JPND-AAL

JOINT WORKSHOP

SUMMARY REPORT

This report is a summary of the discussions that took place at the JPND-AAL Joint Workshop, held on January 27th, 2014, at the Royal Tropical Institute, Amsterdam (Netherlands).
A list of the participants is available in Annex I.

AAL
AMBIENT ASSISTED LIVING

JPND
research
EU Joint Programme – Neurodegenerative Disease Research

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Background to Workshop

Assisted living technologies such as ICT/smart technology offer enormous potential in the development of effective measures for prevention, intervention and care for people with neurodegenerative diseases/dementia and their (in)formal carers.

To join forces and align priorities in this area, the EU Joint Programming Initiative - Neurodegenerative Disease Research (JPND) and the Article-185 initiative - Ambient Assisted Living Joint Programme (AAL JP), are working together towards developing recommendations for joint actions in the area of assisted living technologies for neurodegenerative diseases.

It is recognised that approximately 25% of current AALJP projects are developing ICT-based solutions for support and care of older adults with cognitive impairments. Therefore the objective of JPND – AAL JP engagement is to agree on a common research agenda, to align research priorities for ND and to determine how to implement priorities through partnership.

The objectives of the Amsterdam workshop were:

- to bring together important stakeholders in this area
- to share knowledge on JPND and AAL JP
- to identify gaps and potential benefits of collaboration
- to recommend future joint actions and opportunities

Plenary Session Summary

Welcome

In her welcome address Ms. ***Marie Claire de Vries***, representing the *Dutch Ministry of Health, Welfare and Sport*, expressed the ministry recognition of the necessity of dealing with issues related to the worldwide growing number of elderly people. The ministry supports both AAL and JPND as it recognises the importance of international cooperation on these subjects. Development of technologies that helps people to live in their own homes for a longer time and can contribute to greater efficiency in healthcare. Research on neurodegenerative diseases aimed at finding causes, developing cures and identifying appropriate ways to care for those living with these diseases is also vitally important. She hopes the workshop will offer valuable ideas on cooperation, coordination and use of resources for both JPND research and AAL projects.

JPND – Tackling the neurodegenerative disease challenge

Mr. ***Enda Connolly****, JPND Management Board Member*, gave an overview of the EU Joint Programming Initiative - Neurodegenerative Disease Research (JPND). The challenge of addressing neurodegenerative diseases such as Alzheimer's and Parkinson's is a truly global one. Most neurodegenerative diseases (ND) are incurable and are strongly linked with age. Dementias alone affect more than 7 million people in Europe and their care is estimated to cost €130 billion a year. This heavy burden on the individuals with disease, their relatives, and society as a whole is a problem that will only get worse as the European population inexorably ages, and the number of people working in care continues to decrease. We cannot tackle neurodegenerative diseases by acting as single countries.

JPND is a global research initiative, led by EU member states and has been operating for just over five years. As of today, 28 countries are participating in JPND including 21 EU Member States, 6 Associated Countries and 1 Third Country, Canada. Tremendous progress has been made by JPND in that time in terms of increasing coordination, collaboration and alignment between national research programmes related to neurodegenerative disease research. This has resulted in an unprecedented mobilization of awareness, human resources, actions, contributions and funding to tackle this problem which no country can address alone.

The past 12 months have seen JPND countries work together very effectively in a number of priority areas with activities moving forward in parallel, creating the necessary trust and alignment between the 28 participating countries in order to implement our Strategic Research Agenda (SRA). Guided by our Phase One Implementation Plan (2012-2014), these actions include, but are not limited to

- ***Annual Calls for Proposals*** in priority areas for research
- ***Alignment Actions*** to determine research needs and opportunities in areas such as Longitudinal Cohort studies, Animal and Cell Models and Assisted Living Technologies.
- ***Action Groups*** to promote engagement and partnership, including with the European Commission and other international organisations.

These JPND actions, among others, are bringing together leading scientific experts and funding bodies to investigate the key research questions and barriers to progress in these areas. It is likely that further actions (including calls for proposals) will be developed and launched during this phase, with more than €100 million in total due to be made available. Importantly, this funding will be in addition to, not instead of, other neurodegenerative disease funding.

