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 5.2
Minutes of the Policy Makers’ and Experts’ Workshop
identifying the Recommendations to be taken into account for WP3 and WP5 Final reports

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Policy Makers’ and Experts’ recommendations

The 19 external experts who attended the Policy Makers’ and Experts’ Workshop (Brussels, 21-22 November 2011) validated the final results of the CARICT project (WP3, WP4, WP5) and formulated two sets of recommendations:

- **recommendations for deliverable 3.6**: experts made suggestions for further improvements of the methodological framework. In addition to the recommendations already done by participants to the first Experts’ Validation Workshop (Brussels, 21-22 June 2011), the second Workshop pointed out some more issues to be considered for future developments of the conceptual framework and of the Impact Assessment Methodology (IAM). These recommendations are listed below and will be integrated in chapter 5 of the deliverable 3.6, Final report on the “Methodological Framework” (which already includes recommendations from the first Workshop);

- **recommendations for deliverable 5.3**: experts made a series of policy recommendations concerning the main question: “What role can ICT-based initiatives play in future scenarios of long-term care in Europe and related policy challenges?” (for details regarding the Workshop methodology, see Annexes 4 and 5). Such recommendations are mainly based on the discussion on the so far achieved project results presented during the Workshop, namely deliverables 2.3, Analysis and mapping of 52 ICT-based initiatives for caregivers, 3.1, “Dependency scenarios” proposal, 3.6, Final report on the “Methodological Framework”, 4.3, Final report containing case-by-case detailed description and analysis of selected 12 good practices, and 5.1, Draft final “Integration report”. These recommendations are listed below and will be integrated in chapter 3 of the deliverable 5.3, Final “Integration report”.

**Recommendations for D 3.6**

- **The role of formal carers should be included in future developments of the framework.** Excluding the care workers affiliated to the formal sector could be not the best choice in order to try getting a comprehensive picture of home care contexts and caregiving networks. Future research should clarify how formal carers fit into the framework already drawn. This is important also because care assistants may be paid anyway with public money. Indeed, this should be included in the network of care as a crucial cost issue at macro-level. Adding the formal carer in the framework
has some consequences on the whole methodological framework of course, like the inclusion of an eighth dimension of impact at least – the quality of life of formal carer. The update action can be based taking into account already developed frameworks for long-term care such as the one from the INTERLINKS project (available online: http://interlinks.euro.centre.org/).

- **The role of families and kinships should be further analysed and clarified.** In the conceptual framework, only the primary carer is included in the micro-level: families are assigned to the meso-level as a social network because the research assumption was to focus on the carer-care recipient dyad – i.e. considering only the primary carer. This fact was justified from the current lack of knowledge and research on the topic of secondary and multiple family carers: there is no enough evidence at this time to assess contexts in which many family members provide care to the dependent person. However, future developments of the framework can try to address the multiple carers issue, drawing a network that includes all of them, perhaps considering families themselves as at the boundary between micro- and meso-levels.

- **Applications of the methodological framework should bear in mind that it is a flexible tool to be adapted to contextual situations.** Even if it is already mentioned in the “Guidelines for practitioners” (chapter 4 of deliverable 3.6), it is important to stress and further develop application strategies for the methodological framework. This means that the overall model could consider more in detail who is going to assess the ICT-based initiative, how and for what purpose.

- **Improvement of the indicators included in the dimension Quality of Life of Informal Carer, sub-dimension Health-related Quality of Life.** Indicators at meso- and macro-levels should be supplemented by non-work related indicators of health and well-being for the carer, e.g. derived from self-assessed health status or number of medical or hospital visits.

**Recommendations for D 5.3**

- **National and local policy makers should identify frailest categories that need more attention and support, and activate adequate services to satisfy their needs.** More distinction is needed within the same category of carer. Different target user groups can be identified across Europe:
  - *Co-resident non-working carers:* mainly old spouses, at risk of social isolation and health problems (generated by caring and by own aging). They can suffer of sleep problems and stress in dealing with formal services and care coordination. Social actors should recognise their care responsibility and support this kind of “invisible” carers that could be almost unknown by the
formal sector. Smart regular re-assessment of needs can be carried out by professionals in order to help people understand what help they could benefit from – i.e. discovering which ICT tools can be more useful in their situation (e.g. call centre, telecare systems, smart homes etc.). Also financial support can be put into practice by local authorities, reducing costs for care services on the families.

- **Working carers**: they are usually burdened, very stressed at work, at risk of losing their jobs (because they can be less productive). This category needs flexibility in terms of employment, i.e. possibility to drop out everything if really needed by the situation. More rights should be recognised for their emergency needs by formal sector and employers. In many cases they suffer anxiety because they do not know what is going on at home with their dependent elderly. Such situation can be faced through adequate measures in terms of: ICT tools that allow a remote real-time monitoring of the dependent person; flexible contracts that can be easily turned into part-time or allow temporary absences for caring the family member; 24-hour a day availability of care and support services, that should become accessible not only during working hours but anytime; possibility to have more relief and leisure time for personal recuperation.

- **Carers at risk of giving up care and work**: this people provide care in conditions of illness, poorness or socially isolation, including spouses and children who are not able anymore to carry on both work and care. This group includes those who decide to leave care because they just want to focus on work, with possible negative consequences on the home care provided to the dependent older person.

- **Carers who have given up work or never worked because of care for a long period of time**: this category shares a lot of needs with the previous ones. They are out of the labour market even if they are still in working age because caring for the dependent person was too much time-consuming; the problem of reintroducing them in the labour market is a crucial issue. ICTs can help through life-long learning programmes that can train carers to specific tasks or jobs, and allowing them to have more chances with employers. Also, financial support could be an useful measure in these situations.

- **Migrant care workers**: they play a crucial role especially in some countries (e.g. Italy), in which they are mainly privately employed by households. In other countries they are usually engaged in the formal sector as proper care workers and their working conditions are surely better (e.g. UK). They need assistance to orientate themselves in the care organisation, to match demand and supply of home care, to regulate their position (in many cases, they can have no permit of stay). Personal needs should be addressed as well, concerning the risks of burden, social isolation (even being home sick or not in contact with origin country). Language and cultural differences can be barriers to a proper integration of migrants in the destination country.
National and local policy makers should identify stakeholders that can support carers and dependent older people, as well as appropriate ICT-based service that enable or reinforce their support action. Several actors as individuals and organisations were found to be a great resource of support for home care contexts. ICTs play an important role in this respect, since they can allow brand new services to start or to strength already existing ones. These are the main actors that can be supported by ICT tools in helping carers and dependent elderly:

- **Other family members, children, close neighbours, more distance relatives who live locally.** Possible ICT tools for this category:
  - E-mails and SMS;
  - Informative websites;
  - E-learning programmes;
  - Care coordination systems;
  - Telephone services and call centres;
  - Voice over internet (VOIP) communication;
  - Social networks;
  - Telecare;
  - Telehealth and telemedicine systems;
  - Smart homes;
  - GPS systems.

- **Volunteers.** They usually belong to a non-governmental organisation (NGO) but they can be also engaged through other means. NGOs can be disease-related associations or carers’ organisations. Possible ICT tools for this category:
  - E-mails and SMS;
  - Care coordination systems;
  - Telephone services and call centres;
  - Voice over internet (VOIP) communication;
  - Care coordination systems, allowing volunteers to communicate with health professionals and users.

- **General practitioners (GPs), social workers and health professionals.** The ethical issue arises in cases of sharing health information of dependent person to family members and other carers. Moreover, some barriers can limit the use of ICT tools: generally speaking, professionals in the formal sector usually do not use technologies in their ordinary work. More efforts should be done in order to change practices and protocols in this sector, convincing them to adopt and use ICT tools that can improve the quality of their work as well as the service provided to users. Furthermore, flexibility for end-users is required and referral mechanisms for integrating own work with other stakeholders (e.g. non-profit home care providers). Possible ICT tools for this category:
  - E-mail and SMS for contacting the patients and being contacted by them;
- Standardised software to organise and share health data among health professionals.

**Home care providers.** There could be differences among organisations providing home care and those providing telecare: an integration of the both services is the best solution, since in the future there will be need for care and social workers still, and ICT tools can complement and enhance the provision of services. Also differences can be identified by other factors (e.g. public/private, profit/non-profit etc.) but the nature of services provided can be thought to be the same. Possible ICT tools for this category:
  - E-mails and SMS;
  - Care coordination systems;
  - Telephone services and call centres;
  - Voice over internet (VOIP) communication;
  - Social networks (moderated by the care provider professionals);
  - Telecare;
  - Telehealth and telemedicine systems;
  - Smart homes;
  - GPS systems.

**Migrant care workers.** Possible ICT tools for this category:
  - E-mails and SMS;
  - Informative websites;
  - E-learning programmes;
  - Care coordination systems;
  - Telephone services and call centres;
  - Voice over internet (VOIP) communication;
  - Social networks;
  - Telecare;
  - Telehealth and telemedicine systems;
  - Smart homes;
  - GPS systems.

- **Promoting the adoption of ICT tools among carers, care recipients and stakeholders can be an efficient means to provide easily accessible services with a real-time interaction among the actors.** In particular, some of the technologies and services that were recognised to have a great positive impact and be cost-effective are:
  - **Social network tools:** they can allow text exchange (e.g. on-line fora) or multiple videocommunication (e.g. video-chat for groups). They are very effective in providing peer support (virtual communities of carers or care recipients) but they need to be tailored to target user characteristics and to be really pushed by the service provider, otherwise they can fail. They need only an interface device (e.g. a computer) and a phone connection (e.g. internet connection or mobile network).
- **VOIP communication**: tools like Skype allow users to get easily in touch using only a computer and an internet connection. It is a very effective instrument, since it can overcome distance with a video and audio interaction, simulating a face-to-face meeting. It does not require big digital skills, so it has been seen as a very good tool for allowing users to increase their social participation, interacting with other family members (even younger ones) and other users (carers or care recipients).

- **Home-based ICTs**: they include smart homes, assistive and localisation devices. Even if different, all these types of technologies demonstrated to be effective in making carers’ and care recipients’ lives easier. Smart homes can improve activities of daily living automatising some actions. Assistive devices can support carers in better managing the older person and allowing this latter to be more independent. Localisation devices constantly monitor the position of the elderly, informing carers or service providers if the person is going outside (and potentially in danger).

- **Telecare and telehealth**: they deal with transmission of voluntary or involuntary signals from the care recipient to carers or service providers. They include emergency buttons, social alarms, in-home sensors and systems monitoring health conditions. They are the most investigated tools because of the direct impact on the dependent older person’s quality of life: studies conducted especially in UK demonstrated that such telecare and telehealth tools allow significant cost savings to care providers.

- **On-line information**: such tools are mainly websites that provide in-depth information on several topics, concerning both disease-related issues and care service organisation. They cannot be static but require some kind of interaction to be really useful for the final users: possibility to reach directly health professionals, on-line services and multimedia training materials are only few solutions to make web platforms more interesting to the targeted users.

- **Care coordination systems**: this kind of tools is really required by carers, since one of the causes of stress is related to the difficulties in managing with formal sector. Care coordination systems can be based on standardised protocols and platforms that allow different organisational actors (formal providers, non-profit organisations) and individual users to keep in touch and share information.

- **The involvement of users in developing and designing an ICT-based initiative is fundamental**. Policy makers should push public service providers for engaging carers and care recipients in testing and assessing the usability of ICT-based services. Moreover, more efforts could be done in order to develop compulsory quality standards of technology-based solutions that include also preliminary assessments and user-centred design: in this way, even producers of devices and private service
providers could follow same guidelines and converge the offer towards more standardised types of devices.

- **One of the aims of ICT-based initiatives should be to empower older people to be more independent or to improve their overall quality of life.** On one hand, ICT tools can play a crucial role in allowing elderly people to improve their activities of daily life, feeling less dependent from relatives or other care assistants and giving relief to these latter ones. On the other hand, older people can be still empowered through enabling communication with significant others (social participation), training and self-management. Since these activities were proved to have a positive impact on care recipients but also (in an indirect way) to carers themselves, it is crucial the development of supporting mechanisms for research in the area. Policy makers should take into account the benefits of these initiatives, allocating more resources to test innovative solutions and implement already recognised good practices at local and national level. Improvements of social capital, user productivity and wellbeing are policy issues highly impacted by ICT tools.

- **The formal sector can strongly benefit from the introduction of ICT tools, but different internal barriers exist.** Policy makers should increase the efforts for introducing and making effective some innovative solutions in local health and social care systems. One of the major issues is the care coordination among the different actors: communication between health professionals and users, as well as monitoring systems and exchange of information with other stakeholders (e.g. non-profit organisations) are some of the possible areas of impact of ICT tools. However, health professionals do not contribute much to develop new support practices for the users and to change existing protocols. More education and training of staff from the formal sector is needed in order to promote adequately the added value of ICTs and their benefits for the quality of services and quality of work itself. New regulations and policies can be adopted by policy makers in order to accelerate the phases of technology adoption by health professionals.

