Responsible Development of Self-learning Assisted Living Technology for Older Adults with Mild Cognitive Impairment or Dementia

Evi Zouganeli[1], Flávia Dias Casagrande[1], Torhild Holthe[2], Anne Lund[2], Liv Halvorsrud[3], Dag Karterud[3], Adele Flakke-Johannessen[4], Hilde Lovett[4], Sindre Kjeang Mørk[5], Jørgen Strøm-Gundersen[5], Erik Thorstensen[6], Reidun Norvoll[6], Ruud ter Meulen[7], Mari-Rose Kennedy[7], Richard J. Owen[8], Miltos Ladikas[9] and Ellen-Marie Forsberg[6]

[1]*Oslo & Akershus University College of Applied Sciences, Dept. Electronics and IT, Pilestredet 35, 0166 Oslo, Norway*
[2]*Oslo & Akershus University College of Applied Sciences, Dept. Occupational Therapy, Pilestredet 48, 0167 Oslo, Norway*
[3]*Oslo & Akershus University College of Applied Sciences, Dept. Nursing, Pilestredet 32, 0166 Oslo, Norway*
[4]*The Norwegian Board of Technology, Kongens gate 14, 0153 Oslo, Norway*
[5]*Sensio AS, Brugata 19, 0186 Oslo, Norway*
[6] *Oslo & Akershus University College of Applied Sciences, Work Research Institute, Stensberggata 25, 0170 Oslo, Norway*
[7]*University of Bristol, Whatley Road 39, Bristol, U.K.*
[8]*Exeter Business School, Rennes Drive, Exeter, U.K.*
[9]*Karlsruhe Institute of Technology, P.O. Box 3640, Karlsruhe, Germany*

Keywords: Self-learning Systems, Assisted Living Technology, Welfare Technology, Smart Home, Older Adults, User Involvement, Independent Living, Responsible Research and Innovation (RRI).

Abstract: In this paper we present work in progress in the Assisted Living Project – responsible innovations for dignified lives at home for people with mild cognitive impairment or dementia. The project has a distinctly interdisciplinary approach and engages experts in nursing and occupational therapy, in ethics and responsible research and innovation, and in technology, in particular automation and machine learning. Our approach is to involve the end-users, their family and their care providers and develop technology responsibly together with them. The technological approach employs self-learning systems to develop solutions that provide individualised support in accordance with the user's values, choices, and preferences. The paper presents our approach, current findings and future plans.

1 INTRODUCTION

We report work in progress from the Assisted Living project, an interdisciplinary project that aims to develop technological solutions to support older adults with mild cognitive impairment or dementia (MCI/D) live a safe and fulfilling life at home, with dignity and independence. The project engages experts in nursing and occupational therapy, in ethics and responsible research and innovation (RRI), and in technology, in particular automation and machine learning (ML). Solutions will be developed together with the users and tried out in field trials with around 10-15 end-users.

The main incentive for assistive living technology (ALT) solutions was originally to enable those in need of medical care remain at home and hence reduce costly stays in staffed care units. This can be the case for both outpatients recuperating after for example an operation or an accident, people with chronical diseases, as well as the elderly and people with special needs (Aspnes et al., 2012). Today there is a plethora of home automation and wearable technology to support everyday activity needs related to security, safety, communication, work, social contact, exercising, entertainment, and other. The strong synergies between the care-related and the mainstream home and lifestyle automation, with an enormous growth potential, have led to a

Zouganeli, E., Casagrande, F., Holthe, T., Lund, A., Halvorsrud, L., Karterud, D., Flakke-Johannessen, A., Lovett, H., Mørk, S., Strøm-Gundersen, J., Thorstensen, E., Norvoll, R., Meulen, R., Kennedy, M-R., Owen, R., Ladikas, M. and Forsberg, E-M.
Responsible Development of Self-learning Assisted Living Technology for Older Adults with Mild Cognitive Impairment or Dementia.
DOI: 10.5220/0006367702040209
In *Proceedings of the 3rd International Conference on Information and Communication Technologies for Ageing Well and e-Health (ICT4AWE 2017)*, pages 204-209
ISBN: 978-989-758-251-6

consolidation of solution providers across these two segments and a revisited interest in ALT in recent years.

