



**PersonAAL**



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## **Informal caregivers requirements analysis**

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## EXECUTIVE SUMMARY

Informal caregivers are an important resource both for elderlies and for society. At the same time informal caregivers, like family and friends, may be struggling with their own challenges in terms of coping with the expectancies from their surroundings incl. the elderly, and dealing with the experience of loss that might be triggered by seeing their spouse, parent or friend getting old and fragile. The PersonAAL project aims to assist the informal caregivers with helping elderlies they care for, and to improve exchange of information in order to ensure that the next of kin is well informed about how the elderly is doing. Three prototypical case summaries (personas) in chapter 2 describe realistic scenarios related to the care of elderlies.

Privacy legislations, ethical considerations and individual preferences are all important factors when designing digital solutions for information sharing of personal data. In the informal caregivers' requirement analysis we aim to balance these considerations by exploring relevant legal restrictions and surveying opinions and preferences of informal caregivers. We have focused on the countries where the field trials will be performed, i.e. Norway and Switzerland, but believe the collected information is relevant for most European countries based on the overall goal of standardising legislations and policies in the European Union.

In this document we present recommendations for the further development of the PersonAAL system based on the reviewed and collected information. We emphasize the legal and ethical boundaries of sharing personal information. Within the defined framework, we will aim to provide the needed flexibility for the elderly and informal caregivers in order to negotiate a level of information sharing adapted to the character of their relationship.

In the final version of this document we complemented the findings of the initial version with the results of a workshop with informal caretakers.

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## 1 INTRODUCTION

Informal caregivers are commonly family members of the elderly. The spouse; wife, husband or partner, living together with the elderly, will often be the initial primary caregiver, given that they are not in need of extensive care themselves (Bragstad et al., 2014; Larsson & Thorslund, 2002). An American prevalence studies involving informal caregivers suggest that adult children are the most frequent informal caregivers (41.3%) of elderly who are in need of care, followed by spouses (38.4%) (Wolff & Kasper, 2006). Children-in-law may take part in the caring of elderly, but are typically not the primary caregiver. One study found that 4.4% of the primary caregiver reported to be the elderly's daughter-in-law (Stephens & Christianson, 1986). Common reasons for taking the role as primary care givers are cultural expectations, emotional ties, and moral commitments to the elderly.

An extensive meta-analysis, including 168 studies, suggests that especially the spouses experience higher level of burden of care: *"Spouse caregivers report more depression symptoms, greater financial and physical burden, and lower levels of psychological well-being. Higher levels of psychological distress among spouses are explained mostly – but not completely – by higher levels of care provision. Few differences emerge between children and children-in-law, but children-in-law perceive the relationship with the care recipient as less positive and they report fewer uplifts of caregiving."* (p. 1; Pinquart & Sorensen, 2011).

Informal caregivers may experience a lack of information from formal public or private care providers, and too few opportunities to be systematically involved in the care of the elderly. This is partly due to common legislations securing patient privacy between the care provider and the elderly, and the fact that informal caregivers are not the recipient of the health care services.

This document presents the activities conducted so far in the scope of the PersonAAL project with the aim of characterizing the needs of informal caregivers. The following section describes the project's goals in the context of informal caregivers and introduces three personas and accompanying scenarios to illustrate current challenges and possible solutions. Section 3 characterizes the current situation in Norway, mostly from the legal perspective, while Section 4 addresses the situation in Switzerland from the results of a user survey. Based on the results of both activities, section 5 summarizes a set of recommendations that the project should follow in order to gain acceptance by informal caretakers. Section 6 then presents initial prototypes of tools that could be used by informal caretakers in the PersonAAL platform. Section 7 presents the results of a user workshop with informal caretakers where these prototypes were used to drive discussion about the role of informal caretakers in the daily living activities of seniors.

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## 2 OBJECTIVES AND SCENARIOS

### 2.1 Objectives

The PersonAAL project aims at delivering mechanisms to enable the development of solutions that could contribute to extend the time older adults can live independently in their own homes. These solutions would lead to an increased autonomy of the elderly, supported by increased assistance in their daily living activities, but they will also aim to facilitate care provision by formal and informal caregivers. The PersonAAL work package 2 will in particular gather information on requirements and needs, by collecting, organizing and comparing requirements from all the different categories of users that will interact with the applications and services supported in the project.

In relation to informal caregivers, we aim to collect information about the following:

1. Legal restrictions for information sharing between elderlies and their informal caregivers in systems collecting health related data
2. Investigating the needs of informal caregivers
3. Current practice and preferences for information sharing between informal caregivers and persons they care for

### 2.2 Personas and usage scenarios

In this section we present three personas that illustrate different senior beneficiaries of the future PersonAAL based solutions. These personas are used in scenario narratives that illustrate how informal caretakers would interact with the person being cared for, and the professional caretakers. The scenarios also provide an illustration of different motivations that are pervasive in the formal caretaker user group, and how PersonAAL can support those.

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## 2.2.1 Persona 1 - Maria

## Maria Antónia da Silva



**Age:** 67  
**Work:** Retired. Previously was a shop assistant.  
**Family:** Divorced, two daughters  
**Location:** Coruche, Portugal

### Goals

- Keep in touch with her two daughters.
- Learn new communication technologies.
- Manage her diabetes.

### Frustrations

- Being away from her two daughters.
- Having had to leave her home in Lisbon.
- Low retirement income.

### Bio

Maria worked as a shop assistant until having recently retired. Fifteen years ago, she got divorced and her husband went back to Brazil. This left Maria suffering from severe financial problems, forcing her to move to the village of Coruche where the rents and living expenses are cheaper. She now lives alone, since one of her daughters moved to Japan. The other daughter works as a flight attendant, leaving her little time to spend with her mom.

### Personality

Introvert Extrovert

Analytical Creative

Conservative Liberal

Passive Active

### Motivations

Incentive

Fear

Achievement

Social

Health

Family

Maria is a 67 years old Portuguese who recently retired from her job as a shop assistant in a large suburban shopping center. After her husband, Diego, decided to move back to his home country, Brazil, 15 years ago, Maria suffered from severe financial problems and moved to a small village where rents and living expenses are cheaper. Maria has been staying alone in her apartment ever since her younger daughter, Filipa, accepted a PhD scholarship in Japan. Her older daughter, Raquel, works as a flight attendant and always stayed in the city in order to be close to her friends and to the international Airport. Similar to Filipa, Raquel can visit Maria rather infrequently, as her job requires flexible working hours, stand-by duties and numerous stays abroad.

Nevertheless, both Filipa and Raquel appreciate to talk to Maria as often as they can. Maria has been suffering from adult onset diabetes for a couple of years and so the two daughters are concerned about a potential deterioration of her health condition. Maria used to be regularly checked by a specialized practitioner when she worked close to Lisbon and she took part of a special program for the optimization of weight and nutrition. In her village, however, there are no specialists in this field and therefore Maria has to make the 80 kilometres to the city by public transport every time. Maria's mobility, however, significantly deteriorated lately. The heavy physical work in her job already evoked two intervertebral disk herniations which ever more precludes her from walking long distances and standing upright in the trains and busses. Professional check-ups and behavioural monitoring have thus become less and less frequent.

Raquel and Filipa decided to monitor Maria's behaviour as much as they can to make sure that her increasing forgetfulness does not prevent her from carrying out the essential checks and taking the medication at home. Phone calls, yet, have become more and more irregular due to the roaming costs and time lags the two daughters face abroad. Raquel therefore purchased a

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tablet for Maria to stay connected through the internet. Yet, whereas Maria appreciates to receive mails and recorded video messages from her daughters, she has difficulties to give feedback by herself. She is highly interested in keeping up with new solutions, but never worked with computers so that she has trouble understanding the numerous features of the applications. She also faces difficulties to recognize the light contrast on the screen, to press the right buttons on the touch-keyboard and to deal with the numerous pop-ups and alerts she receives.

Maria feels tired of the tedious reporting and leaves off her tablet more and more often. Raquel and Filipa, consequently, are highly concerned about the reachability of their mother and the completeness of the information they receive. They decide to purchase the PersonAAL software and to install the required infrastructure in Maria's apartment. By use of the system, Maria receives remote assistance from her specialized practitioner in the city, Dr. Santos, and can be monitored by him and her daughters without any tedious reporting. As Maria has accepted to set-up a set of sensors in her apartment and to connect her current measurement devices with the PersonAAL application, data and measures of Maria's conditions and behaviour are automatically collected and transmitted to both Dr. Santos and her daughters. Whereas Dr. Santos receives information in technical medical terminology through a specialized app he installed, Filipa and Raquel receive a consolidated overview rendering basic information about Maria's health conditions and compliance with her required treatment at home.

At the same time, Maria has installed the PersonAAL software on her TV-Screen in the living room where she not only sees what data is being shared with her daughters, but also receives regular reminders about the therapeutical measures she can take at home. These measures can be calibrated remotely by Dr. Santos, according to the current measures and historical trends he receives via PersonAAL. Once Maria's glucose level exceeds the intended level, for example, Maria receives information on how to adapt her nutrition plan and about what additional measures she should submit to keep track of her health conditions. Maria accesses the PersonAAL app on her TV quite often and is highly satisfied with the usability, as running and watching the TV is an integral and familiar part of her daily activities. Raquel decided, after consultation of Dr. Santos, that necessary reminders automatically pop up on her TV screen every night at 20:00 hours, as this is the habitual time for Maria to switch on her screen. The information is very easily understandable through concise categories and unequivocal visualizations. This way, Maria does not forget to carry out the required tests, submit the required information and comply with the measures from her weight and nutrition program. Despite the satisfaction with the TV application, Maria installed the PersonAAL app on her tablet as well. She uses it in connection with the TV whenever she wants to send further, optional information that is not collected by the sensors. Moreover, she can put the tablet on her bedside table during the night. That way, Maria can decide to transmit optional information and alerts to the smartphones of her practitioner and her daughters even at night, which gives her a feeling of comfort and security in the case of emergencies.

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## 2.2.2 Persona 2 - Giuliana

### Giuliana De Luca



Age: 83  
Work: Retired.  
Family: Widow, one son.  
Location: Ancona, Italy

#### Goals

- Remain healthy, active and independent for a long time.
- Take a cruise with her son and daughter-in-law.
- Cook for her grandsons.

#### Frustrations

- Misses her hometown on the countryside.
- Doesn't feel as comfortable as before in the kitchen.
- Hates to take medications, because she tends to forget about them.

#### Bio

Giuliana is an healthy senior, that lived most of her life on the Italian countryside in the Marche region. She became a widow 13 years ago. At that time she moved to Ancona to be near her son, but insisted in living in her own home. She enjoyed cooking very much, and although she can't cook as well as she used to, food is still one of her passions.

#### Personality

Introvert	Extrovert
Analytical	Creative
Conservative	Liberal
Passive	Active

#### Motivations

Incentive	
Fear	
Achievement	
Social	
Health	
Family	

Giuliana is an 83-year-old widow who still lives alone in her two-room-flat. Her son Michele and her daughter-in-law Barbara live nearby and visit her regularly to help with administrative challenges. Regardless her age she has never suffered a severe illness. Giuliana already takes four different medicines because of her high blood pressure. Her weight is too high, but not dramatically. Her intraocular pressure has risen in the last months; therefore she has to take a fifth medicine now. Barbara used to prepare weekly pill boxes with the different medicines for each day. But it was difficult to know whether Giuliana did take the medicine or not. This is where the reminder and the confirmation-function of the PersonAAL system can help. The system reminds Giuliana to take her pills, and by confirming that she took them, Giuliana shows she read or heard the reminder and did react. The system is more convenient than a daily phone call by Barbara.

The PersonAAL system can remind Giuliana vocally. She can very well understand spoken remarks from a computer voice. However, the voice control of the computer does not understand Giuliana, because she in her old age tends to fall back to the dialect of her childhood, and because she lacks several teeth, she mumbles. This makes it impossible for her to give vocal commands to the computer.

Michele and Barbara want to be sure that their mother is safe when they go on vacation. If they one day should move, they hope that the PersonAAL system may help with the caretaking of their mother. Therefore, they decide, together with Giuliana, to place some sensors in the flat – for motion and fall detection. If Giuliana does not get up in the morning, or if she falls over, an alarm will first warn Michele and Barbara, and then the Red Cross.

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In the facility, the PersonAAL system is used to register her weight while performing prescribed exercises and to provide her with direct visual and tactile feedback on how the exercise is performed. Thanks to this method, Anna's health condition improves very quickly and after a few weeks she can return home.

For a while Anna cannot drive, so her daughter Laura, who lives 40 km away from her mother, needs to take her once a week to the doctor to do the medical check-up and adjust prescriptions if necessary. Moreover, Laura is worried as she noticed her mother often forgets to take her medicine and do her regular exercises.

As Anna was so happy about her improvements in health conditions thanks to the PersonAAL system, her doctor suggests Laura to buy the PersonAAL Remote Assistant and Monitoring Medications applications, in order to receive personalized assistance and avoid as much as possible the need of having Anna move into a care facility. The PersonAAL team provides and configures a set of bio-signal sensors for Anna, so she can easily inspect in her home relevant health parameters, and also an electronic pill dispenser. The system is also configured to automatically transmit relevant information via the internet to a cloud computing environment. Through the PersonAAL Remote Assistant web application both Anna and Laura can verify in real time and through different devices (e.g. TV, tablet, smartphone, etc.) the parameters' last measured value and historical trend, rendered in an adapted way according to the characteristics of the device used, the current environment in which the application is used and also the characteristics of the user. For instance, Laura generally accesses these parameters by using her smartphone, because she can perform this check even when she is mobile, while Anna often prefers the TV, because she spends most of her time during the day in the living room and feels very familiar with using this device.

The last time Laura visited her mother, they were discussing Anna's current health status. In particular, Laura remembered some aspects of the latest doctor's report about Anna's health status, which Laura wanted to focus on and discuss with her mother. Laura had just analyzed it before leaving her house to visit her mother, by using the PersonAAL application available on her smartphone. Laura therefore accesses the information from the PersonAAL application on her smartphone and highlights some points to her mother. As soon as Laura shows the smartphone to her mother, Anna complains that the screen is different from what she is used to see in her devices, and much more difficult for her to understand what is being presented. Laura suddenly realizes that the PersonAAL system adapts the applications to their users, and so on her mother's devices the fonts are bigger and there is less information on each screen. Laura concludes that the small display on her smartphone will not allow Anna to properly follow her remarks. Then, thanks to the features available in the PersonAAL system, Laura decides to distribute the user interface by also taking benefit of the large TV screen available in the living room. She then graphically displays Anna's health related information on the TV screen, while keeping her smartphone to control the user interface shown on the TV. In this way Laura is able to easily explain to Anna some aspects of the doctor's report which were not so evident to Anna, also highlighting the fact that, from what is shown on the TV screen, it is clear that Anna's current status is currently improving, although further efforts are needed on her low fat and low salt diet, and her physical activity (the report highlights a lack of recent physical exercise). Indeed, Anna acknowledges that in the last days she spent a lot of time watching TV. After a while, Laura leaves her mother's house and goes back home.

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During the evening, Anna recalls what her daughter highlighted. She remembered that, overall, her health status is going well, but there were some aspects for improvement. However, now Anna does not clearly remember anymore the entire story and she decides to access again that information by accessing the PersonAAL application on her tablet. After Anna accesses the system, she recognizes the interface she used, which has now been automatically adapted by PersonAAL taking into account that the vision of Anna is slightly declining (meaning large fonts are used, the contrast between colours used is enhanced, a vocal feedback is provided to accompany the information graphically visualized). In addition, the report of the doctor is also presented in a simplified manner: the number of options/elements per page is reduced and some details are removed, in order to enable Anna to more easily understand the main concepts. She prefers this much more than her daughter's interface and is now able to fully understand what to do to improve her health status and she promises herself to pay more attention to these aspects in the future.

When coming back to her home, Laura on her part decides to set a more specific adaptation rule for her mother, in which she expresses that if her mother spends more than 3 hours daily on the TV, a notification should be sent to Anna to highlight this and encourage her to do some physical activity, instead of watching TV. In particular, Laura could also decide to specify that, in these cases, if the weather is good and there are some events outside that could be interesting for Anna (Laura enters into the system that Anna is interested in gardening and art exhibits), the system could even suggest Anna to leave the house to socialize, by means of delivering an appropriate message to Anna showing interesting events that are currently taking place in the vicinity of Anna's home. Should Anna be interested in one of these events, the system will also appropriately provide and render on her smartphone/tablet further relevant information (e.g. information about the place and how to reach).

Laura also configured the Remote Assistant application in order to provide Anna with dietary suggestions and exercises recommendations and the Monitoring Medications in order to provide vocal timely reminders about medicines to take. Moreover, the doctor is immediately alerted if a problem is detected in order to ensure support via remote audio/video call or chat. Indeed, through the Monitoring Medications Application, the doctor can monitor all his patients' records from his tablet, and adjust prescriptions as needed.

In addition, both Laura and the doctor can adjust/personalize the system on behalf of Anna. For instance, recently Anna suffered from a bad cough, which did not allow her to sleep properly at night for some days (also the sensor system installed in Anna's house detected this abnormal situation). As a consequence of this, the doctor decided to prescribe some antibiotics to Anna for some days. Furthermore, the doctor, in order to avoid any interactions between the antibiotics and the medicine that Anna was already taking, had to slightly modify Anna's therapy until the cough was over. During that period the PersonAAL system has been very helpful to help Anna avoiding any confusion with the right medicine to take, and at the right time! At the same time, Laura, using the social features provided by the PersonAAL application, checked with the doctor that while Anna suffered from the cough, it was advisable not to overdo the rehabilitation exercises, as Anna felt more tired during the day in that period because she was not able to sleep properly due to the coughing. Laura therefore adjusted the settings for the daily exercises during that period accordingly. Laura also included an adaptation rule in the PersonAAL application so that Anna was advised to do easier rehabilitation exercises with less repetitions during this time, and also set some delays in the exercise reminders planned for the morning to allow Anna to sleep a bit longer in the morning.

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## 3 CURRENT SITUATION IN NORWAY: LITERATURE REVIEW

### 3.1 Relevant national legislations and policies

1. *The Patients' Rights Act*  
In Norwegian: Lov om pasient- og brukerrettigheter (pasient- og brukerrettighetsloven)
2. *The Health Care Personnel Act*  
In Norwegian: Lov om helsepersonell m.v. (helsepersonelloven)
3. *The Health and Care Services Act*  
In Norwegian: Helse- og omsorgstjenesteloven

These three legislations balance the rights of patients, including health care professionals duty of confidentiality, and the rights of next of kin (informal caregivers) in Norway. Family members and persons appointed to be formal next of kin by the patients are regarded as an important resource in the treatment of patients. However, patient confidentiality is intended to ensure patients that information about their health is protected from others, including their next of kin. In most cases, this restricts the information sharing with family members and next of kin to those situations where the patient consents in making information about their health data available for their close ones. Exceptions from this might be emergency situations when a person is not able to give a formal consent or if the safety of the next of kin is threatened. For the relationship between elderlies and their informal caregivers, these legislations only become relevant when the elderly is a recipient of health care services, as described in the definitions below.

The formal definitions in The Patients' Rights Act of the key roles in these matters are (Notice: our translation):

1. *Patient*: A person who approaches health and care providers with a request of health care related services, or who is provided with such care from a health and care provider.
2. *Next of kin (informal caregivers)*: Person(s) that the patient pronounces as her or his next of kin. If patients are not able to provide names of their next of kin, the formal next of kin ought to be the person who have had extensive and regular contact with the person, based on the following order: wife or husband or person living with the patient in a marriage-like relationship, children above 18 years of age, parents, siblings above 18 years, grandparents, other family members with close ties to the patient, and formal guardians.
3. *Health care*: Actions that has preventive, diagnostic, curative or sustainable effects for a persons health conditions, including rehabilitation and caring services, and which is performed by health care professionals.
4. *Health care services*: Public primary and specialist health care service providers, dental services and private health care service providers.
5. *Health care professionals*: Professions listed in The Patients' Rights Act.

