# Eurocarers Study Visit
## Connected carers: the future of a carer-friendly society?
### 12 September 2019, Brussels
### Event Report

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# Introduction

## Background

Against the backdrop of the demographic transition and the pressing need for support to informal carers, who provide most of the long-term care in Europe today, information and communication technologies (ICT)-based solutions can be key assets in the development of innovative approaches to address carers' needs. In particular, they can be instrumental in breaking the isolation that carers often suffer from, due to their caring duties as well as to the lack of recognition of their role in our societies.

Notably, ICT-based solutions can help carers in accessing information, training and validation of skills, as well as peer support, in order to improve the quality of care they provide, as well as their own quality of life and ability to participate in society. They can also facilitate the coordination between carers, as well as with health professionals, supporting the autonomy of the patient and the carers and the delivery of care at home. As a network, Eurocarers has been advocating for adequate and accessible ICT-based solutions to be made available to all informal carers across Europe.

Today, ICT-based support for carers is a fast-evolving domain, with a multiplicity of innovative solutions addressing the various practical aspects of the carer's situation. However, projects promoters and practitioners in the fields are facing numerous obstacles in their laudable endeavour to make ICT-solutions accessible to all. Therefore, the availability of these promising tools remains fragmented and their sustainability is often at stake.

Furthermore, the development of ICT-based solutions raises a series of political challenges, such as their capacity to bridge the gap between informal and professional carers without overburdening the informal carers, or the potential of market-driven innovation to address carers' needs adequately.

## Objectives of the event

This study visit aimed to:
- Provide an opportunity for Eurocarers' members to learn from each other, take stock of our network's knowledge and experience, which is particularly useful in this area where innovative practices are not always documented in detail given the endemic lack of resources;
- Ensure Eurocarers' involvement as a network in relevant EU projects building on our members' expertise. In particular, two sessions focused on the CARE4DEM project, aimed at developing a model of web-based mutual aid groups for informal carers;
- Give participants a chance to benefit from the expertise of selected external guests, from the EU Commission and relevant EU civil society organisations;
- Lay the ground for future joint initiatives at policy and/or practice level.

The event took place on 12 September in Brussels (Palais des Academies) and brought together 28 participants (18 of them were delegates from national carers' organisations, 4 represented national research organisations. In addition, the event benefited from the participation of 6 representatives from the European Commission, Consultancy companies and European umbrella organisations).

# Summary of the day

Claire Champeix (Policy Officer, Eurocarers' Secretariat) welcomed participants by stressing the profound interest expressed by Eurocarers' members in the topic, and by highlighting the numerous initiatives currently being implemented in the field, notably to address the social isolation too often faced by informal carers.

## Setting the scene: The relevance of ICT-based solutions for supporting informal carers, their availability in Europe today

This session was chaired by Anita Vatland, Chairman of Pårørendealliansen (Norway).
Giovanni Lamura (INRCA-IRCCS, Centre for Socio-Economic Research on Ageing, Italy) introduced the session by presenting InformCare (the EU Information Hub on Informal Care) and ENTWINE (the European Training Network on Informal Care). The ambitious INNOVAGE project (FP7 / 2012-2015) made it possible to develop the InformCare platform, aimed at providing carers with reliable information about care and caring in their language in 27 countries. An update of this much-appreciated platform is now foreseen in the framework of the ENTWINE project.
See Giovanni's presentation here.

Alhassan Hassan (INRCA-IRCCS, UNIVPM, Italy), one of the ENTWINE project's PhD Early Stage Researcher, has started to work on the upgrade of the InformCare web platform.
His presentation gave an overview of:
* The importance of ICT-based solutions for informal carers;
* Their perceived needs and concerns in using ICT;
* The challenges and recommendations for the deployment of ICT solutions for informal carers.

Digital illiteracy, the costs of technology, the lack of awareness and the issue of the lack of sustainability of pilot initiatives were highlighted as the most prominent challenges. See Alhassan's presentation here.

In conclusion to the session, Claire Champeix, presented the learnings from two Erasmus+-funded projects aimed at developing ICT-based solutions for informal carers of people with dementia: a training (TRACK) and a model of online mutual aid group (CARE4DEM). Both projects started with studies mapping existing initiatives in the field. A number of these studies' conclusions were quite convergent, stressing notably that:
* There is clear evidence of the potentialities and positive impact on the well-being of informal carers of ICT-based solutions (notably through emotional support, skills developments, social inclusion);
* While some initiatives are implemented, the development of these solutions is still insufficient, extremely fragmented and uneven;
* Most of the initiatives are not evaluated nor documented (especially if developed by CSOs), hence the difficulty of transferring knowledge in the matter;
* There are numerous challenges to overcome to ensure access to ICT-based solutions, including the lack of availability, difficulties written expression, ICT literacy, etc.;
* Such interventions should be embedded with other services in order to foster participation;
* The policy background at local, national and EU levels is also essential.

