What do informal caregivers think of an unobtrusive sensor-dependent communication platform?

‘’A concurrent mixed methods research about the needs, expectations and requirements of informal caregivers of community-dwelling elderly with dementia in The Netherlands towards an unobtrusive sensor-dependent communication platform.’’

Faculty: Science and technology

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Preface

This thesis is written to complete the master Health Sciences, with the specialization 'Personalized Monitoring and Coaching' at the University of Twente. The assignment is completed in collaboration with the University of Twente and Nedap Healthcare.

I would like to thank my supervisors Annemarie Braakman-Jansen, Christian Wrede and Nikita Sharma for giving me the opportunity to do this interesting research under their guidance.

I would also like to thank Jan-Hendrik Croockewit from Nedap Healthcare. Jan-Hendrik provided the opportunity to place the survey in Caren, which resulted in a lot of responses. Caren is a digital health environment and gives patients insight and control over their own health, or that of their relatives.

I would like to thank all informal caregivers who were willing to participate in this research and share their personal information during the interview or when filling out the survey. Because of those participants, the results of this research can be used to improve healthcare in the future by developing this unobtrusive sensor-dependent communication platform.

I hope you will enjoy reading this thesis.

Dineke Brouwer
August 2022, Enschede

Abstract

Background: About 70 percent of people with dementia live at home, whereof 23 percent live alone and are cared for by their immediate family. In total, there are about 350.000 informal caregivers who care for a person with dementia. Caring for a person with dementia (PwD) can be difficult, as informal caregivers often have to deal with new and potentially stressful situations. Research shows that different forms of technology can be useful to support people with dementia and to reduce the burden of care on their informal caregivers. The goals of these technologies are to facilitate remote care. There already exist different in-home monitoring systems, however they all know some disadvantages. Think of wearable alarm systems that provide only little assurance as the elderlies forget to wear them. To overcome these disadvantages a new, unobtrusive in-home monitoring system needs to be developed.

Objectives: The aim of this research is (1) to get insight into the information needs of informal caregivers of community-dwelling elderly with dementia, living in The Netherlands, (2) to explore their conditions towards the perceived usefulness and user acceptance of unobtrusive sensor technology, and (3) to find out what their (design)requirements are for an unobtrusive sensor-dependent communication platform.

Methods: A concurrent mixed method approach was applied in a convergent parallel design. Informal caregivers of community-dwelling elderly living alone at home were included if they were user of Carenzorgt, aged above 18 years, Dutch-speaking, and they deliver informal care to someone with a mild cognitive impairment or dementia. Purposive sampling was used to select the participants for the survey, the participants for the semi-structured interviews are approached in a targeted manner. Multiple-choice questions are presented in an online survey. Perceived usefulness and intention to use (single item variable) were measured using a 7-point Likert scale. The audiotapes of the interviews were transcribed verbatim, thematic analysis was performed. Deductive analysis was used to elicit specific design requirements, therefore the themes of the requirements development approach by van Velsen were used. The four categories of the PSD-model were used to further classify the usability and user experience requirements.

Results: The majority of the participants of both studies were women, who were mainly daughters of the care recipient. The majority of the participants see a fall accident as an emergency. If they do not respond immediately after receiving a notification on their phone, after their loved one has fallen, they want formal caregivers to be contacted. This is the same if their loved one shows agitation. In case of nocturnal unrest the system should send a new notification after five minutes, in case of no response. The highest perceived usefulness score was measured for the participants who are most familiar with a fall situation and the participants who are most familiar with nocturnal unrest, both M=4.1, SD=1.1, which means that they partly agree that the system will be helpful in delivering care. The text in the notifications should be ‘raw data’ which means a short message without interpretations of the information, according to the participants who are most familiar with a fall accident or nocturnal unrest. The participants who are most familiar with agitation or none of the situations prefer an interpretation of the data together with a suggestion. The interviewees prefer to receive a notification with a framework for action, in situations that action is needed. It appears from the survey that informal caregivers primarily want to receive a notification on their phone in all situations. Interviewees prefer to be called in case of emergency. On days without particularities the participants of both studies prefer an update on the communication platform.

Conclusion: It can be concluded from this study that there is support for developing a new sensor system. In general, the participants believe that the system in combination with the communication platform can make a positive contribution to caring for their loved ones. However, concerns about privacy will first have to be mapped out in follow-up research, just like the role the formal caregiver can play in the use of this system in the future.

Contents

1. Introduction

1.1 Mapping the problem

The pace of population ageing is currently much faster than in the past [1]. Life expectancy has increased globally by more than 6 years between 2000 and 2019 [2]. In proportion, the working population in The Netherlands is shrinking, as there will relatively be fewer young and working individuals. This means that there are fewer people who can support the social costs, such as care [3] because there are fewer people who can care for the elderly population in the Netherlands [4]. Of people aged 65 and older, 70 percent have a chronic disease (such as dementia, COPD or diabetes), and 63 percent have two or more chronic diseases (multimorbidity) [5]. The ageing society is therefore a challenge for healthcare [1].

One of the most common chronic diseases is dementia. As a result of the ageing population, the number of people with dementia will increase further to more than 620.000 in total by 2050 [5]. Dementia is a collective name for more than fifty diseases. These diseases affect the brain and cause a gradual decline in a person's cognition. The most common forms of dementia are Alzheimer's, vascular dementia, frontotemporal dementia (FTD) and Lewy body dementia. Alzheimer's is known for its memory problems, vascular dementia for slowness in speaking, thinking and acting, Lewy body for concentration problems and FTD for a change in behaviour [6]. Even though the different forms of dementia have varying characteristics, there are also many similarities, such as memory loss and a decrease in the ability to do daily tasks. As the disease progresses, the person with dementia (PwD) increasingly loses control over their own life and everyday activities are becoming more and more difficult [7]. People with dementia become increasingly dependent on their social environment [6], therefore the burden of dementia on healthcare is high [8].

About 70 percent of people with dementia live at home, whereof 23 percent live alone, and are cared for by their immediate family. The government and municipal policies in the Netherlands are aimed at ensuring that care is provided as much as possible within the social environment and that people stay at home as long as possible [9]. In total, there are about 350.000 informal caregivers who care for a PwD [10]. Caring for a PwD can be difficult, as informal caregivers often have to deal with new and potentially stressful situations. According to several studies they are concerned about the safety (falling, cooking, straying from home), personal hygiene and time orientation (sleep patterns are often disrupted) of the people they care for [11–13]. They also need information about medication and treatments, as well as about water and nutritional needs [11]. Informal caregivers do not always know how to deal with challenging behaviour or how to offer meaningful activities [14]. Therefore, they can experience psychological problems such as anxiety and mood, sleep or eating disorders, and have a higher risk of developing physical and mental disorders [15]. In addition, some informal caregivers experience a lack of time for themselves [12]. On top of that, they feel the need to be with the PwD more often. Otherwise, they experience feelings of guilt, anger, insufficiency and fear [16]. As a result, informal caregivers have less time to socialize outdoors, and as their loved one's dementia progresses, they find it increasingly difficult to socialize with acquaintances in their home environment due to the presence and the need for care for the PwD [17]. As a result, social isolation and feelings of loneliness are lurking [18–20]. From this evidence, it is clear that there is a challenge in how to support informal caregivers of PwD who live alone at home.

1.2 Need for an innovative solution

Formal caregivers (case managers, nurses and therapists) can play an important role in caring for the PwD at home by advising the informal caregiver and making decisions about care. However, currently, the different people within the care network often cannot satisfy the more specific needs of the PwD and their informal caregivers anymore. There are too few formal caregivers and the requests for help are too complex for the home setting [21]. The increasing need for support of both PwD and their informal caregivers in the home setting has already led to innovative solutions [22]. Research shows that different forms of technology can be useful to support PwD and to reduce the burden of care on their informal caregivers by promoting independent living and early identification of problems [23,24]. The goals of technologies to support both PwD and caregivers within dementia care are diverse. These solutions can include assistance for activities of daily living, cognitive and emotional assistance, remote communication, emergency systems, and health and behavioural monitoring [23,25,26]. These monitoring systems are characterized by automation and making human intervention minimal or not needed anymore, like in-home monitoring systems. Such a system appears very promising in reducing the burden of care on informal caregivers. This study, therefore, examines the opinions of informal caregivers about a to-be-developed unobtrusive in-home monitoring system and sensor-dependent communication platform.

1.3 In-home monitoring

There already exist different in-home monitoring solutions that can recognize various physical and physiological human activities. The most common in-home monitoring solutions include wearable sensing systems, vision-based systems, and radio frequency-based sensing systems [27]. However, most of these solutions are not favourable for care for PwD. In particular, wearable alarm systems have been criticized for providing little reassurance, because patients often forget to wear them or because alarm buttons are not always pressed when they should be [28]. Furthermore, vision-based systems can generate false alarms because the technologies are unaware of the PwD's environment [29]. These systems, like Sensara, do not monitor the difference between persons [30]. So if the PwD has a visitor, the system does not know if it is the visitor or the PwD who walks past the sensor, it only monitors the movement. In addition, it is motion-activated, so it cannot measure continuous dynamic human activity. Ethical issues arise when talking about assistive technology and monitoring data [31]. First, the privacy of the PwD cannot be guaranteed while using monitoring technologies, because of risk factors associated with possible usage of personal data and the potential for unjustified paternalism [32]. Second, the autonomy of those living at home shifts away from them [33]. In the event of an emergency, an alarm is sent to the informal or formal caregiver or emergency service. This shifts the decision to seek help away from the PwD, which can lead to reduced autonomy and self-care of the PwD. It appears that these in-home monitoring systems know some disadvantages the to-be-developed system should take into account.

Radio-frequency-based in-home monitoring systems overcome the disadvantages of wearable sensing systems and vision-based systems, mainly because they are unobtrusive. Unobtrusive means to reduce "*characteristics or effects associated with the technology that are perceived as undesirable and physically and/or psychologically prominent*" [34]. Other advantages of these radio-frequency-based in-home monitoring systems are that the PwD does not have to be in the line of sight and that the system is context-aware [35,36]. They require no action from the PwD and can be used to support formal or informal caregivers of older adults, as they can monitor deviant physical and physiological behaviour changes [27,28,35]. This unobtrusive monitoring technology consists of unnoticed sensors that, for example, detect the movement of people indoors, map the food and water intake or measure the night rhythm [29,36]. These technologies are more persistent than human interference and can be in places where humans cannot. For example; because of privacy it is not always acceptable to be there with someone in a bathroom, placing a camera in a bathroom is also a privacy breach, but an unobtrusive in-home monitoring system could be a suitable solution. In-home monitoring systems are developing and driven by the aim to minimize their obtrusiveness, so it can help to intervene at the right time and appropriate place. This study therefore focuses on the state-of-the-art of the unobtrusive in-home monitoring systems. This new generation unobtrusive in-home monitoring systems will overcome a lot of the earlier mentioned disadvantages if developed and implemented well.

1.4 Implementation

Development and implementation of (new) eHealth technologies is often complex. Bastoni et al., [37] performed an umbrella review to explore what factors influence the implementation of technologies in informal dementia care. One of the results is that the specific needs and preferences of individuals must be considered for a technology to be effective, but this does not happen enough. Furthermore the current development of eHealth technology often disregards the interdependencies between technology, human characteristics, and the socioeconomic environment, resulting in technology that has a low impact on health care practices. A new holistic approach to the development of eHealth technologies is needed to overcome these hurdles in the design and implementation of eHealth, to ensure that this to-be-developed system will be found useful in the future. A holistic approach is one that takes into account the complexities of healthcare and the rituals and habits of patients and other stakeholders [38].

The CeHRes Roadmap serves as a guideline for eHealth development, implementation and evaluation [39]. It provides guidelines for a holistic development approach to eHealth technology and will be used during the development, design and implementation of this new unobtrusive system. Implementation of eHealth is complex as it is not a post-design step but is interwoven with the development process. Therefore it is important to make sure that the eventual end-users of the system are involved during the development process.

User Centred Design (UCD) is a design framework that aims to develop solutions to problems by involving the user perspective in all steps of the process. Integrating user-centred design provides the theoretical background for the development, evaluation and implementation of eHealth technologies according to van Gemert-Pijnen et al., [38]. Especially in the context of long-term care, such as caring for a PwD, it is important to develop technologies that can create bonding relationships with the end users. Central are the lives and desires of the people for whom the eHealth technology is designed. The key to a user-centred design process is keeping users and stakeholders in the process, through among other requirements definition [38]. The Practical Multidisciplinary Requirements Development Approach of van Velsen et al., [40] can be used to facilitate the creation of these requirements and therefore eHealth that matters. It gives an idea of what the informal caregivers of PwD need from the unobtrusive in-home monitoring system. Requirements development is a crucial part of eHealth design. It entails all the activities devoted to requirements identification, the communication of requirements to other developers, and their evaluation [40]. These requirements will form the foundation of the design of the new unobtrusive in-home monitoring system.

Next, when the first requirements are clear, the Persuasive Systems Design (PSD) model can be used to make sure that the system will be persuasive. Persuasive technology is integrated into the CeHRes Roadmap to design technologies that are user-friendly and that motivate and engage users to change their attitudes and behaviours. The PSD-model plays an important role in the application of persuasive features (e.g. sending reminders, using suggestions in notifications or using checkmarks as praise) to increase engagement and adherence to technologies. The PSD-model provides the framework to decide and test what kind of features could be applied within this to-be developed unobtrusive monitoring system and communication platform.

While applying these theories and models it is needed to know why users accept and use or reject a technology. The Technology Acceptance Model (TAM) aims to understand this better and will help to improve the user acceptance through design [41]. Important aspects that influence the intentions to use a certain technology are perceptions about ease of use and perceived usefulness. These perceptions are assumptions people have about whether they are able to use technology and can benefit from that use.

1.5 Current study

In previous research Wrede et al., [28] explored the expected benefits, barriers, needs, and requirements for unobtrusive in-home monitoring from the perspective of formal and informal caregivers of community-dwelling people with dementia. He found out that the top 5 monitoring goals seen as most useful include: fall detection and prevention, monitoring day and night rhythm, personal hygiene (e.g., dressing, grooming, bathing, and toileting), nocturnal restlessness, and eating and drinking behaviour. He suggested that future research should investigate differences in needs for different informal care scenarios to create more personalized requirements for unobtrusive in-home monitoring. Therefore, the goal of this research is to explore the information needs, expectations and requirements of informal caregivers of community-dwelling elderly towards a sensor-dependent communication platform. This exploration will be done by answering the following sub-questions:

1. *''What are the information needs of informal caregivers of community-dwelling elderly with dementia towards different situations?''*

2. *''What are conditions towards user acceptance and perceived usefulness of unobtrusive sensor technology of informal caregivers of community-dwelling elderly with dementia towards different situations''*

3. *''What are the (design)requirements for an unobtrusive sensor-dependent communication platform to support informal caregivers in the care of community-dwelling elderly?''*

2. Method

2.1 Design

A mixed-method approach was applied to collect information about the informal caregivers' thoughts and ideas about the unobtrusive in-home monitoring system and communication platform. A mixed-method design is a procedure for collecting, analysing, and mixing both quantitative and qualitative data and methods in a single study to understand a research problem [42]. In this research, the purpose of the mixed-method is to seek convergence, corroboration and correspondence of results from different methods, which is called triangulation [43,44]. The mixed-method approach is applied in a convergent parallel design, as both the interviews and the survey were conducted in the same period of time [44]. The qualitative and quantitative data were analysed separately. The interviews gave in-depth and additional information to the questions asked in the survey. The integration of the qualitative and quantitative data found place in the results point of integrations. This means that after writing down the results of the survey and interviews, the results of the both studies were added and integrated in an additional chapter [44]. In this chapter, the quantitative results are supplemented and further explained with qualitative results. All three sub-questions are answered with the outcomes of the survey and the interviews.

2.2 Survey

2.2.1 Participants and sampling procedure

The participants of this study were recruited via the healthcare platform Carenzorgt. Participants who filled in the survey were users of the healthcare platform Carenzorgt, who were older than 18 years. From April 28th 2022 to May 4th 2022 a pop-up message was made visible on the healthcare platform, for all users, with a link to the survey.

Purposive sampling has been used to select the participants for this study. Only the filled in surveys of participants with the following inclusion criteria were included in this study:

- Users of Carenzorgt
- Aged above 18 years
- Dutch-speaking
- Informal caregiver
- They deliver informal care to someone with a mild cognitive impairment (MCI), dementia or anility
- The person they care for lives alone

Participants with the following exclusion criteria were excluded:

- Aged under 18 years
- Not an informal caregiver of someone with dementia or MCI

2.2.2 Materials

The survey was developed containing multiple-choice questions, which were based on the research questions of this study, previous research in the field by Wrede et al., Oudheusden et al., and de Witte et al., [28,45,46] and the TAM [47]. The survey could be filled in by formal caregivers, informal caregivers and the care recipient themselves. For all three groups, the survey questions were essentially identical, except that the questions were adapted to fit the different roles and the part for the formal and informal caregivers was more extensive than the part for the elderly.

The survey which was filled in by informal caregivers contained three general questions about the background of the respondent: age (continuous), gender and level of education and two about their care recipient: age and comorbidities. Then questions were asked about being an informal caregiver (e.g. how often do they deliver care and how far away do they live from the person they care for). Subsequently, a short explanation of the sensor system was given (see figure 1).

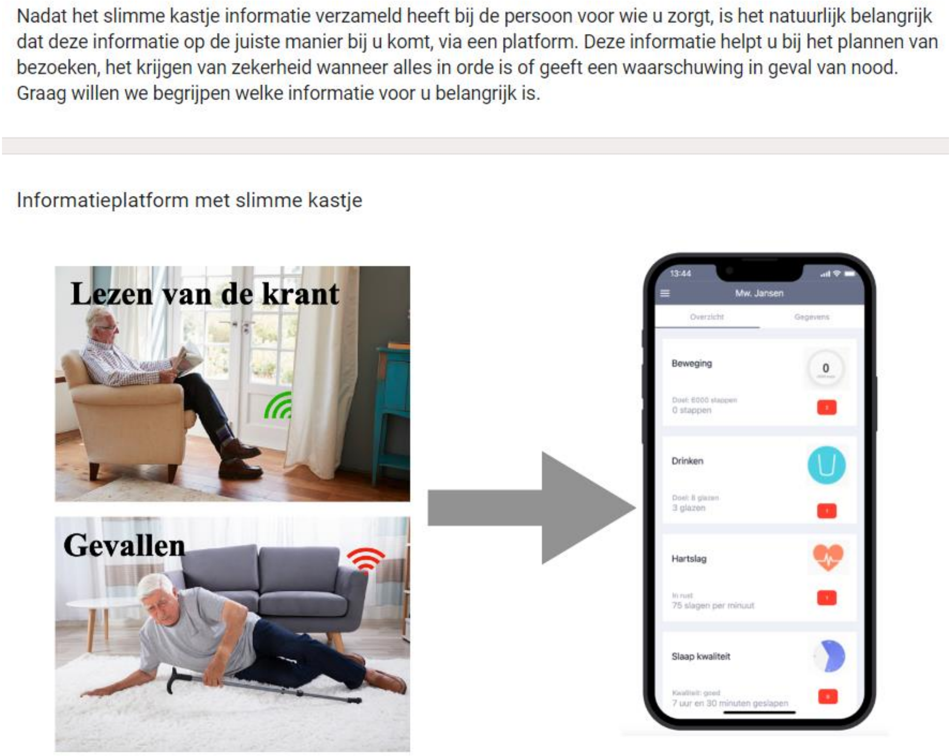
Uitleg over het slimme kastje

De universiteit doet onderzoek naar een nieuwe onopvallende detectietechnologie om bepaalde risico's te signaleren. Dit houdt in dat u niks hoeft te dragen op uw lichaam en geen apparaat hoeft te gebruiken. Zoals u kunt zien in de afbeelding kan er een klein kastje, denk aan een lichtsensor, op een onopvallende plek van uw woning geplaatst worden. Dit slimme kastje kan verschillende activiteiten volgen en belangrijke veranderingen waarnemen, zoals minder drinken of eten, verandering in de hartslag of ademhaling, (on)rustiger slapen, maar ook situaties zoals een val. Houd dit slimme kastje in gedachten bij het beantwoorden van de volgende vragen:

Slimme kastje in huis

Figure 1 Explanation of 'Slimme kastje'

Next, a short introduction to the information communication platform was given. See figure 2.



Nadat het slimme kastje informatie verzameld heeft bij de persoon voor wie u zorgt, is het natuurlijk belangrijk dat deze informatie op de juiste manier bij u komt, via een platform. Deze informatie helpt u bij het plannen van bezoeken, het krijgen van zekerheid wanneer alles in orde is of geeft een waarschuwing in geval van nood. Graag willen we begrijpen welke informatie voor u belangrijk is.

Informatieplatform met slimme kastje

Figure 2 Explanation communication platform

Next four care situations (agitation, nocturnal unrest, fall situation, normal day) were presented. These situations were based on previous research by Wrede et al., [28]. Each respondent could choose one of these four situations they were most familiar with and answer some situation-specific questions, e.g. urgency of the situation, how to be informed in this situation and how the data should be presented. How the data should be presented in the notification from the platform could differ between raw data, interpreted data and interpretation and suggestion. Raw data is the information received by the sensor system, without any interpretation. Interpreted data means that the information from the sensor system is directly analysed by the system before the information is shared via the platform. Interpretation and suggestion mean that the information is immediately analysed by the sensor system, and together with the information a suggestion is made for what action can be taken. The different data presentations were presented for each situation, the respondent could choose which one they preferred or give another suggestion. Each respondent also filled in these situation-specific questions for the normal day scenario. In addition questions were asked about usage of the sensor system, including perceived usefulness and intention to use, using a 7-point Likert scale.

