SHAPES

Smart and Healthy Ageing through People Engaging in supportive Systems

D2.7 – SHAPES Personas and Use Cases

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Table of Acronyms and Abbreviations

Table 3: Acronyms and Abbreviations

Acronym	Full Term
Apps	Mobile applications
DIPEx methodology	Database of Individual Patient Experiences methodology
EU	European Union
GP	General Practitioner
H&C	Health and Comfort
IoT	Internet of Things
NUIM	National University of Ireland Maynooth

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OBJ	Objective
PACT criteria	Program of Assertive Community Services
RA	Receiving Agent
RO	Registration Operator
TP	Technological Platform
UP	Palacky University Olomouc
5thYPE	5th Regional Health Authority of Thessaly and Sterea (Central Greece)
WP	Work Package
SciFy	Science for You

Keywords

PERSONAS, USE CASES, OLDER ADULTS, PRIMARY CARE, ECOSYSTEM

Disclaimer

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Executive Summary

D2.7, the third and final deliverable of task 2.5 presents the development of personas and use cases from M13 to M18. This report presents the multi-Work-Packaging developments within the SHAPES project, new personas and narrative of personas and use cases. In the previous stage, several initial evidence-based personas that mirror the basic types of users of the solutions provided by SHAPES were developed. In addition, the impact of the COVID-19 pandemic has been integrated into this work. Primarily, older adults belong to the highly vulnerable groups of population due to increased isolation, loneliness, and the worsening of most of their previously existing mental health conditions like depression, anxiety, dementia, etc. To create the representative sample, additional personas were added to cover the specific Nordic environment and the situation of formal and informal caregivers as they are the ones to whom the SHAPES Platform is targeted. Moreover, they are the ones supporting older adults in their lives.

This deliverable also further developed the connection between the personas, use cases, user requirements and pilot scenarios. This collaboration with WP6 and WP3 has shown the tight link and narrative that starts with WP2. The persona's needs are manifested in the requirements that are solved by the use cases and scenarios. Beginning with multiple-criteria evaluation approach this final deliverable brings all the stakeholders and tasks involved together in order to present the full picture of the SHAPES Personas and Use cases.

Lastly, special attention was given to the ethical requirements and needs that were co-created with WP8. The last chapter is dedicated to this aspect which is highly important for the SHAPES platform and its user-centred design.

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1 Introduction

This deliverable introduces a consistent narrative for personas, their needs presented by platform requirement (WP3), use cases and scenarios (WP6). This narrative aims to support health, care and independence of older adults in Europe through interoperable solutions by precisely demonstrating a user-centre approach. This approach is supported by concrete methodologies presented in the document. Before the start of the SHAPES project, well-established methods for the development of connections between personas and use cases were not available. After adding newly developed method working with the intrinsic variations of qualitative parameters such as needs, health conditions, perceptual and motor abilities, degrees of cognitive decline, health care requirements, economic situations, digital literacy, health literacy, and affinity to ICT technologies, this deliverable broaden the scope via inclusion of user requirements and final scenarios of the technology usage created by pilots in WP6. All these steps presented in this deliverable represent a significant contribution in achieving SHAPES strategic objectives and goals. This deliverable has a key impact on SHAPES Ecosystem for active and healthy ageing allowing the identification of current and future solutions for active and healthy ageing.

This chapter is based on the basic premises mentioned in the first report, where the main objectives of task 2.5 were presented, with the development of personas and use cases. Based on the on-going cooperation with the other WPs, especially WP3 and WP6, the knowledge of the experts and digital partners of these WPs strongly contributed to the final version of the deliverable. Furthermore, the personas have been extended with data obtained through the analysis of the interviews with the target group and socio-economical background with the emphasis on the national health care system. A clear methodological context of the link between uses cases and personas that was described and explained by multiple-criteria evaluation approach. Use cases are shown in their generic and later developed stage. Moreover, collaboration with pilot sites is demonstrated in the last chapter proposing new co-created personas, user requirements, use cases and scenarios. Recommendations proposed from the technical review were incorporated. During the course of the project strategic goals were set, which make the aims of SHAPES clearer. These aspects are listed below.

1.1 Rationale and purpose of the deliverable

Task 2.5 "SHAPES Personas and Use Cases" aims to contribute to a better understanding of the user needs for SHAPES by developing personas and use cases including scenarios. Basic personas with their attributes, needs, behaviours, characteristics and

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socio-economical background are considered to be an evidence-based knowledge construct that provide models of users of future SHAPES digital solutions and innovations. Utilizing a human centred co-design process, use cases and scenarios were planned to be developed illustrating the interactions between users and the SHAPES digital solutions and innovations in order for the future assessment of functional and non-functional SHAPES platform features. Task 2.5 was planned to inform the core SHAPES Platform and its socio-technological deployment and iterative improvement within future diverse Pilot Sites, contributing also to the fulfilment of the proposed objectives of SHAPES.

This deliverable has three iterations D2.5, D2.6 and the final D2.7. The first iteration was merely focused on creating the base for personas and use cases. The initial personas were created and disseminated across SHAPES. The second deliverable focused on clarifying the connection between personas and use cases. Moreover, pilot's sites co-created few personas to demonstrate their applicability and interconnectedness. Additionally, data from qualitative research and socio-economical background were used to enrich the personas. Last iteration built on the second one and expanded the demonstration of the overall narrative. This narrative starts with the personas and their needs, manifested through the platform requirements. These requirements reflect in the use cases and in the final scenario that shows the real-life application of the solution. This digital solution then logically addresses the persona's needs. The final iteration also reflects on the ethical point of view.

1.1.1 Justification and purpose of performance

The main task of 2.5 "SHAPES Personas and Use Cases" is to contribute to a better understanding of the needs of SHAPES users by creating personas and use cases. Based on the typology of personalities, concrete personas were created. These were enriched by real-life experiences of people and thus the personas became connected with the lived reality of older people. Lastly, the lived reality was emphasised by the national background focusing on health care aspects. On this basis, it is possible to work better with models of future users of digital solutions and SHAPES innovations. This approach will allow the basic SHAPES platform to be linked through social, technical and other environmental aspects. These facts have been key to the pilot stages of the solution in the SHAPES project and offered inputs and important facts for technical solutions. Contact between findings from the primary target group is essential for the comprehensive development and success of the SHAPES platform.

1.1.2 Deliverable objectives

Following the original SHAPES project proposal, the **two main objectives** of Task 2.5 "SHAPES Personas and Use Cases" are:

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- to develop basic personas with their prototypical attributes, attitudes, behaviours and characteristics
- to develop general use cases including scenarios of use of digital solutions

From the second iteration we chose a third objective to develop connections between a demonstrational persona developed in this deliverable and use cases developed within WP6.

1.1.3 Key inputs and outputs

The main aim is to deliver European evidence-based personas and use cases that mirror the basic types of users adapted to the requirements of the target groups of SHAPES. Applying a human centred co-design process, personas and use cases were developed to represent a knowledge base that will be subsequently further developed and adapted within WPs and Tasks. Therefore, personas and general use cases developed within Task 2.5 "SHAPES Personas and Use Cases" are starting points for future development, modifications, and adaptations for particular conditions, i.e., pilot sites, applications, cultures, and target groups. Personas and use cases are therefore the key starting point of the pilot sites and their development of scenarios (WP6). Furthermore, the personas provide important input for the work of WP3.

Another key input for D2.6 and D2.7 was the feedback from the Technical review. Based on the feedback the second and third iteration brings further storytelling and details to the personas´ background. Moreover, it clearly states the connection between the personas and use cases. This narrative has been emphasised in the third iteration by creating the section 5. Moreover, to probe, the work of T3.5 – User and platform requirements was also included. Finally, it proves the integration with WP6 through collaboration on new personas in the pilots´ use cases. Lastly, D2.7 is based on outputs resulting from collaboration with other WPs and task leaders covering the topics that have not been thoroughly processed in previous reports.

The main deliverable of Task 2.5 is a report. This report presents the basic SHAPES personas and use cases as the foundation for the design of the SHAPES architecture and system requirements (WP4). The report is a part of the SHAPES quality policy ensuring high quality output of the action, following successful implementation of the SHAPES plan and promoting models, approaches, and solutions for the extended independent living of older people

1.2 Structure of the document

The report consists of eight chapters. Chapter one provides a rationale of the Task 2.5 deliverables and explains the deliverable objectives and its interconnections and synergies within the whole project. The scope and sense of the updated versions of this

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deliverable will be developed in the subsequent stages of the SHAPES project. Chapter two is dedicated to the theoretical background of the two main deliverables: personas and use cases. Chapter three outlines the methodology of the personas' development, introduces the categories represented by the personas and the main aspects that play a role in understanding the personas. Chapter four is dedicated to the use cases and presents the methods of use case development and thirteen general use cases. Chapter five explains the connection between the personas and use cases, including the input from the pilot sites. Chapter six deals with the ethical aspects of personas as well as of the preparation of these deliverables. Future challenges and risks are described in Chapter seven, and the last, Chapter eight, summarizes the fulfilment of the tasks.

1.2.1 Interconnections of outputs of Task 2.5 to SHAPES strategic objectives

The development of basic personas and general use cases including scenarios is in accordance with the SHAPES strategic objectives (OBJs). Remarkably, with OBJ 1: To build and deliver the innovative European-led SHAPES Platform, providing a broad range of interoperable solutions to improve the health, well-being and independence of older individuals, while enhancing the long-term sustainability of H&C systems in the EU. The development of basic personas and general use cases including scenarios is the first step towards the fulfilment of this goal since the targeting of the user´s attributes, attitudes, behaviours and characteristics prepare a suitable background for the subsequent identification of best practices focused on the elimination of psychological and physical effects of isolation, and loneliness in the elderly.

Furthermore, the development of basic personas and general use cases including scenarios also support the fulfilment of OBJ 2: To create, enlarge and consolidate the SHAPES Ecosystem for active and healthy ageing allowing stakeholders to exchange knowledge and expertise, identify current and future solutions for active and healthy ageing, provide mutual advice, training and support and exploit the collective knowledge for social and commercial purposes. Task 2.5 contributes to the development of knowledge and expertise needed for future solutions for active and healthy ageing. The second iteration of the report probes the understanding of older adults. Personas in detailed context are presented in chapter 3.

Last but not least, the development of basic personas and general use cases is important also for OBJ 3: To promote the adoption of standards in the EU field of integrated care of older individuals, and the identification of standardization priorities to facilitate the deployment of open and interoperable Platforms. In actuality, Task 2.5 contributes to the improvement of integrated care of older individuals in the EU.

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1.2.2 Interdependencies and synergies of Task 2.5 with other SHAPES actions

Task 2.5 is an important part of WP2: Understanding the Lifeworld of Smart and Healthy Ageing Citizens. WP2 is designed to create the knowledge base (data, information, best practices, experiences and solutions) addressing real-world information on how ageing populations live, including empowerment models for healthy living, care pathways, age-friendly environment and social inclusion. Thus, WP2 is the knowledge foundation of the SHAPES Integrated Care Platform (see Figure 1: SHAPES WP Structure and Interdependency to gain a more detailed insight into the links and synergies within the SHAPES project).

The interdependency of various tasks within the SHAPES project is relatively high. For example, Task 2.5 is an important input for WP4, especially Task 4.1: SHAPES TP Requirements and Mapping a Reference Architecture. Based on the use cases developed within Task 2.5, Task 4.1 will start with the assessment of the functional and non-functional requirements of the technological elements to support the anticipated services. At a subsequent phase, the task will address the specification of the reference architecture for the core SHAPES TP, identifying its main elements, their functionality and their interdependencies.

Task 2.5 can also be considered to be the background against which subsequent pilot activities of SHAPES will be conducted. Almost all the Pilot Themes of WP6: SHAPES Pan-European Pilot Campaign is fed by Task 2.5 by providing personas and general use cases. In other words, Task 2.5 provides the knowledge base for further development, modifications, and adaptations for particular conditions within the preparation of the SHAPES small-scale pilots and demonstrations and the large-scale pilots to validate the SHAPES Platform capabilities and benefits to care recipients, caregivers and care service providers. Moreover, after the first iteration the collaboration with the pilot leaders was established and resulted in the co-creation of new personas used for specific use cases in the pilots.

A very important role is to be played by WP8, which focuses on the ethics. In collaboration with LAUREA, the report has gained further development and focus in this area (chapter 6). As rights of older adults are fundamental, attention was paid to data security and an equality approach during the creation of the personas and use cases.

Lastly, the report is a base for numerous tasks within WP3. Namely T3.5, which focuses on the use requirements and needs for the SHAPES Platform.

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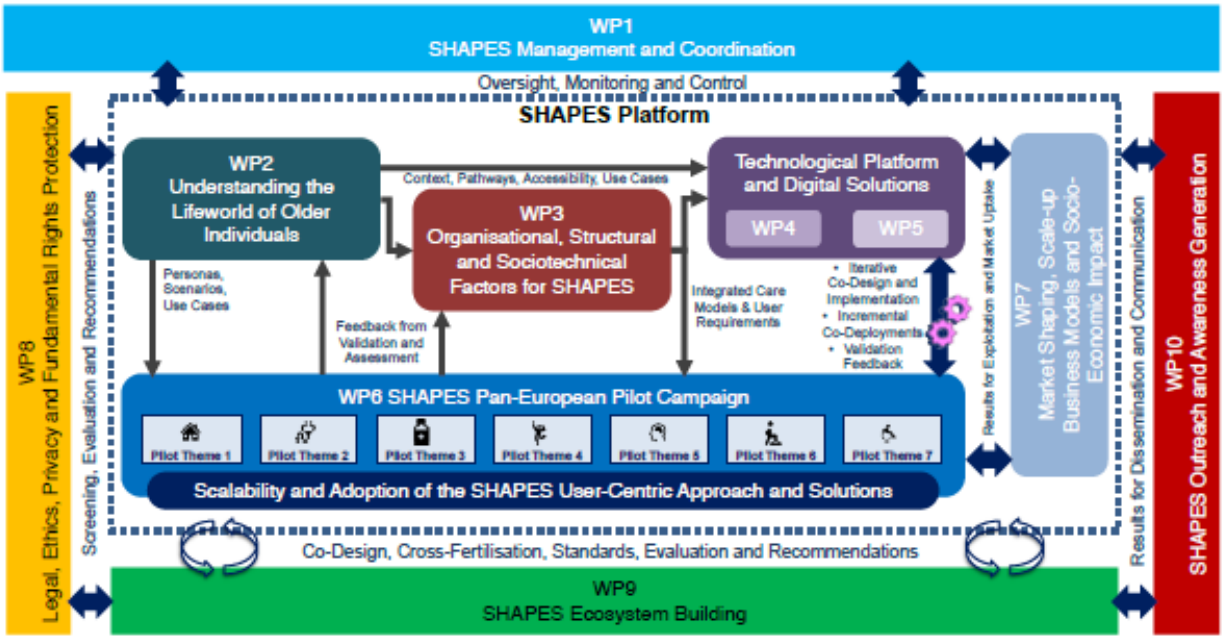

Figure 1: SHAPES WP Structure and Interdependency

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2 Background

This chapter describes the theoretical basis for the understanding of the role of the main deliverables of Task 2.5, personas and use cases, within the main conceptual framework of the person-environment interaction.

2.1 Definitions

The main two objectives of Task 2.5 SHAPES Personas and Use Cases are to develop basic personas and basic use cases including scenarios of use of digital solutions.

How to understand personas and use cases in user experience design?

Persona, also known as "user persona", is a detailed description of a fictional person (often a composite of real individuals) used to communicate the key motivations, concerns, and interests of a user group (Bhattacharyya et al., 2019). Personas include fictitious characters described in narrative form in order to help solve design questions. Personas enable designers to better focus on primary users, especially on their behavioural patterns and user needs (Huh et al., 2016) and are widely used in system design organizations as a complement to individual or other user data. They provide a basic prototype of persons/users for the interaction of an individual with a product/digital solution.

A **use case** is generally a software and system engineering term that describes how a user utilize a system to accomplish a particular goal. It is a methodology used in system analysis to identify, clarify, and organize system requirements. The use case is made up of a set of possible sequences of interactions between systems and users in a particular environment and related to a particular goal. A use case acts as a software modelling technique that defines the features to be implemented and the resolution of any errors that may be encountered. To represent an actor's participation in a system, all aspects of the interaction of a user with a product or service should be addressed in the use case. Use cases encompass human–computer interaction and address usability, usefulness, desirability, and optimal model of interaction with the focus placed on the quality of the user experience and other relevant solutions.

A use case generally comes as a list of actions, scenarios, or event steps defining the interactions between a role (known in the Unified Modelling Language as an actor) and a system to achieve a goal. The **actor** can be a human or other external system. Actors are roles that a user takes when invoking a use case specifying a role played by a user or any other system interacting with the subject. This simply means that the actor is a possible role of a future user. Different kinds of actors can be distinguished such as a receiving agent or registry operator.

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2.2 Theoretical background

The main understanding of the SHAPES digital solutions and innovations can be articulated within the framework of the person-environment exchange processes in later life. This framework is built on recent developments within the fields of environmental gerontology and the ecological theory of ageing (Chaudbury & Oswald, 2019). This framework is an integrative one enabling a complex understanding of models, approaches and solutions as well as SHAPES ecology and SHAPES ecosystem.

Within this framework, technological systems play a key role in the effective promotion of extended independent living of older people. The SHAPES Digital Solutions like assistive robots, eHealth sensors and wearables, Internet of Things (IoT)-enabled devices or mobile applications (Apps) can be understood as important components within a person-environment interaction supporting three basic dimensions, (a) dimension of independent functioning, (b) dimension of social interaction, and (c) dimension of mobility. All these dimensions contribute to the elimination of the psychological and physical effects of isolation and loneliness that very often accompany aging.

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3 Personas Development

This chapter reviews the commonly used methods of personas development in user-centred design and introduces the methodology that was used for the development of the personas within Task 2.5. Each persona represents different aspects of life in older age. These aspects and the categories represented by the personas are described and the ten original personas plus three "co-created" are presented.

3.1 Methods of personas development

There is no set approach to developing personas, so they can be created at the beginning of a design process or emerge in the design and pilot process (Huh et al., 2016). Many studies emphasize the empirical nature of persona creation (Nielsen, 2019; Schäfer, 2019), but some studies also recognize important input from the designers' experiences as well as other possibilities such as *ad hoc* assumptions (Huh et al., 2016). Usual methods to create personas vary between studies. Some studies use only qualitative methods (Goodwin, 2008), where data are gathered mainly using ethnographic techniques, interviews or focus groups, while other studies use mixed methods (Nielsen, 2013) or purely quantitative methods, usually employing a cluster analysis (Huh et al., 2016; Schäfer, 2019).

Due to the limited time, the methodology of the creation of personas in the SHAPES project was a combination of literature study and qualitative methods while making use of the rich experience with the target population of older adults within the UP and NUIM teams. We consulted the creative process with the partners from our WP at this stage of the project. We also incorporated the new approaches suggested by The World Federation of the Deafblind (persona 8) and Intracom Telecom (indexing of the personas and use cases). The process of persona creation had four phases – see Figure 2 below.

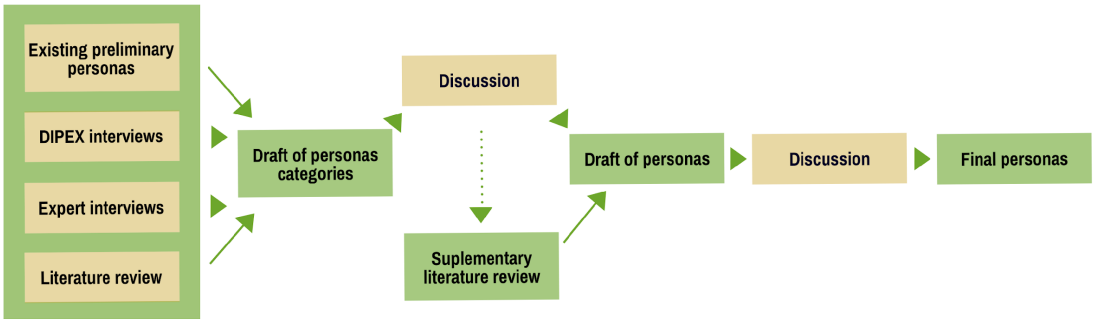

Figure 2: Personas Development

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The first draft of the persona categories aimed at identifying the preliminary persona types and was based on the following data:

1. previous persona files, which were developed for the project submission
2. data from the DIPEx study on active ageing, from the Czech Republic (see list of DIPEX study codes in the Appendix I.)
3. literature review – case studies, qualitative studies on various types of older adults according to health status and behavioural patterns
4. expert interviews with four geriatricians (one of them leading a major geriatric clinic in the Czech Republic) and two social workers who work with older adults
5. discussion with SHAPES experts/members, with long-term former experience in an ethnographic study of older adults

Firstly, the most common types according to health status and behavioural patterns were identified and the first draft of the persona categories was prepared, followed by extensive team discussions (within the UP team and later also with the expert team from NUIM). After the additional literature was reviewed, the draft personas were written based on personas categories and sent to the team members for a second round of discussion, which led to the final personas. In the first stage of the project, in the first iteration D2.5, eight personas were introduced and in the third deliverable, D2.7, two new personas (persona 9 and 10) were created based on the feedback from project partners, mainly pilot leaders.

3.1.2 DIPEx methodology

As the data from the DIPEx study has a significant role in the development of personas, we will summarise DIPEx and its methodology.

Developed in 2001 by the Oxford University Health Experience Research Group (HERG), the Database of Individual Patient Experiences (DIPEx) methodology uses rigorous qualitative research methods to collect interviews on patient experiences of selected health conditions. The data not only serve as a basis for an analysis (usually qualitative thematic analysis (Ziebland, & McPherson, 2006), but also other methods are often used such as grounded theory or narrative analysis) and publications in scholarly journals, but also as a foundation for extensive online information for the lay public and also as a source of training materials for medical staff training. Thanks to the inspiration by the success of the UK DIPEx site, as of now 12 other countries have launched their own DIPEx chapters and joined with the UK to form DIPEx International.

DIPEx research is usually organized within individual modules, while each module presents a particular health condition of a specified target group. In this project we use data from the module “Active ageing" that was conducted in the Czech Republic between 2014-2015. Within this active ageing project 50 in-depth interviews were conducted with

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older adults (age 65+) that explored several important aspects of ageing. Maximum variation sampling was employed, with the aim of approximating the sample to the demographic characteristics of the older Czech population. Even though we could not aim for a representative sampling, our goal was to at least simulate a typical demographic distribution. For the recruitment of our participants, we employed a combination of the snowball technique, approaching older-adult organizations and advertising through social networks. Data were analysed using thematic analysis and narrative analysis (Dubovská et al., 2017) and the final codes and themes are presented in the Appendix I. and II.

3.2 Categories (or segments) representing personas

The personas and their description continue on the following pages. Based on the recommendations of the SHAPES partners we incorporated an indexing of the specific user requirements and user needs (for example "Staying in good health" - P1-Req-1 In the personas). This was suggested to allow our colleagues - solution developers to trace each of the system specifications to the actual user needs.

3.2.1 Active, healthy older adults[P1]

The first persona represents a distinctive group of younger older adults (65 – 75 years of age), that is characterized by generally good health and an active approach to life. These older adults are usually retired but some members of this group are still working or are semi-retired, they often like to travel, have rich hobbies and a satisfying social life. Important is also an active participation in the life of the community through various volunteer works.

While the term “active ageing” implies mainly to associations with a physical activity, for many older adults it also means autonomy, interest, excitement and a “lust for life” (Stenner et al., 2011). Physical activity is one of the main determinants in maintaining satisfactory health in older age and is facilitated by the subjective enjoyment of the particular exercise, wish to maintain a good appearance and also by the social relationships that are associated with the particular activity. A substantial factor that affects the level of physical activity in older adults is the quality of the natural environment. Some environments such as accessible parks or forests support higher levels of physical activity (Franke et al., 2013; Jones et al., 2020).

Satisfaction goes hand in hand with self-reliance, as the citations from our DIPEx module data show: “I don’t want to use swear words, but if you can barely touch your back, how can you be happy?” Josef (67) If an active senior cannot do what he/she used to when they were young, they find something similar to do. “I can no longer play football so instead I coach young players.” Michal (62) To stay healthy it is important to be in good spirits and avoid stress. “Good mood, no stress. I think stress is the worst that can happen to you.”

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Vašek (74) It is important to have a spouse and some social life. By getting together with other people and being actively involved in social activities as if we were young, we prevent cabin fever. This could happen even to couples who used to be fine. Radek (67) explains how to prevent cabin fever. "Once we stayed alone together, I kept my own hobbies and my group of friends and the same goes for my wife." It is equally important to have a sex life and accept its changes. Some people stay sexually active, while some people's sexual desires slowly fade away – "let's leave that for the younger ones." Jan (69) Nevertheless, it is vital to remain intimate somehow (hold hands, sleep in the same bed). "I show my affection to my wife with a joke and an occasional slap on her butt; and also, a good night kiss." Arnošt (81) The most significant role in social life is played by the family and the family sometimes controls the activities as well. (…) they kind of discourage me from activities or tell me not to do certain things." Vašek (74)

There is also recognition of this first group of active and healthy older adults within the data from expert interviews: "and don´t forget to mention the significant group of active seniors, these people are very keen on exercising and living healthily. We have many clients like that" Jana (social worker). "The active older adults who exercise a lot, they usually have high health literacy and thus are well informed." Peter (geriatrist) "In the category of the youngest old and healthy, the main emphasis should be on exercise, training, support of motivation towards a healthy lifestyle. The prevention is very important." Ivana (geriatrician)

Based on all the information the first persona is defined as **Ernst** who lives in Germany. The prevention of health problems and fast and efficient care for those who directly face medical emergencies is emphasized in the German healthcare system. With all residents of the country having compulsory healthcare coverage (insurance), access to healthcare is available to everyone. In this case, Ernst can be assured any health problems he might face will be addressed in a fast and efficient way, both for him or his wife who faces cardiovascular risk. Specialized hospitals are able to treat patients with specific health problems and provide high-level focused care.

Compared to the national averages in physical activity, Ernst is in the relatively rare group of individuals who are physically active and by doing so can increase their physical well-being. Furthermore, his interest in digital health solutions enables him to track his health data and—if his general physician is aware—can enable him to provide regularly tracked data for health evaluation which helps with prevention of illnesses.

As Ernst would like to learn more about after-stroke care for his wife (ischemic heart disease being one of the leading causes of mortality), the general practitioner or a cardiology specialist should be able to provide him with all the information needed. As the majority of German citizens of advanced age have mid- and high levels of education, willingness and the ability to seek out medical information is emphasized. It might be good

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to suggest to Ernst to get a smart watch for his wife, to track her vital functions and offer her specialist physician access to this data as well.

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Smart and **H**ealth **A**geing
through **P**eople **E**ngaging in supportive **S**ystems

MEET ERNST P1

Motto: Staying in good health while still actively participating

Name: Ernst
Country: Germany
Age: 75
Area: Small town

Economical situation: Satisfactory
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Ernst is 75 years old, a recently retired former teacher from a college. He lives with his wife Alberta in a small town in Bavaria in their family home with a garden. Ernst loves to sing in the church choir and regularly does volunteer work for the local church charity. He and Alberta go once weekly to an older adults dancing club. They also love travelling – every year they go on a foreign holiday.
Ernst is in very good health, he exercises every day for 30 minutes in the morning. He likes to try new types of exercises according to his actual problems (usually slight knee pain or back pain) and often takes longer walks. Ernst sometimes worries about Alberta, who suffered a stroke 5 years ago and although she recovered very well, she has to go to regular medical check-ups every 6 months and he is always worried about the results. Together they enjoy doing the cognitive training exercises from the book Alberta got from her doctor.

What is important to Ernst

- Staying in good health P1-Req-1
- Keeping his hobbies P1-Req-2
- The health of his wife P1-Req-3
- Regular contact with his grandchildren P1-Req-4

Daily living

- Able to sustain all daily activities in the house, has cleaning help who comes twice a week to do the bigger cleaning and helps with the garden P1-Daily-1
- Able to drive P1-Daily-2
- Often meets friends personally and also through a social network P1-Daily-3
- Uses a social network for communication with his grandchildren and the wider family P1-Daily-4

Own resources, assets, support

- Economically independent, both his and Alberta´s pensions are enough for daily living and they have some savings and investments P1-Resources-1
- Their two sons with families live in a big city some 50 km away and come for regular visits and often help around the house P1-Resources-2
- Has good knowledge of possible care services in the local community P1-Resources-3

Health concerns and limitations

- Almost none, sometimes slight knee pain or back pain P1-Health-1
- Concerns regarding Alberta P1-Health-2
- Needs glasses for driving and reading P1-Health-3

Health tests/ treatments/ medication

- A complete health check once in two years with his GP P1-Tests-1
- Bowel cancer checks every year P1-Tests-2
- Alberta has regular checks every 6 months P1-Tests-3
- Had both knee joints replaced P1-Tests-4
- Has undergone cataract surgery on his left eye P1-Tests-5

Events, issues, personal concerns, technology

- Regular volunteer work for the church charity – helps with organisation of events, fundraising, leading of the church choir P1-Personal-1
- Loves his wife and cannot imagine living without her P1-Personal-2
- They both enjoy a dancing simulator they bought recently P1-Personal-3
- Ernst is using a smart watch to monitor his heart rate and pressure, plus to monitor his steps taken daily P1-Personal-4

Hopes and dreams/ what brings joy/ quotes

- *"It would be great if I could be sure that Alberta´s condition is not worsening"*
- *"Sometimes I go for a walk alone and it would be nice to have companions"*

Unmet needs

- Ernst thinks he could perhaps benefit from better information about the after – stroke complications and recommended prevention to better support his wife P1-Unmet-1

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Figure 3: Persona 1 - Active, healthy older adults

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3.2.2 Older adults with mild, but multiple chronic conditions[P2]

This persona category describes a significant portion of older adults that have multimorbid chronic conditions, typically diabetes, hypertension, chronic respiratory disease, oncological condition in remission, etc. As aging is related to chronic deterioration of multiple organ systems, multimorbidity is now recognized as the single most common chronic condition in a group of older adults. Accumulation of diseases in older age may result in the loss of resilience and homeostasis and could also bring an onset of accelerated aging (Fabbri, 2015).

One of the main problematic areas in this group of older adults is the need to undergo behavioural change, which is often emphasised by medical personnel. Older adults may experience tension between the need to change, e.g., improve one´s diet, stop smoking, reduce alcohol intake, etc., and one´s wish to be able to keep the lifestyle as usual. This can lead even to some kind of resistance to change (O´Neil & Peterson, 2017), due to the attachment to familiar patterns or in order to keep one´s agency and autonomy.

Self-management of behavioural change may help to enhance overall health, better control of symptoms, avoid unnecessary re-hospitalization, enhance quality of life, and decrease overall mortality. Facilitating behavioural change should take into account the importance of internal motivation, while supporting one's own feelings of autonomy, competence and connectedness (Ryan et al., 2008; Arnautovska et al., 2018).

Another problem that this population is often confronted with is the navigation within the complexity of the health care system. Older adults with multiple conditions consult their GP and a couple of other specialists (for each of the conditions), but not always do these doctors have access to the entire history of the patient, rarely knowing about the chronic conditions for which they had not prescribed. As a result the delivery of the care tends to be fractured, which may cause problems with prescribing errors (Lavan et al., 2016). Furthermore, this may be complicated by lower health literacy, which is more common in less affluent older adults (Matthews et al., 2012). Lower health literacy has a negative effect on the overall quality of communication with the doctors and reduces care efficiency - these patients often ask fewer questions as they feel shame and fear associated with the situation (Aboumatar et al., 2013).

Hypertension, prostate problems, diabetes and others are the most common chronic diseases. Respondents often suffered from stroke, heart attack or oncological conditions: "How about my health? It is not really ideal, is it? Because I had a tumour but now it's gone. Otherwise I have had diabetes since fifty. I also have allergies. It is actually life threatening because if I hadn't taken the pills, I would have suffocated several times. They had to take me to the hospital. But I take it as it is. Now my pressure goes up and down, they call it fluctuating hypertension. Since I was twenty. Once it goes up, once it goes down. But I am still here." Jan (69) The mindset as well as the people around are

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important. “I feel as good as if I were thirty or forty. I am surrounded by young people. That is important.” Jan (69) Responses to medical problems vary. In some people they cause agitation, fear, concerns or depression. In addition to concerns related to their diagnosis, they are also afraid of being a burden on their loved ones who would take care of them if their conditions would worsen. Some of them kept their problems to themselves because they didn’t want to make others worried. However, for some of them it helped when they could confide to their loved ones and share their emotions and thoughts. “Whenever I meet somebody, people start laughing because I am a really cheerful person. And even more now after the disease, I have to let it all out. I don’t keep it to myself, it must get out. This is how the doctors and everybody recommended it as well so I try to do it the way I feel it. I don’t let the troubles bother me too much because it is not good for me. Because I get all wound up and it isn’t good for me as I am sick right now. I don’t let that bother me or try not to let it bother me.” Michal (62) The quality of healthcare is important but the opinions about it vary significantly. Pavel (73) believes the “hospitals and healthcare in general have significantly improved, changed, mostly for the good, over the last 25 years, although it took a while. So, I have definitely a better feeling than before.” On the contrary, Jan (88), thinks that “since doctors got computers to work with, they don’t care about the patients. Here and there they ask about something but if I don’t say it, they know nothing.”

Experts in the interviews were pointing out the importance of behavioural change in the group of multimorbid patients: “Of course the motivation to undergo a behavioural change is very important” Peter (geriatrician) and to the fact, that peer support works very well “Some of the chronic patients learn better from the stories of their friends, from their peers, real people with the same condition.” Alena (social worker)

Based in the previous info, **Roberto’s** persona is defined to represent this segment of population. With the very low digital literacy and use levels in Italy’s advanced age population (65+) we can see that Roberto is not considering tracking his health status by using digital technologies such as a smart watch or specific mobile apps. With an increase in use of these tools, individuals such as Roberto would be able to take more responsibility for tracking their own health indicators and share the data with their physicians. The latter could enable the health professionals to adapt the diagnoses and therapy more efficiently, use notifications to improve regular intake of prescribed medication, and increase the level of trust in this population. By creating a government or Ministry of Health specialized website with illness information and advice, the issue of low trust in online resources could be lowered and key information about health challenges could be able to reach the patients of older age more efficiently while maintaining credibility and trust. However, with a large proportion of physicians being over the age of 55 (39.5%), the adaptation of modern technology as a means to help patients track their health status is not so easy to be adopted.

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The risk factors related to health are in Italy often connected to social activities such as smoking, drinking, and overeating. Along with the lower levels of physical activity—as is the case with Roberto—they increase the risk for chronic ailments in old age, mostly cardiovascular diseases which are the leading causes of mortality in this region.

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Smart and Health Ageing
through People Engaging in supportive Systems

MEET ROBERTO P2

Motto: Managing behavioural change and multiple conditions

Name: Roberto
Country: Italy
Age: 72
Area: Small town

Economical situation: Less affluent
Digital literacy: Low – High
Health literacy: Low – High
Affinity to technology: Low – High

General description: Roberto lives with his wife Bianca in a small Italian town, in a house with a garden. He is the owner of a small shop, which is now run by his nephew. Roberto and Bianca are childless and Bianca was recently diagnosed with Parkinson´s, though she has very mild symptoms so far. Roberto is slightly obese, he has diabetes and hypertension and smokes 20 cigarettes a day. Most of the time he feels quite well and does not like it when their family doctor or other specialists order him to change his lifestyle. That really irritates him, as talking, drinking wine and smoking with his best friends in the evenings is the best time of his day and nobody has the right to tell him how to live. Although, recently, when he was walking up the steps from town to his home, he had to stop for a few minutes, he couldn´t breathe and his heart rate was so high, that for a moment he was worried he might have a heart attack. He was also thinking whether the problem could have been caused by the new pills for diabetes that he started to take, as he was reading on Internet forums that some older people had this kind of problem.

What is important to Roberto

- The health of his wife Bianca P2-Req-1
- To keep his lifestyle P2-Req-2
- Rich social life with friends P2-Req-3
- Family ties with their brothers, sisters, nieces and nephews P2-Req-3

Daily living

- Still does most of the work around the house and in the garden, but sometimes his nephews come to help P2-Daily-1
- Twice a week goes to check the shop and manages orders P2-Daily-2
- Three to four evenings per week he meets friends in a bar for a few glasses of wine P2-Daily-3

Own resources, assets, support

- Owns shop, but profitability is seasonal P2-Resources-1
- Big family, there is always help if needed P2-Resources-2
- Also, he has many friends and a good local community that he can rely on P2-Resources-3

Health concerns and limitations

- Worries that the doctors might not know who prescribes which pills P2-Health-1
- Also worries about Bianca, if she has to go to a nursing home, he would not have the money for that P2-Health-2
- Sometimes he forgets to take his blood pressure pills P2-Health-3

Health tests/ treatments/ medication

- Takes six different medications P2-Tests-1
- Visits several specialists (diabetes, heart condition) every 3 months P2-Tests-2
- Bianca was diagnosed two years ago and goes for regular checks every 6 months P2-Tests-3

Events, issues, personal concerns, technology

- He sometimes reads about various diagnoses on the internet, but wonders what of that is actually true P2-Personal-1
- He doesn't like to go to the doctors, as he always feels a bit ashamed and irritated P2-Personal-2
- Worries that he will have to change his lifestyle after all P2-Personal-3

Hopes and dreams/ what brings joy/ quotes

- *"It would be nice to hear some stories from people, who have the same diagnoses as me or as Bianca, but it needs to be somehow checked by doctors, that it is true"*
- *"It would be great if I had something that would tell me what is my health condition like, without having to go to the doctor. This way I could perhaps keep my evening habit with friends and stop worrying too much"*

Unmet needs

- Roberto would also like to know more about Parkinson´s, perhaps meet other husbands whose wives have the condition, what the future holds, what to prepare for, what are the possibilities P2-Unmet-1

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Figure 4: Persona 2 - Older adults with mild, but multiple chronic conditions

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3.2.3 Older adults with chronic musculoskeletal disorders[P3]

Mobility difficulties, typically arthrosis and vertebrogenic syndrome (back pain), are some of the most common problems of older adults. These conditions may negatively affect the ability to move around the home as well as outside, maintain independence, keep hobbies and often may lead to increased social isolation. In order to preserve the quality of life of this population it is important to maintain their functional capacity for as long as possible (Fejer & Ruhe, 2012).

An important element associated with this condition is the risk of falls, and even more critical, the fear of falls. This has been associated with many negative consequences such as limited movement, decreased muscle strength, higher risk of disability and threat of social isolation (Sheffer et al., 2008). A fear of falls can also develop in people who have never experienced an actual fall and is a predictor of future falls and is also associated with functional decline (Auais et al., 2018).

Older adults with mobility problems are more likely to experience difficulties also with basic daily activities like dressing, combing one´s hair, taking a shower or going to the toilet, and also more instrumental tasks such as preparing meals, shopping or lifting things. The inability to execute routine tasks may cause frustration and embarrassment (Iezonni, 2003). Moreover, they may have to cope with many inconveniences and difficulties at home, such as stairs, narrow doorways, missing railings or other supports. A frequent strategy to overcome these threats is, for example, leaving several walking sticks in strategic places around the house or so called “furniture cruising” or “furniture surfing” (Iezzoni, 2003): placing the furniture strategically, such so it can be grabbed for keeping balance. Most common house adaptations are installing grab bars or special railings, using shower chairs, raised toilet seats, etc. (Iezzoni, 2003). Notable characteristics of the in-house and also outside-the-house movement is extended planning of each, even short, journey.

Whether an older person will cope with all these setbacks depends on many factors, one of the most essential being their resilience. It can be characterized as the ability to achieve good outcomes in spite of serious threats to adaptation or development (Masten, 2001), capacity to bounce back following adversity or trauma (Bonanno, 2004) or simply finding a way to ‘keep going’ (Richardson et al., 2014). Resilience is associated with inner strength or resourcefulness and can be eroded after experiencing several difficult falls or other unpleasant or embarrassing situations (for example such as not being able to get out of the shower).

One of the most frequently mentioned diseases was joint and bone conditions, such as arthritis or osteoporosis. In addition, seniors often talked about knee or back pain. The attitudes vary. Marriage and community established during the productive years are the supportive factors. For instance, Arnošt (81) says: “I have already said that – I can walk,

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I like to eat, I get moving. I am losing teeth but nothing I can do about it. So, the way I see it is that mother nature has been nice to me." For others this is very limiting. Such as Marta (80) "I have lost interest in everything. Maybe it will get better again but at the moment I have these pains and don't sleep well and I have other problems I don't even want to talk about that bother me. It is the movement, you know, legs, hips. And now, I have fallen a couple of times, I hit my shoulders so I cannot hang my clothes in the wardrobe. I put it on the wardrobe and my husband does it because I am down and out. And my arm starts shaking and all. And thus, I am not independent." Some people like physical activities but then they suffer from pain. Such as: "Well, what can I do? Not much you can do about it. You have to wait for it to go away, or use some ointment, it may help. Sometimes it is about the shoes you pick. They may look good but your feet are not comfortable." Vašek (74) Some of them face it but also take advantage of medical and spa treatments. Denny (66) "I do not have joint rheumatism. I have psoriatic rheumatism in my bones. You cannot see it but it actually makes it worse because it annoys me and hurts me here and there. But I don't worry about it as much. So, I go to the spa every year and it helps. And so, you have some arthrosis or whatever. But I would say that I was doing some athletics when I was young and a person who does some sport and does it properly, not really at the competitive level to ruin your body in youth, so the person remains a fighter." Some kind of exercise and joint motivation is important. Such as support from a neighbour. "I would go see her and try to get her out so we can walk the town and she wouldn't just be sitting at home. And then I would definitely advise her to go see the doctor, go have a massage 'cause it is important, right? And that's about it." Marie (71)

Experts stress the importance of reducing the risk of falls: "You should consider the risk of falls - after the first fall it can be devastating, a surprise, they can sometimes bounce back, but after a fourth fall they can become less sure of themselves." Alena (social worker) "Then it is common they use the house equipment to grab on to, it is called furniture surfing." Jana (social worker) Other experts talk about the importance of compensation tools and adjustments around the house: "So, any measures to enable them to have some compensation, I mean individual, to cross the barriers in the flat, for example the sills, carpets. Then some adjustments in the bathroom, shower instead of a bath and other compensation." Ivana (geriatrician) "Some of the women for example have problems with combing their hair, as they may have limited hand movement. So, they may need some tools for that, too." Jana (social worker)

This section introduces a case of **Ayesha**, a resident of the United Kingdom with growing movement problems. While living with her family can help her cope with the daily tasks better (compared to living on her own), Ayesha has already developed multiple fears and anxious tendencies due to unpleasant physical experiences when she fell and could not get up and the inability to move in general. She sees everyday obstacles as potential safety risks and has reduced her movement to a bare minimum all the while sacrificing social contact with people outside her household and minimizing obstacles in her ground-level part of the house with the help of her family. The lack of movement makes the

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osteoporosis diagnosis only progress faster, with increasing levels of pain she feels on a regular basis. Medical advice she could be given to improve her state is sparse as she does not speak the local language and often needs a translator to be able to communicate. In the UK, a novel programme IMPACTAgewell® is creating multidisciplinary hubs in communities to manage patients living at home throughout the NHSCT which links medical and social activities. While Ayesha has a rehabilitation nurse visit her occasionally, having access to multidisciplinary help would improve her overall well-being considerably and the caretaker burden on her family would somewhat diminish. Overall, the pressure on the National Healthcare System is high making the ability of doctors to reach individuals in need such as Ayesha even harder. For Ayesha, a potential solution would be to move to a nursing home where she could get the necessary physiotherapy and around-the-clock care that she needs. However, the capacities are very limited in the UK for such care and the additional issue Ayesha faces in this case is her need for a translator to be able to communicate.

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Smart and **H**ealth **A**geing
through **P**eople **E**ngaging in supportive **S**ystems

MEET AYESHA P3

Motto: Limiting risk of falls while increasing self-sufficiency and mobility

Name: Ayesha
Country: United Kingdom
Age: 79
Area: Outskirts of a big city

Economical situation: Low to moderate
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Ayesha is a widowed 79-year-old Iraqi woman and she suffers from severe osteoporosis. Ayesha lives with her son's family and their children in a two storey terraced house with a small garden. The family runs a small bistro, she used to help there but now she can´t due to her problems. Fortunately, her room is on the ground floor, as for a few years now she has had a big problem to climb up the stairs, even the five steps that are at the front door take her a long time to manage. She used to meet at the nearby café with other women from the muslim community but now cannot go, as she walks so slowly, that she is afraid to walk on the street - too many cars that cross the road feels like a nightmare. But if she happens to go out on some special occasion, she is very carefully in plotting the route: she thinks beforehand about where the benches are on the way, where there is a small wall to sit on, where there are the missing railings… Sometimes she spends much more time on planning the route than on the actual realization. Ayesha has also problems with movement around the house and after a few unpleasant falls she developed a fear of falls, so she is limiting her movement even more. They rearranged the furniture downstairs, so she has places to grab on and she also has walking sticks in almost every corner. But most of the day she just sits in the living room and watches TV or she sits on the chair in the kitchen. Besides walking Ayesha also experiences problems with smaller movements like combing her hair or putting on socks and two years ago she had a very unpleasant accident in the bathroom where she fell and could not get out of the bath. Since then she uses a bath chair. They talk Arabic at home and Ayesha doesn´t speak English too well, se when the rehabilitation nurse comes, the grandchildren always help to translate.

