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# Deliverable 2.4

## Intermediate version of User Requirements and Data Model

Work Package 2: Codesign Process

**affecTive basEd iNtegrated carE for better Quality of Life: TeNDER Project**

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*Table 1 - Consortium Partners List*

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3	DATAWIZARD SRL	DW	Italy
4	UBIWHERE LDA	UBI	Portugal
5	ELGOLINE DOO	ELGO	Slovenia
6	ETHNIKO KENTRO EREVNAS KAI TECHNOLOGIKIS ANAPTYXIS	CERTH	Greece
7	VRIJE UNIVERSITEIT BRUSSEL	VUB	Belgium
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<sup>1</sup> **R:** Document, report; **DEM:** Demonstrator, pilot, prototype; **DEC:** Websites, patent fillings, videos, etc.; **OTHER;** ETHICS: Ethics requirement; ORDP: Open Research Data Pilot.

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## Acronyms and Abbreviations

Acronym/Abbreviation	Description
TeNDER	affecTive basEd iNtegrated carE for better Quality of Life
WPx	Work Package
QoL	(Health related) Quality of Life
AD	Person with Alzheimer’s Disease or other form of dementia or mild cognitive impairment
PD	Person with Parkinson’s Disease
CVD	Person with Cardiovascular Disease

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## Executive Summary

TeNDER is a multi-sectoral project funded by Horizon 2020, the EU Framework Programme for Research and Innovation. We are developing an integrated care model to help patients with chronic diseases such as Alzheimer's, Parkinson's, Cardiovascular Diseases, and, where present, comorbidities. TeNDER aims also to help patient's relatives and others in their care pathway by addressing difficulties experienced in independent living and patient's care arrangement. We will be able to recognize the affective state of a person by using affective based micro tools. We will adapt the system's probes to the person's needs via a multi-sensorial system accordingly. The services developed in TeNDER are intended to automate, support and extend the care supply chain, by covering physical related medical, behavioural, social events and clerical pathway that will be integrated in TeNDER ecosystem. TeNDER services will also create opportunities for facilitating social and health care professionals' communication, moreover, will also ease the communication with carers and others in care services. This will assist the patient, increase his / her autonomy and allow him / her to live more independently.

The WP2 TeNDER tasks ensure that the TeNDER ecosystem is co-designed with all relevant stakeholders (patients, carers, doctors and other professionals). We are defining the scenarios, adopting the requirements and overcoming constraints in terms of ethics, privacy as well as creating the navigation follows of the envisaged components of the TeNDER toolbox in WP2. This document presents the intermediate report on user requirements and intermediate data model for the TeNDER system. As the co-design process has several phases, we have firstly explored the literature, but also the real experiences from potential participants by an observational study that was conducted with surveys and interviews. The analysis was performed according to the expertise of the TeNDER partners from different fields of expertise with people with neurodegenerative diseases, experiences and knowledge from previous projects and by analysing the users' feedbacks. We have created Persona cards (Personas, models) to visualize the needs of the TeNDER users, to define and confirm requirements of various patients with different abilities, people that surround them, and furthermore, with different types of professionals that are included in patients' care pathway. The most important or repeatedly stated issues and opinions on the technology, usability feedbacks are mirrored in the Persona cards as core characteristics. The second Wave of co-design is dedicated to ideate, develop new ideas and to co-create, validate together with users the proposed solutions according to their needs. In collaboration with users, we are performing the TeNDER dashboards' testing for each new version and also real-life testing with the devices that are connected into the first TeNDER system. Herein we report on Mock-up testing and preliminary feedbacks gathered from the piloting sites of the 1<sup>st</sup> Wave of TeNDER piloting up to mid-May. For the time being, as TeNDER is built from technological tools that are still not fully adopted by the end users TeNDER is addressing, TeNDER partners reviewed the potential limitations and addressed feedbacks also from the barriers and possible limitations' perspective.

The intermediate TeNDER data model is presented and linked further to the large-scale piloting phase performed together with people.

## 1 INTRODUCTION

The EU is facing healthcare challenges due to the rising of chronic diseases and the ageing population. One of the greatest care challenges we face, as a result of longer life expectancy and changes in the age composition of the population, is that the number of people with neurological diseases is likely to rapidly grow in the future. Most of them will require health and care services in their own homes or in nursing homes and assisted living facilities with 24-hour care. The families of patients will also need support and care. As already reported in previous WP2 Deliverables we are facing the fragmentation of the care-services in EU. Therefore, TeNDER aims to help patients, their families and others via a care pathway by addressing difficulties experienced in independent living and care management.

Despite the fact that many products are already on the market, some limitations exist and technologies are not widely used among elderlies yet. Moreover, in spite of the proliferation of technology in our everyday lives, there is a lack of knowledge on how assistive technologies may support better quality of life for people with neurodegenerative diseases, especially with dementia. There is still a question if technology has a true potential to enable people with neurologic diseases to continue living in their own homes and assist in daily challenges they face. Therefore, the involvement of users (patients, carers) is crucial to adapt and integrate the technological solutions in real-life situations, as they are the only ones that can test and talk about their own problems, provide "advice" (their opinion, experience, suggestions) and express their rights on how they want to use the technology supported solutions.

Co-design process is thus a non-linear process that involves multiple actors and stakeholders. We are involving patients from different groups (people with dementia, people with Parkinson's disease, people with cardiovascular diseases), their family members and informal carers, formal carers, health and social care professionals, and also other professionals and stakeholders from the field of care. In this process, we involve them in the ideation, implementation and assessment of TeNDER. The aim is not only to improve the efficiency and effectiveness, but also to enhance the satisfaction of those who take part in the co-design process. We are talking about a creative process where new solutions are designed together with people. By bringing in multiple perspectives from many different stakeholders we also encourage divergent thinking within the project group, so to get beyond easy answers and find options that might be truly innovative and bring practical solutions that can be user-friendly and adopted by the people.

The co-design process in TeNDER project allows individual experiences of each potential user of TeNDER to be heard and frame the process by questions of acceptance, usability, human dignity, human rights, fairness, social inclusion, and emotional impact.

The user and person-centred approach, and also the professional driven approach will allow the development of a solution that has the potential to be adopted in wider community.

### **1.1 Purpose and scope**

The intermediate report on the user requirements and data model of the TeNDER system is bringing together the first two co-design phases with the large-scale piloting phase of the project. The purpose is to ease the development with visualization of the “typical users” as core general models and include the in-depth view on user requirements found in the first two co-design phases. The first co-design process phase was set and performed in pre-piloting of the project while the second phase is spanning through the 1<sup>st</sup> and 2<sup>nd</sup> Wave of the TeNDER piloting. The dissemination activities of the project will also inform the participants on the co-design results to offer the wider audience an insight into the achievements of the research in which representative stakeholders participated with their valuable feedback. Herein, the continuous collection of feedback from all user groups is presented up to mid-May. Moreover, as TeNDER incorporates a number of mobile, wearable and other sensorial technologies that may cause limitations to be used by addressed population, barriers reported from the literature are reviewed. According to the protocols and recommendations developed in previous Deliverables of WP2 and work in WP1, the barriers are also identified for TeNDER and the overall report will be included in the next Deliverable (2.5). Herein we also present the intermediate TeNDER data model that is based on HL7 FHIR resources (v4.0.1) [16]. The resources are related between them by identifier keys, which are used as references and are described in Section 5. The intermediate data model describes the entities and devices association with patients and how it is assured that the information is well related and organized, which may provide correct and objective data when requested.

### **1.2 Contribution to other deliverables**

The present deliverable will contribute to the upcoming Deliverables in WP2 (Co-design Process: D2.5 and D2.6), to the development of tools to transform the data acquired into meaningful information for the multiple stakeholders (WP4, Decision Recommendation System). Also, in cooperation with work in WP5 (Services Integration), the user Interfaces and the TeNDER platform will be further developed. Finally, this deliverable is closely related with work in WP6 (Large Scale Piloting) and WP7 (Quality of life Assessment and progress indicators) that rely on the user-centric approaches.

### **1.3 Structure of the document**

The Deliverable 2.4 is structured into seven main sections:

- The presentation of the document, scope and purpose;
- The summarization of user requirements in the first phase of the project;
- Persona cards methodology and results; description of the approaches that will be used to ease the collaboration aspects with different care providers; report on user requirements regarding dashboards collected insofar; brief report on the process for user requirements at 1<sup>st</sup> Wave of piloting insofar;
- Possible limitations from user requirement perspective, including the literature review and first findings in the piloting;
- Intermediate TeNDER data model description and visualization;
- Report of work performed in order to fulfil objective 6 and related KPIs;
- Conclusion with main future guidance form user requirement perspective.



## **2 SUMMARIZATION OF USER REQUIREMENTS FROM PRE-PILOTING PHASE**

### **2.1 Interviews**

Partners have performed interviews with patients, caregivers and professionals in all countries that will be involved in TeNDER piloting according to the description above and work performed in WP2 and WP1.

#### **2.1.1 Patients**

A total of 19 patients were included in the interviews for TeNDER User Requirements before piloting. Interviews took place in October 2020 - December 2020 in Germany, Italy, Slovenia and Spain.

Most participants were aged 61-80 years (age 71-80: n=8, 42%, and age 61-70: n=7, 31%), one was aged under 60 years (n=1, 5%) and three above 81 years (n=3, 16%). Most of the patients interviewed were female (n=12, 63%). The participants were representative of people with Alzheimer's disease or other form of dementia (n=13, 68%), Parkinson's disease (n= 4, 21%), and cardiovascular disease (n=2, 11%).

Most participants are living in a house (n=12, 63%), and receive care from family members (n= 11, 58%). Furthermore, some participants live alone (n=8, 42%) and receive care from either family member that is visiting them or from a hired person.

In most cases patients are already using phones (n=16, 84%), some are also using PCs or tablets (n=8, 42%). Only a few have already used smartwatches and similar devices.

The analysis of the interviews generated three themes:

1. general view on TeNDER system from a patient perspective;
2. opinion on TeNDER functionality offered;
3. preferences and main concerns.

The outcomes of the interviews can be summarized as follows:

Most of the patients don't feel the need to use new technology, but some would try if someone would help. According to their opinions, the functionalities of an intelligent monitoring system are not very useful for them (except for the sleep monitoring and personal calendar with notifications).

Most of the patients see themselves in a stage of the disease, that functions presented are not of great usability for them, but may help other patients and/or patients that are at later stages of the disease. The patients also mention that it would be important that the system does not immediately act but gives the patient time to act him/herself. They said that the system should be simple, with an appealing design, and some proposed large buttons. Moreover, according to patients' opinion, the system should not be intrusive and only report/notify the user if required.

Some patients also expressed the uneasiness that the increase of their independence would lead to decreased face-to face contact with caregivers. Finally, most of the patients expressed that they don't want to be tracked continuously.

### 2.1.2 Caregivers

A total of 24 caregivers took part in the interviews for TeNDER User Requirements before piloting. Interviews took place in October 2020 – December 2020 in Germany, Italy, Slovenia and Spain.

Most participants were female (n=18, 75%) and aged 61-70 years (n=8, 33%). Most participants are taking care of a person aged above 70 years: most are taking care of a person that is 71-80 years old (n=11, 46%), and also of a person that is 81-90 years old (n=7, 29%). Some of the caregivers were from working population: one (n=1, 4%) was aged below 40ies, four (n=4, 17%) representatives were from population aged 41-50.

The participants were representative of caregivers that are taking care of a person with Alzheimer's disease or other form of dementia (n=19, 79%), Parkinson's disease (n= 3, 13%), and cardiovascular disease (n=2, 8%).

Most of the caregivers involved in the interviews are living with a patient. In most cases, caregivers are already using phones, some are also using PCs or tablets.

The analysis of interviews generated four themes:

1. technical affinity;
2. kind of support that would be required;
3. opinion on usefulness of TeNDER functionalities offered;
4. suggestions for the system.

We have found that there are different opinions on different functionalities presented by countries (Germany, Italy, Slovenia, Spain). Most carers accept the technologies that were presented, but some expressed concerns about how caretakers will accept it. They mentioned that technological devices and their interfaces need to be simple with big buttons/fonts/screens. Moreover, technological devices should be adapted to the needs of elder patients with diseases (current solutions are often developed mainly for healthy people). Some carers expressed concerns about the financial perspective, as that the system will be developed only for a small group of people in societies that can afford it.

Most carers agreed that the functions for location tracking, personal calendar, and sleep analyser are useful. For health tracking, there were different opinions: a positive attitude was sensed in Germany, Spain and Slovenia; especially from the caregivers that are taking care of patients with co-morbidities. For the safety functions at home, a positive attitude was sensed among participants in Germany and Italy. The safety functions were well recognized for later stages of the disease and for caretakers that are left alone for most of the day also in Slovenia. For emotional status there were also different opinions, positive attitude was sensed only from some carers form Germany and most of the participants were indifferent on this topic. In Spain, there is a certain level of rejection concerning those functions that could replace the work of carers, such as calendars and the intelligent pillboxes.

### 2.1.3 Professionals

A total of 18 professionals were included in the interviews for TeNDER User Requirements before piloting. Interviews took place in the period October 2020 – December 2020 in Germany, Italy, Slovenia and Spain.

Most participants were female (n=13, 73%) and from different fields of work: psychotherapists, social workers, general practitioners, nurses, psychologists, scientists, neurologists. All professionals are already using different technology: phones, PCs or tablets, also smart watches.

The analysis of interviews generated three themes:

1. use of technologies;
2. opinion on usefulness of TeNDER functionalities offered;
3. what the system should have to be useful and expressed concerns.

According to the professionals that were interviewed, technologies would be useful in professional practices in order to have better data and work management. Technologies would be very useful for patients as well (especially in order to improve the autonomy or the management of daily activities), but they should be simple to use. All functionalities of were well accepted and found useful.

Some professionals claimed that digital measurement devices enable more precise measurement and the collection of more data, which also enables better and easier comparisons. They find communication tool for themselves useful and recognize that online platforms enable better coordination and communication. Professionals find that digital solutions also offer the possibility to better show the user his/her performance in certain tasks, which may increase patient`s motivation. However, they said that technological devices are often complicated, which might be especially difficult for older patients with diseases, thus they emphasized the importance of simple and easy-to-use solutions.

In concrete, the summarisation of recommendations from the co-design are highlighted in the Table 2 below.

*Table 2: The outcomes of the user-requirements co-design process*

No	Recommendation	Why?	Target user
1	Simplicity of interfaces/functionality	The system has to be easy to be used by patients that are not digitally active.	All, especially “patients”. Only 18% of the total are familiar with technology.
2	Interface fonts	Patients might have problems to read/find a functionality.	Patients, elder carers
3	Interface functions	Simple screens, with few components per layout.	Patients, elder carers
4	Customisation	Not all the functionalities are useful to all the users.	Patients, elder carers, some professionals

No	Recommendation	Why?	Target user
5	Data Access	Not all the roles want/can access patients' data.	Professionals
6	Frequency of reports	Customisation might be enabled.	All users
7	Structure of the alerts	Carers shall have priority view/notification on urgent alerts.	Carers
8	Structure of the reminders	To distinguish more important/vital reminders from others.	Patients
9	Feedbacks from the reminders	Carers shall have feedback if the action has (not) been taken by a patient.	Patients, Carers
10	Performance to be shown	To encourage and increase motivation.	Patients
11	Real time activity tracking	Enabling the proper performance with exercises, assuring safety and security	All
12	Accuracy of the functions	To avoid wrong impression and misinterpretation of the reports.	All
13	Multimodal tool for the alerts (voice, text message, e-mail)	To allow broader usage according to the need and technology acceptance.	All
14	Modularity of the system	The progression of the diseases may cause different needs.	Patients, carers
15	Affordability	The system shall be designed in a way the community can afford and benefit from it	All

## 2.2 End users survey

### 2.2.1 Patients

A total of 73 patients were included in the survey for TeNDER User Requirements before piloting. Surveys were circulated and performed in October 2020 - January 2021 in Germany, Italy, Slovenia and Spain. Herein we present the general description of the whole group.

Most participants were aged 71-80 (42,5%), 61-70 (37%) and represented both gender (males 52%, females 48%). The participants were representative of people with Alzheimer's disease or other form of dementia (56,5%), Parkinson's disease (26%), and cardiovascular disease (11%). Nearly half of the participants (49%) reported other chronic diseases (Figure 1).

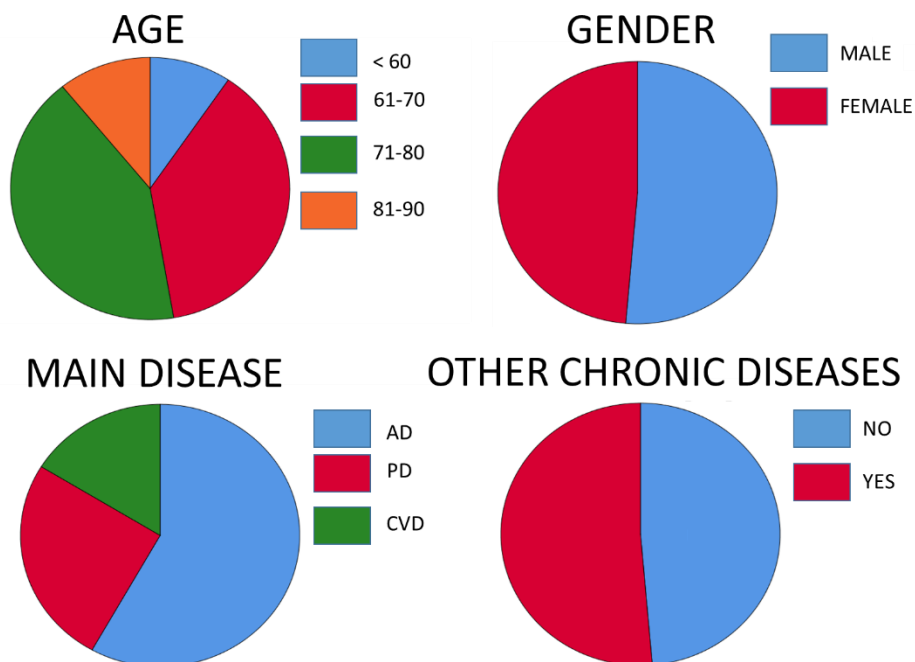


Figure 1: Distribution of age, gender, main disease and other chronic diseases among participants (patient group)

Among the education of patients that participate in surveys, vocational training (26,39%) or university education (25%) were most frequent. However, 31.94% of respondents choose the "other" option. Most of participants responded that they live in urban areas (64,9%) and less than 2% responded that they live in remote countryside. The participants responded that they live mainly in a house (52%) or in an apartment (45,21%).

Most participant answered that they do not spend part of the day in another location (68,1%), 15,28% replied that they are visiting day-care centres, 8,33% responded that they are spending the day also at their relative's residence. Only 2,78% of participants answered that they spend part of the day at the rehabilitation room (Figure 2).

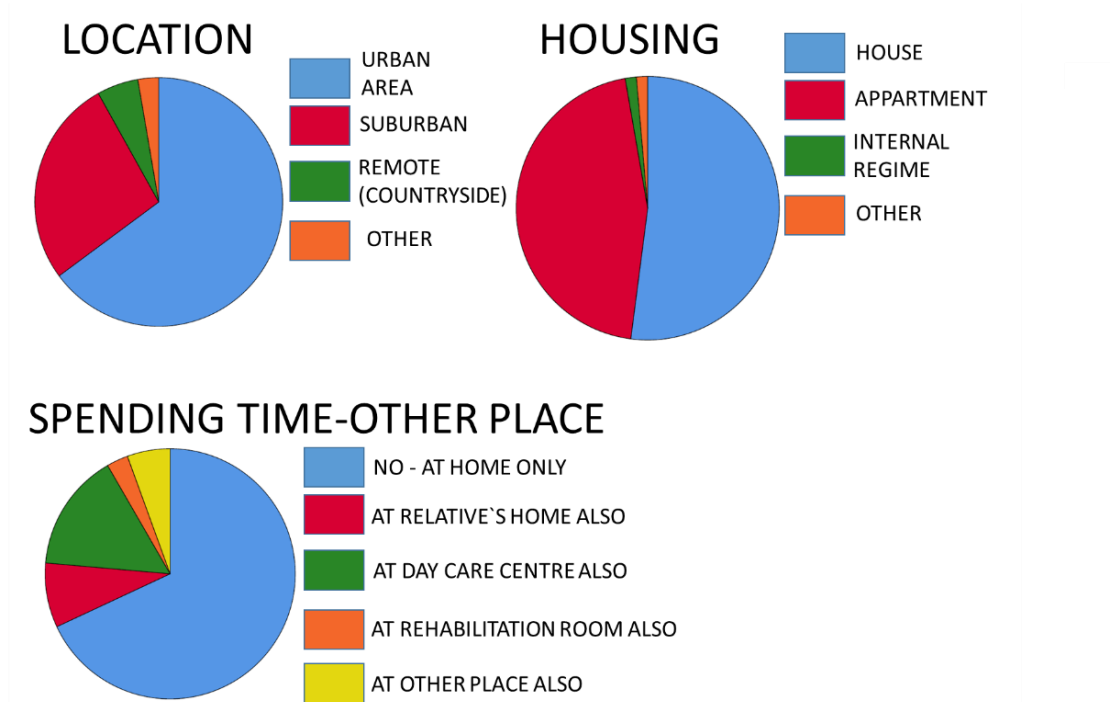


Figure 2: The living environment of the patients

Most of the participants answered that they are living together with a partner that is their carer (58%). Some answered that they are receiving care from other family members (child, other relative) and 24% patients replied that they are living alone (Figure 3). Most of the patients that live with AD receive cared from a person that lives with them or by partner, and only the minority of them are relying on the community or hired care (Figure 3).

