Patient-centred cardio-vascular disease management – end-user perceptions

Baber, Christopher; Dhukaram, Anandhi; de Stefanis, Paolo

Peer-reviewed paper

Patient-centred cardio vascular disease management – end-user perceptions

Anandhi Vivek Dhukaram, Chris Baber and Paolo De Stefanis

Anandhi Vivek Dhukaram and Chris Baber are based in the School of Electronic, Electrical and Computer Engineering, University of Birmingham, Birmingham, UK.
Paolo De Stefanis is based at LABOR Srl, Roma, Italy.

The authors thank all the patients and care-givers. This study is supported by EUROPEAN UNION FP VII project number 248694 (BRAVEHEALTH).

Abstract

Purpose – *The application of pervasive systems to healthcare has increased in recent years, but resistance to such systems by patients remains high. In this study, the aim is to examine patient and caregiver perceptions of this technology to further develop an understanding of the benefits and functionalities that prospective patients deem as desirable, undesirable, inadequate or in need of further development. The study was conducted as part of the European Union BraveHealth project which is developing a patient-centred pervasive healthcare system to support cardiac patients at home in everyday life using innovative monitoring and diagnosis, thereby enabling the patient to be more proactive in heath management.*

Design/methodology/approach – *Focus group studies were conducted in Italy and the Midlands area of the UK, along with a 31-item questionnaire. The findings were categorized under seven main headings: personal profile; benefits; adoption; acceptance; risks; security, privacy and trust; and (use of) cell phone.*

Findings – *In the focus group study, most participants felt that there is a great future for this technology and showed positive response to the potential benefits but there are concerns over reliability, security, privacy and trust.*

Social implications – *Even though this study constitutes only a small group of participants, the Italian and UK study does represent similar patients' and caregivers perceptions towards at-home healthcare systems.*

Originality/value – *This paper contributes to the understanding of the benefits and functionalities that prospective patients and care-givers deem as either desirable or undesirable.*

Keywords *Pervasive healthcare systems, End user aspects, Cardiac patients, Health services, Patients, Cross-cultural studies, Italy, United Kingdom*

Paper type *Viewpoint*

I. Introduction

The European Parliament Heart Group (2009) identified cardio-vascular disease (CVD) as a major cause of death, killing over two million people each year in Europe alone. CVD is mainly caused by the narrowing of blood vessels including the vessels supplying the heart muscle. CVD is related to a variety of conditions including coronary artery disease, heart attack, myocardial infarction, angina, congestive heart failure, hardening of the arteries, stroke and peripheral vascular disease.

Furthermore, the European Parliament Heart Group (2009) estimated the overall CVD costs the EU economy €192 billion a year, of which 54 per cent is due to health care costs and rest due to productivity losses and informal care. In spite of the advances in management, CVD is associated with high rates of hospitalization, poor quality of life and early death. Most of these problems seem to arise because healthcare is not being provided sufficiently early or

because of inabilities of patients to self-identify their symptoms at the right time. In principle, CVD patients are capable of leading a normal life as long as they are continuously monitored and alerted in the event of an emergency (Lorenz and Oppermann, 2009). So, in order to better self-manage, patients need to be monitored continuously at home, have access to doctors, avoid serious complications and be able to communicate with friends and family. One solution to these requirements is through the use of pervasive healthcare systems as shown in Figure 1.

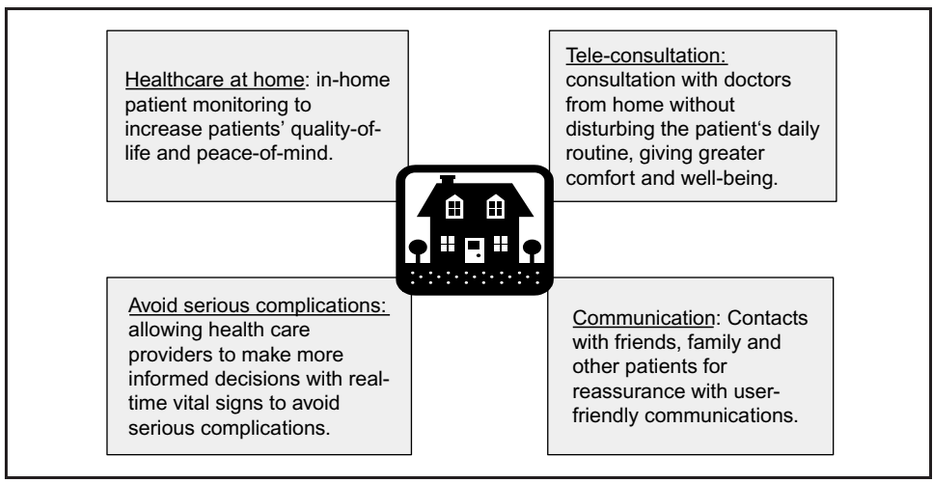
Pervasive patient-centered healthcare systems can be used in patients' homes without disturbing their daily routine. These healthcare systems continuously monitor vital signs using ECG, Pulse Oximetry, Blood Pressure and combinations of other Bio-Sensors, smart-home technologies, video-conferencing and various wireless information networks (Sneha and Varshney, 2009; Varshney, 2007; Hung and Zhang, 2003; Maglaveras *et al.*, 2002; Khoor *et al.*, 2001; Lin *et al.*, 2008; Tablado *et al.*, 2003).

