

# GLOBAL TELEHEALTH 2014

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# Global Telehealth 2014

Edited by

**Anthony J. Maeder**

*University of Western Sydney, Australia*

**Maurice Mars**

*University of KwaZulu-Natal, South Africa*

and

**Richard E. Scott**

*University of Calgary, Canada*

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USA

fax: +1 703 323 3668

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## Preface

e-Health – in its many forms – continues to be implemented throughout the globe, yet sound evidence of its ‘value’ to healthcare systems remains limited, and achieving its successful, sustained integration is a challenge. Telehealth, one component of e-health, also suffers from the same shortcomings, and has not yet reached the necessary tipping point for assuring its universal adoption. Health consultations delivered via videoconferencing, store-and-forward solutions for remote provision of health services, and home monitoring of patients for telecare are examples of some diverse areas of Telehealth that offer gains in quality and efficiency. In contrast, the recent spontaneous growth of mobile healthcare solutions as smartphones become more common amongst healthcare providers, and creation of web-based wellness promotion and health management tools has opened up whole new areas for Telehealth to provide future benefits.

It is becoming crucial that a thorough understanding of global Telehealth activity and opportunity for inter-jurisdictional alignment be developed, in order to allow mutual improvement to be achieved. The developed world can provide interim clinical and educational support as the developing world establishes the necessary capacity to continue to build its own capacity, while the developing world can provide inexpensive and truly innovative solutions to the developed world through reverse innovation. Venues such as Global Telehealth provide a platform for the exchange and development of common understanding of clinical needs and technologically appropriate Telehealth solutions.

Global Telehealth 2014 (GT2014) was the 3rd International Conference in the series, held in conjunction with the ICT4Health Conference 2014 in Durban, South Africa. This year the conference theme was “Integrated, Innovative, Scalable and Sustainable Solutions”, emphasizing the importance of these aspects in achieving wider acceptance and adoption of e-Health and Telehealth. A total of 28 papers were accepted by the international expert reviewer panel for presentation at the event. This book contains selected full papers from those accepted, that align well with the conference theme, and will be informative to those in the global Telehealth community.

Anthony J. Maeder  
Maurice Mars  
Richard E. Scott

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# International Expert Review Panel

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Jennifer Zelmer, Canada Health Infoway, Canada

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# Telehealth as a tool for independent self-management by people living with long term conditions

Carol S BOND<sup>1</sup>

*Bournemouth University, England*

**Abstract.** Telehealth is seen as a key component of 21<sup>st</sup> century healthcare, and studies have explored its cost effectiveness and impact on hospital admissions. Research has been carried out into how to best implement it, and the barriers to its adoption. The impact of telehealth on self-management however has been a neglected area. An evaluation of the implementation of a telehealth programme in one area in the South of England found that some patients were using the telehealth equipment provided to enhance their own self management abilities. Whilst the nurses managing the scheme felt that they had an education role they did not involve their patients in setting goals. The patients equally did not feel that were being educated by their nurses. Patients were using the monitoring equipment independently of the nurses and the scheme to support their self-management strategies. Therefore the concept of graduating from telehealth once good self-management is established needs to be rethought. Patients in this study experienced less face to face contact with their nurse, but also reported that they were happy with the changes. This suggests that for some patients the contact with the nurse may well be able to be reduced or withdrawn however removing the monitoring equipment will remove the very tools essential to continued self-management.

**Keywords.** Telehealth, self-management, participatory healthcare

## Introduction

Self-management for long term conditions is a central tenet of the health policy around the world, [1, 2, 3, 4]. In the UK telehealth is seen as one way of working towards this. Two of the aims of the English NHS (National Health Service) in introducing telehealth for patients living with long term conditions are to achieve ‘more effective self care’ and to ‘increase [patients’] confidence to manage their own health’.

How telehealth can contribute to self management has not however been a major research focus. Studies into telehealth have focused on cost effectiveness[5, 6]; effective working practices [7, 8]; barriers to adoption [9]; and reduction in hospital admissions [10, 11]. Where patients’ experiences were considered the focus was frequently on the perceived reassurance patients feel [12].

Where self management was explored it was frequently in terms of ‘adherence’[13, 14] or ‘compliance’ [15] Fewer studies gave prominence to patient partnerships, although patients prefer having ownership of their self management, and do not want a paternalistic approach [16].

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<sup>1</sup>Corresponding author: Carol S Bond, Bournemouth University, Fern Barrow, Poole Dorset, BH12 5BB, England; Email: [cbond@bournemouth.ac.uk](mailto:cbond@bournemouth.ac.uk)

## 1. This study

This study draws on an evaluation of a telehealth service for people with COPD implemented by the Dorset Clinical Commissioning Group in the south of England. Although evaluating the effectiveness of the service implementation some of the findings have wider implications. The service supplied patients with devices to monitor oxygen saturation, blood pressure, temperature and weight, all managed through an iPad style device that both presented questions about how they were feeling and sent their readings and replies to their nurse. The evaluation lasted 12 months, and included a questionnaire; telephone interviews with patients, and interviews with nurses.

### *1.1 Data Collection*

The patient questionnaires were distributed via the telehealth system. Two questionnaires were used, one close to the patient starting on telehealth and the other after around 3 months to explore differences in attitudes initially and after experience of using the system. Although 299 telehealth pods were installed with users over the evaluation period only 118 had recorded consent to be contacted. 41% of these (number = 48) completed questionnaires.

Qualitative telephone interviews were held with a purposive sample of patients who had given prior consent to be contacted by the research team. 29 participants were interviewed in phase one. 24 follow up interviews were conducted. Reasons for not participating in the second interview were the patient died (n=3) admitted to hospital (n=1) declined a further interview (n=1). In both phases each interview took an average of 10 minutes (range 4-22 phase 1, and 4-24 phase 2). A semi structured approach was adopted, to ensure that common information was obtained from each participant, whilst also being responsive to each interviewee's individual circumstances and experiences.

Due to the availability of staff one focus group of 4 nurses, and 6 telephone interviews were held. All the nurses had been trained in the use of the telehealth system and had at least one patient using the system.

There were limitations in the data collection. To maintain patient confidentiality the evaluation team received pseudo-anonymised information from the referral system. Only patients who had confirmed they were happy to be contacted by the evaluation team were able to be included either the questionnaires or the interviews. Initially patient information received frequently did not have this field completed, so these defaulted to non-consent. A further problem was encountered with the ability of the telehealth system to present questionnaires to users in the way the evaluation team would have preferred.

## 2. Results

The age of respondents ranged from 45 to 95, with both the mean and median being 71. 33% were female and 67% male. 54% had a primary diagnosis of COPD, 31% CHF and 13% both.

## 2.1 Questionnaire

The majorities were satisfied with the way in which the telehealth system had been installed in their home reporting that the installation engineer had been polite, and they had been given clear instructions on how to use the system. They found that monitoring their condition using the telehealth system was easy. The majority felt confident taking their measurements and viewing the results and said they felt involved in their own health care decisions. 80% of respondents looked back over the history of their readings and the same proportion said that they felt telehealth made a difference to their lives with almost all respondents rating the telehealth system as liking or really liking it.

## 2.2 Interviews

The patient participants (identified by pseudonym) fell into two categories; those who felt supported and reassured by the knowledge that nurses were ‘keeping an eye on them’ and those who saw this as an opportunity to better self manage their conditions.

People who valued the reassurance did not perceive the equipment as a barrier, Joan explained ‘Well they’re keeping an eye on me y’know, I know somebody’s watching all the time’ and Bill said ‘(I) talk to it and tell them how ill I am, how I’m feeling and everything and they get back to me’ [Bill]

Others, such as Doris, felt that having the equipment available enabled them to better self manage explaining ‘I’ve been using it once a week, and transfer the details to [nurse] ... but if I’ve felt unwell in the meantime then I’ve used it for my own sort of, to know what my sats are and how to deal with them, ... and regulate the medication if I have to’. John felt that his use of the system increased his confidence in managing his condition ‘I like to know what’s going on so the fact that I can look back at my readings and make comparisons is brilliant. And in a way that gives me confidence to move forward.’

The nurse participants (identified by number) were generally unaware of how some patients were using the equipment to support their self-management.

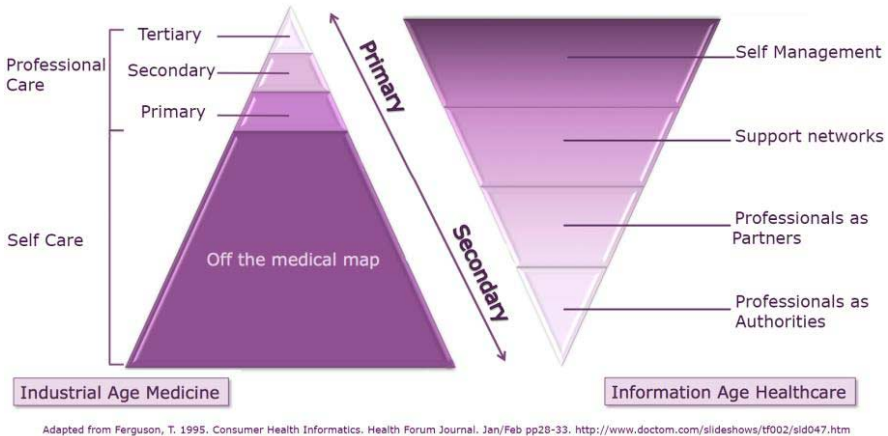
The protocol for starting patients on the telehealth system included setting goals. Nurses were expected to agree these goals with their patients. Patients however did not consider that they had been involved. Peter explained ‘I just do the results and then I press send but that’s all I was told to do’. Comments from the nurses support this finding ‘it’s knowing your patient really ‘cause it’s the nurse that will normally set the parameters and then go through them with the patient’ [N1].

The potential for patient education was a missed opportunity. Peter discussed that he would like to understand more about the readings and what they meant. The nurses however felt that they were using telehealth for patient education; ‘I think generally if they’re being monitored and you’re doing visits anyway you do a lot of education with them’ [N2].

As with many telehealth programmes patients were expected to ‘graduate’ when they were effectively self-managing. Graduation includes removing the equipment so that it can be used for a new patient. One nurse, talking about how long patients expected to stay on telehealth said ‘I’ll say to them this is our property in a nice sort of way and it could come out at any sort of time’ [N3].

### 3. Discussion

It is widely acknowledged that people who are effective self managers are active partners in their care, and share decision making with their care teams [17]. These patients expect to be seen and treated as an equal member of that care team [18]. This model of healthcare is also called participatory medicine, described some 20 years ago as the paradigm shift from industrial age medicine to information age healthcare by Doc Tom Ferguson [19] one of the pioneers of the participatory medicine movement.



Adapted from Ferguson, T. 1995. Consumer Health Informatics. Health Forum Journal. Jan/Feb pp28-33. <http://www.doctom.com/slideshows/hf002/sld047.htm>

**Figure 1.** Self-Management in the Information Age. Adapted from Ferguson (2002)

This study however found that not all patients did feel supported in developing their self management strategies. Whilst most models of self management are healthcare professional lead, however a ‘self agency’ model, where patients placed importance on taking control of their condition, including deciding what information to share with their healthcare professionals is also proposed [20]. This was the approach adopted by some of the patients in this study, who used the telehealth equipment outside of the requirements of the telehealth programme, and made treatment decisions based on their readings.

Some of the nurses felt they had to retain ownership of the telehealth programme. Nurses have been found [21] to find working with self managing patients challenging. A study carried out with stroke therapists [22] found that their normal practice was to act as ‘benign dictators’ working in their patients best interests, but remaining in control. Moving to a model of patient led self management was supported in principle, but the therapists saw obstacles in achieving this change.

A qualitative study of nurses involved in delivering telehealth programmes in three areas of the UK [23] found that there were mixed views about its use. Nursing staff (community matrons and telehealth monitoring nurses) were concerned that it was an adjunct to their patient care, not a replacement. Nurses have also been found to be concerned about the impact of telehealth on traditional nursing roles [24]. The patients in this study did say that they experienced a change in the amount of face to face

contact they had with their healthcare professionals, with it generally being substituted by telephone contact; however they were happy with the changes they encountered.

#### 4. Conclusion

Although this evaluation found that patients were using the telehealth system to support their self management activities and felt more confident in their ability to self manage the process that supported this is not clear, nor is the role of the nurse in that process. Some patients are able to use the system to achieve this with minimal support, whilst others will need some assistance to learn how to use the monitoring equipment to best effect. Although both the policy and the stated aims of the nurses is to achieve effective self-management the paternalistic nature of some of the telehealth relationships is a barrier to moving this forward.

One significant implication of this evaluation is that patients are using the monitoring equipment independently of the healthcare professionals. Therefore the concept of graduating from telehealth once good self-management is established needs to be rethought. Patients in this study experienced less face to face contact with their nurse, but also reported that they were happy with the changes. This suggests that for some patients the contact with the nurse may well be able to be reduced or withdrawn however removing the monitoring equipment will remove the very tools essential to continued self-management.

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# Evaluating success of mobile health projects in the developing world

J. Anupama GINIGE<sup>1</sup>, Anthony J. MAEDER and Vanessa LONG

*School of Computing, Engineering & Mathematics*

*Telehealth Research & Innovation Laboratory, University of Western Sydney,  
Campbelltown, NSW 2560 Australia*

**Abstract.** Many mobile health (mHealth) projects, typically deploying pilot or small scale implementations, have been undertaken in developing world settings and reported with a widely varying range of claims being made on their effectiveness and benefits. As a result, there is little evidence for which aspects of such projects lead to successful outcomes. This paper describes a literature review of papers from PubMed undertaken to identify strong contributions to execution and evaluation of mHealth projects in developing world settings, and suggests a template for classifying the main success factors to assist with collating evidence in the future.

**Keywords.** Mobile health, cellular phone, developing countries, economics, evaluation studies, health impact assessment, telemedicine

## Introduction

Despite the advancement of medical science, people in developing world countries receive inadequate healthcare services, which results in significantly lower life expectancy and quality of life. Some examples of these inadequacies include poor availability of and access to healthcare facilities, resource limitations on provision of treatment and medication, lack of sufficient trained healthcare personnel, and underserved public health programmes.

Mobile information and communication technology has been advanced significantly in the past 15 years to provide close to ubiquitous connectivity. A 2012 study [1] reported 5 billion mobile subscribers worldwide, of which more than 70% were located in low and middle income countries, and determined that 83% of the world's population was able to be reached by wireless services. The catalysing and leapfrog effects of this new telecommunications technology have been argued to support economic development in both the developing and developed world, and narrow the extent of economic separation between them [2].

There have been numerous reports on projects and programs delivering healthcare services in resource-limited areas using mobile technology e.g. [3]. There have also been various analyses of the potential for general development impacts through the

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<sup>1</sup> Corresponding Author: Dr J.A. Ginige, School of Computing, Engineering & Mathematics, University of Western Sydney, Locked Bag 1797, Penrith NSW 2751, Australia; E-mail: j.ginige@uws.edu.au.

upscaling of health services via mHealth e.g. [4]. These prolific examples of developments and deployments prompt us to ask: Can mobile health solutions improve healthcare services in developing countries with resource-limited health settings?

If we are to arrive at a positive answer for this question, some further sub-questions must be explored: What is the nature of the mobile health solution that leads to improvements? How is the mobile health solution created and delivered within the health services environment? What is the nature and extent of the health services improvements? What health benefits and health care cost impacts occur? What are what are the success factors and potential pitfalls in deploying mobile health solutions? This project was undertaken in order to investigate how these questions might be answered by deriving a structured approach from consideration of the clinical literature.

## **1. Background Materials**

Prior contributions in the literature detailing success factors for mHealth projects in the developing world are scarce. In an early publication describing mHealth, Istepanian et al. [5] acknowledged the potential for applicability in that setting, but provided no framework for assuring success of implementations. Some guidance on success factors for Telehealth projects in developing world situations was provided by Wootton et al. [6], but concentrates on analysing issues concerning delivery of individual clinical services, in conventional Telehealth settings rather than mHealth. Latifi [7] presented a case for wide scale deployment of telemedicine services including those delivered by mobile technology, and indicated some contextual influences.

The evaluation of mHealth projects has received more attention in the literature but many publications are directed only at specific projects, and so the generality of any success factors reported is limited. Inadequate choices of parameters such as sample size and diversity, control of confounders, and length of trial period as well as a piecemeal approach to evaluation design and methodology, have led to a dearth of published material providing conclusive findings at high levels of evidence. Tomlinson et al. [8] argued that evaluation was a key aspect for achieving mHealth project success, due to its influence on clinical policy makers. Recently, Chib et al. [9] reported an analysis of 53 mHealth projects in developing world settings and concluded that a lack of evidence exists, due to various reasons including inadequate project design, preferences for technology driven projects without sustained clinical outcomes, and failure to extend projects beyond the pilot stage.

Expert analyses on development opportunities by international agencies and corporate consultants abound in the mobile technologies sector, but relatively few have specifically targeted mHealth. In a recent report by The Boston Consulting Group [1] describing the potential of mHealth based on knowledge acquired from over 500 mHealth projects worldwide, the main areas of opportunity for delivering clinical benefits were identified as:

- Health surveillance
- Information on disease prevention
- Patient monitoring & compliance
- Public wellness apps
- Remote data access
- Remote diagnostics

Another such report produced independently by The World Bank [2] identified a number of similar areas, including some non-clinical aspects such as education and accountability:

- Improving management and decision-making by health care professionals
- Real-time and location-based data gathering
- Provision of health care to remote and difficult-to-serve locations
- Fostering learning and knowledge exchange among health professionals
- Promoting Public Health
- Improving Accountability
- Self-management of patient health

Success factors and obstacles for the adoption of mHealth are also identified in some of these reports. For example, considerations of the experiences from past projects by The World Bank [2] and World Health Organization [4] concluded that the following reasons specific to the health ICT arena are strongly related to the failure of mHealth projects:

- Insufficient financial resources
- Lack of sustainable business models
- Privacy and security concerns
- Limited evidence
- Difficult coordination of stakeholders
- Interoperability issues

However, the aspects suggested to be addressed to ensure success are often generic to major ICT programmes and developing country projects and not specific to health ICT projects. For example, the following set of aims for mHealth projects to increase likelihood of success are listed in a United Nations Foundation report [3] on the potential of mHealth for the developing world, based on 51 mHealth case studies:

- Forge strong partnerships
- Be accessible
- Design with the end user in mind
- Build a long-term funding plan
- Set measurable goals
- Collaborate with other mHealth organizations

By comparison, the abovementioned World Health Organisation report [4] suggests more specific success factors associated with project management and change management:

- Avoid a one-size-fits-all approach
- Maintain flexibility
- Take standards and interoperability into account
- Track key success indicators for monitoring and evaluation
- Ensure quality and content of health information
- Enable public-private partnerships
- Offer training and take literacy into account
- Ensure the commitment of leaders

A report by Advanced Development for Africa [10], based on analysis of 9 widely representative case studies of mHealth projects in the developing world, offers numerous recommendations for successful project outcomes in the categories of

programmatic, operational, policy and global aspects, and identifies the following as success oriented best practices in project execution:

- Plan for scalability and sustainability from the beginning
- Assess real needs and required benefits within the local health landscape
- Identify existing initiatives and avoid duplication
- Educate and engage end-users during development, to support uptake
- Align with local health priorities and existing Health Information Systems
- Secure buy-in from healthcare authorities and partner with stakeholders
- Collaborate with local implementation partners
- Establish strategic partnerships to assist with scaleup
- Perform monitoring and assessment of impacts
- Maintain flexibility during implementation to address changing needs

In summary, it may be observed that many of the above recommendations intersect and are frequently more generally applicable to technology-based projects in the developing world, than merely to mHealth. This suggests that there may be more value in reviewing studies of mHealth projects in the developing world which appear in the clinical evidence literature, with a broader scope than was covered in the above stylized reports. By identifying strong contributions to execution and evaluation of such projects, we hope to suggest a template for classifying the main success factors, in order to assist with collating further evidence more systematically in the future.

## **2. Scoping the Evidence Base**

The goal of this work was to collect representative instances (and grouped instances) of publications on mHealth projects (and the related health services) implemented in developing countries, and conduct analysis of these to identify factors leading those projects to deliver effective use of mobile technology in healthcare. The scope was confined to searching PubMed, as the primary source of clinical evidence through peer-reviewed publication, and limiting this to publications that have appeared since 2000, to ensure currency. Preference was to be given to publications reporting evaluation associated with the project, with explicit identification of the evaluation methodology.

Our initial approach to searching PubMed was to identify concepts within MeSH to help define search contexts which might map to publications of interest. This was not a simple task, because MeSH does not provide terms for qualitative concepts such as “success factors”, nor does it currently recognise “mHealth” (or “m-Health”). A scoping exercise was therefore undertaken to establish relevant MeSH terms to aid in the search. The three basic concepts in the statement of intention for this work were supplied as enquiry terms to a MeSH search: these were “mobile health”, “project evaluation” and “developing world”. None of these terms occurs directly in MeSH but some relevant primary terms were suggested by MeSH. Examining the paths to these terms from parent categories provided justification that they were relevant to the major concepts. Further examination of the paths revealed a number of secondary terms which were also clearly associated with the basic concepts. All the discovered terms and related paths are shown in Table 1.

**Table 1.** MeSH terms and paths related to the basic concepts of this work.

<b>Basic Concept</b>	<b>Primary MeSH Terms</b>	<b>Primary MeSH Term Paths</b>	<b>Secondary MeSH Terms</b>
Mobile Health	Cellular phone  Telemedicine	Information Science Category / Information Science / Communications Media / Telecommunications / Telephone  Information Science Category / Information Science / Communications Media / Telecommunications / Delivery of Health Care  Health Care Category / Health Services Administration / Patient Care Management / Delivery of Health Care	Computers, handheld Medical Informatics Mobile applications Text messaging Wireless technology
Project Evaluation	Evaluation Studies  Health Impact Assessment	Analytic, Diagnostic and Therapeutic Techniques and Equipment Category / Investigative Techniques  Health Care Category / Health Care Quality, Access, and Evaluation / Quality of Health Care / Health Care Evaluation Mechanisms  Analytic, Diagnostic and Therapeutic Techniques and Equipment Category / Investigative Techniques / Epidemiologic Methods / Data Collection  Health Care Category / Health Care Economics and Organizations / Health Planning / Health Services Research / Health Care Surveys	Clinical Trials Epidemiologic Studies Feasibility Studies Intervention Studies Pilot Projects Program Evaluation Validation Studies
Developing World	Developing Countries  Economics	Anthropology, Education, Sociology and Social Phenomena Category / Social Sciences / Internationality / International Cooperation  Anthropology, Education, Sociology and Social Phenomena Category / Social Sciences  Health Care Category / Health Care Economics and Organizations / Economics	Costs and Cost Analysis Economic Development Poverty Resource Allocation

All primary and secondary terms were combined in a PubMed search for publications satisfying the scope of the work, yielding a compound search string as follows:

(((((((((("Evaluation Studies as Topic"[Mesh]) OR "Health Impact Assessment"[Mesh]) OR "Clinical Trials as Topic"[Mesh]) OR "Epidemiologic Studies"[Mesh]) OR "Feasibility Studies"[Mesh]) OR "Intervention Studies"[Mesh]) OR "Pilot Projects"[Mesh]) OR "Program Evaluation"[Mesh]) OR "Validation Studies as Topic"[Mesh]) AND (((((((("Mobile Applications"[Mesh]) OR "Text Messaging"[Mesh]) OR "Telemedicine"[Mesh]) OR "Cellular Phone"[Mesh]) OR "Mobile Applications"[Mesh]) OR "Text Messaging"[Mesh]) OR "Medical Informatics"[Mesh]) OR "Computers, Handheld"[Mesh]) AND (((((((("Developing Countries"[Mesh]) OR "Economics"[Mesh]) OR "Costs and Cost Analysis"[Mesh]) OR "Economic Development"[Mesh]) OR "Poverty"[Mesh]) OR "Resource Allocation"[Mesh]))))

Applying this search returned a list of 5476 publications, and applying each of the three AND-separated sections in turn returned lists in excess of 100,000 publications. Further analysis of those results would be well beyond the capacity of an individual. Inspection of the 5476 initial publications revealed that very few met our criteria for coverage of project execution and evaluation. The MeSH based search approach was therefore abandoned in favour of more general PubMed word searching, accepting that a smaller range of search words would be necessary. Nevertheless, this exercise was useful for determining topics that might occur in publications of interest.

### 3. Literature Search Methodology

To achieve our research goal by using PubMed word searches, a 3-step work plan was formed. Step 1 of the work plan was to refine a search strategy for finding appropriate publications. Step 2 of the work plan was to evaluate publications identified by the search strategy for their suitability for inclusion. Step 3 of the work plan was to perform analysis on the selected publications to extract success factor information.

To find publications of interest, an incremental sequence of search strings was applied, based on inclusion of the search word “m-Health” to be matched in the Title or Abstract fields of PubMed. The search strings and the resulting numbers of publications returned are shown in Table 2: note that a search for “m-Health” also matches with “mHealth”. It was decided that the basic concept “project evaluation” should be excluded from these searches, being the least reliable of the three basic concepts to be expressed directly in text. It was also decided to include the word “e-health” because numerous mHealth projects are badged as eHealth for convenience. However, it was observed that this increased the list size considerably and very many of the publications returned dealt with EHR systems. When it was found that the word “developing” constrained the search too strongly, it was dropped and subsequent searches concentrated on inclusion of words to address “mobile” aspects.

The final list chosen for Step 1 was aggregated from these searches. It is acknowledged that this list may not be a complete coverage of publications reporting mHealth projects in the developing world, but it was deemed large enough to provide a

set of representative example projects, while still being small enough to process the list entries manually for Step 2.

