CARICT

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

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Deliverable 4.3
Final report containing case-by-case detailed description and analysis of selected 12 Good practices

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Introduction

1. Aims of the deliverable
This final report is part of the activity of the **WP4: Analysis of Good Practices** of the CARICT project. In particular, WP4 is divided into two main stages:

- *pre-selection of 15-20 ICT-based initiatives for carers* that illustrate the positive effects of applying ICT solutions in the different dependency scenarios;
- *description and analysis of 12 ICT-based initiatives for carers*, demonstrating their impact to carers.

The aim of the deliverable 4.3 is to provide in-depth descriptions and individual analyses of the 12 selected initiatives.

2. Selection criteria and in-depth analysis
Previous steps of the project identified 52 good ICT-supported initiatives for carers that represent the largest European data-set available in the field at this moment (data collection and analysis have been carried out in the period January-May 2011). All these initiatives are beyond the pilot status and are integrated with the care system. Information on these cases is available in the project 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](http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/CARICTD2.3Mappingof52initiatives.pdf)), which includes both an overall analysis of the selected solutions and a case-by-case presentation of them.

In order to better understand the impact and the success factors of such services, a second stage was conducted. Among the available operational and successful European initiatives, 10 ICT-based services have been selected by IPTS and project consortium. The selection tried also to keep a balance among the different care regimes[^1^] to show ICT application in different national backgrounds. Furthermore, these European cases have been complemented by cases of two initiatives from North America which are recognised examples of high quality impact assessment design and providing convincing evidence of positive outcomes.

The selected initiatives are:

- **Anglosaxon area:**
  - Just Checking (UK)
  - Telecare Scotland (UK)

- **Continental area:**
  - SOPHIA (Germany)
  - Platform for Caring Family Members (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)

A case study method was used to explore each initiative, using a common data collection framework (see Annex 1), and guidance on questions to ask of people and documents. Each researcher was asked to analyse and write the case study in a form appropriate to the particular initiative. The case study method was developed with a three-fold aim:

1. to collect all the impact assessment and evaluation data available from within the service or project, in order to show in the most comprehensive way the actual impact of the service as it had been measured. This included documenting the evaluation methods used, and providing references to the original studies;
2. 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, and use this also to provide a test of the scope of the proposed Impact Assessment Methodology (IAM);
3. to provide an account of the development of the service over time in order 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.
Data collection and analysis for this second stage have been carried out in the period April-October 2011: data was gathered through a small number of in-depth interviews with initiative coordinators and project managers of the services, web-based research and secondary analysis of existing data. Information presented is updated to October 2011: nature and features of services, as well as the geographical context, may change after this date and the submission of this deliverable.

2. Limitations
The selected cases are limited in two ways.

On one hand, the 10 selected European initiatives are not a representative sample of all the operational ICT-based solutions carried on in the continent. The analysis carried out in this section have not the aim of generalising results, but to check if the methodological framework is adequate to describe the complexity of ICT-based initiatives or it needs further adjustments and improvements from a theoretical and conceptual point of view. Such goal is achieved through the discussion of evidence gathered from the selected case studies, that is however limited and cannot provide a comprehensive picture of every ICT-supported service.

As well, the two interventions from North America are not representative of United States of America and Canada contexts. They have been considered to be useful in this work because they can provide some insights on initiatives different from European ones and that may present different approaches for impact assessment.

On the other hand, the cases were based on a very small number of interviews, and existing documents, collected during a relatively short period of time in 2011, so do provide a comprehensive case, for example, giving alternative perspectives on the development and benefit of a service from that of the main person responsible, or exploring in depth the methods and motivation for the specific evaluation and impact assessment studies conducted. Some of the cases were written by those who were closely involved in setting up and running the services, and providing detailed insights, but with of course the methodological limitation of an inside voice which has been addressed by case study design and editorial review.

3. Authorship
This deliverable is based on the data collected by the CARICT project partners who analysed the 12 selected ICT-based initiatives for carers. Data collection and analysis have been carried out in the period April-October 2011. All data included in this report have been collected by the following partners:

- Carlos Chiatti (INRCA): analysis of Cuidadoras en Red (Spain, in collaboration with Trinidad Carrión, University of Málaga);
• Gary Fry (CIRCLE): analysis of Just Checking (UK, with contributions from Celia Price, Just Checking) and Telecare Scotland (UK);
• Elizabeth Hanson and Lennart Magnusson (SNFCCC): analysis of ACTION (Sweden);
• Marco Socci and Carlos Chiatti (INRCA): analysis of CAMPUS (Italy, with contributions from Licia Boccaletti, Anziani e Non Solo) and E-CARE (Italy, with contributions from Carla Fiori, CUP 2000 SpA);
• Andreas Stückler (European Centre for Social Welfare Policy and Research): analysis of Platform for Caring Family Members (Austria), SOPHIA (Germany) and Resources for Enhancing Alzheimer’s Caregiver Health I/II (USA);
• Zsuzsa Széman (Institute of Sociology, Hungarian Academy of Sciences): analysis of Emergency Alarm (Hungary) and Caring for Others (Canada).
• Nadja Widéhn (SNFCCC): analysis of IPPI (Sweden).
**ACTION**

Assisting Carers using Telematics Interventions to meet Older people's Needs

Elizabeth Hanson and Lennart Magnusson²
Swedish National Family Care Competence Centre (SNFCCC)

<table>
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<tr>
<th>Website</th>
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“The ACTION service is directed towards 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 programs in order to 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.”

*from Empirica, WRC & TUW (2010:158)*

Methodological note


**DESCRIPTIVE INFORMATION**

The main objective of ACTION is to maintain or enhance the autonomy, independence and everyday quality of life of the older people with chronic long-standing conditions and their family carers. At the same time, to increase the job satisfaction of care practitioners at the call centre and the overall quality of care for older people in the municipality via working

² Elizabeth Hanson and Lennart Magnusson were directly involved in the development of the ACTION service, as well as in the current implementation. Lennart Magnusson is a board member of ACTION Caring AB, a company that delivers the service in coordination with REACTION Centre AB. Both Lennart Magnusson and Elizabeth Hanson are board members of REACTION Centre AB. At this time, ACTION Caring AB is currently owned on an equal-share basis by the holding company of University College of Borås and REACTION Centre AB. For more details, see http://actioncaring.se/Eng/Engorganisation.htm.
proactively and in partnership with older people and their carers to help empower them in their caring situation at home rather than coming in much later on when a crisis occurs and subsequently taking over the situation.

The ACTION service offers user-oriented, easily accessible, ‘state of the art’ information, education and support to older people with advanced chronic conditions living at home 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 programs and relaxation programs;
- support and social company from other ACTION users via the integrated videophone system;
- support and advice from skilled care practitioners working in an ACTION call centre via the videophone system;
- individual and group computer education about how to use the ICT based service;
- comprehensive education, ongoing supervision and certification programme for care practitioners working in an ACTION call centre.

Each user has a locally installed client application based on Emblaze-VCON’s development kit HDDK 10 v 155 in their own computer or in a computer they have lent from the municipality. The client connects to a web platform, hosted on a dedicated server based on a Linux Redhat enterprise distribution, with an Oracle Application server. The Application server communicates with the Oracle database which is hosted on a dedicated server based on Linux Redhat Enterprise distribution. The ACTION service also consists of multiple video clips which are handled by a Streaming server hosted on a virtual server based on Windows server 2008 32-bit.

The PC also connects to an Emblaze-VCON MXM server hosted on a Virtual server based on Windows Server 2008 32-bit which handles the video calls. The MXM server connects the clients during an encrypted video call with H323 protocol on a client-server basis. No communication client to client occurs.

Internet is used for the communication, the communication is encrypted with SSL and the server requires a client certificate installed on the ACTION-PC. Due to privacy and security only administrators using computers with valid ip-addresses have access to the system through SSL or SSH encrypted connections. All servers are protected by a firewall and are monitored continuously.

The technologies enable access to the following functions:

- extensive information database with illustrations such as drawings, pictures and video clips
- interactive training and relaxation programmes
- video communication, that makes it possible for users to connect to all other users (older people, family carers and practitioners) involved
- Online training and education to use the services
The service was developed using participatory research methods and a user sensitive design model. The service is built on ‘state of the art’ research results and developed and evaluated in close collaboration with older people with advanced chronic conditions and their family carers. The users have been actively involved in all phases of the design work. The information and educational programs are quality assured by expert practitioners in the field.

A Theoretically grounded model

The ACTION initiative was explicitly theoretically grounded within the temporal model of family caregiving and the carer as ‘co-expert’ model (Nolan, Grant & Keady, 1996). This meant that the main outcomes for family carers were focused on enabling family members who wished to care for their older relative at home to go from being a novice carer to an expert carer with regards to their own caring situation via the provision of information, education and support that suited their individual needs and preferences. Further, that the information, education and support was also geared to the phase of caring they were currently experiencing. The core outcomes for family carers were concretely operationalised within the PREP model of family caregiving put forward by Archbold and Stewart which focused on enhancing the Preparedness, Enrichment and Predictability of the family caring situation.

Family carers’ levels of preparedness with regards to their caring situation aimed to be increased via the provision of appropriate and accessible information and education multimedia programs, as well gaining additional advice and support from fellow service users and dedicated care practitioners at the call centre via an integrated videophone system. The ACTION initiative aimed to enrich the everyday quality of life of the carer and frail older relative via their joint involvement in learning to use the technology based system (the computer and videophone application) and in so doing form new informal support networks with others in a similar situation to their own. As well, to find new potential activities of interest that were feasible to them both via information about hobbies, leisure and cultural activities within the multi-media programs.

Finally, the ACTION initiative aimed to increase the predictability of the caring situation via access to appropriate information within the multimedia programs regarding the nature and progression of the illness trajectory of their relative’s chronic illness in the ‘dementia’ and ‘stroke’ programs as well as information within the ‘planning ahead’ program regarding future care options and the range of care and support services available in the ‘service guide’. The EU and early Swedish projects highlighted the need to focus equally on the caring dyad and on enhancing the quality of the caring relationship between the primary family carer and the older relative in need of help and support.

Target users

The ACTION service primarily helps older spousal (or partner) carers, living together in their own home with their aged spouse who has a chronic long-standing condition and
requires help with instrumental and personal activities of daily living. The informal carer often provides the bulk of the care to his/her spouse single handedly and/or with the help from social services such as home help services and respite care services. Family carers are commonly older spousal carers (partners) at least 70 years of age and their spouse is of similar age or older and commonly requires help with both personal and instrumental activities of daily living (PADL and IADL) as a result of chronic illness/es such as stroke, dementia. In fact, information collated from earlier project data and more recent data collected by participant municipalities within implementation projects reveals that service users are predominantly female spousal carers aged between 75 and 85 years of age who are caring for their spouse commonly aged between 75 and 90 years of age living with chronic conditions such as heart and circulatory problems, dementia, cancer, neurological diseases and diabetes. The socio-economic status of users varies. Service users with ethnic minority backgrounds are largely under-represented.

At an organisational level, the service incorporates a staff educational programme which enables a participant municipality to have several dedicated staff at a local ACTION call centre who are educated to inform and support those older people with chronic conditions that require some help with both IADLS and PADLS, who live alone and/or together with their partner/spouse who acts as their primary informal carer. The service is designed to target older people who are socially isolated and who are not regular computer users yet are precisely those potential users that could directly benefit from learning to use the computer and Internet and become part of the current information society. At the same time, as they could directly potentially benefit from creating new social support networks with others in a similar situation to their own via the videophone system as many older people with chronic conditions and their family carers are often housebound, particularly in the winter months. In the later implementation projects, from approximately 2004 onwards, the ACTION service has also targeted carers of working age who provide regular help and support to an older relative who lives close by, most commonly daughters. Thus, it can be seen that ACTION is an ICT support service which provides support to the care recipient and support to the quality of care through the carer. As well, the service supports the carer’s quality of life and enables social inclusion and participation of the caring triad (older person, family carer and care practitioner).

Rationale for starting the initiative

The rationale for the original initiative in 1997 lay in the major policy drivers at that time, which are arguably as relevant if not more so today, concerning ageing demographic trends, which together with finite economic resources led to an increased emphasis on community care policies and ‘ageing in place’ with a renewed focus on the role of the family to support its frail older relatives. At the same time, due to the rapid uptake of the Internet within the workplace and social and private life spheres, EU policies in the mid-nineties began to focus on the active inclusion of older and disabled people within the new information society. The IVth framework of funding within the IST programme called the
'TIDE' initiative (Telematics Integration for the Disabled and Elderly) acted as a form of ‘flagship’ for these key policies. The key ‘selling’ factor within the original EU ACTION project proposal was its unique focus on maintaining or enhancing the autonomy, independence and everyday quality of life of the frail older person via supporting their family carer, as stated in the project’s acronym. Modern, easy accessible ICT was an innovative medium for securing these overall aims. The majority of funded EU projects hitherto had tended to focus exclusively on the older person. Indeed, this trend has continued until more recently when there has begun to be more focus on the family carer given the current economic climate and the need for cost containment and savings within the public care sector in nearly all EU member states. Evaluation data from the EU and early Swedish projects revealed that the service has been able to help those that it was intended to help. Those carers that benefited most from the service had a strong desire to care for their spouse/partner at home, they had a small network from which to draw support and most had little prior knowledge of caring. In contrast, it tended not to benefit those that had been caring for a considerable length of time, were heavily burdened and whom expressed ambivalence about their ability to continue caring for their relative. It tended to be ineffective in reducing the perceived stresses of the caring situation for these carers. It also tended not to benefit those who already had an extensive social network and those that were already proficient computer users.

Development and implementation

Similarly, to other family care support services, the timing of the introduction of the ACTION service is crucial and the data strongly suggested that it is optimal if it is installed early in the caring trajectory, prior to a crisis situation occurring and at a stage conducive for couples to enjoy learning a new skill rather than viewing it as an additional burden. Nevertheless, data from the dementia projects conversely highlighted that there are also issues with introducing the service too early for several service users as spouses/partners of older people with early stage dementia often do not see themselves as ‘carers’ as they tend to offer emotional and psychological support in the early stages of a dementia illness and practical support often takes the form of sensitive reminders whilst extensive ‘hands on’ caring often does not occur until later on in the illness trajectory. Thus, the exact optimal timing and targeting of potential users is highly individual and as such demands considerable skills from practitioners working with the ACTION service in the participant municipalities. Indeed, this subject now forms a key part of the initial and ongoing staff educational program. Earlier Swedish evaluation data highlighted that the service made a positive impact on those practitioners working directly with the service at the call-centres by providing them with new insights into carers’ needs and promoted more inclusive and empowering ways of working. Nevertheless, it revealed that the initiative was much less successful in changing the awareness and attitudes of health and social care practitioners and managers working in traditional care settings for older people. The need for more extensive and ongoing
awareness training sessions carried out on a regular basis by ACTION practitioners was recognised and formed the basis for the ACTION Vinnvård project which established blended learning networks consisting of members from all key stakeholder groups in an attempt to tackle this key issue.

A major problem identified within the Swedish implementation projects is that the municipality staff do not tend to routinely collect sufficiently detailed descriptions of service users. Likewise, there is no clear legal jurisdiction whatsoever for municipality staff to keep records concerning users of family care support services. There is still a lack of a clear national mandate concerning record-keeping of family care support services given that municipalities are largely self-governing. As a result, it varies widely across the country the extent and detail to which records are kept on an ongoing basis concerning family carers. This seriously hampers the ability of municipal staff to clearly highlight the potential effects of services, particularly more innovative services such as ACTION which are highly complex and multifaceted. It would clearly be useful to keep detailed records concerning the physical and mental health status of the older person in need of care and support as well as that of their family carer. As well, a detailed record of their use of services (both health and social care services). Thus, far such data has been obtained solely within the remit of a research project status in which ethical approval has been sought and obtained. It is recognised at national level by policy makers that this represents a considerable challenge to the ongoing quality development of service provision in the municipalities. However, the complexity of the issue with regards to privacy and confidentiality represents a significant challenge and lawyers working for the National Board of Health and Welfare Sweden continue to work with the issue.

Based on direct feedback from service users themselves within evaluation projects it can be seen that in the near future the service needs to evolve by integrating access to physicians and health care practitioners via the video-phone system and also by making it feasible to remotely monitor and treat the older person. Given the current relative lack of direct support services geared to working carers, the service initiators recognise there is a growing argument for the service also to be sufficiently flexible to be able to more directly accommodate the specific needs and preferences of this younger and often more computer literate group of carers. Nevertheless, it is recognised that the adage of ‘not throwing the baby out with the bathwater’ applies here as the primary benefit of ACTION is targeted at very old people with advanced chronic conditions and/or with informal caring responsibilities and few social networks and whom are not regular computer users. Thus, the initiators recognise that that there is a need to culturally adapt the service to better meet the needs and preferences of older people from different ethnic minority backgrounds which is currently lacking.

**OPERATIONAL INFORMATION**

The service has grown slowly but surely from an EU project (1997-2000) to a mainstream service in approximately twenty municipalities in Sweden. ACTION was set up by a consortium consisting mainly of researchers and several care providers and voluntary
organisations from the University of Sheffield, UK together with universities in Northern Ireland and Coimbra, Portugal and University of Borås, Sweden. The project was successful in receiving funding from the EC’s IV Framework Funding within the TIDE initiative and was co-ordinated by the University of Borås. From 2000 onwards, the initiative has been further researched, developed and evaluated with the help of successive external national research and development funding in Sweden. As well, a critical factor in its development is that in 2003 the University of Borås set up a spin-off Research & Development company and went into partnership with Telia Sonera, the largest telecommunication operator in Sweden in order to be able to make the service more widely available, initially across Sweden but also in other Nordic and European countries. A significant development was also the decision by Borås municipality in 2004 to make the ACTION initiative part of its mainstream services for its older citizens living at home and their family carers. Since this time, the ACTION service has been implemented in a further range of municipalities across Sweden in the form of feasibility or implementation projects often with the help of research and development funding and government stimulus monies within the area of care for older people and/or family care support.

It took three years to create the original ACTION prototype within the EU project which was then further culturally adapted and refined to make an integrated service within successive Swedish ACTION projects (2000-2; 2002-4). The ACTION concept has subsequently been further researched, developed and evaluated over the years with the direct input of older people with chronic illnesses, their family carers and care practitioners and managers to create partnership working with older people and their families facilitated by the use of ICT.

The coordinators are researchers who have worked with the ACTION service since its origin and have created a university spin off company that enables the ICT based service to be marketed and continually updated and improved. The municipalities that implement the ACTION service pay for each user. The ACTION service is part of the social care services in several municipalities in Sweden so that the user pays an average fee of 20 Euros per month which is equivalent to the cost of an alarm system. For most of the municipalities the users have to pay for broadband access themselves (approximately 20 Euros per month). The bulk of the research, development and evaluation work is funded by different research and/or development grants. Staff that works within the company are partly employed by the university and partly employed by ACTION Caring Ltd. Sweden. The municipalities finance the service and up to now in the majority of instance this has been in the form of an implementation project with time-limited financial support in the form of a development grant and/or governmental stimulus support monies which are applied for by the staff in the municipality concerned. Thus, income so far has depended predominantly on the state. This is likely to change given the current trend towards opening up home help and home care services and long term care services to the private sector as well as the current focus on working in collaboration with civil society organisations. Recently, based on interview data from external evaluation projects in several municipalities it appears that current service users would be reluctant to pay for the service themselves and see it as the primary responsibility of the municipality to fund such a service.
ACTION Caring Ltd. Sweden has a written agreement with each municipality that has the ACTION service and the length of the contracts vary, although the majority, in line with budget setting in the municipalities, tend to be on a yearly basis. In the case of implementation projects they are usually of two to three years in duration. There are clearly documented costs which consist primarily of costs for the videophone licenses in addition to the database, server maintenance and costs for personnel, offices, logistics and administration. The municipalities provide users with computers to access the ACTION service and they also offer designated practitioners who work with the service via the call centre. The users pay for the broadband connection themselves.

The service does not intend to shift costs from other services to family carers. Rather, it aims to prepare and empower those family members that wish to care for their older relative with advanced chronic conditions by giving them ICT based information, education and support so that they are able to manage their caring situation at home for longer and with a higher quality of life.

All the stakeholders had to be convinced to back the service. Namely, older people with chronic illnesses living at home and their family carers; practitioners and managers working with care for older people and family care support in the municipality, politicians, representatives for voluntary and pensionist organisations, representatives for the university, business partners. In particular, it had to be sold to the politicians and the top care managers within the different municipalities in Sweden. To be able to reach a decision with a municipality to implement the service all the other stakeholders also have to be onboard which means that they also have to be sold on the idea. Once this decision has been agreed, they all have to be continued to be sold on the idea. The key arguments and evidence that has been used to gain support have been the key data from research projects concerning impact on service users’ quality of life, the opportunity to help older people remain in their own homes for longer and without decreasing their quality of life. A key factor is the fact that it is often cheaper for the municipality to enable older people to stay at home rather than placing them in a nursing home. At the same time the service leads to increased social inclusion and reduced social isolation for older users.

**Personnel involved**

In total there are ten people involved in ACTION Caring Ltd. Sweden. There are three people working full time and one part-time in the university spin off company. The other six work part-time on a consultant or voluntary basis. The personnel working for the company have competence within the field of health and social care, ICT, teaching and supervision, implementation of ICT support services for older people and their family carers and R & D and evaluation within all of these areas.

In each participant municipality there are between one and three people who are directly involved in running the service with support from ACTION personnel. These practitioners in the municipalities carry out their work with ACTION mainly in conjunction with their other jobs. For each ACTION information and education program that is created there are between approximately 15 to 25 older people and family carers that assist in the making of
the programs. There are a core group of experienced family carers that regularly provide help and support with the marketing of ACTION and also assist in a variety of R&D projects. There are additional users that participate for a time-limited period depending on the particular needs of the project in question.

**Users and promotion of the initiative**

There are currently 350 people who regularly use the ACTION service. Based on population statistics the coordinators consider that there are at least 80,000 people in Sweden that could potentially benefit from the service. With further translation and cultural adaptations the service could be implemented all over Europe. The coordinators express that if there is a genuine interest then they would be happy to consider providing the service however they believe that it is important that there is a partner in the country where the service is being implemented with whom they can cooperate to effectively deliver the service. There are not many users that stop using the ACTION service. Those that do so discontinue the use of the service because either the one they previously cared for has died or they have been placed in a nursing home. Nevertheless, there have been a number of instances where the Needs Assessor in a municipality has allowed the ACTION service to continue for bereaved carers and carers whose spouse has entered nursing home and it has acted as a valuable form of social support and information and knowledge exchange. The service users often get to find out about the service from care practitioners in the municipalities. However, several potential users may get to hear about the service via their local carer association or pensionist organisation. ACTION call centre practitioners provide information about the service on their municipality’s website and via informing older citizens and carers at local meetings and gatherings which take place at a carer or elder meeting centre. ACTION Caring Ltd. Sweden advertises from time to time and personnel actively take part and are invited to contribute at international, national, regional and local care conferences and exhibitions which helps to promote awareness of the services.

**Requirements for the usage**

In order to start using the service the user needs an ordinary personal computer with a web camera and Internet connection. The users don’t need to have any prior computer skills. The service is very easy to use. ACTION personnel offer a comprehensive education in how to use the service for novice users that forms an integral part of the service. This consists of a five part group education programme each of three hours in duration. The training aims to educate users regarding the service and to promote social support networks amongst users. If the user has completed the education they often have no problems in using the service. Similarly, the ACTION call centre staff have an initial education which includes technical skills and knowledge for using the system and helping to support the users. The practitioners at the ACTION call centre help the users if they have any practical problems with the service. Most often they can do this by offering remote support and instructing the user him/herself rather than taking over the problem
themselves. ACTION Caring personnel help the users if they have any major technical problems with the service.

**ENABLING CONDITIONS AND SUCCESS/FAILURES FACTORS**

The main problems that had to be overcome to implement ACTION as a regular service can be categorised into three main areas. First, the persistent negative attitudes towards ICT-based support services for older people. In particular, the negative attitudes and general scepticism of health and social care practitioners, care managers and politicians regarding the use of ICT based services within health and social care services for older people. This has been tackled by giving information and demonstrations on a regular basis and during that time users were involved in sharing their story and explaining how the service has been of direct benefit to them in their daily life. The second challenge 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 within care for older people so that they tend to test out ICT based services such as the ACTION service 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 Borås municipality evaluation data concerning quality of life of service users together with the cost data highlighting cost savings for the municipality proved to be crucial. The third challenge was to create an efficient, well functioning business model- a model that helped the municipalities to know how much the service would cost and that there would not be any ‘add on’ costs. The model also needed to be designed so that the municipalities’ own ICT department need not be involved.

Issues with regards to how to present the service have occurred which has resulted in objections to the service being voiced by potential users. A key issue has been that when presenting the service as a computer program potential end service users have not been overly enthusiastic. Whereas, presenting the service as an assistive device to help them in their day to day life has had a much more positive reception. There have also been issues with enabling care staff to realize that ICT can act as a valuable tool to help them in their care work with older people. The main reasons for this is that staff often have low opinions of older people’s capacities and skills regarding the use of technology and they assume that caring can only be done ‘face to face’. At the same time, there are a number of older care practitioners (50 plus) who lack computer skills and/or direct access to a computer at home or in the work place so that they are not regular computer users themselves. As a result their feelings of uncertainty about ICT services tend to be transferred over to their elder clients. Awareness training by ACTION call centre practitioners acting as peer role models has been implemented as well as establishing blended learning networks to facilitate learning and sharing knowledge together about use of ICT.

To start implementing the ACTION service a close co-operation with staff working in the municipalities was of crucial importance. As well, having competence within the field of health and social care for older people and family care support, information and
communication technology, user sensitive design methods, teaching and supervision, implementation of ICT support services for older people and their carers and research and development within all of these areas.

IMPACT ASSESSMENT

With regards to the core areas of impact of the ACTION service, they are primarily focused on the quality of life of both the carer and the care recipient and subsequently the quality of care provided by ACTION call centre practitioners in the participant municipalities. Evaluation results revealed that the ACTION service impacts mainly at the level of the individual family unit which primarily includes older adults with chronic, long standing conditions (such as stroke and dementia) and their informal carers who are most often at least 70 years of age and older, spouses or partners who are living at home together. The main impact is on their subjective quality of life, reduction of social isolation as a result of informal support networks with other participant ACTION users; increased sense of security regarding their caring situation as a result of contact with dedicated staff at a call centre and enhanced social inclusion in the current information society as the majority of users are computer novices. With specific regards to family carers, evaluation data revealed higher levels of preparedness with regards to the care of their spouse/partner at home; they expressed higher levels of self-esteem and mastery over their situation and considered that their future caring situation was less uncertain.

Success can be measured in terms of the fact that the ACTION initiative is one of few ICT based support initiatives that has gone from a project to a mainstream service. It is a pioneering example that has been cited as a ‘best practice’ ehealth example at EU level. It can be argued to have been almost ahead of its time when it was initially run as a prototype service in the late 1990s and in so doing it has acted as a catalyst helping to smooth the path for the development of other user-focused ICT based services in Sweden and internationally (both the work of Ducharme in Québec and Marziala in Toronto was inspired from hearing and collaborating with ACTION coordinators). In the future, the ACTION service can be seen as a more effective way of working enabling health and social care staff to provide ‘non hands on’ elements of care remotely, namely, information giving, advice, support and to monitor and treat chronic conditions.

In 2004 the first cost calculation was made that revealed that ACTION gave Borås municipality a saving of 10 000 Euros per year per family. This was as a result of a reduction in the need for home help services and delayed entry to nursing home for a number of service users. This calculation has been presented to other municipalities and it was one of the main reasons why Borås municipality was the first municipality to take on board ACTION as a mainstream service.

The service is primarily intended to increase family carers’ and older people’s quality of life. At the same time, the service helps the municipality to empower and skill-up its staff in the growing area of modern technology and ways of working in partnership with older people and their families so that they are able to manage their situation themselves for as long as it is feasible to do so. In this way the service facilitates a more efficient way of
working. It enables the municipality to save money and also helps to lighten the workload that health care staff has to carry.

An unexpected positive outcome that particularly came to light in a recent implementation project involving several municipalities in the north of Sweden is that the service 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.

A lot of research and development work was carried out with family carers and older people to design the ACTION prototype (see Magnusson et al. 1998, 1999) and improve acceptability of the tool. Involvement of family carers, older people and practitioners to design a multi-media program within the ACTION service was clearly user-oriented (Hanson, Tetley & Clarke 1999; Magnusson 2005), and its development process inspired other works (Hanson et al. 2006). Furthermore, the exploration of the degree of usability and acceptability of the ACTION service was evaluated across all 5 EU partner countries—both qualitative and quantitative methods (Magnusson et al. 2002). In particular, there is also evidence on how older people with early stage dementia and their significant others are involved in the research and development of an ICT based support programme that forms part of the ACTION service, illustrating appropriate methods of user involvement with people with early dementia (Hanson et al. 2007b). Finally, the user centred design model developed by the authors is highlighted as a critical success factor regarding ACTION’s continuation over a 13 year period (Magnusson & Hanson, in press).

**FUTURE PERSPECTIVES**

In the future new outcomes relating more directly to the maintenance of the health status of service users is envisaged via integrating access to physicians and health care practitioners via the video phone system and by also making it possible to remotely monitor clients’ vital signs and treat their chronic conditions. These new outcomes have come directly from service users’ feedback themselves. The ACTION coordinators envisage that this development can be delivered via co-operating with other companies, universities and care providers.

The ACTION coordinators consider that by continuously updating and developing the service it can never go ‘out of fashion’. However, it is important to continue to have a solid business plan. There are no limitations with regards to increasing the numbers of users as the service has a strong database and solid platform for the video conferencing. The whole service can be replicated in other countries, nevertheless there would need to be some translation work and cultural adaptations carried out to ensure the service was sufficiently responsive to the specific context. The original ACTION prototype was developed collaboratively between five European countries and was also piloted in all these countries with positive results so that the conditions for transferability to other local contexts across Europe are favourable.
REFERENCES


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Torp, S., Hanson, E., Hauge, S., Ulstein, I., & Magnusson, L. (2008). A pilot study of how information and communication technology may contribute to health promotion amongst older spousal carer. *Health and Social Care in the Community, 16*(1), 75-85.
“Campus is a system for distance learning and in presence education targeted at social and care services professionals. It is designed for people with low expertise in ICT, it includes audio and video courses, skills tests, exercises, which ease the contacts and interactions between students and teachers, also at distance.”

from CAMPUS website

Methodological note
Unless differently specified, all information for this case study report have been retrieved from the documentation available in the project coordinator website (www.anzianienonsolo.it), in the website of the project PIC Equal ASPASIA (www.equalaspasia.it). Direct information was gathered through both interviews with the project coordinator Licia Boccaletti, who is the director of the social cooperative Anziani e Non Solo, and questionnaires to users of the services. Quantitative information regarding users’ and financial aspects of the initiative have been provided by project coordinators.

DESCRIPTIVE INFORMATION

The CAMPUS project is an ICT based initiative (initially funded by an Equal project) for social and professional inclusion of care workers. The rationale behind this initiative has to be found within the broader context of the Italian Long-term Care system. Whereas Italy is among the oldest countries in Europe, only 3% circa of dependent elderly receive formal care services in public or private institutional facilities. The vast majority of older people are cared at home, but the supply of Italian public social and health care services for the elderly is inadequate to the needs of care. In recent years, the families have increasingly resort to migrant care workers (MCW) in order to meet long-term care need of their dependent elderly relatives. An extensive private care market has developed in the Country, representing this, a sort of “hidden welfare” to meet the growing needs of elderly home care. Cultural changes have indeed contributed to such changes, as for instance the
Increasing participation of Italian women in the labor market has determined the need to hire staff for home care for the elderly. The large supply of immigrant labor (especially foreign women) in the care sector has filled this need, but drawbacks of this phenomenon started to be clear soon. In many cases the MCWs have low or little qualification, thus lacking the knowledges needed for caring after a dependent health-impaired person. The control over the quality of care provided by MCWs is difficult because their work is often undeclared and the homes of the older people are not easily accessible. In addition, the large prevalence of irregular work in the care market is associated with high risk of exploitations from both sides. Episodes of elder abuse and neglect in both directions (perpetrated and suffered by MCWs) are far from being uncommon in the Italian context (Ligabue 2010). Last but not least, the live-in option, although solving the accommodation problems for the MCW and lowering the cost of care for families, may represent an obstacle to the socialisation and to the progressive integration of the migrants into the Italian society. As a proof of the stressful conditions experienced by MCWs, the literature report the effects of the so-called “Italian syndrome” affecting Ukrainian migrant women returning back home with symptoms of paranoia and other mental diseases, following a very isolated, unhealthy life as elder care workers in Italian households (Tolstokorova 2009, Delsere 2009).

In such context, the aim of the initiative is to provide skilled training to caregivers of older people (the so called “badanti”) using ICT (i.e. the platform CAMPUS), promoting the use of ICT-based solution also among those people without computer skills. The main rationale for setting up the initiative was to use ICT to develop innovative and low cost methods for the training of caregivers, which could be easily transferred in others areas. Last data available show that the initiative and in particular its training activities reached more than 1,350 caregivers (both by self-learning and integrated with classes), that improved their abilities in using ICT and PCs, their professional and language skills useful for their care duties and their social integration. It is undoubt that the CAMPUS initiative contributed to fill in a gap in the provision of education and training for migrant care workers in Italy. Beside CAMPUS, no other initiative using new ICT specifically targeted this group, and most of existing (fragmented) educational and training opportunities for migrant care workers use only traditional (in presence) methodologies.

**CAMPUS in a nutshell**

<table>
<thead>
<tr>
<th>Total users</th>
<th>More than 1,350</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers skill assessment</td>
<td>More than 350</td>
</tr>
<tr>
<td>Year of start</td>
<td>2004</td>
</tr>
<tr>
<td>Editions of courses for private care workers held so far</td>
<td>8 (in Ferrara, Prov. Bolzano, Palermo, Bagnolo in Piano, Easy Care, Carpi 1st ed., Medio Campidano, Carpi 2nd ed.)</td>
</tr>
<tr>
<td>Cost of course for MCW</td>
<td>Free</td>
</tr>
<tr>
<td>Cost of services for family caregivers</td>
<td>€ 140.00</td>
</tr>
<tr>
<td>Main source of funding</td>
<td>EU (during the initial stage) and Regional and Municipal authorities</td>
</tr>
</tbody>
</table>
The initiative CAMPUS is managed by the social cooperative *Anziani e Non Solo*. This cooperative works since 2004 with a specific focus on management of project and promotion of products and services in the field of welfare and social inclusion. The activities carried out by *Anziani e Non Solo* concerns, *inter alia*:

a) active ageing and support to frail and dependent elderly;
b) training and support to family carers, informal and formal carers;
c) support to social inclusion of disadvantaged people.

Its areas of competences are: project management and social research, training and e-learning, validation of informally acquired skills, social information, development of software packages for social care and employment services workers.

**Target user groups**

CAMPUS have four different target user groups. The main target group of the CAMPUS initiative are MCWs, the so-called “badanti” (in Italy, they are estimated to be around 1 million of people). These workers are mostly migrant women aged over 45. In the most of cases, they are employed directly by families on irregular basis (and/or often they do not have a regular permission for living in Italy) receiving low level salaries and co-habiting with the care recipient. They often are on duty 24 hours a day, while they normally have one to one and a half free day during the week. As noted, they usually do not have any (or few) qualification or training in the area of care, nor they have access to up to date technologies, and often suffer from social isolation.