- **New opportunities for volunteers in care organisations should be found, as well as for an adequate coordination between formal sector and voluntary organisations.** Volunteers are an important social capital that can be involved in several activities. Individual volunteers, as well as those affiliated to an organisation, provide care and support to users, dedicating some time of their lives to help other people. Opportunities for these high-motivated persons should be increased: policy makers can develop new incentives to sustain especially voluntary organisations and their activity. Furthermore, there is need to carry out more research in the field, analysing good practices and understanding how certain non-profit organisations can combine low-cost services with a high efficiency. Such experiences replicated in different contexts, supported by sufficient policies that allow non-profit organisations to start-up and develop innovative services.
Employers of working carers should be put in the condition to favourite work and care reconciliation. Better work conditions are needed for adults in working age that work and care for a family member at the same time. Their levels of anxiety and stress are usually high and they can even choose to leave work because of care or, on the opposite, to keep the job without caring anymore for the dependent person. Both situations, if not compensated, represent a failure for employment and care policies. New regulations are recommended in order to allow working carers to have more flexible contracts, with clauses concerning leaving the workplace in emergency situations and switching into a part-time job if necessary. Policy makers can plan financial mechanisms for supporting both employers and employees involved in these situations, for instance in terms of co-financements during the absent period of the carer. Furthermore, ICT tools can be really useful in these cases in two areas: on one hand, they can allow working carers to monitor elderly's condition in real-time through telecare and telehealth systems, giving them some relief and reducing anxiety level; on the other hand, ICT tools can be used for teleworking, so that carers can work (partially or totally) at home with the possibility to assist the family member. These potential of ICTs should be taken into account by policy makers and supported by them in order to increase social participation in the labour market by adults: in fact, this category is going to retire later than past standards, and the reconciliation between care and work will become more and more a hot topic in the policy agenda.

Producers and providers of ICT-based solutions should be encouraged to test and deliver them all over Europe. More innovative solutions are needed for the consumer market. Even longstanding initiatives, like the ones working with telecare systems, still need to learn how to adequately address consumers. Understanding the market is a fundamental step in order to develop initiatives tailored to users’ needs. Companies can be supported by policy makers through incentives and investments in new technologies: such financial resources can allow organisations to start-up and find a proper niche in which work and provide products and services. Since some examples of business cases exist, it can be assumed that in next years the market can become wider: if European companies are not competitive in such a sector, a risk is that firms from other countries can enter the market limiting internal competitiveness.

New ICT-based educational programmes and related certification schemes should be offered for improving migrant care workers skills. The issue of migrant care workers’ qualification is important, since migration trends (within Europe and from extra-European countries) are a growing phenomenon. Especially in some countries, these carers are privately hired as care assistants without any certification attesting skills in caregiving. ICT tools can enhance possibilities for migrant care workers to access to training programmes and to improve their knowledge and work competences. As consequence, a certification scheme at European level can be put in place for guaranteeing the recognition of their
education all over Europe. Policy makers can support the development, sustainability and transferability of such ICT-based educational courses, since a better skilled workforce can provide better care to older people, relieving the formal sector from avoidable institutionalisation and hospitalisation patterns, and decreasing the access to care services by migrants too (who often suffer of burden and depression).

- **The supply of ICT-based initiatives should be better promoted and disseminated at local and national levels.** In many cases users do not even know that such innovative solutions are available, where they can find them and how to judge if a tool is adequate for their situation. Good practices in other areas (such as development and promotion of new pharmaceutical products) can be useful to learn how innovation dynamics work. ICTs themselves can be seen as a tool for reaching carers through a provision of significant information and knowledge, enabling them to choose, access and use the appropriate service. Awareness of technology solutions and their availability to users is the first step for adopting them on a large scale. Policy makers can influence producers and providers of ICT-based services to better disseminate results from ongoing initiatives and promote innovative solutions among users through awareness and communication campaigns, as well as training local opinion leaders and interested stakeholders (e.g. health professionals, carers’ associations, employers) to show the wide range of available technologies and possible usage for different contexts.

- **Current evidence lacks of information about successful business plans for companies in the field of ICTs in home care.** Even if some good examples can be found, future research should investigate what are the characteristics of a consumer market in ICTs for caring: research on producers, consumers, intermediaries, quality standards and types of services is needed. Market research would look for what initiatives have great appeal and work, what people want and what technologies can be used in satisfying their needs.

- **Intergenerational solidarity is an important driver for improving dependent older people’s quality of life, and ICTs can play an important role.** As research pointed out, good relationships and frequent contacts between dependent elderly and children/grandchildren make older people more involved in family life. Moreover, they feel less dependent and overall quality of life can increase. Younger generations usually spend few time with older family members. It has been proved (e.g. Skype Care initiative, Hungary) that younger generations are more comfortable in contacting older family members through new media (videochat, SMS etc.). Promoting the use of ICTs within family contexts can improve the intergenerational relationships among the members, the solidarity among generations, and the quality of life of dependent older people. Such communication technologies are not expensive and easily used even by older people. ICT tools should be promoted
among families to make them aware of advantages and potential of telecommunication with dependent older people. As well, public and private stakeholders should be encouraged to enable this service at local level, providing support and information to users.

- **Infrastructural and institutional barriers should be overcome in order to allow everybody to access to support services.** In some cases, users can be neglected to access support services because of infrastructural barriers (e.g. lack of public services) or institutional ones (e.g. fragmentation of services and care competences). Improving the access to support and care services is crucial to increase the possibility to get support by people in need; otherwise, their quality of life or the home care itself could be seriously affected. Current situation and trends in some European countries limit a widespread access to formal services. Very basic technologies can allow many different kind of effective services. Mobile networks or GPS can be used for efficient telecare solutions, as well as internet for interacting with other users or health professionals. Due to the current situation, ICT tools should be seen as an efficient means to provide a real-time and widespread service to citizens in need. Local care providers and stakeholder should be encouraged to enable new ICT-based services or to reinforce the already implemented ones.
Policy Makers’ and Experts’ Workshop: detailed minutes

Please note that abbreviations of participants’ names are indicated in Annex 2.

Monday, November 21st

Participants: Katarzyna Balucka-Debska (DG INFSO), Francesco Barbabella (INRCA/ECV), Annelien van Bronswijk (Utrecht University), Stephanie Carretero (SEAS, Uni Leuven/Valencia), Clara Centeno (IPTS), Carlos Chiatti (INRCA), Kevin Cullen (WRC Ireland), Annette Dumas (Alzheimer Europe), Caroline Glendinning (SPRU York), Elizabeth Hanson (SNFCCC), Giovanni Lamura (INRCA/ECV), Rosi McLoughlin (VOCAL), Michel Naiditch (IRDES), Martin Schmalzried (Coface), Andrea Schmidt (ECV), Arnaud Senn (DG EMPL), Madeleine Starr (Carers UK), James Stewart (IPTS), Zsuzsa Széman (Institute of Sociology), Judy Triantafillou (50+ Hellas), Julia Wadoux (AGE Platform Europe), Verina Waights (DISCOVER Open University), Sue Yeandle (Leeds University)

1. Welcome and presentation

1.1. Clara Centeno, IPTS – Introduction to the project
Presentation of project background and aims, in particular:
- Triple invisibility of carers, ICT in LTC, carers in ICT
- Fragmentation of services
- Lack of user awareness
- Specific restrictions for family-employed assistants

1.2. James Stewart, IPTS – Aims and structure of the workshop
(see Annexes 4 and 5)

1.3. Arnaud Senn, DG EMPL – EU policy background
Social OMC – in-depth reflections on LTC > concern of member states, and growing support from EU institutions: publication (over coming months) staff working paper to take stock of LTC situation in members states (demographic aspects, organisation of supply, which role for the EU to support member states.
Social protection committee: working group comprised of experts/high-ranking civil servants presented main lines of future paper; broadly focused but technology as one of the most interesting options; agreement on user support (improvement of carers’ and patients’ situation). Clear and structured overview of what is going on in Europe at the moment is needed.
Common challenges: ageing > try to underline the most positive developments and be positive (not only start from a negative perspective of scarce workforce in LTC, high costs etc.); in some countries things can be changed in a positive ways, so maybe countries can benefit from those experiences; ICT is at the focus of interests too, especially for the purpose of job creation, CARICT as one of the projects providing good practice examples of projects.

CC: Would be great to have the EC present also in the member states to push LTC up in the policy agenda.

1.4. Katarzyna Balucka-Debska, DG INFSO – The importance of digital inclusion
Practical details on how to implement ICT solutions – DG INFSO strategy on ICT and ageing well > put ICT in a real life context, how much does it costs, what is the business model, what should be the skills, replicability, good experiences with ICT and ageing at system and individual levels >> 2 projects upcoming to see what skills and what kind of ICT are suitable for formal and informal caregivers; what about their socio-economic contexts (e.g. education for migrants; paid employment for informal carers); useful evidence and examples to be provided; also about cutting costs.

- How to insert the good practices we know of in mainstream policies?
- Carers as good examples of digital inclusion contexts (interaction with older people, who are among the most excluded from information society, carers as ambassadors of technologies)

Projects funded: Verina Waights and Elizabeth Hanson are part of the consortia

2. CARICT final results

2.1. Andrea Schmidt, ECV – Mapping of 52 ICT-based initiatives in Europe
(see deliverable 2.3)

2.2. Francesco Barbabella, ECV/INRCA – Development of the methodological framework and implication from the cross-analysis of 12 cases
(see deliverable 3.6, chapter 6)

Comments (I):
MN: Family at the meso level – why? Further 8th dimension: quality of life of formally qualified carers; and where did care coordination go?
SY: Progress made; but big concern – why excluded from the concept of caregivers those outside of the group of family carers/privately paid assistants – this may be the reason why you don’t get much understanding of the macro impact. (Member states: e.g. look at people in hospitals). People may be recruited at personal level, but others may well be paid with public money – so if you look at cost issues at macro level, the network of care is crucial. What does it mean for people paid through the system to provide something considered to be cheaper care.

MS: People paid by families, bought from agencies; model needs to separate people who are paid from those not paid. Quality of life and quality of work/employment is more important to those people paid, than looking at informal carers moving into formal sector. Impact assessment framework needs to capture real people’s lives – Some definitions may need to be revised. Tools for employers would be a massive benefit, flexible tool to be used in practice.

CG: Migrant carers paid through public or private funding, on a more or less formal basis, not just “migrant care workers”. Housing-based ICT initiatives – I missed them: in the UK large movement to create housing especially for older people built into their homes; fantastic opportunity to put ICT into caring context.

Reactions (I):
EH: At the micro level, independent living, housing-based initiatives are included? CG: But it would be relevant also at meso/macro level.
FB: a business case on housing was included; but for employers there are no effective business plans available. Break-even reached for example only after some years, so more investments needed. Family level at meso level in order to capture work-care reconciliation issues – not related to micro impact on individuals.
GL: agree on the network component, but also in the literature micro level is focused only on the primary caregiver. Therefore family was put to the meso level.
MS: But it propagates a poor assumption: e.g. distance caring with 4 siblings, caring for frail parent, ICT systems used, 5 days a week face-to-face with paid care worker and siblings; the framework at the moment does not look like people’s lives.
GL: That’s true but it’s missing in the literature in general, not an ICT problem.
MN: SHARE studies deal with problems of multiple carers, and family economies.
GL: Impact of ICT for one single person (primary carer) or extend to the whole network, but most studies cannot do that due to lack of funding etc. Also, the question is who belongs to the family network (spouse, children…)?
KC: It’s complex, you may put family at the boundary between micro and meso.
MSC: Carer or carer(s) – that would be an idea to improve the framework too.
SY: include also the paid workers at home would need to be seen as part of this network. We should not be abstracting the carer-care recipient dyad. It depends also on the willingness/character of the dependent person (do they accept everyone equally as carers). MN: also the use of ICT may differ from carer to carer, which may influence the impact of ICT.
JS: research on family conflicts within the network – so improvements also need to be done in the research.

Comments (II)
JT: Please explain again the slide on indicators. How is this used?
FB: It is supposed to be a tool to be used in a flexible manner. Up to the practitioners how to be used.
CJC: The model should be made less descriptive – the dimensions are also related to normative assumptions. How can you make the model more adaptive (e.g. to concepts such as efficiency)? It could be more interesting to work on the evaluation of contexts. Do we need to assess everything? If you have a company who wants to sell something, they will take care of evaluation. But if we use public money there is another type of evaluation needed; but maybe the benefit is so evident that you “just” ask a caregiver. We could always find more indicators.
FB: It needs to be kept flexible when and how you use which indicator.

CC: It was a huge task and it is not completed but had to be stopped at one point because it was a lack of funding for such an elephant task.
SY: Many care commissioners are desperate to know whether or not to invest in telecare – so we need to agree on a common framework – all the studies I have seen prove that telecare yields some kind of benefits.
MS: It’s also an issue of market research (employer satisfaction) vs. consumer research (customer feedback – what was it like for you) – different constructs, but it is about WHO is asking the questions, and HOW, and FOR WHAT PURPOSE, and it needs to be methodologically robust.
KBD: Every time it comes to mainstreaming, it is about whether these are solid examples only but not mainstreamed, but we do have some evidence, and we have a framework, so we need to adapt this evidence to specific policy settings. We do the coordination, but where do we focus on in this particular study to answer the policymakers’ questions in your setting?
AS: SPC people discussed this too – in the financial crisis all are struggling whether or not to invest in technologies; therefore evidence is needed. We need to invest further in this or this field.

