First INLIFE Workshop and contributions at the International eHealth, Telemedicine and Health ICT Forum for Education (Med-e-Tel), Luxembourg, 7.04.2016.

Programme & Minutes

Programme

14.00 – 15.20 presentations – Chair Dr Peter Cudd

From User Needs and Requirements to Use Cases for ICT Services Addressed to Elderly with Cognitive Impairments

> Maria Panou, Alvaro Garcia, Evangelos Bekiaris, Katerina Touliou
> Hellenic Institute of Transport, Centre for Research and Technology Hellas, Greece
> Fundacion Instituto Gerontologico Matia – Ingema, Spain

Offering Personalised Cloud-Based ICT Solutions to Elderly with Cognitive Impairments

> Nikolaos Kaklanis, Ioannis Paliokas and Dimitrios Tzovaras
> Information Technologies Institute, Greece

Reliable Information on Accessibility-related Standards: IN LIFE Contribution to Facilitate the Application of Standards

> Christian Galinski, Blanca Stella Giraldo Perez
> Infoterm, International Information Centre for Terminology, Austria

Measuring the Impact of ICT for People Living with Cognitive Impairment

> Katerina Touliou, Maria Panou, Evangelos Bekiaris, Arlene Astell
> Hellenic Institute of Transport, Centre for Research and Technology Hellas, Greece
> ScHARR, University of Sheffield, UK

A Driving Assistant to Help People with Mild Cognitive Impairment or Early Stages of Dementia

> Invited Speaker : Mario Muñoz-Organero
> Carlos III of Madrid University, Spain

Invitation to attend the discussions after refreshments

> Peter Cudd
> President, Association for the Advancement of Assistive Technology in Europe

15. 30 – 16.00 Refreshments

16.00 – 18.00 – workshop of discussions with audience

Workshop introduction by discussion session chair

> Professor Arlene Astell
> Centre for Assistive Technology and Connected Healthcare

Minutes

The discussion was carried out among participants of the IN LIFE consortium and external experts. This report highlights the main remarks and discussion points that were addressed and how the feedback could be used to improve the work carried out in the project.

The story of Brian

(Video presentation to stimulate discussion and the potential impact ICT technologies can have on a demented person's life).

Prof. Arlene Astell, the WP7 leader, presented a case study of Brian and the potential for cognitive training and stimulation in dementia patients.

It was proposed the video could be used as an example, for dissemination purposes; in order to show old people that "no matter how old they are there is always time to learn". Additionally, if we hope learning to be successful, support and encouragement is essential; thus, the role of care givers is of core importance for learning and using the technologies. Therefore, we should focus more on the team (supporting group, formal and informal caregivers) as well as involve them from the very beginning of the process.

It was also discussed that although we cluster the needs of users in order to create Use Cases, the need for a technology is a personal experience; hence, there is no general rule. It heavily depends on the independence of the user.

In order to decide the services and treatment to provide it is also important to take into account their diagnosis; whether they live alone or not, whether the user accepts dementia or not.

In a nutshell, the progress and status of disease play an important role in the technology adherence and acceptance. The presence of a supporting group, timely intervention, and the appropriate medication are key factors for improving or maintaining the person's mental and health status. Another aspect that is often not considered is that knowing the origin of the disease is necessary in order to treat it. An important prejudice that we should fight is that in some countries it is thought that dementia is not a diagnosis, it is something that comes with age, and this is wrong.

Highlights

- The work of the carer is essential in order to help the elderly with cognitive impairment use the technologies. In the early stages of cognitive decline, these tools can be offered directly to the elderly. However, it is more difficult to target people in the later stages. In these cases elderly it would be necessary to target their support team, especially carers.
- One and the same person may comprise the requirements of different 'personas' for different aspects (e.g. tracing when going out or surveillance in the bathroom).
- The most effective option is to offer these tools to people at early stages of cognitive decline, at the moment of the diagnosis, because then they can have a higher impact on their condition.
- Whether these tools are useful for elderly with cognitive impairment or not would depend on the elderly profile and his/her needs. For example, if they are independent or not.
- Some key actors to approach are the national insurances and the regional and local administration which are often in charge of providing these services. For them, the cost of providing these solutions will probably be lower than hospitalisation costs.
- To approach policy makers it is necessary to speak their language. We should keep in mind that it is usually difficult to introduce changes in the public sector. Therefore, it might be faster to target private health providers.

