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Deliverable 2.5
Final version of User Requirements and Data Model

Work Package 2: Co-design Process

affecTive basEd iNtegrateD carE for betteR Quality of Life: TeNDER Project

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The TeNDER consortium consists of the following Partners.

Table 1 - Consortium Partners List

No	Name	Short name	Country
1	UNIVERSIDAD POLITECNICA DE MADRID	UPM	Spain
2	MAGGIOLI SPA	MAG	Italy
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
8	FEDERATION EUROPEENNE DES HOPITAUX ET DES SOINS DE SANTE	HOPE	Belgium
9	SERVICIO MADRILENO DE SALUD	SERMAS	Spain
10	SCHON KLINIK BAD AIBLING SE & CO KG	SKBA	Germany
11	UNIVERSITA DEGLI STUDI DI ROMA TOR VERGATA	UNITOV	Italy
12	SLOVENSKO ZDRUŽENJE ZA POMOČ PRI DEMENCI - SPOMINČICA ALZHEIMER SLOVENIJA	SPO	Slovenia
13	ASOCIACION PARKINSON MADRID	APM	Spain

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[1] **R:** Document, report; **DEM:** Demonstrator, pilot, prototype; **DEC:** Websites, patent fillings, videos, etc.; **OTHER**; ETHICS: Ethics requirement; ORDP: Open Research Data Pilot.

[2] **PU:** Public; **CO:** Confidential, only for members of the consortium (including the Commission Services).

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Acronyms and Abbreviations

Acronym/Abbreviation	Description
AD	Person with Alzheimer's Disease or other form of dementia or mild cognitive impairment
CRDe	electronic data collection notebook
CVD	Person with Cardiovascular Disease
PD	Person with Parkinson's Disease
QoL	(Health related) Quality of Life
TeNDER	affecTive basEd iNtegrateD carE for betteR Quality of Life
WPx	Work Package

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Executive Summary

TeNDER is a multi-sectoral project within which 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. For improving the well-being of a person with dementia, we need to facilitate quality life of that person, the care partner and others involved in the care pathway. Therefore, the inclusive design is needed, that means to listen and understand the peoples` needs and wishes that were summarized under the WP2 work and are generally presented in this document. TeNDER connects several stakeholders that are going to use the tool, therefore, in order to help patient`s relatives and others in their care pathway to address difficulties experienced in independent living and patient`s care arrangement, the requirements span different aspects. In TeNDER, we will adapt the system's probes to the person's needs via a multi-sensorial system accordingly.

The WP2 TeNDER tasks ensure that the TeNDER ecosystem is co-designed with all relevant stakeholders as well as user and functional requirements cover broad parts of the system that is being developed and used. The first co-design process phase was set and performed in pre-piloting of the project while the second co-design phase is spanning through the 1st and 2nd Wave of the TeNDER piloting. The co-design process has thus been carried on throughout surveys, interviews, group sessions and internal discussions, the Mock-Up testing and is spanning through the testing piloting phase through open questions and observations. Accordingly, the insights are reported and possible challenges are discussed so that adaptations may be applied. Herein, the process is described and linked to already reported documents, cases for the interventional requirements are presented accordingly. Through the scenarios we are 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. This document presents the final report on user requirements and final data model for the TeNDER system. According to the methodology that was presented in previous documents, partners developed typical users to facilitate the workflow within the project, but also included broader range of the stakeholders (as institutions, authorities etc.) to enhance the social service component of the tool. We present the findings that mostly show that the stakeholders recognize the usefulness of the social tool that would connect patients, carers and the professionals. Moreover, based on the previously reported insights and the analysis, the main findings from co-design process are summarized, with the emphasis on the interface interaction, implementation, stigma and human contact, but most importantly, the companion of carers and professionals that are involved in patients' care. Finally, the final TeNDER data model is presented.

1 INTRODUCTION

With increasing need for community-based integrated care to meet rapidly ageing societies, but also health and other care services carried out at different living environments of the patients, the value of the technology has increased. As 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, is that the number of people with neurological diseases is likely to grow rapidly. Moreover, we are facing the fragmentation of the care-services as already reported in previous WP2 Deliverables. Therefore, within TeNDER we are empowering patients, their families and others via a care pathway by addressing difficulties experienced in independent living and care management.

Various types of products are already on the market and their related services are being used, but the variety of product can create challenges to the users. Therefore, despite the fact that many products and services 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 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

Codesign brings the opportunity to identify common challenges and values and discuss how best to address them. The concept of co-design emerges from the strategy of User Centred Design that is one of the first's methods to describe the participatory design. The conception of co-design may be different depending on the area but has a common goal to involve as many and different people as possible for a variety of disciplines at the design process to get from the different designs and functionalities a shared consensus of the final product/service that may fit all the cases. Therefore, different groups of stakeholders were included in co-design of TeNDER. The participants have thus been involved in the formulation of our solutions. Through co-design process, we defined typical users as "Personas" (TeNDER Deliverable 2.4) and typical set as "scenarios" (TeNDER Deliverable 2.3).

The final report on the user requirements and data model of the TeNDER system is closing the co-design process of the large-scale piloting phase of the project. The purpose is to summarize the co-design process carried out within TeNDER and the general insights gathered from different stakeholders that are potential users of future TeNDER tool. The reported insights within WP2 are cross-referenced and summarized and the most relevant new contributions in social-service co-design are presented. Finally, the presented final data model of the TeNDER tool is going to be used for the final TeNDER validation step.

1.2 Contribution to other deliverables

The present deliverable will contribute to the final development and validation 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. The update of this document will be in TeNDER Deliverable D2.7.

1.3 Structure of the document

The Deliverable 2.5 is structured into 6 sections:

- Presentation of the document, scope and purpose.
- Summarization of user, functional and general requirements.
- Presentation of reached objectives and KPIs in co-design process.
- Main findings form the co-design process.
- Conclusion with main future guidance from user requirement perspective.
- Data model approach of TeNDER system.