**Table 2.** Incremental PubMed search string results.

<b>PubMed Search String</b>	<b># Pubs</b>
m-health[Title/Abstract]	187
(m-health[Title/Abstract]) OR (e-health[Title/Abstract])	1113
((m-health[Title/Abstract]) OR (e-health[Title/Abstract])) AND developing[Title/Abstract]	96
(mobile services[Title/Abstract]) OR (mobile computing[Title/Abstract])	183
(m-health[Title/Abstract]) OR (mobile health[Title/Abstract])	430
(m-health[Title/Abstract]) OR (mobile health[Title/Abstract]) OR (mobile services[Title/Abstract]) OR (mobile computing[Title/Abstract])	695

The inclusion evaluation process in Step 2 was designed to differentiate pertinent publications from extraneous ones. The main inclusion criterion was that the paper reported a mHealth project with some aspect of evaluation. For a publication to be included for detailed analysis, it had to offer clear descriptive content of the execution and evaluation of an mHealth project in a developing world setting, including detailed information on the type of mHealth technology used in the project, the scale at which it was applied, and any outcomes it delivered. The inclusion process was applied as a coarse-to-fine approach in two phases. In Phase 1, publications were judged based on their title and abstracts only; and in Phase 2, publications were judged based on their contents.

In Phase 1, the title of each of the 695 publications was read, to determine if it was clear that a project was being reported. Sometimes a publication title could determine directly whether it should be accepted, or rejected. If the title did not contain enough information to make that decision, then the abstract was read, and a decision was made from that information. After Phase 1, the 695 unique publications were classified into three groups: 543 rejected publications, 128 accepted publications, and 24 undecided publications. The 152 accepted and undecided publications were included in the rest of the review, because they were directly relevant to our study.

Despite efforts put into retrieving the publications, only 95 of the 152 publications were retrieved as the others were not available from the library network. Phase 2 of the inclusion process was applied only to the 95 retrieved publications. This time, each of the retrieved publication was read, and the inclusion decision was made based on the publication content. This resulted in 62 publications being excluded from further analysis, and detailed analysis was conducted on the remaining 33 publications.

#### **4. Analysis of Publications**

Each of the 33 publications was read in detail, and a critique was made in six categories: healthcare application areas, user acceptance issues, technology issues, government and organisation involvement, identified challenges, and desired characteristics. The categories were loosely derived from the main issues identified in the consideration of

background materials described in Section 1 above. These categories are described in more detail below, using examples from the 33 case studies.

#### *4.1 mHealth application areas*

mHealth systems cover a broad range of health services [11, 16, 24, 27, 30, 31, 33, 39], and they can be distinguished into the following areas:

- Health promotion, well-being education and chronic disease prevention such as lifestyle awareness, monitoring and assessment over mobile phone;
- Administrative support such as scheduling, billing, appointment booking and remote data collection;
- Decision support such as process patient information, diagnostic data management, medical reference, real-time information access;
- Clinical activities such as remote diagnosis and monitoring, reporting and lab test ordering;
- Education and research such as providing access to medicine and medical research;
- Disease and epidemic outbreak tracking and emergency care for natural disasters;
- Treatment support such as sending medication alerts, e-prescribing for repeat prescriptions, transmitting patient records and test results to clinicians, web access to database.

Specific clinical mHealth applications from developed world settings which may be applicable in some developing countries include management of diabetes, asthma, obesity, smoking cessation, stress, depression, mental health care, TB control, patient monitoring, and prenatal management [12, 14, 17, 26]. Out of these application areas, diabetes management has received the most attention. Most patient monitoring is focused on a specific type of health issue, such as cardiac conditions and mental disorders [22].

#### *4.2 Technology issues*

While increasingly many mHealth applications are released in the marketplace claiming to provide benefits to potential users, the literature shows the need for formal, standardised, systematic evaluation approaches to be applied to validate the claimed benefits [21, 23, 24, 26, 33, 36]. Most mHealth products are results of small-scale pilot projects that are not designed to demonstrate large-scale, long-term impacts. Their testing is therefore typically for feasibility rather than for validity in real clinical environments. Currently, there are more than 15,000 health-related apps (free and paid) on app stores. Due to the lack of evaluation standards, there is no study assessing and comparing the apps [17]. Overall, whether mHealth leads to better overall health outcomes will be unknown until rigorous, formal evaluations are defined.

In order to validate the claimed benefits and to allow direct comparison between similar products, repeatable systematic evaluation methods and gold standards need to be defined. The literature suggests that the following factors should be incorporated when defining evaluation methods. Firstly, among other quality measures, evaluation methods should include measures of user satisfaction and cost-effectiveness [18, 27]. Secondly, because mHealth products are built on technology that is rapidly evolving,



evaluations should also be long-term and continuous [21, 26]. Finally, the field of mHealth would be benefited greatly by establishing a mHealth evaluation registration like the one for clinical trials in the U.S. [23].

#### *4.3 User acceptance issues*

User acceptance is fundamentally important to the adoption of mHealth solutions. Users include both medical service providers and patients (customers). Although there is concern over healthcare workers' resistance to mHealth technology due to fear of job losses, the main question for medical service providers is how to integrate mHealth technology into their clinical practice and daily activities [24, 29]. The discussion in the rest of this section focuses on customers, who see costs and privacy as the two main challenges in adopting mHealth services.

Low costs promote usage; high costs can limit usage. Costs, including both hardware costs such as sophisticated phones and costs of using data network, have been a barrier [30, 33, 39]. A survey in China suggests that cost, presumably being passed on to the healthcare consumer, may potentially have an impact on the willingness to subscribe to pay-for-service mobile health programs [36]. Phone sharing is a way to keep costs down: in Ghana, the pricing structure for phone use makes this technique practical [21]. This, in turn, adds another complexity factor to mHealth privacy and data security.

Other barriers are related to mobile technology, such as small service coverage, screen sizes of mobile devices being too small, low quality of apps (e.g. app causes screen to freeze), malfunctioning equipment, limited battery power, limited memory, and quality of care received via a mobile device [12, 30, 31, 33, 35].

#### *4.4 Identified challenges*

It has been recognised that many mHealth barriers go beyond the complexity of the mobile technology itself and are related to broader health systems challenges in the practices of health personnel, the integration of new technology with existing information systems, sustainable funding and appropriate leadership to steer these shifts [27].

Confidentiality of information is a highly sensitive matter, as it is expressed as a concern appearing in every survey regardless of the communities [13, 16, 22, 24, 25, 26, 35]. In the U.S., migrant farm workers concern about confidentiality of information and trust of medical care centres. They fear being caught by law-enforcement agencies because of their immigration status [35]. Other vulnerable populations, such as those in HIV-prevalent areas, express concern about their health status being exposed.

Biomedical devices, especially for telemedicine and mobile health applications, should be sensitive to the issue of privacy in the same way as traditional healthcare services. Another common security issue that occurs with mobile devices is loss of the device due to theft or misplacement by the owner. Guidelines and laws on access rights to data, usage, and storage must be defined in order to promote mHealth.

Apart from privacy and security, connectivity and mobility are two challenges experienced by many users in developing countries. For connectivity, users worry about network reliabilities (which includes network failure and limited or inaccessible

to network) and coverage. Additionally, some remote areas also experience the problems of lacking electricity [22, 28, 32].

Mobility refers to frequent changes in phone numbers due to population movement. China Mobile, for example, reported that 71% of its customers frequently change their mobile phone numbers. Challenges therefore arise in keeping track of and providing medical care for the highly mobile population [15].

#### *4.5 Government and organisational aspects*

Government involvement and co-operations between governments and organisations are crucial, as study show that government support and sufficient funding are major factors behind successful deployment of mHealth in developing countries. There are varied levels of government involvement, and the general expectation is that governments should provide stewardship and leadership. These include building or improving network infrastructures, setting standards and guidelines for best practices, providing funding to organisations, industry and research, define strategies and policy, implementing public policies to decrease resistance to new technology, encouraging open standards-based technologies and workable approaches to interoperability, legislating laws to protect privacy and security; streamlining co-operations between local, regional and national governing bodies as well as academia and industries, evaluating mHealth products and healthcare service qualities, and enforcing standards compliance [15, 16, 19, 20, 22, 24, 27, 32, 33, 34].

Studies also found that there are factors that drive mHealth to success. These include socio-economic aspects and user acceptance of mHealth. It has been found that that socio-economic aspects, rather than technical aspects of mHealth, are a bigger influence on success. Technology must be affordable, reliable, acceptable to consumers and providers, easy to use and convenient and fitting in with existing lifestyles rather than demanding substantial changes in skills or existing practices [19, 33]. Systems do not work unless local staff have a real stake in the process from initial planning to full operation. It is also important to have strong, committed local leadership [18].

#### *4.6 Desired characteristics*

Experts are calling for a user-driven approach to adoption of mHealth. Patient-centric applications are easier to be adopted than technology-driven ones [33, 39]

It has been found that education was a positive and significant predictor as a complement to in-person doctor's office visit [37]. Short-term courses should be provided to both trainer and users, as sufficient training can improve acceptance of mHealth by society, patients, family physicians, specialists and administrators [19].

A concern shared by many patients in projects is the need for allowing communication between physicians in different institutions. A feature that facilitates this is to achieve 'one-patient; one-medical record', and health records should be accessible by both patients and carers [19, 22, 29]. It was found that the single most desired feature is that healthcare should be more patient-focused with personalisation of diagnosis and treatment for each patient [28, 29].

Other desirable features suggested for mHealth apps include the following:

- Personal health information to be transmitted via an unsecured network [28];
- Be reliable in resource-constrained settings [38];

- Be scalable to support home-based counseling and testing program [38];
- Be developed in an open-source methodology to lower the cost of future implementations [38];
- Work on a variety of handheld devices [38];
- Be implemented on a device that has built-in GPS [38];
- Seamlessly integrate with an open-source medical record system [38];
- Seamless transfer of information, integrated care, continuity of practice, extension to electronic health records, and links with existing healthcare processes [33];
- Tools to more rapidly and accurately assessed [13];
- The ability to better document and triage patients to additional services [13];
- mHealth devices should have higher precision, improved sampling frequency, fewer missing data values, greater convenience, and lower costs [26];
- The need for having a framework to ensure that projects align with national health objectives [40];
- Allow the use of photos for documenting physical findings [13].

## 5. Conclusion and Future Work

This paper has provided an analysis of literature on recent mHealth projects which have been evaluated sufficiently to provide relatively strong indications of success factors. While it was conducted with a defined methodology, it does not conform fully with the usual expectations of a ‘systematic review’, in that it has weaker inclusion criteria and does not analyse the evidence quantitatively. As a result of the review, a template for consideration of success factors in future project evaluations has been proposed. The template requires application in some new project settings to gain experience with more comprehensive evaluations of success factors, and to help develop it further.

A phenomenon of high interest in, but low usage of, mHealth apps has been observed in resource-limited settings [12]. This suggests that stakeholders (e.g. healthcare workers and patients) are not necessarily seeing mHealth as a substitute or as a complement to traditional healthcare services [37]. In fact, some people are concerned that use of technology would be detrimental to the human side of their interactions, and mHealth technology could be a threat to healthcare workers’ job securities [13]. A deeper understanding of the relationship between healthcare workers and patients should therefore be gained before developing health programs.

Currently, most mHealth products have resulted from small scale projects, which do not show the social, organisational and cultural elements of successful implementation and adoption of information and communication technology [27]. Despite a vast number of available smartphone-based applications, very few comply with regulated/expert body guidelines [11]. In the US, the majority of cancer awareness and drug compliance apps require external, expert accredited peer-review. Selected mHealth apps need to be approved by the US Food and Drug Administration (FDA). In developing countries, the issues of treatment compliance and awareness have not been fully explored, and so there should be opportunities for future studies [22].

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# The utilization of mobile devices for telemedicine services in a South African public healthcare system

André HARTMANN <sup>a,1</sup> and Liezl VAN DYK <sup>b</sup>

<sup>a</sup>Department for Industrial Engineering, Stellenbosch University

<sup>b</sup>Programme for Industrial Engineering, North-West University

**Abstract.** The purpose of this study is to develop an understanding in the use of mobile devices in administering telemedicine services within the public health care sector of South Africa. An online questionnaire was developed and distributed amongst medical officers, specialists, students and medical staff of one of the health districts of South Africa. This paper describes the design of the questionnaire as well as the most significant outcomes. Results are presented in terms of reasons why healthcare workers use mobile devices, as well as perceptions in terms of transmission security and quality of transmitted information.

**Keywords.** Telemedicine, mobile device, public healthcare, South Africa

## Introduction

The South African public health care system has been struggling to provide the most basic health care services to the South African population. Additional strain is placed on the system due to the rural nature and the financial inequality of the country. Telemedicine has the unique potential to fundamentally improve the South African public health care system. It can do so by establishing a health care system which provides equitable access to quality health care services to all South Africans [1–3].

Advances in the information and communication technology (ICT) sector, the African mobile phone revolution, and the introduction of telemedicine, can provide the appropriate means to battle the issues faced by the public health care sector [4]. Telemedicine is a rapidly developing applicator of clinical medicine. “mHealth”, which is the application of telemedicine services by means of mobile devices, is leading the way in the advances being made in the application of health care in South Africa [5–7].

Telemedicine services and mhealth applications are being implemented more frequently in the public health care sector of South Africa. The volume of available literary information which pertains to the success or functionality of such services and applications in a South African context is insufficient [1,8]. There is a great lack of understanding in the utilisation of mobile devices in conjunction with telemedicine

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<sup>1</sup> Corresponding Author: Andre Hartmann, Department for Industrial Engineering, Stellenbosch University, Private Bag X1, Matieland, Stellenbosch, 7602, South Africa; Email: [Liezl.VanDyk@nwu.ac.za](mailto:Liezl.VanDyk@nwu.ac.za)

services.

The purpose of this study is to develop an understanding in the use of mobile devices in administering telemedicine services within the public health care sector of South Africa.

This paper is structured as follows: First, the method section elaborates on the construction and distribution of the questionnaire, which was utilized to attain the relevant information which pertains to mobile devices in the public health care sector of a South African province. Secondly, the outcomes of the questionnaire are presented in the results section, which are followed by a brief discussion of the results.

## **1. Methodology**

The online "Use of Mobile Devices in Health Care" questionnaire was constructed with the purpose of obtaining information on the utilisation of mobile devices in the public health care sector. The questionnaire was run over a period of six weeks in conjunction with a research study which assessed the maturity of telemedicine services in that region [9]. The Stellenbosch University Health Research Ethics Committee (HREC) approved the questionnaire based on the ethical clearance which was granted for the overarching research study.

### *1.1. Questionnaire Design*

The construction of a questionnaire involves a certain procedure, which includes considering research questions, defining a target population and finally formulating the questions themselves [10].

The questionnaire was thus structured according to the 5M's of manufacturing, namely man, machine, method, money and material (refer to Table 1). Applying the 5M's of manufacturing to mhealth services may seem inappropriate at first, however, the generic description associated with manufacturing processes are similar in nature to those of a telemedicine service. For instance, each mhealth service consists of a wide range of users which interact with the telemedicine system or service (man), using a certain device or platform (machine) to exchange medically relevant patient information (material). These interactions are ideally governed by previously agreed upon work protocols and policies (method), and funded by appropriate financial structures (money). Man, machine, material, method and money are thus defined as the 5 domains which make up a telemedicine service [11].

### *1.2. Target Populations*

The research questions listed in Table 1 and the purpose of the questionnaire provide a clear indication as to the composition of the intended target population. The definition of the target population is of importance as it affects the level and type of the response information extracted. The target population was thus defined to include health care workers and health care professionals who are employed or active in the public sector (i.e. Administrative Staff, Community Service Doctor, Intern, Managerial Staff, Medical Officer, - Specialist, - Student and Nurse).

### 1.3. Distribution of Questionnaire

Six regional and district telemedicine co-ordinators of one of South Africa's provincial health systems assisted in the electronic distribution by e-mailing the description of the study, together with the questionnaire URL to respective staff and colleagues. This enabled the collection of independent telemedicine service data.

Although this method of distribution provided an efficient, timely and cost effective means of collecting relevant telemedicine data, control over the recipients of the questionnaire was lacking. The resulting composition of the sample demographic was thus unclear and had to be determined once the data collection had been concluded.

**Table 1.** Questionnaire Design

Category	Questions
Demographics	What is the job title for your current position? What is your gender? What is your age? What is the highest level of education you have completed? Number of years (health care sector) work experience? What is the name of the Health Care Facility you are currently working at? What type of Health Care Facility do you work at?
Man	What will motivate you to use mobile devices for Health Care purposes?
Machine	Do you use your mobile device to capture, document or transmit medical data? Which type of mobile device are you currently using? Which operating system does your mobile device use? Which mobile service provider do you subscribe to? How would you rate your mobile device signal coverage? Did you purchase your mobile device with the intention of using it in the health care sector? Do you use your mobile device to assist you in your work, by attaining information via the internet?
Material	How do you capture or document medical data with your mobile device? How do you transmit/receive medical information/data via your mobile device?
Method	Does the protocol you follow when using your mobile device deviate from the standard protocol? If yes, are the new protocol formalized in your institution? Does the Health Care Facility you work at have a mobile device policy?
Money	Who purchased your mobile device? Who carries the operating costs of your mobile device? Do you receive any reimbursement for the use of mobile devices to you in your work?

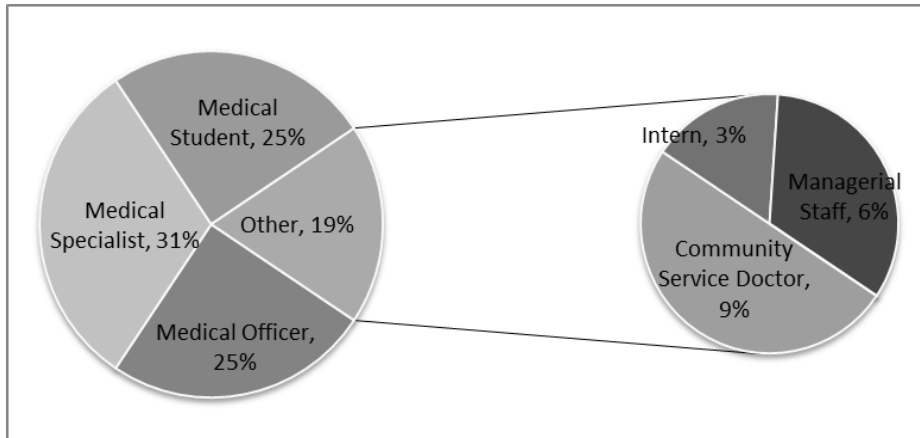
### 1.4. Demographics of Respondents

An analysis of the demographic data concluded that the gender distribution of the sample was approximately two thirds male (69 percent) and one third female (31 percent). The dominant age group was composed of health care workers aged 25-to-35. A lack of respondents in the age group 65-and-older confirmed that the intended target population, ranging from medical students to medical specialists active in the public health care sector, composed the sample. It can therefore be concluded that the sample of the "Use of Mobile Devices in Health Care" questionnaire is representative of a



predominantly male health care workforce aged from 25-to-44, which is an accurate representation of the current public health care sector of the Western Cape.

Previous studies indicated that telemedicine services implemented in the public health care sector of the Western Cape are predominantly utilised by Medical Officers or Specialist Physicians. The sample data supported these hypotheses. The majority of the respondents (94 percent) were medical-orientated personnel, ranging from medical students to highly experienced physicians, who have acquired a specialisation in a certain medical field (see Figure 1).



**Figure 1.** Job title distribution of respondents

According to the demographic data presented, the target population was a fair representation of this province, despite the relatively low response frequency (32 responses).

## 2. Results

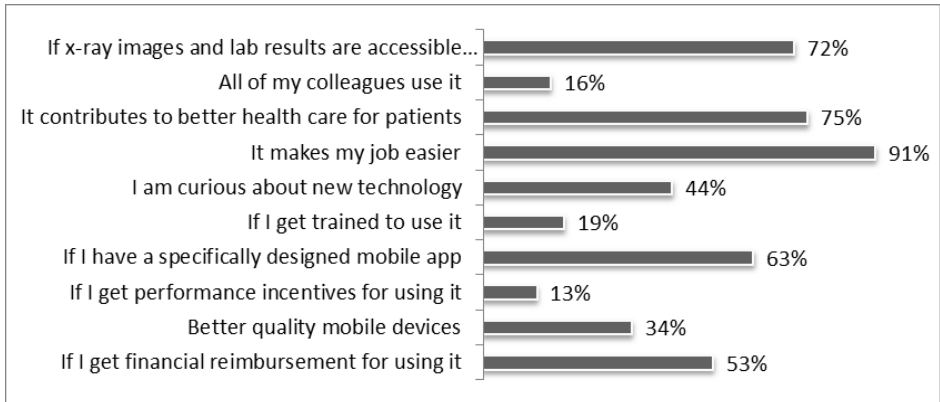
The purpose of the questionnaire was to obtain information pertaining to the use of mobile ICT within the public health care sector of one of the provinces of South Africa. The questionnaire was thus specifically constructed to align with the five domains of a telemedicine service, as previously elaborated on. The results obtained from the questionnaire are therefore represented according to the five domains: Man, Machine, Material, Method and Money. This helps to establish an understanding of the utilisation of mobile devices in health care.

### 2.1. Man

The questions listed under the Man column in Table 1 were formulated with the aim of obtaining information pertaining to an individual utilising a mobile device to administer clinical medical services. The primary purpose of these questions was to

develop an understanding of the factors which motivate medical staff to utilise mobile devices to facilitate health care services.

The synthesis of the sample data revealed that for 91 percent of the sample (29 respondents) the key motivational factor or incentive to utilising mobile devices in the health care environment is the factor that technology makes the job easier (see Figure 2).

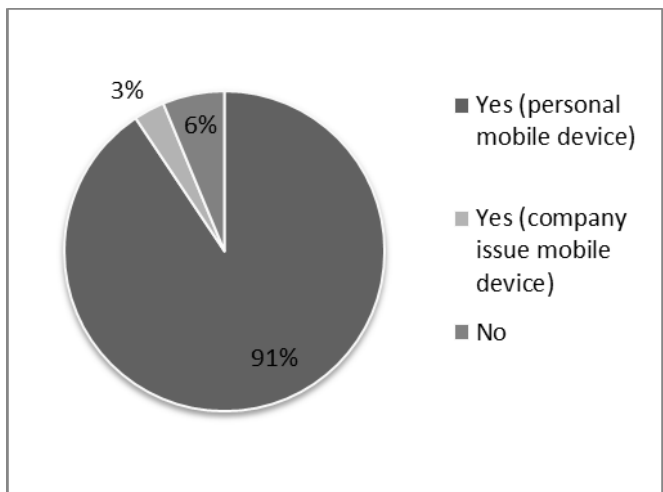


**Figure 2.** Incentives which promote the use of mobile devices to facilitate telemedicine services

Seventy five percent of the sample was of the opinion that the health care benefits accompanied by the implementation of telemedicine services contribute largely to the preferred use of telemedicine services. Likewise, 72 percent of the respondents highlighted the importance of connectivity and accessibility of medical data with respect to telemedicine services. Finally, 63 percent of the sample is of the opinion that telemedicine-specific health care policies would positively impact the use of mhealth services.

## 2.2. Machine

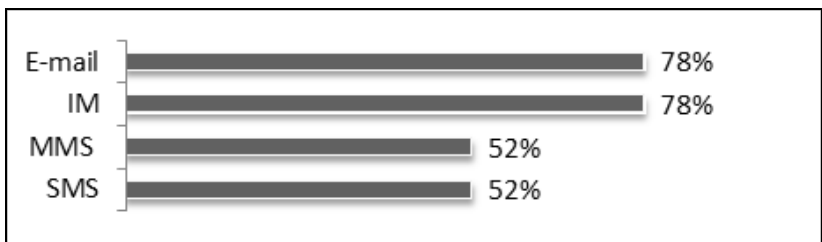
In the Western Cape public health care sector the primary devices utilised to perform telemedicine services are mobile phones. The questions aligned with the Machine domain in Table 1 serve to establish a certainty that the statement is indeed valid. An analysis of the sample data pertaining to these questions revealed that 94 percent of the sample population utilise mobile devices within the public health care sector, for the purpose of administering medical care (see Figure 3). Of the sample population, 64 percent use mobile phones.



**Figure 3.** Percentage of sample population utilising mobile devices for health care purposes

72 percent of the respondents use mobile devices to capture, document and transmit medical information. In other words by using a mobile device to capture and transmit patient data, the health care worker is performing a telemedicine service, or more specifically a mhealth service. 28 percent of the sample utilise the digital camera incorporated in modern mobile devices to capture medical data. 41 percent utilise a combination of text based messages and digital cameras to capture such information. Furthermore, the sample data indicates that 41 percent of the health care workers purchased a mobile device with the intention of utilizing the device in the health care environment.

The synthesis of the sample data concluded that the transmission of medical data is conducted by means of mobile devices utilised in the following applications: e-mail, instant messaging (IM), MMS and SMS (see Figure 4). In addition, a resounding 91 percent take advantage of their mobile devices connectivity and mobility to attain medical information via the internet, instead of consulting other sources of information.



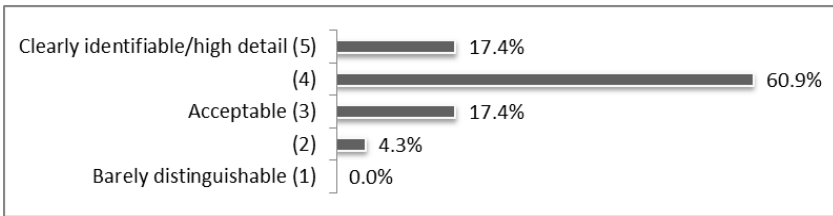
**Figure 4.** Applications utilised for the transmission of medical data

### 2.3. Material

The Material domain of a telemedicine service refers to the type of medical information which is captured, transmitted and, according to which a diagnosis is established. As in the case of the four other domains, it too forms an integral part of a telemedicine service. The average material which is captured, analysed and transmitted in conjunction with a telemedicine service, is rated to be acceptable and relatively secure. The questions associated with the Material domain, as listed in Table 1 are aimed at obtaining data which pertains to the material captured and transmitted by means of mobile devices. A number of conclusions were drawn.