The second target group is represented by the increasing number of Italian women who aspire to work as private paid caregivers. They are often unemployed and looking for a professional outplacement in the field of caregiving. These people do not have adequate knowledge and skills about caring, so they need training.

A third target group can be found among formal care staff and temporary work agencies. In this case, the initiative eases the matching between supply and demand of regular and trained care workers.

Last but not least, an “indirect” target group (of the initiative CAMPUS, although this specific service was not developed in the context of the ASPASIA project) is represented by the informal family-caregivers, to whom is addressed another secondary ICT-based service, i.e. an online training course, based on the Wordpress platform, with advantages in terms of graphics and ease of use.

**Type of activities and services offered**

As migrant care workers access to educational opportunities is constrained by the aforementioned conditions, the project aimed to develop a method to provide them with a basic (or better) training, taking into account the following issues:
a) time: MCW cannot attend traditional classes; in fact, usually the training courses organized by municipalities, provinces or regions (often by public social services staff in collaboration with non-profit and for-profit organization or associations) are realized through training modules in classes that the “badanti” can’t easily attend because of the few free time available.

b) language: Italian is not their first language and it is not fluently spoken in many cases;

c) costs: they can’t afford to pay the training themselves and neither can their employers (i.e. households).

The solution identified by the ASPASIA project was to develop a training course that could be used as a self-learning tool, but also combined with some class meetings to support their social inclusion. The courses are accessible either via e-learning platform (CAMPUS) and DVDs – for those without a pc and an Internet connection – and are translated in seven languages. The costs of such training are notably lower than those of a traditional training course and, moreover, users do not have to pay a fee. Funding to the courses was provided by EU resources and from other local resources (municipalities, inter-professional funds, etc.).

The training for caregivers involved in the project is held in two ways:

1) e-learning activities (through the so-called CAMPUS platform; self-education, distance learning);

2) both e-learning activities and in-presence education: people can participate online and/or in classroom courses organized locally.

It is also possible use training courses on DVD (with a portable DVD player borrowed on request), to facilitate participants without Internet access at home.

CAMPUS homepage
Technologies used and functions of ICT tools

In the context of CAMPUS, technologies are used to support quality of care through carer’s education, support carer’s quality of life and enhance migrant participation to social life. The training tool has a user-friendly and age-friendly design, to meet users’ need of accessibility. It is structured to ease both contact and interaction with teachers/trainers (even not in presence). The e-learning platform CAMPUS is based on Moodle technology. It should be noted again that the course designed is accessible either via the e-learning platform and DVDs, for those not having a pc and an Internet connection. The course for family informal caregivers is developed using Wordpress technology: this system does not track users’ activities as Moodle does (as it is not meant for professional training), but has advantages in terms of graphics, ease of use and manageability.

This training system aims at empowering/raising awareness on issues of long-term care and updating knowledge and skills of family caregivers and private care workers, in particular migrant care workers. Therefore, the specific objective of the initiative is to provide vocational skills to participants. The training tool consists of 23 didactic units and the learning modules include: audio-courses, video-courses, classroom and distance learning. The multimedia contents includes: video, slides, animated show, for a, comprehensive material, tests and tutorials. Slides and videos are accessible either through e-learning platform or DVDs, while tests are accessible via e-learning only. There are several topics covered (i.e. understanding the role and challenges of caregiving; orientation in the social and professional context; care work; local health and social services organisation; major diseases related to ageing; the mobilisation of the cared person; personal hygiene of the elderly; preparation of food and feeding the elderly; etc.).

At the end of the course, users who studied at home (via DVDs or e-learning) can be tested in presence (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 undergo different kind of exercise (fill the blanks, quizzes, matching…) and, after the self-assessment, they are addressed to study those modules of the training course that were not validated (thus saving time and enhancing the skills they already have).

In any case, all users are tested and assessed (in particular the skills acquired) in presence by teachers/trainers. In order to do this, the project coordinator Anziani e non solo drew up a specific system of validation of skills of users.
Module sample, providing information on how to use thickening agent for liquids

Development methodology

The initiative 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), running between 2004 and 2008. Partners of that PIC Equal were: the social cooperative Anziani e Non Solo (project coordinator), the Association Infojob, Anci Services, the Association Aequinet, the Consortium Madre Teresa di Calcutta, the Consortium Quarantacinque. The project was also supported by a network composed by the municipalities in which the initiative takes place and by local structures of two cooperatives (League of Cooperatives and Confcooperative)\(^3\). After the conclusion of the project period, the training courses model developed have been implemented in other local editions, addressing both care workers (including migrant care workers) and family caregivers. Today these courses are active in several Italian regions and municipalities and CAMPUS methodology is now fully operational and is carried out by the former EQUAL project coordinator, the social cooperative Anziani e Non Solo.

The initiative is now fully operational, but it could be further developed by recognising national educational and professional profiles for home carers, which today are still lacking. Only some Regions outlined some of the requirements of these profiles and in some local areas it has been realized a summary of the profiles for the purpose of developing educational and training contents. These experiences have influenced the

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\(^3\) Aims of the project were: a) to create an integrated system of methodologies, models, technologies and services to support social inclusion; b) to improve training and professional qualification of migrant care workers and develop innovative models for home care services; c) to develop an integrated information network between institutions and the third sector; d) to promote synergies and a co-design system between the stakeholders of local welfare.
development of the initiative, especially the identification of topic areas of competence for the design of the training course “units”. In these short educational units (20 minutes maximum per module) it has been used a simple language (with translations in 7 languages, i.e. Italian, French, English, Polish, Russian, Arab, etc.) and multimedia materials (eg. slides and videos). The course contents were realized by professionals from various sectors (including medical doctors, nurses, etc.). The ICT platform CAMPUS was implemented using a user-friendly technology (Moodle), specifically designed for people with low ICT experience (to reduce digital and competence divide).

OPERATIONAL INFORMATION

As before mentioned, the initiative was set up and implemented thanks to the support and funding of the Equal project ASPASIA (2004-2008). Within the project, the tool was piloted among 150 users. It was afterward implemented (with more languages made available, new videos...) and its use was finally consolidated after the end of the project. Its user-friendly structure allows an easy transferability and reproducibility in others national contexts. At the end of the PIC Equal, the project continued its activities also with several local editions (i.e. in the Provinces of Milano in Lumbardy; Venice in Veneto; Ferrara, Reggio Emilia, Rimini, Bologna and Modena in Emilia-Romagna; Medio Campidano in Sardinia; Palermo in Sicily; in the municipality of Bolzano in Trentino-Alto Adige, etc.) of training courses for care workers (including migrant care workers) funded by local authorities (i.e. Provinces, municipalities) and by other sources (i.e. inter-professional funds). The CAMPUS platform has been used also in these courses. The characteristics of single courses (duration, participants) can vary in the different local context. In general, the training courses last three months for a total of 138 hours of which 86 in e-learning (by DVD or CAMPUS platform) and 52 in classes, even if they can have a different numbers of users.

It should be noted again that, following this project, in many municipalities of the province of Ferrara (Emilia-Romagna) and in other areas, several offices have been activated for matching supply-demand of care work. In this regard, the project prevented also the emergence of undeclared work and the enrolment of ASPASIA users to professional registers of trained caregivers. In general, funded by Regions, Provinces and some municipalities, the project implemented “ASPASIA points” in municipalities of three Regions (i.e. Ferrara, Cento, Codigoro, Copparoto in Emilia Romagna; Ragusa in Sicily; Brindisi in Apulia), also with the partnership of some health local authorities (i.e. Ferrara’s AUSL), to provide information, counselling, orientation support, training opportunities, matching of offer and demand of care work, to caregivers and families interested in employing care workers, supporting regular employment in the field of in-home assistance.
Funding and budget

As what concerns the funding and budget to sustain the initiative, users have to pay a fee to benefit from the services for family caregivers (those using Wordpress technology). In this case, this initiative is market-oriented, while those promoted by the project ASPASIA had/have the explicit aim to not charge end-users of training activities. The cost of these training courses for participants is € 140.00 (VAT included) and registration grants access to course contents (online) for 180 days (6 months). Conversely, courses for migrant care workers are free-of-charge (e-learning + classes). Editions of these courses have been carried out in different Italian regions (Emilia-Romagna, Lumbardy, Sicily, Trentino-Alto Adige, Apulia, Sicily and Sardinia), also benefiting from public funding. The initiative benefits from infrastructure (personnel, organisations, equipment etc.) from outside its budgetary capabilities only to a minor extent. These benefits consist mainly in the activities of public bodies (Regions and Municipalities) personnel in advertising the initiatives and in the use of public facilities for the courses.

Stakeholder involvement

The consensus-building process prior to the implementation of the initiative was facilitated by the public awareness regarding the relevance of the issue of qualification and training of care workers in the Country. In this regards, it is worth mentioning that Italy, although being among the oldest countries in Europe, has a limited provision of LTC public services and family relies heavily on the care provided by its members and increasingly by migrant care workers. In addition the availability of EU funding fostered the involvement of the many institutional stakeholders (e.g. municipalities and regions). Consequently, the availability of a free training programme was “warmly” accepted both by public bodies and by the wide audience of migrant private care workers who desired to improve their skill and knowledge.

BOX1 – The stakeholders of ASPASIA project

Among the stakeholders involved in the project there are different Italian Regions (i.e. Emilia-Romagna, Lumbardy, Sicily, Trentino-Alto Adige, Apulia, Sardinia) and many local authorities within these Regions.

These stakeholders funded the project initiatives in several local areas and collaborated (with their personnel, facilities, etc.) with project partners to the implementation of training courses (in classes) and to the creation of “info points”. They also conducted an information campaign and structured networks of collaboration with other relevant actors for the project initiatives (eg. Employment agencies) in their territories.

Formal care staff and employment agencies are involved in the initiative in order to facilitate the matching between supply and demand of regular and skilled care workers.
Personnel involved in the initiative

People involved in running this initiative are the whole Anziani e Non Solo staff, composed by 9 professionals in welfare, caregiving issues, training, e-learning and new technologies, with the contribution of a group of ICT and communication experts that developed both the CAMPUS platform and e-learning courses.

In addition, the initiative benefited from the contribution of a multidisciplinary team, which involved social workers, medical doctors, nurses and ICT professionals in the development of training modules.

Users

As what concerns the number of users reached by the initiative, so far the training tool has been used by over 1,000 caregivers (around 40% Italians and 60% migrants) in different Italian regions, both as a self-learning tool and integrated with classes. In addition, the skills of over 350 caregivers’ skills have been assessed. Summing up, more than 1,350 caregivers improved their confidence in using ICT and computers, their professional and language skills. Drop-out rate from classes was extremely low. Caregivers self-esteem was improved as well from the “official” recognition of their work. Overall, the results seem positive, showing also the presence of a latent demand for training and qualification for caregiving activities, which could be met through a further expansion of the use of ICT tools.

Requirements for usage

As noted above, the ICT platform was designed to facilitate the use of new technologies by people with low ICT experience and to facilitate users without Internet access at home it is possible use training course on DVD. Therefore, 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 at home how to use they system. The carers/users could also refer to operators in the “ASPASIA points” created in the municipalities (at local social services) or employment agencies partners in the areas in which the initiative took place.

However, in general, the acquisition of the ICT skills to use the training tools is very easy, due to the user-friendly interface and the simplicity of access to its content.

Carers get knowledge about ICT-supported services available also through extensive communication and promotion activities carried out by stakeholders, as well as through special arrangements such as the distribution of advertising material in public places such as shops (including ethnic), and parks. An important role is played by word of mouth information as well.

There were no particular problems in the design and implementation of the project and specifically in the development of the platform CAMPUS and of its contents. The main challenge was represented by the need of developing a simple design that could ease access
to people with low ICT skills. In this regards, results seem satisfactory (e.g. in terms of users). One of the key factors (drivers) that allowed the initiative to develop, spread and take root, is that carers highly regards the possibility of following free training courses at home. Formal training courses are, in fact, characterized by high drop out rates because they do not allow reconciliation between care work and training activities outside the home.

ENABLING CONDITIONS AND SUCCESS/FAILURE FACTORS

As for the expertise and resources needed to develop the initiative, an important factor was the opportunity given by both EU funding and budget contribution from the Italian stakeholders. In addition, the initiative took advantage from the affordability of the technologies used: the MOODLE tool represents a valuable resource released with an open source licence available worldwide to private and public actors. The initiative could not be realised without the contribution from a multidisciplinary team, which involved social workers, medical doctors, nurses and ICT professionals.

Some other considerations concerning adoption patterns:

- **Other local context conditions favouring / preventing a wider adoption of the ICT solution:** in the local contexts in which the initiative has first developed there was a strong involvement of stakeholders, which cooperated encouraging the use of ICT in the elderly care sector. 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.

- **Success and failure factors:** as noted above, the results of the project were certainly positive, involving a large number of caregivers and obtaining a direct involvement of various stakeholders who have allowed the spread of the initiative in various Italian regions. Among the contributing factors of the project, it is important to mention the ease of use of the ICT platform, the appreciation of carers for the possibility of following training at home (and/or attending classroom courses) and the relevant impact on the facilitation of the matching of supply and demand of care work, with positive effects on the emergence of undeclared employment, on quality of care and on quality of life of carers involved.

IMPACT ASSESSMENT

*What has already been measured?*

The impact of the initiative has been internally evaluated by course responsible persons of the cooperative Anziani e Non Solo. Based on reports of the project manager and questionnaires completed by participants, in some courses users expressed a high level of satisfaction for the training activities, especially appreciating the possibility to attend
distance learning in the home. In addition, training activities have improved job opportunities (occupation results are very good) and at the same time the quality of care provided to the elderly. Interesting results have also taken place in employment. Up to now, 60-70% of the people trained and enrolled in local professional registers, obtained a job within a year time frame. The percentages were significantly reduced in 2010 for reasons related to the economic crisis and to the fact that many migrant care workers, with long-term migration projects, aim to occupational mobility to other tasks.

The interviewees stressed also the importance of testing how the knowledge has been assimilated after training (education assessment). As above mentioned, the skills of over 350 caregivers’ skills have been assessed and drop-out rate from classes was extremely low.

It is important to note that the training system ASPASIA, in which the platform CAMPUS was developed, was recognized as a best practice from various national and international institutions like: the European Union; the Presidency of the Council (Italian Government); the Department of Equal Opportunities; the region of Emilia-Romagna; the region of Sicily; the province of Reggio Emilia (Emilia Romagna region).

What could be measured to have a more detailed impact assessment?

A more detailed impact assessment could address the following areas:

- The most relevant dimensions of impact are those related to the quality of life of paid assistant and the quality of care provided. Indirectly the initiative influences also the quality of life of care recipients, as this group can benefit from the enhanced skills of direct ASPASIA users (i.e. the migrant care workers).
- The impacts of the initiative expected and related to the quality of life of the paid assistant are:
  a) the increase in the number of carers reporting a better psychophysical health and independence level (effect of ICT in improving their physical abilities, including the ability for their own activities of daily living; on their mental health and related coping strategies; on the reduction of their pain-discomfort);
  b) the reduction in the number of stressed paid assistants due to the use of ICT (thanks to better performance/efficiency in the workplace and to the recognition of their personal skills and abilities).
- In relation to the improvement of the quality of care provided by informal carer and paid assistant, a possible indicator of such achievement could be the increase of informal carers and paid assistants providing better care to dependent older people (this is possible to assess using various tests already validated in the literature).
- Indirectly, the initiative should improve the quality of life of the care recipient. A possible indicator of such improvement could be the increase in the number of care recipients reporting a better physical level, psychological level and independence
level and eventually the number of people that avoided or delayed the institutionalisation (for further details see the grid used during the interviews).

- As what concerns the outcome actually seen for carers, the initiative promoted their social and professional inclusion. One of the secondary effects achieved by the project is the increased integration of carers in the network of local social services, although this has never been measured. For example, dedicated information points (even in many municipalities) and offices for matching demand and supply of care labour have been established. This has had positive effects also for public services themselves, which have had the opportunity to better understand the needs and problems of these people, allowing them to better plan interventions and services to support caregivers in their work and life. As in the case of social care, there were also positive results in relation to health care, the project has fostered a greater dialogue and integration of caregivers with local services, such as promoting a better collaboration between caregivers and professionals/operators (i.e. GP, nurses) of home care services.

- The project promoted also a greater integration of immigrants in destination Countries society. In particular, although this has not been measured, it has been fostered a greater use of the local network of public social and health services and it has promoted the emergence of the irregular work. Another positive result concerns the increasing (notably thanks to the classroom courses and to the attendance at the information desks) of dialogue and a better relationships with a large number of Italian people (not only caregivers).

- As already mentioned, the initiative improved indirectly the quality of life of the care recipient, as they benefited from the improvement of the quality of care provided by the migrant care workers. Success of the initiatives can be easily assessed in terms of current activities, although further outcomes from the uptake of this service are likely to be observed in the next future.

From a financial perspective, a detailed calculation of the return on investment in setting up the initiative is not available, although data available do not excluded that such calculation would be feasible in the next future.

**Possible outcomes for stakeholders, unexpected and new outcomes**

The main outcomes identified for institutional stakeholders related above all to the possibility to provide adequate training and education to informal caregivers and migrant care workers. In Italy the provision of such services is very limited despite the size of the demand. As a consequence of the better quality of the care provided by informal caregivers and migrant care workers, efficiency and effectiveness of care are likely to improve, with benefits in terms of economic costs and sustainability of the welfare.
FUTURE PERSPECTIVES

The project and its model of intervention have demonstrated that the ICT solutions developed for the training of caregivers are efficient and transferable to different local contexts. It is possible to use the platform CAMPUS constantly and, if necessary, its online course contents can be updated. Its sustainability in terms of economic resources is guaranteed (the platform has been just developed) and also after the end of the PIC Equal, as noted above, the project continued its activities, thanks to the interest and funding from several local authorities (and other sources, like the inter-professional funds) wishing to implement this initiative (also using the platform CAMPUS).

- **Scalability capabilities and conditions:** as noted, the ease of use of the ICT platform allows a further implementation of its potential to other local, national and international contexts. A key role in this regard will be played by the choices and investments that stakeholders are willing to spend into the initiative and into the expansion of the provision of training to caregivers. It is especially the initiative addressing migrant care workers which has the potentiality to be offered to a wider market. However, the future of the demand for such services is likely to be influenced by the ongoing financial crisis, which is affecting the number of Italian women who are now unemployed and are again interested in working in the care sector (or, free from work-related duties, are taking back their family care responsibilities). Is not yet possible to predict how the competition between local and migrant workforce will change the characteristics of the care market.

- **Replicability elements:** replicability elements have already been reported (eg. active role and cooperation among stakeholders, dedicated funding, recognition of care work. For more details, see above).

- **Objective conditions for transferability to other local contexts across Europe:** there are evident possibilities for the transferability of the initiative to other contexts across Europe. In order to secure funding at this purpose, two applications were submitted under the “Leonardo program” to transfer methods and tools of ASPASIA in countries such as Greece and Bulgaria, which have suitable characteristics for an effective adoption and implementation of the project. Romania, through ESF funds, requested a cooperation with Anziani e Non Solo to take the project initiatives. Moreover, together with other European partners and research institutions, Anziani e Non Solo bid for a call regarding the promotion of ICT based projects in the field of caregiving. So, the possibilities of transferability of the initiative to a wider European level are real. If it will happen in the next period, adjustments to the contents of the training modules, and to the technologies used for it, will be required.
POLICY IMPLICATIONS

Main policy implications of the initiative can be summarised as follows:

- **Digital inclusion:** the initiative promoted digital inclusion of a high number of care workers/users. Its impact was especially strong for those with no ICT expertise or skills, thanks both to the ease of use of the ICT platform and support provided by project professionals in the help to the familiarization with the use of training tools by users.

- **Social inclusion, Employment, Social care, Health care and Immigration & integration:** see above at point 46.

- **Lifelong learning:** it should be noted the positive impact of its user-friendly design on carers and on the quality of the care provided. The implications for the lifelong learning are related to the educational opportunities offered to people of all ages to improve their skills as caregivers.

An important issue to address in the future is extending the range and use of the platform, in order to integrate this and/or other ICT application in the framework of the supply of health and social services. These issues concern stakeholders and policy decision makers: should this area be further promoted by public investments or left to the initiative to private non- and for-profit sector? Furthermore, a possible factor that could allow the deployment and use of ICT solutions in the care sector is the public investment in extending the coverage of Wi-Fi network, as well as grants and incentives to purchase PCs or for the payment of internet subscriptions. The potential use of ICT based solutions from caregivers is large, but it is important to build user-friendly and age-friendly tools, which could facilitate people with medium to low ICT skills. Furthermore, it would be important to allow the formalization of professional training courses in e-learning figures for other work, such as the Italian OSS (Operatori Socio-Sanitari; personnel aidants), encouraging the use of ICT tools by many migrant care workers who would be interested in carrying out these jobs.

REFERENCES


Caring for Others

Zsuzsa Széman
Institute of Sociology, Hungarian Academy of Sciences

<table>
<thead>
<tr>
<th>Website:</th>
<th><a href="http://www.baycrestcfo.com">www.baycrestcfo.com</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Region(s)/Country:</td>
<td>Canada</td>
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Methodological note
Evidence on Caring for Others is publicly available and led to several publications, among the others: Marziali (2005, 2006, 2008), Marziali & Climans (2009), Marziali & Donahue (2006), Marziali & Garcia (2011), Marziali et al. (2005a, 2005b, 2006, 2010). Additional information was retrieved with the collaboration of initiative coordinator, Prof. Elsa Marziali (University of Toronto).

DESCRIPTIVE INFORMATION

The Caring for others (CFO) Internet-based program evolved from a series of research projects initiated in 2000. The aim was to design a user-friendly Internet-based intervention program for family caregivers of persons with chronic diseases/disabilities (Dementia, Parkinson, Stroke and Traumatic Brain Injury). The CFO research program is located at a research institute within Baycrest, a multiservice health organization for older adults in Toronto, Ontario, Canada.

The results of the studies showed that it was able to replicate online, using group video conferencing, the same outcome results as face-to-face support groups for caregivers. The main improvement was in physical and mental health status and a reduction in stress associated with caring for a relative with a long-term disability. Baycrest is a multiservice health complex for older adults with an internationally renowned neuroscience research institute – the Rotman Research Institute.

Currently, the research product (CFO Internet-based intervention program) is being transferred to a service delivery program within Baycrest. The CFO web site and all content including Technical Training Manual, disease-specific information handbooks (e.g. Dementia Caregiving), and Intervention Training Manual is being licensed for purchase by
health organizations across Canada. Baycrest will support continued updating of the web site content.

Dr. Elsa Marziali who has carried out different research programs has understood how difficult life can be for the caregiver in case her, his family member is under the blanket of a diagnosis of a neurodegenerative disease such as dementia. It has been found that grouping together caregivers of family members with the same diagnosis and having separate groups for spouses versus adult children, allows caregivers to bond, share information, and identify with each other’s sadness, challenges and successes. Therefore an intervention was developed. This is to help caregivers deal with the emotional stress of caring for a family member with a chronic disease and support family caregivers who are often not be able to take time away from home, or those living at a distance from agencies providing face-to-face support groups. According to the research results of Dr. Marziali “caregivers carry a huge emotional burden. Life changes from the moment of the diagnosis.” The care recipients are helped to maintain a reasonable quality of life despite living with a chronic disease. When family carers are helped to manage the stress associated with providing care (frequently 7/24) the care recipient can remain at home longer thus reducing the costs of long-term institutional care.

Studies have shown that the CFO program is effective in improving the physical and mental health status of carers, reducing stress and thus improving the quality of care provided to the care recipient. However, the CFO program is not a panacea – carers need other community support services as the disease progresses, as for example, short-term respite care, day care programs, in-home help, and visiting nurse care.

**Target users**

The CFO users in the projects were family caregivers – primarily women; over 60% spouses. They received online, an evidence-based intervention program provided by a health professional – ten weekly one-hour group sessions through Internet access using web cams and audio head sets. Each group continued to meet weekly online for 10 more mutual self-help sessions with no professional facilitator present.

**Technology used**

There is a password-protected web site, information handbooks by disease type posted on the web site, an intervention training manual to insure reliable adherence to the model of intervention, a computer training manual focused on helping participants to negotiate established web site. The materials and web site are copyrighted and available through licensing so it is an Internet-based program.

The CFO technology simply provides the infrastructure for the delivery of a clinical program that is typically provided face-to-face by health service providers. Using technology to deliver a service makes it more accessible to carers who often cannot leave the person they care for and/or lack transportation, support resources etc.
OPERATIONAL INFORMATION

The CFO service currently being initiated at Baycrest (as mentioned evolved from a series of research projects initiated in 2000 led by Dr. Marziali senior scientist at the University of Toronto, Baycrest) has shown that the intervention model is accessible, that caregivers anywhere in the world can access the program, that using the web site is intuitive, and that any caregiver can be trained to manage the technical aspects of joining the video conferencing intervention program, and so the service has rapidly grown.

The CFO being initiated at Baycrest, a leading research institute, will not cost any more than a face-to-face service delivery program. All health service organizations in North America have the computer technology to support the CFO Internet-based program. Also, family carers, even older spouses, who are computer literate, have the necessary equipment and Internet access.

Budget and funding

All health services in Ontario and throughout Canada are publically funded by federal and provincial ministries of health. No new monies are required to provide the CFO program. The cost of the web site license is based on the amount of customization required.

Baycrest administration was kept current of the CFO research results; they readily supported transferring the CFO program from research to a service delivery program. Baycrest is supporting and promoting the CFO. It is licensing the initiative; likely purchasers are the Alzheimer’s Society of Canada and other health service organizations that serve patients with chronic conditions.

To implement the program the sponsoring organization would need to support training of one clinician, support a technician part time to assist participants (caregivers) with installation of software and training to access the web site. Also a server to support the web site use by participants and clinical staff would need to be provided (these usually are available through IT departments of most institutions).

As mentioned there is mutual help. The group members form supportive bonds and identify readily with each other’s caregiving experiences. They benefit in terms of reduced stress and increased psychosocial support. Grouping together caregivers of family members with the same diagnosis (for example, Alzheimer’s, Parkinson’s, stroke or traumatic brain injury) – and having separate groups for spouses versus adult children, allows caregivers to bond, share information, and identify with each other’s sadness, challenges and successes. It enables caregivers to want to keep their chronically ill family members at home for as long as possible.

Market size, implementation and promotion strategies

The market size is potentially huge; with an aging population health care systems are looking increasingly to families to provide care to persons with long-term chronic diseases. Using the Internet to provide a service that replicates the process and results of face-to-
face clinic-based services increases access to carers at no additional costs to the organization. The CFO web site program can be expanded to include ongoing consultation between a physician, the carer and the patient; meetings among family members living in different parts of the country etc.

The CFO program provides an intervention – 20 sessions – in each study there were very few drop outs. The CFO program has no limitations as to how widely the service can be offered – it is readily translatable to any language and all that is required is a health care professional who can be trained to deliver the online group intervention program. Most healthcare systems have the technology, and families increasingly have equipment and Internet access – at least in North America.

To participate in the intervention program participants need to have access to computers, webcams, audio headsets and high speed Internet service. They log on to their secure, password-protected CFO site and settle in for a chat access and trained those participants who had no experience using computers. They will be shown how to use the computer and once they are online, they could actually see each other.

During the research studies equipment was supplied to those who did not have it, a computer training manual for users, who are often older adults with limited computer skills to enable quick access to the web site. However, increasingly it is found that most caregivers have some computer experience and most have high speed Internet access.

Carers learn about the CFO service through healthcare provider organizations. Baycrest social workers have begun offering the online program to caregivers. Dr. Marziali also encourages caregivers interested in joining an online video-conferencing support group to contact their local Alzheimer Society, Parkinson’s Association, or Heart and Stroke Foundation to ask whether those organizations plan to adopt an online program. There were no objections from carers or professionals who have used the CFO program – in fact, all were highly positive about the experience of having participated in a health care support program that was so beneficial and so convenient to access.

**IMPACT ASSESSMENT**

This initiative is related first of all to the quality of life of informal carers but it has an impact on the quality of life of care recipients. It enables care recipients to stay at home by delaying their admission to a long-term care facility. Studies of the Internet-based intervention for caregivers have shown a reduction in stress pre-post intervention when compared with caregivers who did not receive the intervention, it reduces the need for travel and the costs of face-to-face support groups by providing facilitated sessions on-line and providing consistent clinical information and support activities to caregivers.

It reduces the time that patients are in a hospital or institution or delays admission into long-term care institutions as well. The studies have repeatedly shown positive outcome effects for carers.

A cost-savings estimate was done with regard to keeping dementia patients out of institutions for a period of one year; for dementia patients at the moderate level of severity the annual cost savings to the Province of Ontario by maintaining these patients in the
community versus admission to institutional care, would exceed one billion dollars. By delaying the admission by even one year, savings to the Canadian health-care system are estimated at $5.4 billion annually according to some cost projection. The licensing fee will generate income to support the ongoing dissemination and updating of the CFO program (see publications in the literature listed for the Pilot study). The CFO program includes evaluation instruments so that organizations that adopt and deliver the program are able to evaluate effects in terms of benefits to carers and care recipients. Over time they will be able to build a data base that can be analyzed subsequently in terms of demographics of users and health outcomes. Summarising, the ICT-based program was successful and the service is totally sustainable.

FUTURE PERSPECTIVES AND POLICY IMPLICATIONS

Some considerations concerning future perspectives and policy implications of Caring for Others are the following ones:

- **Scalability and replicability elements**: Expanding the scale of the present service is very easy and all elements were proven to be replicable.
- **Objective conditions for transferability to other local contexts across America and Europe**: The internet-based innovation can be adapted in any country as internet use is widespread, enabling it to be integrated into the eldercare system.
- **Digital inclusion**: Use of the system is simple, it enables access to the web site with limited computer skills. Increasingly most caregivers have some computer experience and with this knowledge they can be considered to have digital inclusion, the digital knowledge gap between generations is disappearing.
- **Social inclusion**: It prevents the social exclusion both of carers having cared for family members with serious mental disease and elderly persons with this disease by delaying their admission to a long-term institution.
- **Employment**: All health service organizations in North America have the computer technology to support the CFO internet-based program. Employment is based on the staff of health organisations.
- **Health and social care**: The family carers help to ease the strain on social care services; the service can be integrated into the system with a high degree of cost efficiency.
- **Any other lessons learned**: To have a very effective, ICT-based solution that can be applied anywhere does not have to be costly and can even have a strong cost-savings effect. The system is simple to use and useful for both the user and the family carer. It can be disseminated rapidly and successfully and incorporated into the system of social services. However, without uniform and sustainable financing, sustainability over the long term could be threatened. The existence of the service in the market segment depends on the financial situation of both the elderly users and their family members.
REFERENCES


**Cuidadoras en Red**

Women Carers’ Network

**Carlos Chiatti**  
Italian National Institute of Health and Science on Aging (INRCA)

with contributions from **Trinidad Carrión**  
Project Manager, University of Malaga

<table>
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<tr>
<th>Website:</th>
<th><a href="http://www.cuidatel.es">www.cuidatel.es</a></th>
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<tr>
<td>Region(s)/Country:</td>
<td>Malaga/Spain</td>
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</table>

**Methodological note**

Unless differently specified, all information for this case study report have been retrieved from the documentation available in the web (e.g. www.cuidateles) and from direct information gathered through interviews with the project coordinator, Trinidad Carrión (University of Malaga), as well as through publicly available assessments (Carrión & Armayones 2006). Quantitative information regarding users’ and financial aspects of the initiative have also been provided by project coordinators.

**DESCRIPTIVE INFORMATION**

“Cuidadoras en Red” (English translation: “Women Carers’ Network”) is an initiative led by the Institute of Innovation for Public Welfare (I2BC) in collaboration with the Nursing Department of the University of Malaga (UMA). This ICT-solution was set up in November 2008 in Malaga (Spain) (although its development started already in the early 2006) and now it works through an on-line network.

It basically consists in a social network for both family caregivers of dependent elderly, social-care workers and private care workers (mostly immigrant women). The initiative aims to increase digital competences and social inclusion of a population group that typically has low access to new technologies. The aims of increasing digital competences and ICT use are linked to the objective of promoting users’ health, quality of life, and improving their skills as carers.

It addresses the negative impact of intense caregiving in non-supporting environments, such as the loss of self-esteem, the lack of knowledge about caring, problems related to anxiety and depression, fatigue with the caring role, and social isolation.

The desired outcomes of the initiative relates to:
1) the reduction of the digital and social divide affecting family carers of older people; 
2) the exploitation of the potential of Internet as a mean to provide information, 
   training and support needs of carers (with special attention to the promotion of self-
   help groups and support initiatives).

The coordinator of the initiative is the “Departamento de Enfermería” of the University of 
Malaga and its technological partner, the “Instituto de Innovación para el Bienestar 
Ciudadano” (the Institute for the Innovation for Human Wellbeing, I2BC). While the 
Nursing Department is responsible for the development and management of the overall 
structure of the social network and of the related contents, the I2BC is in charge of the 
technical aspects. Unfortunately, the I2BC is undergoing a programme of re-structuring, 
therefore all the materials have just migrated to another technological platform.

<table>
<thead>
<tr>
<th>“CUIDADORAS EN RED” in a nutshell</th>
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<tr>
<td>Total users</td>
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<tr>
<td>Communities/Groups on line</td>
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<tr>
<td>• Blogs</td>
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<td>• Videos</td>
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<td>• Photos</td>
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<td>• Files</td>
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<tr>
<td>• Messages</td>
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<tr>
<td>• Microblogging</td>
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<tr>
<td>Cost of the initiative for carers</td>
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<tr>
<td>Maintenance fixed costs</td>
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<tr>
<td>Main source of funding</td>
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**Target user groups**

The main target users group service is trying to support are the family caregivers. The 
focus of the initiative is on those caregivers living in rural/sparsely populated areas, with 
low digital competences. As a consequence of these criteria, most of the potential users of 
the service are middle-aged women, i.e. those population group that still in Spain bear in 
most cases the burden of caregiving within the household. The initiative has been 
developed in two small rural towns, Pizarra and Cártama, in the province of Malaga 
(Andalusia, Spain), where typically the access to ICT has been low compared even to 
Mediterranean standards.
Problems reported by caregivers

“I do not know anything about the illness affecting my husband”. “I do not know how best I can care after him, I feel very insecure”. “When something happens to him, I think it is my fault”. “It is too much work for me alone”. “I have no time for myself”

Requests from the caregivers

“More help from my family, without having to ask for it”. “I wish to learn more about my relative’s disease”. “Easier way to carry out bureaucratic papers”. “Teach me how to take care of my relative”

(Translation of extracts from qualitative interviews carried out among rural family caregivers in Spain by Carrión, 2006)

In principle, the services provided by “Cuidadoras en Red” could be used by other professional caregivers (e.g. public services and private care workers, including migrants), but so far, they mainly addressed the needs of family caregivers.

Types of activities and services offered

The initiative impact on carers though two main activities, which represent a well-balance combination of traditional and innovative learning tools:

a) “in class” workshops with users, aimed at increasing digital competences of new potential users;

b) the use of the online social network “Cuidadoras en Red” (realised and updated in collaboration with the “Instituto de Innovación para el Bienestar Ciudadano”).

The attendance to the workshops is “propedeutic” to the use of the online social network, although not compulsory. The workshops are specifically designed for those users with very low digital competences but desiring to learn how to use the social network. An example of these cousers is the digital Training Programme: “Internet, Health and Quality of Life for Carers”, which during its 60-hours schedule covers issues regarding digital literacy for health and well-being (i.e. the basic information on internet use and advices on web-search strategies to retrieve reliable information on the topics related to care). The other course is entitled “Carers in online social network”, and clearly focuses on the use and characteristics of online social networks (it is also a 60 hours course).