What is important to Ayesha

- Keeping social ties with the community and with her family P3-Req-1
- Limiting risk of falls P3-Req-2
- Staying self-sufficient P3-Req-3

Daily living

- She is able to do some light work around the house, but only on the ground floor P3-Daily-1
- Usually sits in her room or in the kitchen and watches TV P3-Daily-2

Own resources, assets, support

- The family offers big support, but that makes Ayesha often feel like she is a burden P3-Resources-1
- Loves cooking for the whole family but it is getting more and more difficult P3-Resources-2

Health concerns and limitations

- Limping, limited shoulder movement, severe back pain P3-Health-1
- Often relies on pain medication and worries she could become addicted P3-Health-2

Health tests/ treatments/ medication

- Rehabilitation helps, but the nurse comes only once in two weeks P3-Tests-1
- In case of a fall she often has to wait until somebody comes home and helps her P3-Tests-2

Events, issues, personal concerns, technology

- Mobility restrictions led gradually to more isolation P3-Personal-1
- She is often feeling lonely and would like to go out to see friends P3-Personal-2

Hopes and dreams/ what brings joy/ quotes

- *"It would be great if I could see my friends and hear all their news more often"*
- *"I would exercise on my own, but I don´t know if I am doing it right"*

Unmet needs

- Support of better movement, better coping of domestic tasks (cooking, etc.) P3-Unmet-1
- Some physiotherapy that she could follow on her own P3-Unmet-2
- Easier pain management, that would not require a personal visit to the doctor P3-Unmet-3
- Adapting some leisure activities so she can still participate P3-Unmet-4
- Spending more time with friends and her community P3-Unmet-5

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Figure 5: Persona 3 - Older adults with chronic musculoskeletal disorder

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3.2.4 Older adults with neurodegenerative diseases[P4]

The next persona is dedicated to another of the most common health conditions in the older population – Alzheimer´s disease, specifically its early to middle stage, while still staying in home care, which is also associated with the issue of informal caregiving. Due to the associated cognitive decline older adults in this population may often experience embarrassing situations which may result in feelings of shame and a sense of withdrawal. As a result of the fear of stigmatization these older adults may limit their social activity and thus experience loneliness and isolation.

Even as the memory gradually deteriorates, for people with Alzheimer's it is important to keep a sense of who they are. This can be realized through the sharing of narratives - even if these might be fractured, less coherent or even not believable presenting a modified or not real sequence of events, sharing them helps the affected older adults to better keep their sense of identity and social roles (Tatzer, 2019). This form of narrative care (Randall, 2009; Berendonk, 2020) has good results even in more severe phases of the illness (Tatzer, 2019).

Respondents often mention problems with memory. Most of them think that infrequent forgetting is a natural part of getting old. For logical reasons there are no respondents in an advanced stage of this condition. "Well, you forget more, you know, you have to think harder. Quite often it takes me three times to fetch something before I remember what I wanted. So, you are slower." Jiřina (73) Most often seniors mentioned problems with remembering or recollecting names or words. They experience situations when they forgot what they had wanted to do – could not find their glasses, recollect what they wanted to say, where they wanted to go or buy. These minor memory problems were very frequent, and some seniors felt very uneasy about them. To fight against this forgetting some of the seniors took notes in special notebooks. "Well, I keep forgetting and that's the worst. Names are the worst. The interesting thing is you can recall what was happening or whatever or situation, but the names are horrible. So, I started a notebook, we share it with my wife because you meet somebody, you talk to them, you know who they are but you cannot remember their name. And, of course, it is bothering you for a couple of days and all of a sudden it is there. That's why we have the notebook to write it down. And we already have some names there. Terrible, yes, but it is what it is." Karel (67) Forgetting is not nice but you can face the humour. "Often you cannot remember the name or something like that, just everyday forgetfulness, you know, it used to come up right away. Yes, I was rather quick in thinking, not anymore. Not anymore. When you turn 82 no more sharp thinking. I have to stop sometimes to think whether I said it correctly or not. That's the truth. You have to watch what you say now. (laughing) Ludmila (82) "Alright, I just wanted to tell you that sometimes we are talking about different stuff and then we want to say a name, like what his name was, and we all try to remember (laughing) so it makes me very happy that others cannot come up with the name either (laughing) because it feels good when others cannot remember and thus I can say "well, I am not that stupid,

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others or younger ones cannot remember either". So that's that." Eva (76) As they get older the recollection ability deteriorates, just like with Jiřina (91). "Since my son and daughter-in-law take good care of me and they both work, before they come home they give me those assistants, you know, every day I have some, she is from, you know, I cannot remember, how do you say it, oops, I cannot remember now but I will remember in a while. My granddaughter works there."

Seniors are often worried about forgetting and are aware of the problem. "Lately I have noticed that old-age dementia is starting. I could have never imagined what it is but I forget. I forget a lot." Jan (88) And their situation changes along with the diagnostic signs. "I remember what happened during the war when I was six, but I don't remember what happened yesterday, (laughing). Such a common thing, you know, it may come up later but when I need it, nothing, dead, I don't know. And of course, I lose some things for good. I don't even know they happened." Vašek (74) Many seniors try to support their memory with various cognitive exercises or food supplements. "Like I cannot remember, you know, it's a story, I don't know, I read a lot, I read but, in the morning, I could not tell you what I had read last night. And it would take me a long time to remember what I have been reading about. Interesting that crossword puzzles are no problem, you know. But when I talk to somebody, I have to completely switch the subject because I don't remember what I wanted to answer. Marie (66) Fear of progressed condition or dementia was more apparent in people who knew somebody with this condition. "I think, you know, it's really on my mind, maybe if I weren't talking about it. Not sure but I think everybody could tell. Like I stop, I don't know what I want to say. That bothers me. Marie (66)

Being aware of the memory or thinking problem, many of them try to keep their brain active. "The body needs some kind of an engine. When you stop, you know, the entire body stops, and that's not possible. Right? Including the head. Once you stop thinking or contemplating, or my husband at least watches the news, but OK, at least he knows what is going on and has to think about it. You cannot do without. I like doing crossword puzzles or books, just like this one, I like reading, mainly about history, I cannot stand romantic novels. And we like the countryside, going out, that keeps us going. Eva (76) Or for some of them, retiring made them start reading. "Since I retired, I have desired to make my brain busy. I resent when I am somewhere and I have nothing to read, at least crossword puzzles. I really like reading. At the moment I am reading a 35-part saga about the house of Morland. Which is the history of England since the 15th century. And in every part, the author cites the bibliography she used, all historic literature, so it actually corresponds with the history. Just the people, the story is put into the historic context, they are partly fictitious. So, I am totally excited there are thirty-five parts and I have plenty to read." Milena (78)

We have talked with the people taking part in our study about which relationships outside their families are important to them. Many of them talked about their lifelong friends, schoolmates, neighbours or acquaintances. Some of the seniors meet their friends

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regularly every week, some see each other only occasionally to celebrate birthdays or grab a coffee or beer. Thanks to activities done together the time passed faster. Often with the young or active. “Or I live close to the seniors’ home where the retired also get together. But I don’t feel like that yet. I prefer being surrounded with people who are active, not just those remembering their experiences.” Maťka (89) Communities also play their role. “Just like we see each other at church every Sunday, that’s that.” Jarmila (78)

Also, experts stress the importance of relationships in the prevention or slowing down of dementia symptoms: “I would motivate them more to do the visits, as it is proven that cognitive functions are very much positively impacted by relationships and meeting with people. So, the older adults, who have nice relationships, and that doesn't mean they don't argue, but that they are seeing other people and doing some activities together, they have much better prospects.” Ivana (geriatrician)

This leads to the fourth persona description introduces an elderly Spanish lady **Isabel** who has been diagnosed with Alzheimer’s dementia. While the check-ups are relatively sparse, her condition is very serious with increasing memory loss and difficulties navigating for which she often gets lost. The symptoms of memory loss make her ability to adhere to the prescribed pharmacotherapy harder, which—in return—does not help her health status improve. As within the system of care for the elderly with neurodegenerative diseases such as Isabel’s there is some aid available, there is still a large gap present. In Isabel’s case, she is visited by a nurse from time to time, which is why her son **Marco** had to take over caring for her. Furthermore, she is economically dependent on his help as there is no funding available to support her needs. Marco is described as experiencing caretaker stress syndrome: a state of feeling exhausted emotionally, physically, and mentally from the intense needs the person being cared for requires being met. The additional pressure is the uncertainty Marco feels about his mother getting lost or injuring herself with uncontrollable household hazards. Stronger care is needed both in terms of financial aid, more frequent nurse visits, education and support groups for Marco to be able to provide better care for his elderly mother, and in terms of socialization needs for Isabel.

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Smart and Health Ageing
through People Engaging in supportive Systems

SHAPES

P4

MEET ISABEL AND MARCO

Motto: Reimagining care while maintaining dignity; support of informal caregivers

Name: Isabel and Marco
Country: Spain
Age: 75
Area: Small town

Economical situation: Less affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Isabel is divorced and lives alone in a two-room apartment. She was diagnosed with Alzheimer´s two years ago and her illness is in the early to middle stage. After the diagnosis she just got the results and pills and was told to come for a check-up three years.
Isabel is already experiencing some problems with worsening of her memory: she started losing things: recently she misplaced her purse and could not find it for a week. The most embarrassing situation happened when she went out to the town and she got lost, couldn´t find her way home. And what was even worse, she met her old friend and could not remember her name. Recently she also accidentally switched off the electricity in the whole house and the heating was off for two days. Due to often forgetting, Isabel started keeping a notebook with the most important information but sometimes she just could not remember where she had put it. Her son Marco (46) lives nearby with his family and visits Isabel every day, does the chores, brings food. But he also has a part-time job in a factory, so he is often tired, worried and frustrated. He started to experience strange mood swings, especially when Isabel is asking the same question repeatedly. It happened a few times that he raised his voice at her, than he felt ashamed and guilty for his impulsiveness. Marco often worries about his mum when he cannot be with her, and he also worries she will get lost somewhere outside. They also have the help of a field nurse, but only twice a week for a few hours.

What is important to Isabel and Marco

- Maintain dignity and self sufficiency P4-Req-1
- Keep social contacts P4-Req-2
- Stay in home care as long as possible P4-Req-3
- Help Marco to better cope with the caregiving situation P4-Req-3

Daily living

- Able to do lighter chores, but keeps losing things P4-Daily-1
- Often experiences a lack of meaningful activities, feels bored P4-Daily-2

Own resources, assets, support

- Isabel has a small pension, but partly dependent on Marco and also on his wife, who sometimes comes to do the chores P4-Resources-1

Health concerns and limitations

- Cognitive impairments P4-Health-1
- Unhappy with the thought of her son taking care of her, she does not want him to help with hygiene, always waits for the nurse to visit P4-Health-2

Health tests/ treatments/ medication

- Complete health exams every 2 years P4-Tests-1
- Pills for cognitive symptoms P4-Tests-2
- Often forgets to take her medication P4-Tests-3

Events, issues, personal concerns, technology

- Isabel is most frustrated when she forgets names of close ones P4-Personal-1
- Marco is worried that something will happen to her P4-Personal-2

Hopes and dreams/ what brings joy/ quotes

- *"What about some electronic box to which I could store all my memories and it would talk to me and I could ask it whenever I can ´t remember" (Isabel)*
- *"If there was some possibility to keep an eye on mum, something that wouldn´t scare her, but would alert me if anything goes wrong, that would be great"(Marco)*

Needs of caregiver

- Be able to have up to date information on the development of the illness P4-CgNeeds-1
- Monitoring of all sorts of possibly dangerous situations in the house (fire, gas, electricity) P4-CgNeeds-2
- Peer support groups, information, education, nutritional help, emotional support P4-CgNeeds-3 P4-CgNeeds-4
- Respite care to be able to go on holiday P4-CgNeeds-5
- Some technology that would help to keep his mother busy and focused

Unmet needs

- Missing some cognitive training P4-Unmet-1
- Increase personal safety to be able to get out of the house more P4-Unmet-2
- In-home activities customized to her interests and capabilities P4-Unmet-3

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Figure 6: Persona 4 - Older adults with neurodegenerative diseases

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3.2.5 Lonely and/or socially isolated older adults[P5]

The purpose of this persona is to highlight the problem of loneliness, which is a phenomenon that has serious implications for the health and well-being of older adults. Loneliness can be described as subjectively felt dissatisfaction with the amount and/or quality of social relations. More specifically the social loneliness that is presented in this persona is a state of dissatisfaction with the extent of a social group of contacts, or engaging interactions, absence of a group of friends or colleagues with similar interests (de Jong Gierveld & van Tilburg, 2010).

Social loneliness in older adults is connected to a number of factors. It is often evoked by social dislocation, when older adults move away from their former community, so they lose some of the ties to their friends and colleagues. According to many studies the important determinant of social loneliness is the subjective evaluation of neighbourhood quality (Sharf & de Jong Gierveld, 2008), as well as the perceived vulnerability to crime and as a result, a fear of crime, thus the perceived neighbourhood safety (Sharf & de Jong Gierveld, 2008; Kemperman et al., 2019).

Regarding the physical characteristics of the living environment, the following aspects were found as influencing the perceived quality: attractiveness of buildings and the area; quiet and peacefulness of the area; accessibility and quality of parks and open green spaces, sufficiency of street lighting, and paths and pavements (Kearns et al., 2015). In terms of housing, there are some clues that poor social and mental health outcomes of occupants can be associated with living in high-rise flats, caused by the lower familiarity of neighbours and high turnover of residents in high-rise housing, but the evidence is somewhat mixed (Kearns et al., 2005).

Another factor that influences the subjectively felt quality of the neighbourhood is neighbourhood attachment, which means the level of involvement with the neighbourhood, feelings of affinity and shared values and an overall sense of community (Kemperman et al., 2019). Older people might also be adversely affected by changes in the physical appearance of cities, as some urban spaces are increasingly developed to meet the needs of the affluent, younger inhabitants (Sharf & de Jong Gierveld, 2008).

With increasing urbanisation and a higher population of young people living in cities, the incidence of elders moving to large cities is increasing as well. Although they have their family members more readily available, losing the social contacts they had available at their previous place of living causes significant negative feelings of social isolation, boredom, anxiousness, and general feelings of unhappiness related to the place of living. Such a case is the description of another persona - Roisin (Ireland) who has moved from a small village to a large city to her family. While this move does help with the general economic conditions she has available to her and provides her with frequent contact with her family, the pitfalls are considerably decreasing her life satisfaction levels.

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When we talked with the seniors about their old age life, the first thing that came to mind of some of them was loneliness. In this period of life, it is not rare that a person reduces the frequency of social contacts. In some cases, the person wants to be alone at their own discretion and thus we talk about singleness. However, in other cases, the person would want contact with others and is not happy there is nobody to spend the time with. Then we talk about loneliness. Social isolation is not irreversible. People who felt lonely told us about what had helped them to cope with this situation. Simultaneously, the isolation was temporary for some, most often after they had lost a loved one. “Thus, what really matters is not to stay alone. Once you stay alone, you keep going through your memories and I think that for life it is the best to actually live it and take it as is – with all the good and bad. So, loneliness is bad and right now I am lonely. Like I think it is not good to stay alone. You know, I am not totally alone because, of course, I live with my family, but on the other hand I lost my wife and now I have lost my partner. And I just think that the relationship between a man and a woman is very important. Emotionally because you have some emotional life and also physically, they split the chores. I am just saying that you really need to live in a couple, it is life 101, it brings you joy, either as a couple or not at all. To be a couple you obviously have to understand each other and help each other. That’s all about what is important at old age.” Ladislav (80) Some of them expressed fear of the future. “I think it would be good not to have to feel lonely, to always have a team of sharing beings we would understand each other and they would walk with me through life. This is really difficult. Life of a lonely person is very difficult but it is important not to shut away. There is a risk of too much criticism, wanting to always have a say and if expectations are not met, then shutting away. This is a great risk of this age, we should really be careful about it, not to close our door and be able to always see these things and pull the safety break.” Zbyněk (67) Some people are ashamed of their looks and thus they get secluded. “I am embarrassed to go out, everybody is staring at me like a fool. I look like a fool in old age. It is not worth going out so I sit at home all the time. When I was young, I was really something, no kidding. When I was young, I was out all the time. My girlfriend wanted to break up with me because I mostly went out with my friends. So, I decided for my girlfriend and the kids and this is how it stayed (laughing). But really when I was young, I had friends, I had everything I wanted, but now as an old man I can only think about it and reminiscence.” Jan (66) People are also thrown into isolation naturally due to their friends passing away and not looking for new contacts. “It is also important to have friends, it is important but not easy because people around me, for example, I studied at a grammar school, a prestigious grammar school at that time, so five years ago we were three of us left from our class. And now we are only two, so you keep losing friends. You keep losing friends and it is difficult to find new ones because they are not that many peers left. This is something for the old person to be aware of and cope with it somehow.” Ivona (89) Some of them got used to being alone to some degree. “A person is lonelier, oh well. I got used to it, I don’t even mind any more. The kids have their responsibilities, you know. Same for the grandkids, they have grown. While they were small, they used to visit

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grandma but not anymore. Well, here and there. But I don't want to jinx it, my health is still pretty good. I have been independent so far. See what happens next." Marta (78)

Among the ways of dealing with loneliness, one can join various activities, grow their relationship with their family or dedicate oneself to socially engaging hobbies. Ludmila, due to her problems with sight, does not spend much time with other people. Even so, she has found a way how to lower her feelings of social isolation—she started attending group meetings for people with sight limitations. Vlasta (78) does not have many interests: "You could say that I am not entertained by anything. Like I don't have any interests, which I could, one could say, I don't know, like sewing, right. I can no longer see well enough; I lost the feeling in my hands. Exercises like, yes, I don't have anywhere to go, I don't have any motivation, I don't have time. Acquaintances which I would like to meet up with or go somewhere with them, they are in their fifties to sixties. My generation is already too old for me, they are not fun to be around, they do not interest me, they are already very much as I am becoming complaining a lot, crying a lot, like that. Simply put, I see myself in them. I—as I have become in this past year—don't like it much, so basically, I don't feel very motivated but I always live at least for that day." even though they are active in their own way: "When I don't feel like being at home anymore, I come up with some idea. Either I go to the theatre, but on my own, or I go to a concert, but alone. Or I go to the graveyard, also alone, or I go to the park like so, it is a pity, that I don't know, I need to check how is it with swimming, because I should go swimming, but until now I went on Wednesdays to a facility there." Vlasta (78)

In our expert interviews loneliness also stands out as one of the main problems in old age. Some experts emphasize that loneliness does not necessarily mean that the older person is alone: "Even if they live with their children, they might still be very lonely. They mostly see somebody briefly, usually someone brings a meal – but they spend the vast majority of the day on their own and they don't want to be a burden." Peter (geriatrician) "Don´t be a burden, that's the main theme I hear every so often." Jana (social worker) The family relationship is extremely important: "It is so sad to see when the clients are waiting for their grandchildren to come for an announced visit, and they don't come. The sometimes-broken family relations are the main source of depression." Alena (social worker)

Not feeling positive towards the surroundings of one's living place is related to lower motivation to be physically active outside (such as taking walks), which—in Roisin's case—further worsens her knee pain and increases the overall lack of exercise she gets. There is a rather low chance for this individual to seek out and establish meaningful connections with others as she is bound to her family's home and their company. Due to her current circumstances, her feelings of being a burden on her family are increasing, emphasized by her hearing problems for which she feels ashamed to wear a hearing aid. Her diminishing ability to hear what is going on around her clearly is proving to be a problem to establish new social connections and, at the same time, causing her to feel that she is being too loud and disruptive in the family home. With the general drop in life

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satisfaction, research has shown an increase in the likelihood for development of chronic health problems and poor health outcomes.

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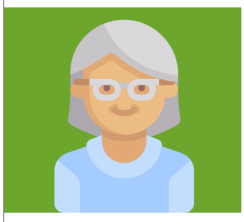
Smart and **H**ealth **A**geing
through **P**eople **E**ngaging in supportive **S**ystems

MEET ROISIN P5



Motto: Support social contact and autonomy

Name: Roisin
Country: Ireland
Age: 84
Area: Suburb of a big city

Economical situation: Less affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Roisin used to live in a village in western Ireland. She has been a widow for 15 years. As she struggled to keep the house financially, her daughter Ciara persuaded her to move to the city and live with Ciara´s family (husband and two kids, who are 14 and 17). They live in a big flat in a new block of flats. Ciara´s husband works in IT and she is a nurse in a hospital.
Soon after moving to the city Roisin realized that it might have been a mistake, as most of the time she had nobody to talk to and started to feel quite lonely. Ciara´s family, for most of the day, are at work or at school, and Roisin doesn´t want to interfere too much with their lives in the evenings. Moreover, she does not feel very well in this city. The buildings are too high, pavements too narrow and too many cars everywhere. A few times she went for a walk or to the grocery shop, but it was not a pleasant experience. Once she even went to the nearest park, some 20 min walk, and came home quite terrified as all the benches were taken by some teenagers probably drinking or consuming something even worse. She also worries about the high crime rate in the neighbourhood and when she is outside she feels like an easy target.

What is important to Roisin

- Going to church, which is a 40 min walk, sometimes her daughter or grandkids accompany her, but feels like it is too much of a burden P5-Req-1
- To have something to fill the day, to look forward to P5-Req-2
- To have somebody to talk to P5-Req-3

Daily living

- Most of the days she is in the flat alone and she is afraid to go outside P5-Daily-1
- Some weekends the family goes together to the park for a coffee or a meal out, she feels very good when she can talk about her memories P5-Daily-2

Own resources, assets, support

- Although she has a small pension, economically she is dependent on her daughter Ciara P5-Resources-1
- Misses her old house with a garden and old friends from the village P5-Resources-2

Health concerns and limitations

- Arthrosis on both knees, sometimes feels moderate pain P5-Health-1
- Lately stopped sleeping well, keeps waking up at night and worries P5-Health-2
- Has hearing impairment and uses a hearing aid P5-Health-3

Health tests/ treatments/ medication

- Complete checks every two years P5-Tests-1
- Does regular exercises for the knees P5-Tests-2
- Uses a hearing aid, but not in public, as she feels ashamed P5-Tests-3
- Takes sleeping pills occasionally P5-Tests-4

Events, issues, personal concerns, technology

- During the day she likes watching TV, but in the evenings she worries that it is too loud P5-Personal-1
- She used to love bingo, but now does not have anybody to go with P5-Personal-2
- Also likes reading historic books P5-Personal-3

Hopes and dreams/ what brings joy/ quotes

- *"Oh, if there was someone who would just like me want to go out for a walk, without it feeling like a burden"*
- *"In an ideal world, I would jump on a teleport and play a session of bingo tonight!"*

Unmet needs

- Help with feeling more secure when going out P5-Unmet-1
- Help to find some companion for bingo, church and walking P5-Unmet-1
- Help being more independent in a big city P5-Unmet-1

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Figure 7: Persona 5 - Lonely and/or socially isolated older adults

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3.2.6 Older adults with alcohol or drug dependency and severe chronic conditions non-complying to medical recommendations[P6]

Alcohol and drug dependency is problematic also in the population of older adults (Busse, 2010) and this issue is even more pronounced when there are associated multiple chronic illnesses (such as diabetes, heart conditions, COPD etc.). This group of older adults usually does not comply with doctor´s recommendations, or even do not visit their GPs and many acute health crises are solved by calling emergency or visiting an emergency room (Choi et al., 2015). Emergency services thus may be often their only point of contact with the health care system. This situation carries a substantial burden for the health care system, and not only in terms of financial costs, but it may also create frustration and feelings of helplessness in medical workers.

The idea behind the highlighting of this persona is that, even if it does not have to be a numerous group of older adults, if there is a solution found to somehow help them to better manage their health situation and reduce the number of emergency room visits, it would mean considerable improvement of their quality of life as well as significant cost savings. Aspects to consider are limited motivation to any change of lifestyle, resentment to be told how to live and the insistence on keeping their autonomy. Therefore, it is viable to consider employing methods of harm reduction, i.e. not to try to cure or change the older person, but offer some solution that could enable and strengthen their own means of controlling and managing their health status.

In individuals with addiction, apart from the burden on the healthcare system, the whole family is affected by the addiction. Family members are often pulled into a game with the person who is affected and have a hard time getting out of it, while, at the same time, feeling guilty when attempting to liberate themselves—most often from their father who is affected. The percentage of treatment success in residential or attendance facilities is rather low. Alcohol is once again becoming one of the most abused substances.

People experience unpleasant age-related experiences, even if they choose to trust doctors. "I don't have a good memory of the hospital, because two years ago, at the orthopaedic clinic at the University Hospital, after three days while I was lying there and I was supposed to be, I was supposed to have a repeated operation, on the operated knee, and after three days, when they gave me the anaesthesia to knock me out and they did not even let me have breakfast, a great visit came with the main doctor, when he found out how old I was, he said, "Go home, no reoperation is possible for you." Basically, he wrote me off, in other words, and threw me out of the hospital. For those three days in the hospital I paid three hundred crowns and with my dignity." Václav (85)

We have not met any participants with addiction. However, trust or adherence to certain procedures from the doctor is also based on the experience of medical staff. For example, Denny (66) says: "Once when I went with the eye, the medics where there. And they

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behaved as if those people were not even there. They were giving each other candy. And they were talking in a way as if those patients were not even there in the doctor's office. That really made me feel shocked, but I guess it is a personal responsibility thing and everyone needs to come to the conclusion on their own. Like being so blunt, right? I don't blame them, since they got a box of chocolates, let them have it. Well, he doesn't have to do it like you're not there. And one is afraid of what they will do with him, and they talked there, I don't know about what bullshit anymore, and they didn't realize it at all. As if you didn't exist there. Like a piece of something, furniture. So, it shocked me that time, I was upset."

For some, the reaction is the opposite based on the diagnosis and is at least partially reduced "It's not like I am some hardcore smoker, but a normal one, basically I smoked. I could not imagine that I would drink a glass and not smoke while drinking. From minute to minute, I just said to myself, "Okay, I'll try." And since then I have not lit up a cigarette and it is at times really hard when everyone around smokes, right. But I managed to endure it. For now, for over two months. As far as the alcohol is considered, that is not so easy. Look right, I don't know. I've stopped drinking the really hard liqueur. Like I got a bottle a bit delayed in May—because my daughter lives abroad, so when she came to visit—of home-made Romanian spirit, simply amazing, I am familiar with it. I have not opened it because it is a burden to all of this. So, I will have the beer, the wine, or the like to drink. I do not want to abstain from drinking. I won't drink those kinds of things that are heavy, well on the heart really. As far as food is concerned, I'm not able to, those fats and things like that, to just completely eliminate or something like that, because as one gets used to it, it is not really possible to eliminate completely." Radek (67)

Some experts also pointed out the problem with addictions in old age: "There is this distinctive group of older people, who just don't want to comply with anything. Or you don't get them to see a doctor, unless it is an emergency. I have seen a man, who visited the emergency room maybe 20 times in two years, he was an alcoholic and chronically ill but did not really care about his health. This creates a great burden for the system." Radim (paediatrician) "Then there is the problem of addictions in old age. Not much talk about it and some GPs just leave it as the patients are too old to change or to stop. But addiction means all the other problems like chronic illnesses get much worse and the clients are usually not very co-operative, they don't follow advice, and often end up homeless, unfortunately. And don't mention the problem of elderly homeless with dual diagnosis, though." Alena (social worker)

The health status of **Jarda's** persona showcases the most common health issues faced by the advanced age population in the Czech Republic: cardiovascular problems, lack of physical activity (with moderate obesity), and use of addictive substances (alcohol, tobacco, etc.). Preventable mortality causes are still above the mean level in Europe, highlighting the issues mentioned in this case: lack of trust in medical experts, unwillingness to take responsibility for one's own health and actively improve quality of

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life. With high avoidance towards medical visits, many preventable health problems could be addressed early on and lower the financial burden on the healthcare system. One of the main focus-points at the moment for Czech health institutions is the improvement of doctor-patient communication, as well as a need to establish publicly available indicators of quality of services and their outcomes. The healthcare system is currently running pilot projects to address certain issues with patient consulting and visits by exploring digital avenues for patient care. For individuals who are not willing to visit their doctor in person, this might be a good option to increase their healthcare utilization.

These indicators and improvements would largely improve the general trust of the aging population in the medical services available and subsequently increase the early detection and treatment of preventable health problems.

One of the main challenges in the increase of healthcare activities related to prevention is the low level of public spending on healthcare as a whole (below EU average) and specifically on prevention as such (3% of total public spending).

Jarda faces the challenge in the form of needing his family's support, both in terms of financial help and potential subsequent informal medical care. As his relationship with his family is strained, his ability to request such help might be limited and lower his physical well-being.

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Smart and Health Ageing
through People Engaging in supportive Systems

MEET JARDA[P6]

Motto: improve quality of life while reducing burden on a healthcare system

Name: Jarda
Country: Czech Republic
Age: 68
Area: Big city

Economical situation: Very low
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Jarda has been, as he likes to say, "happily divorced" for the last 20 years. He lives in a small flat in a housing estate on the outskirts of a big city. Jarda used to play bass guitar in a once quite well known punk rock band called "And it will get worse". He still belongs to the punk rock community, although some of his mates have already died or, what is even worse according to Jarda, they changed their life style and stopped drinking. That is not a threat to Jarda – he loves going to punk events and to his favourite pub. Sometimes it is just a few pints, but other times, it can revert to a three day drinking binge. These binges are quite challenging and lately Jarda has not been able to cope with them very well. The last time his son found him sleeping in front of the house and called an ambulance. Jarda took this as a betrayal.
Although Jarda has severe hypertension and COPD, he refuses the regular visits to his GP, as he is bored with the repeated advice to stop smoking, stop drinking, to exercise and so on. Over the last 15 years he has not visited his GP and his only contact with the healthcare system was in the emergency room. He found out that if he feels bad (often has problems breathing or high blood pressure) and calls emergency, they usually don´t ask too many questions as they are too busy. A few times they wanted to keep him in hospital, but he always signed the release papers and left (as he was starting to feel withdrawal symptoms). A few times he also caused a conflict in the emergency room, as they wouldn´t let him go out for a smoke. Once the doctor even wanted to call the police. Another time a nurse told him that he was obnoxious. But Jarda didn´t really care and told them to shut up and do their job.

What is important to Jarda

- The punk-rock community, friends, events and the pub [P6-Req-1]
- To live his life the way he wants [P6-Req-2]

Daily living

- When he is at home, he usually sleeps or watches TV and eats junk food [P6-Daily-1]
- Likes to connect with the punk community through social networks [P6-Daily-2]

Own resources, assets, support

- He lives from a small pension and sometimes also works at the music shop owned by his friend [P6-Resources-1]
- His son supports him financially despite the fact, that Jarda sometimes doesn´t even talk to him (he is usually nicer when he needs to pay for his bills) [P6-Resources-2]

Health concerns and limitations

- COPD and high blood pressure [P6-Health-1]
- Alcohol dependency [P6-Health-2]

Health tests/ treatments/ medication

- Refuses regular GP visits [P6-Tests-1]
- States of severe breathing and pressure problems leading to ER visits [P6-Tests-2]

Events, issues, personal concerns, technology

- Jarda functions almost normally some of the time, but then once in a few weeks comes the drinking shift and resulting problems [P6-Personal-1]
- His son has an agreement with the neighbour that when Jarda disappears for a few days to make sure to call him [P6-Personal-2]
- Following repeated conflicts the rest of the family (ex-wife and daughter) do not communicate anymore [P6-Personal-3]

Hopes and dreams/ what brings joy/ quotes

- *"If only I could drink so much as I want without these bloody problems"*
- *"Maybe if I got some warning early on, I could avoid these incidents with the ER, but it would have to work without going to the GP"*

Unmet needs

- Jarda´s son would welcome some sort of monitoring, to know when his father has problems, and he also thinks that maybe some online peer group of ex-rockers could help [P6-Unmet-1]

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Figure 8: Persona 6 - Older adults with alcohol or drug dependency and severe chronic conditions non-complying to medical recommendations

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3.2.7 Oldest old and frail[P7]

This persona is dedicated to the oldest old, which is usually defined as the age category over 85 years of age. An important phenomenon in this population is the frailty syndrome that develops as a natural consequence of age-related decline (Clegg et al., 2013). Frailty is common in some part of the oldest old population (one third to one half) and manifests itself as sudden worsening of the overall condition, especially by frequent falls, exhaustion, unexplained weight loss, acute confusion (even delirium), that may be triggered by minor stressors (Clegg et al., 2013). It has a dynamic nature. The acute episodes of frailty may be alternated by periods of normal functioning, so it is often described as good days and bad days, or bad time of day, or frailer seasons (Coker et al., 2019). Frailty increases dependency on others and is associated with the need for relocation to institutionalized settings (Granbom et al., 2014; Scheibl et al., 2019).

The vast majority of older people strongly prefer to age in their own home for as long as possible. Sometimes the decision to move is postponed until some major incident or health crisis that may be related to frailty. The decision process connected to moving can be very complex and demanding and if the older adults feel pressured, they often feel resentment (Scheibl et al., 2019). Sometimes the decision is made with an altruistic motive to make the family happy, to reduce the burden of informal caregivers (Oswald & Rowles, 2006). The motives of the informal carers for the decision to move an old person to an institutional setting are usually concerned around safety issues, while the older person usually prioritizes their autonomy (Scheibl et al., 2009).

Our participants in the age structure for 90 years consider the following important: “Despite sensory and movement limitations, to maintain independence in normal daily activities—dressing, eating, washing or cleaning. To accept things as they are—even with the restrictions that old age brings.” Jiřina (93) Restricted mobility bothers and irritates her and she fears a complete immobility and inability to take care of herself. In life, she considers it is the most crucial to keep everything in balance, the ability to cope with different situations, and the art of accepting things as they are. As for aging, she said, people should try to maintain the level and dignity of an older adult, treat them politely and create a dignified environment close to what they are used to.

Pavel (93) is a widower and has two sons. Prior to his retirement, he worked as a publishing company's sales director. He focuses on holding lectures on the Holocaust, which he himself experienced, as he feels it is his moral duty. "A person who just hangs out at home ages faster," says Pavel. He considers love, whatever its kind, to be the most important thing in life. It can be friendship, tolerance, any kind of love. He wouldn't change much in his life, he's happy he was able to marry a woman he really loved and respected her for her personality. He no longer has expectations for the future. He would like to die in his sleep.

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Jiřina (91) requires constant care. She can no longer take care of herself. She is immobile, so she can only sit up or lie down. She remains in home care, where she is cared for by both her children and caregivers. She is visited twice a week by a nurse, with whom she exercises together and practices walking with the help of a walker. Despite her health condition, she is still in a very positive mood and at least tries to use and exercise her hands. She also has a harder time hearing and seeing, and takes a lot of medication, but she is not in pain. She lacks nothing in life. She is satisfied with the great grace of God. Faith is very important to her in life, it gives her hope. She regularly listens to a religious radio and is visited by priests. Due to her health condition, she can no longer do many things, so she has no interests. She often prays the rosary and the nurses read books to her which she can no longer read on her own. She is able to use a simplified mobile phone with a larger font.

During his life Miloš (90) worked as a doctor in various specializations and as a psychotherapist. His last job was working as a head of the geriatrics department. Thus, he also prepared for old age professionally, and he could draw from his own aging and the aging of his parents to be able to better do his job. Miloš is currently bothered by the gradually growing symptoms of Parkinson's disease and vocal cord disorder, which makes it difficult to talk to others. He also suffers from bradycardia, which made it necessary for him to have a pacemaker. Movement and confidence while moving are significantly affected by the consequences of a sternal fracture. Lately, he has also become more anxious and melancholic. At present, in addition to the state of his health, the biggest problem he is facing is his financial situation. In order to be able to afford to stay in his apartment, he is financially supported by his sons. In old age, he developed a lifestyle to support the upkeep of his cognitive abilities. He gets up regularly at the same time. After morning hygiene, he prepares breakfast himself and reads afterwards until it is lunch time. Lunch is provided by a social service provider. After lunch, he continues reading and works on the computer. His sons provide dinner for him. He then spends the evening watching television and educational programs. At present, Miloš's social circle is not as wide as in the past. He prefers loneliness rather than company. He tells younger people, “Well, don't be afraid of old age. It is, it belongs to, a normal period of life. There is no death without old age, or when there is death and it is before old age, it is a tragedy. And having offspring, because immortality is in our children and grandchildren and offspring, so those who are childless are actually referred to the mortality of their DNA, their genes. It's sad, but you have to deal with it, you too have to deal with it.” Miloš (90)

Some of our respondents in very high age stress the importance of keeping busy with “something that you like”: “I often hear the message to the young” Maťka (89): “some older people say they will be happy to retire. Yeah, they are looking forward to retiring. And I do not understand what it is that they are looking forward to. Yeah, the person that says it. And for those, who also feel like this, they should also make it clear, what am I supposed to look forward to myself. Should I look forward to not having to get up in the morning? That won’t make you happy, you know. They should make it clear for themselves if this

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thing that they are looking forward to has any reason. I don't know how to express this. Perhaps you understand me a little bit. I do not want them to look forward to false things, that's it. They should prepare for good things, prosperous things, for their own joy, but not to bullshit. As my dear partner used to say - you should prepare for a second career after retirement - do the things that you like, just do something".

In our expert interviews the frail oldest old were characterized mainly from the viewpoint of their needs and risks: "This frailty syndrome means a complex and holistic view of the very old person. The frailty means that these clients have reduced functional reserves, so the heart is weaker, all other organs are weaker, and there is a problem with adaptability. So, the risks are much higher." Ivana (geriatrician)

There is also the question of moving to specialized homes: "The most common problem in this category of oldest old is of course the question of staying in their home versus leaving to an institutionalized care. I see it so often how hard it is for their families to decide. Of course, some make that decision quickly after first problems with self-sufficiency. Others see that the move could be sometimes even fatal because of the emotional connection to the place, things, people… It is one of the most difficult decisions to make." Alena (social worker)

One of the most difficult elements of moving is the attachment of older adults to their possessions such as favourite furniture, photographs, and other cherished artefacts. Very often there is a need for some down-sizing of the belongings. Especially if the new space is smaller, this process may cause distress as these possessions are connected to fond memories and can serve as important symbols of identity (Oswald & Rowles, 2006). **Helena**, the next persona, is dependent on help from her loved ones and doctors. In her country, compulsory public health insurance is in place, which covers most medicines and medical procedures. But Helena has to pay extra for above-standard services or more expensive drugs. Her daughter must take her for medical examinations, as the hospital is in a larger city away from her village. Health care is of good quality, but it often depends on who provides the care and in which region of Slovakia. The quality of care of ambulances and hospitals is not sufficiently measured.

Currently, the Slovak healthcare system is facing an increase in the number of chronically ill patients. There are very low numbers of beds available for them. The hospitalization rate is 9% higher than in Western Europe. Patients usually spend more time there compared to the European average. Increased capacity would not bring patients benefits in the form of better care. This can also be a problem for Helena in the event of her health taking a turn for the worse. Hospitals in Slovakia face an unclear concept of long-term care and quality coordination is lacking. Helena may be waiting to move to a nursing home. These places are usually paid for, but not by state insurance. This can place a financial burden on Helena's daughter's family. An equally heavy complication is the lack of beds/rooms and longer waiting times for long-term placement in these facilities.

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Modernization of the healthcare is a goal for the Slovakian Ministry of Health which would provide hope for Helena and her possibly worsening health. Increasing the availability and quality of healthcare from the patient's point of view. Slovakia is also trying to focus on the needs of patients and be more accommodating in their care. One of the pillars is also the focus on digitalisation of patient data.

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MEET HELENA P7

Motto: Safe and cared for while still autonomous

Name: Helena
Country: Slovakia
Age: 93
Area: Small village

Economical situation: Less affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Helena is widowed and lives in her own house with a garden, with her two old cats. Except for arthrosis (it hurts to walk more than a few metres) and worsening of memory Helena had always enjoyed good health, until recently. But during the last year she started to have some bad days, and then she felt extremely exhausted and weak. There were some crisis situations recently: she was making herself a tea and started a fire accidentally. A few times she fell and could not get up and had to wait for her daughter for a few hours. Than the doctor said that she forgot to drink enough water and was dehydrated. Her daughter lives in the nearby village with her own family, so she visits almost every day and brings her food. Her grandchildren also come often and sometimes they stay for the weekend. The daughter is often worried that something bad will happen to mum. After these incidents the family started talking about possible placement into a nursing home. Helena was at first totally reluctant, but then a few more incidents happened, and she started considering this possibility more seriously. The daughter took her to the nursing home for a short visit, just to look around. It was not so bad, but the rooms were just too small Helena was sure that she would not be able to take all of her stuff with her. Since that visit she is constantly thinking about how she could live in such a tiny little room, not allowed to bring her favourite chair and pictures... and what about the cats?! And then, sometimes she thinks that maybe, if she moved, it would be better for her daughter´s family, they would be relieved. So during the last few months Helena has kept thinking about this and she is too afraid to make a decision.

What is important to Helena

- The cats and their wellbeing P7-Req-1
- Being clean and comfortable, regular food and drink, feeling safe P7-Req-2
- To keep old relationships P7-Req-3
- Having always something to do P7-Req-4

Daily living

- Daughter brings food and does more difficult chores P7-Daily-1
- Due to the arthrosis she cannot go far, just to the front garden to sit on her favourite bench P7-Daily-2
- Frequent visits by grandchildren P7-Daily-3

Own resources, assets, support

- Dependent on the support from her daughter P7-Resources-1
- The neighbour sometimes visits and feeds the cats when she feels weak P7-Resources-2

Health concerns and limitations

- Severe arthrosis, difficult walk P7-Health-1
- Frailty – some days are better, some are just bad, when she feels exhausted and often falls P7-Health-2

Health tests/ treatments/ medication

- Regular health checks by the GP P7-Tests-1
- Had cataract operation P7-Tests-2
- Takes sleeping pills P7-Tests-3

Events, issues, personal concerns, technology

- The biggest issue is the hard decision about the possible movement to a nursing home P7-Personal-1

Hopes and dreams/ what brings joy/ quotes

- *"It would be great if I could just stay here and daughter would not worry about my health"*

Unmet needs

- Monitoring of the risk situations around the house (electricity, fire, falls) P7-Unmet-1
- Support of healthy nutrition and drinking regime (with frailty often the risk of dehydration and malnutrition) P7-Unmet-2
- Encourage continued participation in social, neighbourhood and civic activities P1-Unmet-1 P7-Unmet-3
- Support more movement / exercise

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Figure 9: Persona 7 - Oldest and frail

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3.2.8 Older adults with deafblindness (older adults with a dual sensory impairment)[P8]

The following persona represents people with a dual sensory sight and hearing impairment. It was created by representatives from WFDB, therefore direct quotes from the qualitative research are not included. The degree of it varies but it always results in a diverse and unique disability. This has a significant effect on communication, socialisation, mobility and thus their independence. There are people with congenital deafblindness – who were born or became deafblind before spoken, signed or other visual forms of communication were developed. Another type is acquired deafblindness where vision and hearing deteriorate at a later stage of life due to an accident, injury, disease or the aging process.

Representing between 0.2% to 2% of the population, persons with deafblindness are a very diverse yet invisible group. The lack of services severely restricts the social and economic participation of persons with deafblindness, as well as increases the dependency and reduces their educational opportunities (World Federation of the Deafblind, 2018). The fact that vision and hearing play a significant role in communication leads to the dependency of people with deafblindness on assistance (often in the form of interpreter-guides). Persons with deafblindness are both very varied in their communication requirements due to the differences in the extent, type, and history of their sensory impairments; personal characteristics, preferences and the skills they have developed. Situational context also plays a role (e.g., noise, daily shape, mood, etc.) in the ability to communicate, and varies from day to day, and sometimes from morning until late evening. There is a need for the development of more assistive devices to support communication, additional interpreter-guides, and training for hearing and sighted people in communicating with persons with deafblindness (Hersh, 2013). It is vital, therefore, that persons with deafblindness access services that meet each individual's needs and not a combination of services designed for blind or deaf people.

The following types of techniques are used in communication with persons with deafblindness: spoken languages, sign languages (e.g., drawing onto the palm, finger Braille), contact (tactile) techniques (e.g., holding the other person's wrists or touching the other person's chin, lips, or throat). Barriers to communication, information, and mobility can have serious emotional and social consequences, restrict informed decision making, and reduce functional independence and the ability to perform daily living tasks (Bodsworth, Clare, & Simblett, 2011).

Persons with deafblindness who have high quality lives often have several things in common. First, they have each, in their own way, come to accept themselves as individuals who have unique experiences of the world, and valuable gifts to share. This fundamental acceptance of self can occur regardless of the severity of the particular sensory losses or other challenges that a person has. Second, they have had educational

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experiences, which have helped them maximize their abilities to communicate and to function productively (Miles, 2008).

To provide an example, with a general healthcare coverage available to all citizens in Norway, everyone is able to receive treatment at a relatively low cost. The effort to keep the overall cost low is set to provide individuals with free healthcare treatments for a year in case the total cost of treatments exceeds a pre-set limit. This applies for various treatments ranging from surgery, pharmaceutical treatments, psychologist visits, etc. This enables the persona used for this case—**Frederik** from Norway—to rest be assured that no matter the treatment he will need, he does not need to worry about not being able to afford the treatment.

Individuals with a disability—such as Frederik in this case—have a right to receive any support services or assistive products necessary to help them in their everyday functioning and coping with the barriers they might face. The exact rights and support services are specified by laws and, most relevantly for Frederik, ensure he has access to interpreting and accompanying assistance for persons with deafblindness and any hearing or sight-aids Frederik might need. Furthermore, a national association of persons with deafblindness in Norway organises courses for persons with deafblindness and their close ones (relatives, friends), who can support their adjustments and possibly teach them key competencies needed. With specific support and help, Frederik might acquire tools to learn new skills and become more independent. The members of the aforementioned associations may subscribe to a daily newsletter adapted to those who are deafblind, and they organise social events to encourage their members to meet.

