

SHAPES

Smart and Health Ageing through People Engaging in supportive Systems

D2.6 – SHAPES Personas and Use Cases V2

Project Title	Smart and Healthy Ageing through People Engaging in Supportive Systems
Acro	SHAPES
Grant Number	857159
Type of instrument	Innovation Action
Торіс	DT-TDS-01-2019
Starting date	01/11/2019
Duration	48

Work package	WP2: Understanding the Lifeworld of Older Individuals and Improving Smart and Healthy Living
Lead Author	Peter Tavel (UP)
Contributors	Eva Dubovska (UP), Zdenek Meier (UP), Radek Trnka (UP), Markéta Pešoutová (UP), Jana Cohlová (UP), Rania Pinaka (5thYPE), Vagelis Stamatiadis (5thYPE), Fotios Gioulekas (5thYPE), Athanasios Tzikas (5thYPE), Konstantinos Gounaris (5thYPE), Lucia D'Arino and Rune Jensen (WFDB), Pedro Roche (UPORTO), Sari Sarlio-Siintola (LAUREA), Aletta Purola (LAUREA), Pedro Rocha (UPORTO), Paul Isaris (SciFy), Melanie Labor (NUIM), Sonja Grigoleit (FhG), Katja Seidel (NUIM), David Prendergast (NUIM), Jamie Saris





	(NUIM), Ana Martins (UPORTO), Bárbara Guerra (EDGE), Claudia Berchtold (FhG), Fotis Gonidis (GNOMON), Waihang Shek (OMNITOR), Andreas Andreou (UNIC), Ioanna Dratsiou (AUTH)
Peer Reviewers	Sara Cooper (PAL), Nicola Goodfellow (NHSCT)
Version	V2.0
Due Date	30/10/2020
Submission Date	30/11/2020
Dissemination Level	PU Public

Revision History

Table 1: Revision History

Revision #	Date	Editor	Comments
0.1	30.09.2020	Sari Sarlio-Siintola (LAUREA)	Ethics and Security Issues elaborated
0.2	1.10.2020	Rania Pinaka (5thYPE), Vagelis Stamatiadis (5thYPE), Fotios Gioulekas (5thYPE), Athanasios Tzikas (5thYPE), Konstantinos Gounaris (5thYPE),	Pilot´s persona added
0.3	8.10.2020	Pedro Rocha (UPORTO)	Pilot's persona added
0.4	12.10.2020	Paul Isaris (SciFy)	Pilot's persona added
0.5	15.10.2020	Radek Trnka (UP), Eva Dubovská (UP)	Development of multicriteria evaluation of pilots´use cases, broader context of personas, additional personas
0.6	12.11.2020	Sara Cooper (PAL)	Internal revision
0.7	13.11.2020	Nicola Goodfellow (NHSCT)	Internal revision
1.0	30.11.2020	Zdeněk Meier (UP), Markéta Pešoutová (UP)	Final version



Table of Contributors

Table 2: Deliverable Contributors

Section	Author(s)
Introduction	Radek Trnka (UP), Eva Dubovská (UP), Peter Tavel (UP), Zdeněk Meier (UP)
Background	Radek Trnka (UP), Eva Dubovská (UP)
Methods of Personas Development	Eva Dubovska (UP), Eva Dubovská (UP), Peter Tavel (UP), Zdeněk Meier (UP), Markéta Pešoutová (UP), Rania Pinaka (5thYPE), Vagelis Stamatiadis (5thYPE), Fotios Gioulekas (5thYPE), Athanasios Tzikas (5thYPE), Konstantinos Gounaris (5thYPE), Pedro Rocha (UPORTO), Paul Isaris (SciFy)
Use Cases Development	Radek Trnka (UP) and UP team, Rania Pinaka (5thYPE), Vagelis Stamatiadis (5thYPE), Fotios Gioulekas (5thYPE), Athanasios Tzikas (5thYPE), Konstantinos Gounaris (5thYPE)
Ethics and Security Issues	Radek Trnka (UP), Markéta Pešoutová (UP), Sari Sarlio-Siintola (LAUREA)
Future Challenges and Risks	Radek Trnka (UP), Peter Tavel (UP), Zdeněk Meier (UP)
Conclusions and Fulfilment of Goals of Task 2.5	Radek Trnka (UP), Peter Tavel (UP), Zdeněk Meier (UP)

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
юТ	Internet of Things
NUIM	National University of Ireland Maynooth
OBJ	Objective
PACT criteria	Program of Assertive Community Services





RA	Receiving Agent
RO	Registration Operator
ТР	Technological Platform
UP	Palacky University Olomouc
5thTYPE	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

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Executive Summary

The second deliverable presents the development of personas and use cases between M10 and M12. This report presents the multi-Work-Packaging developments within the SHAPES project. In the previous stage, several initial evidence-based personas that mirror the basic types of users of the solutions provided by SHAPES were developed. Continuing forward with this work, this deliverable presents newly reframed evidence-based personas and considers also the very recent impact of the COVID-19 pandemics on the mental health and computer use of older adults. Recently, COVID-19 elicited a strong wave of fears, anxieties, and psychological distress which spread rapidly throughout most of the world. Merely older adults belong to highly vulnerable groups of population due to increased isolation, loneliness, and worsening most of their previously existing mental health conditions like depression, anxiety, dementia and psychosis. This deliverable considers this actual situation and emphasises the key importance of online health interventions for older adults.

Therefore, the first section of this report focuses on the personas. Their development and extensive context of each and one of the presented personas' life, needs, health challenges etc. The second section is dedicated to the development and description of general use cases. Followed by the third section that probes in the development of personas and use cases. Method is based on a multiple-criteria evaluation approach to variations in persona's parameters. This section finishes with presented collaboration with WP2 and WP6. This collaboration is shown through co-created personas. Forth section is dedicated to ethics and security issues.





1 Introduction

To provide 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 Europe, this deliverable also introduces a new method for the development of connections between personas and use cases. Before the start of the SHAPES project, well-established methods for the development of connections between personas and use cases were not available. The recent deliverable introduces a 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, economical situations, digital literacy, health literacy, and affinity to ICT technologies. This method is based on a multiple-criteria evaluation approach to variations in persona's parameters. In this deliverable, this method was also used for the demonstration of the development of connections between a demonstrational persona and use cases developed within WP 6. This method is now ready to use in all the Pilot sites of the SHAPES Platform. Furthermore, the links between the personas, use cases and pilot's scenarios were also newly developed. All these progressive developments presented in this deliverable represent a significant shift in fulfilling the SHAPES strategic objectives, namely to create the SHAPES Ecosystem for active and healthy ageing allowing the identification of current and future solutions for active and healthy ageing, and build and deliver a broad range of interoperable solutions to improve the health, wellbeing and independence of older individuals.

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 cooperation with the other WPs, especially WP3 and WP6, the knowledge of the experts of these WPs based on their activities and mutual discussions has been included as well. Furthermore, the personas have been extended with data obtained through the analysis of the interviews with the target group. A clear methodological context of the link between uses cases and personas that were described as the basic source in the first report is presented. Use cases are listed in a broader context and on the basis of different possible perspectives. A persona accentuating the current pandemic situation has been added with its opportunities and losses. Moreover, collaboration with pilot sites is demonstrated in the last chapter proposing new co-created personas. 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, attitudes, behaviours and characteristics are considered to be evidence-based knowledge bases that provide models of users of future SHAPES digital solutions and innovations. Utilizing a human centred co-design process, basic use cases were planned to be developed illustrating the interactions between users and the SHAPES digital solutions and innovations and innovations in order for the future assessment of functional and non-functional SHAPES platform features. Task 2.5 is designed 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.

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, basic personalities were developed. These were enriched by real-life experiences of people and thus the personas became connected with the lived reality of old people. 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 are key to the pilot pages of the solution in the SHAPES project and offer inputs and important facts for technical solutions. Contact between findings from the primary target group is essential for the comprehensive development of the SHAPES platform.

