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Citizens and Personal Health Records – the Case of Nelson Mandela Bay

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Abstract

This paper explores citizen attitudes towards personal health records. The study was conducted in the Eastern Cape Province of South Africa. A cross-sectional design was used and structured questionnaires administered by data collectors. Most respondents (90%) believed it to be important to extremely important for their healthcare provider to have their complete medical records. Less than half of them (42%), however, believed that the healthcare provider did have their complete medical record available to them. Nevertheless, 69% do not keep a medical record as a way to address this concern. Most of them (84%) were not aware of the existence of electronic tools to capture a personal health record prior to participating in the survey. Concerns relating to the use of online PHRs were identified as privacy (58%), lack of time (27%) and a disinterest in computers (22%). It was found that the existence of a medical chronic condition is a strong predictor of keeping a medical record (albeit mostly in paper-based format).

Keywords:

Personal health records, medical records, personal health record adoption.

Introduction

Personal health records (PHRs) have been said to be beneficial in a variety of ways, through providing tools that facilitate better communication and sharing of information [1] and are widely recognized as a means of patient engagement [2]. In [3] the common elements in the definition of a PHR as provided by three leading organizations, i.e. the Markle Foundation, the American Health Information Management Association (AHIMA) in partnership with the American Medical Informatics Association (AMIA), and the Healthcare Information and Management Systems Society (HIMSS), are identified as electronic, patient-controlled, used for management of health information, and secure and private. Of these elements, the term *patient-controlled* is central to the concept of the PHR in the sense that the patient is both the owner and the main user of the PHR. This means that the PHR cannot exist and would not be utilized without the active ownership and involvement of the patient. Extant literature points to the fact that PHR adoption has been low in the USA and Taiwan [1, 3, 4]. Subsequent research, conducted in the USA (5 studies) and Taiwan (1 study), has focused on identifying factors affecting PHR adoption and use and gaining insight into citizen attitudes towards PHRs [1, 3 – 7]. At the time of conducting this study, no data could be found relating to the South African context.

In this research, the attitude of South African citizens towards maintaining personal health records and using electronic tools to capture a personal health record was explored. A cross-sectional survey was conducted in the Nelson Mandela Bay municipal area. The paper adds to the growing literature on consumers' attitudes and beliefs regarding consumer health IT and does so in an underexplored geographical region. As stated in [6], once awareness of these aspects is gained, they can be addressed in the design and implementation of PHRs.

Materials and Methods

Study design and context

The study was designed to determine a cross-sectional view of citizen attitudes towards maintaining personal health records and the use of tools to capture an electronic personal health record. The data was gathered during July and August 2012 in the Nelson Mandela Bay (NMB) municipal area, South Africa. The city of Port Elizabeth, the nearby towns of Uitenhage and Despatch, and the surrounding rural or agricultural areas comprise NMB.

Questionnaire design and administration

The data collection instrument (questionnaire) was designed to be brief to ensure viability of its completion in the envisaged context of a public area. It contained 18 questions covering demographics, health status, internet access and literacy, perceptions of the current medical record and concerns around creating an electronic medical record. Prior to administering the questionnaire it was pilot-tested with 20 adults. Based on the pilot, a question was added to determine whether the participant had heard of a personal health record (in particular referring to the tool used to capture an electronic personal health record) prior to completing the questionnaire. This was based on the high number of (pilot) participants who did not know about this concept. Additionally, the data collectors were briefed about this issue and that they needed to take enough time to clarify the concept to participants, using an explanation that was included in the questionnaire.

The questionnaire was pre-loaded on tablets and responses entered by the data collectors were immediately captured. Seven data collectors were deployed in the NMB area to collect the data. Thirty-two data collection points (supermarket stores) were selected purposively from an address list of a retail supermarket chain, to ensure coverage of the NMB area. After receiving approval from the store manager, data collectors put up a poster in the store to make citizens aware of the study and also indicated that there was a prize to be awarded to one of the participants. Participants who elected to be entered into the drawing could provide a name and contact details after completion of the questionnaire. These details were captured separately from the questionnaire data. In accordance with ethical requirements, only citizens who were at least 18 years of age and who consented to participate completed the questionnaire. A total of 467 responses were captured.

Analysis

Descriptive statistics are used to characterize respondents and show the distribution of responses using a combination of tabulated data, graphs and discussion. The association between the existence of a chronic medical condition and the keeping of a medical record is investigated using a Chi-squared test.

Limitations

This study was executed in a specific geographical region, which limits generalizability. Although a good response rate was obtained, selection bias may be present as respondents were only recruited at specific data collection points (supermarket stores). Similar to the study conducted in [1], it is conceivable that older, frail respondents and those with chronic health conditions were excluded from this study. However, given the total lack of data on South African citizens' attitudes towards personal health records, this study only purports to *explore* citizen views in the Nelson Mandela Bay municipal area. The attained sample is seen as appropriate for the exploratory nature of the study.

