ASSESSING THE SUITABILITY OF AN INDIVIDUALIZED ELECTRONIC HEALTH RECORD MANAGEMENT SYSTEM (IEHRMS) FOR CARDIOVASCULAR CARE SETTING: A PILOT STUDY RACECOURSE HOSPITAL, ELDORET, KENYA

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ABSTRACT

This paper reports on a research study that aims to obtain feedback on personalized electronic health record management systems for Cardiovascular Care Setting from two user perspectives (patients and medical professionals), focusing on patient empowerment, decision aid, and the perceived benefits. The study on the IEHRMS was conducted as from 18th July 2016. The methodological approach followed a user-participatory design with a total number of 18 participants (10 patients with CVD and 8 medical professionals (MPs). Both qualitative and quantitative research methods were employed. 25 people were initially recruited all residing in Eldoret. Study participants were interviewed face-to-face with semi-structured, written interviews. Patients indicated a high degree of perceived support by the IEHRMS. In total, 7 of patients and 8 of MPs would use the IEHRMS if access were provided. The primary benefits participants perceived were instant sharing of medical reports via an email and SMS, empowerment in health-related decisions and comprehensive insights into the progress of the disease. Major recommendations for improving the IEHRMS encompassed: the implementation of a chat room for patients and medics, contact list of medical specialists within particular locality as well as the overall design. This paper raises imperative insights that are significant to healthcare professionals as well as policy makers. It provides a clear perception on an interactive and needs-oriented web portal, striving towards empowerment and assistance in decision making for patients as well as medical practitioner within the sphere of caring for patients with CVD. The acceptance and willingness to use the IEHRMS emphasizes the potential of interactive electronic health records management systems in a developing country like Kenya.

Key Words: *individualized electronic health record management system (IEHRMS), cardiovascular care setting, racecourse hospital, Eldoret*

INTRODUCTION

Cardiovascular disease (CVD) is the leading cause of death with 17 million deaths worldwide from a total of 57 million annually (WHO, 2011) and 80 percent of all CVD deaths now occur in low and middle income countries (LMIC). While the CVD epidemic is receding in high income countries, CVD mortality rates tend to be higher in many LMICs (up to 300-600 CVD deaths per 100,000 population) than in Western countries and the burden is expected to increase further (WHO, 2011). Due to its assiduous nature and need for ongoing monitoring and treatment, CVD account for a dominant proportion of healthcare resource spending throughout the world and as such have been described as the healthcare challenge of the 21st century (Teviu, et al., 2012) and is reported to reduce economic growth of a country by 0.5% with every 10% increase in the rate of chronic disease (Norman & Binka, 2011). The management of chronic CVD is associated with increasing healthcare costs (Yusif & Soar, 2014). The increasing prevalence of CVD, coupled

with a struggling overburdened healthcare system (Biggam, 2011) requires management solutions like e-health services that can produce positive results both clinically and economically

The need for care in CVD starts early and increases with alongside the severity of the disease, affecting multiple dimensions such as support for household, financial and social activities, up to nearly constant supervision at severe stages. Therefore, services that target the aid and assistance for patients are essential. The internet and mobile industry continues to scale rapidly, with a total of 3.6 billion unique mobile subscribers as at the end of 2014 (GSMA Intelligence, 2015.) Half of the world's population now has a mobile subscription—up from just one in five 10 years ago. Technology advances has seen the use of mobile devices increase significantly in the recent years in African countries and the world at large. The introduction of mobile computing devices such as mobile phones, smartphones, tablets and personal digital assistants (PDAs), has greatly impacted many fields (Lewis, Synowiec, Lagomarsino, & Schweitzer, 2012).

These devices have found their way into the health sector. Studies affirm that smartphones and other high-technology gadgets appear to be increasingly used by healthcare workers and accepted devices in the different healthcare fields (Mahadeen)

In the context of growing middle class societies, studies have highlighted the potential of e-health services like electronic health records, due to affordability and available of internet access and the benefits of flexibility, facilitated accessibility and personalized services (Sandra Schaller, 2013). However, a sustainable implementation of e-Health technologies in general requires including all the stakeholders that are involved. A lack of user involvement often results in usability problems and higher attrition rates (Griebel &Sabine, 2011) Thus, frameworks for e-Health technologies emphasize the importance of continuous and systematic evaluations of e-Health services from the user's perspective early in the development process (Elmar et al., 2012). This pilot study aims to involve all users early in the software development process to enable a user-friendly and suitable design. The overall aim of the study is to provide individualized, personal health information accompanied with an improvement in the quality and acceptance of electronic healthcare services. Interactive Electronic Health Record support services for patients have yet to become widely used in real-life healthcare situations in the CVD care setting.

Currently, the majority of internet-based, supportive interventions for caregivers in CVD are websites or specific educational programs. Minorities of evaluated and published studies were similar to the IEHRMS with respect to a combination of information support and interaction functionalities for instance Caregiver Stress Check System offered Alzheimer's Association aim to help find answers, local resources and support, however do not allow sharing of reports by an email or by SMS. Locally most electronic health records are intranet based and do not have functionality of sharing patient's health records. DHIS2 which is a tool for collection, validation, analysis, and presentation of aggregate and patient-based statistical data do not allow easy sharing of specific patient data. In overall comparison, the IEHRMS differed from previous EHR

solutions by (1) Instant sharing of patient data (2) Tailored support services according to user-specific data in treatment (3) a focus on patient empowerment and decision aid, (4) addressing the role of medics.