AAL – ICT and smart technology for coping with ND's

The *AAL JP President,* Mr. ***Rafael de Andres Medina***, presented the Ambient Assisted Living Joint Programme (AAL JP). The overall objective of the AAL JP (an art. 185 TFEU initiative, approved by a decision of the European Parliament and the Council) is to enhance the quality of life of older people and strengthen the industrial base in Europe through the use of Information and Communication Technologies (ICT) – tools, systems and services. AAL has opportunities to deliver benefit for the person and their families; benefit for support and care systems across Europe; benefit for European economies. AAL can create a critical mass of R&D and innovation at an European level. Since it's start AAL launched six calls for proposals, each in a different area (chronic conditions; social interaction; self-serve society; mobility; home care; occupation in life). The total funding is around € 600 million, 50% public funding (a half by 19 EU members states and 3 associated one and another half by the European Commission), 50% private funding. Project proposals are submitted by large enterprises, SME's, user organisations, research performing organisations and universities. Currently 150 AAL projects have been funded , 30 of them with a focus on people with ND and their carers (see annexe 2 for an overview of these 30 projects). These projects with a focus on people with ND combine some of the following functionalities:

- Signal/alarm to professional or informal care;
- Support ADL / independent living / self care;
- Orientation & navigation;
- Cognitive support & improvement;
- Monitoring Patient Status;
- Support informal care (info/advice/e-learning/experiences);
- Social interaction & Entertainment;
- Surveillance / location (inside & outside the home);
- Physical activity / rehabilitation / mobility;
- Coordination of care.

Besides funding projects AAL JP carries out also support actions like:

- ***AAL2Business:*** to support AAL JP projects to bring their developed solutions to the market within 2 to 3 years after the end of the funding period through activities like coaching, methodology workshops, match-making events, etc.;
- ***AAL collaboration with regions***: aiming at facilitating the deployment of AAL solutions, via workshops with local and regional representatives to raise awareness of AAL JP projects, to foster exchange of experience between European regions;
- ***User involvement in AAL JP projects:*** to provide information to AAL JP projects about involving users in the most appropriate and effective way during research, development and role-out via current state and analysis of user involvement and workshops;
- ***Standards & interoperability in AAL***: to raise awareness on interoperability issues of AAL solutions to facilitate market uptake.

The AAL Association organises an annual AAL Forum, a meeting place for all those involved in AAL with project and industrial exhibitions, scientists, end-users and policy makers, presentations, lectures and discussions and field visits. The AAL JP aims at positioning itself in the near future as the Active and Assisted Living Programme within Horizon 2020, working together with various initiatives on Active and Healthy Aging. Among those initiatives are the joint programming initiatives (JPI) JPND, More Years Better Lives and Healthy Diet for Healthy Life.

Parallel sub-group breakouts

The participants split up into three sub-groups to discuss preset questions:

1. ***User Needs***
   Chair: *Karina Marcus, AAL JP Central Management Unit*
   Rapporteur: *Geja Langerveld, AAL-NCP Netherlands*

2. ***Marketability Aspects***
   Chair: *Enda Connolly, JPND Management Board*
   Rapporteur: *Derick Mitchell, JPND Communications Executive*

3. ***Sub-group 3: Setting Standards***
   Chair: *Pietro Siciliano, Institute for Microelectronics and Microsystems, Italy*
   Rapporteur*:* *Franka Meiland, VU University Medical Center, Netherlands* (ad interim)

The sub-groups' summary reports are detailed below.

Sub Group 1: User Needs & Wishes

This subgroup focussed on the needs & wishes of end users with dementia and methods of user involvement in the design of solutions. In case of people with dementia, informal carers are also important end users. Ethical issues regarding ICT/technology and involvement of people with dementia will be addressed.

- After the introduction of Karina Marcus, Dianne Gove, director for projects at Alzheimer Europe gave a presentation about needs & wishes of people with dementia and informal carers as well as professional carergivers. She also spoke about ethical concerns of different

groups. After this presentation, the AAL JP ALFA project (http://www.aal-alfa.eu/) was presented by Eric Schlangen and Inge Fleur Soede and the AAL JP project MyGuardian (http://myguardian-project.eu/) by Inmaculada Luengo.

QUESTIONS TO DRIVE DISCUSSIONS

Q1 What do you know / did you find out in your research about user needs & wishes?
Q2 How can needs & wishes for care and support of people with ND be assessed? Which methods are suitable and available?
Q3 What can be the role of ICT/smart technology (as being developed in AAL JP) in JPND research about prevention, early diagnosis, treatment and care & support for people with ND and their carers?
Q4 How can the acceptation and uptake of ICT solutions in the life of / care for people with ND be stimulated?
Q5 What are the key recommended actions that need to be taken?

Wishes & Needs of Primary users: people with ND

It is important to focus on possibilities and stimulate what people can do instead of focus on limitations! People with (mild) cognitive impairments can gradually lose the ability to empathize and experience problems in interacting with products (aphasia apraxia, agnosis, short term memory); however they are often able to use products they knew when they were young. Needs for care & support by people with dementia can be different from people with other ND's e.g. parkinsons, mental disabilities etc. Not all people with ND are old.
Having said this the following needs & wishes of people with ND were identified.

