ACCESS FINAL CONFERENCE
30/08/16 AMAZONE - BRUSSELS

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access-project.org
ICT for aging well
The Active and Assisted Living Programme (AAL)

Karina Marcus
Director
AAL Central Management Unit (CMU)
Some demographics considerations

(1) Excluding French overseas departments in 1990; 2010, provisional; 2020-2060 data are projections (EUROPOP2010 convergence scenario).
Source: Eurostat (online data codes: demo_pjanind and proj_10c2150p)
What is AAL?

European initiative to fund projects proposing solutions based on ICT to improve the quality of life of older adults

- **COFUNDING ACTIVITY**
  - Applied research
  - Innovation closer to market

- **TRANSNATIONAL PROJECTS**
  - > 3 countries involved
  - Business / SMEs / Users / R&D

- **USER DRIVEN**
  - Innovation paradigms
  - Conception / Testing / Business
The AAL Programme

• Partner state driven funding program (since 2007)
• Co-funding: national funding organizations, EU, industry co-funding (~50% of public funding)
• Aim: AAL product or service goes to market 2-3 years after end of project
• Total investment: ~600 Mio € (2014 – 2020)
• First phase (2008-2013): 154 projects, over 1000 project partners, ~3900 end-users
• 25% of projects (calls 1-2) have secured follow-up funding for commercialization
Call for proposals 2008-2013

CALL 1: Chronic Conditions
CALL 2: Social Interaction
CALL 3: Self-Serve Society
CALL 4: Mobility
CALL 5: Home Care
CALL 6: Occupation In life
An ageing society faces an increasing need for care, how will ICT contribute to sustainable solutions?

20 projects selected for funding

The contribution of ICT/technology to integrated solutions for supporting active and independent living of older adults in their homes

17 projects selected for funding

Providing integrated solutions based on ICT to support the wellbeing of people living with dementia and their communities

65 proposals received
Additional instruments

Hackathons
• Agile instrument of the AAL program through opening up for shorter projects where requirements are different.

• 5-6 hackathons identified and taking place in the first half of 2016 and close in scope to ageing -> AAL co-sponsors them

Challenge Prize
• AAL is seeking innovations in internet connected devices and technologies (Internet of Things) that will empower older adults to achieve the quality of life they aspire to, socially and independently, with a clear business opportunity and prototype

• 15 finalists were selected and are invited for an academy with coaching sessions to help them improve the ideas
AAL Support Actions

• AAL2Business
• Collaboration with Regions
• User involvement in AAL JP projects
• Standards & Interoperability in AAL
• Information Days
• Presence in European Conferences
• Preliminary studies on
  • AAL Information Portal
  • Market Observatory in AAL
<table>
<thead>
<tr>
<th>Location</th>
<th>Year</th>
<th>Participants</th>
<th>Exhibitors</th>
<th>Posters</th>
<th>Sessions</th>
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<td>500</td>
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AAL FORUM 2016

26-28 September

Register now!

in Sankt Gallen - Switzerland

@AALProgramme
#AALForum

www.aalforum.eu
Thank you for your attention!

- Our Website: www.aal-europe.eu
- AAL Forum website: www.aalforum.eu
Older Persons’s Perspectives: User needs for Qualify of Life

Ilenia Gheno
Research Project Manager

Final Conference – ACCESS project
Brussels, 30 August 2016
AGE Platform Europe

Voicing needs & concerns of 190 million older people in Europe

- **Bringing older people's viewpoint in the EU policies' debates**, regarding the most important dossiers for people aged 50+, e.g. social protection, pension reforms, anti-discrimination, employment, social inclusion, ICT, health, research, accessible mobility and build environment,...
  - 130 Members from all over Europe
  - 14 Task Forces (Accessibility of build environment, transport and ICT, Healthy Ageing, Dignified Ageing, Consumer’s rights, …)

- **Raising awareness on users' needs and wishes**, on the principle and practice of users' involvement, in order to add value to the European research, to industrial production, to the service provision and policy-making.
  - Involvement in EU projects (Advisory Boards, User Fora, pilot visits, …)
  - @ Policy level (EU lobbying, campaigns, e.g. solidarity between generations, age-friendly environments, European Parliament Intergroup on Ageing, …)

- **Pooling with other European NGOs and stakeholders**: facing the challenges brought by the demographic change by working together and by sharing the rationale that nothing can be done without the involvement and consent of those the action is addressed to (“nothing for us without us”).
Guiding principles

- Towards a society of all ages: Promote inter- and intra-generational solidarity
- Older people as a resource: take into account the cultural and professional resource represented by older people
- Older people as self-advocates: older people should be able to speak on their own behalf
Who is old?

• No surprise! We age since we are born
• A very heterogenous group with very different needs and perspectives:

“Older people are a totally heterogeneous group and that is a vital point to learn. You have those who continue to decide on their daily living and those who at the same age have given up. You have those who will grasp the tele-control and flick through the channels and those who leave it in the drawer preferring to push the button”.