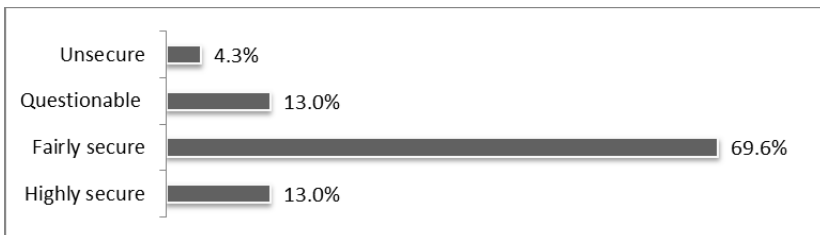
As previously mentioned, 72 percent of the respondents utilise a mobile device to capture, document and transmit medical data. The overwhelming majority (96 percent) capture medical material by means of a mobile device camera.

Question 21 prompted the respondents to rate the quality of medical data captured and transmitted via mobile devices. They made their assertions based on a scale ranging from 'Barely distinguishable' (1) to 'Clearly identifiable/high detail' (5). The majority (60.3 percent) considered the medical material captured and transmitted via mobile devices to be more than acceptable (see Figure 5).



**Figure 5.** Rating of material quality captured and transmitted by means of mobile devices

Further enquires were made to develop an understanding of the presumed safety of the medical data captured and transmitted. A resounding 69.6 percent (see Figure 6) of the sample rated the capture and transmission of patient medical data via mobile device networks as fairly secure, with only 4.3 percent regarding such services as unsecure.



**Figure 6.** Telemedicine material transmission security rating

## 2.4. Method and Money

Current health care policies, procedures and ethics are not formulated to incorporate the use of mobile devices to perform telemedicine services. These policies unfortunately provide the basis upon which financial structures are established. [9].

A financial reimbursement structure thus implies that there are policies governing, and methods of measuring the usage of telemedicine services and vice versa. According to the responses, the majority (92 percent) of the respondents do not receive any financial support for utilising mobile devices in order to administer medical care.

Of the health care facilities represented in the sample, only 7 percent are known to be equipped with health care policies which accommodate the use of mobile devices in health care. This information, coupled with the previously mentioned fact that mobile phones are the primary devices utilised for the provision of telemedicine services, indicates that telemedicine services are implemented even in the absence of appropriate health care and mobile device policies.

## 3. Discussion

The purpose of the questionnaire was to attain an understanding of the use of mobile devices such as mobile phones, laptops and tablets in the health care sector of South Africa, more specifically the Western Cape. The questionnaire participants were considered to be suitably knowledgeable about the South African context and the domain under investigation. They proved to provide a fair representation of the Western Cape health care sector.

The data acquired across the five domains of telemedicine provided ample information pertaining to the more frequent utilization of mobile information and communication technology in the health care sector. Consensus was reached that accessibility, ease-of-use; mobility and connectivity are key factors which promote the use of mobile devices within the health care services.

The majority of the participants utilise mobile phones to capture, transmit and diagnose patient health care data solely because of the added mobility, connectivity, access to information and ease of use. Medical staff executes these services regardless of health care policies or reimbursement structures. The benefit of quality health care outweighs health care policies and financial structures, especially because quality and security of patient data is not impeded.

## 4. Conclusion

This study has certain limitations of which the relative small sample size is of the greatest concern. It is also possible that persons who responded were biased toward telehealthcare. However, despite these limitations the outcomes of the "Use of Mobile Devices in Health Care" questionnaire provide some pointers for consideration concerning the utilisation of mobile devices in the health care sector of South Africa, for example:

- It was found that the majority (91%) of healthcare workers use their own mobile devices in the execution of their professional tasks. This can contribute

the lack of interoperability of systems and be a drawback for the identification of best practices as the formulation of standard practices to enable telehealthcare.

- The most popular reason for healthcare workers to use their mobile phones is that it makes their job easier and the least popular motivational factor is performance incentives. This is a useful consideration to manage change in which mobile devices are playing a pivotal role.
- A few healthcare workers developed their own healthcare apps. This possible indicate a case for bottom-up innovation initiatives instead of top-down initiatives.

The advantages and the utilisation of mobile devices, in combination with telemedicine or mhealth services, is becoming more evident, despite the lack of appropriate health care policies or financial structures. The results of the questionnaire have opened discussions pertaining to mobile devices in health care. These results must be taken into consideration when plans are made to improve the current health care system of South Africa.

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# The design and implementation of a ubiquitous personal health record system for South Africa

Michael KYAZZE<sup>1</sup>, Janet WESSON and Kevin NAUDE

*Department of Computing Sciences*

*Nelson Mandela Metropolitan University, Port Elizabeth, South Africa*

**Abstract.** Doctors can experience difficulty in accessing medical information of new patients. One reason for this is that, the management of medical records is mostly institution-centred. The lack of access to medical information may affect patients in several ways, such as: new medical tests may be carried out at a cost to the patient, and doctors may prescribe drugs to which the patient is allergic. This paper presents the design and implementation of a ubiquitous Personal Health Record system for South Africa. The design was informed by a literature review of existing personal health record standards, applications and the need to ensure patient privacy. Three medical practices in Port Elizabeth were interviewed with the aim of contextualizing the personal health record standards from the literature study. The findings of this research provide an insight as to how patients can bridge the gap created by institution-centred management of medical records.

**Keywords.** Personal health records, ubiquitous access, design, cloud storage

## Introduction

Electronic Health Information is categorized as follows:

1. Electronic Medical Records (EMRs): Issued by each medical practice for their record keeping purposes;
2. Electronic Health Records (EHRs): A legal collection of various electronic medical records by a government body; and
3. Personal Health Records (PHRs): Collection of various medical records that is initiated and maintained by an individual for purposes of continuity of care [1, 2, 3].

Medical records in South Africa are mostly institution-centred [2, 4], which causes fragmenting of medical history. The lack of a complete medical history for patients in South Africa may require patients to take an active role in managing their medical information. Patients can do this by requesting their doctor's notes when travelling.

Current measures that aim to provide complete medical records for patients in South Africa include setting up a nationally accessible Electronic Health Record (EHR) system [5]. Currently, patient management systems do exist at provincial level in public sector hospitals. The South African National Department of Health has recognized the need for eHealth research that aims to improve the effectiveness of the National Health System [6].

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<sup>1</sup>Corresponding author: Michael Kyazze, Janet Wesson, Kevin Naude; Nelson Mandela Metropolitan University, Port Elizabeth, South Africa; Email: {michael.kyazze, janet.wesson, kevin.naude}@nmmu.ac.za}

This paper proposes a practical design of how PHRs can be utilized by both patients and medical practices, which require medical histories of their new patients. The pervasive nature of mobile devices makes them an ideal tool for capturing, measuring and monitoring an individual's health and well-being. This has given rise to mHealth, which is defined as the provision of health-related services via mobile communications [7]. Mobile phones are a versatile tool, which can facilitate ubiquitous access to PHRs. However, little research has been done in South Africa and little attention has been given to the design and implementation of PHR systems to determine their effectiveness and potential usefulness in South Africa [8].

The aim of this paper is to present the design and implementation of a PHR system in South Africa and results from an interview study carried out with three medical practices in Port Elizabeth, South Africa regarding the management of PHRs.

The remainder of this paper is organized as follows. Section 1 discusses PHRs in detail and existing international PHR standards. Sections 2 and 3 discuss related work and the results of an interview study carried out with three medical practices in Port Elizabeth. Section 4 discusses the design and implementation of a PHR system. In Section 5, we suggest opportunities for future research and also conclude the paper.

## **1. Personal health records**

Szolovits, Doyle, Long, & Kohane [9] highlighted the shortcomings of centralised patient management systems that directly exclude patients from the management of their health records. They proposed a personal health system referred to as "Guardian angel" that collects medical data, checks and interprets it and explains to the subject medically relevant facts and plans. This was envisioned to improve the quality of medical decision making and minimize medical errors.

The following benefits can be realised with PHRs [10, 11]:

1. They provide a unified summary of an individual's health history;
2. They encourage family health management, that is having a system for tracking and updating healthcare information can help care givers such as those caring for young children and elderly patients to manage their care;
3. They are easy to understand and use;
4. They provide access to healthcare data from anywhere in the world; and
5. They facilitate continuous communication between patients and physicians.

The benefits of PHRs have been well documented. It is also important to review existing PHR standards before actual design and implementation is carried out. Standards exist to ensure that a given product or service meets acceptable criteria of a given community. Standards are usually documents that provide requirements, specifications, guidelines or characteristics that can be used consistently to ensure quality [12]. Below is a discussion of data encoding standards for PHRs.

### *1.1. Data Encoding Standards*

Health records should be encoded using best practices and globally accepted standards in order to ensure interoperability of the data. Two of the prominent standards are the Clinical Document Architecture (CDA) by Health Level Seven (*HL7*) and the Continuity of Care Record (CCR) by the American Society for Testing and Material International [13].



1.1.1. Continuity of Care Record (CCR)

The Continuity of Care Record (CCR) standard was created by the American Society for Testing and Materials to enable physicians to collect patient care information in a structured, human-readable and transferable format [13]. This standard was incorporated by Health Level Seven (HL7) into their Clinical Document Architecture (CDA).

1.1.2. Clinical Document Architecture (CDA)

HL7 is an international organization focused on developing standards to enable the interoperability of different medical information systems [14, 15]. HL7 created the CDA as the standard format for exchanging clinical documents [16].

The HL7 has several working groups each concerned with an aspect of eHealth. One of such groups is the Mobile Health Work Group which is tasked with the creation, promotion and the maintenance of Mobile Health (mHealth) related standards and frameworks [17]. Figure 1 highlights the functions in the PHR standard.

Personal Health	PH.1 Account Holder Profile
	PH.2 Manage Historical Clinical Data And Current State Data
	PH.3 Wellness, Preventive Medicine, and Self Care
	PH.4 Manage Health Education
	PH.5 Account Holder Decision Support
	PH.6 Manage Encounters with Providers
Supportive	S.1 Provider Management
	S.2 Financial Management
	S.3 Administrative Management
	S.4 Other Resource Management
Information Infrastructure	IN.1 Health Record Information Management
	IN.2 Standards Based Interoperability
	IN.3 Security
	IN.4 Auditable Records

Figure 1. PHR System functions [15].

The functions (PH.1, PH.2, PH.6, S1, IN.1, IN.2 and IN.3) were selected for the proposed system because they are closely related to the main objective of this research, that is, to facilitate the management of PHRs.

Kharrazi, Chisholm, VanNasdale, & Thompson [18] motivate the following data elements as essential for a complete PHR: allergies, immunizations, surgeries, chronic conditions, medications, family history, contact information and imaging data.

## 1.2. PHR Architectures

Fong & Goldfine [19] argued that there is no single correct way to develop architectures for every enterprise. They concluded by stating that an architecture must be customized to a given environment. They identified five components of any given architecture as: *business unit, information, information system, data, and delivery system*. A detailed explanation of the five components was not presented by Fong & Goldfine. However, Steele & Lo [20] extend the argument by Fong & Goldfine [19] and define a PHR architecture as one that provides a description of how it addresses the storage, management and access of its health data. It also provides descriptions of the hardware, software and networking components required for the delivery of data to allow for goals such as the enablement of on-demand access to data. Steele and Lo present three PHR architectures namely: Local (*no internet connectivity is required*), Remote (*continuous internet connectivity*) and Hybrid (*intermittent internet connectivity*). The design presented in Section 4 makes use of the Hybrid PHR architecture.

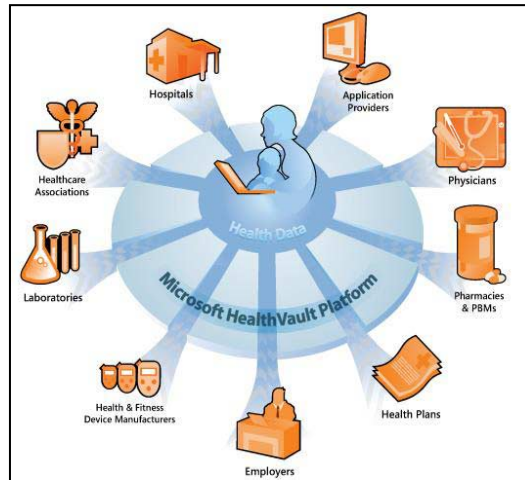
## 2. Related work

Several issues should be considered when innovating health information technologies. These include:

1. Addressing the privacy concerns of system stakeholders (patients and medical practices);
2. Ensuring that the developed artefacts comply with the legislation governing a given geographical area; and
3. Ensuring that system use cases are acceptable to the stakeholders, especially the medical practices.

This related work section takes a high level view of PHR use case scenarios. For the purpose of focusing the discussion, literature on the privacy mechanisms used to secure PHRs is not described here.

Avancha *et al.* [21] refer to Microsoft Health vault (MHV) and Google health (GH) as two well-known PHR services, however Google health was permanently discontinued because of the lack of widespread adoption [22]. MHV is a cloud-based platform that offers a privacy and security-enhanced foundation on which a broad ecosystem of solution providers, device manufacturers, and developers can build innovative new health and wellness management solutions [23].



**Figure 2.** Microsoft health vault platform overview [23].

Microsoft Health Vault is positioned as a *one-size-fits-all* platform that facilitates ubiquitous management of health related data. The data elements highlighted in Section 1.1.2 are captured in MHV. The MHV's one size fits all approach does not cater for the various contexts of use. For example employers and medical providers have different interests in health data. The interview study in Section 3 highlights this limitation.

There are a number of PHR applications, including HealthSpek. HealthSpek was chosen as the winner of the AppyAwards 2013 under the medical category. These awards are dedicated to acknowledging creativity and excellence in application design [24]. Healthspek enables individuals to keep track of their medical history and allows continuous updates with health providers [25]. The data elements specified in Section 1.1.2 are captured by HealthSpek. The American Health Information Management Association maintains a listing of existing PHR applications categorized as either web based, software based or paper based, a total of over 20 applications are listed in their directory [26].

The goal is not to develop yet another PHR application; rather it is to increase the chances of designing and implementing a successful PHR system. Three medical practices were interviewed in order to understand their views on PHRs and how they can make use of them.

### 3. Interview Study

The aim of the interview study was to understand how medical records are currently managed in South Africa and how medical practices can make use of PHRs. Emphasis was put on small practices. The functional and privacy requirements of PHRs that were considered during the interview study were taken from the international PHR System standard by HL7 discussed in Section 1.1.2. The aim was to contextualize the PHR data elements (Section 1.1.2) for use in South Africa.

The interview questions were:

1. Explain how you currently manage your patient medical records.
2. What challenges are you facing in relation to managing patient medical records?
3. What is the process that you use when you get a new patient?
4. Do you think this process could be improved?
5. What is your opinion on patients having an electronic copy of their medical records?
6. Which of the PHR data elements do you currently capture and why?

Participants from two medical practices and a student medical centre at a local university were interviewed. For confidentiality purposes, the medical practices are referred to as Medical Practice A and Medical Practice B.

### *3.1. Medical Practice A*

A medical doctor at Medical Practice A was interviewed. The practice stores patient data in paper files and a spreadsheet is used to cross-reference files. The administrative users find the filing system easy and manageable. The spreadsheet contains patient contact data, insurance data and file look up information, while the paper file contains the actual medical records.

The data is entirely managed by the administrative assistant who is tasked with capturing details and filing. The doctor is not involved with filing patient medical records. The doctor records medical details of the patient onto sheets of paper, which are then passed onto the administrative assistant for filing. The doctor was open to the idea of having a copy of a patient's medical history presented to him by the patient either in paper or digital format. However, the doctor wasn't open to the idea of having to enter the patient's medical details into a computer or mobile device as this would take up his time.

The doctor motivated the need for the following PHR data elements:

1. Allergy Data: If a doctor prescribes a drug and the patient develops an allergic reaction to it, a subsequent doctor may not know about the allergy. In order to prevent more harm to the patient, such data should be made available.
2. Immunization Data: Repeating vaccines makes them ineffective and expensive.
3. Operational Surgery Data: For example, if a patient has had gall stones removed in the Eastern Cape and she shows up elsewhere with the same symptoms, the doctor shouldn't consider gall stones as the possible diagnosis.
4. Chronic Condition Data: Patients may have chronic prescription scripts, such as for diabetes or hypertension. A need exists to keep that information to ensure continuity of care.
5. Medication Data: Doctors need to know what kind of medication a patient has been taking.
6. Family History: A patient's family history can help a doctor in diagnosing an ailment.
7. Imaging Data: The X-ray department sends the doctor medical images, which is considered to be convenient.

The doctor also highlighted the importance of the privacy of medical records. Their medical data is stored in a locked wall filing cabinet.

### 3.2. Medical Practice B

An administrative clerk at Medical Practice B was interviewed. Practice B is a small sized medical practice with one general practitioner and a dentist. The practice stores its patient data in paper files. A file is opened for each new patient. The files are managed by an office assistant. The practice currently captures the following data: immunization, surgeries, chronic conditions, medications, family history and imaging data. They said that doctors need this information when examining patients.

The practice is open to the idea of patients having an electronic copy of their medical records. However, they are concerned about safeguarding the privacy of the patient data. They currently capture all the PHR data elements in physical files and use a computer for file referencing.

### 3.3. Student Medical Centre

A medical administrative clerk at the student medical centre was interviewed. The centre provides the following services to their students: primary health care, occupational health services and HIV and Aids services. The medical centre stores student medical data in paper files. The centre currently captures the following data: immunization, surgeries, chronic conditions, medications, family history and imaging data. The centre currently faces the problem of not having access to student medical histories. Few students are able to provide this information, which the centre deems essential for continuity of care.

The medical centre welcomed the idea of students having partial access to electronic copies of their medical records. However, they argued that information such as doctors' notes should only be shared amongst medical practices. They highlighted the need to have access to medical records from desktop computers rather than mobile devices. The medical centre is concerned about electronic medical records being accessed by unauthorized persons because this violates the privacy of their patients.

### 3.4. Summary of findings from the interview study

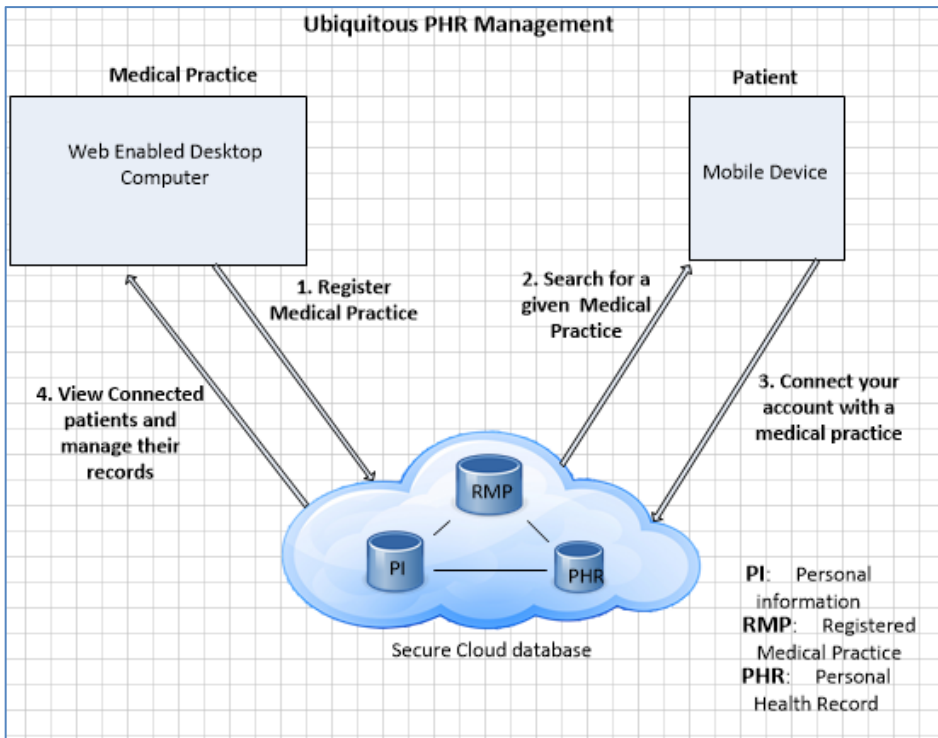
The three practices have processes in place that enable them to adequately manage their patient medical records. However, it was observed that none of the three practices could share medical records amongst themselves. The patient would have to physically request a copy of his/her medical records and take the copy to a different medical practice. One way of addressing this is by empowering patients to be actively involved in the management of their medical records.

Medical practices would like to access complete medical histories of their patients. However, the patient should have little or nothing to do with the actual management of their records. It was also noted that medical doctors should not be tasked with entering medical data for patients as this can waste their valuable time. However, they can be presented with a digital copy of medical data. This information should be presented using desktop computers as this caters for the doctors' context of use. Section 4 presents a ubiquitous PHR design and implementation that limits patient involvement in the management of their records whilst ensuring that medical practices that are geographically separated can easily access this information as needed.

#### 4. Design and Implementation

The design caters for both *Patients* and *Medical Practices*. Patients will make use of their mobile devices to search and connect with registered medical practices. The medical practices will use their desktop computers to manage medical information of their connected patients.

The Hybrid storage architecture [20], which allows data to be stored both on the mobile device and cloud servers for everywhere access will be used. The design supports the two different contexts of use; that is mobile devices for patients and a web application for medical personnel as illustrated in Figure 3.



**Figure 3.** Simplified PHR system architecture showing the different contexts of use.

##### 4.1. Data Requirements

Other than the PHR data elements described in Section 1.1.2, the following elements are also required:

1. Personal data about patients;
2. Data about medical providers; and
3. Data about the medical doctors consulted.

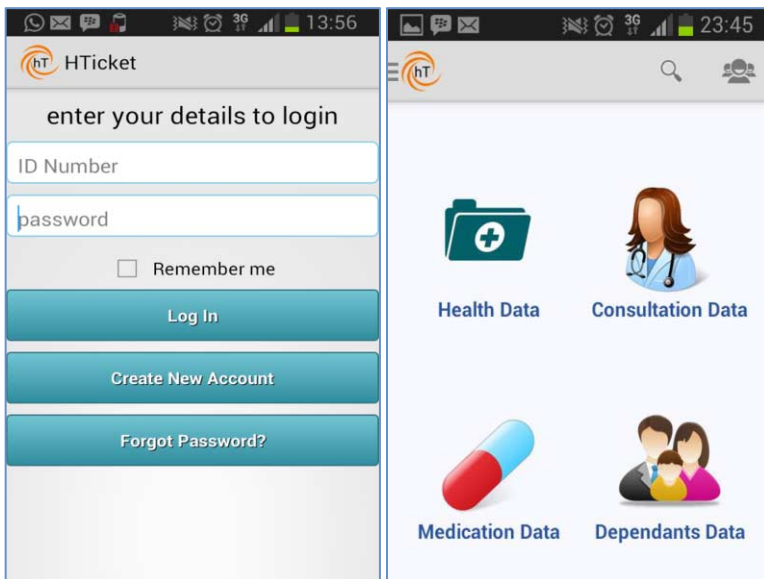
The medical provider and doctor data is important in order to link prescriptions and diagnoses to specific doctors. The medical practices have to be granted explicit permission by a patient in order for them to manage a given patient's PHR data.

## 4.2. Implementation

This section presents the implementation of the ubiquitous PHR system as illustrated in Figure 3.

### 4.2.1. Mobile Application

The mobile user interface as depicted in Figures 4 and 5 presents the data in a format that is easy to use and navigate for the patient. An Android mobile application was developed. The application uses SQLite for local phone storage[27]. MongoDB, which is a JSON document store is used as the cloud database [28].



**Figure 4.** Login and Home Screen

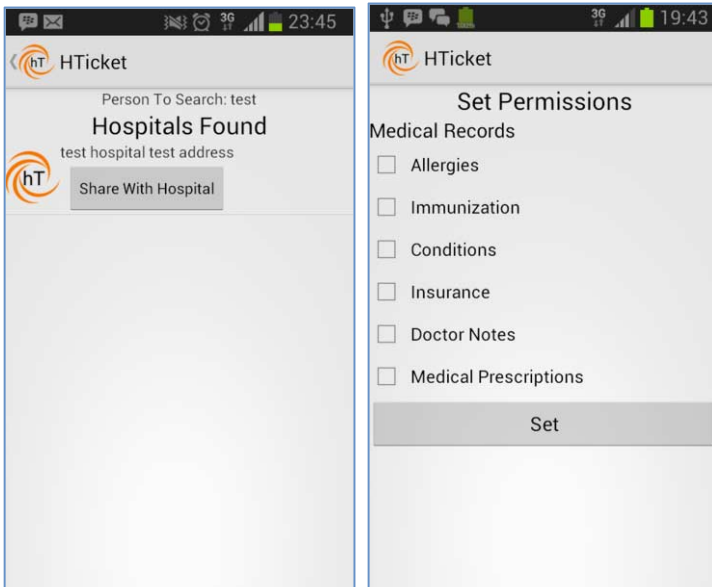
A login screen ensures that only the data owner can access their records. The home screen lists the various functionalities which are:

1. Health data: Individuals can contribute to their health record by self-reporting medical conditions;
2. Consultation Data: Individuals can access a view only version of their medical record or their dependents' medical records;
3. Medication Data: Individuals can access a view only version of their medication record or their dependents' medical records; and
4. Dependents Data: Individuals can contribute to the medical records of their dependents.