Perceived usefulness

Perceived usefulness, which measures to what extent the participants think that the system will be helpful in delivering care to their care recipient, was measured with four statements using a 7-point Likert scale ranging from (0) completely disagree, (1) disagree, (2) partly disagree, (3) neutral, (4) partly agree, (5) agree, to (6) completely agree. The scores of the four items were added up and then divided by four. These items were based on the TAM [47]. For example '*Ik zou dit product nuttig vinden in de zorg voor mijn naaste*' was asked to measure this construct. The scores of the four items were added up and then divided by four. The Cronbach's Alpha was calculated to check the internal consistency of the scale, which was 0,94 [48].

Intention to use

Intention to use, a single item variable, was measured using a 7-point Likert scale ranging from (0) completely disagree, (1) disagree, (2) partly disagree, (3) neutral, (4) partly agree, (5) agree, to (6) completely agree. This item was based on the TAM [47]. The following question was asked to measure intention to use: '*Wanneer ik toegang zou hebben tot dit product, zou ik het gaan gebruiken bij de zorg voor mijn naaste*'.

2.2.3 Procedure

After the Ethics Committee of the University of Twente provided ethical approval for this study (request number 220250), the survey was placed on the healthcare platform Carenzorgt. After clicking on the pop-up message on the healthcare platform Carenzorgt, the participants were linked to the survey made in Google Forms. First, participants were asked to agree with the informed consent. A short explanation of the survey was given and participants were asked if they were over eighteen years old, agreed with the given information about the research and whether the participation was voluntary. After this informed consent, the survey started. It was estimated that it would take the respondent around 15-20 minutes to fill in the survey. The survey can be found in appendix 9.1 Survey.

2.2.4 Analysis

When the dataset was retrieved from Google Forms in Excel, only cases of informal caregivers who care for someone with dementia who lives alone were left in the dataset. Next two cases with typing errors (age of care recipient <10) were excluded from the analysis. Statistical analysis was conducted using RStudio version 4.0.3.

Descriptive statistics were used to describe the different scores of demographic characteristics such as age (of both informal caregiver and care recipient), gender and level of education. The Shapiro-Wilk test was performed to determine normality for the continuous variable age of the informal caregiver and age of the care recipient. Both were not normally distributed.
The information needs of participants are described by descriptive statistics. The urgency of the situations and what the information loop should look like are presented separately for the three situations.

The Shapiro-Wilk-test was conducted for perceived usefulness and showed that it was not normally distributed. The questions about perceived usefulness and intention to use were asked after the situation-specific questions, which made it possible to divide the data into five different groups. The perceived usefulness and intention to use-score are therefore presented in general, for falling, agitation, nocturnal unrest and the group who was not familiar with any of the situations.
What device the participants prefer to receive information on, data presentation and the way of informing are described using descriptive statistics.

2.3 Interviews

2.3.1 Participants and sampling procedure

Participants who matched the following inclusion criteria were included in this research:

- Users of Carenzorgt
- Aged above 18 years
- Dutch-speaking
- Informal caregiver
- They deliver informal care to someone with a mild cognitive impairment (MCI), dementia or anility
- The person they care for lives alone

Participants with the following exclusion criteria were excluded:

- Aged under 18 years
- Not an informal caregiver of someone with dementia or MCI

Participants are approached in a targeted manner based on the inclusion criteria that have been drawn up [49]. Emails were sent out to participants of earlier research by Nedap and to informal caregivers from the social environment of the researcher, who met the inclusion criteria. A message with a short explanation of the research and question to participate was posted on different social media channels to gather participants. Also, participants were contacted if they left their email address and telephone number after filling in the survey if they were interested in participating in follow-up research.

2.3.2 Materials

The semi-structured interviews aimed to identify information needs, expectations, barriers and facilitators, and design requirements of informal caregivers towards the sensor-dependent communication platform.

The first part of the interview consisted of an introduction to the research, explanation of the research and informed consent. Then questions about the background of the participant were asked and current experiences with technology were mapped. Next, questions about the current care zoomed in on how the care was organized and what situations the informal caregivers worried about, to be able to give an answer to the first research question about the information needs of the informal caregivers.

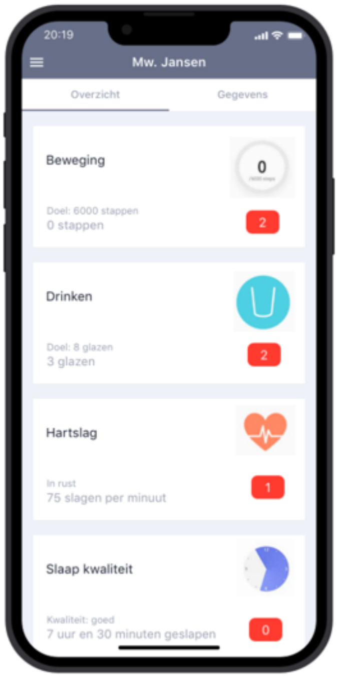


Figure 3 Wireframe prototype of main page of communication platform

Next, an explanation of the sensor system was given based on research by Wrede et al. [28], using a wireframe prototype of the sensor system and communication platform [26]. Wireframes of this prototype are presented to the participant on paper or by sharing the screen in the Microsoft Teams environment, to give the participants an idea of how the system works and the platform could look like. It was used for illustration to provoke a reaction, to get the opinions of the participants about what the platform should look like. The wireframes of the communication platform are designed with the PSD-model in mind [50] while using the proto.io website. Different PSD features, especially from the primary task support and dialogue support category, were implemented in the wireframes [26].

During the explanation of the wireframes the participants had the opportunity to respond and give their opinion. For each wireframe, the researcher gave a brief explanation of what could be seen on the wireframe. Such as the home page, for example, that there could also be other topics than the ones now displayed. At other wireframes the researcher explained what features from the PSD-model were added now, for example the use of suggestions or advice in the notifications, use of images, use of graphs (per day, per week, per month) for monitoring the care recipient as an example of self-monitoring or the use of green checkmarks as praise to know a certain goal has been achieved by the care recipient. After showing all wireframes general questions from the interview guide about what the informal caregivers expect from the information presentation of the platform and what it should look like were asked when needed. These answers are used to give an answer to the third research question about the design requirements. Figure 3 shows the main page of the prototype, further pictures can be found in appendix 9.3 Prototype.

After presenting the wireframes and talking about what the participants wanted and needed, questions about perceived usefulness and intention to use (e.g. ‘What would you think about such a system being used in the care of your loved one?’ and ‘How could this communication platform support you in the care you provide?’) were asked, to be able to answer research question two.

Then questions about design requirements followed by questions about the system credibility support (one of the categories of the PSD-model) were asked, based on research by Oinas-Kukkonen [50], to answer the third research question. In the last part of the interview, about the future, participants could indicate if they would like to use the system in the future and if they were willing to help the system improve. These questions helped to answer the second research question about intention to use. The interview script can be found in appendix 9.4 Interview guide.

2.3.3 Procedure

Before taking part in the research, participants received an email with the information letter of the study, see appendix 9.5 Information letter for informal caregivers. Before the interviews started, informed consent was signed, on paper (see appendix 9.6 Informed consent) or digital. The setting where the interview took place was arranged with the respondent, for example, the house where the respondent lives. Of the seven interviews that were conducted between April 26th 2022 and May 6th 2022, two took place face-to-face and five were conducted digitally via Microsoft Teams. The

interviews took between 60 and 90 minutes. The interviews were recorded, after the approval of the participant, using the record function in Microsoft Teams and an audio recording on a mobile device. At the start of the interview, participants were informed about the structure of the interview.
The participants of the interviews who did not fill in the original survey, because they were not Caren users, were offered a survey with the same questions, without the questions focused on Caren. This survey was sent to the participant a couple of days before the interview took place.

2.3.4 Analysis

The audiotapes of the interviews were transcribed verbatim, using the Amberscript software. Thematic analysis was performed using the software package Atlas.ti 9. First, all interview fragments that were relevant for answering the research question were selected [51]. Next, the codes were sorted (axial coding). Based on themes and categories, quotes from the collected data were labelled by the coder (DB). Inductive analysis was applied: categories and themes have been applied until no new codes were found [49].

Deductive analysis was used to elicit specific design requirements [42,45]. The themes of the requirements development approach by van Velsen et al., were used to organize the design requirements [40,50]. It resulted in four themes: (1) functional and modality requirements; specify technical features and on what kind of technology the system should work, (2) service requirements; these requirements specify how services around the technology, like user support, need to be organized, (3) content requirements; specify the content that must be communicated via the technology, and (4) usability and user experience requirements; specify the interface and interaction design of the technology and how user experience factors, such as trust, should be integrated into the technology. The four categories of the PSD-model were used to classify the usability and user experience requirements, as the features of the PSD-model were integrated in the design of the wireframes.

The categories and themes were discussed with a second researcher (AB) until a consensus was reached, to increase the trustworthiness. The final coding scheme is attached in appendix 9.7 Coding scheme.

3. Results – Survey

Demographic characteristics of participants survey

A total of 6934 people filled out the survey. Eligible participants for the current study were informal caregivers who care for someone who has dementia (or Mild Cognitive Impairment (MCI)) that lives alone. Figure 4 shows an overview of the in- and excluded participants.

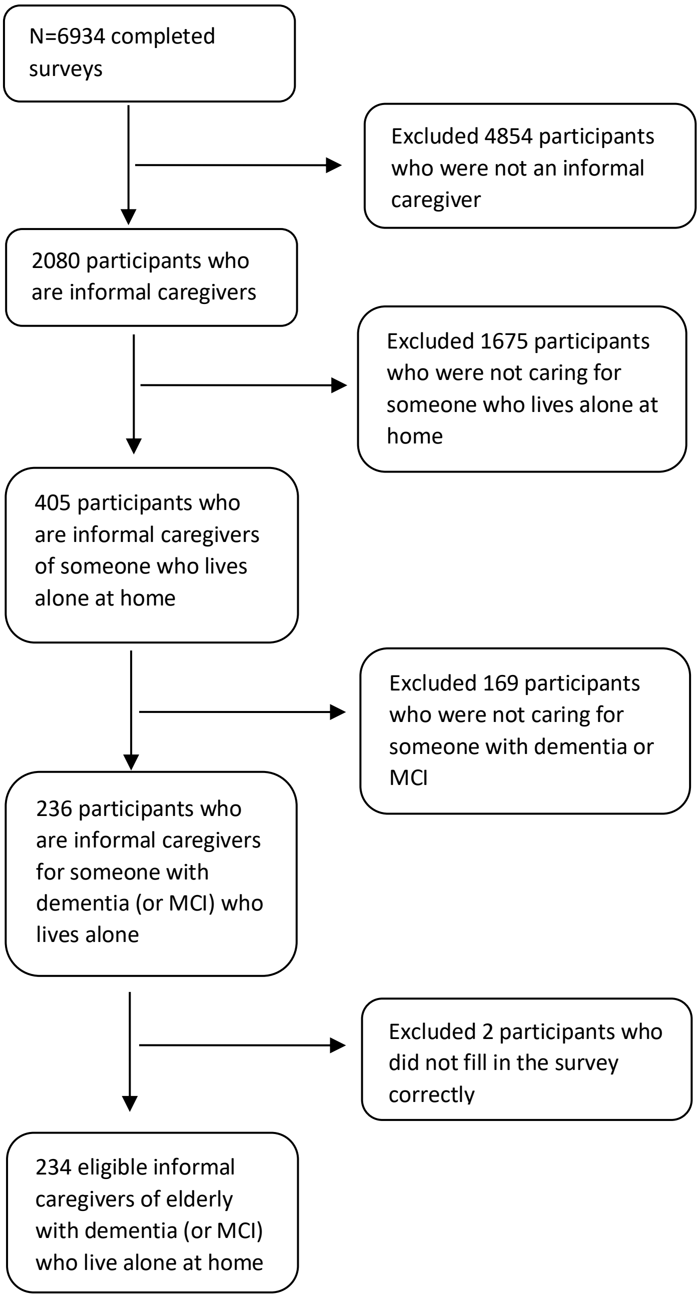


Figure 4. Eligible participants for the survey study

In total, N = 234 respondents were included in the current study with a mean (SD) age of 59 years (7,7). The majority (74%) is female and the daughter of the care recipient. Most informal caregivers are active as informal caregiver for at least two years for this care recipient. The care recipients have a mean (SD) age of 86,9 years (6,1) and 76% of all care recipients have at least one comorbidity.

Table 1 shows an overview of the social demographic characteristics of the participants of the survey and their care recipients.

Table 1.
Demographic characteristics of informal caregivers and their care recipients.

Demographic characteristic	Average	(SD*)	N (=234)	%
Age of informal caregiver in years	59,0	(7,7)		
Gender				
Male			60	26%
Female			174	74%
Level of education				
Primary education			2	1%
VMBO, MBO 1-2			21	9%
HAVO, VWO, HBS, MBO 3-4			74	32%
Bachelor (HBO/WO)			56	24%
Master (HBO/WO)			63	27%
Other			18	8%
How long active as informal caregiver				
0 - 6 months			5	2%
6 months – 1 year			15	6%
1 – 2 years			25	11%
2 - 5 years			95	41%
More than 5 years			94	40%
Number of visits to care recipient				
Multiple times a day			11	5%
Once a day			14	6%
4 - 6 times a week			39	17%
1 - 3 times a week			118	50%
Less than once a week			33	14%
Monthly			19	8%
Relation to care recipient				
Spouse/partner			1	0%
Daughter/son			184	79%
Daughter-in-law/Son-in-law			25	11%
Neighbour/friend			5	2%
Other			19	8%
Travel distance to care recipient				
I live really close (less than 5 minutes			47	20%
I live at 15 minutes travel distance			65	28%
I live at 30 minutes travel distance			52	22%
I live at one hour travel distance			30	13%
I live at more than one hour travel distance			40	17%
Age of care recipient in years	86,9	(6,1)		
Care recipients with comorbidities				
1 comorbidity			84	36%
2 comorbidities			74	32%
3 comorbidities			18	8%

*SD (Standard Deviation), tells how spread out the data is. It is a measure of how far each observed value is from the mean.

Information needs of informal caregivers of community-dwelling elderly with dementia

Table 2 shows the results of the survey regarding the situations and activities participants want to receive information about. Participants were able to choose multiple activities. The majority (57%) of the respondents has a need for information about emergency situations. The second most important (30%) is information about food and water intake. Only a small part (17%) of the respondents has a need for information about personal hygiene. Some participants (12%) do not want to receive any information from the platform, and others (23%) prefer to receive all possible information.

Table 2.

Information needs of informal caregivers who filled out the survey (N=234)

Activities/situations	N	%
All possible information	54	23%
Info about emergency situations	133	57%
Info about food and water intake	71	30%
Info about medicine intake	55	24%
Info about sleep quality/nocturnal unrest	54	23%
Info about daytime restlessness/agitation	49	21%
Info about personal hygiene (such as washing, brushing teeth, and dressing)	40	17%
No information	29	12%

Urgency of situations according to informal caregivers and the corresponding information loop

Participants could choose from three situations which was most familiar to them: falling, agitation or nocturnal unrest. From the sample, N=57 (24%) participants are most familiar with a fall situation, N=37 (16%) with agitation and N=24 (10%) with nocturnal unrest. This means that half, N=116 (50%), of the participants is not familiar with one of these situations. Table 3 shows how urgent the participants think the different situations are and what actions the system should take if they do not respond immediately. It appears that the urgency of a fall accident is seen as more urgent in comparison to agitation and nocturnal unrest. From the participants who are most familiar with a fall accident, the majority (86%) sees falling as an emergency. From the participants who chose agitation, the majority (59%) sees agitation as urgent but no emergency. From the participants who are most familiar with nocturnal unrest, the majority (54%) sees nocturnal unrest as urgent but no emergency. None of the participants who are most familiar with falling, sees falling as a regular situation.

The feedback loop should look different for nocturnal unrest in comparison to fall accidents and agitation, according to the participants. In case of no response after receiving a notification, the majority (51%) of informal caregivers who are most familiar with a fall situation, prefer that formal caregivers are contacted. This is also for the majority (43%) of informal caregivers who are most familiar with agitation. While the majority (38%) of informal caregivers who are most familiar with nocturnal unrest prefer to receive a second notification after 5 minutes.

Table 3.

Urgency of situations and corresponding information loop (N=234)

Information communication	Fall accident (N=57)		Agitation (N=37)		Nocturnal unrest (N=24)	
	N	%	N	%	N	%
Urgency of situations						
Emergency	49	86%	2	5%	2	8%
Urgent but no emergency	8	14%	22	59%	13	54%
Regular situation	-	-	13	16%	9	38%
After no response						
Wait 5 minutes	10	18%	10	27%	9	38%
Contact another informal caregiver	13	23%	7	19%	3	13%
Contact formal caregivers	29	51%	16	43%	6	25%
Call GP/112	1	2%	-	-	-	-
Other	4	7%	3	8%	5	21%
Do nothing	-	-	1	3%	1	4%

Conditions towards perceived usefulness and intention to use

Table 4 shows an overview of the participants' perceived usefulness and intention to use for the different situations separately and combined. Informal caregivers who care for a PwD who shows agitation see less benefit in an unobtrusive in-home monitoring system in relation to informal caregivers who have to deal with fall accidents or nocturnal unrest. This is the same for intention to use, but less distinct. The mean score for the items of perceived usefulness varied between 3.3 and 4.1, which means that overall, participants are neutral to slightly positive towards the perceived usefulness of the system. The highest score (M=4.1, SD=1.1) shows participants partly agree that the system will be helpful in delivering care to their care recipient. The highest perceived usefulness is measured for the participants who are familiar with falling (M=4.1, SD=1.1) and nocturnal unrest (M=4.1, SD=1.1). The table shows that the participants who are unfamiliar with one of the three situations have the lowest perceived usefulness (M=3.3, SD=1.4) and intention to use (M=3.5, SD=1.7). The mean score for the intention to use varied between 3.5 and 4.3, which means that overall, the intention to use the system is slightly higher than de perceived usefulness according to the participants. The highest score (M=4.3, SD=1.4) shows participants partly agree that they will start using the system in the future. Furthermore, participants who are most familiar with a fall situation are most certain to start using the system (M=4.3, SD=1.4).

Table 4.
Perceived usefulness and intention to use the sensor system for different situations

Variables	In general* (N=234)	Most familiar with falling (N=57)	Most familiar with agitation (N=37)	Most familiar with nocturnal unrest (N=24)	Not familiar with any situation (N=116)
Perceived usefulness	3,6 (1,3)	4,1 (1,1)	3,5 (1,3)	4,1 (1,1)	3,3 (1,4)
Intention to use	3,8 (1,6)	4,3 (1,4)	3,9 (1,6)	4,1 (1,4)	3,5 (1,7)

* These questions were asked in general, after completing the situation-specific questions, which made it possible to make this division

Preferred device to receive information on

Table 5 shows via what device the participants prefer to receive information. It shows that the majority (76%) of the participants prefers to receive information through a mobile device.

Table 5.
On what device the informal caregivers prefer to receive information (N=234)

Device	Number of participants	
	N	%
Laptop/computer	63	27%
Tablet	56	24%
Phone	179	76%

Data presentation and way of informing

How the data should be presented in the notifications differs per situation. Table 6 shows that most participants prefer to receive raw data or an interpretation of the data accompanied with a suggestion in the notifications. The majority (47%) of the participants who are most familiar with a fall accident prefer to receive raw data. Only a minority (9%) prefers to receive interpreted data in case of a fall situation. For the N=24 participants who are most familiar with nocturnal unrest, raw data is preferred by the majority (33%). From the participants who are most familiar with agitation, N=15 (41%) participants prefer an interpretation with a suggestion. The percentages about how to receive information for a normal day are close to each other, but a small majority (33%) prefers an interpretation and suggestion.

In all situations, the participants want to receive a notification or pop-up, except for a normal day when the majority (45%) prefers an update on the communication platform. A remarkable amount of the participants (17%) does not want to receive information about a normal day.

Table 6.

Data presentation and way of informing

	Fall accident (N=57)		Agitation (N=37)		Nocturnal unrest (N=24)		Normal day (N=234)	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Data presentation								
Raw data	27	47%	11	30%	8	33%	68	29%
Interpreted data	5	9%	7	19%	7	29%	54	23%
Interpretation and suggestion	24	42%	15	41%	5	21%	78	33%
Other	1	2%	1	3%	3	13%	3	1%
No information	0	-	3	8%	1	4%	31	13%
Way of informing								
A notification or pop-up	23	40%	16	43%	9	38%	66	28%
A text-message/SMS	21	37%	8	22%	2	8%	17	7%
A (priority) email	-	-	-	-	1	4%	7	3%
A phone-call or voicemail	13	23%	1	3%	1	4%	6	3%
An update on the platform	-	-	10	27%	8	33%	105	45%
Not	-	-	-	-	1	4%	39	17%
Other	-	-	2	5%	2	8%	3	1%

4. Results - Interviews

Demographic characteristics of participants interview

In total, N = 7 informal caregivers were interviewed. Four participants identify themselves as female and three identify themselves as male. The mean (SD) age of the informal caregivers is 58 years (7,3). The mean (SD) age of the care recipients is 85 years (6,9). Four care recipients live alone at home, one of the care recipients lives in a nursing home for six months, one is living in a rehabilitation centre temporarily and one lives together with her spouse. Table 7 shows an overview of the relevant demographic characteristics of the informal caregivers and their care recipients.
For the care recipient of P7, it can be said that she started living in the rehabilitation centre quite recently and it is temporary. The interview focused on the period she was living alone at home.