Advancements in pervasive healthcare cannot only assist medical monitoring and diagnosis but can potentially provide the following benefits (Gibbs, 1997; Varshney, 2007; Fensli *et al.*, 2005; Demiris *et al.*, 2004):

- Improved quality of life.
- Individualized care, better treatment and therapy.
- Comfort, peace of mind and healthier lives.
- Continuous support and education from the community and resolve social isolation.
- Better management and monitoring of condition.

Moreover, pervasive healthcare is capable of enabling the patient to be more proactive in health management, and allowing the health care provider to make more informed decisions with real-time data (Sneha and Varshney, 2009). Despite these potential benefits, technical maturity and pilot applications across the world, adoption of such solutions in healthcare delivery is not yet well established. In this paper, a review of existing patient-centered health care systems, together with the proposed BraveHealth system, followed by literature review on patients' perceptions, is presented. The main focus of this study is on the concerns and attitudes of cardiac patients and caregivers towards the concept of pervasive healthcare. The aim of this paper is to further develop an understanding of the benefits and functionalities that prospective patients deem as either desirable, undesirable, inadequate and to take efficient measures to improve user acceptance or usage of the technology. Moreover, this paper describes the method and results of the study to generate input for the design of at-home pervasive healthcare systems.

Figure 1 What do patients' need to self-manage?



II. Background

Since the focus of this paper is on identifying the end-user perceptions towards patient-centered healthcare systems, a brief review of existing systems is given below along with the proposed BraveHealth system.

(i) Pervasive healthcare systems

Patient-centered healthcare systems cover a wide range of topics, such as distributed, ubiquitous and mobile computing, artificial intelligence, sensor networks, wireless devices, expert systems and human-computer interaction. There are several prototypes and commercial applications for pervasive healthcare monitoring for the elderly, children and chronically ill people. A wide range of companies, including Philips, Vodafone, Orange, AT&T Wireless, Avea, Japan's NTT DoCoMo, Telefonica, Intel and Hewlett Packard are exploring these combinations of technology.

Most of the at-home pervasive healthcare systems consist of one or more of the following:

- *Monitoring system* (Mukhopadhyay, 2010; Whitchurch *et al.*, 2007; Ade and Doulamis, 2011; Fensli *et al.*, 2005; Oresko *et al.*, 2010). To continuously monitor physiological vital signs like ECG, Pulse Oximetry and Blood Pressure. This monitoring may be carried out using a wearable unit depending on the patient's condition.
- *Decision support system* (Basilakis *et al.*, 2010). To support the physicians in retrieving physiological vital signs data from the monitoring system along with indications from the patient to carry out a diagnosis and establishing a protocol for patient treatment, at the same time assessing the progression of the pathology.
- *Prompts and alerts* (Karunanithi *et al.*, 2010; Capomolla *et al.*, 2004; Lai *et al.*, 2009). Generated depending on the alert thresholds and notified to the patient and physicians for effective patient management. Alert thresholds are defined according to alert type (like high importance, or low importance), user profiles (like high-risk patient or low-risk patient, current medication) and vital physiological signs parameters.
- *Doctor consultation.* To enable the authorized medical professionals to access the patient data from the web, exchanging useful information and providing advice using online web consultation through computers (Ghosh and Schellhorn, 2011; Sarela *et al.*, 2009) or Television Consultation (Angius *et al.*, 2011; Sarela *et al.*, 2009) or by telephone/SMS messages (Ghosh and Schellhorn, 2011; Kim *et al.*, 2007; Angius *et al.*, 2011; Wac *et al.*, 2009; Sarela *et al.*, 2009; Fensli *et al.*, 2005).

(ii) BraveHealth system

BraveHealth proposes a patient-centric vision to CVD management and treatment, providing people already diagnosed as subjects at risk with a sound solution for continuous and remote monitoring and real-time prevention of malignant events.

The main objective of the project is the development of an architecture with the prime aim to perform early diagnosis and prevention of the occurrence of malignant events or complications in subjects already affected by any form of CVD: this will be made possible by a wearable device (using sensors embedded in the patient's clothing), with the capability of monitoring several clinical parameters in order to perform a timely diagnosis of the patient's conditions, with advanced algorithms and data.

A BraveHealth sample use case is given below to show how the system can be used.

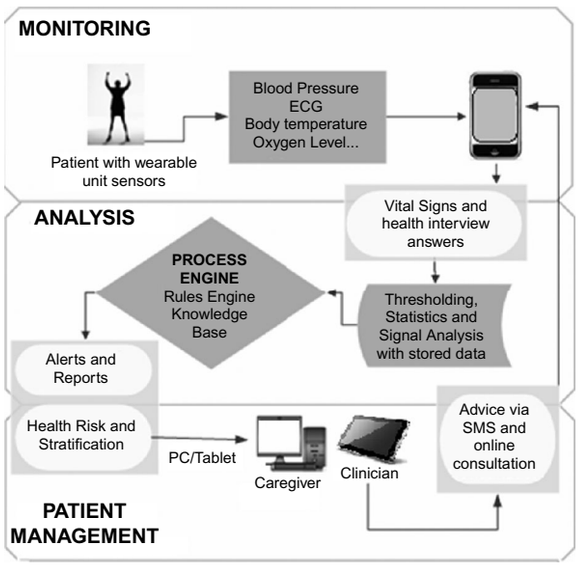
BraveHealth not only offers the system functionalities indicated in the above section on existing pervasive healthcare systems (Figure 2) but also offers a patient-centered approach to the design and implementation of innovative service for effective patient management.

