



# SHAPES

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

## D2.4 – Empowerment of Older Individuals in Health and Care Decision-making

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<b>Lead author</b>	Ilenia Gheno (AGE)
<b>Contributors</b>	Lucia D’Arino (WFDB), Frankie Picron (EUD), Fotios Gioulekas (DYPE), Anna Salmi (LAUREA), Sini Häyrynen (LAUREA)
<b>Peer reviewers</b>	Bárbara Guerra and Marco Manso (EDGE), Rania Pinaka (DYPE)
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## Table of Contributors

Table 1-2 Deliverable Contributors

Section(s)	Author(s) and contributor(s)
<b>All document</b>	Ilenia Gheno, Vera Hoermann (AGE)
<b>1.1.2, 3.3, 3.4, 3.5</b>	Lucia D'Arino (WFDB), Frankie Picron (EUD)
<b>Chapter 5</b>	Fotios Gioulekas, O. Pinaka, E. Stamatidis, A.Tzikas, K. Gounaris (5thYPE), Barbara Guerra (EDGE), Sini Häyrynen (LAUREA), Anna Salmi (LAUREA), Esperança Lladó Pascual (CLINICA), Stella Baur, Stephanie Ehrentraut, (CCS), Tereza Norbertová (FNOL), Pedro Rocha, Luisa Teles (UPORTO), Valentina Fiordelmondo (AIAS), Suzanne Martin (NHSCT), Anna Schüttler (GEWI)

## Table of Acronyms and Abbreviations

Table 1-3 Acronyms and Abbreviations

Acronym	Full Term
<b>CEDAW</b>	Convention on the Elimination of All Forms of Discrimination against Women
<b>CRPD</b>	Convention on the Rights of People with Disabilities
<b>EC</b>	European Commission
<b>ECHR</b>	European Convention on Human Rights
<b>EU</b>	European Union
<b>EU CFR</b>	European Charter of fundamental rights
<b>ICCPR</b>	International Covenant on Civil and Political Rights
<b>ICERD</b>	International Convention on the Elimination of All Forms of Racial Discrimination
<b>ICESCR</b>	International Covenant on Economic, Social and Cultural Rights
<b>ICT</b>	Information Communication Technologies
<b>MIPAA</b>	Madrid International Plan of Action on Ageing
<b>PANEL</b>	Participation, Accountability, Non-Discrimination, Empowerment and Legality
<b>TEU</b>	Treaty on the European Union
<b>UDHR</b>	Universal Declaration of Human Rights
<b>UC</b>	Use Case
<b>UN</b>	United Nations
<b>WHO</b>	World Health Organisation

## Keywords

Empowerment, decision-making, older people, people with disabilities, health and care, participatory approach, contextual factors, barriers and enablers, governance, ecosystem, SHAPES, technologies.

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## Executive Summary

The SHAPES project builds an interoperable platform integrating smart digital solutions for people and the environment in which they live to support healthy and independent living. Engaged to understand the realities of older individuals and to design and support age-friendliness, the project embraces the notion of empowerment and investigates decision-making for health and care, from the perspective of older people.

How people frame their opinions, make their decisions, and take actions shapes their personality and life paths. And this is key for the SHAPES project and for its comprehensive platform, because any technological set of services would be meaningless if not conceived, designed, and developed together with the users it is intended for, and if it does not consider the users in their environments, in their relationships and in their life paths. Therefore, SHAPES is conceived to empower its current and future users, for the quality of the proposed services but especially for the gained quality of life of its users. This is essential for the enjoyment of all human rights, regardless of one's age and abilities, for people's well-being, sense of worth and dignity.

The project embraces a notion of empowerment that is not solely restricted to an individual and personal dimension but extended to the community and the environment in which a person lives. This means addressing the social, cultural, political, and economic determinants of people's lives, and adopting a multi-disciplinary approach. This is true for all ecosystems, and it is especially relevant for the health and care one. Because health and care are not confined to the relationship between a patient and a doctor, but must embrace the wider context, relationships, and environments, among others.

The work on empowerment and decision-making, summarised in this deliverable, investigated such comprehensive ecosystem, starting from the four themes shaping the concept of empowerment at individual level (*having a sense of personal identity; having a sense of choice and control; having a sense of usefulness and being needed; retaining a sense of worth*) to dive into several barriers and challenges to empowerment in decision-making at individual level (e.g., level of literacy and confidence on the domain when a decision is requested; psychological barriers; age, disability, gender, sexual orientation, ethnicity and their intersections; individual characteristics such as personality and life experiences). Our work then addressed the environment, both the technological one and the wider socio-cultural context of people (the "lifeworld of individuals"), with a focus on the health and care sector, and encompassed various participatory approaches suitable to sustain empowerment in decision-making.





# 1 Introduction

SHAPES Work Package 2, entitled “Understanding the Lifeworld of Individuals and Improving Smart and Healthy Living”, encompasses a reflection on decision-making and empowerment in old age for better health and care in its task 2.4.

Based on the outcomes of the project’s research, of the SHAPES Dialogue Workshop dedicated to the topic (October 2021), on the evidence of research literature and on partners’ advocacy, this deliverable explains what empowerment is and how to empower people in decision-making when dealing with one own’s health and care.

Starting from established definitions of decision-making and empowerment and supported by literature, chapter two introduces the selected topics through the lenses of a paramount human rights-based approach and presents the policy framework underpinning a genuine empowerment of people in decision-making.

Through an overview of psychological and contextual factors related to decision-making, and with the support of older people’s own needs and concerns on care, chapter three provides essential suggestions to make space to people in health and care, and reform the system to embrace and empower age and ageing.

Chapter four proposes some participatory approaches to decision-making in health and care, of which one specifically originates from the SHAPES project itself.

Last, chapter five draws the insights gathered by the project so far: thanks to the overview of the pilots’ work on empowerment and an overview of gaps and barriers to empowerment in decision-making, this closing chapter situates SHAPES in a hypothetical empowering spectrum, providing a useful summary for the work yet to come.

## 1.1 *Rationale and purpose of the deliverable*

This deliverable aims to boost individuals and stakeholders to play a more active role in health and care decision-making. Grounded on a human rights perspective and literature review and considering human, societal and contextual factors impacting on empowerment in decision-making, the deliverable suggests steps to shift away from a traditional and paternalistic approach to health and care, and shows new participatory processes, geared toward overall improved quality of care, efficiency, and care outcomes.

In the views of its authors (AGE), such toolkit can be translated into a practical online tool, providing external stakeholders with overviews and insights on decision-making and empowerment, with tips and quotes to sustain the take-up of a human rights-based approach to these topics.

### 1.1.1 Deliverable Objectives

- Offer insights to individuals and associations to sustain empowerment and set up genuine decision-making in health and care.
- Offer a concise overview on key psychological, gendered, and contextual aspects related to decision-making on health and care.
- Convey the concerns of older people, including those with disabilities on health and care, as well as challenges arising from intersectionality (gender, ethnicity, social and economic status).
- Shed light on new participatory processes for decision-making.
- Guide the SHAPES Platform's development regarding the sort and extent of information that is optimal to help older individuals make decisions.

### 1.1.2 Key inputs and outputs

This deliverable incorporates some of the results from:

- Deliverable D2.1 “Understanding Older People: Lives, Communities and Contexts” (Seidel et al, 2021).
- Deliverable D10.6 “SHAPES Dialogue Workshop V1”, with reference to the fourth dialogue workshop on “diversity and empowerment: understanding the realities of older people” (Gheno et al, 2021).
- Deliverable D8.4 “SHAPES Ethical framework” (Sarlio-Siintola et al, 2020).
- Deliverable D5.4 “SHAPES Digital Solutions V2” (Guerra et al, 2021).
- The work carried out by two organisations of persons with disabilities and SHAPES consortium partners, the World Federation of the Deafblind (WFDB) and the European Union of the Deaf (EUD), also via the #SHAPESstories<sup>1</sup>.
- Deliverable D3.1 “Ecological Organisational Models of Health and Care Systems for Ageing” (Labor, M., Cooke, M., et al 2020).
- Deliverable D3.5 “Initial SHAPES Collaborative Governance Model Version 1.0” (Zurkühlen, A., Cooke, M., 2021).
- D3.9 “Final User Requirements for the SHAPES Platform” (Berchtold et al, 2021).

The present work is moreover intended to support the further development of the following results from the project:

- D5.4 Digital Solutions V3 by GNOMON.
- The 6th awareness campaign on empowerment and digital platform by AGE.
- The 6th dialogue workshop on empowerment and digital platform by UAVR.
- The work at pilot site level, within WP6.

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<sup>1</sup> <https://shapes2020.eu/shapes-stories>

## 1.2 *Structure of the document*

The deliverable consists of three main parts.

- I. Chapter 2 defines empowerment and decision-making; it provides insights from research and policy context at international and European level, diving into the notions of empowerment and decision-making in patient care and providing an overview of the role of technology to empower.
- II. Chapter 3 presents some key research findings on the psychology of decision-making and social and contextual factors impacting on empowerment, which sustain a shared approach to decision-making and allows for a focus on older persons' concerns in case and on principles and factors to sustain empowerment.
- III. Chapter 4 presents three participatory practices to sustain empowerment in decision-making. One example has been directly used by the SHAPES project.
- IV. Chapter 5 shows how empowering principles have been embraced so far by the project at pilot level. It moreover offers a summary of key challenges SHAPES must consider in developing its ecosystem.

## 2 Empowerment: making space for people

The notion of “empowerment” is commonly defined as “the process of gaining freedom and power to do what you want or to control what happens to you”<sup>2</sup>, or differently said, empowerment is the process of making choices freely and it is therefore intimately connected to the concept of “decision-making”.

The World Health Organization (WHO) defines empowerment as: “a process through which people gain greater control over the factors and decisions that shape their lives. It is the process by which they increase their assets and attributes and build capacities to gain access, partners, networks and/or a voice, in order to gain control”<sup>3</sup>.

How people frame their opinions, make their decisions, and take actions shapes their personality and life paths. Having one’s voice heard and choice respected is essential for the enjoyment of all human rights, for one’s well-being, sense of worth and dignity<sup>4</sup>.

Empowerment is one of the five P.A.N.E.L. principles of a human rights-based approach, applied to make sure people's rights are put at the very centre of policies and practices. P.A.N.E.L. is the acronym for Participation, Accountability, Non-Discrimination, Empowerment and Legality<sup>5</sup>. Following this approach, empowerment translates in accessible and transparent information to be able to enjoy human rights. Therefore, empowerment requires access to reliable information to make informed choices for a responsible and autonomous life.

“Empowerment means making space for people experiencing human rights issues to have their voices heard. And crucially it means supporting, valuing, learning from and acting on what they say”<sup>6</sup>

Empowerment is not solely restricted to an individual and personal dimension but is extended to the community and the environment in which a person lives. The WHO considers community empowerment being “more than the involvement, participation, or engagement of communities. It implies community ownership and action that explicitly aims at social and political change. Community empowerment is a process of re-negotiating power in order to gain more control. It recognizes that if some people

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<sup>2</sup> <https://dictionary.cambridge.org/dictionary/english/empowerment>

<sup>3</sup> <https://www.who.int/teams/health-promotion/enhanced-wellbeing/seventh-global-conference/community-empowerment>

<sup>4</sup> HelpAge International. (2022). HelpAge Voice Framework. An introduction. Page 2

<sup>5</sup> <https://www.scottishhumanrights.com/projects-and-programmes/human-rights-based-approach/>

<sup>6</sup> [https://www.youtube.com/watch?time\\_continue=36&v=BJDpda0SOfo&feature=emb\\_logo](https://www.youtube.com/watch?time_continue=36&v=BJDpda0SOfo&feature=emb_logo)



are going to be empowered, others will be sharing their existing power and giving some of it up (Baum, 2008). Power is a central concept in community empowerment and health promotion invariably operates within the arena of a power struggle”<sup>7</sup>.

As highlighted by the root of the word itself, empowerment is about power, and power needs to become visible, voiced and heard to succeed<sup>8</sup>.

The process of empowering both individuals and communities necessarily addresses the social, cultural, political, and economic determinants that underpin health, and cannot be carried out in silos but must take into account the context of health and care practices. In the research from SHAPES, the “desire to exercise some choice within a specific environment” is defined as “agency”<sup>9</sup>. Such concept is intrinsically interwoven with decision-making and makes the essential reference to the environment in which choices and voices are expressed and heard (or not).

In this deliverable, empowerment and decision-making are covered in broad terms, and are not confined to an established age range. The assumption is that what empowers in making a judgement and define a decision does not change with age, but rather processes and approaches change on the basis of other factors, e.g., socio-economic, cultural, psychological, and gender-related factors. Nevertheless, the document contains a specific section focused on older people and care, to highlight some barriers perceived by older persons themselves in their health and care pathways.

Moreover, despite most of the research dealing with empowerment and decision-making in health and care from a patient’s perspective, it is important to remind that SHAPES’ scope of action is broader, and encompasses users and citizens, regardless of their health (and patient) status.

## 2.1 *Research insights on empowerment*

Across research looking into health and care pathways in older age, empowerment is understood as a dynamic health process, with the individual active to maintain well-being (Thakur et al., 2020) in an interdependent and complex context. In particular, the Health Empowerment Theory acknowledges the interconnectedness of personal

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<sup>7</sup><https://www.who.int/teams/health-promotion/enhanced-wellbeing/seventh-global-conference/community-empowerment>

<sup>8</sup> HelpAge International. (2022). HelpAge Voice Framework. An introduction. Page 2

<sup>9</sup> Seidel, K., Prendergast, D., Saris, A.J., Foley, J. (2021). D2.1 Understanding Older People: Lives, Communities and Contexts. Deliverable of the SHAPES project (D2.1), page 19



resources and social-contextual resources to support a health process which encourages participation in health care decision-making (Shearer, 2009). The theory is derived in part from Rogers' Science of Unitary Human Beings, and the principle of integrality perspective of human beings, which express "human beings as integral with their environment in their daily living and health experience; characterised by pattern, self-organisation, diversity and innovative change; and as holding individual values and views about health"<sup>10</sup>. This perspective of integrating lived experience with pattern, organisation, and values of health aligns with the overall concept of empowerment, which can function as a multi-level construct seen at the community, group, and individual level (Small, 2013). In the healthcare sector, informed decision-making about treatment and care, better relationships with health professionals, and commitment to adhering to treatment are some aspects which may be improved from patient empowerment. It is important for patients to take ownership of their care responsibilities, while healthcare professionals and systems work to create environments in which support, and resources are available to reach their individual priorities. This creates positive effects in healthcare quality and patient outcomes. In fact, patient empowerment is a crucial indicator of healthcare-outcome quality and patient satisfaction (Yeh et al., 2018). These studies confirm that empowerment in the health sector involves the relationship between the patient and the doctor. "The issue is how patients can be seen as experts in their own conditions and can be enabled to become an equal and active partner in managing their health care"<sup>11</sup>. Grounded on one of the basic principles of the human rights-based approach of equality, healthcare professionals do not hold power over patients but rather share knowledge and learn from them. Moreover, they show how relevant it is to sustain the overall ecosystem around the cared person, thus encompassing healthcare professionals and care givers, as well as other relevant stakeholders. For example, in the case of people with disabilities, sign language interpreters, guide interpreters, personal assistants or support persons, to name a few, are essential to ensure their integration and participation in society, as well as access to health and care services, meaning that it is vital to include them in the empowerment process. Also, the involvement and participation of representative organizations of older people, including those with disabilities, is key. Empowerment can be developed by supporting and encouraging involvement in decision-making, by being inclusive, respectful, and avoiding stigmatization, for the sake of a genuine relationship. An empowered and connected ecosystem represents a strength for all stakeholders involved in the health and care sector.

