

JOIN-IN Senior Citizens Overcoming Barriers By Joining Fun Activities



AAL JOINT PROGRAMME: PROJECT NO. 031121

Deliverable: 6.1

Evaluation plan and guidelines

Date of deliverable: 31-08-12 Final Draft: 1.0

Organisation name of lead contractor for this deliverable:

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Contributions: HMGU, NOR, NST, ITC, JOH

Project co-founded by

The European Commission German Federal Ministry of Education and Research (BMBF) (Lead partner) Finnish Funding Agency for Technology and Innovation (Tekes) National Office for Research and Technology, Hungary Enterprise Ireland, Ireland Research Council of Norway

Dissemination Level: Public – After revision including pilot results

Start date of project: November 2010 (Duration: 36 months)

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1. About Join-In

Join-In aims at providing the methodology and the technologies for elderly persons to participate in social activities and have fun via digital media.

Loneliness in the elderly is a major problem in elderly care. Many of the people over the age of 75 live by themselves. Many of these suffer from loneliness and social isolation [1,2]. Other research indicates the effects of loneliness on the immune system, the cardiovascular systems and the onset of Alzheimer's disease [3]. Activities offered by social services do, however, often not reach those most in need. Reasons for this are: social deprivation, low self-esteem or physical inability.

The Join-In project aims at counteracting loneliness in the elderly by providing a concept, the methodology and technologies for elderly persons to participate in social activities.

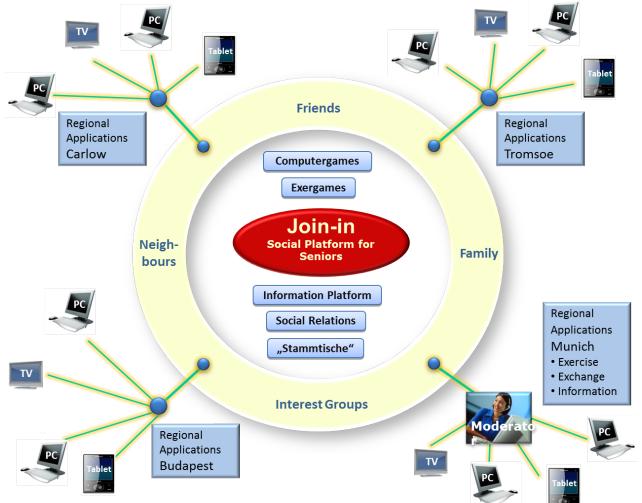


Fig.1 Join-In Platform

Join-In is setting up a social network for the elderly; it allows communication via TV or PC. A multi-player serious game for the elderly is being developed. The interest in gaming is high in seniors: In a survey performed in Germany with 1200 +61s two out of three PC users stated that they enjoy playing games regularly on the internet [4]. Studies [5] could demonstrate the increase of cognitive skills, reaction times, self-esteem and the sense of well-being in the elderly when playing computer games.

Another positive effect is that gaming is multigenerational and enables the elder generation socialising with the younger one, e.g. grandchildren.

The Join-In concept includes exercising either by exergames or by moderated exercises. Physical activity supports good health and at the same time counteracts the feeling of loneliness, while loneliness leads to less physical activity [6]. It is a vicious circle we aim to break. Recent results indicate that exergames create physical benefits; on top of that there are indications that they encourage physical activity, physical ability and that exergames counteract loneliness. [7].

Active participation is vital if the individual is to profit from the Join-In developments Motivation in the elderly is a challenge. Another challenge is the heterogeneity of the elderly. Based on a thorough user requirement analysis Join-In is analysing how to best attract elderly persons the social network and how to motivate them to take part in the Join-In social activities. Digital inclusion and factors hampering its acceptance -such as accessibility, motivation, lack of skills and confidence- will be tackled. User groups were set up in Germany, Hungary, Ireland and Norway. The involvement of user groups in four different countries will help us to achieve a European solution which will also be useful in other countries.

2. Introduction to the deliverable

The final goal of the project is the introduction and long-term use of Join-In social network for the elderly that connects to entertaining activities such as gaming and exercising as an integrative part for "fun" and "socialising". Pilot studies will be performed in the partner countries in order to evaluate the benefits and limitations of the Join-In system.

This deliverable describes the evaluation concept, its layout and set-up of the different pilot sites. It aims to ensure the timely and efficient performance of the pilot. The developments will be evaluated aiming at results that can serve as a basis for, at the one hand, marketing the Join-In products, and, at the other hand, to find the best ways to best possible address and involve the target group. This document will be replenished since evaluation is an iterative process. Additions will be made resulting from the pilot; some aspects will be further concretised (e.g. the exact workflow for the introduction phase) will be defined as soon as the prototypes have been lab-tested and the product definition and target audience for exploitation have been agreed between the project partners.

3. Join-In Evaluation Concept

3.1. Introduction to the Evaluation Concept

The main evaluation criteria are functionality, usefulness and usability of the Join-In system. The evaluation is an iterative process which will also include an evaluation of the user requirements.

The chosen concept follows the guidelines for Good Evaluation Practice in Health Informatics by Nykänen P, Brender J, etal. [8] These guidelines are aiming at supporting evaluations in the health informatics domain. They were achieved by a consensus making process of the EFMI (European Federation of Medical Informatics) and the AMIA (American Medical Informatics Association) health informatics community. They seem to be well suited for the AAL-project "Join-In" as issues relevant for planning, implementation and execution of Join-In are vital aspects in the evaluation guidelines. By applying these guidelines we aim to avoid vital risks and pitfalls in the piloting. On top of that, it will allow for international comparisons regarding, for example, the usability of the Join-In outcomes.

3.2. The context of the evaluation study

Join-In is developing AAL-applications for elderly people. The core of the project is a social network and entertaining activities (games) for socialising in the elderly. By offering facilities for socialising we aim to reduce loneliness in elderly people. The evaluation will be performed in the context of the Join-In project in four countries, Germany, Hungary, Ireland and Norway. So far the name and concept of AAL are not

well known among the elderly population. In addition to this, most of the older seniors lack technical experience or experience with new technologies.

The Join-In Social Network includes entertaining activities such as the Join-In memory game, exergames (walking, exercising and cycling), a set of exercises using "Design-for-all" motion controllers / Kinect

These need to be evaluated concerning their

- Functionality
- Usefulness and effectiveness towards the envisaged goals
- Usability and adaptability
- Acceptance by the users and by those promoting the applications (e.g. carers)

In addition Applicability and effectiveness of the concept needs to be evaluated, for example if Join-In effectively manages to encourage elderly persons to exercise or socialize more often. Furthermore, the general effect of Join-In on the activities and habits of elderly people will be evaluated.

3.3. Evaluation steps

The evaluation study consists of several clearly distinguished phases. Each phase fine-tunes the results of the previous one and adds for information to that. We distinguish the following evaluation stages.

3.3.1. Study exploration

At this very preliminary stage we explore the need for an evaluation. We analyse the research issues and check whether an evaluation will serve vital issues in the project.

This identifies the reason and objectives for the evaluation study, and describes the following

- The information needs / objectives of the evaluation
- The context of the evaluation study
- The stakeholders preliminary identification
- The setting rough sketch
- The evaluation methods to be used preliminary exploration
- The restrictions of the pilot and of the publication of the results preliminary exploration
- Ethical and legal issues

At the end of this phase we will have a rough outline of the study.

3.3.2. Study design

This is a preliminary design of the study. We will define the framework of the study and define

- The study team
- The pilot sites in more detail
- The participants (which, for which tasks, when, how)
- Ethical and legal issues
- Identification of possible risks

- Timeline
- Resources

This is also the time to make decisions between the partners regarding:

- Study methods
- Study type
- Technical settings
- Outcome measures

Finally, we will ensure that

- All stakeholders' needs are covered
- Information needs as described in the proposal / theories have been covered
- The methods to be used for the different research issues fit with the pilot set-ups.

This is an important phase because bad planning of the study may mean that the field study cannot be performed during project runtime.

The detailed piloting and study design plan will be based on this.

3.3.3. Evaluation plan

The evaluation plan will serve as the core tool for managing the evaluation study and the pilot. At this stage we are setting up plans for the pilot and deciding on the procedures to be taken for ensuring a successful pilot and a thorough evaluation study. This stage includes

- Detailed pilot planning
- Designing and finalising the evaluation material
- Setting up the training material
- Designing a training plan
- Evaluation activity mapping
- Quality management plan
- Communication strategy (communication means, tools)
- Recruitment of necessary additional staff
- Revision of the time schedule

Once this stage has been performed the pilot is ready for implementation

3.3.4. Implementation

The pilot study is being performed. The following needs to be done

- Project controlling and risk management
- Observation of changes regarding the planned realisation of the implementation as well as changes in the attitude and habits of the elderly.

- Continuous pilot management
- Performing the evaluation study

3.3.5. Finalisation of the evaluation study

The final step consists of

- Final analysis of the evaluation data,
- Integrating the results into the marketing and business plans
- Reporting and publishing the results

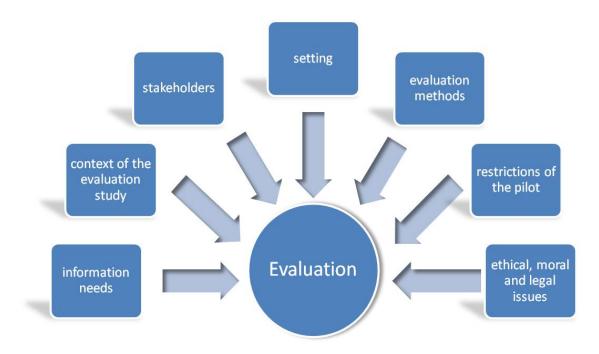
Study Exploration	Study Design	Evaluation Plan	Implementation	<u>Finalisation of</u> evaluation study
Setting - rough sketch	Pilot sites - detailed	Detailed pilot planning	Pilot management	Analysis data
Stakeholders - preliminary	Participants	Training plan	Project controlling	Results to marketing
Information needs	Study team	Recruitment additional staff	Risk management	Reporting results
Evaluation methods - preliminary	Study methods	Evaluation activity mapping	Observation of changes	
Restrictions of pilot	Technical settings	Communication strategy	Evaluation study	
Ethical and legal issues	Study type	Evaluation material		
	Timeline	Revision time schedule		
	Resources	Training material		
	Possible risks	Quality management plan		
	Outcome measures			

Fig. 2 Evaluation Phases

Hg. 2 Evaluation (hases				
3.4. Time Schedule for the	e evaluation study			
Study exploration	M 20			
Study Design	M 21			
Evaluation plan	M 21			
Pilot plan	M 23			
Implementation				
 Preliminary study 	M 24- 26			
 Field test 	M 27- M 35			
Finalisation of the evaluation study M 36				

4. Join-In Study exploration

Join-In is developing a social networking platform and a concept for elderly people to participate in social and fun activities and to escape social isolation. It will enable and facilitate communication by providing the necessary technologies. Join-In will offer a variety of activities to motivate and to stimulate the elderly, such as: communicating by social networking, multiplayer gaming, exergaming, moderated exercising. We aim to encourage socialising and to help the seniors to stay active, to improve their health status -as preliminary studies have demonstrated- and to contribute to the target group's quality of life. We aim to support elderly people maintaining and setting up contacts to family and friends but also to others sharing similar interests and/or being in the same situation.



4.1. The information needs

In order to decide on the issues to be evaluated, i.e. the Information needs, the project description needs to be analysed concerning the preliminaries, objectives and goals of the project. The Document of Work states that

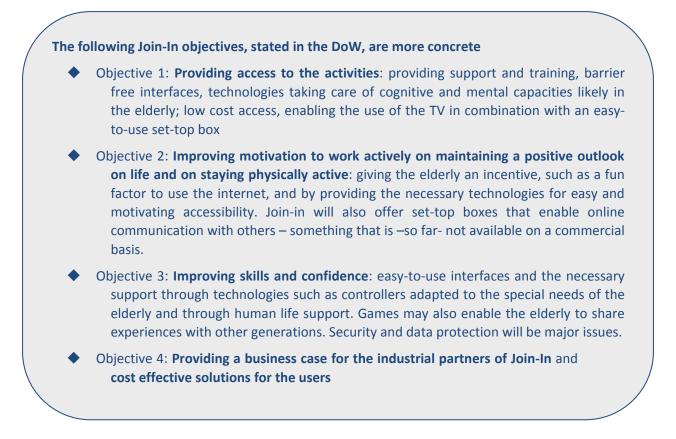
- Computer games can increase the brain activity
- The use of exergames encourages physical exercise
- The use of exergames improves the quality of life for the individual
- The involvement in social activities decreases the feeling of loneliness in the target group

The Join-In applications make the elderly feel less lonely.

These statements are based on literature reviews and on results from other projects. They are long-term objectives. With the existing resources it is not possible to evaluate these statements on a quantitative level. It is, however, possible to obtain indicators for these statements and thus to gain an insight into the effects, the motivation and the attitudes on a qualitative level.

Some of the issues to be considered concerning piloting and evaluation are therefore

- How to channel the activities to increase the beneficial effect on the person/ on the person's state of health
- Identifying the incentives for motivation and pleasure in the target group.



While it will be impossible to evaluate within the framework of the project whether and how far the applications developed will improve the health status and quality of life of the elderly, all of the objectives can be evaluated to a certain degree. It will be possible to obtain indicative data on the subjective effects of the solution. Integrated with the a.m. evaluation criteria (acceptability, usefulness, usability, functionality and business case) the following preliminary information needs can be identified

Functionality

This refers to the features and quality of the outcomes (products and services). Questions to be answered are

- Are the applications reliable, secure and adaptive?
- Do the applications fulfil the particular requirements for the intended use?
- Are the applications conform to the user needs and intended uses?

Functionality tests will be performed in the lab test, and in the pilot.

