WITS BUSINESS SCHOOL

Perceived Value and Barriers to use of Personal Health Records by Patients in South Africa

Mia Erasmus

A research report submitted to the Faculty of Commerce, Law and Management, University of the Witwatersrand, in partial fulfilment of the requirements for the degree of Master of Business Administration

Johannesburg 2014

ABSTRACT

Context: Electronic PHR is a new concept in South Africa and there is little research of how individuals perceive PHR in South Africa. The study fills a gap in that there are no published PHR utilisation studies done in South Africa, likely due to the fact that there were very few PHR systems available before 2012.

Problem statement: Investigate the perceptions of personal health records amongst patients in South Africa. *First Sub-problem*: The first sub-problem is to determine the perceived value of personal health records to patients in South Africa. *Second Sub-problem:* The second sub-problem is to determine the perceived barriers to use of personal health records.

Method: The research methodology chosen is an online survey with analysis of the ordinal data using the Distribution-Fitting Algorithmic Approach. The research analysed a survey sent by email to registered individual users on the My Healthspace database.

Key findings: *Perceived value of PHR to patients*: 1) PHR had enough interactive features. 2) Respondents likely to access their PHR again. 3) Respondents want to be able to access their health records online. 4) Respondents agreed most with usefulness of access to their summary file. 5) Respondents disagreed with PHR decreasing the need to see their doctor in person. 6) Respondents wanted PHR to provide reliable health information.

Perceived barriers to use of PHR: 1) Respondents disagreed that they did not access their file online due to a lack of interest. 2) Respondents saw themselves as computer literate. 3) Respondents agreed that they have regular access to a computer or smartphone. 4) Respondents disagreed with the statement that they were worried about the security of their health information online. 5) Respondents agreed that they are happy to use an online health system as long as it is protected by a password and encryption. 6) Respondents strongly disagreed with paying a monthly fee for access to their online health records. 7) Respondents disagreed that advertisers should be able to target a specific group with adverts.

Conclusion: In conclusion the survey confirmed some of the findings in international research with regards to patient- perceptions about PHR such as respondents desire to have access to their medical information online and for PHRs to provide reliable health information. Similar to other studies it found that patients do not want to pay for access to a PHR.

It differed from the international literature in that patients disagreed with the value of PHR reducing the need to see their doctor in person. This survey also did not demonstrate a lack of trust in the privacy of information as a barrier to use of PHRs.

DECLARATION

I, Mia Erasmus, declare that this research report is my own work except as indicated in the references and acknowledgements. It is submitted in partial fulfilment of the requirements for the degree of Master of Business Administration in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in this or any other university.

Mia Erasmus

Signed at **Johannesburg**

On the 26 day of February **2014**

DEDICATION

I dedicate this research report to my husband Pierre.

ACKNOWLEDGEMENTS

I would like to thank my supervisor Anthony Stacey for his all help with the analysis of the data as well as his guidance and support throughout the research report.

I would also like to thank Terri Carmichael for her advice during the research proposal phase.

I would like to thank all the patients who completed the survey, as well as all those who apologised to me because they never found time to complete it – without their support there would have been no research.

I would like to thank My Healthspace for allowing me to email the patient database with the online survey.

I would like to thank my business partner, Dr Holly, for all the times she stood in for me during the MBA and all her support.

I would like to thank my husband for all his support during the MBA and specifically during this research report.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1: INTRODUCTION

1.1 Purpose of the study

The purpose of this research is to explore the perceived value and perceived barriers to use of personal health records amongst patients in South Africa.

1.2 Context of the study

Personal Health Records (PHR) can be defined as a collection of personal health information controlled by the patient. According to the American Health Information Management Association (AHIMA, 2012), the PHR is "an electronic, lifelong resource of health information needed by individuals to make health decisions" (K. M. Nazi et al., 2010, p. 63). The AHIMA further defines the PHR as being managed and owned by individuals with information coming both from health care providers and the individual; maintained in a secure environment and access determined by the individual. They also note that the PHR does not replace the legal record of the health provider.

PHRs used to be a paper collection of health information kept by the patient, and some people still keep their health records in print (Jones, Shipman, Plaut, & Selden, 2010). However, with the advent of electronic health records and access to medical information online there has been an increasing demand from patients to access their health information electronically (Jones, et al., 2010). "A PHR service allows a patient to create, manage, and control her personal health data in one place through the web, which has made the storage, retrieval, and sharing of the medical information more efficient." (Li, Yu, Zheng, & Ren, 2013, p. 131). For the purpose of this paper, PHR will refer to the AHIMA definition given above, specifically referring to the electronic storage and access to personal health records.

PHR's can differ in functionality but most PHR's have a common purpose to give " patients better access to their own healthcare data and enable them to be stewards of their own information" (K. M. Nazi, et al., 2010, p. 63).

In South Africa PHR as an electronic storage of health information accessible by patients is a relatively new development in the health care sector. Up to 2012 there were very few patient-accessible PHRs that were South African based. Patients who wanted to store their health information securely online could do so mainly by using international vendors such as Microsoft's Health Vault, or the now closed Google Health (Google Health, 2012). However, the largest medical aid in South Africa, Discovery Health, launched a personal health record called Health ID that gives patients access to their pathology results, the diagnosis of doctor and hospital visits and chronic medication (Discovery Health, 2012). A new South African electronic health record service launched in 2012, called My Healthspace, also functions as a personal health record in that it allows patients access to their summary record through a secure web-portal (My Health Space, 2012).

Since electronic PHR is a concept only effectively launched in 2012 in South Africa (disregarding international PHR's like Health Vault) there has been no investigation of how individuals perceive PHR in South Africa. Given the ability to access their health record, questions arise such as do South Africans access it? What is the perceived value of PHR to patients? What are the perceived barriers to use of PHR? The answers to these questions may enable PHR providers to tailor their product offering better. The Department of Health is also committed to improve the public health sector through, amongst other priorities, introducing electronic health records (Department of Health, 2011). This analysis of patient –perceptions of PHR may give guidance to the development of patient-accessible electronic health records for public sector users as well.

1.3 Problem statement

1.3.1 *Main problem*

Investigate the perceptions of personal health records amongst patients in South Africa.

1.3.2 *First Sub-problem*

The first sub-problem is to determine the perceived value of personal health records to patients in South Africa.

1.3.3 *Second Sub-problem*

The second sub-problem is to determine the perceived barriers to use of personal health record.

1.4 Significance of the study

The study fills a gap in that there are no published PHR utilisation studies done in South Africa, likely due to the fact that there were very few PHR systems available before 2012. A survey done in 2007 by US health care giant Kaiser Permanente indicated that only 12% of respondents accessed their health information online while more than half of respondents indicated they would want online access to their health records (Kaiser Permanente, 2007). Do South African users show similar low utilisation rates of PHR's that they have access to? What are the barriers to accessing PHR? A Deloitte survey in 2008 amongst health consumers indicated that 78% were interested in having online access to their medical records (Jones, et al., 2010). Does the interest to access one's PHR translate into individuals using the opportunity when available? Do patients gain value from accessing their personal health record?

The study provides guidance to electronic health record vendors into the potential value of creating patient portals to combine a PHR with medical practices' electronic

health records (EHR). Understanding the perceived value gained and the perceived barriers to use of PHR's or the patient portals of EHR systems can help vendors optimize their product offering. The Department of Health (DOH) may also benefit from the findings as they embark on designing the National Health Information System (Department of Health, 2011). Although the details of the proposed DOH information system is not yet clear the aim is to have patient information stored on the National Health Insurance card that will allow for portability of health information between service providers. While there is no mention of patient-accessibility of their health information, this study may encourage the developers of the DOH smart-card system to develop a patient portal.

Lastly, patients themselves may benefit from this and other studies around PHR indirectly as health information developers define their products better according to patient utilisation patterns.

1.5 **Delimitations of the study**

This study sent survey requests to email addresses of registered users on the database of My Healthspace (2012), an online electronic health system that combines the electronic health record of health professionals with a personal health record. Patients can access their records through a secure online patient-portal. The study was limited to the self-selecting sample of respondents to an emailed online survey. All Patient-users with valid email addresses on My Healthspace were included in the email. Health Professional users were excluded since this study is specifically looking at the patient perspectives of personal health records and not at the use of electronic health records by health professionals. My Healthspace is a fledgling combined EHR/PHR system and as such the study was limited by the number of users registered on the database. Since it is a new site there was an expectation in the growth of patient user numbers but there was a certain amount of uncertainty as to how many users would be registered over the six months following the research proposal. Furthermore, the study was limited by the response to the emailed survey. Should there have been less than a 100 responses to the emailed survey, the survey would have been

supplemented by telephonic surveys to randomly selected registered users on My Healthspace.

1.6 Definition of terms

Personal health record (PHR):

The American Health Information Management Association (AHIMA), defines PHR as "an electronic, lifelong resource of health information needed by individuals to make health decisions" (AHIMA, 2012). Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR does not replace the legal record of any provider (AHIMA, 2012; K. M. Nazi, et al., 2010).