## Empowerment of patient care

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<sup>10</sup> Shearer N. B. (2009). Health empowerment theory as a guide for practice. *Geriatric nursing (New York, N.Y.)*, 30(2 Suppl), 4–10., p.1

<sup>11</sup><https://www.euro.who.int/en/health-topics/noncommunicable-diseases/pages/news/news/2012/4/empowering-patients>



Specifically on patient care, the concept of empowerment has been shaped around four themes in the framework of a qualitative study of patients and their caretakers (Van Corven et al., 2021). The four themes are: having a sense of personal identity; having a sense of choice and control; having a sense of usefulness and being needed; retaining a sense of worth.

#### *Having a sense of personal identity*

This theme highlights the importance of understanding people as they are, through their life history and with individual changes over time. Knowing one's life history can help expand knowledge of one's motivations and explain behaviours which can be useful in adjusting care. By recognizing the individuals as they are in that moment, care is open to change and shift as preferences change over time.

#### *Having a sense of choice and control*

This theme focuses on the importance for individuals to maintain autonomy in decision-making and emphasises the option to opt-out. Choices could be about what to eat, what to wear, where to go, and other everyday activities. In this circumstance, the decision-making is accepted and respected as it is, so that individuals do not feel controlled by the environment.

#### *Sense of usefulness and being needed*

This theme utilizes the existing abilities and skills of individuals, to keep one's autonomy and remain at the steering wheel, with a proactive attitude.

#### *Retaining a sense of worth*

This theme acknowledges the crucial aspect of being valued, seen, and heard as an equal individual in society. Empowerment occurs through the individual but can also be heavily influenced by the way the individual is treated in society to participate in activities, use services, and interact with others.

### 2.1.1 Decision-making in patient care

Shared decision-making is an approach where healthcare professionals and patients “share the best available evidence when faced with the tasks of making decisions, and where patients are supported to consider options to achieve informed preferences” (Gustin, 2019).

According to Gustin<sup>12</sup>, shared decision-making involves a 3-step model: choice talk, which introduces reasonable options; option talk, which provides more details, and decision talk, which leads to a decision.

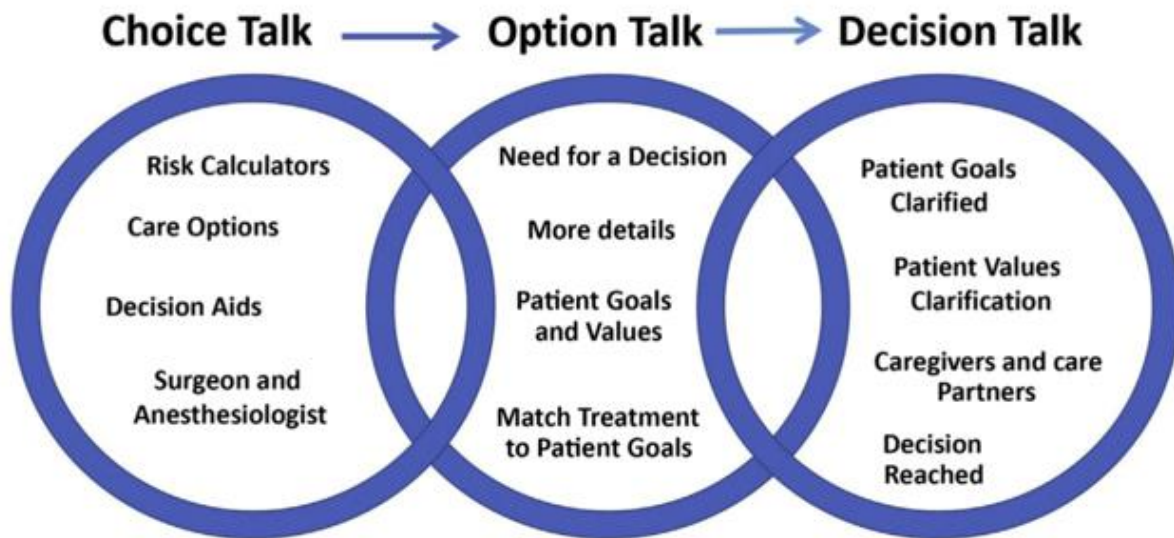


Figure 1 Conceptual framework for shared decision-making by Gustin

The framework outlined in the figure above is intended as a fluid method for shared decision-making. “Decision support tools (2 forms being represented as the decision aid and the risk calculator) provide crucial input into this process. Patients will want time to study new information and consider their personal preferences, particularly for the future that is unknown to them, to think about outcome states that they have never experienced or considered. If the patient desires to make decisions with other friends and family, then the clinician should attempt to make sure the information is provided to everyone for deliberation”.<sup>13</sup>

Among the **barriers** to shared decision-making, Gustin referred to clinician, patient, and institutional factors (Gustin, 2019). The clinician factors encompass lack of familiarity with the concept of shared? decision-making; knowledge of and attitudes on decision-making by clinicians; time commitment and competing priorities; the clinician’s comfort zone and the need to step out of it if necessary; lack of resources. This latter factor is also mentioned as an institutional factor. Among the patient factors,

<sup>12</sup> Gustin, A. (2019). Shared Decision-Making, article in press, <https://doi.org/10.1016/j.anclin.2019.05.001>, 1932-2275/19/a 2019 Elsevier Inc. page 4

<sup>13</sup> Gustin, A. (2019). Shared Decision-Making, article in press, <https://doi.org/10.1016/j.anclin.2019.05.001>, 1932-2275/19/a 2019 Elsevier Inc. page 4



Gustin encompasses health literacy, the patient's cultural background and his/her attitudes to decision-making<sup>14</sup>.

## 2.2 Policy perspectives on empowerment

From a policy perspective, several instruments, and initiatives campaign for empowerment in health and care decision-making, to improve the overall quality of care, efficiency, and care outcomes.

The Universal Declaration of Human Rights (UDHR)<sup>15</sup> sets out, for the first time, fundamental human rights to be universally protected (1946). In accordance with the UDHR, the International Covenant on Economic, Social and Cultural Rights (ICESCR)<sup>16</sup> recognises the inherent dignity and the equal and inalienable rights of all human beings and “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (art.12) since 1976. Interesting to be highlighted, the International Covenant on Civil and Political Rights (ICCPR) and the ICESCR provide a right to non-discrimination on grounds which include ‘other status’. The interpretations of these covenants “have stated unequivocally that ‘other status’ includes ‘age’, amongst other characteristics not explicitly listed in the text of the instruments”<sup>17</sup>. Likewise, the interpretation of the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), and the Convention on the Rights of Persons with Disabilities (CRPD, cf. below) recognised age as a ground of discrimination which intersects with the grounds of discrimination on which the instrument above focuses.

The enjoyment of human rights specifically by older persons is underpinned by the 18 “Principles for Older Persons”, established by the United Nations. Those principles address five key areas of older people's lives and impact on how people experience

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<sup>14</sup> Gustin, A. (2019). Shared Decision-Making, article in press, <https://doi.org/10.1016/j.anclin.2019.05.001>, 1932-2275/19/a 2019 Elsevier Inc. page 7

<sup>15</sup> <https://www.un.org/en/about-us/universal-declaration-of-human-rights>

<sup>16</sup> <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights>

<sup>17</sup> HelpAge International. (2022). Advancing equality for older people (page 37)



their health and care pathways, hence their level of empowerment in making decisions: Independence, Participation, Care, Self-Fulfilment, and Dignity<sup>18</sup>.

At United Nations level, the 2002 Madrid International Plan of Action on Ageing (MIPAA)<sup>19</sup> derives the notion of empowerment from the three priorities areas for older persons' development. MIPAA calls to “educate and empower older persons in the effective use and selection of health and rehabilitation services; utilize technology such as telemedicine, where available, and distance learning to reduce geographical and logistical limitations in access to health care in rural areas”<sup>20</sup>. Such orientation has been confirmed along the various revisions of the MIPAA, including the latest (Rome, 2022) and is still relevant for this deliverable's topic. The Plan of Action refers to the rights of older persons, universal and equal access to health and care services, maintenance of maximum functional capacity throughout the life-course, and promotes the full participation of older persons, also thanks to enabling and supporting environments, care and support for caregivers and the elimination of all forms of neglect, abuse, and violence of older persons.

Another major achievement in recognizing the impact of empowerment for the enjoyment of human rights and the role of enabling environments comes from the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which supports a paradigm shift in human rights law. Article 25 of UNCRPD promotes the right of persons with disabilities to “the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”. A notable aspect of this Article 25 is the protection of “free and informed consent” in decision-making in health care, which includes raising awareness of human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private healthcare. With respect to the notions of agency and decision-making, it is worth underlying that the CRPD Committee distinguishes legal capacity as “the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency)”<sup>21</sup> and mental capacity, which “refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors”.<sup>22</sup>

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<sup>18</sup> <https://www.ohchr.org/en/instruments-mechanisms/instruments/united-nations-principles-older-persons>

<sup>19</sup> [Madrid International Plan of Action on Ageing, https://www.un.org/development/desa/ageing/madrid-plan-of-action-and-its-implementation.html](https://www.un.org/development/desa/ageing/madrid-plan-of-action-and-its-implementation.html)

<sup>20</sup> United Nations, Political Declaration and Madrid International Plan of Action on Ageing, New York, 2003, p. 32, paragraph 74

<sup>21</sup> CRPD/C/GC/1, para. 13

<sup>22</sup> *ibidem*



Building on the MIPAA and aligned with the timing of the United Nations Agenda 2030 on Sustainable Development and the Sustainable Development Goals, the United Nations proclaimed the Decade of Healthy Ageing<sup>23</sup> (2021-2030), a global collaboration, bringing together governments, civil society organizations, international agencies, professionals, academia, the media, and the private sector to improve the lives of older people, their families, and the communities in which they live. All four action areas (age-friendly environments, combatting ageism, integrated care, and long-term care) are underpinned by the principle of empowerment and the respect of human rights across the life span.

At European level, a key provision for older persons and their empowerment is article 25 "[The rights of the elderly](#)" of the European Charter of fundamental rights (EU CFR)<sup>24</sup>. The Charter encompasses civil and political rights, as well as economic, social, and cultural rights. It also incorporates "new" rights, such as the right to data protection (Sarlio-Siintola, 2020). By stating that "the Union recognizes and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life", European institutions and European Member States commit to adopt legislation protecting and fulfilling the rights of older persons.

Moreover, Article 2 of the Treaty on the European Union (TEU) founds the European Union (EU) on "the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minorities" and highlights that these values "are common to the Member States in a society in which pluralism, non-discrimination, tolerance, justice, solidarity and equality between women and men prevail". Further, the individual is at the center of the European Union's work by establishing the citizenship of the Union and by creating an area of freedom, security, and justice" (Preamble of the Charter of the Fundamental Rights of the European Union) (Sarlio-Siintola, 2020). Article 6 TEU provides for the protection of fundamental rights in the EU context, recognizing the rights, freedoms and principles set out in the Charter of Fundamental Rights. Specifically, article 6(2) mandates the EU's accession to the European Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights – ECHR). Article 6(3) TEU affirms that fundamental rights, as guaranteed by the ECHR and as they result from the constitutional traditions common to the Member States, "shall constitute general principles of the Union's law"<sup>25</sup>.

Although the competence in the field of health and care is with national governments, the European Union's remit encompasses health promotion, equality, non-

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<sup>23</sup> <https://www.decadeofhealthyageing.org/>

<sup>24</sup> [https://ec.europa.eu/info/aid-development-cooperation-fundamental-rights/your-rights-eu/eu-charter-fundamental-rights\\_en](https://ec.europa.eu/info/aid-development-cooperation-fundamental-rights/your-rights-eu/eu-charter-fundamental-rights_en)

<sup>25</sup> <https://eur-lex.europa.eu/legal-content/FR/TXT/?uri=CELEX%3A12012M%2FTXT>



discrimination and protections of “consumers” and “victims”, alongside the support to the exchanges of practices and policy reforms in those areas. These topics are relevant for empowerment in decision-making. Over the years, the EU has guided and influenced how European countries shape their policies in those areas; it contributed to set higher standards and helps cyclically the monitoring of countries’ performance.

The launch of a joint report<sup>26</sup> of the Social Protection Committee and the European Commission in June 2021 (as an update of the report published in 2014) reminds the European Union of its power in generating evidence and providing a solid assessment of the situation in the field of care. Co-authored by the European Commission and national ministries responsible for care, the report’s conclusions were endorsed in June 2021 by national ministers responsible for care<sup>27</sup>. Through this endorsement, the EU can advance on an ambitious European Care Strategy as a powerful attempt to materialise the European policy initiative on long-term care that had been announced for some time (AGE Platform Europe, European Care Strategy, 2021). The European Care Strategy, as a follow-up of the Green Paper of Ageing,<sup>28</sup> is also part of the commitments of the Action Plan of the European Pillar of Social Rights.<sup>29</sup> Announced in September 2021 in her State of the Union, Commission President Ursula von der Leyen aims at a European Care Strategy to support women and men in finding the best care and work-life balance for carers, among others. Hopefully, promising steps towards greater and genuine empowerment in decision-making in the health and care sectors looms in the horizon.

### *2.3 The role of technology to empower*

The World Health Organisation (WHO) defines “eHealth”, as “the use of information and communication technologies (ICT) for health”<sup>30</sup>, and similarly the European Commission refers to eHealth as “tools and services that use information and communication technologies (ICTs) to improve prevention, diagnosis, treatment, monitoring and management of health and lifestyle. Digital health and care have the

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<sup>26</sup> <https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8396>

<sup>27</sup> <https://data.consilium.europa.eu/doc/document/ST-9144-2021-INIT/en/pdf>

<sup>28</sup> [https://ec.europa.eu/info/sites/default/files/green\\_paper\\_ageing\\_2021\\_en.pdf](https://ec.europa.eu/info/sites/default/files/green_paper_ageing_2021_en.pdf)

<sup>29</sup> <https://op.europa.eu/webpub/empl/european-pillar-of-social-rights/en/>

<sup>30</sup> <https://www.who.int/ehealth/about/en>



potential to innovate and improve access to care, quality of care, and to increase the overall efficiency of the health sector”<sup>31</sup>.

Alongside the richness and complexity of the concept, a certain confusion on the terminology (e.g., “ambient assisted living”, “active assisted living”) and different technological approaches and solutions exist, making it hard for people to find the right solution to the right need(s) (Meissner and McNair, 2021). Furthermore, national frameworks for technologies and digital strategies vary across countries, as well as health and care legal and institutional framework change across the European Union. It is therefore important and efficient to consider the implementation of technological change in the light of the human right principles with respect to health and care.