Usability

For usability we refer to the ISO 9241 [9] definition "Extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use", whereas

• Effectiveness is the " accuracy and completeness with which users achieve specified goals"

- Efficiency means "Resources expended in relation to the accuracy and completeness with which users achieve goals"
- Satisfaction is "Freedom from discomfort and positive attitudes towards the use of the product".

The evaluation of this aspect has to take into account the context of use of the products. These need to be specified in detail. The socio-economic factors and possible behavioural changes will also be taken into account.

Usefulness

This is an important issue as the work with the target group indicates, that they will not use the solutions offered -even if they are working fine- unless they consider them useful. Questions to be asked in this section can, e.g. are

- Do you think the walking exergame benefits your health?
- Do you think that regularly playing memory will improve your brain performance?
- Will Join-In help you to stay in touch with your friends?
- Acceptability

Even though this sounds easy, it can be quite challenging to assess as acceptability is strongly related to people's expectations. It is very important to distinguish between the different stakeholders -as their interests and expectations are likely to differ -when assessing acceptability for the different stakeholders.

Business case

All of the above issues provide the basis for the business cases. Yet the commercial partners of Join-In will have to pose specific questions to the users concerning e.g.

- Acceptable costs of the product
- Conditions which have to be fulfilled in order for the elderly person to use the product
- Other stakeholders (e.g. family, friends, health professionals)

It is important to remember that the a.m. Information needs might have to be assessed for all Join-In applications. Therefore, each one of the outcomes will have to be analysed accordingly.

4.2. A first sketch of the organisational environment, and the stakeholders

The information needs on the applied technologies and services will be evaluated in field tests. Evaluation studies -based on the same study design- are planned to be done in Germany, Hungary, Norway and Ireland.

4.3. Preliminary description of the pilot sites

<u>Germany</u>

In Germany Join-In will be evaluated in München, in the community of the Diakonie München-Moosach. Diakonie München-Moosach (DMM) is a carrier which has been providing social services in the north-west of Munich since 1965. The main focus of the work of DMM is the work with seniors. Though a large part of this is elderly care nursing, DMM is also offering other activities to this group. Thus DMM has set up "Senior-Clubs". These offers gymnastics, dance classes as well as a cultural and travel events. Some of the

elderly have actively contributed to the user requirements. DMM has regularly informed its members on the Join-In activities and its progress. The pilot study is aiming at about 100 German users.

The pilot implementation will be covering different age groups. It will be performed in two steps: starting off with a small group (3-5persons), evaluating the results, adapting the pilot and then continue with a larger user group including homebound participants.

Recruiting will be done by the members of Join-In and by focus group members.

<u>Hungary</u>

In Hungary the evaluation study will be performed by the Johannita Segítő Szolgálat. These are supporting protestant elderly and persons in need in 7 regional centres spread across Hungary. Their workforce is mainly made up of volunteers. Three main types of user group will be involved, an urban group, a rural town group and a rural village group in different places i.e. Budapest, in Balatonalmádi, in Szombathely, Hódmezővásárhely and in Hencse. It is planned to involve 100 persons.

The pilot implementation will start with a first, smaller group that will be recruited from elderly people speaking not only Hungarian but also German and/or English. The people will be covering different age groups and surroundings.

<u>Ireland</u>

The user group selected for testing in Ireland are part of the Active Retirement Ireland group located in New Ross, County Wexford. There are 110 total members of the group. They provide a mixture or active retirees from approx. 55 – 75 years old. The community meets regularly to take part in different activities such as bowling and dancing. Each member of the group can select the activities they wish to partake in. Some members of the group take part in activities 7 days a week. 14 members of the group attended the user group requirement sessions. The field trials are aiming at 10-15 persons.

In Ireland the pilot implementation will take place in three phases; initially an ethnographic study will be conducted in the community centre with the user group. This will be followed by interviews with care givers of the community centre. Finally, one or more focus group sessions will be held with the user group.

<u>Norway</u>

In Norway the pilot will include the same user group throughout the pilot. Users will be recruited among elderly persons from the Heracleum Elderly Centre, and include elderly with reduced mobility. The senior centre offers a wide range of activities such as different kinds of handicraft, dance session, entertainments, educational speeches, a café, a shop for selling handicraft, hairdresser, etc. They also have a day centre for elderly who cannot come by their own.

The number of participants in the field trials will be 10-15 persons and different age groups will be covered. The participants will be recruited by key persons in the Heracleum Elderly Centre and LHL, the Norwegian Heart and Lung Patient Organisation.

The regular visitors at Heracleum Elderly Centre include elderly with reduced mobility, particularly those living in the housing part of the centre. The senior centre offers a wide range of activities such as different kinds of handicraft, dance session, entertainments, educational speeches, a café, a shop for selling handicraft, hairdresser, etc. They also have a day centre for elderly who cannot come by their own. Heracleum has replaced Seniornett, the original user organisation, since it proved very difficult to recruit users from Seniornett.

LHL is a nationwide interest organization for people with heart and lung disease. LHL's vision is joy of life and good health for all. The organization has approximately 45 000 members, 300 local chapters and twelve district associations.

4.4. Preliminary identification of the stakeholders

We aim at the following stakeholders

- 1. Users
 - age 55+: door openers and multipliers
 - age 65 + (mainly age 75+)
 - regardless of the ethnical background
 - speaking the National language
 - voluntary participation

Exclusion criteria are

- unable to handle the Join-In solution
- unable to give informed consent
- physical conditions that might be at risk by using the Join-In Solution (e.g. epilepsy)
- 2. Family / Friends (if applicable)
 - regardless of the ethnical background
 - speaking the National language
 - suggested by the user

Exclusion criteria are

- unable to handle the Join-In solution
- lack of interest
- 3. Health professionals (if applicable)
 - ambulatory care nurse involved in the user recruitment and support of the pilot
- 4. Potential Business partners interested in marketing the solutions

4.5. Interventions

Join-In provides solutions that are primarily aimed at being implemented in the users' houses. This means

- Setting up Join-In solution in the homes of the elderly
 - It cannot be expected that the target persons will be able to install and set up the solutions by her-/himself, neither that a family member will be able to help.
- Broadband connections must be available to get the best results from Join-In
 - Some persons may not have internet access. This needs to be dealt with
- The pilot participants will be asked to test the different elements of the Join-In solutions (different applications, barrier free interfaces, ...)

Handling new technologies might make them feel uncomfortable

• They will be asked to answer questions on their experience

The questions have to be chosen carefully. Ethical issues have to be considered.

• The work with users requires a high social competence; the interviewers will be instructed in order to ensure a respectful interaction with the users as well as to prevent a distortion of results.

4.6. Ethical and legal issues

The ethical proceeding is based on the following documents

- Declaration of Helsinki: The World Medical Association (WMA) developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human subjects, including research on identifiable human material and data
- European Parliament and Council Directive 95/46/EC of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data Official Journal L 281 of 23.11.1995
- Guidance Note for Researchers and Evaluators of Social Sciences and Humanities Research based on discussions among twenty-eight Ethics Experts with previous experience in Ethics Screening, Review and Audit at European Commission. It deals with privacy and data protection, Informed consent (ftp://ftp.cordis.europa.eu/pub/fp7/docs/ethical-guidelinesin-ssh-research_en.pdf)

The ethical committees as well as the data protection officers receive a detailed description of the study (see 5a) and the informed consent form.

The following will be specified for each pilot site:

- Subject and duration of the study
- Type and extent of data concerned
- How will the people be recruited
- Persons concerned
- Specifying how informed consent will be obtained
- Technical and organisational issues
- Data management Responsibilities and data protection measures

Ethical and legal issues have to be considered at an early stage. It is important that the users' participation in the project pilot is voluntary and that the decision will in no way influence the level and service of any interaction or care or social groups they belong to.

The persons asked to participate in the trial will be explained their rights and obligations regarding the technology and/or the service. The participants are entitled to know about the status and results of the project at any time. They are also entitled to withdraw their permission to participate at any time.

Within the project all participating employees and representatives of the user organisations will be properly trained and instructed.

The national data protection officers and, where applicable, also the ethical officers will be informed and involved.

An Informed Consent will be used. A template of a consent form set up by the World Health Organisation (WHO) is available in App. 1.

The privacy of any participating person has to be respected at any time.

4.7. First exploration of evaluation methods to be used

The following methods will be used:

- Questionnaires (5-Likert-Skale)
- Structured Interviews
- Semi-structured Interviews (Guided Interviews)
- Functionality tests
- Descriptive statistic methods
- Summary content analysis (Mayring)

4.8. Restrictions of study execution

We will solely be able to perform a feasibility study. Neither the improvement of any health status nor the improvement of the quality of life in the elderly persons can be measured statistically sound.

5. Join-In Study design

5.1. Detailing the pilot applications

5.1.1. Pilot Application I: Germany

5.1.1.1. The study team

The study team will consist of various persons

- Recruitment: DMM will be responsible for the recruitment of the participants. The recruitment will be done by a sociologist with the support from key persons from the different areas of work with the elderly.
- Attending: employees from HMGU as well as persons from DMM will be involved attending the elderly people throughout the piloting phase
- The equipment acquisition as well as the organisation of internet access will be handled by Mr Tiedge from PAS
- The technical installation will be handled by as well as employees from HMGU
- The technical assistance will be covered by HMGU and PAS as well a key person

5.1.1.2. Settings and locations

At the beginning of the project we addressed mainly homebound elderly persons. One of the outcomes of the research so far has been that elderly people have to be introduced to new technologies in a careful manner. Results in the user requirement phase showed that, seniors have to get acquainted to new technologies while they are still active. The aim of Join-In is to find the best way of introducing elderly people into new technologies. The results will create a basis on how to involve the elderly.

Key persons will gain access to the elderly people. The key persons will be chosen from the DMM Community.

The solution will be tested in an urban area (Munich in several settings) and in a rural area (Lichtenfels):

the introduction and the first testing will take place at the different premises

- approx. half of the test persons will have the Join-In solution in their homes to test it. They
 will be recruited from dancing groups, senior clubs, village seniors (Olympic village) and
 home care
- additionally, DMM will offer elderly people the possibility to test the Join-In solution at the Diakonie premises as well as at the Olympic village
- some test persons will participate from a Join-In Social-Networking-Station set up in a nursing home

The technical surroundings:

- some of the test persons will have an existing internet connection
- some will get internet installed at their houses
- some will be against an installation of internet and will use Join-In either offline or with UMTS
- some users will access the platform with their own computer
- some will use their television with a STB
- some will need an AiO PC in order to be able to use Join-In

5.1.1.3. The sample size

The pilot will involve 50 – 100 persons.

The pilot study is going to take place in several steps; different groups will test the equipment for a certain amount of time. In order to ensure a close assistance, the participants will not all test the Join-In solution at the same time. We aim at having a maximum of 21 participants from home at the same time. Approximately 3 Persons will be introduced into the Join-In solution per week.

A preliminary study will take place with 3-5 persons and the evaluation will be done through a circular approach.

The participants will be chosen from different activity group of DMM; for a description of the groups see D 2.1.

- by behaviour: active, family centred, rest and peaceful, withdraw and misfortune
- persons with mental impairments will not be considered due to limited decision making ability
- male as well as female participants will be chosen. We aim at meeting the proportion of seniors in Moosach/Munich

5.1.1.4. The possible risks and countermeasures

Regarding the implementation there is a risk that the end-users will not be willing to participate. This may be due to several reasons

- not accepting new technologies
- not willing to having the internet installed in their houses (they will be asked to test at DMM instead)
- fear of not being able to learn how to use Join-In

- lack of interest
- peer/family influence (acceptance of the environment)
- users might consider it too much effort
- fear of letting anyone into the house
- not having enough space to place the Join-In solution
- too high prospective costs

The following possible risks for the participants have been taken into account by the team members

- The participants might feel overwhelmed by the new technologies the team will prepare the workflow in order to prevent such situations. The results from the lab tests will help to prevent such situations.
- The participants might get the feeling that they are being tested and not the new technology.

The risks concerning the participants will be made clear at the beginning of the implementation and will be part of the written informed consent.

Following countermeasures will be taken:

- thoroughly planned workflow
- Iab tests
- careful approach to participants, first access at community centres
- information sheets for the different stakeholders
- detailed information of the participants by trained key persons
- written informed consent
- close user support.

5.1.1.5. The time plan

- Each Person should at least be able to test for two month. That way it is secured, that she/he learns how to use Join-In and that it is not only interesting for the new moment.
- In order to ensure an intensive attendance of the participants, participation will start at different points of time
- Users will be introduced to the technology. The introduction will be realised at the different premises
 - The persons involved in the user tests will be presented to them
 - They will receive an information sheet (which they can take home) and will be asked to sign the written informed consent (if they wish they will have to possibility to take the informed consent home before they sign it)
 - They will receive an overall explanation of how the system and the sensors work
 - The different Join-In elements will be presented to them, followed by tests
 - Users will not be overloaded with too many topics
 - The participants will be offered short manuals (easy to use) on how to start the different elements of Join-In

We plan on groups of 3-5 persons having weekly common Join-In sessions. In addition the users can use the Join-In system whenever they want to

Content of the platform:

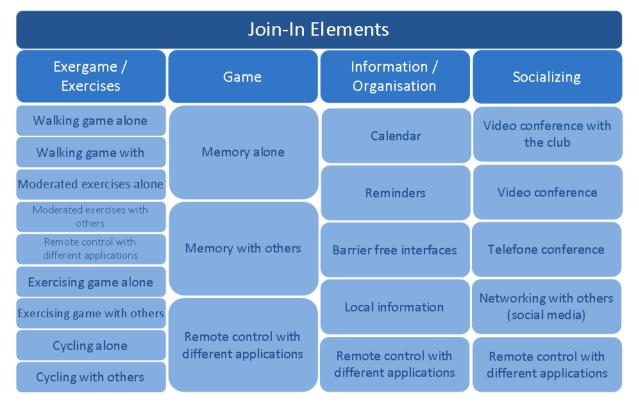


Fig. 3 German Join-In Social Network

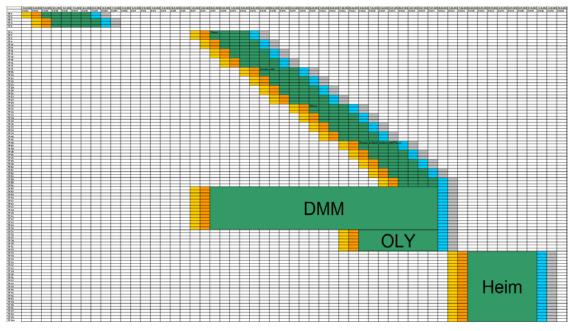


Fig. 4 Time plan Germany

- Participants will be introduced at the Join-In Social Networking Stations
- App. 3 Join-In Solutions per week will be installed at the houses of the participants
- Participants will be able to test the solution at the premises of DMM a OLY(Olympic village)

- A Join-In Social Networking Station will be set up at a nursery home (Heim)
- Since the participants will not be testing the solution at the same time app. 20 equipments will be needed

5.1.1.6. The Resources

Material Resources:

Different set-ups will be offered to the users.

