Deliverable 1.3

D1.3 - Joint need assessment report synthetizing the case finding analyses

Lead Partner:	TU/e
Authors:	Rens Brankaert
Date:	Oct 2016
Revision:	V1.1
Dissemination Level:	PUBLIC

Project Acronym: ENSAFE
Project full title: Elderly-oriented, Network-based Services Aimed at independent liFE
AAL project number: AAL 2014-1-112
With support of:

Content

1 Summary

The ENSAFE project is initiated to look in to the future of supporting elderly by technology and smart services. Currently elderly are motivated to live at their own home for as long as possible, while at the same time the care availability is becoming less. Design and development of coherent technology could play a major role to solve this trend and create a beneficial situation to bridge this gap. To design this technology successful we need to know how elderly persons deal with technology and in what parts of their life they would want it to play an important role. They need to be involved heavily in the development process.

For this reason we asked seniors from Sweden, Italy, United Kingdom and the Netherlands to fulfil a survey on technology usage in their daily life. Secondary, we organised focus groups in each of the countries to discuss the results from the survey and discuss more detailed issues with technology in current care systems. The setup of the different focus groups is in line with the general methodology proposed in D1.1. The stakeholder selection is up to the organizing country, and depends on where they think most value is gained for their role in context. This resulted in the following setup for the focus groups for each country:

IT: Psychologists, Managers and Professional Caregivers; [B] Informal Caregivers and Final Users

SE: Service users, informal caregivers and formal caregivers

UK: Mixed stakeholder discussion, among which users, carers, companies etc.

NL: End users and their caregivers

This report presents the synthesis of the results of the survey and the focus groups and presents an overview of needs to be considered in the technology development.

2 Method: Questionnaire and Focus groups

2.1 ENSAFE Survey on technology use

With the ENSAFE project team partners involved in WP1 a survey was designed. The questionnaire had three main goals: User profiling, project specific questions and in addition one standardized questionnaire on social isolation (The full questionnaire can be found in appendix A in EN).

In total 368 people participated. These were divided over the countries and sexes as following:

	Male	Female
UK	48	60
NL	46	42
IT	30	40
SE	30	72

Table 1: Participant distribution ENSAFE questionnaire.

The responsible partners in each country issued the questionnaires both physically and digitally.

2.2 Focus group Method

The focus groups were less formally organised by the partners. See D1.1 for full details on the focus group setup. The main drivers for these sessions were to get rid of ambiguity in the Survey. Sometimes answers were not fully answered, or interesting trends became apparent which we wanted to discuss further with the relevant stakeholders.

In the sessions 10 – 15 people were present, with among them at least a couple of end-users. First the project is introduced, second the questionnaire results are discussed with the group, third the personal situations or issues with health and technology are discussed, and fourth and finally the general conclusions of the session are summarized.

To analyse the focus group results a qualitative thematic analysis was used (Clarke and Braun, 2003). This allows for trend spotting and clustering of insights of interest for the project.

3 Resulting needs: Questionnaire

The raw results of the survey can be found in deliverable D1.2 (D1.2 Case finding analyses in the four pilot sites), in this section we will present the resulting needs from the questionnaire synthesis. To summarize, In the survey we found the following interesting needs:

3.1 Uses of technology

The main usages of technology we found related to personal use. These were mainly for social and communication purposes (WhatsApp , Facebook, or emailing), practical utilities (Banking and Shopping) and/or fun activities (Playing games, watching photo's or browsing the internet).

One of the main drivers for using technology is a sense of purpose or fun. It is important that there is such an angle to technology use to enable people to start using smartphone devices, and find the willingness to learn them. Technology usage doesn't come naturally for older adults and they need to put effort in learning how to use such a device. Finally there was a low interest in using technology for care purposes. Nevertheless people were very interested in their own health.

