D8.1 – Policy recommendations

WP8 – Policy recommendations and guidelines for the implementation of evidence-based PC

Submission Date	12th June 2023
New submission	18th October 2023
Responsible Partner	AGE Platform Europe

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Project Documentation	
Project Acronym	InAdvance
Project Full Title	Patient-centred pathways of early palliative care, supportive ecosystems and appraisal standard
Grant Agreement	825750
Call Identifier	H2020-SC1-2018-Single-Stage-RTD
Topic	SC1-BHC-23-2018
Funding Scheme	Research and Innovation action (RIA)
Project Duration	54 months
Coordinator	Universitat de Valencia
Website	www.inadvanceproject.eu

Deliverable Documentation	
Number	D8.1
Title	Policy recommendations
Related WP	WP8 Policy Recommendations and guidelines for the implementation of evidence-based PC
Lead Beneficiary	AGE Platform Europe
Nature of Deliverable	Report
Dissemination Level	Public
Submission Due Date	30/06/2023
Actual Submission Date	12/06/2023
Resubmission date	18/10/2023

Quality Control	
Author(s)	
Marine Luc, Vera Hoermann	AGE
Ascension Doñate	UVEG
Clare Bradley, Gordon Linklater	NHS HIGHLAND
Sofia Reppou, Prof. Michael Doumas, George Baxevanis MD, Christina Plomariti, Annita Varella, Maria Karagianni	AUTH
Mariana Camacho, Adriano Fernandes	SCMA
Nadia Moltó Lliso, Maria Eugenia Gas Lopez, María Soledad Giménez Campos	HULAFE
Zoe Valero Ramón	UPV
Junwen Yang	ERASMUS MC
Contributor(s)	
Vera Hoermann	AGE
Javier Sánchez Busó María de los Ángeles Medina Calvo	UVEG
Editor(s)	

Marine Luc, Vera Hoermann	AGE
Reviewed by	
EU Stakeholders, WP8 InAdvance partners	

Revision History			
Version	**Date**	**Comment**	**Author(s)**
V0	04/2022	ToC	AGE
V0.1	07-10/2022	Analysis of the results from Focus Group at pilot sites	AGE
V0.2	11/2022	Analysis of the survey circulated to AGE Members	AGE
V0.3	11/202	Results from internal workshops with InAdvance	ALL
V0.3	10-12/2022	Feedbacks received from pilot sites	ALL
V0.4	12/2022	TOC and first draft for all sections	ALL
V0.5	02/2023	Issues at national level, Best practices, First list of recommendations	ALL
V0.6	03/2023	Final list of recommendations	ALL
V0.7	05/2023	Inclusion of suggestions and feedbacks received by EU stakeholders and AGE members	AGE
V0.9	06/2023	Executive summary Conclusion, references	AGE
V0.8	06/2023	Final internal review	UVEG, AUTH
V0.9	06/2023	External review	Palliative Care Association
V1	06/2023	Final version	ALL
V2	18/10/2023	Revised version	AGE

Keywords

Palliative care, policy recommendations, early identification, Quality of Life, Integrated Care

Disclaimer

Contents

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Abbreviations List

Abbreviation	Meaning
APCP	Portuguese Association for Palliative Care
COPD	Chronic Obstructive Pulmonary Disease
EAPC	European Association of Palliative Care
EoL	End of Life
EU	European Union
EUGMS	European Geriatric Medicine Society
HCPs	Health Care Professionals
ICD	International Classifications of Diseases
ICU	Intensive Care Unit
LTC	Long Term Care
NATPD	Needs Assessment Tool for Progressive Disease
NECPAL	Necesidades Paliativas
NHS	National Health System
OCPC	Portuguese Observatory of Palliative Care
OOH	Out of Hours
PACE	Palliative Care for Older People
PC	Palliative Care
PCU	Palliative Care Unit
PCCT	Palliative Care Community Team
PREMS	Patient reported experience measures
PROMS	Patient reported outcomes measures
QoL	Quality of Life
UK	United Kingdom
VR	Virtual Reality
WHO	World Health Organization
WP	Work Package

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Executive summary

The project *Patient-centred pathways of early palliative care, supportive ecosystems, and appraisal standard* (InAdvance) proposes a novel model of palliative care (PC) based on early integration and personalised pathways addressed specifically to older people with complex chronic conditions. Thus, the overall aim of InAdvance is to improve the benefit of PC by designing effective, replicable, and cost-effective early PC interventions centred on and oriented by the patients.

