution to healthcare – emphasising that the patient's narrative should not only be included, but valued. The survival rate of cancer patients in the UK, USA, Italy and Australia are improving, making it necessary to investigate the use of electronic narratives in private oncology centres. This research, conducted in Cape Town, South Africa, started off by critically analysing available scientific information. Subsequently, a gap was identified regarding the use of electronic narratives as a way of acquiring important data from patients – something that is crucial in the treatment process (from the pre-diagnosis to the follow-up), and in decision-making. The lack of narratives in electronic health records (EHRs) could affect the quality of the decision-making process, particularly for chronic non-communicable diseases (NCD); which could result in administering incorrect dosages of medication leading to deterioration of the patient's health, and in some cases, even death.

The purpose of this research was to explore the use of narratives in electronic health records to support the decision-making process by healthcare professionals in private oncology care. The study was qualitative; hence interviews were used for data collection. A purposive sample of eighteen healthcare professionals (oncologists, psychiatrists and general practitioners) was used in this study. The data was then analysed thematically, and the interpretation thereof done subjectively.

The key findings of this study indicate that electronic health records are used considerably in private oncology care due to benefits such as real-time access to information and easy back-up. Healthcare professionals acknowledge that narratives are present in oncology care, and mainly used in the diagnosis phase. These narratives are mostly in note format (hand-written on paper). These written notes are then later recorded into the patient's electronic health record which, in many cases, results in the omission of important information, because not everything the patient said is transcribed into medical jargon. The current system in private oncology care does not support electronic narratives even though healthcare professionals express an interest in using this. The findings further suggest that to successfully implement electronic narratives,

there are basic prerequisites such as a computer or tablet, recording devices and software. Furthermore, the findings show that electronic narratives are often not used due to limited knowledge, lack of interest, specific cultural practices, and the fear of change.

To alter and positively transform healthcare professionals' and patients' views of electronic narratives, the researcher recommends educating healthcare professionals about the value of patients' narratives. In other words, providing training is crucial as narratives contain values that aid constructive decision-making. Furthermore, since narratives involve patients, extending training to the patients will be beneficial. The findings of this study contribute to the current literature on electronic health records and narratives in private oncology care of South Africa.

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GLOSSARY

Abbreviation	Complete words/term
EHR	Electronic health records
eNarrative	Electronic narratives
ICT	Information communication technology
NCD	Non-chronic disease
HP	Healthcare professional
IBM	International business machines
WFO	Watson for oncology

CLARIFICATION OF BASIC TERMS

Word/Term	Definition
Decision-making	The ability to choose from available alternatives, actions and solutions to resolve a problem in a particular situation (Sharma et al., 2016).
Electronic health records (EHRs)	A digital version of a patient's record connected electronically to the entire medical service network that is accessible in real time (Boonstra, Versluis & Vos, 2014).
Electronic narrative record / eNarrative	A digital version of a patient's narrative which combines video, sound, animation, text, music and narrative voice experienced by both healthcare professionals and patients; to record the diagnosis, treatment and recovery processes and promote well-being (Cunsolo, Harper & Edge, 2012).
Health	The well-being of a person (Brüssow, 2013)
Healthcare	The organized act of taking preventative actions of disease, illness, injury and necessary medical procedures to improve the physical, psychological and social state of a human being (Toon, 2015).
Healthcare professional	An individual who maintains health, provides preventive and curative healthcare services in efficient ways to a community (Birkhäuer et al., 2017).
Healthcare services	The general visible functions (diagnosis, treatments, maintenance and restoration) allowing the delivery of health (Tegegn et al., 2017).
Narrative	An approach used by doctors that allows a patient's story to be heard, experienced by both healthcare professionals and patients to promote well-being (Charon, 2012).
Non-communicable diseases (NCD)	Non-transmissible disease that slowly progresses and last for a long period (time) (Hofman, 2014).

CHAPTER ONE – INTRODUCTION

1.1. Introduction

In the healthcare environment, increasingly more hospitals are becoming reliant on information and communication technology (ICT) (Rouleau, Gagnon & Côté, 2015). Many healthcare facilities subcontract their ICT functions to effectively achieve their objectives, and to be prepared for future changes that may arise in their environment. According to Almeida, Farias and Carvalho (2017), in the years between 1960 and 1990, many healthcare facilities required ICT due to increased manual work demands. These tasks included finding patients' paper records, processing tests results and documenting communication. As result, there were several factors that led healthcare facilities to adopt or subcontract ICT systems such as cost, skills, flexibility and quality.

Roberts, Elaine and Deter (1999) stated that in the 1990's electronic health records arose in healthcare to ease administration processes for healthcare professionals. Even though EHRs have been present in healthcare facilities, the optimum use thereof, in order to benefit from its full potential, still present challenges to healthcare professionals (Ambinder, 2005).

Electronic health records have structured and unstructured data that represent the health history of a person. Unstructured data can be in the of form free text as clinical or patient notes or narratives. Although clinical narratives are more reliable than coded data, the narratives need to be captured by a person with effective listening skills at an available time and place (Savsar & Savsar, 2019). A narrative refers to story-telling and in narrative medicine it is described as a rich grasp of a person's situation (Weiner, 2019). According to Xu et al. (2011) few studies investigated how such data can be extracted, shared or integrated in an EHR. Mining unstructured data provides an opportunity to identify areas to improve healthcare services (Yadav et al., 2016). When regarding the EHR merely as a digital translation of a paper-based record then it does not capatilise its potential to enhance the patient-doctor consultation and Coiera et al.

(2018) propose a digital scribe as a means to utilise EHRs better using speech recognition, natural processing language and artificial intelligence.

In South Africa, certain healthcare facilities use EHRs but some crucial functionalities such as narratives in EHRs are taken lightly or left out entirely.

To determine how the use of narratives in EHRs has failed to reach its full potential; an exploratory research was conducted with the aim of exploring the use of narratives in electronic health records to support the decision-making process by healthcare professionals in private oncology care.

1.2. Background

In the 1990's, the use of EHRs emerged in private healthcare centres which redressed the shortcomings that were present in paper-based records (Roberts, Elaine & Deter, 1999). In both paper-based records and electronic health records, healthcare professionals rely on notes or data captured to make decisions (Ohno-Machado, 2016). In 1998, the term "narrative" was initiated by European healthcare centres (Kalitzkus, 2009), and developed as a medical approach in the late 1990s by Rita Charon and Rachel Naomi Remem (Rosti, 2017). In the years between 2001 and 2005, narratives in healthcare started being converted from handwritten to electronic using advanced technology – this is referred to as electronic narrative (Finn, 2015).

The use of narrative in healthcare records has been successful in countries such as the UK (Ryan, Ward & Jones, 2017), USA, China (Huang et al., 2017), Italy (Polvani et al., 2014) and Australia (Rosti, 2017). Unfortunately, narratives as well as electronic narrative approaches have not been introduced into the healthcare service delivery landscape in South Africa – especially the private sector (Reid, 2014).

Although this study considers patient narratives, it does not consider it to be a study about narrative medicine but rather as notes that describes the situation of a patient as captured by a health professional. It may be clinical notes or any other notes that are important for the patient's care. Liu (2018) alerts to the extra time that is needed to capture the patient's history, diagnosis and treatment plan that lead to frustration and the adoption of workarounds. The use of EHRs influence the user experience of the

healthcare professionals relating to health systems, organizational; and vendor factors (Tutty, et al., 2019). The use of EHRs has led to an increase in time for documentation and decreased time for consulting with patients. It is difficult to find relevant information from the large amount of narrative data when needed (Gong & Guttag, 2018). However, in such cases it provides an opportunity to search and analyse the large amount data provided that the tension between narratives and structured data is addressed (Rosenbloom et al., 2011; Roberts, 2017).

1.3. Research problem

The use of narratives in EHRs has the potential to improve clinical decision-making and ultimately a patient's wellbeing (Cueva et al., 2015). However, it can be argued that the lack of narratives in EHRs could affect the quality of the decision-making process, particularly for chronic non-communicable diseases (NCD) (Mahr, 2015).

The non-usage of narratives in EHRs may result in the misinterpretation of chronic NCD symptoms which, in turn, may result in administering incorrect dosages of medication leading to health deterioration in the patient, and even death (Cognetta-Rieke & Guney, 2014; Johnston, Banner & Fenwick, 2016).

The problem that this research study attempts to address is that even though health narratives have benefits to better grasp the situation of the patient, there are still many challenges in utilising narratives such as time-consuming data capturing; interference with patient interactions; and resulting in medical errors (Balestra, 2017). It is not clear how health professionals use narratives in electronic health records in private oncology care.

1.4. Research aim

The aim of the research was to explore the use of narratives in electronic health records to support the decision-making process by healthcare professionals in private oncology care. The expected outcome is proposed guidelines for considering the incorporation of narratives in an EHR.

1.5. Research questions and objectives

In order to address the problem, one research question was asked and from it, four sub-questions were derived. The objectives and methodology of each question were used to answer the research problem in such a way that the research aim was met. Details are mentioned in Table 1 below:

Table 1: Research question, sub-questions, methodology and objectives

Research Questions	Methodology	Objectives
Research Question: How can narratives be used in electronic health records to support the decision-making process of healthcare professionals?		
SRQ 1: How do the experiences of healthcare professionals while using existing electronic healthcare records influence the outcome of the decision-making process?	Case study using semi-structured questions/ interviews (open-ended questions)	To establish how the experiences of healthcare professionals, with the use of the existing EHRs influence the outcome of their decision-making process
SRQ 2: How can narratives be captured in electronic health records to support the decision-making process?	Case study using semi-structured questions/ interviews (open-ended questions)	To determine how narratives can be incorporated in electronic health records to aid the decision-making process of healthcare professionals in oncology centres.

SRQ 3: What informs the inclusion of narratives in electronic health records to support the decision- making process?	Case study using semi-structured questions/ interviews (open-ended questions)	To establish the requirements of incorporating narratives in electronic health records to support healthcare professionals in decision-making.
SRQ 4: Why are narratives not being used in electronic health records to support the decision-making processes of healthcare professionals?	Case study using semi-structured questions/ interviews (open-ended questions)	To understand the reasons why narratives are yet to be used to support decision-making in oncology care.

1.6. Research Design

A research design is an organised and systematic method of finding answers to an existing problem (Wilson & Creswell, 1996). It includes the processes of collecting, analysing and interpreting data that will be transformed into information (Winship, 2011). Therefore, the research design provides a clear framework that guides the methods and decisions, and sets the terms of interpretation for the researcher. A research design can be shaped as either experimental design, descriptive design, explanatory design and/or exploratory design (Rahi, 2017).

Since this study was aiming to investigate the use of narratives in EHRs to support the decision-making processes of healthcare professionals, an exploratory design was adopted. An exploratory design investigates a problem or situation that has not yet been clearly defined, and it provides insight to the researcher (Gentles & Vilches, 2017). In this case, an exploratory design allowed the researcher to investigate the use of narratives in EHRs to support the decision-making process of healthcare professionals

in oncology care. The research design included a research philosophy which informed the research methods adopted in this study.

1.6.1. Research philosophy

Saunders et al. (2009), define research philosophy as a way a researcher views the world by developing knowledge and determining the nature of that knowledge. Research philosophy enables the researcher to choose an approach, to understand the reason behind the choice and to determine the research strategy and methods of that strategy (Tashakkori & Creswell, 2007). Walsham (1995) listed three categories of philosophy: ontology, epistemology and methodology. These are defined as follows:

Ontology is concerned with how we look at reality, and the assumptions behind that reality.

Epistemology focuses on the origins, nature, methods and limitations of knowledge. It encompasses how the researcher unpacks a reality.

Methodology refers to how the researcher will access what is learned about the reality. It combines methods and procedures to learn about the reality.

This study was guided by ontology, which comes from the Greek words "onto", meaning something that exists, and "logos" signifying logical knowledge. It is a study about what kind of things exist and their nature, vocabulary of terms (how concepts are inter-related) and their specific meaning (Yin, 2012). This process was followed because the researcher is part of the real world and part of the research situation.

Datt (2017) supports Saunders et al. (2009) who emphasises that research philosophy can be further categorised into: pragmatism, positivism, critical realism and interpretivism. In order to investigate the use of narratives in EHRs to support the decision-making processes of healthcare professionals, an interpretivist stance was best suited to this research study. With the interpretivist stance, reality and knowledge are assumed as socially constructed and its outputs are subjective (Goldkuhl, 2012).

This approach sharpened the focus of the study on a specific professional group which permitted in-depth investigation into the use of narratives by healthcare professionals

for decision-making in private oncology care. The focus was on oncologists who suggested that general practitioners and psychiatrists should be involved as they work together.

1.6.2. Research methodology

Research methodology is a collection of methods and techniques that are used to carry out a scientific investigation (Winship, 2011). Research methods are approaches used to facilitate data collection whereas research technics are strategies of enquiry to conduct research (Saunders et al., 2009).

Research methodology includes questionnaires, interviews, focus groups and observations. A research methodology can be based on quantitative, qualitative or mixed approach methods to address the research problem, objective and main research question (Creswell, 2014). The choice of a research methodology will depend on the context and purpose of an investigation (Walsham, 1995).

For this study, a qualitative method was used – it is defined as a method of collecting non-numerical data (Yin, 2012). It was applied to collect nun-numerical data by addressing the below mentioned research objectives:

➢ Objective 1: To establish how the experiences of healthcare professionals while using existing EHRs influence the outcome of their decision-making process
➢ Objective 2: To determine how narratives can be incorporated in electronic healthcare records to aid the decision-making process of healthcare professionals in oncology centres.
➢ Objective 3: To establish the requirements of incorporating narratives in electronic health records to support healthcare professionals in decision-making.
➢ Objective 4: To understand the reasons why narratives are yet to be used to support decision-making in oncology care.

1.6.3. Research approach

There are two research approaches that can be followed during research – inductive and deductive (Saunders et al., 2009). The inductive approach is a method that puts

emphasis on developing a theory using collected data (qualitative data) from participants. The deductive approach, on the other hand, is a reconstruction of theory that already exists to create a new theory.

An inductive approach was adhered to in this study to explore the use of narratives in EHRs to support the decision-making process in private oncology centres of Cape Town. In this study this approach is not intended to develop a new theory but instead to gain insights from the data to answer the research questions.

1.6.4. Research strategy

Yin (2012) defines research strategy as an overall process of how the research questions can be answered. Research strategy entails case studies, experiments, surveys, grounded theory, action research, ethnography and archival research (Saunders et al., 2009).

This study was based on a case study which is defined as a detailed investigation of a specific situation over a determined period of time (Hyatt, Kenny & Dickson-Swift, 2014). A case study can be single or multiple (Edwards, 1998).

Single case study is used when the researcher focuses on an issue or concern and then selects a bounded case to illustrate that particular topic (Dyer & Wilkins, 1991). A bounded case is an issue or problem that is limited to a certain period of time and space – for example, the use of narrative in EHRs for decision-making in oncology at Netcare UCT Private Academic Hospital from July to August.

Multiple case study is used when the researcher firstly focuses on an issue or concern and then selects several bounded cases to illustrate that selected topic (Yin, 2003) – for example, the use of narratives in EHRs for decision-making in oncology at Netcare UCT Private Academic Hospital, Panorama Oncology Centre and Rondebosch Medical Centre from July to August.

Intrinsic case study is used when the researcher studies the case itself focusing on an issue or concern. It is about the case itself especially when it is unique or unusual (Yin, 2003) – for example, the use of narratives in EHRs for decision-making in oncology.

This study adopted a multiple case study because the researcher focused on the issue of using narratives in EHRs in different private oncology centres, and then selected bounded theories illustrating that issue. This enabled the researcher to understand similarities and differences that led to a deeper interpretation of the research problem. The case study looked at research questions presented in Section 1.5.

1.6.5. Data collection

Data collection involves sampling – the process of receiving research participants' points of view over a certain period of time (Sutton & Austin, 2015). Gornall (2013) mentioned that there are five methods of conducting research: surveys, experiments, secondary data studies, observations and interviews.

This study used the interview method which assisted in gathering necessary and valuable information needed for the investigation. An interview is a decided discussion between two or more people (Sutton & Austin, 2015). There are two types of interviews namely semi-structured and structured interviews.

This study used semi-structured interviews as a tool to collect data. This is defined as an open-ended conversation seeking to understand the meaning of what the interviewee is saying (Taylor, DeVault & Bogdan, 2015). Interview questions were open-ended and allowed participants to express their opinions freely (Jamshed, 2014). Using open-ended questions in this study provided detailed information that answered the research problem in Section 1.3.

1.6.6. Sampling

A sample is a smaller group of a population that represents a larger population (Gentles & Vilches, 2017). A sample procedure is categorised into probability and non-probability sampling. This study will apply non-probability sampling which is where some elements have no chance of being selected, and is therefore subjective (Omair, 2014).

Non-probability sampling is categorised into: purposive, quota, snowball and convenience sampling (Omair, 2014). A purposive sampling method was applied in this study. This is where a subset of a population is selected.

Purposive sampling was adopted to identify the sample size – participants in relation to the objectives of the study, which were:

- To understand how the experiences of healthcare professionals while using existing EHRs influence the outcome of their decision-making process.
- To determine how electronic narratives can be incorporated in healthcare records to aid the decision-making process of healthcare professionals in oncology centres.
- To establish the requirements of incorporating electronic narratives in electronic health records to support healthcare professionals in decision-making.
- To understand the reasons why narratives are yet to be used to support decision-making in oncology care.

Purposive sampling is a sampling technique in which the researcher relies on her own judgements when choosing members of a population to participate in a study. Therefore, in this study, participants were deliberately chosen – the researcher selected profiles that fit the study. It was effective in exploring the use of narratives in EHRs to support the decision-making process in oncology care.

A unit of analysis is the key object/entity that is being examined in a study (Suresh, Suresh & Thomas, 2011). This study focused on three private hospitals in Cape Town as the unit of analysis for each case. These hospitals were chosen due to their high use of technology (Singh & Senthil, 2015). They were close to the researcher in proximity and received positive reviews on cancer care.

Every participant in the unit of analysis is known as a unit of observation, because it is from them that data is collected. This study engaged a maximum of ten oncologists, three psychiatrists and five general practitioners which amounts to a total of eighteen participants at which stage the researcher was able to meet a point of saturation.

1.7. Data analysis

Data analysis is a procedure of converting data collected (voice, text, images) into useful information (Sutton & Austin, 2015). The purpose of analysing data is to evaluate,

interpret and convert qualitative data collected into valuable information that responds to the research objective of a study.

Qualitative data analysis tries to understand the significance of data collected from people – it is not about statistical procedures or quantifying data (Taylor, DeVault & Bogdan, 2015). The three steps that were followed to analyse the collected data are:

- Prepare and organise data: Interview notes or records are transcribed and all notes are made available.

- Reduce data into themes: Identify data elements and create categories.

- Present data in a narrative or graphic form: Tables or visual diagrams are used.

Interview questions used five key words from the research study namely private oncology care, healthcare professionals, electronic health records (EHRs), decision-making and electronic narratives.

From the multiple case study, the researcher analysed the case and created themes from the collected data in each case. Common themes from all of the cases were then determined, and the findings were reported.

The unit of analysis for the study is the individual, in this case the doctor, providing a care service to cancer patients. The unit of observation is how the doctor uses the EHRs and narratives as part of a cancer care service in private hospitals. The study therefore focuses on the use of the EHRs from a doctor's perspective and not from a patient perspective.

1.7.1. Thematic analysis

Thematic analysis is a qualitative research method used to analyse, identify, organise, describe and report on themes found in collected data (Aronson, 1995). During the process of thematic analysis, interpreted data is converted into significant information addressing the research questions (Datt, 2017).

The data that was analysed in this study addresses the research questions in Section 1. 5, and it assisted the researcher to reach the aim of the research discussed in Section 1.4.

The following steps were followed in accordance with thematic analysis: Data was coded, in other words, collected data was categorised and subsequently clustered into smaller, more manageable groups. Themes, patterns and relationships began to form and, from this, patterns emerged – similarities and differences from smaller groups were found and data was differentiated from each group. Themes were labelled accordingly, and category systems were developed. A potential overlap and/or redundancy of data was avoided by looking for emerging patterns in data. Lastly, data was summarised and a written report compiled.

1.8. Ethical Considerations

Ethical considerations in research are crucial. The researcher is bound by a code of conduct to uphold the dignity, rights and safety of each participant. No harm should befall participants and the environment as result of partaking in the research study (Rossi et al., 2009). Honesty about reporting of findings is essential.

No patient participated in the research and their personal information was not needed nor collected. Information collected from oncologists did not disclose their private information.

The aim and objectives of the research were presented to participants, and they had a choice to voluntarily participate and to withdraw at any time without repercussion. The researcher presented consent forms to the hospitals' management to allow the study to take place. A consent letter was signed by each participant which granted permission for the collected data to be disseminated as specified.

To ensure anonymity and confidentiality, participants' information was not revealed. All the important documents were secured using passwords and finger prints, and these were kept in a safe place. Documents were only accessed by authorised people such as supervisors.

In collecting data, the researcher ensured integrity by preparing for interviews and meticulously allowing time for each question. Furthermore, the researcher was careful and conscious in the process of collecting data. Intellectual property was respected through thorough referencing, and confidentiality of participants was honored.

Ethics clearance was granted by the ethics committee of the university and permission to collect the data from the health facilities participating in the study. Please refer to Appendix C for the relevant documents.

1.9. Delineation, budget and timeline

1.9.1. Delineation and limitations

This research explores the use of narratives in EHRs to support decision-making processes of healthcare professionals in private oncology centres. Oncology was chosen since it deals with patients over time during their cancer treatment and the nature of oncology lends itself to the inclusion of narratives in health records.

The research was carried out in Cape Town, South Africa and was limited to private oncology centres where participants were oncologists and healthcare professionals. The research was limited to private oncology centres due to their access to technology and the availability thereof. The researcher used primary (interviews) and secondary (journals, books and previous research materials) methods to collect data. No patient participated in this study and no patient information was collected.

1.9.2. Budget

The project budget indicates the costs associated with the research project (Newton, 2005). The budget included the cost the researcher had to incur in moving from one hospital to the next in order to collect data. The budget, however, did not only account for transport but also for hiring a recorder needed to document and save interviews.

Activities	Cost	Total
Data collection and hiring recorder.	R 3000	R3000

1.10. Outcomes, contribution and significance of research

This research will contribute to an existing body of knowledge by providing guidelines on how electronic narratives can be used in EHRs by healthcare professionals to support their decision-making processes. The findings of this study address the impact of the experiences of healthcare professionals while using existing EHRs for decision-

making processes, particularly in oncology. It also focuses on the requirements of integrating narratives in electronic health records to support healthcare professionals in decision-making. Furthermore, this research proposes a conceptual framework towards the use of narratives in EHRs by healthcare professionals for diagnosis and progressive treatment of cancer.

1.11. Conclusion

The use of narratives in EHRs is still a challenging component in healthcare. In Chapter 1, the researcher presents an overview of the research problem, questions, objectives and methodology to support the research aim. The research aim was to explore the use of narratives in electronic health records to assist the decision-making processes by healthcare professionals in private oncology care.

In Chapter 2, the literature behind the research problem is presented. It identifies arguments from different authors, and discusses their opinions on the matter.

In Chapter 3, detailed literature about the research design is discussed. It includes the research philosophy, approach and strategy, data collection techniques and data analysis introduction.

In Chapter 4, collected data from the cases used in this research are explored and analysed, and findings are explained.

Chapter 5 follows an in-depth discussion on the themes that were formulated in Chapter 4 and the associated relevant literature.

Chapter 6 provides a conclusion to the study, and recommendations for further research and contributions to the field.

CHAPTER TWO – LITERATURE REVIEW

2.1. Introduction

The purpose of a literature review is to establish relevant and current knowledge that includes applicable findings, hypothetical frameworks and practical contributions to support a specific topic (Baker, 2016). This section discusses health records, electronic health records and the use of narratives to support decision-making in healthcare delivery.

2.2. Health records

According to Jamoom et al. (2012), paper-based records were introduced in healthcare in the 1960s. These paper-based healthcare records were handwritten summaries of patients' information about their illness which were kept in physical folders. The authors indicated that communication between healthcare professionals and patients was done manually. In other words, when a patient visited the hospital, the healthcare professional had to go through a tedious search for the patient's folder before starting the communication process that would lead to a diagnosis – all of which was written on paper. Since folders were kept in physical storage, it was time-consuming to find patients' records, and folders would often go missing largely due to human errors.

Figure 1: An example of paper- based records in physical store room (Jamoom et al., 2012).

Due to the laborious process of writing and manually retrieving paper-based healthcare records, there was a need for electronic health records (EHRs) to overcome the shortcomings of the paper-based system (Palabindala, Pamarthy & Jonnalagadda, 2016). Further issues such as information loss, illegibility of written information and cumbersome paper storage adversely affected the process of healthcare delivery.

In 1972, Regenstrief Institute developed the first electronic health records to redress the shortcomings of paper-based records. Unfortunately, the innovation lacked buy-in and support from healthcare professionals due to the high costs associated with electronic recordkeeping (McDonald, 1997). However, governmental hospitals were able to implement these EHRs in some of their public facilities. Subsequently, in the late 1990s, EHRs were beginning to be perceived differently due to the emergence of the internet, and the gradual affordability of personal computers (Roehrs et al., 2017).

2.3. Electronic health records (EHRs)

Healthcare services have been greatly impacted by the advancement of technology (Evans, 2016; Ford et al., 2016; Sittig, Belmont & Singh, 2018). Paper health records started being documented digitally and were being shared within and across several medical network services such as hospitals, health insurance, government departments and ministries of health (Linder, Schnipper & Middleton, 2012). Digital records enabled easier access to and retrieval of patient information, improved legibility and the reduction of data loss through electronic backups (Yanamadala et al., 2016). These digital records were known as electronic health records. Electronic health records are health information of a patient that is digitally created, stored, managed and shared by authorised healthcare professionals and staff across more than one healthcare system (Roberts, Elaine & Deter, 1999). EHRs reflect the entire health history of an individual including data from various healthcare settings (Boonstra, Versluis & Vos, 2014).

According to Jamoom et al. (2012), EHRs are adopted depending on the needs of healthcare services and their capacity to introduce technology. The authors added that initiating the EHRs involves different approaches such as preparing the new system,

ensuring privacy and security compliance, designing practice work processes, training healthcare professionals and managing the adoption process.

Electronic health records contain information such as laboratory test results, images from radiology, allergy information and warnings, dates and schedules of patients' immunisations, medications relevant to the patient, diagnoses of the patient, patient's medical records, vital sign readings, progress notes and patient demographics as well as billing and administrative data (Ohno-Machado, 2014). The information stored in EHRs assists healthcare professionals in their decision-making process and can be used for future reference (Devkota & Devkota, 2014).

Most healthcare services that use EHRs have seen the benefits thereof, especially easy communication amongst healthcare professionals, and between healthcare professionals and patients (Ajami & ArabChadegani, 2013). This seamless exchange facilitates data sharing, and reduces cumbersome procedures of transmitting information. It also protects against data loss. Furthermore, the use of EHRs have alleviated healthcare expenses by reducing the use of paper and physical storage since all information is collected and kept digitally (Kruse et al., 2017). Ultimately, EHRs provide easy accessibility to patient information for healthcare professionals in order to enhance their decision-making and to empower patients' self-management to improve overall efficiency, productivity and quality of care. In terms of improving interaction and communication, Linder, Schnipper and Middleton (2012) and Embi et al. (2013) claim that the use of EHRs has resulted in an increase in verbal communication between healthcare professionals, peers and patients. In this vein, EHRs facilitate communication between healthcare professionals, and this improves team work coordination of patient care (Zeng-Treitler et al., 2016). Work coordination in healthcare is the process of handling patient care activities amongst organised groups of healthcare professionals or healthcare facilities with the aim of delivering appropriate healthcare services (Allen, 2018). EHRs assist healthcare professionals in gathering detailed information that includes narratives, physicians' notes, observations and partially structured narrative information for integration and re-use (Liu, Weng & Yu, 2012).

Unfortunately, not all EHRs are identical. Some EHRs do not allow for X-ray results (pictures) to be captured and stored, and a library for medication is not always available. This complicates the decision-making process of healthcare professionals as they have to revert back to paper records and manual processes for certain information (Wu & LaRue, 2017). According to Gesulga et al. (2017), EHRs may experience shortcomings. This includes a delay in the system; for example, when a healthcare professional is in search of x-ray results, the query might take longer due to picture loading. This could be detrimental in the case of an emergency or during time-sensitive clinical procedures.

Furthermore, when healthcare records are presented in different formats (tables, numbers, letters and pictures), data entry may be slow, time-consuming and demanding in terms of effort (Gesulga et al., 2017). The lack of adequate security and storage of data also presents challenges to EHRs (Ajami & ArabChadegani, 2013). It is vital that patient information is protected due to its sensitive and confidential nature. Hence, EHRs require superior information and system security measures.

Wu and LaRue (2017) emphasise that despite concentrated efforts, the implementation of EHRs to support healthcare service delivery can be complex. Recurring issues such as high cost of implementation, security and privacy vulnerabilities, legal barriers to information technology adoption, lack of appropriate policies and regulation, and the absence of data standards still make it difficult to optimally benefit from EHRs. However, despite these shortcomings, EHRs have the potential to enhance the interaction between healthcare professionals and patients which could improve the overall quality of healthcare. EHRs furthermore assist healthcare professionals in understanding their patients' diagnosis and treatment journeys, especially through the integration of narratives in EHRs.

2.4. Integration of narratives in electronic health records

In 1998, the term "narrative" was initiated by European healthcare centres (Kalitzkus, 2009). This introduction added value to EHRs since previously only structured data could be captured, and healthcare professionals' direct collection of patients' data was not facilitated. Structured data refers to information recorded in EHRs that asks the same questions in the same format to every patient repeatedly (Abhyankar et al., 2014).

Narratives have the potential to capture information directly from patients by allowing freedom of expression and immediate feedback which supports the reuse of information and easy communication (Johnson et al., 2008). In turn, the reuse of information and seamless communication assists the decision-making process which directly impacts health service delivery.