1.1.1 Deliverable objectives

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

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

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

1.1.2 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, basic personas and general use cases are planned to be developed to represent a knowledge base that will be subsequently further developed and adapted within WPs and Tasks. Despite basic personas and general use cases being planned to be a kind of prototypes in nature, they are not final versions, since they will be modified, adapted, and fine-tuned during further development of SHAPES. Thus, basic 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 case are therefore the key starting point of the pilot sites and their development of scenarios (WP6). Furthermore, the personas are important input for the work of WP3.

Another key input for D2.6 was the feedback from the Technical review. Based on the feedback this iteration brings further storytelling and details to the personas' background. Moreover, it clearly states the connection between the personas and use cases. Finally, proves the integration with WP6 through collaboration on new personas in the pilots' use cases.

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

1.1 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 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. At the end of Chapter three, ten final personas are presented. 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 pilots' sites. Chapter six deals with the ethical aspects 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). For example, 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. As a matter of fact, 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 probs in the understanding of older adults. Personas in detailed context are presented in chapter 3.

And 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. As a matter of fact, Task 2.5 contributes to the improvement of integrated care of older individuals in the EU.

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 the WP4, especially Task 4.1: SHAPES TP Requirements and Mapping a Reference Architecture. Based on the use cases developed





within Task 2.5, the Task 4.1 will start with the assessment of the functional and nonfunctional 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 a background in 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 of users. In other words, Task 2.5 provides 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's 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 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 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.

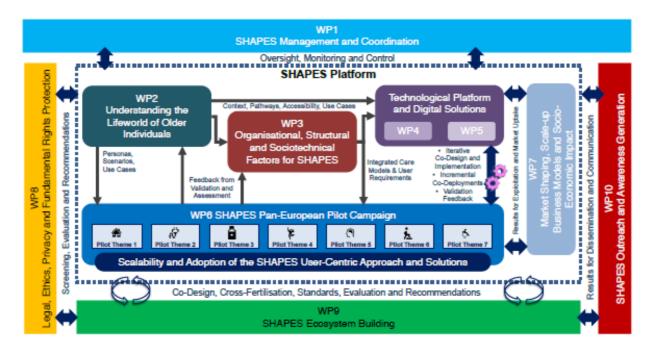


Figure 1: SHAPES WP Structure and Interdependency





2. Background

This chapter describes the theoretical base 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, known also 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 uses 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 registration operator.

2.2 Theoretical background

The main understanding of the SHAPES digital solutions and innovations can be settled 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 aging (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 personenvironment 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.





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 the 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 an 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 on this stage of the project. We also incorporated the new approaches suggested by The World Federation of 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.

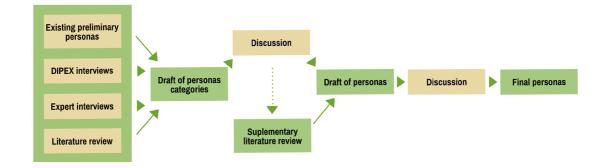


Figure 2: Personas Development

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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)
- 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 geriatric doctors (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

At first 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 eight personas were introduced and in the second phase two new personas (persona 9 and 10) were created based on the feedback from project partners, mainly pilot leaders. As the project develops we consider the number of personas not to be final, as they form a basis for further discussion with other technological partners, designers and pilot leaders, etc.

3.1.2 DIPEx methodology

As the data from the DIPEx study has a significant role in the development of personas, we will shortly introduce 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 realized in the Czech Republic between





2014-2015. Within this active ageing project 50 in-depth interviews were conducted with 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.

3.2 Categories (or segments) representing personas

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 work.

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). The physical activity is one of the main determinants in keeping of 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." 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)

The first persona, Ernst, 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 wellbeing. 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 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.







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 stressed out 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 the 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 they had not prescribed for. 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





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 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, they know nothing."

Experts in the interviews were pointing out to the importance of behaviour 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)

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.

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.

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 (lezonni, 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" (lezzoni, 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. (lezzoni, 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, 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 groundlevel part of the house with the help of her family. The lack of movement makes the 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.

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 guick 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, 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, in Třebíč, look." 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 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." Mat'ka (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)

The persona description introduces an elderly Spanish lady Isabella 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 Isabella's there is some aid available, there is still a large gap present. In Isabella'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 Isabella.

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, 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 case is the description of 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.

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

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 means 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 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 one eye, the medics where there. And they 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 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 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 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.

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 deliriums), 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 of 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).

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 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.

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 elderly person, 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 Mr. 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.

Jiřina (91) requires constant care. She can no longer take care of herself. She is immobile, so she can only sit up or lay 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 primarius in geriatrics. 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 make 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, Milos'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" Matka (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 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 selfsufficiency. 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)

Helena 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. 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.

3.2.8 Older adults with deafblindness (older adults with a dual sensory impairment)^{P8}

The following persona represents people with a concomitant sight and hearing impairment. 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 their social and economic participation of persons with deafblindness, as well as increases their 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 deafblind people 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).

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





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

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 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 impaired functioning—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 the deafblind and any hearing or sight-aids Frederik might need. Furthermore, a national association for the deafblind of Norway organises courses for the deafblind and their close ones (relatives, friends) which can help their adjustment and teach key competencies needed. With the support and help, perhaps 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.

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

3.2.10 Impact of the COVID 19 pandemics on the mental health and computer use of older adults^{P10}

The last persona is dedicated to the impact of the COVID 19 pandemics. 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 has also 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 (Krendl, van Tilburg), worsening of all the existing mental health conditions like depression, anxiety, dementia and psychosis (Forlenza). The pandemics 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.

3.3 Final Personas

The personas 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.