“When considering whether or not a technology is appropriate, it is important to consider both the task driven (the “what”) and the emotional (the “how”) dimensions and whether a technological solution is more appropriate than a human one. This is particularly important when interests may be in conflict, e.g., the ones of the care provider and the care recipient. It is also important to recognize that the relevance of a technological solution will always depend on the specific situation”.<sup>32</sup>

When looking specifically into the impact of assistive technology and robotics, artificial intelligence, and automation on the human rights of older persons, the United Nations Independent Expert on the enjoyment of all human rights by older persons reports that the “use of restraints, disempowering practices, and neglect of the users’ needs, and preferences have been found to violate the standard of dignity in care settings. A robot, for instance, that moves people around or feeds them without consulting them may amount to an undignified way of providing services”. It moreover underlines that “insofar as technology does not help older persons regain agency and fulfil their aspirations, it maintains a dependency culture. Where robots remain the only form of interaction for older persons, technology may even become debilitating and anchor a paradigm of disempowerment”<sup>33</sup>. The report therefore reinvigorates the need for assistive technologies to foster autonomy and independence without increasing social exclusion, to give older persons the choice to accept or refuse the technological support proposed to them and stresses that older persons shall keep control over information that will be collected through technologies, and these technologies should be flexible enough (‘self-learning’) to adapt to older persons’ preferences and lifestyles (Biscay Report, 2022). To sustain empowerment in old age, the access to assistive

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<sup>31</sup> <https://op.europa.eu/de/publication-detail/-/publication/08e68564-67fe-11e9-9f05-01aa75ed71a1/language-en/format-PDF>

<sup>32</sup> Meissner A., McNair S., Ageing and Technologies. Creating a vision of care in times of digitalisations. A paper for policy makers, 2021, page 10.

<sup>33</sup> United Nations. (2017). Report of the Independent Expert on the enjoyment of all human rights by older persons, A/HRC/36/48, page 9.



technologies must be ensured on an equal basis, with technology supporting participation in social and public life.

Within the remit of the SHAPES project, it is also important to consider the impact of artificial intelligence on empowerment and decision-making. If artificial intelligence empowers, through more extensive searches, more in-depth analysis, and planning, basing choices on computer-led information and processes opens a set of questions. Because artificial intelligence is the product of differently biased human brains, it unfortunately mirrors the existing biases in society and thus affects how decisions are made. Gender-based, race-based, or age-based biases may therefore inform the psychological and contextual factors of decision-making. Equally relevant for SHAPES, automated individual decision-making has been extensively covered by Deliverable D8.4 SHAPES Ethical Framework (Sarlio-Siintola, 2020).

Technology can empower patients, carers, and people of any age. But to allow them to benefit from technology and find the needed solution, it is important to ground, develop and market technology on the needs of the users it is intended to and to ensure technology respect those users' rights (cf. artificial intelligence's biased roots). It is moreover important to remind that technology is a means to empower, not a goal. Empowerment, alongside with the other P.A.N.E.L. principles<sup>34</sup>, can be a beacon for the designing and implementation of technology, ensuring technological solutions meet the users' needs, respect people's rights, and sustain their autonomy, dignity, participation, and freedoms.

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<sup>34</sup> <https://www.scottishhumanrights.com/projects-and-programmes/human-rights-based-approach/>

## 3 Empowering in health and care decision-making

The second chapter of this deliverable presented some key features of empowerment of individuals in health and care decision-making. Regardless of age and disability, empowerment is underpinned by human rights and framed within a human rights-based approach. There are several barriers and challenges to empowerment in decision-making, some raised at the individual level (e.g., level of literacy and confidence on the domain when a decision is requested) and at the community level (e.g., in the relationship between patient and healthcare professional, in this relationship and its connections with family and carers, and the wider society).

This chapter provides an overview of which psychological and contextual factors also impact on empowerment in decision-making (paragraphs 3.1 and 3.2). It then considers barriers and facilitators in decision-making (paragraph 3.3), to highlight the essential features on which empowerment in decision-making should be grounded (paragraph 3.4) and closes with a focus on some specific challenges arising in older age (paragraph 3.5).

### 3.1 *The psychology of decision-making*

“What I miss is the freedom to choose, to choose when I get up, what to have for lunch, what to wear today”<sup>35</sup>

Decision-making is the process of making choices<sup>36</sup>. Research shows that decision-making is influenced by multiple factors both related to the decision-makers and their environment: the way decisions are made seem to be depending on a mix of influences, preferences, and perceptions, more often driven by the information available on the very moment (rather than a comprehensive overview of data), and by recent experiences (rather than past events) (Avorn, 2018).

When looking into the psychology of decision-making, two main motivational processes arise: an intuitive, fast decision-making opposed to a rational deliberate decision-making. Decision-making is a mix of both these processes, formulating choices based on intuition, past experiences, spontaneity, and attention (Herlitz, 2016).

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<sup>35</sup> [European Charter of the rights and responsibilities of older people in need of long-term care and assistance](#), 2010

<sup>36</sup> <https://dictionary.cambridge.org/dictionary/english/decision-making>



Despite the many factors influencing how decisions are made, **information and communication** are key across all factors and decision-making processes. Research shows that decision-making is more influenced by easily digestible and salient information rather than an integrated, but more nuanced, overview (Avorn, 2018). In the health and care sector, solutions are better accepted by patients if explained with appropriate and clear information, and patients are less likely to reject a solution if the latter is provided with enough information (Ratzan, 1996). This is also important for healthcare providers, as what and how information is presented can greatly influence patient decision-making.

Specifically in the health and care realm, there are some factors which can negatively affect patient decision-making: bias, affective forecasting, focalism and framing (Schwab, 2008).

- **Bias:** even when healthcare workers are highly skilled and trained in their expertise, this does not prevent them from biased decision-making. And even if patients are highly health literate and informed, decisions can be informed by many biases, e.g., the “last-case bias”, where recent experiences influence more our judgement than remote events (Avorn, 2018). Furthermore, perspectives can be biased by direct-to-consumer advertising and internet research, directly influencing the level of trust of the patient in the healthcare professional.
- **Affective forecasting:** affective forecasting refers to the predictions one may feel about an event in the future. This can affect medical decision-making as beliefs about side effects in the future may affect current decision-making processes. The more serious the side effect to a treatment, the more affective forecasting will be influential in decision-making. Our choices seem motivated by the likelihood to strive for a goal if the pursuit and realisation of that goal are pleasant (Herlitz et al. 2016). Conversely, if reaching a goal requires us to move across unpleasant steps towards that goal, we tend not to pick up such challenge, being biased by such estimation.
- **Focalism:** focalism refers to the inability of individuals to perceive the complexity of events happening in the future. There is a tendency to perceive one’s state only through the event in question, without regarding other events and situations occurring simultaneously. In medical decision-making, focalism may overemphasise some aspects of treatment or recovery to disregard the complex continual process of wellness and health. Research shows that people tend to overestimate small probabilities (such as uncommon drug risks over drug benefits) for the same mechanism that brings people to fear a plane crash more than a car accident – though the latter is far more likely on a per-mile basis (Avorn, 2018; Li, 2009).
- **Framing:** how options are framed can ultimately affect decision, which can have dire consequences in medical decision-making. Decision-making in the health realm often frames decisions through gains and losses such as survival



rates, effectiveness, side effects, and morbidity rates. Framing information can push the choice-maker towards a decision which highlights extreme options.

### 3.2 Contextual factors impacting on empowerment

Psychological aspects have huge impacts on empowerment and decision-making. Additional factors, such as socio-cultural and environmental ones equally play a role in shaping our judgement and decisions for health and care pathways. The AGE-Biskaia government's joint report "Bay of Biscay Bay of Care" mentions "contextual factors" impacting on empowerment, namely socio-economic and educational status, cultural backgrounds, and generational factors, as well as institutionalised ageism.

According to the report, originated from a regional project from the Basque province of Biscay (Spain) to define broad guidelines for a quality model in long-term care, contextual factors such as **social and environmental factors** can limit or empower, both at the individual level and as part of a broader community, as the socio-economic and educational status, income and housing characterize the single person, but also the wider neighbourhood where the person lives and acts. Likewise, **cultural background, gender norms and generational factors** are contextual factors, and they can represent a hindrance, making people "fearful of challenging care providers' plans and must be reassured and empowered to do so"<sup>37</sup>. **Ageism**, which permeates the society at large and is quickly internalised, represents an additional, powerful contextual factor impacting on empowerment and interfering with decision-making. Last, the Biscay Report acknowledges **individual characteristics** (personality, life experiences, disabilities...) as contextual factors inhibiting or empowering an individual.

A short overview of how these factors matter when discussing empowerment and decision-making is offered in paragraph 3.5., showing how age and its intersections play a role and should therefore be taken into great consideration.

The following paragraph dives into the barriers and enablers in the participation to the health and care governance models, in the attempt to summarise both personal and contextual factors playing with empowerment and decision-making.

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<sup>37</sup> AGE-Biskaia Government. Bay of Biskaia. Bay of Care Report. Page 83



### 3.3 Barriers and enablers in the SHAPES ecosystem

The SHAPES deliverable D3.5 “SHAPES Governance Model V1” analysed the level of participation to the health and care governance models by a variety of stakeholders. It moreover offered a definition of the SHAPES Platform as “instrumental”, i.e., “key enabler of function and capacity. SHAPES as an IT (information technology) system mediates the activities of actors within the ecosystem towards the collaborative achievement of their respective goals and needs while accommodating their diversity.”<sup>38</sup>. As such, it can “facilitate the active participation in the governance of health and social care systems and thus can be seen as “participating” in the governance of those systems”<sup>39</sup>.

The SHAPES Platform is therefore intended to be empowering and to sustain an open and inclusive decision-making process across the life span, and especially in old age. And because SHAPES is more than a technological platform, but an ecosystem including socio-economic, cultural, educational and lifestyle factors, it is relevant to recall which barriers and enablers have been deemed relevant for the SHAPES ecosystem. They matter for the participation in governance models, and they equally matter for enabling SHAPES older users to perform their choices in the health and care sectors.

To explore how a range of stakeholders participate in health and social care governance and develop an inventory of related barriers and facilitators, partners involved in WP3 run a survey “to gather information from respondents' own countries, regions, or settings that they knew best, but also examples of factors that may be considered more abstract, theoretical, or possible, that may be more universal, or that they may have heard about in another region”<sup>40</sup>. This work’s results are presented in the table below, excerpt from deliverable D3.5.

Table 3-1 Categories of Barrier and Facilitator<sup>41</sup>

No.	Category	Selected Barriers	Selected Facilitators
1	<b>Knowledge and Awareness</b>	Strong but unstructured knowledge, lack of instruction (or knowledge) available to recipients on how to raise concerns in the	Access to information, knowledge, education, training, evidence-based practice, caregiver having requisite

<sup>38</sup> Zurkuhlen, A., Cooke, M. (2021), page 24.

<sup>39</sup> Ibidem, page 24.

<sup>40</sup> Ibidem, page 109.

<sup>41</sup> Ibidem, page 99.



		correct, official pathway, lack of information on relative performance of health system	experience and knowledge, experience of how the system works
3	<b>Capacity</b>	Cognitive impairment	Physical capacity, cognitive capacity, decisionmaking capacity
4	<b>Motivation and Choice</b>	The influence of the socio-political environment,professionals' choice of enhanced services from an approved list only	Free choice of one's personal physician, ability to seek a second opinion, healthcare systems allowing care recipients to decide
5	<b>Communication</b>	Lack of clarity or communication about what (academic/research) recommendations actually influence policy, speed of the doctor's speech, conflict between stakeholders	Two-way communication with HC providers,conflict may also function as a facilitator, allowing for leverage over decision making
6	<b>Inclusion</b>	Perceived or actual tokenism	Person-centredness, encouragement to be active decision maker, patient, and public involvement (PPI), involving decision makers in technological R&D
7	<b>Social Role</b>	Care recipient	Being and administrator, policymaker, or healthand social care professional
8	<b>Resources – personal or professional</b>		Financial resources, social network
9	<b>Resources – organisational or systemic</b>	Staff turnover due to grant-linked employment (research/academia)	Availability of trained personnel, specialised personnel
10	<b>Power and its distribution</b>	Unequal distribution of power across social roles (for example, physicians having more power at micro level than nurses), feeling disempowered	Empowerment to implement change (which lies mostly with government and insurance companies).
11	<b>Collective voice &amp; action / Solidarity</b>		Labour union membership, professional organisations
12	<b>Organisations &amp; Institutions</b>		International organisations
13	<b>Systems and Services</b>	Specialists operating in silos, insurer' control over pricing of healthcare procedures, linking reimbursement to frequency of activity (e.g., number of	Well organised health and social care systems, integrated care

		patients seen, rather than quality), restricted appointment times	partnerships, integrated care itself, emphasis on prevention, correct navigation of care recipients through system, uploading of outpatient specialists of non-specialised visits; transparency regarding service quality
14	<b>Access (to services)</b>	Physical barriers to service access, cost-related barriers (e.g., out of pocket costs), time-related barriers to access (e.g., waiting lists)	
15	<b>Legal &amp; Ethical Contexts and Tools</b>	Restrictive regulations (for example, on reimbursement, or choice of services)	Regulations, guidelines (for technology use), advance care directive, developed policy

As motivation to participate in decision-making is informed not only by subjective factors, operating on a personal level, but it is also influenced by the environment and the systems in which those decisions are taken, it seems relevant to refer to the above list of barriers and facilitators. “The issues of choice are intertwined with a range of personal and environmental features, including but not limited to service access, availability of participation opportunities, inclusion and equality, technological supports, knowledge, and social supports”<sup>42</sup>. It is to be noted that “a single factor may function as both a barrier and facilitator. Taking education as a particular example; education indeed may function as a facilitator of governance participation. However, education may also operate as a barrier, contingent upon its accuracy, format, delivery, or ideological framework, boundaries, or content”<sup>43</sup>.

The table above served to compile a list of barriers, shortcomings, gaps, and challenges for decision-making (see chapter 5), built by integrating the approach in deliverable D3.5 with the insights gathered for this deliverable.

### 3.4 A shared and empowering approach to decision-making

With all these factors influencing participation, decision-making and impacting on empowerment, a balanced relationship between the various actors involved in each decision is essential and targeting the role of everyone in his/her own health and care pathway leads to a balanced relationship among all stakeholders in decision-making.

<sup>42</sup> Ibidem, page 121.

<sup>43</sup> Ibidem, page 121.



Therefore, approaches like the **person-centred care** and **shared decision-making** shine through. They occur in contexts dependent upon different purposes, publics, context, constraints, and other elements (Ratzan, 1996). Representing a shift away from the traditional paternalistic care models which places power on the expert healthcare providers (Herlitz, 2016), a shared approach to decision-making, which emphasises patient involvement to reach a solution, results in increased levels of satisfaction, commitment, and loyalty to solutions (Ratzan, 1996). A shared, person-centred approach to decision-making allows the individual to remain in the driving seat, to control one's own decision and aims for empowerment through improved communication channels with the patient, caregiver, and healthcare provider (Ratzan, 1996).

In a shared approach to decision-making, family members and caregivers are crucial in the patient's care and treatment through emotional and practical support (Itzhaki, 2016). Family members are often affected by an individual patient's illness, and, in some cases, they also provide decision-making with or for the patient. These surrogate decision-makers take on the responsibility of medical decision-making to represent the patient's interests, views, and preferences. In these circumstances, family members and caregivers are asked to make decisions which would be most consistent with the patient's values. Family members serve as advocates for their relatives either by representing patients' interests before the medical staff or by protecting patients from life-extending hospitalization and unnecessary medication. This can be an emotionally, cognitively, and morally complex process as family members may have opposing views within each other about decision-making, as well as opposing views with the preferences of the patient. **Intergenerational decision-making** involves others who may be affected by a medical decision on a relative. Such involvement is important "to both prepare them mentally and practically for their own new life changes" (Lin, 2021). Health communication, adequate planning (thinking sooner about later) and supported decision-making are crucial and can affect informed decision-making processes (Itzhaki, 2016) for both the cared ones and the carers.

