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Can Technology-based Services support Long-term Care Challenges in Home Care?

Analysis of Evidence from Social Innovation Good Practices across the EU: CARICT Project Summary Report

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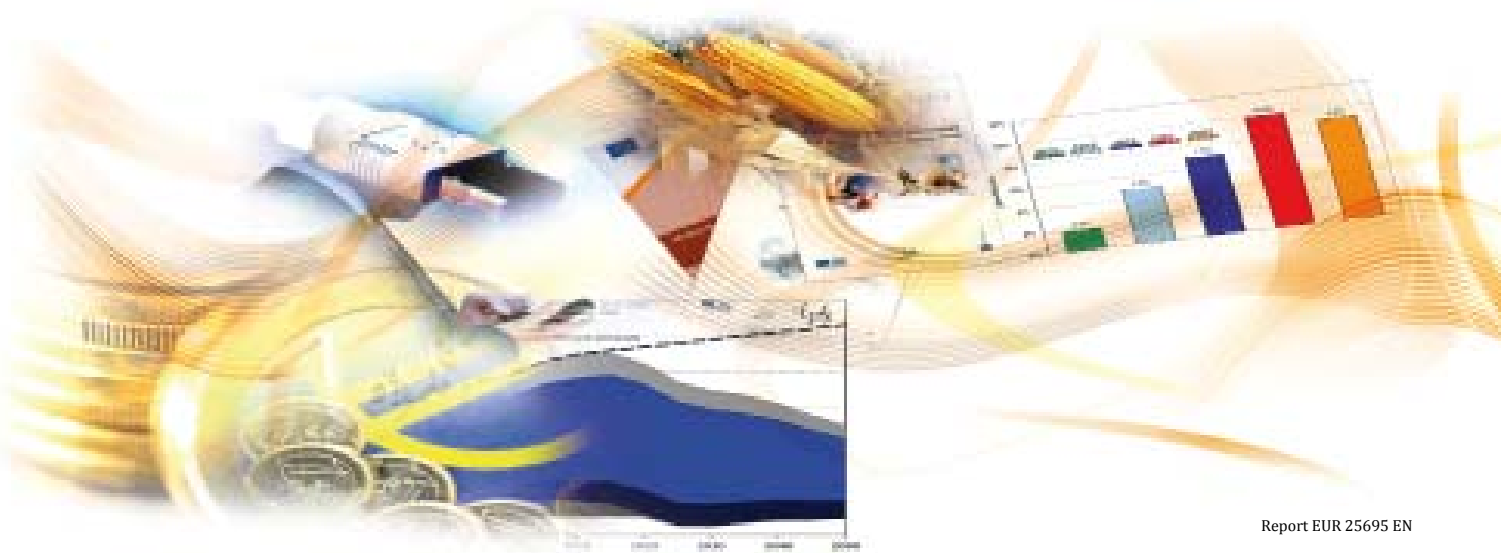

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PREFACE

In 2008, we (JRC-IPTS[1]), in a project co-funded by DG CNECT,[2] highlighted the opportunities offered by ICTs for long-term care of elderly people, and for the first time for informal carers. We showed that ICTs for can help informal carers with their care tasks and improve the quality of care they give and their own wellbeing. Nevertheless, we also concluded that this potential is currently largely untapped, and that research is needed to obtain evidence-based results on impact, scalability and sustainable business models of ICT-enabled care services.

In 2010, DG CNECT asked us to contribute to the i2010 e-Inclusion policy, which was later revised under Chapter 6[3] of the Digital Agenda for Europe (DAE). For this purpose, we signed an agreement in May 2010[4] with DG CNECT, to study the role played by information and communication technologies (ICTs) in the activities of social inclusion actors in an ageing society. We approached this need for research on the evidence-based results for ICTs for informal carers, and we carried out a study entitled 'ICT for caregivers and other social actors: enhancing the sustainability of long-term care and social support' (CARICT) in 2011.

CARICT aimed to find out to what extent ICT-based services for informal carers exist in European countries, their impact and the policy support needed to develop and implement them. These data would allow us to understand whether these services help to create motivated and skilled domiciliary carers, and whether they have an impact on the quality of life of the elderly and carers, and on the quality and efficiency of the care supplied. The study was carried out by a group of experts on ageing, long-term care and informal care, led by the European Centre for Social Welfare Policy and Research (the contractor) and IPTS, through the following activities:

1. The systematic mapping of the most relevant ICT-based initiatives in Europe to support informal carers of older people living in the community. The results of this mapping can be found in the *deliverable '2.3: Analysis and Mapping of 52 ICT-based initiatives for caregivers'*:

   http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/CARICTD2.3Mappingof52initiatives.pdf and

2. A cross-analysis of 12 selected good practices to better understand the impact and the success factors of these services. This analysis is available at the following link for the *deliverable '4.3: Final report containing case-by-case detailed description and analysis of selected 12 good practices:'*

   http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/D4.3FinalreportAnalysisof12goodpractices.pdf

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[1] The Institute for Prospective Technological Studies (IPTS) is one of 7 research institutes that form part of the European Commission's Joint Research Centre (JRC).

[2] Directorate General for Communications Networks, Content and Technology

[3] 'Enhancing digital literacy, skills and inclusion'

[4] This project summary report is framed in the administrative arrangement 'E-Inclusion Strategic Support 2020 –II', contact number – 151969-2010 A08-AT -, as the deliverable *'D2.2.3. Good Practices analysis. Final Report, of the study on 'ICT for caregivers and other social actors: enhancing the sustainability of long-term care and social support'*.

Fundamental to these two activities was the building of an impact assessment methodology (IAM) prototype for evaluating the multidimensional effects of ICT-enabled services in home care. This methodology explores and judges the range and quality of impact evidence available and can be found at the following link for the deliverable *'3.6: Final report on the 'Methodological Framework'*:

(http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/D3.6FinalreportontheMethodologicalFramework.pdf).

In addition, the project ran two expert workshops in June and November 2011. The workshops' minutes with recommendations are summarised in the following reports:

- *´Deliverable 3.4 Minutes of the Expert's Workshop with a set of 'Expert's recommendations for the Methodological Framework'* for the first workshop (http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/D3.4MinutesoftheExpertValidationWorkshop.pdf).
- *'Deliverable 5.2: Minutes of the Policy Makers' and Experts' Workshop identifying the Recommendations to be taken into account for WP3 and WP5'* (http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/D5.2MinutesofthePolicyMakersandExpertsWorkshop.pdf).

All information on CARICT, and this and the other reports are available at: http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/carers.html

TABLE OF CONTENTS

EXECUTIVE SUMMARY

Informal carers are assuming between 50 to 90% of the responsibility for the long-term care of elderly dependent people. However, their role is poorly recognised, their needs are unknown, and they have little access to the available formal services. Social, psychological and educational interventions are among the best strategies for informal carers to manage the pressure of care (Pearlin, Turner and Semple, 1989; Pearlin et al., 1990; Pearlin, 1991; Aneshensel et al., 1995; Pearlin and Skaff, 1995; Gaugler et al., 1999; Zarit, 2002). In this context, new services enabled by information and communication technologies (ICTs) could support individuals more effectively and efficiently than traditional services.

The Digital Agenda for Europe and the European Innovation Partnership on Healthy and Active Ageing highlight the need to empower and socially include informal carers through ICTs. Other European policies also emphasise the role ICTs can play in giving carers digital skills and information on how to care for the elderly. These policies are the 'Voluntary European Quality Framework of Social Services', the flagship "New Skills for New Jobs", the 'European Platform against Poverty and Social Exclusion', and the 2008 Communication on Long-term Care.

This project summary report presents the findings of the CARICT study ('ICT for caregivers and other social actors: enhancing the sustainability of long-term care and social support'), co-financed by DG CNECT and JRC –IPTS of the European Commission, and carried out in 2011. These evidence-based results show the benefits that ICT-enabled domiciliary care services can bring to the lives and health of elderly people and their informal carers, and to other care services and systems. The results can be used as the basis for policy recommendations on how to develop and to better scale, replicate and transfer them in the European Union (EU).

To obtain these results, we mapped and analysed ICT-based services for informal carers developed in Europe. In addition, we cross-analysed the impacts, drivers, business models, success factors and challenges of 12 of these services. In this cross analysis, we developed a prototype impact-assessment methodology to identify the impacts of these services.

A first analysis of 52 ICT-based initiatives for carers pointed to the existence of a wide range of successful ICT-based services for carers across Europe. The more specific cross analysis of 12 of these initiatives indicated that:

- *ICT–based services for informal carers can positively impact on:*
  - The quality of life of the informal carers, helping them to reconcile care and work, and improving their social lives and health conditions.
  - The quality of life of care recipients, improving their health-related quality of life and their social lives.
  - The quality of care provided by informal carers and privately-paid assistants, improving their knowledge of care, skills and competences.
  - The cost of care for end-users, generating savings compared with ordinary services.
  - The acceptability and accessibility of ICTs, in terms of people's greater willingness to use ICT and their satisfaction with it, their acquisition of digital competences, and their wider use of ICT materials.

  Improvements to the quality of life of care recipients could affect the efficiency of social care and health care services. Better quality of life delayed the entry of old people into institutional care, and reduced unplanned hospital admissions and the length

of hospital stays. These reductions in the use of services could generate savings for the health and social care systems.

ICTs for independent living are probably the best-assessed services, since they have been running for a while, whereas the ones specifically for carers have been developed more recently in the European context.

- *The main drivers that motivate actors to develop and implement these services are:*
  - The desire of professionals and older people's families to improve the quality of care and quality of life of older people.
  - The wish to empower and help carers.
  - The search to improve the efficiency and effectiveness in social and health care.
  - The need to realise systematic cost savings.
- *The services operate in a range of different business models,* which partly depend on the perspective of each actor involved. In many cases, an operating company supplies services to a care-providing organisation, which uses the services to provide care to families, financed by a mix of payments from individuals, insurance and public funds. In some cases, many more actors are involved, playing different roles, with different sources of funding.
- *Key success factors to develop, implement and transfer ICT-based services for informal care are:*
  - The involvement of end-users (carers, elderly people and formal care staff) as active players in the design of the services, complemented by training in digital and care services competences.
  - The progressive integration of ICT-based service for informal carers in the formal long-term care system, contributing to the value chain for the provision of care services, empowering formal and informal carers and elderly people as active and cooperative actors.
  - The cooperation between stakeholders, amongst which non-profit organisations (third sector) play a relevant role.
  - The formation of new value chains to provide care, where different kinds of stakeholders act as intermediaries in the delivery of ICT-based services for informal carers.
  - The exploitation of the existing ICT and digital inclusion infrastructure.
  - The development of policies at different functions at multiple levels.
  - The policy role is central for the successful transferability of the service.
- *The main challenges to the development, implementation and transfer of ICT-based services for informal care are:*
  - Technology-specific issues that refer to the need to demonstrate the value of ICT to provide long-term care, the acquisition of digital competences and skills, access to and use of technological infrastructures, and the fact that ICT supposes new forms of organisation of long-term care services, challenging local care organisations (as the main providers of social care).
  - Difficulties associated with the recognition of the role of informal carers in the formal long-term care system as co-providers of care, and also as a group with needs.
  - Overcoming the scepticism, negative attitudes and lack of knowledge about the use of these types of services in long-term care.

- Providing convincing scientific evidence that the service actually helped older people and their family carers and was cost efficient.
- Creating an efficient business model.
- Deploying the initiatives, due to their small scale.

The 12 cases demonstrate that policy leadership to put in place the right combination of complementary existing support and funding programmes for stakeholders is at the heart of the policy recommendations to develop, implement and scale these services. Policy makers looking at policy options using ICT-based services for domiciliary care should consider:

- Promoting cooperation between different kinds of stakeholders, highlighting the importance of cooperation between the informal and formal sectors, and recognising the role of the third sector and volunteers in the delivery chain of long-term care.
- Ensuring the involvement of end-users in the different stages of service development, through continuous research, experimentation and innovation.
- Raising awareness of the opportunities provided by ICT-based services for informal carers among all stakeholders, including policy makers, professionals and carers and care recipients.
- Promoting the exchange of good practices, the collection of evidence and the transferability of optimal solutions to other localities, regions and countries, to encourage the use of existing effective solutions in the EU.
- Sustaining a European market of ICT-based services for informal carers and elderly people.
- Promoting digital inclusion policies.
- Continuing to allocate public funding to initiatives to ensure their development, sustainability and transferability.

These findings contribute to the achievement of the objectives of policies defined in the 2020 Strategy, and more specifically in the Digital Agenda for Europe (DAE) and the European Innovation Partnership on Healthy and Active Ageing (EIP AHA). In line with the aim of the EIP AHA to contribute to the challenge of innovation in the healthcare value chain and the field of active and healthy ageing, this study has demonstrated that ICT-based services for domiciliary care delivered at home benefit the quality of life of older people and carers, improve access to qualified long-term care, and integrate health and social care services better. Moreover, they empower carers, thus ensuring suitable informal long-term care, and generate direct savings, contributing to the sustainability of the system.

We have found that the success of these innovative services depends on cooperation between stakeholders, the involvement of the third sector, the empowerment and strong involvement and proactivity of end-users, creating new value chains in the delivery of long-term care, under a policy umbrella. The CARICT project also analyses 52 successful, not very costly and beneficial ICT-based services for informal care that provide evidence that innovative services can help address a range of carers' needs. In addition, the use of these technological services is helping to develop digital and care competences for informal carers. This sustains the aims of the DAE and other European Commission policy initiatives such as: the 'Agenda for new skills and jobs', the voluntary European Framework of social

services (suitable skills for volunteers and informal carers), and the European Platform against Poverty and Social Exclusion (ICT to enhance employability and life opportunities).

To conclude, these data therefore confirm that, in the European context, effective ICT-based services exist, and that policy at European, national, regional and local levels can promote their successful development, implementation and transferability. This can be achieved by means of funding and regulation and by promoting stronger cooperation between stakeholders including end-users, informal carers, and the third sector, to create a new value chain in the provision of long-term care.

1. INTRODUCTION

This project summary report presents evidence-based results on the potential of ICT-enabled domiciliary care services to improve the lives and health of elderly people and of their informal carers. The report also looks at the impact of these services on other services and care systems. The final goal is to make policy recommendations as to how they could be developed, and how their scalability, replicability and transferability could be improved in the European Union (EU).

These results emerged from the study on 'ICT for caregivers and other social actors: enhancing the sustainability of long-term care and social support' (CARICT). This research project was conducted in 2011 and co-funded by the Directorate General for Communications Networks, Content and Technology (DG CNECT) and the Institute for Prospective and Technological Studies of the Joint Research Centre (JRC-IPTS) of the European Commission.

The report has six sections:

This first section describes the background to this report and its structure.

Section 2 justifies the relevance of the research topic. It gives an overview of the challenge of the increasing number of people in need of long-term care in Europe, and the burden that this represents for policy makers and the families.

Section 3 gives an overview of current state-of-the-art, describing the reasons for carrying out the CARICT project, the policy options proposed and the future scenarios illustrated.

Section 4 presents the main findings of the research:

- The existing ICT-based services for informal carers.
- The selection of the 12 most appropriate and representative initiatives.
- The results of the cross-analysis of the impact of the 12 good practices: the findings as regards the benefits of using these services, the drivers that motivate their development, how they are implemented (business models), what produces positive impacts (success factors), and what are the challenges to implementation.
- Key policy recommendations to draw future options for policy makers to ensure a wider and more efficient use of ICT in the field of home care.
- Four future scenarios to illustrate how the provision of domiciliary care can be enhanced through ICT-based services. These scenarios contain examples of how the quality of care and life of elderly people and carers could be improved if policies for these services are put in place.

Section 5 details the contribution of the CARICT findings to the European policy framework.

Section 6 offers the conclusion of the study.

2. LONG-TERM CARE AND INFORMAL CARE

The increasing need for care of elderly people in the European Union (EU) is a challenge for the Member States. They are committed through the Open Method of Coordination to introducing reforms to ensure accessible and qualified long-term care (LTC) services, maintaining the sustainability of the care systems. Informal carers are a relevant group involved in the daily care of older people. They are relatives, friends and neighbours who give hours of care for free during long periods of time, many hours a day. In some cases, they are helped or even substituted by care assistants, privately-employed by the same households.

In this section, the relevance of challenges related to care for an old person at the present time and in the near future, due to the increasing number of very old people affected by limitation in their daily activities, is explained. Formal services are not enough to attend to the increasing number of older people in need of social and health care, and the investment in multiplying their availability is not sustainable for European governments. Meanwhile, the family and close informal circles are filling the gap left by formal services. Most of them are overwhelmed by the care task and report mental and physical problems, which have a negative impact on their work, economic and social lives. Poor attention has been paid to informal carers and there is little recognition of them as people in need of care and services. As a result, the opportunity that they offer as allies in the provision of long-term care has been lost.

To illustrate this vision, we give an introductory overview of what long-term care is. This includes the factors and data that justify the need for actions due to the increased call for long-term care, the predominant role of families and relatives in its provision, and the lack of services to attend their needs, which often gives rise to the creation of a black market of migrant workers hired by the households to assume their role.

2.1. Definition of long–term care

Long-term care (LTC) is not an easy concept to define in the European Union where different definitions coexist. This is generally due to the fact that each Member State's long-term care system is unique in terms of the services and benefits it offers (European Commission, 2008). Despite these differences, several concepts such as the goals, type of care and services, care recipients, place of care provisions and care providers can help us to reach a working definition (Carretero et al., 2006):

- The goal of LTC is to ensure that an individual who is not fully capable of long-term self care can maintain the best possible quality of life, with the greatest degree of independence, autonomy, participation, personal fulfilment, and dignity. Appropriate long-term care therefore includes respect for that individual's values, preferences and needs (WHO, 2000).
- The care is provided over a prolonged period of time and this refers typically to help with the basic activities of daily living (ADLs), which include bathing, dressing, and getting in and out of bed (Colombo et al., 2011). Instrumental activities (IADLs) refer to household chores like meal preparation and cleaning; life management such as shopping, money management, and medication; and transportation (Stone, 2000).

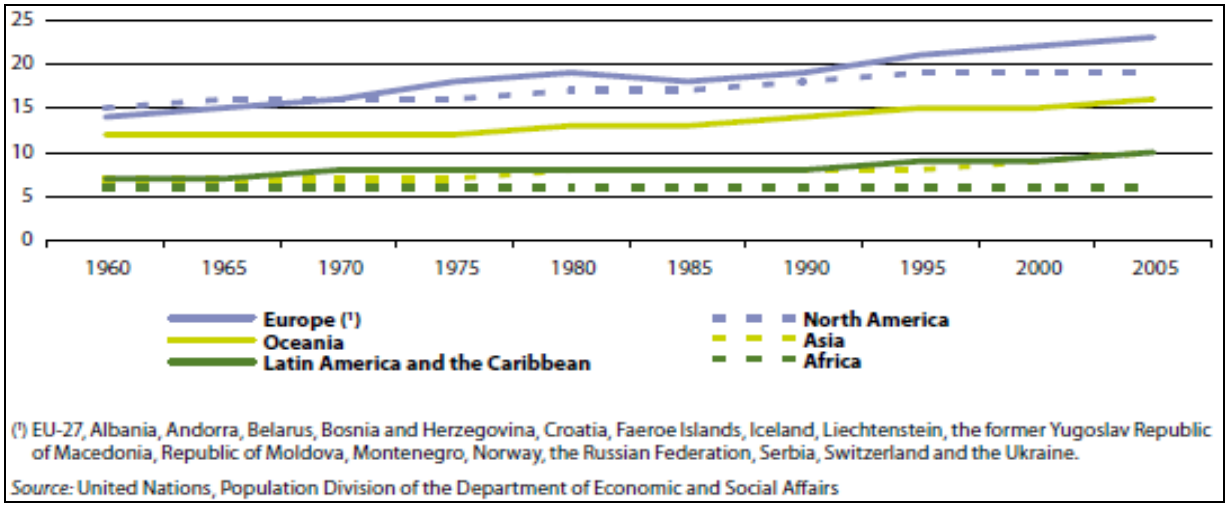
- LTC is organised and delivered as a broad range of services and assistance, in which care is usually provided as an integrated programme, positioned between the health and social sectors as it has components from both sectors (OECD, 2005, 2008). The services include hands-on and stand-by or supervisory human assistance; rehabilitation, basic medical services, home nursing, social care; assistive devices such as canes and walkers; and technology such as computerized medication reminders and emergency alert systems that warn family members and others when an elderly person with a disability fails to respond. They also include home modifications like the installation of ramps, grab bars and door handles that are easy to use (Stone, 2000; European Commission, 2008).
- The LTC services may be provided in a variety of settings, including institutions or homes (OECD, 2008).
- LTC is usually provided to people with physical or mental handicaps and the frail elderly, particularly those who need help in the activities of their daily lives (European Commission, 2008).
- LTC can be provided by formal and informal carers, who are often family members, friends and lower-skilled carers or nurses (Colombo et al., 2011).

2.2. The increasing demand for long-term care in Europe

The increasing needs for long-term care is mainly explained by the demographic and epidemiologic transitions experienced in the European countries (WHO, 2002).

Europe is currently the area of the world where ageing is most evident. In fact, the old age dependency ratio (i.e. the ratio between those over 65 years old and those of working age, i.e. 15-64) is the highest in the world - Figure 1- (Eurostat, 2010).

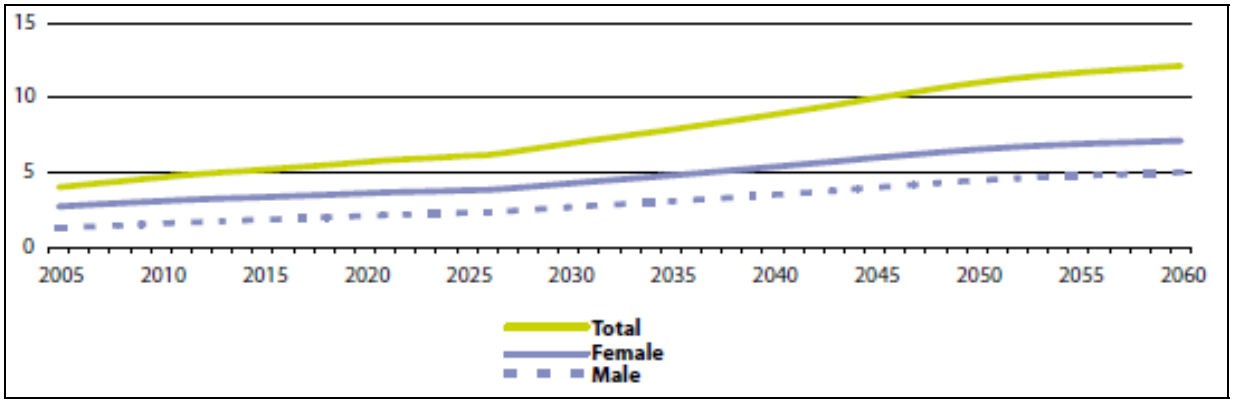
Figure 1: Old-age dependency ratio (%)



Source: Eurostat, 2010.

It is expected that this trend will continue and even intensify over the next few decades (Figure 2), as improved life expectancy will mean that the segment of those aged 80 and older will be the fastest growing of the population (Eurostat, 2010).

Figure 2: Proportion of population aged 80 or more, EU-27 (% of total population)



Source: Eurostat, 2010.

At epidemiological level, increased life expectancy has been accompanied by an increase in chronic diseases. These diseases are not associated with mortality but with limitation in daily life activities, they increase with old age, and are present in multiple and co-morbid pathologies (WHO, 2002). As we can see in Table 1, the percentage of people who perceive themselves to be severely hampered when carrying out the activities of daily life due a health problem is higher in older groups. People over 85 years old and women are the most affected.

Table 1: Self-perceived limitations in daily activities (activity restriction for at least the past 6 months) by sex and age (%) [hlth_silc_07]

	SEVERELY HAMPERED					HAMPERED TO SOME EXTENT				
TOTAL										
AGE	2005	2006	2007	2008	2009	2005	2006	2007	2008	2009
From 15 to 24 years	1,4	1,4	1,4	1,5	1,6	5,5	5,0	5,1	5,2	5,6
From 25 to 34 years	2,3	2,5	2,3	2,3	2,2	7,8	7,4	7,3	7,0	7,5
From 35 to 44 years	3,9	3,8	3,8	3,8	3,9	11,4	11,0	10,8	10,8	10,9
From 45 to 54 years	6,8	7,1	6,9	6,9	6,6	16,0	16,1	15,7	16,3	16,5
From 55 to 64 years	10,4	10,1	10,0	10,9	10,6	23,1	23,0	22,8	23,5	24,1
From 65 to 74 years	14,0	14,3	14,2	14,6	14,7	31,2	30,5	29,8	31,5	32,1
From 75 to 84 years	22,7	23,5	23,8	25,0	25,0	35,8	35,6	35,0	37,1	37,1
85 years or over	36,1	38,3	37,2	39,5	37,6	32,6	31,2	31,4	34,4	35,6
Total	7,7	7,8	7,8	8,1	8,1	16,7	16,4	16,2	16,8	17,4
MEN										
AGE	2005	2006	2007	2008	2009	2005	2006	2007	2008	2009
From 15 to 24 years	1,5	1,4	1,5	1,5	1,7	5,1	4,5	4,4	4,6	5,0
From 25 to 34 years	2,4	2,4	2,4	2,5	2,4	7,4	6,7	6,5	6,7	6,9
From 35 to 44 years	3,8	3,5	3,6	4,0	4,1	10,7	9,9	10,0	9,8	9,7
From 45 to 54 years	6,7	6,8	6,8	6,9	6,4	14,7	14,6	14,1	15,1	15,1
From 55 to 64 years	10,5	10,1	10,1	11,4	11,0	21,6	20,7	21,2	22,0	22,1
From 65 to 74 years	13,0	13,4	13,0	14,0	13,9	29,6	27,9	27,3	28,7	29,9
From 75 to 84 years	20,3	21,2	21,3	22,7	23,0	34,4	33,7	33,7	36,3	34,1
85 years or over	30,9	32,6	32,1	35,2	33,2	32,6	32,7	32,4	34,9	35,8
Total	6,9	6,9	6,9	7,5	7,5	15,2	14,4	14,3	15,1	15,4
WOMEN										
AGE	2005	2006	2007	2008	2009	2005	2006	2007	2008	2009
From 15 to 24 years	1,2	1,3	1,3	1,5	1,4	5,8	5,7	5,8	5,8	6,1
From 25 to 34 years	2,3	2,6	2,3	2,2	2,0	8,3	8,0	8,1	7,3	8,0
From 35 to 44 years	3,9	4,0	4,1	3,5	3,6	12,0	12,0	11,6	11,8	12,0
From 45 to 54 years	6,9	7,5	7,0	6,9	6,8	17,2	17,6	17,3	17,4	17,9
From 55 to 64 years	10,3	10,0	9,9	10,4	10,2	24,4	25,1	24,2	24,8	26,0
From 65 to 74 years	14,9	14,9	15,3	15,1	15,3	32,6	32,5	31,9	33,7	34,0
From 75 to 84 years	24,3	25,0	25,5	26,5	26,4	36,7	36,9	35,7	37,7	39,1
85 years or over	38,6	41,1	39,8	41,6	39,8	32,7	30,5	30,9	34,2	35,4
Total	8,4	8,7	8,6	8,7	8,7	18,1	18,3	18,0	18,5	19,2

Notes. European Union (EU6-1972, EU9-1980, EU10-1985, EU12-1994, EU15-2004, EU25-2006, EU27).
Source: EU-SILC. Eurostat database, http://appsso.eurostat.ec.europa.eu/nui/show.do

Therefore, we can conclude that increases in health expectancy are not always related to better quality of life. Indicators of healthy life years introduce the concept of quality of life and measure the number of remaining years that a person of a specific age is expected to live without any severe or moderate health problems or acquired disabilities (Eurostat, 2010). In 2009, men and women in the EU27 lived 15.5 and 20.4 years with long-term activity limitations, respectively. At 65 years old, they live more than the 50% of their

remaining years of life with a disability.[5] As indicated in Table 2 below, in high income countries – which, in a global context, include most European states – the diseases which have the strongest impact in terms of lost years of health are depressive disorders, cardiovascular and cerebro-vascular diseases, and Alzheimer's and other forms of dementia (WHO, 2008).

