



SHAPES

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

D3.4 – SHAPES Pan-European Integrated Care Policy-making Guidelines

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

Work package	WPx – Work Package Title
Lead authors	Ilenia Gheno, Apolline Parel (AGE)
Contributors	Vera Hoermann (AGE), Vassilis Giannakopoulos (SciFY), Melanie Labor (NUIM), Maureen Spargo (NHSCT), Lucia D’Arino (WFDB), Sari Sarlio-Siintola (LAUREA), Evert-Jan Hoogerwerf (AIAS), Filip Franke (CCS)
Peer reviewers	Mac MacLachlan (NUIM), Frankie Picron (EUD)
Version	V1.0
Due date	M42 – 30/04/2023
Submission date	27/04/2023
Dissemination Level	PU Public



Revision History

Table 1 Revision History

Revision #	Date	Editor	Comments
0.1	19/01/2023	Ilenia Gheno (AGE)	Establishing ToC and editing
0.2	03/02, 08/02 13-14/02/2023	Ilenia Gheno, Apolline Parel (AGE)	Editing
0.3	22/02/2023	Ilenia Gheno (AGE)	Editing
0.4	20-23/02/2023	Ilenia Gheno, Apolline Parel (AGE)	Editing
0.5	24/02/2023	Ilenia Gheno, Apolline Parel (AGE)	Editing
0.6	25/02/2023- 20/03/2023	Vassilis Giannakopoulos (SciFY), Melanie Labor (NUIM), Maureen Spargo (NHSCT), Lucia D'Arino (WFDB), Sari Sarlio-Siintola (LAUREA)	Commenting and editing
0.7	08/03/2023, 14/03/2023, 17/03/2023,20- 21/03/2023, 23/03/2023, 28-29/03/2023	Ilenia Gheno (AGE), Apolline Parel (AGE)	Editing
0.8	20-24/03/2023, 30-31/03/2023	Ilenia Gheno	Editing
0.9	03/04/2023	Ilenia Gheno	Consolidation
1.0	05/04/2023	Ilenia Gheno	Finalisation following Advisory Board's comments
1.1	27.04.2023	Ilenia Gheno	Revision and inclusion of feedback from peer reviews

Table of Contributors

Table 2 Deliverable Contributors

Section	Author(s)
Table of Contents	Ilenia Gheno (AGE)
Introduction	Ilenia Gheno (AGE)
Chapter 2	Ilenia Gheno, Evert-Jan Hoogerwerf (AIAS)
Chapter 3	Ilenia Gheno, Philip Franke (CCS)

Chapter 4	Apolline Parel, Ilenia Gheno, (AGE), Lucia D'Arino (WFDB)
Chapter 5	Ilenia Gheno, Apolline Parel (AGE), Vassilis Giannakopoulos (SciFY)
Conclusions	Ilenia Gheno, Apolline Parel (AGE)

Table of Acronyms and Abbreviations

Table 3 Acronyms and Abbreviations

Acronym	Full Term
CRPD	Convention on the Rights of Persons with Disabilities
LGBTIQ	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer people
WHO	World Health Organization

Keywords

Europe, guidelines, health and care management, human rights-based approach, integrated care, policies, recommendations.

Disclaimer

This document contains information which is proprietary to the SHAPES consortium. Neither this document nor the information contained herein shall be used, duplicated or communicated by any means to any third party, in whole or parts, except with the prior written consent of the SHAPES coordinator.

Table of Contents

DISCLAIMER	III
LIST OF FIGURES	V
LIST OF TABLES	V
EXECUTIVE SUMMARY	VI
1 INTRODUCTION.....	1
1.1 RATIONALE AND PURPOSE OF THE DELIVERABLE	1
1.1.1 <i>Deliverable Objectives</i>	1
1.1.2 <i>Key inputs and outputs</i>	2
1.2 STRUCTURE OF THE DOCUMENT	2
2 INTEGRATED PERSON-CENTRED CARE	4
2.1 INTEGRATED (PEOPLE-CENTRED) CARE	4
2.2 CONTINUITY OF CARE	9
2.3 THE CONTRIBUTIONS FROM SHAPES	10
3 CHALLENGES TO AND ENABLERS FOR INTEGRATED PERSON-CENTRED CARE	12
4 A HUMAN RIGHTS-BASED APPROACH TO INTEGRATED CARE.....	17
4.1 APPLICATION OF A HUMAN RIGHTS FRAMEWORK	17
4.2 PARTICIPATION AND EMPOWERMENT	19
4.2.1 <i>Participation</i>	19
4.2.2 <i>Empowerment</i>	19
4.3 EQUALITY AND NON-DISCRIMINATION.....	19
4.4 ACCOUNTABILITY	20

5	POLICY RECOMMENDATIONS	21
5.1	GOVERNANCE.....	22
5.2	LEGISLATION, ETHICS, AND STANDARDS.....	23
5.3	FINANCES	23
5.4	MONITORING AND REVIEWING	24
5.5	WORKFORCE	25
5.6	RESEARCH.....	25
6	CONCLUSION	27
7	ETHICAL REQUIREMENTS CHECK.....	28
	REFERENCES	30

List of Figures

FIGURE 1	WHO APPROACHES AND INTERVENTIONS FOR ACHIEVING CONTINUITY OF CARE	10
----------	---	----

List of Tables

TABLE 1	REVISION HISTORY.....	II
TABLE 2	DELIVERABLE CONTRIBUTORS	II
TABLE 3	ACRONYMS AND ABBREVIATIONS	III
TABLE 4	PRINCIPLES OF INTEGRATED CARE – WHO (2015) AS PRESENTED IN SHAPES D3.2.....	5
TABLE 5	ZONNEVELD ET AL.’S VALUES OF INTEGRATED CARE, AS ELABORATED BY THE SHAPES D3.2.	7
TABLE 6	SHAPES THINK TANK WORK, APRIL 2022: RANKED ISSUED ON INTEGRATED CARE	13
TABLE 7	SHAPES THINK TANK WORK, JULY 2022: POTENTIAL SOLUTIONS FOR INTEGRATED CARE.....	14



Executive Summary

The SHAPES project, aimed at building an interoperable Platform integrating smart digital solutions to collect and analyse older individuals' health, environmental and lifestyle information, identify their needs and provide personalised solutions that uphold the individuals' data protection and trusts. It adopted a multidisciplinary approach to its research on active and healthy ageing.

Building an ecosystem attractive to European industry and policy makers, SHAPES developed key and concise recommendations for integrated person-centred care intended to support and extend healthy and independent living of older people in Europe. In its deliverable D3.4 "Pan-European Integrated Care Policy Guidelines", SHAPES summarized the essential features of the concepts of integrated (person-centred) care and continuity of care (chapter 2) and the key challenges and enablers of integrated person-centred care. It provided an overview of the complexity of the topic in the perspective of the SHAPES Ecosystem (chapter 3).

With the aim of designing and delivering health and care tailored on the individuals' needs and adapting over time and across different levels of the health and care system, this deliverable is anchored on a human-rights based approach to promote a healthier and empowered population across the life-span (chapter 4). Derived from this approach, policy guidelines have been drawn for European policy makers to work on governance, legislation, ethics and standards, finances, monitoring and reviewing, workforce, and research for integrated person-centred health and care (chapter 5). Contributions from the SHAPES project to the different domains of recommendations have been mentioned for further reference.

These policy guidelines, adapted in their format for an easy and attractive perusal by European policy-makers will be used in the SHAPES event at the European Parliament (6 September 2023) and in other occasions gathering European decision-makers.