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MEET FREDRIK P8

Motto: Support guide-interpreter communication help to retain independence

Name: Fredrik
Country: Norway
Age: 75
Area: Big city

Economical situation: Semi-affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Having vision and hearing impairments since birth, Fredrik went to schools for the deaf as a child, before becoming a certified tablet fitter as a young adult. He also enjoyed quite ordinary activities like dancing, sports, outdoor life and advocacy work, also had a strong interest in chess. Living alone since his divorce in 1980, he has maintained a close relationship with his three kids, grandkids and great-grandkids. After becoming deafblind in the 1980s he acquired a degree in Law at the University of Oslo and started working as a Political Consultant and active self-advocate representing persons with deafblindness.
Fredrik once experienced an acute illness at home and his kids helped him to the hospital. The preliminary examination ended with him being dismissed in spite of being in agony, as the doctor assumed that Fredrik had understood the questions and responded to them, which was not the case. Understanding of deafblindness would have revealed that he had just responded to sounds, not words. Another doctor noticed the disagreement and intervened and finally a more thorough examination was conducted, revealing a potential severe infection, leading to Fredrik being committed to hospital for a week. No interpreter-guides were made available during the initial and critical admission phase.

What is important to Fredrik

- To remain living independently at his own house as long as possible P8-Req-1
- To have access to guide-interpreter services P8-Req-2
- Relationship with family and friends P8-Req-3

Daily living

- Home-help is essential for Fredrik to be able to remain at home. It comes twice per week and must be trained in communicating with deafblind people, otherwise there would be a need for a guide-interpreter P8-Daily-1
- Regular physical actiivity, exercising at home P8-Daily-2

Own resources, assets, support

- His friends are mostly persons with deafblindness themselves, and they are to a certain degree able to communicate directly. P8-Resources-1
- His children and grandchildren provide significant support P8-Resources-2

Health concerns and limitations

- Fredrik has had difficulties learning Braille and therefore has not been able to use modern assistive products like Braille readers/writers to communicate. P8-Health-1

Health tests/ treatments/ medication

- He got CI implants 15 years ago, that enabled him to communicate hearing familiar voices in accommodated environments. Without these implants he would now be totally deafblind. P8-Tests-1
- Slight hypertension, medicated, controls every 6 months P8-Tests-2

Events, issues, personal concerns, technology

- Due to the fast developing virtual world Fredrik has started feeling isolated and more and more unable to interact with society at large without assistance by interpreter-guide services. P8-Personal-1

Hopes and dreams/ what brings joy/ quotes

- *"It would be so nice if there was some technical solution that would at least to some extent replace the human guide/interpreters. Though it must be adaptable to individual needs."*

Unmet needs

- Fredrik always needs to plan very carefully most of his activities, as he relies on the availability of guide-interpreter services. P8-Unmet-1
- Although the law in Norway secures the right to communication assistance, not all institutions know how to comply with that. P8-Unmet-2

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Figure 10: Persona 8 - Deafblind older adults (older adults with dual sensory impairment)

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3.2.9 Informal caregivers for the older adults with neurodegenerative disorders[P9]

As the condition is progressive, so are the care costs, and that is an important factor especially from the viewpoint of socio-economic inequality. Prolongation of the time while still having in-home care may have big consequences for the individual as well as for societal costs. Therefore, it is crucial to understand and support informal caregiving, which is the most common type of caregiving for patients suffering from this condition.

Caregivers of people with dementia are often exposed to social isolation, frustration, exhaustion, burnout and many other negative consequences of their role (McCabe et al., 2016). The first group of identified unfulfilled needs of informal caregivers are associated with the caregiving itself, such as information, respite care, formal care support, informal care support such as peer support groups and help with managing behavioural and psychological symptoms of the recipients of care, such as aggression or agitation. The second type of needs is more personal, and is related to managing the carer´s own mental health and managing their own lives (McCabe et. al, 2019, McHugh et al., 2012).

According to Quinn, Clare, & Woods (2015) the main overarching theme of in-depth interviews with informal caregivers was balancing their own needs against the needs of their relatives. They are facing many dilemmas such as preserving the quality of the relationship, putting up with the fact that their relative´s personality and behaviour is changing, and that they are no longer a support. Also important was to recognize when is the right moment to put their own needs above the needs of the patient, although this often resulted in feelings of guilt.

As some of our experts point out, the care of informal caregivers is extremely critical in the overall approach to the neurodegenerative diseases: “The development of the illness means that there is also personality change. That means a really big burden for especially informal caregivers – spouses, children. We need to think about them and their needs. And I for example think that their loved one with dementia, they still love them, it is still the person who they know and who they knew, but is behaving differently.” Ivana (paediatrician)

Others also emphasise that informal caregivers deserve support “the support of informal caregivers can save the public health system a lot of money. These people do it very well if they have solid support, education, maybe some peer groups. They have the strongest motivation – the relationship with their loved ones.” Jana (social worker) Others point out that informal caregivers are also vulnerable to burn out “But there is a big risk of burn out syndrome, they need respite care, they need support.” Peter, (paediatrician)

Although there are situations when older adults with neurodegenerative disorders prefer professional care: “Sometimes I see the problems that not all the older adults with dementia want their children to take care. If the care gets just too intimate, like in personal

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hygiene, they might prefer a professional caregiver. The main goal should be to respect the client's dignity.” Jan (paediatrician)

To present this phenomenon we introduce **Astrid** – informal caregiver from Belgium. Astrid is taking care of her mother who has been diagnosed with Alzheimer 6 years ago. Despite severe symptoms, Astrid wants to take care of her mother. Unfortunately, it is becoming challenging to keep up with her own needs. Being isolated and caring for her mother sometimes brings Astrid feelings of sadness and anxiety. However, she still manages thanks to keep in touch via social media. She would like to reach out to expand her social circles and potentially go on a date.

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MEET ASTRID[P9]

Motto: Balancing own needs with care demands

Name: Astrid
Country: Belgium
Age: 53
Area: Small town

Economical situation: Less affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Astrid (53) is a single, kindergarten teacher and is living with her mother Tessa (78), who suffers from middle stage of Alzheimer's. Tessa was diagnosed 6 years ago and gradually her symptoms worsened so two years ago Astrid decided to move into Tessa´s house to take better care of her. Despite the fact that Tessa´s symptoms are quite severe (forgetting, problems with personal hygiene, confusion), Astrid still does not want to consider moving her to a special care home. Astrid and Tessa always had a very good relationship and Astrid cannot imagine that she would let her mother be institutionalized. They still have some nice moments together – sometimes in the evenings they watch TV together and they hold hands, the connection is still there, even if Tessa is often confused and it happened a few times that she could not remember Astrid´s name.

Actually for Astrid, it is the only really close relationship she has in her life right now. She has had a few relationships with men, but they didn´t work out, and although she has a few female friends, due to the caretaking she hasn´t seen them very often lately. On the other hand, she is very active on social networks. Actually, that is where most of her social life is happening right now. Astrid is often tired and feels sadness and anxiety about the future, worries about Tessa and also worries that she does not have the right information about the progression of her mother´s illness and she would need to have someone to consult from time to time.

What is important to Astrid

- To give her mother Tessa the best care she can and to keep her safe[P9-Req-1]
- To know what to do in case of an emergency[P9-Req-2]
- To keep her friends, to be able to go on a date[P9-Req-3]

Daily living

- Does all the chores while looking after Tessa[P9-Daily-1]
- Recently she had to limit her job in the kindergarten to part time[P9-Daily-2]
- Very limited social life, feeling guilty when socializing[P9-Daily-3]

Own resources, assets, support

- Living on her mother's pension and Astrid´s own wage, their budget is quite limited[P9-Resources-1]

Health concerns and limitations

- Although she finds the Internet useful, it is difficult to manage the large volume of information for her[P9-Health-1]
- She would welcome to have a channel with tailored information that she needs for better caretaking[P9-Health-2]

Health tests/ treatments/ medication

- With Tessa they go for the doctor´s check-up every 6 months[P9-Tests-1]
- She has help from a social nurse twice a week[P9-Tests-2]

Events, issues, personal concerns, technology

- Almost all her social life is online[P9-Personal-1]
- Would welcome some peer support from other caretakers[P9-Personal-2]

Hopes and dreams/ what brings joy/ quotes

- *"Of course I would like to go out, and go on a date, or be with friends, but I always think about mum, how will she cope here on her own, if she is safe. Bigger part of my social life has already moved online."*
- *"It would really help having more friends / peers who are also caregivers."*

Unmet needs

- Be able to consult online on the development of Tessa´s illness[P9-CgNeeds-1]
- To have some sort of educational and supportive online source of valid information for caretakers[P9-CgNeeds-2]
- Peer support groups, information, education, nutrition help, emotional support[P9-CgNeeds-3]

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Figure 11: Persona 9 - Informal caregivers

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3.2.10 Impact of the COVID 19 pandemics on the mental health and computer use of older adults[P10]

This persona is dedicated to the impact of the COVID 19 pandemic. Beyond the fact that the pandemics has disproportionately affected older adults, who show a much higher risk of hospitalisation, more difficult course of the illness and mortality, the pandemic situation also has an impact on the mental health and behavioural patterns of the older adults. According to a few available studies they are in a much bigger risk of increased isolation and loneliness (de Jong Gierveld & van Tilburg, 2010), worsening of all the existing mental health conditions like depression, anxiety, dementia and psychosis. The pandemic emphasised the importance of online health interventions to help this age group (Xie et al., 2020).

An interesting study investigated the connection between online behaviour and well-being during the COVID19 pandemic in 407 Israeli internet users aged 60 years and over (Nimrod, 2020). The results showed greater internet use early after the onset of the pandemic, mostly chat services, or errands like online shopping or online medical appointments and also social networking and hobbies. The observed associations indicated that these changes reflect coping efforts, so by developing their online communication, participants may have sought emotional support, as well as a connection. The study indicates that although older adults have usually fewer digital skills, they use the Internet for coping with stressful conditions in a manner that is similar to that of young adults. (Nimrod, 2020).

The last persona is actually the upgraded second persona **Roberto** - a representative of the “mild, but multiple chronic conditions” group. Roberto lives in a small town in Italy, the country that suffered one of the worst outbreaks of the COVID19 pandemics which disproportionately affected mainly its oldest citizens. After the initial shock and in order to cope with the strict lockdown rules Roberto started using the Internet much more intensively, in a way he did not use it before, mainly to connect with his family and friends.

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Smart and Health Ageing
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MEET ROBERTO (after first wave of COVID 19) P10

Motto: Improved computer skills and health behaviour as a consequence of the pandemics

Name: Roberto
Country: Italy
Age: 72
Area: Small town

Economical situation: Less affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Roberto lives with his wife Bianca in a small Italian town, in a house with a garden. He is the owner of a small shop, which is now run by his nephew. Roberto and Bianca are childless and Bianca was recently diagnosed with Parkinson´s, though she has very mild symptoms so far. Roberto is slightly obese, he has diabetes and hypertension and smokes 20 cigarettes a day. He realizes he has to change his lifestyle.
The COVID19 pandemics has changed lives not only for Roberto, but for all the people in the city. Almost four months it was not possible to go anywhere and people were very afraid of the infection. Roberto knows several people who have been to hospital and unfortunately one of his best friends died of COVID. Roberto was very scared for himself as well as for Bianca´s life and he was anxiously complying with all regulations. Of course he realized that he was in higher danger due to his being overweight, having hypertension and smoking. Some of his friends were also suffering depression. Paradoxically COVID pandemics caused Roberto to take better care of his health. He started to take regular walks around the house and even ride on the exercise bike. Also, as he could not go out, his nephew taught him how to work better with the internet, Roberto started using social networks and evening videocalls with his friends (with an obligatory glass of wine). With their wider family they started seeing each other on Skype.

What is important to Roberto

- To keep a satisfactory social life even amidst pandemics P10-Req-1
- Family ties of their brothers, sisters, nieces, and nephews P10-Req-2

Daily living

- Still does most of the work around the house and in the garden, but sometimes his nephews come to help P10-Daily-1
- Most of the evenings he meets friends online, once a week personally in the town P10-Daily-2

Own resources, assets, support

- The business suffered during the pandemics, but it is still functioning P10-Resources-1
- Big family, there is always help if needed P10-Resources-2
- Also he has many friends and a good local community that he can rely on P10-Resources-3

Health concerns and limitations

- To keep some of the good habits that he gained in the first wave of pandemics (training, less drinking, healthier food) P10-Health-1

Health tests/ treatments/ medication

- Takes six different medications P10-Tests-1
- Visits several specialists (diabetes, heart condition), recently some of the checks were done by videocalls P10-Tests-2

Events, issues, personal concerns, technology

- He likes to read about various diagnoses on the internet, considers joining some online patient groups P10-Personal-1
- He used to have problems with doctor's visits as he felt ashamed and irritated, but it seems to be much easier with online check-ups P10-Personal-2

Hopes and dreams/ what brings joy/ quotes

- *"it is really awful what happened here in the spring with the COVID 19 pandemics. I hope this will never happen again. But surprisingly, thanks to that horrible situation I learned some new tricks with the internet, I never knew it was so easy to videocall or to find friends on social network. I am very enthusiastic about this new technology and all the possibilities."*

Unmet needs

- Online peer support group of patients with hypertension P10-Unmet-1
- Online intervention to reduce smoking P10-Unmet-2
- Some tools to enhance home training P10-Unmet-3

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Figure 12: Persona 10 - Impact of the COVID-19 pandemics on the mental health and computer use of older adults

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3.2.11 Formal caregiver in the Nordic area[P14]

The next persona was added to provide the insight to the Nordic suburban area. As it has its specificity, previous qualitative research does not cover this reality, therefore direct quotes were not included. Persona **Anna** is 70 years old and lives in a block of flats in a suburban area of a small city in Finland with her spouse **Pekka**, soon to be together 50 years. They sold their big house in the countryside five years ago when Pekka wasn't able to move around the house anymore, because of his ALS. In the block of flats the maintenance is done by a maintenance company, which makes their life easier. Pekka has been feeling progressively worse in the last couple of years, and Anna, who has already been his formal caretaker for 10 years, does not have time for herself. As a formal caretaker, she receives a monthly payment of 800€ in addition to her pension. Anna is happy that her own symptoms of high blood pressure and cholesterol are mild, and with medication she feels ok most of the time. She just needs to remind herself about her own medication. She also feels pain in her back and joints from time to time, but aims not to pay attention, as she feels that she simply doesn't have time to concentrate on herself, and her health concerns are less than Pekka's.

Nevertheless, Anna enjoys her time with Pekka, especially on good days. Anna hopes that she will stay healthy long enough to take care of Pekka for years to come, as neither of them want Pekka to move to an elderly home. In addition to the constant care that Anna provides, the public healthcare system provides Pekka with nurses, visiting him two times a day: in the morning when they help him up and with getting dressed, and in the evening time with night preparations and physically getting him to bed. The current care contact allows nurses to help him in showering merely once a week, and Anna tends to wipe his body with fresh towels in between.

Every day goes along within the same routine of Anna preparing and serving 5 meals a day, then watching television and listening to audio books. Anna knows that Pekka would like to spend more time outside. Unfortunately, she is not physically fit enough to push his wheelchair. She would also like to go outside herself, just spontaneously for a long walk, but she is too afraid that Pekka would need her. Currently, they are mostly living in each other's presence 24/7, and they both wish that Pekka would have the opportunity to do things without Anna and have more independence.

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MEET ANNA P14

Motto: One day at a time, hoping for the good ones

Name: Anna
Country: Finland
Age: 70
Area: Suburb of a small city

Economical situation: Less affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Anna has been living with her spouse Pekka for almost 50 years. They live in a block of flats. Pekka has been feeling progressively worse the last couple of years, and Anna, who has already been his formal caretaker for 10 years, does not have time for herself. As a formal caretaker, she receives a monthly payment of 800€ in addition to her pension. Anna is happy that her own symptoms with high blood pressure and cholesterol are mild, and with medication she feels ok most of the time. She just needs to remind herself about her own medication. She also feels pain in her back and joints from time to time, but aims not to pay attention, as she feels that she simply doesn't have time to concentrate on herself, and her health concerns are lesser that Pekka's. In addition to the constant care that Anna provides, the public healthcare system provides Pekka with nurses visiting him two times a day.

What is important to Anna

- Pekka P14-Req-1
- Daily routines P14-Req-2
- Staying physically capable of acting as the formal caretaker P14-Req-3

Daily living

- Nurses visiting two times a day P14-Daily-1
- Routines regarding daily cooking and eating together are important P14-Daily-2
- Assisting Pekka with all tasks P14-Daily-3
- Having TV on and reading digital newspapers P14-Daily-4

Own resources, assets, support

- Relies on herself in daily life P14-Resources-1
- Calls their private healthcare provider in case needs help for herself or Pekka P14-Resources-2
- Daily support from nurses P14-Resources-3
- Feelings of isolation and loneliness, and sometimes anxiety P14-Resources-4

Health concerns and limitations

- Feeling healthy most of the time, does not experience limitations P14-Health-1
- COVID-19 fear P14-Health-2
- Concerns for Pekka's deteriorating health P14-Health-3
- She need reading glasses (strong nearsightedness) P14-Health-4

Health tests/ treatments/ medication

- Takes pills daily to stabilize hood blood pressure P14-Tests-1
- Yearly health check-ups P14-Tests-2
- Regular dentist visits P14-Tests-3

Events, issues, personal concerns, technology

- Digital active, uses smartphone and tablet daily reading, videocalls and occasionally ordering online P14-Personal-1
- Concerns about data privacy, does not give consent to third parties P14-Personal-2
- Trusts own healthcare service provider P14-Personal-3
- Interested, yet highly suspicious about new digital services and data privacy. She is afraid of 5G and its consequences, especially for bees P14-Personal-4

Hopes and dreams/ what brings joy/ quotes

- *That everything would stay as it is, and nothing surprising would happen*
- *Having as many good days with Pekka as possible*
- *Being able to contribute to the society somehow*

Unmet needs

- Maintaining individual life and participating actively in society P14-Unmet-1
- Feeling guilty for the times being away from Pekka, and not being able to provide him with enough independence and outside activities P14-Unmet-2
- Not having time for herself P14-Unmet-3

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Figure 13: Persona 14

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3.2.12 Refugee's perspective[P15]

The last persona is providing an insight from the refugee perspective. It is noted that although Miral Persona does not correspond to elder people demographic, as defined in SHAPES scope, Miral represents a vulnerable group that faced and overcame difficult social conditions that average Elder European population have not confronted (Hatzidimitriadou, 2010). The life-threatening, stressful experiences of conflict zones are argued (Bhattand and Priya Bathija, 2014; WHO, 2019) to take their toll in life expectancy. In this sense, the age of 60 years old in this specific vulnerable group can be considered as elder adult. Therefore, we included her in the deliverable. About two years ago, 60-year-old **Miral**, originally from Palestine, moved with her 30-year-old son to an apartment in a Greek city, through the ESTIA (Emergency Support to Integration and Accommodation) program which is implemented by UNHCR in collaboration with the local authorities and NGOs and funded by the European Union Civil Protection and Humanitarian Aid (ECHO).

They live in an apartment in the city centre so that ensures access to health care and other public authorities (tax office, unemployment office, etc.), facilitates interconnection with other support actors and participation in the city's social and cultural life. The apartment as well as its bills is paid through the program. In addition, Miral and Emad receive cash cards in order to cover their basic needs such as food, clothing and transportation since both are unemployed. Miral says: "Things are difficult, we are human beings, sometimes we want something and we do not have enough money to buy it."

The journey of Miral's life has been long and difficult over the years. Three years ago, the journey to hope began. From Gaza (Palestine) to Egypt, then to Turkey, and finally to Greece and the hope remains...

She has been living in this city for the last 2 years. In the apartment where she lives, her neighbours love her very much and help her when needed. The day before yesterday a neighbour came to replace a light bulb that had burned out. Another neighbour has given them Wi-Fi codes so they can have free internet access. During this time, she has two or three good friends with whom she likes to walk by the river. In the pre-COVID-19 period she particularly enjoyed the various programs of the local authorities such as: gymnastics, painting, sewing, dance and Greek lessons.

The best time of the day is when she talks via Viber or Skype with her family in Palestine. Of course, there are also moments of loneliness. She says: "When I am alone, I cry! I do not have all the people I love near me. I pray to God daily."

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Shortly after she settled in the city, her health problems began. She says: "I got sick because of the psychological fatigue and all that we had been through all this time until we finally arrived in Greece" and describes:

"One day, two years ago, I was dizzy and fell down. I was admitted by ambulance to the hospital. I stayed for 10 days. When I got out of the hospital I could not walk. I had to use a wheelchair. I remained in that state for 5 months. Then, I cried constantly, I was desperate. Today I am much better. I can walk again."

Miral was diagnosed with a condition called Multiple Myeloma which is a cancer of plasma cells. She knows neither the diagnosis nor the severity of her condition. During that difficult period of her illness, her son had taken care of her. He had fed her, washed her, dressed her, cleaned the house, and gone shopping. He had been the one who cooked for both of them. She laughs and says: "I told him how to cook and he did it. He made it delicious!" Also, the help of an Iraqi neighbour was also significant, who at that time lived in a neighbouring apartment.

Since then and every month Miral has gone to the hospital for her treatment. She says: "I'm fine now. The doctors at the hospital are taking care of me", and she adds: "A doctor loves me very much. Every time she sees me, she hugs me. She's very good. The only thing that bothers me and I would like to change is the long wait on the day of the appointment."

What she wants and wishes for the future is first of all that both she and her son are healthy. She also wants their papers to be processed as quickly as possible so that they can travel to Germany. There, she hopes that her son will be able to find a job, make a better living and be happy!

She says: "The reason I want to live is for my child. I am not afraid of death. If you are a good person and you do good you have nothing to fear. My years have passed; in my country someone of 70 years old is considered to be an old man. Here, I see them groomed, nicely dressed and taking care of themselves. I like that!"

To the question of what she never forgets Miral answers: "What I will never be able to forget, no matter what I have been through, is the experience of war. Bombings, shootings, cold, lack of water, lack of food, lack of electricity. But the worst was the fear and the insecurity! Now, I do not hold a grudge against anyone. I am who I am and I love the whole world!"

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MEET MIRAL P15

Motto: Increase caregiver's confidence to deliver efficient activities of daily living assistance to elder people

Name: Miral
Country: Greece
Age: 60
Area: City

Economical situation: Less affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: About two years ago, 60-year-old Miral, originally from Palestine, moved with her 30-year-old son to an apartment in a Greek city, through the ESTIA (Emergency Support to Integration and Accommodation) programme which is implemented by UNHCR in collaboration with the local authorities and NGOs and funded by the European Union Civil Protection and Humanitarian Aid (ECHO). They live in an apartment in the city centre so that ensures access to health care and other public authorities (tax office, unemployment office etc), facilitates interconnection with other support actors and participation in the city's social and cultural life. The apartment as well as its bills is paid through the program. In addition, Miral and Emad receive cash cards in order to cover their basic needs such as food, clothing and transportation since both are unemployed. Miral was diagnosed with a condition called Multiple Myeloma which is a cancer of plasma cells. She knows neither the diagnosis nor the severity of her condition. Throughout this difficult period of her illness, her son had taken care of her. He fed her, washed her, dressed her, cleaned the house and went shopping. He was the one who cooked for both of them. She laughs and says: "*I told him how to cook and he did it. He made it delicious!*". Also, the help of an Iraqi neighbour was also significant, who at that time lived in a neighbouring apartment.

What is important to Mirai

P15-Req-1
- Stay in good health for long time P15-Req-2
- Keep her good relationships with her neighbours P15-Req-3

Daily living

P15-Daily-1
- Able to go for a walk
- Able to follow various programmes of the locals authorities: gymnastics, painting, sewing, dance, Greek lessons P15-Daily-2
- Able to cook and to do work at home P15-Daily-3

Own resources, assets, support

P15-Resources-1
- Economically dependent, she lives on her husband's pension Wants to be economically independent in the future P15-Resources-2
- She hopes her son will find a job and make a better living
- She hopes to continue to have free healthcare P15-Resources-3

Health concerns and limitations

- She suffers from a serious health condition and wants to continue the treatment P15-Health-1

Events, issues, personal concerns, technology

P15-Personal-1
- Loves her son and she wants him to be happy
- She wants one day in the future to be able to see her own people again P15-Personal-2

Hopes and dreams/ what brings joy/ quotes

- *She wants their papers to be processed as quickly as possible so that they can legally travel to the country they want*

Unmet needs

P15-Unmet-1
- Efficient monitoring through digital technologies
- Access to socio-physical support P15-Unmet-2

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Figure 14: Persona 15

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4 Use Cases Development

This chapter is dedicated to the use cases. The persona-based method of use case development is explained, as well as the PACT criteria for an effective development of use cases and scenarios. The relationship between the personas and the use cases is outlined and the thirteen general use cases are presented at the end of the chapter.

4.1 Methods of use cases development

A persona-based method was used for the subsequent development of use cases. This method includes a kind of prototyping procedure. During the personas development, the basic needs of older people without any serious health problems, with multiple chronic conditions and the frail elderly (i.e. involving serious health problems, low social support, or low income) were characterized, focusing on the intersection of functional and emotional needs with medical and personal needs. An approach that addresses functional needs could improve health outcomes and meeting the fulfilment of emotional needs may contribute to a better well-being of older people. Thus, the combination of the personal, emotional, functional, and medical aspects is considered to be suitable also for the development of use cases since it has the potential to orient care so that it can better manage the coping with life in the elderly (see Figure 15).

Under this task use cases were generally conceptualized as user stories with plots describing the actions and decisions of a user in a particular context (Bhattacharyya et al., 2019). This scenario-based approach can help future SHAPES designers foster a better understanding of user needs and develop suitable service options and tools.

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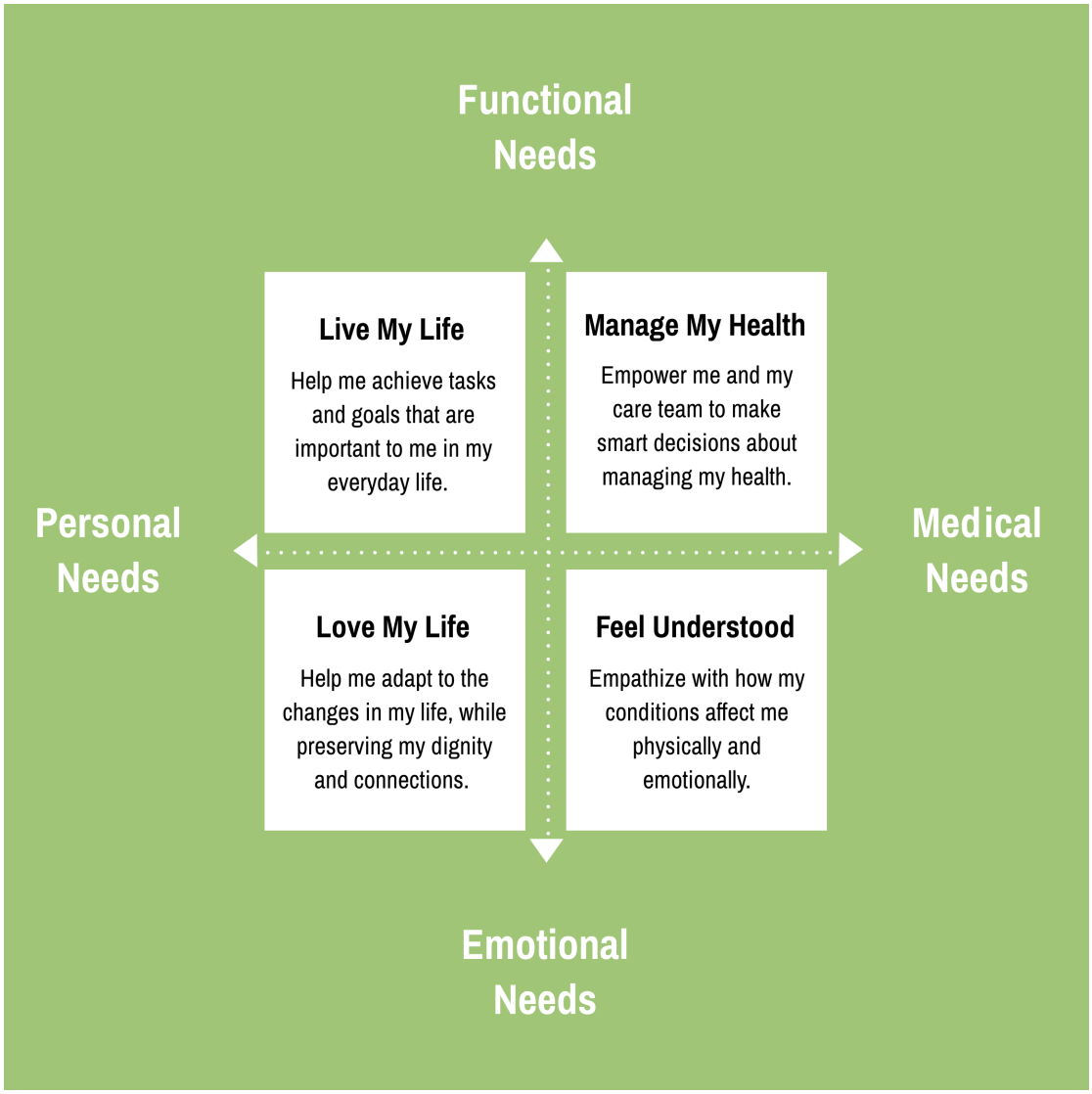

Figure 15: The Intersection of Needs (Source: Bhattacharyya et al. 2019)

The development of use cases proceeded in several steps. At the beginning, rough prototypes of the use cases were created and shared with the team members to gain feedback on the usability and functionality of the tool. These initial prototypes were designed following the PACT criteria (see Table 4) for an effective development of use cases and scenarios (Huis in't Veld et al., 2010). Furthermore, the following criteria were used to select the initial use cases: a) usefulness for Receiving Agent (Registration Operator), b) appropriateness toward personas developed in the previous step of Task 2.5, c) possible risks that may emerge during the use of particular technologies, and d) possible ethical issues that may arise from the application of the digital or technological solution in practice. Based on the feedback from the team members, rough prototypes were subsequently revised and refocused, if needed, to provide a suitable basic path of a scenario. This sharpening of the rough prototypes of the use cases was very important for gaining a fine-tuned use case that mirrors well the needs of typical users and typical context of use.

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Table 4: The PACT Criteria (Source: Huis in't Veld et al., 2010)

Criterion	Definition
People	Roles and/or actors of typical users involved in delivering and receiving the telemedicine intervention.
Activities	Activities to be performed by the actors in order to successfully provide and receive the telemedicine intervention.
Context	Puts the telemedicine intervention in a health-care context. Activities always happen in a context, so there is a need to analyse these two together.
Technology	Typically, to realize telemedicine, technology needs to transform some input data into some output data which can be used by the medical expert and patient to support the activities defined earlier. The features of the technology are input, output, communication and content.

After the finessing of the rough prototypes, the basic forms of the use cases were developed including the descriptions of the basic path of a scenario (i.e. Main Success Scenario), the main scope of the SHAPES use case, and actors included (e.g., RA - Receiving Agent; RO - Registration Operator). After this step, the subsequent task was to suggest suitable components and digital solutions for each use case. Three main sources of available information were used for seeking the most suitable components and digital solutions for each of the basic forms of the use cases:

a) components and digital solutions included in available scientific literature (based on an extensive literature review of papers published in relevant journals, e.g., Journal of Telemedicine and Telecare, Telemedicine and E-health, Journal of Medical Internet Research, Journal of the American Medical Informatics Association, Interactive Learning Environments, Informatics for Health Social Care, BMC Bioinformatics, or International Journal of Medical Informatics);
b) components and digital solutions available by means of offers from providers;
c) components and digital solutions included in the SHAPES project proposal. Based on a synthesis of these sources of information, the most suitable components and digital solutions were chosen and inserted into the use cases.

The general use cases were then subjected to a collaborative evaluation by the team members and were also discussed within SHAPES Calls (teleconferences of the SHAPES network). Based on this collaborative evaluation, the use cases were revised and improved. Furthermore, alternative paths of scenarios, i.e. variations and extensions, were also developed and added to the basic path of scenarios, i.e. Main Success Scenario. Finally, all use cases were evaluated by the team members in terms of usefulness for the Receiving Agent (Registration Operator), appropriateness toward personas developed in the previous step of Task 2.5, possible risks that may emerge during the use of particular technologies, and possible ethical issues that may arise from

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the application of the digital or technological solution in practice. After this evaluation, the use cases were finalized.

Based on the recommendations of the SHAPES partners we incorporated indexing of the specific user requirements and user scenarios in the use cases (for example "RA switches on the device" - UC1-Scenario-1). This was suggested to allow our colleagues - solution developers to trace each of the system specification to the actual user needs and test cases.

4.2 Final use cases and their relationships to personas

Finally, 13 different general use cases were developed. Following the goals of Task 2.5, these general use cases are intended to illustrate the breadth and variability of the technology used for the improvements of the quality of life of older adults, rather than specific use cases developed for designing concrete digital solutions (this will be done in subsequent stages of the SHAPES project, however). Thus, the final set of general use cases include:

- Assistive Technology for Reading
- Self-Management of Chronic Conditions
- Home Environment Monitoring
- In-Home Cognitive Training
- In-Home Glucose-Monitoring
- In-Home Self-Management Heart-Monitoring
- In-Home Post-Hospital Aftercare
- In-Home Video-Monitoring
- Location Tracking
- Meal Ordering
- Medication Reminder
- Motor Exercising with Robot
- Summarizer of Information from Internet

Connection to personas is as follows. Some of the general use cases are serviceable across most of the personas developed in the previous step of Task 2.5, e.g., Assistive Technology for Reading, Summarizer of Information from Internet, Meal Ordering, or Medication Reminder. The general use case Self-Management of Chronic Conditions providing relatively broad and universal spectrum of assistive support, e.g., assisting in daily health and care activities, recommending appropriate dietary recommendations, etc., can also be serviceable across most personas, however, there is a requirement of the absence of neurodegenerative changes as these changes could possibly lead to ignoring or misleading of recommendations provided by the Self-Management of Chronic Conditions application. Thus, this use case is not suitable for Persona 4. In contrast,

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merely use case In-Home Cognitive Training is supportive for this group of older adults (Persona 4), as well as their carers (Persona 9) as it can support the possible improvement of cognitive functions. For Persona 3 that is typical by various musculoskeletal problems, a general use case Motor Exercising with Robot is very useful as it can improve motor abilities and flexibility of a body.

The set of general use cases includes various kinds of monitoring, Home Environment Monitoring, In-Home Glucose-Monitoring, In-Home Heart-Monitoring, In-Home Post-Hospital Aftercare, In-Home Video-Monitoring, and Location Tracking. These monitoring devices serve different functions. For example, Home Environment Monitoring is focused on the control and monitoring of home conditions like the regulation of the Self-Management temperature, light, or various daily used electronic devices. This may help frailty people that are represented by Persona 7, but also people suffering from serious and chronic diseases - e.g., Persona 6, Persona 4 and also their carers (Persona 9). In contrast, In-Home Video-Monitoring is much more focused on the detection of falls and the actual state of the clients that are at the risk of falls, i.e. Persona 7, Persona 5, Persona 3 and Persona 9. The general use case Location Tracking is specifically designed for Persona 4, i.e., demented people that are at a greater risk of being lost when they are travelling or moving uncontrollably from place to place. This use case will obviously also help the people who care for patients with dementia – Persona 9. Furthermore, the general use case Home Post-Hospital Aftercare is designed for the situation of post-hospital aftercare for in-home patients after a surgical operation or another serious medical intervention.

The overview is provided in Appendix III.

In the following pages, all 13 general use cases are presented to gain detailed information about the contents of the general use cases:

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READING ASSISTIVE TECHNOLOGY UC1

Compensatory assistive technology for patients with poor eye sight (use case)

Description: Older people suffering from poor eye sight need assistance technology that enables them to read information on the computer screen

Digital Solution Proposed

- Digital application that processes the image/video on the computer screen and adjusts it to the quality of sight of the Receiving Agent (RA) UC1-Solution-1

Components

- Series of filters within the digital application for smart phones and notebooks UC1-Components-1

Actors

- Receiving Agent (RA) UC1-Actors-1

Scope

- To enable the image/video to be clearly visible on the computer screen for the RA UC1-Scope-1

Preconditions

- RA is able to use the compensatory digital application UC1-Precon-1
- RA is familiar with the type of device technology UC1-Precon-2
- Device is working properly and is charged UC1-Precon-3

Main Success Scenario

1. RA switches on the device UC1-Scenario-1
2. RA opens the required application and inserts the search term UC1-Scenario-2
3. RA uses the compensatory digital application that processes the image/video on the computer screen UC1-Scenario-3
4. The proportion of the image/video on the computer screen is adjusted UC1-Scenario-4
5. RA reads or watches the content of the image/video on the computer screen UC1-Scenario-5
6. RA ends the application and turns off the device UC1-Scenario-6

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Figure 16: Use case 1 - Assistive Technology for Reading

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SELF-MANAGEMENT OF CHRONIC CONDITIONS UC2

For patients with chronic illness (use case)

Description: Patients with a chronic illness need continual monitoring and reminding of various features, e.g., control of medication, assisting in daily health and care activities, recommending appropriate dietary recommendations, and saturating their social needs. Therefore, there is a requirement for a complex system that would cover these needs.

Digital Solution Proposed

- Self-Management of Chronic Conditions tools UC2-Solution-1

Components

- Health care system UC2-Components-1
- System for control of medication UC2-Components-1
- System for being interconnected with relatives as well as medical personal UC2-Components-1

Actors

- Receiving Agent (RA) UC2-Actors-1

Scope

- To provide a complex care to patients with chronic illness UC2-Scope-1

Preconditions

- RA is able to use the system on an expected level UC2-Precon-1
- System is set up for the RA in a proper way to achieve the following instructions by the RA UC2-Precon-2

Main Success Scenario

1. RA gets close enough where he/she can see, hear, and communicate with the customized Self-Management application UC2-Scenario-1
2. The Self-Management application communicates with the RA in an interactive dialog UC2-Scenario-2
3. The Self-Management application reminds the RA about medication as well as important daily health and care activities, involving also dietary recommendations UC2-Scenario-3
4. RA performs the medication as well as important daily health and care activities according to the Self-Management application UC2-Scenario-4

Variations/Extensions

- The Self-Management application can be associated with a smart cup holder that registers the consumed amount of liquid and transfers the gathered data wirelessly to a software assistant. A software assistant can automatically store the amount of consumed liquid and compare it to adaptively adjusted ideal values UC2-Variation-1

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Figure 17: Use case 2 - Self-Management of Chronic Conditions

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HOME ENVIRONMENT MONITORING UC3

Sensors for assisted living (use case)

Description: Older people, whether with some chronic disease or not, want to stay at home as long as possible. However, there is a problem that they often are not able to manage. For example, the regulation of the temperature, light, or various daily-used electric devices. There is a need for an integrated sensor system to enable elderly people, or those at risk, to live independently in their own homes longer, while providing reassurance to their family and carers.

Digital Solution Proposed

- Integrated sensor system for assisted living UC3-Solution-1

Components

- In-home devices (sensor unit measuring the temperature, light levels, noise and motion; power monitors) UC3-Components-1
- Platform for transfer of the data through the Internet (social application, web application, server and database) UC3-Components-2

Actors

UC3-Actors-1

- Receiving Agent (RA) UC3-Actors-1
- Registration operator (RO)

Scope

UC3-Scope-1

- To indirectly monitor the older person´s wellbeing and allow family members or carers to remotely check on their safety and wellbeing

Preconditions

UC3-Precon-1

- The installed system of wireless sensors is fine-tuned by the RO UC3-Precon-2
- Battery is charged up UC3-Precon-3
- The sensor system is tuned correctly for proper operation
- Internet connection is working correctly UC3-Precon-3

Main Success Scenario

1. The system is indirectly monitoring the RA´s activity and wellbeing within the RA´s house during their daily living activities UC3-Scenario-1

2. All the gathered data are transformed into online graphs of activity, accessible through the web application to the RA and selected family members, caregivers, etc. UC3-Scenario-2

Variations/Extensions

- The on-person device may allow the RA to simply make a phone call to a predefined telephone number or send the current GPS location via an SMS message to a different, or the same, predefined phone number in situations when he/she is away from home UC3-Variation-1
- The social interaction application allows messages, pictures and videos to be securely shared by the RA's friends and family to a tablet running the application, located within the RA's home UC3-Variation-1

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Figure 18: Use Case 3 - Home Environment Monitoring

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IN-HOME COGNITIVE TRAINING UC4

For patients in the early stages of neurocognitive deficits (use case)

Description: Older people at risk of further neurocognitive decline should be stimulated to improve their cognitive functions.

Digital Solution Proposed

- In-home digital application enabling mental stimulation exercises UC4-Solution-1

Components

- Systems and games for mental stimulation UC4-Components-1
- Digital communication cards UC4-Components-2

Actors

- Receiving Agent (RA) UC4-Actors-1

Scope

- To engage the RA with a cognitive stimulation task supporting the improvement of memory, attention skills, etc. UC4-Scope-1

Preconditions

- RA is able to communicate with the application on an expected level UC4-Precon-1
- RA is familiar with a similar type of device / technology UC4-Precon-2
- Device is working properly and is charged. UC4-Precon-3

Main Success Scenario

1. RA switches on the device UC4-Scenario-1
2. RA opens the application UC4-Scenario-2
3. RA creates and customizes the interaction mode for the engagement UC4-Scenario-3
4. RA chooses the interaction mode UC4-Scenario-4
5. RA plays mental stimulation games UC4-Scenario-5
6. RA ends the application and turns off the device UC4-Scenario-6

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Figure 19: Use Case 4 - In-Home Cognitive Training

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IN-HOME GLUCOSE-MONITORING UC5

Remote glucometer automatically sending the measured data to the care-provider system (use case)

Description: For patients with diabetes, regular glucose measurements are one of the basic ways to prevent deterioration. There is a need for a simple system that immediately uploads the measurement results to the care-provider's system.

Digital Solution Proposed

- Digital application that provides sending the data from the glucometer to the care-provider's system UC5-Solution-1

Components

- Remote glucometer UC5-Components-1
- Smartphone UC5-Components-2
- Platform for transfer of the measured data through the Internet UC5-Components-2

Actors

- Receiving Agent (RA) UC5-Actors-1
- Care-provider UC5-Actors-2

Scope

- To facilitate patients with diabetes to measure glucose regularly UC5-Scope-1

Preconditions

- RA is able to use the device on an expected level UC5-Precon-1
- Device is working and a charged spare battery is always available UC5-Precon-2
- Glucometer is working and data transfer is possible UC5-Precon-3

Main Success Scenario

1. RA turns on the remote glucometer UC5-Scenario-1
2. RA makes a blood glucose measurement UC5-Scenario-2
3. The smartphone application downloads the glucose readings from the glucometer via the Bluetooth adaptor, than uploads the information to the health-care provider system UC5-Scenario-3
4. Glucose data are immediately available to view by the RA via the Personal health record (PHR) UC5-Scenario-4
5. RA turns off the glucometer UC5-Scenario-5

Variations/Extensions

- Using the insulin pump UC5-Variation-1

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Figure 20: Use Case 5 - In-Home Glucose-Monitoring

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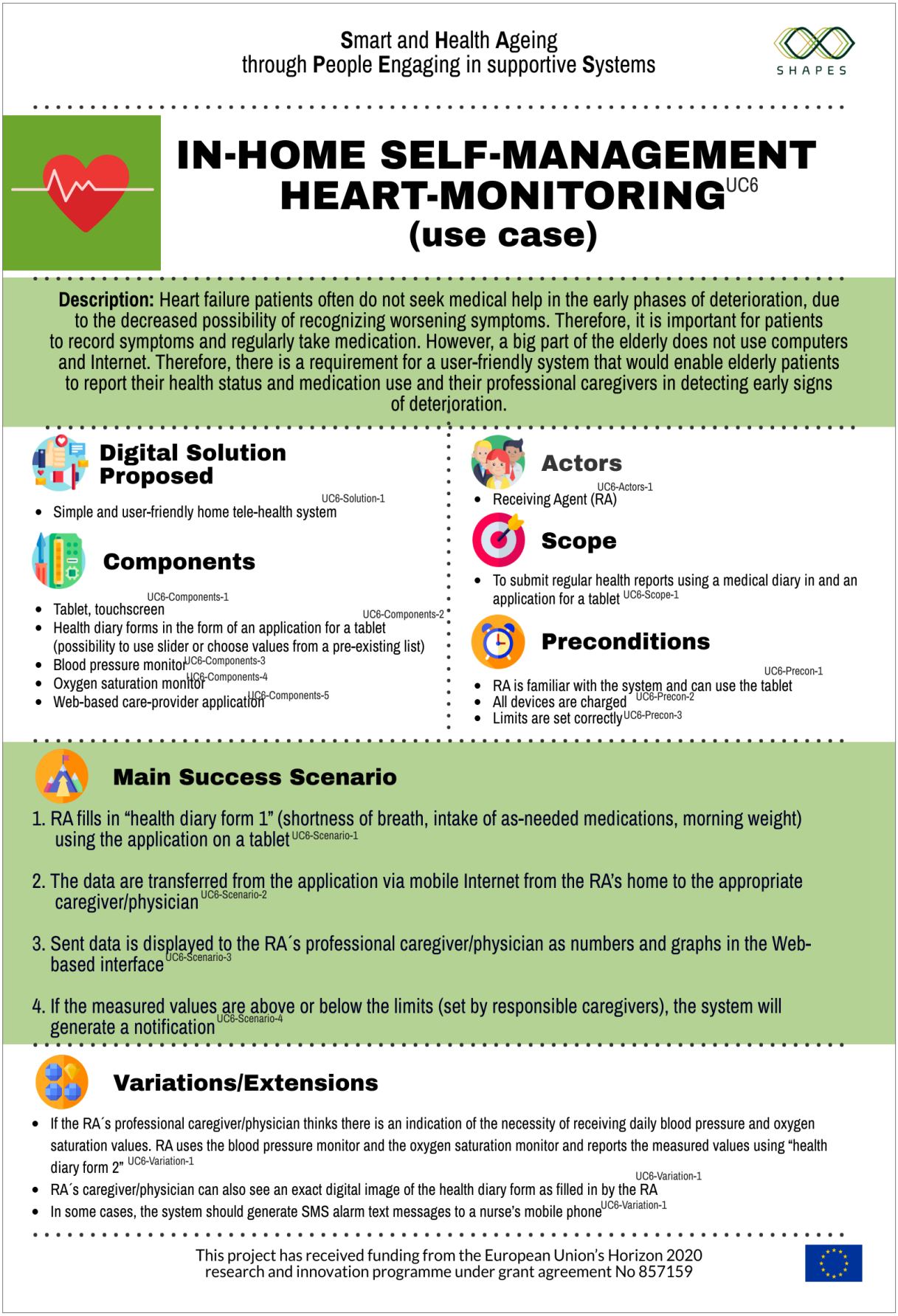

Figure 21: Use Case 6 - In-Home Self-Management Heart-Monitoring

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IN-HOME POST-HOSPITAL AFTERCARE UC7

Post-hospital aftercare for in-home patients after a surgical operation or another serious medical intervention (use case)

Description: In-home patients after a surgical operation or another serious medical intervention often need special coaching and communication with a specialist. Therefore, there is a requirement for a complex system that would cover these needs.