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6. *User/client*: A person requesting or receiving services included in The Health and Care Services Act, that is not health care according to point 3.

### 3.2 Key issues from legislations relevant to the PersonAAL project

1. Informal caregivers are in the PersonAAL project defined as family members, friends, neighbours and other close to the elderly who are not formal caregivers, like health care professionals. In Norwegian legislation the focus is not in particular on the caregiving role, rather on next of kin with emotional ties to the patient. Next of kin can be others than family members and relatives, given that the elderly has appointed them by name, to the service provider.
2. The solutions and services developed by the PersonAAL project are likely to fall into the definition of health care services. Thus, sharing of information collected by the PersonAAL system must comply with the patient confidentiality regulations, meaning that a documented consent with the names of the elderly's preferred informal caregivers will be needed.

### 3.3 The official policy of The Norwegian Directorate of Health on the rights of next of kin

*"Although medical personnel have a duty of confidentiality, there are many cases where next of kin also have a right to information. All next of kin always have a right to general guidance, and only listening does not imply breach of confidentiality.*

*Next of kin are also entitled to receive information when:*

- *The information is already known.*
- *The patient or user consents to it.*
- *When "the circumstances warrant" the disclosure of information, for example in an emergency or if the patient is unable to give their consent.*
- *When the patients clearly are unable to look after their own interests.*

*Parents also have a right to information concerning their children until the child reaches 16 years of age, or until they reach 18 if the information is necessary in order to fulfill the parental responsibility. It is the next of kin who is entitled to receive information. The patient or user is entitled to designate their immediate next of kin. If a person is unable to designate their immediate next of kin, it must be the person who has known the patient for the longest period of time."*

Cited from the website of The Norwegian Directorate of Health, accessed 20.02.2016  
Link: <https://helsenorge.no/other-languages/english/rights/the-rights-of-next-of-kin>

### 3.4 Norwegian surveys and research addressing the needs of informal caregivers

The needs of informal caregivers may typically be divided into two categories: 1) Issues related to the care of others, like what they do for the elderly, but also for additional people as other family members, and 2) Their own needs for comfort and reassurance, and emotional and

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practical support and care, due to sufferings they may experience based on their relationship to the elderly. Several surveys by public entities and research projects have addressed these two types of needs among informal caregivers and next of kin in Norway. Understandably, these two needs might be entwined: Informal caregivers might like to get information about the elderly sometimes for the sake of providing practical information, other times to comfort their concerns. A report from a nursing home outside Bergen, Norway, summarizes how informal caregivers may struggle both with a wish for more and better services for the elderly and at the same time feeling guilt because they are not able to take care of their family member themselves (Tingvatn, 2004). Tingvatn states that informal caregiver have been neglected in the health care services for a long time, both in relation to their own needs and as a resource for the elderly.

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## 4 CURRENT SITUATION IN SWITZERLAND (USER SURVEY)

The target group for the informal caregivers' requirements analysis was defined as family, friends and other types of next of kin, who care for an elderly. Information about the sample was collected as part of the survey in order to validate the quality of the target groups addressed and their matching with the target group for the envisaged PersonAAL system. The research design was developed using input of all consortium partners. Based on the above-mentioned research parameters, partners were invited to state their opinion from the perspective of their background and expertise so that the results can directly contribute to their respective project contributions.

### 4.1 Overview of the survey

Objective:	The requirements regarding the technical design of PersonAAL need to be identified from the perspective of informal caregivers. Whereas a number of technical features and solutions are ready to be integrated into the technical platform, we do not know which of these features will be suitable to solve the specific requirements of the caretakers and in how far these will be accepted for the implementation in their caring activities. The required degree of personalization of the potential features will be subject to scrutiny.
Target group:	Informal caregivers
Method:	Questionnaire, primarily closed questions; dissemination by online survey
Language:	German
Period:	Week 51, 2015 – Week 2, 2016
Location:	Switzerland
Survey design:	Stefan T. Kroll, terzStiftung
Count:	Questionnaires, complete: 13 Questionnaires, incomplete or answering "no" when asked if they care for someone: 107 Only complete questionnaires considered in the following charts
Parameters:	<ol style="list-style-type: none"> <li>1. General information</li> <li>2. Modes of communication / methods of providing health related information</li> <li>3. Use of technical devices</li> <li>4. Usability of technical devices</li> <li>5. Success Factors</li> </ol>

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## 4.2 Method

### 4.2.1 Target Group Specification

The target group for the informal caregiver survey was defined as next of kin of elderly people with or without impairments.

### 4.2.2 Media

As the target group was defined as informal caregivers of elderly people, an online survey was considered the most suitable tool. Sending out a questionnaire through the Internet was considered helpful for reaching a large share of respondents as well as for reaching people who have at least basic experience with using the Internet.

### 4.2.3 Language

As the survey was carried out in the German speaking part of Switzerland, it was entirely designed in German. Since the original research design was developed in cooperation of all consortium partners in English, translations into German had to be made. Questions were not literally translated but in line with their sense. After completion of the surveys, results were transformed back into English. Qualitative comments from text fields were translated according to their sense.

### 4.2.4 Procedure

The online survey started December 17, 2015 and was closed January 15, 2016. It was sent out by an online mailing on December 17, 2015, to the target group from the database of terzStiftung. A reminder was sent out to the same target groups on January 5, 2016. The mailing offered a short project description as well as a link to the online tool LimeSurvey hosting the questionnaire. The sample of addresses was not filtered before sending out the emails and everyone with access to the weblink was able to answer the survey. The filling out was completely anonymous. All questions, including those about personal characteristics, could be answered on a voluntary basis.

### 4.2.5 Response Rate

By January 13, 2016, LimeSurvey registered 120 file counts in the questionnaire, 13 of which were completed and 107 which was incomplete or the respondent had answered that they were not an informal caregiver. Incomplete surveys resulted already from the mere external opening of the survey webpage or by dropping out before the end of the survey. For the underlying evaluation, the sample of 13 completed questionnaires has been further considered as the data base for the results published in this deliverable.

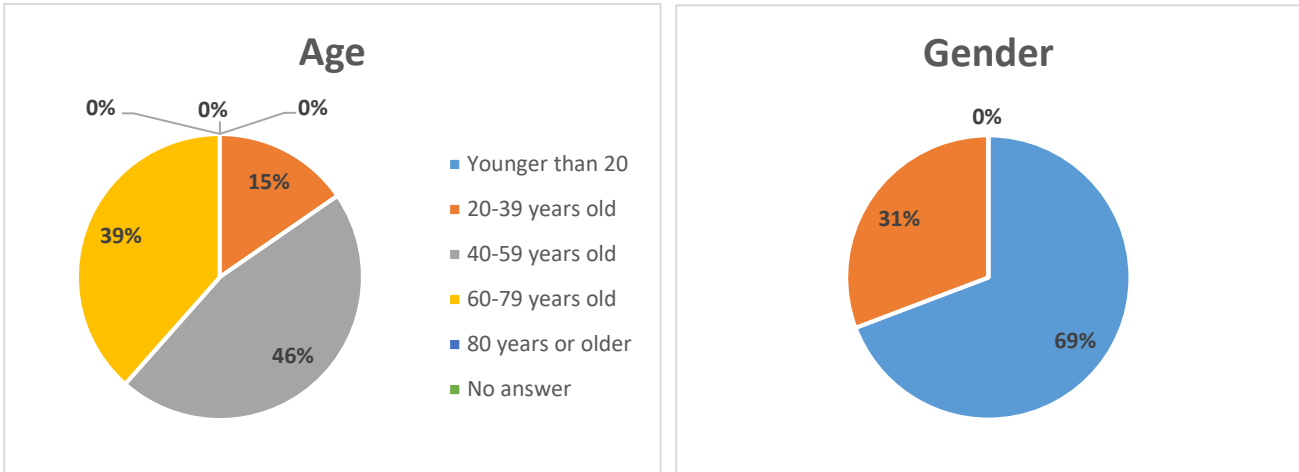
## 4.3 Findings

### 4.3.1 General information

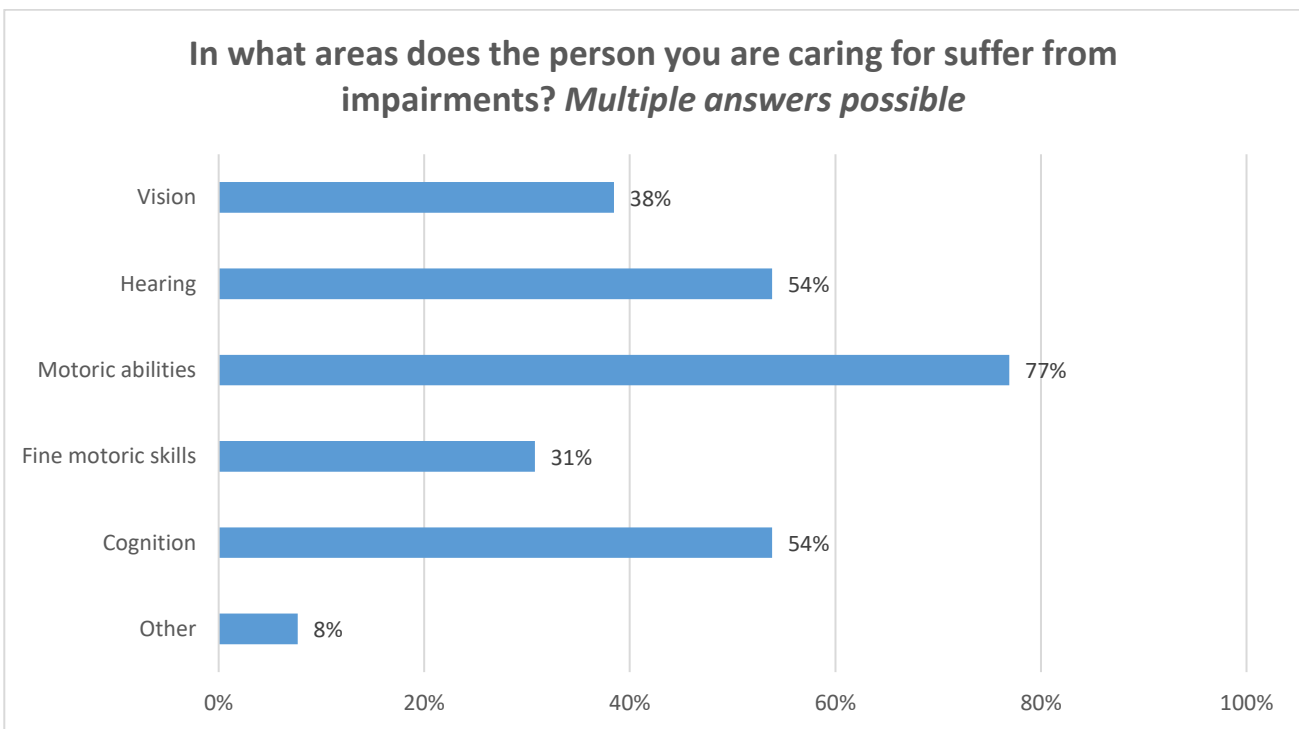
In order to learn more about the sample, all respondents were asked for basic characteristics such as age, gender, living environment and personal (health conditions). As illustrated bellow,

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a large share of the informal caregivers covered by the underlying analysis are themselves part of the elderly generations targeted by the PersonAAL system. About half of the respondents can be located in the age group 40-59 years old, 5 in the age-group 60-79. Only 2 are younger.



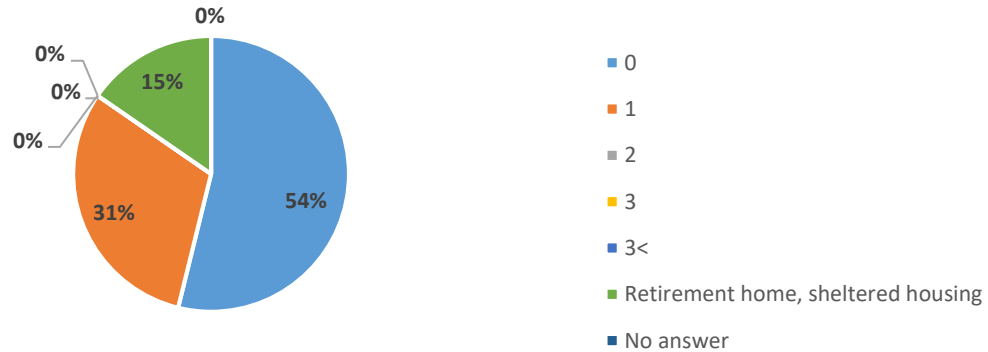
In order to understand the importance and scope of the caring services carried out by the current sample, several questions were asked regarding the status of the person in need.



As shown in the above chart, most of these (10) suffer from motoric impairments. About half (7) of the persons cared for have problems with hearing and their cognitive performance. Vision (5) and fine motoric skills (4) are still important issues regarding requirements for care.

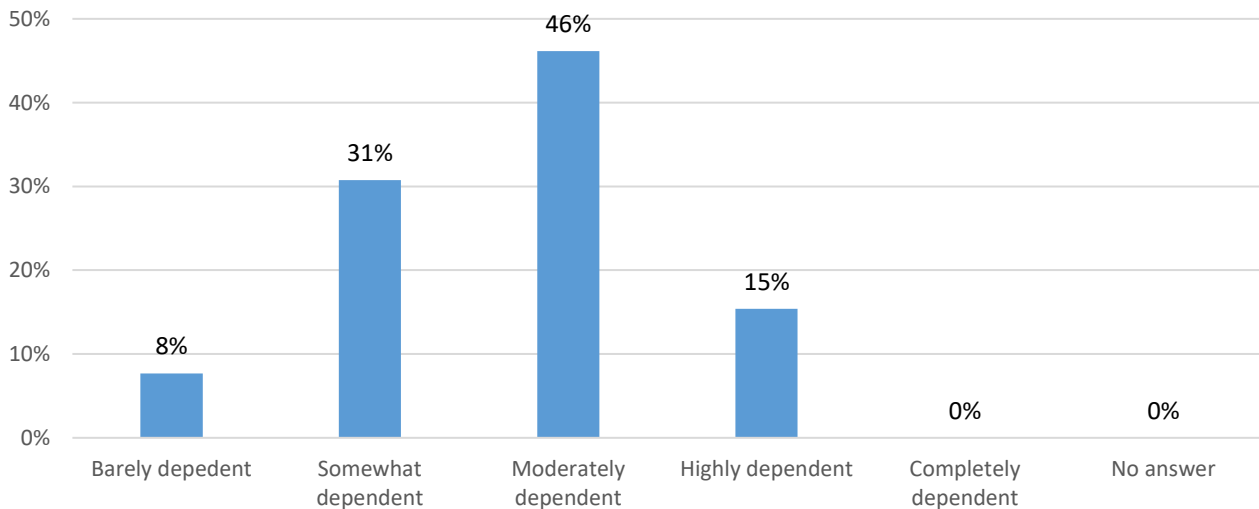
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## With how many people does this person live together?



The living environment is an important factor for the underlying analysis considering that the PersonAAL project envisages prolonged independence of elderly people at home and potential requirements of care given by different target groups. According to the above chart, a majority (7) of the persons in need, who are nursed by the current sample, lives alone. Four live as couples.

## If you consider the organizing and carrying out of that persons` activities. How independent (from required care) do you consider this person to be?



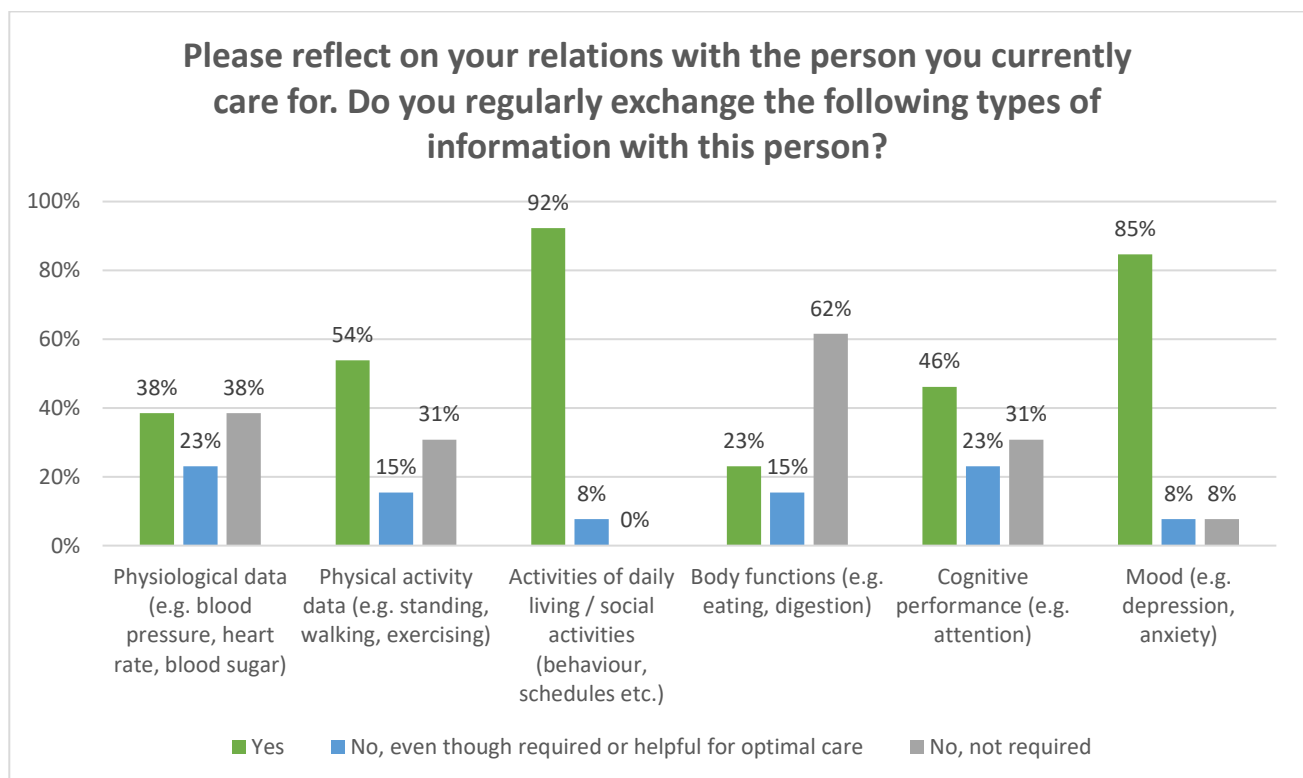
In order to get insights about the strength of the impairments the respective persons suffer from and the scope of potential caring activities, the survey asked for the level of dependency. As it can be derived from the above chart, only 2 of the persons in need are considered highly dependent on their caregivers, whereas 6 are considered moderately dependent. Four receive

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care although they are only little dependent. Considering the range of dependencies, there is reason to assume that a wide range of caring activities will be reflected in the following findings, i.e. activities spanning from basic support to intense treatment.

