WETAKECARE

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Summary on needs and requirements and activities and functions of the system

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Table of Contents

Table of Contents 3
Executive Summary 4
List of Tables 6
Abbreviations 7
1 WeTakeCare and WP1 From needs to concepts and contents 8
2 Methods 9
3 Results 10
4 Implication for Development of WeTakeCare 11
Annex I: Summary of the Scenarios and Personas 13
Scenario 1: “Overwhelming care” Ana and Anthony 13
Scenario 2: “The grumpy grandma” Belén & Brenda 14
Scenario 3: “Effort and perseverance” Karl & Meryl 16
Scenario 4: “Basic Care and support” Pablo & Louis 17

Executive Summary

Background: Societies in Europe are ageing. As people become older, the biological process of ageing leads to a decline in functional capabilities, being its level and impact highly dependent on each individual. This decline, such as reduction of movement ranges, muscular strength or sensorial capabilities, entails difficulties in the performance of Activities of the Daily Living (ADL) and results in need of care in daily life.

Goal of the Project: The WeTakeCare project aims to empower the collaborative caring and training between older persons and non-professional carers in order to promote the independent living of elderly people.

Goal of Work package 1: The project is subdivided into six work packages. Work Package 1 (M1-M12) has the objective to identify through a holistic user-centred approach, the needs and difficulties of older people as well as of their non-professional care givers in the performance of ADL and to define the best strategies to support them with the WeTakeCare system.

Methods: A literature review in databases, re-analyses of four data sets, focus-groups with elderly, caregivers and professionals and a scenario workshop have been conducted. The used data sets were: German Ageing Survey (DEAS), Austrian Health Survey 2007, SHARE - Survey of Health, Ageing and Retirement in Europe, Swiss Household Panel (SHP) and Assessment of Motor and Process Skills (AMPS) database. Three focus groups with elderly have been carried out, two in Switzerland, one in Spain. Two focus group included relatives and other non-professional caregiver (one in Switzerland, one in Spain) and health professional were interviewed in one focus group in Switzerland. Different methods for user-centred design development have been conducted to conceptualize the WeTakeCare program: PERSONA, Scenario method and Selection list. By using PERSONA and Scenario method the archetypical end-users were defined in four different scenarios. The needs, interests, feelings and hopes for the WeTakeCare system were developed in a workshop of the project group. A list of ADLs, that need to be trained as well as other functions of the system has been gathered from the PERSONA and Scenario workshop and was completed by using the results of the previous work (reported in D.1.1.). The Selection list method was carried out by three occupational therapists and a social scientist, all members of the project group. Criteria have been defined to select and prioritize the list of ADLs and functions in very important, important and moderate important.

Results: The literature did not provide enough information to develop the WeTakeCare program. Therefore an additional re-analysis of four data sets from surveys carried out in European population 50 years and older has been conducted. Most problems reported were doing strenuous motor tasks such as climbing stairs, lifting, carrying or moving heavy objects etc. Cultural and gender differences can be observed: a higher percentage of Spanish speaking respondents indicate having difficulties compared to German speaking respondents and a higher percentage of women indicate having difficulties performing an ADL or motor task than men do, with exceptions only in typical household chores such as cooking or doing laundry. Focus group interviews confirmed the information from data: Basic ADLs like eating, drinking, bathing and toileting were reported as difficult in Spain. Limitations in Swiss population were moderate and often related to mobility, dressing, cleaning and preparing food. Participants liked the idea to practice with partner or in a group. Caregivers wanted support in caring through information, communication and contact to others. They needed release from the daily burden through relaxing activities and training for their own health conditions.

From a comprehensive list of ADLs and functions some activities were sorted out because of security risks or because they were not possible to train with the Kinect system. 15 ADLs have

been prioritized as very important and 5 as important. Body functions like endurance, mobility, strength, balance and coordination were also rated as important, because they support the maintaining of performance and independence. Security limits have been defined. For each activity it was determined if exercise, strategies and/or assistive devices will be developed. Other crucial functions for the success of WeTakeCare are: Motivation through fun and relaxing exercises, strategies to integrate the exercises, strategies and assistive devices in daily life (e.g. time table, reminder, report, positive feedback), profiling of users in the beginning, introduction of program use by health professionals and help support for technical questions.