In 1999, narrative was developed as a medical approach by Rita Charon and Rachel Naomi Remem (Rosti, 2017). These narratives were handwritten patient stories that were physically stored in a room and thus did not guarantee patient information security or confidentiality. Securing patient information is at the core of healthcare, and the use of EHRs offers a platform that protects patient narratives (Linder, Schnipper & Middleton, 2012). Narratives have increasingly found greater popularity. From 2001 to 2005, handwritten narratives were being converted to electronic format using advanced technology (Finn, 2015). This is referred to as electronic narratives which are the digital versions of patients' stories recorded in video, audio and images into EHRs (Liu, Weng & Yu, 2012). The authors added that integrating narratives in EHRs has requirements and specific guidelines to follow.

2.4.1. Requirements of integrating narrative into EHRs

Incorporating narrative into EHRs require information technology support that will allow healthcare professionals to be equipped with tablet computers in order to access EHRs (Evans, 2016). These tablet computers have functionalities that can record images, audios and videos about the patient's health journey and their care at the hospital (Tekiner, 2017). When recording patient narrative using tablet computers, healthcare professionals have to explain why they find the patient's story relevant and how it could benefit them and other patients. Asking the patient to fill out a consent form before starting the recording process is a fundamental requirement.

Blijleven et al. (2017) recommend that recorded information is automatically saved onto the tablet allowing for information to be edited or modified at a later stage if the patient requests so. For security purposes, healthcare professionals can upload the recorded patient narrative to a secured server and delete it off the tablet to ensure patient privacy. In this vein, when using EHRs to share patient narratives among other healthcare

professionals and facilities, only patients' first names and/or diagnostic images should be used. Healthcare facilities need reliable internet connections to ease the process of recording, saving and sharing patient narratives using EHRs (Tekiner, 2017), and healthcare professionals need to be trained to work with patients' narrative effectively.

Warner et al. (2016) indicated that although electronic narratives present positive results to support healthcare service delivery, its integration can be challenging. Issues such as trust, time-consuming recording, and legalities still make it difficult for healthcare facilities to benefit from EHRs. Birkhäuer et al. (2017) noted that changing healthcare professionals interrupts patient treatment and the communication process which may, in turn, affect the patient's emotions, and result in the loss of trust. Furthermore, the entire process of collecting narratives - engaging with the patient, signing legal documents, writing and recording into EHRs - is time-consuming. In terms of legalities, there are rules, regulations and other jurisdictions every healthcare facility needs to abide to, and patients must reserve the rights to allow or disallow the process of electronically recording narratives.

According to Hua et al. (2011) and Warner et al. (2016), incorporating narratives in EHRs is considerably more tedious and cumbersome than recording traditional narratives (transcribed notes). Yet, the addition of electronic narratives to healthcare professionals' decision-making process diminishes the likelihood of administering incorrect dosages of medication potentially harmful to the patient (Johnston, Banner & Fenwick, 2016).

2.4.2. Steps of integrating narratives in EHRs

According to the American Health Association (2015) there are nine steps to follow when integrating narratives in EHRs. These phases are:

Create an implementation team: Clinical members (physicians, nurses, medical assistants and administration staff) play a crucial role in implementing new technology. Clinical members also have the ability to teach EHRs skills to colleagues, and present daily challenges to the implementation team.

Configure the software: The healthcare information technology team needs to closely cooperate with the health information technology vendor for the configuration of narratives in EHRs in order to meet appropriate security measures. Configuring software involves protecting computers and network systems, and customising software to optimise workflow. To customise EHR software, external elements need to be constructed and designed such as demographics, treatment protocols, computerised order entry (COE), patient' history settings, encoded billing systems, consent forms, standing orders and medication management settings. The modification of software can be done according to the specifications of healthcare professionals to support narratives and documentation.

Identify hardware needs: Timeous understanding of hardware requirements can save healthcare professionals' time and money. For instance, instead of logging onto the system several times a day, each healthcare professional can access the system using the laptop or tablet they carry with them. It is advisable to employ an information technology service company to assist with the system hardware.

Transfer data: It is crucial that a checklist of items entered into the new EHR system is prepared. Furthermore, the approach for migrating data from the former EHR to the new one should consider the amount of time required to transfer information.

Optimise pre-launch workflows: Healthcare professionals need to clarify optimum workflow procedures before implementing a new EHR – This will avoid inefficient workflows and insufficient staff support. Each step of the implementation should consider whether the step is necessary and whether it adds value to the patient.

Consider the room layout: The design and configuration of the exam room can impact patient care. It is therefore advisable that a semi-circular desk is used – one that allows the healthcare professional and patient to face each other. This creates the "triangle of trust"; – a virtual triangle between the healthcare professional, patient and computer facilitating communication.

Decide on the launch approach: Commencing the project can either be done in a "big bang" approach or, alternatively, on an incremental basis. With the big bang approach,

all users directly switch to the new EHRs on the same day, and transfer all the functions and patient information to the system. This approach minimises the time and cost of managing two systems simultaneously, but it can be highly disruptive when small malfunctions occur. The incremental approach allows for the implementation to be done in a stepwise manner – activating certain functionalities step-by-step, department-by-department, and rolling out slowly to the rest of the clinic.

Develop procedures: for when the EHRs has malfunctions or experience technical issues. Procedures need to be developed to equip healthcare professionals with the necessary knowledge and skills to deal with system challenges. Training should be done on an ongoing basis.

Research done by Pérez et al. (2013) indicates that electronic narratives have been emerging in healthcare as an effective strategy to collect important patient information. Implementing an electronic narrative approach provides a convenient way of giving and receiving information that helps to understand the patient – in contrast with the non-narrative approach. The non-narrative approach consists of patient details and information included in EHRs without adding the patient's personal story. The incorporation of narratives into EHRs has led to the improvement of patient care, enhanced communication within medical network services and thorough decision-making processes (Johnson et al., 2008; Huang et al., 2017). In other words, despite evident deficiencies, narratives in EHRs have the ability to improve how healthcare professionals implement patient care and decision-making processes. Especially in high income countries, this trend has been observed.

2.5. Use of narratives in EHRs for high income countries

In countries with advanced and developed economies such as the UK, USA, Australia and Italy, narratives in EHRs are being used in oncology, and they have proven to be beneficial (Polvani et al., 2014). Electronic narratives improve clarity in decision-making by promoting problem-solving and encouraging self-reflection. It also allows for greater creativity in processing patients' narratives in audio and video format (Begley et al., 2014).

Narratives were introduced in healthcare to counteract the shortcomings of evidence-based medicine (Kalitzkus, 2009). As result, narratives are changing the perspective of healthcare. Traditionally, healthcare professionals' narratives were dominant in producing scientific reports, but today, the focus is increasingly on patients' narrative and the communication aspect between the healthcare professional and the patient (Begley et al., 2014). This is in line with the focus changing to patient-centered care as opposed to an illness-focused model.

Electronic narratives were implemented in oncology as a way to begin conversation and increase cancer awareness (Rosti, 2017). McCartney (2015) investigated "the power of patients' stories" which shows narrative to be a powerful health-messaging tool that assists patients in talking about their sickness. The findings indicate that stories in healthcare are often rich in motivation and inspiration. In fact, narratives in healthcare are the start of conversations between healthcare professionals and patients, and it draws inspiration when used for decision-making purposes. In decision-making, healthcare professionals engage patients' narratives to increase reflection which has a positive impact on the treatment and service outcome. In other words, when patients' stories are valued, healthcare professionals tend to provide improved patient treatment which results in higher self-satisfaction.

Greenhalgh (1999: 323–325) profoundly remarked that *"narratives explain why and how the patient is ill, and how he/she should be treated".* In other words, narratives provide healthcare professionals with the ability to discover the context of a patient's illness – contrary to non-narratives that do not (Charon, 2012). In fact, the non-narrative approach in healthcare does not consider a patient's emotions, thoughts, feelings and/or experiences, but instead solely focuses on obtaining scientific results (Murphy et al., 2013).

Patients' stories open up difficult conversations, especially for cancer patients, and these personal accounts make healthcare professionals more aware and understanding of complicated health messages (Cueva et al., 2015). Healthcare professionals frequently use narrative information to document the different stages of a patient's illness and/or recovery in order to carry out further clinical action (Hall & Powell, 2011;

Rosenbloom et al., 2011; Collins et al., 2013 & Embi et al., 2013). Therefore, narrative-based medicine and evidence-based medicine (scientifically proven) should be complementary (Fioretti et al., 2016).

Narrative in healthcare is characterised with realism, likeability, homophily, empathy and cultural appropriateness (Cueva et al., 2015). Consequently, electronic narratives from people within a community bring inspiration, and they stimulate an interest to learn more, to promote health, and to encourage others by sharing narratives through social media platforms such as Facebook, WhatsApp, and YouTube.

The role that cultural ethics play is a fundamental aspect to consider when creating and sharing narratives. When a healthcare professional records an audio or video narrative of a patient, ethical concerns need to be addressed and complied with to avoid misquotation. Different cultures have different values that must be protected and respected whenever patient information is involved (Russo et al., 2016).

2.6. Narratives in clinical decision-making support system

Most healthcare facilities have implemented clinical decision support systems. These health information technology systems are typically designed to provide healthcare professionals with clinical decision support assisting with decision-making tasks relevant to patient care (Higgs et al., 2018). It is proven that the decision support system can strengthen steps in the patient's journey, from sickness detection and diagnosis to the treatment and after care. This functionality allows the system to be based on evidence and best practice.

According to Higgs et al. (2018), there are two powerful components in the decision support system. Firstly, decision support systems can actively encourage evidence-based decision-making at every stage by recording all the information in the patient' EHRs. Secondly, it can flexibly coordinate the clinical work flow, even when this is distributed across many healthcare facilities, corporate services and independent care providers.

Palabindala, Pamarthy and Jonnalagadda (2016) state that when patients' information such as narratives and pictures from medical tests are stored digitally in EHRs, they can

be reviewed by any authorised person in the patient's care. When healthcare professionals start examining and managing the information in the patient EHR, the system automatically detects possible abnormalities and suggests next steps. The functionality of the system screens patients' results, and starts selecting the most suitable treatment by displaying the advantages and disadvantages associated with each (Devkota & Devkota, 2014). The healthcare professional can then select the most appropriate treatment, and this will automatically be saved in the patient's EHRs, and discussed with the patient. During this process, the healthcare professional will inform the patient of the reason for choosing a specific treatment, and the patient will be given enough information to make their own informed decisions. Decision support systems help summarise relevant patient information, and keep track of the recommended and followed treatment schedule (Ohno-Machado, 2014). The system is useful in recording medical decisions for clinical audit and ethical legal purposes. Narratives in EHRs also assist patients in recording their experiences wherever they are, and they enable healthcare providers to access these remotely (Charon, 2012). Furthermore, the cancer patient can access other patients' narratives in the system to monitor and motivate their own progress.

Promoting active listening is at the core of health narratives as it helps build empathy and a better relationship with the patient, which, in turn, contributes to quality care (Huang et al., 2017). According to Charon (2013), including patients' narratives in healthcare underscores the importance of allowing patients to share their stories. Cancer patients are often fragile, and sharing the personal accounts of their illness requires trust and rapport with the healthcare professional (Bates, Mostel & Hesdorffer, 2017). In the USA, for example, in certain breast oncology centres, the patients are given a private room to write or record their own personal cancer journey. This is then incorporated into the electronic health records. This method assists healthcare professionals in understanding what is important to the patients in order to make appropriate decisions (Pérez, 2013).

Using narrative in EHRs has predominantly been a positive experience for healthcare professionals and patients (Charon, 2012). Unfortunately, its adoption still faces resistance due to the high cost of implementation and maintenance. The required consent from patients has also often proven to be affected by distrust, time consumption

and limited understanding of its incorporation into an EHR system (Morris, 2008; Adams, Robert & Maben, 2015; Palabindala, Pamarthy & Jonnalagadda, 2016). These issues remain at the root of non- adoption in the case of low and middle income countries (Rosti, 2017).

2.7. Narratives in EHRs for low- and middle- income countries

In South Africa, reported cancer cases could increase by as much as 78% by 2030 (Health24, 2017). Cancer patients face depression, fear and rejection when there is no one to share their stories with (Begley et al., 2014). These feelings of despondence and despair are heightened when healthcare professionals do not pay enough attention to emotional and psychological symptoms from patient stories or narratives (Cueva et al., 2015). A shortage of healthcare professionals, cultural issues (ancestral rules, religion and beliefs), fear of change, funding challenges, and the lack of security and privacy are aspects that affect oncology care in South Africa (Li, 2014).

Information and communication technology (ICT) tools are being recognised as drivers to achieve sustainable development goals towards quality health and well-being (Rouleau, Gagnon & Côté, 2015). Acknowledging this trend in healthcare, this study seeks to explore the use of narratives in EHRs to support decision-making process of healthcare professionals' private oncology care in Cape Town.

Katurura and Cilliers (2018) investigated the "electronic health record system in the public health care sector of South Africa" which supports the importance of EHRs in healthcare. EHRs improve accessibility to patients' records, it tracks patient records, and ease the backup of records. The findings of said study show that most public healthcare sectors face barriers such as lack of infrastructure, political influence or strategy, regulations and legislation, and increased cost that obstruct the implementation of EHRs in most healthcare facilities. These barriers critically impact the adoption of EHRs and healthcare service delivery.

Edwards and Greeff (2017) explored grassroots feedback about cancer challenges in South Africa by discussing themes derived from the analysis of 316 photo-narratives. The study discusses cancer challenges, and suggests recommendations for the

improvement of cancer control strategies. The findings show that 92% of cancer patients indicate emotional challenges (stress, fear, anxiety, depression), treatment challenges (diagnosis and treatment delays), and challenges related to a lack of patient-centred care. Several of these challenges experienced by patients were not captured in handwritten notes. In not recording these challenges, it could ultimately lead to the oversight of relevant information, and it could result into poor decision-making and negligent patient care.

The authors suggest that healthcare should be patient-centred, and patient stories should be valued and incorporated. The use of written narratives is present in oncology care of South Africa but only limited to the diagnosis phase (Edwards & Greeff, 2017). Limiting narratives to the diagnosis stage in oncology only helps to discover what the patient suffers from in order to prescribe scientific medicine – it does not cater for ongoing care.

There are hardware requirements needed to incorporate patients' narratives in EHRs such as tablet computers and software. These are fundamental to the implementation of EHRs and allow the healthcare professionals to capture patients' narrative and automatically save it in the patient EHRs. As the patient visits the healthcare facility, narratives are continuously updated. This eases the decision-making process as the summary of the patient narrative is available and digitally displayed. To successfully achieve the implementation of EHRs, the organisational structure of the healthcare facility must be considered. An organisational structure consists of people, process and technology.
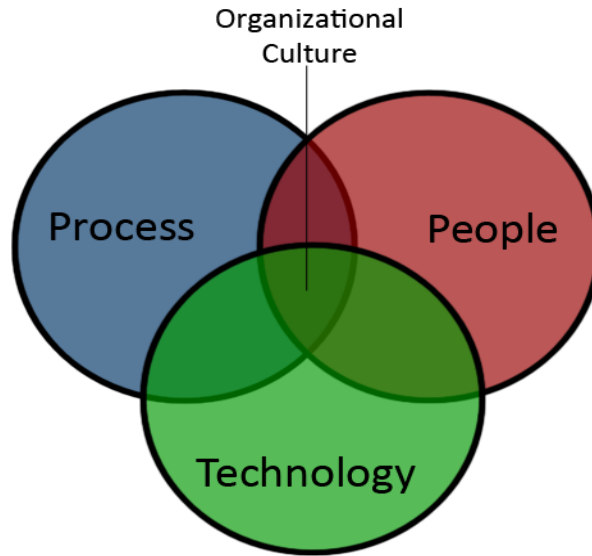
Figure 2: Organisational structure, the centre of implementing new technology

(Braithwaite et al., 2017)

Organisational culture is a combination of beliefs, assumptions, values and methods of communication (Braithwaite et al., 2017). The purpose of implementing new technologies in healthcare is to improve health system efficiency, equity and effectiveness (Mbau & Gilson, 2018). Organisational culture influences the social environment, service outcome and organisational practices such as management style, communication, commitment and participation in decision making. All these must be reviewed to avoid users experiencing problems when using the EHRs after implementation. Erasmus et al. (2017) indicated that to implement new technologies in healthcare, organisational culture and trust are critical. In fact, trust is always at the core of communication in healthcare – when there is no trust, it is impossible for patients to commit to their treatment journey with healthcare professionals (Birkhäuer et al., 2017).

The use of electronic narratives in health records is still at its infancy in South African oncology centres. In fact, literature on the topic is scarce (Edwards & Greeff, 2017). This situation does not only apply to South Africa but also to Yemen in the Middle-East (Mohammed & Mehmood, 2018).

2.8. Types of narratives, collection methods and tools

According to Kalitzkus (2009), there are four types of narratives that are present in healthcare: Physician narratives, healthcare professionals and patient encounter narratives, patients' narratives, and meta-narratives.

In 1970, physicians' narratives were highly respected, and viewed by their superiors before handling a patient. Healthcare professionals' narratives included their own personal biographies – their education levels, their life as physicians and their experience in caring for the sick (Kalitzkus, 2009). Personal healthcare professionals' narrative allowed readers or writers to fully enter the patient's reality and experiences by recognising, describing, and integrating similarities in both narratives; healthcare professional' and patient's (Charon, 2013).

Subsequently, narratives about healthcare professional and patient encounters surfaced. These are narratives about the patient's health or illness as interpreted by healthcare professionals (Kalitzkus, 2009). Healthcare professional and patient encounters are unavoidable in healthcare, and these interactions impact patients' narratives about what they are experiencing. These narratives are indicative of the degree of influence healthcare professionals have in creating the patient's story. These narratives contribute to the patient's treatment and the healthcare professional's personal growth (Charon, 2012).

Since 2000, the focus of narratives started shifting from healthcare professionals' narratives to patient narratives (Aronson, 2000). These narratives are known as patient stories or classic illness narratives (Kalitzkus, 2009). Narratives allow healthcare professionals to make sense of patients' accounts of their suffering and feelings. Patient stories contain biographic and social information about the patient's journey with their illness. Behind every patient's narrative there are grand narratives, also known as meta-narratives, which are sociocultural understandings of a person's health or illness (Kalitzkus, 2009). These narratives impact healthcare professionals' and patients' views of illness because culture and belief significantly influence a patient's illness or health stories (Erasmus et al., 2017). Narratives can be presented in a written, audio or video format.

2.8.1. Written Narratives

Capturing patients' narratives can be done using different methods, one of which is the written note – this is a traditional method that is handwritten but can also be typed or scanned electronically (Thompson & Kreuter, 2014). These notes are collected from questions (about the roots of the sickness) that patients answer on their first encounter with a healthcare professional. Notes taken are often not fully utilised in the decision-making process as they are easily lost or discarded. In the study of Chesi (2018) **"*Tools in narrative medicine*"**, narrative tools are provided to aid communication between healthcare professionals and patients. The findings reveal that these tools are used to extract important narratives from patients and, when properly used, they contribute to crucial decision-making.

Examples of such narratives are:

- Free drawings: These are drawings done on paper that usually help patients share their difficult experiences that they cannot express or write.

- Free narratives on paper: This is unstructured handwritten narrative that helps patients divulge their past or recent emotions and thoughts.

An example of this is a patient disclosing the following to a healthcare professional: "I woke up this morning feeling dizzy and I had stomachache. Then my parents had to give me some pills and after some minutes I threw up and here I am, still feeling uncomfortable".

Using written notes, the doctor will consider what is necessary to aid the patient scientifically (giving medication) without addressing the patient's emotional state (therapeutic condition) (McCartney, 2015). Healthcare professionals should be patient-centered, and extracting value from patient narratives is a necessary step to promoting patient health and better communication. Hence, healthcare practitioners should not only focus on facts, but also on patients' narratives (health stories) that produce facts (Morrise, 2013).

2.8.2. Audio Narratives

This format entails a voice recording of the patient's story about their illness, and it captures the emotions associated with the patient's experiences (Adams, Robert & Maben, 2015). This format provides insight through the various stages of treatment as it can be played repeatedly to extract relevant information that will aid in decision-making and kept for future use. Audio narratives keep patients' stories alive but they can sometimes be boring and time-consuming when having to listen to a long recording played over and over for certain pieces of meaningful information. In audio narratives, we find the below techniques of collecting narrative:

- Oral interview: A structured set of questions are designed to help the patient share their experiences by openly answering them.

- Focus group: Structured and semi- structured interviews designed for a specific group of patients to help them share their stories and relate to similar experiences.

- Forum: An organised platform designed for patients to meet and share their experiences. The patient openly and freely discusses their illness and decides when to start and when to stop the conversation.

This type of narrative can be used as legal proof in the event of a misunderstanding in the treatment process between the healthcare professional and the patient.

2.8.3. Video Narratives

Patient narrative can be collected in video format which visually records the patient's story (Briant et al., 2016). These narratives are often used to help other patients cope with their own health struggles in showing them personal accounts of survival which may give them hope and strength.

Examples of such narratives are:

- Social impulsive writing: Patients share their experiences on social media. Once shared, these narratives can be accessed immediately. This is often impulsive and driven by emotion.

- Reflective writing on paper: This is used as an exercise for reflecting on one's experience by writing about it. This exercise can also be done digitally.

- Photo: Pictures and images can be used to help patients share narratives, feelings and experiences. These narratives work as a therapy session for other patients, especially those who cannot afford it but who can be reached through media using their mobile handsets. Photos also allow the patient's family and friends to share his/her experience of their health journey.

These types of narratives are applied in the process of decision-making which may, if used correctly, contribute to a positive patient care outcome (Bramley & Matiti, 2014).

Thompson and Kreuter (2014) highlight that self-expressive narratives have insightful effects on patients' physical and emotional health. In today's digital environment, initiatives to create electronic patient narratives are allowing healthcare professionals to collate and view the past, current and future health of a patient.

It is recommended that healthcare professionals consider using these tools as a way of gaining and building patient trust, and to garner a deep understanding of patients' experiences. Narrative tools are fundamentally practical and they positively impact the healthcare service outcome in terms of communication between healthcare professionals and patients.

2.9. Use cases of electronic narratives communication in healthcare

2.9.1. Communication between healthcare professionals and patients in oncology

Electronic narratives from patients help healthcare professionals keep track of their patients' past experiences in order to effectively continue treatment (Cognetta-Rieke & Guney, 2014). These narratives can be used for future reference and can be accessed at any time. The easy accessibility of these narratives positively affect not only healthcare professionals, but the patient's family and broader healthcare network as well. Hence, patients' narratives, accumulated through their illness journey, remain real-time material to both healthcare professionals and patients (Hurwitz & Charon, 2013). Furthermore, electronic narratives strengthen communication between healthcare

professionals and patients, and this builds trust (Frank et al., 2014). Electronic narratives in oncology care give directives to healthcare professionals on how the patient would like to be approached and treated which enhance communication.

Similarly, stories of cancer survivors are advantageous as it draws encouragement and support from other cancer survivors. Electronic narratives about cancer can achieve what hours of medical lectures and internet browsing cannot by helping patients and loved ones overcome fear, uncertainty, threat and loss by encouraging hope and love (Frank et al., 2014). Patients' narratives that are posted on social networking sites often create a much needed connection between patients, assisting them in making sense of their own health experiences (Thompson, 2017). This interaction proves beneficial during times of crisis or joy, and have real health benefits like empowerment, inspiration, support and hope.

Audi and video recordings that speak to the journey of cancer survivors' help improve other patients' value of life, and observance to follow-up on healthcare (Pérez et al., 2013). Audios and videos provide motivation and support from verifiable sources which add value to connecting people from around the world (Thompson, 2017).

2.9.2. Technology in oncology care

The daily presence of technology in oncology care is changing the perspective of care delivery by creating new systems that alleviate the workload of healthcare professionals. This contributes to the decision-making process and quality of care (Briant et al., 2016). For example, the presence of IBM Watson for oncology (WFO).

IBM Watson for Oncology (WFO) is a cognitive computing system designed in 2014 by IBM in the USA. Its main purpose is to provide clinical decision support to oncologists at the point of care (Lee et al., 2018). The authors found that 65.8% of users were satisfied using WFO due to its ability to process unstructured data – helping radiologists and pathologists analyse x-rays and digital images. WFO fulfils human imitations by acting as a decision support system but it does not replace humans. WFO further improves healthcare professionals' performance and enhances a patient's quality of care (Lee et al., 2018). Its ability to handle enormous quantity of data gives WFO a sustainable

competitive advantage as it saves time. The authors added that results show that 34.2% of users acknowledge WFO benefits, but they complained about the high cost of integration and maintenance due to increasing data utilisation, and its limited language usability – it is only available in the English language. However, WFO accelerates patient-centred care in oncology which improves decision-making and patient care, and enhances healthcare professionals' skills (Cavallo, 2017; Greenwald, 2018).

According to Lee et al. (2018), WFO can read patients' EHRs and can understand both structured and unstructured data – patient pictures, audios and videos. Data is synthesised into sets of attributes about a patient which provides a comprehensive understanding of the patient, their illness and context. The WFO accesses textbooks, medical journals, professional guidelines and expert input from oncologists in order to make a treatment recommendation for the patient.

A practical example is: "Watson, I have stomachache and a headache on the right side, my eyes hurt and my legs are swollen. I had a fever this morning of 45 degrees Celsius and I am sneezing." Watson will process this information, produce a diagnosis and propose treatment.

In conclusion, WFO has functionalities such as keeping X-ray results (pictures) and a library for medication that existing EHRs in Cape Town oncology care do not yet have access to (Wu & LaRue, 2017).

2.10. The impact of narratives in decision-making as opposed to EHRs in oncology

The quality of decision-making depends on the accuracy of information gathered at the assessment phase. This assessment phase refers to the first encounter between a healthcare professional and a patient (Bekker et al., 2013). EHRs allow healthcare professionals to access the patients' charts faster, irrespective of where they are, and this functionality enhances effective decision-making and improved patient tracking (Alpert, 2016). In this vein, Cognetta-Rieke and Guney (2014) acknowledge the power of EHRs and add that for better decision-making, patients' narratives must be part of EHRs. When narratives are added in EHRs, it results in better analysis and evaluation of patient care and improved service delivery.

Electronic narratives add value in healthcare from patient' care to decision-making (Laing et al., 2017) In fact, in the USA, survival rates of breast and prostate cancer have increased in the past five years due to the use of electronic narratives.

Dohan et al. (2016) investigated "the importance of integrating narrative into healthcare decision-making". The study provides an illustration on how narratives shape decision-making, and explain why it is difficult, but necessary, to integrate narrative into the health sciences. The findings show that patients' narratives that include clinical conditions and demographic characteristics positively impact decision-making and service outcomes in healthcare (Dohan et al., 2016). These narratives assist healthcare professionals in understanding the patient's state in order to enhance their own knowledge. It is suggested that integrating narratives in EHRs requires the ability to extract intrinsic value out of narratives which, in turn, enhances the service outcome.

Contrasting ideas regarding the measuring of the effect of using narratives in decision-making process exist. Narratives have no impact on scientific decision-making (administering pills and drugs) but serve in therapeutic decision-making (psychological state of patient) (Zeng-Treitler et al., 2016). Charon (2013) emphasises that there is no correct treatment procedure when the therapeutic decision does not pair with the scientific decision.

In support of narratives in EHRs, International Business Machines (IBM) designed a specific computing system for oncology that assists healthcare professionals in clinical decision support.

2.11. Problematic aspects of communication when using electronic narratives

Effective communication between healthcare professionals and patients is the key to unlock any barrier between them. This will then result in the sharing of intrinsic information that will lead to health promotion and the treatment of diseases and other clinical problems (Frank et al., 2014). There are several problematic aspects that hinder communication between healthcare professionals and patients. When gathering and giving information (the first step), healthcare professionals obtain primary information of patients that will contribute to their treatment processes (Dell-Kuster et al., 2014).

It is during the communication between healthcare professionals and patients that forms, questionnaires or interviews are used to extract important information regarding the patient's health. Gathering patient information using a questionnaire is the best way for a healthcare professional to get general answers regarding an individual's health (Dell-Kuster et al., 2014). Beattie et al. (2015) argue that gathering patients' information in questionnaire format is often the most challenging part of healthcare since patients are not always prepared to answer all the presented questions. In fact, several challenges arise with the use of questionnaires such as literacy issues, language barriers and the fear of sharing certain information. On the other hand, poor listening skills could also hinder communication between healthcare professionals and patients (Bekker et al., 2013).

Furthermore, neglecting a patient's psychosocial concerns plays a major role in disrupting communication between healthcare professionals and patients (Birkhäuer et al., 2017). For example, a patient that has been suffering from mental issues might not want to talk, and in this case it is up to the healthcare professional to find out why, and to be cognisant of the patient's state. Knowing the patient's psychological state contributes to a healthy and fruitful relationship, and failure to do so adversely affects the entire process of treatment and decision-making.

