

# Technology-based tailored integrated care services to promote wellbeing of patients living with dementia

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## Abstract:

*The rapid adoption and implementation of intelligent systems in care pathways brings many potential benefits and create new care models. The integrated care service is being under development in TeNDER, HORIZON 2020 project that involves 13 partners from 7 European counties. TeNDER includes several resources for data gathering in order to recognize the affective state of a person and then allowing to process and automate, support, and interconnect the care provision chain. The interventions involve actions related to daily management, communication, and adapting the behavior. We defined the functional specifications of the TeNDER ecosystem and services together with people that will potentially use it. Codesign phase began in the pre-piloting phase and was spanning through 2 phases of large-scale piloting. Sleep tracking and indoor location functionalities are the most accepted in Slovenia. However, there is still a question if technology has a true potential to enable people with dementia to continue living in their own homes and assist in the daily challenges they face. We found that people with dementia sometimes don't recognize themselves as being in need of help/assistance and would also prefer that intrusion is minimal. Nevertheless, one of the side effects of the piloting was also increased digital competencies among involved actors.*

Keywords: Technology, care pathways, sleep quality, competences

## Introduction:

Dementia often is defined as a progressive cognitive disturbance leading to a loss of independent function. The economic costs for persons living with dementia and the value of family care partners' time are high, and may persist into future generations. The majority of people with dementia live at home cared for by family members, and there is a recognized failure to acknowledge the stress carers are facing in order to maintain the wellbeing

of a patient, but also about the relationships between carers and care recipients. To maximise the current and future benefits of technology for dementia we need to rethink what people with dementia and their carers need in order to live with dementia now and in the future. Continuing to view dementia as purely a clinical matter addressed with medication and, to a limited extent direct healthcare, is no longer an option as it fails to address the majority of concerns, needs and wishes of people with dementia (Astell et al. 2019). Participating in activities outside the home remains important for persons with dementia, therefore, the technologies that may support the person with navigation and route-finding are promising. Socialising is another key activity that people want to do that is important for their well-being and maintenance of cognitive function. Therefore, supporting social and leisure activities is one of the areas of technological focus in dementia. Caregiving is another key target of dementia technology. Supporting informal caregiving, and delivering care remotely are major challenges that can be addressed at least in part through dementia technology. Existing technology can collect data, model risk and provide supportive monitoring, and thus has multiple potential applications to dementia from diagnosis and assessment to care delivery and supporting progression or elevate it. Therefore, various types of technology based assistive and wellbeing products are already on the market, but the variety of products can create challenges to be used. Related to this, new care models are emerging according to the rapid adoption and implementation of intelligent systems in care pathways (Bates et al. 2003, Arnold 2021). As the technologies are increasingly vital in present activities in homes and communities, the research on the potentials that technology brings is growing. The importance of patient and public involvement in dementia research has been highlighted at a European level by Alzheimer's Europe as a way in which 'transparency, validity, and legitimacy' of research is enhanced (Gove et al., 2017).

TeNDER (Affective Based Integrated Care for Better Quality of Life, H2020-SC1-DTH-2018-2020/H2020-SC1-DTH-2019) is a multi-sectoral project within which we are using various micro tools and developing an integrated care model to help patients with chronic diseases such as Alzheimer's, Parkinson's, Cardiovascular Diseases, and, where present, comorbidities. The important goal is to improve the quality of life of a patient and those that support him/her. The care service that is being developed includes several resources for data gathering.

In the presented article we focus on the experience and results of the co-design with people with mild dementia, their relatives, and carers, professionals employed in various institutions (health-care, social-care) included in the TeNDER service at Slovenia piloting site. Co-design process is a non-linear process that involves multiple actors and stakeholders. The aim is not only to improve the efficiency and effectiveness, but also to enhance the satisfaction of those who take part in the process. By bringing in multiple perspectives we also encourage divergent thinking within the project group that consists of developers, researchers, managers and others. Partners are coming from user organisations, Small Medium Enterprises (SMEs), academic institutions and policy experts from Spain, Portugal, Italy, Slovenia, Greece, Germany and Belgium, and thus as a consortium reflects how EU-funded research can cut across disciplines, sectors and country borders to benefit societies.

