A FRAMEWORK FOR PERSONAL HEALTH RECORDS IN ONLINE SOCIAL NETWORKING

by

Eldridge van der Westhuizen

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Co-Supervisor: Rudi Harmse

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DECLARATION

I, Eldridge Werner van der Westhuizen (student number 9628022), hereby declare that the dissertation for Magister Technologiae in Information Technology is my own work and that it has not previously been submitted for assessment or completion of any postgraduate qualification to another University or for another qualification.

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ABSTRACT

Since the early 20th century, the view has developed that high quality health care can be delivered only when all the pertinent data about the health of a patient is available to the clinician. Various types of health records have emerged to serve the needs of healthcare providers and more recently, patients or consumers. These health records include, but are not limited to, Personal Health Records, Electronic Heath Records, Electronic Medical Records and Payer-Based Health Records. Payer-Based Health Records emerged to serve the needs of medical aids or health care plans. Electronic Medical Records and Electronic Health Records were targeted at the healthcare provider market, whereas a gap developed in the patient market.

Personal Health Records were developed to address the patient market, but adoption was slow at first. The success of online social networking reignited the flame that Personal Health Records needed and online consumer-based Personal Health Records were developed. Despite all the various types of health records, there still seems to be a lack of meaningful use of personal health records in modern society.

The purpose of this dissertation is to propose a framework for Personal Health Records in online social networking, to address the issue of a lack of a central, accessible repository for health records. In order for a Personal Health Record to serve this need it has to be of meaningful use. The capability of a PHR to be of meaningful use is core to this research. In order to determine whether a Personal Health Record is of meaningful use, a tool is developed to evaluate Personal Health Records. This evaluation tool takes into account all the attributes that a Personal Health Record which is of meaningful use should comprise of. Suitable ratings are allocated to enable measuring of each attribute. A model is compiled to facilitate the selection of six Personal Health Records to be evaluated. One of these six Personal Health Records acts as a pilot site to test the evaluation tool in order to determine the tool's utility and effect improvements. The other five Personal Health Records are then evaluated to measure their adherence to the attributes of meaningful use. These findings, together with a literature study on the various types of health records and the evaluation tool, inform the building blocks used to present the framework. It is hoped that the framework for Personal Health Records in online social networking proposed in this research, may be of benefit to provide clear guidance for the achievement of a central or integrated, accessible repository for health records through the meaningful use of Personal Health Records.

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"When you grow up you tend to get told the world is the way it is and your life is just to live your life inside the world. Try not to bash into the walls too much. Try to have a nice family life, have fun, save a little money.

That's a very limited life. Life can be much broader once you discover one simple fact, and that is - everything around you that you call life, was made up by people that were no smarter than you. And you can change it, you can influence it, you can build your own things that other people can use.

Once you learn that, you'll never be the same again."

STEVE JOBS

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LIST OF ACRONYMS USED

ADR	Adverse Drug Reaction
AHIMA	American Health Information Management Association
ARR	American Recovery and Reinvestment
ASC	Accredited Standards Committee
ASTM	American Society for Testing and Materials
CCD	Continuity of Care Document
CCR	Continuity of Care Record
CDA	Clinical Document Architecture
CDO	Care Delivery Organization
CDR	Clinical Data Repository
CDSS	Clinical Decision Support System
CMV	Controlled Medical Vocabulary
CPOE	Computerized Provider Order Entry
CPR	Computerized Patient Record
CT	Computerized Tomography
DICOM	Digital Image Communication
EDI	Electronic Data Interchange
EHCR	Electronic Health Care Record
EHR	Electronic Health Record
EMR	Electronic Medical Record
EPR	Electronic Patient Record
GIGO	Garbage In, Garbage Out
HHS	Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HIT	Healthcare Information Technology
HL7	Health Level Seven
HTML	HyperText Markup Language
ICD	International Classification of Diseases
IEEE	Institute of Electrical and Electronic Engineers
IOM	Institute of Medicine
ISO	International Organization for Standardization

IT	Information Technology
JAHIS	Japanese Association of Healthcare Information Systems
MRI	Magnetic Resonance Imaging
MU	Meaningful Use
MU-PHR	Meaningful Use Personal Health Records
NCPDP	National Council for Prescription Drug Programs
OTC	Over The Counter
PDA	Personal Digital Assistant
PDF	Portable Document Format
PHI	Personal Health Information
PHR	Personal Health Record
USB	Universal Serial Bus

PUBLICATION STEMMING FROM THIS RESEARCH

The following publication stemmed directly from the research conducted in order to complete this dissertation:

- Van Der Westhuizen, E., Pottas, D. (2010). Towards Characteristics of Lifelong Health Records. In: Tekada H. *E-Health: First IMIA/IFIP Joint Symposium, E-Health 2010*, World Computer Congress 2010, Brisbane, Australia, September 20-23, Proceedings, p. 61-70.

LIST OF APPENDICES

A	Publication Stemming from this Research

CHAPTER 1

INTRODUCTION

1.1 BACKGROUND

The medical profession has long been criticised for exerting professional dominance over patients (Pilnick & Dingwall, 2011). There are many reasons for this and one of the most important is the asymmetry of knowledge, where the doctor controls almost all the information and often shares it sparingly (Bleicher, 2008).

Evidence indicates that doctors are sometimes slow to exploit the potential of new information sources, such as the Internet. Traditionally, the adoption of Healthcare Information Technology (HIT) has been slow (Kaushau, Blumentha, & Poon, 2005). Healthcare budgets spend about 50% less on Information Technology (IT) than most other sectors (Bates, 2002). There is a danger that, should this trend continue, people will have to navigate through myth and hearsay, rather than have easy access to health information sources (Great Britain. Dept. of Health, 2008). This could include various types of information, of which Personal Health Information (PHI) is of interest for this research.

PHI is defined as information about an identifiable person which relates to the physical or mental health of the individual, or to provision of health services to the individual, and may include (ISO 27799, 2008):

- Information about the registration of the individual for the provision of health services;
- Information about payments or eligibility for healthcare with respect to the individual;
- A number or symbol assigned to an individual to uniquely identify the individual for health purposes;

- Any information about the individual collected in the course of the provision of health services to the individual;
- Information derived from the testing or examination of a body part or bodily substance; and
- Identification of a person (e.g. a health professional) as the provider of healthcare to the individual.

The American Heritage Medical Dictionary (2007) defines a health record or medical record as a chronological written account of examination and treatment of the patient that includes their medical history and complaints, the physical findings of the physician, the results of diagnostic tests and procedures, and medications and therapeutic procedures. From this definition one can argue that the three main contributors to such a health record can be: the medical aid of the patient or other healthcare payers; the physicians, hospitals, and other healthcare providers; and the patients themselves. Consequently, three different versions of health records have evolved (EHM Executive Healthcare, 2011):

1. The payer-based health record (PBHR), consisting of data known to the medical aid of the patient;
2. The Electronic Health Record (EHR), which includes data known to healthcare providers; and
3. The Personal Health Record (PHR), which contains data known to the patient, but may include data from other sources such as healthcare providers.

Hybrids of these three are also common.

A brief overview of the three sources, namely PHRs, EHRs and PBHRs, which contain PHI, follows. A more in depth discussion is provided in Chapter 3.

The American Health Information Management Association (AHIMA) defines the PHR as “a universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR that is collected from healthcare providers or entered by the individual. The

PHR is maintained in a secure and private environment with the individual determining rights of access - it is separate from, and does not replace, the legal record of any provider" (Informatics Review, 2006, p. 1). PHRs have a wide range of diverse architectures and functions, ranging from "stand-alone" that do not integrate with any other systems, to "tethered" PHRs that provide a patient-oriented view that is integrated with other electronic health information (Ash, Tang, Bates, Overhage, & Sands, 2006). The main purposes of introducing PHRs have been to empower patients with a sense of ownership of their care and to improve communication, between both the patients and clinicians and between the different clinicians involved in the care of the patient (Laugharne & Stafford, 1996). Further discussion of PHRs can be found in Chapter 3, Section 3.2.3.

An EHR refers to a "repository of information regarding the health status of a subject of care, in computer-processable form, stored and transmitted securely and accessible by multiple authorized users, having a standardized or commonly agreed logical information model that is independent of EHR systems and whose primary purpose is the support of continuing, efficient and quality integrated health care" (ISO/TR 20514, 2005, p. 2) . Normal property rights do not apply to EHRs because the care providers have a right to the information, therefore, the patients do not have sole possession or control over their information. Instead, they have privacy rights to protect and control access to their records. Further discussion of EHRs can be found in Chapter 3, Section 3.2.2.

A PBHR is owned and administered by the patient's medical aid. It includes whatever data are available to the health plan but primarily those related to claims. It may include demographic information provided by the patient at the time of enrolment. It does not contain clinical notes; however, owing to the increasing amount of data required in submitting claims to payers, a PBHR may comprise laboratory results, radiological readings, prescriptions, and complete reports for inpatient and outpatient hospital care and other types of information (Common Terms in Health Information Technology, 2008). Further discussion of PBHRs can be found in Chapter 3, Section 3.2.1.

Over the past years, a dramatic shift in the amount of information available to the patient has been witnessed (Nelson, 2009). This shift has contributed to a noticeable increase in patient autonomy and choice in medical care (ACOG, 2008). Information is more easily available due to major advances in technology. This led to the development of consumer-focused health systems and the discussion will focus on these systems now.

The Internet is commonly used, including online social networking sites. These social networking websites function like an online community of Internet users. Depending on the website in question, many of these online community members share a common interest such as hobbies, religion, or in the case of this research, medical care. Once access is granted to a social networking website, socializing can begin. This may include reading the profile pages of other members and possibly contacting them. Web 2.0-based social networking tools have been developed to assist users to easily create online profile pages and share information. Web 2.0 refers to the second generation of the World Wide Web in which content is user-generated and dynamic, and software is offered that mimics desktop programs. Web 2.0 encourages collaboration and communication between users (Dictionary.com, 2009). Web 2.0 websites typically leverage social networking using modern, flexible website design methods and the collective knowledge of the public to create value and quality for users of the website.

Health 2.0 (also referred to as PHR 2.0) is an outgrowth of the Web 2.0 era. Health 2.0 gives the patient the ability to create his own PHR. Examples include PatientsLikeMe, HealthVault from Microsoft, Google Health, and many more. These PHRs allow patients to keep a permanent, longitudinal record of their health data, either manually captured or linked from medical records. They can decide whether to provide access to their records and also what information they would like to share. The transfer of authority over medical records is a major step in patient empowerment (Bleicher, 2008). Patients now have control of their own PHI and can make it available to doctors and other medical practitioners.

However, it is still common, despite the various types of health records that are available, that doctors and patients lack a central repository to search for the health record of an individual (Tamara Wilhite, 2008). This research will attempt to address this issue of the lack of a central or integrated, accessible repository for health records, by looking at PHRs in online social networking as a possible solution.

The term used in this dissertation is “*meaningful use*” (MU). When referring to MU in healthcare, the term is more closely coupled to EHR systems and whether health providers can demonstrate that they are using certified EHR technology in ways that can be measured in quantity and quality. This model is of relevance in America and is mandated by the American Recovery and Reinvestment Act (ARR Act) (American Recovery and Reinvestment Act, 2009). If meaningful use can be achieved, health care providers will receive incentives.

The ARR Act strives to achieve a vision where “all patients are fully engaged in their healthcare, providers have real-time access to all medical information and tools to help ensure the quality and safety of the care provided while also affording improved access and elimination of health care disparities” (The Office of the National Coordinator for HIT, 2009, p. 1).

MU is to be rolled out in three stages by the US Health and Human Services for healthcare providers over a period of time until 2015. Some of the indicators that health care providers need to meet are as follows (Centers for Medicare & Medicaid Services, 2011):

- Implement drug-drug and drug-allergy interaction checks;
- Maintain up-to-date problem list of current and active diagnoses;
- Maintain active medication list;
- Record all of the following demographics:
    - Preferred Language;
    - Gender;
    - Race;
    - Ethnicity;
    - Date of birth; and
    - Date and preliminary cause of death in the event of mortality.

- Record and chart changes in the following vital signs:
    - Height;
    - Weight;
    - Blood pressure;
    - BMI; and
    - Plot and display growth charts for children 2-20 years.
- Provide patients with an electronic copy of their health information (including diagnostic test results, problem list, medication list, medication allergies, discharge summary and procedures) upon request.

For eligible professionals, there is a list of 25 MU objectives and for hospitals there are 24 MU objectives. To qualify for incentives, professionals need to meet 20 of these objectives and hospitals 19.

In terms of this research and the focus being on the individual/patient, the term *meaningful use* must be understood in relation to personal health records in online social networking. The researcher uses the term *meaningful use* with the same intended meaning as that found in literature, but develops his own indicators (or attributes) for meaningful use of PHRs in online social networking. This brings to life the concept of an MU-PHR. MU-PHR refers to health records that are integrated (populated with patient information from various sources), interconnected (accessible by various stakeholders) and where the patient is an important contributor to, and owner of the content of the record.

1.2 PROBLEM STATEMENT

The main problem addressed in this research is **the lack of meaningful use of personal health records in modern society.** Given the focus of this research on personal health records in online social networking, the following research questions arise:

- What should the attributes of an MU-PHR in online social networking be?

- How can online PHRs be evaluated to measure their operation in relation to the identified attributes?
- What should the concepts and components of a framework for the meaningful use of PHRs in online social networking be?

1.3 RESEARCH OBJECTIVES

The Institute of Medicine (IOM) proposes six goals to redesign health care for the twenty-first century, namely: providing safe, effective, patient-centred, timely, efficient, and equitable health care. The ten design rules of the IOM are less well-known and comprise the following (Informatics Review, 2009):

1. Care based on continuous healing relationships;
2. Customization based on the needs and values of the patients;
3. The patient is seen as the source of control;
4. Shared knowledge and the free flow of information;
5. Evidence-based decision making;
6. Safety as a system property;
7. The need for transparency;
8. The anticipation of needs;
9. A continuous decrease in waste; and
10. Cooperation among clinicians.

The views held by IOM include that a new relationship between patients and physicians must be created to achieve the goal of the empowerment of patients. Patients must play a greater role in making decisions concerning their health and be a partner in their health care, not just a bystander or listener.

There is significant potential for these transformational changes in health care delivery to be supported and stimulated by integrated personal health records (Detmer, Bloomrosen, Raymond, & Tang, 2008). However, there are also a number of barriers to realising this potential.

The core objective of this research, therefore, is to propose a framework for PHRs, specifically PHRs in online social networking.

A number of secondary objectives need to be accomplished to achieve this primary objective:

- Identify the attributes of MU-PHRs in online social networking;
- Evaluate online PHRs to measure their operation in relation to the identified attributes;
- Propose the concepts and components of a framework for the meaningful use of PHRs in online social networking.

In order to reach these objectives, it is important that a methodical research process is followed using appropriate research methods. A detailed discussion of the research design and research methods is provided in Chapter 2.

1.4 LAYOUT OF DISSERTATION

The layout of the dissertation is depicted in Figure 1.1 on the page 10.

The first chapter provides background information leading to the problem definition, research questions and objectives of the study.

Chapter 2 focuses on the research design as well as the research processes that were executed to reach the objectives of the study.

Chapter 3 focuses on the evolution of health records – from paper-based systems to modern day. A literature study is done on the various types of records used to store PHI, for example PHRs, EHRs and PBHRs. The barriers that prevent these sources of PHI being used in an integrated solution are investigated. Focus then shifts to the creation of PHRs using social networking media. An in-depth discussion of social networking tools is done and Web 2.0 is covered as the technology of choice in the context of this research. A review of current PHR 2.0 tools is carried out. The chapter concludes with the creation of nine dimensions (or attributes) for MU-PHRs.

In Chapter 4, an evaluation tool is created to measure the operation of online PHRs in relation to the dimensions (or attributes) of MU-PHRs. The evaluation tool is tested on a pilot PHR site and a revised evaluation tool is created. This revised tool is tested against five online PHRs to measure their operation in relation to the concept of an MU-PHR. All the findings are documented.

In Chapter 5 a framework for the meaningful use of PHRs in online social networking is presented.

The last chapter, Chapter 6, presents a review of the dissertation and shows how the objectives of the research were achieved. The benefits and limitations of the research are explained. Suggestions are made for future research.

1.5 CONCLUSION

This concludes the introductory chapter of this dissertation. The main objective of this research is to create a framework for meaningful use of PHRs in online social networking. The following chapter will provide more detail about the research design that was used as well as the research methods that were adopted.

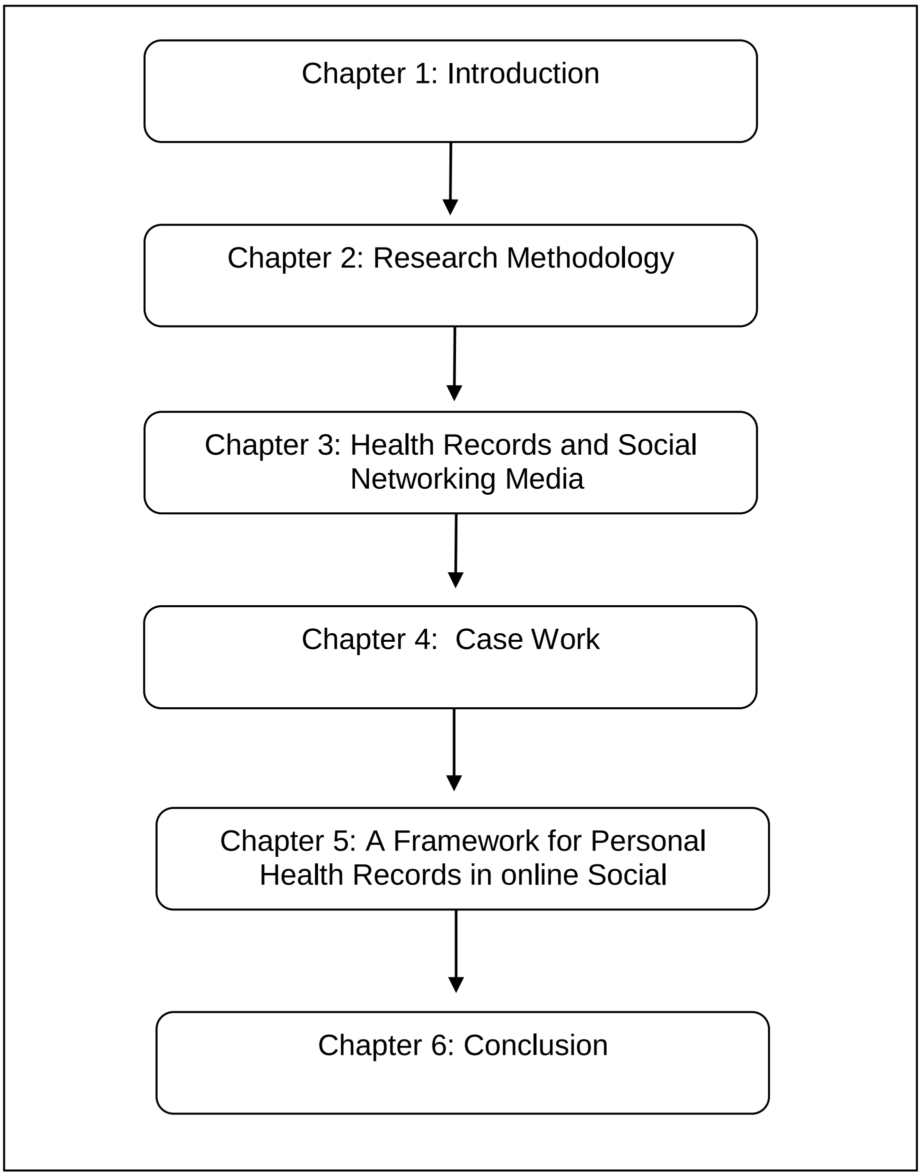

Figure 1.1: Dissertation Layout.

CHAPTER 2

RESEARCH METHODOLOGY

2.1 INTRODUCTION

Methodology implies the way (or route) the researcher will need to take in order to achieve a certain result (knowledge, insight, design, intervention, solution). However, Jonker and Pennink (2010) state that although a route can be established by means of an intentional or unintentional starting- and finishing point, it remains to be seen how the route is elaborated in-between. This chapter examines the research design, research process and research methods that were used by the researcher to ensure the authenticity of this study.

2.2 RESEARCH DESIGN

According to Trochim (2006), a research design can be thought of as the structure of the research – it is the glue that holds all of the elements in a research project together. Therefore, the researcher must select the most appropriate design to meet the aims and objectives of the study (Parahoo, 2006).

The research process was executed in four phases:

1. Literature Study
2. Create and Refine Evaluation Tool
3. Cases
4. Framework

In brief, a literature review was conducted to determine the dimensions of MU-PHR (Phase 1). These were used to create a tool (Phase 2) to evaluate (Phase 3) the strengths and weaknesses of selected PHRs in terms of their conformance with the dimensions of MU-PHR. This led to the creation of a framework for the meaningful use of Personal Health Records in Online Social Networking (Phase 4).

Figure 2.1 illustrates the research process.

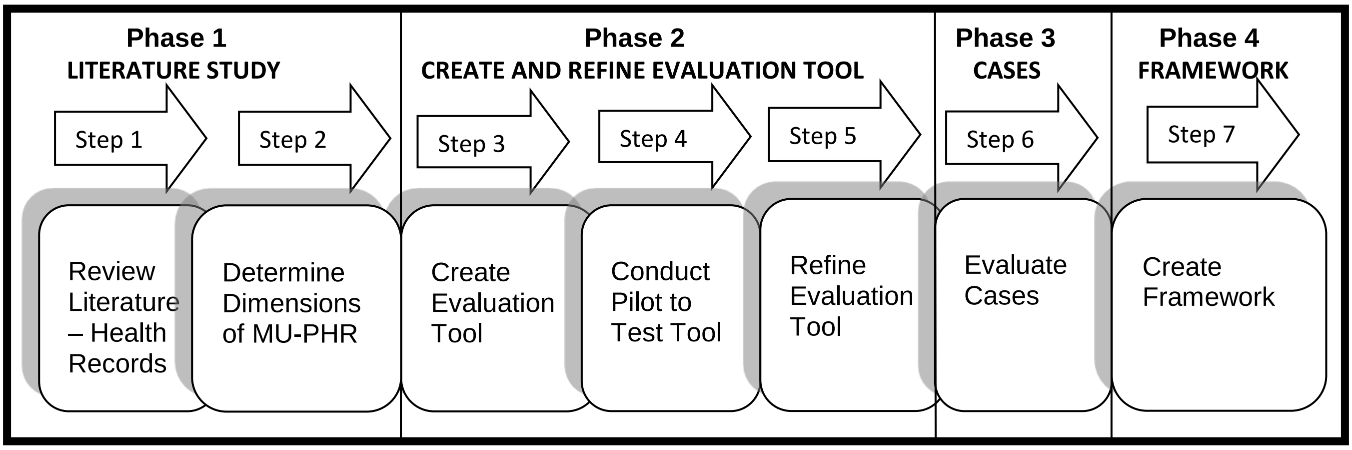

Figure 2.1: Research Process.

These phases are now discussed in detail.

2.2.1 PHASE 1: LITERATURE STUDY

The first phase consists of a literature study whereby a literature review was conducted in 2 parts, shown as step 1 and step 2 in Figure 2.2. In step 1, the various types of records available to store PHI were researched. A comparative analysis was done between the different types of records, examining their origin, similarities and differences, advantages and disadvantages and the possible barriers that each type has to serve as an MU-PHR. Thereafter, the focus shifted to personal health records in social networking environments. Various existing online social networking tools for PHI were identified, supplemented by a literature review of PHR 2.0. These literature studies form the base of the normative data of this research.