The purpose of our pilot study is to obtain feedback form medical experts and also from patients on the IEHRMS for patients early in the IEHRMS development process, focusing on empowerment, decision aid, perceived benefits, most promising functionalities as well as recommendations for further improvement.

SMS Technology

Short Message Service is a communication method in which one person sends a short text message, or simply a text, to another via his mobile device. SMS is a fast, low cost and popular mode of communication found on all mobile phones across all technologies, including GSM, CDMA and 3G. SMS is a short message that can be sent from a phone to phone, and pushed to the recipient's device when sent. Some key advantages of SMS include short messages of 160 characters, good interoperability between networks and technologies (GSM and CDMA); it is low cost and free for the receiver. (Talariax)

SMS messages have a number of characteristics that make them very appropriate for use in a healthcare setting including: direct patient communication, privacy, confidentiality, swift delivery of messages and receipt of responses, convenience for health providers and patients. SMS messaging technology also allows the dispatching of substantial numbers of messages simultaneously, so reducing labor expenditure. (Koshy, Car, & Majeed, 2008)

Web Portal

A Web portal is a specially designed website that often serves as the single point of access for information. It can also be considered a library of personalized and categorized content. A Web portal helps in search navigation, personalization, notification and information integration, and often provides features and application integration which makes them very suitable for use in healthcare setting. As the healthcare industry works toward Stage 2 meaningful use attestation, web portals are becoming a "must-have" for improving patient engagement and facilitating meaningful patient-provider communication as well. (Nerroth &Dan 2014

Cardiovascular Disease (CVD)

Cardiovascular Disease (CVD) includes dysfunctional conditions of the heart and of the blood vessel system (arteries, veins, and capillaries) that among other functions supply oxygen to all body tissues and organs, including vital life-sustaining areas like the brain and the heart itself (Oyeyemi & Wynn, 2014).

Cardiovascular disease now ranks as the world's top cause of death, causing one third of all deaths globally. Approximately 17 million people die each year of CVD worldwide and this

number is expected to increase up to 24 million by 2030. CVD is the leading cause of death in low income countries (Marquez and Farrington, 2013) and over the next ten years SSA is projected to see the largest increase in death rates from CVD, cancer, and other chronic diseases (Aikins, 2010 The global epidemic of CVD is not only rising, but also shifting from developed to developing countries, partly as a result of poor disease management, increasing life expectancy and lifestyle changes. (The University of Texas School of Public Health, 2012)

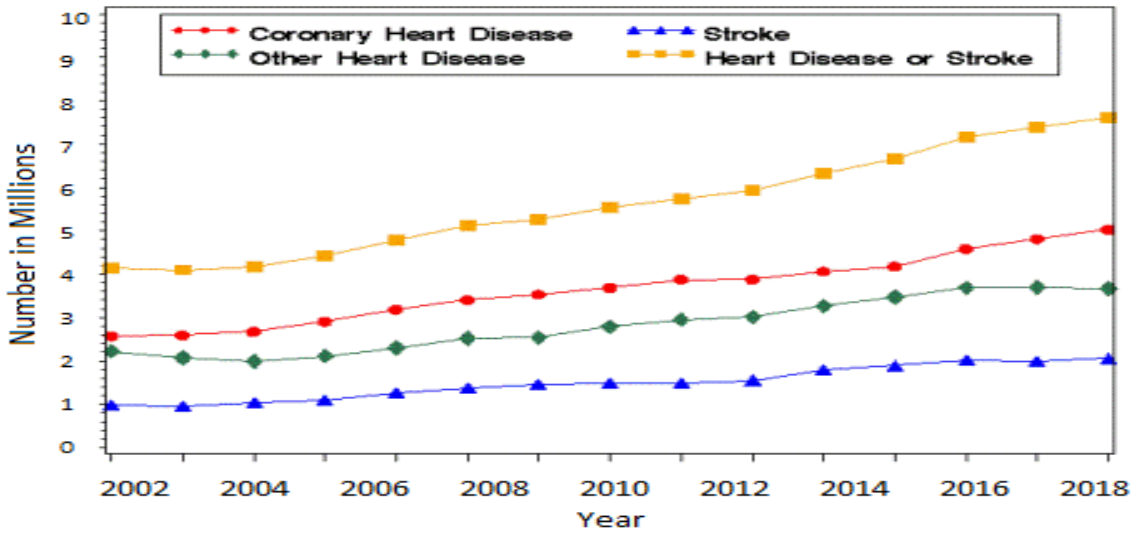


Figure 1: Global Annual Death from Cardiovascular Diseases. Estimation by Centers for Disease Control and Prevention (CDC)

PROBLEM STATEMENT

The use of Information and Communication Technology (ICT) and its associated facilities have grown rapidly in the provision and delivery of healthcare services over the last few decades. Paper-based records are fast giving way to electronic health records (EHR) in most developed countries and crawling gradually into the developing countries. Currently EHR are designed to alleviate the limitations associated with the paper record system and help in the promotion of patient disease self-management (Soleng, & Wynn, 2011). The use of IEHRMS by cardiovascular disease patients has the potential to enhance the patient experience while improving clinical outcomes and minimally impacting resource utilization. The present study developed a user-sensitive and electronic health record management system for CVD care: (IEHRMS). It aims to provide targeted and personalized support for patients with CVD.

