D3.1 Code of Conduct

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	TELLU	Tellu AS
	UU-SERG	University of Ulster, Smart Environments Research Group
	Accord	Accord Group
	StickyW	StickyWorld Ltd.
	ASK	Asker Municipality
	BIS	Berliner Institut für Sozialforschung
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Contents

1 Document scope

This Code of Conduct outlines the ethical guidelines for the research and system development activities in the PIA project. ***Ethics*** in the context of the PIA project is about ensuring the dignity, rights, safety and well-being of research participants and of the users of technology.

2 Overview of the PIA project

2.1 Challenges and solutions

The Challenges and solutions which have been identified to be addressed by the PIA project are to:

1) Support older adults to manage Instrumental Activities of Daily Living (IADL) to prolong independent living at home by using smart devices to support location- or object-relevant content delivery, e.g., video clips.
2) Support formal and informal carers to produce, share and distribute care experience and knowledge content through social network and rich interactions.
3) Provide personalised and intuitive user interfaces to secure accessibility for all, templates and tools to facilitate video clip production and deployment for carers, and guidelines and supporting materials for PIA system deployment.

2.2 Target groups

The target groups for the PIA system are:

1) Primary end-users: older adults living at home and needing some IADL support.
2) Secondary end-users: informal and/or formal carers.

2.3 Technology

The PIA system will use sensing technologies such as NFC and smart devices, e.g., smart phones or tablets. It will make use of: knowledge-based decision support system; online social networking and content sharing; content production, management and personalisation.

2.4 Business model

The business model will be finalised at a later stage in the project; the following outlines the initial assumptions. The PIA system and generic knowledge content will be made available over the Internet, e.g. as an "app" and a knowledge repository respectively. The PIA service provider licenses the PIA system to end-users through a subscription (starting fee plus pay-as- you-go). End-users with installed sensors and internet connection can then use PIA services via smart devices at home. Personalised knowledge content can be generated by informal carers and stored locally in the smart device, and used by the specific user. The PIA system can also integrate technically and organisationally with professional, either public or private, care administration systems to support new care delivery models.

2.5 End-user participation

End-users will participate throughout the project being invited to interviews, focus groups and field trials and will contribute to the development of the user requirements, technology and/or system testing, to field trials and assessment of IADL support, carers stress and QoL. Ethical issues have a prominent role through the dedicated work package WP3.

3 Code of conduct for PIA research activities

3.1 RESPECT Code of Practice

The PIA project consortium have agreed to follow the RESPECT Code of Practice[1] which has been developed as a framework and minimum standards for the conduct of ethical socio-economic research in Europe. The RESPECT code of practice is based on three main principles:

1. upholding scientific standards,
2. compliance with the law, and
3. avoidance of social and personal harm.

3.1.1 Upholding scientific standards

Colleagues planning and conducting research and disseminating research findings must strive to do so with integrity, honesty, objectivity, accuracy, inclusiveness, and clarity. See the RESPECT Code of Practice at http://www.respectproject.org/code/respect_code.pdf for further details.

3.1.2 Compliance with the law (and regulatory systems)

Colleagues in each country need to ensure that they **comply with any relevant regulations**, both European and those applicable specifically within an individual country (for example in Europe the DU Data Protection Directive 1995, and in the UK the Mental Capacity Act 2005 and the Data Protection Act 1998).

3.1.2.1 Data protection

The European Union issued an **EU Data Protection Directive** in 1995; details of this are given in Section 4 on page 5.

3.1.2.2 Gaining ethics approval for research projects

Colleagues also need to ensure that they **comply with any relevant ethics approval systems** (academic, local and/or national):

Each PIA participating country is responsible for applying for any relevant ethical approval.

3.1.3 Avoidance of social and personal harm

Colleagues planning and conducting research activities for the project need to ensure that:

- the research is designed appropriately so that its utility and relevance for the benefit to society is maximised;
- people participating in the research do so on a voluntary basis and on the basis of informed consent;
- the research methodology is suited to the participants and no one is unreasonably excluded from being able to take part;
- information is communicated clearly and in an appropriate way (or ways) for the target audience;
- the views of all relevant stakeholders are taken into account as long as this is not in opposition with other ethical or scientific principles;

[1] http://www.respectproject.org/code/respect_code.pdf

- the interests of participants are given high priority at all times especially those of vulnerable groups such as older people;
- participants do not experience unwarranted material gain or loss through their involvement in the research;
- findings from the research are disseminated to stakeholders in relevant and accessible formats;
- no group is discriminated against;
- participants are protected from undue risk of distress, personal embarrassment, indignity, intrusion, and psychological, social or physical harm;
- the safety and wellbeing of researchers is also given high priority.