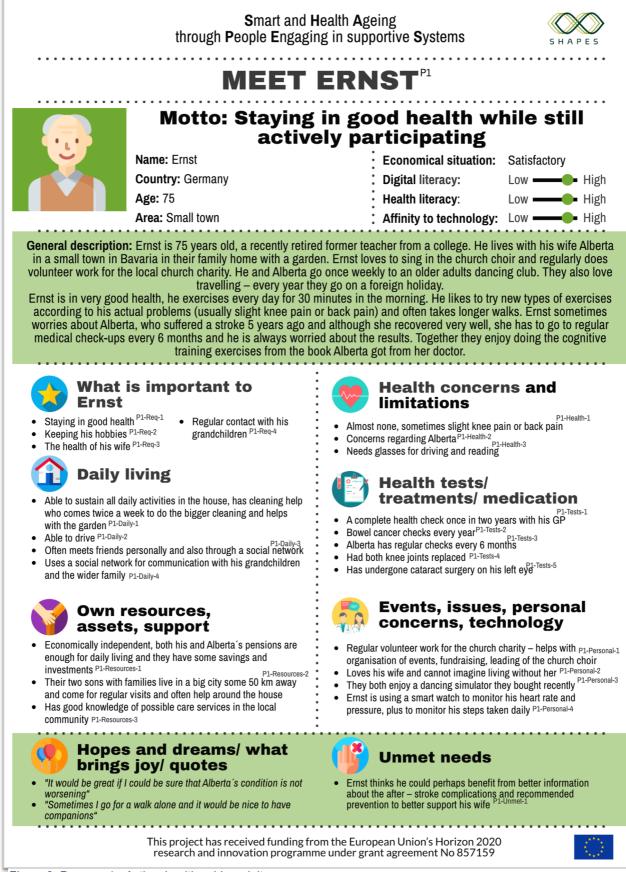


Figure 3: Persona 1 - Active, healthy older adults





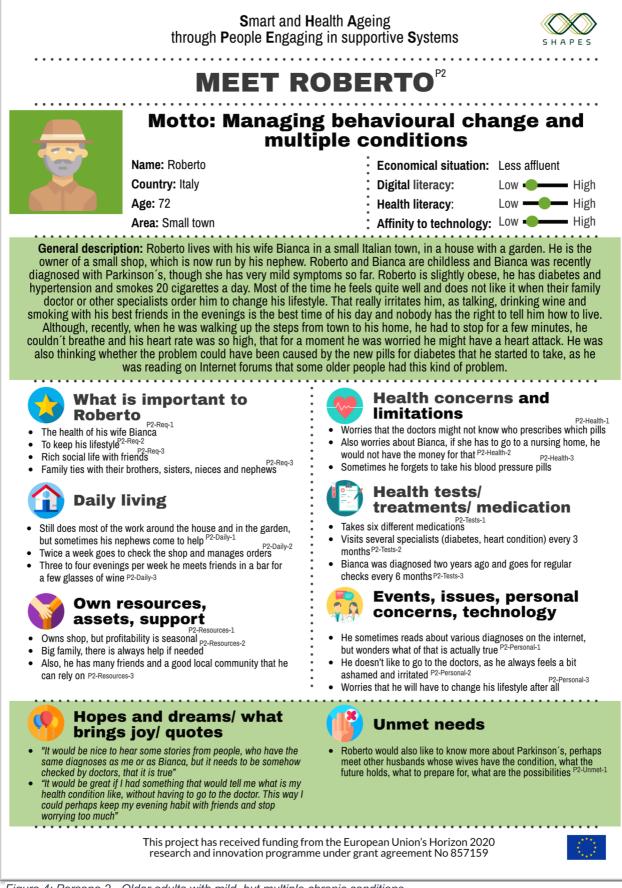


Figure 4: Persona 2 - Older adults with mild, but multiple chronic conditions







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





Smart and Health Ageing through People Engaging in supportive Systems MEET ISABELLA AND MARCO Motto: Reimagining care while maintaining dignity; support of informal caregivers Name: Isabella and Marco Economical situation: Less affluent Country: Spain Low — High **Digital literacy:** Age: 75 Low — High Health literacy: Area: Small town Affinity to technology: Low — High General description: Isabella 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 checkup three years. Isabella 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, Isabella 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 Isabella every day, does the chores, brings food. But he also has a part-time job in a factory, so he is often fired, worried and frustrated. He started to experience strange mood swings, especially when Isabella 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. Health concerns and What is important to limitations **Isabella and Marco** Maintain dignity and self sufficiency Cognitive impairments Keep social contacts^{P4-Req-2} Unhappy with the thought of her son taking care of her, she does Stay in home care as long as $\text{possibl}^{\text{P4-Req-3}}_{\textbf{Req}}$ not want him to help with hygiene, always waits for the nurse to visit P4-Health-2 Help Marco to better cope with the caregiving situation Health tests/ **Daily living** treatments/ medication Complete health exams every 2 years P4-Tests-1 P4-Daily-1 Able to do lighter chores, but keeps losing things Often experiences a lack of meaningful activities, feels bored Pills for cognitive symptoms P4-Tests-2 Often forgets to take her medication P4-Tests-3 **Events, issues, personal Own resources**, concerns, technology assets, support P4-Resources-1 Isabella has a small pension, but partly dependent on Marco and Isabella is most frustrated when she forgets names of close ones also on his wife, who sometimes comes to do the chores Marco is worried that something will happen to her P4-Personal-2 Hopes and dreams/ what **Needs of caregiver** brings joy/ quotes Be able to have up to date information on the development of the illness "What about some electronic box to which I could store all my Monitoring of all sorts of possibly dangerous situations in the house memories and it would talk to me and I could ask it whenever I can (fire, gas, electricity) F 't remember" (Isabella) Peer support groups, information, education, nutritional help, emotional support P4-CgNeeds-3 P4-CgNeeds-4 "If there was some possibility to keep an eye on mum, something Respite care to be able to go on holiday P4-CgNeec Some technology that would help to keep his mother busy and focused that wouldn't scare her, but would alert me if anything goes wrong, -CgNeeds-5 that would be great"(Marco) P4-Unmet-1 Missing some cognitive training P4-Unmet-2 Increase personal safety to be able to get out of the house more Unmet needs In-home activities customized to her interests and capabilities This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 857159

Figure 6: Persona 4 - Older adults with neurodegenerative diseases











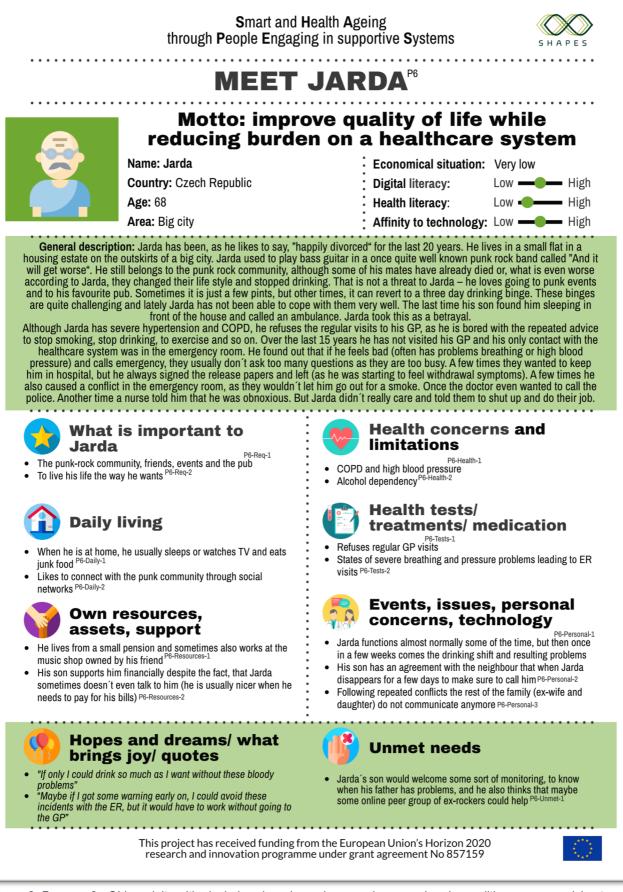


Figure 8: Persona 6 - Older adults with alcohol or drug dependency and severe chronic conditions non-complying to medical recommendations







Figure 9: Persona 7 - Oldest and frail





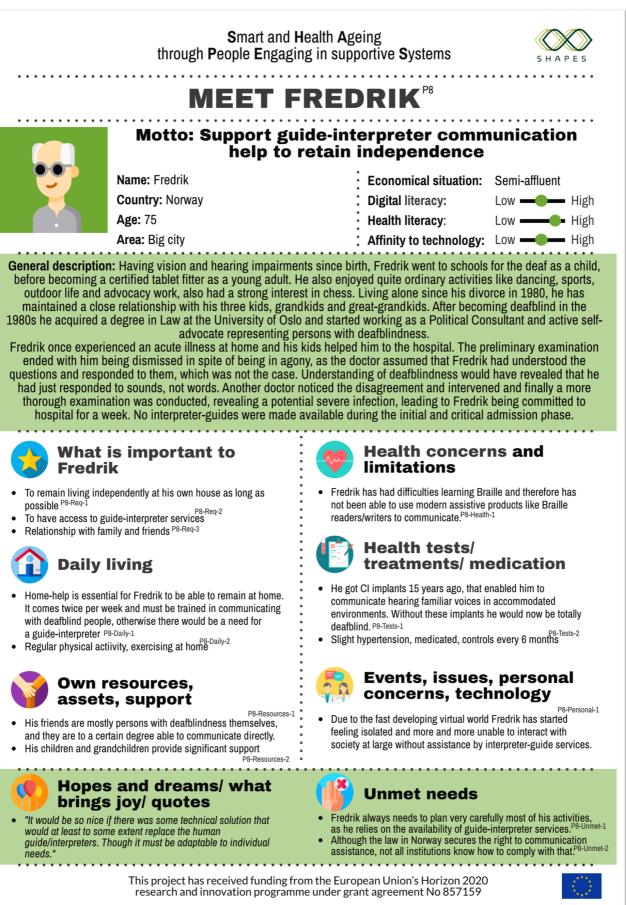


Figure 10: Persona 8 - Deafblind older adults (older adults with dual sensory impairment)





Smart and Health Ageing through People Engaging in supportive Systems



NEET ASTRID



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. Motto: Balancing own needs with care demands

Name: Astrid Economical situation: Less affluent Country: Belgium Low -🗕 High **Digital literacy:** Age: 53 Health literacy: 🗕 🗕 High Area: Small town 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. 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.



