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DL 4.1

Monitoring and Evaluation Report

WP4 – Pilots

Version 3.3

Release: 26th of June 2017

AAL PROGRAMME

1. Document Information

1.1. Purpose of Document

This document outlines the approach adopted in monitoring and evaluating the research undertaken during the project.

1.2. Organisation Responsible

The University College Odisee is the organisation responsible for this deliverable. All project partners are contributors and reviewers of the document.

1.3. Authors and Contributors

Partner	Name	Contribution	Date
UCO	Ellen De Cuyper	Author	02 June 2017
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1.4. Version History

Version	Date	Description	Author
0.1	31th of Mar 2015	Template release for comments.	N. Almeida
1.0	02nd of June 2017	First draft release.	E. De Cuyper
2.0	05th of June 2017	Second Draft Release	K.Poulton
2.1	07th of June 2017	Modifications during consortium meeting	E. Smith

3.0	14th of June 2017	Third Draft Release	E. De Cuyper
3.1	16th of June 2017	Minor modifications to layout & addition of Appendices list	K. Poulton
3.2	19th June 2017	Inclusion of 3rd pilot & minor layout mods.	E. De Cuyper K Poulton
3.3	26th June 2017	Final check & release	K Poulton

2. Executive Summary

2.1. Background

The internet revolution and growth in mobile technologies has changed the way we live, work, play and communicate; in ways that would have been previously unimaginable. Despite elderly populations accounting for a disproportionate use of healthcare resources, this group has traditionally been under-served by the technologies that are changing the way we live in so many other aspects of our lives.

2.2. Purpose of IntegrAAL

Project IntegrAAL (Integration of AAL (Active Assistive Living) Components for Innovative Care Pathways) aimed to explore the fundamental question of how we can first understand the challenges faced by some of these older people, and then take available technologies and design and develop new ways of introducing them in meaningful ways in order to improve health outcomes, quality of life, and cost-effectiveness of delivering care. More specifically, IntegrAAL intends to understand the circles of care that are responsible for delivering the day-to-day care for these populations, both formal and informal, and design and develop systems based on handheld mobile technologies to foster and facilitate communication within the circle of care. In addition, the use of newer Internet of Things devices incorporated into the information management system creates the opportunity to develop new care pathway paradigms that have the potential to revolutionise the approach to care of the elderly living at home.

2.3. Project Exploitation

There are two companies in the consortium which will incorporate the knowledge gathered in this project into a product. This product will be sold, generating recurring revenues.

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3. Table of Contents

AAL PROGRAMME

4. Introduction

4.1. Glossary

AAL	Active Assistive Living
Care pathway	Multidisciplinary management tool based on evidence-based practice for a specific group of patients with a predictable clinical course, in which the different tasks (interventions) by the professionals involved in the patient's care are defined, optimized and sequenced either by hour, day or visit.
IntegrAAL	Project acronym for Integration of AAL (Active Assistive Living) Components for Innovative Care Pathways
Nourish Integra Platform	Cloud-based data management platform to support care providers in managing care data in a person-centred manner. It enables assessment, care planning, care recording using mobile devices, and outcome management as well as reporting. It also enables care providers to make use of IoT devices as well as wearable devices in the context of care provision.
IoT device	Internet of Things device, normally a sensor device connected to the internet enabling the monitoring of location, movement, or temperature amongst others.
Pilot	A small-scale preliminary study conducted in order to evaluate feasibility, time, cost, adverse events, and effect size (statistical variability) in an attempt to predict an appropriate sample size and improve the study design prior to performance of a full-scale research project.
Evaluation	Structured interpretation and giving of meaning to actual impacts of proposals or results.

4.2. Objective

The main objective of this project was to study the effectiveness of care pathways and supportive technology in maintaining or improving independence and quality of life for older people and their carers. Defining the economic impact was outside the scope of this project, however the study sought to provide an indication of the potential to release capacity in care provision. Due to its limited size and duration the results of this study were intended to help define and guide the direction of future research in this area.

A study methodology to be used to assess the impact of the pilots as part of work package 4 had been included in the proposal document. The research protocol was elaborated to provide a more specific framework by the responsible organisation. A set of questionnaires were proposed that sought to introduce a range of validated questions that could be applied consistently across all three pilot areas.

Due to a range of technical and practical issues during the study, the desired volume and quality of information was not able to be produced to generate robust evaluations. In November 2016, the project partners agreed that to fully understand the experience of the older adult, and their circle of care, the three different pilot regions would focus the evaluation on a series of in depth case studies. The case studies were carefully selected to reflect typical participant personas and their general attitudes described in the study. The quantitative data that was able to be collected is presented in DL 4.2.

In addition to the case studies, other experiences of the project staff members involved in the pilots are presented in this report. In the discussion, differences noticed between the three regions are described and recommendations for the further development of the IntegrAAL technology are formulated.

4.3. Appendices

A comprehensive set of appendices are attached to this document as section 10.

5. Research protocol

5.1. Research question

What is the effect of the IntegrAAL technology on maintaining or improving independence and the quality of life of the older adult and his circle of care (formal and informal carers)?

5.2. Study design

A randomised controlled intervention study in 100 older adults and their carers (formal and informal) living in three different regions Dorset (UK), Miranda de Corvo (Portugal) and Brussels (Belgium). A power analysis was performed based on the three regions (see Appendix A)

5.3. Participants

The original inclusion criteria for older adults participating in the study were:

- Over 64 years old
- Living at home
- At least one informal caregiver agrees to participate
- Receives at least one care service at home
- At least one formal caregiver agrees to participate

Exclusion criteria older adults:

- Unable or unwilling to consent
- Highly-dependent care needs due to short term medical intervention
- Severe cognitive impairment (MMSE < 11)
- Holidays longer than 1 month

5.4. Experimental versus control conditions

Participants would be randomly allocated to one of two groups:

- In the experimental condition the older adults would test the IntegrAAL platform and associated IoT devices. Older adults had to complete several questionnaires (see appendices B.1.1.1-3, B.2.1.1-2, B.3.1.1-2)

at baseline and every three months during the study. The formal and informal caregiver would use only the IntergrAAL platform and share their experiences by completing a questionnaire at baseline and every three months during the study.

- In the control condition, older adults would complete the questionnaires at baseline and every three months during the study. The informal caregiver and the formal caregiver would only fill in a questionnaire at the beginning of the study.

5.5. Testing period

The data collection period was planned to last one year. The testing period per older adult would be between six months and one year.

5.6. Measurements

At baseline, demographic data of the older adult and their circle of care together with health problems and care needs of the older adult and the contribution of the circle of care were collected. Also the experience with the use of modern technology by the older adult and the circle of care was questioned. The older adult also filled in the Quality of Life assessment questionnaire of the World Health Organisation (see appendix B.1.1.1, B.2.1.1, B.3.1.1, B.4.1.1).

Every three months the technology (app and integrated devices) was evaluated by the older adult and the circle of care and the Quality of Life assessment questionnaire was also filled in by the older adult. At the end of the testing period or if a participant decided to stop an exit interview was performed (see appendix B.1.4, B.2.4, B.3.4).

5.7. Ethical considerations

Ethical approval was obtained for each region (see appendix C.1-3). Every participant was orally informed by the local researcher, received an information letter and signed an informed consent (see appendix D.1.1-2, D.2.1-3, D.3) before the participation.

5.8. Coordination of data collection over the three pilots

A document “instructions for data collection” was produced for the three end-user organisations, who were responsible for data collection in the three different regions. The document was discussed during the consortium meeting in London (March 2016). A second version of the document was distributed after agreement on the measuring instrument for quality of life (the WHOQOL, validated in the four languages). A third version was created when it became clear that it was difficult to recruit older persons with formal and informal carers prepared to participate in the study. In November 2016, the inclusion criteria were adapted. Beside presentation of the document at consortium meetings, Odisee’s researchers were always present to explain orally through skype meetings. The fourth version of this document is included (see appendix E). It provides more detailed information on the methodology of the study.

In November 2016, the consortium considered the difficulties that had been experienced in collecting completed questionnaires. It was decided that

the limited remaining project time meant that a comprehensive research time-line could not be developed. It was agreed that information be collected reflecting the local circumstances of each pilot area rather than the uniform set of comprehensive information contained in the validated questionnaires. These questionnaires could contain the basis of information collected. It was also decided that the research be refocused to the development of at least one in depth case study in each region as a proxy for participants in the pilots. These modifications to the Description of Work were submitted to the AAL CMU as part of the End of Year Report 2016.