4 The EU Data Protection Directive 1995

All PIA partners must comply with the EU Data Protection Directive, and any additional national data protection regulations in their own countries.

The information in this section is taken from the European Commission website:
http://ec.europa.eu/justice/data-protection/data-collection/obligations/index_en.htm

Under EU law, personal data can only be gathered legally under strict conditions, for a legitimate purpose. Furthermore, persons or organisations which collect and manage personal information must protect it from misuse and must respect certain rights of the data owners which are guaranteed by EU law.

4.1 Collecting and processing personal data: what is legal?

Under the Data Protection Directive 1995, collecting and processing the personal data of individuals is only legitimate in one of the following circumstances laid down by Article 7 of the Directive: Where **the individual** concerned, (the 'data subject'), **has unambiguously given his or her consent**, **after being adequately informed**; or

- if data processing is needed for a contract, for example, for billing, a job application or a loan request; or
- if processing is required by a legal obligation; or
- if processing is necessary in order to protect the vital interest of the data subject, for example, processing of medical data of a victim of a car accident; or
- if processing is **necessary** to perform tasks of public interests or tasks carried out by government, tax authorities, the police or other public bodies; or
- if the data controller or a third party has a legitimate interest in doing so, so long as this interest does affect the interests of the data subject, or infringe on his or her fundamental rights, in particular the right to privacy. This provision establishes the need to strike **a reasonable balance** between the data controllers' business interests and the privacy of data subjects.

It shall be noted that Article 8 prohibits the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life unless one of the exception criteria is met.

4.2 Obligations of data controllers

The Data Protection Directive requires data controllers to observe a number of principles when they process personal data. These principles not only protect the rights of those about whom the data is collected ("data subjects") but also reflect good business practices that contribute to reliable and efficient data processing.

Each data controller[2] must respect the following rules as set out in the Directive:

- Personal Data must be processed legally and fairly;
- It must be **collected for explicit and legitimate purposes** and used accordingly
- It must be adequate, relevant and not excessive in relation to the purposes for which it is collected and/or further processed;
- It must be **accurate**, and updated where necessary;
- Data controllers must ensure that data subjects can rectify, remove or block incorrect data about themselves;
- **Data that identifies individuals (personal data) must not be kept any longer than strictly necessary**;
- **Data controllers must protect personal data** against accidental or unlawful destruction, loss, alteration and disclosure, particularly when processing involves data transmission over networks. They shall implement the appropriate security measures;
- These protection measures must ensure a level of protection appropriate to the data.

4.2.1 Responsibilities towards data subjects

If a data subject is of the view that his/her data has been compromised[3], he/she can send a complaint to the data controller. If the data controller's handling of a complaint is not satisfactory, the data subject can file a complaint to the national supervisory data protection authority (see below).

4.2.2 National supervisory authorities for each country

The Directive states that every EU country must provide one or more independent supervisory authorities to monitor its application. **All PIA participating countries must contact their supervisory authority**. Contact details for all European countries can be found:
http://ec.europa.eu/justice/data-protection/bodies/authorities/eu/index_en.htm#h2-27

In principle, **all data controllers must notify their supervisory authorities when they process personal data**.

5 Ethics and the development of assistive technology

5.1 Ambient Assisted Living Joint Programme guidance

Section 10 of the Guide for Applicants Ambient Assisted Living Joint Programme Call 5 states,

> The nature of AAL projects will raise a broad range of ethical concerns as:

[2] persons or entities which collect and process personal data as "data controllers"
[3] e.g. collected or processed illegally, inaccurately, or misused

- the technology involved is often new and unfamiliar to the end-users,
- vital aspects of the solutions will not be transparent to the end-users and other stakeholders because of a high degree of complexity.

Solutions developed must be trusted, accessible and accepted by all designated user groups.

Ethics in the context of AAL projects is fundamentally about what a project can and shall do for the benefit of those defined as the end-users of that particular project. **Ethical issues may also be raised regarding the relationships and social networks of the involved (or future) end-users**. New AAL solutions might bring about new allocation of resources and responsibilities and thus have an impact that goes beyond the quality of life of primary end-users.