Another definition of PHR: "a private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. The PHR may or may not include information from the electronic health record (EHR) that is maintained by the health care provider and is not synonymous with the EHR. PHR sponsors include vendors who may or may not charge a fee, health care organizations such as hospitals, health insurance companies, or employers. (Jones, et al., 2010, p. 244)

These two definitions concur on many aspects. For the purpose of this paper PHR was defined using the AHIMA definition above.

Electronic health record (EHR):

The International Organization for Standardization (ISO) defines EHR as a "repository of patient data in digital form, stored and exchanged securely, and accessible by multiple authorized users" (Hayrinen, Saranto, & Nykanen, 2008, p. 293)

Department of Health (DOH):

Refers to the National Department of Health of South Africa. References are based on publicly available information from the DOH.

Individual users/ Patient users:

In the database and the surveys this paper analysed, there is a distinction between users registered as patients and users registered as health professionals. My Healthspace uses the term patients and individuals interchangeably referring to non-health professional users that have access to the patient portal but not the health professional portal. This paper referred to patient/individual users on My Healthspace as patient users.

1.7 **Assumptions**

- The first assumption was that My Health Space would continue to grow at its current rate in registering new users. More users would result in a greater number of emails sent out with potentially a larger number of responses to the online survey.

- The second assumption was that a large enough proportion of individuals would complete the survey sent through My Healthspace to their email addresses. The survey was sent out to all patients registered on the site with valid email addresses, whether or not they have previously accessed their PHR or not.

- The third assumption was that the registered users of My Healthspace is representative enough of the general population to generalise findings to other users of PHR in South Africa. Currently the users are mainly Johannesburg suburban residents.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Personal health record keeping is referred to as a patient-centric model of electronic health information exchange (Li, et al., 2013). It aims to combine the potential benefits of information technology (IT) with a patient accessible health record. Some of the benefits of IT in health is the substantial potential to contribute to improving access to care, lowering overall costs, and streamlining operational efficiencies in the health system (Cline & Luiz, 2013). The literature around PHR is mostly dependent on literature from developed countries with a longer history of PHR and patient-accessible electronic health records. While there are a few South African studies looking at electronic health records in South Africa (Cline & Luiz, 2013; Mostert-Phipps, Pottas, & Korpela, 2010; O'Mahony, 2009; Ruxwana, Herselman, Pottas, & Ouma, 2010; Yogeswaran & Wright, 2010), none of them address personal health records or patient-accessible electronic health records. These studies all considered the implementation of electronic health records in South Africa. While they give insight to the difficulties surrounding the implementation of electronic records in both hospitals and rural practices as well as some of the benefits of electronic health records they did not investigate patient accessibility of these EHR's or personal health records in other formats.

This literature review will concentrate on literature concerning personal health records (PHR) as defined earlier in this paper by the AHIMA (AHIMA, 2012; K. M. Nazi, et al., 2010). The AHIMA definition is used as it is a comprehensive definition of PHR, in a country with arguably the most experience with PHR's, or at least the largest number of PHR vendors.

2.2 Definition of topic or background discussion.

PHR is a new and developing concept in South Africa. Looking at surveys conducted in the USA there is a strong interest from patients to have access to their medical records through patient portals or personal health records that are integrated with their electronic health record kept by health professionals (Jones, et al., 2010; Kaiser Permanente, 2007). A recent study showed that in spite of high consumer interest in PHRs and growing availability the adoption remains relatively low overall (K. Nazi, 2013). While in the US there were certain PHR's that saw greater use for example the My Health Manager from Kaiser Permanente saw 4 million out of 9 million members register to use the patient portal and one fifth of military veterans used the My HealtheVet patient access, a "national consumer survey conducted by the Markle Foundation revealed that only 10% of American adults currently use a PHR" (K. Nazi, 2013, p. 3).

Patient portals have been shown to improve patient care, especially for patients with chronic illnesses (Mooney & Boyle, 2011). Patient portals can enable better communication between patients and their health providers as well as better self-management of chronic conditions. Mostert-Phipps et al (2010) showed that there is slow adoption of electronic health records in South Africa. A survey by Frost & Sullivan in 2007 showed that only between 7% and 10% of general practitioners and specialists intended to purchase Electronic Health Records (EHRs) within the next three to five years (Mostert-Phipps, et al., 2010). The slow adoption of EHR has an impact on the adoption of personal health records since many PHR's are patient portals to electronic health records (Jones, et al., 2010). Since there are few health professionals with electronic health records the individual patient user in South Africa has not been broadly exposed to PHR until the widely marketed release of Health ID in May 2012 (Discovery Health, 2012). The lack of experience with PHR in South Africa leaves the question of how individuals will use patient portals or PHR's should they have the option available to them.

2.3 Perceived value of PHR

The first sub-problem is to determine the perceived value of personal health records to patients in South Africa. It will centre on the response from individual users with regards to their perceptions of PHR. It will look at survey responses from individuals registered on My Healthspace, both those users that access their PHR and those that have never accessed their PHR.

2.3.1 *Individual/Patient interest in accessing their health records*

With the growing adoption of electronic health records patients have increasingly been asking for access to their health records (K. Nazi, 2013; Schneider, 2008). Patients are developing an expectation to be able to access their records even if they are not sure how they will use it (Walker, Ahern, Le, & Delbanco, 2009). In a survey of American patients, participants indicated they would prefer it if their providers used electronic health records and regarded electronic records as more efficient than paper records (Kaiser Permanente, 2007).

2.3.2 *Patient expectations of PHR*

While patients show an interest in using a personal health record or accessing their EHR through a patient portal they also have high expectations of the functionality of PHR/patient portals (Weitzman, Kaci, & Mandl, 2009). Weitzman et al (2009) found that respondents had low levels of familiarity with PHRs as well as high expectations for capabilities of these systems, which may complicate their use and adoptions by patient users.

2.3.3 *What aspects of the PHR offer value to individual patient users?*

A study looking at breast cancer patients accessing their electronic records through a patient portal found that the majority of patients accessed their laboratory results and imaging results (Wiljer et al., 2010). Similarly, Burke et al (2010) found that imaging data (including photos of the hospitalised patient and photos of cardiac procedures)

was accessed significantly more than textual data by patients and their families. This pattern could inform creators of PHR/patient portals on how to adjust the PHR to make it more engaging for individuals. However, the PHR that this research report is evaluating, namely My Healthspace, does not have the capability to show imaging data, only textual reports and laboratory results. This will necessarily change the patient usage and expectation of the PHR, although the expectation is that individuals will want access to their laboratory results the most in keeping with experience in the USA.

The available sections in My Healthspace that individuals can access are the following: View my patient file; Update my personal details; View/Update my doctor's list; Update my medical history; View my doctor's notes; View my lab results.

