DL 2.1

User Group Set Up Report

WP2 – Needs Analysis

Version 1.3

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# Document Information

## Purpose of Document

This document contains the report of setting up User Groups for the IntegrAAL project.

## Organisation Responsible

Dorset County Council is the organisation responsible for this deliverable. Huis voor Gezondheid and AlertiSugere Lda are contributors and reviewers of the document.

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# Project Summary

## Background

The internet revolution and growth in mobile- and micro-technologies has generated changes in 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 [[1](#Oli14)], 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.

## Purpose of IntegrAAL

Project IntegrAAL (Integration of AAL (Active Assistive Living) Components for Innovative Care Pathways) aims 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.

## Study design

The first phase of the IntegrAAL project will focus on research, whereby through structured focus groups and one-to-one interviews information will be gathered in order to understand, define and design care pathways and technological innovations to serve them. In the second phase, the technology will be tested by the use of structured surveys, health outcome data collection and in-depth interviews of both subjects and their carers. Comparisons will be made over time as well as against a control group.

## Expected outcomes of IntegrAAL

IntegrAAL will serve as an exploratory project with expectation of developing a marketable output for improved care of the elderly, as well as the foundation for future research on a larger scale.

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# Introduction

## User Groups

This document describes the process of engaging with the Primary (Service Users), Secondary (Family and Care Providers) and Tertiary (Care Commissioners) User Groups within Dorset (UK), Brussels (BE) and Coimbra (POR) the three territories covered by the IntegrAAL Project. Discussions with these groups will define the Needs Analysis Report (DL2.2) which in turn will inform the later Pilot Design and Impact Monitoring phases.

## Glossary

|  |  |
| --- | --- |
| AAL | Active Assistive Living |
| IntegrAAL | Project acronym for Integration of AAL (Active Assistive Living) Components for Innovative Care Pathways |
| DCC | Dorset County Council (UK) |
| NHS | National Health Service (UK) |
| GP | General Practitioner/Doctor (UK) |
| Tricuro | Dorset wide Local Authority Trading Company (LATC) |
| LATC | Company wholly owned by a Local Authority but permitted to act as a business and generate a profit from the services it provides. (UK) |
| Local Authority | Local Government body carrying out statutory duties. (UK) |
| CCG | Clinical Commissioning Group (NHS Commissioning) |
| HvG | Huis voor Gezondheid (BE) |
| LDC De Harmonie | Lokaal Dienstencentrum (BE) – Community Centre |
| Arcus | Brussels based home nursing service (BE) |
| Zorg+ | Project funded by the federal government that organises care for the dependent elderly living at home (BE) |
| ADFP | Associação de Desenvolvimento e Formação Profissional |
| Caritas | Cáritas Diocesana de Coimbra |
| EnferSAD | Enfermeiros em Serviço de Apoio Domiciliário |
| CS-MC | Centro de Saúde de Miranda do Corvo |
| CS-SMB | Centro de Saúde de São Martinho do Bispo |

# Background and Rationale

## Primary and Secondary User groups (UK)

### Engagement

Dorset County Council (DCC) offers direct assessment services to older people in the community and those who care for them and provides support services through a mixture of commissioned provider services. DCC also have a duty to promote wellbeing and prevention through information and advice services. In order to carry out these duties effectively DCC are required to engage with Service Users and Carers and the wider public to take into consideration their views of what they provide. DCC maintains a confidential list of Service Users and Carers who are happy to be contacted to support such work as well as publicising through other channels such as the media, online, surveys and open public forums.

Historically and for many reasons including caring duties, transport and other commitments it is challenging to engage large numbers of Service Users and Carers to contribute to these consultations. However those who are able to engage bring rich experiences to draw and learn from and this was our experience.

This next section of the report covers the work to set up and the learning then applied to the focus groups as set out in the initial Draft Research Plan ([appendix 2a](#_Appendices)) an updated plan is included in [appendix 2b](#_Appendices).

#### 5.1.1.1Location

The location for the first focus group was in a central and known location in Dorchester, The History Centre, in anticipation of 18 to 20 attendees. There was ample parking and public transport stops, access was good and it was located in a large room on the ground floor. The room was set up cabaret style with a projector and screen to allow discussion of information in small groups. Tea, coffee and pastries were provided and a professional photographs were taken to illustrate the activity and for future use in promoting the project.