GENERAL OBJECTIVE

The objective of the pilot study was to assess impact and usefulness of IEHRMS from two user perspectives (patients and medical professionals), focusing on patient empowerment, decision aid, and the perceived benefits in the use of the system.

SPECIFIC OBJECTIVES

1. To develop a platform for individualized personal healthcare services for CVD case.
2. To assess the usefulness of the use of IEHRMS in the Cardiovascular Patient care at Racecourse Hospital in Eldoret town, Uasin Gishu County.
3. To assess the effect on the use of IIEHRMS in the Cardiovascular Patient care setting at Racecourse Hospital in Eldoret town, Uasin Gishu County.

LITERATURE REVIEW

Kenya published her first National e-Health strategy (2011-2017) in April 2011; the rationale was to exploit the expanding ICT in the country for health care. The strategy has five Areas of Implementation: Telemedicine; Health Information Systems; Information for Citizens; M-Health and E- Learning. The Ministry of Health (MOH), the World Bank Group through its Health in Africa Initiative (JiA) and Kenya Investment Climate Program partners prioritized the Health Information pillar and adopted the notion of enterprise architecture as the implementation framework for the strategy. The Electronic Health Record (EHR) is a key component of medical informatics that is increasingly being utilized in industrialized nations to improve healthcare. Although African nations are still lagging behind developed countries in the availability and use of EHR (Kumar 2012) there has been an appreciable increase in the availability and utilization of EHRs in Africa over the last decade. This increase has been driven by collaboration between African institutions and international collaborators mostly in the area of HIV/AIDS treatment and care (Nucita 2010)

The influx of EHRs in Kenya has been facilitated by several factors, key factors being the increased availability of affordable phones, personal computers and increased access to internet. Internet access in Kenya has grown tremendously stands at 31.9 million, making Kenya the 21st most connected population in the world (ITU, 2014). In 2015, 58% of all phones that were sold in the country, estimated 1.8m devices, were smartphones. This represents substantial year on year growth of 112%, compared to just a 3.6% increase in the feature phone category

The EHR Landscape

Successful e-health projects have demonstrated that information and communication technologies facilitate the improvement and efficiency of the quality of health care. For example, the home care system for Type 1 diabetes clients was discussed by Bellazzi et al. (2009) with the goal of: (i) providing clients with an effective insulin treatment, (ii) obtaining an appropriate level of continuous and intensive care at home through tele-monitoring and tele-consultation services, (iii) allowing for cost-effective monitoring, (iv) supporting continuing education of clients through tele-consultation (Bellazzi, Montani, Riva, and Stefanelli, 2011). The Diabetes Education and Telemedicine (IDEATel) project was recently conducted to evaluate the feasibility, acceptability, effectiveness, and cost-effectiveness of telemedicine. The focal

point of this intervention was the home telemedicine unit, which provided four functions: (i) synchronous video-conferencing over standard telephone lines, (ii) electronic transmission for glucose and blood pressure readings, (iii) secure Web-based messaging and clinical data review, and (iv) access to Web-based educational materials (Starren et al. 2012).

According to Ball, Smith, and Bakalar (2012), providing patients with a "dashboard" to manage chronic health conditions allows the patient to have more control and the physician to provide an early intervention. The dashboard can alert the patient to the need for a test, and it can also alert the physician when a blood level (such as glucose) is abnormal. Norris et al. (2012) confirmed that a disease management program can improve glycemic control, including screenings for foot lesions and peripheral neuropathy, in diabetic patients.

An adjustment in medication can prevent future complications and even obviate the need for hospitalization. In addition, it is possible that if patients know they are being observed and monitored by their provider(s) they will be more motivated to adhere to the guidelines provided to them for health maintenance (Green, 2012). Patients may even see their providers as "guardian angels" who are looking over their shoulder (Ralston, Revere, Robins, & Goldberg, 2004). At the very least, the patients can provide data which the provider(s) will use to track and trend various health markers, such as weight and blood pressure.

Heisler et al. (2012) focused on a common chronic condition, diabetes mellitus, and found that the most significant predictor of patient adherence to treatment recommendations (self-management) was provider communication. Their survey asked the participants about the information provided by their physician such as test results, treatment alternatives, and medication side effects. In another investigation of information exchange, Maly et al. (2009) went a step further and included medical record sharing between the physician and patient. Patients were provided a copy of the most recent progress note (a typed document summarizing the office visit) along with a glossary of terms to aid in their interpretation. Medical record sharing did not significantly increase office visit lengths, but did improve the quality of the visit. This was felt to be due to improved patient interest in their medical records and overall patient satisfaction.

Tang and Lansky (2015) agree with the use of a glossary, stating that in addition to access to the health record, patients need tools to aid them in interpreting and understanding the contents of the record. This will improve "health literacy," identified by Lober et al. (2009) as understanding the content of the EHR, including diseases, medications, and terminology. The Joint Commission on National Health Education Standards expands on the need to understand by including competency to use the information to improve health (Nielsen-Bohlman, Panzer, & Kindig, 2014).

