# A Sustainable and Affordable Support System for Rural Healthcare Delivery

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## **ABSTRACT**

In developing countries, especially where a large proportion of the population still resides in rural areas, healthcare access and delivery is often poor, and can benefit from innovative service models and supporting technologies. In these rural areas, the challenges of healthcare quality are many, ranging from poor infrastructure, low literacy, poverty, to inadequate monitoring of patients with chronic or serious diseases. The myriad of challenges requires innovative solutions that are affordable, robust and sustainable over time. Furthermore, due to special characteristics of rural areas and their inhabitants, any healthcare solution should embed a decision support mechanism to prevent basic medical errors and negligence. In this article, we first discuss a healthcare delivery model (home-based health care) in displaced rural areas of South Africa, and then we propose a patient monitoring system for supporting the model using Unstructured Supplementary Service Data (USSD) technology. The proposed system is decision support driven in that it supports medical staff (nurses, doctors) to decide on the course of intervention or further treatment based on the vital signs of the patients that are tele-monitored on a regular basis. This patient monitoring system facilitates patient information flow from home-based care workers to a local clinic or hospital, where the information is presented on a desktop computer used by clinic nurses and doctors for monitoring the patients' health and ultimately speeding up decision making. The proposed system is tested through a prototype, which is applied in practice and generates data for evaluation.

**Keywords:** Healthcare model, rural healthcare, e-health, tele-monitoring, healthcare information system, home-based healthcare.

# INTRODUCTION

The current global healthcare expenditure has grown into an economic sector exceeding 5-trillion-dollars (WHO, 2008) with most of the industrialized countries spending well over 10% of their GDP on healthcare (in the USA it is as high as 16%) and developing countries (e.g., South Africa) making healthcare a national priority. Pivotal issues of 21<sup>st</sup> century healthcare are efficiency and accessibility. Efficiency is becoming a buzzword in discussion with both healthcare managers and decision makers. Behind the term there is enormous complexity; from healthcare processes management to decision making, policy, supporting technology, innovation, and socio-cultural and economic realities - all are interwoven and interrelated into the equation of efficiency. Pertinent to developing countries and specifically their rural areas, the efficiency challenge is dependent on the socio-cultural reality and economic affordance of the

society. This requires innovative yet practical healthcare delivery models and sustainable supporting technologies that can improve the accessibility of healthcare in a rural context. In the following section we will discuss how, within the local rural socio-cultural and economic context, healthcare can be improved. In particular, the determinants of better healthcare in rural areas can become a model with supporting technology that are adequate given limited resources, affordable, robust, and sustainable while ensuring an acceptable level of quality in rural areas, which often have unique characteristics.

Displaced rural areas in South Africa is the result of it's political past, and the object of study in this article, is often characterized by the portion of the population living below subsistence level, whilst also experiencing poor access to basic facilities and services. Populations of rural areas have a lower life expectancy and there is a higher incidence of infectious and chronic diseases. Life expectancy in South Africa is 47 and 49 years for respectively male and female (WHO, 2006), and the estimated prevalence of HIV infected adults is 18.3% (UNAIDS, 2008). This together with other stressors restrains the rural communities from economic growth and development, which is also reflected in the health care delivery. Rural hospitals and clinics are often poorly equipped and understaffed. Inhabitants of rural areas travel a significant distance (10-25 Kilometres) to visit a clinic or hospital, which are mostly walk-in visits without appointments. Commuting from rural areas to the nearest clinics is another foe to the rural areas healthcare delivery (Mattson, 2010).

The nature of healthcare provided (especially in the rural communities) is influenced by what resources are available at health centers, and the daily demand cannot be predicted where a large proportion of the patients are walk-in patients. The result is that patients do not always receive all the needed attention and where clinics cannot provide a sufficient service, the patients are referred to the local- or regional hospitals. Patients can even return home without any treatment. One of the main stressors in this environment is transportation; public transport is expensive and not always available - in some areas these services do not operate due to poor road conditions. Private transport is only available to a few and other residents also pay if they utilize (hire) such private transport. Transport availability and expense mean that patients could sometimes walk long distances to the local clinic. Overall these factors make accessing health care difficult, time consuming and costly. This also negatively affects the health of patients who have no option but to use these available health facilities. To overcome these constraints an innovative and simple model of health care has developed specifically in displaced rural communities. Volunteers from within communities, mainly woman have created what is known as Home-based care (HBC) (Mashiri et al., 2008). By providing a care service to patients within the comforts of their homes, home-based care transcends the former boundaries between patient and clinician (Van Zyl, 2011). The strong tradition of Home-based Care, also referred to as informal healthcare, has become increasingly important, but also threatened to implode under its severe strains (Mashiri et al., 2007). One critical challenge in home-based healthcare is the decision for healthcare caregivers to refer or help to transport a patient to a clinic or hospital. Volunteers report on the conditions of their allocated care patients during interactions with medical personnel at the clinic. These reports are in person but might not take place every day (especially if the care workers work far from the nearest clinic). These interactions, which have the purpose of updating the medical personnel in the clinics and hospitals on the status of the patients, have the format of workshops or meetings, where the caregivers (volunteers) report the latest medical records. The care workers do not make medical decisions as they do not have medical training - they serve as the eyes/ears of the medical staff at the clinic and act upon their recommendations or instructions (Lund, 2010).

In this article, we discuss a solution developed and a prototype tested – a Decision Support System (DSS) based on tele-monitoring of patients. The proposed DSS helps the

nurses and doctors gain more frequent updates of the (home-based) patients' conditions as reported through a set of vital signs. The system can also speed up decisions for further treatment at either the clinic or hospital. This tele-monitoring DSS allows the clinic nurses and doctors to provide better (and faster) healthcare and to effect a more efficient utilization of resources. This solution was made possible partly due to the ubiquity of cell phones and mobile technologies in rural areas, which created certain advantages and opportunities for this system development.