2.3. Francesco Barbabella, ECV/INRCA – Evidence from the cross-analysis of 12 case studies: Current practice in impact assessment and implications
(see deliverable 5.1, chapter 2)

Discussion on cost benefits of telecare solutions
KC: Independent living technologies’ impact is positive, but was there any evidence of negative effects on family carers? Sometimes telecare solutions may actually increase the burden on carers.
MN: Also, what about the avoided costs of hospitalisation compared to the costs of home care (outpatient visits, monitoring, examinations of home care) if we take the latter into account to their full extent.

KBD: I know other cases where the costs of the equipment did increase costs at the beginning but then the telemedicine solutions did actually reduce system costs. More systematic evidence is needed.

3. Presentations of case studies

3.1. Zsuzsa Széman, Institute of Sociology, Hungarian Academy of Sciences – Emergency Alarm case study
(see deliverable 4.3)

Issue of volunteering
MN: In most cases it could be shown that it is useful to have a net of volunteers and then formal services, and it builds solidarity among neighborhoods to help each other, it is not a burden for them.
JS: Carer networks can be quite large, and there are initiatives e.g. in the Netherlands which are very interesting. Ultimately, ICT may contribute to increasing the number of available caregivers.

3.2. Carlos Chiatti, INRCA – CAMPUS case study
(see deliverable 4.3)

Dissemination of service
SC: How are migrants and families informed about the service, and how is it funded?
CJC: Local authorities fund it, but it is mostly about the initial stages. More authorities are interested because service supply does not increase with need in Italy. They then take care of recruitment of migrant carers, too, with their local offices. Most of the migrants do not have formal qualifications, so it is very important.
SC: Who is concerned about their qualifications? Is it the migrants or the families?
CJC: Families have a budget constraint, and they are concerned over the quality of care provided but cannot afford for highly skilled care workers. On the other hand, migrant carers also are interested in higher qualification and better working conditions and more salary. So there is a tension/conflict of interests too.

EU qualifications for carers
JT: I know of a similar programme, developed by Leonardo project, implemented in five countries. Software is in different languages – in Greece, although developed for migrant/formal/informal carers, it is very much focused on formally qualified carers.
There is not much intervention to improve skills of migrant carers. It raises the issue of EU level qualification. It would be great to see improvements in this field for carers.

GL: Emerging undeclared labor is also an issue – an additional allowance is paid if someone is hired with a certain level of qualification.

Languages
ZS: Which languages?
CJC: Romanian and Polish cover the majority of cases. Giovanni’s research showed that 15 percent have a university degree, but in a completely different field such as engineering.

Face-to-face training vs. online training
JS: How does the online training complement with face-to-face training? Carlos: It depends, if you look at different stages of the initiative, the first meeting is very important, some doubts may be very easy to resolve. Michel: peer group effects are important. But it is hard to estimate a standard/balance between the two, it depends on the context.
CJC: Cuidadores en red, a Spanish initiative, found that the number of classes needed to be more frequent, but once peer dynamics started it was easier because carers started to communicate via email with each other.
JS: It is no good if the Commission pays for online training but it is not linked with other existing trainings.
CC: We have done work in NL and SE on “blended learning” > guidance is needed, this is why the social aspects are important, especially for migrants.

3.3. Rosie McLoughlin, VOCAL – VOCAL initiative and the Scottish context
VOCAL is one of the largest care organisations in Scotland – we have seen a big increase in the role of ICT in supporting service users and carers. Nationally, Scotland has driven telecare developments; we want to see how these national developments can be used at local level. In particular, early identification of carers and initiatives such as online training and respite and short break services, booking system for carers, library of carers digital stories, one-stop-shop website, CDs for carers etc. They were influenced by local and national policies, funding from local health boards to improve carers information strategies. NHS staff is also involved.
2010 Scottish government published a new digital strategy to empower users to choose their packages of care; Need for unbiased information and choice brought the need for better information to users to be able to navigate through the system. These initiatives take a lot of burden from local care organisations, and help to avoid duplications. Increased interest in the role of ICT – social media, social networking (Institute for research and social innovation in services just published a report). They make the case for public sector workers to communicate with users via ICT (but often they are not
allowed to access external websites). There is still a large need for harmonisation of IT services e.g. across local health boards, all use different systems.

Skills needed to use ICT should not be forgotten, we should not increase the digital divide by neglecting certain groups of carers. Therefore training to carers is very important. Many authorities are turning to web services to empower users, it is seen as a way of saving too. There should be a balance between adding and reducing values (ICT as replacement of human contact?), ICT should increase the value.

Local identity of carers considered, too – to improve carers’ support at local level. Survey carried out by VOCAL – carers 85% (65+ carers) said website/online services are important to them when looking for support services. In order to measure impact we use a tool developed at governmental level, outcomes approach. Quality of life/micro level approach: confidence in caring, mental health, information levels, economic wellbeing, social wellbeing. This tool is used for all services of VOCAL:

Future developments: we are keen to develop apps for mobile phones and tabloid uses – government and care organisations show large interest, quick ways to get information. Examples are giving carers access about their rights in job search apps.

Generally speaking, in Scotland the developments at national level are well-reflectected.

3.4. Sue Yeandle, Leeds University – Cost benefits assessed in the Telecare Scotland programme
(see also deliverable 4.3)

Gary Fry carried out the study on telecare, and I also contributed to an earlier qualitative study. Headlines in Scotland are an investment of 20 million pounds generated cost savings of 18 million pounds. These were the results of a number of governmental studies, carried out in different disciplines. The assessment is done by asking professionals by “what would have happened if...” not by randomized control trials (RCTs). These would be very costly and cannot be justified properly.

Where do the savings come from? Delayed entry to residential care or unplanned hospital admissions; but is it delayed or avoided hospital admission? It may increase quality of life but not avoid costs in total. In the home care systems you can avoid checking visits (e.g. on a daily basis), which are expensive to be run and administered but do not improve qol of the dependent person.

Some of the savings come from avoided sleepovers (night custody) – so you don't need someone to be with the person all night anymore. Care benefits increase carers’ health, social participation – it is difficult to quantify them but they are important. The way telecare is used for re-enablement after discharge. In the past people might not have been allowed to go home anymore, but now with the support of telecare it is (not risking unplanned admissions to hospitals), and restoring independency.

With dementia: emergency visits by police triggered from complex packages of alarms and alerts can be avoided – instead a voice recorded from someone the person knows asks the person not to leave the house e.g. at an unusual time at night, you avoid searches by police. Also, GPS systems may be used for this.
A lot of money to generate a lot of savings is what we are talking about. The study focused on older people in 85%. The issue is: are you avoiding or delaying? And what about the quality of life aspect, which is different from the cost aspects. Also, the problem of allocating costs to either health or social care in the UK system is a huge issue.

Comments
MS: You could have also significant benefits at other levels, such as the labor market (for carers and employers). We need to find a framework to evaluate all levels, including the individual but also the system level.
Also: how can ICT be used effectively at the workplace? We are developing a service for caring public sector employees who, however, don’t have access to the online support network from their workplace. We are working on improving this service.
MN: You need to invest in panel data to be able to answer the question whether you are just delaying or avoiding costs. But these panel data are expensive, of course.
SY: In the UK care assessments are done by professionals; and it is properly recorded, why telecare is installed and would have had to be done otherwise. It is a medium way but it should provide some answers without massive expense.
JvB: Is it data or a large number of satisfied people that actually push politicians to implement and support such initiatives? In my country I found the latter to be more effective.
AS: We need both, but in times of massive budgetary cuts, ministries of finance need sufficient levels of evidence. They need to be shown that money was saved compared to the previous situation. Given the tremendous budget crises, otherwise no investments will be made.
JS: We need stories to support the evidence. Possibly even shocking stories.
CG: It is incredibly important to have clear description of case studies and factors that make it work: something is transferrable and can achieve certain results but only under these conditions. What makes it so successful in that setting? In order to replicate projects and not mislead people. Being clear about the nature of particular initiatives and what is absolutely essential to make them work.
Tuesday, November 22nd

Participants: Robert Anderson (Eurocarers), Francesco Barbabella (INRCA/ECV), Annelien van Bronswijk (Utrecht University), Stephanie Carretero (SEAS, Uni Leuven/Valencia), Clara Centeno (IPTS), Carlos Chiatti (INRCA), Kevin Cullen (WRC Ireland), Annette Dumas (Alzheimer Europe), Caroline Glendinning (SPRU York), Elizabeth Hanson (SNFCCC), Giovanni Lamura (INRCA/ECV), Rosi McLoughlin (VOCAL), Michel Naiditch (IRDES), Andrea Schmidt (ECV), Arnaud Senn (DG EMPL), Madeleine Starr (Carers UK), James Stewart (IPTS), Zsuzsa Széman (Institute of Sociology), Judy Triantafillou (50+ Hellas), Verina Waights (DISCOVER Open University), Sue Yeandle (Leeds University)

1. Introduction to the second day

1.1. James Stewart, IPTS – Introduction and explanation of the break-out groups
(see Annexes 4 and 5)

1.2. Giovanni Lamura, ECV/INRCA – Summary of the draft of future scenarios
(see deliverable 5.1, Annex 4, and deliverable 3.1)

Results from the Eurofamcare study > clustering the first three clusters (1. inactive daughters with high burden, 2. employed daughters with moderate burden, 3. wives with high burden).
MS: We have to differentiate between use of support services and actual access to services. In the UK the share of people using services is low, but services are also low.
CG: Support services refers to everything that relieves carers? Can we really outcomes and benefits for carers vs. for the dependent person? If someone cares properly for my father this is a huge benefit for me as a daughter, too.
AS: Many women would have to give up professional lives to carry out caring tasks – more facts on this would be interesting for policymakers.
KC: Eurofamcare study is a rich sample, but not representative sample, so we have to be careful. We do have some – limited – European samples for carers. Unfortunately they don’t consider the intensity of care. In the workforce, as there are more men at work, men have a higher percentage, but for intense care women (also employed ones) are much more represented. It is an important point for statistical offices.
ZS: The different working age, and changes in pension systems, need to be considered. The next generation may not be able to care for others because they have to work. With ageing societies also migration may decrease, especially in Eastern European countries.
GL: Migration issues are important to be considered, in terms of future scenarios, too.
SY: Can we identify key groups of carers? Eurofamcare does not give us a forward-looking picture. Can we agree on a primary focus of carers? The conceptually different groups could be, for example:
- Group of carers at risk of falling out of workforce, or extremely stressed: many of them are there, many are women, some men; they need to be supported not to fall out of the workforce and continue to be productive
- Group of carers who are ill or impoverished due to caring responsibilities
- Group of carers who gave up work, from any walk of life, to care over a long period for a dependent person with long-term condition

CG: The second group should explicitly include spouses. MS: With older working population we will have older workers struggling to combine work and care duties.
JS: But can we quantify the numbers of these groups for policymakers? MN: What about SHARE? Everything is there probably. KC: I also know of some studies.
CG: Can we make it a bit broader, including not only migrant carers employed by families but also other groups paid by families? (The Eurofamcare study does not include them). GL: I agree. CG: Most foreign workers work in residential settings, are not employed by families.

GL: Care drain of working migrants – left behind children; mental health of migrants; remittances – how can ICT improve these transfers.
GL: Where do policymakers want to save – employment loss vs. residential care (employed daughters are the ones most likely to be ready to put dependents into residential care).
JS: In the coming session please characterise service-oriented and family-oriented regimes, and decide who to focus on.

2. Break-out group session

2A. Service-oriented care regime
Chair: Sue Yeandle, Leeds University
Rapporteur: James Stewart, IPTS

(see results presented below in paragraph 3)

2B. Family-oriented care regime
Chair: Giovanni Lamura, ECV/INRCA
Rapporteur: Clara Centeno, IPTS

(see results presented below in paragraph 3)
3. Plenary discussion

3.1. James Stewart, IPTS – Summary of discussion in service-oriented care regime group

The service-oriented care regime group discussed mainly issues concerning countries where there are publically organised services that are reasonably available.