#### 5.1.1.2 Learning

Learning from the first focus group was applied to the second focus group, fewer attendees were expected and the venue moved to a smaller community setting that reflected the type of business that could become part of the circle of care. The Old Tea House in Dorchester is popular with local elderly people; many visit daily and eat a weekly dinner there. The owner knows many of her customers very well, and the café serves as a key meeting point for this community. The room was small and for our use only, this much smaller space generated greater intimacy and increased sharing of experiences, giving a much more coherent and inclusive environment for discussion.

### Invitations

An invitation was drafted and then reviewed and amended by the DCC Community Engagement Officers who then sent these out. Over 150 invitations ([appendix 1a](#_Appendices)) were sent or posted out to individuals to take part in the first focus group, invitations were also emailed to GP surgeries, Carers Groups and operational teams to encourage individual Service users and Carers to attend along with clarity about help with transport costs.

#### 5.1.2.1 Learning

The invitation for the second focus group was updated and sent to a much more specific target audience of individuals for the second focus group. This included those who were unable to attend the first group and those who had been identified directly through other channels, specifically through the owner of the café who invited some of her regular customers to attend the focus group.

### Attendance

Given the lack of formal response to the invitations, consideration was given to cancelling the first group, however the DCC Community Engagement officer advised us to continue and 4 Service Users attended. The second group attracted a further 6 attendees and 2 professional members of staff not directly involved with the project.

#### 5.1.3.1 Learning

The experience of the DCC engagement officer was key to the first focus group going ahead. Her understanding of the nature of running community focus groups helped us understand that people just turn up on the day with no confirmations and that it would be very difficult to communicate cancellation of the group. This could lead to people making a wasted journey, incurring costs and reflect poorly on the project and the organisation. This was good advice and the first focus group provided a crucial NHS contact in the form of a local GP surgery.

The second focus group was well attended; the interest generated from the first focus group had raised the profile of the project and learning from the first group was part of the creative process that yielded such rich storytelling from the second focus group.

It also became clear that bringing Service Users who meet project criteria into a group environment would be a challenge. The majority of attendees were Carers, the Service Users who did attend were past Service Users who had accessed support for physical illnesses who were now recovered and living independently in the community. We intend to address this though 1-1 interviews in the homes of the Service Users in the pre pilot phase of the project.

### Structure

The structure ([Appendix 1e](#_Appendices)) was based on previous Occupational Therapy group experiences. Following registration ([Appendix 1c & 1d](#_Appendices)), consent forms ([appendix 1b](#_Appendices)) and refreshments the participants were taken through the project using a PowerPoint presentation ([appendix 1f](#_Appendices)) followed by a group discussion the results of which are recorded in DL2.2 Needs Analysis Report The plan was to allocate a scribe to each table of attendees to capture their discussions. Given the smaller number of attendees all project and public attendees sat together during discussions on both focus groups and this worked really well. The format of the focus group was reused from the previous group.

#### 5.1.4.1 Learning

During the first focus group it became clear that a group led from the front also required the presenter to stop and sit with the group once discussion was started. This deviated from the structure and timings however the structure served its purpose as it was in place to support a group that may be more passive or struggle with the concept of a focus group, to ensure the passing on of information in the initial stages and all statutory requirements (Consent, confidentiality) were met. The aim of the group was to capture views and experiences through discussion and this was successful.

### Other activities with Primary and Secondary User Groups

The opportunity arose to meet informally with a Service User and Carer support group who meet once per month in the target locality. Run by the Alzheimers Society. This group consisted of approximately 10 people, Carers and those that they care for. It was clear that the Carers were experiencing Carer stress and sometimes this was a barrier to discussion. This group were interested to hear about assistive technology and one or 2 carers were very interested in the project and we will be following things up with them in the next phase.

### Learning points to take forward

Some Carers and Service Users who chose to engage with consultation and focus groups may have high levels of stress and it is important to allow time for people to tell their story and feel heard. Following this their experiences and suggestions can be very helpful.

The expectations of group members can be unrealistic as to what problems they want solved and it is important to manage those expectations.