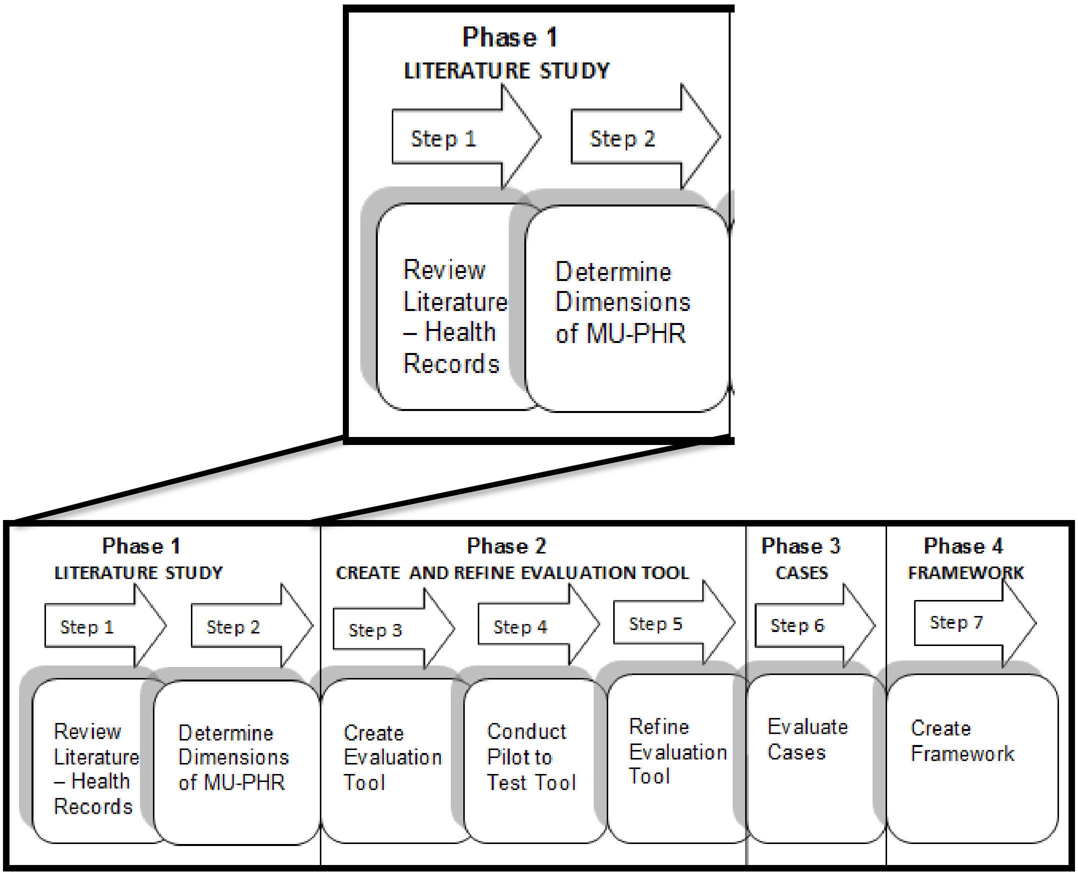

Figure 2.2: Research Process – Phase 1.

In this research, normative data refers to what the literature study shows an MU-PHR should look like, whereas descriptive data refers to the real-world data found during the evaluation process (in Phase 3). In step 2, logical argumentation was used, in conjunction with the results of the literature review to compile the dimensions of an MU-PHR. These broadly stated dimensions constitute the main attributes of MU-PHRs and were used to create the evaluation tool in Phase 2.

2.2.2 PHASE 2: CREATE AND REFINE EVALUATION TOOL

This phase consists of 3 steps and is illustrated in Figure 2.3. In step 3, the creation of the evaluation tool starts. This step used the dimensions for MU-PHR (derived from Phase 1) as input and by using a process of logical argumentation, a set of ratings, used by the evaluation tool, was defined. These ratings enabled the researcher to evaluate different PHR 2.0 sites (in Phase 3) to determine their conformance with the dimensions or attributes of MU-PHR.

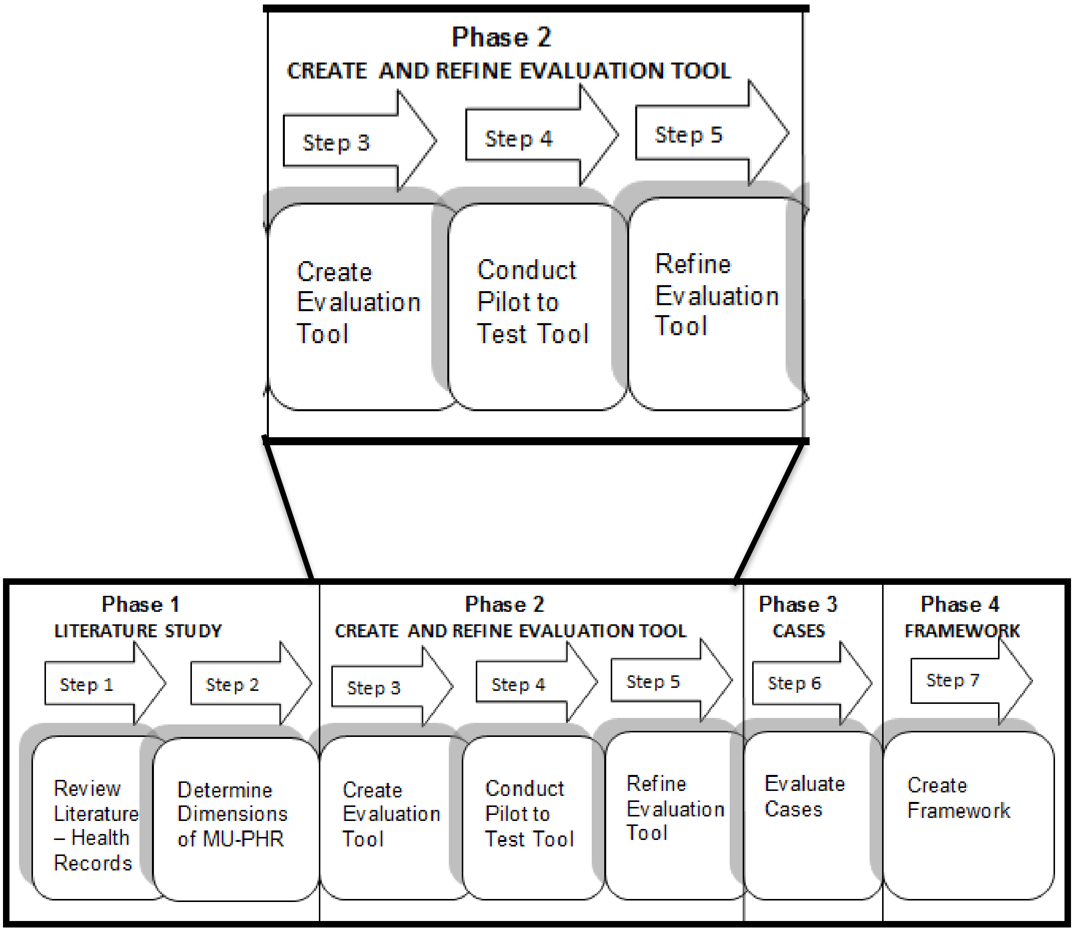

Figure 2.3: Research Process – Phase 2.

However, it was first necessary to test the tool in view of possible improvements before commencing the evaluation of the cases in Phase 3.

In step 4, pilot testing commenced. A pilot PHR 2.0 site was chosen and evaluated using the newly created evaluation tool. The outcome of the afore-mentioned testing led to the refinement of the evaluation tool in step 5. The refined evaluation tool was used to evaluate further PHR 2.0 sites in Phase 3.

2.2.3 PHASE 3: CASES

Before the evaluation of PHR 2.0 sites could start, the researcher first had to select a sample of PHR sites. Therefore criteria needed to be developed to select the sample. These criteria are discussed in detail in Chapter 4.

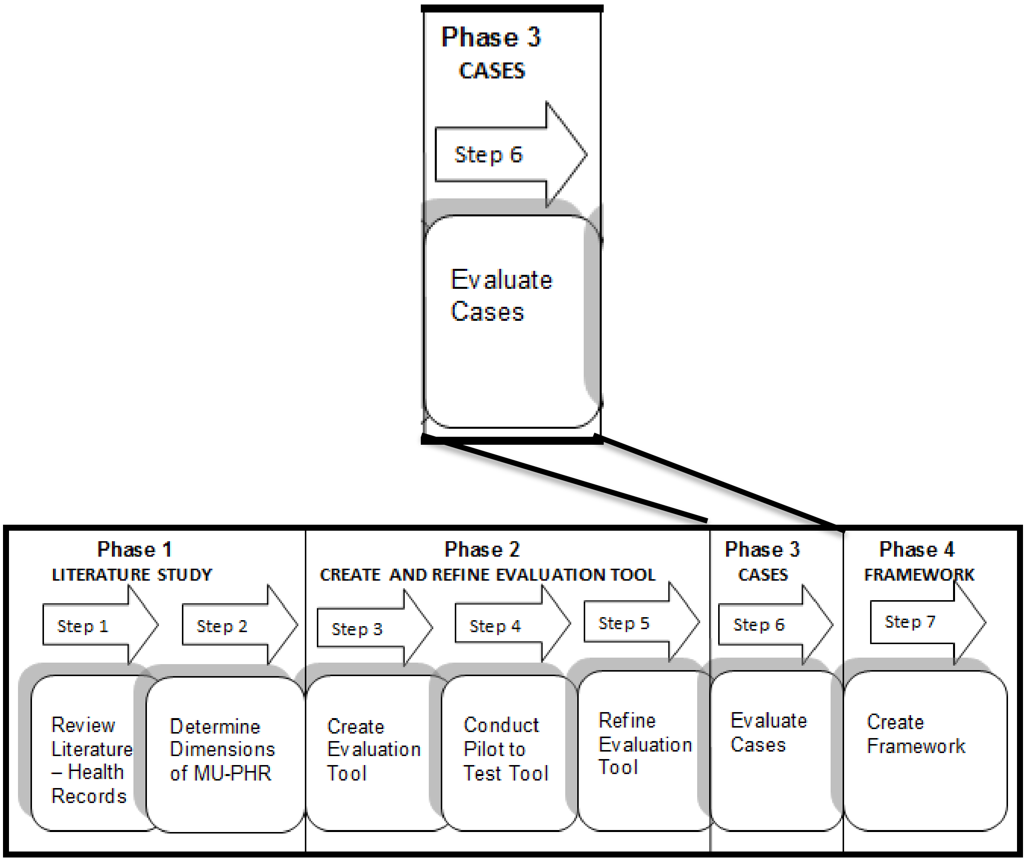

Figure 2.4: Research Process – Phase 3.

In Phase 3 (step 6) of the research, the chosen PHR 2.0 sites were evaluated using the refined evaluation tool. These cases provided critical descriptive data of the selected PHRs and how they compare with the normative data found during Phase 1.

2.2.4 PHASE 4: FRAMEWORK

Phase 4 (step 7) concluded the research with the creation of a framework for PHRs in online social networking. A framework is a fundamental construct that defines assumptions, concepts, values, and practices, and that includes guidance for implementing itself (Tomhave, 2005). The components of a framework may take on various forms, such as steps, principles, guidelines, concepts, questions, challenges and dimensions (Rogers, 2008). The framework for this research consists of concepts and components. The compilation of the framework is discussed in detail in Chapter 5.

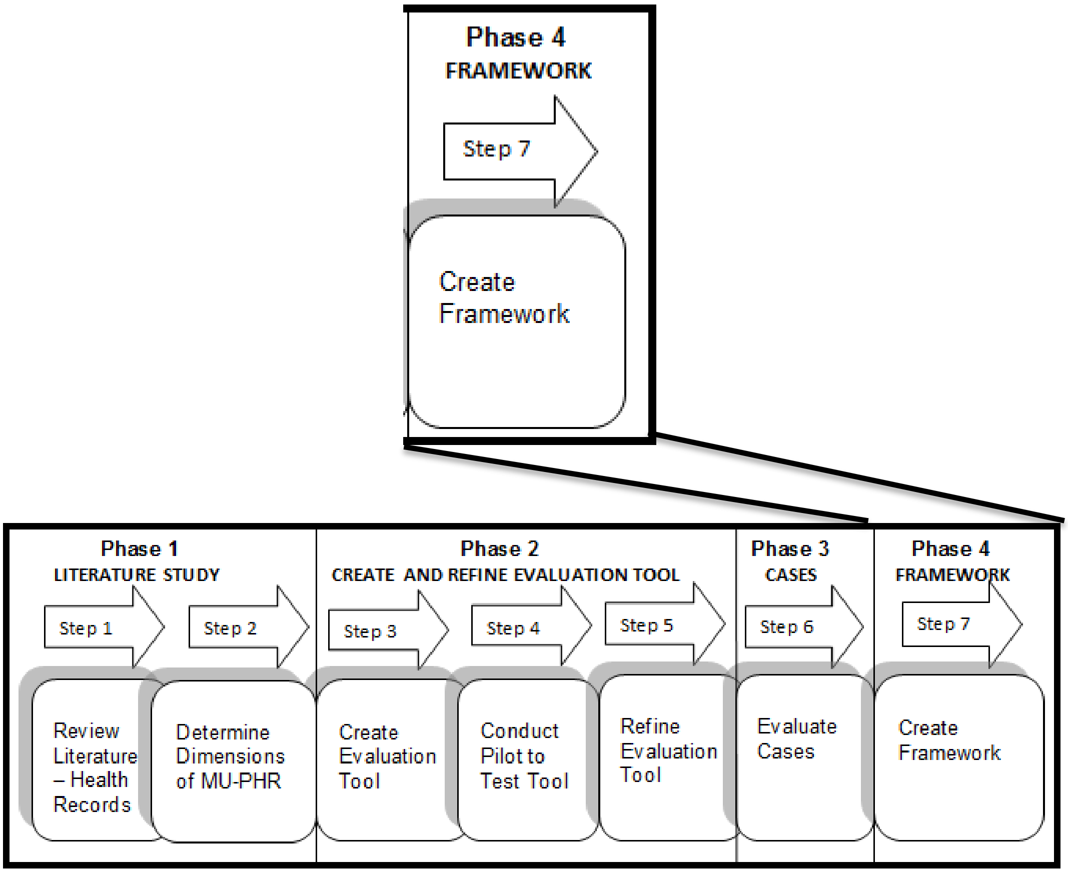

Figure 2.5: Research Process – Phase 4.

2.3 RESEARCH METHODS

Babbie and Mouton (2002) state that a research method consists of a systematic, methodological and accurate execution of the research design. The research methods used during this research comprise:

1. Literature Review
2. Logical Argumentation
3. Pilot
4. Comparative Analysis

The research methods used during each step of the research process are illustrated in Figure 2.6 and described in more detail thereafter.

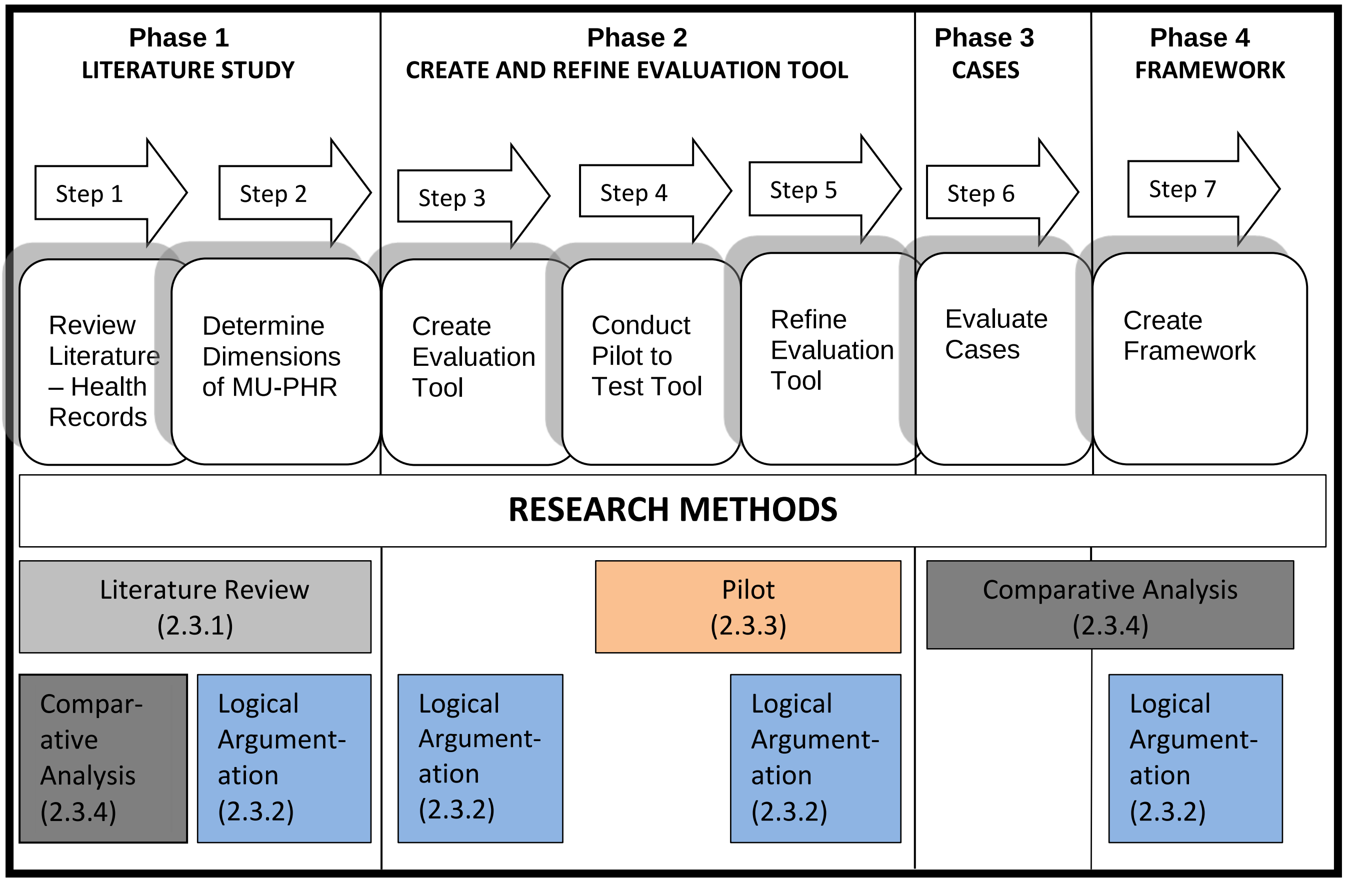

Figure 2.6: Research Methods.

2.3.1 LITERATURE REVIEW

According to Robinson and Reed (1998, p. 58) a literature review can be defined as “a systematic search of published work to find out what is already known about the intended research topic”. It allows the researcher to find out what has been researched in terms of the problem at hand. This ensures that duplication does not occur. In their book Social Research Methods, Bless and Higson-Smith (2000) identify the purposes of a literature review. These include inter alia:

- Sharpen and deepen the theoretical framework of the research;

- Familiarize the researcher with the latest developments in the area of research, as well as in related areas;
- Identify gaps in knowledge; and
- Study the definitions used in previous works.

The literature review for this research was carried out in Phase 1 of the research process. A literature review of the various types of electronic records available to store PHI was initiated to familiarize the researcher with the latest developments in electronic health records in general and PHRs in social networking environments in particular. This informed the theoretical framework and relevant terminology of the research, identified latest developments and gaps in knowledge.

2.3.2 LOGICAL ARGUMENTATION

Larry Wright (1982, p. 4) defines an argument as “the (usually) dispassionate marshalling of support for some statement (or viewpoint, or conclusion or position)”. In the same manner a person would argue a case by citing evidence in its support, the researcher attempts to muster evidence in support of a specific point of view. According to Mouton and Marias (1996), it is the aim of the researcher to demonstrate the validity or invalidity of a given theory or finding by mustering sufficient evidence. This method was used during Phases 1, 2 and 4 of the research.

After the initial literature review, logical argumentation was used to derive the core dimensions of MU-PHR, thereafter to create an evaluation tool by defining a set of ratings for each of the identified dimensions, and to refine the evaluation tool into a final evaluation tool. Finally, the researcher argued towards a framework for the meaningful use of personal health records in online social networking.

2.3.3 PILOT

A pilot is a trial run-through to test the research instrument with a subsample having characteristics similar to those identifiable in the main sample to be evaluated (Gill &

Johnson, 2010; Drummond, 2003). Conducting a pilot before the main evaluation allows any potential problems to be identified and corrected. Felicity Smith (2002) states that the purpose of a pilot study is two-fold: firstly to ensure that it is workable in practice settings in terms of study procedures and data collection, acceptable to participants and others on whom the conduct of the study may impact; and secondly, to check that the study procedures gather reliable and valid data effectively and efficiently. An important task of the pilot work is to ensure that the method is capable of gathering the information required for the study.

The pilot method was used during Phase 2 of this research. The WorldHealthRecord web based PHR (http://www.worldhealthrecord.com) was chosen as the pilot PHR to test the evaluation tool. The newly developed evaluation tool (step 3 of Phase 2) was used to evaluate this PHR. By using the tool to evaluate the site, the researcher could determine the adequacy of the tool and whether refinements were required. The outcome of the pilot study was the creation of a refined evaluation tool to be used during the evaluation of further PHRs during Phase 3.

2.3.4 COMPARATIVE ANALYSIS

Hofstee (2006) states that when doing comparative analysis, the researcher investigates, in a focused and systematic manner, two items (sometimes three, but any more than that can easily become confusing) in depth and compares them to each other to find the reasons for difference or similarity.

Phases 1, 3 and 4 of this research applied the method of comparative analysis. In step 1, the different types of health records were compared by looking at their similarities, advantages and disadvantages and barriers each type of record has to serve as an MU-PHR. In step 6, five web-based PHRs were evaluated using the evaluation tool. A comparison was conducted to analyse the descriptive data describing the five PHRs in terms of their performance in relation to the identified dimensions of the MU-PHR. In step 7, a comparative analysis was done of the descriptive data (attained in step 6) and the normative data (attained in steps 1 and

2), to attain evidence of the gap between the requirements represented by the normative data, and the conformance of tools available in practice.

2.4 CONCLUSION

When conducting research, the process followed and methods applied, are often more important than the actual results. A proper research design is required to ensure the validity of the research results. In this chapter, the research design, process and methods were discussed in detail. The following chapter presents the results of Phase 1, step 1 of the research process.

CHAPTER 3

HEALTH RECORDS AND SOCIAL NETWORKING MEDIA

3.1 INTRODUCTION

Over the last couple of decades, the view has developed that high quality health care can be delivered only when all the pertinent data about the health of a patient is available to the clinician (Langley & Beasley, 2007). Various types of health records have emerged to serve the needs of healthcare providers and more recently, patients or consumers. They take various forms, like paper or electronic form.

The different types of health records that can store PHI are reviewed in this chapter by means of a literature study. This includes an overview of personal health records in social networking environments. Various existing online social networking tools to create PHI are identified, supplemented by a literature review of PHR 2.0. A comparative analysis is done of the different types of records with a view to understanding the attributes or main characteristics of these records. The chapter concludes by formulating the core dimensions (or attributes) that ensure the meaningful use of PHRs in social networking.

3.2 HEALTH RECORDS FOR PHI

For as long as health care has existed, there has been health information stored in some kind of record. Previously such records were kept in the paper files of the provider, whereas currently, a combination of paper and computer media for recording health information is used.

The formal definition of Personal Health Information was provided in Chapter 1, section 1.1. Based on this definition the types of information that may be included in PHI encompasses a wide range, from a basic record of doctors' visits to advanced medical information that may even include payment details to patients' medical aid. This PHI must be stored in a health record.

According to NHS (2010), health records can take many forms and can be on paper or electronic. Different types of health records include:

- Consultation notes taken by GP during an appointment;
- Hospital admission records, including the reason for admission to hospital;
- The treatment received and any other relevant clinical and personal information;
- Hospital discharge records, which will include the results of treatment and whether any follow-up appointments or care are required;
- Test results;
- X-rays;
- Photographs; and
- Image slides, such as those produced by a magnetic resonance imaging (MRI) or computerized tomography (CT) scanner.

For a variety of reasons, these individual health records have become fragmented and dispersed into multiple information systems. At the same time, the information inside the records has become more complex, and is required on a regular basis by an increasing number of commercial, educational, and governmental information systems (Feahr, 2003).

Personal health information is stored in three different versions of health records as identified in Chapter 1, section 1.1. Each version typifies the source or originator of the data. To reiterate, these records include the payer-based health record (PBHR), the Electronic Health Record (EHR) and the Personal Health Record (PHR). While hybrids of these record types are also common, the focus in the subsequent sections is on distinguishing the records types from each other. Each of these record types is discussed in detail in sections 3.2.1 – 3.2.3.

3.2.1 PAYER-BASED HEALTH RECORD (PBHR)

According to Capobianco (2006, p. 1), “a PBHR contains information derived from payer sources: claims data including medical, surgical, pharmacy and behavioural health claims; care management data comprising utilization, case and disease management; and basic demographics found in enrolment data”. PBHRs are compiled by medical aid administrators, who administer the medical finances of the patient. The term medical aid is a local (South African) term which is similar to the terms “health insurance” and “healthcare plan” in the American and European contexts respectively. In the early 1990’s, patient’s had to pay or administer the claims process themselves. This process has become automated and led to the creation of PBHRs. As PBHRs are not the focus of this study, the discussion will focus more on the remaining types of health records, namely EHRs and PHRs.

3.2.2 ELECTRONIC HEALTH RECORDS (EHR)

3.2.2.1 DEFINITION

The need for administrative and clinical e-health systems originated from healthcare providers (Eng, 2001). These systems were created to address the needs of healthcare providers and to provide them with a tool that enables them to be more competent in their daily activities.

Many people in the healthcare industry today use terms that describe health records in electronic format interchangeably, however, according to literature, they describe different concepts. Different terms are used to describe the concept of an EHR in various countries. The United Kingdom refers to an Electronic Patient Record (EPR). The United States of America refers to a Computerized Patient Record (CPR), while the term Electronic Health Care Record (EHCR) is commonly used across Europe.

In this research, the definition from the ISO/TR20514 is adopted. This technical report describes an **EHR** as a "repository of information regarding the health status of a subject of care, in computer processable form, stored and transmitted securely and accessible by multiple authorized users, having a standardized or commonly agreed logical information model that is independent of EHR systems and whose primary purpose is the support of continuing, efficient and quality integrated health care" (ISO/TR 20514, 2005, p. 2).