Angela Cluzel, AGE Expert on the occasion of the AALIANCE Final Conference, Malaga, March 2010

• “When I'm 64”: different ages, different needs… changing in time and space (older people in 1964 had some different priorities and wishes than older people now)
Involving, (em)powering

A win-win situation

✓ User involvement as an added value both to research and practice

✓ User involvement from the outset to ensure that users’ needs and preferences can be better understood and taken into account
Benefits from user involvement

Positive effects when you listen to what people want:

- Feeling of safety – regular monitoring reassures the users i.e. “system” cares for them

- Feeling of connecting – strengthen one’s network of social connections; motivate families to follow health conditions of their older relatives

- Feeling of empowerment - regular monitoring has a positive spill-over on the health status and on the feeling of having control over our own health condition

But remember that technology is not always the and only solution:

“A society for all ages is one that does not caricature older persons as patients and pensioners. Instead, it sees is as both agents and beneficiaries of development… it seeks a balance between supporting dependency and investing in lifelong development”.
Kofi Annan, UN Secretary General, 1998
Challenges from user involvement

When designing and implementing, though, do not neglect…

- Some may not want to change routines and tools – respect the **right to opt out**
- Lack of ICT **skills** can be a barrier – need for user-friendly interfaces, as well as jargon/language barrier
- **Ability** to access personal data varies and requires constant improvement and training
- **Technical obstacles** – availability and reliance of brand band connection e.g. in remote areas
- Financial accessibility and **affordability** – older people on low incomes can have problems in affording ICT tools and internet connection
- ICT cannot replace personal contact, but facilitate and complement it
- **Inclusiveness** – socio-economic bias of the inclusion of end-users and barriers for OP with higher level of frailty and/or more significant social needs
For older people
✓ Participation allows to increase the sense of ownership
✓ It reduces the feeling of being exploited by research
✓ It enhances social participation
✓ It contributes to the development of skills of older people
✓ It allows to keep at pace with (the) research developments and innovation
✓ It helps the users understand their role in the process, technology and methodology used

For researchers
✓ Participation ensures researchers understand users better
✓ It forces researchers and beneficiaries to speak the same language
✓ It explores ways to bring users in the discussion: engaging users means acquiring efficiency, efficacy and consistency, while late involvement often means a high risk that the feedback from the users will not be implemented
✓ It reduces the gap between research and practice
✓ It encourages the consensus between/within stakeholders
✓ It helps achieve better research results, encompassing hard-to-reach groups
✓ It facilitates user/society acceptance and therefore business development of innovation

For society
✓ Participation of beneficiaries diminishes the risk of ageism
✓ Research priorities reflect those of users, ensuring that money and resources are not wasted on research with little or no relevance
✓ Increase real impact of research on society
✓ Improve services and products (i.e. accessibility) for the benefit of society as a whole
AGE worked on a practical guide to user involvement, addressed mainly to researchers, but with the wider scope of highlighting the challenges of engaging with the final beneficiaries in all decision-making processes.

Finalised as part of the INNOVAGE project, the guide presents some common practices and suggestions for allowing the genuine participation of seniors in social innovation process.

The document highlights the complexity of dealing with users and of engaging with them, while suggesting useful methodologies for user involvement, taking into account the inter-disciplinary approach needed when discussing and implementing social innovation.

Available online in AGE website and http://www.innovage.group.shef.ac.uk/
ACCESS conference
The 30th of August, 2016

Round table
Origin of the project

- Share relevant data with the circle of support
Overall Features

- Account Management
- Address book
- Lifebook
- Agenda
- Camera
- My Documents
- Whiteboard
- Antecedents
- Medical history
- Autonomy
- Health Sheet
- Messaging
Use cases

- Seniors (different frailty types)
  - Patients at home (still active) or go in the structure
  - Many care providers (different profiles) / unique care provider
  - Existing data in the separate information systems of care providers
  - Strong need for data exchange between carers and family

- Seniors with cognitive impairment
  - Patients at home, with cognitive impairment
  - Application for doctors, patients and tutors
  - No existing information in databases
Prototype

Seniors (different frailty types)

Seniors with cognitive impairment

Nurses

Professional carers

ACCESS Platform

Information sharing features

Health monitoring features

Common features

Family carers

Medical staff of Hospital center
Use cases in France

- The use of smartphone application (IOS/Android) by referents (the services tested are limited to the shared calendar and address book).
  Number of experimenters: about 45 referent/structure tested the smartphone application.

- The use of the iPad application at home by the beneficiary, the referent and professionals involved (the services tested include the service on medical data and the connection specification).
  Number of experimenters: about 20 beneficiary/structure.

- Ergonomic tests on the iPad at the structure premises by professional.
  Number of experimenters: approximately 5 professional/Structure.
Results in France

- Who used the service?
  - Technophil Seniors
  - The relatives who already exchange by email and sms are more inclined to use the application to exchange with professionnals.
  - Relatives need to see the first names of professionnals displayed on the schedule.
    - Especially when seniors need complex care and are distant.