The mobile and web applications use the cipher-text policy attribute encryption scheme (CP-ABE) [29] and depersonalization of medical information as mechanisms to ensure that the privacy of individuals is guaranteed. The CP-ABE scheme was chosen because an individual can use their public and master private keys to generate

more restricted private keys for medical practices. The private keys have attributes. The individual can revoke a medical practice's access by removing the practice's attribute from a predefined access policy and re-encrypting the given object.

The CP-ABE's Setup algorithm is run on mobile devices of patients. The algorithm generates a public key (PK) and master key (MK) for the patient. When a patient links their account to a medical practice, the CP-ABE'S key generation algorithm is used to generate a private key (SK) for the given medical practice. The select practice's email address and the MK are passed as the arguments to the key generation algorithm. The practice's email address is also added to the access policy ( $A$ ). Encryption of medical record identifiers is done on the phone and the resultant ciphertext is uploaded to the cloud. The encryption algorithm takes the following arguments: patient public key, message to encrypt and the access policy ( $A$ ). The CP-ABE decryption algorithm is run on a server. The medical practices are able to decrypt the medical record identifiers using their patient generated private keys.



**Figure 5.** Search results and permissions screen

An individual is able to search for a given medical practice and selectively grant and revoke access to their medical data with ease.

#### 4.2.2. Web Application

A java web application was developed. The web application connects to the same MongoDB server as the mobile application. The web application provides medical practices access to the medical records of all the patients that have explicitly connected with them. Figure 6 illustrates the home screen of a medical practice with four patients.



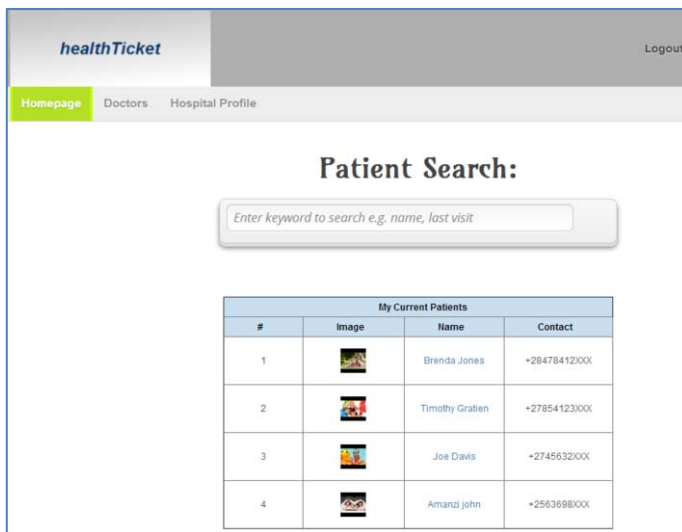


Figure 6. A sample list of patients connected to a practice

A hospital can register the medical doctors associated with them. This allows medical notes to be associated with medical doctors.

Figure 7 illustrates the detailed view of a patient’s medical information. The doctor’s notes tab enables medical practices to upload scanned medical records for storage. The practice can also view doctors’ notes from other practices. The medical notes tab enables medical practices to upload and view medication related information. The health summary tab enables practices to view self-reported medical information by individuals.

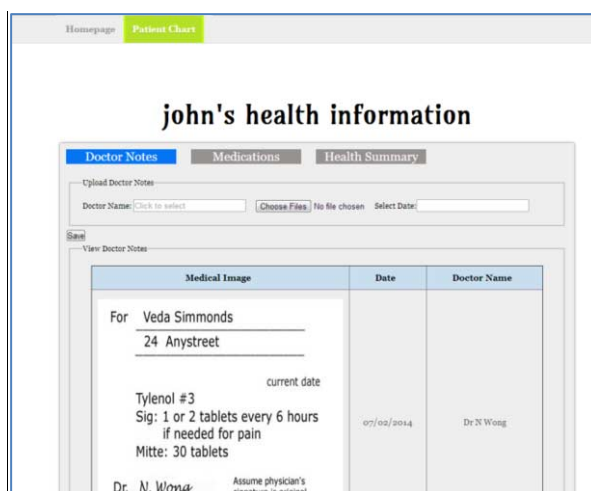


Figure 7. Sample Patient chart

## 5. Conclusions and Future work

The paper has discussed the need for a ubiquitous PHR system in South Africa. The requirements for this system were obtained from a literature review of existing health standards and contextualized by an interview study of three local medical practices. The PHR system design was presented and motivated. An implementation of the design was also presented.

Privacy of health records is critical and failure to address this issue can affect the success of a PHR system. The proposed system uses the CP-ABE scheme to ensure privacy of medical information in a cloud storage environment. Mechanisms such as the separation of medical information from personal information and user login are employed to ensure the privacy of patients.

Preparations are underway for a field study with the student medical centre and their patients. The study will enable us report on the real world impact of PHR systems in a South African medical practice context.

Future work can extend this design to a distributed environment. This is important because, some medical providers may not want to use centralized cloud storage.

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# Providing a USSD location based clinic finder in South Africa: Did it work?

Annie Neo PARSONS <sup>a,1</sup> and Dagmar TIMLER <sup>a</sup>  
<sup>a</sup>Cell-Life NPC, Cape Town, South Africa

**Abstract.** A new mHealth service, *Clinic Finder*, was designed to provide a location-based service for any cellphone user in South Africa dialing a dedicated USSD string to find the nearest public primary health care facility. The service was funded by a European Union grant to Cell-Life to support the National Department of Health. Clinic Finder's aims were to provide a reliable and accurate service, and to assess both the most effective means of advertising the service as well as interest in the service. Users dialing the USSD string are asked to agree to geo-location (Vodacom and MTN users) or asked to enter their province, town and street (virtual network users and those choosing not to geo-locate). The service provider, AAT, sends the data to Cell-Life where an SMS with details of the nearest public primary health care facility is sent to the user by Cell-Life's open-source Communicate platform. The service was advertised on 3 days in 2014 using two different means: a newspaper ad on 20 May 2014 and Please Call Me ads on 30 July 2014 and 14 August 2014. 28.2% of unique users on 20 May 2014, 10.5% of unique users on 30 July 2014 and 92.8% of unique users on 14 August 2014 who agreed to geo-location successfully received SMSs. However, only 4.2%, 0.5%, and 2.4% of unique users responding to each advertisement who did not geo-locate then received an SMS. A small survey of users following the 20 May 2014 newspaper ad found overall interest in the idea of Clinic Finder, though unsuccessful users were more likely to dislike the service. The overall experience of using location based services and USSD for Clinic Finder suggests a need in the field of mHealth for wider availability of data on service usability and effectiveness.

**Keywords.** Location Based Service, USSD, mHealth, South Africa

## Introduction

Clinic Finder is a mHealth service that provides any cellphone user in South Africa with the capacity to find their closest public primary health care facility. Dialing a dedicated USSD string allows a user to either use a network's location based service or specify their location by province, town and the nearest street.

The service was designed and developed by Cell-Life with AAT as the service provider under a 2-year grant awarded by the European Union (EU) to Cell-Life to support the National Department of Health in developing mobile-based health service quality monitoring and health promotion services. Clinic Finder supports South Africa's national policy of promoting primary health care as the entry-point to health services.

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<sup>1</sup> Corresponding Author: Annie Neo Parsons, Cell-Life NPC, 123 Hope Street Avalon 4 Building Gardens, 8001, Cape Town, South Africa; Email: [annie@cell-life.org](mailto:annie@cell-life.org)

Cellphone penetration in South Africa is high, with around 87% of South African adults owning a cellphone in 2013 of which 36% were smartphones [1]. Using Unstructured Supplementary Service Data (USSD) technology allows for any cellphone user to access the service regardless of cellphone capability. Vodacom and MTN subscribers have the option of using the networks' geo-location of their cellphones to automatically receive a Short Message Service (SMS) with the nearest clinic listed. The service did not incorporate GPS technology into the location-based function as this would have restricted users from the target audience of lower-income South African cellphone users without access to smartphones.

Subscribers to the Cell C, Virgin Mobile and Telkom Mobile networks do not have this option; instead, they are asked to select the province, then town and enter the street name of their location. A list of closest street matches is then provided and an SMS with details of the nearest clinic is sent to the user. MTN and Vodacom subscribers who do not choose the automatic geo-location function have the option of following this same process. The database of public primary health care facilities was sourced from the South African National Department of Health.

A limited number of similar mHealth services exist in South Africa on a range of platforms [2, 3, 4], with AAT an experienced service provider in this field [2], but with no available data on service effectiveness or uptake. Though USSD is generally agreed upon as one of the only means of reaching all cellphones regardless of functionality [5], the authors struggled to find data on reliability and usability. A previous study by Cell-Life found that half of a small user sample experienced problems in using USSD, mostly as a result of network or service provider failures [6]. Similarly, though the application of location-based services is a growing field [7], there are some questions around the accuracy of non-GPS location-based services in South Africa [8].

## **1. Aims**

The primary aim of Clinic Finder was to provide a reliable and accurate service for any functionally literate cellphone user in South Africa to locate the nearest public primary health care facility. This supports the National Department of Health in encouraging users of the public health system to access services through primary care facilities where possible, rather than seeking care at referral or specialist institutions and increasing patient load at those facilities.

The secondary aims were to evaluate the most effective means of advertising such a service and to assess interest in the service. Limited data are available in the public sphere on effective marketing of similar services in South Africa, and whether or not these initiatives speak to a national need among potential users.

## **2. Methods**

Clinic Finder was designed to direct users of South African cellphones to their nearest primary health care facilities. The service was designed and developed in 2013, then advertised nationally and evaluated in 2014.

### 2.1. Process

Users dialing the dedicated USSD string from Vodacom or MTN received a home screen asking if the service could geo-locate them. Users answering ‘Yes’ to this question would then get a screen informing them that a SMS would shortly arrive with details of their nearest public primary health care facility. AAT then sent the user’s MSISDN and GPS coordinates to Cell-Life where the request was queried against the database of primary health care facilities used by the national Department of Health and supplied by HISP. Data queries were restricted to facilities tagged as ‘Clinic’, ‘Day Hospital’ and ‘Community Health Centre’. Facilities tagged as ‘For Profit’ were excluded. A resolved query was then passed to Cell-Life’s open-source messaging platform, Communicate, and an SMS sent to the user.

Users on virtual networks – Cell-C, Virgin Mobile, or Telkom 8eta – did not receive a request for geo-location but were instead asked to choose their province, town and street. AAT then provided a list of best matches for the street; the user’s choice was sent as mid-point GPS coordinates to Cell-Life to follow through on the database query and messaging process. Vodacom and MTN users who did not agree to geo-location were asked to go through the same process as virtual network users.

Initially Clinic Finder was designed as a free-to-user service, as up to July 2013 the use of USSD was provided at no cost to users by most of South Africa’s network providers. USSD now costs 20 cents for 20 seconds across networks, but it was decided to continue with the USSD design as it remained the most practical available method of utilizing location based services for lower-end cellphones. Reverse-billed USSD was introduced as an option in April 2014: as there are considerable budget implications it was decided to first assess the existing version.

### 2.2. Advertising

Clinic Finder was advertised three times: once in a newspaper with national circulation (the *Daily Sun*) on Tuesday 20 May 2014 and twice via Please Call Me (PCM) ads on Wednesday 30 July 2014 and Thursday 14 August 2014. The same text was used in each ad. *The Daily Sun* has an estimated national circulation of ~330,000 and targets lower-literacy, lower-income individuals of whom approximately a third are based in Gauteng. This is in line with the target population for ‘Clinic Finder’ as some level of literacy is required to navigate the text-based system. The PCM ads were limited to 110 characters and attached to over 1.1 million PCMs sent by Vodacom users on each day of advertisement.

### 2.3. Assessment

The service usability was quantitatively assessed after each advertisement date by calculating the number of sessions, the number of unique users, how many times a user had to reconnect to complete a session, the number of complete sessions resulting in an SMS being sent to the user (“successful sessions”), and successful sessions according to the user agreeing to geo-location or not. A Cell-Life fieldworker called 68 users who had successfully and unsuccessfully completed a session to conduct a short semi-structured questionnaire following the first advertisement of the service. The objective of these calls was to assess interest in the service among those who attempted using it. There is an implicit bias in these results as users were randomly selected from those

who attempted to use Clinic Finder and therefore had their MSISDNs registered on the service; there was no attempt made to survey those who may have read the ad but not used the service as this was outside the scope of Cell-Life's resources. Of the 68 calls, 10 successful users and 10 unsuccessful users agreed to provide feedback on their perceptions of the service. Qualitative data were thematically analyzed.

### 3. Results

Clinic Finder's uptake was considerably higher when advertised via PCM ad than when advertised in the *Daily Sun*. However, higher user numbers initially meant lower success rates for the service, measured in terms of number of SMSs successfully sent and user agreement to using a network's geo-location. Surveys conducted following the newspaper ad with a small number of users found that Clinic Finder was generally regarded as a useful service, though users who were unsuccessful in receiving SMSs were not inclined to recommend or use it again.

#### 3.1. Reliability and accuracy of the service

The newspaper advert on 20 May 2014 saw a total of 295 attempts on the day of advertisement, with 225 unique MSISDN numbers. Most users only attempted once to dial into Clinic Finder, regardless of whether or not they successfully received an SMS. A similar pattern was observed when Clinic Finder was advertised via PCM ad on 30 July 2014 and 14 August 2014, though the number of attempted sessions was 10-fold higher at 2,026 and 1,952, with the subsequent number of unique MSISDN numbers at 1,739 users and 1,767 users respectively (Table 1).

However, the number of completed sessions varied considerably: on 20 May 2014 there were 59 SMSs sent by the Communicate platform, a final success rate of 26.2% among the 225 unique MSISDN users. Of the 1,739 unique users who tried Clinic Finder on 30 July 2014, only 190 or 10.9% received SMSs (excluding 1 failure generated by Communicate). After extensive work by the service provider, AAT, the number of completed sessions improved considerably on 14 August 2014 to 866 SMSs, or 49.0% of the 1,767 unique users.

**Table 1.** User information for Clinic Finder following advertisement on 20 May 2014, 30 July 2014 and 14 August 2014

Measure	20 May 2014	30 July 2014	14 August 2014
Number of attempted sessions	295	2,026	1,952
Number of unique users	225	1,739	1,767
Average number of attempts per user	1.3	1.2	1.1
Number of SMSs sent by Communicate	59	190	866

This had a particular effect on the percentage of users who agreed to geo-locating and successfully received an SMS. On 30 July 2014 this stood at only 10.5% of users, as opposed to 28.2% on 20 May 2014. By 14 August 2014 this had improved to 92.8% of users (Table 2). Most of the failed geo-location requests were listed on the data sheet

given to Cell-Life by AAT as having received no response from the network (classified as ‘Network error’ in Table 2). This generated a network error rate of 71.8% on 20 May 2014 and 89.5% on 30 July 2014, but dropped to 7.2% on 14 August 2014.

**Table 2.** Geo-location user success data for Clinic Finder on 20 May 2014, 30 July 2014 and 14 August 2014

Measure	20 May 2014	30 July 2014	14 August 2014
Users agreeing to geo-location	156	1,073	1,176
Users agreeing to geo-location and received SMS	44	113	1,091
% Users geolocating who received an SMS	28.2%	10.5%	92.8%
Network error for geo-location	112	960	85
% network error for users agreeing to geolocation	71.8%	89.5%	7.2%

The success rate for geo-location on days when the service was not advertised, prior to the additional extensive work by AAT on the geo-locating, varied according to the number of users attempting to use the service. Days with only 2 attempts to geo-locate had no failures. Higher numbers of attempts led to failure rates. For example, on 26 and 30 June 2014 there were 2 attempts on each day to geo-locate and all were successful, but on 24 May 2014 there were 7 attempts of which only 2 were successful and on 18 June there were 2 successes in 4 attempts.

However, regardless of the additional development work by AAT, Clinic Finder’s success rates were consistently low among Vodacom and MTN users who chose not to use the geo-location option and among virtual network users without the geo-location option (Table 3). Approximately a third of all users on all advertisement days recorded “0” for geo-location, of whom 39.4% (28) on 20 May 2014, 7.8% (49) on 30 July 2014 and 13.0% (101) on 14 August 2014 were from virtual networks. Only 4.3% of users recording “0” for geo-location on 20 May 2014 successfully received an SMS. This went down even further to 0.5% of users on 30 July 2014, and then improved slightly to 2.4% of users on 14 August 2014.

Of the 666 users with “0” listed for geo-location on 30 July 2014, only 66 chose their province, 44 chose their city and 14 entered their street. This implies that the low success rate also reflects willingness to engage with USSD, as well as possible technical error.

Two further errors were noted that affected the service’s technical functioning. Firstly, a user responded to one of the successful SMSs sent on 30 July 2014 (messages sent by users responding to SMSs sent by the Communicate platform are stored in ‘Lost Messages’, which are routinely checked by Cell-Life staff) with a statement that the clinic sent was not the nearest clinic. On investigation it was found that AAT had sent through to Cell-Life the mid-point coordinates based on the town and not on the street. It is not known to what extent this affected the overall service. Secondly, analysis of the requests sent through from AAT to Communicate for 14 August 2014 found that 329 of the 1,195 completed sessions recorded by AAT (or 27.5%) were received by Communicate as containing no geo-location information and did not therefore trigger SMSs to users. It was beyond the scope of this paper to assess the degree to which this latter issue reflects on the technical limitations of LBS service provision.



**Table 3.** User success data for Clinic Finder among Vodacom and MTN users not choosing the geo-location option and among virtual network users unable to use geo-location on 20 May 2014, 30 July 2014 and 14 August 2014

Measure	20 May 2014	30 July 2014	14 August 2014
Users with "0" listed for geo-location	69	666	776
As % of all users attempting the service that day	30.7%	38.3%	43.9%
Users with "0" for geo-location, received SMS	3	3	19
% Users not geolocating who received an SMS	4.3%	0.5%	2.4%

### 3.2. Service uptake and interest

The PCM ads generated considerably more users than the national newspaper ad on 20 May 2014. A possible explanation for this is that potential users of the service who received the PCM ads had cellphones easily accessible (as they would have read them on a cellphone). However, the higher rate of service failures initially experienced with increased uptake was problematic (Table 4), along with the continued failure of non-geolocating users to complete sessions.

**Table 4.** Comparative success rates for users attempting Clinic Finder on 20 May 2014, 30 July 2014 and 14 August 2014

Measure	20 May 2014	30 July 2014	14 August 2014
Successful users (% of total)	59 (26.2%)	190 (10.9%)	866 (49.0%)
Unsuccessful users (% of total)	166 (73.8%)	1,549 (89.1%)	901 (51.0%)
Total number of users	225	1,739	1,767

A randomized sample of Clinic Finder users were called by a Cell-Life fieldworker following its advertisement in the *Daily Sun*, on the 22<sup>nd</sup> and 23<sup>rd</sup> of May 2014. All users attempted the service on the day of the ad. Though numbers for users who did not choose the geo-location option were included in the group of users who did not complete sessions, no additional specific question was asked about the USSD experience (a limitation realized with hindsight). An equal number of men and women agreed to the survey, though the numbers were uneven across the two groups (3 men and 7 women were in the group who received the SMSs; 7 men and 3 women were in the group who did not receive the SMSs).

The two broad rationales for using the service were:

- Testing the service (10 responses).
- Need (10 responses).

Users who cited 'need' as the rationale for attempting Clinic Finder gave a variety of reasons, ranging from trying to find a clinic near campus (1 respondent), to trying to find a clinic other than the one currently being used (2 respondents), to having moved (2 respondents), to wanting one near work (1 respondent), to asking on behalf of someone else (2 respondents), to having an immediate medical concern (2 respondents).

The majority of users who did receive an SMS were largely satisfied. 2 respondents were unhappy as they both failed to find the clinic using the details listed in their SMSs.

6 of the 10 users who did not receive the SMSs were disappointed and/or upset by the outcome. For example: “I felt bad because I ended up not going to seek medical help because I don't know where the clinic is.” 2 users specifically referred to the service as false advertisement. Overall, 8 of the 20 users wanted ‘Clinic Finder’ to include the details of the nearest private health facilities, though 12 felt it should only provide details for public health facilities.

On being asked if they would recommend the service, 8 of the 10 users who received an SMS said yes – the 2 who did not being those who failed to find the clinic listed in their SMSs. 3 of the 10 who did not receive the SMSs said they would recommend the service. Reasons for recommending the service were linked to its convenience, with comments such as “It makes life easy especially if you are new in the area”. Reasons given for not recommending the service focused on its non-delivery.

#### **4. Conclusions**

The consistently low success rate among users who did not use geo-location suggests that USSD is of limited effectiveness. Two potential reasons are that USSD lists are not a popular or well-understood option for this service’s target users, even though the technology is accessible on all cellphones, or that networks’ low prioritization of USSD calls is a more significant factor than envisioned during design of the service. The cost of using USSD (20 cents for 20 seconds) may also have affected user willingness to dial back in if the session was dropped. Consistent collection (and publication) of such data by services utilizing USSD will assist future initiatives in assessing the most effective means of reaching basic and feature cellphone users in poorly-resourced settings where smartphone penetration remains low.

Clinic Finder also showed that providing a non GPS-based location based service was a more complex technical task than initially expected when receiving high user numbers. Though Cell-Life tested the service for several weeks prior to launch at scale (and continually throughout the period analyzed), it was only once significant numbers of users attempted to use the service in a short space of time that issues were revealed. Ultimately Clinic Finder only managed to successfully sent SMSs to just under 50% of users attracted by the last PCM ad on 14 August 2014.

Moreover, advertising of Clinic Finder suggests that cellphone-based services are more effectively advertised when a cellphone is utilized as part of the advertising method. The PCM ads generated 10-fold greater user interest in Clinic Finder than the newspaper ad. This may reflect better familiarity – or curiosity – with cellphone technology among those who read the ad on their cellphones. Clinic Finder’s poor success rate also has implications for any continued interest in the service. Though Cell-Life’s limited telephonic survey of users generally found an interest in the Clinic Finder service, particularly among those who were successful in using it, over a period of time its failure would hinder any possibility of self-perpetuation through word of mouth.

Overall, given the continued need in the mHealth field for successful technologies that can reach all makes of cellphone, Cell-Life’s experiences with Clinic Finder suggest that designing any such service is hampered by a lack of an accessible body of

knowledge on usability. There is a general need for better recording of any service's usage data (for example of network limits on location based services) as well as its publication. In-depth studies on user and network limitations in using USSD will remain necessary until basic and feature phones become obsolete.

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# Monitoring falls in elderly people: Lessons from a community-based project

Habibollah PIRNEJAD <sup>a,b</sup>, Golenur HUQ <sup>a</sup>, Jim BASILAKIS <sup>a,1</sup> & Anthony MAEDER <sup>a</sup>

<sup>a</sup> School of Computing Engineering & Mathematics, University of Western Sydney, Campbelltown, Australia

<sup>b</sup> Medical Informatics Research Center, Urmia University of Medical Sciences, Urmia, Iran

**Abstract.** *Objectives.* This paper describes an evaluation of a community-based fall-detection project using smart phone based tri-axial accelerometry to identify factors that affect adoption and use of such technology by elderly people. *Methods.* A mixed methods study using questionnaires and semi-structured interviews was conducted to evaluate attitudes of the elderly people participating, as well as project stakeholders involved in the project. Information registered in a web-based fall management system was analyzed both qualitatively and quantitatively, using an adapted version of Unified Theory of Acceptance and Use of Technology (UTAUT). *Results.* Adoption rate was 61.7% and attrition rate was 57%, the most common reasons for attrition being health deterioration (50%) and problems with the device and the network (26.2%). *Conclusion.* We identified a number of challenges that affected the success of this project, including problems with the software, usability issues with the device, coverage of the network, training of participants, and inadequacy of providing participants with a strong sense of safety and security.

**Keywords** Tri-axial accelerometer, falls, evaluation, usability, telemonitoring

## Introduction

Assistive technology solutions based on wearable devices and mobile computing have become very popular recently, particularly for “hospital in the home” types of situations such as patients in recovery or rehabilitation, chronic disease sufferers, and disabled or elderly living independently. With the trend of taking technology applications for healthcare from the laboratory to real life settings, there is clear need to evaluate and understand where the main challenges reside and how this technology is appreciated and used. The Telehealth Research & Innovation Laboratory (THRIL) at University of Western Sydney (UWS) was involved in a project on detecting falls in community-dwelling elderly people using tri-axial accelerometers in 2012. By evaluating this project, we aimed to get insight into important factors that affect the “adoption and use” of the fall detection technology by elderly people, and the “challenges” involved in a community-based project.

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<sup>1</sup> Corresponding author: Dr Jim Basilakis, School of Computing, Engineering & Mathematics, University of Western Sydney, Locked Bag 1797 Penrith NSW 2751, Australia; Email: j.basilakis@uws.edu.au

## **1. Study Context**

The evaluated fall detection project was conducted in the Australian Capital Territory (ACT) for six months from May 2012 to October 2012. Three organizations were involved in the project: a Clinical Partner (Anglicare), a Research Partner (University of Western Sydney (UWS)) and a technology Partner (Mediinspect). The Clinical Partner is a charity organization and its agencies work in close cooperation with other community organizations. It receives funding from Federal, State and Local Governments to provide a wide range of health and social services including residential and community aged care. The Clinical Partner was the administering agency under a grant from Australian Government to set up the fall detection project. The Research Partner was involved in the project to provide research advice and support, with a view to test the fall detection technology and collect characteristics of participants' use of the technology from a real world setting. The Technology Partner is a Czech Republic company, which provided the tri-axial accelerometer device for movement and fall monitoring and related data collection software.