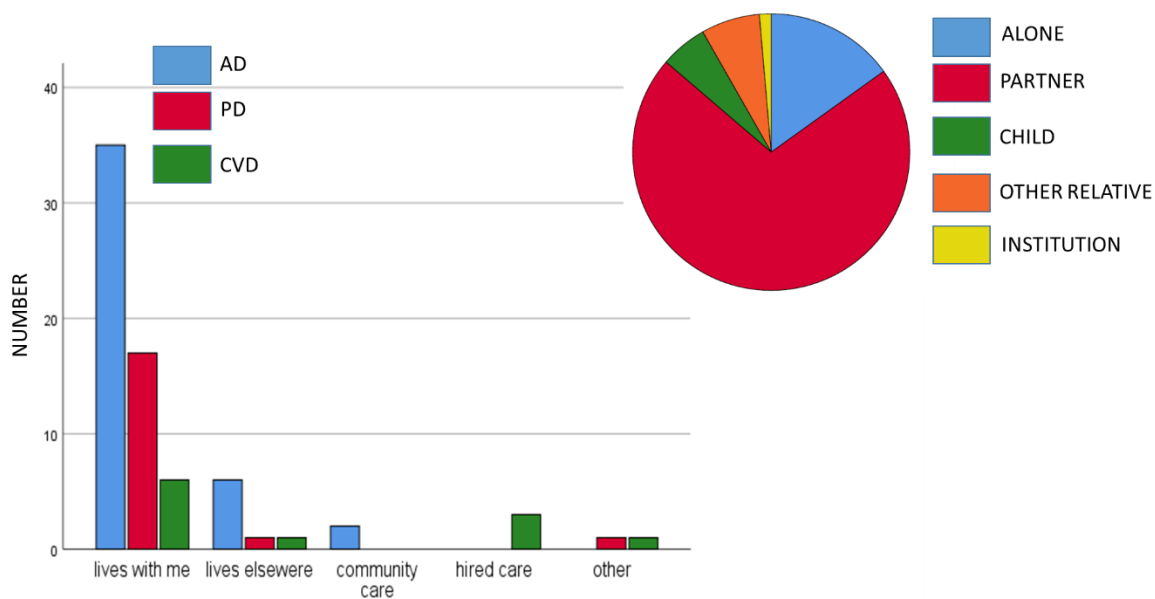


Figure 3: Care received - patient's perspective

Patients expressed that the most support is needed for housework, some is needed also for dressing. However, most of the patient perceive themselves not being in need for much support, only with people living with AD the support for house work is more evident to be needed (Figure 4).

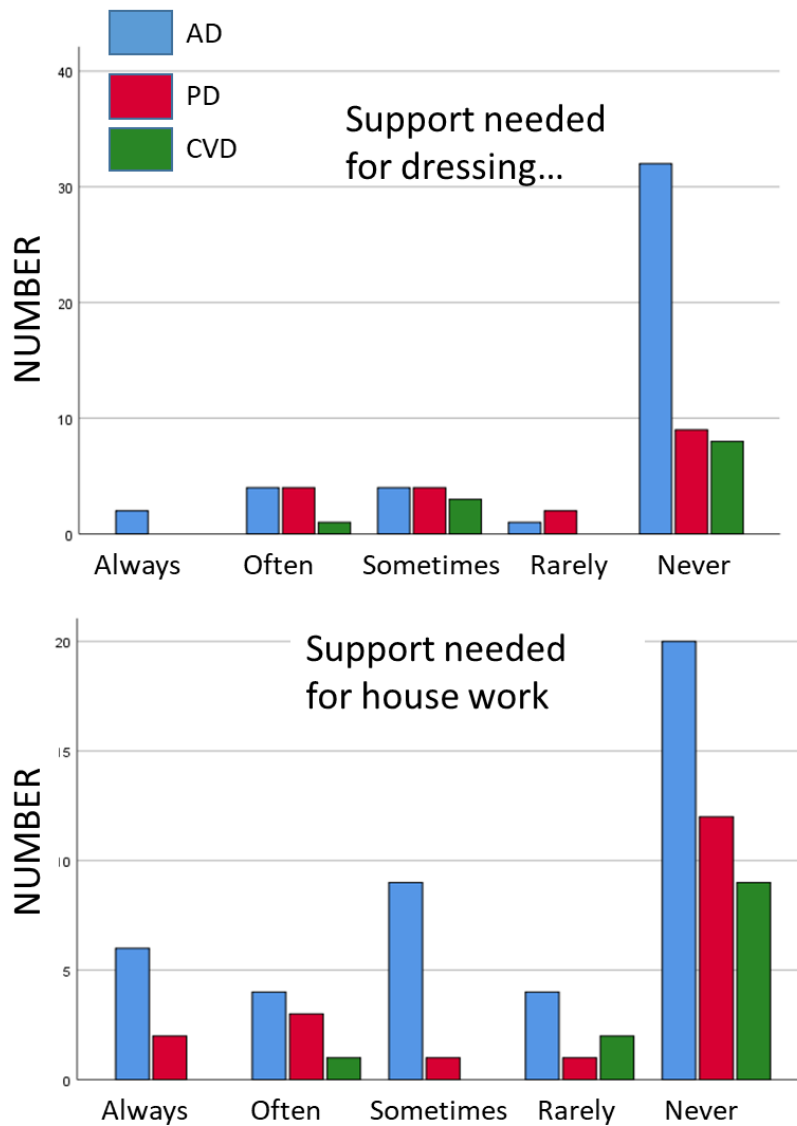


Figure 4: Support needed on daily activity- patient's perspective

Among the patients that were responding to surveys, 18% responded that are always using smartphone and only ~10% answered to always use also tablet, computer and/or internet. Only a few participants reacted that they are familiar with smart bracelet, as 89% of patients responded that never have used it (Figure 5). Moreover, ~30% of patients answered that they are rarely using computer, internet or e-mail and less than a half reported that they are using digital calendar (Figure 5).

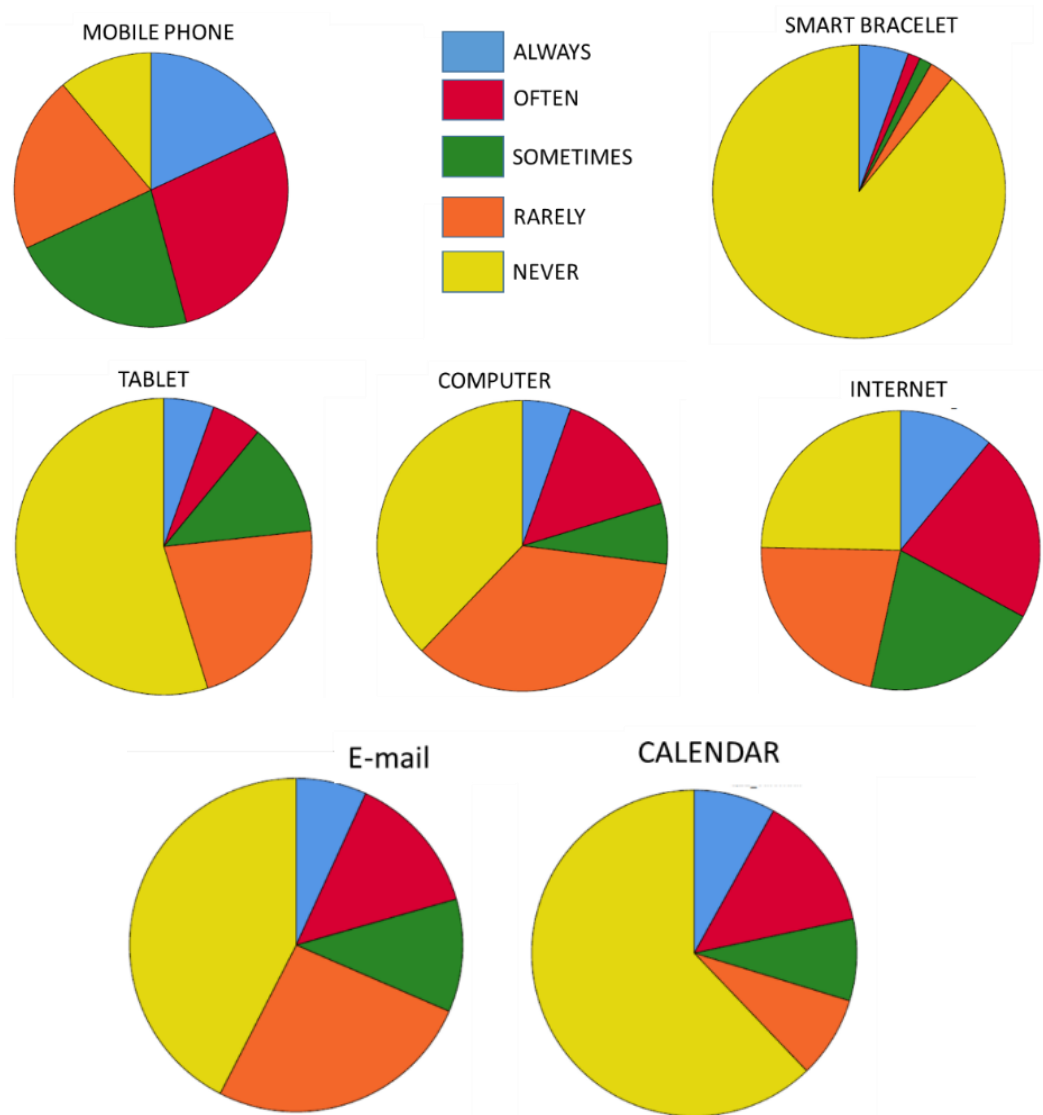


Figure 5: Acceptance of proposed technology by patients

However, more than 75% respondents would try to use new technology, as 36,5% of them clearly stated so, 14,29% would be happy to learn and 25,40% perceived that they would have difficulties in learning (Figure 6). More details on each functionality can be seen on Figure 8 where the acceptance for each solution is presented. As seen in Figure 9, most of the patients would not prefer to have the control of the system on their own, but more than 50% also would not prefer to receive help in using the system from others and would not prefer that others can access the reports about them (Figure 9).



## WOULD YOU TRY...?

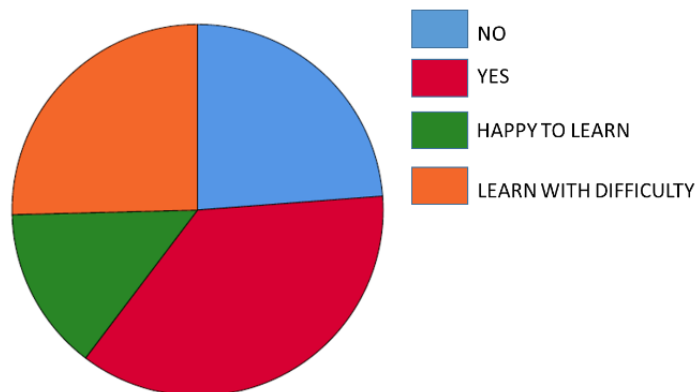


Figure 6: Acceptance and readiness to learn by patients

When looking into the technology acceptance and perception for the usefulness of the proposed functionalities, patients responded that they find location and activity monitoring very useful (26,7%) to useful (43,3%), also for tracking their physical activity (very useful 46% and useful 33,3%). Furthermore, they find calendar with notifications very useful (38,71%) to useful (29,03%). The same applies to medical reminders: 37% of patients responded to find it very useful and 27,42% of them find it useful. Moreover, for the sleep tracking and analysing participants answered that they find it very useful (33,3%) to useful (31,75%). However, patients recruited in survey were more reserved about the toilet usage: 10% were indifferent, 43,3% expressed that it is not really useful and 23,33% answered that is absolutely not useful to them (Figure 7).

Regarding functionalities for safety and wellbeing, participants answered that they find the door status alerts very useful (23,44%) to useful (35,9%) (Figure 7).

We have found that the patients were indifferent for the emotional status detection functionality in 29,23%. However, some responded to find it very useful (12,3%) to useful (20%). For 26,15% of included patients the emotional status detection functionality was not useful and 12,31% of them responded as this is absolutely not useful (Figure 7).

Participants expressed that they would prefer to get notifications from the system as a combination of voice, e-mail and text message (41,43%), only 7,32% responded that they would use solely e-mail (Figure 10). Most participants would not prefer that the doctor would have his /her own access to the reports (46,15% no and 20,5% maybe) and the same applied for their caregivers (54,17% answered as no and 12,5% as maybe).

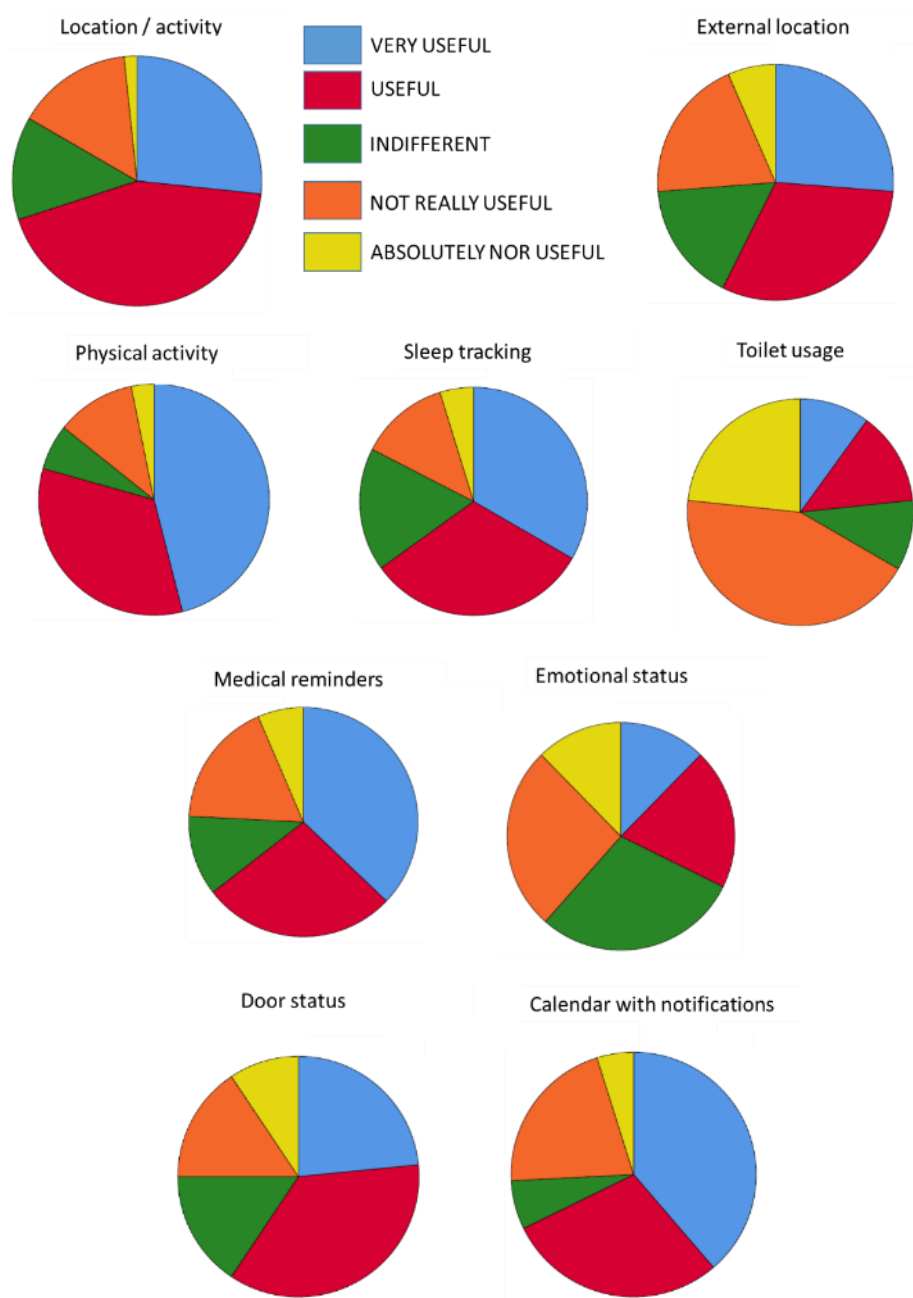


Figure 7: Usability perception of proposed functionalities - patient's perspective

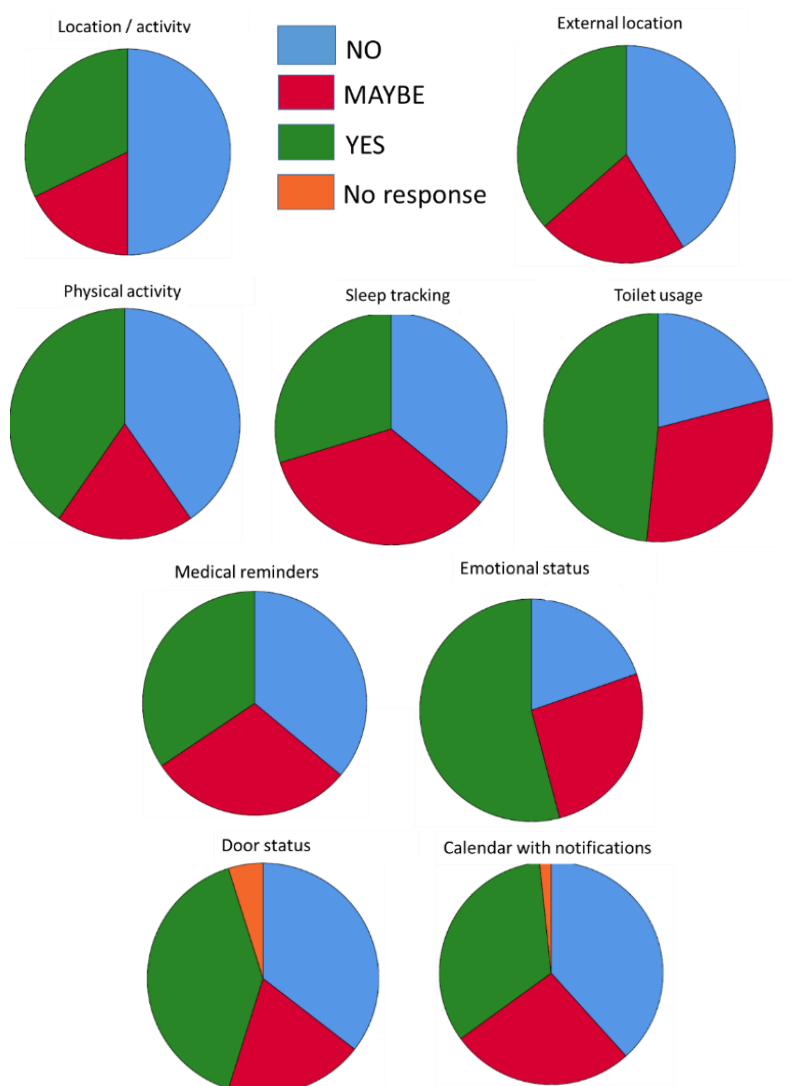


Figure 8: Acceptance of proposed solutions (Would try?) by patients

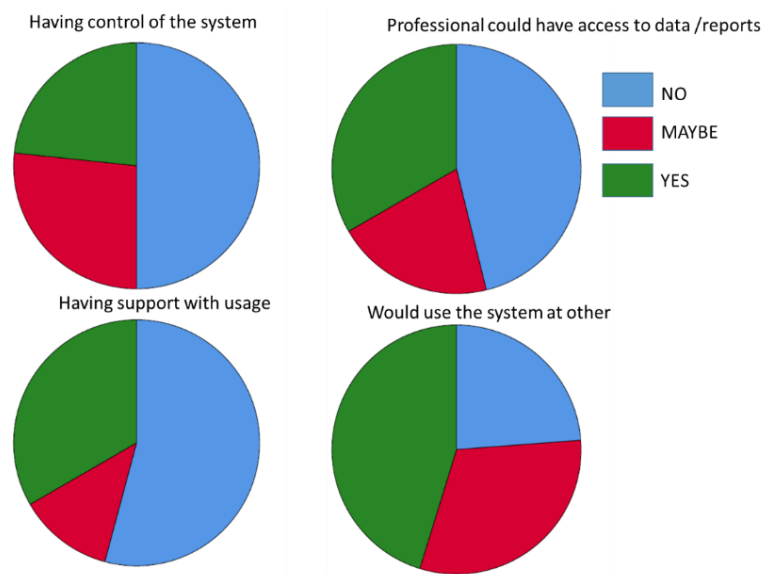


Figure 9: Who could access the data of the patient in TeNDER – patient's perspective

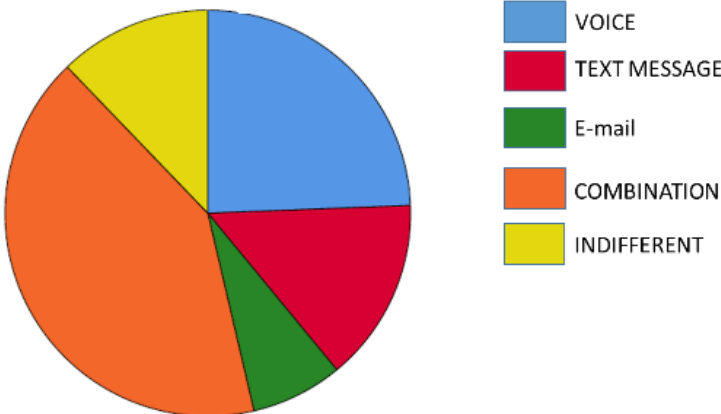


Figure 10: Communication tool for notifications preferred by patients

## 2.2.2 Caregivers

A total of 75 caregivers took part in the survey for TeNDER User Requirements before piloting. Surveys were circulated and performed in October 2020 - January 2021 in Germany, Italy, Slovenia and Spain. Herein we present the general description of the whole group.

Most participants were female (77,3%) and aged 61-70 (32%), 51-60 (22,7%) (Figure 11). Most of them are taking care of a person aged 71-90 years (Figure 11). More than a half of the caregivers had university education (54,7%) (Figure 11). The participants were representatives of caregivers that are taking care of a person with Alzheimer's disease or other form of dementia (62,7%), Parkinson's disease (29%), and cardiovascular disease (5,3%). More than a half of caregivers reported that their caretakers are also having other chronic diseases (62,3%). The stages of disease were reported as mild in 24%, moderate in 41% and 35% in advanced / severe stage (Figure 12). Among the respondents, 61,3% of caregivers stated that they are living together with a caretaker (Figure 12). The caregivers responded that the caretakers are mostly living in an apartment or flat (56,8%), on the 1<sup>st</sup> floor (51,4%) and are having elevator (57,6%), and 35% of them responded that their caretaker lives in a house (Figure 13) and having a patio or garden (67, 6%) (Figure 13).

