	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 the final part of 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.

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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.

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 also on facilitating 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.

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 has 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.

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 the 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.

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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 tablet for Maria to stay connected through the internet. Yet, whereas Maria appreciates to receive mails and tapped 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 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. Maria had learned from her parents that TV-screens should not be touched with fingers, as it leaves filthy prints on the surface and so she does not want to communicate herself by TV. She therefore prefers to push the icons on the tablet once she feels about sending 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.

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

Motivations

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 had to take 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 prepared bags with the five medicines for each day. But the problem is how to control 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 neutral 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

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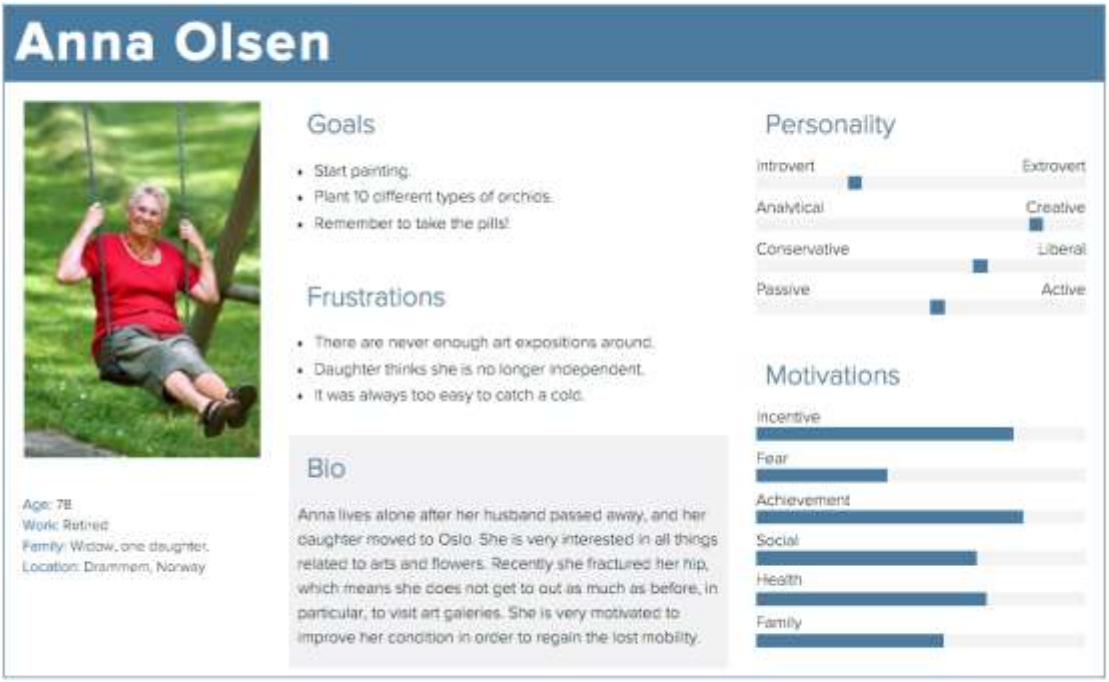
their mother. Therefore, they decide, together with Giuliana, to place some sensors in the flat – for motion and fall detection. If Giuliana does not get up in the morning, or if she falls over, an alarm will first warn Michele and Barbara, and then the Red Cross.

Besides using the alarm function, both "informal caretakers" want to keep in touch with their mother. The personAAL-system is a very good opportunity for that: It is much more simple than to use existing platforms like "Skype" or "WhatsApp" to communicate. Giuliana is too lively and moves about, and tend to forget that she must not move her tablet in videoconferences so that Michele and Barbara get a stable and good view of her on their tablets. Earlier, they tried "Viber", but that was even worse: Giuliana never kept in mind when to wipe off the display and how to initiate a call.

After being informed about the advantages of a direct connection to her caretaker, Giuliana agreed to attach some sensors directly on her body. Her heartbeat and temperature are sent to her caretaker constantly. When she complies with the persuasive suggestion of the PersonAAL-system to go for a walk, this improves Giuliana's fitness and health, and controls her weight, and prevents her from getting other illnesses.

2.2.3 Persona 3 - Anna


Anna Olsen

Age: 78
Work: Retired
Family: Widow, one daughter.
Location: Drammem, Norway

Goals
- Start painting.
- Plant 10 different types of orchids.
- Remember to take the pills!

Frustrations
- There are never enough art expositions around.
- Daughter thinks she is no longer independent.
- It was always too easy to catch a cold.

Bio

Anna lives alone after her husband passed away, and her daughter moved to Oslo. She is very interested in all things related to arts and flowers. Recently she fractured her hip, which means she does not get to out as much as before, in particular, to visit art galeries. She is very motivated to improve her condition in order to regain the lost mobility.

Anna is 78 years old and, after her husband's death and her daughter moved away, she lives alone. She is a very independent person and, despite a gradual decline in her physical capabilities, she has a strong desire to continue living in her own home. She does not have cognitive impairment or mobility restrictions, although she suffers of some cardiovascular diseases, so she needs to control regularly her blood pressure and heart rate, to follow a low

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salt, low fat diet, to do some stretching and aerobic exercises and also to take several medicines prescribed by her doctor.

Unfortunately, she recently was affected by hip fracture. She has been treated by surgery and then had to go to a rehabilitation facility for some weeks. Her doctor suggested her to go in an advanced rehabilitation facility, where the innovative PersonAAL Rehabilitation Application is used. 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, that 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 displacements. The PersonAAL team provides and configures a set of bio-signal sensors for Anna, so she can easily control from home her relevant health parameters, and also an electronic 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.

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, that 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 with 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.

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 legislations 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, is 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 elderlies' 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 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, but in relation to their own needs and as a resource for the elderly.

4 CURRENT SITUATION IN SWITZERLAND: SURVEY DATA

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 will 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:	1. General information

2. Modes of communication / methods of providing health related information
3. Use of technical devices
4. Usability of technical devices
5. Success Factors

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.

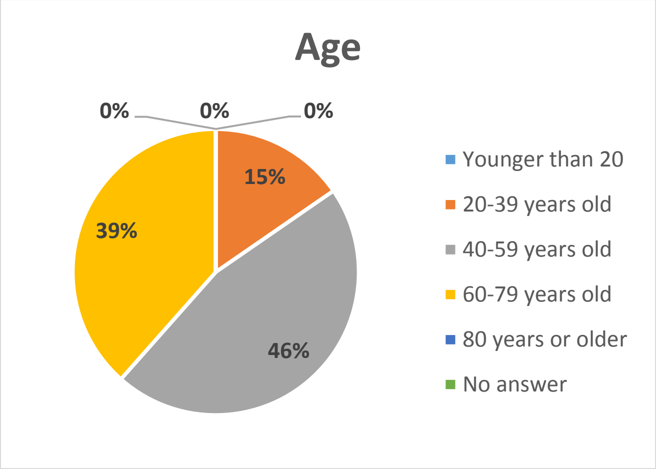
4.2.5 Response Rate

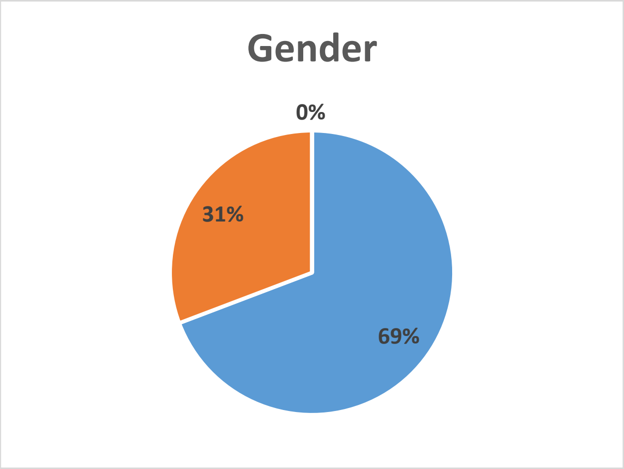
By January 13, 2016, LimeSurvey registered 120 file counts in the questionnaire, 13 of which were completed and 107 which was incomplete or the respondent had answered that she og he was not an informal caregiver. The remaining file counts relate to the mere external opening of the hosting webpage or the 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

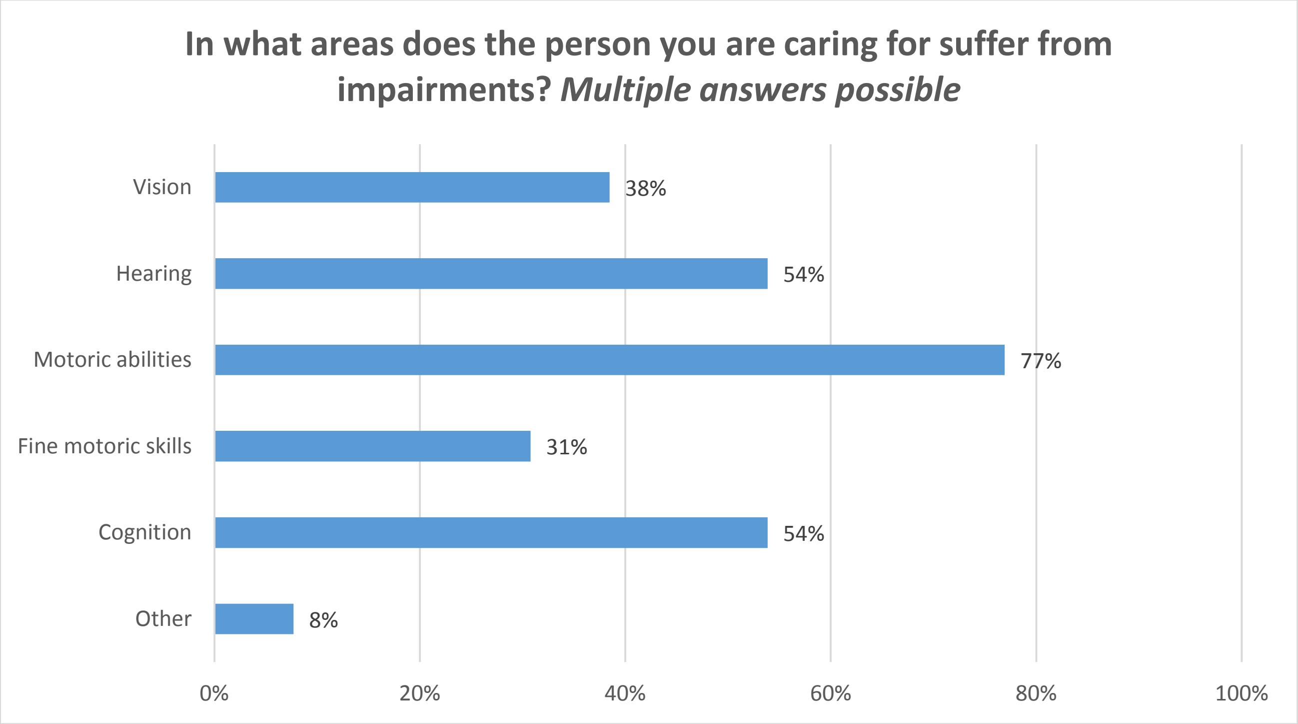
4.3.1 General information

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 above, 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, 39% in the age-group 60-79. Only 15% are younger.

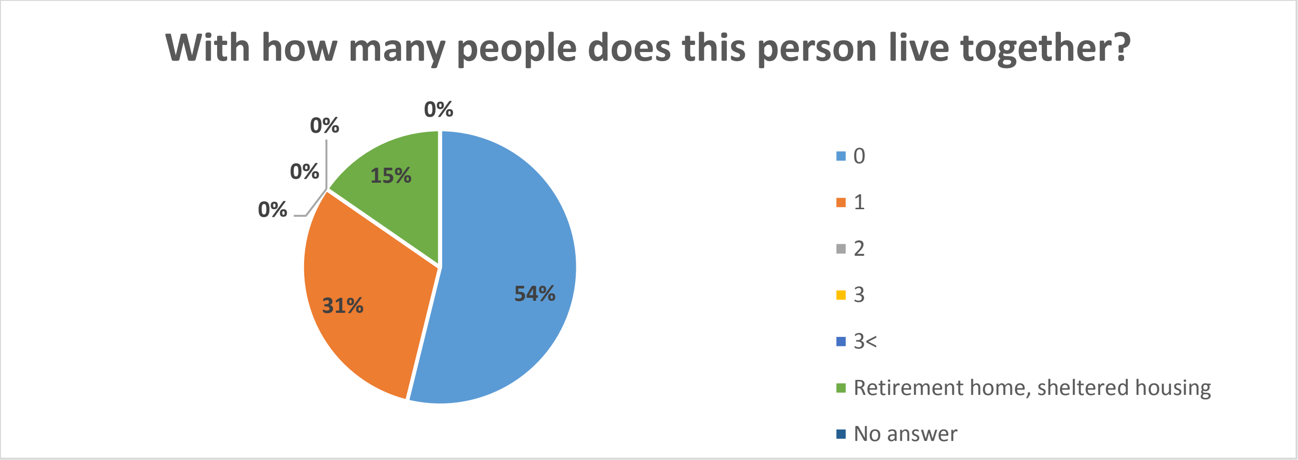




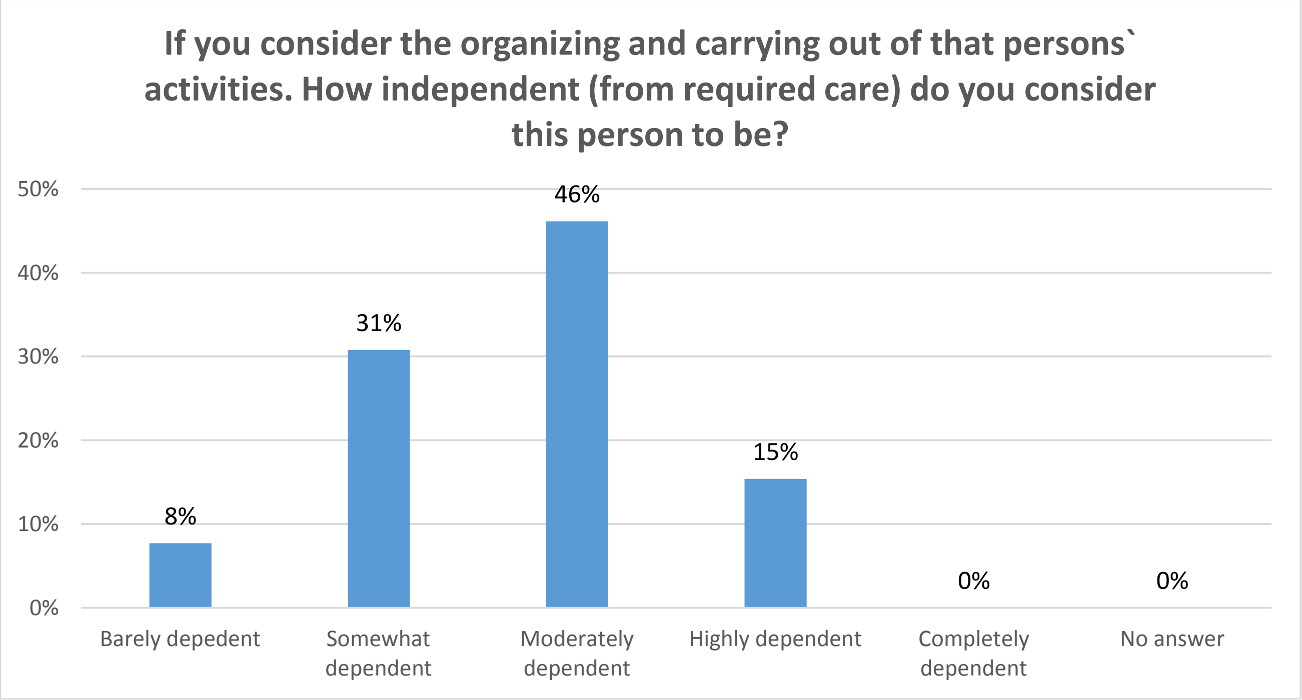
In order to understand the importance and scope of the caring services carried out by the current sample, several questions were asked regarding the status of the person in need. As shown in the following chart, most of these latter suffer from motoric impairments (77%). About half of the persons cared for have problems with hearing and their cognitive performance (54%). Vision (38%) and fine motoric skills (31%) are still important issues regarding requirements for care.



