

Lessons learnt from the participatory design of a mobile care data application in a resource-restricted context

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ABSTRACT

This case describes the participatory process of developing a mobile solution for care givers in a resource-restricted context. The experiences of the designers and developers during this process are shared. mHealth solutions are not yet widely adopted for care giving services and the lessons learnt could be valuable to others designing similar solutions. The literacy level of the care givers as end-users was an important consideration for selecting the right methods to involve them in the design of the solution. It was a challenge to design the solution for the kind of mobile phones used by the care givers in these poorer communities since these phones have limited functionality. The design of the mobile solution as well as the process to involve the end-users were therefore influenced by the constraints of the context of use.

Author Keywords

Care data, home-based healthcare, mobile health, participatory design, service design methods

ACM Classification Keywords

H5.2. User Interfaces.

INTRODUCTION

Home-based healthcare is an essential service to the many communities where patients cannot be accommodated by the overburdened public health facilities that are also often far from the persons in need of care. Care givers provide this very important service and they are mostly from the communities where they live. They currently record data from the patients on paper forms and submit paper reports with the hand calculations to the facility responsible for the care service provision.

A mobile solution seemed to be a possibility to facilitate the capturing, processing, exchanging and reporting of care data. There seemed to be no working electronic systems that were already in use for these purposes in similar contexts.

The novelty of the selected solution is that there is limited information available on similar mobile solutions and there were not really any mature mHealth solutions. A further novelty was that the end-users could not afford any new solutions since the care service provision is

mostly funded from donations and much effort is required to raise the necessary funding for the essential services. No funding is available to develop new electronic systems. Designing a solution for end-users who do not really know what the solution could do for them or how they could use it was a challenge. A further novelty was that the solution was designed by a group of students working as interns for a university. The team included an anthropologist with a masters degree, an industrial designer on masters level and information technology developers with final year up to masters level students. They have never worked in a real-world work situation and also never worked with each other before. There was no training provided to teach them about the participatory process, each others' disciplines or how to engage with communities where the end-users had limited exposure to technology, training or information.

The participatory process evolved and the methods and tools used as well as what the final solution should do and their roles had to be determined on a needs basis. The interns represented not only different disciplines but also different cultures and they were from different countries. This resulted in the participation of people with very diverse views resulting in a "richer" solution. Researching the context; participatory process; design artifacts; and the solution allowed for a better understanding of the different elements and the ability to reflect resulted in identifying the lessons learnt as well as the appropriateness of the solution and process.

The design and development phases are separated and mentioned specifically since different persons were involved with each phase being trained as designers or software developers respectively. This case therefore not only considers the participation of designers and end-users but also considers the interaction between designers, developers and end-users with different combinations of participation.

BACKGROUND TO THE CASE

Home-Based Healthcare (HBHC) is the provision of basic nursing care needs by trained or informal semi-trained caregivers to people in their own homes. This service is available to people who have mental, physical, emotional and social needs. People recovering from strokes, those living with HIV/AIDS, physically or mentally challenged, geriatric care, or those who are terminally ill. The care given is often palliative, meant to restore and maintain the individual's quality of life including comfort level, health and wellness, as well as care towards a dignified death. HBHC is particularly relevant to Third World countries

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whose public health systems and facilities cannot keep up with the growing needs of the population.

The need for HBHC in South Africa is enormously high due to: High incidence of HIV/Aids, TB, cancer and other chronic illnesses; TB is the highest cause of death countrywide; home-based healthcare provides an alternative service to deal with the large amount of population living in rural areas cut off from services and infrastructure.

In South Africa these services are provided by local non-profit, non-governmental organisations (NGOs). A decentralised health service is offered at local clinic level can improve the delivery of services; it would reduce transport costs and significantly improve service access and utilization.

Currently the entire data recording, processing and reporting is done by paper forms. Aggregated data is entered into spreadsheets that are then submitted to the reporting authorities.

OBJECTIVES

The objective of the participatory care data application (CDA) project was to design and develop an innovative mobile solution to facilitate the capturing, processing, reporting, exchange and transmission of care data in a specific context with the active participation of the end-users.

PARTICIPATORY PROCESS

A community was identified to represent the kind of users that are typical of this kind of context. The community was approached and the process started with them agreeing to become co-designers of their solutions, i.e., the solution will be the result of a participatory process.

A team of interns from the design and IT disciplines was compiled and an anthropologist also became part of the team. An incubation space was provided and they had to figure out how they would work together with little knowledge about each other's discipline. The team members had to find mechanisms to translate their discipline specific methods and terminology in order to participate in a meaningful manner. This is the first identified translation between the team members from the different disciplines to participate in a meaningful way.

About three months was spent to conduct an ethnographic study to obtain a sufficient understanding of the context of the end-user and their needs. Data was collected through open ended interviews, observations and by studying the paper forms currently used for recording and transmitting care data of their patients. Context mapping of the home-based healthcare landscape was used to depict the users' conscious and latent needs, experiences, hopes and expectations. At this stage the anthropologist and designer was working together with the community persons and one of the IT developers who could speak the local language also become involved in the participatory process during the needs analysis. This is the second identified translation between the team of designers and developers and the end users.