A brief description of the proposed functionalities along with a high-level BraveHealth system architecture is given below. The purpose of the schematic architecture is to direct attention at an appropriate decomposition of the system without delving into the details

Use case:

John Doe already suffered from heart attack in 2008 and has been sent home from hospital with BraveHealth System. One day, after having filled the daily electronic questionnaire and having reported breath shortness and light chest pain, abnormal data registered by the monitoring system alerts the physician at the Remote Management Centre. The physician then triggers the analysis of ECG, O_2 saturation and thoracic bio impedance, gets the results and sends John an SMS with the medical prescription based on his current condition. One hour later, the physicians check John's vital signs again to make sure that everything is back to normal.

Figure 2 Overview of BraveHealth system



of interface specification. From the technological viewpoint BraveHealth is based on the following devices/platform:

- the wearable unit;
- patient gateway;
- physician gateway; and
- remote server.

The details of the devices are as follows:

1. The wearable unit:
   The wearable unit acts as a monitoring system that will be attached to patients' vests. This includes various functionalities like:
   - perform a first screening of the acquired data, in order to forewarn of possible abnormal situations;
   - to reliably monitor the specific set of parameters correlated to each specific pathology affecting the patient;
   - be able to send alarms to the user even in case the communication link with the mobile phone is broken;
   - must be calibrated to each specific patient; and
   - be able to remotely transmit patient data to offer decision support to clinicians.

2. The patient gateway.
   Patient gateway refers to both the platform and the means by which data exchange can take place. In some instances, the ''gateway'' can function as a router, connecting the platform to the server (or other devices), in other instances, the ''gateway'' can function as a client, receiving information from the server to display to the user, and in other instances the ''gateway'' can function as a local server, receiving data from other devices. In most cases, the ''gateway'' will be expected to fulfill one or more of the functions but that collectively the ''patient gateway'' supports any combination of these functions. The functionalities of the gateway are as follows:
   - to remotely receive data from the server;
   - to communicate with the wearable unit;
   - to recognize its operating context;
   - to recognize orientation (to change display) and context (to determine which input options to present);
   - to ensure both privacy and data integrity; and
   - to act as a client to the remote server so that information will be displayed to provide an indication of current ''health'' prompts for medication or exercise, or requests for information, such as short surveys.
3. The physician's gateway:
   For the physician, for example, a tablet could function like a medical chart (with the added benefit of dynamic display of real-time readings, history/trends, etc.) and can remotely receive data from the server for providing advice on the patient data.
4. The remote server:
   The remote server hosts the BraveHealth database of patient records. It is central to the:
   - patient configuration system (include a unique identifier for the patient and clinical information from electronic health records, alerts and notifications);
   - patient management system (patient pathology, risk and notification profile to be managed by the clinicians); and
   - decision support system (automatic notifications, physician-patient consultations) capabilities in BraveHealth.

These systems support functionalities on the wearable unit, the patient gateway and the physician gateway.

III. Prior research

This section reviews the literature on user perceptions towards pervasive at-home healthcare systems. Pervasive computing has as much to do with the user as it is about the technology, but it is noteworthy that patients are rarely mentioned as a motivation for the design and development of cardiac healthcare systems. There are a few studies on user perceptions of healthcare systems. Some of the studies that are relevant to this paper have explored issues such as: familiarity with mobile devices and initial mobile service usage or likelihood of continuous usage (Koivumoki *et al.*, 2008); perceptions, attitudes and concerns of elderly persons towards wireless sensor network technologies (Steele *et al.*, 2009); older adults' attitudes towards and perception of smart home technologies (Demiris *et al.*, 2004); consumer sentiment towards RFID healthcare technology (Katz and Rice, 2009); and patients' perceptions regarding home telecare (Agrell *et al.*, 2000). Other studies are focused on one or two values of interest, for example security (Haque and Ahamed, 2006), adoption (Orwat *et al.*, 2010) and risks and benefits (Demiris *et al.*, 2000). Generally, these studies showed positive patient perceptions.

In a study conducted by Jasemian (2008) on the elderly patients' attitudes to a modern telemedicine system at home, they found that although participants expressed reasonable

compliance and trust in the application, elderly patients were not satisfied with the weight and the user interface of the ECG device. Rahimpour *et al.* (2007) sought to develop a theoretical framework for patient acceptance of a Home Telecare Management System. However, most of the published studies have investigated patients/elderly satisfaction/perception after receiving telemedicine services and few have been conducted as part of the design process or to explore concept designs.