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 following chart, a majority (54%) of the persons in need, who are nursed by the current sample, lives alone. 31% live as couples.



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 can be derived from the chart below, only 15% of the persons in need are considered highly dependent on their caregivers, whereas 46% are considered moderately dependent. 31% receive 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.



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4.3.2 Modes of communication / methods of providing health related information

As it was done with regard to the survey among elderlies, modes of communication in the context of caring activities were investigated 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 with regard to 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. 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 (46%) and physical activities (54%) of their service recipients. Clearly medically related data, i.e. physiological data and body functions, is only exchanged with 38% and 23%, 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 below, roughly one fifth (23%) of the sample would appreciate the reception of information about physiological and cognitive status of the nursed. 15% each 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.

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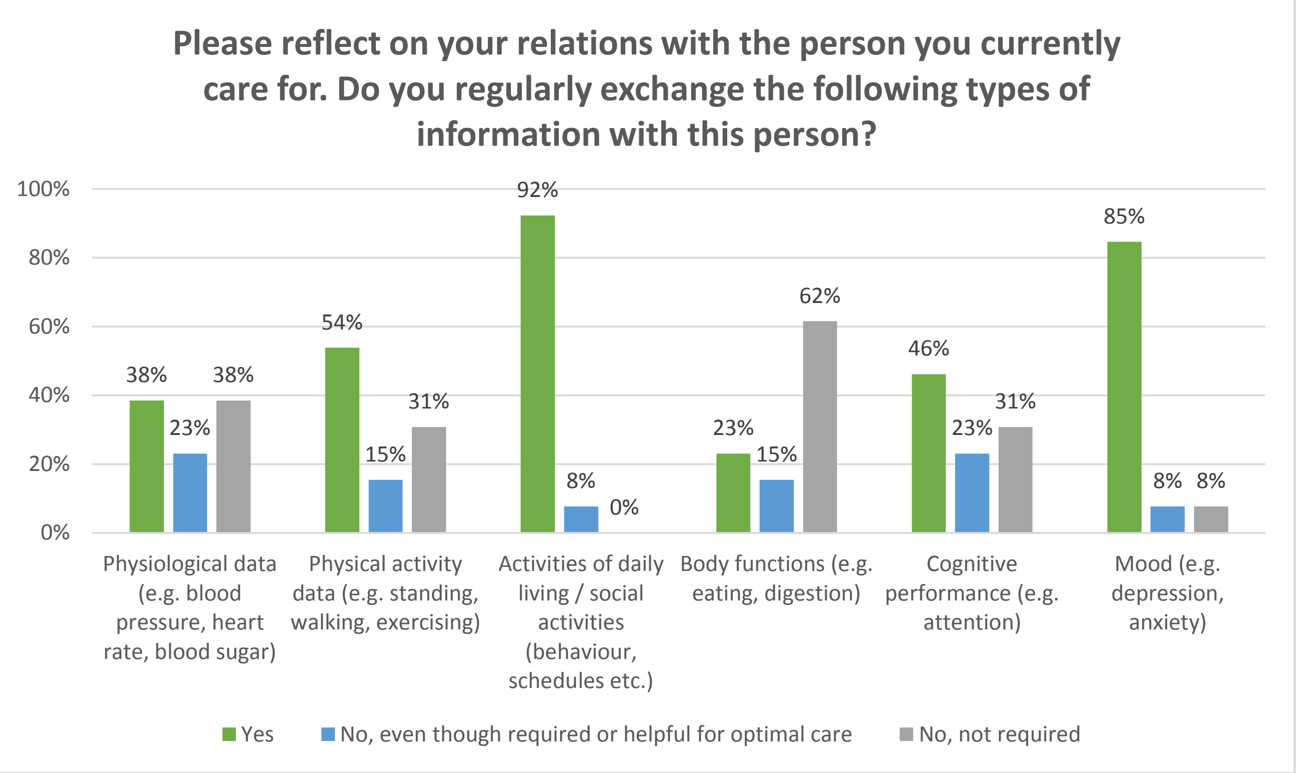
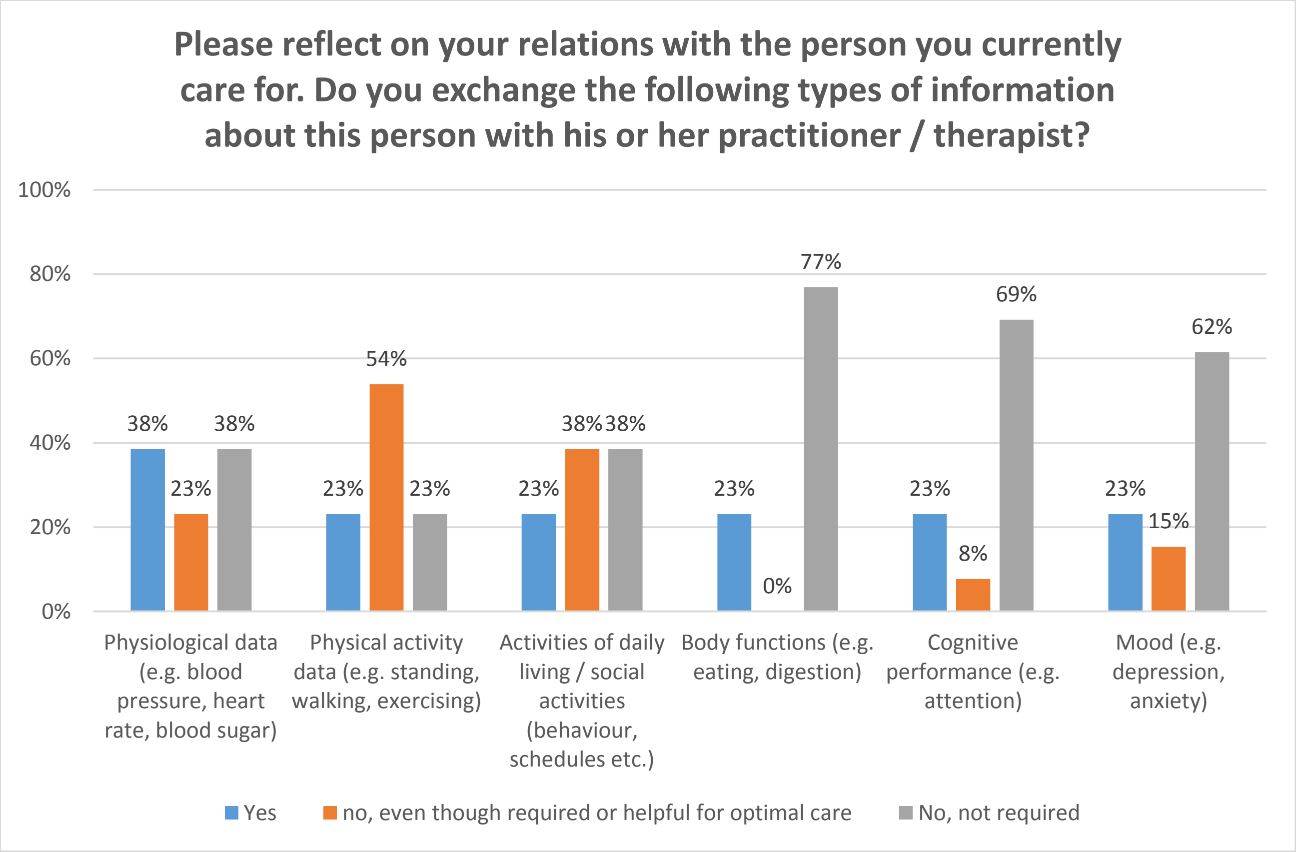
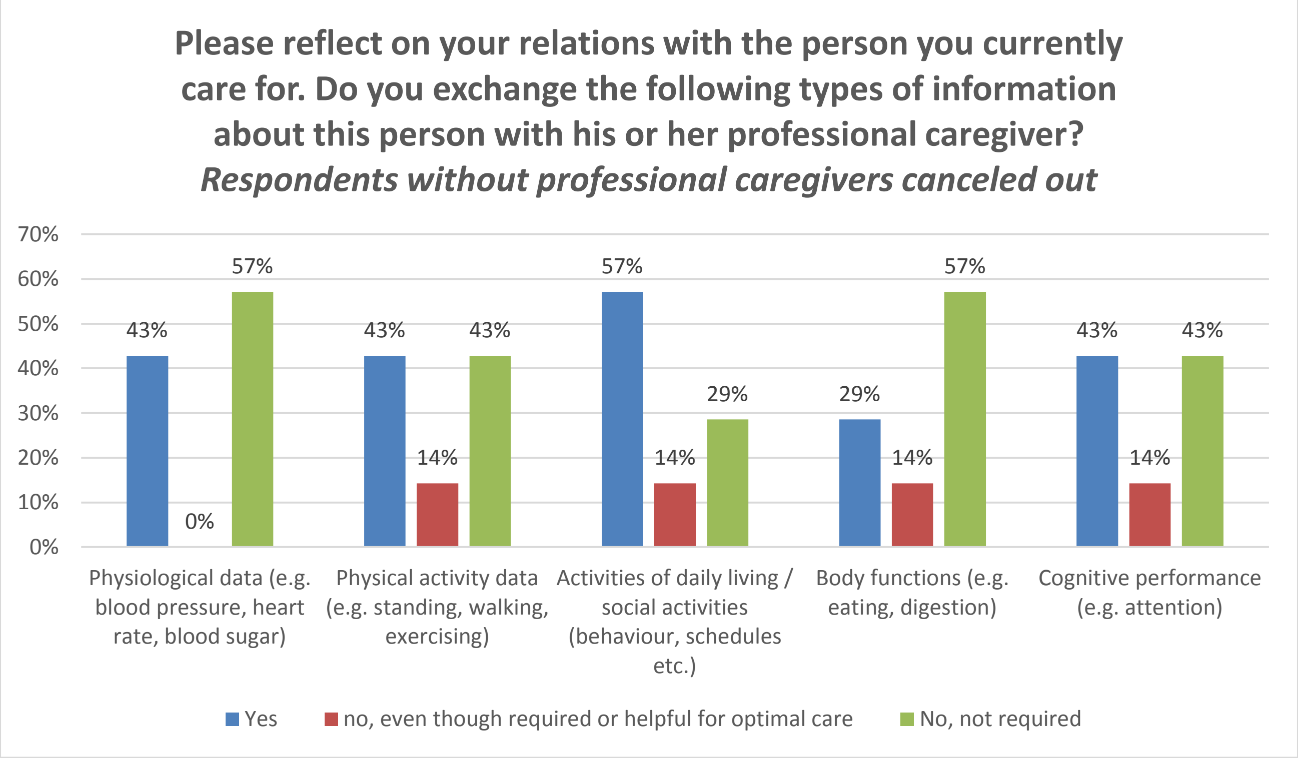


The same types of questions were asked to shed light on the communication between informal caregivers and the practitioners treating the person in need. The charts clearly indicate that only minorities of the informal caregivers exchange the proposed type of information with the healthcare professionals (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 (54%) and activities of daily living (38%) helpful for improved care. Considering that respective information is largely exchanged between informal caregivers and the persons receiving assistance, one may conclude, yet, that the respondents expect practitioners to benefit from these additional insights about their patients rather than caregivers themselves.



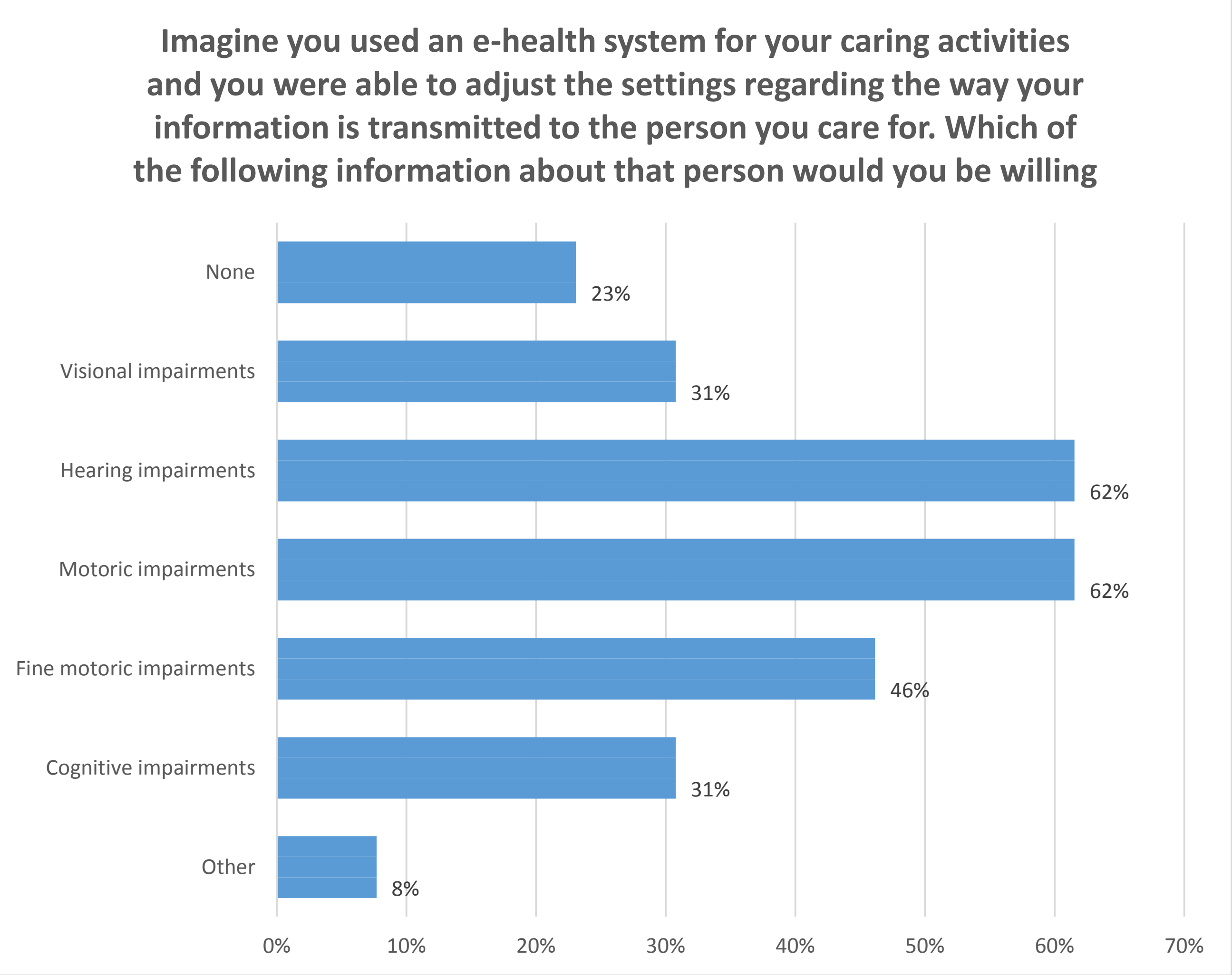
Communication between informal caregivers and professional caregivers is comparatively high in all areas, ranging from shares of 29% (body functions) to 57% (activities of daily living). Respondents missing the exchange of certain types of information, in contrast, are few: Only 14% consider additional 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 majorities (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 save in respective e-health systems.