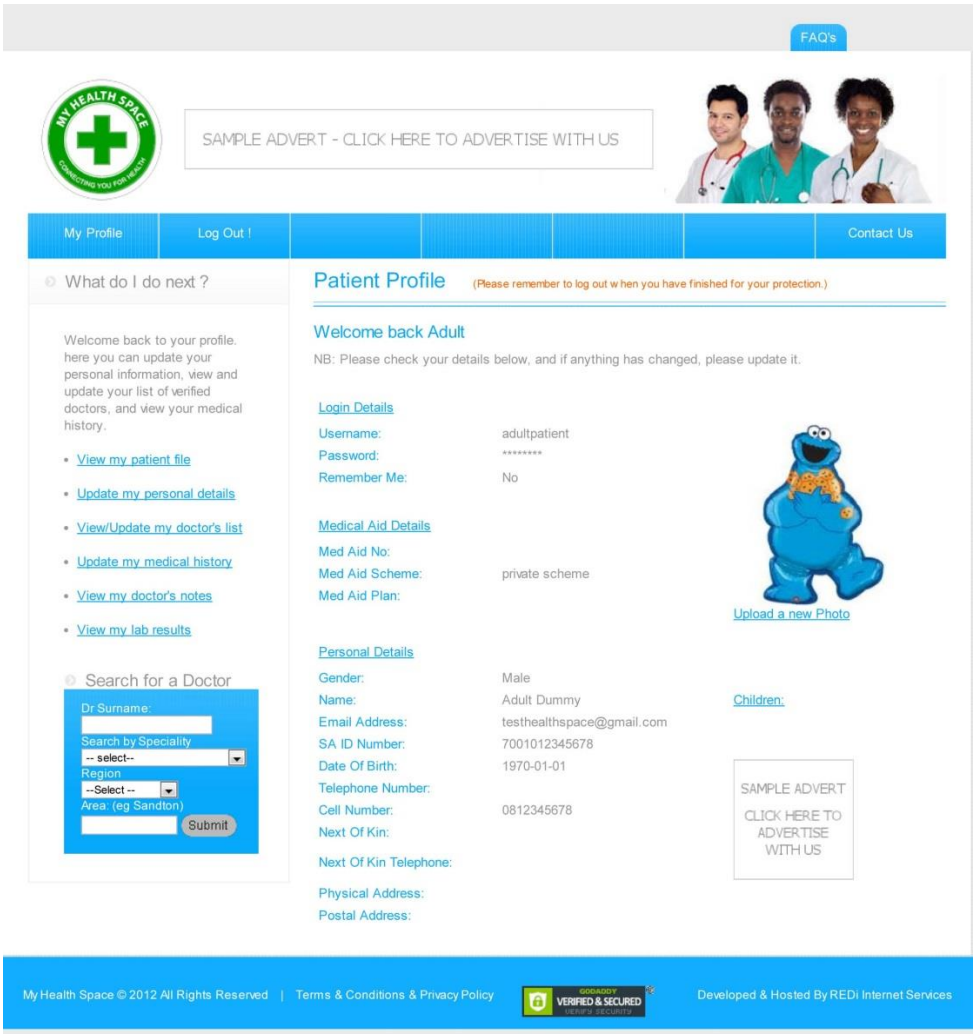

Figure 1: Patient profile on My Health Space

2.3.4 *What do patients use the information for?*

Patients reported that having access to their medical information helped them to better manage their own health (Wiljer, et al., 2010). In two studies patients mostly accessed their laboratory reports and imaging results when accessing their PHR (Burke, et al., 2010; Wiljer, et al., 2010). Patients also have an expectation to reduce in-person visits to their health practitioner through online communication with them and home-monitoring devices (Walker, et al., 2009). Patients use PHR or patient portals also as a source of medical information, depending on the accessibility of information on the patient portal (Koonce, Giuse, Beauregard, & Giuse, 2007).

2.3.5 *Research Question 1*

What is the perceived value of personal health records?

2.4 Perceived barriers to using a personal health record

While there is a growing body of literature that indicates that patients have an interest in accessing their health records online, this interest does not always translate into patient users accessing their PHR. One study showed that while more than half of respondents indicated they would want online access to their health records only 12% of respondents accessed it (Kaiser Permanente, 2007). Another study showed that while approximately 86% of US adults rated electronic access to their PHRs as important only 9% of them used the Internet for tracking PHRs (Wen, Kreps, Zhu, & Miller, 2010). The utilisation of the PHR aspect of My Healthspace at the advent of this research was that only 18 out of 654 registered patient users have accessed their PHR (3%) (My Health Space, 2012). This seems to be even less than the US studies show. The question is what are the barriers for patient users to access their PHR in South Africa?

2.4.1 *Educational level and computer literacy*

Participation in a US-based personal health record was positively correlated with education and knowledge (Fetter, 2009). This implied that vulnerable populations such as the poor and those with limited literacy may not gain the same benefit from health information technology. Patients with limited computer literacy or Internet experience tend to access their PHR less frequently than their computer literate counterparts (Wiljer, et al., 2010). However, another study found that patients with a modest level of education were just as likely to envision benefits from accessing their medical records online than higher educated respondents (Walker et al., 2011).

2.4.2 *Socio-economic status.*

In a study looking at patients with congenital cardiac disease 93 % of patients/caregivers accessed their web-based personal health record provided free of charge by the hospital they attended (Burke, et al., 2010). This high percentage uptake of the PHR was attributed amongst others to it being provided free of charge, and patients and their caregivers trained to use the system prior to discharge from the hospital.

In the USA, the primary providers of Personal Health Records are insurance companies (Crilly, Keefe, & Volpe, 2011). This is not a trend that has become an established in South Africa yet, although one large health insurer, Discovery Health, introduced PHR in South Africa in 2012 (Discovery Health, 2012). Both in the USA, and now in South Africa, these PHRs are limited to the subscribers of the health insurer. This could imply that those populations who are unable to afford health insurance may be excluded from the benefits of PHR if they are limited to subscribers of health insurance (Crilly, et al., 2011).

Patients are loathe to pay for medical information and the cost of providing medical information online is often borne by advertisements on websites (McGoldrick & O'Dell, 2000).

2.4.3 *Health status*

Patients with chronic illnesses are perhaps more likely to access their personal health record as the need for information is often higher. One study looking at patient characteristics and their perspectives around access to health records found that college students were the least likely to keep a copy of their medical records or want access to their electronic record online (Walker, et al., 2009). Although this age group is often seen as more computer-literate than older groups this finding probably reflects more on the general health of college students, with older individuals with chronic health problems more likely to want to access health records. Walker et al (2009) also found that healthy individuals expressed more concern with regards to privacy of PHR than those with chronic illnesses who valued the remote access to information more. Will this research indicate a similar pattern amongst South African users?

2.4.4 *Privacy of medical information*

Privacy of medical information is a major concern amongst patients and providers and a perceived lack of confidentiality may lead to individuals not accessing their PHR (Fetter, 2009). Box & Pottas (2010) argue that health information systems and some of their intended benefits are rendered less effective through a low level of trust between the stakeholders, including patients and health professionals. Patients are concerned that third parties may access their health information and often do not trust PHRs (IMJ Update, 2011). This distrust is seen as one of the biggest barriers to using PHRs and this survey gaged whether this is true for South Africa users as well.

2.4.5 *Research Question 2:*

What are the perceived barriers to use of PHR?

2.5 Conclusion of Literature Review

Personal health records or patient accessible electronic health records is a growing field internationally and has recently become available in South Africa. Examining the

perceptions of individuals of a patient accessible electronic health record system can give valuable insight into the South African user of personal health records. This may assist providers of PHRs to refine their product to the South African market.

PHRs have already shown their ability to improve chronic illness management. They also show potential to reduce health care costs in the long term. In a developing country such as South Africa, the benefits of PHR may improve a disparate and struggling health system.

2.5.1 ***Research Question 1:***

What is the perceived value of personal health records amongst South African patients?

2.5.2 ***Research Question 2:***

What are the perceived barriers to use of personal health records amongst patients in South Africa?

CHAPTER 3: RESEARCH METHODOLOGY

The research methodology chosen is an online survey with analysis of the ordinal data using the Distribution-Fitting Algorithmic Approach (Stacey, 2005).

The research analysed a survey sent out to registered individual users on the My Healthspace database. The survey was sent to individuals registered on the site, both those who have previously accessed their PHR and those that have not. Responses were recorded anonymously. The survey took roughly seven minutes to complete. The survey addressed the two research questions:

- What is the perceived value of personal health records?
- What are the perceived barriers to use of PHR?

The perceptions of patients were tested using a bipolar Likert-type response scale (Likert, 1932). A seven-point scale was used since bipolar rating scales with seven points yield measurement accuracy superior to that of three-, five-, and nine-point scales (Malhotra, Krosnick, & Thomas, 2009).

3.1 Research paradigm

The research paradigm used in this study is a quantitative paradigm. Since this study is looking at the database of an online electronic health record system with a patient accessible PHR, it consists of "hard" data that requires analysis to bring meaning out of it.

Quantitative research methodologies are often seen as coming out of the positivist school of thought (Green & Thorogood, 2009). Positivism implies that there is a "stable reality out there" that can be quantified and understood (Green & Thorogood, 2009, p. 13). This approach lends itself to analysing the survey answers about PHR's and finding the mean values to determine whether respondents agreed or disagreed with statements. However, while quantitative research may often view itself as value-free,

Westmarland (2001) argue that there is no such thing as value free research, even in quantitative analysis.

The assumptions of quantitative research centres around positivism which assumes that a stable reality exists whether we look for it or not and that it is the role of the researcher to reveal this reality (Bruce, Pope, & Stanistreet, 2008). This paradigm fits with descriptive statistics in that the research attempts to reveal the reality, in this case the perceived value of PHR and perceived barriers to use of PHR's.

3.2 **Research Design**

The research used the database of registered users on My Healthspace to send out emailed invitations to participate in the online survey. Emails were sent out to all patient users of the system and participants self-selected. Online surveys have the advantages of convenience and ease of access for both the respondent and the researcher (Hunter, 2012). The disadvantage of this methodology is that it relies on the response of email recipients. Should the response rate have been less than 100 online surveys completed, the research would have been supplemented with telephonic surveys to registered users on My Healthspace. There were 111 participants that responded to the online survey so in the end telephonic supplementation was not necessary.

Online surveys have seen a drop of more than 50% in response rates over the last five years (Puleston, 2011). When designing an online survey one needs to bear in mind how to improve response rates. Furthermore, poorly designed surveys can also increase undesirable respondent behaviours such as speeding, random responses and premature termination (Downes-Le Guin, Baker, Mechling, & Ruyle, 2012).

The survey was pilot tested on two users of My Healthspace known to the researcher and their feedback regarding the survey was taken into account before the survey was emailed to registered users on the site.

3.3 Population and sample

3.3.1 *Population*

The population used was the database of registered individual users on the My Healthspace database. At the point of the research proposal there were 654 individual users registered on the site. At the time of the research most of the users were registered by a GP practice in Parkview, Johannesburg, resulting in most of the users residing in suburban Johannesburg. The data was anonymised.

3.3.2 *Sample and sampling method*

The entire database population was used as recipients of the emailed survey. Not all of the registered users had valid email addresses resulting in a selection that might have excluded those users that are less computer literate. The sample was a self-selecting sample of patient/individual users on My Healthspace who responded to the emailed survey. Out of these survey responses the research looked at both users who accessed their PHR and users who did not access their PHR.