As Steinmueller (2001) affirms, accelerating development by skipping stages in the development trajectory (also known as leapfrogging) holds big opportunities for developing rural areas. The most well-known example of leapfrogging is the rapid expansion of cell phone usage in the developing areas of the world, thereby avoiding the installation and use of landlines, a technology that has been used for decades in the Western world. Pade (2007) argues that the use of Information and Communication Technologies (ICTs) in developmental activities can considerably enhance rural development. However, according to Heeks (2005) one-third of all ICT projects in rural areas are total failures and one-half are partial failures, leaving little room for success. Apparently, ICTs are not always easily adapted to fulfill the role of developmental accelerator. Mobile ICT tools have the following properties that enable their implementation and use in such challenging contexts; the infrastructure is relatively inexpensive, is often available even in rural areas, although the population is mostly poor, many either own a cell phone, or have access to one through friends or family, and developing mobile services is not overly expensive as compared to for example landlines. Critically, developing a mobile service that is appropriate, robust and sustainable in these rural environments has proven to be difficult. (Chetty, 2005).

While the current literature on healthcare, healthcare models, healthcare ICT present a plethora of studies addressing different aspects of healthcare in developed countries, rural healthcare research has not received as much attention. Given that especially in the developing world there are still many areas with large rural populations. This is a promising research direction, which requires significant scientific attention. Our research challenge therefore is to explore how ICT service systems can support the South African informal health care (home-based healthcare) decision processes in rural areas and to develop and test a robust and sustainable prototype of an ICT-based healthcare delivery model. The proposed solution resulted in a tele-monitoring system, which facilitates exchange of patient information between caregivers and clinic staff. of equal importance in this research is understanding the socio-cultural and economic context of the problem and the related design challenges. The prototype of the tele-monitoring system is the result of joint research between Delft University of Technology (Netherlands) and the South African Council for Scientific and Industrial Research (CSIR). This study was driven by a real world problem and the system development was carried out in a period of seven months of fieldwork in addition to desktop research conducted throughout the project The research is based on a design science approach, modified to deal with the specific design requirements for design for development.

The remainder of this paper is structured as follows: in part one we discuss the socio-cultural and economic context, which sets the stage for the research carried out and the results presented in this article; in part we discuss the underlying theoretical foundation on which the presented research is based, which also includes the research objective, challenges, and methods used; in part three we relate the research rigor and relevance to the object of design (DSS for home-based healthcare) and the way the requirements were gathered for the design purpose; in part four the proposed solution is discussed, which also constitutes the core of this article; in part five the designed solution is evaluated and in the concluding part we discuss the research findings, draw conclusions and give a future possible research outlook.

#### SOCIO-CULTURAL AND ECONOMIC CONTEXT

Historically, rural areas, especially in the developing country context, face isolation and have poor levels of access to services and facilities, often including healthcare services. This lack of access to services and facilities puts rural areas at a distinct disadvantage compared to many urban centres (World Health Organization, 2011). The result is often unbalanced development, social and economic injustice and divide, which is common throughout the region (Ouma et al., 2008). Because of past policies, rural South Africa also has high-density population areas and displaced settlements (often in the former homeland territories) where many people live below the poverty line. Present settlement patterns reflect the distortions and policies of the past, and South Africa is still characterised by high levels of poverty, especially in displaced rural areas (Maritz, 2006). Approximately 39% of South Africa's people live in rural areas (Government of RSA, 2011). Their incomes are constrained because the rural economy is not sufficiently vibrant to provide them with remunerative jobs or arrange of self-employment opportunities. Their cost of living is high because they spend relatively more on basic social services such as food and water, shelter, energy, health and education, and transport and communications services (Republic of South Africa, 2000).

Formal primary healthcare in South Africa starts at the clinic level. However, traditionally, a unique model (or level) of healthcare has developed spontaneously within rural communities. This is known as Home-Based Care ((HBC) - it is the provision of basic nursing and home care by formal or informal caregivers to people in their own homes. This service is available to people who have mental, physical, emotional and social needs. The care given is meant to restore and maintain the individual's maximum level of comfort, function and health (Cape Gateway, 2009).

# Home-Based Care (HBC)

The basic home-based care system is similar across South Africa and works as follows: Once discharged from the hospital, a patient with a chronic disease, or a disease requiring follow-up care, can make use of the provisions of the Home-Based Care organization. The clinic or hospital normally informs the local Home-based Care Organization of patients that require ongoing care and the care organization in turn allocates a caregiver to the patient. The caregiver often works on a voluntary basis and visits the patient on a daily to weekly basis. The main tasks of the caregiver ranges from physical care such as bed bathing, wound care, cleaning those with frequent bouts of diarrhea, hygiene, ensuring taking of medication, household support such as preparing food if required. Since the caregiver acts as the direct communication link between the patient and the clinic, he or she is required to provide feedback on the condition of the patients. This takes place in the form of a reporting form and or by having feedback discussions with the clinic nurse held periodically at the clinic (a few times a month).

As mentioned previously the caregivers' activities consist of more than basic nursing: They provide broad social assistance, such as physical, educational, psychological and spiritual care for both patients and their families (Mashiri et al., 2007). By decentralization of health care to the district level, the scope of operations and the quality of the home-based care differ throughout the country. For this research efforts was however focused on a cluster of four specific rural communities, described in the following section.

#### **Research Area: Leroro Communities**

The research area, referred to as the 'Leroro Communities' is located within the north-eastern part of South Africa, and consists of four clustered communities in the Ehlanzeni District in the northern part of Mpumalanga province bordering the Blyderiver Canyon (see Figure 1). As depicted in Figure 2, each community has approximately 9000 inhabitants. One hospital, situated north of Matibidi A, serves the area. Three clinics are located in the communities of Matibidi A, Matibidi B and Moremela. The areas are accessible by surfaced road with the exception of Matibidi B, which can be accessed by gravel road. Mobile phone coverage is good in most parts of the area. Caregivers in Moremela and Leroro report to the nurses in the Moremela Clinic. The Matibidi A and B caregivers report to the Matibidi B Clinic.