Pro and Cons	+flexible +reuse of HD-TV +cheap? - no touch	+touch + flexible -expensive
Main Applications	Exergames Exercises Video-Chat	Demonstration Testing (Lab- and User)
Typical Users	"Standard User" - likes big screen and easy remote control Relative or Peer - uses Standard- PC (for video-chat and gaming)	Seniorclub

Human Resources:

The persons involved in the piloting process will be:

HMGU:

- Y: Will be the administrator of the Join-In solution
- Z: Will support the technical set-up
- V: Will assist with user-support
- X: Will give support Join-In sessions at DMM
- K and J: Will assist the moderated exercises

DMM:

- S: Will be addressing the users, has been gathering user requirements and will be in charge of training the staff for the trials
- I: is involved with the users and will help to coordinate the appointments and assist the trial phase
- H: is part of the DMM community and will also assist the elderly in the trial phase
- R: will assist the moderated exercises
- L and A: will assists the homebound participants

PAS:

- W: will prepare the equipment, and negotiate with the internet providers. He will instruct Mr X in setting up the equipment in order to make it usable
- X: will assist W setting up the equipment and installing it at the elderly peoples` homes

5.1.1.7. The study methods

For study methods see 4.7. In Germany the data will be additionally collected through

- Focus Groups (after 2 or 3 weeks of trials)
- Ethnographic methods
 - Analysis of workflow
 - Analysis of users' behaviour

5.1.1.8. Study Type

The focus of the evaluation will be on the feasibility of the developments; this will include an acceptance study and usability tests. The different elements of the Join-In solution will be tested as well as an overall evaluation of the Join-In solution will be done.

5.1.1.9. Technical settings

The Join-In solution will be tested with the following hardware:

- All-In-One PCs
- STB with TV
- PC
- Kinect and/or remote control

The internet will be accessed through Internet from the Cable Company and with UMTS-Sticks

5.1.1.10. Outcome measures

The analysis will be regarding the following aspects

- relevance to the goals of Join-In
- ease of handling
- established reliability of the system
- adaptation to the persons abilities
- usability of the Join-In products also in relation to different abilities
- effectiveness on socialising
- acceptance of the solutions by the target group

5.1.1.11. The recruitment

The participants will be chosen from the DMM community. The recruitment process has already begun in the different areas of work of the DMM.

The participants will be recruited from the different activity groups of DMM:

- Dancing groups: The participants of these groups are very active, they visit these regular meetings in order to do something for their health and to enjoy the time with others
- Senior clubs: The participants of these groups visit the club on a regular basis; they have their regular seating arrangements. Most of them are between 76-85 years old. Have different educational backgrounds as well as different family constellations.

- Home Care: The participants from this group belong to the care level 1. Persons with mental illnesses will be excluded. One possible addition to Join-In from this group will be Information videos for patients and their family.
- Olympic Village: The participants from these groups belong to the Lutheran and to the Catholic Church groups.
- Nursing home: Some of these participants were/are part of the church community.

5.1.1.12. Ethical Issues and data protection

Type and extent of data concerned: Three data categories will be collected:

- personal data for the organisation: this data will purely be collected for organisational purposes (Information about internet access, television equipment, address, friends of family – depending if the participant wants to contact them via Join-In). This information will be kept separate from any other data.
- **socio demographic data:** age, gender, living situation, etc.
- evaluation and user experience: how the participants evaluate the Join-In solution as well how they experience using the different elements of the Join-In solution

The collected personal data for the organisation will be locked and kept separate from the evaluation data. Each participant will receive a number; it will not be possible to draw conclusions from the number to the person. The anonymised data will only be accessible to the persons responsible for the research. The data entry, blocking and deletion of data will only be possible by the responsible person.

A soon as a participant wishes, all data regarding his participation will be deleted. At the end of the project the personalised data will be deleted.

Ethical issues are cleared:

- Ethical committee of DMM: At this stage the planned procedures as well as the methods are presented to members of the ethical committee of DMM.
- Ethical committee of Diakonisches Werk Bayern: The planned procedures as well as the documents (e.g. informed consent, see Appendix A) regarding the pilot are sent to the data protection officer of the Diakonisches Werk Bayern.¹
- Ethical committee of University: On request of the reviewer the ethical committee of the University has been contacted and consulted concerning further ethical issues. (See Appendix F)

	5.1.1.13.	The r	esponsibilities
Overall Responsil	oility	D	MM
Recruiting & Atte	nding	D	MM/HMGU
Equipment Acqui	sition	Р	PAS
Organisation of ir	nternet acces	s P	PAS

¹ It was orally assured that the data protection officer from the Diakonische Werk Bayern is the correct contact person for Join-In. On request of the reviewers the Consortium is again enquiring about this.

Technical Installation PAS/HMGU Technical Assistance PAS/HMGU/DMM

5.1.2. Pilot Application II: Hungary

5.1.2.1. The study team

The study team will led by JOH. Bull will provide the technical acquisition and quality control for the piloting. The team members and their responsibility will be the following:

- JOH is coordinating five main centres for the study. In each centres one local key person will take care of the users and the posted equipments. If necessary local volunteers will help in the field study to secure the timeline of the piloting. The study is going to be led by Zoltan Bertalan Avar.
- Mr Gabor Avar of Bull will take care of any technical support needed.
- The quality control and ethical issues will be handled by Mr Pál Simon MD. Ph. Sc..

Total team number:

- JOH: 6 persons
- Bull: 2 persons

5.1.2.2. Settings and locations

Due to the country wide network of JOH, and to provide more detailed information for the business plans of the project, pilot locations will take place in five different locations in Hungary. The locations will cover urban area (Budapest), countryside towns (Szombathely, Hódmezővásárhely, Balatonalmádi) and rural village area (Hencse).

In each location

- one community centre will be fully equipped with all the necessary technical equipment for testing and for introducing the ICT technologies to the elderly.
- one key person (local club organizer, elderly caretaker, nurse etc.) will be involved. She will be in everyday touch with the users, and can take care of the well-use of the posted equipments
- app. 20 users will be chosen for the study and for the piloting

In each location users will equipped to test the Join-In solution at their homes. The number of the equipments will depend on the cost of the platform.

At the urban site (Budapest) the users have internet connection.

On the countryside the homebound users will be equipped with the Mobile solution and other Join-In solutions will set up in those houses which are ready have internet connections installed (e.g. who already have a cable TV connection).

5.1.2.3. The sample size

The pilot will involve at least 100 persons. The cost of the equipment determines the testing period for the users. If possible JOH will try to select participants from the user groups who have a more technically equipped background (already have compatible TV or PC at home, have access to the internet or can purchase that at minimum cost).

At pilot start the user group in Budapest with a high acceptance level for new technologies will be studied. At this stage a preliminary study will take place.

In the preliminary stage the key persons and volunteers will be invited to observe the method of setting up the equipment and the data collection.

5.1.2.4. The possible risks and counteractions

Risks in the implementation

- the users do not accept the new technologies
- users do not use the Join-In solutions regularly
- participants reject to cooperate
- elderly users fall nervous about using expensive equipment

These risks can be reduced with a very careful and sensitive introduction of the new technologies. Therefore, JOH aims to take good care by training the key persons of the team and by ensuring access to all the equipments in a neutral place (community centres), too.

5.1.2.5. The time plan

The piloting will be structured as follows

- lab testing in Bull with the team members
- preliminary test and study in Budapest with volunteers to create a good implementation method.
- organised meetings with the user groups in the equipped centres to introduce the Join-In platform and solutions (Training is very important to increase the acceptance).
- recruiting the users from the groups and asking them to sign the informed consent
- installing the systems in the houses

JOH will provide continuous support to the users to overcome barriers using the Join-In equipments.

5.1.2.6. The resources

- The material resources will be defined exactly when the prototype is ready. The minimal need is 50 equipment (10 in each site)
- The same amount of mobile solutions is needed

Human Resources

- JOH: 6 persons will be involved: One is the main coordinator and each of the five sites will have a local coordinator.
- JOH may involve volunteers to help with the pilot
- Bull: 2 persons. One is to provide the technical background for the pilot, and one is to ensure the quality of the study.

5.1.2.7. The study methods

The study will follow the methods described in section 4.7.

5.1.2.8. Study type

The focus of the evaluation will be on acceptance and usability. The study has to collect data for the business plan for the Join-In Project.

5.1.2.9. Technical settings

Test will use various hardware:

- PC
- TV&STB
- TabletPC
- All-in-One PC
- Kinect
- Join-In remote
- Smartphone

Internet connection will be accessed via cable.

Mobile network connections will be provided for the Smart phones by a telecom company.

5.1.2.10. Outcome measures

The analysis will be regarding the following aspects

- relevance to the goals of Join-In
- ease of handling
- established reliability of the system
- adaptation to the persons abilities
- usability of the Join-In products also in relation to different abilities
- effectiveness on socialising
- acceptance of the solutions by the target group

5.1.2.11. The recruitment

The recruitment will be in the community centres of JOH and in its cooperating institutions

- Senor Club of high school teachers, Budapest
- Senior club in Hencse
- Elderly Home and day care institutions of Szombathely and Hódmezővásárhely
- Reformed Church in Balatonalmádi, Senior Club

5.1.2.12. Ethical Issues and data protection

In Hungary an informed consent is under development. The document will be controlled by a lawyer.

Although the data protection is not as strict in other EU member countries. (For more information see: Act CXII of 2011 on information self-determination and freedom of information)

For the Hungarian Informed Consent please see Appendix G.

	5.1.2.13.	The responsibilities
Overall Responsibility		Bull
Recruiting & Attending		ЈОН
Equipment Acquisition		Bull
Organisation of internet ad	ccess	Bull/JOH
Technical Installation		Bull/JOH
Technical Assistance		Bull/JOH

5.1.3. Pilot Application III: Norway

5.1.3.1. The study team

The study team will consist of project members

- Recruitment: Norut via the elderly centre Heracleum and NST via LHL will be responsible for the recruitment of participants
- The equipment acquisition as well as the organisation of internet access will be handled by Norut and NST
- The technical installations and assistance will be handled by Norut

5.1.3.2. Settings and locations

The testing will be performed in the following locations

- Heracleum will offer the Join-In solutions in their premises
- The Join-In solution will be tested in home environments. The users will be recruited either at Heracleum or in other senior groups

The technical solutions in the home environments:

- Some test persons will have existing Internet connections, some internet have to be installed
- some will use their television via a STB some will use a PC and a tablet

5.1.3.3. The sample size

- The pilot will involve 10-15 persons, and at least 5 sets of equipment will be available for the pilot.
- The pilot study is going to take place in several steps where groups will test the equipment for a certain amount of time. We will strive to recruit both male and female participants.

5.1.3.4. The possible risks and countermeasures

These possible risks will be taken into account by the team members

• Users can get sick and have to leave the group, which we have already experienced. We will then have to either work with smaller groups, recruit new users or reorganise the groups. This will depend on the groups and the situations.

- The participants might feel overwhelmed by the new technologies. The team will introduce the technology in a gentle manner, and also take one thing at the time. A sheet with information and contacts for help, as well as a user manual, will be handed out together when the equipment is installed.
- The introduction to the reason behind the testing is must be very clear, to avoid that the participants may get the feeling that they are getting tested and not the technology.
- Elderly, who want to participate, but do not want the equipment at home or do not want to install internet, will be offered the opportunity to participate at Heracleum.
- To meet participants' fears of not being able to cope with Join-In, they will be offered assistance when they use the equipment for the first few times.
- The user organisations are not direct partners in the Join-In project, so their commitment is weaker than if they were partners. We must make sure that the burden on them does not get too big.
- There is a risk that the system is not stable. The first phase of the pilot will, however, be performed at Heracleum and Norut since an unstable system will be far more troublesome being used in a home environment. The system will not be installed in the homes of the senior users unless it is stable and easy to use.

5.1.3.5. The time plan

Each person should be able to test the system for two months. In that way we will ensure that the person learns how to use it, and we will get feedback that is not just based on novelty.

In order to ensure that the participants really test Join-In sufficiently, the testing will be carried out in several stages. After recruitment and before receiving the equipment at home the users will

- 1. get an introduction to the technologies
- 2. receive an overall explanation about how the system, and shall try it out.
- 3. will get a manual, and contact information for help if needed
- We plan on groups of 3-5 persons having two weekly common Join-In sessions. In addition users can use the Join-In system whenever they want to.

In Norway the focus of the pilot will be on socialising through the Join-In exergames integrated in the Join-In system

5.1.3.6. The Resources

Material resources:

- PC / TV / Tablet
- Stationary bike
- Kinect with camera etc

Human resources: Project members from Norut, NST as well as Heracleum and LHL

5.1.3.7. The study methods

For the study method, see 4.7. Qualitative methods will be used.

5.1.3.8. Study Type

The focus of the evaluation will be on acceptability and usability, evaluating the elements of the Join-In solution piloted. Standard questionnaires will be used, and forms with few and simple questions will be chosen due to the nature of the target group. Interviews will also be used.