6. Case studies

The case study approach allows for substantial detail to be collected that would not normally be easily obtained by other research designs. The data collected is a lot richer and of greater depth than can be found through other experimental designs. Case studies record behaviour over time so changes in behaviour can be seen. For these reasons the three case studies, one for each pilot region, were added to the research report.

Each case study gives an in-depth description of one older adult and their circle of care using the IntegrAAL technology. UK and Portugal completed the written case study with a video where the older adult and their circle of care testify about their experiences with the new technology. A precise version of the UK case study is included in this report. The full document that includes more detail is attached as Appendix F. The Belgian project partners did not add a video because the participants of the case study chose not to be filmed. The lessons learned from these three cases will be discussed.

6.1. Case study United Kingdom (Dorset)

Bridie is an 82-year-old lady with vascular dementia, who joined the project in May 2016.

6.1.1. Background

Bridie (fictional name) (82 years) is widowed and lives alone with Bodger - her blind but lively and friendly Jack Russell - in a small rural village just outside the town of Bridport, in Dorset. Originally from Fulham, London Bridie grew up and spent most of her life in London where she attended Grammar school and later worked in the accounts department of the Shell Oil Company. Bridie is private about her diagnosis and doesn't want anyone to know she has dementia.

Bridie and her husband retired to Dorset nearly 30 years ago and after her husband died Bridie continued to live in the same house they moved to. Bridie

has a son David (fictional name), who lives in Australia with his wife and three children, and a daughter Kate (fictional name), who lives a 20 minute drive away. Kate works full time, takes care of her husband (who has been unwell recently) and also supports several of her neighbours (who she helps with pet care, DIY and daily checks). Kate's daughter Anna (fictional name) lives in London, while Ginny (fictional name) is at university in the UK.

6.1.2.Circle of Care

Bridie continues to enjoy living in the small rural village and a positive of this is that Bridie is both familiar with the community and well known to them; most residents in the area Bridie lives know each other and are also elderly and retired. Bridie is well known at the local shop that she visits each morning for her newspaper. The manager Catherine (fictional name) supports her independence and has arrangements with Bridie's daughter Kate about paying for shopping and generally keeping an interest in her wellbeing when Bridie comes in and reporting any issues to Kate.

It's Kate who supports Bridie daily with all other (household) tasks: she arranges all appointments (hair dresser, outings, health checks...), manages her finances and checks daily twice over the phone!

Bridie is also involved with the local church and is in touch with the Vicar and Brenda the Church Warden and there is a coffee morning held in the church each Friday that Bridie used to attend regularly. Bridie also visits and receives social visits from her neighbours a couple of times per week and her friends June (fictional name) - who lives down the road - and Julia (fictional name) - who lives opposite - call in regularly. However, they are all becoming more elderly and not always able to leave the house to visit each other but keep in touch by phone. Walking Bodger isn't possible for Bridie as he is very nervous outside the familiar house and garden.

6.1.3. Medical History

Bridie was successfully treated for breast cancer shortly after she retired. Bridie is type 2 diabetic, has high blood pressure, suffers from depression, has a diagnosis of vascular dementia and had arthritis in her spine and knee. Bridie reports her biggest challenge is her balance and her memory. She reports feeling dizzier and this is affecting her confidence on the stairs. At the start of the project Bridie reported that her memory had been bad for about three years when all of a sudden she couldn't seem to remember anymore, this left her very confused and disorientated, but says her long term memory seemed better now, the everyday stuff is still a problem. Bridie has been a victim of door to door conmen in the past and also vulnerable to phone salespeople, giving large amounts of money to charities that ring up, unsolicited. Bridie reported her mood was often low and she felt depressed a lot but as soon as she sees family or friends she feels ok.

The care situation described below - under 'care needs' - was set up following the fall that lead to a hospital admission, Bridie received reablement after being discharged from hospital. Bridie remains at a high risk of falls and is often unable to get up from the floor. Bridie's dementia has progressed through the project and Bridie recalls what happened when prompted but can be unable to recall finer details.

6.1.4. Care needs

Bridie receives two formal care calls per day that are funded through Adult and Community Services as a statutory provision (Dorset County Council fund care for those with an assessed need who have under £24,000 in savings). Each morning they support Bridie, originally to help with breakfast and to help her get dressed, they now help her get washed and dressed and also shower once per week. Bridie was previously physically independent with this at the start of the project but her care needs are slowly increasing as her conditions progress. They also make her a cup of tea and toast to ensure Bridie has

eaten. Each afternoon the carers visit to make sure she has a hot meal at tea time, *“check I am ok and I have got my Careline pendant on”.*

She also receives visits from Tamsin (fictious name) the care coordinator at the local GP surgery. Tamsin visits about once per month and more frequently acts as a local contact and coordinator for Kate if she notices anything that may need extra support, such as a fall or the start of an infection. Accessing formal carers in a rural area can be challenging, due to the nature of the demographic: Dorset experiences a shortage of carers given the localized high demand. The high cost of living coupled with low wages for formal carers compounds this.

Kate has organized meals on wheels (a local firm run by Norma) for Bridie, to come in each week day to deliver a hot lunch. The drivers going in each day do flag up any concerns they notice, although they do not spend more than a minute in the house.

6.1.5.Assistive Devices

Bridie has a few aids to help her cope with the limitations she experiences. She has a trolley in the house so she doesn't have to carry things. Bed rails *“so I don't fall out”* and grab rails in the toilet, bathroom and outside the doors. Bridie has a walk in shower and uses a swivel cushion in the car. Bridie’s family bought her a day clock *“to let me know the day and time”.* However, Bridie unplugs everything at night so this switched off unintentionally and Bridie does not remember to plug it back in the morning. Bridie also walks with a stick and now wears Careline, a telecare link to use in an emergency (for example in case she falls) which only works in the house.

6.1.6.Attitude towards technology

Bridie is open minded about new technology. In the past Bridie’s role at the Shell Oil Company included using one of the new desktop computers. One of her tasks was to ring up each country for their accounts figures and enter

them into the system and Bridie says she was fairly confident with technology in that role. Currently Bridie has a cordless phone and a mobile phone with an emergency button. When asked about social media Bridie said she would not mind learning about Facebook. She has a tablet computer, is connected to the internet and does a big shop on-line fortnightly with Kate, but does not use the tablet by herself. The downside of living in such a small rural village is that mobile phone signal is very patchy and there are many dead spots including Bridie's street. The signal is poor; the broadband is also very weak and drops out a lot, several times per day. There are also mostly retired people living locally so there is little diversity of skills and abilities to draw on with regard to technology usage and physical ability.

6.1.7. Aims for the client and circle of care and potential solutions planned

Given the large and varied circle of care around Bridie, the potential benefits were identified as assisting Kate to coordinate Bridie's care and keep people up to date with situations without having to make numerous phone calls or emails and to be able to do this from a distance. This would also enable Kate's husband and Anna and Ginny to be more aware of Bridie's situation and support Bridie and each other better as a family.

Bridie's dizziness and falls can be supported with sensors that also work outside the home, like Buddi, to enable Bridie to continue to live independently. Access to the IntegrAAL application in the shop would act as a welfare check each time Bridie is served and they can communicate issues to Kate and Tamsin if concerned. Tamsin will be able to keep track of Bridies wellbeing, record blood sugar and inform Kate of any visits and outcomes without having to contact her specifically. Within the community, access to the app would let the church warden record when Bridie went to coffee morning on Friday. Technology in the home would then allow formal visits from the care agency and meals on wheels to record their visits. This would act as another welfare check and allow concerns to be flagged clearly and to the

relevant parties.

The plan was to build a timeline for Bridie with all interactions and events that take place in her day as well as integrating the signals of the Buddi sensors and the Careline sensors. Give Bridie a personal login so she can use the IntegrAAL app herself it she wishes, share the timeline with the circle of care (by giving logins to everyone involved), issue Kate, Catherine and Tamsin with project phones or tablets to maximize access and interaction to the timeline and also leave a project phone in Bridie's home (for Bridie and visitors to use).