Table 2: Leading causes of burden of disease (DALYs) in high income countries (2004)

	Disease or injury	**Dalys (millions)**	**% of total DALYs**
1	Depressive disorders	10,0	8,2
2	Ischaemic heart failure	7,7	6,3
3	Cerebrovascular diseases	4,8	3,9
4	Alzheimer and other dementias	4,4	3,6
5	Alcohol use disorders	4,2	3,4
6	Hearing loss, adult onset	4,2	3,4
7	Chronic obstructive pulmonary disease	3,7	3,0
8	Diabetes mellitus	3,6	3,0
9	Trachea, bronchus & lung cancer	3,6	3,0
10	Road traffic accidents	3,1	2,6

Source: WHO, 2008

As more people survive to later stages of life, certain conditions related to cognitive impairments such as dementia are expected to affect a growing number of older people (Alzheimer Europe, 2006; Alzheimer's Disease International, 2010). The latest available statistics show that the number of people aged 60 and over suffering from dementia will almost double in Europe between 2010 and 2050. The greatest increase will be for Western and Central European countries due to their different age structures (Table 3).

Table 3: European population aged 60 and over, estimates on prevalence of dementia (2010), number of people with dementia (2010-2050) and % increase

Area	**Over 60 population (millions)**	**Estimated prevalence of dementia (%)**	**Number of people with dementia**			**Increase in %**	
	2010	2010	2010	2030	2050	2010-2030	2010-2050
Western Europe	97,3	7,2	7,0	10	13,4	44	93
Central Europe	23,6	4,7	1,1	1,6	2,1	43	91
Eastern Europe	39,3	4,8	1,9	2,4	3,1	26	66
Europe in total	**160,2**	**6,2**	**9,9**	**13,9**	**18,6**	**40**	**87**

Source: Alzheimer Disease International 2010: 15

[5] Source: Metadata: //epp.eurostat.ec.europa.eu/cache/ITY_SDDS/EN /demo_mor_esms.htm

Nevertheless, there is also a substantial debate about the changes in the prevalence of disability, because longevity increases and there are changes in health behaviours and new treatments appear. In this sense, a compression or expansion of disability can have an impact on the future needs and planning of LTC services. Despite the uncertainties surrounding the health conditions of most older Europeans (Lafortune and Balestat, 2007; Sanderson and Scherbov, 2010), current demographic trends suggest that the absolute number of frail and dependent older people will rise over the next few decades, even if age-specific disability rates decline (European Commission – ECFIN, 2009) (Table 4).

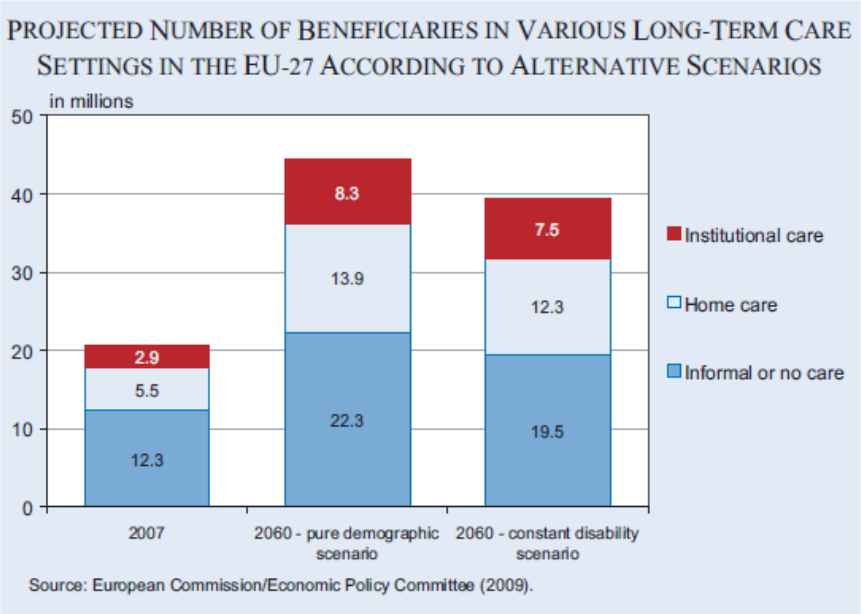
Table 4: Number of older dependent people in the constant disability scenario (thousands, % of change 2007-2060 and the difference to the purely demographic scenario)

								Change 2007-2060		
	2007	**2010**	**2020**	**2030**	**2040**	**2050**	**2060**	*in 000s*	*in %*	*Diff. to pure demographic*
BE	455	475	548	647	765	841	866	*411*	*90*	*-25*
BG	841	840	923	995	1067	1165	1184	*343*	*41*	*-3*
CZ	256	274	343	417	473	516	578	*322*	*126*	*-42*
DK	164	168	199	252	285	304	312	*148*	*90*	*-31*
DE	3201	3383	3982	4469	5076	5563	5190	*1989*	*62*	*-26*
EE	81	81	89	97	106	115	123	*42*	*52*	*-18*
IE	93	101	133	175	227	291	338	*246*	*266*	*-49*
EL	338	368	449	490	570	649	686	*348*	*103*	*-40*
ES	1728	1830	2117	2523	3147	3799	4086	*2358*	*136*	*-37*
FR	2263	2399	2788	3336	3976	4212	4250	*1987*	*88*	*-26*
IT	2515	2659	3024	3362	3873	4379	4407	*1891*	*75*	*-27*
CY	35	37	51	68	84	104	123	*88*	*256*	*-32*
LV	123	124	129	143	155	170	182	*59*	*48*	*-12*
LT	191	197	213	245	280	306	322	*131*	*69*	*-22*
LU	14	16	20	25	32	38	42	*27*	*190*	*-35*
HU	594	612	716	783	869	973	1038	*443*	*75*	*-10*
MT	9	10	14	18	20	21	23	*14*	*143*	*-43*
NL	387	408	502	654	789	856	842	*456*	*118*	*-37*
AT	268	279	312	384	457	524	527	*259*	*96*	*-30*
PL	1485	1526	1967	2433	2738	3053	3285	*1800*	*121*	*-20*
PT	698	735	860	1004	1174	1326	1377	*679*	*97*	*-17*
RO	971	984	1123	1256	1518	1731	1928	*957*	*98*	*-32*
SI	76	81	101	122	139	150	148	*72*	*95*	*-12*
SK	239	248	319	409	478	554	604	*365*	*153*	*-24*
FI	274	288	374	449	479	480	484	*210*	*77*	*-15*
SE	312	318	359	434	479	508	539	*228*	*73*	*-32*
UK	3094	3197	3667	4334	4973	5418	5847	*2754*	*89*	*-20*
NO	155	160	190	239	292	322	348	*193*	*125*	*-24*
EU27	20705	21640	25321	29523	34231	38047	39331	*18626*	*90*	*-25*

Source: European Commission- ECFIN, 2009

Long-term activity limitations imply a need for assistance. Beneficiaries of LTC can give us an idea of the number of people in need of some form of support. In 2004, the number of dependent people aged 65+ in the EU25 was estimated to have been 12.6 million, which is 17% of the total population aged 65+ (Tsolova and Mortesen, 2006). As we can see in Figure 3 below, in 2007, the number of elderly people in need of care grew to 20.7 million. Of these, 12.3 million received informal or no care, 5.5 million received home care and 2.2 million received institutional care. The number of people in need of care (mostly home or institutional care) is expected to almost double from now to 2060. Following a constant disability scenario, 39.3 million dependent people will be in need of care in 2060 (Przywara et al., 2010).

Figure 3: Projected number of beneficiaries in various long-term care settings on the EU-27 according to alternative scenarios.



Source: ECFIN (2009) extracted from Przywara et al., 2010

2.3. The predominant role of families in the provision of long-term care

As mentioned above, LTC is supplied by formal and informal carers. Formal care represents services provided by trained, licensed and qualified professionals, controlled by the state or other types of care organisations and providers. Formal carers have contracts specifying care responsibilities, are paid and entitled to social rights and working regulations, and they have a time schedule and go 'off duty'. Their care tasks are specified according to professional and career qualifications. Informal care is care provided mainly by relatives, close friends or neighbours, who are non-professionals and not trained to provide care though, in some cases, they may benefit from special training. These carers perform a wide range of tasks, including those performed by formal carers, but also emotional assistance, but they do not have contracts for their care responsibilities. They are not paid, although it is increasingly common for them to obtain financial contributions in terms of cash allowances. There are no time limits to the care they provide, they are never/rarely officially 'off duty', and they have no general entitlement to social rights (Triantafillou et al., 2010).

As seen in Figure 3 above, in most European countries, informal carers still provide most of the care delivered to older people in need of LTC (Triantafillou et al., 2010). The family represents one of the most important sources of assistance (Attias-Donut et al. 2005). The financial contribution of family care work surpasses the contribution made by the formal care system to LTC, and it is estimated to range from 50 to 90% of the overall costs of LTC (Triantafillou et al., 2010). In addition, it represents between 20.1% and 36.8% of European GDP (Gianelli et al., 2010). This informal assistance includes the performance of multiple tasks that can generate physical, emotional, social and financial demands (Biegel, Sales, and Schulz, 1991; Williams, 2003). It involves: a) Personal care or routine activities of daily living (e.g. bathing, toileting, eating, dressing), b) Household work (e.g. cleaning, cooking, shopping, laundry), and c) Activities that provide company and emotional assistance ('to listen or just to be here') and promote the social inclusion of people with care needs, or

activities aim to help with administrative tasks (e.g. paying bills, contact with authorities) (Triantafillou et al., 2010).

In 2009, 3% of people in the EU27 stated that they cared for an elderly or disabled relative several times a week. Of these, 9% were women and 3% were men aged 18-plus and they provided care for a relative on a daily basis (Anderson et al., 2009). In most Member States, it is the family's legal obligation to provide and/or finance care to elderly relatives, and in some cases these family duties are legally enforced (Mestheneos and Triantafillou, 2005; Triantafillou et al, 2010). Surveys of European public opinion also show a strong preference for care to be provided by the family or at least at home (Eurobarometer, 2008). This personal preference for informal assistance across Europe seems to be due to drivers such as emotional bonds, the sense of duty, external factors (no alternative or by chance), and religious beliefs. The financial advantages of being a carer can also motivate family and friends to assume the care task (Lamura et al., 2008a).

Caring is still carried out mostly by woman, and at an intensive level. The last OECD report on LTC reports that, across the 16 OECD countries, close to two-thirds of informal carers aged over 50 are women (Colombo et al., 2011). The mean age of carers is 55 (Triantafillou et al., 2010), with ages ranging between 45 and 64-68 years old (Carretero et al., 2006). Children and spouses are the main providers of family care, particularly daughters (and daughters in-law) and wives/partners (Carretero et al., 2006; Hoffman and Rodrigues, 2010; Colombo et al., 2011). Many carers work for 24 hours a week, with the average as high as 45 hours a week (Triantafillou and Mestheneos, 2006; TEUSURE, 2006; Glendinning et al., 2009). The more intensive care in time and burden of activities is provided by women rather than men (Jenson and Jacobzone, 2000; Anderson et al., 2009; Glendinning et al., 2009). The mean length of care spells reported by all studies is 60 months (Carretero et al., 2006; Triantafillou and Mestheneos, 2006; Triantafillou et al., 2010: Garcés et al., 2010, 2011). The frequency of care provided in the household varies between 4 – 10% for 50+ year olds (Sundström et al., 2008): being cared for by someone in one's own household is two to three times more common in the Southern than it is in the Northern and Nordic countries, for example 10% in Spain as against 4% in Denmark and Sweden.

Long-term reliance on informal care for the provision of care to dependent elderly people is not sustainable for two reasons. The first and most important one is the burden and the cost of opportunity for women that providing informal care represents in Europe. A second one concerns the finite availability of informal carers in the future.

On the one hand, informal care has been recognised as a stress factor that negatively impacts the carer and overloads her/him (Zarit, 1998, 2002). In fact, people who take care of a person with dependence problems are likely to experience serious physical and mental health consequences derived from the stress caused by the circumstances in which care takes place. This discomfort and stress for the carer has been conceptualized as a burden (Carretero et al., 2006; Carretero et al., 2007, 2009; Garcés et al., 2011). The physical and mental consequences generated by the provision of assistance to a dependent person may cause carers themselves to need long-term care (Family Caregiver Alliance, 2003), as they too are at risk of becoming patients (Reinhard et al, 2008). Care recipients may also be placed in a nursing home early, or they may be at risk of neglect and abuse (Carretero et al., 2006, 2009; McGuire and Fulmer, 1997; Mockus Parks and Novielli, 2000). These consequences have important impacts on the sustainability of the health and social care system. Care also impacts on the different spheres of carers' lives, and in many cases

causes labour and economic prejudices, increasing carers' risks of poverty, damage to their leisure time and social lives, and family conflicts (Carretero et al., 2006, 2007, 2009; Garcés et al., 2011).

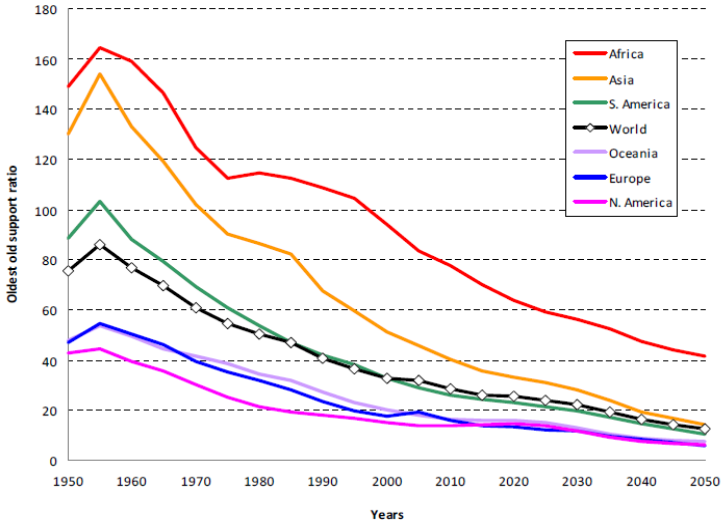
In fact, the three most common profiles of carers identified in CARICT, based on the results of the EUROFAMCARE study (Lamura et al., 2008a; Mnich et al. 2008), are:

1. Highly burdened, cohabiting, non-employed daughters or daughters-in-law of highly-impaired recipients. These tend to be middle-aged carers reporting the highest level of care-related burden and lowest level of quality of life, over proportionally cohabiting with the care recipient and with a very weak social network, and low education and employment rate. Almost 80% of these carers are daughters and daughters-in-law, caring for a highly (also behaviourally and financially) dependent, very old mother, to whom they provide all types of care for almost 70 hr/week;
2. Highly burdened, non-cohabiting, employed daughters or daughters-in-law of slightly/moderately impaired recipients. These tend to be similar to profile 1, but a bit younger, and they seldom cohabit. They have the highest educational level, and are very often employed, but have a weak social network. They often provide 22 hr/week of mainly emotional and domestic care to a much less dependent, but still very old mother;
3. Burdened wives: these older carers have a high burden and low quality of life, and lower educational level. They are mainly retired, with a very weak social network, and provide a large amount (83 hr/week) of all kinds of care to a medium-to-highly dependent partner.

These profiles are later discussed in the future scenarios section.

On the other hand, current demographic change projects a decrease in the availability of informal carers, and in particular, a gap between the demand and the supply of informal care (Robine et al., 2007; Karlsson et al., 2004; Pickard, 2008; Pickard et al., 2009). Robine (Robine et al., 2007; Robine, 2011) has developed the Oldest Old Support Ratio (OOSR) to monitor potential informal care resources. This ratio corresponds to the number of people aged 50-74 potentially available to care for one person aged ≥85. This indicator will help local, national, and supranational planning of care. As we can see in Figure 4 below, there is a worldwide decline in the OOSR.

Figure 4: Worldwide decline in the Oldest Old Support Ratio (OOSR).



Source: Robine, 2011

The social and health impacts of caring on family carers and the probability of a shortage in the future have led policy makers to develop services and policies for informal carers. They are largely focused on compensating economic loss and allowing them to reconcile care and work. Currently they mainly consist of financial measures and in-kind services. Nevertheless, only a minority of carers use the support services that specifically target their needs, such as psychological therapy, respite care, self-help groups, training courses, etc. (Table 5). Particularly low levels of take-up are recorded in Mediterranean and Eastern European countries, but the situation is not so different in States with stronger welfare provision. In the latter cases, for instance in Germany, Sweden and the UK, only one out of five family carers on average makes use of support services for carers (Lamura et al., 2008b:761).

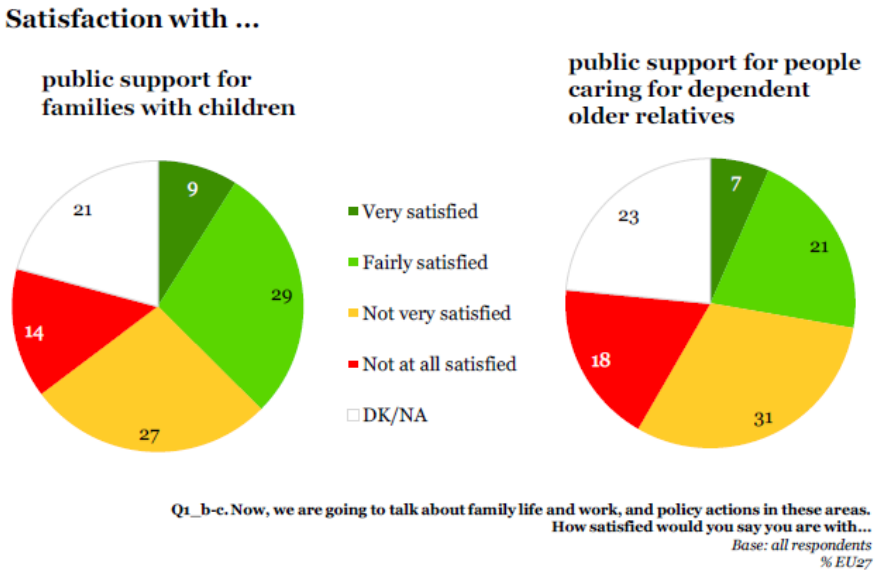
Table 5: Carers using of support services, by type of support and country (% by country)

Type of Service Used	Greece (*N* = 1,014)	Italy (*N* = 990)	UK (*N* = 995)	Sweden (*N* = 921)	Poland (*N* = 1,000)	Germany (*N* = 1,003)	All (*N* = 5,923)
Total percentage of carers using at least one service	*1.4*	*3.5*	*22.5*	*20.5*	*4.2*	*22.8*	*12.4*
Day care services	0.7	2.0	9.0	10.1	0.3	4.2	4.3
Information	0.1	0.1	5.8	0.1	2.6	16.1	4.2
Self-help or support groups	0.1	0.9	4.7	5.2	0.2	5.9	2.8
Counseling	0.2	0.7	3.1	6.7	0.8	2.4	2.3
Respite care (in-home supervision)	0.3	0.1	2.3	6.1	0.9	1.0	1.7
Training	0.0	0.5	1.7	2.8	0.4	2.1	1.2
Assessment of carer's needs/eligibility to support	0.0	0.1	2.0	0.4	0.0	0.0	0.4

Source: Lamura et al., 2008b

Moreover, as shown by the results of the Eurobarometer (2007), around the 50% of families caring for older relatives are not satisfied with the public services available for families (see Figure 5). Per country, the total level of satisfaction with public support for people caring for dependent older relatives ranged from 9% in Portugal and Estonia to 59% in Luxembourg, while the proportion of respondents who said they were very satisfied ranged from virtually zero in Estonia, Slovakia and Latvia to 22% in Denmark. Respondents in Portugal and Greece were again some of the most likely to answer that they were not at all satisfied (40% and 39%, respectively).

Figure 5: Satisfaction with public support for families with dependents.



Source: Eurobarometer, 2007

The factors inhibiting carers' access to these services include insufficient information to navigate complex bureaucratic procedures, service affordability, transportation costs, and the length of waiting lists, in particular in Southern and Eastern European countries (Lamura et al., 2008b). We have also to bear in mind that informal carers find it difficult to attend services like psychological therapy, etc, because they spend so much time in caring for their relatives (Carretero et al., 2006).

2.4. The increasing role of migrant care workers in the long-term care context

The lack of suitable services for family carers is one of the main drivers of the growing demand for migrant care work (MCW) by private households (Hoffmann and Rodrigues, 2010). In several European countries, an increasing number of households provide daily care to dependent older family members with the help of privately-paid migrant care workers. These migrant carers are also mainly women, and often employed on an undeclared basis (Fujitsawa and Colombo, 2009) and inclusive undocumented (Kluzer et al., 2010). After an early concentration in the family-based care regimes of the Mediterranean area (Italy, Spain), the phenomenon is also increasingly affecting Bismarckian welfare states like Austria (Schneider and Trukeschitz, 2008) and Germany (DIP, 2009), and lately even liberal care regimes such as Ireland (Doyle and Timonen, 2008) and the United Kingdom (Cangiano et al., 2009).

It is not easy to quantify this phenomenon in Europe: because care work is often undeclared, official statistics are frequently unreliable in this field. The available figures estimate that in Italy well over two thirds of the now almost 1.5 million people employed in the personal care/household service sector are foreign-born (Lamura et al. 2010a). In Greece, foreign workers account for about 70% of the whole workforce employed in private households (Kanellopoulos and Gregou, 2006). In Spain, the official number of permits for domestic work to foreigners rose seven times between 1999 and 2006, to almost 230,000 (Martinez Bujan, 2010). OECD data referring to care services provided at home in 12 European nations (Austria, Belgium, France, Germany, Greece, Ireland, Italy, Luxembourg, Portugal, Spain, Switzerland and the UK) confirms that the share of foreign-born workers in most countries is larger than that of native-born (OECD, 2008).

Employing migrant carers can be viewed as the most "effective" way to reconcile work and care responsibilities (Williams, 2010). This is especially true in countries where the availability of formal care services and labour-market measures (such as paid/unpaid leaves or flexible working hours) is more limited. The choice of employing migrant care workers is also favoured, in some cases, by the implementation of cash-for-care schemes (as instruments for overcoming the lack of formal services) that allow households to allocate money for hiring a care assistant. Nevertheless, most migrant care workers have limited specific training, or none at all, in health or social care, despite the fact that they have higher qualifications than those required for the job they carry out (Fujisawa and Colombo 2009; Kluzer et al, 2010). Moreover, they have little or no information on the situation they have to face in dependent people's homes or on the tasks they have to perform. Training opportunities are also currently very limited, although some local initiatives have emerged over the last few years (Kluzer et al., 2010). Given that care tasks, are still very much carried out by women, there is also a strong gender dimension associated with these issues.

2.5. Conclusion

As we have seen, an increasing number of older people in need of care is expected for the coming years in the European Union. Informal carers are currently assuming the major part of the provision of care. This situation is unsustainable, mostly due to the impact on the carers' health and social and economic lives. Formal services can help informal carers, but few use them. This is mainly because they do not have enough time to make use of these services and they have little information on them. Moreover, many carers are dissatisfied with the services available. This may be due to their limited availability, their associated costs and the waiting lists. Some families resort to migrant care workers to fill the gap not covered by formal services, but these workers are in general undeclared and not properly trained to provide care.

For this purpose, we discuss in the next section the role of Information and Communication Technologies (ICTs) applied to services for informal carers for a better access to and satisfaction with support services for carers. ICTs can overcome existing barriers mentioned (lack of information, bureaucratic barriers, etc.). ICTs can also be an opportunity to improve the recognition of the situation of informal and migrant care workers, through the acquisition of care and digital competence, to increase their employability and social inclusion, reduce the cost of the provision of long-term care and to promote a European market of ICT services for domiciliary carers.

3. THE ROLE OF ICT-BASED SOLUTIONS FOR INFORMAL CARERS

The research and policy contexts have recognised the potential value of information and communication technologies (ICTs) in services to help informal carers in their tasks in the community. Nevertheless, there is still limited availability and use of ICT-based services for informal carers. There is also a lack of evidenced-based results that give contrasted data on their impact on the health and wellbeing of informal carers and older people and on the sustainability of the care systems. In addition, there is limited data available on the pathways for the transferability of these services to other localities, regions or countries. This study aims therefore to address this lack of data. We also analyse the drivers and success factors for the development and implementation of ICT-based services for informal carers, which will be useful for formulating policy recommendations. Below, we give an overview of the current state-of-the-art regarding the role of ICT-based services for informal carers from research and European policy perspectives, and we explain the objectives and methods followed to develop the CARICT study.

3.1. Overview of the current state of the art

3.1.1 The research context

Interventions to help informal carers are largely based on social support and the development of coping strategies, because these mediate in the carers' stress process (Pearlin, et al., 1989, 1990; Pearlin, 1991; Aneshensel et al., 1995; Pearlin and Skaff, 1995; Gaugler et al., 1999) and Zarit (2002). For example, information, psychological support, social assistance from families and friends and social care can protect carers against the burden and the negative consequences of care task (Garcés et al., 2010). The studies on interventions to reduce caregiver burden have focused above all on programmes that use formal services for elderly people such as respite services and psycho-social programmes that include learning strategies to cope with the care situation and social and emotional assistance. Most of these studies confirm the positive results of such interventions, although some also place doubt on their effectiveness to alleviate the informal carers' burden. Among the barriers related to the lack of efficacy of formal services, we find programmes that lack reliability or quality, or are under used, or used when stress levels are too high, and programmes that are too long, or do not give carer enough time for impact (Garcés et al., 2010).

The care sector has not been immune to the whole scale societal adoption of Information and Communication Technologies (ICTs) in recent years. ICTs are being increasingly perceived as a potential resource to provide a cost-effective way to improve the quality of care and to ease the burden of carers. An older generation of ICT – i.e. the telephone- was a tool for professional carer, especially in rural areas (Hogenbirk et al., 2005). The telephone, and now the mobile phone, is a key tool in the care of the elderly, enabling carers to communicate with the elderly people, their families and other carers. The telephone is the basis of various emergency alarm systems widely used in this type of care. More recently, the Internet has been the site of considerable experimentation and the development of some mainstream services for elderly people and carers. Because this medium provides information on-demand, a host of new technical possibilities, direct access to professional care, and communities of interest become available.

It is generally recognised that the Internet is effective in providing health information to the public (Siow et al., 2003) and in promoting healthy behaviour among the older population (Slootmaker et al., 2005). It also helps older people to communicate with others and reduces their social isolation and loneliness (Westlake et al., 2007). Although there are very few studies that have analysed the impact of internet and other ICT-based services on carers, the latest results point to positive and encouraging results. Several studies report that ICT use can help carers as it:

- Improves their physical and mental wellbeing (Lam and Lam, 2012).
- Develops their problem solving ability (Buis, 2006).
- Increases their self-esteem (Weiner et al., 2005).
- Helps them make links with others (Hill and Weinert, 2004).
- Improves their relations with the health care team (Sanchez, 2004; Shaw et al., 2004).
- Makes them more empowered (Weiner et al., 2005).
- Gives them improved perceptions of their efficacy (Weiner et al., 2005; Gallagher et al., 2007).
- Improves, in their own view, their care skills, such as self recognition skills (Weyner et al., 2005) and being prepared for the job (Hill and Weinert, 2004; Buis, 2006).
- Opens up the possibility of self-training to acquire skills in managing long-term diseases (Weiner et al., 2005; Klemm and Wheeler, 2005; Pierce et al., 2004).

For example, Lam and Lam (2012) found a significant association between internet usage and better mental health among a sample of older carers in Australia. They showed an improved mental health among those who were using internet at the moment of the interview compared with those who used it before. A literature review on technologies and psychological interventions among carers of patients with Alzheimer's disease was developed by Wu and colleagues in 2009. They concluded that these interventions carried out by phone or internet have a positive effect on carers' burden, anxiety, depression, feelings of incompetence and disease knowledge.

Moreover, ICTs add value to the traditional interventions for carers, because they offer (Alexy, 2000; Wu et al., 2009; The Princess Royal Trust for Carers, 2012):

- A link to information.
- Services and communication from and within the home. People are then accessible independently of their mobility condition or transport availability. ICTs enable psychologically or geographically isolated people to access these services.
- Availability 24/7 according to the carers' needs. Carers can therefore benefit from services whenever they need them.
- Access to peers and professionals.
- Social anonymity (Alexy, 2000; Wu et al., 2009).
- More diversity in the kind of services available (The Princess Royal Trust for Carers, 2012).