- Maintaining independence (don't have to say thank you)
- Being accepted and respected for who they are
- Having fun / meaning in life / meaningful activities / self satisfaction
- Experiencing reciprocity; the opportunity to give/contribute instead of only receiving
- Keeping self esteem (learning to master ICT devices is good for self esteem)
- Coming to terms with their situation. Learning adequate strategies to cope with disabilities
- Managing activities of daily living
- Receiving care which respects autonomy and dignity
- Receiving care and support preferably by informal carers / support networks
- Doing something to keep yourself mentally fit in order to prevent deterioration

Wishes & Needs of Secondary users: informal and formal carers

Informal carers

It is important to realize that many informal caregivers are older adults themselves; they can also have disease(s). And sometimes informal caregivers take care for more than one person with ND.
During the session the following needs & wishes of informal carers were identified

- Being free of care giving responsibilities sometimes; the independence of person(s) with ND (from informal carer) is important *(take that into account in case of telemonitoring etc.)*
- Receiving information how to deal with / care for people with ND
- Having concerns about safety of people with ND / prevention of harm
- Getting help for the person with ND in cases of emergency
- Finding people with dementia back
- Receiving psychological and emotional support (informal carers are first victims of depression, anxieties and dementia)
- Receiving information about ICT well in advance.

Formal carers

For formal carers it is important to have the 'right' attitude towards people with ND; e.g assumptions about what they can learn or not.
For formal caregivers the following needs & wishes were mentioned (additionally)

- Improving their working conditions
- Receiving information about the situation people with ND are alone, out of sight
- Having tools to support people with ND and informal carers
- Receiving communication support for all parties/people involved
- Learning communication skills to work with people with ND
- Receiving information about ICT well in advance

Methods for engaging end users

Methods for engaging people with ND

In researching and developing solutions for people with ND and their carers, it is important not to overlook the primary end users! There is a strong tendency to discuss wishes and needs of people with ND only with their informal and formal carers.
When engaging people with ND, it is important to be aware of the following issues.

- Include end users from the very beginning of the project / process; people with ND have different needs; what causes a challenge and what can reduce their frustrations
- Define in an early stage the profile(s) of people for whom you develop the solution; as ND develops over time, different profiles are relevant in different stages of the disease.
- Trust is crucial to engage people with ND and carers; communication skills are esssential
- In early stages of ND, interviews, focus groups etc. can be used to discuss how they perceive their situation and what they see as key issues for the short term and/or the medium term.
- Different communication strategies can be used, even with people in advanced stages of ND. A playful environment often works better than 'sitting down and talk'.Observation of daily behaviour by experts is useful to discover needs & wishes that people with ND cannot verbally communicate.
- Observation on daily behaviour can also be done by means of ambient technologies.
- Look systematically at barriers to overcome the use of ICT as well as facilitators for implementation; build on the knowledge base and/or devices people already know.
- Seniors with ND are very sensitive, decisions are often more emotionally than rationally based.

The *AAL Guideline and Toolbox End User Integration* provides different methods for integrating different types of end users in different stages of developing ICT based solutions. Some methods are suitable for integrating people with cognitive impairments and carers. The toolbox can be downloaded from the AAL website.

Methods for engaging carers

- For engagement of carers also topics as trust, communication skills, changing needs, barriers, etc. are relevant.
- Open discussion with informal carers in early stages of the project is essential.
- Several methods can be used end users in projects, see also the AAL toolbox.

Issues

- Validation: methods for engagement of end users to identify a range of needs & wishes are often qualitative and do not require large numbers of users.
- In test trials to prove effectiveness and worthiness of solutions, this is different: trials with many people in different countries are more reliable; it is suggested to make it part of science and include it in evidence based care.

Potential solutions with ICT to meet the needs & wishes of users and support them

In the plenary presentation an overview is given of 30 AAL projects where systems are developed that cover many different functionalities.

During the discussion the following topics are emphasized in the context of ICT based support.
Primary users – people with ND

- ICT based solutions should maintain peoples with ND functioning, not taking over but support them to prevent deteroriation or even improve their functioning; , ICT can help to provide information and training about dementia, coping and caring
- ICT can support care and social networks and establish links with family/professional care
- ICT can offer functionalities for guidance in daily life activities to support independence
- ICT can help to keep up activities: mental activities, brain fitness, training of cognitive abilities (45+), braintraining games (e.g. http://www.lumosity.com/).
- ICT can support to keep up physical activities to help retain cognitive functioning as well.
- ICT included in clinical protocols can help people to develop strategies skills to create self-efficacy at home
- ICT can help with human activity recognition (sensors/camera's) to create logs that enables informal carers to see what is happening. Attention for privacy aspects.ICT can be used to activate alarms, cut power/water supply) and guide the user to do concrete actions or report to the appropriate carer.