The results have been presented and discussed in the advisory group with end-users and other experts.

List of Tables

Table 1: Anthony. Caregiver scenario 1 13
Table 2: Ana. User scenario 1 14
Table 3: Brenda. Caregiver scenario 2 15
Table 4: Belén. User scenario 2 15
Table 5: Meryl. Caregiver scenario 3 16
Table 6: Karl. User scenario 3 17
Table 7: Louis. Caregiver scenario 4 18
Table 8: Pablo. User scenario 4 18

Abbreviations

ADL	Activities of daily living
BADL	Basic activities of daily living
IADL	Instrumental activities of daily living
IBV	Instituto de Biomecánica de Valencia
KP	Knowledge of performance
KR	Result of the performance
MMF	Mild to moderate frailty
MSF	Moderate to severe frailty
OT	Occupational Therapist
TS	Technological Specialist
WP	Work package
ZHAW	Zurich University of Applied Sciences

1 WeTakeCare and WP1 From needs to concepts and contents

The WeTakeCare project aims to empower the collaborative caring and training between older persons and non-professional caregivers in order to promote the independent living of elderly people. The kick off meeting of the WeTakeCare Project took place in June 2013. Therefore, now we are on month 8th. During this time, the efforts of the consortium have been mainly focused on WP1 (M1-M12). The objective of this first WP is to identify, through a holistic user-centred approach, the needs and difficulties of older persons, as well as of their non-professional caregivers, in the performance of ADL and to define the best strategies to support them with the WeTakeCare system.

WP1 *From needs to concepts and contents* has to establish the base for the future development of the system fixing their activities and functionalities to be implemented as well as the materials of support that have to be developed for the users and caregivers. This development will be based on: (i) gestural controlled ADL exercises with Kinect, (ii) a web platform with courses, workshops and links to main care-giving blogs, forums and social networks and (iii) other general functionalities such as agenda & reminders, communication or TV control.

WP1 is the first of the six WP in which the WeTakeCare project is subdivided:

- WP1. From needs to Concepts and Contents (ZHAW)
- WP2. Product system definition and development (KAASA)
- WP3. Product system integration (CPMTI)
- WP4. Validation and Evaluation (IBV)
- WP5. Dissemination and exploitation (IBV).
- WP6. Project Management (IBV)

At this moment, we are having an intensive work in WP1. We have obtained the first important results in relation to the definitions of user and caregivers needs, and to the activities and functionalities that have to be implemented in the systems during the development work packages (WP2 and WP3).

WP1 is one of the WP with more intensive participation of the users, persons, aged 50+, presenting an initial lost of capabilities and/or having a light to moderate physical disability. This lost of capabilities increases the difficulty to perform ADL, leading frequently to its poor execution and therefore finally taken up by caregivers. This uptake of ADL leads to an over-care situation, which can ultimately diminish autonomy of the older person.

The integration of the end-users in the WeTakeCare project is being very active. They have been involved in the different methodologies to obtain information about needs and requirements of the users (focus groups or personal interviews, meeting with advisory group in Switzerland on 2013.09.26 and 2014.03.04). A representative of VASOS took a very active role during the meeting of the Consortium in Cordoba with the objective, among others, to fix the target group and to define the main aspects of the application.

All the public information of the WeTakeCare project is uploaded in the following website: http://wetakecare.ibv.org/