Digital Solution Proposed

- Tele-coaching tools UC7-Solution-1

Components

- Online communication platform with health care specialists UC7-Components-1
- System for control of medication

Actors

- Receiving Agent (RA) UC7-Actors-1
- Registration Operator (RO) UC7-Actors-2

Scope

- To provide a complex online in-home care to patients after a surgical operation or another serious medical intervention UC7-Scope-1

Preconditions

- System is working properly, charged and is tuned for user usage UC7-Precon-1
- Internet connection is working correctly UC7-Precon-2
- RA is able to communicate with the system on an expected level UC7-Precon-3

Main Success Scenario

1. RA gets close enough where he/she can see, hear, and communicate with the customized tele-coaching application UC7-Scenario-1
2. The customized tele-coaching application communicates with the RA in an interactive dialog UC7-Scenario-2
3. The customized tele-coaching application contacts the RO UC7-Scenario-3
4. RO has a dialog through the online platform in which he/she informs the RA about the actions required for his/her recovery UC7-Scenario-4
5. RA conducts the actions required for his/her recovery UC7-Scenario-5

Variations/Extensions

- RO may have a dialog through the online platform in which monitors the RA´s actual state and the continuation of recovery UC7-Variation-1

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Figure 22: Use Case 7 - In-Home Post-Hospital Aftercare

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IN-HOME VIDEO-MONITORING UC8

Remote monitoring and fall detection system for older people (use case)

Description: Many older people live at home alone and want to stay independent. Frail older people and people with substantial problems with their locomotor system often face the risk of falling down and getting fatal or terminal injuries. Falling is one of the most common and dangerous accidents for elderly individuals and a significant factor affecting the living quality of the elderly. There is a need for remote monitoring to gain an on-going access to the actual state of these patients and to detect falls of older people in the home telecare environment.

Digital Solution Proposed

- A Multimodality Fall Detection and Telecare System UC8-Solution-1

Components

- Multimodality signal sources (accelerometer, activity sensors, pressure sensors, door sensor, microphones, systems of video-cameras for monitoring the Receiving Agent) UC8-Components-1
- Platform for transfer of the data through the Internet UC8-Components-2
- Home-server UC8-Components-3
- Information-sharing platform for the Receiving Agent (RA) and caregivers UC8-Components-4

Actors

- Receiving Agent (RA) UC8-Actors-1
- Registration operator (RO) UC8-Actors-2

Scope

- Continuously monitor the movement of the RA in his/her home and provide immediate assistance in case of a fall UC8-Scope-1

Preconditions

- The installed system of an accelerometer, microphones, and cameras fine-tuned by RO UC8-Precon-1
- System is working properly, charged and is tuned for user usage UC8-Precon-2
- RA agrees with the system UC8-Precon-3

Main Success Scenario

1. All the movements of the RA are monitored by the accelerometer communicating with the home-server via Bluetooth UC8-Scenario-1
2. If triggering conditions are met, the RA's audio message can be used as a speech recognition function to confirm or cancel the alarm UC8-Scenario-2
3. When a fall has been detected, an alarm e-mail is sent to the caregivers (doctor and the RA's relatives) UC8-Scenario-3
4. When the caregivers receive an alarm e-mail, they can review the fall scene video through the Information-sharing platform UC8-Scenario-4
5. Otherwise, the system terminates the current detection and goes back to the initial state UC8-Scenario-5

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Figure 23: Use Case 8 - In-Home Video-Monitoring

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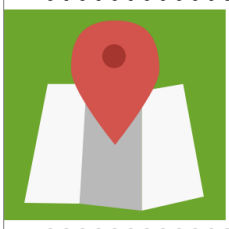

LOCATION TRACKING UC9

Remote monitoring of frail older people with dementia (use case)

Description: Frail older people with dementia are at a greater risk of getting lost or falling when they are travelling or moving from place to place. There is a requirement for a system capable of tracking the senior's position and in case of a fall contact the caregiver.

Digital Solution Proposed

- Location tracking and fall detection system UC9-Solution-1

Components

- Wearable device (accelerometer sensor, GPS, GSM, Wi-Fi module, microcontroller) UC9-Components-1
- Platform for transfer of the data through the Internet UC9-Components-2
- Cloud server UC9-Components-3

Actors

- Receiving Agent (RA) UC9-Actors-1

Scope

- To track an elderly person constantly and in the case of emergency or fall inform the caretaker UC9-Scope-1

Preconditions

- Device is charged and ready to go UC9-Precon-1

Main Success Scenario

1. RA puts on the portable device (attached to a belt) UC9-Scenario-1
2. Device is activated from sleep mode by movement UC9-Scenario-2
3. The device monitors the RA´s position constantly UC9-Scenario-3
4. Device goes to sleep mode without movement to save battery UC9-Scenario-4

Variations/Extensions

- The global coordinates of a location of the RA can be sent to the mobile application in the caretaker's mobile phone. After receiving the latitude and longitude, the global location of the RA can be viewed on Google Maps UC9-Variation-1
- In case a fall is detected, the system can send alert messages to the caretaker via SMS and email with the location information, which was obtained by using a GPS module UC9-Variation-2
- RA can manually activate the system to send alert messages by pressing the button if necessary UC9-Variation-3
- The emergency messages can also be uploaded to a dedicated cloud server for the caretaker to monitor or check the recorded fall history through a web application UC9-Variation-4

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Figure 24: Use Case 9 - Location Tracking

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MEAL ORDERING UC10

Food delivery for elderly people (use case)

Description: Older people living at home alone are often unable to prepare their own nutritious full-fledged meal. There is a need for a simple meal ordering and delivery system.

Digital Solution Proposed

UC10-Solution-1
- Smart application for ordering a ready-to-eat meal, which is then delivered to the Receiving Agent (RA) by the care service

Components

UC10-Components-1
- Platform for ordering a meal through the Internet
UC10-Components-2
- System for delivering the prepared meals to the RA

Actors

UC10-Actors-1
- Receiving Agent (RA)
- Registration Operator (RO) – Meal Service Provider UC10-Actors-2

Scope

- To provide a food delivery system for elderly people living alone at their home UC10-Scope-1

Preconditions

UC10-Precon-1
- Internet connection is working

Main Success Scenario

1. RA uses the platform to select and order the meal UC10-Scenario-1
2. The order data is transferred to the RO via the Internet UC10-Scenario-2
3. RO registers the request and delivers the selected meal to the RA UC10-Scenario-3
4. The meal supplier delivers the meal UC10-Scenario-4
5. RA confirms delivery of the meal UC10-Scenario-5

Variations/Extensions

UC10-Variation-1
- System can inform RA about data transfer failure

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Figure 25: Use Case 10 - Meal Ordering

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MEDICATION REMINDER UC11
(use case)

Description: Older people often show worsened memory as well as insufficient discipline and motivation to follow the doctor´s recommendation of medication. There is a need to remind them about their medication in a suitable time.

Digital Solution Proposed

- Digital application that elicits a sound reminder in time when the Receiving Agent (RA) should take their pills or another form of medication UC11-Solution-1

Components

- Automatic digital timer with a sound system UC11-Components-1

Actors

- Receiving Agent (RA) UC11-Actors-1
- Registration Operator (RO) UC11-Actors-2

Scope

- To provide the RA with a sound signal in a suitable time for the pill intake or another form of medication UC11-Scope-1

Preconditions

- Sound volume is set to the conditions of the RA or more speakers are used to cover the living space of the RA UC11-Precon-1

Main Success Scenario

1. RO programs the timing of pill intake within the device - automatic digital timer with a sound system UC11-Scenario-1
2. RO installs the device into the home of the RA UC11-Scenario-2
3. The device - automatic digital timer with a sound system - performs a sound signal in a suitable time for the pill intake UC11-Scenario-3
4. RA hears the sound signal UC11-Scenario-4
5. RA takes his/her pills or another form of medication UC11-Scenario-5

Variations/Extensions

- Device can notify RA repeatedly in case the sound signal is ignored UC11-Variation-1

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Figure 26: Use Case 11 - Medication Reminder

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MOTOR EXERCISING WITH ROBOT UC12
(use case)

Description: Older people with low mobility should be stimulated to improve flexibility and increase muscle strength. There is a need for a system for a workout that reduces the possibility of injury due to falling from improper balance.

Digital Solution Proposed

- Socially assistive robot performing the chair workout game UC12-Solution-1

Components

- Socially assistive robot programmed to provide chair exercise UC12-Components-1
- Remote control UC12-Components-2

Actors

- Receiving Agent (RA) UC12-Actors-1

Scope

- To engage the RA to workout supporting the improvement of motor skills UC12-Scope-1

Preconditions

- RA is able to use the robot UC12-Precon-1
- Robot and remote control are working and ready to go UC12-Precon-2

Main Success Scenario

1. RA sits in a chair in front of the robot UC12-Scenario-1
2. The robot prompts RA to exercise UC12-Scenario-2
3. RA starts the exercises by pressing the button on the remote control UC12-Scenario-3
4. The robot demonstrates the arm exercises with its own arms and asks the RA to imitate UC12-Scenario-4
5. The robot gives the RA feedback in real time, providing corrections UC12-Scenario-5
6. RA successfully completes the sequence and ends the exercise UC12-Scenario-6

Variations/Extensions

- RA can request a rest break at any time during the interaction by pressing the button on the remote control UC12-Variation-1
- Robot can be replaced by X-BOX with the exercise application UC12-Variation-2

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Figure 27: Use Case 12 - Motor Exercising with Robot

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SUMMARIZER OF INFORMATION FROM INTERNET UC13

An assistive technology supporting the accessibility of information from the Internet (use case)

Description: The everyday leisure activities of active, healthy, older people should be supported. Therefore, the information about various events that active, healthy, older people could take part in should be accessible to them.

Digital Solution Proposed

- Digital application that processes the information from various online sources, filters them according to the Receiving Agent´s (RA) needs and presents them to the RA in an easily and accessible form UC13-Solution-1

Components

- Automatic digital application summarizing various online sources UC13-Components-1

Actors

- Receiving Agent (RA) UC13-Actors-1

Scope

- To provide the RA with information that could be important for his/her engagement in various everyday leisure activities together with other active, healthy, older people UC13-Scope-1

Preconditions

- RA is able to use the device and is familiar with it UC13-Precon-1
- Device is working, charged and ready to go UC13-Precon-2
- Device is preconfigured for relevant information interesting for the RA UC13-Precon-3

Main Success Scenario

1. RA switches on the device UC13-Scenario-1
2. RA opens the application UC13-Scenario-2
3. Automatic digital summarizer of information excerpts the customized information from various online sources UC13-Scenario-3
4. Automatic digital summarizer presents the selected information to the RA UC13-Scenario-4
5. RA reads or watches the content UC13-Scenario-5
6. RA ends the application and turns off the device UC13-Scenario-6
7. RA fastens the device to the charger UC13-Scenario-7

Variations/Extensions

- As a device, a smart TV with a custom application could be used. UC13-Variation-1

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Figure 28: Use Case 13 - Summarizer of Information from Internet

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4.3 Process of use cases development

The process of use cases development had 2 stages: Stage 1: Development of prototypical general use cases (WP2) and Stage 2: Further refinements and diversifications of prototypical general use cases leading to the development of final Pilot Use Cases (WP6). This development follows general RG (Research and Development) procedures and is absolutely in accordance with the originally approved SHAPES project proposal.

In Stage 1, initial prototypes were designed and developed. These prototypical general use cases aimed to provide general types/forms of digital solutions that served as a basic background for the subsequent Stage 2, during which these prototypical general use cases were developed more in regard to the SHAPES applications, i.e. real digital or technological solutions.

During the process of use cases development, several progresses can be observed. Some of them proceeded in terms of further differentiation of prototypical general use cases into more varied use cases. Figure 29 shows the differentiation of a prototypical general use case UC4 into 4 final use cases: UC-PT4-001, UC-PT4-001, UC-PT5-002, and UC-PT2-003. This differentiation illustrates how the progress of the SHAPES project proceeds towards effective and fine-tuned results. Moreover, there is also visible how the differentiation from Stage 1 to Stage 2 also incorporated technical possibilities - the final UC-PT2-003 does not only include the initial idea of cognitive training but enlarges this scope even to the combination of both cognitive and physical training in one LLM CARE digital/technological solution for practical application. All prototypical general use cases and piloting use cases are presented in Appendix IV.

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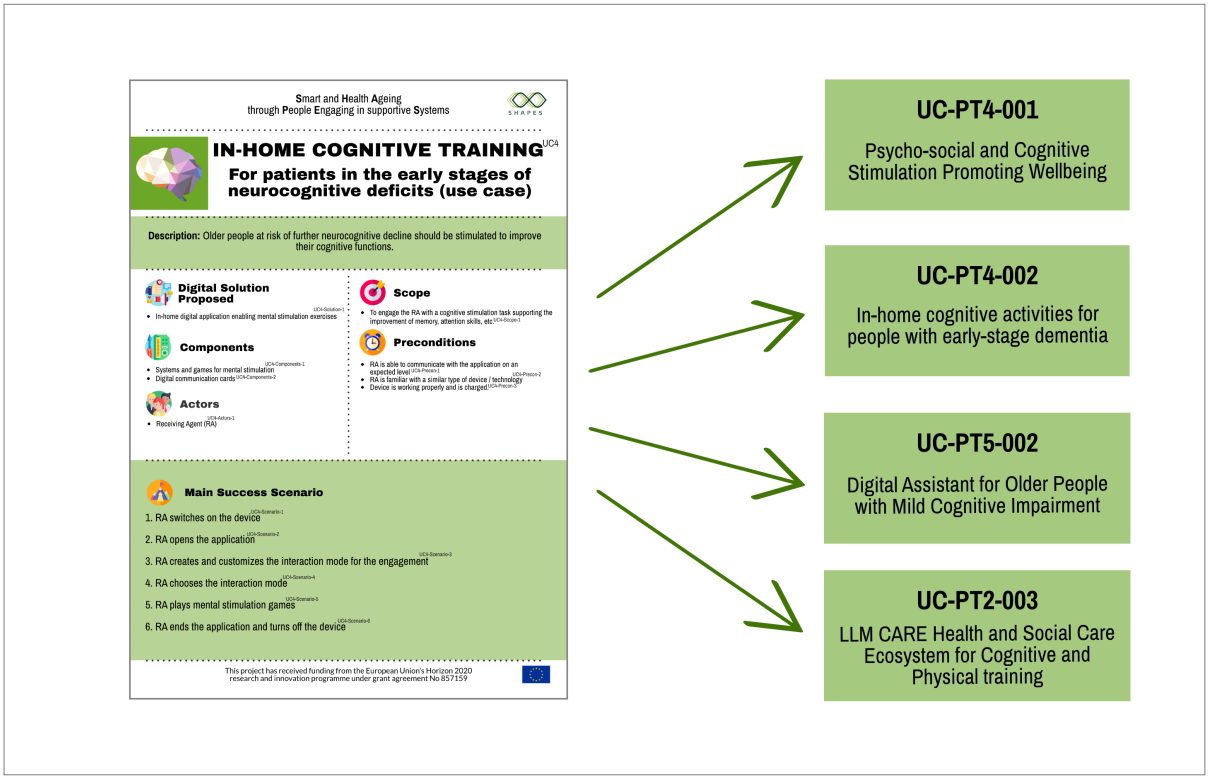

Figure 29: Effective differentiation of a prototypical general use case UC4 into 4 piloting use cases UC-PT4-001, UC-PT4-002, UC-PT4-003 and UC-PT4-004.

The combination of both cognitive and physical training within the piloting UC-PT2-003 demonstrates another process involved, namely the de-differentiation (or synthesis). The focus on physical training was originally involved in the prototypical UC12, but, during the course of the progress of the SHAPES project and the effective interaction between WP2 and WP6, this UC12 later also encompassed the focus of the piloting UC-PT2-003. However, at the same time, UC12 also differentiated itself into 2 other different piloting use cases: UC-PT6-002 and UC-PT6-001 - while UC-PT6-002 includes KOMPAI-based physical rehabilitation at home, UC-PT6-001 is specifically focused on VICOM-based training of orofacial muscles (both are SHAPES partners). Thus, this differentiation was governed by the specificity of user need - i.e., the need for training specifically orofacial muscles. All these bidirectional processes illustrate very well the development of use cases development within the SHAPES project. Both de-differentiation/synthesis and differentiation processes emerged in the course of use cases development. Essentially this synthetically differentiated nature of evolution of use cases leads to fine and complex tuning of piloting use cases for the SHAPES platform in Stage 2 within WP6.

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5 Development of connections between personas and use cases

5.1 Outline of the problem

The development of the connections between the personas and the use cases is a complex task given the fact that to our best knowledge there are no complex methods for this task that would be currently available. Therefore, it is a big challenge for the SHAPES project to develop, at least, a preliminary method of building connections between the personas and the use cases.

There are several problems that we face at the beginning. All natural processes, including also the process of aging, are affected by intrinsic variation. One of the obstacles lies in these variations in the different characteristics of the personas. This means that the personas vary in their:

- health conditions
- perceptual and motor abilities
- degrees of cognitive decline
- health care requirements
- needs
- economical situations
- digital literacy
- health literacy
- affinity to ICT technologies

and many more characteristics or let say "parameters". Apparently, some degrees of these parameters may represent restraints or limitations to the technology use, and thus also for the suitability of the particular use case that could be potentially joined to the given persona. For example, health care requirements cannot be the only criterion for the assessment of the suitability of the use case, because the given persona may show insufficient perceptual or motor abilities to the technology use, insufficient digital literacy, or cognitive impairments that make the use of the particular technology impossible.

Thus, the main problem to be solved is: How to develop connections between the personas and the use cases when each persona shows so many variations in their parameters? What parameter should be used to link the use cases to the personas?

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5.2 Variations in persona´s parameters

Very recently, more and more scholars have realised that aging and life situations of older adults and geriatric patients are a highly complex phenomena. Focusing on only one or a few aspects always represents a risk of both constitutive reductionism and explanatory reductionism (Sarkar, 1992). In contrast, Mount et al. (2015) suggest that "accurately defining complexity is essential to create interventions to improve patient care." For these reasons, the newest wave of interest is focused on the development of complex models of human subjects in different life stages.

Creating methods for the development of the connections between the personas and the use cases requires a complex model that could explain the complexity and variations in the parameters of the personas representing the different prototypes of older adults. But to our knowledge, presently there is no model of complex geriatric patients available. Therefore, the background used for the understanding of variations in needs, health conditions, perceptual, motor and kinetic abilities, degrees of cognitive decline, health care requirements, economical situations, digital literacy, health literacy, affinity to ICT technologies, etc., in the personas representing older adults can be inspired by a recently available model of the complex patient (Figure 30; Manning & Gagnon, 2017).

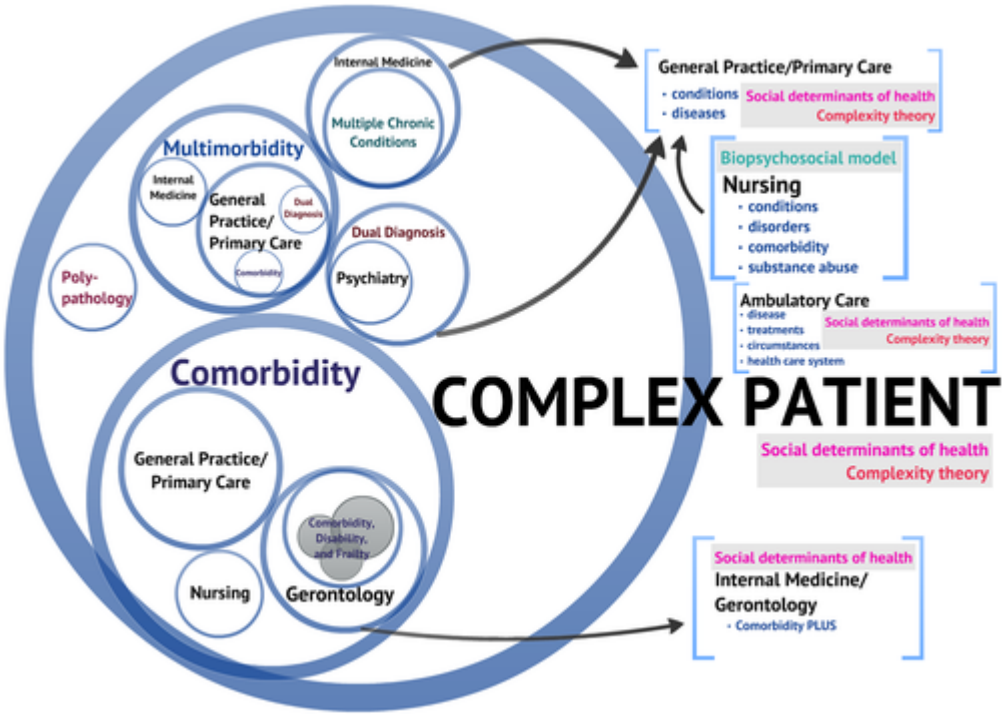

Figure 30: The model of the complex patient (Manning & Gagon, 2017)

This model inspired by the complexity science approach (Turner & Baker, 2019) enables a complex analysis of different parameters and subsystems of various conditions. When coming back to the understanding of variations in needs, health conditions, perceptual

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and motor abilities, degrees of cognitive decline, health care requirements, economical situations, digital literacy, health literacy, affinity to ICT technologies, etc., in the personas developed within the SHAPES project, the above-mentioned variations should be approached within the general complexity science understanding. Simply put, systemic variations are closely connected with change and entropy (a measure of disorder in the environments, i.e., both an internal environment like a human body, and an external environment of the living conditions of the personas). Change is a constant in the course of human development, and it is not only necessary but really vital. A system variable is any element in a system, e.g., parameter in a persona that can take different states. Some system variables are dichotomous, such as the sex of a persona, and some system variables can also be continuous, e.g., digital literacy of a persona. The condition of a variable in a system is generally known as the system state.

5.3 Multiple-criteria evaluation approach to variations in persona´s parameters

Multiple-criteria evaluation is a part of a multiple-criteria decision-making approach (Mardani et al., 2015) and is one of the given possible solutions on how to control more variations in the SHAPES Personas at the same time. In the case of developing a method for the connections between the personas and the use cases, it means to consider variations in needs, health conditions, perceptual and motor abilities, degrees of cognitive decline, health care requirements, economical situations, digital literacy, health literacy, affinity to ICT technologies, etc. Clearly, this problem is a multiple-criteria evaluation problem. Multiple-criteria evaluation problems are defined as problems that consist of a finite number of alternatives, explicitly known at the beginning of the solution process. Each alternative is represented by its performance in multiple criteria. The problem may be defined as finding the best alternative for a decision-maker, or finding a set of good alternatives.

5.4 General criteria for multiple-criteria evaluations of connections between personas and use cases

Within the multiple-criteria decision-making approach, typically, some solutions perform well in some criteria and some perform well in others. At the beginning, it is necessary to adjust the criteria that will be later utilized for the decisions about the development of the connections between the personas and the use cases.

For this pilot attempt, the following basic criteria will be considered. These criteria were selected based on an in-depth reading and exploration of all parameters of personas in this deliverable:

- health conditions

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- perceptual and motor abilities
- degrees of cognitive decline
- health care requirements
- needs
- economical situations
- digital literacy
- health literacy
- affinity to ICT technologies

The methods of Personas development are based on a detailed, qualitative description of a fictional person (often a composite of real individuals) used to communicate the key motivations, concerns, and interests of a user group (Bhattacharyya et al., 2019). Personas include fictitious characters described in narrative form in order to help solve design questions. Qualitative descriptions do not provide quantitative values and also the parameters of a fictional person are developed as a construction of characteristics of a typical person, not a real person. Considering this constructive and qualitative nature of Personas, the later multiple-criteria evaluation is not based on the quantitative criteria values, but on the qualitatively described criteria that are included in the chosen persona. Criterion space representation is thus qualitative in nature to correspond and fit perfectly to the character of the methods of personas development.

5.5 Specific criteria for a persona chosen for demonstration of connection development

For the purpose of a demonstration of multiple-criteria evaluations of the connections between the personas and the use cases, the Persona P2 "Roberto" was chosen. At the beginning, the qualitative criteria of Roberto for multiple-criteria evaluations are derived from the information involved in Persona Roberto (see also Persona section for the complete description of Persona Roberto – P2):

- health conditions = diabetes, hypertension, slightly obese, smoker, drinks wine, he takes 6 medications, he visits diabetes and heart specialists every 3 months
- perceptual and motor abilities = problems with walking, problematic movements because of shortage of breath, but enough strength enabling him to work in the house and garden
- degrees of cognitive decline = occasional forgetting of everyday duties
- health care requirements = change of pills for diabetes as he subjectively believes that his heart-related problems are caused by these new pills, he does not like any change of lifestyle, he does not like to go to the doctor, a requirement to receive more personal experiences from other people with the same diagnosis that he has (and his wife), a requirement to personal feedback about his health condition

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without having to go to the doctor, worries that the doctors do not know who prescribes which pills,

- needs = needs to receive information about heart attack, needs to receive information about his wife´s Parkinson's disease, good health of his wife, to keep his lifestyle, rich social life with friends that provides him social support, to keep rich family ties that provide him with strong social support, to keep his shop
- economic situations (i.e. household economic conditions of persona) = relatively good, owner of a small shop (despite the season variability), owner of a house with a garden, but has worries about paying a nursing home for his wife if needed
- digital literacy = low, but he is able to find some information on the Internet, however he cannot distinguish what is true or false
- health literacy = low
- affinity to ICT technologies = low

5.6 Use cases for the demonstration of multiple-criteria evaluations of connections between personas and use cases

The recently available piloting use cases (6.1) are used for the demonstration of multiple-criteria evaluations of the connections between the personas and the use cases. In short, we can summarize these as follows:

Table 5: Piloting use cases overview

UC-PT1-001 – Well-being Monitoring and Assessment solution
Home monitoring platforms, sensors, IoT products/technology.
Monitoring of home appliances and electrical devices (such as TV, oven, microwave, home presence detectors …).
UC-PT1-002 - Digital Assistant to Support Older People to Live Independently and Remain Socially Connected/ Digital Assistant for Older People with Mild Cognitive Impairment
Smart and safe digital assistant using Automatic Speech Recognition (ASR) and Natural Language Processing (NLP) technologies to provide timely reminders, instructions and communication suggestions. We will use an open-source smart speaker (Mycroft) to be installed in the living room. The caregiver or a closer relative will be in charge of arranging the agenda for the older user with MCI and the digital assistant will be triggered correspondingly. It may involve a speech-based dialog with the user to retrieve his/her acknowledgement or to guide him/her through the actions to take.
The assistant can include ROSA Virtual Nurse (CH) – Chatbot that can integrate nurse- and health-related protocols regarding, for example, medication and general evaluation of health conditions.
UC-PT1-003-Video communication solution with friends and family
Video communication solution with focus on "older Individual to friends & family" communication (and not "patient to medical expert"). Additionally, a survey tool.

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UC-PT2-001-Remote monitoring of key health parameters
eCare: A smart ambient intelligence, health and wellness platform delivering remote monitoring of key health parameters of older individuals, including those with health problems requiring periodic or permanent monitoring
The platform registers vital signs, temperature, weight, heart rate, blood glucose level, blood pressure, weight (also fat mass & muscle mass) and respiration rate. Smart analytics (together with TREE and VICOM) enable the detection of anomalies and the generation of alerts that feed into the remote monitoring platforms of hospitals, clinics, nursing homes and care units.
UC-PT2-002-A digital platform that provides information about the community events
A smart IoT-based living platform that leverages on the smart neighbourhood, smart community and smart city paradigms to deliver relevant information on weather, air quality, pollution, local public works, local transportation and local activities.
DigiRoom: a web-based, no-install communication tool for e.g., the communication with their informal caregivers or family members/friends who are not close by/able to meet physically.
UC-PT2-003-LLM CARE Health and Social Care Ecosystem for Cognitive and Physical training
The Integrated Healthcare System Long Lasting Memories Care (LLM Care) is a certified ICT platform that combines state-of-the-art cognitive exercise with physical activity in an advanced assisted living environment and offers an integrated solution for cognitive and physical health, providing effective protection against cognitive decline and thereby, actively improving the quality of life.
The ideal duration of the LLM Care Healthcare System is 8-10 weeks long and includes physical training 3-5 times a week and cognitive training 4-5 times a week. After this period, it is suggested that participants should re-join the program.
UC-PT3-001-In-home decompensation prediction for heart failure patients
E-care system – Remote health monitoring platform, which captures well-being and health data manually or automatically (using connected devices like activity wearable, BPM and scale) at home environment. (EDGE)
ROSA Virtual Nurse – Chatbot that is in charge of the follow-up of the patient. It reminds the patient and caregivers when the measurements have to be taken, and it also provides the questionnaires that the patient has to complete. (CH)
UC-PT4-001-Psycho-social and Cognitive Stimulation Promoting Well-being
StepMania – a dancing surface and respective software that allows for the personalizing of dance choreographies and music and assesses the performance of the user during the choreography.
UC-PT4-002-In-home cognitive activities for people with early-stage dementia
Social robot adapted to provide cognitive tasks.
UC-PT5-001- Online information and training for informal dementia caregivers
iSupport-Portugal training programme for informal dementia caregivers
UC-PT5-002-Digital Assistant for Older People with Mild Cognitive Impairment
Safe Digital Assistant –a smart and safe digital assistant using Automatic Speech Recognition (ASR) and Natural Language Processing (NLP)

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UC-PT5-003-Technological resources for monitoring diabetic patients with mild cognitive impairment
Activity tracker that measures (steps, falls, sleep pattern, stress level).
UC-PT5-004-Virtual Patient Scenarios (VPS) – Mobile Virtual Patients (MVP)
VPS and MVP are defined as specific types of computer-based programs that simulate real-life scenarios where learners emulate the roles of health care providers. They can be deployed as problem-based learning activities and are considered an innovative approach which may lead to effective outcomes in education.
They support user-centred and active learning for formal caregivers through the interaction with diverse virtual cases and scenarios focused on Neurodegenerative diseases (including Alzheimer's, Parkinson's, dementia, stroke) and other chronic diseases (diabetes, heart disease, etc.), aiming at enhancing their learning skills with regard to symptoms, diagnosis and treatment.
UC-PT6-001-Training of orofacial musculature
Facial gesture detection system – Computer vision component that captures and measures a predefined set of facial gestures and gaze in real time.
UC-PT6-002-Physical Rehabilitation at Home
Rehabilitation after accidents, surgery, strokes, or other musculoskeletal diseases, older individuals require the delivery of at-home or at nursing home of physical rehabilitation services to recover/maintain physical condition.
KOMPAÏ Robot – Provides gait rehabilitation session infrastructure
UC-PT6-003-3D Depth Camera Rehabilitation Tool **UC-PT6-004-Wearable Motion Monitoring Devices**
Use of wearable motion monitoring devices attached to the user's shoes (both shoes) and in a wristband to track the evolution of the rehabilitation processes and the condition of the user.
UC-PT7-001-Monitor older patient with chronic disease when travelling abroad
Older people suffering from chronic diseases (Heart Failure, Type II Diabetes, Chronic Obstructive Pulmonary Disease) need to be constantly monitored. System eHealthPass.
UC-PT7-002-Cross-border Health Data Exchange Supporting Mobility and Accessibility for Older Individuals with physical disabilities
Provided by system AccessEarth.
UC-PT7-003-Preventing and/or handling a medical emergency while visiting another country
Older people suffering from chronic diseases (Heart Failure, Type II Diabetes, Chronic Obstructive Pulmonary Disease) need to be constantly monitored.

5.7. Multiple-criteria evaluation of suitability of use cases

The suitability of the individual use cases for the criteria based on the Persona Roberto was repeatedly discussed during the evaluation sessions of the authors of this report. During these sessions, the above-outlined criteria were evaluated in relation to the individual use cases involved. In the following text, qualitative explanations of suitability/unsuitability of the individual use cases for Persona Roberto are considered:

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UC-PT1-001-Well-being Monitoring and Assessment solution

Results of multiple-criteria evaluation: **Suitable**

Reason: Roberto really occasionally forgets everyday duties. The system works relatively passively, so it can work without demands on the digital literacy of a Persona.

UC-PT1-002-Digital Assistant to Support Older People to Live Independently and Remain Socially Connected/ Digital Assistant for Older People with Mild Cognitive Impairment

Results of multiple-criteria evaluation: Unsuitable

Reason: Roberto has many friends and he has also sufficient face-to-face contact with them. He also does not show marks of Mild Cognitive Impairment. There is no need to support a social connection by installing a speech-based dialog system.

UC-PT1-003-Video communication solution with friends and family

Results of multiple-criteria evaluation: Unsuitable

Reason: Roberto has many friends and he has also sufficient face-to-face contact with them. There is no need to support a social connection by installing a speech-based dialog system

UC-PT2-001-Remote monitoring of key health parameters

Results of multiple-criteria evaluation: **Suitable with limitation**

Reason: Roberto has diabetes, hypertension, and problems with breathing, so the periodic monitoring of weight, heart rate, blood glucose level, blood pressure, and respiration rate is of importance.

Limitation: Only the use of the technology by an external person can be used. Roberto has low digital literacy, so he will not be able to use smart analytics for weight, heart rate, blood glucose level, blood pressure and respiration rate. Furthermore, Roberto occasionally forgets his everyday duties, so it is very likely that he will also forget the periodic monitoring via the smart analytics system.

UC-PT2-002-A digital platform that provides information about the community events

Results of multiple-criteria evaluation: Unsuitable

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Reason: Roberto has many friends and he has also sufficient face-to-face contact with them. There is no need to inform him about community events - he is well informed, he is a villager living in a small-scale village community where the information is perfectly and quickly disseminated during face-to-face contact. Roberto is used to using normal Internet for finding information about weather, etc., so there is no need for a special application.

UC-PT2-003-LLM CARE Health and Social Care Ecosystem for Cognitive and Physical training

Results of multiple-criteria evaluation: Physical training - Unsuitable

Cognitive training - **Suitable**

Reason: Roberto is in relatively good physical condition - he has smaller problems with walking but has enough strength enabling him to work in the house and garden. Cognitive training could be suitable because he shows occasional forgetting of everyday duties, the question is will he not forgot to join the cognitive training 4-5 times a week - it is likely that Roberto will prefer face-to-face contact with friends and working on the garden in the open air instead of looking at a computer or mobile screen.

UC-PT3-001-In-home decompensation prediction for heart failure patients

Results of multiple-criteria evaluation: **Suitable**

Reason: Roberto has hypertension, slightly obese, smoker, and drinks wine. Therefore, in-home wearable measurements of health data could be very suitable because Roberto does not like to go to the doctor.

UC-PT4-001-Psycho-social and Cognitive Stimulation Promoting Well-being

Results of multiple-criteria evaluation: Psycho-social Stimulation - unsuitable

Cognitive Stimulation: **Suitable**

Reason: Cognitive training could be suitable because he shows occasional forgetting of everyday duties, the question is will he not forgot to join the cognitive training 4-5 times a week - it is likely that Roberto will prefer face-to-face contact with friends and working in the garden in the open air instead of looking at a computer or mobile screen.

UC-PT4-002-In-home cognitive activities for people with early-stage dementia

Social robot adapted to provide cognitive tasks

Results of multiple-criteria evaluation: Unsuitable

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Reason: Despite occasional forgetting of everyday duties, Roberto´s state of cognitive functions is far from early-stage dementia.

UC-PT5-001-Online information and training for informal dementia caregivers

Results of multiple-criteria evaluation: Unsuitable

Reason: Despite occasional forgetting of everyday duties, Roberto´s state of cognitive functions is far from early-stage dementia.

UC-PT5-002-Digital Assistant for Older People with Mild Cognitive Impairment

Results of multiple-criteria evaluation: Unsuitable

Reason: Despite occasional forgetting of everyday duties, Roberto´s state of cognitive functions does not meet the criteria of Mild Cognitive Impairment.

UC-PT5-003-Technological resources for monitoring diabetic patients with mild cognitive impairment.

Results of multiple-criteria evaluation: Unsuitable

Reason: Despite diabetes and occasional forgetting of everyday duties, Roberto´s state of cognitive functions does not meet the criteria of Mild Cognitive Impairment, so an activity tracker monitoring steps, falls, sleep pattern, stress level is not needed.

UC-PT5-004-Virtual Patient Scenarios (VPS) – Mobile Virtual Patients (MVP)

Results of multiple-criteria evaluation: Unsuitable

Reason: Despite diabetes and occasional forgetting of everyday duties, Roberto´s state of cognitive functions does not meet the criteria of Mild Cognitive Impairment, so an activity tracker monitoring steps, falls, sleep pattern, stress level is not needed.

UC-PT6-001-Training of orofacial musculature

Results of multiple-criteria evaluation: Unsuitable

Reason: Roberto’s health condition does not need any training of orofacial musculature.

UC-PT6-002-Physical Rehabilitation at Home

Results of multiple-criteria evaluation: Unsuitable

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Reason: Roberto has not had an accident, surgery, strokes, or other musculoskeletal diseases and does not need any physical rehabilitation. Despite smaller problems with walking, Roberto has enough strength enabling him to work in the house and garden.

UC-PT6-003-3D Depth Camera Rehabilitation Tool

Results of multiple-criteria evaluation: Unsuitable

Reason: Roberto has not had an accident, surgery, strokes, or other musculoskeletal diseases and does not need any physical rehabilitation. Despite smaller problems with walking, Roberto has enough strength enabling him to work in the house and garden.

UC-PT6-004-Wearable Motion Monitoring Devices

Results of multiple-criteria evaluation: Unsuitable

Reason: Roberto is not after an accident, surgery, strokes, or other musculoskeletal diseases and does not need any physical rehabilitation. Despite smaller problems with walking, Roberto has enough strength enabling him to work on the house and garden.

UC-PT7-001-Monitor older patient with chronic disease when travelling abroad

Results of multiple-criteria evaluation: **Suitable**

Reason: Roberto suffers from chronic diabetes and hypertension; he could be constantly monitored when travelling abroad.

UC-PT7-002-Cross-border Health Data Exchange Supporting Mobility and Accessibility for Older Individuals with physical disabilities

Results of multiple-criteria evaluation: Decision cannot be made at this stage because of insufficient information about this UC.

UC-PT7-003-Preventing and/or handling a medical emergency while visiting another country

Results of multiple-criteria evaluation: **Suitable**

Reason: Roberto suffers from chronic diabetes and hypertension; he could be constantly monitored when travelling abroad.

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The following Figure 31 shows the overall results of the multiple-criteria evaluation of suitability of the use cases for Persona Roberto. The methods of multiple-criteria evaluation proved to be a suitable methodological solution for developing the connections between the personas and the use cases. This method is also applicable in other parts of the SHAPES project for evaluations of the interactions between the users and the SHAPES digital solutions and innovations of the SHAPES platform features. Overview of the most suitable personas can be found in the Appendix V.

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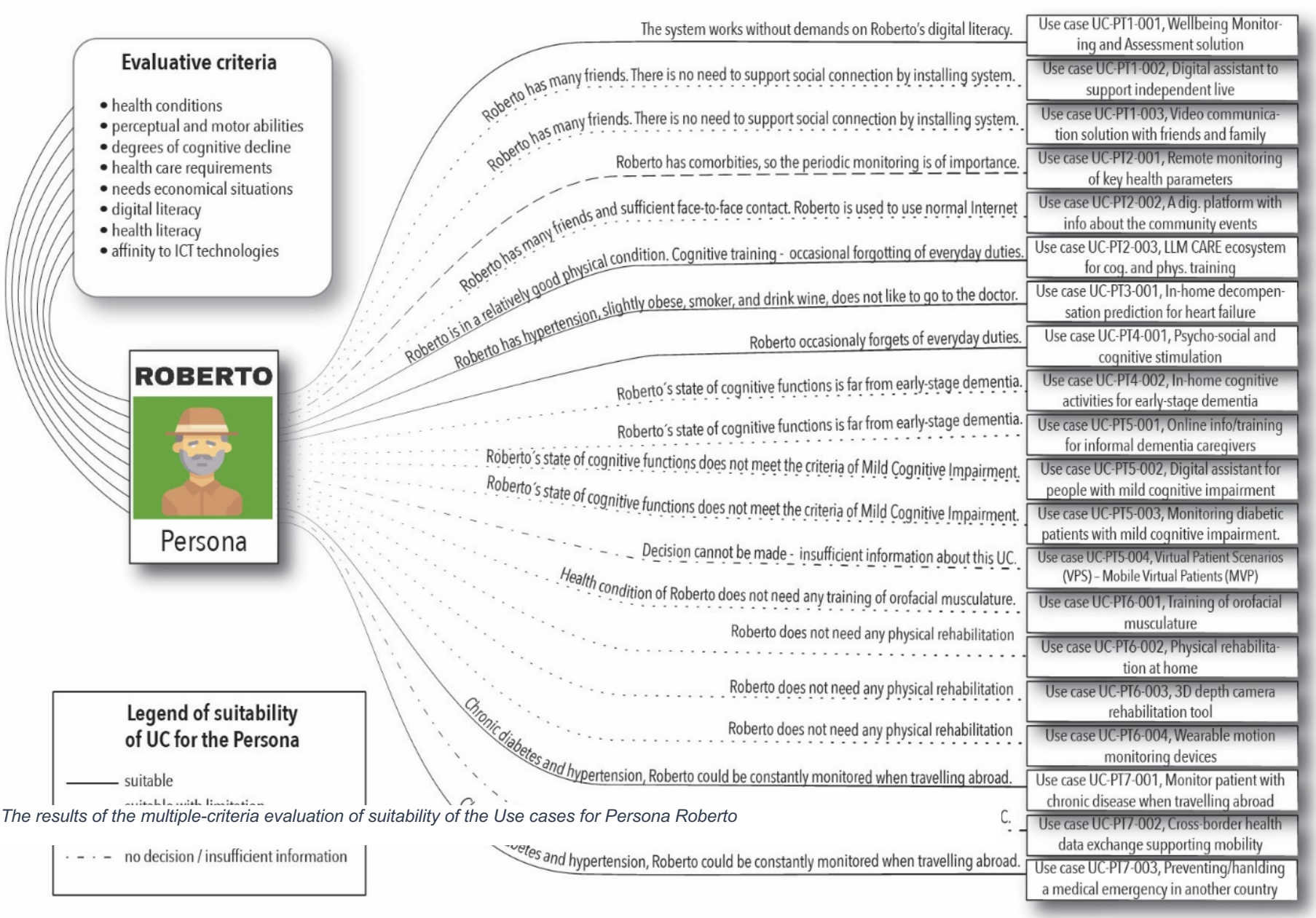

Figure 31: The results of the multiple-criteria evaluation of suitability of the Use cases for Persona Roberto

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5.7 Interconnections between of personas, platform requirements, use cases and scenarios in pilot´s work

Figure 32 shows the SHAPES interconnections between personas, use cases, and user requirements. These interconnections integrate the outputs of 3 WPs: WP2, WP3, and WP6. Personas are outputs of WP2 and these personas represent the basic background, on which further developments were built. Personas inspired the creation of use cases (WP6) as well as platform requirements (WP3). There were many interactions between WP2 and WP6 in the initial stages of SHAPES project as well as between WP3 and WP 6 during shaping user requirements and later also scenarios.

Scenarios are outputs of WP6 and will include most consistent descriptions of roles and/or actors of typical users involved in delivering and receiving the intervention, possibilities of activities and offers that enable access to digital/technological solutions (both for care receiver and care giver), interaction of receiver and care giver within the platform, a detailed scenario of use of a digital/technological solution, and all information/parameter that are relevant including monitoring parameters and feedback modalities. Each scenario connects applicable SHAPES Personas with particular applicable SHAPES Use Case and focuses also on a given pilot site where the scenario/use case will be tested in further development of SHAPES project.

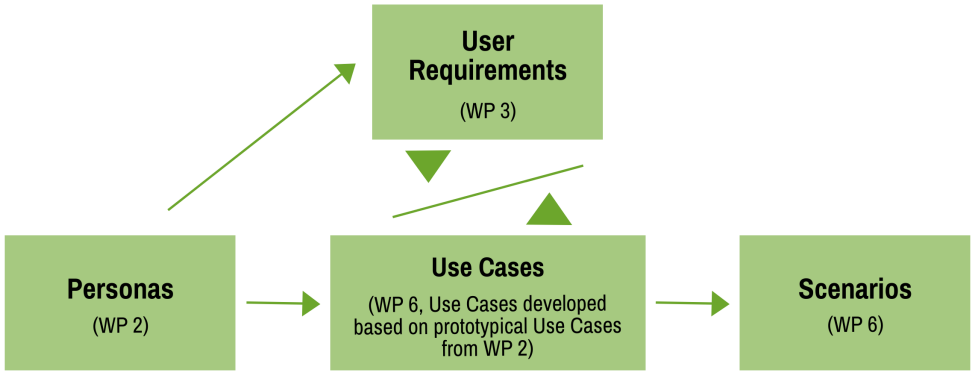

Figure 32: The SHAPES interconnections between personas, use cases and user requirements

5.7.1 Overview of the personas, platform requirements, use cases and scenarios

In this chapter we will demonstrate how the user requirements will be fulfilled for individual personas using the use cases and scenarios.