The overall objective of this deliverable is to provide European policymakers working at global, regional, national and local levels with a universal approach of palliative care. Its aim is to provide them with recommendations on how to deliver health and social palliative care in different PC settings, including communities, coordinate pathways, and promote a healthier population, enabling citizens to live with dignity until the last day of their life.

In the deliverable "D8.1 Policy recommendations", InAdvance is clearly setting out 6 main deficiencies and unsolved issues of PC, addressing respectively evidence-based policy recommendations. The document begins with the issue of access to palliative care and how early detection of palliative care for older people can improve accessibility (Chapter 1). The stigma attached to palliative care and the lack of ongoing training for professionals in this field are some of the main reasons for the decline in palliative care (Chapter 2). Raising awareness among the general public is therefore essential, as a person-centred care on patients, relatives and informal carers to ensure provision of palliative care according to the needs (Chapter 3). This is only possible in the context of integrated care and with different health policies and health care services communicating properly (Chapter 4). While policy makers should provide the financial support necessary to ensure the accessibility of palliative care, it is shown that early detection of palliative care decrease costs (Chapter 5). Finally, this document provides details about the legal provision of PC in Europe and how it can influence the quality of the care provided (Chapter 6). The deliverable eventually explains the societal benefits if action is taken (Chapter 7).

The identification and compilation of the recommendations have been constant and iterative, with various stakeholders contributing to the drafting: EU Stakeholders, older people or representatives of older people in Europe, members of AGE Platform, health and social care professionals and partners of the InAdvance project. This plurality of opinions is therefore represented in the methodology used to draft the recommendations (Chapter 8).

With the aim to impact policy making, the recommendations have been widely disseminated (Chapter 9) through an easy-to-read version available in annex of this deliverable, designed to increase the chance of dissemination. Dissemination of these policy recommendations and awareness raising on the importance of early detection of PC continue beyond the life-span of the project, especially thanks to the work of AGE Platform Europe at policy level, within the Long-Term Care Coalition of European civil society organisations: the legacy of this work will be therefore well ensured and these recommendations are to be kept on the agenda of the Coalition's meetings to inform the European Care Strategy on Long Term Care.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Introduction

"We deserve to live in dignity whatever our age, until we die, including during the last years of our lives" AGE Platform Europe members after stated the consultation on the earlier provision of palliative care conducted by the InAdvance project.

The lack of consideration for the human rights of older persons when they or their relatives are faced with the difficulties of providing palliative care is a real issue in Europe and shows the lack of policy consideration in most Member States [1].

Worldwide, palliative care needs are still rarely able to be fully covered, since it is estimated that just over 10% of people have access to quality palliative care services (Feedback from Member States in response to WHO Director-General's call to strengthen palliative care services, 2022).

However, the lack of accessibility and quality of palliative care is not unknown and recognized in view of the numerous recommendations that already exist on different levels to encourage European states to act:

- Recommendations Rec (2003) 24 of the Committee of Ministers to Member States on **the organization of palliative care**, published in 2003 (Recommendation Rec 24, 2003).
- WHO Europe recommendations "**Better Palliative Care for Older People**" published in 2004 (World Health Organisation Europe, 2004).
- The World Health Organization guidelines on "**Palliative Care for Older people: better practices"** containing numerous examples of good practices in this field, issued in 2011 (World Health Organization Europe, 2011).
- WHO Recommendations on "**Strengthening of palliative care as a component of integrated treatment within the continuum of care"** published in 2014 (Executive Board, World Health Organization, 2014)
- Recommendation CM/Rec(2014)2 Adopted by the Committee of Ministers of the Council of Europe on 19 February 2014 on the **"Promotion of Human Rights of Older People**" and explanatory memorandum on **Palliative Care** (Council of Europe, 2014).
- **"Palliative Care for Older People, a public health perspective**" (Van den Block, 2015) providing policy recommendations towards improving the quality of and access to palliative care for older people, published in 2015.
- **Palliative care for dignity in older age, addressing the needs of older people in Long-Term Care Facilities in Europe**, recommendations published through the PACE project in 2019 (PACE project, 2019).

