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Designing electronic tracking and tagging solutions for people with dementia: Experiences from a Public-Private project collaboration

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Abstract: This paper describes a project collaboration between private companies, research institutions and municipalities. The goal of the project was to improve electronic tracking and tagging solutions for people with dementia. The solutions and strategies for implementation and usage were developed and examined in close collaboration with the users through several workshops were people with dementia, relatives, caregivers, and stakeholders got involved. In this paper we give examples of our findings from the workshop related to the design, information sharing, and suggestions for making the solution accessible to the users at an early stage of their illness. Finally, we discuss our experiences and challenges regarding the collaboration.

Introduction

The aging population and the general demographic shift towards an increasing number of senior citizens has led to an increase in the number of age-related health issues in Denmark as well as many other Western countries. One such issue is the increasing number of people with dementia (Videnscenter for Demens, 2014).

A common trait of people living with dementia is the tendency to wander (Klein D., et al., 1999). Caregivers are for that reason required to spend a considerable amount of time and resources on trying to locate missing residents and/or ensuring that they do not leave the nursing homes/care facilities unattended. Wandering behaviour demands an increased workload

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for the caregivers and a concern that the residents will get lost (Miyamoto, Y., et al. 2002). the consequences of getting lost can be dehydration, hypothermia and in the worst-case fatality (Algase, D. L., 1999; Mcshane et al., 1998). There have been examples of people with severe dementia leaving their nursing homes/care facilities, that later has been found dead as they are unable to take care of themselves, particularly in severe winter climates as found in Denmark (Alzheimerforeningen, 2018).

To ensure the safety of people with dementia electronic tracking and tagging solutions have been suggested and implemented. The caregivers typically use the tracking and tagging solutions to preserve the independence of a person with dementia and to provide them with reassurance about the carers wellbeing (Landau, et al., 2009). However, different researchers (White et al., 2010; Robinson et al., 2007; Landau et al., 2009) have identified technical limitations and human error as weaknesses, which may lead the caregivers into a false sense of security.

Besides solving, the technical limitations of the today's electronic tracking solution there are several other factors that you need to consider when developing and designing electronic tracking solutions. The introduction, the usage and the integration of the system are widely dependent on the individual situation, person and place where the solutions are used. Accordingly, the solution requires a high degree of flexibility in terms of the system configuration to incorporate it into the care routines (Wan et. al 2014). To make things worse the legislation in this area is very strict and is often subject to interpretation making it very cumbersome to work with from the designer's perspective. Another challenge that must be overcome is that caregivers are often reluctant to use the services due to a lack of knowledge and because the care recipient (the person with dementia) are reluctant to use the services (Brodaty 2005). Wan et. al (2014) found that there was a need for technical support and reliable information channels accommodated to the users and not only targeting technological specialists.

To comprehend, the user needs and the context of use, including the legislation and ethical considerations associated with electronic tracking and tagging solutions we have initiated a project in close collaboration with the users and stakeholders with the goal of developing better solutions that can ensure the safety of people living with dementia.

In this paper, we give examples of a project collaboration between private and public actors. In close collaboration with the stakeholders, we address both the design of the product and the intended use. This include strategies for information sharing, and suggestions for integrating the solution into the care routines. In the end, we will discuss our challenges with this type of collaboration and come with recommendations based on our experiences.

Organization

In the project, a consortium was established. The consortium consisted of companies, research institutes, interest groups and 6 municipalities all located in the northern region of Denmark. The organization Life Science Innovation (LSI) facilitated and managed the project consortium. LSI is working with joint value-creating innovation within the field of welfare and health in North Jutland (Denmark). The role of LSI is, through cooperation, user involvement and focused efforts, to bring together companies, users, and citizens.

The municipalities govern most nursing homes in Denmark and likewise, the municipalities are governing other elderly care services such as; home nursing, disease prevention and health promotion. The municipalities, therefore, represent the link to potential users and stakeholders.

The companies included the project owners who also owned the business case along with a few subcontractors each responsible for a specific part of the product (hardware, software, physical interface etc.). The purpose of involving the companies directly in the project was to ensure that we could use the knowledge we obtained through the user studies and turn it into of the shelf products.

The research institutes were involved in the project to share and disseminate research-based knowledge. While there were several research institutes involved in the project, we only address the findings related to our work at Aalborg University (AAU) focusing on the user requirements and the context of use.

At the beginning of the project, the project partners established a committee, within the consortium, with representative from each municipality, the project owner and AAU. Each member of the committee had a say in relation to; ensuring that the solution lived up to the user requirements, when to move on to the next phase, changes to the time schedule or changes to the activities.

Project collaboration and methods

The project started with several workshops focusing on eliciting the user requirements and learning about the context of use. The user requirements came from two different user groups: people with dementia who wears the system and the people operating the system such as caregivers, relatives etc. For each workshop, the committee members from the municipalities would recruit and select people within their municipality to participate in the workshops. To facilitate a discussion between all the different, people who are in touch with the electronic tracking and tagging solutions, we tried to mix the workshop groups with people from different positions and different municipalities. This could for example be nursing home leaders, caregivers, and dementia advisors from different municipalities. Different municipalities have different ways of doing things and different experiences with different products and by putting them together, they had the opportunity to present and discuss their different viewpoints.