Previous work that used focus groups to explore the attitudes of older users towards technology in the home (Mitzner *et al.*, 2010), tends to show a generally positive response, particularly in terms of how the technologies can provide support and convenience for everyday tasks. However, concern often centres on questions of the reliability and security of the technologies. Demiris *et al.* (2004) indicated that older users appreciated potential benefits of devices and sensors to enhance their healthcare (particularly in terms of detecting problems, calling for help and monitoring physiological data), but raised concerns over the usability of such devices. These studies indicate that older users are (perhaps contrary to popular opinion) positive about the benefits of new technologies, providing that these benefits outweigh the potential negative impacts on their daily lives.

Although the above studies reported overall positive attitudes towards patient-centered healthcare technologies, they also expressed concerns about the usability of the devices, lack of personal contact and the need for training the users. As pervasive healthcare systems become more important for preventive healthcare, it is important to involve stakeholders in the process of designing, developing, testing and marketing such systems and thereby uncovering concerns before it is too late to address them.

Few clinical trials have been conducted with in-home context-aware monitoring systems for cardiac patients, largely because it is still very difficult to deploy the enabling sensor technologies affordably on a sufficiently large-scale.

A. Motivation

Even though the literature review revealed that patient-centred services are conceived as offering help to elderly patients, they also highlighted some of the barriers that hinder the deployment of patient-centred healthcare systems including:

- usability;
- a general reluctance to use technology;
- unclear evidence regarding real benefits of these systems;
- lack of skills to use the systems; and
- lack of training.

Also, these healthcare systems may not reflect the real needs of the end-users and for this reason they are considered unsatisfactory. In most cases, this is caused by a misunderstanding of the ability of the user, and user preferences and requirements for the systems and services. Hence, we wanted to find out end-user perceptions before the design of the BraveHealth system to explore the following:

- What are the social and demographic factors associated with these conditions?
- Do patients perceive the benefits of pervasive monitoring systems?
- What do patients see as the most important benefit?
- Do patients see any risk in using the system or the equipment?
- Do patients use any monitoring equipments at home?
- Do patients currently use the internet and mobile phones?
- Can patients understand how to use the system?

IV. Research method

A Focus groups

This study adopted focus group interviews (Gibbs, 1997; Cooper and Baber, 2002) and its results for understanding patient's concerns and perceptions towards pervasive healthcare systems. Focus group discussion is an effective way to gather information in which small groups (five to 12) of participants gather to discuss a specified topic or an issue (Wong, 2008). Focus group studies have been used to explore a wide range of health and medical related issues, including: experiences of health care in relation to their heart condition, understanding of health risks, treatment preferences and impact on quality of life (Rasmussen and Goodstein, 1987); reducing CVD risks (Wong, 2008); and racial disparity in cardiac decision making (Kennelly, 2001).

In the focus group, a moderator conducts the focus group sessions by raising questions about a topic to the group and the group members exchange ideas and comments on each other's experiences or views using the focus group guide developed by the project team. A note-taker is usually present to assist the session (although it is also common practice to record the session using audio or video recording for later review).

Focus group participants were recruited between September 2010 and November 2010 in Italy and England. The studies were carried by Stefanis in Italy and by Baber and Dhukaram in the UK using the questionnaire (Appendix). Access to the UK participants was supported through the local British Heart Foundation and recruitment involved an initial presentation by the researchers at local heart support group meetings followed by an invitation to attend focus group by either mail or phone call or by in-person contact. Patients' who have been diagnosed with CVD were eligible for participation along with or without their caregivers.

A preliminary focus group study was conducted in Italy involving eight patients in Rome. This pilot study helped frame the topics of interest to the study and provided guidance on ways to present the technology concepts to such a user group. Following the preliminary study, five focus groups were conducted with 34 participants from the West Midlands and Cheshire areas of England.

Projects involving human participants require approval from the University of Birmingham School Ethics committee. This requires informed consent to be obtained from participants and for any data collected from them to be rendered anonymous. Participants are also informed that they can withdraw from the study whenever they wish or can request to have any data generated from their responses withdrawn from subsequent analysis. As the study involved the collection of material through questionnaires and focus groups, it was felt that participant level of ethical approval was appropriate.

Each focus group was given an introduction about BraveHealth system functionalities and use case as given above for the patient monitoring system and consultation with physician over the internet or internet protocol television using some of the commercially available systems and video demonstration. Each group session consisted of two parts. The first part was focused on patients' everyday decision making. This has been analysed for a separate paper (Dhukaram and Baber, 2011). The second part, to be explored in this paper, focused on the patient perception of the BraveHealth pervasive healthcare system. We were particularly interested in identifying the concerns and attitudes that patients and their caregiver might have of the concept of pervasive healthcare, as well as exploring potential barriers to acceptance of the BraveHealth system.

Each focus group lasted between 60 and 90 minutes, and all sessions were audio recorded and transcribed field notes were also made by the note-taker. The analysis process began with debriefing sessions at the end of each focus group by the moderator to identify key concepts and messages that the members of the focus group agreed were important. The audio transcripts were made at the end of each focus group session in order to identify the areas to explore in the next meeting. The survey data were saved in Excel spreadsheet at the end of the focus group study; the data were imported into SPSS (IBM Inc.) statistics software for analysis. The focus group findings from Italy and UK study are given below.