Since My Healthspace is a new system this research depended to a degree on larger numbers of users registering on the site and accessing their PHR over the months following the research proposal. It also depended on users responding to the online survey.

3.3.3 *The research instrument*

The research instrument consisted of a short online survey that took about five to ten minutes to complete. Questions were posed to those that have accessed their PHR as well as those who have not.

A seven-point Likert-type response scale was used on the majority of the questions to increase measurement accuracy (Malhotra, Krosnick, & Thomas, 2009). Open ended questions were kept to a minimum since “people do not tend to write lengthy answers to open-ended questions in mail surveys” (Kalof, Dan, & Dietz, 2008).

The questions focused on themes that emerged from the research namely:

- Patient interest in having access to their health records online (Schneider, 2008)
- PHR help patients manage their own health (Wiljer, et al., 2010)
- PHR can help to reduce visits to health professionals (Walker, et al., 2009)
- Patients access/want to access their laboratory results and imaging data (Burke, et al., 2010)
- Patients with poor computer literacy or lower educational level access their PHR less (Fetter, 2009)
- Lower socio-economic circumstances may be a barrier to accessing PHR (Crilly, et al., 2011)
- Cost of online medical information borne by advertisements on sites (McGoldrick & O'Dell, 2000)
- Patients with chronic illnesses are more likely to use a PHR than those in good health (Walker, et al., 2009)
- Privacy concerns is a barrier to using PHRs (Fetter, 2009)

Please see Appendix 1 for the Personal Health Record Survey.

3.4 Procedure for data collection

The website developer provided anonymised data on the number of individual users registered on the site as well as their email addresses. Users were invited via email to participate in an online survey. A token incentive was offered to participants who wished to be entered into a draw after completion of the survey. The prize offered in the draw was a R500 Dischem (a pharmacy chain) voucher. At the end of the survey time a winner was randomly selected and the voucher posted.

3.5 **Demographic profile of respondents**

The survey intended to reach at least 100 respondents via email or with telephonic supplementation. At the time of the survey there were 946 registered users of My Healthspace. The survey was emailed to 717 email addresses of which 608 were delivered.

Out of the 608 patient users who received an email 111 filled in the survey which is a response rate of 18.3%. A low survey response rate could be attributed to survey design and could possibly have been improved by engaging respondents more from the beginning (Puleston, 2011). A high completion rate of 97 out of 111 may indicate that those who started the survey were sufficiently interested in the topic to motivate them to complete it.

Table 1: Emailed survey response

Sent, Delivered		608	64%
Sent, Delivery Failure		109	12%
	Total	717	76%
Not Sent, no address		208	22%
Not Sent, Shared address		10	1%
Duplicate File, Not Sent		5	1%
Dummy or not relevant		6	1%
	Total	229	24%
	Overall Total	946	
Responded to email		111	18.3%
Completed survey		97	87%

Gender: 65 out of 111 respondents were female (59%). There was no assumption as to gender distribution prior to the survey.

In terms of *chronic conditions* amongst respondents the question was asked: "Do you have any chronic conditions such as Diabetes, High Blood Pressure, HIV, High Cholesterol or Asthma that require regular check-ups or regular medication?" To this question 43% of respondents said yes.

In terms of *education* the question was asked "What is your highest level of education attained?" 51% of respondents indicated that that they had a post graduate degree. This agrees with the literature that indicated that education is a predictor of electronic health record use.

3.6 Data analysis and interpretation

The data was analysed using the Distribution-Fitting Algorithmic Approach to analyse the ordinal data from the survey answers. The Distribution-Fitting Algorithmic Approach was used to analyse the results of the survey since it is found to have superior accuracy and validity to arithmetic approaches when analysing ordinal data (Stacey, 2005). Distribution-Fitting Algorithmic Approach "estimates the values of the parameters (typically means and standard deviations) of distributions of underlying attitudes (for example normal or log-normal distributions) together with the attitudinal thresholds that would result in the best fit with the observed categorical response frequencies" (Stacey, 2005, pp. 6-7). This analytic method brought meaning out of the ordinal data from the survey responses.

3.7 Limitations of the study

- The sampling depended on the number of users registered on the My Healthspace website. This was dependent on more health professionals registering on the system and registering their patients on it as individual/patient users. The initial expectation was that if the registering of new participants continued at the rate during the proposal it should have at least more than a thousand individual users registered. At the time of the survey there were 946 registered users.

- The sampling depended on the response of registered users to both the emailed online survey, and failing that the response to telephonic surveys. Poor survey responses could affect the data analysis and the usefulness of the research. In the end there were 111 responses to the emailed survey and telephonic supplementation was deemed unnecessary.

- A self-selecting sample introduces a degree of bias into the research (Kalof, et al., 2008). In this case the research findings needed to take into account that only registered users with active, valid email addresses received the invitation to participate to the online research. Since a lack of a valid email address may

indicate that the patient is less computer literate or lacks access to the internet /computer this can affect the findings regarding one of the purported barriers to using a PHR, namely lack of computer access/computer literacy. To compensate partially for this self-selecting bias the researcher requested the My Healthspace database manager to determine whether those users without valid email addresses have accessed their PHR before, by looking at the database of My Healthspace. None of the registered users without a valid email address had accessed their PHR, in spite of been given a paper printout with their username and temporary password on registration on the site. This confirms the bias that patients without regular access to the internet/ computer are excluded from PHRs.

- The self-selecting bias further comes into play in that those who are likely to respond to the invitation to participate may be persons who naturally engage more online than others. Looking at the database one can determine the number of users who access their PHR as opposed to those who don't and compare this to the survey findings. Looking at the database 264 users have accessed their patient profile out of 2990 users - 9% of the individual users on the My Healthspace database have accessed their PHR before.

- The study was limited to one set of registered users on an online electronic health record system. Individuals are mostly registered by their health professional on this site (although individuals are able to register themselves as well) which may lead to a difference of uptake of their PHR than in systems where the individual registers themselves. This may impact the generalizability of the findings of this research to electronic health records with patient portals instead of stand-alone PHR systems.

- This study was limited to users who consented to be registered on an online system and emailed patients who were registered on an online health record system, My Healthspace. This would exclude patients who are not happy to be registered on an online system and could therefore confound the finding that patient-concern about security of information was not a barrier to using PHR.

The GP practice that first used the online health system found that only about 10 out of 1200 patients in that practice refused to sign consent to be registered on an online health system due to concerns of safety of their health information online. These patients were thus excluded from the survey as they were not registered on My Healthspace.

3.8 Validity and reliability

Validity describes the extent to which a measure accurately represents the concept it claims to measure (Roberts, Priest, & Traynor, 2006).

3.8.1 *External validity*

External validity is concerned with the ability of the findings of the research to be applied to other people and other situations (Roberts, et al., 2006). This speaks to the generalizability of the findings. One of the limitations with this study is the fact that it only analyses one personal health record in South Africa which comes in the form of a patient portal of an online electronic health record system. These findings may not be applicable to stand-alone personal health record systems not linked to an electronic health record. However, there are only two South African PHR systems available, both linked to electronic health records. As there are no South African stand-alone PHR systems the external validity should not be affected too much by it. Furthermore the external validity is limited by the research design using emailed invitations limiting the study to computer literate users. The external validity is likely to be good in populations similar to the research population – i.e. suburban South Africa.

3.8.2 *Internal validity*

Internal validity is concerned with the degree of certainty that the observed effects in the study are the result of the cause rather than extraneous, confounding variables. Internal validity addresses the "reasons for the outcomes of the study, and helps to reduce other, often unanticipated, reasons for these outcomes" (Roberts, et al., 2006, p. 43)

Since this is a survey-based study the internal validity is affected by the personal views held by the researcher and the research instrument needs to be devoid of leading questions which may influence the internal validity. The website's usage and promotion of it by health professionals may impact which individual users will access their PHR or not which may be a confounding factor.

3.8.3 *Reliability*

There are different measures for reliability which in quantitative research usually includes statistical tests such as Cronbach's Alpha Coefficient. "Reliability is the proportion of variability in a measured score that is due to variability in the true score" (Roberts, et al., 2006, p. 42).

The reliability of this study depends on the repeatability of the survey findings. There may be poor repeatability since users accessing their PHR may undergo a shift over time depending on the marketing of the PHR and the expected increasing acceptability of PHR to patients over time. Survey respondents may change their opinion on the questions asked, however, looking at the answers from a specific snap shot of time, the research ought to be repeatable on that specific set of data.

Different types of error could occur that may affect the reliability. The sample is not random in this study since they are self seleting users who responded to an email invitation.

3.9 **Ethics**

Ethical approval was obtained from the University of the Witwatersrand Human Research Ethics Committee. Data was collected through an online survey of registered users that are all over the age of 18. No vulnerable populations such as children, orphans or prisoners will be studied. Respondents self-selected in response to an emailed invitation to participate in the research. Informed consent was obtained through respondents reading the participant information sheet and clicking on the link to the online survey as indication of consent. Participants were not exposed to

potential risk or harm. There was potential for a conflict of interest since the researcher is both a user of My Healthspace as well as part of the development team thereof. This conflict was managed through using questions that come from the literature instead of questions that are of interest to the My Healthspace team specifically. While the results of this study will be of value to the developers of My Healthspace, it should also be of interest to other health record keeping systems as well as the Department of Health. Questions did not relate specifically to My Healthspace but focused on the perceptions of personal health records in general.