A shared approach to decision-making encompasses also **supported decision-making**, defined as practices, arrangements, and agreements that include informal and formal supports from diverse sources (e.g., person-based supports such as peers, paid supporters, family, and technological supports, and educational supports). Re-affirmed by the United Nations Convention on the Rights of Persons with Disabilities,<sup>44</sup> which recognizes the right of legal capacity for people with disabilities, supported decision-making is recognized as a viable alternative to traditional guardianship arrangements that may protect the inherent right of people with disabilities to be involved in decisions about their lives, including decisions about rehabilitation and employment (Schwab, 2008). Supported decision-making includes a variety of

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<sup>44</sup> <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>



informal and formal support arrangements. For example, people with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions or may call on other forms of support, such as peer support, advocacy (including self-advocacy support) or assistance with communication (Sarlo-Siintola, 2020). Furthermore, needed supports may change over a person's lifespan based on changes in environmental demands, necessitating flexible models to enable informed choices (Schwab, 2008).

Research showed that **higher quality communication** remains key to empower all stakeholders involved in the health and care pathway. Quality communication between healthcare professionals, caregivers, and family results in more confidence of family members to act as surrogate of intensive care unit patients and that effective communication among patient, family, caregivers, and clinical team contributes to a collaborative, fully informed decision-making process in cases of life-threatening illness (Itzhaki 2016). As mentioned in chapter 2.1.3, high quality communication is also a matter of accessibility, which remains central in SHAPES.

Collective and synergetic decision-making can provide benefits for patients and caregivers such as reduction of decisional conflict, and improvement in decision concordance (Song, 2015), developing an empowering relation among the stakeholders. Moreover, rethinking health and care pathways through **person-centred and family-based approaches** is essential for a more sustainable and inclusive development of the health and care sector<sup>45</sup>. This requires considering the whole **environment** in which people live and choices are made, well beyond the fences of the institutions providing health and care. Such a perspective reinforces the need to ensure accessibility and universal design principles across the wide chain: from accessible information to make informed decisions, to accessible transports to reach the health and care institutions, to accessible buildings, to accessible communication across the journey. This is very much in line with the idea of independent living, inclusion and participation in the community, ultimately empowering individuals, and societies as a whole.

### *3.5 A focus on older people and care*

The health and care system does not always treat older people fairly. Ageist attitudes and structures can lead to discrimination, exclusion, and rights' denial of older people. Moreover, age intersects with gender and disability, as well as other characteristics, for example older women, and older people with disabilities face multiple challenges, prejudices, stereotypes, and discriminations due to such intersections.

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<sup>45</sup> <https://coface-eu.org/s-h-i-f-t-a-guide-to-shift-towards-meaningful-inclusion-of-persons-with-disabilities-and-their-families/>



Specifically on gender, “medical science and patient care have historically focused on male patients. Many diagnoses in women are still undetermined and it takes several years longer to establish comparable diagnoses in women as in men. Women live longer and have more unhealthy years with ageing than men. Sociocultural aspects vary importantly between the genders and have a different impact on health, wellbeing, and many diseases. [...] Female values, such as creativity, empathy, mutual connection, and emotional skills, are eminent in healthcare”<sup>46</sup> (Maas, 2020). Yet, they are not much prioritised, as well as LGBTQI+ persons’ perspective in health and care are not very visible and extensively studied.

It is key to adopt an intersectional approach when analysing the realities of older people in accessing care, as well as attitudinal barriers. Furthermore, a change in the perception or stigma surrounding older people is necessary, as they are often described as a vulnerable or weak group, which tends to be the case for people with disabilities too. This generalisation often leads to patronizing behavior and discrimination, and this is not only inaccurate for many, but harmful as it removes the ownership and legitimisation of the decision-making and empowerment of older persons. Also, it ignores the fact that many older persons are care givers themselves and can provide different types of support (financial, emotional, etc.).

These are some of the main outcomes of the “Rethinking Care” process carried out by AGE Platform Europe in 2021. Specifically on the health and care sector, around 60 members of AGE Platform Europe reported that ageism is reflected in the existing care and support services, leading to services of bad quality and putting at risk the dignity and the quality of life of the care recipients.

Additional remarks include the following<sup>47</sup>:

*Table 3-2 Rethinking Care process by AGE: overview of remarks and explanations*

Remarks	Explanation
Care for older people is <b>deprioritized</b>	Long-term care for older people is often deprioritized in public debates and policies. Public funding for social care for older people is often lower than for other social policy areas and healthcare.
<b>Paternalistic</b> culture in services	Care and support services tend to infantilize older people. Choices and decisions of older people are not always respected. There is an avoidance of risks at all costs that

<sup>46</sup> Mass, A.H.E.M., (2020). Empower Women in Healthcare to move Women’s Health forward, Maturitas, Volume 136, 2020, online abstract

<sup>47</sup> AGE Platform Europe. (2021). Advocating for better care and support for older people, Powerpoint presentation.



	often hinder older people’s autonomy and ability to make decisions.
<b>Segregation</b>	Care policies and services tend to treat older people as a segregated group without the same rights to equality and inclusion as anyone else. Most people want to stay at home, but many are unable to do so.
<b>Organizational issues</b>	Poor care is often characterized by the lack of coordination of services. Older people who access care often have insufficient or inadequate care.
<b>Difficult working conditions</b>	Care workers experience difficult working conditions, including low wages, lack of training and heavy workloads.
<b>Maltreatment</b>	Care services may aggravate the health conditions of people using them. Prevention and rehabilitation are weak or inexistent. There are situations that may be qualified as abusive. In Europe, one in four older people with high care needs experience maltreatment <sup>48</sup> .

Participants of the Rethinking Care process highlighted what they considered to be the main shortfalls of care systems throughout the European Union<sup>49</sup>. These contextual factors particularly affect the empowerment and decision-making of older people, who are often less health and digital literate, whereas they often need care and support most (AGE Platform Europe, 2021):

- Older people in need of care are confronted with the lack of services or the lack of access to services. Services may exist far from the community, only in institutional settings and/or be unaffordable.
- Ageism and ableism are widespread and impact strongly on older people in need of care, especially those with disabilities, associating care with social stigma. Victim of such stigma, the care system is not prioritized in policy or in society.
- Empowerment and decision-making are hindered: organisational constraints and safety issues are put at front, at the cost of disrespecting people’s needs and decisions.
- As health and care work is seldomly coordinated, synergic, and mainstreamed, the understanding of the whole health and care ecosystems is difficult, especially when a person needs the system most.

<sup>48</sup> World Health Organisation. (2011). European report on preventing elder maltreatment

<sup>49</sup> AGE Platform Europe. (2021). Campaign for a new long-term care model. Page 3





- Care policies target different age groups and disabilities separately. Moreover, prevention is often not part of the top investments in the health and care sectors, thus aggravating the deterioration of the whole system.
- Limited health and digital literacy further forestall equal participation, inclusion, empowerment, and decision-making. Moreover, it is important to consider that changes in the cognitive functioning combined with poor communication, overload of information, limited health, and digital literacy, lead to suboptimal decision-making.

These findings are supported by the stories collected and analysed in the SHAPES deliverable D2.1 “Understanding older people: lives, communities and contexts”. With respect to older people’s issues in navigating hospitals and other formal care systems, the report highlights that “medical language can be intimidating, and interventions and their risks are not always easy to understand. Understandably, information is often parcelled, controlled, and exchanged in an asymmetric manner, especially before a diagnosis or treatment plan is fully determined but it is also sometimes poorly articulated and impatiently delivered at a time of high stress. This is unfortunately often the case also for informed consents, whose understanding and accessibility hinder the genuine participation and involvement of the cared person. It must be underlined the importance of accessible and informed consent, especially for persons with disabilities, with information being available in different accessible formats (braille, large font, sign language, etc), and simple easy to understand language, avoiding medical and administrative jargon. Also, medical information should be provided in a truthful and objective way, avoiding manipulation, harmful or unnecessary practices.”.

Within the experiences of the SHAPES project, some research participants talked openly about the dangers of disagreeing with medical personnel, such as Monica (78) in Northern Ireland who argues that “retribution has fallen on my head from complaining”<sup>50</sup>. Moreover, such difficulty in navigating the system is also aggravated by “staff turnover, language and communication difficulties, navigating complex and often disjointed health environments, insufficient psycho-social supports, and ongoing fears over disease control”.

This is even more true for (older) people not accustomed to the language and the system of a country, e.g., with people coming from minorities and/or with different ethnicities and language skills. Older people may also experience intersectional discrimination for reasons relating to their age and ethnicity, health status, or religion, amongst other grounds. Older people with disabilities might be considered as

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<sup>50</sup> Seidel, K., Prendergast, D., Saris, A.J., Foley, J. (2021). D2.1 Understanding Older People: Lives, Communities and Contexts. Deliverable of the SHAPES project (D2.1), page 100.

“incapable or unwilling to adopt and adapt to new technologies”<sup>51</sup>. Furthermore, “older LGBT people may feel more pressure to conceal their sexual orientation, gender identity or expression, due to historic discrimination, leading to worse healthcare outcomes”<sup>52</sup>. Older migrants also can let specific needs to arise, thus further shaping the health and care system of the future (Lebano et al, 2020).

Other issues that commonly emerge when discussing negative hospital experiences include lengthy hospital waiting lists and queues, the quality of stay, access to ‘step-down’ units, financial assistance, home care support and other resources following or as part of the hospital discharge process”<sup>53</sup>.

Such a perception and evaluation of the care systems move people away from the systems themselves, opting for home-base care instead: as “older people feel their agency stripped while being objectified as a “problem to be managed” rather than a person to be engaged”<sup>54</sup>, home feels like the safe harbour, thus the “preference for “living at home”. But there is nothing about home, per se, that guarantees quality of care or quality of life”<sup>55</sup>.

In the attempt to include a variety of experiences in health and care, transitional moments should also be duly considered. As emerged from recent research (Lotan et al, 2022), both older people and their informal caregivers experience critical and stressful moments in multiple care transitions, negatively impacting on long-term outcomes. “When facing care transitions, older people express feelings of reduced autonomy and increased dependency. Their preference regarding involvement in decision-making varies considerably and their decisions are influenced by healthcare professionals and the support from informal caregivers. Informal caregivers find it important to be involved in the decision-making process, even though they experience the burden of responsibility and report specific difficulties relating to decision-making. Future studies should focus on methods by which to empower older people and

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<sup>51</sup> Report of the Special Rapporteur on the rights of persons with disabilities, UN Doc. A/74/186, para. 42.

<sup>52</sup> Report of the UN Independent on the enjoyment of all human rights by older persons, UN Doc. A/76/157, 2021, para. 42.

<sup>53</sup> Seidel, K., Prendergast, D., Saris, A.J., Foley, J. (2021). D2.1 Understanding Older People: Lives, Communities and Contexts. Deliverable of the SHAPES project (D2.1), page 102.

<sup>54</sup> Seidel, K., Prendergast, D., Saris, A.J., Foley, J. (2021). D2.1 Understanding Older People: Lives, Communities and Contexts. Deliverable of the SHAPES project (D2.1), page 105.

<sup>55</sup> Seidel, K., Prendergast, D., Saris, A.J., Foley, J. (2021). D2.1 Understanding Older People: Lives, Communities and Contexts. Deliverable of the SHAPES project (D2.1), page 105.

informal caregivers in transitional care decision-making”<sup>56</sup>. It is envisaged that SHAPES may share some lessons learnt from the pilot activities at the end of the project with that respect.

### 3.6 Sustaining empowerment

The factors and dynamics highlighted in the previous paragraphs provide an overview of some basic needs, concerns, and expectations of (older) people in their health and care pathways. By listening to their stories and going through evidence, it is possible to seize the key elements helping the conception of fairer policies and interventions, truly addressed to equality and empowerment.

Sustaining empowerment across the lifespan relates to the four principles highlighted by the work of SHAPES (Seidel et al, 2021):

1. Participation: providing older adults with the capability to choose.
2. Process: raising awareness and engaging with change in all stages of life.
3. Practices: recognising and enabling people’s contributions.
4. Purpose: proving the opportunity to live according to one’s own intentions.

In addition, below are three main aspects sustaining empowerment and thus decision-making, inspired by the views of AGE Platform Europe and the European Office of the Red Cross<sup>57</sup>. As the four principles issued by SHAPES, the factors below are also grounding steps to reform the health and care systems, and to move away from the traditional and siloed care, allowing for a balanced of powers in shared decision-making processes:

- *Reframe age (and avoid ageism and ableism)*

Policies and services should put an end to ageism and ableism, and to stereotyping language and portrayal of old age<sup>58</sup>, disabilities and gender, to remove the association of care and stigma, change the narrative on age and ageing, and for promoting

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<sup>56</sup> Lotan, K., De Vlieghe, K., Vandamme, M., Holtzheimer, E., Ellen, M., van Achterberg, T. (2022). Older peoples’ and informal caregivers’ experiences, views, and needs in transitional care decision-making: a systematic review, *International Journal of Nursing Studies*, Volume 134, 2022, 104303, ISSN 0020-7489, <https://doi.org/10.1016/j.ijnurstu.2022.104303>, excerpt of conclusions.

<sup>57</sup> AGE Platform Europe, Red Cross EU Office. (2021). Shared conclusions, November 2021.

<sup>58</sup> “Older people living in residential long-term care are particularly portrayed in a homogenous way. Individuals exposed to stereotypical portrayals could develop a distorted view of the realities of older people and later life. The negative portrayals could harmfully influence older people’s self-esteem as well as younger people’s perceptions of ageing processes” thus impacting on one’s empowerment (Xu, Allen, Euroageism project, page 2).



equality and intergenerational exchanges, while embracing the diversity and intersectionality of each person.

- *Participation and person-centredness*

Participation, contribution, and inclusion of people in shaping their lives and society are opportunities for better health and care. Investing in co-design and co-creation also in the health and care sector is a way to empower people across the life span, and to place them at the core of the system design and organization, thus improving the whole ecosystem. “Including older people’s voices in development and decision-making processes that affect them can lead to better outcomes, including inclusive institutions, improved access to and quality of public services, and positive human development”<sup>59</sup>. These processes should be accessible, inclusive, and respectful. And conversely, “investment in long-term care is an investment in people's quality of life and improves social and intergenerational cohesion”<sup>60</sup>. Through participation, facilitated by friendly and transparent information and communication, empowerment and decision-making are also underpinned, both at individual and community levels. Because “my care assessment should not just focus on my basic needs but look at the support I need to participate in the community”<sup>61</sup>.

- *Adopting a life-course approach to health and care*

It is essential to promote a life-course approach, moving away from rigid categories based on chronological age, which conceive older people as a homogenous group, thus failing to embrace their diversity and hindering their empowerment. In the health and care sectors, a life-course approach considers people’s health throughout their lives and does so with respect to the long-term care needs of people in older age. Investments embracing a life-course approach will gain in sustainability, which also depends on the ability of the health and care system to make us age in good health, from childhood to older age (AGE Platform Europe, Red Cross EU Office, 2021).