### 4.3.2 Modes of communication / methods of providing health related information

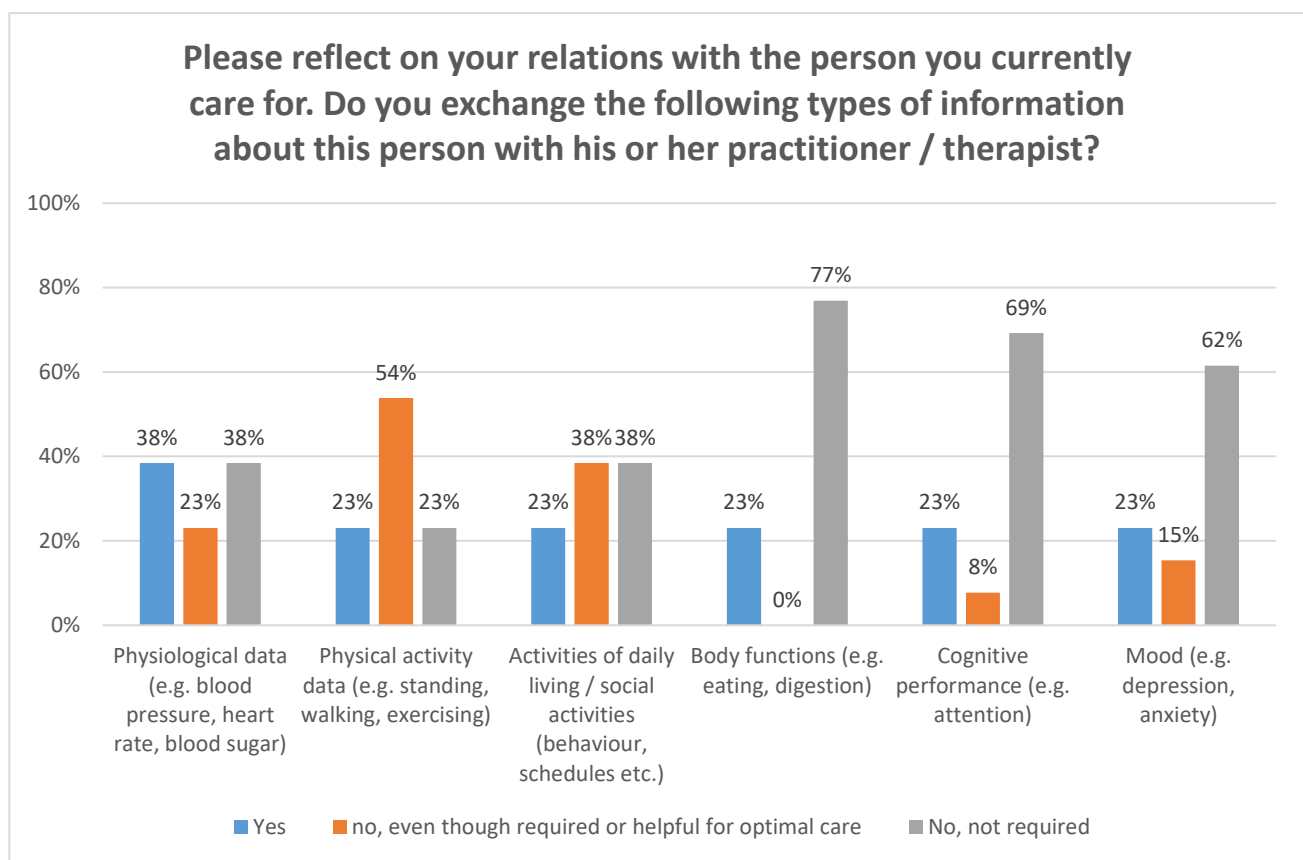
As it was done with regard to the survey among elderlies (presented in D2.1), we investigated modes of communication in the context of caring activities among the current sample of informal caregivers. Unlike the survey among elderly end-users, the current questions do not focus on the attitude of these latter but take the perspective of caregivers themselves. Two major insights can be gained from this point of view. First, the self-assessment of the elderly respondents should be verified. In particular, the dimensions of informational exchange between caregivers and persons receiving assistance can be compared by reference to information from both sides. Second, personal preferences and needs on the side of caregivers should be analyzed regarding possible features of the envisaged PersonAAL system. Like the primary end-users themselves, informal caregivers will be the target group for specific parts of PersonAAL and therefore become end-user themselves, thus being customers with specific requirements, tastes and contexts to be considered. Accordingly, it will be imperative to understand more closely both their interaction with the persons they care for as well as details of their caring activities and their own perspective as a user, i.e. their own dealing with respective technology. The following charts reflect the information exchange between informal caregivers and person in need as well as potential areas for improvements thereof.



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As illustrated, non-medical data is exchanged between these two groups rather intensively, with shares of 92% for daily / social activities and 85% for mood. About one half of the informal caregivers still receive information about the cognitive performance (6) and physical activities (7) of their service recipients. Clearly medically related data, i.e. physiological data and body functions, is only exchanged with 5 and 3, respectively.

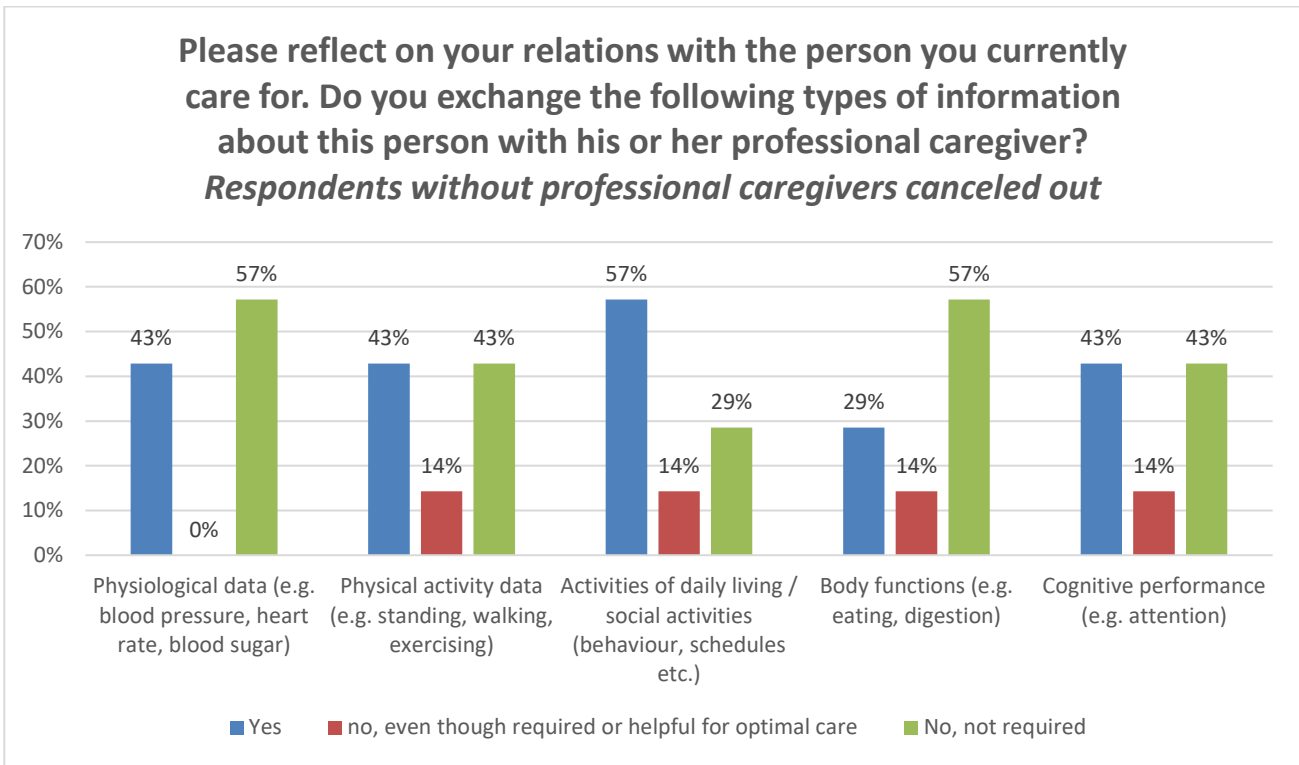
Given the purpose to improve the informational exchange between informal caregivers and the persons being cared for through PersonAAL, the questionnaire asked about areas where respective exchange is missing although helpful for the caring activities. As shown above, roughly one fifth (3) of the sample would appreciate the reception of information about physiological and cognitive status of the nursed. Two would like to be informed about body functions and physical activities. However, these are all minorities compared to those who consider such information irrelevant for the proper caring activities carried out by themselves.



The same types of questions were asked to shed light on the communication between informal caregivers and the practitioners treating the person in need. The charts clearly indicate that only minorities of the informal caregivers exchange the proposed type of information with the healthcare professionals (23% each, except physiological data with a share of 38%). However, there are considerable shares of respondents who would consider the exchange of information about physical activities (7) and activities of daily living (5) helpful for improved care. Considering that respective information is largely exchanged between informal caregivers and the persons

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receiving assistance, one may conclude, yet, that the respondents expect practitioners to benefit from these additional insights about their patients rather than caregivers themselves.



Communication between informal caregivers and professional caregivers is comparatively high in all areas, ranging from shares of 29% (body functions) to 57% (activities of daily living). Respondents missing the exchange of certain types of information, in contrast, are few: Only 2 consider additional information helpful for their caring activities in each category, except for physiological data (none). Concerning the most medically oriented information, namely body functions and physiological data, exchange is considered irrelevant by the majority (57%) of the sample.

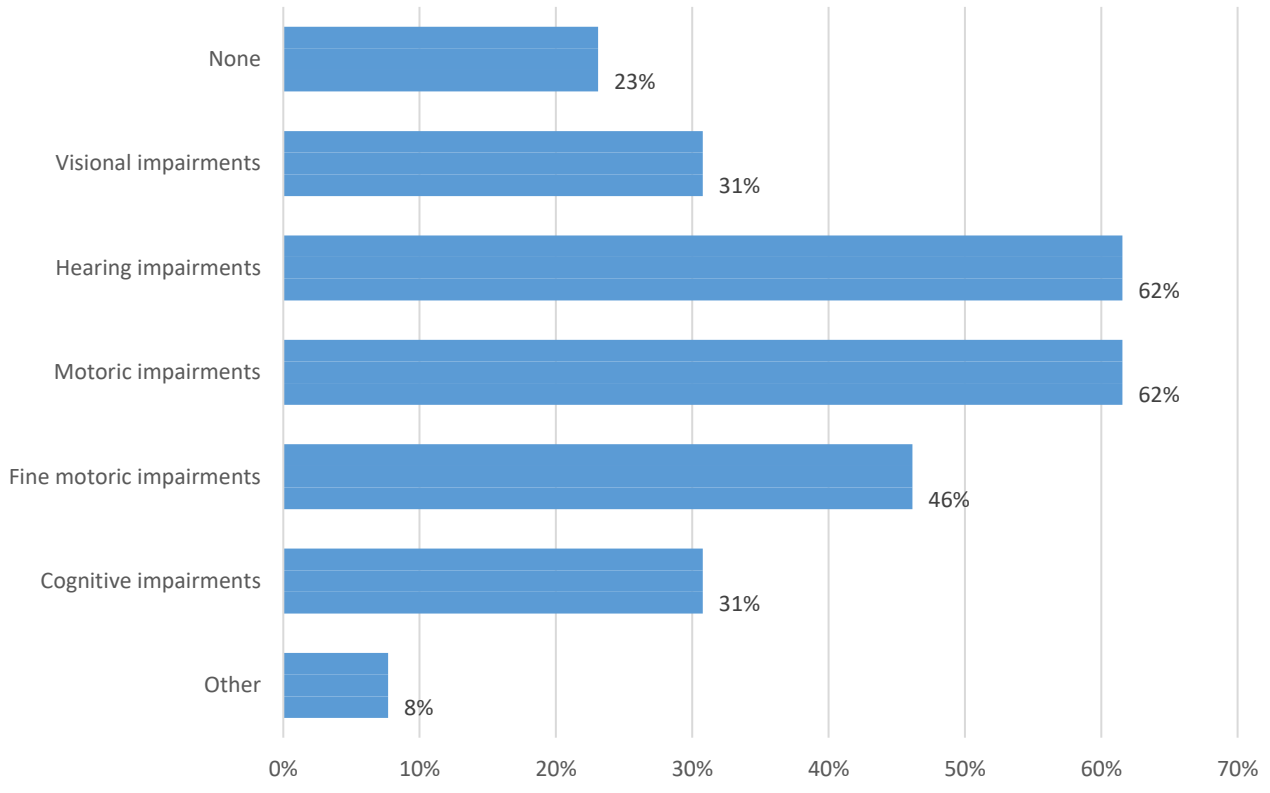
The sharing of information with an electronic health system such as envisaged in PersonAAL can be a fundamental requirement for the personalization of this latter and thus the most effective execution of its functions. Since informal caregivers, however, may share concerns about the sharing of information about the person they care for, for example for reasons of privacy, it is important to know their attitude better. The following question therefore investigated types of information informal caregivers are willing to store in respective e-health systems.

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Imagine you used such a system and you were able to adjust the settings regarding the way your information is transmitted to the person you care for. Which of the following information about the person you care for would you be willing to share with the system so that specific features can be calibrated according to the personal needs of that person?

*Multiple answers possible*



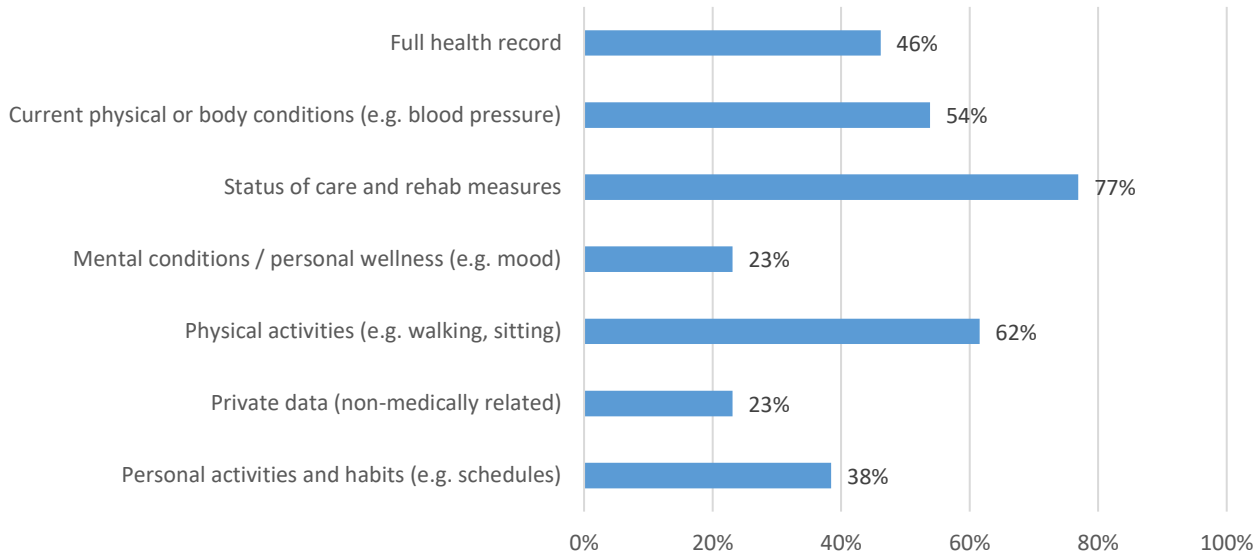
Generally speaking, the propensity to share data necessary for a proper personalization is relatively low. The highest shares of positive responses were filed for hearing impairments and motoric impairments (8), followed by fine motoric impairments (6), visual and cognitive impairments (4 each). Three indicate that they would not share any of such data at all with the system.

Obviously, impairment perceivable by persons other than the nursed persons, namely hearing and motoric abilities, were mentioned the most often, whereas impairments that are difficult to perceive from outside, namely fine motoric and visual impairments, were mentioned less. One may hypothesize that the respondents were inclined to check the categories they are not only willing to share, but also able to share according to their own know-how about the person they care for. One should be careful to conclude that the willingness to share impairments other than those more often, is low.

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### Which of the following information about the person you are caring for would you agree upon to be stored in an electronic health system with access by treating practitioners or caregivers?

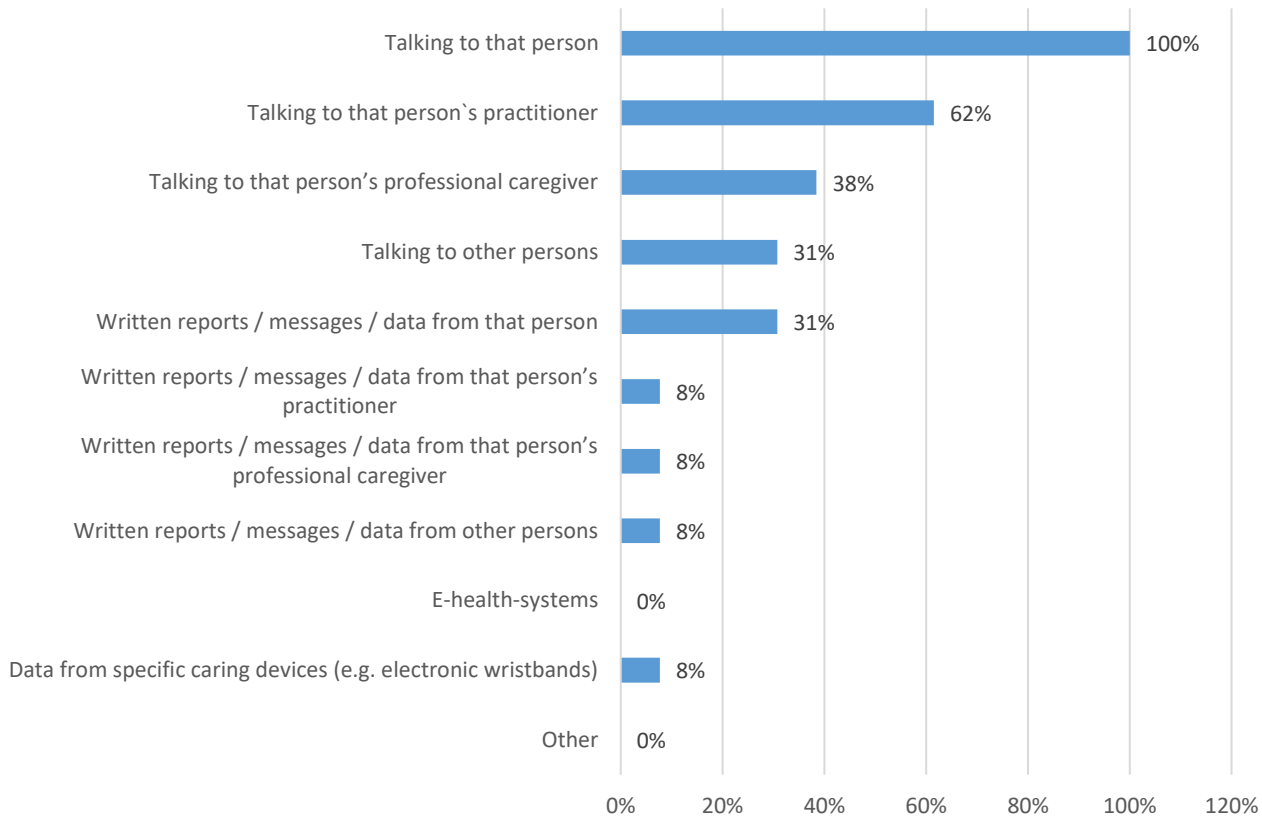
*Multiple answers possible*



Storage of information was investigated as informal caregivers may be closely related to the nursed person and share specific concerns of privacy and data security. Generally speaking, the cumulated total share of those not accepting the storage is higher than the cumulated total share of those willing to store. Still, there are large differences between different types of information. The highest willingness was filed regarding the status of care and rehabilitation measures with approval by 10 respondents, followed by physical activities (8) and current physical and body conditions (7) of the nursed person. Less than every second respondent opted for the full health recorded (6) and personal activities (5). Roughly every fifth agrees with private data and mental conditions such as mood (3 each).