5.1.3.9. Technical settings

The Join-In solution will be tested on the following hardware

- STB with TV
- Kinect and/or remote control
- Stationary bike and a tablet / PC

The internet will be accessed through the most suitable provider for each location.

5.1.3.10. Outcome measures

The analysis will be regarding the following aspects

- relevance to the goals of Join-In
- ease of handling
- established reliability of the system
- adaptation to the persons abilities
- usability of the Join-In products also in relation to different abilities
- effectiveness on socialising
- acceptance of the solutions by the target group

5.1.3.11. The recruitment

The users will be recruited from the regular users of Heracleum and the LHL members

5.1.3.12. Ethical Issues and data protection

- Informed consent signed forms from all participants (See Appendix B)
 - Must inform about the project, also the possibility to withdraw at any time (written form)
 - The participants must be able to understand what they sign
- Register the project with NSD (http://www.nsd.uib.no/personvern/om/english.html) and with "personvernombudet" at UNN
 - Inform about the project, the data we collect and how they are stored.

5.1.3.13. The responsibilities

Overall Responsibility	Norut and NST
Recruiting & Attending	Norut / Heracleum / NST / LHL
Equipment Acquisition	Norut and NST
Organisation of internet access	Norut
Technical Installation	Norut
Technical Assistance	Norut and NST

5.1.4. Pilot Application IV: Ireland

5.1.4.1. The study team

The study team consists primarily of the development team in IT Carlow. A physiotherapist student may participate in the testing if assistance is required in evaluating the test results of the exergames success on physical health.

5.1.4.2. Settings and locations

The testing will occur in the user's homes when they are issued a set-top box to test the software on. The testing may also take place in the user group meeting centre.

5.1.4.3. The sample size

The group size of the Irish Active Retiree group in New Ross, Wexford, Ireland is 110. There are 14 members of the group who will participate in the game testing. The devices issued to the users have the Join-In games and Kinect server preinstalled. The group size is dependent on the number of set-top boxes available.

5.1.4.4. The possible risks

The possible risks of the study include factors such as if the users don't have an internet connection available. If the users fail to fill out the surveys to evaluate the games on the system there will be gaps in the results.

The user organisations are not direct partners in the Join-In project, so their commitment is weaker than if they were partners. We must make sure that the burden on them does not get too big.

5.1.4.5. The time plan

The evaluation period will take place over a 3 month period. Half of the systems will have the version of the game with adaptive difficulty and the other half without. This is to evaluate what affect adaptive difficulty has. The two games will be tested in unison if there are enough set-top boxes such as 10 or more. If there are less systems available the one group will test the game for the first half of the study and then second group will evaluate the other game for the next half.

5.1.4.6. The Resources

A number of set-top boxes are required to perform the study. Each set-top box distributed will also need a Microsoft Kinect. At least 10 set-top boxes would be required to fully test the two game versions.

5.1.4.7. The study methods

Instruments will be used to measure the usability, motivation, physical and cognitive attributes of the game. The game will record relevant data to evaluate user progress. Questionnaires and interviews with the user group will also be conducted.

5.1.4.8. Study Type

The study type is an experiment primarily focusing on the effects adaptive difficulty has on motivating users to play exergames.

5.1.4.9. Technical settings

The game will be testing on a set-top box with the Kinect as the primary input device. An internet connection is required to fully test the system.

5.1.4.10. Outcome measures

The analysis will be regarding the following aspects

- relevance to the goals of Join-In
- ease of handling
- established reliability of the system
- adaptation to the persons abilities
- usability of the Join-In products also in relation to different abilities
- effectiveness on socialising
- acceptance of the solutions by the target group

Following aspects will additionally be taken into account:

- Motivation: A primary goal of this research is to motivate users to exercise frequently. This is achieved by attempting to keep the user in a state of Flow. Intrinsic motivation is measured using the Intrinsic Motivation Inventory (IMI) which contains 45 questions answered by selecting between 1 (not at all true) to 7 (very true). Motivation to exercise may be measured using the Motives for Physical Activities Measure (MPAM) scale. In addition to these instruments in-game data may be recorded to access user motivation. The player data recorded includes the amount of time the user spends playing the game per session and the number of sessions each day and number of sessions in a week.
- Usability: Usability is an important element of any game. The game developed for this project is designed for elderly users who are generally not familiar with video games. This makes ease of use an even higher priority. Software usability will be measured by devising a set of usability metrics and evaluating those metrics using in-game data and questionnaires. The metrics selected are scenario success rate, error rate, scenario completion time and subjective user evaluation. Each user is given a set of tasks to complete, the system measures the time taken, number of errors and if the user can complete the task at all. A usability questionnaire is then administered to gather subjective data from the test group. The Software Usability Measurement Inventory (SUMI) is a 50 item questionnaire designed to measure the perceived quality of use of software.
- Physical effect: The exercise selected for this game is based on step aerobics. The version of step aerobics implemented in the game requires each user to take a step indicated by the in game rhythm. Step aerobics is a low intensity exercise that is suitable for elderly people. The benefits of step aerobics include burning calories, improving flexibility and increasing balance. The benefits of the game will be measured using the Berg Balance Scale to assess a user's risk of falling..

5.1.4.11. The recruitment

The participants are part of the Active Retiree group in New Ross, Wexford, Ireland.

5.1.4.12. Ethical Issues and data protection

The project will follow the institute's ethics guidelines as well as adhering to the Irish data protection act (See Appendices C, D and E).

"Irish Data Protection Law", The office of the Data Protection Commissioner is established under the 1988 Data Protection Act. The Data Protection Amendment Act, 2003, updated the legislation, implementing the provisions of EU Directive 95/46. The Acts set out the general principle that individuals should be in a position to control how data relating to them is used. The Data Protection Commissioner is responsible for upholding the rights of individuals as set out in the Acts, and enforcing the obligations upon data controllers. The Commissioner is appointed by Government and is independent in the exercise of his or her functions. Individuals who feel their rights are being infringed can complain to the Commissioner, who will investigate the matter, and take whatever steps may be necessary to resolve it. (http://www.dataprotection.ie)

The Data Protection Commisioner's office has been contacted; they have assured that the pilot is complaint with the law.

5.1.4.13. The responsibilities

Overall Responsibility ITC / VAL

	5.2. Comparability	y of the Pilot Sites					
		Germany	Hungary	Norway	Ireland		
S	Sites	Urban Area Rural Area	Urban Area Rural Area	Urban Area	Rural Area		
ocation	Elderly		Introduction and Testing with Join-In Social Networking Stations Testing in their home environment				
Settings and Locations	Internet	No internet connection, UMTS No internet connection, offline usage	With existing inte No internet connection, in No internet connection, UMTS				
participants the sample size	The participants	Some younger than 55; mostly older than 75 From different activity groups Male/Female proportion as in pilot surroundings	Older than Male/Female proportion as in pilot surroundings If possible, users with a more technically equipped background	65 years From Heracleum and LHL Will strive to also recruit males	Irish Active Retiree group in New Ross		
The par	The sample size	Preliminary Study with 3 - 5 persons 50 - 100 persons	Preliminary Study in Budapest 100 persons	10 – 15 persons	10 – 15 persons		
e c	Beginning of lab test	15.10.2012					
Time plan	Pilot	01.02.2013 - 31.08.2013					
To be tested		Walking game Social Network (socialising) Remote Control					

	Moderated		Exercising game		
	Memory game Social Network (Information)		(AntiqueHunt)		
			Cycling game		
	Video con				
	Telephone				
	Cycling				
S		Questio			
The study metethods		Structured			
eth		Semi-structur			
Jet	Functionality tests	Functionality tests	Main emphasis on	Main emphasis on	
~	Descriptive Statistical	Descriptive Statistical	(exer)games	(exer)games	
pn	methods	methods			
e st	Sumary content analysis				
The	Focus groups				
	Ethnographic methods				
Ъ	Acceptance Study				
type	Usability Tests				
				Experimental design:	
Study				Effects of adaptive difficulty	
S				on motivation	
	STB with TV				
v a		Kinect and/or r	emote control		
nic	AiO PCs	AiO PCs	Tablet PC		
Technical settings	PC	PC	Smartphone		
Σ Te		Tablet PC			
		Smartphone			

Outcome measures	Relevance to the goals of Join-In
	Ease of handling
	Established reliability of the system
	Adaptation to the persons abilities
	Usability of the Join-In products also in relation to different abilities
	Effectiveness on socialising
	Acceptance of the solutions by the target group
	Motivation Usability Physical effect
Ethical issues	Involvement of ethic committees and data protection officers Written informed consent – signed forms by all participants Must inform about the project, also the possibility to withdraw at any time The participants must be able to understand what they sign Information about how the data is collected and stored

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6. Join-In evaluation plan

The evaluation plan is the final step before piloting. It will prepare for a smooth performance of the pilot and evaluation study. It will help managing the evaluation study and the pilot. The following describes the procedures to be taken for ensuring a successful pilot.

Revision and finalisation of the pilot planning

The study team, the settings and locations, and the sample size will stay as described above. The risks have been identified and will be kept in mind throughout the pilot.

6.1. Detailed description of the Join-In Social Network (from D 4.2)

The Join-In Social Network provides the following plug-in functionalities. * Details can be found in D 4.2 Design and Implementation of the Join-In platform.

6.1.1. Social Contacts

- User Profile which contains the information that defines the user. It works within the social network as identification.
 - Additionally to the name, the User Profile includes:
 - Photo
 Avatar
 Gamer profile
 Skill level (per game)
 High score (per game)
 Favorite games
 Exercise profile
 Favorite exercise
 Interests and hobbies
 Group memberships
 Physical limitation
 All the information will be given on a voluntary basis.
- User Settings including
 - First Name and Family Name User Name / Gamer tag User Id Contact details: Email and/or Telephone number
- Friends/Family
 - The user can add, delete or search new contacts as friends or family.
- Videoconferencing (not used in the Norwegian solution)
 - Videoconferencing allows the users to use video and sound as a communication channel with their contacts.
 - The user will be able to invite his/her friends to a videoconference, making it more private.
 - It will allow the user to play a game while videoconferencing, adding a new social value to the game.

Text Chat

We will add a chat plugin from the ELGG community. Some layout modifications in this ELGG community plugin are needed to improve the user's accessibility.

Messages

With the help of a keyboard (physical or virtual) the users will be able to send and receive written messages (similar to emails) to/from their contacts.

Exchange not used in the Norwegian solution)

The users are able to upload, share, search and comment, and tag different types of information, e.g.

- Photos
- Videos
- Web Links
- Texts: News, Histories, Poetry, etc...

The user may want to find in the history of files some precise content. For that purpose, a search engine is really effective and it will be include in the content exchanged. The need of this functionality needs to be evaluated by users.

6.1.2. Regional information (Only in the solution used in Germany and Hungary)

The regional information is a special set of user content: videos, histories and news from the local senior groups, stories from the neighbourhood, philosophy, theology, history, etc.... The major differences with the normal user content are:

- Open information: The information posted as regional information is accessible to all users or at least to all those users who are members of a defined region.
- Supervised: All the data posted as regional information is supervised by a regional moderator to avoid misuse of the functionality.

This information helps the elderly to stay informed with the activities of their region, get in touch with new people, share photos, videos or opinions with their neighbourhood, etc...

6.1.3. Dates and Calendar

The management of the dates of the users is a functionality strongly connected to others like games, exercises or even groups, helping the users to coordinate their social activities.

Calendar

The user can access a calendar to check personal, group or regional dates, events or reminders.

Dates

The user is able to add, delete or modify appointments or reminders within a graphical interface. This interface is a plugin for managing the users' dates.

A date can be shared between friends or groups members. That is helpful when, for example, an activity moderator wants to establish that date for the next (exer)game or exercise. The moderator can set up an exercise goal, by adding a sequence of dates containing a set of (exer)games and also video exercising.

The users can see their progress in achieving the exercise goals in the calendar interface.

Reminders

A reminder is a special functionality that works directly with the calendar and helps the user to remember appointments.

The user will get an additional notification (e.g. by integrated messaging or email) when a date is occurring.

6.1.4. Games and Exergames

The games are an important part of the Join-In Platform and their integration with the Social Network is a mayor issue. The user can play the (exer)games with other users with or without the supervision of a Moderator, which will show how to play, observe the users movements and/or help and give feedback to the users.

- Game registration
 - Once a game has been developed, it needs to be made available to the user. The social network is a really good tool for this purpose.
 - In order to offer game information to the gamers, there is a need of a plugin to implement the game information acquisition and of its integration in the social network. This plugin is the Game Registration. Once the game is registered, it will be accessible to the users in the game lists.
- Games listing and gamer profile

We will implement a plugin to manage the lists of games offered and the list of games that the user already played. These lists are readable by the Social Media Connector.

Game launcher

It is necessary to provide an easy access to the games. The game launcher gets the information from the registered games on the game list and from the gamer list.

Game metrics performance viewer

Both the cognitive games and exercise games (exergames) will collect performance data from the player over time. Each game that collects such data will allow the player view their in-game progress for a defined period of time. This data will be readable by the Social Media Connector, in order that it can be stored and retrieved by the game servers. Read access may also be provided for future applications that might require access to this data (e.g. care providers who might have an interest in monitoring the progress of the participants).

- For each game the metrics list contains the
 - total number of times the player have played a game
 - total time duration used on a game
 - scores of single gaming sessions (including the high-score)
 - total game score of a game
 - level reached if applicable
 - goal to be reached: future appointments in the calendar

The nature of the data collected will vary by game, for example, the walking game may capture the following metrics per gaming session:

- Total number of steps taken
- Average number of steps taken per minute
- Number of obstacles avoided

• Time to complete the walking challenge

6.1.5. Avatar selection

An external application - similar to a game - enables the user to select and potentially even to modify the look of the avatar.

The avatar that the user chooses will be used in (exer)games the user plays, and possibly for exercising. It can be used in the social network's user interface as an alternative to the user's photograph.