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<sup>59</sup> HelpAge International. (2022). HelpAge Voices Framework. An Introduction, page 2.

<sup>60</sup> AGE Platform Europe, Red Cross EU Office. (2021). Shared conclusions, November 2021, page 3.

<sup>61</sup> Two Moons project. (2017). [My human rights. my well-being](#)

## 4 Good practices and new participatory processes

The review of 100 articles and 5 books on patient participation in healthcare decision-making (Vahdat et al, 2014) led to the identification of six general categories in studying patient's participation: definition of participation, importance of patient participation, factors influencing participation of patients in healthcare decisions, method of patient participation, tools for evaluating participation, and benefits and consequences of patient participation in healthcare decision-making. This review found out that "patient participation in health care decisions is a sign of valuing humanity and individuality of the patient"<sup>62</sup>. This work underlined that "today, patient participation is regarded as a legal right of the patient as well as an international gold standard for healthcare systems, and health professionals strive for this standard. Patients must participate in decisions associated with planning, performance, and evaluation of healthcare". It moreover recommended to plan and provide "patient-oriented healthcare, based on opinions, needs, and preferences of patients"<sup>63</sup>.

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<sup>62</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3964421/>

<sup>63</sup> Ibidem.



**Selected Summary of Some Studies on Patients’ Participation in Healthcare Decisions**

<b>Country of Study</b>	<b>Year of Study</b>	<b>Number of Participants/Study Population</b>	<b>Results</b>
<b>Scotland</b>	2008	13	Participation as cooperation to understand information, not just seeking information
<b>Sweden</b>	2004	10	Participation as trusting, understanding, seeking and maintaining a sense of control
<b>England</b>	2000	44	The relationship of patients’ involvement with underlying factors, type and severity of disease, and patient-specialist relationship
<b>11 European countries</b>	2000	330	The relationship of degree of patients’ involvement with doctor-patient interaction, patients’ desire to participate, patients’ demographics (literacy, high mental agility)
<b>Sweden</b>	2006	26	The relationship between patients’ involvement with knowledge, mental, physical and emotional capacity
<b>Australia</b>	2006	73	The effect of patient-doctor interaction (discussion, trust) and doctors’ interpersonal skills on participation
<b>Scotland</b>	2007	20	The relationship between patients’ involvement with factors of respectful and friendly behavior, non-judgmental approach, doctors’ attention to patients’ views, clear explanation by doctors
<b>Sweden</b>	2006	900	The relationship between patients’ involvement and factors of provision of information and explaining it according to personal needs, staff acknowledgement of patients’ knowledge

Figure 2 Excerpt from review of studies on patients’ participation

The SHAPES project conceives participation as not confined to the status of “patient” but addresses its work to a broad range of users and future users, part of the health and care ecosystem. As stated by other works in SHAPES, participation allows to steer the development of goods and services directly impacting on the quality of life of users, where participation is intended as familiarisation, and empowerment is intended as co-development (Sarlio-Siintola, 2020).

The collaborative development of ideas, products, and services (co-creation) has the potential to deliver long-term benefits. In SHAPES, the co-creation approach has been used for the game-based methodology for empowering in decision-making (cf. paragraph 4.1), as an empowering process, involving various stakeholders in iterative



rounds of consultation and exchange. As pointed out by National Seniors Australia that collected the views of 4,562 older Australians in 2021:

- “Co-design is required at the *individual* level, for every senior to have choice and control over their own care plans, accommodation, transitions and supports, given the immense diversity of needs and preferences present within the community.
- Co-design is required at the *service* level, for system users to innovate appropriate service options and types, including attention to key traits, such as locations, staffing levels, procedures, and provisions.
- Co-design is required at the *facility* level, for aged care residents to be involved in designing spaces and places that enhance safety, accessibility, privacy, and comfort for every older Australian.
- Co-design is required at the *policy* level, for senior Australians to be actively involved in developing new reform initiatives, new legislation, new funding frameworks, and more, for the aged care system.

Embedding co-design in a genuine and ongoing way, in various forms and in various settings, directly challenges ageist norms and assumptions and mitigates against the most pernicious impacts of ageism: disempowerment, lack of control and autonomy, loss of rights. Like all prejudices, stereotypes and discrimination, ageism rests on the ‘otherness’ of older people”<sup>64</sup>.

Following AGE Platform Europe’s work on a human-rights based approach to empowerment<sup>65</sup>, the SHAPES project is encouraged to answer the following questions about its methodologies, products, and services:

- Is the project recognizing older people as **rights-holders/agents** able to improve their own lives/ that contribute to their communities or as passive subjects?
- Is the project aiming to ensure the **full participation** of older people in society, or is it rather focused on cost-efficiency/charity/other considerations?
- Have **older people** been involved actively and meaningfully in the preparation and evaluation of the project’s outcomes? Who has been involved? Does the group involve older people from marginalized communities, those in care settings, individuals experiencing multiple forms of discrimination, etc.?
- Are older people **aware** of the scope and nature of their rights, how they can be realized in practice and how to claim them in case of violation?

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<sup>64</sup> <https://nationalseniors.com.au/uploads/National-Seniors-Codesign-Report-9-June-2021.pdf>, page 46

<sup>65</sup> Credits to Nena Georgantzi and Apolline Parel for their work. Further reference of it will follow once it will be published.



- Do older people receive **training, support, information, and knowledge** to participate in consultations and claim their rights?
- Is attention given to aspects of **accessibility** to enable full participation? (e.g., physical accessibility, but also language).

### 4.1 Some examples of participatory processes

Among the good practices in decision-making, the Ottawa Decision Support Framework (ODSF) is a milestone since 2000. It conceptualizes the support needed by patients, families, and their practitioners when dealing with ‘difficult’ decisions. Such framework helps practitioners evaluating decisional needs, providing decision support, and evaluating their effects on decisional outcomes<sup>66</sup>.

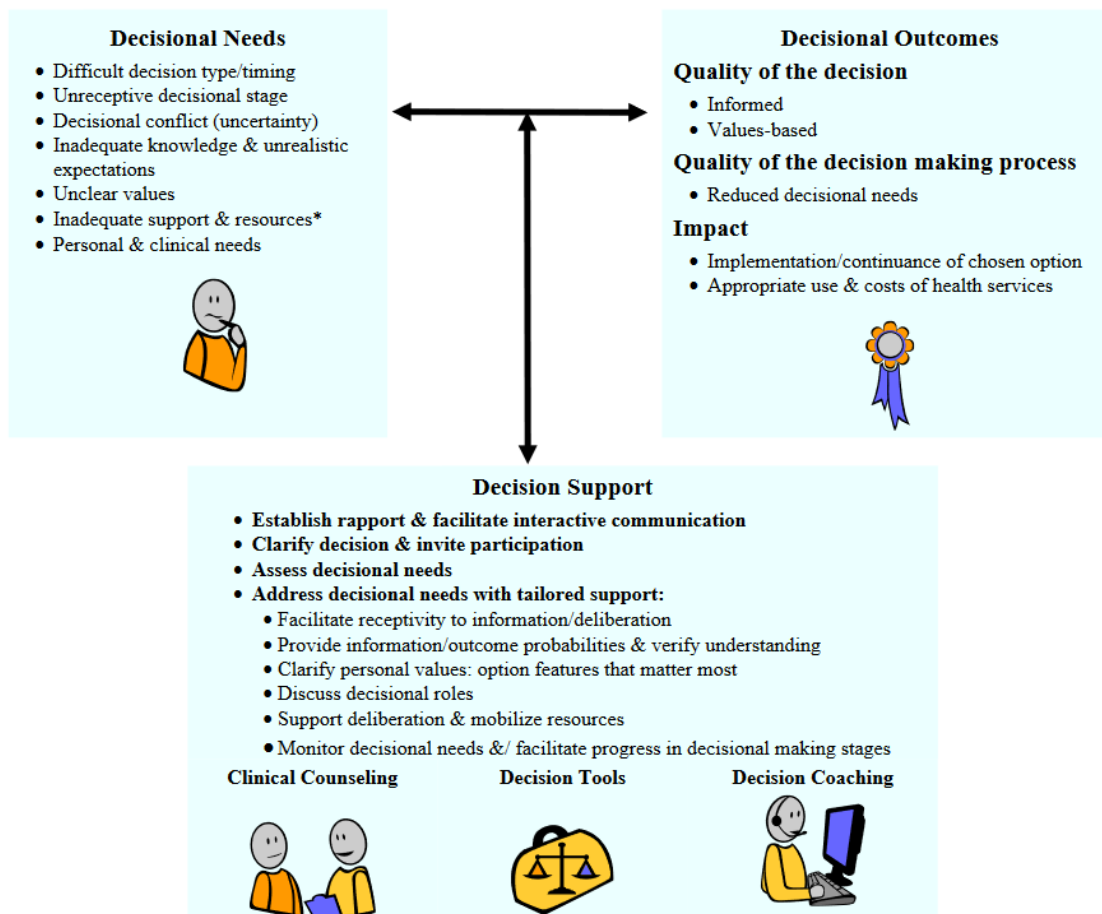


Figure 3 The ODSF in a nutshell

<sup>66</sup> <https://decisionaid.ohri.ca/docs/develop/ODSF.pdf>



In addition to such a well consolidated framework, whose reviews confirmed its relevant and usefulness throughout the years<sup>67</sup>, operational platforms to support decision-making exist<sup>68</sup>. Among the most relevant for this deliverable is the “My ACP Decisions Platform”, issued by a non-profit foundation with a mission to empower patients to make informed medical decisions by engaging in shared decision-making with their healthcare providers<sup>69</sup>. The platform is addressed to patients, offering content suitable to help in the decision-making process; it is equally addressed to health and care professionals, for advance planning and support in end-of-life care; last, it is also useful for administrators, through decision tools to enhance the whole health and care ecosystem.

## The My ACP Decisions Platform

Empower your patients. Manage your team. Measure your success.

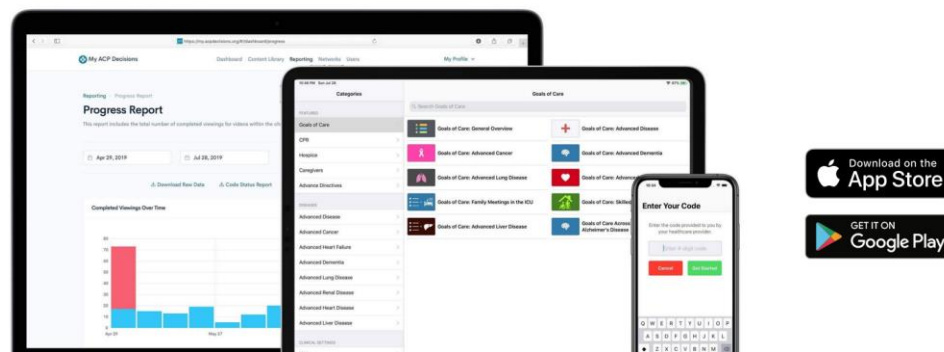


Figure 4 Screen-print of the My ACP Decisions Platform

Ultimately, as highlighted by deliverable D3.5, “improving communication with the person who is being cared for is necessary to set up strategies for handling problematic behaviours”<sup>70</sup>. Every service can design and adapt existing tools and frameworks according to the needs and to the protection of people’s rights, making

<sup>67</sup> <https://pubmed.ncbi.nlm.nih.gov/32428429/>

<sup>68</sup> For example: <https://healthmanagement.org/c/hospital/issuearticle/supporting-diagnostic-and-therapeutic-decision-making-along-the-patient-pathway>. Specifically on supporting health and care managers in decision-making, more insights are from DECIDE project: <https://pubmed.ncbi.nlm.nih.gov/18475113/>

<sup>69</sup> <https://acpdecisions.org/>

<sup>70</sup> Zurkuhlen, A., Cooke, M., 2021, Deliverable D3.5 - Initial SHAPES Collaborative Governance Model Version 1.0, page 67

sure all stakeholders in the process have a say and an impact in the decision-making chain. This is especially more relevant for the SHAPES Platform, an ecosystem made of data, analysis, services, people, and places.

Specifically, the European Union of the Deaf (EUD) pointed out the role of communities to allow the participation of multiple stakeholders in the decision-making process and mentioned the case of the VidAsor service (Confederación Estatal de Personas Sordas, 2021) with that respect. Established in 2017, following the advocacy work of the pressure from the CNSE (Spanish national associations of the deaf), this free video assistance and accompaniment service for deaf older people is offered through conventional television. “These examples illustrate how informal carers and community advocates can educate professionals about the unique care needs of minority groups, such as deaf people. This can foster a more inclusive approach respect for diversities (Navaie-Waliser et al., 2001).”<sup>71</sup>.

Directly from the SHAPES project, Laurea University developed a game-based co-creation method and a related digital tool prototype to support care-related decision-making. Being a serious game (Alvarez et al. 2011), it allows participants to learn about crucial concepts and ways of thinking in design and to reflect on their life choices, needs and wishes concerning their later life in dialogue with family members and caregivers. The game facilitates expressing and sharing experiences and helps participants to reflect on their priorities and communicate them to family members involved in care decision-making. Furthermore, the game can be framed as a design game which is a category of games used in collaborative design or co-design<sup>72</sup>.

The game has been based on the ATLAS Map for Future Service Co-Development research project (2012–2014), developed at Aalto University. In the first phase of the design and development process, the care system, legal and regulative environments, and organizational context of care of older people were analyzed. Based on an understanding of contextual requirements and customers’ needs, values, dreams, and priorities, six interactive game prototypes saw the light. At the point of writing this report, the prototype is ready for user testing and customer feedback.

Catalano et al. give guidelines for effective design of serious games: situate the learning, minimize the cognitive load, engage the player constructively/experientially,

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<sup>71</sup> Ibidem.

<sup>72</sup> Co-design involves the application of specific methods and tools to engage end users and relevant stakeholders in the design of new services and products. Co-design is based on a belief that sharing the creation process with the people the design is supposed to serve will result in services and products that better respond to the needs of the users. Design games can be used to support the participants creativity and imagination as they involve playful characteristics that encourage participation, experimentation and interactions that are emancipating and fun. Also, design games have been found to empower users by enhancing democracy among actors in design. (Vaajakallio, 2012).

facilitate the learning task, flexibility, reusability, and exploitability. These guidelines were followed in the design of the game, along with accessibility as a design driver.

The core mechanic of the prototype is flipping hexagonal cards one by one and having discussions about the topics in them. Each card is then laid out on a grid, to represent relationships between the different cards and to signal progress through the game. As the design was prototyped and tested, it went through many iterations. Prototyping ideas and design concepts with the game engine made it possible to try it out and find out what works and what does not. As most of the development of the game took place during the pandemic, it hindered the possibility of including actual end-users and stakeholders in design. It was not possible to enter senior homes or even visit older relatives within families. Furthermore, the development phase was not optimal for virtual co-creation since it involved the use of digital prototyping tools that were too complex to serve as basis for virtual co-design discussions with ageing individuals. These were unexpected drawbacks that forced to change plans as the pandemic continued. To truly learn about issues in empowerment would necessitate a possibility to interact directly with the users in their ordinary environments. Seeing what they see and feeling what they feel is how the designer often gets to the roots of the challenges that the users and their families are confronted with. As the pandemic does not limit meetings and encounters as starkly as it used to, Laurea will have a possibility to continue the game development on a genuinely inclusive approach.

