Intermediate results
Clear benefits and a heterogeneous innovation landscape

The first output of the study is a review of 53 initiatives that use ICTs to support informal care and carers, using a sample taken in 12 EU countries. Many operate a local level and are undocumented, so were difficult to find. These initiatives represent well established services for families that exist in some countries, such as online information and training and telealarms, more radical use of ICTs in systematic re-organisation of carer-focused public services, through to novel support networks and monitoring tools that provide models of socio-technical experimentation that can inform public policy and the activities of third sector and private organisations. These examples demonstrate the diversity of innovation in ICT-services that can support carers, showing clear demand, both by institutions and families, but also the difficulties in setting up and sustaining services in the face of scepticism about older people uses of ICTs … MORE It also highlights the lack of formal evaluation and impact assessment except in a few examples. The report enable readers to situate the evidence from the cases within the broader context of carer needs and the LTC care environment of the host country. This report is available on the IPTS website.

Methodological and data challenges
Evaluating the impact of support for carers, including those enabled by ICTs, is complex task, balancing factors related to carers, dependent older people, and service providers, in the context of little and fragmented data on the number and needs of informal carers, and the diversity of care regimes. While many services offer benefits, it is hard to assess cost-effectiveness or effectiveness in support particular groups, or in conjunction with other support services. An expert workshop of leading experts on care and carers held in June 2011 reflected ambitious review of literature and preliminary methodological framework made by the consortium, and recommended further investment in development and testing to create a much needed evaluation common toolkit for researchers and service operators alike. This report is available on request from IPTS

Work Currently Underway
Evidence of impact: Case Study analysis

The consortium is assembling case studies that explore in more depth the activities, context and motivations behind 12 of the more established ICT-based services to support carers. The case studies focus on the evidence of benefit to carers and dependents, and of existing and potential impact on carer support services, and critically plot the pathways from initial concept to future aspirations, as the innovators and stakeholder have both delivered benefits to users, and convinced stakeholders of the value of the service to carers and elderly people in need of care. The analysis will identify barriers to adoption and innovation, the technical, organisational and policy steps that can be taken to overcome them, and the types of evidence and arguments that these cases make available to understand the role of ICTs in the future of policies to support social inclusion of carers, and the Long Term Care system existing in Europe.
Policy Challenges

Long-term Care (LTC)
A major policy challenge in the European Union is the aging of the population, and the need to ensure quality Long Term Care (LTC) for the increasing numbers of frail and dependent older citizens. As pressure rises to reduce costs on the welfare state, there is an increasing emphasis on home and community-based care. Even with the promotion of ‘Independent Living’, much of the burden of care is taken by people in the informal caregiving setting – family, volunteers and family-employed care assistants. Failure to promote technical and policy innovation to support the millions of people in this situation in Europe will have severe impacts on employment, economic competitiveness and social inclusion.

ICT for Inclusion
Information and Communication Technologies (ICTs) are being used at small scale across Europe to support caregivers to older people, and when well designed with appropriate support and training, these could be widely adopted and play an important role in improving care in an economically, socially and politically sustainable way. However, the development and uptake of ICT services to support caregivers is still limited and largely unknown by practitioners, and there is currently very little systematic evidence of the impact of ICTs available to inform policy decision-making.

The Study aims to:

- better understand how ICT can support the creation of a sufficient number of available (motivated) and skilled domiciliary caregivers, where family and friends, volunteers and privately-paid care assistants are key components (e.g. their access to training, guidance and other forms of professional support);
- better understand how technology-enabled services and applications can allow informal caregivers and family-employed care assistants to better engage with people they care for, enabling better results in terms of quality of life of the caregiver (e.g. better work-family balance), effectiveness of care given (e.g. better services supplied) and its efficiency (cost savings).