3.2 Barriers in technology use

Second topic concerns the barriers that people experience in using technology. About half of the elderly users that have partaken in the survey experience issues or barriers with using the technology. The most common reasons are the following:

-English language issues
-It is new, and therefore the learning curve is steep
-I know it can do so much, but I don't know how to do it
-I couldn't do it without the help of my children and grandchildren
-There are so many login names and passwords
-Standard information becomes digital (go to www.) or you can find the manual online.
-Difficult to use with my hands
-Too difficult to understand and use

These should be taken into account in the technology design process for older adults as part of the ENSAFE project. Furthermore, these can also be used in retrospect to evaluate the technology already a part of the project trough the partners.

Next to these participants also noted to have positive experience by using technology, mostly mobile technology such as smartphones or tablets. These are fore example:

-It challenges me to keep up
-It allows me to stay in touch with the people I care about
-It is actually useful for a lot of stuff

This shows that some of the participants are motivated to keep up with existing technology trends, and that there are possibilities they are not aware of in technology.

Figure 1: Impression of the dutch Focus group set-up.

4 Resulting needs: Focus groups

In this section we will present the results from the focus groups organised in each of the countries as a follow up to the survey results. Within these sessions we try to find out the specific reasons behind our survey findings (for example: What exactly is difficult about interacting with smart devices? See chapter 3.2).

In follow up co-creation sessions (WP3) the aggregated results will be translated into actual design and technology proposals, together with the users. In several countries the sessions of focus group and co-creation were combined into one session (phase 1 exploration of survey results, phase 2 brainstorming with users about what could be). In this report only the phase 1 results are covered, the co-creation results are presented in a separate document.

The full thematic analysis of the focus group sessions are presented in the Appendices. In this chapter we present a summary of the findings.

4.1 Focus group in the Netherlands

In Appendix B the full analysis of the focus group session in the Netherlands can be found. In general, during two group sessions with elderly users (one group of elderly with chronic diseases (group 1) and one group with healthy elderly (group 2). Many of the perspectives from the users were reflected in the survey results. Some of the focus group participants also disagreed with each other, however this also occurred in the survey and shows needs are complex and varying from user to user.

4.1.1 NL focus group 1 results (Cognitive impairment)

Technology usage

Topics that came out of the focus group are the following. Elderly were troubled with smartphone basics, such as for example the ability to change the first screen or welcome screen. In general bigger buttons, which can be activated, work better in these devices. However, they need to learn that it is possible from an expert or peers.

Barriers

Shortlist output addresses barriers mostly:

- It is complex to understand
- Not everybody is familiar with the Smartphone
- Accidentally touching different buttons
- When your old phone works, you don't need a new one.
- It only works with wifi, or is very expensive
- Data is open
- What happens if I have a virus on my computer or device?

Conclusions

The whole integrated system approach is difficult to explain to the elderly. Therefore it is difficult to extract meaningful ideas for further development or discover possible barriers.

We can conclude that it is important to take away all of these barriers as they might all be a red light during the adoption of the technology. ENSAFE needs to address the benefits of the technology (the smartphone), communicate them clearly to elderly and their informal caregivers. Question raised: should ENSAFE communicate directly to the elderly to let them see the benefits? Or should ENSAFE focus on relatively younger family members to let them see the benefits for the elderly and let them introduce the product to the elderly.

4.1.2 NL Focus group 2 results (healthy elderly)

Technology Usage

The survey indicated a large adoption of tablet usage. In addition most of the participants responded positively to the question of tablet use, and it is their preferred platform. It was even mentioned that tablets are preffered for more complex interaction as opposed to smartphone or PC.

Which services/technologies are elderly familiar with?

From the survey input we can derive four services that are used by elderly in the Netherlands:

1) calls to family
2) Browsing on the internet
3) Online banking
4) Email.

Both focus groups react positively to most of these services; and do use them on their tablet and or desktop computer, or laptop. We might conclude that these categories should be in our service, should be easily reachable, should be used to cconvince people to adopt. Though we do not need to develop them ourselves since they are not our specific USPs, others have them too and it clearly is not 'too' difficult to understand for older adults. Although we might turn them into specific USPs by adding an extra layer to make it more uniform ENSAFE like.