In contrast, an **EHR system** can be defined as a "set of components that form the mechanism by which electronic health records are created, used, stored and retrieved including people, data, rules and procedures, processing and storage devices, and communication and support facilities" (ISO/TR 20514, 2005, p. 3).

The **Electronic Medical Record (EMR)** could be considered as a special case of the EHR, restricted in scope to the medical domain or at least very much medically focused. EMR is a widely used term in North America and a number of other countries including Japan. The Japanese Association of Healthcare Information Systems (JAHIS) has defined a five-level hierarchy of the EMR (JAHIS, 1996):

a) Departmental EMR: contains a patient's medical information entered by a single hospital department;
b) Inter-departmental EMR: contains a patient's medical information from two or more hospital departments;
c) Hospital EMR: contains all or most of a patient's clinical information from a particular hospital;
d) Inter-hospital EMR: contains a patient's medical information from two or more hospitals; and
e) Electronic healthcare record: longitudinal collection of personal health information from all sources.

This attempt at differentiation will be clarified further in the following section.

3.2.2.2 EHR DISCUSSION

EHRs are reliant on EMRs to be in place. Figure 3.1 below shows how the EMR fits in as a subset of EHRs. It has the clinical data repository (CDR) as its foundation. The controlled medical vocabulary (CMV) ensures that the users of the EMR are accessing accurate and comparable data. Without a well-functioning CMV, the clinical decision support system (CDSS) and workflow components will not perform as anticipated. Applications that will thrive in this environment are doctors' documentation, computerized provider order entry (CPOE) for all clinicians and practitioners, as well as pharmacy management (Garets & Davis, 2006).

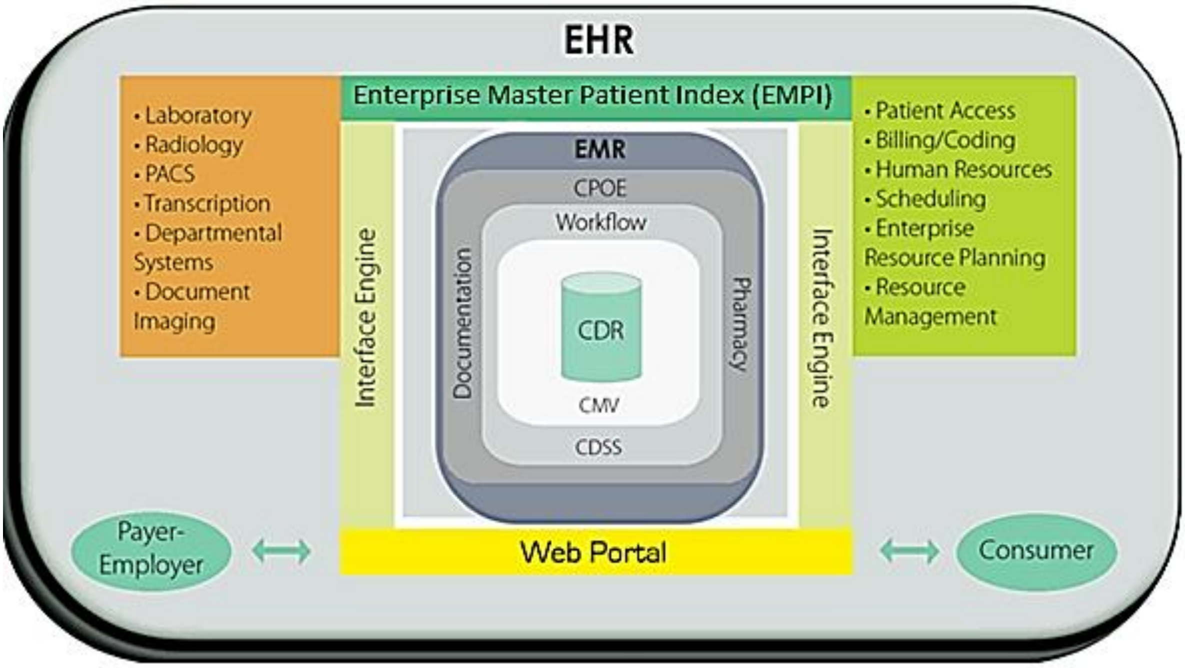

Figure 3.1: EMR vs. EHR (Lightspeed EHR, 2010).

The EHR environment is situated at the top layer and relies on a well-functioning EMR and its core operation is for information exchange between Care Delivery Organizations (CDOs).

One of the major driving factors behind the origin of EHRs is a reduction in medical errors. It is apparent when viewing the medical error statistics of only the United States of America, that the importance of health records cannot be underestimated.

Specific statistics in this regard includes (USA Medical System Is The Leading Cause Of Death, 2007):

- The number of unnecessary medical and surgical procedures performed annually is 7.5 million;
- The number of people exposed to unnecessary hospitalization annually is 8.9 million;
- The number of people having in-hospital, adverse drug reactions (ADR) to prescribed medicine is 2.2 million; and
- The number of unnecessary antibiotics prescribed annually for viral infections was 20 million in 1995. In 2003, this was cited to be tens of millions of unnecessary antibiotics.

These figures raise serious concerns. Most medical errors made at the point of care can be attributed to providers having insufficient or imperfect patient data (Kohn, Corrigan, & Donaldson, 2000). An accurate, complete medical record can reduce medical errors by providing the healthcare provider with the opportunity to correctly diagnose a condition by viewing the complete picture.

Another core reason that led to the development of EHRs is to address the fragmentation of medical care. For example, patients can be treated by their normal house doctor, but also treated by a specialist for another condition. This same patient could have received treatment at an emergency centre while on holiday and away from their normal clinicians. At every point of interaction with a doctor, medical data is generated and kept with the respective caregiver – in silos. These data items need to be combined so that if a patient visits a new doctor, the full medical record can be available in order for the doctor to make the correct diagnoses. The goal of EHRs is therefore to reduce fragmentation in healthcare and to provide a complete view of a patient’s medical record.

3.2.2.3 BARRIERS TO ADOPTION OF EHRs

The most common barriers physicians cite to implementing effective EHR systems are cost and complexity of implementation, uncertain financial returns, workflow changes and disruptions, along with the fact that learning a new computer system takes time away from patient interaction (Hackbarth & Milgate, 2005). Start-up costs of an EHR system can be very high. At the American Health Information Management Association conference in October 2006, panellists estimated that purchasing and installing an EHR will cost over $32,000 per physician, and maintenance about $1,200 per month (Health Care Tracker, 2009). Many physicians are hesitant to invest in a system that will not provide them with a return on their investment. Apart from the start-up costs, there are continuous maintenance costs to keep the system up and running and available 24 x 7 x 365. Additional implementation costs include the training that medical staff must undergo to use the system properly.

Privacy concerns in healthcare also lead to slow adoption of EHR systems. The Health Insurance Portability and Accountability Act (HIPAA) was passed in the US in 1996 to establish rules for access, authentication, storage and auditing and transmittal of electronic medical records (Health Insurance Portability and Accountability Act, 2011). The major issue at hand is the privacy of the health information of patients. Security and privacy must be part of system development and designed into the foundation of the system, otherwise people will not trust the technology and they will not participate in it.

Legal liability in healthcare is an increasing problem. Failure or damages caused during installation or utilization of an EHR system has been feared as a threat in lawsuits (Health Care Tracker, 2009). At least one legal case suggests that providers have a duty to minimize implementation risks during transition period (from paper to electronic). A federal court held that a hospital had a duty to “implement a reasonable procedure during the transition phase” to ensure timely delivery of test results to doctors (Smith v. United States, 2000). Implementation of EHRs may also affect the course of malpractice litigation by increasing the availability of documentation with which to defend or prove a malpractice claim (Goldberg, 2011).

EHRs record all electronic transactions. This information, called metadata, provides a permanent electronic footprint of all activities that took place between patient and caretaker – aka audit logs. These audit logs may prove a provider’s liability or may help when mounting a defence.

Interoperability between different electronic health and medical systems is key to the successful implementation of EHR systems. Interoperability refers to the interconnectedness of multiple healthcare organizations or systems using a model that enables the full interchange of healthcare information. An overwhelming majority of people, currently, receive their care from more than one caregiver or provider. A lack of integration means that choice leads to fragmentation of the health care experience of the patient. Fragmentation, in turn, results in errors, duplication, lack of coordination, and many other problems (Brailer, Interoperability: The Key To The Future Health Care System, 2005). Health information will remain in proprietary silos without both interoperability and health information exchange. Figure 3.2 illustrates the complexity of the EHR design and identifies some of the standards developed to assist with interoperability barriers.

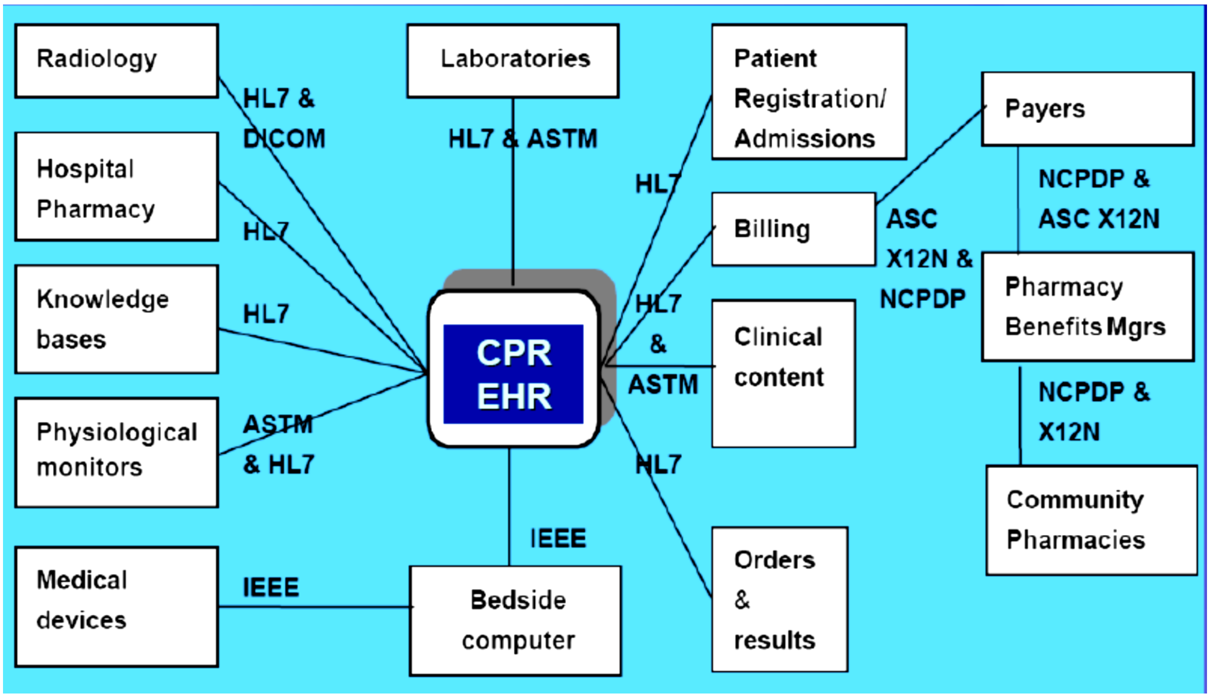

Figure 3.2: EHR communication standards (Dobrev et al., 2008).

Standards are models approved by an authority or by general consent and specify hardware or software, communication protocols, or data definitions (Brandt, 2000). These standards are adopted to enable electronic exchange of data between computer systems by establishing the format and sequence of data during transmission to more effectively manage interoperability between computer systems (Murphy & Brandt, 2001). According to Blair & Cohn (2005), standards can be classified in the following categories:

a) Identifier Standards: Within health care, entities require unique identifiers, including patients, healthcare providers, health plans and employers. HIPAA addressed some of these needs. Others are being defined by the Secretary of Health and Human Services (HHS) under formal rule making procedures.
b) Communication Standards: Communication standards that send and receive information between healthcare entities are called electronic data interchange (EDI) standards. They support functions such as patient registration, admission/discharge/transfer, order entry, results reporting, scheduling, patient care, etc. Both EDI standards and healthcare message format standards define the format of electronic messages, therefore both are referred to as syntax standards.
c) Terminology Standards: This includes vocabularies, nomenclatures, classification systems and code sets. Examples of these are the International Classification of Diseases (ICD) codes which are developed and maintained by the World Health Organization.
d) Quality of Care Indicators, Data Sets, Guidelines and Code Standards: Although there is no national standard for quality of care, there are a number of indicators, guidelines and code standards that are used to aid quality improvements.
e) Medical Record Content, Structure and Documentation Standards: These include standards developed for the content and structure of EHRs and clinical documents.
f) Privacy and Security Standards: These standards have been set forth as federal regulations under the HIPAA Administrative Simplification Provisions (HIPAA, 1996). The regulations provide patients with the ability to protect the

privacy of their health information and specify constraints on the use of patient information.

g) Supporting Models: Models support the development and use of standards. Examples of the types of supporting models include information models, functional models, ontologies, etc.

There are a number of major standards bodies who contribute to the creation of standards within the aforementioned categories as depicted in Figure 3.2 earlier. These include, but are not limited to:

a) Health Level Seven (HL7)
b) Accredited Standards Committee (ASC X12N)
c) American Society for Testing and Materials (ASTM)
d) Institute of Electrical and Electronic Engineers (IEEE)
e) National Council for Prescription Drug Programs (NCPDP)
f) Digital Image Communication (DICOM)

Without proper standards in place that can provide interoperability between dispersed electronic systems, EHR adoption in the healthcare society will be slow-moving. Over the past years, there has been an explosion in the amount of information available on health-related topics. This ease of access has created an exceptionally well-informed population (Frampton & Charmel, 2008). This led to the development of consumer-focused health systems and the discussion will focus on these systems now.

3.2.3 PERSONAL HEALTH RECORDS (PHR)

3.2.3.1 DEFINITION

The term Personal Health Record is not new. The American Health Information Management Association (AHIMA) defines the PHR as “a universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR that is collected from healthcare providers or entered by the individual. The PHR is maintained in a secure and private environment with the individual determining rights of access - it is separate from, and does not replace the legal record of any provider" (Informatics Review, 2006).

The main purpose of introducing PHRs has been to empower patients with a sense of ownership of their care and to improve communication, between both the patients and clinicians and between the different clinicians involved in the care of the patient (Laugharne & Stafford, 1996).

3.2.3.2 PHR DISCUSSION

In its simplest form, the PHR is a standalone application that does not integrate with any other system. Whether it is paper-based, electronic, or web-based, any information stored by patients to keep track of their health, is deemed to be a PHR.

Electronic or web-based PHRs have several advantages over paper-based PHRs. With a paper-based PHR, the patients must carry their records (or copies of it), to the doctor being visited. Electronic PHRs give the patients the ability to copy their PHR onto a disk or USB stick and take this to the doctor. Web-based PHRs have added benefits. The patient's health record can be stored online and the patient has the ability to control access to his record. As long as the doctor's offices are online, the record can be accessed. This can be accessed around the clock; therefore there is no need for the patient to carry their PHI with them. Another emerging type of PHR is portable PHRs. This includes cell phones, PDA's and USB sticks and are an add-on feature to PC-based and web-based PHRs (PHI Wiki Project, 2010).

As mentioned in Chapter 1, section 1.1, PHRs have a wide range of diverse architectures and functions that provide a patient-oriented view that is integrated with other electronic health information (Ash, Tang, Bates, Overhage, & Sands, 2006).

A simple depiction of interconnected PHRs is provided in Figure 3.3 on the next page.

A tethered PHR is a subset of data compiled by a provider, other healthcare entity such as a health plan, or an employer promoting wellness among employees.

The individual can access and update the tethered PHR (Fahrenholz & Buck, 2007).

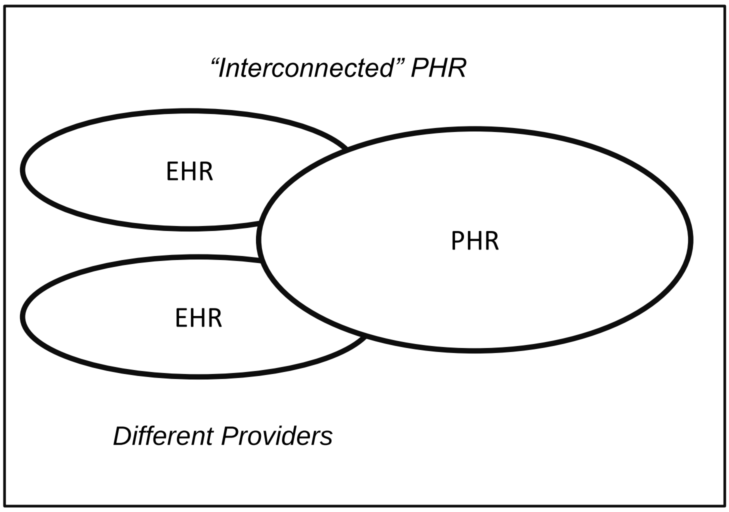

Figure 3.3: Interconnected PHR - adapted from (Eysenbach G. , 2008).

It is linked to another system, such as the hospital's electronic medical record system as depicted in Figure 3.4 below.

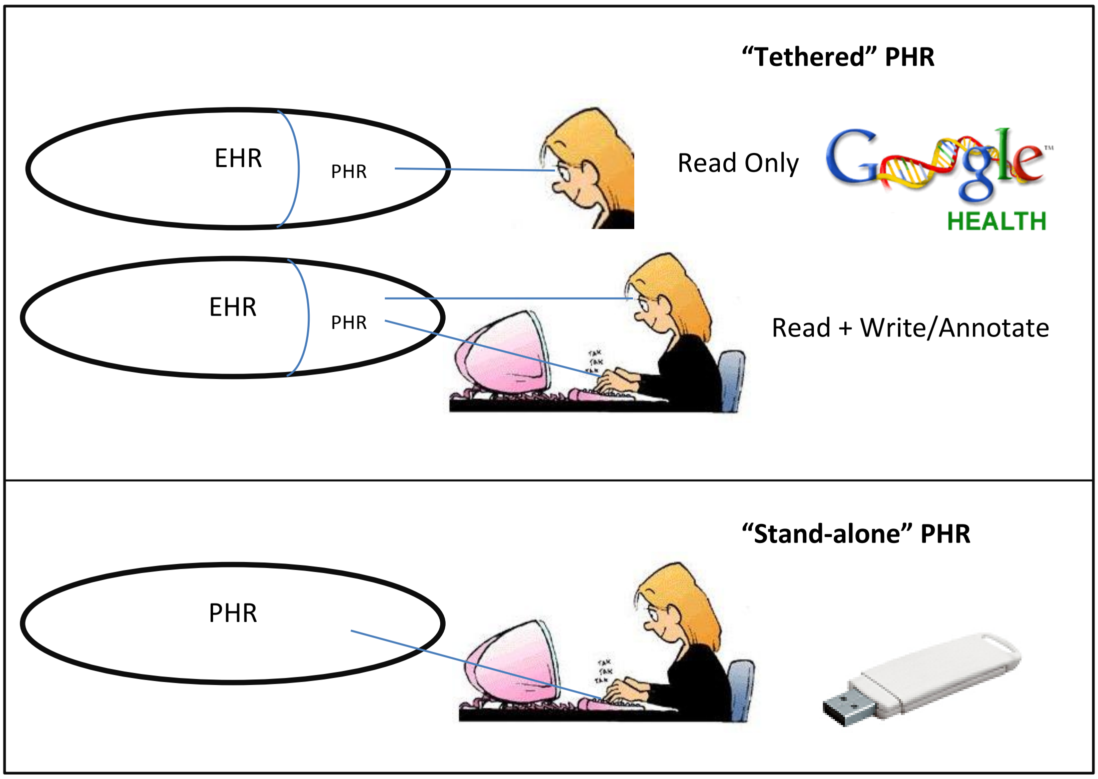

Figure 3.4: Tethered and Stand-alone PHRs – adapted from (Eysenbach G. , 2008).

The growth of tethered PHRs has been slow both because patients sometimes lack trust that the provider is acting in the patient's best interests and because providers often do not have access to all of a patient's health records (Coffield, Ishee, Kapp, Lyles, & Williams, 2011).

With a stand-alone PHR, there are no links to other systems or information sources. All the information in it must be entered by the patient and kept up to date. One of the benefits of a stand-alone PHR is that the health record is completely owned and created by the patient. There is no linkage to an electronic system. This requires more accuracy and completeness when capturing information, but some patients prefer to have full control over their health record. A major disadvantage of stand-alone PHRs is that the health record will become an information island that contains subsets of patients' data, isolated from other information about patients, with limited access and transient value (Ash, Tang, Bates, Overhage, & Sands, 2006).

Arguably, one of the greatest benefits of using tethered PHRs is the ability to collect and store all of a patient's health information from a variety of doctors and medical practitioners in one central place so that it is readily available when needed. Figure 3.5 illustrates this ability.

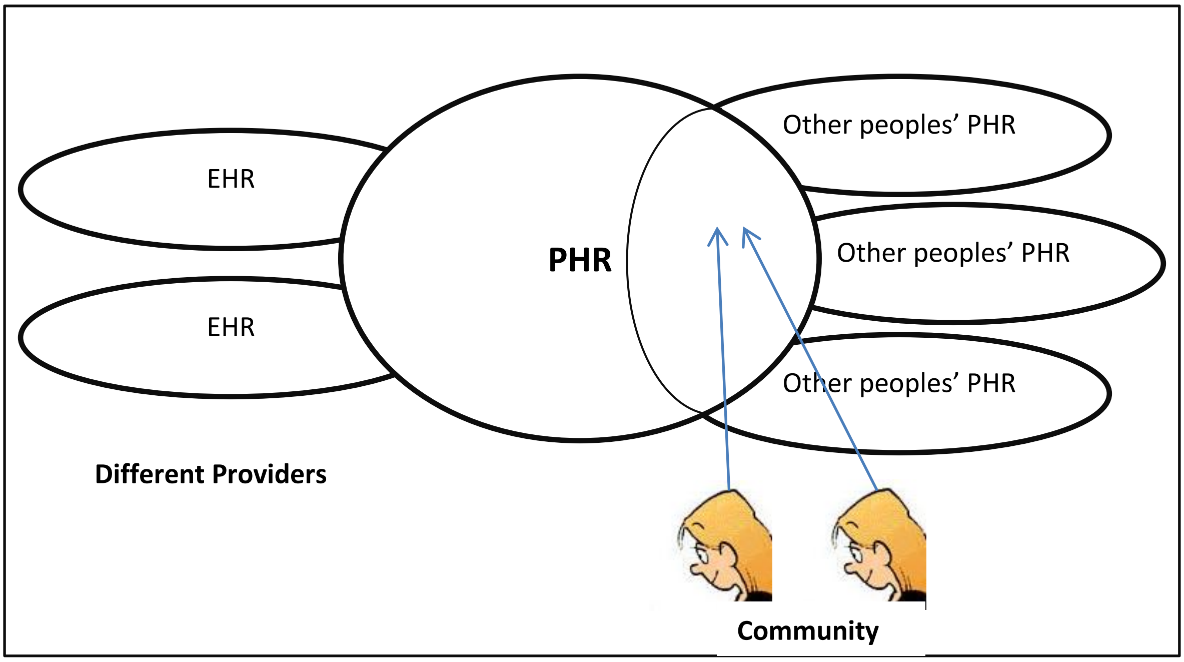

Figure 3.5: PHRs ability to store PHI from various sources – adapted from (Eysenbach G. , 2008).

A tethered PHR also gives the patient access to a wide array of health information, data and knowledge (Ash, Tang, Bates, Overhage, & Sands, 2006). This information empowers the patient to manage and improve their health. PHRs can subsequently improve the quality of healthcare and empower both the patient and doctor with access to swift accurate health data.

The PHRs that have been reviewed thus far can be categorized as first generation PHRs. The past few years have marked a new era of innovative PHR activity and have led to a new term - PHR 2.0 or second generation PHRs. Large technology companies have entered the PHR space, like Microsoft with their HealthVault product and Google with their Google Health product. PHR 2.0 is not merely a data collection application, but rather a platform for the electronic aggregation and storage of health information, as well as the foundation for various applications (Coffield, Ishee, Kapp, Lyles, & Williams, 2011).

PHR 2.0 relies heavily on social networking media and will be discussed in more detail in the following section.

3.2.3.3 PHR 2.0 AND SOCIAL NETWORKING

As discussed in Chapter 1, section 1.1, PHR 2.0 is an outgrowth of the Web 2.0 era where social networking tools have been developed to assist users to easily create and share information online. PHR 2.0 is about building a system that not only contains personal health information, but one that builds a community and a social network around that information (Eysenbach G. , 2008).

One of the major advantages of PHR 2.0 in our modern day is the ability to socialize with people with similar conditions and illnesses. This can lead to patients cutting out the health professionals and relying purely on peer support. Dr Gunther Eysenbach, a Health Policy and eHealth professor at the University of Toronto, called this apomediation. This newly coined term is best explained by Dr. Eysenbach who states that: "Apomediation is a new scholarly socio-technological term that characterizes the process of disintermediation (intermediaries are middlemen or gatekeepers, e.g. health professionals giving relevant information to a patient, and disintermediation means to bypass them), whereby the former intermediaries are functionally replaced by apomediaries, i.e. network/group/collaborative filtering processes. The difference between an intermediary and an apomediary is that an intermediary stands in between the consumer and information/service, i.e. is absolutely necessary to get a specific information/service. In contrast, apomediation means that there are agents (people, tools) which stand by to guide a consumer to high quality information /services/experiences, without being a prerequisite to obtain that information/service in the first place" (Eysenbach G. , 2008).