- 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 $_{\rm P9-Req-2}^{\rm P9-Req-2}$ To keep her friends, to be able to go on a date

Daily living

- Does all the chores while looking after Tessa
- -Daily-2
- Recently she had to limit her job in the kindergarten to part time 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

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

"It would really help having more friends / peers who are also

Hopes and dreams/ what



Health concerns and limitations

- Although she finds internet useful, it is difficult to manage the large volume of information for her $^{\rm P9-Health-1}$
- She would welcome to have some channel with tailored information that she needs for better caretaking P9-Health



Health tests/ treatments/ medication

- With Tessa they go for the doctor's check-up every 6 months She has help from a social nurse twice a week $^{\rm P9-Tests-2}$



Events, issues, personal concerns, technology

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



Unmet needs

- Be able to consult online on the development of Tessa's illness 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

moved online.

caregivers.





Smart and Health Ageing through People Engaging in supportive Systems



P10 **MEET ROBERTO** (after first wave of COVID 1



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 10^{-100} P10-Reg-1
- Family ties of their brothers, sisters, nieces, and nephews

Daily living

- Still does most of the work around the house and in the garden, but sometimes his nephews come to help P10-E
- 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
- Also he has many friends and a good local community that he can rely on $^{\rm P10-Resources-3}$

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.



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



Health tests/ treatments/ medication

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



Events, issues, personal concerns, technology

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



Unmet needs

- Online peer support group of patients with hypertension
- Online intervention to reduce smoking P10-Unmet-3 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





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 13).

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.





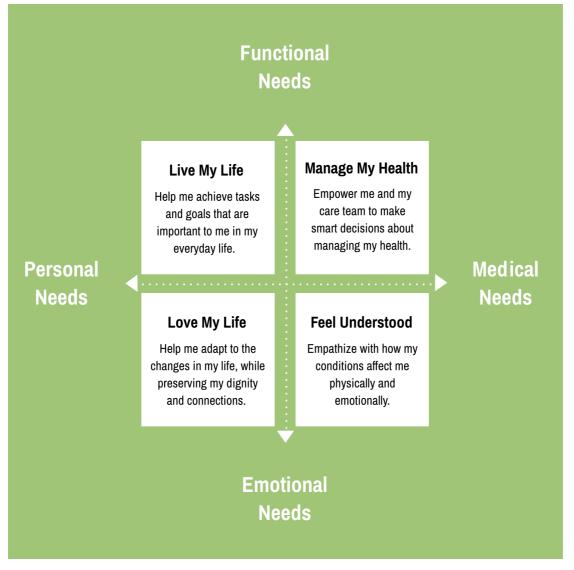


Figure 13: The Intersection of Needs (Source: Bhattacharyya et al. 2019)

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' 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.



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	ctivities 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 Activities always happen in a context, so there is a need t 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 sharpening 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 in offer of 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 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 aimed 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.,

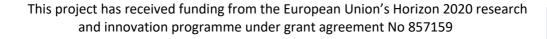




can also be serviceable across most personas, however, there is a requirement of the absence of neurodegenerative changes as these changes could possibly lead to ignoring or misleading of recommendations provided by the Self-Management of Chronic Conditions application. Thus, this use case is not suitable for Persona 4. In contrast, 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 the 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 motoric abilities and flexibility of a body.

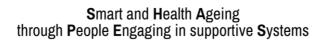
The set of general use cases includes various kinds of monitoring, Home Environment Monitoring, In-Home Glucose-Monitoring, In-Home Heart-Monitoring, In-Home Post-Hospital Aftercare, In-Home Video-Monitoring, and Location Tracking. These monitoring devices serve different functions. For example, Home 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 electric 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.

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











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



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 RA is familiar with the time of device of
- RA is familiar with the type of device technology UC1-Precon-2 Device is working properly and is charged UC1-Precon-3

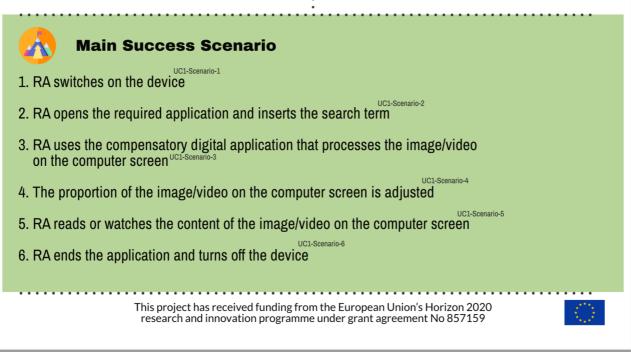


Figure 14: Use case 1 - Assistive Technology for Reading



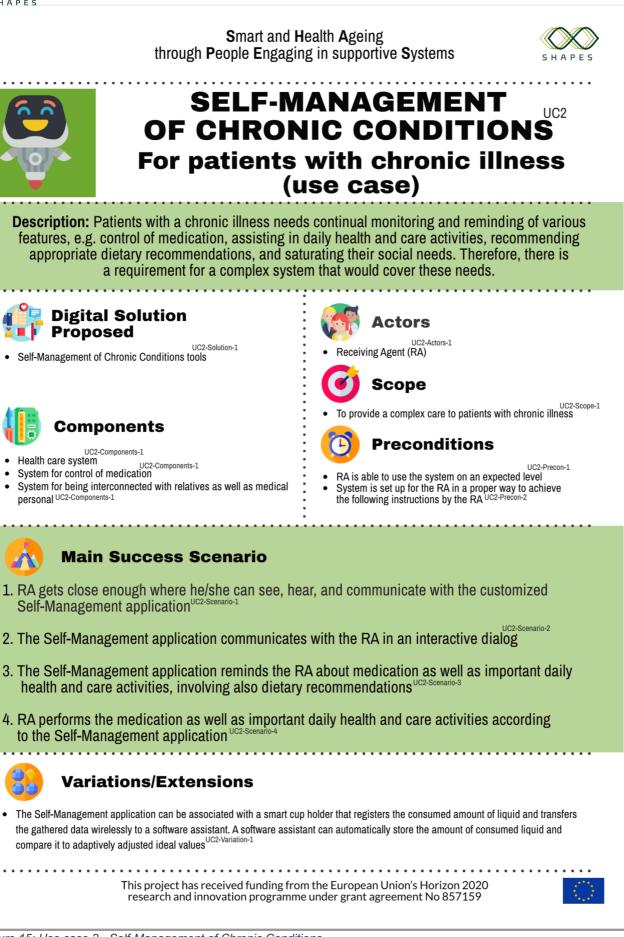
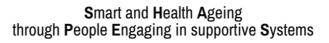


Figure 15: Use case 2 - Self-Management of Chronic Conditions

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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

UC3-Solution-1 Integrated sensor system for assisted living



Components

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



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



Actors

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

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
- 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.

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 $^{\mbox{UC3-Variation-1}}$

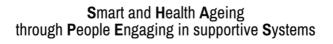
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Figure 16: Use Case 3 - Home Environment Monitoring

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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

In-home digital application enabling mental stimulation exercises



Components

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



Receiving Agent (RA)



To engage the RA with a cognitive stimulation task supporting the improvement of memory, attention skills, etc. $^{\rm UC4-Scope-1}$



Preconditions

- RA is able to communicate with the application on an expected level ^{UC4-Precon-1}
 UC4-Precon-2
- RA is familiar with a similar type of device / technology
 Device is unarrived in the second life presentation of the second life pre
- Device is working properly and is charged.^{UC4-Precon-4}