Data privacy and security

Another important topic that was raised and is in line with the major objectives of Horizon 2020 is the data protection and privacy issues and strategies. The project has dedicated two deliverables, namely the Ethics manual and the data management plan. The external expert raised the point of

using any type of clinical data and how important is, in this case, to contact the respective National Authority (National Body) in charge of protection of data regulations. In case data are collected in one country and stored in another country, as it may be the case with a DDBB created on another country (different from where the trials are carried out), compliance to the strictest legislation and guidelines apply.

Another point discussed is whether people with cognitive impairments need specific protection. It was agreed that sharing of information, if not related to personal data, shouldn't be a problem. There is not a cross-national agreement on sharing of data, and it is something that should be addressed by policy makers.

It is also essential to train the team (in charge of this data, and/or these systems) on how to use the system, in order to make it in a proper and secure way and, of course, to effectively train the participants. In this regard, it is essential to have an e-health file that can be securely shared (i.e. not sharing personal information), in order to identify potential risks on other people, or other kind of emergencies (including medical services that would need to be provided). And the user should have access rights to their medical file.

A new level of data sharing in Europe is required in the form of a new model. This is something that should be addressed with policy makes, and national insurance houses/ companies.

But again, it is very important to train people on how to use new systems that allow these new sharing of data, in order to prevent potential security risks.

Highlights

- To what extent do patients accept their disease/interventions (and how to explain it to them)
- How can data security and privacy be secured? – different rules in individual countries, especially, if medical files have to be /fully or partially/ shared by several people or institutions/services
- Variations in regulations among EU countries; strictest legislations should be definitely be covered and addressed.
- Each pilot site needs to comply with national regulations which may differ from country to country, therefore, the IN LIFE platform must comply with national rules, if a service is offered only in one country – some national authorities must grant the use of personal data even in projects ('data strict'). Pilot site responsibles have to check the respective national regulations with multiple national regulations simultaneously, if a service is offered in more than one country.
- Emotional and cognitive aspects are affected, other than memory, should be considered when protecting a person with dementia.
- The IN LIFE platform must provide the technical means to assure data security and privacy.
- Ethical issues need to be thoroughly dealt with in the education/training of staff carrying out or promoting the services or products in the marketing activities for services and products.
- An ideal situation for the elderly with cognitive impairment would be to live at home but with the possibility of being permanently connected with professionals who could assist them properly. These professionals should have access to the health file of the patient. For this, a data sharing agreement is needed.

Business rules and cases

From the point of view of the external participant, these costs of implementation and deployment of a system like IN LIFE should be covered by local administrations / national insurance houses. Thus, a public approach was proposed and the reason for this is that this new model / system allows to save costs (better monitoring / tele assistance would avoid people to go to the doctor / hospital).

Across Europe there are very different approaches in the health systems. In order to have successful business models it is important to involve politicians and policy makes on the design and decision processes.

An important aspect from an economic point of view was the fact that AAL technologies can be less expensive that hospitalization. In terms of devices/systems for individuals and for service delivery organizations, the term SDO has been criticized. It should better be called service providing organizations – SPO):

- Individuals or all stakeholders;
- National insurances or other insurances;
- Paying for what: data interchange/provision (as a service);
- Maintenance of platforms, etc.

Highlights

- It would also be a good strategy to target GPs.
- The Business Models must take into account the different situations across countries (for example, in the UK a big customer is the NHS). In Spain private companies provide tele-care services but they are contracted by the public authorities (usually regional). Companies compete among them. In Slovenia, some IN LIFE products and services could be under the public health system, others might be funded by the private sector. In Austria, there are different actors involved which have sometimes opposite interests (public administration, public and private hospitals, care homes, doctors, doctors representatives, etc.).
- It is also necessary to take into account the relationships between social care and healthcare in each country.
- For having a successful commercialisation, IN LIFE needs to present a success story to the relevant stakeholders.

As a recommendation for project partners, and especially commercial partners:

"*You need to take advantage of the project to get a success story. Then, thanks to this success story, you can sell it. Otherwise it is very difficult.*"