Apomediation is affected in a health record through current advances in technology. The contents of a health record can be enriched with collaborative filtering and recommender systems like bookmarking, blogs, wikis and communication tools. These networked/collaborative systems enable the creators of health records, to better capture information contained in scripts, the notes written by healthcare providers and general written information contained in the paper-based patient file. For example, certain terminology and abbreviations are meaningless to a non-medical person, but through having access to these blogs, wikis and other tools, it is possible to capture the record accurately and have a sense of understanding while doing so.

3.2.3.4 BARRIERS TO ADOPTION OF PHRs

While PHRs have many benefits to patients, doctors, caregivers and institutions, widespread adoption has not occurred as most experts expected (Lewis, 2011). According to Ash et al. (2006), the barriers to the adoption of PHRs can be characterized as environmental or individual barriers. Environmental barriers include organizational, economic, legal and privacy concerns while individual barriers include workflow models, behavioural change, and recognition of value by the patient and challenges to provider autonomy (Lober, et al., 2006).

A subset of environmental barriers is economic and market forces. Some of the PHR providers have not been financially successful with their products and this had led to the closure of these commercial PHR products. This creates an unsure consumer climate and loss of faith in the product, while putting serious strain on the development of PHR as a whole.

PHR providers also see the possibility of legal risks arising from the adoption of PHRs. There is a general concern among some practitioners that negligence charges might arise in cases where physicians make faulty care decisions based on inaccurate PHR information entered by the patient (Health Resources and Services Administration, 2010). Along with legal barriers come privacy concerns. A new national consumer survey for the California Healthcare Foundation (2010) found that 75 percent of individuals who have not yet used PHRs, cited privacy concerns as their major stumbling factor.

Privacy concerns are a double edged sword. While consumers desire protection of their personal health information, aggressive protection measures might hamper PHR access by patients and doctors and impede optimal care (Ash, Tang, Bates, Overhage, & Sands, 2006).

On the other hand, individual barriers also influence the growth of PHRs. PHR developers and users must understand both the patients' and clinicians' mental models of health care processes and the related workflow (Ash, Tang, Bates, Overhage, & Sands, 2006). For a PHR to be used daily and to be of actual value to the user, the PHR must fit into the flow of the day to day activities of an individual. As soon as there is any intrusion in normal activities of a user and the user needs to introduce change to adapt to the PHR, then the PHR adoption by the user will most likely be slower. Humans are creatures of habit and resistant to change. Therefore a study needs to be done on the exact workflow patterns that a PHR requires to fit into the day to day activities of an individual, rather than the individual adapting to the workings of the PHR (Borycki, Kushniruk, Kuwata, & Kannry, 2006).

Patient/Provider autonomy is another individual barrier to the adoption of PHR in communities today. Healthcare providers will have to deal with issues of autonomy and control. According to Suchman, Botelho & Hinton-Walker, (1998) autonomy support in healthcare is defined as the extent to which providers listen fully to patients, take the patients' perspective, provide patients with meaningful information about their condition, and offer patients choices about how to deal with their health. In contrast, control refers to providers' pressuring patients to behave in particular ways.

Both the patient and the provider need to adopt a different mindset when it comes to PHRs. The provider needs to trust the patient more and encourage them to be clinical and thorough when entering information into their health record. The information on the health record should also be tamper proof. In order to achieve this trust, the PHR must ensure that no unauthorized person is able to add, remove or change any data in the patient's health record. Patients, on the other hand, must trust the providers that they will only use the information in the health record for the patient's benefit.

Both the environmental and individual barriers need to be addressed and overcome for PHRs to be implemented on a large scale and for the general patient community to start using this type of health record actively and effectively.

3.2.4 COMPARISON OF HEALTH RECORDS

Although there are various similarities between EHRs and PHRs, they do differ as well. In EHRs, all data is documented electronically. With a PHR, it is documented both (or either) electronically and manually. A PHR contains information about medicine taken, symptoms, exercise logs, special diets and many more. On the contrary, an EHR is a digital version of the paper charts in the clinician's office. A PHR helps a person to be more alert in their healthcare, whereas an EHR helps the doctor to evaluate a patient's overall medical condition and give the best treatment possible.

PHRs (including PHR 2.0) can be compared to EHRs as depicted in Table 3.1.

Electronic Health Records	**Personal Health Records (including PHR 2.0)**
The legal record of the care delivery organization (CDO)	The record created and owned by the patient (patient empowerment)
A record of clinical services for patient encounters in a CDO	Subset (i.e. Continuity of Care Record or Continuity of Care Document) of information from various CDO's where patient has had encounters as well as personal information entered by the patient
Owned by the CDO – Physician-Centric	Owned by the patient – Patient-Centric
These systems are being sold by enterprise vendors and installed by hospitals, health systems, clinics, etc.	Free online systems available like Google Health, Microsoft Healthvault, Patients like Me, etc.
May have patient access to some information through a portal – but is not interactive	Provides interactive patient/physician access as well as ability for the patient to append information or import from various sources
Contains information from all the clinicians involved in patient's care – including digital version of the paper charts	Contains information about patient's health condition, including exercise logs, diets taken, personal hygiene, doctor's notes, etc.

Table 3.1: Comparison between EHR and PHR – adapted from (Garets & Davis, 2006).

Table 3.1 above demonstrates a very clear distinction between EHRs and PHRs, particularly when looked at from the record owner side. The patient is in control of his PHR, while the physician/hospital is in control of the EHR. A PHR therefore empowers individuals to take control of their health.

This concludes the comparison between EHRs and PHRs.

From this literature review, it can be seen that each type of health record has a purpose and is created by different stakeholders in the course of performing their daily duties. However, it is conceivable that such a health record must have certain characteristics or attributes that ensure that it is suitable for its intended purpose, i.e. that it can be used meaningfully. In the context of this research, these attributes are termed dimensions, more specifically dimensions of MU-PHRs, as the context of the research is the meaningful use of PHRs in social networking.

3.3 DIMENSIONS OF MU-PHRs

Using the literature study reported in this chapter, the researcher will synthesise a list of nine dimensions that a personal health record should have for it to be deemed of meaningful use. These dimensions will now be discussed in sections 3.3.1 – 3.3.9.

3.3.1 INTEROPERABILITY

Interoperability, as discussed in section 3.2.2.3, refers to the interconnectedness of multiple healthcare organizations or systems using a model that enables the full interchange of healthcare information.

Standardization is core to Interoperability. Standardization, in the field of health informatics, strives to achieve compatibility and interoperability between independent information systems and devices, and to reduce the duplication of effort and redundancies. Healthcare Information Technology (HIT) standards are developed, adopted, or adapted by standards development organizations, government agencies, professional associations, and care providers (Health Informatics, 2009). The creation of an MU health record will be unattainable without standards which facilitate proper interoperability between the different types of health records.

For a PHR to be used meaningfully, it must have the ability to interoperate properly with other health systems. This can only be achieved if the health record supports the ability to import and export data into health standards, like HL7 v2 or v3 CDA (clinical document architecture). MU-PHRs should be able to exchange health data with other health systems using common standards. This should be done safely and securely.

3.3.2 INTEGRITY

An MU-PHR must provide information to improve care quality. The healthcare provider must trust that the information provided in the health record is correct for this to be considered true. The general principle of integrity implies that no unauthorized person is able to add, remove, or change any data in the health record. Therefore only authorized persons should have the ability to alter information in the health record. To prove that no unauthorized changes have been made to a record, the system housing the health record should be enabled with auditing (see section 3.3.8 below). The system should also be capable of recovering to a legal version of the health record before unauthorized changes were made (if any were detected).

3.3.3 ACCURACY

Accuracy implies that the information captured in the health record, reflects exactly the original meaning of the paper copy or diagnosis made by the healthcare provider. This maps closely to the garbage in, garbage out (GIGO) concept. Valuable input is attained from the health record when the information that is captured is accurate.

This dimension focuses strongly on the prevention of human input errors. It is the function of the system housing the health record to provide user-friendly tools to assist in accuracy, for example, drop down boxes, error checking, confirmation prompts, etc. The PHR should also be intelligent enough to manage duplication avoidance. This means that entries that the patient or doctor made that have already been entered, should be reported back to the data owner in an error message and corrective action must be taken.

3.3.4 COMPLETENESS

Completeness implies that all the relevant information about the health of the patient is contained in the health record. There should be no significant delay between when the data is entered into the record and when it becomes available to the different healthcare providers (Wainer, 2008).

There has been much discussion in literature about what data or information belongs in a health record. Advances in data storage devices and their related capacity have made this a less pressing issue. A health record should contain any information relevant to the health of the patient. Examples of information to be captured include the following (Groen, 2007):

- Personal identification, including name and birth date;
- People to contact in case of emergency;
- Names, addresses, and phone numbers of the physicians, dentists, and specialists of the patient;
- Health insurance information;
- Living wills, advance directives, or medical power of attorney;
- Organ donor authorization;
- A list and dates of significant illnesses and surgical procedures;
- Current medications and dosages;
- Immunizations and their dates;
- Allergies or sensitivities to drugs or materials, such as latex;
- Important events, dates, and hereditary conditions that occur in the history of the family;
- Results from recent physical examinations;
- Opinions and notes of clinical specialists;
- Important tests results; eye and dental records;
- Correspondence between an individual and his or her healthcare provider; and
- Diet and exercise logs, in addition to a list of over-the-counter (OTC) medications.

3.3.5 APOMEDIATION

Apomediation was discussed in detail in section 3.2.3.3. It comprises the process of enriching health records with collaborative filtering and recommender systems like bookmarking, blogs, wikis and communication tools. These systems enable the creators of health records, to better capture information contained in scripts, the notes written by healthcare providers and general written information contained in the paper-based patient file. Certain terminology and abbreviations are meaningless to a non-medical person, but through having access to these blogs, wikis and other tools, it is possible to capture the record accurately and have a sense of understanding while doing so.

3.3.6 PRIVACY

Privacy implies that the patient gives consent for other parties to access their personal health information. Patients can allow or deny sharing their information with other healthcare workers. Consent is either implied or explicitly given before the act of sharing. Van der Linden (2009) explains that implicit consent assumes the patient to have consented by default unless they specifically state otherwise. This is referred to as opt-out. Explicit consent or opt-in is the reverse, where the access to the information is prohibited unless the patient gives consent.

Patients must have the ability to grant or revoke access to their health records. The access control should also be granular and purpose driven. This means that a patient could give access to certain portions of their health record only and revoke access to other portions (Dewan, Luo, & Lorenzi, 2010). One of the more important aspects of privacy is the fact that patients must have the ability to revoke access legally to their health record – not only for the local system housing it, but also for all interconnected systems (Hall, 2010). As owner of their data, they must be able to legally revoke access to all information in their record if need be.

3.3.7 CONFIDENTIALITY

Confidentiality requires that proof is given that the information has not been made available or disclosed to unauthorized entities, whether persons or systems. This can be implemented in two ways. Either information is tagged with metadata about its confidentiality status or confidentiality is enforced through access rules (De Capitani di Vimercati, Samarati, & Jajodia, 2005). The use of access rules to enforce confidentiality relies on audit logs to verify that confidentiality has not been breached.

Applied to this research, confidentiality means that online health records must only be accessible to authorized parties. Access control must also be in place to grant access to specific people as well as specific sections in the health record.

3.3.8 AUDITABILITY

Auditability refers to the ability to (van der Linden, 2009):

- Monitor access to and possible misuse of records, preferably in real-time;
- Keep track of previous versions of records for review purposes; and to
- Verify claims about what information was available and whether it was accessed for legal purposes.

One mechanism which supports auditability is to use audit logs which document all the actions performed on the records as well as the users who performed those actions. This enables the restoration of a past state of the data and the identification of the originators of all actions. The logging should include all events and not be restricted to the information handled. This leads to a huge amount of audit data that should be kept secure for future analyses. For best security, audit logs should be kept and stored separately from the record.

As a dimension of MU-PHRs, auditability means that all online health records must contain audit logs of some form. Some PHRs only provide basic audit logs, like log in times, and whether a change was made to the health record – but no specific details. More advanced PHRs provide full auditing – tracking of all changes, additions and deletions. These audit logs can be used to rollback changes and therefore give the owner the ability to look at various versions of the health record before changes were made. Online PHRs must also support non-repudiation. This means that those participating in the modification of the health record cannot afterwards repudiate their participation (Saranummi, Piggot, Katehakis, & Tsiknakis, 2005).

3.3.9 AVAILABILITY

A health record must be available when the healthcare provider needs it; therefore it is necessary for the system housing the health record to be robust. Failure of the health record system is not an option, because human lives are at risk. A health record is deemed to be of meaningful use when it is continuously available.

The accessibility of health records can be contentious. Ease of accessibility increases the risk that the record can be compromised. Alternately, a record that is too secure and cannot be accessed in case of emergency, nullifies the sense of creating a health record. Any access control mechanism that protects the healthcare data needs to be relatively simple and fast. These mechanisms should protect the privacy of the patient by disclosing information only in those situations when it is needed. This latter requirement requires a highly complex mechanism and is hard to combine with the first requirement of a simple mechanism. A middle way needs to be found that addresses the problem of availability versus confidentiality.

A health record should be accessible online 24x7x365 for data capturing and data retrieval by both patient and physician. An additional feature that would enhance a PHR is the ability to use software to capture information when the patient is offline. This can then be uploaded when online again. The PHR must also be developed in such a way that emergency access can be granted to healthcare professionals when the patient physically can’t allow access. This could be the key between a life or death decision.

This concludes the discussion on the dimensions of MU-PHRs. These nine dimensions change the healthcare experience for patients and families by incorporating meaningful use in the health record. The benefits of meaningful use are depicted eloquently in Figure 3.6.

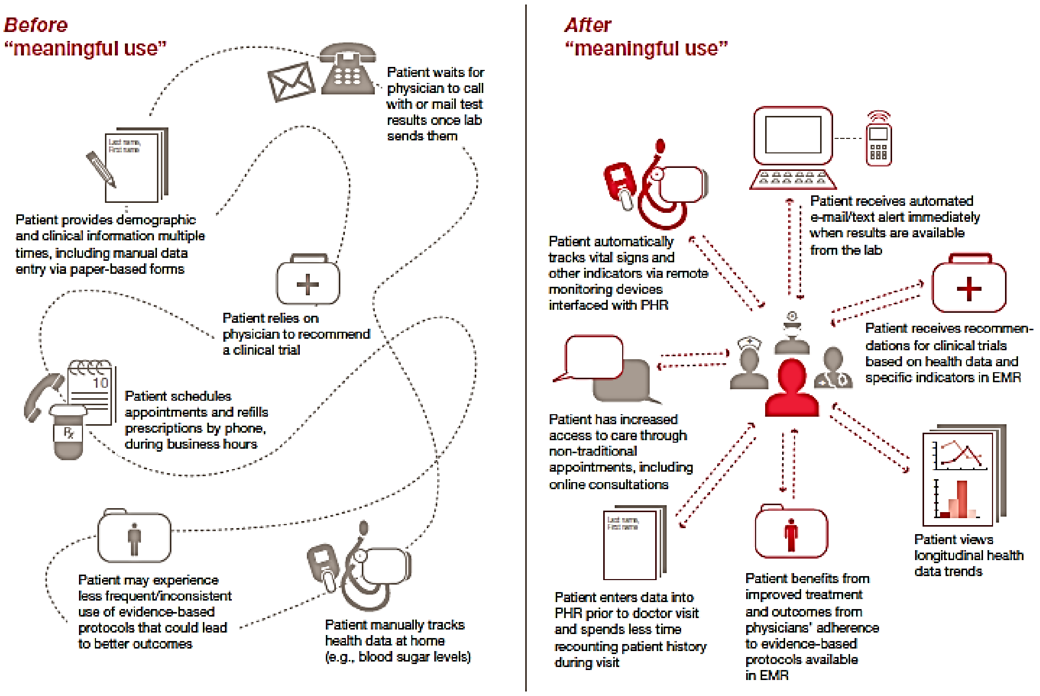

Figure 3.6: Meaningful use advantages (PwC Health Research Institute, 2011).

3.4 CONCLUSION

In this chapter, various sources of PHI were identified, researched and compared. A new generation of health records, namely PHR 2.0, which gives patients the ability to create their own interactive health records and to collaborate with their peers, was included in this overview. The outcome of the chapter was a list of dimensions or attributes of MU-PHR, which ensures that health records can be used meaningfully, or are fit for their intended purpose.

The dimensions proposed in this chapter will be used as a starting point in Chapter 4 to create an evaluation tool that can measure the operation of PHRs in social networking in relation to the dimensions.

CHAPTER 4

CASE WORK

4.1 INTRODUCTION

The literature study conducted in Chapter 3 led to the creation of nine dimensions for MU-PHRs, namely Interoperability, Integrity, Accuracy, Completeness, Apomediation, Privacy, Confidentiality, Auditability and Availability. In this chapter, the dimensions form a base for the creation of an evaluation tool, which is used to evaluate PHRs in terms of conformance to the afore-mentioned dimensions. The evaluation tool is first tested against a pilot PHR site to allow for improvements. The outcome of this pilot testing is assessed and a refined evaluation tool created. Thereafter a further five PHRs are tested against the refined evaluation tool and the outcome is reported. The evaluation of the PHRs and related services was done through creating test data using the researcher's own medical history and fictitious data when required.

4.2 EVALUATION TOOL

With the knowledge obtained from the literature study done in Chapter 3, each of the nine dimensions was given ratings to use for the purpose of evaluating the PHRs. The first version of the evaluation tool can be seen in Table 4.1 below.

The ratings given to the *Interoperability* dimension are discussed as an example. Six ratings were given to the *Interoperability* dimension, ranging from 1 to 6. A “1” rating, the lowest rating, means that the PHR only has the ability to import data. This includes normal data capturing as well as the ability to upload data into the given PHR. A “2” rating, means that the PHR also has the functionality to export data – into any non-medical format, for example PDF, HTML, etc. A “3” rating is achieved when the PHR can export the health record into known health standards, for example HL7 or any CDA. A “4” rating, means that the PHR has the ability to exchange some data online with other health systems. There is no need to first export the health record into a standard and then manually transferring it to another health system for it to be imported. A “5” rating is achieved when the complete health record can be exchanged with other online health systems using common heath standards. A rating of “6”, the highest rating, is achieved when a PHR can securely exchange all health data with another online health system. This means that the health data is encrypted when the data is in transit and totally secure.

The ratings given are indicative of the type of functionality required to support the achievement of each particular dimension. A PHR site will achieve weak performance with a rating of 1 for a particular dimension, but strong performance if the maximum rating is achieved. It should be noted that each dimension has a minimum rating of 1, whereas the maximum rating is unique to each dimension.

Before the evaluation tool shown in Table 4.1 could be used to evaluate PHR sites, the researcher had to (1) select PHR sites which could be evaluated; and (2) conduct a pilot evaluation to test the tool to allow potential problems to be identified and corrected proactively. The selection of the PHR sites is discussed in section 4.3 and the pilot evaluation in section 4.4. Thereafter, the evaluation of the five case sites is reported in section 4.5.

EVALUATION TOOL (version 1)

Dimension	Rating
Interoperability	1. Ability to import data 2. Ability to export data 3. Ability to export data into standards, like HL7 v2 or v3 CDA 4. Limited data exchange functionality between systems 5. Supports two-way data exchange with other health systems using common standards 6. Supports secure two-way data exchange with other health systems using common standards
Integrity	1. Only authorized persons have ability to alter information in health record without audit logs 2. Information can be altered, updated, appended with full audit log capability to ensure integrity 3. Recovery capability
Accuracy	1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc. 2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries
Completeness	1. Ability to easily append information in order to keep record complete 2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen 3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc. 4. Contains complete health record information such as health insurance information, diet and exercise logs, etc.
Apomediation	1. Provides education about condition, surgery, medication, etc. 2. Ability to interact with patients with similar illness/condition 3. Bridge language and cultural divides
Privacy (Patient Driven)	1. Patient has the ability to grant/revoke access to his record 2. Purpose driven access control 3. Revoke access legally (with the ability to retroactively do this) - local system only 4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems

Confidentiality (Non-Patient Driven)	1. Online health record can only be accessed by authorized parties 2. Access control granted to specific people 3. Access control granted to specific sections of health record to specific people
Auditability	1. Record contains audit logs 2. Supports non-repudiation 3. Provides full auditing – tracking of all changes, additions, deletions, etc. 4. Versioning
Availability	1. Accessible by patient (stand-alone) 2. Accessible by patient in shared environment, but tool does not provide access 3. *Online* access to health record by both patient and physician 4. Ability to capture information via software to upload to online health record later (when offline) 5. Accessible by patient and physician 24x7x365 *online* 6. Provides emergency access to health professionals in case of emergencies

Table 4.1: Evaluation Tool (version 1).

4.3 SELECTION OF PHR PILOT AND CASE SITES

The process followed to select the PHR pilot and case sites is now explained. It must be kept in mind that sites that required a fee to capture a PHR were not included in the selection.

An analysis was done of all the services currently available on the sites listed at The Informatics Review Journal (Sun, 2001). The PHR selection model used by The Informatics Review Journal to compare the different PHR sites is shown in Table 4.2 (Sun, 2001).

CATEGORY	DESCRIPTION	TYPE OF RATING
Site Information	Status/Type of PHR	☐ Fully Functional PHR ☐ In Development PHR ☐ Health Information Source Only ☐ Disease specific health profile ☐ Internet based Medical Record ☐ No Longer Exists ☐ Cannot Be Determined (CBD) ☐ Other (description)
	Cost of PHR	☐ Free ☐ Cost
	Public Access	☐ Yes ☐ No ☐ Comment
Features of the PHR	1. Personal Information 2. Family Medical History 3. Immunization History and Planner 4. Allergies to Food and Drugs 5. Personal Medical History 6. Medications and/or Supplements 7. Contact Information for Other Health Care Practitioners/Clinics/Etc. 8. Other Features	☐ Yes ☐ No ☐ N/A ☐ Intended ☐ CBD (Cannot Be Determined)
Site Services	☐ Access to other health information materials ☐ Demo-tour (educational material on how to use a PHR) ☐ Access to a health care practitioner on-line ☐ Health risk appraisal	☐ Yes ☐ No ☐ Varies ☐ Partial ☐ Intended ☐ CBD (Cannot Be Determined) ☐ Other (list any existing)

	¨ Data exchange with other health care practitioner or facilities ¨ Privacy, Security and Confidentiality Technology/Information ¨ Customized services for i.e, consumers, clinicians, etc. ¨ Other services	
Usability Rating	¨ Ease of navigation ¨ Quality and quantity of information available ¨ Site presentation	¨ Below Average ¨ Average ¨ Above Average ¨ CBD (Cannot Be Determined) ¨ N/A

Table 4.2: PHR Selection Model.

This model was developed in 2001 and the sites listed and categorized did not include any modern sites. Although most listed sites were out-dated, the model nevertheless helped the researcher to determine which criteria and ratings to apply to assist with the PHR selection process.

In conjunction with this model, a tool was used provided by myPHR (http://www.myphr.com/resources/choose.aspx) to choose a PHR that will suite the patient's needs based on the following criteria:

1. Format
    a. Web-based
    b. Software-based
    c. Paper-based
2. Cost
    a. Free
    b. For purchase

This tool included all modern day PHRs and together with the sound principles of The Informatics Review model of 2001, the researcher could start to reduce the number of PHRs. The myPHR tool provided a list of 109 PHRs in total which can be categorized as follows: 63 are strictly Internet-based for purchase and 29 are strictly Internet-based and free, one is standalone software for purchase and zero is standalone software for free, 13 are paper-based for purchase and three are paper-based for free. The scope of this research focuses on the free internet-based tool. Therefore, the researcher was still left with a large number of PHRs – 29 to be exact to choose from.

Another online tool provided on PHRsToday was used next to give the researcher further insight into the site selection (http://www.phrstoday.com/supplier.php). Various factors were taken into consideration, like cost vs. free, integration with other PHRs, ability to export, and many more. Free to use PHRs listed by this tool totalled to 23. Ability to integrate with other health systems, totalled to 25. Twenty-three PHRs had the ability to export data and 22 PHRs had the ability to upload documents.

At this point in time, the researcher had a number of PHR lists to consolidate in order to choose six PHRs for evaluation. The selection tools from myPHR and PHRsToday, in conjunction with the principles and selection criteria from The Informatics Review model of 2001, were used to develop a new consolidated model to choose the six PHR sites to be investigated. This model was based on the following criteria:

1. The PHR must be free to use
2. The PHR must be Web-based
3. Source intersection between the models mentioned above
4. User base (if publicly available)

PHR sites that appeared in the already reduced lists of both the myPHR and PHRsToday tools, were included (source intersection). Based on this new consolidated model, the number of PHRs to choose from were halved. Due to scoping reasons, a single PHR was chosen for an initial pilot investigation and five additional PHRs were chosen to be evaluated using the evaluation tool created in this research. A random sampling technique, along with user base usage and feedback reports, were used on the already reduced list of PHRs.