TeNDER combines technologies that are easy to use and well-known to the population, such as smartphones, fitness/health smart-bands, sleep trackers,

domotics and environmental sensors and other similar devices. By facilitating communication between social and health care professionals, and extending the autonomy of patients that can live independently, as well as making TeNDER's model for integrated care fit for widespread implementation, the project results can benefit people beyond project years. However, we can see that people will accept an intelligent system if they trust it, find it useful, and can afford it. As trust involves a very complex cluster of concepts, people need to be confident that the system will do well for them or to them. As there is an absence of evidence about differences in the way different social groups engage with the technologies - for health and other purposes (Honeyman et al. 2020), the inclusion of a diverse group of people to collaborate in system development is a core mission. The most pressing gap for further research is what factors influence people's engagement with digital health technologies, and the differences across groups in these factors (Honeyman et al. 2020; Ibrahim et al. 2021). To successfully engage some of the participants, that haven't yet been exposed to complex "smart" technology-based systems, it is necessary to use a proper dialogue. In a dialogue approach, it is expected that participants change their opinions during the meeting (Elbrase et al. 2011) either because of a new input of other participants either/and reflection on their own perspectives.

## **Methods**

Preliminary research was performed through the descriptive observational study that involved patients with dementia, carers, and professionals from helathcare and social care field. The survey was circulated among users involved in Spominčica-Alzheimer Slovenia activities that were either a person with dementia, his/her family member, other informal carer (neighbour, volunteer...), and people that provide care for paid work (social and health care professionals or other care service delivers). The data collected were: basic demographic data, questions regarding people's need for service, and their views on the applicability of services for dementia in their daily living and for the future. The survey was circulated online and data were collected also with phone interviews. This exploratory phase was used to provide a basic description for the design of the TeNDER services. The subsequent phase of the testing involved large-scale intervention where people with dementia, carers and professionals were thesting the TeNDER with actions related to the daily management, communication and feedback gathering. It was carried out in 3 different waves with the service adaptation in between accordingly to the feedbacks collected. General inclusion criteria for the patients were that he/she had to be at least 60 years or older, should be able to understand the local language, and in case of patient's dependency, he/she had to have a reference person or carer. Carers of the selected person were who were aware of the pesrons's health and social situation and who provide direct care or support for daily activities. In addition, they must have a user level in the use of a smart mobile phone. Carers who did not understand the local language were excluded. Helath, social and other professionals that were working in the field of dementia or in the care institutions were included. Legal and ethical risk management in the TeNDER pilots was developed at the beginning of the project prior to the start of the first wave of pilots. Accoridng to the freely given consent to

be a participant in the study, the participants were offered the functionalities of the service that they pre-selected to test in order to be involved in codesign of the larger service. The functionalities involved in Slovenian pilot site were sleep quality monitoring, position tracking, recommender service and activity tracking. The researchers that were testing the solutions with people were included in additional survey in order to provide feedback about the observations during the real-life testing with people. Accordingly, they were asked to answer the questionnaire about their perception of the protocol, inclusion, ethical challenges, concerns expressed by different participants, feedback about usability, and perception of efficiency and provide comments.

## **Results**

Among persons with dementia, from 20 participants included in the survey (n=20; 14 females, 6 males), most of them (19 of 20) were living in a private house; additionally, 4 were included in an interview (n=4; 2 males, 2 females), 3 of them were living in a private house and 1 in an apartment (2<sup>nd</sup> floor). Among carers, 20 were included in the survey (n=20; 19 female, 1 male) and additionally, 7 carers were included in interviews (n=7; 5 females, 2 males). Among professionals, 10 were included in the survey (n=10; 8 females, 2 males), and additionally, 4 were included in the interviews (n=4; 2 males, 2 females). At the end of the testing phase, 3 researchers (n=3; 2 females, 1 male) were invited to provide feedback with the pre-set questionnaire.

The analysis of the survey and interviews in Slovenia generated several themes (Table 1). Most of the patients reported that they are by now doing fine and don't need anything, but the system presented may be beneficial to other people that have the "addressed problems". Some patients also said that more than technological services they would appreciate to have more human company, as they are often bored and left alone, especially in Covid-19 times. In general, they stated that functionality related to safety at home is not really needed. The main positive comment towards having it was that the added value would be detecting if the doors were locked or unlocked. Further, the functionalities that were related to affective state were not accepted and the location tracking was viewed as useful by 50% of participants and mostly they viewed it useful concerning for helping in case someone needs it (but not themselves - it was viewed as a service that may be beneficial for other people that may have orientation and confusion problems). They were interested in fitness monitoring - heart rate and counting steps. However, they expressed concern in using the smartbracelet, if they would not know how to use it. The sleep tracking was the most accepted functionality in Slovenia.