2 SUMMARY OF USER, FUNCTIONAL AND GENERAL REQUIREMENTS

In the first phase, partners jointly checked the existing provisions flow and together developed the service matching table (Annex 1) that guided the partnership in the development of the tool. The existing situation in the different countries involved was summarized, the knowledge from previous projects and from the state of the art relevant literature was integrated (TeNDER Deliverable 2.1).

According to this, we defined common approaches towards the primary (patients, that are and must be at the core of the co-creation process) and secondary users (their caregivers and health care professionals), for inclusive research of their common and differential needs (TeNDER Deliverable 2.1 and 2.2, TeNDER Research Book). Use case stories reflected daily problems faced by a person with disease and his / her carers, also support that can be provided by professionals (reported in TeNDER Deliverable 2.3). TeNDER solutions and services that may be applied were framed. The key outcomes were the report on existing service provision and guidance for conducting the study. The users` needs were investigated further on through the observational study with questionnaires and interviews and summarized findings were presented as Persona cards (TeNDER Deliverable 2.4, Figure 1). "Personas" are fictional representations of the actual users. Taking common user needs and bringing them to the forefront of planning is key component for the future design. Persona cards therefore provided the insights with a shared understanding of users in terms of goals and capabilities to the entire TeNDER team. Moreover, they also gave an opportunity to discuss critical features. Since Personas focus on the needs of the users, the team can walk through the proposed scenarios and determine optimal placement of content to support the goal of the product. Because Personas are fictional representations of actual users, they'll only work if we fully understand who our users are – or will be. Therefore, several domains were checked and through the reported needs, the customization was allowed. Partners also analysed the potential limitations for the use of the technology and the barriers were discussed to allow the user-friendly development of TeNDER tool. The insights from the field work and reports in Deliverables was continuously passed to the technical team of TeNDER.

2.1 Methodology for delivering user requirements

To facilitate the inter-consortia information flow, regular online meetings were established, and partners developed joint documents where the service provisions were defined according to the previous knowledge and the proposed TeNDER tool. Service provisions were developed for each patient group (AD, PD, CVD) and environment of the testing (home, day-care centre, rehabilitation room, hospital). The proposed functionalities were grouped, the devices were assigned and brief description (general purpose of use, if any, target group), general description of operation (if any additional setups, any risks with installation foreseen), type of possible collected data, requirements for the device installation (steps for installing the device at premises of end users), proposed device location and basic concepts were described. The service cluster was assigned for each of those and possible open questions on the ethics, barriers, data protections were discussed (Annex 1).

User requirements were gathered according to the methodology following the procedures described in previous deliverables (for pre-piloting Deliverable 2.1; Methodology for co-creation process; Deliverable 2.2; Assessment methodology; Deliverable 2.3; TeNDER common approach and methodology; Real-world scenarios and use cases; and Deliverable 2.4). Therefore, the requirements from patients, caregivers and professionals have been collected about their (met and unmet) needs, as well as their perceptions 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 TeNDER Deliverable 1.3.

The continuous internal discussion within the consortia and by involving the health and social professionals to identify different types of interactions that could occur in the TeNDER system allowed partners to broaden the approaches. Consortia used the Centralized User Requirement Table (Table structure in Annex 2) to facilitate the navigation through the requirements and cross-referenced in detailed descriptions in other project documents (like: question and answer documents, excel tables with proposed text and statements, PPT with comments for the visualizations, pictures for the proposed visualizations from existing Apps that are already on the market, reports from meetings with users, reports from the interviews…). Partners therefore collected requirements from TeNDER partners and previous experiences from field work, from different users (patients, carers, professionals) through interviews and working groups/sessions and from technical partners. The categories were: device requirements, general functionality requirements, virtual assistant requirements, TeNDER App for patients and carers requirements, TeNDER WebApp for the professionals' requirements, TeNDER platform requirements for the administration profile, and TeNDER system requirements (Annex 2). TeNDER partners responsible to perform the piloting with patients, caregivers and professionals conducted meeting on a weekly basis and continuously gathered insights from colleagues and other relevant potential users, so that the functionalities, type of the interactions and requirements were as wide as possible. Thereafter, the partnership defined the most relevant and feasible requirements that were forwarded to the technical team and the discussion and evolvement happened. Moreover,

during the piloting phase, partners used observations and open questions for views and requirements collections at the end of the testing to validate the course of system development. During this latter period, partners also checked for user requirements from several other stakeholders (institutions, developers, authorities, professionals…) with the emphasis on TeNDER tool. Finally, within the TeNDER consortium, partners used several channels (online meetings, documents to gather possible scenarios for each functionality, collections of the listed requirements, question and answer documents etc.) to continuously pass the insights and brainstorm the possibilities to overcome the barriers with the design and implementation of the tool.

Partners performed interviews (Annex 3) with members of other institutions, local communities and authorities about the social service requirements and general requirements (reported in Section 2.3). Moreover, the dedicated social service component requirements for TeNDER were checked within the partnership and the feedback collection has been carried out through a questionnaire-designed ad-hoc hosted in an electronic data collection notebook (CRDe) within the EUSurvey[3] platform. The study population included the healthcare professionals that belong to each of the institutions participating in the pilots of the TeNDER tool.

The questionnaire (Annex 4) consists of 8 questions about their opinion on a social interaction tool for patients, carers, and professionals. Once they explored the tool being created, they were provided with the link to access the questionnaire. Half of the questions were Likert-type scales ranging from 1 (Strongly Disagree) to 5 (Strongly Agree).