The WorldHealthRecord web based PHR (http://www.worldhealthrecord.com) was chosen as the pilot PHR to test the completeness of the new evaluation tool.

Upon completion of the pilot testing and refinement of the evaluation tool, the following PHRs were evaluated:

1. Google Health (http://www.google.com/health)
2. Juniper Health (https://www.juniperhealth.com)
3. MyMediConnect (PassportMD) (https://www.mymediconnect.net/phr.php)
4. RememberItNow (https://app.rememberitnow.com)
5. WebMD Health Manager (http://www.webmd.com/health-manager)

The evaluation of the pilot site is subsequently discussed.

4.4 PILOT

In order to test the evaluation tool, a pilot evaluation was conducted using the WorldHealthRecord PHR. The test medical data used for capturing was the researcher’s own information, scripts, conditions and medical history. The ratings achieved by the WorldHealthRecord PHR measured against the ratings for each dimension, can be found below in Table 4.3. The rating (or score) attained for each dimension is shown in brackets after each dimension.

Evaluation Tool Version 1 (WorldHealthRecord Rating)		
Dimension	**Rating**	**Yes/No**
Interoperability**(2)**	1. Ability to import data	**Y**
	2. Ability to export data	**Y**
	3. Ability to export data into standards, like HL7 v2 or v3 CDA	**N**
	4. Limited data exchange functionality between systems	**N**
	5. Supports two-way data exchange with other health systems using common standards	**N**
	6. Supports <u>secure</u> two-way data exchange with other health systems using common standards	**N**

Integrity**(1)**	1. Only authorized persons have ability to alter information in health record without audit logs	**Y**
	2. Information can be altered, updated, appended with full audit log capability to ensure integrity	**N**
	3. Recovery capability	**N**
Accuracy**(1)**	1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc.	**Y**
	2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries	**N**
Completeness**(2)**	1. Ability to easily append information in order to keep record complete	**Y**
	2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen	**Y**
	3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc.	**N**
	4. Contains complete health record information such as health insurance information, diet and exercise logs, etc.	**N**
Apomediation**(0)**	1. Provides education about condition, surgery, medication, etc.	**N**
	2. Ability to interact with patients with similar illness/condition	**N**
	3. Bridge language and cultural divides	**N**
Privacy **(0)** (Patient Driven)	1. Patient has the ability to grant/revoke access to his record	**N**
	2. Purpose driven access control	**N**
	3. Revoke access legally (with the ability to retroactively do this) - local system only	**N**
	4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems	**N**
Confidentiality**(0)** (Non-Patient Driven)	1. Online health record can only be accessed by authorized parties	**N**
	2. Access control granted to specific people	**N**
	3. Access control granted to specific sections of health record to specific people	**N**
Auditability**(0)**	1. Record contains audit logs	**N**
	2. Supports non-repudiation	**N**
	3. Provides full auditing – tracking of all changes, additions, deletions, etc.	**N**
	4. Versioning	**N**
Availability**(2)**	1. Accessible by patient (stand-alone)	**Y**
	2. Accessible by patient in shared environment, but tool does not provide access	**Y**
	3. *Online* access to health record by both patient and physician	**N**
	4. Ability to capture information via software to upload to online health record later (when offline)	**N**
	5. Accessible by patient and physician 24x7x365 *online*	**N**

	6. Provides emergency access to health professionals in case of emergencies	**N**

Table 4.3: Evaluation of the WorldHealthRecord PHR site.

These findings can be depicted using a radar diagram as in Figure 4.1. The rating attained for each dimension is normalized to a scale of 0 to 6 in order for the radar diagram to show a visually balanced view of the performance of the WorldHealthRecord PHR. The radar diagram shows that the WorldHealthRecord PHR is very weak in the dimensions of apomediation, privacy, confidentiality and auditability.

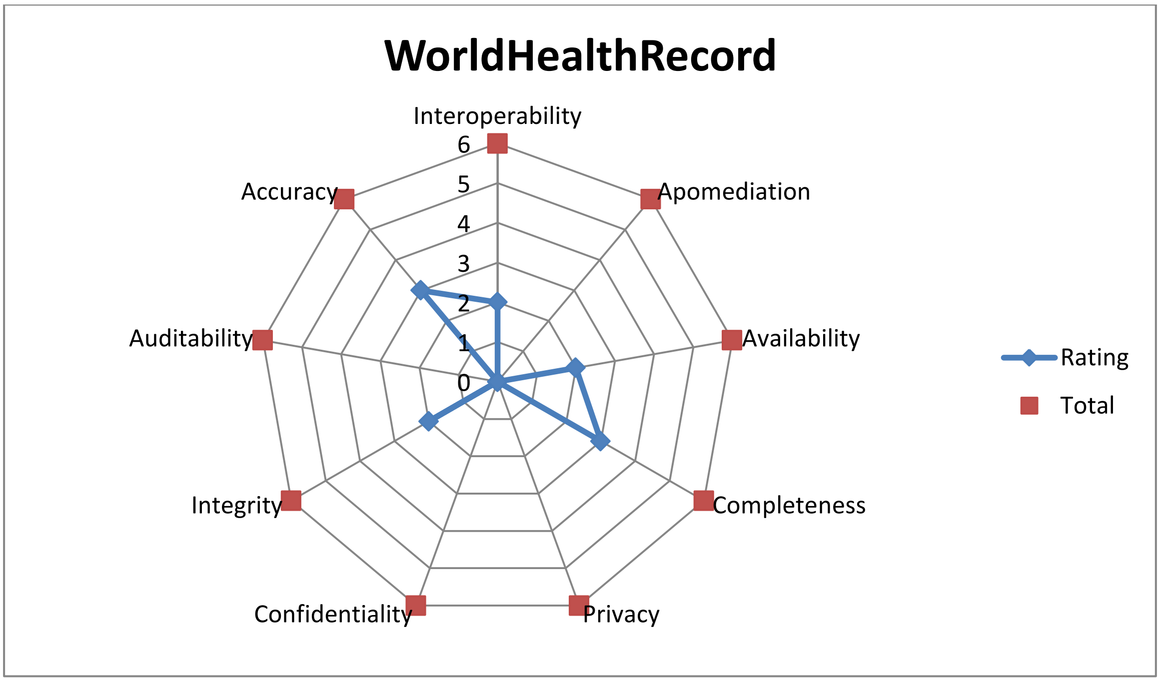

Figure 4.1: WorldHealthRecord findings.

The interface was well designed and it was very easy to register on this site. The site redirects to a secure connection when the user logs in to prevent eavesdropping on any request or data entries made. Difficult terminology and medical jargon were explained at all times so that the user feels confident about the selection of certain options.

When entering historical medication facts, users are forced to enter dosage, dosage unit and frequency of use. This was very difficult to capture, as it is historical data and difficult to recall. Therefore the site forces possible erroneous capturing of data which affects the accuracy of the data.

Medication capturing was not user-friendly. There was no edit function. Once an erroneous entry was captured, the user had to delete all the information for that entry and recapture the correct information. Overall, the take on process for information was average. The site did give the user the ability to print a medical card and to upload documents. Some dental scans were uploaded easily as a test. The ability for doctors to access this information was not yet possible, but statements were made on the site that this will be available in the future.

Upon completion of the initial pilot testing to evaluate whether the evaluation tool is adequate, the WorldHealthRecord site notified all its users that the site will be discontinued from February 1, 2011 due to the fact that costs for maintaining the service had exceeded the user base. It was very unfortunate that this service was discontinued; nevertheless, the testing of the evaluation tool using this PHR did indicate some gaps in the evaluation tool.

It was noted that the completeness dimension was missing a 5th rating for the tracking of medical expenses. The major gap in the tool was regarding the apomediation dimension. It was found that ratings needed to be included for doing health risk assessments and having access to healthcare practitioners. The other ratings for the dimensions were found to be sufficient.

It was also established that the possibility might occur that a PHR will skip a single numbered rating by being rated non-compliant, but might comply with the next rating one level up. It was decided to allow skipping of one rating for the sake of compromise, because it was difficult to create ratings that are indicative of increasing (rather than exclusive) functionality in all cases. However, should a PHR's performance in a dimension skip more than one rating, this would not be allowed. If one rating is skipped, for example rating n-1 is achieved, rating n is skipped, but rating n+1 is achieved, the PHR's performance will be rated at n, otherwise the rating of the PHR’s performance in the dimension may be skewed. If more than one rating is skipped, for example rating n-1 is achieved, both n and n+1 are skipped, but rating n+2 is achieved, the PHR’s performance will also be rated at n. Based on these changes, the modified tool to evaluate Health 2.0 social networking sites is as shown in Table 4.4.

EVALUATION TOOL (version 2)

Dimension	Rating
Interoperability	1. Ability to import data 2. Ability to export data 3. Ability to export data into standards, like HL7 v2 or v3 CDA 4. Limited data exchange functionality between systems 5. Supports two-way data exchange with other health systems using common standards 6. Supports secure two-way data exchange with other health systems using common standards
Integrity	1. Only authorized persons have ability to alter information in health record without audit logs 2. Information can be altered, updated, appended with full audit log capability to ensure integrity 3. Recovery capability
Accuracy	1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc. 2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries
Completeness	1. Ability to easily append information in order to keep record complete 2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen 3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc. 4. Contains complete health record information such as health insurance information, diet and exercise logs, etc. *5. Track medical expenses*
Apomediation	1. Provides education about condition, surgery, medication, etc. *2. Health risk assessment* 3. Ability to interact with patients with similar illness/condition *4. Access to healthcare practitioner* *5. Bridge cultural divides by providing support in your own language*
Privacy (Patient	1. Patient has the ability to grant/revoke access to his record 2. Purpose driven access control

Driven)	3. Revoke access legally (with the ability to retroactively do this) - local system only 4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems	
Confidentiality (Non Patient Driven)	1. Online health record can only be accessed by authorized parties 2. Access control granted to specific people 3. Access control granted to specific sections of health record to specific people	
Auditability	1. Record contains audit logs 2. Supports non-repudiation 3. Provides full auditing – tracking of all changes, additions, deletions, etc. 4. Versioning	
Availability	1. Accessible by patient (stand-alone) 2. Accessible by patient in shared environment, but tool does not provide access 3. *Online* access to health record by both patient and physician 4. *Accessible by patient and physician 24x7x365 online* 5. *Ability to capture information via software to upload to online health record later (when offline)* 6. Provides emergency access to health professionals in case of emergencies	

Table 4.4: Evaluation Tool (version 2).

4.5 EVALUATION OF CASE SITES

The selection of the five case sites was described in section 4.3. The results of the evaluation of the sites, Google Health, Juniper Health, MyMediConnect, RememberItNow and WebMD Health Manager are reported in sections 4.5.1 – 4.5.5. The evaluation of the sites provided descriptive data about the performance of the sites using the evaluation tool as a measure of their meaningful use in terms of the nine dimensions. A comparative overview of the descriptive findings is presented in section 4.5.6.

4.5.1 GOOGLE HEALTH

Google Health has the ability to import data and exchange data with 25 sources. This online PHR also has the ability to download or export the medical record in PDF or CCR (Continuity of Care Record) format and securely exchange data with a predefined list of PHR systems. Auditing can be enabled to show who viewed the patient profile (if access was given), who edited it, deleted it or added information to the profile.

The capture process is very user friendly, by providing drop down boxes to choose medication from. When the same information is accidentally added, the user is alerted to the duplicated entry. The site also provides the user with helpful links to conditions that have been captured. The links are up to date and from reputable sources.

The findings of the evaluation are shown in Table 4.5.

Evaluation Tool measured against Google Health

Dimension	Rating	Yes/No
Interoperability**(6)**	1. Ability to import data	**Y**
	2. Ability to export data	**Y**
	3. Ability to export data into standards, like HL7 v2 or v3 CDA	**Y**
	4. Limited data exchange functionality between systems	**Y**
	5. Supports two-way data exchange with other health systems using common standards	**Y**
	6. Supports secure two-way data exchange with other health systems using common standards	**Y**
Integrity**(2)**	1. Only authorized persons have ability to alter information in health record without audit logs	**Y**
	2. Information can be altered, updated, appended with full audit log capability to ensure integrity	**Y**
	3. Recovery capability	**N**
Accuracy**(2)**	1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc.	**Y**
	2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries	**Y**
Completeness**(4)**	1. Ability to easily append information in order to keep record complete	**Y**
	2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen	**Y**
	3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc.	**Y**
	4. Contains complete health record information such as health insurance information, diet and exercise logs, etc.	**Y**
	5. Track Medical Expenses	**N**
Apomediation**(1)**	1. Provides education about condition, surgery, medication, etc.	**Y**
	2. Health Risk Assessment	**N**
	3. Ability to interact with patients with similar illness/condition	**N**
	4. Access to healthcare practitioner	**N**
	5. Bridge cultural divides by providing support in your own language	**N**
Privacy **(4)** (Patient Driven)	1. Patient has the ability to grant/revoke access to his record	**Y**
	2. Purpose driven access control	**Y**
	3. Revoke access legally (with the ability to retroactively do this) - local system only	**Y**
	4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems	**Y**
Confidentiality**(2)** (Non-Patient Driven)	1. Online health record can only be accessed by authorized parties	**Y**
	2. Access control granted to specific people	**Y**
	3. Access control granted to specific sections of health record to specific people	**N**

Auditability**(3)**	1. Record contains audit logs	**Y**
	2. Supports non-repudiation	**Y**
	3. Provides full auditing – tracking of all changes, additions, deletions, etc.	**Y**
	4. Versioning	**N**
Availability**(4)**	1. Accessible by patient (stand-alone)	**Y**
	2. Accessible by patient in shared environment, but tool does not provide access	**Y**
	3. *Online* access to health record by both patient and physician	**Y**
	4. Accessible by patient and physician 24x7x365 *online*	**Y**
	5. Ability to capture information via software to upload to online health record later (when offline)	**N**
	6. Provides emergency access to health professionals in case of emergencies	**N**

Table 4.5: Evaluation of the Google Health PHR site.

The visual depiction of the findings is displayed in Figure 4.2 with the results again normalized to a scale of 0 to 6 (as will be done for all of the evaluations reported hereafter). The radar diagram shows that the Google Health site is exceptionally strong in the dimensions of interoperability, privacy and accuracy, with the only very weak result in the dimension of apomediation.

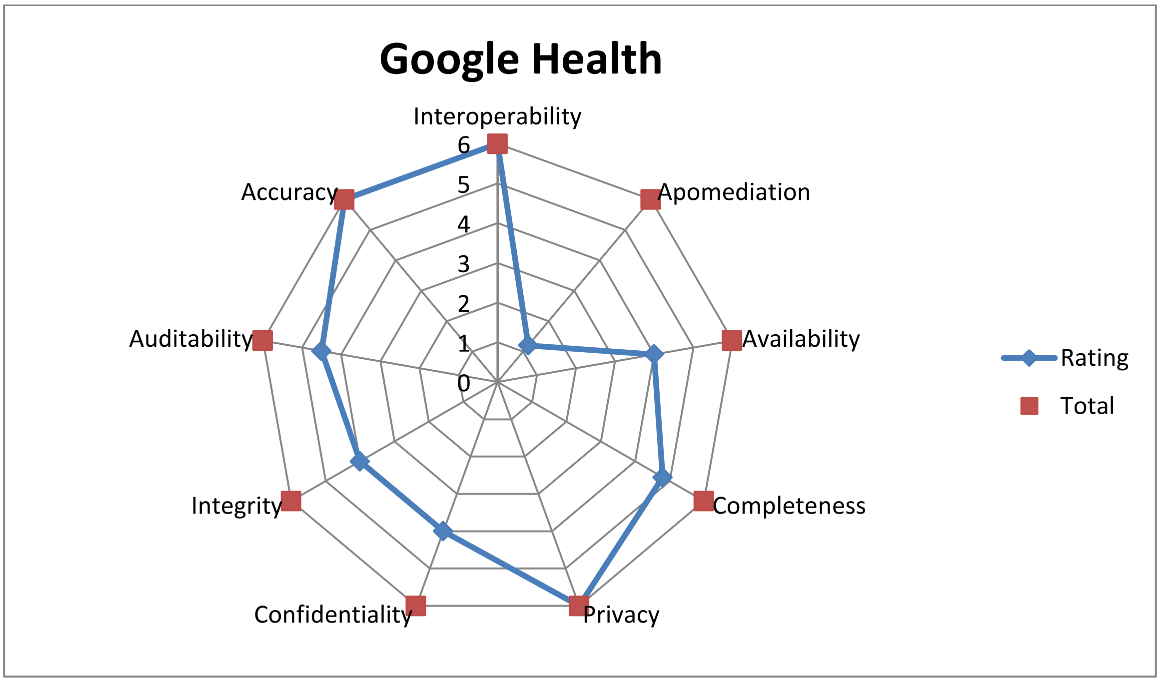

Figure 4.2: Google Health findings.

After completion of the evaluation, Google Health also announced its withdrawal from the PHR market from January 1, 2012. Downloading of captured data will be allowed through January 1, 2013.

To justify their decision, Google wrote in a blog post on the 24th of June 2011 (Brown, 2011):

"When we launched Google Health, our goal was to create a service that would give people access to their personal health and wellness information. We wanted to translate our successful consumer-centred approach from other domains to healthcare and have a real impact on the day-to-day health experiences of millions of our users. Now, with a few years of experience, we've observed that Google Health is not having the broad impact that we hoped it would."

Google state in the blog post that they haven’t found a way to translate the limited usage of Google Health into widespread adoption by millions of people as aimed for. According to a blog post at the Washington Post, Google’s demise was because they couldn’t find a way to make the offering of this service financially viable (Washington Post, 2011). A report in the New York Times (2011) states that a major reason for Google Health's demise was that its personal health record was hard to use and was not seen as having great personal value, or in the words of a former manager of Google Health, the idea "did not have a compelling consumer proposition." (Charette, 2011). As with the discontinuation of the WorldHealthRecord PHR, the envisaged closure of the Google Health site is disappointing considering the potential of its utility.

4.5.2 JUNIPER HEALTH

This PHR was still in BETA mode when the evaluation was done. The site displayed much about possible improvements and new features, but for the purpose of this research, the site was evaluated on the features available at the time of evaluation.

After account creation, this PHR commences a very user-friendly health survey asking relevant questions and providing suggestions to overcome any potential or current problems. Once the survey is completed, a list of To-Do’s are created. These To-Do’s are based on the results of the survey and provide personalized feedback to the user. For example, if a user specifies in the survey that less than one fruit per day is consumed on average, suggestions will be given on how to correct this and what amount of fruits should be consumed daily to be healthy and reduce the risk of health problems. The system retains this in the form of a To-Do list. It took more than an hour for the researcher to complete the survey, which might be too lengthy for the average user to get started. Multiple medical conditions were listed for pre-selection though, which limited input required from the user. The survey was very thorough on the different areas of health.

When capturing medication, the user is assisted with a drop-down box of preloaded medicine names. However, medicines that were not included on the list could not be added. As it is impossible to preload a complete list of all medicines available, this constitutes a problem for users of this PHR.

Basic measurements like weight and height could only be captured in pounds and inches (no option to switch to kilograms and centimetres). The findings of the evaluation of Juniper Health (Beta) are shown in Table 4.6.

Evaluation Tool measured against Juniper Health BETA		
Dimension	**Rating**	**Yes/No**
Interoperability**(0)**	1. Ability to import data	**N**
	2. Ability to export data	**N**
	3. Ability to export data into standards, like HL7 v2 or v3 CDA	**N**
	4. Limited data exchange functionality between systems	**N**
	5. Supports two-way data exchange with other health systems using common standards	**N**
	6. Supports secure two-way data exchange with other health systems using common standards	**N**
Integrity**(1)**	1. Only authorized persons have ability to alter information in health record without audit logs	**Y**
	2. Information can be altered, updated, appended with full audit log capability to ensure integrity	**N**
	3. Recovery capability	**N**
Accuracy**(1)**	1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc.	**Y**

	2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries	**N**
Completeness**(3)**	1. Ability to easily append information in order to keep record complete	**Y**
	2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen	**Y**
	3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc.	**Y**
	4. Contains complete health record information such as health insurance information, diet and exercise logs, etc.	**N**
	5. Track Medical Expenses	**N**
Apomediation**(1)**	1. Provides education about condition, surgery, medication, etc.	**N**
	2. Health Risk Assessment	**Y ***
	3. Ability to interact with patients with similar illness/condition	**N**
	4. Access to healthcare practitioner	**N**
	5. Bridge cultural divides by providing support in your own language	**N**
Privacy **(0)** (Patient Driven)	1. Patient has the ability to grant/revoke access to his record	**N**
	2. Purpose driven access control	**N**
	3. Revoke access legally (with the ability to retroactively do this) - local system only	**N**
	4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems	**N**
Confidentiality**(1)** (Non-Patient Driven)	1. Online health record can only be accessed by authorized parties	**Y**
	2. Access control granted to specific people	**N**
	3. Access control granted to specific sections of health record to specific people	**N**
Auditability**(0)**	1. Record contains audit logs	**N**
	2. Supports non-repudiation	**N**
	3. Provides full auditing – tracking of all changes, additions, deletions, etc.	**N**
	4. Versioning	**N**
Availability**(2)**	1. Accessible by patient (stand-alone)	**Y**
	2. Accessible by patient in shared environment, but tool does not provide access	**Y**
	3. *Online* access to health record by both patient and physician	**N**
	4. Accessible by patient and physician 24x7x365 *online*	**N**
	5. Ability to capture information via software to upload to online health record later (when offline)	**N**
	6. Provides emergency access to health professionals in case of emergencies	**N**

Table 4.6: Evaluation of the Juniper Health Beta PHR site.

* Allowed to skip one non-compliant rating

The findings for Juniper Health (Beta) are depicted graphically in Figure 4.3. The radar diagram shows that Juniper Health is not particularly strong in any dimension. The best dimension was completeness and the weakest dimensions were interoperability, privacy and auditability.

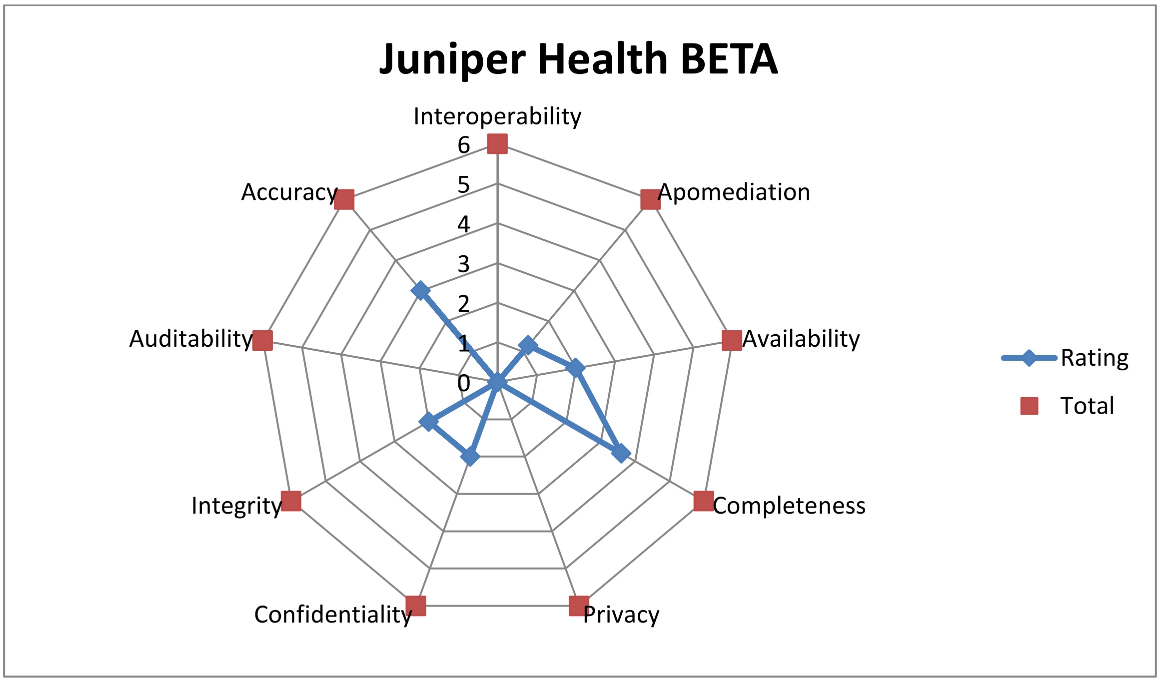

Figure 4.3: Juniper Health Beta findings.

4.5.3 MYMEDICONNECT (PASSPORTMD)

The MyMediConnect PHR (previously known as PassportMD) is primarily for users in the US, although it is possible to circumvent this restriction.

During the registration process, the users are forced to select a State in the US and enter a ten digit valid phone number. For the purpose of testing, dummy information was entered.

This PHR gives users the ability to download their medical information in HTML format. The HTML document contains links to images and documents that were uploaded to MyMediConnect PHR. The record contained in MyMediConnect can easily be synchronized with users' data as contained in Microsoft HealthVault.