Barriers

During the focus group it becomes clear that the beginning is very hard for the participants. To start with the new device a person needs to transfer old data to the new phone, maybe even the simcard - it might need to be cut while not every telecom provider will help when the person has a contract with a different provider. Sometimes it is needed to reboot the system and all the apps are lost. Thus, to get for example a phone use-ready, to go to the right retailer and get the right amount of help is already a large step.

In addition to the start-up phase the learning process takes a lot of time. Some participants note that they are improving quickly, though other see it as hurdle. The manuals are often not clear and not easy to use. This provides us with the question if we can transfer this knowledge in a different manner; by organising start-up moments, training retailers, training or adding healthcare facilities to sell the devices including the right amount of support

When users are a little more experienced and use the phone they bump into the personalization of the device. A couple of users experienced 'annoying messages'as the initial settings included a home address that was not the users'.

Another user added the language barrier, that a lot of apps use technical (English) terms which are difficult to understand without any elaboration on the wording.

The last barrier was the wifi vs no wifi. It is not clear when services need wifi and when they do not, what are the extra costs without wifi? What are the benefits of having internet everywhere? Which services cannot be used without wifi? These questions are not clear for users as the concept of internet, wifi and 3G are difficult.

The concluding results of the focus groups have been analysed and translated into a graphical overview as following:

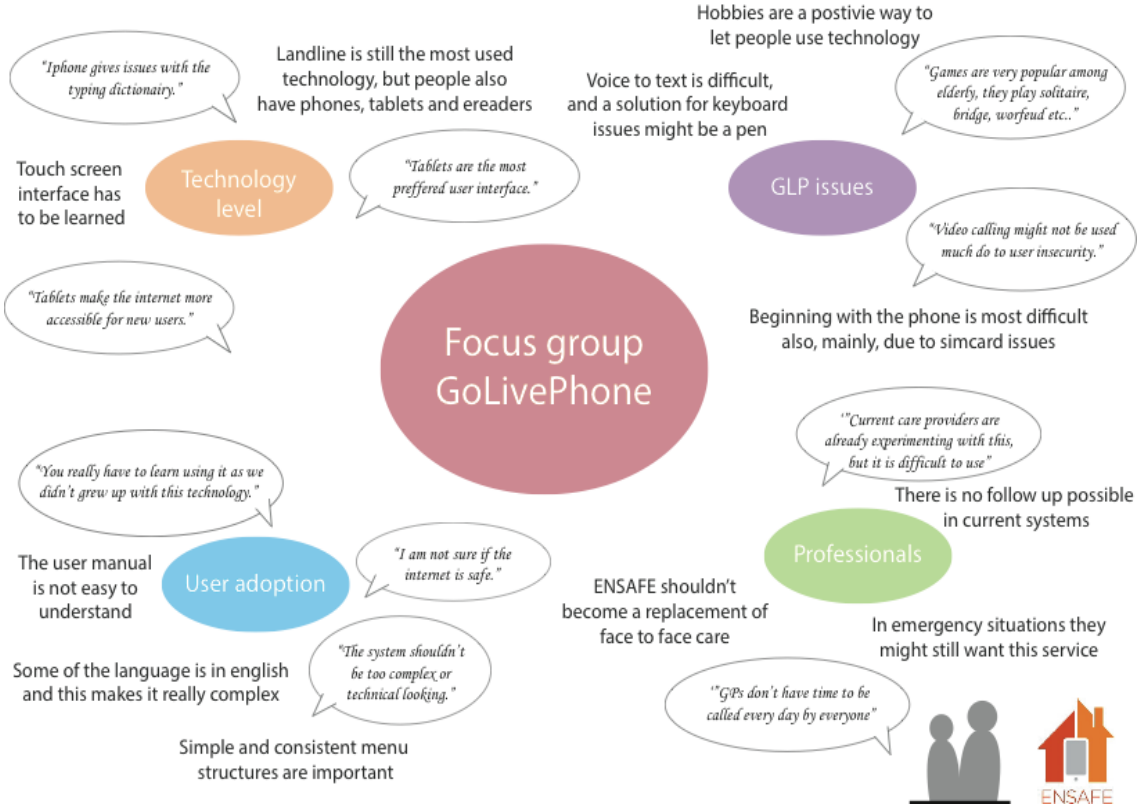

Figure 2: Thematic clustering of focus group results.