CHAPTER 4: PRESENTATION OF RESULTS

4.1 Introduction

Results of the survey were analysed using the distribution fit algorithm (Stacey, 2005). The mean values obtained from this are used to determine whether respondents agreed or disagreed with statements and the p values to determine the significance of the results. In the analysis of the results the p-value was significant at the 5% confidence level.

4.2 Results pertaining to Research Question 1: What is the perceived value of personal health records amongst South African patients?

4.2.1 *Access to electronic health records*

The first question asked if respondents had previously accessed their patient file on My Healthspace to which 27% (28/111) replied yes. Those that replied yes were directed to questions about the electronic health record portal.

Of the respondents that accessed My Healthspace (28/111), 86% (24/28) said that this was the first time they had access to their patient information online.

A question was also put to respondents if they had previously stored/accessed their health information online on systems other than My Healthspace e.g. Discovery HealthID, Microsoft HealthVault or other proprietary electronic health record systems. In response to this question 20% said yes..

4.2.2 *Value of electronic records online*

Table 2: Value of electronic records

Question	μ	σ	t- value	p-value
I found the website useful to manage my health	0.1499	0.6153	1.2886	0.2089
I found the website trustworthy	0.0746	0.6741	0.5853	0.5634
I found it did not have enough interactive features for me	-0.6133	0.7129	-4.5524	0.0001
I am likely to access it again	0.5309	1.0387	2.7043	0.0119

In response to the questions " I found it useful to manage my health" and " I found the website trustworthy" the mean is low positive indicating that respondents agreed with it and the standard deviation (SD) is relatively close to 0 indicating that responses were grouped quite close together; the p-value however is not significant in both questions. In response to the question "I have accessed my health records on My Healthspace and found" there were two conclusions that were significant namely that respondents disagreed with the statement " It did not have enough interactive features for me" and that they agreed with the statement " I am likely to use it again".

4.2.3 *Perceived value of access to online Personal Health Records (PHR)*

Table 3: Perceived value of access to PHR

Question	μ	σ	t- value	p-value
I want to be able to access my records online	0.4732	0.9151	5.1187	0.0000
I think it may improve my health to have access to my records	0.1108	0.7973	1.3755	0.1722
I will be better able to manage my chronic health condition through access to my PHR	-0.0477	0.7100	-0.6652	0.5075

In terms of the perceived value of access to online records the only significant result was that respondents agreed strongly with wanting access to their records online. The other two questions did not have significant p –values. With regards to the question "I think it may improve my health to have access to my records" there is a low positive mean indicating most respondents agreed with the statement but the p value is not significant. With regards to the question around managing chronic health conditions patients disagreed with the statement, indicated by a negative mean and t-value. However, the p- value is not significant.

4.2.4 *Usefulness of online PHR*

"The section of my Personal Health Record (PHR) that I find/will find most useful is:"

Table 4: Usefulness of PHR

Question	μ	σ	t- value	p-value
My Laboratory Results	0.4393	0.6148	7.0732	0.0000
My X-ray Reports	0.2480	0.7483	3.2805	0.0014
My Patient File Summary with Prescriptions and Diagnoses	0.5533	0.7716	7.0978	0.0000

All three questions had significant p-values and strongly positive means in the responses. Respondents agreed strongly with the usefulness of all three aspects of PHR namely the laboratory results, x-ray results and the file summary. The strongest agreement was with the usefulness of the patient file summary.

4.2.5 *Perceived expectations of PHR*

Table 5: Perceived expectations of PHR

Question	μ	σ	t- value	p-value
Reduce the need to go and see my doctor in person	-0.5395	0.8053	-6.6322	0.0000
Give me access to reliable health information	0.2842	0.7082	3.9734	0.0001
Enable me to add home-monitoring results e.g. blood pressure/glucose readings to my patient file	-0.0253	0.7324	-0.3414	0.7335
Enable me to write the history of my current health problem on my patient file before I see the doctor	-0.1246	0.7291	-1.6924	0.0938

The first two questions in this section had significant findings. With regards to the question "Reduce the need to go and see my doctor in person" the mean is negative with a small spread or standard deviation. This shows that patients strongly disagreed with the statement and the p-value is significant for this question. The question "Give me access to reliable health information" the mean is positive with a strongly positive T value and the p value is significant indicating that patients agreed with the statement. The question "Enable me to add home-monitoring results e.g. blood pressure/glucose readings to my patient file" had a negative mean and the t-value indicating that patients disagreed with this statement but the p-value is not significant. Similarly the last question that said "Enable me to write the history of my current health problem on my patient file before I see the doctor" patients disagreed with the statement but the p- value was not significant.

4.3 Results pertaining to Research Question 2: "What are the perceived barriers to use of PHR?"

4.3.1 *Perceived barrier to using the specific PHR system My Healthspace*

Table 6: Perceived barrier to using My Healthspace

Question	μ	σ	t- value	p-value
Due to technical issues such as not knowing my username/password/website address/unable to login.	0.1542	1.2250	0.9752	0.3335
I am not interested in having access to my medical records online	-1.1968	1.1626	-7.7033	0.0000
I am interested in having access to my PHR and have the needed user information to log in but just have not gotten around to it	-0.2485	1.0354	-1.8895	0.0637

As to the question regarding access to My Healthspace the only significant result was that respondents disagreed with the statement that they have not previously accessed it because they are not interested in having access to their health information online. Interestingly on the statement that patients have not accessed their PHR "Due to technical issues such as not knowing my username/password/website address/unable to login" the mean was low positive, there is a wide standard deviation and the p-value is not significant indicating that there was a wide range of opinions with no specific answer dominating.

4.3.2 *Potential barriers to using an online Personal Health Record system:*

Table 7: Potential barriers to using online PHR

Question	μ	σ	t- value	p-value
I see myself as computer literate	1.0794	1.2727	8.3529	0.0000
I have regular access to a computer or smart phone	1.1184	0.6687	16.4729	0.0000
I am worried about the security of my information on an online health record system	-0.4586	0.9161	-4.9308	0.0000
I am worried about the security of my information with any electronic health record system	-0.4502	0.8683	-5.1065	0.0000
The benefit I gain from access to my health information online outweighs the concerns I have regarding security	-0.1238	0.7303	-1.6689	0.0984
As long as the online health system is protected by a username, password and encryption (green lock symbol) I am happy to use it	0.2080	0.7116	2.8785	0.0049

Respondents agreed with the statement that they see themselves as computer literate shown by a positive mean and t-value and a significant p-value. They also agreed that they have regular access to a smartphone. With regards to the two questions relating to online security namely “I am worried about the security of my information on an online health record system” and “I am worried about the security of my information with any electronic health record system” respondents strongly disagreed with the statements shown by a negative mean value and the p-values for both questions were significant. It also showed that if the system is password protected respondents are happy to use it.

4.3.3 *Advertising on online PHR as a barrier*

Table 8: Advertising on PHR as a barrier

Question	μ	σ	t- value	p-value
I am happy to have advertising on the site to subsidize the data-costs related to a free online health record system.	-0.1558	0.7663	-2.0024	0.0481
I would rather pay a monthly fee to have access to my health information online than have advertising on the site	-1.0548	0.7226	-14.3772	0.0000
I think it is acceptable that advertisers can target their advertising to specific groups	-0.3851	0.7445	-5.0941	0.0000

All the responses were significant and showed that respondents did not want advertising on the site but neither did they want to pay a monthly fee to have access to health information online. Respondents disagreed that advertisers should be able to target specific groups with advertising.

4.4 Summary of the results

The significant results can be summarised in the following tables:

Table 9: Perceived value of PHR to patients

The online PHR on which the survey was based had enough interactive features for respondents.
Respondents are likely to access their PHR again
Respondents want to be able to access their health records online
Respondents found the three different aspects namely access to laboratory results, access to x-ray results and access to their summary file all useful with the strongest agreement with the usefulness of access to their summary file.
Respondents disagreed with the possible PHR value of decreasing the need to see their doctor in person.
Respondents agreed with the value of PHR to provide reliable health information.

Table 10: Perceived barriers to use of PHR

Respondents disagreed strongly with the statement that they did not access their file online due to a lack of interest in their health information..
Respondents saw themselves as computer literate
Respondents agreed that they have regular access to a computer or smartphone
Respondents disagreed with the statement that they were worried about the security of their health information online
Respondents agreed that they are happy to use an online health system as long as it is protected by a password and encryption.
Respondents disagreed somewhat (low negative t value and significant only at the 5% confidence interval) that they were happy to have advertising on the site
Respondents strongly disagreed with paying a monthly fee for access to their online health records.
Respondents disagreed that advertisers should be able to target a specific group with adverts.