The PHR provides easy to use data capture techniques and provides a list of possible medication/conditions. Doctors can be added from a predefined list (all US based doctors) and allowed to see the user's medical record, images and notes. As may be expected all measurements are only in US metric.

The PHR provides a "health education centre" that contains health information and gives patients the ability to search for conditions that they might suffer from or need more information about. The findings for MyMediConnect are displayed in Table 4.7.

Evaluation Tool measured against MyMediConnect		
Dimension	**Rating**	**Yes/No**
Interoperability**(6)**	1. Ability to import data	**Y**
	2. Ability to export data	**Y**
	3. Ability to export data into standards, like HL7 v2 or v3 CDA	**Y**
	4. Limited data exchange functionality between systems	**Y**
	5. Supports two-way data exchange with other health systems using common standards	**Y**
	6. Supports secure two-way data exchange with other health systems using common standards	**Y**
Integrity**(1)**	1. Only authorized persons have ability to alter information in health record without audit logs	**Y**
	2. Information can be altered, updated, appended with full audit log capability to ensure integrity	**N**
	3. Recovery capability	**N**
Accuracy**(1)**	1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc.	**Y**
	2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries	**N**
Completeness**(5)**	1. Ability to easily append information in order to keep record complete	**Y**
	2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen	**Y**
	3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc.	**Y**
	4. Contains complete health record information such as health insurance information, diet and exercise logs, etc.	**Y**
	5. Track Medical Expenses	**Y**
Apomediation**(2)**	1. Provides education about condition, surgery, medication, etc.	**Y**
	2. Health Risk Assessment	**Y**
	3. Ability to interact with patients with similar illness/condition	**N**

	4. Access to healthcare practitioner	**N**
	5. Bridge cultural divides by providing support in your own language	**N**
Privacy **(4)** (Patient Driven)	1. Patient has the ability to grant/revoke access to his record	**Y**
	2. Purpose driven access control	**Y**
	3. Revoke access legally (with the ability to retroactively do this) - local system only	**Y**
	4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems	**Y**
Confidentiality**(3)** (Non-Patient Driven)	1. Online health record can only be accessed by authorized parties	**Y**
	2. Access control granted to specific people	**Y**
	3. Access control granted to specific sections of health record to specific people	**Y**
Auditability**(0)**	1. Record contains audit logs	**N**
	2. Supports non-repudiation	**N**
	3. Provides full auditing – tracking of all changes, additions, deletions, etc.	**N**
	4. Versioning	**N**
Availability**(5)**	1. Accessible by patient (stand-alone)	**Y**
	2. Accessible by patient in shared environment, but tool does not provide access	**Y**
	3. *Online* access to health record by both patient and physician	**y**
	4. Accessible by patient and physician 24x7x365 *online*	**y**
	5. Ability to capture information via software to upload to online health record later (when offline)	**N**
	6. Provides emergency access to health professionals in case of emergencies	**Y ***

Table 4.7: Evaluation of the MyMediConnect PHR site.

* Allowed to skip one non-compliant rating

The findings from Table 4.7 are depicted diagrammatically in Figure 4.4. The radar diagram shows that MyMediConnect shows strengths in the dimensions of interoperability, completeness, privacy and confidentiality, while the weakest dimension was auditability.

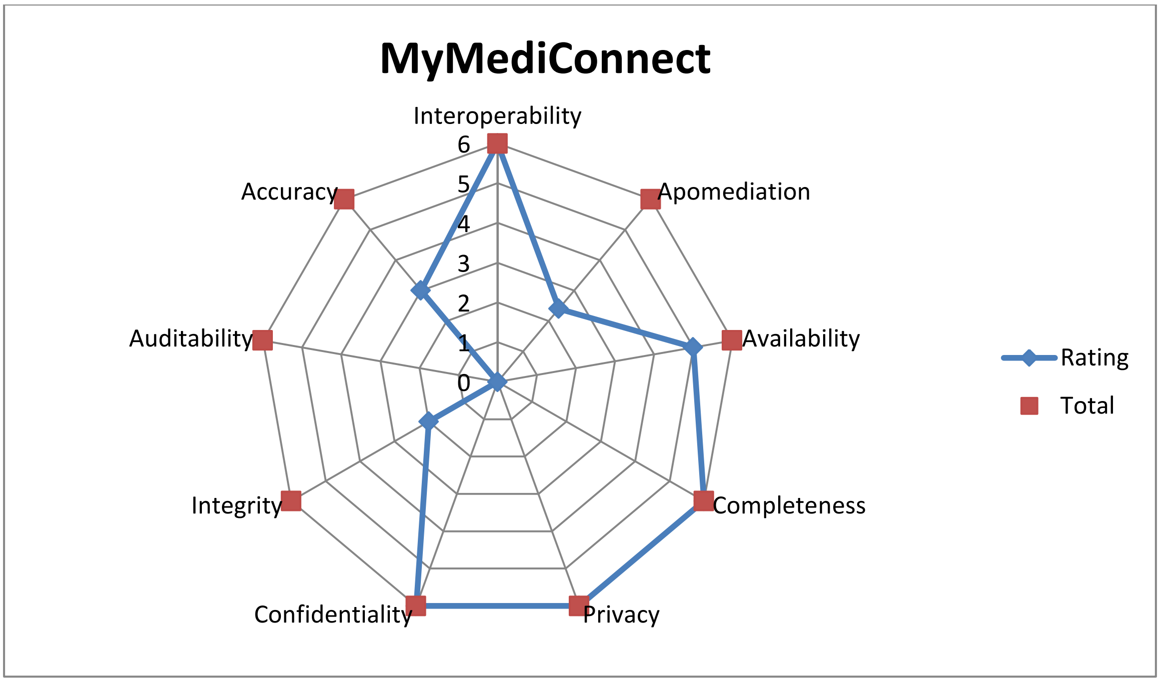

Figure 4.4: MyMediConnect findings.

4.5.4 REMEMBERITNOW!

RememberItNow! displays greater strength as an online health diary with functionality for journals, calendars, reminders and tweets. The main purpose of the PHR is stated as: "RememberItNow! helps you remember medications and appointments, track prescriptions, locate your contacts and favourite links, keep a health journal, and track your stats. Share your schedule with caregivers and healthcare providers and you'll help them remember as well." (RememberItNow!, 2009). The findings of the evaluation are displayed in Table 4.8.

Evaluation Tool measured against RememberItNow!		
Dimension	**Rating**	**Yes/No**
Interoperability**(1)**	1. Ability to import data	**Y**
	2. Ability to export data	**N**
	3. Ability to export data into standards, like HL7 v2 or v3 CDA	**N**
	4. Limited data exchange functionality between systems	**N**
	5. Supports two-way data exchange with other health systems using common standards	**N**
	6. Supports secure two-way data exchange with other health systems using common standards	**N**
Integrity**(1)**	1. Only authorized persons have ability to alter information in health	**Y**

	record without audit logs	
	2. Information can be altered, updated, appended with full audit log capability to ensure integrity	**N**
	3. Recovery capability	**N**
Accuracy**(1)**	1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc.	**Y**
	2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries	**N**
Completeness**(3)**	1. Ability to easily append information in order to keep record complete	**Y**
	2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen	**Y**
	3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc.	**Y**
	4. Contains complete health record information such as health insurance information, diet and exercise logs, etc.	**N**
	5. Track Medical Expenses	**N**
Apomediation**(0)**	1. Provides education about condition, surgery, medication, etc.	**N**
	2. Health Risk Assessment	**N**
	3. Ability to interact with patients with similar illness/condition	**N**
	4. Access to healthcare practitioner	**N**
	5. Bridge cultural divides by providing support in your own language	**N**
Privacy **(0)** (Patient Driven)	1. Patient has the ability to grant/revoke access to his record.	**N**
	2. Purpose driven access control	**N**
	3. Revoke access legally (with the ability to retroactively do this) - local system only	**N**
	4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems	**N**
Confidentiality**(1)** (Non-Patient Driven)	1. Online health record can only be accessed by authorized parties	**Y**
	2. Access control granted to specific people	**N**
	3. Access control granted to specific sections of health record to specific people	**N**
Auditability**(0)**	1. Record contains audit logs	**N**
	2. Supports non-repudiation	**N**
	3. Provides full auditing – tracking of all changes, additions, deletions, etc.	**N**
	4. Versioning	**N**
Availability**(2)**	1. Accessible by patient (stand-alone)	**Y**
	2. Accessible by patient in shared environment, but tool does not provide access	**Y**
	3. *Online* access to health record by both patient and physician	**N**
	4. Accessible by patient and physician 24x7x365 *online*	**N**
	5. Ability to capture information via software to upload to online health record later (when offline)	**N**

	6. Provides emergency access to health professionals in case of emergencies	**N**

Table 4.8: Evaluation of the RememberItNow! PHR site.

Visually the findings from the evaluation of RememberItNow! can be depicted as in Figure 4.5. The ratings achieved by this PHR show weakness in the dimensions of auditability, privacy and apomediation, whereas the dimension of completeness rated the best, but only with a mediocre score of 3.6 out of 6 (normalized).

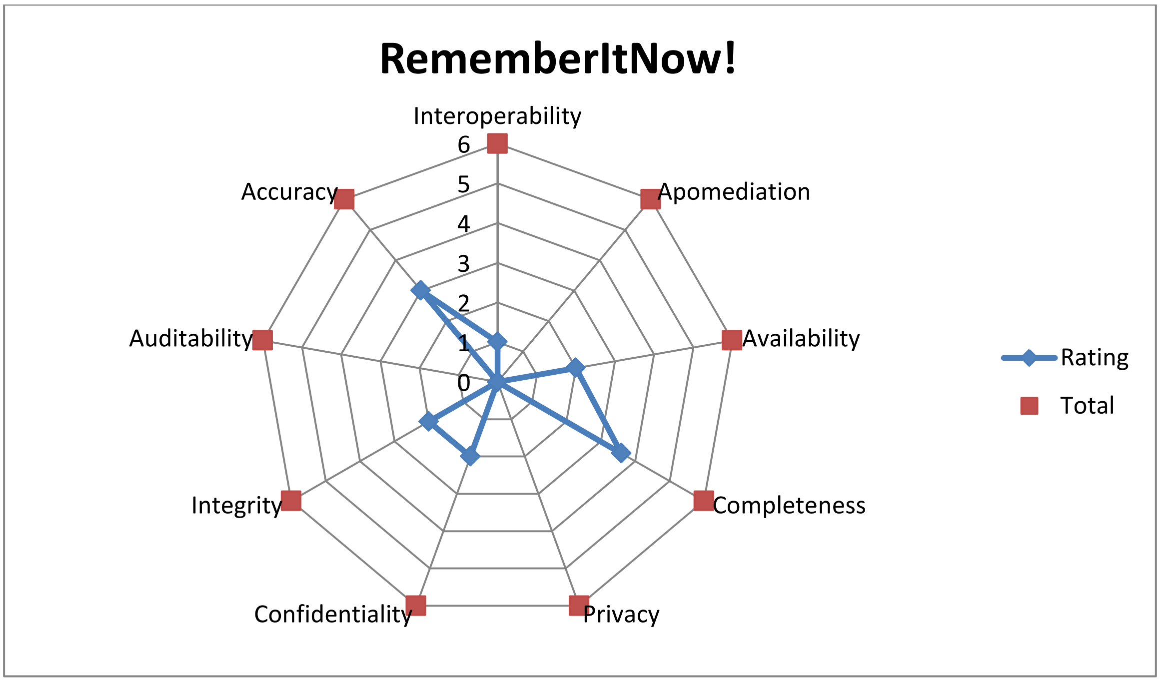

Figure 4.5: RememberItNow! findings.

4.5.5 WEBMD HEALTH MANAGER

This PHR is a subset of the comprehensive WebMD medical portal. An exceptionally user-friendly interface makes it easy for the patient to capture details. It provides an easy search/complete facility to select correct medication and conditions. This PHR provides health assessment tools and the ability to link a patient's record to their child's record. The tool does log when the site was created and when it was visited, but there is no audit logging of changes, appending and deletion of details. Remote access for doctors and healthcare professionals were envisaged to be added post the date of this evaluation. The results of the evaluation for WebMD Health Manager are shown in Table 4.9.

Evaluation Tool measured against WebMD Health Manager

Dimension	**Rating**	**Yes/No**
Interoperability**(2)**	1. Ability to import data	**Y**
	2. Ability to export data	**Y**
	3. Ability to export data into standards, like HL7 v2 or v3 CDA	**N**
	4. Limited data exchange functionality between systems	**N**
	5. Supports two-way data exchange with other health systems using common standards	**N**
	6. Supports <u>secure</u> two-way data exchange with other health systems using common standards	**N**
Integrity**(1)**	1. Only authorized persons have ability to alter information in health record without audit logs	**Y**
	2. Information can be altered, updated, appended with full audit log capability to ensure integrity	**N**
	3. Recovery capability	**N**
Accuracy**(2)**	1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc.	**Y**
	2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries	**Y**
Completeness**(4)**	1. Ability to easily append information in order to keep record complete	**Y**
	2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen	**Y**
	3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc.	**Y**
	4. Contains complete health record information such as health insurance information, diet and exercise logs, etc.	**Y**
	5. Track Medical Expenses	**N**
Apomediation**(2)**	1. Provides education about condition, surgery, medication, etc.	**Y**
	2. Health Risk Assessment	**Y**
	3. Ability to interact with patients with similar illness/condition	**N**
	4. Access to healthcare practitioner	**N**
	5. Bridge cultural divides by providing support in your own language	**N**
Privacy **(1)** (Patient Driven)	1. Patient has the ability to grant/revoke access to his record	**Y**
	2. Purpose driven access control	**N**
	3. Revoke access legally (with the ability to retroactively do this) - local system only	**N**
	4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems	**N**

Confidentiality**(1)** (Non-Patient Driven)	1. Online health record can only be accessed by authorized parties 2. Access control granted to specific people 3. Access control granted to specific sections of health record to specific people	**Y** **N** **N**
Auditability**(1)**	1. Record contains audit logs 2. Supports non-repudiation 3. Provides full auditing – tracking of all changes, additions, deletions, etc. 4. Versioning	**Y** **N** **N** **N**
Availability**(2)**	1. Accessible by patient (stand-alone) 2. Accessible by patient in shared environment, but tool does not provide access 3. *Online* access to health record by both patient and physician 4. Accessible by patient and physician 24x7x365 *online* 5. Ability to capture information via software to upload to online health record later (when offline) 6. Provides emergency access to health professionals in case of emergencies	**Y** **Y** **N** **N** **N** **N**

Table 4.9: Evaluation of the WebMD Health Manager PHR site.

Visually the findings from the evaluation of WebMD Health Manager can be depicted as in Figure 4.6. The ratings achieved by this PHR show that the strongest dimension is accuracy, with the weakest dimensions being auditability and privacy.

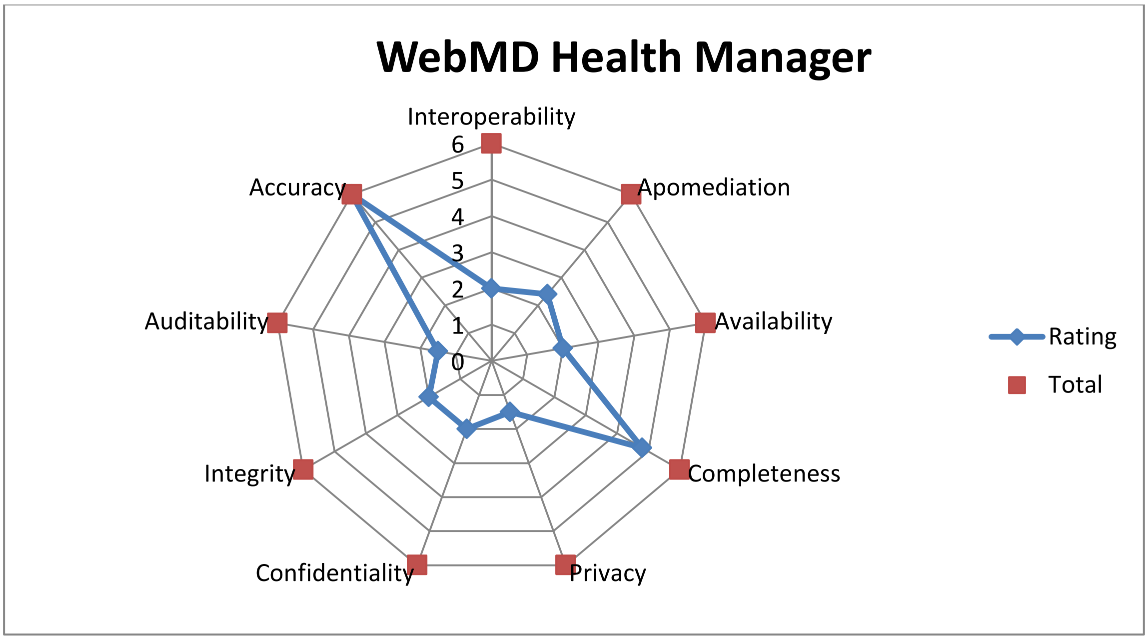

Figure 4.6: WebMD Health Manager findings.

4.5.6 CONSOLIDATION OF DESCRIPTIVE FINDINGS

The outcome of the evaluation of the five PHRs is now consolidated and considered from a comparative point of view. The combined findings are depicted in Figure 4.7 using a radar diagram.

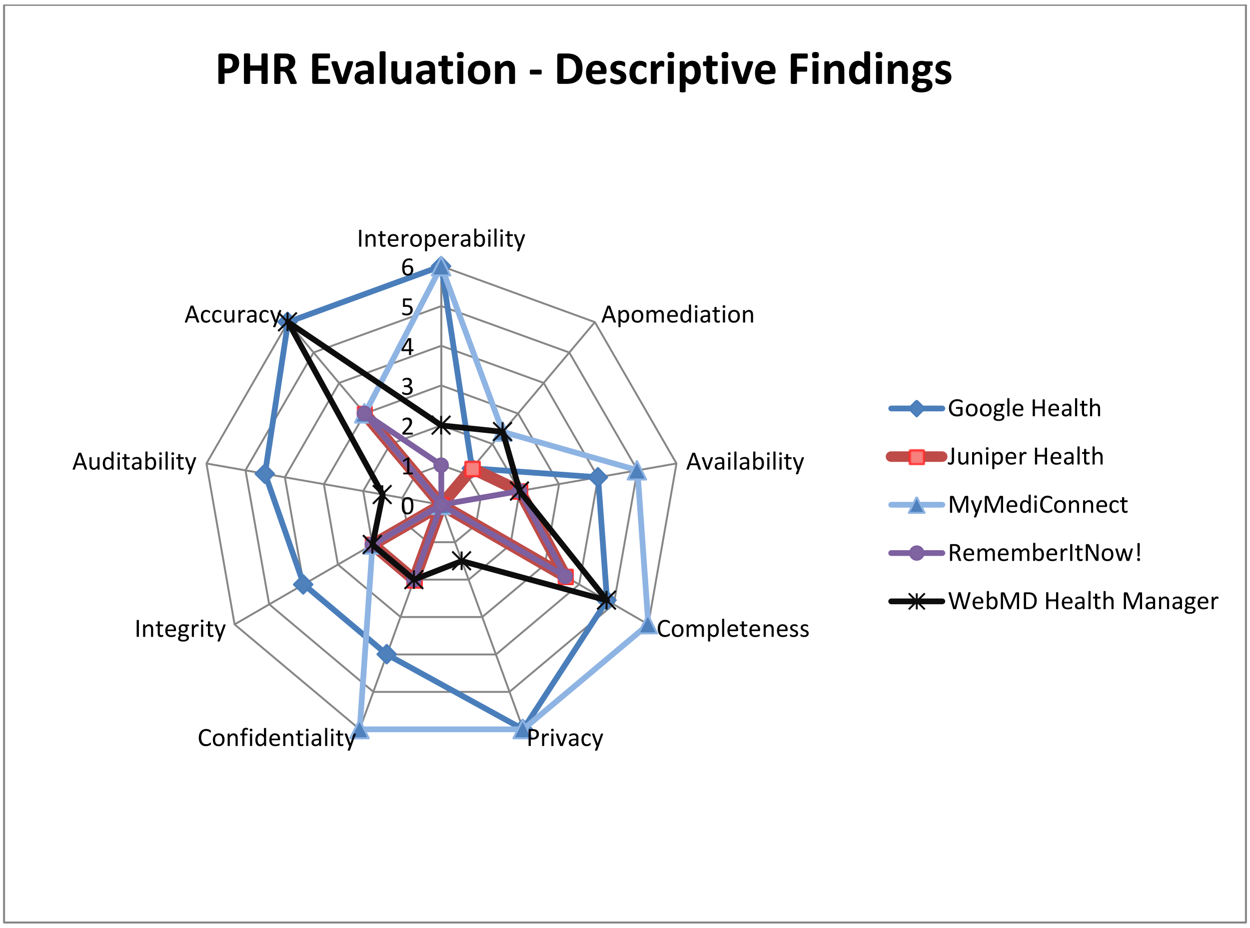

Figure 4.7: Consolidated PHR Evaluations.

Also find Table 4.10 representing the consolidated findings and the various totals per PHR and per dimension.

	Google Health	MyMediConnect	WebMD HealthManager	Juniper Health	RememberIt Now!	TOTAL
Completeness	4.8	6	4.8	3.6	3.6	22.8
Accuracy	6	3	6	3	3	21
Confidentiality	4	6	2	2	2	16
Interoperability	6	6	2	0	1	15
Availability	4	5	2	2	2	15
Privacy	6	6	1.5	0	0	13.5
Integrity	4	2	2	2	2	12
Apomediation	1.2	2.4	2.4	1.2	0	7.2
Auditability	4.5	0	1.5	0	0	6
TOTAL	40.5	36.4	24.2	13.8	13.6	

Table 4.10: Consolidated PHR Evaluations in Tabular Form.

The maximum achievable score for each PHR is 54 as there are nine dimensions with a maximum score of 6 (normalized). The maximum achievable score for each dimension, calculated as the total of the scores achieved by each PHR for that dimension, is 30. The results in Table 4.10 have been arranged from highest to lowest scoring PHR (left to right) and from highest to lowest scoring dimension (top to bottom).

According to the evaluation tool, the PHR that scored highest was Google Health with a total of 40.5 out of the maximum of 54. The only dimension that scored very weak is apomediation. A close second is MyMediConnect with a total of 36.4 out of 54. This PHR scored badly in the auditability dimension.

Juniper Health, RememberItNow! and WebMD Health Manager all scored less than a 50% average of the total of 54, with WebMD Health Manager scoring the highest of the three due to strengths in the completeness and accuracy dimensions.

Based on the total rating that a health record obtains when measured against the evaluation tool, it could be argued that the health record could be categorized as either of very low, low, medium, high or very high meaningful use.

For ease of reference, Table 4.11 below repeats the total rating achieved by the five evaluated PHRs.

PHR	Google Health	MyMediConnect	WebMD Health Manager	Juniper Health	RememberIt Now!
TOTAL	40.5	36.4	24.2	13.8	13.6

Table 4.11: Normalized Findings – PHRs measured against tool.

In terms of meaningful use, patients might feel more at ease using a PHR like Google Health and MyMediConnect. These PHRs achieved the highest total rating of the five PHRs.

Although a PHR can achieve a higher level of meaningful use, it must be kept in mind that a specific dimension might not be adhered to at all. A PHR is only as strong as its weakest dimension. For example MyMediConnect did not provide any auditing capabilities. Although its overall rating was good, the tool will point out in which area a PHR is weak. Therefore, the argument that PHRs can be categorized into levels of MU based on their overall score is flawed. Each patient values certain dimensions differently than the next and to argue that one PHR is of more MU than the next because of their overall rating, is unsound. The patient can then base their decision of using this health record on overall achievement, as well as individual dimension achievement and what they deem important in their field of use.

The descriptive data obtained through evaluating the five PHRs is now analysed in more detail by considering the consolidated results for each dimension of MU-PHR.

- COMPLETENESS (22.8 out of 30):

During the evaluation of the five selected PHRs, it was found that the dimension that was adhered to in most cases was completeness. All PHRs gave the patient the ability to keep their record up to date and enter basic or advanced medical information and medical history. The Google Health and WebMD Health Manager online PHRs achieved close to a full mark. They only lacked a medical expenses tracking system. The MyMediConnect online PHR scored full marks.

- ACCURACY (21 out of 30):

The chosen PHRs scored strongly when measured against the evaluation tool in this dimension. Both Google Health and WebMD Health Manager scored full marks. The remainder of the PHRs did provide tools to support accuracy, for example drop down boxes, error checking, confirmation prompts and more, but did not pass the duplication avoidance check.

- CONFIDENTIALITY (16 out of 30):

MyMediConnect scored full marks when measured against the evaluation tool for this dimension. All other evaluated PHRs did support confidentiality by only allowing access to the health record for authorized parties. In addition to this, Google Health also had the ability to grant access to specific people.

- INTEROPERABILITY (15 out of 30):

Of the five evaluated PHRs, both Google Health and MyMediConnect achieved a full mark for interoperability by supporting secure two-way data exchange with other health systems. The other three PHRs lacked the ability to export data into common standards and only gave the patient the ability to export data in an arbitrary format like PDF or text. At the time of evaluation, Juniper Health did not allow the patient to import or export at all.