6.1.8. Intervention and impact

Bridie and her family were interviewed to establish the care routine for Bridie. Due to the early phase of the project, Bridie's timeline was built in the Beta area of the IntegrAAL app. This was challenging for the pilot team as the basis for the new app was the Nourish Care Home system so it appeared quite inflexible. It took some time to learn ways in which this needed to be changed and to adapt existing functions away from fixed tasks; towards a dynamic record of daily activity and interactions. Bridie, Kate and her family were given individual logins and the project team met with Kate and her husband to download the beta app onto their devices and establish logins and train them on the basic functions. The learning from the requirements of this formed the basis of the 'how to use' factsheet (including where to find the app, how to download and open it, setting up logins and entering tasks and alerts). Kate and her husband were easily able to access the app and put entries on there, however without the secure timeline sharing no other parties were able to enter information so any benefit was unclear to them. A couple of months later the organisation element for Bridie's timeline was replicated and moved to the new app version. However this wasn't communicated clearly so no support was available and Kate and her husband could no longer login (as they had a different version of the app). Once this was identified attempt to rectify this were made, however the profile copied over from Bridie only

included profile and care plan elements. The timeline, that had been so time consuming and complicated to setup, hadn't been replicated. This was required to be rebuilt manually and only done some months later; this delay impacted on the continuity of the use of the app and hasn't been used yet.

Bridie was issued with a Buddi and this was set up. Several meetings had taken place with Buddi and Nourish and in theory the timeline was able to integrate with the Buddi unit, however this didn't happen on this occasion. So the Buddi unit was essentially a stand alone piece of technology without the ability of remote review by a project member to give extra support. Only on completion of the questionnaires was it discovered the issues that had been experienced by the family using a Buddi unsupported by the project. The associated wrist worn falls detector was too sensitive resulting in many false alarms. Bridie was panicked by an alarm, called Kate and didn't know what to do: she couldn't work out where the voice on the unit was coming from as it was so quiet. With the phone it kept dropping out of signal as it is so poor in the area so the GPS location isn't sent and the two way voice is unclear. The battery often went flat as Bridie turns it off at the mains each evening then she would phone Kate and say, *"That thing doesn't work, that thing is flashing at me"*. Kate had to ring Bridie on each alarm raised and if she didn't answer assume she had fallen so it took a lot of time and National Health Service personnel to check the false alarms. Anyhow, *"Given that there were phone calls we found that reassuring even though they were false alarms.it was good having that information relayed to us* (Kate)". The Buddi did detect one fall correctly: Bridie was on the floor unable to get up, Kate was away but was able to call Tamsin to go round.

Eventually Bridie decided she didn't want the Buddi anymore and her granddaughter Ginny requested that it be removed.

Tamsin was also given a login and training from the project team during a couple of sessions. Tamsin was open and supportive to the project but not at all confident with the technology, one of the training sessions required how to use the smart phone, this included how to turn it off and on and the various screen locks and screen swipes. This limited experience and the developmental stage of the app meant there were barriers to Tamsin feeling comfortable enough to start using the app independently.

This situation replicated with Catherine, who was very open and willing to be involved. The login was set up and a project phone was left behind the counter to log whenever Bridie had visited. The phone wasn't accessed at all: not one visit was logged, it simply didn't factor in the daily routine of the staff that were behind the counter. A consideration here was did each staff member need a different login or would a global login for the shop be sufficient? Having to log in each time was another barrier to using the app in this situation. Many professionals are used to secure systems to record notes in some way; this simply isn't applicable in community settings. The secure timeline sharing element of the app was required for this to be used with confidence, with various levels of privacy; this could have mitigated the need for a formal login requirement.

The project was discussed with Brenda from the Church who was very reticent, she was unable to understand the concept of what we were trying to achieve and not sure that it was something they would be able to be involved in, she would be happy to support Bridie but wasn't confident in becoming part of the project.

The project showed the app to the private carers that came to visit Bridie, they were very positive about the potential for it to help them communicate any issues to the family but they were unable to complete any tasks not on their

task list in Bridie's care plan and suggested we would need to contact the office. The office was phoned and a discussion took place about the project; we were informed that the registered Manager would have to approve this and we left various messages but our calls were not returned.

One of the most promising responses from the community was from the meals on wheels service. The project was explained and - although unsure of the part they could play given the very little time they spent in each client's home - the service was very open to try something. Even though they couldn't see a long term benefit or any way this could be expanded out into the community or how we could work with the drivers to populate the app. This would involve the driver on Bridie's route to either carry a smartphone or use the smartphone in Bridie's house, neither of which were popular, since many of the drivers were retired and doing this as a part time job so most had never owned a mobile phone never mind a smartphone. Besides, the poor signal in the area hadn't only affected the function of mobile phones, it had also affected the culture and the community who hadn't yet evolved to rely on them. They actually were quite well connected already, so the app didn't offer them anything: they phoned, visited and spoke to each other on a regular basis.

A group of reablement workers (RW) began to use the app to record their care notes, to populate the timeline and began feeding back their experiences of using the app and the true impact of the lack of signal and the behaviour of the app in poor signal areas came to light. The RW were using the App on Dorset County Council tablets, best practice for the app was to remain logged in all day. However this was counter to Dorset County Council advice that RW only log into the tablets to check their rota and enter mileage and then log off to save data charges and battery. This logging off behaviour had the impact of losing any unsaved notes in the app when there was poor signal in the area; the other issue of poor signal was it caused the app to stall when in areas of

poor signal, making it impossible to add notes in the first place. This led to the RW creating a ‘work around’ where they would write up notes on the app at home or later in their shift and having to log on and log off at home or within a good signal or wifi area. It took considerable time to identify there were two different issues and to resolve to impact of the signal. The stalling was only identified when a developer came to the UK and went on a field visit to witness the impact, he immediately knew that the app was identifying a signal present and automatically tried to refresh, however the app wasn’t able to discern sufficient strength of data signal. Hence it was trying to refresh in areas with insufficient or no data signal causing the app to run very slowly and impacting on the usability. This experience was frustrating for the RW and remains a shadow over their experience on the project; it is yet to be fully resolved.

There was a lot of support and enthusiasm in the community for the potential that the app could provide at the start of the project and this was tempered by the very early developmental stages of the software, giving limited functionality. The RW and families can clearly see the benefit and would wish to remain engaged with some form of technology if the improvements such as the timeline sharing and the integration with Careline and Buddi were available. Older adults had a more passive acceptance of the technology, seeing that it could be of use to others who are supporting them but not wanting to have anything to do with it themselves, thinking that you need to be clever to use it.

Halfway through the study the need for ongoing support, advice and review of technology became evident and the realisation that this couldn’t be the role of one person, illustrated by the absence of a lead in Nourish for almost a year and of the pilot lead for several months. Even in a pilot of this size, the requirement for ongoing support to use technology had been massively underestimated. Towards the end we still found people were optimistic and

open, keen to see the developments promised come to fruition, even with all the issues above the concept remains well received. Given the rocky path that the UK pilot took it has left a remarkably positive impact on those that have been involved. Very little happened as planned yet so much experience and learning came out of that; of things going wrong and of the challenges. These are gems that can be mined to create a far superior user experience in the future. Much more work has to be done in the community to raise skills in using devices that in turn will offer more choice.

"The project is really good and needs to be supported. The issue of people living to a great age is going to define the century. And we need to find ways of supporting them and their families as we grow old together!" (Kate, Family Member)

Some comments on the question whether people would like to continue using the technology were:

"Given a fair wind yes, the expansion would be that everyone would use it. But we we're the only ones putting comments in [...] (Kate)."

"Just to give it a go as anything is better than nothing and it steers itself in the right direction with things like this [...] (participant)."

"It would have been really good if it had worked… I expect the first version of the iPhone was not much cop… [...] (Kate)."

"The response of everyone involved was good, the support from Buddi and the response was good [...] (Kate)."

"The idea is good and I struggle to see how it could be designed differently. The number of times I hit my watch in a day. It is the same for the falls detector, Buddi [...] (Kate)."

6.1.9. Adaptations to the technology

Some reflections on possible adaptations to the tested technology were:

"Mum thought it was a phone but forgot to charge it so it was often dead when we got there. I don't know how you would get around that [...] (Kate)."

"With greater flexibility I think it could. Adding things onto it but it needs to be very flexible rather than rigid tasks. It would be better on a tablet and needs to be responsive rather than didactic. Rather than tick boxes it needs to be … This is what happened… [support people at home] (Kate)."

The Buddi was collected however Ginny called the council directly and ironically we do not know where the Buddi is or who collected it. This also raises consideration given to asset marking and processes to follow on management of hardware, these relatively small, mobile and expensive items must be maintained more closely than other aids or equipment.