Table 7.
Demographic characteristics of informal caregivers and their care recipients (interviews)

Characteristics	P 1	P 2	P 3	P 4	P 5	P 6	P 7
Informal caregiver							
Age	55	51	48	72	59	60	61
Gender	F	F	F	F	M	M	M
Years active as informal caregiver	2	5	4	14	2	13	2
Care hours per week	8	10	10	8	12	20	10
Situation they worry most about	Falling	Falling	Medication intake	Nocturnal unrest	Food intake	Unrest during day and night	Agitation
Relation with care recipient	Daughter	Daughter	Daughter	Partner	Son	Son	Son
Care recipient							
Age	81	83	86	73	92	96	86
Gender	F	F	M	M	F	F	F
Time since diagnosis (in years)*	2	-	-	14	0,5	13	-
Type of cognitive impairment	Vascular dementia	MCI, Anility	MCI, beginning dementia	Parkinson's disease	Alzheimer	Vascular dementia	Anility & MCI
Comorbidities	Parkinsonism	-	COPD, heart failure, diabetes	-	Broken back, knee prothesis	-	Broken hip
Living situation of care recipient	Lives with partner	Lives alone	Lives alone	Nursing home	Lives alone	Lives alone	Rehabilitation centre
Number of informal caregivers	2	2	1	1	1	2	2

*When missing no diagnosis for dementia was stated

Situations informal caregivers need information about

Table 8 shows a summary of the situations informal caregivers need information about. These are situations related to the background of the participants, as these are situations they recognize from their own experience. All participants need information about at least one of the situations which also appeared in previous research by Wrede et al., (falling, food intake, unrest, agitation) [28]. Most participants (five out of seven) need information about falling and fluid intake. Medication intake, food intake and wandering are also situations multiple participants (three out of seven) worry about and would like information about from the communication platform.

Table 8.
Situations informal caregivers need information about, mentioned during interviews

Situations	P1	P2	P3	P4	P5	P6	P7	Total number of participants
Fall accidents	**X**	**X**	**X**		**X**	**X**		5
Fluid intake	**X**	**X**	**X**		**X**	**X**		5
Food intake		**X**	**X**		**X**			3
Medication intake		**X**	**X**		**X**			3
Wandering				**X**		**X**	**X**	3
Nocturnal unrest				**X**		**X**		2
Agitation					**X**		**X**	2
Cooking	**X**					**X**		2
Selfcare (washing, dressing)		**X**					**X**	2
Sedentary behaviour		**X**						1
COPD exacerbation			**X**					1
Use of telephone			**X**					1
Smoking cigarettes	**X**							1

Information needs of informal caregivers of community-dwelling elderly with dementia

In table 9 the information needs mentioned by the informal caregivers during the interviews are presented. Participants want to know that everything is alright, also on good days (no particularities) a confirmation that everything is alright is needed. Participants need information about both the physical and mental well-being of the person they care for. They need to know if their care recipient eats and drinks enough, takes the right medication at the right time, and in the right quantity. Participants appoint the need to know how their care recipient is feeling and if they are panicking or feeling helpless. The participants want to know what their care recipient is doing and where they are.

Table 9.
The information the informal caregivers need

Information needs	Participant number	Quote
Wellbeing care recipient		
Physical wellbeing	**1, 2, 5, 7**	P5: Well, I'm afraid that for example, she fell once and that was just outside the kitchen door, so then you are outside and that was in the winter. So yes, well, then someone must hear her calling and otherwise you'll be lying there overnight. Doesn't seem really [nice] to me. I do not want that.
Mental wellbeing	**1, 2, 4**	P1: What me, what I find the most annoying, because then I think possibly, because she had really hurt herself and ehm yes then and in the helplessness she must feel at that moment there, because she can no longer get up on her own. Yes, I think that is terrible.
Overall wellbeing	**2, 5, 6, 7**	P2: We call a lot now. As control. I want to know that she got up, that she got through the day and so every morning, every evening, I call to see or I've stopped by and otherwise I just call to find out how things are going.
Activities		
Knowing what someone is doing	**2, 4, 5, 7**	P5: How often she goes to the toilet, how often she walks during the day, how often she walks around the room, how often she goes to the kitchen, that actually. All physical movements.
Information about drug intake	**3, 5**	P3: So yes, I would just like to know if he injected himself, or if he took the tablets, I mean there are blood thinners in, tablets for the heart and for COPD and he also has a nebulizer and I also have very often, I say to him ''have you already nebulized?'': yes, once this morning, but he may do that three or four times a day.
Information about food intake	**3, 5**	P5: Whether she actually ate it, what time she ate it, or whether she threw it away.
Location		
Knowing where the person is	**1, 4, 6**	P4: If you go up the stairs or if you enter a certain danger zone, or he enters the, he opens the garden door or he goes on the balcony ... and certainly also if he falls.

Preconditions for use

Table 10 presents the preconditions for use of the participants for the system and platform. The system should not be dependent on Wi-Fi as a lot of elderly do not have Wi-Fi in their homes. The uptime of the data in the notifications should be (nearly) real-time. The system should be safe and account for power outages. The adopters, both informal caregivers and care recipients, should also be willing to use the system.

Table 10.
Preconditions for use

Preconditions for use	Participant number	Quote
Technology		
Not dependent on Wi-Fi	**2, 5, 6**	P2: And yes, with WiFi you also have to realize that there are many old people who do not have WiFi at the moment.
Reliability	**5**	P5: The uptime that would, that's almost impossible, but it should be 100 percent reliable.
Account for power outages	**5, 6**	P5: And it should for example also after a momentary power cut it should not reset, it should reset itself, it should check itself
Safe system	**1, 2**	P2: For example, that you cannot be bugged, that you cannot be hacked. That is important, because otherwise someone else can listen in on what you say or do all day long. I don't think that's the intention. So that, I think, is a very sensitive subject.
Adopters		
Care recipient	**3, 7**	P3: We have told him about such an alarm, you know what he can wear, but he doesn't want that. Because he says I'll hit everything with a button and then I accidentally press it and then that alarm goes off every time. And he didn't want that.
Informal caregiver	**2, 4, 7**	P4: and you must want to make it your own, yes, your own. But that's with so many things

Advantages of unobtrusive in-home monitoring system and communication platform

Table 11 shows which advantages the sensor system and communication platform have according to the participants. The participants believe that the system can give the care recipients reassurance because if something happens the caregivers will be warned. Use of the system and platform can make sure that the care recipient can live longer in their own home. The informal caregivers will experience more freedom and have more time for themselves, next to a higher mental wellbeing. The informal caregivers do not think their care tasks will change a lot, but the system does give them reassurance and insight into the behaviour of the elderly, which gives them the opportunity to notice changes in behaviour earlier. Informal caregivers believe that use of the system will improve the performance of their work, because it will help in delivering a higher quality of care and helps them to anticipate fast on changing situations. The system will also guarantee some sort of safety for both the informal caregiver and the care recipient.

Table 11.
Advantages of the communication platform according to informal caregivers

Advantages	Participant number	Quote
Care recipient		
Mental wellbeing	**3, 4, 5**	P4: Yes, and maybe also a bit of reassurance that the help, for those in need, I'll say. Also, trust: 'they will come if I really need to', that's a nice feeling, yes.
Longer stay in own home	**3**	P3: I think that would be better for him too. Purely also for the fact that he can stay at home longer.
Informal caregiver		
Mental wellbeing	**1, 2, 3, 4, 5, 6**	P1: I think especially reassuring, because you know there is an extra eye
Freedom	**2, 4, 5**	P2: So but yes, a little extra pair of eyes is never wrong and yes, that you can pass by a little less than and that you know that it is going well
Personal time	**2, 5**	P5: I would also have more time for myself. I would need less time for higher quality care because I can just plan it better.
Perceived usefulness		
Higher quality of care	**2, 3, 5**	P5: The quality of care would improve, because I could provide more targeted care.
Fast anticipation	**1, 3**	P3: And that if there is something, that you can immediately take action.
Insight in wellbeing	**2, 4, 6, 7**	P7: That could be a signal. If you get that every day, then you have to think about it, hey, do I have to do something with this. That would trigger it for me.
Safety		
Safety	**1, 2, 5, 6**	P6: The purpose of the system is that you want to create extra safety

Disadvantages of unobtrusive in-home monitoring system and communication platform

Table 12 shows what disadvantages the sensor system and communication platform have according to the participants. The participants are concerned about the possible loss of privacy of the people they care for, and themselves when visiting. In addition, an information overload due to too many notifications should be prevented.

Table 12.
Disadvantages of the communication platform according to informal caregivers

Disadvantages	Participant number	Quote
Care recipient		
Loss of privacy	1, 2, 3, 6	P2: Yes, well, look, if you do the whole thing that you indicated what is possible, yes, you do have a lot of insight into someone's life. And yes, that is an invasion of privacy. So you should be very careful with that. And yes, can anyone do that?
Informal caregiver		
Information overload	**1, 3, 7**	P1: And look, the more information you get, the more you too. It can reduce care, but it can increase care. No, because sometimes it is also what does not know that does not hurt, then ignorance is, can also be a blessing so to speak. So I think that's a drawback as well.
Loss of privacy	**1, 2, 3, 6**	P3: Yeah, I don't know, I don't know how, how or what, because it's with sound too, so I mean what what do you all hear, what? Yes, it is possible that there are visitors, I mean, then not everyone has to pick up that conversation of course.

Information loop

Table 13 presents what the information communication should look like. Almost all informal caregivers want to receive the notifications themselves. But, in case of an emergency, professional care should be warned at the same time. One of the participants mentioned that someone who can provide the care that is needed should be warned and after that the informal care. Two participants also mentioned the need to inform emergency services themselves, they do not want the technology to take over that role.

The content of the notification should be short and clear. Also, a confirmation that everything is going well is desired. The notifications should be received via phone, preferably a pop-up which is prioritized over all other screens by the operating system. Two participants would like to receive emails via laptop, and only in case of emergency a notification on the phone. After a fall, participants would like to be called, instead of receiving a notification. The moment to receive the notification differs per situation, just as what to do when the informal caregiver does not respond after receiving a notification. Some prefer that formal caregivers are warned, while others prefer to have another informal caregiver or contact person to be warned.

Table 13.
Information loop

Information communication characteristics	Participant number	Quote
Way of informing		
Pop-up/notification	**3, 5, 6, 7**	P7: The simplest, and most reliable, is a pop-up from the app, yes a notification if it's an alarm, that that really takes precedence over other notifications, even if you're on the phone, that you get the pop-up of the alarm.
Call	**1, 2, 3**	P2: If she really fell then I would prefer a phone call.
Moment of informing		
When the situation occurs (medication intake)	**3**	P3: Yes. The notification of when it happened, because I think he doesn't really stick to fixed times, then I think I get a message more often because he hasn't done that purely because he does it on different times
After specific activities (good day)	**6**	P6: But those are the notifications you get if nothing goes wrong, yes, if you get such a notification three times a day or four times, the meals have been done, you drank today, you are now in bed.
After a couple of days (food intake)	**5**	P5: Yes, if, for example, she has eaten very poorly for three days, that I will really get an alarm, but on the first day I don't need an immediate warning. Because yes, if you eat uh in the evening cake instead of hot food, you'll survive that, but you shouldn't keep that up for a week. But that, I'd like to set that freely.
Immediately (falling)	**1, 2**	P2: No, I would like to have a notification immediately, because then I can respond and in any case ask how things are going, even if she gets up immediately, something has happened. Well, I assume a bit, that only has to have been something very small, but then that I have contact for a while.
When leaving particular zones (wandering)	**4**	P4: Not immediately, I think, no. But it should if you can imagine for example if you go up the stairs or if he is in a certain danger zone, or he goes the the, he opens the garden door or he goes on the balcony.

Information receiver		
Depending on content	**1, 2, 3, 4, 5, 6, 7**	P5: I think the notifications only the caregiver and the alarms the professional care, nurses.
Informal caregiver	**1, 3, 5, 6**	P3: So I'm like come to me, because then, if I can't myself, I can call my other brother and have a quick look.
Someone who adds value at that time	**7**	P7: I think you should call someone you know will come. And then you soon fall back on 1-1-2, on ambulance
Both informal and formal caregiver at the same time	**1, 2, 6**	P2: Then I would like Livio to be aware of that right away, that we can discuss who is going there. Then, for example, am I nearby, or am I not able to go there at all and can any of them act quickly?
Information receiver after no response		
Other informal caregiver	**1, 6, 7**	P1: Well, that also applies if it is an urgent matter to me and if I do not respond within five minutes to my sister. But all other general information only to me I think
Other contact person	**3**	P3: A red notification anyway and maybe you can do a second contact, well just a phone number, or something
Formal caregiver	**2, 4, 5**	P4: And then the first contact person becomes and only when there is no response, then they come from home care or something.

Requirements

The following paragraphs will give insight into the requirements the participants have regarding the sensor system and communication platform. The requirements development approach by Van Velsen et al. [40], was applied deductively to the interview data. It resulted in four themes: (1) functional and modality requirements; specify technical features and on what kind of technology the system should work, (2) service requirements; these requirements specify how services around the technology, like user support, need to be organized. (3) content requirements; specify the content that must be communicated via the technology, and (4) usability and user experience requirements; specify the interface and interaction design of the technology and how user experience factors, such as trust, should be integrated into the technology.

Functional and modality requirements

Table 14 gives an overview of the functional requirements participants stated. The majority of the participants prefers to receive notifications on their smartphone. The participants need the system to be unobtrusive; the sensor should not have any lights and keeping privacy in mind, it should be possible to turn off the system when visiting the care recipient. The sensors should be able to monitor movements outdoors, to know if someone fell outdoors. The sensors should also be able to monitor the use of devices, to know if someone turns on the stove for example. The platform should be able to speak to both the care recipient and the informal caregiver when needed. Participants mentioned the need for the possibility to have contact with formal caregivers via the platform. It would be really helpful if the platform supported sharing information with the pharmacy for example. One of the participants mentioned that it would be interesting to link Artificial Intelligence to the sensor system to be able to predict someone’s mood.

Table 14.

Functional and modality requirements

Requirement	Participant number	Quote
Device to receive notifications		
Smartphone	**1, 3, 4, 5, 6, 7**	P3: Yes, then the telephone seems the most useful to me.
Laptop	**1, 2**	P2: A notification on the laptop or something is fine.
Smartwatch	**5**	P5: Preferably digitally in the app, suitable for all mobile devices, but also for wearables, a smartwatch.
Unobtrusiveness		
No lights (unobtrusive)	**6**	P6: A tip for the technicians then; my mother triggers on lights .. she watches all the time. 'What is that light' and then she pulls the plug.
Being able to turn off 'listening'	**3**	P3: Yeah, I don't know, maybe that, suppose I go to visit him and I want to discuss something important with him, which is no one's business, that I might have an option to turn off the sound or something like that.
Technical features sensor system		
Also be able to use outside and on devices	**2**	P2: Because also outside, yes, look, yes, in that sense it is also useful, for example, to place a sensor outside
Technical features communication platform		
Platform needs to be able to speak to care recipient	**2, 7**	P2: That that is also an option, what can be included in it, for example, that you can talk to the system, or ask, Mrs huppeldepup is everything going well. Just as an extra option in case of emergencies
Platform needs to be able to speak to informal caregiver	**7**	P7: For example, a switchboard operator who coaches those people when they are there, for example, would also be an idea
Possibility for contact with formal caregivers	**2, 3, 6**	P6: If those messages arrive there [at home care], that's nice as some kind, some kind of email or something
Easy sharing of information	**1, 5, 6, 7**	P1: Then it is very useful for me at the moment when a general practitioner or a doctor prescribes a medication change that it is automatically changed from the pharmacy in the app and that all care providers are immediately aware of the dosage has changed, or other drugs or less drugs.
Monitoring behaviour		
Artificial intelligence	**5**	P5: Can we invent an automation piece of AI that determines what she would like to eat at that moment based on her mood?

Service requirements

Table 15 shows what service requirements the participants have. To be able to use the system, a good instruction should be given. Other preconditions are mainly focused on that it should be a safe system, which is tested before implementation. Also, how it will be funded is a topic a lot of participants have an opinion about. They think it should be funded in some way, via health insurance or the municipality.

Table 15

Service requirements

Service requirements	Participant number	Quote
Financing	**1, 2, 3, 4, 6**	P1: We now have the municipality or something like that if you, for example, do not have that much money to spend, because I would find it very bad that that is a reason that you cannot use the system
Good instruction	**4, 5, 7**	P4: Yes, you have to be somewhat digitally skilled to be able to do that, eh. But you must have good instruction with it
Trialability	**1, 2, 7**	P1: Well, I, look, if something like that is put in place, I'm going to assume that that's good, that it was preceded by good research and testing phase and, huh, you know, well, that is, it's been tested and in 95 percent of the cases, the correct action was chosen

Content requirements

Table 16 shows what topics the informal caregivers want to see on the main page of the communication platform and what notifications should look like. It was understood from the interviews that participants require all relevant topics displayed as individual tiles on the main page so that a quick overview can be generated. In total 12 such topics were mentioned. These are food intake, fluid intake, heartbeat, blood pressure, movement, good day, GPS, sleeping, emergency, falling, positive particularities, and information of the nurses/therapists. In table 16, food & fluid intake, heartbeat & blood pressure and emergency & falling are combined because these topics were often mentioned in the same context. Participants also mentioned the need for information about the general well-being of the care recipient throughout the day as one of the tiles. One of the participants would also like to see an extra topic with extra positive information, so for example if someone drank a bit more or ate something extra. Another participant prefers to see the information and reports of the formal caregivers on the communication platform. The notifications should consist of a framework for action, so the informal caregivers know how to act.

Table 16.

Content requirements

Content requirements	Participant number	Quote
Tiles the main page of the platform should consist of		
Food & fluid intake	**1, 2, 4, 5, 6, 7**	P7: The basic necessity of eating, drinking in this case is very important to me.
Heartbeat & blood pressure	**4, 6, 7**	P4: But if you then get to that fall, it is then noticed, movement. And if you can put that next to it or that or that heartbeat, yes, that's not yet, the blood pressure, quite something else of course. Whether there is a correlation.
Movement	**1, 2, 4, 6, 7**	P2: No, but I do want movement too, just not in steps, yes, I don't really know how, but, yes, maybe in time. Something. Yes, that she did move, yes.
Good day	**1, 2, 3, 4, 6, 7**	P6: I just want to go and see gosh, what happened today? It has been a quiet day and she has eaten, drunk, all that.
GPS	**7**	P7: But that's handy, especially if someone goes wandering, my mother who walks here, who then loses her way, that could be good to look, where is she now? Then I'll pick her up there when you get a signal.
Sleeping	**2, 4, 7**	P2: And so she sleeps quite a lot in that sense, and then it's a little. Yes why? Why do you sleep and then it is good to know how much she sleeps? Does she sleep until seven o'clock in the morning or does she sleep until nine o'clock?
Emergency & falling	**1, 2, 3, 4, 6, 7**	P3: I just think that you have a kind of button, like now is an emergency that you can click something, that the GP is informed or other caregivers, that you can go there together..
Positive peculiarities/abnormalities	**5**	P5: For example, whether she made extra coffee once.
Information from the nurses/therapists	**6**	P6: That you can see that they have been and what have they done? Oh, they either got her in the shower or they didn't get in the shower again, they made food for her. They've done this, done that.
Content of notifications		
Information presentation	**1, 2, 3, 4, 6, 7**	P7: But then say something like 'fact + an action required'. A kind of action framework ... and yes, keep it as practical as possible and as simple as possible, because the strength often lies in the, not in the extensiveness, but much more in the practical: how do you put it away?

Usability and user experience requirements

Table 17 shows what usability and user experience requirements the interviewees mentioned. The main codes used are the four categories of the PSD-model in addition to user experience. The notifications should make use of colours for a quick overview, so users can see quickly if everything is alright (green) or something is wrong (red). In case of emergency, the notification should also have a sound. The information the platform gives should be tailored, the platform must show the information that the caregiver needs at that moment. The main page should be personalized to the user; therefore it should show the topics this informal caregiver is most interested in first. In addition, the platform should consist of a convenient main page with tiles per topic. After clicking on a tile, a second layer should show additional information, such as how much someone drank in a day or movements in the last week. The platform should be compatible with different devices and self-monitoring to give insight into behaviour over an amount of time.

The notifications sent by the platform should consist of suggestions about how the informal caregiver should act in a particular situation. The opinions of the participants differ regarding praise, as not all participants want to receive praise, but some do.

It is important that the system provides information that is trustworthy, this means information that is truthful, fair and unbiased. Therefore an uptime of 100% is required. Informal caregivers mentioned that false alarms are unavoidable and they prefer a false alarm over not getting an alarm. Also, privacy is an important topic, but when comparing it to the safety of their loved ones, privacy is subordinate. The platform should provide the users with the possibility to have contact with their own healthcare professionals, like their general practitioner or physical therapist.

Finally, informal caregivers would also like to have the possibility to have contact with other informal caregivers via the platform, to share experiences and have a social comparison about how others handle specific situations.