1 Introduction

The aim of the SHAPES deliverable D3.4 is to establish policy recommendations for supporting pan-European management and delivery of health and care services in a care continuum. This care continuum should implement a human rights-based approach and should be person-centred as to consider the individual's needs over the life course.

This work is built upon the contributions from the SHAPES outcomes from WP2 “Understanding the Lifeworld of ageing individuals and Improving Smart and Healthy living”, WP3 “Organisational, Structural and Sociotechnical Factors for the SHAPES Ecosystem”, and WP8 “SHAPES Legal, Ethics, Privacy and Fundamental Rights Protection”. It is also based on different global Treaties, such as the Convention on the Rights of Persons with Disabilities (CRPD) and European policies, including policies that go beyond integrated care, alongside literature and projects' experiences.

The overall objective of this deliverable is to provide European policymakers working at global, regional, national and local levels with a more holistic approach on integrated care. Its aim is to provide them with recommendations on how to deliver health and social care in communities, coordinate pathways, and promote a healthier population, enabling citizens to live an empowered and dignified life.

1.1 Rationale and purpose of the deliverable

As described in Work Package 3 “Organisational, Structural and Sociotechnical factors for the SHAPES Ecosystem”, deliverable D3.4 will summarize key policy guidelines for integrated care that are addressed to policymakers to improve the continuity of integrated care and the sustainability of health and care systems across Europe. The deliverable will provide policy recommendations that will feed into deliverable D3.11 “SHAPES Recommendations”. These latter ones will provide guidance for the implementation, adoption and scale-up of the SHAPES Platform and the SHAPES digital solutions across Europe.

1.1.1 Deliverable Objectives

As part of Work Package 3, this deliverable will:

- Support the management and delivery of health and care services on a care continuum that is designed according to individuals' needs over time and

across different levels of the health and care system so as to ensure optimal health and care outcomes;

- Suggest policy strategies based on a human rights-based approach aiming to make integrated health and social ecosystems work together;
- Determine how policymaking can improve the continuity of care, reduce barriers to integrated care, diminish the fragmentation of health and social care systems, and ultimately contribute to the sustainability of health and care systems across Europe.

1.1.2 Key inputs and outputs

This deliverable refers to findings, analysis, and results of five other SHAPES deliverables. Those other deliverables are: D3.1 Ecological Organisational Models of Health and Care Systems for Ageing, D3.5 Governance Model, D3.2 Scaling-up Improved Integrated Care Service Delivery v1, D3.3 Scaling-up Improved Integrated Care Delivery, and D2.4 Empowerment and decision-making in health and care.

Moreover, it encompasses the findings and considerations from the SHAPES Think Tank group (WP9) and makes references to inputs from WP8, namely D8.14 SHAPES Ethical Framework.

This deliverable also benefitted from the revision and feedback from the SHAPES Advisory Board, both offline and thanks to a dedicated meeting with Advisory Board members (April 4th, 2023).

Additional relevant inputs are derived from different domains of literature (i.e., academic, projects-related, and from the WHO). The frameworks set up by the WHO have been mostly considered to derive the policy recommendations in this deliverable.

This deliverable is intended to support the further development of the D3.11 SHAPES Recommendations.

1.2 Structure of the document

Chapter 1 aims to present the content and rationale of deliverable D3.4.

Chapter 2 introduces the concepts of integrated person-centred care and continuity of care based on literature. It also provides the essential features that can support pan-European management and delivery of health and care services along a care continuum. An overview follows of the relevant SHAPES work on health and care systems, governance for integrated care, and empowerment for decision-making. This underpins the understanding of integrated person-centred care and paves the way to SHAPES being able to make a set of policy recommendations.

Chapter 3 summarizes the main challenges and enablers to integrated person-centred care, by taking stock of both relevant literature and projects, and including essential policy work. Examples of these include the right to health and access to health services that is one of the two focus areas of the 13th Session of the United Nations Open-Ended Working Group on Ageing in 2023.

Chapter 4 develops the concept of a human rights-based approach to integrated person-centred care. The human rights-based approach is based on different pillars: application of a human right framework, participation and empowerment, equality and non-discrimination and accountability. Based on these pillars, the deliverable provides a better understanding of how to apply this approach in integrated care.

Chapter 5 presents policy recommendations supporting policymaking for integrated person-centred care in six fields: governance; legislation, ethics, and standards; monitoring and reviewing; finances; workforce; research.

The deliverable ends in Chapter 6 with a set of conclusions and shares the plan for the use of these guidelines at European level.

2 Integrated person-centred care

This chapter explains the concepts of integrated person-centred care and continuity of care. It is then followed by the contributions from SHAPES.

2.1 *Integrated (people-centred) care*

The widely used term, ‘integrated care’, is a multi-faceted concept related to the co-ordination of care around people’s needs. The WHO refers to integrated person-centred care¹ as aiming to achieve universal health care and ensure that no one is left behind.

In the literature (Pim et al, 2013), integrated care was initially defined as ‘improved connectivity between different activities of the health system to provide better quality health services to users.’ Nowadays, the concept of integrated care encompasses multiple levels of complexity, blending patient-centred care, care coordination, continuity of care, chronic disease management and integrated healthcare delivery (Pim et al, 2013). According to WHO, integrated care is ‘often contraposed to fragmented and episodic care, and it is used synonymously to terms like coordinated care and seamless care, among others. However, there is no unifying definition or common conceptual understanding of integrated care, which is most likely a result of ‘the polymorphous nature of integrated care itself’. In effect, the perspectives that construct the concept are likely to be shaped by views and expectations of various stakeholders in the health system’ (WHO, 2016).

Integrated care refers to initiatives that aim to enable better coordinated and more continuous care, including service provision. Such coordination is reported as being both ‘horizontal’ and ‘vertical’. In the literature, horizontal integration links together similar levels of care, such as multi-professional teams and peer-based collaboration. In contrast, vertical integration is associated with different levels of care, such as primary, secondary and tertiary care (Gröne, Garcia-Barbero, 2002).² Pim et al, 2013 suggested that it is necessary to cope with the fragmentation of services derived from the high specialisation of services and domains in health systems.

During a joint conference with AGE Platform Europe and Eurohealth, Eurodiaconia - the European-based umbrella organization operating in the field of health and care, listed the key features of effective person-centred integrated care (Eurodiaconia,

¹ https://www.who.int/health-topics/integrated-people-centered-care#tab=tab_1

² Gröne, O & Garcia-Barbero, M (2002): Trends in Integrated Care – Reflections on Conceptual Issues. WHO, Copenhagen, EUR/02/5037864

2014). The six-part list gives an indication of the priorities for integrated care from the perspectives of civil society organizations (Ibid, 2014, p2):

- Coordination and shared responsibility among institutions and service providers.
- Multidisciplinary/multifunctional teamwork establishing a partnership between patient/service users and formal and informal carers and professionals.
- Person-centred approach with a clear case management and a single entry/contact point for the patient.
- Support and training for formal and informal carers and professionals.
- Coordination of communication and shared information, while ensuring compliance with data protection laws.
- A focus on quality of services for people and “outcome-oriented services”.

Integrated (person-centred) care is taken up in materials published by the WHO (2015). From an academic and institutional perspective, the World Health Organization’s Global Strategy on People-Centred and Integrated Health Services Interim Report (WHO, 2015, p11) identified a set of 16 core guiding principles that underpin integrated person-centred care (see Table 1).