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 (62%), followed by fine motoric impairments (46%), visual and cognitive impairments (32% each). 23% 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.


Imagine you used an e-health system for your caring activities 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 that person would you be willing

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 77% approval, followed by physical activities (62%) and current physical and body conditions (54%) of the nursed person. Less than every second respondent opted for the full health recorded (46%) and personal activities (38%). Roughly every fifth agrees with private data and mental conditions such as mood (23% each).

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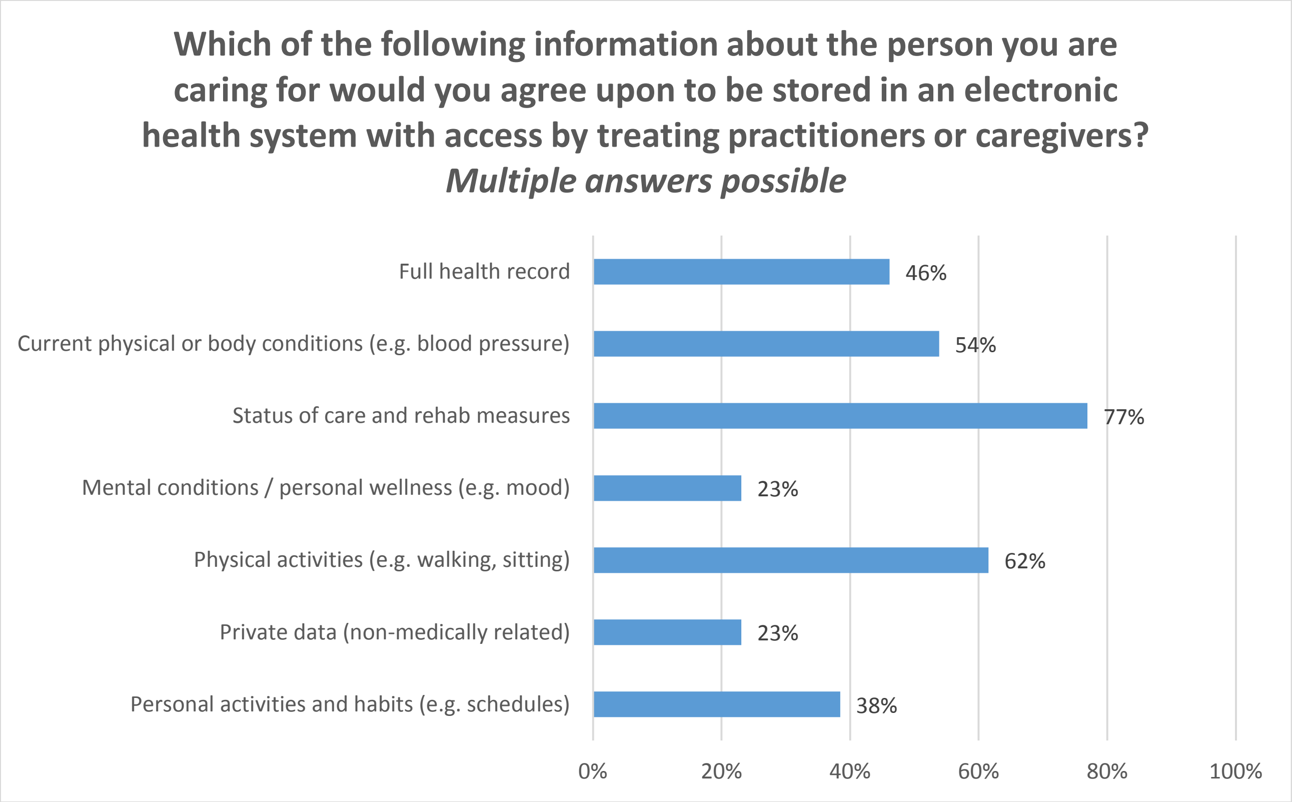
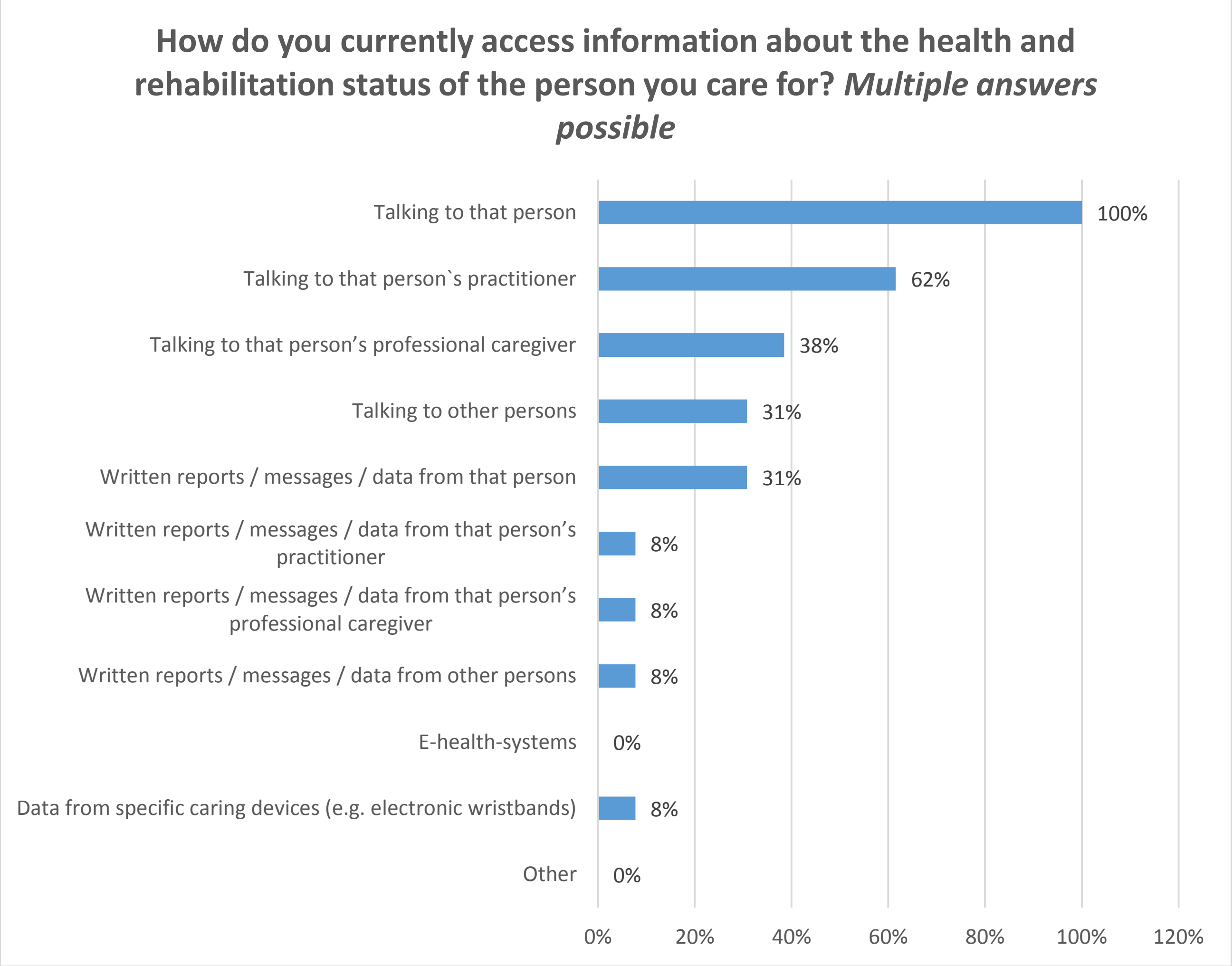
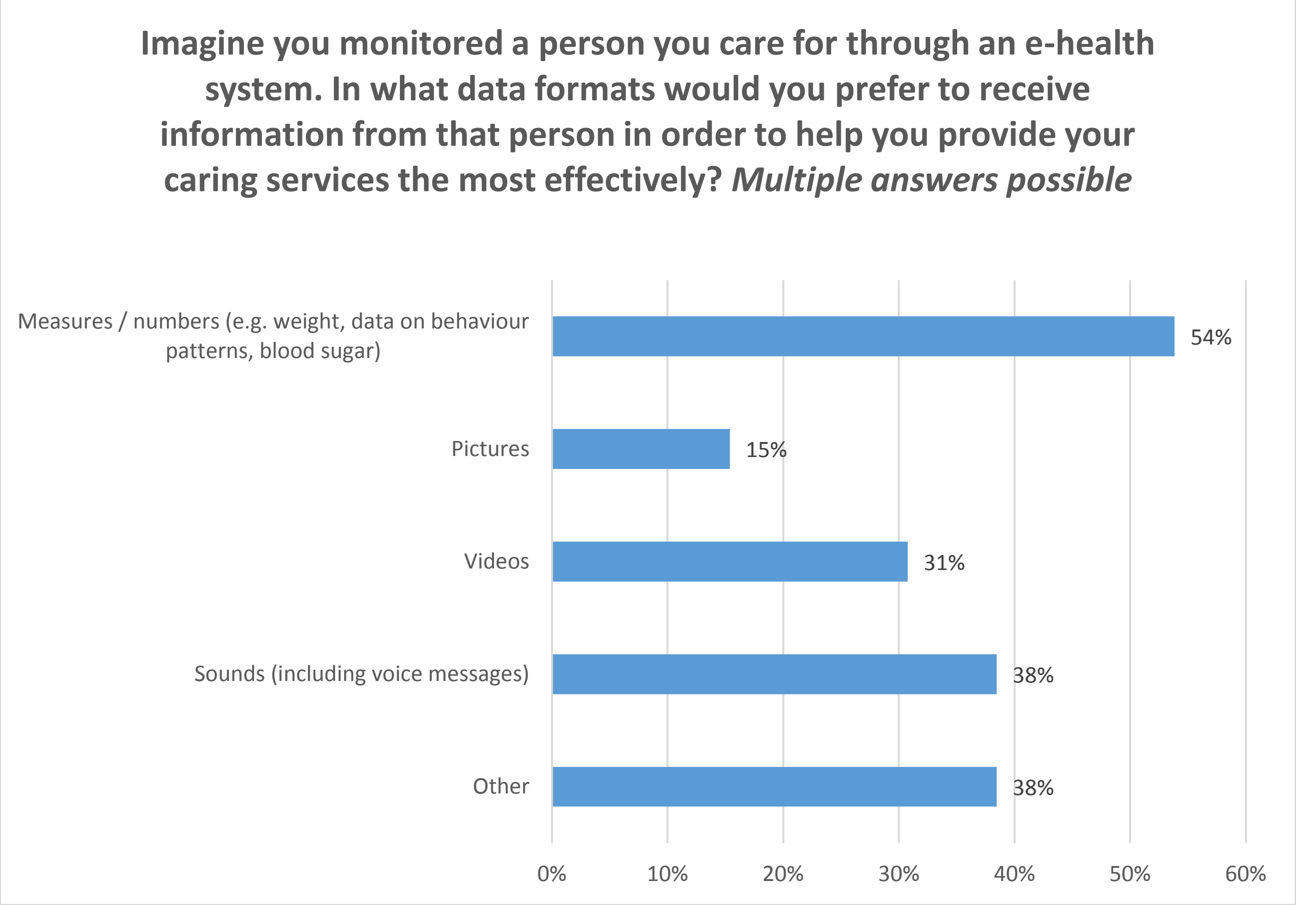


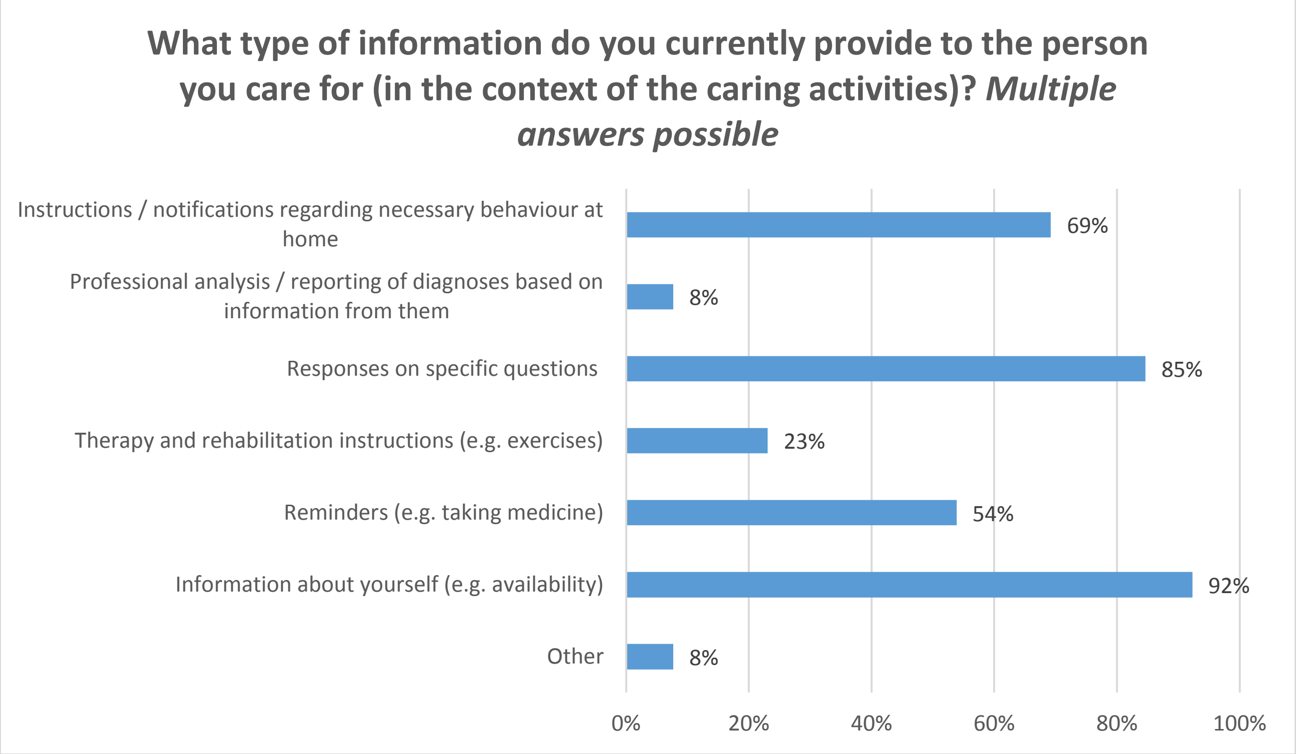
Taking into account the current modalities for access to infromation about the nursed person may give further indications for requirements regarding suitable forms of communication in the envisaged PersonAAL system. All participants mentioned direct tallks as a current means, whereas 62% indicated that they talk to the person in need's practioner. Talks to other persons and writings from the nursed person are considered by only roughly one third, whereas only minorities of 8% currently refer to alternative modes such as reports from practitioners and data from specific caring devices. None of the respondents uses e-health systems to date their knowledge up.