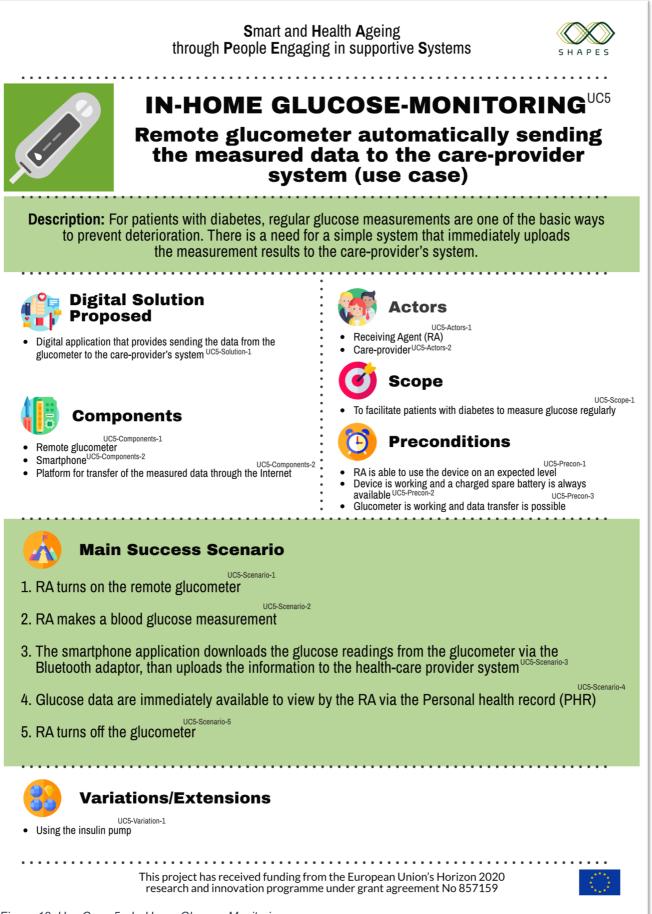
Main Success Scenario

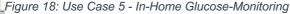
- 1. RA switches on the device
- 2. RA opens the application
- 3. RA creates and customizes the interaction mode for the engagement
- 4. RA chooses the interaction mode
- 5. RA plays mental stimulation games
- 6. RA ends the application and turns off the device



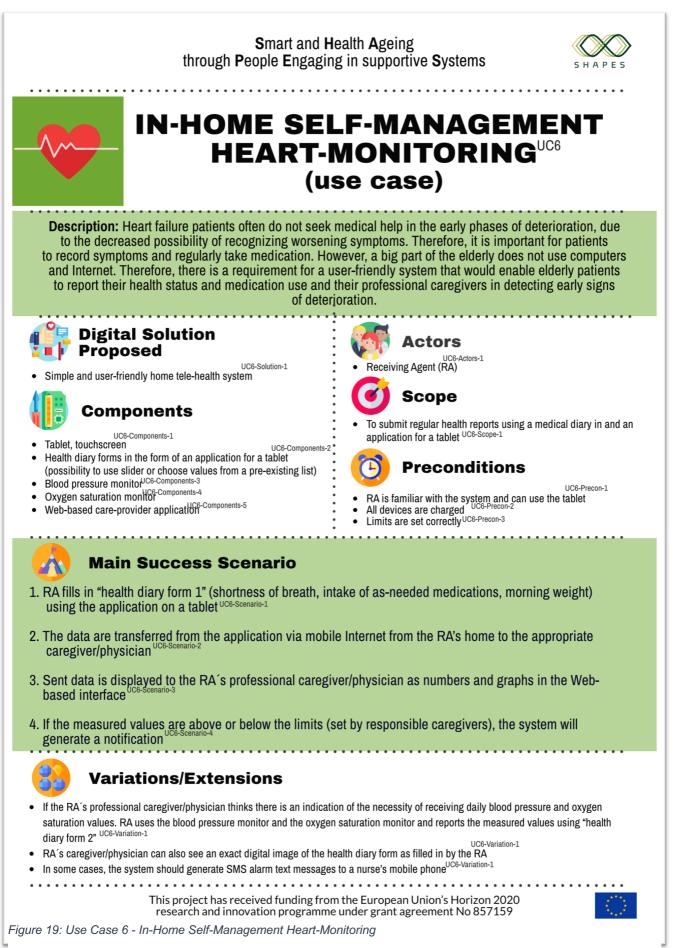
Figure 17: Use Case 4 - In-Home Cognitive Training



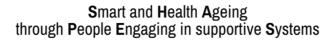














UC7-Scope-1



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

UC7-Solution-1 Tele-coaching tools



Components

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



Actors

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



- 1. RA gets close enough where he/she can see, hear, and communicate with the customized telecoaching application^U
- C7-Scenario-2 2. The customized tele-coaching application communicates with the RA in an interactive dialog
- 3. The customized tele-coaching application contacts the RO
- 4. RO has a dialog through the online platform in which he/she informs the RA about the actions required for his/her recovery^{uc}
- UC7-Scenario-5 5. RA conducts the actions required for his/her recovery

Variations/Extensions UC7-Variation-1 RO may have a dialog through the online platform in which monitors the RA's actual state and the continuation of recovery This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 857159



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Preconditions

Scope

System is working properly, charged and is tuned for user usage^{UC7-Precon-1} UC7-Precon-2

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

- Internet connection is working correctly RA is able to communicate with the system on an expected level ^{UC7-Precon-3}



Smart and Health Ageing through People Engaging in supportive Systems





IN-HOME VIDEO-MONITOR 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

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



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



Actors

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



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

UC8-Scenario-5



Preconditions

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

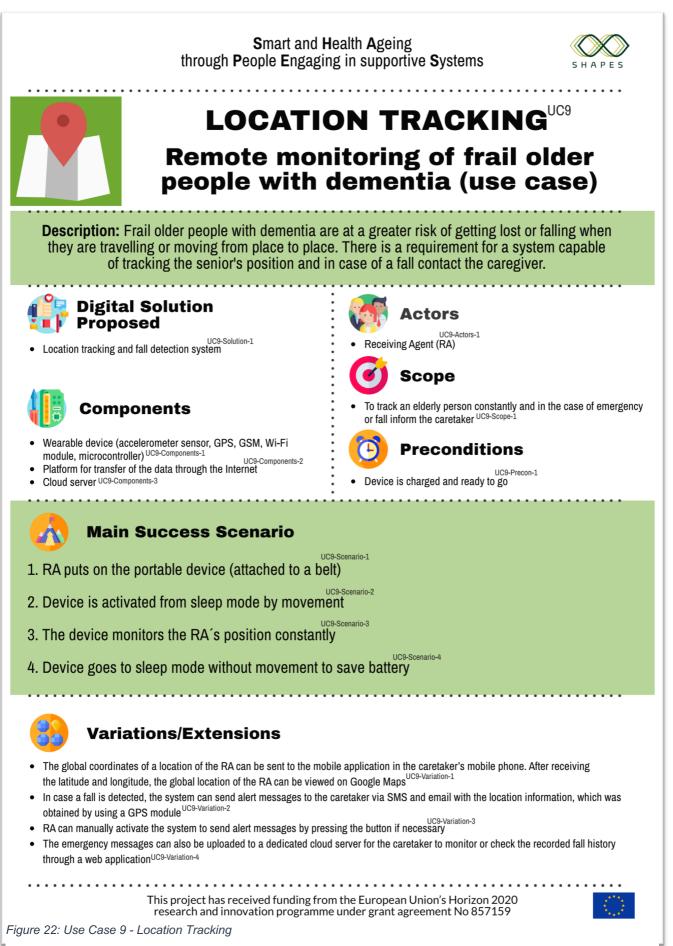


Main Success Scenario

- 1. All the movements of the RA are monitored by the accelerometer communicating with the homeserver via Bluetooth
- 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
- 3. When a fall has been detected, an alarm e-mail is sent to the caregivers (doctor and the RA's relatives) ^u
- 4. When the caregivers receive an alarm e-mail, they can review the fall scene video through the Information-sharing platform
- 5. Otherwise, the system terminates the current detection and goes back to the initial state