2.2. User and Functional requirements

Partners identified the following functionalities that could be used for dedicated diseases in different environments of the TeNDER potential users:

- Medical examination (calendar for inputs)
- Adherence to drug treatment
- Quality of Sleep (nocturnal activities)
- Toilette usage (nocturnal activities)
- Emotional state detection (emotional status)
- Room-level localization (at the premises)
- Entrance door statuses (safety and wellbeing)
- Indoor environmental monitoring (safety and wellbeing)
- Fall detection (safety and wellbeing)
- Wandering prevention & Safety parameter (safe zones at the caretaker's or patient's premises)
- Medical examination/ daily plan schedule
- Physical activity (safety and wellbeing)
- Social service matching

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[3] https://ec.europa.eu/eusurvey/runner/SocialCocreation

The devices (sensors, PCs, mobile phones, wearables) were assigned to each functionality thereafter and adaptation of the feasible functionalities that could be tested within TeNDER was done. Technical development continued throughout this process and modular system was continuously checked together with users and taken into account their needs and expectations.

Figure 1: Persona cards examples (Reported in Deliverable 2.4)

According to some patients (especially those living with dementia), there is not a big need to use the technology. However, there was a difference observed on the personal level. Some people were very acceptable and would gladly try the system, while some expressed the interest to participate mostly based with the attitude to help others that have problems (as they perceived themselves as not having problems). The best accepted functionality for people with dementia was the sleep tracker, that needs no personal interaction, and a user just can check the report on the sleep data from the previous night, or cumulative data on the week or month. The patients also mention that it would be important that the system does not immediately act but gives the patient time to act by 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. Furthermore, the patients' motivation can be enhanced by showing their performance. Nevertheless, there are some tailored differences based on the disease and, especially, based on the stage of the disease. Therefore, the modularity of the system is needed, and different functions shall be adapted accordingly during the time of use.

The carers had, in some cases, different opinion on the state of the caretaker. Most carers accept the technologies, 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. Older carers also felt that they would need some training to be able to use the new technology independently and thus can benefit from it.

Finally, the professionals find the technology useful in professional practices in order to have better data and work management. Some professionals claimed that digital measurement devices enable more precise measurements 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 between sectors (TeNDER Deliverable 2.4).

The requirements collected through the centralized table (Annex 2) aimed to enable easy cross-referencing among different module development, but they also allowed an easy extraction of subsets of requirements that have been relevant to each of the core components of TeNDER, making it easier for developers, integrators, and pilot partners to comply with them. The specifications are primarily based on the outcomes of the users` needs and requirements analysis performed in WP2 and detailed in previous deliverables of this WP. Accordingly, several new specifications have been added to the list and reported through a Trello task tracker up to M33.

Patients` care monitoring requirements is covered within the TeNDER technical WPs. The carer is able to see the patient status and also able to communicate with the patient through the mobile TeNDER App. Then, a daily and weekly report is generated and can be visualized. Therefore, the carer can use monitoring data and information to analyse situation and start/adjust the level of support accordingly. The carer is also able to track the reminders that were created by him/her to the patient and if the patient checks/misses the important actions.

Further on, partners developed the Service Cluster 6 that is dedicated for the Communication according to the requirements that are presented in in Section2.3 of this document. The requirements for the Service Cluster 2 for Social Services Matching were collected and the

proposed questionnaire for the patients` and carers` needs was developed. Thereafter, partners collected possible output options (recommendations and proposed links to the local websites) that can be used by the professional that will communicate with the patient or carer.

2.3 Proposed cases for the intervention requirements

Based on the collected user needs, the proposed interventions were developed and have been precisely enhanced through the work in WP4 that will produce the Recommender module of TeNDER system.

Table 2: Interventional requirements

No.	Intervention requirement
1	a carer gets the alert/notification that the front door is opened / involved sensors: front door binary sensor
2	a patient gets the notification (only at night) that the front doors are left open / involved sensors: front door binary sensor
3	a carer gets the alert/notification that the front door is opened/(if) the patient may be leaving the apartment / involved sensors: (if) localization, front door binary sensor
4	a notification to a carer to check the patient due to the prolonged presence in a room (bathroom, … and/or low activity assumption) / involved sensors: localization sensor, binary sensor
5	a notification to a patient that the windows are left opened if he/she leaves the environment/ involved sensors: binary sensor on windows, (if) localization sensor
6	an alert to a carer to check the visualization of the environmental parameters in TeNDER/check the patient, a reminder to the patient (virtual assistant) / involved sensors: environmental sensor - possible rising of the temperature in the room - constantly high/low temperature in a room - high/low humidity detected
7	an alert and doctor/caregiver notification to check the measured data / involved sensors: Fitbit, heart beat rate
8	notification to a carer to verify the fall / involved sensors: Fitbit, (if)Kinect, (if)microphone
9	recommendation to the carer to check the sleep quality data / involved sensors: Withings analyser (sleep sensor) - general sleep score - duration of the sleep - sleep depth - sleep regularity (sleep habits) - interruptions of the sleep

10	notification to a carer and/or patient for the medication intake / App reminder scheduler
11	notification to a patient /App reminder for the events, appointments
12	notification to a carer if the event/appointment was not checked by a patient /App reminder or that a patient is skipping the activities
13	notification to a carer to check the patient /involved sensors: microphone for emotional detection, depth camera for emotion detection

2.3 Social impact and General requirements for the social service module

The study of social requirements involved the dedicated contribution from end-user entities and medical bodies in TeNDER. This way, we analysed the available technologies as well as we further collected needs and requirements of each specific category of end-users. The needs and requirements were collected in terms of services solution characteristics, interface and contents together with current fields of interaction among the involved actors.

The actors that were involved were health professionals, caregivers and associations, local authorities in the pilot countries. In order to achieve a complete picture of the system that incorporates the needs of all stakeholders and is supported by medical and social evidence, semi-structured key informant interviews were conducted (Table 4).