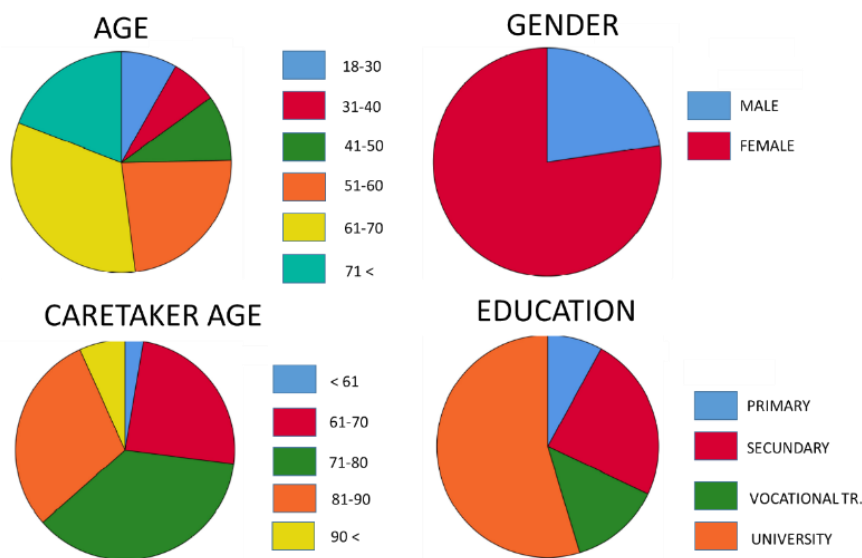


Figure 11: Age, Education and gender characteristics of caregivers

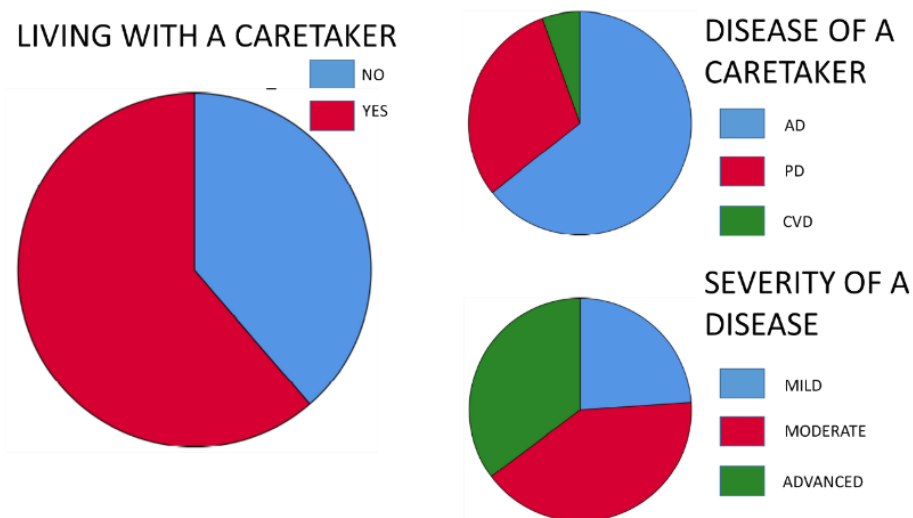


Figure 12: Disease of a patient and whether a caregiver is living with a patient

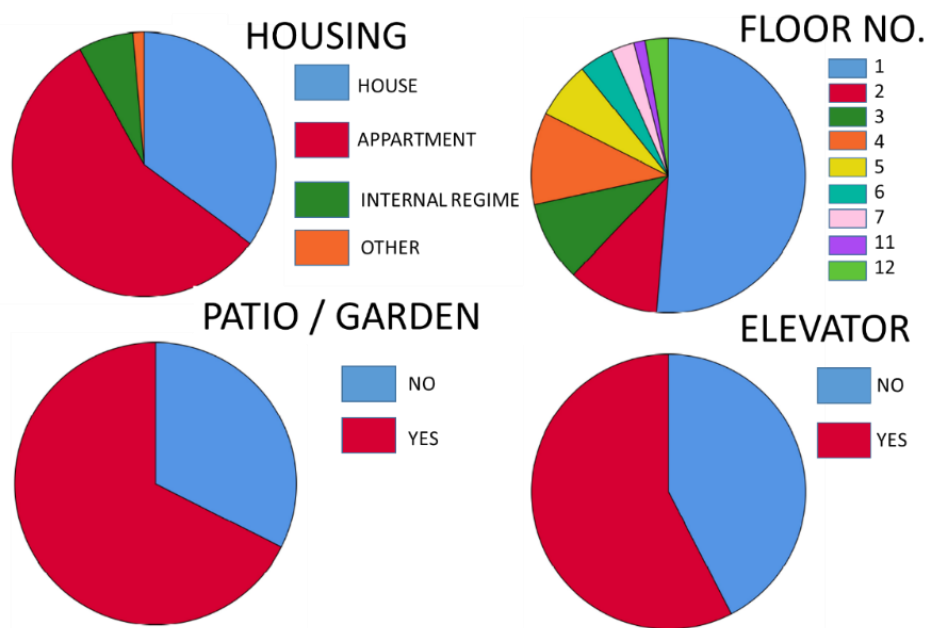


Figure 13: Characteristics of living environment of a patient (caregiver's)

The caregivers answered that the care needed is provided for 24/h day in 34% cases, and more than 3h/day in 18,8% cases (Figure 14). The care that is needed for less represented 47% of responses (less than 3h /day in 15,5%, at weekends in 5,6%, only when needed in 18,3% and irregular in 8% of responses). Caretakers reported that the care need is often as a support in self-care of a patient (20,5%). Some caregivers (19%) replied that they never need to support their caretaker at self-care. They also reported that rarely (24,3%) or never (45,9%) is care needed with eating and similar but is always (in 54,2%) or often (27%) needed at household work (Figure 14).

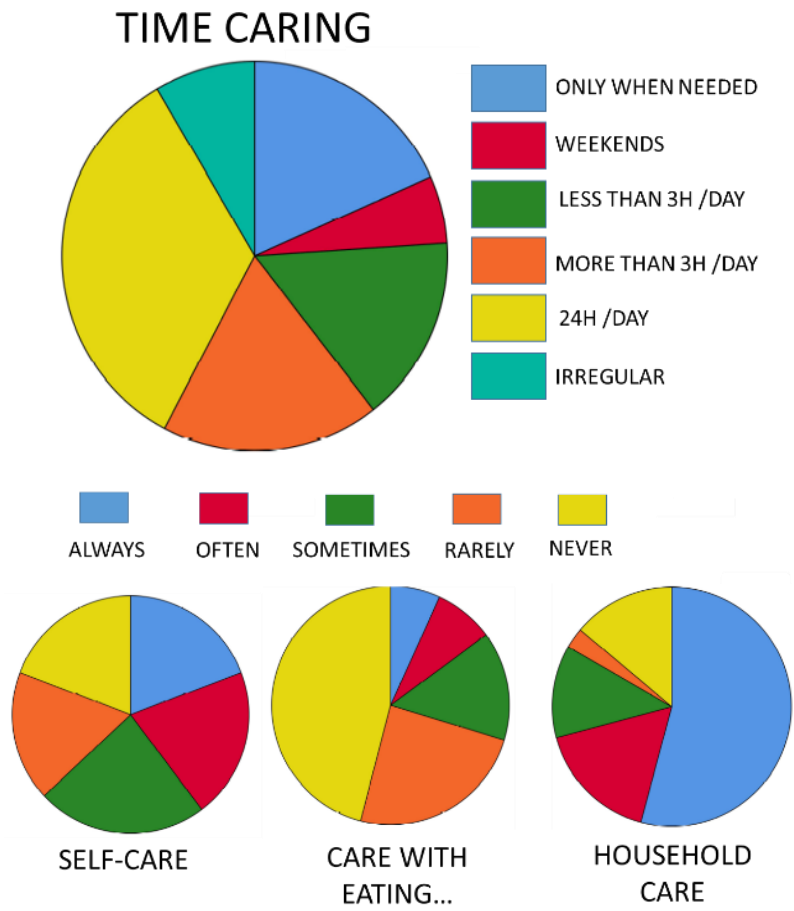


Figure 14: Care characteristics of a patient (caregiver's perspective)

Regarding the technology usage and acceptance, the respondents answered to use the mobile phone every day in 82%. Near 10% of caregivers answered that they are using smart bracelet or activity tacker and 87% of caregivers answered that they don't use an activity tracker (Figure 15). Moreover, 50% of respondents stated that they are not using tablet. Among those caregivers that are using tablet, 22% are using it on a daily basis and 18% on a weekly basis (Figure 16). More than a half of caregivers reported that they are using computer frequently (54% on a daily basis, 18% a few days per week and 10% once per week). Caregivers replied that they are also using internet (60% daily, 18% a few days per week, 6% once per week), but 11% of caregivers reported not to use it at all. Also, the caregivers answered that they use the calendar function in 38,6% every day, 16% use it a few days per week, but also 27% responded not to use the calendar function at all. More than a half (59%) caregivers answered that they are using e-mail on a daily basis, 16% use it a few days per week. However, 14% of caregivers reported that they are not using e-mail at all (Figure 16).

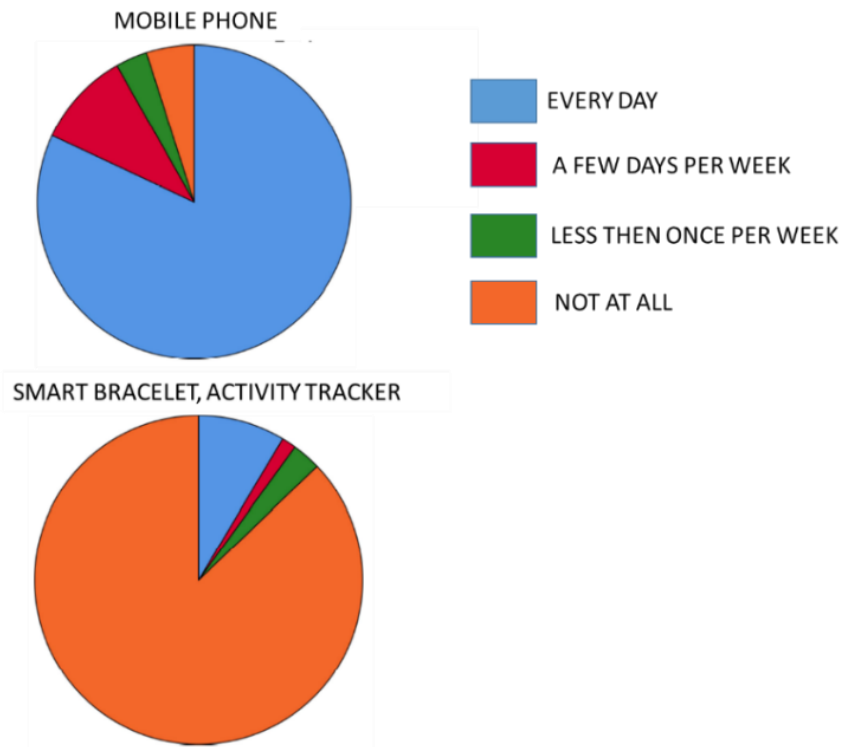


Figure 15. Usage of mobile phones and activity trackers/smart bracelets by caregivers

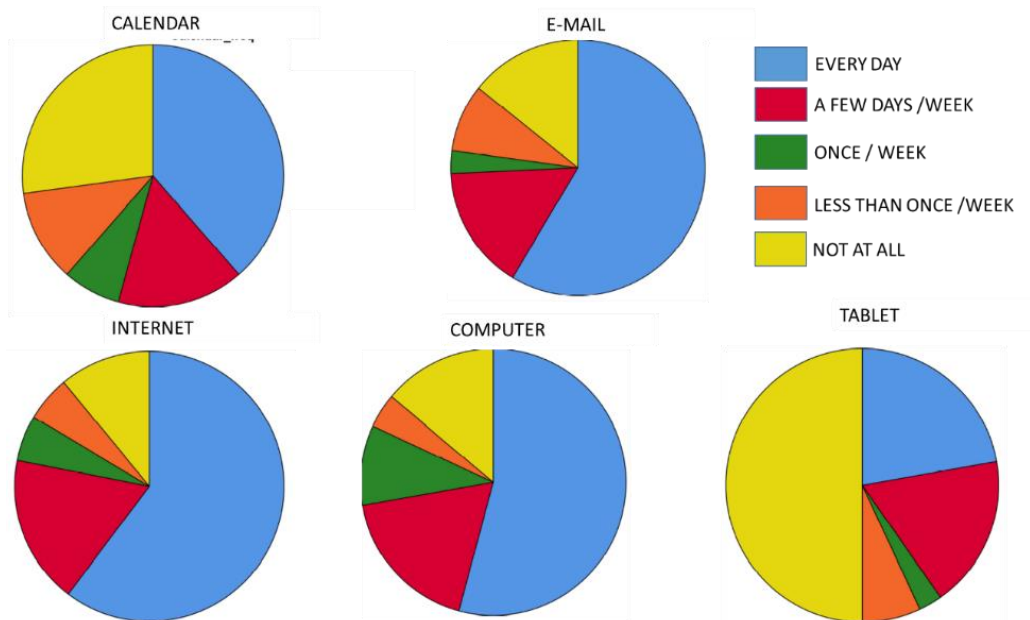


Figure 16: Usage of ICT tools by caregivers



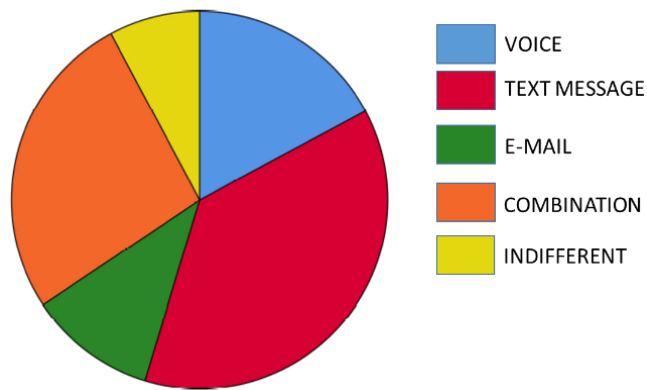


Figure 17. Communication tool for the notifications preferred by caregivers

Caregivers reported to prefer to use voice notification (17,2%), text messages (37,5%), via e-mail (11%) or the combination (27%). Among the respondents 7,3% were indifferent on how to use the notification system (Figure 17).

### 2.2.3 Professionals

A total of 49 professionals were included in the survey for TeNDER User Requirements before piloting. Surveys were circulated and performed in October 2020 - January 2021 in Germany, Italy, Slovenia and Spain.

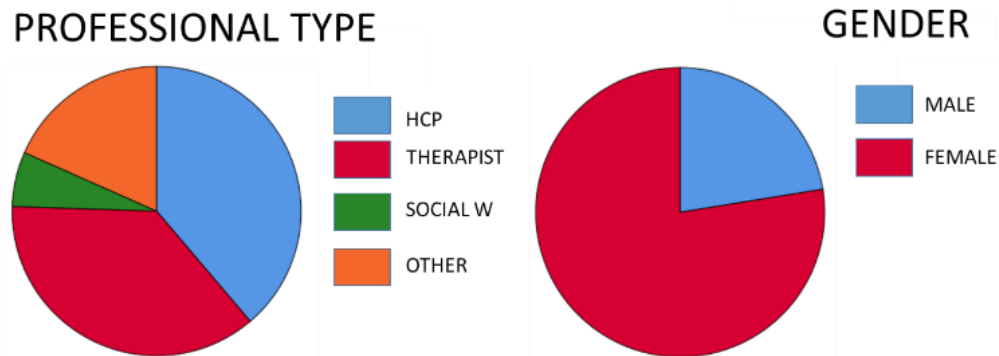


Figure 18: Type of profession and gender

Most participants were females (77,6%) and from different fields of work: 40% from health-related profession, 36% as therapists, 6% social worker and 18% participants belong to other professions (Figure 18). Most professionals (~ 95%) answered that they are using mobile phone, e-mail and internet on daily basis (Figure 19), ~ 47% of them also replied that they are familiar with activity trackers and smart bands. However, 43% of them reported not to use the tablet at all (Figure 19).

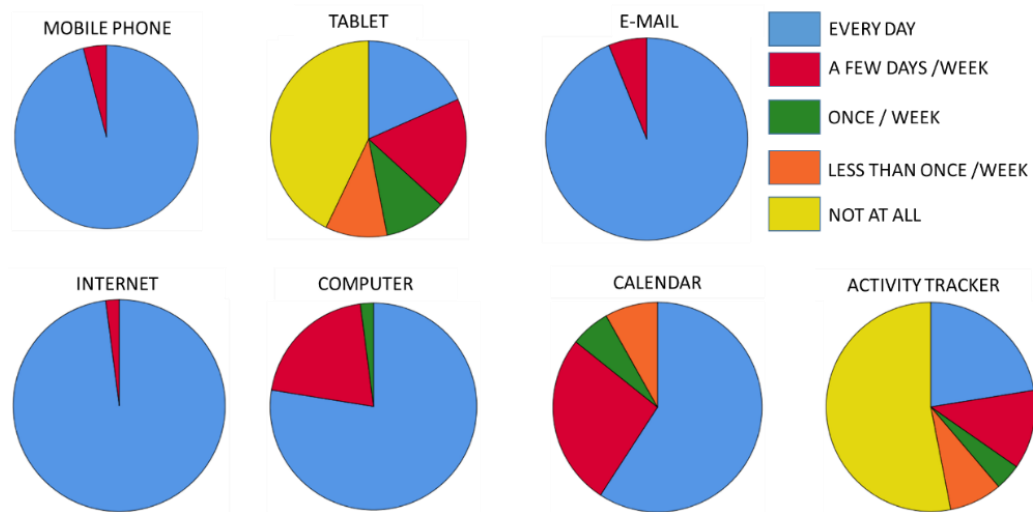


Figure 19: Use of ICT tools and technology form professionals

All the professionals that responded to the survey find technology tools to be useful for patients (very useful 46%, useful 54%) and that the Information & Communications Technology tools can be applied to all types of diseases (to be used by people living with AD, people living with PD, people living with CVD) (Figure 20).

From professionals` perspective the activity and location functionality can be useful (very useful 39%, useful 55%) and can be mostly applied to patients with AD and PD (Figure 21). Regarding the tracking of the external location functionality professionals expressed that it

can be useful (very useful 69%, useful 30%) and can be mostly applied to patients with AD and PD, less for CVD (Figure 21). The physical condition monitoring and activity functionality was answered to be well accepted by professionals as they expressed it can be useful (very useful 44%, useful 48%) and can be applied to all patients, the best proposal was for patients with CVD (Figure 22).

Moreover, the sleep quality functionality was answered that it can also be useful (very useful 37%, useful 53%) and to be mostly applied to patients with AD and PD (Figure 24). However, professionals responded that the toilet usage functionality may be useful (very useful 17%, useful 35%), 17% of them replied that it is not useful, and 31% of professionals were indifferent for this functionality. Toilet usage functionality is showing the divided views and in none of the disease seems to be very applicable (Figure 25). From professionals` perspective the medication regime functionality is reported to be useful (very useful 57%, useful 43%), and to be applied for all type of diseases (Figure 26).

The safety at home functionality is also well perceived by professionals according to their answers, as they expressed it can be useful (very useful 52%, useful 40%). However, some professionals were indifferent (6%) or expressed that it is not useful (2%). According to their answers, it can be mostly applied for patients with AD, also PD (Figure 27). Finally, professionals answered that emotional status recognition functionality can be useful (very useful 19%, useful 50%), some were indifferent (17%) or answered that it is not useful (14%). he professionals answered that it may be applied for patients with AD (75%), PD (60%), also CVD (38%) (Figure 28).

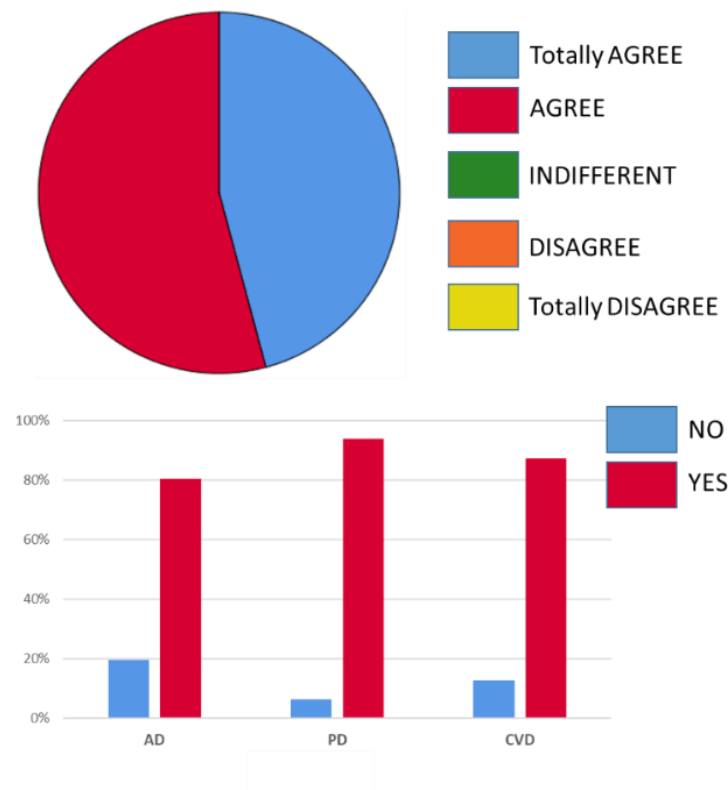


Figure 20: Professionals` perception on usefulness of the technology for patients

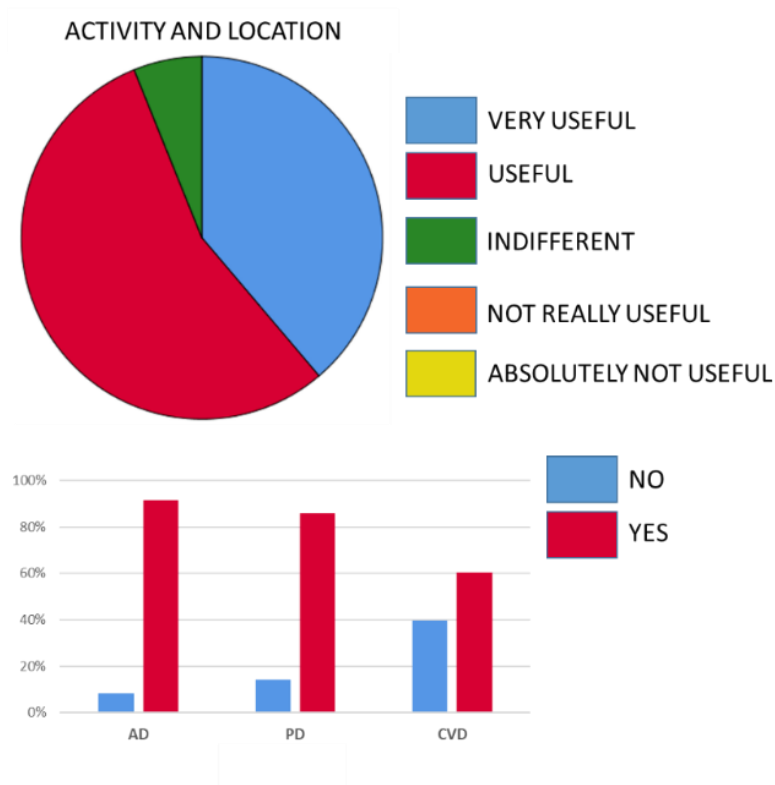


Figure 21: Activity and localization functionality usefulness (professional's perspective)

