User involvement and adaptability of the systems

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1. Introduction

Based on our experience from previous projects and development of applications for elderly and disabled people we found out that the most important issue in AT and AAL is active involvement of potential users. At present the users do not have many problems with accepting the technology but many questions arise concerning collected data, data privacy and security, data accessibility by other people. Although there exist legal regulations concerning medical data, it is not yet fully solved how the data should be handled in home care and how long and where the data should be stored, etc.

In case of long-term monitoring the possibility of application of adaptive systems should be considered. The systems can be personalized because they learn from the data of a particular person. The idea is to recognize changes of health state and cognitive abilities of the potential users. Let us mention few illustrative examples. Degradation of motoric abilities that is not observable at first glance but can be detectable from measured data should initiate actions such as proposal of corresponding rehabilitation and/or medical examination leading to cause identification. Similarly detection of cognitive problems, e.g. memory degradation should invoke proposal of mental training, activate reminder, inform family members, etc.

To summarize the ´gaps´ from our point of view, the following issues are important: higher involvement of potential users in the development process; education of the users – showing them that technology can help them and they need not fear of technology; harmonizing technological solutions with legal and ethical regulations.

2. User Involvement

If we plan to offer and test new technological solutions for improving quality of life of seniors and challenged persons, the solution should be very low cost and easy to use; it should provide entertainment and health care functionalities, support their independence when living on their own at their homes with tele-assistence, e.g. of local public services. The solution may combine tele-medicine, tele-assistance, tele-entertainment and tele-company into a federated internet based system usually intended for 3 very different and complementary groups of users: the customers (elderly persons who need some sort of support), their care givers (e.g. organized in public or non-for-profit services) and health professionals (medical doctors and nurses). Each of these groups requires/ensures specific type of services and consequently the developed system should provide them by group specific access rights.

The design must consider different types of users that may potentially use the system. Since these systems should be in use for a longer time period they should be designed as easy-to-use, plug-and-play systems which can be easily customized towards the needs of the individual user by modifying the set of ensured services for several types of application scenarios. For example the system focused on elderly persons can use three basic scenarios. The simplest base level scenario is intended for a vivacious elderly who requires no extra services but who can benefit from more social contacts – this level includes communication and tele-company through a low-cost PC and open-source internet based software. The intermediate level is complemented by simple sensors (e.g. to measure the ambient temperature) for the management of generic monitoring situations (e.g. very hot

periods in the summer). Finally, an upper and tailored level scenario expects that there will be engaged health-monitoring sensors depending on the health profile of the user. Moreover, this most complex level has to be ready to create, send and handle an alarm signal generated automatically in the case the monitored signals of the considered patient meet certain predefined condition. Different types of scenarios are to be defined for other groups of potential users, as handicapped persons.

When designing the systems for laic users special attention has to be given to the design of communication interface for the customers who are not expected to be accustomed to using computer and internet. Especially for the elderly users it can be advantageous to hide the technology from the users and ensure all communication, for example, through a television screen controlled by a remote controller customized for that purpose. Since the user interaction with such a system is not only purely technological issue but also contains many psychological aspects, we discuss them separately in the next section.

3. Psychological Issues

Each of us is a personality with unique experience, background knowledge, emotional and psychological setup, acceptance and perception of other humans and also technology. Thus we will find high variation in attitude towards high tech installations, especially in our homes. Frankly speaking, how many of us would be happy to be monitored by cameras and other devices 24 hours a day without knowing who has access to this data? It recalls "big brother" from Orwell´s 1984. However, the continuous monitoring is a standard at intensive care units in hospitals. Moreover, surveillance by cameras is nowadays used in many public places, e.g. airports, train stations, in some cities in public transport. Usually we are not aware of it or simply we do not care or sometimes we know that the technology is there for enhancing our safety. On the other hand being at work and having elderly grandparents or parents at their homes and knowing they have certain health problems it would be good to check from time to time what they are doing and whether there is no problem without instant phoning them (they might get the feeling they are permanently supervised). However, we have to explain them why the technology should be installed in their home.

As we are so different, it is difficult to design a general system that is easily acceptable for everybody. Therefore a lot of research must be done in interaction with as large set of potential users as possible. These users must be selected from a large variety of population, i.e. city/village, healthy / motoric disabilities / visual impairment / hearing impairment / cognitive disorders – all on different levels, male / female, different age, different experience with technology (none/weak/medium/intensive). The key issue is also proper design of the experiments – real life scenarios. In this respect, popularization and introduction of these topics into public awareness and possibility of visiting such model homes are options that can make this technology more familiar to broader public.