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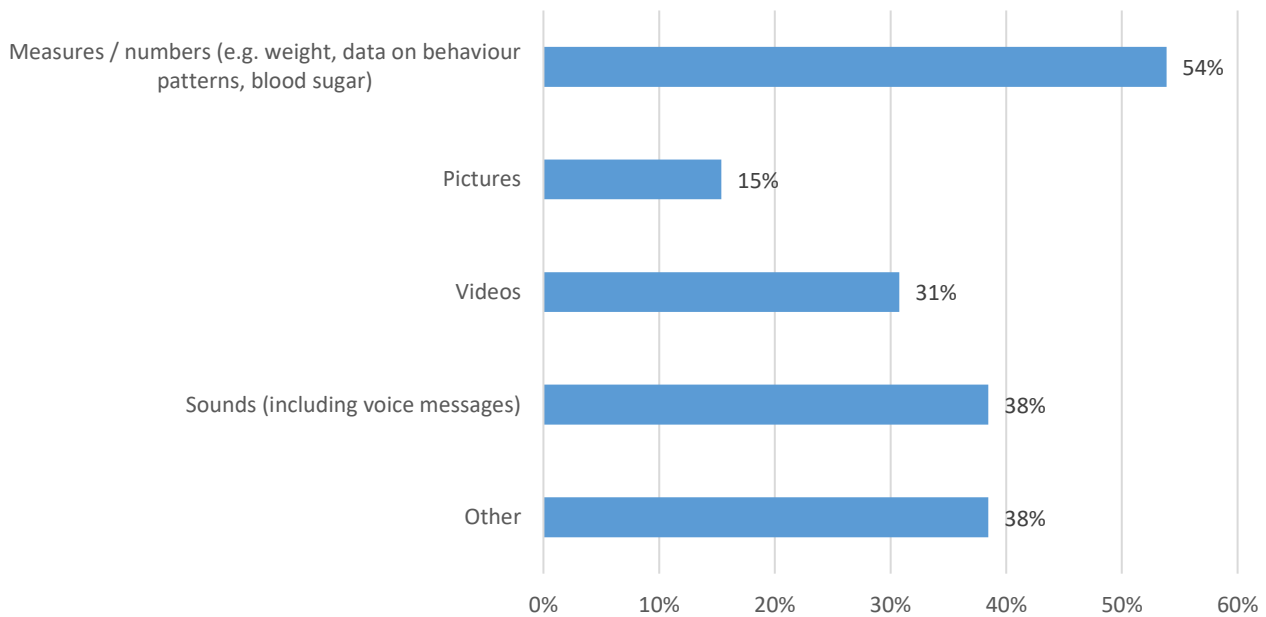
## How do you currently access information about the health and rehabilitation status of the person you care for? *Multiple answers possible*



Taking into account the current modalities used for access to information about the nursed person may give further indications for requirements regarding suitable forms of communication in the envisaged PersonAAL system. All participants mentioned direct conversations as a current mean, whereas 8 indicated that they talk to the treating practitioner. Discussions with other persons, as well as written communications from the nursed person are considered by roughly one third, whereas only one currently refers to alternative modes such as reports from practitioners and data from specific caring devices.

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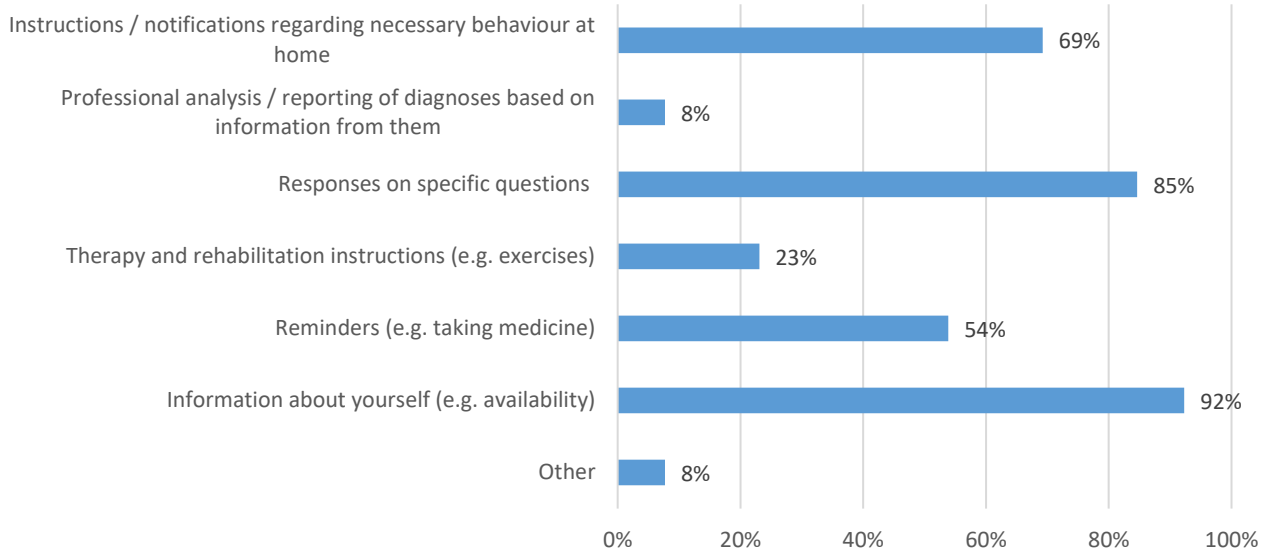
Imagine you monitored a person you care for through an e-health system. In what data formats would you prefer to receive information from that person in order to help you provide your caring services the most effectively? *Multiple answers possible*



As was done for the primary end-users, preferences for data formats in the respondents' communication via e-health systems was analyzed. When asked about what data formats they would prefer, 7 mentioned impersonal measures / numbers, whereas more personally intimate types such as videos (4) and pictures (2) are less popular.

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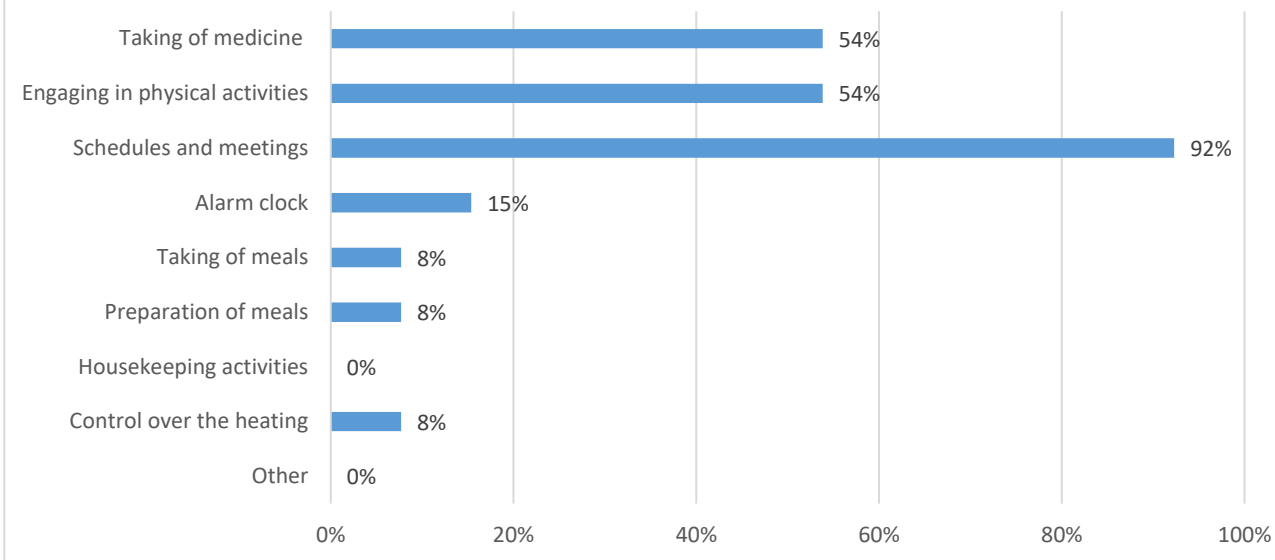
## What type of information do you currently provide to the person you care for (in the context of the caring activities)? *Multiple answers possible*



As regards the unidirectional provision of information from informal caregiver to the person receiving assistance, the information provided by most (12) of the respondents were information about themselves (e.g. availability), responses on individual questions (11) and instructions or notifications (9). Less important is information that may be associated with professional caregivers and practitioners, namely professional diagnoses (1) and therapeutically instructions (3).

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### Provided you could send reminders to the person you care for through an e-health system. What type of reminders would you send?



About every fifth informal caregivers provides reminders to the person they care for. Looking in more detail into different types of reminders the participants could send through an e-health system, the following picture is depicted: A large majority of 12 indicates their propensity to send reminders for schedules and meetings to the persons they care for, which might be an indication for a lack of trust in the latter's cognitive performance or a strong desire for their personal peace of mind. About half (7) would remind for the intake of medicine and the engagement in physical activities. Other types of reminders are mentioned by comparatively low shares of the sample.

Asked qualitatively about what additional sort of information the respondents currently cannot exchange with the person they are caring for but would like to exchange with them, the following was mentioned.

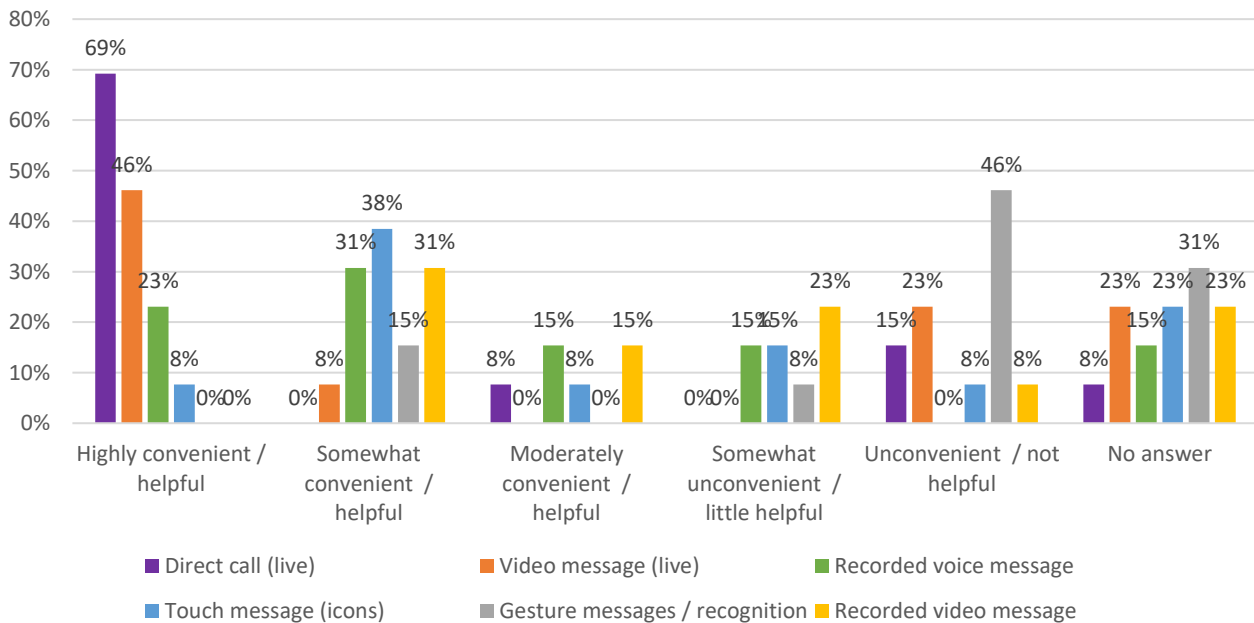
- Daily feelings of well-being
- Blood pressure
- Change of health conditions and caring activities
- Mood
- Data on weight and carrying out of exercised when I am away
- Nutrition and taking of medicine
- Psychological state of mind
- Day-to-day feeling of contentment

Similar to the investigation among the elderly people targeted by the PersonAAL system, the current survey was interested in the convenience of different modes of informational exchange including both direct interaction and delayed modes. In contrast to the question asked earlier

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about accepted data formats, this question was not based on optional choice but on scale so that each way of communication can be analyzed in more detail.

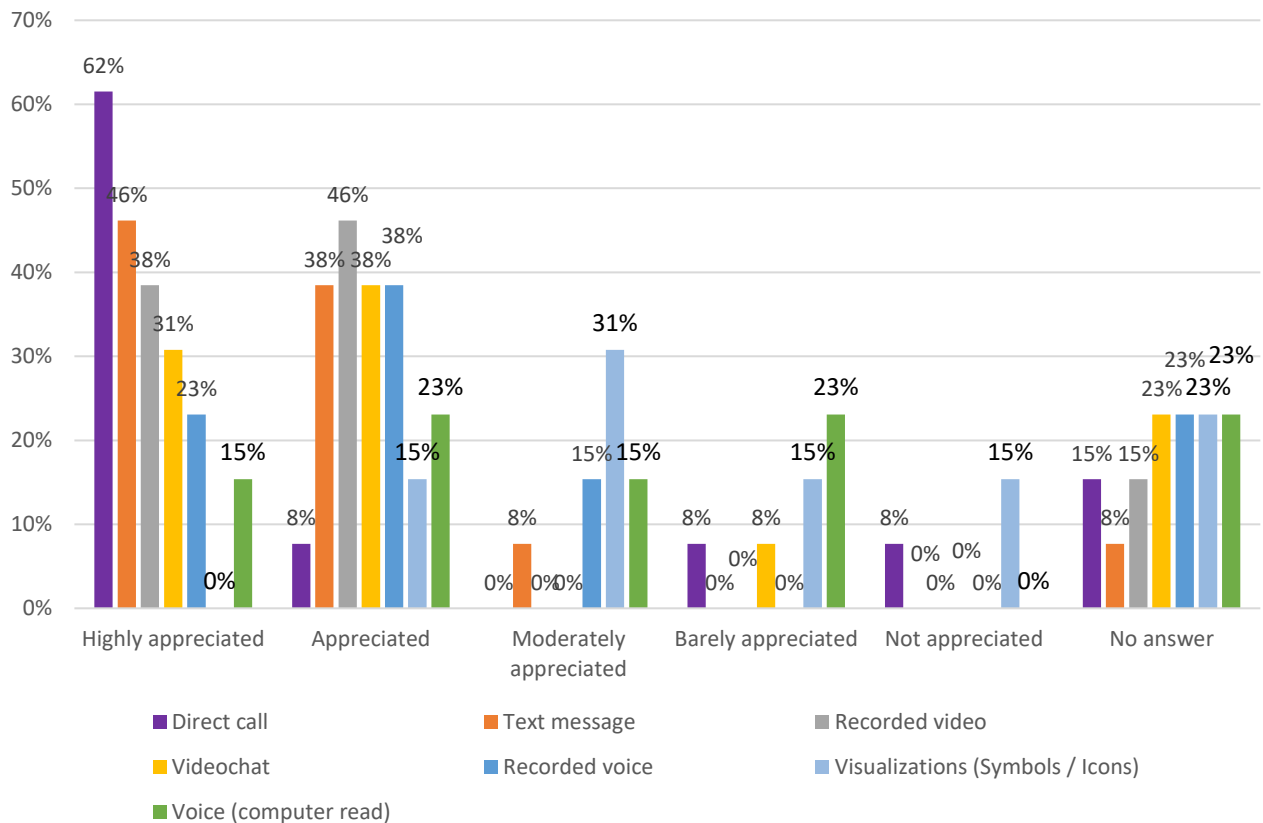
**Imagine a system by use of which you can exchange information with the person you care for from your house. How do you rate the convenience / helpfulness of the following ways to transmit your messages to them?**



As illustrated in the above chart, most respondents consider direct interaction, namely direct call (9) and video call (6) highly convenient. Recorded voice messages, touch message and recorded video also appear rather promising with 9, 7 and 6 respondents considering these options at least moderately convenient. Gesture gained rather low shares for the underlying purpose.

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## How do you rate the following options to receive information from the practitioners or caregivers of the person you are caring for?



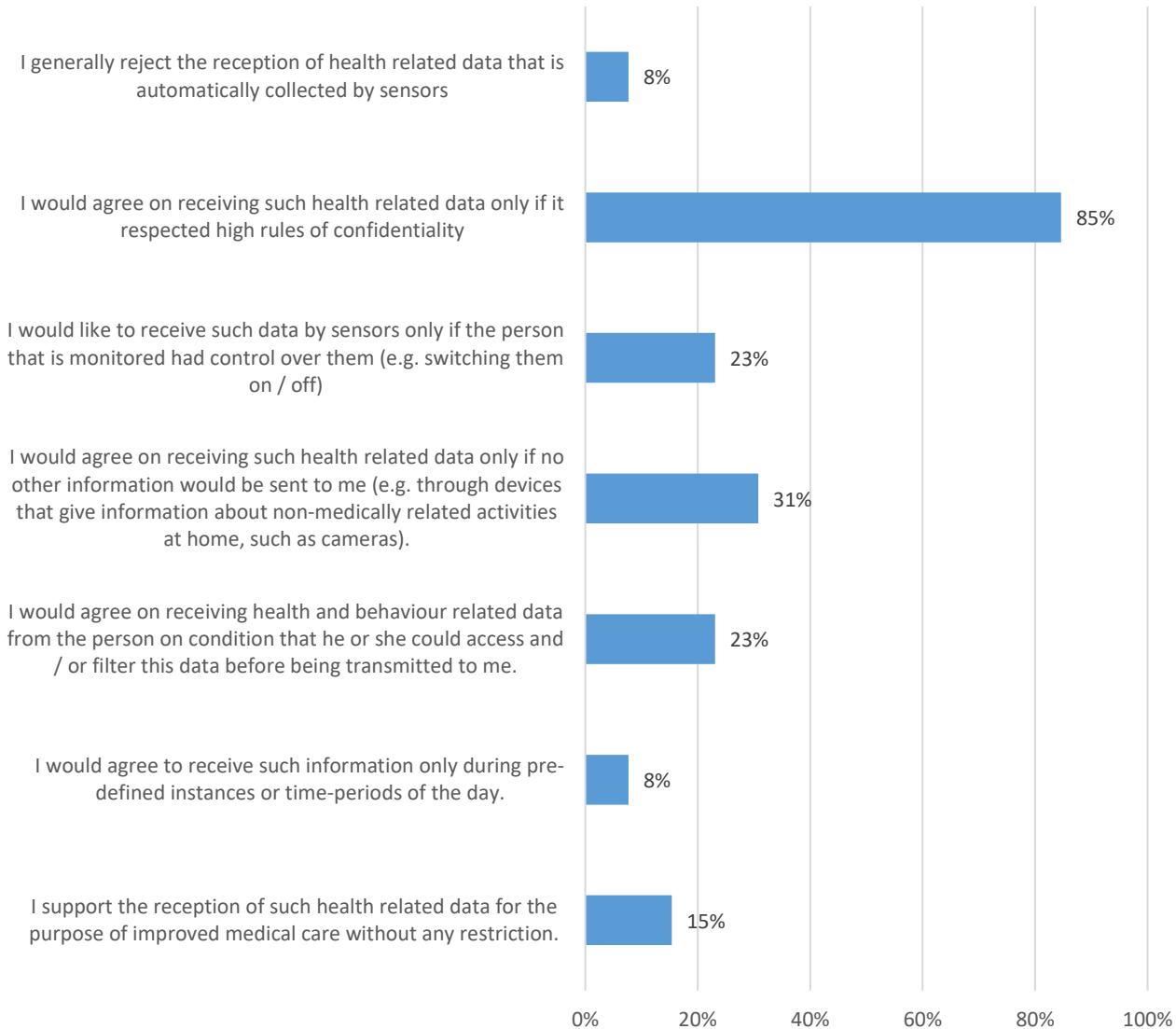
As regards the mere reception of information from practitioners, almost all of the proposed media reach high shares, with 50% or more of the respondents indicating at least appreciation of the respective medium at hand. Exceptions to this rule are computer read voice messages (5) and the visualization through symbols or icons (2). Text messages (11), recorded video (11) and direct call (9) reach the highest cumulated share for respondents indicating high appreciation or appreciation for the proposed media.

