

USER INVOLVEMENT IN DESIGNING A WEB-BASED SUPPORT SYSTEM FOR YOUNG CARERS

- inspiring views and systemic barriers

Mikael Elf

Department of Psychology, 2013

Avhandling för filosofie doktorsexamen i psykologi, som med vederbörligt tillstånd av Samhällsvetenskapliga fakulteten vid Göteborgs Universitet kommer att offentligens försvaras fredagen den 24 maj, 2013, kl 9.00, sal F1, Psykologiska institutionen, Haraldsgatan 1, Göteborg.

Fakultetsopponent: Professor Anne Marie Kanstrup, Department of Communication and Psychology, Aalborg University.

The thesis is based on a summary and the following four studies.

- I. Elf, M., Skärsäter, I. & Krevers, B. (2011). "The web is not enough, it's base" – an explorative study of what needs a web-based support system for young carers must meet. *Informatics for Health and Social Care*, 36(4), 206-219.
- II. Elf, M., Rystedt, H., Lundin, J. & Krevers, B. (2012). Young carers as co-designers of a web-based support system - the views of two publics. *Informatics for Health and Social Care*, 37(4), 203–216.
- III. Elf, M., Rystedt, H. & Krevers, B. (20XX). *Handling user influence in participatory design – a grounded theory study of the internal work of a design team*. Manuscript submitted for publication.
- IV. Elf, M., Rystedt, H., Skärsäter, I. & Krevers, B. (20XX). A comparison of intended and real use of a research web health portal and its implementation. Manuscript submitted for publication.



UNIVERSITY OF GOTHENBURG



Abstract

Elf, Mikael. (2012). *User involvement in designing a web-based support system for your carers - inspiring views and systemic barriers*. Department of Psychology, University of Gothenburg, Sweden.

The studies in this dissertation have their origin in the research project PS Young Support. This project aimed to develop and evaluate a web-based support system (WBSS) for young people living close to someone with mental illness. To make this support relevant, and to achieve legitimacy and trustworthiness it was found important to cooperate with prospective users in developing it through a participatory design (PD) process. The dissertation follows two lines of investigation. One of these relates to how PD can inspire new views on design, while the other is about barriers to involvement of users. Specifically, inspiring views aims at how a PD process with prospective users as co-designers has influenced the way we think about WBSSs. Moving on from the common idea of a WBSS as a stand-alone intervention, Studies I and II show that WBSSs can be used as a tool to reach real-life support. Earlier research suggests that online support is rarely the preferred support; the present research show that young carers viewed it as a starting point for reaching real-life contacts and real-life support. Furthermore, young people with poor mental health are more prone to seek support online compared with those with less poor mental health. Hence, a WBSS could serve as a means to capture the former group and offer them online support. At the same time it could serve as a tool for reaching real-life support and external services. In this way the WBSS could offer a help path to individuals in need of support. Study IV investigates meta design, i.e. how users have really used the WBSS and the conditions for redesign. The development WBSS and its implemented version are compared with respect to their intended use (thing design) and how they really were used (use design). The context of use was found to be critical, since data collected in an experimental setting may be misleading and not reflect real use. Consequently, natural settings are recommended for user feedback.

The second line of investigation in this dissertation concerns systemic barriers including barriers to user influence. It is not common in PD to focus on the designers. However, Study II and III reveal two types of barriers, both of which are connected to the designers. They are “systemic” barriers as they are a part of the setting that constitutes design. They cannot really be avoided, just handled. The first barrier has to do with the fact that users and designers do not regularly share the same social conditions, and consequently that they have different assumptions, implying that they may have difficulties to understand each other. Assumptions of shared views and the fact that understanding is a process that takes time may increase the effect of this foundational difference. Study II reports crucial differences in the views of what the WBSS should support. The second barrier concerns the impact of deadlines on designers’ attitudes to users’ contributions. Study III reports that halfway through the design process, designers reorganized their work and put more effort into the act of producing an artefact. Along with this shift, designers’ preferred type of knowledge seemed to change, from knowledge based on user experience to expert knowledge.

Keywords: Design process, meta design, online support, participatory design, public, user involvement, web-based health support, young carers.