6.2. Case study Portugal (Miranda do Corvo)

Laura is a 78 year old lady who has a mobility impairment (using a walking stick), who joined the IntegrAAL project in May 2016.

6.2.1. Background

Laura (fictional name) (78 years), was born in a village four kilometers from the headquarters of the municipality of **Miranda do Corvo**. Her parents had their own home in which they lived with their four children (of which Laura was the oldest). Her father was a timber merchant in a wood transport company, while her mother took care of the kids and household. The entire family practiced subsistence agriculture: they grew corn, potatoes, beans, olive oil and vegetables and also had pigs, chickens and rabbits.

Laura's parents were illiterate, so they made sure that Laura and the other children all went to school at least until the 4th grade (which was not mandatory at the time). Afterwards she went home to help her mother with the household and agricultural tasks. Every Sunday she went to mass, sang in the Chapel' choir and followed catechesis. At the age of fifteen, Laura started selling bread in nearby villages in order to have some money. She also learned how to sew at a seamstress in the village and later on did some 'home sewing' (for her relatives or other people).

During her adolescence Laura did not have much to entertain her and only left the house accompanied by her mother. Laura married at the age of 19 and moved into her husband's house in a village one kilometer away from the county council. She worked as a maid until her first son, Manuel (fictional name), was born. Afterwards she became a housewife, did some sewing, helped at her husband's farm and had two other children: Antonio and José (fictional names). At the age of 29, Laura became a widow. Her husband suffered from chest pain, refused to see a doctor and eventually passed away. This meant that Laura had to raise her three sons (eight, six and four years old) on her own, which she describes as a very difficult time. Laura didn't receive help from her parents or in-laws and could only rely on a neighbor. As Laura was raising her children, she was unable to work to earn money, until she started working on a farm where the owner allowed her to take her children with her. Later on, she also took care of the owner of the farm - a lady who became sick - and did some sewing tasks. Laura's children had to finish their studying after primary school, because she needed their help to earn money to live. After the farm owner passed away, Laura focused on her sewing business.

Currently, Laura lives alone in the same house where she lived with her husband. The house is in good condition but now that she is older there are some architectural barriers. For example, there is a very steep staircase between the street and first floor that Laura struggles to climb. The home is situated in an agricultural zone where people rarely pass.

6.2.2. Medical History

Laura had **hip surgery** on her right hip at the age of 60. Five years later, she also started suffering from arthritis in her left knee and required surgery which she initially refused; eventually at the age of 75 a **knee prosthesis** was placed. Unfortunately, her body rejected the prosthesis and resulted in no flexibility in her lower left limb.

Consequently, she spent a year in a Continuing Care Unit for recovery and afterwards stayed for two months at the home of one of her sons.

6.2.3. Care needs

Since Laura really likes her independence, she moved back home with help of her children, daughters-in-law and grandchildren. But eventually, in April 2015, she arranged **home assistance** to help her **daily** with personal hygiene, getting dressed, grooming, meal delivery, medication preparation and **weekly** cleaning of her house. (Fundação ADFP – Assistência, Desenvolvimento e Formação Profissional). Once a **month**, someone of the home support service visits her to assess her care needs and invites her to go FADFP (Fundação ADFP) to participate in activities.
Laura still manages her own shopping and banking matters and independently goes to the hairdresser by calling a cab. On a regular basis, after lunch Laura goes to a cafe about 200 meters from home to drink a coffee, read the newspaper and talk to some neighbors. At home, she deals with the basic domestic tasks and watches some TV.

6.2.4.Assistive Devices

Since Laura has a mobility impairment, she uses **a walking stick**. Laura has had three falls at home, where she remained for several hours on the floor until the domiciliary support service found her.

6.2.5.Circle of Care

Laura's primary care network consists of her **children; Manuel, António and José,** and her grandchildren. Manuel lives with his wife and son in Madrid, while his daughter lives in Lisbon. Antonio lives in Coimbra with his wife and daughter, his son lives in the same region but doesn't live at home anymore. José lives in Miranda do Corvo with his wife and son, his daughter lives in the same region but doesn't live at home anymore either.
Antonio's son is the primary person who visits Laura and who deals with any situations, while José accompanies her to doctor visits. Contact between Laura and her six **grandchildren** has reduced since five of them moved to other towns because of their job, but sometimes she phones them.

6.2.6. Attitude towards technology

Laura **does not use or know technology**. She does **have a mobile phone**, but only uses it to make calls. Laura does not have the internet or a tablet/computer and she does not think she'll be able to use it. The only device she's used to work with is her sewing machine.

6.2.7. Aims (for the client and circle of care) and potential solutions planned

Laura lives on the first floor of a house, which she accesses via a steep staircase, in a very isolated area and in the event of a fall she would only be found by someone of the domiciliary support service.

Laura was receptive to the proposal to use True-Kare. **The fact that she had episodes of falling** made it clear that she could benefit from this type of device. *"I feel more at ease knowing if something happens to me, I can ask for help soon."* Antonio and José were also enthusiastic to try this device. They wanted **to monitor the signals daily** and so encouraged their mother to give it a shot.

The IntegrAAL project proposed the **True-Kare** mobile phone, as it means remote monitoring of Laura is possible when she's away from home and in particular be aware whether she returned home. The True-Kare also has a panic button that allows Laura to call her support network with a single touch. This way Laura feels safe (because she knows that she has an always accessible communication device) and her family can observe the signals on a regular basis (observing Laura's daily routine). The system also allows the user to see if the phone is properly charged, ensuring 24-hour monitoring.

6.2.8. Intervention and impact

The fact that **Laura** was familiar with the use of a mobile phone helped to become familiar with the True-Kare system. For her it was rather a transition from a normal mobile phone to one with a panic button. However, there were some false alarms due to the fact that she pressed the button inadvertently. But this did nont discourage her to continue its use; on the contrary Laura noticed how everyone contacted her to know if she was okay.

She followed the advice that was given to her by the researcher, in order to obtain information and construct a behavior pattern during the first try out week. Laura gets up every day around the same time, picks up the phone from the dock station and puts it back, also around the same time, before bedtime. The fact that this routine was in place made the data that were distributed to the support network - about four to six times a day - was relevant and reassuring.

For formal as well as informal caregivers, routine observation became a habit. Laura's (grand) children also used the option to leave notes on the platform.

Formal caregivers were enthusiastic about the platform because this facilitated the routine registration of services provided, information about the older adult and articulation with other caregivers, *"Which is important for the quality of life of the older adult".* With some creativity it was possible to create a registry of important and obligatory data at the level of the HACCP (Hazard Analysis and Critical Control Point) System and registration of occurrences that is obligatory by law. They report they can't imagine returning to registration on paper and would like to continue using the application, because they feel it's much more practical. Formal caregivers didn't seem to have adaptation suggestions concerning the True-Kare because they don't know a lot about existing technology.

Laura has not decided whether she wishes to continue the use of the True-Kare and application. Nevertheless, her children already have expressed their willingness to continue after the pilot phase of the project.

With regards to evaluating the project development, there were major constraints from not having access to funding that prevented them from obtaining to the material/ devices required to put place in the users home; more timely access would have meant more time to support both the users and the informal caregivers.

In terms of the platform development, the ability for informal caregivers to share and access information meant they had a broader experience of the overall network of care (primary and secondary network). When visiting their relative, there could already be notes left of the system for them to access. However, the elderly access

to the technology was limited; although they recognized the value the technology could add to their lives, as long as it did not require input/intervention from them personally. The family themselves have more familiarity using apps, and thus did not prove to have difficulty using the system, although the pilot did not explore this directly.

From health services (GP's) there was definite interest in collaborating to define parameters that allowed formal caregivers to record information important for user and service evaluation; particularly for intervention/changes when an elderly person's situation becomes more severe (including palliative care). This partnership was in the initial phase of development which is intended to continue, which will only be possible with the support of the Nourish platform.

At management level, it was possible to abandon the old system with paper requisitions and so eliminate the excessive use of paper and time spent.

6.2.9. Adaptations to the technology

It wasn't necessary to spend much time on training all users, throughout the pilot. However, the existence of an instruction manual (brochure) would have been helpful. The fact that the application often turned into the English language was the most displeasing aspect of the pilot, to both family members and formal caregivers. Including an entertainment part (with games) within the application for cognitive stimulation would be interesting.

6.3. Case study Belgium (Brussels)

Alexander is a 78-year-old men with Alzheimer's disease, who joined the IntegrAAL project in December 2016.