In this setting, the Clinical Partner recruited the elderly participants; obtained their informed consent; captured their relevant clinical information; deployed the device for their use; educated them on how to use the system (in collaboration with UWS); set up a call centre to support the project; monitored the movement data collected; and responded to fall and emergency events detected by the fall detection technology. Recruitment took place through advertising in ACT using two main screening criteria: age 65 and over, and living independently in the community. The project coordinator was responsible for managing the call centre and arranging visits to the participants regularly and irregularly whenever it was necessary, for example in case of losing connection. The Technology Partner developed the tri-axial accelerometer application for falls detection, the central data repository, and the fall management web-based system. It also customized the technology and provided remote technical support. Their fall management system was used exclusively for monitoring detected events (including notifications of possible fall events). UWS hosted the fall management system and the data repository via the THRIL computing infrastructure; installed and configured the fall detection software on devices; provided local technical advice and research support for the Clinical Partner; and liaised for technical issues between the two other partners. UWS was also responsible for supporting research and analyzing the collected data.

The architecture of the project consisted of software to detect over-acceleration from a waist-mounted device containing tri-axial accelerometer technology (installed in a smart phone), a communicating mechanisms to transfer data packets from the smart phone to the fall management and data storing systems over a network, and a call centre for monitoring recorded Possible Fall (PF) and Emergency Alarm (EA) events of the participants. The fall detecting software was installed into a smart phone with capability to detect movement using tri-axial accelerometers. The system was able to detect over-accelerations ( $>27 \text{ m/s}^2$ ) due to PFs and broadcast them to the fall management system over a GSM digital cellular network. The technology included an "alarm" functionality that allowed sending alert messages to the call centre either automatically in case of sustained fall, or manually through touching a red touch-button on the device's touchscreen. Following detection of PF or EA events, the system also sent SMS messages to a clinical caregiver (the project coordinator) for follow up.

A web-based fall management system was used for listing broadcasted events despatched by the smart phones. Each participant had a personal profile held in the fall management system database. This profile included the elderly person's basic demographic data, important medical history (including fall history), and a record of all the sentinel events received from his/her smart phone. The project coordinator had access to this system and was in charge of monitoring the received events and handling them. Four types of sentinel events were recorded in the system: possible fall (PF), emergency alarm (EA), low battery, and lost connection. The coordinator contacted the participants to gather information about each of their events registered in the system, confirmed if a real fall had happened, collected information regarding each of the recorded events, and inserted comments on them on the subject's profile.

## 2. Theoretical Background

A major focus in our study was understanding the experiences of the users of the fall detection technology (the elderly people) and the way they responded to this technology. Many theories have been advanced to understand how users adopt and use innovative technologies. Unified Theory of Acceptance and Use of Technology (UTAUT) combines different theories in this field based on principles of Technology Acceptance Modeling (TAM) to explain users' intentions to use a technology and their subsequent behaviour in using the technology [1]. This theory has been used to evaluate technology adoption and utilization in various fields' areas of mobile technology and information technology [2, 3]. Therefore, we selected UTAUT as an appropriate theory to interpret our findings in this study.

Considering specific characteristics of our users (being elderly, having no previous experience with similar technology, and volunteering to use it), we adapted the theory for our purpose. Figure 1 provides a summary of the influential factors in our UTAUT approach. "Behavioural Intention" in UTAUT terms is a subjective probability that a person will engage in a given behaviour [4]. In the adapted form of UTAUT, there were three main determinants for "Behavioural Intention": "Performance Expectancy" which is defined as 'the perception or belief that using a system will enhance or improve person's quality of life performance'; "Effort Expectancy" which is defined as 'the degree of ease associated with the use of a system'; "Social Influence" which is defined as 'the degree to which an individual perceives that important others believe he or she should use the new technology'.

"Facilitating Conditions" is defined as a degree to which an individual believes that organizational and technical infrastructure exists to support use of the system. "Behavioural Intension" and "Facilitating Conditions" are considered the main determinants of actual "Use Behaviour" and continuing with a technology use [1]. Gender is considered as one user characteristic that might influence actual "Use Behaviour" by affecting "Performance Expectancy", "Effort Expectancy", and "Social Influence".

In interpreting the results of the study, a socio-technical perspective was adopted. This frame of reference states that it is not only the technology and its qualifications that determine the outcome of its implementation and use in a real world environment. The final outcome results from the interactions between the technology and the social, organizational, and cultural characteristics of the implementation environment [5, 6]. If

not managed properly, these socio-technical interactions can add up to the existing technical complexity and aggravate the effects of technical shortcomings [7].

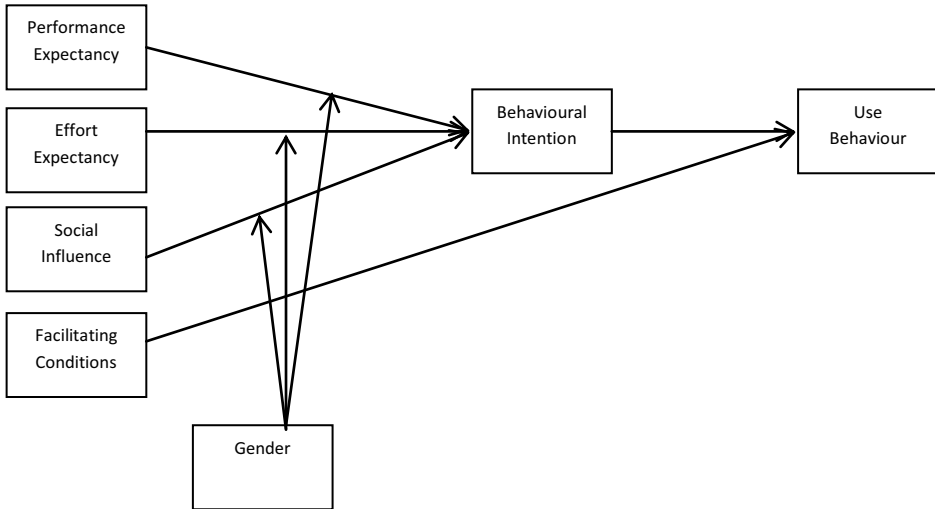


Figure 1. Adapted UTAUT model for use in the study.

### 3. Study Methodology

This was a cross sectional mixed methods evaluation study, using qualitative and quantitative research methodologies as follows.

#### 3.1. Data Collection

Qualitative data were collected through two questionnaires (one for the participants and one for the project stakeholders), and interviews (with project stakeholders). In addition, three semi-structured, face-to-face, and one-on-one interviews were conducted with the project stakeholders, each one lasting from 10 to 35 minutes. Another source of data was the web-based fall management system. By the end of the project, a wealth of information about each of the participants and their recorded sentinel events was registered in the system.

All participants who received the devices and managed to use them for all or part of the project, were included the study. Three project members from UWS, the project contact person from Mediinspect, and the project coordinator from Anglicare were also included. The fall detection project ended in October 2012; the evaluation study started in May 2013. Data collection, including interviews, surveys, and data extraction form the fall management system, took 4 months. The questionnaire used for the elderly people was intended to evaluate their satisfaction and problems in using the device as well as to learn from their feedback on how the project could be better. The questionnaire did not collect any identifying information from the subjects. There were

11 questions with yes/no/not sure answers, 1 multiple choice question, and 3 open ended questions.

The project coordinator, who had developed a close relationship with the elderly and could provide them with further explanation about the questions, distributed and collected the questionnaires. The questionnaire for the stakeholders included 10 open-ended questions and was intended to learn about the project objectives from different stakeholders' point of view, the organization of the project, and the main challenges and problems that they encountered during the project. Further follow up questions or interviews were organized in case more information or clarification was needed. The interviews were focused on elaborating upon the concepts came from the stakeholders' questions. For example, more specific questions were asked from the project coordinator about difficulties experienced in following up the registered events in the system. From the fall management system, the elderly's demographics, their fall history, notes about each registered event, and information registered concerning the elderly's problems during the project or their reasons for leaving the study were of interest. Data with respect to the participation changes in the course of the project were also collected from the fall management system.

### *3.2 Data Analysis*

The demographics data and information collected from the fall management system were used to provide an overview about the project with descriptive statistics. The number of the participants and their changes over the course of project were also obtained from the fall management system. Adoption rate of the technology and attrition rate of the participants were calculated and their differences between the two genders were tested using two-sample z-test at a significance level of 0.05. Reasons for attritions, PFs, and EAs were categorized and frequency of each category provided. Categorization of the registered PF events and their clinical relevance was performed considering previous studies [8, 9]. Written comments and answers for the open-ended questions from the questionnaires, written notes on the fall management system, and transcripts of interviews were pooled and analyzed qualitatively. Inductive method of qualitative data analysis (grounded theory) was used to recognize important themes appeared in "adoption and use of the fall detection technology" and "challenges" of the project. Themes found through inductive analysis related to the concepts from the adapted UTAUT. The findings were discussed between the authors to reach agreement.

## **4. Quantitative Results**

Before the project started 120 (F:M= 90:30) elderly people were interviewed and agreed to participate in the trial. Of these, 74 people (F:M=56:18) ultimately were issued with the device and commenced participation in the study. The average age of the participants was 81 years (F:M=80.4:82.4). 29 participants (53.7%) had a history of one or more previous falls. The total adoption rate of the technology was 61.7% (74/120). Comparing the adoption rate between female (56/90) and male (18/30) genders, using a two-sample z-text, showed no significant difference ( $p>0.05$ ).

Of the 74 participants who received the devices, 42 stopped using the device and left the trial for several different reasons (attrition rate=57%). Health deterioration (e.g., myocardial infraction, and worsening dementia) was recorded as the most common



reason (50%) for leaving the trial. The second common reason (26.2%) was problems with the device and the network (Table 1). Comparing the attrition rates between female (47/56) and male (15/18) participants, using a two-sample z-test, showed no significant difference ( $p>0.05$ ). Of the 32 participants who stayed in the project, only 14 (18.9%) termed ‘consistent users’ had their data recorded consistently in the system throughout the trial period (F:M=9:5).

**Table 1.** The number of participants that left the project and their reasons for leaving.

Reasons for leaving the project	Number	Percentage
Health deterioration (e.g., heart attack)	21	50
Problems with the device and network	11	26.2
No special reason determined/stated	6	14.3
Personal reasons (e.g. going on holiday)	4	9.5
Total	42	100

The participant questionnaire and results are presented in Table 2, for 54 participants who responded. Most of the respondents (87%) did not have any problem with their activity data being collected and thought that the device did not restrict them during their daily activity. Many of them (61%) were satisfied with the device in general. However, only 37% found the device easy to understand; only 27% found it easy to use, and many of them (65%) did not feel more comfortable when using a mobile phone. The majority (91%) felt that they were contacted as often as they needed during the project; however, only 43% thought that the device would be of benefit in their life and only 35% stated that they felt safer while wearing the device. Many (65%) thought that even with 24/7 call centre the device would not help them to live longer in their home.

**Table 2.** Questionnaire used for 54 elderly people who completed the trial.

Question	Yes %	No %	Not sure %
1 Did you feel you were limited in your daily activities whilst you were wearing the device?	13	87	0
2 Do you believe the device would be of benefit to you in your daily life?	43	43	14
3 Did you find the device easy to understand?	37	59	4
4 Overall were you satisfied with the device used in the study?	61	35	4
5 Do you believe the hilly terrain of Canberra affected the efficiency and reliability of the device?	35	39	26
6 Did you feel safer whilst wearing the device?	34	66	0
7 Do you currently or have you ever used a medical alarm service?	34	66	0
8 Did you feel that you were contacted as often as you needed to be during the project?	91	8	1
9 Do you feel comfortable with having your activity data collected and sent to your health care team?	87	13	0
10 Did using the device during the study make you feel more comfortable when using a mobile phone?	35	65	0

11	Do you think with a 24 hour call centre the device would help you to live independently for longer in your own home?	35	65	0
12	Did you find the smart phone device which is fitted with the touch screen easy to use?	57	39	4

## 5. Qualitative Results

Many sociotechnical issues were encountered during the project, which have been grouped under six relevant themes related to adoption and use of the technology.

### 5.1. Device Issues

There were many problems with the device that contributed to its full function during the trial. Some of them were related to the fall detecting software but many others were related to the smart phone used in the project. All stakeholders of the project agreed that they had difficulties in getting the software ready to be used in the trial. The software was not prepared specifically for the project purpose and the decision on using it on a smart phone rather than a custom wireless communications platform was a last minute decision. The software was in Beta release and had to be debugged repeatedly before a reliable version was attained. The inbuilt algorithm detected many of the elderlies' daily routine activities (e.g., walking down stairs, picking up something from a shelf, or sitting on a chair) as possible falls events.

After the Alarm button was touched, the software responded by playing a voice message for the user telling them what they should do in case of an emergency. However, this message was sometimes unintelligible because of hearing problems, and also confusing for some users. A participant stated that: "Often it speaks, but I could not hear or understand what it was saying". There were also many notes from the coordinator in the fall management system stating that a device was "chattering and needed resetting". It was not clear why this happened but in many cases the coordinator had to reinstall the software. Moreover, the participants had 7 real falls that were not recorded in the system: all happened while they were not wearing the device. There was no way to make sure whether they were wearing the device on a regular basis.

There were also a number of physical aspects of the smart phone complicating the above-mentioned problems further. Perhaps the most important issue was the short battery life of about 1 day. The phone needed to put on charge immediately when it stated "battery low", otherwise it turned itself off and needed turning on again after it had finished charging. More often than not, the participants forgot to recharge the phone and in some cases it remained off until the coordinator noticed and contacted them. Another issue was the sensitive touch screen of the phone. The Alarm went off very easily, for example as a result of bumping against something or bending down.

Using a smart phone with touch screen and multiple functionality (including normal cell phone functionalities) made understanding and using the device difficult for participants. They stated that it was hard for them to read the screen (because of their poor vision), and use the Alarm button. One elderly stated that: "It was over my head". Many stated that they would rather to have a real button instead of 'touch button' on the screen. Moreover, the phone's other functionalities were interfering with

its fall detection purpose. One participant stated that: “It was a multifunctional device and received messages and telephone calls not relating to the trial”. Some participants suggested that the project could be improved if the device was “more simple and serving as a unique fall detector and not a multifunctional one”.

The phone was waist-mounted with the use of a belt and a pouch. This method turned out to be problematic too, as phones were not sitting firmly in place and could slip out frequently. Dropping the device was a common reason for PFs, and happened more frequently when users were changing their clothes e.g. before bedtime and when they were visiting the toilet. Some participant found it inconvenient using the belt and the pouch and preferred to put the device in their pocket instead. In responses to the questionnaire, it was suggested that a better way of attaching the phone was needed.

### *5.2. Network Issues*

Some of the participants in our study were living in a mountainous area with patchy GSM network coverage, which turned out to be a big issue. This caused a problematic data collection and monitoring in some cases as the phone connection was going on and off. Loss of connection was annoying for some participants and an important reason for them to quit. In one case the project coordinator noted: “Reception to the network at her home was poor. The device had to be turned off and on again each day and did not always see the network anyway. She has had enough of dealing with the device and asked that I collect it.”

### *5.3. Training Issues*

The project coordinator provided a training session for each of the participants before delivering the phone. The training continued as needed each time the coordinator visited. Nevertheless, lack of enough and appropriate training and education was an important complaint in many cases. A participant stated: “Occasionally the phone would ring and I didn’t know how to answer it. Was I not told?” Many of the participants proposed increasing training sessions as a way of improving the project too.

### *5.4. Sense of safety and security*

The Clinical Partner as an active community organization and as a project authority invited the participants to join the project and use the technology. The objective of the project was only monitoring of the elderly and no intervention was intended. With this monitoring, the project was expected to increase the feeling of safety and security in elderly people lived at their own home. However, lack of good understanding of the phone and feedback from the project team detracted from this and the participants lost faith in the technology and the project gradually. A participant stated that: “It gave me no feeling of security because I did not understand what it was recording and even if it worked.” In some cases the phone even created an extra source of stress for them. The project coordinator noted: “It made her aware of her balance problems and constantly trying to correct them was stressful for her. Her blood pressure at this time also became uncontrolled and she needed extra medication”.

### 5.5. Organization of the project

Shortage of grant funding overshadowed many aspects of the project. For example, there was not enough money to buy a better smart phone, or to recruit more people to work in project support. Only one person was recruited to work as the project coordinator, as well as fulfilling the roles of system operator, and participant educator. The stakeholders commonly agreed that better results could be achieved if a call centre with more operators was set to work 24/7 and to communicate with participants immediately after an event was detected. Participants commented that they felt they needed more training. The start-up training might have been more useful if it was followed by refreshing sessions. The project did not have any planned intervention, but, our findings showed that the participants were expecting more than just monitoring.

Besides the above-mentioned problems, there were also difficulties with respect to coordination between the project stakeholders. The project stakeholders were located in different geographical locations (in different countries and in different cities) which disrupted ease of coordination and efficient progression throughout the project. This problem was more notable between UWS and Mediinspect, as they worked together a lot to get the fall detection application up and go, and to keep it working smoothly. A stakeholder stated that: “UWS and Mediinspect spent a lot of time talking and many skype sessions were needed to get briefed and communicate software faults”.

## 5. Discussion

With the perception that the technology would benefit elderly persons' health (positive “Performance Expectancy”) and with Anglicare's invitation (positive “Social Influence”), the technology received good attention. The participants developed positive “Behavioral Intention” and the adoption rate of the technology was good. The social Influence of Anglicare played a very important role in the high adoption rate. Previous studies have shown when elderly people become increasingly dependent on external help such as health and social services, people from those services take strong opinion formers and advisor position for the elderly [6]. However, in the course of the project, the users confronted with many problems which were rooted in the quality and performance of the technology (i.e., the fall detection software, the smart phone usage, and the network) and elderlies' physical and mental abilities to use the technology. Those problems attenuated the early positive “Performance Expectancy” and “Social Influence” factors. In the context of insufficient training, many of them found the device hard to understand and use, and therefore developed a negative “Effort Expectancy” towards the technology. This negative attitude was augmented by poor “Facilitating Conditions” because of insufficient support throughout the project. Therefore, despite the early positive “Behavioural Intention”, the actual “Use Behaviour” of the technology was affected negatively. We believe this chain of events explains the high attrition rate of the participants throughout the project. There was no significant difference ( $p>0.05$ ) in adoption and attrition rates between female and male participants in our study. This finding showed that in our study, gender did not have a noteworthy impact on adoption and use of the fall detection technology.

For the project stakeholders, recruiting participants was not a big issue. The real challenge was to keep them in the project and to motivate them to continue wearing the device. Only a few of the participants remained loyal to the project and used the device

throughout the trial regularly. Through analyzing the qualitative data, we were able to recognize five main categories of challenges that negatively affected the continuation of use. They were: device issues, network issues, training issues, failure to provide sense of security and safety, and issues with organization of the project.

One of the important challenges of the project was using software which was not specifically developed to be used on a smart phone and had not been tested in real life settings previously. As a consequence, during the project many customizations were required to the software and the fall detection algorithm. These types of problems are not rare for a technology that is being used in a real world setting for the first time. However, as they take unexpected time and energy from the project investigators, they can be discouraging if they are too frequent. Therefore, for better results, it is recommended that the software stability and its functionality should be tested in a small-scale pilot before launching the main trial. The same argument is true for the GSM network. In our study, the network coverage should have been tested in different residential locations of the participant, and appropriate solutions for poor coverage of the network had to be planned before launching the trial.

Another important challenge was the choice of smart phone. It was not an appropriate choice in many respects. The device's design and its usability characteristics were inappropriate for the elderly people. This inappropriateness created unexpected complex sociotechnical problems and caused the majority of the EAs and many of the PFs events to be recorded. Considering elderly people's physical and mental abilities and what they value in use of a new technology is critically important in the technology's successful adoption and use. Previous studies indicated that in adoption and use of a technology, elderly people would value services that can make their everyday life and tasks easier and provide added safety [6]. Therefore, a simplified usability characteristic with good functionality (e.g., real alarm button) is preferred over the state-of-the-art technology (e.g., touch screen alarm button). Proper education, training, and practice are very important too. Recently, researchers also showed that, contrary to the deterioration of perceptive abilities and memories of elderly people, through proper instruction, training, practice, iteration and communication, elderly people can maintain their cognitive abilities and benefit from new technology or services [11]. The survey of the elderly showed that the majority of them (87%) had no problem with recording their movement data and many of them (61%) mentioned that they were happy with the device in general. This satisfaction was related to the objective of the device (and the project) and not to the choice of the smart phone, as they also found the phone hard to learn (59%) and not easy to use (69%).

Health related issues and multiple morbidities in elderly people are a very important challenge to continuation of technology use. Dealing with and managing these issues properly is necessary to keep the involved participants in the project and to prevent high attrition rate. In our project, 50% of the attrition was due to health issues. This high attrition rate could be prevented if the project was part of their health problems' solutions, for example by providing necessary medical advice whenever they needed. Such a health related intervention was necessary to preserve the users' trust in the project. If fall-detection projects are expecting to prevent psychosocial damage of fall in elderly and to increase sense of safety and security for elderlies who live at their own home, they need to have a plan on how to handle their different health related issues in the course of the project.

The current tri-axial accelerometer based fall detection technology needs further development, due to typically very high false positive rates. Managing false positives

while making sure that no real alarm is missing is a resource intensive task. In the long term, too many false alarms can bring ‘alarm fatigue’ and undermine the objectives of the fall monitoring projects [10]. Therefore, the number of alarms has to be reduced in an appropriate way. Many elderly people may suffer from medical conditions (for example total knee replacement) that affect their gait. Therefore, the technology need to be adjusted based on elderly people’ individual medical conditions. The current technology is one-for-all and the possibility of easy adjustment to the needs of different groups of participants was not foreseen in its development. It might be necessary to produce different versions of fall detection algorithms and software to choose the appropriate ones among them based on each participant’s physical and mental characteristics. Another problem that should be addressed through further development of the fall detection technology is feedback on wearing the device. The technology needs to accommodate a complementary mechanism to show whether or not a person has worn the device. Such wearing feedback is especially helpful when the device does not detect any movement data.

## **Conclusion**

This study had many limitations which should be considered in interpreting and generalizing its findings. First, the survey for participants was not standard, and it was not designed to test UTAUT. Therefore, we could not fully determine the constructs of the UTAUT concepts, nor could we determine the weight of each concept on actual use behaviour. Moreover, it was not possible for us to interview participants and therefore we missed an important source of qualitative data in our study. A lot of information that we analyzed came from the notes on the fall management system which were written by the project coordinator. The workload of the project coordinator and the post-hoc nature of the notes leave much possibility for bias and omission.

“Performance Expectancy” and “Social Influence” play important roles in acceptance of the fall detection technology and joining of the elderlies to the project. However, continuation of the use depends very much on “Effort Expectancy” and “Facilitating Conditions”. Continuation of a technology use can benefit from its simplicity (less complexity), ease of use, and considering elderly people’s physical and mental limitations in its usability design and training programs. Support of users is also important. This support should include not only the technical aspects of the use, but also a plan on how to handle elderly persons’ health related issues to reduce the negative effects on their continuation of use.

## **Acknowledgement**

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# Applying change management metaphors to a national e-Health strategy

Chad SAUNDERS <sup>a,1</sup>, Richard E. SCOTT <sup>b,c</sup>

<sup>a</sup> Assistant Professor, Haskayne School of Business, University of Calgary, Calgary, Alberta, Canada

<sup>b</sup> Professor, Department of Telehealth, University of KwaZulu Natal, Durban, South Africa

<sup>c</sup> Director, Office of Global e-Health and Strategy, University of Calgary, Calgary, Alberta, Canada

**Abstract.** Recent attempts at a collective understanding of how to develop an e-Health strategy have addressed the individual organisation, collection of organisations, and national levels. At the national level the World Health Organisation's *National eHealth Strategy Toolkit* serves as an exemplar that consolidates knowledge in this area, guides practical implementations, and identifies areas for future research. A key implication of this toolkit is the considerable number of organisational changes required to successfully apply their ideas in practice. This study looks critically at the confluence of change management and e-Health strategy using metaphors that underpin established models of change management. Several of Morgan's organisational metaphors are presented (highlighting varied beliefs and assumptions regarding how change is enacted, who is responsible for the change, and guiding principles for that change), and used to provide a framework. Attention is then directed to several prominent models of change management that exemplify one or more of these metaphors, and these theoretical insights are applied to evaluate the World Health Organisation's *National eHealth Strategy Toolkit*. The paper presents areas for consideration when using the WHO/ITU toolkit, and suggestions on how to improve its use in practice. The goal is to seek insight regarding the optimal sequence of steps needed to ensure successful implementation and integration of e-health into health systems using change management models. No single model, toolkit, or guideline will offer all the needed answers, but clarity around the underlying metaphors informing the change management models being used provides valuable insight so potentially challenging areas can be avoided or mitigated.

## Introduction

Almost since the inception of the use of information and communications technology (ICT) in health (i.e., e-Health) [1], there have been publications concerning architecture, infrastructure, implementation, change management, evaluation, sustainability, and integration. Recently, reports and toolkits regarding e-Health strategy have been published. Each publication offers different perspective and

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<sup>1</sup> Corresponding author: Chad Saunders, Assistant Professor, Haskayne School of Business, University of Calgary, Calgary, Alberta, Canada. Email: chad.saunders@haskayne.ucalgary.ca



recommendations. Perhaps as a consequence we have still not resolved how best to ensconce e-health within existing health systems. Introducing e-health has typically been approached in a linear and stepwise manner, proceeding from strategy through to integration, with 'change management' (CM) as a discrete activity occurring after or concurrently with implementation. However, critical review of current best practices suggests there is a need for CM throughout an e-health initiative - from conception to integration. The applicable CM model may be different at different stages, therefore understanding the underlying assumptions inherent in any such model is essential to aligning the stage of the e-Health initiative with appropriate CM practices.