Table 177.
Usability and user experience requirements, classified according to the PSD model

Usability & user experience requirements	**Participant number**	**Quote**	**Meaning of the feature for this design**
User experience			
Use of colours	**1, 2, 3, 4, 5, 6, 7**	P2: You also showed something about colors. That often does a lot indeed. If it is really acute, for example that you receive in red or if it is just general information, to inform you that that is just green. Or something that you have a certain risk in, that that is orange, I think that would also have added value.	Notifications and tiles on the main page should have a colour on the background, so that it is clear at a glance what the urgency of the situation is
Use of sounds in case of emergency	**1, 2, 3, 4, 7**	P7: If that would go through the app, or a message, then it would be nice that it would be a different sound. Yes.	Notifications in case of an emergency should have deviating sounds
Primary task support			
Tailoring	**1, 2, 3, 5, 6, 7**	P2: In my case it doesn't have to be too specific yet, and by not too specific I mean that I am not waiting for a message with how	The platform should show tailored information (some people prefer amount of

		many steps she has made. That, that goes too far for me. I can imagine that it is for someone else, but not for me. I also have the same with the heart rate, which I think is yes, no, that is information, I can't really do much with it, but on the other hand, for someone with a heart problem it is very important. But then it is nice of the system that you can choose certain things.	steps and others minutes of movement).
Convenient	**1, 5**	P5: P5: Yes, that seemed clear to me, something along the lines that you can see at a glance under the various headings, for example, what was drunk after you, or what is going on	The platform needs to be convenient, the tiles should show immediately per topic how it is going
Personalization	**1, 5, 6, 7**	P5: And in that platform, that actually the parts, so for example the food or drinks or medicines, where something is wrong, that they are at the top with a certain color, that you know oh, I have to tap or see what's going on. And all the other parts that go well; she did not fall and she went to the toilet and she slept well that does not necessarily have to be seen at that moment. Do I want to look at that myself? I can always scroll further.	The platform should present the information the user needs first.
Compatibility	**3, 5, 6, 7**	P5: Suitable for all mobile devices, but it is also for the wearables, a smartwatch.	The platform should be compatible with all mobile devices, also a smartwatch
Self-monitoring	**1, 5, 7**	P5: If you put it in the long term, you will get an overview of what she is walking on average and then you can see on a monthly basis, for example, whether they will walk more or less. That's the image you get, and then I think you also have to compare that to age, to someone who has motor problems, who will probably walk fewer steps than someone who doesn't. What do numbers say without explanation, you see, I would very well add what, yes, what is normal?	After clicking on a tile the platform should show an overview over the past period. This gives insight into the wellbeing of the user.

Dialogue support			
Praise -	**1, 4, 5**	P5: Yes feedback. A compliment, then it almost starts to get a bit commercial like I got ten compliments this week. No, that misses its goal.	Praise should be optional, as not everyone wants to receive compliments. Some prefer feedback over compliments.
Praise +	**2, 3, 6, 7**	P7: Yeah, well, what's a compliment? Look, I find a compliment, I think it should always have an explanation. I think we should give much more compliments, even in a normal daily situation I completely agree and only, we tend to often put the things that are not going well, to put them down in feedback, but things that go well, you should definitely get it back.	Praise should always be clarified, why does someone receive praise?
Suggestion	2, 3, 5, 6, 7	P3: And if such a system says well, maybe you should have done this or that, that's always welcome, I think. It can also help me, I don't always know what to do, so.	The platform should give suggestions on how to act in situations a second time
System credibility support			
Privacy	3, 4, 5, 6, 7	P5: Data privacy is secondary to security	The platform must be secured
False alarms	1, 2, 4, 5, 6, 7	P7: Of course something can always go wrong or something can be overlooked. But that can happen to me too.	The platform should not give too much false alarms
Uptime	5	P5: The uptime that would, that's almost impossible, but it should be 100 percent reliable.	The platform should be 100% reliable, because of a (nearly) real time uptime
Real-world feel	3, 4, 5, 6, 7	P3: So see if I could still get in touch with the GP or something via that platform, yes, that would be very nice.	The platform should facilitate the possibility to have contact with healthcare professionals
Social support			
Social comparison	3, 4, 5, 6, 7	P6: It would be useful if you also get the experience of other caregivers. That's handy	The platform should facilitate the possibility to share experiences with other informal caregivers

5. Results – combined

Regarding the demographic characteristics, it is noteworthy that the majority of the participants were women (74%) who completed the survey. These were mainly daughters (79%) of the care recipients. Also, the interviewees were mainly children (6 out of 7) of the care recipients. It appears from both the survey and interviews that informal caregivers primarily want information when their care recipient has fallen (57%). Food and fluid intake comes in second place in both studies. From the interviews, it can be supplemented that informal caregivers also like to receive information about medication intake and wandering. The reason the informal caregivers want to receive information about these situations differs, it appeared from the interviews that knowing where their care recipient is, what they are doing and how their wellbeing is are important reasons.

The urgency of the situations differs according to the participants of the survey. For example, they consider a fall accident an emergency but if their loved one shows agitation or nocturnal unrest they consider this urgent but not an emergency. There is no one who considers a fall accident a normal situation. More than half of the participants want formal caregivers to be informed when the PwD has fallen and the caregiver does not respond immediately. The majority (43%) also wants this in case of agitation. In case of nocturnal unrest, they prefer the system to wait a while and then send a second notification. During interviews it emerged that the informal caregivers themselves want to be warned in all cases and that they have doubts about what role the formal caregiver can play in this. However, in case of emergency they would prefer that someone is alerted who has added value at that time, often this will be the emergency services.

The highest perceived usefulness score was measured for the participants who are most familiar with a fall situation (M=4.1, SD=1.1) and the participants who are most familiar with nocturnal unrest (M=4.1, SD=1.1). This score (4.1 out of 7.0) means that they partly agree that the system will be helpful in delivering care to their care recipient. During the interviews the interviewees mentioned that the system would help them in delivering a higher quality of care, will make them able to anticipate fast and give them more insight into the well-being of the care recipient. Although, the interviewees mentioned they are afraid for a loss of privacy because of the in-home monitoring system or an information overload if the platform sends too much notifications. The system should not be dependent on Wi-Fi as a lot of elderly do not have Wi-Fi in their homes. The uptime of the data in the notifications should be (nearly) real-time. The system should be safe and account for power outages. The adopters, both informal caregivers and care recipients, should also be willing to use the system. These are conditions which have impact on the user acceptance, which should be taken into account. However, when comparing privacy of the community-dwelling elderly with their safety, safety is more important. The intention to use had overall a slightly higher score than the perceived usefulness. Again, the highest score was measured for participants who are most familiar with a fall situation (M=4.3, SD=1.4). These participants are most certain they will start using the system in the future.

The desired method of receiving information differs between the participants. The participants of the survey prefer an update on the platform in case of a normal day, which they can check whenever they want. In the other situations (fall situation, nocturnal unrest and agitation) they prefer a notification on their phone, while the interviewees mentioned that it is important to prevent that they will get an information overload. However the interviewees also want to know why it was a normal day and want to know what positive particularities of the day are. The interviewees mentioned that receiving a notification on the phone makes you able to quickly look at it and gives the possibility to decide to do something or not. The notifications should also be able to be received on a smartwatch, to make sure no notification is missed. Calling in case of an emergency is also preferred by the interviewees, to make sure they do not mis a notification that is really important.

How the data should be presented differs for the different situations. The participants who are most familiar with a fall accident or nocturnal unrest prefer to receive a notification with raw data, while the participants who are most familiar with agitation or who were not familiar with one of the situations (normal day), prefer an interpretation of the data together with a suggestion. Of the participants who were not familiar with one of the situations, a noteworthy amount of participants (13%) does not want to receive any information. The other participants are divided between raw data (29%), interpreted data (23%) or interpretation and suggestions (33%). The interviewees prefer to receive short and concise notifications with a framework for action when needed, so they know how to act in a specific situation.

6. Discussion

From the results of this study can be concluded that the majority (57%) of informal caregivers who take care of community-dwelling elderly with dementia (or MCI), would like to receive information about their loved ones in case of a fall accident. Food and fluid intake are the second most important topic, 30% of informal caregivers want to receive information about this topic, and 23% of the informal caregivers would like to receive information about all possible topics. It can be concluded that informal caregivers also want to receive information about normal days and other positive events. The majority (76%) prefers to receive notifications on their phone. In case of an emergency, informal caregivers would like to be called instead of receiving a notification. The data presented in the notifications should be raw data or interpreted data with a suggestion of how to act, depending on the situation.

The perceived usefulness of the system, which measures to what extent the participants think that the system will be helpful in delivering care to their care recipient, is the highest for the participants who are most familiar with a fall accident or nocturnal unrest. When using the system it is possible to deliver a higher quality of care, anticipate faster and have more insight into the well-being of the care recipient. The results show that there are some conditions towards the user acceptance, such as that the system should not be dependent on Wi-Fi as a lot of elderly do not have Wi-Fi in their homes, the uptime of the data in the notifications should be (nearly) real-time and the system should be safe and account for power outages.

It can be concluded that the system should handle the privacy of the community-dwelling elderly safely. Nevertheless, the interviewees indicated that the safety of the community-dwelling elderly is more important than their privacy. The informal caregivers mentioned clear requirements for the design of the sensor system and communication platform. They need a convenient main page with tiles for each topic they want to receive information about. It is important that the platform is personalized to the information needs of the user by for example showing the tiles with new information at the top. After clicking on a tile, more information about that topic should be presented (e.g. by making use of graphs). It is important that the sensors do not have any lights, because this can disturb the PwD.

6.1 Critical review of the results

This current study is a follow-up to previous research that found out in what situations formal and informal caregivers would like to use an unobtrusive in-home monitoring system [28]. The results of this current study confirm the conclusion of the qualitative study of Wrede et al., [28]. However in this study also medication intake and wandering were part of the top 5 information needs, which are not mentioned in the research of Wrede et al., [28]. This can be explained by the fact that Wrede made use of a topic list with monitoring goals in his interviews. These goals were based on previous literature and the experience of experts. Participants were then asked how relevant the goals were for them. Medication intake and wandering were not included in the list of goals, so participants were not able to choose these situations. The fact that these situations (wandering and medication intake) did not appear in a list with 16 goals based on literature, while they did in this research, indicates that the information needs of informal caregivers differ mutually. Some situations mentioned in the research of Wrede et al., [28], were not mentioned in this current study. This can be explained by the fact that this research only included informal caregivers while Wrede et al., [28] included both formal and informal caregivers and due to the fact that no saturation was reached in the current study.

It appeared that several participants want to receive notifications on days with no particularities, to know if everything is going well and that informal caregivers prefer to alert emergency services themselves, next than receiving notifications in other situations. This shows that informal caregivers want to hold autonomy. Previous research confirms that older people prioritize personal autonomy in care provision [33]. However, the total number of notifications will likely lead to attention theft, also known as exogenous orientation, as informal caregivers like to receive information about a lot of different topics. Exogenous orientation is stimulus-driven attention, which means being driven by external events in the environment [52]. This means that the attention of the informal caregivers will be shifted to the received notifications, which can cause them to have more stress instead of having peace. On the other hand, only receiving notifications in case of emergency can be a barrier to using the system, which Kjallman Alm et al., also reported in their study [53]. A possible explanation is the subject of the information. The information is often about the decline of the patient and can therefore be understood as negative, which may be hard to accept [54]. It is therefore important that the system will not send too much notifications and not only about negative topics.

An interesting result is that privacy is subordinate to the safety of the PwD according to their informal caregivers. It does depend on the content of the data, as it does not matter if data thieves know what an elderly person has eaten, as long as they do not interfere with the data, causing it to become inaccurate. However, there is little literature that has the same result. Privacy is a topic that is seen in several studies as a prerequisite or barrier to the use of an in-home monitoring system. Two literature reviews show that privacy is the main barrier to the adoption of assistive technologies in older adults [37,55]. Informal caregivers are often concerned that their and the privacy of their care recipients may not be properly protected [56]. In the context of older adults with visual impairment, the perceived benefits from an in-home monitoring system are secondary to general concerns regarding privacy and security [57]. Other research presents that older adults have generally expressed willingness to adopt in-home monitoring technologies, the importance of maintaining independence superseded concerns about privacy or security. An exception to that high acceptance was the general discomfort with video monitoring of the elderly. However, that is not something the participants of this study have to worry about, as no video footage will be made [58]. Only one research was found that concluded that safety and mobility are more important than privacy. However, the participants in this study did have a say in when the alarm should be raised [59]. Maybe this is a feature that should be added to the to-be-developed in-home monitoring system. Further, it will be really important to keep discussing with the informal caregivers and other end-users how they feel about using the system.

The questions in the interview guide are formulated in such a way that they focus on all problems and negativity the informal caregivers encounter in daily life. It was the goal to get to know what all went wrong and should be changed, so that the to-be-developed unobtrusive monitoring system could help dealing with all these problems. However, therefore the information gathered in the interviews is overall quite ‘negative’ as it is needed to know what is wrong at this moment and should be changed with the new system. The positive aspects of caring for a loved one are barely mapped out, therefore it is unsure what ‘positive’ aspects the system should not change.

6.2 Strengths and limitations of the conducted study

Regarding this research some strengths and limitations will be mentioned. A strong point of this study is that the interview guide and survey were prepared by different researchers and others involved. This prevents many ambiguities. The interviews allowed the researcher to get more information than the survey provided and to go more in depth. A third strength of this study is the anonymity of the participants. The participants of the survey were all assigned a research number and their personal information was not visible. The participants of the interview were also assigned a research number, so that their data could not be tracked back to a person.

This research also contains some limitations. The study obtained results over a small period of time, the survey was online for only a couple of days. In total, Carenzorgt has around 460.000 users of which 6934 users filled in this survey during the days it was available. Where at first sight almost 7000 responses appear like a large number, it means only 1,5% of the users of Carenzorgt have filled in this survey. Because of the small sample, it is therefore probably not representative for all informal caregivers of PwD using Carenzorgt, let alone all informal caregivers of PwD in The Netherlands. In addition, there is a suspicion that precisely the people who are less familiar with technology did not complete this questionnaire because they probably either (1) do not make use of a digital healthcare platform, (2) make little use of Caren and therefore did not see the survey or (3) found completing the survey (too) complex. This can cause the first overall impression to be more positive in terms of technology acceptance.

A limitation of the qualitative part of this study is the fact that while coding the last interview few new codes were found, therefore saturation was not achieved. Next to that, only five out of seven participants are informal caregivers of community-dwelling elderly. The other two participants are informal caregivers of elderly people with dementia living at home but not alone. However, in these two interviews, not many new codes appeared. In the data analysis this was also taken into account by assuring that almost none of the emerged themes was only mentioned by these participants. The fact that no saturation was reached, makes it very likely that there are more opinions among other informal caregivers that remain unknown. This could change the conclusion of this study because there might be a shift in the priority of information needs for example.

6.3 Practical implications and future research

An important addition to the current system is that it should not only be an in-home monitoring system, but it should also be able to notice movements and falls outside of the home.

The CeHRes Roadmap should be used as a guideline for future research, to make sure the development and implementation of the to-be-developed unobtrusive in-home monitoring system are executed well. First, a thorough investigation of the context is important. Wrede et al., [28] already investigated how formal and informal caregivers look towards an unobtrusive in-home monitoring system. He gave a first overview of information needs, advantages, barriers and requirements that specified functions of the in-home monitoring system from the perspective of formal and informal caregivers of community-dwelling people with dementia. This current study complemented Wrede's earlier research on why informal caregivers have these information needs and exactly what information they want to receive in which situation. However this study did not reach saturation, therefore more time is needed to gather more participants and achieve saturation. During extra interviews with informal caregivers topics like privacy and when and how to receive notifications should be mentioned. It would be interesting to zoom in on the privacy versus the safety of the community-dwelling elderly, as this was a topic all interviewees mentioned. By letting the end-users make a cost-benefit analysis where privacy is sacrificed for the benefit of mobility and safety [59], it will make clear to what level the informal caregivers put the safety of the community-dwelling elderly above their privacy. The topic about when and how to receive notifications differed a lot per situation, it is interesting to zoom-in on this topic to find out what reasons are why this differs. It is foreseeable that new situations informal caregivers want to receive information about or extra preconditions for use will occur in these additional interviews. This could change the conclusion of this study because there might be a shift in the priority of information needs for example.

In follow-up studies the various end-users of the system need to be involved. Grol and Wensing found out that it is desirable that those involved in the implementation process are open to change [60]. This means that next to informal caregivers, formal caregivers (therapists, nurses and case managers) and the community-dwelling elderlies themselves need to be included in follow-up research. The role of the formal caregiver needs to be mapped out, as they often have a less personal bond with the care recipient and care for multiple patients, which can result in other outcomes. The goal of the study including the formal caregivers will be to find out how they think the system should function and to what extent they want to and can be involved in the process around the system, as informal caregivers mentioned in this study that they have their concerns about what role the formal caregivers can play in the use of the monitoring system. It is needed to know whether they are able to respond to notifications of emergencies for example.

Additional in-depth interviews could be conducted to find out about the expectations, needs and wishes of the PwD who live alone themselves, to create a more complete image of how different stakeholders look at unobtrusive in-home monitoring systems. Only a few studies report on the involvement of people with dementia throughout the entire development process [61]. Until now there is too little knowledge on appropriate methods and materials for active involvement of people with dementia in technology development. Future research is needed to improve the desired role of people with dementia in meaningful technology development. It is important to know how community-dwelling elderly think about the use of an unobtrusive in-home monitoring system.

The research with the formal caregivers and the community-dwelling elderly can have a comparable design to this study, so a mixed-method design with a survey and additional in-depth interviews. Other authors also expressed the need for mixed methods using both quantitative and qualitative designs [38]. Additionally, a focus group with the different formal and informal caregivers combined can give extra insights on particular topics where the groups have divergent opinions.

Also, a first wireframe prototype has been presented in this study and therefore more concrete (design) requirements have emerged. After mapping out the contextual inquiry and the value specification it is important to zoom in on the design. A clickable, interactive lo-fi prototype can be made [26], based on the design requirements that appeared in this current study. This prototype will help to get more specific design requirements in follow-up research. This prototype can be presented to the different stakeholders during a focus group or design thinking-workshop. The goal will then be to get more specific design requirements to be able to move closer and closer to the final design. Personas can assist during the development of the prototypes. Personas are defined as representative demographic and fictional profiles of target groups or end users written like a story about a specific person. According to van Velsen et al., [62] personas can be the linking pin in the development process of eHealth. Personas can be used to get more insight into what the information communication should exactly look like in different situations the informal caregivers of the PwD who live alone encounter in daily life [26,62]. How the sensors and the communication platform will look, causes an essential difference in the usefulness and ease of use for the informal caregivers. It largely affects the acceptance of the system [26].

Future research should use The Nonadoption, Abandonment, Scale-up, Spread and Sustainability-framework (NASSS-framework) next to the CeHRes Roadmap, as different literature shows that implementation often goes wrong at the organizational level [63–65]. The NASSS-framework is found helpful in considering challenges to the implementation of a range of technology-supported health or care programs [65] and could especially play a role in how this to-be-developed system will eventually be implemented in the organization of care.

7. Conclusion

This research explored the needs, expectations and requirements of informal caregivers of community-dwelling elderly with dementia towards an unobtrusive in-home monitoring system and communication platform. It can be concluded from this study that there is support from informal caregivers who participated in this research for developing a new unobtrusive in-home monitoring system. In general, the participants of this study believe that the system in combination with the communication platform can make a positive contribution to caring for their loved ones. It will help the informal caregiver in delivering a higher quality of care, anticipate faster and give insight into the well-being of their care recipient. Various concerns about privacy, unobtrusiveness and information overload have to be considered as they are likely to hinder acceptance. The (design)requirements mentioned by the participants can support the development of unobtrusive (in-home) monitoring technologies to support the informal caregivers of community-dwelling elderly. The participants have a clear idea about that the communication platform should be able to function on smartphone and smartwatch. It needs to be a convenient application that shows the information the informal caregiver needs first. The concerns about privacy will first have to be mapped out in follow-up research, just like the role the formal caregiver can play in the use of this system in the future.

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9. Appendices

9.1 Survey

Beste gebruiker van Caren,

Hartelijk dank voor uw bereidheid om deel te nemen aan dit onderzoek. Dit onderzoek bestaat uit twee delen. In het eerste deel staan de gebruikerservaringen met Caren centraal. In het tweede deel laten we u kennis maken met een nieuw soort, nog te ontwikkelen, sensorsysteem. Het hier aan gekoppelde communicatieplatform moet nog vormgegeven worden en we willen graag weten hoe u hier over denkt.

Dit is een onderzoek van de Universiteit Twente in Enschede in samenwerking met de ontwikkelaar van Caren, Nedap Healthcare. Deelnemen aan het onderzoek kost ongeveer 15 minuten. Gegevens worden volledig anoniem en op veilige wijze verwerkt en zijn niet te herleiden tot uw gebruik van Caren. Deelname aan het onderzoek is vrijwillig, wat betekent dat u op elk gewenst moment kunt stoppen met het invullen van de vragenlijst. Uw antwoorden op de vragen worden maximaal 10 jaar bewaard door de Universiteit Twente, de samenvatting van de antwoorden wordt minimaal 10 jaar bewaard door Nedap.

Indien u vragen heeft over dit onderzoek of graag meer informatie wilt ontvangen, kunt u contact opnemen met Dineke Brouwer, email: n.e.j.brouwer@student.utwente.nl, Nikita Sharma, email n.sharma@uwente.nl of Dr. Annemarie Braakman-Jansen, email: l.m.a.braakman-jansen@utwente.nl.