Figure 1: Research area in South Africa

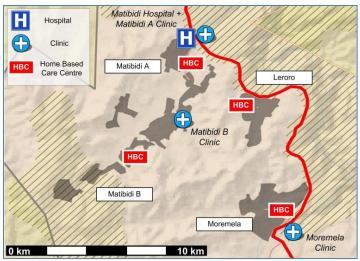


Figure 2: The four communities in Ehlanzeni District, Mpumalanga

## DESIGNING ICT-BASED HEALTHCARE FOR RURAL COMMUNITIES

Acceptance of mobile communications and network technologies for health care systems itself is a challenge in developing countries and especially in culturally diverse countries (Ganapathy and Ravindra, 2008). When designing IT solutions for developing communities, it is important to have sustainability of the service, by the community itself as a key design objective (Pade, 2007).

The high rate of failure in ICT programs is explained by Heeks (2002, p. 101) as a "mismatch between Information System design and local user actuality." Researchers Morales-Gomez and Melesse (1998) blame poor analysis of the social and cultural dimensions in the user's context for inappropriate outcomes. For this, the project needs to be approached from a strong user-centered perspective, and by making use of participatory approaches. As developing projects are often initiated by the providing party, they are often based on 'invented needs' instead of actual needs and problems identified in the community. This often causes unsustainable projects that cease to work once the supporting party has left (Pade, 2007). In order to design a sustainable service in a developing context, it is important to use a user-centered design approach. Stakeholders should be involved in a participatory component to define development priorities and goals, which can then be used to determine the need for external support (Gigler, 2004).

Apart from using a participatory approach, the project needs to be approached as a business plan, where in the end, the service is self-sustainable. For this, human capacity, creating a favorable environment for business creation, and infrastructure development are critical conditions (Pade, 2007). Furthermore, it is highly important that the project is integrated and anchored in local community activities and processes (Pade, 2007). Not all IT solutions are feasible in rural and developing communities. Robust, simple and flexible IT solutions are more likely to succeed (Fortier, 2003; Fourie, 2007,). Infrastructure is an important pre-condition here. If vital infrastructure for the project is unreliable or non-existent, the project is unlikely to succeed. In the case of this research project, electricity-, and regular land line phone networks are unreliable. However, a cell phone network with good coverage is available which made amobile phone solution a more logical choice. Still, infrastructure and technology provision alone are not sufficient for the success of the proposed solution (Fourie, 2007). The design and acceptance of a new way of working that solves real and experienced problems of the community is much more critical.

## **DESIGN SCIENCE APPROACH**

In order todesign a robust healthcare solution and to better understand the design process for a Decision Support System in a development context, the implications for design drawn from the previous section is combined with the design science approach for Information Systems as described by Hevner et al. (2004). Design science is a rapidly growing approach to IS design and research (Piirainen, et al, 2010). In design science, design is proposed as a research strategy to gain knowledge and understanding about a known research problem, though design of an object with an embedded solution to that problem (Peffers et al 2007).

Design science advocates three cycles of inquiry; a *relevance cycle* to study the context and requirements for the design and to test the design in the field to verify its relevance, a *rigor cycle* to study appropriate methods and theories from literature to use in the design, and to add findings from the design study to this knowledge base, and a *design cycle* in which theory or understanding is derived from designing the solution. Design science provides seven guidelines

for research with a design component. These guidelines call for addressing the innovative artifact that is to be designed, the problem it solves, the evaluation criteria for success, the research contribution, the rigor of the research methods used, the design approach itself, and the communication of findings. The objectives of this study according to these guidelines are detailed in the following sections.

# **Research Objectives**

The overall objective of this research is improve healthcare provision for inhabitants of rural areas, which is also efficient and sustainable. This overall objective is further divided into two key objectives: to develop a DSS solution for decision making in rural healthcare processes, and to reflect on the use of design science in the context of design for sustainability in development of rural communities. The practical problem we aim to address is the lack of constant communication between home-based caregivers and the clinic, which makes it difficult for both the clinic and the home-based caregiver to advise the patients on their course of treatment, including whether they have to visit the hospital or clinic for proper examination. In this project the success criteria are the following: the extent to which the clinic has accurate information about the condition of patients, and the sustainability of the DSS solution in the rural context. The contribution of this research is a set of guidelines for sustainable design and implementation of communication and decision support solutions in a rural healthcare context that yields better healthcare and a more efficient use of resources.

# **Research Challenges**

Originating from many forms of inequalities and experiences with corruption and political mismanagement, the rural population has a low esteem of government actions. This lack of trust along with a general high failure rate of development projects has resulted in a certain 'reserve' towards new projects and it affects caregivers' and nurses' motivation and willingness to share information with the researchers (Wouters et al., 2009). Furthermore, many projects that have taken place, started by government or non-government organizations, have delivered 'white elephants' rather than a sustainable system. The idiom of 'white elephant' (Robinson and Toryik, 2005, p. 2) is commonly referred to as investment projects with negative social surplus.

Some other aspects that make it difficult to gather valid information are: informality of business processes, 'yes-nodding,' and stigma attached to some diseases such as HIV/AIDS. Burdened with more fundamental problems, caregivers and nurses are skeptical with respect to a new system or processes. Care giving volunteers have limited professional training and are of semi-or low literacy level. This limits the extent to which system requirements can be elicited from caregivers. Furthermore, a substantial part of the patients does not have faith in western medicine and more traditional medicine is practiced.

# **Research Methods**

The methods used in this research are field observation, individual interviews, joint workshops, and a literature review. During the field observation, researchers met with and interacted with the local people and a photographic record was kept of the locations and people in order to portray the local socio-economic realities. Individual interviews were used for initial study of the need for a patient's tele-monitoring decision support system (DSS). The design was approached in a participatory way in order to avoid the pitfall of trying to implement an externally developed solution (to a different reality), then trying to customize the local socio-cultural reality to the solution. The research project involved the end users throughout the development process, which benefitted the project at the later stages of implementation and actual usage of the prototype.

Attracting participation of the users is a critical success factor in designing new systems. The objective of participation is about treating the client, for whom the solutions are designed, as *client-designer*. In this role, the client is participating in the design process as a designer, although it is not a smooth and easy way for the client partners to enter the design world (Weedman 2008).

## **DESIGN RIGOR AND RELEVANCE**

In this section, in light of the design science approach to designing information systems, the relevant knowledge base and frameworks will be explored to inform the rigor cycle in designing a sustainable decision support system for home-based healthcare. Next the environment base, the context, requirements and constraints that inform the relevance cycle in designing a sustainable decision support system for home-based healthcare will be addressed.