Table 3: Results from the interviews on social impact

Questions (Annex 4)	Actors involved	Key words
1	Local authorities	Social isolation
		Quality of life
		Chronic disease.
		Community based services
		Institutional care service
		Carers
	Health Professionals	Social isolation
		Life expectancy
		Quality of life
		technology as a solution
		Interdisciplinary mobile teams
		Professionalized care
		Chronic disease.
	Carers & Associations	Social isolation
		Ageing
		professionalized care
		Dependency
		Patients and carers
2	Local authorities	Funding
		Independence
		Inequalities
		Long-term care act
		Implementation
		Socio-sanitary resources
		Dependency Law.
		Economic impact,
	Health Professionals	Independence
		Accessibility
		Equality
		Investment
		Social policies
		Dependency law

	Carers & Associations	Independence
		Social and health resources.
		Adaption on time, low level of inclusion
3	**Local authorities**	Funding
		Socio-sanitary resources
		Economic impact
		Dependency Law
		Regulation of the status (informal care)
		Adapted environment
		Independence
		Medical devices
		Quality of life
	Health Professionals	Funding
		Informal caregivers
		Care training
		Financial resources
	Carers & Associations	Funding
		Informal caregivers
		Economic resources
		Support
4	**Local authorities**	Technology
		Advertisement
		Purpose
		Advertisement
		Purpose
		Public funding
		Competences
		Personal contacts
	Health Professionals	Technology
		Adaptation of technology to user
		Use of technologies
		Training
		Funding
	Carers & Associations	Technology
		Technology, monitoring, autonomy
		Advertisement
		Purpose
		Public funding
		Personal contacts
		Social activities and real contacts
		Privacy

The questionnaire on social service (Annex 4) was answered by a total of 12 health professionals. By participating institutions, SPO had 33.3% participation; APM and SERMAS had 25% participation each; and SKBA had 16.7%.

Out of all the professionals who responded to the questionnaire, 66.7% reported that having a social tool to communicate with patients and carers is useful. Only 25% of them stated that they were unsure of its usefulness. *From the professional point of view, it should be a help, a channel that facilitates their work, not an additional burden, so it is necessary to establish rules of contact, limit the type of interactions between the different stakeholders to avoid misunderstandings.*

Regarding the adequacy of the current application, 66.6% felt that the screen home was adequate. Those who did not perceive it as adequate offered the following recommendations:

- "I'm not sure if it's adequate":
    o *It would be more operational for me to see the messages addressed to me first, and then I could see other things. Also, to be able to clearly identify whether a professional, a caregiver or a patient is speaking, perhaps with a symbol for each.*
    o *More attractive, more visual and more intuitive.*
- *"I think it is inadequate":*
    o *Sometimes it is helpful to explain a little the purpose of the site. Also, for patients, in some countries, to feel safe about where to write comments, the use of official logos can help.*
    o *The interface is not intuitive or user-friendly. For older or less technologically savvy people, it is difficult to understand and manage. Implement a simple logic of use, very schematic. Better simple and useful than wanting to develop a lot of tools that people don't know how to use.*
- *"I think it is totally inadequate":*
    o *The home screen it has no order. There is a lot of letters and I cannot discriminate what is important*

When asked whether they found the interface intuitive and easy to use, 66.7% said yes. While those who felt otherwise offered the following recommendations:

- *"Until I get to a place where I can write and share my opinion is strongly difficult".*
- *"I would make a home page with some small instructions on how to use the interface".*

The 58.3% of the professionals thought that the menu and its options were complete and had everything they needed. The remaining percentage said the following:

- *"It could be more simplified – just to communicate and being in a group maybe; not too many subgroups".*
- *"It would establish a filter of information to share between different users".*
- *"It would be great to input a check-list (medication intake, feels good etc.)"*
- *"What means blog and what is the difference with giving my opinion in the activity group?"*

Half of the professionals interviewed stated that they would use it on a regular basis if it were available to them and included the recommendations they have provided. The remaining 50% are not sure about this, and comment as follows:

- *"Because it seems older people will get confused with a social platform. It is difficult for them to understand interactions through internet instead face2face".*
- *"Probably, most of this type of blogs/debates/feeds are usually carried out in a mobile app".*

In order to get more information and to be able to adapt the tool to their needs, they were also asked what they would need to use it often, to which they responded:

- *"Easier to use. In the first page a place where to write and share".*
- *"It should work quick and should save time. I am not interested into writing".*
- *"To have control over everything. As an administrator".*

Finally, the strengths of the tool as identified by practitioners are listed:

- *"It is very simple that is good, but it might be a little too much possibilities to choose from".*
- *"It is a good thing to have social contact".*
- *"It is useful and it saves time and gives security that patient is ok!"*
- *"It will be a quick and efficient way to communicate with other professionals, carers and patients."*
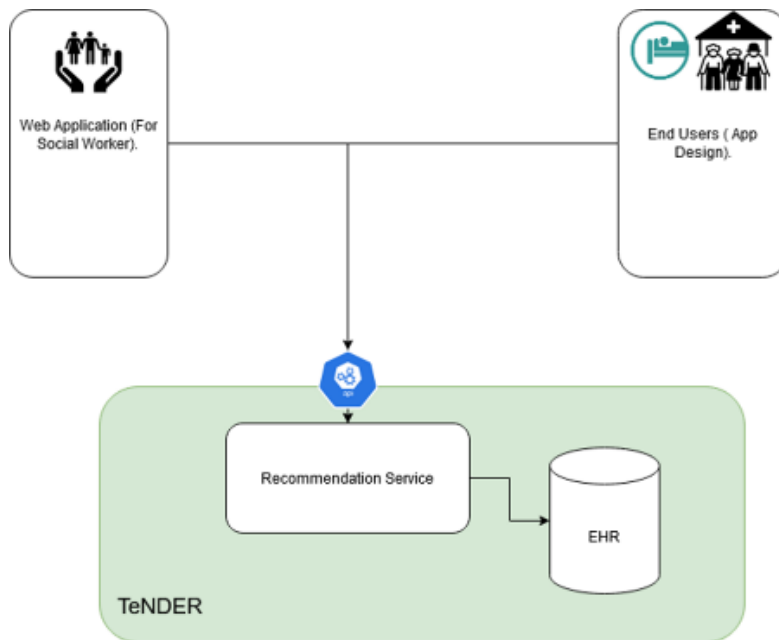
Figure 2: Logical diagram of the implementation of the Social Service Matching, done in WP4