People may remember selectively, it is important to give them some written information to refer back to.

## Tertiary group (UK)

### Engagement

Senior managers in DCC have been kept informed and updated with the project through the Head of Service who is closely associated with the project and feeds in and feeds back at a Senior level and played a significant role in retaining the essential engagement of Tricuro after the formation of the LATC.

A meeting with the senior commissioner gained his strong support and interest for the project and he wishes to be kept involved.

This led to a meeting with a further 2 commissioners to demonstrate the system and introduce the project. This was very well received and a good discussion took place. One of the commissioners has significant management experience in Community Care Provision and is very keen to remain involved. The availability of the experience of this side of the sector is important and inclusion on the project will be invaluable.

From the first focus group contact we were able to attend a GP surgery and present the project to them. Often there is a 12 moth wait for these opportunities and the GPs wished to remain involved with the project. This is a huge achievement in terms of the pilots and the future.

A senior CCG IT Officer present at the meeting has invited the project to present at an event for senior health and social care commissioners and managers in January 2016.

The Managing director of Tricuro attended a project update meeting on 17 December and a presentation and discussion of the work of the project resulted in her full support to the project and wish to remain engaged at a senior level. Some discussion around pilot locality occurred and this is to be confirmed by Tricuro. Discussions with workers unions are also required.

### Going forward

Traditional ways of working will be challenged and the engagement work done so far has had a good impact on gaining the interest and support of senior commissioners. The next phase will include updating Unions and Senior Managers and Commissioners and to maintain interest and presence with regular updates presented in a way which is informative but not onerous. To ensure engagement at this level continues and creates the opportunities for the project to link in with the services that will benefit from the project and its outcomes.

## Primary User groups (BE)

## 5.3.1. Engagement

Huis voor Gezondheid (HvG) is a networking organisation that stimulates collaboration and networking between healthcare professionals and organisations. HvG aims to improve the access to and the quality of healthcare. As HvG is not an end user organisation, collaboration was sought with organisations that have direct contact with elderly patients and clients.

Arcus is a home nursing service active in Brussels. Arcus recruited patients to participate in the focus groups.

LDC De Harmonie is a community centre located in the centre of Brussels, offering meals, activities, courses and other services to their elderly visitors. LDC De Harmonie also recruited clients.

## 5.3.2. Location

The first focus group was held in the HvG offices, located centrally in Brussels, accessible by car and public transport. The meeting room was located on the first floor of the office building, accessible by a lift. A projector and screen was available to allow discussion. A light lunch and drinks were provided.

A second, third and fourth focus group was organised in LDC De Harmonie, a community centre for the elderly located centrally in Brussels. The building where the LDC is located consists of one large room with a dozen tables where visitors have meals, play games and do other activities. There is a small office where the coordinator works and one other small meeting room, where courses take place. The focus groups were held in this meeting room and at one of the tables in the main room. Each focus group had a break where coffee and pastries were offered.

5.3.2.1. Learning

Although its proximity to public transport, invitees found the HvG offices difficult to reach. The attendees were driven to the venue by the carer from Arcus. Others wanted to join but were unable to travel to the venue because they felt insecure or were physically unable to. Those people were interviewed at their homes afterwards. It was decided to hold future focus groups in accessible places elderly people know and regularly visit, such as the LDC.

## 5.3.3. Recruitment

An invitation (Appendix 3a) in Dutch and French was drafted and sent to the coordinators of Arcus and LDC De Harmonie.

The coordinator of Arcus personally contacted patients who fit the inclusion criteria and the invitation was given to provide more information on the concept of the project and the focus group.

Clients from the LDC who fit the criteria were recruited via the coordinator, the teacher of the computer course and the activities manager. The invitation appeared in centre’s newsletter and posters were hung.

5.3.3.1.Learning

The invitation proved to be a useful document providing information to interested people. However a more detailed explication of the project was necessary to have the participants fully grasp the purpose of the focus group and the project.

The recruitment through Arcus was very focused and personal and these participants were well informed of the concept and had the right expectations. Recruitment via the LDC was broad and some participants did not fit the inclusion criteria. It was necessary to explain the concept and method of the focus group meeting and temper expectations. Students of the computer course in the LDC were invited specifically because of their supposed interest in computers and new technologies.