# **Knowledge Base**

In the development of a sustainable system, a key requirement is that the community adopts and maintains the system and has a sense of ownership with respect to the system. To achieve this, user involvement in all stages of the development process is considered very important. In order to ensure commitment from stakeholders in using and maintaining the system, the model of Meyer and Allen (1991) was used in which three components of commitment are distinguished:

- Affective or emotional commitment, based on the personal relation between caregiver and patient.
- Continuance commitment, based on the benefits or utility people obtain from their participation.
- Normative commitment, a felt obligation to continue, strengthened by the sense of community and being needed.

Thus, a key factor in commitment and sustainability is the utility or value of the system. This is also a primary factor in the Value Frequency Model, positioned by Briggs et al. (2006). As depicted in Figure 3, this model predicts change of practice and adoption of a new work practice with associated technology. The model posits that the key factors relevant to adoption are the perceived net value of the new work practice. This value is then multiplied by the frequency in which this value is derived. Beside the value and the frequency in which this value occurs, the model posits that it is important that users have some certainty that they will derive this value. Finally an important factor is the transition costs. We will use the models on value frequency and commitment to establish insight in the incentives for users to adopt and sustainably use the new work practice and the associated decision support system. Using the value frequency model and the commitment factors of Meyer and Allen, we designed our solution on existing frameworks in literature, thus establishing rigor in the study.

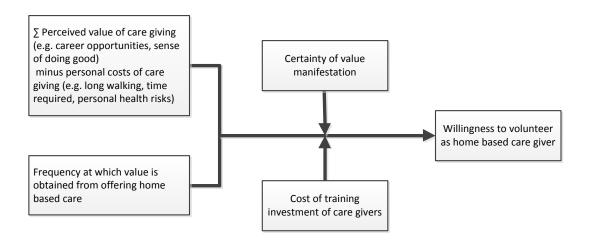


Figure 3: Value frequency model: Factors affecting willingness to volunteer and to sustain home-based care systems

#### **Environment Base**

The context of our research involves three major stakeholders: the medical staff (nurses and doctors), the caregivers (mostly volunteers), and the patients and their family. The hospitals and clinics do not have sufficient resources to provide appropriate care to the community they serve. The distance between the clinic, hospitals and villages is large; there are very few doctors compared to the size of the community they serve, and the lack of equipment such as emergency vehicles, vehicles for visiting patients, and medical equipment, makes it difficult for the clinic to provide appropriate far reaching care. As a main problem, the patients face mobility constraints due to the lack of transport to a clinic or hospital, which compromises the whole purpose of better healthcare and healthcare efficiency.

Transport is scarce, irregular and expensive, and this poses a major barrier to go to the clinic in time for proper treatment. Furthermore, it is difficult to get patients to be at appointments for this reason, and vice versa; patients sometimes show up at the hospital, when they cannot be treated. The caregivers are volunteers and mostly woman. They followed short training programs mostly in first aid, basic hygiene and dealing with HIV Aids to enable them to provide better support to their patients.. The shortage of basic equipment combined with the lack of transportation means, makes the caregivers quite helpless in providing better healthcare support. They visit the patients travelling by foot daily or weekly, and also walk to the clinic to report on the status of the patients weekly (or a few times a month). The patients also have limited resources to pay for regular transport to the clinic. Furthermore, if they want to contact either a caregiver, the clinic, or emergency medical services, they often have no means for communication. The result is that they either wait for the care giver, or go to the clinic in person.

The problem is the following: there is insufficient patient condition information available to the clinic medical personnel to be able to visit critically ill patients, or to advise the patients to come to the clinic or hospital. Secondly, if caregivers attend a critically ill patient, they often cannot contact the clinic or hospital for help without bearing the costs involved. Thirdly, the caregivers did not collect and provide standardized medical information on the condition of the patients that would allow clinic medical staff to take action. Finally, the patients cannot contact the caregivers or the clinic.

The organization of the Home-based Care can be quite informal; often the manager of the Leroro HOME-BASED CARE is one of the volunteering caregivers. The resources of the HOME-BASED CARE are also limited and mentioned the caregivers do not have standardized equipment to take standardized measurements of vital signs. In the context of this research, normative commitment has a critical additional factor, that is, the tradition and informal ways of working in the current system are valuable to the community and should not be stopped. The preceding reality was that the Home-based Care organization and members in Leroro did not use technology such as mobile phones, the Internet to serve their needs. There were no databases of patients or any system (apart from an inefficient paper record system) that could support Home-based care services or the local clinic and hospital in terms of decision-making. Finally, generic constraints are imposed due to the level of literacy and IT skills of the actors involved in the home-based care system. This implied that any new system had to be simple and easy to maintain, as the skills to adapt, maintain or repair a support system are limited in the area. Though interviews, site visitis and a highly interactive design approach we continuously monitored the relevance of our solution in this challenging context.

# **Requirements Elicitation**

Given these constraints, the following steps ware taken to derive the requirements for the system and to develop a prototype that meets these requirements. We did a site visit to identify and discuss the problems with respect to healthcare communication with different stakeholders. We did informal interviews with the nurse and healthcare volunteers, where necessary with help of translators. Finally we did a participatory workshop with caregivers and managers of the four HBC centers, a sister from Moremela clinic and the hospital clinic, to further refine the requirements. Besides these observations, informal interviews and workshop we used previous research on IT solutions in developing countries to identify requirements and to restrict the solution space; We looked at what is available in terms of technology, we investigated best and worst practices, and we derived requirements from comparable information systems, and finally by analyzing the environment. The available technology and infrastructures are particularly of importance to consider in this rural context as it is a critical factor in the sustainability of the solution. To balance the rigor and relevance in this study, we looked for key values and factors that would optimize the value of volunteering in the home-based Care system for caregivers. and that would stimulate their commitment. These factors will improve the chances for sustainable adoption of the design. The engagement process identified two critical resources that were lacking especially when it came to recording and transmitting patient information during visits. Firstly care workers did not have the medical equipment to in a standardized manner, assess the health of the patient, such as thermometers, blood pressure meters and first aid materials. Secondly they did not have a means to communicate recorded vital signs to the nurse timely enough for quick decision-making, or to ask the nurse for assistance. However, to structure the information in order for the nurse to support decision making, an affordable and sustainable communication approach is required. The user requirements elicitation process indicated that frequent communication of the vital signs could increase normative commitment due to more regular feedback, and it should increase the perceived frequency value of care giving, as the effort of the caregiver is more visible to the nurse. Furthermore, the system should solve the problem of irregular and out of date information collection and -transfer that affects the decision making process of the clinic's medical staff. This is especially important where the patient need to visit the clinic again. The intention was also to reduce unnecessary and costly trips, make already limited healthcare more accessible and use current constrained resources more efficiently.