6.1.6. Exercising

Join-In offers the users a variety of exergames for improve their physical fitness. In addition to these exergames, the elderly can participate in a remote gymnastic program, which can be with or without a moderator. For this purpose, the video sharing and the videoconferencing are helpful functionalities, as well as the calendar for organizing the exercises sessions.

6.1.7. Security and authentication issues

The Join-In social is designed as a private network, which allows access for registered users only. To achieve acceptance of the users obeying the users right on privacy and data protection is vital.

Authentication

The user has different options to get authenticated to the Social Network:

- Paper form: A user can register in the Join-In Platform filling a form in one of the regional user centres. Here the User Support will give the login data to the user and help the user with the registration.
- Email: For users who own an email account. The user can access to a registration form within the Join-In Portal, where he will be asked for "User Name", "Email" and "Password". Once the User Admin has confirmed the registration process, the user will get a confirmation email, allowing him/her to access the portal.

The user need to login on to the portal using "User Name" and "Password". To avoid inserting the login every time, the information can be stored in the user's machine.

6.1.8. Help

There will be a user manual consisting of several chapters.

- One part describes the social platform, the way the network is handled and how its features and tools are used.
- An additional guideline explains step-by-step the course of action (for example: "enter your first name now"- click -using the mouse- the large blue button "Confirm" at the bottom of the screen). Thus the user can easily get acquainted with the platform. Screenshots and pictures will lead to a better understanding. This part will also be available as a printed manual.
- Another part is directed at persons that are regularly using digital media, e.g. grandchildren. It explains in detail all the tools, functions and functionalities of the platform and how to manage these.
- A support centre will provide additional help. The "Help"-Menu provides a telephone number that can be called at a certain period of time. A person at the Call Centre will answer the questions of the users. He/she will also be able to remotely access the user's

computer over the network– if the user has activated this option in the user setting- to resolve any technical problems.

The Join-In Social-Network is based on the results of the analysis of the user requirements

6.1.9. Results from the Analysis of the user requirements

6.1.9.1. Socialising

- Socialising is a vital issue for the elderly in all 3 countries.
- The main interest lies in the contact with the grand children, followed by friends
- The main interests stated were
 - In Germany: playing games, cultural activities, music, philosophy, handcrafting and religion.
 - In Norway: exercising (particularly walking and dancing), watching film (six out of ten), sewing and knitting (five out of ten),
 - In Ireland: sports, walking, gardening

6.1.9.2. Platform

- the possibility to interact and communicate with family and friends in and outside of games/exercises
- a simple and intuitive interface
- the possibility to play/interact/communicate with limited fine motor skills, limited eyesight, limited mobility (sitting down)
- the possibility to play/interact with stranger;
- data protection (possibility to choose which data is available to others)
- visibility of other persons participating
- cultural offers

6.1.9.3. Gaming

- For the involved user groups in the 3 countries gaming is a favourite past-time only in Germany. In Norway and Ireland some people play card games occasionally. It was, therefore, decided to Concentrate the gaming requirement activities on Germany
- The (German) users preferred a communicative and at the same time competitive, braintraining game; one group asked for "Rommée").
- The users decided on a Join-In Memory Game
- The following requirements on the technical solutions were put forward by the users on gaming
 - the possibility to interact and communicate with family and friends in and outside of the game
 - a choice of individual difficulty and speed levels
 - the story of the game should relate to real life
 - the possibility of following one's progress

- the benefit of exercises/games should be explicit
- easy to follow gaming rules; yet the possibility to enter a higher level once the basic rules are clear
- the possibility to play cooperative and competitive
- the possibility to play/interact with strangers
- the possibility to do specific exercises
- the possibility to correct ones mistakes
- layout/graphics should be adequate for elderly

6.1.9.4. Exercising and Exergaming sessions

- In all countries the user groups are interested in sports and exercising as they feel this could help them to stay fit longer. Many of the German users do sessions offered on TV (Telegym) regularly, but find many of the exercises not age- related. They stated that exercises for their age group offered by Join-In would be beneficial. Join-In decided to include exercises designed by a physiotherapist in the pilot phase
- It was decided to give exergaming more importance (than gaming) in the project
- The favourite activity amongst the elderly was hiking or taking walks, the Consortium, therefore, decided to develop a walking game.

6.1.9.5. Exergaming

- the possibility to interact and communicate with family and friends in and outside of the game
- the exergames should be perceived as useful, not only for fun
- exercises should be tailored to the users' needs
 - easy start of the game
 - positive feedback
 - no calorie counting
 - handicap compensation
 - adjustable speed needed
 - possibility to take a break
 - avatars to represent the different participants

6.1.9.6. Social Network

- Social contact functionalities, such as user communication and profile setting
- An easy possibility to link to add applications
- The possibility for developers to modify the layout
- Requirements serving the special needs of the target group
- Simple access for the elderly users
- Accessibility providing for users with physical limitations

• Multilingualism providing for the users in the Join-In partner countries.

6.2. Evaluation material

Following methods will be used:

- Questionnaires (5-Likert-Skale)
- Structured Interviews
- Semi-structured Interviews (Guided Interviews)
- Functionality tests
- Focus Groups
- Ethnographic methods
 - Analysis of workflow
 - Analysis of users' behaviour
- Descriptive statistic methods
- Summary content analysis (Mayring)

The categories that will be surveyed are the following:

- Acceptability
- Usefulness and effectiveness towards the envisaged goals
 - Motivation
 - Physical benefit
 - Mental benefit
 - Quality of life
- Usability and adaptability
- Functionality: to be measured against the specific requirements of the users

The business case will be considered throughout the process

The specific questions will be discussed at the next project meeting (1.-2. Oct 2012). Scales as the SUS, SUMI, SF-36 or EQ-5D will be considered and discussed. In order to make the study as useful as possible the product definition and single selling point have to be kept in mind.

6.3. Activity mapping

At this stage it is important to map the activities in order to start and perform the different tasks on time

- Organising the study team/Recruitment
 - Designing training material

- Manual for carers
- Manual for users

After recruitment and before receiving the equipment at home the users will

- 1. be given an introduction to the technologies
- 2. receive an overall explanation about how the system works, and shall try it out.
- 3. will get a manual, and contact information for help if needed
- We plan on groups of 3-5 persons having two weekly common Join-In sessions. In addition users can use the Join-In system whenever they want to at the Join-In Networking Stations..
- designing a training plan
- Setting up a study protocol
- Lab testing
- Operation schedule of involved employees and volunteers
- Operation schedule technical resources for the users
- Organisation of internet access
- Technical Installation
- Confidential disclosure agreement regarding all information about the users
- Data Collection
- Data Management
- Analysis

6.4. Quality management plan

- The responsibilities and tasks of each partner /participant are clear; they will be together with the respective person reviewed at 4-weekly intervals
- 3- weekly study group meetings
- Contact for persons outside of the consortium
- Control compliance with the protocol
- Quality indicators:
 - data usability
 - international comparability of data
 - project management issues
 - on time intermediate and final solution
 - quality of the solution
 - extent of user need being met
 - sustainability
- Review the risk plan and identify any problems as early as possible
- Ensure the distribution and maintenance of material

- Ensure the data ownership
- Keeping the time schedule
- Exit strategy

6.5. Communication strategy

- training of all those who will be looking after /involved with users
 - advising them of the fears/specifics of the elderly users
- aiming at setting up contacts to the targeted persons via persons of trust
- ensuring Means of Contact (Call Centre, Contact details,

6.6. Time schedule

- Coordination of the system and the questions at the next project meeting (1-2. Oct. 2012)
- Lab testing with the team members
- Pre-testing with volunteers (3-5) system with volunteers
- Setting up Join-In Social Networking Stations in the centres
- Recruiting the users from the different groups, informing and introducing them to the system and asking them to sign the informed consent
- Installing the systems in the houses

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Appendix A: Informed Consent German



Information und Einverständniserklärung zur Mitwirkung an der Nutzerstudie des europäischen Projektes "Join-In – Mach mit"

Ziel der Untersuchung:

Das Projekt ermöglicht Senioren Spaß zu haben und die Verbindung zu anderen Personen, durch diese Technologien, zu fördern. Wir möchten herausfinden, ob die entwickelte Lösung einfach zu nutzen und zugänglich ist. Des Weiteren möchten wir wissen, ob die Lösung eine Motivation für die Teilnahme an Aktivitäten ist und ob sie einfach zu bedienen ist. Wir möchten erforschen, ob die Lösung nützlich ist oder nicht und ob die unterschiedlichen Funktionen akzeptiert werden oder nicht. Das Wissen wird der Forschungs-Gemeinschaft für zukünftige Entwicklungen zu gute kommen, um die Erfüllung der Bedürfnisse sicherzustellen. In Zukunft sollen Senioren von den entwickelten Lösungen profitieren und durch diese dazu beitragen, dass sie länger in ihrer gewohnten Umgebung leben können.

Ablauf:

 Sie werden voraussichtlich schnelles Internet benötigen (DSL), falls Sie über keinen Internetanschluss verfügen, werden wir diesen zur Verfügung stellen. (nähere Informationen werden noch hinzugefügt)

- Das Gerät wird an Ihren Fernseher angeschlossen.

Sie werden gebeten die Lösung regelmäßig zu nutzen (etwa 2 mal wöchentlich) für einen Zeitraum von etwa 8 Wochen.

 Sie werden zu 1-2 Gruppendiskussionen und 3 Interviews eingeladen und werden gebeten kurze Fragebögen auszufüllen.

Weiterverarbeitung der erhobenen Information:

Die von uns erhobenen Daten werden anonymisiert verarbeitet und ggf. wissenschaftlich veröffentlicht. Ein Rückschluss auf Ihre Person, wird anhand der Veröffentlichung nicht möglich sein. Die Daten werden ohne Ihren Namen und Kontaktdaten gespeichert. Personen außerhalb des Projektes werden keinen Zugriff auf die Daten haben.

HelmholtzZentrum münchen Deutsches Forschungszentrum für Gesundheit und Umwelt





Kosten und Aufwandentschädigung:

Für die Studie entstehen Ihnen keinerlei Kosten. Für Ihre Teilnahme erhalten Sie eine pauschale Aufwandsentschädigung von XX, € (wird noch geklärt)

Rechte:

Ihre Teilnahme an dieser Untersuchung ist vollkommen freiwillig. Es ist Ihre Entscheidung ob Sie teilnehmen oder nicht. Falls Sie entscheiden nicht teilzunehmen, wird dies keine Auswirkung für Sie auf die Verbindung zur Diakonie München-Moosach haben. Sie können es sich auch zu einem späteren Zeitpunkt anders überlegen und die Teilnahme abbrechen, auch wenn Sie vorher zugestimmt haben. Es entstehen für Sie keinerlei Kosten. Wir bitten Sie nur um Ihre Zeit. Sie können das Interview, die Gruppendiskussion oder auch die Testphasen jederzeit und ohne Angabe von Gründen abbrechen, ohne dass für Sie Nachteile entstehen. Sie können auch Fragen überspringen, falls Sie dies wünschen.

Datenschutz:

Jegliche Angaben, die Rückschlüsse auf Ihre Person zulassen, werden von den Projektmitarbeitern vollkommen vertraulich behandelt und somit nicht an Dritte, bzw. Menschen außerhalb des Forschungsprojektes weitergegeben oder veröffentlicht. Sollten Sie eine Informationsweitergabe an Dritte wünschen (bspw. andere Mitspieler), so würde dies ausschließlich auf Ihre schriftliche Veranlassung hin geschehen. Nur Mitarbeiter des Forschungsprojektes haben Zugang zu den erhobenen Daten. Die Daten werden nach Ablauf des Projektes gelöscht. Falls Sie die Teilnahme abbrechen, werden Ihre Daten auf Wunsch sofort gelöscht.

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Erklärung:

- Ich wurde von der verantwortlichen Person f
 ür die oben genannte Studie vollst
 ändig aufgekl
 ärt. Ich habe das Informationsschreiben gelesen und verstanden.
- Ich hatte die Möglichkeit Fragen zu stellen. Meine Fragen wurden f
 ür mich klar und umfassend beantwortet.
- Ich weiß, dass Daten über meine Person nur anonym verarbeitet werden, und dass alle autorisierten Projektmitarbeiter, die Zugang zu meinen Angaben und Daten haben, unter Schweigepflicht stehen.
- Ich weiß, dass ich jederzeit das Interview/die Diskussion abbrechen kann bzw. eine Frage überspringen kann, wenn ich mich bei der Beantwortung nicht wohl fühle.
- Ich weiß, dass einige der Fragen mich evtl. dazu bringen an Dinge zu denken, die mich traurig machen. In diesem Falle kann ich jederzeit mit einer/m Mitarbeiterln sprechen.
- Ich weiß, dass die entwickelte Lösung bewertet wird und nicht meine technischen F\u00e4higkeiten.
- Ich bin über die, mit der Teilnahme an der Studie verbundenen Risiken und auch über den möglichen Nutzen informiert.
- Ich habe eine Kopie des Informationsschreibens und dieser Einverständniserklärung erhalten.
- Ich weiß, dass ich diese Einwilligung jederzeit widerrufen kann.
- Ich erkläre hiermit meine freiwillige Teilnahme an dieser Studie.

Ort, Datum: ______

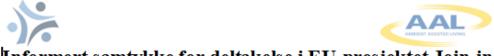
Teilnehmerln:

ProjektmitarbeiterIn: _____

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Appendix B: Informed Consent Norwegian



Informert samtykke for deltakelse i EU-prosjektet Join-in

Mål med prosjektet

Prosjektet Join-In er et EU-prosjekt hvor målet er at eldre skal kunne være sosiale og ha det morsomt sammen på nye måter ved hjelp av teknologi.

I Norge ser vi spesielt på trenings-spill som er tilpasset eldre, og hvor det også skal være mulig å bruke sin TV for å trimme sammen fra forskjellige plasser.