2 Methods

Different methods have been conducted to investigate the needs of the user and functions and requirements of the WeTakeCare system. The general theoretical background for (virtual) training of Activities of daily living (ADL) was reviewed and implications for the project summarised. Activities of daily living, that are difficult for elderly people (50+) to perform were focused in a literature review. It was carried out in four databases: PubMed, Cinahl, OTseeker and Ovid SP Wolters Kluwer. The following search terms were used: “activities of daily living”, “independent living”, “elderly living”, “elderly”, “aged”, “older adults”, “senior”, “occupational performance”, “functional limitations”, “mobility limitations”, “functional impaired elderly” and “participation”. Because the literature review provided only little information on ADL problems in ageing societies, a data set re-analysis was made. The used data sets were: German Ageing Survey (DEAS), Austrian Health Survey 2007, SHARE - Survey of Health, Ageing and Retirement in Europe, Swiss Household Panel (SHP) and Assessment of Motor and Process Skills (AMPS) database.
As a next step closer to the users, focus group interviews were carried out. Three focus groups with elderly were made, two in Switzerland, one in Spain. Two focus group included relatives and other non-professional caregiver (one in Switzerland, one in Spain) and health professional were interviewed in one focus group in Switzerland. A comprehensive list with ADLs, general health activities, functions and requirements of the WeTakeCare systems was collected from these methods.
To conceptualize the WeTakeCare program PERSONA, Scenario method and Selection list method have been used. By using PERSONA and Scenario method the archetypical end-users were defined in four different scenarios. The needs, interests, feelings and hopes for the WeTakeCare system were developed in a workshop of the project group. A list of ADLs, that need to be trained as well as other functions of the system has been gathered from the PERSONA and Scenario workshop and was completed by using the results of the previous work. The Selection list method was carried out by three occupational therapists and a social scientist, all members of the project group. Criteria have been defined to select and prioritize the list of ADLs and functions in very important, important and moderate important. Annex I contains a brief summary of the definition of Scenarios and Personas used during the development of WP1.

3 Results

Performing ADLs and IADLs independently or with little help is important for an ageing generation in Europe. To remain capable in performance people need to stay active and adaptable to changes in their health conditions. Activities and body functions need to be trained but also new ways of performing routines have to be learned. That includes often the use of assistive devices. Theories of change management support the relationship between cognitive believes and commitment to training. Learning theories show that fun, feeling of success and positive body experience foster the dedication to training and learning. Theories of motor learning provide the knowledge for creating effective training exercises. Virtual training in a simulation environment has positive effect on performance. Educational and technical aspects have to be considered for creating the simulation environment.

Eight studies could be included in the literature review about difficulties of ageing populations in Europe in performing ADLs. All eight included studies reported “walking outdoor” (which includes activities such as “do grocery shopping”, “go for a walk”, “walk a block”) as the most often mentioned problematic task for older people. Constraints in the tasks “bathing/showering” were mentioned in five from eight studies. “Dressing upper/lower body” was also noticed as problematic by elderly in four different studies.

Four data sets from surveys conducted in European population 50 years and older have been analysed. The target population of surveyed people in all datasets reported to be quite able and self-sufficient with almost no difficulties performing an ADL until the age of about 80. The older the age of the surveyed person the more frequent are reported problems performing an ADL. The more strenuous a task is, the higher is the percentage of people indicating having difficulties. Most problems were reported doing strenuous motor tasks such as climbing stairs, lifting, carrying or moving heavy objects, vacuuming etc. A higher percentage of difficulties were reported doing complex ADL compared to simpler tasks. A cultural effect can be observed: a higher percentage of Spanish speaking respondents indicate having difficulties compared to German speaking respondents. This is in part a real difference in health status. A gender effect can be also be noticed: a higher percentage of women indicate having difficulties performing an ADL or motor task than men do, with exceptions only in typical household chores such as cooking or doing laundry. Also sport is more popular amongst men. Internet use is sparse in the population over 70 years of age especially amongst women.

Focus group interviews conducted in Spain and Switzerland confirmed the information from data: elderly people in Spain reported more and severe limitations in performing ADLs than Swiss people did. Some of the caregiver reported severe problems in memory of the elderly that resulted in not remembering how to perform a task. Basic ADLs like eating, drinking, bathing and toileting were reported as difficult. Limitations in Swiss population were moderate and often related to mobility, dressing, cleaning and preparing food. All participants could not image the elderly installing and start using the WeTakeCare program without help. Participants liked the idea to practice with partner or in a group. The Swiss caregiver recommended using the program also in nursing homes because there are only little entertaining and training possibilities. Some caregivers in Switzerland were interested on gaming and training with their relatives online from a distance. Caregivers wanted support in caring through information, communication and contact to others. They need release from the daily burden through relaxing activities and training for their own health conditions.