In fact, a recent survey with carers in UK found that 7 out of 10 online carers said that the internet saves time and 5 out of 10 found that it helps them save money. In the same study, the 42% of online carers said that the internet helps to reduce their feeling of isolation (The Princess Royal Trust for Carers, 2012).

IPTS (Kluzer et al., 2010) and more recently the Princess Royal Trust for Carers (2012) have identified the opportunities of ICTs for domiciliary carers. Specific ICTs for care of the elderly like telecare, telehealth and assistive technologies, can help in alleviating the carers' burden. Though these technologies are not primarily targeted at carers, they help them to perform tasks from a distance. They also give the carers a sense of security, because they allow them to check whether their elderly charges are safe or whether they have carried out a task. General ICTs like telephones, computers and Internet are also helpful for carers because:

- They provide online and telephone-based information and advice, e.g. through information websites or podcasts.
- They offer online training that facilitates access to educational contents and reduces time spent out of the home, for example through e-learning platforms.
- They sustain communication, coordination and cooperation with all those involved in care. They also facilitate the participation of multiple actors in caring such as volunteers. Online social networks are examples of internet tools that allow carers to link virtually with people they already know in the real world for emotional or practical support around their caring responsibilities.
- They enable online communities and informal exchanges among carers. These exchanges provide them with information, advice and peer support. Forums and chat rooms are some examples.
- They allow carers to maintain online contact with family and friends.
- They help carers to make care arrangement online and book caring breaks.
- For migrants in particular, ICTs offer access to content and services in their mother tongue, and a means of learning the host country language.

As shown in Table 6, some evidence and good practices on the use of ICTs for informal carers and migrant care assistants has already been identified in a previous study carried out by IPTS (Kluzer et al., 2010). Moreover, a recent study in the UK shows that online carers mostly use emails (99%), instant messaging (almost 45%), video-chat (20%) and online shopping (94%) (The Princess Royal Trust for Carers, 2012).

Table 6. Cases of ICT-based initiatives and services addressing informal carers

Needs and type of initiative	Illustrative cases in the four countries studied
Communication with care recipient; access to her status, assistance planning etc.	Sophia (DE) LifeSensor (DE)
Information and guidance on LTC, referral information on LTC services, online consultation	Pflegewiki (DE) Carers Direct Helpline (UK) Telephone Befriending Scheme (UK) Carers in Hertfordshire's website (UK) Ser cuidador (ES) Un cuidador, dos vidas (ES) CEAFA, Website of Spanish confederation of Alzheimer families associations (ES)
Peer support, mutual assistance, information exchange (online forums, blogs, social networks)	Carers UK's Discussion Forum (UK) SEKIS Berlin (DE) Seniorlotse Bremen (DE) Forums and personal blogs on the web site of the German Alzheimer Society (DE) Cuidadoras en Red (ES)
Training on care giving (through multimedia, online tools)	Caring with Confidence (UK) City & Guilds – Learning for Living (UK) Coidanet (ES) Spain's Alzheimer Foundation, FAE (ES) Aspasia (IT)
Information and training on using ICT to support/enhance care functions (addressing care workers and informal carers)	List of local authorities' websites devoted to telecare opportunities in England (See England report p.68[1]) Nottingham City Council's telecare project (UK) TATE (Through Assistive Technology To Employment) project (UK) Home Farm Trust's CTEC Centre (UK)

Note: [1] This report ' The potential of ICT in supporting domiciliary care in England' is available at http://ftp.jrc.es/EURdoc/JRC56438.pdf

Source: Kluzer et al., 2010

Until today, however, the use of ICT by informal carers has followed a pattern partly similar to that of other traditional support services described in terms of its take-up. Hence, while the deployment of ICT-based solutions such as first generation of telecare and assistive technologies is already relatively established in some countries, strong differences subsist in between or even within countries. Moreover, the use of other ICT-based solutions such as smart homes and telehealth services remains far from being mainstreamed in most countries (Empirica and WRC, 2010).

A series of factors or barriers contribute to this situation. Firstly, most family carers are middle-aged to old women with a low to middle educational levels (Glendinning et al., 2009; Lamura et al., 2008b; Huber et al., 2009). These socio-demographic characteristics are often associated with a low level of ICT expertise (Empirica and WRC, 2008). Secondly,

there is no demonstrated business case (in telecare, telehealth and other ICT-based technologies to help carers), and a lack of evidence on the long-term impact and sustainability of ICT solutions beyond trials and pilots. This has led to considerable variations in the perceived role and importance of such technologies, from the point of view of users and health and care providers and professionals as well as policy-makers. Additional barriers arise from the lack of interoperability between the systems used, and by the fragmentation of administrative responsibilities of health and social care systems in many countries (Empirica and WRC, 2010).

Barriers to a proper access to the use of ICT solutions might be even stronger in the case of migrant care workers. The lack of appropriate language skills could be one of the causes for this (Kluzer et al., 2010), thus preventing even the use of simple devices. Furthermore, when the migrant care worker lives with the person they care for, there might be resistance from the care recipients' family to allow MCW to use a computer or other ICT facilities (Kluzer et al., 2010:73), if it is not in strict connection with their caregiving tasks. On the other hand, it should be pointed out that the younger age and possibly higher education of some MCWs (Kluzer et al., 2010:39) could represent a positive enabling factor, allowing them to easily get acquainted with the use of devices requiring some more sophisticated skills.

Previous research by IPTS (Kluzer at al., 2010) stated that policy intervention is needed to address the above barriers. Policy and public awareness of the concerns and needs of informal carers should be raised, carers should be informed of their rights and the support available, and informal carers should be integrated in the provision of care. This policy intervention should contain specific measures and incentives such as:

- Actions to raise awareness of the opportunities offered by ICTs for caregivers among stakeholders.
- Targeted digital inclusion policies addressing the profile, conditions and needs of carers.
- The development of online and multi-lingual information and training material on the context and practices of care. This also promotes foreign-language learning among migrant carers.
- The development of the ICT industry and service providers for long-term care.
- Actions to improve cooperation between all the players involved in home care.

In order to sustain the implementation of these policy measures, IPTS identified that more research is needed in order to provide (Kluzer at al., 2010):

- Comparable, reliable, comprehensive statistics on the role of informal care givers in general and of immigrants and ethnic minorities in particular in care jobs.
- Better knowledge of the profile of formal and informal carers, work conditions, tasks, carers' needs and the potential of ICT.
- A better understanding and evidence of the impact of current ICT-based products, applications and services in improving the quality and efficiency of care, on the wellbeing of the carers and in supporting an increased availability of carers.
- A better understanding of how policy can help to develop, scale or replicate existing good practices in other contexts within the EU, and
- The identification of sustainable business models to finance ICT infrastructure, applications, devices and services across actors.

This study addresses the first three points.

3.1.2 The policy context

In 2010, and as part of the EU 2020 Strategy, the flagship initiative Digital Agenda for Europe (DAE) established that the deployment of ICT is becoming a critical element for delivering policy objectives for an ageing society. The DAE stresses the relevance of extending eHealth technologies in Europe to improve the quality of care, reducing medical costs and fostering independent living, even in remote places, and the Ambient Assisted Living (AAL) technologies. The DAE reinforces the EU AAL-dedicated Joint Programme with Member States and related advanced research, as well as applications such as telecare and online support for social services. This support covers the certification of carers, and also new ways of putting ICT at the service of all people, especially the most vulnerable. Regarding this, the voluntary European Quality Framework of Social Services emphasises that social services should be provided by skilled and competent workers under decent and stable working conditions. This implies a manageable workload, suitable skills and a encouraging environment for all care workers, including volunteers and informal carers. These conditions can be promoted through training programmes, life-long learning schemes, mentoring by experienced workers, competence certification of the professional and inter-personal skills and accessibility and assistive technology.

The DAE also aims to enhance digital literacy, skills and inclusion for those that have never used the internet. This group represents around the 150 million Europeans – some 30% - and is largely made up of people aged 65 to 74 years old, people on low incomes, the unemployed and the less educated. Making digital literacy and skills is also a priority of the "New skills for new jobs" Flagship launched in 2010. Given the transversal role of digital competences across the economy, the DAE is an essential catalyst that can help provide the right digital competences for workers and job-seekers. The DAE can promote basic digital literacy for the job market for those with the fewest competences (the elderly, less-educated persons or SME employees) but also specialised and advanced ICT competences for those holding specific job profiles (such as ICT practitioners).

In the framework of the DAE, the Commission reinforced the potential of ageing as Europe's opportunity for the future. In 2011, it launched the European Innovation Partnership in the field of active and healthy ageing (the EIP AHA). The aim of the partnership is to increase by 2 years the average number of healthy life years (HLYs) in the European Union by 2020. It aims to secure a triple win for Europe by: 1) enabling EU citizens to lead healthy, active and independent lives while ageing;; 2) improving the long-term sustainability and efficiency of health and social care systems, and 3) enhancing the competitiveness of EU industry through an improved business environment providing the foundations for growth.

The EIP AHA has identified a need for urgent action to shift the focus from acute, reactive, and hospital-based care to long-term, proactive and home-based care, integrating both health and social settings. This should also be underpinned by health promotion, disease prevention, independent living and integrated health, social, community and self care. In addition, living and working environments need to be adapted to empower older people to remain functional and active for longer. To do so, the Partnership must overcome or reduce barriers in the area of active and healthy ageing, by identifying cross-cutting solutions, bridging sectors, competences and instruments and sharing best practice, in a wide, results-oriented, collaborative effort, which maximises the use of existing knowledge and best practice.

Long-term care has been a key component of the social protection systems of the Member States, since 2004, when the Council endorsed the Social Protection Committee (SPC)'s Opinion on the Commission's Communication regarding the application of the Open Method of Coordination to health and long-term care (COM (2004)304).

Member States are committed to accessible, high-quality and sustainable health care and long-term care by ensuring:

- Access for all, to suitable health and long-term care and that the need for care does not lead to poverty and financial dependency; and that inequities in access to care and in health outcomes are addressed.
- Quality in health and long-term care and by adapting care, including developing preventive care, to the changing needs and preferences of society and individuals, notably by developing quality standards reflecting best international practice and by strengthening the responsibility of health professionals and of patients and care recipients.
- Suitable and high quality health and long-term care remains affordable and financially sustainable by promoting a rational use of resources, notably through appropriate incentives for users and providers, good governances and coordination between care systems and public and private institutions. Long-term sustainability and quality require the promotion of healthy and active lifestyles and good human resources for the care sector (European Commission, 2008).

Regarding this, long-term care represents a key area for intervention in many Member States. For this purpose, they are involved in reform processes to improve the efficiency, access, effectiveness and sustainability of the long-term care and social service provision and the quality of life of service users.

The last Communication of the European Commission on LTC, "Long-term care in the European Union", in 2008 informed us that to meet the foreseen increase in demand for an accessible, efficient and high quality long-term care provision, Member States should strive to:

- Ensure a sustainable mix of public and private sources of finance including changes in financing mechanisms.
- Boost the care coordination within the various long-term care systems for a high level of quality and an efficient use of resources and suitable continuum of care.
- Find mechanisms to provide universal access to long-term care, independently of the individual ability to pay, or the share of private sources of financing.
- Ensure high level of quality of care in residential or community settings, through measures including uniform standards and quality accreditation mechanisms coupled with legally enforced evaluation methods.
- Ensure suitable long-term (formal and informal) care workers, through measures like higher wages, the improvement of training and working conditions and the formalisation, where possible, of informal carers into the social security schemes.

As stated by the last SPC Communication (SPC, 2011), recent changes have been focused on comprehensive policy and strategy reforms, mainly due to the increasing costs associated with long-term health and social care. Furthermore, some Member States have planned, or will soon launch specific plans either to improve access to affordable long-term care and thus improve social inclusion or to organise and guarantee long-term

sustainability of LTC systems. Others have recently implemented many measures (Home care package scheme, Nursing Home Support scheme, etc.) whose practical impact is to improve the financing of this type of care. For example, France opened at the beginning of 2011 a national debate on dependency with the participation of stakeholders and the society, and from the reports of the four working groups available from June 2011, policy and decision actions will be taken[6]. DG Employment is preparing, together with the SPC, a new Staff Working Paper on long-term care to be published as part of the Social Investment Package for Growth and Cohesion at the beginning of 2013. In this document, Member States have requested a positive approach to facing the challenges of LTC through the role played by technologies in prevention, independent living, rehabilitation and care and cure of dependencies at older ages.

In this context, the European Platform against Poverty and Social Exclusion established that an accessible use of Information and Communication Technologies in the era of internet enhances employability and life opportunities, the inclusion in the local communities, the use of online public services and the access to modern and efficient care, thus facilitating social inclusion. This statement calls for sustained efforts to bridge the digital divide through enhancing digital literacy, skills and regular internet use for disadvantaged people, as well as providing inclusive and targeted online services in key areas (employment, housing, health and other social services) that to empower users, in particular from vulnerable groups. Education can play a crucial role to avoid a further widening of the digital divide.

3.2. The CARICT research project: aims, methodology and research team

3.2.1. Aims

The CARICT study ('ICT for caregivers and other social actors: enhancing the sustainability of long-term care and social support') was co-financed by DG CNECT and JRC-IPTS of the European Commission, and run throughout 2011. CARICT aimed to find out to what extent ICT-based services for informal carers exist in European countries, their impact and the policy support needed to develop and implement them. These data would allow us to judge whether these services help to create motivated and skilled domiciliary carers, and whether they have an impact on the quality of life of the elderly and their carers, and on the quality and efficiency of the care supplied.

These policy issues arose from previous research, also funded by DG INFSO and the JRC-IPTS, which revealed a lack of detailed and widely-disseminated knowledge on this topic. These findings reflected the *triple invisibility* of 1) informal carers in long-term care policy and formal practice, 2) ICT use in long-term care, and 3) informal carers in the development of ICTs in the field of ageing and care.

For this purpose, specific objectives of CARICT were to understand:

1) whether ICT can help to create of a sufficient number of available (motivated) and qualified (skilled) informal domiciliary carers, where relatives, friends, volunteers and migrant care workers are key components, and
2) whether technology-enabled services and applications can allow carers to care better, improving the quality of life of carers and the efficiency of care give.

[6] http://www.dependance.gouv.fr/

The research tasks centred on answering the following questions on ICT-based services for informal carers:

1. What initiatives are there in the EU and abroad?
2. How do these good practices operate?
3. What are the enabling conditions, success and failure factors and barriers? and
4. What is their impact?

The project was based on the research work of a network of experts in the field of ageing, long-term care and informal carers. They addressed the above questions by studying initiatives that have deployed Information and Communications technologies (ICTs) to assist families and family-employed carers in European countries and North America.

3.2.2. Methodology

In order to attain the objectives of the CARICT study, the following methodology was applied:

1. First, a mapping and analysis of relevant ICT-based initiatives to assist carers of older people living in the community in 12 Member States of the EU.
2. Second, a literature review of impact assessment methodologies (IAMs) for home care in order to produce a first prototype of IAM for evaluating the impacts of ICTs in this context.
3. Third, an in-depth analysis of 12 good practices to better understand their impact and their success factors and formulate policy recommendations based on a cross-analysis of these initiatives.
4. Fourth, the development of four scenarios to illustrate how the provision of long-term care can positively change with policy recommendations for ICT-based services for informal carers.

We explain each of these steps below.

1. The mapping and analysis of relevant ICT-based initiatives in Europe to assist carers of older people living in the community. Initially, we carried out a focused search for examples of ICT-based initiatives for carers across 12 countries, and 5 care 'regimes' (Anglosaxon, Continental, Scandinavian, Mediterranean, and Eastern European ones). This search aimed to ensure a diversity of geographical regions in Europe and care regimes, functions for carer activities, and types of technologies. We selected and documented a sample of 52 initiatives, which represents the largest European data-set available in the field at the moment. All these initiatives are beyond the pilot stage and are integrated in local care systems.

   The research consortium identified ICT-based initiatives through a review of the available literature and by gathering existing data and/or expert interviews. They used a common template and the following 8 criteria to select the most relevant initiatives.

Criterion 1: Geographical coverage. All five care regimes (Anglosaxon, Continental, Mediterranean, Scandinavian, and Eastern European care regimes) were represented in the sample. Although Western EU countries (e.g. Austria and France) and those countries explored already in our previous study[7] (such as the UK, Germany and Spain) were

[7] See Kluzer et al., 2010

prioritized in selecting the case studies for this report, an effort was made to also find good practice examples in other EU Member States in Eastern Europe.

Moreover, to be able to consider national care systems it was agreed that a minimum of three good practice examples per country needed to be found. In Eastern Europe, however, given the larger number of countries belonging to the Eastern European care regime (compared to the other four care regimes), it was deemed reasonable to cover more countries but with a lower number of cases in each country.

Criterion 2: Maturity. An attempt was made to ensure that ICT-based initiatives for this report were in operational status (beyond pilot status). Exceptions have been made with innovative or promising cases, and also with Eastern European countries where operational ICT-based initiatives were very difficult to identify.

Criterion 3: Types of ICT used. The purposive sampling of initiatives was done according to a taxonomy of different types of services developed on the basis of earlier research funded and carried out by IPTS. This allowed us to ensure a diversity of examples of types of services in different countries (see Table 7). The services comprise those initially focused on elderly people, such as independent living services, but also those focused on informal carers. They refer to information and learning, personal support and social integration, and care coordination.

Table 7: Typology of ICTs for carers used in the CARICT study

Types of services to support carers using ICTs	Function and examples.
Independent living and social participation for older people	They include ICTs that help older people to stay at home, without the continual presence of formal or informal carers. Elderly people and carers can live more independently and the latter are less burdened. Some of these services support communication and social participation of older people with limited mobility. *Examples:* Telecare services; social alarms; call centres; monitoring, wandering alarms, granny cams, ambient assisted living technologies; environmental controls (e-health can be included if relevant to support of carers); Internet and mobile communications services.
Information & learning for carers	Lack of knowledge about the care needs of dependents, about how to care, and services available to help in caring are some of the key issues in family-supported home care. These services improve access to information and training about caring, health and care issues for the dependent older persons, coping with caring, and training for life - language, other work skills, accreditation of caring skills, etc-. *Examples:* Online information; training materials (websites, video, games, etc); personalised and localised information via mobile phone; learning support services – including telephone.
Personal support & social integration for carers	Isolation and poverty are key aspects of social exclusion of carers. Counselling services and other forms of emotional support may be too expensive, inaccessible or require high investment of time to carers. These services provide them with social, emotional and peer support, leisure, relief of isolation more effectively and efficiently. They can enhance the participation in civil society and work. *Examples:* Social networking systems for peer support; intra-family communication, etc; volunteer call networks (mobile, internet); call centres for counselling; access and support for internet access for e-commerce, e-government services, entertainment.
Care coordination	Lack of coordination of care and health services, and lack of informational and inflexibility of formal care services to needs to older people and their carers are a major issue in LTC. These services and tools help to coordinate the formal and informal care sector. They also facilitate the organization of respite and the sharing of information on recipient's and carers needs. They improve quality of care, reduce stress on carers, and help carers to balance competing responsibilities. *Examples:* Organizational systems with carer access, or for use by networks of both formal and informal carers; IT systems that facilitate health service professionals to refer carers to carer services.

Criterion 4: Support functions of ICT initiatives. In order to reflect the diversity of ways in which ICT solutions may assist carers, five main categories were identified to classify support functions of ICT-based services and applications: support to care recipient; support to quality of care through the carer; support to carer's quality of life; participation; and migrant-related function.

Criterion 5: The care recipient's dependency scenario. This category aims to reflect the different needs of older dependent people with physical impairments from those with cognitive impairments (such as Alzheimer or dementia patients) or with psychological impairments (such as depression). It covers a broad range of initiatives to assist carers for older people with different functional conditions.

Criterion 6: Presence of impact assessment. Initiatives were favoured if impact assessments had been conducted previously.

Criterion 7: Main objective. We specifically selected services with objectives that were closely related with those of the study.

Criterion 8: Overall fit of the initiative with the criteria. When an initiative was judged as fulfilling satisfactorily the criteria mentioned above, more information on the service was collected. Both quantitative and qualitative data in four main areas was collected: background and set-up, operation information, impact assessment, and future perspectives. 52 initiatives were finally identified and analysed. The list and results of the analysis are summarised in Section 4.1.

More information on the methodology, criteria and data collection and analysis to map the selected initiatives is available in Deliverable 2.3. 'Analysis and mapping of 52 ICT-based initiatives for caregivers'.[8]

2. A literature review of impact assessment methodologies (IAMs) for home care and the production of a prototype IAM for evaluating the multidimensional effects of ICTs in this context were further developed. This IAM refers to a comprehensive instrument built up from a coherent conceptual framework able to take into account the multidimensional impact of these technologies. The impacts refer to individuals (micro-level), to social relationships and organisations – like local care providers and employers (meso-level) – and also to the overall care and social protection systems (macro-level). Guidelines are also provided for further developments and adaptations of IAMs in this field, underlining the methodological issues to face in such a challenge and the requirements for building a suitable IAM.

   On the basis of the conceptual framework developed and of a comprehensive literature review carried out (see Deliverable 3.6, Chapter 2[9]), a first attempt to build an Impact Assessment Methodology (IAM) was made. The IAM has been structured in three levels: dimensions of impact, levels of analysis and indicators. We explain them below:

- Dimensions of impact: seven different dimensions have been identified to be assessed in the context of an ICT-based initiative to carers (see Table 8 for details).

[8] Deliverable 2.3. Analysis and mapping of 52 ICT-based initiatives for caregivers, available at http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/CARICTD2.3Mappingof52initiatives.pdf

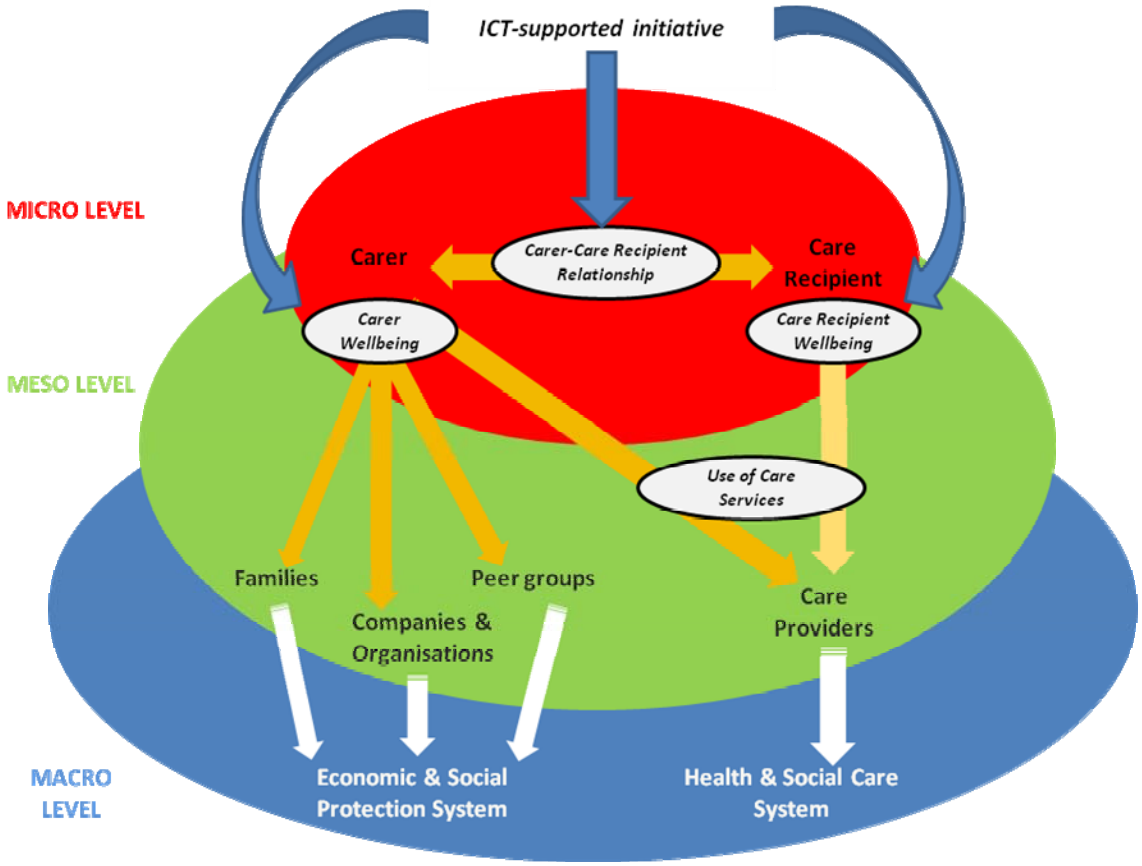
[9] Deliverable 3.6, Final report on the "Methodological framework", available at http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/D3.6FinalreportontheMethodologicalFramework.pdf

Table 8: Description of the 7 Dimensions of impact to be assessed in the context of an ICT-based initiative to carers

Dimensions		Description
1. Quality of Life of Informal Carer	*Reconciliation between care and work*	This concerns the possibility for informal carers to keep their jobs, ensuring they have enough time to dedicate to caring activities. Other related aspects concern the possibility for carers who do not work to enter into the labour market. For carers who still work, impact refers to improvements in their working conditions and the availability of personal resources (e.g. time).
	Social life	This concerns all the aspects related to carers' social relationships, social participation, and their interactions with significant others.
	Other dimensions of quality of life (health, leisure etc.)	This covers all the aspects of a carer's wellbeing other than social participation and work. This sub-dimension concerns the health of the carer, its prerequisites and effects.
2. **Quality of Life of Paid Assistant**		This covers all the aspects of a carer's wellbeing including social participation and work. This dimension concerns the health of the carer, its prerequisites and effects, as well as the social life and work-related aspects.
3. **Quality of Life of Care Recipient**		This covers all the aspects of the older person's wellbeing including relationships with relatives and others in general. This dimension concerns the health of the care recipient, its prerequisites and effects, as well as the social relationships he/she can count on.
4. **Quality of Care provided by Informal Carer and Paid Assistant**		This concerns the necessary prerequisites and the outcome of the care provided by carers, both paid and unpaid ones. In this case, the carer is considered as a proxy: the quality of care is investigated through the carer's activities.
5. **Care Efficiency & Sustainability**		This concerns both the economic sustainability of the initiative and the efficiency in terms of costs and quality of the final outcome.
6. **Acceptability**		This concerns the aspects making the initiative attractive towards the main actors at all levels. For the carers, it includes both external (e.g. organisation, effectiveness) and internal (e.g. satisfaction) factors.
7. **Infrastructure & Accessibility**		This concerns the impact of infrastructure facilities on the access by the users to the support services.

- Levels of analysis: each dimension has been articulated at all three levels of analysis (micro, meso, and macro), already identified in the conceptual framework, we can see it in the figure 6 below.

Figure 6: The impact of an ICT-based initiative at micro, meso and macro levels.



- Indicators: a series of indicators have been selected among a range of standardised and validated published instruments. In particular, indicators allow us to provide standardised definitions on the aspect to assess (explaining exactly what is being measured) and also provide selected tools from available literature (Table 9).

Table 9: Structure of the Impact Assessment Methodology (IAM)

Dimension		Micro	Meso	Macro
1. Quality of Life of Informal Carer	*Reconciliation between care and work*	E.g. Possibility to balance well care & work activities	E.g. Efficiency at work	E.g. Number of carers that balance care & work activities
	Social life	E.g. Positive social contacts & relationships	E.g. Reduction in family conflicts	E.g. Increased social cohesion & inclusion
	Other dimensions of quality of life (health, leisure etc.)	E.g. Psychophysical health & life satisfaction	E.g. Number of non-stressed carers	
2. **Quality of Life of Paid Assistant**		E.g. Psychophysical health and independence level	E.g. Number of non-stressed carers	
3. **Quality of Life of Care Recipient**		E.g. Physical level; Psychological level; Independence level	E.g. Number of reported cases of abuse/neglect by family members	E.g. Target number of dependent older people supported
4. **Quality of Care provided by Informal Carer and Paid Assistant**		E.g. Improvement of caring activities by direct (e.g. training) or indirect (e.g. decreasing burden of carer) factors		
5. **Care Efficiency & Sustainability**		E.g. Care efficiency (in terms of quality and cost containment) and sustainability for care recipients and families	E.g. Efficiency and Sustainability for care providers	E.g. Efficiency and Sustainability for Social Protection and Care systems
6. **Acceptability**		E.g. Acceptability by carer and care recipient	E.g. Marketability of ICT devices (from ICT device producer point of view)	E.g. Resources of Care system to support ICT devices (e.g. public investments in ICT)
7. **Infrastructure & Accessibility**		E.g. Accessibility of initiative by carers	E.g. Availability of services (from care provider point of view)	E.g. Availability of services (from system point of view)

The methodological framework developed is included in deliverable 3.6, Final report on the "Methodological framework".[10]

3. Third, the in-depth analysis of 12 good practices to better understand the impact and the success factors of such services. The initial sample of 52 initiatives was used as the source for the selection of 12 initiatives. For this purpose, 20 initiatives were first pre-selected, following two set of criteria:

- First set of criteria. They ensure a diversity of:
    - Support functions (support to care recipient, support to quality of care through carer, support to carer's quality of life, participation, and migrant-related).
    - Types of ICT (ICTs for independent living, ICTs for information and learning, ICTs for personal support and social integration, and ICTs for care coordination).
- Second set of criteria:
    - The degree of availability of data for impact measurement/analysis.