According to these values, there is no indication regarding general preferences for delays vs. direct interaction and personal contact vs. impersonal contact. Rather, it seems that the current findings largely reflect common experience and general establishment of the formats at hand.

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**Imagine a situation where a technical system collects data on the physical (health) conditions and progress of rehabilitation measures by use of sensors in the home of the person you are caring for, so that you can optimize your care for this person. Which of the following statements reflects your opinion?**

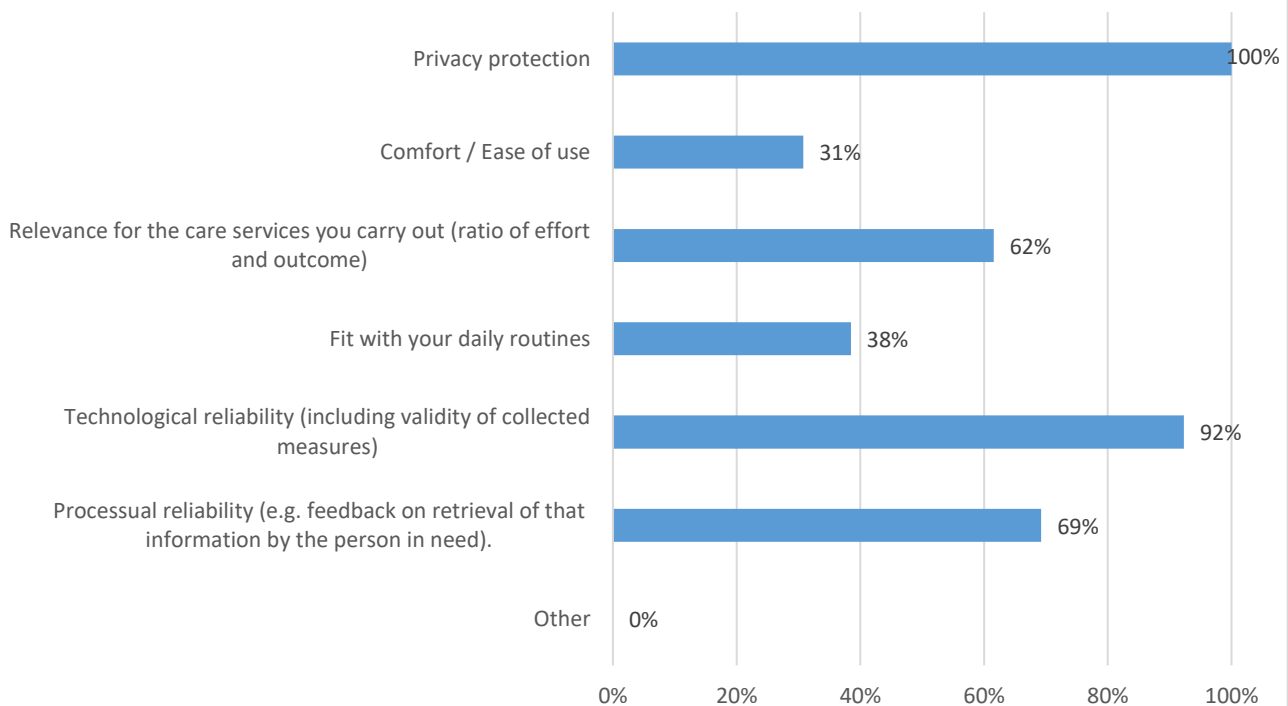


Privacy was highlighted in the survey among end users as an important issue in the context of the overall exchange of health-related data through an e-health platform. As the PersonAAL system intends to collect health-related data by use of different sensors, the respective acceptance of such data collection was also accepted on the part of informal caregivers. As can be clearly derived from the following chart, 11 of the 13 respondents clearly require the assurance of confidentiality in the case that the nursed person's status is being monitored by sensors.

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Almost every third (4) demands the clear separation of medically required information from data usable for additional purposes. Only 2 accept the installation of sensors in the house of the cared person without restriction.

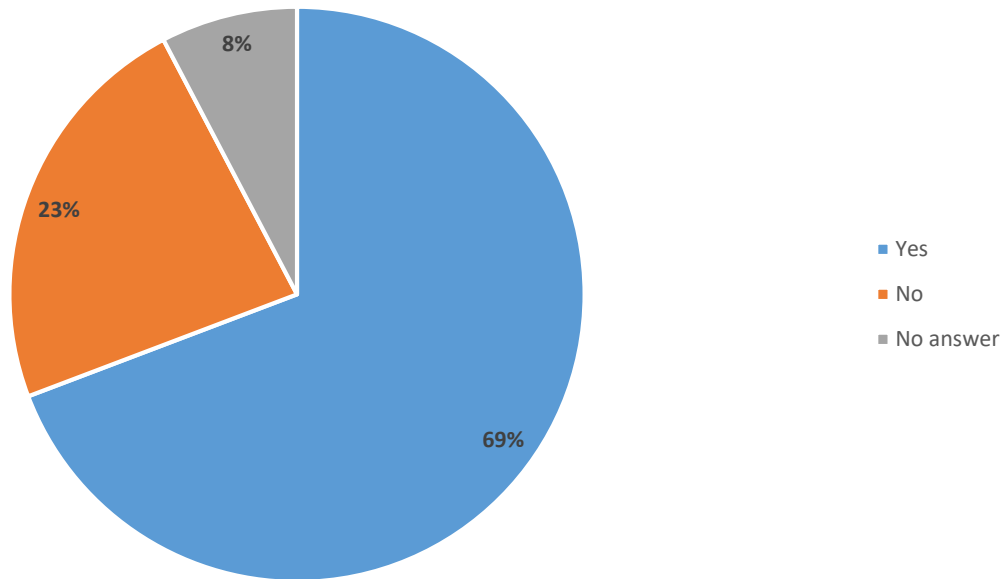
**Imagine a technical system by use of which you receive automatically collected information about the health status and rehabilitation measures of the person you care for and where you are able to send instructions to that person based on the data you receive. Ignoring the costs or cost-benefit-ratio of installing such a system. What would be the most relevant conditions for you to use it? *Multiple answers possible***



The requirement of data protection is confirmed in the following analysis. Considering prerogatives for the use of a system like PersonAAL, privacy was marked by 100% of the respondents. Generally speaking, the minimum requirements from the informal caregivers' perspective are manifold. Technological reliability (12), processual reliability (9) and relevance for the care service offered (8) are further issues checked by most participants. Comfort / ease of use (4) and fit with the informal caregivers' own daily routines (5) were still mentioned by significant shares.

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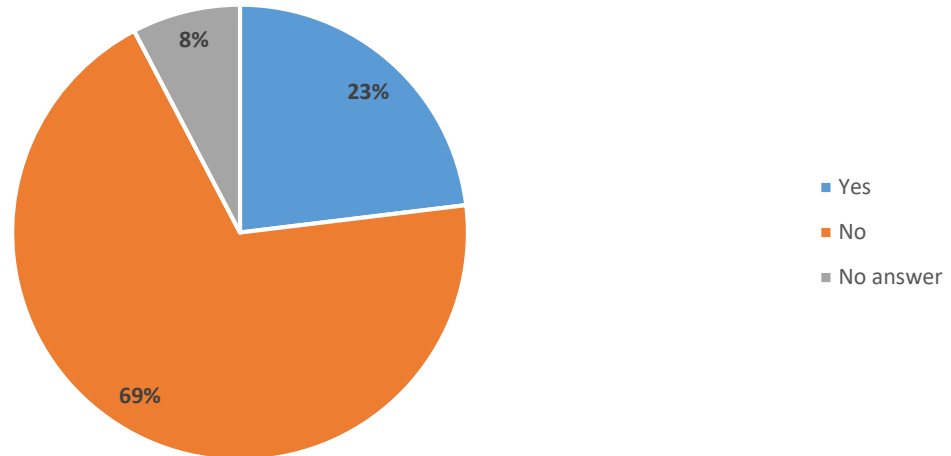
Please imagine an electronic health system that collects daily information about the physical status and rehabilitation measures of the person you are caring for (e.g. through sensors) and which can exchange this information with the treating practitioner / therapist and carepersons . Do you expect that such a system can significantly improve the treatment you give to that person?



Despite the high minimum requirements, a system such as envisaged by PersonAAL is still considered useful. Nine out of 13 participants indicate that they expect a significant improvement of the treatment they give to the person in need upon usage thereof.

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**Would you consider to reduce your personal presence at the person in need's house if such a system was totally reliable and if it allowed you to carry out all required caring activities remotely?**



Nevertheless, such a system is considered a device for additional care rather than a substitution of personal presence. Only 3 participants indicate that they would reduce their physical presence provided the system works reliably. Important reasons may be social aspects and care services requiring physical assistance.

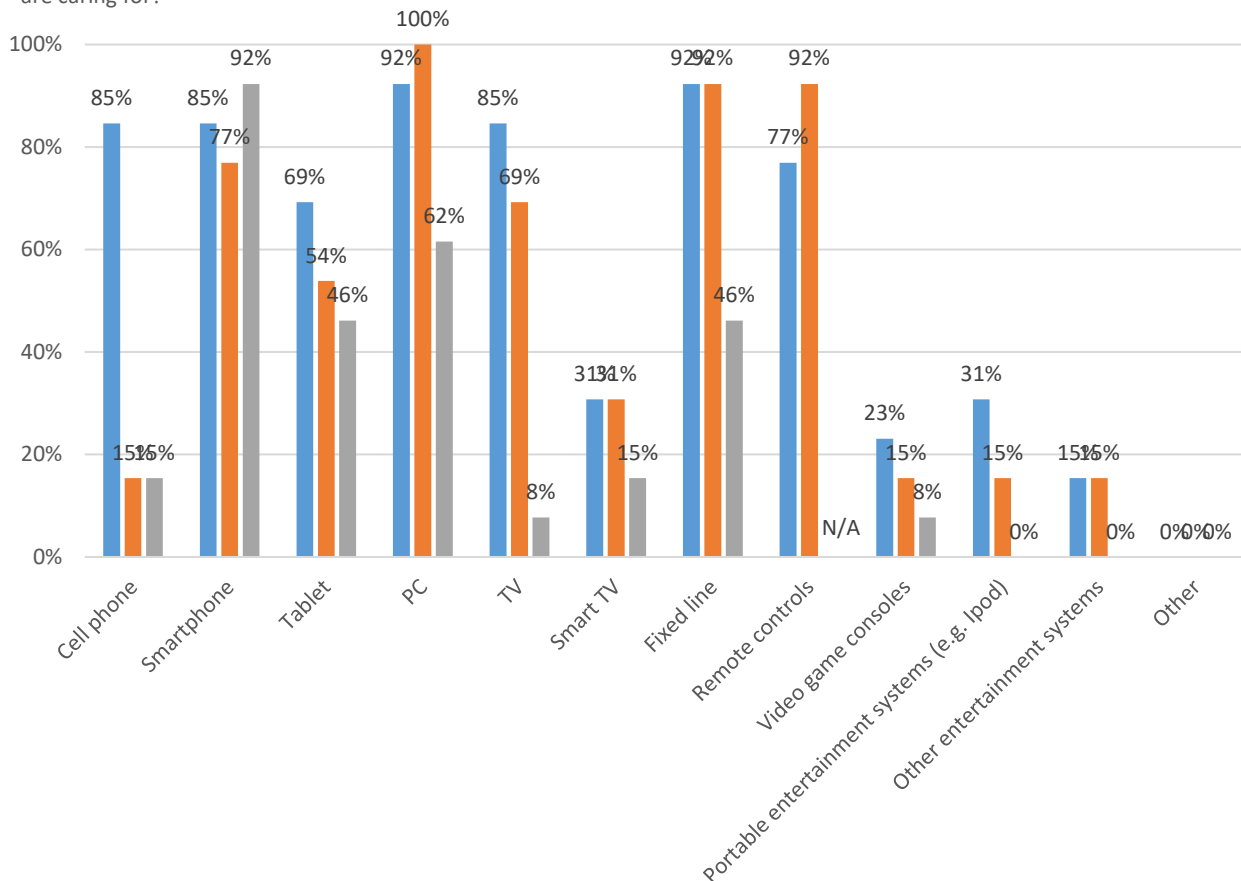
### 4.3.3 Use of technical devices

Equal to the survey among elderly end-users the current use of technical devices was investigated among informal caregivers in order to learn more about their habits and familiarity with modern technological devices. As outlined earlier, informal caregivers are not only the largely involved in the usage of the envisaged PersonAAL system and should therefore be considered in their role as consumers. Also a large share of informal caregivers ranges themselves in the age group defined as 'elderly people' and may therefore face similar usability issues.

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## Which of the following devices do you...

- ... do you think you are comfortable with / you can handle well?
- ... do you use at least once a day?
- ... would you be willing to use regularly to receive information about your health status / rehabilitation progress of the person you are caring for?

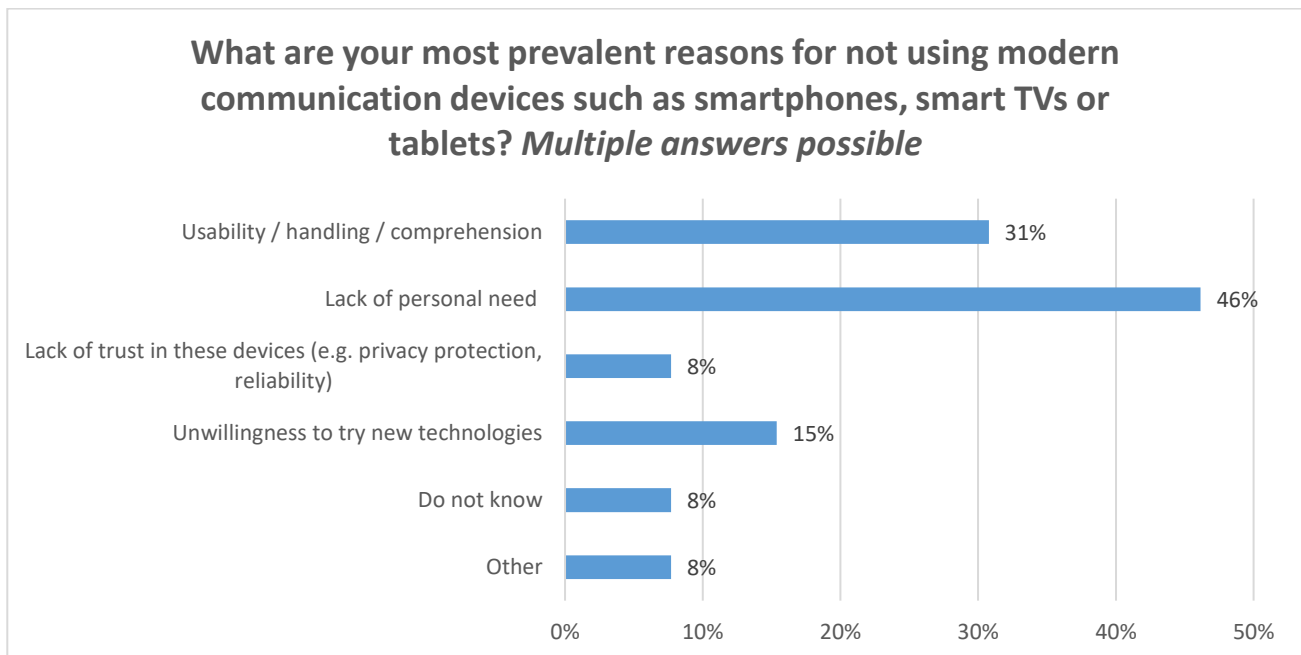


As shown in the above chart, the sample addressed by the current survey is extensively familiar with modern communication devices. Twelve out of 13 feel comfortable with PC, 11 each with tablet, cell phone and smartphone. The daily usage is also rather extensive. All respondents indicate the everyday usage of their PC. Ten use smartphones and 7 use tablets every day. Regarding a suitable platform for the communication of information, TV also appears rather promising. Eleven feel familiar with TV, 9 use it every day. The same is true for fixed lines,

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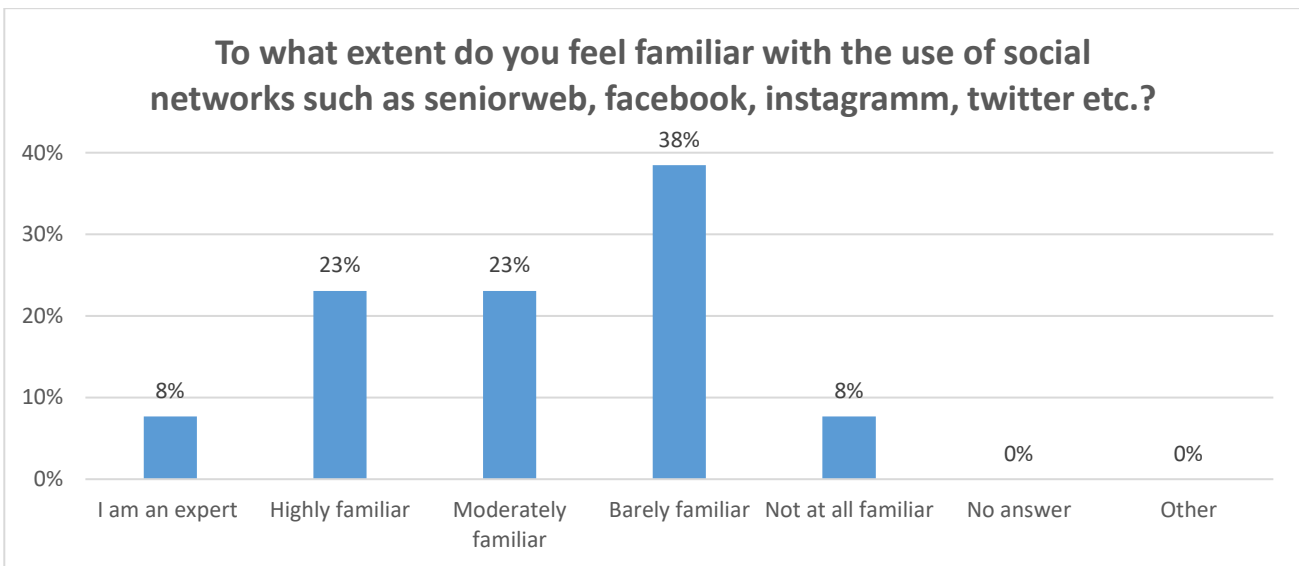
reaching shares of 92% both for daily usage and familiarity. Smart TV, in contrast, is only used by 4 out of 13 participants.

Regarding their own preferences for the usage of devices in the context of an electronic health system such as envisaged by PersonAAL, the highest shares were recorded for smartphones (12), followed by PC (8), fixed line and tablets (6 each). Only 1 out of 13 considers TV the adequate medium.