Next the design of the prototype system was undertaken using a participative approach where the various stakeholders could be involved throughout the process. This meant that the user requirement for the solution could be constantly evaluated with the relevant stakeholders, and a shared understanding of the value of the new way of working, could be established. Caregivers indicated during latter sessions that they appreciated being consulted during the design of the DSS, and that being involved in the design process also helped them to understand the added value of the system (measured as part of the questionnaire described below). At the start of the design process, the problem, the solution and its possible technologies were flexible and depended on stakeholders' input, thus the developers did not come with preconceived ideas. Informal semi-structured interviews in small groups were held during the first two visits to assess users' needs. A workshop organized at the start of the project was attended by all relevant stakeholders and intended to define problems they typically encounter and to indicate how such problems could potentially be addressed. A secondary goal was to achieve consensus amongst participants and build commitment for the project. The workshop helped to elicit and rank the first basic requirements given their importance.

During the third set of interactions, more detailed requirements were again discussed in small groups. Participants could state their technology preference (call center, spoken dialogue system, SMS or USSD) after simulating on paper interaction with these technologies. To encourage the commitment and continued involvement of the caregivers, they were provided with medical equipment (necessary for taking standardized vital sign measurements) and limited basic medical supplies. Following the issuing of the equipment training sessions was organized by the clinic sisters to train care workers in the correct use of the equipment. In parallel with these activities the ICT prototype was designed taking the requirements elicitation and follow-up work session inputs into account. Prior to the implementation of the project, desktop computers had to set up for the clinic staff overseeing and using the prototype. The computers were linked through the Internet to an online database that would capture and present patient condition information collected via the prototype. Crucially training also had to be provided; to the clinic staff who would access the information and evaluate patient records. Caregivers were also trained in the use of the USSD system, chosen as the appropriate technology for the prototype system. The visits undertaken after launching the prototype system was to resolve problems and to retrain some users, as well as for usability and usage observations. During the last visit questionnaires were administered to evaluate the system.

## PROTOTYPE DESIGN

In the previous section the design approach, the social context and its associated challenges was described. The goal was to design a robust and affordable ICT enabled system through which caregivers can submit vital patient information to the clinic nurses; nurses and doctors can use the system to track patient conditions and to make decisions and allocate resources accordingly; and collectively, to create a system that improves healthcare services. The prototype, which has been in use since January 2009, met its functional and technical requirements for the most part.

# **System Prototype**

The Leroro area, selected because it had an established home-based care structure, consists of four main villages (see figure 2). In each village, three caregivers, each nursing about twenty patients, were selected and equipped with basic medical instruments (see Figure 5). After visiting patients and measuring their vital signs, the readings are submitted via a USSD menu on their own mobile phones. Once submitted, two nurses in the Moremela and Matibidi B clinics have immediate online web-based access to the submitted data via a desktop computer. A home-based care coordinator based at the care center in Leroro is assigned the role of information manager, to update the online information system with the new patients and to

correct and update patient profiles. Implementation and training took place near the end of December 2008 and the system is operational and self-sustainable since January 2009. Although a fair amount of data have been collected for such a small-scale prototype, additional evaluation and monitoring activities were undertaken. Technically, the system is expected to be of low cost, free access, intelligent (teachable), usable, confined to current communication means and structured to handle confidential patient information. Costs for the use of the USSD system is R 0.20 (\$ 0.02) per 20 seconds. One session takes roughly one and a half minute, which is approximately R 1.20 (\$ 0.12) on average per session. No cost benefit analyses have been carried out as yet. One constraint has been the cost for airtime – users have to load airtime (using vouchers) on their mobile phones for the system to work. During the research the project purchased and supplied airtime to users (who mainly use prepaid phones). The use of airtime cannot be managed and for the test period it was not possible to redirect airtime costs to one account. The solution is to create a toll free account available to users of the system. This matter is currently being explored together with the relevant government departments and mobile phone service providers such as Vodacom in conjunction with the Department of Health.

## **Technical Architecture**

In designing the system, the research team followed the service system design framework (van de Kar & Verbraeck, 2008). The system uses the USSD (Unstructured Supplementary Service Data) technology available in the area. USSD allows for the transmission of information via the Global System for Mobile communication (GSM) network. USSD is best explainable as an interactive SMS'. Text messages are sent to and received from a caregiver's mobile phone through a real time connection to the GSM network. A wireless service access provider (WASP) routes the messages from the mobile network to a server with the application and database. Nurses and information officers have web-based access to the application and personal health records (PHR) via a 3G modem and a desktop computer. Figure 4 presents an illustration of the technical architecture of the system. A big advantage of the use of USSD is that it is easily accessible (by simply dialing a number) and easy to use due to a simple menu structure. USSD works on almost all mobile phones and it is generally used in South Africa, for example to load airtime on a mobile phone, for mobile banking etc. A drawback is that the open connection is disabled after three minutes.

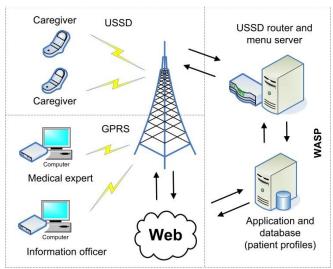


Figure 4: Technical architecture of information system



Figure 5: Caregiver equipment containing a thermometer, weighing scale, blood pressure meter and stethoscope, watch, urine-strips and first aid kit

Each caregiver is equipped with a kit of basic equipment (see Figure 5) containing a thermometer, weighing scale, blood pressure meter and stethoscope, watch, urine-strips, and a basic first aid kit.