### 5.3.4. Attendance

Because of the difficulty in reaching the venue, only 3 attendees participated in the first focus group. The other 5 people recruited via Arcus were interviewed in their home.

The focus groups in the LDC attracted more participants and it was decided to hold the focus groups over the course of two days. The first focus group consisted of 7 participants while the second focus group attracted 17 participants. As the size of the group on the second day was large, it was split up in two separate groups of 7 and 10, one in Dutch and one in French. Almost all participants were patients or carers. One formal and one informal carer participated in a focus group.

5.3.4.1.Learning

Since the recruitment through Arcus was very focused, it brought together a small group of people. Discussions however were lively and interesting and the attendees actively participated. It proved to be an ideal size for a first focus group. Recruitment through the LDC yielded a lot of interested people who were contacted personally when they visited the centre, who read about it in the newsletter or who participated in the computer course. Keeping in mind the successful small first focus group, it was chosen to split the group up into smaller groups to safeguard open discussion.

### 5.3.5. Structure

The structure (Appendix 3b) of the focus group followed the example of the focus groups that took place in the UK. Following registration, filling out the consent forms (Appendix 3c) and refreshments the participants were given an overview of the project using a PowerPoint presentation (Appendix 3d and 3e) in Dutch and French. This was followed by a group discussion in two parts of about 45 minutes, with a short break in between. The first part consisted of a discussion around the care received, which health problems affect the participants’ daily lives the most, what care services they already receive. The topic of the second part of the discussion was the participants’ view on the use of technology, specifically in healthcare.

The discussions were audio recorded and notes were taken by the project attendees. The participants’ were asked to leave their contacting details if they wanted to stay involved in the project.

The individual interviews followed a similar structure and were also audio recorded.

#### 5.3.5.1. Learning

At the start of the second focus group in the LDC it was clear that the group was too large and needed to be split up. Also, the focus group held the day before was bilingual which resulted in some people not fully understanding the details of what was being discussed. It was obvious to split the group in two focus groups, one in French and one in Dutch. The structure of the presentation was followed and discussions were very active. It was however necessary to have two project attendees present, to lead discussions, write down notes and operate the presentation. The focus groups succeeded in gathering views, sharing opinions and experiences through discussion.

## 5.4 Secondary and Tertiary User Groups (BE)

Since HvG is not an and user organisation, we teamed up with organisations that have direct contact with patients, clients and elderly people in general. Involving Arcus was a logical choice since they have direct contact with their patients and are interested in new innovative technology. To broaden the perspective, the active involvement of LDC De Harmonie was vital. The social workers in the LDC are not trained health care professionals but have a very broad knowledge of the daily lives of elderly people and the challenges they face every day. The coordinator of the LDC as well as the teacher of the computer course are interested in the project and want to stay involved. Lastly, a coordinator of Zorg+ was involved since they have close contact with dependant elderly who fit the inclusion criteria. They were interested in the project and will be involved for further recruitment in the course of the project.

There has been some interest from the Flemish government in the project and they wish to stay informed and to be kept updated of the project’s results.

# Conclusion

The very people we wish to engage with are by the nature of their circumstances often not able to engage with us with our chosen models. Be this Service Users abilities, Carers capacity, or Senior Managers Diaries. This means we must explore different methods of reaching out to them so that their voice can be heard and their views can shape the project. Most challenging so far has proved engagement with the very people at the heart of the project, the Service Users themselves. The project will address this through home visits and 1-1 interviews with Service users at their convenience. It is planned that Service Users identified by Tricuro will be engaged in this way in the pre pilot stage.

Common experiential feedback indicates it is difficult to convey the new ways of working we are exploring in a theoretical and conceptual way, all groups need product demonstration, firm scenarios and case studies in order to gain the understanding required to generate opinion and appropriate feedback.

Engaging end users in Brussels proved to be fairly straightforward. More challenging is involving their formal carers, since they mostly are independent workers and lack time for and interest in these type of projects. Involving informal carers should be easier, and they will have be engaged further.