Commercial devices have attained a certain degree of maturity. There is also a formidable and steadily increasing list of "stand alone" applications. The number of integrated systems that provide seamless and holistic solutions both in the home and ubiquitously is, however, relatively small and the degree of integration is still quite limited. Standardisation and regulation are now promoting an open model where applications and devices from an ecosystem of providers shall be possible to plug in on demand. An open model will facilitate a flexible environment where some of the devices and services are provided by the national health system or a health insurance, and others are purchased by the individual. This is, however, far from the case at the moment as solutions are more of a non-interoperable proprietary patchwork.

This position paper presents our approach to developing solutions for people with MCI/D as well as some of our current findings. Our approach builds upon two main hypotheses/ positions:

i. When developing ALT solutions it is vital to involve all user groups and all stakeholders – throughout the process and right from the start. In our opinion this is especially important in the case of people with MCI/D and other groups with cognitive impairments and similarly other vulnerable groups whose ability to contribute is underestimated and hence their voice tends to be overheard.

ii. The use of self-learning systems can provide people with cognitive impairments with the appropriate degree of cognitive enhancement and enable them continue to live independently, in accordance with their values, personal choices, and individual needs. Indeed, each person is an individual and "one-size-fits-all" types of solutions are by definition quite unlikely to serve the individual well and in all circumstances.

In the following we present some more details regarding our approach as well as current evidence that supports these positions.

1.1 Background

Politicians and health care providers share today great optimism regarding the potential of emerging technology to support older people at home. Technology is expected to reduce the pressure on needs for public health services, and to contribute to independence and dignity for older people with mild cognitive impairment and early phase of dementia (Lindqvist et al., 2013; Nygård and Starkhammar, 2007; Øderud et al., 2015). However, matching technology to a person's needs successfully, depends upon several things: the ability to reveal needs for support in the "subject of care"; the degree of individualization to the user's needs and context; the maturity and user-friendliness of the technology; and the robustness and predictability of the technology as sustainable solutions (Arntzen et al., 2016; Jentoftet al., 2014; Winblad et al., 2004). Further, an important factor concerns creating a supportive network for the user (Rosenberg et al., 2012). Therefore, investigating the potential of current technologies to support older adults, and in particular how to individualize such devices/solutions to address individual needs and preferences, is a vital component for developing useful new services.

Our approach is to involve the residents in a seniors' care dwelling, by discussing their habits, needs and preferences, as well as their experience with current technology, in order to identify possible pitfalls and success criteria.

1.1.1 Mild Cognitive Impairment

Participants in our study may have Mild Cognitive Impairment (MCI) or be in an early phase of dementia. Cognition encompasses attention, concentration, memory, comprehension, reasoning, and problem solving. Mild cognitive impairment was described by Winblad et al. (2004) to be a useful term as both a clinical and research entity. MCI is more than a pre-clinical stage of Alzheimer's disease. MCI may 1) progress over time 2) be stable, or 3) the person may recover. Risks of mortality seems high for all types. Hedman et al. (2013) studied patterns of functioning in older adults with MCI and found that they exhibited different patterns; stable, fluctuating, descending or ascending patterns. The patterns may change over time, and thus individual support is needed (Hedman et al., 2013).

1.2 User and Stakeholder Involvement

User involvement can be conducted for epistemic, normative and/ or instrumental reasons. (Fiorino, 1990). Our project epistemically aims at "co-production of knowledge". This is defined as being engaged in the process of mutual learning, and taking part in identifying solutions (Askheim, 2016). This is in line with the normative idea of empowerment. The participants are given the authority to decide what is right for them. This indicates that power relations are changed, the person is actively involved, and perceived as an expert on own health and life (Tveiten and Knutsen, 2011).