Table 4 Principles of Integrated Care – WHO (2015) as presented in SHAPES D3.2

1. Comprehensive
A commitment to universal health coverage to ensure care is comprehensive and tailored to the evolving health needs and aspirations of people and populations.
2. Equitable
Care that is accessible and available to all.
3. Sustainable
Care that is both efficient, effective and contributes to sustainable development.
4. Co-ordinated
Care that is integrated around people’s needs and effectively coordinated across different providers and settings.
5. Continuous
Continuity of care and services that are provided across the life course.
6. Holistic
A focus physical, socio-economic, mental, and emotional wellness.
7. Preventive
Tackles the social determinants of ill-health through intra- and inter-sectoral action that promote public health and health promotion.
8. Empowering

Supports people to manage and take responsibility for their own health.

9. Respectful

To people’s dignity, social circumstances and cultural sensitivities.

10. Collaborative

Care that supports relationship-building, team-based working and collaborative practice across primary, secondary, tertiary care and other sectors.

11. Co-produced

Through active partnerships with people and communities at an individual, organisational and policy-level.

12. Endowed with rights and responsibilities

All citizens should expect exercise and respect.

13. Governed through shared accountability

Shared accountability between care providers for quality of care and health outcomes to local people.

14. Evidence-informed

Such that policies and strategies are guided by the best available evidence and supported over time through the assessment of measurable objectives for improving quality and outcomes.

15. Led by whole systems thinking

Considering the system as a whole, while taking into account the interactions between single parts.

16. Ethical

Finding the balance between risks and benefits in all interventions, respecting the individual’s rights and protecting the most vulnerable.

As highlighted in the SHAPES deliverable [D3.2 Scaling-up Improved Integrated Care Delivery V1](#), these 16 principles are better coupled with the value system to fully grasp integrated person-centred care and its implementation. Derived from the work of Zonneveld et al. (2018), which notes that “‘value’ refers to the amount of success an integrated care provider has in meeting the needs of its clients, relative to its costs, whereas ‘values’ relates to the set of attributes possessed by the care system, such as integrity, transparency and efficiency”,³ SHAPES has identified 23 underlying values of integrated care (see Table 2).

³ SHAPES D3.2 Scaling-up Improved Integrated Care Delivery V1, page 7-8.



Table 5 Zonneveld et al.'s Values of Integrated Care, as elaborated by the SHAPES D3.2.

1. Collaborative
Professionals work together in teams, in collaboration with clients, their families and communities, establishing and maintaining good (working) relationships.
2. Co-ordinated
Connection and alignment between the involved actors and elements in the care chain, matching the needs of the unique person. Between professionals, clients and/or families, within teams and across teams.
3. Transparent
Openly and honestly giving insight in information, decisions, consequences and results, between clients, their families, professionals and providers.
4. Empowering
Facilitating and supporting people to build on their strengths, make their own decisions, manage their own health and take responsibility for it.
5. Comprehensive
The availability of a wide range of services, tailored to the evolving needs and preferences of clients and their families.
6. Co-produced
Engaging clients, their families and communities in the design, implementation and improvement of services, through partnerships, in collaboration with professionals and providers.
7. Shared responsibility and accountability
The acknowledgment that multiple actors are responsible and accountable for the quality and outcomes of care, based on collective ownership of actions, goals and objectives, between clients, their families, professionals and providers.
8. Continuous
Services that are consistent, coherent and connected, that address the needs and preferences of clients across their life course.
9. Holistic
Putting the clients and their needs in the centre of the service, whole person oriented, with an eye for physical, social, socio-economical, biomedical, psychological, spiritual and emotional dimensions.
10. Goal-orientated
Working with clearly described, and concrete, measurable, common goals and objectives for clients, their families, professionals and providers.
11. Personal
Delivering care by establishing personal contact and relationships, to ensure that services and communication are based on the unique situations of clients and their families.
12. Evidence-informed
Working processes, policies and strategies are guided by evidence-based knowledge, data and information, supported by technology and periodic assessment.

13. Respectful

Treating people with respect and dignity, being aware of their experiences, feelings, perceptions, culture and social circumstances.

14. Equitable

Services are accessible and available for all people, and they are all treated equally.

15. Sustainable

Services are efficient, effective and economically viable, ensuring that they can adapt to evolving environments.

16. Led by whole systems thinking

Taking interrelatedness and interconnectedness into account, realising changes in one part of the system can affect other parts.

17. Flexible

Care that is able to change quickly and effectively, to respond to the unique, evolving needs of clients and their families, both in professional teams and organisations.

18. Preventative

Early detection and action for clients and their families that promotes individual and public health.

19. Reciprocal

Care based on equal, interdependent relationships between clients, their families, professionals and providers, and facilitate cooperative, mutual exchange of knowledge, information and other resources.

20. Innovative

Supporting, facilitating and creating space for innovation and future improvements in professional teams and organisations.

21. Trustful

Enabling mutual trust between clients, their families, communities, professionals and organisations, in and across teams.

22. Proficient

Knowledgeable and skilful services are provided by professionals, with a focus on quality.

23. Safe

Care services that are safe for clients, their families and professionals, including privacy and confidentiality protection.

Merging the principles and values developed by the WHO (2015) and Zonnenfeld et al (2018), and further elaborated by SHAPES, means embracing a human rights-based approach to integrated (person-centred) care. Chapter 4 presents what a human rights-based approach is and how it applies to the SHAPES project.

2.2 Continuity of care

‘Continuity of care’ and ‘care continuum’ are concepts involving an integrated system of care following a patient (rather than multiple patients) over time (Gulliford et al, 2006).

The WHO (2018, p9) defines ‘continuity of care’ as “the degree to which a series of discrete health care events is experienced by people as coherent and interconnected over time and consistent with their health needs and preferences” and ‘care coordination’ as “a proactive approach to bringing together care professionals and providers to meet the needs of service users, to ensure that they receive integrated, person-focused care across various settings”⁴.

The WHO (Ibid, p16) underlines how continuity and care coordination are closely related: care coordination is enabled by the care continuum, as it sets up the conditions and relationships to “support seamless interactions among multiple providers within interdisciplinary teams or across care settings or sectors”⁵.

The ‘continuity of care’ implies the full spectrum of health and care services related to patient care across multiple services, caregivers, and institutions and spans all levels of intensity of care. It is the process by which the patient and his/her care team are involved in ongoing health care management to maximize quality and cost-effectiveness of care.

This broad concept can differ based on at least two perspectives: one is that of the patient, the other is that of health care professionals. Continuity of care is intended perceived by patients as a ‘continuous caring relationship’ with an identified health care professional. From the perspectives of health and care professionals, the care continuum means to deliver a ‘seamless service’ through integration, coordination, and the sharing of information between different providers (Gulliford et al, 2006).

The WHO outlines the key approaches and interventions for achieving continuity of care, as illustrated in Figure 1 below (WHO, 2018). It identifies four main categories of continuity: interpersonal, longitudinal, management, and informational. Interpersonal continuity refers to the subjective relationships between carers and care recipients; longitudinal continuity refers to the “interactions with the same health care professional in a series of episodes”; management continuity refers to teams’ collaboration for

⁴ WHO (2018). Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services, page 9.

