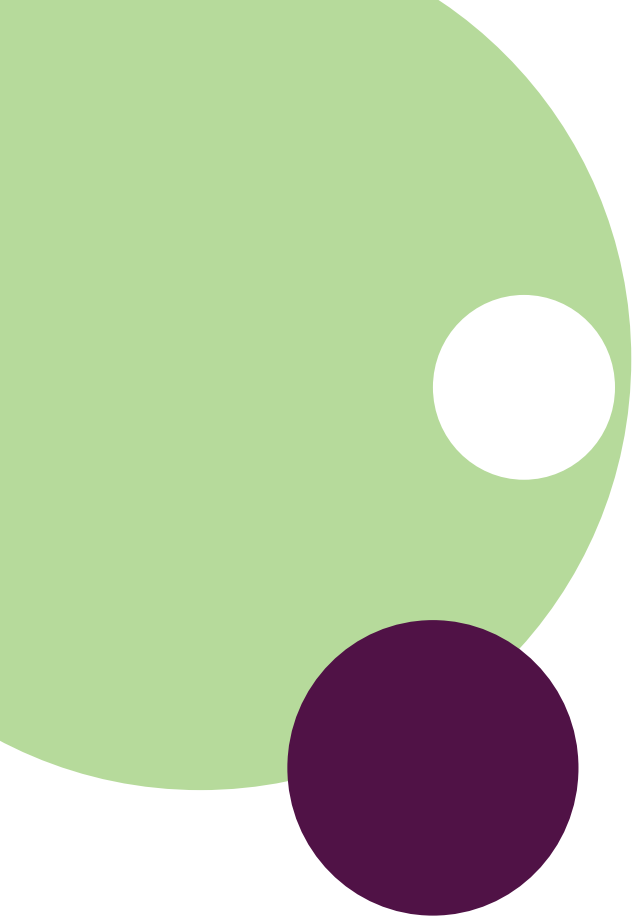


Information & Communication Technology (ICT) for informal carers

Most ICT-based solutions are proving very useful to address the needs and improve the quality of life of both informal carers and the persons they care for.