Secondary end users – informal and formal carers

- ICT can support education & training (e.g. about the stages and progression of dementia, the effects on behaviour and wellbeing, how to deal with that etc.)
- ICT can support informal carers in discharging their daily stress (e.g . Breathe programs)
- ICT can provide communication support as well as participation of other carers and social/community network in the care process
- ICT can provide remote monitoring away from the home of people with ND.
- ICT can help to improve working conditions for professional carers(remote monitoring / supported decision making). ICT/ technology (e.g. imaging) can be used to measure certain indicators that could be used to early diagnose (already 45+) a certain disease. ICT based behaviour monitoring can detect behaviour changes that might indicate progression of the disease and report about it remotely.

Issues to take into consideration

- Security and reliability of ICT based solutions are a big issue.
- Mobile versus fixed devices: people with ND can forget to take devices with them. They also forget to charge a device. On the other, fixed devices like a TV screen can only be used in one place.Privacy and autonomy: what information is needed to monitor, who needs to know what level of information etc. Who has the right to make decisions.The greater the distance of monitoring, the more seems to be acceptable.
- For people with ND privacy often is a trade-off with autonomy. Deciding for others; feeling uneasy about overriding the known wishes of the person with dementia (violating the person's integrity and autonomy) in the interests of security, and peace of mind of carers
- Fears of stigmatization and the effect on quality of life have to be taken into account
- The level of E-skills and digital literacy is generally not (yet) sufficient by end users; training is necessary , but it can also be an obstacle / demotivation; do not give up too quickly and/or think it is too difficult for people with ND; many people can learn to handle ICT devices.
- People with dementia/ND and their carers (formal and informal) have often different – sometimes even conflicting - needs and wishes. Balancing these different needs & wishes is important to create a workable and 'liveable' situation for all people involved.

- Challenging stereotypes like: global loss of capacity, dementia as consisting solely of the advanced stage, lack of quality of life, loss of person status.
- Focus on 'person with dementia' instead of 'dementia patient' (i.e. consider the person, not the disease)
- Introduction of telemonitoring (=constant awareness of the situation) might create more work for professionals and more care burden for informal carers instead of less; it creates more unplanned care. Concerns about broaching the topic of ICT solutions in the relationship with people with ND (and carers)
- Ethical and legal aspects, responsibilityand liability issues
- Costs and benefits; care organisations may have different / conflicting needs (e.g. costs etc.) from careworkers; different payers and benefits
- Community level also has to deal with people with dementia (police, firemen etc.)

How can the acceptation and uptake of ICT solutions in the life of / care for people with ND be stimulated?

- Information and creation of awareness about the possibilities of ICT for primary and secondary users, e.g. via Alzheimer Associations etc. to create demands for ICT solutions.
- Creation of a reference web site that provide access to proven solutions so people can see the benefits and consequences of the use of ICT based solutions.
- Providing solutions that can be adapted to the progress of the disease and are adaptable to the changing conditions of their users.
- Improving usability of solutions and reducing unnecessary complexity.
- Solutions should have added value (compared to the current situation).
- Focus on early adopters to innovate in the development phase and large groups in pilots.
- Training; carefully choose and train the persons that introduce the technology to the usersThe person must be trusted, use understandable language; don't give up too quickly!
- More general use of ICT by older people will make the adoption of ICT based care solutions easier; things that make life worth living, create fun, social connection; not only for 'fixing' things.
- The team of patient and caregivers has to be trained in the use of the ICT system.
- People in the future will be more used to communicating via devices.
- For acceptance by professionals: analyse the use of technology in daily work to build on that and/or to learn how to innovate.
- Share knowledge about successful ways to promote acceptation. But: different types/groups of users have a negative attitude towards technology, so also good solutions can be denied.

What are the key recommended actions that need to be taken?

On top of the different points raised in the questions above, the following points were added:

- Creation of a Roadmap on research on ICT for ND that controls how the different projects progress and which is the real impact, and establishes challenges. Any roadmap should be done by researchers in strong consensus with user's representatives.
- ICT can help to get information about the behaviour of people with ND and aggregate information from a big amount of people and make findings of the population that could provide leads to research actions in discovering common aspects related to behaviour.

Sub Group 2: Marketability Issues

This sub-group focused on how to develop markets for/address barriers to, the uptake of ND-relevant ICT technology in healthcare. Discussions included for example, industry access

mechanisms, sustainability issues, as well as replication of innovative measures across regional, national and EU levels.

After a short introduction by the chair, Enda Connolly, three presentations followed. First, Ms. Gwendolyn Carpenter of the Danish Technological Institute, Denmark spoke on the TechnolAGE initiative – "*best practices of ICT solutions for aging well around Europe*". Secondly, Dr. Denis Curtin, University College Dublin, Ireland spoke on the Applied Research for Connected Health (ARCH) Centre in Dublin. Thirdly, Prof. Alan Smeaton, Dublin City University, Ireland spoke on the REMPAD initiative – "*Reminiscence Therapy Enhanced Material profiling in Alzheimer's + other Dementias"*.