Door deze vragenlijst te starten geeft u aan dat u:

- Bovenstaande informatie gelezen hebt en hiermee akkoord bent
- Vrijwillig meedoet aan het onderzoek
- 18 jaar of ouder bent

Section 1: Demografische kenmerken en vragen over Caren

1. Wat is uw leeftijd? Graag antwoorden met cijfers

    a. Wat is uw geslacht?
    b. Man
    c. Vrouw
    d. Anders

2. Welk apparaat gebruikt u meestal voor Caren?
    a. Laptop/computer
    b. Tablet
    c. Telefoon
    d. Anders, ….

3. Hoe vaak gebruikt u Caren?
    a. Een aantal keren per dag
    b. Een keer per dag
    c. 4-6 keer per week
    d. 1-3 keer per week

   e. Minder dan een keer per week
   f. Maandelijks

4. Hoe vaak gebruikt u de verschillende onderdelen van Caren? U kunt de opties sorteren van meest vaak naar minst vaak
   a. Kalender
   b. Berichten
   c. Dossier
   d. Notities

5. Waarom gebruikt u Caren?
   a. Ik ontvang hulp → sectie 2a
   b. Ik geef hulp als mantelzorger (bijvoorbeeld familie, vrienden of buren) → sectie 2b
   c. ik ben zorgprofessional (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) → sectie 4

Section 2a: Ik ontvang zorg

6. Wat is op u van toepassing?
   a. Mijn mantelzorgers (bijvoorbeeld familie, vrienden of buren) kunnen mijn zorgpagina zien → Vraag 7
   b. Mijn zorgverleners (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) kunnen in Caren mijn zorgpagina zien → Vraag 8
   c. Mijn mantelzorgers en zorgverleners kunnen mijn zorgpagina zien → Vraag 9 + 10
   d. Ik weet het niet (sla dan vraag 7, 8, 9 en 10 over)
   e. Geen van bovenstaande (sla dan vraag 7, 8, 9 en 10 over)

Toepassing: mijn mantelzorgers

7. Hoeveel mantelzorgers (bijvoorbeeld familie, vrienden of buren) van u gebruiken Caren?
   a. 1
   b. 2
   c. 3
   d. Meer dan 3

Toepassing: mijn zorgverleners

8. Welke zorgverleners (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) van u gebruiken Caren? Kies alle opties die op u van toepassing zijn
   a. Behandelaar (zoals ergotherapeut, fysiotherapeut, maatschappelijk werker, arts, psycholoog)
   b. (wijk)verpleegkundige/zuster
   c. Verzorgende
   d. Begeleider
   e. Niet van toepassing

Toepassing: mantelzorgers & zorgverleners

9. Hoeveel mantelzorgers (bijvoorbeeld familie, vrienden of buren) van u gebruiken Caren?
    a. 1
    b. 2
    c. 3
    d. Meer dan 3

10. Welke zorgverleners (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) van u gebruiken Caren? Kies alle opties die op u van toepassing zijn
    a. Behandelaar (zoals ergotherapeut, fysiotherapeut, maatschappelijk werker, arts, psycholoog)
    b. (wijk)verpleegkundige/zuster
    c. Verzorgende
    d. Begeleider
    e. Niet van toepassing

Vervolg: ik ontvang zorg

11. Hoe lang gebruikt u Caren?
    a. Minder dan 1 jaar
    b. Tussen de 1 en 3 jaar
    c. Meer dan 3 jaar

12. Wat is de reden dat u zorg ontvangt? U kunt meerdere opties kiezen:
    a. Ouderdom
    b. Dementie of milde cognitieve beperking
    c. Lichamelijke beperking
    d. Psychische stoornis
    e. Slechtziend of slechthorend
    f. Verstandelijke handicap
    g. Anders

13. Hoelang ontvangt u mantelzorg (van bijvoorbeeld familie, vrienden of buren)?
    a. 0 tot 6 maanden
    b. 6 maanden tot 1 jaar
    c. 1 tot 2 jaar
    d. 2 tot 5 jaar
    e. Meer dan 5 jaar

14. Woont u alleen?
    a. Ja
    b. nee

15. Wat is uw woonsituatie?
    a. Ik woon in een eigen (huur)woning
    b. Ik woon in een aanleunwoning/ouderenwoning
    c. Ik woon in een verzorgingshuis/verpleeghuis

16. Hoe vaak wordt u bezocht door iemand die zorg aan u verleent?
    a. Een aantal keren per dag

b. Een keer per dag
c. 4-6 keer per week
d. 1-3 keer per week
e. Minder dan een keer per week

Uitleg over het slimme kastje

De universiteit doet onderzoek naar een nieuwe onopvallende detectietechnologie om bepaalde risico's te signaleren. Dit houdt in dat u niks hoeft te dragen op uw lichaam en geen apparaat hoeft te gebruiken. Zoals u kunt zien in de afbeelding kan er een klein kastje, denk aan een lichtsensor, op een onopvallende plek van uw woning geplaatst worden. Dit slimme kastje kan verschillende activiteiten volgen en belangrijke veranderingen waarnemen, zoals minder drinken of eten, verandering in de hartslag of ademhaling, (on)rustiger slapen, maar ook situaties zoals een val. Houd dit slimme kastje in gedachten bij het beantwoorden van de volgende vragen:

17. Zou u dit slimme kastje in uw woning accepteren om uw dagelijkse activiteiten zoals eten, drinken en het innemen van medicijnen te volgen?

    a. Helemaal niet
    b. Niet
    c. Misschien
    d. Wel
    e. Zeker wel

18. Zou u dit slimme kastje in uw woning accepteren om noodsituaties zoals een val te monitoren?
    a. Helemaal niet
    b. Niet
    c. Misschien
    d. Wel
    e. Zeker wel

19. Denkt u dat dit slimme kastje uw zorgverleners kan ondersteunen bij het leveren van betere zorg en zorg op het moment dat die gewenst is?
    a. Helemaal niet
    b. Niet
    c. Misschien
    d. Wel
    e. Zeker wel

20. Denkt u dat dit slimme kastje u zal helpen om langer zelfstandig en veilig thuis te kunnen wonen?
    a. Helemaal niet
    b. Niet
    c. Misschien
    d. Wel
    e. Zeker wel

21. Mogen uw zorgverleners en mantelzorgers ook de informatie uit het slimme kastje ontvangen?
    a. Ja, alleen mijn zorgverleners (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) → Vraag 22
    b. Ja, alleen mijn mantelzorgers (bijvoorbeeld familie, vrienden of buren) → Vraag 23
    c. Ja, zowel mijn mantelzorgers als mijn zorgverleners → Vraag 22 en 23
    d. Dat weet ik niet zeker

22. Indien toepasselijk: Welke informatie mogen uw zorgverleners (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) zien?
    a. Alle informatie
    b. Alleen informatie over noodsituaties
    c. Alleen informatie over dagelijks welzijn
    d. Niet toepasselijk

23. Indien toepasselijk: Welke informatie mogen uw mantelzorgers (bijvoorbeeld familie, vrienden of buren) zien?
    a. Alle informatie
    b. Alleen informatie over noodsituaties
    c. Alleen informatie over dagelijks welzijn
    d. Niet toepasselijk

24. Wat is uw hoogst behaalde diploma? (optioneel)
    a. Geen diploma
    b. Basisonderwijs
    c. VMBO, MBO 1-2
    d. HAVO, VWO, HBS, MBO 3-4
    e. Bachelor (HBO/WO)
    f. Master (HBO/WO)

25. Heeft u nog opmerkingen over deze vragenlijst?

26. Wilt u deelnemen aan een volgend onderzoek over het verlenen van zorg?
    a. Ja
    b. Nee
    c. Misschien

Informatie delen: mijn zorgverleners

27. Welke informatie mogen uw zorgverleners (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) zien?
    a. Alle informatie
    b. Alleen informatie over noodsituaties

    c. Alleen informatie over dagelijks welzijn

28. Wat is uw hoogst behaalde diploma? (optioneel)
    a. Geen diploma
    b. Basisonderwijs
    c. VMBO, MBO 1-2
    d. HAVO, VWO, HBS, MBO 3-4
    e. Bachelor (HBO/WO)
    f. Master (HBO/WO)

29. Wilt u deelnemen aan een volgend onderzoek over het verlenen van zorg?
    a. Ja → Vraag 37
    b. Nee
    c. Misschien → Vraag 37

Informatie delen: mijn mantelzorgers

30. Welke informatie mogen uw mantelzorgers (bijvoorbeeld familie, vrienden of buren) zien?
    a. Alle informatie
    b. Alleen informatie over noodsituaties
    c. Alleen informatie over dagelijks welzijn

31. Wat is uw hoogst behaalde diploma? (optioneel)
    a. Geen diploma
    b. Basisonderwijs
    c. VMBO, MBO 1-2
    d. HAVO, VWO, HBS, MBO 3-4
    e. Bachelor (HBO/WO)
    f. Master (HBO/WO)

32. Wilt u deelnemen aan een volgend onderzoek over het verlenen van zorg?
    a. Ja → Vraag 37
    b. Nee
    c. Misschien → Vraag 37

Informatie delen: zorgverleners & mantelzorgers

33. Welke informatie mogen uw zorgverleners (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) zien?
    a. Alle informatie
    b. Alleen informatie over noodsituaties
    c. Alleen informatie over dagelijks welzijn

34. Welke informatie mogen uw mantelzorgers (bijvoorbeeld familie, vrienden of buren) zien?

    a. Alle informatie
    b. Alleen informatie over noodsituaties
    c. Alleen informatie over dagelijks welzijn

35. Wat is uw hoogst behaalde diploma? (optioneel)
    a. Geen diploma
    b. Basisonderwijs
    c. VMBO, MBO 1-2
    d. HAVO, VWO, HBS, MBO 3-4
    e. Bachelor (HBO/WO)
    f. Master (HBO/WO)

36. Wilt u deelnemen aan een volgend onderzoek over het verlenen van zorg?
    a. Ja → Vraag 37
    b. Nee
    c. Misschien → Vraag 37

37. Contactgegevens

Vul dan hier alstublieft uw mailadres in, of als wij u mogen bellen uw telefoonnummer, zodat wij contact met u kunnen opnemen.

Section 2b: Ik ben een mantelzorger

38. Aan hoeveel mensen verleent u mantelzorg? Graag antwoorden met cijfers

39. Hoe lang bent u al actief als mantelzorger?
    a. Minder dan 1 jaar
    b. Tussen de 1 en 3 jaar
    c. Meer dan 3 jaar

40. Hoe lang gebruikt u Caren?
    a. Minder dan 1 jaar
    b. Tussen de 1 en 3 jaar
    c. Meer dan 3 jaar

41. Bent u tevreden over Caren?
    a. zeer tevreden
    b. tevreden
    c. neutraal
    d. ontevreden
    e. zeer ontevreden

Denk bij het beantwoorden van de volgende vragen aan één specifieke persoon aan wie u mantelzorg verleent:

42. Wat is de leeftijd van de persoon aan wie u zorg verleent?

43. Aan hoeveel zorgorganisaties bent u gekoppeld in Caren?
    a. 1

   b. 2
   c. 3
   d. Meer dan 3

44. Welke zorgverleners zijn aan u gekoppeld in Caren? Kies alle opties die op u van toepassing zijn
    a. Behandelaar (zoals ergotherapeut, fysiotherapeut, maatschappelijk werker, arts psycholoog)
    b. (wijk)verpleegkundige/zuster
    c. Verzorgende
    d. Begeleider
    e. Niet van toepassing

45. Hoe vaak bezoekt u de persoon voor wie u zorgt?
    a. Een aantal keren per dag
    b. Een keer per dag
    c. 4-6 keer per week
    d. 1-3 keer per week
    e. Minder dan een keer per week
    f. Maandelijks

46. Wat is de reden dat u zorg verleent? U kunt meerdere opties kiezen:
    a. Ouderdom
    b. Dementie of milde cognitieve beperking
    c. Lichamelijke beperking
    d. Psychische stoornis
    e. Slechtziend of slechthorend
    f. Verstandelijke handicap
    g. Anders

47. Hoe lang verleent u al zorg aan deze persoon?
    a. 0 tot 6 maanden
    b. 6 maanden tot 1 jaar
    c. 1 tot 2 jaar
    d. 2 tot 5 jaar
    e. Meer dan 5 jaar

48. Wat is uw relatie tot de persoon voor wie u zorgt? Ik ben…
    a. Echtgenoot / partner
    b. Dochter/zoon
    c. Schoondochter / schoonzoon
    d. Kleindochter / kleinzoon
    e. buren / vriend(in)
    f. Anders

49. Welke woonsituatie is op u van toepassing?
    a. Ik woon in hetzelfde huis als de persoon voor wie ik zorg
    b. Degene voor wie ik zorg woont niet bij mij in huis → Vraag 50

Woonsituatie

50. Wat is de woonsituatie van de persoon aan wie u zorg verleent?

    a. Hij/zij woont alleen in een eigen (huur)woning
    b. Hij/zij woont samen met ander(en) in en eigen (huur)woning
    c. Hij/zij woont alleen in een aanleunwoning/ouderenwoning
    d. Hij/zij woont samen met partner in een aanleunwoning/ouderenwoning
    e. Hij/zij woont in een verzorgingshuis/verpleeghuis

51. Hoe ver vandaan woont u van de persoon voor wie u zorgt?
    a. Ik woon erg dichtbij (op minder dan 5 minuten reistijd)
    b. Ik woon op ongeveer 15 minuten reisafstand
    c. Ik woon op ongeveer 30 minuten reisafstand
    d. Ik woon op ongeveer 1 uur reisafstand
    e. Ik woon op meer dan een uur reistijd

Section 3: Vragen over het sensorsysteem

De universiteit doet onderzoek naar een nieuwe onopvallende detectietechnologie om bepaalde risico's te signaleren. Dit houdt in dat u niks hoeft te dragen op uw lichaam en geen apparaat hoeft te gebruiken. Zoals u kunt zien in de afbeelding kan er een klein kastje, denk aan een lichtsensor, op een onopvallende plek van uw woning geplaatst worden. Dit slimme kastje kan verschillende activiteiten volgen en belangrijke veranderingen waarnemen, zoals minder drinken of eten, verandering in de hartslag of ademhaling, (on)rustiger slapen, maar ook situaties zoals een val. Houd dit slimme kastje in gedachten bij het beantwoorden van de volgende vragen:

52. Zou u dit slimme kastje in de woning van uw naaste accepteren om hun dagelijkse activiteiten zoals eten, drinken en het innemen van medicijnen te monitoren?

    a. Helemaal niet
    b. Niet
    c. Misschien
    d. Wel
    e. Zeker wel

53. Zou u dit slimme kastje in de woning van uw naaste accepteren om noodsituaties zoals een val te monitoren?
    a. Helemaal niet
    b. Niet
    c. Misschien

    d. Wel
    e. Zeker wel

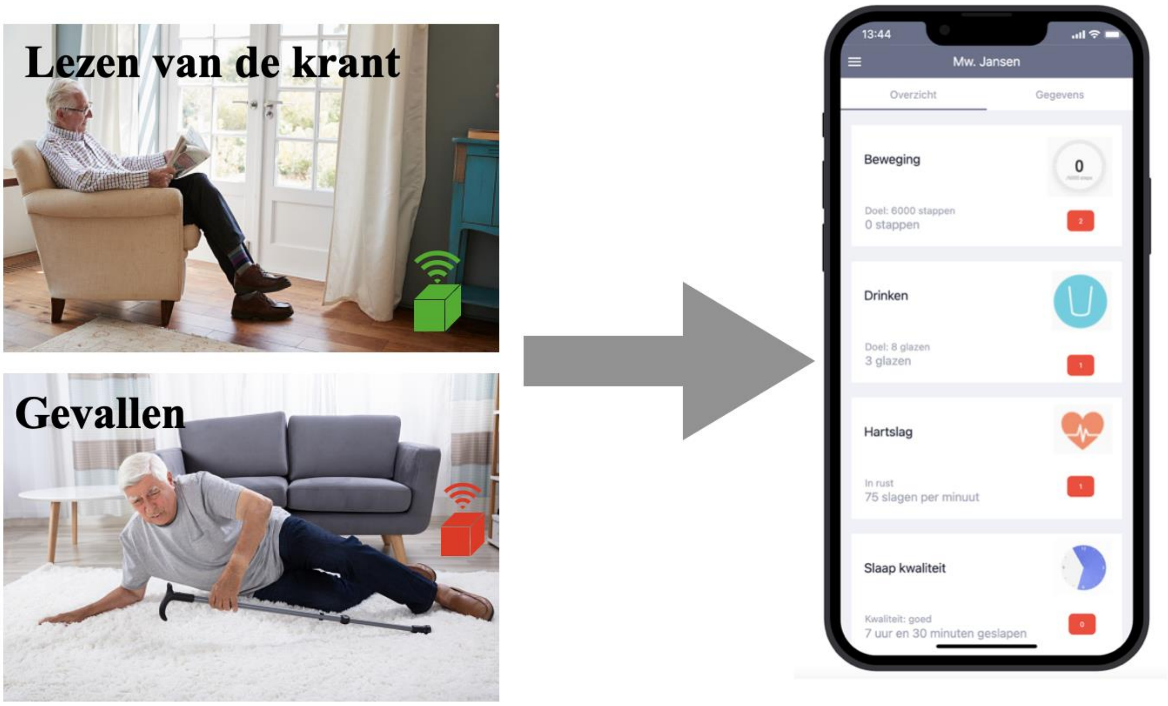
54. Denkt u dat dit slimme kastje u kan ondersteunen bij het leveren van betere zorg en zorg op het moment dat die gewenst is?
    a. Helemaal niet
    b. Niet
    c. Misschien
    d. Wel
    e. Zeker wel

55. Denkt u dat dit slimme kastje de persoon voor wie u zorgt zal helpen om langer zelfstandig en veilig thuis te kunnen wonen?
    a. Helemaal niet
    b. Niet
    c. Misschien
    d. Wel
    e. Zeker wel

56. Zou u zo'n slim kastje in het huis van de persoon voor wie u zorgt willen gebruiken?
    a. Helemaal niet
    b. Niet
    c. Misschien
    d. Wel
    e. Zeker wel

Informatieplatform

Nadat het slimme kastje informatie verzameld heeft bij de persoon voor wie u zorgt, is het natuurlijk belangrijk dat deze informatie op de juiste manier bij u komt, via een platform. Deze informatie helpt u bij het plannen van bezoeken, het krijgen van zekerheid wanneer alles in orde is of geeft een waarschuwing in geval van nood. Graag willen we begrijpen welke informatie voor u belangrijk is.



57. Welke informatie wilt u ontvangen? (meerdere antwoorden mogelijk)
    a. Alle informatie die verzameld kan worden
    b. Alleen informatie over noodsituaties (zoals een val)
    c. Informatie over slaapkwaliteit/nachtelijke onrust
    d. Informatie over medicatie inname
    e. Informatie over inname van water en voedsel
    f. Informatie over persoonlijke hygiëne (zoals wassen, tandenpoetsen en aankleden)
    g. Informatie over onrust overdag/agitatie
    h. Ik wil deze informatie niet ontvangen

58. Op welk apparaat wilt u informatie ontvangen over het slimme kastje?
    a. Laptop/computer
    b. Tablet
    c. Telefoon
    d. Anders, …

59. Welke van onderstaande scenario’s is het meest herkenbaar voor u?
    a. De persoon voor wie ik zorg valt (regelmatig) → ga naar situatie 1 en 4
    b. De persoon voor wie ik zorg ervaart nachtelijke onrust → ga naar situatie 2 en 4
    c. De persoon voor wie ik zorg ervaart agitatie (onrust) → ga naar situatie 3 en 4
    d. Geen van bovenstaande scenario’s is herkenbaar voor mij → ga naar situatie 4

Situatie 1 een val:

Het is maandagochtend, rond 11.00 uur heeft het slimme kastje een val gedetecteerd. U wordt geïnformeerd door het platform dat uw naaste gevallen is en op de badkamervloer ligt.

1. Wat vindt u van deze situatie?
   a. Een noodgeval
   b. Wel urgent, maar geen noodgeval
   c. Normale situatie

2. Op welke manier wilt u ingelicht worden door het slimme kastje in het geval dat uw naaste is gevallen?
   a. Een notificatie of pop-up, zoals die van Caren
   b. Een tekstbericht/SMS
   c. Een (prioriteit) email
   d. Een telefoontje of voicemail
   e. Een update op het platform, zodat ik zelf kan kijken wanneer ik tijd heb
   f. Anders, …

3. Moet het kastje u een melding sturen wanneer uw naaste gevallen is?
   a. Ja, meteen
   b. Ja, na een paar minuten als mijn naaste niet is opgestaan
   c. Ja, maar alleen op bepaalde momenten die ik zelf heb ingesteld
   d. Nee, ik controleer zelf zodra ik tijd heb → sla vraag 4 over

4. Wie moet er een bericht ontvangen wanneer uw naaste gevallen is?
   a. Alleen ik zelf moet een melding ontvangen
   b. alleen alle mantelzorgers (bijvoorbeeld familie, vrienden of buren) moeten een melding ontvangen
   c. alleen de zorgverleners (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) moeten een melding ontvangen
   d. alle mantelzorgers en zorgverleners moeten een melding ontvangen
   e. alleen ikzelf en de zorgverleners (bijvoorbeeld verpleegkundige, thuiszorg of therapeut) moeten een melding ontvangen
   f. alleen ikzelf en de mantelzorgers (bijvoorbeeld familie, vrienden of buren) moeten een melding ontvangen

5. Wat moet het slimme kastje doen als u niet meteen (binnen een minuut) de melding opent als uw naaste is gevallen?
   a. Wacht 5 minuten, zodat ik de tijd heb om de melding te bekijken
   b. Neem contact op met een andere mantelzorger van mijn naaste
   c. Neem contact op met de zorgverleners van mijn naaste
   d. Bel de huisarts/112
   e. Iets anders ….