Table 6: Use case PT1-001 with Isabel and Marco (P4)

Persona	P4 Isabel and Marco

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User requirement	FR-HS-3 Health data collection and management (and sharing) of health parameters FR-HS-9 Medical emergency alert system
Use case and scenario	UC-PT1-001 Remote In-Home Wellbeing Monitoring and Assessment

Isabel (75) has an early stage of Alzheimer's and lives on her own in an apartment. She recently started to have some problems with memory – forgetting names, losing things, recently she has also accidentally switched off the electricity in the whole house and the heating was off for two days. Her son Marco lives with his family in a nearby village and visits Isabel every day, does the chores, brings food. Thanks to the SHAPES project they have decided to use the Remote In-Home Wellbeing Monitoring and Assessment. Several sensors will be installed in Isabel´s house to monitor her complex daily living activities, and also to identify possible risky situations or detect signs of early physical or cognitive decline. The daily data recorded will be available for Marco for review.

Table 7: Use case PT1-002 with Ernst (P1)

Persona	**P1 Ernst**
User requirement	FR-HS-7 Medication reminder / support Reminder for clinical readings/appointment
Use case and scenario	UC-PT1-002 Digital Assistant to Support Older People to Live Independently and Remain Socially Connected

Ernst is 75 years old, recently retired former teacher at a college. He lives with his wife Alberta in a small town in Bavaria in their family house with a garden. Ernst is enjoying very good health, however he is often worried about his wife Alberta, who suffered a stroke 5 years ago and sometimes forgets to take her medication or about her appointments. Digital assistant will be installed in their home to assist with Alberta´s daily living activities to remember appointments, or to make/solve certain basic situations such as cooking, taking medication, using home devices, etc. The output from the digital assistant will be reviewed by Ernst on a daily basis.

Table 8: Use case PT1-003 with Ayesha (P3)

Persona	**P3 Ayesha**
User requirement	FR-IS-1 Easy to use communication systems
Use case and scenario	UC-PT1-003 Overcoming the fear of digital technologies – competent usage of technologies – problem solving in the community

Ayesha is a widowed 79-year-old Iraqi woman, and she suffers from severe osteoporosis. Ayesha lives with her son's family and their children and due to her illness, she often feels lonely and misses her friends and also members of the family who live in Iraq. Her

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grandchildren repeatedly tried to teach her to use online tools for communication, but she is afraid of using the technology.

Thanks to the SHAPES platform she decided to try the video communication solution, which helped her to overcome the fear of digital technology and raise her feelings of competence. Family members were part of the program too and now Ayesha is able to use the device on her own to call friends and relatives.

Table 9: Use case PT1-004 with Isabel and Marco (P4)

Persona	P4 Isabel and Marco
User requirement	FR-HS-13 Appliances Monitoring (on/off; duration of use); FR-HS-7 Medication reminder / support, Reminder for clinical readings/appointments
Use case and scenario	UC-PT1-004 Robot to Support Older People to Live Independently and Remain Socially Connected

Isabel (75) has an early stage of Alzheimer's and lives on her own in an apartment. She recently started to have some problems with memory – forgetting names, losing things. She has also problem to remember her appointments and when to take her medicine, to remember recipes when cooking and so on. Her son Marco lives with his family in a nearby village and visits Isabel every day, does the chores and brings food. Thanks to the SHAPES project they have decided that Isabel would use the socially assistive robot, that will not only remind her of medicines, appointments, names, etc., but can approach Isabel and initiate the interaction, use non-verbal behaviour by the use of its arms and offer touch-screen tablet experience in order to enrich the interaction and offer the option to display image/video content.

Table 10: Use case PT2-002 with Roisin (P5)

Persona	P5 Roisin
User requirement	FR-IS-1 Easy to use communication systems; FR-IS-7 Information about support services: peers and networks
Use case and scenario	UC-PT2-002 Supporting the interaction of the individual with the community

Roisin (84) used to live in a village in western Ireland, she is 15 years widowed. Roisin moved to her daughter Ciara and her family in the suburbs of a large city. There she feels very alone because the family members work or are at school during the day and in the evening, Roisin does not want to restrict them. But Roisin does not feel comfortable in her new surroundings. She has hardly any contact with the community, but she would be very happy if she could have more social contact playing bingo or doing exercises for her knee.

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Roisin decided to try out the digital platform that provides information about the community events and respective information. Roisin has a medium affinity for technology, but also a low digital competence. That is why she asked her daughter Ciara to register with her on the platform. The platform creates a profile and activities are suggested to Roisin. The platform remembers individual interests and can make offers tailored to the needs of each person. For example, the platform recognizes that good weather is to be expected during the day and suggests that Roisin take part in the senior citizens' walk in the afternoon. For the next few days, Roisin will get proposed a bingo-afternoon, a trip to a city museum, a visit to the cinema, a reading by an author and sports activities. Roisin is very satisfied that she can later show the offers to Ciara and register to selected events with Ciara's support. Roisin is looking forward to next week, as she has some nice activities planned.

There is a bus stop directly in front of Roisin's flat. The platform suggests a route to Roisin, which will allow her to arrive on time and with enough time to change buses for the bingo afternoon. She is very happy about this, because nobody can drive her by car at this time of day. After Roisin has taken part in an activity, she can evaluate the event. In this way, the platform can remember what Roisin liked and propose similar events to her in the near future.

Table 11: Use case PT2-004b with Helena (P7)

Persona	**P7 Helena**
User requirement	FR-HS-9 Medical emergency alert system FR-LS-1 Assisted mobility at home FR-LS-3 Sensors to monitor falls FR-LS-4 Sensor to monitor dangerous situation (fire, gas, electricity)
Use case and scenario	UC-PT2-004b Night Surveillance Rounds in the Home-Setting

Helena (93) lives in a small village with a garden and her cats. Her daughter lives nearby and takes care of her almost daily. Helena´s state of health is fluctuating. Besides arthrosis she sometimes has bad days. Then she falls down, forgets to drink enough or generally feels very weak. In order to relieve her daughter and to prevent bad events, Helena is considering going into a nursing home. But she feels uncomfortable leaving her familiar surroundings and is sad to have to give up her favourite furniture and cats.

Helena is very happy that she has the opportunity to use the KOMPAI robot that provides night-time surveillance service, and her daughter is also relieved. Helena is slowly getting used to the robot. She is relieved that she can support herself on it, because her arthrosis often causes her pain. Helena also likes the call function. She has adjusted to the fact that

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the robot does not follow her automatically, but that she simply has to call him once and he comes to her.

After Helena fell down more often, her daughter could not sleep well at night because she was very worried. The robot makes Helena's nightly situation easier. She takes pills in the evening to help her sleep, and these can have the side effect of confusing her at night when she wakes up and wants to go to the toilet. She is grateful that she can hold the robot as a walking aid. The robot also gives her light, and she can move around her house alone at night. For Helena it was good that the robot can reach someone in an emergency. Helena fell down once and could no longer help herself. Last time she had to wait several hours on the floor until she was found. Now she could command the robot to call her emergency contact. If it should happen again that Helena should fall down, she would call KOMPAI to her. First, she tries to straighten up with his help and if that doesn't work, KOMPAI calls her daughter. She could help her in this case. But if her daughter does not answer the phone and Helena needs medical help, KOMPAI calls the emergency doctor. So Helena gets help quickly when she needs it.

Another feature that Helena likes very much is the entertainment aspect. She feels very lonely in her house and her cats are not always there and are very old. She can make a video call with her family members or friends. She can talk to the robot. Additionally, Helena can command the robot to play her favourite poems or music. Helena also uses the game function a lot. For her the online games are a completely new and very entertaining way to pass the time.

Table 12: Use case PT3-001 with Roberto (P2)

Persona	P2 Roberto
User requirement	FR-HS-3 Health data collection and management (and sharing) of health parameters FR-HS-4 Processing of health data: risk assessments, action plans FR-HS-9 Medical emergency alert system FR-HS-12 Predictive Medicine
Use case and scenario	UC-PT3-001 In-home decompensation prediction for heart failure patients

Roberto (72) lives with his wife Bianca in a small Italian town in a house with a garden. Roberto is slightly obese. He has diabetes and hypertension and smokes 20 cigarettes a day. Recently, he suffered a heart attack and his cardiologist has recommended to

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Roberto to use some preventive measures. Roberto decided to try the SHAPES platform in-home decompensation prediction for heart failure patients.

Roberto will be provided with the following devices/software and respective connectivity with the SHAPES platform: Scale, pulse oximeter, BP monitor, pedometer Mobile App – chatbot. One of the key goals is to optimize his medication plan, which will lead to fewer decompensations. The main objectives are to monitor adherence (chatbot questionnaires) to plan interventions accordingly, update list of medicines to be provided, establish relationships between medicines and side-effects/non-desirable effects and to carry out interventions (including pharmaceutical interventions) in order to prevent decompensations from occurring.

Table 13: Use case PT4-001 with Astrid (P4)

Persona	P4 Astrid
User requirement	FR-HM-1 Mental exercises for care receivers and care providers FR-HM-2 Physical exercises FR-HS-3 Health data collection and management (and sharing) of health parameters
Use case and scenario	UC-PT4-001 Psycho-social and Cognitive Stimulation Promoting Wellbeing

Astrid (53) is a single kindergarten teacher and is living with her mother Tessa (78), who suffers from middle stage of Alzheimer's. Tessa was diagnosed 6 years ago and gradually her symptoms had worsened so two years ago Astrid decided to move in to Tessa´s house to take better care of her.

Astrid is often tired and feels sadness and anxiety about the future and worries about Tessa. Her mother´s illness has also impacted her social life – Astrid only very seldom goes out to meet friends or to the cinema or concerts, as she does not want to leave Tessa alone.

After they heard of the SHAPES platform, Astrid and Tessa decided to try the psycho-social and cognitive stimulation, and Tessa very quickly started to like Stepmania. Stepmania is a dancing surface and respective software and it allows for the choice of the music and the dancing movements (choreography) in line with Tessa´s preferences. It has a system of lights that prompt Tessa to perform a specific movement in a specific sequence and, therefore, requires Tessa´s attention and memory to identify and record patterns.

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Tessa became such fan of Stepmania that she can easily spend a few hours dancing on her own. Thanks to that Astrid has much less worries and remorse to leave Tessa at home and go out with friends.

Table 14: Use case PT6-001 with Jarda (P6)

Persona	P6 Jarda
User requirement	FR-HM-2 Physical exercises
Use case and scenario	UC-PT6-001 Training of orofacial musculature

Jarda is a 68-year-old man living in the South of Spain. He is a well-educated (14 years of formal education; holds a bachelor degree), middle-income person. Jarda uses technology and the Internet on a daily basis to catch up with news, social media, manage his bank account and shop online, normally using his tablet or smartphone. He has affinity with technology and enjoys using some mildly sophisticated devices (e.g., smartwatches).

Four months ago, Jarda suffered a stroke and, as a consequence, he has a facial paralysis. The doctor said there is a great chance for the paralysis to partly disappear if Jarda performs a set of orofacial exercises. He lives alone and, for the moment, he cannot drive. He lives on the outskirts of a big city so he decided to use the Phyx.io platform that provides a mirror like training interface and assistance for orofacial training.

Jarda wakes up every morning and goes to the living room where the mirror is located. Jarda wakes up the system with a “Hello, mirror”. The system wakes up and asks Jarda how he is feeling today. The system is also equipped with an emotion detection that will use this answer to run. Phyx.io has Jarda’s profile along with the exercise routines that he has to follow. Jarda does not have to worry about what exercise has to be done as this is already the responsibility of the system, from the information provided by the therapist.

And if Jarda is not in the mood for exercising and he is not paying much attention to the exercises, the system will encourage him with some motivational messages to follow the indications and perform a more precise execution.

Table 15: Use case PT6-002 with Roberto (P2)

Persona	P2 Roberto
User requirement	FR-HM-2 Physical exercises
Use case and scenario	UC-PT6-004 Wearable Motion Monitoring Devices

Roberto (72) lives in a small Italian town. He has a sedentary life, suffers hypertension and is overweight. He has decided to start living a healthier life. For this reason, he has decided to wear a smart band to assess his activity level and improve it towards a healthier and more physically active life.

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The SHAPES cloud will keep track of all his movements and recognize the intensity and level of activity. The smart band measures the heart rate, blood pressure, level of oxygen, as well as the activity and the number of steps. At the end of the day, the SHAPES platform provides a summary of different activities carried out during the day. This will also be accompanied by some advice about how to improve the level of activity. The system will also show the improvement achieved as a consequence of living a healthier life like improving the quality of the sleep hours or reducing the heart rate.

5.7.2 Concrete examples from the pilots

5.7.2.1 5thYPE – Pilot Theme 7

5.7.2.1.1 Introduction

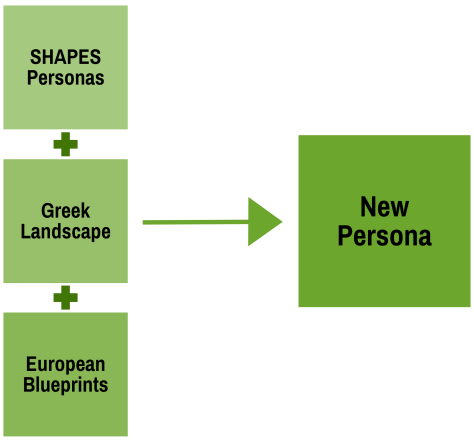

Figure 33: New Persona Creation Process

During this first year of the SHAPES project, 5thYPE has engaged in numerous meetings and activities, both internal and with SHAPES partners, to design and develop the pilot scenarios, the use cases and identify the digital solutions to be tested and validated within each phase of the pilot campaign. These activities have been producing a number of interesting results with respect to assessing 5thYPE's cohort of patients over 65 years of age (Table 16), in order to recruit the pilot participants to validate the SHAPES digital solutions and services, as well as provide the blueprints – in conjunction with WP2's Personas – for developing these pilots and use cases.

Initially based on the SHAPES Personas, it immediately became apparent that these personas required significant adjustments to describe the use cases and pilot scenarios in a more inclusive and effective way, especially within the Greek Primary Care landscape. Therefore, the 5thYPE team restructured the canvas for creating new patient profiles, to a 3-tier basis (Figure 33):

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- The use of the SHAPES Personas as a starting point (Deliverable 2.5)
- A bottom-up capitalization on what constitutes the Greek landscape out in the field (Table 15)
- The use of 5thYPE's knowledge from previous e-Health European Research Programs (Figure 34)

Table 16: Greek patients and participants assessment results

Cohort of 758 patients over 65 years old	Social profiling of 80 patients	Psychogeriatric analysis of 25 patients
	Interviews in alignment with SHAPES Task 2.1 interactions and themes (2-8):	Interviews using mental and geriatric instruments:
Age	Life - History and Identity	Mini-Mental State Examination
Gender	Family neighbourhood and community	Instrumental Activities of Daily Living Scale (IADL)
Vaccination profile **Influenza vaccine** **Pneumococcal vaccine** **Herpes Zoster vaccine**	Everyday Life	Lawton Scale
Cardiovascular diseases	Forms of Labour	Geriatric Depression Scale - GDS
Hypertension	Home, Objects and Technology	
Ca	Transport and Mobility	
Respiratory Diseases	Health, care, well-being	
Hyperlipidaemia		
Psychotic disorders		
Prostatic hyperplasia (males)		
Dementia		
Diabetes		

Over the past years, the European Commission has been using a personas approach to define the blueprint for the development of eHealth applications in National Health Systems, focusing on the identification of heath and care needs of the population. The "European Blueprint on Digital Transformation of Health and Care for the Ageing Society" reflects the common policy that civil society, professional

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organizations, industry and European policy makers envisage. Based on the evaluation results and findings of previous European Projects, mainly the large-scale eHealth Research Programs – United4Health & Renewing Health – that 5thYPE ran in Central Greece, the European Commission created the persona "Nikos" to ensure the best fit of future eHealth initiatives and applications (Figure 34):

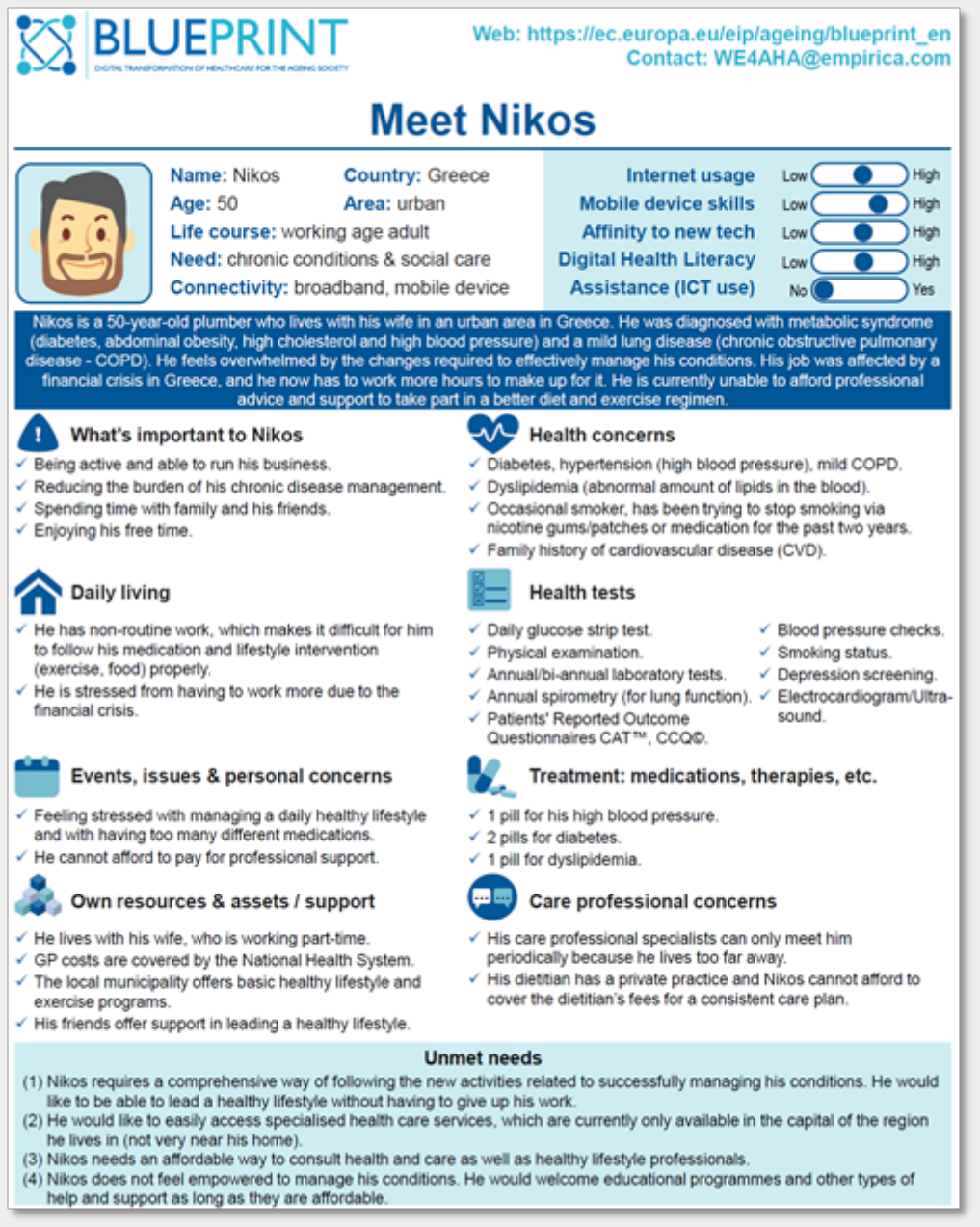

Figure 34: Nikos: a prototype for using MAFEIP-outcomes for personas

In the pages that follow, 5thYPE is introducing the new persona to be included in the SHAPES Personas and Use Cases deliverable. This persona is included in pilot theme 7 (Cross-border Health Data Exchange Supporting Mobility and Accessibility for Older Individuals).

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5.7.2.1.2 Meet Maria[P11]

Maria lives in a village in central Greece. She has been a widow for 10 years. She has two children, one daughter who is married and childless and lives in the same village as Maria and a son who is married and has two children and lives in a nearby village. She used to work as a cook in her husband's shop which was housed on the ground floor of their house. She stopped working after her husband's death. Nowadays she uses this space to meet her friends and have a cup of coffee and to make sweets and pies for the ladies club.

Maria lives alone in a two-storey terraced house. Unfortunately, she lives on the second floor and she has a big problem to climb up the stairs. She is an obese person and a smoker; she smokes 10 cigarettes a day. She has been diagnosed with knee osteoarthritis and suffers from lower back pain for which she takes daily painkillers. Lately she has had a few unpleasant falls and she has developed a fear of falls, so she has decided to limit her movement.

Apart from osteoarthritis, she suffers from several serious problems. She has been diagnosed with heart failure, atrial fibrillation, hyperlipidaemia, obstructive sleep apnoea and depression. Every month she visits her GP for her medicine prescription. Although her doctor advises her to stop smoking, cut down on eating, and exercise, she does not follow the advice. Maria visits her cardiologist and her pulmonologist once a year. Because of the obstructive sleep apnoea her pulmonologist prescribed a CPAP machine, four years ago, in order to have a good quality sleep. Twice a week she needs to take a strip test for glucose. Once a day she checks her blood pressure. Overall, she needs to see her GP for regular check-ups, annual laboratory tests with specialists and annual spirometry.

Maria realizes that a significant part of her health problems could be solved if she could lose weight. She tried several times to lose weight either by trying on her own or by going to a dietitian, which she had to pay from her pension money. Unfortunately, she could not do it. The weight loss is important because there is a risk of developing diabetes in the future which will worsen her health condition.

Maria had a serious episode of depression three years ago. For a long time, she did not go out of the house, she was not in the mood to do the housework and she did not meet her friends. She visited a psychiatrist and was diagnosed with depression. From then on, she has received medication.

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MEET MARIA P11

Motto: Support guide-interpreter communication help to retain independence

Name: Maria
Country: Greece
Age: 69
Area: Small village
Life Course: Retired

Economical situation: Satisfactory
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

Maria lives in a village in a two-storey terraced house in central Greece. She has been a widow for 10 years. She has two children. She used to work as a cook and stopped working after her husband's death. Nowadays she uses this space to meet her friends and have a cup of coffee and to make sweets and pies for the ladies' club. She lives on the second floor and she has a big problem to climb up the stairs. She is an obese person and a smoker; she smokes 10 cigarettes a day.

She has been diagnosed with knee osteoarthritis and suffers from lower back pain for which she takes daily painkillers. Except for osteoarthritis she suffers from heart failure, atrial fibrillation, hyperlipidemia and obstructive sleep apnea. Every month she visits her GP for her medicine prescription. Although her doctor advises her to stop smoking, cut down on eating, and exercise, she does not follow the advice. Maria had a serious episode of depression three years ago. For a long time, she did not go out of the house.

What is important to Maria

- Family ties with her children and grandchildren P11-Req-1
- Social life with friends P11-Req-2
- Limiting risk of falls P11-Req-3
- Having always something to do P11-Req-4

Daily living

- Loves cooking for family and friends P11-Daily-1
- Often meets friends personally P11-Daily-2
- Once a week she likes to go to the public market P11-Daily-3
- Once a month she goes on a trip to monasteries with her friends P11-Daily-4

Own resources, assets, support

- Economically independent, her pension is enough for daily living P11-Resources-1
- Sometimes she helps her daughter financially P11-Resources-2
- GP costs are covered by the National Health System P11-Resources-3
- The local community offers physiotherapy once a week P11-Resources-4

Health concerns and limitations

- Arthrosis on both knees, severe back pain P11-Health-1
- Wants to lose weight and stop smoking P11-Health-2
- Heart failure, atrial fibrillation, sleep apnea, depression P11-Health-3

Health tests/ treatments/ medication

- Takes 8 different medications P11-Tests-1
- Regular health checks by the GP P11-Tests-2
- Visits several specialists (cardiologist, pulmonologist) once a year P11-Tests-3
- Uses CPAP machine P11-Tests-4

Events, issues, personal concerns, technology

- Regular volunteer work for the church charity P11-Personal-1
- She used to go on more excursions, but now she does not trust her knees P11-Personal-2
- She likes knitting P11-Personal-3
- She would like to have a smart watch to monitor her heart rate and pressure and an oximeter to measure saturation P11-Personal-4

Hopes and dreams/ what brings joy/ quotes

- *"I wish for a magic box that could check all my health problems and inform me of my health condition"*
- *"If I had more money and a good health condition I would like to travel all over the world"*

Unmet needs

- Easier pain and health status management that would not require a personal visit to the doctor. P11-Unmet-1
- Communication with the physicians and various caregivers. Monitoring her vital signals and medication adherence will prevent health status degradation P11-Unmet-2
- A diet that she could follow on her own is a problem P11-Unmet-3
- Reminders about the physical activities to perform or meals to follow to be empowered to keep on a daily nutrition plan P11-Unmet-4

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Figure 35: Persona 11

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5.7.2.1.3 Introducing informal caregiver persona

Defining the need

During the execution of SHAPES WP2, the team of the 5thYPE suggested the development of a new persona targeted towards the informal caregiver that will not only refer to the care of people with neurodegenerative diseases but also to patients with chronic diseases and disabilities or inabilities to independent living and self-care. Chronic and disabling disease affects not only the sufferer but also the family, which take on the caressing role of the caregiver.

The aim of the design of this persona is to help address distinct needs of informal caregivers like education, skills development, psychological empowerment, exhaustion or burnout syndrome mitigation, thus improving life (caregivers and patients) through liaison with local agencies and associations in the context of achieving integrated care and best supporting their efforts.

In light of these matters, 5thYPE set the basis for the creation of this new persona profile of the informal caregiver persona. Consequently, we developed the “ELLE” Informal Caregiver following the methodology described in section 2. The name “ELLE” has been derived from the Greek name “Eleftheria”, which means liberty.

Method used for the development of the Informal Caregiver Persona

A family member or someone with a personal relationship who provides unpaid care to patients is addressed as an informal caregiver. There have been a significant number of endeavours to identify and assess the characteristics of informal caregivers toward understanding better their role, their mission, their needs and the psychological status while caring for their patients (Schulz & Tompkins, 2010; Li & Song, 2019; Kataoka-Yahiro et al., 2019; Jacobson et al., 2015; Zigante, 2018; Batista et al., 2014; Rozen, 2017; Williams, 2010). Figure 36 depicts the method followed in the development of the ELLE Persona.

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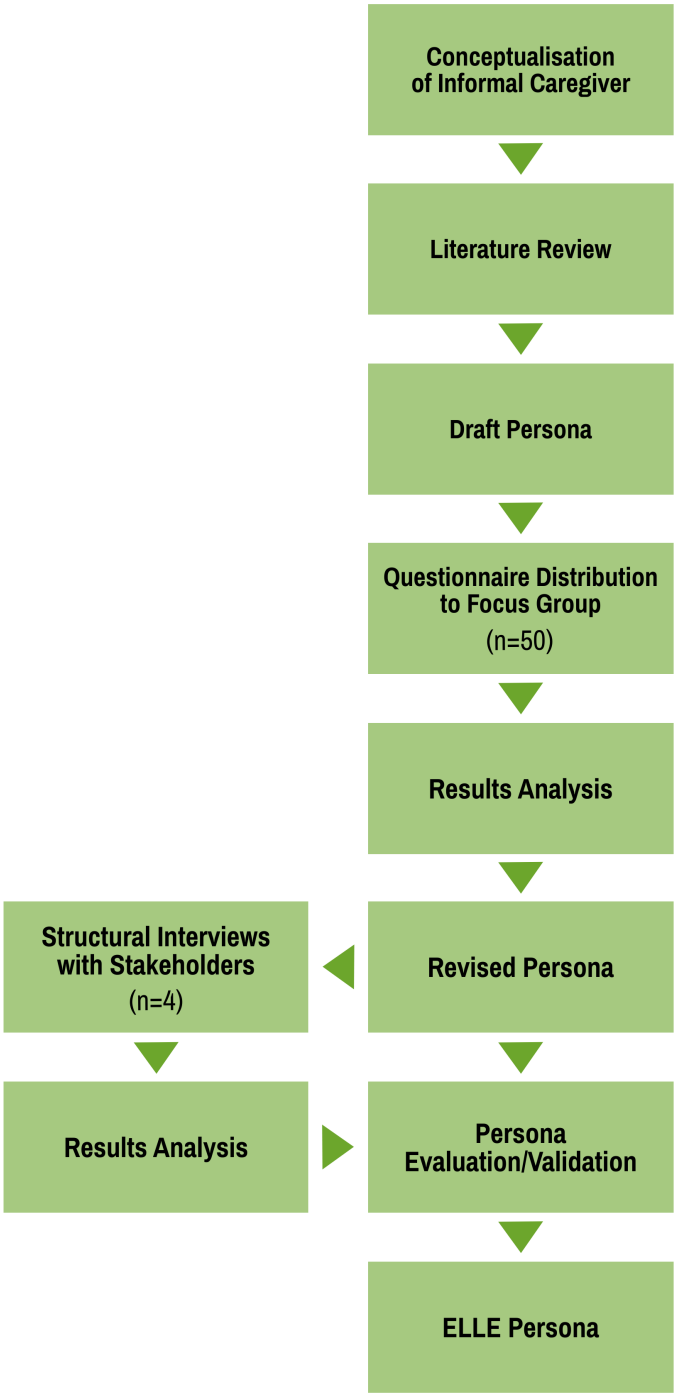

Figure 36: Method of the development of ELLE Persona

After an extensive literature review the Local Primary Health Care Unit (TOMY) in the Ambelokipoi district in Larissa City studied the local socio-demographic characteristics, the psychological burden and the quality of life of the informal caregivers of patients with dementia (Routa, 2019) (prior to SHAPES project). A draft persona for an informal

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caregiver was envisaged while questionnaires that consisted of three parts (demographic and personal data, the Zarit burden scale and the SF - 36 questionnaire on quality of life) were administered and completed at the Local Primary Health Care Unit from November 2018 until April 2019 (Routa, 2019). The sample size consisted of 50 adult dementia caregivers (informal caregivers). The Kolmogorov-Smirnov test was used to determine the distribution of the variables examined. Statistical significance is reported as $p < 0.05$. The majority of participants were females 76% versus 24% males, with an average of 57.3 years (STD ± 13.8). The majority of caregivers were children having completed secondary education and with a stable income while the most common type of dementia of patients was Alzheimer's disease. The average daily care was 12 hours (STD 8.4) and the average duration in months was 29.1 months (STD ± 19). The average score of the burden scale was 48, indicating moderate to severe burden, especially for women when compared to men in the burden and general health status, they found themselves to be more burdened and have a poorer quality of life, but there was no statistically significant difference ($p = 0.114$ and $p = 0.094$, respectively). These results concluded to an intermediate version of the informal caregiver. The 5thYPE team that supervises the Local Primary Health Care Unit (TOMY) in the Ambelokipoi district conducted structural interviews in informal caregivers based on the SHAPES interview guide (SHAPES, T2.1). Specifically, 4 informal caregivers (supporting people over the age of 65 years old) who visited the TOMY unit of 5thYPE agreed to participate in these interviews. These interviews validated our previous findings of mental and physical exhaustion and lack of the presence of digitally assisted technology and trainings conducted by local primary healthcare agencies. The outcome of these interviews further refined and validated the intermediate /revised persona) and led to the definition of the ELLE Persona described in the following section.

5.7.2.1.4 Meet Elle[P16]

Elle is a 73-year-old woman. She lives with her husband Thanos, who is 85 years old, in a small house near the city centre. They have two daughters and five grandchildren who are particularly busy with their work and their responsibilities and they visit them once a month.

Elle's life has changed in the last ten years since the beginning of Thanos's health problems. Thanos suffers from a number of serious health problems. He has been diagnosed with diabetes, hypertension, COPD and dementia. He has not been out of the house for the last 3 years, while in the last year he has been lying down and cannot get out of bed. Elle is the one who has undertaken exclusively all the care and support of Thanos.

She is responsible for feeding, bathing, toileting, dressing, transportation, companionship and emotional support for Thanos. Apart from all these she has the daily care of the house: dusting, cleaning, ironing, washing, shopping, completing paperwork, managing finances, visiting the doctor for prescriptions, and visiting the pharmacy.

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Elle has health problems as well. She suffers from hypertension and from arm and back pain. In fact, the arm and back pain have worsened in the last year, since Thanos stopped getting out of bed. This situation made her problems even more difficult, so she needs to take daily painkillers to stop the pain.

Elle sometimes feels like she is losing hope but quickly regains her strength and returns to her daily routine. What she wants is to be healthy and to be able to offer help to her husband in the best and safest way. She would also like a little more time for herself.

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MEET ELLE P16

Motto: Taking care of your loved one while taking care of oneself

Name: Elle
Country: Greece
Age: 73
Area: City

Economical situation: Less affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Elle is a 73-years-old woman. She is married to Thanos, who is 85 years old. They live together in a house near the city centre. Thanos worked as a taxi driver until he retired. He was pleasant, cheerful, generous and enjoyed amusement! Their lives have changed the last ten years. Thanos suffers from a number of serious health problems. He has been diagnosed with diabetes, hypertension, COPD and dementia. He has not been out of the house for the last 3 years, while in the last year he has been lying down and cannot get out of bed. Elle is the one who has undertaken exclusively all the care and support of Thanos. She provides him assistance with tasks such as: bathing, feeding, dressing, toileting, ambulating. Elle is very concerned about his safety. Among other things, what concerns Elle is the state of her own health. She is very afraid if something might happen to her, and in that case, what will happen to Thanos and his life will change. She says: "*Our children have their own lives, their own problems.*"

What is important to Elle

- A way to provide the most correct and safe care for her husband, reducing as much as possible unnecessary transportations and doctor visits because they both cost financially and psychologically P16-Req-1
- Increase house safety P16-Req-2
- Understand the nature of particular disease P16-Req-3
- Family ties with her children and grandchildren P16-Req-4

Daily living

- Helping hand in her daily home care jobs and for her husband's care P16-Daily-1
- Once a week she likes to go to church P16-Daily-2
- She loves watching old films on TV P16-Daily-3

Own resources, assets, support

- Economically dependent, she lives on her husband's pension P16-Resources-1
- GP costs are covered by the National Health System P16-Resources-2
- When a health emergency arises, she borrows money from her daughter P16-Resources-3
- Thanos needs to visit several specialists (cardiologist, pulmonologist, neurologist) P16-Resources-4

Health concerns and limitations

- Control her hypertension P16-Health-1
- Reduce the burden of her chronic back pain P16-Health-2
- Keep her husband's health in a stable situation P16-Health-3

Health tests/ treatments/ medication

- Check blood pressure once a day (Thanos and Elle) P16-Tests-1
- Twice a day glucose strip test for Thanos P16-Tests-2
- Thanos takes 5 different medications P16-Tests-3
- Elle takes 2 different medications P16-Tests-4
- Annual laboratory tests P16-Tests-5
- Regular checks by the GP P16-Tests-6

Events, issues, personal concerns, technology

- She would like to have smart machines to monitor their health status P16-Personal-1
- She would like to have a way to pleasantly occupy her husband P16-Personal-2

Hopes and dreams/ what brings joy/ quotes

- *"If I had more money, I might be able to offer more services to my husband"*

Unmet needs

- Easiest and safest health status management P16-Unmet-1
- Communication with social workers/ psychologists to strengthen their physical and mental health P16-Unmet-2
- Help from local authorities P16-Unmet-3

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Figure 37: Persona 16

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5.7.2.1.5 Meet Nikolas - Access to Healthcare system[P17]

In addition to the Maria Persona included in SHAPES deliverable D2.5, the team of 5thYPE, based on the qualitative analysis of the interviews conducted using the interview guide of Task 2.1, created two more personas, one addressing an elder over 65 years old (Nikolas Persona) and the other one a refugee of 60 years old (Miral Persona).

General Description: Nikolas, an 84-year-old man from Greece lives with Mary, his wife of the same age, in a privately owned house near the city centre. They have two sons. One resides in Athens, about 400 km away and is divorced. The other son, unemployed for two years, has been hosted with his wife at his parents' house until their financial situation improves. Nikolas is economically independent with his pension sufficiently covering the couple's daily living expenses, but the additional support of their son strains their finances. Two years ago, Mary had a stroke. She recovered very well and continues to receive treatment. Nikolas helps Mary with the housework and also goes shopping in the bakery or at the grocery store. He is also the one who pays the bills and goes to the pharmacy for prescriptions.

Nikolas is a cancer survivor. He had a very serious problem with colorectal cancer in 2005, which he overcame after surgery. In 2007, he presented with episodes of bradycardia for which he had to get a pacemaker on the advice of his cardiologist. In 2014, he had vision problems in both eyes and underwent a cataract operation. A year later he had a problem with his bile which also required surgery. All these health issues were first attended to in the emergency rooms of the public hospital, but the surgeries were performed in private clinics. This happened not because Nikolas chose it but because the waiting times for the operations were too long at the Public Hospital.

Nikolas says: "Your needs show you where to go and what to do. When you face a problem, especially a health problem, you want a solution immediately." He adds, "I trust and appreciate the doctors in the hospitals. Every time something serious happens to me, I visit the public hospital but the procedures that are followed are not convenient and beneficial to the citizens and this must change."

Nowadays, Nikolas is in very good health. The only health problems he faces are hypertension and prostatic hyperplasia for which he takes medication on a daily basis. For his chronic health issues and the prescriptions needed, Nikolas visits the primary health care unit of his region called TOMY1. Nikolas says: "TOMY is wonderful! Access is easy and fast. Appointments are pre-arranged and without delay. My doctor knows me well and I trust him but there is a problem here, too. When I want to visit a specialist there is no connection between the structures and I have to arrange it by myself." Furthermore, he adds: "This lack of clear referral mechanisms and pathways between the primary health care unit, the specialists and the hospital, obliges me to pay a lot for my health. This is

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money that I don't really have and it deprives me of other things, such as getting my wife a gift or going on a trip sometime."

It is very important for Nikolas that both he and his wife are in good health. He wants to be able to take care of his wife and himself until the end of his life. He does not want to burden his children. However, if the need arises and his family cannot provide the required care, he will be forced to go to a nursing home or a clinic. But Nikolas believes that older adults in these institutions are unfortunate. "They are suffering", he says, "It is ok to be able to go to a facility, something like a nursing home, for as long as you can eat on your own and go to the toilet on your own. Then they better let you die! Besides, you are not doing anything else there, you are just waiting to die!"

Healthy ageing is Nikolas' wish for the rest of his life. When being asked by his doctor about his wellbeing, his response is, "I'm not well. Can you make me better?" adding, with a mischievous smile on his face "If you can't, I'm fine." For as long as possible he wants to take care of his garden and to keep riding his bicycle, which he loves because it makes him feel free, much like when he was a small child. Every year he eagerly awaits the summer to visit his seaside house and enjoy the sea

Note: 1 TOMY: The opening of new primary health care units in December 2017 was an effort towards establishing modern, people-centred primary health care services in Greece. The Primary Health Care Units, called Topikes Monades Ygias (TOMY) in Greek, are key elements of the newly designed primary health care system and serve as the first point of contact and the main coordinator of care for people in the area. Multidisciplinary teams (general practitioners/family doctors, paediatricians, nurses, health visitors and social workers) provide health care for people in a continuous manner, looking at disease prevention, health promotion, diagnosis, treatment, monitoring and care.

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MEET NIKOLAS P17

Motto: Easy access to primary healthcare

Name: Nikolas
Country: Greece
Age: 84
Area: City

Economical situation: Satisfactory
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Nikolas, an 84-year-old man from Greece lives with Mary, his wife of the same age, in a privately owned house near the city centre. Nikolas is economically independent with his pension sufficiently covering the couple's daily living expenses but the additional support of their son strains their finances. Two years ago, Mary had a stroke. She recovered very well and continues to receive treatment. Nikolas helps Mary with the housework and also goes shopping in the bakery or at the grocery store. He is also the one who pays the bills and goes to the pharmacy for prescriptions. Nikolas is a cancer survivor. He had a very serious problem with colorectal cancer in 2005, which he overcame after surgery. In 2007 he presented with episodes of bradycardia for which he had to get a pacemaker on the advice of his cardiologist. Nowadays, Nikolas is in very good health. The only health problems he faces are hypertension and prostatic hyperplasia for which he takes medication on a daily basis. He also occasionally takes painkillers when he has a problem with his prostate. For his chronic health issues and the prescriptions needed, Nikolas visits the primary health care unit of his region called TOMY.

What is important to Nikolas

- Staying in good health P17-Req-1
- His wife's health P17-Req-2
- Keeping his hobbies P17-Req-3

Daily living

- Able to go for a ride on his bicycle P17-Daily-1
- Able to go shopping alone P17-Daily-2
- Able to do work at home and in the garden with his son's help P17-Daily-3
- Able to go to the family doctor and to the pharmacy for the prescription every month P17-Daily-4

Own resources, assets, support

- Financially independent, his pension is enough for daily living but because his son has been unemployed for the last two years, he is trying to help him P17-Resources-1
- One of his sons lives in Athens, about 400 km away from Larissa and is divorced. The other son who is unemployed has been hosted with his wife at his father's house P17-Resources-2
- Has good knowledge of possible care services in the local community P17-Resources-3

Health concerns and limitations

- He suffers from slight pain in the neck and in the back and that bothers him to lift weights P17-Health-1

Health tests/ treatments/ medication

- He was operated on for bowel cancer, he has a chronic anemia which is treated with drugs P17-Tests-1
- Last year because of his anemia he did a colonoscopy and gastroscopy according to his gastroenterologist P17-Tests-2
- He underwent a surgery for cataracts in both eyes P17-Tests-3
- He thinks that because of the lack of clear referral mechanisms between PHC and the Hospital, he needs to pay a lot for his health at private sector. P17-Tests-4

Events, issues, personal concerns, technology

- Loves his wife and cannot imagine living without her P17-Personal-1
- Hopes his son finds a job so that he can go to live in another house with his wife P17-Personal-2
- They both enjoy going to their house in the seaside every summer P17-Personal-3

Hopes and dreams/ what brings joy/ quotes

- He hopes to stay in a good health condition
- He is afraid to go to a nursing home, because he believes that the elderly in these structures don't have a good time

Unmet needs

- He hasn't had any training in technologies P17-Unmet-1
- He doesn't know how to use a computer or a smart phone P17-Unmet-2
- He would like to go on organized trips with his wife and friends P17-Unmet-3

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Figure 38: Persona 17

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5.7.2.1.5 Requirements

Table 17: 5th YPE personas requirements

User requirements for above mentioned personas	
An eHealth call centre to support platform user needs to be available 24/7 for all users.	FR-HS-1
The platform should include tutorials and help cards regarding its use and the use of the devices connected to it. Also, a glossary of terms should be available.	FR-HS-2
Health data collection and management (and sharing) of health parameters	FR-HS-3
Processing of health data: risk assessments, action plans	FR-HS-4
Recording the perceived state of well-being / self-assessment tool	FR-HS-5
Help for dealing with legal issues (e.g., advanced care plans; end-of-life care)	FR-HS-6
Medication reminder / support Reminder for clinical readings/appointments	FR-HS-7
Pain management system	FR-HS-8
Medical emergency alert system	FR-HS-9
Track and record clinical device characteristics regarding maintenance/calibration, make, model number	FR-HS-10
SHAPES platform should be explicit about the benefits of its use (prompts, feedbacks, rewarding messages, etc.)	FR-HS-11

5.7.2.1.6 Scenarios

Maria dreams of traveling all over the world. Unfortunately, her health condition discourages her from selecting the recreational experience of travelling to other locations (abroad or domestic). Both the need for medical assistance (especially with her chronic diseases) and the little-to-no knowledge of the destinations' accessibility and safety conditions, act as a turn-off for any decision-making process for traveling and tourism activities. Assessing and identifying the safety/accessibility levels of potential destinations, as well as being able to navigate her way when she visits those destinations, can enhance her travelling decision-making capability and overall contribute to her active and independent living.

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Maria, as well as Nikolas and his wife, need to have their health condition constantly monitored. This need becomes stronger when travelling to another country, adding up to theirs and their caregivers' anxiety. Therefore, they must be empowered to efficiently manage their condition outside their "comfort zone". Additionally, certain conditions carry the risk of resulting in critical events (e.g., Maria's heart failure), often with life-threatening implications. Monitoring and analysing their health and lifestyle data can act as predictors of such events, thus triggering specific precaution measures to avoid those events from happening (or to give them enough time to reach an emergency room).

In case of an emergency situation, it is of critical significance that access to their medical data (medication and patient summary) is available, as well as communication between them, their physician (back home) and the emergency physician (visiting destination), in order to perform the best-informed medical practice.

Ensuring the above will increase Maria and Nikolas's feeling of safety, preserving the feeling that they "never left home".

5.7.2.2 UPORTO – John and Joan in Pilot Theme 5

5.7.2.2.1 Persona[P12]

A new persona is designed and proposed by this use case, which was inspired by the SHAPES Personas, "P1 Ernst, P3 Ayesha, P4 Isabel and Marco, and P6 Jarda. The new persona, "John and Joan", is a dyad/couple of older adults with MCI and their family caregiver who lives in-cohabitation. They live in a dyad/couple and they share *attributes, attitudes, behaviours and characteristics*, which provide a *model of user* of *SHAPE digital solutions and innovations*, especially on the context of in-home daily life and lifestyle

Theoretically, it has already been studied (Giddens, 1992) that intimate relationships between a couple are a great positive impact on well-being and life satisfaction, as well as for physical health and life expectancy. In this regard, positive correlation of intimate relationship and quality and sleep patterns, health and well-being, and caregiver straining were found.