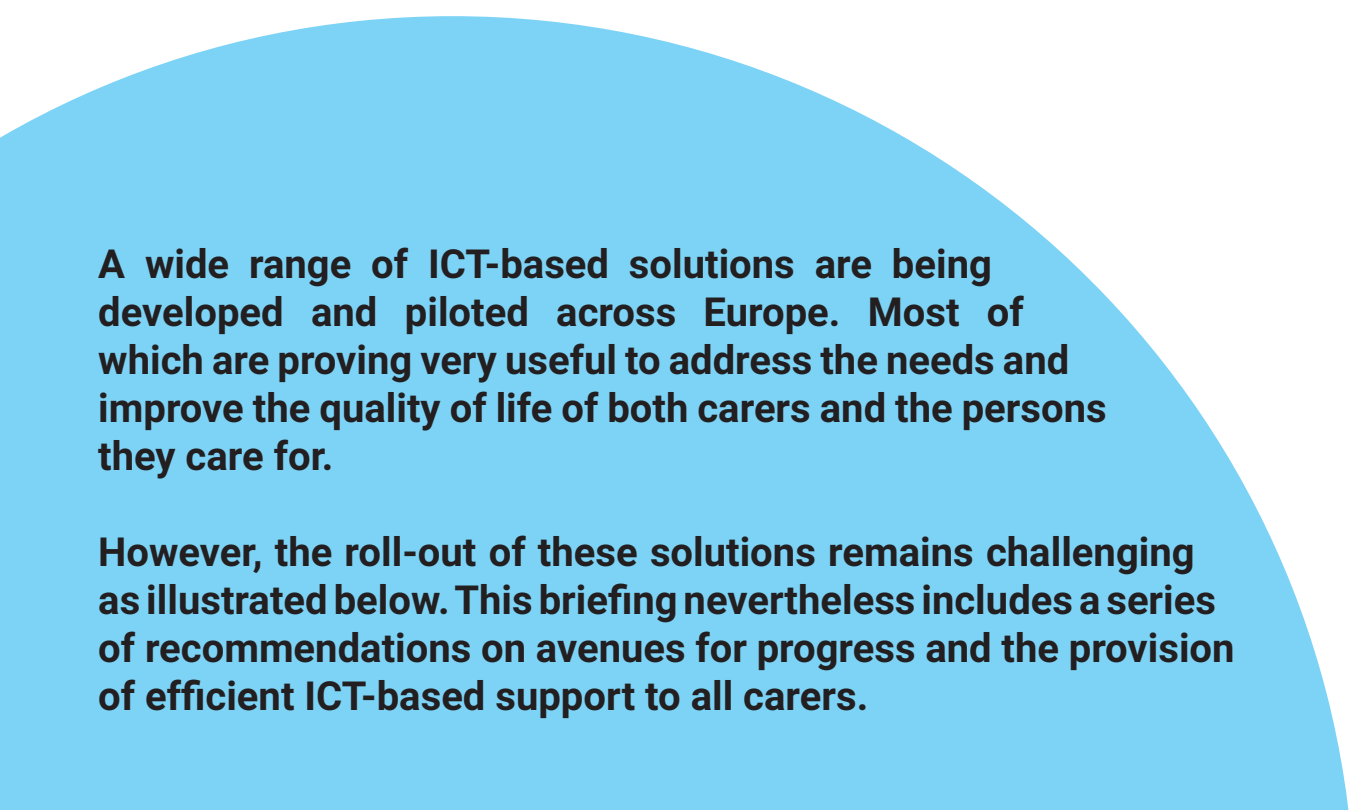


Demographic ageing in Europe leads to a growing incidence of age-related frailty and diseases, a growing demand for care and a real sustainability challenge for our social and health care systems. According to recent EU-funded research, informal carers across the EU provide over 80% of all care, with women providing approximately two thirds of care mainly as daughters (in law) and wives/partners. However, their role is poorly recognised, their needs overlooked, and they are not sufficiently supported by the formal services that are available.

Carers frequently suffer poor physical and mental health outcomes as a result of their caregiving activities, when not adequately supported. Social, psychological and educational interventions are among the best strategies for informal carers to manage the pressure of care, and get supported in their caring role. Some European governments have put in place various supports, mainly financial measures and in-kind services, to help informal carers compensate for their economic loss and to allow them to reconcile care and work. Nevertheless, these solutions seem to only partially cover their needs.

Evidence shows that informal carers have a wide range of social and care needs: recognition, psychological support, information, advice and counselling about care, caring and care-life balance, training and recognition of skills, health prevention, respite, participation in the labour market and in the community and development of their rights.

Against this backdrop, and at a time when new technologies bring transformation to our entire society, there is clear evidence of the added-value that ICT can bring to informal caring as well as to informal carers and care recipients.



A wide range of ICT-based solutions are being developed and piloted across Europe. Most of which are proving very useful to address the needs and improve the quality of life of both carers and the persons they care for.

However, the roll-out of these solutions remains challenging as illustrated below. This briefing nevertheless includes a series of recommendations on avenues for progress and the provision of efficient ICT-based support to all carers.

ICT-based solutions can provide essential support to informal carers



ICT as a pathway to information and skills development

In most cases, the relatives of a dependent person take on a caring role without any preparation, often overnight. Because they have to manage caring on top of their day-to-day responsibilities, informal carers may lack the time to consult health professionals (at least to the extent they may need to), or to attend trainings in order to gain the information and skills they require to manage their tasks in a comfortable and healthy manner. In addition to the time pressure, medical deserts in some areas as well as the lack of offers for training tailored to carers' needs generate additional obstacles for those carers who are willing to develop their competencies.