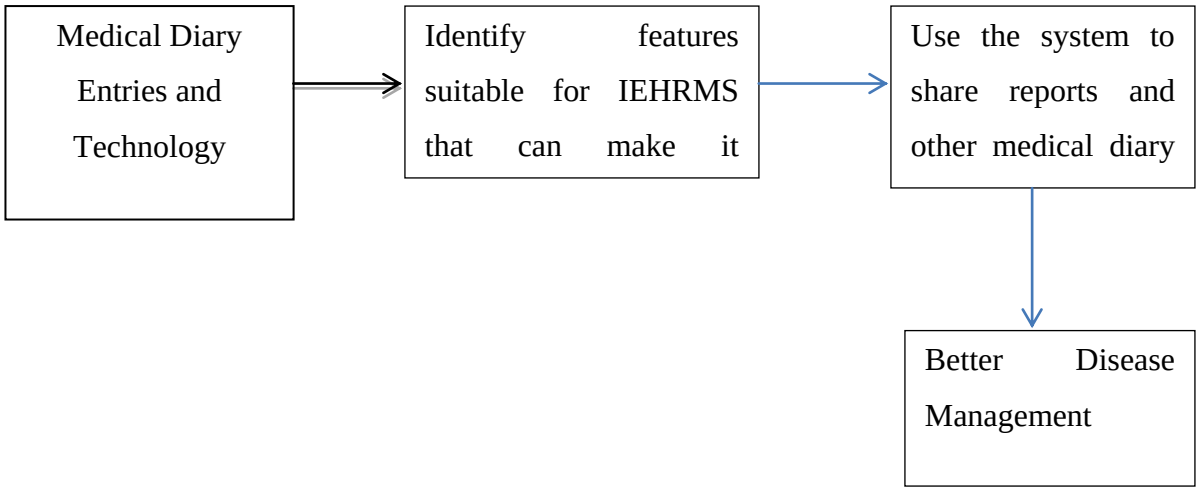
Tang and Newcomb (2010) also found improved satisfaction when patients are provided an after-visit summary of an encounter with a physician. This computer generated summary

included vital signs, medication allergies, current medications, laboratory tests ordered, instructions, and educational materials. Ralston et al (2013) cautioned against sharing too much information, stating that patients may not find access to a full medical record as helpful as some basic information (test results, medication refills, and care plans). Patients appreciate a summary in printed format and feel it shows that the physicians are organized and professional. Graphs of blood pressure levels over several visits for hypertensive patients can be considered a "motivator" by some of the patients to continue following therapeutic regimens. Tailoring information to a patient's condition not only personalizes and improves communication but also allows the patient to see the value of the numbers in relation to his or her own health status. Using "plain language" at a level the patient can understand enhances understanding and communication (The Joint Commission, 2009). Providers are encouraged to take time to tell patients the action steps that are needed and use multiple forms of communication to improve understanding (Oates & Paasche-Orlow, 2009).

CONCEPTUAL MODEL

One of the conceptual models specifically about a personlised health records managaengent system identified was developed by (Osorio et al., 2014) figure 2. It proposes system enviroment that is potentially useful to consider within this study's framework, aimed towards Patient empowerment and decision aid .The variables identified in the above framework which are key in the implementation of IIEHRMS include time delivery , motivation of the patients and clinicians and personal health records .

Figure 2: Conceptual Framework



RESEARCH METHODOLOGY

Design

The pilot study on IEHRMS was conducted at Racecourse hospital based in Uasin Gishu County, Eldoret town. A research design with active user participation based on semi-structured, written interviews. The questionnaire was developed according to research questions and consisted of instruments assessing the perceived usefulness of the IEHRMS with regard the attitude toward using it, perceived benefits and concerns, as well as recommendations of both patients and medical experts. The content of the introduction included a detailed explanation of all the features and functionalities of the system.

The IEHRMS was semi-functional, after an introduction, the IEHRMS was accessed by the presenter, using a dummy account and dummy data representing an informal patient. Based on the individual profile, the IEHRMS functionalities were demonstrated and explained to patients and to medics as well. This approach has been recommended in previous reviews and studies on eHealth interventions (e-health evaluations Norman, K.L. 2009). During the demonstration, questions from study participants were allowed and explanations given. Each demonstration lasted on average 30 min. Afterwards, I conducted the semi-structured interviews.

Quantitative Measures

Usefulness: Attitude toward Using by patient and medical experts

The attitude toward using the IEHRMS was assessed via the item "I think that IEHRMS is a good concept" and intention to use via the item, "If I had access, I would use IEHRMS." Both were rated on a 5-point Likert scale (1=strongly agree to 5=not agree at all).

Usefulness: Decision Aid (patient, Professionals)

I used this to measure perception of the IEHRMS with regard to decision support. Based on 5 items, the preparation for decision making is rated on a 5-point Likert scale (5=a great deal, 1=not at all).

Usefulness: Perceived Benefits to both patients and medics

The benefits for each user group were assessed via specific items that were rated on a 5-point Likert scale (1=strongly agree to 5=not agree at all). The questionnaire items were derived from current literature as well as pretest results of the IEHRMS.

Qualitative Interviews

In addition to the quantitative data, the perceived usefulness was explored through a semi-structured interview focusing on users' perception on benefits, major concerns, and further desired functionalities and improvements. The rationale was to assess the impact on users'

perception of the IEHRMS. The semi-structured, written interviews lasted approximately 30 minutes.