# **Caregivers Interaction Process**

The following describes the steps the caregivers follow when using the system: after measuring a patient's vital signs, a caregiver dials a USSD number (\*120\*667\*4247# in the test case, see Figure 6a). The application recognizes the phone number of the caregiver and answers "Hello caregiver {Davis, #98}, please enter your personal code". After entering and sending her personal code, the application responds 'please enter patient number now' (Figure 6b). The application recognizes the submitted patient number and answers with the main menu. Figure 6c is an example of the main menu for patient number 0001, an imaginary patient named "Patient Fakes". The main menu shows five types of vital signs (option 1-5), the alarm (option 6) and the Submit data option (option 7). The caregiver can choose to enter the vital signs in any order. For entering the temperature, she answers by sending a '1'. The next screen (Figure 6d) requests the temperature value. After entering the temperature, the application returns the main menu, including the reading of the temperature she has just entered. Figure 6e presents what a fully entered main menu would look like. If all vital signs are entered, the caregiver chooses option 7 to submit the data although this is redundant, because the application already has received the information. During user testing caregivers indicated that they preferred to end the process with a confirmation message.

A complaint raised often by the caregivers was that they didn't know how to act when they encountered a critically ill patient. The 'ALARM' option, number 6 in the main menu, addresses this need by allowing the caregiver to the clinic sister an automated SMS, containing the patient's name and caregiver's name and phone number. The sister upon receiving this emergency SMS can call back the caregiver to assist with the particular situation.

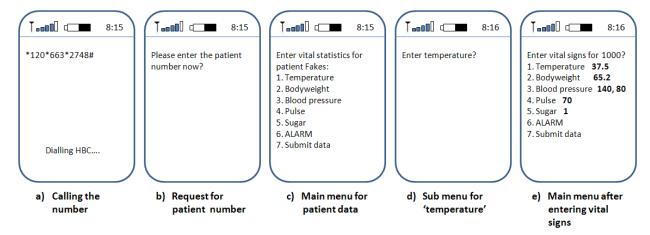


Figure 6: Some screenshots of the USSD interface on a cell phone: a. Calling the number; b. Request for patient number; c. Main menu for 'patient Fakes; d. submenu 'temperature'; e. Main menu after entering all vital signs

#### **Nurses Interaction Process**

Using a 3G modem, a nurse can access the Internet on her desktop computer in the clinic. The online application is stored on a website, which has been set up as the home page. After logging in, the nurse has access to the patients listed by patient number, or the patients whose vital signs have been submitted during the last few days. After clicking on a patient name, his or her personal health record (PHR) pertaining to the system is displayed.

Figure 7 shows an example of a personal health record. More options can be added to the site, such as displaying line charts, adding comments, or viewing patient's clinic history. To develop an implement the prototype is was decided to create a lean and simple interface.

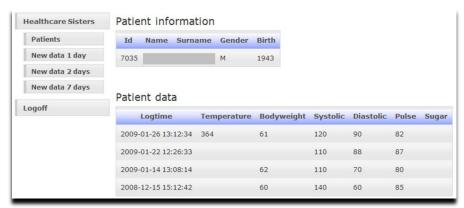


Figure 7: Screenshot of a web based personal health record

## PROTOTYPE EVALUATION

As mentioned previously, the actual use of a new system is an important indicator for the successful development and implementation of the system. The following section discusses the scientific models used to evaluate the usefulness and usability of the prototype system.

# **Evaluation Approach**

The goal of testing the prototype is to determine its success and to investigate its potential replication or application in other similar areas. In this research, we are not only interested in the actual usage of the prototype, but also in the users' perceived value, both from a personal and from a healthcare improvement perspective, and in the factors that determine these perceptions. It is possible to find a high usage during prototype testing, while at the same time the perception value, and thus attitude toward using it, could be negative. This is an undesirable outcome, meaning that it is unlikely that the same system will be successful in other communities under comparable conditions. Two rationales for this possible outcome are, firstly, that the long-term presence of the research group may have established certain compliance among the caregivers and nurses, and secondly, it may have caused a situation in which the caregivers and nurses want to live up to expectations that are raised. This effect is referred to as subjective norm (see for example Aizen and Fishbein, 1980, Davis, 1993). Another example of subjective norm is where caregivers feel compelled to use the system. Although being volunteers, local charismatic people like Home-based care managers or nurses could incite the caregivers to use the system, without being convinced that it has added value. Secondly, the perception of value could have been strengthened during the participatory design stages. All participating care workers were frequently consulted about their opinions and preferences using informal interviews and site visits. This has undoubtedly led to a better understanding of the design choices that have been implemented.

Submitted patient information by caregivers and login data from nurses, questionnaires and user observations will be used to disentangle factors that led to high or low user acceptance. By investigating these factors future behavior and or potential can be assessed, although such an assessment would be a decision maker assessment.

## **Evaluation Results**

#### Observations

Besides the experiences of the researchers that the attitude towards the system is very positive, one of the most obvious findings is the variation in usage behavior amongst nurses and amongst caregivers. For example: One nurse was very enthusiastic and cooperating. She monitors patients on a daily basis and contacts caregivers if submitted data seem untrustworthy. The nurse in another clinic is more reserved in using the system. Although enthusiastic and cooperative, she hardly started up the system after the implementation of the prototype, which can in part be explained by her lack of experience in using computers. The variation in usage between caregivers is also distinct: Not only the degree of system usage, but also the number of mistakes and reliability of patient data differs greatly. Most caregivers mastered the USSD system within a few trials, but some of them were still struggling after weeks of practice. Medical instruments were handled improperly, which resulted in an emphasis on new medical training sessions instead of focusing on using the ICT system. Some instrument such as those used for taking blood pressure readings were replaced by more automated devices. This in itself was a good sign, both nurses and caregivers felt that accurate measurements are a necessary precondition to using the system. Another variance is the difference between the caregivers in the various regions. In the more successful region, the nurse that is monitoring the patients has a higher usage of the system and this seems to be a reinforcing mechanism for the caregivers, creating a normative commitment effect. High caregiver usage and accurate patient information motivates the nurse to use the system, which in turn reflects on the caregivers and motivates them to keep using the system. Another reason for better performance of caregivers from one region compared to another is the nature and personality of the Home-based Care manager in

the region, resulting in a relationship of commitment between caregiver and manager. Usage behavior of the system seem to be better in areas/communities where the living standards, infrastructure and education seem to be slightly better. During the test phase the number was not toll-free yet and airtime vouchers needed to be distributed which caused considerable problems and unintended use of this airtime. This confirmed the necessity for caregivers to have "free" access for the system. The system usage was also lower in areas where mobile phone network coverage was not always available.