Targeted groups of carers:
1. Invisible co-resident carers: spouses and children, often impoverished
2. Those currently combining work and carer, at risk of stopping work

3.1.1. Needs

Needs of invisible co-resident carers:
- Mainly spouses.
- Tendency to Social isolation
- Health problems generated by caring and by own aging
- Sleep deprivation - Leads to need for emotional support For stress management
- Stress in dealing with formal services – care coordination. (relief of being able to email)
- Need Recognition of care responsibility by society
- Depends on the type of social support network
- Information about help.
- Physical Assistive technologies – smart
- Regular re-Assessment of needs by professionals
- (Care plan – to help people understand what help they could benefit from)

Needs of carers combining care and work:
- Need Flexibility in terms of employment – more than flexibility - ability to drop everything. Rights to emergency needs.
- Recognition of status, especially by firm
- Information on benefits, rights etc
- Anxiety comes from not knowing what is going on at home. Need to now that you will be informed when something goes on
- Not worry about falling behind, not keeping up with needs of organisations
- Many part time – suffering financial penalty
- Need Support to develop careers
- Caring services only accessible in working hours - need them outside
- Need time off caring – leisure, personal recuperation

Particularly challenging care situations for both types of carer can be identified in:
- Dementia
• Frailty. Already dependent person who can fall into much greater disability/illness in cascade, severe. Places more stress, and these are the people most at risk of hospitalisation. (5 criteria of frailty.)
• Cancer
• Depression

3.1.2. Actors providing support to carers and role of ICTs

Possible actors that can provide support to the invisible coresident carers:

• Other family members, children, close neighbours, more distance relatives who live locally.
  o Websites, information;
  o Coordination websites;
  o Telecare. Is it used in co-resident? symptom monitoring (carer blind)
    Smart incontinence pads.
  o Get out of bed monitor – sleep deprivation.
  o Beyond pilots in UK. E.g. Leeds 8k, Scotland 50k
  o GPS systems for wandering. The use depends on the family – for freedom or for constraint. Issues of consent.
• Volunteers – usually belong to an NGO; NGOs like disease/carer organisations.
  o Care coordination – allow volunteers to communicate
  o Booking breaks services? May not be used so much by this group.
• GPs, Social work and health professionals
  o Used to contact the patient.
  o Organise their own work
  o Privacy and ethical consideration to wider use. (e.g. not allowed to share data).
  o Need protocols to share information.
  o Big obstacles to use of infrastructures.
  o Need to change the practices and protocols of these groups.
  o Home help report – paper records. NL family members not allowed to read these. Notes left by home help to family carer. No non-co-resident
• Home care providers; individual home care assistants
  o Homecare could use telecare replace or enhance issue.
  o Cultural differences between homecare and telecare organisations.
  o Skype-type solutions. NL not for co-residents.
  o Public authorities e.g. from Upsalla. Network of 70 carers

Possible actors that can provide support to the carers combining care and work:

• Broader Family and friends
  o telephone, skype; care coordination websites. Weshare etc. Social networking. Spreads the pressure. Keeps people in work
• Employers
  o Telework
  o Allow Use of internet to access services.
  o Companies providing portals etc
• GPs, social workers etc
  o flexibility for end users, making it easy
  o Referral mechanism to carer orgs – help GPs
• Home care provider
  o Use SMS, email etc
  o Homecare workers maybe not allowed to do this. Pilots and works well

In particular, ICTs can play a relevant role in improving support services provided by the above mentioned actors. Some of the technologies and services that may have a huge impact are:
• Social network tools.
  o Ready, but need the consent of the older person.
  o How to link to formal and voluntary systems? These services would not connect to the commercially provided.
  o How to normalise that people talk about our health behind our backs!
  o Sharing info with social care – slippery slope to residential care.
• Home-based ICT
• Information on what help is available
• Syndication of info from different providers
• Localisation
• On mobile phone, apps
• Personalisation
  o Done by local orgs, but infrastructure should be most economically funded nationally...
  o Evidence of cost effectiveness available in UK

3.1.3. Current situation and trends in the care regime

Current situation
• Driver of change- economy. Keep older people at work.
• Barrier of pensionable age – less care. More people in this situation.
• Personalisation, Cash for care, consumer choice etc
  o Risks and benefits
  o Policy makers and professionals would like to do deliver this, but it is very hard
• Privatisation of these services

Issues and trends
• Big business opportunities
• Regulation
• Competition
• Intermediaries: user led, brand led, subverted
• Helping consumers to make choices
• Who to trust? Misselling to older people common.
• Why cannot we just buy services off the shelf?
• Quality of the service.
• Role of professionals – in assessment
• What level of devices and services should be available? Telecare.
  o Should this be the state?
  o The product should be certified. Especially human services behind.
• What things are ready for consumer market?
• What things are ready? When will certain produced become market ready?

3.1.4. Towards the ideal scenario
• Care coordination: ideal, but very complex, will take a long time to align players. Many barriers.
• Employers: not many initiatives around. Remote working: not very used. ICT solutions can be easy investment for employers. France not there; UK and Nordic much more promising. Self-rostering for some jobs.
  o Barriers of attitudes to older workers. How to support employers to support working carers? Weak rights lead to positive outcomes, but not in France.
  o Examples for big firms – but mostly concern over SMEs. Work team level?
• Carers to not identify themselves – how to make this easier? Possible solution: carer passport (UK). Need senior leadership self identifying as carers.
• People at point of giving up work – need advice.
• Large national orgs have the national info, but not the local info that people need in their everyday life.
• Clear need for more appropriate evidence in the field.

3.2. Clara Centeno, IPTS – Summary of discussion in family-oriented care regime group
Targeted groups:
1. Those extremely burdened, very stresses at work, at risk of loosing their jobs (their employer want them to be productive) -employed
2. Those who have given up work or never worked because of care for a long period of time, including spouses
3. Those providing care in conditions of illness or impoverished or socially isolated, including spouses and children ... “at risk of giving up care and work” categories.
There are big studies on that (Kevin) .. this group could be even bigger (as you would could decide to leave care because you just want to work)

4. migrants as a separate specific group part of paid support outside formal care services:
   o Regularization of family employment
   o Sufficient supply for demand and issues related
   o Migration flows implications
   o Labour force issue
   o Needs a lot of attention

These target groups are considered also from a policy point of view: employment, sustainability of care systems, poverty.

3.2.1. Needs

- Working carers
  o Work place support
  o Care services
  o Employment statutory rights
- Not working carers
  o Support for own well-being
  o Care services and
  o Financial support
  o Affordable services support
  o Return to work support after caring period
- At risk
  o Health
  o Social integration
  o Financial support
- Migrants
  o Peer support
  o Counselling
  o Specific needs

Across the target group categories, the following needs have been identified:
- Care management tools
- Counselling and emotional support
- Information services
- Peer support

3.2.2. Actors providing support to the carers and the role of ICTs
Across all the target groups, carers can be supported by:

- **Services provision:**
  - statutory actors
  - private
  - informal and community (civic)
  - voluntary sector NGO

- **Other support:**
  - employers
  - policy makers, legislators

In particular, ICTs can play a relevant role in improving support services provided by the above mentioned actors. Some of the technologies that may have a huge impact are:

- Alarm services
- Internet-based information system
- Skype (and VOIP in general) care

### 3.2.3. Current situation and trends in the care regime

**Current situation**

- Little support from public institutions, insufficient
- NGO playing an important role in some countries, Church in PL?
  - service provider as a private organization
  - building capacity
  - mobilization of volunteers (mobilize, credit, recruit, train, participate)
  - care time banks
  - role of regulation to stimulate and protect NOGs and volunteers (rights)

- Some formal services
- Minimum number of families have access formal services
- Varied (countries) and mixed solutions: family, NGO, live-in support (black labour market)
- A problem for lower economical level (not in IE)

**Trends**

- Moving from carer to care community, and future service will have to focus on this trend.
- In Central European: the role of NGOs expected to increase
- An policy enabler would be the integration of policy areas / moving from “carer” to “caring” / care is an issue of the whole population ->> mainstreaming caring into other policy areas (Public health)

### 3.2.4. Towards the ideal scenario

- Based on existing solutions
- From Skype for social inclusion and telecare to a remote consultation system
Stage 1: Deploy HU Skype Care Case

- Social inclusion benefits
- Saves time to carer for presence
- Young volunteers participation for digital inclusion (developing civic participation, intergenerational relations in the context of care)
- Developing digital skills of home workers
- Develops market potential
- Support working carers
- Supports sharing of care among several actors

- From Skype for social inclusion and telecare to a remote consultation system

Stage 2: Remote consultation

- From PC based Skype to more sophisticated ICT
- Videoconference
- Include medicine administration
- Collect medical data
- Link to GP, hospital, formal carer

Challenges for the adoption of ICT-based solutions for carers:

- Infrastructure availability
- Funding of equipment and internet connections
- Sensitivity re. young carers
- Links to health and formal care

Possible measures for facing the challenges:

1. Look at the Skype Care (Hungary) case
   - Support NGOs
   - Promoting volunteering (regulation?)
   - Work with employers (EfC)
   - Digital skills in care to several actors
   - Funding schemes (kick-off)

2. Study transferability to each context

3.3. Discussion of results

Intergenerational solidarity

GL: Intergenerational solidarity can use simple technologies: they might become more interesting in the future, especially in family care regimes. JS: Support families in helping themselves, and each other within the family. MS: packaging tools for care management together to “sell” them better.

ZS: by learning the Skype tool older persons do not feel dependent anymore. Older people can use video tools in order to show what they do during the day (hobby). All people wants long conversation: young population wants to talk with older people.
Family members shared Skype. The dependency scenario changes: they do not feel dependent anymore. JvB: very dependent people in Quebec trained French young people in English language. Teenagers in France had more opportunities in the labour market.

SY: This is nice to support older people, but I am not sure it helps really stressed carers for dementia patients or significant physical limitations, we need to focus on ICT for these kinds of conditions. JvB: However, in the experiment I told you about it was found that older people also felt less restrictions.

GL: invisibility is crucial. Burden is so high, ICT can support this area. Even in working carers, know that children or younger generation can connect to older ones is positive through new technologies. JvB: infrastructure required can vary among EU countries, in Netherlands all families have internet access.

GL: The low-cost solutions were on our mind very much. In the other group visibility was a main topic – this is very important, because you can do something in a very different spirit, and ICT can contribute to that very much. Involving grandchildren into care can be helpful in that. SY: At the moment it is mostly spouse carers who are not so well connected.

Challenges
- Availability of broadband
- Institutional barriers: privacy (talking about care needs with neighbors etc.) – although sometimes older people may be reluctant and need to be convinced
- Solutions for heavily burdened carers
- Empowering older people
- Educating health professionals
- Create better work conditions
- ICTs as a tools for reaching carers: for ICTs the question is not ICTs providing services, but ICTs as a tools for reaching carers with information and knowledge about support, and enabling them to access and use the appropriate support. There are a lot of European differences. Furthermore information needs change continually: static information provision is not enough. More efforts from local authorities to reach possible users of ICTs in home care explaining the potentiality.
- Organisation and innovation: actors should be flexible because they have to satisfy individual needs. Business of home care can be applied in service economies.
- Telecare: how to make it accessible for carers, give them a say in it. MS: awareness of technology solutions is the first step – low-hanging fruit services, easily deployed or made available. Many older people don’t know about technology solutions in this field. JvB: even in different countries developments may differ a lot from each other, and future directions too.
- European fragmentation: there are different needs in different European countries. More research at the national level should be done in order to understand concretely what is needed by the actors.

Actors and stakeholders
SY: In Britain we have a tendency to include carers as expert partners, within health and social care organisations. RC: Or even as equal partners. JvB: They don’t want to be equal partners. They are taught to even have authority towards the patient even (formal workers). MN: Giving them technology may even make them feel better, but if you give it to the dependent person you are back again to non-differentiating between formal and informal carers? GL: ICT as a tool to give fight over power in care between formal and informal sector.
JvB: understand role of formal professionals. GL: probably they don’t have even a strong relationship with family carers. Difficult to convince formal professionals that ICT can help.
JvB: Consumers will start to launch change also among professional care workers. JS: Who will address consumers? Intermediary organisations to build trust in these consumer services? SY: Partly employers, if carers are working, they need to have employers directing them. MS: GPs also should know about telecare. JvB: Telecare companies still need to learn how to address consumers. JS: Who are the people who know how to address consumers? NGOs? SY: Otherwise Chinese companies are going to take over the market. Companies should take the opportunity now before other countries. KC: Age UK they recommend and produce. Market will develop on the basis of traditions and care regimes. MS: We have to take an imaginative leap – technology is going to transform this area (e.g. like it transformed the workplace etc.).

Research questions for the future
MS: market research, what looks great and works, what people want. Balance professional and entrepreneur approaches. GL: Maybe the statutory services as intermediaries are not necessary. It is possible to overcome the idea of a statutory market. MS: Reach people where they are, this is why employees are more easily reachable. SY: How about a tele-care advisory service in every hospital? JS: Tax incentives might be an option – tax breaks after installing. JvB: If you set up a youtube video on telecare, it would be interesting as case studies, but you would need to translate these into different languages.
JS: More local than the national level. JvB: In the NL provinces have their own websites, done by governments or NGOs, often connected with local radio or TV. GL: Think more on non-profit organisations, how they can combine low cost services with high efficiency. Not only to small groups and how can it be transferred, by which means, cost-effectiveness of the initiative. Estimation, calculation of macro-level data and business case analysis. RC: Local organisations are important stakeholders, but carers also must be able to access the information. One of the problems is that ICTs are changing very fast and it is hard to keep people updated. MS: How about making devices available to everyone?
MS: Research on how to reach people. How do you disseminate the information? Not, is it valuable? You can always build another evidence base, but the biggest issue is rolling it out. So how do you deploy the information. Results should be in different languages.
SY: research on (private) home care providers, some of them are international actors and it would be good to look at why they don't use telecare.
MN: Like in the pharmaceutical company it starts with small pilot companies developing a product, so looking at innovation dynamics in this area would be helpful.
ZS: For me the innovative role of NGOs would be interesting, how can they combine low-cost services with high efficiency.
MS: Awareness raising among employers for the needs of carers. SY: Employers could be made aware of productivity gains arising from there.
Annex 1: Agenda of the Workshop

Brussels, 21st/22nd November 2011
JRC, Square de Meeûs 8, 1050 Brussels

This workshop consists of 2 Parts:

**Day 1** Presentation and discussion of the results of the CARICT study on ICT-enabled services to support carers for the elderly, in the context of Long term Care Policy and eInclusion policy

**Day 2** Scenario-based workshop to build policy, research and practice recommendations on how to exploit the potential for ICT-enabled services to support carers for the elderly for different target groups across the spectrum of Long Term Care regimes in Europe.