Examples of topics covered by the discussions open in the social platfrom are: “Alzheimer and other dementias”; “Self-caring”; “Immigrants in the family care”; “The Dependency Law 39/2006 for the Promotion and Personal Care for people in situations of dependence”; “Health Care”. The nature itself of this network requires that its contents are constantly updated, in order to allow users to retrieve correct information on e.g. the benefits to which are entitled or innovative ways of providing care to their relatives (domotics, new drugs, etc).

In addition, as the users are often inexpert in the use of such ICT tool, it requires that more expert users act as “animator” and promoter of new blogs, fora, and discussions.
Topics/Areas of interests for family caregivers identified and addressed by the initiative “Cuidadoras en red”

<table>
<thead>
<tr>
<th>Area of Care:</th>
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<tbody>
<tr>
<td>1.1. Basic nursing care,</td>
<td>according to the level of dependency of the care recipient</td>
</tr>
<tr>
<td>1.2. Recognizing markers</td>
<td>symptoms of illnesses</td>
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<tr>
<td>1.3. Solutions to the social</td>
<td>and health problems</td>
</tr>
<tr>
<td>1.4. (Tertiary) Prevention of</td>
<td>social and health care problems</td>
</tr>
<tr>
<td>Area of Self-care:</td>
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<td>2.1. Knowledge and acceptance</td>
<td>of the role of Family Caregiver</td>
</tr>
<tr>
<td>2.2. Postural hygiene and</td>
<td>physical exercise</td>
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<tr>
<td>2.3. Techniques for coping</td>
<td>with stress, relaxation and communication</td>
</tr>
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<td>2.4. Time Management</td>
<td></td>
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<tr>
<td>Area of Social and health</td>
<td>care resources:</td>
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<td>3.1 Social and economic</td>
<td>assistance from different public organisms and private entities</td>
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<tr>
<td>3.2 Guides from Mutual</td>
<td>Support Associations and Volunteers</td>
</tr>
<tr>
<td>3.3 Mutual Support Groups on</td>
<td>Internet</td>
</tr>
<tr>
<td>3.4 Current legislation</td>
<td>regarding Family Support and the services offered by the Formal</td>
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<tr>
<td>Healthcare System</td>
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<tr>
<td>Use of ICT:</td>
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<tr>
<td>4.1 Computer skills</td>
<td></td>
</tr>
<tr>
<td>4.2 Internet skills</td>
<td></td>
</tr>
<tr>
<td>4.3 Potential economic aids</td>
<td>for use of ICT</td>
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<tr>
<td>Technologies used and functions of ICT tools</td>
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This initiative is one example of the use of Web 2.0 applications to create a community specifically for informal caregivers. Therefore, the initiative mainly uses mainstream technologies such as Photo albums, personal blogs, community blog, community forum, group files, messages, and videos.

The technical solution deriving from this combination of tools offers the targeted population a broad framework for communication, cooperation and training in caregiving. The users can communicate using online tools and synergies can be created between the different groups or communities. Several web communities are open at this moment and are focused on care-related issues such as: “Alzheimer and other dementias”; “Self-caring”; “Immigrants in the family care”; “The Dependence Law 39/2006 for the Promotion and Personal Care for people in situations of dependence”; “Health Care organisation”.

Development methodology

The development of the initiative was possible after a preliminary investigation carried out by Prof. Trinidad Carrión as part of her Ph.D. research. It represents a case of participatory action research and, thus, of direct transferability of research findings into “real world” practice. The Ph.D. work originally aimed to examine the ways Internet can help those
looking after elderly dependants and it can evaluate the suitability of the eHealth services for addressing family carers’ needs (in order to propose improvements for the better use of these services. The research had a qualitative design). An ethnographic study and focus groups were carried out in order to examine the needs of family caregivers (also by means of in-depth interviews). Then, the investigators realised a review of existing eHealth services for family caregivers of elderly dependents, using internet as main source of information. The earlier phase of the initiative lasted two years and led to the realisation of a feasibility study which clearly showed the potentials of a web-based initiative in the rural area around Malaga.

### The phases of the development of the initiative “Cuidadoras en red”

<table>
<thead>
<tr>
<th>Phase</th>
<th>Period</th>
<th>Goal(s)</th>
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<tbody>
<tr>
<td>Phase 1</td>
<td>Since 2004</td>
<td>• To explore how the use of Internet can support family Carers and their dependent relatives</td>
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</table>
| Phase 2 | Since 2006 | • To strenghten digital competences of the potential users of the initiative, with particular reference to the use of ICT in the area of health and social care.  
• To include female Carers into the “Net Society”. |
| Phase 3 | Since 2008 | • To design an Open Source Social Network to be validate with Carers of Pizarra (Málaga). |
| Phase 4 | Since 2009 | • To improve Health Promotion and Quality of Life of the Carers and their dependent families, through the use of new ICT tools. |

Home page of the “Cuidadoras en red” social network
OPERATIONAL INFORMATION

The sustainement of service is possible thanks to the extremely low costs of maintenance. The workshops are held by the responsible of the initiatives on a volunteer basis, and classes are held in the rooms made available by the local authorities, with the collaboration of the personnel working there. The database required for the social network will be transferred in the servers of the Nursing Department of the University of Malaga.

Funding and budget

The initiative is not market-oriented. This means that it does not have to be be sold to anybody. It can be considered as a public service. As a consequence, the previous and actual costs have not been clearly documented and it is impossible calculate a return on investment in setting up the initiative. What it is rather clear, instead, is that the most important driver of cost in the earlier phase of the initiative was represented by personnel. However, as the people involved in the project were mostly university staff and other public servants, this cost has been fully borne by the public sector.

The initiative does not intend to shift costs from other services to carers (e.g. substituting informal caregivers to formal ones in some specific tasks), but only to support caregivers in performing their daily (care- and not care-related) activities.

The initiative benefited from infrastructure (personnel, organisations, equipment etc.) from outside its budgetary capabilities. First of all benefited of the results of the Guadalinfo Project in Pizarra, a Andalusian Project for Rural Digital Inclusion which provides places with free access to computer and internet and training in all the villages of Andalucia with less than 20,000 inhabitants.

Today the initiative is clearly under-funded. Further resources could only be expected from the public sector and from other subjects in the civil society (NGOs, volunteer organisation, associations etc.), but the recent financial crisis put increasing constraints on the budgets available for such innovative initiatives.

Personnel involved

At the moment, only one person (the responsible of the project, Prof. Trinidad Carrion) is involved in the initiative and she is mainly investing in updating and animating the discussion in the social network. During the “in class” workshops, the personnel employed by the local authorities of Pizarra and Càrtama and responsible for the managament of the tele-centres, support the participants with the use of computer.

Since the beginning of the initiative, no one has been formally employed to work on it. All the personnel inputs have been made possible thanks to voluntarism and synergies created with other institutional actors in the area (e.g. local authorities, university, and I2BC).
Users

Those who most benefited from the initiative are those who attended the workshops (i.e. 38 female caregivers from the town of Pizarra and Càrtama in the Málaga area (Spain). It is known the socioeconomic profile: these are middle-aged women, with a low formal educational background and an initial low competence with the use of ICT. The most common problem that workshops attendees face is linked to the limited time that they can have and to their care duties at home. The consequence of the unpredictability of care duties results in absenteeism. However, drop-out rate from the course was very low (around 20%). Those who had to leave the course were in most cases compelled by care responsibility, the impossibility to have a substitution in the care activities, and the choice of withdraw from the course was not led by unsatisfaction with the initiative.

The social platform “Cuidadoras en red” received over 3,300 visits in the last year (Google Analytics, 25sept2010-24sept2011) and can count on the participation of 348 active members. No detailed information regarding the profile of people who use the network are available, only information on gender can be retrieved.

Trends in the use of the Webplatform “Cuidadoras en red”

The potential 'market size' for this service (although the term “market” is not fully applicable as the initiative is free and openly accessible) can be measured considering the following parameters: In Spain, 17% of the population (n=7,780,830) is older than 65 years, and 32% of these individuals (n=2,489,866) suffer from limitation in their activities of daily living and need to receive care on a regular basis (IMSERSO, 2009).
Requirements for usage

The initiative requires internet connection and a computer. In addition, potential users of “Cuidadores en red” need to know how the social network works, and have basic digital and information competences. For overcoming these possible problems, the initiative provides information and digital training for the target population through in-class workshops. As before mentioned, classroom training on competence in digital and healthcare resources are held in a telecentre arranged by the Guadalinfo Project of the Junta de Andalucía.

ENABLING CONDITIONS AND SUCCESS/Failure FACTORS

The initiative benefited of the results of the Guadalinfo Project in Pizarra, an Andalusian Project for Rural Digital Inclusion which set up a network of public telecentres with free access to computer and internet in the smaller villages of Andalucia. The use of the social network “Cuidadoras en red” slowly increased thanks to word of mouth and by the dissemination of information made by users themselves. Although the strong “voluntary base” behind the initiative represented undoubtfully a key success factor for its early development, it also constitutes a barrier for its further development.

Other barriers which have been identified are related to a lack of technological infrastructure (many family carers in the rural areas do not have a computer, especially the older ones). In this regard, public or private incentive for the purchase of ICT equipment would have a highly beneficial effect.

Another important input for a further growth of the initiative could be provided by the professionals involved in the care process. These professional could have an active role in both both updating and improving the contents available online (maybe as result of their training activities, e.g. as output of their formal training sessions) and in disseminating information regarding the availability of the service.

The widespread barriers for a further uptake of the initiative, as reported by the participants themselver, are “lack of time” and “lack of financial resources to buy a computer and to get access to Internet at home”. Among professionals, the most common objections are “lack of time” and “lack of competences for using the technology platform”. A possible exploitation of the potential of the initiative could be achieved by incentiving the use of the social platform among the professional. An interesting match between different typologies of caregivers could be achieved in this way, allowing mutual learning and knowledge between those who provide care in formal and informal settings.
IMPACT ASSESSMENT

The most relevant dimensions addressed by the initiative is the “Quality of Life of Informal Carer” (and to a lesser degree the “Quality of Care Provided”). However, the most systematic assessment has been carried out in the area of digital competences.

*Impact assessment during phase II.* Activity with 1st and 2nd cohorts (5+7=12 rural carers) Assessment of the impact of the Training Program (face to face) “Internet, Health and Quality of Life for Carers”. Digital and information literacy for health and well being (60 hours) showed that 75% of carers have achieved digital skills, including: use a word processor, surfing the net and use the email. 41.6% have achieved the skills to Recognise their information needs, identification and evaluation of information, store and retrieve information and make effective and ethical use of information.

*Impact assessment during phase IV (from Oct 08 to June 09).* Results on the 1st, 2nd and 3rd cohorts of participants (5+7+11=23 rural carers). 100% of carers have achieved digital skills, including: use a word processor, surfing the net and use the email. 43.4% have achieved the following skills: recognising their information needs, identification and evaluation of information, store and retrieve information and make effective and ethical use of information. 40% of the rest have managed to navigate the online social network and have applied information to create and communicate knowledge through the social network.

Among the positive unexpected results of the workshops there is: a high motivation to learn, the increase in social relations between them and the increase of intergenerational relationships, mostly between the caregivers and their children or nephews. An unexpected result, but negative, was the lack of technological resources and of support for carers who are at home.

FUTURE PERSPECTIVES AND POLICY IMPLICATIONS

Clearly the initiative demonstrates that:

- 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.
- The use of social network promotes social relation between carers and, also, improves the relationships with younger members of the family (daughters, sons, granddaughters, grandsons, nieces).
- ICT tools are very effective for learning at home and they encourage carers to study what they have not been able to study before.
In the current circumstances, the service is sustained at a very low cost. Nevertheless, failure to obtain financing in a short period will be likely to result in a suspension of the service.

At present, the most urgent need is to restore the technological support (after the restructuring of the technological partner of the initiative, I2BC). Once restored, it will be a key success factor to provide computers and Internet connection for caregivers who cannot have it in their homes for economic reasons. In addition, more qualified human resources are required to meet all the needs that family caregivers have expressed in the areas of information, training and support.

The coverage and the range of users of “Cuidadores en Red” could be further increased if a stronger support from the other public institutions will be achieved. Collecting stronger evidence regarding its outcome can be an effective way to gain further support.

In addition to the effectiveness of the dependent service, it could be useful to measure the effectiveness of online interaction of health professionals carers when it occurs. Currently, results are satisfactory in relation to the planned objectives. However, the whole project development will be made possible only with the participation of health professionals and other service sectors such as respite care, online shopping, online training, work online, and so on.

REFERENCES


The 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. The 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"

*from Moruzzi (2005: 204)*

**Methodological note**

Unless differently specified, data for this case study have been retrieved from service provider website ([www.cup2000.it](http://www.cup2000.it)) and from interview with initiative coordinator Carla Fiori. Furthermore, some material is publicly available: Cipolla & Guarino (Eds.) (2009), Fiori (2010), Lupi & Orsi (2007), Malvi et al. (2009), Moruzzi (2005).

**DESCRIPTIVE INFORMATION**

The E-CARE, which initially was configured as a project, after a phase of experimentation, has taken on the nature of a service, fully integrated into the network of local welfare and care policies for older people and carers. Currently the E-CARE is a strategic service under continuous evolution and development. It represents a strenght point in the innovative public supply of health and social care. More specifically, the E-CARE system is an innovative service which uses new technologies as an instrument to foster integration between the different health and social services.

In particular, the initiative aims at creating an innovative and integrated service network for the care of older people using ICTs (telecare, telemonitoring, telemedicine, teleinformation, etc.: see below for more details). Among its objectives there is the need of
responding to social and health needs of elderly population through an integrated approach. In order to maintain and support users in their living environment, this goal is carried out providing home care in safety conditions and delaying the need for costly institutionalisations and hospitalizations (with positive effects in terms of savings/optimization of public resources). Other aims of E-CARE are to improve the quality of life and increase opportunities for socialization of older people (also with the support of associations and voluntary organizations), to raise their self-awareness of own health status, to ensure continuity of care, promoting "personalized" pathways of services and a centralized online reservation service. The E-CARE system aims also to develop the help and support to caregiver burden and to spread the use (at regional and national level) of ICT, to renew and integrate the provision of social services in the public health care system.

The E-CARE is an important experience dealing with the problems related to the progressive ageing of the population through the use of ICT applications. E-CARE can promote the quality of life and independent living among frail older people, limiting the high costs of the health system. The service therefore aims to cope with and respond in an innovative logic to the socio-demographic changes and related new, growing and complex health needs of older people (and their impacts on health and social care systems). For example, Emilia-Romagna is the second Italian Region with the highest proportion of older people: in 2008, people over 65 years were the 22% of the regional population (968 thousand people, including 291,000 over 80) and in the Provinces of Bologna and Ferrara the ageing trends are similar. In fact people over 65 are 27% in the Province of Bologna (including 8.9% over 79 years) and 25.5% in the Province of Ferrara (of which 12% are over 80 years). In the Municipality of Bologna (in 2007), people over 74 years were 53,553, representing 14.39% of the population: forecast for the next few years indicate a significant increase of this group of citizens.

These data outline the importance of the ageing of the population in this territory, and implies the need to adopt innovative initiatives (also through the use of ICTs) to address the growing health care needs. This issues are also related to family changes, increasingly unable to support and take responsibility for the care needs of the elderly population (weak/scarcity of informal networks and dissemination of the phenomenon of older people living alone). E-CARE is therefore a highly innovative initiative to address these problems through an integrated approach between services, the involvement of the local stakeholder network, using new technologies and innovative methods of intervention.

In this way, the E_CARE represents a strategic and primary process for the renewal and the development of health and care services (for more details, see below and section on “Policy Implications”).
The E-CARE is promoted by the Region Emilia-Romagna, Provinces, Municipalities and Local Health Authorities of Bologna and Ferrara. It has been developed by CUP 2000 Spa (that manages and coordinates the project from 2005), in cooperation with a wide network of other stakeholders (e.g. non-profit organizations, trade union associations, etc.). CUP 2000 Spa is an industrial organization leader in Italy in e-health and Internet networks for care. It is a quoted private company operating in-house (with total public capital) with the Emilia-Romagna Region, Provinces, Local Authorities and Local Health Authorities of the Region: it is an operative means of the Region in the e-health sector.

**E-CARE in a nutshell**

<table>
<thead>
<tr>
<th>Total users</th>
<th>More than 5,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of start</td>
<td>2004</td>
</tr>
<tr>
<td>Services offered to users</td>
<td>telecompany, telemedicine, telecare, telemonitoring, teleinformation, reservations for health services; support programs for caregivers of older people with dementia or of patients discharged from hospitals with heart failure</td>
</tr>
<tr>
<td>Cost of services for older people and family caregivers</td>
<td>Free for people with low income; proportional according to income levels for other users</td>
</tr>
<tr>
<td>Main source of funding</td>
<td>Regional and Municipal authorities</td>
</tr>
</tbody>
</table>

**E-CARE homepage**

 Una rete a favore del mantenimento della qualità della vita delle persone anziane.

 È la rete di presa in carico del cittadino che si rivolge al livello Home Care dei servizi socio-sanitari, favorendo un più elevato livello di integrazione e buone pratiche, come parte integrante degli obiettivi enunciati nel Fondo Regionale per la Non Autosufficienza. L’e-Care favorisce i processi di deospedalizzazione, di mantenimento delle persone fragili o non autosufficienti nel loro contesto sociale e abitativo e di gestione di eventi eccezionali in termini di emergenze sanitarie, ambientali e di sicurezza. L’e-Care mette in relazione tra loro le reti di assistenza già attive sul territorio: la rete dei servizi sanitari, dei servizi sociali, del volontariato e delle relazioni amicali e famigliari dell’assistito.

**Source:** CUP 2000 website
CUP 2000 Spa operates in the areas of planning, research, development, testing, management of ICT services and products for e-Health and E-CARE networks, generated in the Internet, for the fields of health and social care and personal services. It is a leader company in: implementation and management of Metropolitan Cup systems (electronic access to health care), communication networks between hospital and territory (link general practitioners and others professionals through on-line instruments), archiving of electronic hospital records. CUP 2000 manages the largest call-contact center of the Italian health system.

**Target users**

The main target group of recipients of the interventions of the E-CARE are older people with more than 75 years in conditions of loneliness or with difficulties: functional (problems in nutrition, movement, etc.); clinical (cardio-respiratory problems, complex disease, chronic pain, hospitalization, depression); social (people with ongoing needs for assistance, who live in distant or degraded areas, with low incomes, with inadequate housing, with weak or absent family and informal support networks). Another target group of the initiative is represented by caregivers (often married, old, or migrant care workers). They receive support in situations in which they provide home care for older people. The carers are also involved in specific initiatives of E-CARE system, such as projects aimed to help carers of older people with dementia, projects placed at the Hospital “Maggiore” of Bologna and in the West District of Local Health Authority of Ferrara. In the latter area, it is estimated that about 1,200 families provide home care to relatives in various stages of dementia. Caregivers involved in these projects have the following characteristics (data are referred to Ferrara project, but in Bologna data are similar): 75% women, mean age 56 years, 13% <75 years old and in some cases over 90 years old, low levels of education (only 32% attended lower secondary education), 45% has a job (outside the home), 28% stopped working because of the care burden. Most of them are spouses and children (71% overall); in the remaining cases, informal carers are relatives/neighbors. Around 30% of families are supported in their care duties by migrant care workers (the so-called “badanti”), for an average amount of 13 working hours per day, although more and more frequently (especially when family members live or work outside the home) the care is fully delegated to them (24 hours/7 days). The burden of care for family carers involves several critical issues. Among the most important:

1) the continuity of care work: to provide assistance 24 hours per day deals with health (as well as bureaucratic) problems,

2) the burden of care is progressive, due to the inevitable loss of autonomy of their relatives in the activities of daily living (ADL),

3) care is complicated and difficult due to behaviour/psychological disorders of the elderly affected by dementia (Behavioral and Psychological Symptoms of Dementia - BPSD),
4) family caregivers are not supported due to improper use and/or availability of local services to cope with the loss of autonomy (or BPSD problems) of their cared for.

As mentioned, in the context of this problematic picture, specific services have been activated as part of E-CARE, to support these caregivers (see below for details). Beyond what described above, it is important to consider that in the future the initiative plans to involve younger users with other social and/or health problems.

**Types of activities and services offered**

The E-CARE system is organized as a call centre but, in addition, depending on the needs of the users, it offers a wide range of services: e.g. telecare, telealarm (panic button), videophone and video-conference, and telemedicine. In addition, for each user a personal record file is created, containing information regarding his/her well-being, health conditions and needs. In case of need, the E-CARE system is directly linked to the CUP (i.e. the service which is responsible to book outpatients visits within the Italian NHS). In this way, users and their caregivers do not have to turn to the CUP by themselves.

Beyond what is already stated above, more specifically, the E-CARE offers a call contact center service (where work qualified and specialized professionals) 24 hours on 24 and 7 days per week. It provides frequent and personalized telephone support (the number of calls "outbound", i.e. made by operators, is based on specific user's needs, and provides at least one call per week up to daily contacts) through which is possible monitoring clinical and social frailty of the user.

Health-related behaviours are promoted among users, as well as their compliance to therapeutic prescriptions. The monitoring system also allows for timely reporting of critical situations to health services. The system also maintains a complex socio-medical dossier that allows stakeholders to register, manage and use relevant information for the care and supervision of users.

The E-CARE also offers and provides other services, such as ICT-based “telecompany”, telemedicine, telecare, telemonitoring, teleinformation and make reservations for health services (through CUP). Family caregivers can benefit of specialised consultancy from E-CARE professionals and receive support and dedicated services in specific situation (like in contexts of dementia, as already mentioned).

In essence, E-CARE mixes services to face the fragility of older people (telecare, telecompany, telealarm, home automation), the ones to help hospital discharges (telecare, telemonitoring, home automation), health services for chronic diseases (telemonitoring and telemedicine), and the planning and controlling services established by the Regional Fund for long-term care (information services for scheduling and controlling costs). These services have been included in several projects, also European, many of them still in progress, and had a natural evolution in their integration (European project OLDES, Mia casa sicura, T'informo-Social information desk, Emergenza Caldo, Giuseppina Project, Dimissioni protette, Teleortogeriatria; Scompenso cardiaco by Local Health Authority of
Bologna, European project Telemedicine; Siss-Social and Health Informatic Service; SOLE project by Emilia Romagna Region). They represent a great part of the current service supply of E-CARE. During these projects has been also developed new technologies to provide services to citizens.

In detail, the E-CARE integrated services are detailed as follows:

- **Telecompany**: has the role of listening and dialogue, and also aims to involve users in social activities - where possible - to reduce involuntary loneliness. The telephone calls provide relational support and information on various relevant issues for older people's and caregivers' lives (e.g. vaccination campaigns, heat waves, etc.).

- **Telecare**: it is a help system aimed to provide tax and social security assistance, shopping service at home, processing of small committees, medicine delivery, and accompanying users to specialist visits. It is composed by a free telephone line and provides support to user interaction with local social services, general practitioner (for many issues such as monitoring therapy and medical condition, difficulties in managing themselves and in the execution of daily tasks), associations and non profit organizations (for particular activities e.g. shopping delivery at home, assistance in reading and understanding administrative practices, help to control home safety accompaniment to social activities such as community and cultural centers, church, gym). Are included also services for health reservations (examinations and visits to specialists) and provided information public services such as transport.

- **Telemonitoring** of health conditions and factors of fragility, with the possibility to activate nurses and social workers in case of alerts.

- **Telealarm**: it is an emergency system activated by the user in cases of extreme difficulty; where available is operative an environmental emergency system (gas, flooding, etc.). The service is available by calling the call center 24 hours 24 year-round.

- **Telemedicine**: through the use of technological devices (panic button, provided free to users), it allows the continuity of care of people discharged from hospital through the monitoring user medical situation. It is possible because the health centers receiving data and can communicate via videophone with their patient. In this way, medical professionals can prevent health risks (e.g. cardiac disease).

- **Teleinformation** for the selection of the services provided by the social and health authorities, creating a network with local stakeholders and care staff.

It should also be noted that there are two configurations or models of E-CARE services: a "basic" and an "intensive" one, which differ in relation to the intensity of care needs of the user and for the quantity and quality of services offered. In fact users are not classified in a generic way, but based on 15 categories of vulnerability developed by a multi-disciplinary team that used objective benchmarks and indicators validated in the the scientific literature.

As mentioned above, the frailty conditions of target groups identified by the multidisciplinary team useful for providing different types of services to users are:
functional, clinical and social. Among the criteria/items used to define the categories of vulnerability of users, the multidisciplinary team include the following: respiratory and cardiac disorders; diseases with complex therapies; diseases with frequent clinicians monitoring and/or check-ups; chronic pain; hospital admissions; depression; difficulty in feeding; difficulty in movement; falls; sensory deficits; live in isolated or degraded areas; low income; inadequate housing conditions; the absence or inadequacy of care support provided by family members or relatives.

For the definition of vulnerability categories various tests/tools validated in the scientific literature have been used, such as the ADL (Activities of Daily Living), the IADL (Instrumental Activities of Daily Living), the CIRS (Cumulative Illness Rating Scale), the CBA (Caregiving Burden Assessment).

The basic formula (in which are involved users with 1 to 5 factors of frailty) involves the insertion of the users in a program of weekly telephone monitoring of their psycho-physical conditions, as well as the provision of a range of services (information, advice, health services reservations, etc.). The intensive formula (in which are involved users with 6 or more factors of frailty) is aimed at older people at higher risk of dependency or with other serious problems, that anyway can be still managed at home with adequate support. In addition to those provided for the basic formula, therefore the intensive one offers a wide range of services (e.g. accompaniment to health services, companionship, home delivery of medications and shopping, etc.).

It also offer contacts and networking with GPs, nurses and social services, and provide additional services and activities for users, focusing on the enhancement of relationality and socialization (e.g. bereavement counseling service, transportation for visits to relatives ill patients in healthcare facilities, delivery of books, organizing lunches on festive occasions, such as Assumption, etc.). Moreover, in situations of protected discharge, persons with special problems (e.g. elderly with heart failure), are activated specific processes like telemonitoring and telecare. In parallel, it is provided a personalized monitoring activity of issues and needs of their caregivers (about 300 units), through the management of a personalized socio-medical dossier, and, when operators identify potential problems, they activate the intervention of staff from social services (social workers of Municipalities) and/or health professionals (nurses or doctors).

Within the project aimed at carers of older people with dementia, at the Hospital “Maggiore” of Bologna and in the West District of Local Health Authority of Ferrara, specific “Alzheimer Expert Centers” have been established. For example, in the Alzheimer Center of Ferrara there is a clinic whose mission is to support (also economically) the diagnosis and treatment of dementia, providing help and intervention services for families and caregivers which care for these patients. This clinic uses a multidisciplinary team (geriatricians, psychologists, nurses, neurologists, etc.), and offers - through the fundamental help of the volunteer (Alzheimer’s Association "Francesco Mazzuca", a non-profit organization) - activities to support caregivers, organized into four main lines of action:

1) daily support: emotional support, legal advice, a call center (active since 2004), and as part of its activities in 2007 has been developed the project "Telemonitoring of needs" (see below);
2) training/information to caregivers, in collaboration with the Management Association of Social-welfare authorities (Municipality lead: Cento);
3) social activities, through projects developed under the Health Plans of the Province of Ferrara;
4) integration with the network of local services, that are in contact with family carers and connected with many initiatives to support carers (e.g. self-help groups).

The Alzheimer Expert Centre also carries out research aimed at mapping the needs of caregivers and develops tools to measure their stress. Even the Alzheimer Center of Bologna Hospital support caregivers of older people affected by dementia problems, through a constant monitoring of their mental and physical conditions (with the management of an individual socio-health dossier), paying attention in highlighting implicit suffering or borderline conditions. In general it offers psychological and social health support services, promotes opportunities for socialization and strengthening relationship network, thanks to the contribution of voluntary associations (e.g. establishment of "Alzheimer's cafe", meeting points in which carers share care work experiences and can participate in recreational events).

It should be noted that these measures are part of a general regulatory and policy framework (Regional Fund for Long Term Care, Dementia plan, Regional Plan for the Promotion of Social Inclusion) in which the Emilia-Romagna Region recognizes the fundamental role of family carers as a subject of care and considered of strategic importance to spread education and support programs of family members, to create new forms of "therapeutic alliance" between professionals and informal caregivers.

In this context, the Region highlights the need for the network services to recognize the "subjectivity" and the initiative of the family carers, not only as "objects" of attention and support, but also as key actors in the process of care. In addition, the regional action plan for the promotion of social inclusion indicates as one of the main areas of intervention that one aimed to support both family caregiving and the neighborhood solidarity network.

The actions addressed to family members and promoted by the Regional Municipalities and Local Health Authorities involved in E-CARE include: specific initiatives aimed at caregivers listening, opportunities of meeting and socialize); supply of flexible support and relief services (day care centers, information/advice/training); support the activities of self-help groups; the dissemination of adequate services for dementia: meeting centers, the "Alzheimer's cafe", dedicated services, with counseling, support groups, associations and self help).

Technologies used and functions of ICT tools

During the experimentation and consolidation phases of E-CARE, for the provision of services it has been chosen to adopt user-friendly interfaces and "low intensity", "minimally invasive" technology for users. They may use a dedicated phone line for communications and contacts with the call center (inbound and outbound). For frail users
and older people in situations of protected discharged (e.g. patients with heart failure), is
made available (on free) a special device (panic button) to allow them to alert emergency
services of the E-CARE network.
However the project focused mainly on investments and technological developments for
improving software and appropriate tools (e.g. computerized individual social dossier to
monitor older people and caregivers needs) in order to manage the network of services,
monitor and assess activities, promote connections and collaborations between different
actors and stakeholders involved through the ICTs.
In particular, a central software has been developed (for the creation and operational
activity of call centers) as the core of the system, supported by a range of tools and
technologies designed to facilitate networking among stakeholders. For example, using
CRM systems, CUP 2000 developed a complex software to help the integration with other
informatics systems used by the Local Health Authorities and the Municipalities, for the
management and the exchange of information on services offered to the elderly and E-
CARE users in general. For the exchange of data, also Web services are used, as in the case
of "BOS" (Bologna Solidale), a platform to support organizations and non-profit
associations, a social network for communication and information sharing on project
issues. In the framework of E-CARE particular attention is given to the development of
applications, technologies and ICT tools for the construction of the services network,
through which the initiative support: care recipients, carer's quality of life, quality of care
through carers , inclusion and participation of users. For what concern the general
framework for supporting carers in E-CARE as well in the whole Regional context, see
information provided above.
The E-CARE Network has its strength point in the call centers and provides, as mentioned
above, additional services, in a network logic and by progressive integration between
health, social services and stakeholders (public ones - Municipalities, Provinces, Local
Health authorities, "Dementia Centers", etc. – social resources and voluntary-non profit
associations). The main task of the call center is to promote a significant improvement in
the quality of life of older people (alone and/or fragile) and their families/carers. The call
center provides support, companionship and assistance with qualified professional staff, in
cooperation with local social resources. Users are involved on the basis of a personalized
plan of action, using a personnel dossier (a computerized procedure that maintains a
database with various detailed information: social, health, health status, habits, living
environment), containing data for the activation of the E-CARE network and to orient an
appropriate use of social and health services in the territory. Users are then personally
followed by operators, professionals and can benefit of the service network of the project
according to their specific needs. In particular, the provision of E-CARE services to users is
exemplified by the following synthesis schemes, relating to the territory of Bologna.
Services provided by the network E-CARE Bologna; years 2008-2009

<table>
<thead>
<tr>
<th>Type of service provided</th>
<th>2008</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telecompany, Telemonitoring (services/calls)</td>
<td>42,880</td>
<td>84,638</td>
</tr>
<tr>
<td>Information (services/calls)</td>
<td>4,338</td>
<td>8,985</td>
</tr>
<tr>
<td>Accompaniments (visits to health care, socialization, bureaucratic issues, etc)</td>
<td>498</td>
<td>786</td>
</tr>
<tr>
<td>Bath at home</td>
<td>162</td>
<td>100</td>
</tr>
<tr>
<td>Delivery shopping, drugs and medical reports</td>
<td>65</td>
<td>106</td>
</tr>
<tr>
<td>Socialization</td>
<td>37</td>
<td>177</td>
</tr>
<tr>
<td>Monitoring individual specific cases or support to bereaved</td>
<td>8</td>
<td>198</td>
</tr>
<tr>
<td>Total</td>
<td>47,988</td>
<td>94,990</td>
</tr>
</tbody>
</table>

Source: Fiori (2010)

Type of calls, E-CARE Bologna; years 2007-2009

<table>
<thead>
<tr>
<th>Call center activities</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inbound</td>
<td>4,225</td>
<td>5,549</td>
<td>10,710</td>
</tr>
<tr>
<td>Outbound</td>
<td>40,334</td>
<td>55,905</td>
<td>90,168</td>
</tr>
<tr>
<td>Total</td>
<td>44,589</td>
<td>61,454</td>
<td>100,878</td>
</tr>
</tbody>
</table>

Source: Fiori (2010)

The call center in Ferrara made 27,746 calls outbound in 2007-2008 and received 6,258 contacts inbound from users included in the project. The activities offered by the E-CARE service of Ferrara in favor of home care and independent living of frail elderly patients are numerous and of different types. In addition to standard services of telemonitoring and telecompany, the initiative provides more complex activities, such as reports to social services cases of frail older people in need of help, through a shared process with social workers. The call center also handles complex information supporting the elderly in the orientation within the social and health services and provides support in arranging visits or specialist tests. This action is realized becouse CUP 2000 governs the unified reservation centers of Ferrara Local Health Authority. Users also have benefited from more than 3,500 accompaniments to and from places of socialization and care. For what concern others details on services for carers, see point14.

Development methodology

As already noted, for monitoring users’ needs, in the context of the project has been created a personalized model of social-health dossier, developed through ad hoc software by CUP 2000. The E-CARE approach, aimed at further developing the culture of integration between social and health services, has the objective of creating a new record-dossier, to promote its integration with other electronic health records and files used by various services in the care sector for the elderly. The main problem is the fact that the dossier-record used by E-CARE and those used by others health care stakeholders (e.g. Local Health
Authorities) are characterized by different codes used to monitor the profile and needs of users. The creation of an integrated regional social and health care dossier represents therefore a priority policy aim of CUP 2000 and other stakeholders. The scope is to develop methodologies and technologies of E-CARE and in the same time promoting the sharing and integration of information between local health and social services, for a better management of health care problems of older people (and carers), and further strengthening the effectiveness and efficiency of the supply of regional welfare. The project also aims to expand the range of the supply of services for users, increasing even more synergy and collaboration with the social resources of the territory (voluntary associations, trade unions, etc.).

OPERATIONAL INFORMATION

In Emilia-Romagna, in recent years have been activated several actions to counteract the long-term care. In particular, integrated in the programming provided by the Regional Fund for Long Term Care (RFLTC), the E-CARE has been included among the key services to develop and finance within the same RFLTC. The idea of the project has been developed in connection to the strong experience related to the heat emergency of 2003, when many older people died because of complications due to the exceptional heat wave. This led local authorities to develop projects and services aimed at supporting older people to prevent fragility privileging home care and avoiding improper use of health services. In addition, simultaneously, the project was promoted through a reflection around a strategy of reform and development of local welfare, aimed at creating an integrated network of health and social services, activating local resources of volunteer for the elderly and their caregivers. In a first phase, the project (trial) was launched in the Province of Bologna and then extended to the territory of Ferrara. In particular, in 2004, the Province of Bologna, in collaboration with CUP 2000, the Local Health Authority (AUSL) of Bologna, some Municipalities of the district (Bologna, Budrio, San Lazzaro, San Pietro in Casale, Vergato) as well as with the Municipality of Ferrara and Ferrara E-CARE Consortium, has begun testing social services of the E-CARE initiative. The perspective was to provide to older people in conditions of fragility (and/or loneliness) and their families a network of communication and support, a better knowledge about access to health and social services and social resources in the area.