Ethics

Based on the interview guide developed for the purpose of the study, all interviewers were trained before the study. The pilot study was conducted from 15/08/2016 to 19/08/2016. All participants were informed of the objectives and the scope of the study, and provided their informed consent for participation. Data collection and analysis was conducted with exclusively anonymized data.

Data Collection Techniques

Data was gathered throughout the development process and analysed using excel: patients were recruited from Racecourse hospital. Eligibility criteria for patients included: a) A person with CVD (according to World Health Organisation) Cardiovascular diseases (CVDs) are illnesses that involve the blood vessels (veins, arteries and capillaries) or the heart, or both - diseases that affect the circulatory system. b) at least 18 years of age and c) able to speak, read, and write English d) Able to use internet enabled phone. 8 medical experts were recruited from Racecourse Hospital Eligibility criteria for medics included: a) qualified personal in CVD treatment and/or care, b) Working at Racecourse Hospital.

SYSTEM DESIGN

The system was developed with the following technologies:

1) The back-end of the application is based on Liferay open source framework (SOA architecture), open source Web platform for developing server-side scripting codes
2) The front-end of the application is based on HTML5 and CSS
3) Apache web server for hosting the application
4) Use of a SMS Short code service – for sending and receiving messages

Open source technologies were chosen because of their low cost, ease of acquiring the software and their stability due to a robust support through the active developer community globally. In addition the use of open-source technology solutions is relevant for the developing countries as they demand less financial input, flexibility and wider support for its stability and viability.

System features

LOGIN

User logins in using user name and password. For the purpose of my study I created one account which I used to demonstrate to users.

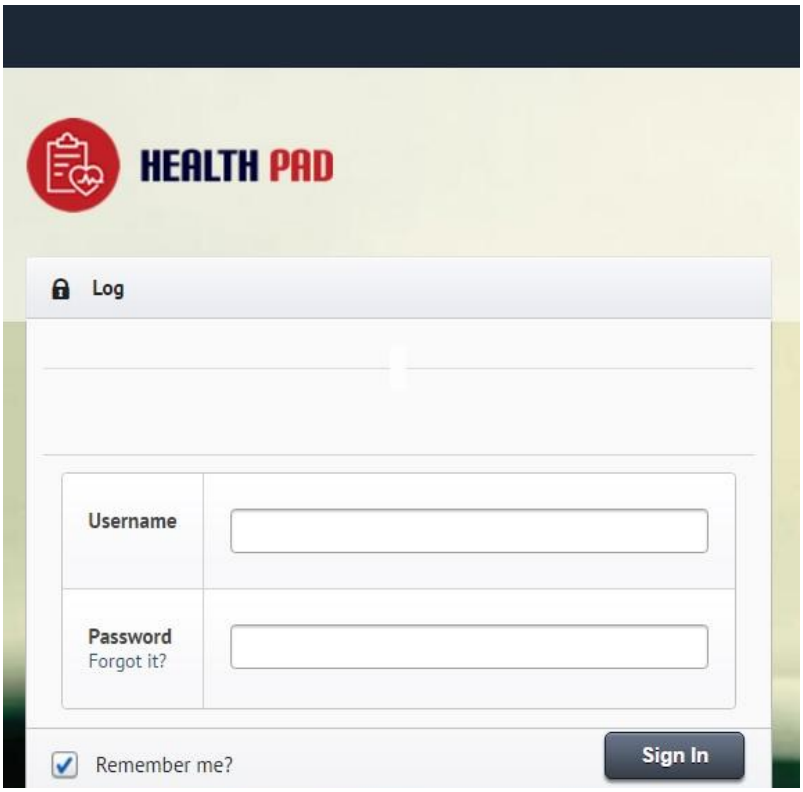


Figure 3

After successful login, user is taken to home page.

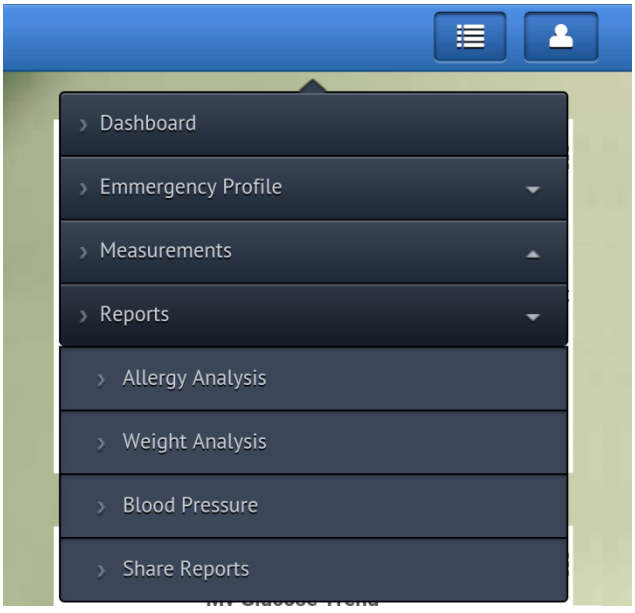
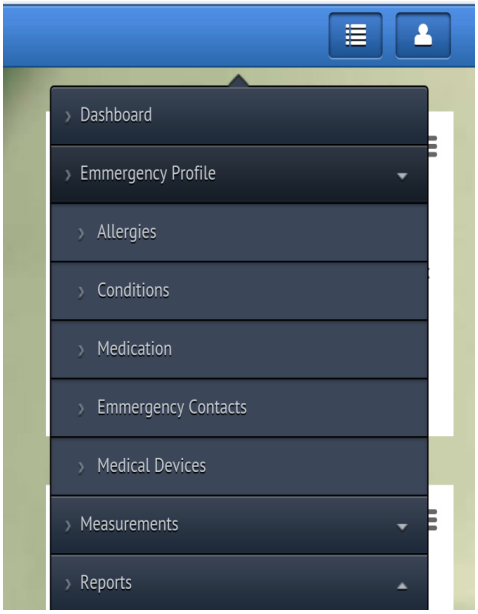


