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Eurocarers' Position Paper

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Information & Communication Technology (ICT)

for informal carers

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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.

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 for whom they care.

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.

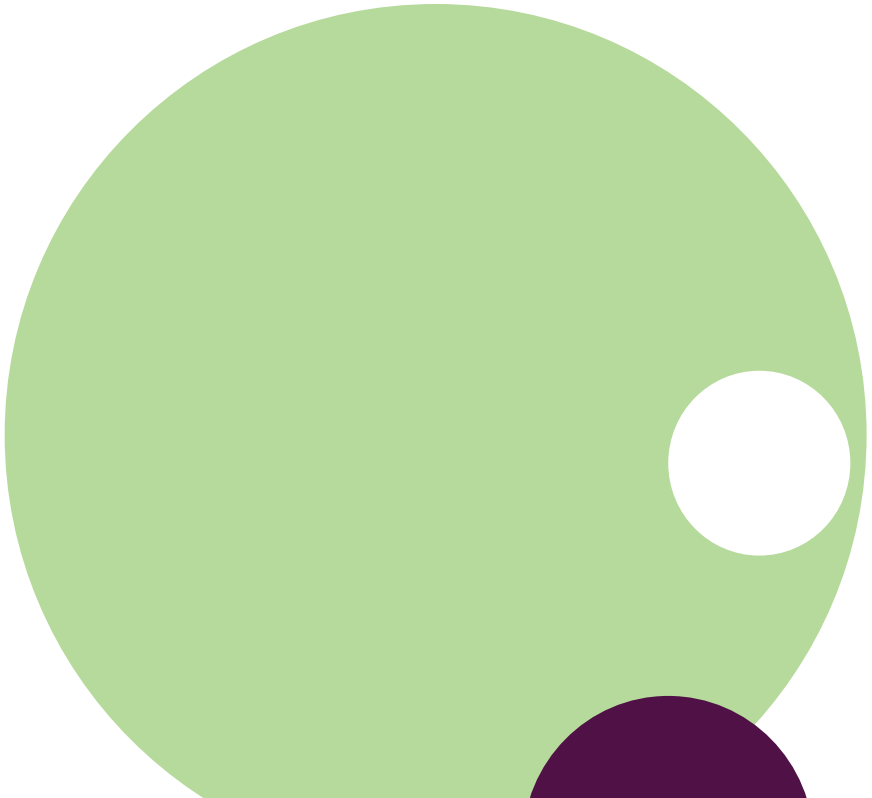
"The Carers UK online forum is a lifeline. It's very reassuring to know that other people feel the same and it makes you feel that you are a normal person. It's just a help to know that you're not alone" said a member of this forum.

In some countries, online spaces offering peer sup- port 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 pro- posed 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 success- fully 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 plat- form 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.

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 dis- ease 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, of- ten 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.

Carers' willingness to pay for ICT-based support services

For ICT-based support services to become part of care systems, it is necessary to understand their affordability and perceived value by carers. Willingness to pay for ICT is one of the major components of the consumer-based cost benefit analysis and it is directly influenced with carers' demographic, socio-economic and caring circumstances. Indeed, gender, relationship to the care recipient, duration of the care bout, total household income as well as the monthly amount spent on professional care service are all factors that may influence carers' willingness to pay for ICT. These may also include consumers' attitudes about who is actually responsible for the payment. In healthcare, consumers may feel that digital health technologies are entitlements and that, consequently, the government - not the individual – is the appropriate payer.

The following section seeks to shed light on some of the factors driving carers' willingness to pay for ICT-based support services:

Caring experience:

Research shows that carers' willingness to pay for digital support services is shaped by their caring experience. For instance, care duration is a strong predictor as carers who have provided care for two years or less are more likely to be willing to pay for digital support services compared to those at a later stage of their care journey. Evidence from literature suggests that carers are open to incorporating technology into their care routine. Nevertheless, digital support services must be offered early in the caregiving process and their support function should be adaptable over the course of the caring trajectory.

Total household income:

Total household income is also a significant predictor of carers' willingness to pay for ICT. Informal carers from lower socioeconomic backgrounds may be less able to afford digital support solutions, which may lead to inequalities. The literature highlights a potential social justice issue in cases where ICT-based solutions are not valued by governments and pricing policies are based on the user-pays principle – i.e. it is up to consumers to pay the full cost of the goods that they consume. This essentially limits the accessibility of solutions to those who can afford to pay only.

Monthly amount spent on professional care services:

Evidence shows that the more carers spend on professional care services, the more they are likely to be willing to pay for ICT-based support. However, they may not be able to afford a high amount without government subsidies and research demonstrates that carers expect governments to allocate more funds to ICT based support services and the enhancement of digital infrastructures.