⁵ WHO (2018). Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services, page 16.

seamless care and informational continuity refers to the “availability of clinical and psychosocial information at all encounters with professionals”.⁶

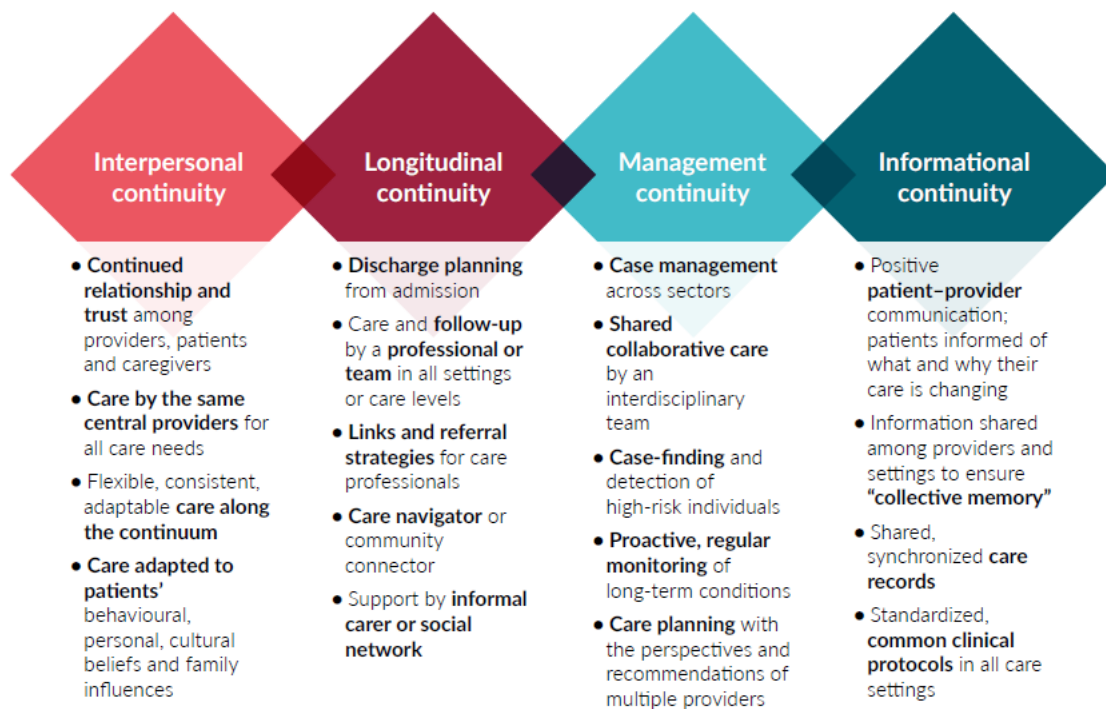


Figure 1 WHO approaches and interventions for achieving continuity of care⁷

Across the four main categories of continuity, the care continuum is thus perceived as a key feature of integrated person-centred care, very much intertwined with it.

2.3 The contributions from SHAPES

The SHAPES project has worked on integrated person-centred care from multiple angles. Three SHAPES work packages have contributed to this assignment: they are WPs 2, 3, and 9.

Much of the work of SHAPES' WP3 was dedicated to investigating integrated person-centred care. Four of the work package's deliverables are oriented towards person-centred integrated care delivery, models, and governance.

⁶ WHO (2018). Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services, page 17.

⁷ WHO (2018). Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services, ISBN 978-92-4-151403-3. Page 18.

Focusing on health and care recipients, the SHAPES deliverable D2.4 “Empowerment of Older Individuals in Health and Care Decision-making” covers the diversity of the SHAPES users, which represents the underlying heterogeneity of views, needs, and preferences expressed by today’s older adults on their health and care pathways. This deliverable refers to the notion of empowerment, both at the individual and the community dimension. It reaches out to the environment in which a person lives and thus addressing the social, cultural, political, and economic determinants of people’s lives, and adopting a multi-disciplinary approach.

A second SHAPES deliverable, D3.1 “Ecological Organisational Models of Health and Care Systems for Ageing”, provides an analysis of health and care systems in the European countries involved in the SHAPES piloting activities. Deliverable D3.1 focuses on structures and processes governing health and care service provision and reveals gaps in current systems to guide and sustain the development of the SHAPES Platform. To overcome these gaps, SHAPES partners identified necessary or desired changes in the areas of technology, structure and procedure, training and support, policy and innovation, investment, and financing to improve pan-European health and care provision to improve health and care systems.

Two SHAPES deliverables – D3.2 “Scaling-up Improved Integrated Care Service Delivery V1” and D3.3 “Scaling-up Improved Integrated Care Delivery” – offer definitions of principles and values for integrated person-centred care. They highlight the factors that impact on the deployment, scaling-up and transfer of integrated care programmes, by paying particular attention to the role of person-centred technology.

In addition to the Think Tank work, SHAPES D3.4 “Pan-European Integrated Care Policy Guidelines” sought guidance and feedback from both WP3 partners and the SHAPES Advisory Board on how to develop a more comprehensive and international approach to European policy guidelines for integrated care.

More specifically on governance for health and care, the SHAPES D3.5 “Governance Model”, which is still evolving, offers a summary of the concept and practice of governance relevant to the SHAPES Platform. It summarizes the structures, processes, and values that govern clinical care and home care in relation to the wider environment in which the SHAPES Platform is embedded.

Furthermore, the SHAPES project set up and worked with experts on its Think Tank on European integrated care. Developed and implemented in Work Package 9, the Think Tank established a list of issues and solutions related to integrated care within the context of the project. The goal was to generate recommendations for sustainable integrated care. The outcomes of this Think Tank work are presented in chapter 3 and helped shaping the policy recommendations issued by the SHAPES project.

3 Challenges to and enablers for integrated person-centred care

Just some of the variables challenging European health and social care systems are increased longevity, life expectancy, quality of life in old age, migration patterns, female employment rates, informal carers, financial constraint, public and private policies, co-morbidities, and the impact of emergencies like the 2019-2020 Covid-19 pandemic.

It is a difficult task to summarize the needs and challenges of integrated person-centred care across the many different health and care systems in Europe. Three challenges, however, are obvious. The “Developing the long-term care empowerment model” report (AGE Platform Europe, Bizkaia Government, 2022) contains a section on integrated care pathways. It mentions how integral care is key at local level as fragmented “services delivered by different providers often result in delays, waste, harm and a poor care experience through failures of communication, inadequate sharing of information and missed or duplication of assessments or investigations”⁸ It provides a good overview of:

- The population structures
- The socio-economic landscapes
- The epidemiological landscapes

Under these three macro-categories, the 2022 report covers a range of nine issues such as life expectancy and healthy life expectancy, the prevalence of chronic conditions and long-term illness, mental health and cognitive decline, functional limitations, income and wealth, housing and age-friendly environments, living arrangements and social connectedness, social participation, and quality of life in later life.

Alongside these issues, the following 12 additional and transversal sub-categories help completing the picture of how long-term care can currently be perceived and experienced across European countries: ageism, quality of care, accessibility and affordability issues, administrative barriers, health and care organisation and coordination, political and organisational management, staff shortages, payment models, insurances, insufficient funding, fragmented information and technology services, fragmented data and data management, among others.

8

https://www.bizkaia.eus/documents/12219373/13161256/Bay+of+Biscay+Bay+of+Care+Report_EN.pdf/d06c0699-2655-5870-3f83-c02a02de95b8?t=1664527516789



Gaps are still persistent, and research on integrated care remains scarce (Tsasis et al, 2012). Two major factors contribute to this gap: one is the lack of conceptual understanding of integrated care and two, insufficient focus on care systems' capacity for self-organisation (Tsasis et al, 2012). This means that policies and management practices should promote system awareness, relationship-building, and information sharing in order to achieve integrated care.

