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Using Participatory Design Technique in the Design of the Mobile Phone-Based Health Application for Patients. A Case from Uganda

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Abstract - Mobile health represents a relatively new trend in the field of health and involves the use of mobile devices to support healthcare. Despite this, there are still open challenges with respect to design, functionality and implementation aspects. The aim of this paper is to illustrate how to involve patients in the design and testing of the mobile phone-based Personal Health Record (PHR) system called M-Health App, and report our two-hour participatory design sessions with patients at Allan Galpin Health Centre - Uganda. The paper further presents insightful results from our formative evaluations, which will be used in the further implementation of M-Health App.

Keywords: – Personal Health Record, Mobile Health, Participatory Design, Paper Prototyping.

I. INTRODUCTION

Personal electronic health records (EHRs) have received considerable attention as a tool where patients can access, use and share their personal health information thus improving the quality of healthcare. Although there is no generally agreed definition of personal health records (PHRs) [12], it has been described as "an electronic application through which individuals can access, manage and share their health information in a secure and confidential environment" [4]. Over time, researchers have made significant effort to design and implement PHRs of which some are employer sponsored (Dossia, sponsored by Wal-Mart, BP and AT & A), provider sponsored (My-HealthVet, sponsored by the United States Department of Veterans Affairs), and others are independent products e.g. Microsoft HealthVault. However, the development of appropriate and scalable personal health systems in developing countries has been difficult to achieve [14, 18, 9]. Some have completely failed e.g. MEDCAB [10] and FUCHIA [8] and researchers urge that the disappointments are due to failure to address user's real needs. Similarly, despite recommendations from organisations such as IOM [7] that patients be involved in the design and testing of health technologies, very few implementation reports describes how to involve patients in a meaningful way throughout the development process. Therefore, as researchers in ICT4D and HCI4D, we propose that by involving patients in the design, we can get deeper knowledge of their needs, identify specific requirements, and ensure that they accept and use the technology developed [2]. The purpose of this paper therefore is to illustrate how to involve patients in a low-fidelity paper prototyping design and testing and report our two-hour participatory design sessions with patients at Allan Galpin Health Clinic – A Uganda Christian University Medical Centre. The research further presents insightful results from our formative evaluations, which will be used in the further implementation of our mobile health application.

The rest of this paper is organised as follows; section 2 gives a brief overview of participatory designs, followed by M-health application design and evaluation. Section 3 details lessons learnt with patients and finally, conclusion and future work comes in section 4.

II PARTICIPATORY DESIGN

Participatory design (PD) is an approach that was adopted from the Scandinavian approach of workplace in decision making. In PD, the end-users that are intended to benefit from the system play a critical role in designing the system. Participatory approach to design forms part of Patient-Centred Design (PCD) [19]. It departs from the idea of top-bottom approach that advocates for greater use of theoretical perspectives that are not founded on a rational and mechanistic view of the end-users. PD views the design process within the context of the user's environment, and considers the attitude and perceptions of the end-users towards the technology, and their interaction with each other in the design process [6]. Therefore, PD makes end-users equally accountable for the design decisions made about the system.

However, critics of the participatory design method have questioned the merits of treating end-users as equal partners in the design process. For example, Scaife and Rogers [16] argued that end-users do not know enough to be equal partners, and they can only be informants in the design

process. Similarly, Young and Chang [20] described that asking end-users what information they would like to receive is not efficacious due to the fact that users are normally not well versed in "system operations"; what end-users are very good at is identifying the functionalities they would like to have at the moment they are experiencing system.

To bridge this gap, Marsden, Maunder, and Parker [11] proposed a technique that makes use of Human Access Points (HAP). The technique allows a person in the community who is more knowledgeable about the potential of the technology to act as a proxy for the community in the design process. It relies on the assumption that the HAP is actually interested in the design process, has the ability to participate, has knowledge of the envisioned technology, and is actually available to participate. Additionally, HAP technique also assumed that the HAP can articulate the needs such that the system being built will address those needs [6].

In the context of this study, the Human Access Points (HAP) was chosen for the following reasons: the key characteristics of the majority of patients in developing countries such as Uganda are digital illiteracy, have insufficient education and even lack access to electronic PHRs. As a result, we needed to use Human Access Points in the design of M-Health App system.