Figure 4



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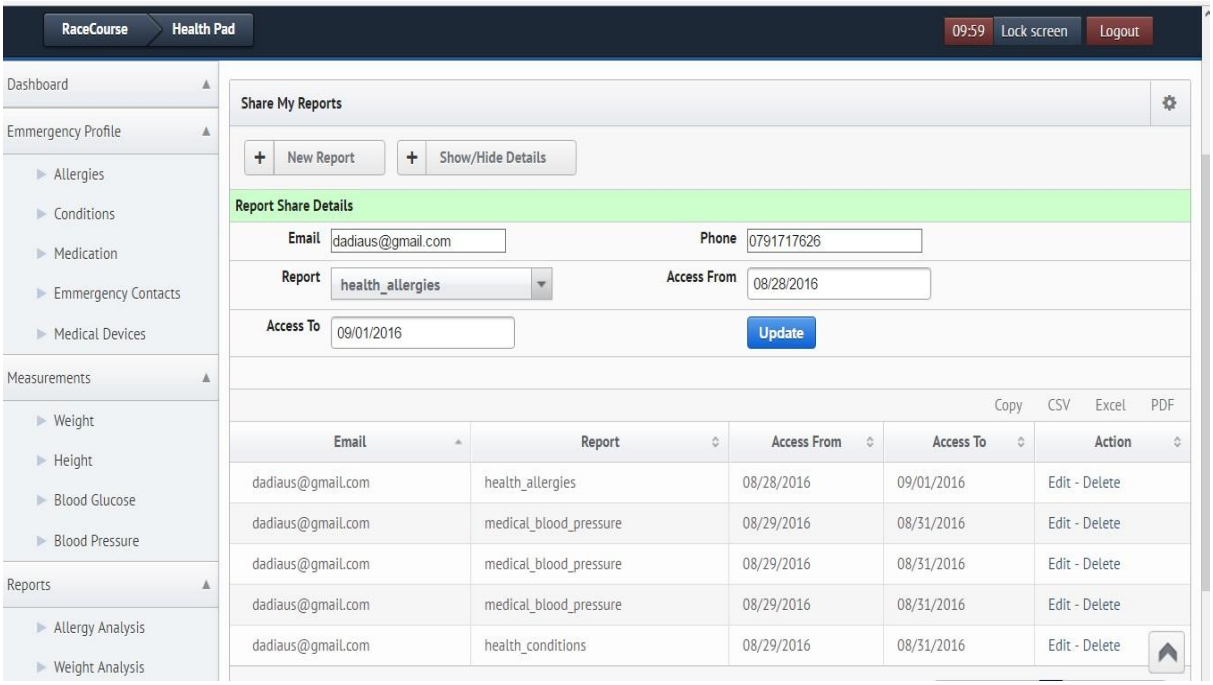

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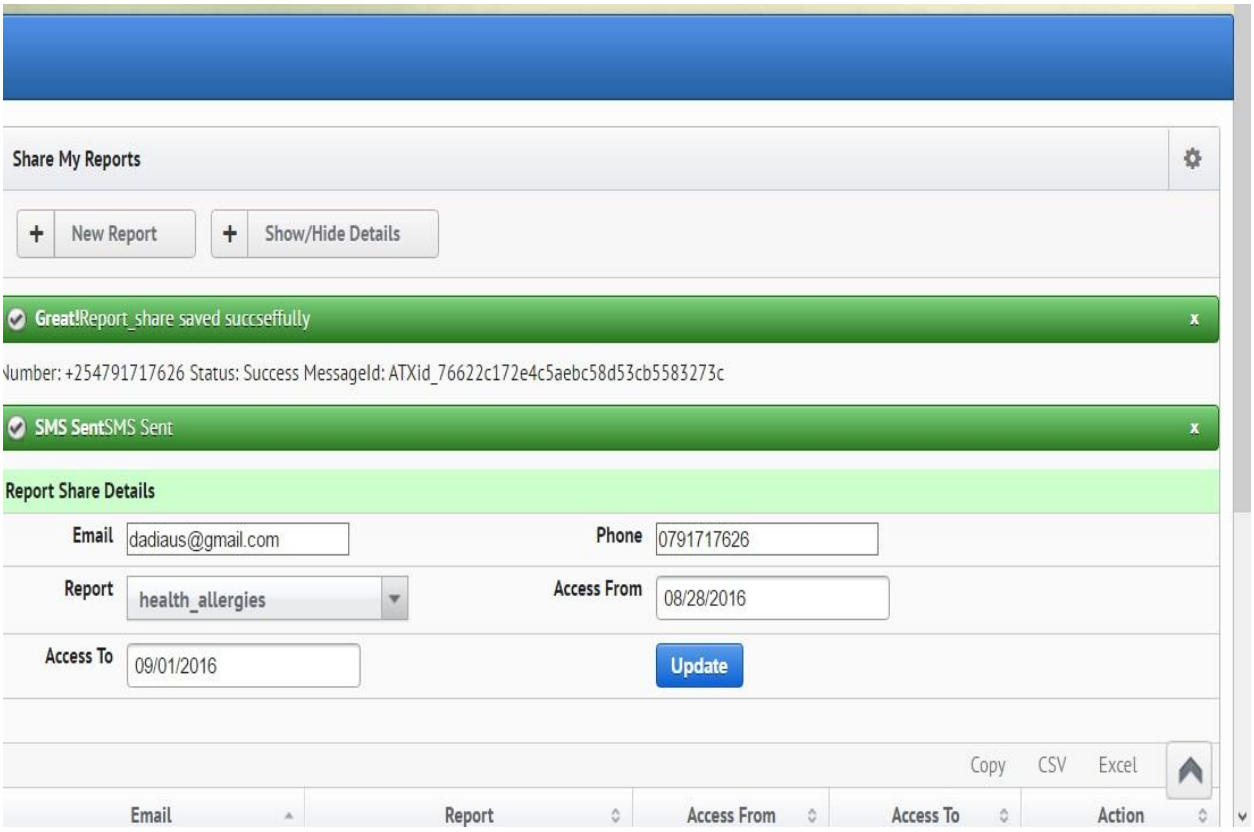