In the conduct of an AAL project, ethical issues concern *inter alia* the correct recruitment and involvement of end-users.

5.2 Common principles

Researchers developing assistive technologies commonly use the following four principles identified by Beauchamp and Childress (2002) to guide their decisions and solutions: Beneficence, Non-maleficence, Autonomy, and Justice. The *Telecare and Ethics* factsheet from the UK Care Services Improvement Partnership (2005) defines each of these:

1. ***Beneficence*:** involves finding the balance between risk tolerance and risk aversion. There may be a dilemma between beneficence and safety and independence.
2. ***Non-maleficence*:** will involve a balance between avoiding harm and respecting decisions, dignity, integrity and preferences.
3. ***Autonomy*:** enabling people to live full lives in the same way as they did before, which may be more about promoting continuity of self rather than about making decisions. This should include informed consent, which needs to be voluntary, competent and include sufficient information. Carers may need to help/guide in this process.
4. ***Justice*:** treating fairly and respecting rights, including what the Mental Capacity Act calls making "eccentric or unwise decisions". (Mental Capacity Act, 2005)

6 Applying codes, regulations and guidelines to specific areas of the PIA research activity

Ethical and legal issues as described in the PIA proposal document are presented in Appendix 1.

6.1 Privacy (data protection)

After confirmation of the participant's wish to take part (informed consent), all personal data (name, address, contact information etc.) must be **stored safely and securely** where no unauthorised person can gain access to it. No personal information provided by participants will be disclosed to a third party without the explicit consent of the participant concerned.

Each individual participant must be assigned an identification number. This identification number should then be used on interview sheets, questionnaires etc. instead of the person's name or address

so that the information gathered is **anonymous**. This **information must be stored separately from their personal data** (name, address, etc.). Databases linking personal information with code numbers should be password protected.

6.1.1 Social media

Carers must be very careful when sharing any material through the PIA social media, whether this be opinions, experiences, or video clips. It is not appropriate to make public reference to the older person's cognitive problems as this is private health information. It is also not appropriate to indirectly share any private health information, or any other personal information, without informed consent of the primary user.

Example:

Using a video recorder is commonly difficult, and not being able to use one does not necessarily indicate that a person has any problems (such as memory deficit), other than what anybody might experience with complicated technology. So, this is probably not sensitive information. On the other hand, showing in detail how to boil water may reveal that the user of the video clip suffers from cognitive decline. Also, video clips showing how to manage daily medication may easily reveal sensitive health information through pictures of medicines.

Appropriate advice to carers must be provided to them during the project tests and trials. Useful tips must be developed and made easily available for and through the social network of the PIA system.

6.2 Informed consent

All participants taking part in the focus groups or trials of the PIA project will be asked to complete an "Informed Consent From". Informed consent must be given based upon a clear appreciation and understanding of the facts, implications, and future consequences of participation in the PIA project. This will include the provision of clear and easy to understand information sheets.

In order to give informed consent, the individual participant must have **adequate reasoning faculties** and be in possession of all relevant facts at the time consent is given.

Care must be taken to ensure all participants, both the end-user and carer, are **taking part willingly** and have not been coerced to do so (for example a carer might convince the user to take part as he/she feels it would help him/her).

Consent will be re-established verbally at the beginning of any subsequent focus groups or interviews during the trials to make sure that participants still wish to take part. Participants will be free to leave the project at any time. It is good practice for the **consent procedure to be seen as a process** rather than a one-off event, with individuals being given information about the project on a repeated basis and having the opportunity to withdraw as they wish.

Informed-consent forms should guarantee transparency and should cover the following issues:

- a description of the project and its aims (accessible with respect to language and content),
- a specification of the role(s) of different end-users in the project,

- self-determination of the end-users (must be able to turn off systems or services at their own discretion),
- compensation provided to the primary end-users (expenses or fees paid, etc.),
- contact person in the project (for ethical issues and related questions),
- exit rights for individual end-users (procedure for withdrawal from the project at any time, without giving a reason and without incurring costs or penalties).

(Source AAL Guide for Applicants Call 5).

Drafts of the forms for informed consent in the PIA project are presented in Appendix 2. Drafts of the forms for use of the PIA equipment are presented in Appendix 3 and 4.

6.3 Autonomy of participants

6.3.1 Convenient times

All appointments with participants for interviews must be at a date and time convenient for the participant, not for the interviewer. Interviews may take place (if the participant agrees) at his/her house, so that he/she does not need to leave and can feel as comfortable as possible in a well-known environment.