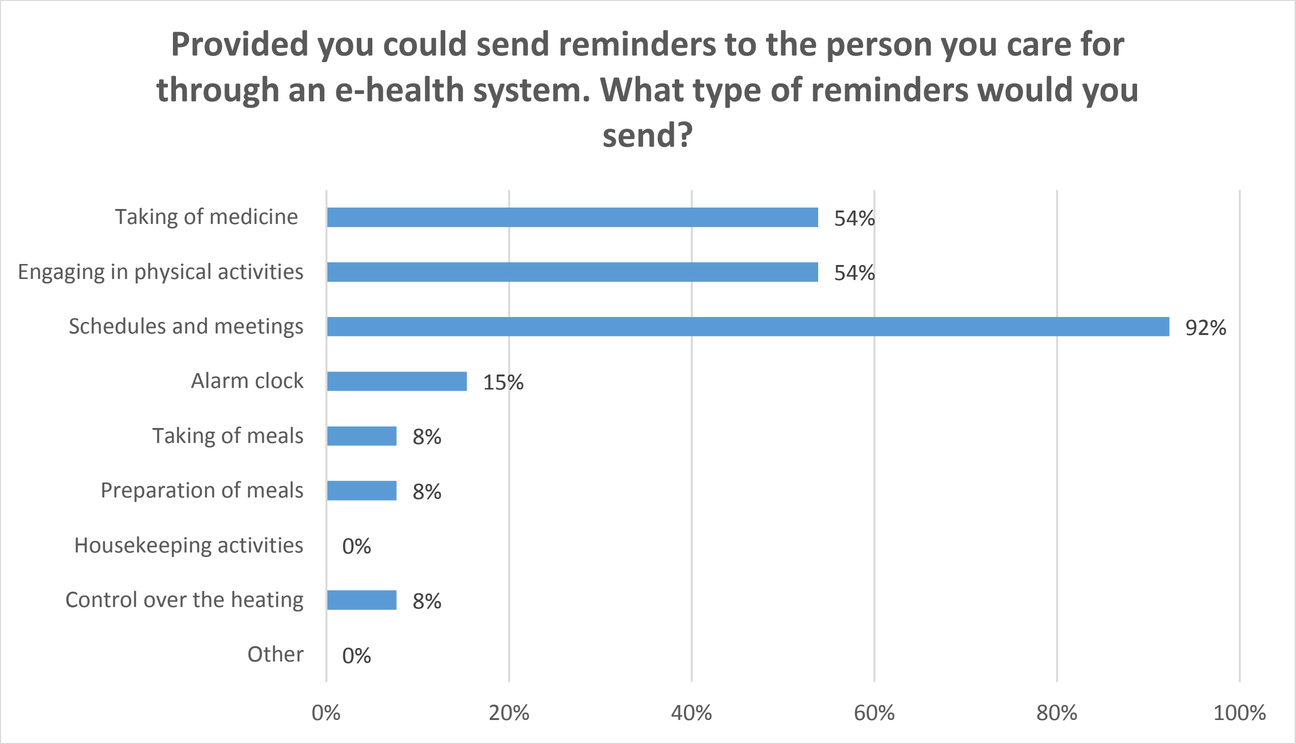
As was done for the primary end-users, preferences for data formats in the respondents’ communication via e-health systems was analyzed. When asked about what data formats they would prefer, 54% mentioned impersonal measures / numbers, whereas more personally intimate types such as videos (31%) and pictures (15%) are less popular.



As regards the unidirectional provision of information from informal caregiver to the person receiving assistance, the information provided by most of the respondents were information about themselves (e.g. availabilities 92%), responses on individual questions (85%) and instructions or notifications (69%). Less important is information that may be associated with professional caregivers and practitioners, namely professional diagnoses (8%) and therapeutically instructions (23%).



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 92% 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 (54% each) 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.

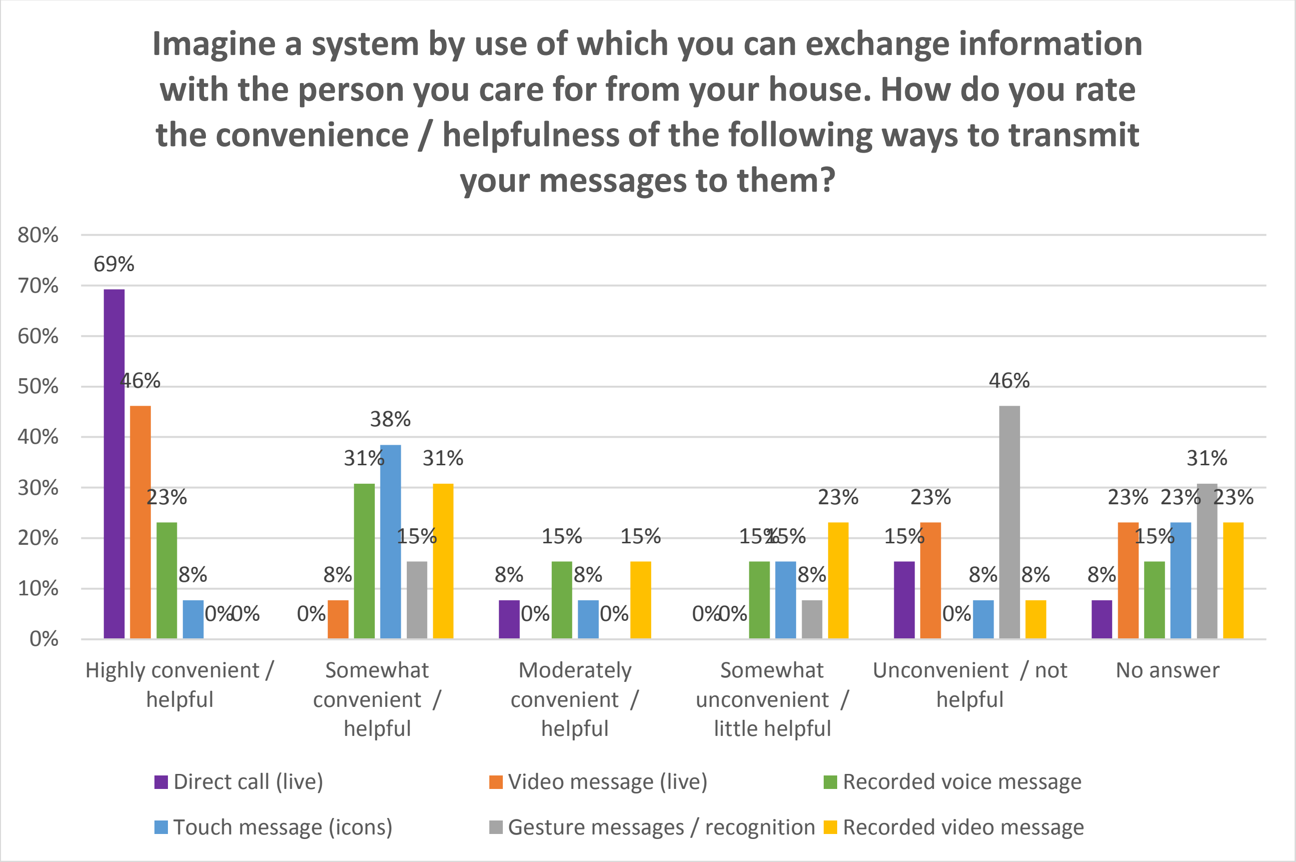


Asked qualitatively about what additional sort of information the respondents currently cannot exchange with the person they are caring for but would like to exchange with them, the following was mentioned.

- 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 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.

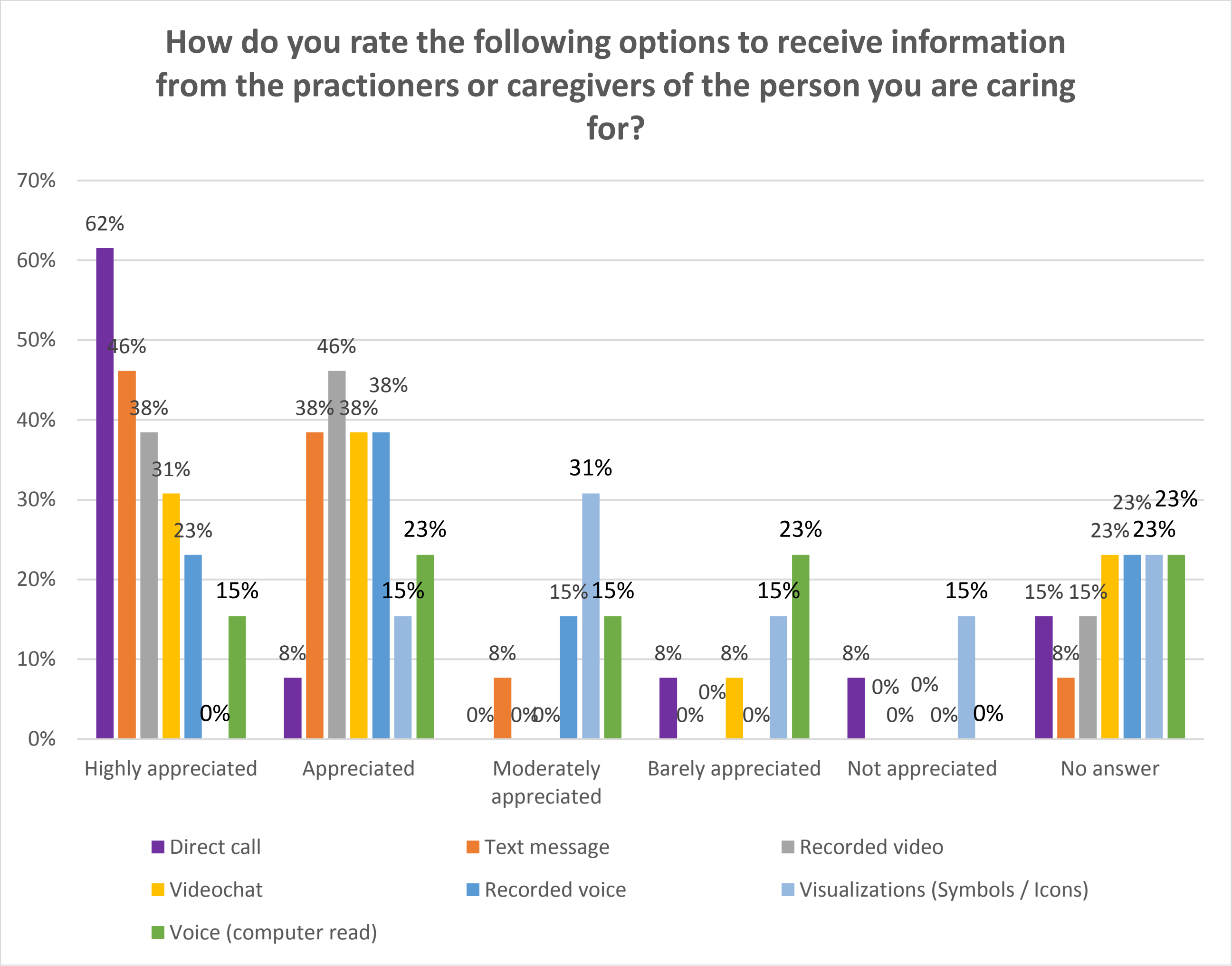
As illustrated in the following chart, most respondents consider direct interaction, namely direct call (69%) and video call (46%) highly convenient. Recorded voice messages, touch message and recorded video also appear rather promising with 69%, 54% and 46% considering these options at least moderately convenient. Gesture gained rather low shares for the underlying purpose.



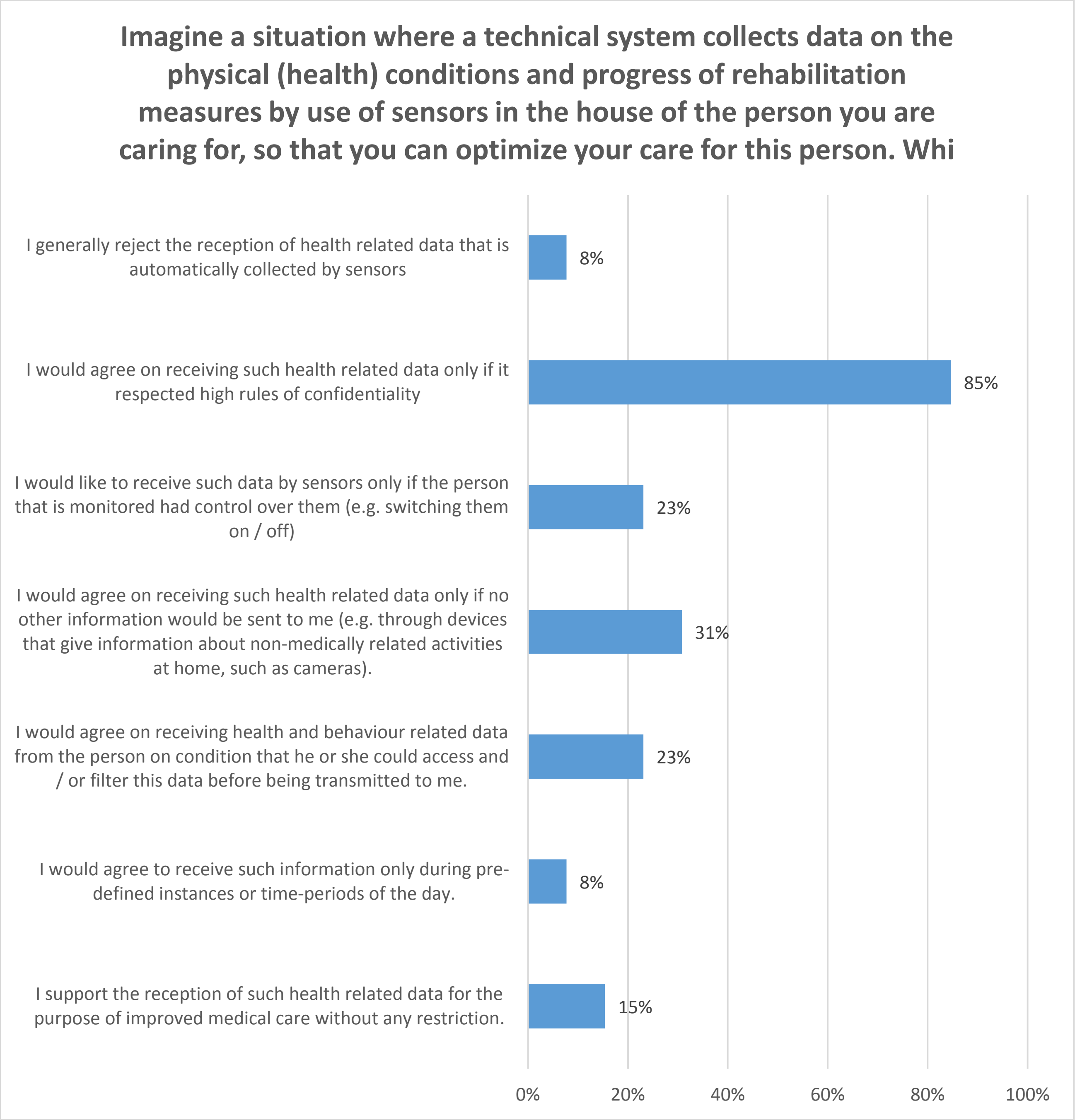
Imagine a system by use of which you can exchange information with the person you care for from your house. How do you rate the convenience / helpfulness of the following ways to transmit your messages to them?