**Monday, 21st November 2011**

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<tr>
<th>Timetable</th>
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<tr>
<td>11:30-13:00</td>
<td>Registration and Lunch</td>
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<tr>
<td>13:00-13:30</td>
<td>Introduction and Aims of the Workshop</td>
<td>Clara Centeno, JRC</td>
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<td>Policy questions related to Long Term Care</td>
<td>Arnaud Senn DG EMPL</td>
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<tr>
<td>13:30-15:00</td>
<td>Presentation and Discussion of CARICT Results, including cross cutting analysis, overview of 52 cases surveyed, and impact assessment findings</td>
<td>Chair: IPTS</td>
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<td>Chair: IPTS</td>
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<td>Presentation of D2.3</td>
<td>Francesco Barbabella</td>
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<td>Presentation of D3.6 and 5.1</td>
<td>presentations of D3.6 and 5.1</td>
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<td>15:00-15:30</td>
<td>Coffee</td>
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<td>15:30-17:15</td>
<td>Presentation and discussion of some cases in detail.</td>
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<td>Zsuzsa Széman</td>
<td>presentation of Emergency Alarm</td>
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<td>Carlos Chiatti</td>
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<td>Rosie McLoughlin</td>
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<td>Sue Yeandle</td>
<td>presentation of Telecare Scotland</td>
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<tr>
<td>17:15-18:00</td>
<td>Expert presentation and discussion on broad context: What works for carers and elderly people in need of care (non-ICT specific)?</td>
<td>Chair IPTS</td>
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<td>20:00</td>
<td>Dinner</td>
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### Tuesday, 22nd November 2011

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<tr>
<td>09:00-09:20</td>
<td>Aims of breakout groups, and explanation of method.</td>
<td>Chair: IPTS</td>
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<td>James Stewart presentation of break-out groups</td>
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<tr>
<td>09:20-10:00</td>
<td>Presentation and discussion of dependency scenarios developed in Deliverable D5.1</td>
<td>Chair: IPTS</td>
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<td>Giovanni Lamura presentation of a draft of future scenarios</td>
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<tr>
<td>10:00-13:15 (including coffee)</td>
<td>Development of policy and research recommendations, using evidence, expertise and material from dependency scenarios, in breakout groups.</td>
<td>Service care regime group Chair: Sue Yeandle</td>
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<td>Rapporteur: James Stewart</td>
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<td>Family care regime group Chair: Giovanni Lamura</td>
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<td>Rapporteur: Clara Centeno</td>
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<td>13:15-14:00</td>
<td>Lunch</td>
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<td>14:00-15:30</td>
<td>Conclusions and Close</td>
<td>Chair: IPTS</td>
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<td>James Stewart summary of results from the service care regime group</td>
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<td>Clara Centeno summary of results from the family care regime group</td>
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<td>Plenary discussion</td>
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Planned division of participants among the two groups.

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<td>European Foundation for the Improvement of Living and Working Conditions/Chair of Eurocarers</td>
<td>Ireland / Europe</td>
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<td>Katarzyna Balucka-Debska</td>
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<td>2</td>
<td>Annelies van Bronswijk</td>
<td>Utrecht University and International Society for Gerontechnology</td>
<td>Netherlands</td>
<td>2</td>
<td>Stephanie Carretero</td>
<td>President Sociedad Española de Asistencia Sociosanitaria (SEAS) /Uni Leuven/ Uni Valencia</td>
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<td>Confederation of Family Organisations in the European Union (COFACE)</td>
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# Annex 2: List of participants

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<td><a href="mailto:s.m.yeandle@leeds.ac.uk">s.m.yeandle@leeds.ac.uk</a></td>
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**EXPERTS from the EC**

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<td>EC DG EMPL</td>
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<td>22</td>
<td>GL</td>
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<td><a href="mailto:lamura@euro.centre.org">lamura@euro.centre.org</a> <a href="mailto:g.lamura@inrca.it">g.lamura@inrca.it</a></td>
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<td><a href="mailto:schmidt@euro.centre.org">schmidt@euro.centre.org</a></td>
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Annex 3: Participants’ biographies

Francesco Barbabella, MA, is a doctoral student in Theory of Communication from the University of Macerata (Italy): his research focuses on health promotion and health education issues, as well as with the role of ICTs in long-term care. Currently he is a grant recipient from INRCA and a visiting doctoral student at the European Centre for Social Welfare Policy and Research, Vienna (Austria). These collaborations deals with several ongoing international projects on ageing-related topics, such as FUTURAGE, ASPA, and CARICT. Moreover, he has experience in the field of knowledge management concerning the semiotic assessment of graphic user interfaces, software usability, and structure of contents.

Stephanie Carretero, PhD in Psychology. She is Juan de la Cierva postdoctoral researcher at the Polibienestar Research Centre of the University of Valencia (Spain) and she is currently doing a postdoctoral stay at the Institute of Health and Society at the Université Catholique de Louvain (Belgium). Regarding support for carers, her research has been focused in the impact of social services on the health and social status of the informal caregivers in charge of dependent people as well as the integration of the informal sector in the long term care system. Some of her publications on informal care are: How to Get the Future of Mental Health of the Families in Charge of their Elders (Ed. Nova Publisher INC); Evaluation of the home help service and its impact on the informal caregiver's burden of dependent elders (International Journal of Geriatric Psychiatry), Thecare of the informal caregiver’s burden by the Spanish public system of social welfare: a review (Archives of Gerontology and Geriatrics) and The role of informal care in Long Term Care in Spain and from an European Overview (INTERLINKS project).

Carlos Chiatti holds a Master in Economics and a PhD in Epidemiology. He is a research fellow at the Italian National Institute of Health and Science on Ageing (INRCA) and visiting fellow at the University of Newcastle upon Tyne. In addition, he teaches Health Economics at the University of Ancona. In his past professional experience, he was consultant for many public and private health institutions in projects aimed at improving services organisation and the Information Systems within the Italian National Health Service. His doctoral thesis was specifically focused on social inequalities in health and health care but he has also worked on several international projects in the field of active ageing. At INRCA, he is currently working on the project FUTURAGE, aimed at defining the roadmap for future ageing research in Europe. He recently received a research grant from the Ministry of Welfare, for a large community trial (UP-TECH project) aimed at improving the provision of health and social care for patients affected by Alzheimer Disease, through a better integration of existing services and the use of new technologies.

Annette Dumas Over the past 14 years, Annette Dumas has been involved in European political and advocacy work. Since 2006, she has been acting as the EU Public Affairs Officer for Alzheimer Europe, the umbrella organisation of Alzheimer associations in Europe. Her mission is to raise awareness about the challenges of dementia among the EU policy makers and ensure dementia is a European public health, research and social priority. Since that date, thanks to the commitment of EU and national policy makers, the close collaboration with Alzheimer Europe's members, a series of EU and national dementia initiatives have been put in place.
In 2007, Annette set up the European Alzheimer’s Alliance, a non-exclusive, multinational and cross-party group who brings together Members of the European Parliament committed to support Alzheimer Europe and its members to make dementia a public health priority in Europe. Annette has participated in European conferences and roundtables to share her experience, either as a speaker or as a member of the organising committee. She has also published articles in professional and EU publications.

**Caroline Glendinning** is Professor of Social Policy in the Social Policy Research Unit, University of York. She is an Associate Director of the National Institute for Health Research School for Social Care Research; Chair of the UK Social Policy Association; and a Trustee of the Thalidomide Trust.

**Elizabeth (Liz) Hanson** is a Senior Lecturer at the Linnaeus University, Sweden and acts as Scientific Leader of the Swedish National Family Care Competence Centre. She holds a Visiting Reader post at the University of Sheffield School of Nursing in the UK. Her research areas include informal care and the quality of life and care for older people with advanced chronic illnesses. She has been living and working in Sweden for the last eleven years and is research leader for the ACTION initiative (Assisting Carers using Telematics Interventions to meet Older people’s Needs) which began as an EU project in 1997 and in 2004 became a mainstream service in Borås municipality in West Sweden. She has a long-standing interest in the potential of new technologies to help empower frail older people and their family carers in their daily lives who are often excluded from the potential benefits afforded by the current information society. Her current interests lie in the successful implementation and integration of telecare and telehealth services within existing health and social services for older people and their families.

**Kevin Cullen** is a founder and director of Work Research Centre (WRC). He graduated in 1981 from University of Dublin, Trinity College, with a first class honours degree in psychology and has worked in socioeconomic research and consultancy throughout his career. As WRC's principal researcher/policy analyst in the area of social and economic aspects of the information society he has conducted many studies and policy assignments on a variety of themes (including eAccessibility, ICT and Ageing, technology and care/carers, eInclusion, eHealth, telecare/telehealth....). He also has conducted many studies on a variety of broader socioeconomic themes (including informal/family carers, long-term care for older people, health and social service innovation etc.). He is a nationally and internationally recognised expert in a number of these fields, including informal/family carers, eAccessibility, ICT and Ageing and eInclusion, amongst others. Recent publications include Kubitschke, L. and Cullen, K. (2010) ICT & Ageing: European Study on Users, Markets and Technologies. Report for European Commission.; Cullen K et al (2009) Survey of Older People and ICTs in Ireland (2008). Report for the Department of Communications, and a study: Company initiatives for working carers (2010-2011): study for European Foundation for Improvement of Living and Working Conditions.

**Giovanni Lamura** graduated in Economics in Italy and obtained his PhD in “Life course and social policy” at the University of Bremen (Germany). Since 1994 he has been working as gerontologist at INRCA (the Italian National Institute of Health and Science on Ageing), gaining experience in international research in following fields: family care of the elderly; reconciliation of professional and caring responsibilities; migrant care workers; quality of life in older age; prevention of elder abuse and neglect; long term care; older workers; ICT for informal care.
2006 - 2007 he was visiting researcher for one year at the University of Hamburg-Eppendorf, Institute of Medical Sociology, Hamburg (Germany), to work on the EUROFAMCARE project on family carers of older people. Recently he has been involved in projects such as "ABUEL: a multinational prevalence study on elder abuse"; "ASPA" (Activating Senior Potential in an Ageing Europe); "Care@work" (on the reconciliation of employment and elder care); "EURHOMAP" (aimed at mapping home care services in Europe); "Futurage" (aiming at outlining a "road-map" for future research on ageing in Europe); CARICT (ICT-based solutions for caregivers). Until August 2011 he is seconded to the European Centre for Social Welfare Policy and Research in Vienna.

**Rosie McLoughlin** is Carer Information and Communications manager for VOCAL (Voice of Carers Across Lothian), a carer organisation based in Edinburgh, Scotland. She has led the development of two carer websites - edinburghcarers.co.uk and carerstraining.co.uk - and is leading practical developments within VOCAL on carer digital engagement, linking carers to social media, and developing online solutions to support carers. She has participated in steering groups for the development of a national online respite database and a stroke carers e-learning website. She holds a MA and BA degree from University College Dublin, PgDip in Multimedia Systems (Napier University) and PgCert in Social Enterprise (Glasgow Caledonian University).

**Michel Naiditch** is a medical doctor, and research associate at IRDES (Institut de recherche en économie de la santé), Paris. Ses principaux domaines de recherche sont la performance hospitalière, l'information et la participation des usagers au fonctionnement du système de santé, l'évaluation des réseaux de soins. He was a research partner on the EU InterLinks project.

**Andrea Schmidt** graduated from Maastricht University, Netherlands, with an MSc degree in Public Policy in 2009, specialising on social policy financing and socio-economic determinants of health. She obtained her first master's degree in intercultural communication sciences at the Karl-Franzens University of Graz, Austria, in 2007 (MPhil). She has been working as a research assistant in the Department of Health and Care at the European Centre for Social Welfare Policy and Research in Vienna, Austria, since March 2010, where she has participated, among others, in publications and research projects on financing of long-term care systems in Europe and active ageing. She has been actively involved in research projects at national level, for example on activation of older workers in the Austrian labour market, and at EU level such as ‘ECAB’ (Evaluating Care Across Borders in Europe) and ‘CARICT’ (ICT-based solutions for caregivers). In the latter she has worked mainly on the comparative analysis of 52 ICT-based initiatives for family caregivers in 12 European countries. Her main research interests include equity in long-term care and cross-border movements to European countries in the health and long-term care sector.

**Madeleine Starr** is Head of Policy Development at Carers UK, which she joined in 2000. From 2002 to 2007 she managed the innovative Action for Carers and Employment (ACE National) partnership, funded by the ESP EQUAL Community Initiative Programme, which developed and tested support in and into paid work for carers. Key outcomes from the partnership were Learning for Living, a pre-vocational e-learning programme for carers, the establishment of Employers for Carers, a forum for employers committed to developing and promoting good practice to support carers in the workplace, and the Carers, Employment and Services Report Series, the most comprehensive ever quantitative and qualitative research into carers and
employment, carried out by Professor Sue Yeandle. Madeleine has worked in the field of caring and employment since 1998. She was recently recognised as a Working Families Pioneer for ‘her sustained and successful campaigning for carers’ employment rights, and for her influence in establishing Employers for Carers’.