2.12. Conclusion

This chapter discusses literature related to the study. The available literature explores the experiences that healthcare professionals encounter when using electronic health records, narratives and electronic narratives. In thoroughly consulting and analysing existing literature, the researcher clearly understood the landscape of this particular field of study. This assisted the researcher in narrowing down the research study to focus on electronic health records in oncology care – the use of narratives and electronic narratives. The critical literature review was done using books, academic journals and other information from credible websites. Based on the literature, a conceptual theoretical framework that contextualises the study was created from the identified concepts from the literature to guide the study.
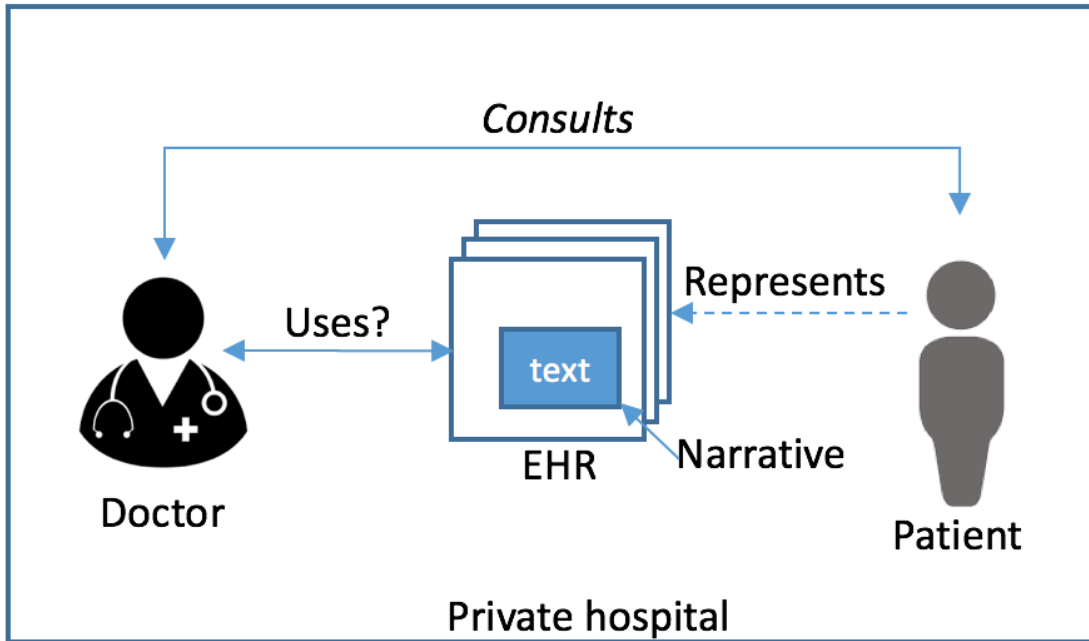
Figure 3: Study conceptual framework

The above conceptual framework provides a summary of what the research is based on – the use of narrative in EHRs to support the decision-making in private oncology care. The conceptual framework shows the interaction of healthcare professional (doctor) with patients' narratives in EHRs. The patient, although represented by the EHR, was not directly involved in the study because the focus was on the use of narratives by healthcare professionals.

CHAPTER THREE – RESEARCH DESIGN

3.1. Introduction

According to Saunders and Bezzina (2015), research is an investigative process directed at addressing a research problem through questions in order to meet the research objectives. To understand research methodology, Saunders, Lewis and Thornhill (2016) consider the research onion as the best guideline to inform the philosophy, approach, method, strategy and technique to be used. To address the research problem of this study, defined research processes were followed. In other words, a careful selection of procedures was adhered to, and these provided guidelines in order to contribute to knowledge in a particular field (Saunders & Bezzina, 2015). Therefore, to explore the use of narratives in EHRs to support decision-making processes for healthcare professionals, the research procedures in Figure 4 were followed. The research process starts with problem discovery and concludes with the dissemination of results.
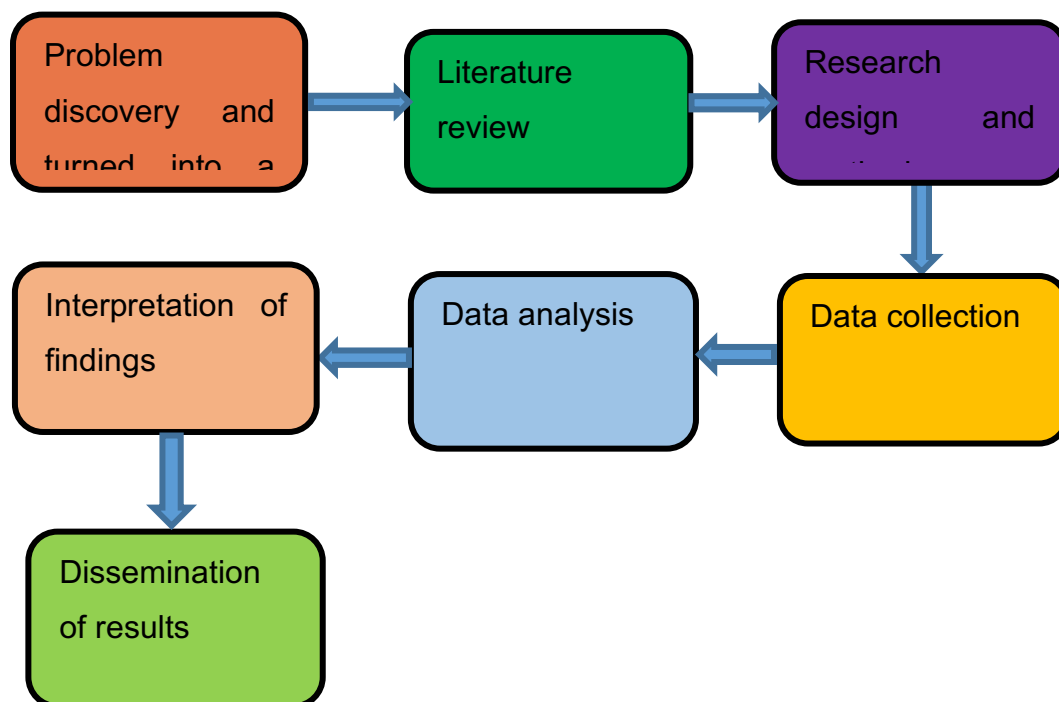
Figure 4: Research processes (Saunders & Bezzina, 2015)

3.2. Research Design

Research design is a systematically organised method of finding answers to a problem by including processes of collecting, analysing and interpreting data (Wilson & Creswell, 1996; Winship, 2011; Wright et al., 2016). In other words, the research design provides a clear framework that guides the methods and decisions of research, and it sets the terms for data interpretation.

According to Rahi (2017), a research design can be exploratory, explanatory and descriptive or experimental. These types of research are discussed below.

3.2.1. Exploratory Research

Exploratory research is an initial investigation that looks at things theoretically or hypothetically (Rahi, 2017). It either focuses on new topics (a new idea that is undiscovered), or it concentrates on new angles to existing concepts. In short, exploratory research is suitable when investigating phenomena about which very little or no information is known. This type of research is concerned about answering the "what" question which makes the foundation of conducting scientific research valuable. An exploratory research approach is used when the consideration is to bring clarity into research.

This study applied the exploratory research design since it aimed to understand the integration of electronic narratives as a tool in EHRs to support the decision-making by healthcare professionals in private oncology centres.

3.2.2. Explanatory Research

According to Winship (2011), in explanatory research the focus is to explain the reason why an event occurs, and/or to test specific theories to elaborate or amend existing theories. It is also known as causal research design and is mainly concerned with "why" questions about any phenomena.

Explanatory research is conducted to connect ideas in order to determine causes and effects (Strydom, 2014). It further focuses on analysing the situation of a specific problem by explaining patterns of relationship between variables.

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This approach was not used in this study because the researcher was not explaining the causes of the use of electronic narratives in EHRs. Instead, the intention of the researcher was to unpack the potential associated with the use of electronic narratives in EHRs to improve the outcomes of decision-making by healthcare professionals.

3.2.3. Descriptive Research

Descriptive research provides rich information about what exists on a specific topic without changing or manipulating its nature (Gentles & Vilches, 2017). The researcher provides in depth definitions to deliver a broader understanding of a certain subject matter. Descriptive research addresses "what" and "how" questions (Lewis & Thornhill, 2016). This means that descriptive research enables the researcher to test their hypothesis through scientific procedures until valid conclusions about links between dependent and independent variables can be drawn (i.e. obtaining information concerning the current phenomena).

This study is not testing hypotheses nor is it concerned with finding links between variables. For this reason, this method was not applied.

In summary, an exploratory research design was used as part of a suitable research approach. The research approach refers to the philosophical principles and methodology through which the investigation was conducted.

3.3. Research Approach

A research approach can be categorised as deductive or inductive (Saunders et al., 2009). Saunders et al. (2009) define the inductive approach as a method that emphasises theory development with the use of collected data (qualitative data) from participants. The deductive approach, on the other hand, is the reconstruction of a theory that already exists in order to create a new theory. With the inductive approach, observation of the phenomena under investigation is a strategy that the researcher uses to create a new theory, whilst with the deductive approach, the existing or current story is used to solve the phenomena under investigation.

To achieve the aim of this study, an inductive approach was used to investigate the use of narrative in EHRs to support the decision-making process of healthcare professionals in private oncology care in Cape Town. To further elaborate, an inductive approach is associated with interpretivism while the deductive approach is connected to positivism. The choice and selection of a research philosophy is discussed in the sections that follow below.

3.4. Research Philosophy

Research philosophy is defined as the way a researcher views the world by developing knowledge and determining the nature of that knowledge (Saunders et al., 2009). Walsham (1995) describes three categories of research philosophy namely ontology, epistemology and methodology. Ontology and epistemology assist the researcher in determining the reasons behind their choice of research, strategy, approach and methods (Walsham, 1995; Tashakkori & Creswell, 2007).

3.4.1. Ontology

Ontology is concerned with how we look at reality and the assumptions behind the nature of reality. Ontology addresses questions about the nature of being, reality and existence, and what is known about it (Gregor, 2006). In other words, ontology is interested in addressing the question "what is reality?"

To answer this question there are two philosophical stances – objectivism and subjectivism (Datt, 2017). Objectivism claims that social phenomena and their meanings have an existence that is independent of social actors. In other words, it implies that social reality exists without the influence of individuals. Subjectivism, on the other hand, argues that social actors play an active and crucial role in the construction of social reality. Ontology can thus be subjective or objective. It is subjective when assumptions and personal opinions are applied, and it is objective when only existing facts are considered (Yin, 2012).

This study adopted a subjective ontological stance since the researcher sought to understand the reality of using electronic narrative in EHRs which is dependent on individual information. The feedback obtained from the participants is socially

constructed according to their truth or reality. In order to understand and acquire knowledge, a subjective reality is informed by epistemology – the theory of knowledge.

3.4.2. Epistemology

Epistemology is a theory of knowledge that focuses on the origin, nature, methods and limitations of knowledge (Wilson & Creswell, 1996). It is concerned with how the researcher perceives, understands and unpacks reality.

It applies the following questions: What is the truth? What is real knowledge? What is the relationship between the researcher and the subject? It is concerned about how we examine reality, and addresses the question "how can I know reality?" (Scotland, 2012).

Epistemology is aligned with three philosophical approaches to answer research questions namely positivism, interpretivism and pragmatism. For the purpose of this study, an interpretivist stance was adopted because of the nature of the research objective which is to understand the reality of using electronic narrative in EHRs to support the decision-making in oncology care.

3.4.2.1. The Interpretivism Paradigm

The interpretivism paradigm assumes that reality and knowledge are socially constructed and its outputs are subjective (Goldkuhl, 2012). Knowledge is created not only by observing the phenomena but also by describing people's intentions, values, reasons and beliefs.

This philosophy acknowledges that social problems exist, and research descriptions do not rely on numerical or statistical data analysis. Since this philosophy is based on the concept that reality is socially constructed, the researcher focuses on understanding the construction rather than producing facts.

Interpretivism paradigm is based on the ontology stance that "there are multiple realities" and in epistemology stance that "knowledge need to be interpreted to discover the underline meaning".

To investigate the use of narratives in EHRs to support the decision-making processes of healthcare professionals, an interpretivism paradigm was best suited to the study.

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This was beneficial as it concentrated the focus of the study on a specific social group and targeted literature in order to find multiple realities, views and opinions from participants regarding the research problem. This specific group focus enabled an in-depth investigation into the research problem.

Table 2: Research philosophies summary

Philosophical Stance	Research Approach	Ontology	Axiology	Research strategy
Interpretivism	Inductive	Subjective	Biased	Qualitative case study

3.5. Research Methodology

A research methodology is a collection of methods and techniques that are used to carry out a scientific investigation (Winship, 2011). Research methods are approaches used to facilitate data collection whereas research techniques are strategies of enquiry to conduct a research (Saunders et al., 2009). The choice of a research methodology always depends on the context and purpose of a study (Walsham, 1995). A research methodology can be based on quantitative, qualitative or mixed approach methods to address the research problem, objective and main aim (Creswell, 2014).

3.5.1. Quantitative Research Methods

The quantitative research method is used to provide numerical data of a large group of people in order for it to be generalised (Yin, 2012). Quantitative research entails methods such as surveys, simulations, laboratory experiments and mathematical modelling (Kalra, Pathak & Jena, 2013). Therefore, questions used for data collections are fixed and close-ended. These type of questions do not give participants the choice to answer as they please but rather to follow instructions and answer what is presented to them. Findings in quantitative research are usually associated with deductive studies, and generally do not give elaborate answers, explanations and/or details.

Exploring the use of electronic narratives to support healthcare professionals in the decision-making process in private oncology care in Cape Town requires an in-depth understanding of the phenomena. With a subjective approach and perspective, the researcher is not collecting numerical data, therefore an alternative methodology is discussed in the section below.

3.5.2. Qualitative Research Methods

Qualitative research is a non-numerical method that provides information about meaning and context concerning people and environments of study (Yin, 2012). Findings in qualitative research are mostly not generalised as result of small population sizes and limited ranges of participant groups.

In qualitative research, the focus is mostly on understanding the perspectives with which the participants address the problem of the study. In other words, the researcher tries to find meaning behind a concept as seen from participants' perspectives (Kalra, Pathak & Jena, 2013). Qualitative research tends to focus on the human experience and theoretical information linked to inductive studies. To further elaborate, it includes case studies, action research, ethnography and grounded theory that are text-related studies (Kalra, Pathak & Jena, 2013).

The mixed approach research methodology is a combination of qualitative and quantitative research methods that complement one another (Yin, 2012). In this study, the qualitative method was most suitable, and therefore applied. This method contributed to collecting non-numerical data addressing the below-mentioned research objectives.

➢ Understanding how the experiences of healthcare professionals while using existing EHRs influence the outcome of their decision-making process.
➢ Determining how narratives can be incorporated in electronic healthcare records to aid the decision-making process of healthcare professionals in oncology centres.
➢ Establishing the requirements of incorporating narratives in electronic health records to support healthcare professionals in decision-making.

➢ Understanding the reasons why narratives are yet to be used to support decision-making in oncology care.

3.5.2.1. Case Study

A case study is an intensive investigation of a particular unit under consideration. It aims to obtain a complete and detailed account of a social phenomenon or event of a social unit (Dyer & Wilkins, 1991). Case studies enable the researcher to closely explore and investigate data within a specific context (Yin, 2003).

A case study can either be single or multiple depending on the focus of the research (Edwards, 1998). In a single case study, the researcher tries to find in-depth information about the case itself. The focus is therefore on the single issue or theme. On the other hand, in multiple case studies, the researcher focuses on a research topic or phenomenon in order to gain an understanding of the research problem as it occurs in different cases. The cases are usually not more than four to five studied in one context.

In case study research, data can be collected from single and/or multiple sources by using any qualitative method of data collection such as interviews, observations, secondary data, documents, records and artefacts (Yin, 2003). In applying these qualitative methods for data collection, the researcher gains an in-depth understanding of the research at hand. This also involves careful and complete observation of a case in data analysis. An in-depth examination was used on multiple cases (three hospitals) involved in this study. This provided a systematic way of observing the event in data collection and reporting the results in a limited time.

Hyatt, Kenny and Dickson-Swift (2014) explains that a case study can be descriptive, explanatory and exploratory. An exploratory case study involves the in-depth research and analysis of why whereas an explanatory case study focuses on establishing causes and effects. A descriptive case study presents a complete description of an event within a concept. The tools of enquiry most suitable to engaging participants in collecting qualitative data are discussed below.

3.6. Data Collection

Data collection is the process of obtaining the opinions, views and considerations of research participants over a certain period of time (Sutton & Austin, 2015). Gornall (2013) mentions that there are five methods of conducting research namely surveys, experiments, secondary data studies, observations and interviews. This study used interviews for data collection with the purpose of exploring participants' views, experience and beliefs about the use of narratives in EHRs (Gill et al., 2008).

Interview data was captured in audio format and then transcribed. This study used semi-structured interviews – questions were open-ended to allow participants to talk freely and openly without being restricted by a fixed format (Davies & Hughes, 2014). Research done by Dohan et al. (2016), titled "the importance of integrating narrative into healthcare decision-making", motivated the use of interviews to capture rich data.

Data collection started with obtaining permission from top management of selected private hospitals. Once the request was approved, selected participants were contacted through emails to request their availability, and those who could not respond to emails, were contacted telephonically. Some selected participants declined to participate, and in total ten respondents accepted. In the process of collecting data some participants suggested eight other individuals who were also willing to participate. In total, data was collected from eighteen participants. Consent forms were signed before collecting data, and all participants were made aware of the ethical guidelines and considerations pertaining to this research study.

3.6.1. Literature Study

A literature study was carried out to explore relevant background knowledge available on the topic of this research (Baker, 2016). The information included in the literature review was mostly obtained from journals, articles, conference papers, reports, books and websites. A literature review essentially evaluates and analyses the work of others done in a similar field of study.

As part of the literature study, it is crucial that other researchers are acknowledged, and this is done through accurate referencing.

The literature review was incorporated throughout this study. It was used and applied to investigate the use of electronic narratives in EHRs to support the decision-making process of healthcare professionals in private oncology care of Cape Town.

3.6.2. Interviews

An interview can be defined as a purposeful discussion between two or more people. This is typically guided through the use of questions aimed at obtaining detailed information about something or someone (Saunders et al., 2009). Interviews are categorised as structured, semi-structured and/or in-depth. The process that guides the identification and selection of appropriate participants to interview is referred to as sampling which is discussed in Section 3.7.

Interview questions for this study were formulated based on the main research question and sub-questions. The interview questions were developed with the intent of meeting the research aim. Keywords that were present in the interview questions are: The experience of using EHRs, the use of narratives and electronic narratives, decision-making processes, and requirements of including narratives in EHRs.

The interview guideline used in this study to collect data from participants can be viewed in Appendix A.

3.6.3. Limitations in data collection

Due to participants' busy and demanding schedules, a fixed timeframe was adhered to for interviews. In other words, interviews were scheduled in advance and conducted at a time and place most convenient for participants – mostly hospitals and private practices. Interviews were sometimes interrupted by other doctors but this did not derail the interviews as the nature of the interview content did not render participants uncomfortable with a lack of privacy.

Due to the demanding work schedule of healthcare professionals, a delay in the response to requests for interviews was experienced by the researcher. This resulted in the data collection process taking longer than what was initially anticipated.

Furthermore, the researcher experienced a unique challenge within the intimate setting of an interview as the researcher's mother tongue is French and the participants spoke English. The researcher is however fully conversant in English and was able to effectively communicate with participants in order to extract valuable information.

Lastly, allocated funds to this research was not enough for renting the recording material and, as result, the researcher did use a cell phone towards last interviews.

3.7. Sampling

Sampling can be defined as the process of selecting a subset of a population that represents a larger population (Gentles & Vilches, 2017). The researcher focuses on that subset of the population due to the lack of resources (time and money) and workload.

In sampling, determining the sample frame, size and technique is very important (Sutton & Austin, 2015). In this study, the sample frame was on private oncology hospitals, and the size was selected due to the researcher's ability to reach them. From the sample frame, three private oncology hospitals were selected, and the sample size was determined by the profession of participants relevant to this study. In sampling, participants are known as "units of observation". A sample procedure is categorised into probability and non-probability sampling (Omair, 2014). These procedures are discussed below.

3.7.1. Probability Sampling

Probability sampling is also known as representative sampling. With this method of sampling, each and every element has an equal chance of being selected to participate in the study (Etikan, Musa & Alkassim, 2015). The equal probability of being selected in a study is due to randomisation.

Probability sampling is divided into four techniques which are simple random sampling, systematic sampling, stratified sampling and cluster sampling. In probability sampling, the opportunity of selection is fixed and known. The research is also conclusive, and the result unbiased. This method of sampling uses statistical inferences. Hypotheses are

also tested and the method is objective. The advantage of probability sampling is that, if done correctly, it represents a larger population (Sutton & Austin, 2015).

3.7.2. Non-probability Sampling

Non-probability sampling is also known as non-representative sampling. This method implies that some elements have no chance of being selected (Omair, 2014).

Non-probability sampling is divided into four techniques which are quota sampling, convenient sampling, judgmental sampling and purposive sampling. In non-probability sampling, the opportunity of selection is not specified and is often unknown to participants. Furthermore, the research is exploratory, and the result is biased. This sampling uses analytical inferences from a subjective perspective.

This study applied non-probability sampling since the aim of the study was to explore the use of narratives in EHRs to support the decision-making process of healthcare professionals in oncology care. This particular method proofed to be more cost effective and convenient because the researcher focused on a small targeted group of people who met the study requirements.

3.7.2.1. Purposive Sampling

Purposive sampling is a non-random sampling technique also known as judgmental, selective or subjective sampling. This technique does not focus on existing theories or a set number of participants (Tongco, 2007). A purposive sample was used in this study as the research is not aimed at producing statistical results, but instead relies on the researcher's judgment to select participants (Wilmot, 2005).

For this study, private hospitals were selected as units of analysis as the cases and participants were purposely chosen – the researcher selected profiles that were aligned with the study. This method was effective in exploring the use of narratives in EHRs to support decision-making processes in oncology care. This study focused on three private hospitals in Cape Town that have oncology departments, and a total of eighteen participants contributed. Oncologists were initially the units of observation, and selected as the main participants. During interviews, said oncologists suggested to the

researcher that she broadens the interview scope to include general practitioners as they are often the first doctors to be made contact with by a patient. Furthermore, oncologists recommended that psychiatrists are interviewed as well as they frequently deal with a patient's mental and emotional challenges.

With qualitative data collection, the saturation point was reached when no new data was received from participants. This study reached a point of saturation after eighteen participants were interviewed. The sample size was based on participants' availability and their willingness to participate. Details are shown in the table below:

Table 3: Participant table

Title	Participants	Number
Doctors	Oncologists	10
	General practitioners	5
	Psychiatrists	3

3.8. Data analysis

According to Watkins (2017), data analysis involves qualitative and quantitative methods. In order to achieve the research aim and objectives in qualitative research, interviews, focus groups and experiments are used. These assist the researcher in identifying similarities between patterns which are then critically analysed. In other words, the responses from participants are broken down into smaller, more manageable pieces of data. In quantitative research, figures and numbers are critically interpreted in order to justify the rationale behind the occurrence of the key findings.

In qualitative data analysis, recorded data is transcribed and thematically analysed. This was a crucial step in this study, and the process was aided by keeping the raw data simple and understandable (Sutton & Austin, 2015). Data analysis is defined as a research technique that describes the collected content in a detailed and concise manner. It is often considered the most challenging aspect of research since it focuses

on systematically matching the data to the study objectives. Data analysis can be statistical, verbal, documents, content and/or thematic (Watkins, 2017). For this study, thematic analysis was selected as the most suitable technique because it helped the researcher summarise, organise and categorise data into understandable themes.

3.8.1. Thematic analysis

Thematic analysis is a qualitative research method used to analyse, identify, organise, describe and report on themes found in collected data (Aronson, 1995). During the process of thematic analysis, interpreted data is converted into significant information addressing the research questions (Datt, 2017).

The data that was analysed in this study addresses the research questions discussed in Section 1.5., and it assisted the researcher to reach the aim of the research discussed in Section 1.4.

The following steps were adhered to in accordance with thematic analysis: Data was coded, in other words, collected data was categorised, and data was then clustered into smaller, more manageable groups. Themes, patterns and relationships began to form and, from this, patterns emerged – similarities and differences from smaller groups were found and data was differentiated from each group. Themes were labelled accordingly and category systems were developed. A potential overlap and/or redundancy of data was avoided by looking for emerging patterns in data. Lastly, data was summarised and a written report compiled.

3.9. Interpretation

Once the findings were derived from the identified themes, they were interpreted to attach meaning to them. This was done by comparing the findings with existing literature, and explaining the relevance of collected data (Walsham, 2006). In other words, data patterns were clarified and contextualised. Interpretation can therefore be described as the subjective process during which the researcher makes sense of the study findings. The researcher thus plays an integral role in the process of data interpretation.

3.10. Conclusion

This chapter explains the data collection method that was used in this study. A qualitative method was selected because the researcher collected nun-numerical data through the use of semi-structured interviews. This type of interview was used to allow participants to freely express themselves so that important information could be extracted. Purposive sampling was applied to select appropriate participants which means there was bias in the selection process. Data was analysed to generate findings which were later analysed thematically.

Existing research philosophies guided the researcher through the study. Since the phenomenon was socially constructed and subjective to human nature, an interpretivism paradigm was used to support and execute the study.

The next chapter discusses the research findings.

CHAPTER FOUR – DATA ANALYSIS AND FINDINGS

4.1. Introduction

The aim of this study was to explore the use of narratives in electronic health records (EHRs) to support healthcare professionals' decision-making process in private oncology care in Cape Town. This chapter presents the context of the research site where data collection took place, and it provides a descriptive presentation of the collected data elicited through semi-structured interviews with participants. The data analysis and findings (Chapter 4) is divided into five sections: introduction, context, data analysis process, descriptive presentation of findings, and a conclusion to the chapter

4.2 The context
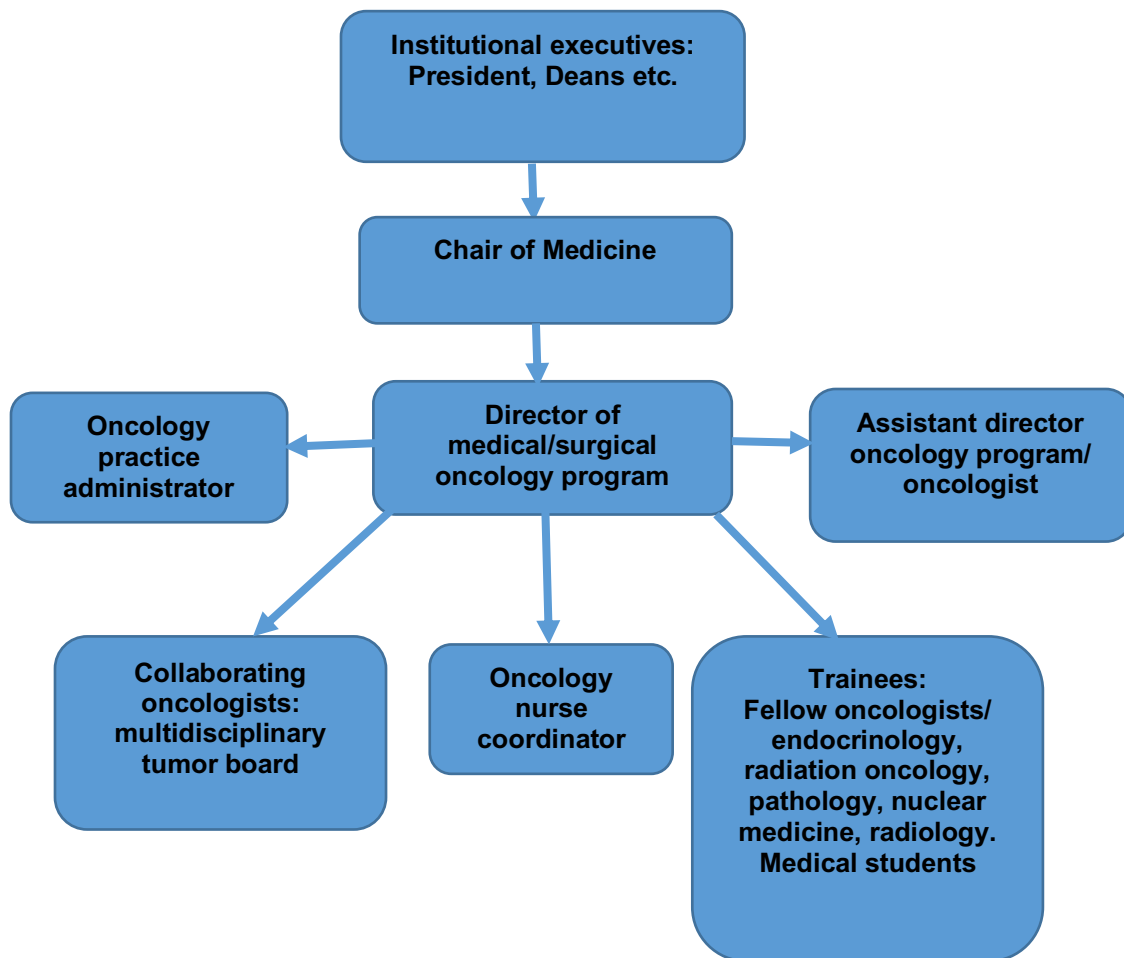
Figure 5: Organisational structure in oncology care

The organisational structure (Figure 5), illustrates the hierarchy of functions in oncology care which include: duty allocation, coordination and supervision tailored towards achieving the aims of the organisation.

The researcher selected three private hospitals in Cape Town that offer different healthcare services including oncology care which, was the focus area of this research. Two hospitals are located in the southern suburbs and one in the northern suburbs. All three of these hospitals are general hospitals providing oncology care services from Cancercare. In 1989, Dr. Leon Gouvs founded Cancercare, the aim of which was to provide oncology services. Cancercare has nine private oncology centres in different hospitals with a total of 25 specialist oncologists (Cancercare, 2019). Each year at least 2500 to 3000 new patients are registered, and Cancercare has more than 90 000 patient contacts per year.

According to Burger and Christian (2018), there is inequality in South Africa's health system structure. Most patients are unable to afford private healthcare, and, as result, financially disadvantaged patients receive healthcare services from under-resourced public healthcare facilities whilst the few who can afford private healthcare enjoy sophisticated, well-funded and technologically superior private healthcare. Most patients in private healthcare belong to a subsidized private medical aid.

For more details on the geographical location of the study sample, a small map is presented below:

Figure 6: Hospitals Map

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To realise the objectives of this study (as stated in Section 1.5), the researcher purposively selected private hospitals that provided oncology care as a multiple case study. The reason to choose multiple case study, was to collect sufficient information to reach saturation point. The total number of participants engaged for the purpose of the research was eighteen. Private hospitals were selected because of their proximity to the researcher, easy accessibility and a relatively strong implementation of health technology in oncology care. The researcher sought permission from the hospital managers and healthcare professionals by sending emails, and in some cases made phone calls. Some selected participants responded directly via emails and others requested the researcher's physical presence to be assured that it was for study purposes.