As 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 (cumulated 38%) and the visualization through symbols or icons (cumulated 15%). Text messages (84%), recorded video (84%) and direct call (70%) 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.



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, 85% of the current respondents clearly require the assurance of confidentiality in the case that the nursed person’s status is being monitored by sensors. Almost every third (31%) demands the clear separation of medically required information from data usable for additional purposes. Only 15% accept the installation of sensors in the house of the cared person without restriction.



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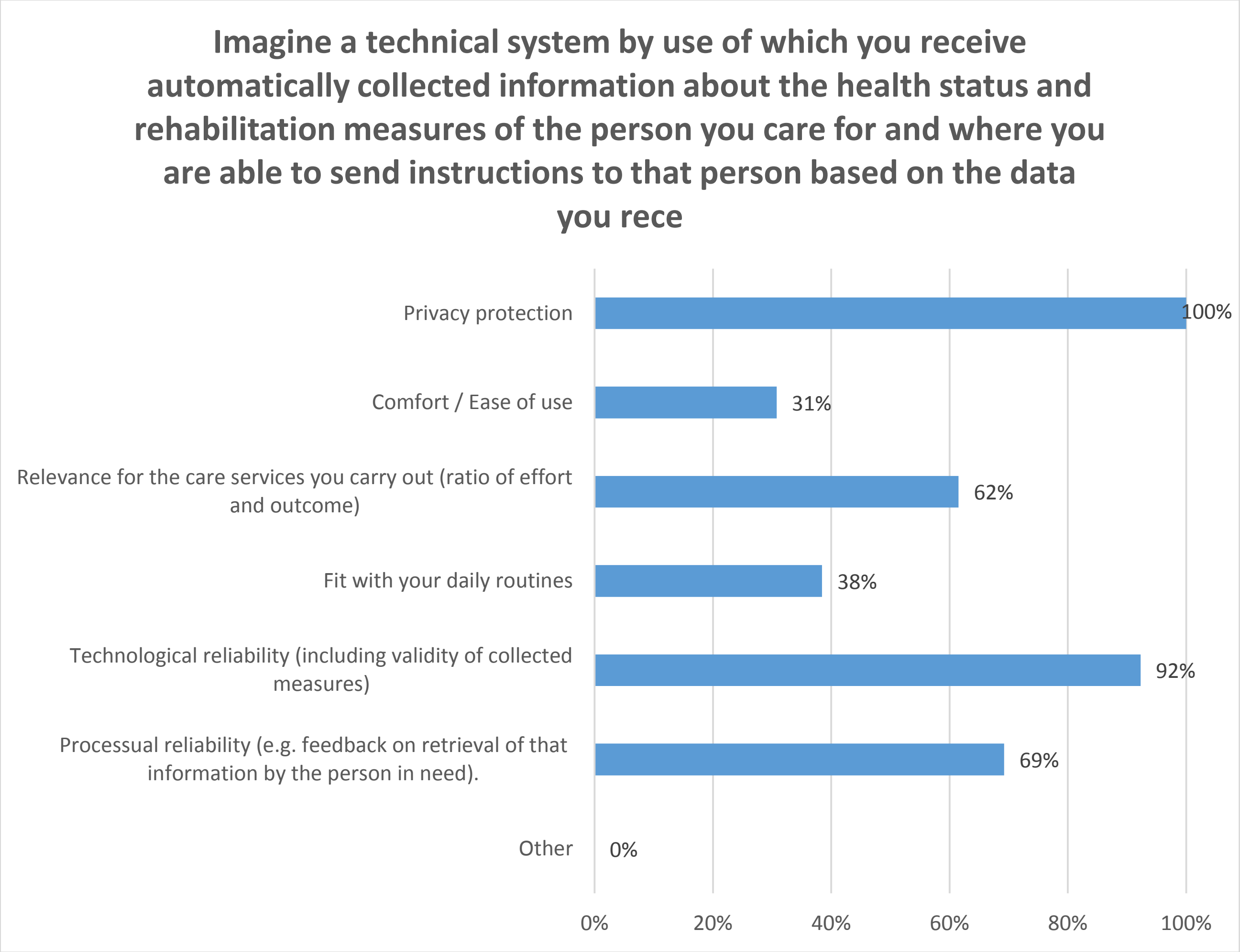
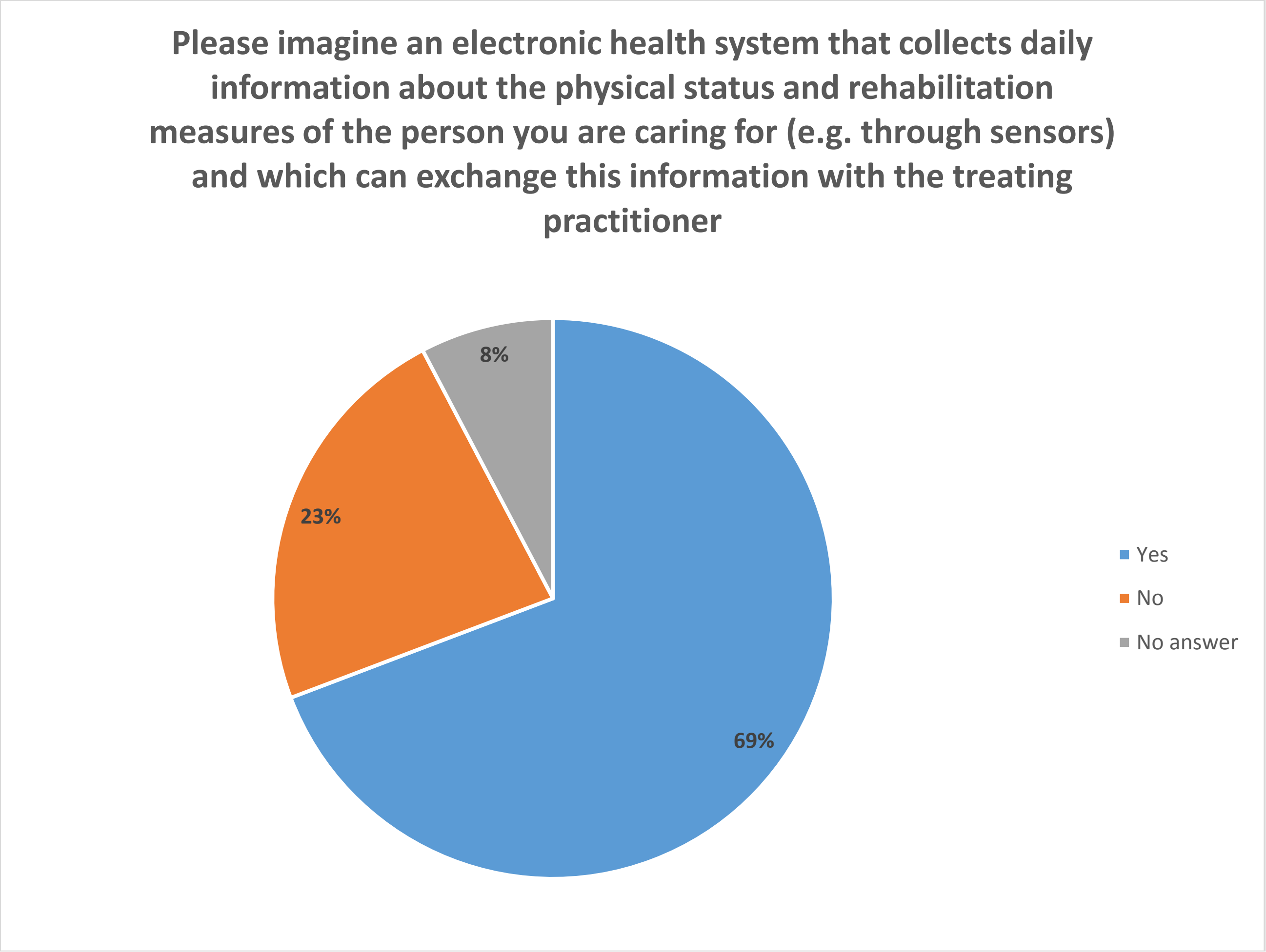
The requirement of data protection is confirmed in the following analysis. Considering prerogatives for the use of a system like PersonAAL, privacy was marked by 100% of the respondents. Generally speaking, the minimum requirements from the informal caregivers' perspective are manifold. Technological reliability (92%), processual reliability (69%) and relevance for the care service offered (62%) are further issues checked by majorities. Comfort / ease of use (31%) and fit with the informal caregivers' own daily routines (38%) were still mentioned by significant shares.



Despite the high minimum requirements, a system such as envisaged by PersonAAL is still considered useful. 69% indicate that they expect a significant improvement of the treatment they give to the person in need upon usage thereof.



Nevertheless, such a system is considered a device for additional care rather than a substitution of personal presence. Only 23% 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.

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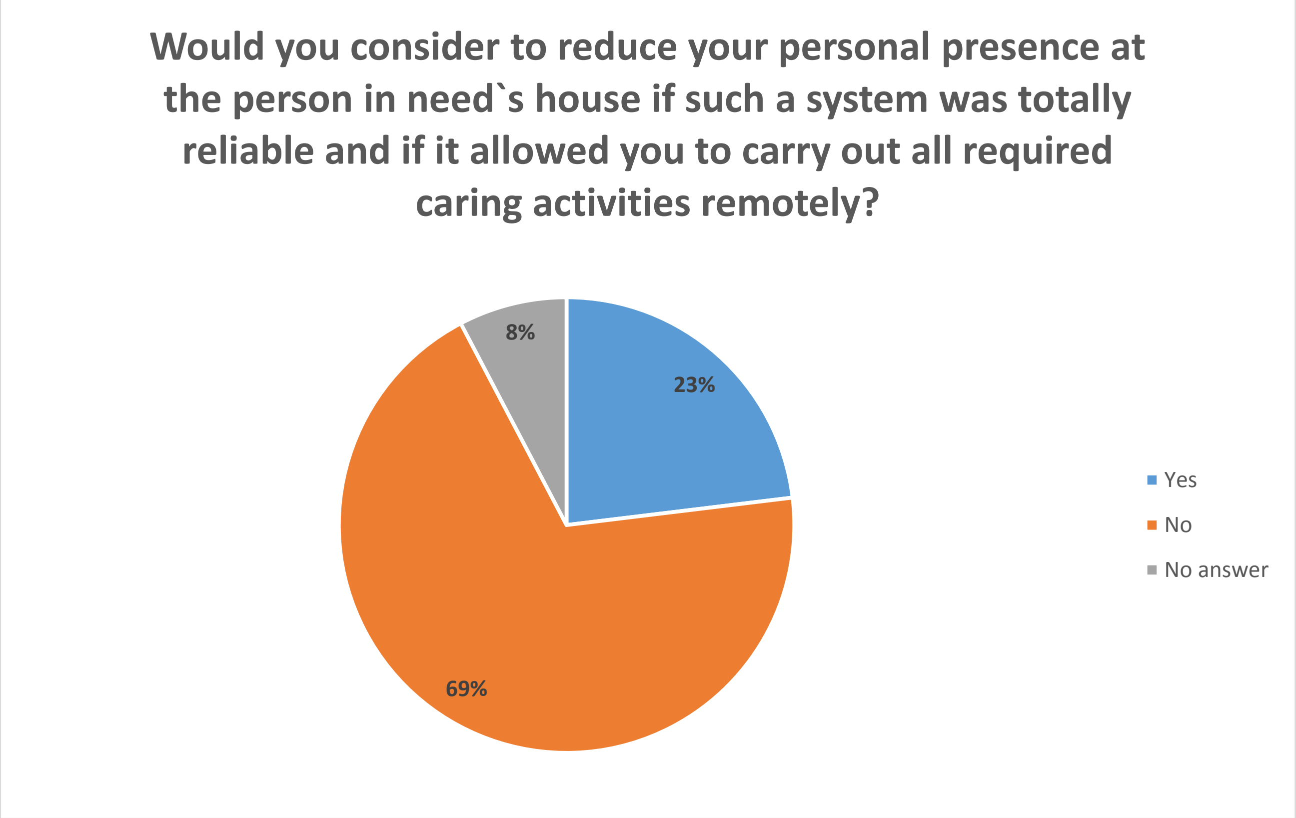

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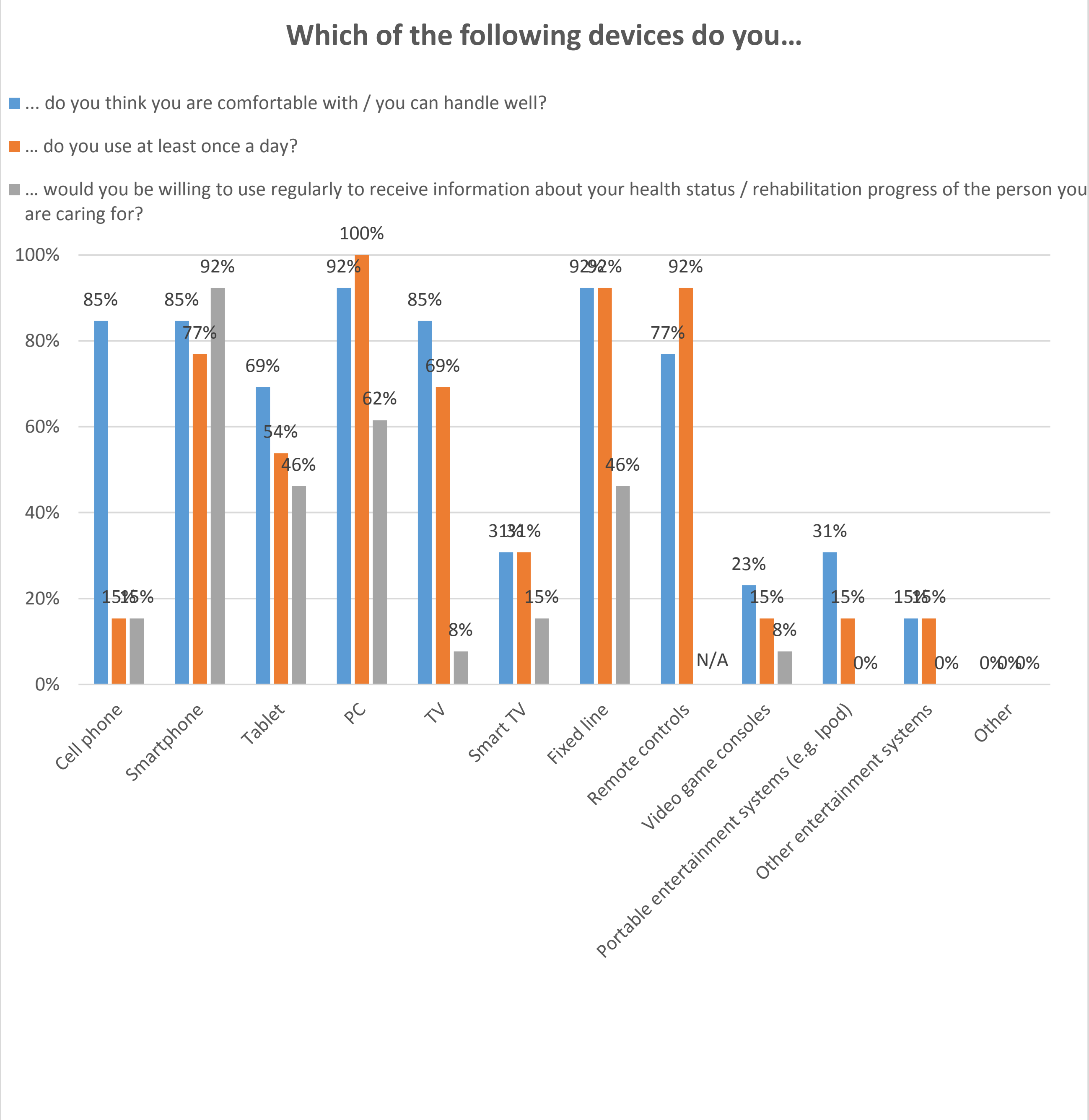
4.3.3 Use of technical devices