Moreover, in current times (called post-modernism or last modernism), especially in the Western world, patterns of family and intimate relationships are being determined by individual negotiations (e.g., emotions, feelings, intimacy, sexuality, interests, partnership, etc.) rather than social conventions (e.g., community, religion, tradition, etc.) – a movement toward pure relationships (Giddens, 1992).

Meet John and Joan. Joan is John's second spouse. John's first spouse died during childbirth, and he became a widower and a single father of his first son, a boy named Albert. John met Joan through common friends when she arrived where John lived to

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teach at an elementary school. At that time, John was a general technician at a small company. While Joan and John were dating, John went to work for a bigger company as a mechanic technician and she stayed at the local primary school.

They married one year later and they are parents of twins: one boy, Oliver, and one girl, Amanda. John was 27 and Joan was 24 years old. John's son was 5 years old. At this time, they bought a small villa with a back garden, where they spent a lot of time (meals, relaxation, playing with children, gardening). They never changed homes. She was 65 years old when she retired; he worked for three more years, until 70 years old. When he retired, they remodelled the house thinking about ageing issues, such as: accessible toilet, energy efficiency, safe floors and steps, wide doors, stair elevator, garden and entrance accessibilities, and others. This option was strongly influenced by Joan's cancer. John and Joan's children live in their own homes, with different situations. Nevertheless, they meet at their parents' home every 3 months.

As for health literacy, both used to be healthy and active during their lives, especially caring about their diet, physical activities (running, walking, gardening) and cognitive stimulation (reading, playing card games on smartphone/computer). Supported by a public health care and insurance, both have regular primary healthcare, with one/two routine health consultations per year, as well as health work assistance. However, when Joan was 64, she was diagnosed with breast cancer and they had to increase their health literacy.

John's family lives in the same area, but Joan's family is from a rural area, where Joan´s mum Brenda, who is 95 years old, lives at home with daily professional caregiver support, provided by a social organization: meals, shower and house cleaning. Joan's mum has the neighbour's support, as well. Despite this, Brenda is autonomous enough, Joan and John (or only Joan) spend one weekend per month in her home. When Brenda has any health issues, she stays in Joan's house.

They both enjoy exercising: matinal basic exercise (full body stretching); 2 hour walk per day; John runs 30 minutes 3 times per week in the public park; Joan does swimming and water aerobics 2 times per week. Additionally, they love national tourism 6 times per year (museums, parks, monuments, sanctuaries); international tourism 2 times every 5 years; local events (exhibitions, local markets, celebrations, music, theatre).

At the end of the house remodelling, John was 71 years old and started to forget things, especially regarding the remodelling. John forgot some appointments with friends. At the beginning, Joan was not worried because she thought it was stress. However, after the remodelling, from 71 to 72, John decreased his 'normal' performance for carrying out the instrumental activities of daily life, but specially the healthy and active lifestyle: he woke up later and did not sleep regularly; John stopped walking every day and ran weekly; he remained most of the time watching TV or reading. Firstly, Joan thought it was depression

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related to retirement, and she called her physician, who has been following her since the cancer surgery. Joan's GP did a MMSE test that showed cognitive decline. The couple met the neurologist and another psychologist, and the diagnosis was MCI. Joan didn't alert their children until they were sure.

John accepted the diagnosis very well and he didn't want to become a burden on Joan. For that reason, he created an agenda for the couple's activities, both domestic and public, in order to maintain a 'normal' couple's daily life and lifestyle, namely: domestic work, gardening, physical activities (walk and run), cognitive training (read, playing cards), healthy diet, social networking (meeting friends, going to church, senior university, Joan's mom, doing the family meets and celebrations, etc.), and cultural events (theatre, music, cinema). Normally, John scheduled and organized the social and cultural activities, which became a challenge for the couple. He desired to maintain this job, but often he made small mistakes (forgetting, confusing), and Joan tried to help him but unsuccessfully because she had all the major domestic work and her own commitments.

John' first son, Alberto, is living in Boston (USA) and he invited his parents to visit him. John's son had planned to take his father to an American expert, but the diagnosis was the same. However, during Alberto's stay, an unexpected solution came up for John and Joan. Alberto had Alexa on, a digital voice assistance from Amazon, and the couple 'fell in love' with Alexa's capacities: voice speech, programming, wiki solutions, connection with phone and online shops, social and cultural agenda, connection with the house doors, windows, blinds, lights, etc. They made a decision: they wanted an Alexa at home to support their daily life and lifestyle.

Economically, John worked in industry as a technician; his highest salary was €1,000. Joan worked in education as an elementary school teacher; her highest salary was €1,500. They live with two retirement pensions totalling €2,500. Note: minimum salary is €600. As for digital literacy, they had professional training in new Information and Communication Technologies during the 90s, when there was the digitalisation of the work process, both industry and services. They bought a computer at the end of the 90s for the family (couple plus three kids). Nevertheless, they only developed basic user skills because the kids used to provide technological support. Both use a smartphone with internet connection, especially for calls and social networking (basic user skills and low-level usability). They share a computer with printer, scanning and internet connection (basic user skills for internet explorer, word and excel, and managing a personal folder with documents).

Where they live, there are several public and private health care facilities, and both have access to public and private health systems. Often, they choose public health and care systems. Their unmet needs are related to the complexity of the public health care system, especially lack of communication within health specializations and between the public and

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private health care systems. Moreover, there is no database with a public health history of the individuals.

Smart and Health Ageing
through People Engaging in supportive Systems

SHAPES

MEET JOHN AND JOAN P12

Motto: Enjoy each other as long as we can

Name: John and Joan
Country: Portugal
Age: John - 73, Joan - 70
Area: Small town

Economical situation: Middle Class
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: John and Joan are a couple. She was 65 years old when she retired; he remained working for three more years, until 70 years old. When he retired, they remodelled their house thinking about ageing issues. Suddenly, John started forgetting things, meetings or could not remember past events. John decreased his 'normal' performance for carrying out the instrumental activities of daily life: he woke up later and did not sleep regularly; John stopped walking every day and run weekly; he remained watching TV or reading most of the time. Joan's GP did a MMSE test, that showed cognitive decline. John accepted the diagnosis very well and he didn't want to become a burden on Joan. For that reason, he created an agenda for the couple's activities, both domestic and public, in order to maintain the 'normal' couple daily life and lifestyle.

What is important to John and Joan

- To keep strong social ties with family and friends. P12-Req-1
- To support their children's independence and autonomy during adulthood. P12-Req-2
- To maintain a high-level of their quality of life, especially the autonomy and independence. P12-Req-3

Daily living

- Basic daily life activities: preparing meals, medication, personal hygiene, home and clothes cleaning, shopping etc. P12-Daily-1
- Physical exercise P12-Daily-2
- Social and cultural routine: call (daily) and met (often) family and friends; participate on local events (celebrations, music). P12-Daily-3

Own resources, assets, support

- Economically independent, with the high monthly income from pensions and a savings account for unexpected problems. P12-Resources-1
- They own their home and a small land in Joan's village that is an inheritance from Joan's family. P12-Resources-2
- They have a car for local transportation and visit the children's homes. P12-Resources-3

Health concerns and limitations

- John was tested for MCI disorders and Joan had breast cancer and she had surgery. P12-Health-1
- They are starting to feel obese, arthrosis, cerebrogenic syndrome (back pain), fear of falls (after John's fall on the stairs), and exhaustion. P12-Health-2
- They feel hypertension and respiratory difficulties when they are stressed or during the summer (heat waves). P12-Health-3

Health tests/ treatments/ medication

- Complete health exams each year. P12-Tests-1
- Cognitive training / therapist for John P12-Tests-2
- Therapist for Joan P12-Tests-3
- Neurologist examination for John P12-Tests-4
- Cognitive and neurological pill for John. P12-Tests-5
- Cancer control pills for Joan. P12-Tests-6

Events, issues, personal concerns, technology

- Self-management of their ageing to enhance the overall health, better control of symptoms, avoid unnecessary re-hospitalization, enhance quality of life, and decrease overall mortality. P12-Personal-1
- Internal motivation, while supporting one's own feelings of autonomy, competence and connectedness. P12-Personal-2
- Technology interest is gradually increasing for John and Joan's routine, especially after the Covid-19 lockdown, namely the social networks and videocalls. P12-Personal-3

Hopes and dreams/ what brings joy/ quotes

- *Sense of community.*
- *Active participation in the life of the community through various volunteer work.*
- *Tourism*

Unmet needs

- Quality of the environment: attractiveness of buildings and the area; quiet and peacefulness of the area; accessibility and quality of parks and open green spaces, sufficient street lighting, and paths and pavements P12-Needs-1

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Figure 39: Persona 12

5.7.2.2.2. Requirements

Table 18: User Requirements for John and Joan - Voice Assistance

User Requirement	Ranking (Low, Medium, High)	Expected Behaviours from End-Users		
		Older Individual with MCI	Informal Caregiver (familiar)	External End-User or Stakeholder
Health Support				
Medication Intake Reminders	**High**: DS have to provide daily reminders, at least three times per day (meals).	Listen to reminders and confirm the reception and behaviour	To receive alert if confirmation or behaviour didn't occur, by caregiver panel and email. To program the Caregiver Panel with Reminders-Agenda and Instructions.	An external party, such as GP, Social Workers, Academia, could be access to this information, as well as could insert news, in order to improve the user-experience and indicators.
Medical Appointments Reminders				
Daily Healthy Advice	**High**: DS have to provide advice daily, at least three times per day (meals).			
Daily Care Advice				
Periodic questions with close answers (yes/no; 1 to 5; Likert)	**Medium**: DS will do direct questions with a close answer, three times per week. DS will also provide alerts about answers' rates, and pre-program advices.	Listen to question and options and answer the suitable option	Receive alert if answer didn't occur, by caregiver panel and email. Receive alerts, advice and reports, by caregiver panel and email. To program the Caregiver Panel with Questions and Answers.	
Advice and alerts link with periodic answers		Listen to advice and alerts and confirm the reception		
Information Services (IS)				
Alert for caregivers if	**High**: DS or/and Platform send alerts if expected	Listen to advice and alerts and	Receive alerts, advice and reports	An external party, such as GP, Social

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behaviours change	(pre-programed) behaviours didn't happen or have a critical rate.	confirm the reception	about DS events, by caregiver panel and email.	Workers, Academia, could be access to this information, as well as could insert news, in order to improve the user-experience and indicators.
Weekly Reports for Health Support	**High**: DS or/and Platform provide automatic reports weekly with data about DS events (graphics, alerts, advices, etc.)	N/A		
Educational and Research Materials	**Medium**: DS or/and Platform have to store both educational materials about DS and data collected by DS.	Listen to alerts about availability of materials and confirm the reception. These materials are available on caregiver panel and email. To program the Caregiver Panel with Questions and Answers.		
eHealth Tutorials and Instructions	**Low**: DS or/and Platform could be integrating news about eHealth innovations, that could be shared by DS.			
Health Maintenance Support (HMS)				
Therapeutic Instructions **Care Instructions** **eHealth Instructions** **Health System Instructions** **Other Instructions**	**High**: DS or/and Platform have to provide instructions about therapeutics prescribe by GP, therapist, other subject that interests to the end-users, about healthy behaviour or care's practices, but also lifestyle, active ageing, cultural participation	Listen to instructions and confirm the reception and the usability	Listen to alerts about usability of instructions and steps didn't confirm, by caregiver panel and email. To program the Caregiver Panel with Instructions.	An external party, such as GP, Social Workers, Academia, could be access to this information, as well as could insert news, in order to improve the user-experience and indicators.

Facing new demographic trends, the World Health Organization recommendations point out that *healthy behaviours and lifestyles throughout the life course*, among others, as a solution for maintaining both physical and mental long-term individual independence and autonomy. In this regard, the literature has been pointing towards the association between a healthy and active lifestyle and later cognitive ageing, and cognitive ageing as a

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multidimensional process which is related to individual *experiences, health status, lifestyles, education, attitudinal and emotional factors, socioeconomic status, and genetics*, and cognitive ageing trajectory as well.

Literature finds a strong association as well between cognitive ageing and negative effects on daily-life activities, especially those that are important for maintaining a healthy and active lifestyle, for instance: eating habits, cooking, medication, grooming, bathing, sports, leisure, shopping, sleep patterns, among others. This situation is worse in case of MCI or other neurodegenerative impairment. Despite the boundaries between 'normal' cognitive ageing and MCI not being absolutely clear, they are distinct.

Focusing on MCI, the literature also pointed out the higher rate of MCI in later ages, and its association with the loss of people's abilities for carrying out the daily life activities, autonomously and independently, and maintaining a healthy and active lifestyle, which means making serious errors, such as to forget to turn-off the cooker or to forget medication or to replace medicines. At the same time, both people with MCI and their primary carers are at risk of social isolation: on the one hand, people with MCI may lose communication skills and abilities for engaging in social activities; on the other hand, their primary carers have less time for leisure and entertainment.

For both groups, the daily-life challenges could decrease the Quality of Life (QoL) at-home, if individuals with MCI, their social network (family, community) and health and care systems promote an autonomous and independent daily life and a healthy and active lifestyle. Moreover, improved Quality of Life (at least, the perception of it) could be a motivational experience to maintain an autonomous and independent daily life and a healthy and active lifestyle.

Additionally, digital health (eHealth) – especially the Assisted Living Technologies and Digital Solutions implemented at-home (robotics, sensors, telemedicine, management apps, mobile tracking devices, video games) – has been seen as a new approach for promoting healthy and active ageing within people with MCI and their primary carers, namely digital and technological solutions that support old people living independently and autonomously at home, maintaining healthy and active lifestyles, and improving the pharmacological intervention and treatments.

5.7.2.2.3. Use Case

Framed on this rational, the "**Use Case 002. Digital Assistance in-home for improving the quality of life in older adults with MCI and caregivers**" aims to evaluate the eHealth digital assistance in-home solution for increasing the Quality of Life of older adults with MCI and their familiar caregivers.

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This digital solution should be to improve the Quality of Life (QoL) of older individuals, both the older individuals with MCI and the respective primary carer, in four indicators. The Use Case intends to evaluate the impacts of digital assistance in: Health and Active Ageing; Care Burden (formal / informal); Life Satisfaction; and Smart Ageing.

Table 19: Use case John and Joan

PACT Scenario	UC-PT5-002
Activities Activities to be performed by the actors in order to successfully receive the intervention	The digital solution will be an "In-Home Digital Voice Assistance", that is a smart speaker and its related caregiver administration panel that will be installed in older individuals' home. These devices are a friendly voice or interface, and participants have to interact with the devices naturally, using: voice, hearing, texting, reading, touch buttons, selecting options, go back/go forward, up/down. As a natural routine, the users will be helped by digital assistance interaction skills: **Reminders:** Pill Intake; Birthdays; Social Events; Doctor appointments; Call Somebody; Calendars; Home Appliances (kitchen; machines; cleaning; possibly danger situations); Others (TBD); a caregiver can define reminders to the person being cared. ▪ **Follow Ups:** ask to user a self-report (1-10) about feelings, behaviours, events, news; define alerts if personal status is changing (or reminders); and give them feedback *(Note for the audience: skills 2 is not "fixed" and they can be modified according to the needs of the consortium. The reason of this skill proposal is because we've found them to be the ones that most adjust to the UCs).* ▪ **Follow-ups** for instrumental activities of daily life and healthy and active lifestyle *(how I do this? Find physical exercise for people with MCI?)*. Plan the dialogue to complete a task *(First, you must go for here; Second, you must…)*. ▪ **Schedule / register** (learn) new information from user *("Remind me of my doctor's appointment tomorrow at 4pm"; "You are scheduled to meet David tomorrow at 4. Would you like to cancel David's appointment?"; "Yes please cancel David's appointment and replace with the doctor's appointment. "Ok, I will remind you of your doctor's appointment tomorrow (insert date) at 4pm one hour before").* ▪ **Read Back Confirmations** *("Remind me of my doctor's appointment tomorrow at 4pm"; "Ok, what time would*

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	you like to be reminded"; "Remind me one hour before my appointment"; "Ok, I will remind you of your doctor's appointment tomorrow (insert date) at 4pm one hour before").
Context Puts the intervention in a health-care context. Social-medical relevance of the intervention; privacy issues; risks for the patient; locations	**Smart Speaker (Voice Assistance)** A "Smart Speaker" will be installed in the older individuals' home, with three skills: reminders, follow ups, and health data registration. Daily, this speaker will provide specific information/data, which is previously uploaded (by a caregiver panel) or learned (through IA), for improving autonomy and independence of older individuals with MCI, in home and community. Older individuals will be trained to have voice interactions with the speaker, such as: say "good morning" when they wake up, and ask for daily agenda; plan events for a day "Speaker, remind me to take my medicine at 8pm"; or follow up, "How are you Mr John today?", etc. Then, they will use it at home, independently and autonomously. **Caregiver Administration Panel (Tablet or Computer)** A caregiver administration panel (friendly interface) is connected with voice assistance (smart speaker) to allow specific data and information uploading. This option was designed for caregivers, but can be used also by older with MCI, if he/she is able to do it. Both will be trained to upload data and information successfully. The main goal is to upload instructions for a smart speaker that could support the caregiver performance or replace him/her (during an absence): e.g., "don't forget medicine", "remember to call your friend / doctor", "the jacket is in the room", etc.
Technology Typically, to realize telemedicine, technology needs to transform some input data into some output data which can be used by the medical expert and patient to support the activities defined	**Infrastructure:** Smart Speaker (voice assistance); Tablet/Computer (caregiver administration panel); Smart Devices (e.g., bracelet); Interconnection (Internet Devices 3G - 5G). **Architecture**: Input and output is text-based. **Natural Language Understanding:** understands what the user is saying. **Dialogue Management:** plans the interaction to fulfil a given task. **Response Generation:** creates a comprehensible way to communicate the response to the user.

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earlier. The features of the technology are input, output, communication and content	**Skills:** the digital solution will provide transversal interaction skills that can adapt from one domain to another. **Interoperability:** during the interaction, the bot can exploit and communicate with other services and DDBBs. Multiple smart devices could be inter-connected to improve the user experience of digital assistance and their outcomes (clinical/well-being).

The Use Case will provide an installation of Digital Voice Assistant in the older adults' home, where a sim card will be installed in each unit. The device should be in the home for 8 weeks, and all interactions should take place via telephone (except the protocol baseline and mock-up phase) weekly (Covid-19 management risks).

During the intervention, data collection should be limited to device usage statistics which should be gathered by the digital assistant and fed back to a central server. In a post intervention, data collection will mirror the pre-intervention for comparison purposes. All participants will be assessed by a Geriatrician using the Quick Mild Cognitive Impairment Screen (http://www.qmci.ie) in the baseline and post intervention.

5.7.2.2.4 PACT Scenario

SHAPES D6.1 identified two scenarios: the PACT framework (People-Activities-Context-Technology), that ensures "to think about (…) relevant stakeholders (…), actions, (medical) context (…), and technological innovations"; and the FICS approach (Function and events, Interactions and usability issues, Content and structure, Style and aesthetics), for providing "insights for technicians to consider the technical specifications", especially "how the intended system mediates the actor's activities and therefore form an operative service description of the intended system".

Description (natural scenario for being reproduced by intervention)

An eHealth Digital Assistance in-home system will be installed in the older individuals' home, which is composed by a Voice Assistance (Smart Speaker) and a respective Caregiver Administration Panel (for Tablet and Computer). They are a couple and one of them was diagnosed with MCI and is losing capacity for living autonomously and independently. At the same time, the caregiver burden is increasing. The couple's life satisfaction is decreasing because of the misunderstandings and conflicts. They asked for advice from their GP, and he/she recommended voice assistance, instead a pharmacological intervention, which is integrated on a European Platform called SHAPES.

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With a prescription from their GP, the couple went to the pharmacy to buy the voice assistance and they realized some differences. The trained pharmacy technician will explain the digital device features (financially, therapeutic, technical, digital, training, etc.), and he/she will do a first questionnaire (oral) for understanding the couple's needs and interests (Why they will use it? For what? Where (place in-home)? When (part of the day)? Which expectations?).

The questionnaire will be studied by a company and a multidisciplinary team will install and train the users, according to the information from the questionnaire and other technical contacts (by calls). During this time, the team will evaluate the end users, with basic usability and user acceptance tests. How user experience was? Which challenges? How many errors? What's the matter? Therefore, the final prototype of eHealth Digital Assistance Environment in-home will be concluded and the devices will be installed in-home.

The couple (or end users) will use digital assistance as they were trained and supported by a Helpdesk team. Often, they only use the voice assistance as a "personal secretary", who speaks with the end users about several topics regarding reminders, social and cultural agenda, wiki-how, or other learned subjects (through artificial intelligence). Despite initial challenges (language misunderstanding, upload data), after 2 months, the couple was able to use the voice assistance autonomously, and they have already connected another smart device (smart bracelet), and they are studying the connection with their GP and National Health System.

5.7.2.3 SciFY – Dimitris in Pilot 2

5.7.2.3.1 Introduction

Partner SciFY has created Persona "Dimitris" for "Use Case UC-PT2-003 LLM Care Health and Social Care Ecosystem for Cognitive and Physical training" in Pilot Theme PT 2 – Improving In-Home and Community-based Care T6.3

This use case is addressed to:

- Older people with or without Neurocognitive disorder
- Older people with Mild Cognitive Impairment and Mild Dementia
- Patients with chronic and mental disorders (Schizophrenia)
- People with disabilities (older people who have communication issues due to movement impairments or difficulties in speech (e.g., tracheostomy combined with mobility limitations, or with kinetic disabilities with not enough exercise during occupational therapy)
- and the persona was designed accordingly, mostly to better address the needs of people belonging to case (4) above.

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For the creation of the persona, SciFY used a) its experience from the development process of Talk and Play digital solution, in which multiple interviews had been conducted with occupational therapists and psychologists in the field, and b) a new in-depth interview with an experienced occupational therapist.

In the pilot, the "Talk and Play" digital solution (http://www.scify.gr/site/en/impact-areas-en/assistive-technologies/talk-play) created by SciFY will be used along with other solutions. Talk and Play is a digital application that helps people with disabilities (older people who have communication issues due to movement impairments or difficulties in speech (e.g., tracheostomy combined with mobility limitations, or with kinetic disabilities with not enough exercise during occupational therapy). It allows them to communicate, listen to music, watch videos and practice cognitive skills. Users can use different input methods, based on their abilities, and carers can customize most components to the needs of the end user.

5.7.2.3.2 Meet Dimitris[P13]

Meet Dimitris, a 65-year-old senior surgeon in one of Greece's most prominent hospitals. He is happily married to Sofia, a fitness instructor, and the couple have 3 kids aged 2-12 years old. Sofia has stopped working to take care of the children. Dimitris' income is enough to sustain the family. Within the hospital, Dimitris also teaches university students at the Medical School of Athens. Although this double role is rather tiring, he loves the interaction with the students. This part of the job refreshes him, as his role in the hospital has a psychological cost that is increasing: the hospital has a lack of personnel and oftentimes of critical medical supplies because of the economic crisis.

One evening, after the end of a very long and tiring shift at the hospital, Dimitris had an accident with his motorbike. He was brought back to the very same hospital he had been working a few minutes ago, but this time as a patient in critical condition. He entered the Intensive Care Unit with a severe brain injury that left him in a coma for 3 months. He stayed at the unit for a total of 6 months, in very critical condition that included a tracheostomy. He also had right hemiplegia and aphasia. This new reality meant he could not move the right parts of his body and could not speak either. After exiting the intensive care unit, he entered the Increased Care Unit for 3 more months, where he gradually regained part of his mobility. He can now use Yes and No and therefore has a basic communication with his carers.

On exiting the Increased Care Unit, the need for occupational therapy, physiotherapy and speech therapy was evident and urgent. It is imperative that he gain back his independent mobility, at least to the possible extent. Entering public rehabilitation centres is extremely difficult and time consuming in Greece. Due to the financial crisis, such centres are few, and the waiting list is too long; you may need to wait many months to get an admission. What is more, they most probably would not accept him due to his tracheostomy. The lack

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of resources does not allow such centres to accept these conditions. Fortunately, being a senior doctor for many years has resulted in him having enough money at the bank to allow him to afford a private rehabilitation centre. He shudders at the idea of what would happen if he had not had these resources.

After 9 arduous months in such a centre outside of Athens, he did not need a tracheostomy anymore, and has regained enough mobility so that he can now stand and walk a few meters alone. He has also improved his speech and can have a basic communication, more than the initial Yes and No. He can now return home and decide how to proceed.

After this experience, it is crucial for Dimitris to find new sources of income: His disability allows him to get a state aid of 380 euros/month. This is the new family income, which is next to nothing, especially for their needs. Moreover, he needs to find support for housekeeping and for tending to the 3 kids and Dimitris: Sofia must cater for practically everything, but she cannot handle all of this on her own. Dimitris needs to be able to make some very basic chores and/or stay with the elder kids for some time when Sofia is out. Dimitris's family have been supportive. They have also supported them financially. But they live far from Dimitris and Sofia's house. Therefore, they cannot help with their everyday challenges. Neighbours help Sofia with the kids (take them to school and back and help with the kids' other activities).

Apart from these everyday burdens he needs to take care of his health and find ways to do more occupational therapy, speech therapy and physiotherapy every week. He needs to train every week both at home and in a specialized centre. Dimitris still needs speech therapy and physiotherapy that are not covered by the state. Going to an institution away from home is neither desirable nor financially feasible. All this time, the expenses were enormous, and they cannot keep this going. Fortunately, he managed to find a place in a public centre to work his cognitive skills. This also allows him to get out of the house once more and meet other people.

Moreover, structural changes were needed at the house: The couple needed to change the house to make room for Dimitris's rollator and wheelchair. They needed to make changes to the bathroom, the kitchen...practically every room had to change. This meant more work for Sofia and more expenses. Fortunately, the occupational therapist that is helping them suggested an unexpected solution for their case. A Greek not-for-profit organization has been developing assistive technologies and offers them for free. They have created "Talk and Play", a software for people with cerebral palsy that can also help Dimitris.

Among the needs for Dimitris are the ones of his wife Sofia. Sofia needs to know that Dimitris is exercising his cognitive skills in a low-cost (zero-cost is ideal) manner. Talk and Play is vital for this. She also needs technologies that will inform her when/if something happens to Dimitris when she is not at home (e.g., when he falls, when he needs to go to

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the toilet, etc.). She would then notify a nearby relative to go and help him. Sofia would also love to have cameras in all the rooms, so that she can see how Dimitris is doing. For now, most of these technologies are not affordable.

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Smart and **H**ealth **A**geing
through **P**eople **E**ngaging in supportive **S**ystems

MEET DIMITRIS P13

Motto: Trying to manage hemiplegia and aphasia with no financial means

Name: Dimitris
Country: Greece
Age: 65
Area: Big city

Economical situation: Less affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

Dimitris, 65, is a senior surgeon. He is happily married to Sofia, a fitness instructor, and the couple have 3 small kids. Sofia has stopped working to take care of the children. Dimitris' income is enough to sustain the family. After the accident with his motorbike he spent 3 months in a coma. He stayed at the unit for a total of 6 months, in very critical condition that included a tracheostomy. This new reality means he cannot move the right parts of his body and cannot speak, either. Entering public rehabilitation centres is extremely difficult and time consuming in Greece. Luckily, Dimitris managed to get to one. After 9 arduous months in such a centre outside of Athens, he does not need a tracheostomy anymore, and has regained enough mobility so that he can now stand and walk a few metres alone and communicate more than yes and no.

What is important to Dimitris

- His wife and kids P13-Req-1
- Make sure family is taken care of P13-Req-2

Daily living

- External support is needed in order to keep the life before the accident P13-Daily-1
- House needs to be adjusted in order to have enough space P13-Daily-2

Own resources, assets, support

- Some income is gained by the government support P13-Resources-1
- Big family is supportive if needed P13-Resources-2
- Savings will be gone soon P13-Resources-3

Health concerns and limitations

- Regaining cognitive and physical abilities P13-Health-1

Health tests/ treatments/ medication

- Check-ups with the neurologist P13-Tests-1

Events, issues, personal concerns, technology

- Enjoys using technologies, welcoming the on-line word P13-Personal-1
- Would try using mobile apps if mobility allows P13-Personal-2

Hopes and dreams/ what brings joy/ quotes

- *"I wish one day I will be back again. Maybe not using my motorbike but giving lectures again, that would be great. I wish I could support my family again, after their enormous support when I was unable to take care of myself."*

Unmet needs

- Access to an affordable communication support system P13-Unmet-1
- Access to an affordable system to practice cognitive skills P13-Unmet-2

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Figure 40: Persona 13

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5.7.2.3.3 Requirements

The user will use the SHAPES platform to easily access a digital solution that will allow him/her to better communicate, listen to music and/or videos, and use mental exercises. When the user accesses the digital solution, (s)he will be able to:

- **FR-HM-1g** Communication through an interface showing pictures/words with associated sounds that the user can use to communicate needs/feelings when not able to speak/move adequately.
- **FR-HM-1h** Use of customizable communication card.
- **FR-HM-1i** Ability for the caregiver to customize the mental exercises' difficulty level.
- **FR-HM-1j** Ability to select music to listen to/videos to watch on their own, even when there are mobility restrictions.

5.7.2.3.4 Use Case

The use case for this persona will be *"UC-PT2-003 LLM Care Health and Social Care Ecosystem for Cognitive and Physical training"* in Pilot Theme PT 2 – Improving In-Home and Community-based Care T6.3

The use case is described as follows:

Cognitive skills are considered key elements in the daily functioning of older adults. Although, for some of these cognitive skills (e.g., memory, problem-solving activities or speed processing), decline is inevitable in the process of ageing (Harada et al., 2013). This kind of decline undermines the older adults' ability to maintain an independent lifestyle (Ball et al., 2004). However, technology assisted solutions may facilitate the older adults' continued independent living (Zarem, 2010). In this vein, Lab of Medical Physics developed a service which is addressed towards adults and integrates both physical and cognitive training through web service technologies (Konstantinidis, 2010) aiming at improving their health condition, and thus their quality of life.

The Integrated Healthcare System Long Lasting Memories Care (LLM Care) is a successful example of commercializing the "Long Lasting Memories" research program (http://www.longlastingmemories.eu/), which was built on the broad foundations of long-term research (pan-European and initially funded by the European Commission under the coordination of Greece). LLM Care is an innovative social care service provided by the Laboratory of Medical Physics School of Medicine of the Aristotle University of Thessaloniki.

Specifically, LLM Care is a certified ICT platform that combines state-of-the-art mental exercise with physical activity in an advanced assisted living environment and

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offers an integrated solution for cognitive and physical health, providing effective protection against cognitive decline and thereby, actively improving the quality of life.

This service is a non-pharmaceutical intervention against cognitive deterioration, qualitative results in the specific brain functions, affected by ageing, as well as the psychological state of the participants with a series of scientific contributions in International and European Conferences and Journal. The combination of physical and mental exercise reduces the risk of diseases and prolongs the time of independent and autonomous living. It also provides a comprehensive solution that has a direct impact on improving the quality of life of individuals, including older people or other vulnerable groups, Intellectual disabilities and Down syndrome, women with breast cancer, Parkinson's disease patients, etc.

5.7.2.3.5 Scenario to be used

The scenario we are going to run in order to test how Talk and Play works for people like Dimitris is briefly described below:

1. The user (usually the caregiver for this functionality) opens the application and double-clicks on the default user, or on the custom user that was created for them.
2. The user (caregiver /occupational therapist) customizes Talk and Play for the end user (our persona)
3. The user (persona/caregiver, depending on the case) selects one of the following available actions: "Communication", "Entertainment", and "Games"

Users are going to use Talk and Play's Communication module (where appropriate). This works as follows:

User (persona/caregiver, depending on the case) selects Communication action button:

a) User (the Persona) selects the desired word by pressing the button, when the cursor is at the relevant word box, as shown in Figure 41.

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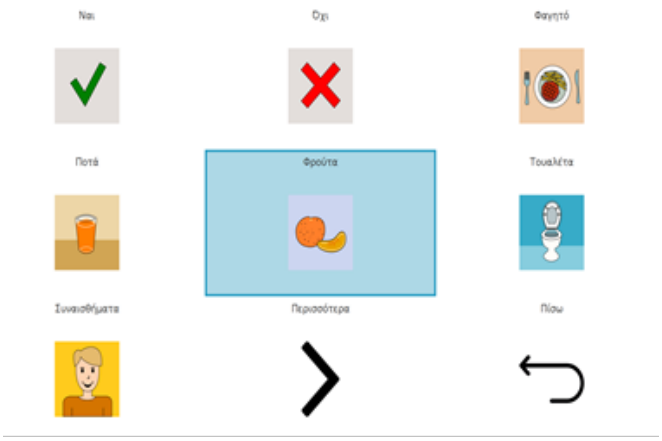

Figure 41 Example of the device usage

For the Entertainment module, we are going to use it (where appropriate) to allow users to listen to music/watch videos as follows:

b) User selects **Entertainment** action button:

If the caregiver has set a folder from which audio and video files will be streamed, the user can select either to listen to the audio files, or watch videos, using customizable input methods.

c) User selects **Games** action button:

User accesses the created games from the following categories: “Reaction”, “Time Sequence”, and “Find Similarities”.

- User selects the **“Reaction”** category. A game is presented aiming to train the user that when he/she presses a button, a particular reaction is presented on the screen.
- User selects the **“Time Sequence”** category. A game is presented aiming to train the user to set the images in the correct time order.
- User selects the **“Find Similarities”** category. A game is presented aiming to train the user to click on the most similar shape, after being given a certain shape.

4. The user clicks the “Back” button and exits the application.

5.7.2.4 Meet Daphne – formal caregiver AUTH

5.7.2.4.1 The need for introducing a Formal Caregiver Persona

During the design and development of PT5-UC-004 *Virtual Patient Scenarios (VPS) & Mobile Virtual Patients (MVP)* AUTH team was confronted with a difficulty in matching the UC with an appropriate persona. Having looked further into the

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developed personas, a persona that would be adequate for our UC could not be identified. More specifically, our UC is addressed to formal healthcare caregivers aiming at developing decision making, reasoning and training skills in their workplace competency and provide sufficient day care and support to older adults with Neurodegenerative diseases, including Alzheimer's, Parkinson's disease and mild cognitive impairment. In the light of this matter, our team set the ground for creating a new persona profile and in particular proceeded in the development of a new formal caregiver persona aiming at reflecting our UC and pilot scenario in a more inclusive and effective way.

To this end the AUTH team developed the ''DAPHNE'' Formal Caregiver Persona following the methodology below (Figure 42):

1. **Investigation of Deliverable 2.5** and exploitation of SHAPES Personas as starting point
2. **Literature review** and **AUTH's experience** from participation in previous health-related research projects – Development of draft persona
3. **Focus group with nurses.** An online workshop was carried out, where nurses (N=5) working in a nursing home participated in order to collect essential feedback on their needs, concerns, experience, etc. A short narrative and key points of our draft persona were presented to participants and a fruitful discussion was conducted, where participants shared their insights and thoughts on the persona.
4. **Evaluation of persona.** Participants reviewed the revised persona and subsequently, evaluated the persona using the Persona Perception Scale - Finalization of persona

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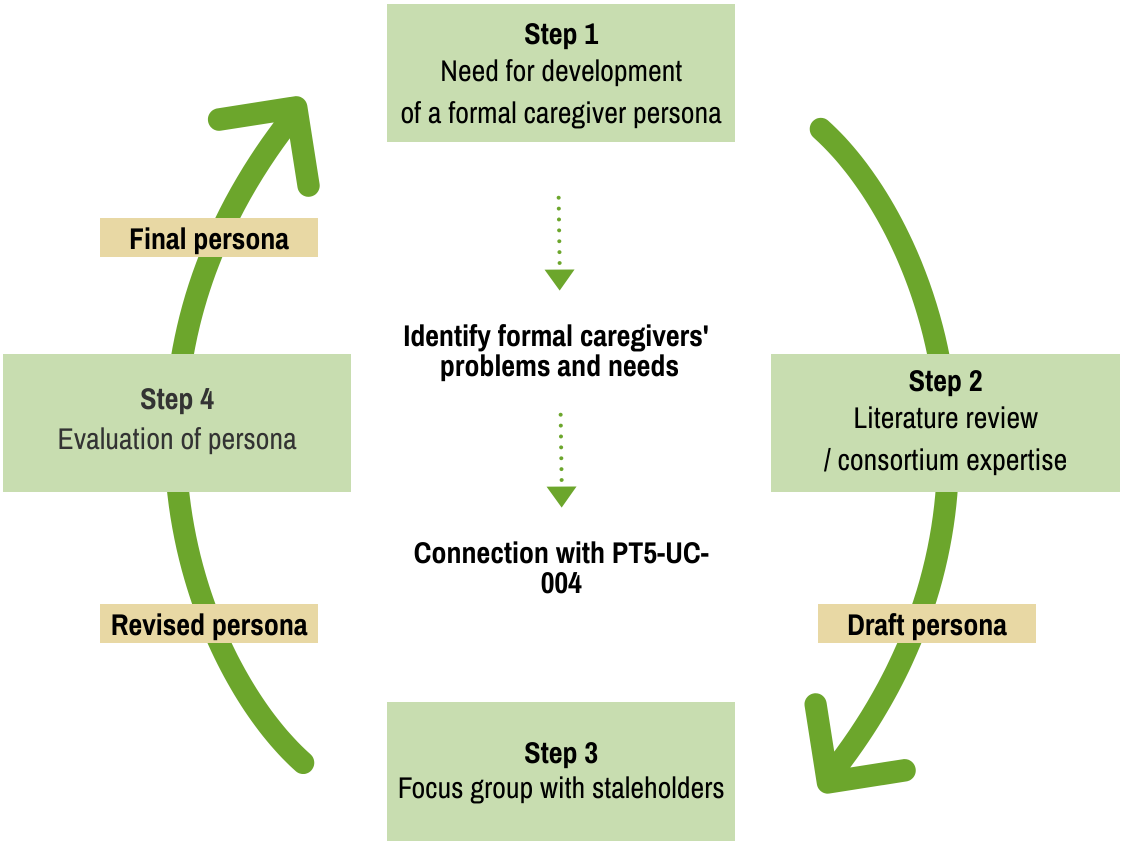

Figure 42: Methodology of developing the Formal Caregiver Persona

5.7.2.4.2 Meet Daphne[P18]

Daphne is a 45-year-old nurse who has worked the last 6 years in a Nursing Home, in which a Daycare Centre for patients with Alzheimer's disease and related dementias (AD/RD) is operating, in an urban area in Greece. Daphne is divorced and lives with her two underage children, 10-year-old daughter, Nefeli, and 7-year-old son Nikola, in the suburbs of Thessaloniki. She also takes care of her 70-year-old mother, who lives in a flat downstairs, and suffers from early signs of dementia. Daphne's sister is visiting on the weekends to help with the care of their mother and any potential errands. Daphne does not have much free time, as she has to take care of many patients - her shifts may last up to 10 hours- while she suffers from severe backache and pain in both of her knees, due to long standing and improper lifting and transferring of patients.

Daphne recently started having second thoughts about her overall performance as a nurse. In particular, she often feels that she lacks in professional readiness and that her care giving skills need improvement, while she is daily confronted with high-stress situations that cause her to be haunted by anxiety and fear of making a medical error. Additionally, sometimes she fails to appropriately communicate and understand the emotions and inner affinity of patients, while she wishes she could better address common

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needs for AD/RD caregiving, but also better comprehend their unique caregiving needs. Indeed, while surfing on the Internet, she found out that fellow colleagues from other countries receive individual training through new technologies that help them identify and manage different symptoms and needs of people with different types of AD/RD. She realizes that developing an individual care plan with details on the individuals' unique needs, medications, dietary requirements and restrictions is of utmost importance. Daphne understands that technology could act as an important tool in terms of computerisation of patients' health data and communication with her co-workers and she wonders whether new technologies could also help her advance her skills through training.

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Figure 43: Persona 18

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5.7.2.4.3 Requirements

To support Daphne at work, the SHAPES platform should include the following platform requirements:

- **FR-IS-3** Provide questionnaires to monitor health-related quality of life, medicines adherence, symptoms, etc.
- **FR-IS-5** Easy to navigate dashboard and summary for care receiver **FR-IS-6** Easy to navigate app/dashboard for service user/carer to review
- **FR-IS-12** Provision of training material for care providers
- **TS-IO-3** Allow for the use of mobile devices
- **TS-IO-7** Compatibility with different browsers to be determined (NHSCT contribution)

5.7.2.4.4 Scenario

Daphne often feels that she lacks in professional readiness and that her care giving skills need improvement, while she is daily confronted with high-stress situations that cause her to be haunted by anxiety and fear of making a medical error. Additionally, sometimes she fails to appropriately communicate and understand the emotions and inner affinity of patients, while she wishes she could better address common needs for AD/RD caregiving, but also better comprehend their unique caregiving needs. Indeed, while surfing on the Internet, she found out that fellow colleagues from other countries receive individual training through new technologies that help them identify and manage different symptoms and needs of people with different types of AD/RD. She realizes that developing an individual care plan with details on the individuals' unique needs, medications, dietary requirements and restrictions is of utmost importance. Daphne understands that technology could act as an important tool in terms of computerisation of patients' health data and communication with her co-workers and she wonders whether new technologies could also help her advance her skills through training.

In this light, the principal of the Daycare Centre, in which Daphne works, introduced a training program aimed at enhancing employees' skills in order to ensure quality care. A training plan can help Daycare operators maintain a highly skilled workforce. Under this perspective, Daphne interacts with the **Virtual Patient Scenarios (VPS) and Mobile Virtual Patients (MVP),** which have been increasingly used as educational resources in healthcare education. More specifically, they are defined as specific types of computer-based programs that simulate real-life scenarios where learners emulate the roles of health care providers. VPS and MVP can be deployed as problem-based learning activities and are considered an innovative approach which may lead to effective outcomes in education. In this vein, Daphne has the opportunity to interact with diverse

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virtual cases through scenarios and therefore familiarize herself with a range of Neurodegenerative diseases (including Alzheimer's, Parkinson's, dementia, stroke) and other chronic diseases (diabetes, heart disease, etc.), aiming at enhancing her learning skills with regard to symptoms, diagnosis and treatment. Thus, she considers VPS and MVP a valuable learning tool for encouraging decision making, reasoning skills, as well as self-assessment.

5.7.2.5 Monitoring a family – Use case from UNRF

5.7.2.5.1 Meet David[P19a], Mary[P19b] and Elina[P19c]

Fairly often health difficulties are not a case for only one family member. Family members can face different challenges and yet, they also need to support each other. To represent this case, UNRF created a family persona.

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Smart and Health Ageing
through People Engaging in supportive Systems

MEET DAVID, MARY AND ELINA P19a

Motto: Taking care of each other - health care in family context

Name: David
Country: Cyprus
Age: 67
Area: Urban

Economical situation: semi-affluent couple
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: David is a retired academic teacher. He lives with his wife Mary, who worked as a teacher. They live in the city centre of Nicosia in a private apartment. Their family ties are stable, and they have daily contact with their relatives, daughters and grandchildren. David was never good at exercising, nor did he have a healthy diet. As a smoker, David is severely affected by COPD (chronic obstructive pulmonary disease) and has difficulty moving around the house. Mary has heart disease. She needs to monitor her heart condition regularly and adjust her medication accordingly. David loves innovation and likes to try new things - he does what he can, from new flexible applications to gadgets and clinical smart devices. Mary has recently showed the first stages of dementia, thus asked help from a professional specialist. Elina is a nurse who Mary contacted. She is a specialist as she can diagnose and treat dementia patients. David loves travelling, but with movement dysfunctions, travelling is almost impossible for him.

What is important to David

- Reverse Mary's memory loss or slow the progression of dementia P19a-Req-1
- Be continuously informed about Mary's heart condition P19a-Req-2
- Exercising daily to rehabilitate from mobility impairment P19a-Req-3
- Restart travelling at least once a year P19a-Req-4
- Discover new innovative devices P19a-Req-5

David's daily living

- Reading daily news from his tablet P19a-Daily-1
- Talking online with friends and family P19a-Daily-2
- Remind Mary about medication P19a-Daily-3
- Attend to an online course for rehabilitation exercises P19a-Daily-4
- Play online chess with grandchildren P19a-Daily-5

David's and Mary's own resources, assets, support

- They are financially independent as their pensions are enough for daily leaving P19ab-Resources-1
- The General Healthcare System (GHS) of Cyprus is a comprehensive healthcare system that offers equal access to healthcare services for all citizens, with the option to choose their healthcare provider from both the private and the public sector with a limited economic contribution P19ab-Resources-2
- Nonprofit organizations, local community and faith-based organizations provide care services P19ab-Resources-3

David's health concerns and limitations

- Chronic obstructive pulmonary disease P19a-Health-1
- Mobility Impairments P19a-Health-2
- High blood pressure P19a-Health-3
- Low oxygen levels P19a-Health-4

David's health tests/ treatments/ medication

- Regular general practitioner visits P19a-Tests-1
- Sever breathing and pressure problems leading to the requirement for breathing machine P19a-Tests-2
- Does regular exercises for mobility impairments P19a-Tests-3
- Using the Internet for smoking cessation programs P19a-Tests-4
- Regular assessment of oxygenation by pulse oximeter P19a-Tests-5

David's events, issues, personal concerns, technology

- The weakening of mobility has gradually led to more splendid isolation and elimination of travelling P19a-Personal-1
- Worried about Mary P19a-Personal-2
- Exercise and evaluate his condition at home by taking instructions on the TV screen. After each exercise, the information is sent to the clinic P19a-Personal-3
- He is a municipal online community member for seniors P19a-Personal-4
- Monitor his progress via a smartphone connected to a body sensor that monitors its pulse P19a-Personal-5

David's hopes and dreams/ what brings joy/ quotes

- *"I wish I could go travelling again."*

David's unmet needs

- David would like to know more about dementia, perhaps enter a group of informal caregivers for dementia patients P19a-Unmet-1

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Figure 44: Persona 19a

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Smart and Health Ageing
through People Engaging in supportive Systems

MEET DAVID, MARY AND ELINA P19b

Motto: Taking care of each other - healthcare in family context

Name: Mary
Country: Cyprus
Age: 73
Area: Urban

Economical situation: semi-affluent couple
Digital literacy: Low High
Health literacy: Low High
Affinity to technology: Low High

General description: David is a retired academic teacher. He lives with his wife Mary, who worked as a teacher. They live in the city centre of Nicosia in a private apartment. Their family ties are stable, and they have daily contact with their relatives, daughters and grandchildren. David was never good at exercising, nor did he have a healthy diet. As a smoker, David is severely affected by COPD (chronic obstructive pulmonary disease) and has difficulty moving around the house. Mary has heart disease. She needs to monitor her heart condition regularly and adjust her medication accordingly. David loves innovation and likes to try new things - he does what he can, from new flexible applications to gadgets and clinical smart devices. Mary has recently showed the first stages of dementia, thus asked help from a professional specialist. Elina is a nurse who Mary contacted. She is a specialist as she can diagnose and treat dementia patients. David loves travelling, but with movement dysfunctions, travelling is almost impossible for him.