Different service design methods such as unstructured interviews; assumptions; observations; conversation cards; touch points; context mapping;

journey mapping; and stakeholder map were used during the ethnographic study and experience targeting; personas; scenarios; co-workshop; word of mouth; concept sketching; and prototyping were used during the design of the solution. Presentation charts; storyboards; filmmaking; journals; blogs and an online space were used for communication between the participants. In all cases the end-users were active participants to co-design the mobile solution. At this stage the IT developers were also involved in the participatory process and learnt how to use these methods – they were not familiar with the methods prior to this project. Initially the caregivers were sceptic of the phone capability; navigation and data capturing preferences indicated that they preferred not to enter text but to use drop down lists and selection boxes; lo-fidelity prototypes are easy to understand; the care givers were excited about the digital memory and automatic functional advantages. Findings specific to the methods are: hand drawn materials are friendlier than hard coded technology; hand drawn materials are more susceptible to change than hard coded technology; paper prototyping saves valuable time on programming.

A prototype of the mobile interface was developed and demonstrated to the end-users. Once the prototype was according to the end-users' preferences agile methods were used to develop the Care Data Aid (CDA) mobile applications using open source software. The following software were used: Java; Open source DBMS; JSON to retrieve and send Information to the DB; WAP to send and receive data; LWUIT framework to create the specified look and feel on the mobile phones. The developers were not familiar with mobile development and the software they had to use and there were no working mobile solutions available for them to consider for best practices. It also became clear at this stage that the original design of the database as part of the back-end system based on the participatory design with the end-users did not support the technology requirements of the solution and had to be redesigned based on the identified hardware and software.

The translation of the mobile interface design to code was difficult because the limitations of mobile phones used as well as the level of the users presented serious constraints on what was possible and appropriate; different versions of code is necessary to support the different mobile phones used; network coverage and availability is an important consideration that influences how and when data is transmitted; the translation from the emulators used to develop the mobile application on a personal computer to the actual phone did not always produce the same results on the mobile phone; it was difficult for team members to understand what each other has done and to learn how to use the new development tools; testing was much more difficult than expected where mobile applications introduce more variables to consider during testing. This became the third translation, i.e., the translation of the technology components and code to the specified design.

During the more technical part of the development process the designer and end-users became uninvolved since they did not understand the technical details of the process and could therefore not participate. This stage

lasted a while which resulted in the designer becoming disinterested in the process and the end-users being left in the dark. When the prototype was ready to be demonstrated to the end-users in their context and although the designer and end-users were participating the mobile phones were operated by the software developers with the designer and end-users watching from a distance since they were not involved in most of the technology development.

Testing was difficult – there were too many variables that had to be considered for a functional working prototype of the solution before usability testing could be done. Most of the functional testing has to be done by the developers with the designer and end-users having a very small role. Usability testing on the other hand is again a participatory process where the designer, developers and end-users perform the different tests together.

With reference to the team's performance and especially their participation during the design and development of the mobile solution, the following were found: The inclusion of non-IT persons in IT development adds much value with a better understanding of the problem setting and the persons who will use the solutions resulting in more appropriate and relevant solutions; the diversity of the team resulted in a better understanding of each other's role in the team and exposed them to many alternative views; mentoring of more junior members by the more senior students happened automatically; all the students indicated that their involvement in the project exposing them to the difficulties experienced in communities in stress allowed them to become better people with more appreciation of their role in technology development.

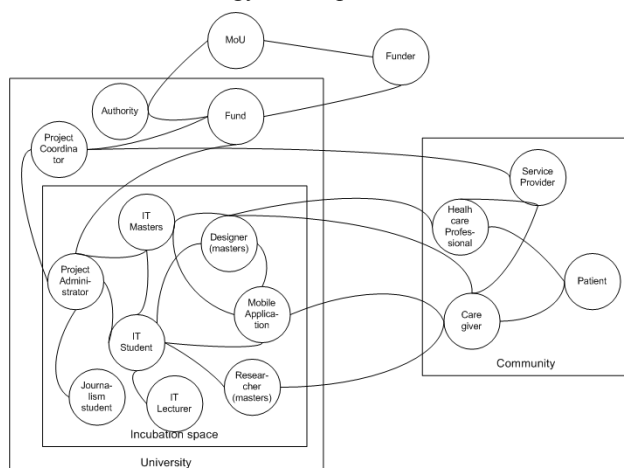


Figure 1. Participants presented as a network of collaboration

In Figure 1 the different participant roles are represented as a network of collaboration. Not everyone will be equally active participating during the process but in the end the involvement of all to co-design, co-develop and co-deploy the solution will determine the usefulness of the solution.

BENEFITS/OPPORTUNITIES

The biggest opportunity was to design a solution that would help the end-user to provide a very important care

service in a resource-restricted community. It was also possible to experiment with mobile solutions where very little good mature mobile solutions were available. Using the different service design methods provided an opportunity to establish which methods work well with this kind of design and development.