4 Implication for Development of WeTakeCare

Based on theories of performance as a result of the interaction of person, environment and task, exercises in **WeTakeCare program will have to consider**: individual capabilities and goals of the person, practicing in different environments (real and simulated, with and without adaptation or devices, alone, with partner or in group) and adaptation of task. Different ways of instruction (visual, verbal), feedback (verbal, visual, of result or performance) and practice (massed or distributed, randomized or blocked, in parts or whole) have to be provided. Generalization and transfer in daily life need to be supported. Positive experience, success and social interaction are important to foster commitment of using the program. This is as well important for development of exercises as for the design of interface and program. Support for installation of the program and help features are crucial for a successful use.

Based on the user-centred methods the most important ADLs that should be trained with weTakeCare system could be selected:

Very important activities are:

- Bending down
- Picking up things
- Ergonomic moving and caring
- Stand up after falls
- Getting up and down from chair, toilet, bed
- Walking
- Reach out
- Preparing simple meals/cooking
- Open bottles, cans and glasses
- Toileting
- Bathing or showering
- Dressing upper body
- Dress and undress of socks, shoes and tights
- Integration of program and activities in daily life

Important activities are:

- Kneeling down
- Going up and down stairs
- Shopping groceries
- Lifting and carrying weights
- Moving weights

Training of body functions has also been rated as important:

- Endurance
- Mobility
- Strength of arms, legs, grip
- Balance and coordination
- Hip movements

Other important functions of the system are fun and relaxing exercises and fitness games.

Cultural and gender differences should be considered as different levels and contexts to use WeTakeCare. Interface needs to be simple and adaptable to different devices and functions. Individual profiles help to shape the program and reduce complexity. Not all activities can be trained with Kinect. Alternative strategies to perform a task and the use of assistive devices will complement the exercises. WeTakeCare programme does not aim to support people with severe mental disabilities like dementia. It could help to sustain the most common BADL (e.g. eating, dressing/undressing), specially addressed to caregivers with physical moderate disabled persons but not for severe problems, which need treatment. Limitations of the program and security advices need to be defined and communicated to users. Reminder functions for scheduling and report of training success could be helpful to support the commitment to training.

For caregivers it would be useful as well to receive knowledge about how to support the persons cared for in order to extend their autonomy as much as possible. Caregivers would appreciate the system includes resources that allow them to relieve stress of daily routine (contributing to their relaxation). Additionally caregivers would be benefited from personal training in ergonomic, 'good practice' around caring (e.g. transferring, healthy postures) and in the possibility to train their own fitness with the program.

The results of all user-centred methods were validated in the advisory group in March 2014. The group suggested adding the following information:

- How to use a walker
- Adapting environment e.g. bed, chairs, carpets etc. to prevent falls and support activities
- How to cope with tremor

It was also discussed if it is possible to use real objects in the training with Kinect and if fine motor skills could be trained. The technical possibilities with the new Kinect Box need to be further examined to answer these questions. Individual profiling of exercises is important. The development of profiling, exercises and information will be the next steps of the project.

Annex I: Summary of the Scenarios and Personas

Scenario 1: "Overwhelming care" Ana and Anthony

This scenario poses one main questions: **how can WeTakeCare system get Ana more active?**

Anthony is a very active guy. He loves Ana and will do anything to protect and aid his wife. He makes the ironing and the shopping, keeps an eye on the home daily finances, and tries to avoid any physical effort to his wife, "she is so frailty!" Anthony has a large net of friends and loves travelling around. Since the hip replacement of his wife he stopped travelling and lately he has stopped seeing his golf friends. He is 65 years old, has blood pressure and overweight.