[10] Deliverable 3.6, Final report on the "Methodological framework", available at http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/D3.6FinalreportontheMethodologicalFramework.pdf

- The degree of impact and its policy relevance.
- Its potential scalability and transferability to other contexts.

Among these 20 available operational and successful European initiatives, 10 ICT-based services were selected, complemented with two initiatives from North America. These two American initiatives were recognised examples of high quality impact assessment design and there was convincing evidence of positive outcomes. The selection tried also to keep a balance among the different care regimes[11] to show ICT application in different national backgrounds. The in-depth analysis was developed using interviews with key promoters, and a review of available documents and impact studies. The aim of this analysis was to describe not only the impact, but also the processes behind setting up the services, documenting barriers and success factors.

A case study method was used to analyse each initiative. It was done with a common data collection framework, and guidance on questions to ask of people and documents. The case study method was developed with a three-fold aim:

- To collect all the impact assessment and evaluation data available from within the service or project. It aimed to show the most comprehensive way the actual impact of the service as it had been measured. This included documenting the evaluation methods use, and providing references to the original studies.
- To explore what sort of impact assessment and evaluation had been carried out along the lifetime of the service, the methods used, the limitations and gaps, and the conditions under which this evaluation had been made. This information also provided a test of the scope of the proposed Impact Assessment Methodology (IAM).
- To provide an account of the development of the service over time to contextualise the impact assessment, and provide the information necessary to inform the analysis of potential for scaling transferability and development. This description identified key enabling factors, barriers to development and how they were overcome, the actors, the way the technology, financial and professional support was developed, the decision points, the way that evidence of impact was used to inform decisions.

Results are available in deliverable 4.3, *Final report containing case-by-case detailed description and analysis of selected 12 good practices*, and implications for the methodological framework are included in deliverable 3.6, *Final report on the "Methodological framework"*, as well as in the deliverable 5.3, *Final "Integration report"*. In Section 4.2, a summary of the analysis of the 12 cases is offered.

Moreover, as a second stage and based on these case studies, a cross-analysis of the 12 good practices analysed at individual level has been produced. An analysis about the impact, business models, drivers, success factors and challenges of the initiatives has been developed taking them as a whole, and not case by case. This allows us to give a general overview on variables associated with the design, development, implementation, transfer and scaling of ICTs services for informal care.

4. Fourth, the development of four scenarios to illustrate how the provision of long-term care can positively change with the commitment with policy recommendations with ICT-based services for informal carers. The stories were built on the assumption of the

[11] See: Simonazzi, A. (2009). Care regimes and National employment models. *Cambridge Journal of Economics*, 33, 211-232.

existence of different contexts in which ICT-based services for informal carers can be used. These contexts of use were determined by the following four factors:

i) The characteristics of the end-users: the main user - the informal care - and other actors involved in the provision of care. The experts identified four profiles of primary end-users (informal carers) in more urgent needed of intervention.

ii) Their needs or objectives to get with the use of the ICT-based services: referring to which is the need they want to cover through the use of the services.

iii) The ICT-based services for informal carers available today, and

iv) The environment of care where the services will be used. In general two main living environments were possible: to use the services at home or at work.

Data on these contexts of use to build the scenarios emerged from a two-day workshop discussion in November 2011 with experts and policy makers from a range of background and countries, that were grouped in two working groups organised by care regimes[12]: the one mainly based on non-family or 'formal' elderly-care service ('the service regime') and the regime primarily relying on family-based care (the 'family regime'). Experts identified that currently the service-oriented care regime is focused on keeping older people at work and increasing the pensionable age, which generates a higher number of working, elderly carers. Policy trends regarding long-term care are focused on the development of a system based on the consumer choice and models of personalisation of care through cash for care. Privatisation of services is also in the agenda. Moreover, countries are aware that ICT-based services for carers represent business opportunities, where regulation and competition are still needed.

Experts agreed that the family-based care regime is currently characterized by little support from public institutions to provide care, the current formal services for carers are insufficient in order to relieve them from their daily task and a minimum member of families have access to them. For this reason, NGOs are filling the gap between the formal and informal sector in some countries as a service provider, through the mobilization of volunteers that provide help to domiciliary carers. In some countries, the black market of migrant carer workers is even relieving some families of the care tasks, and it is for this reason that mixed solutions with different sets of actors providing care to dependent elderly people composed by families, NGOs and black labour market of migrant workers currently exist. The economic crisis is not helping in solving this problem. Current trends are focused on moving the carer from home to community, and in some countries like Central Europe, the role of NGOs is expected to increase. In this sense, a policy enabler would be evolving from specific policies focused on carers within the integration of all policies concerned 'caring'. This differentiation was helpful to raise the different profile of carers (main users), but it was not used to differentiate the different scenarios, and each of them can be developed in any of these regimes.

[12] These two care regimes are a simplification of care provision across Europe. No attempt was made to scientifically analyse and assign countries or regions to particular regimes, but all the participants recognised the logic, and were able to situate their national experience within a regime, and were happy to participate in one of the two working groups in these regime categories.

3.2.3 Research team

The CARICT study was led by JRC-IPTS inside its existing programme of work on ICT for Carers in domiciliary settings. This programme aims at providing evidence and options for policy in the areas of long-term care and ICT for Inclusion. The JRC-IPTS coordinator was James Stewart and the IPTS action leader was Clara Centeno.

The research activities were developed by the principal contractor, the European Centre for Social Welfare Research, and the project consortium included four national partners: the Centre for International Research on Care, Labour and Equalities (CIRCLE) of the University of Leeds; the Italian National Institute of Health and Science on Aging (INRCA); the Institute of Sociology of the Hungarian Academy of Sciences; and the Swedish National Family Care Competence Centre (SNFCCC). Carers UK, on behalf of EUROCARERS, also participated in the study as international advisor.

The lead researcher for the contractors was Giovanni Lamura, with the research consisting of Francesco Barbabella, Andrea Schmidt, and Frédérique Lamontagne-Goodwin. They were mainly in charge of collecting and analysing the case studies, developing the methodological framework, to propose policy recommendations, and draft future scenarios on the basis of project findings and workshops organised with experts and policy makers.

The project results have been validated by a group of 41 experts (detailed in Table 10) and through two expert workshops:

1. An expert validation workshop, held in Brussels (21-22 June 2011). It involved 22 external experts which validated intermediate results of the project; and
2. A policy makers' and experts' validation workshop, held in Brussels (21-22 November 2011), involved 19 external experts which validated the final CARICT outcomes.

Table 10: List of experts participating in the CARICT validation workshops

Name	Institution	Country
	EXPERTS	
James Barlow	EPSRC funded Health and Care Infrastructure Research and Innovation Centre (HaCIRIC) , Imperial College London	UK
Sophie Beale	York Health Economics Consortium	UK
Werner B.F. Brouwer	Institute of Health Policy and Management Erasmus Universiteit	Netherlands
Stephanie Carretero	President Sociedad Española de Asistencia Sociosanitaria (SEAS) / Polibienestar Research Institute, University of Valencia	Spain
Peter Cudd	Health Services Research Section, School of Health and Related Research University of Sheffield	UK
Emiliano Deferrari	Care Assistance Search Agency (C.A.S.A)	Italy
Hanneli Döhner	Medical University Hamburg Eppendorf	Germany
Åke Fagerberg	Chairman, Carers Sweden	Sweden
Lajos Győri	Head of Magyar Máltai Szeretetszolgálat	Hungary
Jane Hendy	Imperial College Business School	UK
Lutz Kubitschke	Empirica	Germany
Elsa Marziali	University of Toronto	Canada

Kevin McKee	Professor of Gerontology, Dalarna University & Dalarna Research Institute	Sweden
Heidrun Mollenkopf	Heidelberg University & BAGSO	Germany
Margarita Perez Garcia	Fundacion MENON	Belgium
Angelo Rossi Mori	eHealth Department, Italian National Scientific Council	Italy
Richard Schulz	Department of Psychiatry and University Center for Social and Urban Research, University of Pittsburgh	USA
Stéphanie Vincent	Institut FEPEM	France
Julia Wadoux	AGE Platform Europe	Belgium
Robert Anderson	European Foundation for the Improvement of Living and Working Conditions/Chair of Eurocarers	Ireland / Europe
Johanna E.M.H. van Bronswijk	Eindhoven University of Technology and International Society for Gerontechnology	Netherlands
Carlos Chiatti	INRCA	Italy
Kevin Cullen	Work Research Centre (ICTs, health and carer research)	Ireland / Europe
Annette Dumas	Alzheimer Europe (EU Public Affairs Officer)	Belgium / Europe
Caroline Glendinning	SPRU, York University, York	UK
Rosie McLoughlin	Vocal (Carers organistion)	UK
Michel Naiditch	IRDES / INTERLINKS project	France
Martin Schmalzried	Confederation of Family Organisations in the European Union (COFACE)	Belgium / Europe
Madeleine Starr	CARERS UK	UK
Judy Triantafillou	50plus Hellas	Greece
Julia Wadoux	AGE Platform	Belgium / Europe
Verina Waights	DISCOVER, Open University	UK
Sue Yeandle	University of Leeds	UK
	EXPERTS FROM THE EC	
Katarzyna Balucka-Debska	EC DG INFSO	Belgium / Europe
Arnaud Senn	EC DG EMPL	Belgium / Europe
Francisca Rosario Garcia Lizana	EC DG INFSO	Belgium / Europe
Anna Maria Sansoni	EC DG INFSO C1	Belgium / Europe
Clara Centeno	EC JRC-IPTS	Spain/Europe
James Stewart	EC JRC-IPTS	Spain/Europe

4. MAIN FINDINGS

4.1. Analysis and mapping of the 52 ICT-based initiatives for family carers

We searched for examples of ICT-based initiatives for carers across 12 countries, and 5 care 'regimes' (Anglo-Saxon, Continental, Scandinavian, Mediterranean, and Eastern European ones). We then selected and documented a sample of 52 initiatives, which represents the largest European data-set available in the field at this moment.

As showed in Table 11, there are 10 cases in the Anglo-Saxon care regime (of which 3 are in Ireland and 7 in the UK), 16 cases in the Continental care regime (of which 4 are in Austria, 6 in France and 6 in Germany), 8 in the Scandinavian care regime (of which 5 are in Sweden and 3 in Finland), 9 in the Mediterranean care regime (of which 5 are in Italy and 4 in Spain), and 9 cases in the Eastern European care regime (of which 5 are in Hungary, 2 in the Czech Republic and 2 in Slovenia).

Table 11: Geographical a care regime coverage of the 52 mapped ICT-based initiatives for family carers

Care regime	Country	Mapped initiatives
Anglo-Saxon (liberal)	Ireland	3
	United Kingdom	7
	Overall number per care regime	***10***
Continental (corporatist)	Austria	4
	France	6
	Germany	6
	Overall number per care regime	***16***
Scandinavian (Nordic)	Sweden	5
	Finland	3
	Overall number per care regime	***8***
Mediterranean	Italy	5
	Spain	4
	Overall number per care regime	***9***
Eastern European	Hungary	5
	Czech Republic	2
	Slovenia	2
	Overall number per care regime	***9***
	Total	**52**

The list of 52 initiatives surveyed is included in Table 12.

Table 12: Sample of the 52 ICT-enabled services in 12 countries collected for the CARICT Study

Name	Country	Independent Living	Information & Learning	Personal Support & Social Integration	Care Coordination
Leeds City Council Telecare Service	UK	X			
Carers UK online forum:	UK		X	X	
HFT (formerly Home Farm Trust)	UK	X		X	
Book Your Own Breaks	UK	X		X	X
Telecare Scotland	UK	X		X	X
Just Checking	UK	X	X		
Nottingham Community Housing Association	UK	X	X	X	
Fold Group	Ireland	X		X	X
Try It	Ireland	X		X	X
Emergency Response Ltd	Ireland	X		X	X
Hilfswerk Notruf	Austria	X			
Alzheimer Website	Austria		X		X
n@tzwerk pflege	Austria			X	
Platform for family carers	Austria		X		
Cyber France	France	X	X	X	
Salveo	France	X			X
Maison Vill'age	France	X			X
Forum aidants	France			X	
Web-napperon	France	X		X	
Open and distance learning	France		X		
SEKIS	Germany		X	X	
Pflege Wiki	Germany		X		
Vitaphone	Germany	X			
Sophia	Germany	X			
Paul	Germany	X			

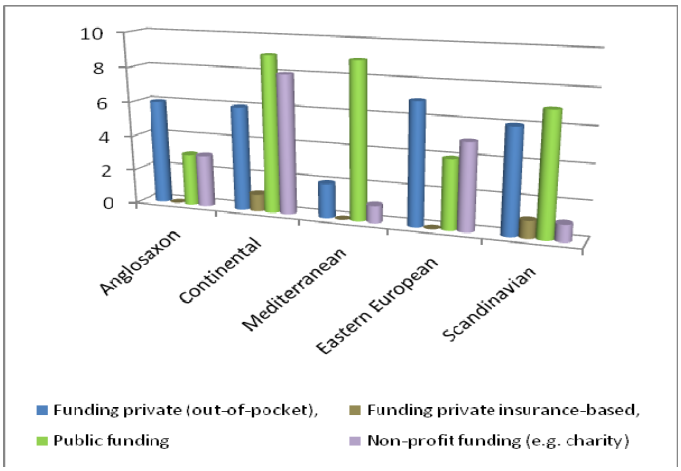
Alzheimer Blog	Germany			X	
Vivago Watch	Finland	X			X
The CaringTV (Hyvinvointi TV)	Finland	X			
Everon	Finland	X			
My Joice TV	Sweden	X			X
Action	Sweden		X	X	X
Family Care Support Portal (Anhörigstödsportalen)	Sweden		X	X	X
Gapet	Sweden		X	X	
Ippi +Amigo	Sweden	X	X	X	X
Skype care	Hungary			X	
Emergency Alarm	Hungary	X			
Mohanet	Hungary	X			
Életvonal 24	Hungary	X			
Body Guard	Hungary	X	X		
Seniors' Telephone – Crisis Helpline (Zivot 90)	Czech Republic	X		X	
Careion Emergency Care	Czech Republic	X	X	X	
Red button telecare	Slovenia	X			
My healthcare personal reminder	Slovenia	X			
CAMPUS	Italy		X	X	
E-CARE	Italy	X	X	X	X
C.A.S.A. (Care Assistants Search Agency)	Italy		X		X
Ring Project (Transferring supports for caregivers)	Italy		X		
T-Seniority Project	Italy	X	X	X	X
Andalusian Telecare Service	Spain		X		
Un cuidador, dos vidas (A carer, Two lives)	Spain	X	X	X	X
Ser cuidador	Spain		X	X	
Tele-gerontologia	Spain	X	X	X	X

Most initiatives (46 out of 52) are operational and are integrated to varying degrees in local care systems. Where pilots were selected (6 out of 52), they were innovative examples (in France, Sweden and Finland) or ensured diversity and a sufficient number of interesting initiatives in each country (this was the case for two initiatives in Hungary and one in Italy).

A literature review, an internet-based search and interviews with key actors of the selected initiatives produced the following main findings:

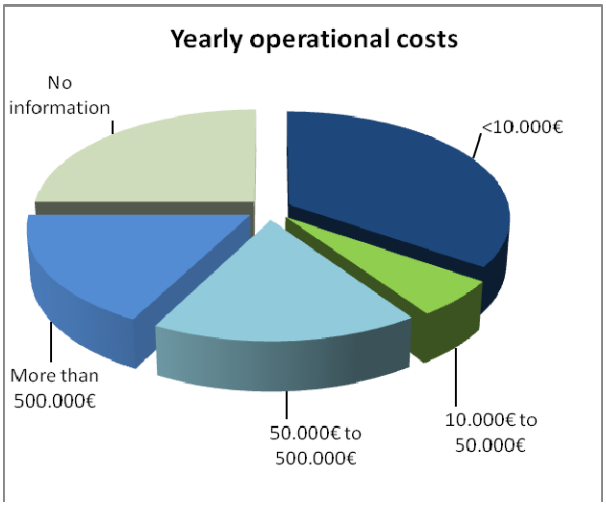
- Good practice examples of ICT-based services for carers in Europe are still rather difficult to find. In the CARICT study, however, we found 75 case studies, of which 52 were compared, showing that a wide range of successful examples do actually exist across Europe.
- Many successful initiatives may be carried out a local level, are disconnected or remain undocumented, which makes it especially hard to gather information about them.
- Telecare and emergency alarm are the most frequent technologies to carers. These services help older people and indirectly affect the carers. Direct services for carers are psychological therapies, information and training, labour-market or migrant-related support services. Training sessions for carers and older people to use ICT devices help to ensure the success of these services because they give digital competences and overcome fears and prejudices towards new technologies. The amounts of out-of-pocket payments required from users to access ICT-based services differ not only according to the national care systems, but also to the complexity of each service. In every case, public funding – and thus less investment required from users – may help key initiators of ICT-based services to overcome financial difficulties at early stages of development and convince users of their benefits.
- The services are mostly privately-led with mixed funding, from public, third sector and out-of pocket contributions (Figure 7). Non-profit actors like research institutions, charities or civil associations set up these services mostly in countries with a low level of state involvement (Eastern European countries) and with limited involvement in LTC of private for profit actors (such as in Germany or Austria). By contrast, in Sweden, where municipalities have to deliver services for carers, a mix of different actors develops ICT-based services.

Figure 7: Funding actors of the 52 ICT-based services for informal care



- Volunteers play a key role in many initiatives. They provide a valued contribution to the quality of care (high satisfaction of end-users with volunteers) and to the sustainability of the service.
- Many initiatives are not very costly, but financially vulnerable (Figure 8).

Figure 8: Yearly operational cost of the 52 ICT-based services for informal care



- A condition for success is cooperation between public authorities, health and social care services and carers. In countries where programmes for carers have been implemented at national or regional level, such as Spain, Sweden and Finland, ICT-based services are much more easily scaled up and sustainable than in countries like Hungary, where sudden policy changes have removed funding for ICT services, causing their disappearance from the social care system. For this reason, raising awareness among both policy makers and formally qualified carers for ICT-based services, overcoming their scepticism about formal long-term care sector services for (informal) carers, and making sufficiently trained staff available are also highly relevant factors to ensure a positive outcome.

The mapping and results of the analysis are available at Deliverable 2.3. *Analysis and mapping of 52 ICT-based initiatives for carers.*[13]

[13] Deliverable 2.3, Analysis and mapping of 52 ICT-based initiatives for caregivers, available on-line, available at http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/CARICTD2.3Mappingof52initiatives.pdf

4.2. In-depth description and analysis of selected 12 good practices

4.2.1. General information on the selected 12 good practices

The selected 12 initiatives are:

- *Anglosaxon area*:
  - Just Checking (UK).
  - Telecare Scotland (UK).
- *Continental area*:
  - SOPHIA (Germany).
  - Platform for Family Carers (Austria).
- *Scandinavian area*:
  - ACTION (Sweden).
  - IPPI (Sweden).
- *Eastern European area*:
  - Emergency Alarm (Hungary).
- *Mediterranean area*:
  - CAMPUS (Italy).
  - E-CARE (Italy).
  - Cuidadoras en Red (Spain).
- *North America*:
  - Caring for Others (Canada).
  - Resources for Enhancing Alzheimer's Caregiver Health I/II (REACH I/II) (USA).

Table 12 summarises the 12 cases and includes the service description and how the services for carers. In the next point (4.2.2), we summarise the in-depth analysis of the 12 cases, with a table per initiative. Telecare systems are highly represented in the sample, partly because these are some of the most developed and well-evaluated services. However, their impact has seldom been analysed from the perspective of informal care. Comprehensive and detailed information can be found in the Deliverable 4.3. '*Final report containing case-by-case detailed description and analysis of selected 12 good practices*'.[14]

[14] Deliverable 4.3, Final report containing case-by-case detailed description and analysis of selected 12 good practices, available at http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/D4.3FinalreportAnalysisof12goodpractices.pdf

Table 12:. Summary of 12 selected good practices

Name (Start year)	Country	Service description	Care support means	Independent living	Information & Learning	Personal support & social integration	Care coordination
ACTION (1998)	SE	University Spin-off provides technical system, training and support to municipal care services, which use the service to facilitate quality home care.	Elderly spouse carers can use Web-based training support, video phone links to a social care call centre, to communicate with network of families and specialised practitioners.		X	X	X
CAMPUS (2004)	IT	Care organisation develops and provides training material to local municipalities and individuals.	Set of online and DVD-based training material for informal carers to improve caring skills and life chances for families, carers and migrant care assistants.		X	X	
CARING FOR OTHERS (2000)	Canada	Multi-service health service organisation programme verified by research and standardised and documented to be licensed to other care-providing organisations trying to reach housebound carers.	10 weekly group training sessions via internet video to high burden housebound carers, with follow-up video support group, and online information.		X	X	
CUIDADORAS En RED (2008)	ES	University/voluntary-led initiative with local ICT centres in rural areas to support carers in Andalucia.	Training courses on ICT-skills to improve access to information and social support, primarily for female family carers and care assistants. Online community.		X	X	
E-CARE (2005)	IT	Regional and local health and care planning and coordination platform run by a private company, but involving a large range of public and private organisations.	Care planning and coordination with multiple agencies, families and volunteers; provides call centres, tele-alarms, tele-health, video conferencing, online information, tele-friending	X	X	X	X
IPPI +AMIGO (2004)	SE	Services sold by private company to local care authorities and some individuals in Sweden to help them meet mandatory care requirements. Exploring market in Asia.	TV-based communication system for older people to communicate with care services and family, (including teenagers) with call centre for relatives to update and coordinate care.	X	X	X	X
EMERGENCY ALARM (1994)	HU	Service provided by a large NGO in welfare services to local authorities and other care-providing organisations (e.g. churches) in urban and rural areas.	Social alarm over GSM, with call centre staffed primarily by volunteers, facilitating home care.	X			
JUST CHECKING (2003)	UK	Private company provides technology, service and training via subscription to local care commissioners in the UK	Electronic Monitoring of movements of early-stage dementia sufferers living at home helps professionals and family better understand care needs, building trust, and facilitating independent living and home care.	X	X		
PLATFORM FOR CARING FAMILY MEMBERS (2006)	AU	A central government-funded and operated service providing information to carers nation wide, building on an existing counselling hotline. 92,000 website visits in 2010	Information web site and hot line in two languages about caring, services etc.		X		

REACH I/II **(experimental** **1995, 2001)**	USA	Research-driven project (RTC) to determine scientifically design and test effective multi-component support interventions for carers across a range of US locations.	Integrated service supported by nurses, online, video and telephone including therapy, advice, a bulletin board and training which aims to reduce the burden and depression in family carers, to support carers of dementia sufferers		X	X	
SOPHIA **(2005)**	DE	Initiative by housing company to support tenants who wish to remain in their homes, in cooperation with local care services and a service provider company operating in many regions. End users pay for 2 different service packages. 3,500 users in Germany in 2011.	Multiple types of social alarm, and a call centre to support identification of older people's needs, and provide phone-based social support to older people and carers from volunteers.				
TELECARE SCOTLAND **(2006-2011) now mainstream service**	UK	National programme to develop telecare to support home care in care regions across Scotland, involving change in central team, local authorities, private technology suppliers and carer support associations. Incorporated into 'NHS24' service in 2012.	Social alarm and home care sensors to help local care services and family members care for older people in the community.	X		X	X

4.2.2. Individual analysis of the 12 good practices

Name of the good practice	ACTION -Assisting Carers using Telematics interventions to meet Older people's Needs		
Region/Country	Sweden	**Website**	www.actioncaring.se

Summary

"The ACTION service is directed at frail older people who prefer to stay in their own homes but who are in need of support. The service includes remote provision of dedicated information and education programmes which strengthen the self-management capabilities of older people and their families, thus enabling them to better cope with their situation. By means of ICT, family carers can get on-demand support from local service centres that are staffed with qualified professionals. Also, networking and mutual exchange between service users is facilitated. The service is available in several municipalities." Empirica, WRC & TUW (2010:158)

Descriptive information

ACTION aims to maintain or enhance the autonomy, independence and everyday quality of life of older people with chronic long-standing conditions and their family carers, and to increase the job satisfaction of care practitioners and the overall quality of care for older people at home. The initiative is theoretically grounded within the temporal model of family caregiving and the carer as 'co-expert' model (Nolan, Grant & Keady, 1996), which focus on enabling family members who are novice carers to become expert carers with regards to their own caring situation via the provision of information, education and support that suits their individual needs and preferences. The ACTION service primarily helps older spouse (or partner) carers (co-resident and non working carers), and carers of working age who provide regular help and support to an older relative who lives close by, most commonly daughters. The ACTION service offers information, education and support to older people and their family carers via the following elements: access to an extensive information database about caring in daily life, services available and coping strategies; physical and cognitive training and relaxation programmes; support and social company from other users via the integrated videophone system; support and advice from skilled care practitioners working in the call centre via the videophone system; individual and group computer education about how to use the ICT-based service; and comprehensive education, ongoing supervision and certification programme for care practitioners working in an ACTION call centre. Technically, the service uses a local client, connected to a purpose-built web platform on the host server.

Operational information

The service has grown from an FP4 EU project (1997-2000), co-ordinated by the University of Borås, to a mainstream service in approximately twenty municipalities in Sweden. Since 2000, the initiative has been further researched, developed and evaluated with the help of successive external national research and development funding in Sweden. The creation of a spin-off by the University of Borås and its partnership with Telia Sonera, the largest telecommunication operator in Sweden, and the adoption of the Borås municipality of the ACTION as its mainstream services for its older citizens living at home and their family carers have been decisive in the development of the service across Sweden. The service is now part of the social care services in several municipalities in Sweden: the municipalities finance the service and pay for each user and the user pays an average fee of 20 Euros per month and the broadband access costs. There are currently 350 people who regularly use the service. In order to start using the service the user needs an ordinary personal computer with a web camera and Internet connection. No prior computer skills are needed. Users receive education in how to use the service and remote support.

Impact assessment

The service impacts mainly on subjective quality of life. It reduces social isolation, increases sense of security regarding their caring situation and enhances social inclusion in the current information society of elderly people and their carers. More specifically, it increases carers' levels of preparedness with regards to their care task, gives them higher levels of self-esteem and mastery over their situation and reduces uncertainty about their future. In 2004, ACTION saved the Borås municipality 10 000 Euros per family by reducing the need for home help services and delaying the entry of the care recipients into nursing homes. The service also represents a more environmentally friendly way of working for staff as they use the video-system when contacting service users, thus there is a reduced need for staff to travel and carry out home visits to clients.

Enabling conditions, success/failure factors

Several actions enabled the development of the service on a regular basis: regular information and demonstrations and involvement of users; confirmation of the cost efficiency of the service in the Borås municipality and the creation of an efficient, well functioning business model. Moreover, presenting the service as an assistive device to help end-users in their daily lives has had a much more positive reception than to present it as a computer programme. ACTION requires a high level of commitment by the local municipality at the implementation stage: close co-operation with staff who are competent in the fields of health and social care for older people, family care support and information and communication technology; user-sensitive design methods; teaching and supervision within care organisations; implementation of ICT support services for older people and their carers and research and development in all of these areas were of crucial importance.

Future perspectives

To integrate the maintenance of the health status of service users via video-phone access to physicians and health care practitioners and to remotely monitor clients' vital signs and treat their chronic conditions; to have a solid business plan for ongoing updating and development of the service; to possibly replicate the service in other countries in local contexts with translation work and cultural adaptations.