Moreover, the Social Services Matching has been developed together with the users as a part of co-design process. According to the diagram (Figure 2), all partners presented use case stories in WP4 accordingly. The main purpose has been to prepare set of services devoted to bring the social supply to the patients. The questionnaire was created according to partners' experiences and needs and gap analysis from the first part of TeNDER project (WP2 and WP4). The following requires that the patient and the carer is able to receive the questionnaire in their native language through the TeNDER App that is installed in the mobile phone or tablet and has the section "Questionnaire" is addressed in WP4. Patients and carers can select an answer to a specific question in regards to companionship, loneliness, financial status, care service support need/instrumental activity, need for involvement in support-group. Thereafter, the professional can communicate with the user based on the results obtained in the TeNDER platform. The social professional as the TeNDER included participant can be given access according to the patient wishes, will be able to receive the answers from the patient and/or the carer in the WebApp interface, and can prepare the personalized intervention and recommendation to the specific person. Accordingly, the person can also get the personalized type of assistance available locally or have information about type of assistance provided or available. They can follow their own status and wellbeing, getting suggestions/instructions. Accordingly, carers can start/adjust the level of the support and send the patient the reminder or message through the system. Feedback from monitoring or change in available services may lead to modification of level of support. The services requirements were developed for the formal or informal carers and for the social worker (and institutions).

3 Presentation of reached objectives and KPIs in co-design process

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 development to practically guide the functional specification gathering) and the TeNDER ecosystem with services.
- the assessment phases that will base on 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 two 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 5.

Table 4: KPI-s of the Co-design process

No. KPI	KPI description	Reached KPI
KPI1	Producing more than 10 intervention programs.	Reached (Table 3)
KPI2	Include over 3 different types of stakeholders and service users across the various co-design phases	Reached (pre-piloting: reported in Deliverable 2.4 and piloting: reported herein + observations report in WP1 and WP6)
KPI3	Involve at least 20 end-users in co-design process	Reached (pre-piloting: reported in Deliverable 2.4: ~90 patients, ~90 carers, ~60 professionals) and piloting Deliverable 2.6: all participants are invited to provide feedback at the end of the testing + observations are taken according to set Evaluation in WP1)
KPI4	100% coverage of end-user requirements through functional validation during TeNDER' test phases	User requirements gathered through observations and interviews with each participant (included patients with AD, PD, CVD, their carers, health professionals, social workers and other workers); Reported in Internal Task documents and WP2 deliverables, insights passed to development team as issue tracker, wish list tracker, Trello, communicated at technical and general Telcos + Centralized User Requirements document. The coverage is assured through the usability assessment that gives the final feedback form the users and is reported in documents of the dedicated WPs that will report the findings of the testing.

4. Main findings from co-design process

Important focus of the TeNDER partners` team was on engaging diverse users in the TeNDER development and validation process. In addition, public engagement activities were promoted from the beginning of the project.

As the technologies are increasingly vital in today's activities in homes and communities, the importance of Patient and Public Involvement in dementia research has been highlighted at a European level by Alzheimer's Europe as a way in which to enhance the 'transparency, validity and legitimacy' of research (Gove et al., 2017).

As reported in social service component analysis among different stakeholders, e.g. policy-makers, care professionals and researchers often see technology applications as promising solutions to promote independence and autonomy in people with Parkinson` disease, cardiovascular disease and people with dementia.

However, the users' ability to manage products and services has been largely neglected or taken for granted. Therefore, the co-design process is crucial to engage the people to whom the services are being developed.

The question that is addressing which technology can be accepted in daily lives of patients, which technology is for them affective and how is these best evaluated remains.

Successful implementation of the technology in care process depends not merely on its effectiveness but also on other facilitating or impeding factors on a micro, mezzo and macro level, related to e.g. the personal living environment (privacy, autonomy and obtrusiveness); the outside world (stigma and human contact); design (personalisability, affordability and safety), and ethics on these subjects (INDUCT 2019).

In relation to the interfaces and user interaction TeNDER`s findings are:

- Allow the users to provide feedback on working prototypes rather on paper prototypes.
- Observe users to evaluate the interaction but also ask about their views.
- Adapt the language to the national language and to the type of user.
- Present the information graphically and make the content of each section easily identifiable, incorporating a representative image.
- Allow font size customization.
- Allow customization of light or dark backgrounds.
- Adapt the content to the type of user, showing only that content that is suitable for them.
- Allow customization of profiles according to the preferences of each individual user.
- Keep the mobile app as simple and intuitive as possible, considering the possible age-related technology gap and take into account vision, auditory and cognitive capacities.
- Involve carers and professionals in delivering interventions that enable people with cognitive disabilities to use the tools that they have.
- Study the accessibility adaptations that are appropriate, for example, in the case of PD it is important to consider that patients may suffer from tremor and need large icons.

In relation to feedback:

- Possibility of including recurring pop-up asking to rate the design of the different screens, like when google asks you to rate with a value from 0 to 5 stars and allow to add comment to the rating.
- Involve carers and professionals in delivering interventions that enable people with cognitive disabilities to use the tools that they have.
- Add a permanent functionality that allows to send the opinion, comments, or suggestions about the app/web/system.

There is also a need to tackle stigmatization perceptions about the technology, but also what may work and for whom. For example, the sleep tracker was well accepted in the group of patients with dementia and their carers, as the interaction needed was little to none. Nevertheless, some of those participants were able to use also other devices and the acceptance was framed by their personal experiences and view, feeling about the technology. We shall also pay attention to which environmental dimensions and which personal needs are needed to address to optimize the individual`s engagement to use the tools in daily lives.