For å utvikle noe som vil tas i bruk, er det viktig at noen i målgruppen bidrar med sine meninger. Vi trenger noen som kan være med på diskusjoner og utprøvinger av det vi lager. Den informasjonen vi samler inn vil gi en bedre kunnskap om hva som er morsomt og er lett å bruke, og for treningsspillene hva som har de rette øvelsene. Informasjonen vi får vil bli brukt av forskere for å videreutvikle ideene.

Gjennomføring

- Spillene vil både bli prøvd ut på Heracleum og/eller hos Norut og hjemme hos noen.
- Prosjektet vil bistå med alt det tekniske, og også bidra til opplæring og være til stede på de første forsøkene.
- Alle deltakere vil få en beskrivelse samt telefonnummer de kan ringe hvis de trenger hjelp.
- For å kunne prøve det hjemme, kreves en god internettforbindelse.
 Prosjektet kan bistå med installasjon av internett hvis det ikke finnes.
- For test hjemme vil vi koble utstyr til din TV og du vil bli bedt om å delta et visst antall ganger på bestemte tidspunkt over en periode på to måneder.
- Etter utprøving hjemme vil vi intervjue deg og vi vil be deg fylle ut et enkelt spørreskjema.
- · Alle kostnader vil dekkes av prosjektet.

Videre bruk av innsamlet informasjon

Informasjonen som blir samlet inn vil i første omgang brukes til å forbedre de produktene som utvikles i prosjektet. I tillegg vil noe bli brukt som grunnlag for vitenskapelige publikasjoner.

Rett til å nekte deltakelse eller trekke seg

All deltakelse i prosjektet er frivillig, og du kan når som helst trekke deg fra diskusjoner eller utprøvinger eller trekke deg fra hele prosjektet.





Du kan velge å la være å svare på spørsmål som du syns er ubehagelige eller av en eller grunn ikke har lyst til å svare på. Det vil ikke ha noen konsekvenser for deg om du velger å trekke deg fra hele eller deler av prosjektet.

Konfidensialitet

All informasjon som du gir vil bli behandlet konfidensielt, og ingen utenom betrodde personer i prosjektet vil få innsyn. Når prosjekter er over vil alle personidentifiserbare data bli slettet. Hvis du velger å avbryte prosjektet, vil vi slette dine data så fremt det er mulig å knytte det til din person.

Erklæring

- · Ansvarlige for prosjektet har forklart alt om deltakelse i prosjektet for meg
- · Jeg har lest informasjonsarket og forstår alt
- Jeg har hatt mulighet til å stille oppklarende spørsmål, og jeg har forstått svarene
- Jeg er klar over at data fra undersøkelsen vil bli anonymisert og at bare betrodde personer i prosjektet vil få innsikt i detaljer
- Jeg vet at jeg kan avbryte alle undersøkelser og intervjuer, og at jeg kan hoppe over spørsmål jeg ikke ønsker å svare på
- · Jeg har blitt informert om risiko og fordeler ved å delta
- Jeg har mottatt en kopi av denne erklæringen
- Jeg vet at jeg når som helst kan trekke tilbake min erklæring
- · Jeg bekrefter herved at jeg deltar frivillig i dette prosjektet

Kontaktperson:	Ellen Brox,	tel 918 47 928
eller	Gunn Evertsen	tel 990 08 160

Tromsø _____.2012

Deltakers navn:

Signatur

Appendix C: Research Code of Practice IRL

INSTITUTE OF TECHNOLOGY CARLOW

Research Code of Practice²

Honesty

At the core of all research endeavour, regardless of discipline or institution, is the need for researchers to be honest in respect of their own actions in research and in their responses to the actions of other researchers. This applies to the whole range of research, including experimental design, generating and analysing data, applying for research funding, publishing results and acknowledging the direct and indirect contributions of formal collaborators 0and other researchers. All individuals in the Institute's employment must refrain from plagiarism, deception or the fabrication or falsification of results and committing any of these actions is regarded as a serious disciplinary offence. Researchers are required to declare on the Institute Postgraduate application forms and Postgraduate Progress Reports conflicts of interest.

Openness

Whilst recognising the need for researchers to protect their own research interests in the process of planning their research and obtaining their results, the Institute encourages researchers to be as open as possible in discussing their work with other researchers and the public. Once results have been published, the Institute expects researchers to make available relevant data and materials to others, on request (provided that this is consistent with any ethics approvals and consents which cover the data and materials and any intellectual property rights in them).

Leadership and Cooperation

The culture and tone of procedures within any organisation must be set by those in authority. Within the Institute it is the responsibility of the Director and Institute Officers, Heads of Schools, Heads of Departments, senior staff and principal investigators to ensure that a research climate of mutual cooperation is created which allows research to be conducted in accordance with good research practice.

² This Code of Good Practice closely follows the Statement on Safeguarding Good Scientific Practice issued by the Biotechnology and Biological Sciences Research Council (UK) [BBSRC] (1998) and the UCD Code of Good Research Practice..

Within a research group, responsibility lies with the group leader. These individuals should create a research environment in which all members of a research team are encouraged to develop their skills and in which the open exchange of ideas is fostered. They must also ensure that appropriate direction of research and supervision of researchers and research students are provided.

Research misconduct is least likely to arise in an environment where good research practice (e.g. documentation of results, peer review, regular discussion and seminars) is encouraged and where there is adequate supervision at all relevant levels. It is the responsibility of Heads of Departments to clearly convey the standards and protocols for Research in their Departments (e.g. supervisors' responsibilities including frequency of contact, scrutiny of primary data, development needs of research trainees) and to ensure that adherence to these standards is integral to the life of the Department.

Documenting Results and Storing Primary Data.

Throughout their work, researchers are required to keep clear and accurate records of the research procedures followed, approvals granted and of interim and final results. This is necessary not only as a means of demonstrating proper research practice, but also in case questions are subsequently asked about either the conduct of the research or the results obtained. Data generated in the course of research must be held securely in paper or electronic format. The Institute requires such data in areas which it will define or which the funding agency defines, to be securely held for a period of two years after the completion of a research project (or as required by the funding agency).

Publication

It is normally a condition of research funding that the results are published in an appropriate form, usually as papers in refereed journals. This has long been widely accepted as the best system for research results to be reviewed (through the refereeing process) and made available to the wider research community. The Institute requires, as a minimum, that anyone listed as an author on a paper should accept responsibility for ensuring that s/he is familiar with the contents and can identify their contribution to it. The practice of honorary authorship is unacceptable.

Acknowledging the role of collaborators and other participants.

In research, the contributions of formal collaborators and other researchers who contribute to the research must be properly acknowledged.

Training

It is the responsibility of the Heads of Departments and research group leaders to ensure that all researchers have the opportunity to receive appropriate research training including attendance as necessary on relevant courses and guidance from professional bodies. As part of this responsibility, the Institute will make available appropriate training courses. In this regard, the needs of new researchers are of paramount importance. Responsibility for ensuring that new researchers and students understand and adopt best research practice as quickly as possible rests with all members of the research community, but particularly with Heads of Departments and group leaders.

Integrity in submitting research proposals and managing research projects.

Principal Investigators must take all reasonable measures to ensure the accuracy and completeness of information contained in applications for funding and in managing research projects, to ensure compliance with all sponsor, institutional, legal, ethical and moral obligations.

Conflict of Interest

It is the responsibility of researchers, group leaders, senior staff and Heads of Departments to identify and declare any potential or actual conflicts of interest, whether financial, personal, ethical, legal, or other, so that this does not become a complicating or actionable issue, and to comply with the Institute's policies on intellectual property, conflict of interest and consultancy and external work.

Ethical Practice

All research Involving Human Participants (or Human Biological Samples) requires approval of an appropriate Ethics Committee.

Ethical approval is required from the appropriate Institute, University and/or Hospital Research Ethics Committees and from other regulatory bodies as relevant. Researchers should also ensure the informed consent and confidentiality of personal information relating to the participants in research and that the research fulfils any legal requirements such as those of the Data Protection Act and the Freedom of Information Act.

Approved: Academic Council/Governing Body: March 2005

Appendix D: Policy and Procedures on Ethics in Research

Policy and Procedures on Ethics in Research

General Principles

Maintenance of high ethical standards in research is a central and critical responsibility of the Institute of Technology Carlow (IT Carlow). It is important that the ethics and integrity of research are beyond question as the individual has a responsibility not only to him/herself but also to society. This policy should be interpreted in such a manner that is consistent with the Institute's community have the responsibility to act in accord with the highest standards of integrity and to conform with legal and Institute codes of practice and policies. IT Carlow has published its *Research Code of Practice* (Appendix A) and policy on *Misconduct in Research* (Appendix B) in its *Policy and Procedures for Postgraduate Research Students*.

1. Institute Research Ethics Committee: Function and Composition

Impartial ethical review is designed to maintain ethical standards of practice in research, to protect participants in research and research workers from harm or exploitation, to preserve the subject's rights, including the right to privacy and to provide reassurance to the public that all of this is being done. The primary task of the Research Ethics Committee is the protection of he welfare and the rights of participants in research. Another important role is to facilitate and support the progress that the research community seeks to achieve.

- 1.1. The Institute Research Ethics Committee has responsibility for the independent, ethical review of research proposals that include, but are not necessarily limited to, the following specific activities:
 - (a) Clinical trials involving human participants
 - (b) New treatment or interventions
 - (c) Research involving human remains, cadavers, tissues, discarded tissue (e.g. placenta), biological fluids
 - (d) Physiological studies
 - (e) Comparing an established procedure, whether therapeutic, nontherapeutic or diagnostic, with other procedures which are not recognized as established by virtue of their recent development, discovery or use in a new or unfamiliar way
 - (f) Innovative practices in health and disability services
 - (g) Research conducted by students, which includes all activities that meet the definition of research with human participants
 - (h) Observational clinical research
 - Access to personal information by means of questionnaires, interviews or other techniques of information gathering

- (j) Research involving the secondary use of data (use of data not collected for that research purpose), if any form of identifier is involved and/or if health information pertaining to individuals is involved
- (k) Case studies, when a series of subject observations allow possible extrapolation of generalisation of the results from the reported cases and when there is an intent to publish or disseminate the data
- Case studies, where a seriess of company based observations allow researcher access to commercially sensitive information.
- (m) Research involving vertebrate animals

Note to item (g) above: As supervised student research is conducted primarily for the purpose of educating students on research techniques and methodologies, the Research Ethics Committee should review research protocols with a view to contributing to the students' education concerning scientific and ethical principles governing research.

Review by the Research Ethics Committee may not be required for:

- (a) Research utilising existing publicly available documents or data
- (b) Observational studies in public places in which the identity of the participants remains anonymous
- (c) Case study of one patient with the proviso that written informed consent has been obtained from the relevant subject
- (d) Quality assurance studies
- (e) Audits

The opinion of the Research Ethics Committee should be sought whenever there is any doubt about the applicability of this guidance to a particular research project.

The Research Ethics Committee is responsible for the development and recommendation of policies and procedures in relation to ethics in research, which may from time to time become necessary

1.2. The Research Ethics Committee will consider, on behalf of the Director of IT Carlow, and, if appropriate, approve work, which requires the approval of an Institute Ethics Committee, before it can receive external authorisation to proceed (and/or draw down funds from a research grant.) The Research Ethics Committee will have discretion on behalf of the Institute and in the light of ethical considerations to disallow the proposed research or to require such modifications as it may think fit. The Research Ethics Committee will advise the Director on research projects having important ethical implications for the Institute.

1.3. Composition of the Research Ethics Committee

The guiding principle for appointing members to the Research Ethics Committee is to ensure that the committee has the appropriate expertise, skills, knowledge and perspectives to ensure an adequate and thorough ethics review. The Research Ethics Committee is multidisciplinary and multi-sectoral in composition. Attention is paid to age and gender balance. The membership includes lay member(s). The qualifications of lay member(s) are independence from IT Carlow under whose authority the Research Ethics Committee is established and their non-involvement in scientific, clinical practice and legal work. Those who have no experience in professions associated with research on human beings are more likely to bring a truly lay perspective.

The Research Ethics Committee is established by the Director of IT Carlow and membership includes, but is not necessarily restricted to, the following:

- (a) member(s) with knowledge of and current experience in the areas of research which are regularly considered by the Research Ethics Committee (e.g. scientist)
- (b) members(s) with knowledge of and current experience in the professional care, counseling or treatment of people (e.g. nurse, medical practitioner, clinical psychologist, as appropriate)
- (c) member(s) with training in ethics (e.g. ethicist, philosopher, theologian)
- (d) member(s) with a qualification in law
- (e) member(s) with training in statistics
- (f) lay member(s)

The Research Ethics Committee is chaired by the Director or Directors Nominee. The Vice-Chair will be nominated by the committee and ratified by the Director.

The quorum for a meeting will be defined by the committee. There should be a reasonable representation of members, which must include the chairperson, or in his/her absence the vice-chairperson; a member with relevant clinical and/or methodological expertise; a lay member and a member who is independent of IT Carlow under whose authority the Research Ethics Committee is established.

The Research Ethics Committee may appoint a person to act as an alternative for each member of the committee, where the alternate satisfies the same membership criteria as the member. The standard operating procedure of the Research Ethics Committee should identify the primary member for whom each alternate member may substitute. When alternates substitute for a primary member, the alternative member should have received and reviewed the same material that the primary member received or would have received. An alternate can only vote if the member for whom he/she acts as an alternate is absent.

Where a chairperson or members of the Research Ethics Committee believe there is insufficient expertise on the committee to assess an application or an issue, the committee should seek additional expert advice. Experts may have specialist knowledge in particular fields of science or medicine or they may be representatives of communities or special interests groups. Co-opted expert members are not entitled to vote.