Name of the good practice	CAMPUS		
Region/Country	Emilia-Romagna/Italy	**Website**	www.anzianienonsolo.it/?page_id=21

Summary

"Campus is a system for distance learning and in-presence education targeted at social and care service professionals. It is designed for people with low expertise in ICT. It includes audio and video courses, skills tests, and exercises, which ease the contacts and interactions between students and teachers, also distance." (from the CAMPUS website).

Descriptive information

The aim of CAMPUS is to provide skilled training to carers of older people (the "badanti") using ICT (i.e. the platform CAMPUS). The initiative CAMPUS was set up thanks to the support and funding of the Equal project ASPASIA (Elderly home care: integrated system of services for people and firms), which ran between 2004 and 2008. It is managed by the social cooperative Anziani e Non Solo. The courses are accessible via either an e-learning platform (CAMPUS) or DVDs – for those without a pc or an Internet connection – and are translated into seven languages. The costs of the training are notably lower than those of a traditional training course and, moreover, users do not have to pay a fee. Funding for the courses was provided by EU resources and from other local resources (municipalities, inter-professional funds, etc.). At the end of the course, users who studied at home (via DVDs or e-learning) can be tested in person (in specific centres, usually located in the offices of the local social services). It is also possible for users with over 1 year of work experience to self-assess their skills through a Moodle-based tool (the ICT platform). In this case, users complete different kinds of exercises (filling in the blanks, quizzes, matching…) and, after the self-assessment, they are asked to study those modules of the training course that were not validated (thus saving time and enhancing the skills they already have). Today these courses are available in several Italian regions and municipalities and CAMPUS methodology is now fully operational.

Operational information

The initiative was set up and implemented thanks to the support and funding of the Equal project ASPASIA (2004-2008), and it is present now in many municipalities of the province of Ferrara (Emilia-Romagna) and in other areas. Users have to pay a fee to benefit from the services for family carers, and courses for migrant care workers are free-of-charge. There are currently over 1,000 carers (around 40% Italians and 60% migrants) in different Italian regions, who use the courses both as a self-learning tool and integrated with face-to-face classes.

The consensus-building process prior to the implementation of the initiative was facilitated by public awareness regarding the relevance of the issue of qualification and training of care workers in the country.

No specific ICT skills are required to use this training tool. If necessary, users/carers acquire the ICT skills needed to use the platform CAMPUS thanks to a project operator who shows them how to use the system at home. The carers/users can also refer to operators in the "ASPASIA points" created in the municipalities (at local social services) or employment agency partners in the areas in which the initiative took place.

Impact assessment

High satisfaction with the training activities. Up to now, 60-70% of the people trained and enrolled in local professional registers, obtained a job within a year. The main outcomes identified for institutional stakeholders related above all to the possibility to provide suitable training and education to informal carers and migrant care workers.

Enabling conditions, success/failure factors

An important factor was the opportunity given by both EU funding and budget contribution from the Italian stakeholders. In addition, the initiative took advantage of the affordability of the technology used: the MOODLE tool. The initiative could not have been realised without contributions from a multi-disciplinary team, including social workers, medical doctors, nurses and ICT professionals. Other enabling factors: strong involvement of stakeholders, who cooperated to encourage the use of ICT in the care of the elderly. The creation of partnerships with employment agencies and formal care staff encouraged the matching between supply and demand for care work, contributing to the regularization of illegal work in this sector. It involved a large number of carers and involved various stakeholders, who have allowed the spread of the initiative to various Italian regions.

Future perspectives

The project and its model of intervention have demonstrated that the ICT solutions developed for the training of carers are efficient and transferable to different local contexts. It is possible to use the platform CAMPUS at any time and, if necessary, its online course contents can be updated. Its sustainability is guaranteed mainly by the funding provided by several local authorities.

Policy implications

The initiative promoted digital and social inclusion, employment, and lifelong learning of a high number of care workers/users.

Name of the good practice	Caring for others (CFO)		
Region/Country	Canada	**Website**	www.baycrestcfo.com
Summary			
'The CFO website was designed to help you stay in touch with other carers. You will also be able to access useful information to help you care for your family member'. (Main message from the website).			
Descriptive information			
The CFO website evolved from research initiated in 2000 by Baycrest (a research centre at the University of Toronto). It aimed to provide a user-friendly Internet-based programme for family carers of people with chronic diseases/disabilities. Family carers receive online an evidence-based course provided by a health professional, consisting of ten weekly one-hour group sessions through Internet access using web cams and audio head sets. Each group continues to meet weekly online for 10 more mutual self-help sessions with no professional facilitator present. There is a password-protected web site, information handbooks by disease type posted on the web site, an intervention training manual to ensure reliable adherence to the model of intervention, a computer training manual focused on helping participants to negotiate established web site. CFO technology simply provides the infrastructure for the delivery of a clinical programme that is usually provided face-to-face by health service providers.			
Operational information			
The CFO is supported and promoted by Baycrest and publicly funded by the Canadian federal and provincial Ministries of Health (like any other kind of health service). Its implementation required by Baycrest to support the training of one clinician, a technician part time to assist carers with installation of software, training to access the web site, and a server to support the web site. The CFO programme provides 20 sessions – in each study, there were very few drop outs. It is readily translatable to any language and all that is required is a trained health care professional. In order to participate, carers log on to their secure, password-protected CFO site and settle in for chat access. Carers learn about the CFO service through healthcare provider organizations. Baycrest social workers have begun to offer the online programme to carers.			
Impact assessment			
Studies of the intervention showed that CFO reduced the need for travel, the costs of face-to-face support groups, and the time that patients are in a hospital or institution. It also delays admission into long-term care institutions. The savings made by a one year delay were estimated at $5.4 billion annually for the Canadian health-care system..			
Policy implications			
Expanding the scale of the present service is very easy and all elements were proven to be replicable. In addition, this internet-based innovation can be adapted to any country. The system allows carers to be digitally included prevents them and their loved ones from being socially excluded and increases the employability of health care workers.			

Name of the good practice	Cuidadoras en Red - "Women Carers' Network		
Region/Country	Malaga/Spain	**Website**	www.cuidatel.es
Descriptive information			
"Cuidadoras en Red" is an initiative led by the former Institute of Innovation for Public Welfare (I2BC) in collaboration with the Nursing Department of the University of Malaga (UMA). It was set up in 2008, and consists of a social network for family carers, social-care workers and private care workers (mostly immigrant women). It aims to increase digital competences and social inclusion of informal carers living in rural/sparsely populated areas. The social network creates a community specifically for informal carers, using photo albums, personal blogs, community blog, community forum, group files, messages, and videos. It also includes an "in class" workshop for digital competences and the participation of experts who act as "animators" and promoters of new blogs, fora, and discussions.			
Operational information			
The service is non market-oriented and not for profit. The maintenance costs of the service are low. The workshops are developed voluntarily by the person responsible for the initiative in rooms of the Guadalinfo Project telecentre (of the Junta de Andalucía). The platform received over 3,300 visits in the last year (2010-2011) and counts on the participation of 348 active members. No detailed information regarding the profile of people who use the network is available, only information on gender can be retrieved.			
Impact assessment			
The programme increases the digital skills of carers, and their social and intergenerational relationships.			
Enabling conditions, success/failure factors			
The use of the social network increases thanks to word of mouth and to dissemination of information by users themselves. The strong "voluntary base" behind the initiative represented a key success factor for its early development, but a barrier for its further development. It is relevant for a further growth of the initiative a higher availability of technological infrastructure by families and the implication of the professionals involved in the care process.			
Future perspectives			
The service is sustained at a very low cost. The failure to obtain financing in a short period has caused a suspension of the service.			
Policy implications			
The initiative demonstrates that: a) even the Carers with low levels of education and a great burden in everyday life are motivated to learn to use ICT through a face-to-face training programme; b) the use of social networking promotes social relations between carers and improves the relationships with younger members of the family; and c) ICT tools are very effective for learning at home and they encourage carers to study what they have not been able to study before.			

Name of the good practice	E-CARE		
Region/Country	Emilia-Romagna/Italy	**Website**	www.cup2000.it/reti-ecare

Summary

"E-CARE works to facilitate the management of electronic services distribution, including public services and services of public interest. This system is a connection between the Web and the health sector, through the contribution of knowledge and by integration with specialized sites for health. E-CARE is a network of networks, based on the spread of E-Services, in particular those related to social, health and safety areas, in response to needs of the citizens, especially elderly". Moruzzi (2005: 204).

Descriptive information

The E-CARE system coordinates and integrates an ICT-based service network for elderly people and carers and generates personalised care pathways for the care of older people at home. E-CARE is promoted by the Region Emilia-Romagna, Provinces, Municipalities and Local Health Authorities of Bologna and Ferrara, and is part of a general regulatory and policy framework. It was developed from 2005 by CUP 2000 Spa, an industrial organization on e-health and Internet networks for care in Italy, in cooperation with a wide network of other stakeholders. The main target group consists of older people who are more than 75 years old and live alone. They may have other functional, clinical and social difficulties and domiciliary (informal and migrant) carers. The E-CARE system is organized as a 24 hours/ 7 days week call centre, that offers a wide range of services (mainly ICT-based) according to the needs of the elderly users and carers and a personal health and social record (information regarding his/her well-being, health conditions and needs). The system is also directly linked to the CUP service that books outpatients visits within the Italian NHS. Integrated services include: telecompany, telecare, telemonitoring, telealarm, telemedicine and teleinformation, in combination with a basic and intensive formula of provision of services for the carrying out of daily life activities according to the dependency level of the elderly users and a personalized monitoring activity of issues and needs of their carers. A specific intervention for carers of older people with dementia include: daily emotional and legal support through the call centre, training/information, social activities and integration with the network of local support services. A central software has been developed as the core of the system, supported by a range of tools and technologies designed to facilitate networking among stakeholders. The call centre in Ferrara made 27,746 outgoing calls in 2007-2008 and received 6,258 incoming contacts from users included in the project.

Operational information

The idea of the project was developed in response to the heat wave emergency of 2003. A first trial phase, of the project (trial) was launched in 2004 in the Province of Bologna and then extended to the territory of Ferrara. Te E-CARE Project in Bologna and Ferrara has gone from experimental design to a structured and consolidated service for citizens in the knowledge society. It exploits the potential offered by new ICTs to build a New Welfare of Networks. In the first phase of the project (testing), the E-CARE initiative was funded by local banks, and is currently funded entirely (its budget is around 700,000 Euros) by the Regional Fund for Long-term Care, activated in 2007. The services are free and there are no co-payments by users on low incomes. The project's implementation has been entrusted to CUP 2000, in collaboration with associations, social cooperatives and pensioners' unions. About 250 groups joined the project and work closely to highlight the crucial role played by volunteers in the E-CARE network. In 2011, the number of users reached 3,350 units in Bologna and Ferrara. Users get knowledge about E-CARE services available through extensive communication and promotion activities carried out by stakeholders.

Impact assessment

Users express maximum satisfaction with the service (90%), achieve an improvement in their health status (66.3%), perceive more safety (72.1%) and less loneliness (78.2%) and have expanded their friend network (70.6%). Over 80% of carers involved in the initiative were satisfied, showing appreciation for the services and highlighting the positive relationships with operators of E-CARE call centre. Moreover, the service has provided ongoing support to family carers, reinforced home care of elderly people with dementia and has attenuated relational discomfort and stress. In two years, a reduction in the number of admissions to hospitals has been observed (100 fewer), with a cost saving for the health-care system of 600,000 Euros. In addition, 50% of users decreased their use of hospital services; producing a significant reduction in health-care costs

Enabling conditions, success/failure factors

The advanced level of development of the regional welfare system is the main and decisive factor that has encouraged the adoption and consolidation of the initiative and its positive results. Since 1980, Bologna has developed the Metropolitan CUP a system of electronic access to health care that has evolved into E-CARE with the cooperation of stakeholders (CUP 2000, Municipalities, Local Health Authorities of Bologna and Ferrara, unions, associations, volunteering, etc.) and the setting up of the Regional Fund for long-term care.

Future perspectives

The service's sustainability is at risk due to the recent reduction of public contributions from central government to local governments' budgets. The service can be reproduced and transferred to other territories than the Emilia-Romagna, with proper policy, funding and an effective cooperation between local stakeholders. CUP 2000 is willing to expand to other European regions.

Policy implications

E-CARE promotes digital inclusion and communication between citizens and the welfare system, through a communication model based on a multiservice integrated network. It promotes social inclusion, breaks isolation and offers services of listening, and monitoring of health and social needs. It also enables the activation and intervention of local services for citizens' personal needs, and provides a structure for an innovative, efficient and effective redefinition of welfare and social health systems, even on a national scale.

Name of the good practice	Emergency Alarm		
Region/Country	Hungary	**Website**	www.maltai.hu
Descriptive information			
The Emergency Alarm system can send alarm signals from a device worn by elderly people to the 24-hour control centre of a Maltese home care organisation. The system is targeted at frail elderly people living at home alone and already receiving social care from local government-run formal care centres. The alarm system gives the older people a feeling of safety as they know they will receive immediate help, and it also eases the burden and responsibility of family carers as it replaces institutional care or postpones the time of admission to this kind of care. The alarm system is a wireless network based on radio waves.			
Operational information			
In 2000, the model programme that began in 1993 with 30 people was incorporated into the Social Welfare Act and became part of the system of care for the elderly. By 2011, the number of people with the emergency alarm exceeded 30,000. The service is provided exclusively within the structure of public social care for the elderly by the local authority, or a body under the contract to the locality or the church. Users contribute a small payment to the running costs. In 2011, around 2,500 people participated in running the initiative providing the ICT-based care service and over 1,000 token fee volunteers also helped in the care work. The number of volunteers working in the organisation's own care centre is increasing. The organisation's professional carers have secondary-level health qualifications, and the volunteers receive 20 hours training. Supervision is carried out in the regular monthly meetings and there is also continuous communication with the informal carers, who help to care for the elderly and check that the recipients of care use the device properly. There is no need for any special skill to use the system.			
Impact assessment			
Results from a survey carried out in 2011 on the service showed that: a) carers psychological needs are attended to, they experienced an improvement in somatic problems, had more leisure time, and were able to reconcile work and care; and b) it allowed care recipients to live independently, and replaced admission to a residential home or hospital (only 15% and 3% were admitted to a residential home and hospital, respectively; the number of applicants for residential homes fell by 40%), or shortened the period of rehabilitation there. The annual cost to the state of the emergency alarm system is only one seventh of what is paid to institutions maintained by the state (100,000-200,000 HUF vs 700,000-1,250,000 HUF).			
Enabling conditions, success/failure factors			
There is some discontinuity in the provision of the service. Users stop using the service because they go to a nursing home or hospital, or because they no longer receive copayment from the local authority			
Future perspectives			
All elements of the service are replicable and easily transferable to any system of care for the elderly. Sustainable financing is necessary for its sustainability and, over the long term, this could be threatened.			
Policy implications			
The system allows elderly people and their carers to be digitally and socially included, and carers to balance care and work, and health and social care system to be more efficient and sustainable.			

Name of the good practice	IPPI		
Region/Country	Sweden	**Website**	www.ippi.se

Summary

"Ippi opens up new channels of communication for people who currently remain outside the digital society. In addition to increased contact with family and friends, via ippi and their regular TV, individuals can also easily communicate with health-care providers, medical care and service providers such as the local cleaning company, pharmacy, grocery store, hairdresser, pedicure, etc. For the ippi-user, this means that important information is readily available in one place. In addition, individuals can have a voice in their own daily lives and the support and the services which concern them." from Ippi AB

Descriptive information

Ippi AB is a spin-off from Ericsson, which uses existing infrastructure in homes such as television and mobile networks. This service is designed to help older and disabled people to participate in the digital society. It also helps health-care providers to simplify and improve health care interventions through communication with the carers via ippi. It facilitates the care situation for relatives, by overcoming geographic and generational boundaries, and helps family carers with an additional service called AMIGO that offers them the opportunity to join a social support network.

All that is required to use ippi is a TV set and a mobile network. The ippi device can be easily connected to the TV set in users' homes and operated by them with a remote control. The user can then receive via the television audio, video and text messages sent using MMS, text and e-mail, and voice messages from an ordinary telephone. The user can also use the remote control to record, write and send messages to anyone with ippi, computer or mobile phone. The ippi has a regular mobile phone number and an e-mail address associated with a SIM card in the ippi. There is no installation required of the ippi and the user only needs the technical expertise to be able to start a TV and use a simple remote control. Via the ippi, the user can easily keep in contact with loved ones, but also with healthcare providers. Ippi offers healthcare providers a web-based ippi central, so they can easily send messages and information and ask questions to one or more users. The health care provider can also inform the user about staffing or implementation plans directly from its computer system, so the user is more involved in their own care situation.

Operational information

The development of the ippi service took about five years continuous work with user-driven development with designers and researchers, and the help of user participation and a user-based approach. User involvement proved to be significant for the ippi initiative to bear fruit. Today Ippi AB has 400 users among the elderly and the disabled and their relatives, and is being tested in India, Singapore, Spain, Aland Islands and Kenya.

Ippi is sold primarily as a subscription service to municipal and private health care providers. The cost consists of an initial charge of 384 € and a monthly fee of 33 € per ippi unit. The telephone company will also charge the cost of GSM traffic, but this is only a fraction of what a broadband subscription would cost (approximately 22-33 €).

Impact assessment

Ippi helps carers to rediscover a sense of control and power over their own situation. It strengthens the individual and improves their quality of life as they can communicate from a distance about the care situation and maintain a social network. It also involves older people in the provision of their care, increases the quality of care provided and quality of life for care staff in the sense that working conditions are improved. It also breaks generational boundaries in the sense that teenagers who are more accustomed to texting than calling have begun to have more contact with older relatives by sending messages and pictures from their mobiles.

Enabling conditions, success/failure factors

The service was successfully developed thanks to the funding of private investors (business angels) and public support. Moreover, although initially the service was targeted at the private market, with a focus on older people who did not use computers, the company changed the target audience to health care providers and relatives, and today municipalities have also taken the initiative to offer the service.

A major challenge in introducing the service is to get the support of the staff who may be sceptical about new technology. A solution by Ippi AB has been to contact health care providers to show what opportunities are available with ippi, and show references from other customers.

Future perspectives

Today there are plans for a cost-benefit evaluation, that will be finished in 2012.

Name of the good practice	Just Checking		
Region/Country	United Kingdom	**Website**	www.justchecking.co.uk

Summary

"Just Checking (JC) is an electronic monitoring system that requires no active input from the person being monitored. Small, wireless sensors in the key rooms of the house are triggered as a person moves around their home. Data from the sensors are gathered by the controller, a small box, and sent via an integral mobile phone to the Just Checking web-server. As a person moves about the house, the sensors are triggered, making a mark on a chart. The activity recorded on this chart can be read by an authorised person wherever there is Internet access. It therefore provides objective, reliable and continuous information about the movements of people who are unable to give an account themselves. It is relatively unobtrusive, consisting of a control box which requires a power supply and wireless sensors which can be mounted by Velcro in any room." from Just Checking website

Descriptive information

Just Checking (JC), established in 2003, aims to help people in the early stages of dementia to continue to be independent and to enjoy life, with the help of carers. The JC system is easily installed, with internet-based log-in to view charts. Installation is straightforward, with sensors attached to doors and their frames in the home by Velcro tabs, and movement sensors also attached to doorframes to ensure a maximum scannable range of each room. The controller simply plugs into an electricity mains socket, and sends data to the main JC database via a mobile phone network. Activity monitoring can be carried out from any location in the world, as long as there is Internet access. Users of the JC system only require access to the Internet to make use of an 'authorised user' part of the JC website and monitor the activities of the care recipient. JC currently employs 15 people, has around 1000 log-ins a day, and 132 out of 205 UK councils with social services responsibilities are currently using it. Professional users utilise JC for short term assessment, typically 3-6 weeks, make adjustments to care plans, and then move the system to the next client. Family users usually have the system for around 18 months. Payment for the JC system varies, with costs ranging from £500 to £1,000, with a monthly web service fee of approximately £7 per week. The various systems can be hired for approximately £70 per month. There are a range of packages, tailored to suit the service users' needs, with systems specifically for carers and care workers, and also multi-person packages. Family users find out about the service mainly through health and social care staff who are using the system with their relatives.

Operational information

Most business's clients are currently local authorities with social services responsibilities (these have a statutory responsible for care assessment), PCTs and mental health trusts. Public sector clients sign up for 1 year or 3 year contracts, and it is JC's task to make sure these contracts are regularly renewed. Key issues identified for the good operating of JC: training on ethical and mental capacity of dementia patients, an installation period of four weeks to alleviate users' concerns on the intrusive nature of the service, presentation of JC as a service to improve need assessment, its potential for intervention, and a clearly defined policy on staff and family carer access to JC data.

Impact assessment

The system has been evaluated in various parts of the UK. Results showed that planning of care support packages, was improved, support to carers was provided, residential admissions were reduced by 43% and the system was cost effective, with an average saving of £119,400 per annum and per client due to their maintenance at home.

Enabling conditions, success/failure factors

The proprietor of JC believes that the sustainability of the business will depend on appropriate management of the business during the growth of the project

Future perspectives

Plans for the development of JC are already underway, with 'roll out' to many English local authority councils. In line with recent government policy, councils are at present focused on reducing costs and, at the same time, on delivering services designed for carers and service users, including the use of ICT. JC has also just established a partnership with the leading supplier of telecare equipment in the UK, Tunstall. This partnership will allow JC to greater access to social service departments in local authorities, especially the telecare services they provide, thereby increasing the system's 'roll out' capacity in a significant way. One strand of this local authority work relating to JC is the provision of services for adults with learning difficulties, and this is seen a potentially large market for JC, requiring an adaptation of the equipment so it can be used safely and effectively with adults belonging to this group.

Name of the good practice	Platform for Caring Family Members ("Platform für pflegende Angehörige")		
Region/Country	Austria	**Website**	www.pflegedaheim.at
Descriptive information			
The Platform for Caring Family Members was set up in 2006 by the former Federal Ministry of Social Security and Generation, in addition to the "Pflegetelefon" (care hotline) that started in 1998. The platform aims to support informal carers and migrant care workers by providing relevant information, especially about 24 hour care and the care allowance. The platform is an online information tool available day and night and provides comprehensive information on diverse care-related issues: care allowance, counselling services, aids for everyday life, 24 hour care and further services like "meals on wheels", residential and nursing homes, hospices, self-help groups, therapies, relevant literature and publications. Moreover, there are several links (concerning administrations, social insurance etc.) and important forms to download (e.g. application for care allowance).			
Operational information			
This publicly-funded platform is operated and administered by the staff of the Ministry as one of their routine tasks. The contents of the platform are adapted at regular intervals and the information provided is kept up to date. The platform registers approximately 92,000 visits a year (2010).			
Impact assessment			
The comprehensive information provided by the platform enhances the knowledge of people concerned with care issues.			
Enabling conditions, success/failure factors			
Access to a computer and the internet and sufficient digital skills are the most fundamental requirements to use this online platform. No specific barriers were found in setting-up the initiative, although the forum was in little demand and finally removed.			

Name of the good practice	REACH I/II – Research for Enhancing Alzheimer's Caregiver Health I/II		
Region/Country	USA	**Website**	www.edc.gsph.pitt.edu/reach/ www.edc.gsph.pitt.edu/reach2/
Descriptive information			
The REACH research programme was established in 1995 and sponsored by the National Institute on Aging and the National Institute on Nursing Research. Its main purpose was to develop and test initiatives designed to enhance the quality of life and ease the burden of family members caring for people with Alzheimer's disease and related disorders. REACH had two programmes (Reach I and Reach II) at different sites. REACH I at the Boston site included an automated telecare system and structural family therapy (Structural Ecosystems Therapy - SET) augmented by a Computer-Telephone Integrated System (CTIS). It was designed to support carers in managing problem behaviours of care recipients with Alzheimer's disease by means of computer-mediated automated interactive voice response (IVR), which provides carers with stress monitoring and counselling, information, a voice-mail carer bulletin board, an ask-the-expert call option, and a care recipient distraction module to reduce disruptive behaviours. Reach II at the Miami site, uses an in-home family therapy system to reduce carers' distress and enhance family functioning. As the study showed, the therapy had a greater impact if it was augmented by an innovative Computer-Telephone Integrated System (CTIS) with screen phones that enabled enhanced access for the therapist to the carers and their families, and allowed people to attend the therapy sessions who would otherwise not have been able to attend for health reasons or because they lived too far away. The therapy developed by REACH II consisted of many in-home sessions to develop the carer's ability to manage care recipient problem behaviours and their own stress and well-being by using different strategies tailored to carers' special needs. Additionally, a computer-integrated telephone system (like the one at REACH I) was applied. It facilitated group conference calling and interaction among carers.			
Impact assessment			
In REACH I, SET alone had no impact on carer depression, but a significant decrease was reported at the 6-month follow-up when a combination of SET+CTIS was implemented. Moreover, the use of CTIS obtained great improvements particularly for the care recipients' wives who exhibited low mastery[15] and high anxiety. REACH II's main result was a significantly greater improvement in quality of life of carers in the intervention group than of those in the control group who were simply provided with information materials about dementia and Alzheimer's disease, caring, safety, and community resources. In particular, the prevalence of clinical depression was lower (12.6% in the intervention group versus 22.7% in the control group, p = .001). A NREPP report (SAMHSA's National Registry of Evidence-based Programs and Practices) on the REACH II project estimates the implementation costs at about $1,212 per carer-care recipient pair, including $1,064 for the in-home intervention components and $148 for telephone support.			

[15] Mastery is the sense that one regards one's life chances as being under one's own control.

Name of the good practice	SOPHIA- SOZIALE PERSONENBETREUUNG – HILFEN IM ALITAG		
Region/Country	Germany	**Website**	www.sophia-franken.de www.sophia-hausnotruf.de
Descriptive information			
SOPHIA emerged from a previous pilot project by the "Joseph Foundation", started in 2002 funded by the German federal government and the regional government of Bavaria in Bamberg. It was founded as a service in 2004 and now operates in five German states. It aims to provide support for people with limited mobility and enable them to live more safely and autonomously in their own home environments, combining personal assistance with the use of easy to handle and intelligent communication tools. Personal assistance is mainly provided by voluntary 'godparents' who make regular phone calls. The godparents remind the elderly people to take their medication or just chat with them and inform them about leisure facilities in their neighbourhood. Additionally, professional members of staff play an advisory role and the system also conveys other services like nursing, craftsmen or shopping assistance. ICT tools are used for social alarm systems and video communication systems. The social alarm systems include: a) a wristband or a special mobile phone that enables people to call for help by pressing an emergency button. The system also documents the activity of the participants and identifies sleep/wake cycles. It would register a care recipient's lack of movement and organise individual help; b) a GPS mobile phone with an emergency button that sounds an alarm in the SOPHIA emergency call centre. The GPS locates the participant and rapidly inducing emergency measures; and c) a GSM emergency call device for temporary use, e.g. when relatives are on holiday or after returning from hospital. The video communication system facilitates image communication by means of a television set, which has a videophone function. In this way, people were able to make phone calls and see who they were talking to on the screen. The service also included a user-friendly remote control with big lit buttons which was used for operating the normal TV-set and the video communication system. The cost of the system varies from 18.90 to 34.90 Euros per month, depending on the service package. Costs have to be paid by the users. The long- term care insurance funds cover part of the costs, and an association provides allowances for people in need.			
Operational information			
Following the two-year pilot project, the SOPHIA organisation was founded in Franken in 2004. In 2005, the SOPHIA holding was founded together with a Northern Bavarian housing company (THS Wohnen GmbH). In 2006, the initiative began to expand through central service points in several German regions. At the moment, SOPHIA is operating in Franken (Northern Bavaria), Nordrhein-Westfalen, Southern Bavaria, Hessen, and Berlin/Brandenburg. Most users are mainly placed by housing companies and nursing services cooperating with SOPHIA and by physicians or nursing services. Flyers and websites are also used. A considerable role in sustaining the service offered by SOPHIA is played by volunteers, who are at the heart of the SOPHIA service centres. They act as godparents of the users and provide valuable personal support. In Franken the service is run by100 people, of whom 15 are formally employed and 85 are volunteers. In the region, approximately 1,450 participants currently use the services provided, especially the safety wristband. Throughout Germany, the number of users amounts to about 3,500. With regard to "drop-out rates", it can be stated that about 25 people per month (in Franken) stop using the service, mainly due to death or relocation to a care home. There are no special requirements to use the social alarm systems offered by SOPHIA. These systems work both with analogue telephone connection and mobile telephone systems. In the course of a counselling interview, the devices and their functions are demonstrated to the participants. Also, the technician, who finally installs the social alarm system, shows them how to use the tools and, for instance, how to change or recharge the batteries.			
Impact assessment			
SOPHIA can provide carers with relief from sorrow, contribute to the balance between work and care, and respite from constant care as it gives carers the confidence that they can leave the house safely for a while. For the care recipients, the system contributes to maintain them in their own homes and to improving their social lives.			
Enabling conditions, success/failure factors			
A significant reason for user satisfaction may be the personal assistance provided by voluntary godparents. On the contrary, video communication was not accepted and finally removed from the system. The particular conditions helpful to develop this initiative were the great public interest in the pilot project, the shared the funding of the initiative, the cooperation between stakeholders, namely housing companies and nursing services, and the commitment of numerous volunteers to providing regular personal contact.			
Future perspectives			
Sustainable funding appears to be guaranteed. SOPHIA is predominantly funded by user fees, and the demand for services provided by SOPHIA continues to be high. The service centre of SOPHIA Franken registers between 40 and 50 new users per month. Activities envisaged for the future are the continuous improvement of technologies applied of the services offered. For instance, it is intended that the safety wristband will provide further functions (fall detection and heart rate monitoring). Moreover, SOPHIA aims to set up more service centres in German regions where no SOPHIA services are available at the moment.			