- AVAILABILITY (15 out of 30):

All evaluated PHRs allowed online access to the health record for the patient/creator. Only Google Health and MyMediConnect allowed access to both patient and physician. An exceptional feature of MyMediConnect was the ability to setup emergency access to a patient's health record. None of the evaluated PHRs allowed a patient to capture information while not online.

- PRIVACY (13.5 out of 30):

Of the 5 evaluated PHRs, both Google Health and MyMediConnect scored full marks when measured against the evaluation tool. Notably Juniper Health and RememberItNow! did not score any points for this dimension, which is a serious flaw considering the importance of protecting patient privacy. The WebMD Health Manager provided basic ability for the patient to grant and revoke access to their online health record.

- INTEGRITY (12 out of 30):

All evaluated PHRs allowed only authorized changes to the health record. Google Health was the solitary PHR which also provided an audit trail of what additions, changes or deletions were made. None of the PHRs had the ability to revert back to a previous version or roll back from certain changes made.

- APOMEDIATION (7.2 out of 30):

The lack of implementation of apomediation is clearly visible in the five chosen Web 2.0 PHRs. Although this dimension was not the weakest dimension overall, the weak result was expected as it is based on a new socio-technological term. Some of the evaluated sites gave patients the ability to further their education about conditions they are suffering from. In rare cases, a health risk assessment was available. There was an overall lack of interaction with fellow patients and online health professionals. Not one of the PHRs provided an option to select a language of the user's choice. The ability to capture medical records in the patient's native language, does give the patient a sense of ownership, improved understanding of and confidence in the health record.

- AUDITABILITY (6 out of 30):

During the evaluation of the five selected PHRs, it was found that the weakest dimension was auditability. Juniper Health, MyMediConnect and RememberItNow! all scored zero when rated against the evaluation tool. WebMD Health Manager provided functionality for very basic audit logs. Only Google Health provided full audit logs and supported non-repudiation – although the ability to rollback to previous versions was not possible.

This concludes the discussion of the consolidated results for the evaluation of the five PHRs. A possible reason as to why some of the PHRs are being discontinued could be a lack of consumer confidence in the product. The evaluation results clearly show that on average only 39.6% of the desired ratings were achieved by the PHRs that were evaluated. If the users of the online PHR feel that their PHI is not securely protected, lacks auditing, does not give them the ability to capture certain information and it is more of an effort to work with than being a helpful tool, then adoption will be slow and most users will eventually stop using it.

4.6 CONCLUSION

In this chapter, an evaluation tool was created to evaluate the meaningful use of PHRs. A new consolidated model was developed to choose the pilot PHR and five PHRs to be evaluated. After the initial pilot PHR was evaluated against the evaluation tool, gaps in the tool were highlighted and this enabled the creation of a new and more correct version of the tool. The refined tool was then used to evaluate the chosen five PHRs.

The outcome of this chapter was the descriptive findings from applying the evaluation tool and how these findings differ from the normative findings in Chapter

3. The differences between the descriptive and normative findings will lead to the creation of guidelines which form part of the framework of PHRs in online social networking. The following chapter focuses on the creation of this framework and consolidates the concepts and components that form part of the framework.

CHAPTER 5

A FRAMEWORK FOR PERSONAL HEALTH RECORDS IN ONLINE SOCIAL NETWORKING

5.1 INTRODUCTION

In this chapter, a framework for meaningful use of PHRs in online social networking is presented. A framework is a fundamental construct that defines assumptions, concepts, values, and practices, and that includes guidance for implementing itself (Tomhave, 2005). The components of a framework may take on various forms, such as steps, principles, guidelines, concepts, questions, challenges and dimensions (Rogers, 2008). The framework proposed in this chapter is comprised of concepts and components. These concepts and components emerged during the execution of the research as reported in earlier chapters and are consolidated into a framework in this chapter.

Each of the concepts and components of the framework is discussed in the subsequent sections as follows:

- Concepts – Section 5.2
    - Meaningful Use – Section 5.2.1
    - Attributes – Section 5.2.2
    - Instrument – Section 5.2.3
    - Directives – Section 5.2.4
- Components – Section 5.3
    - MU-PHR – Section 5.3.1
    - Dimensions – Sections 5.3.2

  - Evaluation Tool – Section 5.3.3
  - Guidelines – Section 5.3.4

5.2 CONCEPTS

The four concepts comprising the proposed framework are meaningful use, attributes, instrument and directives. After discussing the concepts in sections 5.2.1 – 5.2.4, the interrelationships between the concepts are illustrated.

5.2.1 MEANINGFUL USE

To reiterate the discussion in Chapter 1, Section 1.1, the term "*meaningful use*" (MU) in the context of EHR systems refers to whether health providers in America can demonstrate that they are using EHR technology meaningfully according to specified indicators, in which case financial incentives are available to these providers.

The foundation of the framework for meaningful use of PHRs in online social networking is built upon the concept of patient-owned health records being used meaningfully.

5.2.2 ATTRIBUTES

In the context of this research, attributes are the qualities required of a PHR in a social networking environment to enable its meaningful use. Each attribute serves as a benchmark for the utility of the PHR in regard of the particular attribute.

5.2.3 INSTRUMENT

At a fundamental level an instrument is something that is used to do a particular piece of work (Cambridge University Press, 2011). The work that needs to be executed in this research is the evaluation of PHRs in social networking environments to measure whether they satisfy the attributes of meaningful use. The instrument must enable the measuring of each attribute in order to reach a decision of the PHRs performance in relation to the attribute.

5.2.4 DIRECTIVES

According to the Oxford Dictionary, directives can be defined as "involving the management or guidance of operations" (Oxford Dictionaries, 2011). The directives that form part of the framework for this research consist of advice or guidance on how to use the instrument to determine the PHRs conformance to the attributes of meaningful use. Guidance will be given on how to rate each attribute using a normalized scale. Advice is also given on "known gaps", i.e. what is typically found in practise today and what to look out for.

Figure 5.1 below illustrates the concepts that comprise the proposed framework as well as the relationships between them and how the concepts map to the components of the framework.

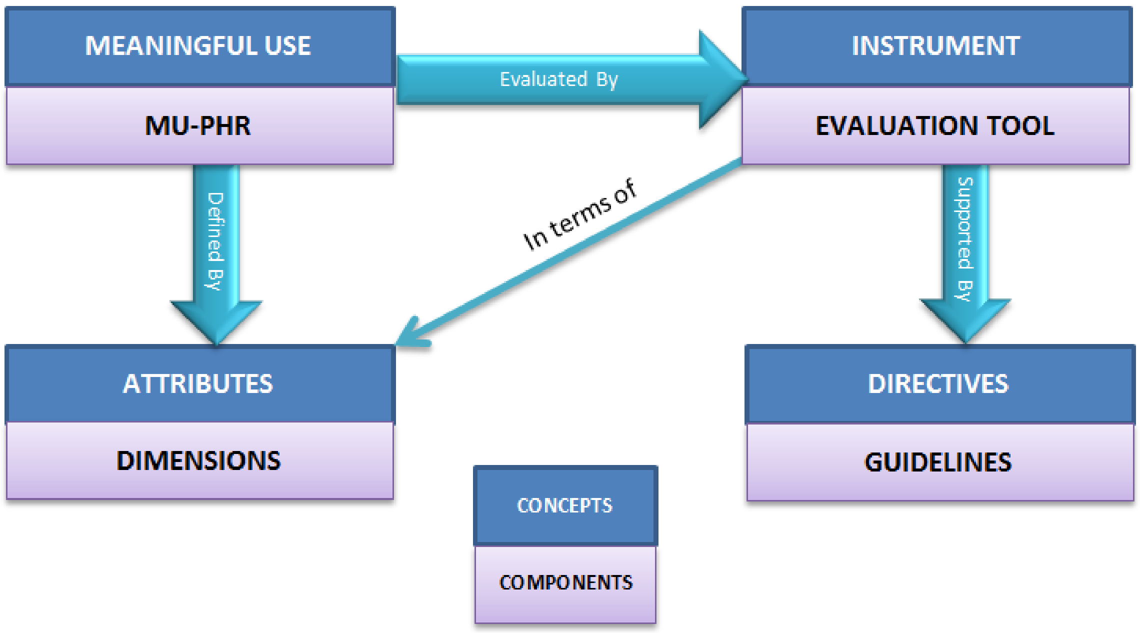

Figure 5.1: Concepts and components comprising the proposed framework.

From Figure 5.1 it may be seen that the concept of **meaningful use** is evaluated in terms of the **attributes** of meaningful use, through the use of an **instrument** and supported by **directives**. This narrative describing the relevant concepts of the framework, maps as follows to the components of the framework:

MU-PHR is evaluated in terms of the **dimensions** of meaningful use, through the use of an **evaluation tool** which is supported by **guidelines**.

The concepts of meaningful use (*MU-PHR*), directives *(guidelines)*, the instrument *(evaluation tool)* and the attributes *(dimensions)* are now expounded, providing comprehensive detail of these concepts as functional **components** in the framework.

5.3 COMPONENTS

The four components comprising the proposed framework are MU-PHR, dimensions, evaluation tool and guidelines. These components are now discussed in sections 5.3.1 to 5.3.4.

5.3.1 MU-PHR

The acronym MU-PHR is used to represent the meaningful use of PHRs in online social networking. MU-PHR refers to health records that are integrated (populated with patient information from various sources), interconnected (accessible by various stakeholders) and where the patient is an important contributor to, and owner of the content of the record. MU-PHR may lead to significant improvement in the health of the individual/patient through increased patient involvement (Health Resources and Services Administration, 2011).

5.3.2 DIMENSIONS

The nine dimensions of MU-PHRs were defined and discussed in Chapter 3, Sections 3.3.1 – 3.3.9 of this dissertation. These dimensions are summarized in Table 5.1. The table represents the component in terms of the meaning of each of the dimensions (normative) and the descriptive findings of the evaluation of PHRs that was reported in Chapter 4.

DIMENSION	NORMATIVE	DESCRIPTIVE
INTEROPERABILITY	Ability to interoperate with other health systems – importing and exporting into health standards	3 of the 5 evaluated PHRs lacked the ability to export data into common standards
INTEGRITY	No unauthorized additions, deletions or alterations – must be tracked by auditing logs	Only 1 of the 5 evaluated PHRs provided an audit trail of activities
ACCURACY	Information must be captured accurate and correctly, by implementing tools to prevent human error	All PHRs implemented basic error prevention tools, but 3 of the 5 evaluated PHRs lacked advanced tools that could avoid further errors
COMPLETENESS	Health records must not only contain basic personal information, doctor visits, check-up notes and diagnoses, but should also contain information like diet and exercise logs, health insurance information, etc. to be deemed complete	Strongest MU dimension. All evaluated PHRs give the patient the ability to capture basic and some advanced information. 4 of the 5 evaluated PHRs lacked advanced information, like tracking medical expenses, etc.
APOMEDIATION	Health records should educate patients and assist them in capturing the record with a sense of understanding. Patients must also have ability to interact with other patients and doctors. Own language support	Overall lack of patients' ability to interact with other patients or doctors. No mother language support. Only 2 of the 5 evaluated PHRs provided education on medicine and conditions
PRIVACY	Patient must have ability to grant or revoke (including legally) access to health records. Granular purpose driven access control.	Only 2 of the 5 evaluated PHRs conform to all of the privacy ratings. The remaining 3 scored badly in this dimension

DIMENSION	NORMATIVE	DESCRIPTIVE
CONFIDENTIALITY	Health records must only be accessible to authorized parties	All of the evaluated PHRs have the ability to allow authorized access to the owner/creator. Only 2 of the 5 evaluated PHRs have the ability to grant access to specific people (doctors and caregivers)
AUDITABILITY	Health records must contain audit logs tracking access, changes, additions and deletions. Must support non repudiation	Weakest dimension in terms of meaningful use. Only 1 of the 5 evaluated PHRs had minimal audit logging enabled
AVAILABILITY	Must be accessible by both patient and physician 24x7x365. Emergency access must also be enabled	All PHRs were available 24x7x365 online for patients, but less than half provide access to physician as well. Only 1 of the 5 PHRs evaluated provided emergency access

Table 5.1: Dimensions of MU-PHRs.

The framework addresses the ideal PHR based on the normative data collected in Chapter 3, but data collected during the case evaluations as reported in Chapter 4, provided evidence of a gap between the requirements represented by the normative data, and the conformance of PHRs available in practice. This leads to the creation of gaps between what is expected and what is reality. These gaps will be addressed in the discussion of guidelines as a component of the framework in Section 5.3.4.

5.3.3 EVALUATION TOOL

The evaluation tool developed in Chapter 4 can be used to determine to what extent a PHR system supports MU. The evaluation tool provides an indicator of MU in terms of nine dimensions, each qualified by ratings that serve as indicators of a PHR's performance in a particular dimension.

The refined evaluation tool used in Chapter 4 is provided again in Table 5.2 as a component of the framework proposed in this chapter.

EVALUATION TOOL

Dimension	Rating	
Interoperability	1. Ability to import data 2. Ability to export data 3. Ability to export data into standards, like HL7 v2 or v3 CDA 4. Limited data exchange functionality between systems 5. Supports two-way data exchange with other health systems using common standards 6. Supports secure two-way data exchange with other health systems using common standards	
Integrity	1. Only authorized persons have ability to alter information in health record without audit logs 2. Information can be altered, updated, appended with full audit log capability to ensure integrity 3. Recovery capability	
Accuracy	1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc. 2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries	
Completeness	1. Ability to easily append information in order to keep record complete 2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen 3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc. 4. Contains complete health record information such as health insurance information, diet and exercise logs, etc. 5. Track medical expenses	
Apomediation	1. Provides education about condition, surgery, medication, etc. 2. Health risk assessment 3. Ability to interact with patients with similar illness/condition 4. Access to healthcare practitioner 5. Bridge cultural divides by providing support in your own language	
Privacy (Patient	1. Patient has the ability to grant/revoke access to his record. 2. Purpose driven access control	

Driven)	3. Revoke access legally (with the ability to retroactively do this) - local system only 4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems	
Confidentiality (Non-Patient Driven)	1. Online health record can only be accessed by authorized parties 2. Access control granted to specific people 3. Access control granted to specific sections of health record to specific people	
Auditability	1. Record contains audit logs 2. Supports non-repudiation 3. Provides full auditing – tracking of all changes, additions, deletions, etc. 4. Versioning	
Availability	1. Accessible by patient (stand-alone) 2. Accessible by patient in shared environment, but tool does not provide access 3. Online access to health record by both patient and physician 4. Accessible by patient and physician 24x7x365 online 5. Ability to capture information via software to upload to online health record later (when offline) 6. Provides emergency access to health professionals in case of emergencies	

Table 5.2: Evaluation Tool (version 2).

In order to work with comparable ratings in each dimension, the tool applies normalization of all ratings to a scale of 0 - 6. Hence, for a PHR to conform entirely to the requirements of all dimensions of an MU-PHR, a rating of 6 must be achieved for each of the 9 dimensions, representing a total score of 54. Although the tool recognizes that the total score achieved by a PHR (as a total of the scores achieved in all dimensions) can serve as an indicator, it does not propose this approach as such. Rather a comparative view should be taken of the results achieved by PHRs in the various dimensions with particular attention paid to the dimensions that are very weak.

5.3.4 GUIDELINES

Guidelines for each of the nine dimensions are subsequently discussed. These map to the dimensions discussed in Chapter 3, Sections 3.3.1 to 3.3.9. For each dimension, the discussion starts by restating the rating used in the evaluation tool for the particular dimension. This shows the range of options used to measure the PHRs' conformance in relation to the dimension. The discussion thereafter builds on the descriptive findings summarized in Table 5.1 in order to formulate guidelines for each dimension. Advice is given on what is typically found in practise and the consequences of a strong or weak dimension is highlighted. Ultimately a weak dimension impacts the MU of the PHR.

5.3.4.1 INTEROPERABILITY

RATING
1. Ability to import data 2. Ability to export data 3. Ability to export data into standards, like HL7 v2 or v3 CDA 4. Limited data exchange functionality between systems 5. Supports two-way data exchange with other health systems using common standards 6. Supports <u>secure</u> two-way data exchange with other health systems using common standards

Table 5.3: Interoperability Rating Chart.

Descriptive findings revealed that 3 of the 5 evaluated PHRs lacked the ability to export data into common standards. The ability to interoperate with other health systems is a core principle that health records must adhere to. Without this ability, the PHR is of limited use to the patient and acts as a stand-alone system. On the other end of the spectrum, a PHR that supports secure two-way data exchange with other health systems using common standards will immediately be used by more patients because it cultivates a stronger relationship between physician and patient (Merrill, 2009).

5.3.4.2 INTEGRITY

RATING
1. Only authorized persons have ability to alter information in health record without audit logs 2. Information can be altered, updated, appended with full audit log capability to ensure integrity 3. Recovery capability

Table 5.4: Integrity Rating Chart.

Only 1 of the 5 evaluated PHRs provided an audit trail of activities. This means that if access is granted to users of the PHR and there is no audit logging, changes will not be tracked or logged whatsoever. This means that the owners of health records cannot examine changes to their health record. With auditing enabled, the owner of the health record will be able to examine changes and take corrective action if required. Hence integrity of the health record is kept intact at all times and the record is free from corrupting influences or motives. The ideal PHR will provide recovery capability meaning that the PHR can return to what it looked like at a certain point in time before corruption occurred or possible illegal changes were made.

5.3.4.3 ACCURACY

RATING
1. Provision of easy help tools to assist in accuracy such as drop down boxes, error checking, confirmation prompts, etc. 2. Duplication avoidance – intelligence to quickly recognize and overcome duplicate entries

Table 5.5: Accuracy Rating Chart.

All PHRs implemented basic error prevention tools, but 3 of the 5 evaluated PHRs lacked advanced tools that could avoid further errors. Human beings, in any line of work, make errors. The capturing of medical information in a health record could include errors due to human mistakes. The more tools provided by a PHR that could prevent errors, the better the chance of having good quality medical data as most errors would be prevented. By implication this means that the patient will receive better healthcare, because it will be based on accurate data.

5.3.4.4 COMPLETENESS

RATING
1. Ability to easily append information in order to keep record complete 2. Contains basic personal information and doctor visits, check-ups, diagnoses, etc. of healthcare providers seen 3. Has capability to capture more advanced detail when entering doctor visits, check-ups, diagnoses, etc. 4. Contains complete health record information such as health insurance information, diet and exercise logs, etc. 5. Track medical expenses

Table 5.6: Completeness Rating Chart.

This was the strongest MU dimension. All evaluated PHRs gave the patient the ability to capture basic and some advanced information. A PHR must contain the entire health history of a patient to be complete. This includes personal information and doctors' visits, check-ups, diagnoses, as well as more general health information like diet and exercise logs, health insurance information, etc. (Health Technology

Center/The Children's Partnership, 2009). 4 of the 5 evaluated PHRs lacked advanced information, like tracking medical expenses, etc. Although the tracking of medical expenses does not relate directly to the health of the patient, this is a value added benefit that would benefit patients. Therefore, the PHR that provides support for the capturing of more advanced information would be of more meaningful use to the patient.

5.3.4.5 APOMEDIATION

RATING
1. Provides education about condition, surgery, medication, etc. 2. Health risk assessment 3. Ability to interact with patients with similar illness/condition 4. Access to healthcare practitioner 5. Bridge cultural divides by providing support in your own language

Table 5.7: Apomediation Rating Chart.

The evaluated PHRs showed an overall lack of patients’ ability to interact with other patients or doctors. All the evaluated PHRs did not provide own language support. Only 2 of the 5 evaluated PHRs provided education on medicine and conditions. The ability to enrich the patient’s health experience by providing the opportunity to talk to fellow patients and doctors, providing education on medical conditions and providing a health record in their own language, are critical to the meaningful use of the record. The more support the PHR provides to patients, the more patients will use the record to capture their details, because they can be educated about their condition and talk to fellow patients with similar ailments. The patient feels more involved and starts to value the benefits a PHR can provide.

A functionality that may attract patients to use PHRs, is the ability to do a health risk assessment. More and more people are becoming health conscious and are choosing to live healthier (Hinde, 2011). If a PHR lacks these functionalities, patients will lose their interest in the PHR as it then is a pure capturing tool without added benefits.

5.3.4.6 PRIVACY

RATING
1. Patient has the ability to grant/revoke access to his record
2. Purpose driven access control
3. Revoke access legally (with the ability to retroactively do this) - local system only
4. Revoke access legally (with the ability to retroactively do this) - all interconnected systems

Table 5.8: Privacy Rating Chart.

Only 2 of the 5 evaluated PHRs conform to all the privacy ratings defined for the privacy dimension. The remaining 3 scored badly in terms of this dimension. A PHR without the ability to grant or revoke access to it cannot be used meaningfully. Furthermore, a PHR must provide the ability to provide granular access control by means of granting and revoking rights to the health record. To revoke access legally is a challenge. This means that not only will physical access to the health record be revoked, but if the information was printed or downloaded, this information could no longer be used legally and needs to be discarded. This is more of a legal matter addressed in the policies and terms of use of the PHR, but if a PHR provides this ability, patients would be more inclined to make use of it as their privacy is of major concern (Anderson, 2010).

5.3.4.7 CONFIDENTIALITY

RATING
1. Online health record can only be accessed by authorized parties
2. Access control granted to specific people
3. Access control granted to specific sections of health record to specific people

Table 5.9: Confidentiality Rating Chart.

All of the evaluated PHRs have the ability to allow authorized access to the owner/creator. Only 2 of the 5 evaluated PHRs have the ability to grant access to specific people (doctors and caregivers). The ideal PHR must be able to control access to specific people to specific sections of a health record. This implies that information in the record can be shared with fellow patients and physicians as required and controlled by the patient.

5.3.4.8 AUDITABILITY

RATING
1. Record contains audit logs
2. Supports non-repudiation
3. Provides full auditing – tracking of all changes, additions, deletions, etc.
4. Versioning

Table 5.10: Auditability Rating Chart.

This dimension was the weakest in terms of meaningful use. Only 1 of the 5 evaluated PHRs had minimal audit logging enabled. A PHR without auditing enabled cannot support non-repudiation (one cannot deny making or changing an entry in the health record). Auditing ensures that the integrity of the PHR is kept intact and that patients and physicians can have assurance regarding the content of the PHR. An added benefit of having auditing enabled is the ability to support version control in order to maintain the integrity of the record. This means that as each change is made to a record, a previous copy (before the changes) is kept and available to look at. Auditing therefore contributes to the PHR's ability to retrospectively fix unauthorized or erroneous changes.

5.3.4.9 AVAILABILITY

RATING
1. Accessible by patient (stand-alone)
2. Accessible by patient in shared environment, but tool does not provide access
3. Online access to health record by both patient and physician
4. Accessible by patient and physician 24x7x365 online
5. Ability to capture information via software to upload to online health record later (when offline)
6. Provides emergency access to health professionals in case of emergencies

Table 5.11: Availability Rating Chart.

All evaluated PHRs were available 24x7x365 online for patients, but less than half provided access to physicians. For a health record to be used meaningfully, the physician must have access to it. For physicians to be well-informed and make a professional decision, they need to have access to the patient’s medical history.

An added benefit that PHRs can provide, is the ability to capture medical information via software when the patient is offline and uploading the information later when online again. This will eliminate the possibility that the patient will forget to capture information when they are not online.

A functionality that increases the utility of PHRs is emergency access to health professionals, but only 1 of the 5 PHRs evaluated provided emergency access. In case of an emergency, human beings would like to be able to provide as much medical information to emergency room doctors. This can be the difference between life and death but cannot be done if the patient is unconscious.

This concludes the discussion of the guidelines as a component of the framework for personal health records in online social networking. In sections 5.2 and 5.3, the concepts and components constituting the afore-mentioned framework have been discussed. In section 5.4 the discussion is consolidated by presenting a diagrammatic depiction of the concepts and components of the framework.

5.4 FRAMEWORK FOR PHRs IN ONLINE SOCIAL NETWORKING

The framework is depicted graphically in Figure 5.2. In the diagram, the concepts are positioned in the centre and the components placed in layers around the concepts.