## 5 Shaping the SHAPES Platform

“The ecosystem of SHAPES includes the technological aspects, but more importantly the sociocultural, knowledge and informational, educational, economic, and lifestyle aspects of SHAPES in context”<sup>73</sup>. The SHAPES Platform is addressed to older people, but also to all citizens interested in active and healthy ageing.

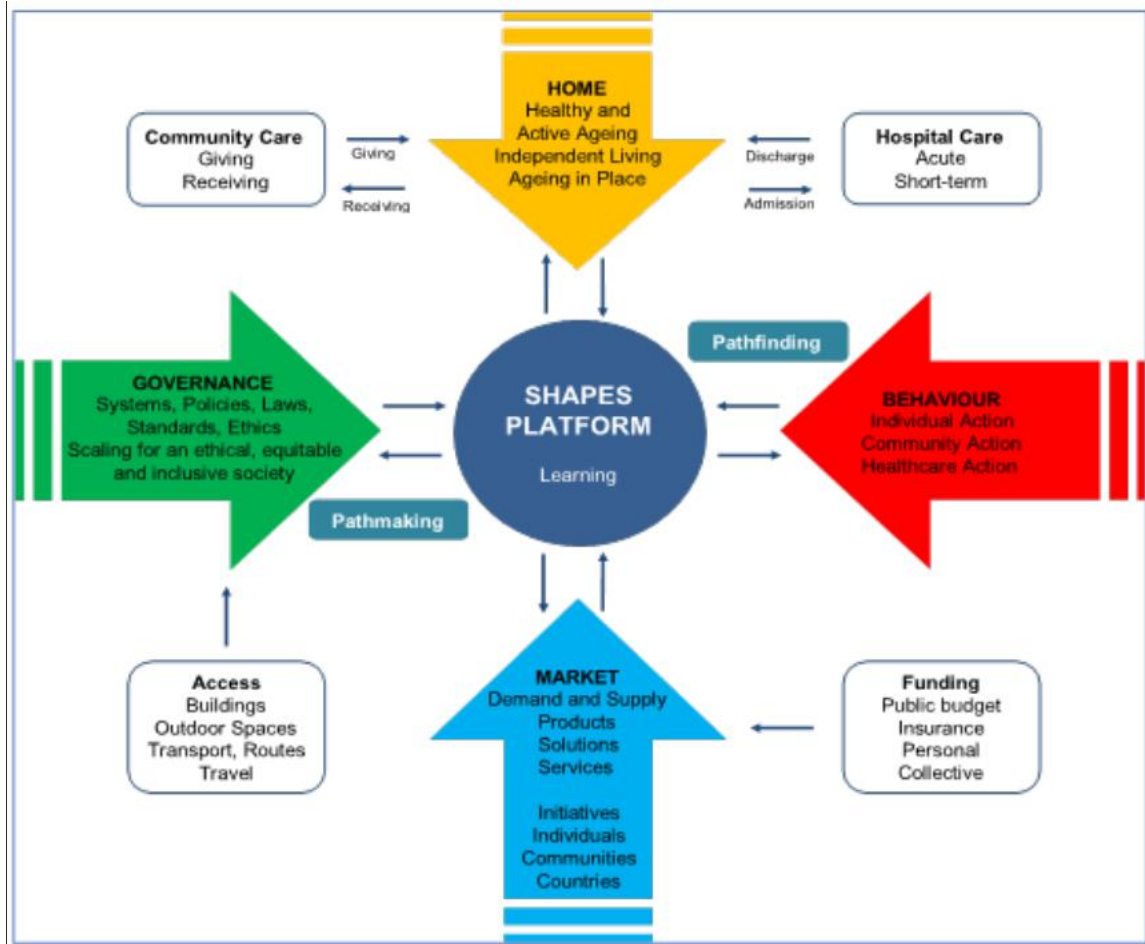


Figure 5 SHAPES Integrated Care Platform (Description of Action, page 85)

As pointed out by deliverable D8.4, the SHAPES Platform iteratively learns from the needs and preferences elicited by its users, thus enhancing the level of coherence for the best users’ experience, in full security and reliability (Sarlo-Siintola, 2020). Such an engaging system towards and with its users wants to be empowering and support their decision-making along the users’ health and care pathways.

<sup>73</sup> Zurkuhlen, A., Cooke, M., 2021, Deliverable D3.5 - Initial SHAPES Collaborative Governance Model Version 1.0, page 23

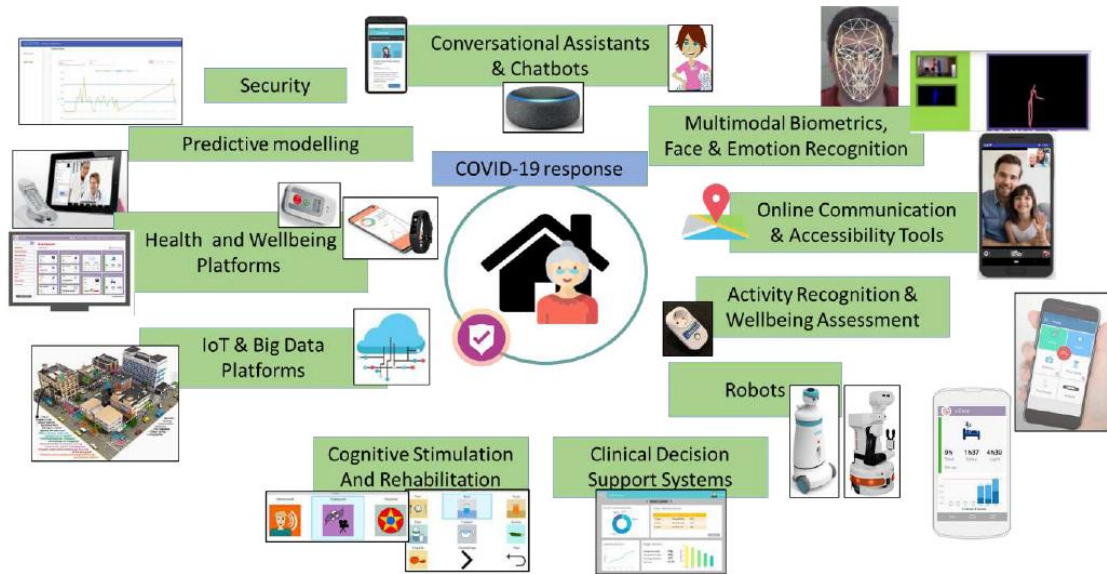


Figure 6 Overview of SHAPES Digital Solutions and Their Main Application Areas

All SHAPES solutions aim to empower their users, in very diverse contexts and environments. With respect to the technological component of the SHAPES Platform, the project provides a coherent approach where users can check their vital signals, control medication adherence and diet schedules and, at the same time, through a real-time link, have frequent interactions with their physician, caregiver, or nurse. Furthermore, cognitive methods for psycho-social support, robot interaction, tools for physiotherapy, mobility and accessibility comprise an environment for improving the users' knowledge and inclusion in decision-making, while supporting the users across their different level of digital literacy. With respect to the broader conception of SHAPES, its methods (e.g., co-design), approaches (e.g., personas and use cases), processes (e.g. informed consent, consultations, interactions) and the environment where decisions are made is geared towards empowerment and agency, as:

1. The SHAPES Platform provides opportunities for older people to make informed choices.
2. The SHAPES Platform allows older people to effectively use their opportunities to make decisions.
3. The SHAPES Platform provides the tools to translate the choices made into intended results.

These three stages come across through the piloting activities as they unfold, as highlighted in paragraphs below. Because it is not only about having the opportunity to choose; it is also about exercising that opportunity and about achieving the intended outcome. Then, true empowerment is in place.

The following paragraphs indicate how SHAPES exhibits features or paths that support people’s empowerment and decision-making by addressing the following criteria in the project’s piloting campaign. The relevant empowerment indicators, derived by 2.1.1 – Empowerment of patient care, are the following:

- *Having a sense of personal identity*
- *Having a sense of choice and control*
- *Sense of usefulness and being needed*
- *Retaining a sense of worth*
- *Embracing the users’ health priorities*
- *Relational continuity*, intended as the therapeutic relationship between a user and one or more providers that spans various healthcare events and results in accumulated knowledge of the user and care consistent with his/her needs.

These empowerment indicators embrace the concept of agency in SHAPES: it is not only important to provide the opportunity for older individuals to make a choice; it is important that they act on that opportunity and that they translate their choice into the intended outcome. SHAPES delivers an environment that fosters empowerment and agency, providing capacity-building tools (methods, approaches, processes, applications, technologies, information) to help realize the goals and expected outcomes of empowering older individuals in health and care decision-making.

Within the timeframe of this deliverable, it was possible for pilots 1, 2, 3, 4, 5 and 7 to provide useful information, compiled in the tables below. This exercise allows the pilot leaders and evaluators to assess their action and the impact of their services based on empowerment indicators.

### 5.1 Overview from pilots: examples from Pilot 1

Table 5-1 Overview from pilot 1

Empowerment & Decision-making Criteria	Pilot 1: Smart Living Environment for Healthy Ageing at Home
<b>Having a sense of personal identity</b>	<p>UC-001: the user receives personalized feedback based on the individual health and wellbeing data as well as the predefined goals that are jointly identified in the beginning.</p> <p>UC-002: the user interacts with the digital assistant on personal information like appointments, reminders, drug intake, questionnaires. This information is entered at the beginning and can be adapted anytime.</p>



<b>Having a sense of choice and control</b>	<p>UC-001: the monitoring and display of the individual's health and wellbeing data enables users to become aware of their own health status and act. This is further supported by giving recommendations and reminders formulated in an open, non-judgmental, and non-directive way to give the user a sense of choice and likewise motivate them to take action and control over their health status.</p> <p>UC-002: the information entered in the digital assistant can be deleted anytime.</p> <p>UC-003: the user can choose whether to use the video telephony to interact with family and friends or not.</p>
<b>Sense of usefulness and being needed</b>	<p>UC-001: the personalised feedback and option to predefine individual goals aligned with the user's abilities supports the user of becoming aware of these and motivate them to make use of them.</p> <p>UC-002: The user can manage the daily life autonomously with the help of little reminders.</p>
<b>Retaining a sense of worth</b>	<p>UC-001: the aim of the UC is to detect risky situations at home and to monitor and improve the wellbeing of the user. The app supports the user to experience this sense of worth.</p> <p>UC-003: the aim of the UC is to reduce loneliness and isolation and to overcome the fear of digital technologies, supporting the person to use the technologies in a confident way. This can improve the participation in the social life, as digitization is a big part of the daily life.</p>
<b>embracing the patient's health priorities</b>	<p>UC-001: users receive constant feedback on their health/wellbeing status allowing them to actively intervene and adjust towards identified goals. This input is prerequisite.</p> <p>UC-002: the app also can involve a formal and informal caregiver of the user that is known to the user to interact on a personal level. Involving a personal relationship allows to consider and meet the user's priorities in care or support.</p>
<b>relational continuity</b> <i>(therapeutic</i>	<p>Caregivers can be involved in every UC, but it is not mandatory.</p>

<p><i>relationship between a patient and one or more providers that spans various healthcare events and results in accumulated knowledge of the patient and care consistent with the patient's needs)</i></p>	
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## 5.2 Overview from pilots: examples from Pilot 2

Table 5-2 Overview from pilot 2

<b>Empowerment &amp; Decision-making Criteria</b>	
<p><b>Having a sense of personal identity</b></p>	<p>UC-001: the user receives personalised feedback based on the individual health and wellbeing data, as well as the predefined goals that are jointly identified in the beginning.</p> <p>UC-002: the user receives recommendations on events that are aligned with the user’s personal information regarding the living situation and individual preferences. This information is inputted in the beginning and can be adapted any time.</p> <p>UC-001: the user receives personalised feedback based on the individual health data as well as the predefined goals that are jointly identified in the beginning</p> <p>UC-002: the user receives recommendations on events that are aligned with the user’s personal information regarding the living situation and individual preferences. This information is inputted in the beginning and can be adapted any time.</p> <p>UC-003: all users undergo a physical pre-assessment and start with a basic level-1 training protocol to be acquainted with the training system. Based on a following physical</p>



	<p>assessment and health data collected, each user receives personalised feedback and training (continue with level 1 training protocol or start level 2 training protocol).</p> <p>In addition, following the cognitive pre-assessment, each user starts a personalized training session during the cognitive training and create a schedule considering the 29 BrainHQ exercise. Based on the Personal Trainer feature, each user can interact with exercises where he/she has the greatest opportunity for improvement, and this measure typically changes from session to session depending on his/her last training session.</p>
<p><b>Having a sense of choice and control</b></p>	<p>UC-001: the monitoring and display of the individual health and wellbeing data enables users to become aware of their own health status and act. This is further supported by giving recommendations and reminders formulated in an open, non-judgmental, and non-directive way to give the user a sense of choice and likewise motivate them to take action and control over their health status.</p> <p>UC-002: the events and activities can be freely selected and deleted anytime.</p> <p>UC-003: Participants will be informed about the objectives of the study and methodology to be used, details of participation, inclusion criteria, conditions for participation and the type of measures adopted to ensure the confidentiality of personal data protection will also be explained. Participants can withdraw at any time.</p> <p>Participants will use the technological platforms autonomously at any time and any place of their convenience and select the scenarios they will exploit.</p> <p>UC-004:</p> <p>a) The residents in the nursing home can chose whether to interact with the robot and use its different functionalities.</p> <p>b) the user in the home setting can chose whether to interact with the robot and use its different functionalities.</p>

<p><b>Sense of usefulness and being needed</b></p>	<p>UC-001: the personalised feedback and option to predefine individual goals aligned with the user’s abilities supports the user of becoming aware of these and motivate them to make use of them.</p> <p>UC-003: the personalised feedback and option to predefine training protocol aligned with the user’s health condition and abilities supports the user of becoming aware of these and feel that he/she is valuable.</p> <p>UC-004:</p> <p>a) the regular night patrolling of the robot in the nursing home as well as relieving the burden on caregivers shall make the residents feel save; moreover, the robot’s presence offers the environment to explore and experience their abilities and skills.</p> <p>b) The robot supports the individual in their home setting to stay independent and autonomous for longer while equally ensuring a safe and justifiable environment for the individual through supporting them in situations that might pose a threat to their independence (accompanying the person to the toilet during night, detecting a fall...). This allows the user to make use of their abilities and skills and experience a proactive attitude without ignoring potential risks that arise with age and might pose a threat to their independence (accompanying the person to the toilet during night, detecting a fall...).</p>
<p><b>Retaining a sense of worth</b></p>	<p>UC-002: the aim of the UC is to support individuals at risk of isolation to participate with and integrate in society. The app supports the user to experience this sense of worth.</p> <p>UC-003: the aim of the UC is to support individuals at risk of isolation to participate with and integrate in society. Interaction both the cognitive and training system supports the user to experience this sense of worth.</p>
<p><b>embracing the patient’s health priorities</b></p>	<p>UC-001: the users receive constant feedback on their health status allowing them to actively intervene and adjust towards identified goals. This input is prerequisite.</p> <p>UC-002: the app also involves a formal and informal caregiver of the user, that is known to the user to interact on</p>