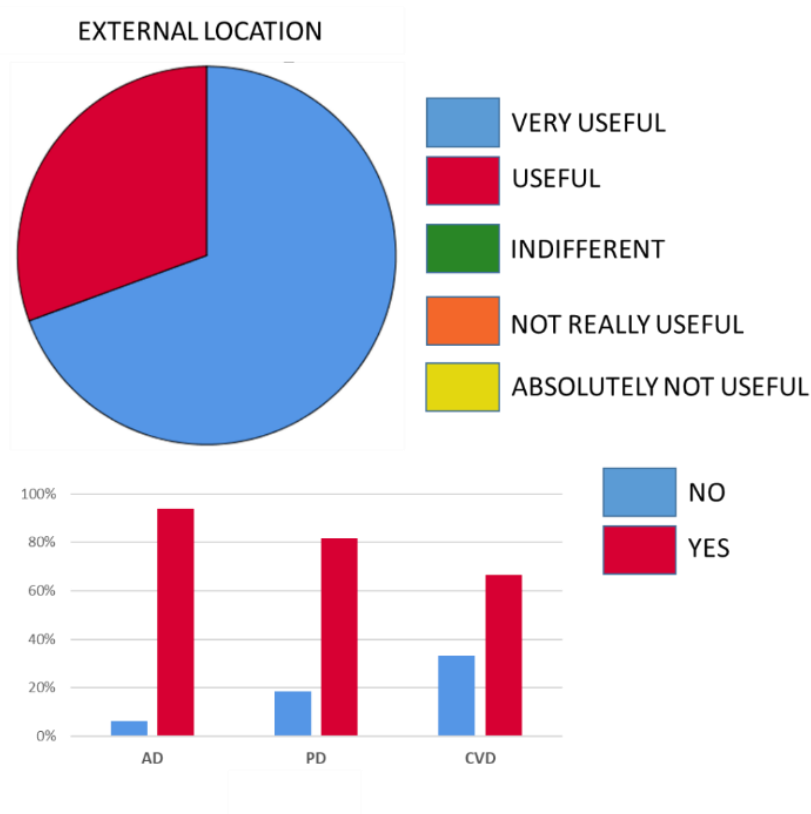


Figure 22: External location functionality usefulness (professional's perspective)

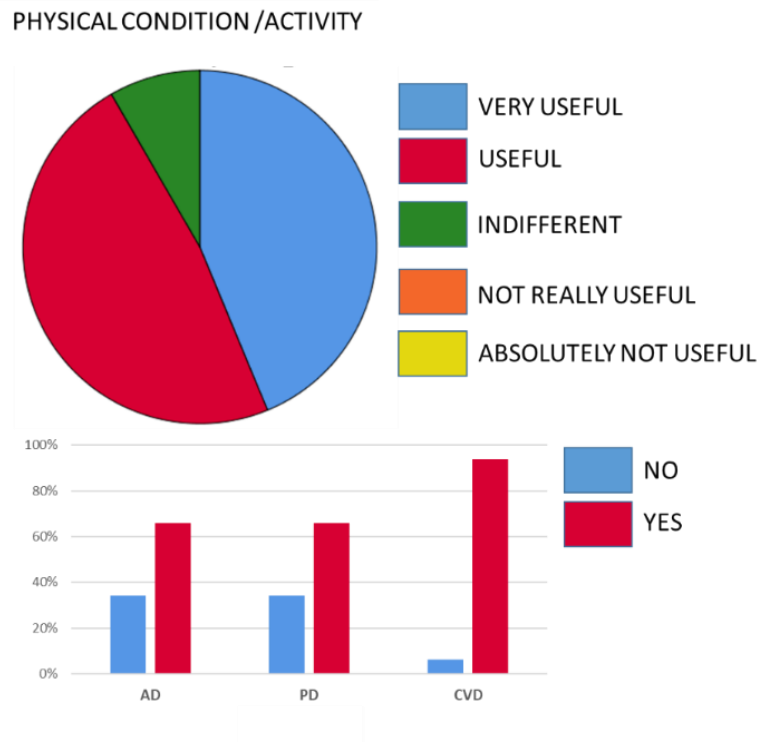


Figure 23: Physical condition/activity functionality usefulness (professional's perspective)

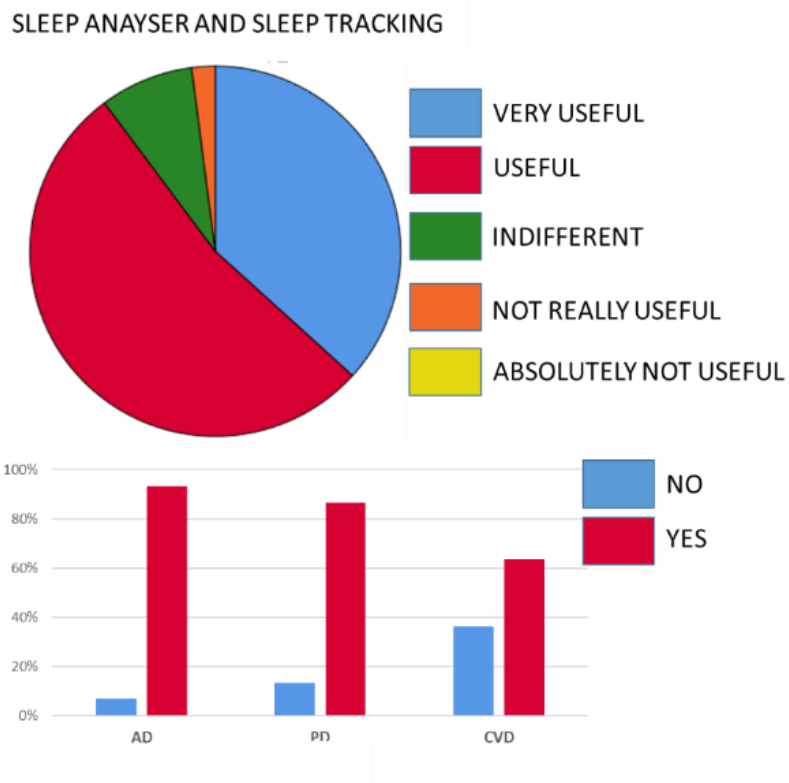


Figure 24: Sleep tracking and analysing functionality usefulness (professional's perspective)

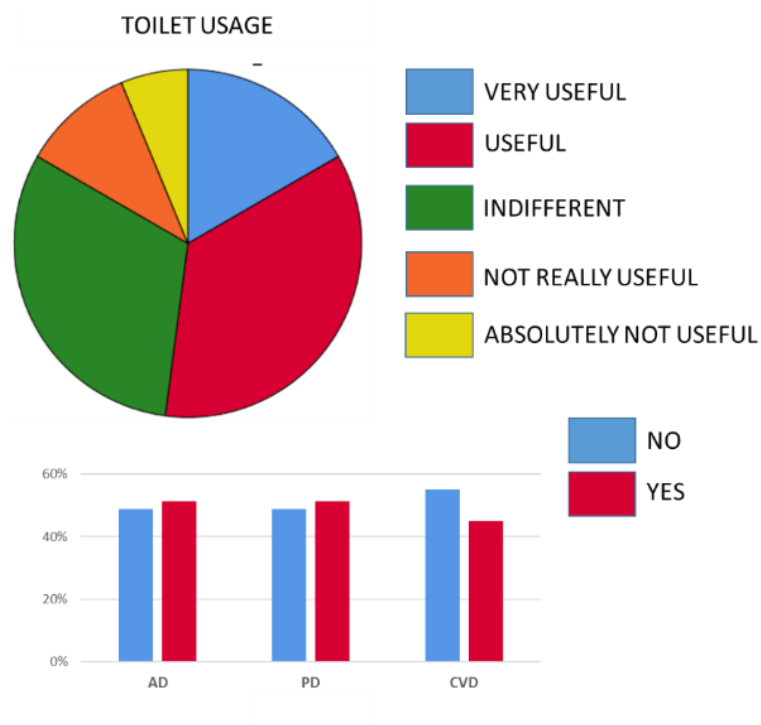


Figure 25: Toilet usage functionality usefulness (professional's perspective)

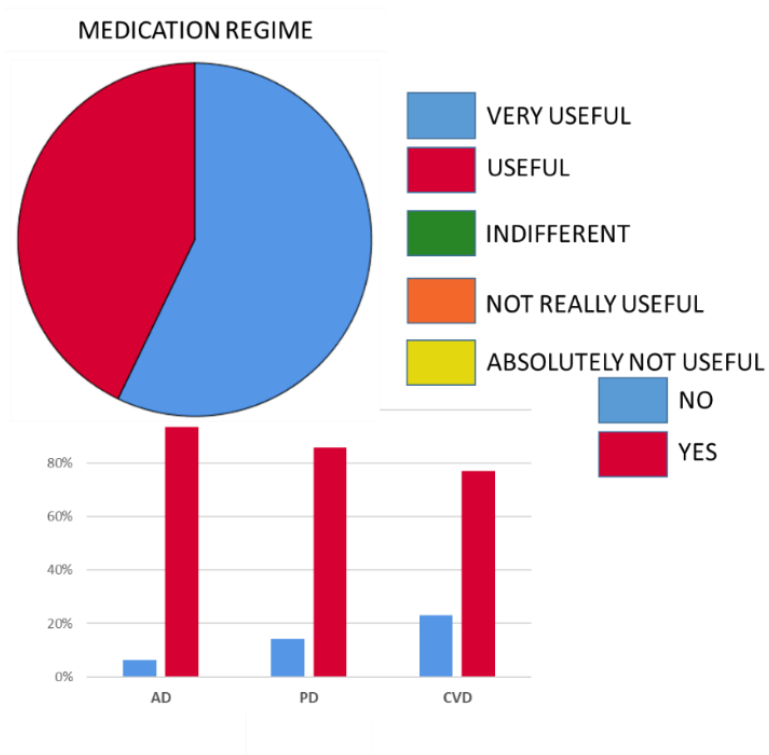


Figure 26: Medication regime functionality usefulness (professional's perspective)

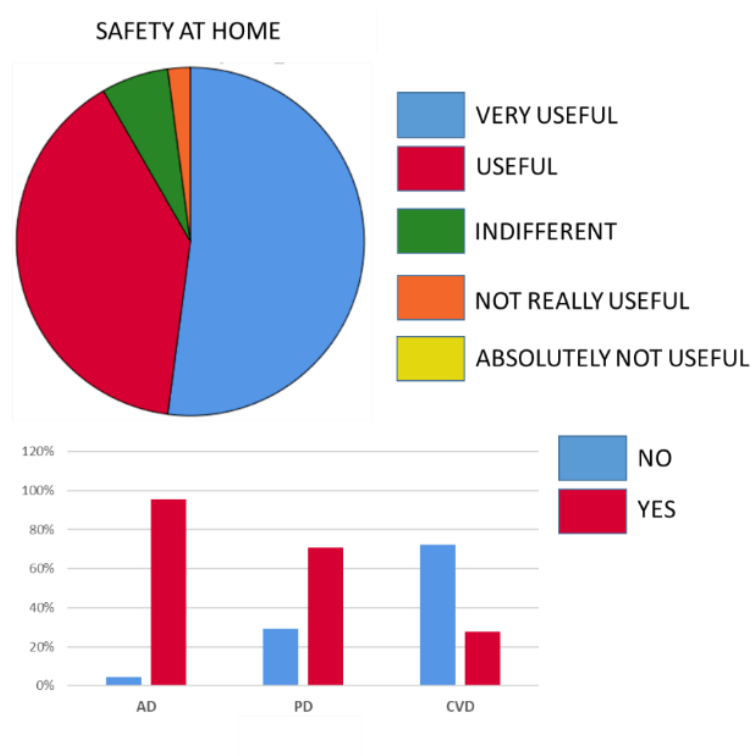


Figure 27: Safety at home functionality usefulness (professional's perspective)

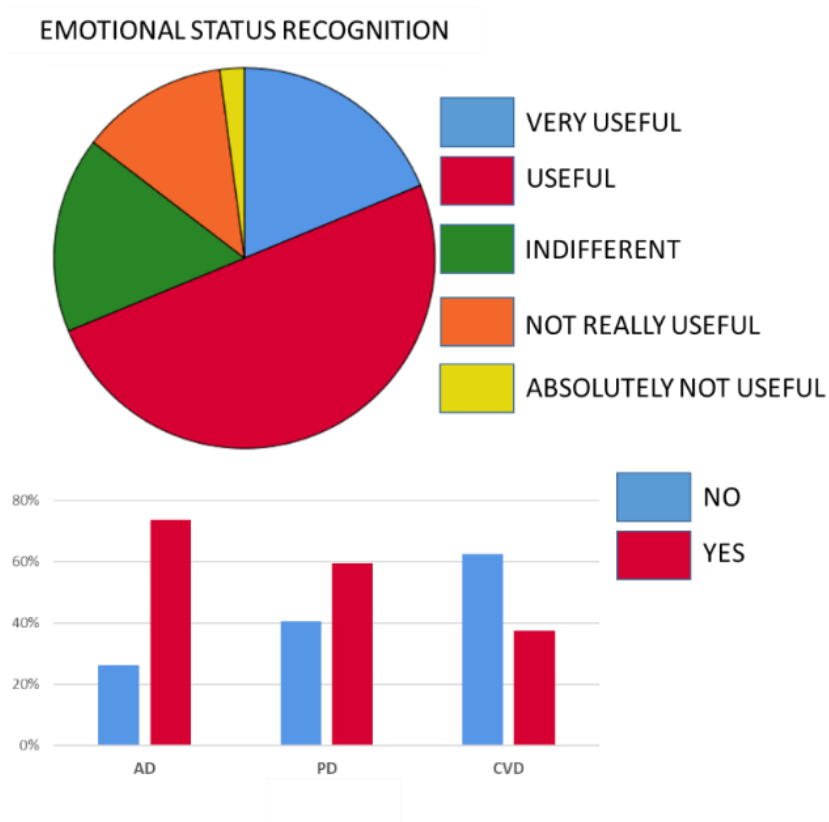


Figure 28: Emotional status recognition functionality usefulness (professional's perspective)

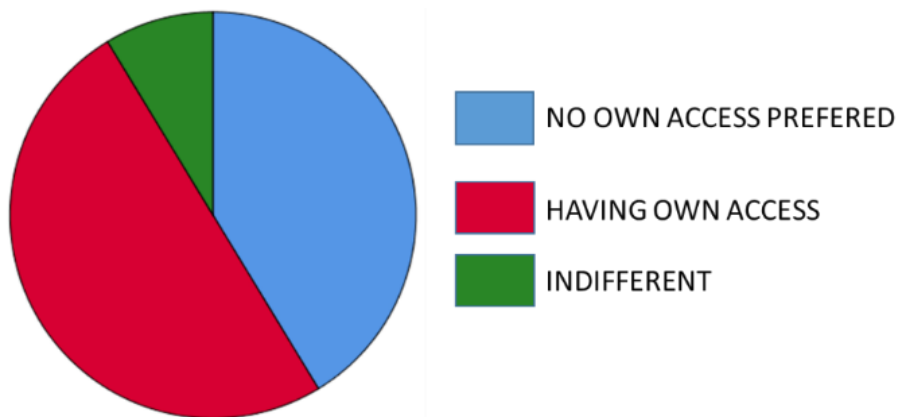


Figure 29: Access to the reports/alerts preferred by professionals

Professionals answered show that they are divided according their wishes to have the access to the reports and notifications on their own: 50% replied that they would prefer to have the access, 41% would prefer that a caregiver or a patient would bring the report (or show) and they discuss, and 9% professionals answered that they are indifferent about having the access (Figure 29).



### 3 PERSONA CARDS AND TeNDER SYSTEM REQUIREMENTS

TeNDER Use stories, a technique used to describe the requirements of a digital solution from a user perspective, were presented in Deliverable 2.3. where the proposal of the role that the TeNDER product/service will play was presented based on the expertise of TeNDER partners.

In Deliverable 2.3 Use case stories reflected daily problems faced by person with disease and his / her carers, also support that can be provided form health-care professionals. Use case stories were developed for home scenario, day care centre scenario, rehabilitation room scenario and hospital scenario. TeNDER solutions and services that may be applied were also framed (Deliverable 2.3, Section 2: Real-world scenarios and use cases).

Herein we describe the outcomes from the surveys` and interviews` analysis with people with dementia, people with Parkinson`s disease, people with cardiovascular diseases, their carers and professionals (health professionals, therapists, social workers, other professionals). The observational research was aimed to involve as much participants as possible into the solution development and to test our hypothesis on the solutions (presented as Use stories) that may be of benefit for different users. The outcomes are presented as "Persona cards".

A "Persona" is a fictional representation of an actual user and is applied in the early stages of product development or can be used for a product redesign. Personas are vital to the success of a product because they drive design decisions by taking common user needs and bringing them to the forefront of planning. Personas provide the team insights with a shared understanding of users in terms of goals and capabilities. Personas give also an opportunity to discuss critical features of a redesign when designing an applying the solution. Moreover, they help team members share a consistent understanding of the user group they are addressing. Since Personas focus on the needs of the users, the team can walk through proposed scenarios and determine optimal placement of content to specifically support the goal of the product. Personas provide a "face" to the user story, creating more empathy and understanding about the person using the product: this prevents designers and developers from applying their own mental models to the product design which may not align with actual user needs. Because Personas are fictional representations of actual users, they'll only work if we fully understand who our users are – or will be. The development of personas for TeNDER is based on the data analysis form surveys and interviews as described below. Moreover, partners have enriched the personas also with their expertise and knowledge form working with people with dementia, people with Parkinson`s disease and people suffering with cardiovascular problems, as the sampling with the interviews and surveys happened in challenging times of covid-19 spreading and thus the representation from data gathered lacks some insights due to the sample of people that could be reached.

Therefore, persona cards have been developed using survey results as a statistical basis and post-hoc fine-tuned with the results of interviews and TeNDER user partners' expert knowledge. Pictures of people are informative and accessed from free pixabay.com [54]. Three respondents` groups were analysed: patients, caregivers and professionals. The division is justified by different form and scope of questionnaires filled by those groups.

### 3.1 PATIENT PERSONA CARDS

To help the persona development, a multivariate statistical method for classification was used. Clustering algorithm operates on sets of objects with measurable attributes. In our case Respondents correspond to objects and the answers to questionnaires questions converted to numbers (on nominal or ordinal scale) are object attributes. Due to a large number of attributes, some of them were chosen for clustering:

- health status;
- demographic variables;
- living environment;
- care characteristics;
- technology and device adoption and usage.

In the first step hierarchical clustering was applied to estimate the number of clusters in the survey sample of 74 respondents. Included variables were normalized and standardised to minimize the different scales effects on the clustering. Based on the included attributes, the respondents decided to be grouped into five different clusters.

In the second step we have applied the k-means algorithm for clustering the respondents into different clusters, each of them consisting of respondents with similar characteristics. The list of attributes chosen for analysis is presented in Table 4. All attributes have been assigned arbitrarily chosen weights. The highest weights were assigned to primary disease type (AD, PD, CVD), respondent's gender and age, living environment and care characteristics. Based on the k-means algorithm each respondent was assigned cluster membership (1-5). To determine the persona card characteristics for all measured variables, including TeNDER functionalities acceptance and perceived usefulness, median values for each cluster were used. In the analysis we have discovered the PD respondents sub-sample was highly uniform, therefore we have developed another PD patient person based on our expert knowledge and interviews results. The sub-sample for CVD patients was relatively small (n=7) and we have fine-tuned the persona cards with user partners' expert knowledge and interviews results. The numbers of the Respondents in the particular clusters are shown in Table 3.

*Table 2: Numbers of the Respondents in the particular clusters*

Persona/cluster	P1	P2	P3	P4	P5	P6
Disease	AD	AD	PD	PD	CVD	CVD
Number of Respondents in cluster	15	24	18	expert knowledge	3	4

Table 3: Objects attributes used for Respondents clustering

Variable	Attribute	Range	Weight	Weighted range
Q1	age	1 - 4	5,0	5 - 20
Q2	gender	1 - 2	20,0	20 - 40
Q3	education	1 - 6	1,0	1 - 6
Q4	Where is your home located?	1 - 4	2,0	2 - 8
Q5	What kind of housing do you live in?	1 - 4	1,0	1 - 4
Q6	Do you spend part of your day at another place?	1 - 6	1,0	1 - 6
Q9	Who do you live with?	1 - 5	4,0	4 - 20
Q10	Who helps you?	1 - 5	1,0	1 - 5
Q11	How often do you need the support in self-care?	1 - 5	2,0	2 - 10
Q12	How often do you need the support for eating and drinking?	1 - 5	2,0	2 - 10
Q13	How often do you need the support in household?	1 - 5	2,0	2 - 10
Q14	Do you have any of these health problems?	1 - 4	20,0	20 - 80
Q15	Do you have any other chronic diseases?	1 - 2	5,0	5 - 10
Q16	How often do you use a mobile phone?	1 - 5	1,0	1 - 5
Q17	How often do you wear a smart bracelet or activity tracker?	1 - 5	1,0	1 - 5
Q18	How often do you use a tablet?	1 - 5	1,0	1 - 5
Q19	How often do you use a computer (Laptop or PC)?	1 - 5	1,0	1 - 5
Q20	How often do you use the Internet?	1 - 5	1,0	1 - 5
Q21	How often do you use email?	1 - 5	1,0	1 - 5
Q22	How often do you use the calendar / notifications on a smart device?	1 - 5	1,0	1 - 5
Q24_1	Use computer for spare time, entertainment, socializing	1 - 2	1,0	1 - 4
Q24_2	Use computer for office procedures	1 - 2	1,5	1,5 - 3
Q24_3	Use computer for shopping	1 - 2	1,5	1,5 - 3
Q25	Have you ever used a smart watch that records your heart rate, steps, are you walking/running or anything else about you?	1 - 2	1,5	1,5 - 3

Use cases are described in Deliverable 2.3.



Suzanne  
[person  
with AD]

Demographics

76 years old,  
female, lives with her partner  
Secondary education  
Lives in a small house with garden  
in a suburban area, and is not  
spending time in another place  
(other family member's home, day  
care centre, rehabilitation room)

Care characteristics

Gets support from her husband  
that lives with her  
Never needs help with self-care,  
cooking, laundry, ...