Now we can only estimate what the results of new studies could be. But based on the recent studies it is obvious that the main and most important issue is human technology interface. It seems that it definitely must be adaptable to user needs, behaviour and abilities and it must be evolvable in time. That means when the user needs and abilities change (usually they worsen – deterioration of cognitive and/or motoric abilities) the system has to recognize it and adapt the interface and functions accordingly.

The designer must obtain a thorough understanding of the users, their disabilities, their environments, and their problems. The greatest challenge for the designer is not solving the problem but understanding the problem. User evaluation is an essential tool for obtaining proper understanding. Technology developed for use by lay users must have such control or user interface that is easily accessible, usable and useful for its intended users. Therefore the user-centered design process must be used.

In the development phase it is highly advisable to use a tool known as the Virtual Usability Laboratory for software development [1]. Such a tool is designed to unobtrusively monitor users of web-based applications remotely. At the same time the tool allows querying users after their interaction with the application. After experiments when a large number of users have tested the application the usability data is collected and analyzed. This data contains, for example, browsing patterns, system invocations, user interactions. Similar approach is

used in standard Usability Laboratory [2], where tangible devices and tools are tested from all aspects of their design, i.e. functions, ease of use, ergonomy, safety, demands on cognitive and motoric abilities.

4. Social Issues

Humans are social beings. Mostly they do not live as lonely survivors of a shipwreck on a waste island. However, many elderly people spend most of their time isolated in their homes, especially in winter when the weather conditions hinder them to go out. Great challenge is to offer them socializing virtually, in an unobtrusive way. There are, for example, projects using a TV set and a webcam for dialogue of a home care client and a nurse in a call centre. So why not using this idea for interconnecting people who know each other and want stay in contact? They could communicate among themselves remotely when their state does not allow them physical presence in one place. In this way they can organize a sort of a teleconference quite easily. The important feature is that they stay in contact with other people.

Technically capable people having Internet connection may use social networking on the Internet. However, it is necessary to stress that there might be a potential danger of misuse of information exchanged in the group. The elderly people are usually more gullible and in this respect fragile. Although there are quite regular warnings in TV and radio broadcastings there are new cases of wilful deception of elderly people. There should be a reliable person who will supervise such network and identify possible intruders. For the beginning, the simplest measure is that the participation is by invitation only, possibly confirmed by several trustful participants.

5. Ethical Issues

The major ethical issues arise about the handling of sensitive data about health and data about daily activities. Explicit informed consent must be asked to the participants in order to include their sensitive data in the EHR or local storage, and to their data being shared, transmitted and analyzed by authorized personnel within the designed system.

All the procedures must conform to relevant EU legislation (in EU countries) and to national legislations related to the principle of respecting confidentiality. Since a proportion of clients are presumably affected by some degree of cognitive impairment, special precautions must be taken as regards such patients. The restrictive rules applied in case of Clinical Trials must be used (Directive 2001/20/Ec of the European Parliament and of the Council of 4 April 2001) [3]: " In the case of other persons incapable of giving their consent, such as persons with dementia … omissis … the written consent of the patient's legal representative, given in cooperation with the treating doctor, is necessary before participation in any such clinical trial. The notion of legal representative refers back to existing national law and consequently may include natural or legal persons, an authority and/or a body provided for by national law".

The necessity of inclusion of such patients into AAL systems derives from: 1) the high prevalence of cognitive impairment among elderly patients (up to 50% in 85+); 2) the high correlation among cognitive impairment, chronic diseases, and functional disability; 3) the need of providing structured intervention plans for cognitively impaired patients.

When designing an AAL system all subjects must participate voluntarily after being informed of the objectives and methodologies of the project. Explicit informed written consent will be asked for. Since some difference in respecting privacy could arise between different subjects, two different forms for informed consent/authorization should be used: 1) subjects who will authorize treatment of personal data; 2) physicians who consent to use their information and knowledge about patients who already agreed to participate. To be enrolled, both consents are needed.

All the researchers involved who take part in the analysis of non-anonymous data must be asked for an explicit declaration of respecting confidentiality.

Personal data must not be used for commercial purposes.

6. Conclusion

We have tried to address some of the technological, psychological, social and ethical issues that must be solved in the future. The technological development in recent years has brought many innovative sensor systems, devices and tools that can be utilized in the area of AAL. However, system integration is not fully solved yet. In this paper we have not focused on the technological issues but we have tried to identify at least some non-technical problems linked with introduction of technology allowing continuous monitoring of persons' health state and activities in their homes. We have shown that before starting implementation of such systems it is necessary to perform detailed acceptance study with successive evaluation. The aim is that the lay users (mostly elderly people or people with different impairments) will be willing to use the technology, will accept it and it will not cause them any problems. The designers and developers have to have in mind that the design must be user centered.

Acknowledgement

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