4.2 Focus group the United Kingdom

Partners from the UK (in both ICE creates and the Innovation Agency) performed an extensive analysis of their focus group session. The setup and a summary of the findings can be found here, the full thematic analysis is presented in a separate document.

4.2.1 Introduction

On the 10th of February 2016, ICE creates facilitated a focus group to a mixed audience at the Liverpool Jury's Inn (See methodology for sample). The purpose of this focus group (FG) was to begin exploring and capturing insight into how people deliver and receive care with and without technology.

Questions were selected ahead of the FG that would gauge the audience's perspective both for the current and future state. Using clean language and laddering techniques, we were able to dive deep into opinions and beliefs without influencing the participant's responses. (See methodology).

The answers provided by the participants are vital in giving us an account and broad picture of how Health, Care and Technology is perceived and valued in the UK from the various roles that were represented on the day.

The outcome of these focus groups in combination with the recently established ENSAFE products and services (ENSAFE I, II, III, IV), will help progress to a second round of Focus Groups where work with a specific group of people that fit in to a single ENSAFE product/service solution. It is here that we will be able to ascertain how citizens and formal/informal care givers want the service to be run and what products they would like to use.

4.2.2 Method

Thirteen individuals and two facilitators took part in this focus group. The group was made up of the following participants:

- A Primary Care GP from Liverpool
- The Head of Clinical Innovation, Liaison & Deployment from an Academic Health Science Network
- The Founding member of the University of the 3rd Age Groups in West Lancashire
- A Social Worker from a Local Authority
- An Assisted Technology Worker – PSS
- The Digital Care & Innovation Programme Manager at a local CCG
- A member of a local Assisted Technology Centre – ATC
- A New Initiatives Housing Officer at a regional housing group – YHG
- Principal Manager at a Local Council – HBC

- A Citizen living independently looking after his mother
- 3 X Citizens living in independent living retirement block

To ascertain the participants' personal experiences of living with a medical condition or providing care to others participants were asked "What conditions are we aware of either through living with them ourselves or caring/providing for someone close to us?" Participants' answers to this question are shown in table in the thematic analysis document.

2.1.2 Thematic analysis

The responses of participants who took part in the focus group were transcribed and analysed using an iterative and well-documented thematic analysis approach. Thematic analysis is a foundational qualitative analysis method, and a common building block of many established theoretical approaches (e.g. grounded theory). The transcript was analysed using the qualitative analysis software Atlas Ti. Example quotations are included within the body of the text of this report to provide evidence of the identified themes. Of note, throughout the report, when quotations are included, the participant ID includes a participant number and brief description of their role.

4.2.3 Key findings

From the benefits and barriers which emerged during this focus group we can begin to understand some of the factors which must be taken into account when creating a health-related technology product. Some important considerations are summarised below:

Health-related technology should make life easier for people

"...it's just got to make your life easier." (P1_GP)

One benefit of health-related technology which emerged from this focus group was that technology could make life easier for people (section 3.3.2). Making life easier, whether for the individual with a health need or care-providers, was also stated to be an important requirement for health-related technologies when participants thought towards the future. As well as the individual with a health need, some participants questioned whether technology could also make life easier for the individual's family and/or caregiver. Technology which makes life easier by enabling people to manage their own health or simply carry out everyday tasks could help them to prolong their independence, maintain their way of life and keep or gain control over their life (section 3.3.2). This benefit is likely to be important, because the responses of participants suggested that they believe that prolonging independence is an important outcome of good care (section 3.1).

Health-related technology could make life easier for HCPs, but must not increase their workload

Participants' responses suggested that the introduction of health-related technologies could make the lives of HCPs easier, by providing them with the data they need to predict and prepare for hospital admissions, or prevent them in the first place by identifying health issues before an individual deteriorates (section 3.3.1).