Disease and co-morbidities

Dementia  
Diabetes

Cognitive and mood disorders:

- Reduced motivation

Digital competences

Sometimes is using mobile  
phone and internet; rarely  
tablet or computer, e-mail,  
and never used smart bracelet  
or activity tracker or digital  
calendar.

Does not use technology for  
spare time, gaming,  
socializing, shopping...  
Would try a smartwatch or  
other device and will be able  
to use a simple device (phone,  
tablet) with minor help.

Hobbies: Reading, music, cooking

<u>TeNDER functionalities acceptance</u>		
<b>FINDS USEFULL</b>		<b>WOULD TRY</b>
maybe	Activity and location tracking	maybe
indifferent	External location tracking	no
useful	personal calendar and medication regime	maybe
useful	sleep quality	maybe
no	toilet usage	indifferent
useful	physical condition	indifferent
useful	safety and wellbeing at home	maybe
indifferent	emotional state recognition	maybe

TeNDER interaction and development

She wants to be the one to control when the device is turned on or off  
and to decide together with her husband. Maybe she would allow  
professionals to have the access to the reports. For the notifications  
and alerts she prefers to have a combination of voice, message.

Concerns: Privacy, not being able to use the system right.



## Simon [person with AD]

### Demographics

79 years old,  
male, lives with his partner  
Vocational training  
Lives in a house in a urban area,  
and is not spending time in  
another lace (other family  
member`s home, day care centre,  
rehabilitation room).

### Care characteristics

Gets support from his wife that  
lives with him. Never needs help  
with self-care, sometimes with  
house-work, ...

### Disease and co-morbidities

Dementia  
High cholesterol

### Cognitive and mood disorders:

Getting angry

### Digital competences

Rarely is using mobile phone  
and never is using computer  
or tablet, e-mail, and never  
used smart bracelet or activity  
tracker or digital calendar.  
Does not use technology for  
spare time, gaming,  
socializing, shopping...

Would have difficulties to try  
a smartwatch or other device.

### Hobbies: gardening

<u>TeNDER functionalities acceptance</u>		
<b>FINDS USEFULL</b>		<b>WOULD TRY</b>
useful	Activity and location tracking	maybe
useful	External location tracking	maybe
useful	personal calendar and medication regime	maybe
useful	sleep quality	maybe
no	toilet usage	indifferent
useful	physical condition	maybe
useful	safety and wellbeing at home	maybe
indifferent	emotional state recognition	no

### TeNDER interaction and development

He wants to be the one to control when the device is turned on or off  
and to decide together with his wife, that can have insights into the  
reports. He would allow professionals to have the access to the reports.  
For the notifications and alerts he prefers voice and message alerts.

Concerns: Privacy, not being able to use the system right.





**Demographics**  
 78 years old,  
 male, lives with his partner  
 Secondary education  
 Lives in a house with no patio/garden in a urban area, and is not spending time in another place

**Care characteristics**  
 Gets support from his wife that lives with him. Rarely needs help with self-care, never with eating, cooking, ...

**Disease and co-morbidities**  
 Parkinson`s disease

**Digital competences**  
 Often is using mobile phone, sometimes computer, e-mail and internet; and never is using tablet, never used smart bracelet or activity tracker or digital calendar.  
 He uses technology for spare time, gaming, socializing, shopping...  
 Would try a smartwatch or other device.

TeNDER functionalities acceptance		
FINDS USEFULL		WOULD TRY
useful	Activity and location tracking	yes
useful	External location tracking	yes
useful	personal calendar and medication regime	maybe
useful	sleep quality	maybe
indifferent	toilet usage	no
useful	physical condition	maybe
useful	safety and wellbeing at home	yes
useful	emotional state recognition	no

**TeNDER interaction and development**  
 He wants to be the one to control when the device is turned on or off. His wife can have insights into the reports. He would allow professionals to have the access to the reports. For the notifications and alerts he prefers e-mail and combination of voice, message alerts.

**Concerns: to be for his benefit**



## María

### [person with PD]

**Demographics**  
 68 years old,  
 female, lives with her husband and her younger son who is getting divorced  
 Housewife  
 Lives in a fourth floor without lift

**Digital competences**  
 Often is using mobile phone, sometimes; and never is using tablet, never used smart bracelet or activity tracker or digital calendar.  
 She took a basic computer course a few months ago offered by the senior citizens' centre in her neighbourhood.  
 Would try a smartwatch or other device.

**TeNDER functionalities acceptance**

FINDS USEFULL		WOULD TRY
useful	Activity and location tracking	yes
useful	External location tracking	maybe
useful	personal calendar and medication regime	yes
useful	sleep quality	maybe
indifferent	toilet usage	no
useful	physical condition	yes
useful	safety and wellbeing at home	maybe
useful	emotional state recognition	no

**TeNDER interaction and development**  
 She wants to be the one to control when the device is turned on or off. Her sons would love to have an alert system that would let them know if they need help or if a fall occurs.  
 She would like to be able to connect with the professionals who treat her and receive feedback from them.

**Concerns: Fear of not knowing how to use the system**



Patrick  
[person  
with CVD]

Demographics

61 years old,  
male, lives with his partner  
Vocational training  
Lives in a house with a garden in a  
remote area in the countryside,  
and is not spending time in  
another place.

Care characteristics

Never needs help with self-care,  
with eating, cooking, ...

Disease and co-morbidities

Cardiovascular diseases

Digital competences

Frequently is using mobile  
phone, often uses e-mail,  
internet and digital calendar;  
and never used smart bracelet  
or activity tracker.

He uses technology for spare  
time, gaming, socializing,  
shopping...

Would try a smartwatch or  
other device.

<u>TeNDER functionalities acceptance</u>		
<b>FINDS USEFULL</b>		<b>WOULD TRY</b>
useful	Activity and location tracking	maybe
indifferent	External location tracking	maybe
useful	personal calendar and medication regime	yes
indifferent	sleep quality	maybe
no	toilet usage	no
useful	physical condition	maybe
indifferent	safety and wellbeing at home	no
no	emotional state recognition	no

TeNDER interaction and development

He wants to be the one to control when the device is turned on or off.  
His wife can have insights into the reports. He would maybe allow  
professionals to have the access to the reports. For the notifications  
and alerts he prefers combination of e-mail, voice, message alerts.

Concerns: Privacy





Clara  
[person  
with CVD]

Demographics  
65 years old,  
female, lives with his partner  
University education  
Lives in an apartment with  
elevator and also she has a garden  
in a urban area.

Care characteristics  
Rarely needs support with self-  
care or house work, never with  
eating, cooking, ...

Disease and co-morbidities  
Cardiovascular disease

Digital competences  
Often is using mobile phone,  
computer, e-mail and  
internet; and rarely is using  
tablet, smart bracelet or  
activity tracker or digital  
calendar.

She uses technology for spare  
time, gaming, socializing,  
shopping...

She is familiar with  
smartwatches and her  
experience is good.

<u>TeNDER functionalities acceptance</u>		
FINDS USEFULL		WOULD TRY
Very useful	Activity and location tracking	yes
useful	External location tracking	maybe
indifferent	personal calendar and medication regime	maybe
indifferent	sleep quality	no
no	toilet usage	no
useful	physical condition	yes
indifferent	safety and wellbeing at home	maybe
no	emotional state recognition	no

TeNDER interaction and development  
She wants to be the one to control when the device is turned on or off.  
No one shall have insights into the reports. For the notifications and  
alerts she prefers e-mail.

Concerns: Privacy

### 3.2 CAREGIVER PERSONA CARD

Caregiver persona cards were developed with clustering statistical methods. In the first step hierarchical clustering was applied to assess the number of clusters in the survey sample of 75 respondents. Included variables were normalized and standardised to minimize the different scales effects on the clustering. Based on the included attributes, the respondents were grouped into four different clusters.

In the second step we have applied the k-means algorithm for clustering the respondents into different clusters, each of them consisting of respondents with similar characteristics. The list of attributes chosen for analysis is presented in Table 6. All attributes have been assigned arbitrarily chosen weights. The highest weights were assigned to living environment, respondent's gender, caretaker's primary disease type (AD, PD, CVD), it's severity, age and care characteristics. Based on the k-means algorithm each responded was assigned cluster membership (1-4). To determine the persona card characteristics for all measured variables, including TeNDER functionalities acceptance and perceived usefulness, median values for each cluster were used. The sub-sample for CVD patients was relatively small (n=4) and uniform, so no specific cluster was discovered. Respondents with missing values were listwise excluded from cluster analysis and persona development (n=10). We have developed the persona cards with CVD user partners' expert knowledge and interviews results. The numbers of the Respondents in the particular clusters are shown in Table 5.

Table 4: Numbers of the Respondents in the particular clusters

Persona/cluster	P1	P2	P3	P4	P5	P6
Disease	AD	AD	AD	PD	PD	CVD
Number of Respondents in cluster	11	20	17	13	expert knowledge	4 + expert knowledge

Table 5: Objects attributes used for Respondents clustering

Variable	Attribute	Range	Weight	Weighted range
Q1	Age of a caretaker	1 - 5	0,5	0,5 - 2,5
Q2	Age of a caregiver	1 - 6	3	3 - 18
Q3	Gender of a caregiver	1 - 2	20	20 - 40
Q4	Education of a caregiver	1 - 5	0,25	0,25 - 1,25
Q5	Do you live with the caretaker?	1 - 2	20	20 - 40
Q6	What kind of housing does the person you take care for live in?	1 - 3	1	1 - 3
Q11	How much time do you spend on caring?	1 - 5	2	2 - 10
Q13	How often do you provide that support in self-care?	1 - 5	1	1 - 5
Q14	How often do you provide the support in eating and drinking?	1 - 5	1	1 - 5
Q15	How often do you provide support in household?	1 - 5	1	1 - 5
Q16	Does the person you care for have any of these problems: AD, PD, CVD?	1 - 4	10	10 - 40
Q17	In your opinion, what is the severity level of the disease of the person you take care for?	1 - 3	3	3 - 9

Use cases are described in Deliverable 2.3.



**Carmen**  
[carer  
of a person  
with AD]

Demographics

68 years old,  
female,  
university education  
lives with her husband with  
moderate AD (74y) in an  
apartment with 3 rooms on the 2<sup>nd</sup>  
floor, with the elevator and a  
garden

Care characteristics

Caring 24h/day for the person  
with AD. Providing help mainly in  
supporting household care and  
self-care. Person with AD has also  
comorbidities.

Digital competences

Using mobile phone  
daily, computer and  
internet once per week.

Intended use mainly for

- spare time,
- entertainment,
- gaming, movies.

Not using intelligent devices for  
health and activity tracking.

Carmen has good experiences  
with digital calendar, but is  
indifferent on using new  
technologies at home.

TeNDER functionalities acceptance

**FINDS USEFULL**

- + activity and location tracking
- + personal calendar and medication regime
- + sleep quality
- + toilet usage
- + physical condition
- + safety and wellbeing at home
- 0 emotional state recognition

**WOULD TRY**

- +
- +
- +
- 0
- 0
- +
- 0

TeNDER interaction and development

Carmen prefers to receive notifications via email messages.  
System should enable her to have more freedom / time for himself.  
Use of functionalities should adapt to the severity of the disease and thus  
should be able to change according to the respective needs of a person she is  
taking care. Carmen would prefer to have a kind of map of the house to be  
shown with the actual location of the person with AD, to allow her to leave  
the apartment.

Concerns

The price would be to high to afford. Privacy should be assured and no data  
shall be passed to third parties. Carmen prefers that the devices can be  
turned off whenever they wish.



**Max**  
[carer of a person with AD]

Demographics

67 years old, male, University education  
Lives with a person with mild AD in an apartment (city) with 5 rooms, on the 1<sup>st</sup> floor; doesn't use elevator and they are having a patio.

Care characteristics

Max is taking care of a person with AD more than 3h/day, the support for self-care, eating and drinking are rarely needed; support with cooking and household tasks are always needed.

Digital competences

Uses mobile phone, computer and internet a few days in a week. Doesn't use a smart bracelet or activity tracker.

Intended use mainly for

- spare time,
- entertainment,
- gaming, movies,
- socializing and administration
- shopping.

Max is indifferent about using smart devices.

TeNDER functionalities acceptance

FINDS USEFULL	WOULD TRY
+ activity and location tracking	+
++ personal calendar and medication regime	+
0 sleep quality	+
0 toilet usage	0
0 physical condition	0
+ safety and wellbeing at home	+
+ emotional state recognition	0

TeNDER interaction and development

Max would like be trained in the use of digital solutions and expand his knowledge.  
Max prefers to receive notifications with combination voice /text /email messages.  
System should enable him to have more freedom / time for himself.  
Use of functionalities should adapt to the severity of the disease and thus should be able to change according to the respective needs of a person he is

Concerns

The person he is taking care would not accept the functionalities.  
Max is concerned who will take the responsibility for actions or unintended damage (if happens).  
Privacy should be assured and no data shall be passed to third parties.  
Max prefers that the devices can be turned off whenever he wish.



Enya  
[carer  
of a person  
with AD]

Demographics

50 years old,  
female,  
University education  
Caring for a person with moderate  
AD (72y) that lives in a house with  
a garden.

Enya doesn't live with a person .

Care characteristics

Enya takes care for a person with AD for  
less than 3h/day. No need for support  
with eating and drinking, but  
sometimes with household tasks:  
cooking, laundry, work on the garden...  
Person with AD has also comorbidities.

Digital competences

Uses daily mobile phone,  
computer and internet. Enya  
doesn't use a smart bracelet or  
activity tracker.

Intended use mainly for

- spare time,
- entertainment,
- gaming, movies,
- socializing and  
administration
- shopping.

Enya would try the smart  
devices with a person with AD.

TeNDER functionalities acceptance

FINDS USEFULL	WOULD TRY
+ activity and location tracking	+
++ personal calendar and medication regime	+
0 sleep quality	+
0 toilet usage	0
0 physical condition	0
+ safety and wellbeing at home	+
+ emotional state recognition	+

TeNDER interaction and development

Enya prefers to receive notifications with a text messages.  
Use of functionalities should adapt to the severity of the disease and thus  
should be able to change according to the respective needs of a person she  
is taking care.

Concerns

The person she is taking care would not accept the functionalities.  
Privacy should be assured and no data shall be passed to third parties.



Rok  
[carer  
of a person  
with PD]

Demographics

51 years old,  
male,  
education  
Doesn't live with a patient with PD (79y). The person with PD lives in an apartment with 3 rooms in the street level floor, with no elevator or patio/garden

Care characteristics

Rok takes care for a person with PD only when it is needed, mainly for support at household tasks.

Digital competences

Uses daily mobile phone, computer and internet. Doesn't use a smart bracelet or activity tracker. Rarely uses tablet and is indifferent about calendar notifications (doesn't use).

Intended use mainly for

- spare time,
- entertainment,
- gaming, movies,
- socializing and administration
- shopping.

Rok would try the smart devices with a person with PD, has good experience with using the technology.

**TeNDER functionalities acceptance**

FINDS USEFULL	WOULD TRY	
+ activity and location tracking	0	
++ personal calendar		+
0 medication regime		0
+ sleep quality	0	
+ toilet usage	0	
+ physical condition		+
+ safety and wellbeing at home		+
0 emotional state recognition	/	

TeNDER interaction and development

Rok prefers to receive notifications by text messages.  
Use of functionalities should be adaptable to a person.  
Would prefer to go through reports on activities to keep the person with PD motivated.

Concerns

To overburden the person with use of the technology.





Luisa  
[carer  
of a person  
with PD]

Demographics  
72 years old,  
female,  
Basic education  
Husband has been suffering from PD for 10 years

Care characteristics  
Luisa lives with her husband He is currently self-sufficient but needs support in some specific tasks and especially when he is in an OFF period.

Digital competences  
Uses daily mobile phone, During the lockdown she has learned to use some applications such as Skype.  
Intended use mainly for

- spare time,
- entertainment,
- socializing

Luisa would try smart devices with a person with PD if this can help provide safety and support.

<u>TeNDER functionalities acceptance</u>	
<u>FINDS USEFULL</u>	<u>WOULD TRY</u>
+ activity and location tracking	0
++ personal calendar	+
+ medication regime	+
+ sleep quality	0
+ toilet usage	0
+ physical condition	++
+ safety and wellbeing at home	+
0 emotional state recognition	/

TeNDER interaction and development  
Luisa prefers to receive notifications directly in the app. She thinks that the activity reports can make her husband aware of what he needs to work on.

Concerns  
She is not sure if her husband will accept the use of these devices.



## Monika [carer of a person with CVD]

### Demographics

Age 63  
Female  
Married  
No children  
Works as office employee, but only half-time as she needs to care for her husband  
Lives in own house

### Care characteristics

Caring for husband who has dementia at a medium stage  
Needs to check up on him every few hours  
Supports him on more complex activities of daily living (cooking, finances, health care etc.)

### Digital competences

Using mobile phone daily, computer and internet once per week.

Intended use mainly for

- spare time,
- entertainment,
- Shopping
- Movies.

Monika has good experiences with digital calendar, but is indifferent about using new technologies at home.

### TeNDER functionalities acceptance

#### FINDS USEFULL

+ activity and location tracking  
++ personal calendar  
0 medication regime  
++ sleep quality  
+ toilet usage  
+ physical condition  
++ safety and wellbeing at home  
0 emotional state recognition

#### WOULD TRY

0  
+  
+  
0  
0  
+  
+  
/

### TeNDER interaction and development

Monika prefers to receive notifications on the phone by text messages.  
Use of functionalities should be adaptable to a person.  
Would prefer to go through reports on activities to keep the person with CVD motivated.

### Concerns

Is concerned about data protection, but is willing to take the „risk“ when system is reliable and usefull  
Wishes more security, less responsibilities, less stress (peace of mind)  
more time to spend on own interests  
Husband gets lost or is a security threat (e.g. leaves oven on/water running)  
Loosing control, no time for herself



### 3.3 PROFESSIONAL PERSONA CARD

The persona cards for the professionals were developed with specific professional sub-group analysis: healthcare professionals (HCP), social professionals (SCP), therapists and other professionals. We have analysed healthcare and therapists' sub-samples also for gender differences as this groups included also male respondents (4).

To determine the persona card characteristics for all measured variables, including TeNDER functionalities acceptance and perceived usefulness, median values for each cluster were used. Professional persona cards were post-hoc fine-tuned with the results of interviews and TeNDER user partners' expert knowledge. The numbers of the respondents in the particular persona are shown in Table 7.

Use cases are described in Deliverable 2.3.

*Table 6: Numbers of the Respondents in the particular persona*

Persona	P1	P2	P3	P4	P5	P6
Type	HCP/ male	HCP/female	Therapist/ male	Therapist /female	SCP	Other
Number of Respondents	4	15	4	14	3	8



## Dominic Health-care professional

### Male

Dominic is familiar with the technology.  
Mainly using for: spare time, entertainment, office procedures and at work.  
Using mobile phone, computer and e-mail every day, tablet once per week.  
Dominic uses calendar with notifications.

Dominic hasn't been using smart watches.

+ Usefulness of the intelligent system that can monitor the patient

### TeNDER functionalities acceptance

FINDS USEFULL	AD	PD	CVD
activity and location tracking	++	+	+
external location tracking	++	+	+
physical condition	+	+	++
sleep quality	++	+	0
toilet usage	+	0	0
Reminder of medical prescription	+	+	+
safety and wellbeing at home	++	+	0
emotional state recognition	+	0	0

### TeNDER interaction and development

Dominic would prefer the patient or caregiver would bring the summary reports to the consultation. Dominic finds communication tool very useful and recognizes that online platforms enable better coordination and communication among professionals. General reports on vital parameters would be interesting, especially reports on abnormal parameters.

### Concerns

Dominic expects some more visits and calls to check things with patients and carers and would not prefer to be overloaded. The main concern expressed was the approach with technology, concerning the privacy and dignity of a person. Technological systems in general should be error-prone and long-lasting batteries are essential to ease the use.



## Charlotte Health-care professional

### Female

Charlotte is familiar with the technology.  
Mainly using for: spare time, entertainment, office procedures and at work.  
Using mobile, computer and e-mail phone every day, tablet once per week.  
Charlotte uses calendar with notifications.

Charlotte hasn't been using smart watches.

+ Usefulness of the intelligent system that can monitor the patient.

### TeNDER functionalities acceptance

<b>FINDS USEFULL</b>	<b>AD</b>	<b>PD</b>	<b>CVD</b>
activity and location tracking	++	+	0
external location tracking	++	+	0
physical condition	+	+	++
sleep quality	++	+	+
toilet usage	+	0	0
Reminder of medical prescription	+	+	+
safety and wellbeing at home	++	+	0
emotional state recognition	+	0	0

### TeNDER interaction and development

Charlotte would prefer to have the access to the reports and communicate with patients and carers. Charlotte finds communication tool very useful. Charlotte is interested in reports on sleep apnea. She recognizes that the reports might give the possibility to draw conclusions on factors that lead to (abnormal) sleep patterns (e.g. eating before sleeping) and also might explain (abnormal) behaviors of the patient due to bad sleep.

### Concerns

Technological systems in general should be error-prone and long-lasting batteries are essential to ease the use. Older people may have difficulties using new technologies (because of the difficulty of handling them). The technology should ask them for the minimum interaction and offer them an incentive that is very attractive to them which is their health care (reports of their health status easy to understand for them and their carers).



## Josephine Therapist

### Female

Josephine is familiar with the technology.  
Mainly using for: spare time, entertainment, office procedures and at work.  
Using mobile phone and computer phone every day. She doesn't use tablet and calendar with notifications.

Josephine hasn't been using smart watches.

+ Usefulness of the intelligent system that can monitor the patient

### TeNDER functionalities acceptance

FINDS USEFULL	AD	PD	CVD
activity and location tracking	++	+	+
external location tracking	+	+	+
physical condition	+	+	++
sleep quality	++	+	0
toilet usage	+	0	0
Reminder of medical prescription	+	+	+
safety and wellbeing at home	+	+	0
emotional state recognition	+	+	0

### TeNDER interaction and development

Josephine would prefer to have the access to the reports and communicate with patients and carers. Josephine finds communication tool very useful and recognizes that online platforms enable better coordination and communication. She recognizes the benefit if they can directly enter therapy sessions on the calendar according to the time schedule of the patient.

### Concerns

Josephine wonders if it is possible that it will give false impression of independency and security to the caregiver. She also expressed that the introduction of novel technologies is good to empower them to have more data and insights, however, impacts and changes on the dimension of care should also be reflected. Technological systems in general should be error-prone and long-lasting batteries are essential to ease the use.



# Sebastian Therapist

## Male

Sebastian is familiar with the technology.  
 Mainly using for: spare time, entertainment, office procedures and at work.  
 Using mobile, computer and e-mail phone every day, tablet once per week.  
 Sebastian uses calendar with notifications.