CHALLENGES

The biggest challenge was to design a solution that was seriously constrained by the context, e.g., for a mobile phone from the bottom end of feature mobile phones, end-users are semi-literate or illiterate and the language of the interface was in English that was the second third language of the end-users. Another constraint was the lack of experience to design and develop mobile solutions using participatory methods. It was also difficult to determine the needs of the users because they were not used to technology solutions.

OUTCOMES

The specific outcomes of this participatory project co-designed with the end-users were:

- A model of organizing and managing an innovative incubation space for participatory mobile development for specific contexts
- A model for collaborative multi-disciplinary development of mobile solutions with the active participation of end-users
- An ethnographic study of home-based healthcare in a specific context and the context mapping of the care givers of that community
- Examples of how the service design methods were used to co-design the mobile care data solution
- A working prototype of the CDA co-designed with the end-users and developed by IT interns
- Interface designs co-designed with the end-users and database designs designed by the IT interns
- Documentation of the design and development processes, concepts, source code
- Research papers, studies and cases

CONCRETE LESSONS LEARNT

The following concrete lessons were learnt from this experience:

- **Context:** Enough time must be spent on understanding the context of the end users and it is important that a qualified person does the ethnographic study. A strong recommendation would be to involve an anthropologist at this stage
- **Relationship:** It is essential to build and maintain the relationship between the design and development team and the community representative(s). It is important to not create unrealistic expectations of what the proposed solution could do but to make sure that the end-users through their continuous involvement also become aware of the problems experienced during the design and development process

- **Space:** A suitable space for collaborative design is essential since only a supportive environment will stimulate the development of creative ideas for innovation. It must be suitably furnished and have the right equipment to support active participation
- **Team:** It is important to compile the team with persons from different disciplines and if cultural diversity is important for the context of the solution then the team should include persons from that culture to assist with “translation” problems. Translation is not only from one language to another but also from one perception of anticipated use to a common understanding of the perceived anticipated use in practice
- **Project:** It is essential to appoint an experienced project manager and/or project administrator who can manage the process, deliverables, documentation and human aspects (conflict, time, commitment, etc.)
- **Buy-in:** It is essential to get the buy-in and commitment of (university) management as well as the community representative(s) and manager(s) at the beginning of the process to avoid bureaucratic stumbling blocks
- **Methods:** It is important to use a variety of design methods to stimulate active participation of the design and development team and the end-users. Service design methods are suitable for collaborative design and to facilitate the process to sufficiently interpret the users’ understanding of their needs and the proposed solution
- **Participation:** It is advisable to involve designers and developers during the entire design and development process with the end-users and although the designer will facilitate the process to establish the end-users needs, it is important for the developers to also actively participate. It is also important for designers to be part of the development process to understand the challenges experienced with developing technology solutions
- **Progress:** It is crucial to make the progress of the technology solution visible especially to the end users and even if there are no new deliverables to demonstrate, it is still important to involve the end-users during the process
- **Design vs. development:** It is important to manage the participation between the designers and developers to make sure that the one group is not excluding the other group at the different stages of the process, e.g. when the designer(s) does not understand the technicalities of the backend design
- **Technology:** It is important to conduct a study on the kind of mobile phones used by the end-users and to consider the connectivity, power limitations and suitable software when deciding how to develop the technology solution. Different types of handsets, e.g. Nokia and Samsung and then different models for a mobile provider; different mobile service providers that could result in different connectivity availabilities; battery power considering how often to recharge and what to do in the case of power outages
- **Social:** It is important to consider how the social factors of the context will influence the type of solution, its deployment and how the end-users should become involved in the participatory process. Factors that should be considered are: theft of the mobile phone; weather that will influence how the solution is used in practice; safety of care giver carrying a perceived valuable item, etc.
- **Testing:** It is important to spend enough time on testing. In addition to functional testing usability testing is crucial and should actively involve designers, developers and end-users. It is important to avoid “technocratic” testing where developers try to convince end-users that “it works, only press this and then that....” or “the other version works...”
- **Deployment:** It is important to develop a suitable deployment strategy with special consideration of Intellectual Property (IP) and ownership. It may be necessary to involve technology transfer specialists
- **Legality:** It is advisable to consider the legal aspects of the proposed solution (IP), ownership, privacy, etc. from the onset of the process

RECOMMENDATIONS

A participatory design approach is recommended for solutions where the end-users determine the usefulness of the solution. It is essential that the anticipated use of the solution based on the understanding of the designers and developers is established with the active participation of the end-users. This will ensure that the anticipated use of the design is close to the actual use in practice of the solution. It is essential to have a supportive environment that will encourage active participation. It is important to use many suitable methods to help with the participatory process and to encourage active participation. It is absolutely essential to understand the context of where the solution will be used and in which the end-users operate when general purpose solutions are not appropriate – it is not advisable to transfer one solution from one context to another assuming that it will work in the same way without determining this first.