6.3.2 Entitlement to quit

Every trial participant must be allowed to quit the interviews, focus groups and trials at any time without giving a reason.

6.3.3 Exit strategy for field trials

The PIA project proposal outlined actions to be taken if participants leave field trials before the full term has been completed. It also proposed the strategy to be taken at the end of the project to address impact of the possible termination of the PIA system and service which could cause problems to participants if they have become used to, and possibly reliant on, it.

❶ The end-users of the trial environment(s) may become dependent of the PIA system they use in the trials, although the described IADL support solution is meant only as a supplement to existing IADL support provided by carers. In case of early exit, the PIA equipment (sensors, tablets etc.) will be returned to the project. In case of completed tests/trials, we will offer the end-users the chance to keep the PIA system and equipment for 6 months. For these months, an appropriate instruction to the primary end-user's carer will be provided, such that she/he is able to provide personal assistance. In this case, it will also be made clear for the users that the project may not be able to provide system operations support. A cautious weaning will then be initiated in collaboration with carers. Eventually, the equipment shall be returned to the partner that provided it.

❷ All test and trial participants (primary and secondary end-users) will be informed about their right to exit the project at any time during the on-going user tests or field trials. In these cases, the researchers will to debrief each individual exiting user. This will give us knowledge about how users view the situation and what possible problems might arise in the future. The users will, for quality assurance reasons, be asked for the reason of exit. It will be made clear that there is no obligation to give an answer. To avoid situations in which the secondary end-user

wants to exit the project (leaving the primary end-user in a tricky situation, information about possible consequences will be provided to the secondary end users before the trials.

6.4 Integrity and dignity

All researchers must respect the participant's needs, to maintain the participant's dignity as well as avoid confusion or frustration, for example by giving appropriate support for adjusting the settings on a tablet according to the primary end user's needs and abilities. If it becomes clear that the primary or secondary user is stressed or frustrated by her/his participation (for example by the questions while the interview or by not being able to handle the PIA device), the researcher must (after discussing this with the primary and secondary end user) terminate the participation.

6.5 Reliability of PIA system

The functional capability of the PIA service must be tested several times before starting the trials, so that the participants can use a **reliable and stable system**. While the trials are going on, the secondary end user must have the chance to check important technical data (e.g., battery life, screen on/off, connection to the power net, and connection to the system/Wi-Fi) via the internet, to avoid confusion caused by a device that is not working properly.

There must be a **technical support and clear procedure** for every country so that any problems are solved as quickly as possible.

6.6 Freedom from harm

Care must be taken to ensure that participants' **properties are not damaged** as a consequence of them taking part in the project (installation of devices, etc.).

Advice to researchers and carers must also be provided to **ensure the personal safety of the primary PIA user**. This is important in the context of the content production.

Example:

Daily activities that may be dangerous or harmful to the primary user must be avoided. For instance, changing light bulbs or the battery of a smoke detector that require climbing on a chair or household ladder, may be too hazardous activities and therefore not suitable as PIA videos. Also, managing medication may introduce a danger (taking wrong medicines, or that the user does not follow the advice at all whilst the carer believes this is done because of the PIA video instruction).

7 Applying codes, regulations and guidelines to specific areas of the PIA system development activity

7.1 Data protection and security

The PIA system will need to be designed to collect and store "only relevant information" (Ikonen et al. 2008b: 3). It has to be ensured that only a limited and authorised circle of people has access to the personal data. It has to be transparent for the users, "what data are collected, where they are stored, and for what purposes they are used" (ibid.). Simultaneously users have to give, "permission to the collection of data, storing and redirecting" (ibid.). See Section 4 on page 5 for details of the EU Data Protection Directive.

Personal information must be secured properly. This covers user names and passwords, management of personal user profiles etc. The technical solution must also secure that it will not be possible to access personal user information through the social network of the PIA system.

7.2 Autonomy and beneficence

Autonomy demands good knowledge of the technology and how to control it. In the case of the application design it has to be ensured that, "the control using the system stays with the user, even if the system is invisible or continuously on"; the user has to have "tools to start, stop and configure applications", "gets clear feedback on applications and functions that are on" and "gets sufficient feedback on what is happening in the application" (Ikonen et al. 2008b: 5).