	<p>a personal level and recommend activities that align with the user’s preference and interest. Involving a personal relationship allows to consider and meet the user’s priorities in care or support.</p> <p>UC-003: integrates both a physical and a cognitive component into a ludic and appealing environment. The combination of cognitive and physical training provides an effective protection against cognitive decline as age-related, thus, improving overall quality of life through the enhancement of physical condition and mental health, while preventing any deterioration and social exclusion.</p> <p>UC-004:</p> <p>a) the deployment of the robot shall reduce the workload of the staff in the nursing home. This shall offer the capacity for caregivers to concentrate and meet the individual’s expectations and priorities in care.</p> <p>b) for most people, independence, self-determination, and autonomy are core values that are often followed by intense feelings of fear and loss of control. The robot picks up on these basic wishes and priorities by support the individual in their home setting to stay independent for longer while equally ensuring a safe and justifiable environment for the individual through supporting them in situations that might pose a threat to their independence (accompanying the person to the toilet during night, detecting a fall...).</p>
<p><b>relational continuity</b> <i>(therapeutic relationship between a patient and one or more providers that spans various healthcare events and results in accumulated knowledge of the patient and care</i></p>	<p>UC-001: there is no caregiver involved in the UC.</p> <p>UC-002: the app offers (informal) caregivers to regularly recommend events and activities to their care receiver and interact with them via video call, supporting their relationship.</p> <p>UC-003: healthcare professionals and formal caregivers that have been previously trained in the use of the cognitive and physical components are involved in the use case. Supervision and guidance are provided by healthcare professionals and caregivers to older adults during training, while social interaction and recommendation of activities that align with the user’s preference and interest are also ensured.</p>

<i>consistent with the patient's needs)</i>	UC-004: a) the deployment of the robot shall reduce the workload of the staff in the nursing home allowing them to concentrate more on the individual's needs and relationship with the residents. b) there is no caregiver involved in this UC.
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### 5.3 Overview from pilots: examples from Pilot 3

Table 5-3 Overview from pilot 3 – part I

<b>Empowerment &amp; Decision-making Criteria</b>	<b>PT3-general and PT3-001</b>
<b>Having a sense of personal identity</b>	N/A
<b>Having a sense of choice and control</b>	PT3-general and PT3-001 - older individuals with multiple long-term conditions are supported to self-manage their chronic conditions through the daily use of a digital health solution (SHAPES App) that can also facilitate the remote monitoring of a person's health status. The goals of the intervention are to help older people to self-monitor their health conditions, physiological parameters, and medicines adherence to promote safer and more effective use of medicines in their own home. It is proposed that through the use of the App, individuals may have an increased sense of control (e.g., improved ability to take action due to increased understanding of their condition through self-monitoring).
<b>Sense of usefulness and being needed</b>	N/A
<b>Retaining a sense of worth</b>	N/A
<b>embracing the patient's health priorities</b>	PT3-general and PT3-001 – through the use of the SHAPES app, older individuals could gain an increased understanding of their condition through self-monitoring which could increase their confidence to raise issues with healthcare providers, therefore helping to promote their health priorities.
<b>relational continuity (therapeutic)</b>	PT3-001 - The solution provides a control panel that allows HCP to daily monitor the health status of patients, the

<p><i>relationship between a patient and one or more providers that spans various healthcare events and results in accumulated knowledge of the patient and care consistent with the patient's needs)</i></p>	<p>definition of their care plans, medication, and treatments and to overview their adherence. The solution works through an alert system that optimizes doctors' interventions. Thanks to this system, fewer decompensations are expected which will lead to a better management of patients, a decrease of the use of health care resources and an overall improvement of patients' quality of life.</p>
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Table 5-4 Overview from pilot 3 – part II

Empowerment & Decision-making Criteria UC-PT3-001c and UC-PT3-COPD	
<b>Having a sense of personal identity</b>	The SHAPES solution presents a feature accessing the patient's medical history. The solutions communicate with the patient in the first name basis.
<b>Having a sense of choice and control</b>	The SHAPES solution presents a feature to opt-out from the study. Possibility to engage a videoconference with a physician. Progress monitoring visible for patients.
<b>Sense of usefulness and being needed</b>	A possibility of the SHAPES solution to manually input measurements in case of automatic read-out failure. Communication with medical staff through the personal chat.
<b>Retaining a sense of worth</b>	The SHAPES solution communicates with the patient in the first name basis. Progress is being appreciated by the motivational statements.
<b>embracing the patient's health priorities</b>	Patient health priorities are being continuously adjusted by monitoring vital signs, gathering the responses of administered questionnaires and last but not least via videoconferences between the patient and the physician. This is also combined with a possibility to append short text message to each measurement. There is also a possibility to conduct an extra measurement which can be also connected to the explanatory message for instance

	regarding the worsening of the actual patients' health condition.
<b>relational continuity</b> <i>(therapeutic relationship between a patient and one or more providers that spans various healthcare events and results in accumulated knowledge of the patient and care consistent with the patient's needs)</i>	Relational continuity is being achieved by communication layer of the SHAPES solution.

### 5.4 Overview from pilots: examples from Pilot 4

Table 5-5 Overview from pilot 4

Empowerment & Decision-making Criteria		Pilot 4: Psycho-social and Cognitive Stimulation Promoting Wellbeing
Having a sense of personal identity		UC-001: the user receives personalised feedback about the dance performance.  UC-002: users have a unique user within the system and the robot recognises them when they sign in to play.
Having a sense of choice and control		UC-001: The participants have access to a pool of music from different styles to choose from, according to his/her personal taste and have the possibility of asking for music not already included.  UC-002: The participants have access to a pool of different games, and they can choose according to their preferences.

	There is the option for caregivers and professionals of uploading customised games.
<b>Sense of usefulness and being needed</b>	UC-001 / UC-002: the possibility to participate in a scientific study gives participants a sense of usefulness.
<b>Retaining a sense of worth</b>	<p>UC-001: testing an innovative technology at home and having the possibility to contribute to its improvement through regular feedback contributes to participants' sense of worth and feeling of appreciation.</p> <p>UC-002: testing an innovative technology (the humanoid robot) and its functionalities and having the possibility to contribute to its improvement through regular feedback contributes to participants' sense of worth and feeling of appreciation.</p>
<b>embracing the patient's health priorities</b>	<p>UC-001: the SHAPES solution integrates both a physical and a cognitive component into a ludic and appealing social activity (dancing). Physical and cognitive training is a health priority to most participants as they want to get older without physical or cognitive impairments.</p> <p>UC-002: The robot and the integrated games offer cognitive stimulation for older adults. Games and dynamics have been adapted to participant's needs thanks to the feedback collected during phase 2 and 3 of the project.</p>
<b>relational continuity</b> <i>(therapeutic relationship between a patient and one or more providers that spans various healthcare events and results in accumulated knowledge of the patient and care</i>	<p>UC-001: there is no caregiver involved in the UC.</p> <p>UC-002: caregivers are involved in the use case; they can upload customised games and track the progress of participants. This fact helps building the relationship between carer and patient and helps carers to have more information about the patients' needs.</p>

consistent with the patient's needs)

## 5.5 Overview from pilots: examples from Pilot 5

Table 5-6 Overview from pilot 5

Empowerment & Decision-making Criteria	Pilot Theme 5: Caring for Older Individuals with Neurodegenerative Diseases
<p><b>Having a sense of personal identity</b></p>	<p><b>Use Case 1 - Online Information and Training for informal Dementia Caregivers (iSupport)</b></p> <p>iSupport allows the caregiver (the user) to personalize their training program, according to his needs, interests, and preferences. The program has personalization features embedded which include adapting the program’s text contents to the personal/sociodemographic features of the caregiver and the care recipient (e.g., relationship with the person in care, name of the person in care).</p> <p><b>Use Case 2 - Digital Care Community for Older People with Cognitive Decline</b></p> <p>A care team will assess clinical and behavioral parameters to define a personalized care plan composed by behavioral plan (nutrition, physical activity, sleep patterns, therapeutic adherence), physiological parameters plan (heart rate, blood pressure, calories, weight), and social plan (events, communications). This team will also assess the digital literacy and skills of each participant to define what technological device he/she should use.</p> <p>Care teams will assess the “monitoring data” (collected by technology) to elaborate the personalized “assistance data”.</p> <p>Care team and IT developers will visit participants in their homes to install technological devices and to train participants.</p> <p>Participants will use technological devices autonomously to adhere to the personalized care plan.</p>



<p><b>Having a sense of choice and control</b></p>	<p><b>Use Case 1 - Online Information and Training for informal Dementia Caregivers (iSupport)</b></p> <p>Participants can visit the platform at any time and any place of their convenience and select the themes (sessions) and areas of interest, i.e., personalize their training program. The program is designed as a self-help tool, where the caregivers use the sessions autonomously.</p> <p>As iSupport is an online intervention programme that uses cognitive-behavioural techniques to support informal caregivers, it allows them to acquire new skills and to restructure their thoughts, fostering a greater capacity to control the situation in which they find themselves.</p> <p><b>Use Case 2 - Digital Care Community for Older People with Cognitive Decline</b></p> <p>Data will be used for the purposes agreed in the informed consent.</p> <p>Participants will also be informed about the objectives of the study and methodology to be used, details of participation, inclusion criteria, conditions for participation and the type of measures adopted to ensure the confidentiality of personal data protection will also be explained.</p> <p>Participants can withdraw at any time.</p> <p>Participants will use technological devices autonomously to adhere to the personalized care plan.</p> <p><b>Use Case 3 - BRAINCODE for Cognitive Impairment Diagnosis in Older Adults</b></p> <p>Data will be used for the purposes agreed in the informed consent.</p> <p>Participants will also be informed about the objectives of the study and methodology to be used, details of participation, inclusion criteria, conditions for participation and the type of measures adopted to ensure the confidentiality of personal data protection will also be explained.</p> <p>Participants can withdraw at any time.</p>
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	<p><b>Use Case 4 - Virtual Patient Scenarios (VPS) &amp; Mobile Virtual Patients (MVP)</b></p> <p>Participants will be informed about the objectives of the study and methodology to be used, details of participation, inclusion criteria, conditions for participation and the type of measures adopted to ensure the confidentiality of personal data protection will also be explained. Participants can withdraw at any time.</p> <p>Participants will use the technological platforms autonomously at any time and any place of their convenience and select the scenarios they will exploit.</p>
<p><b>Sense of usefulness and being needed</b></p>	<p><b>Use Case 1 - Online Information and Training for informal Dementia Caregivers (iSupport)</b></p> <p>Through this intervention programme, users can acquire and train their caregiving skills (self-care, deal with negative aspects of caregiving), which can contribute to a perception of self-efficacy, promote, and recognize positive aspects of caregiving and consequently the recognition of the caregiver's role.</p> <p><b>Use Case 4 - Virtual Patient Scenarios (VPS) &amp; Mobile Virtual Patients (MVP)</b></p> <p>Through the MVP and VPS platforms, users can acquire and train their skills with regard to patients' symptoms, diagnosis, and treatment. The platforms are specifically valuable for formal caregivers and healthcare professionals in promoting decision-making as well as reasoning and learning skills. In that regard, the sense of usefulness and being needed is accounted for.</p>
<p><b>Retaining a sense of worth</b></p>	<p><b>Use Case 1 - Online Information and Training for informal Dementia Caregivers (iSupport)</b></p> <p>Participation in psychoeducational programmes such as iSupport, which provides caregivers with a deeper understanding of dementia and practical examples of situations that are difficult to manage on a daily basis, allows caregivers to better accept the most difficult and emotionally demanding moments, contributing to their self-</p>

	<p>understanding and sense of value in their role as a caregiver.</p>
<p><b>Embracing the patient's health priorities</b></p>	<p><b>Use Case 1 - Online Information and Training for informal Dementia Caregivers (iSupport)</b></p> <p>Informal caregivers of people living with dementia are more likely to experience burden and depression or anxiety disorders than the general population (World Health Organisation, 2015).</p> <p>In this sense, interventions with caregivers who present this symptomatology are seen as a health priority affirmed in ageing and dementia action plans (World Health Organization and Alzheimer's Disease International, 2012; World Health Organization, 2017).</p> <p>iSupport is an education and support program, which is multicomponent (including problem solving and cognitive therapy intervention techniques as e.g., skills training, psychoeducation, techniques for self-care, changes in the caregivers' setting). Preliminary evidence (Teles, Ferreira &amp; Paúl, 2022) has favoured iSupport with respect to its contributions to minimize anxiety symptoms and improve environmental quality of life as well as knowledge about dementia.</p> <p>iSupport is a platform that allows caregivers to choose program sessions that address the care recipient's most pressing health challenges/problems.</p> <p><b>Use Case 2 - Digital Care Community for Older People with Cognitive Decline</b></p> <p>The care team will assess clinical and behavioral parameters to define a personalized care plan composed by behavioral plan (nutrition, physical activity, sleep patterns, therapeutic adherence), physiological parameters plan (heart rate, blood pressure, calories, weight), and social plan (events, communications).</p> <p>Intervention outcomes: Improve older people's perceptions of quality of life, effectiveness in daily activities, social support, and social participation. Increase the level of health literacy of older people in terms of disease knowledge and</p>

	<p>health care. Improve physiological indicators (heart rate, calories), people's sleep patterns and physical activity (walking, running) of older people. Improve older people's adherence to clinical (e.g., medication) and behavioral (e.g., nutrition) therapeutic plans. Reduce cognitive decline in older people.</p> <p><b>Use Case 3 - BRAINCODE for Cognitive Impairment Diagnosis in Older Adults</b></p> <p>Technology is an opportunity to deliverable an early, extensive, accurate, and cost-effective clinical diagnosis of neurocognitive disorders.</p> <p><b>Use Case 4 - Virtual Patient Scenarios (VPS) &amp; Mobile Virtual Patients (MVP)</b></p> <p>The efficient training through the VPS and MVP platforms allows formal caregivers and healthcare professionals to develop decision-making, reasoning, and training skills in their workplace competency. In that way they are able to embrace the users' health priorities and provide sufficient care and support to older people with neurodegenerative diseases, including Alzheimer's, Parkinson's disease, and mild cognitive impairment.</p>
<p><b>Relational continuity</b> <i>(therapeutic relationship between a patient and one or more providers that spans various healthcare events and results in accumulated knowledge of the patient and care consistent with the patient's needs)</i></p>	<p><b>Use Case 1 - Online Information and Training for informal Dementia Caregivers (iSupport)</b></p> <p>This use case only involves informal caregivers.</p> <p><b>Use Case 2 - Digital Care Community for Older People with Cognitive Decline</b></p> <p>A care team will assess clinical and behavioral parameters to define a personalized care plan composed by behavioral plan (nutrition, physical activity, sleep patterns, therapeutic adherence), physiological parameters plan (heart rate, blood pressure, calories, weight), and social plan (events, communications). This team will also assess the digital literacy and skills of each participant to define what technological device he/she should use.</p>

	<p>Weekly, care teams will assess the “monitoring data” (collected by technology) to elaborate the personalized “assistance data”.</p> <p><b>Use Case 4 - Virtual Patient Scenarios (VPS) &amp; Mobile Virtual Patients (MVP)</b></p> <p>This use case promotes and enhances the clinical training of formal caregivers and healthcare professionals. However, through this process, caregivers and professionals will acquire enhanced clinical, reasoning, and behavioural skills that will allow for the better management of patients’ disease and treatment as well as enhance the communication among patients and caregivers.</p>
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### 5.6 Overview from pilots: examples from Pilot 7