V. Findings

Each participant in the focus groups was asked to fill in their responses to the questionnaire (Appendix) to get an insight into their perceptions. The questionnaire was explained using the use cases and BraveHealth functionalities. The questionnaire was categorized under seven main headings: personal profile; biomedical devices; wearable unit; Touch Screen.

A. Italy Study

A.1 Personal Profile. During the preliminary focus group, six heart failure patients, aged between 59 and 79 (all male) completed the BraveHealth – user study questionnaire (Appendix). After the presentation of the components of the system, the patients were asked to answer questions about the usability of biomedical devices, wearable units, touch screen technologies and virtual communities.

All participants had used biomedical devices previously, and four of them were familiar with wearable devices. Five of them carried a mobile phone. However, even if they all can use mobile phones and computers, only three out of six felt confident in being able to use advanced functions of those technologies.

A.2 Biomedical devices. All the patients appeared compliant with both daily and nightly use of biomedical devices.

One preference that came to light was to autonomously control the functioning of the device. The patients suggested a system they can wear and that they can switch on or switch off manually. The device they imagined should even notify its state of functioning, making them aware if it is charged and well settled on the body.

All the patients asked for the implementation of a button to warn doctors or caregivers about emergencies.

A.3 Wearable unit. All the patients evaluated the size and the weight of the wearable unit as average (neither too small, nor too big), easy to switch on, easy to use, simple to apply and remove from the body.

Three of those interviewed would like a fully integrated unit, i.e. as part of their clothing. Notifications from the wearable unit should be visible and clear, even if two patients suggested other modalities of warning like tactile and acoustic.

A.4 Touch screen. Two patients out of six did not answer the questions about the touch screen. However, the others showed high interest, and they gave a positive overall evaluation of the technology. Four out of six estimated the touch screen as comfortable to use, but slow in the interaction. Three out of this four favour numeric tables instead of diagrams for the descriptions of monitored data.

B. UK study

The user study questionnaire (Appendix) was categorized under seven main headings: personal profile; benefits; security, privacy and trust; adoption; risks; acceptance; and (use of) cell phone. Following this, content analysis was conducted on the transcriptions in terms of these categories. The questionnaire was administered to participants at the end of the focus groups and the results from the questions are summarized in this section.

B.1 Personal profile. Table I shows the demographics of the study population. The study group consisted of 22 males and 12 females. While we make no claim for the representativeness of the gender imbalance in this sample, discussion with practitioners suggests that men are more likely to be at risk from cardiac conditions than women and married men are more likely to attend support groups (such as those from which the focus groups were drawn). Most of the participants were in the age group of 60 to 79 years of age. The level of education is varied among the study group; however, most participants did not attend college. Also, most of the participants were either not employed or retired and had suffered from the condition for more than three years. It is interesting to note that patients

Table I Demographics of participants

	Number of participants
Gender	
Male	22
Female	12
Age	
50-59	5
60-69	18
70-79	10
80-89	1
Education	
Graduate education	5
College	8
Secondary school	7
Did not Graduate from high school	14
Employment	
Employed	5
Not employed	15
Retired	14
History of heart condition	
Less than 6 months	4
6-1 years	2
2-3 years	2
4-5 years	8
5-10 years	11
10 + years	7
Have you gathered information from friends and family?	14 (yes) 20 (no)
Do you have a family history of cardiac problems?	7 (yes) 21 (no) 6 (not sure)

were not always able to discover if they had a history of cardiac conditions in their family or have not sought such information.

B.2 Benefits. When asked about the potential benefits of the BraveHealth concept, all the patients felt that the technology could save time for physicians. 25 out of 34 participants felt that BraveHealth could be beneficial in improving their general health, whereas 29 participants felt it would improve their wellbeing and in monitoring health condition. 27 participants felt that BraveHealth could be a convenient form of health care delivery for them and 29 participants believe it could make it easier for them to contact the physician.

Thus, as with the previous studies of older people's attitudes towards technology, this demonstrates an open-minded and positive attitude to some aspects of the concept. This is illustrated by the following comments drawn from the focus group transcripts and notes:

> People don't have time, for regular checkups on health. Sometimes getting a doctor's appointment is very difficult. If you can do the consultation through internet that would be great (Focus Group 1, Male).
>
> My husband had a cardiac arrest and he didn't have any feeling or if there is a pain. He thinks it was just indigestion. I think this (monitoring) would have been great (Focus Group 5, Female).

B.3 Adoption. 27 out of 34 participants believe it would be easy to learn to use the technology. More than half of the participants use some sort of equipment at home for personal health monitoring, mobile and internet. The equipment used at home includes devices such as scales, blood pressure monitor, heart pressure and glucose.

During the focus groups, participants indicated widespread use of the internet, e.g. to stay in touch with their family and friends, emails, banking, insurance and for research. Although most of the participants seem to be using the internet for various things at least on a weekly basis, they still do not want to use it for medical research purposes. Thus, participants

indicated that use of the technology would not be a challenge, although 22 participants intend to use the technology. Majority of participants felt that some basic prior training would be useful before use and that helpdesk or instruction manual might be of some help in case of problems. This is shown in Figure 3 and the following comments drawn from the focus group transcripts and notes:

> Blood meter everyday (Focus Group 1,2,3,4,5, Male and Female).
>
> Use computer for email, banking, and insurance (Focus Group 1,2,3,4,5, Male and Female).
>
> Continuous monitoring should be useful (Focus Group 1,2,3,4,5, Male and Female).
>
> Continuous monitoring would make me too conscious about my health (Focus Group 3,4, Female).
>
> Weighing scales every day (Focus Group 1,2,3,4,5, Male and Female).
>
> Variety of things at home you may or may not use, you wouldn't necessarily do that but use scales regularly (Focus Group 1, Male).
>
> I don't use much socially, use only for information (Focus Group 4, Male).