Moreover, the carers said that the devices and the interfaces shall be simple as mainly they will be responsible to manage them. Some carers also said that person with dementia doesn't want to have new devices in his/her living environment. Carers also pointed out that services should be adaptable to the progression of impairments due to dementia and thus should be able to change according to the respective needs. They also emphasized that for them it is

of great importance that a system/service enables them to have more freedom/time for themselves. They pointed out that they surely don't prefer to be overloaded with notifications and alerts and they expressed the need of an affordable and easily-installed system, especially if it is meant to be used in home environment.

**Table 1: Themes generated through the survey and interviews**

<b>Person with dementia</b>	<b>Carer</b>	<b>Professional</b>
general view	technical affinity	usability of technologies
opinion on different functionalities (sleep quality monitoring, localization monitoring, tracking steps taken per day, monitoring heart rate, affective state monitoring, communication tool etc.)		
preferences		
main concerns	level of required support	main concerns
	suggestions for the system	suggestions for the system

Finally, technologies should be simple to use also according to the professionals' view. They accepted presented functions well and were looking forward to using an integrated service that would connect patients with carers, but also professionals from different field. Some professionals expressed concerns if we expect from the patients to be actively involved in several functionality testing at the same time. Therefore, they reflected that more burden could be on the cares. They also mentioned that being involved in the system could mean extra work as some of the patients could need more interaction to clarify the views of the data and the reports. So, they expect some more visits and calls to check the reports and discuss the findings. Reminders on health habits for good sleep quality, labeled appointments, important dates, medication intake, encouragement to get some fresh air and do more steps per day were recognized to be very useful and facilitate the patient following their healthy daily routine. On the other hand, they mentioned that technological devices on the market are often causing challenges for elderly carers and patients. Professionals recognized the localization functionality as useful, especially for space-time disorientation that may be present with dementia. However, their main

concerns were expressed due to the privacy and possible intentional or unintentional surveillance that arises with the usage of this function. Some of them also pointed out that we shall carefully present and use affective state functionality. However, they recognized an added value for the patients and carers, to look at the reports and have more reliable data and time series when presenting issues during the consultations with the professionals. On the other hand, some of them expressed concerns that this could also have a negative impact if the patient would get upset because of not reaching the goals or having the low score or data would reflect something different than he/she is experiencing. Finally, most of them expressed that they would not prefer to have direct access to the data and reports and would mostly prefer that carers or patients bring them reports or send them in advance directly before the visit.

More than 80 participants were involved in testing and there were some topics raised by the participants before they were included in the research according to the researchers' feedback. The most common topic was privacy: who will have access to the data (not only to the reports, but also to the live data), who will be involved in viewing the results, whether some functionalities may be disabled during the testing, the accessibility of the data, how long would the data be stored and where, and similar. Further, researchers pointed out that participants' self-confidence may be affected when testing as the system was in the development phase and not everything worked as expected all the time. They reported that several persons with dementia didn't perceive their health status to be already appropriate for having assistive technology and perceived themselves as autonomous and capable enough to take care of themselves. The challenge was to explain and motivate the participants to participate. Finally, the challenge how the system would be accepted within the families, if people would accept such a tool and the "dehumanization" of care was expressed.

## **Discussion**

The extent to which technology may be able to support people with dementia and their carers along the care pathway and in different care settings is of interest to policy makers and governments. At the early stages of dementia, technologies such as memory aids target people with dementia to support independent living for as long as possible while ensuring the ability to communicate or to be located in case something goes wrong. Safety remains an important function: considerably more tools than at earlier stages are available in the 'care delivery' area for both people with dementia at this stage and for carers and professionals. Interventions developed for paid carers and other professionals include interactive online games to help the assessment of care recipient's needs or systems enabling professionals from different sectors to exchange information (Lorenz et al., 2017). Moreover, there is the need to identify and map the context of technological provision over time within the changing lives of people with dementia and their carers (Lariviere et al. 2021). In TeNDER pre-piloting phase, all the participants were reflecting on the technology based tools and modular system presented that had the functionalities: sleep quality tracking, activity tracking,

communication module, recommender module. The results show that there was surprisingly little interest by people with dementia in actively using such system. Even there is some evidence, that technology may empower well-being activities, actual devices may have limited functionality and impact, mainly limited to safety and with a group of persons with dementia encounters some difficulties (Lauriks et al. 2007, Teipel et al. 2016). The system may be technically functional, but it seems that still may not work for specific individuals. A person may not respond well to a specific type of technology - system assistance. Moreover, the person with dementia quite sometimes doesn't recognize himself/herself as being in need of help/assistance. What is more, due to the privacy and inner feelings of embarrassment he/she prefers that intrusions to him/her is minimal. When developing tools for people with dementia, social activities are most heavily affected by spatial disorientation, which increases the risk of getting lost and exhibiting wandering behavior, patients may reduce outdoor mobility leading to a more sedentary lifestyle when dementia progresses. Therefore, recognizing challenges on time and supporting and maintaining activities is a major theme for future treatment and prevention of dementia and/or its progression.

