integraal.

DL2.2

Needs Analysis Report

Prepared under work package 2

Version 1

integraal.

1. Circulation Lists and Classification

Internal Circulation List
All partners
External Circulation List
Public

1.1. Authors and Contributors

Partner	Name	Contribution	Date
1	Nuno Almeida	Author	31/12/2015

1.2. Version History

Version	Date	Description	Author
1	31/12/2015	Reviewed by NCS	N. Almeida

2. Project Summary

2.1. 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], 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) 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.

2.3. 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.

2.4. 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.

3. Table of Contents

4. Introduction

4.1. Rationale

This document is a summary of the findings resulting from focus groups which took place in the UK, Belgium and Portugal during the first year of the project.

4.2. Scope

This document describes the wants and needs of the section of population that took part in IntegrAAL's focus groups. This information was used as the foundation to make informed designed decisions and guide the requirements for the product being developed as part of the project.

4.3. Audience

This document was produced for all participants in the IntegrAAL project, and it creates a common understanding between practitioners, people living with frailty and their families, as well as the design teams, user experience practitioners, and software development teams involved in the project.

4.4. Reference Documents

Reports from user groups in the UK and Belgium presented at project review meetings;

5. Focus Groups

Focus groups took place in Dorchester, Belgium and Miranda do Corvo. The results from these focus groups were presented at several milestone reviews.

5.1. UK Focus Groups

First focus group: 14th of May 2015

- Key outcomes:
    - There is an overall desire to remain independent: people want to avoid care homes and care services for as long as possible.
    - Co-ordination and communication within the circle of care often fails: carers who don't know if the district nurse has been or is planned to come;

- o Acknowledging the importance of non-professional care (e.g. friends, neighbours, family) which may be crucial but not identified and documented;
- o Acknowledging the role of a GP surgery (primary health care) as a perceived hub for coordination of care by families;

Additional insight: *people in old age have the perception that hospital admission may lead to loss of mobility, which may lead to them having to go into a care home.*

Second focus group: 1st of July 2015

- Key outcomes:
  - o Detailed Person Centred care is essential in practice, not just a label: personal preferences can have a significant impact in the effectiveness of the support they receive;
  - o Communication of care support information received from circle of care to formal care givers is essential;
  - o Support for those without English as a first language;
  - o Carers require support to co-ordinate care provision;
  - o Carers require a way to indicate their wellbeing and flag to their group when something isn't right;

Additional insight: *small details have a sizeable impact when communication between families and formal carers fails. The example of carers asking if the person wanted "salt&pepper" combined with an advanced stage of dementia, meant that the person understood they were being asked if they wanted "pepper" – as they only understood the end of the sentence. This led to refusal, which led to food not being seasoned with salt, which led to the person not enjoying the food and not eating as much as they needed to. This led to recurring cases of weight loss and loss of muscle mass. Leaving notes around the house to tell the carer how to ask was not effective as these are ignored.*

5.2. Belgium Focus Groups

Held in July and August 2015

- Key Findings:
  - o Desire to remain independent and to remain living at home
  - o Fear of going to a retirement home, driven by a fear of losing independence

- Patients are satisfied with the care they receive and their care (self care, formal and informal care) is often already well organised
- Reliable informal care is an important reason why patients can stay at home
- Acknowledging the importance of informal carers: family, friends and neighbours
- Not afraid of innovative technology and will accept it if it improves their self and home care
- In order to continue living at home, patients will consider all types of home care, traditional and innovative
- Difficulties with communication between carers and patients, need for a straightforward communication system
- Patients want to be informed and given access to their health records and want to be involved as an equal partner (self-management)
- Patients may already use professional care services and technology driven devices (PAS, smart pill box, …) which allow them to remain independent
- Elderly people often use technology without realizing it (mobile phone, computer…)
- Technology needs to be straightforward and should be adapted to the elderly person using it
- Sharing data is desirable, but some concerns rise about data safety and privacy
- Language barrier possibly leading to lower quality care
- Care organisations may have their own digital records and habits of keeping information
- Elderly are often not familiar with using computers, tablets and smartphones. They might be unwilling to learn using them
- Carers might not have the time to use the tools
- Cost of the tools might be a barrier
- Only desirable for a certain part of the patient population
- Disabilities and physical limitations for using the devices
- Potentially not enough people in circle of care for effective use of the tool
- System should be accessible to the patient's habitual carers

Additional insight: *it is clear that the main barrier to adoption of technology by both older people and carers is the poor user experience offered by existing products.*

5.3. Portugal Focus Groups

Focus groups in Portugal are delayed due to contractual delays.