Sebastian hasn't been using smart watches.

- + Usefulness of the intelligent system that can monitor the patient

<u>TeNDER functionalities acceptance</u>			
<b>FINDS USEFULL</b>	<b>AD</b>	<b>PD</b>	<b>CVD</b>
activity and location tracking	++	+	0
external location tracking	++	+	+
physical condition	0	+	++
sleep quality	++	+	0
toilet usage	0	0	0
Reminder of medical prescription	+	+	+
safety and wellbeing at home	++	+	0
emotional state recognition	+	0	0

## TeNDER interaction and development

Sebastian would prefer to have the access to the reports and communicate with patients and carers. Sebastian finds communication tool very useful and recognizes that online platforms enable better coordination and communication. He recognizes that digital measurement devices enable more precise measurement and the collection of more data, which also enables better and easier comparisons. He also recognizes that when used in therapy, more precise and targeted movements and increases performance can be enabled. These solutions also offer the possibility to better show the user his/her performance in certain tasks, which may increase motivation. The reports on emotional state would be interesting in order to better plan therapy sessions.

## Concerns

Sebastian expects privacy is handled. Technological systems in general should be error-prone and simple to use. Users may be confused with notification. The user really needs to understand the message or report form the system.



### Female

Gabriella is familiar with the technology.  
Mainly using for: spare time, entertainment, office procedures and at work.  
Using mobile phone, computer and e-mail every day, tablet once per week.  
Gabriella uses calendar with notifications.

Gabriella hasn't been using smart watches.

+ Usefulness of the intelligent system that can monitor the patient

### TeNDER functionalities acceptance

FINDS USEFULL	AD	PD	CVD
activity and location tracking	+	+	+
external location tracking	+	+	+
physical condition	+	+	+
sleep quality	+	+	+
toilet usage	+	+	+
Reminder of medical prescription	+	+	+
safety and wellbeing at home	+	+	0
emotional state recognition	+	0	0

### TeNDER interaction and development

Gabriella would prefer to have the access to the reports and communicate with patients and carers. Moreover, she find the communication service with other professionals very useful.

The assistive tool for tracking daily activity and maintain the patient daily schedule is very useful. She finds useful to be able to monitor patients who live alone and do not have a carer and to receive social alerts in order to detect situations in which the patient has and needs to be assessed for some kind of support or help through the social services.

### Concerns

She expressed concern regarding the relationship between a caregiver and the patient, if the system would allow independency and the caregiver would accept this as less care for the patient is needed. She is concerned that use of ICT tools may reduce face-to-face contact between caregivers and patients, and may lead to the de-professionalization of care workers

She expressed concern of quality of life assessment related to ICT tools, as measuring an improvement of quality of life of a person is an individual-personal-subjective domain and not to mislead the participants with wrong expectations.





Stephanie  
Other  
professional

Female

Stephanie is familiar with the technology.  
Mainly using for: spare time, entertainment, office procedures and at work.  
Using mobile phone, computer and e-mail every day, tablet once per week.  
Stephanie uses calendar with notifications.

Stephanie hasn't been using smart watches.

+ Usefulness of the intelligent system that can monitor the patient

TeNDER functionalities acceptance

FINDS USEFULL	AD	PD	CVD
activity and location tracking	+	+	+
external location tracking	+	+	+
physical condition	+	+	+
sleep quality	+	+	+
toilet usage	+	0	0
Reminder of medical prescription	+	+	+
safety and wellbeing at home	++	+	0
emotional state recognition	+	0	0

TeNDER interaction and development

Stephanie would prefer to have the access to the reports and communicate with patients and carers.

Stephanie finds communication tool very useful. Technologies could help professionals in communication between patients and other professionals, in time management and in the management of data. It can be interesting to know the mood of the patient, if she/he has fallen or any other situation in which she/he requires assistance. She finds it useful to talk with the patient and carer about the reports.

Concerns

Stephanie is concerned that technological devices are often complicated, which might be especially difficult for older patients with diseases.

She expressed concerns that this could also have a negative impact if the patient would get upset because of not reaching the goals.

### 3.4 HEALTH- AND CARE- SERVICES COLLABORATION ASPECTS

The TeNDER System and the information that its sensors are able to collect are the ideal place for the creation of tools that encourage communication between the different types of users of the application. Likewise, personalised recommendations can be defined based on the information collected and processed in higher levels of the system, providing support and enabling personalised interaction among patients and care providers. To meet these conditions, the design of different services is proposed:

1. Social services communication: Social needs are sometimes difficult to be detected for various reasons. For example, many users are unaware of the existence of services, or where to go for information. Moreover, as found in the service provision flow and feedback gathered from the participants, people often miss the information on the reference person to contact (who their social worker of reference is). Sometimes there may be a certain reluctance to ask for this type of resources to the care provider. It is therefore important to promote awareness of the resources, ease the access, and adapt them to the needs of the users.

The TeNDER System can help in this process by identifying users' needs and connecting them with possible solutions from care providers.

In order to determine the need for social resources, 3 key factors need to be studied: degree of loneliness, disability, and economic situation. In order to determine the degree of each of these factors, a short questionnaire has been designed and will be launched through the application, which will help to find out the users' need for social resources. Once the need is determined, the system will send to the user a message with a personalised recommendation. These recommendations can be of several different types: easing the contact with the social worker of reference, sending links to specific pages to request resources, and providing information about specific resources.

2. Communication system between the different profiles within the System: In order to favour interaction among different actors involved in the care process, a messaging system will be established through which carers and patients will be able to communicate with the different professionals. Professionals will be able to send answers to the questions raised and carers and patients will receive the notification in their own app. In addition, the system will be extended to ease the interaction among professionals from different disciplines (both medical and social), in such a way as to favour multidisciplinary care and a global vision of the situation of those that are affected by challenges faced due to neurological conditions.



### 3.4.1 **System of recommendations and alerts based on the data collected by the sensors.**

The different devices and sensors that build the TeNDER System are able to collect and process the information about the physical state of the patients (for example: camera in the rehabilitation room; physical daily activity collected by wristband), falls and festination and/or freezing events (for example: cameras in the homes, microphones), description of the time spent in different parts of the house and time spent outside (localization sensor, door status sensor), quality of sleep and interruptions together with breathing problems during the night (sleep analyser).

The collected information will be analysed by the System in such a way that different recommendations and alerts can be defined. Some examples could be:

- The System has detected that the patient is often freezing with the consequent risk of falling: an alert is sent to inform about this situation and some advice to avoid these events or strategies to overcome them are attached;
- The System detects that the patient is constantly coming and going from the kitchen suspecting that some irregular behaviour is taking place: an alert is sent about this fact and/or report can be assessed;
- The System detects poor sleep quality or several interruptions during sleep: a report can be assessed when sleep disturbances are indicated and the professional might decide that a regime of light exercise and physical activity will assist in reducing symptoms;
- In the rehabilitation room, the System detects that in recent weeks the patient is experiencing difficulties in making movements with the left upper limb: an alert is sent and the patient is put in contact with their referral therapist;
- The carer may not have the opportunity to be present at all times to initiate and support all activities throughout the day. The TeNDER System may help initiate daily activities like: going outdoors when remaindered, initiate house work (tasks can be divided into simple parts to follow), taking exercise, reading a book, meeting with people...;
- The calendar function may be used so that the carer experiences less obstacles when following up with the routine and daily activities of a person. They may plan for activities based on the recommendation set form the System and list ideas for future activities.

Such services add value to the TeNDER Platform by trying to increase patients' and caregivers' sense of security, support and reassurance, as well as providing valuable information for the care process.

### 3.5 USER REQUIREMENTS REGARDING DASHBOARD

TeNDER interface development in WP5, Task 5.2, relies on the User requirements and will define the user's interface of the TeNDER platform. In particular, there are 3 different interfaces provisioned within TeNDER: (1) Web platform (professionals oriented) (2) Mobile interface for caregivers and patients, and (3) Smart TV /Tablet (patients oriented). In order to address the user-friendliness of the introduced interface and to allow the easy and comfortable use for participants who may experience motor and/or cognitive difficulties, the efficiency of the proposed solutions is being followed.

The feedback was being gathered in two cycles for each new version of the interface. Every evaluation cycle was documented and the results integrated in the next development steps.

In the period December 2020 – January 2021, the technical partners responsible for the TeNDER interface development have proposed the first interface mock-up for all 3 groups of the participants (patient, carer, professional). End user partners collected feedback from the potential users (patients' mock-up (n=7), caregiver's mock-up (n=9), professional's mock-up (n=9)) in anonymous way, and also reflected and annotated the information according to their professional experiences. Due to COVID-19 the feedback was mainly provided from researchers, cares and professional. Two Patients with chronic diseases could express their opinions. The collected feedback was mainly addressing the contrast of the text and displayed messages and easy-to-read issues (size of the text, number of objects and amount of text), a more intuitive design of the registration procedure, amount of the information presented. Partners also tested and presented this first version of the app with the participants on the cell-phone.

After the first Mock-ups were tested, a second version of the TeNDER interface was created based on the collected feedback. The revised version was tested in February 2021, again in a similar procedure. The interface for patients and carers was presented and discussed together with end user partners and the technical partners responsible for the interface development.

The pilot partners' researchers asked patients (n=2), caregivers (n=4), and professionals (n=13, nurses, psychologists, physiotherapists and administrative workers) following questions while showing them the draft version of the TeNDER interface:

1. *What is your general impression from the mock-ups?*
2. *Do you think the app is user-friendly? What could be improved?*
3. *What do you think about specific sections?*

- *Login*

- *Home*

- *Settings*

- *Notifications*

- *Services*

4. *Would you like to use the app?*

Feedback addressed data protection issues for the patients' registration process, the layout of the contents, and mainly the high complexity of the UI. The need to address the family member of a caretaker and/ or the professional was risen and suggestions on how to implement this were provided. Some participants were satisfied with the visualization, some proposed colour changes (for better readability for the patients). A few participants addressed the language, how are we addressing the users (friendly language). Besides privacy issues, patients mentioned that they don't want to be controlled all the time. Many participants expressed that assessing the static dashboard mock-up is difficult and would prefer to test the real App to provide proper comments. The questions served as potential guideline and observations, comments and answers were collected.

### **Feedback from patients` perspective**

Patients mainly had difficulties to understand the app in general and some were not able to understand the sequence that the app follows to move from one screen to another. That may be due to the mock-up shown on paper. Besides, the problem of understanding the language (mock-ups were presented in English, because there was no translation into the individual language so far), the main concern in all pilots was a high-contrast coloured and readable text. Another point was the overload of each screen or too small letter size that made it difficult to read.

### **Feedback from carers` perspective**

For most of the caregivers the same problems that occurred for patients were mentioned as well: readability, overloaded screens, language difficulties. Additionally, they comment, that they don't care too much about the design but the functionality of the final version. Caregivers would prefer to have a personalized approach (to use more or less functions) and to adjust the notifications individually, as maybe some information or functions are not needed.

### **Feedback from professionals` perspective**

For the professionals, the suggestions were mainly due to options to filter the information and the optional insights that can be provided. The option to slide left-right between the pages was suggested, the importance of an appealing and clear structured design of the home page, and large home icon on all pages was proposed. To avoid the overload of the screen with text, it was mentioned that a big navigation or pop-up option would be good and would help to organize each section better. Also, the need for a personalized view with filtered information (if wanted) was expressed and to have the option of one-hand use. Regarding the home section of the TeNDER interface, professionals would prefer individualized screens for each patient and it should be represented in the same order, to sort the information for each patient in a logic way. Too much information on one screen could become redundant. As a professional related to the patient, it would be also helpful to see the personal calendar (of the patient) simultaneously with patient's emergency notifications or open communication points. Professionals also found the text illegible due to the colour. For a better usability in general, professionals suggested that the system should address the user nicely with their name and not with "patient" or "caregiver".

Concerns regarding the usability for the patients were mentioned, and the fear that patients with no experience or difficulties in the use of technical devices will not use the application at all. Therefore, an easy and structured patient-registration process and supervision during the log-in, was suggested.

In conclusion, the feedback mainly addressed the contrast of the text and displayed messages and easy-to-read issues (size of the text, number of objects and amount of text), clearer view on the registration procedure, amount of the information presented. Nevertheless, the second Mock-up-test was a success and the users are curious and want to test the final version to give a more detailed feedback about the functionality.

For further insights regarding a user interface, SKBA is currently collaborating with the European Project "Rehyb" where we are conducting a requirement analysis on technical interfaces in general. The analysis includes interviews and questionnaires of 25 therapists and patients with Alzheimer's disease and other forms of dementia, Parkinson's disease or cardiovascular diseases (mainly stroke).

### 3.6 INTERMEDIATE USER REQUIREMENTS FROM PILOTING (1ST WAVE)

As mentioned in previous deliverables, the aim of this section is to be as close as possible to real-world environments. During each Wave, the state-of-the-art technology will be tested in real-world scenarios, end-users will be supported by researchers from each responsible institution. Based on the reflection from users, the technology will be improved and new functionalities will be added to the TeNDER system. This will help to synchronously adapt user requirements and new functionalities and result in co-created scenarios for the validation phase (3<sup>rd</sup> piloting Wave). The status of the technology and available functionalities at the time of starting the 1<sup>st</sup> Wave of *piloting* is presented in Table 8.

Table 7: Assistive technology user requirements in piloting

	Functionalities and improvements to be included	Status of implementation in TeNDER system
<b>Home environment</b>		
<b>Medical examination schedule</b>	Reminds of therapies, appointment	Reminders: caregiver-patient to be shown upon the implementation in TeNDER App during the 1 <sup>st</sup> Wave (translated into local languages)
<b>Adherence to drug treatment</b>	Monitor medication intake	To be assessed upon the implementation within reminders and calendar notifications
<b>Health state</b>	Blood pressure Body weight Breathing frequency	To be assessed upon the implementation, during the 1 <sup>st</sup> Wave through the TeNDER App
<b>Emotional state detection</b>	Emotional status: aggressive, sad, happy, angry, apathetic, anxious; Changes in tone, stuttering	To be ready during the 1 <sup>st</sup> Wave for general emotional detection for sad/happy in the apartment (nonselective measurements) and assessed through the TeNDER App, other assessment will be performed upon the implementation of enhanced functionality
<b>Nocturnal activities</b>	Hours of deep sleep; Hours of light sleep; N <sup>o</sup> of night awakenings To identify incontinence, urinary infections, or possible causes of insomnia;	Currently available through the consumer app, to be assessed upon the implementation in TeNDER App during the 1 <sup>st</sup> Wave
<b>Global localization</b>	Manages global location of Caretaker (location tracking) Heart rate, physical activity	N/A
<b>Room-level localization</b>	Movement tracking Recognition of unusual behaviours Heart rate, physical activity	The view in professionals' interface, to be assessed upon the implementation during the 1 <sup>st</sup> Wave and enriched for the carers in the 2 <sup>nd</sup> Wave
<b>Safety and wellbeing</b>	Temperature, Lights, Water spills, Electrical appliances, Entrance door, Refrigerator door, All windows Fall detection	Functionality is mostly not available; will be assessed upon the implementation of functionalities; the fall detection will be assessed in the 1 <sup>st</sup> Wave in controlled environments

	Functionalities and improvements to be included	Status of implementation in TeNDER system
<b>Hospital environment</b>		
<b>Medical examination schedule</b>	Reminds of therapies, appointment	To be assessed upon the implementation of the reminders form the doctor during the 1 <sup>st</sup> Wave
<b>Adherence to drug treatment</b>	Monitor medication intake	To be assessed upon the implementation of the functionality in the calendar
<b>Emotional state detection</b>	Emotional status: aggressive, sad, happy, angry, apathetic, anxious;	To be ready later during the 1st Wave for general emotional detection in the apartment for sad/happy (nonselective measurements) and assessed through reports in doctor's interface, other assessment will be performed upon the implementation of enhanced functionality
<b>Nocturnal activities</b>	Hours of deep sleep; Hours of light sleep; N <sup>o</sup> of night awakenings To identify incontinence, urinary infections, or possible causes of insomnia;	Currently available through the consumer app, to be assessed upon the implementation in the TeNDER App during the 1 <sup>st</sup> Wave
<b>Room-level localization</b>	Movement tracking Recognition of unusual behaviours Heart rate, physical activity	To be assessed upon the implementation in the TeNDER App during the 1 <sup>st</sup> Wave
<b>Safety and wellbeing</b>	Temperature Lights Water spills Electrical appliances Entrance door Refrigerator door All windows Fall detection	To be assessed upon the implementation of functionalities and implementation in the TeNDER App and interface, for the 1 <sup>st</sup> Wave the fall detection functionality
<b>Rehabilitation room environment</b>		
<b>Room-level localization and activity recognition</b>	How is the patient's performance: balance, body posture, walk, coordination, mobility of the different corporal areas, in order to assess the patient's state Compare the patient's performance in sessions over time	Collection possible only for predesigned system; to be assessed upon the implementation during the 1 <sup>st</sup> Wave
<b>Day care centre closed</b>		
N/A for the timeframe reported		

Subsequently, a report on the whole system and for each of the functionalities will be issued based on all the feedback and will give an approximation of the needs, shortcomings and requirements in each of the environments (Table 8 describes status at the beginning of the 1<sup>st</sup> Wave, April-May 2021). Within the evolution and user involvement, there will be a final version of the user requirements for the 1<sup>st</sup> and 2<sup>nd</sup> piloting Waves that will create co-designed

scenarios. The scenarios that will be developed together with users will be presented in Final version of User Requirements before the validation phase of TeNDER (3<sup>rd</sup> Wave of piloting). From the beginning of the 1<sup>st</sup> Wave, the TeNDER application has not been available to end-users in a way that they could see the real data gathered from the system installed at their site. However, since the objective of this 1<sup>st</sup> Wave was mainly data collection and algorithm training, it was decided to implement the technology and end users were able to use the consumer applications associated with the piloted devices. This is an important limitation in what we understand as the TeNDER ecosystem, as there is no system-level operational communication channel between patients - caregivers – healthcare and social care professionals. In any case, among the partners of the consortium we decided to continue co-creation with end users and use also Mock-ups and other resources like proposed dashboards with no real data, to collect users' feedback. For the implementation of the technology / system the observations have been collected with each user, if applicable (first reactions, barriers encountered, comments on the usefulness of the technology). During the 1<sup>st</sup> Wave the evolvement of TeNDER system will allow to test the interfaces and the App in local languages.

Table 8: Functionality user requirements in different scenarios in piloting

Functionalities	
<b>Home environment</b>	
<b>Medical examination schedule</b>	through the reminders (caregiver- patient)
<b>Adherence to drug treatment</b>	pending implementation (through calendar and reminders)
<b>Health state</b>	through reports of data from wristband
<b>Emotional state detection</b>	for general emotional state in the apartment (sad/happy events in general), other functionalities pending
<b>Nocturnal activities</b>	through reports of data form sleep analyser or wristband
<b>Global localization</b>	N/A
<b>Room-level localization</b>	reports on localization in the professional interface
<b>Safety and wellbeing</b>	pending implementation
<b>Hospital environment</b>	
<b>Medical examination schedule</b>	through the reminders (doctor- patient)
<b>Adherence to drug treatment</b>	pending implementation (through calendar)
<b>Emotional state detection</b>	for general emotional state in the apartment, other functionalities pending
<b>Nocturnal activities</b>	through the reports of data from sleep analyser
<b>Room-level localization</b>	reports on localization in the professional interface
<b>Safety and wellbeing</b>	fall detection, other functionalities pending

Day care centre environment	
Medical examination schedule	ALL CLOSED
Adherence to drug treatment	
Health state	
Emotional state detection	
Room-level localization	
Safety and wellbeing	
Rehabilitation room environment	
Room-level localization and activity recognition	fall detection, other functionalities pending

Moreover, the system for the communication among the professionals is being co-created with users upon the related function implementation in TeNDER system. Therefore, the 1<sup>st</sup> Wave of piloting is proceeding with all three groups of participants as shown in Figure below. The participants facing neurological or cardiovascular diseases are able to test the sleep analyser, wristbands, microphone for emotional detection, localization sensor and the Kinect Azure camera to reflect also on the first reports available when implemented. Their careers can communicate with them through the reminders and also are able to see the reports of a person status due to the functionalities implemented. Moreover, the professionals are able to communicate with the person and see the reports of the status according to the function implementation. The goal is, that based on the reports and insights, all the participants are able to assess the proposed tool and also may adapt the daily schedule, perform counselling, intervene at patient`s habits etc., so that personalized approach is enabled.

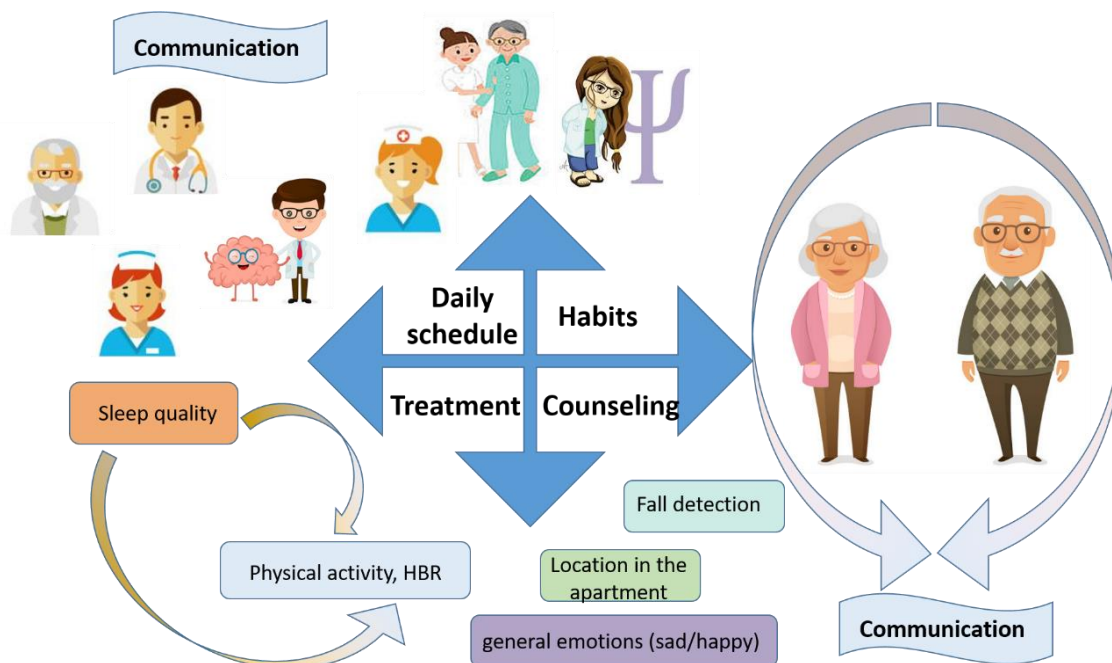


Figure 30: Intermediate user requirements

Picture is adopted by using free images (clipart) from pixabay.com [54] and clipart-library.com [55]



## 4 USE OF THE TECHNOLOGY AND POTENTIAL LIMITATIONS

### 4.1 LITERATURE REVIEW

There are more and more new technologies on the market that promise successful approaches and improvements for the independent living of older people. Smartwatches and wristbands are blooming in the electronics retail market. Their primary purpose is to monitor daily activity and lifestyle including movement and sleep, in order to promote health and well-being [40]. There are also many products and information technology-supported services on the market that promise users to slow down cognitive decline, increase autonomy, traceability, prevent risks and other tools [24, 26, 30, 32, 35, 36, 37, 41, 44]. However, evidence shows that some limitations exist and technologies are not widely used yet [11, 45].