ICT-based tools can offer timely, easy and flexible access to reliable information and knowledge, concerning the needs of the dependent person as well as the support services that may be available locally. E-learning platforms designed for informal carers or adaptable to their specific needs, can also provide them with the caring competencies they need help them strengthen their transversal skills (time management, coordination, communication...) as well as their ability to maintain their own physical and mental health. Such training opportunities also open up the way for the recognition of skills already acquired on the job, through the management of a long-term conditions or a disability. Besides developing carers' self-confidence, this can reveal useful to help carers re-enter the labour market.



ICT as an instrument to foster peer-support and counter isolation

Isolation and stigma are too often painful by-products of the carer's difficulty to participate in aspects of life outside the home.

Dedicated online spaces such as forums or private groups offer new opportunities for carers to alleviate the loneliness they experience and to exchange information, good practices and advice in a relaxed and friendly environment. When organised at local level, online spaces can allow carers to identify the support available in their neighbourhood.

“The Carers UK online forum is a lifeline. It's very reassuring to know that other people feel the same and it makes you feel that you are a normal person. It's just a help to know that you're not alone” said a member of this forum.

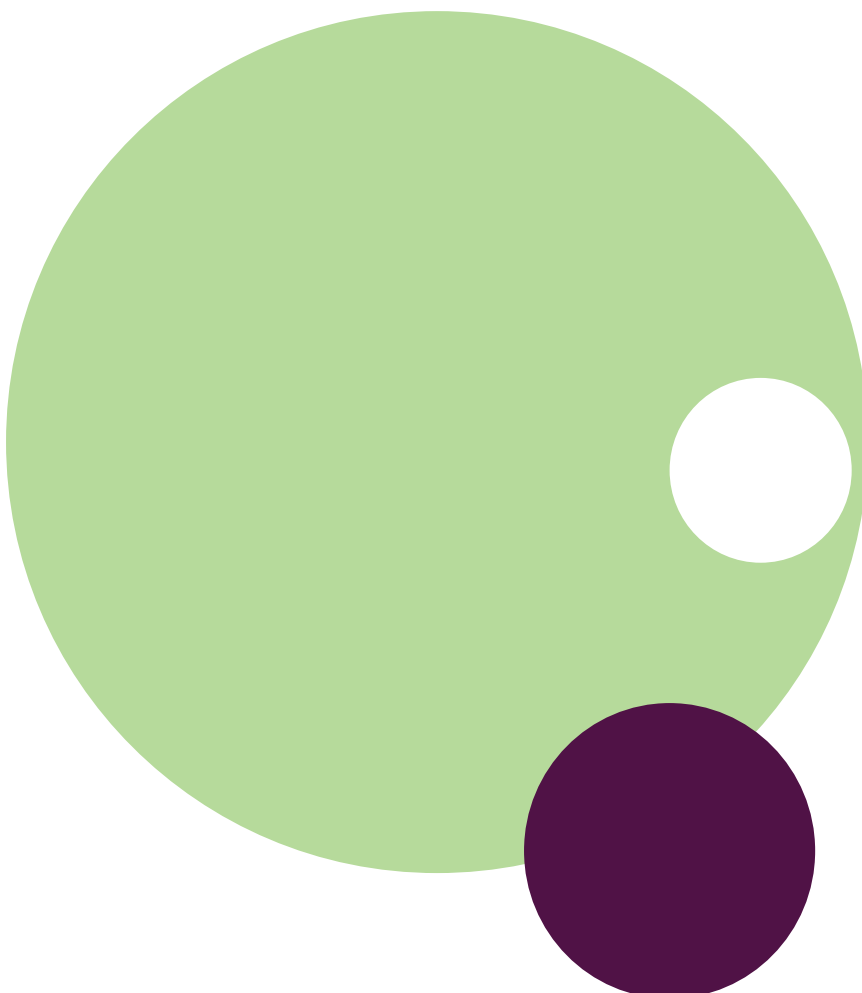
In some countries, online spaces offering peer support and relevant information about care and caring are put in place and financed by public authorities or health insurance companies, as a service offered to informal carers.