To make complex health technologies more useful and applicable for users, it is crucial to involve all users, including staff, in the early phase of development of these interventions. Pilot studies should be conducted (as will be reported in TeNDER Deliverable 6.4) to help inform and reduce technical problems and improve accuracy prior to evaluating the effectiveness of new interventions. Our study of TeNDER showed that people may find useful the presented apps for self-management and meaningful activities. However, our observations showed that when people experienced technical problems, they were sometimes not able to provide useful feedback about TeNDER. For instance, some participants did not use the intervention anymore after they encountered technical problems. Even though a development and pilot study were conducted technical problems still occurred, such as: apps not being available anymore, explanation videos which did not work, personal settings not being saved, the button to go back being difficult to find, and links that did not work. To ensure that technical problems are resolved timely and do not interact with the evaluation of the tablet intervention, it is important to monitor for technical barriers by regular contact with people using the intervention in evaluation studies. Meaningful activities for people with dementia have proven value for their social health. When persons with dementia use technology for meaningful activities this may not only impact their own quality of life but also the well-being of their (primary) family carers. Moreover, the effectiveness of the technology usage often relies on information from and involvement of family carers when we involve people with dementia in the research of this topic. As they may already be (over)burdened by their caregiver tasks, participation in effectiveness research may be denied or minimized and therefore the true potential for improving the quality of life of people with dementia may be missed or underscored. It will be therefore helpful to think of methods to support informal carers to participate.

5. TeNDER DATA MODEL

The Intermediate TeNDER Data Model was described in TeNDER Deliverable 2.4 where data model for patient, formal caregiver, professionals, related person, living environment, device and signal are specified. The following information described below is added to the Final TeNDER Data Model.

5.1 Organization

The organization entity is directly linked with entity contact, its domain is defined as Resource and contains relevant information about a specific organization and some relationship it could have like "partOf".

(Source: https://www.hl7.org/fhir/organization.html)
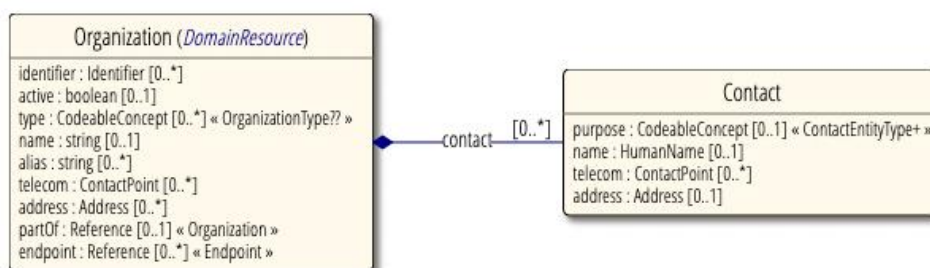
Figure 3: Association of an Organization with a Contact

(Source: https://www.hl7.org/fhir/organization.html)

Figure 4 Association data model

5.2 Observation

The observation entity is linked to Component and ReferenceRange entities and it belongs to the domain Resource. It is an entity to insert specific data about a patient and annotation about its health condition.