The most recent guidance regarding e-Health strategy comes from the World Health Organisation (WHO) and International Telecommunications Union (ITU) [2]. Although termed the '*WHO/ITU National eHealth Strategy Toolkit*', it is less about strategy and more about the process of introducing e-Health to a country. It has three parts, each of which builds on the work of the previous one – it is a linear model taking users from '*National eHealth Vision*' (Part 1) through '*National eHealth action plan*' (Part 2), and to '*National eHealth Monitoring and Evaluation*' (Part 3). As such it takes the user from inception (national e-health vision), through introduction and evaluation (national e-health action plan; national e-health monitoring and evaluation), ideally leading to e-Health being ensconced within a countries health system. While 'change management' is mentioned only twice, the topic of 'change' appears prominently with approximately 147 occurrences in the 223 page document. CM is identified as desirable expertise in the leadership of the 'management and operation' component, and as an example of the type of resource required during the delivery of the action plan.

The Toolkit document also speaks of 'strategic e-health architecture'. This is a worrisome term, since it mixes two specific concepts (strategy and architecture), and for many healthcare organisations, strategic thinking can be quite a different mindset from the current approach. Furthermore, only now is 'strategy' being resolved as an important and discrete entity by itself, and that development of clear and evidence-based strategy comes before, indeed guides, development of the required 'architecture' [3,4].

While it is still too early to evaluate the impact of this Toolkit on practice, this paper proffers that a key aspect missing from the literature in general (and specifically from the Toolkit) is a complementary approach to deal with the type, level, timing, and consistency of CM needed to deliver and capture the full value from using this and similar tools [4]. Currently CM is typically viewed as necessary at the time of implementation (i.e., the point where CM efforts are directed towards seeking acceptance of the project or collection of projects). However, some of the most significant 'changes' will and must, arguably, occur much earlier when dealing with 'strategic' discussions as well as much later when dealing with the sustainability of the changes.

This study leverages and presents this perspective as an opportunity. Four organisational metaphors are applied within established models of CM, and used to critically evaluate the underlying assumptions of the *WHO/ITU National eHealth Strategy Toolkit*.

## 1. Organisational Metaphors of Change Management Metaphors

An underlying premise for e-Health initiatives, especially those of large scope covering regional or national mandates, is that there are benefits to understanding the healthcare system holistically, then determining how to change it, while attempting to determine where resistance will occur. However, there is also the possibility that planning change, especially at that scale, is not possible at all. To help determine where along this spectrum to position e-Health it is necessary to critically assess the underlying metaphors, and allow them to guide conceptualisation of organisations. This insight can then be used as the basis for reflection on whether these assumptions will hold for particular initiatives at a given point in time, and whether those assumptions will also change over time.

To achieve this, Gareth Morgan's [5] work on metaphors is taken and adapted based on an approach by Cameron and Green [6] to highlight four metaphors (of the original eight) that are particularly relevant for understanding how organisations work in the context of the changes associated with e-Health initiatives. The four selected metaphors are organisations as: machine, political system, organism, and flux and transformation. Those not selected were organisations as: brain, culture, psychic prison, and instruments of domination. Those selected are summarised in Table 1, and discussed in greater detail below.

- *Organisations as machines.* Under this metaphor, which dominates modern management thinking and is typical of bureaucracies, organisations are structured and well defined and how the various components are connected is clearly understood [6]. Central to this is the division of labour and management by objectives, who in turn decide when and how change is needed and purely work to manage the shifts in the organisation, including any resistance. Managers simply 'pull the levers' that collectively lead to the required changes. This approach potentially works well in highly stable environments and for incremental changes, but can lead to disastrous results if implemented fully within more dynamic contexts and for more radical or disruptive change.
- *Organisations as political systems.* This metaphor highlights the roles that power, competing interests, and conflict play in organisations. Individuals vary in the levels of power they have in various situations and need to build support for their position as they establish a new coalition and navigate the political map [6]. The challenge with this approach is that since it requires winners and losers (i.e., zero sum game) it can foster a political war zone with 'behind the scenes' negotiating that ultimately leads to a poisoned work environment.
- *Organisations as organism.* This metaphor purports the need for alignment between the organisation and the environment in which it operates. Organisations are collections of inter-related subsystems with changes arising only in response to changes in the external environment [6]. A key assumption is that there is no optimal design or way to manage the organisation, however responses to changes in the environment can be managed in the sense that they can be designed and worked towards. The challenge with this approach is that it does not recognize the possibility for the organisation to influence the environment in which it operates.

**Table 1.** Approaches to Change in Organisations (Adapted from Table 3.1 in [6])

Metaphor	Change Management Approach	Who is Responsible	Key Assumptions
Machine	Targets are set; timelines are established using a top down approach; training is used to address resistance.	Senior management	Change and resistance can be managed and are not problematic
Political System	A new coalition is created which (after various debates / manoeuvrings) leads to the new coalition winning or losing. Others then fall in line with the change.	The powerful coalition	Winners and losers
Organism	Data is gathered, evaluated, and a solution collaboratively developed. Training and support is provided for significant changes.	Business improvement / human resource managers	Broad awareness and involvement in the change, collaboration and support
Flux and Transformation	Change is emergent, as is how to deal with the change.	Someone with authority to act	Change cannot be managed

- *Organisations as flux and transformation.* This metaphor suggests that order naturally emerges out of chaos through self-organising mechanisms and that change cannot be fully managed [6]. The role of management is to create the conditions for change, while embracing tensions and conflicts. This metaphor can be troubling for management since their role seems diminished; it does not lend itself to an agenda or action plan. Instead change is emergent.

## 2. Implications for Theoretical Models of Organisational Change

The previous section provided insight into the underlying assumptions regarding change and how (or if) change can be managed. Below, these metaphors are used to better understand prominent theoretical models of organisational change that have been applied to e-health. This allows academics and practitioners to better understand established e-Health strategy guidelines such as the *WHO/ITU National eHealth Strategy Toolkit*, which is used as an example to illustrate points.

Each of these models exhibit aspects of the various metaphors so it is critical for e-Health scholars and practitioners to recognise the various metaphors in play and, thereby, the underlying CM model(s) being employed since there are contradictions, conflicts, and catastrophes awaiting if these are misaligned in practice. We consider three prominent CM models that cover a range of metaphor combinations.

### 2.1 Bullock and Batten Planned Change [Machine metaphor]

The model of change presented by Bullock and Batten [7] is guided by principles of planned change that is influential within project management. There are four phases, including (i) exploration, (ii) planning, (iii) action, and (iv) integration. During exploration the need for change is verified and resources secured, after which planning can be completed by experts, a diagnosis made and actions identified and organised in a change plan. Integration occurs when the actions are completed and any policies, incentives, and communications are updated as needed to reflect the change.

The machine metaphor dominates this model of change by treating the organisation as parts that can be isolated and modified as needed in an unproblematic way, often with a focus on technical considerations. The *WHO/ITU Toolkit* adopts this CM model and the underlying machine metaphor. For example, the framework for a national e-Health vision (Figure 4 p.12) provides a componentised view of the methods for developing a national e-Health vision that starts with drafting an initial vision, adding resources, assessing the gaps, and refining the process. From a planning and project management perspective this approach has great appeal since it is systematic, easy to understand, and presents reasonable next steps to move the organisation from the current state to some envisioned future state. The challenge with this approach is that it potentially under-estimates the complexity inherent in the organisation leading to unrealistic timelines for the change to occur and potentially misses key barriers to change represented by the lack of consideration for the strong political influences, especially in the context of national e-Health strategies.

### *2.2 Lewin's Three Step Model (and Force Field Analysis) [Machine and Organism metaphors]*

Lewin [8] proposes a three-step process which is built upon a force field analysis that identifies the forces enabling and constraining the intended change. For change to occur the forces enabling the change must be greater than the forces constraining the change. Thus from an organisational change perspective the enabling forces would need to be increased or the constraining forces decreased or some combination of the two. The overall organisational change is viewed as having three steps, with the first step involving unfreezing the way things are currently done so that change can occur. The second step moves from the current state to an envisioned future state, and the third step involves refreezing with new policy, incentives, and standards in place.

Lewin's three-step model [8] is very similar to the Bullock and Batten model [7] in terms of the steps and incorporating key aspects of the machine metaphor. Lewin extends the metaphors to also include aspects of the organism metaphor through the concept of homeostasis, which is the tendency for an organisation to return its prior state even after a change is introduced. Viewing the *WHO/ITU Toolkit* through this model and metaphors, an opportunity arises to incorporate similar thinking that would allow the toolkit to be extended to incorporate the force field analysis and the concept of homeostasis in the refreezing activities.

### *2.3 Senge's Systematic Model [Organism, Political, and Flux and Transformation metaphors]*

Senge et als. [9] approach to organisational change extends beyond a focus on the early stages (e.g., creating a vision, planning, resources, etc.) and instead takes a longer strategic view of change. They begin with some guiding principles (start small, grow steadily, don't plan the whole thing, and expect challenges since it will not go smoothly) and then simply provide ideas for consideration to articulate the forces enabling and constraining change without being prescriptive. They embrace more of the complexity inherent in organisations, recognising the interrelated actions that might take years to play out in an organisation. A critical tipping point for sustaining the change is when the early adopters start to exhibit success and these changes start to have broader impact and implications for the entire organisation.

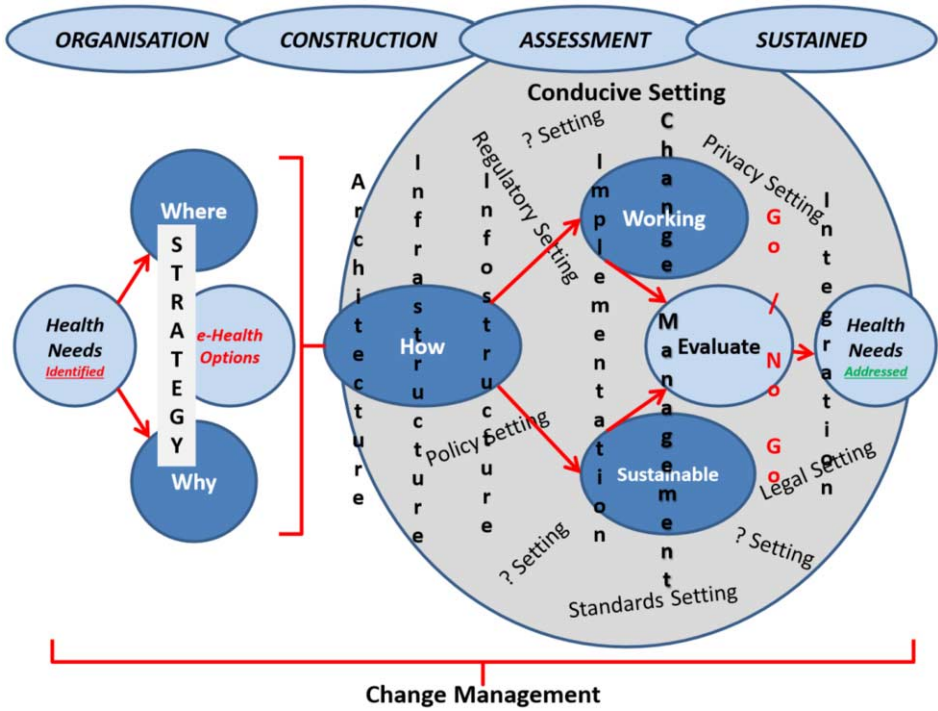
Senge et als. model [9] is based upon the metaphors of organism, political, and flux and transformation. This expands the scope and complexity of understanding of what is needed to not only instigate changes in organisations but also to ensure those changes have a reasonable chance of being sustained in the organisation. The *National e-Health Strategy Toolkit* has the potential to be implemented in a manner that more fully recognises the tenets of this model, but this is certainly not automatic. In particular, the recognition of the political influences is embedded in the toolkit through the recognition of politicians as key stakeholders in the national e-Health strategy. What is not apparent however is a deeper recognition of the political forces that can both enable and constrain these activities and that these cannot always be addressed simply through stakeholder engagement. This model also provides a significant infusion of the complexity inherent in many organisations. Healthcare and e-health can certainly be considered highly complex endeavours and the flux and transformation metaphors serve to remind us that rapid changes are unlikely in this context and that longer time horizons are more realistic if sustainable changes are to happen and not have the organisation simply rebound to the previous way of doing things.

### 3. Discussion

Viewed through these metaphors, we can see that documents such as the *WHO/ITU National eHealth Strategy Toolkit* (as an example) demonstrate a strong ‘machine’ metaphor (i.e., even referring to the document as a toolkit). This perspective is driven by a project management approach, assuming that one phase of the work leads into the next, and that all this can be ‘managed’ and any change is unproblematic. The *WHO/ITU Toolkit* does recognise the cyclical nature of aspects of this but fails to recognise the potential for feedback among phases highlighted by the ‘organism’ metaphor. Similarly, using the ‘political system’ metaphor, political aspects are recognised as being key, with political stakeholders needing to be engaged and on board, but no guidance from a CM perspective is provided on how to actually do that. Nor is there explicit recognition of how political agendas (and not just those of politicians) can undermine all aspects of this. Finally, the ‘flux and transformation’ view argues that many of the aspects we normally think of managing are really beyond our control and influence, and really the role of management is very different in this view. Each of these metaphors can be seen to have direct association with elements of the Toolkit, but are unrecognised and unsupported.

Figure 1 is an attempt at capturing the level of complexity involved in strategic thinking around e-Health. The diagram (not exhaustive) highlights the range of issues, stakeholders and interdependencies among phases that are encountered in practice. While full consideration for all of this complexity is impossible in practice we have highlighted the need to recognise this and make reasonable assumptions around the scope of what we include and exclude and provide some explanation of our reasoning.

This has significant implications for e-Health theory and practice. If we prescribe to an approach like that presented in the *WHO/ITU National eHealth Strategy Toolkit* then we need to be cognizant of the underlying theoretical assumptions around the perspectives on CM that are either explicitly supported in the approach or implicitly inherited by following the guidelines as presented.



**Figure 1.** An illustration of the linear thinking and complexity typically associated with e-Health initiatives – from strategy, through conception and application, to integration. Change Management, often conceived as a single step just before integration, actually requires consideration – and different approaches – throughout an initiatives life-cycle.

**4. Conclusion**

e-Health is complex. Organisations are complex. The successful way to deal with complexity is to embrace it and understand how best to manage it. For complex e-health initiatives to prove sustainable it is essential they be integrated into existing organisations which can be akin to ‘fitting a round peg into a square hole’. Identifying an organisation as aligning with predominantly one (or two) organisation metaphors and then considering underlying CM theories can reveal new or alternate possible approaches for successful integration. Different ‘organisations’ may be influential at several stages in the life-cycle of an e-health initiative, e.g., government during conception, consultant during architecture design, healthcare facility during infra- and info-structure determination, technology vendor during implementation, etc.. As a result, repeating the metaphor / CM theory process along the life-cycle will equip managers, practitioners, and scholars to apply different and appropriate CM approaches along the way leading to successful and sustainable integration.

By viewing organisations more broadly and applying accepted organisational metaphors we can better understand established models of CM and identify assumptions explicitly or implicitly influencing extant guidelines, frameworks, and toolkits. This in turn allows identification of areas where certain key assumptions might be overlooked (e.g., political dimensions) and require inclusion, or where it is

necessary to recognise the limitations of our analysis by explicitly stating why we made those assumptions in work.

The goal of this research is to seek alternate insight regarding what is needed to ensure successful implementation and integration of e-Health into health systems using appropriate CM practices at all stages of an e-Health initiative's life-cycle. Future research will expand on the depth of analysis of available e-health strategy guidelines using an enhanced metaphor/CM theory framework where the number of metaphors and CM models is expanded to provide a more comprehensive analysis. It is unlikely any single model or metaphor will offer all the needed answers, but clarity around the sequence of stages in an e-health initiatives life-cycle and application of different CM metaphors at each stage is arising.

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# The spectrum of needed e-Health capacity building – towards a conceptual framework for e-Health ‘training’

Richard E. SCOTT<sup>a,b,1</sup>, Maurice MARS<sup>a</sup>

<sup>a</sup> Department of Telehealth, University of KwaZulu-Natal, Durban, South Africa

<sup>b</sup> NT Consulting – Global e-Health Inc., Calgary, Alberta, Canada

**Abstract.** To ensure the benefits of e-Health are maximised, e-Health capacity building requires a formal and logical structure that describes broad areas that must be addressed. In this paper a *Conceptual Framework for e-Health Training* is derived that could guide well-thought-out and consistent development of future capacity building efforts. Consideration of e-health education needs is the mandate of the International Society for Telemedicine and eHealth (ISfTeH) Education Working Group. Through this Group a structured but generic 2 - 3 day telehealth training programme for healthcare professionals was developed and trialed, and the Group has been asked to develop a telehealth curriculum. Ongoing debate and feedback has made it clear that this is insufficient. In an effort to establish a *Conceptual Framework for e-Health Training* four aspects or levels of instruction are considered necessary at this time: ‘education’ of a small number of personnel leading to an academic graduate qualification (MSc, PhD); ‘instruction’ of a slightly larger number of personnel (e.g., to provide proficient network managers); ‘teaching’ of a still larger number of personnel in terms of the use of specific technologies, devices, and services; and ‘awareness’ of the general populace. Collectively this is referred to as e-health ‘training’. If implemented in a coordinated and structured manner, such an approach would stimulate e-health growth and application globally. It would generate demand (awareness), allow that demand to be filled (teaching) and guided (instruction), with the focus on technologically appropriate and needs-based solutions (education). The Education Working Group intends to develop outlines of recommended instructional and informational content for training at each level. Here the four levels are highlighted and the terms, hierarchy, and descriptions of the Education Working Group’s proposed approach to its *Conceptual Framework for e-Health Training*, are formalised.

**Keywords.** e-Health Training Conceptual Framework, global, training, awareness, teaching, instruction, education

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<sup>1</sup> Corresponding author: Prof Richard E. Scott, c/o Department of Telehealth, University of KwaZulu-Natal, Pvt Bag 7, Congella, Durban 4013, South Africa; e-Mail: [scottr@ukzn.ac.za](mailto:scottr@ukzn.ac.za); [NTC.eHealthConsulting@gmail.com](mailto:NTC.eHealthConsulting@gmail.com); [www.ntcehc.ca](http://www.ntcehc.ca)



## Introduction

It has been said that we live in a ‘knowledge economy’ where knowledge is the most valuable commodity a person can have to offer. Why then does it seem that within e-health (the use of Information and Communications Technology in health [1]<sup>2</sup>) there is little opportunity for gaining quality knowledge, and so little awareness of e-health amongst the general population? There are few formal programs available globally by which to gain graduate-level e-health qualifications, and opportunity to obtain quality insight via continuing education is equally sparse. An exception in the e-health field is Health Informatics which developed as a profession and has numerous professional educational opportunities available through professional societies (e.g., International Medical Informatics Association, IMIA; Healthcare Information and Management Systems Society, HIMSS). Otherwise, for e-health and related components (telehealth, e-learning, e-commerce) slide presentations and other content are available on the Web but they often lack context (are not framed within an overall setting that provides larger meaning and understanding), lack continuity (are one-off presentations without succession or flow to present a coherent picture on a topic), lack formality (are not sponsored by respected entities to ensure quality and rigour), lack recognition (do not provide any certification or even recognition of completion), and are often dated in their content. Examples of sources of such material include SlideShare, PowerShow, authorSTREAM, and [newfreeppt.com](http://newfreeppt.com). Of what value are these sources and routes, and what damage might any inaccuracies do to the lay opinion and perception of e-health? Other ‘self-instructional’ content targeting adult learners is available from universities for independent and group on-line study, but the dedication and behavioural change they require to be effective makes their value and impact questionable. Rarely, and mainly in developed countries, there may be ‘commercials’ through radio and television raising awareness through speaking of local e-health initiatives. Fundamental questions arise when considering this dilemma: what kind of knowledge is needed, where, and for whom?

In response to its membership, the International Society for Telemedicine and eHealth (ISfTeH; <http://www.isfteh.org/>) established the Education Working Group in 2007. At that time the fields of telemedicine and e-health remained largely enthusiast driven. There was recognition of the broad need for e-health but also of the persistently low uptake of this specialty (especially in developing countries), and the marked lack of capacity building and development opportunities across the globe. The Group was asked to develop a basic telehealth training programme for health workers and support staff that could be used anywhere in the world, and subsequently adopted and applied by ISfTeH members. This was achieved, and the resulting program was trialed [2, 3]. Over recent years, the ISfTeH has received a number of requests from member nations for a generic telehealth curriculum, a task the Education Working Group is currently pursuing.

As this process unfolded fundamental questions arose: what was the relative value of a telehealth curriculum, why was the basic introductory course insufficient, and was there the need for a new and broader approach to overall instructional opportunities for *all* groups of stakeholders? This necessarily expanded the perspective of the Education

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<sup>2</sup> e-Health is considered to encompass telehealth (including telemedicine), health informatics, e-learning, and e-commerce.

Working Group, which was initially established to “develop a workforce with a basic practical knowledge of telemedicine and competence in the ethical use of telemedicine and tele-education”. Ongoing debate has led to acceptance of the need for “practical knowledge ... and competence” to extend beyond the workforce to the general population, i.e., embracing the particular needs of ‘stakeholders’ of varying socio-economic status (income, education, literacy, employment, occupation) and need (raising awareness through to graduate education) in developed, developing, and least developed countries. Accepting the latter, the applicability of common pedagogical and andragogical principles and structures (typically derived from and applied to developed world health professionals) was questioned [4, 5]. This led to the *ab initio* identification and differentiation of four levels of insight: awareness, teaching, instruction, and education. The base assumptions are threefold. First, that providing understanding for the broader e-Health community (from healthcare practitioners to the poverty stricken) is necessary. Second, that high quality but socio-culturally appropriate insight to raise the level of expertise or understanding must be readily available and accessible. Third, that proportionately fewer people are in need of greater and more in-depth knowledge and expertise as progression proceeds from generic user to expert.

Thus, everyone requires ‘awareness’ (all potential stakeholders must know of the existence of, and potential value to them of, e-health); significantly fewer people require ‘teaching’ related to specific aspects of e-health (e.g., telehealth related skills that enable recipients (e.g., healthcare providers; chronic disease patients) to safely use e-health technologies); still fewer people require ‘instruction’ that helps recipients meet their new or planned roles and responsibilities confidently, effectively, and efficiently (e.g., detailed information about how an e-health program should be designed and operated); and even fewer people require ‘education’ (that is, training at the Masters or Doctoral level in order to pursue research and develop new knowledge and understanding around e-health).

Each level is synergistic to the others, but places different emphasis on the objectives, level of knowledge, and desired outcomes to be achieved by these audiences. At one time the possibility of a single hybrid programme was considered, encompassing all levels, yet flexible enough to satisfy the needs of healthcare providers, administrators, decision-makers, and the public alike. This is no longer considered viable. Rather, distinct instructional or informational content is required for each level and anticipated audience, and must be sufficiently flexible to be readily adapted to local and regional differences in clinical practice, regulation, services, literacy, infrastructural, and infostructural circumstances.

The Education Working Group intends to proceed and further develop its *Conceptual Framework for e-Health Training*, and thereafter must budget its time - would it's time be better focused on developing an e-health awareness program, or work towards an international telehealth curriculum with necessary competencies, or could it simply identify and endorse existing initiatives [6]. In addition it must address related practical issues - is there a need to find individual solutions to awareness, teaching, instruction, and education; will development status of countries impact instructional or informational content and if so how; is evidence of actual knowledge uptake essential for all levels, and if so how would it be determined; and how will any

solution address local needs, capabilities, and culture? The scope is large, and heralds opportunities for others to join this effort.

There is a sense of urgency. Little has changed in the e-health instructional setting in many years. For example, some consider there is such a marked absence of the required critical mass of e-health knowledgeable personnel to drive e-health in Africa that the phrase “Building the Capacity to Build Capacity” has been coined as the first essential step [7]. As a prelude to the next step of the Education Working Group in addressing this need, we introduce and formalise the *Conceptual Framework for e-Health Training*.

## 1. Defining Four Levels of ‘Training’

Prior work had identified a hierarchy of three levels of training [7], but four have evolved with time. Several terms had been commonly applied almost interchangeably – train, teach, educate, instruct, and awareness. It was necessary to develop some distinction and rationale for the use of individual terms to describe each level. As is frequently the case with the English language, the issue turned to semantics. According to the Oxford English Dictionary, the primary contextual definition for each is:

- Train: Teach a person a particular skill or type of behaviour through *sustained practice and instruction*
- Teach: Impart knowledge to or instruct someone as to how to do something
- Instruct: Give information to someone
- Educate: Give intellectual, moral, and social instruction to someone, *typically at a school or university*
- Awareness: Knowledge or perception of a situation or fact

The definition of ‘Awareness’ was clearly distinct. That for ‘Educate’ contained the phrase ‘typically at a school or university’, making it clear this referred to a higher level of structured and long term experience. However, the distinction between train, teach, and instruct was considered more subtle. ‘Train’ used the term ‘teach’ within its own definition, and ‘teach’ also included ‘instruct’ in its definition. ‘Teach’ and ‘Instruct’ seemed very perfunctory – implying a brief encounter to casually pass information along, while ‘Train’ specifically referenced ‘sustained practice and instruction’ giving it a greater sense of substance.

Synonyms were examined to determine if a distinction could be made, and if alternate terms might be more suitable. ‘Instruct’ was clearly distinct, as no synonyms overlapped in terms of teach, train, or educate. However, differentiation of ‘Train’ and ‘Teach’ was not possible as each was used as a synonym for the other, and both included ‘Instruct’ and ‘Educate’. Several other terms were common synonyms also, but seemed inappropriate (e.g., indoctrinate), or again were common to both (e.g., instruct) (Table 1).