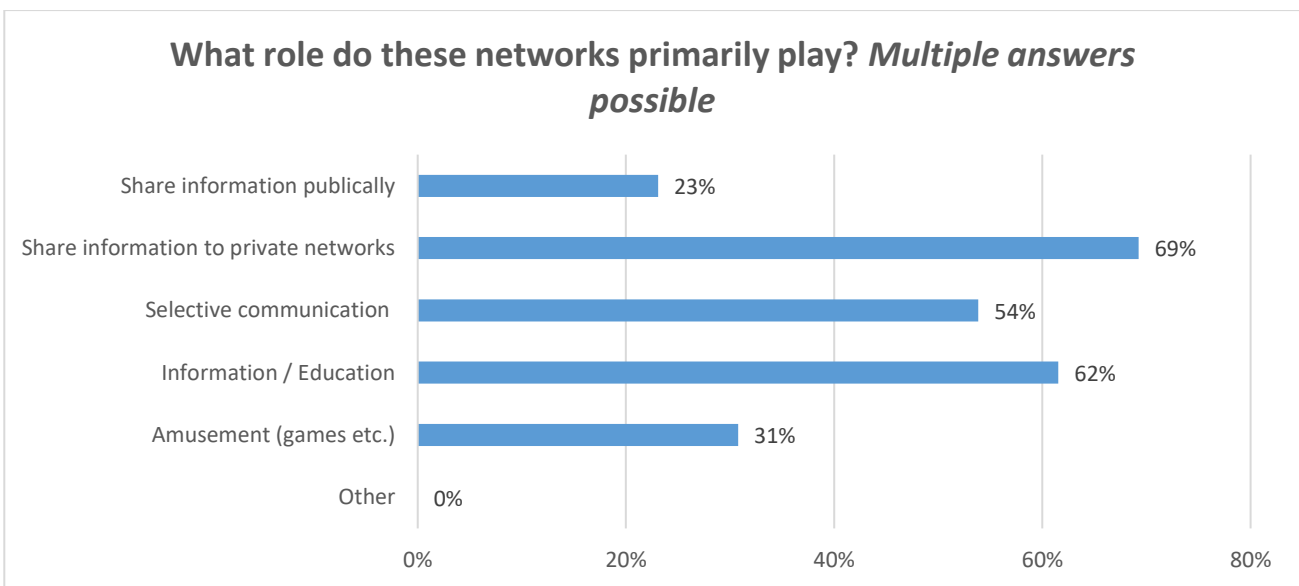


Major reasons for not using modern communication devices such as smartphones, smart TVs or tablets are a lack of personal need (6) and usability issues (5). This confirms the claim brought forward earlier that informal caregivers themselves need to be considered in their function as customers with their own desires, preferences and problems. In addition to designs taking into account potential impairments of the informal caregivers, the PersonAAL system will need to solve specific problems of the informal caregivers as well and sensitize these latter for their specific benefits resulting from the use of the envisaged system.

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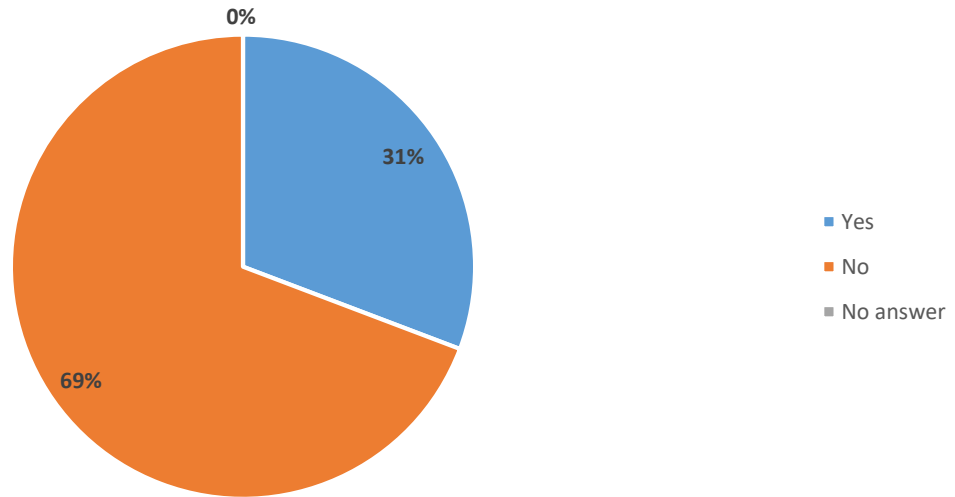
About half of the participants feel at least moderately familiar with social networks. Only one does not feel familiar with social networks at all.



Asking about the role of social networks, the sharing of information to private networks ranks the highest in terms of overall shares (9 out of 13), followed by educational purposes (8) and selective communication to individual addresses (7). Four out of 13 participants use social networks for reasons of entertainment.

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Do you already have experience with a system for the tracking of health conditions or rehabilitation measures (e.g., portable measurement systems, reminders, alarm systems)?

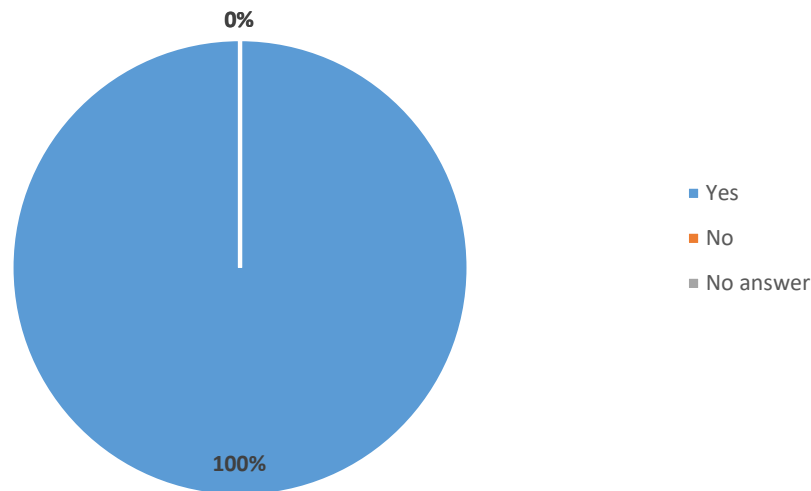


The experience with tracking systems is given by four elements of the sample.

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**Would you be willing to use any new device on a daily basis if it is easily comprehensible and if it assists you to carry out your monitoring of a person in need more effectively?**



However, the general willingness to use additional devices is given, provided such devices are easily comprehensible and assist through the monitoring of a person in need so that this assistance becomes more effective. Among the small sample considered for the purpose of this study, all respondents indicated such a willingness.

#### 4.3.4 Usability of technical devices

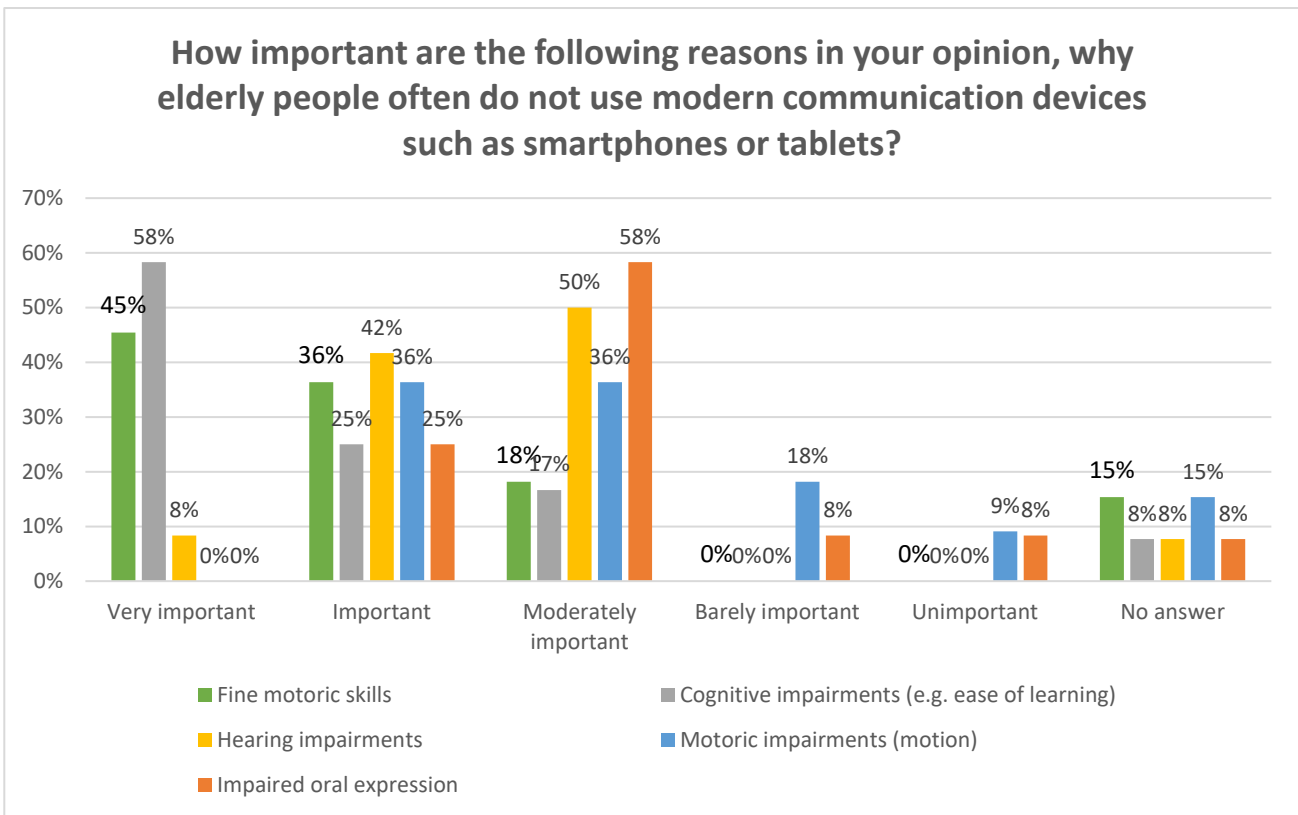
As was claimed in the survey among elderly people (end users), the familiarity with modern technological devices gives only some information about the potential success the different hardware could have for usage with the PersonAAL application. Equally important is the usability, i.e. comprehensibility, handling and ease of learning associated with them. The survey therefore investigated in more detail what types of usability issues both informal caregivers from the current sample and elderly people, in the view of informal caregivers, are concerned with.

The following reasons were mentioned as major reasons why informal caregivers reject the usage of certain communication devices.

- Data protection and security
- Commercials
- Radiation
- Privacy (accessibility)
- Cannot replace personal contact
- Misinterpretations
- No excitement to learn functionalities in a playful way
- No need to use specific ways to communicate

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- Existence of substitutes (e.g. PC replacing tablet)

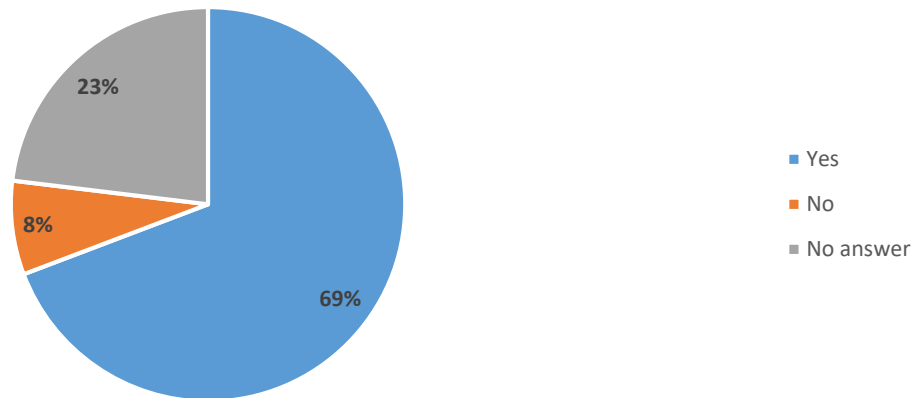


The chart above reflects the informal caregivers' perspective on the rejection of modern communication devices by elderly users. According to their assessment, major reasons why elderly people often do not use such devices are primarily the lack of fine motoric skills and the existence of cognitive impairments. At least 92%, 73% and 72% of the respondents also consider hearing impairments, impaired oral expression and motoric abilities at least moderately important reasons for that. None of these factors are considered barely important or unimportant by any significant shares of the sample.

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### 4.3.5 Success Factors

**Do you think that a reliable e-health-system monitoring the health and rehabilitation status of the person you are caring for would give you more confidence to let that person live independently at home for a longer period of time?**

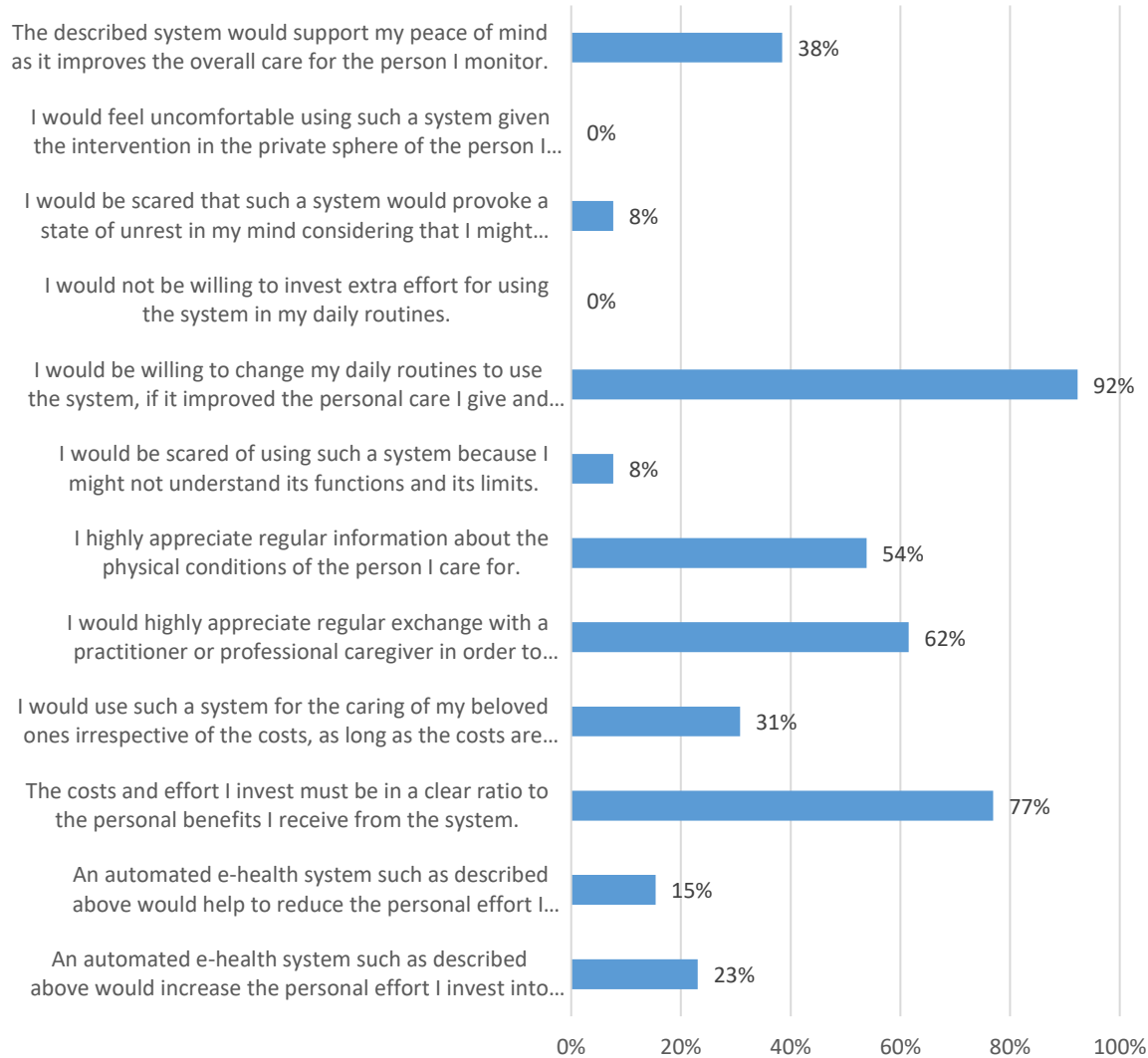


More than two thirds (9 out of 13) of the informal caregivers covered by this study consider a reliable e-health system beneficial for reasons of confidence to let the person they are caring for live at home independently for a longer period of time. Only 1 does not have such a trust in respective systems.

Despite the overall favourable attitude towards the use of an e-health system, it was found earlier that the actual usage will be subject to qualifications and meeting of fundamental requirements such as in terms of usability, purpose and technical as well as operational design. In order to find out more about general success factors, all participants were confronted with particular statements, the approval of which can give valuable information about fundamental requirements of usage.

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**Which of the following statements reflect your opinion? Please imagine a scenario where you use a system that monitors the health and rehabilitation status of a person you care for at home and which allows direct with him or her and his or her practitioner / professional caregiver**



The chart above illustrates that the system is generally appreciated by large shares for the purpose of exchanging information with practitioners and professional caregivers (8 out of 13) as well as for regular information about the physical conditions of then nursed person (7). Five participants expect that the use of a respective system would give them peace of mind and 12 would even be willing to change their daily routines if the system effectively improved the personal care they provide. At the same time, a large share of respondents (10 out of 13)

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indicates that the system inevitably needs to provide clear benefits and keep in balance adequate ratios between costs and benefits of using the system, opposed to 4 who would use the system irrespective of the costs it inflicts on them. Those expecting an increase of effort by using the system (3) are even slightly more numerous than those expecting respective reductions.

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Schweizerische Eidgenossenschaft  
Confédération suisse  
Confederazione Svizzera  
Confederaziun svizra

## 5 RECOMMENDATIONS FOR INFORMATION SHARING BETWEEN ELDERLY USERS (PRIMARY USERS) AND INFORMAL CAREGIVERS (SECONDARY USERS)

### 5.1 Privacy

The PersonAAL system will need to regulate information sharing and access according to the privacy legislations in the countries it is operating in. However, the following issues are of great relevance in any country that the system is going to be used in:

- a) The elderly would need to control what information she or he may share with informal caregivers. This means that the “administrator” access rights to the system ought not to be given to the informal caregiver. Not even in the cases where the elderly is willing to confirm this by written consent since the elderly would no longer have technical control over the information sharing and access.
- b) The elderly may choose to share information automatically based on the following categories of data:
  - i. *Restricted emotional information* (e.g. “(Today) I’m fine” or “Not feeling so well this morning”)
  - ii. *Aggregated activity data* (e.g. number of steps per day or week, or categorical information like “less active than average”, “normal activity level” or “more active than average”)
  - iii. *“Everything is normal”-status updates* (e.g. a brief message stating that the elderly is ok and nothing more based on self-report and sensor data from the home of the elderly)
  - iv. *Alarms and messages only generated when there are reasons for concern*
  - v. *No data* (the elderly must have the technical opportunity to share no data)
- c) The elderly may choose to share more detailed information manually through a “share screen” set-up in a web-based safe log in system, where formal and informal caregivers may be invited in for a time limited session.
- d) Direct communication (text, audio, pictures or video) initiated by the elderly or invited contacts
  - i. The elderly contacts a caregiver
  - ii. A caregiver contacts the elderly
  - iii. Conference call/multi-participants’ communication
- e) Set of action rules agreed upon by the elderly and the caregiver
  - i. The elderly and the caregivers would need to make an agreement on which action either party should take as a consequence of certain events or situations like if an alarm message is generated or the caregiver receives an automatic message saying “Today I do not feel so well”.
  - ii. These actions ought to be pre-programmed so the elderly and the caregiver can choose from a list of options when the system is set up or modified later on.