6.3.1.Background

Alexander (fictional name) (78 years) and his wife Elana (fictional name) (70 years both) grew up in Greece, but never ran into each other. They learned how to read and write at primary school in Greece and both moved to Belgium in early adulthood to work, while their families stayed in Greece. Elana worked as a cleaning lady in Liège together with her aunt; Alexander worked as a labourer in construction.

Alexander and Elana met in Belgium and were married after several months. They bought a modest home in a working-class neighbourhood in Brussels to live in. Elana then worked in a factory until she gave birth to her first daughter, Theresa (fictional name). Two years later her son Zacharias (fictional name) was born and another two years later her second daughter Xenia (fictional name). Elana stopped working to take care of the children, while Alexander worked as asphalt layer (until his retirement).

All three of their children left the family home as young adults, but they all remained in Brussels. Alexander and Elana have five grandchildren between the ages of five and 22. Even though the grandchildren are very busy, they regularly visit Alexander and Elana during the weekends and on special occasions (for example Eastern, which is an important day for the Greek-orthodox believers) the whole family gathers together.

6.3.2.Circle of Care

Alexander's wife, Elana, takes care of the household as well of her husband (for example she has to support him with daily activities). Elana is scared to leave the house and her husband alone, even to go to the supermarket. Until now, Elana and Alexander have lived at home without support from formal caregivers. Their oldest daughter Theresa, lives just around the corner so she visits her parents from time to time; sometimes just to say hello, but also to help with administration (banking operations) and to accompany her parents to the doctor. Of course, the two other children, Zacharias and Xenia, help if necessary.

6.3.3.Medical History

Seven years ago - during their Easter dinner - Theresa noticed a difference in her father's behaviour; he was less involved in the conversations, less present and also seemed a bit disorientated. She mentioned this to her mother and siblings, but they didn't seem alarmed, because at that time his sight and hearing had decreased due to his aging. But three years later, he had a car accident during a holiday with his wife in Greece. This accident was an eye opener for Elana: she felt that something was wrong. Especially since a year later, Alexander started to ask the same questions over and over again. For example, several times a day he wondered what the documents in his wallet (his subway pass, his bankcard etc.) were for. Theresa

contacted a geriatrician at a hospital in Brussels for an appointment. Following this, Alexander received a diagnosis of Alzheimer' disease in June 2015, after which his treatment was started.

Alongside his memory impairment, ten years ago Alexander was also diagnosed and treated (surgery and chemotherapy) for prostate cancer. The first year there was a follow up at the hospital where he was treated, but afterwards a general practitioner was appointed to do the follow up. Although the tumor marker was slightly elevated according to the regular blood samples, the GP wasn't alarmed by this. A couple of years later, the GP retired but didn't transfer the needed documents to another doctor who could take over. As a result, the follow up of Alexander' prostate cancer was accidently stopped. Nine months ago they went to the hospital where Alexander gets treated for his Alzheimer' disease, and a generalized cancer of the prostate was discovered. All the glands are invaded and all organs show metastases. A hormonal therapy was re-started, aimed at slowing down the cancer and reducing possible complaints. Currently, Alexander doesn't really 'suffer' impact from this cancer.

Both diseases, the Alzheimer's disease and the advanced prostate cancer with metastases in several parts of his body, cause problems (memory loss, difficulties in orientation and the intention to sleep a lot). Elana and her daughter Theresa are very concerned about which of the two diseases will evolve the fastest, and what consequences this will have on symptom control, disease management and care needs.

6.3.4. Care needs

Beside the medical treatment that was prescribed and the checkups (for both Alzheimer' disease and the prostate cancer), the geriatrician also encouraged the family to keep Alexander daily active. Since Alexander used to go outside a lot and walk around in the neighbourhood (for example, to buy cigarettes) the family wanted to maintain this habit. As Alexander became more disorientated, however, Elana and Theresa feared that he would get lost; a fear that was reinforced by a family story. One time, Alexander's father, who lived in Greece and also suffered from dementia, went for a walk and got lost. The family only found him after a long search, and found he had died of deprivation.

6.3.5. Assistive Devices

Until the IntegrAAL project, Alexander didn't use any assistive device, except for his mobile phone (see text below).

6.3.6. Attitude towards technology

Alexander and Elana are used to the fixed line at home and they also both have a mobile phone (but not a smartphone) to make and receive calls when they go outside. Alexander still can answer the phone at home, but doesn't know how to make calls anymore. Also, he has lost his previous limited knowledge of how to use his mobile phone (for example, pressing the answer button) due to his dementia. Alexander and Elana were not familiar with the internet or other recent technologies before the IntegrAAL project.

Theresa, their daughter, uses more modern technology: she has a smartphone and a PC with internet connection at home. She uses this technology to communicate by email, use social media, look for information, do bank transactions and shop online.

6.3.7. Aims (for the client and circle of care) and potential solutions planned

The geriatrician, who provides the follow up for Alexander' Alzheimer' disease, proposed to the family to participate in the IntegrAAL study using the True-Kare phone, because this could offer the possibility to track him if necessary (if they wanted to know or if Alexander used the alarm button). Theresa and Elana were willing to give this a chance, as they wanted Alexander to continue to be able to go outside; both because it was important to do physical activity and because he enjoyed doing so.

Elana and family were not as keen to use the IntergrAAL app. This is because Elana coordinates the majority of her husband's activities and no formal carers are involved. Elana and family do not encounter any communication problems, so prefer how they are used to communicating (via the home phone, text messages or meeting at home). The researchers of the Brussels pilot nevertheless explained the IntegrAAL app as a means of clearer communication and access to a timeline of activities. The family were still not convinced the IntegrAAL app would improve the communication

within the circle of care, so they decided not to use the app for communication. They were, however, willing to explore the app as a platform to see the integrated signals of the True-Kare device.

6.3.8. Intervention and impact

Considering, as aforementioned, the families fear that Alexander would get lost during his walk, the mobile phone with GPS-localization (True-Kare) seemed an appropriate device to try. So the information regarding the localization mechanism of the True-Kare phone and its use and integration of the True Kare signals into the IntegrAAL app was provided.

Unfortunately, by the time the researchers of the Brussels pilot installed the IntegrAAL app and the True-Kare phone (December 2016), there wasn't yet an integration of both technologies as promised. The only integrated signal from the phone into the app was whether Alexander left the house or entered, but no specific information about where exactly he was outside. This was disappointing, since the family joined the project because they wanted to try out this localisation mechanism. Also, the information that was provided on the app was unnecessary (and not what was promised); Elana always knows if Alexander is at home or not since she's always around. A delay of getting the full integration ready in the following days, turned into weeks, months and eventually no integration was realised by the end of the pilot deadline.

Since a localisation via the IntegrAAL app wasn't possible, the family got introduced to the True-Kare web page (the provider of the GPS-phone) by which they could locate Alexander. Even though this worked, Theresa felt that this access was not user friendly. Opening the website in a browser on her smartphone was unclear and difficult, so she always needed to use her PC. This was time consuming (to start up) and only accessible at her home, which is contradictory to the result she was expecting: quick, easy and accessible wherever and whenever she needs it; particularly since a disappearance is a stressful event.

During the testing period, it became clear that Alexander's ability and willingness to use the simple True-Kare mobile phone decreased quickly, or in fact was never present. This was the same with phoning someone, picking up the phone or using

the alarm button. Even though Theresa and Elana explained it to him several times, the use of the phone seemed too difficult for Alexander to remember. Also, Alexander was a bit resistant to it, since he didn't understand the goal of the phone and the overall purpose of the project. Another problem, not technical of nature, was the fact that Alexander didn't always take the GPS-phone with him when he went out for a walk. Sometimes he forgot. And even though his wife and daughter reminded him regularly, they also forgot it from time to time. Zacharias and Xenia weren't keen to try the app nor the phone. So the only real participants were actually Elana and Theresa. After the final follow up visit, Theresa and Elena decided to continue using the GPS locator for the time the contract gets paid by the project (about one year). Once the contract is ended they aren't willing to pay the monthly fee themselves. For Elana, who wasn't familiar with internet, websites or applications, it was too difficult to use the app herself, even if it would have been useful. Theresa is of the opinion that technology can help people with the medical condition as her father to stay longer at home, but she suggested some changes that would improve the concept as it is now.