The M-Health App Tool Design

In our previous works, we conducted a conceptual inquiry study with the patients and healthcare givers at Allan Galpin Health Centre (AGHC) in order to understand how the current healthcare system works, and assess the end-user needs. We observed two common and persistent challenges that hinder AGHC to attain its goals: 1) fragmented paper-based patients' information and 2) unprotected patients' records. These issues were common in all departments that we visited regardless of the size. Additionally, the survey demonstrated a desire for patients to have access to electronic personal health information.

In order to assist in automating patient's personal health information, we organized three participatory design workshops with the patients from AGHC, in which the researcher was the designer and facilitator. In particular, we used the work of [17] to develop low –to –high fidelity prototypes during the participatory design sessions.

Methodology

The research approach employed in this study was deeply influenced by the participatory design approach. The choice of the research approach is also in agreement with healthcare organisations such as the Institute of Medicine that advocates for patient-centric approach when developing healthcare technologies for patients.

Participatory Design (PD) enables end users to become part of a design team as well as test the usability of the new technology. Therefore, involving users in design facilitates the elicitation of requirements and early refinements. In this study, we used patients from AGHC. Typically, industrial environments use from seven participants and more during PD sessions [3]. Therefore, we feel that the twelve participants used in this study are sufficient. The patients were told that they were users of the proposed technology, and that they were going to be involved in designing the M-Health App tool. Thus as users, they know their specific needs and their involvement in the design would ensure use of the system.

Procedure

After three months of being at Allan Galpin Health Centre (AGHC), and analysing the data collected, we noted three themes that could inform the design of a possible interactive PHR system. The three themes were: design for handset users; design for offline access of PHRs; and design for low literacy users. These themes informed the structure, flow and interactiveness of M-Health App system.

Recruiting Representative Human Access Points (HAP) for M-Health App Designs

Recruiting representative patients was one of the challenges we faced during this phase of development. Patients at Allan Galpin Health Centre (AGHC) come to the facility, get treatment and leave. Tracing these patients at their home and/or place of work was very difficult, since majority of the population move by necessity rather than choice, with no orderly and lawful migratory channels available. A total of 12 patients who get healthcare services at AGHC were recruited to participate in the design process. This number was considered ideal because industrial environments normally use seven participants and more during participatory design sessions [3]. The participants were randomly but purposely recruited to take part in the design process. They were mainly students who were earlier participated in the design of the Clinic information system, and thus familiar with the digital technology. Therefore, they were used for design ideas and initial testing of the prototypes. Three of the subjects had participated in our earlier formal interviews.

Participatory Design

Two participatory design sessions were conducted at the meeting room, faculty of science and technology, Uganda Christian University. Eight participants were divided into two groups, each with four participants in which the researcher acted as the facilitator for each group. Figure 1 below shows an example from our PD sessions. Participants were reminded that they were the users of the mobile application and that is why they were developing the application. They were also asked to think about the things that they do frequently during

and after visiting the doctor or any healthcare professional. Participants were also asked to prioritize this information/activities although the clinical officer highlighted that all the information requested from patients are of equal importance.

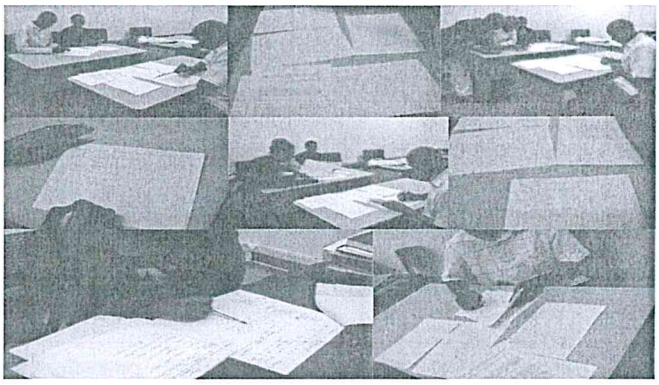

Fig. 1. Few Examples from our PD sessions

An introduction to paper prototyping technique was given and the following aspects were explained to the participants as proposed by Snyder [17];

1. Introduction of paper prototyping, its history, relevancy and how it relates to participatory design
2. Participants were also informed that there is no right or wrong answer during paper prototyping and they are free to show their creative side
3. Participants were briefed and provided stationery and materials used to develop paper prototypes. Samples of paper prototypes were shown to them in order to stimulate their designs
4. The benefits of paper prototyping were highlighted throughout the session in order to encourage participants give full commitments.