6. Als het slimme kastje mij informeert over de val, dan wil ik deze informatie het liefste als volgt ontvangen:

a. Ruwe data: de informatie die ontvangen is door het slimme kastje, zonder enige interpretatie, bijvoorbeeld:

> Het slimme kastje heeft een val in de badkamer geregistreerd en uw naaste is niet in staat om op te staan. De bloeddruk van uw naaste had een plotselinge bloeddrukdaling van 20 mm Hg.

b. Geïnterpreteerde data: de informatie van het slimme kastje wordt direct geanalyseerd door het kastje, vervolgens wordt de informatie gedeeld door het platform. Bijvoorbeeld:

> Het slimme kastje heeft een val gedetecteerd, uw naaste is gevallen door een bloeddrukdaling

c. Interpretatie en suggestie: de informatie wordt direct geanalyseerd door het slimme kastje, samen met de informatie wordt er een suggestie gedaan voor welke actie u kunt ondernemen. Bijvoorbeeld:

> Het slimme kastje heeft een ernstige val en bloeddrukdaling geobserveerd. U wordt geadviseerd om uw naaste te bezoeken of iemand anders te vragen om langs te gaan.

d. Anders, namelijk: …

7. Zou u feedback aan het systeem kunnen geven over hoe u gehandeld heeft in een bepaalde situatie?
   a. Zeker wel
   b. Waarschijnlijk wel
   c. Misschien
   d. Waarschijnlijk niet
   e. Zeker niet

8. Is het behulpzaam als het platform u een compliment of feedback geeft op basis van hoe u gehandeld heeft?
   a. Zeker wel
   b. Waarschijnlijk wel
   c. Misschien
   d. Waarschijnlijk niet
   e. Zeker niet

Situatie 2 nachtelijke onrust:

U heeft uw naaste om 1 uur ‘s nachts aan de telefoon gehad waarin hij/zij u vertelde dat hij/zij slecht kan slapen. Om 3 uur ’s nachts observeert het slimme kastje dat uw naaste steeds aan het draaien is in bed, uit bed komt en door het huis dwaalt.

1. Wat vindt u van deze situatie?
   a. Een noodgeval

   b. Wel urgent, maar geen noodgeval
   c. Normale situatie

2. Op welke manier wilt u ingelicht worden door het slimme kastje in het geval dat uw naaste nachtelijke onrust vertoont?
   a. Een notificatie of pop-up, zoals die van Caren
   b. Een tekstbericht/SMS
   c. Een (prioriteit) email
   d. Een telefoontje of voicemail
   e. Een update op het platform, zodat ik zelf kan kijken wanneer ik tijd heb
   f. Anders, …

3. Wilt u een melding ontvangen elke keer als uw naaste opstaat uit bed?
   a. ja
   b. nee
   c. ik wil zelf deze optie kunnen aanpassen

4. Wilt u een melding ontvangen elke keer als uw naast weer naar bed gaat?
   a. ja
   b. nee
   c. ik wil zelf deze optie kunnen aanpassen

5. Wilt u graag een gedetailleerd rapport ontvangen over de nachtelijke onrust van uw naaste?
   a. Ja, iedere dag
   b. Ja, observeer een paar dagen en stuur een rapport als de onrust aanhoudt.
   c. Ja, observeer een paar weken en stuur een rapport wanneer de onrust aanhoudt.
   d. Nee, verstuur deze informatie naar de zorgverleners
   e. Anders, ….

6. Wat moet het kastje doen als u niet meteen (binnen een minuut) de melding opent als uw naaste nachtelijke onrust vertoont?
   a. Wacht 5 minuten, zodat ik de tijd heb om de melding te bekijken
   b. Neem contact op met een andere mantelzorger van mijn naaste
   c. Neem contact op met de zorgverleners van mijn naaste
   d. Bel de huisarts/112
   e. Iets anders ….

7. Als het kastje mij informeert over de nachtelijke onrust, dan wil ik deze informatie het liefste als volgt ontvangen:
   a. Ruwe data: de informatie die ontvangen is door het slimme kastje, zonder enige interpretatie, bijvoorbeeld:

Het slimme kastje heeft geconstateerd dat uw naaste tien keer is opgestaan vannacht. De afgelopen 5 uur was uw geliefde veel aan het draaien in bed.

   b. Geïnterpreteerde data: de informatie van het slimme kastje wordt direct geanalyseerd door het kastje, vervolgens wordt de informatie gedeeld door het platform. Bijvoorbeeld:

> Het slimme kastje heeft geconstateerd dat uw naaste last heeft van nachtelijke onrust, waardoor uw naaste niet goed kan slapen.

c. Interpretatie en suggestie: de informatie wordt direct geanalyseerd door het slimme kastje, samen met de informatie wordt er een suggestie gedaan voor welke actie u kunt ondernemen. Bijvoorbeeld:

> Het slimme kastje heeft geconstateerd dat uw naaste al een paar nachten last heeft van nachtelijke onrust. Wij raden u aan om uw naaste te bezoeken in de aankomende dagen of iemand anders te vragen om even langs te gaan.

d. Anders, namelijk ….

8. Zou u feedback aan het systeem kunnen geven over hoe u gehandeld heeft in een bepaalde situatie?
   a. Zeker wel
   b. Waarschijnlijk wel
   c. Misschien
   d. Waarschijnlijk niet
   e. Zeker niet

9. Is het behulpzaam als het platform u een compliment of feedback geeft op basis van hoe u gehandeld heeft?
   a. Zeker wel
   b. Waarschijnlijk wel
   c. Misschien
   d. Waarschijnlijk niet
   e. Zeker niet

Situatie 3 Agitatie (onrust of geprikkeldheid overdag):

Het slimme kastje detecteert steeds vaker dat uw naaste overdag onrustig en geprikkeld is. Zo gooit hij/zij de krant op de grond, schopt hij/zij tegen de tafelpoot of reageert boos wanneer de bus stopt bij de halte voor het huis.

1. Wat vindt u van deze situatie?
   a. Een noodgeval
   b. Wel urgent, maar geen noodgeval
   c. Normale situatie

2. Op welke manier wilt u ingelicht worden door het slimme kastje in het geval dat uw naaste onrust of geprikkeldheid vertoont overdag?
   a. Een notificatie of pop-up, zoals die van Caren
   b. Een tekstbericht/SMS
   c. Een (prioriteit) email
   d. Een telefoontje of voicemail

e. Een update op het platform, zodat ik zelf kan kijken wanneer ik tijd heb
f. Anders, …

3. Wanneer wilt u deze informatie ontvangen:
a. Op elk moment van de dag
b. Alleen op bepaalde momenten, die ik zelf aangegeven heb
c. Nooit

4. Wilt u graag een gedetailleerd rapport ontvangen over de onrust of geprikkeldheid van uw naaste?
a. Ja, iedere dag
b. Ja, observeer een paar dagen en stuur een rapport als de onrust aanhoudt.
c. Ja, observeer een paar weken en stuur een rapport wanneer de onrust aanhoudt.
d. Nee, verstuur deze informatie naar de zorgverleners
e. Anders, ….

5. Wat moet het kastje doen als u niet meteen (binnen een minuut) de melding opent als uw naaste onrust of geprikkeldheid vertoont?
a. Wacht 5 minuten, zodat ik de tijd heb om de melding te bekijken
b. Neem contact op met een andere mantelzorger van mijn naaste
c. Neem contact op met de zorgverleners van mijn naaste
d. Bel de huisarts/112
e. Iets anders ….

6. Als het kastje mij informeert over onrust of geprikkeldheid overdag, dan wil ik deze informatie het liefste als volgt ontvangen:

a. Ruwe data: de informatie die ontvangen is door het slimme kastje, zonder enige interpretatie, bijvoorbeeld:

> Het slimme kastje heeft geconstateerd dat uw naaste vaak tegen voorwerpen aanschopt en veel snelle bewegingen met de handen maakt.

b. Geïnterpreteerde data: de informatie van het slimme kastje wordt direct geanalyseerd door het kastje, vervolgens wordt de informatie gedeeld door het platform. Bijvoorbeeld:

> Het slimme kastje heeft geconstateerd dat uw naaste onrust vertoont sinds een paar uur.

c. Interpretatie en suggestie: de informatie wordt direct geanalyseerd door het slimme kastje, samen met de informatie wordt er een suggestie gedaan voor welke actie u kunt ondernemen. Bijvoorbeeld:

> Het slimme kastje heeft geconstateerd dat uw naaste onrust vertoont, waardoor hij/zij niet kan rusten. Wij adviseren u om uw naaste vandaag nog te bezoeken of te vragen of iemand anders even langs kan gaan.

d. Anders, namelijk ….

7. Zou u feedback aan het systeem kunnen geven over hoe u gehandeld heeft in een bepaalde situatie?
   a. Zeker wel
   b. Waarschijnlijk wel
   c. Misschien
   d. Waarschijnlijk niet
   e. Zeker niet

8. Is het behulpzaam als het platform u een compliment of feedback geeft op basis van hoe u gehandeld heeft?
   a. Zeker wel
   b. Waarschijnlijk wel
   c. Misschien
   d. Waarschijnlijk niet
   e. Zeker niet

Situatie 4 normale dag:

Het is een normale dag waarin het slimme kastje niks afwijkends heeft waargenomen. Uw naaste heeft een gezonde dag gehad waarin er voldoende gegeten, bewogen en geslapen is.

1. Op welke manier wilt u ingelicht worden door het slimme kastje in het geval dat uw naaste een normale dag heeft?
   a. Een notificatie of pop-up, zoals die van Caren
   b. Een tekstbericht/SMS
   c. Een (prioriteit) email
   d. Een telefoontje of voicemail
   e. Een update op het platform, zodat ik zelf kan kijken wanneer ik tijd heb
   f. Anders, …

2. Wanneer wilt u deze informatie ontvangen:
   a. Op elk moment van de dag
   b. Alleen op bepaalde momenten, die ik zelf aangegeven heb
   c. Nooit

3. Hoe vaak wilt u een update ontvangen?
   a. Ik wil een update ontvangen na elke activiteit (geslapen, gegeten, bewogen)
   b. Stuur mij de informatie aan het einde van de dag
   c. Ik hoef hier geen informatie over te ontvangen
   d. Ik zal zelf op het platform kijken zodra ik tijd heb
   e. Ik wil zelf graag in kunnen vullen welke informatie ik ontvang en wanneer
   f. Een andere oplossing, namelijk …

4. Wat moet het slimme kastje doen als u niet meteen (binnen een minuut) de melding opent dat uw naaste een normale dag heeft?

   a. Wacht 5 minuten, zodat ik de tijd heb om de melding te bekijken
   b. Neem contact op met een andere mantelzorger van mijn naaste
   c. Neem contact op met de zorgverleners van mijn naaste
   d. Bel de huisarts/112
   e. Iets anders ….

5. Als het slimme kastje mij informeert over een normale dag, dan wil ik deze informatie het liefste als volgt ontvangen:

a. Ruwe data: de informatie die ontvangen is door het slimme kastje, zonder enige interpretatie, bijvoorbeeld:

De hartslag van uw naaste is 80 slagen per minuut. De bloeddruk is 120/80

b. Geïnterpreteerde data: de informatie van het slimme kastje wordt direct geanalyseerd door het kastje, vervolgens wordt de informatie gedeeld door het platform. Bijvoorbeeld:

Het slimme kastje ziet dat alles goed gaat met uw naaste

c. Interpretatie en suggestie: de informatie wordt direct geanalyseerd door het slimme kastje, samen met de informatie wordt er een suggestie gedaan voor welke actie u kunt ondernemen. Bijvoorbeeld:

Het slimme kastje ziet dat alles goed gaat met uw naaste, u hoeft zich nergens zorgen over te maken.

d. Anders, namelijk ….

6. Zou u feedback aan het systeem kunnen geven over hoe u gehandeld heeft in een bepaalde situatie?

   a. Zeker wel
   b. Waarschijnlijk wel
   c. Misschien
   d. Waarschijnlijk niet
   e. Zeker niet

7. Is het behulpzaam als het platform u een compliment of feedback geeft op basis van hoe u gehandeld heeft?

   a. Zeker wel
   b. Waarschijnlijk wel
   c. Misschien
   d. Waarschijnlijk niet
   e. Zeker niet

Technologie acceptatie

Houd het eerder genoemde slimme kastje in combinatie met een communicatieplatform als product in gedachten bij het beantwoorden van de volgende vragen.
Geef aan in hoeverre u het eens bent met de volgende stellingen:

1. Het gebruik van dit product zou mij de zorgverlening makkelijker maken.
   a. Helemaal mee oneens
   b. Mee oneens
   c. Deels mee oneens
   d. Neutraal (niet mee oneens/niet mee eens)
   e. Deels mee eens
   f. Mee eens
   g. Helemaal mee eens

2. Het gebruik van dit product zou mij in staat stellen de zorg te leveren die mijn naaste nodig heeft
   a. Helemaal mee oneens
   b. Mee oneens
   c. Deels mee oneens
   d. Neutraal (niet mee oneens/niet mee eens)
   e. Deels mee eens
   f. Mee eens
   g. Helemaal mee eens

3. Het gebruik van dit product zou mijn effectiviteit bij het zorgen voor mijn naaste vergroten.
   a. Helemaal mee oneens
   b. Mee oneens
   c. Deels mee oneens
   d. Neutraal (niet mee oneens/niet mee eens)
   e. Deels mee eens
   f. Mee eens
   g. Helemaal mee eens

4. Ik zou dit product nuttig vinden in de zorg voor mijn naaste
   a. Helemaal mee oneens
   b. Mee oneens
   c. Deels mee oneens
   d. Neutraal (niet mee oneens/niet mee eens)
   e. Deels mee eens
   f. Mee eens
   g. Helemaal mee eens

5. Het leren omgaan met dit product zou voor mij gemakkelijk zijn
   a. Helemaal mee oneens

b. Mee oneens
c. Deels mee oneens
d. Neutraal (niet mee oneens/niet mee eens)
e. Deels mee eens
f. Mee eens
g. Helemaal mee eens

6. Ik zou dit product makkelijk vinden in gebruik
a. Helemaal mee oneens
b. Mee oneens
c. Deels mee oneens
d. Neutraal (niet mee oneens/niet mee eens)
e. Deels mee eens
f. Mee eens
g. Helemaal mee eens

7. Wanneer ik toegang zou hebben tot dit product, zou ik het gaan gebruiken bij de zorg voor mijn naaste.
a. Helemaal mee oneens
b. Mee oneens
c. Deels mee oneens
d. Neutraal (niet mee oneens/niet mee eens)
e. Deels mee eens
f. Mee eens
g. Helemaal mee eens

8. Wat is uw hoogst behaalde diploma? (optioneel)
  a. Geen diploma
  b. Basisonderwijs
  c. VMBO, MBO 1-2
  d. HAVO, VWO, HBS, MBO 3-4
  e. Bachelor (HBO/WO)
  f. Master (HBO/WO)

9. Heeft u nog opmerkingen over deze vragenlijst?

10. Wilt u deelnemen aan een volgend onderzoek over het verlenen van zorg?
a. Ja → ga naar vraag 11
b. Nee
c. Misschien → ga naar vraag 11

Contactgegeven – mantelzorger

11. Bent u geïnteresseerd in deelname aan vervolgonderzoek over ondersteunende technologie voor het verlenen van zorg aan uw naaste, vult u dan alstublieft uw mailadres of telefoonnummer in zodat wij contact met u kunnen opnemen.

Section 4: Vragen voor zorgverleners

1. Aan hoeveel cliënten bent u gekoppeld in Caren?

a. 1
b. 2
c. 3
d. Meer dan 3

2. Hoe lang gebruikt u Caren?
a. Minder dan 1 jaar
b. Tussen de 1 en 3 jaar
c. Meer dan 3 jaar

3. Heeft u toegang tot het elektronisch cliënten dossier van de cliënt(en) (bijvoorbeeld via ONS, HIX of Ysis)?
a. Ja
b. Ja, maar niet voor alle gekoppelde clienten
c. Nee

4. Wat is/zijn de belangrijkste reden(en) om Caren als zorgprofessional te gebruiken (meerdere opties mogelijk)
a. Communicatie met de andere mensen in het mantelzorgnetwerk
b. Meelezen in het zorgdossier
c. Agenda afspraken inzien en beheren
d. Anders …

5. Wat is uw hoogst behaalde diploma? (optioneel)
a. Geen diploma
b. Basisonderwijs
c. VMBO, MBO 1-2
d. HAVO, VWO, HBS, MBO 3-4
e. Bachelor (HBO/WO)
f. Master (HBO/WO)
g. Anders

6. Heeft u nog opmerkingen over deze vragenlijst?

7. Wilt u deelnemen aan een volgend onderzoek over het verlenen van zorg?
a. Ja → ga naar vraag 8
b. Nee
c. Misschien →ga naar vraag 8

Contactgegevens – zorgprofessional

8. Vul dan hier alstublieft uw mailadres in, of als wij u mogen bellen uw telefoonnummer, zodat wij contact met u kunnen opnemen.

9.2 Short introduction

Beste lezer,

Wij benaderen u, omdat u aan een eerder onderzoek van de Universiteit Twente heeft deelgenomen of interesse hiervoor heeft getoond. Wij voeren op dit moment een vervolgstudie uit waarvoor wij u van harte uitnodigen.

Wij zijn als Universiteit Twente geïnteresseerd in de ervaringen die mantelzorgers hebben met huidige ondersteunende technologie. Zoals bijvoorbeeld beeldbellen, een slimme medicatiedispenser of GPS. Wij willen onderzoeken in hoeverre er behoeftes en wensen zijn, zodat we bestaande technologie kunnen verbeteren voor de toekomst of nieuwe technologieën kunnen ontwikkelen

Wij willen voor het ontwerpen van een nieuw soort communicatieplatform graag met u in gesprek om uw wensen en behoeften in kaart te brengen. Bent u geïnteresseerd in deelname aan dit onderzoek?

We willen u vragen om op deze mail te reageren en de volgende vragen te beantwoorden:

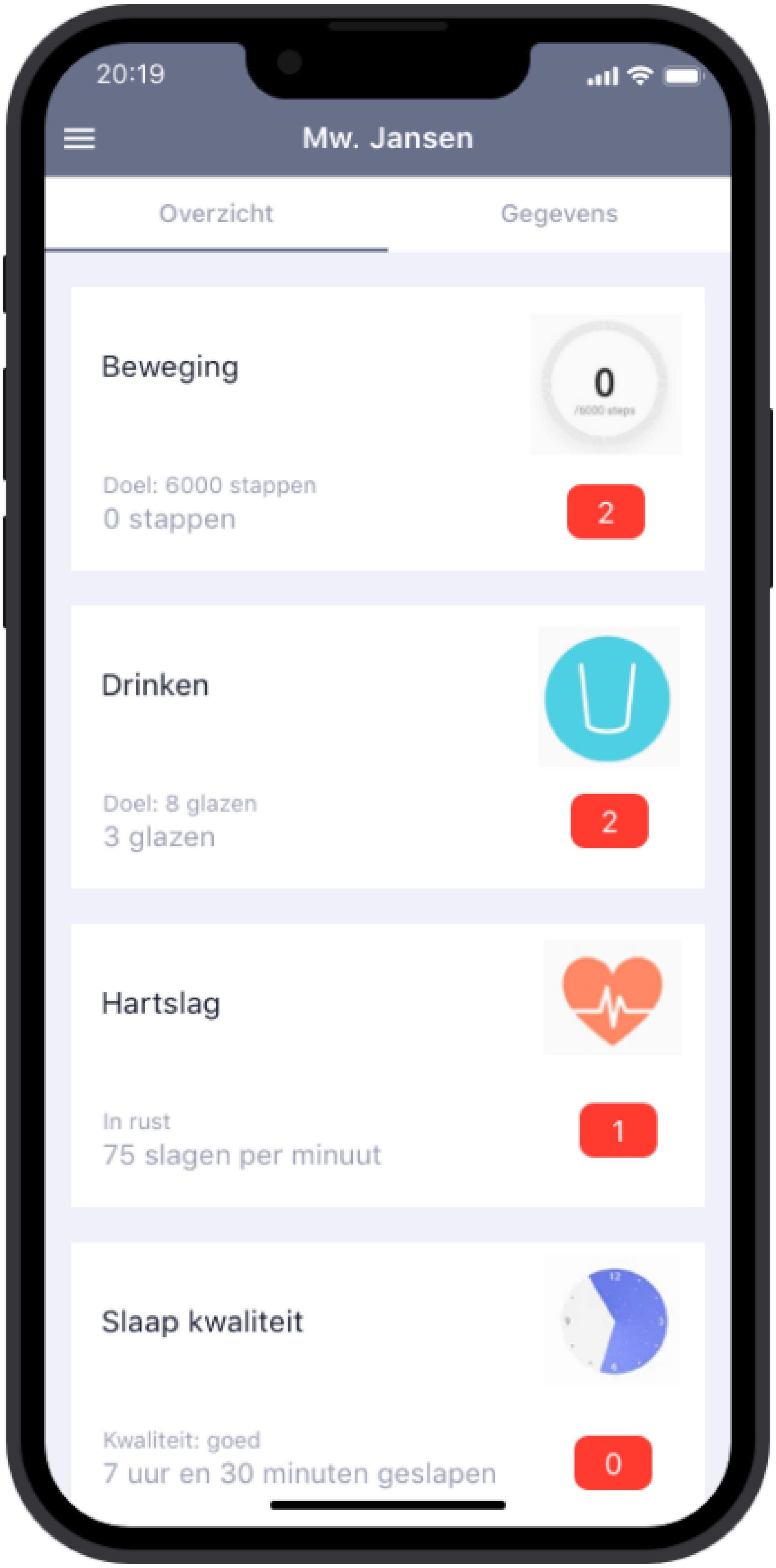
- Verleent u op dit moment mantelzorg aan iemand?
    - ○ Ja
    - ○ Nee
- Wat is de reden dat u voor deze persoon zorgt?
- Welke woonsituatie is op u van toepassing?
    - ○ Ik woon in hetzelfde huis als degene voor wie ik zorg
    - ○ Degene voor wie ik zorg woont niet bij mij in huis, hij/zij woont ergens anders
    - ○ Degene voor wie ik zorg woont niet bij mij in huis, hij/zij woont zelfstandig
- Wilt u deelnemen aan een interview over hoe dit communicatieplatform er uit moet komen te zien?
    - ○ Ja, op dit moment wil ik deelnemen. Ik weet dat ik nog meer uitleg over het onderzoek krijg en op ieder moment kan beslissen om toch niet deel te nemen
    - ○ Nee, ik wil niet deelnemen
- Hoe kunnen we contact met u opnemen?
    - ○ Via dit mailadres
    - ○ Via een ander mailadres;……
    - ○ Via telefoon;……

Wij danken u bij voorbaat voor uw waardevolle bijdrage en kostbare tijd.