Table 4: Participant's profile

Unit of observation	Number of Participants		
3 private hospitals in Cape Town	**Selected**	**Suggested**	**Responded**
Oncologists	15	-	10
General practitioners	0	6	5
Psychiatrists	0	4	3
Total number of participants			18

Table 3 indicates the unit of observation on the left and the eventual number of willing participants on the right. The researcher primarily set out to interview fifteen participants but accumulatively ended up with eighteen respondents which include ten oncologists, five general practitioners and three psychiatrists. These interviews were the primary data collected and consequently analysed to answer the main research question and address the research problem.

4.3. The Data Analysis Process
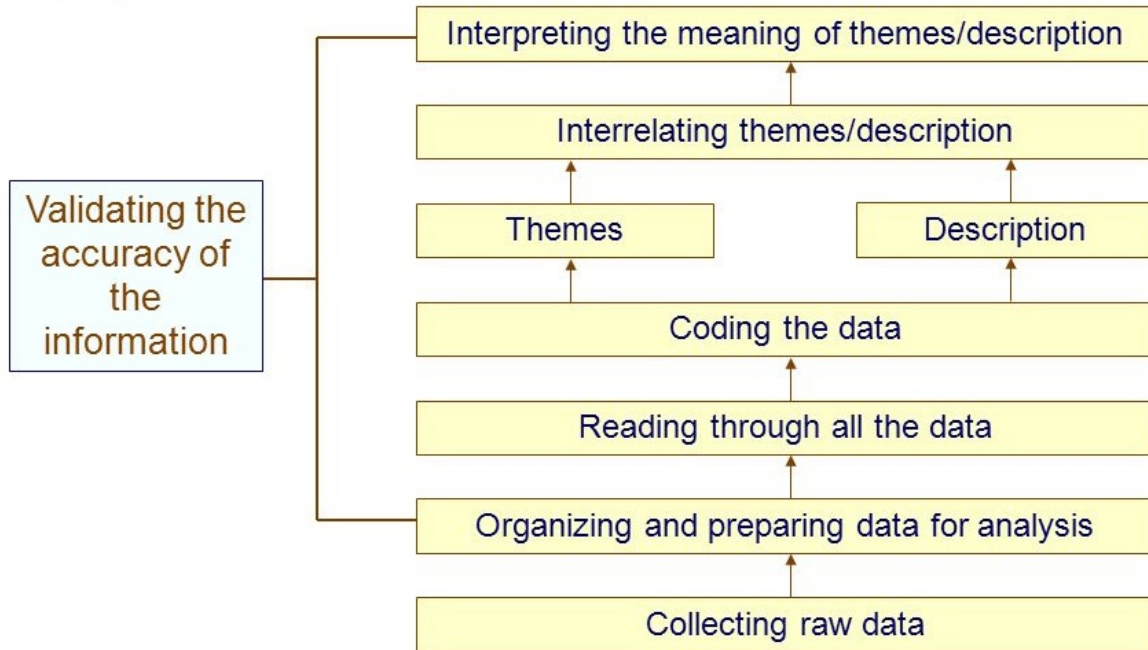
Figure 7: Data analysis processes in qualitative research (Creswell, 2014)

The data analysis process was carried out using thematic analysis. Thematic analysis involves identifying words or phrases that underpin the key variables in each of the sub-questions. This is done using multiple coding processes to unpack the qualitative data. To validate the accuracy of information, the analysis phase followed the structure illustrated in Figure 5 to address the research aim.

The researcher followed the following steps as recommended by Saldana (2009). Firstly, the collected data was transcribed from voice-record to text. Once the transcription was completed, the researcher was able to identify codes from transcripts. Secondly, descriptive codes were assigned to data transcripts. The assignment and application of these descriptive codes allowed the researcher to identify attributes or key concepts of the variables in each sub-research questions. After, the researcher searched for links between codes and generated key concepts, themes were created. During this step, the researcher identified specific findings that presented answers to each of the research sub-questions. Themes were identified in accordance with the aim of the study, its objectives and the literature. Subsequently, the developed themes were

revised. The revision of emergent themes was carried out by the researcher for quality assurance purposes, and it was used to categorise themes. To avoid redundancy in the findings, the researcher used a theme once irrespective of how many times it was repeated, and formulation of themes was based on the researcher's own judgment. The last steps require findings to be presented in a narrative or graphic format. The researcher descriptively presents findings to each of the research sub-questions towards addressing the research problem – as extensively discussed in Chapter 5.

#		Code	Key concept	Category
2	4.07	EHR system need upgrade.	Facilitate work	EHR challenges
3	3.16	IT skills required to use eNarrative	Narrative use preference	eNarrative challenges
2	1.69	Ability to see patterns	EHR use experience	EHR benefit
2	4.05	Absence of eNarrative.	Facilitate work	eNarrative challenges
1	1.03	Access to patient history	EHR use experience	Access
1	1.53	Adoption issues	Effect of challenges	
1	1.40	Allocate regulated time for narratives	Effect of challenges	Narratives
1	1.10	Automated work functions	Impact of EHR on work	Work functions
1	1.52	Automated work functions	Effect of challenges	Work functions
2	1.63	Automated work functions	Impact of EHR on work	Work functions
1	1.58	Backups	EHR use experience	Backups
2	4.08	Complexity of EHR system	Facilitate work	EHR challenges
1	2.27	Confidentiality issues	Narrative impact	Data protection
1	1.50	Cost of adding narratives	Challenges of using EHR	Cost of EHR
3	1.76	Cost of hardware replacement	Challenges of using EHR	Cost of EHR
1	1.49	Cost of new system	Challenges of using EHR	Cost of EHR
3	1.77	Cost of software upgrades	Challenges of using EHR	Cost of EHR
1	1.51	Cost of system could increase cost of service	Effect of challenges	Cost of EHR
1	1.47	Cultural practices	Challenges of using EHR	
2	1.65	Data loss	Challenges of using EHR	Data loss
1	1.20	Data protection	Challenges of using EHR	Data protection

Figure 8: sample of code

4.4. Descriptive presentation of findings

This section describes the findings derived from the coding and analysis processes. The researcher coded the data into smaller groups. Then, similarities and differences from patterns were labelled in themes, and eventually categorised to reduce overlapping and redundancy.

The findings were generated from each case (each private oncology hospital) for the four research sub-questions. A multiple case study was used to allow the researcher to collect enough data regarding the study and to have different point of views from participants in different private hospitals. These findings were summarised and presented in a table.

To comply with privacy and ethical concerns, the researcher anonymously coded the participants as indicated below.

Table 5: Participants' codes

Hospital code (PH= private hospital)	Participants	Code
PH1	Oncologist (OC) Psychiatrist doctor (PD) General Practitioner(GP)	OC1-PH1 OC2-PH1 OC3-PH1 PD1-PH1 OC4-PH1 OC5-PH1 GP1-PH1
PH2	Oncologist (OC) Psychiatric doctor (PD) General Practitioner(GP)	OC6-PH2 GP2-PH2 OC7-PH2 OC8-PH2 GP3-PH2 PD2-PH2
PH3	Oncologist (OC) Psychiatric doctor (PD) General Practitioner(GP)	OC9-PH3 OC10-PH3 GP4-PH3 PD3-PH3 GP5-PH3

Data description was presented using the four sub-research objectives presented in section 1.5, that were developed to address the research problem. In each sub-research objective, a title was formed through research keywords. In research methodology, the researcher stated that case study will be used in data collection.

At the end of each case's data description, a table summarising themes, categories and key concepts is presented. Consequently, the themes that emerged from the presentation of data analysis in chapter 4 are further discussed in Chapter 5.

In the research methodology, the researcher mentioned that cases will be used in this study. As result, the study was carried out in three different cases (three private hospitals), which is the reason why participants' answers are separated in their respective cases and the summary tables of each case are found in appendix B.

4.4.1. Healthcare professionals' experiences using EHRs

The description below indicate the responses obtained from interview questions that answered this sub-question: How do the experiences of healthcare professionals while using existing electronic healthcare records influence the outcome of the decision-making process? The key concepts are derived from the sub research questions and were used in the interview questions.

The researcher divided the answers into four keywords which are: The experience of using EHRs, the impact of using EHRs for decision-making, the challenges experienced in using EHRs and the effect of EHR use.

The key concepts to this question are shown below.

Interview Question	Key concept
1.1	EHR use experience
1.2	EHR use impact
1.3	EHR use challenges
1.4	Effect of EHR use

The responses of the participants are indicated with a respondent code (refer to Table 5) and the interview question number, e.g. r1.1, r1.2, etc.

1. Case 1: Private Hospital 1 (PH1)

The findings show that all participants (seven out of seven) reported positive experiences in using EHRs due to the benefits associated with EHRs. These benefits include easy accessibility, effortless referencing, well organised files, available patient history, on-demand printing capabilities, editable data and the ability to summarise and share patient information.

Whilst indicating the benefits of EHRs, a respondent said that: "*EHRs have been evolving in oncology care and have impacted the way patients' records are viewed*" **(OC1-PH1-r1.1)**. To substantiate this point, another respondent indicated that *"EHRs are easy to access because patient records are well organised and patient information history can be back tracked*" **(OC2-PH1-r1.1)**. From these responses, it is evident that healthcare professionals attribute an improvement in managing patient records to the use of EHRs. In using this, EHRs assist healthcare professionals in the eventual decision-making process.

Decision-making is the ability to choose from available alternatives, actions and solutions to resolve a problem in a particular situation (Sharma et al., 2016). In oncology care, decision has to be made after diagnosing the patient, allowing healthcare professionals to choose the appropriate medication and treatment process.

When asked how EHRs support healthcare professionals' decision-making, six out of seven respondents believed that EHRs positively influence the decision-making process. One respondent said: "…. *absolutely*" **(OC2-PH1-r1.4)** since all information regarding a patient is accessed on one screen and can be summarised. Another respondent explained that "*patients' EHRs can be modifie*d" which facilitate the "*easy sharing of information*" **(OC6-PH2-r1.2)**. "*EHRs create a paperless practice that makes it more efficient*" as recounted by **(OC3-PH1-r1.2),** and if the healthcare professional is replaced "*another healthcare professional is able to access the patient's EHRs quickly and easily*" **(OC4-PH1-r1.2)**. Again, the usefulness of EHRs can't be over-emphasised – essentially EHRs simplify activities within the decision-making process by automating certain work functions relating to patient records.

The easy accessibility of patients' healthcare records makes healthcare professionals less prone to errors when making decisions, and EHRs speed up the process of decision-making and recording data. Contrary to the responses above, one of the seven participants was of the opinion that "*EHRs do not really help in decision-making*" **(OC5-PH1-r1.4)** as the decision-making is based on "a *patient's past medical history, surgical history, life circumstances, family history and findings during consultation*". *Yet, some EHRs do not have this information nor the options to save it* **(OC5-PH1-r1.4)**.

From this response, it is evident that not all EHRs are unified or have the same functionalities. In EHRs, **functionality** is the sum of processes any software application can do for healthcare professionals to facilitate the delivery of service (Evans, 2016). This appears to have a negative impact on how healthcare professionals perceive the management of patient records. Despite the positive experiences of healthcare professionals due to the benefits of EHRs, six out of the seven respondents mentioned that they encountered challenges while using EHRs. These challenges include technical issues, loss of information, data capturing issues (omitted information), maintenance, data protection and privacy (security).

Upon request for clarity on the challenges faced with EHRs in oncology care, one participant explained that "*data that has been captured gets lost when connectivity is lost before content was saved, or it could even be deleted*" **(OC3-PH1-r1.3).** In addition to this challenge, a respondent mentioned that "*there are issues with data protection and privacy*". The challenges mentioned by the participant include "*theft, vandalism, eavesdropping and hacking*".

In the context of using EHRs in healthcare, **eavesdropping** pertains to the interception of real-time email transmissions, phone calls, instant messages and video conversations without participants' awareness (Salem et al., 2018). **Hacking,** on the other hand, refers to the intended and unauthorised access to EHRs in order to alter the system or its security features for an illicit purpose (Rader & Wash, 2015). Seemingly, these security issues also affect EHRs when notes and written narrative functionalities are added as one out of seven respondents said *"the use of written narratives does not*

guarantee the security of information as it can easily be misplaced, stolen or lost" **(OC3-PH1-r2.3)**.

From these replies, it is clear that EHRs present challenges that could slow down the activities of healthcare professionals, and ultimately negatively impact the decision-making process.

Out of the seven participants, three stated that EHRs were not alike in functionality **(OC1-PH1-r1.3, OC4-PH1–r1.3; OC5-PH1-r1.3)**. In fact, EHRs differ between hospitals, and sometimes from one doctor to another. Due to a lack of uniformity, EHRs are still a work in progress. In this vein, six of the seven participants pointed out that EHR systems do not include pathology information, x-rays, radiology content and/or a library of medication. The lack of this type of information delays certain work-related tasks since healthcare professionals have to search for what they require that is not available on EHRs. As one participant put it: "*There is no functionality to assist with a library of medication in EHR*s. *You have to manually type every medication and reference them*" **(OC4-PH1-r1.3)**.

When healthcare professionals were asked what they do when they cannot access the patient's EHRs, a respondent explained that they "*examine the patient and cross-check the data with the patient*" **(PD1-PH1-r1.3)**. This is "*time consuming and allows for errors to be made in decision-making*" **(GP1-PH1-r1.3)**. In other words, when healthcare professionals experience challenges with EHRs, they revert to manual processes of engaging with patients to validate patient data which is time consuming and prone to duplication and even discrepancy errors.

Due to the aforementioned challenges, there is a minority of participants (two out of seven) who said that they prefer the old method of recording patient data using a paper-based system **(OC5-PH1-r1.4, GP1-PH1-r1.4)**. As one participant explained "*EHRs have many functionalities and I did not have enough time to practice, therefore I prefer paper-based records since it is faster*" **(OC5-PH1-r1.4)**. The typical functionalities of EHRs pertain to managing patient medication lists, incorporating patient history as well as surgical history, and capturing clinical documents and notes.

"There is no need to waste time on recording information into a system. I have no passion for IT-based systems, it has a lot of complicated mechanics" **(GP1-PH1-r1.4)**. The issue of time also affects EHRs when other functionalities such as patient narratives (written narratives) are added. In fact, five out of seven participants mentioned that they interrupt their patients while they are sharing their stories as the health professional feels pressed for time, and therefore matters need to be addressed quickly **(OC3-PH1-r2.1; PD1-PH1-r2.1; OC4-PH1-r2.1; OC1-PH1-r2.1; OC3-PH1-r2.1)**.

In this vein, the majority of participants (six out of seven) suggested that it is better for healthcare professionals to set up longer appointments so that they can listen to patients' stories and extract value from these. One out of seven participants suggested that narratives should have a "…*regulated time*" **(OC1-PH1-r3.1)**. In other words, a patient's story should be limited to three minutes and only *"relevant/important information"* should be recorded **(OC1-PH1-r3.1)**. As one participant put it: "*In giving a cancer patient a listening heart, healthcare professionals are able to extract enough information about what is important to the patient who can then be treated accordingly*" **(OC1-PH1-r2.2)**. This affirmation of the positive impact of patient narrative in EHRs was confirmed despite the process of writing and recording patients' narratives being considered tiresome and laborious **(GP1-PH1-r2.3; OC2-PH1-r2.3)**.

When a new EHR system is implemented, it takes time for users to feel comfortable using it. The need and/or desire to use the previous system is often overwhelming, and most users are reluctant to change. This is known as a cultural issue where it becomes difficult to drop or quit a habit. Two participants **(OC4-PH1-r1.4; GP1-PH1-r1.4)** illustrated this point when they mentioned that they are comfortable using both EHRs and paper-based records. They further admit that registering paper-based information into EHRs leave a potential gap in the decision making-process when translating the patient's information into medical jargon. The gap is present when "*valuable information is left on paper because some EHRs do not have functionalities to register information such as the patient's story*" **(OC4-PH1-r1.4)**.

Furthermore, four out of seven participants mentioned that culture can also be an issue when adopting and implementing narrative in EHRs. As two out of seven participants

clarified: "…*many patients are conservatives, they value customs and belief*" **(OC1-PH1-r4.1), "***sharing their stories will be a challenge but creating awareness will defeat their fear*" **(OC2-PH1-r4.1)**.

Integrating a new system in healthcare is costly in terms of implementation and maintenance. One of the seven respondents mentioned that… "*Healthcare services are increasingly becoming more and more expensive due to new IT services and inventions*" **(OC4-PH1-r1.4)**. In the case of adding narratives to EHRs, the majority of participants (six out of seven) said that adopting EHRs with basic functionalities is expensive… "*Customising it to meet healthcare's requirements in terms of patient narratives will be costly*" **(OC1-PH1-r2.2; OC2-PH1-r1.4; OC3-PH1-r1.4; PD1-PH1-r1.4).** *This expense does not only affect the healthcare facility but also puts financial pressure on the patients as they are expected to pay for the services*" **(OC4-PH1-r1.4)**.

EHRs appear to simplify work activities for healthcare professionals within the decision-making process by automating certain work functions relating to patient records. However, the costs and resistance to change associated with EHRs still affect the adoption thereof.

2. Case 2: Private Hospital 2 (PH2)

The findings show that all participants (six out of six) recounted positive experiences in using EHRs. These benefits include easy access and referencing since all information is streamlined under one database. It also resulted in more accurate health records that reduce redundancy, and the effective management of drug prescriptions and real time information. This allows healthcare professionals to base their decision-making on updated information which is safely stored on the system.

To support the above information on the benefits of EHRs, a respondent said that: "*EHRs positively impact the daily practice of oncology" (***OC6-PH2-r1.1)**. To confirm this point, another respondent specified that "*with real time access to information in EHRs, the decision-making is made easier*" **(OC8-PH2-r1.1)**. It is evident that EHRs ease healthcare professionals' work by positively impacting patient care and service outcomes.

When asked how EHRs support healthcare professionals' decision-making, four out of six respondents believed that EHRs definitely influence the decision-making process. As one respondent (OC7-PH2-r1.4) said: "…*easy access to patients' records make decision-making more efficient since healthcare professionals rely on patients' summarised information.*

Another respondent added that "*EHRs have reduced the use of paper-based records which simplify healthcare professionals' work with real time data processing functionalities*" **(OC6-PH2-r1.1)**. The effectiveness of EHRs cannot be over-emphasised – they essentially simplify healthcare professionals' activities by automating work functions related to patient records. However, one of the six participants contradicted this point of view: "*EHRs do not support the decision-making process entirely because some patients' records such as family history and past medical history are rarely registered*" **(GP3-PH2-r1.4)**.

Overall, healthcare professionals mentioned that they have positive experiences when using EHRs in oncology. Some challenges were nonetheless reported: "*Data loss and security issues may occur when using EHRs*" **(GP2-PH2-r1.3)**. When the researcher asked what healthcare professionals do when they cannot access patients' EHRs, one participant said that "*when we have no access to patients' EHRs, due to the loss of data, it is usually difficult to regain patients' trust because the moment they know we are not able to access their records, they feel that we do not value their information*" **(OC8-PH2-r1.4)**. The same participant added that a delay in decision–making can be experienced when the above-mentioned challenges occur.

3. Case 3: Private Hospital 3 (PH3)

The majority of participants (four out of five) described EHRs as an effective tool in oncology care. The benefits mostly listed by participants are easy information sharing, convenient reporting on health issues, inclusion of patient history, the detection of patient health patterns, and, as result of these, improved decision-making. In clarifying these EHR benefits, one respondent said: "*EHRs have made oncologists' work easier, especially with the simple recording process of patient information*" **(OC9-PH3-r1.1).**

Another respondent added that "*EHRs allow oncologists to seamlessly trace patients' health history*" **(OC10-PH3-r1.1)**.

When asked how EHRs support healthcare professionals' decision-making, three out of five respondents said that "*there is no doubt about EHRs supporting decision-making as it conveniently displays patient information on one screen,*" **(OC9-PH3-r1.4)**. Another respondent added that *"EHRs efficiency cannot be compared to previous paper-based records since it can be accessed anytime and anywhere"* **(GP5-PH3-r1.2)**.

From these responses, it is evident that EHRs assist healthcare professionals in doing their work which eases the decision-making process. There are however certain challenges that arise when using EHRs. As one participant explained: "It *is difficult to protect data from unauthorised access, and the cost of replacing hardware and upgrading software on a regular basis is considerable*" **(GP4-PH3-r1.4)**. In other words, adding and upgrading a functionality such as electronic narratives can be costly in terms of software and security. Another participant added that EHRs "*provide overdependence on technology which affects the focus of oncologists*" **(PD3-PH3-r1.4)**. This implies that, as result of EHRs, oncologists often focus more on what is broadcasted on the internet than basing the facts on their own experiences. When healthcare professionals were asked what they do when they cannot access the patient's EHRs, a respondent explained that they *"sometimes transfer the patients to another hospital or they revert to written notes if available"* **(GP5-PH3-r1.3)**. These notes are more often summarised and therefore they do not provide in depth background on the patient and their health concern. As result, errors may occur which can negatively impact the decision-making process. One participant **(GP4-PH3-r1.4)** further added that the *"lack of training can also negatively impact the decision-making process"*. Even though recording patient information in EHRs is time consuming, EHRs efficiency cannot be overlooked.

The table below indicates themes, categories and findings based on the first set of interview questions pertaining to the first sub-question mentioned above. In other words, the findings discussed above discuss the experiences of healthcare professionals when

using EHRs for decision-making. The number of occurrences of the codes for each theme is indicated by the number in the parenthesis next to the theme.

Table 6: Summary of findings on healthcare professionals' experiences using EHRs from three cases.

Sub Research Question	Key Concept	Themes	Categories
SRQ 1: How do the experiences of healthcare professionals while using existing electronic healthcare records influence the outcome of the decision-making process?	1.1 EHR use experience	- EHR Benefit (9)	- EHR benefit - Paper-based vs EHR - Sharing
		- Patient Information (5)	- Access - Modifiable - Patient information source - Summarising
		- Technology use benefit (6)	- Access - Backups - Organisation - Reduced paper use - Redundancy
	1.2 EHR use impact	- EHR benefit (5)	- Decision-making - Patient record viewing
		- Technology use benefit (1)	- Paper-based vs EHR
		- Work functions (3)	- Work functions
	1.3 EHR use challenges	- Patient information (10)	- Access - Information loss - Patient information completeness
		- Context (1)	- Context
		- Patient narratives (2)	- Narrative impact - Narratives
		- Technology use challenges (15)	- Connectivity - Consistency - Cost of HER - Data loss - Decision-making - EHR challenges - Functionality - Technical issues - Time-consuming capturing - Training - Uniformity
	1.4 Effect of EHR use	- Patient consultation (4)	- Consult with patient - Consultancy time increases - Patient trust

- Patient information (2)	- Availability
- Patient narratives (1)	- Narrative sharing
- Technology use (2) -	- Paper-based preference
- Technology use challenges (13)	- Cost of EHR - Discrepancies - Duplication - Narratives - Paper-based vs EHR - Paper-based preference - Resistance to change - Time to learn new systems - Time-consuming capturing
- Work functions (1)	- Work functions

	A	B	C	D	E	F
1	Q#	Theory code/Key concept	Code	Category	Sub-theme	Theme
2	1.1	EHR use experience	Ability to see patterns	EHR benefit	EHR Benefit	EHR
3	1.1	EHR use experience	Easy recording	EHR benefit	EHR Benefit	EHR
4	1.1	EHR use experience	Easy to manage prescriptions	EHR benefit	EHR Benefit	EHR
5	1.1	EHR use experience	EHR effective tool	EHR benefit	EHR Benefit	EHR
6	1.1	EHR use experience	EHR effective tool	EHR benefit	EHR Benefit	EHR
7	1.1	EHR use experience	Trace patient history	EHR benefit	EHR Benefit	EHR
8	1.1	EHR use experience	Easy printing	Paper-base versus EHR	EHR Benefit	EHR
9	1.1	EHR use experience	Easy referencing	Paper-base versus EHR	EHR Benefit	EHR
10	1.1	EHR use experience	Easy sharing	Sharing	EHR Benefit	EHR
11	1.1	EHR use experience	Access to patient history	Access	Patient information	Patient information
12	1.1	EHR use experience	Data protection	Access	Patient information	Patient information
13	1.1	EHR use experience	Editable data	Modifyable	Patient information	Patient information
14	1.1	EHR use experience	Only one source	Patient information source	Patient information	Patient information
15	1.1	EHR use experience	Summarised patient data	Summarising	Patient information	Patient information
16	1.1	EHR use experience	Easy access	Access	Technology use benefits	Technology
17	1.1	EHR use experience	Real-time information	Access	Technology use benefits	Technology
18	1.1	EHR use experience	Backups	Backups	Technology use benefits	Technology
19	1.1	EHR use experience	Organised patient files	Organisation	Technology use benefits	Technology
20	1.1	EHR use experience	Reduced paper use	Reduced paper use	Technology use benefits	Technology
21	1.1	EHR use experience	Reduced redundancy	Reduncy	Technology use benefits	Technology
22	1.2	Impact of EHR on work	Less errors	Paper-base versus HER	Technology use benefits	Technology

Figure 9: Sample of themes under healthcare professionals' EHRs use.

4.4.2. Incorporation of narratives in EHRs to aid the decision-making process in oncology

The below responses are generated from the second set of interview questions that answered this sub-question: How can narratives be captured in electronic health records to support the decision-making process?

Table 7: Key concepts for interview question 2

Interview Question	Key concept
2.1	Note taking during consultation with patient - Patient engagement methods
2.2	Narrative use
2.3	Narrative for decision-making
2.4	Narrative impact

1. Case1: Private hospital 1 (PH1)

When asked about the use of narratives in oncology care, the findings show that the majority of participants (six out of seven) use narratives to interact with their patients. They emphasised that patients' narratives are at the core of oncology care because 90% of oncology work revolves around patients' narratives.

Narrative is an approach used by doctors that allows a patient's story to be heard and experienced by both healthcare professionals and patients. These narratives are used to record the diagnosis, treatment and recovery process to promote well-being (Charon, 2012). In this case, narratives that are present in oncology care are mostly written narratives that are usually on paper and later typed in EHRs.

For further clarification on the presence of narratives in oncology care, one of the seven participants said: "*Written narratives are present in oncology care, but limited only to the diagnosis phase because it is a phase based on the patient's story*" **(OC1-PH1-r2.1)**. These narratives are often "*answers given by patients through interviews or by filling out questionnaires which are later typed into the patient's EHRs*" **(OC4-PH1-r2.3)**. Written narratives guide healthcare professionals in their patient treatment approach, but unfortunately with the use of questionnaires *"important information is left out by the*

patient due to laziness, compromised literacy levels or a reluctance to share information in writing" **(OC4-PH1-r2.3)**.

When asked how the use of patients' written narratives impact the outcome of decision-making and the treatment process, five out of seven participants said that every patient's story is important as it defines the diagnosis process as well as the subsequent treatment. That why EHRs comprise "*initials of patients' written narratives and comprehensive notes*" **(OC1-PH1-r2.2)** to make sure that *"no important information that support the scientific results is omitted"* **(OC2-PH1-r2.2).** *"I strongly believe that narratives in oncology can do wonders as most patient stories present the root to their sickness and the beginning of the treatment process"* **(OC4-PH1-r2.4)**. As one out of seven participants said: "*I allow my patients to tell their story, because I wish to extract intrinsic value from their narratives for better care and decision-making* **(OC1-PH1-r2.2)**.

Even though written narratives are used in oncology care, most healthcare professionals said: *"We don't convert everything in the patient's story into medical jargon"* **(OC1-PH1-r2.4)**. *We include some elements of what the patient said, and in some cases, we quote the patient's narrative for components that were very specific or of crucial importance"* **(OC3-PH1-r2.2)**.

Five of the seven participants were of the opinion that using patients' written narratives throughout the entire medical journey does not only enhance decision-making, but also provides healthcare professionals with a better understanding and proficiency in dealing with patients. In other words, patients' narratives are used for better decision-making, and therefore they have a positive impact. Decision-making in healthcare depends on scientific processes and on what story the patient tells. As one participant put it *"...whatever the story is, will determine the treatment"* **(OC1-PH1-r2.4)**. In fact, when patients' narratives are used in decision-making and in the treatment process "*the outcome is always satisfactory no matter what the circumstances are*" **(OC4-PH1-r2.4)**.

From the above responses, it is obvious that written narratives are present in the diagnosis phase of private oncology care, and they play a major role in the decision-making process. It has however been established that when the method of obtaining patient narratives is questionnaires, and not interviews, errors in the decision-making

process may occur. This especially applies when questionnaires are not fully completed by the patient, yet their partially filled out information is typed into the patient's EHRs.

When asked about the use of electronic narratives (audio and video) in oncology care, all the participants (seven out of seven) mentioned that currently there is no presence of electronic narratives (audio and video) in oncology care. **Electronic narrative** is a digital version of a patient's narrative which combines video, sound, animation, text, music and narrative voice. This assists both the healthcare professional and the patient with regards to recording the diagnosis, as well as the treatment and recovery process (Cunsolo, Harper & Edge, 2012).

When asked about the use of electronic narratives to support decision-making in oncology care, it was evident that there was a lack of knowledge about the subject. Nevertheless two out of seven participants mentioned that they have been reading and familiarising themselves with narratives in healthcare **(OC1-PH1-r2.4; OC2-PH1-r2.4)** . In this vein, five of the seven participants said that they were eager to see electronic narratives implemented in their oncology care centres. One of the participants said: "*Narratives in oncology care are interesting. I did not know that patients' stories can be part of EHRs or that it could change the way we treat cancer patients*" **(OC1-PH1-r2.4)**.

Another participant added*… "I am doing an online course about narratives in oncology care and I am eager to apply it in my daily practice"* **(OC2-PH1-r2.4)**.