**Table 1.** Synonyms associated with some terms

Term	Synonyms			
Train	Teach	Instruct	Educate	Coach; Instruct; School; Tutor; Upskill; Drill; Indoctrinate
Teach	Train	Instruct	Educate	
Instruct	-	-	-	Inform; Tell; Apprise; Enlighten; Prime; Ground

To resolve the dilemma, common usage was considered. Typically people refer to ‘training programmes’ and not ‘teaching programmes’ when considering forms of continued instruction (e.g., Continuing Education; Continuing Professional Development). As a result ‘teaching’ was applied to the interim level of imparting knowledge, and ‘training’ to the overall activity which collectively embraced awareness, teaching, instruction, and education, and would most likely involve sustained activity.

## 2. Describing Four Levels of ‘Training’

### 2.1. Awareness (*knowledge or perception of a situation or fact*)

Who needs awareness training? Initially it was thought the answer was healthcare workers, policy makers, and administrators. However, one reason adoption and integration of e-health is failing lies in it being unknown to its greatest number of potential users – the global population. Some consider there is a ‘threshold effect’. Poorly articulated in the e-health literature, this is the general belief that the true impact of e-health will not be seen until it is ubiquitous. But as exemplified by the entertainment industry, it is necessary to first create a demand. Once aware, the global population will demand availability of and access to e-health in its myriad forms. Given the diversity of local infrastructure, services offered, maturity of e-health initiatives, and government or institutional support, might the Education Working Group be able to identify sufficient commonality that generic guidance on Awareness could be provided?

The goal would be to provide sufficient information that people wish to learn more about accessing and using e-health within their daily lives – to maintain wellness, to ease limitations of daily living or a chronic disease, or to handle a period of illness; i.e., to change their behavior. This is a notoriously difficult thing to achieve; human nature is one of habit and avoidance of effort and change. How then do we create multiple channels of communication appropriate for the prevailing culture and ICT infrastructure (to vary content and delivery method), and messages that are simple (easy to grasp) yet specific (insight that encourages action), and capable of continual reinforcement? Mass media campaigns have been shown to produce positive changes or prevent negative changes in health-related behavior [8], but in this day and age, would gaming be a more effective approach [9]?

## *2.2. Teaching (imparting knowledge to or instructing someone as to how to do something)*

As demand grows for e-health interventions, there will be a growing need for some (e.g., healthcare providers, family members, patients) to be instructed in the use of, or to gain very specific knowledge about application of, e-health interventions. This is more akin to the work already performed by the Education Working Group in developing the basic telehealth training programme. With time some of this need will be accommodated through routine undergraduate curricula at medical and health science schools, but the need to address others (family members, patients) will prevail. For now, while there are generic skills and issues in which people can be taught (photography, e-mail encryption, use of videoconferencing equipment, legal and ethical issues) there will also be specific aspects related to the local setting that will be required (e.g., operating a specific piece of equipment). Given the different needs and requirements for healthcare providers, support services, technicians, site co-ordinators, administrative staff, and patients, and the need for some teaching to perhaps be disease specific, what guidance might the Education Working Group be able to provide?

## *2.3. Instruct (give information to someone)*

With growing demand will also come the need for integration of successful e-health implementations into current healthcare systems. This will necessitate existing and future administrative and clinical managers to have training and knowledge in how to design, manage, and incorporate a telehealth program or network, or other e-health implementation. Such a qualification might be at the Diploma or Certificate level, and involve significant commitment. Although the definition of 'Instruct' was seemingly perfunctory, the definition of 'Instruction' was clearer; i.e., 'detailed information about how something should be done or operated'. This was in accord with the intent to convey the provision of detailed understanding and insight regarding process. Similarly, synonyms for 'instruction' included - directions, guide, handbook, and reference manual which again were in accord with the intent.

## *2.4. Education (giving intellectual, moral, and social instruction to someone, typically at a school or university):*

In this context, education leads to higher level graduate qualifications, such as Doctoral or Masters awards. Arguably, and within the health sciences, a Masters provides evidence of sufficient understanding and capability to be able to participate in and contribute to research, and a Doctorate provides evidence of the greater ability to independently conceptualise, design, perform, and report research. As noted, there is a need for only a small number of people to be educated in e-health at this level. Why then are we 'educating' people at all (what is the demand), and what are we educating them for (what is the career path)? Understanding advances through performance of research is one stimulus for development. Also research (defined as systematic investigation and study to establish facts and reach new conclusions) will - to some degree - always be needed (including for e-health). Yet there is little evidence of demand for such highly qualified individuals. Only a handful of programs exist

globally that award Doctoral or Masters (as well as Postgraduate Diploma or Certificate qualifications) in e-Health, or even related fields such as Informatics, Telehealth, or Telemedicine. Examples include: University of Edinburgh, Scotland; University of East London, UK; Swansea University, UK; University of Tromsø, Norway; Queensland University, Australia; University of KwaZulu Natal, South Africa; UC Davis, USA; Russian Association of Telemedicine, Russia) [10]. Furthermore, once e-health research has sufficiently demonstrated its value, and it has become an integral component of healthcare, there will be less need for such highly qualified individuals.

### 3. Discussion

What technology might be adopted to facilitate awareness building, teaching, instruction, and education? Options have changed considerably in recent years, with distance education originally using print media, then audio, image, animation, video, and computer-based technologies. Advances in the latter (together with the Internet and wireless technologies) gave rise to web-based e-learning, often facilitated through 'learning management systems' (LMSs), and for which multi-media and 'on-line' options now predominate. More recently social media options became available with global reach (e.g., instant messaging, chat rooms, discussion forums), or more sophisticated options such as simulation based training or interactive avatars (e.g., Second Life™) for more targeted audiences. But for each of the 4 levels of e-Health training identified, and for the many different settings and socio-economic groups around the globe, which approach and technology would be optimal? For making people 'aware' can you make health 'fun' through use of video games [9]? For teaching and instruction would immersion in 'real-life' scenarios through interactive simulation or virtual reality be effective [11]? How can social media be leveraged for health [12]? Does any of this matter for the approximately 1 Billion poverty stricken vulnerable individuals living on less than \$1.25 per day – those most in need?

What of the social side of training – how do you build and maintain interest and a sense of community at a distance for large numbers of participants? Can individual and population behaviour change really be instigated and sustained through distance learning [13]? How do you overcome barriers to distance learning such as conflict with family and work responsibilities [14]. Is life-long learning, accepted and practised by many professionals, even an appropriate concept for the general population? These and many other questions are important, but beyond the scope of the Education Working Group. The need for collaborative and informed research is great.

### 4. Next Steps

The Education Working Group will continue development of its *Conceptual Framework for e-Health Training*, and determine which aspects it is best able to assist with. The scope of this concept is such that others will be able to identify areas where their expertise is relevant, and pursue such aspects collaboratively or independently. In the interim, the Education Working Group will continue to promote its generic

telehealth training programme for health workers and support staff, and focus its attention on addressing the current request of the Group to develop a generic telehealth curriculum.

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# Refocussing our attention on ‘need’ in the application of telehealth

Richard E. SCOTT <sup>a,b,1</sup>, Louise C. AFFLECK-HALL <sup>b</sup>, and Maurice MARS <sup>a</sup>  
<sup>a</sup> *Department of Telehealth, University of KwaZulu-Natal, Durban, South Africa*  
<sup>b</sup> *NT Consulting – Global e-Health Inc., Calgary, Alberta, Canada*

**Abstract.** Given that e-health (including telehealth) is an opportunity cost (i.e., redirecting already scarce healthcare resources away from more traditional healthcare delivery needs), performing needs assessment ensures that investment of resources in e-health is appropriate. Yet the current literature shows research is on clever, narrow, or ‘one disease’ telehealth applications (e.g., tediabetes; telesurgery), or creation of electronic records (e.g., EHR’s; EMRs; HIS’s) and accumulation of ‘big data’ (e.g. biosurveillance). Given the reality of comorbidity, the complexity of telesurgery, and the lack of successful country-wide EHR implementations, are we using our investments in e-health wisely? The requirement for needs assessment to guide selection and implementation of evidence-based and needs-based e-health solutions is seldom adhered to. We must refocus our efforts on more pragmatic needs. Where might insight to evidence-based health needs come from? Using South Africa as an example, this paper highlights several readily available resources, and how they may guide future telehealth implementations in South Africa and elsewhere.

**Keywords.** Needs assessment, telehealth, e-health, burden of disease, South Africa

## Introduction

The importance of e-health (e.g., telehealth) interventions to be ‘needs-based’ has been noted since its inception, yet there is little guidance available [1], and little evidence – from either the literature or personal experience – that needs assessments are performed before determining if an e-health implementation should be pursued. This is of concern. e-Health (telehealth, health informatics, e-learning, e-commerce) is an opportunity cost, with resources spent on technological solutions potentially being redirected away from such things as immunisation programmes, healthcare provider’s salaries, sanitation, and clean water. To ensure any investment is wise, it is essential that telehealth solutions, for example, focus on issues that have been shown to be a health need, and therefore represent the ‘best bang for the buck’. Where might we look to see potentially valuable insight? Below several examples are given in relation to South Africa which provide evidence-based needs at various levels, and potentially

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<sup>1</sup> c/o Department of Telehealth, University of KwaZulu-Natal, Pvt Bag 7, Congella, Durban 4013, South Africa; e-Mail: [scottr@ukzn.ac.za](mailto:scottr@ukzn.ac.za); [NTC.eHealthConsulting@gmail.com](mailto:NTC.eHealthConsulting@gmail.com); [www.ntcehc.ca](http://www.ntcehc.ca)



provide direction for where to focus attention when considering application of e-health, specifically telehealth.

## 1. Country Studies

### 1.1. Medical Research Council (MRC)

The first Burden of Disease study performed in and by South Africa, for the year 2000, was published in 2003 [2]. Although the website indicates a further BOD study is planned, the 2000 study was the only one for which data could be located. It concluded with several recommended actions to address priority health issues: reducing the transmission of HIV and delay mortality from AIDS (through improving treatment of sexually transmitted infections, improving the voluntary counselling and testing services, provision of antiretroviral treatment to pregnant HIV-positive and HIV-positive patients and promoting safe sex); improving TB control; developing strategies to reduce violence and injuries; promoting healthy lifestyles (including diet, physical activity, and reduce smoking, alcohol, and substance abuse); and improving the integrated management of childhood diseases. Similarities exist between these health issues, and those seen in the Global Burden of Disease (GBD) study below. No mention is made in this MRC report of e-health and its potential in tackling these evidence-based, priority issues.

### 1.2. Health Systems Trust (HST)

The South African Health Review 2011 provides insight on many policy related health issues, but also a section on core health issues, and one on 'indicators' that offers a selection of South Africa's best available data [3]. Importantly, it also contains a chapter on '[Health Technology for Equitable Access to Quality Health Services](#)'. This chapter mentions e-health, describing it quite well, and indicating it encompasses a range of services or systems and includes both telemedicine and m-health. The section concludes that "research is required to determine the feasibility and sustainability of the pilot telemedicine projects currently being undertaken in SA". A better conclusion would have been to determine the *appropriateness* of current e-health projects in SA, i.e., whether they are addressing priority health issues (as promoted here), and whether they contribute to - or are contrary to - a strong evidence-based, needs-based, and defensible South African e-Health Strategy developed as recommended in the literature [4]. To some degree a part of this process is underway through an audit of assets in public health facilities; similar to many developing – and developed – countries, it is very likely that telehealth (and other e-health) equipment will have been purchased and deposited in healthcare facilities and either left unpacked, unused, or minimally used (e.g., due to a lack of training or clear mandate).

### 1.3. National Department of Health's (NDoH) Annual Performance Plan (APP) 2014/15-2016/17

The Annual Performance Plan provides insight regarding priorities as seen by the NDoH [5]. In terms of disease, the 2014-2015 APP provides a Situational Analysis that

includes an Epidemiological Profile that highlights the common trend of many developing countries. High fertility rates and high mortality from communicable diseases is giving way to lower fertility rates and changing lifestyles. This has resulted in an 'aging' population facing "lifestyle related diseases" (non-communicable diseases) such as diabetes and hypertension, cancer and other chronic ailments. However, being in the midst of this transition, South Africa continues to also face the burden of major communicable diseases (mainly HIV, AIDS, and TB).

In regards to e-Health, the 2014-2015 APP uses this term 4 times (neither telehealth nor telemedicine appear), indicating a major objective is the progressive implementation of a 'National Integrated Patient-based Information System'. Currently the DoH is focused on development of the necessary business and enterprise architecture with the system design to be completed by 2018-2019. This is considered the first step in implementation of the National eHealth Strategy.

## 2. Global Studies

### 2.1. World Health Organisation (WHO)

Healthcare is a complex issue, typically consuming more and more resources every year, with many factors other than simply disease leading to ill health (i.e., social determinants of health). This is exemplified by the WHO's definition of health which defines it as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". The WHO examined the pattern of health globally in 2008, and reported common contradictions, all of which prevail [6]:

- Inverse care. Where people with the most means (and typically less need) consume the most care. Consequently public spending on health services often benefits the rich more than the poor.
- Impoverishing care. Where there is lack of a social safety net, and catastrophic out-of-pocket expenses at the point of service can lead to poverty.
- Fragmented and fragmenting care. The propensity towards specialisation and narrowly focussed disease control programs discourages a holistic approach, and discourages continuity of care. This situation is worsened by fragmented (highly focussed) development aid. Consequently health services for poor and marginalized groups are often highly fragmented and severely under-resourced.
- Unsafe care. Poor health system safety and hygiene standards leads avoidable death and disability (e.g., through hospital-acquired infections; medication errors).
- Misdirected care. Curative services consume most resources to the detriment of primary prevention and health promotion which, potentially, could prevent up to 70% of the disease burden.

Whilst considerable progress has been made, these concerns also relate to South Africa [7]. Resolution, even addressing, these issues is more political and social in nature. Specific telehealth facilitated interventions are unlikely to impact these directly. Attention must be drawn instead to diseases or conditions for which telehealth interventions (e.g., education, care provision, surveillance) would be most beneficial. Other sources of health data must be sought for this purpose.

## 2.2. Institute of Health Metrics and Evaluation (IHME)

The IHME performs ongoing Global Burden of Disease studies. The data from the 2013 study is now being published, however, country profiles are available only from the 2010 study, e.g., South Africa [8]. Data are presented in several formats. The disability-adjusted life year (DALY) measures overall **disease burden** and is calculated as the cumulative number of years lost due to ill-health, disability, or early death. It is considered better than simply Years of Life Lost (YLLs) because it takes into account the impact of disability (i.e.,  $DALY = YLL + YLD$ ). An example of the value of this approach is highlighted by the recent growth in concern with, and research into, mental health. In 1990 the WHO reported leading causes of disability in DALYs, and 5 of the 10 were revealed to be psychiatric conditions – a previously unappreciated fact. Although these conditions accounted for just ~1.4% of all deaths and 1.1% of years of life lost (YLL), they contributed significantly to years lived with disability (~30%), and their population impact was only revealed through use of DALYs.

For South Africa the GBD 2010 data show the top five leading causes of Years Lived with Disability (YLDs) to be: HIV/AIDS, major depressive disorder, low back pain, iron-deficiency anemia, and chronic obstructive pulmonary disease [8]. For disability-adjusted life years (DALYs), the top three causes in 2010 were: HIV/AIDS, diarrheal diseases, and interpersonal violence [8]. Because comparison between 1990 and 2010 data is also available, insight to trending is possible. For example, causes that were in the 10 leading causes of DALYs in 2010 but *not* in 1990 were HIV/AIDS, diabetes mellitus, and major depressive disorder [8]. It would seem reasonable to suggest that these represent conditions for which intervention at this time may curb future burden. In addition, Risk Factors (RFs) are also presented. A risk factor is 'something that increases a person's chances of developing a disease'; e.g., cigarette smoking is a risk factor for lung cancer, and obesity is a risk factor for heart disease. Overall, the three risk factors that accounted for the most disease burden in South Africa in 2010 were alcohol use, high body-mass index, and high blood pressure. The leading risk factors for children under 5 and adults aged 15-49 years were suboptimal breastfeeding and alcohol use, respectively.

## 3. Discussion

Reliable sources of health related information are available that can guide policy- and decision-makers, health managers, and researchers in regard to the most valuable telehealth interventions that will quickly and positively impact a country, sub-national region, or healthcare facility. For example, focusing on Risk Factors would allow a population's most pressing health issues to be addressed, while focusing on YLDs might lead to a healthier and more productive workforce, or focusing on DALYs might lead better public health overall. As an example, excess bodyweight is a major public health concern. This is evidenced by the recent GBD 2010 study [8, 9]. Although body mass index (BMI) is less than  $21.5 \text{ kg/m}^2$  for both sexes in a few countries in sub-Saharan Africa, in South Africa female BMI has increased markedly and was greater than  $29 \text{ kg/m}^2$ . The paper by Finucane et al. concludes that interventions and policies to curb the increase, and mitigate the health effects of high BMI, are needed in most countries [9].

One concern is how to resolve and respond to discrepancies. For example, the NDoH APP highlights South Africa's 4 leading causes of Years of Life Lost (YLLs) to be TB, pneumonia, diarrheal diseases, and heart disease (the first 3 related to HIV/AIDS). In contrast. The GBD 2010 study indicates the 4 leading causes of YLL to be HIV/AIDS, diarrheal diseases, interpersonal violence, and lower respiratory infection. Some of the discrepancy is semantic (emphasising the need for adherence to international standards), but omission of interpersonal violence (which was still #4 in 1990) is of concern, although it is noted in a separate section of the APP (Violence and Injuries).

Where are telehealth implementations directed in South Africa? Recently the Telehealth Department, University of KwaZulu Natal surveyed and examined current telehealth practice in the 9 Provinces, and also examined the scientific and grey literature [10]. One hundred and seventy (170) relevant literature resources were reviewed, in addition to survey responses, performance plans, and annual reports. Each Province had evidence of telehealth (telemedicine) activity, but practice or capability focussed on teleradiology, telepsychiatry, teleophthalmology, teledermatology, teleaudiology, telecardiology, telepaediatrics, telepathology, and tele-education, as well as teleultrasonography.

m-Health activities also existed, although no examples were found in peer reviewed literature. In contrast, the Groupe Speciale Mobile Association (GSMA) website lists 96 m-Health projects in South Africa. Most were categorized as 'Health Worker Empowerment' or 'Health Systems' focused, with only 3 being wellness focused (one offering fitness tips by SMS). Most did not specify their medical focus, but for the small number that did TB was most common, followed by AIDS/HIV, and then diarrhea, diabetes, malaria, and cardiovascular issues.

Essentially no telehealth facilitated interventions currently in place or planned within South Africa actually address the issues of concern identified through available evidence; as an example, the GBD study - e.g., excess body weight in women.

#### **4. Conclusion**

Why does the telehealth fraternity continue to seek 'low hanging fruit' or 'early wins' and ignore the oft stated requirement for 'needs assessment'? Highly reputable sources of health data show which major health issues are of concern for South Africa, yet telehealth interventions in the country do not address such needs in a systematic manner. It is time to refocus attention on responding to these evidence-based needs, establishing technologically appropriate telehealth solutions (and other e-health solutions) that address these issues in effective ways.

This paper provides insight regarding sources of evidence-based health need, to which investment in e-health solutions should be directed to allow optimal impact. Other data sources may be available to decision- and policy-makers, therefore it is not the intent, nor is it appropriate, to proffer definitive statements regarding optimal telehealth solutions for priority health needs noted in this paper. All available data sources must first be identified and considered during a process performed by the country, sub-national region, or healthcare facility involved. The role of this paper is to encourage policy- and decision-makers (e.g., facility managers, healthcare providers) to acknowledge this opportunity, and refocus application of telehealth in light of available evidence of health need.

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# Assessing user engagement in a health promotion website using social networking

Rhys TAGUE <sup>a,1</sup>, Anthony J MAEDER <sup>a</sup>, Corneel VANDELANOTTE <sup>b</sup>,  
Gregory S KOLT <sup>c</sup>, Cristina M CAPERCHIONE <sup>d</sup>, Richard R ROSENKRANZ <sup>e</sup>,  
Trevor N SAVAGE <sup>c</sup>, Anetta VAN ITALLIE <sup>b</sup>

<sup>a</sup> School of Computing Engineering & Mathematics, Telehealth Research & Innovation Laboratory, University of Western Sydney, Sydney, Australia

<sup>b</sup> Centre for Physical Activity Studies, School for Human Health and Social Science, Central Queensland University, Rockhampton, Australia

<sup>c</sup> School of Science and Health, University of Western Sydney, Sydney, Australia

<sup>d</sup> School of Health and Exercise Science, University of British Columbia, Canada

<sup>e</sup> Department of Human Nutrition, Kansas State University, United States of America

**Abstract.** Remote provision of supportive mechanisms for preventive health is a fast-growing area in eHealth. Web-based interventions have been suggested as an effective way to increase adoption and maintenance of healthy lifestyle behaviours. This paper describes results obtained in the “Walk 2.0” trial to promote physical activity through a self-managed walking programme, using a social networking website that provided an online collaborative environment. Engagement of participants with the website was assessed by monitoring usage of the individual social networking functions (e.g. status post). The results demonstrate that users generally preferred contributing non-interactive public posts of information concerned with their individual physical activity levels, and more occasionally communicating privately to friends. Further analysis of topics within posts was done by classifying word usage frequencies. Results indicated that the dominant topics are well aligned with the social environment within which physical activity takes place. Topics centred around four main areas: description of the activity, timing of the activity, affective response to the activity, and context within which the activity occurs. These findings suggest that strong levels of user awareness and communication occur in the social networking setting, indicative of beneficial self-image and self-actualisation effects.

**Keywords.** Health promotion, online collaborative environment, physical activity, preventive health, social networking, user engagement, website, user profiling

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<sup>1</sup> Corresponding Author: R. Tague, School of Computing, Engineering & Mathematics, University of Western Sydney, Locked Bag 1797, Penrith NSW 2751, Australia; Email: r.tague@uws.edu.au

## Introduction

In the light of issues such as escalating costs, constrained resources, and the aspiration to improve longevity while maintaining the highest achievable quality of life, there is a global impetus for health system reforms. One area of emphasis in many reform agendas has been gaining increased value from health promotion and associated behaviour change supportive measures. For instance, greater use of preventive health interventions has been identified as one of the top national health priorities in Australia, as a means to reduce downstream utilisation impact on the health system [1]. Preventive health reforms can address issues arising at a population level, such as demographic changes and ageing profile, where there is much concern over increased prevalence of lifestyle related diseases, or infectious diseases and public health issues.

Recently, there has been much enthusiasm for remote provision of supportive strategies for preventive health and health promotion, making this a new and fast-growing area in eHealth and Telehealth. Web-based or online interventions have been suggested as an effective way to increase adoption and maintenance of healthy lifestyle behaviours, such as increased physical activity, improved nutrition, and reduction of alcohol and smoking habits [2, 3]. These interventions have the advantages of reaching a large user community, easily and at an affordable cost, while allowing individualised usage patterns to be developed to suit user preferences.

Online health applications are a fast growing area within the scope of Telehealth, both due to the remote nature of the computer-based source, and due to their connection with personal monitoring through self-reporting or logging data from wearable devices. The ease of access through conventional computers equipped with web browsers, or mobile devices such as computer tablets and smart phones, ensures that this area will continue to develop as consumer attractiveness and demand increases.

### 1. Social Networking Interventions

Within the web-based interventions domain, a particular area of focus has been the provision of social networking and social media interventions, to provide collaborative online environments in which users can interact and thereby mutually reinforce behaviour change activities. Reviews on the efficacy of these interventions [4] reveal that current evidence is not strong for the degree of behaviour change, nor can the influential factors affecting it be readily identified [5]. User engagement and motivation have been suggested as factors contributing to behaviour change [6, 7], despite a lack of clear and widely applicable definition of these aspects.

In social networking theory, the use of web-based online collaborative environments equates to the forming of social groups [8], which can provide certain influences for behaviour change [9]. These influences may be inferred from characteristic usage patterns observed within these environments [10] and the corresponding formation of social ties and norms [11]. The principles of collaboration as described theoretically in sociology [12] can be realised by establishing the existence of a number of collaborative usage patterns [13] in a certain social interactive setting, and classifying user habits accordingly.

An open issue is the choice of suitable models and metrics to describe these usage patterns, especially in a way that they can be causally linked with behaviour change. Simple measures such as degree of connectivity and volume of interaction traffic [14]

have been augmented by measuring communication, engagement and relevance [15]. The characterisation of engagement is of particular interest here, as the working hypothesis in this project has been that increased engagement through social network collaboration is the primary factor in achieving participant behaviour change. Indicators for engagement are typically related to stereotypical relationships developed between a user and the technology [16], and so the appraisal of engagement depends on the choice of the model used for describing such relationships.

## 2. “Walk 2.0” Project

The “Walk 2.0” study was established in 2010 with funding from the Australian National Health and Medical Research Council to develop and investigate the use and efficacy of Web 2.0 features in a physical activity promotion website to enhance self-managed programmes for daily walking and associated exercise. Using Internet or web-based physical activity interventions such as this, which incorporate innovative Web 2.0 features [17] including social networking support, have the potential to reach large groups of individuals and contribute to physical activity promotion.

The project aims to determine the effectiveness on participant attraction, engagement, retention and physical activity behaviour change in a 3-arm randomised controlled trial with sample size of more than 500 participants [18]. A further ecological trial component will explore the behaviour and experiences of users in the online aspects, based on open recruitment of a much larger number of users. It is expected that the findings from the two trials will enable generalisation of the functions provided in the web-based setting, and allow informed design, development and customisation of further online social collaborative environments for other health promotion purposes.