Autonomy and beneficence for the primary end-user are driving forces behind the AAL initiative. In a homecare situation, application of such assumptions and principles is not always straightforward, given, e.g., conflicts of interest between different parties (the person in need of care, the primary carer, the family etc.). There is a need to evaluate what "feels right or wrong". To address these aspects it is reasonable to suggest that technology deployment departs from a relationships analysis between the person in need of care, the formal and informal carers, paid staff, the family etc. Trust and comfort are key issues. Possible conflicts or stressful relations between primary and secondary end-users (e.g. family requiring monitoring/tracking, and the primary end-user refusing to be monitored or "wired") will clearly not offer a fruitful or ethically acceptable point of departure for any test, trial or pilot. Distributive ethics from the perspectives of justice, equality of access, choice) will be applied in the PIA project. This concerns the overall balance between technology-driven, business-driven and socially-driven research. Transparency of interests and orientations, given the strong industry/business involvement in this research, is crucial.

7.2.1 Useful questions for developers to answer and revisit during the project

1. Who are the real beneficiaries of the PIA system? (end-user, the carer and/or the care organisation, or other?)
2. Whose definition of benefit is being applied?
3. What are the costs and benefits (physical, emotional, psychological, ethical, financial) of using the PIA system, and to whom do they apply?
   E.g.
   a. Does it support the person's autonomy or simply reduce risk?
   b. Can a balance be struck, ensuring the wellbeing of both/all parties?
   c. Is an individualised risk and wellbeing assessment is needed?

7.3 Integrity and dignity

AAL technologies should not be a substitute for real social contact and, "level of intervention should be restricted to what is really necessary for the situation" (Empirica and WRC 2009: 29). For dignity, the project must support self-activity and self-fulfillment, social contact, positive self-image, and one's own realisation of security and satisfaction (Norwegian Board of Technology 2009: 10).

7.4 Reliability

Technology must be reliable, dependable and usable not only for the person receiving care, but also for caretakers. On the other hand the user should be in a position to turn off the system when she/he feels bothered by it. The PIA system has to take care for such a situation by making sure that

the end user cannot be harmed (Empirica and WRC 2009: 38). Safety is a sensitive matter in the intersection of autonomy and reliability.

7.5 Role of technology in society

Applications and assistive technologies should be developed for increasing the quality of life, reducing harm and producing benefits for its user.

The PIA system aims to increase quality of life through supporting the independence and autonomy of the end user, and through reducing burden on carers. The system could potentially reduce harm for end users through its provision of clear guidance on how to carry out tasks. However, particular care needs to be taken to identify potential risks for end users and carers and to take all reasonable steps to reduce the likelihood of either party coming to any harm.

7.6 Social media / networks

The PIA system will include a video sharing and social network service. Terms of Service must be available in writing for this, and communicated in an understandable way to the secondary end users, who will create accounts for this service and connect them to their PIA accounts. When they give PIA access to the video sharing and social network account, the secondary end users must be aware of what this entails. The data protection, security, autonomy, reliability and other concerns also apply to the video sharing and social network service.

On-line guidelines will be developed to assist end-users in the publication of video clips (including information about intellectual property), and in sharing information (including information about not sharing sensitive information about other persons).

7.7 Equality of access

The application should be designed for every user group; respectively, "no user group should be ignored without strong reasoning" (ibid.: 9). However, it may be required to make a difference between people with minor cognitive impairments and people with dementia, or people with other disabilities. Therefore it should be possible to offer different services for specific needs of different groups.

"The lack of adequate infrastructure in certain regions and the absence of computer literacy in certain sections of the population" (Empirica and WRC: 12) have to be minded. Therefore, minimal requirements for implementation and an, "age-friendly or layperson-friendly design" is an important goal. It has to be ensured that people are able to use these technologies and knowing about, "purposes, functions and what use they may get from them" (ibid.: 14).

The design of the PIA system will be based on user requirements that have been determined from the user involvement activities, as well as from well-regarded accessibility guidelines such as Web Content Accessibility Guidelines WCAG 2.0[4]) to user interaction such as:

- Adopt familiar user interface concepts; based UI/UX designs on established user patterns.
- Ensure clarity of presentation and aesthetics of IADL multi-media material in all modalities (pictures, video clips, sound, etc.).