To do this it will:

1. identify to what extent do initiatives / good practices exist in the EU and abroad, and document 50 good initiatives to illustrate the diversity;
2. build an Impact Assessment framework in order to measure and assess in qualitative and quantitative terms the outputs and outcomes of those initiatives;
3. conduct in depth case studies of successful 12 initiatives to explore the benefits they bring to care-givers and recipients, development path and conditions, the success factors and pitfalls;
4. identify those with potential to scale up or to be transferred and redeveloped in other contexts across Europe given the diverse and changing environment for care in Europe;
5. identify and measure the actual and potential socio-economic impact of these initiatives;
6. develop Future Scenarios for Long-term Care using this impact assessment; and,
7. identify the policy challenges and opportunities to support and stimulate the social, market and technical innovation needed to facilitate this development.

Outputs

June 2011: Report ‘Mapping and Analysis of 50 Initiatives’
March 2012: Report on Impact Assessment and Policy Options

Workshops (TBC)

June 2011: Expert Workshop
November 2011: Expert and Policy Workshop
**ICTs work for carers by facilitating:**

**Independent Living for older people**
Technology systems to allow elderly people in need of care to stay at home without continual formal or informal care support, thus relieving pressure on care-giver. It may allow caregiver to leave recipient alone, or help them in caregiving.

**Information and Learning**
Tools that give access to information and training about caregiving, health and care issues for the dependent older persons, information and training about coping with caring; training for life - language, other work skills, accreditation of skills etc;

**Care Coordination**
Tools for coordinating formal sector and informal and family employed carers. Allows organisation of respite, sharing information on recipient's and carers needs etc, addressing one of the main sources of frustration for family carers.

**Personal support and social integration**
These provide a means of social, emotional & peer support, leisure, relief from isolation and chances for participation in work, civil society etc.

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**Background: Carers, Caregiving and ICTs**

While traditions of care vary widely across Europe, caregivers are overwhelmingly represented by spouses and daughters of the care recipients, and to an increasing extent by (mainly female) migrant care assistants, employed, often on an undeclared basis, by private households. The latter trend currently occurs on a large scale especially in Mediterranean countries. Caregivers can be stuck at home 24 hours a day; many carers of working age have to give up work; young caregivers may forgo education. This exacts not only a personal cost, but also a cost to the wider economy in terms of a reduced and less skilled workforce and increased poverty. Older caregivers often find their own physical and mental health challenged by caring for a dependent family member, increasing the burden on health and social care services.

Despite many positive aspects of caregiving, the negative aspects are multiple: caregivers frequently suffer psychological problems and social isolation, struggle with the demands of caring, and often lack basic knowledge about how to best care for a dependent older person. This translates to increased risks to those they care for. Even in the most developed welfare systems, caregivers seldom draw on the services available to support them (psychological support, respite care, self-help groups, training courses etc.), which in many cases are inadequate, bureaucratic and underfunded. Where governments make cash payments for care or individual circumstances allow, many families turn to cheap migrant workers to share the caring burden, and abuse and exploitation of family-employed migrant caregivers is an increasing problem.

Preliminary evidence suggests that ICTs can provide a cost-effective way to improve the quality of care provided to dependent older people, to ease the burden on informal caregivers and family-employed care assistants, and improve the quality of life of both groups. However, most ICT development programmes focus on the care recipient, and often ignore the role of the family and family-employed caregivers who take ultimate responsibility for care. Despite the success of tele-alarms, of promising, but still small-scale experiences in using ICTs, and an increasing number of online resources and social networks, uptake is still low. Barriers to stronger innovation and a more widespread adoption of such tools include poverty, lack of experience and skills among caregivers, and limited expertise and awareness among suppliers and policy makers of the role of the caregiver and the possibilities of ICTs.
## 52 Mapped Initiatives By Country