Last September 2022, the European Commission presented the European Care Strategy (European Comission, 2022) to ensure quality, affordable and accessible care services across the European Union and improve the situation for both care receivers and the people caring

[1] https://publications.europa.eu/code/en/en-4100400en.htm

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

for them, professionally or informally. The recommendations to Member states have been adapted by the European Council in December 2022. Despite the adopted Council recommendations largely welcomed by representatives of older people, on Access to Affordable, High-Quality Long-Term Care, the recommendations did not specifically mention palliative care. There is still progress to be made to enhance the urgency to respond to the needs of older people in Europe when considering palliative care. Thus, the importance of the wide dissemination of the InAdvance recommendations.

Policy makers need to take into consideration the situation of the poor provision of Palliative Care in Europe (quality and adequacy) and the dramatic consequences it has on older persons' health and on the health of health care professionals. Poor provision has a direct impact on the costs of palliative care systems (when it exists) and selective financial support from governments won't change the structural issues the system is facing. These new policy recommendations stem from solutions developed by the InAdvance project over the last 5 years, the early detection and referral of palliative care for older people and its positive impact on the quality of life of older patients and families as well as its cost-effectiveness. The pilot sites involved more than 360 older participants in the following regions:

- Fundación para la investigación del hospital universitario La Fe de la comunidad valenciana (HULAFE) in Valencia, Spain.
- National Health Service (NHS) Highland, Highland Hospice, Inverness, UK.
- Aristotle University of Thessaloniki (AUTH), Thessaloniki, Greece.
- Santa Casa da Misericórdia da Amadora (SCMA), Amadora, Portugal.

Through these recommendations policy makers will understand why a political response is relevant, applying the human rights-based approach. When the recommendations are mainly focused on older people, they also can be applied to anyone regardless of age.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

1. Palliative care is neither available nor accessible for all

In the context of the InAdvance project, 6 main challenges have been identified impacting the quality and accessibility of palliative care. This chapter focuses on the lack of human and material resources impacting access to palliative care in Europe for older people.

1.1. Absence of a common EU strategy to ensure access to palliative care

Despite multiple available resources on the importance of palliative care policy - recommendations from the Council of Europe (Recommendation Rec 24, 2003), WHO resolutions on Strengthening of palliative care as a component of comprehensive care throughout the life course (Executive Board, World Health Organization, 2014), the recommendations from the European Association for Palliative Care, the joint manifesto from EAPC-EUGMS 'Better Palliative Care for Older People" (EUGMS - EAPC - Fondazione Maruzza, 2021), the European Union is still lacking a common strategy for older people to access palliative care. Inequalities in Europe should be reduced to ensure access by all older persons, independently of their social, cultural and economic background. There are great differences across EU countries in the state of development of palliative care policies in general and in policies for better palliative care for older people in particular. Diverse health and social care systems across Europe are co-existing which makes the configuration of a common strategy to guarantee access to palliative care challenging.
The main concern about the access of palliative care from older people[2] consulted in the drafting of these policy recommendations is that their dignity is at risk, palliative care being a human right that every citizen in Europe should equally enjoy, regardless of age.
« *No palliative care services are available* ***in rural areas*** » Germany.

"*It [palliative care services] is not sufficient****, hardly accessible, very expensive, low quality***" Bulgaria.

« ***For everybody, from everywhere,*** *a guarantee to access palliative care* » Italy.

"*There should also be more opportunities to use* ***home palliative care****, and not necessarily palliative centres in hospitals or outside home"* Poland.

"Too often palliative care seems to ***be restricted to those with needs due to cancer***" the UK.

« Guidance documents, monitoring and regular check by an assigned body are needed. Performance indicators and evaluation of the Services provided which must be available to the public. Legal support to be able to fine or close the premises" Cyprus.

[2] Members from AGE Platform Europe, older people, or representatives of older people, have been consulted to draft these policy recommendations during InAdvance project.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

"Government needs to provide mandatory information by social security or complementary assurances" France.

AGE Platform Europe members are corroborating the need for a common strategy to improve access to Palliative Care in Europe, which is further developed in the sections below.
Issues related to access palliative care in Europe are fundamentally the same and share a lot of commonalities. Common issues will be set out clearly with specific examples from the pilot regions of the project InAdvance, in the following session of this document.