[4] http://www.w3.org/TR/WCAG/

- Place emphasis on the ease of use of interactive elements.
- Reduce speed of spoken messages and other sound-feedback.
- Avoid childishness, special and overly decorative design elements of any information.
- Make sure that icons and other graphics on the primary end-user's IADL tablet are logical and self-explanatory to this age group.[5]

Special attention needs to be given to the principles for **Universal Design** (UD) and **Design for All**. UD-principles such flexibility in use, simple and intuitive use, perceivable information, tolerance for error, low physical effort, size and space for approach and use need to be integrated with the PIA project's working practices.

8 Responsibilities and procedures

All colleagues in the PIA consortium are required to read and comply with the content of this document.

The nominated PIA Test Officers in each country are responsible supervising the fulfilment of this code of conduct throughout the project.

Any ethical questions arising during the PIA project need to be referred to the nominated Ethics Manager (Rachael Dutton at Accord, UK) who has a coordinating role for this. It is possible that ethical concerns or dilemmas will need to be referred to ethics committees if ethics approval had been required in a particular country.

9 References

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10 Appendix 1: Ethical and legal issues from the PIA proposal

Assistive technologies for independent living at home offer a lot of promise. However, attention needs to be given to a number of ethical concerns. Some are directly related to the characteristics of the technology, some to issues of preferences and choices. Ethical aspects in the PIA project concern the fieldwork and involvement of end-users (starting from analyses of end-user needs, requirements and personal preferences, and proceeding to user tests and field trials), the management of research data, and the use of the technology itself, as described below.

The PIA consortium has solid experience from working with older persons, and ethical issues that may arise. The user organisations work mainly with primary end-users (older persons). Several of the consortium partners have expertise in involving people with memory impairments and intellectual disabilities in their research and development work. Karde AS has performed a number of projects with involvement of older persons (e.g., Mylife, Multimedia technology for independence and participation for people with dementia (2011-2012); AAL Joint Programme, Call AAL-2010-3). The consortium's knowledge of the target group is also based on a literature review carried out by Petrina Duff, Work Research Centre, Dublin, and input form focus groups on the new products with experts and secondary end-users. MAmI is involved in a National Project (Talisman+) financed by Science & Innovation Ministry for supporting daily life of elderly at home.

First of all, we will ensure that all fieldworkers have or receive appropriate **training and knowledge** concerning ethical issues of undertaking research with end-users, including user test, field trials or pilots, will be carried out in compliance with established ethical and privacy regulations. In particular, the test/trial/pilot planning will consider the ethical guidelines for research in science and technology as established in each country conducting user tests and field trials, guides concerning reporting and careful handling of personal data, and regulations of use of personal data within research projects. Ethical guidelines for field work **(Code of Conduct – CoC)** will be developed in WP3. In particular, these will include procedures to manage issues that might arise relating to possible discomfort or even misuse of the intended products or technologies introduced to the primary end-user. All involved parties will sign a **non-disclosure agreement**.

Any handling of personal data will comply with the respective **national data acts** and the following legal entities:

- Charter on the fundamental rights of the European Union (2000/C364/01).
- The 95/46/EC Directive on the processing of personal data.
- The RESPECT Code of Practice[15] as reference material for development of PIAs ethical guidelines.

In case challenging ethical issues arise during the project, national ethical committees will be consulted. At all test and trial sites of the project, a **test officer** (TO) will be appointed (Chapter 3.2). The TO is responsible for the application of the ethical guidelines (CoC) for field work by all test personnel, in all user tests and field trials. This supervision will be based on a detailed follow-up-schema for all test and trial activities. System logs that enable end-user identification will be **made anonymous**. In all cases of fieldwork, the **dignity** of all involved end-users will be treated appropriately. By dignity we mean the personal experience of confidentiality and personal comfort when using or being monitored by ICTs, including sensors, alarms or the like. The primary end-user of the PIA system uses **non-stigmatising devices**, such as generally available tablet PCs. This strategy is adopted by the PIA project in order to stimulate the use of the PIA system by older persons who wish to appear as users of modern technologies, and bring this achieved capability into the later use situations in which more support is needed, but where there still is a need *not* to exhibit use of "elderly-technology". **Procedures, information material and schemas** for **informed consent** will be developed for user tests, trials and pilots. In particular, formal and informal carers will be contacted in each individual case. Adequate and appropriate information material about the project and its goals and methods will be prepared for informing both primary and secondary end-users. User tests

and field trials will reveal the most important parameters with respect to dignity. These test results will be taken into account very precisely in order to produce an acceptable design for users with privacy concerns.