(Source: https://www.hl7.org/fhir/observation.html)
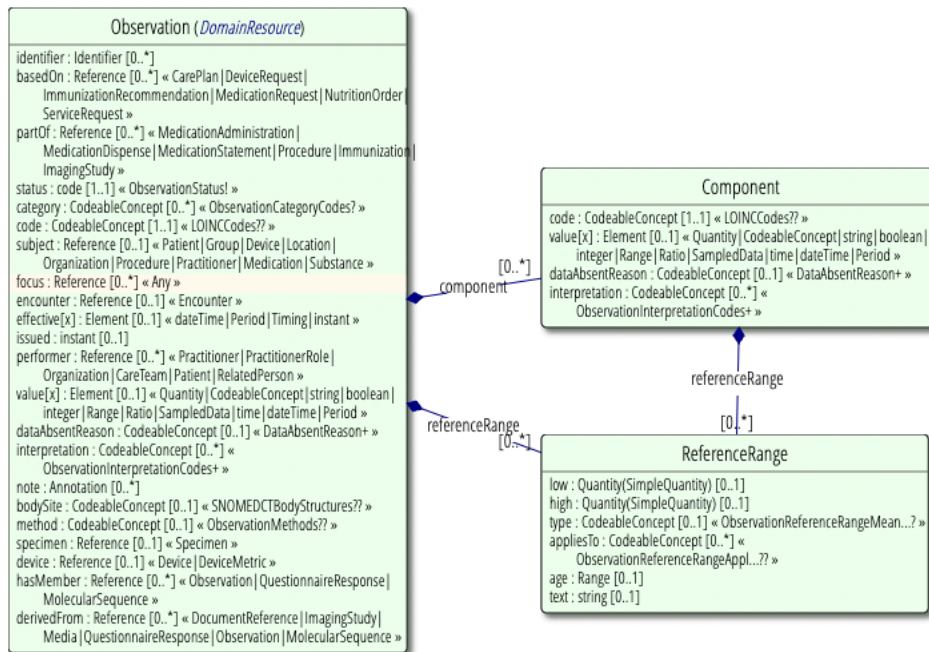
Figure 5: Observation entity structure

```
{
  "resourceType" : "Observation",
  // from Resource: id, meta, implicitRules, and language
  // from DomainResource: text, contained, extension, and modifierExtension
  "identifier" : [{ Identifier }], // Business Identifier for observation
  "basedOn" : [{ Reference(CarePlan|DeviceRequest|ImmunizationRecommendation|
   MedicationRequest|NutritionOrder|ServiceRequest) }], // Fulfills plan, proposal or order
  "partOf" : [{ Reference(ImagingStudy|Immunization|MedicationAdministration|
   MedicationDispense|MedicationStatement|Procedure) }], // Part of referenced event
  "status" : "<code>", // R!  registered | preliminary | final | amended +
  "category" : [{ CodeableConcept }], // Classification of  type of observation
  "code" : { CodeableConcept }, // R!  Type of observation (code / type)
  "subject" : { Reference(Device|Group|Location|Medication|Organization|
   Patient|Practitioner|Procedure|Substance) }, // Who and/or what the observation is about
  "focus" : [{ Reference(Any) }], // What the observation is about, when it is not about the sub
ject of record
  "encounter" : { Reference(Encounter) }, // Healthcare event during which this observation is m
ade
  // effective[x]: Clinically relevant time/time-period for observation. One of these 4:
  "effectiveDateTime" : "<dateTime>",
  "effectivePeriod" : { Period },
  "effectiveTiming" : { Timing },
  "effectiveInstant" : "<instant>",
  "issued" : "<instant>", // Date/Time this version was made available
  "performer" : [{ Reference(CareTeam|Organization|Patient|Practitioner|
   PractitionerRole|RelatedPerson) }], // Who is responsible for the observation
  // value[x]: Actual result. One of these 11:
  "valueQuantity" : { Quantity },
  "valueCodeableConcept" : { CodeableConcept },
  "valueString" : "<string>",
  "valueBoolean" : <boolean>,
  "valueInteger" : <integer>,
  "valueRange" : { Range },
  "valueRatio" : { Ratio },
  "valueSampledData" : { SampledData },
  "valueTime" : "<time>",
  "valueDateTime" : "<dateTime>",
  "valuePeriod" : { Period },
  "dataAbsentReason" : { CodeableConcept }, // C? Why the result is missing
  "interpretation" : [{ CodeableConcept }], // High, low, normal, etc.
  "note" : [{ Annotation }], // Comments about the observation
  "bodySite" : { CodeableConcept }, // Observed body part
  "method" : { CodeableConcept }, // How it was done
  "specimen" : { Reference(Specimen) }, // Specimen used for this observation
  "device" : { Reference(Device|DeviceMetric) }, // (Measurement) Device
  "referenceRange" : [{ // Provides guide for interpretation
    "low" : { Quantity(SimpleQuantity) }, // C? Low Range, if relevant
    "high" : { Quantity(SimpleQuantity) }, // C? High Range, if relevant
    "type" : { CodeableConcept }, // Reference range qualifier
    "appliesTo" : [{ CodeableConcept }], // Reference range population
    "age" : { Range }, // Applicable age range, if relevant
    "text" : "<string>" // Text based reference range in an observation
  }],
```

```
  "hasMember" : [{ Reference(MolecularSequence|Observation|
   QuestionnaireResponse) }], // Related resource that belongs to the Observation group
  "derivedFrom" : [{ Reference(DocumentReference|ImagingStudy|Media|
   MolecularSequence|Observation|QuestionnaireResponse) }], // Related measurements the observat
ion is made from
  "component" : [{ // Component results
    "code" : { CodeableConcept }, // R!  Type of component observation (code / type)
    // value[x]: Actual component result. One of these 11:
    "valueQuantity" : { Quantity },
    "valueCodeableConcept" : { CodeableConcept },
    "valueString" : "<string>",
    "valueBoolean" : <boolean>,
    "valueInteger" : <integer>,
    "valueRange" : { Range },
    "valueRatio" : { Ratio },
    "valueSampledData" : { SampledData },
    "valueTime" : "<time>",
    "valueDateTime" : "<dateTime>",
    "valuePeriod" : { Period },
    "dataAbsentReason" : { CodeableConcept }, // C? Why the component result is missing
    "interpretation" : [{ CodeableConcept }], // High, low, normal, etc.
    "referenceRange" : [{ Content as for Observation.referenceRange }] // Provides guide for int
erpretation of component result
  }]
}
```
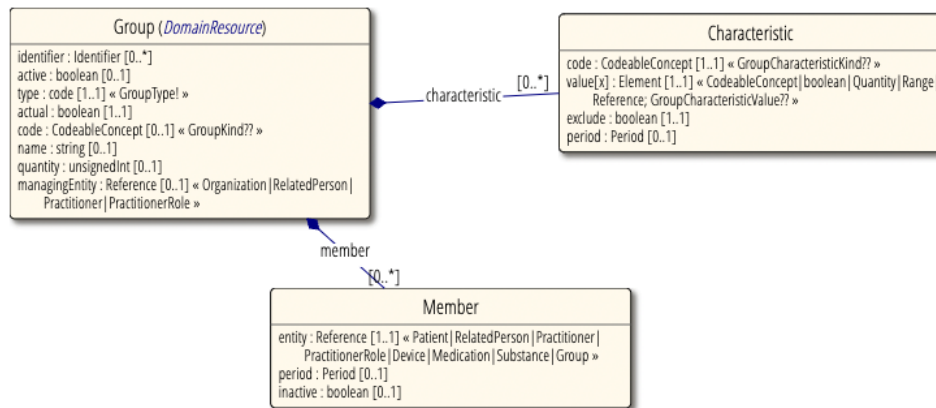
(Source: https://www.hl7.org/fhir/observation.html)

Figure 6: Observation data model

5.3 Group

It contains information about different groups that a patient, a practitioner or Related person can be associated to; it is linked to Member and Characteriscs to define who is linked to a specific group.

(Source: https://www.hl7.org/fhir/group.html)

Figure 7: Group entity and its secondary related entities

(Source: https://www.hl7.org/fhir/group.html)

Figure 8: Group data model

6. CONCLUSIONS

The purpose of the assistive technologies is to empower and aid people by including a wide variety of equipment that people are not necessarily familiar with. Therefore, to reach the true potential, people not only need to come to use it but also need to express their wishes and needs in order to allow the sustainable development of new tools and services by the use of those technologies. TeNDER user requirements were gathered throughout all system development phases, from the beginning of the project and continuous involvement has been enabled within the piloting testing phases. This process includes the analysis of the existing provision flow within the countries that have been involved in large-scale TeNDER piloting; accordingly, different devices and proposed services were included into service matching. Partners analysed the literature and shared their knowledge from previous projects to allow the understanding of the general requirements. Moreover, several stakeholders were included in an observational study to collect further requirements and analyse the individualized needs and finally, the observations during the testing piloting phase have also been performed with individuals as primary and/or secondary users.