Assistive technology is something many people have heard of, but don't know about in any detail. While technology seems to be a promising solution, its adoption is often challenging for end-users, especially older people, but also for healthcare professionals. The same devices that are chosen for monitoring the status of a person might be quite uncomfortable, heavy and too complicated for users, diminishing the outcome, which is particularly important in the case of people with dementia [40]. Therefore, in spite of the proliferation of technology in our everyday lives, there is a lack of knowledge as to how assistive technologies may support better quality of life for people with neurodegenerative diseases, and if they have a true potential to enable them to remain living in their own homes. Older people, their family and caregivers can face considerable stress with the newly introduced technological components. People express technology-related concerns, while the perceived benefits of technology might be more abstract to them.

What is more, technologies are very heterogeneous, also in terms of efficiency [6, 47]. When it comes to the introduction of new technologies, people with dementia mostly do not want to be overwhelmed and want to maintain independence [11, 19, 24, 43]. In addition, people with dementia experience certain difficulties in introducing technologies into their daily lives, which is understandable, as these people encountered new technologies relatively late in their lives. Resistance to adopt technology-based solutions by elderly people, but sometimes also by care workers and family carers, is an important obstacle. The low level of digital experience and skills among old adults, especially women, – the age groups which most care givers and recipients belong to – is a crucial factor.

Therefore, in contrast to today's generation, people over 65 have not grown up with technologies such as the Internet, smartphones and tablets and are therefore less experienced in using them. This could give rise to concerns as to whether a health intervention with sensors and other technical devices would even be accepted by this target group. However, studies show that when it comes to health and its monitoring, healthy elderly are thoroughly positive about it. A study in which healthy seniors aged 80 to 86 were monitored over 13 weeks by means of a triaxial acceleration sensor attached to the waist, among other things with regard to falls, reported a high acceptance of these devices among the study participants [27]: the device was described as unobtrusive, comfortable and easy to use. Compliance rates were also high, with the device worn on 88% of study days. In addition, mobile applications may also increase treatment adherence in elderly patients [30].

Moreover, the limitation when implementing the technology as a solution is that the health and care needs of real people are extremely heterogeneous, even when they have the “same” condition. If the solution is not covering several services, the implementation and adoption is not widely. What is more, chronic health conditions and care needs are also strongly patterned by social determinants [48]. The timing of the introduction of technologies appears to be crucial, since it came up in several studies among various stakeholders and various technologies. In research on the needs of people with dementia, the aspect of inclusion needs to be highlighted especially from an ethical perspective [2].

It is important for people who may already have signs of cognitive decline to be encouraged to remain independent as much as possible and to maintain an active role in their lives [5, 46] and the technology has the potential to assist them. Much of the daily needs and desires of people with dementia have been identified [16, 33, 40, 43], but the question arises as to whether technologies are valued primarily in terms of safety and physiological needs, and less in terms of intervening and influencing user self-image. Currently wearables are reaching maximum to 14-day battery life, which may cause a barrier of usage. People also expressed some critical concerns with regard to privacy issues of handling data from caregivers and clinicians [8, 34, 40]. Financial costs have also been identified as a major concern of people with dementia and their caregivers regarding wearable sensors and remote monitoring technologies [8, 10, 40, 42, 49]. Moreover, some authors also report that it was highlighted also that the water-resistance is of high importance since the people with dementia may not be able to remember to remove it before taking a bath or washing their hands [40].

Dementia is a complex disorder; manifestation and progression can vary greatly, and the condition is poorly characterized and understood as well as unpredictable. All of this complicates the use of technologies. Some studies clearly state that ease of use is hard to be determined, since the participants cannot conceptualize and visualize themselves using the technology unless they have used it before. It may be more enlightening to observe users through focus groups, by trying out a prototype interface [40, 49]. The most common challenges when implementing assistive technology with people with dementia are [5]:

- The person with dementia may not remember to use the device;
- Batteries are required for operation and battery life is not more than 14-days;
- Can the person with dementia see and understand the interface?
- Who will programme /set up the device, monitor battery life or ensure that it is plugged into the mains electricity supply?
- Will the person with dementia accept new device in their home?
- Some types of the technologies require the user to press a button to hear the reminder message. The user needs to understand and remember how and when to do this;
- Person with dementia needs to be able to understand and respond to the alerts provided from the technology-tools and be motivated to react;
- All parties involved in care need to be coordinated in knowing who is responsible for filling and programming the devices that are used;
- If the device is meant to be worn or carried - will the person with dementia do this?
- Voice quality provided from the device may be an issue and older adults may not understand the message;

- Will the person with dementia recognize or respond to the voice from the device, will he /she be startled or distressed by the voice?
- Usage of text and images needs to be appropriate to the person and take into account culture and literacy issues;
- Person with dementia may be agitated by the message from the device telling him /her what to do;
- Person with dementia may not understand the device`s function and remove it;
- Person with dementia may get confused or startled if alarm goes off;
- The technology may unnecessarily restrict the person`s freedom to leave home;
- Person with dementia may be agitated if it is not clearly set who will respond to alerts;
- Some technologies may potentially decrease autonomy and restrict movement of a person;
- The confidentiality and privacy of a primary users and others that are present in the same place (apartment) shall be addressed;
- The mobile network signal and compatibility to the phone may be an issue for ease the usage;
- For a mobile phone: someone needs to be available or remember to keep it charged;
- There is a potential risk of being over relied on or used to replace the need to visually check on the person with dementia.

Looking from perspective of people living with cardiovascular disease management, there is also the potential for the assistive technology to increase the quality of life. Stroke is the second most common cause of death worldwide and about 40% of the stroke survivors experience long term disabilities as a result [8]. Sensorimotor deficits are very common among stroke survivors, with about 80% of the patients having a paresis of the upper limb [19]. In regard of the demographic change, the burden of disabilities due to stroke is commonly anticipated to increase significantly in future [8]. With regard to an already existing shortage of health care workers [49], the development of assistive methods during everyday life will be of great value for both, the individual patient and the health system. Various studies suggest that health monitoring systems can give seniors an increased sense of security and thus improve their quality of life because, for example, they could expect help more quickly and safely in the event of a fall [1, 38]. Contactless monitoring as a way to live longer and more independently at home in familiar surroundings is rated as useful by adults over the age of 60 [9] and can therefore also be considered for patients with stroke.

In general, the acceptance of electronic technology from people living with cardiovascular disease is as among older adults and depends on several factors [13, 34, 52]. Among these, low familiarity, access to technological devices and lack of trust in technology are important barriers [13]. Factors that play a role in the phase of implementing such as the technical device are diverse [34, 52]: on the one hand, concerns such as the costs, restriction of privacy, obtrusiveness of the devices and lack of user-friendliness are expressed; on the other hand, the expected benefits such as increased sense of security and increased independence in daily life are of importance. The possible relief for relatives -not only of patients with stroke, but in general - is also considered positive. To increase the acceptance of technical devices and in specific mobile devices, Kuerbis and colleagues [21, 22] provide a number of recommendations: For example, supportive training and an appropriate learning

environment during instruction on the devices, feedback, e.g., after a correctly performed task, and the unobtrusiveness of the devices to protect privacy as well as reduce feelings of excessive observation and shame. Nevertheless, the most common challenges when implementing assistive technology with people after stroke will be their physical and mental impairment. Therefore, the design should also be adapted to the cognitive and physical needs, especially of older patients. Large displays, contrast full colours, icons and fonts, not too much information on one page, a logical and intuitive structure, and the integration of a panic button, e.g., on a cell phone, are recommended product features.

Finally, there is also literature reviewing technology acceptance among Parkinson's disease patients. The possible limitations we might find in these persons are similar to those of patients with dementia and cardiovascular disease. On the one hand, there are studies that find that older patients with Parkinson's disease have a less favourable view regarding the role of technology in communicating with healthcare providers and understanding their care [12]. On the other hand, studies that suggest that once technology is feasible and widely adopted among PD communities, then it will broaden our understanding of PD patients' individual lives and priorities, leading to more targeted and individualized treatments and better outcomes for PD patients and their families [6].

AlMahadin and colleagues [3], report a qualitative study interviewing PD patients about their use of technology. Most of the patients had not heard of or used wearable technology. But after an explanation of its purpose, most stated that they would be willing to use it and be monitored 24 hours a day, as long as the device is not invasive or on an unwanted part of the body (preferred to be placed on the wrist, as one would wear a watch). People as participants want that the device should be comfortable, easy to use, non-invasive, and easily worn under clothing without snagging or disturbance. It should also be water resistant, washable, durable and easy to fasten to minimize daily interruptions. Issues related to technology, such as violation of privacy, difficulty in learning to use it, fear and discomfort of using it, and lack of human interaction, were not particularly prominent in the discussion. Finally, they report that participants were interested in participating in the design of the devices and proposed options that would increase user acceptance and adoption [3].

As stated before, the "value" of the technology may differ according to different stakeholders. For patients, for example, there is often a trade-off between the potential benefits of technologies, their costs (and the person's willingness and ability to contribute to these), the work required to use them (and the person's capacity to do so), and the desirability of medicalization and surveillance [22, 23].

In summarization, top common barriers in the adoption of technology by older people is the familiarity and access, need for assistance, trust, privacy implications, design, reduced dexterity, precision, and physical issues (e.g., hearing loss), the cost of the device, forgetting how to operate technology, false alarms and how to turn them off, obtrusiveness, low ease of use, potential negative effect on health, loss of control over technology and stigmatization, functionality and suitability for daily use, perception of no need, fear of dependence, limited training tailored to older learners, feeling of embarrassment, autonomy, loss of dignity, and social inclusion [3, 8, 11, 12, 18, 25, 34, 40, 42, 52, 53]. One of the reasons found is that different stakeholders that are involved have different perspectives on technology use (i.e., needs, wishes, attitudes, possibilities, and difficulties). Moreover, a crucial component to

integrate and accept technology in real-life situations (e.g., at home) is to design and develop user-friendly user interfaces [25].

Regarding the adoption and the implementation, Lehoux and colleagues [23, 24] also distinguish between a health technology's upstream value as viewed by investors (especially the business case for generating profits, further spin-offs, and highly qualified jobs), drug and device regulators (preliminary evidence of efficacy and safety), and financial regulators (auditable business processes and governance), and its downstream value as viewed by clinicians and policy makers (including its impact on patients and health care costs). The technology development and its potential to enter and stay in the market is often characterized by poor alignment between supply-side and demand-side value [14, 22, 23, 24, 27].

## 4.2 PRE-PILOTING

Opinions from patients, caregivers and professionals have been collected about their met and unmet needs, as well as their opinions regarding the usefulness of the TeNDER functionalities were gathered in the pre-piloting phase. The main tool for feedback gathering from the participants in pre-piloting were interviews and surveys (developed under WP2, co-creation process, templates were finalized in Deliverable 2.2 and time plan was set in Deliverable 2.3). The results from the interviews were reported in Internal Report 1 Evaluation Strategy and Protocols, and summarized later on in Deliverable 1.3.

The main barriers that were recognized were: **(1) awareness:** proposed types of devices and services are usually not yet a part of care management; their usefulness is not well recognized by patients; a more positive attitude was sensed from caregivers and professionals; **(2) trust:** concerns about ethics, privacy and concerns on devices capability to assist with the personal autonomy were recognized; the concerns in regard to potential impact on the care process and impact on personal relationships were expressed; and **(3) empowerment:** mainly patients don't feel comfortable and up-to the use of new technologies alone; caregivers have the perception that they would need to do more - will need to substantially assist the caretakers with using the new ICT devices; professionals commented that the system should be simple to use.

## 4.3 PILOTING – 1<sup>ST</sup> WAVE

During the first Wave, the opinions of patients, carers and professionals are collected at different points of the intervention (Table 10). In this way we can follow the possible limitations encountered by each end-user at different times and how this might influence the acceptance of the TeNDER system.

*Table 9: User requirements gathering through the observations (1<sup>st</sup> Wave of piloting)*

OBSERVATIONS TAKEN	TIME FOR THE OBSERVATIONS
1st reaction	1st day
1st barriers - within few days	within 3 days
Barriers of usage - in weeks	in between 8-15 + days
Special feedbacks and Complaints	to be added depending what report participant in each moment
Notes at the end of testing	end of testing

This will give the approach to give a description of the most frequent and most impact limitations found during the intervention. The Internal report on overall limitations found during the 1<sup>st</sup> Wave of piloting will be done in the following first month after the end of the 1<sup>st</sup> Wave (August 2021). Moreover, TeNDER partners will constantly reflect on observed findings through Monthly reports (as set in Evaluation strategy and protocols, Deliverable 1.3) where the possible limitations, complaints will be reflected. By the end of the 1<sup>st</sup> Wave, the summarization will be presented in the report of WP2 and will be used (together with all monthly reports along the way) to adapt the system for the validation phase.

## 5 TeNDER DATA MODEL

In previous deliverables, we provided the first draft of entities to follow a logical data model to give a structure to all types of data to collect, handle and save in Tender Hub and platform. In this description we are not going to take into consideration the data workflow, so we are going to describe the entities overlying the low-level subsystem and high-level subsystem subdivision.

Since we used the HL7 FHIR resources (v4.0.1) [44], there is an obligation on using its data model. It's a verified and valid structure and cannot be changed but it's possible to create extensions.

To create the entities and their relations, we relied on Health Level Seven International as a guideline. It is a global authority on standards for interoperability of health information technology approved by the European Commission. Nowadays, HL7 FHIR contains more than 100 resources that provide the necessary tools for the correct and efficient behaviour of the platform that integrates it. The resources are related between them by identifier keys, which are used as references.

For a better organization and search, these resources can be grouped by different keys [16]:

- **Category:** the resources are separated into five general categories (Foundation, Base, Clinical, Financial and Specialized) that contain more specific and objective ones to improve and facilitate their identification.
- **Alphabetical:** they are grouped in alphabetically ascending order.
- **R2 Layout:** the resources are organized in six different categories (Clinical, Identification, Workflow, Infrastructure, Conformance, and Financial) similar to the "Category" key but using a different identification approach.
- **Maturity:** they are divided by maturity levels, from zero to level five. The higher the level, the more stable and complete the resource is.
- **Security Category:** the resources are organized by security categories (Anonymous, Business, Individual, Patient, Not Classified, and Not Applicable).
- **Standards Status:** they are organized by normative (content is stable and has been 'locked') and trial use status (approved as an official standard but it has not yet seen widespread use in production across the full spectrum of environments).
- **Committee:** the resources are grouped by different committees that are responsible for their certification and correct use.

For the first wave of piloting, we used the resources that were better suited to the data that we need to store with the intent of future improvement, both in terms of the amount of information and its correct allocation.

Regarding the users, we define them with three types of resources:

- *Patient*: for patients.
- *Practitioner*: For professionals and formal caregivers. Each Practitioner can have several roles by using the "PractitionerRole" resource, where practitioners can be associated with an organization and a specific role.
- *RelatedPerson*: for informal caregivers and family members that will take care of patients.

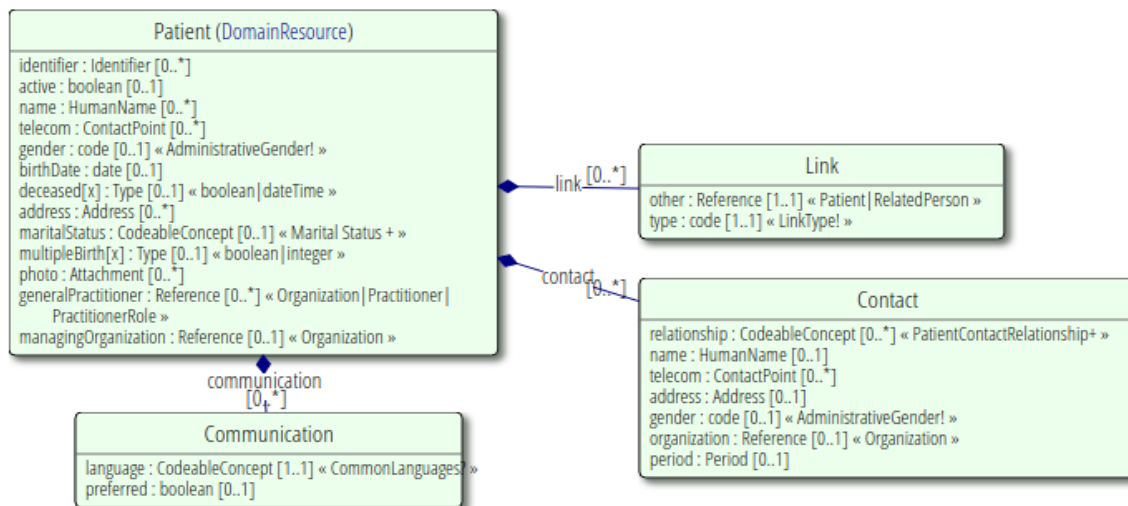


Since the platform must include several different organizations, they can and should be created to guarantee an organized structure. The resource “Organization” it’s responsible for the management and storing of each organization registered on the server. Having this layer, we can associate groups, persons, roles, and all non-general information to an “Organization” using its unique identifier, which is created automatically by the system (all resources implement this feature).

For a better explanation about the most important resources, the following subsections refer to how they are structured in the database and how they communicate with each other. Some examples will be shown to explain how the information can be requested.

### 5.1. Patient

The following example show the Patient’s model where we can see several external references, which provides crucial connections.



(Source: <https://www.hl7.org/fhir/patient.html>)

Figure 31: Data model for patient and relations to others

In the image above, it’s exposed the Patient’s model domain resource and the integrated resources. In the Patient’s model, we can verify several references values that can be defined like:

*generalPractitioner*: [ { reference: “Practitioner/123123” } ]

With the following reference, the patient will be related to the Practitioner with the unique identifier “123123”.

The Patient’s model can be better understood in the following JSON format.



```

{
  "resourceType" : "Patient",
  // from Resource: id, meta, implicitRules, and language
  // from DomainResource: text, contained, extension, and modifierExtension
  "identifier" : [{ Identifier }], // An identifier for this patient
  "active" : <boolean>, // Whether this patient's record is in active use
  "name" : [{ HumanName }], // A name associated with the patient
  "telecom" : [{ ContactPoint }], // A contact detail for the individual
  "gender" : "<code>", // male | female | other | unknown
  "birthDate" : "<date>", // The date of birth for the individual
  // deceased[x]: Indicates if the individual is deceased or not. One of these 2:
  "deceasedBoolean" : <boolean>,
  "deceasedDateTime" : "<dateTime>",
  "address" : [{ Address }], // An address for the individual
  "maritalStatus" : { CodeableConcept }, // Marital (civil) status of a patient
  // multipleBirth[x]: Whether patient is part of a multiple birth. One of these 2:
  "multipleBirthBoolean" : <boolean>,
  "multipleBirthInteger" : <integer>,
  "photo" : [{ Attachment }], // Image of the patient
  "contact" : [{ // A contact party (e.g. guardian, partner, friend) for the patient
    "relationship" : [{ CodeableConcept }], // The kind of relationship
    "name" : { HumanName }, // A name associated with the contact person
    "telecom" : [{ ContactPoint }], // A contact detail for the person
    "address" : { Address }, // Address for the contact person
    "gender" : "<code>", // male | female | other | unknown
    "organization" : { Reference(Organization) }, // C? Organization that is associated with the
    contact
    "period" : { Period } // The period during which this contact person or organization is vali
    d to be contacted relating to this patient
  }],
  "communication" : [{ // A language which may be used to communicate with the patient about his
  or her health
    "language" : { CodeableConcept }, // R! The language which can be used to communicate with
    the patient about his or her health
    "preferred" : <boolean> // Language preference indicator
  }],
  "generalPractitioner" : [{ Reference(Organization|Practitioner|
  PractitionerRole) }], // Patient's nominated primary care provider
  "managingOrganization" : { Reference(Organization) }, // Organization that is the custodian of
  the patient record
  "link" : [{ // Link to another patient resource that concerns the same actual person
    "other" : { Reference(Patient|RelatedPerson) }, // R! The other patient or related person r
    esource that the link refers to
    "type" : "<code>" // R! replaced-by | replaces | refer | seealso
  }]
}

```

Figure 32: Patient's model in JSON format

It's possible to visualize each key and its value's type, which can be a simple value like a boolean (true or false), a date, a code, or a more complex structure, *CodeableConcept*. Its structure is a collection of values that provides a more complete and flexible definition of the key. It can include anonymization codes, display text, etc. The following image exposes an example of a *CodeableConcept* object.

```

"valueCodeableConcept": {
  "coding": [
    {
      "system": "http://snomed.info/sct",
      "code": "260385009",
      "display": "Negative"
    }, {
      "system": "https://acme.lab/resultcodes",
      "code": "NEG",
      "display": "Negative"
    }
  ],
  "text": "Negative for Chlamydia Trachomatis rRNA"
}

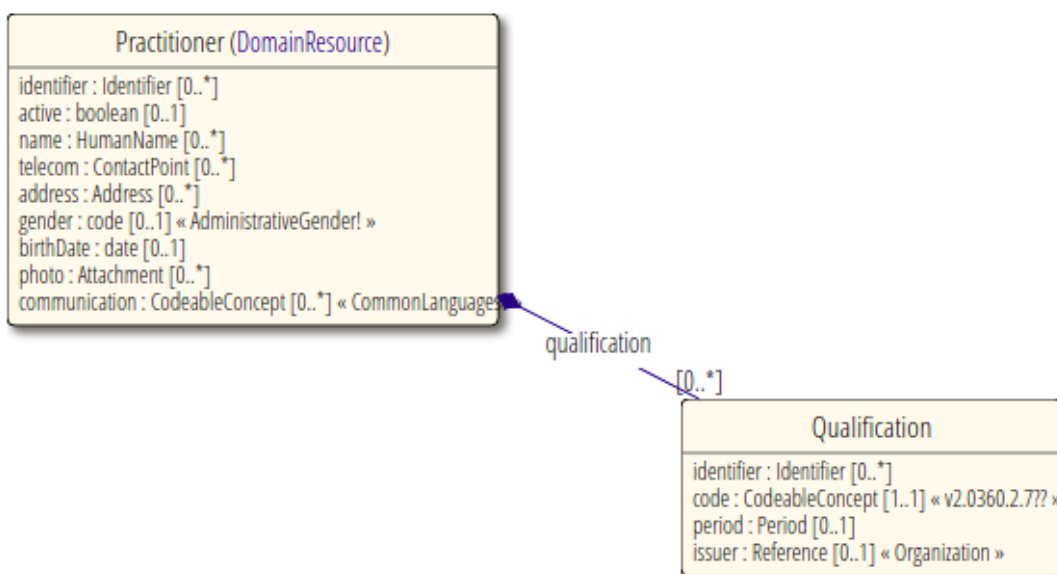
```

(Source: <https://www.hl7.org/fhir/datatypes.html#CodeableConcept>)

Figure 33: Codeable Concept

## 5.2 Practitioner

As we provide in the Patient’s model, the following image exposes the Practitioner’s data model.