Met vriendelijke groet,

Dineke Brouwer (Master Health Sciences, UT), n.e.j.brouwer@student.utwente.nl,
Nikita Sharma (Ph.D., UT), n.sharma@utwente.nl en
Dr. L.M.A. Braakman-Jansen (Assistant Professor, UT), l.m.a.braakman-jansen@utwente.nl

9.3 Prototype



Beweging

Doel: 6000 stappen
0 stappen

Drinken

Doel: 8 glazen
3 glazen

Hartslag

In rust
75 slagen per minuut

Slaap kwaliteit

Kwaliteit: goed
7 uur en 30 minuten geslapen

Slimme kastje

Het slimme kastje heeft een val in de keuken geregistreerd en uw naaste is niet in staat om op te staan. De bloeddruk van uw naaste had een plotselinge bloeddrukdaling van 20 mm Hg.

Slimme kastje

Keuken

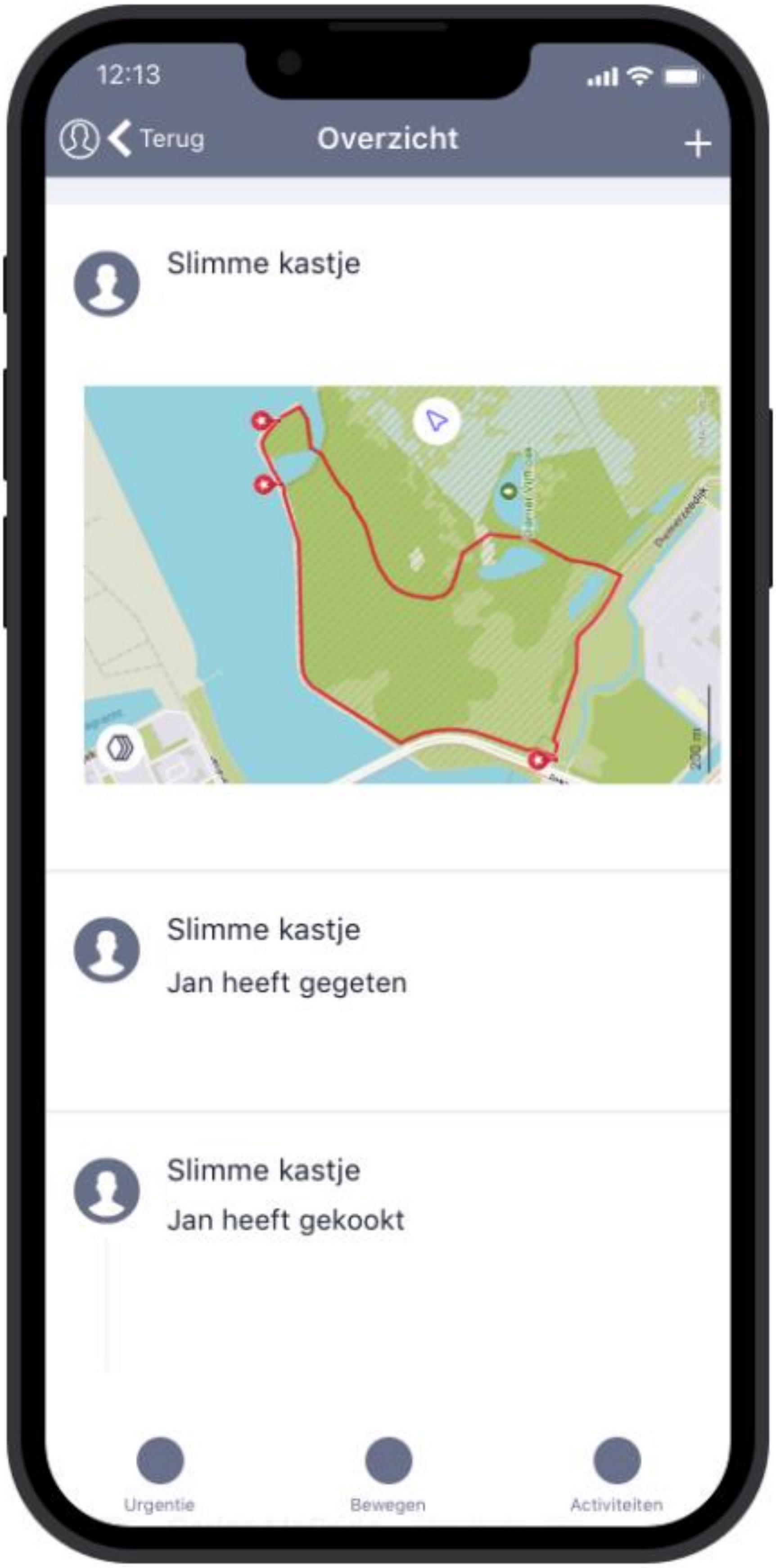
Het slimme kastje heeft een ernstige val en bloeddrukdaling geobserveerd. U wordt geadviseerd om uw naaste te bezoeken of iemand anders te vragen om langs te gaan.

Slimme kastje

Keuken

Het slimme kastje heeft een val gedetecteerd, uw naaste is gevallen door een bloeddrukdaling

Slimme kastje



Slimme kastje

Slimme kastje

Jan heeft gegeten

Slimme kastje

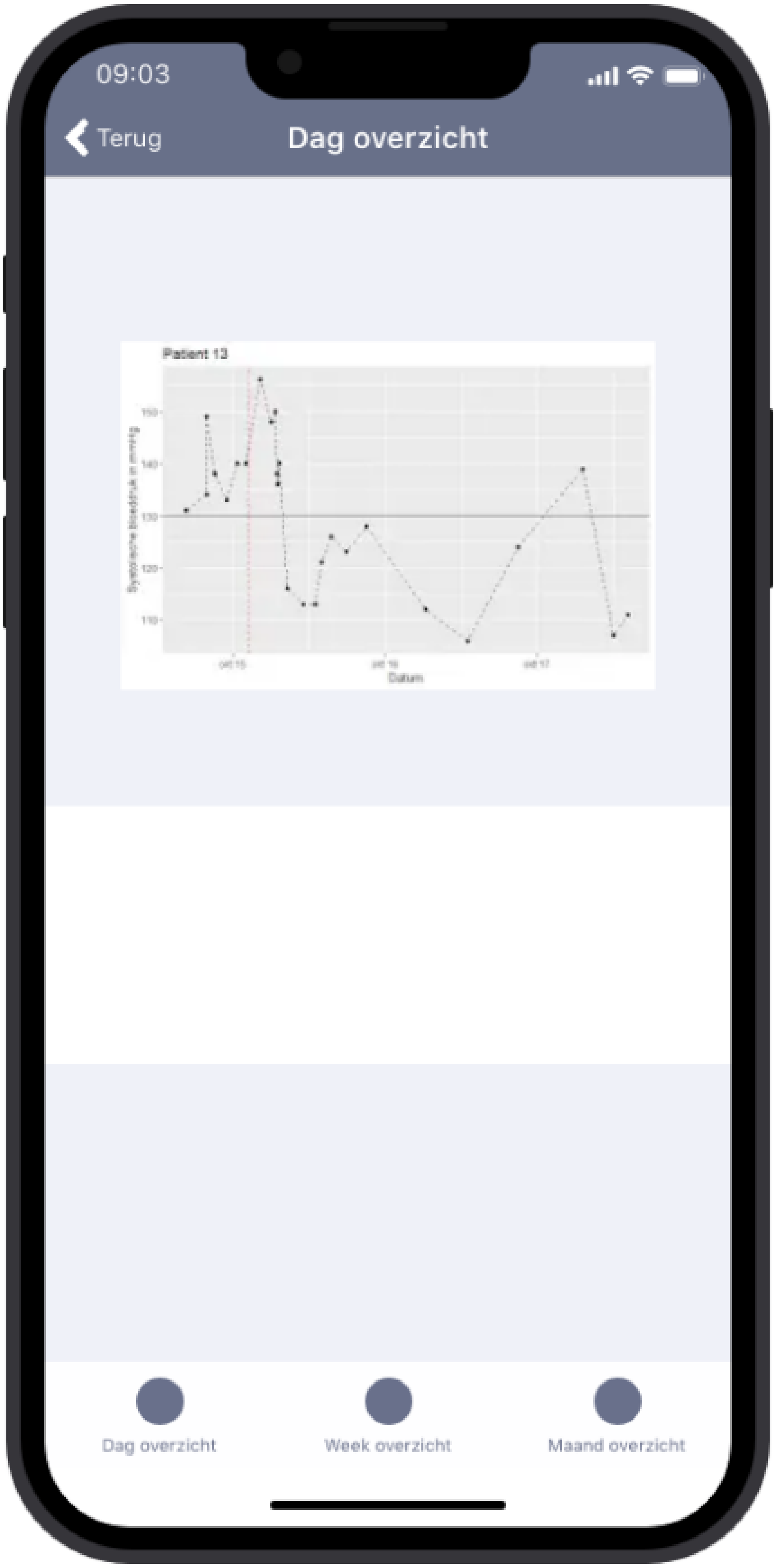
Jan heeft gekookt

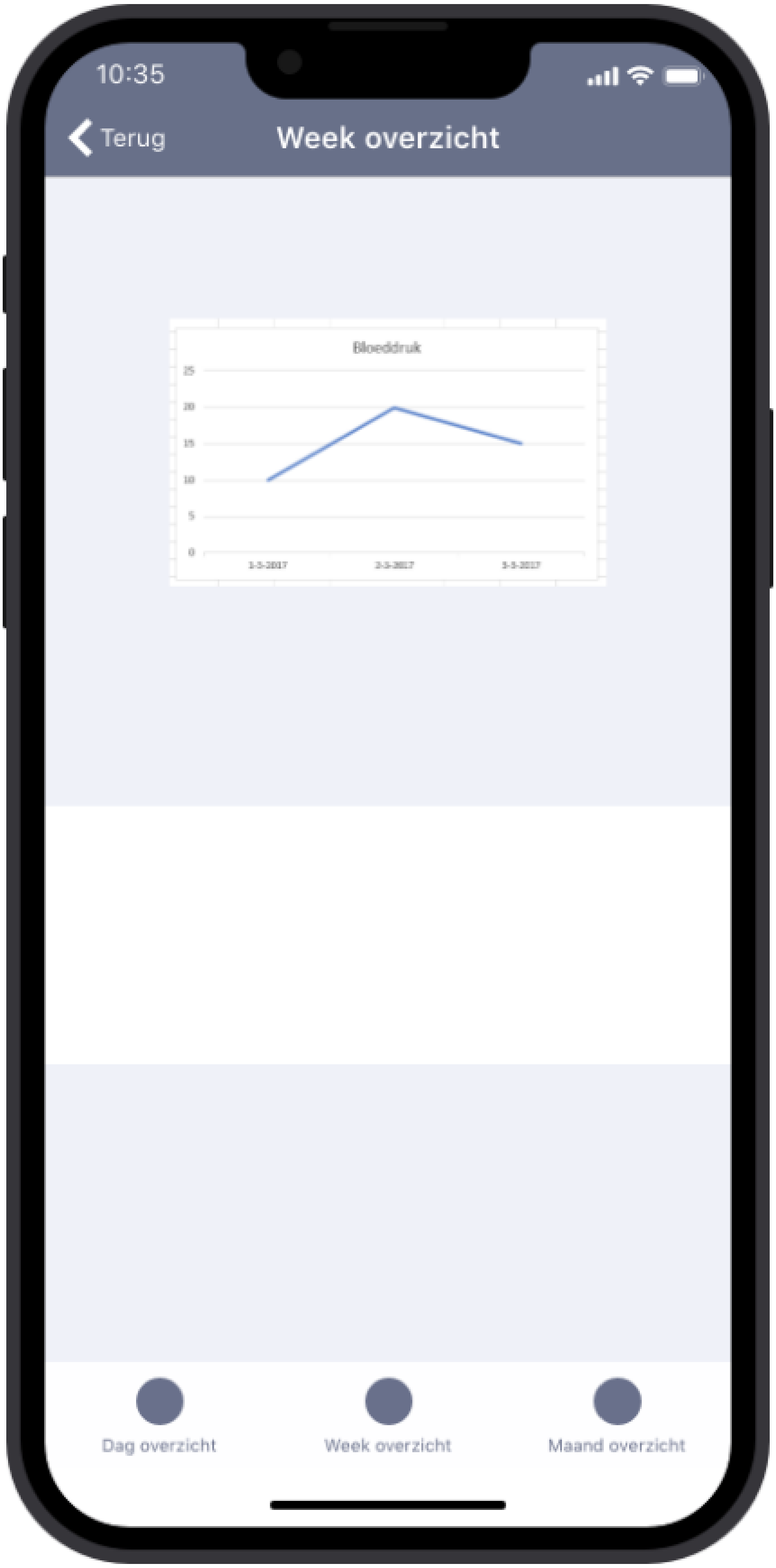
Slimme kastje
5 april 2022

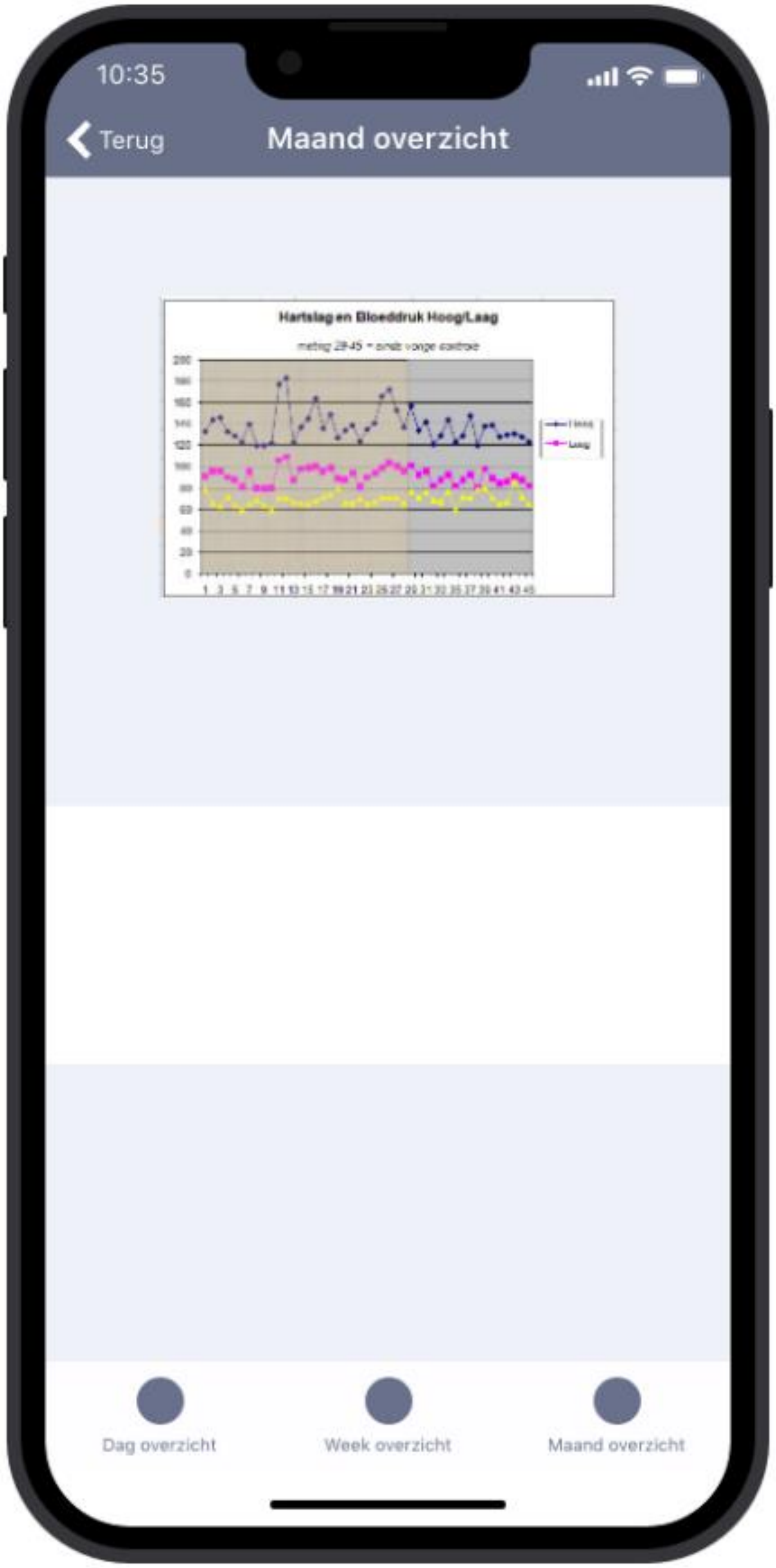
Jan heeft vandaag 3428 stappen gezet.

Slimme kastje
4 april 2022

Jan heeft vandaag 6439 stappen gezet.


09:03
Terug
Dag overzicht
Patient 13
Systolische bloeddruk in mmHg
150
140
130
120
110
okt 15
okt 16
okt 17
Datum
Dag overzicht
Week overzicht
Maand overzicht


10:35
Terug
Week overzicht
Bloeddruk
25
20
15
10
5
0
1-3-2017
2-3-2017
3-3-2017
Dag overzicht
Week overzicht
Maand overzicht


10:35
Terug
Maand overzicht
Hartslag en Bloeddruk Hoog/Laag
meting 29-45 = sinds vorige controle
200
180
160
140
120
100
80
60
40
20
0
1 3 5 7 9 11 13 15 17 19 21 23 25 27 29 31 33 35 37 39 41 43 45
Hoog
Laag
Dag overzicht
Week overzicht
Maand overzicht

Slimme kastje

Jan heeft een glas water gedronken, in totaal 4 vandaag.

Slimme kastje

Keuken

Jan heeft vandaag 3 glazen water gedronken. Pas op, dit is weinig.

Slimme kastje

Keuken

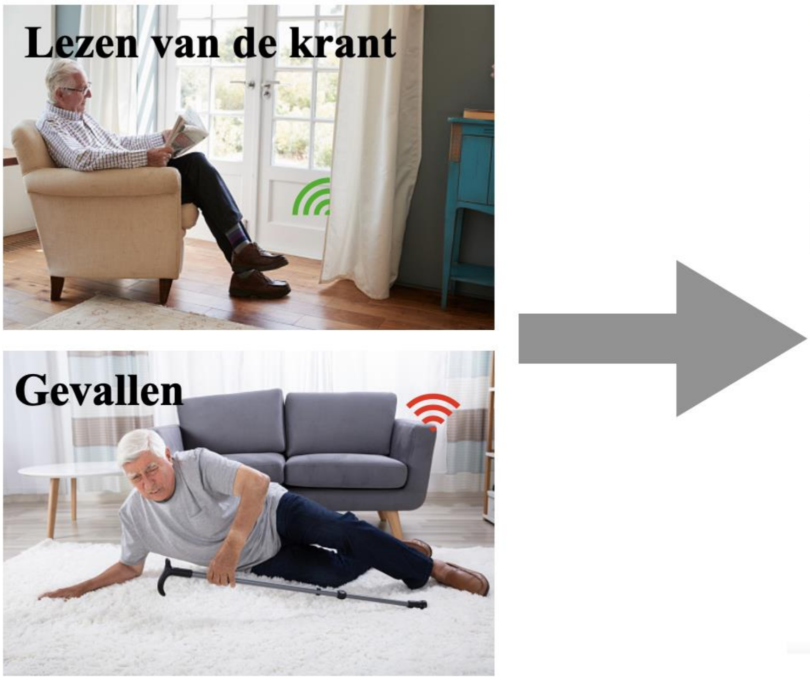
Jan heeft vandaag in totaal 7 glazen water gedronken

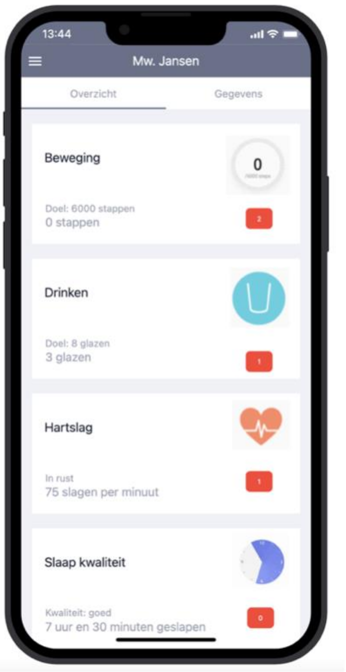
Slimme kastje

Het slimme kastje heeft een ernstige val en bloeddrukdaling geobserveerd. U wordt geadviseerd om uw naaste te bezoeken of iemand anders te vragen om langs te gaan.