The two groups worked separately in the development of the prototypes. At the end of the sessions, a number of requirements were produced. All members in each group developed the prototypes collaboratively.

Participant were then presented to the storyboards showing activities that stimulated the production of the paper-based M-health Application design. They were requested to re-arrange them starting with what they would want to see first. After each session, a walk through was done in order to identify any issues and for participants to justify their choices. Each group then started developing the prototypes with the researcher as the facilitator.

Evaluation – The Paper Prototypes

At this stage, our goal was not to come up with a complete design but to gather more requirements through paper prototyping. Each participant provided one to two incomplete screens and several issues were identified by the facilitator with the prototypes; incomplete interfaces and reluctance from two of the participants to sketch the interfaces. Simplicity towards the interface/screen designs was the first observation noted by the facilitator. In order to harmonise all the functionalities that appeared on the screens, there was a need to strike a balance between these functionalities and the number of steps needed to accomplish the needed task. Participants agreed about what the patients need in order to view and share their records;

1. Locate the application from the website and then download it to the mobile phone
2. Install the application to the mobile phone
3. Download the records using your PIN
4. View and share the records with the healthcare professional.

Figures 2 (a) and Figure 2 (b) below illustrates two samples of paper prototypes that were created by the participants. Through 5 (five) iterations, and consultation with AGHC clinical officer, we came up with a set of two paper screen elements. We then transformed these screen elements into the digital screen captures, using Java. Figures 3 and 4 shows the screen elements of the M-Health App, and the system architecture