The user-centered approach is also embedded in the Responsible Research and Innovation (RRI) methodology (Forsberg et al., 2015; von Schomberg, 2013). The most central values are according to Owen et al. (2013) reflection on the intersections between science and society; clear distribution of responsibility for future events, built-in precautionary measures; and discussions over the intent of research and innovation. The RRI framework applied in this project has four integrated dimensions: Anticipation, Reflexivity, Inclusion and Responsiveness (Stilgoe et al., 2013). Central to RRI is an idea of mutual transdisciplinary learning and taking part in identifying solutions (Wickson and Carew, 2014). Porcari et al. (2015) distinguish between designing **for** users and designing **with** users, where participatory development with users is a "responsible approach" finally leading to more acceptable products.

2 USER INVOLVEMENT

We employ a combination of techniques and methods in order to understand the users' preferences and needs related to challenges in everyday living, the use of and attitudes towards technology, and their perceptions of own health. We combine the use of standardized questionnaires (such as Rand-36, Hospital Anxiety Depression Scale, Lawton and Brody ADL), dialogue cafés and semi-structured individual interviews. Also focus groups with staff are performed.

We use a stepwise process in order to invite, recruit and retain participants in the study. The process aims to engage the residents in the seniors' care dwelling and involve them as much as possible during the intervention.

Introductory discussions with the leaders and housekeepers in the seniors' home were used to anchor the project. All residents were then invited to a presentation of the project during one of the regular "house meetings". Approximately 20 residents consented and participated in semi-structured interviews with questionnaires about technology, perception of health, memory and quality of life. The researchers showed up at the seniors' care dwelling approximately 2-3 times a week in the beginning, to get acquainted with the seniors, and inform about the project.

All residents were invited to a first dialogue café (DC1) to discuss challenges they experienced in their daily life. The dialogue café method was developed with inspiration from several methods for user involvement; scenario workshops (Barland, 2013), dialogue conferences (Pålshaugen, 1998) and world café. In addition to obtaining information on needs, the dialogue café method stimulates for peer learning. DC1 was organized as group discussions, using user stories to help the residents relate. We wanted the DC1 to be as open as possible without a technology aspect. At a second dialogue café (DC2) we discussed examples of technological solutions. We designed user stories with cartoons to facilitate the group discussions with the residents. The choice of user stories and the group discussions at DC2 reflected both technical alternatives and ethical considerations. For example, are the residents willing to allow a camera in their home; who can have access to the images; are the residents willing to be localized in order to facilitate social contact, and under what conditions.

Dialogue cafés have so far proved to be an efficient and creative way for engaging the seniors, presenting ideas and thoughts, stimulate peer learning, and for understanding and discussing both challenges and solutions. In particular, it has been very useful for the project team to receive immediate feedback on whether the suggested user stories were of any interest for the residents at all. This directed the work onwards.

We will further invite the residents to new dialogue cafés for presenting and discussing concrete solutions, and to proceed in a similar manner to ensure that the residents are involved throughout the development process.

Further discussions and individual interviews with the residents are planned to reveal the individual needs and wishes beyond what is expressed in a public and social setting. In addition, further discussions regarding the detailed features of different technical alternatives are required in order to identify solutions for the first trial. These are required to meet needs, abide to wishes and choices, as well as be within the project's resource and technical constraints.

3 SUMMARY OF FINDINGS

3.1 User Needs

The most prominent user needs that resulted from DC1 related to eight areas:

1. **Falls** – the fear of falling, injury and not getting help. Some of the residents have a security/pendent alarm button that is provided by the national health system. Although help shows up within short time, a number of limitations – only operating indoors, requiring consciousness, not knowing whether the alarm actually has been received and when help is coming – are major shortcomings.
2. **Being outdoors** and access to fresh air. Being safe when out of the house was crucial. Also physical mobility and secure and predictable transportation are important.
3. **Ability to orient oneself at night**. Dark environment and possibly impaired vision may influence navigation/orientation at night, e.g. for a toilet visit, and can increase the risk of falling.
4. "**Button-phobia**". Technology can be difficult to use, due to small buttons and unfamiliar interfaces, as well as passwords and codes.
5. **Social contact** with others, both inside and outside the seniors' care dwelling can be challenging.
6. **Safety at home**. This is multifold and associates to not always getting help when required and within short time, access to their apartment by helpers even if the door is locked.
7. **Sleeping** sufficiently and well. Challenges include the difficulty to fall sleep, waking up frequently during the night, and/ or waking up too early in the morning.
8. **Self-sufficiency and autonomy**. Even if the residents do feel relatively autonomous and self-sufficient, their daily routines need to conform to the schedule of others. The schedule of family, nurses and staff can compromise the individual's preferred activities and daily routines, introduce long waiting and create unpredictability and diminished control over own life.