Structured peer support interventions are also proposed online, in the form of online discussions facilitated by professionals or experienced carers, and through moderated forums. As such, peer support is highly valued by informal carers, and recommended by health professionals as well as academic research. The use of ICT offers here new opportunities which have not yet been exploited to their full capacity.



ICT based solutions to support work-life balance

The vast majority of carers wish to maintain a professional life, not only because it gives them a source of income but also because it helps them preserve vital social networks, and a sense of purpose and worth. Research has indeed highlighted that the majority of working age carers are currently in employment, some part time but the majority full time. Still, flexible working arrangements are essential to allow carers to adapt their working patterns to their needs. In this regard, the “digital revolution” offers opportunities to improve work-life balance which are currently not being utilised. Technological support for working carers, such as tools to remotely monitor the safety and wellbeing of the dependent person during working hours can prove instrumental in helping carers strike a good level of work-care balance. ICT tools can therefore help carers successfully fulfil their caregiving responsibilities while protecting their professional life.



ICT-based solutions **can positively** **contribute to the shift** **towards integrated** **care systems rooted** **in the needs of care** **recipients and their** **carers.**



ICT as a tool to enable and support independent living

Technologies that allow dependent people to remain at home without continuous care support help relieving pressure on carers and support carers in their caring role. Examples of ICT for independent living include home alarm systems, telecare, tracker devices (GPS), and (gas, temperature, bed) sensors. Combined with the provision of adequate professional home care, these technologies can give more independence to older people and their informal carers, as well as easing the constant worry of the latter. Besides meeting the preferences of older people for living at home, such care arrangements can delay the entry of older people into institutional care, and reduce unplanned emergency hospital admissions and the length of hospital stays, contributing to a more efficient use of health services.



ICT as an instrument for care coordination

Online tools can also prove effective to coordinate care tasks among professional, informal and family-employed (domestic) carers, allowing therefore information sharing and respite. For example, some apps are developed, offering informal carers a platform for communication and coordination between all those providing care to the same person, a forum to exchange with other carers, and/or the possibility of arranging services online.

ICT-based solutions are not a panacea that will address all the difficulties faced by informal carers. However, there is now clear evidence of the positive impact that they can bring for the well-being of informal carers as regards:

- Carers' care and work reconciliation;
- Carers' health outcomes and social lives;
- Carers' caring skills and transversal competences (and, in turn, the quality of the care they provide);
- A more efficient use of available resources devoted to long-term care.

Besides, ICT-based solutions that satisfactorily meet the needs of informal carers can help bridge the digital gap that continues to exist in our society by demonstrating the relevance and user-friendliness of ICT, and by encouraging carers to acquire the essential digital skills that they lack.

However, while the use of ICT-based solutions targeted at patients is on the rise in the health sector, the deployment of ICT tools designed for informal carers remains marginal, despite their now-established potential in contributing to meeting the needs of Europe's main care providers, as part of a comprehensive set of tools.



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Obstacles to the wider deployment of ICT-based solutions to support carers

Despite a growing interest in the potential offered by ICT-based solutions for informal caregiving, obstacles to their development, implementation and roll-out still remain. While some initiatives are successfully implemented, the development of ICT targeted at carers is still insufficient, extremely fragmented and uneven. While the situation greatly varies from one country to another, depending on the way long-term care is organised and the degree of digitalisation, the following challenges seem to prevail across Europe.

From the side of potential users:

- The low degree of digital literacy, aggravated in some areas by the lack of access to ICT, in particular among vulnerable groups;
- Distrust in technology as well as the fear that ICT might replace other support measures;
- The lack of digital health literacy¹;
- The lack of awareness of the potential added-value of ICT-based tools, among carers and health and care professionals.