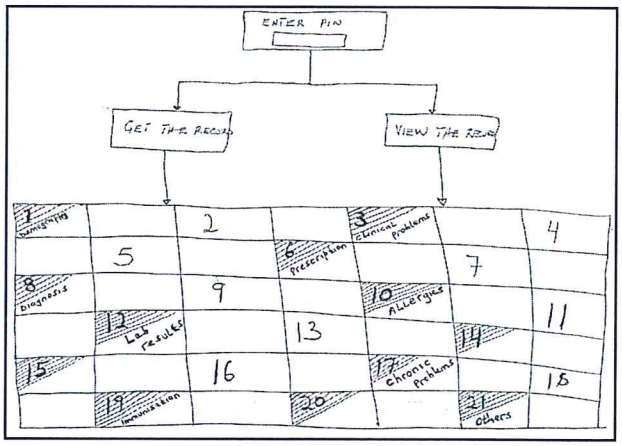

Fig. 2 (a). Sample paper prototype 1

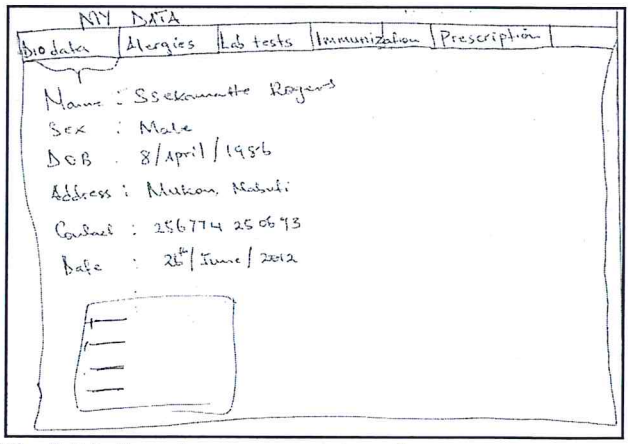

Fig. 2 (b). Sample paper prototype 2

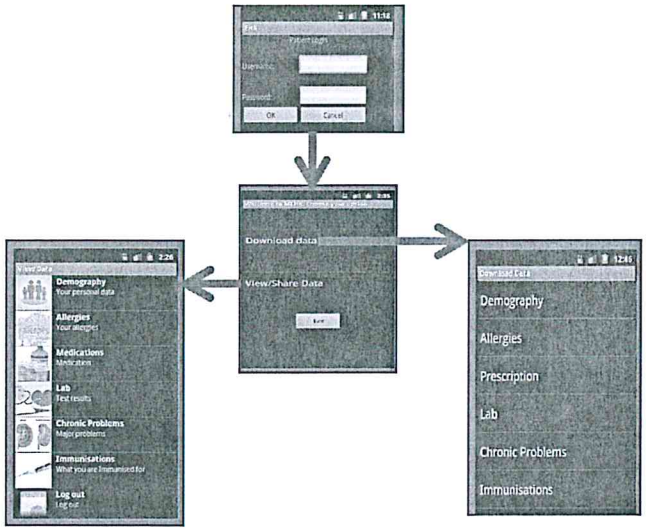

Fig. 3. Screen elements of the M-Health App

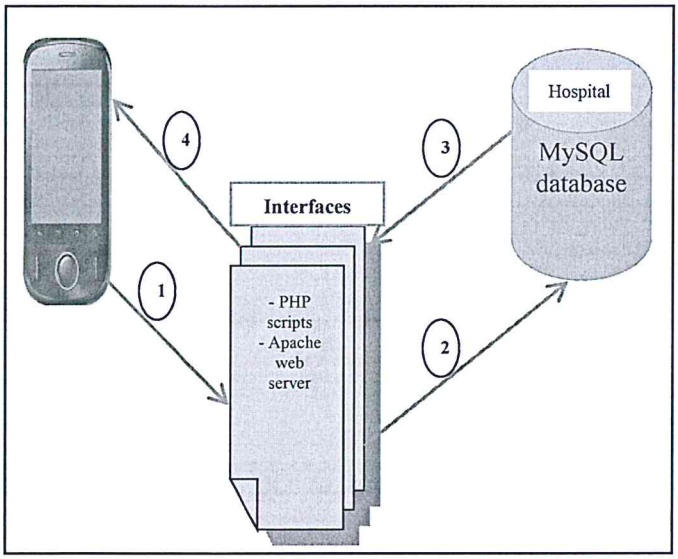

Fig. 4 System overview of M-Health App architecture

The architecture comprises a mobile application interface to the server, running an apache web server and storing health records on MySQL database. Furthermore, it also interacts with a web server that is maintained by the hospital. The web server supports read access to a patient's health records. Patients are authenticated via Personal Identification Number (PIN) to the web service to retrieve their health records. Once the records are downloaded to the mobile phone, the M-Health App system breaks down the records into an XML structure such that records are viewed selectively. Contrary to the previous approaches, our architecture enables patients to download and update their PHRs onto the mobile phone, and share their records with healthcare providers in an offline mode i.e. when hospital servers are offline due to unstable main electricity and/or unreliable Internet connection.

Formative Evaluation

According to Rogers, Sharp and Preece [15], formative evaluations are done during the design process to check that the system continues to meet user's needs. It covers a broad range of design process, right from the development of the early sketches and prototypes through to perfecting an almost finished system.

To ensure that M-Health App system indeed fulfils its purpose, we needed to test its functionality and features with a wider range of users with different characteristics. Up to this point, following the path of Human Access Points approach [11], we had been interacting with students (those that had visited AGHC for treatment) and relying on their expertise. Therefore, it is imperative to allow the system to be evaluated through engagement with other users/beneficiaries.

We started by recruiting seven patients, five male and two female from the Allan Galpin Health Centre who individually acted as end-users. The reason for individual sessions is attributed to the fact that patients visit the clinic at different times. Our sample size was based on the previous study conducted by Dabbs et al. [5]. The participants were then given an introductory briefing about the high-fidelity prototype, user goals and the requirements derived from our PD sessions. We tested the prototype on Huawei *IDEOS* phones, running Android OS, with 256MB of RAM. The IDEOS phones in particular were chosen as they were designed specifically for developing countries. The evaluation was driven by the following scenario: *Assume you are Cliff - a patient at Allan Galpin Health Centre. Cliff's electronic medical records are stored on the clinic's database server. Cliff is now required to get a copy of his records from the hospital server to his mobile phone and then selectively share them with the healthcare professional using his pin as ucu242. Please spend the next few minutes using the M-Health App system.*

The participants were also given a debriefing questionnaire in order to capture their experiences with the interface. We also used an audio recorder to capture the think-loud interaction and interface usage [13, 1]. The analysis of the data was divided into Likert-type responses and the narrative.