Results

Sample

The distribution of the respondents' demographic characteristics is shown in Table 1. It should be noted that all variables are shown as number (percentage) and percentages have been rounded to the nearest whole number.

Table 1 – Demographics of respondents (n=467)

Demographic	Number (%)
Gender	
Male	231 (49)
Female	236 (51)
Age	
18-29	201 (43)
30-39	108 (23)
40-49	73 (16)
50-59	56 (12)
60+	29 (6)
Home Language	
Afrikaans	144 (31)
English	107 (23)
Xhosa	197 (42)
Other	19 (4)
Education	
High school or less	368 (79)
Uncompleted tertiary	29 (6)
Completed tertiary	70 (15)

Females were slightly more represented (51%) than males (49%) in the sample. Most respondents were aged between 18 and 29 (43%) with a high percentage (66%) being younger than 40 years of age. The majority had completed high school or less (79%).

Health Status

Twenty-one percent of the respondents reported that they suffer from a chronic medical condition. This characteristic of the sample was analyzed to understand its significance in relation to the act of maintaining personal health records, the result of which is presented in the discussion section of this paper.

Internet access and literacy

A high percentage of respondents (70%) indicated that they do have access to the Internet for private (non-work) use (Table 2). The preferred device for accessing the Internet for private use was a PC/laptop (43%) with mobile phones also constituting a substantial preference (27%).

The number of hours that respondents spent online in a typical day for own private use was explored in order to gauge willingness to use this resource, based on the assumption that the respondent is also willing to carry the cost of Internet access associated with this use. A significant percentage (31%) of respondents typically spent between one and three hours per day online for private use.

Of further interest is the respondents' ability to navigate the Internet. Less than half of the respondents considered themselves to be 'skilled' or very skilled' at navigating the Internet to search for information (45%) and uploading and downloading information (47%). Slightly more of the respondents (52%) considered themselves to be 'skilled' or very skilled' at sending emails.

Table 2 – Access to the Internet and frequency of use

Internet access	Number (%)
Access to the Internet for private use	
None	140 (30)
Preferred device for Internet access for private use	
PC/laptop	200 (43)
Ipad/tablet	5 (1)
Cell phone/smart phone	124 (27)
No access	138 (30)
Hours (online) per day for private use	
Less than 1 hour	124 (27)
1 - 3 Hours	144 (31)
4 - 5 Hours	38 (8)
6 Hours or more	23 (5)
No access	138 (30)

Medical record availability

Not surprisingly, more than 90% of respondents indicated that it was important for their healthcare provider to have their complete medical records available and know their full medical history. Within this group, 6% felt it was 'important', 20% selected 'very important' with a majority of 70% indicating 'extremely important'.

Respondents were not confident that their medical record is in fact available to the healthcare professional, with a significant 42% indicating that the healthcare provider is not informed of their full medical history and that the complete medical record is not available.

Capturing of medical history

Most respondents (69%) do not keep or capture a medical record, either paper-based or through other means (Table 3). It should be noted that respondents could select multiple options. It is evident that of those respondents who do keep a record, it is primarily done through paper-based means (28%). Respondents who make use of electronic means to capture their medical history are a negligible few.

Table 3 – Capturing of medical history

Mode of capturing of medical record/history	Number (%)
None	324 (69)
Paper-based	133 (28)
PC/laptop (no Internet)	10 (2)
Internet-based service	7 (1)

Awareness of online Personal Health Records

The explanation of an online PHR that was provided to participants was that it is typically an online tool that allows an individual to create and manage a summary of all of his health information in one convenient place and that it contains information on past and current illnesses, allergies, immunizations, medication, procedures, and test results.

Participants did not find this a difficult concept to grasp, however, most of them (84%) simply were not aware of the existence of such tools prior to participating in the survey.

Concerns about using a PHR

Three concerns relating to the use of a PHR to capture and store a medical record were explored, viz. the privacy of personal health information (PHI), the time it takes to capture the data and in general, a dislike of computers and the Internet. This is depicted in Figure 1.

The majority of respondents (58%) 'agreed' or 'strongly agreed' that they would be concerned about the privacy of their PHI when using a PHR. This concern is also highlighted in [1] and [6]. A smaller percentage (27%) felt that it would take up too much time to use a PHR. Twenty-two percent indicated a general dislike in computers and the Internet leading to a disinterest in the use of PHRs.

Discussion

This study found that most citizens in the Nelson Mandela Bay municipal area (84%) were not aware of PHRs. Therefore this is potentially a significant barrier to the adoption and use of online PHRs. This finding concurs with [6] where awareness is noted as a barrier to PHR adoption since "many consumers have never heard of a PHR". Other potential barriers identified in the NMB study include a dislike of computers and the Internet, a lack of time and concerns about the privacy of PHI.