Participants did note that health-related technologies which monitor an individual's health and transmit that data to their GP could result in the GP becoming overloaded with information. Although not stated by participants in this focus group, GPs may be reluctant to promote health-related technologies to their patients if they believe that it will make their life harder, given that the role of a GP is already very intensive. As one GP who was participating in the focus group suggested, the data transmitted by such devices may need to be 'filtered' and 'condensed' to ensure that GPs are only alerted to important information (section 3.4.3). Behavioural economics tell us that people prefer not to make a change from the way things are currently done (known as status-quo bias). Making it as easy as possible for HCPs to integrate health-related technology into their role could help overcome any feelings of inertia or reluctance to change. Furthermore, ensuring that GPs and HCPs have a positive opinion of health-related technology may be important if they are to play a role in recommending health-related technologies to their patients, so support and HCP-engagement activities may be needed if a new health-related technology is to be introduced.

Health-related technology should be easy to use and accompanied by support and training

A potential barrier to the use of health-related technology was that people may not be capable of using it. Reasons given for why this may be the case included that technology may not be available to some people or may not be designed specifically for people with health needs to use. Any health-related technology specifically designed to help individuals with health needs must be designed with the individual in mind and practical barriers, such as a lack of Wi-Fi signal, must be taken into account.

There was also a concern that some people lacked knowledge of how to use technology and may fear using it. Support and training may therefore be required to educate people on how to use technology and to overcome any fear or reluctance they have towards using it (section 3.4.1). Participants suggested that such training may be more effective if it is aimed at getting older individuals comfortable with technology prior to them becoming unwell.

People need reassurance that health-related technology is not a replacement for one-to-one care

When asked to consider what care meant to them, participants used words such as personal, social and human, and appeared to value the human interaction and relationship element of caring for another person or being cared for (section 3.1.1). This perception of care being a personal relationship or human interaction may be at odds with individuals' misconception of technology, which is often seen as being impersonal and remote. If people believe that care will suffer as a result of the introduction of health-related technologies then they may be reluctant to use them. There were indications that participants were concerned about the role that technology will play in care and it may, therefore, be important to highlight that technology is a "tool" and "enabler" to help people to manage their own or another individual's health (section 3.4.4.2). Given that many of the perceived benefits of health-related technologies which emerged during this focus group related to prolonging independence (section 3.3), it may help if technology is instead seen as a way to make people's lives easier and prolong the amount of time before people need more intensive, one-to-one care. Furthermore if people who provide care believe that one-to-one care is integral to their role then they may resist any change to the way things are currently done (their status-quo).

Respondent 1: "There is a thing with this around the way it is marketed, because technology needs to be the enabler. To connect people rather than it just be as a replacement. That's the tool that can give someone the confidence to leave their house or do whatever they need to do, knowing that that support network is sat behind there. It's how we kind of pitch that and encourage that interaction." Respondent 2: "Nail on the head there for me in terms of, it's not a replacement, if anything, it's a supporting tool/enabler." (Respondent 1; P8_ATC, Respondent 2; P14_facilitator)

"Just relating back to the earlier discussion about being able to get to people, at the right points. I think this bit of the conversation is kind of highlighting it into two sides. The first is formal care, the stuff that we do, and then there's that ability to care as a human. I'm not saying that they are two distinct, but I think in terms of how you sell this concept to citizens, you're going to have to make that distinction aren't you? It's a product that can possibly connect people, can make people more informed. For those people that don't have anything to do with care and health services, kind of, the immediate thing that they think of about care, I think, is the human side of it, rather than that formal

service provision. So using the term care, I would avoid using the term care if you're trying to position the product." (P7_CCG)

Health-related technologies are unlikely to be one-size-fits-all

Finally, participants reiterated throughout the focus group that people need to have a choice in how they manage their health and that any health-related technology is unlikely to be one-size-fits-all. It will therefore be important to ensure that health- related technologies are "co-produced" with the people who will use them, which is a key aim of this project. One participant summed this up by stating that "ENSAFE should start off by saying 'What do you want?'".

