User-sensitive Home-based Systems for Successful Ageing in a Networked Society

Deliverable 1.4 – Ethical policy

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Contact: John Waterworth

Umeå University
Sweden

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Table of Contents

1. Approach to legal and ethical issues in AGNES

Ethical issues arising from the project are mostly in the areas of privacy (especially in relation to personal data), informed consent, and respect for the integrity, safety of participants outside the AGNS consortium.

As a general policy, AGNES will always follow the recommendations of the European group on ethics in science and new technologies to the European Commission, and national legal and ethical requirements of the Member States where the research is performed will be fulfilled.

1.1 Privacy and personal data

In the course of conducting the research we will collect data on cognitive, emotional, and possibly physiological states of the elderly participants, as well as patterns of movements of individuals in their own home.

There will be arrangements for protecting the confidentiality of personal data of participants at any time of the research. The database for collection of particpant data will be designed so that it is not possible to reproduce private or other confidential data. This will be achieved by appropriate data annotations, database architecture, and data access tools.

1.2 Integrity, safety and informed consent

There will be no payment, inducement or other financial-like benefits given to test participants. Fundamental safety issues of good laboratory practices will be respected at all times. The Consortium shall take all measures to assure that appropriate environmental safety provisions are fulfilled in the course of the project by all contractors. Potential safety implications of AGNES will be clearly indicated.

All test participants will give informed written consent to participate, all the subjects will be strictly volunteers, and all personal data collected will be treated as strictly confidential.

All test volunteers will be provided with the following in their own language:

- an understandable written description of the project
- project goals
- planned project progress
- testing and examination procedures
- advice on unrestricted disclaimer rights on their agreement
- information on how to complain if necessary
- information on how to terminate their participation if they wish to

All interventions will be approved in advance by the appropriate Ethical Committees of the local universities or other organizations involved in this research.

Steps will be taken to ensure that all AGNES team members involved in contact with users have knowledge about how to report and respond to any failures or other situations arising that could potentially harm participating volunteers in any way.

1.3 EU Charter of Fundamental Rights

The regulations of the EU Charter of Fundamental Rights which are most applicable to the project will be respected and are the following:

RELEVANT ARTICLES	HOW THEY WILL BE RESPECTED
Art.6 Right to liberty and security Everyone has the right to liberty and security of the person	By helping elders maintain independence and participation in the community and by maintaining the patient's safety.
Art.7 Respect for private and family life: Everyone has the right to respect for his or her private and family life, home and communications	By using only the minimum data necessary. They will be handled confidentially. The elderly person or family members will be in control of ambient sensors being switched on or off and can decide which data are recorded at which places.
Art.8 Protection of personal data: 1) Everyone has the right to the protection of personal data concerning him or her. 2) Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law…	By using only the minimum data necessary. They will be handled confidentially. The elderly person or family members will be in control of ambient sensors being switched on or off and can decide which data are recorded at which places. Only under the consent of the user or his/her legal tutor will the system be used. The developed devices and the database will be designed so that it is not possible to obtain data other than needed for the described purpose. Access to the network will be strictly limited and secured using the latest network security technology.
Art.25 The rights of the elderly The Union recognizes and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life	By helping to • Continue the satisfactory performance of routine activities in their home environments. • Maintain the social interaction. • Provide detection and intervention in risky situations. • Avoid having to depend all the time on the presence of a carer.
Art.26 Integration of persons with disabilities The Union recognizes and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.	By helping elderly people to live longer in their homes by assisting the performance of daily activities and promoting social interaction.
Art. 34 Social security and social assistances The Union recognizes and respects the entitlement to social security benefits and social services providing protection in cases such as (…) dependency or old age …	By creating a new system that helps elderly people to perform daily activities, providing social interaction and emotional support and increasing the security of the elderly within their own homes.

2 User involvement in AGNES

2.1 The key role of users

Real user involvement reflects both the scientific approach to be taken, and an ethical perspective based in respect for the users as individuals. A first principle of all work in AGNES is that the target population of older people (and their families and other carers) is central to the project and should be involved at every stage, including requirements specification, prototype design, verification of the suitability of systems and their components, and field testing of systems embedded in the user's own home. An important part of this process of involvement is to understand the psychological characteristics, needs, and desires of the users, and how these can be met by the technology developed within the project.

Use cases will be developed together with the end-users that act as a starting point for the involvement of the elderly and their families. First interviews with end-users will investigate the users' reaction to possible display and interaction means, and acceptance of different types of sensors (cameras, mobile phones). Interviews and use-case development will cover two months of the first rapid prototype being deployed in some users' homes. These selected users will also be involved in evaluation interviews of this first system, giving valuable feedback for developing the next versions. Field-testing and user impact evaluation (accessibility, usability, effectiveness, appeal, psychological assessment, and ethical issues) will continue with subsequent iterations of the project - as more advanced features are progressively added. Methods will include interviews, participant observation, and cognitive testing.

2.2 Designing and testing AGNES

Requirements specification and other design insights and feedback will be obtained in a variety of ways, including focus groups (formed through organizations representing users, such as day-care centres and healthcare authorities) and most importantly with individual potential users in their own homes. Our strategy of starting with a working network, then building increasingly sophisticated applications and functions in an iterative manner, is aimed at ensuring three things: real user involvement throughout the project; integrated solutions that work in context and holistic perspectives; real advances in the application of science and technology. Without examples of working prototypes, it is very difficult if not impossible to involve end-users fully in the design process.

The sensing network architecture as well as sensing devices will be conceptualized based on the input from first user meetings and developed use cases. The resulting concept will be discussed with the end-users (carers and the elderly) to guarantee later acceptance and to get further input on improvements. With the rapid prototype, sensors will be deployed in some users' homes as early as possible (Month 4) to get first practical insights on both technical feasibility and user acceptance. It will also be used to collect first data needed to build and try out the analysis algorithms and classifiers.

During development, the collected data will be stored in anonymized form in a protected database. The data will be annotated by experts as well as actual users as far as is possible and where needed. Data analysis and state classification will also be conceptualized in close cooperation with and approved by the end users. In particular, decisions on which states are relevant, their characteristics, and desired network reactions will be discussed with carers and cared-for persons alike. For privacy reasons, in the final system no raw data (video) will need to be stored. Feature extraction will be performed close to the sensors, which will then transmit only the feature vectors.

To verify that our objectives have been reached, formal evaluation and verification involving end-users will occur at several key points in the project, and cover multiple aspects. Detailed system and component testing will verify the functionality and effectiveness of the technology. Field trials of the prototypes will be conducted and evaluated by psychology experts specializing in normal and pathological ageing to identify the psychological (cognitive and functional well-being) impact on the users the older people and their carers. Use, usability and user experience will be assessed on the actual systems in real use. This will also allow us to identify patterns of communication and levels/characteristics of use, and to gather meaningful qualitative assessments from older users, family members, and others.