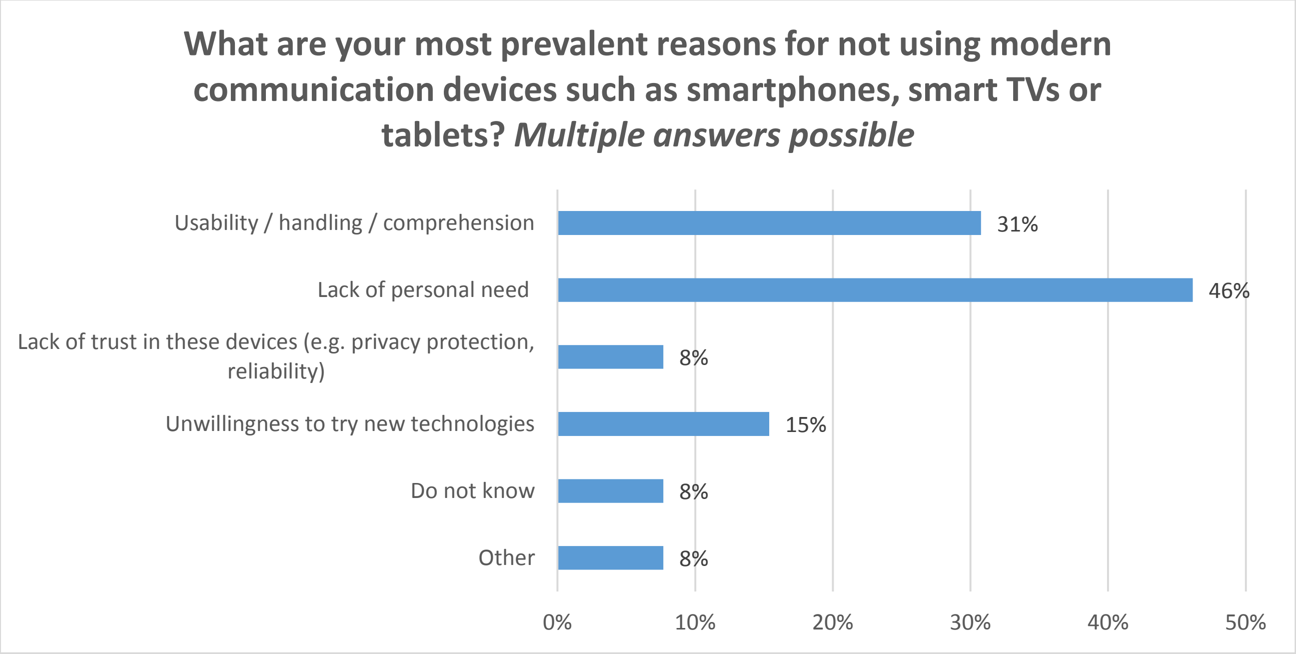
Equal to the survey among elderly end-users the current use of technical devices was investigated among informal caregivers in order to learn more about their habits and familiarity with modern technological devices. As outlined earlier, informal caregivers are not only the largely involved in the usage 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.

As shown in the following chart, the sample addressed by the current survey is extensively familiar with modern communication devices. 92% feel comfortable with PC, 85% each with tablet, cell phone and smartphone. The daily usage is also rather extensive. All respondents indicate the everyday usage of their PC. 77% use smartphones and 55% use tablets every day. Regarding a suitable platform for the communication of information, TV also appears rather promising. 85% feel familiar with TV, 69% use them every day. The same is true for fixed lines, reaching shares of 92% both for daily usage and familiarity. Smart TV, in contrast, is only used by every third person, reaching 31% each in the two categories.

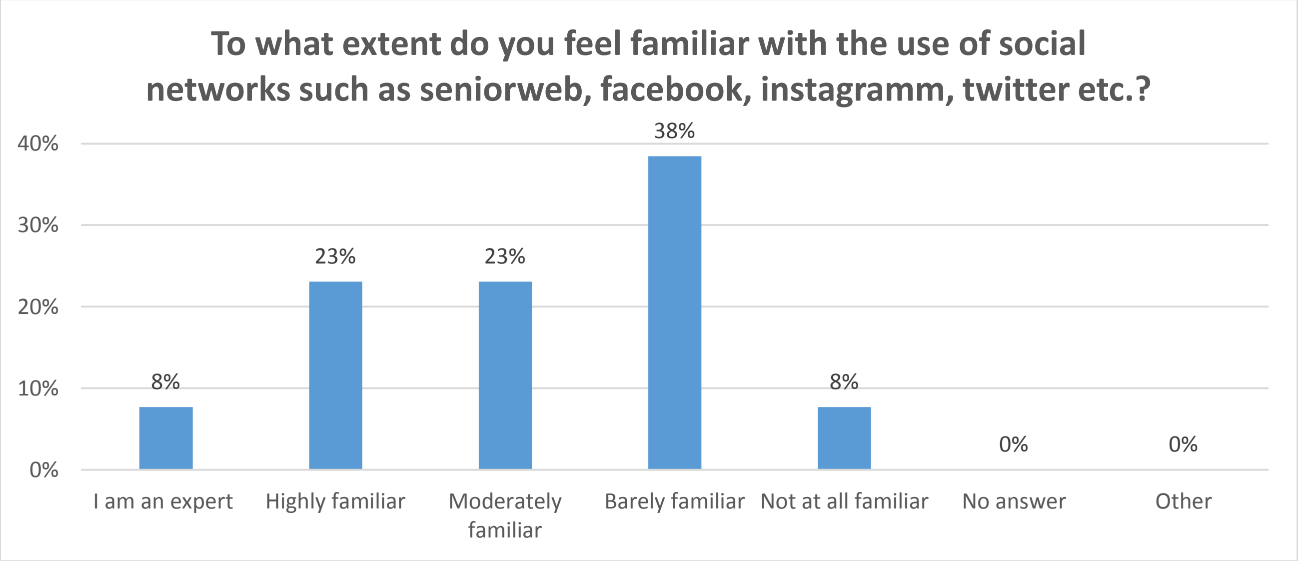
Regarding their own preferences for the usage of devices in the context of an electronic health system such as envisaged by PersonAAL, the highest shares were recorded for smartphones (92%), followed by PC (62%), fixed line and tablets (46% each). Only minorities (8%) consider TV the adequate medium.



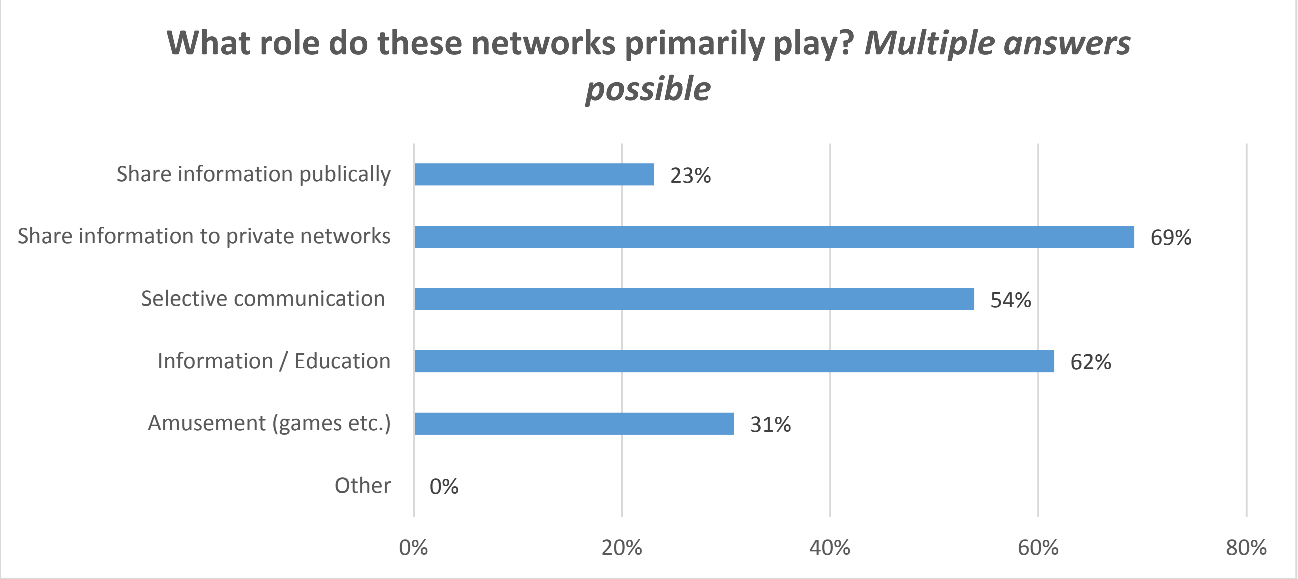
Major reasons for not using modern communication devices such as smartphones, smart TVs or tablets are a lack of personal need (46%) and usability issues (36%). This confirms the claim brought forward earlier that informal caregivers themselves need to be considered in their function as customers with 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.



About half of the participants feel at least moderately familiar with social networks. Minorities (8%) feel not 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 (69%), followed by educational purposes (62%) and selective communication to individual addresses (54%). Every third participant uses social networks for reasons of entertainment (31%).



The experience with tracking systems is given by about one third (31%) of the sample.

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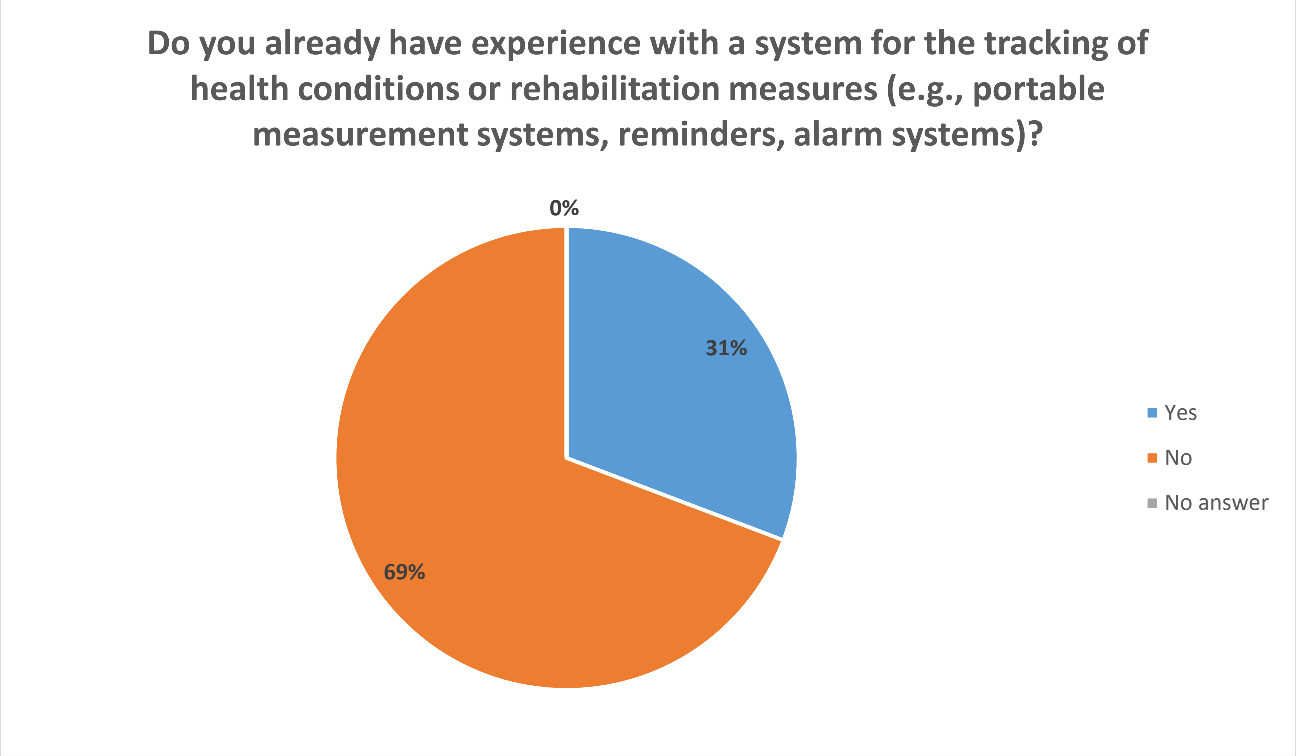

However, the general willingness to use additional devices is given, provided such devices are easily comprehensible and assist through the monitoring of a person in need so that this assistance becomes more effective. Among the small sample considered for the purpose of this study, all respondents indicated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