Furthermore, one out of seven participants responded: *"If written narratives (paper-based) give us the indices of what is wrong with the patient when we start a conversation, I can only imagine how much more effective audio and video narratives in EHRs can be. I admit it can help in decision-making, and it could also serve as a reminder in case some important information is left out during the treatment process of a patient"* **(OC1-PH1-r2.4).**

When asked how narratives can be captured, a respondent suggested: *"I believe narratives can be in written, audio and/or video format* **(OC2-PH1-r2.3)**. The same respondent concluded that by "*incorporating audio and video narratives in EHRs, it can provide health practitioners with a clear picture of what is wrong with the patient over a*

prolonged period. This will help in decision-making as EHRs have the capacity of summarising patient information on a screen which helps health practitioners in taking further action". An additional benefit to electronic narratives is that proof exists should "*legal issues*" **(OC1-PH1-r2.2)** arise between healthcare professional and patient.

Five out of seven participants considered the functionality of recording patients' narratives in EHRs "*the best gift they can offer to their patients and to themselves"* since "*most family members request their relative's EHRs* **(OC1-PH1-r2.2; OC3-PH1-r2.2)**. Several participants (five out of seven) said that the inclusion of audio and video narratives in EHRs is of high importance because electronic narratives can *"increase the willingness to communicate, and it can also teach both patient and health practitioner about different cultures which, in turn, should encourage empathy and optimism"* **(OC1-PH1-r3.2; OC2-PH1-r3.2; GP1-PH1-r3.2; PD1-PH1-r3.2)**.

It can therefore be said that there is a need for electronic narratives in oncology care. In fact, healthcare professionals testify to how valuable patients' electronic narratives are, and how the use of electronic narratives with evidence-based results can improve decision-making.

There are however legal and ethical considerations that should be applied when incorporating narratives in EHRs. Patients' narratives are confidential and the moment patients realise that they will be recorded, "*it may change the dynamic of their stories, and create trust issues*" **(PD1-PH1-r2.3)**.

From the above responses, it is evident that narratives in EHRs are still at an infancy stage in private oncology care centres of Cape Town.

2. Case2: Private hospital 2 (PH2)

When asked about the use of narratives in oncology care, the findings show that the majority of participants (five out of six) use narratives. One participant said: "*Narrative is an essential element of treatment in oncology – without patients' narratives, the treatment is incomplete*" **(OC6-PH2-r2.1)**. For further clarification, the participant added…"*we use written notes (paper) to collect patients' narratives, and these are recorded in the patients' EHRs at a later stage* **(OC8-PH2-r2.3)**. This is not "*an efficient*

way of collecting patients' narratives as it is time consuming and it diverts our focus away from patients' narratives to writing" **(OC7-PH2-r2.3)**. These notes are…"*always summarised and recorded in EHRs in short form (abbreviation) which sometimes makes the decoding of it challenging for other healthcare professionals*" **(GP3-PH2-r2.3)**.

When asked how the use of patients' written narratives impact the outcome of decision-making and the treatment process, three out of six participants said that patients' narratives provides essential information at the root of the sickness. Having access to such crucial information supports the overall decision-making of health practitioners **(OC6-PH2-r2.3; OC8-PH2-r2.3; GP2-PH2-r2.3)**. As one participant said: "*The foundation of treating a cancer patient begins with his/her story, therefore, narratives instil value in decision-making*" **(OC7-PH2-r2.2)**. Unfortunately, "*patients are not given enough time to express themselves because healthcare professionals are often simply too busy*" **(OC8-PH2-r2.2)**. Four out of six participants said that "*it is so unfortunate that patients' narratives are limited to the diagnosis stage as this leaves a gap in the decision-making process*" **(OC6-PH2-r2.3; OC8-PH2-r2.3; GP2-PH2-r2.3)**.

When asked about the use of electronic narratives (audio and video) in oncology care, all participants (six out of six) mentioned that presently there is no electronic narratives (audio and video narrative) in oncology care. When asked about the use of electronic narratives to support decision-making in oncology care, it was obvious that there was limited knowledge about the subject. However, one out of six participants mentioned that he had been reading about narratives in oncology, and said: "*I believe electronic narratives can support the decision-making process since detailed information of patients' health can be retraced to support evidence-based treatment (laboratory results)*" **(OC8-PH2-r2.4).** When asked how narratives can be captured, the same respondent said*: "I trust narratives can be in written and audio format"* **(OC8-PH2-r2.3)**.

The above responses prove that the presence of narratives in EHRs is limited to the diagnosis phase. In other words, despite the advantages of EHRs, it is evident that electronic narratives have not been introduced in private oncology care of Cape Town.

3. Case 3: Private hospital 3 (PH3)

When asked about the use of narratives in oncology care, the findings show that the majority of participants (four out of five) use narratives in short form notes. These notes are "*written when healthcare professionals are interacting with patients*" **(OC9-PH3-r2.1)**. These narratives are important for healthcare professionals "*to understand the source of the patient's health problem in order to decide on an appropriate treatment process*" **(OC10-PH3-r2.3)**.

When asked how the use of patients' written narratives impacts the decision-making and the treatment process, two out of five participants said: *"Decision-making cannot be processed if patients' narratives are not involved*" **(GP4-PH3-r2.3)**. Another participant further added: "*Patients' narratives are the driving force behind treatment decision-making*" **(OC10-PH3-r2.2)**.

When asked about the use of electronic narratives (audio and video) in oncology care, all participants (five out of five) said, electronic narratives have not been used because… "*There is no appropriate system put in place*" **(OC9-PH3-r2.1)**. Another respondent added that: "*I believe there is limited knowledge available on narratives and electronic narratives*" **(GP5-PH3-r2.3)**. Participants however did express that they believe electronic narratives can support decision-making. As one participant pointed out: "*Stories are powerful and they contribute enormously to the patient's well-being*" **(PD3-PH3-r2.4).**

The findings for the second sub research question are presented in Table 7 on the next page.

Table 8: Findings on incorporating narratives in EHRs to aid the decision-making process in oncology from the 3 oncology centres.

Sub Research Question	Key Concept	Themes	Categories
SRQ 2: How can narratives be captured in electronic health records to support the decision- making process?	2.1 Patient engagement methods	- eNarrative use challenges (5)	- eNarrative use challenges
		- eNarrative use benefits (1)	- eNarrative use benefits
		- Patient consultation (3)	- Patient consultancy - Time-consuming capturing
		- Patient information (2)	- Patient consultancy - Patient record completeness
	2.2 Narrative use	- eNarrative use challenges (9) -	- eNarratives - eNarratives use challenges
		- eNarrative use benefits (9)	- eNarratives - eNarrative use benefits
		- Narrative interest (1)	- Narrative interest
		- Narrative use (7)	- Narrative use - Narrative use benefits
		- Patient information (3)	- Narrative use benefits - Patient record completeness - Summarise
		- Patient narratives (1)	- Summarise
	2.3 Narrative for decision-making	- Narrative support decision-making (3) - Patient information (1)	- Narrative support decision-making - Narrative use benefits - Patient record completeness
	2.4 Narrative impact	- eNarrative use challenges (1)	- eNarratives
		- Narrative impact (2)	- Narrative impact
		- Narrative support decision-making (4)	- Narrative impact - Narrative support decision-making
		- Patient information (1)	- Data protection

	A	B	C	D	E	F
82	Q#	Theory code/Key concept	Code	Category	Sub-theme	Theme
83	2.1	Narrative during consultation	Narrative add value to patient information	Narrative use benefits	eNarrative use benefit	eNarrative
84	2.1	Narrative during consultation	Narrative only partially captured	Narrative use challenges	eNarrative use challenges	eNarrative
85	2.1	Narrative during consultation	Noting narratives divert attention away from patients	Narrative use challenges	eNarrative use challenges	eNarrative
86	2.1	Narrative during consultation	Recording narratives may intimidate patients	Narrative use challenges	eNarrative use challenges	eNarrative
87	2.1	Narrative during consultation	Narrative notes on paper	Patient consultancy	Patient consultation	Patient consultation
88	2.1	Narrative during consultation	Narratives recorded later	Patient consultancy	Patient consultation	Patient consultation
89	2.1	Narrative during consultation	Limited time for patients to tell their stories	Time-consuming capturing	Patient consultation	Patient consultation
90	2.1	Narrative during consultation	Narratives as short notes	Patient consultancy	Patient information	Patient information
91	2.1	Narrative during consultation	Incomplete capturing of narratives	Patient information completeness	Patient information	Patient information
92	2.1	Narrative during consultation	Narrative time consuming	Patient consultancy	Narrative use challenges	Patient narratives
93	2.1	Narrative during consultation	Note taking during consultation	Patient consultancy	Narrative use challenges	Patient narratives
94	2.2	Narrative use	Electronic narratives can have communication benefit	eNarratives	eNarrative use benefit	eNarrative
			Electronic narratives could have			

Figure 10: Sample of themes under narratives in EHRs.

4.4.3. Requirements for incorporating narratives in EHRs to support decision-making in oncology care.

The answers below were generated from the third set of interview questions regarding this sub-question: What informs the inclusion of narratives in electronic health records to support the decision-making process?

Table 9: Key concept for sub research question 3

Interview Question	Key concept
3.1	Narrative use preference

1. Case1: Private Hospital1 (PH1)

When asked about the requirements of incorporating narratives in EHRs to support decision-making, three out of seven participants said: "*Incorporating narratives in EHRs will require some electronic devices such as tablets, computers and even headphones. Recording software is also crucial to enable patients' electronic narratives to be captured*" **(OC1-PH1-r3.1)**. Therefore, it is important that "*narrative recording techniques are well understood and utilised*" (**OC2-PH1-r3.1)**

When asked how healthcare professionals would prefer patients' narratives to be included in EHRs to support decision-making, five out of seven participants mentioned that they prefer patient-recorded audios to be on the same page that displays the latest

patient EHRs **(OC1-PH1 -r3.1; OC2-PH1-r3.1; OC3-PH1-r3.1; OC4-PH1-r3; GP1-PH1–r3.1)**. Since written narratives are always typed in EHRs, "*functionalities to accommodate audio and video should be included to manage that type of information*" **(OC1-PH1-r3.1)**. In this vein, electronic narrative records should include aspects such as "*patient demographics, vital signs, diagnosis, medications, allergies, radiology images, audio, progress notes and test and laboratory results*" **(OC3-PH1)**.

1 out of 7 participant believed that: playing the audio record before taking further action on treating the patient "*fills the therapeutic gap in decision-making*" (**OC1-PH1-r3.1**). unfortunately, … "*we don't have a system that can record patients' electronic narratives, otherwise it could help to double check the story since it can automatically be saved in the system and can be accessed anytime*" **(OC2-PH1-r2.2)**.

When asked if patients' narratives in EHRs can support the decision-making process, six out of seven participants said that since 90% of oncology work revolve around patients' narratives, it is possible for electronic narratives to support the decision-making process. Two out of seven participants mentioned that including narratives in EHRs will, "…*definitely support the decision-making process*" **(OC4-PH1-r3.2, GP1-PH1 –r3.2)** because "*personal stories affect the judgements and values people have and the choices they make*" **(OC4-PH1-r3.2, GP1-PH1–r3.2)**. One of the seven participants however stated that... "*there is insufficient evidence about narratives supporting decision-making because we have no experience yet*" **(GP1-PH1 –r3.2)**.

2. Case 2: Private Hospital2 (PH2)

When asked about the requirements of incorporating narratives in EHRs to support decision-making, one out of six participants said: "*I believe that we need computers and a stable internet connection to record patients' narratives in EHRs*" (**OC6-PH2-r3.1**). Four out of six participants mentioned that patients' narratives are important and that they "*would like narratives to appear on the patient' EHRs summary page*" **(OC6-PH2-r3.1; OC7-PH2-r3.1; OC8-PH2-r3.1; PD2-PH2-r3.1)**. The same respondents believed that electronic narratives can support decision-making in oncology care. As one participant said: "*The accessibility to patients' narratives have the power to positively*

impact decision-making as detailed information on the patients' state of health is always available" **(OC7-PH2-r3.1)**.

3. Case 3: Private Hospital3 (PH3)

When asked about the requirements of incorporating narratives in EHRs to support decision-making, the majority of participants (four out of five) stated that they do not have the knowledge on what is required. As one respondent said: "*This question can be answered by people with information technology experience*" **(OC9-PH3-r3.1)**. When asked how healthcare professionals would prefer patients' narratives to be included in EHRs to support decision-making, one out of five participants said: "*I would prefer patients' narratives to be registered as a priority in patients' EHRs, so that it can be viewed before proceeding with patients' treatment*" **(OC10-PH3-r3.1)**. All participants (five out of five) believe that electronic narratives can support the decision-making process in oncology care **(OC9-PH3 -r3.1; OC10-PH3-r3.1; PD2-PH3-r3.1; GP4-PH3 – r3.1; GP5-PH3 –r3.1)**. One respondent suggested that "*patients' electronic narratives contain value that can save patients' lives if well understood and applied*" **(GP4-PH3 – r3.1)**.

Table 10: Findings on requirements for incorporating narratives in EHRs to support decision-making in healthcare from the 3 oncology centres.

Sub Research Question	Key Concept	Themes	Categories
SRQ 3: What informs the inclusion of narratives in electronic health records to support the decision-making process?	3.1 Narrative use preference	- eNarrative requirement (2)	- Narrative integration - Requirement
		- eNarrative use challenges (1)	- eNarrative challenges
		- eNarrative use benefits (1)	- eNarrative use
		- Narrative impact (1)	- Narrative impact
		- Narrative support decision-making (4)	- eNarrative support decision-making - Narrative support decision making
		- Narrative use (2)	- Narrative use benefits
		- Patient consultation (1)	- eNarrative during consultation
		- Patient information (1)	- Patient information completeness

- Patient narratives (1)	- eNarrative use
- Technology use challenges (3)	- eNarrative challenges - eNarrative use
- Technology use benefits (1)	- eNarrative patient information

Figure 11: Sample of themes under requirements for incorporating narratives in EHR

4.4.4. Barriers to the use of electronic narratives to support decision-making in oncology.

The responses below are from the set of interview questions from this sub-question: Why are narratives not being used in electronic health records to support the decision-making processes of healthcare professionals?

Table 11: Key concepts for research question four

Interview Question	Key concept
4.1	Diagnosis and treatment initiatives
4.2	Facilitate work

1. Case 1: Private Hospital 1 (PH1)

To understand the reasons why narratives are yet to be used to support decision-making in oncology care, one participant mentioned that "*limited knowledge about narratives and electronic narratives exists*" **(OC1-PH1-r4.1)**. Current EHRs do not support the inclusion of patients' stories but only allow for small notes. Therefore, there is a "*need for upgrading existing EHR systems*" **(OC3-PH1-r4.2)**. The same participant

(OC3-PH1-r4.1) stated that recording patient narratives will need "*extra expertise*" on how to deal with narratives in EHRs.

One out of seven participants mentioned that even if a system that processes patients' electronic narratives was available, he will "*prefer not to deal with patients' stories*" **(OC5-PH1-r2.4)**. Furthermore, one out of seven participants **(OC5-PH1-r2.4)** explained that they did not see the use of patients' narratives aiding decision-making as they would rather rely on scientific processes and results that they can trust.

2. Case 2: Private Hospital 2 (PH2)

To understand the reasons why narratives are yet to be used to support decision-making in oncology care, the majority of participants (five out of six) mentioned that electronic narratives are non-existent in their practice **(OC7-PH2-r4.1, PD2-PH2-r2.4, OC6-PH2-r4.1)**. To illustrate this point, one participant said: "*I have not heard of electronic narratives*" (**GP3-PH2-r2.4**). Another participant added that "*the current EHRs system does not have enough space for oncologist notes let alone patient electronic narratives.*" **(OC8-PH2-r4.1)**. Furthermore, one out of six participants said: *"EHRs are already complex. Adding electronic narratives will make it even more complicated, and it might change existing functionalities in EHRs"* **(OC6-PH2-r4.1)**. Participants shared the view that changes to EHRs or new EHRs would require significant training and expertise. One out of six participants did however say that "*electronic narratives can contribute to decision-making if these provide facts, and if the health practitioner is meticulous in following up on each patient's treatment*" **(OC7-PH2-r2.4)**.

3. Case 3: Private Hospital 3 (PH3)

To understand the reasons why narratives are yet to be used to support decision-making in oncology care, all participants (five out of five) mentioned that electronic narratives were new to them, and that it would take time to familiarise themselves with it. As one participant mentioned: "*I heard of the term electronic narratives but I have not yet had time to read or research it*" **(OC10-PH3-r4.1)**. Another participant added that "*training on the subject will be of importance in oncology care"* **(OC9-PH3-r4.1)**. From the above information, it is evident that there is limited knowledge about electronic

narratives in oncology care. Raising awareness about electronic narratives is important and should not only be limited to healthcare professionals but should also be extended to patients since narratives revolve around them.

Table 12: Findings on barriers to the use of electronic narratives to support decision-making in oncology from the 3 oncology centres.

Sub Research Question	Key Concept	Themes	Categories
SRQ 4: How can narratives be captured in electronic health records to support the decision- making process?	4.1 Diagnosis and treatment initiatives	- eNarrative use challenges (5)	- eNarratives
		- Technology use challenges (1)	- EHR challenges
	4.2 Facilitate work	- eNarrative requirement (2)	- Requirements plus
		- Technology use challenges (2)	- EHR challenges -
		- eNarrative use challenges (4)	- eNarrative challenges
		- eNarrative use benefits (1)	- eNarrative use

	A	B	C	D	E	F
154	Q#	Theory code/Key concept	Code	Category	Sub-theme	Theme
155	4.1	Diagnosis and treatment initiatives	Limited knowledge about narratives and eNarrative.	eNarratives	eNarrative use challenges	eNarrative
156	4.1	initiatives	Limited EHRs capacity.	EHR challenges	Technology use challenges	Technology
157	4.2	facilitate work	Expertise needed.	Requirement+	eNarrative requirement	eNarrative
158	4.2	Facilitate work	Necessity of training on eNarrative.	Requirement+	eNarrative requirement	eNarrative
159	4.2	Facilitate work	eNarrative use benefit	eNarratives	eNarrative use benefit	eNarrative
160	4.2	Facilitate work	Absence of eNarrative.	eNarrative challenges	eNarrative use challenges	eNarrative
161	4.2	facilitate work	Fear to embrace eNarrative.	eNarrative challenges	eNarrative use challenges	eNarrative
162	4.2	Facilitate work	Lack of eNarrative knowledge.	eNarrative challenges	eNarrative use challenges	eNarrative
163	4.2	Facilitate work	Lack of knowledge on eNarrative.	eNarrative challenges	eNarrative use challenges	eNarrative
164	4.2	Facilitate work	EHR system need upgrade.	EHR challenges	Technology use challenges	Technology
165	4.2	Facilitate work	Complexity of EHR system	EHR challenges	Technology use challenges	Technology

Figure 12: Sample of themes under barriers to the use of eNarratives.

4.5. Themes

It was found during the coding process that the same codes appear in different sub research questions which could be an indication of the participants' understanding of the questions. The coding process resulted in categories that in some cases are

combined to a sub theme. The coding table were then sorted by theme, sub-theme, category and code as indicated in Table 9 below.

Table 13: Themes across research questions

	Theme	Number of Sub-themes	Number of Categories	Number of Codes
1.	EHR	1	5	14
2.	eNarrative	3	7	33
3.	Patient consultation	1	6	8
4.	Patient information	1	10	25
5.	Patient narratives	4	12	32
6.	Technology	2	26	44
7.	Work functions	2	2	5
	Total	14	68	161

It is clear from the above table that technology, patient narratives and patient information represent most of the issues mentioned by the participants.

The themes mentioned below will be discussed in Chapter 5.

1. EHR   4. Patient information   7. Work functions

2. eNarrative   5. Patient narratives

3. Patient consultation 6. Technology

4.6. Ethical Considerations

Ethical considerations in research are crucial. The researcher is bound by a code of conduct to uphold the dignity, rights and safety of participants, and to ensure that the environment and participants are not harmed (Rossi et al., 2009).

No patient participated in the research and their information was not collected. Information collected from oncologists did not disclose any private patient information. The aim and objectives of the research were presented to the participants which gave them an overview of the study. Participants had a choice to voluntarily participate and/or to withdraw at any time without fearing potential repercussions. Consent letters were signed to grant official permission for the interviews and the research.

The research was carried out in Cape Town, South Africa and was limited to private oncology centres where participants were oncologists and associated healthcare professionals.

4.7. Conclusion

The researcher used thematic analysis to analyse the qualitative data. This technique was used to aid the researcher in arranging data according to participants' point of view based on a subjective understanding. From the collected data, themes were created, and findings were generated. The interview was structured around the four sub-questions that aimed to answer the main research question. The aim of the research was to explore the use of narratives in electronic health records to support the decision-making processes by healthcare professionals in private oncology care. This was met through analysing each and every interview question.

The findings show that EHRs have a positive impact on how healthcare professionals perceive the management of patient records which, in turn, contribute to improved decision-making. This does not exclude the fact that EHRs present some challenges that may slow down and frustrate healthcare professionals. Overall though, EHRs appear to simplify work activities for healthcare professionals especially within the decision-making process as EHRs automate certain manual work functions relating to

patient records. However, cost and resistance to change still affect the adoption of EHRs to include patients' narratives.

When asked about the presence of narratives in healthcare, most respondents admitted that 90% of healthcare work rely on patient narratives. Written narratives are present in healthcare – these narratives are mostly collected through questionnaires and/or interviews and directly typed into the system. This leaves a gap in the decision-making process as only scientific information that will provide evidence-based results is mostly retained and recorded. Furthermore, narrative is predominantly limited to the diagnosis phase during which information is collected by means of questionnaires. These forms are often not fully completed by the patient due to laziness, ignorance and/or discomfort with sharing personal experiences on paper. In summary, the absence of electronic narrative records (audio and video) is due to a lack of proper infrastructure, limited knowledge about narrative in EHRs, and conflicting cultural beliefs. It can therefore be said that narratives in EHRs are still at the infancy stage in oncology care centres of Cape Town.

CHAPTER FIVE – DISCUSSION OF FINDINGS

5.1. Introduction

The aim of this study was to explore how oncology specialists use narratives in electronic health records to support the decision-making process in patient care. In particular, the study focused on the use of patient narratives in EHRs, and it explores potential reasons behind not incorporating or using electronic narratives in private oncology care. This chapter presents a descriptive and informative discussion of findings in relation to the literature review. The study used a thematically analysis, resulting in seven important themes that are discussed in detail in this chapter.

5.2. Presentation of themes

5.2.1. Electronic Health Records (EHRs)

According to Ford et al. (2016), the adoption of EHRs has steadily increased in high income countries like the USA. The authors highlighted that since 2014, the implementation of EHRs has been growing due to availability of affordable technology and devices such as computer tablets. In fact, 97% of healthcare facilities have been using basic EHRs with a minimum use of core functionalities that are essential to an EHR system (Evans, 2016; Ford et al., 2016; Sittig, Belmont & Singh, 2018). The core functionalities of EHRs are necessary information needed in healthcare for proper service delivery. These include patient medication lists, patient history, surgical history, clinical documents and clinical notes. Jamoom et al. (2012) argue that most low and middle income countries are struggling to adopt basic EHR systems with minimum core functionalities due to financial constraints.

Boonstra, Versluis and Vos (2014) stated that there are requirements needed to consider before adopting EHRs such as:

Practicing readiness assessment: The healthcare facilities must have proper infrastructure, processes and skilled personnel that are trained to effectively make use of the system.

Practicing transition planning: Healthcare facilities must apply for recovery and reinvestment funding, transition plans, change management, vendor selection, contract negotiations and training requirements. These factors are required to facilitate the smooth transition of information into the new system.

EHR implementation: There is a need for project management oversight, work overflow redesign, change management, training, and installation before going live with an EHR system.

There are challenges oncology care face when adopting EHRs. These challenges manifest when converting or transitioning information from one EHR system to another type of EHR system. It may result in significant system delays (Ajami & ArabChadegani, 2013). The adoption of a new system may even initially result in two systems running simultaneously. This process is costly and time consuming, but essential, since users often first have to familiarise themselves with the new system. Therefore, there is a need for flexibility when using EHRs due to the variety of EHR systems available and their respective connections to external systems such as x-ray results and libraries of medication. As result, it is crucial that EHRs are fully integrated by the time they are used in order to avoid malfunctions and unnecessary challenges.

EHR systems have the potential to significantly improve the quality of patient care. However, there are barriers to the implementation of EHRs, and these need to be addressed by the oncology management team before committing to the adoption (Palabindala, Pamarthy & Jonnalagadda, 2016). Barriers include legal complications and an increased risk of medical error.

Legal complications: System providers are responsible for reducing errors during the transition phase (from one system to another), and healthcare facilities have the duty to ensure that healthcare professionals have timely access to laboratory results. Furthermore, healthcare facilities are responsible for ensuring appropriate policies and technical support are always available to prevent any incidents that can arise while using the system. Should these not be in place, the hospital may face the risk of losing their operating license.

Risk of medical error: System providers must remain involved after the implementation phase has been completed. No electronic system is ever fully guaranteed, therefore system providers must ensure that maintenance and updates are done on a regular basis.
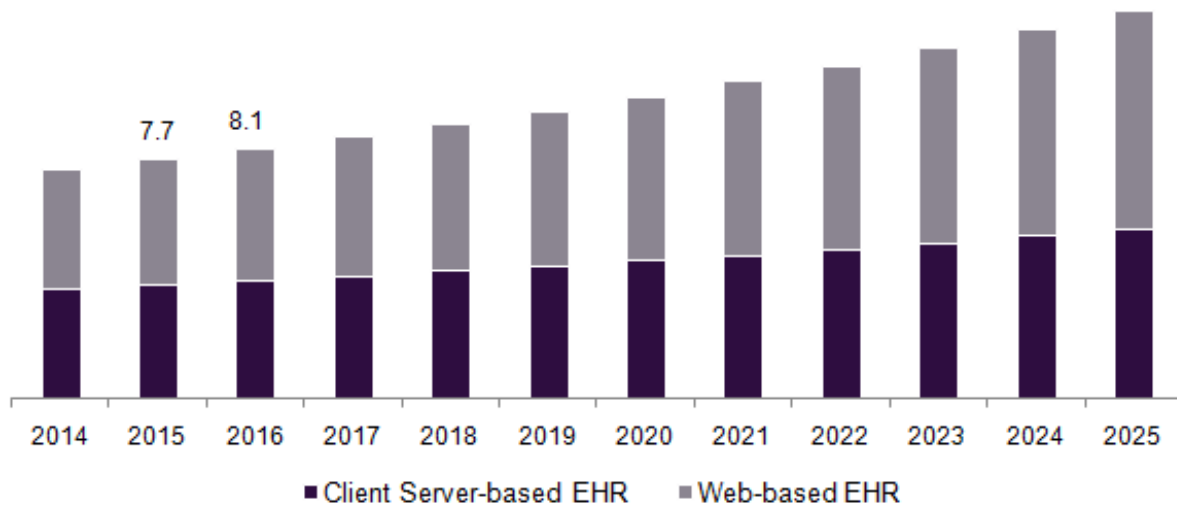
Figure 13: EHRs use and adoption prediction by 2025 (Evans, 2016).

The figure above demonstrates the historic adoption of EHRs, and the predictions forecasted for the implementation and use of EHRs. It confirms that EHR adoption is increasing every year (Ford et al., 2016 & Evans, 2016).

According to Ford et al. (2016), there are three key aspects to consider when adopting a new EHR system in oncology care. These are culture, time and cost.

5.2.1.1. Culture

The adoption of new systems or functionalities in oncology care is sometimes not well received by all users, and this may result in a slow adoption process. When implementing new technologies, the unique aspects of individual users are frequently not discussed (Russo et al., 2016). These include patients' preferences, cultural beliefs, personal values and expectations. If these are not incorporated or acknowledged, it could create a gap in the delivery of healthcare. In this vein, two participants (OC8-PH2-r1.4; GP4-PH3-r1.4) mentioned that they are comfortable using both EHRs and paper-

based records, yet they admitted that registering paper-based information into EHRs leaves a potential gap in the decision-making process when interpreting patient's information. The gap is especially evident when valued information *"is left on paper because some EHRs do not have the required functionalities to register information such as the patient's story or x-ray results" (*GP4-PH3-r1.4).

Furthermore, eight participants mentioned that culture is at the core of adopting and implementing new functionality in EHRs. For example, two participants clarified that "*many patients are conservatives, they value their customs and beliefs*" (OC1-PH1-r4.1). Similarly, another participant confirmed that "*for some patients, sharing their stories is challenging*" (OC10-PH3-r4.1). Hence, considering patient narratives will bridge communication gaps and provide more patient-centred care.

Erasmus et al. (2017) described the role of cultural ethics as a fundamental aspect to consider when creating and sharing narratives. When a healthcare professional records an audio or video narrative of a patient, ethical concerns need to be addressed and complied with to avoid misquotation (Erasmus et al., 2017). Two participants mentioned that even if a system that processes patients' electronic narratives was available, they will "*prefer not to deal with patients' stories*" (GP1-PH1-r4.1; OC9-PH3-r4.1). Two other participants emphasised that they would rather rely on scientific treatment processes because tests can be done which produce results that are used in decision-making (OC5-PH1-r2.4; GP3-PH2-r2.4). Ford et al. (2016) said that healthcare professionals usually resist the adoption of new systems because it requires new knowledge and skills that would necessitate additional training.

The authors added that it takes between eight to twenty hours of training before healthcare professionals feel confident with the use of a newly implemented system or functionality in EHRs. Different cultures have different values that must be protected and respected whenever patient information is involved (Russo et al., 2016).

5.2.1.2. Time

According to Poissant (2005), time plays a major role in the delivery of healthcare. In order for a health practitioner to make correct decisions, patient data must be accurate.

EHRs ease the process of saving patients' records digitally, and this enhances the overall process of documentation (Gesulga et al., 2017; Kruse et al., 2017). Healthcare professionals may however experience a delay in the system. This is especially experienced when healthcare professionals search for x-ray results that take longer due to picture loading. This could result in time pressure constraints when healthcare professionals do not easily access evidence to support their decisions. It could even produce errors in the decision-making process (Chen, Huang & Yeh, 2017).