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## 5.2 Emotional support

The emotional dimension of the relationship between the elderly and the informal caregivers will in many cases be a key element of such a digital system, e.g. family members and close friends might be concerned about the wellbeing of the elderly, or the elderly may appreciate more frequent support and contact than what is possible when living alone. A solution that stimulates emotional support and reduces worries and distress would enhance the wellbeing for both the elderly and the informal caregivers. A fairly recently launched British smartphone app serving a very different purpose, the Stay Alive app<sup>1</sup>, has been developed to strengthen emotional and social support from the informal caretakers of persons with high suicide risk. The app sends information to the caretaker about the emotional state of the persons with suicidal thoughts on a daily basis, and the caretakers have the opportunity to respond back. In the case of elderly living alone such close contact and monitoring of emotional states would of course not be needed and may also be perceived as an invasion of the private life of the elderly. Hence, the PersonAAL system should allow for great flexibility and customization of the social contact between the elderly and the informal caregivers, in line with the following concerns:

- a) Communicating wellbeing and that the elderly is safe (purpose: reducing worries among caregivers)
- b) Stimulating social interaction between the elderly and caregivers (purpose: to prevent loneliness for the elderly and increasing quality of life for both parties)
  - i. Sharing information about daily activities and experiences
  - ii. Direct communication (text, audio, pictures or video)

## 5.3 Practical support

Communication regarding practical help might be regarded as a lesser intrusion of privacy, especially if it is generated directly by the elderly or the caregiver, and not automatically generated by the PersonAAL system. Relevant practical issues might be help with shopping, paying bills, preparing visits, planning maintenance of the apartment, and so on.

## 5.4 Decision making aid for the elderly and the caregivers

When new users are introduced to the PersonAAL system, they ought to be taken through a decision-making process where they make informed decisions about privacy, information sharing and access, and frequency of contact. The purpose of such a decision-making process is to increase awareness on what types of information will be shared, and to ensure that the system is individualized to the values and preferences of the elderly.

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<sup>1</sup> [http://www.prevent-suicide.org.uk/stay\\_alive\\_suicide\\_prevention\\_mobile\\_phone\\_application.html](http://www.prevent-suicide.org.uk/stay_alive_suicide_prevention_mobile_phone_application.html)

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## 6 CARETAKER'S INTERFACE MOCKUPS

PersonAAL aims to explore the knowledge caretakers have about the person being cared for, to improve the efficacy and efficiency of the caretaking support provided, but also to create an interactive environment that is more motivating for the ones being cared for. Caretakers' knowledge about habits or preferences can be used to provide a personalized experience to the beneficiaries of the system. They can also use it to set reminders for medication intake or other activities that need to be performed by those being cared for.

To allow caretakers to benefit from this kind of support, PersonAAL will offer an interface where caretakers can express the rules they wish the system to put into practice. These rules have two main components: a trigger that decides when the rule is to be applied; and an action that is to be executed by the system when the rule is triggered. Figures 1 to 5 present initial mockups used to explore this concept. They illustrate a use case, where the caretaker is setting up a rule that will trigger an alarm on the user's smartphone if the user is not out of bed by 9AM.

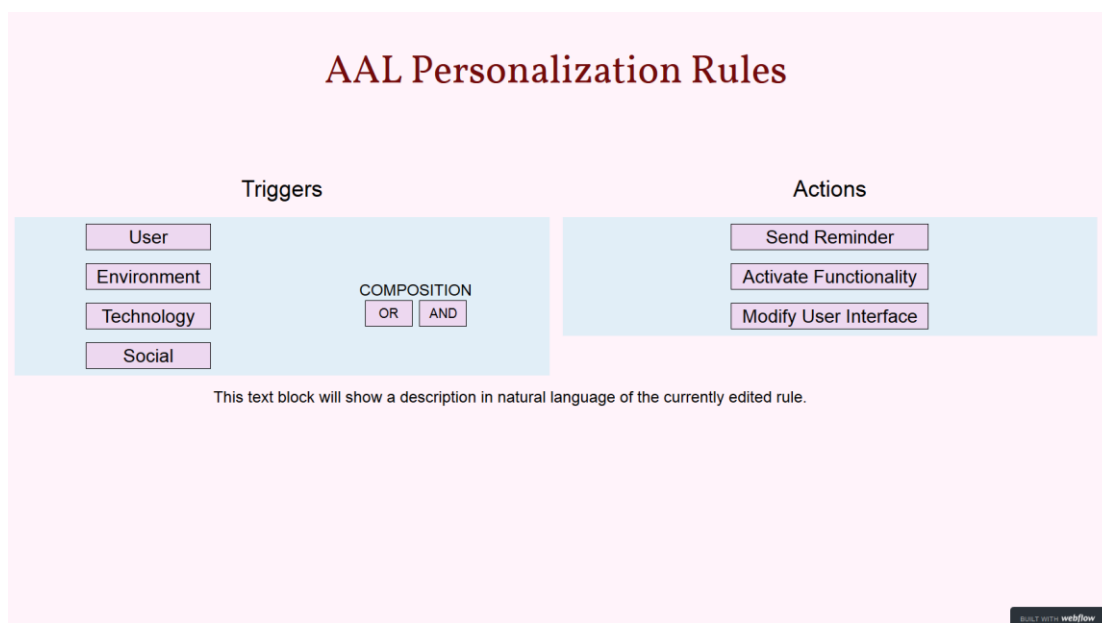


Figure 1 – Initial step for rule setting. The caretaker should start by selecting what will trigger the rule. In this example, the caretaker selects "User".

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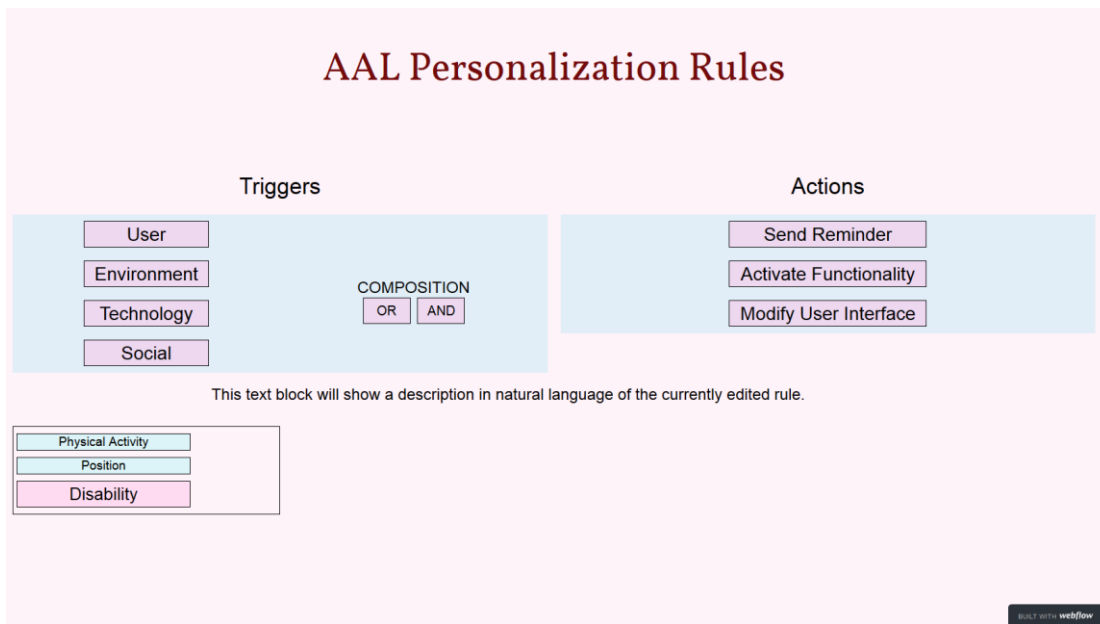


Figure 2 – Rule trigger definition. The caretaker now selects one of the user settings to trigger the action. In this example, the caretaker selects “Physical Activity”.

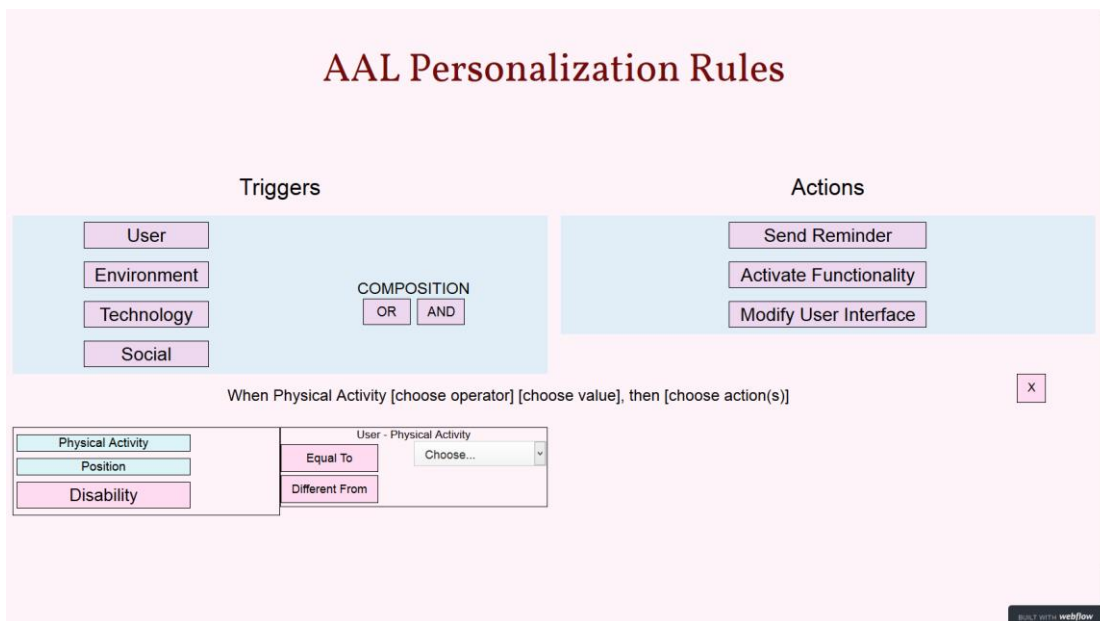


Figure 3 – Rule trigger details. The caretaker now has to select which activity will trigger the action. In this example, the caretaker selects “Lying down”.

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## AAL Personalization Rules

### Triggers

User

Environment

Technology

Social

COMPOSITION

OR AND

When Physical Activity IS EQUAL TO Laying down, then [choose action(s)]

Physical Activity	User - Physical Activity
Position	Equal To <span style="border: 1px solid #ccc; padding: 2px;">Laying down</span>
Disability	Different From

### Actions

Send Reminder

Activate Functionality

Modify User Interface

Figure 4 – Compose rule triggers. The caretaker can include several triggers composed by AND and OR operators. In this example, the caretaker included another trigger – Environment Time is equal to 9AM – and composed both with the AND operator, before setting the action.

## AAL Personalization Rules

### Triggers

User

Environment

Technology

Social

COMPOSITION

OR AND

When Physical Activity IS EQUAL TO Laying down AND Time IS MORE THAN 9:00, then send reminder "It's late, get up!" to the smartphone

Noise	Environment - Time
Weather	Equal To <span style="border: 1px solid #ccc; padding: 2px;">9:00</span>
Time	Less Than
	More Than

### Actions

Send Reminder

Activate Functionality

Modify User Interface

### Send reminder

It's late, get up!

DEVICE: Smartphone TV Desktop PC

Figure 5 – Rule action definition. In a similar manner to what was done for the triggers, the caretaker sets the action to be performed. In this example, the caretaker selects the Send Reminder action, chooses in which device the reminder will appear, and enters the content of the reminder.

The previous example illustrates a trigger-action rule-setting interface, which could be implemented on top of the PersonAAL framework. However, for the scenarios considered in the

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scope of PersonAAL, it might be important to have information about the person being cared for without requiring setting rules. This will be useful for PersonAAL automated interface adaptations, for example. Figure 6 presents a mockup of an interface where caretakers could provide information about the health condition or contextual factors affecting the one being cared for. With this kind of mechanism, the caretaker could select from a pre-set list of conditions or factors that the PersonAAL could interpret, the ones that afflict the person being monitored by the system.

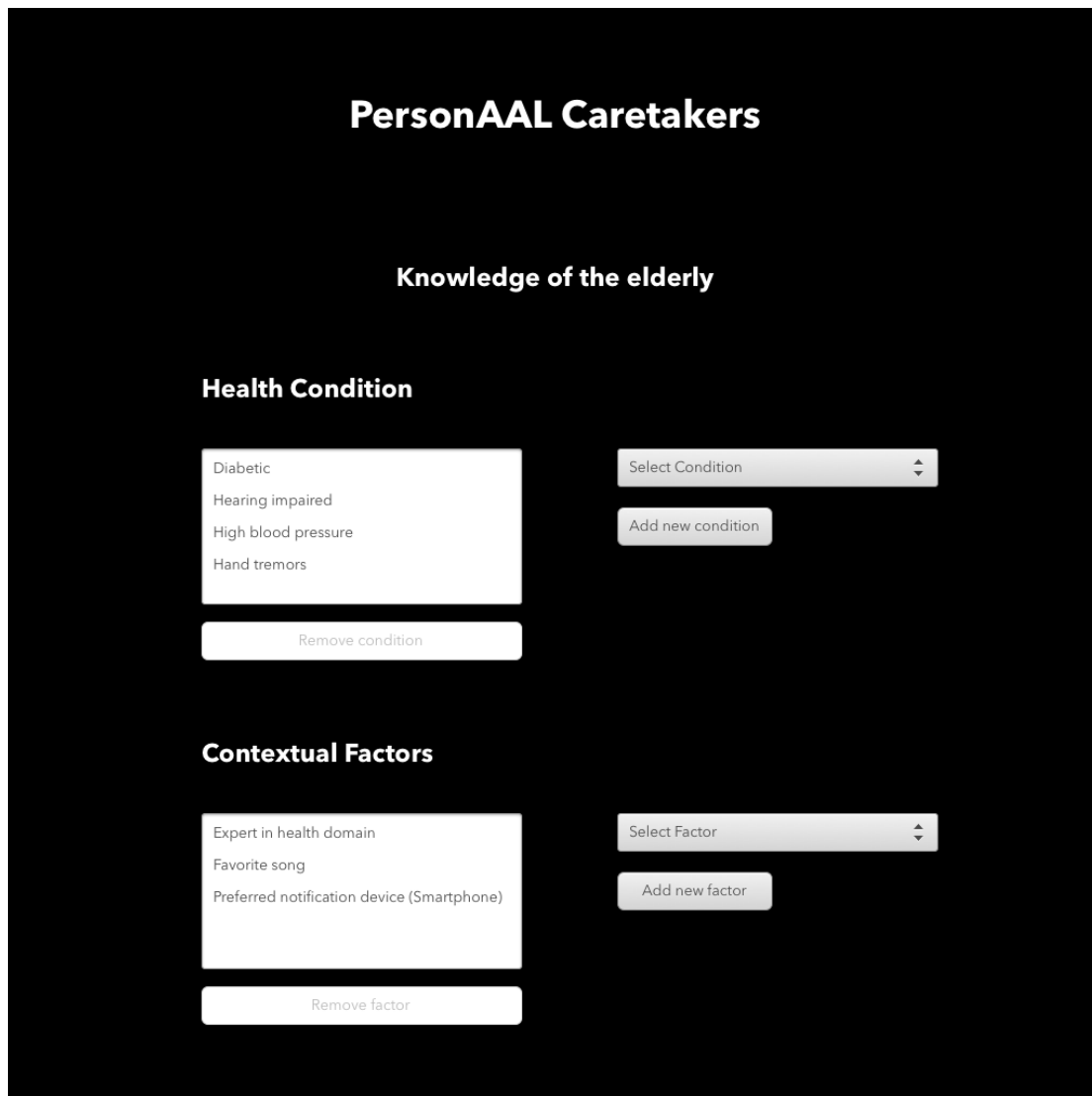
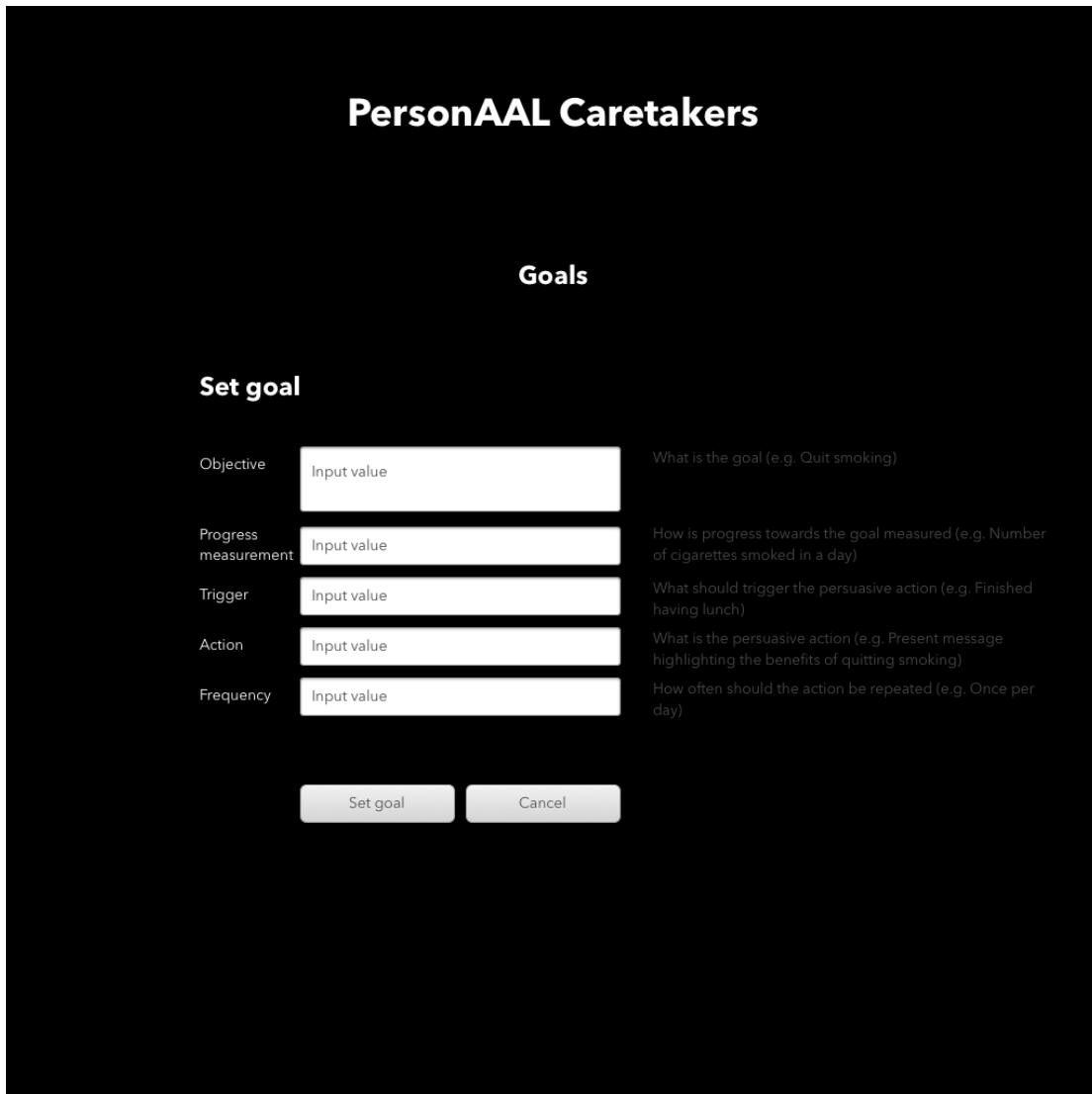


Figure 6 – Providing information about the person being cared for.