> *4.3 "I think it's important that, when it's produced, it's co-produced. A word we use all the time but I mean properly co-produced so you can tell the difference between something that's been totally tokenistic and they want someone to tick a box. ENSAFE should start off by saying "What do you want"." (P10_HBC)*

4.3 Focus groups in Italy

2In Italy two focus group meetings were organised of about 3 hours each. In these five people and 2 groups are involved. During these sessions a SWOT analysis (Strengths, Weaknesses, Opportunities and Threads) was used during the focus group session. With this they had t goal to discuss and point out any remark, need, expectation and warning about the testing of technological devices in everyday life and caregiving situations.

4.3.1 Analysis Summary Group 1

Strengths. Technology is rapidly increasing and reaching a friendly format. “We are ready to manage it”. Dissemination opportunities (due to organisation’s ‘big numbers’). Professional start-skills already available. Informal caregivers will cooperate.

Weaknesses. Caregiving teams are overloaded. “Will we find time to use this tools?”. “Small-scale pilots will provide us enough information? Will be a reliable test?”. “We don’t have specific technical skill, so we’ll need external supervision and support”.

Opportunities. Large amount of information. Objectivity. Trends detection. More time for human relations in caregiving. Better communication between different. Groups and people. Early detection. Better effectiveness.

Threats. Relying on technology as a possible replacement of the human factor. Fear of some kind of remote control (“Big Brother Effect”). Lack of human presence. Sense of confusion.

What function/information would you like to count on? Fall/fall risk; Sleep report; Bathroom-presence report; Mobility report (position changes, etc.); Elder location; Doors/windows opening.

4.3.2 Analysis summary Group 2

Strengths. Technology has a big power, could be a huge help. Technology is everywhere: this means velocity and effectiveness in problem-solving. “Technology doesn’t lie” (more control on caregiving quality).

Weaknesses. Elderly are not so confident with technology. Use of tech devices needs skills and it costs. “Some houses are not ready for tech implementations”.

Opportunities. Staying in close-touch with relatives and friends. Feeling able to learn new skills. Feeling safer at home. Knowing more about ourselves.

Threats. More tech means less ‘human’ caregiving? Any health risk (electrical pollution, EM fields)? This tools will be really safe? Budget-oriented solution (“Best solution for the companies, worst for the elderly?”). More costs for the families or the elderly?

What function/information would you like to count on? Connect to relatives/other people; Safety reports (flood, gas alert); How many people are at home; Location of the elder (bed, couch, bathroom, etc.); Physiological parameters; Distress/Panic button.

Follow up: the groups will be asked to give more suggestions and feedbacks during the pilot phase

4.4 Focus group in Sweden

4.4.1 Introduction

On Thursday August 25, 2016 the first co-creation workshop of the Swedish partners took place in Norrköping, a town south of Stockholm where both SICS and Gaia are based. 9 participants (6 users and 3 informal caregivers) were involved in the session.

The users are a mixture of Ensafe 1, 2 and 3 (See technological description of ENSAFE). They all have mobile phones, a majority have smartphones and 2 of the participants have taken part in a local project educating elderly aged 85 or more in the use of iPads.

The group therefore contained a mix of novice users (minimal skill in interaction with smart devices) normal users (skilled in sending text messages, web browsing, email etc) and advanced users (active use of social media, video chat, social gaming etc).

Figure 3: Impression of the co-creation session in Norrköping on July 29,2016.

4.4.2 Method

The workshop started with a description of the ENSAFE project and its goal to improve the independence of elderly living at home, or with the support of informal caregivers, and/or in formal care. The aim of the workshop was to document the users' perception of their current level of care, and to hear their needs and wishes in relation to their existing experiences of the care they currently receive.