Questions to drive discussions
To drive marketability and address barriers to uptake of ND-relevant technology in healthcare;

Q1: What are the issues that are preventing the development of markets or restricting uptake?

Q2: What are the conditions or environments that need to exist?

Q3: Are there possible enabling incentives or interventions?

Q4: What are the key recommended actions that need to be taken?

Introduction by the chairperson

- A number of constraints are evident in this area, at both the universal level (across IT and Health Technologies) and the local level (national approaches to innovation). Subsequently, there are differences in what is feasible within different countries, as well as the types of support available.
- There was a clear acknowledgement that this is a complex environment that requires engagement with multiple stakeholders. There is therefore a need to create actions to encourage this engagement, particularly with clinical and regulatory stakeholders.
- It was noted that in order for AAL solutions to bring changes to healthcare pathways and healthcare systems, the technological aspect of solutions needs to be matched with the clinical need. Ideally, the driver of the opportunity is the clinician/healthcare professional identifying the need.

Current challenges

- A general lack of understanding of the role of regulatory bodies in this area (a positive example mentioned was that of Ireland's HIQA body producing a review of care homes) as well as how technology can be applied to change healthcare systems.
- AAL solutions are competing within an environment currently dominated by pharmaceutical-based interventions. The pharmaceutical industry is investing heavily in this area (it was noted that in the 2013 AAIC congress, the vast majority of the submitted intervention-based abstracts were pharma-based).
- A lack of understanding of the business model and market opportunity that exists in this area, particularly among both large MNCs and smaller SMEs. Very often, MNCs will only move if there is a billion dollar market opportunity.
- Very often, national public healthcare systems do not think in terms of healthcare solutions and are slow to grasp opportunities to improve care processes (e.g. smart procurement).
- Most health services are in general, not user-centered, and are designed and delivered according to traditional systems of care (Primary, Secondary etc.)
- The relationship between healthcare and social care models and systems results in difficulties in moving money between them.

- The difficulty for public institutes/small companies to access funding sources for commercialization was raised as a challenge.

Current markets

- Current markets for AAL solutions include national public healthcare systems and public/private insurance companies. However, AAL businesses need to tap more into the pension market with its very motivated user population.
- A real opportunity exists within the pharmaceutical and medical devices industries. The same issues regarding reimbursement / compliance apply here, and they all need technology. Also, considering the changes in the pharmaceutical cost model (patent cliff, cost of drug development), multinational corporations (MNCs) are increasingly prepared to take more risks, and to share the risk. This could be an opportunity for AAL businesses.

Can AAL technologies create new markets?

- The real innovation within the AAL field is in how technologies can change the model of care. This requires integration of health, social and voluntary care models. Also, the connections between formal and informal care environments are changing, so the potential exists to support interventions and technologies capable of encouraging greater connection between these care models.
- It was noted that if a healthcare system encourages consumer co-payments, they are more willing to invest in 'disruptive' technologies.
- The consumer market requires a re-education of the AAL industry – e.g. "use the language of the app" or try to capitalize on "turnaround moments" in time (e.g. HAILO taxi app)

Models of financing

- Engagement and involvement of payors at an early stage can lead to innovative ways to pay for solutions (the example was given of the Danish ministry of finance investing in AAL solutions). eGovernment and social innovation models could also serve as new ways of financing.
- We should be encouraging public funders to integrate consumer-led interventions or 'disruptive' technologies to improve decision-making in healthcare. Home-sensing and home-mapping technologies can lead to more personalized approaches to both treatment and care.

Market analysis

- AAL JP has plans to develop an "observatory" of current activities in AAL technology development, with the objective of identifying emerging patterns. A "second arm" of the observatory could look at the potential economic impact of small interventions in healthcare (e.g. cheap apps), from which a peer-reviewed report could prove essential for the area.
- Explaining the value of an AAL product needs to take into account who the buyor/payor is – an aspect which has been neglected to date. AAL interventions can be much more effective and cheaper than pharma-based interventions. Dementia could be used as an example area where the impacts may be showing the greatest value.

Education and training

- Encourage complimentary and interdisciplinary skillsets among academics for the marketplace (e.g. business development, entrepreneurship) – perhaps in association with Marie Slodododoska-Curie / Socrates actions.
- There is a need to increase understanding of the routes to market and to investigate how this can be integrated into existing funding schemes.

National agenda setting by the aal industry

- A suggestion was made for an industry-led forum for shaping where funding goes (e.g. horizon scanning) and for recoordination of funding instruments (e.g. the IMI model). The Dutch model of competence centres was highlighted as a possible model to follow.