CHAPTER 5: DISCUSSION OF THE RESULTS

5.1 Introduction

This discussion will look at results pertaining to research questions 1 and 2 that had a significant p value. The demographic profile of the respondents will also be discussed.

5.2 Demographic profile of respondents

The average age of respondents was 40 years old, with a median of 38 years and a mode of 35 years. This is in keeping with the literature review that found that college aged adults are the least likely to want access to their medical records. While the younger age groups are seen as more computer literate they are the least likely to be interested in access to their health records (Walker, et al., 2009). The average age of 40 may reflect a compromise between age groups more likely to be computer literate and older age groups with chronic health care problems. From the literature patients with chronic health care problems are expected to show greater interest in their health care information (Walker, et al., 2009). This is reflected in the demographics of survey respondents with a high number of 43.3% of respondents agreeing that they have a chronic medical condition.

There was no assumption made with regards to gender prior to the survey. Survey respondents were predominantly female (67%). Since survey respondents were selected from patients registered by a general practitioner this may be a bias that came from the demographics of the online health system as females are more likely to visit their general practitioner than males.

The literature review showed that participation in a US-based personal health record was positively correlated with education and knowledge (Fetter, 2009). Participants in the survey reflected this with 82% having a university degree (31%) or higher (51%) and all respondents had finished school.

In terms of income distribution it was expected that most respondents would have an income reflecting suburban Johannesburg. The majority of respondents (63%) had a total family income of R40 000 per month or higher which is even higher than anticipated. This could be strongly influenced by the fact that poorer patients registered on My Healthspace often do not have valid email addresses and were therefore not included in the survey. It could also be influenced by the affluent northern suburbs that surround the practice that registered patients on My Healthspace. This is in keeping with the findings from the literature that poorer populations may be excluded from the benefits of PHR (Crilly, et al., 2011).

5.3 Discussion pertaining to the perceived value of personal health records amongst South African patients.

Results pertaining to research question 1 are discussed below.

5.3.1 *Individual/Patient interest in accessing their health records*

Respondents agreed that they want to be able to access their health records online. This finding is in keeping with the literature that shows that patients are increasingly asking for access to their health care records (Schneider, 2008).

Respondents agreed that they are likely to access their PHR again which concurs with findings in the literature (Walker, et al., 2011).

In response to the questions if patients had had previously stored/accessed their health information online on systems other than My Healthspace e.g. Discovery HealthID, or other proprietary electronic health record systems, 20% said yes. This result is higher than the utilisation rate of 12% reported by Kaiser Permanente as well as higher than the 10% of American adults who currently use PHR, as found in a national consumer survey conducted by the Markle Foundation (Kaiser Permanente, 2007; K. Nazi, 2013)

5.3.2 *Patient expectations of PHR*

There were two significant findings in this section. The first was that respondents disagreed with the statement that the PHR did not have enough interactive features. The literature review showed that while patients show an interest in using a personal health record or accessing their EHR through a patient portal they also have high expectations of the functionality of a PHR/patient portals (Weitzman, et al., 2009). However, the finding of the survey was that respondents disagreed with the statement that the PHR My Healthspace did not have enough interactive features for them. As My Healthspace has minimal interactive features and only allows patients to view their file summary, view their results and upload a personal photo one can surmise that South African patients differ from their US counterparts in terms of high expectations of a PHR. This may be influenced by the lack of available PHR systems to choose from.

The second significant finding was that respondents agreed with the statement "I am likely to use it again". This finding is in keeping with literature from the US that indicated that patients wish to be able to access their health records (K. Nazi, 2013).

5.3.3 *What aspects of the PHR offer value to individual patient users?*

Respondents found the three different aspects namely access to laboratory results, access to x-ray results and access to their summary file all useful with the strongest agreement with the usefulness of access to their summary file.

The literature review found that patients accessed their imaging data and laboratory results more often than their textual data (Burke, et al., 2010). However, this survey found the strongest positive response in terms of respondents accessing their patient file summary (textual data) rather than their laboratory results or x-ray (imaging) data results. The PHR that this research report is evaluating, namely My Healthspace, does not have the capability to show imaging data, only textual reports and laboratory results. This would have influenced the patient usage and expectation of the PHR, although the expectation was that individuals will want access to their laboratory results the most in keeping with the experience in the USA. Contrary to USA studies,

South African respondents wanted access their textual data (patient summary file) the most, more than access to laboratory results or imaging data.

5.3.4 *What do patients use the information for?*

Respondents disagreed with the possible PHR value of decreasing the need to see their doctor in person. The literature review found that patients had an expectation that PHR would reduce in-person visits to their health practitioner through online communication with them and home-monitoring devices (Walker, et al., 2009). However, the survey respondents disagreed with this proposition. This could be related to cultural differences between North American patients and South African patients in terms of online communication with health professionals.

Respondents agreed with the value of PHR to provide reliable health information. The literature review found that patients used PHR as a source of medical information (Koonce, et al., 2007). This survey found a similar expectation from respondents that they wanted a PHR to be source of reliable health information. The online PHR they accessed, My Healthspace, does not provide any health information apart from the patient's personal health records. This is therefore a finding that could help developers of this system, as well as others, tailor the product to perhaps include health information in the system.

The literature also indicated that patients use PHR's to better manage their health (Wiljer, et al., 2010). However, the survey did not have any significant responses to questions regarding PHR assisting patients to manage their health. This may pertain to the relative newness of PHR in South Africa and perhaps PHR has not been integrated into the health system yet to the degree where patients can use it to better manage their health.

5.4 Discussion pertaining to the perceived barriers to use of PHR.

In looking at potential barriers to use of PHR the discussion will focus only on results with a significant p value.

5.4.1 *Interest in accessing health information*

Respondents disagreed strongly with the statement that they did not access their file online due to a lack of interest in their health information. Technical issues such as not knowing their password or username to access their patient file on the system had a positive t value but the p value was not significant. The interesting find is that while only a small percentage had previously accessed their My Healthspace file, the respondents showed a strong interest in accessing their health information. This seemingly contradictory finding is also found in the literature with regards to patient behaviour in other countries.

The literature review showed that while approximately 86% of US adults rated electronic access to their PHRs as important only 9% of them used the Internet for tracking PHRs (Wen, et al., 2010). This survey asked respondents "Have you stored/accessed your health information online on systems other than My Healthspace e.g. Discovery HealthID, Microsoft HealthVault or other proprietary electronic health record systems?" Twenty per cent of respondents (20/101) in this survey indicated that they have accessed their health information online previously – likely the Discovery HealthID system as this is the most widely used patient-accessible EHR in South Africa. This is higher than the 9% and 12 % found in the literature review but it may be biased by a self-selecting sample of email respondents which may select for users already comfortably with technology.

5.4.2 *Educational level and computer literacy*

The vast majority of respondents saw themselves as computer literate. They also agreed that they have regular access to a computer or smartphone. However, the literature found that patients with limited computer literacy and internet experience

accessed their PHR less frequently (Wiljer, et al., 2010). As this survey was emailed to respondents it was more likely that respondents would be computer literate and have access to the internet if they responded to the online survey and hence confounded investigating computer literacy and computer access as barriers as was found in the literature review. This study can only find that computer literacy and access to computers are not barriers to access of PHR's in South African populations similar to the study population, i.e. the Northern suburbs in Johannesburg.

In the literature it was also found that educational level correlated positively with participation in a PHR (Fetter, 2009). In terms of this survey respondents were highly educated (82% of respondents had a university degree or higher) and the vast majority had access to a smart phone or computer (95/97).

Since this survey was based on a self-selecting sample of respondents that responded to an emailed invitation to participate, the survey findings are confounded by respondents already having access to email. In terms of educational level as a barrier to access of PHR, the high educational level of respondents in this study may contribute to the fact that participation in a PHR (20%) is higher in this study than other reports from the literature.

5.4.3 *Socio-economic status.*

The literature found that since many PHR systems are provided by health insurers those unable to afford health insurance may be excluded from the benefit of PHR (Crilly, et al., 2011). In this survey respondents were predominantly affluent with more than 86% of respondents having a family income of R20 000/month or higher. The finding that respondents to this emailed survey were predominantly affluent can infer that those of poorer socio-economic circumstances were excluded from participating in the survey due to a lack of access to email/internet as well as excluded from participating in PHR.

The literature also found that patients are loathe to pay for medical information and the cost of providing medical information online is often borne by advertisements on

websites (McGoldrick & O'Dell, 2000). With regards to advertising subsidizing the costs of the PHR the survey found that respondents disagreed somewhat that they were happy to have advertising on the site. However, they strongly disagreed with paying a monthly fee for access to their online health records. This finding corresponds with the literature indicating that patients are loath to pay for medical information online.

This leaves the question as to who patients feel should be funding the data costs. Looking at the results it seems that patients disagreed stronger with paying for access to their PHR than with advertising on the site and one could infer from that that perhaps advertising would be tolerated on PHR systems if it ensured that patients do not have to pay for access to PHR.

As to the question if advertisers should be able to target a specific group with adverts respondents disagreed with the statement. This would imply that any advertising on PHR websites should be generic.