Name of the good practice	Telecare Scotland		
Region/Country	United Kingdom	**Website**	www.jitscotland.org.uk/action-areas/telecare-in-scotland/

Summary

"Telecare is a term that covers a range of devices and services that harness developing technology to enable people to live with greater independence and safety in their own homes. Examples include devices that trigger a response from a call centre, such as fall monitors and motion sensors. The responses may range from a phone call to the person, to alerting a local carer or neighbour or social service, to alerting emergency services if appropriate. Other examples include devices that directly alert the person in the home to a particular hazard, such as a water level monitor in a bath. IT developments are continually extending the range of devices and services available and, as a result, the scope for telecare to help people with particular health and social care needs – such as older people and people with disabilities – to remain in their own homes and optimise their independence and quality of life." from Telecare Scotland website

Descriptive information

From 2006-2011, the development of telecare services was supported in Scotland through an initiative called the Telecare Development Programme (TDP), which invested over £20 million. In the Scottish government's key strategy Seizing the Opportunity, the role of telecare in meeting future challenges in the provision of health and social care was outlined, including the following aims: increase awareness of telecare and its benefits, increase the use of telecare in mainstream service provision, improve assessment procedures for service users, train service providers' staff to incorporate telecare within care packages, ensure telecare services are delivered to recognised standards, and enhance innovation in telecare services.

Operational information

Most Scottish partnerships used the social services as the principal route for clients to access telecare services, and many partnerships reported adapting social services assessment processes to include telecare. From 2007 onwards, over 43,000 people accessed telecare services. Carers are mostly referred to telecare by social services and/or social workers or by health professionals.

Installation of the equipment has been unproblematic, and most carers have been instructed in how to use it by a professional. All carers felt the equipment had been demonstrated well, and a contact telephone for further assistance was provided for further support. Since 2008, a framework ensures that all aspects of telecare service are regulated through recognised standards, with an accreditation system. By early 2010, 19 partnerships were members: five had achieved accreditation and another 10 were working towards it. Operating costs differ across different partnerships: in some cases the service charges the care recipient (£6 -£15) or the carer and in other cases, the carer receives the same service with no charge.

Impact assessment

Jarrold and Yeandle (2009) found that effective telecare service was an essential part of any social care system, and impacts of telecare on carers' health and well-being, combining employment and care, recreation time, caring roles, and access to other services. Moreover, telecare had an impact on preventing admission to hospitals and rest homes. Comparisons between the period of 2006-2010 and 2010-2011 showed that the average number of hospital bed days saved due to a reduction in delayed hospital discharge was 11, the average number of hospital bed days saved for each unplanned hospital admission avoided was 9, and that the average number of care home bed days saved per care home admission avoided was 143. This means that financial benefits arising from TDP expenditure in 2010/11 was over £30 million. The value of benefits from telecare expenditure from the start of the programme in 2006 to its end in 2011 was approximately £79 million. Nearly half of these savings arose from avoidance of care home admissions, while a similar figure arose from avoiding hospital inpatient stays.

Future perspectives

Since the TDP ended, the Scottish government acting with the Technology Strategy Board has announced a new telecare/telehealth initiative that will run from 2012-2015 called Delivering Assistive Living Lifestyles at Scale (DALLAS). The NHS24/Scottish Centre for Telehealth and Telecare has been commissioned to deliver the Scottish part of this UK-wide scheme. DALLAS is regarded as phase one of a wider Scottish Assisted Living Programme which aims to utilise new technologies to support people with health and social care needs in their own homes.

4.3. Cross–analysis of selected 12 good practices

This section describes the results of the cross-analysis of the 12 selected good practices, which have been evaluated individually in the previous section. This cross–analysis gives an overview of the impact, business models, drivers, success factors and challenges in the design, development, implementation and transfer, replication or scaling up of ICT-based services for informal carers.

We present, for this purpose and in this order, the results of the cross-analysis of the impact of the good practices. They give information on the benefits of the use of these services at micro, meso and macro level. Later, we show the reasons or drivers that motivate the development of these services, how they were implemented (business models), what works to get positive impacts (success factors), and the challenges found during implementation.

4.3.1. Impact

This study assesses the evidence available on the impact of the 12 good practices. It is based on the framework of the Impact Assessment Methodology (IAM) described in Section 3, where:

- We specify 7 dimensions of impact in relation with quality of life of informal carer, quality of life of paid assistant, quality of life of care recipient, quality of care, care efficiency and sustainability, acceptability, and infrastructure and accessibility.
- The 7 dimensions are connected with several indicators that measure these impacts according to three levels of analysis at micro (on the carer and care recipient), meso (on families, companies and organisations, peer groups and care providers) and macro levels (on the economic and social protection systems, and the health and social care systems).

In general, while anecdotal evidence was widespread, good quality qualitative and quantitative evidence was much harder to obtain.[16] Although many of the studies are rather limited and small scale, the case studies chosen represent some of those where good quality research has been conducted, allowing us to find impacts verified by quantitative and qualitative data mostly at micro and meso level. At the macro level, there is even less evidence, but these cases offer a few of the best examples.

Table 13 summarises the main findings regarding the impacts at micro, meso and macro level and highlights the different impacts per type of services (following the typology defined for this study explained in Section 3). We present first the results of the impact analysis per level of analysis, and later also by type of services. This can also give us an idea of the opportunities of each kind of service offers informal carers and care recipients.

[16] Some of the principal methodological issues affecting the data are: 1. Lack of population data on carers; 2. Lack of longitudinal studies of impact; 3. Lack of controlled studies; 4. Difficulty of separating out the effects of any particular service innovation from a package of parallel service improvements.

- Impact by level of analysis.

More concretely, at micro level, cross-analysis of the 12 initiatives showed that ICT–based services positively impact on:

- The quality of life of the informal carers, helping them to reconcile care and work, and improve their social lives and health conditions.
- The quality of life of care recipients, improving their health-related quality of life and their social lives.
- The quality of care provided by informal carers and paid assistants, raising their knowledge of caring, and their related skills and competences.
- The cost of care for the end-users, generating savings compared with ordinary services.
- The acceptability and accessibility of ICT, as users are more willing to use ICT, get more satisfaction from doing so, acquire digital competences and use ICT materials more often.

Regarding the improvements in the quality of life of informal carers (Box 1), independent living technologies can help informal carers to *reconcile care and work* because they allow these carers to participate in paid employment and remain in a job even if they also have to continue caring for a dependent older person. This result is the indirect consequence of informal carers' relief (e.g. they do not feel they have to be constantly "on call", when they are at work) provided by telehealth and telecare systems.

The improvement in *social life* is clear in technologies for personal support and social integration. Social tools (e.g. on-line fora, video-chats) that address both personal needs (through the interaction with professionals and/or self-help groups) and social integration needs (through the interaction with other carers and/or other people like relatives and friends) help informal carers to reduce their social isolation and improve their social activities and intergenerational relationships.

ICT-based services for domiciliary care also improve the *health* of informal carers. The main improvements reported are: better physical and mental health status, reductions in the burden, better emotional condition, lower scores for depression and certain amount of relief of sorrow. These results are the direct effect of informal carers' use of technologies for personal support and social integration and the indirect impact of other technologies such as those for care coordination. For instance, these allow families and health professionals to better coordinated and communicated and therefore home care and care services to better integrated. This in turn lead to less stress and more relief for the carer, as proved by the ACTION, IPPI and Just Checking initiatives.

Box 1: Examples of impacts of the initiatives on the quality of life of informal carers

Impact assessment revealed that the initiatives achieved the following improvements in informal carers' quality of life:

ACTION: the reduction of social isolation, an increased sense of security, better subjective quality of life, a more environmentally friendly way of coordinating care as formal staff and carers use the video-system for communicating.

CARING FOR OTHERS: better physical and mental health status, a reduction in the stress associated with caring.

CUIDADORAS EN RED: improved social activities and of intergenerational relationships.

EMERGENCY ALARM: it was easier for family carers to reconcile care with work after the installation of the emergency system, they received improved psychological support, had fewer health problems and more leisure time and relief.

IPPI: facilitates communication between relatives and healthcare providers, making better planning possible. Lack of time and geographical distances are no longer major obstacles, and generational boundaries disappear: younger generations have more contact with older relatives.

JUST CHECKING: gives a better insight into how the care recipient is affected by his/her condition (e.g., the consistency of their daily and nightly patterns of activity) through monitoring.

REACH I/II: ICT-based interventions under the REACH programmes obtained significant improvements in mastery of care, depression and anxiety (data gained through multi-site randomised controlled trials).

TELECARE SCOTLAND: Telecare helped some carers to participate in paid employment. It helped them to remain in a job they might otherwise have had to give up. It resulted in approximately three-quarters of all carers reviewed feeling 'less stressed'. The beneficial impact most often cited was that it offered the carer 'peace of mind' about the well-being and safety of the dependent person.

ICT-based services for informal carers also improve the quality of life of care recipient. Independent living technologies (ACTION, E-CARE, Emergency Alarm, IPPI, Just Checking, SOPHIA, Telecare Scotland) and even those for the personal support and social integration of the informal carers (ACTION, Caring for Others) can help care recipients in improving health-related quality of life and their social life (including relationships with relatives and others) – Box 2 -. Major improvements for care recipients are: reduction of social isolation and increased sense of security; reduction of patients' admissions to hospital or institution; and improved subjective health status.

Box 2: Examples of impacts of the initiatives on the quality of life of care recipient

Impact assessment revealed that the initiatives achieved the following improvements in care recipients' quality of life:

ACTION: mainly improved care recipients' subjective quality of life, by reducing social isolation and giving them an increased sense of security.

CARING FOR OTHERS reduced the time that patients are in hospital or an institution. It can also delay admission into long-term care institutions.

E-CARE: A significant percentage (66.3%) of elderly people claimed to have achieved an improvement in their health status.

EMERGENCY ALARM: In trials of this system in 2008, there was a 40% drop in the number of applicants for residential care and a 40% fall in the number of days spent on rehabilitation in health care institutions.

IPPI: its greatest benefit for patients (and of course carers) is that it enables them to maintain a social network.

JUST CHECKING: Residential admission rates were reduced by 43% thanks to a pilot initiative which included Just Checking and other services.

SOPHIA: The personal assistance provided by voluntary godparents contributes to a considerable improvement of social life of the elderly.

TELECARE SCOTLAND: Preventing admissions to hospitals and rest homes was the main outcome.

The quality of care provided by informal carers and paid assistants is also improved. In particular, information and learning technologies can help informal carers and paid assistants to improve their knowledge, skills and competences in caring. This result is the direct consequence of carers' training programmes and access to informative materials (Box 3).

Box 3: Examples of impacts of the initiatives on the quality of care

Impact assessment revealed that the initiatives achieved the following improvements on the quality of care:

ACTION: evaluation data revealed that family carers were better prepared to care for their spouse/partner at home.

CAMPUS: this initiative increased job opportunities for migrant care workers: up to 70% of the people trained enrolled in local professional registers and obtained a job in one year.

In terms of cost of care for the end users (care efficiency and sustainability), we have found that some initiatives are more affordable for individuals and households. ICT-based initiatives seem to be cost-effective if compared with similar ordinary care and support services (Box 4).

Box 4: Examples of impacts of care efficiency and sustainability

Impact assessment revealed that the initiatives achieved the following improvements on care efficiency and sustainability:

CARING FOR OTHERS: Personal support and social integration technology can help family carers to save money because they can access services remotely instead of travelling and participating in face-to-face support groups (an important issue for people who live in rural areas).

ICT-based initiatives can also help carers to use support services provided through a specific ICT tool more effectively (Acceptability). The main improvements were high levels of satisfaction, low drop-out rates, and high levels of willingness to use the ICT tool. These results were a direct consequence of solution providers designing the intervention to take into account users' needs and perceptions, and the usability of interfaces and devices (through user-driven development with designers and pilot tests).Furthermore, ICT-based initiatives can make carers more satisfied with the service and its use, due to additional training, information and assistance given by service providers (Box 5).

Box 5: Examples of impacts of the initiatives on the acceptability of ICT

Impact assessment revealed that the initiatives achieved the following improvements on the acceptability of ICT:

ACTION: This service underwent extensive usability and user acceptance work, based on a user-centred design model.

CAMPUS: Users expressed high levels of satisfaction with the e-learning activities. The overall drop-out rate was extremely low.

E-CARE: High levels of satisfaction with the service were found among carers.

IPPI: This service is based on a long-established user-driven development with designers and researchers.

JUST CHECKING: Carers felt the system was very easy to install. Several carers had considered purchasing Just Checking (JC) themselves and expressed a willingness to have JC permanently installed as a means of monitoring their relative's activities. They felt it could reassurance them that their relatives were safe and help them to respond quickly to a crisis situation. After JC had been removed, several carers reported missing the reassurance the system had offered.

The use of different types of technology can help carers to access services through ICT-based solutions (Infrastructure and Accessibility). Major improvements were better access to and ease of use of technical devices to use different ICT-based materials (e.g. on-line and DVD) and education on digital skills and competences These results are the direct consequence of specific intervention designs made by solution providers, which can positively influence access by users to support services (Box 6).

Box 6: Examples of impacts of the initiatives on infrastructure and accessibility

Impact assessment revealed that the initiatives achieved the following improvements on access to infrastructure and accessibility:

ACTION: made efforts to make the service easily accessible, even for those with low digital skills.

CAMPUS: Users were provided with different materials based on their technical possibilities and time availability.

CUIDADORAS EN RED: Digital skills and competences were built up or improved through digital literacy sessions.

EMERGENCY ALARM: did a preliminary assessment in order to adapt the service to different geographical and social contexts.

IPPI: was developed to be a standardised tool that can be used with any kind of TV and phone.

At meso level, there are some impacts on the quality of life of the care recipient, that have notable benefits for efficiency in the use of social care and health care services. The impact analysis identified many significant savings to the care and health services as a result of improving the conditions of home care through ICT support to carers, older people and formal care services. Many initiatives[17] attempted to estimate savings in various parts of the health and care system, by extrapolation from micro-data, or comparisons with alternative care scenarios (Box 7). The result depends considerably on the local costs of conventional care, but the savings claimed are considerable.

For social care, impacts at meso level reported in the cases due to the use of ICT-based services for informal care on the quality of life of care recipient are:

- Delayed entry into institutional care for the older person.
- Reduction in the number of formal home care visits.
- Reduction in overnight care stays.
- Improvements to the quality and effectiveness of formal care.

In health care the principal impacts for care recipient are:

- Reduction in unplanned hospital admissions.
- Reduction in the length of hospital stays (including reduced in-hospital rehabilitation).

Regarding the care efficiency and sustainability, the highest savings come from reduction in use of institutional care, although considerable savings are also found in reducing home care services such as respite and care visits. There is evidence of cost savings from integrating independent living technologies in local care systems. Emergency Alarm and Just Checking made comparisons between ICT-based services and ordinary care services, confirming that independent living technologies can help reduce the number of home care visits and delay the necessity of admission to residential care.

[17] ACTION (Sweden) E-CARE (Italy), EMERGENCY ALARM (Hungary), TELECARE SCOTLAND, JUST CHECKING (UK) and CARING FOR OTHERS (Canada).

Box 7: Examples of impacts of the initiatives at meso level

Impact assessment revealed that the initiatives achieved the following improvements at meso level:

ACTION: studies on the use of this carer support service in Sweden found that institutionalisation was delayed in a large proportion of the families included in the sample, with potential gross savings of over 200,000 Euros/year of delayed institutionalisation per family. In 2004, this service, which combines mainly information and learning and personal support and social integration technologies, made the Borås municipality a saving of 10,000 Euros per year per family. This was a result of a reduction in the need for home help services and delayed entry into a nursing home for many service users.

E-CARE: Over a period of two years, a reduction was observed in the number of admission to hospitals and the number of users accessing hospital services decreased by 50%.

EMERGENCY ALARM: In Hungary, the institutionalisation in residential and health care institutions dropped 40%, and home care was calculated to be seven times cheaper than institutional care. This indicates that ICT-based home care is effective in prevention of the causes of institutionalisation and hospitalisation.

JUST CHECKING reduced the rates of admission to residential care by 43%. It found that the costs of subscribing to the service (between 7-14 GBP/day) represented a considerable saving on the typical costs of a home-care assistant (60 GBP per day) for someone with mild dementia. Its cost effectiveness in comparison to an admission to an institution has been verified.

TELECARE SCOTLAND: In 2011, delays in hospital discharges, and reduction of unplanned hospital admissions and in care home admissions were higher than expected. Hospital early discharge increased among the 43,000 people for who received the service over 5 years.

The impacts at macro-level were also related with efficiency in terms of savings for the health and social care systems. This was mainly due to the reduction of the need for assistance of formal care both to the carer and to the older person. Hospital admissions and the length of hospital stays were reduced. Moreover, it is also interesting to note the economic impact that work-care reconciliation could have on the reduction of labour costs for the employer and the social security system. Although this study has not been able to capture these kinds of economic indicators, other studies give us some data that deserve to be mentioned here. For example, a US study found that a 5% reduction in the employer cost due to annual lost of productivity for employees doing intense caring could generate the equivalent to 2.2 billion Euros per year (Metlife Mature Market Institute and National Alliance for Caregiving, 2006). An Australian study calculated that a 5% reduction in loss of earnings due to informal care is equivalent to a profit of 3.9 to 5.5 billion Euros per year (Access Economics and Carers Australia, 2010).

Impacts were also observed on the accessibility of ICT. For example, there was better access to information support services through a web-based solution at country level. The care system also benefits from improved accessibility, i.e., it can reach a higher number of people, and make the target user group wider than the one reached through ordinary non-ICT services. This result is the direct consequence of enabling all target users to access the service without any local mediator or additional device (Box 8).

Box 8: Examples of impacts of the initiatives at macro level

Impact assessment revealed that the initiatives achieved the following improvements at macro level:

CARING FOR OTHERS: Savings exceeded one million dollars (in one year) in the Province of Ontario, due to improving care recipients' quality of life and reducing the number of institutional admissions.

E-CARE: savings amount to 600,000 Euros (in two years) in the municipality of Bologna, due to improved care recipients' quality of life and the reduced number of hospital admissions.

TELECARE SCOTLAND: savings amount to over 78 million pounds (period 2006-2011) in Scotland, mainly due to improved quality of life for care recipients and reductions in both care home admissions and unplanned hospital admissions.

PLATFORM FOR CARING FAMILY MEMBERS: around 92,000 users from across Austria accessed this platform in 2010, quite a big number considering that approximately 425,000 persons older than 17 years are performing care for one or more family members or friends in Austria.

- Impact by types of technology.

The evidence of impact assessment provided above allows us to make some statements about the effectiveness of ICT-based initiatives on the basis of their type of technology.

Independent living technologies are probably the best assessed ICT-based services, because those focused on elderly people have been running for a while, whereas the ones specifically for carers have been developed more recently. They help to manage health and social conditions of the care recipients, and therefore provide relief, independence and peace of mind for informal carers. This allows carers to have more active social lives and more time for themselves. Independent living technology also helps households and local care providers to save money: using these tools can guarantee a decreased in demand by carers and care recipients for support and care services. It is estimated that financial benefits at individual and community levels could be important. Finally, independent living technology usually deals with simple user-friendly ICT devices that do not needs any specific infrastructure or accessibility requirements. However, even though independent living technology should not present problems to users in theory, there is a lack of hard evidence and more assessment on these aspects is recommended.

Information and learning: ICT-based initiatives that fit into the information and learning technologies have mainly been assessed as regards their impact on the quality of care provided by informal carers and paid assistants. Evidence gained allows us to state that such initiatives provide very effective training courses for carers and even for care recipients (allowing them to care for themselves better): knowledge and competences in caring are directly influenced and improved. However, no available evidence on direct or indirect impact on carers' and care recipients' quality of life is available. These dimensions should be taken into account when assessing the impact of this type of technology. Moreover, these technologies enable effective user-friendly services (positively impacting on acceptability), and also guarantee a high levels of accessibility to the ICT solution. Finally, the initiatives that provide only informative material without any learning features

(i.e. training courses and interactions with professionals) cannot be considered to have an effective impact on any dimension other than infrastructure and accessibility.

Personal support and social integration: there is enough evidence on this type of technology to allow us to state that it is effective in improving carers' quality of life. ICT tools can allow people to get in touch more often with relatives, friends and others in similar conditions (both carers and care recipients), and also to improve their contacts with professionals for counselling, and psychological and emotional support. These functions are very important since carers are often isolated and they do not have the time or the opportunity to ask somebody for help. Indeed, personal support and social integration technologies provide very effective relief to carers (and even care recipients themselves), and directly affect their quality of life. This technology also demonstrates an indirect impact on care recipients' quality of life: carers in better health and psychological condition can take better care of dependent older people. Furthermore, it is estimated that this technology could ensure cost savings for households and local care providers. Finally, the use of these services helps people to accept and access ICTs if their design is user driven and the system they use is interoperable.

Care coordination: this type of technology is not usually stand-alone but integrated with others. Separating its impact from that of the others is not easy, because it concerns the better communication between carers, care recipients and professionals from the formal care system. These improvements in care coordination can lead to an indirect impact on carers' quality of life: for instance, it can decrease their levels of stress and depression. However, not enough evidence is available to assess this specific type of technology, or isolate it from the others.

Table 13: Indicators of impacts of ICT-enabled services on carers and elderly people, and health and social services and systems

IMPACT ANALYSIS (MICRO LEVEL)			IMPACT ANALYSIS (MESO-MACRO LEVEL)	
Services	**Impacts for Informal carer**	**Impacts for Older person**	**Social Services**	**Health Service**
Independent Living (services for older people and carers)	- hours of care - eliminates the need for constant presence + peace of mind - anxiety + health-related quality of life + reconciliation of care and work and family + supports participation of other actors in care (family, volunteers)	+ independent living & delay dependency + health status + perception of safety + compliance in treatment + improved relation carer-older person	1- reduces number of care visits 2- reduces overnight care stays 3 - delays institutional care of older person, because carer "can cope"	3- reduces hospital admissions (because carer can provide better care and is in better health)
Communication (Services for older people)	- burden of carer + supports participation of other members of the family + promotes volunteering	+ strengthen and develop social networks + promotes self-care + health status - isolation		
Information & Learning (Services for informal carers)	+ accessibility to training + finding and receiving appropriate information + caring skills and digital competence + employability + sense of security	+ Quality of care	1- delays institutional care of older person 2- reduces number of care visits 3- reduces overnight care stays 4- improves quality and effectiveness of formal care	5- reduces hospital admissions 6- reduces length of hospital stays
Personal Support & Social Integration (Services for informal carer)	+ promotes development of informal social networks of carers that provide practical and emotional support - isolation - stress + Quality of life + reconciliation of care and work and family	+ Quality of care + Quality of life + Improved relation carer-older person		
Care Coordination	- stress + Quality of life - burden of care + reconciliation of care and work and family +builds trust with professionals	+ Quality of care + Quality of life + health status	1- reduces number of care visits 3 - delays institutional care of older person, because carer "can cope"	
			1,5,6: Savings of 79 m GBP (over 5 years), for 20m GBP investment	

4.3.2. Drivers of development

The cross–analysis of the 12 cases of ICT-based services for informal care indicated that there are four drivers that motivate a multiplicity of actors to develop and implement these services:

- The desire of professionals and families to improve quality of care and quality of life of older people. This was by far the dominant concern of the stakeholders in these initiatives.
- The wish to empower and help carers, by enabling:
    - older people to live at home and independently for longer.
    - carers to look after family members in a way that does not impose on them an excessive burden which could lead to the breakdown of care (including abuse of the elderly, carer health problems, etc.).
- The search for improvements in efficiency and effectiveness of social and health care, mainly motivated by:
    - a shift from expensive and often low quality institutional care to home care for the elderly.
    - a wish to improve the working conditions of care professionals.
    - the need to integrate different aspects of the health and social care service to provide more effective and efficient services.
- The need to realise systematic cost savings, mainly to reduce the costs of formal institutional support to home care.

If we compare these drivers with those of European policy, described in Section 3.1.2, we can see that most of them are similar. This constitutes an opportunity to work in the same direction.

4.3.3. Business models

The services operate in different business models (Box 9), which partly depend on the perspective of each actor involved. In many cases there is an operating company that supplies services to a care providing organisation, which uses the services to provide care to families, financed by a mix of payments from individuals, insurance and public funds. However, this is by no means the rule. In many cases there are many more actors involved, playing different roles, with different sources of funding.

Concretely, each service in this study has a different funding model for operational costs. Funding is usually split between state, insurance where relevant, the older person and in some cases the family. Many services reported here are supplied with a charge to end users (co-payment), in a mixed funding regime (user contribution plus public funding). Services in Germany and Sweden often make a charge of 20-35 Euros to the end user. Public contribution is important for business models, especially for those people who are unable or unwilling to pay for the service. For example, in the Emergency Service (the Hungarian initiative), the lack or removal of public funding to pay for the service generates a fall of 28% in the demand for this service when the public subsidy to end-users was withdrawn.

The sustainability of the services depends on the sustainability of the service providers, often SMEs or NGOs. The cases highlighted the difficulties that these organisations have had in gaining financial sustainability. While their customers were buying services that

brought them savings or quality improvements, some of the suppliers, particularly the less well established start-ups were surviving on start-up capital, or the fees earned from running trials and demonstrations. Contracts between service and care providers of 1-3 years requiring renewal are also challenging to maintain. For a service company, sustainability comes from providing common services for many corporate customers, in order to recoup investments, and concentrate resources in common facilities, such as call centres. The service companies responsible for E-CARE and SOPHIA claimed sustainability. Other independent services, however, have attempted to make partnerships with larger organisations to gain faster access to markets, or expand in to overseas markets.

Box 9: Examples of business models of ICT-based services for informal carers

Model 1: An independent service organisation (company or NGO) provides a service to a care provider, which finds it a cost effective way to deliver a mandatory level of service. Income for the care organisation comes from direct public funding and co-payments from end users who receive direct public or insurance payments. Care providers may or may not pass on costs to end users. The cases suggest that ICT-based services, such as tele-alarms, carer support services etc operate sustainably in a variety of systems. The cases of ACTION (SE), Just Checking (UK), and IPPI (SE) have a model of contracts of 1-3 years between the service and the care organisation.

Model 2: A service company that is set up and owned by a public-private consortium provides a range of services. The model for SOPHIA (DE) and E-CARE (IT) is that of a technology-focused company which is tightly linked to other business and care activities. In both these cases, the ICT-based services were considered sustainable and even profitable activities. The German SOPHIA service is an interesting example of finding value in a home care service. One of the founding companies provides rental housing, and a key value for their business is maintaining existing housing customers in the homes they have been renting as they grow old.