People with dementia was also involved in the elicitation of user requirements and the design of the system but between the project partners, it was decided to interview people with dementia and their relates, subsequently, in more safe environments such as, dementia cafes where people with dementia and their caregivers come and discuss their dementia diagnosis, get answers from health professionals or simply come to meet people in similar situations to their own.

For each activity, the findings were reported to the committee and the next step was discussed. This way we ensured that the project was on the right track as the committee would constantly validate the findings. At these briefings, things such as strategies or good experiences that you could transfer from one nursing home to others would also be discussed.

Examples of findings

One finding from the workshop was that people with dementia often are reluctant to use the device, as they do not understand what it is, and they do not recognize it as belonging to them. A suggested solution was to introduce the electronic tracking and tagging solutions at an early stage while the people with dementia are still able to understand what it is. As the symptoms would increase, they might still forget why they are wearing it, but they would not feel alienated towards it.

As a solution, we tried to design a system that people with dementia could use from right after they are diagnosed with dementia, and the first symptoms

appear. As the person with dementia' symptoms get more severe functionality could progressively be added as the need for safety increased. With this solution, people with dementia would not have to wear a new solution each time their needs changed and at the same time, the caregivers would not have to learn to operate multiple systems. To support this, it would require the municipality to agree to use the solution at their nursing homes and it would also require that the solutions were introduced to the people with dementia while they are still living at home, as most people experience the first symptoms at this stage.

The first contact the municipality has with the people with dementia after they get diagnosed is through the dementia advisors who come and visit the person with dementia and their relatives in their homes. This would be an ideal point to introduce the solution and for the people with dementia to start wearing the solution and get used to it before the symptoms become too severe for them to recognize the solution.

One suggestion was that future scenarios and interventions were discussed with the people with dementia, at this early stage and written into the advance directive. This way the people with dementia had a chance to influence their future while they were still conscious about their choices. An obstacle to this was that several of the dementia advisors we spoke with mentioned that either there were too few of them in the municipality to cover the task or they were lacking the needed knowledge about the current solutions to advise the people with dementia and their relatives. This issue was broad to the committee's attention and strategies for improving this in the future were discussed.

Challenges and experiences

At the start of the project, the project partners had different expectations to the project that originated from the different backgrounds of the project partners. To accommodate for the differences the partners all agreed on a project description at the start of the project that included a matching of expectations. Among other things, the project description stated that the product development should be based on user centered design. However, as the different partners came from different fields the interpretations of what this entitled were also different. This became evident after the first workshop where some of the partners were ready to start developing the technology after listening to the initial feedback from the workshop. Due to a lack of communication and a misconception of what were supposed to be shared,

they started the development process before the user requirements were fully descripted. Consequently, we had to reconsider and alter several parts of the concept at a later stage. Overall, it seemed like multiple members of the team had trouble understanding the need for user involvement and were reluctant to spend the necessary time on doing it. Although, the developers were involved in the workshops and other activities with the users it was still evident that they were lacking an understanding of the domain and people for whom they were designing a solution for. Even though the municipalities and thereby the stakeholders were an active part of project it still seemed like there was a gap between them and the developers and it was a constant struggle to keep them on track.

Having the municipalities involved in the project was a great asset and made it easy to get in contact with the users when needed. The municipalities would simply recruit the users for the specific workshop or activity when asked. In the beginning, nursing home leaders and people from management positions were a bit overrepresented compared to caregivers and other people who are in direct contact with the people with dementia. However, after mentioning this to the municipalities and as the information about the project spread through their organizations we got in contact with a bigger variety of users.

Besides the obvious benefits of integrating and involving users and stakeholders in the development it also meant the users were familiar with the solution before it even hit the market and thereby improving the business case for the company.

Conclusion

The project collaboration has provided us with a unique opportunity for bringing private and public actors together with the joint goal of increasing the safety for people with dementia by developing solutions in collaboration with the users. While there were a few troubles regarding the collaboration many of the challenges we address in the paper is not unique for this project. In most development projects with user involvement you will, at least to some the extent, meet similar challenges. However, when bringing in people from different companies and different fields it is even more important to ensure that the project partners share the same vision and idea about the product development.

The purpose of this project has been to improve the existing tagging and tracking technology, but the focus has not solemnly been on the technology

alone. Due to the interaction and information sharing between the users and project partners we have been able to work holistically with the problems. As a result, the users have influenced the design of the solutions and how the solution are integrated and used.

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Trine Søby Christensen Holds a Bs. degree in Nursing and a M.Sc. degree in Clinical Science and Technology. Since 2012, she has worked with public-private innovation collaborations within Life Science and has more than 10 years' experience with project management. She has been responsible for evaluation of welfare technologies on both strategic and political levels and she has experience with development of business plans as well as business models.

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