3.2 Priorities

A summary of the main findings will be presented at the conference whereas the details of these will be described in a separate publication. Some of the key reflected characteristics were:
i. The high importance/ priority of being independent, self-sufficient, and in control over own life. Most of the residents were also wary of troubling their family and friends.
ii. The wish to remain active and a fear that relying on help from others or from a system may cause a deterioration of their cognitive ability.
iii. A willingness to trade-off privacy for better safety.

3.3 Current Experience with User Involvement

Our overall experience with user involvement so far supports our original hopes and expectations. Indeed, both the care providers and the residents themselves have provided us with invaluable feedback. Note that next-of-kin have not yet been interviewed. In several occasions the research team was reminded of how difficult it is to understand the needs and preferences of other people and speak for others. This is the case despite the best intentions, a lot of expertise, and even personal experience through the researchers' own elderly family members. Indeed, many of our predictions regarding which solutions would appeal to the residents were quite wrong.

4 THE ROLE OF SELF-LEARNING SYSTEMS

Typically, commercial smart-home solutions provide assistive devices such as reminders, calendar, night lights, electric cooker timers, medicine dispenser, picture phone, etc. (Topo et al., 2004; Jones, 2004). More complete solutions integrating several functionalities have also been developed. The portable device in the COGKNOW project provided memory-aids, social contact (e.g. picture dialing), help on daily activities (e.g. lamp control), and safety functions (Mulvenna et al., 2010). This was integrated with two additional systems for the Rosetta project (Hattink et al., 2014). This system recorded behaviour patterns to analyse sleep-awake rhythms, mobility, meal preparation and personal hygiene. It also detected emergency situations such as falls and alarmed carers. In general, these systems were well received, especially when introducing functionality that enhanced the feeling of safety.

Especially in the past five-ten years there has been an emergence of solutions that employ machine learning (ML). ML is used for example for better fall detection (Choi et al., 2011), automatic activity recognition (Chen et al., 2010), or to monitor/ study behaviour patterns (Cook et al., 2015). ML has been also used to generate prompts to assist daily activities in the CASAS smart home (Das et al., 2012). A number of projects address the difficulty of executing daily activities. For example, the COACH system (Hoey et al., 2007) assists people with dementia in the hand-washing activity via a camera and provides automatic cues to assist activity completion. Feki et al. (2009) deploy several sensors to monitor activity execution (i.e. meal preparation and eating) and issue automatic prompts in case of error. Karakostas et al. (2015) in the Dem@Care project developed a semantically integrated multi-sensor system that provides holistic support and tested it on one dementia patient.

Yet the potential of ML is largely untapped. The self-learning and self-adapting potential of ML-techniques are important characteristics that enable individualised solutions without the need to manually tailor individually – a process that is prohibitively costly in traditional systems. With ML the system can in principle observe, learn and adapt accordingly on its own. As presented in section 1.1, MCI/D is an example of a condition that is more of an individual spectrum of characteristics and impairments rather than one simple to define condition. Here every person is indeed an individual case and pre-fitting the system to the user is not only costly but in reality quite limited, if at all possible. Moreover, the condition progresses in an individual manner and at an individual speed. This demands a technology that can sense and adapt to evolving needs. In addition, a self-learning system is potentially capable to evolve and meet a set of preferences and requirements that are latent and to an extent unknown to both the user, and the care provider/ health expert.

Beyond the personalisation of services and care, there is an untapped potential for higher level semantic system intelligence and cognitive enhancement on the person's own terms. The idea is that a system shall comprehend the overall situation – the objective facts, potential hazards, as well as the person's subjective experience and personal choice – and support the human achieve their current goal. The idea of the smart-home has been gradually evolving from that of a simple automation towards the vision of an unobtrusive interconnected environment, that is sensitive and adaptive to the inhabitants' needs and behaviour (Aarts and Wichert, 2009). This extends both within and outside the home following new possibilities in the advent of the Internet of Things (Zouganeli and Svinnset, 2009). Current smart-home paradigms rely on creating good user-interfaces and voice-interfaces are positive steps to that end.

