



The state of play of co-created ICT based Alzheimer care solutions: A summary of the Co-Care project report

The Co-Care project aims to stimulate user-led design in the development of ICT-based Alzheimer care solutions for informal carers. It brings together universities, ICT professionals, the health and social care sector and, most importantly, informal carers themselves to improve teaching and learning approaches and foster entrepreneurship in the ICT and health and social sector.

It was important for the Co-Care project to begin with an accurate picture of the current situation of co-created ICT based Alzheimer care solutions around Europe. In order to see what needs to be improved we had to first explore what exists. The state of play report aims to present the status of digital tools designed for informal carers of people living with Alzheimer's in Spain, Portugal and the United Kingdom. It intends to describe, analyse and classify these ICT solutions and their process of design and development. To do this, a thorough literature review of relevant documents published in the past 5 years was conducted. These documents included journal articles, policy papers and research projects and had to be related to co-creation, digital solutions, and informal caregiving. A main principle of the Co-Care project is to foster entrepreneurship and design thinking in the professionals of tomorrow. Therefore the report also analyses training programmes available on the topic.

Two research questions guided this piece of work: Are the digital solutions available (1) designed to improve the life of informal Alzheimer's caregivers? And (2) designed to meet the needs of caregivers? Our results suggest that in the last 5 years there has been an investment from associations, companies and universities to address the constraints and difficulties felt by informal caregivers in their daily life. However, there is still room for further development. Our literature review showed that there are technological tools that can improve the practical life and well-being of caregivers, namely: educational resources and development of competences, psychological health and social engagement. There are also digital solutions which focus on specific needs of caregivers such planning, personal health and caregiving tasks. Despite this, there is still a lack of digital resources in many other important domains, such as the physical health of the carer, the management of responsibilities or crisis planning to mention a few.

When looking into the design process, we found that the available ICT solutions are still at an early stage of development and at the level of exploration and initial implementation. More worryingly, caregivers had not played an active or influential part in the design of these tools. In fact, in 85% of the literature found, references to co-design processes were absent. Our research shows that, when caregivers were included, they were mainly requested to contribute at the end of the process with potential improvements. Meaningful participation during the design phase, where it is needed most, is still scarce.

The state of play report also looks at training programmes available in the field of co-created ICT-based Alzheimer care solutions. Results show interesting differences between the countries. In fact, there are training opportunities in Dementia or Alzheimer studies, but these are mostly offered by British institutions. Both students and staff involved in these trainings are mainly related to health sciences and engineering/informatics, but it is unclear if professionals from the sector play a role. The consideration of caregivers' needs also appears unrecognised in these trainings.

Our research provides important input and insights for the rest of the work to be done by the Co-Care project. It can provide relevant knowledge and further reflection that may help to fill in the gaps and overcome current limitations found in this area of research and practice. It is clear that there is space to improve user-led design and co-creation in the development of these ICT solutions. The Co-Care project intends to create the resources and tools to make this happen. So that the needs of informal caregivers of Alzheimer patients are better catered for and better designed for.

[To read the full state of play report on co-created ICT-based Alzheimer care solutions click here.](#)

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