See Claire Champeix's presentation here.

## Comments

Frank Goodwin (Family Carers Ireland) insisted that these new tools should not contribute to put an additional burden on carers, and in particular on the small number of full-time carers who are not in employment and are doing the most intensive care. He insisted on the need to review the contractual arrangement around these situations and reminded that, in some countries, when a patient is discharged at home, the hospital is no longer responsible and no professional has any responsibility.

## Round table discussion: How can the EU level support the development of ICT based solutions for carers? What partnerships are needed?

The roundtable discussion was chaired by Giovanni Lamura, Centre for Socio-Economic Research on Ageing, Italy.
Giovanni introduced Birgit Morlion, Programme Officer at the European Commission (DG CONNECT, eHealth, Well-being and Ageing ), Silas Olsson, Director of the 'Health Access' consultancy (Sweden) and Dorota Sienkiewicz, Policy Coordinator at EuroHealthNet (see speakers' biographies here).

## Main challenges

First, the panellists were asked to reflect on the challenges they identify in the sector. Birgit Morlion underlined that new technologies bring transformation to our entire society, that needs to be taken on board by the Health Sector. She added that the increasing reliance on carers, given the demographic change and the shortage of formal carers, the shift from hospital-based to community-based care, as well as the capacity of new technologies to empower patients and their carers all form part of the main challenges to be addressed. Ms. Morlion also emphasised that evidence about the added value that ICT can bring in the life of people is now available. She detailed that, while many researches are undertaken and pilots implemented, the deployment of such solutions is yet to be achieved. The main obstacles to upscaling include the lack of digital skills and the need to secure a safe ICT environment.

Dorota Sienkiewicz, referring to the 'Policy Précis' on Digital Health Literacy just published by EuroHealthNet, stressed the need to invest in Digital Health Literacy in order to avoid the digital divide between ages and groups widening pre-existing health inequalities. 'Techno phobia' of certain people has to do with a lack of trust, linked to issues in relation to ethics, protection of data and privacy. She insisted that a new legislative environment - building on a large partnership - is required to put in place solutions to reach health equity.

Silas Olson, insisted on the necessity for our Health and Care systems to address the current challenges threatening sustainability. Against this backdrop, he pointed out the announcement of the new EU Commission as a window of opportunity for the Eurocarers network to bring in its views, engaging notably with the Commissioners respectively responsible for Health, Digital policy and Cohesion. He also agreed that the current move from hospital to home-care is a key challenge, and that many changes would be needed for home-care to be adequately supported by both professionals and informal carers.

## Comments

Sebastian Fisher (VOCAL, Scotland, UK / Wir Pflegen, Germany) insisted that we should stick to the term 'carers', pointing out that 'caregivers' was an American wording. He also raised the importance of seizing opportunities, notably the fact that more than 85% of the European population is equipped with smartphones, opening up a huge potential for ICT-based support. He also stressed that our approach should be underpinned by the notion of 'active citizenship', according to which we should develop self-

directed solutions rather than following the traditional pattern of 'offering services to carers. "Carers are not services users; they are service providers" he concluded.

Patrick Hofer (We+Care, Switzerland) agreed that informal carers should have tools at their disposal, "just like any other care providers".

Dorota Sienkiewicz, while agreeing on the need to build on 'active citizenship', highlighted the risk to develop a two-tier system leaving aside the most socially deprived, lacking digital skills and digital health literacy, while major investments go into ICT developments.

Kate Hamblin (University of Sheffield, UK) highlighted one additional challenge in the UK, which is the lack of adequate ICT infrastructure in some areas including rural areas, resulting in a lack of qualitative access to the internet

Adding to the list of challenges, Frank Goodwin referred to the unfair and unbalanced relationship between informal carers and professionals.

Silas Olson stated that better cooperation between both groups could be facilitated by ICT solutions.

## How the EU can help?

Birgit Morlion drew the attention of participants to the existing programmes aimed at supporting the development of infrastructure in specific geographical areas. She also mentioned that the EU Commission is working on the new 'Horizon Europe' research programme which will replace 'Horizon 2020'. Horizon Europe includes a big cluster devoted to 'active ageing', including 'independent living'. She warmly invited us to voice our concerns.
She also referred to other relevant EU activities, namely:
- The Digital Europe Programme, focusing on the digital transformation of the society, including a 5th Pillar on Digital Skills;
- The Active Assisted Living Programme, likely to provide support and possibilities to projects with a focus on users;
- The European Innovation Partnership on Active and Healthy Ageing focusing on mutual learning at local and regional levels;
- The Research and Innovation Days; and
- The Regional Development Funds, which can also provide an important leverage.