Another type of information useful for the system are the goals set for the person being cared for. These could for example relate to rehabilitation activities or to the promotion of healthier lifestyles. Goals can be handled in a similar manner to rules, in that some trigger and action are required to prompt the user to perform something to achieve the goal. However, they require

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more information: the system needs to be able to assess if the user is closer to the goal. Figure 7 presents a mockup of an interface where a caretaker could supply this information.



**PersonAAL Caretakers**

**Goals**

**Set goal**

Objective	<input type="text" value="Input value"/>	What is the goal (e.g. Quit smoking)
Progress measurement	<input type="text" value="Input value"/>	How is progress towards the goal measured (e.g. Number of cigarettes smoked in a day)
Trigger	<input type="text" value="Input value"/>	What should trigger the persuasive action (e.g. Finished having lunch)
Action	<input type="text" value="Input value"/>	What is the persuasive action (e.g. Present message highlighting the benefits of quitting smoking)
Frequency	<input type="text" value="Input value"/>	How often should the action be repeated (e.g. Once per day)

Figure 7 – Interface for setting goal. The caretaker can provide how is progress towards the goal measured, and when, what and with what frequency are persuasive actions taken to promote goal achievement.

The mockups presented in this section will be used to demonstrate the possibilities of the PersonAAL system to caretakers, and evaluate if formal caretakers perceive the concepts represented in them.

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## 7 USER WORKSHOP

In June 2016 we conducted a workshop to assess initial prototypes of tools for informal caregivers. In the context of this workshop we also discussed how caregivers support the activities of the persons being cared for. While the results of the prototypes review will be later presented in D2.4, in this section we focus on the findings related to the types of activities a system such as PersonAAL would be more useful in supporting.

### 7.1 Method

#### 7.1.1 Target Group

For the first user workshop, informal caregivers of elderly persons with or without impairments were invited to take part. Eight people followed the invitation and supported the workshops with their knowledge and experience. The participants were aged between 55 and 80 years. Because of the number of people the workshop was divided into two groups with the same research focus. The aim was to gather information about situations in which PersonAAL can support informal caregivers in carrying out their support. The workshops were designed in a way that both informal caregivers' requirements and primary user requirements could be collected from the point of view of informal caregivers. This document only focuses on the requirement of informal caregivers (for older adults requirements, please see D2.1).

#### 7.1.2 Research Design and Implementation

As research design an interactive workshop where the participants are actively involved was used. Using this method, it is possible to gain deeper insight of the daily work of informal caregivers. The aim of the workshop was to understand the types of daily work from informal caregivers and the intensity of this work.

Two different methods were applied to discuss and work out this daily work. First, a timeline with five time slots was used to reconstruct a typical day of elderly persons with dependency needs and the assistance of informal caregivers. The timeline was intended to help the target group to recall typical activities and processes that take place in different phases of a typical day. Second, a table with five main contents of a typical older adults' day was used to complete the results from the first workshop part. These main contents were derived from the results from the timeline and helped to complement findings even for target users with less structured day routines. Both exercises were carried out by resorting to a mixture of card techniques and group discussions. Card techniques were considered especially suitable for situations in which participants should not be influenced by the ideas of their peers or even be intimidated by lead ideas generated by the group. As all colored cards were written individually, a higher degree of creativity, memory and thus more diverse information was expected. All results were discussed in groups after presentation of individual findings in order to complement the thoughts of other participants and validate the respective importance for PersonAAL.

The participants were selected by terzStiftung, after a public call among the pool of volunteers in the terzStiftung database. They were invited personally by the terzStiftung and received a short project description before the workshop started. During the workshop, they received a detailed description about the project and an informed consent to assure ethical treatment. Participation took place on a voluntary basis and none of the attendees was forced to answer the questions.

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German into English. Answers and qualitative comments were translated according to their meaning.

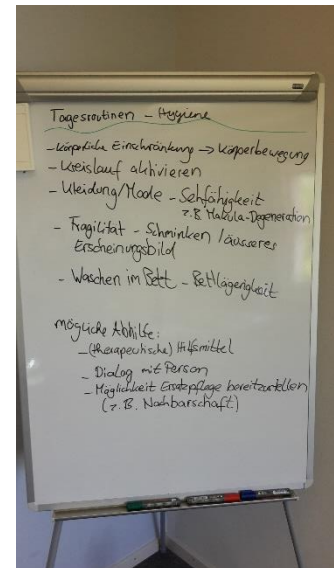
## 7.2 Findings

Helping informal caregivers is part of the target of the PersonAAL project. Discovering the daily work of the secondary end users is one of the main targets of a requirement analysis. It is important to understand how informal caregivers interact with their elderly relatives and where PersonAAL can assist. One of the targets is to find out more about the daily work of our potential secondary end user group and where PersonAAL fits in.

### 7.2.1 Hygiene and Start of the day

To understand the typical work of informal caregivers and the needs of elderly persons, a closer look should be taken of daily care activities.

The findings show that most informal caregiver help their relatives with their daily hygiene. Because of the physical age-related restrictions of the elderly persons their informal caregivers need to help them having a shower or bath and to dress them. Men could need help with shaving, women with their finger nails or make-up.

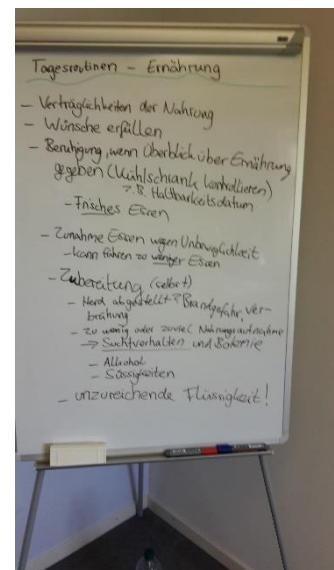


### 7.2.2 Nutrition and drinking

Considering the age-related restrictions, healthy nutrition seems to be very important for elderly people. Informal caregivers need to take care of providing a healthy and balanced nutrition to the persons in need. Some of their relatives are not used to "modern" nutrition or do not have the current knowledge about it. Furthermore, sometimes they do not have enough physical energy to cook by themselves. This is why informal caregivers often need to help them with their nutrition.

Another point mentioned during the end user workshops was the reassurance informal caregivers have when they monitor the fridge and the pantry. The informal caregiver thus can have some control about the nutrition and the amount of food their relative uses.

Elderly people could have problems to find the right amount of food. On the one hand, if they eat too much, the weight could increase, because of insufficient physical activity. On the other hand, if they start eating less, because they forget it or think they have eaten too much, the opposite case can happen. Regarding this phenomenon, it is important to remind senior people with some impairments to eat regularly healthy food.



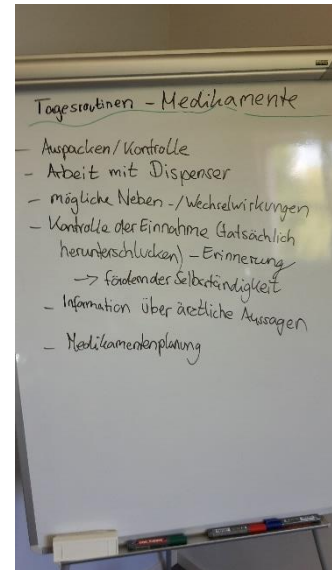
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## 7.2.3 Medication

A lot of older people take several medications during the day. Some of them are very important and should not be forgotten. In order not to forget them, informal caregivers sometimes write a "medication plan" and show their relatives how to use it. Using this tool both sides the informal caregiver and the older person have some control about the intake.

Beside the control of the intake, it is important to check potential side effects or interactions. Older people often have difficulties when reading the small font of the package insert. To help them with this, informal caregivers read the package insert to them and talk about the potential interactions with other medications. Doing this they can make sure that their relatives understand the medication and its effects.

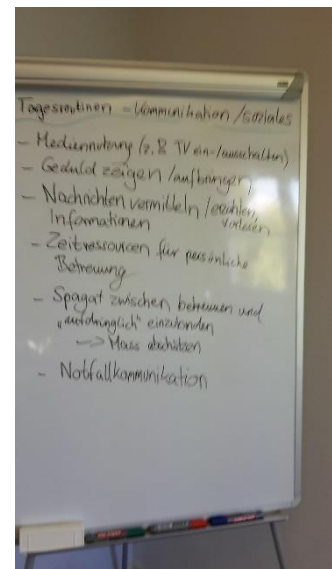
Taking some medicine often includes some information about the medical statements. It is important for informal caregivers to write this (e.g. instructions) down, so their caretaker knows when and how the medicine needs to be taken. In summary, the medication intake of older people means a lot of organizational work and control/monitoring.



## 7.2.4 Communication and Social Meeting

Nearly all older people attach great importance on news. Beside the news on TV they read the newspaper and magazines. Some of them have problems with their eyes and cannot read clearly anymore. In this cases their informal caregivers read the news to them or narrate them. This form of communication can be very important. On the one hand the informal caregiver can spend some time with his relatives and give her or him some social support. On the other hand, they can have some control about the behaviour of their relative and recognize if something is "strange". Especially for older people living alone having this communication and indirect control is very important for caregivers.

It is difficult for informal caregivers to keep the border between "caring" for the person and "being intrusive". On the one hand, they have a deep relationship to them, but on the other hand they need to be careful with patronising them. This is one behaviour especially close relatives (e.g. wife/husband or daughter/son) recognized.



## 7.2.5 Activity

Especially for elderly people it is important to stay active as long as possible. To help them, their informal caregivers motivate them to do some physical exercises or accompany them for a walk outside.

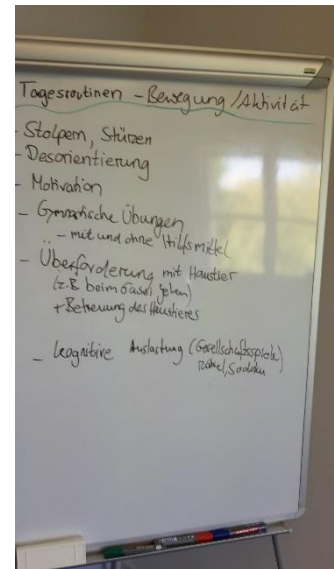
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This is not only important for their physical health, but also has a social component. They are outside their home and have the possibility to meet other people. This is a great assistance for the informal caregivers, because they do not need to be around them all the time.

Informal caregivers are the most important social contact for elderly people. Nearly all informal caregivers reported that it is important for the health and well-being of their relatives if they have someone to talk with. This personal relationship influences the aging process a lot.

In addition to the relationship between informal caregivers and their caretakers, neighbors or friends could adopt some light and less intimate work and be a support for the informal caregivers. Informal caregivers reported that this social contact is important because they do not need to be around the whole time.



### 7.3 Workshop Summary and Recommendations

The findings from the first end user workshops give an overview about the daily routines of the daily work of informal caregivers. As the results show, informal caregivers must do physical and non-physical work with the person in need.

According to the findings above there are some recommendations to be made for the further development of the "remote assistance application" of the PersonAAL system. These recommendations are guidelines for the further development of the system.

The results show that older people with or without age-related impairments have daily routines where they need the assistance of informal caregivers.

These routines indicate the intimate care like body hygiene, health nutrition and medication intake. Beside this social contact and being part of the social environment are important parts informal caregivers need to take care when caring for the person in need.

#### Nutrition and drinking

Some older adults do not drink enough. But drinking is very important to them and should be monitored by caregivers. As the system pursue the target to support informal caregivers it should make sure to assist easy care processes like using a drinking reminder for regularly and sufficient drinking.

#### Local news

As the findings show older adults are interested in current and/or local news. Some of them have problems with their eyes and cannot read anymore. In this case their informal caregivers read the news to them. Supporting informal caregivers, the system must make sure to have a "news page" where the person in need can either read or hear the current (local) news.

#### Social contact

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Recording to the findings above social contact is one mature part of informal caregivers. Informal caregivers are the most important social contact for people in need. Nevertheless, older adults still like to go outside and are open to new contacts. The importance of social activity and social contacts should be considered in the further developing process.

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## 9 ANNEX 1

### PersonAAL workshop June 2016 on Informal Caregivers App

#### Workshop outline

(The greyed out parts of this annex correspond to the workshop parts that are not relevant for this deliverable)

#### Date & place

2016/06/09 and 2016/06/10

Berlingen, room: "Bregenz"

Participants: 3 and 5

Duration: 4 hours

#### Objectives of the workshop:

##### 1. Content:

What types of routines, health related activities, devices should be covered in addition to those listed so far?

For which daily care activities is PersonAAL geared to?

##### 2. Understandability/ Usability:

Can they handle the app and solve specific exercises?

##### 3. Functionality:

In how does the app fulfil its purpose, regarding...

- a. (Medical) care activities and mentoring
- b. Communication, social requirements
- c. Informal requirements/ peace of mind

#### Materials:

- Coloured cards, markers, magnets, etc.
- Laptop, beamer
- 3 Tablets for the participants
- 1 Mobile white board
- 3 Pinboards
- Flipchart

#### Agenda items:

1. Welcome, program ..... ( 5 Min)
2. Assignment 1: Content review ..... (40 Min)
3. Discussion ..... (45 Min)
4. Short presentation of the app..... (10 Min)
5. Individual testing of the app ..... (15 Min)
6. Assignment 2: Individual assignments ..... (40 Min)
7. Discussion ..... (15 Min)
8. Assignment 3: functional evaluation, 3 types of functions ..... (30 Min)
9. Discussion ..... (15 Min)
10. Global review and final results ..... (15 Min)

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## Assignment 1: Contents

- What are typical daily care routines you have?
- Which health related activities of your care recipient should be supported?
- Which devices should be covered in addition to those listed so far?
- What kinds of household activities does your care recipient do?
- Are there some hobbies, which need monitoring support?
- Are there some medical necessities, which need monitoring support?

### a) Timeline:



### b) Table:

Hygiene/ Getting dressed	Nutrition	Medication/ Health	Communication/ Social meeting	Activity

## Assignment 2: Understandability

### Exercise 1:

The doctor of your care recipient gave her/ him some medicine. The dosage of the medicine should be 3 times a day and the therapy ends after 4 days.

- Make a reminder for this medication on the tablet
- List your experience on the matrix

### Exercise 2:

Your care recipient has an appointment for having a walk with the neighbour. To get ready timely you would remind her/ him.

- Remind your care recipient at 3pm by TV
- List your experience on the matrix

### Exercise 3:

PersonAAL send you a message that your care recipient forgot to take her/ his blood pressure medication.

- Inform your care recipient that she/ he don't worry.
- Send your care recipient a message that she/ he should take the medication next time.
- List your experience on the matrix

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### Exercise 4:

Your care recipient forgets regularly to switch off the TV when she/ he goes to bed.

- Create a rule for switching off the TV at 11pm.
- List your experience on the matrix

### Exercise 5:

Your care recipient doesn't exactly know how to increase the volume of the TV.

- Create a rule for increasing the volume of the TV when there is high noise.
- List your experience on the matrix

### Exercise 6:

PersonAAL shows you an alert on the monitor.

- Add this alert to the diary.
- List your experience on the matrix

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Handout

### Understandability

Exercise	Problems	Improvements

### Assignment 3: Functional Evaluation

Three groups in rotation:

1. (Medical) care activities and mentoring
2. Communication, social requirements
3. Informal requirements/ peace of mind

For each group:

- Does the function fulfil its purpose?
- Is the app helpful to reach your goal?
- What additional function would simplify your action?
- Are there some devices to be covered?
- What difficulties do you have with the description of the function?
- Which functions would be necessary to optimize your action?

### Flipcharts/Pinboard

Improve medical care / monitoring

Function	Pro	Contra	Improvements
Monitor			
Medication			
Reminders			
Diary			
Mary			
<ul style="list-style-type: none"> <li>• Interests</li> <li>• Alerts</li> <li>• Rules</li> <li>• Devices</li> </ul>			

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### Improve communication

Function	Pro	Contra	Improvements
Monitor			
Medication			
Reminders			
Diary			
Mary			
<ul style="list-style-type: none"> <li>• Interests</li> <li>• Alerts</li> <li>• Rules</li> <li>• Devices</li> </ul>			

### Create peace of mind

Function	Pro	Contra	Improvements
Monitor			
Medication			
Reminders			
Diary			
Mary			
<ul style="list-style-type: none"> <li>• Interests</li> <li>• Alerts</li> <li>• Rules</li> <li>• Devices</li> </ul>			

### Global review and final results

- Summary of the results and final discussion for improvements

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## Handout zu Aufgabe 2:

Bitte lesen Sie sich die Aufgabe durch und lösen Sie die dabeistehende Anwendung.

- Was hat Ihnen Probleme bereitet?
- Haben Sie mögliche Verbesserungsvorschläge?

Aufgabe	Probleme	Verbesserungsvorschläge
<p>1. Der Arzt verschreibt Ihrer/Ihres Angehörigen ein Schmerzmittel. Es soll drei Mal am Tag eingenommen werden. Die Therapie soll dabei vier Tage dauern.</p> <ul style="list-style-type: none"><li>• <i>Erstellen Sie eine Erinnerung für dieses Medikament mithilfe der App</i></li></ul>		
<p>2. Ihr/e Angehörige/r hat eine Verabredung zum Spaziergehen mit dem Nachbar. Um rechtzeitig bereit dafür zu sein, möchten Sie sie/ihn erinnern.</p> <ul style="list-style-type: none"><li>• <i>Erstellen Sie eine Erinnerung um 15 Uhr auf dem TV</i></li></ul>		
<p>3. PersonAAL sendet Ihnen eine Nachricht zu, dass Ihr/e Angehörige/r vergessen hat die Schmerzmittel zu nehmen.</p> <ul style="list-style-type: none"><li>• <i>Informieren Sie Ihr/e Angehörige/r über das Tagebuch, dass er/sie nicht</i></li></ul>		

<p><i>besorgt darüber sein muss.</i></p> <ul style="list-style-type: none"> <li>• <i>Senden Sie Ihrer/Ihrem Angehörige/n über das Tagebuch eine Nachricht, dass sie/er die Medikamente zum nächsten Zeitpunkt nehmen soll.</i></li> </ul>		
Aufgabe	Probleme	Verbesserungen
<p>4. Ihr/e Angehörige/r vergisst regelmäßig den Fernseher auszuschalten bevor er/sie zu Bett geht.</p> <ul style="list-style-type: none"> <li>• <i>Generieren Sie eine Regel, die den Fernseher um 23 Uhr automatisch ausschaltet.</i></li> </ul>		
<p>5. Ihr/e Angehörige/r ist sich verunsichert, wie sie/ er die Lautstärke des Fernsehers reguliert, sobald die Umgebung lauter wird.</p> <ul style="list-style-type: none"> <li>• <i>Erstellen Sie eine Regel, die die Lautstärke des Fernsehers verändert, sobald die Umgebung</i></li> </ul>		

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<p><i>der/des Angehörige/r lauter wird.</i></p>		
<p>6. PersonAAL schickt Ihnen eine Warnung, dass sich Ihr/e Angehörige/r heute noch nicht körperlich betätigt hat.</p> <ul style="list-style-type: none"> <li>• <i>Schicken Sie ihr/ihm eine Nachricht über das Tagebuch</i></li> </ul>		

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