Following a positive assessment of the first phase of the experimentation (2005-2006), carried out by the Province of Bologna (project coordinator) in 2007, thanks to regional funding, has begun a clinical and therapeutic trial of the service, by which the E-CARE initiative has been extended to the entire territory of the Local Health Authority of Bologna (including 50 municipalities and 9 districts of the city of Bologna). In general, since 2007 it has been observed an improvement in the quality of service, which takes advantage through dedicated funding provided by the RFLTC and becomes an integral part of the regional and local welfare policies to combat the frailty, the develop long-term care, home care and the prevention and management of the elderly needs, through an integrated network of health and social services. In addition, in 2008 the
The project came under the activities related to the E-CARE "Heart Failure" program, which had previously benefited from a regional ad hoc financing, as part of ICT projects. As already shown, also in the territory of Ferrara the local institutions have identified E-CARE as a priority for the welfare of the frail population resident.

The initiative in Ferrara provides many social and health services developed by the E-CARE Ferrara Consortium (composed by CUP 2000 and municipal pharmacies) in collaboration with several local institutions. In such context, the contribution of both CUP 2000 and the call center E-CARE was very crucial. Between the various services offered as a part of the broader framework of supply network E-CARE Ferrara, we can highlight the following: in 2006 the project “Uffa che afa” for the management of heat emergency, an experiment in teleortogeriatria (for the continuity of care), the project “T’informo” (it covers social care for the vulnerable population resident). In 2007, an innovative project began: “Giuseppina”, it is an initiative aimed at older people (over 75 years) living alone, which provides delivery of drugs, home shopping services and transportation to places of care and socialization (in collaboration with the voluntary associations). In all the mentioned initiatives, the role of both call centers and network E-CARE are fundamental, accomplishing tasks as monitoring of needs, analysis and management of users needs (through the use of dedicated software and dossiers by the operators), addressing them to social and health services. Recently, the Municipality and the Province of Ferrara, Ferrara healthcare authorities (Local Health Authority and University-Hospital St. Anne), pharmacies, public and private universities of Ferrara and CUP 2000 also established a planning committee to enhance, develop and coordinate projects and researches in the field of E-CARE, with particular attention to the promotion and development of strategies for the application of ICTs in health, social and socio-health organizations.

Based on this framework, it is clear that the initiative has developed over the years as a network of citizens, associations, institutions, professionals, offering support and relational networks to frail elderly. The project, after the experimental stage, now is a service fully integrated in the local welfare system. It is now fully operational in both areas of Bologna and Ferrara, and services offered have been expanded.

In essence, the E-CARE Project in Bologna and Ferrara, from an experimental design, now it is a structured and consolidated service for citizens in the knowledge society, exploiting the potential offered by new ICTs through which build a New Welfare of Networks. The operational objectives of this initiative thus aims to promote the integration of health care networks, health, social care, safety for users, developing the potential of ICTs through the realization of a “Network (E-CARE) of the Networks".
In 2007, the West Local Health District of Ferrara, the Association “Francesco Mazzuca” (a non-profit organization), through the District Dementia Center, the associated management of local social services, the International Geriatrics Program of the Local Health Authority of Ferrara and CUP 2000, under the program E-CARE, started the experimental project “Telemonitoring of the needs of dementia”. This is an innovative experiment, included in the Regional Fund for Long-Term Care, with the fundamental objective to provide ongoing support to family caregivers of people with dementia whose care burden is particularly high and difficult to manage. The Telemonitoring service (in collaboration with the activity of a call center) is offered by healthcare personnel, via telephone and the Internet. It has created a permanent contact between the caregivers of older people with dementia and care staff (general practitioners, geriatricians, social workers, nurses, etc.) addressing the family caregivers needs to the professional services of competence and optimizing the resources available and avoiding improper use of the same. Further purposes of this project are both experimental and operational. Among the first: check the feasibility of a call center service by trained non-health workers, expand the time range of telephone reception (15 to 45 hours), to develop, with the E-CARE network and CUP 2000, dedicated technology systems (software, networking); effectiveness and efficiency verification on outcomes (e.g. quality of life of patients and family caregivers). Among the latter, e.g.: to provide, through telephone listening call center, ongoing support to family caregivers, promoting home care for elderly people, reduce burn-out of family carers, optimize the use of services and strengthen the network integration of local services, enhancing responses to the needs of older people and carers. In particular, it has to be noted that CUP 2000 (and the E-CARE network) has created a call center (open from Monday to Saturday) with non-health workers trained to respond with a standardized checklist to health and social care needs of users. It was also developed a specific software version (Costumer Relationship Management), for the registration of non-health activities and data of the patient. CUP
2000-E-CARE assess the economic costs, health care consumption, characteristics of the call centers service and related health and social services (learning, satisfaction with E-CARE services and connected network).

**E-CARE Telemonitoring of the needs of dementia: the operative model**

![Diagram](image)

*Source: Pirani (2008)*

**Funding and budget**

In the first phase of the project (testing), the E-CARE initiative was funded by local banks resources. The initiative is currently funded entirely by the public sector. In particular the E-CARE service can benefit from the investment made in the project by the Region and local stakeholders, as part of the overall health planning and of the Regional Fund for the Long-Term Care (RFLTC), activated in 2007. In 2011 the amount of RFLTC funding for E-CARE project activities is 630,000 euros, with a marked decrease from the previous year (around 700 thousand euros). The funding covers the organizational and technological development costs of CUP 2000, operative costs and those for the call center staff, as well as costs for some specific services (eg. telemedicine, telecare/panic button) and for the reimbursement of support activities provided to users by volunteers. The Municipalities contribute with own resources to cover users cost of telephone service (inbound calls), in proportion to the income of the same users. The services are free and there are no co-payments by users with low income.

The recent reduction of public Contributions transferred from Central Government to Regional Government Budget Increase the risk of future underfunding. To try to face these risks it has been implemented a strategy to maximize the appropriateness of the services in favor of groups of people most at risk of frailty (older people and caregivers in critical social and health conditions), further developing the integration and collaboration between different actors of the local social and health network.
**Stakeholder involvement**

The project was an explicit strategic choice of local and regional welfare policy, and was realized through the involvement and collaboration between stakeholders, institutions (Regions, Provinces, Municipalities, Local Health Authorities) and not (associations and third sector in general, trade unions, etc.). In particular, the stakeholders involved in the project are:

- Emilia-Romagna Region (*funding*);
- Local Authorities and Local Health Authorities of the Provinces of Bologna and Ferrara (*the promoters*);
- Province of Bologna, Socio-Health Territorial Conference; Province of Ferrara, Social and (*role and functions of coordination*).

The project implementation is entrusted, as noted above, to CUP 2000, in collaboration with associations, social cooperatives and unions pensioners (CGIL, CISL, UIL). There are about 250 groups that joined the project and work closely with (27 at the central regional level and 225 at the local level), highlighting the crucial role of volunteering in the E-CARE network.

The services offered by voluntary associations are different (accompaniments to visits, companionship at home, tax and retirement advices and counseling, telecompany, etc.). They are also involved in health care facilities and hospitals (ie, Dementia Center of the Hospital “Maggiore” of Bologna, West District of the Local Health Authority of Ferrara) in the implementation of specific projects to support older people with dementia and their caregivers in conditions of particular psychosocial risk connected to the physical burden of care.

In general, it should be noted that E-CARE is characterized by a specific strategy with the goal of widespread the involvement, promotion and enhancement of volunteering associations, in order to contribute to the identification of care needs of users and to the delivery of services related to the E-CARE network. A part the importance of having signed agreements and protocols of collaboration with the stakeholders involved in E-CARE, the voluntary associations shared activities and operating procedure, which is a clear communication between each association and the hub represented by the E-CARE call center (creation of a communication flow - workflow) for the operational cooperation in providing services and carrying out the activities for users. Thanks to the collaboration of voluntary associations it has been favored the possibility of providing help and services to a wider number of older people and caregivers involved in E-CARE.

**Personnel involved**

Concerning the organizational structure of CUP 2000 SpA, besides the President and the General Director, it is composed of a Board (5 members, including the President), and a Scientific Committee of 7 members (senior researchers of different scientific fields). The corporate organization of CUP 2000 (management) is based on a horizontal structure.
matrix, organized by projects. According to the reference architecture of the e-Health and E-CARE consolidated on a scientific level, responding to the characteristics of e-health projects CUP 2000 has as its main objective the enhancement of communication in health and social care.

In particular, in addition to the management, within the organizational structure of CUP 2000 are involved at the operational level in the implementation of the E-CARE 14 dedicated professional social workers, trained (attending courses of 1 month with periodic updates). They work at the call center. They are employees of the organization, which by its nature and mission emphasizes the assumptions, and not use atypical workers such as the vast majority of call centers operating nationwide. In addition, the organization aims to encourage employee retention, thanks to the training of workers, and especially thanks to their experience "on the job". They are assets of the organizations and not easily replaceable with other operators. The company CUP 2000 would be available to increase the number of its employees operators, but fears of further reductions in resource transfers from central government to local governments (and therefore also to the Emilia-Romagna Region) at the time does not allow to proceed in that direction.

In addition to call center operators, CUP 2000 provides: 6 human resources dedicated to E-CARE for the management of activities and to promote partnerships with other stakeholders and operators involved in the project (social workers, representatives of voluntary associations, etc.); several engineers involved in the development and maintenance of software (personalized social dossiers of older people and caregivers;) and in the management of strategic information on project performance (in terms of costs and services are operational). The technicians are also involved in the development of technologies for the growing integration with computer networks of various stakeholders of the project, to facilitate the sharing of knowledge and information on users.

The system also involve many professionals and operators of health and social services of the Local Health Authorities and a network of voluntary associations (in favor of whom were organized 21 specific training initiatives to provide them appropriate cognitive and relational tools for carrying out the project activities, and referring to latest data available, for example, 70 users are telemonitored by volunteers specifically trained for these duties). Over time, in parallel to the development of project initiatives, the number of volunteers has grown, partly as a result of initiatives by the project coordinators to promote and further disseminate the associative network.

Users

During the first testing phase of the project (2005-2006) more than 600 older people have been assisted and monitored in the Provinces of Bologna and Ferrara. As a result, the number of users of the service E-CARE has grown progressively: Bologna goes from 675 in June 2007 to 1,835 users in December 2008, 3,091 in December 2009, reaching 3,350 units (last data available in September 2011).

The coverage of the frail elderly residents in Bologna Local Health Authority followed by the E-CARE is 19%. Between users there are about 300 caregivers directly involved in
monitoring programs and personalized support. Overall, users are 74% women, and the predominant age group is over 85 years. Users therefore in the majority are "very old". Over time, support interventions have been increasingly targeted to those most in need. In fact, it has increased the appropriateness of the service, which now involve mainly older people at higher risk of long-term care. The percentage of users with severe frailty, involved in the intensive E-CARE, pass by 7% in 2007 to 40% in 2010. Users in charge of the E-CARE Ferrara rose from 940 in June 2007, to 1,290 in June 2008, to 1,679 in December 2008 (latest figure available).

In the territory of Ferrara were also involved in the specific project for the telemonitoring of dementia around 200 informal caregivers (and relatives cared for with mild to moderate dementia). As noted above, the informal caregivers telemonitored are 2 on 3 women, middle aged (but over 1 on 10 are aged more than 75), low-educated, over 4 on 10 employed (but over 1 on 4 stopped work for the increasing care burden). Overall, therefore, the large number of users involved in the initiative is particularly significant, and growing over the recent years. In addition, it should be noted that on the basis of data collected and analyzed on a comparative scale by the National Observatory of the E-CARE Network, the initiative analyzed is the largest telecare network of Europe.

Requirements for usage

As noted above, the project preferred use user-friendly interfaces and technology tools (eg. dedicated phone and equipment for emergency services/telecare) that do not require special skills to use by citizens/users or specific technical support by services operators (except training in use the equipment for emergency services). Users get knowledge about E-CARE services available through extensive communication and promotion activities carried out by stakeholders. Until 2009 CUP 2000 also played a pro-active and direct role in contact and recruit in the project frail people and individuals at risk, from lists of names provided by regional social and health services. Later, people are reported by local health and social services that seek to select users according to criteria of appropriateness (subjects with greater fragility). Self-nominations are possible too, in fact people know the initiative thanks to communication campaigns, or information obtained by word of mouth as well.

As already noted, the E-CARE network of services is one of the qualifying innovative measures in the context of the regional welfare policy system aimed at supporting the elderly and their families. It benefit of a systematic and effective collaboration between the local in stakeholders in the stage of experimentation and in successive development. From this strategic choice stakeholders don’t want go back: E-CARE is one of the pillars for the regional welfare reform in an innovative and technological driven way. The only issues that could negatively influence both the evolution of the initiative and the use by users of its services is the risk of a further reduction of resources transferred from the central government to the Region so that it would be difficult to maintain current budget levels (which as noted have already known a downturn in the recent period). Another problem concerns the diffusion of telemedicine technology, whose high costs of implementation are
also difficult to sustain, again because of the possible contraction of public resources in the medium term.

**ENABLING CONDITIONS AND SUCCESS/Failure FACTORS**

The traditional 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. For example, since 1980 in Bologna has been realized an experience of “citizen network”, appreciated by the citizens: the Metropolitan CUP, the first major system of electronic access to health care in Europe. The CUP, over the years has grown throughout the Province as one of the largest network for the citizens in Europe. In 2005 has provided around 13 million of health services of 1,852 different types.

The Metropolitan CUP was a great innovation in the Italian health system: started from Bologna the initiative spread in many other cities and Regions and became a model in Europe. It is a network that has evolved with the Internet and electronic user's care, representing a new project based on an innovative network for health care, safety and the National Health System: E-CARE. On this background the project started with the cooperation of stakeholders (CUP 2000, Municipalities, Local Health Authorities of Bologna and Ferrara, unions, associations, volunteering, etc.).

Key factor was and the setting up of the Regional Fund for Long-Term Care. This measure has been the innovative regional regulatory framework for structuring innovative welfare policies to face the long-term care issues, to promote innovative forms of assistance and care of frail elderly and their caregivers, making available adequate financial resources for the implementation of the project. The advanced culture of the local welfare, the strong cooperative and operational attitude between professionals and organizations of the public health and social services, the expertise of professionals and stakeholders involved in the initiative are the ingredients that have further facilitated the implementation of the project, finding high levels of satisfaction among users of E-CARE services.

**IMPACT ASSESSMENT**

The evaluation made allows to know the number of users, the health records and their satisfaction with the service. In general, the impact of the initiative has been evaluated: internally, by project personnel of CUP 2000, and through independent analysis commissioned to external researchers of the University of Bologna (Department of Sociology).

The assessment of the project in general has focused on the following dimensions: satisfaction and quality of life of care recipient, informal carer quality of life, quality of care provided, acceptability, care efficiency and sustainability. To assess the effectiveness of the E-CARE service specific indicators have been prepared for: satisfaction with the services offered, quality of life of older people, quality of life and stress of caregivers, measured by specific tests and questionnaires. Among this, were used, for example, the following: the
Caregiver Burden Assessment (CBA), for the determination and quantification of stress in caregiving; the Psychological General Well-Being Index (PGWBI), for the determination and quantification of perceived well-being (providing also in some cases simplified versions of the tools/tests to facilitate the compilation of users and increasing their compliance; eg: Mini Caregiver Burden Assessment – MCBA) and specific QoL evaluation tools. Others specific assessment indicators have been prepared for the maintenance of functional status and ability of carrying out common activities of daily living, measured by means of telephone test administration, therapeutic compliance, assessed by the information system and interviews with older people and caregivers, the economic cost of the target population in relation to consumer health and appropriateness of services (also to evaluate the possible savings in relation to the specific costs of E-CARE support service), measured by the CUP 2000 informative system. Analysis and assessments about the characteristics of the target population, the number and characteristics of calls to and from the call center were also carried out.

In general, the project make periodic assessment of overall operative activity, made by the internal informative system of CUP 2000, with processing and analysis of indicators of effectiveness/efficiency of the service made available to the management to assess the activities and set up strategies to manage and develop services. This activity is part of the organizational routine of CUP 2000, which, as certified company, produces regular assessments surveys (eg. CRM) for internal management and clients/members. Reports and statistics produced in this work are obviously confidential and internal to the company.

As regards the assessment of users satisfaction with services and the quality of life of users, as noted above, this is an activity carried out both internally in CUP 2000 (from a specific operative area o, "independent" from E-CARE), and in outsourcing.

Based on reports of the analysis of researcher and project manager, users expressed at high level of satisfaction for the E-CARE services, especially appreciating the possibility of being able to obtain, beyond the social and health services, personal support, companionship and listening, facing social isolation and loneliness, increasing the perception of personal safety and strengthening/expanding social networking/friendship. In particular, a survey on a representative sample of 400 users in charge of the project carrying out a high degree of satisfaction for E-CARE services: on a scale between 1 to 5, 90% of the sample E-CARE shown the highest rating of satisfaction, while another 8.9% attributed a score of 4. It has been very much appreciated the fact that the operators speak at length with the elderly, and the respondents, point out, never hastily. Equally pleasing is the "free" style in which the contact is run, without forcing the conversation with rigid questions, operators still collect the necessary information to fill in the social personal dossier of users.

The benefits, however, are also found at the level of perceived quality of life of users. In this sense, for example, as pointed out by the project coordinator, an interesting result is that a significant percentage (66.3%) of elderly people claimed to have achieved an improvement in their health status. This circumstance is explained mainly in relation to a perception of greater psychological well-being, thanks to the support offered by the operators (call center and social network) and by the E-CARE services network. Regarding the assessment of specific projects aimed at caregivers of demented elderly, have been highlighted positive
results regarding: support received by carers in terms of information provided by operators (e.g. on cognitive and functional conditions of the users, with tips on appropriate access and use of health services and facilities); collection of news from the operators of call centers and network of professionals involved in the E-CARE (e.g. doctors, nurses) on burden of caregiving, stress disorders, psychological risks, burn-out of caregivers with monitoring the conditions of carers and older users (issue / update personal dossier) and any health alert and activation of specialists (e.g. sent to psychologists in cases at risk). In addition, it has been successful in structuring and operating a dedicated service (call centers) to provide functional support to family caregivers in overcoming the difficulties in caring at home for relatives with dementia. According to an ad hoc survey carried out for monitoring and evaluating the project as a whole, over 80% of caregivers involved in the initiative were satisfied, showing appreciation for the services and highlighting the positive relationships with operators of E-CARE call center.

Anyway 62% of caregivers of older people with dementia live as "very high" the burden of care that they face (score in a range 13-20 of MCBA), but carers involved in E-CARE (telemonitoring users of dedicated call center) show a better quality of life rather carers not users of the service.

The impact of the system on all the caregivers involved in various initiatives E-CARE is very positive and important on several fronts. For example, get support and help in charitable activities through information and continuous monitoring of the conditions of the elderly and their personal networks have integrated social welfare that is activated in the emergence of any critical health condition, perceive an improvement in their quality of life (e.g. in terms of social relations and health and mental well-being) and relationships of care (decrease in situations of conflict and tension with their patients), increased awareness of the activities related to the work of care and have been improvements in the quality of care provided.

The main goals achieved by the E-CARE network for caregivers, as highlighted by evaluation activities, are the following. The service: has provided ongoing support to family caregivers, to reinforcing home care of elderly people with dementia; has attenuated the relational discomfort and stress has improved the gratification of family caregivers.

Besides what has already been stressed, in general terms, the assessment work highlighted how the project activities, focusing on data collection and needs, and the exploitation of the potential users (older people and carers) have fostered the connection between them and social resources of the territory, enabling the ability to create a network between the actors involved in care activities. Experience has shown the ability to use tools and technologies designed for the early detection of conditions of fragility, the enhancement of relations can improve the quality of life of the elderly, through the empowerment of the local social context. The experience of the initiative has also confirmed the possibility of using ICTs to integrate formal and informal networks of support and assistance at home for fragile/dependent elderly.

In terms of assessing the impacts of the service about care-efficiency and sustainability of the welfare system, an epidemiological and qualitative survey promoted by the Local Health authority of Bologna has highlighted the following key results of the project. In two years, it has been observed: reduction in the number of admissions in hospitals (100 less),
with a cost saving for the health-care system of 600,000 euros (average stay: 10 days, the average cost of a day of hospital stay: 600 euros), the 50% of users decreased the use of hospital services (given that over 70% of the users has over 80 years it is a very important result). Therefore, the scientific data analyzed show that in addition to improving the quality of life of clients, E-CARE produces a significant reduction in health-care costs. In addition, another survey (qualitative) conducted by the same organization shows a good appreciation of the service among a representative sample of professionals (social workers and health professionals) involved in the project. On a scale between 1 and 10, social workers, on average stress a degree of 7, while the relative value between the doctors is equal to 6.4. For the professionals interviewed, E-CARE is especially notable for the following strengths for users: it is useful because it provides information on health and social services, reduces the sense of loneliness, increase the perception of security, helps to meet the relational needs, increases compliance on requirements/treatments; reduces improper access to health and social services.

Thus, as emerges from the analysis, the E-CARE initiative is widely appreciated by both users and among the professionals involved in providing services. It should also be noted that overall, there is an extensive and consolidated assessment activity of the project, which confirms the attention to these issues from stakeholders, with the use of validated instruments and indicators, and functional management and business development design. The impact of the project on older people, carers and professionals involved and the local care system as a whole is well documented in the analysis, from which emerge particularly successful results on several fronts.

Finally, as mentioned above, the project E-CARE is part of a number of other initiatives carried out in Emilia-Romagna in the area of ICTs and health. The project coordinator CUP 2000 (on behalf of the Emilia Romagna Region) is also involved in monitoring and assess the "National Networks of E-CARE" promoted and funded by the Ministry of Health (dedicated website: www.onecare.cup2000.it). E-CARE is a project also recognized as a best practice both nationally and internationally (by the European Union).

As noted several times in the analysis, the benefits for the older people and their carers are several. Among these, in summary, we underline: support in activities of daily living, personalized monitoring of social care needs, service orientation and activation of the network of agencies and operators of social services, recognition of unexpressed needs, development of personal resources of users, socialization, cope with the fragility, promotion of home care (and parallel reduction of improper institutionalization) and of the quality of life of users and carers, of the quality of care provided, better relationships between older people and caregivers, promotion and enhancement of a networking approach, positive influences on the health of users, broadening the sense of security of the elderly and their families, services for the management of difficult discharge from hospitals and specific services to support carers with psycho-physical risks (e.g., in cases of care for relatives with dementia). It is therefore a comprehensive framework that shows very positive benefits for users: older people and carers. For details on these aspects, please refer to the appropriate sections of this document.

To provide some specific evidences, an ad hoc survey (Fiori, 2010) on changes in the quality of life perceived by users after their entry into the E-CARE services shows, fro
example, that 72.1% of users perceived more safety, 78.2% less loneliness, 70.6% have expanded the network of friends, and 2/3 perceive an improvement in health conditions.

From a financial perspective, a detailed calculation of the return on investment in setting up the initiative is not available, although data available do not excluded that such calculation would be feasible in the next future.

As noted during the analysis, the main outcomes identified for institutional stakeholders related above all to the possibility to provide adequate support to frail older people and informal caregivers, with an innovative network of services. As a consequence of the better quality of the care, efficiency and effectiveness of care are likely to improve, with benefits in terms of economic costs and sustainability of the welfare state.

FUTURE PERSPECTIVES

Sustainability model and perspectives

As previously noted, the economic and operational sustainability of the initiative can benefit from the investment made in the project by the Region and local stakeholders, as part of the overall health planning and of the Regional Fund for the Long-Term Care. However, the recent reduction of public contributions transferred from central government to local governments budgets increase the risk of future underfunding with potential critical in maintaining the supply of current services. In the hopeful hypothesis that these potential funding problems will not occur, the intention of the stakeholders and project coordinator CUP 2000 is to expand the range of services provided to older people and caregivers, trying to improve the appropriateness of the target group, favoring those with more fragile and/or with greater difficult conditions: social exclusion, economic and relational problems, health and psychological risks.

Scalability capabilities and conditions

The E-CARE project and related services, in addition to their scheduled deployment to the entire territory of the Emilia-Romagna (e.g.: soon be the project will be implemented in the Province of Ravenna), have wide margins to be reproduced and transferred to other territorial contexts of the country, thanks to well tested ICT based system. But, for this, it needs a proper policy, funding and an effective cooperation between local stakeholders.

Objective conditions for transferability to other local contexts across Europe

The specific nature of in-house company that characterizes the regional implementing agency and project manager, CUP 2000, by law (Bersani law of 2006) has limitation in working within Europe with a direct role in the transferability of the E-CARE in other countries. However, as pointed out above, there are active collaboration as partner in several European projects and experiments (e.g. OLDES European project, Telemedicine,
initiatives within the framework of Ambient Assisted Living Joint Programme of the EU) which enhance the ICT applications for assistance to older people and caregivers. In the future the aim is to strengthen these partnerships to further develop services and activities in the field.

POLICY IMPLICATIONS

Digital inclusion

With regard to digital inclusion, has been promoted a series of training courses directed to the learning and the use of IT tools (PCs, Internet) in favor of members of associations and voluntary organizations, to promote their ability in sharing information for collaboration in the supply of E-CARE services. In this regard, as noted, for example, was created the Third Sector Portal “BOS” (Bologna Solidale -www.bolognasolidale.it) as a social network of all the volunteers and organizations participating in the project to share information about events and services.

More generally, the development of the E-CARE aims to promote digital inclusion and communication between citizens and the welfare system, through a communication model based on the shift away from a monoservice approach to a multiservice integrated network, where a variety of services are delivered to the target population by a network of providers. In this sense, the E-CARE network is characterized by: 1) taking electronic charge of the citizen, with data collection and processing, 2) organization of the different actors involved in the supply of social health and welfare in a multiservice network. The innovation of the project, therefore, refers to technology that is used to create this network (software that connects all nodes that can be activated). In this regard, it has been realized a computerized system designed to allow doctors, nurses and social workers to receive communication that one of his user has been included in E-CARE and consequently they access to the personnel file of the elderly (social and health dossier), highlighting any changes, care problems and identifying the most appropriate use of the network of social and health services in the area.

Social inclusion

As noted, the project promotes an active role of the elderly and their caregivers to improve their quality of life, enabling them to play a leading role in their communities, expressing and enhancing their capabilities and resources as people (relational networks, skills, knowledge, experiences, interests, ideas, etc.). Are promoted for this purpose forms of mutual-help and community participation in social life, thanks to the contribution and voluntary associations. The project intervenes in particular in support of social inclusion of older people (and their carers) in conditions of vulnerability, social isolation, often without relational resources, low income, poor housing conditions. In particular, the project contributes to the emergence of needs submerged, as the frail elderly and in conditions of social distress, often not used to turn to local services, remaining in the shadows with the
needs of such carriers. This is done by creating a support network around frail elderly (creation of the "network of networks"), ie offering all services and free resources that can be activated and used to support the best in the demands of everyday life and in particular moments of social and health needs.

Ultimately, the service e-Care helps to translate the latent demand for quality of life of senior citizen, otherwise unexpressed, trying to offer any support. The network of contacts and services built around the citizen has as its primary purpose the maintenance of the elderly person at his home, through the use of rational and budget resources of the territory, preventing inappropriate or premature hospitalization / institutionalization. In this sense, it was verified the ability of the service E-CARE to develop / improve social cohesion and combat the isolation of the patient, enhancing the network resources and the citizens themselves.

A part what stated above, as regards more specifically the caregivers, E-CARE contributes to their social inclusion, breaking their isolation and offering services of listening, monitoring of health and social needs, and enabling the activation and intervention of local services for their personal (as well of their patients) needs.

**Employment**

The employment purposes are not among the priorities of the project. However, by CUP 2000 there would be the intention, alongside the development of project activities through the provision of additional services, to increase in the future the employment base of the operators involved in the delivery of these services, but this goal is currently frustrated by the risks of reduction of financial resources transferred from central government to the Region.

However, from another side, it should be noted that thanks to the assistance and services provided by E-CARE, has emerged the possibility for some carers to better combine care duties with work activities. Although no qualitative data are available, the analysis of project documentation allows to confirm that a group of carers was able to maintain a job or to enter in the labor market.

**Social Care and Health Care**

As repeatedly stressed the importance of the E-CARE lies in to be part of a clear strategy of offering innovative services to reform regional health and social welfare policies for the older people. A welfare system that focuses on the elderly (and their carers) as a citizen, and that aims to the growing integration of social services and community health. This is accomplished through the promotion, coordination and development of networks and a of culture of network work between local services, the integration of information communication and promotion of a professional operation and stakeholders based on overcoming the division of labor between services and expertise.

As previously noted, the E-CARE service combines the potential strategic context of the formal system of care with those of the informal system of care, identifying possible
synergies from the same requirements of quality of life of the patient. Finally, the E-CARE project, providing a support network, technological and organizational support of the frail elderly as an integral part of the action initiated by the Regional Fund for a the Long-Term Care promotes health home care, offering a new culture of social and health services, through an increased computerization and integration of supply, A project which aims to structure an innovative, efficient and effective redefinition of welfare and social health system even on a national scale.

REFERENCES


Emergency Alarm

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**Methodological note**
Data has been retrieved from interviews with the initiative coordinator from the Hungarian Maltese Charity Service (service provider) and internal assessments (carried out in 2010 and Autumn 2011). Furthermore, some information is still publicly available in organisational reports (among the others: Hungarian Maltese Charity Service 2008, 2009).

**DESCRIPTIVE INFORMATION**

The Hungarian Maltese Charity Service (MMSZ) was established in 1989 and had an important role in the early ‘90s after the systemic change in the efforts to solve the growing social problems at a time when the state was unable to cope with them. By 1998 it had become a nation-wide organisation covering the whole country and helping people in need. The organisation helps different social strata at risk (such as the disabled, handicapped, health impaired, big families, minorities, homeless, older people, frail older people). After the change of welfare system (1990) the organisation strove to answer social problems of the society and has developed methods to meet these challenges. It started to set up model programmes and has developed technical innovations in eldercare as well.

The emergency alarm system that was created with the help of work done by the Institute of Sociology of the Hungarian Academy of Sciences first appeared in 1994 in the form of a model programme in eldercare covering 30 persons. For a long while it was the only technical device used in elder care. It aimed at combining technology and formal home care for the first time: alarm signals sent from a device worn by the elderly were received in a 24-hour control centre of Maltese home care. Because of their state of health many elderly persons in the model programme received help that was given mainly by the care centre of the local government of a district in Budapest and many of them needed additional help of
family members. The burden of the family carers was eased by the new technology entirely unknown at that time in Hungary. The main objective of the organisation is to provide an emergency alarm for frail older people living at home through its professional staff. The model programme focused on frail elderly living at home alone and already receiving social care provided by the formal care centres of local governments. The alarm system on the one hand gives the older people a feeling of safety as they know they will receive immediate help, and on the other hand it eases the burden and responsibility of family carers as it replaces institutional care or postpones the time of admission to such care. The technology introduced by the organisation and focused originally on frail older people receiving care from the formal care sector has had a double effect. The original aim of the organisation was to ensure an independent life for older persons by enabling them to send alarm signals from a device worn on their body. On the other hand they have realised how important is this solution for family members.

**Target users**

To explore the scope of help a representative survey (662 persons, random sample, structured open-ended questionnaire) was carried out by the organisation in autumn 2011, representing 3% of the family carers in Hungary. The results of the survey have shown that family carers as well received great support from the ICT used by older care recipients. The support affected one family member (in 45% of cases), two (30 %), three or four family members (18%) and in 5% of the cases it affected more than 5 family members. The majority of the family carers were daughters or sons and their wives or husbands (70%); grandchildren and their wives or husbands (8%); sisters/brothers (5%); the wife/husband of the care recipient (4%) or other relatives (12%). Family care-givers’ education, status, income differs but they include non-active family carers, retired (or other non-active, e.g. women with a child at home). Among carers some are retired, many others still work on the labour market. The majority of family carers live far away from their relatives. Care recipients generally belong to the older age groups (70+ 80+) mainly women with a relatively low income. Their educational, financial background and health status differ.

The service, integrated into the system of basic social services is available principally for those with poor social and health status. Persons receiving home care (help) can apply for it, but there is a need to assess the potential demand for such an ICT service outside the scope of basic services.

**Development and implementation methodologies**

The innovative solution developed by the organisation is part of the eldercare provided by the local authorities. The local authority contracted out the service to the organisation which provides it, continuously develops the technology and makes up for the deficit in the local authority’s services and technology.
The alarm system is a wireless network based on radio waves. The organisation developed a modified solution not affecting the basic technology but taking into account the various regional, geographical and settlement structures and the form of social help provided. This made it possible to extend the service to elderly people living on isolated farms in the poorest and most backward regions. The professional carers, or in the case of isolated farms and scattered settlements the village caretakers assess the existing demands in basic care that can be met in the social sphere in the manner regulated by the legislation in force.

**OPERATIONAL INFORMATION**

By 2000 the model programme that began in 1993 with 30 persons was incorporated into the Social Welfare Act and became part of the eldercare system. The innovation successfully links home help, a form of eldercare, with technical innovation and the Hungarian Maltese Charity Service played different very important roles in this and served as a national innovator. After conclusion of the model innovation programme in 1993-1994 (pilot period), in 1994 the programme entered the operational stage. The organisation continuously further developed and adapted it to meet different demands. It provided the service exclusively within the social public eldercare structure, but at the same time elaborated the regulation and methodology for the service that was now in the operational stage. As a result it was given the right to operate as the methodological centre, making it possible for them to supervise and monitor the ICT-based service provided by others, and hold short 2-4 day training courses for formal carers or token fee volunteers providing the service in the public sphere. The growth was achieved in part by winning the support of the macro level, through the legal regulation of the ICT-based care it had initiated, itself participating in the elaboration of that regulation. In addition it succeeded in securing the necessary funding, at first through a successful tender and later through a normative funding. By 2011 the number of those receiving the emergency alarm exceeded 30,000. In their present field of operation the coordinators of the organisation work without ICT-based programmes, but believing that it can have a positive influence on eldercare they have begun new development projects drawing on their experience in eldercare. For a long time the service was sustained by development grants.

**Budget and funding**

After its integration into the care system according to the general regulation financing is based on a normative sum from the budget (which is available for organisations providing an emergency alarm service in the social sphere). Users have to pay a sum determined by the local authority within the frames set by the Social Welfare Act. Most recipients of care are very old and have low pensions, so the sum to be paid is very small or they receive the service free of charge.
According to a survey carried out for the Methodological Centre of the Hungarian Maltese Charity Service in 2010 among the service providers, more than half do not charge a fee (public sphere). Close to a third charge a very small, fixed sum that does not exceed 2% of the income. The emergency alarm system was able to spread rapidly because in the late 1990s state social policy considered it important and supported it as a way of improving the health situation and reducing the social risk of the elderly.

Compared to local governments whose financial source depends solely on the normative from the central budget, the organisation has its own funds and provides a certain number of users with its own equipment. Technical development of ICT is at low risk. However maintaining the ICT-based care in the social sphere is at high risk. Eldercare is part of the system of social services not of the health care system and the two systems are not financed in the same way. The former is financed from the central budget while the latter is based on social insurance.