ITC:Ethics Policy: Approved: AC/GB May 2006:SK

2. Institute Research Ethics Committee: Procedures

The Institute Research Ethics Committee has responsibility for the ethical review of research proposals where appropriate (see Section 1)

2.1. Ethical Review and Research Proposal Submission

When a research proposal is required either by a funding agency (e.g. Wellcome Trust) or from within the Institute to be critically ethically assessed, it is referred to the Institute Research Ethics Committee. Principal Investigators/Project Supervisors are responsible for submitting proposed projects and informing their Head of Department and should be aware of their vulnerability if they proceed without reference to the Research Ethics Committee when this is required. Heads of Departments must ensure that all staff and students are kept informed of the Ethics Policy operating in the Department and that they are kept well informed of all projects in their Departments that might fall within the Research Ethics Committee's terms of reference. If time permits, proposals should be submitted to the Research Ethics Committee before any formal application is made for external funding. No contract or other agreement should be entered into in advance of the committee's decision.

- a) Submissions are the responsibility of the Principal Investigator.
- b) The Principal Investigator submits a list of research proposals, co-signed by the Head of Department and Head of School, that require critical ethical consideration to the Chair of the Research Ethics Committee.
- c) Submissions involving human participants should complete the form -Application for Ethical Approval of a Research Project Involving Human Participants (Appendix C).

2.2 Conducting Research with Humans and Human Derived Material

All applications or proposals for research involving human subjects or human derived material external to IT Carlow must be submitted to the Research Ethics Committee for review, even when an external institution (e.g. hospital or research institute) is primarily responsible for obtaining permission to carry out the proposed research. It should be noted that many grant awarding bodies now request that ethical permission be in place, or applied for, prior to funding a project involving human/human derived material. Applications must be made to the Research Ethics Committee for human related research such as:

- a) Intervention or interaction with a living individual(s)
- b) Data derived from secondary sources, e.g. interviews about an individual(s)
- c) Identifiable private information about individual(s)
- Human remains, cadavers, human organs, tissue and biological fluids from identified subjects.

2.2.1. Respect for Human Dignity

The rights and dignity of human participants in research must at all times be maintained. IT Carlow requires due consideration to the following principles whenever research involving human subjects takes place.

- a) In all circumstances, researchers must consider the ethical implications and, where applicable, psychological consequences for the participants in their research. Researchers have a primary responsibility to protect participants from physical and mental harm during the investigation. The risk of harm should be no greater than that in ordinary life i.e. participants should not be exposed to risks greater than or additional to those encountered in their normal lifestyle.
- b) For research with human derived material the dignity of the donating person must be respected.

2.2.2 Respect for Vulnerable People

Researchers have a special responsibility for safeguarding the interests of vulnerable people. These may include under-privileged groups, children, or people who are institutionalised.

- a) Even though there is a special obligation to highlight the situation of such groups, vulnerable groups may not always be best equipped to protect their interests in relation to research. Accordingly, the normal procedures for obtaining information and consent may need to be examined further.
- b) Furthermore, research which aims to gather information on the behaviour of persons and groups should avoid using designations which could give rise to unreasonable generalisation, resulting in possible stigmatisation of particular social groups.

2.2.3 Informed consent

The right of the individual to give informed consent is paramount whether research is directly related to the individual or to material derived from the individual.

- a) The researcher should inform all participants of the objectives of the investigation.
- b) This should include all aspects of the research intervention that might reasonably be expected to influence willingness to participate. When research is carried out with human derived material the type and manner in which the tissue will be taken, its use, duration and method of storage and disposal must be informed.
- c) At the onset of the investigation, researchers should clearly indicate to participants their right to withdraw from the research at any time.

d) The collection of human derived material from individuals must be carried out with full informed consent of the individual. For individuals lacking in competency or deceased donors, consent must be sought from a relative/guardian or third party.

2.2.4 The Right of Confidentiality

Subject to the requirements of legislation, including Data Protection Act and Freedom of Information Act, information obtained about a participant is confidential unless otherwise agreed in advance.

- a) A person has the right to confidentiality, privacy and/or anonymity in all aspects of human/human derived research.
- b) In all events IT Carlow will ensure that results from research work will not be used deceptively or without the consent of the participant.

2.2.5 Minimising Risk

Individuals must not be exposed to unnecessary risk.

- a) Where research may involve behaviour or experiences that participants regard as personal and private the participants must be protected from stress by all appropriate measures, including the assurance that answers to questions need not be given.
- b) Participants should be informed of the procedures for contacting the researcher within a reasonable time period following participation should stress, potential harm or related questions or concern arise despite the precautions undertaken by the researcher.

2.2.6 Blood specimens

On occasion it is necessary for researchers to obtain blood specimens (<10 ml) from a peripheral vein to act as controls in human subject-based research.

- a) Although this is classified as a minimal risk procedure, any such proposal must be submitted to the Research Ethics Committee for review and authorisation (Appendix C).
- b) A blood specimen Consent Form must be supplied to all participants (Attached D). In this case, blood specimens can be obtained from Institute based staff or student volunteers. At all times the following guidelines must be followed: All donations must be anonymous.

2.2.7 Consent Forms

The following consent forms are attached

- Human Participants (Appendix C)
- Blood samples (Appendix D)

3. Sources of information.

This policy is based on the ethics policy developed by the National University of Ireland Maynooth and University College Dublin with reference to *Operational Procedures for Research Ethics Committees: Guidance 2004* issued by the Irish Council for Bioethics.

Additional Sources from:

- University of Albany "Research Rights" (<u>http://www.albany.edu/research/office/63.html#ResearchRights</u>)
- Policy on ethics in research and research training. Mc Gill Institute.
- Freedom of Information Act, 1997
- Data Protection Act, 1988
- International Committee of Medical Journal Editors. Uniform Requirements for Manuscripts submitted to Biomedical Journals. Ann Intern Med. 1997;126:36-47.
- Australian Vice- Chancellors' Committee Joint NHMRC / AV-CC Statement and Guidelines on Research Practice. May 1997
- The Wellcome Trust (2002) Guidelines on good research practice (http://www. wellcome.ac.uk/en/l/awtvispoigrpgid.htm)
- American Society of Mechanical Engineers .APPENDIX TO SOCIETY POLICY P-15.7 ETHICS PUBLICATION OF PROFESSIONAL/TECHNICAL ARTICLES, PAPERS AND REPORTS. A statement of the Board of Professional Practice and Ethics Of The American Society of Mechanical Engineers May 24, 1991 POLICY STATEMENT ON PUBLICATION OF PROFESSIONAL/TECHNICAL ARTICLES, PAPERS AND REPORTS.
- University of Melbourne's Code of Conduct for Research, Regulation 17.1.R8².
- University of Calgary Policy Statement Ethical Conduct for Research Involving Humans
- Cruelty to Animals Act, 1876
- SI No 17- European Communities (Amendment of Cruelty to Animals Act, 1876) regulations, 1994 (European Directive 86/609/EC)
- European Science Foundation (2000) Good Scientific practice in research and scholarship. European Science Foundation Policy briefing.
- The British Psychological Society (2000) 'Code of Conduct, Ethical Principles and Guidelines' The British Psychological Society, Leicester, UK.
- The Council of the School of the Biological Sciences, Cambridge Human Biology Research Ethics Committee, Application for ethical approval of a research project form. (<u>http://www.bio.cam.ac.uk/sbs/hbrec/</u>)

- The National Committee for research ethics in social sciences and the humanities, The Research Council of Norway. Guidelines for research ethics in the social sciences, law and humanities. (http://www.etikkom.no/NESH/eretn.htm)
- Uniform Requirements for Manuscripts Submitted to Biomedical Journals as presented in JAMA 1997:277:927-934.
- University of Melbourne 'Guidelines for Management of Research Data and Records'

(http://www.unimelb.edu.au/research/admin/res.conduct/code.html#GRD)

- University of South Australia, Human Research Ethics Policy (http://www.unisa.edu.au/admininfo/policies/research/res02-0.htm)
- University of York Academic Support Office. Ethics committee Terms of reference (http://www.york.ac.uk/admin/aso/ethics/ccttee.htm)
- World Health Organization. Operational guidelines for ethics committees that review biomedical research. Geneva: WHO, 2000.

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Appendix E: Application to the ITC Ethics Committee

Application to the IT Carlow Research Ethics Committee for Ethical Approval of a Research Project involving Human Participants (Individual Participation or donation of human derived material)



Please append any relevant interview schedules, consent forms, detailed research proposals etc. that are available.

Name of student submitting research proposal: Mr Dale Cantwell

Thesis advisor(s): Dr. Greg Doyle, Dr. Daire O Broin, Mr Ross Palmer

Medical Consultant:

Project Title: Motivating Elderly People to Exercise Using a Social Collaborative Exergame with Adaptive Difficulty.

Describe the basic purposes of the research proposed.

To produce and exergame designed for elderly people. The goal of the game is to motivate users to exercise frequently by means of an adaptive difficulty system.

Outline the design and methodology of the project.

The methodology will include using qualitative interviews and questionnaires and game metric behaviour assessments.

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Describe the research procedures as they affect the research subject and any other parties involved.

Members of the senior user group will be issued questionnaires to evaluate their individual experience playing the game. Additionally inputs and actions from the user will be recorded to create game behaviour metrics, which may be used to determine how the user is playing the game.

What in your opinion are the ethical considerations involved in this proposal?

- Consent from each participant to partake in the research
- Secure and comfortable setting to conduct interview
- Confidentiality information disclosed at interviews and data gathered from questionnaires to be used solely for the purpose of study and will not be issued to third parties.
- Respect and sincerity for all research participants
- Handling of data no identifying data will be published.

Outline the reasons, which lead you to be satisfied that the possible benefits to be gained from the project justify any risks or discomforts involved.

It is important for the project to develop an exergame that is designed specifically for the target audience.

Who are the investigators (including assistants) who will conduct the research and what are their qualifications and experience?

N/A

Are arrangements for the provision of clinical facilities to handle emergencies necessary? If so, briefly describe the arrangements made.

No

ITC:Ethics Policy: Approved: AC/GB May 2006:SK Specify whether subjects will include students or others in a dependent relationship.

No

Specify whether the research will include children or those with mental illness, disability or handicap. If so, please explain the necessity of using these subjects. No

Will payment be made to any research subject?

No

Describe the procedures to be used in obtaining a valid consent from the subject. Please supply a copy of the information sheet provided to the individual subject.

- Email from researchers to inform research participants of the research
- > Forwarding information sheet and consent form from researcher to each research participant

Comment on any cultural, social or gender-based characteristics of the subject which have affected the design of the project or which may affect its conduct. No

Give details of the measures, which will be adopted to maintain the confidentiality of the research subject.

All data gathered will be stored solely on the researcher's work computer encrypted inside a secure password protected archive.

Will the information gained be anonymised? If not, please justify.

Yes

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Will the intended group of research subjects, to your knowledge, be involved in other research? If so, please justify.

No

Date on which the project will begin: April 2011

Please state location(s) where the project will be carried out.

IT Carlow.

Signed:

Date:

Project supervisor or Principal Investigator

Signed:

Date_____

(Supervisor of student)

COMMENT FROM HEAD OF DEPARTMENT/GROUP/INSTITUTE/CENTRE

Signed: _____

Date_____

(Head of Department/Group/Institute/Centre)

ITC:Ethics Policy: Approved: AC/GB May 2006:SK

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Appendix F: Correspondency Germany

Von:	Preu-Use	Cornelia		[preu-use@diakonie	e-bayern.de]
Gesendet:	Dienstag,	22.	Mai	2012	10:56
An:		Stefanie			Wengel
Betreff: AW: Ei	nverständniserklärung Fo	rschungsprojekt			

Sehr geehrte Frau Wengel,

beide Einwilligungserklärungen sind soweit rechtlich in Ordnung, allerdings sollten kleinere Änderungen vorgenommen werden:

Zum einen ist in der "nicht so ausführlichen Fassung" die Möglichkeit der jederzeitigen Beendigung nicht so klar formuliert, hier sollten die Formulierungen der WHO- Fassung einbezogen werden (die da wären:

Ihre Teilnahme an dieser Untersuchung ist vollkommen freiwillig. Es ist Ihre Entscheidung ob Sie teilnehmen oder nicht. Falls Sie entscheiden nicht teilzunehmen, wird dies keine Auswirkung für Sie auf die Verbindung zur Diakonie München-Moosach haben. Sie können es sich auch zu einem späteren Zeitpunkt anders überlegen und die Teilnahme abbrechen, auch wenn Sie vorher zugestimmt haben. Es entstehen für Sie keinerlei Kosten. Wir bitten Sie nur um Ihre Zeit.

und

Ihr Recht abzulehnen und zurückzutreten

Wie bereits eingangs erwähnt, müssen Sie nicht an dieser Untersuchung teilnehmen, wenn Sie es nicht wünschen. Die Entscheidung über eine Teilnahme wird ihre Soziale Integration in der Gemeinschaft beeinflussen. Diesen Satz empfehle ich zu streichen, da er als negativer Zwang verstanden werden könnte.

Sie können jederzeit die Teilnahme abbrechen. Ich werde Ihnen am Ende des Interviews/der Diskussion die Möglichkeit geben Ihre Beiträge zu überprüfen. Wenn Sie dies wünschen, können wir etwas verändern oder Passagen entfernen, falls Sie nicht mit meinen Notizen einverstanden sind oder falls ich Sie falsch verstanden habe.)

Zum anderen sollte noch darauf hingewiesen werden, was mit den bereits erhobenen Daten bei Beendigung der Teilnahme während des Projekts geschieht (vermutlich werden sie dann gelöscht). Am Ende der Einwilligung –also vor der Unterschrift- sollte auch noch einmal deutlich darauf hingewiesen werden, dass die Einwilligung jederzeit widerrufen werden kann.

Ansonsten halte ich beide Versionen für sehr umfangreich, aber verständlich und nachvollziehbar. Die Ergänzungen bitte ich noch vorzunehmen.

Für weitere Rückfragen stehe ich Ihnen gerne zur Verfügung.

Mit freundlichen Grüßen,

Cornelia Preu- Use

Diakonisches Werk Bayern e.V.