Overall summary

The overall view of the sub-group was that many technologies, products and service innovations currently exist which can and will transform health and social care in the coming decade. However, it is a complex under-developed market where a number of constraints and barriers are impeding the uptake of technology both universally and locally. It was noted that, apart from a small number of areas of exception (e.g. imaging), the sector has not traditionallly been a leader or driver in the adoption and usage of technology. However it was felt that despite the constraints, this may now be changing and the time may be right for this sector, like others before it, to be able to feel the impact and benefits of technology. A number of areas of constraint were highlighted:

- There are substantial variations in the supports available both at national and regional level for the development and implementation of technologies into practice, use and commercial exploitation.
- There is a need to develop better understanding of the market opportunites and of the competitive business models for both for SME's and large companies for technologies in the health sector
- The availablity of impactful evidence which clearly demonstrates the effectiveness and cost savings of use of technologies in health is needed.
- In a health context, the application of technology is often driven first and foremost by a clinical or service need change rather than by a technology change. Although this may be changing as the consumer adoption of ubiquitous mobile/social technologies pushes the demand for their use in health care.
- There was a general view that there has been a failure to adopt "smart" or "innovation" procurement approaches which encourage the testing or validation of technologies.
- Adopting and validating technologies in health is often a complex environment involving the engagement of many stakeholders and in which regulations are also complex and inconsistent.

In this context, the workshop recommended **six areas of action** which it was felt might address some of the constraints or barriers as follows:

Action areas

a) Initiatives should be taken at both a European and at a national level to **engage health insurers** whether they be public, semi-public or private to encourage a better understanding of the value technology as a driver/enabler of care change and efficiency.
b) Health delivery systems should be **incentivised to engage in care model** change enabled by technology.

c) Direct financial supports should be made available for **research commercialisation** at the different stages of the innovation value chain at both European and national levels.
d) **New innovatiove funding models** should be researched and highlighted where they exist across the community. In particular an emphasis should be placed on demonstrating how the models worked and how they delivered value.
e) Reports **demonstrating the value of small innovations** in dementia care enabled by technology, should be undertaken and compared to the enormous costs of innovations in pharmacological interventions
f) A technology watch or **observatory** should be established that should go beyond simply reporting, by providing additional components such as **trend analysis and economic value** and outcome benefits assessment.

Sub Group 3: Setting Standards

This sub-group focused on how to set standards for evaluating measures and testing in different cultures on the base of different projects' experiences within the local, real-life context of patients.

After a short introduction by the chair, Pietro Siciliano, three presentations followed. First Dr. Franka Meiland, VU University Medical Centre, the Netherlands, on 'Evaluation of the Rosetta system: user friendliness, usefulness and impact in daily life', second Dr. Alberto Pilotto, S. Antonio Hospital, Italy, 'ICT-based outcome predictive tools in clinical decision making' and Michiel Sprenger PhD, National IT Institute for Healthcare in the Netherlands, on 'Setting and Using Standards in Care'.

QUESTIONS TO DRIVE DISCUSSIONS

Q1: *What are the most relevant standards and interoperability requirements in ND application in terms of non-technical (i.e. standardisation of user needs, standardisation of design, standardisation of installation, standardisation of usability, etc.) items? Which standards in terms of technical items (i.e. equipment and environment, technology, specific domain, etc.) are crucial for non-technical standards?*

Q2: *What can a system developer do to implement standards in terms of non-technical items?*

Q3: *When setting standards in terms of non-technical terms, which instruments and values are critical for the patient at home?*

Q4: *How do you measure the standardisation of evaluation methodologies (involvement mechanisms, acceptability, experimental protocols and results) and privacy and how can they be harmonised in order to overcome non-technical barriers?*

There are many different types of standards needed and developed:
- User assessment (functioning, needs and outcomes) ICF, MPI, CGA, CANE
- Information (HL7, EN13606)
- Infrastructure (IT standards)
- Software
- Interoperability (IHE, Continua)
- Privacy issues (STORK)
- Study designs (controlled designs, mixed-methods duration, number of people)

This many standards leads to both overlap and gaps.

- Regarding user assessment we need a standard tool for user needs. Based on information from different projects, use the same tools. Look at the INTERDEM paper on psychosocial outcomes measures.
- We should share the knowledge gathered from many studies starting with user needs: personae, scenarios, goals (rich descriptions, what went well, what went wrong and why; database to be added). These offer a good starting point for further research, in which to include information from caregivers.
- A uniform description of target groups is needed. To reach this description use the WHO ICF Framework (International Classification of Functioning, Disability and Health). If needed, make additional descriptions of the consequences of diseases.
- For personalization of support provided we need a standard for adaptability to personal needs.
- As for technical standardization look at design for modularity and integration of new technologies.
- Pay ample attention to ethics: how to approach people, evaluations, use of data (consent)
- In the current AAL project setting with its three year approach, it is difficult to complete development and evaluation. Clinical trials can't be done in three years. We need good quality results, thus a longer period than three years.
- Population studies depend on outcome measures. For this we need strong study designs (RCT) and active control groups. A minimum standard for study design, including mixed method design, is essential.