B.4 Risks. 23 out of 34 participants (Figure 4) expressed concern that physical contact with the physician might be lost. Moreover, some of the issues highlighted during the discussion show patients concern over the reliability of the equipment. This is illustrated by the following comments drawn from the focus group transcripts and notes:

> In an emergency I would contact doctor or 999 rather than trusting the equipment (Focus Group 1, Female).

Figure 3 Factors influencing potential adoption decisions

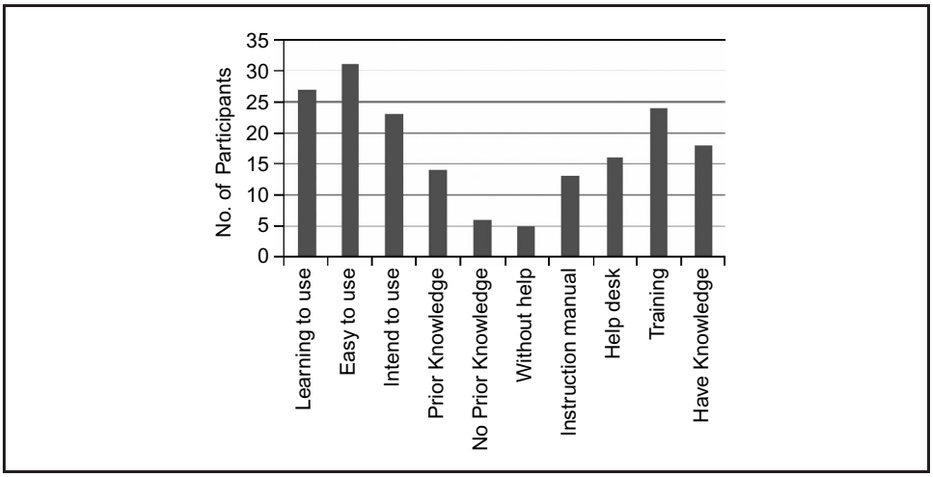
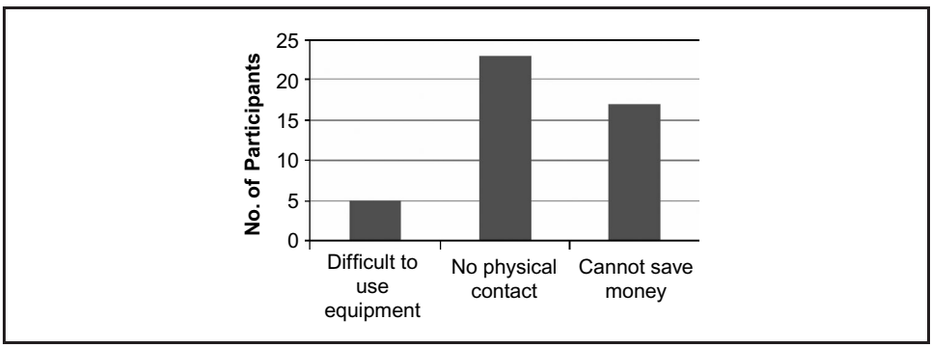


Figure 4 Concerns over potential risks



> New technology should not interfere with existing devices like; I have a pacemaker fitted in and once my pacemaker stopped because of some equipment there (Focus Group 4, Male).
>
> If you go to the hospital they go through all the procedures like urine test, check weight . . . you are in touch with what is going on. . .I am afraid you won't be getting it there (Focus Group 3, Female).
>
> If monitoring all day, how do you know if they (doctors) are getting messages (my health records)? (Focus Group 5, Male).

B.5 Security, privacy and trust. 26 out of 34 participants (Figure 5) raised concerns about data confidentiality or trust, although interestingly, 20 participants feel that BraveHealth would not violate security. The group discussion raised some concern over privacy in data transmission to the hospital as expressed below in the following transcripts drawn from the focus group notes:

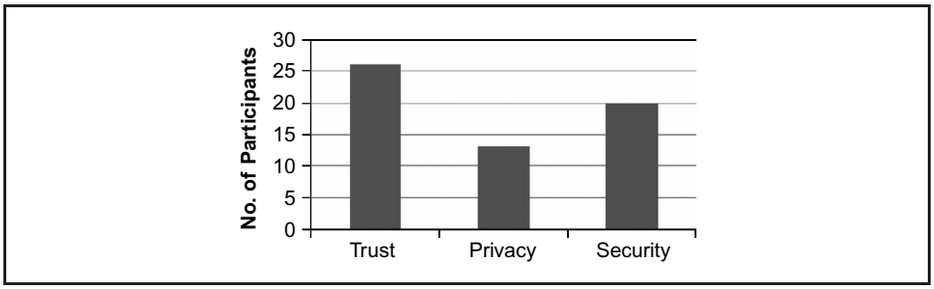
> I don't know what's going on in the computer and who sees my records. I would be wary of it. I am very protective (Focus Group 3, Female).
>
> At the moment based on my state of health I won't be passing my information over the internet . . . , I prefer to go to hospital and use their own (hospital) equipment for monitoring (Focus Group 1, Female).
>
> If (the health data you are passing over the internet goes to) my own GP then it is fine but if it goes to others then it is not good (Focus Group 5, Female).
>
> If they could put security (on the health data) so that people can't hack, then I would not worry (Focus Group 5, Male).