Similar conclusions are raised by the Think Tank group set up by the SHAPES project for analysing integrated care in Europe. During a working meeting in April 2022, each of the 14 Think-Tank members assigned a total of 5 points each to two categories – one being ‘impact’ and the other, being ‘frequency’, where ‘impact’ refers to the level of damage the issue causes to an integrated care project, and ‘frequency’ refers to the number of times the issue comes up among integrated care projects. The result of this exercise is presented in Table 2, which ranks the Think Tank experts’ views on the seven most crucial “open” issues for European integrated care. The seven issues are shown in sequence, from the top issue, (1) to the last three (5-7). (1) was ranked as having the most impact and being the most frequently experienced. Issues (5-7) were ranked as having the same degree of impact and a lesser (but similar) degree of frequency.

Table 6 SHAPES Think Tank work, April 2022: ranked issued on integrated care

Rank	Issue	Impact	Frequency	Sum
1	Lack of assessment and awareness of short and long-term benefits of integrated care	6	7	13
2	Lack of financing to implement new solutions / payer dominance in terms of financial decision making	5	5	10
3	Fear of misuse of data (lack of data protection)	4	4	8
4	Governance and safety - who will assume responsibility for monitoring (multidisciplinary)	3	4	7
5	Health and social care systems tend to resist to innovation and change	3	2	5
6	Different stakeholders (patients, developers, funders, care providers, etc.) often have very different and sometimes conflicting interests/aims	3	2	5
7	Lack of collaboration tools and processes in the competitive healthcare environment	3	2	5

A later working meeting in July 2022 took the analysis further. In a subsequent meeting held in July 2022, the Think Tank experts described potential solutions to the seven issues (challenges) that they had identified. The findings of the Think Tank deliberations are summarized in Table 4.

Table 7 SHAPES Think Tank work, July 2022: potential solutions for integrated care

Issues	Sub-issues (relevant only for few issues)	Potential solutions
Lack of assessment and awareness of short and long-term benefits of integrated care		<ul style="list-style-type: none"> - Define quality standards for digital solutions and self-management apps - EU financing for awareness-creating bodies and awareness campaigns - Training of health and care providers as awareness multipliers
Lack of financing for implementation of new solutions / payer dominance in terms of financial decision making	-	<ul style="list-style-type: none"> - Pilot and short-term post pilot phases: users / patients pay per use - Scaling-up of fast-track assessment and reimbursement pathways - Create strong incentives to change to adapt health and care financing systems to the dynamic and fast-developing digital sector - Address health and care for prevention - Health economic evaluation of the

		way/amount to which integrated care is provided
Fear of misuse of data (lack of data protection)	-	<ul style="list-style-type: none"> - Create and communicate user benefits - Make users aware that their health data remains in silos - EU policy to ensure a top-down approach on electronic health records
Governance and safety - who will assume responsibility for monitoring (multidisciplinary)	-	<ul style="list-style-type: none"> - Strong governance by the public sector and connection between health and social care - Policy framing processes for evaluation and financing of care
Health and social care systems tend to resist to innovation and change	-	<ul style="list-style-type: none"> - Create strong incentives to adapt health and care financing systems to the dynamic and fast-developing digital sector - Create an enabling environment for stakeholders to innovate
Different stakeholders (patients, developers, funders, care providers, etc.) often have very different and sometimes conflicting interests/aims	<ul style="list-style-type: none"> - Differing health and care levels of a country - Engagement of big technology corporations in organization of health and care 	<ul style="list-style-type: none"> - Use tools and processes that have worked in previous successful collaboration(s)

	- The frequent failure of scaling up of integrated care projects and / best practices	
Lack of collaboration tools and processes in the competitive healthcare environment	<ul style="list-style-type: none"> - Lack of impact of EU guidelines and policies - Lack of impact after exchange of knowledge 	<ul style="list-style-type: none"> - Create an enabling environment for stakeholders to innovate - Use tools and processes from previous successful collaboration(s)

This analysis contains the elements (i.e., potential solutions) underpinning a potential framework to achieve an integrated continuum of long-term care provided by the WHO (WHO, 2021) and echoed by the Bizkaia report (AGE Platform Europe, Bizkaia, 2022).

The above analysis and comments, coupled with a literature review and various of SHAPES’ own reflections and considerations, supported the design of the policy recommendations presented in Chapter 5 of this deliverable. These guidelines will be formalised in deliverable D3.11 “SHAPES Recommendations” that will be completed in the last month of SHAPES’ work.

4 A human rights-based approach to integrated care

To develop integrated person-centred healthcare, policymakers need to improve the continuity of care, reduce barriers to integrated care, and diminish the fragmentation of health and social care systems to ultimately contribute to the sustainability of health and care systems across Europe.

SHAPES used an awareness of this rights-based approach to develop a set of recommendations on integrated care (see Chapter 5).

In 2018, the European Fundamental Rights Agency published a report⁹ entitled *Shifting perceptions: towards a rights-based approach to ageing* that argues for the need to mainstream a rights-based approach to ageing in EU legislative measures and policies. Instead of articulating the concept of old age around ‘deficits’ that create ‘needs’, a rights-based approach creates a paradigm shift towards **human rights that are universal, inalienable, and indivisible**. European Member States have an obligation to respect, protect, and fulfil the human rights of everyone, regardless their age. The ultimate purpose of a rights-based approach would be to ensure the full and equal enjoyment of all human rights by all people.

The European human rights-based approach is portrayed as a conceptual framework that is based on four pillars:

- Application of a human rights framework
- Participation and empowerment
- Equality and non-discrimination
- Accountability and monitoring.

4.1 *Application of a human rights framework*

A human rights-based approach, which is linked to national, European and international human rights law, requires the recognition of rights as legally enforceable entitlements, for which States have an obligation to respect, protect and fulfil.

The **right to health** is enshrined in European legislative instruments such as:

- **European Social Charter** (Council of Europe), Article 11 – The **right to protection of health**

⁹ Fundamental Rights Agency, *Shifting perceptions: towards a rights-based approach to ageing*, 2018, https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-fundamental-rights-report-2018-focus_en.pdf



- **European Charter of Fundamental Rights** (European Union)
 - Article 3 – **Right to integrity of the person**
 - Article 35 – Healthcare
- **The Convention on the Rights of Persons with Disabilities (CRPD)**. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.
 - Article 5 – Equality and non-discrimination
 - Article 9 – Accessibility
 - Article 19 – Living independently and being included in the community
 - Article 20 – Personal mobility
 - Article 25 – Health
 - Article 30 – Participation in cultural life, recreation, leisure and sport.

In addition, other EU policy documents, albeit non-binding, place particular emphasis on a rights-based approach. Among them are the following three documents:

- **European Care Strategy**: the European Care Strategy affirms the **right to care** and that beneficiaries have a central role to play in how they want to receive care. It underlines that the design, implementation, and evaluation of health and care systems at all levels must involve **all relevant stakeholders**: care beneficiaries, care providers, informal carers, and workers' representatives. It clearly sets out care services as 'services of general interest', which can enjoy special protection by Member States. The European Care Strategy also stipulates that Member States have a responsibility in better supporting informal carers with adequate income and services by implementing and upgrading the provisions of the European Union (EU) Work-Life Balance Directive. It emphasizes the need to integrate and coordinate health and social care. It specifies that the EU should invest in innovative digital and non-digital solutions to improve care. The communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions mentions that 'a strategic and integrated approach to care is needed Approaches that are person-centred and conducive to independent living are often lacking, exacerbated by insufficient integration between long-term care and healthcare, or between informal care, home care, community-based and residential care'.¹⁰
- **European Pillar of Social Rights**

¹⁰ Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, 2022, file:///C:/Users/Apolline%20Parel/Downloads/COM_2022_440_1_EN_ACT_part1_v11.pdf



Art. 18 – Long term care: Everyone has the **right to affordable long-term care services of good quality**, in particular homecare and community-based services.