Model 3: Independent services, often local, but occasionally national, are assisted by a mix of voluntary and funded by institutional contributions. An example is CUIDADORAS EN RED. This type of service depends on obtaining local contracts to help carers, or is incorporated into national NGOs for carer or patients In the sample of 52 cases, there is a whole range of these independent services, particularly targeted exclusively at carers.

Model 4: National online services. A final model for the use of ICTs is public or NGO (with mixed funding) running national information and training services, and social support service, taking advantage of the huge reach of the internet. A first step for its cost effectiveness is to improve the quality of information access and to reach a large proportion of the caring population.

4.3.4. Success factors

- **Key success factors for the development and implementation of ICT-based services for informal care**

Key success factors emerging from this cross-analysis of the 12 cases related to the development and implementation of ICT-based services for informal care are:

- The involvement of end-users, including carers, elderly people and formal care staff, as active players in the design of services, complemented by training in digital and care services competences;
- The progressive integration of an ICT-based service for informal carers in the formal long-term care system. This contributes to the creation of a new value chain of provision of care services, because it empowers formal and informal carers and elderly people as active and collaborative actors in long-term care;
- The cooperation among stakeholders;
- The formation of new value chains to provide care, where different kinds of stakeholders act as intermediaries in the delivery chain of ICT-based services for informal carers.
- The exploitation of existing ICT and digital inclusion infrastructure, and
- The development of policies to help decision makers and providers with different functions at multiple levels.

Further details of these success factors are given below:

- The involvement of end-users, which includes carers, elderly people and formal care staff, in the design of services, complemented by training in digital and care services competences (Box 10). Customisation and user-focused design methods were important in producing usable services that led to easy adoption and use. The involvement of carers, elderly people and formal care staff was relevant, not just in the early stages of service development but in the continuous improvement and renewal of services. Users were often cited as important sources of innovation, new configurations and uses. Universities were often constituted an important resource for expertise on new technologies, on carers and the needs of the elderly, and on continual improvement.

  However, design is seldom enough, being also relevant the use and adoption of ICT through training in digital competences and/or support services. For many types of initiatives, competence development was a key aim, focused primarily on the family carers as key actors to care for an older person, and as the interface to a range of other services. For ICT-enabled services, basic training in how to use ICTs is a prerequisite; however, this can vary considerably depending on the particular use of technology. This training can be incorporated into general training on caring and how to access care services. It can be provided by specialised trainers: some services specifically used volunteers to do initial ICT training, but for some simpler ICT services, such as some of the TV-based systems or telecare, it can be provided by professional care workers. Training programmes are needed for the range of care professionals involved to assist carers, but also to help them learn new working practices and the value and limitations of the new tools.

Box 10: Examples of end-users involvement in ICT-based services for informal carers

In CAMPUS, carers appreciated the ease of use of the ICT platform and the possibility of following training at home (and/or attending classroom courses).

For ACTION, it was a success for the acceptance of the ICT service to present it as an assistive device to help the elderly in their day to day life.

IPPI service that turns the TV into the communication device built on the familiarity of the technology for people of all ages.

- Progressive integration of the ICT-based services for informal carers into the formal social and health care system. Most of the cases illustrate services that started off on a relatively small scale, and were established without complex change in the system organisation, or commitment to spending. However, over time they evolved toward a more holistic approach, increasingly covering needs of carers and older people. These cases demonstrate that while they provide measurable individual benefits for carers and older people, they can also achieve more systematic benefits if they are integrated within formal services. They thus create a new value chain for the delivery of care, where informal and formal systems are interlinked. The empowerment of carers and elderly people as responsible for the provision of care in cooperation with the formal system helps the penetration of the service, and increases the choice and appropriateness of available services that can be used according to user needs. In this context, the development of systemic value from the use of ICT-enabled services becomes primarily a process of change management, rather than ICT implementation.
- Cooperation between stakeholders and professionals (Box 11). The initiatives reported a slow process of learning about the value that different stakeholders could bring to the service, the barriers to engaging them, and how these difficulties could be overcome.

  The stakeholders identified in the cases were:

  - Carers and older people.
  - Service providers: private (profit and non-profit) care service providers and housing providers.
  - Innovation and service developers: universities, entrepreneurs and other private service developers.
  - Health and social care professionals: frontline care staff, health service front line staff, and care managers.
  - Authorities: Regional care service authorities.
  - Non-profit organisations (third sector): carer and patient organisations, volunteer organisations.

  Especially relevant for the success of the initiatives was the engagement of non-profit organisations (third sector). Many of the cases feature non–profit organisations that work for carers and families, providing support and services. In some cases, they are local organisers providing services such as counselling, information, social activities or respite. In other cases (e.g. Carers UK, Alzheimer's Association) they can be national organisations that run information services, consulting services to care authorities, lobby activities, and fund research and evaluation. This type of organisations was shown to be active in setting up and running these initiatives. They provide valuable

input with knowledge of carers' needs, lobby for improved services, and act as intermediaries between public and private players, and local care authorities.

The engagement of volunteers also plays a key role in ICT-based initiatives. Long-term care in many countries relies on the work of volunteers, often coordinated by NGOs or local care services. Volunteers were often targeted as key actors in setting up services and making them sustainable in the long term. 'Expert' volunteers such as young people were engaged to train older people in IT skills; or worked in telecare as 'god-parents', making regular calls to particular old people. Volunteers thus brought skills and time, but required training.

Box 11: Examples of cooperation among stakeholders in ICT-based services for informal carers

In ACTION, close co-operation between staff working in the company with staff working in the municipalities was of crucial importance when implementing the service initially.

In the case of CAMPUS, the contribution from a multi-disciplinary team (social, health and ICT) and the strong involvement of local stakeholders, which cooperated encouraging the use of ICT in the elderly care sector were both relevant for the success of the service.

In ECARE, the strong cooperative and operational attitude between professionals and public health organizations and social services was beneficial, while in SOPHIA, the cooperation between housing companies and nursing services was important.

In SOPHIA, a significant reason for user satisfaction was the personal assistance provided by voluntary godparents through regular phone calls.

- The formation of new value chains to provide care, where different kinds of stakeholders act as intermediaries in the delivery chain of ICT-based services for informal carers. This success factor is connected with the previous one, as co-operation among different stakeholders (identified in the previous success factor) helps form the new value chains. Stakeholders lead, develop, and support knowledge transfer, and coordinate the development of these innovative services. They can all act as important nodes for innovation and bridges between local services for the transfer of practice and knowledge. They can offer services to formal (generally state-funded) care services, and thus negotiate multiple contracts locally. Others can provide services nationally, such as online carer support, online training, patient support groups, and some telecare services (Box 12).

Box 12: Examples of intermediaries in ICT-based services for informal carers

ACTION, CAMPUS, JUST CHECKING, IPPI and SOPHIA are examples of services developed by universities and private companies that have then sold these services to local care providers. They run some of the services from central offices, but these are configured and used locally.

The 'National Networks of E-CARE' is a monitoring and assessment programme, run partly by CUP 2000 (E-CARE's private partner) and funded by the Ministry of Health. ECARE is delivered by a service company that supplies the care services and technologies to local public organisations, and a regional authority that links private and public organisations.

TELECARE SCOTLAND is an example of a state innovation coordination service, that develops best practice and standards, endorses local services, and brings together state, private and NGOs to develop programmes and coordinate change.

CARERS UK, and FEPEM (FR) are examples from the 52 cases where NGOs have developed national services (such as training online). PLATFORM for CARING FAMILY MEMBERS is a similar state-operated central service. CARERS UK also provides advice to local care and carer organisations.

The MALTESE CROSS CHARITY, which runs the Hungarian Telealarm is an example of an NGO that delivers a range of services nationally, with funding from a variety of sources, both local and national.

- The exploitation of existing ICT and digital inclusion infrastructures has been identified as another relevant success factor. The availability of established ICT systems, networks and devices provides strong resources on which to build services around care. Some of these are specifically related to health and care infrastructures, but many of the services were built on general ICT infrastructures. These include the widely available broadband internet infrastructure, TV-set, GPS tracking, but also the GSM system for alarms (which, for instance, was used in Hungary for the alarms where fixed line and internet was not available). Open Source software provides some low cost platforms to develop training resources and online communities. Digital inclusion infrastructures are available in many countries, especially in areas with low internet access and uptake, and can be brought into fruitful partnerships. An example is the Guadalinfo Project in Pizarra, used by Cuidadoras en Red, which runs a network of public telecentres with free access to computer and internet in the smaller villages of Andalucia (Spain).
- Finally, the development of policies that help decisions makers and providers at multiple levels and functions has been seen relevant for the success of ICT-based domiciliary carer services. The following policy approaches were identified as successful pathways for the setting-up, development and implementation of ICT-based services for informal carers:
    - Policies at national, regional and local level that sustain the development and use of ICTs in health and social care, and in public services more broadly, can effectively facilitate the appearance of these types of services. Statutory requirements to provide care and central budget cuts have encouraged care commissioners to adopt new practices including ICT-enabled services to improve the effectiveness of public spending.

- A strong regional or national policy leadership to put in place long-term strategic change programmes that incentivise local care organisations, NGOs and private firms was shown to be effective. These programmes provided the necessary commitment to build multi-stakeholder partnerships, including the private and voluntary sector, to raise the profile of carers and home care, to reduce the need for institutionalisation, and to exploit the value of integrated services addressing specific groups in need. This encourages and legitimises spending on ICTs in care in both the public and private sector
- Public funding was important for the setting-up of these services and at different points of their development and implementation process: e.g. for initial research and development; to trial, test, and to collect convincing evidence and demonstrations of impacts relevant to different stakeholders. In fact, the key to success was the coordination of public funding to cover the various stages of development, and help leverage private funding into the process. Various European, national and regional funding schemes were mentioned, including various European Commission funds, Scottish Joint Improvement Team Change fund, the Italian Regional Fund for Long-term Care, the Federal Ministry of Health and Social Security and the Bavarian State Ministry of Labour, Social Affairs, Family and Women.
- Moreover, funding R&D allowed the promoters of these services to develop more efficient ways of customising services to a greater range of target conditions, and documenting diverse practice to provide models for local implementation.
- A multi-level policy framework to adopt ICT helps businesses, NGOs and care services to work together to overcome professional scepticism, and financial and non-financial barriers to the use and development of novel ICT-based services. This has been carried out through actions such as good quality training and removing financial barriers to purchasing ICT services.
- The systemic savings associated with these services. For example, Commissioning studies reveal reduction of hospitalisation through online carer support and training and overall efficiencies.

Box 13 shows examples of policy actions developed in order to meet the challenge of promoting much wider use of ICTs to support care and carers.

Box 13: Examples of policy actions for ICT-based services for informal care

ACTION: EU and national research funding; local ICT policy for public services; weak policies/programmes in social and health care at regional and national level can be problematic.

CAMPUS – EU funding for R&D; local policy environment favourable.

E-CARE – Strategic initiative promoted by regional, provincial and local authorities; regional fund for long-term care; support to integrate local authority and health IT systems; policy to involve volunteering associations; strong local welfare system; long-term programme of informatisation of public services for citizens.

EMERGENCY ALARM – Welfare act that made telealarm a basic service triggered widespread adoption; Set of subsidies for different providers, and for rural areas. Withdrawal of central government subsidy led to 28% drop in use.

JUST CHECKING – Centrally-driven programme of public service and care improvement. Budget cuts by care authorities are driving search for more effective solutions such as Just Checking.

PLATFORM FOR CARING FAMILY MEMBERS – part of central care policy.

SOPHIA – comes from a two-year pilot project funded by the central and regional government. Two years later, it became a holding, to which a private company also contributed funding.

TELECARE SCOTLAND – Initially the result of a local care authority investment, it then was adopted as a central change plan, prompting considerable government investment in telecare. Support to carers, personalisation. Policy framework driven by professionals.

- **Key success factors for the transferability/scalability**

Transferability or scalability refers to the potential to develop a practice or service that is available in one locality into other locations. Service transfer is a knowledge transfer, where knowledge about a change in practice in one location considered 'good practice', is used to improve a practice in another place. It will often involve the adoption and modification of codified procedures, standards, organisational structure, technologies and services. A powerful tool for transferability is technological systems and devices. These offer many elements that facilitate the introduction of a new service. The risk of focusing on the technological elements is that many important organisational, legal and cultural issues are either encoded in the system, or not recognised as fundamental to successful operation. Replication should not be taken as simple copying of a technical system.

The cases show that the transfer is a multiple-way process. The learning process and redevelopment at each new attempt to replicate is part of the continual process of innovation, and the intermediaries play a key role in accumulating this knowledge, and in some cases, such as the national and regional change programmes, in explicitly shaping good practice, and encouraging dialogue between existing service locations. It is important to reemphasise the role of intermediaries of different sorts, whether they be NGOs specialised in carers, service firms, or public change organisations. Nonetheless, CARICT shows that policy is central for the success of the transferability of ICT-based services (Box 14). Concretely, three main pathways for successfully transferring practices were identified

across the cases, where the policy implications were fundamental to making services available to more people:

- There was a transfer of experience from one locality to another by intermediaries, integrating ICT-based services with other types of services. Policy played a role in the transfer through two mechanisms: a) national or regional care programmes that coordinated exchange of best practice, and provide change funds, but may not mandate centrally. This seemed to be a successful way to transfer a service, which also required considerable political leadership and investment, and b) support in reaching customers to small scale independent providers that sold services from one local area to another local area.
- Services could spread out over several nearby care areas, by a mix of policy and private intermediaries; and mainly through the role of home care providers that operate across many localities (even nationally and internationally).
- National health and care services led regional transfer and capability building, and in addition European funds were involved in successful international transfers.

Box 14: Examples of policy actions for the transfer of ICT-based services for informal care

ACTION – .In 2004, the Borås municipality decided to make the ACTION initiative part of its mainstream services for its older citizens living at home and their family carers. Since then, the ACTION service has been implemented in other municipalities across Sweden as feasibility or implementation projects, often with research and development funding and government funding to stimulate assistance for the care of older people and/or family care.

JUST CHECKING – Most customers are currently local authorities with social service responsibilities.

EMERGENCY ALARM- This service has been developed by a national NGO and offered to local public authorities and care providers.

CAMPUS – After the European funding for the project came to an end, the initiative continued its activities with several local editions of training courses for care workers funded by local authorities and other sources (i.e. inter-professional funds). Courses for migrants were carried out free-of-charge in different Italian regions, with public funding.

E-CARE – In the first phase of the project (testing), the E-CARE initiative was funded by local banks. The initiative is currently funded entirely by the public sector. In particular, the E-CARE service benefits from the investment made in the project by the region and local stakeholders, as part of the overall health planning of the Regional Fund for the Long-Term Care activated in 2007.

TELECARE SCOTLAND – From 2006-2011, the Telecare Development Programme (TDP) sustained the development of telecare services, investing over £20 million. In the Scottish government's key strategy *Seizing the Opportunity,* the role of telecare in meeting future challenges in the provision of health and social care was outlined

4.3.5. Challenges

The cross-analysis revealed the following challenges in starting-up, developing and implementing ICT-based services for informal care:

- One of the main challenges was related to technology-specific issues in long-term care. The cases studied faced the following specific challenges related to the technological component of the ICT-based service:
    - To demonstrate the value of ICT in the provision of long-term care. First, care for the elderly is one of the most 'human' of all activities, reliant on face-to-face and bodily contact in conditions of close emotional relationships. Economically, this has been seen as a service that is not particularly amenable to rationalisation and efficiency gains from capital technology investments.18 Therefore, technology has been seen as irrelevant to the care of the elderly, or even as objectionable. The cases show that this is not the case, however they reported that the attitudes of various decision makers about the value of ICTs in care was their main challenge. Nonetheless, these objections are not entirely unfounded: the value of ICTs is not always obvious, or a direct translation of the value found in other areas of activity. For example, building trust, encouraging family cooperation, ensuring dignity, and caring people in distressed emotional states require quite specific and sensitive applications of technology that are demonstrated in these cases. The challenge was to find ways to develop uses of technology that are sensitive to this, and give those who understand the issues, older people, carers, and care professional, the means to shape the technology.
    - The acquisition of digital competences and skills and the access to and use of ICT infrastructures. The deployment of ICTs requires that those directly involved (the elderly, their informal and formal carers, and organisations involved in care) acquire a range of specialised knowledge and competences. They must also have access to IT infrastructure. This is challenging as we are working with people with low digital competences and there is a lack of technological infrastructure available and financial resources to acquire IT materials.
    - ICT supposes new forms of organisations of long-term care services. The conventional organisation of formal care services (predominantly local, focused on management of people) may be challenged by the economics of ICT-based services (which may operate from platforms and be economically viable on a much larger scale). Much of the development of ICTs around ageing is related to health and telehealth, which also challenges the locus of control, scale of deployment, and traditional separate between health and social care.
- Another challenge concerns difficulties associated with the recognition of the role of informal carers in the formal long-term care system as co-providers of care, and also as a group in need of support. Services (ICT or non ICT) are needed to ensure their function, without overloading them and the long-term care system. In fact, successful services allow informal carers to be integrated in the formal system, as relevant stakeholders in the delivery chain of care.
- Another challenge faced by the cases studied was overcoming scepticism, negative attitudes and lack of knowledge about the use of these types of services in long-term

[18] E.g. (Galouj 2002).

care. Of particular concern is the widely encountered scepticism among professionals in social and health care and also families about the use of ICTs in care. Probably the hardest to convince were decision makers and care managers, who express reservations about older people using, or benefiting from ICT systems. The initiatives show that promoters had to dedicate considerable efforts to raising awareness, giving information and demonstrations on a regular basis to different stakeholder groups, and to motivating them to use these services.

- A common challenge faced by the initiatives was providing convincing scientific evidence to prove that the service actually helped older people and their family carers and was cost efficient. Many municipalities are unwilling to make a significant investment in technology-based services in care for older people. Instead, they tend to test out ICT-based services with a small number of users which makes it difficult to build up a critical mass of users to secure the evidence required for mainstreaming the service on a much wider level. In the Borås municipality, the availability of evaluation data concerning quality of life of service users and cost data which showed cost savings for the municipality proved to be crucial.
- The creation of an efficient business model that showed the municipalities how much the service would cost and convinced them that there would not be any 'add on' costs was another challenge. The model also needed to be designed so that the municipalities' own ICT department need not be involved.
- Another challenge is that the initiatives are run on a small scale by innovation players, making their wider deployment difficult. While there are some successful institutional programmes incorporating ICTs, and a few larger scale commercial players, many services are still developed and provided by rather small scale organisations, often start ups or NGOs. The fragmentation of care services is a barrier to the entry of these new organisations to the market, and they find themselves required to build new relationships and repeatedly demonstrate the value of their services.

4.4. Key policy recommendations

This study leads us to recommend that the right combination of complementary, existing support and funding programmes be put in place. These programmes should motivate and help stakeholders to develop, implement and scale ICT-based services for domiciliary care. Specifically, we propose the following policy interventions:

- To promote cooperation between different kinds of stakeholders to build partnerships between the public sector, NGOs and private players. These partnerships will encourage the creation of a new value chain in the delivery of care. To achieve this, it is necessary:
    - To stress the importance of cooperation between the informal and formal sector. The use of ICT-based services for informal carers together with formal services facilitates the integration of the two systems (formal and informal). Carers and elderly people are then empowered as responsible for the provision of care together with the formal system. This helps the penetration of the service and increases the choice and appropriateness of available services that can be used according to the user needs.
    - To recognise the role and the value of the third sector and volunteering, and to support the participation of both in the provision of ICT-based service for informal care. Carers' and patients' associations emerged as new

intermediaries active in setting up and running these services. Their knowledge of carers' needs enables them to provide valuable input, lobby for improved services, and act as intermediaries between public and private players, and local care authorities. Moreover, the involvement of volunteers emerged as a key factor for the sustainability of ICT-based services. For this purpose, it may be appropriate to create incentives to help voluntary organisations.

- To ensure the involvement of end-users (carers, elderly people and formal care staff) in the different stages of service design, development and implementation, and to continue to fund research, experimentation and innovation. Research at universities and research institutes is effective in guaranteeing the involvement of the end-users in the design of services according to their needs. Experimentation and innovation in ICT-based services for domiciliary care is also relevant. All the cases studied indicated that the involvement of users was important for constant innovation and improvement of services. Many improvements could be made by deploying new technologies, developing new standards for interoperability of information and devices and enhancing integration with existing ICT systems in health and social care. However, it is important to continue to promote experimentation and innovation and not focus exclusively on standardising and replicating existing services.
- To raise awareness of the opportunity provided by ICT-based services for informal carers among all stakeholders, including policy makers, professionals and carers and care recipient. This has been identified as one of the main challenges across the 12 initiatives analysed in-depth in this study. Available data needs to be disseminated through awareness campaigns directed at different stakeholders, informing them that ICT-based services for informal care are useful in reducing the costs associated with long-term care, increasing the quality and efficiency of care, and improving the quality of life of carers and care recipients.
- To promote an exchange of good practices, the collection of evidence and the transferability of optimal solutions among localities, regions and countries, in order to ensure the smart use of existing effective solutions in the EU. The use of ICTs in services for the care of older people is still in the early stages, demonstrated by the difficulty in finding some of the services documented here, and the small scale of their deployment.
- To sustain a European market of ICT-based services for informal carers and elderly people. These services present an important market opportunity, as there are a considerable number of carers who, though they are willing to care for their family members, must balance this care with their own commitments. They need help, and are not satisfied with many aspects of the help that they or their family members received. There is a market opportunity for services that take advantage of the established benefits of ICTs to provide timely information, share responsibilities, communicate within families or with other carers, or obtain on-demand support, and that family members would be willing to pay for themselves. The key here will be to encourage the supply side, but also to work with the intermediary organisations. These organisations, for example carers' and patients' associations, could help broker the market, and would be capable of regulating quality and providing access to trusted market information. The development of quality standards is relevant for the accessibility and quality of care.
- To promote digital inclusion policies, promoting the access and use of IT infrastructures and materials, and the development of digital competences.

- To continue to allocate public funding for initiatives to ensure their development, sustainability and transferability.

4.5. Future scenarios of domiciliary care supported by information and communication technologies

This project has confirmed that:

- In the European context, there are effective ICT-based services that improve carers' and older people's quality of life, the quality of care provided by informal carers, and the sustainability of long-term care systems in different Member States.
- Policy can act to promote their successful development, implementation and transferability, both through funding and regulation and by promoting stronger cooperation between end-users and the stakeholders involved.

With these two main findings in mind, we propose four scenarios to illustrate how the provision of long-term care could be developed with the incorporation of ICT-enabled services, if the supporting factors and conditions including policy support action, are in place. The scenarios were built on the assumption that different contexts in which ICT-based services for informal carers can be used exist.

As explained in Section 3.2.2, data on the contexts for building the scenarios emerged from a two-day workshop held in November 2011. The participating experts and policy makers from a range of backgrounds and countries were divided into two working groups: 'the service regime' group (the non-family or 'formal' care of the elderly service) and the 'family regime' group (relying primarily on family-based care). This differentiation was helpful in raising the different profile of carers (main users), but it was not used to differentiate the different scenarios, and each of them can be developed in any of these regimes.

4.5.1. Scenario 1. Older carers who take care of their co-resident spouses, and are retired: they want to use ICT-based services to be more socially included, less stressed and informed on services available

Context of use

The characteristics of the users (the informal carers) and other actors involved in the use of the system: Older carers, mainly spouses, who live with the care recipient and do not work (they are already retired). Family and neighbours, volunteers, social and health professionals and also home care providers are the main actors who interact to help this group of carers in home care. The burden of care can be reduced by sharing the responsibilities among these main actors and regularly exchanging information on needs and support.

Their needs or objectives relevant to the use of the ICT-based services: This group of carers is in high need of:

- Social relationships and psychological support. The principal risk these carers face is social isolation. Being outside the job market with demanding care responsibilities creates fewer options for maintaining and creating social relationships. They are affected by mental and physical health problems due to both the care burden and their own ageing. They also have sleep problems as they are the only person looking after the care recipient during the night.
- Information on formal services and how to access and coordinate them, as they experience stress in dealing with the bureaucratic systems of different, often

disconnected formal health and social care services. In fact, smart regular re-assessment of needs carried out by professionals could help them to understand what help they could benefit from and which services are most appropriate to both the carer's and care recipient's needs. Allowances could also be put into place by local authorities, reducing the cost to the families for paid-for care services.

- Societal recognition of their role: This profile of carers is mostly invisible to the rest of society and to the formal sector. Recognition of their role could help them to legitimise their need for assistance at formal and informal spheres (family, friends and neighbours).

Therefore the objectives in using ICT-based services for informal carers are to improve their social relationships, their mental and physical health, to have information on formal services, and to coordinate them better, and be more included.

ICT-based services for informal carers available are:

- Basic ICT tools such as short message service (sms) and emails, and care coordination websites with standardised protocols and platforms that allow different organisational actors (formal providers, non-profit organisations) and individual users, including many different informal carers, to keep in touch and share information could improve the efficiency of communication between actors. These tools can help raise the visibility of care work by different carers with their social contacts, e.g. the elderly carer's children or neighbours would be more aware of his/her care work, where otherwise they may have been reluctant to discuss care and health issues.
- Telehealth systems (telemonitoring, telecare and telemedicine) that monitor the health and movement of care recipients and GPS systems to track the movements of elderly people can also relieve the carers' stress, and be used by main carers, other family members and neighbours. Telecare and telehealth involve the transmission of voluntary or involuntary signals from the care recipient to carers or service providers. They include emergency buttons, social alarms, in-home sensors and systems to monitor health conditions. They are the most investigated services because of their direct impact on the dependent older person's quality of life. Studies conducted in UK, for example, demonstrated that these telecare and telehealth tools allow significant cost savings to care providers. More recently, localisation devices can constantly monitor the position of elderly people, informing carers or service providers if they go outside (where they are potentially in danger).
- Carers' needs for information and coordination of services can be addressed through on-line and dynamic information websites. These websites can provide carers and their informal contacts with in-depth information on relevant topics, concerning both disease-related issues and care service organisation.
- Health and social care professionals need in standardised software to organise and share patient health and social data with other professionals and to organise their own work. Ethical issues arise when dependent people's health information is shared with family members and other carers (for example, volunteers). Moreover, barriers can limit the use of ICT tools: generally speaking, in much of Europe, professionals in the formal sector do not usually use ICTs extensively in their work. Changing the practices and protocols available to professionals and convincing them to adopt and use ICT tools that can improve the quality of their work as well as the service provided to users will be a long-term project. Home care providers could also take advantage of telecare and

telehealth systems and integrate this type of service in their other care services system in order to improve the coordination of services.

The environment where the services will be used: ICT-based services for informal care are then needed to be used mainly in the home environment.

Description of the scenario

We can illustrate this context of use with the following scenario (Scenario 1) about Ad, an old and retired spouse who cares of his wife, Merel, affected by Alzheimer Disease, in the Hague (The Netherlands).

Scenario 1: Ad, an old and retired spouse who cares for his wife, Merel, affected by Alzheimer's Disease, in The Hague (The Netherlands).

Ad, 66 years old, has been married for 40 years to Merel, a strong and clever business woman who decided on her 40th birthday to build her first company, a small clothes shop in the middle of The Hague. They have a son, Floris, who is 35 years old and works as an investment advisor in London. When she was 64 years old, Merel arrived home one day late and exhausted. She told Ad that she did not know what had happened, as she had suddenly felt lost and didn't know the way home. Ad thought that Merel was just too stressed with the inventory of the shop, but the mistakes and disorientation increased and a year later, Merel was diagnosed with Alzheimer's Disease. Ad was then 65 years old, and just retired from a very active working life as a Professor at the University. He had been lecturing almost every day and had enjoyed mentoring his students on how to develop their careers or their research. He liked playing chess every Wednesday with his colleagues from the university. Every weekend, Ad and Merel went out to the theatre or to see an exhibition, which Merel loved, with their friends. Sometimes they travelled abroad, mainly to visit their son in London.

Ad needs help to take care of Merel. He mainly needs to be informed of the services available which can help him to manage the care of his wife better, carry out social activities and keep in touch with their friends as a respite to his care responsibilities, and share the care task with his son.

