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ListeningTime; participatory development of a web-based preparatory communication tool for elderly cancer patients and their healthcare providers

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ABSTRACT

Objective: This paper outlines the participatory development process of a web-based preparatory communication tool for elderly cancer patients and their oncological healthcare providers (HCPs). This tool aims to support them to (better) prepare their encounters. An overarching aim of the project is to develop the tool in a participatory way to increase uptake and use.

Methods: Scrum, a participatory framework originated from software development, was applied to develop the tool. Using constant feedback loops, elderly (former) cancer patients, oncological HCPs and their representatives were, as end-users, involved.

Results: During six 'sprints', the communication tool 'ListeningTime' was developed with input from end-users. The use of scrum in developing an innovative tool was challenging in this context, because of time constraints of seriously-ill patients and busy HCPs and the co-creation involving non-profit scientific researchers and a for-profit development company.

Conclusions: The collaboration with end-users facilitated the development process of ListeningTime. Early involvement of end-users and flexibility in terms of planning and setup appear to be preconditions for creating a bottom-up inspired development procedure. Several challenges emerged from using scrum as participatory framework. Nevertheless, the 'pressure cooking situation', using scrum, resulted in a quick development process and a product ready for implementation.

1. Background

In oncology, both healthcare providers (HCPs) and patients are responsible for achieving effective communication during encounters. HCPs usually control the interaction, while patients are expected to participate actively. This is, however, not always reflected in daily oncology practice, especially in case of older patients. Elderly cancer patients ask fewer questions, find it hard to communicate their informational needs or preferences, and show less active behavior than younger patients (Posma et al., 2009; Jansen et al., 2010; Rademakers, 2014). Recently, 47% of elderly cancer patients (≥ 65 years) have indicated to experience barriers in communicating with their oncological care providers and expressed their need for supportive interventions (Noordman et al., 2017). Frequently reported barriers were: not wanting to be bothersome, remembering topics only afterwards, feeling nervous and having the perception that there is too little time (Noordman et al., 2017). These findings indicate the importance of not only training providers in communication, but also supporting elderly cancer patients. Modelling videos, demonstrating different communication strategies of simulated patient-provider encounters, can serve as a supportive intervention to overcome communication barriers. Modelling has proven to be effective in patient-targeted skill building interventions (Henselmans et al., 2013; Roter et al., 2012; Krouse, 2001). Also, previous studies show that listening back to audio recordings can enhance recall, improve decision making and the communication with family members and reduce anxiety (Watson and McKinstry, 2009; Hack et al., 2013). Combining these strategies can support elderly cancer patients in overcoming their communication barriers. Such supportive interventions can be especially helpful when delivered online, as the content and type of online interventions can be computer tailored to patients' needs and preferences, it is easily accessible, time-efficient and the cost of implementation is minimal once

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developed (Cegale, 2006; Noar et al., 2009). Compared to human-delivered interventions, intervention fidelity can also be more easily maintained in web-based interventions (Noar et al., 2009). However, many eHealth interventions report attrition (like drop-out, non-usage) and adoption problems (i.e. poor uptake after implementation) (van Gemert-Pijnen et al., 2011; Eysenbach, 2005). By actively involving patients and providers in developing a web-based intervention, the use and uptake of the intervention is expected to increase. Actively involving patients with cancer in designing and evaluating a web-based supportive communication tool appears to be feasible and appreciated (van Bruinessen et al., 2014). The process of involving patients and providers in developing a web-based intervention is not often described, yet can be helpful for researchers and developers in achieving the aim of a user-centered tool. For example, Green et al. (2016) showed that applying a participatory framework to involve service users in developing an aid for physical healthcare results in quality improvement. In addition, Winterling et al. (2016) found that the collaboration between researchers and young cancer patients contributed substantially to the development of a self-help web-based intervention. Another study reported that service users and healthcare professionals perceived their involvement as having a positive impact on mental health services (Omeni et al., 2014).