Thus, a proper presentation and the dialogue can enhance the trust and help people to lose their fear against the unknown. In TeNDER, the support for autonomous outdoor mobility empowering participation in social events of patients with mild dementia through the TeNDER App reminder was tested. In addition, the carer could encourage the person with dementia to be more active. However, both were not significantly accepted and the most acceptable was the quality of sleep tracking, as it was the less intrusive one and needed the less interaction by people. Based on the sleep quality reports, people could decide to adapt daily management and being more careful (if needed) on the healthy habits in regards to sleep behavior. However, when talking with people involved in testing, the main concern reported was the privacy and data access, but also time the participants had to spend on learning how to use the App and to be involved. Accordingly, there is a common issue on trust concerning the technology and who can access the data, but also people are concerned about the intrusion into their personal life and viewing their life-style as data-generated information. Sometimes the data don't show the same picture as the person perceives. As also, the literature suggests that familiarity with a device/service determines its usability until more advanced stages of dementia (Teipel et al. 2016) it is quite challenging to introduce new Apps/services that are not compatible with the mobile phones that the person is already using or even sometimes if it is compatible, it is a challenge for a person to use it. Therefore, the providers shall take into account that as the devices and Apps are constantly updated, but also new versions and models are coming into the market every few years, this may be a barrier for usability for some people. Technological advances are important, but must be underpinned by industry and service providers following a user-centred approach to design and delivery (Greenhalgh et al. 2015).

As mentioned, the researchers reported that several participants were concerned about the maturity of the system and the amount of time that would need to be spent with the technology and the testing and also about the amount of the feedback (messages, alerts, reports) that would be tested. In the literature on cardiovascular disease management and usage of assistive

tools, it is already reported that there is little known about the optimal dosing, frequency, and content of text messages, the duration of interventions, or the individual and group characteristics that may identify patients most likely to benefit from such tools (Piette et al. 2015). Also, the environmental mediators included workload, task complexity, and time constraint are recognized. Therefore, it is a challenge how much information and feedback to provide to the people through the system. On the other hand, some other researches questioned the tendency to over-rely on the technology-based insights for caring purposes (Goddard et al. 2012). Overall, the relevant knowledge of patients and carers is mainly based on their experience in daily life, but the professionals are already quite used to participating in different tool assessments. The results gathered from interactions with the professionals showed that there is a need for a reliable, error-prone system in order to include mentioned parameters in decision-making in the future and to allow that daily events and data gathered could benefit to personalize the approach to a person in a proper manner. There is an obvious challenge from the professionals' perspective, that they would not prefer to have additional workload with the testing, messaging, etc., and would prefer that the patient and/or carer brings reports or views to them (or send them before the visit), but they would not prefer to have the access to and to be challenged to view the information by themselves continuously. This can also be explained by the timing of the testing phase, as the last two years were colored with the covid-19 epidemic, and professionals were already overloaded with their work.

Among the discussed risks, there is also a social risk for reduced human contact because of the use of the technology based care services and was reported through the social workers' feedback. As mentioned from other researchers, we need to be aware of the tendency to over-rely on the technology-based insights for caring purposes (Goddard et al. 2012). Social engagement may be a protective factor against cognitive decline at older ages (Seeman et al. 2001) and thus this risk needs to be carefully addressed. In addition, thoughts that were expressed mainly by carers, but also by health professionals, social workers, and other professionals, were related to the affordability of such systems and the potential cause of social inequalities. People living in rural areas have less access to, and slower, internet infrastructure, and older people are less likely to own smartphones or connect to the internet (Honeyman et al. 2020), this is at least how we generally view it. But that is also, what TeNDER researchers reported that was raised several times by the participants.

However, one of the side effects of the TeNDER piloting was increased digital competencies among involved carers and some patients as the researchers provided some basic training for the use of the smart devices and apps. We will analyse the impact of TeNDER on the quality of life of people as the findings from studies that have examined the impact of the technology access on outcomes related to the quality of life and well-being in older adult populations are still mixed (Dickinson et al. 2006, Choi et al. 2012, Cotton et al. 2013, Czaja et al. 2018).



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