The ICT-based alarm system has been integrated into the system of social services. As a result, currently there are several forms of financing for the service developed by the organisation, depending on which actor provides the service: if it is provided by the local authority or a body under contract to the local authority it is based on the normative payment from the central government. The contracting partner can supplement this sum from its own sources. In the case of a church service provider the basic normative is supplemented by the 80% church supplementary normative.

In micro regions with a low population density and in generally backward areas an incentive sum of 25% is added to the basic normative sum. Within this structure the fees to be paid for the service can be kept at a low level, but in the current economic circumstances with the lack of sources within the social system, there is little chance of expansion. There is a need for a sector-neutral, uniform system based on social insurance. The rates charged in the market segment are largely influenced by the financial situation of the target group, but a big demand can only be expected if the market price is low.

The organisation has separate rules and cost documentation for the technical and the care categories. The organisation does not intend to shift the cost to carers; the recipients of care pay a low sum defined in the regulation of the local authority. The organisation provides the service free of charge for those in social need, supplying its own equipment and uses its own personnel and additional financial resources (tenders, sponsors) and sometimes its volunteers as well.

**Personnel involved**

For a long while the spread of the system came up against the attitude of the public sphere that tended to avoid innovation, did not understand the use of ICT in care and favoured human resources. The resistance of the macro system first changed in the late 1990s when the opportunity arose to apply for special funding, then a change of attitude in the ministry responsible for eldercare made possible the spread of innovation. This also encouraged the appearance of market actors and from 2000 market actors in fact, began to appear.
The organisation was in an exceptional position because it had an overview of the entire system, structure and regulation of eldercare as well as of regional and local differences which it was able to take into account in making continuous developments and in formulating proposals for the macro level. In this way it had a fully up-to-date picture of the ICT-based service it had developed; according to the data of its methodological centre, in 2011 around 2500 persons participated in running the initiative providing the ICT-based care service and over 1000 token fee volunteers (they receive a small sum) also helped in the care work.

The overwhelming majority of people involved in running the initiative work full time. There are also persons receiving a token fee mainly on night duty and almost two-thirds of them are skilled persons (retired nurses). The number of volunteers working in the organisation's own care centre is increasing, in contrast with the national trend that has appeared recently in the public sphere. Volunteers who received a token fee but participated in the public sphere later flowed into the NGOs and churches.

The organisation's professional carers have secondary-level health qualifications, the volunteers receive 20 hours of training, supervision is carried out in the regular monthly meetings; there is also continuous communication with the informal carers, they help in eldercare and check that the elderly recipient of care uses the device properly (e.g. that it has not been removed from the body, placed in a glass cabinet, etc.).

The Hungarian Maltese Charity Service uses 60 persons in its care unit and has approx. 30,000 on the national level, but there is a demand for twice this number and it could use 60,000 persons. The reason for the big difference between the two figures is the strict process for screening volunteers, the limited capacity of the social care system and the limited financial sources. Because of the financial circumstances of the elderly, only a narrow stratum are able to afford the market-based service.

Promotion and technical support strategies

The organisation offered the ICT-based service to the public sphere, the largest segment using the service. This is supplemented by the organisation's own related service, compared to these the purely market segment is tiny. The spread is not linked to ICT knowledge and there is no need for any special skill, only a simple explanation that can be provided by anyone. Service users can learn about the ICT-based service through various channels: from carers in the care centres, from a doctor, a family member, a family carer, the mass media, the advertisements of market service providers, or from the internet.

The Hungarian Maltese Charity Service presents the service on its website. No serious problem arose on the side of the users; it is the task of the carers to avoid this and to check that they are using the service properly. If the mental state of the elderly person deteriorates and he or she is unable to use the device which thus becomes superfluous, it is used in future by someone else and another solution (technical, institutional care, intensified care) must be found for the elderly person with dementia. It is the task of the carers to determine whether the elderly person is capable of using the device alone (43 and for this the carers need health qualifications.
ENABLELING CONDITIONS AND SUCCESS/FAILURE FACTORS

A representative survey among the service providers in 2010 (structured questionnaire) showed the reasons for discontinuing use of the service. In general the demand for the service typically ends in one of two ways: the user is admitted to institutional health care, residential home (nursing department) or dies. Sometimes the old person goes to live with family members (but this is not typical). In these cases the termination of use does not mean a reduction in the services provided: such occurrences make it possible to satisfy new demands. However there is another reason for termination: this is the fee charged by the local authorities. There is a change on macro level policy, instead of normative financing local authorities must now submit applications for funds to operate the service. This often resulted in the termination of the free service and although the fee set did not exceed 2% of the income it resulted in many requests from care recipients to discontinue the service (28%). Obviously, these elderly persons do not appear among the users of market services.

Under the provisions of the Social Welfare Act the ICT-based service is part of the basic services but not a mandatory one. Its spread in the social sphere depends on the degree of development of the local authorities and that is determined not by the potential users but by the possibilities (financial conditions) of the local authorities for access to ICT. The spread of the service on the market depends on the prices offered by the market and the current financial situation of the elderly; an increase in the number of market actors and the resulting competition can lower prices and speed up the spread.

IMPACT ASSESSMENT

Core dimension of impact covers “Quality of Life of Care Recipient” and in an indirect way also the “Quality of Life of Informal Carer”. The ICT-based service very often has a positive impact on informal carers. The representative survey carried out in 2010 among service providers (mentioned above) revealed that in less than half of emergency calls the reason was not a real emergency but psychological problems (fright, fear of something, etc. need to talk to somebody).

The 2011 representative survey (already mentioned as well) carried out among family members confirms these results. The situation caused by psychological problems of older peoples were solved by the staff of the emergency call centres. Family carers declared that without the emergency alarm they would faced great difficulties as they had to carry out earlier both physical and mental caring tasks (physical tasks: personal hygiene, insuring warm food, nursing, tending the garden, help in housework, cleaning, shopping, accompanying to the doctor, handling official affairs, administering medication). However conversation, reassurance” and “nursing, administering medicines” represent almost half of the solutions provided by the emergency alarm service, together with calling a doctor (12%) and “care” (10%).

Interviews in depth with family carers were also carried out (18 cases) in 2011. They revealed that for family carers it was very difficult to work on the labour market and do
caring tasks as well. The need to leave the workplace in case of emergency, to work overtime to make up for such time spent away in cases of emergency caused almost everyone stress, with somatic problems in many cases (high blood pressure, gastric problems, need for medicines, etc.). However, after the installation family carers gained psychological support, somatic problems disappeared, they had more leisure time, and work and care could be reconciled. 

The ICT solution supports the care recipient, enabling his/her independent living as well. According to the impact assessment studies carried out on behalf of the Methodological Centre of the Hungarian Maltese Charity Service by the organisation in 2006 (survey among service providers), and their calculation (taking account the different public expenditure spent for different types of eldercare) they had a conclusion that the ICT-based home care largely replaced admission to a residential home or hospital, or shortened the period of rehabilitation there. According to the representative survey only one seventh of recipients were admitted to a residential home and 3% to hospital. The number of applicants for residential homes fell by 40%, and there was a reduction in the number of days spent on rehabilitation in health care institutions.

The annual state expenditure on support for providers of emergency alarm services (100,000-200,000 HUF) is only one seventh of the support paid to institutions maintained by the state (700,000-1,250,000 HUF). The support paid to churches and micro regions is even less compared to the residential homes (the latter receive respectively 80% and 25% more support). Market firms also receive support, but this amounts to only 30% of the base rate. That means if an elderly person is able to continue living at home for only one year longer on average, the cost of the ICT-based service is returned to the state at least sevenfold.

In addition, the wish of most old people is fulfilled: they are able to continue living at home and do not die in an institution. The quality of life of the recipients of care improves. An unexpected outcome however can be the result of a bad choice by the carer (e.g. giving the device to a person with mild dementia), thereby neutralising the good technical solution. In the case of a service provided in the social sector (there has been no measurement of service providers in the private sector), precise assessment of the mental state of the elderly person by the carer and monitoring of any change was important. During the training (to formal carers) and subsequent supervision the organisation monitors the existence of these conditions and suitable use of the device.

Continuous technical development of the service and regular training of the carers ensure the future high standard of the service and its sustainable development. From the technical viewpoint and the tasks related to practice of the service, the risks are low. At the same time the negative impact of the economic crisis has also affected the system of eldercare in the state sector and among the market actors only big companies with diversified activities that do not rely solely on sales of technology are viable, but even these companies most face a shrinking market demand.
FUTURE PERSPECTIVES AND POLICY IMPLICATIONS

Some considerations concerning future perspectives and policy implications of Caring for Others are the following ones:

- **Scalability and replicability elements**: Expanding the scale of the service would present no difficulty and all elements of the service are replicable.
- **Objective conditions for transferability to other local contexts across Europe**: The system is technically easily transferable and can be adapted to the regulatory structure of any given country, enabling it to be integrated into the eldercare system.
- **Digital inclusion**: Use of the system is relatively simple, but it does represent a step forward towards digital inclusion for the elderly.
- **Social inclusion**: It prevents the social exclusion of elderly persons at risk for health reasons as well as of the family members caring for them. It also assists the reintegration of family carers helping them to reconcile work and care, easing the mental burden of care and improving their state of health.
- **Employment**: It makes possible for family carers (if they have problems to work and care simultaneously) to reconcile work and care.
- **Health and social care**: It can be very successfully implemented in health and social care. It improves: the health of family carers (no stress, disappear of somatic problems of family carers caused by caring of older people medicine); cost saving; living at home for the older person (avoiding or postponing admissions to residential homes or hospitalisations).
- **Any other lessons learned**: An innovative ICT device that is simple to use and useful for both the user and the family carer can be disseminated rapidly and successfully and incorporated into the system of social services. However, without uniform and sustainable financing, sustainability over the long term could be threatened. The existence of the service in the market segment depends on the financial situation of both the elderly users and their family members.

REFERENCES


“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 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 concerns them.”

from Ippi AB

**Methodological note**

Evidence on IPPI is publicly available: Fagerberg (2010), Östlund & Lindén (2011), Scandurra (2011), Sjölinder & Nylander (2010). Additional information was gathered through interviews with Jon Simonsson and Elisabeth Persson at IPPI AB, as well as from the official website.

**DESCRIPTIVE INFORMATION**

Ippi AB is a spin-off from Ericsson, which started after Ericsson previous long work to develop services with broadband solutions. After collaboration with Svenska bostäder with a focus on health care, it became clear that there was a need for a service without the complexity technologies and installations can bring. From this was formed the idea of a new service, which was to use existing infrastructure in the home in the form of television and mobile networks. The authors applied for a patent on the new service named Ippi. The company InView was started to develop the service, but is now called Ippi AB.

The organization’s main goal is that more people can participate digitally and benefit from digital communication in healthcare contexts. The ambition is that all who have the
cognitive ability to start a TV and change the channel also will be able to take part in the
digital society.

**Target users**

Ipipi is primarily designed to help older and disabled people to participate in the digital
society on their own terms. The service also aims to help health-care providers to simplify
and improve health care interventions, in that they can inform and communicate better
with the caretakers via ipipi. Ipipi also aims to facilitate the care situation for relatives, by
overcoming geographic and generational boundaries. The ippi services in its self does this
in the way that caretakers more easily can communicate with relatives, with means that’s
widely used by the younger generation. But IPPI also aims to help and support familycarers
with an additional service called AMIGO specially made for familycarers that creates
opportunities for a supportive social network. Today it’s estimated to 40 AMIGO users and
400 ippi users.

An ippi service includes (Fagerberg, 2010):

- Ipipi devices for users.
- The web-based service ippi-central.
- Service through: support, performance monitoring, software updates, management
  of GSM subscriptions and traffic, and more.

All that is required to use ippi is a TV set and a mobile network. The ippi device is easily
connected to the TV set at the home of the user and controlled by a remote control that is
designed to be as user friendly as possible. Via television, the user can receive 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 concept is to channel digital communications such as email and mobile traffic through
the TV set. 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 does
not need more technical expertise than to be able to start a TV and using a simple remote
control. Via the ippi the user can easily keep in contact with loved ones, but also with
health care. Ipipi offers healthcare providers a web-based ippi central, so they easily can
send messages, information and ask questions to one or more users. There is also an
opportunity to inform the user about staffing or implementation plans directly from the
healthcare provider’s computer system, so he or she can be more informed and involved in
their own care situation.

In addition to the directly intended target groups, ippi has also been able to help people
who may not have been the first in mind. This is information that will benefit ippi
employees in contact with local authorities, and sometimes directly with users. One
example is a man with Parkinson’s disease that no one thought could use technological
means because he has symptoms of very strong shaking. The man said that he very much
wanted to try the ippi service which has worked very well. The simple design of the remote control allows him to use it on his own. The man has said that it changed his life because he had much more contact with loved ones and could more easily get information from health care. There are also ippi users who have previously used communication technology as computers, but for reasons such as dementia cannot do this anymore. Ippi makes it possible for them to use communication technology again because it is simpler to use television and remote control which is usually a very habitual behavior that feels natural to the user.

Type of support provided

The ippi service is primarily a support for dependent older people but also a support to quality of carer's quality of life. The service focuses primarily on improving the health situation of the caretakers. The tool allows the caretakers to maintain their social networks and be more involved in their care situation. This helps caretakers to live longer in their own homes, but also to simplify and improve care. The latter is made possible by medical staff being able to easier communicate with and inform the caretakers. Relatives are in this aspect not the main focus but are involved in the sense that they are part of the social network that is important for enabling the caretakers to use ippi.

Ippi focuses also on supporting relatives in their personal and emotional life, in that they can maintain a social network directly from the home. Relative users have stated that the ippi helps them create a sort of clearing-house for the family on the health care situation in that they can more easily communicate and update each other. This have been concluded in a evaluation made by Swedish Institute of Computer Science (SICS) 2010, with the aim to investigate if and how a simple communication solution can be used to create and empower social and supportive network for familycarers. Methods in the project contained involvement of familycarers who tried the service at home and participated in workshops and individual interviews, and also knowledge input from National Family Federation (continues as NFF) as well as municipality familycarers consults. (Sjölinder, 2010)⁴. At the same time Ippi AB worked with NFF in a larger project to develop a service for relatives. In the project’s final report made by The Swedish Institute of Assistive Technology it was concluded that contact with a social network is important for relatives as well as for the caretakers. But it also revealed a need for relatives to have other support measures in the form of information and support with particular focus on relatives. (Fagerberg, 2010). The project has through this generated the family support service AMIGO where the ippi service is one of three parts:

- Ippi, a communication support via the ordinary TV set.
- AMIGO call center, dialog, support and guidance.
- Handbook for familycarers, a digital knowledge bank with different types of applications. (Ippi AB).

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Although the AMIGO service is specially focused on family carers needs it also benefits the caretaker in the way that both can use it at home and that they more easily can communicate with each other when the family carer are not at home. According to the evaluation made by The Swedish Institute of Assistive Technology (SIAT), AMIGO succeeds in helping family carers to maintain a social supporting network, and also makes it possible for family carers without a social network to build one with help from the call center. The evaluation also sees great possibilities for the municipalities to at a higher extent reach family carers with municipality care support, health and social services. The evaluator's highpoint that this would be an important step to be able to give information as a preventive intervention, instead of letting the carer be forced to ask for extended aid intervention as a result of a crisis.

As mentioned the collaboration started with a project, in which NFF developed, tested and evaluated two parts, AMIGO callcenter and handbook for family carers. The company behind the ippi service, In View AB, developed, tested and evaluated the ippi communication support for family carers (see the earlier mentioned study by SICS). All three projects were carried out with the help of family carers who participated and tested the three different services. During these projects NFF and In View collaborated in the way that NFF contributed with knowledge and experience about the target group, and they also did part of the communication with family carers via ippi. (Fagerberg, 2010).

OPERATIONAL INFORMATION

The ippi service including the technology aims to enable that expected results are produced by a simple and cost effective way to make communication technology available even to those who cannot use mobile phones or PCs. The simple design of ippi is an essential part of this in the sense that it is not dependent on IT personnel, installation or complex equipment. Another important aspect is the adaptation according to user needs and cognitive ability. This is done by the ease of use with ippi, i.e. the remote is easy to use and manage, but also by ippi's user-based offers.

The motivation to meet users’ needs in this way relates to the scientific medical evidence regarding, inter alia, impaired learning ability that comes with age. (Sjölinder, 2010). The idea of using ippi with a television monitor is based on the idea that older people are more likely to embrace new technology if it is based on an entrenched behavior, such as using a TV set.

Lund University carried out a study 2010 with the aim to investigate if and to which extent lifelong experience of watching TV reduces older people’s uncertainty on the eve of using TV-based applications as the ippi service. The method contained workshops and focus groups with elderly people how had tried the service at home for six months. In the study it was concluded that the connection to the TV significantly contributes to the user daring to try ippi. However, they also conclude that continued and frequent use is dependent on an existing social network. The user must be able to see a direct personal benefit, such as contact with loved ones. (Östlund, 2011).
From ippi’s side, work is therefore based on the strategy of first offering users the social possibilities, i.e. the ability to easily communicate with loved ones. Other offers are then introduced in steps as the user wants to learn more, such as contact with health care. The idea behind this is to create curiosity and inspiration in the user.

There are examples of people who were expected to benefit from ippi, but where it appears that the service has not been as helpful as was hoped. Usually, it has been about people who do not have an existing social network, which is an important prerequisite for the service to be of use. If that is the case, another player can step in and take social responsibility for communication, such as a voluntary organization or a community meeting place. Other ippi users can also serve as a new social network.

**Development and implementation methodologies**

The development of the ippi service has taken about five years continuous work with user-driven development with designers and researchers, including SICS, R&D Seniorum, R&D Sörmland, Swedish Institute of Assistive Technology and Lund University. Ippi service has evolved and continues to develop with the help of user participation\(^5\) and a user-based approach\(^6\), (Sjölinder, 2010) (Fagerberg, 2010). Examples of functions that have been developed at the request of users is textogram using speech synthesis, i.e. that a voice reads a text message.

2011 R&D Seniorium carried out report based on a project invested by VINNOVA with the aim to develop communication services with the help of the ippi service, that’s suited for a modern care home facility and daily care facility for elderly citizens. The project developed a method for implementation of the service and performed pilot studies in four municipalities. User involvement proved to be significant for the ippi initiative to bear fruit. In the development project it has been concluded that a user-based approach is important to anchor the local service in the municipalities, because conditions are different in different municipalities regarding the interaction between partners, communication patterns, and practical circumstances. This has been shown by the fact that ippi has been applied differently in the municipalities depending on local conditions, meaning that users and end-users have their own thoughts and ideas of what they want the ippi service to offer. For an example there has been a noticed need in one municipality to do something about the “home map” that contains the caretakers care planning and information. Therefore a digital home map was created, that easily can be updated, maintained and viewed via ippi. In another municipality there’s a common range of spoken languages, which led to the idea of communications support via pictograms. Although even if these outputs are created from different local conditions, they still can be spread and make benefit for other municipalities with ippi users.

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\(^5\) Participation and input from caretakers and families.

\(^6\) Participation and input from local authorities / health care providers, including caretakers and families.
Users and market opportunities

Potential customers (healthcare providers and users) involvement in the project has led to that they have continued to use ippi after the project. This is related to the reasoning that involvement in innovation processes is important for how participants relate to the outcome. Participation has in some cases been so important to the participants that it overshadowed the result. (Scandurra, 2011). This is something that is also shown in the SIAT report where project involvement has been very valuable for relatives of users, because they feel a community with the group of other project participants and that they are involved in developing new technologies. (Fagerberg, 2010).

To optimize the conditions for the introduction of ippi, municipal and health care providers are offered help and support. Ippi AB also provides seminars for clients such as health care providers, potential customers and researchers which enable them to share experiences, tips and ideas. Representatives from ippi also participate and provide information on trade shows and conferences to promote the service. Potential users are made aware of the service through their care and service providers.

Today Ippi AB has 400 users within the target groups elderly, disabled and relatives. Evaluation results have shown ippi to be of greatest benefit to older people or people with disabilities that limit cognitive ability. Young people with disabilities are often experienced computer users. Ippi AB has started a development project on behalf of the Swedish communications authority Post and Telecom Agency (Post och Telestyrelsen) with the aim that users will be able to pay bills electronically through the ippi service. This is to be done through a further development of the ippi technology platform so that it has the same OS as an Android phone. By extension, this means that all general information from the mobile and internet world can be made available via the ippi. The functions will however, as the Bank function, be selected according to target group needs and work as applications, exactly as in an Android mobile. From a critical standpoint, such a range of applications will be a generalization of the target group and the user will therefore not be as free to seek information on the Internet. Thus there might also be a risk that the user abides by what is offered rather than developing with the help of the technology.

The project which is planned for completion in autumn 2012 means that there will be a new target group, consisting of the large group of people who for various reasons cannot handle a computer. Today ippi is tested in India, Singapore, Spain, Aland Islands and Kenya. The simplicity of the ippi only requires a TV set and mobile coverage and the fact that messages are sent to the ippi via telephone, text, MMS and e-mail strengthens the argument that ippi is applicable wherever there is a mobile net and a television set. However, as mentioned earlier, an evaluation showed that generalization of the use and frequencies of use have their limitations, as the use of the service depends on local conditions. It is as previously mentioned possible to counter this but a good deal of work with user-based development is necessary to adapt the service to the local context. It has also proved difficult to adapt the service for each individual. Some adjustment is however necessary when the needs varies among the users. (Sjölinder, 2010). The developers have therefore added three different user modes based on what different users can handle. (Scandurra, 2011).
Marketing and courses of action concerning the current offer of ippi would in the international distribution have to be adapted to each country's organization of health care. Probably one model could be to turn to a provider that offers similar type of solutions. Ippi AB is headed by the CEO and Vice CEO who is also chief technology officer. The organization also has a developer with responsibility for system development of ippi and ippi central. The company has a board of seven members including investors, founders of the company and experts.

**Personnel involved**

In three years, the operation of Ippi AB has grown from three to eight full-time workers. CEO and one of the founders of the company Jon Simonsson has worked as founder and CEO of a software company in the telecom industry. He is alumni of Harvard Business School and civil engineer from Linkoping Institute of Technology. Previously, Jon worked as a nursing assistant. Kjell Lindén is Vice CEO and CTO and founder of the company. Kjell is a civil engineer from the Royal Institute of Technology and has previously worked as Head of Research and Development at Ericsson. Peter Peldan is the system architect behind the ippi platform and responsible for the technical development. He is a doctor of technology at Chalmers University of Technology and has worked as a post doc. in theoretical physics at Penn State University, USA. Peter has over 20 years experience in complex system design and development. Fredrik Degerblom, who works with product management and support, is a graduate engineer within industrial economics. Elisabeth Persson is responsible for costumer relations and marketing, and has a social care degree as well as a master in management. Beatrice Gustafsson also works with customer relations and is head of education. She has a degree as a high school teacher and a degree in political science. Karin Leksell is a senior project leader and has a degree in resource management. Added to that there are suppliers of services, manufacturing and telecommunications.

**Budget and funding**

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. Caregivers who bought the service decide how much users will pay and have chosen to solve it in different ways. Some municipalities choose to handle it as an entitlement to support (biståndsbedömning), which means that the user pays the monthly fee. In other municipalities ippi has instead been implemented as a communication system for an entire housing, making the housing instead of the individual caretakers pay the cost. There will also be costs associated with the introduction of ippi depending on how much work is needed to support the municipality. Ippi provides a benefit analysis for potential customers to give them an idea of costs and benefits of the service, in relation to overall health care.

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interventions. 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 €). There are no intentions to transfer the costs to individual users. As mentioned above the municipalities choose themselves how they manage costs, and relatives have a statutory right to receive help and support of the municipality. Since the ippi service is a cost effective solution compared to other municipal support, there is a possibility of not having to transfer those costs to relatives. From an implementation view, it has been shown to be important to justify the imposition of ippi as a good condition to meet the Social Services Act and LSS requirements. Therefore, a business model has been developed with this purpose (Scandurra, 2011).

There are always financial risks when a service depends on the economy of care providers, but this is countered by the company continually developing the service to the extent possible, making it cost effective and meeting customers’ needs. A very important factor for the success of ippi is that the development of society means that communication between health and social care and the care recipient has to be in digital form in some way in the future. Since the ippi solution also costs very little in comparison with ordinary care communications / information, the service is very sustainable. Ippi service takes advantage of infrastructure outside the initiative’s budgeted capacity, by health care providers who purchase the service being able to decide who can communicate with users via ippi. So there are opportunities through ippi to give users access to contacts with NGOs, libraries, pharmacies, transportation, etc.

**ENABLING CONDITIONS AND SUCCESS/Failure FACTORS**

The main difficulties that needed to be overcome in developing and marketing of ippi was funding and delimitation of the focus / target group. The company has been mainly financed by private financiers, known as angel investors, but also through public support from the Swedish Institute of Assistive Technology and Vinnova, as well as through sales revenue. The ippi service has not yet become profitable for the company and therefore a return on investment calculation could not be made. Initially the service was targeted for the private market, with a focus on older people who did not use computers. Soon, however, the company chose to turn to health care providers to more easily reach the target audience and offer benefits for both healthcare providers and care recipients. Soon also relatives were found as a target group, which initiated the cooperation with National Relatives Association (Anhörigas riksförbund). Gradually, the municipalities themselves have taken the initiative to offer the service even to people with disabilities, which added the target group LSS.

A major challenge in introducing the service is to get the support of the staff that may be skeptical of new technology. Therefore it is important to convince also health workers and inspire them to think from a development perspective. The risk otherwise is that they reject the aid as a burden before they try it and see the benefits. Most often worsening illness is the reason for users to stop using ippi, but sometimes it is caused by a lack of support from caregivers. As previously described, it is very important that the user has
both social and supportive networks for the service to be of use. Thus it is important that all parties at all levels are motivated and convinced when the service is implemented in a municipality or by a health care provider. Ippi AB contacts health care providers to show what opportunities are available with ippi, and show references from other customers. Developers at health care providers are often curious and interested in innovative solutions and have proven to be good contact persons. When a decision has been made about implementing the service, the project leader in the municipality or from the caregivers side, has a crucial role and is often a person with a specially driving spirit. Other key persons are ippi ambassadors in the shape of staff members who will work with the service.

**IMPACT ASSESSMENT**

In evaluations conclusions have been reached that it is very important that municipalities or health care providers have leadership and strategies to develop how they work if they are to participate in projects to further develop a service like ippi. This is for results to be achieved but also maintained. It is also important that such a process is allowed to take time for the different partners to learn to collaborate and cooperate for common goals. The main argument for applying ippi is that the evaluations have shown that ippi helps caretakers to rediscover a sense of control and power over their own situation and strengthening the individual. Caretakers at existing customers are very positive. Staff report that caretakers are much more involved in the sense that they can prepare themselves better for what will happen but also influence what will happen during the day. One example is that service users previously used to ask the staff who is going to work in the evening. Not knowing these things, but instead having to wait all the time to see who comes and what will happen create a sense of powerlessness over their own situation. With ippi caretakers can easily get the information in the morning, which means that it is instead the caretakers who inform the staff about who is going to work in the evening. The feeling of control that this entails is something that employees perceive as very valuable for the caretakers. (Scandurra, 2011). Ippi has also been described as making older people to a party involved, instead of just being recipients of information. (Sjölinder, 2010).

All four pillars of impact dimensions are relevant based on the following reasoning: Quality of care provided and quality of life for care staff is increased in the sense that working conditions are improved. The staff can easier inform caretakers and ask questions, making it easier to plan the work and the need to respond to anxiety and frustration of caretakers decreases. (Ippi AB) (Scandurra, 2011).

"It gives you a great sense of security to know who is working. Being able to find information without having to ask for it, increases independence for our caretakers. "

Staff at centrumboendet, Nyköping. (Ippi AB).
"Our caretakers are not always listening to what the staff says, but when it is the ippi who tells it, it’s usually no problems."
Håkan, staff at group home Garnsviken Sigtuna. (Ippi AB).

Ippi also helps the staff to contribute to a pleasant atmosphere by small simple means. One example is that staff in group homes sends out a small riddle that all then talk about at lunch, which is much appreciated. (Scandurra, 2011). Health professionals have indicated that sound, picture and text messages via ippi have been a very good option when factors such as dementia or aphasia may complicate a phone call. Familiar images and voices in an audio message is also something that strengthens the sense of security for people with dementia. (Sjölinger, 2010).

Ippi has shown clear effects on relatives’ quality of life because the service facilitates the care situation by making it easier to communicate. The lack of time and geographical distances are no longer major obstacles to coordinating communication with each other and with the caretakers about the care situation. Also generational boundaries disappear with the help of ippi, 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 the mobile. In that way it can be said that by empowering caretaker and help them maintain a supporting network, the burden for relatives are being eased and changes family care dynamics. (Sjölinger, 2010). The study highlights the possibility that ippi can contribute to better contact and planning between healthcare and relatives, which would curb the need for more comprehensive care interventions as a result of a crisis situation (Sjölinger, 2010). From a critical standpoint, there are flaws in this conclusion because, as mentioned earlier it has been considered to be a need to supplement the ippi service with additional support for family carers, focusing on information and contact with health care and other social functions. (Fagerberg, 2010).

Most relevant in this context is the increased quality of life for caretakers. The greatest benefits for caretakers and relatives are to use the ippi to maintain a social network. (Sjölinger, 2010) (Östlund, 2011).

"Ippi contributes to increased communication with loved ones and is in itself furthering health and leads to a better quality of life. It also facilitates the maintenance of an active lifestyle and the preservation of the social network." Håkan Johansson, Tre Stifelser Gothenburg City. (Ippi AB).

"It makes me happy when my ippi flashes, then I know that I have received mail. Ippi has made me more a part of my family and my friends’ lives." Karl-Rune 84 years, Öresundsbro. (Ippi AB).

"I get messages from children and grandchildren, its great fun and very easy. Ippi is my computer." Karin 85 years, Halland. (Ippi AB).
"It was fun to get pictures of the elk that my son shot. For me, this is something new, as lumberjack you have not had much contact with new technology." Donald 86 years, Jämtland. (Ippi AB).

"It’s fun to get these postcards from my grandchildren, and one need not wait for the mail." Martta 87, Linkoping. (Ippi AB).

"It feels good to get greetings and know that someone thinks of you." Olaf 90 years, Jämtland. (Ippi AB).

Through evaluations and information from health care consumers themselves, ippi also has been shown to help caretakers become empowered and feel a greater degree of control in their own situation. This is shown through stories about users who have experienced the great importance of getting early information about which personnel will come, or get questions from staff via ippi about how he or she wants to plan their day. (Scandurra, 2011). There are also clear connections to major economic benefits for municipalities in that ippi contributes to caretakers being able to continue to live in their own homes, before they are forced to move to special housing. This is thanks to making relatives’ situation easier, but also by giving caretakers greater influence and control in their care situation. However, this is very difficult to prove through statistics and would require more extensive studies.

There have been many unexpected, but positive results. One example is a female relative who lives very far away and therefore has great use of the ippi. When she travelled to relatives she brought the ippi on her own initiative, and plugged it into her children’s television sets. This worked very well because the ippi is so easy both to connect and to unplug. In this way she could show the kids her photos and messages, and continue to receive and read messages even though she was on the move. Another example is a paralyzed man who wanted to use ippi, whereupon the staff connected the ippi to a remote control he has on his neck. In Vänersborg Municipality physical therapists send training videos to caretakers, whom they can use and train between the physiotherapist’s house calls. The physiotherapist can use preset messages that are sent automatically at set times, which means that the caretakers can get new workout videos as often as they want. In Täby Municipality a group of elderly women (dependents) has previously met in a project to discuss and influence the development of the ippi service. This has resulted in that they continue to meet as a study circle.

The examples above are some of the many stories that representatives from ippi have heard from municipalities and care providers. This is often done in writing, by press release, but also in direct meetings with staff and users. The examples also show how municipalities, providers and users themselves find new uses for ippi which the creators themselves had not thought of. These are processes which have proved very beneficial in development projects. (Scandurra, 2011).

"It’s a good technology for our elderly and disabled. There are endless possibilities and that is what is so exciting." Monica Hallgren, Project Manager. (Ippi AB).
FUTURE PERSPECTIVES

Looking ahead, the initiators expect to manage to get quantified benefit results that municipalities can use as a basis for decisions to invest in the service. Today there is plans for an economical benefit evaluation, that will be finished 2012. It’s intended that this will be performed by external part. Another external but qualitative benefit evaluation will be done by the school of health science in Jönköping. This will be collaboration with NFF and Värnamo municipality where the AMIGO service was implemented 2011.

In this case report ippi proves able to make a decisive impact for caretakers, relatives and health-care providers with respect to the following:

- Communication between caretakers and health-care providers improve.
- The caretakers are more influential in their care situation.
- Caretakers are better able to maintain a social network.

It’s also important to illuminate the benefits with the AMIGO service:

- Relatives can more easily communicate with the dependents (when they live far away), or with friends (when they are caring for relatives at home) and thus more easily collaborate on the care situation.
- Support and information to familycarers.
- Familycarers are better able to maintain a social network.

The simple design of ippi also makes it easy to install and bring. Because of that the service will be very cost effective. People with severe physical disabilities can use the technology independently. From a critical standpoint, it can be argued that the simplicity of the ippi with all its benefits, at the same time is a disadvantage in that the user is limited to what is offered, despite the concept that everyone can be digitally involved. An excessive striving to simplify the technology can also mean that the challenge to learn and cope with the technology disappears, which otherwise could contribute to an increased self-confidence. It is worth thinking about if this restricts the company from reaching for example young people within the target group of people with disabilities, but also the older generation where some computer skills are becoming increasingly common. Ippi’s move with alternative user modes are in this respect a significant development.

The target group relatives has been added later and it is found that in addition to the ippi additional support functions are needed to assist relatives in their everyday situation. As viewed in this case study, this has been addressed by collaboration with the National Family Federation that resulted in the AMIGO service. At the ippi webpage a special section for familycarers holds information about the specially oriented service.
REFERENCES


Just Checking

Gary Fry
Centre for International Research on Care, Labour and Equalities (CIRCLE), University of Leeds

with contributions from Celia Price
Director, Just Checking

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“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

Methodological note
Unless otherwise stated, all information presented in this case study is based on interviews with Celia Price, Director of Just Checking, or on information publicly available on the company’s website (www.justchecking.co.uk). Further evidence is publicly available: Department of Health (2008), Herefordshire County Council & PCT (2009), Leeds Partnerships NHS Trust (2009), Roworth-Gaunt et al. (2009), University of Nottingham & Nottinghamshire County Council (2010), Warwickshire County Council (2006).

DESCRIPTIVE INFORMATION

Just Checking (JC) was established in 2003 when the proprietors\(^8\) were involved in a number of European funded research projects, largely concerned with dementia and how

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\(^8\)JC was founded by Celia Price and Simon Price, now co-Directors, both of whom were previously involved in European research and the development of assistive technology. The business is based in Warwickshire, England.
to support patients and the people who cared for them. A constant theme emerging from these studies related to family carers wanting to be able to monitor elderly parents suffering from dementia without always having to be in attendance with them. This led the owners to begin experimenting with various technological solutions to this problem and soon developing a prototype portable tool – the first version of the JC system – in which they got a local county council interested.