From the first day of diagnosis, Ad, as Merel's main carer, was identified by the primary doctor as being in need of care to help him avoid the psychological and socioeconomic problems linked to his new responsibility. An exhaustive analysis of his needs, preferences and daily activities were carried out, together with a social and health care evaluation of Merel, by the primary doctor. She stored all the information on CDRIC[19] (a Common Data Repository Information on Carers), where social and health care professionals and also the Care Voluntary organization from The Hague have access. Ad and Merel gave their consent to access to their information on CDRIC with their digital fingerprints. As soon their digital fingerprints were registered, Marcus, a volunteer who lived 3kms from Merel and Ad's house, received an alert that a new case had been registered. The alarm[20] just informs him of new case that needs to be attended to and that he has one day to decide whether or not to take the case. Once a volunteer has agreed to help to a new case, and has signed the data protection form, he/she can access the information stored on CDRIC.

[19] ICT for care coordination

[20] Volunteer call network

Marcus agrees to take the case, and sends an SMS to Ad to set up a face-to-face visit with Ad to inform him about possible services, such as counselling, which could help him to come to terms with caring and his new life as a carer as well as a husband. While Marcus is doing this, a first proposal of appropriate services for Ad is proposed and registered on CDRIC by the case manager. Marcus just has to access CDRIC the day before in order to prepare for the meeting with Ad and Merel. In this appointment, Ad and Merel talk to Marcus about their needs, and Marcus rearranges the care plan a little bit. His proposals are checked on CDRIC by the case manager. Floris also has the possibility to be involved in the meeting through a Voice Over Internet Protocol like Skype,[21] and all the needs from the main family core have been detected.

Some proposals from Marcus have been working for several months. When he wakes up, Ad checks the different activities he needs to do this day on his smartphone calendar.[22] The calendar is shared with his son, where each activity is organized between the two of them. Floris is usually in charge of different kinds of daily activities that he can do from a distance, like checking bank details,[23] doing the shopping online,[24] helping his father to be involved in leisure activities,[25] or keeping an eye on his mother while his father is outside or cooking.[26] Ad and Floris exchange emails and chats through a messenger system everyday in order to agree on whatever extra help or activity is needed for this day, or to check that some activity has been done. Ad and Floris can also connect to CDRIC in order to get information on carer services and any type of benefits they can apply for,[27] send request of information to the case manager, access a reassessment system and propose alternative plans in order to personalize their care.[28] The case manager, Marcus, Floris and Ad have a meeting on a video chat (like Skype) each month in order to do the follow up and agree on new and old needs and services. Video chat is very helpful for the family as keeps them in touch, but perhaps the activity most appreciated by the family is using the online TV where Merel can connect with her grandchild and to look at paintings together or visit virtual museums, or where Ad is teaching him how to play chess.[29] The same system is used by Floris to regularly check how his mother is getting on or by the primary doctor or social care professionals to do the regular check ups.[30]

In addition, Ad has begun to share his experiences on a local online carer network, which encourages him to exchange his feeling with other people in the same situation.[31] This network has been developed by the carer association together with the municipality of The Hague and ex-carers, and offers several types of leisure activities (going to museums, concerts, having a coffee, or just meeting to chat, etc). Ad goes out once a week to an activity of this kind. Floris, who uses a flexitime system at work, keeps an eye on his mother through a telecare system,[32] that is connected to a web cam in the house and

[21] Voice Over Internet Protocol.
[22] Organisation system for use by networks of both formal and informal carers.
[23] Access and support for internet access for ecommerce.
[24] Access and support for internet access for ecommerce.
[25] ICT for personal support and social integration.
[26] Environmental controls.
[27] Online information (websites).
[28] Organisation system for use by networks of both formal and informal carers.
[29] Entertainment and family communication.
[30] Environmental controls.
[31] Social Networking systems for peer support.
[32] Social alarm.

sensors that alert him to any unexpected movements.[33] An alarm to the health care services can be activated by Floris, and also sent to Ad in order to warn him of an emergency. Ad can also look, if he wants, on his mobile phone at what is going on at home. All the emergencies are stored in CDRIC. Home care providers also have access to one part of the CDRIC system - mainly the calendar - in order to manage the different services they provide.[34]

Ad and Floris attend together once a week an online self support group for carers that is being developed by a London municipality.[35] Through his TV online system, Ad can connect and be involved in the group which Floris physically attends. This group has been very helpful in teaching them how to manage stressful situations and to talk about their feelings, but the main benefit has been to make the father-son relationship closer and to make them feel they are not alone in this responsibility but rather that it is shared.

4.5.2. Scenario 2: Working carers who need to use ICT-based services for informal care to stay in the job market and feel less stressed

Context of use

The characteristics of the users (the informal carers) and other actors involved in the use of the system: Working carers are usually burdened with juggling and combining paid work and family care, which can lead to them either giving up (or losing) their jobs, or giving up care (which may then need to be taken over by formal services, often state-funded). This not only has a cost for individuals and the State, but also for employers, who may lose valuable employees, and face the costs of recruiting and training replacements. In this case, therefore, employers can play an important role as well as families, friends, health and social care professionals and home care providers.

Their needs or objectives regarding the use of the ICT-based services: These working carers are in need of:

- Recognition of their role inside the job market. Working carers suffer multiple financial penalties as many have to take part time jobs and also pay for carer services. They also feel stressed and anxious about trying to work and care simultaneously. Once at work, they worry about their lack of control over the wellbeing of the care recipient at home when he/she is alone and about being able to react to and address emergencies in time. Moreover, despite formal recognition and support from employers, carers often do not receive support from colleagues and line managers, and sometimes try to hide their caring responsibilities (until doing so becomes unsustainable). In this sense, giving them flexibility at work to deal with emergency situations affecting the care recipient and to access formal care services (often available in working hours) would form part of the process of recognising carers' contribution to society. Support policies and initiatives to develop their careers, care management tools and information on their rights and benefits would also contribute.
- The constant pressure of managing care and work can lead these carers to need psychological support, as well as time off for caring, for leisure and personal recreation.

[33] Environmental control and wandering, monitoring alarms.
[34] Organisational system for use by networks of both formal and informal care.
[35] ICT for personal support and social integration.

The objectives in using ICT-based services for informal carers are to be able to work with more flexibility and be accepted and recognised in their role by their employers and colleagues. Thus they could remain in the labour market without damaging their health. They also need to be able to develop social and leisure activities away from their duties and receive psychological support that relieves them of stress.

ICT-based services for informal carers available are:

- The recognition of the carer's role by employers can lead them to adopt measures such as flexible working, telework or to facilitate the use by carers of communications over internet (with computers, tablets or smartphones). This helps carers to do at least some work at home, to access online care services, to leave their work stations when necessary, to keep in regular contact with family members and other carers, to be able to resolve emergencies, and to share the workload with other carers.
- Psychological support and time for leisure needs can be addressed through VOIP as more social participation and contact with friends could be done through videoconferencing. Social network tools could also allow carers to exchange text (e.g. online fora) or multiple video communications (e.g. video-chat for groups). These tools are very effective in providing peer support (virtual communities of carers or care recipients).

The environment where the services will be used: ICT-based services for informal care need to be used mainly in the workplace and in the carer's and care recipient's home environment.

Description of the scenario

Scenario 2 below, in which Therese and Johanna - two working sisters - care for their father, Thomas, in Gothenburg (Sweden) helps us to understand the future of the provision of care at home with ICT-based services.

Scenario 2: Therese and Johanna, two sisters who work and care for their father, Thomas, in Gothenburg (Sweden).

Therese and Johanna were at work when they received a call from the hospital that their father, Thomas, had just had a stroke. Therese is 32 years old, married, with no children. She is the director of a consulting company with 40 employees. Johanna is a waitress, divorced with two children of 10 and 12 years old. After the stroke, Thomas's cognitive ability was maintained but his ability to carry out activities of daily life, like walking and dressing, was damaged, and even after rehabilitation, he could not do them without help. Moreover, a few weeks later he fell and fractured his which made rehabilitation more difficult. Now he is in a wheelchair. Taking charge of their dad was a difficult option for Therese and Johanna, as they had to go on working to be able to maintain the quality of care of their father and children. Working was also their preferred life-choice option (mostly for Therese).

Therese and Johanna need to continue working. They also need some psychological support to face the demanding tasks of caring for their father. Thomas needs to be able to maintain his independence as far as possible.

Therese and Johanna went to the carer website of the municipality of Gothenburg where they lived to find information on different useful services, how they could benefits from these and the costs.[36] It was very easy as the carer website of the municipality has an online questionnaire on the carer and care recipient's needs and other social and financial information. It provides quick ideas and recommendations about the appropriate service and how to receive it. A telehealth system that integrates video, and is compatible with a tablet was selected.[37] This system allows them to check on Thomas and communicate with him when they are working. Moreover, health and social professionals are alerted to emergency situations by sensors connected around the house which detect unexpected behaviour or emergency calls. They can then check up through the tablet. This system includes different health apps, which are used by Thomas for his daily health checks and to report them to his doctor.[38] The same system is integrated into Therese and Johanna's tablets and the doctor and social worker can contact them if results are worrying or there is an emergency situation.[39] They decided on a tablet as they can also incorporate a home domotic system,[40] which allows Thomas to control the environment: open the doors, switch on the light, put on the microwave, or switch on the TV. The tablet also allows Thomas and his daughters to be in touch, to make or answer requests or just talk.[41] Thomas's grandchildren have taught him how to use the tablet. This amuses all of them, as the grandchildren have begun to exchange pictures, messages, news and to chat with their grandfather.[42] This system is part of the care services of the municipality, with the involvement and cooperation of the home care providers and the health and social care system.

At work, Therese has joined to the carer programme of her company and can do teleworking[43] some days per week. She spends this time at her father's home and also to attend online psychological therapy for carers.[44] On the corporate website, Therese has access to a specific online system for carers with tips and frequently asked questions.[45] The same system is accessible to her employer, who uses it to be aware and informed about carer's situation and needs. Moreover, Johanna has been given more flexible duties at work which allow her to connect with her father at any time through her tablet. A specific place is available in the office for those who wish to use their tablets in private. Both sisters have daily, direct and online face-to-face contact with their father through a VOIP (like Skype) application and can communicate and resolve problems at any time.[46]

Therese and Johanna have joined an online network for carers where they can express their worries and can have a better understanding of their responsibilities.[47] This network has allowed them to make new friends and organize online free time activities. Through this network, they have taken virtual trips to museums in different places in Europe, signed on to reading clubs, and exchanged tips on care and rights.

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[36] Online information (websites).
[37] ICT for independent living.
[38] E-health.
[39] Organisation system for use by networks of both formal and informal carers.
[40] Environmental controls.
[41] Family communication.
[42] ICT for personal support and social integration.
[43] ICT for personal support and social integration.
[44] ICT for emotional support.
[45] Online information (websites).
[46] VOIP.
[47] Social networking systems for peer support and entertainment.

4.5.3. Scenario 3. Non-working long-term carers who need ICT-based services to be more socially included, be ready to return to the labour market, and improve their health status

Context of use

The characteristics of the users (the informal carers) and other actors involved in using the system: Carers who have given up work or have not worked for a long period of time because of care, who are out of the labour market even though still of working age because their care for the dependent person was too time-consuming. The problem of re-entering the labour market is a crucial issue. Many are also providing care while they are themselves ill, impoverished or socially isolated.

Their needs or objectives relevant to the use of the ICT-based services: These working carers are in need of:

- Social relationships and psychological support. These carers face social isolation; being outside the job market and with demanding care responsibilities creates fewer options to maintain and create social relationships. They are also affected by mental and physical health problems due to the chronic stress they are faced to.
- Information on care services as they experience stress in dealing with the bureaucratic systems of different, often disconnected formal health and social care services.
- To return to or re-enter in the labour market after the caring period.

ICT-based services for informal carers available are:

- Psychological support and time for leisure needs can be addressed through VOIP as more social participation and contact with friends can be done through videoconference. Social network tools can also allow carers to exchange text (e.g. on-line fora) or multiple video communications (e.g. video-chat for groups). They are very effective in providing peer support (virtual communities of carers or care recipients).
- Carers' need for information and coordination of services can be addressed through on-line and dynamic information websites. These websites can provide carers and their informal networks in-depth information on various topics, covering both disease-related issues and how care services are organised and can be accessed.
- ICT for information and learning can give access to information and training about caring, as a way of re-integrating into the labour market as a formal domiciliary care worker.

The environment where the services will be used: ICT-based services for informal care need to be used mainly in the home environment.

Description of the scenario

Scenario 3 below about Ana, unemployed, and her son Toni take care of Ana's mother in Sevilla (Spain) illustrate how ICT services can help in the context.

Scenario 3: Ana, unemployed, and her son Toni take care of Ana's mother in Sevilla (Spain).

Ana has taken care of her mother, Luisa, for 5 years. Luisa fell ill and became dependent after a hip fracture when she was 80 years old, widowed and living alone. Ana, divorced, has three children who at that time were 7, 10 and 12 years old. The fall and later the hip

operation were very painful for Luisa. After her hip replacement and several post-surgery complications, Luisa was discharged from hospital. Once at home, Luisa was afraid to move and go outside alone in case she fell down again. Other complications arose due to her lack of movement, such as decreased mobility and circulatory problems. Luisa needed more and more help. The home help service began to come to clean the house and dress Luisa every morning, but it was not enough for Ana. At that time, her children were too young to help her, and it was not possible to combine work with caring for her children and her mother. So she decided to stop working and brought Luisa to live at her house.

Ana feels exhausted and has some health problems, mainly caused by the stressful activity that she has been carrying out for 5 years. She now needs more help from her eldest son Toni, and training to rejoin labour market. Emotional support to manage her high levels of stress is also important for her.

In fact, Toni began to help her two years ago. Now it seems easier to carry out the caring activities and Ana feels much better. Toni has helped her mainly in using new technologies to better care for his grandmother. Ana has enrolled in an e-learning course[48] funded by her locality in Sevilla. This course is given by retired people, who were previously professionals in the care of elderly people. She attends the course at home and also does exams. This has helped her to better understand her mother's disease and dependency problems, and learn new skills which could make it possible for her to work as a carer, although her main idea is to set up a social enterprise to teach to other people digital literacy and carer competences. The e-learning system also allows volunteers to provide emotional relief.[49] She has a remote session with a volunteer once a week, where she can talk about her situation and her feelings. They also have a telecare system now,[50] which makes her feel more secure when her mother is at home alone. The telecare system consists of a watch with GPS that can be activated by the older person when something is wrong. It can also be activated by unexpected activity. Her son does the daily shopping online shopping and controls the bank details.[51]

Recently, they have incorporated an e-calendar[52] in the telecare system to manage the different care and activities they have to do every day, this helps them to be more organized and effective. Home care providers are also connected to this online calendar, and can inform Ana and Toni about the timetable of care carried out and planned. All this coordination has also allowed Ana to plan 5 days holidays for the first time in 5 years. The first day was very difficult but she can talk on her smartphone every evening with her mother and make sure that everything is going well.[53]

[48] ICT for information and learning.
[49] Call centre for counselling and emotional support.
[50] Social alarm.
[51] Access and support for internet access for ecommerce.
[52] Organisation system for use by networks of both formal and informal carers.
[53] Access and support for internet access for family communication.

4.5.4. Scenario 4: Migrant care workers that need ICT-based education in care and language to be inserted in the labour market and in the context of care, as well as to connect with other people to maintain social relationships

Context of use

Characteristics of the users (the informal carers) and other actors involved in using the system:

Migrant care workers play a crucial role especially in some countries (e.g. Italy, Spain, Germany) where they are mainly privately employed by households. In other countries, they are usually engaged in the formal sector as regular care workers where their working conditions are likely to be better (e.g. UK).

Their needs or objectives in using ICT-based services: These working carers are in need of:

- Assistance to orientate themselves in relation to how care is organised, and to match demand and supply of home care.
- To regulate their position (in many cases, they can have no permit of stay).
- Personal needs should be addressed as well, concerning the risks of burden, social isolation (including being homesick or not in contact with country of origin).
- Language and cultural differences can be barriers to a proper integration of migrants in the destination country.

The ICT-based services for informal carers available are:

- Carers' need for information and coordination of services can be addressed through on-line and dynamic information websites. These websites can provide carers and their informal contacts with in-depth information on various topics, covering both disease-related issues and care service organisation.
- Psychological support and time for leisure needs can be addressed through VOIP as more social participation and contact with friends can be done through videoconference. Social network tools can also allow carers to exchange text (e.g. online fora) or multiple video communications (e.g. video-chat for groups). They are very effective in providing peer support (virtual communities of carers or care recipients).
- ICT for information and learning can give access to information and training about caregiving, as a possible way of becoming formally integrated in the labour system as a home care worker.

The environment where the services will be used: In these cases, ICT-based services for informal care are then needed to be used mainly in the home environment.

Description of the scenario

Scenario 4: Tania, a Lithuanian carer in Lecce (Italy).

Tania is from Vilnius (Lithuania) and is 35 years old. She moved to Lecce (Italy) to take care of Manuela, a 75 year old woman affected by Chronic Obstructive Pulmonary Disease (COPD) who needs daily support.

Tania needs to get appropriate care skills such as speaking good Italian to provide qualified care to Manuela. As she has newly arrived in the country and the care tasks leave her little time to meet people, she feels alone. She needs to have more contact with people outside the care context and do more social activities. Manuela's family also need a carer able to develop the different daily care tasks that Manuela needs.

Tania found the job when she was still in Lithuania, through CARI an Italian website specialised in offering carer jobs.[54] This website was in Italian and Lithuanian so it was easy for Tania to use. Manuela's daughters and sons were offering the job because they cannot take care of their mother without help, and a government direct grant allows them to pay for a carer. The CARI website is designed to offer online education in care for elderly people to applicants who are offered jobs. The cost of the education is funded though an agreement between European Commission and the Italian and Lithuanian governments.

So when Tania arrived in Lecce, she had a certificate for domiciliary carers and the skills to care for Manuela and her family. Regarding this, CARI also gave her specific skills on health and social care in order to be able to attend to the daily needs of a dependent person. She also received education on the care situation and strategies to deal with the emotional and educational needs of informal carers. Thanks to the CARI training, Tania is able to give information on the health and social care services available in the municipality and at regional level. This is very valued by Manuela's sons. In fact, on her advice, they have installed a video calling (skype) system at Manuela's home, with which they can communicate with her and Tania.

Tania and Manuela's family also use a smartphone to organise the different services that Manuela receives, and the daily tasks that each of them needs to carry out. Manuela's family manage an e-calendar, and Tania checks everyday the different tasks she has to do. She can also propose new tasks, and make comments on a particular task. For example, the other day, Manuela could not sleep at all during the night. Tania reported it on the e-calendar, Manuela's family called her on receiving the information and an appointment with the doctor was arranged.

CARI has also a forum for all domiciliary carers (migrants and non migrants) that helped Tania to be involved in forums and social groups before arriving in Lecce.[55] She has therefore had the possibility to meet new people online in the same situation as her, and can exchange personal feelings about her tasks, and also ask about daily living (supermarkets, doctors, hairdressers, social activities in town). This has allowed her to make social contacts with people who have been in Lecce longer, and to meet them to go to the cinema, have a drink or just go for a walk. Tania also uses a video calling system to keep in touch with her friends in Vilnius, and show them through the web cam where she lives now.

[54] ICT for information and learning.

[55] Social Networking system for peer support.

5. CONTRIBUTION OF THE CARICT STUDY TO THE EU POLICY FRAMEWORK.

As stated in Section 3.1.2: 'The policy context', this study contributes to achieving the objectives of the EU 2020 Strategy and more concretely to the following four of its seven flagship initiatives:

- Digital agenda for Europe (DAE).
- Innovation Union, European Innovation Partnership on Healthy and Active Ageing (EIP AHA).
- An agenda for new skills and jobs.
- European platform against poverty and social exclusion (EPAPSE).

The CARICT study also assists other European policies in relation with long-term care, such as:

- The voluntary European Quality Framework of Social Services.
- The Open Method of Coordination to health and long-term care.
- The new Staff Working Paper on long-term care (to be published at the end of 2012).

CARICT's main contribution, however, is to the European Innovation Partnership in the field of Active and Healthy Ageing (the EIP AHA). At stated in Section 3, the EIP AHA aims to add 2 years to the average number of healthy years (HLYs) people can expect to live in the European Union by 2020, by:

- Improving the health status and quality of life of European citizens, with a particular focus on older people.
- Improving the long-term sustainability and efficiency of health and social care systems.
- Enhancing the competitiveness of EU industry through an improved business environment providing the foundations for growth.

The results obtained in the CARICT project demonstrate that development and implementation of ICT-based services for informal carers can contribute to improving the health and quality of life of older people and their carers (objective 1) and the sustainability and efficiency of the long-term care systems (objective 2), thus boosting a European market for these technological services (objective 3).

These findings highlight the relevance of innovation to produce home-based services to care for older people. The CARICT project describes 52 beneficial, often not very costly (around a 30% costs less than 10,000 Euros) ICT-based services for informal care. This shows that innovative services can bring added value to addressing carers' needs by: supporting and giving them relief from their care task, helping them to manage work and care (independent living), providing them with information and training on caring (information and learning), allowing them to maintain social relationships and activities, offering emotional support (personal support and social integration), and coordinating care services (care coordination).

The project shows the relevance of home-based services and the proactivity of end-users in the delivery chain of care. The project has identified some success factors and business models to develop and implement these innovative services, which can help the stakeholders involved in the EIP AHA to overcome barriers and bottlenecks associated with

innovative ICT services for healthy and active ageing. The main success factors for ICT-based services for informal carers were:

- The active involvement of end-users in the design of the service.
- Including informal carers in the delivery chain of long-term car.
- Cooperation between stakeholders as intermediaries in an innovative chain of long-term care provision, where non-profit organisations (volunteering and the third sector) can play an important role.
- The exploitation of existing ICT and digital inclusion infrastructures.
- The development of a policy framework.

Thus the EIP AHA, as an EU policy umbrella, is working to address the challenge of innovation for healthy and active ageing, through collaboration among stakeholders, the empowerment and strong involvement and proactivity of end-users and also the delivery of services at home.

Regarding the Digital Agenda for Europe, CARICT makes available successful ICT-based services for informal carers to improve their knowledge of caring, and related skills and competences, through training programmes and access to informative materials. These services also promote independent living and digital competences for disadvantaged groups like carers. CARICT's findings indicate the success factors, drivers and business models for the development, scalability and transferability of these ICT services, increasing therefore the quality of care and employability of carers.

Finally, the CARICT findings also help in attaining some of the objectives for digital and care competences of more disadvantaged groups in the 'Agenda for new skills and new jobs', the 'voluntary European Quality Framework of Social Services', and the 'European Platform against Poverty and Social Exclusion'. For these policies, we found that volunteering and the third sector improve the (financial) sustainability and the quality of the services. Volunteers in third sector organisations play a role not only for the success of ICT service deployment, but also as a business model strategy as it promotes the sustainability of the initiatives beyond the pilot stage. Volunteering offers an opportunity for people to acquire skills and competences in the care sector. This could be a path to employment for young or older people to work in the household sector, and a cost-effective way of training them in this field. However, finding effective and successful models for cooperation (for example, public-private-third sector partnerships) is still a challenge.

6. CONCLUSIONS

This project summary report presents evidence-based results from the CARICT study on the potential of ICT-enabled domiciliary care services to improve the lives and health of older people and their informal carers, and other services and care systems. It also makes policy recommendations about how they could be better developed, scaled, replicated and transferred in the European Union (EU).

The CARICT study addressed ICT–enabled services for informal carers and focused on analysing: 1) what services there are in the EU and abroad, 2) how they operate, 3) what the enabling conditions, success and failure factors and barriers are, and 4) what their impacts are.

First, the results show that ICT-enabled domiciliary care services can indeed improve the lives and health of older people and their informal carers, and other services and care systems. We found that:

- ICT-enabled services for carers and older people improve the quality of care and quality of life for older people and carers in different personal situations, and welfare regimes.
- ICT-based services allow informal carers to maintain a better balance between care and work, and to remain active in the labour market.
- ICT-enabled services help increase the availability of care for older people, by enabling families to provide quality care, promoting the role of volunteers and NGOs, and enabling care organisations to reallocate resources.
- By empowering family carers and formal care professionals, the use of these services accelerates the shift from institutional care to sustainable home care.
- A desire to improve the quality of care and empower older people and their carers drives many of the initiatives documented, demonstrating that technology is not deployed in a way that dehumanises care in the name of economic efficiency.
- ICT services make existing services more effective by improving the diversity, accessibility and quality of services as part of an integrated service. In many cases the use of ICTs helps to transform and integrate services from different agencies.
- Many ICT services are very modest in their costs, and thus affordable. They do not require large investments in technology, or long-term commitments. In many cases, they generates direct savings in the provision of statutory care over traditional approaches.
- These services are financially sustainable at an operational level, and have been demonstrated to deliver substantial systemic savings, particularly by reducing institutionalisation and hospitalisation, but also by reducing the need for formal home care.
- The use of these services could generate a reduction of labour costs due to informal care, for the employers and the social security systems.

The study has demonstrated that ICT-based services for domiciliary care improve quality of life for older people and carers, access to qualified long-term care, and the integration of health and social care services. They empower carers and ensure that suitable informal care can continue long-term. They generate direct savings that contribute to the sustainability of the system. These findings are especially relevant for current European policies, particularly the Digital Agenda for Europe and the EIP on healthy and active

ageing. The successful use of ICT for the provision of care and for the empowerment of informal carers can help to achieve the objectives of these policies, as we have shown that the deployment of ehealth technologies, telecare and online support for social services improve the quality of care, reduce medical costs, and provide digital and care skills and can increase the employability and therefore the social and digital inclusion of domiciliary carers. These objectives are also common to various other EU policies such as the voluntary European Framework of social services (suitable skills for volunteers and informal carers) and the European Platform against Poverty and Social Exclusion (ICT to enhance employability and life opportunities). Moreover, the development and implementation of these ICT-based services for informal care will speed up the shift from institutional to home-based care. These services will empower people to become co-producers of their health and linked to the system, in line with the approach of the EIP AHA. All of these indicators contribute to achieving access, quality of care and sustainability of long-term care systems of the Open Method of Coordination.

Secondly, on the question of how policy can contribute to and support the development, scalability and replicability of ICT services in the European Union (EU), the results of this research indicate (as exemplified in the 12 cases) that policy actions need to lead on putting together the right combination of complementary, and existing support and funding programmes for stakeholders. These programmes should incentivise and support local care organisations, NGOs and private firms and also provide ICT-based services for domiciliary care at different stages of development and transfer. In this framework, more concretely policy interventions are:

- To promote the cooperation between different kinds of stakeholders, particularly between the informal and the formal care sectors, recognising the role played by the third sector and volunteers in the delivery chain of long-term care and giving them support.
- To ensure the involvement of end-users in the different stages of service development, through the continuous funding of research, experimentation and innovation.
- To raise awareness of all stakeholders (i.e. policy makers, professionals, carers and care recipients) of the opportunity provided by ICT-based services for informal carers.
- To promote the exchange of good practices, the collection of evidence and the transferability of optimal solutions among localities, regions and countries, in order to ensure the smart use of existing effective solutions in the EU.
- To sustain a European market of ICT-based services for informal carers and older people.
- To promote digital inclusion policies, through the exploitation of existing ICT and digital infrastructures.
- To allocate public funding to these initiatives in order to ensure their development, sustainability and transferability.

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Abstract
Deployment and use of technological services for informal carers is still limited, mainly due to users' low digital skills, the lack of demonstrated business cases, and the poor evidence of the impact and sustainability of these services. The CARICT project aimed to collect evidence-based results on the impact of ICT-enabled domiciliary care services, and to make policy recommendations to develop, scale and replicate them in the European Union. The methodology was based on a mapping of 52 ICT-based services for informal carers developed in Europe, and a cross–analysis of 12 of these initiatives to get data on their impacts, drivers, business models, success factors, and challenges.

The main results show that there is a wide range of successful, not very costly and beneficial examples of ICT-based support for carers across Europe. The cross-analysis indicated that these services had positive impacts on the quality of life of elderly people and informal carers, the quality of care and the financial sustainability of the health and social systems.

The data also confirm that policy at European, national, regional and local levels can promote the successful development, implementation and transferability of these services through funding, policy leadership and by promoting stronger cooperation among stakeholders including end-users, mainly from the third sector and informal carers, to create a new value chain in the provision of long-term care. These findings help to achieve the objectives of European policy defined by the 2020 Strategy, and more specifically the Digital Agenda for Europe (DAE) and the European Innovation Partnership on Healthy and Active Ageing (EIP AHA).

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