Consequence ethics ("insight from consequences") is an important approach in technology deployment for elderly users. Autonomy and beneficence for the primary end-user are driving forces behind the AAL initiative. In a homecare situation, application of such assumptions and principles is not always straightforward, given, e.g., conflicts of interest between different parties (the person in need of care, the primary carer, the family etc.). There is a need to evaluate what "feels right or wrong". To address these aspects it is reasonable to suggest that technology deployment departs from a relationships analysis between the person in need of care, the formal and informal carers, paid staff, the family etc. Trust and comfort are key issues. Possible conflicts or stressful relations between primary and secondary end-users (e.g. family requiring monitoring/tracking, and the primary end-user refusing to be monitored or "wired") will clearly not offer a fruitful or ethically acceptable point of departure for any test, trial or pilot. **Distributive ethics** from the perspectives of justice, equality of ac-cess, choice) will be applied in the PIA project. This concerns the overall balance between technology-driven, business-driven and socially-driven research. Transparency of interests and orientations, given the strong industry/business involvement in this research, is crucial. Finally, an important ethical issue that is connected to the **use of the PIA social network** by the carers. We will develop **on-line guidelines** which assist end-users in publication of video clips (ad. intellectual property), and in sharing information (ad. sensitive information about other persons). All ethical matters will be treated and managed in WP3.

1.7.1 Ethical "declaration" table

Ethics declaration of proposals in the AAL-Joint-Programme	Described on page or "not relevant"
How is the issue of informed consent handled?	Chapter 1.7, p. 8
What procedures does the proposal have to preserve the dignity, autonomy and values (human and professional) of the end-users?	Chapter 1.7, p. 8
If the proposal includes informal carers (e.g. relatives, friends or volunteers) in the project or in the planned service-model - what procedures exist for dealing with ethical issues in this relationship?	Chapter 1.5, p. 6
If the proposal includes technology-enabled concepts for confidential communication between the older person and informal and formal carers, service providers and authorities – what procedures are planned for safeguarding the right to privacy, self-determination and other ethical issues in this communication?	Chapter 1.7, p. 8
What "exit" strategy for the end-users involved in the project does the proposal have (in terms of end-users leaving the project during its implementation and after the project's end)?	Chapter 1.5, p. 6
How are the ethical dimensions of the solution targeted in the proposal taken into account? (Brief description of distributive ethics, sustainability et.al.)	Chapter 1.7, p. 8 WP3, Chapter 2.5

11 Appendix 2: Consent forms

PIA Focus Group Consent Form: All Participants [Draft 1]

This project is about finding out your views on the PIA system. If you have any questions please ask the project worker before you decide to take part.

I have spoken to _____(name of project worker) about the PIA project.

This conversation took place on_____(date)

For each statement below please tick a box for either yes or no:	**Yes**	**No**
I have read the information sheet		
I have had the chance to ask questions		
I am clear about what this project is and what it is for		
I understand that if I don't want to take part I don't have to, and don't need to give a reason why		
I understand if I don't want to take part it would not affect any help or services I am getting now or in the future		
I understand that I can change my mind at any time and can leave the focus group if I want to		
I am happy to take part in a focus group discussion about PIA		
I am happy for researchers to tape record the focus group discussion		
I am happy for non-confidential information about my views of PIA to be used anonymously (without my name) in reports, at conferences and on appropriate websites		

Your name: _____

Your address: _____

Your signature: _____

Today's date: _____

We will not use your name or address in any of our publicity. We request your details only for our records.

For more information speak to XXX {contact details}

Photo of researcher

PIA Field Trial Consent Form: Primary End-User [Draft1]

This project is about finding out how the PIA system works for you. If you have any questions please ask the project worker before you decide to take part.

I have spoken to _____(name of project worker) about the PIA project.

This conversation took place on_____(date)

For each statement below please tick a box for either yes or no:	**Yes**	**No**
I have read the information sheet		
I have had the chance to ask questions		
I **am clear about what this project is and what it is for**		
I understand that if I don't want to take part I don't have to, and don't need to give a reason why		
I understand if I don't want to take part it would not affect any help or services I am getting now or in the future		
I understand that I can change my mind at any time if I don't want to carry on		
I am happy to use PIA in my home		
I am happy to talk to the project worker about myself and my experiences of using PIA		
I am happy for project workers to look at the system logs to find out how and when I have been using PIA		
I am happy for the project worker to tape record our discussions about PIA		
I am happy for the project worker to take photographs of me using the PIA system		
I am happy for the project worker to video me using the system and talking about the system		
I am happy for non-confidential information about my experience with PIA, along with photographs and video, to be used anonymously in reports, at conferences and on appropriate websites		

Your name: _____

Your address: _____

Your signature: _____

Today's date: _____

We will not use your whole name or address in any of our publicity. We request these details only for our records.