- **Availability and affordability of Palliative Care services in Europe**

There is a very substantial **discrepancy in Europe between the demand for palliative care services and the provision** of such treatments.

Situation in Greece
Currently, there are only three Specialized Palliative Care programs operating, seeing about 1800 patients per year in total. Public hospitals also cover 57 pain clinics and 40 oncology clinics providing palliative care services. A specific home palliative care programme is being improved to better serve patient groups other than older people.

In Greece, between 120,000 and 135,000 patients and their families **are thought** to need palliative care services each year. Only around 3.5% of these patients **may require** hospitalisation at any time, and more than 95% of them **could ideally get** palliative care at home.

This lack of services affects not only the patient but also their family as they are expected to take care of their loved one. In the best case, the family can afford a paid caregiver or a private care home but most people can't afford the expensive private services and in many cases they are sacrificing their professional and personal life. If the patient in need of PC does not have the financial means or a family to take care of them, they end up in a pathological clinic spending their last days in a hospital.

Situation in Portugal
The main gap in Portugal is the unavailability of Palliative Care services. Following the criteria developed by the European Association for Palliative Care and adopted by the government to be implemented at national level in the 2019-2020 *Strategic Plan for the Development of Palliative Care*, the ratio necessary to fulfil the current needs would be **the provision of 1 community palliative care team for each Health Centres Cluster or Local Health Unit.**

Where not enough resources were gathered to create these community teams (e.g., lack of availability of qualified professionals, lack of infrastructures), **palliative care home support teams** were created to respond to the existing needs. But still, in a 2015 listing by the Portuguese National Health Service, the lack of existing Palliative Care teams providing support to patients at home was specifically pointed out (Alves, 2020).

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

It is to be noted that Covid had some impact in the distribution of resources as well. According to the Strategic Plan (Comissão Nacional de Cuidados Paliativos, 2021-2022)"With the start of Pandemic COVID-19 in March 2020, many of the national resources have been redirected, as have the human resources and even infrastructure of the PC teams." **This now calls for the need to reclaim and reorganise all resources for the functions originally envisaged in palliative care teams**. At the time of the elaboration of the plan, in continental Portugal (excluding islands) there were **24 communities** of palliative care support teams and **3 palliative care home support teams** available, for a total of **46 Health Centres Clusters and 8 Local Health Units**, meaning only **half of the necessary resources were available.**

The 2021-2022 Strategic Plan estimated the need for each PCU (Palliative Care Units) beds in Portugal to range from 392 to 490 beds. However, studies already indicated that **the number of beds needed could be approximately double of that**, as the population of non-cancer patients with palliative needs is increasing, as well as the prevalence of chronic conditions related to the ageing of the population. At the time of the plan, only 16 Palliative care Units were available in continental Portugal, **representing 227 beds for an average bed-necessity of 441.**

Regarding the provision of palliative care in Public Hospital despite the 43 Intra-Hospital Palliative Care Support Teams available back to 2020 the teams still required financial support for human resources, facilities and equipment.

The APCP, Portuguese Association for Palliative Care, urges the Government to leave behind the "hospital-centric model" and to create more responses in the community.

Situation in Spain

In Spain, care provided to patients with advanced illnesses and at the end of **life is a social benefit included in the Spanish legislation since the 1990s.** Various national and autonomous strategies are periodically launched and implemented in health institutions with the aim of improving the Quality of Life (QoL) of Palliative Care (PC) patients and their relatives.

Although the concept of PC is widespread in Spanish healthcare institutions, where several PC and chronic care units are working to provide these services to patients**, there is still a clear gap in early care and early provision of PC services.** The focus should be on improving the QoL of patients and their families.
In terms of early provision of PC, **easy and well-organised accessibility to PC** for patients with these needs would be one of the different solutions to be implemented.

- **Inequality in access for PC patients suffering with chronic diseases (other than cancer) and wrong referral processes.**

In the context of delivering PC for patients affected by complex chronic diseases, focus of InAdvance project, the main barriers influencing the access to PC programs are listed below. It should be noted that their impact is even more pronounced when accessing palliative care.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

This inequality in accessing PC services from non-cancer patients can be, at least, partly explained due to the resource scarcity and the prevalence of care fragmentation. There is a discrepancy in inclusion criteria between patients with similar conditions so that it is difficult to make decisions to establish both the prognosis and the treatment goals. As a consequence, sometimes patients have unequal access to early PC.