Patient's Satisfaction

Table 1 describes patients' perceptions on ease of use of the M-Health App system. The table demonstrates that 71.4% (5) of our respondents thought that the interfaces can be used without thinking; i.e. it is intuitive, and 28.6% (2) indicated that the application is confusing due to the fact that some icons do not relate the functions. We further explored other opportunities for icons that can represent the M-health functions and patients suggested a number of icons.

Of the six subjects that participated in the study, 80% (4) noted that the prototype features can be explored using trial and error, and also that performing tasks are straight forward,

and only one subject did not understand what "download" meant. As such, she needed some clarification. Overall, all the participants agreed that the sequence of screens is not confusing. This, therefore, confirms that the majority of participants found the prototype easy to navigate, enjoyable and easy to use.

SD – **Strongly Disagree**, D – **Disagree**, A – **Agree** and SA – **Strongly Agree**

TABLE 1. PATIENT'S SATISFACTION

Patient's Satisfaction	**SA**	**A**	**D**	**SD**
M-Health App can be used without thinking		71.4%	28.6%	
Terminologies related to the task is not understandable		14.3%	85.7%	
The sequence of screens are confusing			100%	
Performing tasks are not straight forward		14.3%	85.7%	
M-Health App Icons does not relate to the functions		14.3%	71.4%	14.3%
You can explore M-Health App features using Trial and Error		71.4%	28.6%	

Learning Effectiveness

The evaluation of perceived learning effectiveness of the M-Health App gives satisfactory results. Table 2 describes the results. The results confirm that users found the high-fidelity prototype easy to learn, navigable, enjoyable and easy to learn after training. However, two respondents indicated that: "…. navigating the application need to be improved such that the tool provides meaningful alerts…." For example, when downloading the records, the application should tell the user that it is downloading.

TABLE 2. LEARNING EFFECTIVENESS

Learning Effectiveness	**SA**	**A**	**D**	**SD**
M-Health App is easy to use	14.3%	57.1%	28.6%	
It is not easy to navigate M-Health App		14.3%	57.1%	28.6%
M-Health App is enjoyable to use		71.4%	28.6%	
M-Health App is easy to learn after training	42.9%	57.1%		

Perceived Benefits

Table 3 describes patients' perceptions on the benefits and ease of use of M-Health App system. The table reveals that majority of respondents (85.7%) gave positive results about our high-fidelity prototype.

TABLE 3. PERCEIVED BENEFITS

Perceived Benefits	**SA**	**A**	**D**	**SD**
M-Health App may make sharing my medical records easier	14.3%	85.7%		
M-Health App functions facilitates the easy with which my records can be shared		100%		
It is easy to understand the features provided by M-Health App		85.7%	14.3%	

III LESSONS LEARNT

Several participants' suggestions for improving the application and introducing new services have been collected. A compilation of these suggestions follows and will certainly be taken into account in our future work.

Feedback

- Three of the users suggested that the navigation needed to be improved such that the tool provides meaningful alerts. For example, when downloading the records, the application should tell the user that it is downloading.

Terminology

- One respondent did not understand what "download" meant. She needed clarification on some of the terms. She preferred GET RECORDS instead of download. She also suggested that the tool would be user-friendly if it is translated into local language

Functionality

- A need to know when records were last downloaded was also highlighted by 2 respondents.

The tool was also given to the clinical officer for evaluation and various comments were recorded;

- The clinical officer suggested to add emergency function to include patient's emergency information that may be important during emergency situations.
- The clinical officer further recommended that information on previous medication should include dates, indicating when such medications were taken.

IV CONCLUSION AND FUTURE WORK

In this study, we have presented some of our initial experiences in designing mobile phone-based PHR system for patients in Uganda. Based on ideas presented by the Human Access Points (HAP) during the co-design sessions, paper prototypes of M-Health App system were generated and validated to produce a final low-fidelity prototype. The low-fidelity paper prototype was then transformed into a functional prototype that was evaluated by the final beneficiaries. The results of the evaluation re-affirm that HAP can bridge the illiterate gap in the design process by using a third party from the community who understands the potential benefits of the technology to articulate end-user needs and requirements on behalf of the final beneficiaries.

Future work will involve implementing full features and functionalities of the M-Health App in order to allow patients access the encrypted records on their mobile phones and selectively shares them with the healthcare provider.