6.3.9.Adaptations to the technology

According to Theresa, the phone should only have one button. The same button to answer the phone (if an informal caregiver is worried) as to phone (if the older adult himself is worried). The phone should be simplified, in accordance with the 'skills' of someone with dementia. Theresa liked the cascade system, automatically contacting another informal caregiver if the previous one did not answer. However, she thinks it would be more useful if the phone could recognise who is closest by to the older adult and autonomously compose the cascade list based on the localisation (and availability) of the informal caregivers. Elana also suggested an adaptation. For her, accessing the app via the use of speech technology could possibly be a solution.

7. Other experiences

Alongside the findings collected through the questionnaires and case studies, project staff members also noted additional elements to be taken into account to improve the existing technology.

7.1. Observations in recruitment of participants

7.1.1. General experiences

In the UK, the project staff members worked with the care provider, Tricuro, to access older adults and formal and informal carers through their reablement service. In Portugal, formal carers and older adults were recruited through ADFP, partner of the IntegrAAL project. They experienced difficulties to recruit the informal carers. Most older adults live alone and isolated. Although they have a family, they have their jobs and / or live far away, so they do not have much time to spend with their loved ones.

In Belgium, the situation was different due to the specificity of Belgian health system.

The Belgian health system is based on the principles of equal access and freedom of choice, with a Bismarckian-type of compulsory national health insurance, which covers the whole population and has a very broad benefits package. Compulsory health insurance is combined with a private system of health care delivery, based on independent medical practice, free choice of physician and predominantly fee-for-service payment[1].

[1] Corens, D. (2007). Belgium Health system review. Health Systems in Transition. *European Observatory on Health Systems and Policies 9*(2), 1-194.

In Belgium, there are no care commissioners who employ formal carers. Instead, formal carers in domiciliary care can be independent (e.g. one physiotherapist), work in a group practice (e.g. four general practitioners) or work in larger specialised domiciliary care organisations (e.g. for domiciliary nursing). The older adult chooses freely all formal carers (GP, specialists, nurses, other domiciliary services), which results in a completely different circle of care. With regard to participation in the IntegrAAL project, if one formal carer wanted to participate, it wasn't certain that the other formal carers wanted to participate. The researchers had to convince, inform and instruct each formal carer separately, which was very time consuming. This was also reflected in the UK pilot, where the recruitment of the circle of care outside of Tricuro, was very time consuming.

For the Belgian pilot, different recruitment strategies were applied. The domiciliary nursing care company that collaborated for the needs analysis wanted to participate within the pilot phase of the project, but as the start date was postponed month after month, they decided to stop the collaboration. The service centre where three focus groups were held for the needs analysis wanted to participate to the pilot in two ways. First, as an informal care community watch for older adults visiting the centre and second as a formal carer; the centre also delivered some services at home (meals, cleaning). Different older adults who could benefit from the project were selected by the coordinator, however they declined to participate. Since this service centre was situated in a socially disadvantaged neighbourhood, some people wanted to participate for the wrong reasons (e.g. get a smartphone or free internet) or didn't feel able to participate (e.g. were ashamed to receive any visitors at their modest homes). A third way to recruit was via the ambulatory geriatric department of two hospitals in Brussels. Several patients were referred by the geriatrist and two older adults were included in the pilot. One independent physiotherapist was contacted but he didn't see the advantage of the project for himself, compared to the way he was taking care of his patients now. A large domiciliary care company (nursing, care, household) didn't want to

participate because they already participated within other ICT projects that were very time consuming. The work pressure already present with taking care of patients and the time investment needed to learn to work with new technology was an argument formulated several times by formal carers to refrain from participation. Recruiting via the community or neighbourhood wasn't possible, for the simple reason that Brussels is a major capital city without a tight social community fabric. One older adult was recruited through the researchers own network.

7.1.2.E-health policy of the Belgian federal government

Another major problem in recruiting formal carers within the Brussels pilot was the missing link between the IntegrAAL technology and the E-health policy of the federal government in Belgium. This concerns among other things the electronic data-exchange of the Belgian health care system. Belgian formal domiciliary healthcare workers have to report their activities monthly; i.e. doctor's prescriptions, assessments that determine the degree of reimbursement of care for the patient, and so on. To do this, they already use a digital patient record form that is connected to the E-health platform. The necessary data is automatically transferred. New software packages for the management of patient health records can be licenced by the federal Belgian government if they meet the ICT related standards. The government gives a registration number and publishes it on their website. This registration procedure takes several months. Currently, 19 patient record forms for nurses are registered[2].

For this reason, the IntegrAAL platform as a digital patient record form for formal carers was not tested in Belgium during the pilot. All data input in the

[2] Federal Government Belgium. (2017). Ehealth: Registratie van medische software pakketten. Retrieved from https://www.ehealth.fgov.be/nl/ehealth-de-praktijk/registratie-van-de-medische-softwarepakketten

app would need to be copied at the end of each month and this proved too time consuming for the formal carers we contacted. The Belgian E-health policy was explained by project partner Huis voor Gezondheid to the consortium at the consortium meeting in September 2015 held in Coimbra.

7.1.3. Difficulties specific to older adults and their circle of care in the three pilot regions

A lack of familiarity with technology and technological skills was observed across the three pilots. Some older adults refused to participate since they weren't keen on (or afraid of) getting to know how to work with a smartphone or tablet. Because it's something they don't know (and they feel comfortable with the things they do know) or because they feel too old to learn. But some of them also just have misconceptions about technology, for example the belief that once an internet connection is installed, it will be installed forever and you'll receive all kind of undesirable messages.

Not all informal carers of participating older adults use a smartphone. Often the informal carers are already retired themselves, have limited technological experiences and rely on their grandchildren for technological support and help. Learning to work with the hardware proved to be a significant barrier to uptake, as the need and motivation to use the IntegrAAL app has to be very prominent for any carer to learn to work with new technology. Technology seems to be a very low priority for most people who are caring for a loved one. Families are often entrenched in unsustainable solutions to current problems, which means the investment of time and energy required to set up the new technology is not always possible. Some formal caregivers also did not feel confident with the technology, and felt that one training session was not enough to start using the technology confidently.

Many older adults did not fit the inclusion criteria (e.g. hospitalization for a certain period or only receiving help from an informal caregiver but not from a formal caregiver). This resulted in changes to the criteria, but without significant change to the number of participants. Loneliness and poverty are not uncommon across the three regions . Therefore, a lot of people we met

were only interested to hear what we had to say about the project because they wanted to talk with someone or because they were interested in (temporary) free internet or devices.

The UK project staff members also mentioned that the IntegrAAL platform is only useful if everyone in the circle of care is engaged. If one party is not engaged, the effectiveness and efficiency of the app is disproportionately affected. It is difficult to engage everyone within the circle of care due to conflicting priorities.

7.2. Observations of the IntegrAAL technology in the three pilot regions

A key limitation expressed in all regions, was that the assistive devices were not integrated to the timeline. Therefore, there was very little to offer to informal carers, families, who would be the only people inputting details into the app. This did not present an issue for the formal carers as they could share organisational information within the professional group.

In the UK and Portugal, the biggest impact was the app behaviour in low signal areas. Although the app works well offline, in areas of low signal, the app starts to work very slowly as it is constantly attempting to make a connection. This led to user frustration, very slow loading and at times loss of information. This presented a significant barrier to the progress of the project and meant that some staff had to write up notes on the app at home in their own time.

In addition, Portugal and the UK experienced network issues relating to the GPS-enabled assistive devices (i.e. True Kare and Buddi). In the urban region of Brussels there were no connectivity problems.

Three assistive devices were originally selected for the pilots, however only one of them was partially integrated from the user's perspective. Integration of the devices proved to require more resources than expected and numerous technological issues were faced. A detailed explanation is provided in the DL

3.1 System Design report. This has consequently limited the way technology could help a wide range of older adults with their own care needs. For example, in the UK many participants had a Careline button. As this was not integrated, the information of the usage was not available to the circle of care or the project. The devices chosen for the project also did not always function in the appropriate way. For example, the Buddi GPS locator was replaced by the True Kare phone during the data collection period in Portugal and Belgium.

The configuration of the app by the pilot leads in all regions was more challenging and time consuming that anticipated. This identified that their needs to be clarity within care providers on who is responsible for this task (see DL 4.3 Skills Evaluation and Plan). As there are no formal care manager roles in the Belgian context, there would be no clear line of responsibility for this task.