Although a substantial percentage (30%) of citizens did not have access to the Internet at all, a large percentage (70%) indicated that they have access for private purposes. The percentage of citizens in the sample who access the Internet using a mobile phone (27%) holds promise for the emerging mobile PHR (mPHR) market, which is fueled by the availability of mPHR applications on all major mobile marketplaces [8].

Internet literacy is a factor to be considered, with only approximately half of respondents considering themselves as skilled or very skilled in browsing, uploading and downloading of information and sending of emails.

In [1], it is concluded that "the 'digital divide' between those with varying levels of Internet access and experience may hinder widespread adoption and use of PHRs". The factors of Internet access and Internet literacy can therefore not be discounted as barriers to adoption and use of PHRs.

A Chi-squared test was performed to determine the significance of the relationship between the existence of a chronic medical condition and the response to whether citizens keep or capture a medical record (Table 4).

Table 4 – Chronic medical condition influencing keeping of medical record

Chronic medical condition	Do not keep medical record	Keep medical record
No	282	89
Row %	76,01%	23,99%
Yes	42	54
Row %	43,75%	56,25%
Totals	**324**	**143**

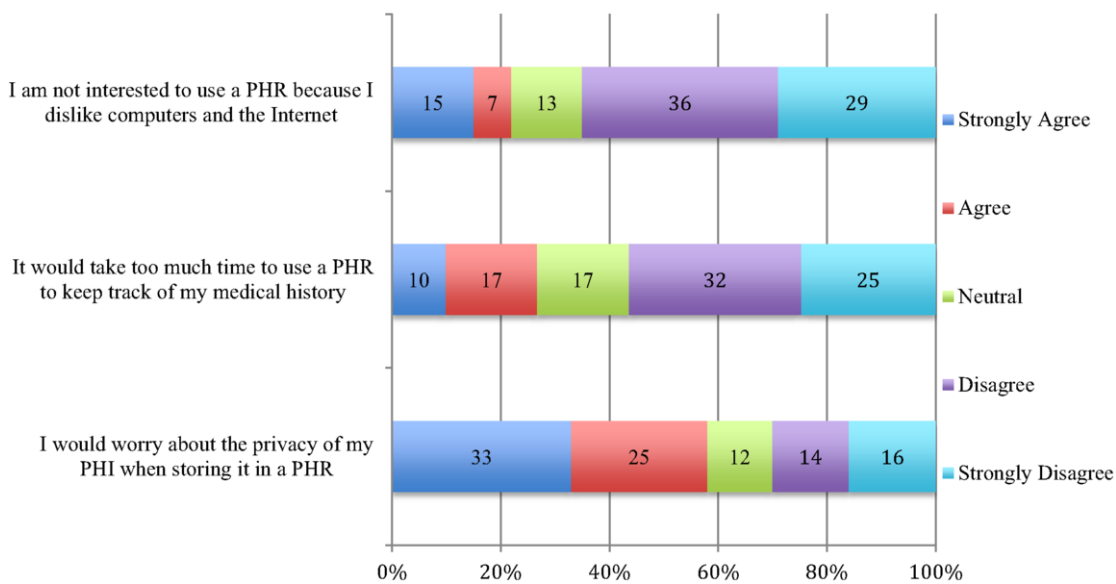

Figure 1 - Concerns relating to the use of a PHR

The test yielded a statistically significant result at the 5% level (Chi-square=37.36; df=1; p=0.00000). From Table 4 it can be seen that it was more likely (76.01%) for citizens without a chronic medical condition not to keep a medical record than those with a chronic medical condition (43.75%). Conversely those without a chronic medical condition were less likely (23.99%) to keep a medical record than those with a chronic medical condition (56.25%). The statistical significance of the result is of medium practical significance (Cramer's V=0.28).

In [2] the frequent monitoring required by chronic conditions and the related benefits to patients with chronic conditions using PHR systems are mentioned. The results of the study reported in this paper show that citizens with a chronic medical condition already demonstrate a preference for keeping medical records, which means that this section of the population might show increased interest in adopting electronic tools to capture their records. This aspect requires further research.

Conclusion

This study provides baseline information about citizen attitudes towards maintaining personal health records and the use of tools to capture an electronic personal health record in the Nelson Mandela Bay municipal area in the Eastern Cape, South Africa.

The lack of awareness of PHRs is considered to be an important contributor to slow adoption and usage of PHRs. Other barriers include a dislike in computers and the Internet, a lack of time, access to the Internet, Internet literacy (or illiteracy) and concerns about the privacy of PHI. A chi-squared test showed a strong (positive) relationship between the existence of a chronic medical condition and the keeping of medical records (even though in paper-based format).

While recognizing that there may be other predictors of PHR adoption and use, it is argued that the waning adoption and use of this technology might point to the fact that the "PHR for all" approach is not necessarily ideal. Further research is required to establish citizen needs in regard to PHRs and to ensure that they are addressed in the design and implementation of PHRs.

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