Acknowledgments

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REFERENCES

1. Als, B.,S., Janne J., J., Mikael B., S. Comparison of think-aloud and constructive interaction in usability testing with children. In Proceedings of the 2005 conference on Interaction design and children, pp. 9-16. ACM, 2005.
2. Boehner, K., Janet, V., Phoebe, S., Paul, D. How HCI interprets the probes. In Proceedings of the SIGCHI conference on Human factors in computing systems, pp. 1077-1086. ACM, 2007.
3. Boy, G., A. The group elicitation method for participatory design and usability testing. interactions 4, no. 2 (1997): 27-33.
4. Connecting for Health. Connecting Americans to their healthcare. Final report of the working group on policies for electronic information sharing between doctors and patients New York: Markle Foundation, 2004. www.connectingforhealth.org/resources/final_phwg_report1.pdf.
5. Dabbs, A.,V., Brad A., M., Kenneth, R. M.C., Jacqueline, D., Robert, P. H., Alex Begey, Amanda, D. User-centered design and interactive health technologies for patients. Computers, informatics, nursing: CIN 27, no. 3 (2009): 175.
6. Gitau, S. DESIGNING UMMELI. A case for Mediated Design, a participatory approach to designing interactive systems for semi-literate users. PhD thsis, University of Cape Town, South Africa, December 2012.
7. Institute of Medicine. Crossing the quality Chasm. The IOM health care quality initiatives report 2001. Accessed on the 19th July 2012, from http://iom.edu/~/media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf.
8. Tassie, JM., Balandine, S., Szumilin, E., Andrieux-Meyer, I., Biot, M., Cavailler, P., Belanger, F., Legros, D. Fuchia: a free computer program for the monitoring of HIV/AIDS medical care at the population level. Int. Conf. AIDS, (14:C11029), 2002.
9. Kalogriopoulos, N., A., Jonathan, B., Amit, J. N.,John G. Webster. Electronic medical record systems for developing countries: review. In Engineering in Medicine and Biology Society, 2009. EMBC 2009. Annual International Conference of the IEEE, pp. 1730-1733. IEEE, 2009.
10. Kamadjeu, R., M., Euloge, M., Tapang, Roland, N., Moluh. Designing and implementing an electronic health record system in primary care practice in sub-Saharan Africa: a case study from Cameroon. Informatics in primary care 13, no. 3 (2005): 179-186.
11. Marsden, G., Maunder, A., Parker, M. People are people, but technology is not technology. Philosophical Transactions of the Royal Society A: Mathematical, Physical and Engineering Sciences, 366(1881), 3795-3804, 2008.
12. National Committee on Vital and Health Statistics: Personal Health Records and Personal Health Record Systems: A Report and Recommendations. Retrieved [12/02/2014], from [http://www.ncvhs.hhs.gov/0602nhiirpt.pdf], U.S. Department of Health and Human Services; 2006.
13. Nielsen, J. Estimating the number of subjects needed for a thinking aloud test. International journal of human-computer studies 41, no. 3 (1994): 385-397.
14. Omary, Z., Dennis, L., Fredrick, M., and Bing, W. Challenges to E-healthcare adoption in developing countries: A case study of Tanzania. In Networked Digital Technologies, 2009. NDT'09. First International Conference on, pp. 201-209. IEEE, 2009.
15. Rogers, Y., Sharp, H. Preece, J. Interaction Design: Beyond Human-Computer Interaction, 3rd Edition, John Wiley and Sons, Ltd, publication, 2011.
16. Scaife, M., Yvonne, R.,. Kids as informants: Telling us what we didn't know or confirming what we knew already. The design of children's technology (1999): 27-50.
17. Snyder, C.,. Paper prototyping: The fast and easy way to design and refine user interfaces. Newnes, 2003.
18. Tierney, W., M., Marion, A., Elaine, B., April, B., Paul, B., Paul, B., Daniel, K., et al. Experience implementing electronic health records in three East African countries. Stud Health Technol Inform 160, no. Pt 1 (2010): 371-375.
19. Tran, D. T., Zhang, X., Stolyar, A., Lober, W. B. Patient-centred design for a personal health record system. In AMIA Annual Symposium Proceedings. American Medical Informatics Association. (Vol. 2005, p. 1140), 2005.
20. Young, S., Jinn-Shyn, C. "Implementation of a patient-centred and physician-oriented healthcare information system." Informatics for Health and Social Care 22, no. 3 (1997): 207-214.