Cornelia Preu-Use

Beauftragte für den Datenschutz des Diakonischen Werkes Bayern

Pirckheimerstr. 6			
90408 Nürnberg			
Tel:	0911	/	9354-490
PC-Fax:	0911	/	9354-34-490
Fax:	0911	/	9354-471
Email:			preu-use@diakonie-bayern.de
Web: www.diakonie-bayern.de			

Von:		Stefanie			Wengel
Gesendet:	Mittwoch,	22.	August	2012	09:35
An:		'Preu-Use			Cornelia'
Betreff: AW: Einve	erständniserklärung Fo	orschungsprojekt			

Sehr geehrte Frau Preu-Use,

vielen Dank für die damalige schnelle Nachricht. Die Vorbereitungen für die Testphase schreiten voran.

Wir würden gerne die zu erhebenden Daten und den Datenumgang abklären. Kann ich mit diesen Fragen erneut an Sie wenden, oder sollte ich hierfür das Landesamt für Datenschutzaufsicht kontaktieren? Gibt es weitere Vorgehensweisen die wir berücksichtigen sollten?

Vielen Dank im Voraus für Ihre Unterstützung.

Mit freundlichen Grüßen

Stefanie Wengel Dipl.-Soz.

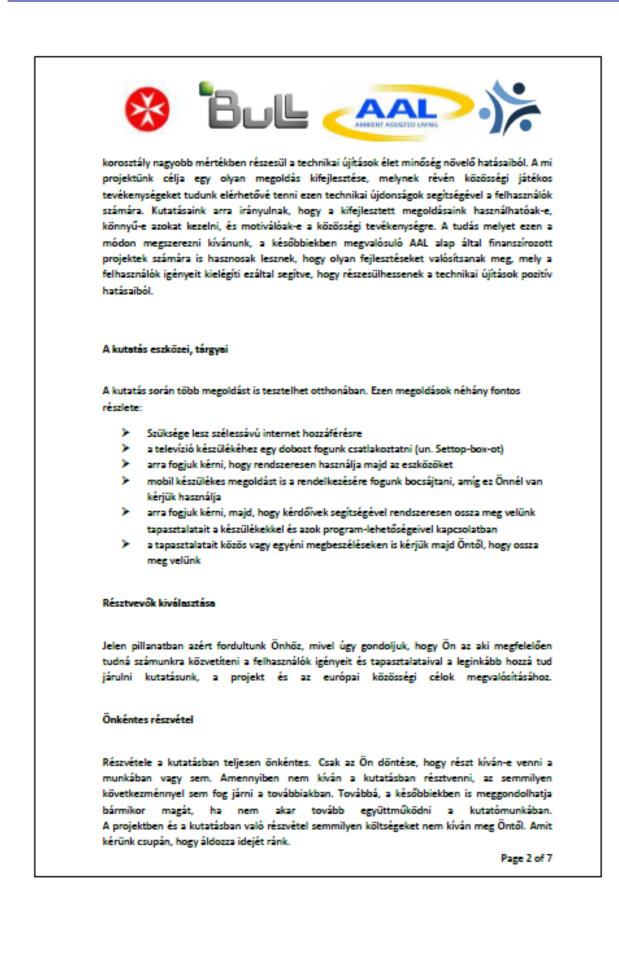
Diakonie München-Moosach e.V. Hugo-Troendle-Str. 51 80992 München Tel. 089 / 23 06 95 7 33 Fax 089 / 23 06 95 7 55 E-Mail wengel@diakonie-moosach.de

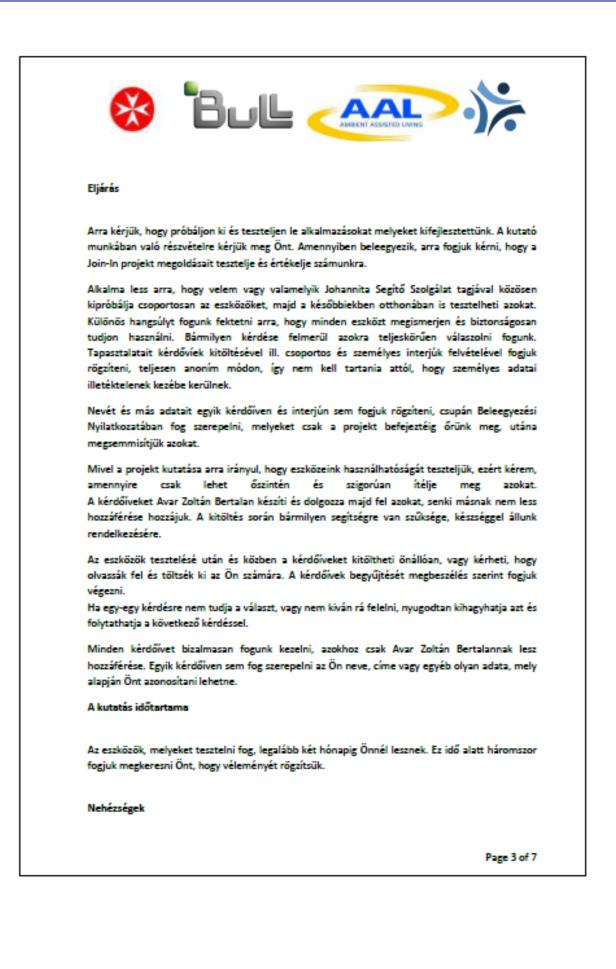
Homepage www.diakonie-moosach.de

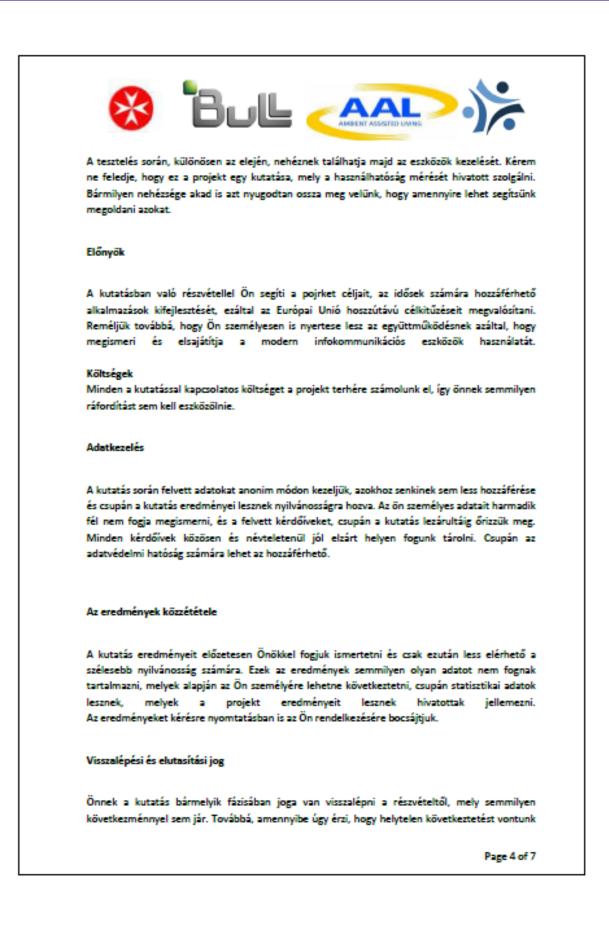
Diese E-Mail enthält vertrauliche und/oder rechtlich geschützte Informationen. Wenn Sie nicht der richtige Adressat sind oder diese E-Mail irrtümlich erhalten haben, informieren Sie bitte sofort den Absender und vernichten Sie diese Mail. Das unerlaubte Kopieren sowie die unbefugte Weitergabe dieser Mail ist nicht gestattet.

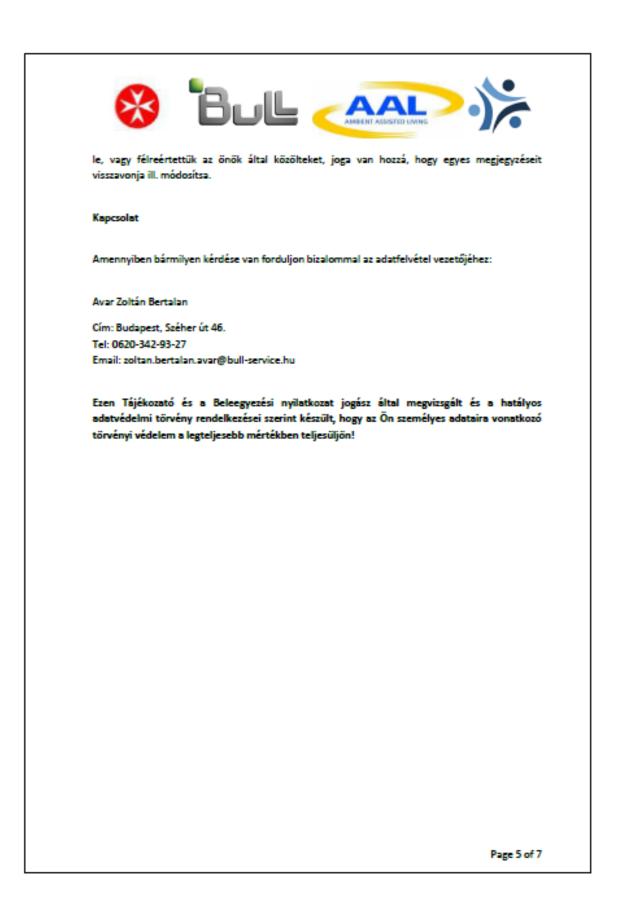
Appendix G: Informed Consent Hungary

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Johannita Segitő Szolgálat A porjekt newe: Join-In: Senior Ottizens Overcoming Barriers by Joining Fun Activities Ezen Írásos Beleegyesési Nyilatokati Űrlap két részből áll: • Tájékostató (a tanulmánnyal kapcsolatos információkat tartalmazza) • Beleegyeső Nyilatkozat (űrlap, melyen aláírásával igazolhatja, hogy a projektben, mint felhasználó, részt kíván venni, megértette és elfogadta az ezen tájékostatóban szereplő információkat és feltételeket) A teljes Írásos Beleegyező Nyilatkozatot megkapja egy példányban! Első rész: Mar Zoltán Bertalan vagyok . A Johannita Segítő Szolgálattal és a Bull Magyarország Kft-vel kösössen, egy projekten dolgozom, melynek célja, hogy idős emberek számára tegyen elérhetővé játékos kösösségi tevékenységeket. A továbbiakban tájékostatom Önt a projektről és arra fogom kérni, hogy vegyen részt ennek a projektnek a munkájában. Természetesen nem kell azonnal dönteni, hogy részt kírán- evenni, nyugodtam fontolja meg döntését! Döntkes előt beszálje atjékostatóban esetleg előfordulhatnak, olyan kífejesések, melyeket nem ért, esért nyugodan sakison félbe, ha valami nem világos számára. Amennyiben kérdése merül fel, kérem nyugodtan tegye fel nekem azokat.		
Ezen Írásos Beleegyezési Nyilatokati Ürlap két részből áll: • Tájékoztató (a tanulmánnyal kapcsolatos információkat tartalmazza) • Beleegyező Nyilatkozat (űrlap, melyen aláírásával igazolhatja, hogy a projektben, mint felhasználó, részt kíván venni, megértette és elfogadta az ezen tájékoztatóban szereplő információkat és feltételeket) A teljes Írásos Beleegyező Nyilatkozatot megkapja egy példányban! Első rész: <u>Tájékoztató</u> Bevezetés Avar Zoltán Bertalan vagyok . A Johannita Segítő Szolgálattal és a Bull Magyarország Kft-vel közösen, egy projekten dolgozom, melynek célja, hogy idős emberek számára tegyen elérhetővé játékos közösségi tevékenységeket. A továbbiakban tájékoztatom Önt a projektről és arra fogom kérni, hogy vegyen részt ennek a projektnek a munkájában. Természetesen nem kell azonnal dönteni, hogy vegyen részt ennek a projektnek a munkájában. Természetesen nem kell azonnal dönteni, hogy vegyen részt ennek a projektnek a munkájában. Természetesen nem kell azonnal dönteni, hogy vegyen részt ennek a projektnek a munkájában. Természetesen nem kell azonnal dönteni, hogy vegyen részt ennek a projektnek a munkájában. Természetesen nem kell azonnal sziksége nek i kartja, hogy részvét vesze a kutató munkában A tájékoztábban esetleg előfordulhantak, olyan kífejezések, melyeket nemért, esért nyugodan sziksége fel nekem azokat. A kutatás célja		
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	Page 1 of 7	









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Második rész:	
	Írásos Beleegyezési Nyilatkozat
	A Join-In projekt tesztelésében való résztvételre
projekt kutatásá Beleegyezem a hogy beleegyez	
	egyezési Nyilatkozat aláírásával kifejezem részvételi szándékomat az ismertete
kutatásban. Tudomásul vesz kézhez kapom.	zem, hogy a Tájékozató és az Írásos Beleegyezési Nyilatkozat egy példány:
	rása:
Dátum:	

	A kutató nyilatkozata
	[2] kijelentem, hogy tiszán és világosan felolvastar a Tájékoztatóban foglaltakat a lehetséges résztvevő számára, és n megtettem mindent azért, hogy a következők világosan érthetőe
kifejlesztett > A résztvevők	k tesztelni fogják ezen eszközöket, vagy egy részüket. k kérdőíveket és interjúkat fognak adni a tapasztalataikról az eszközökkel
Megerősítem, hogy legjobb tudásom sze nyomás alatt sem vo önkéntes.	zök használatához internet csatlakozásra is szűkség van. a résztvevőnek lehetősége volt kérdéseket feltenni és azokat helyesen és a erint megválaszoltam. Kijelentem továbbá, hogy a résztvevő semmilyen olt, hogy beleegyezését adja a részvételre, elhatározása teljesen szabad és írásos Beleegyezési Nyilatkozat egy-egy példányát a résztvevőnek
A kutató aláírása: Dátum:	
(1) A BETEG NEVE NY (2) A KUTATÓ NEVE I	YOMTATOTT BETÜKKEL