What is important to Mary

- Relationships with relatives, daughters and grandchildren P19b-Req-1
- Manage forgetfulness and memory difficulties P19b-Req-2
- Visiting monasteries P19b-Req-3
- Socialization P19b-Req-4
- Health care advice anytime P19b-Req-5

Mary's daily living

- Cooking with voice instructions from tablet P19b-Daily-1
- Online grocery shopping P19b-Daily-2
- Brain exercises to boost memory
- Going to church P19b-Daily-3
- Meet her friends personally P19b-Daily-4

David's and Mary's own resources, assets, support

- They are financially independent as their pensions are enough for daily leaving P19ab-Resources-1
- The General Healthcare System (GHS) of Cyprus is a comprehensive healthcare system that offers equal access to healthcare services for all citizens, with the option to choose their healthcare provider from both the private and the public sector with a limited economic contribution P19ab-Resources-2
- Nonprofit organizations, local community and faith-based organizations provide care services P19ab-Resources-3

Mary's health concerns and limitations

- Mild cognitive impairments P19b-Health-1
- Arthritis on knees causing pain, stiffness, and sometimes swelling P19b-Health-3
- Heart failure symptoms P19b-Health-2
- Early symptoms of dementia P19b-Health-4

Mary's health tests/ treatments/ medication

- Evaluation of heart rate regularly P19b-Tests-1
- Improving her memory with supplements P19b-Tests-2
- Adjustment of the medication every six months depending on the heart condition P19b-Tests-3
- Assessing cognitive impairment once a month P19b-Tests-4
- Confused about medication dose P19b-Tests-5

Mary's events, issues, personal concerns, technology

- She has a smart pill dispenser, where her doctor can suggest the right dose and its flexible application reminds her to take the right pills at the right time P19b-Personal-1
- Pressing the "emergency" button on the mobile app can contact someone who can calm her down and educate her on what to do P19b-Personal-2
- She feels frustrated when she forgets the names of relatives and friends P19b-Personal-3
- Worries about David when she is not home P19b-Personal-4
- Uses the smartwatch to monitor her vital signs P19b-Personal-5

Mary's hopes and dreams/ what brings joy/ quotes

- *"It would be nice to know that David is fine when I am not home"*

Mary's unmet needs

- Mary would like to remember all her daily tasks P19b-Unmet-1

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Figure 45: Persona 19b

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Smart and Health Ageing
through People Engaging in supportive Systems

MEET DAVID, MARY AND ELINA P19c

Motto: Taking care of each other - healthcare in family context

Name: Elina
Country: Cyprus
Age: 43
Area: Urban

Economical situation: satisfactory
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: David is a retired academic teacher. He lives with his wife Mary, who worked as a teacher. They live in the city centre of Nicosia in a private apartment. Their family ties are stable, and they have daily contact with their relatives, daughters and grandchildren. David was never good at exercising, nor did he have a healthy diet. As a smoker, David is severely affected by COPD (chronic obstructive pulmonary disease) and has difficulty moving around the house. Mary has heart disease. She needs to monitor her heart condition regularly and adjust her medication accordingly. David loves innovation and likes to try new things - he does what he can, from new flexible applications to gadgets and clinical smart devices. Mary has recently showed the first stages of dementia, thus asked help from a professional specialist. Elina is a nurse who Mary contacted. She is a specialist as she can diagnose and treat dementia patients. David loves travelling, but with movement dysfunctions, travelling is almost impossible for him.

What is important to Elina

- Be competent in diagnosing dementia P19c-Req-1
- Be proficient at treating patients with dementia P19c-Req-2
- Discover novel technological devices for her work P19c-Req-3
- Keep up to date regarding research applying technology to dementia P19c-Req-4
- Manage to reverse cognitive decline and dementia P19c-Req-5

Elina's daily living

- Visiting her patients to evaluate their daily situation P19c-Daily-1
- Assignment of memory exercises P19c-Daily-2
- Assessing new patients P19c-Daily-3
- Conduct research about novel techniques for dementia P19c-Daily-4
- Attend lectures and conferences regarding her work P19c-Daily-5

Elina's own resources, assets, support

- Elina is financially independent as she works 10-hour shifts with many patients P19c-Resources-1
- Paid from GHS also as she is registered as a healthcare provider P19c-Resources-2
- Getting support from a cognitive centre for new assessments with screening tests (MMSE and MoCA) P19c-Resources-3

Elina's core challenges

- Making work a priority P19c-Health-1
- Remembering to take care of herself P19c-Health-2
- Figuring out what to expect in the future P19c-Health-3
- Require a straightforward, quicker path to diagnosis P19c-Health-4

Elina's key needs

- An understanding of warning signs for dementia P19c-Tests-1
- A reputable source for info on symptoms P19c-Tests-2
- Someone knowledgeable to talk to about her concerns P19c-Tests-3
- A straightforward, quicker path to diagnosis P19c-Tests-4
- Training on how to safely do primary care and increasing medical tasks P19c-Tests-5

Elina's events, issues, personal concerns, technology

- Home modifications for the health and safety of her patients P19c-Personal-1
- Needs a way to educate David about Mary and her needs P19c-Personal-2
- Advice on taking care of herself in a stressful situation P19c-Personal-3
- A way to continually monitor her patients P19c-Personal-4
- Online access and knowledge about a support group P19c-Personal-5

Elina's hopes and dreams/ what brings joy/ quotes

- *"It would be great if I could monitor my patients remotely"*

Elina's unmet needs

- Elina would like to be able to monitor all potentially dangerous situations in her patients' houses P19c-Unmet-1

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Figure 46: Persona 19c

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5.7.2.5.2 User Requirements

To satisfy the personas's needs, the following requirements need to be covered by the SHAPES platform:

- **FR-HS-1** An eHealth call centre to support platform users e-needs to be available 24/7 for all users
- **FR-HS-2** The platform should include tutorials and help cards regarding its use and the use of the devices connected to it. Also, a glossary of terms should be available
- **FR-HS-3** Health data collection and management (and sharing) of health parameters
- **FR-HS-3b** Measuring daily exercises (time of exercise, intensity, objectives)
- **FR-HS-3g** Monitoring of vital signs (weight, blood pressure, blood glucose, bioimpedance, heart rate, blood oxygen level, etc.)
- **FR-HS-3f** Medication tracking
- **FR-HS-4** Processing of health data: risk assessments, action plans
- **FR-HS-7** Medication reminder/support. Reminder for clinical readings/appointments
- **FR-HS-9** Medical emergency alert system
- **FR-HS-12** Predictive Medicine (Predict risk of health events including decompensations in patients with heart failure, exacerbations of COPD, and hypo/hyperglycaemia in patients with diabetes. Using smart data analytics and predictive algorithms and Ambient Intelligence Health and Wellness Platform.)
- **FR-HS-13** Appliances Monitoring (on/off; duration of use)
- **FR-IS-1** Easy to use communication systems
- **FR-IS-3** Provide questionnaires to monitor health-related quality of life, medicines adherence, symptoms, etc.
- **FR-IS-6** Easy to navigate dashboard and summary for care receiver
- **FR-IS-4** Allocate tasks to specific healthcare professionals through the dashboard and mark as 'ongoing', 'complete', 'further follow-up required' or ability to leave notes e.g., handovers/updates
- **FR-IS-4a** Scheduling of specific tasks for different users (care receiver, care giver, etc.)
- **FR-IS-4b** Provide motivation/encouragement sentences to the care receiver: These set of sentences are to be provided on a regular basis or based on the values of other data, completion of tasks, etc.
- **FR-IS-7** Information about support services: peers and networks
- **FR-IS-8** Information about support services: mental and physical help
- **FR-IS-10** Create logs for personal data (e.g., who has seen/modified personal data and when)
- **FR-IS-12** Provision of training material for care providers

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- **FR-HM-1** Mental exercises for care receivers and care providers
- **FR-HM-2** Physical exercises
- **FR-LS-1** Assisted mobility at home
- **FR-LS-2** Assisted mobility and devices to monitor movement outside/ travel outside
- **FR-LS-3** Sensors to monitor falls
- **FR-LS-4** Sensor to monitor dangerous situation (fire, gas, electricity)
- **FR-LS-6** Food shopping and similar support
- **FR-LS-5** Home Monitoring (temperature; humidity; air quality)
- **FR-HM-1a** A mood assessment function is available for self-completion with ratings and free text assessment options. A mood graph/mood history is displayed to represent mood progress over time
- **FR-HM-1c** Various different relaxation exercises are available with options based on muscular relaxation and on imagery-based relaxation
- **FR-LS-7** Accessibility information for public spaces
- **Ts-IO-2** Enable and support the exchange of information between different tools
- **Ts-IO-5** Link with existing patient profiles
- **Ts-IO-5a** Interconnecting patient data across communities

5.7.2.5.3 Scenario

It is based on:

- UC-PT3-gen entitled ‘Supporting multi-morbid older patients’ (Replicating)
- UC-PT5-004 entitled ‘Virtual Patient Scenarios (VPS)- Mobile Virtual Patients (MVP)’ (Replicating)
- UC-PT7-001 entitled ‘Monitor older patient with chronic disease when travelling abroad’ (Replicating)

David and Mary need some specific help to get through the day, and the care kits partially meet their different needs. Because of COPD, David’s true abilities are being tested. Do all the preparation and evaluations at home to get instructions on the TV screen? After each exercise, the information is sent to the clinic. At that moment, he talks to a physiotherapist and a specialist through the television. David is beginning to get to know the clinical team exceptionally well, regardless of the fact he has been at a distance for quite some time. To cover the full cost of COPD equipment, David must complete a training program. Nevertheless, he got another gadget that accurately measures and summarizes pulse and lung information. He finds it exciting to watch his progress. Maria examines her heart, pulse and weight every day. However, he only realizes and remembers it when he is called by the doctor who finds an abnormality in the EKG or blood pressure. However, Mary is a little confused about all the medication she needs to take. The dose is continuously changing. It relies on the smart pill dispenser, where its

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PCP can suggest the right quantity and its flexible application reminds it to take the right pills at the right time. David contacts the municipality's technical support in case of system errors or cannot understand the software updates. David realizes that there are many more sophisticated gadgets and sensors that could be valuable to him. Unfortunately, they remain costly for them, and they have to adhere to the standard care package. Mary faces the first stage of dementia symptoms as she forgets essential things including the confusion she feels about her medication. Therefore, they called Elina, a professional caregiver for dementia patients who suffer from cognitive impairments. Elina initially evaluates the situation as she does with all her patients using an innovative solution through a mental centre. After Mary's assessment with screening tests, Elina proceeded by informing David about what to expect and how to manage each case. David loves travelling and believes that one day he will be able to travel again.

5.7.2.6 Heart failure - FNOL

5.7.2.6.1 Meet Jan and Alena[P20]

Jan (64) and his wife Alena (63) live 55 km away from the regional city of Olomouc. The couple live in a 5-storey block of flats on the 4th floor. Their son and daughter live relatively far away in other cities in the Czech Republic (Brno and Pardubice) and visit their parents twice or three times a year only. Jan and Alena were smokers in the past. They retired quite early in the 2010s when they lost their jobs and couldn´t find new ones as many of companies in the region collapsed. So, they are rather on a budget as they did not manage to save too much extra money during the productive period of their lives.

Jan had a heart attack when he was 50 and 7 years ago he was diagnosed with chronic heart failure. The disease has been progressing over time. His status is classified as NYHA III with prognoses towards most advanced stage NYHA IV. Jan has been twice hospitalized in the regional hospital specializing in cardiac diseases and during his last visit to the outpatient department the cardiologist told him he would probably be indicated for a heart transplant, which may probably be preceded by a longer stay in the hospital (the regional or even more distant one specialized in transplants). He sometimes does not feel safe and "losing his head" when frequently thinks of his health status and may need psychologic support.

Alena was relatively healthy for a long period of time, but she is obese, about 140 kg since her late 40´s and has slight hypertension. There are also heart diseases in her family history. Her local general practitioner told her the last time that her levels of LDL cholesterol elevated above normal and she will need specialized care by a cardiologist, whose office is not so close to Alena´s home. Alena has difficulties walking for long outside. Alena can still act well as an informal carer for Jan and the couple have been able to help each other as needed. Jan normally does most of the necessary shopping as

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the shops are nearby. Both are afraid of infection by a virus as they are obviously vulnerable people.

The block of flats has a lift. However, even this lift has been installed in the building so that people must go at least 8 steps twice, one on the ground floor and then on the section to the floor they go. Both Jan and Alena are accustomed to overcoming these obstacles with steps as they have been living in the house for about 35 years, so going around the house has never been extra complex for them. They have a garden plot in front of the house, which they maintain, and it brings them relaxation, besides fresh vegetables in the season. Both have local friends with whom they have developed several community activities.

However, a trip to the city or to the hospital is becoming a real problem if a car cannot be used. Until now, it was overcome by the help of neighbours as Jan and Alena have friends in the building and they were even able to help them with transport from the flat to the nearest bus stop or Bruntál centre: the bus stop is located about 800m away from the block of flats, down the hill, which especially makes the return trip for them extra challenging. However, the couple cannot rely on such help of these neighbours for long, not only because the trips may be more frequent but also the neighbours are ageing. Jan still has a driver´s license but his old car was not found technically sound during its last inspection and so he sold it.

Healthcare homecare has not been assigned to Jan yet by his local general practitioner: Social care services are not sufficiently developed in Bruntál and if they are available they are so not well affordable for Alena to rely on them for a long time if Jan should stay in hospital for weeks and months with his disease. Various ICT technologies may help to ease the life of this couple. Either in their old location or in a new one that would be at least partially more convenient with respect to their health conditions and be equipped with technologies. The technologies may enable a longer stay at home without Jan being forced into hospitalization weeks before the transplant. To Alena, some ICT based technologies may help to establish a closer contact with her cardiologist so that her visit to the office could be reduced and get more intensive training how to lose some weight. The couple is not able to afford general commercial “smart home” solutions that would not anyway be interconnected with their healthcare providers and therefore would not significantly help in their disease development. However, they welcome user-friendly ICT technologies that may help in caring for their health and safety if help is needed and maintain more frequent audio-visual contact with their children.

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Smart and **H**ealth **A**geing
through **P**eople **E**ngaging in supportive **S**ystems

MEET JAN AND ALENA P20

Motto: Receiving health specialists´ support on distance while staying active in local environment

Name: Jan and Alena
Country: Czech Republic
Age: Jan - 64, Alena - 63
Area: Small town

Economical situation: On budget
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Jan is 64 years old and his 63-year-old wife Alena live 55 km from the regional city of Olomouc. Jan had heart attack when he was 50 and 7 years ago he was diagnosed with chronic heart failure. The disease has been progressing over time. Jan has been twice hospitalized in the regional hospital specializing in cardiac diseases and during his last visit of the outpatient department the cardiologist told him he would probably be indicated for a transplant, which may probably be preceded by a longer stay in the hospital (the regional or even more distant one, specialized in transplants). He sometimes does not feel safe and "is losing his head" when frequently thinking about his health status and may need psychologic support. Alena has difficulties to walk for long outside. Alena can still act well as an informal carer of Jan and the couple have been able to help each other as needed. Jan normally does most of the necessary shopping as the shops are nearby. Both are afraid of infection with a virus as they are obviously vulnerable people. However, a trip to the city or to the hospital is becoming a real problem is a car cannot be used. They can afford to go for groceries thanks to their friend. The couple is not able to afford general commercial "smart home" solutions that would not anyway be interconnected with their healthcare providers and therefore would not significantly help in their diseases development. However, they welcome user-friendly ICT technologies that may help in caring for their health and safety if help is needed and maintain more frequent audio-visual contact with their children.

What is important to Jan and Alena

- Staying in a stabilized, not significantly worsening health condition – be able to continue in everyday activities, avoid unnecessary hospitalizations and long trip to healthcare specialists in the distant city P20-Req-1
- Maintain contacts with local community P20-Req-2
- Continue in their favourite hobbies P20-Req-3
- Regular contact with their grandchildren P20-Req-4

Daily living

- Able to sustain all daily activities in the house, garden by themselves without regular help of other persons P20-Daily-1
- Often meeting friends personally P20-Daily-2
- Using ICT to communicate with grandchildren and wider family P20-Daily-3

Own resources, assets, support

- Economically living from month to month, still independently, welcoming every saving of expenses but not opting for receiving gifts by either from the family or the community P20-Resources-1
- Try not to extend physical help provided by kind neighbours P20-Resources-2
- Considering moving to more convenient accommodation in the city P20-Resources-3
- Mapping local social care and healthcare home-care services that may be useful in the future P20-Resources-4

Health concerns and limitations

- Severe concerns by Jan about his health status and as a heart transplant may be risky in his age; frequent re-hospitalizations cause discomfort and complications for both in the couple P20-Health-1
- Alena has also some concerns in the view of her family history of cardiacs. Her obesity is also a risk of developing heart failure P20-Health-2
- The couple is quite compliant and can be proactive in caring for their own health, and they trust doctors P20-Health-3
- Both are afraid of virus infections P20-Health-4

Health tests/ treatments/ medication

- Distant support by specialist (cardiologists) focused on the chronic disease and health check by GP P20-Tests-1
- Instructions for daily exercise and movement, with checks of achievements P20-Tests-2
- Support by psychologist P20-Tests-3
- Medication support (drugs ordering, prescription, obtaining) P20-Tests-4

Events, issues, personal concerns, technology

- Participation in local community activities P20-Personal-1
- Alena being able to provide informal care to Jan; Jan being able to support Alena in household where he can P20-Personal-2
- Be in closer contact with grandchildren P20-Personal-3
- Not to obtain further disease P20-Personal-4
- Making progress in using ICT technologies P20-Personal-5

Unmet needs

- Jan thinks of better support in his health status including better information about his future and staying safe at home P20-Needs-1
- Alena, realizing health status development, considers means that she can use to keep her health status not worsening and be able to support Jan P20-Needs-2
- The couple is thinking of a more conveniently situated accommodation with less stairs P20-Needs-3

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Figure 47: Persona 20

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5.7.2.6.2 Requirements

Based on the aforementioned challenges the following requirements on the SHAPES platform seems to be relevant for them:

- **FR-HS-3** Health data collection and management (and sharing) of health parameters
- **FR-HS-3a** Measuring daily steps (to measure daily activity)
- **FR-HS-3g** Monitoring of vital signs (weight, blood pressure, blood glucose, bioimpedance, heart rate, blood oxygen level, etc.)
- **FR-HS-3h** Capability to enter manual data
- **FR-HS-4** Processing of health data: risk assessments, action plans
- **FR-HS-5** Recording the perceived state of well-being/self-assessment tool
- **FR-HS-7** Medication reminder/support, Reminder for clinical readings/appointments
- **FR-HS-10** Track and record clinical device characteristics regarding maintenance/calibration, make, model number
- **FR-HS-12** Predictive Medicine (Predict risk of health events including decompensations in patients with heart failure, exacerbations of COPD, and hypo/hyperglycaemia in patients with diabetes. Using smart data analytics and predictive algorithms and Ambient Intelligence Health and Wellness Platform.)
- **FR-IS-1** Easy to use communication systems
- **FR-IS-2** Video conferencing to complete medicines reviews
- **FR-IS-3** Ability to provide questionnaires to monitor health-related quality of life, medicines adherence, symptoms, etc.
- **FR-IS-4** Easy to navigate dashboard and summary for healthcare professional review
- **FR-IS-5** Ability to allocate tasks to specific healthcare professionals through the dashboard and mark as ‘ongoing’, ‘complete’, ‘further follow-up required’ or ability to leave notes e.g. handovers/updates
- **FR-IS-5a** Scheduling of specific tasks for different users (care receiver, care giver, etc.)
- **FR-IS-6** Easy to navigate app/dashboard for service user/carer to review

5.7.2.6.3 Use case

As an appropriate solution for these personas seems to be an application of the following technical solution:

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Table 20: Alena and Jan technical solution

Code	UC-PT3-001c	Version	2.2	Date	2021/02/08
Applicable SHAPES Persona	Alena & Jan				
Applicable SHAPES use case	UC-PT3-001c Advanced telemonitoring of patients with heart failure in home environment				
People Roles and/or actors of typical users involved in delivering and receiving the telemedicine intervention	• 25 patients - 60+, live in their own homes located in the Region. No cognitive and relevant physical impairment at recruitment into the study. Advanced (based on NYHA classification) chronic heart failure (CHF) patients (Jan) and newly diagnosed CHF ones (Alena) with possible comorbidities like diabetes, hypertension, chronic obstructive pulmonary disease and has multiple daily medications. Very limited experience in the use of ICT technologies, most have never used a smartphone/tablet before. • Healthcare professionals (HCPs) - nurse and doctor, who would plan and assess the medical treatment plan and specific tasks as parts of the medical treatment plans. In the cases of results being below or above (based on the observed parameter) desired thresholds, they will alert the patient and adjust the medical treatment plan. HCPs have average level computer literacy allowing them to conduct daily routine without major problems. • Biomedical engineer or IT technician – to provide technical support for both patients and healthcare professionals in the cases of connectivity issues, medical device malfunctions, SW issues etc. • Informal carers – typically family members who live either with the patient or at a different location and want to support the patient in everyday life.				
Activities Activities to be performed by the actors in order to	**Patients** • Measure systolic and diastolic blood pressure once a day • Measure weight once a day • Measure heart rate once a day				

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successfully provide and receive the telemedicine intervention *procedures for the professional and the patient; Parameters that determine the measures used in the intervention*	• Measure oxygen saturation once a day • Measure daily activity with use of a pedometer • Measure ECG once a day • Complete daily/weekly/monthly/one-off questionnaires (HF related questionnaires, Quality of Life related questionnaire, user acceptance related questionnaire) • Send the data from the aforementioned measurements to the cloud/platform • Are empowered by an option to communicate synchronously with their healthcare professionals, typically in scheduled meetings as needed by the care protocol. • Are supported by interactive features enabling to remind pills intake in right time, order drug recipe, review information about the treatment with personalized information, basis information about the disease(s) and healthcare provider, as well as review the results of their measurement of biomedical parameters. **Healthcare professionals** • Healthcare professional to review clinical data on a regular basis and make changes to patient care as required. This could be a consult provided via telemedicine application. • Use predictive model to identify if patient's health condition is deteriorating and interventions taken to avoid this e.g., decompensations in heart failure. • Schedule on-line meetings with the patients to check and review the development of the status of the patients and his disease(s). Inform the patients about the plan of the care for the next period. • May amend the medication as needed based on complex available information, as well as act in time e.g., to call patient to come (to the hospital). **Technical support** • Provides introductory tutorial for both patients and healthcare professionals to achieve their correct use of hardware and software solutions which are applied in the use case. • Provides support to resolve technical issues related to both connectivity and functionality. • Provides regular maintenance of the hardware and software tools where applicable.
Context Social-medical relevance of the	• Tablet and smart medical devices (telemedicine) to be used in patient's own home to monitor several patients' parameters, that are relevant to monitor the condition of patients

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telemedicine intervention; privacy issues; risks for the patient; locations	with heart failure. Measured data are being assessed by healthcare professionals and analysed by digital analytical tool. • Particular goals are as follows: ○ Optimize treatment plans ○ Improve patients' outcomes and reduce probability of possible readmissions ○ Reduce frequency of regular check-ups in hospital. ○ Increase quality and accuracy of the care by using digital telemedicine tools (incl. video consultations) ○ Empower the patients so that they will be able to understand their status, the disease, adhere to medication and be able to better cooperate with healthcare professionals. • Maintaining high standards of data privacy handling • GDPR and ethics in line with WP8 • Data and servers must be located within the EU • Translation into the Czech language will be provided by the local team • Location: University hospital Olomouc, Olomouc region, Czech Republic
Digital solution proposed	• **In-home decompensation prediction tool for heart failure patients**
Technical partners & tasks involved	• **VICOM, FNOL, TREE**
Components	• **Heart Failure Decompensation Predictive Model** – Using the data captured by the various health sensors and the questionnaire answers used for the calculation of decompensation probability for a given patient. (VICOM) • **Telemedicine system/Medimonitor** – Telemedicine system of FNOL including commodity mobile communication devices and high quality (medically certified) sensors (SpO2, body weight monitor, blood pressure monitor, oximeter) for the patients. Mobile devices equipped with enhanced cybersecurity protection. • **Vitals control analytic** – personalized control ranges will be provided for blood pressure, heart rate and oxygen saturation by using Statistical Control Process techniques. These control ranges will help the HCP to monitor changes in the variables as well as the effects of medication changes. (TREE)
Equipment requirements	• 25 tablets (e.g., Lenovo TAB M10 Plus) • 25 body weight monitors with Bluetooth connectivity (e.g., Omron VIVA) • 25 blood pressure monitors with Bluetooth connectivity (e.g., Omron Evolv)

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- 25 oximeters with Bluetooth connectivity (e.g., Beurer PO60)
- 25 ECG devices with Bluetooth connectivity (e.g., Beurer ME90)
- 25 open-source smart watches with possibility to be used as a pedometer (e.g., Mi Smart Band4)
- Medical devices with CE certification
- Medical devices communication protocols are bases on open standards, preferably Continua Compliant
- Application software is an integral part of Medimonitor system

5.7.2.6.4 Scenario

This technical solution will be applied as per the following scenario:

Jan is 62 years old and lives in the city of Bruntál, 55 km away from the regional city of Olomouc, and has a wife Alena, 61 years old, and a son and a daughter. The couple lives in a 5-storey block of flats on the 4th floor without an elevator. Their son and daughter live relatively far away and visit their parents twice or three times a year only. Jan is a regular smoker. Alena was a smoker in the past. They retired quite early in the 2000s when they lost their jobs and couldn´t find new ones as many of the companies in the region collapsed after the 1990s. So they are rather on a budget as they did not manage to save extra money during their productive period of life. Jan had a heart attack when he was 50, and 7 years ago he was diagnosed with chronic heart failure. The disease has been progressing over time. His current status is classified as NYHA III with prognoses towards most advanced stage NYHA IV. Jan has been twice hospitalized in the regional hospital specializing in cardiac diseases and during his last visit of the outpatient department the cardiologist told him he would probably be indicated for a transplant.

Various ICT technologies may help to ease the life of this couple. The technologies may enable longer stay at home without Jan being forced to hospitalization weeks before the transplant. As this couple is on a budget the ICT technologies are usually out of their reach. Consequently, the ICT literacy of both of them is rather low. Therefore, help of a healthcare provider in both providing the technology together with the training how to use it would be beneficial.

Consequently, Jan is being chosen to be monitored within the project related to the use of ICT within healthcare. Jan agrees as he sees a chance to make his health better, avoid often readmissions to hospital and spend his precious time with his wife. Before participating in this project, an electrocardiography and echocardiography will be conducted together with his blood being sampled for urea, creatinine, tissue factors, haemoglobin, etc.

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After the admission tests, Jan will go to the nurse dedicated to heart failure patients. The nurse will give the patient a short introduction into the handling of the provided medical devices, especially regarding the frequency of the measurements being conducted within the patient's in-home setting. Jan will also meet the biomedical engineer or an IT technician who will briefly instruct him about the use of the medimonitor, which communicates with the provided medical devices. First use of the whole system is conducted the very same day so the healthcare professionals together with the technical support team are absolutely sure that the system is prepared for daily routine operation. Before Jan leaves the hospital, the healthcare professionals will also make sure that he understands the ethical and privacy aspects. Jan's understanding of these aspects will be recorded with the use of an informed consent.

Jan's physician will prepare a personalized treatment consisting of specific tasks that are assigned on a daily basis through the medimonitor.

The healthcare professionals will also provide medical devices to monitor the patient's current state of health. Jan's health will be monitored by body weight scales, which can identify if the body fluids are being retained.

Jan also has an ECG monitor, blood pressure monitor, oximeter and smartwatches to assess arrhythmia, changes in blood pressure, amount of oxygen in the blood, heart rate variability and monitor daily activities (e.g., walking).

Jan's daily routine starts with body weight measurement, ECG, blood pressure and SpO2. Jan also puts the smartwatches on his wrist so the daily number of steps can be counted and his physical activity assessed as a part of his treatment plan. The measured values are being transmitted through Bluetooth into the tablet which Jan also has available. To simplify the user's workflow Jan is using the medimonitor application that collects the data from all of the devices that Jan is using.

Together with the measurements from the medical devices Jan is also filling in special questionnaires that are sent to him irregularly to also assess his subjective feelings regarding his current medical state and wellbeing.

The recorded measurements are being checked on regular basis by a nurse. In case of any unexpected changes she will contact Jan's physician. If the physician decides that he needs to contact Jan directly he can use a feature for video consultations that is already implemented in the medimonitor.

In parallel the measured data is also being analysed as a pilot test of VICOM's HF predictive tool. Based on the data collected by the devices provided to Jan, a risk factor is calculated. This number gives the physician the information about the trend leading towards the need of the patient's readmission to the hospital.

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6 Ethical requirements

6.1 Ethical requirements of the SHAPES Personas

The ethical requirements for SHAPES Integrated Care Platform and Digital solutions are developed in WP8 (see Deliverable 8.4). However, these requirements do not cover specific ethical needs of personas. By specific ethical needs we mean persona-specific values, motivational and social needs which are strongly linked to ethics and are dominant for a persona in question. Personas presented in this deliverable have different ethical needs, which need to be translated into the requirements for the solutions.

While most of the studies around the ethics of elderly people concentrate on ethical care, the ethical needs and challenges as encountered by elderly people themselves are not well described in relation to each of the personas. We identified the need for developing an approach that would allow SHAPES developers to take a truly user-centred approach in the development of the SHAPES Integrated Care Platform and Digital Solutions, connecting ethical requirements with the specific needs of individuals, represented by SHAPES personas. This is especially important when developing customized solutions such as SHAPES Integrated Care Platform, which is targeted to users with diverse and often specific needs in regard to ethics.

The ethical requirements identified by the SHAPES project are related to technology, user support processes, business and governance, as well as to general development, and represent a set of requirements for the developers, which are common to all users (e.g., privacy and data protection). This approach often overlooks user/persona specific needs, which can be translated into persona-specific ethical aspects. Ethical aspects include both perceptions of the users regarding certain requirements, as well as specific needs relevant to a certain group of users. For example, while Privacy and Data Protection is a common ethical requirement fundamental for all personas and use-cases, the need for privacy varies significantly depending on the persona's digital proficiency and degree of digital technologies usage. In a similar manner, the needs related to the feeling of safety and security, inclusiveness and affordability are linked to the personas' profiles and thus there is a big variation between e.g., an informal/formal caregiver (Personas 9 and 14) in regard to their security aspects or the feeling of isolation.

There is no well-defined methodology identifying ethical needs of personas and translating them into requirements. As no taxonomy exists to classify and analyse needs; instead, needs are often classified and analysed from a common sense point of view (Bergvall-Kåreborn & Ståhlbröst, 2010). For the purpose of Task 2.5 we developed the following approach:

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1) All ethical requirements for the SHAPES Platform (listed in Deliverable 8.14) have been analysed specifically including the ones relevant from the end-user process point of view. These requirements are presented in Appendix VI.
2) Analysis of the existing personas was conducted in a workshop.
3) Using literature review, and content analysis of D8.14 and workshop results regarding personas developed earlier, end-user ethical needs were clustered into 6 categories

- E_NEED_1: Digital mistrust
- E_NEED_2: The feeling of Safety and Security
- E_NEED_3: Accessibility limitations
- E_NEED_4: Demand for Inclusion and Non-Discrimination
- E_NEED_5: Supported decision-making
- E_NEED_6: Affordability of care

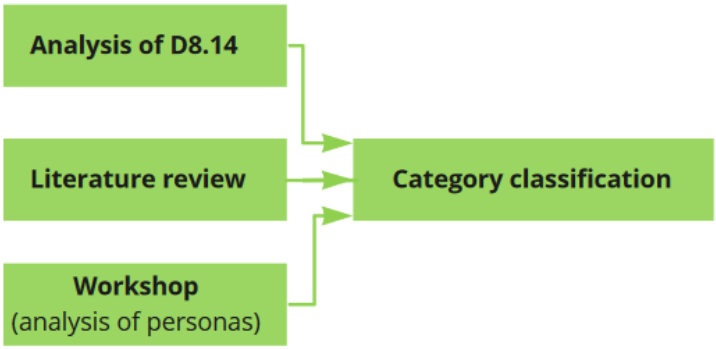

Figure 48: Approach to developing the ethical needs

These persona-specific ethical needs and their connection to ethical requirements in D8.14 are presented below.

4) Finally, the degree of the importance of each ethical need has been included in the persona description.

Below we include two examples of personas' ethical needs definition.

This approach allows SHAPES developers to understand better what ethical aspects should be taken into consideration when designing and evaluating solutions based on certain personas. It also illustrates that the degree of importance of certain ethical issues differs among different customer groups. While this chapter covers a general approach of identifying ethical needs of specific personas, further work needs to be done to match pilot specific use cases with personas and their ethical needs.

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Table 21: Ethical (personal specific) needs for SHAPES personas

Code	Persona-specific ethical need category	Connection to D8.14 ethical requirements
E_NEED_1	1. Digital mistrust	GE2, GE3, GE6, GE37, GE49
E_NEED_2	2. The feeling of Safety and Security	GE2, GE3, GE6
E_NEED_3	3. Accessibility limitations	GE3, GE7, GE47, GE48, GE49, GE50, PE1, ME3
E_NEED_4	4. Demand for Inclusion and Non-Discrimination	E2, GE7, GE47, GE48, GE49, GE50, ET2, PE1, PE2, PE3, ME3
E_NEED_5	5. Supported decision-making.	GE1, GE3, GE4, GE5, GE6, GE7, GE37, GE49, ET13, PE1, PE2, PE3, ME3
E_NEED_6	6. Affordability of care	GE49, ME3

E_NEED_1. Digital mistrust:

This need category addresses persona needs related to privacy and digital literacy, as well as their willingness to share personal and health information when using digital technologies and services. For example, Kim and Choi (2019) concluded that older adults lack confidence and trust in sharing personal information. They are suspicious as to how the collected data is processed and how privacy is maintained (Kim & Choi, 2019). The need is related to the level of digital literacy; however, no direct correlation can be found between the digital mistrust and the usage of technologies. The need is relevant both to personas not using technologies such as smart phones or tablets, as well as to personas that use digital devices daily, yet feel suspicious about trying new services and sharing even more data with service providers.

Supporting digital trust is one of the key ethical needs that must be overcome by e.g., designing elderly user-friendly interfaces and consenting processes, as well as making it clear for potential users what type of data is collected and shared.

E_NEED_2. The feeling of Safety and Security

This need category is defined as “feeling”, which reflects subjective perception of a user, not necessarily reflecting the level of security of a Digital Solution. Safety and Security in this need category include both physical and digital security and safety. For example, home monitoring devices can create a high level of digital mistrust (E_NEED_1), but at the same time satisfy the feeling of security (E_NEED_2). This needs category is especially relevant to personas who rely on assistive technologies, including medicine reminders and alerts. In addition, the needs are strong among users with disabilities.

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E_NEED_3. Accessibility limitations

This need category covers limitations caused by physical disabilities, including visual impairments or movement-related limitations. In addition, the category covers accessibility issues related to cognitive, physical, financial and social resources. A simple example of such need can be related to an elderly person not being able to type on a small screen of a smart phone. Digital services have to be organized and delivered in an accessible manner, and assistance has to be provided to the users.

E_NEED_4. Demand for inclusion and non-discrimination

This need category primarily relates to elderly people living alone, as well as caregivers who often feel trapped at home with their caretaker, without much social contact outside. The feeling of exclusion from society develops into a need to be included in a digital society, or in the need of using digital services enabling human interactions. In addition to exclusion and the feeling of loneliness associated with it, the need category also addresses issues related to age, gender and cultural aspects.

SHAPES aims to prevent non-discrimination, e.g., by the language used about the ageing population/older persons and persons with disabilities, and by improving their capabilities to participate in everyday life.

E_NEED_5. Supported decision-making

Supported decision-making comprises a variety of support options that encompass both informal and formal support arrangements of varying types and intensity. The need for support can be related to support persons assisting them in certain types of decisions or actions, such as support with financial arrangements or house chores; or it can be related to assistive technologies/digital support making decisions about the use of digital services easy to make. When identifying the most appropriate support, careful attention must be paid to the situation of the individual (Quinn 2009, 105–106).”

E_NEED_6. Affordability of care

While this need has not been dominant in the analysis of SHAPES personas, the affordability of care has a direct impact on the usage or non-usage of the digital services. SHAPES personas include descriptions of their financial situation, however it does not always reflect the need for affordability, as it is also affected by whether or not healthcare services are provided by public or private providers; paid by the person themselves or e.g., by insurance companies. If older adults feel they cannot afford mHealth devices and services, they will not use it, regardless of the acknowledged personal needs and benefits.

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Figure 49: Ethical needs

Below two figures (Figure 50 and 51) show the application of the ethical needs in personas. These personas stand as an example for the future use and check for the ethical needs on SHAPES platform. Moreover, these needs apply to the whole SHAPES ecosystem. Therefore, they are to be monitored constantly.

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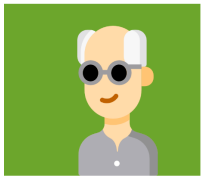
Smart and Health Ageing
through People Engaging in supportive Systems

MEET FREDRIK P8



Motto: Support guide-interpreter communication help to retain independence

Name: Fredrik
Country: Norway
Age: 75
Area: Big city

Economical situation: Semi-affluent
Digital literacy: Low — High
Health literacy: Low — High
Affinity to technology: Low — High

General description: Having vision and hearing impairments since birth, Fredrik went to schools for the deaf as a child, before becoming a certified tablet fitter as a young adult. He also enjoyed quite ordinary activities like dancing, sports, outdoor life and advocacy work, also had a strong interest in chess. Living alone since his divorce in 1980, he has maintained a close relationship with his three kids, grandkids and great-grandkids. After becoming deafblind in the 1980s he acquired a degree in Law at the University of Oslo and started working as a Political Consultant and active self-advocate representing persons with deafblindness.
Fredrik once experienced an acute illness at home and his kids helped him to the hospital. The preliminary examination ended with him being dismissed in spite of being in agony, as the doctor assumed that Fredrik had understood the questions and responded to them, which was not the case. Understanding of deafblindness would have revealed that he had just responded to sounds, not words. Another doctor noticed the disagreement and intervened and finally a more thorough examination was conducted, revealing a potential severe infection, leading to Fredrik being committed to hospital for a week. No interpreter-guides were made available during the initial and critical admission phase.

E_NEED_3 & E_NEED_4

E_NEED_4

What is important to Fredrik

- To remain living independently at his own house as long as possible P8-Req-1
- To have access to guide-interpreter services P8-Req-2
- Relationship with family and friends P8-Req-3

Daily living

- Home-help is essential for Fredrik to be able to remain at home. It comes twice per week and must be trained in communicating with deafblind people, otherwise there would be a need for a guide-interpreter P8-Daily-1
- Regular physical actiivity, exercising at home P8-Daily-2

Own resources, assets, support

- His friends are mostly persons with deafblindness themselves, and they are to a certain degree able to communicate directly. P8-Resources-1
- His children and grandchildren provide significant support P8-Resources-2

Health concerns and limitations

- Fredrik has had difficulties learning Braille and therefore has not been able to use modern assistive products like Braille readers/writers to communicate. P8-Health-1

E_NEED_3

Health tests/ treatments/ medication

- He got CI implants 15 years ago, that enabled him to communicate hearing familiar voices in accommodated environments. Without these implants he would now be totally deafblind. P8-Tests-1
- Slight hypertension, medicated, controls every 6 months P8-Tests-2

E_NEED_2

Events, issues, personal concerns, technology

- Due to the fast developing virtual world Fredrik has started feeling isolated and more and more unable to interact with society at large without assistance by interpreter-guide services. P8-Personal-1

E_NEED_4

E_NEED_3

Hopes and dreams/ what brings joy/ quotes

- *"It would be so nice if there was some technical solution that would at least to some extent replace the human guide/interpreters. Though it must be adaptable to individual needs."*

Unmet needs

- Fredrik always needs to plan very carefully most of his activities, as he relies on the availability of guide-interpreter services. P8-Unmet-1
- Although the law in Norway secures the right to communication assistance, not all institutions know how to comply with that. P8-Unmet-2

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Ethical needs

E_NEED_2. The feeling of Safety and Security	Low — High
E_NEED_3. Accessibility limitations	Low — High
E_NEED_4. Demand for Inclusion and Non-Discrimination	Low — High

Figure 50: Persona 8 with ethical requirements

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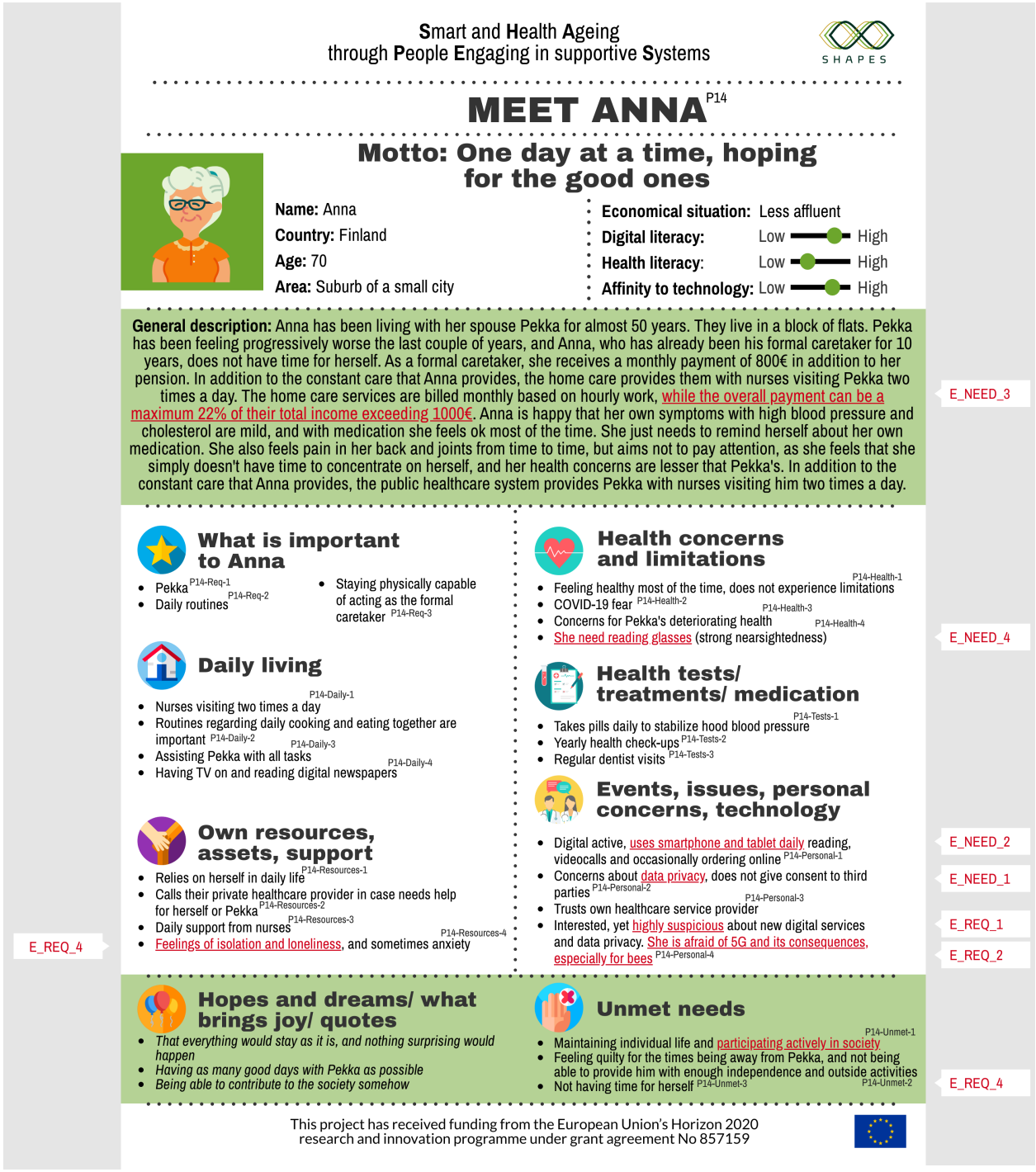

Ethical needs

E_NEED_1. Digital mistrust	Low — High
E_NEED_2. The feeling of Safety and Security	Low — High
E_NEED_3. Accessibility limitations	Low — High
E_NEED_4. Demand for Inclusion and Non-Discrimination	Low — High
E_NEED_6. Affordability of care	Low — High

Figure 51: Persona with ethical requirements

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6.2 Ethical requirements of the report

We declare that all works conducted in Task 2.5 and all works during the preparation of this Deliverable/Report were in accordance with Article 8 of the European Convention on Human Rights [European Court of Human Rights. Case of Roche 32555/96 (19.10.2005)] that serves as an interpretative aid to the member states when it comes to determining the ambit and extent of fundamental rights and fundamental legal principles at the level of their own constitutional law.