Recommendations:

- Develop a **standard tool** for the assessment of **user needs**.
- **Evaluate and share knowledge** from studies starting with user needs.
- Use the WHO ICF Framework to develop a **uniform description of target groups**.
- For development and evaluation of projects, allow more time than the standard 3 years in AAL.
- Set a **minimum standard for study design**.
- Provide input at next AAL meeting (**Support Action Standardization and Interoperability**) on February 19-20, 2014, www.cip-reaal.eu/events/macsi-2014.
- Give the participants the opportunity to proceed with these discussions at **a follow-up workshop**.

Closing Remarks

Chaired by Mr ***Peter Saraga***, chair of the AAL JP Advisory Board, a representative from each sub-group gave a summary of the discussions in their sub-groups. All sub-group representatives mentioned a lot of enthusiasm from the participants for this workshop. This resulted in lively discussions. As the recommendations from the sub-groups were quite extensive, this report refers to the sub-groups' summary reports above.
In their closing statements, ***Enda Connolly*** and ***Rafael de Andres Medina*** expressed their gratitude to all participants and the Dutch Ministry of Health, Welfare and Sport. The discussions resulted in a large number of issues to be dealt with. It was important for the representatives from both AAL en ND research to meet and become acquainted with each others' expertise. It will take some time to really get to know the others' languages. The discussions prove to be helpful for both the JPND and AAL JP on their way to define actions and find common ground for cooperation. The report from this joint workshop will be discussed in both the AAL General Assembly and the JPND Management Board. After that, further actions will be defined.

Enda Connolly and Rafael de Andres Medina thanked the participants for their attendance and useful contributions to the discussions. A summary report of this joint workshop will be distributed among the participants and will be available on the JPND website: http://www.neurodegenerationresearch.eu/initiatives/jpnd-alignment-actions/assisted-living-technologies and on the AAL website.

Annex I List of Participants

Arlene	Astell	Canada + UK
Gabor	Avar	MyGuardian (AAL Project)
Henk	Bakkerode	EUROCARERS / NL
Soledad	Ballesteros	AGNES (AAL Project)
Thomas	Becker	JPND
Gwendolyn	Carpenter	Denmark
Enda	Connolly	JPND
Gabriella	Cortellessa	EXCITE (AAL Project)
Denis	Curtin	Ireland
Rafael	de Andres Medina	JPND / AAL
Marie Claire	de Vries	Ministry of Health, Welfare and Sport, NL
Francis	Deboeveria	SONOPA (AAL Project)
Rocio	Diaz	EMOSION (AAL Project)
Francisco	Flores-Revuelta	BREATHE (AAL Project)
Alain	Franco	AAL Advisory Board
Dianne	Gove	Alzheimer Europe
Constanze	Hahn	JPND
Ruth	Hersche	ALMA (AAL Project)
Claudia	Hildebrand	JOIN IN (AAL Project)
Thorhilt	Holte	Norway
Jacqueline	Hoogendam	JPND
Igone	Idigoras	ASSISTANT (AAL Project)
Martin	Kampel	FEARLESS (AAL Project)
Bernd	Klein / CIBEK	ROSETTA (AAL Project)
Marie	Krag	E2C/Com'ON (AAL Project)

Tony	Lam	CAMELI (AAL Project)
Geja	Langerveld	AAL
Inmaculada	Luengo	MyGuardian (AAL Project)
Margje	Mahler	Netherlands
Peter	Makai	Netherlands
Karina	Marcus	AAL
Franka	Meiland	ROSETTA (AAL Project)
Derick	Mitchell	JPND
Sean	Mulvany	Ireland
Adolfo	Muñoz	Spain
Damien	Nicolas	TUDOR (AAL Project)
Alberto	Pilotto	HOPE (AAL Project)
René	Prijkel	AAL
Antonio	Remartinez/ Ibernex	BEDMOND/NACODEAL (AAL Project)
Peter	Saraga	AAL Advisory Board
Luca	Scascighini	ALMA (AAL Project)
Eric	Schlangen	ALFA (AAL Project)
Christian	Schoen	HOPE (AAL Project)
Pietro	Siciliano	JPND AAL Action Group
Andrew	Sixsmith	Canada
Alan	Smeaton	Ireland
Inge Fleur	Soede	Alzheimer Netherlands
Vidar	Sorhus	Norway
Luiza	Spiru	CONFIDENCE (AAL Project)
Michiel	Sprenger	Netherlands
Hendrik	van den Bussche	Germany
Vincent	van Pelt	Netherlands
Myrra	Vernooy-Dassen	JPND SAB