We will be working with {XX name of secondary end-user} on this project with you.

Signature of secondary end-user: _____

For more information speak to XXX {contact details}

Photo of researcher

PIA Trials Consent Form: Secondary End-User [Draft 1]

This project is about finding out how the PIA system works for you and your relative. If you have any questions please ask the project worker before you decide to take part.

I have spoken to _____(project worker) about PIA

This conversation took place on_____(date)

For each statement below please tick a box for either yes or no:	**Yes**	**No**
I have read the information sheet		
I have had the chance to ask questions		
I am clear about what this project is and what it is for		
I understand that if I don't want to take part I don't have to, and don't need to give a reason why		
I understand if I don't want to take part it would not affect any help or services I am getting now or in the future		
I understand that I can change my mind at any time if I don't want to carry on		
I am happy to help {XX name of primary end-user} use PIA in		

their home		
I am happy to talk to the project worker about myself and my experiences of using PIA		
I am happy for project workers to have access to my PIA passwords for {?????}		
I am happy for project workers to look at the system logs to find out how and when I have been using PIA		
I am happy for project workers to tape record our discussions about PIA		
I am happy for project workers to take photographs of me {and xx primary end-user} using PIA		
I am happy for project workers to video me and {xx primary end-user} using PIA and talking about PIA		
I am happy for non-confidential information about my and {xx primary end-user} experience with PIA, along with photographs and video, to be used anonymously in reports, at conferences and on appropriate websites		

Your name: _____

Your address: _____

Your signature: _____

Today's date: _____

We will not use your whole name or address in any of our publicity. We request your details only for our records.

We will be working with {XX name of primary user} on this project with you.

Signature of primary end-user _____

For more information speak to XXX {contact details}

Photo of researcher

12 Appendix 3: Use of PIA equipment during the trial

Use of PIA system/device – ownership and responsibility [Draft 1]

Thank you very much for being part of the PIA trial.

As part of PIA trials all participants will be given a ??? to use and the following conditions will apply:

- All use of PIA is at your own risk.
- Costs for data traffic is the responsibility of _____
- The ??? is not insured by the PIA project, and users will not be covered by the project should the ??? cause any damage.
- If your ??? is lost or destroyed, the PIA Project is not required to replace it..
- The ??? is to be borrowed and must be returned (depending on circumstances[6]) if you leave the trial before it ends so that it can be given to another participant.

I/we would like to accept the use of a ????, No. _____, to be able to use the PIA system and take part in the project, and I/we accept the above conditions.

If we no longer use the ???? for PIA, or otherwise wish to return it I/we are aware that I/we should contact _____, tel: _____.

Signed: _____

_____

Name Location Date

[6] Criteria for this will need to be clear.

13 Appendix 4: After-use of PIA equipment

Post-trial use of PIA system/device – ownership and responsibility [Draft 1]

Thank you very much for being part of the PIA trial.

As part of PIA trials all participants were given a ??? to use.

Now the studies are finished and you can keep your ??? so that you can continue to use the PIA system. Updates for the system may discontinue now the project had come to an end. This is because PIA was a research project, which is now closed, there is no guarantee that the service will continue forever. We believe that the service will continue in its current form for approximately ??? (until ???). The system is being evaluated for commercialisation. If it becomes available to buy we will let you know so that you can decide whether you want to transfer to the commercial version or not. There is no requirement that you have to buy the commercial version.

The following conditions will apply if you want to keep the ??? for use of PIA:

- All use of PIA is at your own risk.
- There is no longer support available from the PIA project should you have any problems with your ???? or the software on it.
- [All costs for data traffic are to be transferred to you by ???]
- The ??? is not insured by the PIA project, and users will not be covered by the project should the??? cause any damage.
- If your ??? is lost or destroyed, the PIA Project is not required to replace it.

Please tick one of the two boxes below:

Yes, we want to continue to borrow ??? No. _____ for the continued use of PIA system and accept the above conditions.	☐
No, we do not want to continue using the ???? for PIA and wish to return it.	☐

Signed: _____

_____

Name Location Date