Table 22: Ethical issues

Ethical issue (corresponding number of D8.4 subsection in parenthesis)	How we have taken this into account in this deliverable (if relevant)
Fundamental Rights (3.1)	Rights of the participants of the DIPEx module was assured by the ethical committee of Palacký University. Participants were also able to withdraw from the research or erase certain parts of their interview. Data were anonymized and protected. Diversity of the participants was ensured through maximum variation sampling. Further information provided about each persona was in line of respect, integrity and dignity of older adults. With respect to the equality of men and women the same number of women and men are represented as personas.
Biomedical Ethics and Ethics of Care (3.2)	**N.A.**
CRPD and supported decision-making (3.3)	The creation of personas and use cases developed together with the deaf and blind community in order to ensure its inclusivity. This collaboration led to the creation of a specific persona (8).
Capabilities approach (3.4)	The use cases in this deliverable are mostly related to a person's capabilities for bodily health and life (use cases 2, 4, 5, 6, 7,9, 10, 11, 12). However, a summarizer of information from the Internet (13) and reading assisting technology (1) are use cases which can support e.g., capabilities of sense, imagination and thought, practical reason, play, control over own

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	environment. Use cases related to monitoring (8,9) are critical since they may violate the integrity of a person if not designed carefully
Sustainable Development and CSR (4.1)	**n.a.**
Customer logic approach (4.2)	**n.a.**
Artificial intelligence (4.3)	**n.a.**
Digital transformation (4.4)	**n.a.**
Privacy and data protection (5)	Privacy, data protection and cyber security are critical in all the use cases, especially In-Home Video-Monitoring (8) and Location Tracking (9). Data gathered from these use cases need to undergo high protection.
Cyber security and resilience (6)	Security of the data protection is supervised by LAUREA.
Digital inclusion (7.1)	The following use cases support digital inclusion: -Summarizer of Information from Internet -Assistive Technology for Reading
The moral division of labour (7.2)	Especially the following use cases are related to the new roles of end-users: -Self-Management of Chronic Conditions -In-Home Self-Management Heart-Monitoring
Care givers and welfare technology (7.3)	Caregivers' needs and problems are reflected in Persona 9. Focus is also on the digital technologies usage.
Movement of caregivers across Europe (7.4)	Caregivers' needs and problems are reflected in Persona 9. Focus is also on the digital technologies usage.

All works conducted in Task 2.5 and all works during the preparation of this Deliverable/Report also follows the RESPECT Code of Practice (http://www.respectproject.org/code/), i.e. a code that synthesizes the contents of a large number of existing professional and ethical codes of practice, together with current legal requirements in the EU.

We declare that all data used during the preparation of the personas were non-personal and that the handling of these non-personal data was fully in accordance with the Regulation on the free flow of non-personal data (FFD) [Regulation (EU) 2018/1807].

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Furthermore, there were no international data flows during the works on Task 2.5 and during the preparation of this Deliverable/Report, however, despite that we fully respected the European rules and values as formulated in The European Strategy for Data [COM(2020) 66 final].

Despite no specific digital services being provided to end users during the course of Task 2.5, all the general ideas about the proposed future digital solutions (general use cases) were prepared in respect to The Digital Content Directive [Directive (EU) 2019/770] that contributed to empowering individuals by introducing contractual rights when digital services are supplied to consumers who provide access to their data.

Furthermore, all the proposed general ideas about the future digital solutions were prepared also fully in accordance with particular security acts, especially in accordance with the Cybersecurity Act (CSA) [Regulation (EU) 2019/881].

Despite no personal data being gathered within the course of Task 2.5, all the sources used for the preparation of basic personas fulfilled the Data Protection Directive and General Data Protection Regulation (GDPR).

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7 Future Challenges and Risks

As mentioned above, the main goals of Task 2.5 were to develop SHAPES personas and general use cases. The previous challenge (from D2.5) to collaborate and impact the pilots' sites was successfully overcome by thorough cooperation with WP6. Furthermore, the collaboration has been shown by the co-creation of detailed personas of different pilot sites (presented in D2.6). Moreover, for the third iteration (D2.7) this challenge was addressed by creating the final line between personas, general use cases, requirements, piloting use case and their scenarios. This final narrative represents SHAPES mission to create a user-centred platform. In addition, the ethical aspects of personas and their needs were covered.

However, within these follow-up actions, an acceptance of the digital solutions from the perspective of the final users will be challenged. At this stage and based on the background we acquired during our past research experience, the lack of engagement of the end-users should be considered as a possible risk for the implementation of the SHAPES small-scale and large-scale pilots planned within WP6. Thus, in future stages of the SHAPES project, the potential barriers for users from the population of older people should be explored to open an avenue for further fine-tuning of the SHAPES actions and practical implementations of the digital solutions. To address this challenge, WP2 has been involved in WP6 meetings and different pilot phases in order to share the insight from the field and previous research experience with older adults. This cooperation and knowledge exchange has been found to be very fruitful.

For this purpose, several remarks should be taken into account here. Importantly, the strategy of coping with late life has been revealed to be one of the important factors influencing the adoption of a new digital solution to the life of older people (Golant, 2017). As figure 52 illustrates, the choice between adoption of a new digital solution or inclination towards a more traditional coping solution is influenced by an individual appraisal of a digital solution and its user-friendliness (Figure 52).

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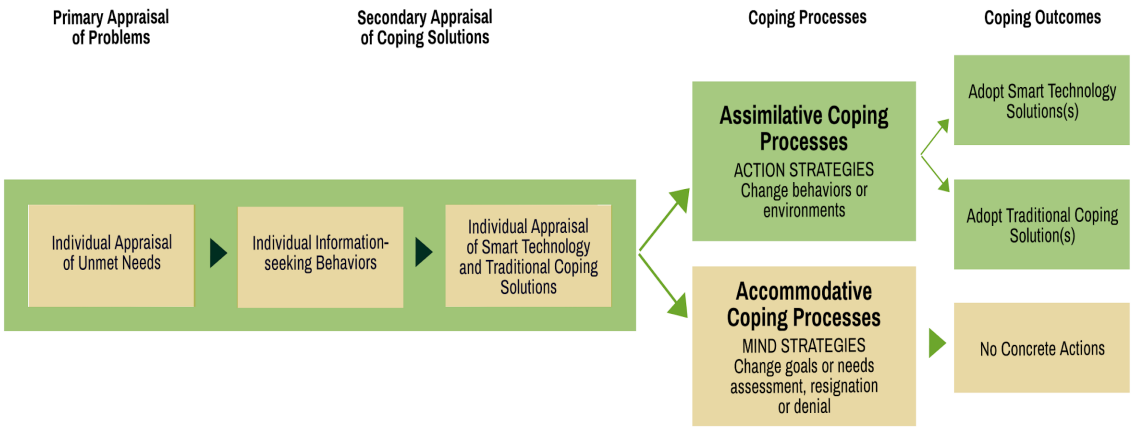

Figure 52: Individual Appraisal and Coping Processes Underlying the Adoption of Coping Solutions (Source: Golant, 2017)

Therefore, further SHAPES actions focused on the implementation of digital solutions into the lives of older people within the SHAPES Pan-European Pilot Campaign should take an individual appraisal of digital technologies into account. Moreover, it is important to seek new ways of influencing the attitudes toward digital technologies in older people because there is still a large number who simply do not like digital technologies or new systems at all, because they feel an aversion and show resistance to the use of digital technologies in their daily lives.

Lastly, currently biggest challenge is Covid-19 pandemic that is not providing the opportunity to engage with older adults directly. This risk will hopefully be overcome by the vaccination and decreased number of cases across Europe.

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8 Conclusion

As proposed in the original project proposal of the SHAPES project, Task 2.5 had three main Deliverable objectives:

- to develop basic personas with their prototypical attributes, attitudes, behaviours and characteristics
- to develop general use cases including scenarios of use of digital solutions
- to develop connections between a demonstrational persona developed

All of these objectives have been fully fulfilled and in the course of the project they are being continuously refined to reflect the development in the connected project areas. The present Report Deliverable presents fourteen original personas plus six "co-created" that are ready to be used in future stages of the SHAPES project. The methodology of the persona development was advanced in this deliverable by persona stories, socio-economical and demographical context, samples of data from DIPEx interviews as well as samples from expert interviews that were the foundation for the personas´ development. Lastly, personas were enriched with the ethical point of view and reflection of their needs and requirements.

Moreover, the third objective: to develop connections between a demonstrational persona developed in this deliverable and use cases developed within WP6; has been fulfilled. Moreover, it has been extended with information from T3.5 and scenarios from WP6. This deliverable also introduces a new method for the development of connections between personas and use cases that is based on a multiple-criteria evaluation approach to variations in the persona´s parameters. This method was also used for the demonstration of the development of the connections between a demonstrational persona and use cases developed within WP6 and it is now ready to be used in all the Pilot sites of the SHAPES Platform.

Both the personas and general use cases represent a preliminary, evidence-based knowledge base that provide general models of users of future SHAPES digital solutions and innovations, respecting also the requirement of a high-quality output of the action that will enable successful implementation of the SHAPES plan and promoting models, approaches, and solutions for the extended independent living of older people. The personas and general use cases developed within Task 2.5 contribute to a better understanding of the user needs for future designing of the SHAPES architecture and system requirements. The new method of multiple-criteria evaluation approach to variations in the persona´s parameters will enable better utilisation of the potential of both the personas and use cases pursuant to the project objectives and tasks. Lastly, we finished the line of personas – general use cases – use cases and scenarios in

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collaboration with WP6 and the pilot leaders. Our aim was to create a coherent concept feasible for further use within the SHAPES consortium and platform.

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References

Aboumatar H. J., Carson K. A., Beach M. C., Roter D. L., & Cooper L. A. (2013). The impact of health literacy on desire for participation in healthcare, medical visit communication, and patient reported outcomes among patients with hypertension. *Journal of General Internal Medicine, 28*(11), 1469-1476. https://doi.org/10.1007/s11606-013-2466-5

Arnautovska, U., O'Callaghan, F., & Hamilton, K. (2018). Behaviour change techniques to facilitate physical activity in older adults: What and how. *Ageing and Society*, *38*(12), 2590-2616. https://doi.org/10.1017/S0144686X17001027

Auais, M., French, S., Alvarado, B., Pirkle, C., Belanger, E., & Guralnik, J. (2018). Fear of falling predicts incidence of functional disability 2 years later: A perspective from an international cohort study. *The Journals of Gerontology: Series A, 73*(9), 1212-1215. https://doi.org/10.1093/gerona/glx237

Ball, M.M., Perkins, M.M., Whittington, F.J., Connell, B.R., Hollingsworth, C., King, S.V., Elrod, C.L., Combs, B.L. (2004). Managing Decline in Assisted Living: The Key to Aging in Place. J. *Gerontol. B Psychol. Sci. Soc. Sci*;59:S202–S212

Bamidis, P. D., Konstantinidis, E. I., Billis, A., Frantzidis, C., Tsolaki, M., Hlauschek, W., et al. (2011). A Web services-based exergaming platform for senior citizens: the Long Lasting Memories project approach to e-health care. Conf. Proc. IEEE *Eng. Med. Biol. Soc*; 2505–2509

Batista, M. P. P., de Barros, J.O., de Almeida, M. H. M., Mângia, E. F., Lancman S. (2014). Formal caregivers of older adults: reflection about their practice. Oct; 48(5): 732–738. *Rev Saude Publica.* doi: 10.1590/S0034-8910.2014048005270

Berendonk, C., Blix, B. H., Hoben, M., Clandinin, D. J., Roach, P. M., Compton, R. M., Cave, M. T., & Caine, V. (2020). A Narrative Care approach for persons living with dementia in institutional care settings. *International Journal of Older People Nursing, 15*(1), e12278. https://doi.org/10.1111/opn.12278

Bhattacharyya, O., Mossman, K., Gustafsson, L., & Schneider, E. C. (2019). Using human-centered design to build a digital health advisor for patients with complex needs: Persona and prototype development. *Journal of Medical Internet Research*, *21*(5), e10318. https://doi.org/10.2196/10318

Bhattand, J. & Bathija,P. (2018). Ensuring Access to Quality Health Care in Vulnerable Communities. *Academic Medicine,* Vol. 93, No. 9.

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 857159

Bergvall-Kåreborn, B., & Ståhlbröst, A. (2010), User Expressions Translated into Requirements. *An Interdisciplinary Journal on Humans in ICT Environments*, Volume 6 (2), November 2010, 212–229, ISSN: 1795-6889

Bodsworth, S. M., Clare, I. C. H., & Simblett, S. K. (2011). Deafblindness and mental health: Psychological distress and unmet need among adults with dual sensory impairment. *British Journal of Visual Impairment*, *29*(1), 6–26. https://doi.org/10.1177/0264619610387495

Bonanno, G. A. (2004). Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *The American Psychologist, 59*(1)*,* 20-8. https://doi.org/10.1037/0003-066X.59.1.20

Bookwala, J. (2005). The role of marital quality in physical health during the mature years. *Journal of Aging and Health*. 17(1): 85-104.

Brown, S., & Kawamura, S. (2010). Relationship quality among cohabitors and marrieds in older adulthood. *Social Science Research.* 39(5): 777-786.

Busse, R., Blummel, M., Scheller-Kreinsen, D, & Zentner, A. (2010). *Tackling chronic disease in Europe. Strategies, interventions and challenges*. Geneva, Switzerland: WHO. Retrieved from: http://www.euro.who.int/en/health-topics/Life-stages/healthy-ageing/publications/2010/tackling-chronic-disease-in-europe-strategies,-interventions-and-challenges-2010

Cash, B; Warburton, J & Hodgkin, S. (2019). Expectations of care within marriage for older couples. Australasian Journal of Ageing. 38(1): 19-24.

Chaudhury, H., & Oswald, F. (2019). Advancing understanding of person-environment interaction in later life: One step further. *Journal of Aging Studies*, *51*, 100821. https://doi.org/10.1016/j.jaging.2019.100821

Choi, N. G., Marti, C. N., DiNitto, D. M., & Choi, B. Y. (2015). Alcohol use as risk factors for older adults' emergency department visits: A latent class analysis. *The Western Journal of Emergency Medicine*, *16*(7), 1146-1158. https://doi.org/10.5811/westjem.2015.9.27704

Clegg, A., Young, J., Iliffe, S., Rikkert, M. O., & Rockwood, K. (2013). Frailty in elderly people. *The Lancet*, *381*(9868), 752-762. https://doi.org/10.1016/S0140-6736(12)62167-9

Coker, J., Martin, M., Simpson, R., & Lafortune, L. (2019). Frailty: An in-depth qualitative study exploring the views of community care staff. *BMC Geriatrics, 19*(1), 47. https://doi.org/10.1186/s12877-019-1069-3

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 857159

Craik F, Salthouse T. (2002). *The Handbook of Aging and Cognition.* 2nd ed. Mahwah, NJ: Lawrence Erlbaum.

de Jong Gierveld, J., & van Tilburg, T. (2010). The De Jong Gierveld short scales for emotional and social loneliness: Tested on data from 7 countries in the UN generations and gender surveys. *European Journal of Ageing, 7*, 121-130. https://dx.doi.org/10.1007%2Fs10433-010-0144-6

Diehr, P.H., Thielke, S.M., Newman, A.B., Hirsch C., & Tracy R. (2013). Decline in health for older adults: Five-year change in 13 key measures of standardized health. J. Gerontol. *A Biol. Sci. Med. Sci*;68:1059–1067.

Dubovská, E., Chrz, V., Tavel, P., Poláčková Šolcová, I., & Růžička, J. (2017). Narrative construction of resilience: Stories of older Czech adults. *Ageing & Society, 37*(9), 1849-1873. https://doi.org/10.1017/S0144686X16000581.

Dupre, M. & Meadows, S. (2007). Disaggregating the effects of marital trajectories on health. Journal of Family Issues. 28(5): 623-652.

European Blueprint on Digital Transformation of Health and Care for the Ageing Society. *Making the Digital Transformation of Health and Care for the Ageing Society sustainable: assessing cost-effectiveness.* Online from: https://ec.europa.eu/eip/ageing/news/making-digital-transformation-health-and-care-ageing-society-sustainable-assessing-cost-0_en

Fabbri, E., Zoli, M., Gonzalez-Freire, M., Salive, M. E., Studenski, S. A., & Ferrucci, L. (2015). Aging and multimorbidity: New tasks, priorities, and frontiers for integrated gerontological and clinical research. *Journal of the American Medical Directors Association*, *16*(8), 640-647. https://doi.org/10.1016/j.jamda.2015.03.013

Fejer, R., & Ruhe, A. (2012). What is the prevalence of musculoskeletal problems in the elderly population in developed countries? A systematic critical literature review. *Chiropractic & Manual Therapies*, *20*(1), 31. https://doi.org/10.1186/2045-709X-20-31

Franke, T., Tong, C., Ashe, M., McKay, H., & Sims-Gould, J. (2013). The secrets of highly active older adults. *Journal of Aging Studies, 27*(4), 398-409. https://doi.org/10.1016/j.jaging.2013.09.003

Gee, N. R., Mueller, M. K., & Curl, A. L. (2017). Human-animal interaction and older adults: An overview. *Frontiers in Psychology*, *8*, 1416. https://doi.org/10.3389/fpsyg.2017.01416

Giddens, A. (1992). *The transformation of intimacy*. Stanford University Press.

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 857159

Golant, S. M. (2017). A theoretical model to explain the smart technology adoption behaviors of elder consumers (Elderadopt). *Journal of Aging Studies*, *42*, 56-73. https://doi.org/10.1016/j.jaging.2017.07.003

Goodwin, K. (2008). *Getting from research to personas: Harnessing the power of data*. Retrieved from http://www.cooper.com/journal/2008/05/getting_from_research_to_perso.html.

Granbom, M., Löfqvist, C., Horstmann, V., Haak, M., & Iwarsson, S. (2014). Relocation to ordinary or special housing in very old age: Aspects of housing and health. *European Journal of Ageing: Social, Behavioural and Health Perspectives, 11*(1), 55-65. https://doi.org/10.1007/s10433-013-0287-3

Harada, C.N., Natelson Love, M.C., Triebel, K. (2013). Normal cognitive aging. *Clin Geriatr Med*; 29(4):737–752.

Hatzidimitriadou, E. (2010). *Migration and ageing: settlement experiences and emerging care needs of older refugees in developed countries.* Hellenic Psychological Society, https://core.ac.uk/display/1534845

Hersh, M. (2013). Deafblind people, communication, independence, and isolation. *The Journal of Deaf Studies and Deaf Education*, *18* (4),446–463. https://doi.org/10.1093/deafed/ent022

Hughes M & Waite L (2009). Marital biography and health at mid-life. Journal of Health and Social Behavior. 50(3): 344-358.

Huh, J., Kwon, B., Kim, S., Lee, S., Choo, J., Kim, J., & Yi, J. (2016). Personas in online health communities. *Journal of Biomedical Informatics, 63*, 212-225. https://doi.org/10.1016/j.jbi.2016.08.019

Huis in't Veld, R. M., Widya, I. A., Bults, R. G., Sandsjö, L., Hermens, H. J., & Vollenbroek-Hutten, M. M. (2010). A scenario guideline for designing new teletreatments: A multidisciplinary approach. *Journal of Telemedicine and Telecare, 16*, 302-307. https://doi.org/10.1258/jtt.2010.006003

Ibrahim, E. & El-Lassy, R. (2017). In-Service Training and Alzheimer's Formal Caregivers. *Alexandria Scientific Nursing Journal,* 19(2), pp.133-146.

Iezzoni, L. (2003). *When walking fails: Mobility problems of adults with chronic conditions* (Vol. 8). Berkeley, CA: University of California Press.

Jacobs, M., Van Tilburg, T., Groenewegen, P., & Broese van Groenou, M. (2015). Linkages between informal and formal care-givers in home-care networks of frail older adults. *Ageing and Society, Cambridge*

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 857159

Press. https://www.cambridge.org/core/journals/ageing-and-society/article/abs/linkages-between-informal-and-formal-caregivers-in-homecare-networks-of-frail-older-adults/43243AD3B96D12E5D257B27FDBF82D6D

Jones, S. A., Alicea, S. K., & Ortega, J. D. (2020). A self-determination theory approach for exercise motivation in rural dwelling older adults. *Activities*, *Adaptation & Aging, 44*(1), 24-41. https://doi.org/10.1080/01924788.2019.1581022

Kataoka-Yahir, M.R., Davis, J., Ka' opua L. S. (2019). Sociodemographic Characteristics and Preferences for Family (Informal) and Formal Caregiver Help with ADLs. *Home Health Care Management and Practice.* Vol. 31(2) 120-127. DOI: https://doi.org/10.1177/1084822318801811

Kearns, A., Whitley, E., Tannahill, C., & Ellaway, A. (2015). 'Lonesome town'? is loneliness associated with the residential environment, including housing and neighborhood factors? *Journal of Community Psychology, 43*(7), 849-867. https://doi.org/10.1002/jcop.21711

Kemperman, A., van den Berg, P., Weijs-Perrée, M., & Uijtdewillegen, K. (2019). Loneliness of older adults: Social network and the living environment. *International Journal of Environmental Research and Public Health, 16*(3). https://doi.org/10.3390/ijerph16030406

Kim, T. K., & Choi, M. (2019). Older adults' willingness to share their personal and health information when adopting healthcare technology and services. *International Journal of Medical Informatics,* 126, 86–94. doi:10.1016/j.ijmedinf.2019.03.010.

Konstantinidis, E. I., Billis, A., Hlauschek, W., Panek, P. & Bamidis, P. D. (2010). Integration of cognitive and physical training in a smart home environment for the elderly people. *Stud. Health Technol. Inform*;160: 58–62.

Lavan, A. H., Gallagher, P. F., & O'Mahony, D. (2016). Methods to reduce prescribing errors in elderly patients with multimorbidity. *Clinical Interventions in Aging*, *11*, 857-866. https://doi.org/10.2147/CIA.S80280

Li, J. and Song, Y. (2019). *Formal and Informal Care.* Encyclopedia of Gerontology and Population Aging. DOI: https://doi.org/10.1007/978-3-319-69892-2_847-1

Manning, E., & Gagnon, M. (2017). The complex patient: A concept clarification. *Nursing & Health Sciences, 19*(1), 13-21.

Manzoli, L., Villari, P., Pirone, G. & Boccia, A. (2007). Marital status and mortality in the elderly: a systematic review and meta-analysis. *Social Science & Medicine Journal*. 64(1): 77-94.

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 857159

Mardani, A., Jusoh, A., Zavadskas, E. K., Khalifah, Z., & Nor, K. M. (2015). Application of multiple-criteria decision-making techniques and approaches to evaluating of service quality: A systematic review of the literature. *Journal of Business Economics and Management, 16*(5), 1034-1068.

Marmot, M. (2005). Social determinants of health inequalities. *Lancet.* 365(9464): 1099-1104.

Martins, G., Corrêa, L., Caparrol, A.J.D.S., Santos, P.T.A.D., Brugnera, L.M. and Gratão, A.C.M. (2019). Sociodemographic and health characteristics of formal and informal caregivers of elderly people with Alzheimer's Disease. *Escola Anna Nery*, 23(2).

Masten, A. S. (2001). Ordinary magic. Resilience processes in development. *The American Psychologist, 56(3)*, 227-38. https://doi.org/10.1037/0003-066X.56.3.227

Matthews, L. A., Shine, A. L., Currie, L., Chan, C. V., & Kaufman, D. R. (2012). A Nurse's Eye-View on Health Literacy in Older Adults. In *NI 2012: 11th International Congress on Nursing Informatics, June 23-27, 2012, Montreal, Canada.* (Vol. 2012). Montreal, Canada: American Medical Informatics Association.

McCabe, C., Dinsmore, J., Brady, A.M., Mckee, G., O'Donnell, S. & Prendergast, D. (2014). Using action research and peer perspectives to develop technology that facilitates behavioral change and self-management in COPD. *International Journal of Telemedicine and Applications,* https://doi.org/10.1155/2014/380919

McCabe, M., You, E., & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. *Gerontologist, 56*(5), 70-88. https://doi.org/10.1093/geront/gnw078

McHugh, J. E., Wherton, J. P., Prendergast, D. K., & Lawlor, B. A. (2012). Teleconferencing as a source of social support for older spousal caregivers: Initial explorations and recommendations for future research. *American Journal of Alzheimer's Disease & Other Dementias*, *27*(6) 381-387. https://doi.org/10.1177/1533317512453491

Miles, B. (2008). *Overview on Deaf-Blindness. National Center of Deaf-Blindness.* National Center on Deaf-Blindess. https://www.nationaldb.org/info-center/overview-factsheet/

Monitoring and Assessment Framework for the European Innovation Partnership on Active and Healthy Ageing (MAFEIP). *United4Helath.* Online: https://www.mafeip.eu/sites/default/files/MAFEIP_UC8_U4H.pdf

Monitoring and Assessment Framework for the European Innovation Partnership on Active and Healthy Ageing (MAFEIP). *Renewing Health: Telemonitoring for Type 2*

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 857159

Diabetes Patients in Thessaly, Greece. Online: https://www.mafeip.eu/sites/default/files/MAFEIP_UC13_Renewing%20Health_Greece.pdf

Mount, J.K., Massanari, R.M., Teachman, J. (2015). Patient care complexity as perceived by primary care physicians. *Fam. Syst. Health, 33*, 137–145.

Nielsen, L. (2019). *Personas -- user focused design (Human-computer interaction series) (*Second edition). London, United Kingdom: Springer. https://doi.org/10.1007/978-1-4471-7427-1

Nolan, M., Walker, G., Nolan, J., Williams, S., Poland, F., Curran, M., & Kent, B. C. (1996). Entry to care: Positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing*, *24*(2), 265-274. https://doi.org/10.1046/j.1365-2648.1996.01966.x

O´Neil, E, & Peterson, L. (2017). *How Leaders in Aging Can Remove Resistance to Change. Aging Today*. Retrieved from: https://www.asaging.org/blog/how-leaders-aging-can-remove-resistance-change

Oswald F., & Rowles G. D. (2006). Beyond the relocation trauma in old age: New trends in today's elders' residential decisions. In Wahl H.W., Tesch-Römer C. & Hoff A. (eds). *New dynamics in old age: Environmental and societal perspectives* (pp. 127-52). Amityville, NY: Baywood Publishing.

Quinn, G. (2009). *A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities Part I: Articles and Short Commentaries*. Teoksessa Quinn, G- & Waddington, L. (ed.). 2009. European Yearbook of Disability Law. Vol. 1. Antwerpen, Hart Publishing. p. 89–114.

Randall, W. L. (2009). The anthropology of dementia: A narrative perspective. *International Journal of Geriatric Psychiatry, 24*(2), 322–324. http://dx.doi.org/10.1002/gps.2179

Reichman, W. E., Fiocco, A. J., Rose N.S. (2010) Exercising the brain to avoid cognitive decline: examining the evidence. *Aging Health*;6(5):565–584

Richardson, J., Grime, J., & Ong, B. (2014). 'Keeping going': Chronic joint pain in older people who describe their health as good. *Ageing and Society, 34*(8), 1380-1396. https://doi.org/10.1017/S0144686X13000226

Robles, T., Slatcher, R., Trombello, J. & McGinn, M. (2014). Marital quality and health: a meta-analytic review. *Psychological Bulletin Journal*. 140(1): 140-187

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 857159

Routa, E. (2019). *The psychological burden and the quality of life of informal caregivers of dementia patients in Ampelokipous neighborhood in Larisa city*. Master Thesis, Faculty of Medicine, University of Thessaly, Larissa, Greece.
Rozen, S. (2017). *Caregivers from Eastern Europe*. Hotline for Refugees and Migrants.https://din-online.info/pdf/mk14e.pdf

Ruggiano, N., Brown, E. L., Shaw, S., Geldmacher, D., Clarke, P., Hristidis, V., Bertram, J. (2019). The potential of information technology to navigate caregiving systems: perspectives from dementia caregivers. *Journal of gerontological social work*; 62(4):432-50.

Ryan, R. M., Patrick, H., Deci, E. L., & Williams, G. C. (2008). Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *The European Health Psychologist, 10*, 2-5

Saleh, S., & Szebenyi, S. (2005). Resource use of elderly emergency department patients with alcohol-related diagnoses. *Journal of Substance Abuse Treatment, 29*(4), 313-319. https://doi.org/10.1016/j.jsat.2005.08.007

Salthouse, T. (2012). Consequences of age-related cognitive declines. *Annu Rev Psychol*; 63:201–226.

Sarkar, S. (1992). Models of reduction and categories of reductionism. *Synthese, 91*(3), 167-194.

Schäfer, K., Rasche, P., Bröhl, C., Theis, S., Barton, L., Brandl, C., Wille, M., Nitsch, V., Mertens, A. (2019). Survey-based personas for a target-group-specific consideration of elderly end users of information and communication systems in the German health-care sector. *International Journal of Medical Informatics, 132,* 103924. https://doi.org/10.1016/j.ijmedinf.2019.07.003

Scharf, T., & de Jong Gierveld, J. (2008). Loneliness in urban neighbourhoods: An Anglo-Dutch comparison. *European Journal of Ageing, 5,* 103. https://doi.org/10.1007/s10433-008-0080-x

Scheffer, A., Schuurmans, M., van Dijk, N., van der Hooft, T., & de Rooij, S. (2008). Fear of falling: Measurement strategy, prevalence, risk factors and consequences among older persons. *Age and Ageing, 37*(1), 19-24. https://doi.org/10.1093/ageing/afm169

Scheibl, F., Farquhar, M., Buck, J., Barclay, S., Brayne, C., Fleming, J., & Phinney, A. (2019). When frail older people relocate in very old age, who makes the decision? *Innovation in Aging, 3*(4). https://doi.org/10.1093/geroni/igz030

Schulz, R. & Tompkins, C. A. (2010). Informal caregivers in the United States: Prevalence, Caregiver Characteristics, and Ability to provide Care. National Research Council. *The*

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 857159

Role of Human Factors in Home Health Care: Workshop Summary. Washington, DC: The National Academies Press. DOI: https://doi.org/10.17226/12927 .

SHAPES WP2: "Understanding Older People: Lives, Communities and Contexts Interview Guide for Phase 1 – Remote and online Interviews", Task2.1: "Understanding Older People: Lives, Communities and Contexts"

SHAPES WP2: "Understanding the Lifeworld of Older Individuals and Improving Smart and Healthy Living", Task 2.5: "SHAPES Personas and Use Cases", Deliverable 2.5: "SHAPES Personas and Use Cases"

Sołtys, A. and Tyburski, E., 2020. Predictors of mental health problems in formal and informal caregivers of patients with Alzheimer's disease. *BMC psychiatry,* 20(1), pp.1-11.

Stenner, P., McFarquhar, T., & Bowling, A. (2011). Older people and 'active ageing': Subjective aspects of ageing actively. *Journal of Health Psychology, 16*(3), 467-77. https://doi.org/10.1177/1359105310384298

Stokes, J. (2017). Marital quality and loneliness in later life: a dyadic analysis of older married couples in Ireland. *Journal of Social and Personal Relationships.* 34(1): 114-135.

Tatzer, V. C. (2019). Narratives-in-action of people with moderate to severe dementia in long-term care: Understanding the link between occupation and identity. *Journal of Occupational Science, 26*(2), 245-257, https://doi.org/10.1080/14427591.2019.1600159

Troxel W, Robles T, Hall M & Buysse D (2007). Marital quality and the marital bed: examining the covariation between relationship quality and sleep. *Sleep Medicine Reviews.* 11(5): 389-404.

Turner, J. R., & Baker, R. M. (2019). Complexity theory: An overview with potential applications for the social sciences. *Systems, 7*(1), 4.

Uchino B. (2006). Social support and health: a review of physiological processes potentially underlying links to disease outcomes. *Journal of Behavioral Medicine*. 29(4): 377-387.

Umberson, D; Crosnoe, R & Reczek, C (2010). Social relationships and health behavior across the life course. *Annual Review of Sociology*. 11(36): 139-157.

World Healht Organisation (WHO) (2019). *Promoting the health of refugees and migrants.* Seventy-Second World Health Assembly, 25 April 2019.

Wienke, C. & Hill, G. (2009). Does the "marriage benefit" extend to partners in gay and lesbian relationships? Evidence from a random sample of sexually active adults. *Journal of Family Issues*. 30(2): 259-289.

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No 857159

Wilde-Larsson I., Nordström, B. & Johansson, I. (2015). Formal caregivers' perceptions of quality of care for older people: associating factors. *BMC research notes,* 8(1), 623.

Wilde-Larsson, B., Nordström, G. & Johansson, I. (2015). Formal caregivers' perceptions of quality of care for older people: associating factors. *BMC research notes*, 8(1), pp.1-9.

Williams, A. P., Peckham, A., Kuluski, K., Montgomery, R., Mortonand, F., Watkins, J. (2010). *Formal and Informal Care for Older Persons: Assessing the Balance in Ontario*. Department of Health Policy, Management and Evaluation University of Toronto, Canada. https://www.ryerson.ca/content/dam/crncc/knowledge/relatedreports/balancecare/HMRU_caregiver_report_2010.pdf

Wilson, R., Rochon, E., Leonard, C. & Mihailidis, A. (2012). *Formal caregivers' perceptions of effective communication strategies while assisting residents with Alzheimer's disease during activities of daily living.*

World Federation of the Deafblind (2018). *At risk of exclusion from CRPD and SDGS implementation: Inequality and persons with deafblindness*. Global report on situation and rights of persons with deafblindness. (Report). http://www.wfdb.eu/wp-content/uploads/2019/04/WFDB-global-report-2018.pdf

Zarem J.E. (2010). *Today's Continuing Care Retirement Community* (CCRC) LeadingAge; Washington, DC, USA: American Seniors Housing Association; Washington, DC, USA: National Investment Center; Annapolis, MD, USA.

Zhang Z & Hayward M (2006). Gender, the marital life course, and cardiovascular disease in late midlife. *Journal of Marriage and Family*. 68(3): 639-657.

Ziebland, S., & McPherson, A. (2006). Making sense of qualitative data analysis: An introduction with illustrations from DIPEx (personal experiences of health and illness). *Medical Education, 40*(5), 405-414. https://doi.org/10.1111/j.1365-2929.2006.02467.x

Zigante, V. (2018). *Informal Care in Europe. Exploring Formalisation, Availability and Quality*. London School Economics and Political Science, Directorate-General for Employment, Social Affairs andInclusionDirectorate A —Employment and Social GovernanceUnit A.4—Thematic Analyss. https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8106&furtherPubs=yes

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Appendix

APPENDIX I. LIST OF THEMATIC CODES FROM DIPEX STUDY

Table 23: Appendix I. List of thematic codes from DIPEx study

Category	Thematic codes
Experience of aging	
	Physical changes
	Retirement
	Attitude towards own older age
	Acceptance of older age
	Non-acceptance of older age
	What is older age
	Coping
	Well-being
	Motivation
	Active aging
Older age and society	
	Attitudes of society toward older people
	Expectations from older adults
	Generational differences
	Opinions on the social situation
	Ageism/stigma
Cognition in older age	
	Memory
	Cognitive training
	Dreaming
	Sleep
	Forgetting
	Cognitive decline
General health	
	Health condition
	Health problems
	Pain
	Medications
	Relationship to doctors and healthcare
	Supplements and aids
	Impact of the illness on the well-being in old age
Health problems - chronic	
	High blood pressure
	Diabetes
	Stroke
	Cardiovascular problems

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	Monitoring
	Health checks
Health problems - cognitive	
	Dementia and needs
	Dementia and relationships
	Memory loss
	Caregivers
	Fear of dementia
Health problems - movement	
	Falls
	Chronic pain
	Limited mobility
	House amendments
	Aids
	Physiotherapy and exercise
	Motivation to exercise
Mental health	
	Isolation
	Loneliness
	Depression
	Anxiety
	Trauma
	Anti-depressants
	Fear of stigmatisation
	Professional mental health help
Institutional care	
	Decision on move into institution
	Fear of going to institutional care
	Living in institutional care
	Relationships institutional care
Social aspects of older age	
	Family
	Partners
	Loss of a loved one
	Friends and community
	Sex and intimacy
	Establishing new relationships
	Social isolation
	Pets
	Conflicts
	Body Image
Activity in older age	
	Hobbies
	Nature
	Physical activity

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	Everyday activities Travel Social life Social commitment Performance Self-sufficiency What it means to age well Motor skills training Food, alcohol and smoking Personal development
Finance	
	Debt Savings Risk of fraud
Housing	
	Garden Feeling of home Home improvements Self-sufficiency City versus countryside
Technology	
	Mobile phones Internet TV Radio
Values and moral beliefs	
	Life balance and wisdom The most important events in life Life patterns Myths
Spirituality	
	Meaning of life Death Faith Religion Locus of control
Messages to others	
	Messages to young people Messages to the old Messages to paramedics Messages to politicians
Future	
	Plans Worries Arrangements

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APPENDIX II. LIST OF THEMATIC CODES FROM EXPERT INTERVIEWS

Table 24: Appendix II. List of thematic codes from expert interviews

Category	Topics
General issues	
	Preventive measures
	Disability
	Self-sufficiency
	Dignity
	Health literacy
	Stay at home vs. institutional care
	Well-being
	Rehabilitation
	Palliative care
	Health care system limitations
	Social work
	Social pathology
Active aging	
	Prevention
	Physical activity
	Cognitive training
	Motivation to exercise
Chronic diseases	
	Multimorbidity
	Diabetes
	Cardiovascular diseases
	Hypertension
	Chronic Pulmonary Disease
	Oncological
	Monitoring of vital functions
	Motivation to regular medical check-ins
	Education
Restricted mobility	
	Arthrosis
	Vertebrogenic syndrome
	Back pain
	Pain management
	Addiction to painkillers
	Physiotherapy
	Barriers in house
	Urbanisation
	Movement outside the house
	Compensation movement aids
	Fear of falling

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Dementia	
	Prevention of cognitive decline
	Diagnostics of dementia
	Types of dementia
	Risks in the household
	Risks outside
	Monitoring
	Informal caregivers' functions
	Informal caregivers needs
	Formal care
	Institutional care
	Problems with hygiene
	Aggression
	Change of personality
	Effect on close relationships
Problems with sensory organs	
	Impaired vision
	Impaired hearing
	Deaf-blindness
	Compensation aids for sensory deficits
	Stigmatisation
Frailty	
	Frailty syndrome
	Moving to institution
Mental health	
	Depression
	Loneliness
	Isolation
	Addiction
	Non-complying to medical recommendations
	Family relationships
	Happiness
	Spirituality
	Resilience
	Coping

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Appendix III. PERSONAS AND GENERAL USE CASES

Table 25: Appendix III. Personas and general use cases

	GENERAL USE CASES												
		UC1	UC2	UC3	UC4	UC5	UC6	UC7	UC8	UC9	UC10	UC11	UC12	UC13
PERSONAS	P1	x	x	x										x
	P2					x	x	x				x		
	P3							x	x		x	x	x	
	P4			x	x					x				
	P5								x			x		
	P6			x										
	P7			x					x					
	P8													x
	P9	x	x	x	x				x	x				x
	P10							x						
	P14	x										x		x
	P15		x		x									x

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Appendix IV. GENERAL USE CASES AND PILOTING USE CASES

Table 26: Appendix IV. General use cases and piloting use cases

		GENERAL USE CASES												
		UC1	UC2	UC3	UC4	UC5	UC6	UC7	UC8	UC9	UC10	UC11	UC12	UC13
PILOTING USE CASES	UC-PT1-001	x		x					x					
	UC-PT1-002		x					x				x		
	UC-PT2-001		x			x	x	x				x		
	UC-PT2-002									x	x			x
	UC-PT2-003				x									
	UC-PT3-001		x				x					x		
	UC-PT4-001				x								x	
	UC-PT4-002				x								x	
	UC-PT5-001				x									x
	UC-PT5-002		x	x	x									
	UC-PT5-003		x			x								
	UC-PT5-004				x									

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	UC-PT6-001	x											
	UC-PT6-002								x				x
	UC-PT6-004		x	x									
	UC-PT7		x							x			

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Appendix V.: PERSONAS AND PILOTING USE CASES

Table 27: Appendix V. Personas and piloting use cases

		PERSONAS																			
		P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	P16	P17	P18	P19	P20
PILOTING USE CASES	UC-PT1-001	x																			
	UC-PT1-002			x																	
	UC-PT2-001							x								x					
	UC-PT2-002					x															
	UC-PT2-003													x							
	UC-PT3-001		x								x										x
	UC-PT4-001				x					x											
	UC-PT4-002				x					x											
	UC-PT5-001				x					x											
	UC-PT5-002												x								
	UC-PT5-003																			x	
	UC-PT5-004																		x	x	
	UC-PT6-001						x														

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	UC-PT6-002						x								x					
	UC-PT6-004											x								
	UC-PT7											x					x	x		x

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Appendix VI.: ETHICAL REQUIREMENTS RELEVANT FROM END-USER PROCESSES POINT OF VIEW

Table 28: Appendix VI. Ethical Requirements

End-user starts using services/updates choices of services	
PE1 Essential	Create and update a process for the implementation of services for single end-users (older persons) + and for the assessment of the suitability of the services from time to time (including a process to assess the digital literacy of the end-user and adapt the services according to end-user needs and capabilities). The process should include more time to discuss choices or have an advocate regarding important appointments in order to make notes and help the person understand or remember choices.
PE2 Mandatory	Create and update a detailed process to determine if the older person is able to decide on accessing the services and secondly if she/he is able to give informed consent for the collection of the information. In that work take into consideration also local regulations.
PE3 Mandatory	Provide for the end-user (older persons) plain language materials, information in visual form (including information on each service and how it operates and what data it collects, what is the regulation behind).
PE4 Mandatory	Create/provide training material on data protection to end-users who need to understand data protection (older persons, caregivers).
PE5 Mandatory	Provide training (materials) related to cybersecurity requirements (TBD).
PE6 Mandatory	Create/provide a process for executing data subject rights in SHAPES (e.g., access to data).
PE7 Essential	Define skills and specific competences needed for the care givers using the SHAPES services and provide training materials.
GE48 Essential	Acknowledge the heterogeneity of older persons that materialise in the diversity of how older persons adopt and use digital devices (exclusion and inclusion). Also, other end-users. Care workers see GE12, GE13, PE7.
GE49 Essential	Acknowledge the barriers and facilitators of older persons' usage of digital devices (perception of usefulness, user requirements, self-efficacy, sense of self, privacy and confidentiality, cost). Also, other end-users. Care workers see GE12, GE13, PE7.
ET2 Essential	Consider cultural diversity of users; e.g., create avatars that represent different genders and cultures and let the user choose what to use. (TBD)
ET3 Mandatory	Create functionalities for the end-user to switch off/on various sensors and services whenever they want to. (TBD)

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Technology-related ethical requirements related to the use of SHAPES & ending of it	
ME5 **Mandatory**	Define/deploy responsibilities regarding SHAPES and each of its various services (e.g., if something goes wrong). This includes processes related to the personal safety solution that require organisational arrangements.
ME6 **Mandatory**	Create/deploy processes and guidelines regarding the incidental findings when using or analysing SHAPES data.
ET4 **Essential**	Data subject rights: right of access – build/update a self-service portal where the data subject can get access to his/her data.
ET5 **Mandatory**	Data subject rights: right to rectification – ensure that the data can be corrected in all places (incl. storage).
ET6 **Mandatory**	Data subject rights: right to be forgotten – build capabilities for deleting personal data.
ET7 **Mandatory**	Data subject rights: right to restriction – build a capability for restricting data processing.
ET9 **Mandatory**	Data subject rights: right to data portability – create a capability to transmit data to the data subject/third party in a structured, commonly used and machine-readable format.
ET10 **Mandatory**	Data subject rights: right to object: 1) ensure that the information about automated decision-making can be given to the user (the data subject) before the process starts; 2) create the capability to prevent the data subject's data to be part of profiling if a data subject has objected to profiling.
ET11 **Mandatory**	Data protection principles: storage minimisation – ensure that there are technical capabilities to erase or anonymise personal data after the relevant data retention period. Ensure that data will be removed from all systems. Define automated functions if this is possible.
ET13 **Mandatory**	Legal basis: a) ensure that there are sufficient technical capabilities for asking consent as part of the service and that the consent is documented properly (obligatory); b) build up a repository where consents can be collected centrally (optional – to be defined if it brings value to SHAPES). Note that there are also users who cannot give their own consent but it is given by a legal representative. Harmonized process (several consents)
ET15 **Mandatory**	Automated decision-making: Ensure that there's a capability to re-direct the decision to a manual process.
ET18 **Mandatory**	Personal data breach: create capabilities to identify potential personal data breaches and identification of personal data breaches.

Co-creation of SHAPES with end-users

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GE8 **Essential**	Note that the participation of older persons in the development of SHAPES can in itself be seen as a service that supports a person's human capabilities. Ensure that end-users have real power and impact in service development as part of the SHAPES ecosystem.
GE9 **Essential**	Consider working methods and tools in the end-user collaboration so that they support a person's capabilities and ensure that essential information on end-users' needs is captured. (incl. the use of suitable service design tools in order to acquire and communicate properly end-users needs). Create/investigate tools for agile and ethically justifiable co-creation/design in SHAPES with its various stakeholders.

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