Table 1: Anthony. Caregiver scenario 1

<table>
<tr><td colspan="2">Hello my name is… Anthony</td></tr>
<tr><td>
Image courtesy of StockImages / FreeDigitalPhotos.net[2]</td><td>Story of life
"I need to keep on going"

<u>My background and personality</u> (relevant data for WeTakeCare)

I have to deal with my high blood pressure and my overweight. That's an open fight against chocolates!
"I have always been quite active (walking, cycling, swimming, golf) but now, uff! I feel that I have to (re)take care from myself. I don't want one of those enormous bellies"

<u>My daily live</u> (activities in my daily life and my problems)

"I like to take care of my sweetie wife"</td></tr>
<tr><td colspan="2">"Since the hip operation I help Ana with her dressing and the buttons of the clothes and to as much household work as I can."
"I like to read newspapers and know about the political situation. World may looks wrong but there is always something we can do to get it better "

My expectations and motivations facing toward WeTakeCareProject
"It would be nice to recover a better shape"</td></tr>
</table>

Ana is 65 years old. She likes to spend time on internet, always discovers anything knew, and allows her to keep on touch with the "kids" and the grandchildren. Some fine motor skills are so difficult for her. "Arthrosis and whatsapp are a bad team". Going through a hip replacement had a huge impact in Ana's life. She still thinks she needs to rest and still has some pain. Consequently, she tries to avoid any activity implying walking. She is especially scared of doing many things outside home because she feels frailty.

[2] Available at: http://www.freedigitalphotos.net/images/Mature_Men_g217-Laughing_Senior_Man_p77759.html [15/01/2014]

Table 2: Ana. User scenario 1

Hello my name is … Ana	
	Story of life "Without the kids life is a little bit sad". **My background and personality** (relevant data for WeTakeCare) "Wikipedia and internet are fun" "The operation of my hip has been a trauma" **My daily live** (activities in my daily life and my problems) "Things are becoming difficult. I am scared" "I have problems in opening food jars and bottles since I have arthritis problems in my hands" My expectations and motivations facing toward WeTakeCare Project "I would like to be stronger but I don't know what to do"

Source: http://www.agefotostock.com/age/en/people-stock-photos.aspx?licence=2&searchfilters=37,42,22&perpage=200

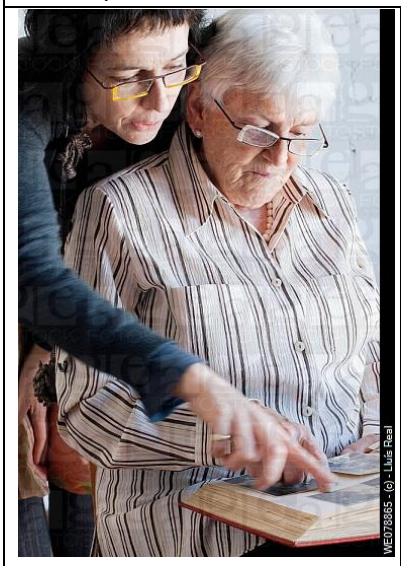
Scenario 2: "The grumpy grandma" Belén & Brenda

This scenario poses two main questions: (1) **How can WeTakeCare system reduce Brenda's burn out?** and (2) **How can WeTakeCare help Belén to become more active and independent?**

Brenda has 24h 7days a week her mother on mind. "Go to work is a release". She loves her mother but sometimes it is difficult. She is 57 years old and loves her job in the local library. She gets up quite early to prepare everything for her mother, and before leaving for work, she helps her mother to get ready. At the end of the days she cleans the house, it is the "never-ending story". Brenda deals with technology at work because "it is unavoidable" but she doesn't like all this moderns gadgets.

Brenda thinks that a program with exercises could be entertaining for her mother and also help to improve her health.

Table 3: Brenda. Caregiver scenario 2

Hello my name is… **Brenda**	
	**Story of life** I am 57 years old **My background and personality** (relevant data for WeTakeCare) "I know I have the right to do so and that is good for me, but when I do something for my own I can't stop feeling guilty". **My daily live** (activities in my daily life and my problems) "I am absolutely worried about my mum." "When the day finished I am exhausted. Too much worries, too much work." **My expectations and motivations facing toward WeTakeCareProject** "I would like to have my space and time"

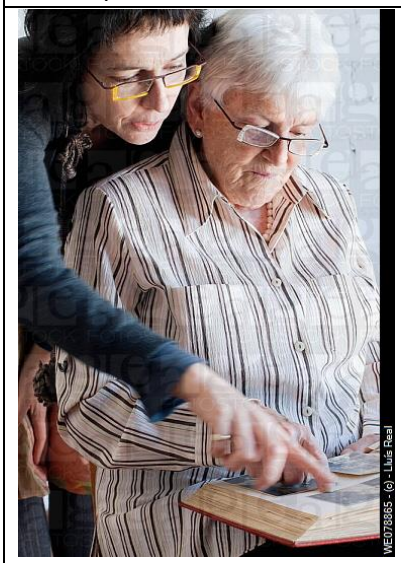
Source: http://www.agefotostock.com/en/Stock-Images/Royalty-Free/WE078865