The purpose of the initiative is to help people in the early stages of dementia to continue to be independent and to enjoy life. It encourages users – principally, informal carers and formal care workers – to focus on what the person can still do, and helps them to support themselves with prompts and reminders relating to key tasks in their lives. JC offers carers and care workers a clearer indication of how someone is managing to cope when they are alone in the house, whether they are retaining a daily pattern of activity, and when they need more assistance. It offers carers and care workers increased opportunities to support people in their own home, where most report they would prefer to be when suffering from conditions such as dementia. It has been argued that the familiarity of the home helps people with dementia to make sense of their changing world, providing clues and reminders about what to do. Moving elsewhere at this stage may increase their dependency, something which makes the JC system an invaluable tool in supporting them to remain at home.

Carers and care workers benefit from the flexibility that the JC system offers, allowing them to monitor from a remote location the activities of the cared for person at home. In the case of carers, this process frees up time and offers ‘peace of mind’, allowing them to pursue other activities such as those relating to employment and recreation, while remaining confident in the knowledge that the cared for person can be assisted if required.

JC works with three different users, each of whom are discussed below:

1. The service user\(^9\) – the person with dementia, in whose home JC is installed. Evaluations (discussed in more detail below) have found that among the benefits for the service user are that it provides objective information about the user’s living patterns, which they may not be able to articulate for themselves, and which is nearly always better than expected, therefore providing more opportunities to be supported at home rather than moving to residential care.

2. The family user – usually a relative of the service user: e.g., a son or daughter, although sometimes these can be brother/sisters. JC was originally developed for the family user trying to look after a relative with dementia who was living alone. Its expected benefit was to give ‘peace of mind’, especially as relatives tend to fear the worst after noticing mental deterioration. However, daily patterns are often maintained and can be supported. The unexpected benefit of JC was that it can change a relative’s perspective of the person, enabling them to concentrate more on what the person is still able to do (rather than what they cannot do) and also to focus on social visits rather than visits involving ‘checks for peace of mind’.

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\(^9\) Social care staff usually call their clients ‘service users’. Health staff use the term ‘patients’, although if it is community based services, such as intermediate care, which is often a joint health and social care team, the term ‘service user’ is more usual.
3. The professional user – health and social care professionals who are involved in the assessment\textsuperscript{10} of the person with dementia, and/or delivery of care. Typically these are social workers, occupational therapists, care managers, community psychiatric nurses, and support workers. It was a social worker who pointed out the potential to use JC for care assessments, and the proprietors subsequently worked with two local authorities to format the system to make it portable, simple to install by health and social care staff, and easy to re-use time and time again.

As can be seen above, quite a number of people are involved in the implementation of the JC system. The profiles of the users of JC are discussed below:

- \textit{Service users}: The profile of this group is not known because no personal details are held by JC, because these are usually clients of its professional users. These people are assessed by social services or are part of other dementia support services. They are usually elderly people, living alone.
- \textit{Profile of family users}: A wide range of family users use JC. On the whole, the system is bought and used for assessment by a local authority or NHS trust, and family members are given log-in authorisation to use the system, too. Some family users then buy or rent the system for on-going use. This group tends to be in their 50s or 60s, technologically adept (including Internet use), and often still in paid employment (although sometimes only part-time). As the cost of renting the JC system is approximately £70 a month, it is thought that this probably puts off people on relatively low income levels. Some people in this category have ‘power of attorney’\textsuperscript{11}, however, and pay for the system from service user’s bank account.
- \textit{Profile of professional users}: See above.

In practice, the proprietor of JC feels that it is a difficult task to target family users cost effectively, at a time when they would be receptive to using this type of technology. There is a relatively short ‘window’ of opportunity between their not being prepared to interfere with a person with dementia, or broach the subject of the benefits of monitoring (e.g., a common complaint is that ‘my mum wouldn’t accept having sensors around her house’) to usually a crisis point, when typically statutory services are involved, and only then use JC. However, attitudes to the possibility of monitoring are beginning to change as conducting more and more important tasks on-line becomes more normal.

A recent evaluation of JC (University of Nottingham/Nottinghamshire County Council, 2010) revealed that the main issues identified as needing further consideration included the following key areas:

\begin{itemize}
  \item \textsuperscript{10} At a care assessment, a specialist – often an occupational therapist – looks at individual needs and discusses them. This is so that the right support can be provided. Services need include healthcare, equipment, help in the client's home or residential care. The assessment should show which needs are most important. It should also show the risks if the client is not given any help. If necessary, local health and social services teams will put together a package of support. They will discuss this with the client and write a care plan. This may include services from both private and voluntary organisations.
  \item \textsuperscript{11} A power of attorney is a written authorisation to represent or act on another’s behalf in private affairs, business, or some other legal matter.
\end{itemize}
- **Training:** If staff with little experience of providing dementia care intend to use the JC system, they must be trained on the ethical and mental capacity issues related to the people they are caring for.

- **Installation period:** A maximum installation period of four weeks might alleviate concerns about the perceived intrusive nature of ‘monitoring’ that some people believe JC involves. This installation period could be reduced as professional staff gain more experience of using the equipment.

- **Timing:** It may be that JC is considered as something to use only after every other support option has been exhausted. The optimal timing for installation appears to be after an individual loses capacity and before residential care is inevitable. JC could be presented more accurately as a means to improve assessments of need while a person is still at home.

- **Potential for intervention:** The possibility of using JC or similar equipment in real time to intervene should be considered. As the use of telecare becomes more common and acceptable, and as technology develops, the potential for remote interventions will increase. There should therefore be a debate about the circumstances in which it might be in a person’s best interests to permit access to more information, including visual and audio monitoring, and to utilise this to intervene in the case remotely.

- **Access to data:** Some consideration should be offered to the issue relating to which people should have access to JC data, and whether families should be given the option of accessing this data. Professional staff with experience of dementia who used JC regularly felt that they could interpret the data with satisfaction, but staff less skilled in dementia care required greater support. A clearly defined policy on staff and family carer access to JC data is therefore essential. This also raises the issue of whether there is a need for a central JC data repository, supported by dedicated staff.

Plans for the development of JC are already underway, with ‘roll out’ to a number of English local authority councils. In line with recent government policy, councils are presently focused on reducing costs while also focusing 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 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.

Some care providers are beginning to look at a version of JC which will, they hope, help to deliver relevant services at appropriate times of the day – that is, more flexible rather than regimented care visits, with home visits by formal care workers when they are most
required. Additionally, some intermediate care services use the JC system to give feedback on how the intermediate care is affecting the cared for person.

The JC web service has also recently been expanded, so a greater number of people can be supported by the system. It is additionally hoped that the JC system can soon be transferred across national boundaries, a development considered eminently possible because its web-based operating system is easy to use and can be accessed all over the world.

There are currently no direct competitors to JC on the commercial market, though a similar system has been developed in the USA, but this does not yet appear to have had much impact in the UK.

**Finance and budget**

JC is a commercial business, a supplier of equipment and web-service to the formal care sector who but its products, and has been funded by the owners since its inception. The majority of the business's clients are currently local authorities with social services responsibilities (who have a statutory responsible for care assessment), PCTs and mental health trusts. The owners do not expect this situation to change drastically (although they have developed a test consumer (family user) marketing campaign planned for autumn 2011, in the hope of attracting this user group to the service). Public sector clients sign up for 1 year or 3 year contracts, and it JC's task to make sure these contracts are regularly renewed. Although the company has clearly documented accounts, these were not available for the purposes of this case study.

JC currently employs 15 people, all who are permanently employed and most of whom work full-time. Among the business's staff are the co-directors/co-founders, a customer support team (four people), and a small group of Occupational Therapists. There are no voluntary workers currently affiliated to the business.

**Numbers of users and user engagement issues**

The JC system is highly active, with around 1000 log-ins (clients viewing activity data) a day. This is a large user group, though it is observed that there are up to 270,000 people with dementia who live alone in the community, with family carers and professional care staff around them. 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, and give it up when the person with dementia dies or moves to residential care if they have deteriorated to a point where they can no longer manage at home. The length of time family users make use of the system is potentially much longer if they were to be introduced to it earlier, but usually their introduction is at the point at which statutory services have already become involved. The system is re-used by many clients and this varies between four and 12 times a year. This often depends on the type of team involved in using the system – for example,
intermediate care teams tend to limit the time the service is offered (for example, six weeks), so JC is removed at the end of the intermediate care period. If a person requires on-going care, they will be referred to an on-going community service, while the JKit is reused by the intermediate care team for the next client.

The systems are used regularly by health and social care staff, so the numbers of people who have been involved in using the service is difficult to calculate. However, 132 out of 205 UK councils with social services responsibilities are currently using JC, so this figure can be assumed to be very high. Only an approximated calculation of care assessments has been carried out and this is thought to be around 9,000 assessments.

As the JC system is a self-install kit (pictured below), with internet based log-in to view charts, the service can be offered to many people and used very widely. Installation is straightforward, with door sensors easily 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. This makes the system highly flexible for users. Users of the JC system (carers and/or care workers) require only access to the Internet to make use of an ‘authorised user’ part of the JC website and monitor the activities of the person they are caring for. This allows the system to be used by anyone familiar with standard computer software and Internet access, restricting few people from the service. Nevertheless, some users have been reported to be wary about operating the system, though these concerns are usually overcome by training, information and support provided with JC by an Assistive Technology support team based at JC. Once JC staff have provided useful data for care planning, users’ reservations are commonly put aside and the data convinces them of the benefits of JC.

No specific training is given to informal carers in the use of JC. The icons and techniques used on the system’s website are common with many websites and intuitive to use if a person is familiar with websites. Given that most family carers seem to be in 45-65 age group, and many are working, there is little problem with familiarity with websites. If someone does not wish to use a website they are unlikely to use JC. Some practitioners occasionally print off charts to share with family members without Internet access in a care assessment follow-up meeting. Interpreting the chart poses no problem to those who have some knowledge of the person – for example, a family member or practitioner working with the family.
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 tailored 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 using the system with their relatives. Health and social care staff use it for assessment as part of their job12 (professional users), so family users often get what amounts to a free trial before they decide to buy the system. Some professionals are happy to provide details about JC if they are using it for assessments. Others, however, are cautious about being seen to recommend a commercial service. In memory clinics, there is a very unclear picture; although there is an expectation that points of contact here should have a role in signposting useful information/services, there is a lack of ethos of promoting services (other than what can be provided by the memory clinic itself), and no active seeking of up-to-date information. These clinics tend to be staffed by health staff who are used to rationing scarce resources among the large groups of potential service users. Third sector organisations – e.g., Alzheimer’s Society – have also been cautious about promoting information about commercial offerings such as JC. Therefore, although the system is offered by some professional organisations, as well as by JC itself, there remain barriers to overcome before it is commonly recommended by all social care organisations.

During its period of development, the JC system had has to overcome a number of difficulties. One problem related to workers being concerned about the way that data could potentially be misinterpreted. For instance, the data might suggest that someone was accessing a kitchen or bathroom, but this does not necessarily mean that they were eating, drinking or managing their personal care at these times. Similarly, if the JC system showed someone leaving the house, this would not necessarily mean that it is ‘risky’ behaviour. Nevertheless, with increasing experience with the JC system, service users felt that their confidence in data interpretation also grew. The system was felt to be especially good for

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12 Each local authority or NHS trust has their own care assessment protocol, although some have shared information with others in this regard. There is not much evidence of involving informal carers in drawing up the protocol, though each local authority has an overall approach on involving informal carers. It has been observed that informal carers are generally involved in the assessment process itself, and the JC charts are certainly shared with them.
detecting absences from home and also any unusual patterns of movement within the home. However, when someone was more active, it proved more difficult to interpret the data, with a variety of possibilities available to make sense of regular movement around the home.

Users have claimed to check the data daily when it was first installed, but less regularly after this early period; however, this practice could vary. All discussed the inappropriateness of using JC as an alert system, unless other systems were in place to respond to any problems arising. Some key workers feel that more than one worker should always look at the data to assist interpretation, but this raised the question of who should have access to this data. There is also a concern about data ‘overload’ if the number of systems in use were to increase greatly.

Some users have noted that it might be helpful to use JC at an earlier stage in assessment and care planning processes, despite current guidance suggesting that the system should be considered only after all other options have been explored. More experience with JC may be needed before it is possible to develop comprehensive guidance on when JC can be most useful. It is also felt that expertise in working with dementia was an essential skill among staff seeking to recommend or implement the JC system. Additionally, staff should establish trust and rapport with the service user prior to implementing the system.

Users have expressed a number of concerns about the use of the JC system. One concern relates to whether workers who are more risk averse than others might use JC data as a reason for proposing inappropriately restrictive services or recommendations for the service user, such as premature residential care placements.

Concerns about the ethical implications of the JC system may have an impact on some users’ attitudes towards using the system. These concerns include fears that JC might be used by families to monitor their relative, something regarded as inappropriate when care of the person is clearly the priority. However, this is not a clear-cut point, with some finding, after using the system, that such monitoring offers relatives greater ‘peace of mind’, leaving them secure in the knowledge that the cared for person is safe, and also allowing them freedom to participate in otherwise restricted areas of their lives, such as employment and recreation. As stated above, it was a common experience for users of the system to grow more comfortable with its monitoring aspects once benefits for the cared for person had been demonstrated (University of Nottingham/Nottinghamshire County Council, 2010).

**OPERATIONAL INFORMATION**

Recently, JC made a profit for the first time, in its 5th year of operation. Calculations have been made on a return on investment in setting up the initiative, though these are presently available to shareholders only. It is assumed by the proprietor that JC would not sell if it did not bring advantages to the purchasers. For professional users, it provides a comprehensive assessment tool, enabling support to be more effectively targeted and more efficient. For family users, it brings peace of mind and a means to manage the care of a
person with dementia in their own home, concentrating human input on social activity (rather than their making short ‘checking’ visits).

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. She also reports that she believes technology/ICT has a major role to play in future health and social care systems, and can be used to tackle major demographic challenges, especially for people in need of constant care supervision/monitoring (e.g., dementia patients and adults with learning difficulties).

**IMPACT ASSESSMENT**

JC has been widely evaluated, with trials and tests conducted in various parts of the UK (e.g., Warwickshire, Herefordshire, Staffordshire, Leeds and Nottinghamshire). Most of these evaluations were conducted by organisations independent of JC which were keen to seek cost-effective strategies for supporting service provision networks for older people. This fits in with the UK’s national policy-driven ‘personalisation’ agenda, where people in need of social care are encouraged to live for as long as possible in their own homes, to have choice and control, and dignity. These evaluations are discussed in some detail below.

In Warwickshire, over a period of nine months in 2006, JC was installed in the homes of six service users with dementia (Warwickshire County Council et al., 2006). The system was used by four care managers, two nurses and 11 family carers. Interviews with five staff, seven carers and one person with early stage dementia revealed a positive assessment, with carers and care workers gaining a better insight into how the condition affected the cared for person – e.g., the consistency of their daily and nightly patterns of activity. This had led to improved planning of care support packages, involving care worker visits at key periods during the day, when the cared for person would benefit from these most. One way in which the system offered carers confidence was in overcoming what they later identified as ‘unnecessary worries’ about the person they cared for. The behaviour of the cared for person at home alone was often imagined to be different from when the carer was in attendance, but the JC system showed them that it was manageable during these periods and that suitable care packages could help. Although limited in its scope (the sample of participants was rather low), early lessons from this evaluation informed the ‘roll out’ of the JC technology.

In Herefordshire (Herefordshire County Council and PCT, 2009), the JC system was deployed as part of an initiative which included specialist intermediate care, electronic falls monitoring and roving night staff. Residential admission rates were reduced by 43% in the pilot area of the county in the first three months. Six months later, of the first 39 users of the service, 78% were still living at home and two-thirds of those needed only low level on-going support13. One innovation in this location was the use of ‘smart’ mobile phone technology coupled with JC to access the web-based activity charts from any location.

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13 Caveat: the evaluation report does not include details on how many people were assessed in this scheme.
However, while the overall programme was claimed to be cost effective, the impact of JC (which was not used in every case) cannot be isolated from the other support provided. In Staffordshire, 21 installations were assessed (Department of Health, 2008). For 11 clients, care packages remained the same following JC monitoring and for ten they increased, with eight people entering residential care. One conclusion from this research is that JC can offer an alternative solution to residential/nursing care by monitoring risk and activating support when needed. At the time of this evaluation, the cost of a JC system was £14 per week, which was the equivalent of one hour’s home care. One night’s sitting service to support an assessment was £150m while one week in residential care/nursing home care was approximately £350 per week, and day Care was £60 per day. The report concluded that the cost effectiveness of JC was clear, estimating that the average saving for each of the clients who remained at home compared to admission to an institutional setting was £2,300 per week or £119,400 per annum.

In Leeds, a trial of JC and an evaluation was led by occupational therapists who utilised the system with 55 service users over the course of a year (Roworth-Gaunt et al, 2009). The evaluation found that JC was a powerful and effective assessment tool for people with dementia living alone in their own home. It improved the quality of assessment, and as a result, the outcomes for the service user. Support workers felt that the system provided a clearer picture of what was going on, and that this was helpful in scheduling their care visits, identifying risks, understanding behaviour (particularly the impact of restless nights and sleep patterns) and reducing the necessity for multiple ‘checking’ visits by carers and care workers.

The latest evaluation of JC was conducted in Nottinghamshire (University of Nottingham/Nottinghamshire County Council, 2010). 21 individuals, including 13 key workers and eight family carers were interviewed about their use of 30 installations. It was not possible to interview users of JC in this study, because it was found that, with one exception, the technology was only applied when people were judged to lack mental capacity. However, carers were approached via care workers, and for each carer interviewed about a relative, a staff member was also interviewed, enabling validation of findings. Although the number of participating individuals was limited, the depth of data emerging from this evaluation (qualitative interviews) renders it a useful addition to the literature on JC.

In some cases, where a service user is cognitively impaired and living alone, it was shown that there is ample evidence that JC offers support for informal carers and can assist care workers in planning formal care inputs, leading to greater confidence and more sustainable care packages. Early reservations about the system expressed by carers were also addressed; one carer put it this way:

“... you always think a bit “Big Brother”, don’t you? ... I was a little bit concerned about how it’d go and wondered whether it would flash red lights ... I was a bit worried that it would be a bit intrusive...”

However, experience of using the system overcame these concerns and carers’ initial wariness was eventually overcome in most cases.
Other carers, living remotely from the person they cared for, were also able to feel more secure in having immediate knowledge of the person’s whereabouts and activities. One care worker put it this way:

“... [the family member] liked it because she lived very far away so it actually gave her reassurance that this is alright [sic] and [the person cared for is] OK.”

Some carers even lived abroad and were fascinated by the information it provided and often checked it frequently. There was a risk of becoming overly reliant on the system to the exclusion of other sources of information and visits, but the data was nonetheless a great reassurance to distant family carers.

Among the carers with no access to data collected by JC, several felt that it would have been useful to monitor activity themselves. However, others were content if the care worker kept them informed, and felt that they did not need further information.

Several carers had considered purchasing JC themselves and expressed a willingness to have JC permanently installed as a means of monitoring their relative’s activities, feeling that it could provide reassurance 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.

Several carers felt that it would have been helpful to have had JC at an earlier stage in their relative’s illness; they had been struggling for some time before it was suggested. One carer felt that if it had been used earlier, her father might not have been inappropriately admitted to hospital on several occasions; his confusion and lethargy during the day was shown to be as a result of not sleeping at night rather than an underlying medical reason. The JC system, it was felt, could have identified this.

All these outcomes can be achieved at a relatively low cost per case. At the time of this evaluation, the average cost per hour of home care in Nottinghamshire was approximately £13, and the average annual cost of residential care as approximately £20,000 (2009 prices). In many cases, as was shown above, JC has helped reduce the number of home care visits and delay the necessity of admission to residential care, thus making cost savings in the social and healthcare systems. Therefore, the use of JC as a monitoring and assessment tool can be seen to have significant cost benefits.

Finally, telephone interviews conducted for the purposes of this case study with carers using JC revealed a number of ways in which the system could benefit them in their everyday lives while continuing to care for a relative. What follows are a number of illustrative comments from these interviews:

“Just Checking is a tool to provide me with some information as to the daily life patterns from a distance as I travel globally and extensively in my job. I am employed by my own company so make caring and work mix is much simpler in my case.”

– male carer
“Without the Just Checking system in my mother’s flat she would have been in residential care years ago. With the help of this system plus other technology in her flat we have been able to care for her in her own home which for somebody with Alzheimer’s is most important.”

– female carer

“I am a carer for my father who has Alzheimer’s and he lives alone. I am relatively young for a carer (37 years old) and have my own family (husband and two young children) and am healthy and active, leading a fulfilling life, but with the stresses of making sure my dad is well and cared for. It does not impact hugely on my life as the systems I have in place, including Just Checking makes me feel that Dad is safe and well whilst maintaining his independence and a level of quality to his life.”

– female carer

**SUMMARY**

This case study has presented a range of data on the social care initiative Just Checking and can be summarised thus:

- The purpose of the initiative is to help people in the early stage of dementia remain independent in their own homes.
- The system is easy to use and install, requiring only basic Internet skills and a mobile phone network.
- Its costs involve between £500 and £1000 for the equipment and weekly subscriptions of approximately 7. The system can be hired at approximately £70 per month.
- Informal carers and formal care workers benefit from the flexibility JC offers, including ‘peace of mind’ to pursue recreational and occupational activities, and the facilitation of care assessments.
- JC is very much an initiative in development, with such issues under consideration as: ethical concerns over its potentially intrusive nature; capacity to serve as a tool of intervention in care situations; who should have access to its data and where this should be stored.
- The system is already commonly used by a wide range of English local authorities, though its owners believed it has great potential for wider use.
- Independent evaluations have demonstrated that JC can: help carers feel more secure about the care they offer; can improve formal care assessment procedures; can result in costs savings for social and healthcare systems; can reduce/delay access to residential care.
REFERENCES


Platform for Caring Family Members
Plattform für pflegende Angehörige [original German name]

Andreas Stückler
European Centre for Social Welfare Policy and Research

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<tr>
<th>Website</th>
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Methodological note
All information used for this case study report have been retrieved from the initiative webpage and through interviews by mail with contact persons at the Austrian Federal Ministry of Labour, Social Affairs and Consumer Protection (BMASK) in March and in August 2011. Moreover, additional information was gathered through questionnaires to users of the initiative: contacts with these users have been predominantly ensured by an Austrian self-help group for family caregivers caring for people with dementia (Alzheimer Angehörige Austria, www.alzheimer-selbsthilfe.at). Further data have been gathered from publicly available documents: BMASK (2008a, 2008b).

DESCRIPTIVE INFORMATION
The platform for caring family members (“Platform für pflegende Angehörige”) was set-up in 2006 by the former Federal Ministry of Social Security and Generations (BMSG; now Federal Ministry of Labour, Social Affairs and Consumer Protection, BMASK) in addition to the “Pflegetelefon” (care hotline) that started its service in 1998.
The platform aims to support informal carers in accomplishing their everyday life affected by their care responsibilities by providing relevant information, especially in terms of 24 hour care and care allowance. It was designed as a day and night service, since flyers, information brochures as well as the care hotline are not always available for caregivers or people in need of care.
Another motivation for setting up the initiative has been the provision of support in cases of deficient interface management (in terms of a lack of linkage and communication among different support systems relevant for caregivers), the social integration of informal caregivers as well as facilitating exchange of experience among caregivers. The platform can be regarded as an additional service to the earlier established “Pflegetelefon”.

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Therefore, its main objective is to provide relevant basic information for people concerned with care that can be supplemented by continuative counselling by the “Pflegetelefon” if necessary.

**Target users**

The initiative targets informal carers from all main dependency scenarios: cohabiting, non-cohabiting caregivers as well as spouses caring for at least moderately impaired persons. As mentioned before, the main goal of the platform is the provision of information relevant for caregiving relatives who provide care for family members at home. Indeed, target users are most likely females, even older people caring for their spouses. Since the website is available in Slovakian language, the initiative also addresses migrant care workers, particularly Slovaks whose nationality represents one of the most frequent to be found in the field of 24 hour care in Austria. There is no valid information on user profiles provided by initiative’s web statistics. Also, the ministry is not able to provide data on potential “market size” of the online platform. As we will see later, the use of the online platform might correlate with the level of digital skills. In other words, at least a minimum of digital skills of the users may be a basic requirement for the use of the platform, and the helpfulness of the initiative, in this respect, a matter of adequate digital inclusion.

**Services provided and functions of ICT tools**

With regard to type of activities and services offered, the platform as an online information tool (and in addition to the existing care hotline) provides comprehensive information on diverse care-related issues available day and night: care allowance, counselling services (e.g. the care hotline provided by the ministry), several aids for everyday life (such as learning aids, special nursing beds etc.), 24 hour care and further services like “meals on wheels”, residential and nursing homes, hospice, self-help groups, therapies, relevant literature and publications. Moreover, there are several links (concerning administrations, social insurance etc.) and important forms for download (e.g. application for care allowance). Originally, the platform also offered a forum for exchange of experiences among caregivers. But it had to be shut down after a run-time of three years due to marginal use.

**Development methodology**

“Plattform für pflegende Angehörige” is an initiative by the Federal Ministry of Labour, Social Affairs and Consumer Protection. In November 2005, a care prevention work group with the involvement of internal and external experts was convened whose main concern was the creation of a comprehensive information offer for family caregivers. In 2006, the online platform was set-up in addition to the already existing care hotline. The care hotline
was established in 1998 as a counselling service addressing people in need of care, their relatives and all persons concerned with care and care-related problems. Particularly, it includes information on care allowance, privileged public pension scheme, opportunities for care in the own home environment, financial support or family hospice leave. The counselling offer of the care hotline can be used Austrian-wide, free of charge and confidentially on weekdays from 8 a.m. to 4 p.m. The limited availability of the care hotline was one of the main reasons for the ministry to set up the online platform. Using the online platform, caregivers are able to obtain information day and night anonymously without having to make a phone call within a predefined time window.

**OPERATIONAL INFORMATION**

As mentioned repeatedly, the platform started its service in 2006 as an initiative of the Federal Ministry of Social Affairs. The ministry has also provided a care hotline providing care-related information since 1998. In this respect, the online platform serves as an additional service to the care hotline.

**Funding, budget and personnel involved**

As an initiative established by the Austrian Federal Ministry of Social Affairs, the online platform is publicly funded. Funding of the initiative is temporally unlimited but of course the budget depends on the budget of the ministry in general. Detailed information on the initiative’s budget is not available since it cannot be calculated separately. The platform is operated and administrated by the staff of the ministry as one task among others, adapting the contents of the platform in regular intervals and keeping information provided up to
date. Thus, personnel costs, for instance, are not directly related to the platform but exclusively to the activities of the ministry as a whole. There is no information on how many people are involved in running the initiative. As mentioned above, the platform is maintained by employees of the Federal Ministry who keep the information provided up to date. With regard to sustainability, the initiative is actually unlimited. Future funding depends on the budget of the Ministry of Social Affairs in general. Concerning future activities, provision is made for the continuation of the established offer of information as well as the update of contents and the completion of missing information.

**Users**

The platform registers approximately 92,000 visits a year (2010). From January to August 2011, about 61,000 visits were registered. But these web statistics hardly facilitate the deduction of an adequate estimation of actual users the initiative is reaching. Data on potential “market size” is also not available since there is no official registry of informal caregivers or regularly updated statistical data available in Austria. In 2002, the Austrian central bureau of statistics (Statistik Austria) once conducted a special census survey on informal caregiving, indicating that in Austria approximately 425,000 persons older than 17 years were performing care for one or more family members or friends.\(^\text{14}\)

In principle, every person concerned with care in Austria provided with computer and internet connection as well as corresponding abilities to use these tools is potentially benefitting from this type of service. According to a statement of the ministry, about 80 percent of the Austrian population is using the internet. This is equivalent to approximately 5.7 million people.

Information on how users find out about the service is not provided by web statistics and thus not available. As for advertisement, the online platform is promoted in several publications and brochures by the ministry. Furthermore, there is a link to the platform on the front page of the ministry website. Information about the online platform can also be found on other websites related to health and care issues. For instance, the website of that self-help group the caregivers interviewed during this case study were recruited from provides a link to the “Plattform für pflegende Angehörige”.

**ENABLING CONDITIONS AND SUCCESS/Failure FACTORS**

Computer, internet access and sufficient digital skills are the most fundamental requirements to use the online platform. At large, the platform is well-structured and easy to handle for people who are habituated to use the internet regularly. But to benefit from this type of service, at least a minimum of digital skills is required.

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According to the contact persons from the ministry interviewed during the mapping phase (March 2011), there have been no important barriers or difficulties in setting up the initiative. But it appears that interactive functions like fora are in little demand. Thus, the primarily offered forum was discontinued because usage had been very low. Challenges for the provider particularly are the update of information and to adapt the contents on societal and policy developments. Also, it is an extensive task to keep external links up to date.

As far as people have internet connection and appropriate skills to use it, there are also no noteworthy barriers for users. Information on objections given by users are not available. With regard to the interviews with users of the platform (that are, of course, not representative due to small sample size), satisfaction with the service and the information provided by the platform seems to be rather high.

The decision to run this service can be situated in the Austrian care policy in general. Traditionally, care for older people in Austria – in contrast to, for instance, Scandinavian countries – is a responsibility that has to be beared by the families of care recipients. About 80% of care recipients are cared for by a family member. Care-related policy in Austria is, therefore, primarily focused on support (first and foremost in financial terms) of informal caregivers. In this respect, the provision of the information platform can be seen as another brick in the public caregiver support efforts. There is also a temporal correlation between the platform (set-up in 2006) and the legalisation of 24 hour care in Austria in 2007. This may particularly true for the provision of information in Slovakian language for migrant care workers.

As for the running of the service itself, comprehensive experiences in terms of specific information needs of informal caregivers were available for the development of the platform due to the “Pflegetelefon” established in 1998.

Failure factors have been already mentioned. Originally, the platform also included a forum for exchange of experiences among the caregivers. But it appears that this kind of service is in little demand, and after a run-time of three years this function was discontinued.

**IMPACT ASSESSMENT**

There has not been an explicit evaluation of the online platform so far. But according to the contact persons from the ministry, it can be assumed that the comprehensive information provided by the platform will enhance the knowledge of people concerned about care issues. For instance, there are information on care allowance, social and labour law-related security of caregivers (e.g. family hospice leave), 24 hour care, mobile social services, different care aids, therapies in case of domiciliary visits, courses and self-help groups, financial privileges and in-patient long-term care. Also, attention is drawn to respite offers such as leave for caring family members, short-term care, and grants for supporting of family caregivers. As a service offer, information on counselling offers of the BMASK, several aids, studies and publications, forms and relevant journals as well as interesting care-related links are available. All contents offered are updated continuously.
In this respect, the quality of life of the carer has to be seen as the core dimension of impact. Also, the platform is explicitly focused on caring family members and provides valuable and comprehensive information on several care-related issues. Considering the interviews with users of the platform, suppostitions made by the contact persons from the ministry appear to be rather confirmed. Information provided by the initiative seems to imply a considerable support for caregivers in their caring role. Satisfaction among the caregivers interviewed with the information offer of the platform is fairly high. They also indicated a rather high willingness to use the ICT tool. Probably, it has to be added that the majority of the interviewees valued their abilities and digital skills necessary to use the website as very sophisticated. This underlines the importance of digital inclusion. But – to say it again – the conduction of a handful of interviews does of course not provide any evidence on actual impact.

To a certain degree, there are further pillar dimensions – beyond the quality of life of caregivers – potentially relevant as the comprehensive information provided by the initiative might contribute to several dimensions. For instance, the platform might affect the caregiving provided by migrant care workers since the availability of the platform in Slovakian language explicitly addresses Slovaks active in the field of 24 hour care in Austria. In this respect, the quality of life of paid assistants and the quality of care they provide could be relevant as well as long as paid assistents have access to internet.

As all information provided by the platform – especially those on care allowance – potentially affects the quality of care performed by the caregiver, there might also be an impact on the quality of life of the dependent.

Being an additional service to the “Pflegetelefon”, a further impact of the platform might exist on organisational level insofar as it relieves the care hotline and in this way contributes to a reduction of workload. The platform provides basic information for caregivers that can be supplemented by continuative counselling by the “Pflegetelefon” if necessary. Therefore, the care hotline will usually be consulted only in more complicated cases that cannot be solved by means of basic information from the website, or by caregivers without internet connection or appropriate digital skills.

REFERENCES


INTRODUCTION

REACH (Resources for Enhancing Alzheimer’s Caregiver Health) is an American research program whose primary purpose is the development and testing of interventions designed to enhance the quality of life and ease the burden of family members caring for people with Alzheimer’s disease and related disorders. Established in 1995 and sponsored by the National Institute on Aging and the National Institute on Nursing Research, REACH was performed in two phases:

REACH I was designed as a multisite study implementing a variety of different interventions at six different sites. Each site developed and evaluated one home- or community-based intervention to support family caregivers in coping with the stresses by which caring for a person suffering from Alzheimer’s disease is attended. These interventions included information and support strategies, family systems therapy, psychoeducational trainings, home-based environmental interventions as well as advanced communication technologies.

Based on the results of REACH I, REACH II was targeted on assessing the efficacy of one specific intervention strategy and its impact on different stress-health components such as depression risk or caregiver’s burden. Depending on the needs of each individual, the
intervention involved a variety of strategies ranging from provision of information and role playing to skills training and stress management techniques, including 12 (predominantly in-home) sessions and 5 structured telephone support group sessions. A special focus of the REACH program lies on the inclusion of caregivers from race and ethnic minority families since these are populations not well represented in former intervention trials. The text at hand shall provide an overview on the REACH program, its interventions developed as well as key findings, particularly focusing on the role of ICT.

BACKGROUND

The establishment of the REACH program has to be considered against the background of the increasing number of people suffering from Alzheimer’s disease. Projections are that by the year 2050 14 millions Americans will be affected (Eisdorfer et al. 2003). Since the majority of these patients are cared for at home by family members, the challenges and responsibilities family caregivers are bearing become more and more the focus of attention. Caring for a family member with dementia is very time-consuming and places enormous demands. Quite often, as a consequence of their care responsibilities, caregivers also become increasingly isolated. Therefore, performing care is frequently experienced as burden and stress, not least affecting physical as well as mental health. For instance, caregivers appear to be at significantly higher risk for depression. Illnesses like that are not only harmful to the caregivers but also influence their ability to provide care or continue caring, and thus affect the quality of care they are providing as well as the quality of life of the care recipient. In this respect, the development of ways to support family caregivers in managing their daily activities and coping with their stresses of caring must be seen as a major public health challenge. The very development of ways to help caregivers of family members with Alzheimer’s disease and related disorders is the main objective of the REACH program.

REACH I

As mentioned before, the REACH program was performed in two phases. REACH I started in 1995, and REACH II – built upon the findings of REACH I – in 2001. The goal of REACH I was the testing of the effectiveness of multiple different interventions for family caregivers that were implemented at six different sites (Boston, Birmingham, Memphis, Miami, Palo Alto, and Philadelphia). These interventions included skills training for caregivers to cope with care-related stressors, automated telecare intervention, psychoeducational and psychosocial support (e.g. behaviour and mood management), family systems therapy designed to enhance family functioning and to reduce caregiver’s distress (additionally augmented by means of a computerised telephone system facilitating communication among therapists, caregivers etc.), as well as an environmental skill-
building program providing technical support for caregivers to modify the home in correspondence with caregivers’ and care recipients’ needs.

Effectiveness of each intervention was assessed by common measures on several indicators like caregiver’s mental health or well-being and depression at baseline and follow-ups at 6, 12, and 18 months. Furthermore, results from active interventions were compared to those from control groups including either a (telephone-based) minimal control condition or a usual care control condition. The former consisted of biweekly calls (monthly calls after the first 6 months of the study) providing caregivers with contact and support such as active listening and empathic comments by the interventionist. Usual care control condition included the provision of written information on dementia caregiving and referral resources.