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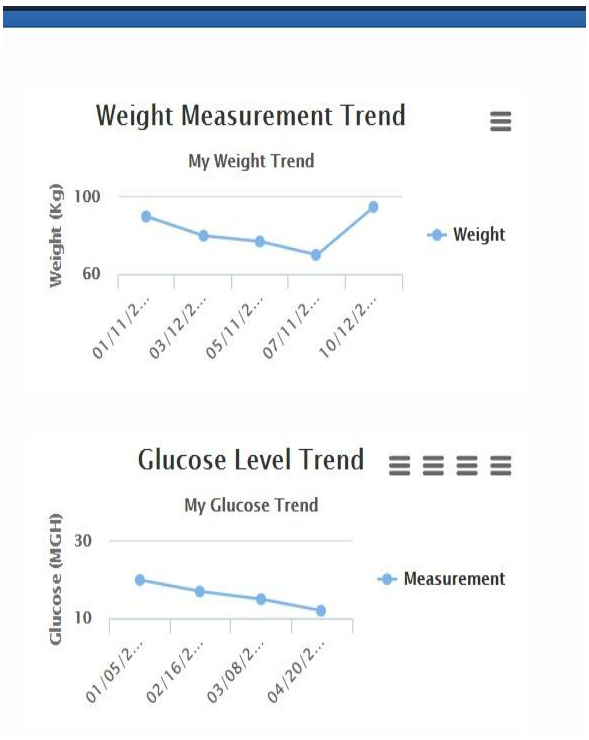

Figure 8

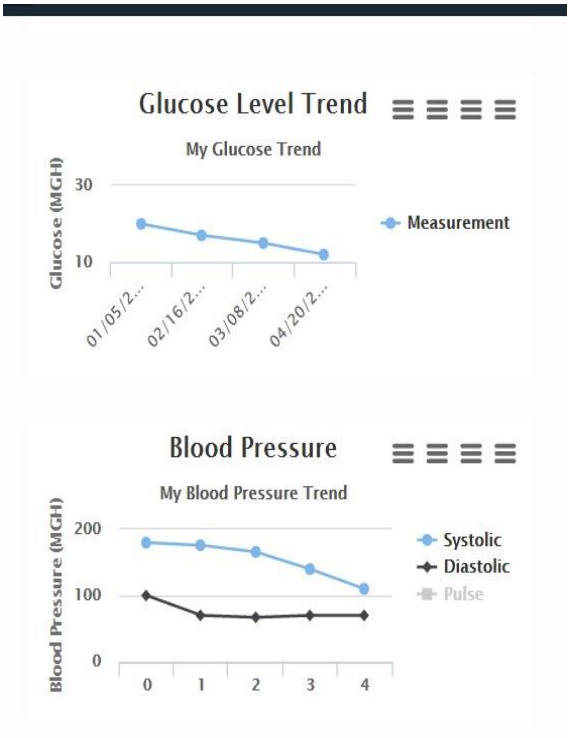

Figure 9

System Overview

This system enables medics to capture and share medical information instantly

User Login

The system enables a user to login using created user name and password as shown in Figure 3.

Main Parameters

After successful login user is taken to home page that contains the following main parameters as shown in Figure 4, 5 and 6;

1. Dashboard that contains graphs that are generated from diary entries captured by medical expert
2. Emergency profile measurements that captures contact details of next of kin of patient or person who can be contacted in case of an emergency
3. Reports contains analyzed reports which can be shared with patient or another hospital

Emergency profile

This function enables the user to capture data on the following and shown in figure 7.

1. Allergies
2. Medical conditions
3. Medication
4. Data captured from medical devices

Reports sharing

This functionality as shown in figure 8 enables medical experts to share medical reports with patients via an SMS or email.

Dashboard

This contains generated graph features which are helpful in increasing awareness to patients in terms of knowing how they are managing their weight, blood pressure and glucose level.