James Stewart is a temporary Scientific Officer at the Institute for Prospective Technology Studies at the European Commission, in the Action on ICTs for Social Inclusion, with responsibility for the CARICT project. He is a lecturer and research fellow at the University of Edinburgh in the Institute for Science, Technology and Innovation, where he teaches on issues related to the Information Society, and innovation in ICTs. He has a BEng in Electronics, and a PhD in Science and Technology Studies. His research interests are focused on the appropriation and innovation done in technology, policy and practice as new technologies, in particular ICTs, are shaped to support the activities and relationships of particular domains of everyday life, industry or government. He has particularly focused on ICTs in the home, in research, and for women, and on the role of design, users and end-user intermediaries.

Zsuzsa Szeman is a Sociologist, leader of the Welfare Mix Team, Institute of Sociology, Hungarian Academy of Sciences, Budapest, and Her research interests include exploring the different social problems of the elderly such as care, mobility, quality of life, social and health services on local and regional level, labour market, pension system, older people at risk, the changing relationship between state/public/local and regional government, problem of poverty in old age. She is a member of several international bodies; and has taken part in projects such as MOBILATE (Enhancing Mobility in Later Life —Personal Coping, Environmental Resources, and Technical Support; ENABLE-AGE (Enabling Autonomy, Participation and Well-Being in Old Age: The Home Environment as a Determinant for Healthy Ageing); EUROFAMCARE–NABARE (Support and Relief for Family Carer of Older People); Ageing and Employment: Identification of Good Practices to Increase Opportunities and Maintain Older Workers in Employment (2004); Employment Initiatives for an Ageing workforce. Eurofound (2006-2007). Author and editor of numerous books and papers (e.g. “Caught in the Net in Hungary and Eastern Europe” Nonprofit Research Group–Institute of Sociology, Budapest (2000); “Social Quartet”, Nonprofit Research Group–Institute of Sociology, Budapest (2000), H. Mollenkopf, el al (Eds.) Enhancing Mobility in Later Life—Personal Coping, Environmental Resources, and Technical Support. The out-of-home mobility of older adults in urban and rural regions of five European countries, Assistive Technology Research Series 17, IOS Press, Amsterdam.

Judy Triantafillou is a UK trained medical practitioner, working in Greece in the field of primary care and in research at both national and European levels into healthy ageing, services and family care for older people www.sextant.gr. She is a founder member of the first Greek NGO for older people 50plus Hellas www.50plus.gr and has represented the organisation on the Administrative Council of the AGE Platform Europe http://www.age-platform.org/; as a member of AGE’s Health Expert Group she has been involved in user evaluations of projects on IT and older people, including a site visit to the DREAMING project (elDeRly-friEndly Alarm handling and MonitorING) in Langeland, Denmark. Together with Prooptiki Co. she represents 50+ Hellas in the EU INTERLINKS FP7 project, on Health and Long term Care Systems for Older People in 14 European countries (2008-2011), being a member of the Scientific Management Team and leading Work Package 5 on the role of informal care within LTC, as well as contributing to the INTERLINKS Framework for LTC http://interlinks.euro.centre.org/.
Other recent projects include EUROFAMCARE ("Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage", 2003-2005) http://www.uke.de/extern/eurofamcare/ and CARMEN ("Care and Management of Services for Older People in Europe Network", 2002-2004) www.ehma.org/index.php?q=node/56, as well as work with the National School of Public Health, Athens, the European Foundation for the Improvement of Living and Working Conditions, Dublin and the WHO.

Julia Wadoux - Policy Officer in charge of health, ICT and accessibility at AGE Platform Europe. AGE Platform Europe is a European network of around 160 organisations of and for people aged 50+ which aims to voice and promote the interests of the 150 million senior citizens in the European Union and to raise awareness on the issues that concern them most. Besides the policy and advocacy work done on different issues such as health and ICT, AGE is involved in different EU project like Dreaming, Home Sweet Home or OASIS that deal with ICT support for independent living and health monitoring. In addition, AGE is leading the WeDO project for a European Partnership on the Well-Being and Dignity of Older people that looks more specifically at quality in long-term care settings.

Verina Waights is a Senior Lecturer in Professional Health Care Education at The Open University in the UK. She is cofounder of the Interdisciplinary Older People and Technology Research Group and a member of the Centre for Aging and Biographical Studies. She worked with the Department of Health, England and Wales, in a small team developing an online assurance framework for Community Matrons, which provided a framework for assessing the competencies necessary to be fit for practice. Her research focuses on older people’s use of new and emerging technologies and she is a co-investigator in the pan-European Grundtvig-funded project OPT-in: Older People and Technological Innovations (total funding €88 500), which in collaboration with AgeUK MK, explores older people's engagement with new technologies through play and a co-investigator in the UK ESRC-funded seminar series: ’Older People and Technological Inclusion, exploring technological inclusion in relation to older people's experiences of everyday life’. She has worked with Birmingham City Council UK on workshops for carers exploring digital skills and the NET-EUCEN scenario: building digital skills for carers (Network of European Stakeholders for Enhance User Centricity in eGovernance accessed at http://www.net-eucen.org/scenarios.php)

Sue Yeandle is Professor at the University of Leeds, and Director of CIRCLE (Centre for International Research on Care, Labour and Equalities). Under Sue's leadership, CIRCLE has developed an internationally recognised programme of research on carers, including the National Evaluation of the UK Department of Health’s ‘Carers Strategy Demonstrator Sites programme’ (2009-11), the ‘Carers, Employment and Services' Study (published by Carers UK in 2007) and the ongoing ‘AKTIVE’ project (Advancing Knowledge of Telecare for Independence and Vitality in Later Life) funded by the UK Technology Strategy Board and the Economic and Social Research Council. Sue was Special Adviser to the House of Commons Work and Pensions Committee for its ‘Inquiry on Carers’ in 2007-8 and a member of the ‘Carers and Employment Task Force’ which advised the UK Government on the National Carers Strategy in 2008. Her research interests centre mainly on the relationship between work and family life. Between 2003 and 2006, Sue led the Gender and Employment in Local Labour Markets research programme.
Annex 4: Workshop brief

Context
In the context of European Commission Joint Research Centre (JRC) research actions to support policy in the areas of Long Term Care, and Information and Communication Technologies (ICTs) for social inclusion, the Institute for Prospective Technological Studies’ (IPTS) and DG INFSO commissioned a study aimed at providing evidence and policy options on the role of ICT-enabled services to support informal carers and family-employed care assistants. A consortium lead by the European Centre for Social Welfare Policy and Research was asked provide evidence to inform two policy questions:

1. to what extent do initiatives / good practices exist in the EU and abroad, what is their actual socio-economic impact? and,
2. how can policy support development, scalability, transferability or replicability of existing good practices in other contexts within the EU?

Goals of the Workshop
This workshop has been convened to hear and discuss the evidence and analysis produced by the study group and to use this new evidence to formulate policy options / recommendations for the development, scaling, replication and transfer of ICT-enabled carer support services. Experts have been drawn from practice, research and policy circles, with an emphasis on those bridging these boundaries, bringing in depth knowledge of local, national and European issues.

Following the Workshop, the suggestions coming from the workshop discussion will be integrated in the final integration report (deliverable 5.3) in form of policy recommendations: that will address the main question “What role can ICT-based initiatives play in such future scenarios and policy challenges?”, linking already drafted dependency scenarios and proposed issues with possible policy options for improving ICT adoption in the field.

Input required by participants
In preparing for the workshop, the participants are invited to consider the following questions, based on the evidence now available summarized in the document 'D5.1’ included with this brief, and more comprehensively developed in other on-line deliverables listed in the section below.

1. Does this new evidence and analysis suggest that ICT-enabled services can play a significant role in supporting carers and the sustainability of LTC in Europe?
2. More concretely, for different scenarios (clusters) of carers and related dependent elderly people, how could ICT-enabled services be used to support carers and improve the family care environment so as to support home-based care in the context of different regional care regimes?

3. Which are the actors / stakeholders (carer organizations, health and care organizations, technology providers, service providers, enterprises, policy actors, etc) that play or could play a role in developing ICT-enabled services that support carers?

4. From the above examples, in light of limited governmental budget for investment, what ICT-enabled services would offer the most cost effective outcomes with modest investment?

5. What challenges and therefore which actions need to be taken, and by which stakeholders, to facilitate the maximum benefit of ICT-enabled services to carers and dependent elders?

6. What new research and development is necessary, including additional evidence on impact, to make ICT-enabled services more effectively deployed by the different stakeholder involved in family and home care?

7. How can the evidence produced by the project be used to put the role and needs of family carers on the agenda of Long Term Care policy and into (technology-based) innovation policies and support processes?

In order to answer these questions, the workshop will be structured around two working groups, each addressing the needs, resources, motivations and potential benefits of these services for specific target care clusters: heavily burdened older spouses and heavily burdened daughters. Among other issues, the first group will have a special focus on dementia, and the second consider issues of reconciliation of care and work.

The participants will be provided with a framework of types of ICT-supported services, and a Dependency Scenarios proposal (both include in D5.1 and to be presented), outlining a range of core background information on motivation, problems with existing services, values, national differences etc.

If you would manage to send any comments before the meeting, we would be able to use them in the introduction to the group discussion.
CARICT Project Activities and Main Outputs

The study CARICT was based on prior work by JRC-IPTS documenting the use of ICTs to support informal carers and family-employed care assistants (available on-line)\(^1\). Final study output aims to provide evidence of the diversity of long-term care situations in which ICT can make a contribution; and to describe and analyse 12 established initiatives, identifying their current and potential socio-economic impact. This will form the basis for policy options / recommendations for the development, scaling, replication and transference of ICT-enabled care support services that will incorporate the recommendations of the workshop.

A number of steps have been taken during the project to collect the evidence to be presented and discussed. This is available in the following deliverables which can be downloaded from the following address: http://dl.dropbox.com/u/2572583/CARICT%20documents.zip

1. A **mapping and analysis of 52 ICT-based initiatives for carers** (deliverable D2.3)\(^2\) which analyses the types of established services currently being provided across Europe. This document provides also the most complete empirical reference to the use of ICTs to support informal carers and family employed care assistants available at this time in Europe.

2. A **methodological framework** (deliverable 3.6) which includes both a conceptual framework and a prototype of Impact Assessment Methodology (IAM). This latter is a multi-layered instrument that developed in detail a large range of indicators for assessing outcomes of ICT-based solutions for carers. This is the first attempt made in Europe to build a methodological framework focused on informal carers and privately paid assistants. Furthermore, this document includes also a cross-analysis based on the 12 good practices report (see below, deliverable 4.3) aimed to test the methodological framework and better understand gaps between theory and practice in impact assessment.

3. A **dependency scenarios proposal** (deliverable 3.1) has been developed in order to explore the potential impact in for a range of care situations and across Europe. It draws some projections on children and spouses caring for dependent older people in Europe in the medium and long-term. Based on available data, this report provides estimations of future needs of carers, taking into account three basic situations: (1) cohabiting, non-employed daughters of highly impaired older people; (2) non-cohabiting, employed daughters of moderately impaired care recipients; (3) spouses of a moderately to highly impaired partner.

4. A **description and analysis of selected 12 good practices** (deliverable 4.3) which aims to analyse in-depth some good initiatives selected in Europe, integrated with

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\(^1\) http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html

\(^2\) Public report available separately

http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/documents/CARICTD2.3Mappingof52initiatives.pdf
two other ones from North America. Operational details and evidence of impact assessment previously carried out is provided in order to have a broad view of how such ICT-based solutions work, what is commonly assessed, and what are their possible implications for transferability and sustainability, as well as for policy issues (e.g. social inclusion, impact on health and social care system etc.).

5. A draft integration report (deliverable 5.1) that summaries the outputs of the methodological framework and of the description and analysis of 12 good practices. It provides also a cross-analysis of the 12 case studies in order to better understand the established evidence of these initiatives, i.e. to define what kind of positive outcomes can be really expected from which kind of technologies and services. Finally, possible impact at policy (macro) level are proposed on the basis of the gained evidence.

As a reminder, this project and the advice provided in the workshop has as its aim to support the European policy development process, both on Long term care and Information Society policies, and provide practical tools to stakeholders, with the aim of enabling development, scalability, transferability or replicability of existing good practices that will support carers in many different European contexts.

*The Deliverables you have been sent are still in Draft form, so please do not circulate them outside of this meeting without asking permission from ECV or IPTS.*
Annex 5: Outline of scenario exercise

Aims
In the context of a desire to improve support for family carers and the overall sustainability of Long Term Care for the Elderly in Europe, but in light of limited governmental budget for investment, the workshop is today invited to consider the following questions, based on the evidence now available and presented on Monday 21st Nov:

1. Which ICT-enabled services would offer the most (cost) effective outcomes with modest investment in the short to medium term in order to improve the support to the most burdened family carers and the dependent elderly people they care for in the European Union?
2. In order to implement these services, identify the actors that play or could play a role in their development, the challenges they face, and therefore which actions need to be taken by different stakeholders, including policy makers, to make it happen?

Means
The focus of the research and evidence available, and the work of many of the experts present is on the ‘care dyad’ – the principal carer and the older person they care for, so the workshop is build up from this focus, first by introducing the significant care support actors, then how their support role can be enhanced by ICT-enabled services, and finally how these actors can be supported by policy in developing this capability. It takes an actor-focused approach (rather than technology-led, or disciplinary analysis approach).