B.6 Acceptance. 29 out of 34 participants were willing to accept such a technology and felt it would be a great addition for their future healthcare. However, during discussion some participants indicated they would prefer to talk to the physician face-to-face rather than using videoconferencing. Those that were less concerned about videoconferencing tended to have had experience of using applications such as Skype. Some of the quotes gathered are as follows:

> If I am okay then there is no point in going to hospital, this can be brilliant, but I am still wary (Focus Group 3, Male).
>
> If you are not feeling well, how do you know it on the internet? . . . you won't get the best (Focus Group 3, Male).
>
> I think, I am confident in front of the consultant, but in online consultation, I don't know if the doctor has looked into my files (Focus Group 3, Male).
>
> Particularly, it becomes more difficult to get appointment. I don't need to wait for a week (Focus Group 1, Female).
>
> Online is great but occasional chat with doctor (Focus Group 4, Male).
>
> Ship information online to doctor but not for consultation. Only face-to-face consultation (Focus Group 4, Male).
>
> Heart attack is a silent killer, I never knew I had, . . . if you can reduce it then it is good (Focus Group 2, Male).

B.7 Cell phone use. In these focus group discussions, 32 participants had a mobile phone and most of them tended to restrict their use of mobile phones for ''emergency calls'' or for texting (due to the cost of phone use) and many of them tended to keep their phones

Figure 5 Attitudes towards Security, privacy and trust



switched off. Also the types of phone the participants have are older phones, as the phones seem to be passed on to them by their children.

VI. Discussion and summary

Overall, findings from this study suggest that at-home healthcare technology adoptions are affected by numerous factors including benefits, risks and security, privacy and trust. This can be affected by varied individual characteristics of the participants in our study which are driven by many individual demographic factors like: age, gender, education, socio-economic and family history. Mostly participants were driven by worries regarding the privacy of information exchanged using technology, reliability of devices and the quality of both the information received and the interaction. Although participants in this study use various technologies like health monitoring systems, computers, internet and cell phones, results show that participants are divided in their response to online consultation and most like having face-to-face consultation with the physicians whenever they are unwell or in case of emergency with online consultations for reassurance. This can be due to participants' unfamiliarity with the technology or the low-internet bandwidth that they tended to experience as some mentioned during the study. Moreover, participants who did not want to accept the technology have indicated their willingness to undertake training and try the technology so that it can be easier for them to use and adapt to it.

Participants raised concerns regarding privacy, security of the data and the reliability of the devices. Few patients were worried that their health data might be visible to everyone in the hospital like the nurses or other doctors whom the patient is not familiar with. Concerns might stem from patients' hesitancy with current social networking sites and possible misconceptions. However, patients did want to try out the technology as they felt it would be highly beneficial once the participants were told that the records would be disseminated to others based on their authorization. As participants do not have much awareness of these healthcare systems, it is important that they get actively involved in their creation for better patient empowerment and to enhance trust.

Some patients also raised concerns regarding the frequency of monitoring. Some of the patients felt that 24 hours monitoring would not be essential and it would only make them too worried about their health, while some felt that it would be very beneficial to detect adverse effect as sometimes it is hard for them to interpret their symptoms. Therefore, it was decided for BraveHealth that monitoring of patients would depend on the risk level of the patients; that is, high-risk patients would be continuously monitored based on patient consent and low-risk patient monitoring to be carried out depending on the advice of the physician. So it is important that this is taken into consideration during the creation of healthcare systems.

Also, participants raised concerns about the usage of the mobile phone interface for the BraveHealth system as most of them were using old models (three to four years) of mobile phones which had been passed on to them by their children. Moreover, due to the nature of the phones, most participants had been using them only for emergencies or to receive calls. Only a few use the SMS or text services. As part of the BraveHealth development, we are guessing that patients will be using smart phones (simply because by the time the system is produced, these will be the phones that this demographic will be using either because they will be given to them by their children or they will be buying them on new contracts).

For the present study, it is interesting to note that there is a subgroup of patients who are not aware of family history. This might be related to participants' self-awareness of the condition. Some patients did express their need for more information about their disease. So technology which provides adequate support and education about disease could have a bright future for pervasive cardiac healthcare.

Winkelman *et al.* (2005) propose that simply providing technology to patients may have little benefit without also providing a sense of ''illness ownership'' (by the patient), a capability to support patient-initiated communication, a level of support that is tailored to the individual patient and mutual trust between patients and medical professionals using the technology. The majority of participants felt that there is a great future for BraveHealth and expressed

a willingness to adopt the system. While half of the participants felt confident that they have adequate skills to handle the technology, they felt some support through further training and access to help desk would help them to use the technology.