Belén would like to be younger and stay with her husband, who died a year ago, "no one is able to make her such as lovely breakfast!" She doesn't understand the new mobile her daughter gave her "to ensure she wouldn't be able to call her at the library". She is 80 years old. Her sister now and then brings her a book "to keep her occupy but she always bring me the boring ones".

The physician has recommended making some exercise to improve Belén's health, but she doesn't want to do it alone. "And with my daughter? No way!" But probably she would engage if she could share the experience with some friends outside the stressful home environment.

In addition, the negative thinking of Belén makes very difficult for Brenda to try to help her.

Table 4: Belén. User scenario 2

Hello my name is … **Belén**	
	Story of life I am 80 years old. "My physician insists that I have to make more exercise to improve my health. I know myself better, what would he know!" **My background and personality** (relevant data for WeTakeCare) "I have taken care of my daughter my whole life. Now is time for her to taking care of me. It's just like this." **My daily live** (activities in my daily life and my problems) "I can do everything but I am not going to make all the housekeeping of my daughter" **My expectations and motivations facing toward WeTakeCareProject**

	"I know to find someone like my husband is impossible but sometimes I feel I would be better with more friends"

Source: http://www.agefotostock.com/en/Stock-Images/Royalty-Free/WE078865

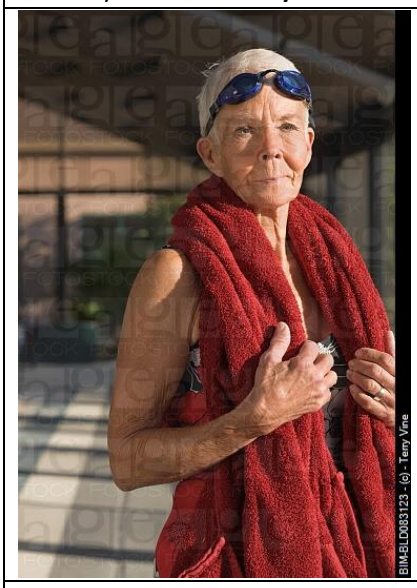
Scenario 3: "Effort and perseverance" Karl & Meryl

This scenario poses one main question: **how do we design WeTakeCare system to be able to motivate Karl?**

Meryl has a full agenda. She is very busy at work and loves to make sport. Sometimes she thinks his husband is becoming "a little bit lazy and far too comfortable". She helps her husband with the trousers and clothing, but she tries hard Karl keeps doing as much as possible things independently. Meryl has a big circle of friends. She is very active in the neighbours association and in the political arena.

Table 5: Meryl. Caregiver scenario 3

Hello my name is … **Meryl**



Story of life

"I am a very active woman in several files, sports friends and social implication."

"I love Karl and I'm happy to say that we always have kept our personal spaces; probably that's the secret of our success as a couple."

My background and personality (relevant data for WeTakeCare)

"There are so many things in the world I would like to visit…"

"Some people find it strange but I am always ready for an intelligent political discussion "

My daily live (activities in my daily life and my problems)
"I'm keen on sports, one day without sport is not a good day! I am lucky to work in this field"

My expectations and motivations facing toward WeTakeCareProject
"I say Karl, wake up! We have a life to live and I am going for it!"