Furthermore, when healthcare records are presented in different formats (tables, numbers, letters and pictures), data entry may be slow, time-consuming and demanding (Gesulga et al., 2017). As one participant mentioned: "*EHRs have many functionalities and I did not have enough time to practice, but I prefer paper-based records since the process is faster*" (OC8-PH2-r1.4). Another participant said: "*There is no need to waste time on recording information into a system…I have no passion for IT-based systems – they are too complicated*" (GP4-PH3-r1.4)*.* From the above responses, it is clear that healthcare professionals prefer the simplest and easiest way to record data into EHRs.

The issue of time also affects EHRs when other functionalities such as patient' narratives (written, audio and video) are added. The majority of participants mentioned that they interrupt their patients very early on in their stories as they are pressed for time and need to address the matter quickly (OC3-PH1-r2.1; PD1-PH1-r2.1; OC4-PH1-r2.1; OC8-PH2). Warner et al. (2016) said that narratives present positive results to support healthcare service delivery, but integrating narratives can be challenging because it is time-consuming when recording. In addition, the majority of participants suggested that healthcare professionals should set longer appointment times so that patients' stories can be heard and valued. One participant suggested that narratives should have a "*regulated time*" (OC10-PH3-r3.1). In other words, a patient's story should be limited to three minutes and only *"relevant/important information"* should be recorded (OC10-PH1-r3.1)*.*

5.2.1.3. Cost

According to Palabindala, Pamarthy and Jonnalagadda (2016) the estimated cost of EHRs ranges from USD $15,000 to USD $162,000 per provider. Many factors

contribute to the cost of EHRs. Firstly, the development and design of the system: EHRs are characterised by the interfaces and integration processes it offers, particularly with respect to other EHRs and external systems. Implementation decisions, regulatory requirements, compliance and certification impact the cost of EHRs. In-house or locally-hosted systems tend to be expensive. Integrating a new system in healthcare is further costly in terms of implementation and maintenance. As one respondent mentioned: "*Healthcare services are increasingly becoming more and more expensive due to new IT services and inventions*" (OC4-PH1-r1.4).

Secondly, the customisation, implementation and maintenance of a new system contribute to the overall costs. New functionalities and interfaces also require training which can be costly. In the case of adding functionality such as narratives to EHRs, the majority of participants said that "*customising EHRs to meet the needs of healthcare practitioners like patients' narrative will be costly*" (OC8-PH2-r2.2). In this vein, one participant explained that **"***this expense does not only affect the healthcare facility but also the patients as they will be expected to pay for the service*" (OC4-PH1-r1.4). Narratives are recorded in different formats – written, audio, images and videos. According to Reis et al. (2017), securing such rich information often increases healthcare costs. Other additional costs are experienced through regular system upgrades. These also create a fragile and/or unpredictable environment for healthcare practioners which adds to their reluctance to incorporate additional EHRs functionalities.

Palabindala, Pamarthy and Jonnalagadda (2016) advise that it is best to compare EHR pricing from different service providers, and to critically scrutinise EHRs functionalities to determine what is best suited to the needs of any particular practice or hospital. In this process, questions pertaining to data migration costs and training timelines should be addressed. Despite costs playing an important role in the adoption of EHRs, healthcare facilities and healthcare professionals are increasingly pressured to implement and utilise EHRs as the health industry is seeing clear benefits as result of it (Reis et al., 2017). According to Kruse et al. (2017), the use of EHRs have actually reduced healthcare expenses. This is mostly as result of the reduction of paper usage and physical storage since all information is collected and kept digitally. Furthermore, EHRs generate detailed and customised financial reports, electronic medical accounting and charting software which lessens transcription costs and the outsourcing of services. In

addition, the use of email efficiently facilitates task management and increased communication (Schnipper & Middleton, 2012; Embi et al., 2013; Ohno-Machado, 2014).
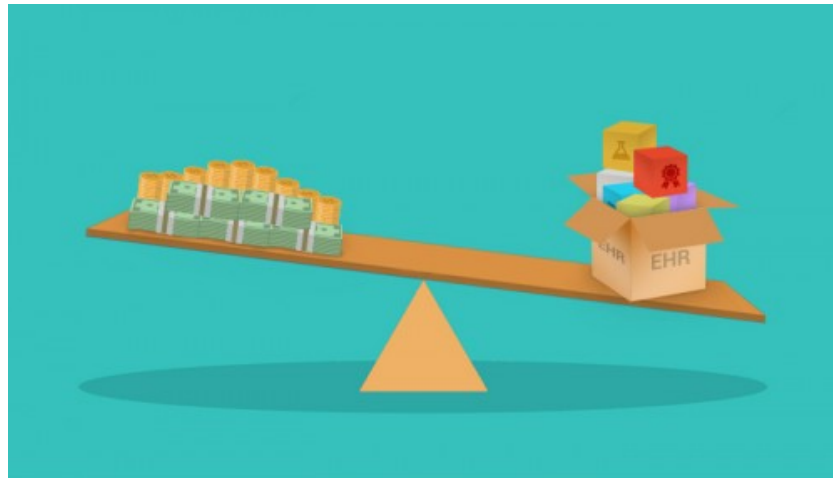
Figure 14: EHR Cost (Reis et al., 2017)

5.2.2. Work functions

The data analysed under this topic aims to explore how the experiences of healthcare professionals, with the use of existing EHRs, influence the outcome of their decision-making process.

The findings indicate that electronic health records (EHRs) have been adopted in private oncology care centres. Considerable benefits have been reported such as easy accessibility, effortless referencing, well organised files, available patient history, on-demand printing capabilities, editable data, and the ability to summarise and share patient information. These functionalities transform clinical oncology research and activities as previous manual processes are simplified and expedited (Kruse et al., 2017). In this vein, some participants mentioned: *"EHRs have been evolving in oncology care and they have positively impacted the way patients' records are viewed"* (OC1-PH1-r1.1; OC10-PH3-r1.1; OC8-PH2-r1.1; OC4-PH1-r1.1). To support this point, another respondent indicated that *"EHRs are easy to access because patient records are well organised, and patient information history can be easily backtracked"* (OC2-PH1-r1.1). Ajami and ArabChadegani (2013), Devkota and Devkota (2014), and Kruse et al. (2017) argue that the true benefits of EHRs in oncology are increased productivity, uplift in

revenue, reduction in costs, improved clinical decision-making, enhanced documentation, and ultimately, better delivery of patient care.

5.2.2.1. Increase productivity

Automation of clinical processes enables healthcare professionals to save time. In clicking a patient's name on the EHR system, all patient information is summarised and available. One participant (OC2-PH1-r1.4) responded that "*EHRs absolutely increase productivity since all the patient's information is summarised on a screen*". Conversely, the issue of saving time can be disrupted when healthcare professionals encounter delays as result of certain functionalities not being integrated into EHRs (Gesulga et al., 2017). In the context of health information technology, functionality is the sum of processes a software application can perform for healthcare professionals to facilitate the effective delivery of service (Evans, 2016). The integration of diagnostic devices and results such as x-rays, images and medication libraries are fundamental to the successful usage of EHRs. One participant said: "*There is no functionality to assist with a library of medication in EHRs. You have to manually type every medication and reference them*" (OC6-PH2-r1.3). This illustrates that although EHRs are adopted depending on the needs of healthcare services and their capacity to introduce technology, the lack of preferred and specific functionalities in EHRs could impede the decision-making process (Jamoom et al. (2012). As it stands currently, healthcare professionals often have to add and search for information missing from the EHR. This could be time consuming which, in turn, may reduce the intended efficiency of EHRs (Wu & LaRue, 2017).

5.2.2.2. Improve clinical decision-making

Palabindala, Pamarthy and Jonnalagadda (2016) said that EHRs provide built-in tools to enhance decision support at the point of care. These built-in tools support diagnoses, prescription of medications, automated health maintenance reminders and treatment plan recommendations. The information stored in EHRs assists healthcare professionals in their decision-making process, and can be used for future reference (Devkota & Devkota, 2014). EHRs contain information such as laboratory test results, images from radiology, allergy information and warnings, dates and schedules of patients' immunisations, medical dictionaries,

adverse drug event (ADE) alerts, generic drug and dosage recommendations, diagnoses, medical records, vital sign readings, progress notes, patient demographics, and billing and administrative data (Ohno-Machado, 2014). This information in EHRs contributes to the reduction of prescription errors, and it increases the adherence to clinical protocols. Furthermore, it improves population disease management and risk mitigation. Some participants confirmed that EHRs improve decision-making due to real time access to information (OC2-PH1-r1.4; OC9-PH3-r1.2). However, there are instances where healthcare professionals cannot access the patient's information in EHRs due to technical issues. A respondent explained that when such an incident arises, healthcare professionals usually "re-*examine the patient and cross-check previous data with the patient*" (PD3-PH3-r1.3). This can however "*contribute to* errors *in decision-making since not all information can be remembered*" (GP5-PH3-r1.3). Contrary to the responses above, one participant was of the opinion that "*EHRs do not really help in decision-making*" (OC5-PH1-r1.4). This participant argued that decision-making is based on "a *patient's past medical history, surgical history, life circumstances, family history and findings during consultation. Yet, some EHRs do not have this information nor the options to save it*" (OC5-PH1-r1.4). As Ohno-Machado (2014) mentioned, different EHRs in healthcare have different functionalities. If not correctly and effectively utilised, healthcare professionals may never experience the full potential of EHRs.

5.2.2.3. Enhance documentation and accessibility

EHRs increase accuracy by permitting multiple authorised users to access patients' charts simultaneously for real time documentation (Evans, 2016). Furthermore, EHRs increase legibility and completeness of patient records as well as the ability to customise data for reporting, research, drug recalls and patient marketing. The lack of adequate security and storage of data present challenges to EHRs such as hacking and eavesdropping (Ajami & ArabChadegani, 2013). One of the participants mentioned that "*there are issues with data protection and privacy. For example, theft, vandalism, eavesdropping and hacking*".

It is vital that patient information is protected due to the sensitive and confidential nature thereof. As a participant commented: "*We must ensure that the system is not easily hackable*" (OC2-PH1-r1.3). In can therefore be concluded that EHRs require superior information and system security measures.

5.2.2.4. Deliver better patient care and scheduling

EHRs increase patient satisfaction by offering self-assisting features that enable patients to schedule/cancel appointments online or access lab reports from home (Belmont & Singh, 2018). EHRs further improve in-patient access to care by using a secure internet connection that allow healthcare professionals to conduct web consultations and/or generate reports from home or office. In addition, EHRs also contribute to an improvement in preventive care by tracking patient health maintenance reminders, compliances and follow-up activities (Ajami & ArabChadegani, 2013).

According to Wu and LaRue (2017), EHR benefits are experienced and evaluated depending on the different EHRs functionalities. Decision-making in oncology care depends on the available information in the patient EHRs. If there is missing information, the service outcome could be inadequate (Devkota & Devkota, 2014). Evans (2016) said that EHRs positively impact decision-making due to its easy accessibility and information summary displayed on the screen that render healthcare professionals less prone to errors.

Despite the advantages that EHRs present, there are challenges that healthcare professionals face when using EHRs such as technical issues, loss of data, data capturing, and omitting information when typing in EHRs (Gesulga et al., 2017). As one participant explained: "*Data that has been captured gets lost when connectivity is lost before content can be saved, or it could even be deleted*" (OC3-PH1-r1.3). Data loss can impact healthcare service outcomes since healthcare professionals may not have access to relevant information at that specific moment (Wu & LaRue, 2017). As result, one participant shared that "*we must be conscious of regularly backing up data off site*" (OC4-PH1-r1.3). As Yanamadala et al. (2016) said, the reduction of data loss can only be done through electronic backups.

5.2.3. Electronic narrative / eNarrative

In this section, the researcher discusses the research findings to establish the essential requirements for incorporating narratives in electronic health records to support healthcare professionals in decision-making.

According to Langhan et al. (2014) the methods and reasons for adopting new technologies are often poorly understood by healthcare professionals. The driving force behind the decision to implement new technologies must always be communicated when the technology is introduced. Ideally, healthcare professionals should be a part of the decision-making team to implement a new system. Healthcare professionals are the primary end users of technologies such as EHRs – they understand, perhaps better than anyone, what the challenges of their daily tasks imply (Liu, Weng & Yu, 2012). Healthcare professionals are often frustrated and stressed about the adoption and implementation of any new IT system. This is mostly as result of unknown realities they fear they may face when using the newly introduced system.

All participants mentioned that currently there is no presence of electronic narratives (audio and video) in oncology care. Electronic narrative is a digital version of a patient's narrative records which combines video, sound, animation, text, music and narrative voice (Cunsolo, Harper & Edge, 2012). The authors added that electronic narratives are used to record the diagnosis, treatment and recovery processes to promote patient well-being. The findings show that there is limited knowledge about electronic narrative in oncology care. Nevertheless, some of the participants mentioned that they have been familiarising themselves with narratives in healthcare (OC1-PH1-r2.4; OC2-PH1-r2.4; OC10-PH3-r2.4) while the majority of participants (thirteen out of eighteen) said that they were eager to see electronic narratives implemented in their oncology care due to its focus on patient-centred stories.

The research done by Pérez et al. (2013) proved that electronic narratives have been emerging effectively in healthcare as a strategy to collect important patient information. One of the participants commented that *"if written narratives (paper-based) give us the indices of what is wrong with the patient when we start a conversation, I can only imagine how much more effective audio and video narratives in EHRs can be. I admit it can help in decision-making, and it could also serve as a reminder in case some important information is left out during the treatment process of a patient" "* (OC10-PH3-r2.4). According to Thompson and Kreuter (2014), Adams, Robert and Maben (2015) and Briant et al. (2016), narratives can be captured in written, audio and video format. Participant (OC10-PH3-r2.3) mentioned that "*incorporating audio and video narratives in EHRs can provide health practitioners with a clear picture of what is wrong with the*

patient over a prolonged period. This will help in decision-making as EHRs have the capacity of summarising patient information on a screen which helps health practitioners in taking further action. An additional benefit to electronic narratives is that proof exists should "*legal issues*" (OC6-PH2-r2.2) arise between a patient and the healthcare institution. According to Wolderslund et al. (2015), digitally captured narratives in EHRs are relevant for recording important information of a patient with the purpose of adding value to the decision-making process, and serving as a reminder of past patient records in a clear and concise way.

Participants considered the functionality of recording patients' narratives in EHRs "*the best gift they can offer to their patients and to themselves*" …since "*most family members request for their relative's EHRs* (OC7-PH2-r2.2; OC8-PH2-r2.2). Most participants welcomed the idea of the inclusion of audio and video narratives in EHRs because electronic narratives can *"increase willingness to communicate, can teach about cultures, can build empathy and can promote positive attitude"* (OC7-PH2-r3.2; OC8-PH2-r3.2; GP3-PH2-r3.2; PD2-PH2-r3.2). In a study conducted by Chesi (2018) on tools in narrative medicine**,** communication was enhanced between healthcare professionals and patients when tools such as free drawing and free written narratives were used during the diagnosis phase for patients who found it difficult to express themselves verbally. The author found that these tools can assist health practitioners to extract key narratives from patients and, when properly used, they contribute immensely to the decision-making process. Furthermore, there are tools used in audio narratives such as oral interviews, focus groups and forums that target a specific group of patients sharing similar diagnoses and health challenges.

There are however legal and ethical concerns that must be taken into consideration when incorporating narratives in EHRs (Russo et al., 2016). Patients' narratives are confidential and the moment patients realise that they will be recorded, "*it may change the dynamic of their stories and create trust issues*" (PD1-PH1-r2.3). According to Fioretti et al. (2016), a change in patients' stories can affect decision-making since patients' treatment depends on their narratives. The moment patients do not openly and freely narrate everything related to their health issues, the decision-making can result in the administration of wrong drugs and/or

treatment. The authors added that to avoid such incidents, healthcare professionals must make patients aware of the importance of their narratives.

It is evident from the findings that narratives in EHRs are still at the infancy stage in private oncology care in Cape Town. Wu and LaRue (2017) emphasise that the implementation of EHRs to support healthcare service delivery and decision-making can be complex due to issues such as high costs of implementation, security and privacy vulnerabilities, legal barriers to IT adoption, and the lack of appropriate policies and regulation. Furthermore, the absence of data standards still makes it difficult to benefit from the meaningful use and integration of narratives in EHRs for decision-making.

5.2.4. Patient information

Decision-making is the ability to choose from available alternatives, actions and solutions to resolve a problem in a particular situation (Sharma et al., 2016). Incorporating patient narratives and evidence-based procedures can improve the quality of healthcare and enhance decision-making (Charon, 2012). Two participants said that including narratives in EHRs will "*definitely support the decision-making process*" (OC4-PH1-r3.2; GP4-PH3 –r3.2) because "*personal stories affect the judgements and values people have and the choices they make*" (OC4-PH1-r3.2; GP4-PH3 –r3.2). Data in oncology care is derived from different sources. These sources may include therapeutic decisions, archive systems, pathology or laboratory systems, EHRs and research databases (Gesulga et al., 2017). The diversity of data in oncology care creates a level of complexity in terms of decision-making. In fact, data complexity in oncology is often a real challenge for health professionals as a delay in decision-making may occur while the health practitioner is waiting on data from different sources (Wu & LaRue, 2017). It can therefore be said that there is a need to manage the complexity that arises from both clinical treatment decisions and new clinical research. Effective data management can be done through data-driven analytics and insights (Dagliati et al., 2018).
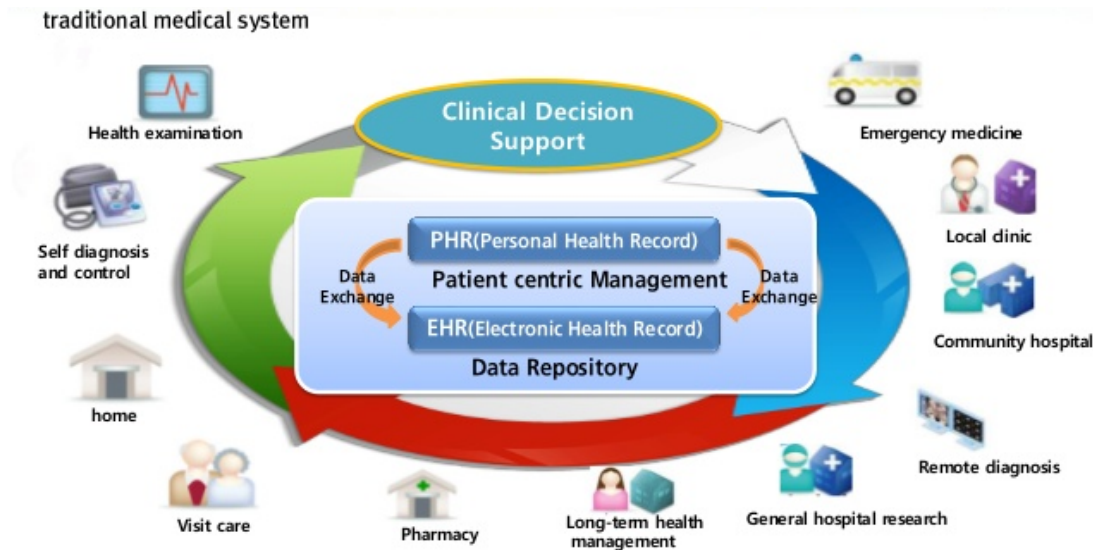
Figure 15: Various sources of data triggering complexity in clinical decision-making (Dagliati et al., 2018)

In the drive towards excellence in clinical decision-making, certain aspects should be considered. These are data accuracy, applicable knowledge and proper problem-solving skills (Keyworth et al., 2018). A study done by Keyworth et al. (2018) suggested that it is important to evaluate the additional functionalities added to EHRs to avoid confusion. In fact, any functionality added or enhanced on EHRs should support the health practitioner and provide them with better clarity on the patient's situation. In the case of this research study, the functionality that will be added to EHRs is audio and video narrative. The evaluation of additional functionalities must be taken into consideration due to the large amount of data healthcare professionals have to absorb before decision-making (Dagliati et al., 2018). Incorrect decisions informed by inaccurate data would negatively affect patient care and the outcomes thereafter. One participant holds the opinion that "*listening to a patient's audio record before taking further action on treatment fills the therapeutic gap in decision-making*" (OC6-PH2-r3.1). Unfortunately, "*electronic narratives have not been adopted in our healthcare facility. I believe that electronic narratives could help to double check the patient's story at every step of the treatment since it can be accessed anytime*" (OC7-PH2-r2.2). Healthcare professionals require accurate and current knowledge during decision-making. In other words, it is important for health practitioners to have broad medical knowledge and easy access to information resources. Despite the positive outlook expressed by some participants regarding the integration of narratives to support decision-making, one participant felt that "*there is insufficient evidence to suggest that narratives support decision-making. I believe that the lack of evidence*

is due to limited expertise on the use and access of narrative information in oncology care"
(OC7-PH2-r3.2).

5.2.5. Technology

There are basic requirements that need to be adhered to when integrating narratives in EHRs. These are: Tablet computers, internet, personnel, system service providers, rules, regulations and time. For the audio recording process, a reliable audio interface and headphones are necessary to effectively record patient narratives (Evans, 2016).

Several participants said that incorporating narratives in EHRs will "*require electronics such as tablets, computers, solid audio interfaces and headphones. Correct software applications are also necessary to handle patients' electronic narratives. Furthermore, narrative recording techniques and tools must be well understood and utilised*" (OC2-PH1-r3.1). These requirements will determine if and how healthcare professionals use electronic narratives to extract important information that will aid decision-making during the treatment process.

Tekiner (2017) says that audio and video narratives complement each other. In other words, when a patient's health history is displayed using graphics, an audio or voice record is often useful for additional explanation. The author adds that the graphics in video narratives can be used in emergencies as they provide brief illustrations of the patient's condition. In this vein, there is support to suggest that electronic narratives are important tools during all treatment stages – diagnosis to follow-up. Furthermore, electronic narratives present a more secure way of saving data than written notes. The latter easily get lost and, they often lack nursing evidence related to the overall patient analysis (Tekiner, 2017). It can therefore be said that electronic narratives play a significant role in the decision–making process by providing elaborate patient care information which provides logical assistance to healthcare professionals for an extended period.

Despite the above advantages, Tekiner (2017) says electronic narratives (audio and video) present shortcomings during recording, listening, editing and tracking. In this vein, healthcare professionals often encounter frustration when tracking a particular aspect of the patient's condition in narratives as the audio or video has to be played several times to find the sequence needed. Healthcare professionals often cannot determine when to stop listening to patients' narratives which may result in lengthy periods of unproductive time.

According to Blijleven et al. (2017) successfully incorporating narratives in EHRs require healthcare professionals to register each patient narrative in EHRs using a unique code, such as a bar code, to avoid information being mixed up and/or misplaced. The patient barcode can be scanned every time new patient information is included in the EHR system – this will ease the process of tracking patient electronic narratives. Existing EHR systems in oncology care do not include electronic narratives despite the fact that most healthcare professionals use written narrative and appreciate the value thereof. The existing system eases the decision-making process by summarising patients' records on one sheet. There is however no evidence that this assists in providing better patient-centred care. The use of electronic narratives do however help healthcare professionals in their decision-making as patients' audio and video narratives contain facts that are relevant to the treatment process. Electronic narratives strengthen information flexibility as it can easily distribute information to care services in different departments and facilities. As result, integrating all relevant documentation is simplified (Blijleven et al., 2017).

5.2.6. Patient narratives

The discussion under this topic addresses the objective to determine how narratives can be incorporated in electronic health records to aid the decision-making in oncology care.

The findings of this study show that narratives are present in oncology care but limited to the diagnosis phase. Some of the evident benefits of acquiring patient narratives are: Acknowledgement of the patient's emotional and physical state, promotion of patient cooperation, improvement in communication, and trust between patient and healthcare professional. Narrative is an approach used by doctors that allows a patient's story to be heard and experienced by both healthcare professionals and patients' throughout the treatment process (Bramley & Matiti, 2014). This approach encourages the monitoring of patients' well-being and it assists with the decision-making process for healthcare professionals particularly in oncology care (Charon, 2012). The findings reveal that the narratives present in oncology care of private hospitals in the Western Cape are mostly written narratives. These written narratives are usually on paper and later typed in EHRs. One participant said: *"Written narratives are present in oncology care, but limited only to the diagnosis phase because this phase concentrates on the patient's story"*

(OC1-PH1-r2.1). These narratives are often "*answers given by patients through interviews or by filling out questionnaires which are later typed into the patient's EHRs*" (OC7-PH2-r2.3). Narratives guide healthcare professionals in their patient treatment approach and they further support decision-making since the basis thereof is patient-centred. According to participants, every patient's story is important – it plays a key role from the diagnosis process to the follow-up. *"I strongly believe that narratives in oncology can do wonders. Most patients' stories discuss the root of their illness, and that is the beginning of the treatment process"* (OC4-PH1-r2.4)*.* Unfortunately, with the use of questionnaires as the collection method "*important information is often left out by the patient due to laziness, unwillingness to complete the questionnaire, and compromised literacy levels."* (OC4-PH1-r2.3). It can be argued that in cases where closed-ended questions are posed to patients, vital information may be omitted which can negatively impact the decision-making process. Usually, EHRs comprise "*initials of patients' written narratives and considerable detailed notes*" (OC6-PH2-r2.2). This is done to make sure that *"no important information that supports scientific results is omitted"* (OC10-PH3-r2.2). *"As oncologists, we don't convert everything in the patient's story into medical jargon"* (OC8-PH2-r2.4). Oncologists usually *"quote the patient's narrative* for *components that were very specific or of crucial importance"* (OC10-PH3-r2.2). According to Tekiner (2017), it is important to include narratives in EHRs, because narratives shed light on patient information in different clinical departments, and EHRs provide audio and graphic presentation of the disease. Furthermore, narratives in EHRs create trustworthiness between healthcare professionals and patients. This essentially demonstrates the therapeutic benefits associated with patient's narratives.

The majority of participants (OC1-PH1 -r3.1; OC6-PH2-r3.1; OC10-PH3-r3.1; OC4-PH1-r3.1, GP4-PH3–r3.1) were of the opinion that using patient written narratives throughout the entire medical journey does not only enhance decision-making, it also provides healthcare professionals with a better understanding and proficiency in dealing with patients. In other words, patients' narratives are used for better decision-making, and therefore they have a positive impact. Decision-making in healthcare depends on scientific processes and on what story the patient tells. As one participant put it: *"Whatever the story is will determine the treatment"* (OC1-PH1-r2.4). In fact, when

patients' narratives are used in decision-making and in the treatment process, "…. *the outcome is always satisfactory no matter the circumstances*" (OC4-PH1-r2.4). Healthcare professionals frequently use narrative information to document the different stages of a patient's illness and/or recovery in order to carry out further clinical action (Hall & Powell, 2011; Embi et al., 2013). As recommended by Fioretti et al. (2016), narrative-based medicine and evidence-based medicine (scientifically proven) should be complementary. The complementary nature of narrative-based medicine and evidence-based medicine benefits oncology care. It leads to more accurate information, better diagnoses, and improved treatment. Simply put, precise patient information positively impacts the decision-making process (Fioretti et al., 2016; Rosti, 2017). The authors added that both narrative-based and evidence-based medicine promote greater consideration of narratives in healthcare professionals' daily practice.

5.2.7. Patient consultation

In this section, research findings are discussed to understand the reasons why narratives are yet to be used in EHRs to support decision-making in oncology care.

The internet has become a prominent source of medical information which assists healthcare professionals to work efficiently to improve patient care (Baker, Xiang & Atkinson, 2017). However, there is information that oncologists do not always access due to a lack of interest and/or knowledge. As one participant explicitly said: "*There is limited knowledge about electronic narratives*" (OC10-PH3-r4.1). Therefore, a research team in information technology is needed in healthcare facilities to bring awareness of new inventions or software that can be useful to healthcare professionals. Present EHRs do not support the inclusion of patients' narratives but they do allow small notes, hence, there is a "…*need for upgrading existing EHR systems*" (OC1-PH1-r4.2). The decision to explore or implement the adoption of a new system must be shared with employees so that they can be prepared and informed. Change often renders people uncomfortable or frustrated especially when they do not understand the motives behind it. (Baker, Xiang & Atkinson, 2017). In other words, change is often accompanied by a fear of failure or criticism, and even the fear of success (Li, 2014). Therefore, training sessions are required to make employees comfortable with the system, and these

sessions should be done on a regular basis to keep employees abreast of new changes, and to refresh their current knowledge. Raising awareness should not only be limited to healthcare professionals. Patients also need to be informed of the new technologies and the impact thereof. This is especially important when belief systems and cultural practices are involved (Erasmus et al., 2017). Healthcare professionals must be aware of their responsibilities regarding the recording of narratives that provide in depth and detailed information (Linder, Schnipper & Middleton, 2012). This will minimise the risk of malpractice and litigation. Through the transparent reporting of healthcare professionals' experience, healthcare management will have an understanding of what systems need to either be implemented or upgraded. According to Parand et al. (2014), managers in healthcare have the obligation to ensure high quality patient care. In addition, healthcare management, mandates policy, systems, procedures and organisational climates.

5.3. Study visualisation

The findings of the study are visualised in Figure 16 on the next page.

If electronic narrative is processed, it will:

EHRs ENABLERS

. Patient-centeredness, communication
. Timeliness
. Efficiency and equity.
. Technical assets (tablets, computers, solid audio interface, headphones)
. Recording software

Enable EHR adoption

ELECTRONIC NARRATIVE RECORDS (audio, video narratives):

. Improve patient care: effectiveness in patient-centered care, enhance trust and communication, real-time tracking and monitor patient progress

. Fills the therapeutic gap in decision-making.

INPUT Screening

. Cross-examination of patients.
Diagnosis
. Diagnosis with the use of written narratives (paper-based narratives)
Treatment Follow-up

Transfer Information

EHRs PROCESSES

. Access patient information

. Sharing of information with concerned healthcare professionals

. Manage patient information (summarising, adding, printing)

. Process scientific information based on scientific results for decision-making.