## Measurements

To measure the perceived value of the new system, and the commitment towards using this new system, a questionnaire was applied with the participating caregivers (12) It applied afive point standardized Likert scale ranging from strongly agree to strongly disagree. The average age of caregivers was 35, and they had on average five years of experience as caregivers.

The perceived value of use was established for both the quality of Home-based Care system and for the caregivers, as depicted in Table 1.

Table 1: Perceived value of use

Questions perceived value for Home-based Care system	Average	Standard deviation
The added value of the system was clear from the start	1.3 (agree)	0.5
The DSS increases life expectancy of the patients	1.5 (agree)	0.5
The DSS increases life quality of the patients	1.4 (agree)	0.5
The DSS enables the nurses to make earlier diagnoses	1.3 (agree)	0.5
If I see a critical patient I'm happy I can send and Alarm	1.4 (agree)	0.7
The DSS reduces patients unnecessary transport	1.6 (agree)	0.7
Questions perceived value for caregiver	Average	Standard deviation
The DSS improves my job performance	1.3 (agree)	0.5
Using the DSS allows me to accomplish more work that would otherwise be possible	1.9 (agree)	0.9
I can see more patients per day as a result of the DSS	1.5 (agree)	0.7
After I take the readings of the patient, I have a proper picture of the health conditions of the patient	1.5 (agree)	0.5
By using the DSS I can show my capabilities to the nurse, which might result in a career step	1.3 (agree)	0.5
The DSS reduces the workload for the caregiver	1.3 (agree)	0.5
I have more joy in the work that I do because of the DSS	1.4 (agree)	0.5
The fact that we have the medical equipment and the DSS fives me the feeling that my work is more appreciated	1.3 (agree)	0.5
The DSS reduces my daily unnecessary transport	1.5 (agree)	0.5

Overall we see that caregivers perceived to get value from using the DSS, both for themselves and to improve healthcare service though Home-based Care for their patients. This is a positive indicator of usefulness. While the number of caregivers that could be approached was low, the very low standard deviation in the results strengthens confidence in the design. In addition, the subjective norm did not reduce the confidence in the design. Caregivers reported a strong disagreement (4.7) with the statement that they used the DSS because other caregivers used it, and a neutral (2.7) felt obligation to use the DSS if they didn't want to, given their volunteer status. While caregivers reported that participation in the design helped them to understand the DSS, the researchers did not feel that this created a perceived obligation to use the system.

## **DISCUSSION AND CONCLUSION**

This paper discussed two innovative components that together facilitates better rural healthcare and more efficient use of resources namely, a home-based care health delivery model and a tele-monitoring patient system that support this healthcare. The research presented here was driven by a theoretical foundation and field proven approaches. In particular, the combined use of design science and participatory approaches proved valuable as it focused the designers' attention on key values and the related sustainability challenges. It is worth noting that the socio-cultural and economic context, in which this research was conducted, is not well represented in mainstream literature. It is an area that deserves more academic and research interest...

The article provided an overview of several design processes that, in combination with a design science approach, have led to a prototype of a tele-monitoring system that provides valuable support to the operation of home-based care organizations in four clustered rural communities in South Africa. In this type of healthcare delivery, regular communication and patient data exchange are one of the most important factors in providing better home-based care, which is currently weakened by the current financial, social and local circumstances.

An ICT-enabled system with twofold functionswas discussed: as a healthcare information system, caregivers can transmit patients' readings of vital signs to the clinics and keep records of the patients; as a decision support system, the medical staff in the clinics and hospitals, where the patient information is transmitted, can use the system when deciding a proper course of further treatment or resource allocation. In the light of these two main functions, the discussed system contributes to the efficiency and better healthcare for the inhabitants of the targeted rural areas. The design efforts were driven by certain quality criteria such as ease of use, sustainable solution, and adequacy to the traditional practices to preserve the existing time proven best practices.

Caregivers submit the vital sign data via USSD technology using their own mobile phones. The medical staff (nurses, doctors) examines the personal health records on the web via a desktop computer. USSD is best explained as "interactive SMS" which is very easy accessible and easy to use. The proposed research approach had a social problem solving perspective and the researchers strived for a highly participatory design process. Preliminary results are therefore very promising. The DSS was evaluated based on the perceived value for the improvement of Home-based Care, and on the personal value for the most critical stakeholders; the volunteering caregivers. The results show that the perceived value was high for both. This creates a path for a more sustainable solution, as it is in the interest of the caregivers to sustain the use of the DSS. Some tantalizing challenges remain in sustaining the use of this DSS to improve healthcare decisions. Caregivers and nurses have been trained to operate the system in a very short period and although medically trained, caregivers lack practice with the medical equipment. For some caregivers this resulted in inaccurate readings and unreliable submitted data. This places at risk the trust in the system by health care professionals at the clinic. On the

flipside, proper system usage by caregivers motivates the nurses and this reinforces the use among caregivers. A general impression has been that patients, caregivers and nurses see the added value that this system can provide. A positive outcome has been that caregivers and nurses now communicate more often and and they experience more joy in their care work. One of the negative experiences is that patients regard the monitoring system as a replacement for a visit to the clinic and not as a supplementary service. This makes some of them reluctant to travel to the clinic.

For future research, the interoperability of the proposed system with conventional systems (electronic medical records) at regional and national level might be of interest to pursue. However, from a theoretical point of view, the impact of the proposed system on the quality of healthcare, errors elimination, decision support and accuracy of alerting of critical cases pose an interesting direction for future research. Lastly, it is important when developing any ICT for development application /solution to have a good relationship with the community involved as the risks of failure are often due to human behavior. A process must also be followed to ensure the research incorporates the ethical sensitivities – especially when the information is of sensitive or personal nature.