RESULTS

A total of 18 participants (10 patients; 8 MPs) took part in the pilot study. 4 of the MPs are medical doctors, 3 Nurses from a patient support and 1 counsellor

10 patients, 28 to 56 years old, participated in the study. The mean age was 38 years and (50 %) of the patients were male. The Sharing of health report through SMS and e-mail was rated 'very relevant' by 50 % of the patients and as 'relevant' by 30 %, whereas a further 10 % had chosen 'undecided' with the remaining 10 % choosing 'less/not important'.

Patient needs and empowerment

Patients indicated a high degree of perceived, individual support from the IEHRMS (average mean = 2.2; SD = 0.9 on a 5-point Likert Scale from 1='I totally agree' to 5='I disagree'; The provision of individualized information on CVD treatment, The graphs were perceived as the most useful functionalities. In addition, the majority of the patients expressed the need for a chatroom within the IEHRMS and technical support for those less proficient in using the internet. Patients highlighted one issue that is relevant for the daily use of the IEHRMS: A quantitative summary of diary entries.

Table 1: Patients' perceived support from the IEHRMS (%)

	1 **I totally agree (%)**	**2** **I agree (%)**	**3** **Un-decided (%)**	**4** **I rather disagree (%)**	**5** **I disagree (%)**
Patients' perceived support by IEHRMS (in %)					
Measuring trend , weight and blood pressure	70	20	10	0	0
Report sharing	60	30	0	10	0

Medical decision support for medics

Medics indicated that the IEHRMS captures relevant information that is needed in management of CVD which is normally very difficult to access (longitudinal data about the disease, time provided for care, medication history i.e. Allergies, Medication, Condition and Measurements).

In total, 8 of the medical professionals reported that the IEHRMS provides relevant information for medication treatment, and 5 % stated that IEHRMS readily contributes to establishing contact with another MP/specialist unit. However, medics highlighted the need for further, additional functionalities within the IEHRMS: An upload function for documents/instruments, the inclusion of information on medical history such as taking blood or ECG results, an improved interaction functionality for communication between doctor and chat functionality with patients.

Primary benefits and recommendations as perceived by the user

The primary perceived benefits and advantages of the IEHRMS for patients were: the acquisition of individualized information based on diary entries (70 %), instant relaying of medical report (60 %) followed by a detailed graph overview of the course of the disease

Overall, 8 of the patients stated that the IEHRMS is a good concept and would use the IEHRMS if they had access. The overwhelming vocal concerns about the IEHRMS were privacy and data security (40 %). From the doctors' perspective, the following perceived benefits of the IEHRMS improved interaction with patients (60 %), improved interaction with other doctors especially on sharing of reports involved in the treatment and care of CVD patients (60 %), empowerment of patients (40 %).

DISCUSSION

This report describes the participation and viewpoint of patients and medical professionals for an Individualized Electronic Health Record Management System (IEHRMS) early in the development process. This study aims to contribute to scientific research by providing new understandings into the development of eHealth solutions in cardiovascular care setting from two important user perspectives. This is crucial for the further development and uptake of electronic health record solutions in the cardiovascular care setting. Furthermore this is particularly relevant against the environment of growing middle class society willing to use internet and mobile electronic devices, rapid increase of CVDs and limited healthcare expenditures of health care systems in developing countries.

The findings from this pilot study indicate the potential of the IEHRMS for patients with regard to patient empowerment in management of the conditions (knowledge, decision aid and promoting interaction with medics. This result is of great importance, as the IEHRMS was designed to complement and not substitute existing Electronic Health Record Management Systems.

From the patients' perspective, the implemented graph features are helpful in increasing their awareness how they are managing their weight, blood pressure and glucose level.
Further, in providing assistance in making particular decisions in response to individual diary entries. One of the major factors that contributed to these findings was functionality of providing instant messages to the patients which supports the findings by Brodaty et al. (2010) where users felt that SMS and email communication are very useful in receiving medical reports. The information provided and interactivity with medical experts are major benefits, particularly for reaching patients that are immobile ('home-bound' due to health status or a lack of transport, public or otherwise) or isolated (e.g. living in rural areas). Thus, the IEHRMS can lower the threshold of access to health care information by accessing support in the privacy of their own. Another perceived usefulness is reduction in consultation time especially when a patient visits a different hospital.

CONCLUSIONS

The outcomes indicate that the IEHRMS has the potential to meet a number of demands and needs of patients with CVDs in a home-based care setting. The perceived benefits and willingness to use the system, combined with an increasing number of people using internet regularly, emphasize the potential of personalized and web-based support services for patients.
Assistance in decision making and empowering patients are essential in the management of CVDs.

LIMITATIONS

Although the findings in my study provided important and new there are certain limitations that must be taken into account. The first drawback is reflected in the rather small number of participants. However, the strength of my study is that different user perspectives (patients and medics) were included. The second limitation was that the systems was not deployed and used for substantial period of to gauge its effectiveness, although a demonstration itself was provided. As outlined in the introduction and methods sections, the aim of this study was to involve the user's perspective early in the development process of the IEHRMS. However a field trial of the portal at the last stage of the project, including the implementation of the pilot study's results should provide new insights into the impact of the IEHRMS on day-to-day circumstances of patients and medical experts.

RECOMMENDATIONS

Further aspects that must be taken into account for future IEHRMS development are average frequency of use, time of use as well as technical support. There is also a need to address barriers of adoption (e.g. privacy issues, impact on patient time, computer skills of users).

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