Patient Involvement in a Software Development Project - Developing an Electronic Diary for Patients Suffering Extreme Obesity

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Abstract and objective

Lifestyle diseases, such as obesity and its coherent complications, are a growing problem in the Western world. The combination of lifestyle related morbidity and an aging population will contribute significantly to widen the gap between healthcare resource availability and needs in most countries. In design – including that of software - user driven or participatory design methods of innovation have been promising when it comes to developing better products. Throughout this project, patients are used as resources in all steps of the interaction process that is involved in developing an electronic diary. The purpose is to investigate whether patients need special treatment during the process.

Keywords:

Telemedicine, Personal health systems, Home care, Participatory design, Chronic disease, Patient centered medicine, Medical informatics, ehealth.

Introduction

By the combination of ICT, patient empowerment- and user-driven-methodologies, there is potential to distribute high quality health care. The current maturation state of Internet based software is named WEB 2.0 or "social computing applications". A WEB 2.0 application enhances its value for the user as the application is used, since it has mechanisms that enhance the personal context.

Methods

As part of the Morbid Obesity Center in Norway's South-Eastern Regional Health Authority program against obesity, our hospital takes care of a group of patients whose treatment consists of exercise and nutritional advice. Patients gave their informed consent before their participation in the project. At all stages of the project, video-observation was employed. Groups of patients participated in 2 focus-group interactions, and opinions were gathered through semi-structured interviews. Following the conceptual process, the videos were transcribed and plotted into MindMaps. Subsequently, Use Case diagrams were made, and paper based prototyping performed with 6 patients and 6 staff. A specification was made from the videos, and used as starting point for the technical development, using Scrum methodology. The prototype was then tested using Camtasia software with a new group of 6 patients and 6 therapists. The application is now undergoing clinical test runs on the internet (10 active users).

Results

Participants in the focus groups of development projects are normally a mix of professionals that share a common language and feel secure in their roles. Patients, on the other hand, reflect the population as a whole and lack the common experience of professionals. To make patients feel comfortable and secure whilst participating in focus groups, special care and attention are therefore required. In the paper based usability testing, however, there was no major difference between patients and staff. There was no recorded time difference in the usability testing of the electronic prototype between patients - who had fewer errors - and therapists. When questioned, the patients all said that participating was a good experience and that the idea of being part of the development felt good.

Discussion

In this project, standard techniques for interaction with users were used, but modified under the influence of 30 years of personal clinical experience. The preliminary results indicate that patients are as quick to assimilate to the electronic diary as therapists. Bringing patients in to the development cycle of health related software enables empowerment and engagement in the treatment, and has the possibility to enhance development of user friendly technology and the delivery of healthcare.

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