In some countries (e.g. Greece) due to the lack of an adequate health care infrastructure, **most palliative care is provided by default to patients at home rather than in hospitals or hospices.** When occasionally there is a need for a short-term hospitalisation from patients to manage severe symptoms, this short-term need can be transformed into **long hospitalisations** in public or private clinics. As specialised palliative care settings are lacking, patients are taken care of until the end of their lives in hospitals, while they only need a short time intervention, occupying beds that other patients need to be treated for other pathologies, within care departments not specialised in palliative care.

Lack of primary care resources limits the possibility to work under the necessary conditions with patients and caregivers, especially in terms of time and proactivity. The care provided by primary care teams is crucial to establish longitudinal relationships with patients and their families to help them understand their prognosis and make decisions about their care planning and preferred therapeutic strategies. **The lack of resources and overload in primary care end in patients being referred to other services.** Due to the patients' profile, it could cause a domino effect on the emergency departments (frequent referral of exacerbation episodes) and on the specialised community care services (patients who could have been treated under generalist PC schemes).

- **Challenge of geographical disparities: Palliative care provision is sparsely distributed.**

Equitable access to specialist palliative care services is, first and foremost, **challenged by geography.** Travel to the Hospice can be time consuming and expensive for patients, and their families, living in remote regions. In some European regions, (e.g Highland) a sparse population comes **sparsely distributed health care provision**, with most palliative care delivered by generalist primary care and community services. The recognition of palliative care needs, onward referral and management of palliative care at home relies on the knowledge and awareness of primary / community-based health care professionals.

Situation of Highland, UK

Specialist palliative care services within the NHS Highland Health Board area are provided by the Highland Hospice and NHS Highland. The Highland Hospice in Inverness provides a 11-bed inpatient hospice facility and delivers outpatient multidisciplinary palliative care services both face to face and remotely, by telephone or video call. However, these services are provided to a population of 320,000, dispersed over a land area equivalent to that of Belgium – the most sparsely distributed population served by any health board in the UK. Outside the main population centre of Inverness, in which the Highland Hospice is situated, the population is distributed across small towns and very remote rural areas. Transport links are limited. As a result, the vast majority of patients who access hospice services live within

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

a 20-mile radius of Inverness.

In rural areas, there is significant variability in the care facilities available to patients who cannot manage at home Care may be provided in district general hospitals, 'cottage hospitals', care homes with specified palliative beds or residential care without nursing input. However, the exact location and quality of care will depend on location and availability. Some patients may be placed a long distance from friends, family, and their normal care team.

Situation in Portugal
The Portuguese Palliative Care Observatory (OPCP) draws attention to geographical disparities and asymmetries in Portugal (Alves, 2020). This assessment considers, on the one hand, the number of deaths, the level of ageing of the population, the main causes and places of death and geographical characteristics and, on the other, the organisation and provision of palliative care put in place to meet regional needs.

- **Lack of trainings of Health Care Professionals (HCPs)**

Importantly, patients interviewed before the clinical trial implemented in the InAdvance project valued the quality of their relationship with local Health care professionals (HCPs) and the sense of caring and support. However, **HCPs themselves reported a lack of formal training and self-identified skills and confidence gaps with respect to delivering palliative care**. Health care professionals practising in remote areas can access specialist palliative care advice and education sessions through the Hospice. But, delivering face to face specialist health care to the remote and rural population is expensive and time-consuming, therefore availability and flexibility of such services can be limited with the main population centres.

- **Communication between professionals, patients and the fragmentation of care**

Situation in Highland, UK
Health care professionals (HCPs) and patients involved in the InAdvance project identified the importance of good communication between multidisciplinary services in order to optimise the delivery of palliative care to Highland patients. HCPs identified some well-established and functional informal and formal communication networks. **But they also described how lack of integration of services impacts negatively on timely decision making and diminishes the effectiveness of specialist roles**. Furthermore, they identified organisational structure as a barrier to developing integrated services. This issue of fragmentation of care will be further discussed in a dedicated chapter of this document (See Chapter 4).