A new paradigm can envisage systems that understand the intention of the human, anticipate hurdles, device solutions, predict outcomes, and are an extension of the human on the human's terms. This creates of course new challenges as autonomy, safety, privacy and ethical considerations need to be thoroughly safeguarded throughout. The rapid advance of artificial intelligence and adjacent fields may enable such solutions in the not too far future.

5 SUMMARY

We have presented work in progress and our approach to developing technological solutions for people with MCI/D. We argue that the users need to be involved all the way in order to develop good systems, and this holds not least for people with MCI/D. Our preliminary experience supports this view. We have also made the case for self-learning systems as well as presented our vision regarding the future evolution of these.

ACKNOWLEDGEMENTS

The authors wish to thank the residents and the housekeepers in the seniors' care dwelling at Skøyen Omsorg+ and in Oslo Municipality. The project is financed by the Norwegian Research Council under the SAMANSVAR programme (247620/O70).

REFERENCES

Aarts, E. & Wichert, R., 2009. Ambient intelligence: A Survey. *Technology Guide, 43(4), pp.244–249.*

Arntzen, C., Holthe, T., & Jentoft, R. 2014. Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family carers. *Dementia: The International Journal of Social Research and Practice, 15(4).*

Askheim, O. 2016. Samproduksjon som velferdssektorens kinderegg. *Tidsskrift for omsorgsforskning, 2*(1), 24-36.

Aspnes, E. et al. 2012. Velferdsteknologi i boliger, Available: *http://www.sintef.net/globalassets/project/velferdsteknologi/velferdsteknologi_i_boliger_rapport_revidert_120312.pdf [Accessed January 4, 2017].*

Barland, M. 2013. Scenario workshop method description, Available: *http://www.pacitaproject.eu/wp-content/uploads/2015/01/PACITA-D-6-1-Method-description_stakeholder-scenario-workshop_v4-_2_.pdf*

Chen, C., Das, B., Cook, D.J, 2010. A data mining framework for activity recognition in smart environments. *Procs. of the Sixth International Conference on Intelligent Environments, pp 80-8*3.

Choi, Y., Ralhan, A.S. & Ko, S., 2011. A study on machine learning algorithms for fall detection and movement classification. *2011 International Conference on Information Science and Applications, ICISA 2011, (May 2011).*

Cook, D.J., Schmitter-Edgecombe, M., Dawadi, P., 2015. Analyzing activity behavior and movement in a naturalistic environment using smart home techniques. *IEEE J Biomed. Health Informatics, 19(6), pp 1882-92.*

Das, B. et al., 2012. PUCK: An automated prompting system for smart environments: Toward achieving automated prompting-challenges involved. *Personal and Ubiquitous Computing, 16(7), pp.859–873.*

Feki, M.A., Biswas, J. & Tolstikov, A., 2009. Model and algorithmic framework for detection and correction of cognitive errors. *Technology and Health Care, 17(3), pp.203–219.*

Fiorino, D. J. 1990. Citizen Participation and Environmental Risk: A Survey of Institutional Mechanisms. *Science, Technology, & Human Values*, *15*(2), 226–243.

Forsberg, E., Quaglio, G., O'Kane, H., Karapiperis, T., Van Woensel, L., & Arnaldi, S. 2015. Assessment of science and technologies: Advising for and with responsibility. *Technology in Society, 42, 21-27.*

Hattink, B.J.J. et al., 2014. The electronic, personalizable Rosetta system for dementia care: exploring the user-friendliness, usefulness and impact. *Disability and rehabilitation. Assist. Technology, 3107(Mci), pp.1–11.*

Hedman, A., Nygard, L., Almkvist, O., & Kottorp, A. 2015. Patterns of functioning in older adults with mild cognitive impairment: A two-year study focusing on everyday technology use: Corrigendum. *Aging & Mental Health, 19(6), 569.*