The following table provides a description of REACH interventions and control conditions by site as well as an overview on site-specific outcomes:

As we can see, among all caregivers combined, active interventions were significantly more successful in reducing caregiver burden and thus superior to control conditions that simply included the provision of basic information and minimal telephone-based interventions. Also, the analysis shows differential results with regard to race/ethnicity, caregiver-care recipient relationship and gender. For instance, active interventions were superior especially for women but not for men.

*Family-based Structural Multi-system In-home Intervention (FSMII)*

Focusing on the role of ICT, interventions implemented by the Miami site are of special interest, particularly since the results indicate a higher impact of ICT-supported interventions on depression reported by caregivers relative to other interventions (Eisdorfer et al. 2003). As noted in the table above, the Miami site developed and evaluated a structural family therapy intervention (Structural Ecosystems Therapy – SET) whose goal was “to identify and restructure specific interactions within the family and between the family and other systems that may be linked to the caregiver’s burden” (ibid., p. 4).

In the initial sessions with the caregiver and his/her family members, family histories (particularly on the caregiving experience) were gathered by the therapist in order to establish therapeutic goals. Afterwards, the therapist assessed family interactions and determined problematic ones that might be targeted in treatment, aiming at enabling the caregiver, the care recipient and other family members to develop an understanding of family functioning and better collaborate in the caregiving effort.
<table>
<thead>
<tr>
<th>Site</th>
<th>Description of Active Interventions and Control Conditions</th>
<th>Site-Specific Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birmingham</td>
<td><strong>Skill Training Condition</strong> – Problem-solving training designed to increase caregivers’ ability to manage care recipients’ behavioral excess and deficits, and to increase caregivers’ ability to cope with these and other daily stressors. <strong>Control:</strong> Minimal Support Condition – Telephone-based intervention that provides caregivers with contact and support such as active listening and empathy and written information about dementia and caregiving.</td>
<td>Behavioral skills training intervention showed differential effects for African American and nonspouse caregivers with each of these groups showing greater benefits than comparison groups of White and spousal caregivers, respectively.</td>
</tr>
<tr>
<td>Boston</td>
<td><strong>REACH for TLC (Telephone Linked Computer) System</strong> – Telephone-based intervention designed to reduce caregiver stress. The system provides automated monitoring of caregiver stress levels, a voice-mail caregiver bulletin board, an ask-the-expert call option, and care recipient behavioral distraction to reduce disruptive behaviors. <strong>Control:</strong> Usual Care – Caregivers receive written information on dementia caregiving and referral resources.</td>
<td>Wives who exhibited low mastery and high anxiety benefited the most from an automated telecare intervention.</td>
</tr>
<tr>
<td>Memphis</td>
<td><strong>Behavior Care</strong> – Caregivers receive written information plus skills training and materials in patient behavior management (periodic consultations and phone calls with behavior management interventionist to manage care recipients’ behaviors). <strong>Enhanced Care</strong> – Caregivers receive written information and skills training plus behavioral modification strategies to decrease stress for the caregiver (relaxation training, coping strategies). <strong>Control:</strong> Usual Care (Information and Referral) – Caregivers receive written information on dementia caregiving and referral resources.</td>
<td>A long-term education intervention based in a primary care setting was effective in reducing caregiver stress and burden.</td>
</tr>
<tr>
<td>Miami</td>
<td><strong>Family-based Structural Multi-system In-home Intervention (FSMII)</strong> – In-home family systems therapy designed to reduce caregivers’ distress of managing and living with care recipient, and enhance family functioning. <strong>FSMII + Computer Telephone Integration System (CTIS)</strong> – Designed to augment FSMII with a computerized telephone system. The CTIS system is used to facilitate communication among the therapist, caregiver, family, and other support systems by providing messaging, conferencing, access to prestored information, and respite functions. <strong>Control:</strong> Minimal Support Condition – Telephone-based, minimal intervention that provides caregivers with contact and support such as active listening and empathy and written information about dementia and caregiving.</td>
<td>Caregivers in the combined family therapy and technology intervention experienced a significant reduction in depressive symptoms at 6 months. The 18-month follow-up data indicated that the intervention was particularly beneficial for Cuban American husbands and daughter caregivers.</td>
</tr>
<tr>
<td>Palo Alto</td>
<td><strong>Coping With Caregiving Class</strong> – Psychoeducational class designed to teach caregivers coping and mood management skills. <strong>Enhanced Support Group</strong> – Support group patterned after local community support groups (standardized meeting frequency, duration, length of time in group and educational materials). <strong>Control:</strong> Minimal Support Condition – Telephone-based, minimal intervention that provides caregivers with contact and support such as active listening and empathy and written information about dementia and caregiving.</td>
<td>Improved coping among female caregivers who participated in an intervention designed to enhance skills for managing distress.</td>
</tr>
<tr>
<td>Philadelphia</td>
<td><strong>Environmental Skill-building Program</strong> – Home-based intervention that provides caregivers with skills and technical support to modify the home to manage excess care recipient behaviors. Problem areas addressed may include managing ADLs, excess agitation, wandering or incontinence, and caregiver need for respite. <strong>Control:</strong> Usual Care – Caregivers receive written information on dementia caregiving and referral resources.</td>
<td>Environmental skill-building intervention resulted in less upset with memory-related behaviors and better affect in intervention caregivers when compared with individuals in the control condition. Also, women in intervention tended to benefit more than men did in areas of mastery and ability to manage daily caregiving tasks.</td>
</tr>
</tbody>
</table>

*Note: ADLs = activities of daily living*

*from Schulz et al. (2003)*
This intervention was compared to a minimal intervention control group (provision of short periodic telephone calls and information material about dementia) as well as to another comparison group provided with the same type of intervention that was augmented by an innovative Computer-Telephone Integrated System (CTIS). Via screen phones both text and voice could be sent and received during an interactive session, facilitating linkages of the caregivers with supportive resources outside the home environment. Moreover, family members, for instance, who were unable to attend sessions due to frailty or living out of town, were enabled to participate in therapy, and the therapist was able to get enhanced access to the caregivers and their family members.

The Miami sample included 225 family caregivers (114 Cuban American and 111 White American. Primary inclusion criterion was the provision of care for at least 6 months and for a minimum of 4 hours a day. The mean age of the caregivers was 69 years. 75% of them were women, 43% wives and 27% daughters. The core battery of measures focused on the presence of depressive symptoms (CES-D scale) as well as upset and burden with the presence of patient memory and behaviour problems (Revised Memory and Behavior Problems Checklist, RMBPC). Furthermore, caregivers' satisfaction with social support was measured.

The results indicated, overall, a significant decrease of reported depressive symptoms of subjects in the SET+CTIS condition at the 6-month follow-up (reduction of CES-D scores of over 5 points). With regard to ethnicity and caregiver-care recipient relationship, the intervention was particularly beneficial for Cuban American husband and daughter caregivers with a reduction of CES-D scores of over 5 points up to 6.5 points at the 6-month follow-up and still almost 5 points after 18 months, whereas, for instance, Cuban American wife caregivers experienced an increase of almost 4 points, and both White American husband and wife caregivers only minimal changes (6-month follow-up). In contrast, the Structural Ecosystems Therapy by itself (without CTIS) did not have significant effects on caregiver depression (ibid., p. 7 ff.).

_TLC (Telephone Linked Computer) System_

Also relevant, considering the role of ICT, is the automated telecare system implemented at the Boston site (Mahoney et al. 2003). That concerned a computer-mediated automated interactive voice response (IVR) intervention providing stress monitoring and counselling information on how to manage behavioural problems of the care recipient, a personal voice-mailbox for communication with experts such as nurses, a bulletin board (similar to a computer chat group) and automated activity-respite conversation. "In the IVR system, the caregiver heard a digitized human voice (...) that spoke a computer-mediated script. Caregivers responded to the questions and comments they heard by pressing designated numbers on their touch-tone key pad, such as 1 for yes and 2 for no" (ibid., p. 558). Stress monitoring took place in a weekly caregiver's conversation. The system narrator queried the caregiver about disturbing behaviours of the care recipient and offered tips to manage them. If the caregiver's stress level significantly increased, the system generated an alert. The personal mailbox allowed for anonymously sending and receiving confident
messages and in this way communicating with specialists who were able to directly answer caregiver’s questions. The bulleting board provided group voice mail and facilitated the posting of messages and the receiving of responses from other users. Finally, activity-respite-conversation as a feature of the IVR system means a “care recipient distraction module designed to reduce disruptive behaviors and to provide caregivers with respite time. When initiated by the caregiver, this module offered the care recipient a personalized pleasant conversation designed to engage the listener in a safe, comforting, and nondemanding activity” (ibid., p. 559).

With regard to sample design, 100 persons were participating in the study (49 in the technology intervention group, 51 in a usual care control group where caregivers solely received written information on dementia caregiving and referral resources). Inclusion criteria were the same as in the study explained above (caring for at least 6 months and for a minimum of 4 hours a day).

Main indicators used concerned the presence of depressive symptoms (CES-D scale), bothersome behaviour (RMBPC), anxious symptoms (State Anxiety Inventory, STAI) and caregivers’ mastery (Caregiver Mastery scale). As the results indicate, the intervention had, overall, no significant effects, neither on bother scores and depression scores nor state anxiety. But they suggest variations among participants with low levels of mastery compared with those with high levels. Participants with low to mid levels of mastery at baseline (up to 0.5 SD above the sample mean) experienced a greater decline in bother scores (p = .040) and in depressive (p = .007) as well as anxious symptoms (p = .012) over the 18-month study period, whereas there were no significant differences between changes in study outcomes for persons at high mastery level (p > .05). In particular, wife caregivers exhibiting low mastery and high anxiety seemed to benefit most from this type of intervention (ibid., p. 562 f.).

REACH II

Based on the findings of REACH I, especially with regard to the important role ICT might play in the enhancement of caregivers’ quality of life, particularly in the reduction of depressive symptoms, REACH II was established in 2001.

Unlike REACH I, REACH II did not intend to develop and evaluate different types of interventions but rather focused on the development of a singular intervention strategy to be tested by means of randomized clinical trials at 5 different sites.

As the REACH I study suggested, caregiving places multiple challenges that are not easy to address, and a “one size fits all” approach to caregiver interventions is likely to be ineffective. Therefore, the intervention was designed multi-component, ranging from the provision of information, didactic instruction, role playing, problem solving, skills training, stress management techniques, and telephone support groups (Belle et al. 2006).

All these strategies aimed to enhance caregivers’ emotional well-being and skills for mood management (and thus decrease their risk of depression), enhance caregiver skills for managing the burden of care, enhance self-care behaviours, emotional and social support, and caregiver ability to manage care recipient problem behaviours.
The sample included 642 participants, each a third White, Black/African American and Hispanic/Latino. Depending on the individual risk profile obtained from the baseline assessment, the intervention was tailored to meet the specific and typically varying needs of the caregivers.

The assessment included caregiver depression (CES-D scale), caregiver burden (Zarit Caregiver Burden Interview), self-care (focusing on the caregiver's diligence in looking after his or her own health), social support (assessing received support, satisfaction with support and negative interactions or support), and care recipient problem behaviours (again RMBPC). Each intervention occurred over 6 months and was followed by a new assessment in order to measure the intervention's effect on these domains. Interventions included 12 sessions (9 in-home sessions and 3 telephone sessions) and 5 structured telephone group sessions. Participants were supplied with resource notebooks containing educational material about dementia, taking care of oneself and other relevant areas, and with screen phones linked to a computer-integrated telephone system facilitating group support conference calling.

Intervention visits intended “to develop the caregiver's ability to assess and manage care recipient problem behaviors and manage their own stress and emotional well-being. The interventionist and caregiver jointly engaged in a problem-solving process (...) to find effective and workable solutions to problem behaviors identified” (ibid., p. 731). Additional telephone-based support group sessions were designed “to reinforce the information or training presented during the one-on-one intervention sessions and to provide caregivers with an opportunity to interact with other caregivers and express their feelings and concerns” (ibid.).

As a main result, REACH II shows a significantly greater improvement in quality of life of caregivers in the intervention group than of those in the control group who were simply provided with information materials about dementia and Alzheimer's disease, caregiving, safety, and community resources. In particular, prevalence of clinical depression was lower (12.6% in the intervention group versus 22.7% in the control group, p = .001).

Moreover, there were differential results with regard to race/ethnicity and caregiver-care recipient relationship: obviously, Hispanics and White benefit more from REACH interventions than Black/African-American caregivers. Among Hispanics, net improvement across all 5 domains was greater in the intervention group than in the control group (45.1% versus 6.9%, that is a difference of 38.2 percent points). For White American caregivers this difference in net improvement adds up to 24.5 percent points, whereas for Black/African American persons there were no clinically significant effects found except for black spouse caregivers (net improvement difference 62.7 percent points) suggesting differential effects with regard to caregiver-care recipient relationship. However, no other statistically significant effects for caregiver-care recipient relationship were found (Belle et al. 2006).
SUMMARY

A number of interventions for family caregivers developed and assessed during the REACH studies are based on different types of ICT:

- REACH I included an automated telecare system and a structural family therapy intervention augmented by a Computer-Telephone Integrated System (CTIS). The automated telecare system implemented at the Boston site was designed to support caregivers in managing problem behaviours of care recipients related to Alzheimer’s disease. By means of a computer-mediated automated interactive voice response (IVR) intervention providing caregivers with stress monitoring and counselling information, a voice-mail caregiver bulletin board, an ask-the-expert call option, and a care recipient distraction module to reduce disruptive behaviours. This type of intervention obtained great improvements particularly for wives exhibiting low mastery and high anxiety.

- At the Miami site, an in-home family systems therapy was implemented in order to reduce caregivers’ distress and enhance family functioning. As the study showed, the therapy intervention had a greater impact if it was augmented by an innovative Computer-Telephone Integrated System (CTIS) including screen phones that enabled enhanced access for the interventionist to the caregivers and their families, and allowed people for attending the therapy sessions who would otherwise not be able to attend, for instance in case of frailty or not living nearby. The greater impact consisted in a significant reduction of depressive symptoms, especially for Cuban American husbands and daughter caregivers.

- The intervention developed during REACH II comprised of a number of in-home sessions intending to develop the caregiver’s ability to manage care recipient problem behaviors as well as their own stress and well-being by means of different strategies that are tailored to the special needs of the caregivers. Additionally, a computer-integrated telephone system (like the one at REACH I) was applied. It facilitated group conference calling and interaction among caregivers. Beneficiaries of this type of intervention were particularly spouses and Hispanics as well as white caregivers whereas African-American caregivers and nonspouses did not appear to show similar improvements in the enhancement of caregivers’ quality of life.

There is no information available if REACH interventions have been adopted beyond the experimental situation by now or practically applied in terms of initiatives like those investigated during the CARICT project. Also, the sources used for the report at hand do not contain any data on the costs being attended by the implementation of REACH interventions. A NREPP report (SAMHSA’s National Registry of Evidence-based Programs and Practices) reviewing the REACH II project indicates estimations on implementation costs of about $1,212 per caregiver-care recipient pair, including $1,064 for the in-home intervention components and $148 for telephone support.\textsuperscript{15}

\textsuperscript{15} http://nrepp.samhsa.gov/ViewIntervention.aspx?id=129 (last access: 15 October 2011).
REFERENCES


SOPHIA
SOziale Personenbetreuung – Hilfen im Alltag

Andreas Stückler
European Centre for Social Welfare Policy and Research

**Methodological note**
Unless differently specified, all information used for this case study report has been retrieved from the SOPHIA websites and from an interview with Martina Saalmüller, head of the SOPHIA service centre in Bamberg (SOPHIA Franken). Further evidence is available in publicly available reports: Empirica, WRC & TUW (2010), Mollenkopf et al. (2010).

**DESCRIPTIVE INFORMATION**
SOPHIA is an acronym standing for “SOziale Personenbetreuung – Hilfen im Alltag” (“social personal assistance and help in everyday life”). Emerging from a previous pilot project, the SOPHIA holding was founded in 2005 and operates in five German states by now. The aim of the initiative is the provision of support for people with limited mobility and the enabling of a safer and more autonomous life in their own home environment. The initiative tries to relieve them and their relatives of a lot of sorrows like: Who is helping in the case of emergency? Who is taking over those tasks that are hard to handle for older or disabled people? And where to find personal assistance?

The main characteristic of SOPHIA is that it responds to all those needs by combining personal assistance with the use of easy to handle and intelligent communication tools. The heart of its support system is the SOPHIA service centre. The assistance for its customers is predominantly provided by voluntary godparents who make regular phone calls, reminding their “fosterlings” of taking medication or just chatting with them and informing them about leisure time facilities in their neighbourhood.

Additionally, professional staff fulfils an advisory function, e.g. giving advice on the adaption of living space or providing support in dealing with formalities in terms of public
health care. Furthermore, SOPHIA conveys – on demand – different services like nursing services, craftsmen or shopping assistance services.

Beyond qualified personal support and facilitation of human relations and social contacts provided by volunteers, safety in the own home is the core element of SOPHIA by applying intelligent and convenient technologies, especially social alarm systems. These enable persons with a higher need of safety to call for help by pressing an emergency button on a wristband or on special mobile phones. Until recently, SOPHIA also provided video communication systems facilitating image communication via television set with the SOPHIA service centre as well as with the customer’s next of kin.

SOPHIA is focused on the provision of support for people with limited mobility and a higher need of safety, particularly for older people but also for people with disabilities in general. Its main objective can be seen as to enable them to stay as long as possible in their own home environment and to avoid (or at least delay) institutionalisation. Certainly, services provided by SOPHIA are potentially attended by a relief for informal carers, at least in less severe cases of dependency. But considering the focusing of SOPHIA, these potential outcomes are more or less side effects. There is no data available on family caregivers, since the customers of SOPHIA are exclusively the users, that is the older people themselves. It is not documented if a user is cared for at home by a family member. But it can be stated that in many cases – according to the SOPHIA project coordinator – SOPHIA draws attention of relatives who want to make sure that their father or mother is provided and safe, and thus the service is put across to users by their next of kin. Hence, a benefit for informal caregivers is obvious but impact on caregivers has not been measured by now, so there is no clear evidence yet. The primer intention of SOPHIA is, however, the facilitation of a more independent and autonomous life of people with limited mobility who would otherwise have to be cared for by their relatives to an increased extent or even leave their home environment and move to a home for elderly.

**Target users**

The main target user group of SOPHIA are elderly with limited mobility but little or at most moderately need of care. Those people are able to live a comparatively independent, autonomous life despite age- and health-related restrictions and want to stay in their own homes as long as possible. Also, SOPHIA serves as a supplement to assisted living or mobile care services. New customers of SOPHIA are interviewed at the beginning about health-related issues like medication or the like that might be important for the handling of emergency calls. With regard to user profiles, it can be stated that SOPHIA is significantly more used by women. Income level is no variable requested in these interviews since it is not of interest for the initiative. As far as the SOPHIA project coordinator is able to estimate, SOPHIA is used by persons from several income groups. Furthermore, there is a support association providing an allowance for poor to cope with the costs of the social alarm system.

Apart from elderly, the service provided by SOPHIA is used by disabled people in general, regardless of age.
As noted above, there is no clear evidence that SOPHIA creates outcomes for informal caregivers. Of course they are potentially benefitting from such an initiative but the impact of the initiative on family caregivers is still to be assessed. At the moment, this report has to rely on estimations made by the SOPHIA initiative coordinator. According to her, the benefit for family members lies in the fact, that they, for instance, can go on holiday without any bad conscience or being anxious about their loved ones. They feel certain that the older person is able to easily make an emergency call if necessary and will not be lying helplessly in their home after a fall or a collapse. Moreover, the project coordinator supposes a potentially positive effect on the professional life of people concerned if their parents are supported in living an independent life and if there is no need to look after them permanently. It implies also a relief for older people if they feel confident that there is no need to bother their relatives with all their everyday problems. In this respect, as the initiative coordinator said, family members are a not primarily focused target group but not an unexpected one either. The benefit of family members is inherent in the objective of SOPHIA: a more independent life of elderly contributes to a prevention or at least to a delay of dependence on care. For people who are already performing care – in case of little or moderate need of care – SOPHIA might ease their burden insofar as they can leave the house for some time, e.g. to go shopping or even to go out at times, which adds to an improvement of social life. But – to repeat it – all these “impacts” on family members and caregivers are estimations concerning potential effects expressed by the initiative coordinator during the interview that still have to be verified (or falsified) by means of an in-depth impact assessment.

Services provided and functions of ICT tools

As mentioned at the outset, SOPHIA is an initiative responding to particular needs of people limited in their mobility and enabling them to stay at their own home environment as long as possible. It combines social personal support provided by volunteers and professionals with application of ICT technologies. The most important ICT-based service offered by SOPHIA is the “safety wristband”. This is a social alarm system allowing for getting connected with the SOPHIA emergency centre by pressing an emergency button on a wristband in case people are feeling dizzy or they have been falling. The wristband is waterproof and can therefore be used in the shower or in the bath tub too. As a special function, the wristband documents the activity of the participants and identifies sleep/wake cycles. Thus, it is able to register motionlessness off their habits and daily routines. On the basis of these data, individual help can be organised. For instance, the analysis of activity trajectories may be relevant for relatives and caregivers as well as for
professional care services insofar as irregular sleep/wake cycles indicate a beginning dementia.

As a service of similar type, SOPHIA offers a GPS mobile phone with an emergency button to automatically sound an alarm in the SOPHIA emergency call centre. GPS allows for locating the participant and rapidly inducing emergency measures. Therefore, this tool provides safety when people are outside their home environment, e.g. for a walk.

A further social alarm tool offered by SOPHIA is a GSM emergency call device, applicable in particular for short-time use, e.g. when relatives are on holiday or after returning from hospital. It is also useful in case of no analogue telephone connection available.

Originally the main ICT tool offered, SOPHIA (until recently) also provided a video communication system. It facilitated image communication by means of a television set including a videophone function. In this way, people were able to make phone calls and at the same time see their conversational partner on the screen. This ICT tool was designed as a service particularly for people with limited mobility who – due to age- or health-related restrictions – have to stay at home most of the time and are more or less isolated. Often, their children or other relatives live quite far away, and social contacts are often scarce. Using the SOPHIA videophone system, the relatives or the user's godparent from SOPHIA were able to “drop in” and have a talk with him/her, certainly provided that the user wanted them to. The service also included a user-friendly remote control with big and lighted buttons which was used both for operating the normal TV-set and the video communication system. As it will be described later in detail, the image communication tool encountered low acceptance by the users. For this reason, this type of service had to be discontinued recently whereas the safety wristband represents the most frequent demanded service tool provided by SOPHIA. Video communication appears to be too complicated or too “technical” for the mainly older users.

At present, SOPHIA offers two different service packages and several additional services described in the list below. Costs have to be paid by the users. In case of allowed care level, costs are partly accepted by public health care. There is also a support association providing allowances for people in need.

Before video communication was excluded from the range of services, SOPHIA offered two further packages: SOPHIA Kontakt (contact package) including the video communication system (plus the basic services) and SOPHIA Komfort (comfort package) combining the services of the basic package, the safety package as well as the contact package.
<table>
<thead>
<tr>
<th>SOPHIA packages</th>
<th>Services included</th>
<th>Price</th>
</tr>
</thead>
</table>
| SOPHIA Basis (basic package)    | • 24h service of the SOPHIA service centre via telephone  
• regular phone calls from SOPHIA team  
• support with search for general services and home services | €18,90 / €20,90 per month<sup>1</sup>       |
| SOPHIA Sicherheit (safety package) | • All services of the Basic package  
• Social alarm system (by Vivago) via intelligent security wristband and follow-up care service (e.g. phone call). | €29,90 / €32,80 per month<sup>2</sup>       |
| SOPHIA Wohnungs-Sicherheit (safety in the home) | • Alarm in case of smoke/fire, water or heat  
• Panic button | Price varies and must be paid extra                        |
| SOPHIA GPS          | • All services of the basic package  
• Mobile phone for emergency calls to the SOPHIA service centre, relatives and friends by pushing a button.  
• GPS technology allows for exact location of the user.  
• Including mobile phone contract. Minimum contract duration: 6 months | €34.90 per month plus phone call costs<sup>3</sup> |
| SOPHIA GSM | • A GSM emergency call device for fast and short-term use |                                             |

<sup>1</sup> Prices vary among SOPHIA providers. Excluding start-up cost of €100  
<sup>2</sup> Fees vary among SOPHIA providers. Excluding installation fee varying between €40 and €100. In case of allowed care level, costs up to €18.36 are accepted by public health care.  
<sup>3</sup> Excluding €49.80 installation fee. Only available in combination with one of the SOPHIA packages (Basis or Sicherheit)

**Development methodology**

SOPHIA emerges from a pilot project by the "Joseph Foundation", started in 2002 and funded by the German federal government and the regional government of Bavaria in Bamberg. The project’s objective was a “virtual home for elderly” in terms of an ICT-based assisted living service. By means of a special TV set serving as a videophone – as mentioned above –, services should be put across to people with limited mobility. Furthermore, participants should have the opportunity to easily get in touch with staff of the SOPHIA service centre as well as with their relatives. Using the video communication system, they should be able to have conversations and at the same time see the person they were talking with on the screen. However, acceptance of this tool was quite low, and as a result SOPHIA focused more and more on social alarm services. Meanwhile, the offering of this image communication tool has been totally ceased. The low acceptance of image communication is traced back by the initiative coordinator to a certain
dread or dissociation from innovative technologies due to the old age of the users. The mean age of users is more than 80 years, and it appears that everything beyond the pushing of an emergency button overstrains them (at least psychologically) or is too complicated. Another reason might lie in the visibleness that is necessarily attended by this kind of service. The advantage of seeing the person communicating with on the screen can, on the other hand, be perceived as an intrusion into the privacy. When the older person's godparent from SOPHIA is calling on the videophone he or she is able to look – at least partly – into the user's living room. For some people, this is an unpleasant fact. Probably, this is particularly the case with elderly. Obviously, this kind of ICT support is, in a way, ahead of the times and has entered the market too early. Finally, a third reason might simply be the costs. The SOPHIA package including video communication was significantly more expensive than the safety wristband – perhaps too expensive for older people who often hold small pensions.

By now, SOPHIA predominantly offers social alarm systems, such as the safety wristband, a special GPS mobile phone with emergency button or a GSM emergency call device (based on mobile telephone system). The safety wristband is also able to identify sleep/wake cycles of the participants. Further functions envisaged for the future in order to improve the service provided by SOPHIA are a fall detector and a heart rate monitor.

**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. Until now, SOPHIA is operating in Franken (Northern Bavaria), Nordrhein-Westfalen, Southern Bavaria, Hessen, and Berlin/Brandenburg.

2004 Set-up of SOPHIA Franken  
2006 Start of SOPHIA service centre in Nordrhein-Wesfalen  
2007 Start of SOPHIA service centres in Southern Bavaria (Holzkirchen) and Berlin  
2008 Start of SOPHIA service centre in Hessen

How do people get knowledge about SOPHIA and the service it provides? The majority of users are placed by housing companies and nursing services cooperating with SOPHIA. SOPHIA is also recommended to potential users by physicians or nursing services. The initiative also advertises by means of flyers that are specifically forwarded to social and nursing services, hospitals and pharmacies. And not least, there are several SOPHIA websites providing detailed information about the services offered.

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**Budget and funding**

SOPHIA is exclusively funded by user fees and franchising with several project partners (predominantly housing companies and nursing services – as described in the next chapter). Fees have to be paid by the users. In case of allowed care level, costs are partly accepted by public health care. A considerable role in sustaining the service offered by SOPHIA belongs to volunteers who are the beating heart of the SOPHIA service centres by acting as godparents of the users and providing valuable personal support.

The bigger part of current costs documented is accounted for the financing of ICT devices like safety wristbands or special mobile phones.

**Stakeholders’ involvement**

The most important stakeholders are housing companies and nursing services cooperating with SOPHIA by means of franchising. The idea behind SOPHIA attracted wide interest, and so it didn’t take long until the foregoing pilot project was financially backed by several public institutions. In 2005, the SOPHIA holding was jointly founded with the Bavarian housing company THS Wohnen GmbH. The service provided by SOPHIA is relevant for the housing industry, since it – with regard to the proceeding demographic change – represents an ideal amendment of their housing offer. Housing companies in the first instance want to be attractive for tenants and to „keep“ them as long as possible. SOPHIA contributes to that insofar as its services attract people with a higher need of safety, particularly older people. And if they feel safe in their home environment, this helps avoiding a high fluctuation of tenants.

Since the aim of SOPHIA is the assistance of impaired people who want to stay in their home environment as long as possible and to keep up an independent and autonomous way of life, its service is, of course, also of special interest for nursing services. By way of example, there are cooperations with institutions like Caritas or Diakonie.

**Personnel involved**

As information is mainly retrieved from an interview with the head of the SOPHIA service centre in Bamberg (Franken), this chapter is thus primarily focused on SOPHIA Franken. At present, SOPHIA Franken involves about 100 persons in running the service, whereupon 15 are formally employed and 85 are volunteers. The number of volunteers is continuously increasing. Volunteers come from different social backgrounds (housewives and nurses as well as university graduates) and are predominantly female (approx. 75%). Ages range from 30 to 80 years, but the majority of volunteers is 55 and older. As described above, volunteers play an important role as godparents providing personal support by phone, seeing their “fosterlings“ at regular intervals, accompanying them to the doctor or helping them with shopping. Their main tasks are related to human relations and social contacts. Formal
employed personnel is predominantly concerned with administration, follow-up care of emergency alarms as well as professional counselling of users (e.g. in terms of public health care).

There are no special skills required for volunteers. What they need is a little empathy and a sense for the needs of older people. After a phase of sitting in on, a volunteer gets referred to a user in order to make regular phone calls. Of course, it is possible to change, for instance if a woman prefers to be provided by a female instead of a male. There are no specific trainings for volunteers but in periodic meetings they have the opportunity to exchange experiences as well as to be trained on several issues like common age-related diseases or strategies for coping with bereavement (particularly relevant when a user’s spouse has recently died).

**Users**

In the region SOPHIA Franken is operating, approximately 1,450 participants are currently using the services provided, especially the safety wristband. Throughout Germany, the number of users amounts to about 3500. The potential “market size” for this kind of service extends in principle to all people with limited mobility in all of Germany who want to stay in their home environment as long as possible despite some age- or health-related restrictions. Detailed information on total potential market size is not available, thus relation of total population SOPHIA is targeting and people using its services cannot be defined at this point. A basic condition for further growth of SOPHIA is an adequate number and a nationwide availability of potential project partners, in particular nursing services, cooperating with SOPHIA.

With regard to “drop-out rates”, it can be stated that about 25 persons per month (in Franken) stop using the service, mainly due to death or relocation to a care home. Cancellations as a consequence of dissociation from or not getting along with the ICT tools offered are rather scarce. Backwards, the increase of users adds up to 40 to 50 persons per month.

**Requirements for usage**

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 system. On rare occasions, there are problems on the countryside if there is neither analogue telephone connection nor mobile telephone system available. Technical skills are not required. Users have only to press an emergency button to get connected with the SOPHIA service centre. In the course of a counselling interview, the devices and their functions are demonstrated to the participants. Also, the technician who is finally installing the social alarm system shows them how to use the tools and, for instance, how to change or recharge the batteries.

According to the SOPHIA project coordinator interviewed, the handling of the video communication tool which had to be ceased due to low acceptance was not more
complicated than the safety wristband. It was operated like a conventional TV-set, and the remote control was very user-friendly with big buttons. However, it seemed too demanding for the mainly older users, and the service was discontinued.

ENABLING CONDITIONS AND SUCCESS/FAILURE FACTORS

Failure factors have been already mentioned in the course of this report. Video communication, originally the main ICT tool offered, did not work with regard to user acceptance, and in further consequence SOPHIA focused on social alarm systems. As mentioned repeatedly, the most important lesson learnt is the low acceptance of video communication which originally had been the main technology applied by SOPHIA and had finally to be discontinued. Obviously, the target user group – predominantly older people – is not prepared for this type of service at present. Thus, in the course of time, SOPHIA more and more focused on the provision of social alarm services. Apart from the fact video communication did not prove itself, there are no notable objections given by users or potential users. A significant reason for satisfaction of the users might be the personal assistance provided by voluntary godparents. As the head of the SOPHIA service centre stated during the interview, most users come for the emergency alarm system but in the end the bigger part of their satisfaction is due to regular phone calls by volunteers from the SOPHIA service centre and, as a consequence thereof, to an improvement of elderlies’ social life.

As for enabling conditions to develop the initiative, the great public interest in the pilot project has been a very important factor. There were several public institutions taking a share in the funding of the initiative, e.g. the Federal Ministry of Health and Social Security or the Bavarian State Ministry of Labour, Social Affairs, Family and Women. Another important factor is the cooperation with the stakeholders, namely housing companies and nursing services. These also deliver valuable knowledge and expertise about the needs and wishes of older people. Not least, the initiative particularly benefits from the commitment of numerous volunteers. It is exactly the provision of regular personal contact by those which appears to be one of the most considerable success factors of SOPHIA.

IMPACT ASSESSMENT

Outcomes for carers/family members

As mentioned before, there is no evidence for outcomes for carers (or family members in general) since there has been no detailed impact assessment so far. SOPHIA is primarily focused on older people living alone and with a higher need of safety (see chapter “Target user groups”, p. 2). Impacts on family members and caregivers are in this respect more or less side-effects. The primary potential impact on family members – discussed during the interview with the SOPHIA coordinator – consists in a certain relief of sorrows: They do not have to worry about their father or mother living alone and to be anxious that he or she
could collapse and would have to lie helplessly in the home. By pressing the emergency button on the safety wristband he or she would be able to get help easily and rapidly. Family members, for instance, can go on holiday without any bad conscience, also due to the opportunity of short-time solutions like the GSM device offered by SOPHIA. Furthermore, this type of service might also contribute to the working life of relatives who would otherwise have to look after the older person more frequently or perhaps even have to exercise care responsibilities. Thus, SOPHIA impacts on (potential) caregivers insofar as the service provided facilitates a more independent and autonomous life of older people and in this way contributes to a delay of dependency on care. According to the initiative coordinator, it is in many cases the son or the daughter who come to know about SOPHIA and initiate the purchase of its service in order to make sure that their father or mother is provided.

In case of already performing care in little or at most moderately cases, the service provided by SOPHIA might also imply a relief. The burden of informal caregivers might be eased insofar as they are able to leave the house for some time, e.g. to go shopping or even to go out at times, which adds to an improvement of social life. Perhaps, it also enables caregivers to better reconcile care with work or go back to work at least part time. Basic prerequisite is a certain autonomy of the care recipient. In severe cases of dependency – for instance, if the care recipient is bedridden – SOPHIA and its services can hardly be of help.

Outcomes for dependents

The most relevant dimension of impact of the initiative is related to the quality of life of the care recipient. The main objective of SOPHIA is the provision of support for people with limited mobility, and thus for older people in particular. SOPHIA aims to enable them to stay as long as possible in their own home environment despite age- and health-related restrictions. Social alarm systems provided allow them for getting connected with the SOPHIA emergency centre by pressing an emergency button on a wristband or a mobile phone – a type of service that responds to a higher need of safety among this population group by providing easy-to-handle ICT tools. But the most positive effect SOPHIA is able to achieve, seems to concern rather the social life than the increased need of safety of older people. Often, older people have to stay at their homes most of the time due to limited mobility, and their children have to work and live quite far away. As a consequence, social contacts are very scarce. In this respect, the personal assistance provided by voluntary godparents contributes to a considerable improvement of social life of the elderly. According to the head of SOPHIA service centre interviewed, participants in many cases come for the emergency alarms, but finally their satisfaction with the services provided appears to be mainly a result of the regular contact and conversations with the volunteers from SOPHIA. She told about former participants who had to move to a care home, and when cancelling the service for that reason, explicitly presented compliments to their godparents. In any case, this kind of service might have a notable impact on the quality of life of older people.