<table>
<thead>
<tr>
<th>UK</th>
<th>France</th>
<th>Sweden</th>
<th>Slovenia</th>
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<tbody>
<tr>
<td>Leeds City Council Telecare Service</td>
<td>Cyber France</td>
<td>My Joice TV</td>
<td>Red button telecare</td>
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<tr>
<td>Carers UK online forum:</td>
<td>Salveo</td>
<td>ACTION</td>
<td>My healthcare personal reminder</td>
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<tr>
<td>HFT (formerly Home Farm Trust)</td>
<td>Maison Vill'age</td>
<td>Family Care Support Portal</td>
<td>Italy</td>
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<td></td>
<td>(Anhörigstödsportalen)</td>
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<tr>
<td>Book Your Own Breaks</td>
<td>Forum aidants</td>
<td>GAPET</td>
<td>CAMPUS</td>
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<tr>
<td>Telecare Scotland</td>
<td>Web-napperon</td>
<td>IPPI &amp; AMIGO</td>
<td>E-CARE</td>
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<tr>
<td>Just Checking</td>
<td>Open and distance learning</td>
<td>Hungary</td>
<td>C.A.S.A. (Care Assistants Search Agency)</td>
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<tr>
<td>Nottingham Community Housing Association</td>
<td>Germany</td>
<td>Skype care</td>
<td>Ring Project (Transferring supports for caregivers)</td>
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<tr>
<td>Ireland</td>
<td>SEKIS</td>
<td>Emergency alarm</td>
<td>T-Seniority Project</td>
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<tr>
<td>Fold Group</td>
<td>Pflege Wiki</td>
<td>MOHANET</td>
<td>Spain</td>
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<td>Try It</td>
<td>Vitaphone</td>
<td>Életvonal 24</td>
<td>Andalusian Telecare Service</td>
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<tr>
<td>Emergency Response Ltd</td>
<td>SOPHIA</td>
<td>Body Guard</td>
<td>Un cuidador, dos vidas (A caregiver, Two lives)</td>
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<tr>
<td>Austria</td>
<td>PAUL</td>
<td>Czech Republic</td>
<td>Ser Cuidador (Being a caregiver)</td>
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<tr>
<td>Hilfswerk Notruf</td>
<td>Alzheimer Blog</td>
<td>Seniors' Telephone – Crisis Helpline (Zivot 90)</td>
<td>Tele-gerontologia</td>
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<td>Alzheimer Website</td>
<td>Finland</td>
<td>Careion Emergency Care</td>
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<td>n@tzwerk pflege</td>
<td>Vivago Watch</td>
<td></td>
<td>Bonus case! Employers for Carers’,UK</td>
</tr>
<tr>
<td>Plattform für pflegende Angehörige</td>
<td>The CaringTV</td>
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A few findings from the mapping:

**Book your own breaks – Online respite Care Booking Service, UK**

Carers greatly value respite care to give them a break. However the inflexibility of conventional organisation undermines their effectiveness. This initiative addresses this problem.

“The world disappeared from my view when my husband Victor became shrouded in a sinister, creeping grey mist that clouded our lives. Aged 61, he had retired from a successful career as an RAF and private airline pilot. Plans were in the making for a fun packed retirement. Then like an uninvited guest Dementia came to stay”.

Crossroads Care and especially Book your own Breaks has given Jan peace of mind – if she has to go out to attend meetings or socialize with friends, Victor is being cared for, he is safe and it does not put a strain on their finances as they are able to use the Carers break grant, but more importantly it allows Jan the flexibility to book a carer at a time convenient to her. Since being in touch with Crossroads and using the BYOB system to book a Carer Support Worker on line, Jan feels it has allowed her more freedom to use her time more effectively, as 99% of the time Jan is able to book the same Care Support Worker allowing for consistency and building up a trust and rapport both for her and her husband.

**User centred-ness makes for effective services: ICTs can help deliver this**

Successful services such as those offered by SOPHIA, Germany, Fold Group, Ireland, Try IT in Ireland, Leeds City Council in the UK and ACTION in Sweden enable services to be coordinated around carers and elderly dependents, and let families and carer workers select appropriate packages of support. ICT services can become an integral part of needs assessment too.

**Supporting family-employed caregivers**

A great deal of care outside the formal sector is provided by family-employed caregivers, often immigrants, without training or support. Internet based services, such as the extensive training service provided by FEPEM (France), by the CASA Agency model (Italy), or the Ser Cuidadora service (Spain) can be part of the means to improve skills, combat social isolation and regularize their status in the workforce.