This exploratory study was conducted to investigate CVD patients' and caregivers' perceptions towards at-home healthcare systems. Although this study constitutes only a small group of CVD patients and caregivers, our Italian and UK study does represent similar patients' and caregivers' perceptions towards at-home healthcare systems. Overall, participants in these focus groups show a positive response in regards to the potential benefits of the BraveHealth concept. In general, these responses relate to the benefits of real-time monitoring of a range of parameters and the capability to receive a quick response to potential problems. However, there concerns remain about reliability, security, privacy and trust. These findings echo the previous studies reviewed in this paper.

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Appendix – questionnaire

APPENDIX– QUESTIONNAIRE

Title Of Study: Patient Centric Approach for an Integrated, Adaptive, Context Aware Remote Diagnosis and Management of Cardiovascular Diseases.

We want to know the profile of people included in our study. Therefore this form asks you for your ethnic origin, gender, education, employment, sexuality and age. **The information you provide in this part of the form is confidential.**

1) I am:

[ ] Female [ ] Male

2) Age

[ ] 40-49 [ ] 50-59 [ ] 60-69 [ ] 70-79 [ ] 80-89[ ] 90-99 [ ] above

3) My ethnic group?

Choose one section from A to F, then tick the appropriate box to indicate your cultural background.

[ ] A: White
[ ] B: Mixed Any mixed background
[ ] C: Asian; Asian Scottish; Asian British
[ ] D: Black; Black Scottish; Black British
[ ] E: Other ethnic background
[ ] F: Prefer not to answer

4) Education Background

[ ] Did not graduate from high school
[ ] High school graduate
[ ] College Education
[ ] Graduate Education

5) Employment Background

[ ] Employed
[ ] Not Employed

6) I came to know about my heart problem.

[ ] Less than 6 months [ ] 6 months– 1 year [ ] 2-3 years
[ ] 4-5 years [ ] 5-10 years

7) I have gathered more information from family/ friends who have undergone similar heart problems

[ ] Yes [ ] No

8) Family history of heart disease

[ ] Yes [ ] No [ ] Not sure

(*continued*)

9) Do you have a cell/ mobile phone?
[ ] Yes [ ] No
10) BRAVEHEALTH can violate my privacy.
[ ] Yes [ ] No
11) Would you be favorable to be treated with a system like BRAVEHEALTH?
[ ] Yes [ ] No
12) The use of the necessary equipment seems difficult to me.
[ ] Yes [ ] No
13) I can be as satisfied talking to the physician over the computer as talking in person.
[ ] Yes [ ] No
14) BRAVEHEALTH cannot save me any money.
[ ] Yes [ ] No
15) BRAVEHEALTH can save time for the physicians.
[ ] Yes [ ] No
16) BRAVEHEALTH can improve my general health.
[ ] Yes [ ] No
17) Using BRAVEHEALTH the physician will be able to monitor my condition well.
[ ] Yes [ ] No
18) I don't like that there is no physical contact during a BRAVEHEALTH visit.
[ ] Yes [ ] No
19) BRAVEHEALTH is a convenient form of health care delivery for me.
[ ] Yes [ ] No
20) BRAVEHEALTH makes it easier for me to contact the physician.
[ ] Yes [ ] No
21) BRAVEHEALTH saves me time.
[ ] Yes [ ] No
22) BRAVEHEALTH will be a standard way of health care delivery in the future.
[ ] Yes [ ] No
23) BRAVEHEALTH can be an addition to the regular care I receive.
[ ] Yes [ ] No

(*continued*)

24) I cannot always trust the equipment to work.

[ ] Yes [ ] No

25) Learning to use BRAVEHEALTH would be easy for me.

[ ] Yes [ ] No

26) If I were to adopt BRAVEHEALTH it would be easy to use.

[ ] Yes [ ] No

27) I intend to adopt BRAVEHEALTH technology as soon as it becomes available.

[ ] Yes [ ] No

28) Over the ensuing months (if possible) I'd like to experiment BRAVEHEALTH.

[ ] Yes [ ] No

29) I have the knowledge necessary to use BRAVEHEALTH.

[ ] Yes [ ] No

30) Using BRAVEHEALTH could improve my well being.

[ ] Yes [ ] No

31) I could use BRAVEHEALTH technology...

a. if I had prior usage of similar technologies.
b. even if I had never used a technology like it before.
c. even if there is no one around to tell me what to do.
d. even if I only had the instruction manuals as reference.
e. if I could always call the help desk if I got stuck.
f. if someone showed me how to use the system beforehand.

Author Queries

JOB NUMBER: 147985

JOURNAL: JAT

Dear Author

Please address all the numbered queries on this page which are clearly identified on the proof for your convenience.

Thank you for your cooperation

Q1 Please check and confirm the sentence "The questionnaire was categorized under seven main headings: Personal Profile; Biomedical Devices; Wearable Unit; Touch Screen" mentioned 7 main headings, but only four have been given.

Q2 Please provide complete details for reference ''Gibbs, 1997''.

Q3 Please provide volume number for reference ''Mukhopadhyay, 2010''.