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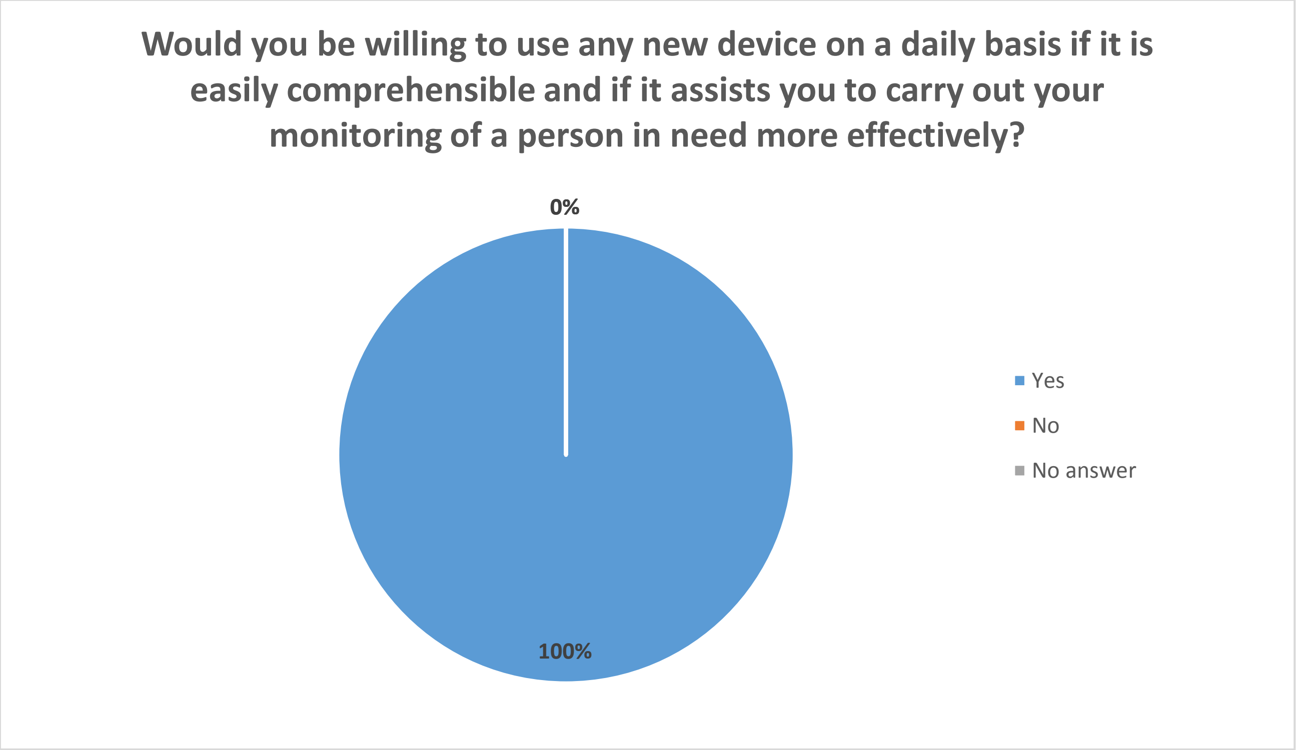

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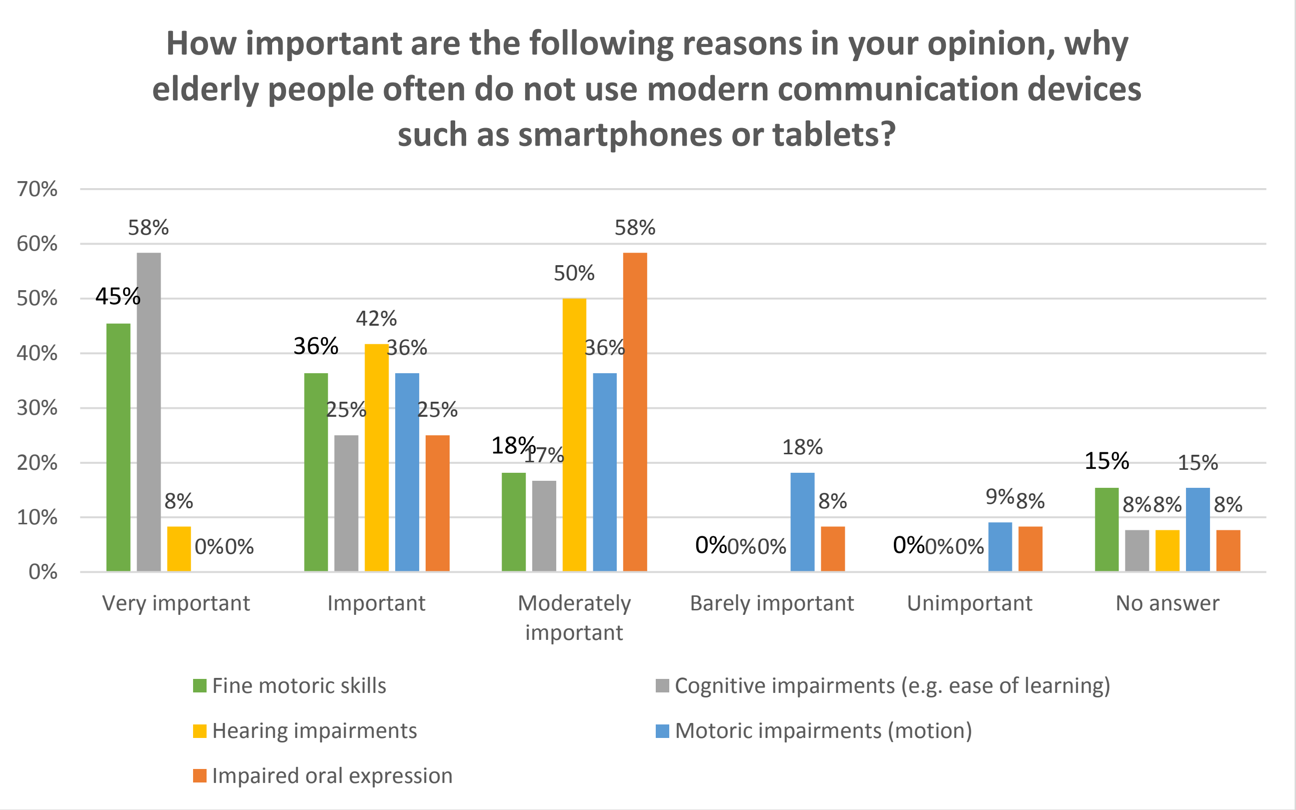
4.3.4 Usability of technical devices

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.

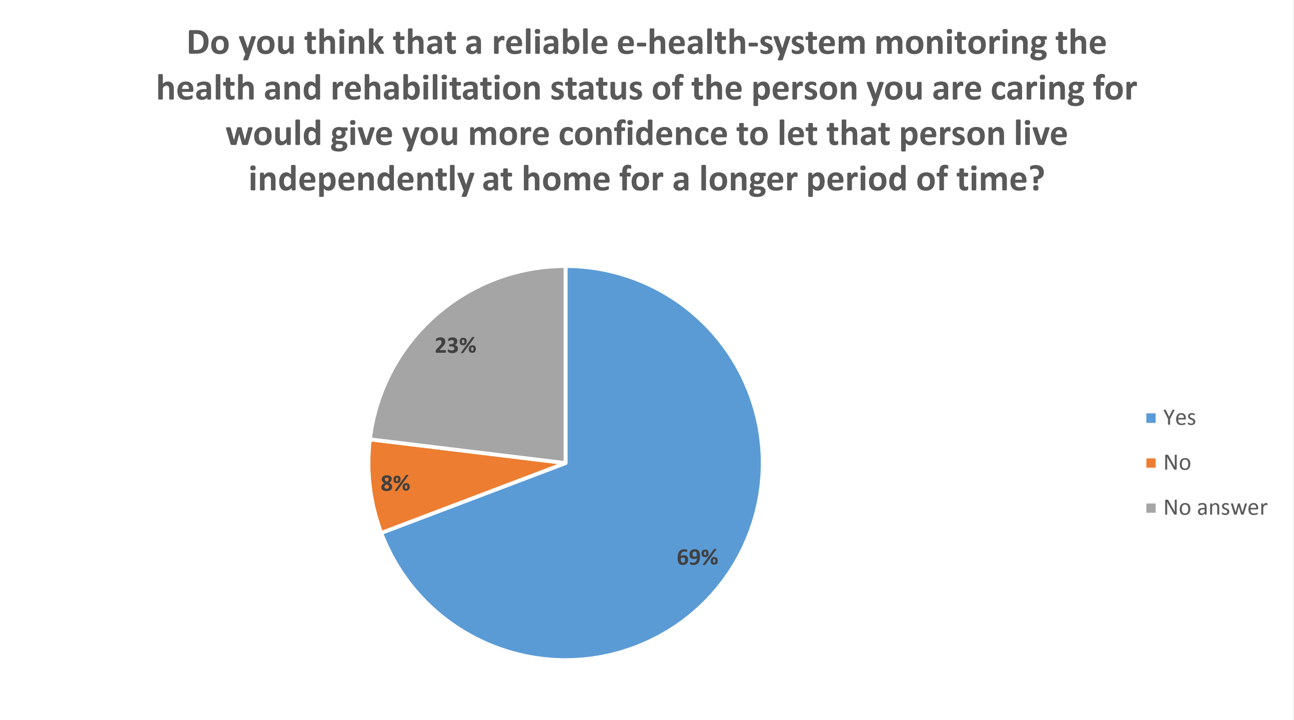
- Data protection and security
- Commercials
- Rays
- Privacy (accessibility)
- The personal contact cannot be replaced by them
- Misinterpretations
- No excitement to learn functionalities in a playful way
- No need to use specific ways to communicate
- Existence of substitutes (e.g. PC replacing tablet)

The following charts reflects the informal caregivers’ perspective on the rejection of modern communication devices. According to their assessment, major reasons why elderly people often do not use such devices are in the first place fine motoric skills and 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 barley important or unimportant by any significant shares of the sample.


How important are the following reasons in your opinion, why elderly people often do not use modern communication devices such as smartphones or tablets?
70%
60%
50%
40%
30%
20%
10%
0%
45%
58%
8%
0%0%
36%
25%
42%
36%
25%
18%
17%
50%
36%
58%
0%0%0%
18%
8%
0%0%0%
9%
8%
15%
8%8%
15%
8%
Very important
Important
Moderately important
Barely important
Unimportant
No answer
Fine motoric skills
Cognitive impairments (e.g. ease of learning)
Hearing impairments
Motoric impairments (motion)
Impaired oral expression

4.3.5 Success Factors

More than two thirds (69%) 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 8% do 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.

The following chart illustrates that the system is generally appreciated by large shares for the purpose of exchanging information with practitioners and professional caregivers (62%) as well as for regular information about the physical conditions of then nursed person (54%). 38% expect their own peace of mind to be contributed to by use of a respective system and 92% would even be willing to change their daily routines, if the system effectively improved the personal care they provide. At the same time, large shares (77%) indicate 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 31% who would use the system irrespective of

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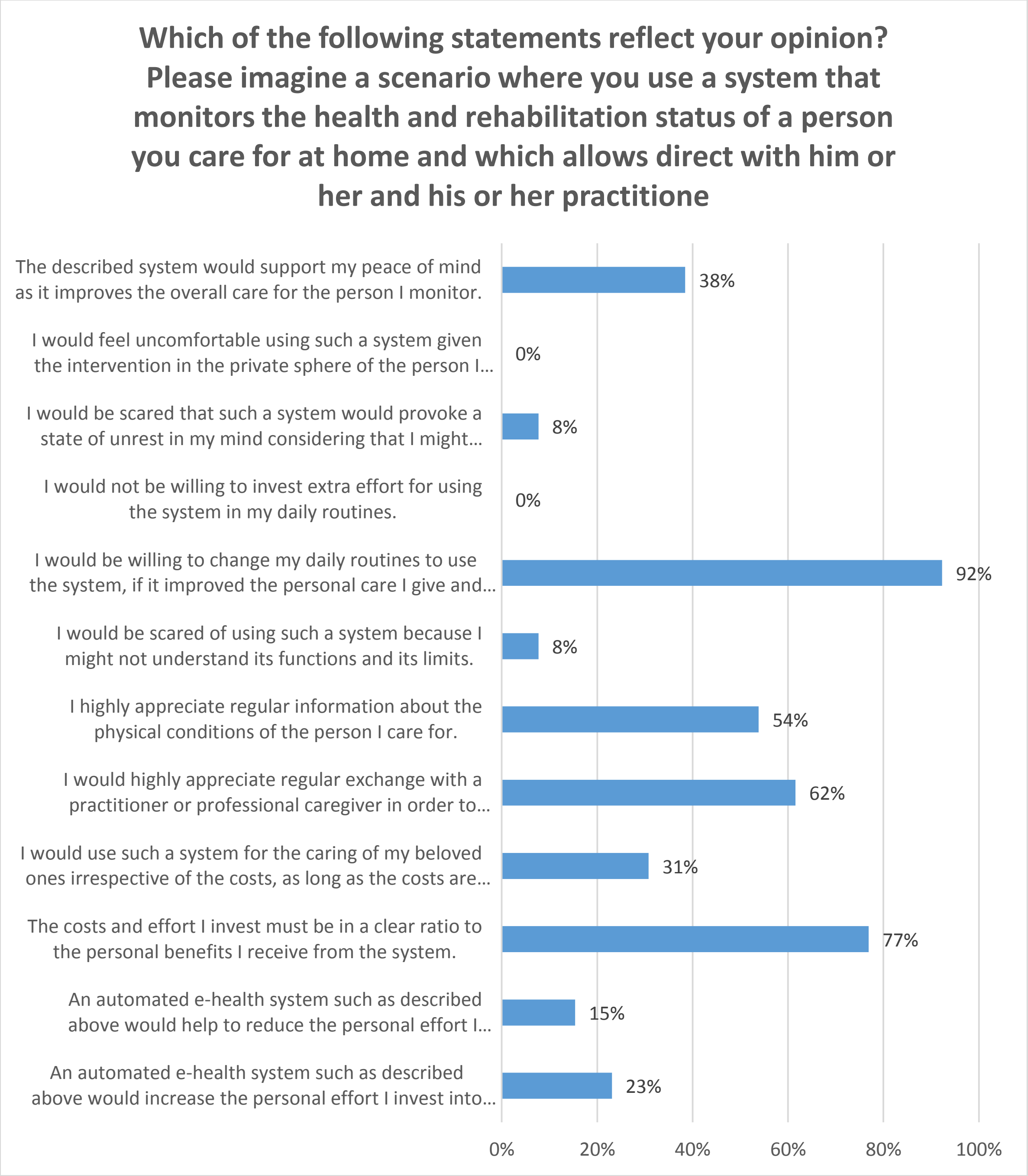
the costs it inflicts on them. Those expecting an increase of effort by using the system (23%) are even slightly more numerous than those expecting respective reductions.



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 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.

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 well being 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 well being for both the elderly and the informal caregivers. A fairly recently launched British smartphone app serving a very different purpose, the Stay Alive app, 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 well being and that the elderly is safe (purpose: reducing worries among caregivers)
b) Stimulation 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)

Link to further information about the Stay Alive app: http://www.prevent-suicide.org.uk/stay_alive_suicide_prevention_mobile_phone_application.html

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.