**ICTs deliver for carers of people with cognitive impairment**

For carers of people with conditions such as Alzheimer’s, ICTs offer a number of important supports. Monitoring technology, such as the Just Checking (UK) system helps family and professional carers understand a sufferer's condition better, while Everon (Finland) allows caregivers to safely leave monitor wandering relatives. Concerns over privacy can be overcome in well managed systems.

Most countries have very active online family support associations that provide extensive information and support online. However much can be done to make sure family carers get the right information at the right time.

**ICT skills?**

Easy-to-use ICT services were the basis of innovations such myjoice TV (Sweden). However the attitudes of professional carers, and care service managers who doubt the relevance of ICTs for elderly carers and dependents play an important part in putting up barriers to services such as Skype Care (Hungary) or ACTION (Sweden).

**Low cost, but still hard to expand**

A number of different actors may be involved in setting up ICT services for family caregivers: local governments, non-profit organizations, civil associations, private companies or research institutions. More often than not, however, partnerships arise and have proven to be the most successful ways in setting up sustainable services. Ensuring funding from more than one source may prove beneficial to maintaining ICT-based services in the longer run. At the onset, however, policy incentives and public-private partnerships may be of utmost importance to ‘kick-start innovative services. One of the main challenges remaining is then to secure funding beyond pilot status. A large number of ICT-based initiatives seem to be able to operate with a relatively small budget. More cost-benefit analyses are needed to be able to judge the real amounts needed per case for ICT-based services, and to demonstrate the place of these services in the financial jigsaw of carer support and
Contact

CAR ICT Research Consortium

Project funders:
European Commission:
- Joint Research Centre (JRC), Institute for Prospective Technological Studies (IPTS)
- Directorate General for Information Society and Media (DG INFSO), Unit H3 (ICT for Inclusion)

Consortium Leader:
European Centre for Social Welfare Policy and Research in Vienna

Consortium partners:
- CIRCLE (Centre for International Research on Care, Labour and Equalities) - University of Leeds (England, UK)
- INRCA (National Institute of Health and Science on Aging), Italy
- Institute of Sociology, Academy of Sciences, Budapest, Hungary
- Swedish National Family Care Competence Centre, Sweden
- Eurocarers, the European federation bringing together national carers’ organisations as well as research and development centres

Policy Challenges:
Long-term Care (LTC)
ICT for Inclusion

Study Objectives:
Develop systematic policy evidence on best practice in ICTs for informal domiciliary caregivers and family-employed assistants
Assess and Develop Impact Assessment Methodologies
Draw policy conclusions on options to support innovation and adoption of ICT for LTC

Time Scale:
2011, 12 months

Potential Users:
Policy makers at EU, national and regional level in areas of Social Welfare, Employment, Health, Information Society, Innovation, Immigration and Education

Outputs:
2 Expert Workshops; Summaries of 50 Best Practices; Verified Impact Assessment Methodology; Impact Measurement and Assessment based on 12 In-depth Cases; A Report on Implications for Policy; Scenarios for Future Development of Long-term Care.

The Institute for Prospective Technological Studies’ (IPTS) work on Inclusion
IPTS has a mission to provide evidence to inform policy on the key European Union objective of ICTs for Inclusion: the development of ICT technologies and services that bring benefits to all citizens, and the use of ICTs to achieve wider socio-economic inclusion objectives. These objectives include innovation to support elderly people by increasing their quality of life, autonomy and safety, and the improvement of digital literacy among groups at risk of exclusion, which includes many elderly people and their caregivers. This project will extend an existing programme of work at IPTS on ICT for Caregivers in domiciliary settings aimed at providing evidence and options for policy in the areas of Long-term Care and ICT for Inclusion. (http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html)

Contact
IPTS Project Coordinator: James Stewart, james.stewart@ec.europa.eu
Lead Contractor: Giovanni Lamura, lamura@euro.centre.org
IPTS Action Leader: Clara Centeno, clara.centeno@ec.europa.eu
http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html