- [Strategy on the Rights of persons with Disabilities 2021-2030](#)

This human rights framework enables general recommendations for developing integrated person-centred healthcare to be drawn.

4.2 *Participation and empowerment*

4.2.1 Participation

- Participation ensures that older people are consistently consulted when designing policies around integrated care. This can be achieved through the systematic consultation of non-governmental representative organisations of older people at national and European levels to make sure that their voices are heard. It includes underrepresented older persons (i.e., people from an ethnic minority, people with disabilities, etc.) in participatory processes as, otherwise, their perspectives are less likely to be taken into account.
- It considers beneficiaries of care **as rights holders**, whose right to health the Member States have obligations to respect, protect, and fulfil. Integrated care services should be aligned with individuals' changing needs.
- It places older people, their families, support systems, and communities at the centre of the design of integrated care, involving them in decision-making processes when possible.
- Finally, it develops collaboration between care professionals and beneficiaries.

4.2.2 Empowerment

Empowerment promotes the autonomy and dignity of beneficiaries. On this basis, integrated care should be an enabler of participation, autonomy and dignity, and ensure that everyone can contribute and participate fully in society.

4.3 *Equality and non-discrimination*

- The pillars of equality and non-discrimination applies an intersectional approach to integrated care. According to the European Institute for gender Equality (EIGE), intersectionality is an 'analytical tool for studying, understanding and responding to the ways in which sex and gender intersect with other personal characteristics/identities, and how these intersections

contribute to unique experiences of discrimination.’¹¹ In the health and care sectors, that means that intersectionality recognizes the existing inequalities and power dynamics. Some individuals face structural barriers when it comes to accessing different elements of care, such as information-sharing, and access to (health)care services. Some individuals can face multiple and intersecting forms of discrimination based on the grounds of e.g., their gender, sexual orientation, race, age, nationality, ethnicity, social class, or disability. Life-long disadvantages have an impact on older persons’ health status, with further inequalities being experienced by e.g., older women, Roma, and LGBTIQ people).

- Equality and non-discrimination address attitudinal barriers (including stereotyping, stigma, prejudice, and discrimination). Examples of such attitudes include seeing older people as weak, vulnerable, ill, or incapable of making their own decisions.
- The life-course approach should enable everyone, regardless of their age, to benefit from integrated care.

4.4 Accountability

- Accountability develops regular and mandatory monitoring of access to integrated care services.
- It also develops monitoring systems that allow for the measurement of good quality of life of individuals.

Based on this rights-based approach, several policy recommendations and guidelines have been developed by the SHAPES project to develop an integrated person-centred care in Chapter 5 of this deliverable.

¹¹ European Institute of Gender Equality (EIGE), <https://eige.europa.eu/thesaurus/terms/1263>

5 Policy recommendations

To cope with the multiple challenges of integrated person-centred care, clear and impactful guidelines are necessary to support European decision-making.

This chapter is grounded in a human rights-based approach to health and care and inspired by the work of the WHO in 2021 on the “Continuum of Care”, the development of a long-term empowerment model by the Government of the Bay of Biscay in Spain, and AGE, the SHAPES Think Tank working group, and the above-mentioned SHAPES deliverables. It outlines the main recommendations that will leverage various current beneficial trends and improve the existing gaps.

Emerging from the analysis of the paper, “Developing the Long-term care Empowerment Model” (Bizkaia, AGE, 2022), the goals of care systems in Europe are:

- To ensure dignity, equality and non-discrimination, autonomy and self-determination.
- To support people to lead meaningful lives, to promote quality of life and to be empowered throughout the life span.

The recommendations listed in this chapter bring health and care in line with the human rights-based approach outlined in chapter 4. Following the work of the WHO (WHO, 2021), the following six recommendations can be listed (several of which quote directly from the WHO’s work):

- **Governance:** different types of participatory and empowering cooperations are suitable to deliver accountable and sustainable work.
- **Legislation, ethics, and standards:** laws, regulations and standards ensure equality and non-discrimination for the healthcare system across governance levels. Member States have an obligation to achieve human rights for everyone, including in the healthcare sector, since health is a human right according to WHO.¹²
- **Finances:** embracing a human rights-based approach to finances means to increase, pool, and attribute funds, purchase services, and coordinate reimbursements in a participatory and non-discriminatory way.
- **Monitoring and reviewing:** defining and organising in a way where systems, mechanisms, outcomes and impacts are monitored and reviewed. It ensures

¹² [https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health#:~:text=The%20WHO%20Constitution%20\(1946\)%20envisages,acceptable%2C%20and%20affordable%20health%20care.](https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health#:~:text=The%20WHO%20Constitution%20(1946)%20envisages,acceptable%2C%20and%20affordable%20health%20care.)



that governance, legislation, regulations, standards, finances and workforce remained focused on human rights.

- **Workforce:** embracing a human-rights based approach to members of the workforce in the health and care sector will, for example, recognize ageism and age discrimination; and detect and correct unconscious biases through workforce education and training.¹³
- **Research:** policymakers' knowledge needs to improve continuously so that emerging challenges can be addressed. Data collection in fields of health and care research is key.

Further details are then given on each of these recommendations (see section 5.1 – 5.7).

5.1 Governance

Governance for health and care is about strategic planning and implementation, across governmental levels, bodies, and time, and it is about the necessary power(s) to steer regulations and resources.¹⁴

Recommendations on governance for integrated person-centred care include:

- Promote collaborations, cooperation mechanisms, and collaboration tools across governmental levels and across sectors (whether public or private or public and private sectors also working together) and disciplines.
- Collect, analyse and use data, segregated by different age groups, related to the use of services, their finances, and their geographical distribution..
- Frame a comprehensive agenda to implement goals, including the requested synergies across disciplines, bodies and services.
- Implement a holistic approach for the delivery of integrated person-centred care across the care continuum.
- Develop a clear understanding of the regulatory framework underpinning the organization and provision of health and care.
- Set up coordination and communication systems across all levels for better integration of services and to maximize resilience.
- Develop a periodically revised innovation and research plan across governance levels, that will underpin high quality research.

¹³ Choices to be made in relation to the health and care workforce(s) are closely intertwined with choices and processes derived from previous categories of recommendations relating to governance, legislation, finances, and monitoring and reviewing.

¹⁴ Reference to literature and different definitions of 'governance' can be found in SHAPES Deliverable D3.5 Governance model.

- Promote “quality of education and capacity-building of human resources”¹⁵, also by means of the use of proper and inclusive terminology.
- Raise awareness throughout the health and care system of relationship-building, information sharing, and health literacy to achieve optimal outcomes.
- Set up incentive systems for innovation and adaptation in the health and care sector.

SHAPES contributes to policy recommendations on governance for integrated (person-centred care) namely through: D2.1 “Understanding Older People: Lives, Communities and Contexts”, D2.3 “Cultivating Age-Friendliness”, D2.4 “Empowerment of Older Individuals in Health and Care Decision-making”, D3.5 “Governance Models”, D3.1 “Ecological Organisational Models of Health and Care Systems for Ageing”, D3.2 and D3.3. “Scaling up Improved Integrated Care Delivery”.

