

# CO-CARE

Co-Care project "Co-created ICT solutions for Alzheimer's Informal Caregiving"



The Co-Care project has come to an end and we take this opportunity to reflect on the key achievements of the project and how they can help stakeholders. But beyond this project, our work is not over! The Co-Care partners will continue to work hard to stimulate user-led design in the development of ICT-based Alzheimer care solutions, and to improve the conditions of informal carers.

We are counting on your support too!

## FINAL EUROPEAN CONFERENCE

On December 14, the Co-Care partners, together with various stakeholders, gathered at the Thon EU Hotel in Brussels to discuss the key outcomes of the project, as well as to share their impressions and experiences on the current needs and opportunities together with the next steps to further improve support for informal carers.

Opening the event, **Maya Doneva, Secretary General at EASPD**, introduced the event by contextualising the **Co-CARE project**. CO-CARE focuses on fostering co-creation in the development of ICT solutions to facilitate the work and daily life of informal caregivers of people with Alzheimer's. In this sentence, every concept is essential for our work.

- **Co-creation** is an essential approach to put the service users at the centre of service provision,
- **ICT solutions** have become more available in the care sector, but we must steer them toward inclusion,
- **Informal caregivers** are too often not supported despite how important their work is,
- **Alzheimer's** is a crucial challenge for our ageing society and a real test of how we support the members of our communities with greater care needed.

In her keynote speech, **Claire Champeix, from Eurocarers**, presented the situation of caregivers from a sociological, economic and policy standpoint. Crucial aspects were discussed, such as the trilemma of care: reliance on informal carers; LTC needs improved coverage; insufficient public expenditure. Other areas that need to be worked on to support caregivers include: financial support, employment, pension credits, regular breaks, information and training, and recognition and choice.

To achieve these, there exist various instruments such as the **European Care Strategy** and the European Pillars of Social Rights (Principle 18: Long-Term care). Many key issues are addressed by the Strategy: accessibility, affordability, quality, adequacy and working conditions. All in all, it constitutes a positive outcome for informal givers: positive framework for policy reforms for improving LCT and identification and support of informal carers. But it is not enough: the Strategy is not directly legally binding, there is a lack of data, competing priorities and budgetary constraints, weakened coordination and reporting and fragmentation at national level.

In this context, ICT tools can greatly help informal caregivers, especially since their greater adoption following the COVID-19 pandemic. Nevertheless, these tools also contain significant barriers, including user access and literacy, sustainability, and affordability.





The participants of the conference also learned about the **key outputs of the Co-Care project, including the State of Play report, the Training, and the Toolkit**. Have a look at the next pages of this newsletter if you wish to find out more about these tools.

In the afternoon, the participants engaged in interactive sessions to reflect on their own experiences with health applications and on the importance of co-creation in their design. This was followed by a live demonstration of the brand-new Co-Care Online Community of Practice.

In her conclusions to the event, Co-Care Project Coordinator Anna Ramon-Aribau, from the **University of Vic**, mentioned that caregivers represent a large enough percentage of the population to consider them targets of attention at all levels (health, economic, innovation, technology...), in particular with regard to their opportunities of participation into society and to maintain their social network, and to their quality of life and mental health. On behalf of the Co-Care partners, Ms Ramon-Aribau pledged to **continue working intensively to achieve more visibility to improve the conditions of caregivers**.

And now, for a look back on the key outputs we have developed throughout the duration of the Co-Care project, and how we hope they will support stakeholders across Europe:

## STATE OF PLAY: CO-CREATED ICT-BASED SOLUTIONS FOR INFORMAL CAREGIVERS OF PEOPLE WITH ALZHEIMER'S DISEASE: LITERATURE REVIEW

The Co-Care partners have researched and analysed the published literature/materials (over 174 materials) to reach a broad overview of Digital Solutions developed in co-creation to support caregivers' needs. This is an essential report to understand the existing solutions, but also the gaps and needs. In its findings, the report highlights that there are already available solutions focusing on specific needs of caregivers; however we are still lacking digital resources in relevant domains and purposes. Other issues include the lack of participatory methods and caregivers' involvement.

The report stresses that the involvement of users is of foremost importance. **Users are an immense source of knowledge and creativity that can help to transform products or services into more innovative ones, which will also strengthen the communities where they live**. So far, co-creation has been insufficiently integrated into existing practices. The CO-CARE project has attempted to give a greater emphasis to co-creation and user involvement, as we will show with the Training and the Toolkit that we have developed.