There are several participatory frameworks available to involve end-users in the development of web-based interventions, e.g. intervention mapping, CeHRes framework and 4Pi National Involvement Standards (van Gemert-Pijnen et al., 2011; Green et al., 2016; Bartholomew et al., 1998; de Beurs et al., 2017). For the present project, a 'scrum' framework (Schwaber and Sutherland, 2011) was used to guide the participatory development process. Scrum is an iterative approach that allows input from end-users on meaningful, small steps in the development process of an online intervention. The present paper outlines the participatory development process, by using a scrum framework, of a web-based preparatory communication tool for elderly cancer patients and their oncological healthcare providers.

2. Material and methods

2.1. Aim

The project aspired to develop 'ListeningTime', a web-based preparatory communication tool for elderly cancer patients (≥ 65 years), in order to help them (better) prepare their encounters with oncological HCPs. The tool was also designed to support HCPs in preparing their encounters with elderly patients. An overarching aim of the project was to develop ListeningTime in a participatory way to increase uptake and use. In this paper, we describe this development process; how we applied a participatory framework and the lessons learned during this process.

2.2. Participants and recruitment

Elderly cancer patients (≥ 65 years), their oncological healthcare providers, and representatives of the patient organization NFK (Nederlandse Federatie van Kankerpatiënten organisaties) and the 'Quality institute for oncological and palliative research and practice' were involved in the development of ListeningTime.

(Former) cancer patients (with all types of cancer, ≥ 65 years, and sufficient mastering of the Dutch language) were recruited via the patient organization NFK. Oncological healthcare providers (e.g. oncologists, oncology nurses) were recruited via the NFK, the 'Quality institute for oncological and palliative research and practice' and the network of the authors.

3. Calculation

3.1. Participatory framework: scrum

For the content and technical development of ListeningTime we used a 'scrum' framework. Scrum is defined as "A framework within which people can address complex adaptive problems, while productively and creatively delivering products of the highest possible value" (Schwaber and Sutherland, 2011). Scrum is a popular 'agile working' framework in software development (Fowler and Highsmith, 2001). It is an iterative, dynamic and flexible way of working, guided by input of end-users.

Scrum is characterized by short sprints (1–4 weeks, with regular meetings). Every sprint contains some form of analysis, design, implementation, evaluation and planning for the next steps. This enables the scrum team to deliver a first version of the product in the earliest stage of the development process. Moreover, it creates constant feedback loops involving all end-users; i.e. end-users reflect upon every version of the product.

We applied scrum to the development of ListeningTime in the following way: a sprint was defined as two weeks and six sprints were planned by the software company, in agreement with the researchers. The researchers were the initiators of ListeningTime (the product owners and the development team of the content) and contacted an external software company to develop the technical part of the online intervention (the software development team). The scrum team consisted of two researchers (JN and JD) and three employees of the external software company (scrum master, software engineer and designer).

During the two weeks of a sprint, members of the scrum team worked on the product components within their own expertise. As many as possible end-users were involved during each sprint; i.e. (representatives of) elderly (former) cancer patients and oncological HCPs. At the end of the two weeks, a meeting with the scrum team was planned, to present the product components and to discuss with the team members and the end-users. Next, appointments for the next sprint(s) were made. The aim was to deliver a working web-based preparatory communication tool at the end of the sixth sprint. Moreover, through participatory development we aimed to increase the uptake and use of ListeningTime.

ListeningTime was based on a similar intervention designed for patients with malignant lymphoma (van Bruinessen et al., 2014). The previously developed intervention contained tailored simulated video-fragments of patient-provider encounters, among others. For ListeningTime we also used tailored simulated video fragments of patient-provider encounters, but the content and tailoring of the video fragments was based on subjects indicated as relevant by elderly cancer patients and their HCPs.

No specific aims per sprint were defined beforehand, as the aims supposed to be defined during the process based on the previous sprint outcomes. In the result section a detailed description of every sprint as executed is presented, and how the involvement of end-users influenced the development of the tool.

4. Results

Between September and December 2015, four two-week and two three-week sprints with six meetings of ± 1 h between the scrum team and end-users were executed to develop ListeningTime. In addition, meetings between end-users and researchers took place (see details below). The tool was launched in March 2016. See Box 1 for a short description of the final version of ListeningTime.

4.1. Input for sprints and intervention

Before the first sprint, the authors performed a needs assessment