5.4.4 *Health status*

The literature found that patients with chronic illnesses are more likely to want access to their PHR (Walker, et al., 2011). This survey found that while 43% of respondents noted that they have a chronic medical problem the survey did not find a significant result in terms of respondents using the PHR to better manage their health. Non-communicable disease (chronic illnesses) contributes about 35 % to the disease burden in South Africa (Chopra et al., 2009). Since this survey had a higher percentage (43%) of self-reported non-communicable disease one could infer that, similar to findings in other countries; South African patients with chronic illnesses are more likely to participate in PHR than the general population.

5.4.5 *Privacy of medical information*

The literature review showed that distrust of PHR's is one of the biggest barriers to using PHRs (Fetter, 2009). Patients are concerned that third parties may access their health information and often do not trust PHRs (IMJ Update, 2011).

This survey found surprisingly the opposite amongst respondents. Respondents disagreed with the statement that they were worried about the security of their health information online. Furthermore, respondents agreed that they are happy to use an online health system as long as it is protected by a password and encryption.

While online privacy is a thorny issue in society in general these days it seems that respondents are comfortable with their health information online as long as it is protected by security measures such as a username, password and encryption. This may indicate a future shift towards PHRs and patient-accessible EHRs.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter will summarise the findings of the research and give recommendations as to further research.

6.2 Conclusions of the study

In conclusion the survey confirmed some of the findings in international research with regards to patient- perceptions about PHR such as respondents' desire to have access to their medical information online and for PHRs to provide reliable health information. Similar to other studies it found that patients do not want to pay for access to a PHR.

It differed from the international literature in that patients disagreed with the value of PHR reducing the need to see their doctor in person. This survey also did not demonstrate a lack of trust in the privacy of information as a barrier to use of PHRs.

This study was limited by using emailed surveys in terms of identifying educational level or lack of access to a computer/internet as potential barriers to using PHR as was demonstrated in other studies since almost all respondents in this survey were well educated and had access to a computer.

6.3 Recommendations

PHR/EHR developers:

This research showed that South African patients want to have access to reliable health information available through their patient portal. PHR developers should consider this view and provide patients not only with access to their own health record but also to reliable information on general health issues.

Patients also indicated that while they are concerned about the safety of their health information online, it is not a barrier to using online PHR. This can encourage other electronic health record providers to also develop patient portals for their products, provided they use standard security measures such as password protection and encryption.

The survey found that patients were loath to pay for access to their health information. PHR developers then either have to get the health professional to bear the cost on behalf of their patients or health insurers such as Discovery would need to provide the PHR. Alternatively, advertising on PHR is an acceptable alternative to bear the data cost of PHR instead of patients paying for access to their health information.

Department of Health:

The findings of this survey suggest that patients with poorer socio-economic background are excluded from personal health records. The survey was predominantly completed by patients with higher education levels and higher income which suggests that patients of poorer socio-economic groups are less likely to have access to their PHR; in this survey one of the main reasons poorer patients could have been excluded was a lack of a functional email address to send the survey link to. The Department of Health needs to consider this and design PHR that is accessible through more widely used technology such as cell phones and not reliant on Internet and data usage as the latter is still expensive in South Africa.

The research also showed that patients want access to their health information, so the Department of Health needs to take this into consideration to design a system that allows some sort of patient access to their personal health record.

6.4 Suggestions for further research

6.4.1 *Is a lack of internet access a barrier to PHR's?*

Further research needs to be done to evaluate the lack of internet access as a barrier to patients accessing their PHR. While this research showed that a lack of internet access was not a barrier to PHR, this was an emailed online survey, which excluded patients that did not have functional email or Internet access from participating in the survey. In the South African context the majority of South Africans do not have reliable internet access due to the high cost of data and the cost of electronic devices.

While cell phones are readily available in low income countries like South Africa, internet-capable devices are less so. The high cost of data may also limit the accessibility of online PHR systems, even if the PHR's are compatible with most cell phones. A follow up study using a different survey approach such as a paper based approach would be able to evaluate this further. Surveys could either be mailed in the post to potential respondents or patients in medical facilities can be approached in person to complete a survey.

A quantitative study method is suggested for the following research question: "Is a lack of internet access and/or the cost of data a barrier to South African patients to access their personal health records?"

6.4.2 *Exploring the security concerns around online PHR /EHR systems:*

While this study did not find security concerns as a barrier to access PHR's, the minority of patients (10/1200) who opted not to register on the online EHR system due to security concerns were excluded from the survey as they were not on the database. A different study method, other than emailed surveys to patients registered on an online system, would need to be employed in order to explore security concerns among this group. It is likely that a qualitative study using in depth interviews with this group of patients may bring out the reasons for distrusting the PHR clearer than a quantitative survey method would. Sometimes understanding minority views in

qualitative studies can bring a different perspective and richness to the research. Understanding the security concerns of those patients who do not wish to register online may result in creating more secure, acceptable systems to the general population as well.

A qualitative study method such as in depth interviews is suggested for the following research question: “Why do some patients choose not to register on an online PHR system?”

6.4.3 *Perceived level of trust in funder-based PHR systems.*

Independent systems that are not provided by a health insurer may engender more trust than insurer-controlled systems could. Patient’s fear that health information available to the funder could potentially influence their health benefits may result in similar distrust levels found in other countries with regards to funder-controlled PHR. Patients sometimes do not wish for all their medical records to be under the scrutiny of the funder as they fear their benefits may be reduced or they may suffer penalties. This may sometimes lead to using the PHR of the insurer sub-optimally and some of the benefits of a shared medical history between patients and health professionals may be lost. This may form the basis of another study – comparing perceived trust levels between users of insurer- based PHRs and independent PHRs.

Either a quantitative or qualitative study method could be employed with the following research question: “Do independent PHR/EHR systems engender more trust from users than funder based PHR/EHR systems?”

6.4.4 *Funding of PHR/EHR systems*

The question around who should fund the data cost of PHR or patient-accessible EHR were left somewhat ambiguous in this study. While patients somewhat disagreed to have advertising on the site they strongly disagreed with paying for access to their health information. This leaves the question as to who should pay for patient accessible EHR or PHRs. A follow up study could investigate this more in depth –

perhaps a qualitative interview based study method could be used to investigate patients' perceptions around the cost of data.

Personal health records and patient-accessible electronic health records are becoming more widely used in South Africa. As the use of PHR grows more research questions will come to light and problems with privacy, usability and cost will likely remain important questions with various subthemes to be investigated.

REFERENCES

AHIMA. (2012). myPHR Retrieved 26/08/2012, from http://www.myphr.com/Default.aspx

Box, D., & Pottas, D. (2010). Trust--can it be controlled? *Studies In Health Technology And Informatics, 160*(Pt 1), 651-655.

Bruce, N., Pope, D., & Stanistreet, D. (2008). *Quantitative Methods for Health Research: A Practical Interactive Guide to Epidemiology and Statistics* John Wiley & Sons Ltd

Burke, R. P., Rossi, A. F., Wilner, B. R., Hannan, R. L., Zabinsky, J. A., & White, J. A. (2010). Transforming patient and family access to medical information: utilisation patterns of a patient-accessible electronic health record. *Cardiology In The Young, 20*(5), 477-484.

Chopra, M., Lawn, J. E., Sanders, D., Barron, P., Abdool Karim, S. S., Bradshaw, D., . . . Coovadia, H. (2009). Achieving the health millennium development goals for South Africa: Challenges and priorities. *The Lancet, 374*(9694), 1023-1031. doi: 10.1016/s0140-6736(09)61122-3

Cline, G., & Luiz, J. (2013). Information technology systems in public sector health facilities in developing countries: the case of South Africa. *BMC Medical Informatics And Decision Making, 13*(1), 13.

Crilly, J. F., Keefe, R. H., & Volpe, F. (2011). Use of Electronic Technologies to Promote Community and Personal Health for Individuals Unconnected to Health Care Systems. [Article]. *American Journal of Public Health, 101*(7), 1163-1167. doi: 10.2105/ajph.2010.300003

Department of Health. (2011). National Health Insurance in South Africa: Policy Paper. *Government Gazette*.

Discovery Health. (2012). Health ID Retrieved 12 August 2012, from http://www.discovery.co.za/discovery_za/web/logged_out/you_and_your_family/landing_page_content/health_id.xml

Downes-Le Guin, T., Baker, R., Mechling, J., & Ruyle, E. (2012). Myths and realities of respondent engagement in online surveys. [Article]. *International Journal of Market Research, 54*(5), 613-633. doi: 10.2501/ijmr-54-5-613-633

Fetter, M. S. (2009). Personal Health Records: Protecting Behavioral Health Consumers' Rights. *Issues in Mental Health Nursing, 30*(11), 720.

Google Health. (2012). Google Health has been discontinued as of January 2, 2012 Retrieved 07 August 2012, from http://www.google.com/intl/en_us/health/faq.html

Green, J., & Thorogood, N. (2009). *Qualitative methods for Health Research* (Second ed.): SAGE Publications Ltd.