Monetary outcomes
From a financial perspective, a detailed calculation of a return on investment is not available. SOPHIA does not envision itself as a primarily profit-oriented business company but rather as fulfilling a social mission. According to the initiative coordinator, SOPHIA is cost-effective and profitable (1-2% of business volume), and with regard to the still increasing interest in and to the ongoing growth of the initiative, future funding seems guaranteed.

Possible outcomes for stakeholders

As mentioned before, the most important stakeholders are housing companies as well as nursing services. The interest of housing companies in SOPHIA is rooted in the amendment the services provided by SOPHIA imply for their housing offer. Thus, the outcome for housing companies consists in the enhancement of services for their tenants. Data on return on investment is not available.

In the case of nursing services, SOPHIA contributes to a reduction of workload insofar as the SOPHIA service centre provides assistance in many everyday commodities that have not to be done by nursing services then.

FUTURE PERSPECTIVES

As already noted, sustainable funding appears to be guaranteed. SOPHIA is predominantly funded by user fees, and the demand for services as provided by SOPHIA is constantly high. Per month, the service centre of SOPHIA Franken registers between 40 and 50 new users. Activities envisaged for the future are the continuous improvement of technologies applied as well as of the existing service offer. For instance, the provision of further functions of the safety wristband is intended (fall detection and heart rate monitoring). Moreover, SOPHIA aims for growing further and establish more service centres in German regions where no SOPHIA services are available so far.

REFERENCES


“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 falls 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 support 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

Methodological note

DESCRIPTIVE INFORMATION

Population growth in Scotland is estimated to alter dramatically in the future, with the number of people of pensionable age\textsuperscript{17} projected to rise from 1.02 million in 2008 to 1.07

\textsuperscript{17} “Pensionable age is 65 for men, 60 for women until 2010; between 2010 and 2020 pensionable age for women increases to 65. Between 2024 and 2026 the pensionable age for both men and women increases to 66 and changes again, in two further steps, to 68 by 2046.” GROS, 2009: 4.
million in 2018 (an increase of 6 per cent) and projected to rise more rapidly after this period, reaching 1.34 million in 2033 (an increase of around 31 per cent compared to 2008) (GROS 2009). These increases will result in a greater need for appropriate health and social care, with nearly two thirds of people over the age of 65 suffering at least one limiting illness and over a quarter of people over 75 suffering two or more. Providing care for this growing number of people is likely to become problematic, with a greater emphasis on care given by family, friends and neighbours. New approaches are also likely to be adopted which can assist with the care provided by unpaid carers (Jarrold and Yeandle, 2009).

The Scottish government has acknowledged these challenges and developed a number of initiatives intended to tackle long term health and social care needs. The Joint Improvement Team (JIT) was established in 2004 to work with Scottish local partnerships in providing practical support and additional capacity to deliver better health and social care services, with a budget of approximately £70 million. Key issues for carers include carer involvement in service development, patient centred care, joint assessments of carers and their dependents, ‘joined up’ health and social care services, and the use of telecare in supporting clients and the care they provide/receive.

A significant component in a wider approach to tackling health and social care challenges, telecare has been identified as playing an important role in new models of service delivery, with the following potential benefits:

- enabling people to stay in their homes for longer
- reducing the need for home care
- delaying admissions to residential care
- reducing the number of hospital admissions
- reducing the number of delayed discharges from hospital

As well as helping to support carers and their dependents, telecare is also expected to lead to considerable cost savings in the health and social care system. Additionally, through active lobbying by Carers Scotland, the impact on carers has been built into the telecare development programme.

From 2006-2011, the JIT supported the development of telecare services through an initiative called the Telecare Development Programme (TDP), 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, 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

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18 For a full list of Scottish local partnerships, see Table 3.
• enhance innovation in telecare services

The TDP began in August 2006 and ended in March 2011. Of the £20.35 million invested, £2.75 million financed an innovation programme and met management costs, while the remainder was allocated to care partnerships, enabling service expansion. Each Scottish local partnership submitted a bid for funding for its own telecare project, based on a strategic plan. After allocation of funds, the JIT supported each local partnership to develop a telecare scheme, with a focus on innovative approaches to cater for local needs.

Since the TDP ended, the Scottish government acting with the Technology Strategy Board has announced a new telecare/telehealth initiative running from 2012-2015 called Delivering Assistive Living Lifestyles at Scale (DALLAS), with NHS24/Scottish Centre for Telehealth and Telecare 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.

OPERATIONAL INFORMATION

Some local partnerships had already implemented telecare services before accessing TDP funding, which had allowed them to use these funds to develop their service. Beale et al. (2009) cites the example of West Lothian, whose early commitment to telecare led to the installation of ‘smart technology’ in over 2,000 homes before 2006, allowing its TDP funding to be used to develop a mainstream telecare service. However, other partnerships, starting telecare projects ‘from scratch’, had experienced difficulties in implementing the service (such as delays). Differences between partnerships have also been ascribed to different levels of commitment from managers, with a high level of commitment commonly resulting in good progress (Newhaven Research, 2009).

The mainstreaming of telecare was part of the JIT’s funding strategy. Nevertheless, key stakeholder interviews by Jarrold and Yeandle (2009) reveal uncertainty about how telecare services would be resourced beyond 2011, with many claiming that this had hindered partnerships’ ability to develop their telecare activities. There had also been challenges involved in making ‘cultural changes’ conducive to mainstreaming telecare. Some interviewees in the Jarrold and Yeandle study felt there was resistance in the health and social care system to develop integrated models of telecare. Other key points emerging from these stakeholder interviews included:

• a lack of knowledge and awareness about telecare among health professionals, (particularly GPs)

19 NHS24 is a health advice and information service provided by NHS Scotland. Embedded within NHS24, the Scottish Centre for Telehealth and Telecare was established in 2006 to support the development of telehealth for clinical, managerial and educational purposes across Scotland. Its work involves operating across boundaries with industry, academia, local authorities and NHS Boards to develop recognised models for redesigning care.
20 For a comprehension review of this case, see Bowes and McColgan, 2006.
- resistance to telecare among some paid care workers
- a feeling that a lack of training and information about telecare was holding back developments

Similarly, a review conducted by Boddy and Henderson (2009) identified a number of common barriers to the expansion of telecare in Scotland, which included:

- lack of clarity around key local outcomes
- limited, inconsistent or poor project management
- lacklustre sponsorship/engagement by senior decision makers
- lack of buy-in from key stakeholders
- limited understanding and skills to implement service redesign

Acting on the assumption that these issues could become more acute as partnerships developed telecare services, the JIT used this information to inform additional guidance for local partnerships to draw upon when required (Boddy and Henderson, 2009). By contrast, Jarrold and Yeandle (2009) report that other stakeholders involved in delivering telecare services were happy with progress and reported systems already in place to effectively implement telecare solutions. What characterised successful approaches in this study was the way local partnerships had established independent policies for installing telecare and identifying target clients groups. Most interviewees felt the infrastructure for the implementation of telecare in Scotland was highly suitable. Nevertheless, although demand had proved manageable to date, interviewees expressed a concern that if demand grew, current staffing levels might need to be expanded to respond to it.

In a comprehensive assessment of telecare in Scotland, The Sergeant Review (2010) examined national and local developments. 31 of the 32 care partnerships in Scotland returned a questionnaire, providing a detailed picture of service provision; key findings included:

- all partnerships were attempting to move telecare services from a project basis to mainstream provision
- many partnerships were making progress towards integrating telecare into local service options
- there was a commitment to integrating telecare into wider service provision over the next five years

The Sergeant Review reported that the great majority of Scottish partnerships were using social services as the principal route for clients to access telecare services, and that many partnerships reported adapting social services assessment processes to include telecare (one had required staff to justify not using telecare). Other findings from this review included:
all partnerships were providing telecare services to older people and those with a diagnosis of dementia
all partnerships had explored the use of telecare to support a wider range of groups
almost all partnerships were making telecare services available to people with learning disabilities, including redesigning group home living venues

Despite many advances in the development of telecare services, partnerships in this review also reported a number of issues impeding progress, including:

- problems with supplier relationships and equipment reliability.
- difficulties in recruiting and training staff
- lack of engagement among 'stakeholders' in the implementation process
- limited commitment to telecare from senior management
- largely undeveloped local performance management systems.

**Numbers of users and user engagement issues**

Across the TDP funding period, there was a gradual rise in new clients making use of telecare services in Scotland, though these were offset by other clients ceasing to use the service (because it was no longer needed or had proved unsuitable). Data available in the literature focuses on the cared for person, though it can be assumed that the great majority of these clients have carers actively involved in the care they receive and will make use telecare services on a daily basis (see below for assessment of impact on carers).

Data from the annual Newhaven Review\(^{21}\) of telecare service development in Scotland reveals that from 2007 onwards, over 43,000 people accessed a telecare service, with more than 30,000 still receiving one in March 2011. For the period of 2010/11, over 14,000 new clients received a telecare service, though almost 6,000 people stopped receiving it. This means the growth in telecare service for this funding period was just over 8,400 new users (Newhaven Research, 2011).

**Table 1 TDP Funded Telecare Service Users**

<table>
<thead>
<tr>
<th></th>
<th>2007-8</th>
<th>2008-9</th>
<th>2009-10</th>
<th>2010-11</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Clients</td>
<td>7,902</td>
<td>8,580</td>
<td>12,807</td>
<td>14,376</td>
<td>43,665</td>
</tr>
<tr>
<td>Stopped</td>
<td>679</td>
<td>1,819</td>
<td>4,861</td>
<td>5,968</td>
<td>13,327</td>
</tr>
<tr>
<td>receiving a</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New clients</td>
<td>7,223</td>
<td>6,761</td>
<td>7,946</td>
<td>8,408</td>
<td>30,338</td>
</tr>
</tbody>
</table>


\(^{21}\) This research presents data on telecare development throughout the TDP funding period. It is based on quarterly reports submitted over the five year period by Scottish local care partnerships and incorporates findings from previous studies (York Health Economics Consortium; Newhaven Research, 2009; Newhaven Research, 2010) to demonstrate progress over the period 2006-11.
Fifty-five per cent of clients in 2010/11 were provided with a basic telecare service, while the remaining clients received an enhanced telecare service\(^2\) (these percentages were unchanged from 2009/10) (Newhaven Research, 2011).

Data on users of telecare services in Scotland reveals a number of key demographic issues. Table 2 summarises information on the care group profiles of those assisted through TDP funding in 2010/11, and compares this with data for previous years.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>TDP Client Demographic and Care Group Profiles (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>2007-8</td>
</tr>
<tr>
<td>Less than 16</td>
<td>0.2</td>
</tr>
<tr>
<td>16-64</td>
<td>9.5</td>
</tr>
<tr>
<td>65 or more</td>
<td>85.0</td>
</tr>
<tr>
<td>Unknown</td>
<td>5.3</td>
</tr>
<tr>
<td>Sex</td>
<td>2007-8</td>
</tr>
<tr>
<td>Male</td>
<td>32.6</td>
</tr>
<tr>
<td>Female</td>
<td>62.4</td>
</tr>
<tr>
<td>Unknown</td>
<td>5.0</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>2007-8</td>
</tr>
<tr>
<td>White</td>
<td>84.5</td>
</tr>
<tr>
<td>Mixed</td>
<td>-</td>
</tr>
<tr>
<td>Asian</td>
<td>0.1</td>
</tr>
<tr>
<td>Black</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>1.6</td>
</tr>
<tr>
<td>Unknown</td>
<td>13.8</td>
</tr>
<tr>
<td>Caring for</td>
<td>2007-8</td>
</tr>
<tr>
<td>Older</td>
<td>63.1</td>
</tr>
<tr>
<td>Mental health</td>
<td>2.5</td>
</tr>
<tr>
<td>Dementia</td>
<td>7.9</td>
</tr>
<tr>
<td>Physical disability</td>
<td>18.3</td>
</tr>
<tr>
<td>Dementia</td>
<td>2.2</td>
</tr>
<tr>
<td>Substance misuse</td>
<td>0.5</td>
</tr>
<tr>
<td>Unknown</td>
<td>5.5</td>
</tr>
</tbody>
</table>


As can be seen, two-thirds of clients are female and most are aged over 65. However, the proportion of clients younger than 65 receiving telecare has increased over time, as has the proportion of people with dementia, a learning disability, or a physical disability. Additionally, the proportion of people recorded as 'older' has decreased slightly. These data have implications for carer groups, with older people likely to be cared for by adult children – a group more likely to have family of their own, to be in employment, and to use telecare to manage complex lives.

Research on carers using telecare services in Scotland is limited in number, though a detailed review was conducted by Jarrold and Yeandle (2009). Forty-three carers were recruited from 13 different partnerships across Scotland to participate in either a telephone interview or a focus group. Although numbers of participants were quite modest,

\(^2\) A basic service was defined as a telecare hub unit together with a pendant and an integrated smoke alarm. An enhanced package was defined as one that goes beyond the basic configuration and includes any other sensors or monitoring equipment.
this qualitative study allowed carers to identify issues related to telecare in their own terms. Additionally, most participants were female and over half were caring for an older person, which makes the sample representatives based on the national-level data presented above.

It was found in this study that all carers had been involved in the decision to install telecare, with most referrals coming from social services and/or social workers or from health professionals. Most carers had been unaware of telecare before a professional had drawn their attention to it, but had been keen to embrace its possibilities.

Installation of the equipment had been unproblematic, with most carers present and 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. The demonstration proved reassuring to carers, especially in cases where the person being cared for had a condition like dementia and had difficulties in understanding how to use the equipment.

Most felt that telecare staff were approachable and supportive, and some carers felt having telecare installed had improved their relationship with service providers, with many feeling better ‘supported’ as a consequence. Most carers thought highly of the telecare equipment, with few reporting problems. Most carers were satisfied with the equipment they had been allocated, with none claiming they required more support or that other necessary equipment was unavailable to them (Jarrold and Yeandle, 2009).

Other research has highlighted differences in telecare charging policies across different parts of Scotland. Data cited in one evaluation by Beale (2009) show that in 2007, 20 of the 32 local partnerships charged for their telecare services and that prices varied in different parts of the country. Carers from different partnerships in the study by Jarrold and Yeandle (2009) also reported paying different charges for telecare, though none reported having paid for installation. Although charges for home-based health and social care services in Scotland are regulated by official guidance, charges for telecare services are discretionary, and different interpretations of guidance have led to variable charges for telecare services. Operating costs also differ across different partnerships, with over half of the carers in Jarrold and Yeandle’s study reporting a charge, which was paid either by themselves or by the person they cared for (e.g., through welfare benefits). However, other carers in different partnerships received the same services with no charge. These differences were not determined by different types of equipment. In one partnership a personal alarm system could cost between £6 and £15, whereas in another someone using many different pieces of telecare equipment paid nothing.

However, in this study, most carers considered charges for telecare to be reasonable, with most reporting that the fee was worth it for ‘peace of mind’. A few carers felt telecare should be made cheaper or even free, and most with this view were also concerned about financial hardship resulted from caring responsibilities. Some carers were concerned that charges, affordable now, might increase in the future, and some pointed out that, in partnerships where costs were high, people on a limited budget might be unable to access the equipment.

As part of the TDP, a work-plan was established to ensure that all aspects of telecare service were delivered to recognised standards, with partnerships encouraged to seek
accreditation under a recognised framework (The Scottish Government, 2010). This framework was launched in 2008 and by early 2010, 19 partnerships were members, with five having achieved accreditation and another 10 were working towards it. Three bodies are now involved in telecare regulation:

- the Care Commission registers and inspects telecare services
- the Social Work Inspection Agency seek to ensure partnerships include telecare services in a consistent way
- the Scottish Social Services Council supports staff in relation to training standards and registration requirements

Training of health and social care staff was not implemented in the early stages of the TDP, though was acknowledged to be a key issue to address in 2009/10. A training and education strategy for 2010-12 has since been published, which reports no accredited training currently available for staff involved in equipment provision or call handling. Where training has been provided for call handlers, it has been developed by partnerships or enlisted from telecare equipment suppliers. Training for staff who respond to telecare calls has also been developed by partnerships, with no official accredited training currently available. Paid response staff not required to have a professional qualification (The Scottish Government, 2010).

Nevertheless, a series of practice guides has been developed as part of the TDP to support professional staff in the use of telecare with different user groups, including people with dementia, learning disabilities, physical disabilities and sensory impairment. Additionally, an induction programme for call handling staff has also been developed and made available to all partnerships for local delivery (The Scottish Government, 2010). The Scottish Telecare Learning Network has been established by the JIT to support health and social care staff to share knowledge and good practice, and to enhance innovation. The Learning Network meets quarterly and produces documentation to inform practitioners of developments and progress.

Awareness raising around telecare in Scotland has included the development of a multimedia toolkit of resources, which includes a DVD and a range of ‘digital stories’ highlighting benefits of the equipment (much of which is distributed by Carers Scotland). Many partnerships have also developed their own awareness raising materials. However, Henderson (2010) reports that these activities have not been equally effective, and partnerships continue to report a lack of awareness of the potential of telecare among carers as well as among health and social care professionals.

**Finance and budget**

As noted earlier, the Scottish government’s investment in telecare exceeded £20 million from the years 2006 to 2011, of which £17.6 million was allocated to care partnerships to enable service expansion. Over the year 2010/11, partnerships reported total TDP expenditure of £3.1 million. This brought the total reported TDP expenditure by
partnerships since the beginning of the programme to £13.6 million (Newhaven Research, 2011).

TDP funding for 2010/11 involved partnerships seeking match funding (this was also true of 2009-10, but not of previous years). At the beginning, £5.7 million was promised in match funding, though partnerships indicated that around £3.2 million match funding was spent over the course of the year. Combining the reported TDP and match funding figures, the TDP programme was responsible for a minimum of £6.3 million expenditure in 2010/11, and across the 5 year programme, this figure was approximately £19.5 million (Newhaven Research, 2011).

Table 3  Local Partnerships in Scotland: allocation of telecare funds 2006-2008

<table>
<thead>
<tr>
<th>Local partnership area</th>
<th>Initial funding through the TDP (£s)</th>
<th>Local partnership area</th>
<th>Initial funding through the TDP (£s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aberdeenshire</td>
<td>316,248</td>
<td>Inverclyde</td>
<td>123,922</td>
</tr>
<tr>
<td>Aberdeen City</td>
<td>266,174</td>
<td>Midlothian</td>
<td>111,845</td>
</tr>
<tr>
<td>Angus</td>
<td>154,741</td>
<td>Moray</td>
<td>121,280</td>
</tr>
<tr>
<td>Argyll and Bute</td>
<td>141,953</td>
<td>North Ayrshire</td>
<td>131,140</td>
</tr>
<tr>
<td>Clackmannshire</td>
<td>75,000</td>
<td>North Lanarkshire</td>
<td>452,127</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>219,964</td>
<td>Orkney Islands</td>
<td>75,000</td>
</tr>
<tr>
<td>Dundee City</td>
<td>141,755</td>
<td>Perth and Kinross</td>
<td>190,825</td>
</tr>
<tr>
<td>East Ayrshire</td>
<td>181,500</td>
<td>Renfrewshire</td>
<td>241,048</td>
</tr>
<tr>
<td>East Dunbartonshire</td>
<td>143,260</td>
<td>Scottish Borders</td>
<td>159,932</td>
</tr>
<tr>
<td>East Lothian</td>
<td>82,401</td>
<td>Shetland</td>
<td>50,000</td>
</tr>
<tr>
<td>East Renfrewshire</td>
<td>125,176</td>
<td>South Ayrshire</td>
<td>157,400</td>
</tr>
<tr>
<td>Edinburgh (City)</td>
<td>565,711</td>
<td>South Lanarkshire</td>
<td>419,728</td>
</tr>
<tr>
<td>Falkirk</td>
<td>197,162</td>
<td>Stirling</td>
<td>122,527</td>
</tr>
<tr>
<td>Fife</td>
<td>485,376</td>
<td>West Dunbartonshire</td>
<td>142,429</td>
</tr>
<tr>
<td>Glasgow (City)</td>
<td>911,102</td>
<td>West Lothian</td>
<td>220,163</td>
</tr>
<tr>
<td>Highland</td>
<td>331,527</td>
<td>Western Isles</td>
<td>75,000</td>
</tr>
<tr>
<td><strong>Total investment in Scotland</strong></td>
<td></td>
<td></td>
<td><strong>£7,323,885</strong></td>
</tr>
</tbody>
</table>

*Source: Joint Improvement Team (2007) Summary of Current and Developing Telecare Services in Scotland.*

Detailed data for TDP fund allocation to each partnership in Scotland for the years 2006-2008 is shown in Table 3. It can be seen that financial allocation ranged from approximately £50-75,000 in small, isolated areas (e.g., Shetland, Orkney Islands) to over half a million pounds in heavily populated cities (e.g., Edinburgh and Glasgow, which actually received nearly a million pounds from the TDP) (The Scottish Government, 2010). In 2008-2010, allocation of TDP funding was altered. Allocations in 2006-8 were based on population size in partnership areas. However, for 2008/9, each partnership assessed to be progressing well received £200,000, and those judged to be progressing on only a satisfactory basis received £125,000. All these changes to allocation were intended to reward successful delivery and encourage long term financial commitment to telecare service delivery (The Scottish Government, 2010).
Nine partnerships were judged to have made slower than expected progress to March 2008, and these were offered assistance to explore local potential for telecare and ways to overcome barriers. By March 2010, these reviews were completed, and in some cases further allocations of funding were made to struggling partnerships.

**IMPACT ASSESSMENT**

Telecare in Scotland has been evaluated and assessed in a range of publications detailing the programme’s development against original aims and its effectiveness in meeting carers’ and cared for people’s needs, and cost effectiveness and service support in the social and healthcare system. Data from this research will be discussed in this section.

In the study conducted by Jarrold and Yeandle (2009), interviews identified that social and healthcare professionals felt telecare offered significant benefits to carers as well as to service users, and one Telecare Lead Officer claimed that an effective telecare service was an essential part of any social care system. However, several professionals in this study felt that more needed to be done to mainstream telecare.

A summary of findings from the interviews / focus groups with carers in this study is presented in Table 4, which details impacts on health and well-being, combining employment and care, impact on recreation time, impact on caring roles, and access to other services.

As can be seen, carers claimed that telecare helped in a variety of ways, with benefits to health and well-being complimented by positive impacts on the carer’s capacity to cope with caring and other aspects of their life. Despite these positive experiences, however, some concerns issues were also expressed by carers in this study:

- carers’ knowledge about the types of telecare equipment available is low
- carers have access to a limited range of telecare equipment
- carers feel faster referrals to telecare services and enhanced equipment would benefit carers of people with demanding conditions like dementia
- even when telecare is in place, carers often continue to need home care services to support them
Table 4 Evaluation of carers’ experiences of telecare in Scotland (Jarrold and Yeandle, 2009)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Impact</th>
</tr>
</thead>
</table>
| **Carers’ health and well-being** | The beneficial impact of telecare most often cited was that it offered the carer ‘peace of mind’ about the well-being and safety of the person they cared for. Other carers had felt more confident about the person they cared for. Carers’ confidence in the reliability of telecare services was high. Most said they felt sure that they, another named contact, or the emergency services would be alerted if necessary. Many carers reported feeling less stressed, anxious and tired, citing these as the main differences telecare had made to their health and wellbeing. As one carer noted:  
*I can sleep easier knowing that a call out will happen if something is wrong.* |
| **Ability to combine work and care, and access to recreation time** | Telecare helped some carers participate in paid employment. Some carers in the study emphasised feeling less tired, reporting that they no longer felt constantly ‘on call’ while at work. Telecare had enabled some carers to remain in a job they might otherwise have had to give up, and (in one case) to gain employment. There were also impacts on carers’ free time and their ability to take a break from caring. Carers emphasised that telecare was not a replacement for care, and many benefited from being able to spend at least some time on their own or to relax. One explained:  
*It has allowed me to do more things at home, like reading a book. Before I would have to be constantly aware of my husband – it invaded my own time.* |
| **Ability to care** | A few carers noted that the introduction of telecare had had a beneficial impact on their relationship with the person they cared for, emphasising advantages for each person as well as improvements in their interactions and the emotional aspects of their relationship. Most carers in the study felt that telecare equipment complemented their caring role rather than reducing or replacing caring tasks. They regarded the main benefits as providing added support and relieving some of the worry of caring by appropriate agencies when there was a problem rather than replacing the care arrangements. As one explained:  
*My caring role is the same, but it is just easier and more manageable now. It is not a replacement for a carer, but it does replace the running up and down I had to do, to constantly check he was all right.*  
Most carers in this study did not feel that the amount of time carers spent caring was reduced by having telecare; rather, the equipment was said to make most impact by reducing the need for carers to repeatedly check on the person they care for. |
| **Access to other services** | Having telecare in place had not reduced the amount of support carers received from paid home care support. Where home care was already in place, none of the carers reported that this service had been reduced or removed. Carers saw telecare and homecare support as two different forms of support, with different benefits. Homecare gave carers a break from the physical tasks of caring, whereas telecare offered continuous support through reassurance about the person’s safety, health and wellbeing. The highly flexible nature of telecare allowed it to be used in a more complex or tailored combination of support for each individual caring situation. |
A similar study geared towards carers was conducted by the Scottish Government (Beale et al, 2009), which used a range of research instruments including case studies, quarterly returns from local partnerships, and surveys distributed to carers by collaborating partners. The survey invited carers to contribute comments on telecare and the following findings were reported:

- about three-quarters of respondents felt that they were either ‘a bit’ or ‘a lot less stressed than before’ the installation of telecare equipment, while fewer than one-in-twenty felt that their stress levels had increased
- time spent with the cared for person had remained the same for three-quarters of respondents, with smaller proportions spending both more time and less time with the cared for person
- carers felt that the equipment gave them ‘peace of mind’ as they worried less
- even if stress levels had fallen, some respondents claimed that caring can be very demanding and stressful (telecare could sometimes add to this if the client would not use their equipment)
- many carers were very positive about telecare and grateful for it

All these findings, derived from quantitative methods, are consistent with the qualitative material presented in the Jarrold and Yeandle study.

The Newhaven Research reported in 2011 that the reasons partnerships gave for assigning telecare systems to clients had remained consistent over the previous three years, with ‘meeting a low level need’ the most common reason, followed by ‘improving carers’ peace of mind/giving them a break’ (Table 5). Other important reasons for installation include preventing admission to hospitals and rest homes. These data reveal that telecare’s impacts specifically on caring communities (as explored above) is a principle reason why telecare is installed in many cases.

<table>
<thead>
<tr>
<th>Table 5 Recorded Reason for Offering Telecare to New Clients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevent admission to a care home</td>
</tr>
<tr>
<td>Prevent/lessen hospital admission risk</td>
</tr>
<tr>
<td>Facilitate hospital discharge</td>
</tr>
<tr>
<td>Improve carer piece of mind/respite</td>
</tr>
<tr>
<td>Meet a low level need</td>
</tr>
<tr>
<td>Other reason</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>


Preventing admissions to hospitals and rest homes was also found to be an important reason why telecare had been installed in many cases, and the Newhaven Research report found that in 2011, partnerships’ expectations in this area were exceeded by achievements in terms of delaying hospital discharges, reducing unplanned hospital admissions, and
reducing care home admissions (Table 6). When compared with progress from 2006-11, these figures show that last year telecare achieved a significant proportion of its expectations, which suggests that it is now becoming embedded in the health and social care system (Newhaven Research, 2011).

<table>
<thead>
<tr>
<th>Table 6 TDP Outcomes 2006-10</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Partnership Expectations</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Reduction in delayed discharges from hospital</td>
</tr>
<tr>
<td>Reduction in the number of unplanned hospital admissions</td>
</tr>
<tr>
<td>Reduction in the number of care home admissions</td>
</tr>
</tbody>
</table>


In Table 7 (Newhaven Research, 2011) reveals the following impacts of telecare:

- hospital bed day savings in 2010/11 due to a reduction in delayed discharges exceeded expectations, but for 2006-11 performance was lower than expected
- hospital bed day savings achieved due to a reduction in unplanned hospital admissions were higher for both 2010/11 and for 2006-11
- the largest impact was on care home bed days purchased, where the expectation of 317,000 saved in 2006-11 was exceeded by a saving of 546,000 days
- nights of sleepover/wakened night care and home check visits saved were below expectations (though TDP funding spanned a period when these services were being reduced for other reasons, which can account for the shortfall)

When data presented in Table 6 is compared with that in Table 7, the Newhaven Research (2011) reports the following efficacies of telecare:

- the average number of hospital bed days saved per reduced delayed hospital discharge was 11
- the average number of hospital bed days saved per unplanned hospital admission avoided was 9
- the average number of care home bed days saved per care home admission avoided was 143
Table 7  TDP Generated Efficiencies 2006-10

<table>
<thead>
<tr>
<th></th>
<th>Partnership Expectations</th>
<th>Partnership Achievements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of hospital beds days saved due to reduction in number of delayed discharges</td>
<td>8,789</td>
<td>53,893</td>
</tr>
<tr>
<td>Number of hospital bed days saved due to reduction in number of unplanned hospital admissions</td>
<td>27,013</td>
<td>62,343</td>
</tr>
<tr>
<td>Reduction in number of care home bed days purchased</td>
<td>129,125</td>
<td>317,224</td>
</tr>
<tr>
<td>Number of nights sleepover care saved</td>
<td>25,430</td>
<td>80,857</td>
</tr>
<tr>
<td>Number of home check visits saved</td>
<td>164,781</td>
<td>779,764</td>
</tr>
</tbody>
</table>


The Newhaven Research report has presented all these savings in term of financial figures, too. Table 8 shows that financial benefits arising from TDP expenditure in 2010/11 was over £30 million. The value of benefits arising 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. The Newhaven Research report states that the remaining savings, in the form of reduced sleepover care and home check visits, is most likely to have benefited local authorities.

In total, all these savings can be seen to have an impact on carers, with some benefits extremely positive (such as reduction in hospital admissions, which many carers find stressful and onerous) and others resulting in more involved caring roles (such as a reduction in care home admissions, leading the cared for person to staying at home and requiring more care). Much research has shown that many carers want the person for whom they care to remain in their own home if possible, because this offers them dignity and allows carers to play an active role in their care. From the evidence presented in this case study, it is clear that telecare in Scotland is taking considerable steps towards achieving this goal, while also benefiting the health and social care system in terms of multiple efficiencies.

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23 The value was calculated on the basis of reported costs through NHS sources.
### Table 8 Estimated Value of TDP Funded Efficiencies

<table>
<thead>
<tr>
<th>Efficiency Description</th>
<th>2010/11</th>
<th>2006-2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased speed of discharge from hospital</td>
<td>£4,292,840</td>
<td>£9,988,754</td>
</tr>
<tr>
<td>Reduced unplanned hospital admissions</td>
<td>£9,661,648</td>
<td>£24,289,642</td>
</tr>
<tr>
<td>Reduced care home admissions</td>
<td>£14,824,425</td>
<td>£37,816,787</td>
</tr>
<tr>
<td>Reduced sleepover/wakened nights care</td>
<td>£617,329</td>
<td>£2,776,270</td>
</tr>
<tr>
<td>Reduced home check visits</td>
<td>£344,698</td>
<td>£2,979,088</td>
</tr>
<tr>
<td>Procurement efficiencies</td>
<td>£347,172</td>
<td>£753,569</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£30,088,112</strong></td>
<td><strong>£78,604,110</strong></td>
</tr>
</tbody>
</table>


### SUMMARY

This case study has explored the role of telecare in the lives of carers in Scotland and its impact on the Scottish health and social care system. Its key findings are as follow:

- over the last five years, the Scottish Government has worked to implement telecare developments to benefit carers as well as those they care for, involving a significant financial investment
- each Scottish partnership submitted a bid for funding its own telecare project, based on a strategic plan
- some partnerships have performed more successfully than others, through a combination of existing experience with telecare, senior level support, and creative strategies in engaging clients and supporting professionals
- funding for partnerships differed according to demographic factors in the early stages, and with delivery success at later stages, with less successful partnerships offered formal support if required
- most carers feel that telecare supports them in their caring role, with benefits to their health and well-being, employment and recreational time, and confidence in their everyday lives
- some carers and professionals lack knowledge about telecare services, have access to a limited number of systems, and do not consider the equipment as a replacement for the care they provide
• statistical evidence suggests that telecare can reduce hospital admissions and admissions to rest homes, offering clients a chance to be cared for at home; telecare can also save on hospital bed days and reduce numbers of home checks, which also impacts positively on carers
• financial evidence suggests that telecare can have a positive impact on the health and social care system in terms of cost efficiencies.

REFERENCES


## Annex 1: Template for reporting case-by-case information

<table>
<thead>
<tr>
<th><strong>Descriptive Information</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Website</td>
</tr>
<tr>
<td>Region(s)/Country</td>
</tr>
<tr>
<td>Rationale and motivation for the initiative</td>
</tr>
<tr>
<td>Objective of the organisation</td>
</tr>
<tr>
<td>Target user groups</td>
</tr>
<tr>
<td>Type of activities and services offered</td>
</tr>
<tr>
<td>Technologies and applications are used</td>
</tr>
<tr>
<td>Functions provided by ICT technologies and applications</td>
</tr>
<tr>
<td>Development methodologies</td>
</tr>
<tr>
<td>Categorization of stakeholders</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Operational Information</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Starting operational (– ending) dates and operational status</td>
</tr>
<tr>
<td>Funding and budget</td>
</tr>
<tr>
<td>Other resources</td>
</tr>
<tr>
<td>Stakeholders’ involvement</td>
</tr>
<tr>
<td>Personnel involved in providing the service</td>
</tr>
<tr>
<td>Number of users reached</td>
</tr>
<tr>
<td>Requirements (e.g. skills, devices) to use the application / service</td>
</tr>
<tr>
<td>If needed, how did carers acquire the needed ICT skills</td>
</tr>
<tr>
<td>How do carers get knowledge about available ICT-supported services</td>
</tr>
<tr>
<td>Drivers and barriers for usage (from users and implementers’ perspective)</td>
</tr>
<tr>
<td>Reasons why they use an ICT-based service (and not only personal care)</td>
</tr>
<tr>
<td>Innovations introduced by ICT in connection to the context in which they are applied</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Enabling conditions and success/failure factors</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Enabling conditions</td>
</tr>
<tr>
<td>Other local context conditions favouring / preventing a wider adoption of the ICT solution</td>
</tr>
<tr>
<td>Success and failure factors</td>
</tr>
</tbody>
</table>
### Impact Assessment

<table>
<thead>
<tr>
<th>Core dimensions of impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major proved benefits for carers and care recipients</td>
</tr>
<tr>
<td>Monetary outcomes</td>
</tr>
<tr>
<td>Possible outcomes for stakeholders</td>
</tr>
<tr>
<td>Possible unexpected outcomes</td>
</tr>
<tr>
<td>New outcomes</td>
</tr>
</tbody>
</table>

### Future Perspectives

| Sustainability model and perspectives |
| Scalability capabilities and conditions |
| Replicability elements |
| Objective conditions for transferability to other local contexts across Europe |

### Policy Implications

| Digital inclusion |
| Social inclusion |
| Employment |
| Social care |
| Health care |
| Immigration and integration |
| Lifelong learning |
| Any other lessons learned |