Chapter 17
Privacy and Data Protection towards Elderly Healthcare

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ABSTRACT

Developed societies are registering a dramatic change in terms of population evolution, the most important fact being the ageing population. An alarming fact is that the birth-rate is dropping very fast, inverting the ageing pyramid that used to have a higher incidence on the young population, now having a higher incidence in the older population. In the quest to provide answers to some problems the elderly population has, applications and projects arise from the Ambient Assisted Living area, providing services that help the user in his daily life, providing the needed help and trying to be as non-invasive as possible. The fact is that these systems operate optimally by using information about the user, assisting him according to his preferences. The data gathered for such events is highly personal and sensitive. This can cause a loss of privacy and affect personal data. In this chapter, the authors present an Ambient Assisted Living project towards assistance to an elderly population. The problems and possible solutions in the legal area towards loss of privacy and personal data and information use is also covered.

INTRODUCTION

The most developed countries in Europe register a tendency for a fast and progressive ageing of the community, mainly because of decreasing both in mortality and in fertility. Due to advances on the medical field, ordinary people is benefiting of increased longevity. Actually, in the past few years, life expectancy increased exponentially, and in the last 10 years life expectancy increased 12 years. The combination of the increase in life expectancy and a simultaneous decrease of births

induced changes in the way people live their daily life, such as family composition, living arrangements, housing demand and even in the type of health care services (Nations, 2009).

Both Society and Health Care Services need to get responses to this ageing revolution. There is a need to rethink planning and health care provisioning in order to improve the quality of life of ordinary people. The current availability of medical care and healthcare providers, in form of continued care and surveillance of the user, like nursing homes, are very scarce and are also very limited. Adding to the fact that such services are costly, and most of the persons do not have the resources to sustain it. As technology and computer science progresses towards the construction of applications in the medical and social area, like monitoring software that is used to aid the user in everyday tasks (Chisholm & Evans, 2007), the use of personal information through these applications also increases. This concept is represented on the Ambient Assisted Living paradigm, embracing applications that help the user perform his daily tasks, using personal information about him, to further enhance the services provided.

Ambient Assisted Living

The Ambient Assisted Living (AAL) paradigm states that a person in need should always be assisted, by persons or technology. This paradigm means that the person should be safe and cared in his own environment, his home(Nehmer, Becker, Karshmer, & Lamm, 2006).

Projects are commonly being developed in terms of visual monitoring and domotics, they provide the monitoring and automation much needed to help the user. Thus the user benefits from constant surveillance and help with basic tasks, but far more interesting help could be provided. The new advances are from discrete processes such as transparent and ubiquitous technology, and intelligent interfaces(Rubel et al., 2004).

These technologies adapt to the user, to provide a better and personalized service, adjusting to the user needs. This means that the users that suffer from diseases, such as cognitive problems, mobility difficulties and visual or hearing problems can benefit from personalized assistance, in form of specially adjusted applications. The interfaces can provide an easier way to operate and interact with the rest of the system, being constructed to provide an intuitive interface that can be used by persons with no technological knowledge.

A common problem with those systems is that they require total cooperation of the user and are heavily based on the user profile and decisions. In order to be useful, the systems have to collect several data in real-time so they can adapt to the variables the user encounters at a certain point, so they can be able to respond accurately to the presented situation. An initial profiling system also requires the interaction with humans who formulate questions; the system avails the responses of the user in order to create a base profile of the system.

Typically these systems require that personal and sensible data are shared between several persons and in some systems the information is also available to other users and relatives, for instance projects that are heavily based in social networks. Although most projects are suggestive, a feature that is often present is the automatic changes related to the execution of events or tasks. The fact that the systems make individual decisions, not consulting the user, can overtake his life and proceed to make substantial changes in it, and the user will only realize some of these changes when serious consequences arise. About this, several questions must be faced: how the knowledge will be protected? How much of the information matters and what should be released? What is the impact of the automated decisions? How sensitive information should be categorized? What control should the user be allowed on the use of his data?

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