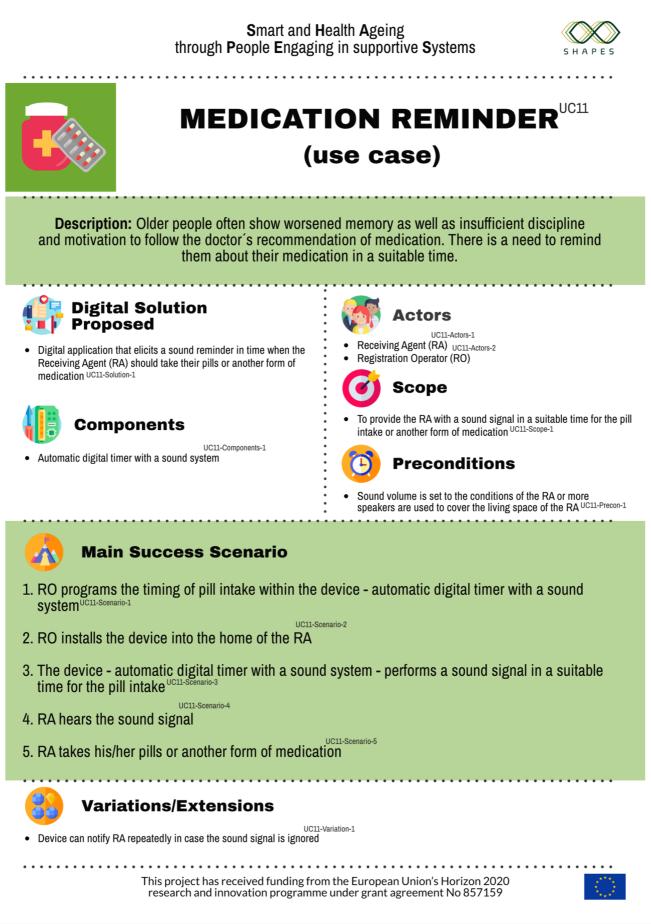
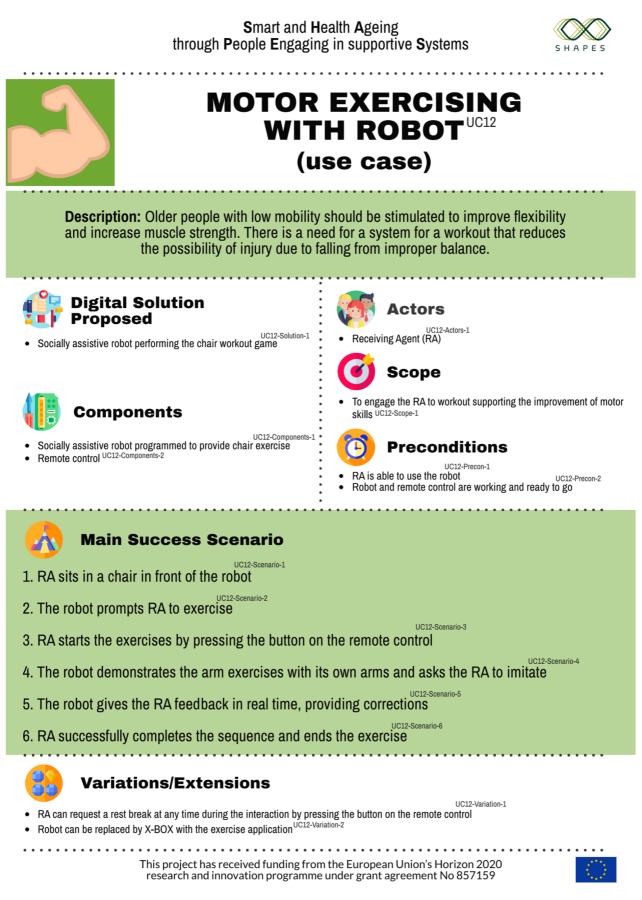


Figure 24: Use Case 11 - Medication Reminder

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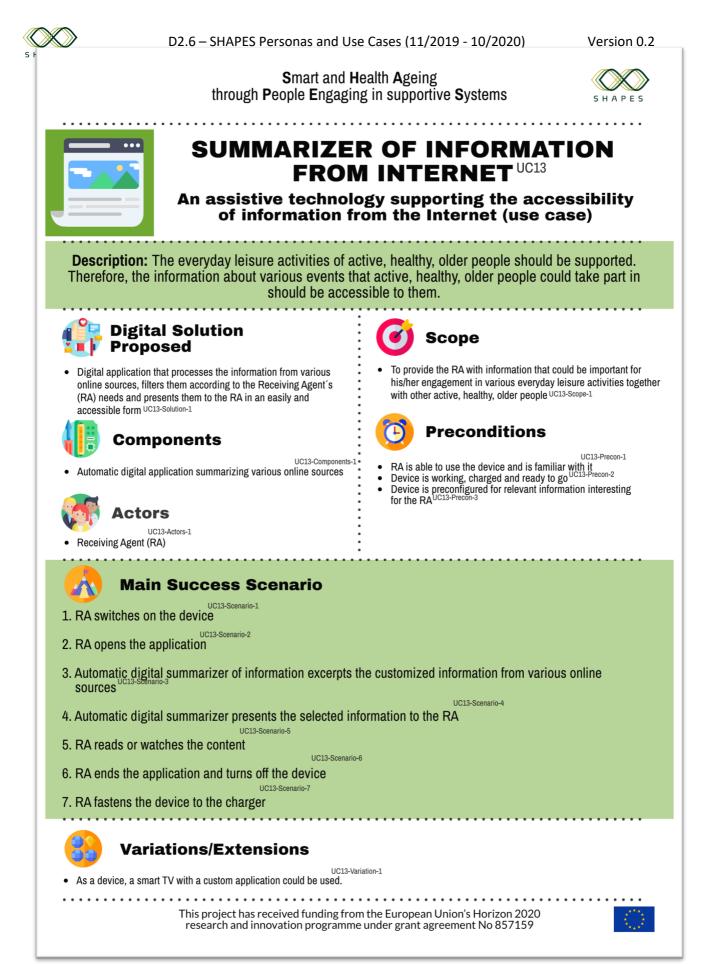


Figure 26: Use Case 13 - Summarizer of Information from Internet



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 there are no well-established methods for this task that would be recently 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 for 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 for 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 for linking the Use Cases to the Personas?





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, recently there is no model of complex geriatric patients available. Therefore, the background used for the understanding 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 27; Manning & Gagnon, 2017).

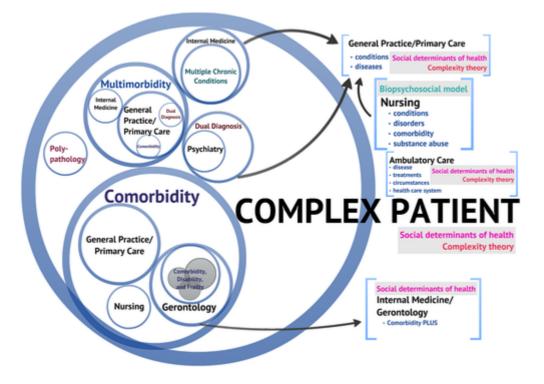


Figure 27: The model of the complex patient (Manning & Gagon, 2017)

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





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 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. Apparently, 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





- 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):

- 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 on 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





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 that were developed within WP6 are used for the demonstration of multiple-criteria evaluations of the connections between the Personas and the Use Cases. In short, we can summarize them as follows:

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 ...)
- The system must be simple to use, low cost and send messages to SHAPES TP once the device is turned on or off by the user

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 speechbased 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")
- Survey tool

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 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)

UC-PT5-005-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)

• Support user-centred and active learning

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. (VICOM)

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 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

• 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
- DigiRoom

5.7. Multiple-criteria evaluation of suitability of Use Cases

The suitability of 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 individual use cases involved. In the following text, qualitative explanations of suitability/unsuitability of individual use cases for Persona Roberto are considered:

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 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

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 a relatively good physical condition - he has smaller problems with walking but has enough strength enabling him to work on 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 screeen.

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 on 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

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

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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-PT5-005-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

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-PT6-003-3D Depth Camera Rehabilitation Tool

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-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.

The following Figure 28 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.