1.2. Best practices and evidence from InAdvance

Based on the experience of the pilot sites from Thessaloniki in Greece for InAdvance, the following best practices can be replicated in other countries in Europe.
Empowerment of patients and their caregivers: Supporting patients and caregivers with e-tools increasing their knowledge on their disease and offering a holistic approach to joint

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

decision-making progress. Within the InAdvance project, the pilot site developed **a cross platform application addressed to patients and their caregivers.** The application provides virtual patient scenarios targeting specific diseases and aspects of PC, e.g., diseases and symptom management scenarios, schemes for dealing with pain and grief. The feasibility study aiming at evaluating the usability and user-friendliness of the application contacted during and after the development of it, **revealed that patients and caregivers support the existence of similar apps.** One evidence from the use of this app is that **it has brought comfort to patients and helped them to manage their situation better**. Empowerment of patients and caregivers is a best practice that can be employed when independence is at stake and during rough times where the users might need psychological support. Of course, they cannot replace visiting HCPs, but they can sustain a supportive role.

Frequent monitoring of the mental and psychological state of the patients and their caregivers can provide valuable insights to the process of PC and help identify potential stressors and barriers in a timely manner. In all pilots of InAdvance, patients and caregivers were identified and were frequently contacted by HCPs to collaborate with them for completing questionnaires that aimed to evaluate the physical and psychological state of the participants. **In the period of the study, the participants reported changes in their status, which could be easily and in a timely manner identified**. This contact and communication **made them feel safe and formed bonds with the HCPs that conducted the trials and, as a result, formed bonds with them.** The participants reported that such frequent communication helped them in their everyday life.
The main conclusion that comes from this experience is that HCPs should establish regular communication with their patients and their families, as it can lead to better communication and early identification of potential relapses.

1.3. Recommendations for an adequate provision of Palliative Care for older people

To provide an equal and accurate accessibility of palliative care, regardless of age, gender, geographical area, health or digital literacy, **policy and decision-makers should:**
Safeguard the right of older persons to live with dignity until they die through the provision of care by responding to the patient's demand for care (availability of beds, and professional teams, services, geographic coverage). To cover these needs, different PC settings need to be adequately provided, being provision at home, hospice, hospitals, nursing home or rehabilitation centres. A community based-approach should complement an hospital-based approach **with general practitioners and clinicians providing early education to patients** potentially in need of palliative care services.

To ensure an adequacy between offer and demand, **policy makers should put in place evaluation frameworks that enable comparisons and measurement**. Defining national indicators, setting minimum targets and quality standards, and investing in audit and quality improvement are all necessary if change is to take place at national level, e.g., Patient-reported quality of life, Palliative care education/training, International Classification of Diseases (ICD) codes, primary care providers management, specialist palliative care services referral, place of death, opioid utilisation, etc. **Local/regional/national guidelines should**

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

be established and tailored to the specific needs and characteristics of the targeted population with respect to cultural particularities and religious beliefs.

Member states should invest in the early identification of patients. Patients' needs in palliative care should be assessed early to co-construct adequate pathways through a multidisciplinary approach, as the ones created for InAdvance (see Section 4.2 of this document). Adequate resources (economical, workforce, time and infrastructure) need to be allocated to create safe spaces following specific standards for the provision of PC.

Member states must consider the real decline in cost coverage as the population ages today, health insurance not fully covering palliative care in Europe. **Policy makers must ensure that everyone, regardless of age, health insurance or economic situation, has the right to access the care they need.**

Member States should specifically integrate palliative care into the national action plans emanating from the EU Care strategy, including a strategy for early identification of palliative care and specifically addressing the needs of older people (see section 2.4). This strategy should include **a comprehensive support program, including psychological support**, which is needed not only for the patient, **but also for informal carers**, who should benefit from these policies, as they are personally impacted by their informal work.

To ensure health literacy and ensure the same terminology between professionals and patients is used, EU Member States should **implement public health education** (e.g, via media campaigns or training) to create awareness on the exact definition and availability of palliative care services or provision in their own country. Member states need to further invest in research, development, and education of patients as well as healthcare professionals HCPs.

2. Education and public awareness about Palliative Care is lacking

2.1. European citizens, including professionals, are not educated enough nor aware of what is palliative care

The lack of education in Europe impacting the access to Palliative Care is supported by the responses received from AGE members representing older people and consulted in the context of the InAdvance project (see chapter 8 of this document).