A fundamental issue in the organisation of Long Term Care and relieving the burden on carers relates to the supply of formal care services. This is known to vary widely across Europe, but can be broadly captured by using two ideal-type scenarios: 1 a ‘family'-oriented care regime, and 2. service-oriented care regime. While this is a gross simplification of the real world, for the purposes of this short workshop, it can be taken as a working tool familiar to most workshop participants.

To arrive at answers to the workshop questions, work will be carried out in two groups, one working within this ‘family'-oriented care regime scenario, and the other in the service-oriented care regime scenario. The workshop participants have been allocated to the two groups according roughly to the type of care regime of their country of origin. See page 3. If you wish to change group please speak up during the introductory session!

The group work of the participants will be facilitated to make the most of the limited time by a series of tasks that call for the identification of a limited number of key actors,
service and actors out of the many possibilities that could be discussed, the results of which decisions are carried over to the next task.

Each group will have a Chairperson, Giovanni Lamura for the 'family' regime, and Prof Sue Yeandle for the 'service' regime. IPTS staff will act as rapporteurs, and ECV staff will take minutes and provide expert input based on the CARICT study.

Resources
1. On Monday the workshop heard the presentation of the latest research results, and had a chance to question and consider the quality of evidence, and draw conclusions from that evidence as to whether we can identify positive examples of 'good practice' that has a verified impact in any particular region, and understand the factors shaping and steps taken to develop that good practice, and existing limitations.

2. Prior to the breakout sessions ECV will present a Dependency scenario proposal, which proposes a focus on three specific target care clusters of heavily burdened carers, looking after family members with physical and cognitive disabilities: Burdened wives; cohabiting/non-working daughters and non-cohabiting/working daughters. The Experts will have had a chance to consider and debate this proposal, and the empirical data, for example, highlighting the role of sons compared with daughters, husbands compared with wives, and the role of non-family carers, particularly in relation to older people with no direct family to care for them. The idea of the 'dyad' approach will also be discussed briefly.

The Dependency Scenarios document is available as part of CARICT D5.1 and in an extended form (CARICT D3.1), outlining a range of useful background information on motivation, problems with existing services, values, national differences etc, along with the in depth case studies, and the analytical frameworks developed by the CARICT consortium.

3. A small set of printed tables and list related to the typologies used in the CARICT study.
   - An non-exhaustive list of support actors: Family members; formal care services, both health and care; carer support organisations; volunteers; telecare organisations etc (in the printed annex)
   - Tables and visual supports of types of ICT-enabled services, functional descriptions of supports to carers, and examples of real service.

Timetable and Tasks
To build up consensus and to focus the work, the experts will work in 3 stages.

Stage 1 Building an understanding of need and key actors (10:00-11:20)
Stage 2 Identifying the most promising ICT-services and how to develop and implement them within the regime scenario (11:35-13:15)
Stage 1: Building an understanding of need and key actors  
10:00-11:25  
This stage focuses on the people in need of support, and those who can directly provide it.  

Task 1.1. **Identify the needs, resources, motivations and expectations of the carers discussed in the dependency scenario proposition, who are particularly heavily burdened by their responsibilities.** (20mins)  
The focus of attention is the care dyad of principal carer and dependent older person, how their needs and expectations change over the care cycle, and reasons why pressures on individual carers have built up.  
**Question:** Why do some family carers suffer excessive pressure related to care responsibilities, and what support do they need and expect?  
**Question:** What are the main differences in needs and expectations of carers identified in the dependency scenario proposal?  

Task 1.2. **Who supports these carers and how?** (20mins)  
Identify the roles, strengths and limitations of those individuals, organisations and social groups (Support actors) that support both members of the care dyad, but with a focus on the needs and concerns of the principal caregiver. (In the family regime, the role of migrant family employed caregivers will be considered.)  
See list on page 9.  
**Provocation:** Rank these actors in terms of importance in providing support.  
**Question:** What motivates these support actors, and what constrains them?  
Identify the 2-3 main ways each type of actor provides support and the 2-3 main limitations of current types of support (or failure to support).  

Task 1.3. **How can ICT helps these support actors?** (40mins)  
For these 2-4 main actors identified in the previous task, identify **how they could facilitate and use the ICT-enabled services** to enable them to better support carers and the care dyad, selecting 2-3 most promising types of service.  

Stage 2 Identify the most promising ICT-services and how to develop and implement them within the regime scenario  
(11:35-13:15)  
This stage implicitly involves identifying existing best practice, and considering how it can be developed and adapted from existing settings and configurations to support a broader population.
Task 2.1 What characterises a family/service oriented care regime? (25mins)

A discussion to characterise a ‘family’ or a ‘service’ oriented care regime, and the limitations of the concepts and important divergences to bear in mind. In this type of care regime scenario identify key themes and change trajectories in LTC and carer support (stakeholders, policy, discourses, demographic trends etc), drawing on the actor-focused discussion of the previous stage.

Questions:

What are the drivers of change?
What are the limitations to change?

Please rank the importance of different types of actor and stakeholder in driving change in care and support for carers,

Task 2.2. Outline an ideal scenario for using ICTs to support heavily burdened carers.

Using the choices and factors from the previous tasks, the group will select a desirable goal for change that involves development and implementation of ICT-enabled services. Select a small number of ICT-enabled services that together could have the most potential impact on carers and that could realistically be exploited by the different support actors and stakeholders identified within the scenario regime. The experts will explore in more detail the challenges faced in implementing these services, contingent factors, the role of different actors, and ways and means to support these actors and stakeholder in overcoming these challenges.

To focus the scenario building, the groups will choose a guiding idea, for example:

Option 1. Drawing on the trajectory of care for the regime identified in 2.1 build a scenario on how different ICT can contribute to arriving at the ideal scenario. E.g. joining up acute health care and social care; empowering families; professionalising informal care sector; changing the culture of care responsibility etc. The task is to explore how ICT-enabled services that support this trajectory can be developed.

Option 2. Identify a single type of support actor, and work on how best these actor and use and benefit from a range of ICT-enabled services: for example, employers, extended family, carer associations, telecare companies. The question would then be: what can be done for and by [this type of support actor] to enable them to exploit a range of ICT-enabled services to the maximum effect across this care regime?

Option 3. Focus on 1-3 particular ICT-enabled services that are identified are providing clear benefits, but are not widely available and used, should be developed. Using the rankings and suggestions from task 1.3 the group should select 1-3 to consider as the desirable to support. It might be easier to select one, but there is very likely to a number of interrelated services, or ones which are complementary. The task is to identify which actors need to be mobilised, and the challenges and resources needed.
Stage 3 Plenary comparison of discussion results
In stage 3, the two working groups will come together to compare findings, discuss implications and draw conclusions. (1hr30)

3.1 Presentation of working group conclusions by rapporteurs (IPTS)

3.2 Discussion of these conclusions
Questions
1. What are the most promising services? Are their clearly identifiable 'low hanging fruit’?
2. What are the main challenges? Are there common challenges in Europe, and can we identify best practice?
3. What are the actors and stakeholder that require policy support (including technology and infrastructure development), particularly at European level?
4. What, if any, new research is necessary to produce more convincing evidence to assist in improving quality of support to family carers?

3.3 Summing up and final comments
This is an opportunity to reflect on ‘where next’ and the value of this workshop and the new evidence in the work of the participants to support family carers and develop LTC.

Question:
How can this evidence help strengthen overall support for the family caregivers in the a) LTC policy and b) technology-focused innovation policy.

Support material
Target Clusters proposed by CARICT project
The workshop will focus on the most burdened carers. Using primarily EUROFAMCARE data and analysis, the CARICT project identifies 3 main clusters of burdened carers Burdened wives; cohabiting/non-working daughters and non-cohabiting/working daughters.
Reference will of course be made to other clusters, but within the context of these principal groups (especially sons compared with daughters, husbands compared with wives, and the role of non-family carers particularly in relation to older people with no direct family to care for them).

1. Highly burdened, cohabiting, non-employed daughters(-in-law) of highly impaired recipients (hereafter “cohabiting/non-working daughters”): middle-aged carers reporting the highest level of care-related burden and lowest level of
quality of life, over proportionally cohabiting with the care recipient and with a very weak support network, low education and employment rate, almost 80% of whom are represented by daughters and daughters-in-law, caring for a highly (also behaviourally and financially) dependent, very old mother, to whom they provide all types of care for almost 70 hr/week;

2. Highly burdened, non-cohabiting, employed daughters(-in-law) of slightly/moderately impaired recipients (hereafter “non-cohabiting/working daughters”): same as Cluster 1, but a bit younger, seldom cohabiting, highest educational level, very often employed, with a weak support network, providing 22 hr/week of mainly emotional and domestic care to a much less dependent, still very old mother;

3. Burdened wives: older carers reporting high burden and low quality of life, lower educational level, mainly retired, with a very weak support network, providing a high amount (83 hr/week) of all kinds of care to a medium-to-highly dependent partner;

For the two groups of working age daughters, a policy concern is reconciliation of care responsibilities and participation in the formal labour force.

For older carers a key policy concern is the increasing number of people in this situation, and the gender shift as men live longer.

**Dimensions of impact identified by CARICT project**

1. **Quality of Life of Informal Carer**: this dimension covers all the relevant areas of individuals, such as reconciliation between care and work, social life (including social participation), psycho-physical health and life satisfaction;

2. **Quality of Life of Paid Assistant**: paid assistant’s quality of life needs a different analysis because it deals with other conditions (e.g. salary, working time etc.);

3. **Quality of Life of Care Recipient**: this dimension covers the direct impact on dependent older people. Even if these initiatives are mainly focused on care recipients (e.g. telecare), they may give some kind of relief to the carer;

4. **Quality of Care provided by Informal Carer and Paid Assistant**: ICT-supported initiatives may be aimed at improving carer’s knowledge, skills, and competences about caregiving with an indirect impact on care recipients through the carers;

5. **Care Efficiency & Sustainability**: this dimension covers the direct effects of ICT-supported initiatives in relation to many economic-related issues, such as the efficiency of the service (considering both the quality of care provided and costs);

6. **Acceptability**: it refers to the impact of ICT-supported initiatives on the use itself. Even if a device is efficient and less expensive than other solutions, it could be unacceptable to the final user;
Types of Carer Support Actor

- Family members
- Significant others (friends, neighbours, peers)
- Volunteers and other civil social actors
- Formal care services:
  - Social care provider organisations (public, NGO and for-profit)
  - Care managers/assessors
  - Care workers
  - Chronic health care providers
  - Acute health care providers
  - National/regional support agencies
  - Insurance companies
- Carer/family support organisations;
  - Local carer support services
  - National carer, family or disease-focused organisations
- Telecare providers
- Migrant family employed care assistants.
- Employers
- etc
# Types of Technology Enabled Carer support

<table>
<thead>
<tr>
<th>Types of technologies</th>
<th>Support functions</th>
<th>User-oriented dimensions of impact</th>
<th>Examples of ICT-based initiatives (not an exhaustive list!)</th>
</tr>
</thead>
</table>
| **Independent living** | carer’s quality of life (direct or indirect) | 1. Quality of life of informal carer AND/OR 2. Quality of life of paid assistant | • Social alarms  
• Video surveillance  
*These devices give some kind of relief to the carer who may benefit in terms of improved health-related quality of life or social activities.*  
*Smart homes designed for care recipients  
*Assisted Ambient Living (AAL)* |
|                       | carer’s social participation (direct or indirect) | 3. Quality of life of care recipient |  |
|                       | dependent older person | 4. Quality of care provided |  |
|                       | quality of care through carer (direct or indirect) | |  |
| **Information & Learning** | carer’s quality of life (direct or indirect) | 1. Quality of life of informal carer AND/OR 2. Quality of life of paid assistant | • Health information on websites  
• E-learning courses  
• Training materials  
*In the case of a migrant-related support, these services are integrated with language/culture courses or translation facilities/settings.* |
|                       | migrant-related | 2. Quality of life of paid assistant |  |
|                       | dependent older person (indirect) | 3. Quality of life of care recipient |  |
|                       | quality of care through carer | 4. Quality of care provided |  |
| **Personal Support & Social Integration** | carer’s quality of life | 1. Quality of life of informal carer AND/OR 2. Quality of life of paid assistant | • Counselling  
• Call centres for psychological, personal, and emotional support  
• Support groups  
*In the case of a migrant-related support, above services (for personal support and/or social integration) are available in different languages and/or have a focus on migrant care workers’ context.* |
|                       | carer’s social participation | |  |
|                       | migrant-related | 2. Quality of life of paid assistant |  |
| **Care Coordination** | carer’s quality of life (direct or indirect) | 1. Quality of life of informal carer AND/OR 2. Quality of life of paid assistant | • Coordination with formal care services (less stress)  
• Access to e-health records  
• Organisation of public care services  
*In the case of a migrant-related support, these services are available in different languages and/or have a focus on migrant care workers’ context.* |
|                       | migrant-related | 2. Quality of life of paid assistant |  |
|                       | dependent older person (indirect) | 3. Quality of life of care recipient |  |
|                       | quality of care through carer (indirect) | 4. Quality of care provided |  |
Annex 6: Written feedback from experts

Expert: Judy Triantafillou
November 20, 2011 (before the workshop)

Please note that expert’s contribution is underlined

In preparing for the workshop, the participants are invited to consider the following questions, based on the evidence now available summarized in the document ‘D5.1’ included with this brief, and more comprehensively developed in other on-line deliverables listed in the section below.