The study has involved the development and testing of a Web 2.0 based collaborative environment [19] (embodied in the Walk 2.0 website, [www.walk.org.au](http://www.walk.org.au)) to investigate the effects of a “new generation” web-based application offering options such as blogs, posts and other social networking functions (see Figure 1). This intervention is being compared with an existing publically available Web 1.0 physical activity promotion website (the Australian 10,000 Steps website, [www.10000steps.org.au](http://www.10000steps.org.au)) which provides a more conventional static environment, and also compared with manual logging of physical activity without computer assistance (via logbook).

By the end of the study, participants in the randomised controlled trial will have been monitored over 18 months using pedometers to log actual daily step counts, and presenting for detailed follow-up physical examinations and interviews. The information collected will enable the investigators to assess changes in levels of physical activity and other health indicators, as well as comparative impacts of utilization of the websites compared with each other and with the logbook, for user engagement and retention. It is hoped that understandings gained from analysing the characteristics of usage patterns and the influence of user interactions on the participants, will provide insights to inform the design of similar web-based interventions in the future.



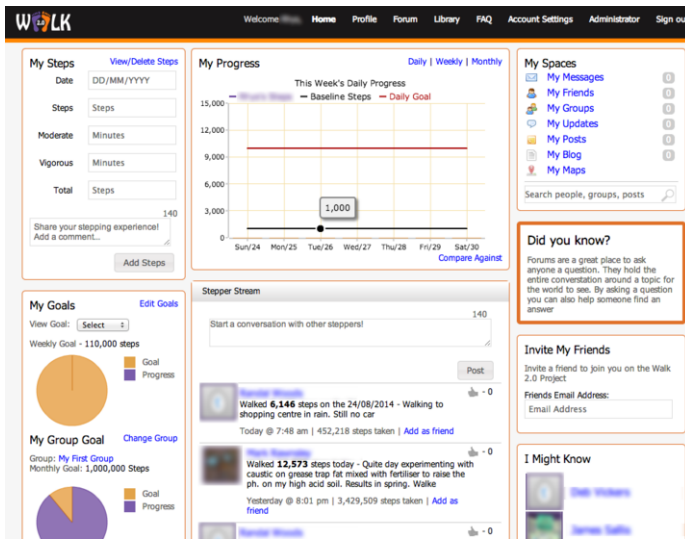


Figure 1. The “Walk 2.0” health promotion website, with social networking features.

### 3. User Engagement

The project methodology was not designed to specify a particular model for user engagement with the website, so a simple set of web usage measures were adopted, loosely based on the work of Burke et al. [20]. Posting was chosen as the surrogate for engagement on the basis that it offered users options for communicating with each other comparable to traditional offline conversational communication. The raw data for assessing user engagement was derived from a total of 5,481 user posts generated by 254 active and unique users on the Walk 2.0 website over a 3-month period determined by a user’s registration date, observed via transaction counts for all sessions logged in the application database. The transaction counts indicated an average of 21.6 posts per user (with standard deviation of 123.3), based on a total of 132,185 words posted by all the users. The average number of words per post was 24.1, equating to an average of 520.4 words per user overall.

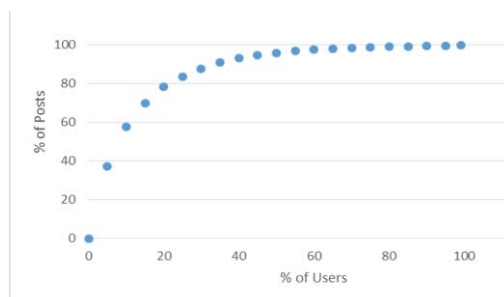
Five separate posting functions were provided for users in the application: Progress, Status, Private, Blog, and Forum. Progress is a public posting of an automated fixed single line message of user step count combined with open text situational information (comment) provided by the user, which is broadcasted to the user base upon posting (users keep track of daily number of steps taken using a pedometer provided by the research team). Status is an open-text user-entered short public posting of current user situational information. Private is an open-text user-entered private posting of a message sent to another user profile. Blog is an extended open-text user-entered long public posting to an individual user-designated posting area through the user profile. Forum is an open-text user-entered public posting in one of six public topic categories, to allow discussion in a series of interleaved messages from multiple users responding to each others’ comments. Only Forum posts can be publicly replied to by all users.

Table 1 shows the distribution of posting function usage across the 5,481 user sessions. The automated Progress posts made up by far the greatest volume of session traffic on the website at 79.4%: it is surmised that this is because of the ease of generating the posting automatically. The next highest source of traffic was Status posts at 13.3%, a form of public post with wide visibility without initiating further direct interactive public communication. Private posts were at 4.0% and Blog posts at 1.8%: this indicates that users were disinclined to post where exposure was limited and/or less social in nature. Use of Forum posts was negligible at 0.5%. These results reveal that users generally preferred contributing through broadcasting of semi-automated open text information about their individual physical activity, with some lesser amount of private communication with friends and reflective blogging, than seeking a highly collaborative mode of communication.

**Table 1.** Overall posting function usage across all users.

Posting Function	Posting Count	Posting Percentage
Progress	4350	79.4
Status	727	13.3
Private	220	4.0
Blog	96	1.8
Forum	26	0.5

Next, we considered the habits of users who were most active in the online collaborative environment to establish whether they showed similar usage patterns. It was established that 50% of the posts (2,781) were made by 21 users out of 254 (8% of all users), and 25% of the posts (1,416) were made by 8 users (3% of all users). The highest number of posts made by the top user was 259, almost 5% of the total number of posts and equating to a rate of approximately 3 posts per day. The average number of posts was equalled or exceeded by 65 users (25% of all users). Fewer than 5 postings were made by 126 users (50% of users), and only one posting was made by 77 users (30% of all users). This highly skewed distribution is typical of social networking sites [20]. Figure 2 shows the posting rate, ordered (left to right) from most to least active users.



**Figure 2.** Cumulative posting rate for all users.

Table 2 shows the distribution of the number of postings of all types made in the top 50% (25%) of postings. The patterns of usage are comparable with those in the whole population of users shown in Table 1, with some discernible increase in Progress postings and decrease in Status, Private and Blog postings, which is even more marked in the top 25%. It appears that more online-active users wish to spend less effort communicating in open text and instead concentrate on the easy automated broadcast mechanism offered by Progress postings.

**Table 2.** Posting function usage by most active users making 50% (25%) of all posts.

Posting Function	Posting Count 50% (25%)	Posting Percentage 50% (25%)
Progress	2251 (1261)	80.9 (89.1)
Status	408 (116)	14.7 (8.2)
Private	78 (22)	2.8 (1.6)
Blog	37 (14)	1.3 (1.0)
Forum	3 (2)	0.1 (0.1)

#### 4. Topic Analysis

Further indication of engagement and the emergence of collaborative social norms between users can be gauged by analysis of task-related topics covered during postings. Following a simplified probabilistic topic modelling approach [21], a frequency count was made of all unique words occurring within the 132,185 words contributed by user open text. A total of 240 words were found to occur 50 or more times, with the most frequent words occurring almost 1,000 times (day = 974; steps = 885). Trivial words such as prepositions, which did not convey meaningful concepts, were excluded from the analysis.

A random sample of approximately 10% of the text in the 5,481 postings was read and four distinctive topics were identified, associated with the typical user behaviour and general social environment within which the main task (i.e. physical activity) takes place. These topics were:

- Description of the activity (e.g. intensity, timing, variety)
- Timing of the activity (e.g. time of day, duration, repetition)
- Affective response to the activity (e.g. emotions, reflections, attitudes)
- Context in which the activity occurs (e.g. other forms of physical activity, companionship, lifestyle, location).

Words associated with each of these topics were grouped according to similarity of meaning or intent. The similarity criteria were developed from the postings read, by establishing links between frequently occurring words. Table 3 provides details for some of the more frequent words in these groupings. There are relatively few groupings in each topic, indicating that the posts are generally narrowly focussed around topical themes and users are not directing their comments to matters outside the online social collaborative environment.

**Table 3.** Selection of frequent words for the four topics.

Topic	Words
Description of the activity	step/steps/walk/walked/walking (2,245); pedometer (198); goal (121); extra (97); exercise (84); count (75);
Timing of the activity	time/hour/day/week/month (1,224); night/morning/early/late (359); today/tomorrow/yesterday/daily (279);
Affective response to the activity	few/some/more/short/long/many/much/again (1,023); good/better/hard (418) ; active/busy (234); hope/happy (115);
Context in which the activity occurs	house/home (286); weather/rain (174); gym (114); group/family/couple (203); dog/dogs (162); shopping (98); bike (71); beach (70); down/up/around/back (696);

Considering the size of word counts for major groups of concepts associated with the undertaking of the desired physical activity, it can be inferred that users were posting comments that were highly relevant to their activities in meeting their goals. Very few words indicating distraction from purpose were detected. These findings suggest that strong levels of user awareness and communication of intent occur in the collaborative social media setting, which are indicative of beneficial self-image and self-actualisation effects. This claim is supported by the presence of a number of strong affective responses displaying positive attitudes and messages of mutual encouragement.

## 5. Conclusion

This paper has presented some initial findings from a project which aimed to explore the effect of a Web 2.0 based social collaborative user environment, specifically for influencing user engagement for increasing and maintaining their level of physical activity. Without a specific model for the emergence of social relationships which such an environment could support, a basic analysis was undertaken using simple models of social collaboration behaviour.

The patterns of use for website functions that were provided for posting information revealed that broadcast, non-interactive communications (in the form of comments) were preferred to interactive or private discussions. This may be a consequence of the focussed nature of the task, which is a highly individual and personal challenge endeavour, or the approach to recruitment being a randomised controlled trial where participants were socially unrelated. The topic analysis showed that users' attention is very well aligned with the task, as most high frequency words are directly related to the undertaking of the physical activity. Further insights could be gained by conducting interviews with users to establish reasons for their preferences in use of the functions, and whether they were subject to peer pressure when using those functions which encouraged them to adopt a different priority than they naturally would.

It is acknowledged in the literature [22] that web based interventions are complex to evaluate, and that their effectiveness is subtle to measure. It would be beneficial to develop and apply specific models to analyse such situations, based on the conjunction

of available functions for user communication and interaction, and the user goals which exist in the underlying intervention. Use of such models could provide more consistent and comparable quantitative results concerning user engagement and reinforcement.

## Acknowledgement

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# Telehealth for chronic disease management: Do we need to RE-AIM?

Marlien VARNFIELD <sup>a,1</sup>, Mohan KARUNANITHI <sup>a</sup>, Hang DING <sup>a</sup>,  
Dominique BIRD <sup>b</sup>, Brian OLDENBURG <sup>c</sup>

<sup>a</sup> *The Australian e-Health Research Centre, Digital Productivity and Services Flagship, CSIRO, Herston, QLD, Australia*

<sup>b</sup> *Centre for Online Health, The University of Queensland, QLD, Australia*

<sup>c</sup> *Academic Centre for Health Equity, Melbourne School of Population & Global Health, University of Melbourne, VIC, Australia*

**Abstract.** An increasing number of individuals are living with long term health conditions which they manage most of the time by themselves. This paper evaluates the use of information and communications technology platforms to provide evidence-based programs to help people with chronic disease to self-management these. It describes two different self-management strategies for chronic conditions, and the evaluation of their implementation in clinical trials, specifically in terms of reach, implementation fidelity, adoption and user perceptions. It also discusses the challenges in replicating trial findings in the real world, using the RE-AIM framework.

**Keywords.** Telehealth, chronic disease, self-management, implementation

## Introduction

One of the major epidemiologic trends of the current century is the rise of chronic diseases in Australia and world-wide. Increasing prevalence of conditions such as cardiovascular disease (CVD) and type 2 diabetes mellitus (T2DM) is placing enormous financial and societal burden on many countries. To address the spiraling demand on health service resources, there is an urgent need for alternative, affordable strategies to support the management of these diseases effectively in the community. National and international attention is increasingly being focused on utilizing the advances in information and communication technologies (ICT), to design and develop new platforms for chronic disease management. The explosive growths of the Internet, personal computers and other digital devices, mobile phones and associated software applications continues unabated and have resulted in the emergence of technologies that could be used outside the clinical setting to monitor health status, improve clinical outcomes and augment home-care and self-management.

Many innovative health strategies and interventions which exploit the current advances in ICT have been developed and tested, with varying success. In general

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<sup>1</sup> Corresponding Author: Marlien Varnfield, The Australian e-Health Research Centre, Digital Productivity and Services Flagship, CSIRO, Level 5, UQ Health Sciences Building, Royal Brisbane and Women's Hospital, Herston, QLD, Australia, 4029; E-mail: marlien.varnfield@csiro.au.

however, evidence suggests that ICT supported health interventions can increase efficiency of chronic health provision without compromising the quality of care delivered [1, 2].

Many researchers who develop disease management interventions intend to promote evidence-based interventions to the broader population from which the study sample was drawn or the public health or clinical practice settings in which the intervention was originally tested. The assumption has often been that tools and interventions deemed efficacious within clinical or community-based trials would be readily transmitted to the field. There is, however, a lack of “fit” between an intervention/ research design on the one hand and the realities inherent to the ultimate target practice setting and the information needed by policymakers on the other hand. This often leads to low adoption and implementation in the real world [3]. Even when interventions have been tested within the scope of clinical trials, the development of knowledge to support their broader effective implementation in the real-world often remain unaddressed [4]. This disconnect in what is supposed to be a linear transition between efficacy and effectiveness studies has also been pointed out by Glasgow and colleagues [5].

There are many interacting reasons for the general failure of health interventions to translate into practice, including economic and social policy, as well as scientific factors [6]. The aim of this paper is to present the evaluation of two different strategies for supporting self-management of chronic conditions; these include a platform utilizing mobile phones and the internet to deliver cardiac rehabilitation (CR) at home, and an automated telephone linked care system for supporting individuals living with T2DM. We used a ‘process evaluation’ framework [7] to evaluate specific program components for the two targeted programs, in controlled research settings. Furthermore, we discuss the challenges in replicating trial findings under real world conditions using RE-AIM, a framework for strategizing, operating projects, and making programming decisions to help plan programs and improve their chances of working in real-world settings [8, 9]. According to the RE-AIM framework, to be successfully integrated in health delivery systems, it is important that interventions reach those most in need, are effective, adopted, appropriately implemented and maintained as a complement/alternative to traditional care.

## **1. Methods**

We have investigated two new self-management support strategies utilizing ICT, one for secondary prevention of heart disease and the other for the interrelated condition, T2DM, in terms of efficacy and the feasibility of implementation in the real world:

The Care Assessment Platform (CAP) model was the first to employ new generation smartphones, mobile applications and the Internet to deliver the major components of CR at home. Figure one presents an illustration of the CAP CR program. Patients are provided with a smart phone to enter/monitor their health and exercise at home, using a health diary application. The mobile phone has an integrated accelerometer to measure physical exercise and users are also able to view their progress in graphical form. The patients are additionally delivered with multimedia motivational and educational materials and daily SMS messages through the course of a 6-week CR program. A dedicated Mentor uses an Internet portal to view patients’



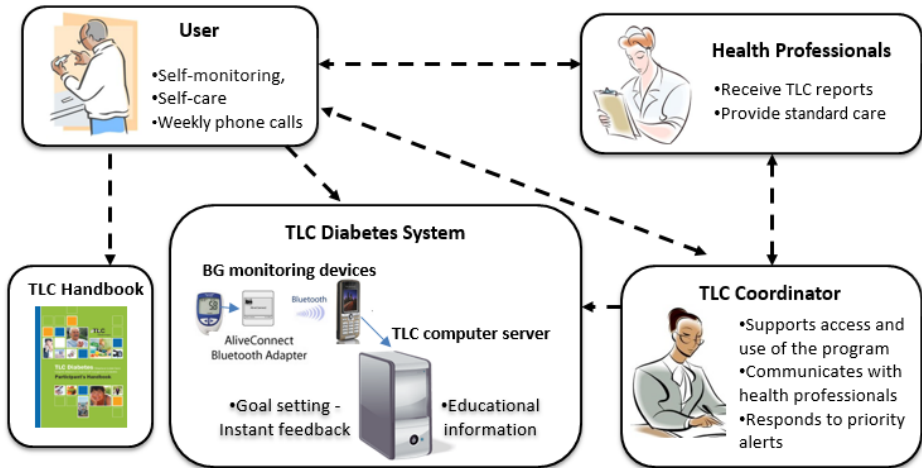
progress and monitor their risk factor measurements prior to weekly phone consultations.



**Figure 1.** An illustration of the CAP CR program. The mobile phone acts as the communication medium through which a mentor provides mentoring and goal setting, daily motivational messages, educational videos and relaxation audio are sent, and self-observations and measurements are entered to a health diary application.

To validate the CAP model for its capacity to improve CR participation rates and demonstrate health benefits similar to that of traditional center-based programs (TCR), the model was tested in a randomized controlled trial (RCT) at Metro North Health and Hospital Services in Brisbane, Australia [10]. The clinical outcomes of the RCT are reported elsewhere [11] and in this paper we present how we used process evaluation methods [7], to explore the potential of implementing CAP CR in clinical practice. We analyzed data from the RCT in terms of the program reach (participation rate), implementation fidelity (usage of the smartphone health applications and measurement devices, and exposure to educational and motivational content), program adoption (participants who adhered to the CR program), and user perspectives. Data were extracted from the CAP server and from evaluation questionnaires administered at the end of the CR program to patients and clinicians.

The Australian Telephone-Linked Care (TLC) Diabetes program is an automated interactive and conversational intervention which uses voice recognition to engage and support individuals living with T2DM to better self-manage their condition. It consists of a computer connected to the phone network, equipped with high quality speech recognition, over 2,000 pre-recorded conversation statements and a database in which each caller's responses are stored to enable tailored feedback and information during a weekly telephone call [12]. Users upload their blood glucose (BG) readings to the TLC server, for use in their pre-scripted conversations with the system, via a Bluetooth device connected to a mobile phone. Figure 2 presents an illustration of the TLC Diabetes program.



**Figure 2.** Australian TLC Diabetes program. The program consists of the TLC Diabetes System which includes blood glucose monitoring devices and the TLC server, and support components - the TLC Handbook, TLC Coordinator and Health Professionals

The TLC intervention was also tested through a RCT [13]. The main clinical outcomes are reported elsewhere [14] but we also explored feasibility of implementing such a program in real world conditions through the same process evaluation methods as described for CAP. Usage data were extracted from the TLC server and user perceptions of the TLC Diabetes program were evaluated from responses to a participant evaluation questionnaire administered at the end of the intervention.

## 2. Results

The results of the CAP RCT demonstrated CAP CR to deliver health outcomes similar to that of traditional center based CR and to significantly improve uptake, adherence and completion rates [11]. Reach, defined as those who enrolled in the trial and by implication intended to participate in CR, was 33% (120/369). The mobile phone and its software applications as well as supplied measuring devices were used daily by >80% of the intervention participants. Motivational and educational text messages were often or always read by 94% of the participants and most participants viewed the multimedia videos in full as required. Adherence to health monitoring and uploading information to the server was exceptionally high (>90%) and showed no decline over the intervention period of six weeks. User perceptions of the mobile phone applications, multimedia videos, relaxation audio and mentoring components of the CAP program were highly positive with all these components rated as easy to use, motivational (especially the inbuilt step counter, the health diary and mentoring), useful, providing a better understanding of their condition and recommendable to other individuals in the same situation. Clinicians perceived the CAP CR program to be a viable alternative to center-based CR programs.

Evaluation of the clinical outcomes of the TLC Diabetes program showed a significant decrease in glycaemic control measured with HbA1c and also a significant improvement in mental health function [14]. Reach in the TLC Diabetes program was high, with a large proportion (70%) of eligible adults with diabetes who registered their interest to hear more about the study, agreeing to take part. Out of the small number who declined to participate, a significant proportion did so for reasons not related to use of the technology system, but rather research-related reasons, i.e. difficulty attending the data collection appointments. TLC system usage was very good with average call duration of 11 minutes and average completion of expected weekly calls at almost 80%. Excellent adoption of the TLC Diabetes program was illustrated by retention of 90% of participants in the program, with only a slight decline in calls made to the TLC system in the second half of a 6-month intervention period. Very high ratings (>80%) of satisfaction, ease of use and perceived advantages offered by the TLC Diabetes program, were achieved.

### **3. Discussion**

Provision of chronic care, particularly for aged populations who often have multiple conditions, requires systems that can directly support people self-manage their long term health conditions. Health services around the world are therefore actively exploring delivery systems which could increase the efficiency of chronic health care provision without compromising the quality of care provided.

This paper uses a process evaluation framework to evaluate two different strategies for supporting self-management of chronic conditions, specifically in terms of reach, implementation fidelity, adoption and user perceptions. The results of the CAP RCT demonstrated CAP CR to deliver health outcomes similar to that of TCR and to significantly improve uptake, adherence and completion rates. Furthermore, using process evaluation methods to explore the potential of implementing CAP CR in clinical practice, results showed that it is an accessible and acceptable option for delivering CR for individuals that are not willing or able to attend TCR. Similarly, the TLC Diabetes program demonstrated efficacy in terms of clinical outcomes, very high reach with individuals at risk of diabetes complications and good level of implementation fidelity and adoption. The results demonstrate the potential for this type of program's scalability, and present a promising approach to delivering self-management support to the growing number of individuals living with T2DM.

The investigation of programs such as the CAP CR and TLC Diabetes programs is the first step in the important process of building the evidence base that could eventually lead to their integration into existing health care systems. Nonetheless, the two mentioned interventions are two amongst a multitude of other ICT- supported health programs available today, but the need to establish criteria for translation and dissemination into the real-world of clinical care is not answered in many cases. Often such programs are supported by time-limited external resources, and even if proven effective, are shelved when the projects are completed because they cannot easily be integrated and supported by ongoing care services [2].

Evaluation is needed to explore how to establish and maintain interventions in community and healthcare settings, with the required systematic consideration of the individuals who might use it, the specific behaviours that are targeted for change, the type of technologies that will be used, the time frame of the program, the costs, and the

strategies to integrate the programs into a broader program of comprehensive care. Additional factors to be considered are security, governance and confidentiality of data, which are more difficult to apply outside the controlled environment of clinical trials.

Goode and Eakin offer recommendations on what is optimally involved on the part of the researchers to facilitate successful dissemination efforts [15]. Using the RE-AIM model [16], they emphasize the importance of substantial initial and ongoing research provision around program uptake, delivery, and evaluation. RE-AIM is an evolving framework which has been extensively used in the literature for guiding evaluations and to inform program implementation decision-making. According to the RE-AIM framework, to be successfully integrated in health delivery systems, it is important that interventions reach those most in need, are effective, adopted, appropriately implemented and maintained as a complement/ alternative to traditional care. The RE-AIM framework would therefore be valuable to facilitate and evaluate future real world implementation of the two interventions included in this paper, in terms of:

### *Reach*

In terms of CAP CR and the TLC Diabetes program, barriers and enhancers need to be investigated especially in health regions with limited access to health services. The ability to deliver both these interventions without ongoing face to face contact, not only provides an opportunity to reach large numbers of people, but may be particularly useful in recruiting people who do not have health care services available due to remoteness.

### *Effectiveness*

Effectiveness under real-world conditions needs to be evaluated in terms of relevant outcomes when compared to the original more controlled evidence-based trial outcomes. Replication studies would establish whether the effect sizes observed in the current studies can be repeated.

### *Adoption*

The proportion and representativeness of settings or program providers (e.g. health organizations, health departments, general practitioners etc.) that take up (adopt) these programs for delivery need to be determined. Care systems have been relatively slow to adopt self-management programs and to integrate them into more comprehensive care for patients with chronic disease. An important issue to consider in future development of programs such as CAP CR and TLC Diabetes is that technological interventions could be perceived as undermining important aspects of care, with implications for caring roles [17]. This highlights the importance of carers' perspectives when designing, implementing and evaluating such interventions, and the need for programs to also meet carers' requirements.

### *Implementation*

In future studies, it needs to be verified whether implementation of the interventions is feasible in various contexts and groups, including remote areas and minority groups.

Technologies such as those utilised in CAP CR and TLC Diabetes allow program components to be delivered automatically, providing a specified dose, depending upon participant actions. Tailored variables can be measured and used to assign an optimum dosage of program components (albeit for CVD or T2DM management) to participants in real or near-time.

### *Maintenance*

Further studies are needed with longer follow up periods to establish whether the individual behavioural changes seen in the current research are maintained in the long term. On organizational level it would be necessary to track the extent to which these programs become a routine part of existing delivery services. No amount of excellent intervention research will contribute to improved health outcomes without effective and sustainable translation into policy and action. At the Australian state and federal level, policymakers are cutting budgets and may be reluctant to shift even modest resources from the core activities. To move forward, the necessary funding will have to be obtained from government and private agencies.

## **4. Conclusion**

As the prevalence of chronic diseases continues to grow, with corresponding increase in human and societal costs, there is an urgent need for effective, convenient, easily accessible, and scalable approaches for improving self-management of these diseases.

Despite differences between different chronic conditions, the expectations on the people living with these diseases are similar: to make day-to-day decisions in response to changes in disease condition, to alter behaviour, and to deal with social and psychological impacts of living with the conditions. The CAP CR and TLC Diabetes programs, even though using a variety of different technologies, have shown potential for expanding care from traditionally delivered face to face encounters to care that reaches into the patient's home and community. However, challenges exist in replicating trial findings in the real world. If properly developed, implemented and evaluated, according to a strategic tool such as the RE-AIM framework, ICT platforms such as these have excellent potential to support and improve the self-management of chronic disease.

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