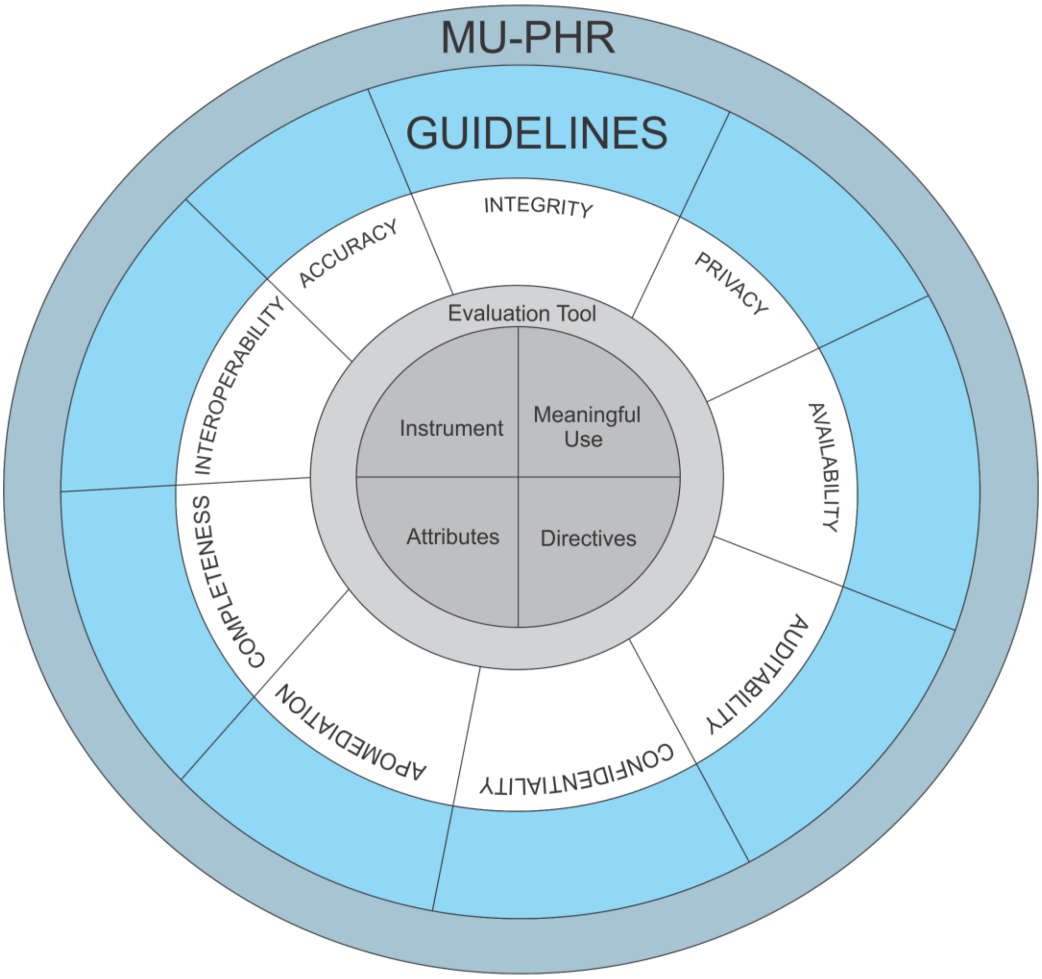

Figure 5.2: Framework for PHRs in Online Social Networking.

As shown in Figure 5.2, the framework is comprised by concepts and components. The concept of meaningful use (MU-PHR) can be achieved by using an instrument (evaluation tool) to evaluate health records in terms of their attributes (dimensions) and how they rate. The directives (guidelines) are in place to give advice on how to appropriately use the evaluation tool in order to make an informed decision when evaluating a PHR. The combination of the concepts and components constitute the framework for PHRs in online social networking as proposed in this research.

5.5 CONCLUSION

In this chapter, a framework for meaningful use of PHRs in online social networking was presented. This framework comprised of concepts and components. The relationships between the concepts and how these concepts map to the components of the framework were presented. A set of guidelines were developed for each dimension which highlighted the consequences of both strong and weak dimensions.

The outcome of this chapter was the creation of a framework for PHRs in online social networking, consisting of concepts and components. The concluding chapter, Chapter 6, will revisit the reason for this research, by looking at the problem statement and objectives. A chapter review will be done to establish whether all objectives were met during the research. Research limitations as well the potential for future research will be highlighted.

CHAPTER 6

CONCLUSION

6.1 INTRODUCTION

The adoption of information technology in healthcare is a primary facilitator of electronic medical records. EHRs have major advantages over paper-based systems and enable healthcare providers to be more competent in their daily activities. As discussed in Chapter 3, Section 3.2.2.2, one of the major driving forces behind the origin of EHRs was a reduction in medical errors. With an accurate, complete medical record, the healthcare provider has the opportunity to correctly diagnose a patient.

EHRs can address the fragmentation of medical care by combining all medical data of a patient into a single system. The lack of adoption and use of the EHR by physicians, together with the need to empower patients, led to the creation of PHRs. A similar record was required to assist patients in a comparable way that an EHR assists physicians. The emergence of online social networking aided the creation of a new generation of online PHRs. PHRs aim to empower patients with a sense of ownership of their care and to improve communication between patient and physician. PHRs have become an important modern day tool to allow patients to control and manage their health.

This research was motivated by the lack of a central, integrated and accessible repository to store the health record of an individual. An investigation was made whether PHRs in online social networking can serve as a possible solution. Therefore, the objective of this research was to propose a framework for PHRs, specifically PHRs in online social networking. This purpose was motivated by the need for meaningful use of PHRs in terms of health records that are integrated (populated with patient information from various sources), interconnected (accessible by various stakeholders) and where the patient is an important contributor to, and owner of the content of the record.

As part of conducting this research a number of objectives were addressed. The problem statement of the research and the objectives are revisited in the following section.

6.2 REVISITING THE PROBLEM STATEMENT AND OBJECTIVES

6.2.1 THE PROBLEM STATEMENT

The main problem addressed in this research is **the lack of meaningful use of personal health records in modern society.** Seeing that the focus of this research was on personal health records in online social networking, the formulation of the objectives of this research was closely coupled to PHRs in online social networking. These objectives will be revisited in Section 6.2.2 below.

6.2.2 OBJECTIVES AND SECONDARY OBJECTIVES

The core objective of this research was **to propose a framework for PHRs, specifically PHRs in online social networking**.

A number of sub-objectives needed to be accomplished to achieve this primary objective:

1. Identify the attributes of MU-PHRs in online social networking;
2. Evaluate online PHRs to measure their operation in relation to the identified attributes;
3. Propose the concepts and components of a framework for the meaningful use of PHRs in online social networking.

The achievement of these objectives is illustrated through the chapter review in Section 6.2.3 below.

6.2.3 CHAPTER REVIEW

Firstly, Chapter 1 provided the background information and overview of the research problem at hand. The research problem, research questions and objectives were formulated. A brief discussion followed on the research methods to be used and the chapter layout of the dissertation was presented.

Chapter 2 focused on the research design, research processes and the research methods the researcher adopted in order to achieve the objectives stated in Chapter 1.

In Chapter 3, a literature study was conducted on the various types of records used to store personal health information. PHRs, EHRs and PBHRs were scrutinized. Their advantages and barriers to implementation were presented. Also addressed were the current Web 2.0 technology and social networking tools for personal health information. This in-depth literature study led to the creation of nine dimensions that PHRs must adhere to, to be used meaningfully. This addressed the first of the sub–objectives, which was to identify the attributes of MU-PHRs in online social networking.

In Chapter 4, an evaluation tool was created to measure the performance of online PHRs against the dimensions of meaningful use which were reported in Chapter 3. This tool was first tested against a pilot PHR site and then refined. This revised tool was then used to evaluate five PHRs and all the findings were documented. This addressed the second sub-objective, which was to evaluate online PHRs to measure their operation in relation to the identified attributes.

The third and last sub-objective, which was to propose the concepts and components of a framework for the meaningful use of PHRs in online social networking, was addressed in Chapter 5. The concepts and components of a framework for PHR in online social networking were presented and their interrelationships were highlighted.

This chapter, Chapter 6, concludes with an overview and highlights how the objectives were addressed. The limitations of the research will be presented next, along with suggestions for future research.

6.3 RESEARCH LIMITATIONS

The case work reported in Chapter 4, used the refined evaluation tool to evaluate only free web-based PHRs selected using a model to limit the selection and then random sampling was applied. The application of the evaluation tool against a wider range of PHRs (including software-based and non-free products) wasn't addressed. Access to certain major PHR contributors, like Microsoft HealthVault, could not be obtained, because it was only available to certain countries at the time of evaluation.

The refinement of the evaluation tool and the evaluation of the five PHRs were conducted only by the researcher due to scoping reasons. This means that the results of this study may have been influenced by subjectivity on the part of the researcher.

Lastly, the main objective of the research, which was to propose a framework for PHRs in online social networking, did not include a specific target audience (or user for the framework). Therefore the framework is considered to be generic at this stage with a large inclination towards technical content. For example, the rating **purpose driven access control** (2) in the privacy dimension of the evaluation tool, may not be clear to an end-user (or non-technical person). The framework has therefore not been compiled with a non-technical audience in mind, which limits its future utility in terms of the focus of the research on patient-owned records, which is populated by non-technical users.

Following from the limitations of the research discussed in this section, some suggestions are provided for future research in section 6.4.

6.4 FUTURE RESEARCH

In order to attain descriptive data which is more generalizable in terms of the status quo of PHRs as measured against the dimensions of MU-PHR (or meaningful use), the sample of cases needs to be extended beyond free and online PHRs. An interesting project for future research could be to attain a comparative view across the various PHR types, for example stand-alone vs. online and free vs. online and at cost. This could be achieved by using the framework in its current format.

The second proposal for future research centres on the current lack of a target audience for the proposal. It is proposed that the framework could be extended and modified for a specific target audience, more particularly non-technical users. The new framework would enable these users to evaluate PHRs for selection for their own use.

Both the current framework, and a framework targeted at the end-user population, would benefit from exposure to a wider audience, to eliminate subjectivity from the researcher.

6.5 CONCLUSION

This chapter concludes this dissertation and illustrates that all of the objectives established at the beginning of this research project were accomplished. An overview of the information covered in the various chapters of this dissertation was provided as it relates to the objectives of the research project. Finally specific issues that require further investigation were mentioned in order to establish future research directions based on the output of this research.

With the demise of WorldHealthRecord and Google Health over the course of this research, there might be a feeling of discouragement and lack of belief in the abilities of PHRs. The future of the successful implementation of PHRs depends on the creation of meaningful PHRs instead of PHRs that lack in some or most of the dimensions identified in Chapter 3, Section 3.3. It is hoped that the framework for PHRs in online social networking proposed in this research, may be of benefit to provide clear guidance for the achievement of a central or integrated, accessible repository for health records through the meaningful use of PHRs.

“Success is to be measured not
so much by the position that one has
reached in life as by the obstacles
which he has overcome”

Booker T. Washington

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APPENDIX A

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Towards Characteristics of Lifelong Health Records

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Abstract. Since the beginning of this century, the view has developed that high quality health care can be delivered only when all the pertinent data about the health of a patient is available to the clinician. This viewpoint brings forth the notion of a lifelong health record. Various types of health records have emerged to serve the needs of healthcare providers and more recently, patients or consumers. The purpose of this paper is to present a set of characteristics or best practices for lifelong health records which are seen independently from implementation constraints such as technology and operational context. The characteristics, comprised by four core characteristics and nine dimensions, are synthesized from the characteristics of various types of health records used by healthcare providers and consumers. Examples are provided of evaluation measures that give an indication of compliance to the broadly stated characteristics of lifelong health records.

Keywords: Lifelong Health Record, Personal Health Record, Electronic Health Record, Electronic Medical Record

1 Introduction

For as long as healthcare has existed, there has been health information stored in some kind of record. The earliest such records were kept in the paper files of the provider, whereas currently, a combination of paper and computer media for recording health information is used. For a variety of reasons, these individual health records have become fragmented into multiple information systems and dispersed across the planet. At the same time, the information inside the records has become more complex, and is required on a regular basis by an increasing number of commercial, educational, and governmental information systems [1]. Factors like these, have led the quest to create a single lifelong health record that is easily accessible, comprehensive and complete.

A health record or medical record is a chronological written account of examination and treatment of the patient that includes their medical history and complaints, the physical findings of the physician, the results of diagnostic tests and procedures, and medications and therapeutic procedures [2]. A degree of interaction is required between both the doctor and patient for this health record to be complete. For many years, the doctor/patient relationship has been asymmetric, with the doctor traditionally seen as holding the balance of power and the patient as being dependent. There are many reasons for this and one of the most important is the asymmetry of knowledge; the doctor controlled almost all the information and often shared it sparingly.

Technology has developed along the same lines. The need for administrative and clinical e-health systems originated from healthcare providers. Electronic Medical Records (EMRs) and Electronic Health Records (EHRs) were created to address the needs of healthcare providers and to provide them with a tool that enables them to be more competent in their daily activities. Over the past years, a dramatic shift in the amount of information available to the patient has been witnessed. This shift has contributed to a noticeable increase in patient autonomy and choice in medical care. Information is more easily available due to major advances in technology. This led to the development of consumer-focused e-health systems.

The developments in healthcare provider versus consumer-directed e-health systems have resulted in two main types of electronic health records, based on the ownership of the record. These include healthcare provider-owned health records, for example, EMR/EHRs and consumer- or patient-owned health records, for example, Personal Health Records or PHRs. Hybrids between these two types are common. Operationally, each of the health record types can satisfy the need of being a truly lifelong health record to a greater or lesser extent [3].

The purpose of this paper is to present a set of characteristics or best practices for lifelong health records which are seen independently from the implementation constraints such as technology, operational context and similar. The characteristics, comprised by four core characteristics and nine dimensions, are synthesized from the characteristics of the various types of health records used by healthcare providers and consumers. Examples are provided of evaluation measures that give an indication of compliance to the broadly stated characteristics of lifelong health records.

2 The case for lifelong health records

It is apparent when viewing the medical error statistics of only the United States of America (US), that the importance of lifelong health records cannot be underestimated. The total number of medical errors and deaths in the US is equivalent to six 747 aircraft crashes daily for a year. Specific statistics in this regard include [4]:

- 7,000 patients die annually because of careless handwriting;
- 7.5 million unnecessary medical and surgical procedures are performed annually;
- More than half of the U.S. population has received unnecessary medical treatment which equates to 50,000 people per day;
- 42% of people have been directly affected by a medical mistake, procedure or drug;
- 84% of the population personally know someone who has been a victim of a medical error;
- Preventable medication mistakes affect 1.5 million patients yearly;
- Nearly 14% of doctor visits were missing test results and other documentation resulting in 44% of patients being adversely affected;
- Over 59% of patients have received delayed care or duplicate services with doctor visits; and
- 160,000 lab misidentification errors occur each year.

These figures raise serious concerns. An accurate, complete lifelong health record could reduce these medical errors by providing the healthcare provider with the opportunity to correctly diagnose a condition by viewing the *complete* “picture”.

This leads to the question of what precisely constitutes a lifelong health record. It is important to conceptualize the core intentions of the various health record types to characterize the true essence of lifelong health records, as seen from a generic point of view.

3 The True Essence of Lifelong Health Records

Various authors have defined the characteristics of the different types of health records [5],[6],[7],[8],[9],[1]. This paper synthesizes these characteristics into four core characteristics and nine associated dimensions of generic *lifelong* health records. These broadly stated core characteristics and dimensions are taken to represent the characteristics of lifelong health records. These are summarized in Table 1 and discussed thereafter.

Table 1. Characteristics of Lifelong Health Records

CHARACTERISTICS OF LIFELONG HEALTH RECORDS	
Core Characteristics	**Dimension**
Interoperability	Standardization
Comprehensiveness	Integrity Accuracy Completeness Apomediation
Legal Value	Privacy Confidentiality Auditability
Availability	Accessibility

3.1 Interoperability

Interoperability refers to the interconnectedness of multiple healthcare organizations or systems using a model that enables the full interchange of healthcare information. An overwhelming majority of people, currently, receive their care from more than one caregiver or provider. A lack of integration means that choice leads to fragmentation of the health care experience of the patient. Fragmentation, in turn, results in errors, duplication, lack of coordination, and many other problems [10] as confirmed by the statistics provided in Section 2. Health information will remain in proprietary silos without both interoperability and health information exchange.

Standardization is the main dimension of Interoperability. Standardization, in the field of health informatics, strives to achieve compatibility and interoperability between independent information systems and devices, and to reduce the duplication of effort and redundancies. Healthcare Information Technology (HIT) standards are developed, adopted, or adapted by standards development organizations, government agencies, professional associations, and care providers [11]. The creation of a lifelong health record will be unattainable without standards which facilitate proper interoperability between the different types of health records.

3.2 Comprehensiveness

Comprehensiveness can be subdivided into four dimensions, namely *Integrity*, *Accuracy*, *Completeness* and *Apomediation*.

A lifelong health record must provide information to improve care quality. The healthcare provider must trust that the information provided in the health record is correct for this to be considered true. The general principle of *Integrity* implies that no unauthorized person is able to add, remove, or change any data in the health record.

Accuracy implies that the information captured in the lifelong health record, reflects exactly the original meaning of the paper copy or diagnosis made by the healthcare provider. This maps closely to the garbage in, garbage out (GIGO) concept. Valuable output is attained from the lifelong health record when the information that is captured is both accurate and correct.

Completeness implies that all the latest relevant information about the health of the patient is contained in the health record for it to be considered lifelong. There should be no significant delay between when the data is entered into the record and when it becomes available to the different healthcare providers [3].

There has been much discussion about what data or information belongs in a lifelong health record. Advances in data storage devices and their related capacity have made this a less pressing issue. A lifelong health record should contain any information relevant to the health of the patient. Examples of information to be captured include the following [12]:

- Personal identification, including name and birth date;
- People to contact in case of emergency;
- Names, addresses, and phone numbers of the physicians, dentists, and specialists of the patient;
- Health insurance information;
- Living wills, advance directives, or medical power of attorney;
- Organ donor authorization;
- A list and dates of significant illnesses and surgical procedures;
- Current medications and dosages;
- Immunizations and their dates;
- Allergies or sensitivities to drugs or materials, such as latex;
- Important events, dates, and hereditary conditions that occur in the history of the family;
- Results from recent physical examinations;
- Opinions and notes of clinical specialists;
- Important tests results; eye and dental records;
- Correspondence between an individual and his or her healthcare provider;
- Diet and exercise logs, in addition to a list of over-the-counter (OTC) medications.

Apomediation - The term apomediation was defined by Dr. Gunther Eysenbach, a Health Policy and eHealth professor at the University of Toronto. This newly coined term is best explained by Dr. Eysenbach who states that: "Apomediation is a new scholarly socio-technological term that characterizes the process of disintermediation (intermediaries are middlemen or gatekeepers, e.g. health professionals giving relevant information to a patient, and disintermediation means to bypass them), whereby the former intermediaries are functionally replaced by apomediaries, i.e. network/group/collaborative filtering processes. The difference between an intermediary and an apomediary is that an intermediary stands in between the consumer and information/service, i.e. is absolutely necessary to get a specific information/service. In contrast, apomediation means that there are agents (people, tools) which stand by to guide a consumer to high quality information /services/experiences, without being a prerequisite to obtain that information/service in the first place" [13].

Apomediation is affected in the lifelong health record through current advances in technology. The contents of a lifelong health record can be enriched with collaborative filtering and recommender systems like bookmarking, blogs, wikis and communication tools. These networked/collaborative systems enable the creators of lifelong health records, to better capture information contained in scripts, the notes written by healthcare providers and general written information contained in the paper-based patient file. Certain terminology and abbreviations are meaningless to a non-medical person, but through having access to these blogs, wikis and other tools, it is possible to capture the record accurately and have a sense of understanding while doing so.

3.3 Legal Value

The addition of legal regulations and amendments to current regulations, with the intention of increasing security pertaining to HIT, is a norm in the modern day society [14]. This underscores the importance of the *Legal Value* core characteristic. The three main dimensions of this core characteristic are *Privacy, Confidentiality* and *Auditability*.

Privacy implies that the patient gives consent for other parties to access their personal health information. Patients can allow or deny sharing their information with other healthcare workers. Consent is either implied or explicitly given before the act of sharing. Implicit consent assumes the patient to have consented by default unless they specifically state otherwise. This is referred to as opt-out. Explicit consent or opt-in is the reverse, where the access to the information is prohibited unless the patient gives consent [9].

Confidentiality requires that proof is given that the information has not been made available or disclosed to unauthorized entities, whether persons or systems. This can be implemented in two ways. Either information is tagged with metadata about its confidentiality status or confidentiality is enforced through access rules. The use of access rules to enforce confidentiality relies on audit logs to verify that confidentiality has not been breached.

Auditability refers to the ability of the lifelong health record to be used for the following [9]:

- The monitoring of access to and possible misuse of the record, preferably in real-time;
- Review purposes to keep track of previous versions;
- Legal disputes to verify claims about what information was available and whether it was accessed.

One auditability technique is to use audit logs which document all the actions performed on the information and the users who perform those actions to enable the restoration of the past state of the data. The logging should include all events and not be restricted to the information handled. This leads to a huge amount of audit data that should be kept secure for future analyses. For best security, audit logs should be kept and stored separate from the lifelong health record.

3.4 Availability

A lifelong health record must be available when the healthcare provider needs it. It is necessary to make the system housing this lifelong record robust. Failure of the lifelong health record device is not an option, because human lives are at risk. A health record is deemed lifelong when it is continuously available. The main dimension of this characteristic is *Accessibility*.

Accessibility of the health record can be contentious. Ease of accessibility increases the risk that the record can be compromised. Alternately, a record that is too secure and cannot be accessed in case of emergency, nullifies the creation of a lifelong health record. Any access control mechanism that protects the healthcare data needs to be relatively simple and fast. These mechanisms should protect the privacy of the patient by disclosing information only in those situations when it is needed. This latter requirement requires a highly complex mechanism and is hard to combine with the first requirement of a simple mechanism. A middle way needs to be found that addresses the problem of availability versus confidentiality.

This concludes the discussion on the core characteristics and dimensions of a lifelong health record. The next section provides examples of measures towards evaluating compliance with the characteristics. The strengths and weaknesses inherent to the various health record types can be identified by applying the evaluation measures, while taking cognizance of the implementation constraints of technology, social context and similar.

For example, an EHR might be weak in the area of *apomediation* because when it was designed, the intent was not to allow for user collaboration and patient interaction. Alternately, the PHR developments by Microsoft and Google do not satisfy *integrity* and *legal value* when measured against these characteristics [3].

4 Evaluation Measures

The evaluation measures listed in Table 2 can be used to determine whether a particular health record type satisfies the dimension that the measure represents. The list is not exhaustive and can be supplemented if required. Each evaluation measure must be used to quantify the extent of achievement of the relevant dimension.

Table 2. Evaluation Measures

CHARACTERISTICS OF LIFELONG HEALTH RECORDS		
Core Characteristics	**Dimension**	**Evaluation Measures**
Interoperability	Standardization	▪ Does the record support (secure) two-way data exchange? ▪ Does the record use common standards, like XML and PDF/H? ▪ Does the record have the ability to store non-text data such as x-rays, scans and MRI's?
Comprehensiveness	Integrity	▪ Is this record in a state of entirety and free from corrupting influences or motives?
	Accuracy	▪ Is this record up-to-date? ▪ Do the data values in the record correspond to the real world objects or events? ▪ Does the data entry application provide for drop-down boxes and checklists to eliminate possible errors?
	Completeness	▪ Is this record complete, i.e. does it contain the entire health history and all health providers seen?
	Apomediation	▪ Does the online record provide education about condition, surgeries, medications, etc. of the patient and the ability to interact with patients with similar illness to achieve a more complete and correct health record? (Health Information Portal) ▪ Does the record bridge language and cultural divides by providing skills to increase the health literacy of the patient and therefore supporting the accuracy of the record?
Legal Value	Privacy	▪ Does the patient have the facility to grant and/or revoke access or consent to his online record?

	Confidentiality	▪ Can the online record be accessed by unauthorized parties? ▪ Can changes to the record be limited to authorized parties?
	Auditability	▪ Does the online record contain access logs? ▪ Does the health record support non-repudiation (one cannot deny making an entry)? ▪ Does the record provide full auditing features, like tracking of all changes, additions, deletions, etc.? ▪ Can the record be restored to a past state? ▪ Are audit logs stored separately from the lifelong health record?
Availability	Accessibility	▪ Can the online record be accessed from any place at any time by patient and health care providers? ▪ Is the system housing the health record robust? ▪ Can emergency access be enabled for health professionals? ▪ Does the capturing frontend provide an offline mode to capture and synchronize later when online?

From Table 2 it is clear that the health record by itself (i.e. the *data*) is not the only contributor to the success or failure of satisfying a particular dimension. Kaelber et.al. [15] state that three primary components of a health record can be identified, viz. *data*, *infrastructure*, and *applications*. For example, the *accuracy* of the record can be improved if the *application* supports data entry through the use of drop-down boxes and checklists. Other obvious examples include provision for educational material and sensitivity to cultural divides, which must be supported through HIT applications. Again, the role of implementation constraints, in this case technology, comes to the fore in the "performance" of the lifelong health record.

5 Conclusion

The main output of this paper comprises a set of characteristics of lifelong health records, which are expanded to include associated dimensions and examples of relevant measures. The set is not necessarily complete, but represents a first attempt at providing such a guideline for lifelong health records. The conceptual nature of the characteristics precludes the consideration of technological, legal, social or economic aspects that relate to the implementation of lifelong health records. However, when evaluating compliance with the characteristics, operational realities tend to determine the extent of achievement of particular health record types. For example, the integrity value of the patient-owned PHR is debatable, given the right of patients who are not health professionals, to update their health records.

While this paper proposes a set of characteristics of lifelong health records, no single solution exists to satisfy all of the stated requirements. As proposed in Wainer [3], it seems that the most one can do is to prioritize and accept that not all the core characteristics and associated dimensions will be achieved. The solution will be geared to the socio-technical, economic and medico-legal requirements of the operational context, while the goal will always be to improve healthcare costs, quality, and efficiency.

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