"As the main carer of my mother dying of cancer, I had to make a very difficult decision with no sufficient knowledge. It would have helped me a lot detailed instruction on how to proceed and a psychologist who could have helped me to negotiate with my mother when to get morphine and when not" from Italy

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

"The education is needed. It is necessary to explain the essence and benefits of palliative care, which is mainly associated with the hospice and with " The place where you die", at the end people should learn to talk about their death" from Poland.

"The society needs to disconnect the palliative care just from death and the terminal stadium of life in our minds. This leads to tabooing the topic." From Czechia

"We need better public information. Must be close to the patient's own surroundings (home)" from Finland.

"We have a lack of training and a lack of qualification of the staff in institutions of LTC [long-term care] and a lack of information about palliative care in families as informal caregivers, lack of qualified family doctors" from Germany.

During this consultation, answering the question "Would you say that you are fully aware of what exactly palliative care is and what types of services, pathways and care might be offered to a person in need of palliative care?" **only 19.2% of AGE members answered that they were perfectly aware of palliative care and the offered services (See Figure 1).**

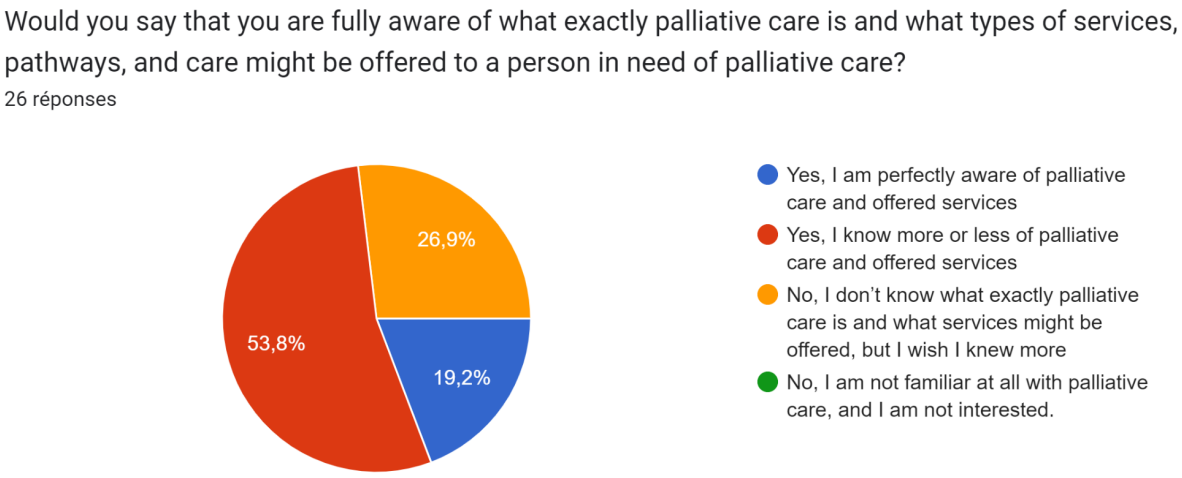

Figure 1 Result from the survey circulated to AGE members - Awareness about palliative care

The lack of knowledge about palliative and end-of-life care, both amongst the public and the social and healthcare professionals presents a barrier for patients' awareness and understanding of the treatment and care options available to them and, therefore, of the access to the proper care required.

Issues in Europe are fundamentally the same and share a lot of commonalities. In the following section, common issues are clearly set out with specific examples from the pilot regions of the project InAdvance.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

- **Ageism and age-discrimination as a barrier to access palliative care**

Older people when receiving PC might face ageist stereotypes and discrimination impacting their health and wellbeing, which may cause barriers to equal opportunities to access health care. This is related to the concept of **ageism** that can be self-directed or other-directed, implicit, or explicit, positive, or negative and can be expressed on a micro (provider to patient through attitudes towards, beliefs about and clinical practices with older people), meso or macro-level (attitudes and practices at cultural and institutional levels). Negative implicit ageism can be expressed in different ways in health care, such as believing that older people do not fit in the hospital environment and believing that older patients cannot tolerate the same treatment administered to younger patients (Sousa, Filipe, Ilinca, Buttigieg, & Larsson, 2019) .