. Process electronic narrative records to support decision-making (not used yet)

Hinder EHR adoption

Improve

Produce

OUTPUT

. Improve process of decision- making If used in screening, diagnosis, treatment and follow-up in oncology care

EHRs INHIBITORS

. Cost (implementation and maintenance)

. Culture (belief, fear and trust)

. Lack of proper infrastructure
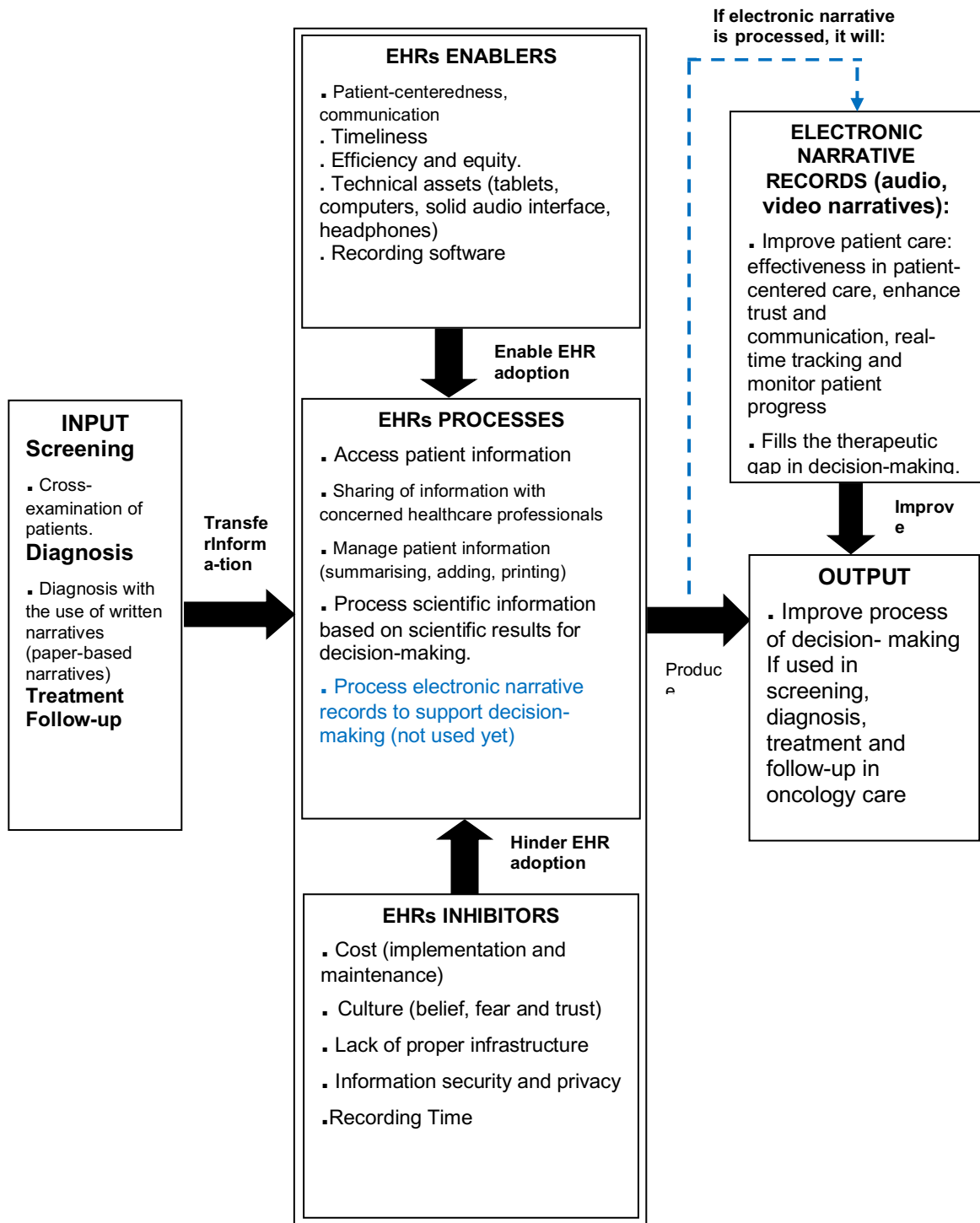
. Information security and privacy

. Recording Time

Figure 16 : Study Visualisation

On the left hand of the framework is the input box which constitutes the four main activities oncologists deal with in the treatment process of patients. This involves screening, diagnosis, treatment and follow-up. As seen in the framework, only

information from screening and diagnosis is transferred to the processing steps because patients' written narratives are limited to those phases. The framework illustrates the various EHRs processes detailing how the adoption of narratives in EHRs are subject to enablers and inhibitors. The processed information helps improve decision-making and service delivery.

On the top right of the framework is the electronic narrative box. This is a step that the oncology care centres in Cape Town have not embraced – electronic narrative records are therefore indicated in blue in the processing box. If electronic narrative records are processed, it will improve patient care and enhance the effectiveness of patient-centered attention. Furthermore, it will improve trust and communication between patient and healthcare professional, and it will allow for real-time tracking and successful monitoring of patient progress. In addition, electronic narratives fill the therapeutic gap in decision-making when used in screening, diagnosis, treatment and follow-up steps in oncology care.

5.4. Conclusion

This chapter entails a detailed discussion of dominant themes found in Chapter 4 that contrast existing literature on narratives in EHRs. The findings show that the adoption rate and usage of EHRs by healthcare professionals' in oncology care is increasing. However, despite many advantages that EHRs present, healthcare professionals still use hand written notes to record patients' narratives. The use of written patient narrative notes limits the decision-making process as some information can be omitted when recording into EHRs. The majority of participants were interested in exploring electronic narratives, but the current EHRs are saturated with an overload of information from different sources. Present information in the patient EHRs creates complexity of the system which results in a slow decision-making process. To solve the complexity of data in EHRs, healthcare facilities must do data-driven analytics before the integration of electronic narratives. Once the system is integrated, training is the next step to implement.

CHAPTER SIX – CONCLUSION, RECOMMENDATION, CONTRIBUTION AND FUTURE STUDY

6.1. Conclusion

As indicated in previous scientific research, the use of EHRs with basic functionalities is prominent in oncology care facilities in both high and low-medium income countries. The basic functionalities of EHRs does not include the patient's electronic narrative records. For this reason, the use of narrative in EHRs to support the decision-making process was researched. This study was carried out in three private hospitals in Cape Town, South Africa.

The aim of the research was to explore the use of narratives in electronic health records to support the decision-making processes of healthcare professionals in private oncology care. To achieve the study aim, the researcher used the research philosophy, research method and research technique detailed below.

An interpretivist stance was best suited to this research study. This approach assumes that reality and knowledge are socially constructed. The output of this philosophy is always subjective which gave the researcher room to interpret the information according to her own understanding of the study.

The study was qualitative meaning nun-numerical data was collected with subjective interpretation based on how the researcher perceived the phenomenon from the participants' perspective. The researcher engaged with scientific literature (secondary data) to acquire background information on the use of narratives in EHRs. Semi-structured interviews were used as a method of data collection. In this vein, primary data was elicited through a series of open-ended questions which enabled participants to freely express their opinions. The interview sessions were conducted in the participants' place of work which they found most convenient and comfortable. This ensured participants felt at ease and confident which facilitated trust toward the researcher.

There are several data collection methods such as surveys, observations, questionnaires and focus groups. These methods were not used since this study is descriptive in nature and not explorative. Through the use of one-on-one personal interviews, the researcher was able to derive a sense of voice, intonation and body language relevant to the answers participants were giving after each question. The responses were audio recorded to guarantee the accuracy of information, and some notes were taken in case the recording device malfunctioned. Although face-to-face interviews are suitable to this study, some challenges emerged. Obtaining additional information was difficult and it often diverted the context of the study. As result, the researcher concentrated predominantly on the pre-structured questions. On the other hand, there were time and cost constraints – traveling long distances and conducting comprehensive interviews were time consuming and costly, especially when interviews had to be rescheduled. Every participant in the study contributed to the research objectives, which were:

➢ To understand how the experiences of healthcare professionals, with the use of existing EHRs influence the outcome of their decision-making process

➢ To determine how narratives can be incorporated in electronic health records to aid the decision making process of healthcare professionals in oncology centres.

➢ To establish the requirements of incorporating narratives in electronic health records to support healthcare professionals in their decision-making.

➢ To understand the reasons why narratives are yet to be used to support decision making in oncology care.

The findings have shown that the use of EHRs is considerable in private oncology care centres. Hence, healthcare professionals have a high level of awareness of the usability of EHRs due to its performance and positive outcomes.

Findings further indicate that EHRs were adopted to redress the shortcomings of paper-based records in order to improve healthcare professionals' work processes, and, in turn, enhance patient care. The evidence indicates convenient and simple sharing of information within and across several medical network services, easy accessibility and

retrieval of information, and a reduction of data loss through backups. In other words, it is clear that the use of EHRs is of great importance in healthcare as its advantages are linked to the healthcare professionals' work processes which impact the execution of decision-making. However, there is still a limited number of healthcare professionals that are reluctant to use EHRs due to culture, belief, values and their own expectations. This often creates a gap in their care delivery. In fact, some participants mentioned that they resist change because they are not comfortable with embracing new technology even though training and information technology support is provided by the hospital management.

When the topic about patient narrative was introduced to participants, they displayed knowledge about patient written narratives. This, however, was limited to the diagnosis phase. Furthermore, participants had limited knowledge about electronic narratives (audio and video) in EHRs. Although healthcare professionals perceive using electronic narratives as an effective practice to enhance their service and expertise, they still experience challenges with the current system. The current EHR systems can only contain basic functionalities such as laboratory test results, images from radiology, allergy information and warnings, dates and schedules of patients' immunisations, medications relevant to the patient, diagnoses of the patient, patient's medical records, vital sign readings, progress notes, and patient demographics as well as billing and administrative data. There is a need to upgrade the current system for it to handle functionalities such as x-rays, and to retain and analyse patient electronic narrative records (audio and video).

This research study showed that there is a need for oncology care centres to have the proper infrastructure to make meaningful use of narratives in EHRs. Participants mentioned that there is concern around the financial impact of such an implementation. This will not only affect healthcare management but patients as well since the cost of treatment will inflate. Other obstacles participants conveyed involved the training of healthcare professionals, information technology legislation, and consent documentation which all contribute to the cost of implementation Additional maintenance costs also need to be factored in after implementation. Cultural differences

should be taken into consideration whenever a new system is implemented as people have opposing thoughts and backgrounds, and in some cultures there are certain medical practices that are unacceptable. This does not only involve patients but healthcare professionals as well as they too associate with certain cultures. Since EHRs contain crucial information about patients, security must be at the core of implementing any system or adding functionalities to EHRs. The use of narratives in oncology care is still in its infancy.

In summary, it is recommended that whenever a new system is implemented, EHR vendors must be consulted, and users must be part of the implementation process.

6.2. Recommendation and limitations

The focus of this study was on the use of narratives in EHRs to support the decision-making process of healthcare professionals in oncology care. The participants proved that written narratives are used but limited to the diagnosis stage, and in most cases not recorded in EHRs.

Participants showed interest in using narratives in EHRs but only when their current EHRs are upgraded from basic functions to the ones that can process patients' narratives. Therefore, educating and training healthcare professionals to value patients' narratives is crucial as narratives contain values in patient treatment decision-making. In the case of this study, training is not only reserved for healthcare professionals but patients too as narratives revolve around them.

Healthcare professionals should not be challenged by the idea of giving primacy to the patient's voice. Listening for meaning more than facts may contribute to the evolution of patients' narrative in healthcare.

The limitations of this study is that it only considered the health services of oncology care and since the data may differ in the EHRs of other health services, the findings may not apply as presented.

6.3. Contribution and significance of research

The output of the research contributed to the existing body of knowledge by giving guidelines on how electronic narratives can be used in EHRs by healthcare professionals to support the decision-making process. The findings of the study discussed the following:

➢ The experiences of healthcare professionals with the use of existing EHRs for decision-making, particularly in oncology.

➢ Knowledge on the requirements of integrating narratives in electronic health records to support healthcare professionals in decision-making. This research proposes a conceptual framework towards the integrative use of narratives in EHRs by healthcare professionals in oncology care.

6.4. Guidelines to the integration of narratives into EHRs

As recommended by American Health association (2015), there are nine steps when integrating narratives in EHRs. The researcher discusses these steps in relation to empirical data in the paragraphs below.

Guideline 1: Implementation of narratives with the involvement of healthcare professionals

When implementing new functionalities such as narratives in EHRs, oncology care must identify a group of people that will lead the initiative – this group is known as an implementation team. The implementation team must include healthcare professionals since they are ultimately the primary key users, and they are patently aware of the challenges associated with existing functionalities in EHRs. The researcher found that oncology care centres, in fact, do not have an implementation team that includes healthcare professionals when executing changes in existing EHRs or when adding other IT related functionality. The lack of involvement from healthcare professionals in the implementation phase have a definite effect on the overall configuration of software. Therefore, the IT team in oncology care centres recommend working collectively with health IT vendors.

Guideline 2: Considering the functionalities of the specific care service, e.g. oncology care

The IT team in oncology care centres does not have adequate experience with functionalities in EHRs to meet the expected security demands. For this reason, it is crucial that healthcare professionals are involved in every aspect of integrating narratives in EHRs. It is further advisable to appoint an IT service company to assist with the system hardware and software.

Guideline 3: Determine the hardware needs of the healthcare professionals using the EHR

The IT team in oncology care centre must identify the hardware needs of healthcare professionals. The researcher found that most oncology care centres have stationary computers that healthcare professionals have to go to in order to log on every time they want to check or assess patient records. The process of going back and forth from the stationary computers is time consuming for healthcare professionals.

Guideline 4: Consider the exchange requirements of sharing e-narratives

If the hardware needs are correctly identified, the software configured optimally, and the implementation effectively concluded, the transfer of data from one EHR functionality to another functionality such as narrative can be done successfully.

Guideline 5: Consider the workflows of the care service prior to implementation to ensure proper integration

Implementing a new functionality such as narratives in EHR requires oncology care centres to optimise their pre-launch workflows. The pre-launch workflow will assist the implementation team in critically analysing each step of the implementation to establish if the change is necessary, if it adds value to the patient, and if it is done properly by the appropriate person. The answers to these questions will impact the patient care service delivery in oncology care centres.

Guideline 6: Consider the layout of the consultancy areas to determine the use of technology during consultations

Furthermore, for narratives to be effective in oncology care, the layout of the consulting rooms should be considered since it is the place where the patient meets the healthcare professional and where trust is established and built. Essentially, this means that the healthcare professional must focus their attention on the patient and not purely on typing information into the computer. When executed effectively, a "triangle of trust" is created in which the healthcare professional faces the patient to facilitate communication and the computer is set aside and not in front of the patient.

Guideline 7: Consider the use of technology such as speech recognition, natural language processing or artificial intelligence to avoid disrupting the interaction between the patient and health professional

In most cases, because of time constraints, healthcare professionals tend to type information while listening to the patient – this is disruptive to the patient, and the healthcare professional runs the risk of losing focus on the patient narrative.

Guideline 8: Adapt procedures to incorporate the use of e-narratives in EHRs

The IT team in oncology care centres determines the launch approach and develops procedures and steps to follow in case there are issues or malfunctions with the new functionality added in EHRs.

Guideline 9: Provide sufficient training opportunities and follow-up sessions for healthcare professionals to optimise the use of e-narratives

Healthcare professionals need to be trained thoroughly on the EHR system since they have the ability to teach narrative in EHRs skills to their colleagues, and they can also highlight the challenges experienced to the implementation team.

Guideline 10: Consider the cultural aspects of the organisational environment to deal with the fear associated with the introduction of new technologies

Many healthcare professionals are still not convinced of the benefits of using technology as part of their service provision and there is a need to promote the use of narratives as part of EHRs.

6.5. Future study

The complexity of information available in EHRs is limiting healthcare professionals in fully explore its potential. Technology has undoubtedly made a great impact on healthcare, and it continues to aid decision-making and patient care. It has been proven that among the many advantages of EHRs, building a communication bridge between healthcare professionals and patients has been a particular field of interest. On the one hand, EHRs can give healthcare professionals more time to make use of narrative techniques in EHRs, but, on the other hand, EHRs may reduce the opportunity of face-to-face patient narrative. Although narrative provides a starting point for discussion between healthcare professional and patient, electronic narratives are still at an infancy stage. Future studies can explore ways on how to reduce the complexity of data in EHRs so that healthcare professionals can uphold the integrity of evidence-based medicine, and apply the use of narratives to guide them through the treatment process. Furthermore, there is a need for additional evaluation studies on the proposed conceptual framework that informs the use of electronic narratives for decision-making in electronic healthcare records.

6.6. Summary table of finding, themes and recommendations

A summary of the findings for the study based on the research questions are presented in Table 10 on the next page.

Table 14: Summary Table

Research question: How can narratives be used in electronic health records to support the decision-making processes of healthcare professionals?			
Sub-questions	**Findings**	**Themes**	**Recommendation**
1. How do the experiences of healthcare professionals while using existing electronic healthcare records influence the outcome of the decision-making process?	1. There is a high level of EHRs usage and awareness for patients' records management. 2. There are positive experiences due to the advantages of using EHRs. 3. There are Privacy and security issues in EHRs. 4. There is lack of EHR uniformity in different healthcare facilities due to different types of data (images, x-rays, notes etc.) they handle. 5. EHRs have a positive impact on decision-making. 6. In terms of cost: EHRs present high maintenance and implementation cost. The same applies to any additional functionality such as narratives which raises the patient's bills. 7. In terms of time: recording the information on paper into the system and searching manually for missing information present delays in decision making. For narratives, there must be limited time for patients to narrate their stories. 8. In terms of culture: there is fear to embrace new technologies. The same applies to the use of narrative as culture and belief play a role in creating fear of sharing narratives and embracing change	1. EHR 2. Patient consultation	EHRs do not only impact healthcare professionals but every facet of the practice so, consulting EHRs vendors is recommended before its implementation or before any changes in the system. Cloud hosted EHRs options are best suited in oncology care, meaning there will be no servers or hardware in your workplace beside your own computer. This cut maintenance and technical support cost. For training, some EHRs vendors provide training at no- extra cost to make sure everyone is conversant with the new software. To ensure EHRs data privacy and security, healthcare facilities must be covered under health insurance portability and Accountability act. Regarding EHRs uniformity in healthcare facilities, it's challenging as they are different in size, in data to capture and in operability. For any acquired system, healthcare facilities must raise awareness especially when patients are involved for example, in the case of narratives.

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2. How can narratives be captured in electronic health records to support the decision-making process?	9. Prevalent use of written narratives during the diagnosis phase but narratives can also be in video and audio format. 10. There should be rules and regulations to consider before recording a patient's story such as consent form to be signed by both parties. 11. There are recording techniques and tools in electronic narratives such as such as room settings depending on what the patient wants	3. Patient narratives	Capturing written, audio and video narratives must be done with the right instruments such as recording software and devices such as…computer, solid audio interface, headphones etc. Recording patients must be done by the right people; this primarily offer data security and privacy.
		4. eNarrative	There are processes to follow when recording the patient story: • Creating an implementation team • Configuring the software • Identify hardware needs • Transfer data • Optimise pre-launch workflows • Consider the room layout • Decide on the launch approach • Develop procedures for when the EHR has malfunction issues
		5. Work functions	Using electronic narratives in health influence decision making and enhance healthcare professional's expertise. Further studies need to be done so medical evidence and healthcare professionals judgements can shape the decision making, since narratives are rarely included in health science research.
3. What informs the inclusion of narratives in electronic health records to support the decision-making process?	13. The implementation of narratives in EHRs requires collection tools such as tablet computers, internet, personnel, system vendor, rules and regulations and time. 14. There is interest in using electronic narratives in decision making but only important information should be recorded in narrative.	6. Patient information	There is a need for a system with functionalities to include patients' electronic narratives to aid in decision making and to do so, healthcare facilities must be financially ready. Using patient electronic narrative is important because it upholds enough patient information that is rarely extracted by healthcare professional for proper delivery of care.

4. Why are narratives not being used in electronic health records to support the decision-making processes of healthcare professionals?	15. There is limited knowledge about electronic narratives	7. Technology	Medical schools and healthcare centres are required to educate about narratives in EHRs and train students and healthcare professionals on how to use Information Technology tools so it may contribute to a success in the implementation process.

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Appendix A: Interview questions

Cape Peninsula
University of Technology

<u>**Semi-structured interview- open ended questions**</u>

<u>**Introduction remarks**</u>: In the late 1990's the use of electronic health records (EHRs) started emerging in public healthcare centres of South Africa to redress the shortcomings that were present in paper based records. In both paper based records and electronic health records, healthcare professionals rely on notes or data captured to make decisions. In the years 1998 "narratives" emerged in healthcare. In 2001 - 2005, narratives in healthcare started being converted from handwritten to electronic using advanced technology, this is referred to as electronic narrative. Unfortunately, narratives as well as the electronic narrative approaches have not been introduced in private oncology centres in South Africa

<u>**The aim:**</u> of this research is to explore the use of narratives in electronic health records to support the decision-making processes by healthcare professionals in private Oncology care.

You are kindly requested to answer the questions listed below in good faith. Your responses will be used specifically for the purpose of this study only and they will be treated with the highest degree of confidentiality and privacy. Also, participation in this interview is voluntary and guarantees anonymity as well as autonomy of participants willing to participate in this research study.

<u>**Participant's details**</u>

Name: _____ surname:_____ Position: _____	Date:_____ Contact No:_____

<u>**Section A: Demographic information**</u>
I'd like you to introduce yourself in terms of your position and your work practice

Definition
Decision making: is the availability of alternatives, actions and solutions to choose from to solve a problem or act to a situation (Sharma et al., 2016).
Section B: Questions
Research Question: How can narratives be used in Electronic health records to support the decision-making processes of healthcare professionals?

Objective: To understand how the experiences of healthcare professionals with the use of the existing EHRs influence the outcome of their decision making process.

SQ1: How do the experiences of healthcare professionals while using the existing Electronic healthcare records influence the outcome of the decision making process?

IQ 1.1. Please describe your experiences when using EHRs to assist in decision making?

IQ 1.2. How do these experiences impact on the outcomes of your activities?

IQ 1.3. What challenges do you encounter in terms of using EHRs to facilitate aspects of your work activities?

IQ 1.4. How do these challenges affect the outcome of your work activities especially to support decision making?

Comment:

Objective: To determine how electronic narratives can be incorporated in electronic health records to aid the decision making process of healthcare professionals in oncology centres.

SQ2: How can narratives records be captured in electronic health records to support decision making process?

IQ 2.1. What are the methods used to engage or interact with cancer patients, leading up to their diagnosis and treatment process?

IQ 2.2. Do you use any form of storytelling when engaging with patients?

IQ 2.3. How can the patient's stories be used in the process of decision making and treatment process?

IQ 2.4. How does the use of these patients' stories impact the outcome of decision making and the treatment process?

Comment:

Objective: To establish the requirements of incorporating electronic narratives in electronic health records to support healthcare professionals in decision making.

SQ3: What informs the inclusion of electronic narratives in health records to support the decision making process?

IQ 3.1. How would you prefer these patient stories to be included in the EHR to support decision making process?

IQ 3.2. Do you think patient's stories in EHRs can support the decision making process? If yes, how? If no, why not?

Comment:

Objective: To understand the reasons why narratives are yet to be used to support decision making in oncology care.

SQ4: Why are narratives records not being used in electronic health records to support the decision making processes of healthcare professionals?

IQ.4.1. please tell me what initiatives are currently used to improve the diagnosis and treatment of cancer patients

IQ 4.2. How so these initiatives assist your work activities as an oncologist?

Comment:

Thank you for your time and patience in answering the questions. Your contribution is highly appreciated.

Appendix B: Summary tables of each case study

Q1: Healthcare professionals' experiences using EHRs
<u>Case 1</u>

Interview Answers	Code	Theory theme
The findings show that all participants (7 out of 7) reported positive experiences in using EHRs due to its benefits. These benefits include easy accessibility, effortless referencing, well organised files, available patient history, on-demand printing capabilities, editable data and the ability to summarise and share patient information.	Benefits (easy access, referencing, organized patient files, access to patient history, printing, editable data, sharing & summarizing) Evolving to how patient records are viewed	Positive experience using EHR because of its benefits Evolving way of viewing patient information
Whilst indicating the benefits of EHRs*,* a respondent said that: "*EHRs have been evolving in oncology care and have impacted the way patients' records are viewed*" **(OC1-PH1-r1.1)**. To substantiate this point, another respondent indicated that *"EHRs are easy to access because patient records are well organised and patient information history can be back tracked"* **(OC2-PH1-r1.1)**. From these responses, it is evident that EHRs are perceived by healthcare professionals to improve the management of patient records and this could aid how the records assist in the eventual decision-making process. **Decision-making** is the ability to choose from available alternatives, actions and solutions to resolve a problem in a particular situation (Sharma et al., 2016). In oncology care, decision has to be made after diagnosing the patient, allowing healthcare professionals to choose the appropriate medication	EHR support decision-making Summary information Editable information Easy sharing Paper-less practice Sharing information Some Work functions related to PR automated Impact – easy access less errors Speed-up DM process Incomplete EHR – not supporting DM	Support decision-making Use of patient information Benefit Automated Work Impact – less errors Impact – speed-up Challenge Challenges

	Inconsistent EHRs	
When asked how EHRs support healthcare professionals' decision-making, 6 out of 7 respondents believed that EHRs positively influence the decision-making process. A respondent said: "…*absolutely*" **(OC2-PH1-r1.4)** since all information regarding a patient is accessed on one screen and can be summarised. Another respondent explained that "*patients' EHRs can be modifie*d" which facilitate "*easy sharing of information*" **(OC6-PH2-r1.2)**. "*EHRs create a paperless practice that make it more efficient*" as recounted by **(OC3-PH1-r1.2),** and if the healthcare professional is replaced "*another healthcare professional is able to access the patient's EHRs quickly and easily*" **(OC4-PH1-r1.2)**. Again, the usefulness of EHRs can't be over-emphasised in the sense that EHRs simplify activities within the decision-making process by automating certain work functions relating to patient records.	Challenges: technical issues, loss of information, data capturing issues, maintenance, data protection and privacy Lost connectivity results in loss of data Data security, privacy (theft, eavesdropping & hacking)	Challenges Challenges Challenges Effect of challenges Challenges Challenges same for PB & EHR
The easy accessibility of patients' healthcare records makes healthcare professionals less prone to errors when making decisions, and EHRs speed up the process of decision-making and recording data.	Hand-written narratives also have security issues (misplacement, stolen, lost)	Effect of challenges
Contrary to the responses above, 1 of the 7 participants was of the opinion that "*EHRs do not really help in decision-making*" **(OC5-PH1-r1.4)** as the decision-making is based on "a *patient's past medical history, surgical history, life circumstances, family history and findings during consultation*". *Yet, some EHRs do not have this information nor the options to save it* **(OC5-PH1-r1.4)**.	Differences in functionality across facilities Lack of uniformity Lack of functionality: EHR systems lack all functions Manual information still needed	Effect of challenge Effect of challenge Effect of challenges Effect of challenges
From this response, it is evident that not all EHRs are unified or have the same functionalities. In EHRs, **functionality** is the sum of processes any software	Work-around: when no access to HER	Effect of challenges Effect of challenge

application can do for healthcare professionals to facilitate the delivery of service (Evans, 2016). This appears to have a negative impact to how healthcare professionals perceive the management of patient records. Despite the positive experiences of healthcare professionals due to the benefits of EHRs, 6 out of the 7 respondents mentioned that they encountered challenges while using EHRs. These challenges include: technical issues, loss of information, data capturing issues (omitted information), maintenance, data protection and privacy (security).	check info with patient Time-consuming Prone to errors (duplication or discrepancy) Paper-based preferred Paper-based perceived to be fast Time to capture information into the system Dislike IT Narrative time-consuming Limited consultancy time	Preference Preference Challenges Preference Challenge Effect of challenge Effect of challenge
Upon request for clarity on the challenges faced with EHRs in oncology care, one participant explained that "*data that has been captured gets lost when connectivity is lost before content was saved, or it could even be deleted*" **(OC3-PH1-r1.3).** In addition to this challenge, a respondent mentioned that "*there are issues with data protection and privacy*. For example, theft, vandalism, eavesdropping and hacking. For clarity on eavesdropping and hacking, below are the definitions: **eavesdropping** is interrupting a real-time email transmission, phone call, instant messages and video conversation without participants' awareness (Salem et al., 2018). Whereas **hacking** is the unauthorised access to alter with the system or security features for an illicit purpose (Rader & Wash, 2015). Seemingly, these security issues also affect EHRs, when notes and written narratives functionalities are added as 1 out of 7 respondent said *"the use of written narratives does not guarantee the security of information as it can easily be misplaced, stolen or lost"* **(OC3-PH1-r2.3)**.	Ideally longer consultancy time to cater for narratives Narratives should be allocated regulated time Only relevant/important information in narratives Important to listen but then to capture important information Narratives time-consuming Take time to learn new systems Reluctance to change Gap between paper-based and EHR Converting story into medical jargon	Challenge of narrative Challenge of narrative Challenge of narrative Information completeness Effect of narratives Effect of EHR Effect of challenge Information inconsistency Challenge Challenge Challenge Challenge (patient) Challenge

From these replies, it is clear that EHRs present challenges that could slow down the activities of healthcare professionals' and ultimately, negatively impact the decision-making process. Out of the 7 participants, 3 stated that EHRs were not alike in functionality **(OC1-PH1-r1.3, OC4-PH1–r1.3; OC5-PH1-r1.3)**. The difference is peculiar from one hospital to another and sometimes from one doctor to another. Due to a lack of uniformity, EHRs are still a work in progress, because 6 of the 7 participants pointed out that EHR systems do not include pathology information, x-rays, radiology content and/or a library of medication. The lack of these information delays certain work-related tasks since healthcare professionals have to search for what they require that is not available on EHRs. As one participant put it: "*There is no functionality to assist with a library of medication in EHR*s. *You have to manually type every medication and reference them*" **(OC4-PH1-r1.3)**. When healthcare professionals were asked what they do when they cannot access the patient's EHRs, a respondent explained that they "*examine the patient and cross-check the data with the patient*" **(PD1-PH1-r1.3)**. This is *"time consuming and allows for errors to be made in decision-making"* **(GP1-PH1-r1.3)**. Healthcare professionals revert to manual processes of engaging with patients to validate patient's data which is time consuming and prone to duplicate and even discrepancy errors. Due to the aforementioned challenges, there is a minority of participants (2 out of 7) who said that they prefer the old method of recording patient data using a paper-based system **(OC5-PH1-r1.4, GP1-PH1-r1.4)**. As one participant said "*EHRs has many functionalities and I did not have enough time to practice …* but… *I prefer paper-based record since it is fast*" **(OC5-PH1-**	EHR not providing for all information Cultural practices Fear to share stories Cost of new system Adding narratives will be costly Cost of system could increase cost of services EHR simplify work because of automation Still adoption issues	 Challenge Challenge Benefit Challenge

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r1.4). Example of some EHRs functionalities: managing patient medication lists, patient history, surgical history, clinical documents and notes; capturing external clinical notes or documents; maintaining patient records etc.