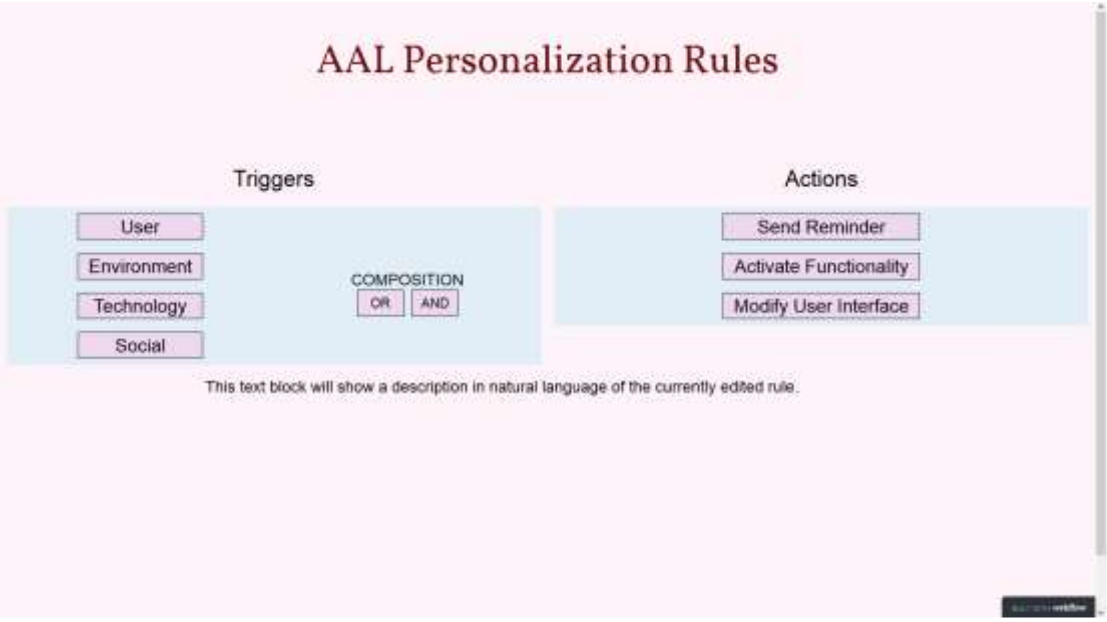
5.4 Decision making aid for the elderly and the caregivers

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 that will be shared, and to ensure that the system is individualized to the values and preferences of the elderly.

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.



This text block will show a description in natural language of the currently edited rule.

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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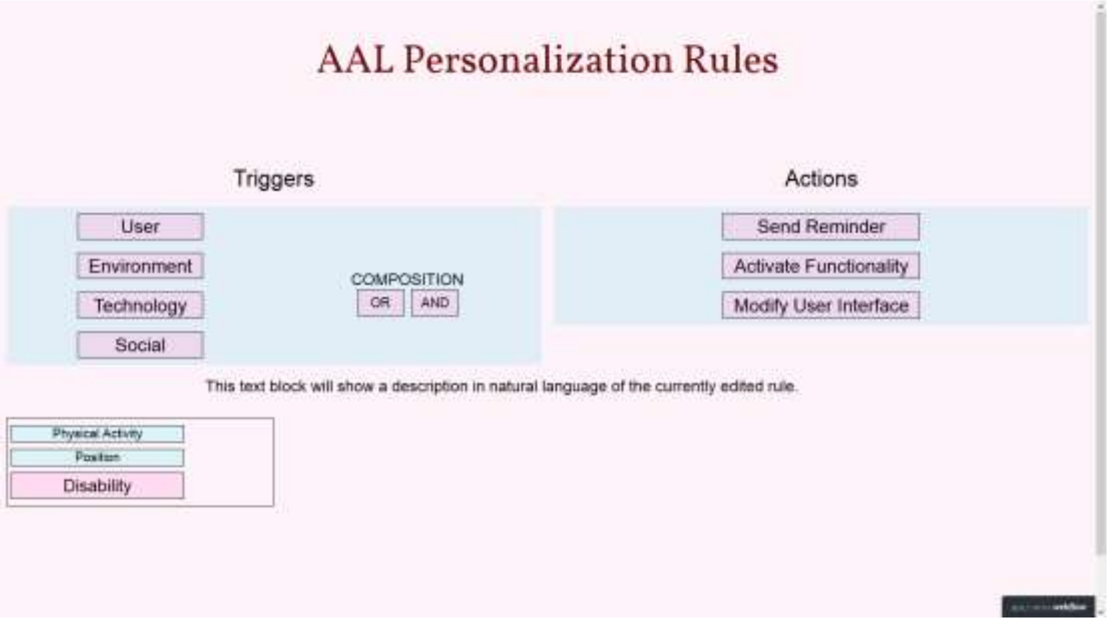
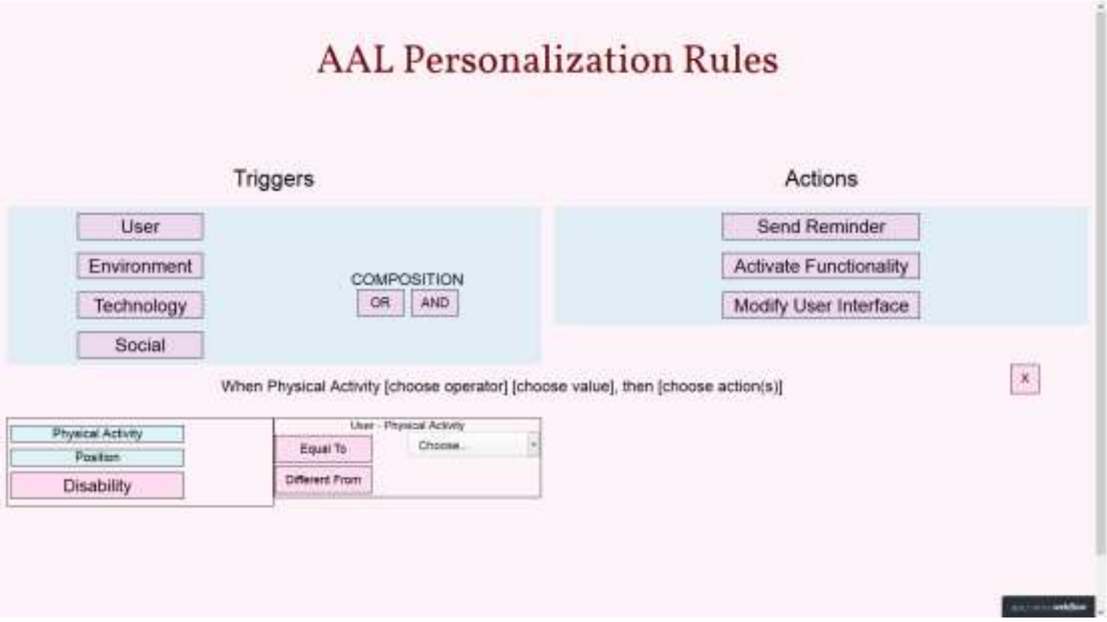


AAL Personalization Rules

This text block will show a description in natural language of the currently edited rule.

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".



AAL Personalization Rules

When Physical Activity [choose operator] [choose value], then [choose action(s)]

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

Laying down

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.

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

9:00

It's late, get up!

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, choses in which device the reminder will appear, and enters the content of the reminder.

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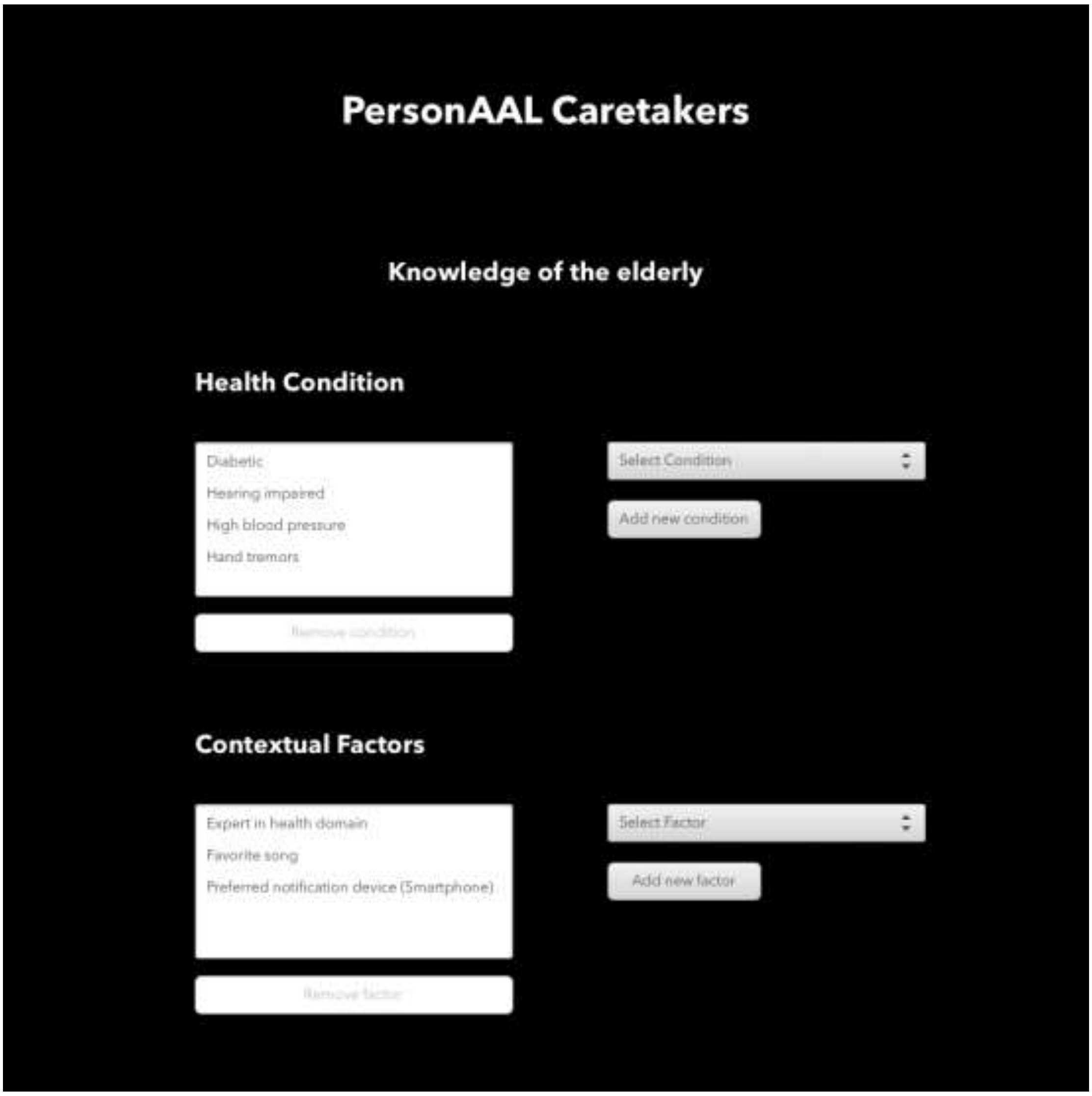
The previous example illustrates a trigger-action rule-setting interface, which could be implemented on top of the PersonAAL framework. However, for the scenarios considered in the scope of PersonAAL, it might be important to have information about the person being cared for without requiring setting 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.



PersonAAL Caretakers

Knowledge of the elderly

Health Condition

Diabetic
Hearing impaired
High blood pressure
Hand tremors

Contextual Factors

Expert in health domain
Favorite song
Preferred notification device (Smartphone)

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

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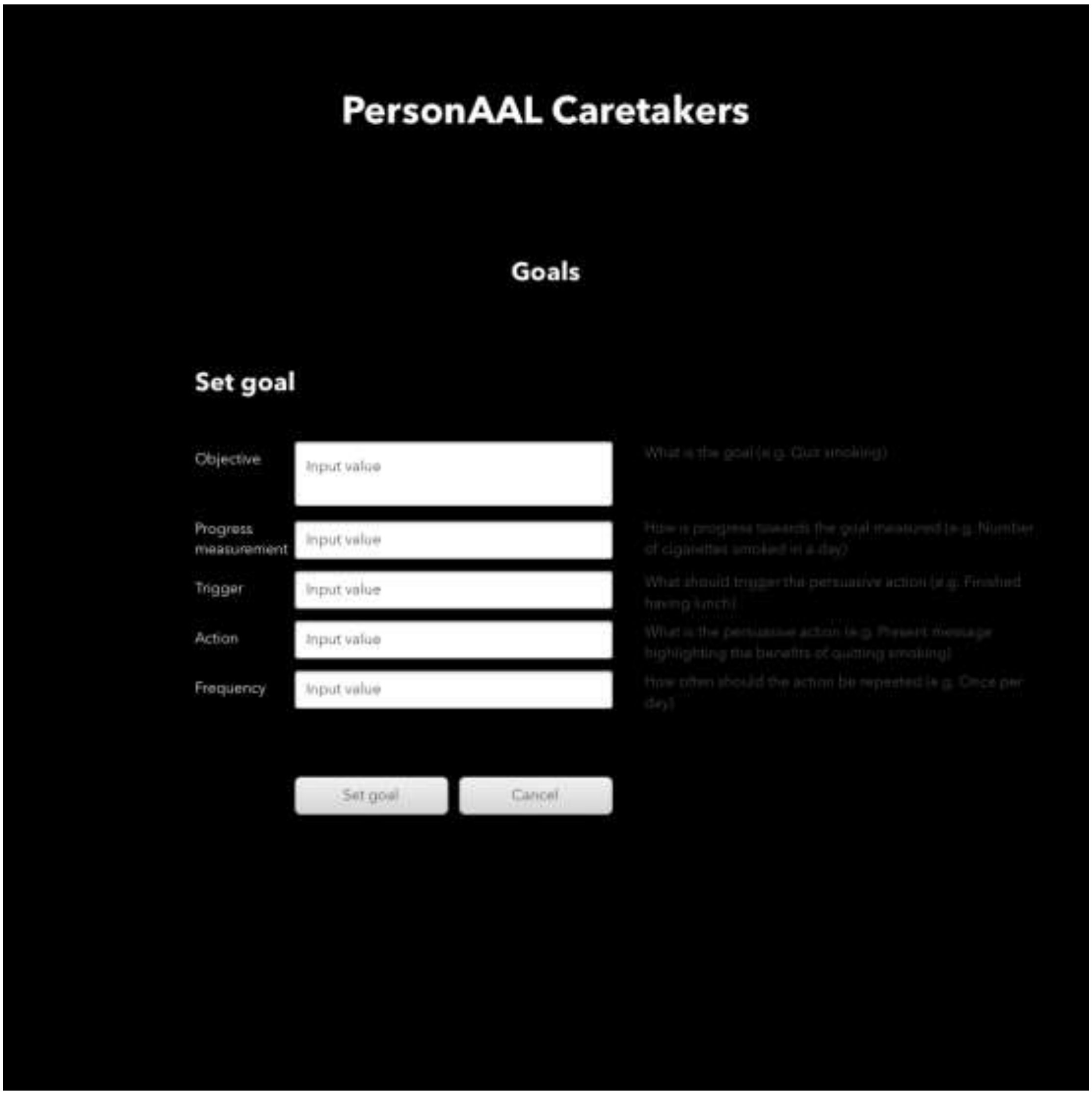
Another type of information useful for the system are the goals set for the person being cared for. These could for example relate to rehabilitation activities or to the promotion of healthier lifestyles. Goals can be handled in a similar manner to rules, in that some trigger and action are required to prompt the user to perform something to achieve the goal. However, they require 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 value	What is the goal (e.g. Quit smoking)
Progress measurement	Input value	How is progress towards the goal measured (e.g. Number of cigarettes smoked in a day)
Trigger	Input value	What should trigger the persuasive action (e.g. Finished having lunch)
Action	Input value	What is the persuasive action (e.g. Present message highlighting the benefits of quitting smoking)
Frequency	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.

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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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