Source: http://www.agefotostock.com/age/es/Search.aspx?query=Mayor

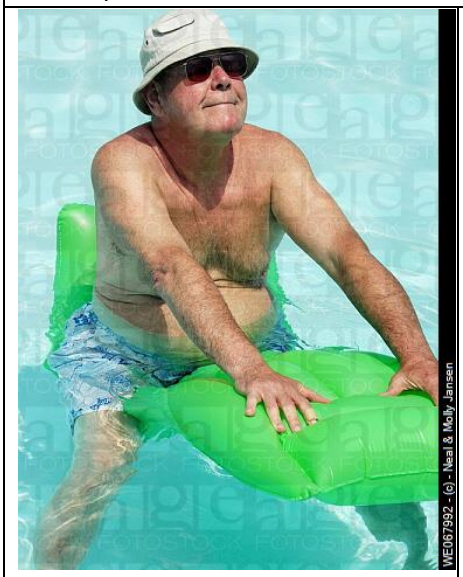
Karl always makes a customized version of an Italian proverb "silence means consent and is useful to avoid a quarrel with any fool in front of you". He is afraid of this all-new technology although he knows his grandchildren adore the phone "wash up". He is 66 years old with a slight physical disability, especially in the arms.

Since his retirement, as much other men, he feels "left out". He lacks motivation to begin with new activities. And the old hobbies? They are just that, old hobbies he feels too tired to rescuing

from the past. Would be possible to integrate part of his professional background into WeTakeCare to improve his motivation to stay going?

Table 6: Karl. User scenario 3

Hello my name is … **Karl**



Story of life

"My friends say I am a quiet man"

My background and personality (relevant data for WeTakeCare)

"I am reading a lot about my new situation. So I am sort of expert in my illness. But from theory to practice there is such a huge jump, oh dear!"

My daily live (activities in my daily life and my problems)

"Sometimes I need Meryl to help me with my socks and shoes, I can't reach them"

"Don't laugh at my picture, is Meryl always thinking in how keeping me in good shape"

"I loved my work and now I feel a bit useless"

My expectations and motivations facing toward WeTakeCareProject

"To keep going with my happy life"

Source: http://www.agefotostock.com/age/es/imagenes-stock-gente.aspx?licence=2&searchfilters=22,3,40

Scenario 4: "Basic Care and support" Pablo & Louis

This scenario poses one main questions: **how can WeTakeCare system satisfy a sophisticated/smart users?**

Louis has two daughters and lot of work. He is always thinking how to make easier to his father the ADL including the incorporation of some innovative stuff. However, at the end he finishes doing the things instead of his father, dressing him and assisting him in the preparing of food.

Louis likes the idea of playing with his father from distance or at least to know how he is doing and try to give positive feedback to reinforce the activity or Pablo.

Table 7: Louis. Caregiver scenario 4

Hello my name is … **Louis**	
	Story of life **My background and personality** (relevant data for WeTakeCare) "I love my daughters and concerning grandpa, they are doing very well" **My daily live** (activities in my daily life and my problems) "I am in the hospital most of the time. I would like to help more to my father but I feel that I don't know how to do it"
My expectations and motivations facing toward WeTakeCareProject "To have the feeling that everything is under control with dad"	

Source: http://www.freedigitalphotos.net/images/Healthcare_g355-Aged_Doctor_Holding_Clipboard_p102365.html

Pablo is an ancient mathematician with 75 five years old. He loves technology and has all sorts of ICT gadgets. Now he has to fight against his degenerative disease. Now he becomes tired quite easily, "thanks to his son who helps him dressing". I love my son but since I come here he is always on me, too much worried in case I may have a fall.

Pablo takes a lot of time to do the ADL, however he is very inventive to help him to do the tasks. He is willing to do everything possible to improve his health and stay independent. He is always willing to try new "gadgets" if with them he is able to improve his performance of the activities. Sometimes he needs to customize them to take out all the profit.

Table 8: Pablo. User scenario 4

Hello my name is … **Pablo**	
	Story of life "My friends always say that I am the 'smart' guy of the group" **My background and personality** (relevant data for WeTakeCare) "I like to play with my granddaughters; they also have fun with me. And what is more important they let me win, shisss!" "I would like to be younger, but 75 years with a few bolts and nuts loosen, it's fair enough"
My daily live (activities in my daily life and my problems) "I have some physical tricks to deal with every day, but my mind is still working smooth and nice" **My expectations and motivations facing toward WeTakeCareProject** "I want to keep my brain healthy and working smoothly" "I would like to share with other users my own solution and strategies"	

Source: http://www.freedigitalphotos.net/images/Mature_Men_g217-Man_With_Mobile_p43592.html