Hoey, J. et al., 2010. Automated handwashing assistance for persons with dementia using video and a partially observable Markov decision process. *Computer Vision and Image Understand., 114(5), pp.503–519.*

Jentoft, R., Holthe, T., & Arntzen, C. 2014. The use of assistive technology in the everyday lives of young people living with dementia and their caregivers. Can a simple remote control make a difference? *Int Psychogeriatr, 26(12).*

Jones, K., 2004. Enabling Technologies for People with Dementia. *Report of the assessment study in England.*

Karakostas A., Lazarou I., Mediskos G., Stavropoulos T. G., Kompastianis I., Tsolaki M. 2015. Sensor-based in-home monitoring of people with dementia using remote web technologies. *Int. Conf. on Interactive Mobile Comm. Tech. and Learning (IMCL). Thessaloniki, 19-20 Nov. 2015.*

Mulvenna, M. et al., 2010. Designing & Evaluating a Cognitive Prosthetic for People with Mild Dementia. *Proceedings of the 28th Annual European Conference on Cognitive Ergonomics - ECCE '10, (August), p.11.*

Lindqvist, E., Nygard, L., & Borell, L. 2013. Significant junctures on the way towards becoming a user of assistive technology in Alzheimer's disease. *Scand J Occupational Therapy, 20(5).*

Nygård, L., & Starkhammar, S. 2007. The use of everyday technology by people with dementia living alone. *Aging & Mental Health, 11.*

Owen, R., Stilgoe, J., Macnaghten, P., Gorman, M., Fisher, E., & Guston, D. 2013. A Framework for Responsible Innovation. *In R. Owen, J. Bessant, & M. Heintz (Eds.), Responsible Innovation (pp. 27–50). John Wiley & Sons, Ltd.*

Porcari, A., Borella, E., & Elvio, M. 2015. A Framework for implementing Responsible Research and Innovation. In *ICT for an ageing society (No. D2.4). Italian Association for Industrial Research (AIRI) /Responsible-Industry.*

Pålshaugen, Øyvind. 1998. Organization development through development organization. In: Development coalitions in working life, ed. Bjørn Gustavsen, Tom Colbjørnsen, and Øyvind Pålshaugen. *Amsterdam: John Benjamins Publishing Company.*

Rosenberg, L., Kottorp, A., & Nygard, L. 2012. Readiness for technology use with people with dementia: The perspectives of significant others. *J Appl. Gerontology, 31(4).*

Stilgoe, J., Owen, R., & Macnaghten, P. 2013. Developing a framework for Responsible Innovation. *Research Policy 42.*

Topo, P., Saarikalle, K., Holthe, T., et al., 2004. Enabling Technologies for People with Dementia. *Report of Picture Gramophone assessment: National findings from Finland, Ireland, Norway and UK and cross national results.*

Tveiten, S., & Knutsen, I. 2011. Empowering dialogues - the patient's perspective. *Scand J of Caring Sci, 25.*

Von Schomberg, R. 2013. A Vision of Responsible Research and Innovation. *In R. Owen, J. Bessant, & M. Heintz (Eds.), Responsible Innovation (pp. 51–74). John Wiley & Sons, Ltd.*

Wickson, F., & Carew, A. L. 2014. Quality criteria and indicators for responsible research and innovation: learning from transdisciplinarity. *Journal of Responsible Innovation, 1(3), 254–273.*

Winblad, B., Palmer, K., Kivipelto, M., Jelic, V., Fratiglioni, L., Wahlund, L., Petersen, R. 2004. Mild Cognitive Impairment - beyond controversies, towards a consensus: *report of the International Working Group on Mild Cognitive Impairment. J of Internal Medicine, 256.*

Zouganeli E., Svinnset I. E., 2009. Connected Objects and the Internet of Things – a Paradigm Shift. *Invited. Conf. Procs., Photonics in Switching, Pisa, Italy, Sept 15-19.*

Øderud, T., Grut L, & Aketun S. 2015. Samspill - GPS i Oslo. Pilotering av Trygghetspakke 3. Bruk av GPS for lokalisering av personer med demens. *SINTEF-rapport A27121.*