Het slimme kastje heeft geconstateerd dat uw naaste onrust vertoont, waardoor hij/zij niet kan rusten. Wij adviseren u om uw naaste vandaag nog te bezoeken of te vragen of iemand anders even langs kan gaan.

Het slimme kastje ziet dat alles goed gaat met uw naaste, u hoeft zich nergens zorgen over te maken.





Beweging

Doel: 6000 stappen
0 stappen

Drinken

Doel: 8 glazen
3 glazen

Hartslag

In rust
75 slagen per minuut

Slaap kwaliteit

Kwaliteit: goed
7 uur en 30 minuten geslapen

9.4 Interviewguide

Introductie

- Welkom heten en voorstellen
- Doel onderzoek uitleggen (de universiteit doet onderzoek naar een nieuw soort onopvallende technologie. Dit is een technologie die het mogelijk maakt dat u uw naaste op afstand in de gaten kunt houden. Vervolgens kan al deze informatie met u gecommuniceerd worden middels een platform. Maar, dat moet nog helemaal vormgegeven worden en bepaald worden hoe dat precies werkt. En dat wil ik vandaag graag samen met u onderzoeken. Hoe moet dit platform functioneren? Welke informatie moet het communiceren, wanneer en hoe?)
- Data verzameling en gebruik
- Structuur van het interview
- Voordat we starten met het interview wil ik graag de informed consent ondertekenen.
- Er zijn geen goede of foute antwoorden, u mag vragen overslaan die u niet wil beantwoorden
- Heeft u vragen tot nog toe?

Achtergrond participant

- Wat is uw leeftijd?
- Wat is uw beroep?
- Wat is uw relatie met de persoon voor wie u zorgt?
- Wat is de leeftijd van hem/haar?
- Hoe lang verleent u al zorg aan uw naaste?
- Wat is de reden dat u voor hem/haar zorgt? Wat zorgt ervoor dat u zorg blijft geven? Wat is uw motivatie?
- Weet u hoelang hij/zij al deze aandoening heeft, of wanneer er een diagnose gesteld is?
- Wat is uw woonsituatie? Woont u in hetzelfde huis, ergens anders?
- Hoeveel uur per week levert u gemiddeld zorg?
- Wat zijn uw zorgtaken, wat doet u allemaal?
- Bent u de enige mantelzorger of zijn er ook andere mantelzorgers betrokken? Welke taken hebben zij? Hoe vaak komen zij langs?
- Zijn er nog andere zorgprofessionals betrokken? (thuiszorg) Hoeveel uren of dagen per week? Welke taken hebben zij?
- Hoe ervaart u de samenwerking en communicatie met zorgverleners nu?
- Welke informatie deelt u en welke juiste niet? Wat kan er beter, wat moet hetzelfde blijven?

Ervaring technologie

- Hoe deelt u deze informatie op dit moment?
- Maakt u gebruik van technologie of een communicatieplatform om de zorg om uw naaste te organiseren? (wat zijn de namen van de systemen?)
- Wat is uw ervaring met dit systeem/deze technologie? (zowel positief als negatief)

Huidige zorg

Wanneer uw naaste alleen thuis is, zijn er dan bepaalde situaties waar u zich zorgen over maakt?	- Wat maakt het (trigger) dat u zich dan zorgen maakt? (prioritering) - Wanneer doen deze situaties zich voor? - Als zo'n situatie zich nu voordoet, wat doet u dan? Wat gaat goed?/Wat gaat niet goed? - Wat zou u in zo'n situatie kunnen helpen? Wat zou u willen weten? (prioritering) Welke informatie mist u dan? - Kunt u uitleggen waarom dat belangrijk voor u is?

Uitleg systeem *Prototype laten zien en uitleggen hoe het zal werken. (plaatje van survey laten zien)* *De universiteit doet onderzoek naar een nieuwe onopvallende detectietechnologie om bepaalde risico's te signaleren. Het is onopvallend, wat inhoudt dat u of uw naaste niks hoeft te dragen op het lichaam en geen apparaat hoeft te gebruiken. Zoals u kunt zien in de afbeelding kan er een klein kastje, denk aan een lichtsensor, op een onopvallende plek van de woning geplaatst worden. Dit slimme kastje kan verschillende activiteiten volgen en belangrijke veranderingen waarnemen, zoals minder drinken of eten, verandering in de hartslag of ademhaling, (on)rustiger slapen, maar ook situaties zoals een val.* *Het systeem kan leren om bepaalde situaties te herkennen en u als mantelzorger daarover informeren. De vraag is nu welke situaties relevant zijn voor u, wanneer zou u informatie willen ontvangen van het platform? En wat wilt u dan precies weten, hoe en wanneer. Om dit systeem verder te ontwikkelen willen we daarom weten wat u als eventuele gebruiker van dit platform nodig zou hebben.* *Op basis van eerder onderzoek zijn er al verschillende thema's naar voren gekomen, dit is een vervolgonderzoek.*	
Perceived usefulness	
Ingaan op 1 situatie: - Vallen - Nachtelijke onrust - Medicatie inname - Inname van voedsel/water - ADL (hygiëne) - Agitatie/onrust overdag En ingaan op een dag zonder bijzonderheden *dikgedrukte vragen meteen ook stellen voor normale dag, vergelijking maken*	- Wat zou u ervan vinden wanneer een dergelijk systeem ingezet zou worden bij de zorg voor uw naaste? Voor- en nadelen - Hoe zou dit communicatieplatform u kunnen ondersteunen in de zorg die u levert? Hier ingaan op situatie - **Wat zou u willen weten / welke informatie zou u willen ontvangen?** - Hoe gedetailleerd moet de informatie zijn? - Hoe moet de informatie er uit zien? (nu vs toekomst, feit vs advies, huidig vs voorspelling, meting vs interpretatie) - Hoe zou u deze info willen ontvangen? App/sms/telefoontje/pop-up/e-mail. Waarom? - **Wanneer wilt u geïnformeerd worden over deze situatie?** - Wie moet de meldingen ontvangen? Hoe moet de informatieoverdracht plaatsvinden? - Welke informatie moet gedeeld worden en welke informatie niet? Met wie? Door wie? Hoe? (andere mantelzorgers en zorgprofessionals) - Wat vindt u van de toevoeging van extra sociale aspecten? Denk bijvoorbeeld aan dat je ervaringen kunt delen via het platform? Of adviezen ontvangen? o Interactie met anderen? (hoe wilt u contact hebben) o Verbinding met andere mantelzorgers of professionals, waarom wel/niet?
Design voorwaarden voor het platform en systeem	
Als u dit prototype ziet, wat is dan uw eerste indruk?	- Welke informatie moet meteen zichtbaar zijn na het openen van de app/website? Zouden noodgevallen hier tussen moeten staan? - Wat verwacht u van de informatie presentatie/de opmaak van het platform? Hoe moet het er uit zien? Hoe zou u de informatie presenteren? - Hoe zou een melding er volgens u uit moeten zien? (kleur, tekst, geluid, stem ..) - Wat moet het platform allemaal kunnen? Wat moet het allemaal bieden?

	- Is dit als app duidelijk? Of is een website beter? Waarom? - Op welk apparaat zou u het platform willen gebruiken? - Wat wilt u allemaal kunnen aanpassen in het platform? o Bijvoorbeeld het moment dat meldingen verstuurd worden, hoelang nadat de situatie zich voordoet, naar wie - Wat moet het platform doen in het geval van nood - Wat vindt u ervan als het systeem u een herinnering stuurt als u niet reageert in geval van nood?
Wat is er nodig om u gerust te stellen/zekerheid te bieden over het welzijn van uw naaste? (Betrouwbaarheid/geloofwaardigheid van het systeem (system credibility))	- In hoeverre zou u zo'n systeem vertrouwen?/wat is voor u belangrijk om vertrouwen te kunnen hebben in dit systeem? - Wat beïnvloedt uw vertrouwen in dit systeem? Wat moet er gedaan worden om dit vertrouwen te behouden? - Welk verschil maakt het als het systeem aangeeft hoe zeker het is van een observatie? - Hoe beïnvloedt dit vertrouwen uw gebruik van het systeem? - Hoe zou dit (of een vergelijkbaar) systeem u kunnen ondersteunen in het waarborgen van de veiligheid van uw naaste? - Hoe kijkt u naar het gevoel van veiligheid ten opzichte van de privacy van uw naaste? Wat bedoelt u daar precies mee? - Wat denkt u van valse alarmen? Wat doet dat met uw vertrouwen?
Toekomst	
Hoe zou u dit platform in de toekomst willen gebruiken?	- Hoe zal de inzet van dit system uw zorgtaken veranderen? In hoeverre zal het de zorg verbeteren? - Op welke vlakken heeft het systeem een meerwaarde? - Wat zou u nodig hebben om het te kunnen gaan gebruiken? - Wat heeft u nodig om het systeem te blijven gebruiken? - Zou u het aanraden aan andere mantelzorgers? - Zou u er geld voor over hebben? - Zou u het systeem willen helpen verbeteren door het feedback te geven door na meldingen op ja/nee te klikken over de juistheid van de melding? - Hoe zou u feedback aan het systeem kunnen geven over hoe u gehandeld heeft in een bepaalde situatie? Over dat u actie heeft ondernomen na het ontvangen van de melding? Of u er op tijd was? - Wat vindt u ervan als het platform u een compliment of feedback geeft op basis van hoe u gehandeld heeft?
Is er nog iets wat nog niet aan bod is gekomen wat u graag wilt toevoegen?	

9.5 Information letter for informal caregivers

Titel onderzoek: Informatie en communicatie behoeften en vereisten van mantelzorgers voor een sensorafhankelijk communicatie platform

Beste deelnemer,

Bedankt dat u wil deelnemen aan dit onderzoek. Dit onderzoek is bedoeld om inzicht te krijgen in uw behoeften op het gebied van informatie communicatie, om uw wensen voor een sensorafhankelijk zorgplatform in kaart te brengen.

Op dit moment wordt er onderzoek gedaan naar een nieuw soort monitoringsysteem. Dit systeem kan, met sensoren die in de woning geplaatst worden, uw dierbaren in de gaten houden. Het systeem vraagt geen aandacht van uw dierbare, zij hoeven het niet te dragen of actief te gebruiken. Het monitoringsysteem geeft informatie over het dagelijks leefpatroon, gedrag en stemming van uw dierbare door middel van een bewegings- en geluidssensor op een centrale plek in de woning. Het systeem kan verschillende dagelijkse activiteiten volgen wanneer u niet bij hen bent, zoals de inname van water en voedsel op een dag, toiletgebruik, of als uw dierbare gevallen is. Dit houdt in, zoals u kunt zien in de afbeelding, dat er een soort detectie box (een soort wifi-router) in een hoek van het huis geplaatst wordt. Deze sensoren volgen automatisch alleen de dingen die relevant zijn voor u en de persoon voor wie u zorgt. Deze informatie kan vervolgens op ieder moment actueel op een digitaal communicatie platform worden laten zien. Op deze manier kan het u helpen bij het leveren van adequate zorg wanneer dat nodig is.

Dit soort informatie zou u wellicht kunnen helpen het plannen van bezoeken door bijvoorbeeld het ontvangen van waarschuwingen in geval van nood. Daarnaast kan het ook rust en zekerheid geven door te weten dat alles in orde is. Bovendien streven we er niet alleen naar om de technologie onopvallend te maken, maar ook om de informatiecommunicatie niet storend en gepersonaliseerd te maken door rekening te houden met uw werkelijke behoeften en vereisten.

Als eerste stap bij het ontwerpen van het communicatieplatform willen we daarom uw behoeften en vereisten voor zo’n platform begrijpen. Daarvoor hebben we een korte vragenlijst ontworpen die u al heeft ingevuld. Nu als vervolgonderzoek willen we graag met u in gesprek om uw wensen en behoeften nog beter in kaart te brengen. Hoe moet dat platform er uit komen te zien? Bent u geïnteresseerd bent in deelname aan dit onderzoek?

Aan het begin van het interview zal er toestemming, ‘informed consent’, worden gevraagd. Dit betekent dat de gegevens vertrouwelijk en alleen voor onderzoeksdoeleinden worden gebruikt. Uw antwoorden worden anoniem bewaard. Uw identiteit zal nooit zonder toestemming aan iemand worden bekendgemaakt. We willen u ook informeren dat dit onderzoek uitmaakt van ENTWINE – The European Training Network on Informal Care, ondersteund door de Europese Unie (https://entwine-itn.eu). Dit onderzoek is uitgevoerd door een team van onderzoekers van de Universiteit Twente en Nedap Healthcare.

Als u bezwaar heeft tegen bovenstaande, is het niet mogelijk om deel te nemen aan het onderzoek. U kunt zich op elk moment uit het onderzoek terugtrekken als u enig ongemak ervaart bij het beantwoorden van een van de vragen. Tot slot kunt u op elk moment voor, tijdens of na dit onderzoek contact opnemen met de onderzoekers. Hun gegevens kunt u hieronder vinden.

Wij danken u bij voorbaat voor uw waardevolle bijdrage en kostbare tijd.

Dineke Brouwer (Master Health Sciences, UT), n.e.j.brouwer@student.utwente.nl
Nikita Sharma (Ph.D., UT), n.sharma@utwente.nl
Dr. L.M.A. Braakman-Jansen (Assistant Professor, UT), l.m.a.braakman-jansen@utwente.nl

9.6 Informed consent

- ○ Hierbij verklaar ik dat ik op voor mij duidelijke wijze ben geïnformeerd over het focusgroep-onderzoek, getiteld "**Informatiecommunicatie behoeften en vereisten van mantelzorgers voor een sensorafhankelijk informatiecommunicatie platform**''

- ○ Ik ga uit eigen vrije wil akkoord met deelname aan dit onderzoek

- ○ Ik behoud me het recht voor om deze toestemming in te trekken zonder dat ik daarvoor een reden hoef op te geven en ik ben me ervan bewust dat ik me op elk moment uit het onderzoek kan terugtrekken

- ○ Als mijn onderzoeksresultaten worden gebruikt in wetenschappelijke publicaties of op een andere manier openbaar worden gemaakt, worden deze volledig geanonimiseerd

- ○ Mijn persoonsgegevens worden zonder mijn toestemming niet aan derden verstrekt

- ○ Als ik nu of in de toekomst meer informatie over het onderzoek wil, kan ik contact opnemen met betrokken onderzoekers (Dineke Brouwer: n.e.j.brouwer@student.utwente.nl, Nikita Sharma: n.sharma@utwente.nl en Annemarie Braakman-Jansen: l.m.a.braakman-jansen@utwente.nl).

Mocht u klachten hebben over dit onderzoek, dan kunt u deze richten aan de secretaris van de Ethische Commissie van de Faculteit Elektrotechniek, Wiskunde en Computerwetenschappen en de Faculteit Gedrags-, Management- en Sociale wetenschappen van de Universiteit Twente, Postbus 217, 7500 AE Enschede (NL), e-mail: ethicscommittee-bms@utwente.nl.

Ik geef mijn toestemming:

Naam: …………………

Datum: ____ - ____ - 2022

Handtekening: ……………..

9.7 Coding scheme

Themes	Main- and subcodes	Participant number	Total
Information needs	**Wellbeing care recipient**		
	Physical wellbeing	**1, 2, 5, 7**	4 (57%)
	Mental wellbeing	**1, 2, 4**	3 (43%)
	Overall wellbeing	**2, 5, 6, 7**	4 (57%)
	Activities		
	Knowing what someone is doing	**2, 4, 5, 7**	4 (57%)
	Information about drug intake	**3, 5**	2 (29%)
	Information about food intake	**3, 5**	2 (29%)
	Location		
	Knowing where the person is	**1, 4, 6**	3 (43%)
Preconditions for use	**Organisation**		
	Funding	**1, 2, 3, 4, 6**	5 (71%)
	Good instruction	**4, 5, 7**	3 (43%)
	Trialability	**1, 7**	2 (29%)
	Technology		
	Not dependent on Wi-Fi	**2, 5, 6**	3 (43%)
	Uptime nearly real-time	**5**	1 (14%)
	Account for power outages	**5, 6**	2 (29%)
	Safe system	**1, 2**	2 (29%)
	Adopters		
	Care recipient	**3, 7**	2 (29%)
	Informal caregiver	**2, 4, 7**	3 (43%)
Advantages	**Care recipient**		
	Mental wellbeing	**3, 4, 5**	3 (43%)
	Longer stay in own home	**3**	1 (14%)
	Informal caregiver		
	Mental wellbeing	**1, 2, 3, 4, 5, 6**	6 (86%)
	Freedom	**2, 4, 5**	3 (43%)
	Personal time	**2, 5**	2 (29%)
	Perceived usefulness		
	Higher quality of care	**2, 3, 5**	3 (43%)
	Fast anticipation	**1, 3**	2 (29%)
	Insight in wellbeing	**2, 4, 6, 7**	4 (57%)
	Safety		
	Safety	**1, 2, 5, 6**	4 (57%)
Disadvantages	**Care recipient**		
	Loss of privacy	**1, 2, 3, 6**	4 (57%)
	Informal caregiver		
	Information overload	**1, 3, 7**	3 (43%)
	Loss of privacy	**1, 2, 3, 6**	4 (57%)
Information loop	**Way of informing**		
	Pop-up/notification	**3, 5, 6, 7**	4 (57%)
	Call	**1, 2, 3**	3 (43%)
	Moment of informing		

	When the situation occurs	**3**	1 (14%)
	After specific activities (good day)	**6**	1 (14%)
	After a couple of days (food intake)	**5**	1 (14%)
	Immediately (falling)	**1, 2**	2 (29%)
	When leaving particular zones (wandering)	**4**	1 (14%)
	Information receiver		
	Informal caregiver	**1, 3, 5, 6**	4 (57%)
	Depending on content	**1, 2, 3, 4, 5, 6, 7**	7 (100%)
	Someone who adds value at that time	**7**	1 (14%)
	Both informal and formal caregiver at the same time	**1, 2, 6**	3 (43%)
	Information receiver after no response		
	Other informal caregiver	**1, 6, 7**	3 (43%)
	Other contact person	**3**	1 (14%)
	Formal caregiver	**2, 4, 5**	3 (43%)
Functional and modality requirements	**Device to receive notifications**		
	Smartphone	**1, 3, 4, 5, 6, 7**	6 (86%)
	Laptop	**1, 2**	2 (29%)
	Smartwatch	**5**	1 (14%)
	Technical features		
	No lights (unobtrusive)	**6**	1 (14%)
	Being able to turn off ‘listening’	**3**	1 (14%)
	Technical features sensor system		
	Also be able to use outside and on devices	**2, 6**	2 (29%)
	Technical features sensor system		
	Platform should be able to speak	**2, 7**	2 (29%)
	Platform needs to be able to speak to informal caregiver	**7**	1 (14%)
	Platform needs to be able to speak to care recipient	**2, 7**	2 (29%)
	Possibility for contact with formal caregivers	**2, 3, 6**	3 (43%)
	Easy sharing of information	**1, 5, 6, 7**	4 (57%)
	Monitoring behaviour		
	Artificial Intelligence	**5**	1 (14%)
Content requirements	**Tiles of communication platform**		
	Good day	**1, 2, 3, 4, 6, 7**	6 (86%)
	Food & fluid intake	**1, 2, 4, 5, 6, 7**	6 (86%)
	Heartbeat & blood pressure	**4, 6, 7**	3 (43%)
	Movement	**1, 2, 4, 6, 7**	5 (71%)
	GPS	**7**	1 (14%)
	Sleeping	**2, 4, 7**	3 (43%)
	Emergency & falling	**1, 2, 3, 4, 6, 7**	6 (86%)

	Positive peculiarities/abnormalities	**5**	1 (14%)
	Information from the nurses/therapists	**6**	1 (14%)
	Content of notifications		
	Use of sounds in case of emergency	**1, 2, 3, 4, 7**	5 (71%)
	Use of colours	**1, 2, 3, 4, 5, 6, 7**	7 (100%)
	Information presentation	**1, 2, 3, 4, 6, 7**	6 (86%)
Usability and user experience requirements, according to PSD	**Primary task support**		
	Personalization	**1, 5, 6, 7**	4 (57%)
	Convenient	**1, 5**	2 (29%)
	Self-monitoring	**1, 5, 7**	3 (43%)
	Tailoring	**1, 2, 3, 5, 6, 7**	6 (86%)
	Compatibility	**3, 5, 6, 7**	4 (57%)
	System credibility support		
	Privacy	**3, 4, 5, 6, 7**	5 (71%)
	False alarms	**1, 2, 4, 5, 6, 7**	6 (86%)
	Uptime	**5**	1 (14%)
	Real-world feel	**3, 4, 5, 6, 7**	5 (71%)
	Dialogue support		
	Praise -	**1, 4, 5**	3 (43%)
	Praise +	**2, 3, 6, 7**	4 (57%)
	Suggestion	**2, 3, 5, 6, 7**	5 (71%)
	Social support		
	Social comparison	**3, 4, 5, 6, 7**	5 (71%)