Version 1.0

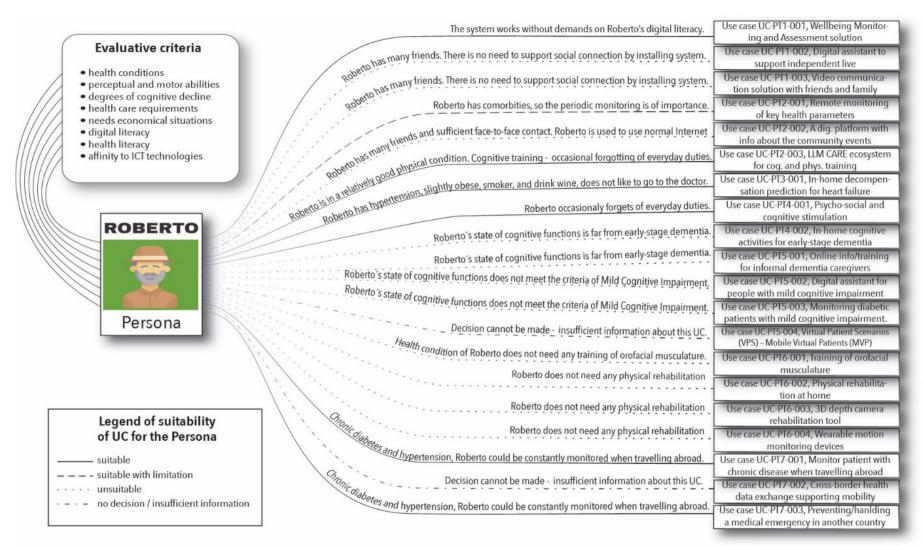


Figure 28: The results of the multiple-criteria evaluation of suitability of the Use cases for Persona Roberto

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This project has received funding from the European Union's Horizon 2020 research and No 857159





5.7 Application of personas and use cases in pilot's work

Personas and general use cases were created to bring the real-life experience from older adults into the SHAPES ecosystem. However, as the number of the personas is limited our pilot partners collaborated with UP to create their own prototype participant. The personas in the previous chapters were used as a main source. Here are few examples of the work of T2.5 impacting the pilots' work.



5.7.1 $5^{TH}YPE$ – Maria in Pilot Theme 7

Figure 29: 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 5*), 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 29*):

1. The use of the SHAPES Personas as a starting point (Deliverable 2.5)





- 2. A bottom-up capitalization on what constitutes the Greek landscape out in the field (*Table 5*)
- 3. The use of 5thYPE's knowledge from previous e-Health European Research Programs (*Figure 30*)

Table 5: 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	
Са	Transport and Mobility	
Respiratory Diseases	Health, care, well-being	
Hyperlipidemia		
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 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 30):

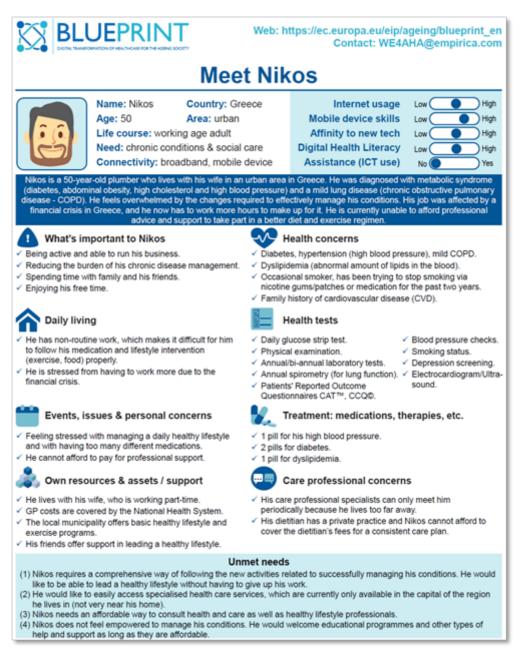


Figure 30: Nikos: a prototype for using MAFEIP-outcomes for Personas

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).



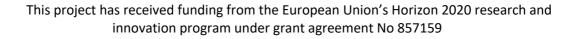
Maria lives in a village in central Greece. She has been a widow for 10 years. She has two children, one daughter who is married and childless and lives in the same village with Maria and a son who is married and has two children and lives in a nearby village. She used to work as a cook in her husband's 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, hyperlipidemia, obstructive sleep apnea 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 apnea 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 checks her blood pressure. Overall, she needs to see her GP for regular check-ups, an annual laboratory tests with specialists and an 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 for depression. From then on, she has received medication.





High

Smart and Health Ageing through People Engaging in supportive Systems



P11 MEET MARIA



Motto: Support guide-interpreter communication help to retain independence Name: Maria

Country: Greece Age: 69 Area: Small village

Life Course: Retired

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

High High

Maria lives in a village in a two-story 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 to work 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 with 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
- Social life with friends P11-Rec
- Limiting risk of falls P11-Req-3 P11-Reg-4
- Having always something to do

Daily living

- Loves cooking for family and friends Often meets friends personally^{P11-Daily-2}
- Often meets friends personally Plany 2 Plany 2
- Once a month she goes on a trip to monasteries with her friends

Own resources, assets, support

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

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'

Health concerns and limitations

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



Health tests/ treatments/ medication

- Takes 8 different medications p11-Tests-1 Regular health checks by the GP •
- Visits several specialists (cardiologist, pulmonologist) once a year P11-Tests-3 Uses CPAP machine



- **Events, issues, personal** concerns, technology P11-Personal-1
- Regular volunteer work for the church charity
- She used to go more excursions, but now she does not trust her knees^{P11-Personal} . sonal-3
- She likes knitting
- She would like to have a smart watch to monitor her heart rate and pressure and an oximeter to measure saturation P11-Perso

Unmet needs

- Easier pain and health status management that would not require a personal visit to the doctor
- asser pain and nearin status management that would not require a personal visit to the doct formunication with the physicians and various caregivers. Nonitoring her vital signals and nedication adherence will prevent health status degradation P11-Unmet2 diet that she could follow on her own is a problem P11-Unmet3 terminders about the physical activities to perform or meals to follow to be empowered to kee n a daily nutrition plan P11-Unmet4

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 857159

Figure 31: Persona 11

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5.7.2 UPORTO – John and Joan in Pilot Theme 5

The power of intimate relationship

Theoretically, it has already been studied that intimate relationships between a couple are a great positive impact on well-being and life satisfaction, as well as for health and physical health and life expectancy. In this regard, some studies find positive impacts of intimate relationship quality and sleep patterns, health and well-being, sexual orientation, and caregiver straining.

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).

Thereby, a new Persona has been designed and proposed by this Use Case, which was inspired by SHAPES Personas, "P1. Ernst, P3. Ayesha, P4. Isabella and Marco, 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.

Meet John and Joan. Joan is John's second spouse. John's first spouse died during childbirth, and he became 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 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, rest, 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.

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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 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.



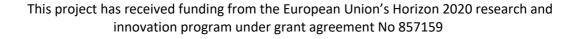


John' first son, Alberto, is living in Boston (USA) and he invited his parents to visit him. John's son had planned to take his father to an American expert, but the diagnosis was the same. However, during Alberto's stay, an unexpected solution came up for John and Joan. Alberto had Alexa on, a digital 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 \in 1,000. Joan worked in education as an elementary school teacher; her highest salary was \in 1,500. They live with two retirement pensions totalling \in 2,500. Note: minimum salary is \in 600. As for the 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 private health care systems. Moreover, there is no database with a public health history of the individuals.

This persona is used in UC_PT5_002 scenario development.







Smart and Health Ageing through People Engaging in supportive Systems



MEET JOHN AND JOAN 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 more three years working, until 70 years old. When he retired, they remodelled its house thinking on ageing issues. Suddenly, John started forgetting things, meetings or could not remember past events. John decreased him 'normal' performance for carrying out the instrumental activities of daily life: he woke up later and did not sleep regularly; John stopped to walk every day and run weekly; he remained most of time watching TV or reading. Joan's GP did a MMSE test, that shows cognitive decline. John accepted the diagnosis very well and he didn't want to become a burden for Joan. For that reason, he created an agenda for the couple 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.
- To support their children independence and autonomy during adulthood. P12-Req-2
- To maintain a high-level of their quality of life, especially the autonomy and independence. $^{\rm P12-Req-3}$



- · Basic daily life activities: preparing meals, medication, personal hygiene, home and clothes cleaning, shopping etc.^{P1:} Physical exercise ^{P12-Daily-2}
- Social and cultural routine: call (diary) and met (often) family and friends; participate on local events (celebrations, music).^{P12-Daily-3}



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

Hopes and dreams/ what brings joy/ quotes

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

Health concerns and limitations

- John was tested with MCI disorders and Joan had a breast cancer and she did a surgery.
- 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).

Health tests/ treatments/ medication

- Complete health exams each year.
- Cognitive training / therapist for John Therapist for Joan^{P12-Tests-3} P12-Tests-3
- Neurologist examination for John

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-Person
- Technology interest is gradually increasing for John and Joan routine, especially after the Covid-19 lockdown, namely the social networks and videocalls. P12-Personal-3

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, sufficiency of street lighting, and paths and pavements P1

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 857159

Figure 32: Persona 12

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5.7.3 SciFy – Dimitris in Pilot 2

The last persona was created by the partner SciFY. They conduct their pilots in the second theme using Talk and Play app. 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 crucial 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 gained 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 of resources does not allow such centres to accept these conditions. Fortunately, him 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

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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' 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 out of 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' 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 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.