- A lot of observations regarding the Lifebook: need to visualize what the others knows.
  - Transmission written by... / read by ... / and date. )
  - Be able to check first who can read the message and then to choose the recipients.
  - View the message history. (Function: monitoring patient)
  - Be alerted by an event that involves further action: notifications of a new event on the home page
    - what level alerts for what information. Urgent/not Urgent
Results in France

- Regarding ergonomic evaluation, users’ feedback:
  
  Easy using of the tool in general.
  
  Usefulness of the service (schedule for relatives with names (complex care), of the features (access rights...), and usefulness of the role repository.

- Globally, high contrast situations.
  ■ A good start to identify variables that can influence the expectations of the tool.
    ■ Technophiles, professional, relationship with the senior.
Use cases in Belgium

- The use of the **iPad application** was tested in 6 NOAH’s in Flanders and 16 clients were involved in the test. Number of experimenters: 16 clients.

- **Ergonomic tests on the iPad** were done by the coordinator of the NOAH and by the person who was responsible for the test.

- The use of **smartphone application** we could not execute the test with Dutch software.
  Number of care professionals: 9 ‘Family carers’.
  Also 1 informal caregiver participated to the test.
Use of the Ipad and evaluation protocol (family carer)

In Belgium
Results in Belgium

- Who used the service?
  - The clients of the NOAH's
  - The professionals of FAMILIEHULP, working in NOAH
Telemedicine in the home of people with dementia

AAL - ACCESS PROJECT - Results

The ACCESS system to monitor effects of acetylcholinesterase inhibitors on the heart of patients with dementia

Giuseppe Sancesario
Gianfranco Raimondi

Bruxelles, August 30th, 2016
Surveillance of Safety of the Drugs which Are Used in Clinical Practice of Patients with Dementia.

- Adverse drug reactions occur in 5% of patients with Alzheimer's Disease or other dementias treated with commonly prescribed Drugs:
  - acetylcholinesterase inhibitors to improve memory;
  - neuroleptics to manage sleep and behavior disorders.

We evaluated the usefulness of an innovative device named **Pulse**, coupled to a tablet running the ACCESS application, to monitor the daily heart rate activity and to timely detect adverse drug reactions in patients with dementia in their home.
The Pulse is a battery operated sensor, wearable on the chest: it acquires, digitalizes, stores and periodically transmits data via a Bluetooth radio link, connected to a medical service.

ACCESS App and Pulse device

Pulse is a multi-parameter analysis system recording continuously:

- ECG
- Breathing rate
- Physical activity
- Body position

Clinical protocol and patients

- We scrutinized 144 consecutive outpatients with a definite diagnosis of dementia of mild to moderate degree. Given its exploratory nature, the study included subjects on medications with or without AChE-I, and other drugs with a potential to affect HRV.

- All patients underwent basal ECG recording for five minutes.

- Exclusion criteria were the presence of pacemaker (n= 3) or cardiac arrhythmia (n= 6).

- 77 patients did not adhere to the study for the lack of a caregiver able to use the Pulse device and manage the tablet. In 3 cases there was an allergic skin reaction to the Pulse patch.

- 58 Patients were enrolled and started Pulse monitoring but finally only 29 (16 F and 13 M, 75.6 ± 8.3 years) patients completed the study, lasting one-week. The drop-outs were due to lack of compliance of the patients or to errors committed by caregivers during data acquisition.
Blue columns: day-night motor activity levels (AL). Red columns: day-night breath frequency (BF). In all the patients, as expected, we observed a reduction in motor activity levels during the night, and no significant day-night variations in the breath frequency.
Blue columns: patients untreated with acetylcholinesterase inhibitors (no CI). Red columns: Patients treated with acetylcholinesterase inhibitors (CI). The heart rate (bits/min) was not significant different between the 2 groups during the day-night cycle. However, the hearth rate was a few bits lower in patients treated with acetylcholinesterase inhibitors (CI). In particular, no episodes of bradycardia were detected.
Conclusions

The advantage of the ACCESS App with Pulse device is the possibility to record and analyze at a time a heart rate, respiration rate and activity level calculation algorithm, allowing management of information messages from/to the caregivers.

Limitations:

- Dependent on the caregiver collaboration, which limits the number of patients who can benefit from such an investigation.
- The tablet is not easy to carry around, it would be preferable the use of a smartphone.
- Record longer than one-two days is not well accepted by patients.

Future developments:

- Independence of the ACCESS app from the caregiver: the medical team should set the ACCESS system on the patient and the patient can return back to the Alzheimer center after 48 hours.

Prevision:

- The ACCESS system may have a widespread use in neurology and psychiatry.
Acknowledgment
The ACCESS team in Italy

The ACCESS project in Italy has been carried on by the Alzheimer’s Center at the Tor Vergata University, with the contribution of La Sapienza University Group of Cardiology, and by the technology partner Liferesult.