Gerard	von Wolferen	ASSAM (AAL Project)
Sigrid	Weiland	EC, DG RTD
Andy	Wolff	HELP (AAL Project)

Annex II Overview of AAL projects with focus on people with ND

Features	Surveil inside	Surveil. outside	ADL supp	Social interact	Monitor Patient status	Signal informal care	Signal formal care	Self care	Physical rehab.	Enter-tainment	Cogni t. Supp.
Call 1 - ICT for the management and Prevention of chronic conditions of older adults											
AGNES User-sensitive Home-based Systems for Successful Ageing in a Networked Society www.agnes-aal.eu				X		X	X				X
ALADDIN - A Home Care System for the Efficient Monitoring of Elderly People with Dementia www.aladdin-project.eu				X	X			X			
BEDMOND – Behaviour pattern based assistant for the early detection and management of neurodegenerative diseases www.bedmond.eu					X		X				X
CCE - Connected Care for Elderly Persons Suffering from Dementia www.cceproject.eu			X			X	X				X
HELP - Home-based Empowered Living for Parkinson's Disease Patients http://help-parkinson-aal-project.tid.es/					X		X				
HERA - Home sERvices for specialised elderly Assisted living www.aal-hera.eu				X	X	X			X		X
HOPE - Smart HOme for the elderly People www.hope-project.eu/					X	X	X				
ROSETTA - Guidance and Awareness Services for Independent Living www.aal-rosetta.eu	X				X						X

Call 2 - ICT Based solutions for the advancement of social interaction of elderly people											
M3W – Maintaining & Measuring Mental Wellness www.m3w-project.eu											
Call 3 - ICT-based Solutions for Advancement of Older Persons' Independence and Participation in the "Self-Serve Society"											
2PCS - Personal Protection and Caring System www.2pcs.eu	X	X							X		
FEARLESS - Fear Elimination As Resolution for Loosing Elderly's Substantial Sorrows www.cogvis.at	X	X					X				
MYLIFE - Multimedia technology for independence and participation for people with dementia www.karde.no/MYLIFE_english.html			X	X						X	
ALFA - Active Living For Alzheimer-patients www.aal-alfa.eu	X		X		X		X				
NACODEAL - Natural communication device for assisted living www.nacodeal.eu/en/			X								

Features	**Orientat.Assist.**	**Navigat. Assist.**	**Contact persons**	**Alarm function**	**Infor-mation**	**Physical mobility**			
Call 4 - ICT based solutions for Advancement of Older Persons' Mobility									
ALMA - Ageing without Losing Mobility and Autonomy www.aal-europe.eu/projects/alma/	X	X							

ASSAM - Assistants for Safe Mobility www.assam-project.eu	X	X	X	X					
CONFIDENCE- Mobility Safeguarding Assistance Service with Community Functionality for People with Dementia www.salzburgresearch.at/en/projekt/confidence_en/			X						
HAPPY WALKER - www.happyassistedliving.com/en/		X		X	X	X			
MYGUARDIAN - A Pervasive Guardian for Elderly with Mild Cognitive Impairments www.myguardian-project.eu	X	X	X						
NAVMEM - Navigation Support for Older Travellers with Memory Decline www.navmem.eu	X	X		X					
MOBILE.OLD - Residential & outdoor services advancing the mobility of older persons www.mobile.old.eu					X				
EMOSION - Elderly friendly MObility Services for Indoor and Outdoor sceNarios www.emosion-project.eu		X	X	X					
EXO-LEGS - Exoskeleton Legs for Elderly Persons www.exo-legs.org/						X			
GUIDINGLIGHT - Ambient Light Guiding System for the Mobility Support of Elderly People www.guiding-light.labs.fhv.at		X							
Features	**Support informal care**	**E-learning**	**Sharing experiences**	**Tailored advice**	**Coord. with profess.**	**Support dementia at home**	**Localisation Ob/Subject**	**Diverse services**	**Cognitive support**

Call 5 - ICT-based Solutions for (Self-) Management of Daily Life Activities of Older Adults at Home									
UNDERSTAID - A Platform that helps informal caregivers to understand and aid their demented relatives www.understAID.com	X	X		X					
ICARER - Intelligent Care Guidance and Learning Services Platform for Informal Carers of the Elderly http://icarer-project.azurewebsites.net/	X	X	X		X	X			
NITICS - Networked InfrasTructure for Innovative home Care Solutions www.nitics.eclexys.com/						X	X		X
ECH- eCare@home www.aal-europe.eu/projects/ech/	X					X		X	X
BREATHE – www.breathe-project.eu	X							X	
CHEFMYSELF - Assistance solution for improving cooking skills and nutritional knowledge for independent elders www.aal-europe.eu/projects/ahead/						X		X	