Therefore, as the new integrated care services may encounter challenges in the implementation, the co-design process allowed to quantify and mitigate potential issues that may appear. In this WP, common approaches were included towards primary users (patients with AD, PD and/or CVD), as well as their carers and professionals involved in care pathway, as also other stakeholders as authorities, board members of nursing homes, health canter managers, members of local communities and other. By analysing the knowledge from the literature, setting the evaluation strategy and defined ethical and legal frames, and also trough survey and interview analysis, the partners created typical users, defined stories and scenarios that guided technical developments of the TeNDER services. Therefore, grouping different devices into functionalities and combining them within proposed services could happen. All these were evidence-based, supported with real users that were involved to provide their own views and express their perceptions and needs while being included in either interviews, group sessions or in TeNDER testing. A common view of the user requirements that were constantly collected by partners on the fieldwork was synthesized with the TeNDER Persona cards and with the Centralized User Requirements document. The latter consisted of different user requirement layers and was interlinked with other live documents within the project. TeNDER co-design was implemented in the system design with the good collaboration of all TeNDER partners that shared the insights and knowledge, but also discussed potential issues at weekly meetings, through different documents and issue trackers.

The TeNDER architecture was released and herein we report the final data model for TeNDER. Dedicated contributions from patients with different neurological diseases, their carers, medical bodies, professionals, social workers and other relevant stakeholders were included in the requirements that were internally reported and discussed.

Herein, the general user and functional requirements are represented, with some examples that were collected and with the proposed cases for the intervention requirements that would be delivered through using TeNDER system. Moreover, the social impact and general requirements for the base for the social service that has been developed within WP4 is presented. Finally, the overall main findings from co-design process are presented and

interlinked with previous work done in WP2 and reported in different documents of TeNDER project. Therefore, the important focus was not only to engage as many users as possible, but also divers users and their different aspects, so that TeNDER validation process could be performed in the next project phase.

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ANNEXES

Annex 1: Service matching table

disease related (AD, PD, CVD)	environment (Home/day care centre/ rehabilitation room / Hospital)	Functionality
		Monitoring
		Devices assigned
		Brief description (general purpose of use, if any, target group)
		General description of operation, (if any additional setups, any risks with installation foreseen)
		Collected data (type of data collected)
		Device installation (steps for installing the device at premises of end users)
		Device location (where exactly the device will be located at premises of end users)
		Service Cluster (related to hi-level clusters of TeNDER services)
		Concept
		Questions (to be filled by end-user partners and/or technical partners)

Annex 2: Centralized user requirements table

Centralized User Requirements
requirement number
Which part of the system is addressed: **d:** device/**f:** general functionality/**v:** Virtual Assistant/**t:** TeNDER App/**u:** TeNDER WebApp – user/**a:** TeNDER WebApp – admin/**s:** TeNDER system
When was the requirement first proposed (date, month/year or time span)
Reference to the document in which the requirement was proposed
Brief description of the requirement
Stakeholders addressed: TeNDER partner/patient/caregiver/health professional/social worker
Priority
Decision about Requirement "accepted"/"pending"/"rejected"
Date of the decision and name of responsible partner
Comments on decision
The reason for a rejection (e. g., which kind of additional information is needed, what technical obstacles are in the way to implement the requirement)
Status for 1st wave: passed to testing/partly passed/not implemented
Status for 2nd wave:

Annex 3: Interviews on social impact

Proposed interview script:

1. According to the World Health Organisation, most older people prefer to live at home for as long as possible, despite having chronic illnesses such as cardiovascular disease, Alzheimer's or Parkinson's. How do you see this reality?

2. Do you think that effective public policies have been implemented to facilitate this independence for the elderly?

3. In all European countries, informal care accounts for the majority of care hours. However, the majority of public funding for long-term care is still spent on institutional care. How do you see these measures in the long term, and what would you suggest in your experience?

4. As for the social isolation of older people, unfortunately, it is becoming an increasingly common problem in Western countries. Even in nursing homes, residents remain in their private rooms in solitude, without participating in social activities. Given that social isolation has serious consequences, such as disuse syndrome, increased domestic accidents, depression and non-adherence to treatment among others, do you think technology could help here? in what way?

Annex 4: Questionnaire on social service

<u>**Questionnaire on the co-creation of a social tool**</u>

We are working on the co-creation of a social interaction tool for patients, carers and professionals. Your feedback is invaluable in helping us to successfully develop it.

We invite you to explore the tool and answer a few questions. It won't take you long.

Thank you very much.

1. *How useful would you find it to have a tool to communicate with patients and carers?*

1	2	3	4	5
Not useful	*Not useful at all*	*Unsure*	*Useful*	*Very Useful*

So you know about the tool we are creating, we need you to be honest about it to help us improve it.

2. *I think the home screen is adequate:*

1	2	3	4	5
Strongly Disagree	*Disagree*	*Undecided*	*Agree*	*Strongly Agree*

2.1 Can you suggest anything that would help us to improve it?

(Free text)_____

3. *I find the interface intuitive and user-friendly.*

1	2	3	4	5
Strongly Disagree	*Disagree*	*Undecided*	*Agree*	*Strongly Agree*

3.1 Can you suggest anything that would help us to improve it?

(Free text)_____

4. *I consider the menu and options completed and contained everything necessary:*

1	2	3	4	5
Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

4.1 Can you suggest anything that would help us to improve it?

(Free text)_____

5. *Once we introduce the proposed suggestions, do you think it will be a tool that you will use regularly? (Please explain why you think so).*

(Free text) _____

5.1 If not, what would it need to be like for it to be useful to you on a regular basis?

(Free text) _____