The workshop focused on 2 areas:

- *Firstly an investigation of the users' current situation with regard to the level and quality of healthcare, use (or lack of use) of digital services, and home care services.*
- *Secondly the group discussed opportunities, concerns and interest in potential future digital services, based on both the current scope of the ENSAFE project, and any other ideas the group may wish to see realised in a digital future. This section is covered in a separate ENSAFE deliverable.*

4.4.3 Findings

Current care situation

- Most users and their carers who are currently dependent on frequent home care visits (daily or more) expressed frustration with their current situation.
- This is due to both frequent changes in staffing among care personnel, and to the perception that the staff do not have time to do their job properly. The users do not appreciate the large number of different people sent to take care of them in their homes, nor the fact that the staff often appears stressed for time.
- Users receiving a less frequent level of care (e.g. twice weekly) did not express the same dissatisfaction.
- Some users are currently successfully using digital services to book visits with their doctor. This is seen as a great improvement on the previous solution which involved the need to telephone daily, often only to be told that all the day's time slots were already booked.
- There is currently a lack of communication between formal care givers and informal care givers. Current communication is more or less limited to emergencies, so informal care givers never know what the formal care givers have done during the day. Having this information would be very valuable to informal care givers.
- The users' lack of English language skills is in many cases perceived as a handicap.
- The elderly feel forgotten and marginalised by politicians and decision-makers. And they feel privileged and important when they are involved in projects such as this one.

4.4.4 Short conclusion

- In general – the more independent the users in this group are, the happier they are with their situation.
- Users' attitudes to new technology can be greatly improved by involving them in projects that educate them in its benefits and teach them how to use devices such as tablets and smartphones.
- The discussion concluded that digital services could be beneficial from a number of main points of view:
    - To ease the burden on formal carers, allowing them instead to spend more time in personal interaction with the elderly themselves. This would improve the users' perception of the quality of the care they receive.
    - To give informal care givers greater insight into what has and hasn't happened during the day
    - To invigorate users and create in them a sense of still being vital and independent
- The users and their informal care givers are therefore positive to the implementation of new digital services.

The participants found the session valuable, and they are keen to continue their involvement in the process of developing new digital services to increase their independence.

5 Conclusions

Overall the focus groups were successfully executed in all four regions. Each of the setups differed slightly as could be seen in chapter 4, however the main protocol structure was adhered to. In addition, it makes sense that the sessions were slightly different as all partners have a different role in the ENSAFE project.

5.1 Main findings

The results from the survey showed us the perspective of the elderly population. Sometimes struggling with technology, sometimes using it for their full benefit. What we have learned is that many still find it very difficult and technical and that personal interest (through games, social network, utilities) is the best way in for elderly to use the devices.

The participants in the focus groups confirmed many of the issues that came up in the survey. Some of the focus groups showed additional issues that could be related to specific health care systems, conditions or personal circumstances. In these sessions there was time for a more deep discussion on what is actually going wrong with technology nowadays.

As can be seen in chapter 4 many of the outcomes were similar showing these have to be included into the development part of ENSAFE. Overall we can conclude that it is important to take away the found barriers as they might all be a red light during the adoption of the technology. ENSAFE needs to address the benefits of the technology (for example the smartphone) and communicate them clearly to elderly and their informal caregivers.

Furthermore, tablets are the most preferred interaction platform and should also have a role in ENSAFE. Furthermore they stress the complexity should be low, manuals easy to understand, supported in learning process and consistent throughout.

Next steps

The results found in the survey and focus group sessions will be used to feed into the co-creation sessions and the technology work package. In these session we can look with the elderly towards the future of technology and ENSAFE. As such the core issues will be solved together with the users, ranked on what is most important and tinkered about with them. Following this the technology partners need to translate the new design proposals into working software and hardware for the ENSAFE pilots.

6 Appendices:

6.1 Appendix A, The questionnaire:

The original questionnaire can be found in document D1.1.

6.2 NL FOCUS GROUP Thematic analysis:

Thematic analysis focus group sessions 1 + 2. See PDF in D 1.3.1.

6.3 Appendix B, UK FOCUS GROUP:

Thematic analysis focus group sessions 1 + 2. See PDF in D1.3.2.