*There is no need to waste time on recording information into a system…*and *I have no passion for IT based system …it has a lot of manoeuvres"* **(GP1-PH1-r1.4)**. The issue of time also affects EHRs when other functionalities such as patient' narratives (written narratives) are added, ….5 out of 7 participants mentioned that they interrupt their patients very early on, in their stories as they are pressed for time and need to address the matter rather quickly **(OC3-PH1-r2.1; PD1-PH1-r2.1; OC4-PH1-r2.1; OC1-PH1-r2.1; OC3-PH1-r2.1)**.

Though majority of participants (6 out of 7) suggested that it is better for healthcare professionals to set longer appointment time so that they can listen to patients' stories and extract value from these. 1 out of 7 participants suggested that narratives should have a "…*regulated time*" **(OC1-PH1-r3.1)**. In other words, a patient's story should be limited to three minutes and only *"relevant/important information"* should be recorded **(OC1-PH1-r3.1)**. As one participant put it: "*In giving a cancer patient a listening heart, healthcare professionals are able to extract enough information about what is important to the patient and treat him accordingly*" **(OC1-PH1-r2.2)**. Even though, the process of writing and recording patients' narratives seems tiresome **(GP1-PH1-r2.3; OC2-PH1-r2.3)**.

When a new system is implemented not all users get

comfortable, as the need to use the previous system still controlling and most users are reluctant to change. This is known as a cultural issue, where it becomes difficult to drop or quit a habit. For example, of, these two participants **(OC4-PH1-r1.4; GP1-PH1-r1.4)** who are comfortable using both EHRs and paper-based records, yet admit that registering paper-based information into EHRs leave a potential gap in the decision making-process when interpreting patient's information into medical jargon. The gap is present when valued information "…*is left on paper because some EHRs do not have functionalities to register all information e.g. patient's story"* **(OC4-PH1-r1.4)***.*

Furthermore, 4 out of 7 participants mentioned that culture can also be an issue when adopting and implementing narrative in EHRs. As 2 out of 7 participants clarified: "…*many patients are conservatives, they value customs and belief*" **(OC1-PH1-r4.1), "***sharing their stories will be a challenge but creating awareness will defeat their fear*" **(OC2-PH1-r4.1)**.

Integrating a new system in healthcare is costly in terms of implementation and maintenance. As (1 out of 7) respondents mentioned that… "*Healthcare services are progressively becoming expensive due to new IT services and inventions*" **(OC4-PH1-r1.4)**. Seemingly in the case of adding narratives in EHRS; Majority of participants (6 out of 7) said that adopting EHRs with basic functionalities is expensive… "*Customising it to reach the need of healthcare as to record patients' narrative will be costly*" **(OC1-PH1-r2.2; OC2-PH1-r1.4; OC3-PH1-r1.4; PD1-PH1-r1.4).** *This expense does not only affect the healthcare facility but weight on patients too as they have to pay for the services"* **(OC4-PH1-r1.4)**.

EHRs appears to simplify work activities for healthcare

professionals within the decision-making process by automating certain work functions relating to patient records; but its cost and resistance to change still affect its adoption.		

Case 2

Interview Answers	Code	Theory theme
The findings show that all participants (6 out of 6) re-counted positive experiences in using EHRs. These benefits include easy access and referencing since all information is streamlined under one database, more accurate health record that reduce redundancy, manage drug prescriptions, real time information that allow healthcare professionals to base their decision-making on updated information and create back-up.	All positive use experience Benefits (easy access, one source, reduced redundancy, manage prescriptions, real-time information, backups) Positive impact daily practice Easier decision-making	Positive use Benefits Impact on daily practice Impact on DM Impact on DM
To support the above information on the benefits of EHRs, a respondent said that: "*EHRs positively impact oncology daily practice*" **(OC6-PH2-r1.1)**. To confirm this point, another respondent specified that "*with real time access to information in EHRs, the decision-making is made easier*" **(OC8-PH2-r1.1)**. It is evident that EHRs ease healthcare professionals' work by providing a positive impact on patient care and the service outcome.	EHR influence on decision-making (easy access)	Use – benefit Benefit – automation Challenge completeness
When asked how EHRs support healthcare professionals' decision-making, 4 out of 6 respondents believed that EHRs definitely influence the decision-making process. As respondent said: "…*easy access to patients' records, make decision-making efficient*" **(OC7-PH2-r1.4)** since healthcare professionals rely on patients' summarised information. Another respondent added that, "*EHRs has reduced the use of paper-based records which simplify healthcare professionals' work, with real time data process*" **(OC6-PH2-r1.1)**. The effectiveness of EHRs can't be over-emphasised because EHRs simplify healthcare professionals' activities by automating work functions related to patient records. Differing to the above responses, 1 of the 6 participants said that *"EHRs do not support the decision-making entirely because some patients'*	Reduced paper-based use Automate work functions Incomplete EHR not supporting decision-making Challenges: data loss; security Difficult to regain	Challenge data loss, security Effect of challenge Positive use

Interview Answers	Code	Theory theme
records such as family history and past medical history are rarely registered" **(GP3-PH2-r1.4)**.	patient trust due to data loss	
Healthcare professionals mentioned that, they have positive experiences when using EHRs in oncology, however some challenges such as: "*data loss and security issues may occur when using EHRs*" **(GP2-PH2-r1.3)**. when asked, what healthcare professionals do when they can't access patients' EHRs; One (1 out of 6) participant said that "*when we have no access to patients' EHRs, due to loss of data, it is usually difficult to re-gain patients' trust because the moment they know, we can't access their records, they feel that we don't value their information*" **(OC8-PH2-r1.4)**. The same participant added that, a delay in decision–making can be experienced when the above mentioned challenges occur.		

Case 3

Interview Answers	Code	Theory theme
3. Private Hospital 3 (PH3)		Benefits of use
Majority of participants (4 out of 5) described EHRs as an effective tool in oncology care as it provides more benefits such as: easy information sharing, create and update health issues, include history of patients' information, help healthcare professionals find patterns of patient's past health issues across other EHRs and improve decision-making. In clarification with EHRs benefits, a respondent said: "*EHRs has made oncologists work easier, especially with the easy recording process of patient's information*" **(OC9-PH3-r1.1)**. Another respondent added that "*EHRs allow oncologists to trace past patient's health history*" **(OC10-PH3-r1.1)**.	EHRs effective tool Benefits (easy information sharing; ability to see patterns, easy recording, trace patient history

Summarised patient information EHR efficiency – anytime anywhere | Impact on experience

Benefit

Challenges |
| When asked how EHRs support healthcare professionals' decision-making, 3 out of 5 respondents certainly said... "*The fact that EHRs summarise patient information on one screen, there is no doubt about EHRs supporting decision-making*" **(OC9-PH3-r1.4)**. Another respondent added that "*EHRs efficiency, can't be compared to previous paper-based record since it can be accessed anytime and anywhere*" **(GP5-PH3-r1.2)**. | Challenges: data protection against unauthorized access, cost of hardware replacement and software upgrades Over dependency on technology – attention away from | Impact

Impact

Impact |
| From these responses, it is evident that EHRs assist healthcare professionals work and ease the decision-making process. Although there are some challenges | patient When information not available - | Challenge Challenge |

| that arise when using EHRs such as "*protecting data from unauthorised access and cost of replacing hardware and upgrading the software on regular basis*" **(GP4-PH3-r1.4)**. For example, adding and upgrading a functionality such as electronic narratives can be costly in terms of software and security.

Another participant added that EHRs "*provide overdependence on technology, which affect the focus of oncologists*" **(PD3-PH3-r1.4)**. For example, many oncologists focus more on what is written on the internet than basing the facts on their experiences. When healthcare professionals were asked what they do when they cannot access the patient's EHRs, a respondent explained that they *"sometimes transfer the patients to another hospital …or they revert to written notes if available"* **(GP5-PH3-r1.3)**. These notes are more often summarised hence, does not provide the entire health issue of the patient, and as a result, an error can occur which can negatively impact the decision-making process.

The participant further added that: the *"lack of training can also negatively impact the decision-making process"*. Even though recording patient information in EHRs is time consuming, EHRs efficiency can't be overlooked **(GP4-PH3-r1.4)**. | transfer patient, revert back to handwritten notes
Lack of training
Capturing time consuming | |

Q2: Incorporation of narratives in EHRs to aid the decision-making process in oncology
Case 1

Interview Answers	Code	Theory theme
For further clarification on the presence of narratives in oncology care, 1 out of 7 participants said "*written narratives are present in oncology care, but limited only to the diagnosis phase because it is a phase based on the patient's story*" **(OC1-PH1-r2.1)**. These narratives are often "answers *given by patients through interviews or by filling out questionnaires which are later typed into the patient's EHRs*" **(OC4-PH1-r2.3)**. Written narratives guide healthcare professionals in their patient treatment approach, unfortunately with the use of questionnaires "*important information is left out by patient*…due *to laziness, unwillingness to fill in every information and literacy level."* **(OC4-PH1-r2.3)**.	Diagnosis narrative Patient questionnaire response Incomplete questionnaire Patient story important	Narrative use Narrative use

When asked how the use of patients' written narratives impact the outcome of decision making and the treatment process, 5 out of 7 participants said that every patient's story is important as it is the root of diagnosis process to the follow–up process. That why EHRs comprise "*initials of patient's written narratives and a lot of detailed notes*" **(OC1-PH1-r2.2)** to make sure that "*no important information that support the scientific results is omitted*" **(OC2-PH1-r2.2)**. "*I strongly believe that narratives in oncology can do wonders…as most patients' stories present the root to their sickness and that is the beginning of the treatment process*" **(OC4-PH1-r2.4)**. As 1 out of 7 participants said… "*I allow my patients to tell their story, because I wish to extract intrinsic value from their narratives for better care and decision-making* **(OC1-PH1-r2.2)**.	Narrative inform diagnosis Narrative root of illness Narrative add value to patient information Narrative only partially captured Only important components captured	Narrative use Narrative use Narrative use Narrative use
Even though written narratives are used in oncology care, most healthcare professionals said… "*We don't convert everything in the patient's story into medical jargon*" **(OC1-PH1-r2.4)**. We include some elements of what the patient said, and in some cases "*quote the patient's narrative for components that were very specific or of crucial importance*" **(OC3-PH1-r2.2)**.	Narrative can enhance decision-making	Narrative during consultation Narrative during consultation
5 out of 7 participants were of the opinion that using patient written narratives throughout the entire medical journey, not only can enhance decision-making, but gives healthcare professionals better understanding and proficiency in dealing with patients. In other words, patients' narratives are used for better decision-making, and therefore have a positive impact. Decision-making in healthcare depends on scientific processes and on what story the patient tells; as "*...whatever the story is, will determine the treatment*" **(OC1-PH1-r2.4)**. In fact, when patients' narratives are used in decision-making and in the treatment process, "*…the outcome is always satisfactory no matter the circumstances*" **(OC4-PH1-r2.4)**.	Narrative improve patient care Narrative in decision-making positive impact Narratives increase patient care	Narrative for decision-making Narrative for decision-making Narrative impact
From the above responses, it is obvious that written narratives are present in the diagnosis phase of private oncology care and play a major role in decision-making process despite its collection method of using questionnaires and interviews; which leaves a gap in decision-making process when partial filled questionnaire information is typed into the patient' EHRs.	Incomplete capturing of narratives No electronic narratives	Narrative impact Narrative during consultation
When asked about the use of electronic narratives (audio & video) in oncology care, all participants (7 out of 7) mentioned that currently there is no presence of electronic narratives (audio and video narrative) in oncology care. **Electronic narrative** is a digital version of a patient's narrative records which combines video, sound, animation, text, music and narrative voice experienced by both healthcare professionals and patients; to record the diagnosis, treatment and recovery processes to promote well-being (Cunsolo, Harper & Edge, 2012).		Narrative use
When asked about the use of electronic narratives to support decision-making in oncology care, it was evident that there was lack of knowledge about the subject. Nevertheless 2 out of 7 participants mentioned that they have been reading and familiarising themselves with narratives in healthcare **(OC1-PH1-r2.4; OC2-PH1-r2.4)** whereas 5 of 7 participants said they were eager to see electronic	Limited exposure to narratives	Narrative use

narrative implemented in their oncology care centres. 1 out of 7 participants said "*Narratives in oncology care are interesting …I did not know that patients' stories can be part of EHRs or can change the way we treat cancer patients*" **(OC1-PH1-r2.4)**. Another participant added *"I am doing an online course about narratives in oncology care and I am eager to apply it in my daily practice"* **(OC2-PH1-r2.4)**. Furthermore, 1 out of 7 participants responded: *"If written narratives (paper-based) give us the indices of what is wrong with the patient when we start a conversation, how much more audio and video narratives registered in patient's EHRs! …I admit it can help in decision-making and as a reminder if some important information is left out during the entire treatment process of a patient"* **(OC1-PH1-r2.4).**	Narrative can change patient care Interest in narrative in care Narrative add value Electronic narratives have potential	Narrative impact Narrative use Narrative impact Narrative use
When asked how narratives can be captured a respondent said *"…I believe narratives can be in written, audio and video format* **(OC2-PH1-r2.3)**. The same respondent added that… "*Incorporating audio and video (images) narratives in EHRs …can give us a clear picture of what is wrong with the patient from a long period of time. This will help in decision-making as EHRs has the capacity of summarising patient information on a screen and help us take further action"*. An additional benefit to electronic narratives is that proof exists should "*legal issues*" **(OC1-PH1-r2.2)** arise between healthcare professional and patient. 5 out of 7 participants considered the functionality of recording patients' narratives in EHRs "*as the best gift they can offer to their patients and to themselves"* since "*most family members request for their relative's EHRs* **(OC1-PH1-r2.2; OC3-PH1-r2.2)**. Most participants (5 out of 7) said that the inclusion of audio and video narratives in EHRs is of high importance because electronic narratives can *"increase willingness to communicate, can teach about cultures, can build empathy and can promote positive attitude"* **(OC1-PH1-r3.2; OC2-PH1-r3.2; GP1-PH1-r3.2; PD1-PH1-r3.2)**. It can therefore be said that, there is a need of electronic narratives in oncology care, as healthcare professionals show how valuable patients' electronic narratives are and how the use of electronic narratives with evidence-based results can improve decision-making. There are however legal matters and ethical considerations that must be taken into consideration when incorporating narratives in EHRs. Patients' narratives are confidential and the moment patients realise that they will be recorded, "*…it may change the dynamic of*	Electronic narratives potential for patient's condition EHR summarises patient information Electronic narrative useful for legal issues Electronic narratives to inform patients and family Electronic narratives can have communication benefit Incorporating electronic narratives in EHR may have legal and ethical concerns Confidentiality issues Recording narratives may intimidate patients Electronic narratives still at	Narrative use Narrative use Narrative use Narrative use Narrative use Narrative use Narrative use Narrative during consultation Narrative use

Interview Answers	Code	Theory theme
their stories and create trust issues" **(PD1-PH1-r2.3)**.	infancy stage	
From the above responses, it is evident that narratives in EHRs still at the infancy stage in private oncology care of Cape Town.		

Case 2

Interview Answers	Code	Theory theme
When asked about the use of narratives in oncology care, the findings show that majority of participants (5 out of 6) use narratives. One participant said: "*narrative is the essential element of treatment in oncology, without patients 'narratives, the treatment is incomplete*" **(OC6-PH2-r2.1)**. For further clarification…"*we use written notes (paper) to collect patients' narratives that are later recorded in the patients' EHRs*" **(OC8-PH2-r2.3)**. This is not "*an efficient way of collecting patients' narratives as it is time consuming and divert our focus on patients' narratives to writing*" **(OC7-PH2-r2.3)**. These notes are… "*always summarised and recorded in EHRs but in short form (abbreviation), which sometimes give healthcare professionals a hard time to decode the information*" **(GP3-PH2-r2.3)**.	Narrative essential for treatment

Narrative notes on paper

Narratives recorded later

Narrative time consuming

Noting narratives divert attention away from patients

Narratives summarized in EHR | Narrative use

Narrative during consultation
Narrative during consultation
Narrative during consultation
Narrative during consultation

Narrative use |
| When asked how the use of patients' written narratives impact the outcome of decision-making and the treatment process, 3 out of 6 said that patients' narratives provide the root of the sickness and support the decision-making **(OC6-PH2-r2.3; OC8-PH2-r2.3; GP2-PH2-r2.3)**.

As one participant said: "*the foundation of treating a cancer patient begins from his/her story…and narratives instil value in decision-making*" **(OC7-PH2-r2.2)**. Unfortunately, "*patients are not given enough time to express themselves …because healthcare professionals are too busy*" **(OC8-PH2-r2.2)**. 4 out of 6 participants said that "*it is so unfortunate that patients' narratives are limited to the diagnosis stage, as this leaves a gap in the decision-making*" | Narratives support decision-making

Narrative add value to decision-making
Limited time for patients to tell their stories

Narratives currently only for diagnosis | Narrative for decision-making

Narrative impact

Narrative during consultation

Narrative use |

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(OC6-PH2-r2.3; OC8-PH2-r2.3; GP2-PH2-r2.3).	No electronic narratives yet	
		Narrative use
When asked about the use of electronic narratives (audio & video) in oncology care, all participants (6 out of 6) mentioned that presently there is no electronic narratives (audio and video narrative) in oncology care. When asked about the use of electronic narratives to support decision-making in oncology care, it was obvious that there was limited knowledge about the subject. However, 1 out of 6 participants mentioned that he has been reading about narratives in oncology, and said… "*I believe electronic narratives can support the decision-making since detailed information of patients' health can be retraced and support evidence-based treatment (lab result)*" **(OC8-PH2-r2.4).** When asked how narratives can be captured, the same respondent said "*…I trust narratives can be in written and audio format* **(OC8-PH2-r2.3)**.	Limited knowledge about electronic narratives	
	Some interest in electronic narratives	Narrative use
	Electronic narratives could have potential	
		Narrative use
		Narrative use
The above responses prove that narratives presence in EHRs is limited to the diagnosis phase despite its advantages, and it is evident that electronic narratives have not been introduced in private oncology care of Cape Town.		

<u>Case 3</u>

Interview Answers	Code	Theory theme
When asked about the use of narratives in oncology care, the findings show that majority of participants (4 out of 5) use narratives in short form notes. These notes are "*written when healthcare professionals are interacting with patients*" **(OC9-PH3-r2.1)**. These narratives are important for healthcare professionals "*to know the source of the patient' health problem and to select the appropriate treatment process*" **(OC10-PH3-r2.3)**.	Narratives as short notes	Narrative during consultation
	Note taking during consultation	Narrative during consultation
	Narratives useful to identify source of health problem	Narrative use
	Narrative useful for treatment	Narrative use
When asked how the use of patients' written narratives impact the outcome of decision-making and the treatment process, 2 out of 5 participants said: "*decision-making can't be processed if patients' narratives are not involved*" **(GP4-PH3-r2.3)**. Another participant further added: "*patients' narratives are the driven force of patients'*	Narratives essential for decision-making	Narrative for decision-making

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Interview Answers	Code	Theory theme
treatment decision-making" (**OC10-PH3-r2.2**).		
When asked about the use of electronic narratives (audio & video) in oncology care, all participants (5 out of 5) said, electronic narratives have not been used because… "*There is no appropriate system put in place*" (**OC9-PH3-r2.1**). Another respondent added that… "*I also believe that there is limited knowledge on narratives and electronic narratives*" (**GP5-PH3-r2.3**). But all believe that electronic narratives can support decision-making. As one participant said: "*stories are powerful and enormously contribute to patient well-being*" (**PD3-PH3-r2.4).**	Electronic narratives not yet used	Narrative use
	System inadequate for electronic narratives	Narrative use
	Limited knowledge on electronic narratives	Narrative use
	Electronic narratives have potential	
		Narrative use

Q 3: Requirements for incorporating narratives in EHRs to support decision-making in oncology care.

Case 1

Interview Answers	Code	Theory theme
The answers below were generated from the third set of interview questions regarding this sub-question: What informs the inclusion of narratives in electronic health records to support the decision making process?	Technology requirements	Requirements
When asked about the requirements of incorporating narratives in EHRs to support decision-making, 3 out of 7 participants said: Incorporating narratives in EHRs will "…*require some electronics such as tablets, computers, solid audio interface, headphones etc. With additional recording software that will be able to handle patients' electronic narratives*" (**OC1-PH1-r3.1**). Furthermore, "*narrative recording technics must be well understood and utilised*" (**OC2-PH1-r3.1)**…. *recording technics…such as room settings, list of questions (printed or recorded)* (**OC4-PH1-r2.3**).	eNarrative	eNarrative during consultation
	Narrative integrated into EHR	eNarrative integration
When asked how healthcare professionals would prefer patients' narratives to be included in EHRs to support the decision making, 5 out of 7 participants mentioned that they prefer patient-recorded audio to be on the same page that displays the latest patient EHRs (**OC1-PH1 -r3.1; OC2-PH1-r3.1; OC3-PH1-r3.1; OC4-PH1-r3; GP1-PH1–r3.1**). Since written narratives are always typed in EHRs, "functionalities to accommodate audio and video should be included to manage that type of information" (**OC1-PH1-r3.1**). In this vein, electronic narrative records should include component such as "*patient demographics*, *vital signs, diagnosis, medications, allergies, radiology images, audio, progress notes and test and laboratory*	Narrative technology Patient information	Technology use eNarrative patient information
	eNarrative recording	eNarrative use

Interview Answers	Code	Theory theme
results" **(OC3-PH1)**.	Technology +	Technology
1 out of 7 participant believed that: playing the audio record before taking further action on treating the patient "*fills the therapeutic gap in decision-making*" **(OC1-PH1-r3.1)**. unfortunately, …" *we don't have a system that can record patients electronic narratives, otherwise it could help to double check the story since it can automatically be saved in the system and can be accessed anytime*" **(OC2-PH1-r2.2)**.	Narrative support decision-making	eNarrative for decision-making
When asked if patients' narratives in EHRs can support the decision-making process, 6 out of 7participants said that since 90% of oncology work evolve around patients' narratives it is possible for electronic narratives to support the decision-making process. 2 out of 7 participants said including narratives in EHRs will, "…*definitely support the decision-making process*" **(OC4-PH1-r3.2, GP1-PH1 – r3.2)** because "*personal stories affect the judgements and values people have and the choices they make*" **(OC4-PH1-r3.2, GP1-PH1–r3.2)**. Whereas 1 out of 7 participants said that "*there is insufficient evidence about narratives supporting decision-making*" **(GP1-PH1 –r3.2)** because we have no experience yet.	Patient stories Narrative supporting decision-making	eNarrative for decision-making

Case 2

Interview Answers	Code	Theory theme
When asked about the requirements of incorporating narratives in EHRs to support decision making, 1 out of 6 participants said: "*I believe that, we need computers and internet connexion to record patients' narratives in EHRs*" **(OC6-PH2-r3.1)**. 4 out of 6 participants mentioned that patients' narratives are important and … "*would like narratives to appear on the patient' EHRs summary page*" **(OC6-PH2-r3.1; OC7-PH2-r3.1; OC8-PH2-r3.1; PD2-PH2-r3.1)**. The same respondents believed that electronic narratives can support decision-making in oncology care. As one participant said: "*the accessibility to patients' narratives have the power to positively impact the decision-making by giving detailed information on the patients' health state*" **(OC7-PH2-r3.1)**.	eNarrative requirements Narrative + Narrative supporting decision-making Narrative impact	Requirement eNarrative integration Narrative for decision-making eNarrative impact

Case 3

Interview Answers	Code	Theory theme
When asked about the requirements of incorporating narratives in EHRs to support decision-making, majority of participants (4 out of 5) said that, they don't have the knowledge on what is required. As one respondent said "*this question can be answered by people with information technology knowledge*" **(OC9-PH3-r3.1)**. When asked how healthcare professionals would prefer patients' narratives to be included in EHRs to support the decision making, 1 out of 5 participants said: "*I would prefer patients' narratives to be registered as priority in patients' EHRs, so that it can be viewed before proceeding with patients' treatment*" **(OC10-PH3-r3.1)**. All participants (5 out of 5) believe that electronic narratives can	Lack of knowledge on eNarrative IT skills required to use eNarrative Narrative + Narrative	Challenge Requirement eNarrative integration Narrative for decision-

Interview Answers	Code	Theory theme
support decision-making process in oncology care **(OC9-PH3 -r3.1; OC10-PH3-r3.1; PD2-PH3-r3.1; GP4-PH3 –r3.1; GP5-PH3 –r3.1)**. One respondent said: "*patients electronic narratives contain value that can save patients' lives if well scrutinised*" **(GP4-PH3 –r3.1)**.	supporting decision-making.	making

Q 4: Barriers to the use of electronic narratives to support decision-making in oncology.

Case 1

Interview Answers	Code	Theory theme
To understand the reasons why narratives are yet to be used to support decision-making in oncology care, one participant mentioned: "…*limited knowledge about narratives and electronic narratives exists*" **(OC1-PH1-r4.1)**. Present EHRs do not support the inclusion of patients' stories but allow small notes, there is a "…*need for upgrading existing EHR systems*" **(OC3-PH1-r4.2)**. The same participant **(OC3-PH1-r4.1)** stated that recording patient narratives will need "*extra expertise*" on how to deal with narratives in EHRs. Whereas 1 out of 7 participants mentioned that even if a system that processes patients' electronic narratives was available, he will "…*prefer not to deal with patients' stories*" **(OC5-PH1-r2.4)**. Furthermore, 1 out of 7 participants **(OC5-PH1-r2.4)** explained that they did not see the use of patients' narratives in decision-making as they would rather rely on scientific processes and results that they can trust.	Limited knowledge about narratives and eNarrative. Limited EHRs capacity. Expertise needed. Fear to embrace eNarrative.	Challenge challenge Requirement+ Challenge

Case 2

Interview answers	Code	Theory theme
To understand the reasons why narratives are yet to be used to support decision making in oncology care, majority of participants (5 out of 6) mentioned that electronic narratives are non-existent in their practice yet **(OC7-PH2-r4.1, PD2-PH2-r2.4, OC6-PH2-r4.1)**. For example, one participant said: …"*I have not heard of electronic narratives*" (**GP3-PH2-r2.4**). Another participant added that, "*the current EHRs system we use does not have enough space for oncologist notes, how much more of patient electronic narratives?*" **(OC8-PH2-r4.1)**. Furthermore, 1 out of 6 participants said, "*EHRs is complex, adding electronic narratives will make it more complex and it might change some functionalities in EHRs*" **(OC6-PH2-r4.1)**, the change will require training and expertise. Whereas 1 out of 6 participants said: "*electronic narratives can enormously contribute to decision-making by providing facts and a proper follow-up on each patients' treatment*" **(OC7-PH2-r2.4)**.	Absence of eNarrative. Lack of eNarrative knowledge. EHR system need upgrade. Complexity of EHR system eNarrative use +	Challenge Challenge Requirement+ Challenge Narrative for decision making.

Case 3

Interview answers	Code	Theory theme
To understand the reasons why narratives are yet to be used to support decision-making in oncology care, all participants (5 out of 5) mentioned that electronic narratives is a new topic for them and the best to do, is to familiarise themselves with it. As one participant mentioned: "*I heard of the term electronic narratives but I have not taken time to read about it*" **(OC10-PH3-r4.1)**. Another participant added that "training on the subject will be of importance in oncology care" **(OC9-PH3-r4.1)**. From the above information, it is evident that there is limited knowledge about electronic narratives in oncology care. Raising awareness about electronic narratives is important and should not only be limited to healthcare professionals but should also be extended to patients since narratives revolve around them.	2.1	Challenge Requirement+

Appendix C: Ethics Approval

Cape Peninsula
University of Technology

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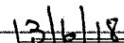| Office of the Faculty Research Ethics Committee	Faculty of Informatics and Design

13 June 2018

Ethics approval was granted to Ms Chantal Kalorho Musimwa, student number 215217098, for

research activities related to the MTech: Information Technology at the Faculty of Informatics and

Design, Cape Peninsula University of Technology.

Title of the proposal:	The use of electronic narratives records to support the decision making process in oncology care at private hospitals of Cape Town

Comments

Research activities are restricted to those detailed in the research proposal.

Signed: Faculty Research Ethics Committee	Date

RESEARCH ETHICS COMMITTEE
INFORMATICS AND DESIGN
ETHICS APPROVAL GRANTED

1 3 JUN 2018

Cape Peninsula
University of Technology

Appendix D: Sample of signed consent letter

I●●●●●●●● in my capacity as Radiation Oncologist in a solo practice in Constantia give consent in principle to allow Chantal Musimwa , a student at the Cape Peninsula University of Technology, to collect data in this practice as part of his/her M Tech (IT) research. The student has explained to me the nature of his/her research and the nature of the data to be collected.

This consent in no way commits any individual staff member to participate in the research, and it is expected that the student will get explicit consent from any participants. I reserve the right to withdraw this permission at some future time.

In addition, the company's name may or may not be used as indicated below. (Tick as appropriate.)

	Thesis	Conference paper	Journal article	Research poster
Yes				
No	no	no	no	no

_____

10/07/18