Table 5-7 Overview from pilot 7

Empowerment & Decision-making Criteria	Pilot 7: Cross-border Health Data Exchange, Supporting Mobility and Accessibility for Older Individuals
<b>Having a sense of personal identity</b>	<p>UC-001: the user receives personalised feedback based on their individual health data and a personalised treatment plan that has been prepared by their physician based on their health data and medical history.</p> <p>UC-002: The user defines their access needs and individual preferences to be provided with customized recommendations regarding destinations and points of interest. The needs and preferences can be adapted any time.</p> <p>UC-003: The user receives personalised messages, recommendations, and warnings that are based on the real-time monitoring and analysis of their individual vital signs and health data. In case of a health emergency, their physician can videocall the user to provide a more personal attention.</p>

<p><b>Having a sense of choice and control</b></p>	<p>UC-001: the user has a clear understanding and awareness of their health status which empowers them to self-manage their condition. Additionally, the user may co-decide with their physician upon the activities plan best fitting their lifestyle and daily routine.</p> <p>UC-002: The user can make an informed decision on the destinations and points of interest they can visit, that best fit their accessibility needs, health, and well-being status, without compromising safety and independence.</p> <p>UC-003: the user has a clear understanding and awareness of his health status which empowers them to self-manage their condition. Their chronic health issues are no longer a deterrent to choose their next travelling destination since they are able to enjoy an active and independent living without worrying about potential health emergency events.</p>
<p><b>Sense of usefulness and being needed</b></p>	<p>UC-001: the user has a clear understanding and awareness of his health status which empowers them to self-manage their condition. This enables them to overcome any anxieties and concerns of the past, due to their health condition, that made them refrain from providing support to family and friends.</p> <p>UC-002: The user can make an informed decision on the destinations and points of interest, that best fit their accessibility needs, health, and well-being status, without compromising safety and independence, thus being enabled to visit those destinations jointly with friends, reinforcing their feel of safety and inclusion.</p> <p>UC-003: the user has a clear understanding and awareness of his health status which allow to retain his/her role and functions, and thus the sense of usefulness and empowers them to self-manage their condition.</p>
<p><b>Retaining a sense of worth</b></p>	<p>UC-001: the user has a clear understanding and awareness of his health status which empowers them to self-manage their condition. This enables them to overcome any anxieties and concerns of the past, due to their health condition, that made them refrain from participating actively in their community (and thus losing sense of worth).</p>

<p><b>Embracing the patient's health priorities</b></p>	<p>UC-001: the user has a clear understanding and awareness of his health status which empowers them to self-manage their condition. The user also has a tailor-made treatment plan that has been prepared by their physician based on their health priorities and medical data.</p> <p>UC-002: The user receives personalised recommendations regarding destinations and points of interest, based on their access needs, health concerns and individual preferences.</p> <p>UC-003: the user has a clear understanding and awareness of his health status as well as a direct, open channel of communication with their physician who attends to their health needs and priorities, thus preserving the feeling that the user “never left home”.</p>
<p><b>Relational continuity</b> <i>(therapeutic relationship between a patient and one or more providers that spans various healthcare events and results in accumulated knowledge of the patient and care consistent with the patient's needs)</i></p>	<p>UC-001 and UC-003: The physician and/or medical professional increase their effectiveness and productivity. They can remotely monitor their patient health status and vital signs. They can create customised treatment plans, check adherence and follow-up. They can train / educate their patients to be more effective in their disease self-management. At the same time, Health Providers improve their patient management, especially within the context of delivering primary care services in their community. This improvement is also supported by direct communication channels with every individual in need of their services, whilst maintaining and exchanging sensitive data with safety, security, and integrity.</p>

## 5.7 Some key challenges to empowerment in SHAPES

After having highlighted a set of SHAPES responses to empowerment and decision-making at pilot level, this paragraph offers a view on barriers, shortcomings, gaps, and challenges to empowerment in decision-making looking at the overall ecosystem, from the individual to the collective level, from the technological spheres to the governance ones. Building on the literature review conducted for this deliverable, on the survey and research perform for deliverable D3.5 and on the insights gathered by AGE in its “Rethinking Care” process, such non-exhaustive list can be used by the SHAPES project to detect challenges at the level of the overall ecosystem.

Table 5-8 Some key challenges to empowerment

No.	Category	Overview of challenges
1	<b>Knowledge and Awareness</b>	<ul style="list-style-type: none"> <li>Unstructured knowledge,</li> <li>Lack of instruction (or knowledge)</li> <li>Lack of information</li> <li>Inaccessible information</li> <li>Lack of evidence</li> <li>Language skills</li> <li>Psychological barriers</li> <li>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</li> <li>Individual characteristics/stories</li> </ul>
3	<b>Capacity</b>	<ul style="list-style-type: none"> <li>Health literacy</li> <li>Digital literacy</li> <li>Lack of accessibility</li> <li>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</li> <li>Psychological barriers</li> <li>Individual characteristics/stories</li> </ul>
4	<b>Motivation and Choice</b>	<ul style="list-style-type: none"> <li>Undermined by one or the combination of more barriers listed herewith.</li> </ul>



5	<b>Communication</b>	<p>Lack of clarity or communication</p> <p>Inaccessible communication</p> <p>Fragmented and/or conflicting communication</p> <p>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</p> <p>Psychological barriers</p> <p>Individual characteristics/stories</p>
6	<b>Inclusion</b>	<p>Perceived or actual tokenism</p> <p>Patronization</p> <p>Lack of accessibility</p> <p>Segregation resulting from discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</p> <p>Psychological barriers</p> <p>Individual characteristics/stories</p>
7	<b>Social Role</b>	<p>Lack of meaningfulness</p> <p>Downgraded perception</p> <p>Lack of accessibility</p> <p>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</p> <p>Psychological barriers</p> <p>Individual characteristics/stories</p>
8	<b>Resources – personal or professional</b>	<p>Lack of financial resources</p> <p>Lack of personal resources (network, support)</p> <p>Lack to access to financial and personal resources</p> <p>Lack of training in the use of resources</p> <p>Transitions</p> <p>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</p> <p>Psychological barriers</p> <p>Individual characteristics/personal stories</p>
9	<b>Resources – organisational or systemic</b>	<p>Fragmented cooperation across services</p> <p>Lack of available trained staff</p>

		<p>Hierarchical bottlenecks</p> <p>Lack of proper training/update</p> <p>Lack of time at work</p> <p>Lack of accessible resources</p> <p>Lack of financial resources</p> <p>Transitions</p> <p>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</p> <p>Psychological barriers</p> <p>Individual characteristics/stories</p>
10	<b>Power and its distribution</b>	<p>Unequal distribution of power across social roles (for example, physicians having more power at micro level than nurses)</p> <p>Feeling disempowered</p> <p>Lack of accessibility</p> <p>Lack of inclusion</p> <p>Bureaucracy</p> <p>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</p> <p>Psychological barriers</p> <p>Individual characteristics/stories</p>
11	<b>Collective voice &amp; action / Solidarity</b>	<p>Inaccessible content</p> <p>Bureaucracy</p> <p>Fragmented or siloed information</p> <p>Fragmented or siloed communication</p> <p>Failure to meet the individual needs (e.g., too specific, or too vague)</p> <p>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</p> <p>Psychological barriers</p> <p>Individual characteristics/stories</p>
12	<b>Organisations &amp; Institutions</b>	<p>Bureaucracy</p> <p>Inaccessible organisations/institutions</p>

		<p>Lack of information</p> <p>Inaccessible communication</p> <p>Siloed implementation</p> <p>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia...)</p> <p>Psychological barriers</p> <p>Individual characteristics/stories</p>
13	<b>Systems and Services</b>	<p>Bureaucracy</p> <p>Siloed implementation</p> <p>Lack of information</p> <p>Lack of communication</p> <p>Poor navigation of care</p> <p>Lack of resources</p> <p>Lack of trainings</p> <p>Psychological barriers</p> <p>Individual characteristics/stories</p> <p>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia,)</p>
14	<b>Access (to services)</b>	<p>Bureaucracy</p> <p>Physical barriers to service access, cost-related barriers (e.g., out of pocket costs), time-related barriers to access (e.g., waiting lists)</p> <p>Discrimination (ageism, ableism, racism, sexism, classism, homophobia, xenophobia,)</p> <p>Psychological barriers</p> <p>Individual characteristics/stories</p>
15	<b>Legal &amp; Ethical Contexts and Tools</b>	<p>Restrictive regulations (for example, on reimbursement, or choice of services)</p> <p>Inaccessible or lack of information</p> <p>Inaccessible or lack of communication</p> <p>Lack of inclusion, e.g., discrimination</p>

This overview serves the design and use of the SHAPES Platform to overcome gaps and barriers highlighted above, in an integrated approach. Moreover, so many and diverse challenges can nevertheless be overcome by following and integrating the four

principles highlighted by the work of SHAPES (Seidel et al, 2021). As mentioned in paragraph 3.6, participation, process, practices, and purpose can support across the various shortcomings reported in the table above, bearing in mind to communicate and commit to action following a person-centred approach and a life-course approach.

1. **Participation:** providing older adults with the capability to choose.
2. **Process:** raising awareness and engaging with change in all stages of life.
3. **Practices:** recognising and enabling people's contributions.
4. **Purpose:** proving the opportunity to live according to one's own intentions.

That is an attempt to shape an empowering environment in health and care decision-making, through the actual empowerment of users and stakeholders. The work carried out at pilot site level does actively uphold these guidelines, with the expert support of the whole consortium.

## 6 Conclusion

This deliverable intended to embrace the diversity of the SHAPES users, underlying the heterogeneity of views, needs and preferences expressed by older adults today for their health and care pathways. Such diversity is moreover enriched by different levels of digital and health literacies, and by being interwoven in both the individual and the collective spheres.

This work embraces a notion of empowerment as not solely restricted to an individual and personal dimension but extended to the community and the environment in which a person lives. This means addressing the social, cultural, political, and economic determinants of people's lives, and adopting a multi-disciplinary approach. This is true for all ecosystems, and it is especially relevant for the health and care one. Because health and care are not confined to the relationship between a patient and a doctor, but must embrace the wider context, relationships, and environments, among others.

The work on empowerment and decision-making, summarised in Deliverable 2.4, investigated such comprehensive ecosystem. It started from the four themes shaping the concept of empowerment at the individual level (having a sense of personal identity; having a sense of choice and control; having a sense of usefulness and being needed; retaining a sense of worth) to dive into several barriers and challenges to empowerment in decision-making at the individual level (e.g., level of literacy and confidence on the domain when a decision is requested; psychological barriers; age, disability, gender, sexual orientation, ethnicity and their intersections; individual characteristics such as personality and life experiences).

This work then addressed the environment, both the technological one and the wider socio-cultural context of people (the "lifeworld of individuals"), with a focus on the health and care sector.

With respect to the technological environment, SHAPES does not only consider whether or not a technology is appropriate but looks for its interaction with the user and its emotional dimension, recognising that the relevance of a technological solution always depends on the specific situation. This is a vital point for the SHAPES Platform.

When looking into the realities of older people, the process of empowerment necessarily addresses the social, cultural, political, and economic determinants, up to the governance systems modelling such complex contexts. Based on literature and consultations of older people, light was shed on some challenges to empowerment in decision-making at the community level (e.g., in the relationship between patient and healthcare professional, in this relationship and its connections with family and carers, and the wider society). It is highlighted how socio-economic and educational status, cultural backgrounds, and generational factors, as well as institutionalised ageism, highly matter in empowering people. Building on the work carried out by WP3

(organisational, structural, and sociotechnical factors for the SHAPES ecosystem), barriers and facilitators for the participation in the governance have been retraced, as relevant to the SHAPES older users to perform their choices, especially in the health and care sectors.

When focusing on older people, the dynamics of empowerment in decision-making for health and care are heavily affected by ageist attitudes, environments, and structures, leading to discrimination, exclusion, and rights denial of people as they age. Moreover, age intersects with gender and disability, as well as other characteristics; for example, older women, and older people with disabilities face multiple challenges, prejudices, stereotypes, and discriminations due to such intersections. It is therefore key to adopt an intersectional approach when analysing the realities of older people in accessing care, as well as attitudinal barriers. Furthermore, a change in the perception or stigma surrounding older people is necessary, as they are often described as a vulnerable or weak group, which tends to be the case for people with disabilities too.

With all these factors influencing participation, decision-making and impacting on empowerment, a balanced relationship between the various actors involved in each decision is essential. Therefore, approaches like the person-centred care and shared decision-making shine through. They both are possible only if the communication flows correctly, in an accessible and inclusive way. Research showed that higher quality communication remains key to empower all stakeholders involved in the health and care pathway. Quality communication between healthcare professionals, caregivers, and family results in more confidence of family members to act as surrogate of intensive care unit patients and that effective communication among patient, family, caregivers, and clinical team contributes to a collaborative, fully informed decision-making process in cases of life-threatening illness.

Furthermore, sustaining empowerment across the lifespan relates to the four principles highlighted by the work of SHAPES (Seidel et al, 2021):

1. Participation: providing older adults with the capability to choose (and being inclusive).
2. Process: raising awareness and engaging with change in all stages of life (life-course approach).
3. Practices: recognising and enabling people's contributions (moving away from stigma and discriminations).
4. Purpose: proving the opportunity to live according to one's own intentions (person-centredness).

These general principles, coupled with the individual indicators for empowerment (having a sense of personal identity; having a sense of choice and control; having a sense of usefulness and being needed; retaining a sense of worth) have been investigated at pilot site level.

Such empowerment indicators embrace the concept of agency in SHAPES: it is not only important to provide the opportunity for older individuals to make a choice; it is important that they act on that opportunity and that they translate their choice into an intended outcome. For this, deliverable D2.4 will hopefully inspire the work of WP5 on the SHAPES digital solutions; of WP6, informing the work at pilot site level; of WP10 for the 6<sup>th</sup> awareness campaign on empowerment and digital platform and the related 6<sup>th</sup> dialogue workshop.

## 7 Ethical Requirements Check

The focus of this compliance check is on the ethical requirements defined in D8.4 and having impact on the SHAPES solution (technology and related digital services, user processes and support, governance-, business- and ecosystem models). In the left column there are ethical issues identified and discussed in D8.4.(corresponding D8.4 subsection in parenthesis). For each deliverable, report on how these requirements have been taken into account. If the requirement is not relevant for the deliverable, enter N / A in the right-hand column.

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)	Chapter 2 and across the deliverable
Biomedical Ethics and Ethics of Care (3.2)	N/A
CRPD and supported decision-making (3.3)	Chapter 2 and across the deliverable
Capabilities approach (3.4)	Chapter 3
Sustainable Development and CSR (4.1)	N/A
Customer logic approach (4.2)	N/A
Artificial intelligence (4.3)	Chapter 2
Digital transformation (4.4)	Chapter 2
Privacy and data protection (5)	Chapter 2
Cyber security and resilience (6)	N/A
Digital inclusion (7.1)	Chapter 2
The moral division of labor (7.2)	N/A
Care givers and welfare technology (7.3)	Chapter 2 and Chapter 5
Movement of caregivers across Europe (7.4)	N/A

**Comments:** \_\_\_\_\_



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