Dorota Sienkiewicz mentioned that in 2018, EuroHealthNet completed a project on the use of European Structural and Development Funds in the area of health (http://esifundsforhealth.eu/ ) This project sheds light upon the numerous projects currently trying to deploy ICT solutions for health.
Based on their findings, EuroHealthNet called for:
- An EU Joint Action to improve Digital Literacy and Digital Health Literacy,
- A discussion on good practices that could be guided by the EU Commission

Silas Olson underlined the many opportunities offered with the installation of the new Commission, stressing that Eurocarers was in a very good position to contribute as it brings together organisations from a large number of countries.

Responding to Martha MacKay's intervention deploring the lack of interest of the industry to ICT-based solutions for carers, Dorota Sienkiewicz mentioned the 'Invest EU' programme, a system of loans aimed at boosting the attractivity of the social sector in the eyes of the financial sector, which includes a window for 'Social Investment'.

## Partnerships

Reflecting on the partnerships that would be needed to achieve progress, Birgit Morlion emphasized the complexity of the area, which is "cross-levels, cross-policies, cross-sectors". *"It is key to bring more actors around the table, even if it means that it will take more time, the partnership will be stronger"* she said. She insisted that stakeholders should keep their eyes open for opportunities to input in the ongoing discussion, and come up with a 'how' as well as stressing 'what' is needed.

Concerning partnerships, Silas Olson mentioned other relevant umbrella organisations, such as AGE platform Europe. On this point, Claire Champeix indicated that AGE, as well as other organisations such as Eurocities and the Internal Association of Mutual Organisations have been invited to the event but were not able to attend.

Silas Olson also reported that the Committee of the Regions will adopt a proposal on "active and healthy ageing" next month, mentioning carers. In his view, municipalities are also likely to play an important role in paying for online services for carers, which could be designed by the industry in cooperation with users' organisations.

## Comments

On this last point, Sebastian Fisher commented that carers are not participating in the design of solutions in the countries where there is no or under-funded carers' organisations. Innovative ways of consulting them are needed, for example through national census. *"You would not build a fire station without firemen; you shouldn't design solutions without carers"* he said.

Dorota Sienkiewicz agreed on the need to involve the industry and raised also the potentialities of working with the finance and banking sectors, as well as the upcoming generation of carers (represented by the European Youth Forum), and Health Professionals. It will be also important to work with the new European Parliament in particular on digital literacy, educational initiatives, including lifelong learning.

Martha MacKay underlined the need for public investment in ICT-based solutions so that they remain affordable to all.

Giovanni Lamura stated that a partnership with the medical professions is also crucial.

## First set of presentations:  Breaking carer's isolation through online information and training

The session was chaired by Claire Champeix and featured three presentations:
- Maryse Montangon, FNAAF (France). Read the presentation here.
- Giusy Trogu, Anziani e Non Solo (Italy). Read the presentation here.
- Marina Makri, Association of Alzheimer Disease and Related Disorders (Greece) Read the presentation here.

## Second set of presentations:  Facilitating the coordination of care

The session was chaired by Martha Mac Kay (Spain) and featured two presentations:
- Anna de Siún, Family Carers IE (Ireland): Family Carers Ireland App. Read the presentation here.
- Patrick Hofer, Pro Aidants (Switzerland): WE+CARE. Read the presentation here.

## Third set of presentations: Fostering online peer support

### CARE4DEM: Update and discussion

CARE4DEM is developing a model of online Mutual Aid Group for informal carers of people with dementia, with a specific focus on the group facilitator's competences. Eurocarers is involved as a network in this Erasmus + project. The objective of this session was to ensure that members interested are updated about the developments of the projects, have the opportunity to contribute to the outcomes' developments, and the possibility to use them in their own activities. Giusy Trogu, representing the project coordinator Anziani e Non Solo (Italy) presented in detail the CARE4DEM model of online Mutual Support Group for informal carers of people with dementia (Intellectual Output 02).
Read the presentation here.

Claire Champeix presented the Competence Profile of the Mutual Support Group facilitator defined in relation to the CARE4DEM model (Intellectual Output O3). Both insisted that the outcomes of the project are principally aimed at reinforcing the capacities of organisations in the field, who will be free to use the outcomes of the project to be available mid-2020. They insisted that, because it is building on the competences that informal carers acquire through their experience of caring, the project highlights the competences of informal carers. Encouraging co-facilitation by a professional and an experienced carer, it is also contributing to bridging the gap between professionals and informal carers.
Read the presentation here.