The app was intended to be made available in four languages (English, Portuguese, Dutch and French), for which the project staff members of the consortium provided the translation. However, insufficient resources were available to reach the quality and quantity of translation required to be accessible. For instance, in the questionnaires of the French version all accents on letters were omitted due to a conversion error what made it almost impossible to understand the questions. This was a problem for both the Belgian and Portuguese pilot, however this was amplified in the Brussels context where there are two languages.

Personal logins were often corrupted or forgotten and although a forgotten password option was available, participants did not have skills with technology to reset their password. This added pressure to project staff, as it required personal/phone support to clients and carers to reset passwords. It also meant that participants did not use the app for long periods of time as they could not access it.

For the UK pilot a positive response to the concept of the project was consistently reported. Some participants had difficulty understanding that it

was a research project, and expected a finalised working product with fully integrated devices, which was not the case. Proactive families could see the benefits of the technology, but the technology and supporting culture are not yet mature or reliable enough to sustain a vulnerable person.

7.3. Other observations

Using technology requires a change in routine and systems from all parties involved, and this adaptation in behaviour can be difficult. Similarly, some of the devices require too much user input. For example, if an older person forgets to take the True-Kare phone with them or forgets to charge the battery of the phone or accidently turns the device off, he would not be able to be localised if necessary. A device that requires a vulnerable person to change their behaviour does not support their needs, and would not be sustainable. Even when we ask an older person to substitute an existing mobile phone by another that provides assistive functions, the person refuses or avoids using it. It was observed in two cases in Portugal that the person becomes stressed and very concerned. In once case, the person thought that the phone was different from the usage perspective (even showing that the phones were exactly the same I terms of operation). On the other case, the person was afraid of dropping the new equipment and eventually being requested to pay it back.

This would be similar with other members of the community and local businesses involved, who wish to support vulnerable people. They would require simplicity in order to participate, and user input would need to be limited.

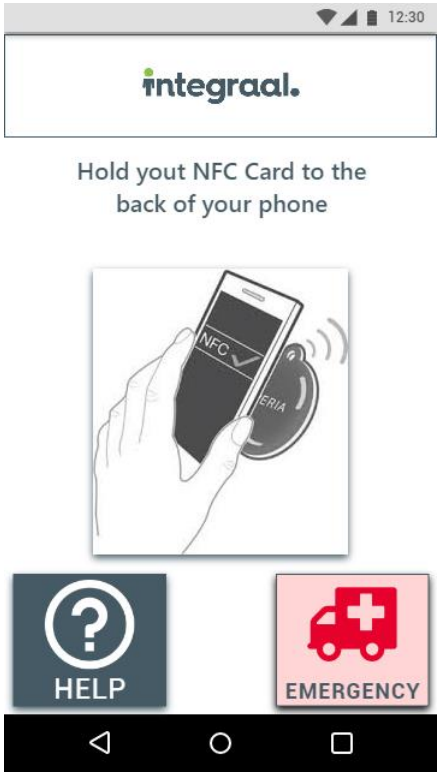
7.4. Third party development of an app by graduating bachelor students in applied computer science

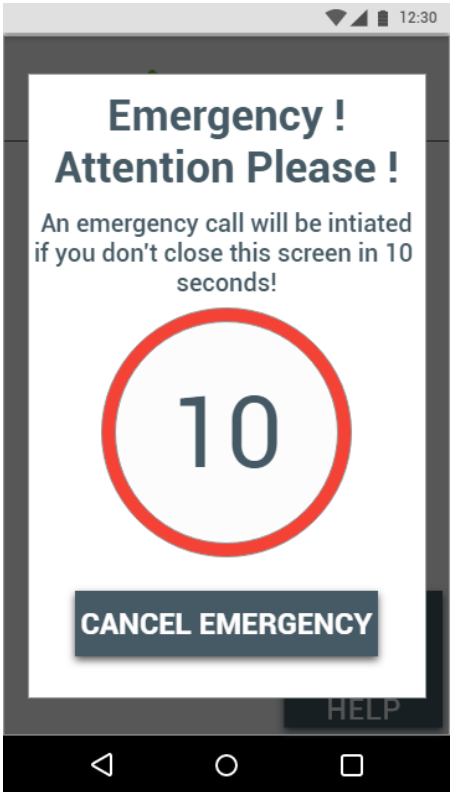
It was specified in the proposal that an opportunity would be provided to Odisee's applied computer science students to develop a related app to

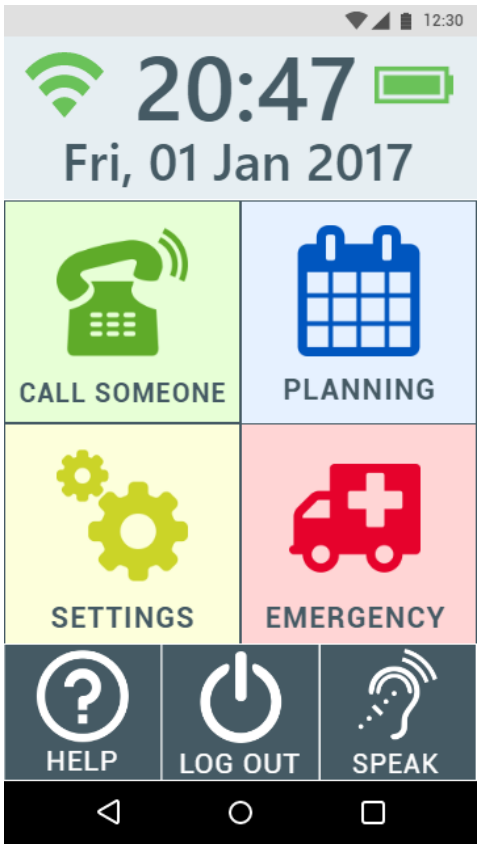
demonstrate how a third party could develop and integrate applications with the IntegrAAL platform. Two students took advantage of this opportunity during a three months internship to perform their final thesis as part of the bachelor degree studies in applied computer science (see appendix G.1-2).

The Belgian project staff members felt that the older adult was too little involved in his own care because only the formal and informal carer use the IntegrAAL platform at the moment. Therefore, the objective for the app was real participation of the older adult if they wish to, by using the IntegrAAL app adapted to their skills and limitations. This would be as a means of supporting self-management and coordination of their own care, an overall goal of the project.

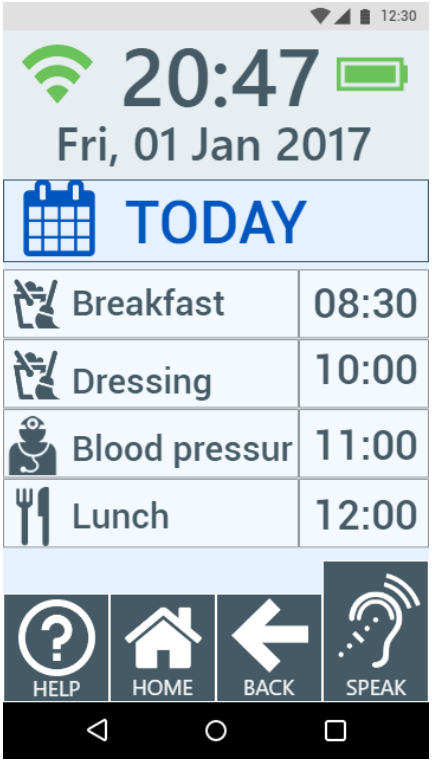
The two students consulted the Belgian project partners regularly throughout the period of development. They have built an application that combines speech to give orders and some big buttons on the smartphone screen to navigate through screens. The functionalities included are: seeing and adapting their own timeline, communication with informal carers by speech and an alarm function. To activate the phone, an NFC tag is used.