Hayrinen, K., Saranto, K., & Nykanen, P. (2008). Definition, structure, content, use and impacts of electronic health records: A review of the research literature. *International Journal of Medical Informatics, 77*(5), 291-304.

Hunter, L. (2012). Challenging the reported disadvantages of e-questionnaires and addressing methodological issues of online data collection. (Cover story). [Article]. *Nurse Researcher, 20*(1), 11-20.

IMJ Update. (2011). Patients Don't Trust EHRs. [Article]. *Information Management Journal, 45*(3), 12-12.

Jones, D. A., Shipman, J. P., Plaut, D. A., & Selden, C. R. (2010). Characteristics of personal health records: findings of the Medical Library Association/National Library of Medicine Joint Electronic Personal Health Record Task Force. [Article]. *Journal of the Medical Library Association, 98*(3), 243-249. doi: 10.3163/1536-5050.98.3.013

Kaiser Permanente. (2007). Americans Prefer Electronic Health Records. [Article]. *Information Management Journal, 41*(4), 8-8.

Kalof, L., Dan, A., & Dietz, T. (2008). *Essentials of Social Research*: Open University Press.

Koonce, T. Y., Giuse, D. A., Beauregard, J. M., & Giuse, N. B. (2007). Toward a more informed patient: bridging health care information through an interactive communication portal. [Article]. *Journal of the Medical Library Association, 95*(1), 77-81.

Li, M., Yu, S., Zheng, Y., & Ren, K. (2013). Scalable and Secure Sharing of Personal Health Records in Cloud Computing Using Attribute-Based Encryption. *Parallel and Distributed Systems, IEEE Transactions 24*(1).

Malhotra, N., Krosnick, J. A., & Thomas, R. K. (2009). Optimal design of branching questions to measure bipolar constructs. *Public Opinion Quarterly, 73*(2), 304-324. doi: 10.1093/poq/nfp023

McGoldrick, C., & O'Dell, S. (2000). The Road to E-Health: Marketing Implications. [Article]. *Marketing Health Services, 20*(4), 32-34.

Mooney, B. L., & Boyle, A. M. (2011). Power to the patient. *Medical Economics, 88*(9), S12-S14.

Mostert-Phipps, N., Pottas, D., & Korpela, M. (2010). A socio-technical approach to continuity of care and electronic records in the South African context. *Studies In Health Technology And Informatics, 160*(Pt 1), 406-410.

My Health Space. (2012). My Health Space Retrieved 12 August 2012, from https://www.healthspace.co.za/

Nazi, K. (2013). The Personal Health Record Paradox: Health Care Professionals' Perspectives and the Information Ecology of Personal Health Record Systems in Organizational and Clinical Settings. *Journal of Medical Internet Research, 15*(4).

Nazi, K. M., Hogan, T. P., Wagner, T. H., McInnes, D. K., Smith, B. M., Haggstrom, D., . . . Weaver, F. M. (2010). Embracing a Health Services Research Perspective on Personal Health Records: Lessons Learned from the VA My HealtheVet System. *JOURNAL OF GENERAL INTERNAL MEDICINE, 25*.

O'Mahony, D. (2009). Implementing an electronic medical record system in a rural general practice. *South African Family Practice, 51*(4), 346-347.

Puleston, J. (2011). Improving online surveys. [Article]. *International Journal of Market Research, 53*(4), 557-560. doi: 10.2501/ijmr-53-4-557-562

Roberts, P., Priest, H., & Traynor, M. (2006). Reliability and validity in research. [Article]. *Nursing Standard, 20*(44), 41-45.

Ruxwana, N. L., Herselman, M. E., Pottas, D., & Ouma, S. (2010). Advocating a quality assurance model for the implementation of e-health solutions in rural South Africa. [Article]. *Health Information Management Journal, 39*(1), 36-40.

Schneider, J. M. (2008). My HealtheVet: Fighting for Health with Information. [Article]. *Journal of Consumer Health on the Internet, 12*(1), 13-21. doi: 10.1080/15398280802081410

Stacey, A. G. (2005). The reliability and validity of the item means and standard deviations of ordinal level response data. *Management Dynamics, 14*(3).

Walker, J., Ahern, D. K., Le, L. X., & Delbanco, T. (2009). Insights for Internists: "I Want the Computer to Know Who I Am".

Walker, J., Leveille, S. G., Ngo, L., Vodicka, E., Darer, J. D., Dhanireddy, S., . . . Delbanco, T. (2011). Inviting Patients to Read Their Doctors' Notes: Patients and Doctors Look Ahead Patient and Physician Surveys. *Annals of Internal Medicine, 155*(12).

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2009). *Acceptability of a Personally Controlled Health Record in a Community-Based Setting: Implications for Policy and Design*.

Wen, K.-Y., Kreps, G., Zhu, F., & Miller, S. (2010). Consumers' Perceptions About and Use of the Internet for Personal Health Records and Health Information Exchange: Analysis of the 2007 Health Information National Trends Survey. [Article]. *Journal of Medical Internet Research, 12*(4), 5-5.

Westmarland, N. (2001). The Quantitative/Qualitative Debate and Feminist Research: A Subjective View of Objectivity. *Forum: Qualitative Social Research, 2*(1), 223.

Wiljer, D., Leonard, K. J., Urowitz, S., Apatu, E., Massey, C., Quartey, N. K., & Catton, P. (2010). *The anxious wait: assessing the impact of patient accessible EHRs for breast cancer patients*.

Yogeswaran, P., & Wright, G. (2010). EHR implementation in South Africa: how do we get it right? *Studies In Health Technology And Informatics, 160*(Pt 1), 396-400.

APPENDIX A

Personal Health Record Survey

Thank you for agreeing to participate in this WITS Business School MBA research project. Your views are valuable to us. This research survey should take 10 minutes to complete.

Section 1: Personal Health Record (PHR) use

Have you accessed your patient file on My Healthspace?

- Yes
- No

Is this the first time you have had access to your patient information online?

- Yes
- No

Have you previously stored/ accessed your health information online on systems other than My Healthspace e.g. Discovery HealthID, Microsoft HealthVault or other proprietary electronic health record systems?

- Yes
- No

“Do you have any chronic conditions such as Diabetes, High Blood Pressure, HIV, High Cholesterol, and Asthma that requires regular check-ups or regular medication?”

- Yes
- No

Section 2: Perceived Value of PHR

I want to be able to access my own health records online:

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I have not accessed my health records on My Healthspace before because of technical issues such as not knowing my username/password/website address/unable to login.

- Completely Agree
- Mostly Agree
- Slightly Agree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree
- Not applicable

I have not accessed My Healthspace previously because I am not interested in having access to my medical information

- Completely Agree
- Mostly Agree
- Slightly Agree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree
- Not applicable

I have accessed my health records on My Healthspace and found the website useful to manage my health

- Completely Agree
- Mostly Agree
- Slightly Agree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree
- Not applicable

I have accessed my health records on My Healthspace and found the website trustworthy

- Completely Agree
- Mostly Agree
- Slightly Agree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree
- Not applicable

I think there is value in it for me to be able to see my patient information online:

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I use or intend to use this access to my personal health record to improve my health

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree

- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I think I am/will be better able to manage my chronic health problems through having access to see my patient information online at any time

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I want the online personal health record to help me reduce the need to go see my doctor in person

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

The section of my PHR that I find/will find most useful is to see my laboratory results

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

The section of my PHR that I find/will find most useful is to see my x-ray reports

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

The section that I find/will find most useful is to see my patient file summary where I can see previous prescriptions and diagnoses

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I want my PHR to give me access to reliable health information

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I want to be able to add home monitoring results such as blood pressure or glucose readings to my patient file

- Completely Agree
- Mostly Agree

- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I want to be able to write up the history of my current problem on the PHR before I see the doctor

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

Section 3: Perceived barriers to using PHR

I see myself as computer literate

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I have regular access to a computer or smart phone

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree

- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I am worried about the security of my medical information on an online system

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I am worried about the security of my medical information with any electronic health record system

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

The benefit I gain from having access to my health information online outweighs the concerns I have regarding security.

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

Websites/online health portals that are protected by a username, password and encryption (shown by a lock symbol in the web address) are trustworthy to store my medical information

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I am happy to have advertising on the site to subsidize the data-costs related to a free online health record system

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I would rather pay a monthly fee to have access to my medical information online than have advertising on the site

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

I think it is acceptable that advertisers can target their advertising to specific groups for example " females 20-45 years"; "males > 65 years"

- Completely Agree
- Mostly Agree
- Slightly Agree
- Neither agree nor disagree
- Slightly Disagree
- Mostly Disagree
- Completely Disagree

Section 4: Demographic information

Gender: male female

Age: _____

Educational level:

- Not finished school
- Matric certificate
- Diploma/College certificate
- University degree
- Post graduate degree

Family Income:

- <R3000 per month
- R3000-R10 000 per month
- R10 000-R20 000 per month
- R20 000 – R40 000 per month
- >R40 000 per month

If you wish to be entered for the draw to win a R500 voucher for Dischem please enter your email address (this will not be linked to your answers but will entered into the draw)_____