Concerning the solutions developed:

- The shortcomings in the design of the solutions, and the lack of usability of the technology used, which is not always integrated in all different devices;
- The lack of co-designed solutions focused on users' needs and demand rather than supply;
- The capacity to ensure the respect for privacy;
- The lack of specificity, as regards to the particular needs of carers, which depend very much on

a variety of factors, including the particular disease of the person they care for, the type of relationship they have with this person, the stage at which they are on the care journey...

- The fragmentation of support solutions offered;
- The lack of evaluation of innovative practices implemented on a small scale, undermining their dissemination and transferability;
- The lack of sustainability of pilot initiatives, often due to budget limitations and lack of business model.

Besides, the deployment of innovative ICT-based solutions for carers requires enabling conditions which are often not fulfilled:

- Synergies remain to be developed between relevant research on ICT-based solutions for carers and potential providers of ICT-based solutions in the industry sector;
- ICT-based solutions involving carers as partners in care are efficient only if embedded in integrated long-term care provision systems centred around the needs of users;
- At a societal level, the lack of recognition of the role of informal carers as co-providers of care and also as a vulnerable group with specific needs hinders the development of relevant measures addressing their situation.

1- Digital health literacy is "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to preventing, addressing or solving a health problem". Definition adapted from WHO https://www.who.int/global-coordination-mechanism/working-groups/digital_hl.pdf

How to move forward?

Eurocarers, building on the collective knowledge of its members, as well as on the learning of the various innovative projects exploring the potentialities of ICTs for carers, recommends the following actions, to be implemented in the framework of comprehensive strategies for carer-friendly societies:

- **Research should be further developed** to consider aspects which haven't been covered sufficiently, notably the well-being of carers supported by ICTs in the long-term, the gain deriving from the integration of informal care in the care team through ICT, for the health and care system and for the society as a whole. So far, the analysis of the benefits of ICT-based services has been mainly focused on their impact at the level of users themselves but the effects of ICTs for carers at the organisational and system levels are scarcely documented.
- **Carers should be more systematically involved** in the design, development, testing and evaluation of ICT-based solutions which concern them. Designers of ICT-based solutions for informal carers should follow a participatory design approach aiming at addressing the variety of carers' profile and needs. In particular, they should involve older informal carers in the design process as much as possible, as opposed to simply testing with younger demographics. Technology solutions that are user-friendly for younger adults may not be user-friendly for older users.
- Actions to **build informal carers' digital skills early in the caregiving process** are important for optimal use of available ICT-based support solutions. Training and technical support for informal carers should be offered throughout the care journey.
- ICT-based support solutions should provide **dynamic, flexible, and customizable content** based on a structure that favours interaction with professionals and peers, such as online community support. Feedback loops should be integrated in the different solutions to improve tailoring and allow the content to be adaptive to changing needs over time.
- ICT-based solutions should be proposed as part of **a comprehensive set of tools for carers**, including notably information and counselling, training, respite care, financial support and measures supporting work-life balance.
- **Large partnerships** gathering all stakeholders involved (including the industry, public decision makers, carers' organisations, health and care services providers...) need to be put in place in order to address the complex challenges attached to the deployment of ICT-based solutions including carers.

ICT-based services for informal carers tend to be beneficial for their end-users, as well as for governments as they can generate a more efficient use of services and more sustainable social protection systems. Research shows that ICT-enabled services save carers' time and money, increase their wellbeing and self-esteem, help link them with others and with the health-care team, and empower them, thus developing their problem-solving ability, perceptions of self-efficacy and care skills. This should help convince stakeholders of the need to recognise the role of informal carers within long-term care service provision, as well as to deploy accessible and qualitative ICT-based services for their support.



EURO CARERS

European Association **Working for Carers**

Learn about Eurocarers' projects exploring ICT-based support for carers here:
<https://eurocarers.org/projects/>

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