**[Read the report here!](#)**

Célia Soares from IPS Portugal presents the report: [here](#)



## TOOLKIT FOR INFORMAL CARERS

The Co-Care partners have developed a toolkit to improve the autonomy and quality of life of informal caregivers of people with Alzheimer's.

Its main aims are to:

- Give informal carers tools to choose ICT-based solutions to facilitate their daily work/life as caregivers.
- Develop and improve their skills to better use ICT-based solutions in terms of navigation but also critical thinking and contrasting use and benefits of tools.
- Give caregivers the chance to connect with peers in the same situation to share and exchange impressions regarding solutions but also their role as family caregivers.

To develop this toolkit, a variety of stakeholders have been involved in every step, such as caregivers from Spain, Portugal and the UK, and experts in healthcare and the ICT sector. In line with the project's values regarding co-creation, the prototype of the toolkit has been extensively tested and revised. Discover the toolkit [here](#)!

Marta Corona from Knowledge Biz (Portugal) presents the Toolkit: [here](#)





## TRAINING COURSE

The Co-Care partners have produced a document that justifies why it is necessary to have a training course in university education systems that brings together future technologists, health and social care professionals and caregivers of people with Alzheimer's / dementia, in order to learn how to propose, design, develop and evaluate technological solutions in a co-created way. The document explains the training course in detail, including aspects like the framework, content and structure and sustainability of the course and will prove very useful for interested higher education institutions.

[Read it here!](#)

## ONLINE COMMUNITY OF PRACTICE

Finally, and looking to the future, the partners have concluded the development of our Online Community of Practice (OCoP). The OCoP is a place where informal carers, ICT designers and providers, and students, lecturers and researchers from higher education institutions are able to interact with each other, share knowledge, and work together.

### In what scenarios can the OCoP be useful for me?

- **As a caregiver**, I want to receive concrete tips about technologies that I can use and connect with other people facing the same challenges I face, in order to improve my quality of life and the support I give and receive.
- **As a student**, I want to understand better the existing solutions and the needs of users of technology tools and exchange ideas with developers and entrepreneurs, in order to develop better tools.
- **As a researcher**, I want to access data and resources on informal care of Alzheimer's / dementia and identify existing research gaps, in order to inform the research agenda.
- **As a curious person**, I want to interact and exchange with various stakeholders in the sector.
- **As a policy maker**, I want insight into how co-production initiatives can be supported at a governmental level.

### How to join the OCoP?

- Go to this URL: <https://co-care.eu/en/register>
- Twitter : @CoCare\_Eu
- Or use the following QR



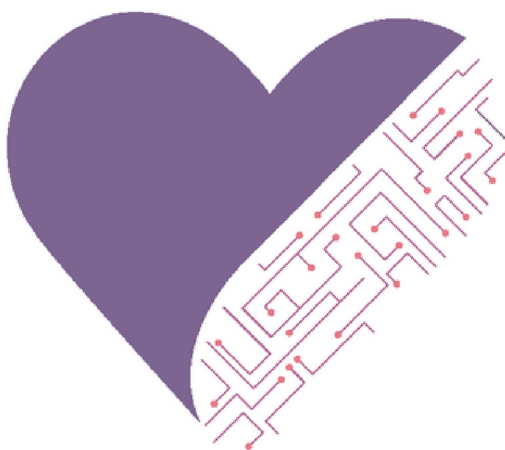
With this community we aim to encourage the connections and maintain the work already done by the Co-Care project on joining these groups so that they can create real technological solutions to aid informal caregiving. This is a key aspect of our efforts to maintain the momentum of Co-Care beyond the end of the project, and we are relying on the participation of all our partners to strengthen the community and ensure further improvements for informal caregiving of persons with Alzheimer's/dementia!

## COMING UP

With our final project meeting in Brussels on December 13 to 15, the partners have wrapped up the last deliverables of Co-Care and said goodbye for now. But only for now! **Because our work is not over.** There are still many barriers and needs for co-creation in the development of ICT tools to support informal caregivers, and the partners remain committed to addressing these challenges. We will continue to promote key news and outputs, as well as to work together in projects, research, events, and other activities. Stay tuned!

On behalf of the Co-Care consortium, the University of Vic – Central University of Catalonia (UVic-UCC), the Fundació Pasqual Maragall, the Instituto Politécnico de Setúbal (IPS), the European Association of Service Providers for Persons with Disabilities (EASPD), Confluència, Alzheimer Portugal, Alzheimer's Society, the University of Derby, MarkedImprovement, and Knowledgebiz, we thank you for your support throughout the implementation of this project, and we hope you will continue to use and promote the tools we have developed!

See you soon.



**Co-Care**  
SHARE TO EVOLVE, CONNECT TO REMEMBER