5.2 Legislation, ethics, and standards

- Implement a human rights-based approach in EU laws regulations and standards.

Resources from SHAPES contributing to legislations, ethics and standards for integrated (person-centred care): D2.1 “Understanding Older People: Lives, Communities and Contexts”, D2.3 “Cultivating Age-Friendliness”, D8.3 “Regulatory Framework Facilitating Pan-European Smart Healthy Ageing”, D8.4 “SHAPES Ethical Framework” and D8.14 “SHAPES Ethical Framework Final Version”.

Upcoming relevant resources built through the support of SHAPES are ISO 25553 Smart Multigenerational Standards and ISO technical committee ISO/TC 314 Aging societies.

5.3 Finances

Increasing, pooling and attributing funds, purchasing services, and coordinating reimbursements are some of the key aspects of finance for health and care. Policy recommendations that are seeking to ensure the sustainability of financing mechanisms and facilitating equal and universal coverage of integrated care include:

- Identify public and private funds and their allocation and distribution across governance levels so as to define sustainable plans adhering to the human rights-based approach for equal and universal coverage.

¹⁵ WHO (2021), Framework for countries to achieve an integrated continuum of long-term care, p27.



- Monitor costs to optimize the use of funds and their allocation.
- Provide adequate and sustainable funding and investments.
- Provide incentives to mobilize private sector funding resources (e.g., the provision of state/European-level co-financing that will complement private sector resources around specific priorities).

SHAPES contributes to policy recommendations on finances for integrated (person-centred care) namely through: D3.5 “Governance Models”, D3.1 “Ecological Organisational Models of Health and Care Systems for Ageing”, D3.2 and D3.3. “Scaling up Improved Integrated Care Delivery”.

5.4 Monitoring and reviewing

Maintaining essential health services across people’s life course requires an efficient and coordinated planning and governance underpinned by an accurate set of laws, regulations, and standards (see section 5.2). Monitoring and reviewing health and care services are also relevant parts of the overall decision-making process, in order to inform choices and steer integrated care. Ideally grounded on human rights considerations, recommendations in this field include:

- Map services, bodies and stakeholders involved in health and care provision. This includes members of the workforce, their needs and distribution.
- Set up quantitative and qualitative measures and monitoring plans for integrated care policy goals and implementation.
- Monitor goals and their implementation, e.g., through regular reviews and audits, including on finances.
- Conduct regular surveys/polls on the health and care of populations, and their key parameters, so as to anticipate future health and care needs.
- Monitor service delivery and appreciation.
- Identify “intersectoral indicators of care distribution, quality and equity (for example, provision of home modifications, transportation and food and nutrition security)”.¹⁶
- Formulate “control mechanisms to ensure that providers (public, private non-profit or commercial) are respecting (minimum) standards conducted by independent institutions, inspections, and public reporting”.¹⁷

Resources from SHAPES contributing to monitoring and reviewing for integrated (person-centred care): D3.5 “Governance Models”, D3.1 “Ecological Organisational Models of Health and Care Systems for Ageing”.

¹⁶ WHO (2021), Framework for countries to achieve an integrated continuum of long-term care, p14.

¹⁷ WHO (2021), Framework for countries to achieve an integrated continuum of long-term care, p24.



5.5 Workforce

The workforce in the health and care sector is the engine of the overall system, and it is key to embrace and implement person-centred integrated care aligned with the human-rights based approach. To support the essential role of members of the health and care workforce, it is crucial to provide them with healthy working conditions.

- Pay special attention to members' overall health status (i.e., their mental and physical well-being both at work and outside work) and capacity (i.e., through training and retraining courses).¹⁸
- Also pay attention to employees' non-work conditions (e.g., childcare provisions; transportation provision; pension provisions).

Resources from SHAPES contributing to workforce for integrated (person-centred care): D2.1 "Understanding Older People: Lives, Communities and Contexts", D2.3 "Cultivating Age-Friendliness", D2.4 "Empowerment of Older Individuals in Health and Care Decision-making", D3.5 "Governance Models", D3.1 "Ecological Organisational Models of Health and Care Systems for Ageing", D3.2 and D3.3. "Scaling up Improved Integrated Care Delivery".

5.6 Research

- Develop policymakers' knowledge, notably on emerging challenges.
- Build up bridges between the policymakers and researchers by facilitating cooperation among different stakeholders and knowledge sharing.
- Collect data in the field of health and care research, more specifically age segregated data by different age groups.
- Fund research in knowledge gaps that exist in the domain of health and care and their potential impact, so as to be able to effectively prioritise funding and efforts.

Resources from SHAPES contributing to research for integrated (person-centred care): D2.1 "Understanding Older People: Lives, Communities and Contexts", D2.3 "Cultivating Age-Friendliness", D2.4 "Empowerment of Older Individuals in Health and Care Decision-making", D3.5 "Governance Models", D3.1 "Ecological Organisational

¹⁸ The Covid-19 pandemic highlighted these types of workforces' needs in a dramatic way. The Opinion of the Expert Panel on effective ways of investing in Health (EXPH) "Supporting mental health of health workforce and other essential workers" (2021)" provides clear guidance and policy recommendations on mental health). Expert Panel on effective ways of investing in Health (EXPH), Supporting mental health of health workforce and other essential workers, 2021



Models of Health and Care Systems for Ageing”, D3.2 and D3.3. “Scaling up Improved Integrated Care Delivery”.

An additional resource, supported by SHAPES, is the CEN (2023). Workshop Agreement on “Digital health innovations — Good practice guide for obtaining consent for the use of personal health information for research and innovations”.



6 Conclusion

Deliverable D3.4 Pan-European Integrated Care Policy Guidelines explored the concepts of integrated (person-centred) care and continuity of care, building on literature analysis and the contributions from the SHAPES project, namely in the field of governance models, ethical framework, scaling up of integrated care solutions, and of empowerment for decision-making on health and care.

Analysing current and past literature and projects' experience, the deliverable tent to summarize challenges and enablers of integrated person-centred care, providing an overview of the complexity of the topic in the perspective of the SHAPES Ecosystem. To deliver health and care designed according to the individuals' needs over time and across different levels of the health and care system to ensure optimal health and care outcomes, D3.4 used a human-rights based approach to provide a renewed focus on policy-making to deliver health and social care and to coordinate care pathways, promoting a healthier and empowered population.

Thanks to this work, policy recommendations have been drawn, in the attempt to bring health and care in line with the human-rights based approach. Guidelines refer to the realms of governance; legislation, ethics, and standards; finances; monitoring and reviewing; workforce; and research. The connections between those domains and the SHAPES project have been highlighted in terms of relevant SHAPES deliverables sharing useful references and evidence from pilots' work and research.

Several partners contributed to this deliverable. Special thanks go to NHSCT, AIAS, CCS, SciFY, LAUREA, WFDB, EUD and NUIM, as well as to the members of the SHAPES Think Tank and the SHAPES Advisory Board.

A more concise version of this deliverable is in the pipeline: these guidelines will be shared with Members of the European Parliament in the form of a short and colourful leaflet and/or infographic. A first occasion to disseminate such ready-to-read material will be the event organised by SHAPES at the European Parliament and hosted by the Members of the European Parliament Sirpa Pietikäinen on 6 September 2023. If needed, these policy recommendations will be updated and its new version will be further disseminated to European policy makers in the occasions of other events that AGE will organise at European level, for the current and next legislatures (2024-2029).