(Source: <https://www.hl7.org/fhir/practitioner.html>)

Figure 34: Practitioner’s data model

In Practitioner resource, it’s defined the general info of the user where its qualifications can be added, to validate its roles.

```

{
  "resourceType" : "Practitioner",
  // from Resource: id, meta, implicitRules, and language
  // from DomainResource: text, contained, extension, and modifierExtension
  "identifier" : [{ Identifier }], // An identifier for the person as this agent
  "active" : <boolean>, // Whether this practitioner's record is in active use
  "name" : [{ HumanName }], // The name(s) associated with the practitioner
  "telecom" : [{ ContactPoint }], // A contact detail for the practitioner (that apply to all roles)
  "address" : [{ Address }], // Address(es) of the practitioner that are not role specific (typically home address)
  "gender" : "<code>", // male | female | other | unknown
  "birthDate" : "<date>", // The date on which the practitioner was born
  "photo" : [{ Attachment }], // Image of the person
  "qualification" : [{ // Certification, licenses, or training pertaining to the provision of care
    "identifier" : [{ Identifier }], // An identifier for this qualification for the practitioner
    "code" : { CodeableConcept }, // R! Coded representation of the qualification
    "period" : { Period }, // Period during which the qualification is valid
    "issuer" : { Reference(Organization) } // Organization that regulates and issues the qualification
  }],
  "communication" : [{ CodeableConcept } // A language the practitioner can use in patient communication
}

```

(Source: <https://www.hl7.org/fhir/practitioner.html>)

Figure 35: Practitioner's model in JSON format

Since a *Practitioner* can have several roles in several organizations, to define them, the FHIR provides a resource already referred to, named *PractitionerRole*. This resource has the necessary fields to define which *Practitioner* will have a specific role in a specific organization.

For the *Practitioner's* users, we have professional's and formal caregiver's roles.

### 5.2.1 Formal Caregiver

For this type of user, the following code is used.

```

"coding": [
  {
    "system": "http://snomed.info/sct",
    "code": "133932002",
    "display": "Formal Caregiver"
  }
]

```

Figure 36: Code for the formal caregiver as a user

This 'coding' it's defined in the *PractitionerRole* and it's the value that enables the differentiation between roles. The 'system' and 'code' values are real values and are used for anonymization purposes.

### 5.2.2 Professionals

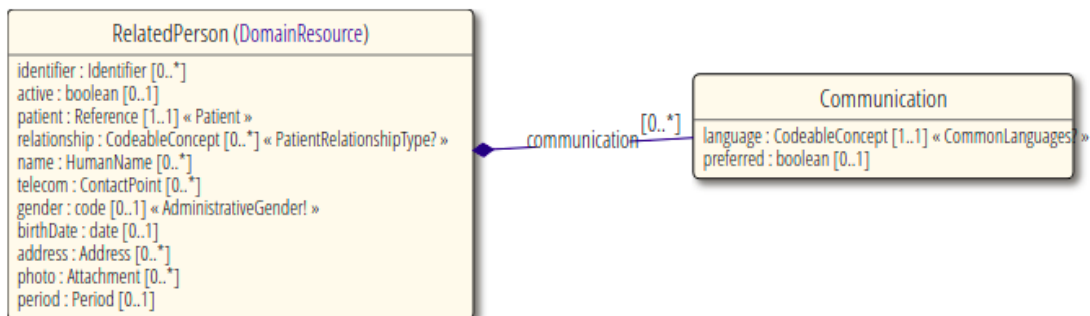
The professional's users have three types of possible roles:

- Health Professionals;
- Social workers;
- Other Professionals.

Each role has a specific code, like in the formal caregiver case. This is an important step to deferred all the possible roles and defines their permissions in the platform.

### 5.3 Related Person

This resource it's used to create users that are not associated with a specific organization. Their relation's only with the patient. The following image exposes the *RelatedPerson*'s data model.



(Source: <https://www.hl7.org/fhir/relatedperson.html>)

Figure 37: Related Person's data model

The 'patient' field will have the reference to a specific patient, using its identifier ('id') for the correct association. It's a simpler model since there are no additional resources for the role's definition or to the organization's association.

```

{
  "resourceType": "RelatedPerson",
  // from Resource: id, meta, implicitRules, and language
  // from DomainResource: text, contained, extension, and modifierExtension
  "identifier": [{ Identifier }], // A human identifier for this person
  "active": <boolean>, // Whether this related person's record is in active use
  "patient": { Reference(Patient) }, // R! The patient this person is related to
  "relationship": [{ CodeableConcept }], // The nature of the relationship
  "name": [{ HumanName }], // A name associated with the person
  "telecom": [{ ContactPoint }], // A contact detail for the person
  "gender": "<code>", // male | female | other | unknown
  "birthDate": "<date>", // The date on which the related person was born
  "address": [{ Address }], // Address where the related person can be contacted or visited
  "photo": [{ Attachment }], // Image of the person
  "period": { Period }, // Period of time that this relationship is considered valid
  "communication": [{ // A language which may be used to communicate with about the patient's health
    "language": { CodeableConcept }, // R! The language which can be used to communicate with the patient about his or her health
    "preferred": <boolean> // Language preference indicator
  }]
}
    
```

(Source: <https://www.hl7.org/fhir/relatedperson.html>)

Figure 38: Related Person's model in JSON format

It's important to mention that only one patient can be related to the user-created through this resource.

Using the same object as mentioned in *Formal Caregiver*, the 'relationship' field it's used to define the specific role of each user. For the TeNDER case, it was defined two types of related persons: informal caregiver and family member. For now, both have the same permissions but they will be changed for the next pilot.

#### 5.4. Living Environment

For the living environment, at least two resources are used.

Since each patient will have specific main environments associated, they are chosen on its registration process. The possible environments are:

- Home;
- Hospital;
- Day-care Center;
- Rehabilitation Room;

Each environment has its internal locations. For these locations, the *Location* resource it's used to enable the creation of locations and the association with the main environments. The following image it's related to the Location's data model.

```

{
  "resourceType": "Location",
  // from Resource: id, meta, implicitRules, and language
  // from DomainResource: text, contained, extension, and modifierExtension
  "identifier": [{ Identifier }], // Unique code or number identifying the location to its user
  "status": "<code>", // active | suspended | inactive
  "operationalStatus": { Coding }, // The operational status of the location (typically only for a bed/room)
  "name": "<string>", // Name of the location as used by humans
  "alias": [ "<string>" ], // A list of alternate names that the location is known as, or was known as, in the past
  "description": "<string>", // Additional details about the location that could be displayed as further information to identify the location beyond its name
  "mode": "<code>", // instance | kind
  "type": [ { CodeableConcept } ], // Type of function performed
  "telecom": [ { ContactPoint } ], // Contact details of the location
  "address": { Address }, // Physical location
  "physicalType": { CodeableConcept }, // Physical form of the location
  "position": { // The absolute geographic location
    "longitude": <decimal>, // R! Longitude with WGS84 datum
    "latitude": <decimal>, // R! Latitude with WGS84 datum
    "altitude": <decimal> // Altitude with WGS84 datum
  },
  "managingOrganization": { Reference( Organization ) }, // Organization responsible for provisioning and upkeep
  "partOf": { Reference( Location ) }, // Another Location this one is physically a part of
  "hoursOfOperation": [ { // What days/times during a week is this location usually open
    "daysOfWeek": [ "<code>" ], // mon | tue | wed | thu | fri | sat | sun
    "allDay": <boolean>, // The Location is open all day
    "openingTime": "<time>", // Time that the Location opens
    "closingTime": "<time>" // Time that the Location closes
  } ],
  "availabilityExceptions": "<string>", // Description of availability exceptions
  "endpoint": [ { Reference( Endpoint ) } ] // Technical endpoints providing access to services operated for the location
}

```

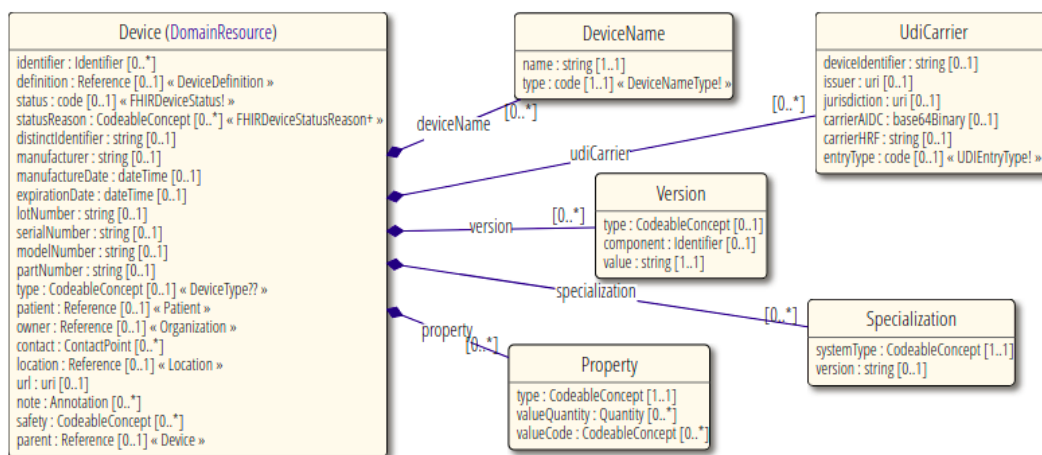
(Source: <https://www.hl7.org/fhir/location.html>)

Figure 39: Location's data model

In order to manage the correct organization and association, the main environments are defined as main locations as well. Then, the locations on each environment are created with the field *'partOf'*, where the main location's identifier it's added. Through this step, all the locations are correctly set which enables the addition, edition, or even the removal of the child locations.

## 5.5. Device

Since the TeNDER solution includes the usage of several devices, they need to be registered and posteriorly associated with the patients.



(Source: <https://www.hl7.org/fhir/device.html>)

Figure 40: Association of the devices with a patient

By visualizing both data model structure and the fields' type and explanation (Figure 39 and 40), it's possible to see the complexity and the countless fields that this resource provides. Each Device can be associated with a specific user (patient) and still be related to an organization as its owner. It's even possible to define their location with the available locations previously created for each environment.

```

{
  "resourceType": "Device",
  // from Resource: id, meta, implicitRules, and language
  // from DomainResource: text, contained, extension, and modifierExtension
  "identifier": [{ Identifier }], // Instance identifier
  "definition": { Reference(DeviceDefinition) }, // The reference to the definition for the device
  "udiCarrier": [{ // Unique Device Identifier (UDI) Barcode string
    "deviceIdentifier": "<string>", // Mandatory fixed portion of UDI
    "issuer": "<uri>", // UDI Issuing Organization
    "jurisdiction": "<uri>", // Regional UDI authority
    "carrierAIDC": "<base64Binary>", // UDI Machine Readable Barcode String
    "carrierHRF": "<string>", // UDI Human Readable Barcode String
    "entryType": "<code>" // barcode | rfid | manual +
  }],
  "status": "<code>", // active | inactive | entered-in-error | unknown
  "statusReason": [{ CodeableConcept }], // online | paused | standby | offline | not-ready | transition-disconnected | hardware-disconnected | off
  "distinctIdentifier": "<string>", // The distinct identification string
  "manufacturer": "<string>", // Name of device manufacturer
  "manufactureDate": "<dateTime>", // Date when the device was made
  "expirationDate": "<dateTime>", // Date and time of expiry of this device (if applicable)
  "lotNumber": "<string>", // Lot number of manufacture
  "serialNumber": "<string>", // Serial number assigned by the manufacturer
  "deviceName": [{ // The name of the device as given by the manufacturer
    "name": "<string>", // R! The name of the device
    "type": "<code>" // R! udi-label-name | user-friendly-name | patient-reported-name | manufacturer-name | model-name | other
  }],
  "modelName": "<string>", // The model number for the device
  "partNumber": "<string>", // The part number of the device
  "type": { CodeableConcept }, // The kind or type of device
  "specialization": [{ // The capabilities supported on a device, the standards to which the device conforms for a particular purpose, and used for the communication
    "systemType": { CodeableConcept }, // R! The standard that is used to operate and communicate
    "version": "<string>" // The version of the standard that is used to operate and communicate
  }],
  "version": [{ // The actual design of the device or software version running on the device
    "type": { CodeableConcept }, // The type of the device version
    "component": { Identifier }, // A single component of the device version
    "value": "<string>" // R! The version text
  }],
  "property": [{ // The actual configuration settings of a device as it actually operates, e.g., regulation status, time properties
    "type": { CodeableConcept }, // R! Code that specifies the property DeviceDefinitionPropertyCode (Extensible)
    "valueQuantity": [{ Quantity }], // Property value as a quantity
    "valueCode": [{ CodeableConcept }], // Property value as a code, e.g., NTP4 (synced to NTP)
  }],
  "patient": { Reference(Patient) }, // Patient to whom Device is affixed
  "owner": { Reference(Organization) }, // Organization responsible for device
  "contact": [{ ContactPoint }], // Details for human/organization for support
  "location": { Reference(Location) }, // Where the device is found
  "url": "<uri>", // Network address to contact device
  "note": [{ Annotation }], // Device notes and comments
  "safety": [{ CodeableConcept }], // Safety Characteristics of Device
  "parent": { Reference(Device) } // The parent device
}

```

(Source: <https://www.hl7.org/fhir/device.html>)

Figure 41: Associations



As explained earlier, most of the *Device* is associated with one patient only. It could bring some problems to the creation of localization devices. These devices are in a room and collect data from several patients. To manage this specific case scenario, we create several *Devices* with the same name and serial number/MAC address, changing, of course, the patient identifier. Having all the *Devices* created, depending on the user who is in the room at a specific time, the administrator needs to deactivate or activate them. It is a time-consuming process, but a task scheduler is being developed to help with this type of management. It will provide the correct tools for each administrator to plan the activations and deactivations, which will occur automatically.

#### 5.4. Signal

With the explanation of some of the used resources and their internal relations, we can verify that the information is well related and organized, which provides correct and objective data when requested. Since the API provided by the HAPI FHIR is quite flexible (allows the use of several specific parameters to improve the filtering and search), all the data can be easily accessed (depending on the permissions), which enhances the data workflow.

It's important to mention that, first of all, all the data is verified before its storage, which prevents the storage of bad structured or duplicated data. In this case, signal entities are connected to devices, as in Table 11.

Table 10: Devices and signal entities connection

Position-tracker	
Attributes	Description
<b>Id</b>	Patient's identifier. Type: text
<b>Session</b>	Session's ID code. Type: text
<b>Client</b>	Client's ID number. Type: integer
<b>SensorID</b>	Sensor's identifier. Type: text
<b>Timestamp</b>	Time-stamp in which data are transmitted. Type: datetime
<b>Rssi</b>	Received signal strength indicator. Type: integer
<b>Mac</b>	Medium Access Control address. Type: text
<b>Location</b>	Geographical location identifier. Type: text
<b>last_time_ping</b>	Date of the last ping received from the remote host. Type: datetime
Sleep-tracker	
Attributes	Description
<b>Id</b>	Patient's identifier. Type: text
<b>Session</b>	Session's ID code. Type: text
<b>Client</b>	Client's ID number. Type: integer
<b>SensorID</b>	Sensor's identifier. Type: text
<b>Timestamp</b>	Time-stamp in which data are transmitted. Type: datetime
<b>heart_rate</b>	Number of heart-beats per minute. Type: integer
<b>respiration_rate</b>	Number of breaths per minute. Type: integer
<b>snoring_rate</b>	Snoring intensity. Type: integer
<b>sleep_state</b>	Indicates whether the individual is sleeping or not. Type: integer
<b>device_name</b>	Device's name. Type: text



Voice-tracker	
Attributes	Description
<b>id</b>	Patient's identifier. Type: text
<b>SensorID</b>	Sensor's identifier. Type: text
<b>predicted_class</b>	Predicted voice's class. Type: text
<b>timestamp</b>	Time-stamp in which data are transmitted. Type: datetime
<b>score</b>	Voice-tracker's score. Type: float
<b>features</b>	Voice-tracker's features (e.g. MIC level, Frequency response, Physical dimensions). Type: list
Physical-tracking (wristband)	
Attributes	Description
<b>id</b>	Patient's identifier. Type: text
<b>Band_ID</b>	Band's identifier. Type: text
<b>Client</b>	Client's ID number. Type: integer
<b>SensorID</b>	Sensor's identifier. Type: text
<b>timestamp</b>	Time-stamp in which data are transmitted. Type: datetime
<b>Move_evolution</b>	Movement identifier. Type: text
<b>Bio-measures</b>	Biological measurements (e.g. blood pressure, height, weight). Type: text
Azure Kinect / Kinect v02	
Attributes	Description
<b>id</b>	Patient's identifier. Type: text
<b>Skeleton ID</b>	Skeleton's identifier. Type: integer
<b>SensorID</b>	Sensor's identifier. Type: text
<b>timestamp</b>	Time-stamp in which data are transmitted. Type: datetime
<b>Move_evolution</b>	Bodies' Coordinates. Type: float
<b>Measures</b>	Fall

## 6 Objectives in Co-design (pre-piloting phase and 1st Wave of piloting)

The main objective "Follow participatory design process" (Objective 6) covers the Co-design with relevant stakeholders (elders, carers, doctors) during all TeNDER stages:

- the definition of the functional specifications of the TeNDER ecosystem and services;
- the elaboration of the functional specifications into actual platform requirements;
- the design of the sub-goals that will drive the service recommendations;
- the current and realistic evaluation procedure, where elderly will use existing solutions (early in the project to practically guide the functional specification gathering) and the TeNDER ecosystem and services; and
- the assessment phases that will receive their feedback coming from the evaluations and use it to refine and improve TeNDER offerings.

The co-design process with all stakeholders is spanning through the pre-piloting phase, and the 2 Waves of the piloting phase. As concerns the objective mentioned above, TeNDER measures its success through key performance indicators (KPIs) improvements, described in the Table 12.

Table 11: KPI-s of the Co-design process

	KPI description	pre-piloting phase	Mock Up testing and 1st Wave of piloting (ongoing)
KPI 1 (Obj 6)	Producing more than 10 intervention programs.	General service provision flows defined for people with AD, PD and CVD.	Production will be performed with all the stakeholders recruited, especially professionals and validated accordingly
KPI 2 (Obj 6)	Include over 3 different types of stakeholders and service users across the various co-design phases	Patients (AD, PD, CVD), caregivers and professionals included in surveys and interviews	Patients, caregivers and professionals included in Mock-Ups interfaces testing and for feedback gathering in piloting phase
KPI 3 (Obj 6)	Involve at least 20 end-users in co-design process	70 < patients 70 < caregivers 50 < professionals	60 < patients 30 < caregivers 40 < professionals
KPI 4 (Obj 6)	100% coverage of end-user requirements through functional validation during TeNDER' test phases	Covered 100%: User requirements gathered through interviews and surveys with patients from all groups (AD, PD, CVD), their caregivers, professionals from health and social sector	Covered 100%: User requirements gathered through observations and interviews with each participant (included patients with AD, PD, CVD, their caregivers, health professionals, social workers and other workers, as recruited participants will be reported in D6.2)

## 7 CONCLUSIONS

Herein TeNDER partners report on user requirements in so far of the project development and also present the intermediate TeNDER data model. Co-design process provides TeNDER partners insights for a better understanding of participants and at the same time engages the participants in the development of the solutions that are better responding to their particular needs. This process brings people with real experience on the subject into the TeNDER design process as active participants while collaborating with a variety of actors and stakeholders to maximize the implementation of the solutions resulting from this process.

As TeNDER is built on the technological tools that are still not well adopted from users TeNDER is addressing, we are maximizing all stakeholders` involvement to ensure the optimal project outcomes. The TeNDER system was framed and firstly relied on an initial perception of what people really want, need and what are the conditions for introducing the technologies, mainly from the knowledge from previous projects (ICT4Life). The engagement of participants was set from the very beginning, with first phase – the observation-exploration phase that included expertise and knowledge from several project partners and when the observational study was performed with interviews and surveys. Thus, we are all continuously improving our knowledge of users` real needs, which will facilitate the validation of the system and ensure long-term benefits. Following the participatory design, partners are continuously involving as much users as possible to collect their feedback and advice on the development of the tools. Through co-design process we then define typical users as "Personas".

Moreover, we have also checked the latest literature on user perception and limitations found when implementing the technology with dedicated groups and a brief literature review is included in this document. Accordingly, we have merged our previously reported barriers found from the work in Task 1.4 and we are expanding it through the piloting phase of the project in accordance to the evaluation strategies and protocols set in Deliverable 1.3.

The document also contains the description of Intermediate TeNDER Data model with related contents in regard to patient, practitioner, related person, but also living environments included in testing, devices association with patients and how it is assured that the information is well related and organized, which may provide correct and objective data when requested.

The future work in co-design process is proceeding in WP2, Task 2.3, where the collaboration aspects that are going to be tested in the next Wave of piloting, will be addressed. Partners are piloting the first TeNDER solution with the participants and observations and feedbacks are gathered. In the piloting Wave that will also allow the active participation of different professionals involved, the involvement of health care and social care professionals will be implemented to synchronize the health- and social- services and allow the communication flows among different professionals. The platform evolution and the communication channels will be co-created together with the users and will facilitate integrated care service from different care perspective to reach the patient.

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