## Primary, Secondary & Tertiary User groups (PT)

### Engagement

Associação de Desenvolvimento e Formação Profissional (ADFP), is a non-for-profit care provider in the centre interior of Portugal. ADFP provides domiciliary care within the community to an older population, including meal delivery, social interaction, housekeeping and personal hygiene. ADFP is one of the largest organisations in the area, with a strong influence and impact on the community.

As part of the IntegrAAL project, ADFP, is engaging with Service Users, Carers, Public Bodies and the wider public to take into consideration their views on the subject-matter undertaken by this project. ADFP is an end user organisation, so the access to primary and secondary users is facilitated, however, the IntegrAAL project partners would like to broaden the perspectives by listening other organisations views.

Therefore, the project partners decided to start this work by inviting third party organisations directly involved on elderly care, and, on a second stage, organize focus groups internally with ADFP own staff and service users.

The next section of the report covers the work being carried and what has been learned so far.

### Invitations

Among the Portuguese partners, it was possible to identify and contact a group of target organisations in Coimbra’s region.

Meetings have been scheduled by phone and email, agreeing the dates and locations accordingly with the best interest of the invitees. Some of the contacted organisations requested a brief summary of the project in advance. A presentation has been prepared and sent in order to increase their interest.

From the initial list, the following organisations have been contacted and answer positively for a first meeting:

- Cáritas Diocesana de Coimbra (Caritas), is a large national trustee, offering a range of services to the community such home care and domiciliary care. At this stage, Caritas participated on a meeting, bringing a managers and cares. On a second phase, they will recruit services users from their Domiciliary care in Penela, a rural area in the surroundings of Coimbra and Miranda do Corvo.

- Enfermeiros em Serviço de Apoio Domiciliário, EnferSAD, is a private owned company, offering personal care and nursing care. EnferSAD‘s management team, a nurse and a geriatrist have participated in the meetings.

- Centro de Saúde de Miranda do Corvo Secondary (CS-MC), is a local health care centre that covers the village of Miranda do Corvo. Two nurses from the domiciliary care have attended the meetings.

- Finally, Centro de Saúde de São Martinho do Bispo (CS-SMB), another local health care centre, have been also invited, and two nurses and their manager have attended the meetings too.

The first objective of the meetings have been to introduce the IntegrAAL project and gather a first impression from the different kind of caring organisations

The project was very well received and a good discussion took place. Among the people selected there is a lot of experience and in-depth knowledge coming from the field.

The interaction with the selected organisations we will let us find a wide variety of users, (primary, secondary and tertiary), Actually, the group includes a good range of professionals (managers, nurses, doctors, care assistants, geriatrist). The group includes also different management policies (from a trustee, private and public management). It also includes different types of geographies, (deeply rural, to small villages and also the city centre)

### Locations and attendance

The meetings with the external organisations have been hold on each organization facility, except the meeting with the CS-MC. On this case, the two nurses appointed came to ADFP site.

Some individual contacts with primary users from ADFP have ben hold at the ADFP office, benefiting from some service users visiting ADFP office for administrative purposes.

On a later stage, the team will organize meetings with largest groups to present some of the findings in order to discuss how to move forward.

These meeting would be held by ADFP

#### 6.1.3.1 Learnings and conclusions

Given the lack of time from the professionals and some individuals involved, at this stage, the approach of contacting the persons directly and meeting them at their own work place, proved to be very efficient.

The initial presentation that has been sent by email, and later explained in deeper detail at the meeting, helped to set up the group, providing the mind set for discussion and ideas sharing.

From the first round of meetings, our conclusion is that the persons are available and willing to participate and contribute. Still, their expectations are quite different. There are people with high expectation, believing that the ICT based systems can do a lot on this field. This group of people has also strong ideas about what the systems should provide and how they look like. On the other extreme, there is the people that are reluctant on the usage of technology or the ones that think that the organizarions or the elderly cannot afford complex technology.

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# Appendices

Appendix 1

(1a) (1b)  (1c)

(1d) (1e) (1f)

Appendix 2

(2a) (2b) 

**Appendix 3**

(3a) Invitation focus group Brussels

(3b) Agenda focus group Brussels

(3c) Informed consent Brussels

(3d) Presentation focus group Brussels

(3e) Presentation focus group LDC