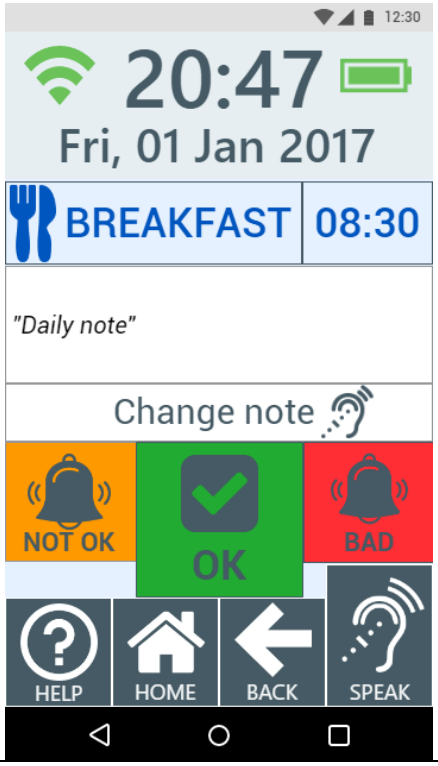





12:30
20:47
Fri, 01 Jan 2017
CALL SOMEONE
PLANNING
SETTINGS
EMERGENCY
HELP
LOG OUT
SPEAK


12:30
20:47
Fri, 01 Jan 2017
PLANNING
SHOW PLANNING
ADD ACTIVITY
HELP
HOME
BACK
SPEAK


12:30
20:47
Fri, 01 Jan 2017
TODAY
Breakfast 08:30
Dressing 10:00
Blood pressur 11:00
Lunch 12:00
HELP
HOME
BACK
SPEAK


12:30
20:47
Fri, 01 Jan 2017
BREAKFAST 08:30
"Daily note"
Change note
NOT OK
OK
BAD
HELP
HOME
BACK
SPEAK

To link the app to the IntegrAAL platform, the students encountered two major limitations in using the existing API. Documentation was not detailed enough and the test interface did not work. Regarding the documentation of the API: Not every available function was documented. They did not know which type the parameters had to have. They were unable to know in advance what the structure of the API response would be and could not handle it automatically. Finally, the answers were not provided in a format they found helpful. With regards to the interface, they were given access to a test interface, which unfortunately did not function correctly. The existing features were listed there, but didn't work when they wanted to use it. They had to open a command line for each function (one hundred) themselves and find for all possible input fields a combination that would work and then interpret the answer. The two students contacted Nourish Care, but due to timing restraints as regards to their bachelor theses, the students decided to build their own API (light version of the existing one with only the features required).

8. Discussion

8.1. Characteristics of the three test regions

The three regions were chosen to measure the research question across different demographics, geography and culture.

A key difference observed was related to internet connectivity. In UK and Portugal, characterised by more rural locations, this proved a real challenge, cause frustration to users and identified needed developments to the app (see DL 5.2 Business Plan). Brussels, being a capital city, experienced no such connectivity problems.

Another difference between the different regions was the structure and role of social community network. Within Dorset, the local community were open and willing to be involved in supporting vulnerable people to remain independent. This is similar to Miranda do Corvo, where the social infrastructure is well developed and supported by locally elected authorities. However, this dynamic is not as apparent in Brussels. The government has created some initiatives to support community centres, which offer affordable meals, activities and services, in an attempt to support the Brussels vulnerable population. Despite these differences in approach, there continues to be a significant need for support of the vulnerable older adult across all regions.

A substantial part of the pilot populations, across all regions, live in a below average socio-economic situation. This generation of older adults tend to have received less education, and have had less experience in the use of modern technology. The older generation also tends to be more cautious and therefore less inclined to engage with unproven concepts.

Overall, despite this caution older adults in the Dorset were enthusiastic about the concept and potential benefits of IntegrAAL. However, while many believed it could help other people to live independently, they could not always relate it to their own situation. The community is also very supportive and open about the project, however concrete development and

implementation needs to be improved. In Brussels, the overall tone was less positive. Formal carers couldn't use the IntegrAAL platform as a patient record form because it wasn't integrated with the Belgian e-health platform of the federal government. Informal carers were not very motivated to use the app because the devices weren't integrated. In Miranda do Corvo, it was experienced that older adults wanted to participate but were prevented by limited available funds; if there was no cost involved, older adults and their families would engage fully.

A key observation noted, across all pilots, was that the project didn't seem to be designed for all kind of older adults; interestingly the most vulnerable, isolated adults seemed to have the least access to the project. Loneliness and poverty are not uncommon across the three regions.

8.2. Recommendations for further development of the IntegrAAL technology

Throughout the project it became clear that the development of the technology together with the integration of the chosen devices was not as simple as had been anticipated. The technical challenges involved in deploying and integrating "off the shelf" devises as well as collecting information from a variety of formal and informal carers was a major conclusion from the study. Without a stable intervention that could be tested over a certain period of time the planned effect study of the technology became challenging.

The effectiveness of the deployment of the technology varies across the three pilot regions. It proved particularly difficult in Brussels where configuring the app for the specific situation of each older adult and the circle of care proved problematic. The impact of these technological difficulties proved all the more difficult due to reliance on support from partners in other countries. Despite the best endeavours of partners providing this support in hindsight these difficulties might have been eased had a technological company based in Brussels been included within the project team.

The three case studies illustrated that health care problems and care needs of an older adult can change very quickly. The technology has to be adapted all the time (new services, new formal carers, change of devices). A care coordinator taking the time to configure all these changes is necessary. For all regions, it is not currently clear who could fulfil this task. A possible solution within the UK and Portugal, would be a close collaboration between care providers and the software provider. In Belgium, the care environment would require a different arrangement.

To be consistent and sustainable, technology must be designed for older adults, taking into account their limitations and making use of skills that they already master. Similarly, informal carers are often themselves of advanced age and may lack the skills required for modern technology. The assumptions that participants understand and can use the 'intuitive' software and hardware is misplaced (see DL 4.3 and 5.3). The third party research app may provide an initiative to address this.

Continuity in support will be essential for successful implementation. During the pilot phase, for instance, some participants were expected to adapt to weaknesses in technology design and implementation and this created confusion, disengagement with the project or bad habits.

The asset management of small mobile and expensive items, such as a smartphone or a tablet device, must be maintained more closely than other aids. In the Dorset pilot, a removal request of a Buddi device was collected, but it is not clear who collected the device or where it is currently.

The time required to onboard every member of the circle of care, assess the level of need, configure the app, installing the devices and provide training to each participant is significantly underestimated. Within the context of the project, the staff members were able to complete these tasks, but there is a question of who will be able to fulfil this role should the product be brought to the market.

9. Conclusion

The project proved that the app and related technologies provide the opportunity to redesign services and support provided to older adults in need. However, this will prove especially useful to the next generation. There is a need to further develop the app and also the integration with other devices. There is also a skills training issue which prevents the app from achieving its potential, and allows the system to be person-centred as designed.

A problem encountered was the immaturity of external devices. They tend to be standalone and are not designed for integrated solutions. One of the objectives was to integrated the existing solutions, but this proved difficult in the context of limited continuity/ availability in market solutions. It is not a technology problem itself, but the way the technology is being implemented. If the devices are not integrated, the app relies heavily on single user input.

The concept of the IntegrAAL design is promising for its participants but is currently of more interest to care providing organisations that operate in the socio technical environments such as exist in the UK and Portugal. The app offers the potential to reduce costs and improve resource management in care provision and operational staff are empowered to direct care; allow them to provide a better quality of care.

There is a need to really understand the context of the specific health care culture you are working in – therefore it is not possible to make a universal product, it needs to be flexible enough to be applicable to local environments – driven by statutory services but not controlled by them. Sensitive translation to included the nuances of local languages are needed to ensure acceptance by local communities. The app and devices were not applicable to everyone. The societal application of the IntegrAAL platform is also more useful in areas across Europe that demonstrate established community network such as in parts of the UK rather than in the urban region of Brussels.

Specific features that should be improved in order to bring the product to the market are the product timeline sharing, level of access sharing, phone signal

management, better API for future integration, and care plan and timeline templates for specific areas, more user friendly and accessible for the older adults. The app would benefit from further development to meet the need from formal carers to demonstrate the improvement over traditional paper methods. The further development that might be required to extend the commercial application of the product is described in DL 5.2 Business Plan.

10. List of appendices

Appendix A: power analysis

Appendix B: Questionnaires

B.1 UK questionnaires

B.1.1 Older adult

B.1.1.1 Wellbeing WHOQOL

B.1.1.2 Wellbeing ASCOT

B.1.1.3 Other questionnaires

B.1.2 Informal carer

B.1.3 Formal carer

B.1.4 Exit interview

B.2 Dutch questionnaires

B.2.1 Older adult

B.2.1.1 Wellbeing WHOQOL

B.2.1.2 Other questionnaires

B.2.2 Informal carer

B.2.3 Formal carer

B.2.4 Exit interview

B.3 French questionnaires

B.3.1 Older adult

B.3.1.1 Wellbeing WHOQOL

B.3.1.2 Other questionnaires

B.3.2 Informal carer

11. Partner logos