### REFERENCES

- 1. Ajzen, I. and Fishbein, M. (1980). Understanding Attitudes and Predicting Social Behavior, Englewood Cliffs, NJ: Prentice-Hall.
- 2. Briggs, R. O. (2006). The Value Frequency Model: Towards a Theoretical Understanding of Organizational Change. International Conference on Group Decision and Negotiation, Karlsruhe, Universtatsverlag Karlsruhe.
- 3. Cape Gateway (2009). Government Information Portal for the Western Cape, www.capegateway.gov.za/eng/yourgovernment/gsc/595/services/11501/6392.
- 4. Chetty, M., (2005). Developing locally relevant applications for rural South Africa: A Telemedicine example., University of Cape Town.
- 5. Davis, F. D. (1993). User acceptance of information technology: system characteristics, user perceptions and behavioral impacts, International Journal of Man-Machine Studies, 38, 475-487.
- 6. Fortier, F. (2003). Sustainable rural networking community ownership and appropriate technologies. Challenge and prospective of bridging digital divide in China rural areas. Tongnan county, Chongqing Municipality, China.
- 7. Fourie, L. (2007). Enhancing the livelihoods of the rural poor: The role of information and communication technologies. Country report South Africa.
- 8. Ganapathy, K. and Ravindra, A. (2008). mHealth: A Potential Tool for Health Care Delivery in India, Making the eHealth Connection: Global Partnerships, Local Solutions conference Bellagio, Italy.
- 9. Gigler, B.-S. (2004). Including the exluded Can ICTs empower poor communities? 4th International Conference on the Capability Approach. University of Pavia, Italy.
- 10. Government of the Republic of South Africa, (2011). National Climate Change Response Green Paper. Department of Evnironmental Affairs. Document sourced on 9 September 2011 from http://www.climateresponse.co.za/sites/default/files/GreenPaper\_3\_Dec.pdf
- 11. Heeks, R. (2002). Information systems and developing countries: Failure, success, and local improvisations, Information Society, 18, 101-112.

- 12. Heeks, R. (2005). ICTs and the MDGs: On the wrong track? Manchester, Manchester University, Institute for Development Policy and Management.
- 13. Hevner, A., S. March, et al. (2004). Design Science Research in Information Systems. Management Information Systems Quarterly 28(1): 75-105.
- 14. Lund, F., (2010). Hierarchies of care work in South Africa: Nurses, social workers and home-based care workers. *International Labour Review*, **149**(4), pp. 495-509.
- 15. Maritz, J. (2006). PhD Proposal: Impact of use of virtual communication on physical communication via changing accessibility patters in the rural developing area context (South Africa), Utrecht University: Faculty of Geographical Sciences.
- 16. Mattson, J., (2010). Transportation, Distance, and Health Care Utilization for Older Adults in Rural and Small Urban Areas. *Transportation Research Record*, **2265**, pp. 192-199.
- 17. Mashiri, M.A.M, Nkuna, Z., Chakwazira, J., and Maponya, G., (2008). Strengthening informal health care delivery: Gender perspectives, *CSIR Conference: Science real and relevant!* 17-18 November 2008 2008, CSIR.
- 18. Mashiri, M., Maponya, G., Nkuna, Z., Dube, S. and Chakwizira, J. (2007). PG Report: Rural Accessibility & Development. Unpacking the Relationship between Rural Healthcare, Mobility & Access, 31 March 2007, CSIR, Pretoria.
- 19. Meyer, J. P. and Alien, N. J. (1991). A three-component conceptualization of organizational commitment, Human Resource Management Review, 1, 61-89.
- 20. Morales-Gomez, D. and Melesse, M. (1998). Utilising information and communication technologies for development: The social dimensions, Information Technology for Development, 8.
- 21. Ouma, S. and Herselman, M. E. (2008). Digital divide affecting e-health implementations in rural hospitals; Case study of Kenya, 2nd IFIP International Symposium on Wireless Communications and Information Technology in Developing Countries, Pretoria, South Africa, 6-7 October 2008.
- 22. Pade, C. I. (2007). An investigation of ICT project management techniques for sustainable ICT projects in rural development, Rhodes University. Masters.
- 23. Republic of South Africa (2000). Integrated Sustainable Rural Development Strategy (ISRDS), November 2000, Ministry in the Office of the President of General Information, http://www.info.gov.za/otherdocs/2000/isrds.pdf.
- 24. Robinson, J. A. and Torvik, R. (2005). White elephants. Journal of Public Economics, 89, 197-210.
- 25. Steinmueller, W. (2001). Possibilities of leapfrogging to higher value-added production for developing countries as a result of new information and communication technologies. International Labor Review 140(2): 193-210.
- 26. UNAIDS (2008). Country Situation, South Africa, July 2008, UNAIDS, http://data.unaids.org/pub/FactSheet/2008/sa08\_soa\_en.pdf.
- 27. Van de Kar, E., & Verbraeck, A. (2008). Designing Mobile Service Systems. 2nd Edition.
- 28. Van Zyl, I. (2011). Mutual Isolation and the Fight for Care An Ethnography of South African Home-based Healthcare Contexts. Journal of Health Informatics in Developing Countries, Volume 5, Number 1, pp 15-37
- 29. Weedman, J. (2008). Client as designer in collaborative design science research projects: what does social science design theory tell us? European Journal of Information Systems, Volume 17, Number 5, October 2008, pp. 476-488(13)

- 30. WHO (2006). Country Health Fact Sheet 2006, South Africa, World health Organization, www.who.int/whosis/en/.
- 31. WHO (2008). The World Health Report 2008WHO, (2011). The WHO global policy recommendations on increasing access to health workers in remote and rural areas through improved recruitment and retention: The South African situation. Centre for Rural Health.
- 32. Wouters, B., Barijs, J., Maponya, G., Maritz, J. and Mashiri, M.A.M., (2009). Supporting home based health care in South African rural communities using USSD technology, 15th Americas conference on Information Systems, San Francisco, California, United States of America, 6-9 August, 2009, August 6-9 2009, Association for Information Systems.