

ICTs to support the family caregivers of older people

Study on “ICT-based solutions for caregivers: assessing their impact on the sustainability of long-term care in an ageing Europe”



European Commission
Joint Research Centre (JRC)
Institute for Prospective Technological Studies (IPTS)



<i>Policy Challenges:</i>	Long-term Care (LTC) ICT for Inclusion
<i>Study Objectives:</i>	Develop systematic policy evidence on best practice in ICTs for informal domiciliary caregivers and family-employed assistants Develop and verify Impact Assessment Methodologies and conduct Impact Assessment Draw policy conclusions on options to support innovation and adoption of ICT for LTC
<i>Time Scale:</i>	2011, 12 months
<i>Funders:</i>	European Commission: <ul style="list-style-type: none"> • Joint Research Centre (JRC), Institute for Prospective Technological Studies (IPTS) • Directorate General for Information Society and Media (DG INFSO), Unit H3 (ICT for Inclusion)
<i>Potential Users:</i>	Policy makers at EU, national and regional level in <i>areas of Social Welfare, Employment, Health, Information Society, Innovation, Immigration and Education</i>
<i>Lead Contractor:</i>	European Centre for Social Welfare Policy and Research (Vienna, Austria)
<i>Outputs:</i>	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>)

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.

IPTS is working with a consortium of specialists led by the **European Centre for Social Welfare Policy and Research**. A key output will be the Impact Assessment and Measurement used to draw conclusions about actual and potential impact of investment in ICT for caregivers on social welfare, employment and welfare costs.

Outputs

June 2011: Report 'Mapping and Analysis of 50 Initiatives'

November 2011: Report on Findings: 12 example Good Practices

December 2011: Report on Methodological Framework

December 2011: Report on Impact Assessment and Policy Options

Workshops (TBC)

June 2011: Expert Workshop aimed at reviewing findings from 50 examples of best practice, and verifying the Impact Assessment methodology developed by the study consortium

November 2011: Expert Workshop aimed at validating Impact Assessment, identifying policy implications, and discussing future scenarios for sustainable long term care developed by IPTS

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.

Give your Input!

IPTS and the study contractors are looking for examples of successful initiatives from across Europe, and for the participation of experts and those involved in the support of informal caregivers. Please contact the project leader if you can provide information or wish to participate.

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



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<http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html>