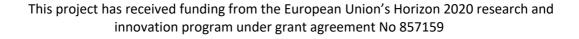






Figure 33: Persona 13

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6 Ethical requirements

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 6: 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 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 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 lead to the creation of a specific persona (8).
Capabilities approach (3.4)	The use cases in this deliverable are mostly related to persons capabilities for bodily health and life (use cases 2, 4, 5, 6, 7,9, 10, 11, 12). However, 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 environment. Use cases related to monitoring (8,9) are critical since they may violate the integrity of persons if not designed carefully
Sustainable Development and CSR (4.1)	N/A

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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.
	The following use cases support digital inclusion:
Digital inclusion (7.1)	-Summarizer of Information from Internet -Assistive Technology for Reading
	Especially the following use cases are related to the new roles of end-users:
The moral division of labor (7.2)	-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 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].

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).

Comments: ____





7 Future Challenges and Risks

As mentioned above, the main goals of Task 2.5 were to develop basic personas and general use cases. However, it is necessary to say that the SHAPES team is at the beginning of a 4-year SHAPES project, so initially, the basic personas and general use cases represent a rather basic background than final prototypes. The future challenge will be to adapt and modify the basic personas and general use cases to particular conditions of the pilot sites (for the Pilot Themes of WP6). The collaboration has been already established after the first iteration of this report. However, it is still a big part of the T2.5 impact in the SHAPES project. Furthermore, the collaboration has been shown by the co-creation of detailed personas of different pilot's sites. Moreover, for the third iteration this challenge will be addressed by creating the final line between personas – general use cases – pilots' use case – scenarios and overall user requirements.

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 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 34 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 34).





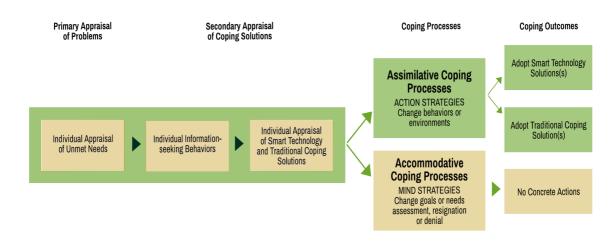


Figure 34: Individual Appraisal and Coping Processes Underlying the Adoption of Coping Solutions (Source: Golant, 2017)

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.





8 Conclusion

As proposed in the original project proposal of the SHAPES project, Task 2.5 had two 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

Both of these objectives have been 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 ten original personas plus three "co-created" that are ready to be used in future stages of the SHAPES project and compared to the previous stage have been enhanced by two new personas to better represent the needs of the informal caregivers and also show the impact of the COVID-19 pandemics on mental health, social relationships and development of computer literacy in older adults. The methodology of the persona development was advanced in this deliverable by persona stories and samples of data from DIPEx interviews as well as samples from expert interviews that were the foundation for the personas' development.

Moreover, the third objective of this deliverable: to develop connections between a demonstrational persona developed in this deliverable and use cases developed within WP6; has been fulfilled. This deliverable also introduces a new method for the development of connections between personas and use cases that is based on a multiplecriteria evaluation approach to variations in 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 WP 6 and it is now ready to use in all the Pilot sites of the SHAPES Platform. Furthermore, the links between personas, use cases and pilot's scenarios were also newly developed.

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 persona's parameters will enable better utilisation of the potential of both the personas and use cases pursuant to the project objectives and tasks. In the next phase we want to finish the line of personas – general use cases – use cases and scenarios in





collaboration with WP6 and the pilot's leaders. Our aim is to create a coherent concept feasible for further use within the SHAPES consortium and platform. Lastly, the personas will gain a final enrichment of further context and background.





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

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

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

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

Dupre M & Meadows S (2007). Disaggregating the effects of marital trajectories on health. Journal of Family Issues. 28(5): 623-652.

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. <u>https://doi.org/10.1017/S0144686X16000581</u>.

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

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

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

89





multidisciplinary approach. *Journal of Telemedicine and Telecare, 16*, 302-307. https://doi.org/10.1258/jtt.2010.006003

lezzoni, L. (2003). *When walking fails: Mobility problems of adults with chronic conditions* (Vol. 8). Berkeley, CA: University of California Press.

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

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

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. <u>https://doi.org/10.2147/CIA.S80280</u>

Monitoring and Assessment Framework for the European Innovation Partnership on Active and Healthy Ageing (MAFEIP). *United4Helath*. Online: <u>https://www.mafeip.eu/sites/default/files/MAFEIP_UC8_U4H.pdf</u>

Monitoring and Assessment Framework for the European Innovation Partnership on Active and Healthy Ageing (MAFEIP). *Renewing Health: Telemonitoring for Type 2 Diabetes Patients in Thessaly, Greece.* Online: <u>https://www.mafeip.eu/sites/default/files/MAFEIP_UC13_Renewing%20Health_Greece.p</u> <u>df</u>

Manning, E., & Gagnon, M. (2017). The complex patient: A concept clarification. *Nursing* & *Health Sciences, 19*(1), 13-21.

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.





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

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.

Marmot M (2005). Social determinants of health inequalities. Lancet. 365(9464): 1099-1104.

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/

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.

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

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

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. <u>https://doi.org/10.1016/j.jsat.2005.08.007</u>

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

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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

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, <u>https://doi.org/10.1080/14427591.2019.1600159</u>

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.

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.

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

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. <u>https://doi.org/10.1111/j.1365-2929.2006.02467.x</u>





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.







Appendix

APPENDIX I. LIST OF THEMATIC CODES FROM DIPEX STUDY

Category	Thematic codes
Experience of aging	
	Physical changes
	Retirement
	Attitude toward 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 societ	У
	Attitudes of society toward older people
	Expectations from older adults
	Generational differences
	Opinions on the social situation
	Ageism / stigma
Cognition in older ag	je
	Memory
	Cognitive training
	Dreaming
	Sleep
	Forgetting
	Cognitive decline
General health	
	Health condition 95

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	Health problems
	Pain
	Medications
	Relationship to doctors and healthcare
	Supplements and aids
Health problems ab	Impact of the illness on the well-being in old age
Health problems - ch	High blood pressure
	nigh blood pressure
	Diabetes
	Stroke
	Cardiovascular problems
	Monitoring
	Health checks
Health problems - co	
	Dementia and needs
	Dementia and relationships
	Memory loss
	Caregivers
	Fear of dementia
Health problems - mo	ovement
	Falls
	Chronic pain
	Limited mobility
	House amendments
	Aids
	Physiotherapy and exercise
	Motivation to exercise





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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 old	
	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	
	Life balance and wisdom
	The most important events in life
	Life patterns
L	





	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





APPENDIX II. LIST OF THEMATIC CODES FROM EXPERT INTERVIEWS

Category	Topics
General issues	Dressetting
	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 100





	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
	Foor of folling
-	Fear of falling
Dementia	Prevention of cognitive decline
Dementia	
Dementia	Prevention of cognitive decline
Dementia	Prevention of cognitive decline Diagnostics of dementia
Dementia	Prevention of cognitive decline Diagnostics of dementia Types of dementia
Dementia	Prevention of cognitive decline Diagnostics of dementia Types of dementia Risks in the household
Dementia	Prevention of cognitive decline Diagnostics of dementia Types of dementia Risks in the household Risks outside
Dementia	Prevention of cognitive declineDiagnostics of dementiaTypes of dementiaRisks in the householdRisks outsideMonitoring
Dementia	Prevention of cognitive declineDiagnostics of dementiaTypes of dementiaRisks in the householdRisks outsideMonitoringInformal caregivers functions
Dementia	Prevention of cognitive declineDiagnostics of dementiaTypes of dementiaRisks in the householdRisks outsideMonitoringInformal caregivers functionsInformal caregivers needs





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	Aggression
	Change of personality
Problems with sen	Effect on close relationships
FIODIEIIIS WILLI SEI	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