1. Does this new evidence and analysis suggest that ICT-enabled services can play a significant role in supporting carers and the sustainability of LTC in Europe?
   - Appears to be more useful in well developed service systems, but has an important developmental role in emerging services
   - Linking and coordinating formal and informal care
   - Cost-benefit still difficult to estimate, due to multi-system interventions and known difficulties of evaluating and measuring specific and various benefits to users

2. More concretely, for different scenarios (clusters) of carers and related dependent elderly people, how could ICT-enabled services be used to support carers and improve the family care environment so as to support home-based care in the context of different regional care regimes?

3. Which are the actors / stakeholders (NGOs for and of older people, carer organizations, health and care organizations, technology providers, service providers, enterprises, policy actors, etc) that play or could play a role in developing ICT-enabled services that support carers?

4. From the above examples, in light of limited governmental budget for investment, what ICT-enabled services would offer the most cost effective outcomes with modest investment?

5. What challenges and therefore which actions need to be taken, and by which stakeholders, to facilitate the maximum benefit of ICT-enabled services to carers and dependent elders?

Philip Swennen, AGE user evaluation comment following site visit to Barbastro for the DREAMING project:
- Lastly, the use of ehealth raises the question of the reorganisation of the health system delivery. Indeed, IT creates a new relationship between the patient and the health worker (not necessary face to face) and between primary care and the hospital. IT creates new functions in the health chain, new tasks to distribute among health workers and thus it raises questions about the role and the way to reorganise the
health first line and the need of coordination within and between the health and long term care systems. This change in paradigm in the health system is of great importance.

6. What new research and development is necessary, including additional evidence on impact, to make ICT-enabled services more effectively deployed by the different stakeholder involved in family and home care?

7. How can the evidence produced by the project be used to put the role and needs of family carers on the agenda of Long Term Care policy and into (technology-based) innovation policies and support processes?

Use of INTERLINKS Framework for Classification of Policies and Measures to support ICs, to differentiate more clearly between measures primarily to support ICs and measures to support OP and IC:

- **Specific direct measures** are those that explicitly target informal carers in order to help them in performing their caring tasks.
- **Specific indirect measures** are those that aim to support and facilitate the caring option for both employed and non-employed informal carers.
- **Non-specific measures** are those targeting both the older person and the informal carer; they are sub-divided into non-specific direct, when they primarily target informal carers and non-specific indirect when they primarily target the older person.

Examples: *(detailed Framework and references will be provided)*:

<table>
<thead>
<tr>
<th>Specific measures</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct (hand-in-hand approach)</td>
<td>Information, training, education, opportunities for the exchange of experiences, peer support groups, devices, ICT solutions Training for formal carers in how to include and support informal carers in a shared provision of care</td>
</tr>
<tr>
<td>Indirect</td>
<td>Care leave, flexible working arrangements, care allowances, pension and accident insurances</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Non-specific measures</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct (primarily informal carers)</td>
<td>Respite care, support and stress relief by voluntary work initiatives</td>
</tr>
<tr>
<td>Indirect (primarily older people)</td>
<td>All types of home and residential care services for older people Housing accommodation and adaptation, meals on wheels, technical supplies, attendance allowance</td>
</tr>
</tbody>
</table>
In preparing for the workshop, the participants are invited to consider the following questions, based on the evidence now available summarized in the document ‘D5.1’ included with this brief, and more comprehensively developed in other on-line deliverables listed in the section below.

1. Does this new evidence and analysis suggest that ICT-enabled services can play a significant role in supporting carers and the sustainability of LTC in Europe?
   - Appears to be more useful in well developed service systems (according to impact assessment), but also has an important developmental role in emerging services
   - Linking and coordinating formal and informal care
   - Cost-benefit still difficult to estimate, due to multi-system interventions and known difficulties of evaluating and measuring specific and various benefits to users (informal carers and cared-for older people)

2. More concretely, for different scenarios (clusters) of carers and related dependent elderly people, how could ICT-enabled services be used to support carers and improve the family care environment so as to support home-based care in the context of different regional care regimes?

3. Which are the actors / stakeholders (NGOs for and of older people, carer organizations, health and care organizations, technology providers, service providers, enterprises, policy actors, etc) that play or could play a role in developing ICT-enabled services that support carers?

4. From the above examples, in light of limited governmental budget for investment, what ICT-enabled services would offer the most cost effective outcomes with modest investment?

5. What challenges and therefore which actions need to be taken, and by which stakeholders, to facilitate the maximum benefit of ICT-enabled services to carers and dependent elders?

   Philip Swennen, AGE user evaluation comment following site visit to Barbastro for the DREAMING project:

   “Lastly, the use of ehealth raises the question of the reorganisation of the health (and care) system delivery. Indeed, IT creates a new relationship between the patient/client and the health (and care) worker (not necessary face to face) and between primary care and the hospital. IT creates new functions in the health (and care) chain, new tasks to distribute among health (and care) workers and thus it raises questions about the role and the way to reorganise first line/primary health care and the need of coordination within and between the health and long term care systems. This change in paradigm in the health (and care) system is of great importance.”

6. What new research and development is necessary, including additional evidence on impact, to make ICT-enabled services more effectively deployed by the different stakeholder involved in family and home care?
7. How can the evidence produced by the project be used to put the role and needs of family carers on the agenda of Long Term Care policy and into (technology-based) innovation policies and support processes?

See attached - INTERLINKS Analytical Framework to describe and classify informal carers’ support measures (also available at http://interlinks.euro.centre.org/).

Specific comments from Draft Deliverable 5.1 Annex 1

Annex 1 Impact Assessment Methodology: dimensions and indicators

Maybe I am confusing different sub-dimensions, evidence and indicators, as some of these are also covered in Dimensions 3, 4 and 5 – but I feel there is some confusion in this section (1.3 Health-related QOL of informal carer). Also, as I suggest below, I am not really sure if the impact of the health status of the carer on the care recipient should be included in the meso or micro level – or indeed if it should be included in this dimension??

1. QOL of informal carer
   1.1 Reconciliation between care and work
   1.2 Social life
   1.3 Health-related QOL

Definition of sub-dimension: health related QOL covers all aspects of carer well-being, other than social participation and work – it concerns the health of the carer, its pre-requisites and effects

Evidence: according to this definition, meso and macro should not relate only to workplace, social relationships and workforce and ??should be supplemented with – “meso: care has a negative impact on health and well-being of cared for person”, and “macro: care has a negative impact on use of health services by carer”

Indicators selected at meso -(1,3.ME.1) and macro- (1.3.MA.1,2) level only reflect well-being related to work ??should be supplemented by non-work related indicators of health and well-being for both carer and cared-for e.g. derived from self-assessed health status, number of medical or hospital visits etc

Attachments:
- INTERLINKS analytical framework for classification of informal carer support policies and associated measures (draft report)
- INTERLINKS Informal care in the long-term care system. Executive Summary
In preparing for the workshop, the participants are invited to consider the following questions, based on the evidence now available summarized in the document 'D5.1' included with this brief, and more comprehensively developed in other on-line deliverables listed in the section below.

1. Does this new evidence and analysis suggest that ICT-enabled services can play a significant role in supporting carers and the sustainability of LTC in Europe?
   - The answer is yes as long as they are seen as a complement and not as a substitute to human services. By that I mean that no technology can alone bring the optimal outcome. They may for example help in linking and coordinating formal and informal care and also professional and informal career. But prerequisites (such as common training in using them) and supervision of their use will be necessary conditions.
   - So the issue is here to insure that it is not only used to fill the gap for human services but in complement to new type of services delivered by new type of professionals

2. More concretely, for different scenarios (clusters) of carers and related dependent elderly people, how could ICT-enabled services be used to support carers and improve the family care environment so as to support home-based care in the context of different regional care regimes?
   If we consider on one side working carers, then the use of low cost and easy access technology such as smart phone and internet is a good way to try to make real breakthrough in the firm culture around this issue. On one side good working conditions have prove to exert a positive impact on productivity. On other side, IT based measures can contribute to better working conditions by releasing career’s stress and burden. Only when firms staff will be convinced that they can keep some of their best salaried at a “low organizational cost”, will they change their mind and push for more consistent measures (care leave, all type of flexible working arrangement. But this may be more difficult in countries not friendly to sandwich generation, womens and more seniors workers

Regarding older carers out of the market place for different reasons (either having quit or housemaid women) the issue here is in how IT can contribute to give them opportunities either for some to rejoin the work market, and for others to continue to care the longer as possible without ruining their health and social conditions. It is clear that without providing enough professional services; IT alone will not solve the issue.

3. Which are the actors / stakeholders (NGOs for and of older people, carer organizations, health and care organizations, technology providers, service providers, enterprises, policy actors, etc) that play or could play a role in developing ICT-enabled services that support carers? How to align all stake holders position is a crucial problem as each of them carry their own stakes. Financial coherent financial incentives alone will not provide the solution as they will not be able to promote all cultural and organizational changes that will follow from the use of these technology and specially the relationship between the user (patient/carers) and the health (and care) worker (not being necessary face to face) and between primary care and the hospital (at distance relationship)
4. From the above examples, in light of limited governmental budget for investment, what ICT-enabled services would offer the most cost effective outcomes with modest investment? Cost-benefit analysis are necessary but they raise many issues: One is being able to measure outcomes for both stakeholders as their direction may not always conflate (in this regard see interlink classification of support measures). Also designing low cost and sound design by not abusing of much more costly RCT, is another one. In this regard being able to build evidence on existing population representative surveys and/or cohorts by using econometrics techniques to control for confounding is a real challenge.

5. What challenges and therefore which actions need to be taken, and by which stakeholders, to facilitate the maximum benefit of ICT-enabled services to carers and dependent elders? As stated above the use of technology raises the question of the reorganisation of the health (and social care) system delivery at large. On one side it can simplify some functions and lower redundancies. But on other it creates new tasks thus entail the emergence of new profession, bringing in more complexity and thus calling for more coordination at the three usual levels which may look paradoxical.

6. What new research and development is necessary, including additional evidence on impact, to make ICT-enabled services more effectively deployed by the different stakeholder involved in family and home care? We certainly need more surveys on IT services bringing more information on carers specific objective and subjective conditions. But these should be coupled with corresponding older people data in order to capture the interactions between both stake holders. Only then can we capture the context in which these take place and better understand its importance in scaling up and moving experiments into real life.

7. How can the evidence produced by the project be used to put the role and needs of family carers on the agenda of Long Term Care policy and into (technology-based) innovation policies and support processes? Using the "young generation" expertise and convincing power in order to transform the representation of older people as IT un competent could help as evidence alone will not change the professional vision and practice regarding carers and has no persuasing power for the older generation.

Specific comments from Draft Deliverable 5.1 Annex 1
I mentioned during the seminar that impact on professional quality services is a crucial dimension to add to the seven. Of course it is an indirect outcome but like its informal counterpart it may impact on both quality of life stakeholders.

There are some issue also in the chosen indicators. I mention only the first one.
1. Quality of Life of Informal Carer

1.1. Reconciliation between care and work

**Definition of the sub-dimension**

The reconciliation between care and work concerns the possibility for the informal carer to keep his/her job, assuring anyway enough time to dedicate to care giving activities. Other related aspects concern the possibility, for carers who do not work, to enter into the labour market and, for carers who still work, to improve the work condition and the availability of personal resources (e.g. time).

**Evidence**

- Micro: care has a negative impact on number of working hours, income level, developing career, training, permanence into the labour market, quality of life at workplace, relationships with colleagues.
- Meso: care has a negative impact on productivity, retention rate (?).
- Macro: care has a negative impact on general workforce.

**Indicators chosen**

*Micro-level*

1.1.MI.1 Number of working hours
1.1.MI.2 Possibility to continue or restart working
1.1.MI.3 Income level
1.1.MI.4 Efficiency in the workplace
1.1.MI.5 Relationships with colleagues
1.1.MI.6 Wellbeing at the workplace

*Meso-level*

1.1.ME.1 Leaving work because of care
1.1.ME.2 Reducing working hours
1.1.ME.3 Not developing their career
1.1.ME.4 Not attending training
1.1.ME.5 Experiencing absenteeism, interruptions or other events
1.1.ME.6 Negative relationships with colleagues
1.1.ME.7 Experiencing stress or burden due to care-related issues

*Macro-level*

1.1.MA.1 Work less to have more time for caring
1.1.MA.2 Work or work more and reducing caring time

Comments: I don’t understand why “possibility to restart or continue to work” is at micro level indicator and reducing hours is at meso level.

Also efficiency in the workplace relationship with colleagues or well being at wplace could be meso s it may impact on the organization productivity. While ME7 should be micro. Also MA1 and 2 macro indicators are not macro but meso or micro. A macro indicator could be percentage of working carers among different carers categories

So there is a clear problem of comprehensiveness and consistency here. I have found some others in other dimensions which I have no time to show. But this issue should be tackle ot at least mentioned.