Other factors influencing carers' willingness to pay for ICT

Recommendation by healthcare professionals and/or carer organisations

Research highlights that the recommendations of healthcare professionals and carers' organisations increase carers' willingness to pay for digital support services. This suggests that the interaction between healthcare professionals, informal carers and other parties with an interest in supporting them (e.g. carer advocacy organisations) is an integral part of the value chain that underpins the communication and coordination of services. All of these parties should be more actively engaged in the design and assessment of digital support services targeted at informal carers.

Availability of data protection measures

Informal carers show concerns regarding data ownership and privacy. ICT solutions with clear security authentication measures such as passwords, strong encryption mechanisms and informative privacy policies are more likely to draw the interest of carers.

Factors influencing carers' use of ICT

The use of ICT by informal carers may be influenced by their demographics, socioeconomic resources and caring circumstances. Consequently, mapping the profiles of those informal carers who use (or not) ICT-based support can help to improve the quality of these services. Research shows that carers' age, gender, health status, educational attainment, weekly hours of care, relationship with the care recipient as well as the care recipient's gender, age, level of dependency and total household income all have an impact on carers' usage of ICT.

The following section sheds light on some of these influential factors:

Age

Evidence shows that age is an important predictor of carers' use of ICT. Research indeed demonstrates that the use of Internet to access health information is relatively common across age groups, up to the age of 65 where frequency of use begins to decrease. However, age is not the only predictor of use. Therefore, should the ageing of current – more ICT-proficient - generations contribute to bridging the digital divide, other socio-economic inequalities will need to be addressed to maximise the potential offered by ICT-based solutions.

Gender

Women play a central role in the provision of informal care. Evidence shows that they are also more likely to seek health information online than men.

Caring experience

Patterns of ICT use are naturally driven by the caregiving experience. The number of weekly hours of care is indeed a key factor as high-intensity carers tend to report higher levels of information and service needs. In turn, these carers are more likely to perform frequent Internet searches. Moreover, while carers still consider health and social care professionals as the main source of information, direct contact with them may be limited. As a result, high-intensity carers may turn to the Internet for online support services given their availability and convenience.

Education

Carers' education level is also linked to the frequency of their online activities. Evidence indeed shows that better-educated carers are more likely to get engaged in more frequent online activities.

Income

While literature suggests that a frequent use of the internet for general purposes is more likely in higher-income households, carers from lower-income households may turn to the internet as a source of support and assistance whereas carers from higher incomes may have access to other means of support.

Digital divide in the EU and carers' use of ICT

While the use of internet to access health information has been somewhat less common in Southern European countries, carers' use of ICT-based support is increasing in the region. Southern European countries are still characterised by family-based care systems and carers often have limited access to the support of care professionals and to training opportunities. These shortcomings may increase their need for information and services. Digital support services can therefore prove a suitable alternative to give carers remote access to information and training about care and caring-related issues. Yet, the digital divide may hinder carers' use of ICT and the socioeconomic status of users seems to be a significant driver of the remaining digital divide (even more so in Southern European countries when comparing with Northern countries). Socioeconomic inequalities thus need to be addressed in order to address the digital divide and support carers' use of ICT.

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 sup- ported 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 de- sign approach aiming at addressing the variety of carers' profile and needs. In particular, they should involve older informal carers in the de- sign 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 old- er 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 in- formal 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.

- **Addressing socio-economic inequalities** is likely to be key to reduce the digital divide in carers' use of ICT. Care professionals and other parties with an interest in supporting carers should also pay particular attention to those carers who are older and less educated given the influence of age and education on the digital divide. Access to computers and internet connections at public facilities, such as local libraries, community and senior centres should be provided with extra support to accommodate carers' information needs and overcome any barriers to use.

- Informal carers form a group of people for whom time is very precious, hence they prefer **simple and easy-to-operate technologies**. ICT solutions should therefore be integrated in different devices and not only be web-based. Web platforms should be optimized for use on devices other than computers (e.g. tablets and smartphones) to provide handy information to carers who report both higher levels of information/service need and higher intensity levels of caregiving.

- **Policy makers, care professionals and stakeholders with an interest in supporting informal carers all have a role to play** in the identification of carers' preferences and in the design of ICT-based interventions that can help meet them, in consultation with carers. There is no 'one size fits all' approach in the realms of policy and practice targeted at carers. However, it is important to consider the specific characteristics and needs of both carers and care recipients.

The care sector is undergoing a fast transformation and expansion also due to the direct and indirect effects of the COVID-19 pandemic. Health and social care delivery systems experience a technologically-supported transition towards home care. 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 healthcare 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.

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

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