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 4, human-rights based approach
Biomedical Ethics and Ethics of Care (3.2)	Chapter 5, mention of D8.3 Regulatory Framework Facilitating Pan-European Smart Healthy Ageing, D8.4 SHAPES Ethical Framework and D8.14 SHAPES Ethical Framework Final Version
CRPD and supported decision-making (3.3)	Chapter 5, mention of D8.3 Regulatory Framework Facilitating Pan-European Smart Healthy Ageing, D8.4 SHAPES Ethical Framework and D8.14 SHAPES Ethical Framework Final Version
Capabilities approach (3.4)	N.A.
Sustainable Development and CSR (4.1)	N.A.
Customer logic approach (4.2)	N.A.
Artificial intelligence (4.3)	Chapter 5, mention of D8.3 Regulatory Framework Facilitating Pan-European Smart Healthy Ageing, D8.4 SHAPES Ethical Framework, D8.14 SHAPES Ethical Framework Final Version, D3.2 and D3.3. Scaling up Improved Integrated Care Delivery.
Digital transformation (4.4)	Chapter 5, mention of D8.3 Regulatory Framework Facilitating Pan-European Smart Healthy Ageing, D8.4 SHAPES Ethical Framework, D8.14 SHAPES Ethical Framework Final Version, D3.2 and D3.3. Scaling up Improved Integrated Care Delivery.
Privacy and data protection (5)	Chapter 5, mention of D8.3 Regulatory Framework Facilitating Pan-European Smart Healthy Ageing, D8.4 SHAPES Ethical Framework, D8.14 SHAPES Ethical Framework Final Version, D3.2 and D3.3. Scaling up Improved Integrated Care Delivery.
Cyber security and resilience (6)	N.A.
Digital inclusion (7.1)	Chapter 5, mention of D8.3 Regulatory Framework Facilitating Pan-European Smart Healthy Ageing, D8.4 SHAPES Ethical Framework, D8.14 SHAPES Ethical Framework Final Version, D3.2 and D3.3. Scaling up Improved Integrated Care Delivery.

The moral division of labor (7.2)	Chapter 5, mention of D8.5 Governance Models, D3.2 and D3.3. Scaling up Improved Integrated Care Delivery.
Care givers and welfare technology (7.3)	Chapter 5, mention of D8.5 Governance Models, D3.2 and D3.3. Scaling up Improved Integrated Care Delivery.
Movement of caregivers across Europe (7.4)	N.A.

Comments: _____

References

American Psychological Association. (2010). Publication manual of the American Psychological Association (6th ed.). Washington, DC: Author.

AGE Platform Europe, Biskaia Gouvernement. (2022). Bay of Biskay. Bay of Care Report. Developing the Long Term Care Empowerment Model, Bay of Biscay Report.

AGE Platform Europe. European Office of Red Cross. (2021). Shared conclusions.

AGE Platform Europe. (2021). Towards an EU Age Equality Strategy: Delivering equal rights at all ages.

Borgermans, L., Devroey, D. (2017). A Policy Guide on Integrated Care (PGIC): Lessons Learned from EU Project INTEGRATE and Beyond. International Journal of Integrated Care, 17(4): 8, pp. 1–12, DOI: <https://doi.org/10.5334/ijic.3295>.

Eurocarers. (2020). Informal carers, left aside again? <https://eurocarers.org/download/28249/>.

Eurodiaconia (2014). Recommendations to support and deliver integrated care. <https://www.eurodiaconia.org/fr/eurodiaconia-publishes-recommendations-on-integrated-care/>.

European Commission. (2021). Green Paper on Ageing: Fostering solidarity and responsibility between generations.

EuStacea project. (2010). The European Charter for the rights and responsibilities of older people in need of care and assistance.

Ferrer, L., Goodwin, N. (2014). What are the principles that underpin integrated care? International journal of integrated care, 2014; 14: e037. Epub 2014/12/05. DOI: <https://doi.org/10.5334/ijic.1884>.

Fundamental Rights Agency. (2018). Shifting perceptions: towards a rights-based approach to ageing.

Goodwin, N. (2015). How should integrated care address the challenge of people with complex health and social care needs? Emerging lessons from international case studies. International journal of integrated care, 2015; 15: e037. Epub 2015/11/04. DOI: <https://doi.org/10.5334/ijic.2254>.

Grone, O and Garcia-Barbero, M. (2001). Integrated care: a position paper of the WHO European Office for Integrated Health Care Services. *International journal of integrated care*, 2001; 1: e21. Epub 2006/08/10. DOI: <https://doi.org/10.5334/ijic.28>.

Gulliford, M., Naithani, S., Morgan, M. (2006). What is 'continuity of care'? *J Health Serv Res Policy*. 2006 Oct;11(4):248-50. doi: 10.1258/135581906778476490. PMID: 17018200.

Kodner, DL., Spreeuwenberg, C. (2002). Integrated care: meaning, logic, applications, and implications--a discussion paper. *International journal of integrated care*, 2002; 2: e12. Epub 2006/08/10. DOI: <https://doi.org/10.5334/ijic.672>.

Labor, M., Cooke, M. (2020). D3.1 – Ecological Organisational Models of Health and Care Systems for Ageing.

MacLachlan, M., McVeigh, J., Cooke, M., Ferri, D., Holloway, C., Austin, V., & Javadi, D. (2018). Intersections Between Systems Thinking and Market Shaping for Assistive Technology: The SMART (Systems-Market for Assistive and Related Technologies) Thinking Matrix. *International Journal of Environmental Research and Public Health*, 15(12), 2627. doi: 10.3390/ijerph15122627.

Pim, P., Sanneke, M., Wilfrid, O., Marc, A. (2013). Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care, *International Journal of Integrated Care*, 17(4): 8, pp. 1–12, DOI: <https://doi.org/10.5334/ijic.3295>

Sarlio-Siintola, S. Seidel, K., Prendergast, D., Saris, A.J., Foley, J. (2021). D2.1 Understanding Older People: Lives, Communities and Contexts. Deliverable of the SHAPES project

Shaw, S., Rosen, R., Rumbold, B. (2011). *A conceptual Exploration of Integrated Care in the NHS: What is integrated care?* London, United Kingdom: Nuffield Trust.

Tsasis, P., Evans, J.M., Owen, S. (2012). Reframing the challenges to integrated care: a complex-adaptive systems perspective. *Int J Integr Care*. 2012 Sep 18;12:e190. doi: 10.5334/ijic.843. PMID: 23593051; PMCID: PMC3601537.

Eurodiaconia (2014). Recommendations to support and deliver integrated care. <https://www.eurodiaconia.org/fr/eurodiaconia-publishes-recommendations-on-integrated-care/>(2015). Global strategy on people-centred and integrated health services. Geneva: World Health Organization. <https://apps.who.int/iris/handle/10665/155002>.

World Health Organization (2015). *WHO global strategy on people-centred and integrated health services: interim report*.

World Health Organization (2018). Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services, ISBN 978-92-4-151403-3.
<https://www.who.int/publications/i/item/9789241514033>.

World Health Organization (2021), Framework for countries to achieve an integrated continuum of long-term care, ISBN: 9789240038844,
<https://www.who.int/publications/i/item/9789240038844>.

Zonneveld, Nick; Driessen, Naomi; Stüssgen, René & Minkman, Mirella (2018). Values of integrated care: a systematic review. International Journal of Integrated Care, 18(4), 9, 1-12. DOI: <https://doi.org/10.5334/ijic.4172>.