Responding to comments, Claire clarified that:
The tools are not necessarily reserved for professionals and can also be used by experienced informal carers. Besides, the CARE4DEM model can also be used for creating a group of carers concerned by another disease.

These presentations were followed by an outline of four other projects facilitating online peer support, as part of members' regular activities or EU research projects.
- Michael Shann, Carers UK (UK): The challenges of running an online community. Read the presentation here.
- Maria Cavalli, En Bra Plats (Sweden): En Bra Plats & Demenslotsen. Read the presentation here.
- Richard Illet, Family Care Competence Centre (Sweden): The Me-We Project. Read the presentation here.
- Sebastian Fischer, Wir Pflegen (Germany): Online Peer Support for Carers. Read the presentation here.

### How to move forward as a network regarding ICT-based solutions for carers?

This session was chaired by Kate A. Hamblin (CIRCLE, University of Sheffield, UK).
The last discussion aimed at outlining our collective policy messages and reflecting on how we would like to work together as a network in this area. Kate started by reminding participants of the key points emerging from the previous discussions:
- It is clear that ICT solutions bear great potential to support informal carers;
- However, this potential will only be unlocked if a series of challenges are overcome;
- The main challenges include the accessibility and affordability of ICT-based solutions, the lack of digital skills of informal carers, the difficulties in upscaling the many promising pilots undertaken.
- These challenges concern different policy areas (IT infrastructures, the development of eHealth, the digitalisation of our society, as well as the future of our Healthcare Systems).
- In spite of the huge variety in the levels of development of ICT-based solutions across countries, it is clear that Eurocarers' members share the above-listed expectations and challenges.

The discussion led to the following conclusions:

## Future work within the network

There is a clear need for pursing the exchanges of information and experiences within the network (in the form of a similar event, or/and a dedicated Facebook Group, webinars, with different themes which could interest a proportion of – if not all – Eurocarers members).
Concerning the CARE4DEM project, a webinar will definitively be proposed when the project outcomes are available in June 2020. It was also suggested to organise a workshop to exchange ideas with evaluation of ICT-based solutions as a focus.

## Carers should be at the core of the evaluation of ICT-based solutions

- In countries where public authorities develop portals referencing ICT-based solutions, we should analyse how the selection is done and define our own set of criteria regarding the effective participation of carers in the selection/development of these apps.
- A new project could be built around the development of a carers' expert panel across Europe, testing existing apps. Such a panel should also involve carers from countries where there are not yet represented. This project could build on the Apps4Carers project, looking at more than 400 apps, specifically addressing carers needs. It might develop a role for Eurocarers in providing a "seal of approval" for certain apps.

## Research needed

- The evidence available on the potential offered by ICTs for carers needs to be completed by longitudinal studies concerning the well-being of carers using ICT-based tools.
- Research should also explore the gain deriving from the integration of informal carers in the Health and Care system through ICT-based solutions, including not only cost reductions in the care delivery, but also the impact on the labour market and the level of productivity.

## Partnerships

- Our network should engage with the cutting-edge IT industry (i.e. Microsoft), to improve our digital competency and understand what is the upcoming developments for carers.
- We should bring it up to the strategic decision-making level at the level of the EU, engaging with 'big player' to overcome the limitation of our resources.
- We should map out what are the stakeholders and potential partners at the national, EU and international level who can help scaling up promising practices, which is now of paramount importance.
  Examples of ICT training from unexpected sources (e.g. the post office in Italy, banks in the UK offering training on avoiding online scams) invite us to explore new potential partnerships.
- It will be important to follow-up on Eurocarers application to be part of the e-Health stakeholders' group and see how we can build on this opportunity, as well as on other opportunities occurring at EU level.

## Policy asks

- Equipping informal carers is essential in view of the quickly developing digitalisation of the society, if we want to avoid informal carers to be even more excluded and make sure that they can access the potential of ICTs for improving their situation. Eurocarers could ask and promote some investments across Europe in this area.
- A short policy document could bring together our knowledge and asks in a simple way, and co-signed by other relevant organisations as a basis for common action. This approach should take into consideration the full picture of the digitalisation of society in general and care in particular, and reflect on our role in this context.

- Developing short videos can be a powerful way of conveying our message, complementary to policy documents. Companies' support can be instrumental in helping us develop communication tools and disseminate widely (see for example Carers UK's video widely disseminated in cinemas).

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*"ICT is a quickly developing area that can help us get closer to our goal". G. Lamura*

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