Discrimination based on age can be found in clinical practice and decision-making among health care -providers at diagnosis, treatment or management and expressions of ageism can be found in PC services. For instance, older age has been associated with less access to inpatient and outpatient specialist PC services in comparison to younger patients (Gott, Ibrahim, & Binstock, 2011).

Moreover, according to Gardiner et al. (Gardiner, Cobb., Gott, & Ingleton, 2011), professionals have reported that they consider older patients are less in need of psychosocial support at specialist PC services. Thus, ageist stereotypes and prejudices among healthcare professionals may affect the quality and quantity of care that older people receive and derive into negative health outcomes (Wyman, Shiovitz-Ezra, & Bengel, 2018).

- **Stigmas around palliative care**

Despite PC being aimed at **reducing the severity of symptoms and improving the care and quality of life of patients with serious illness**, **most patients do not receive PC until the very last days of their lives**.

One reason for this underutilization is the **stigma surrounding PC** as something that represents failure and is associated with death and dying (Smith, et al., 2012). There is a false dichotomy of beliefs between curative and palliative that contributes to the perception that PC is exclusively for those who are dying or when no other treatments could be useful. For this reason, professionals may feel guilt and shame when referring patients to PC. Moreover, when patients are referred to PC, they and their relatives may feel devaluation, fear of abandonment, fear of loss of care, hopelessness, dependency or closeness to end-of-life (Zimmermann & Hannon, 2016). Thus, targeting false stereotypes about individuals receiving PC might be an effective way to improve the utilisation of PC (Shen & Wellman, 2019). At a broader scope, literature states that there is a need to reframe PC through explicit renaming (especially in early provision), more education for professionals, more public awareness, better explanations by healthcare professionals to patients and routine involvement of PC at the diagnosis of chronic conditions (Zimmermann & Hannon, 2016). Despite a change of the name could be considered as necessary, it is fundamental also in the manner in which PC is practised and presented among users and the society in general.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

This stigma and culture-related aspects also tie in with the lack of adherence to advance care planning, or the lack of awareness on its existence and its finalities, further preventing a comprehensive care plan that allows one to prepare for the future. The stigma around palliative care prevents people from discussing and initiating appropriate advance care planning.

Patients without prior experience of palliative care services, or who are unaware that their own needs may be addressed through palliative care, are more vulnerable to misconceptions and may perceive the topic of palliative care as a more emotive topic. There is also a common public misconception that palliative care is predominantly for cancer patients.

- **Misconceptions of Palliative care from patients and families**

Aside from the lack of knowledge regarding treatment, patients might also need an additional, previous, step which is awareness raising on the concept itself. The patients themselves do not fully understand the concept of palliative care.

Patient misconceptions about palliative care can lead to difficult conversations and can be a barrier to patient acceptance, especially when the topic of palliative care is broached suddenly and the patient and family are unprepared for the conversation**. For non-cancer patients with serious chronic disease, the unpredictable disease trajectory can make it hard for patients and health care professionals alike to recognise when palliative care conversations are appropriate.** Such patients may find themselves having an unexpected conversation about palliative care, at a time of acute decline and with a healthcare professional who does not know them well. **In these circumstances, emotions and fear around these discussions can be magnified.**

- **Misconceptions of Palliative care from health and care professionals**

The provided care should take several dimensions of the patient into account, and be at the same time human and scientific, with a multidisciplinary team adequately trained. However, several factors are affecting health professionals and organisations' views and attitudes towards palliative care, **namely the purely curative mentality, that disregards other factors impactful on wellbeing and quality of life; the lack of knowledge of prognosis; and the fear of making the patient lose hope**. There are also other factors preventing professionals from conducting referrals to PC **such as the refusal of the patient or family members; the lack of knowledge on the appropriate moment for the referral; and the lack of knowledge about the objectives and possibilities of PC** to impact symptomatic control and improvement of the quality of life (Cruz Rodrigues, 2014).

Quite often palliative care is mistaken for end-of-life care, and this hinders health care professionals from seeking the adequate and needed resources as, in their words, "they are not dying", and, for most people, it is not easy to approach the subject of

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

death. This brings the added challenge of having to overcome the stigmas associated with palliative care to ease the accessibility to it.

- **Absence of undergraduate or post graduate program available in Europe**

In terms of lack of awareness about the importance of PC and end-of-life care, it would be interesting to achieve that PC and end-of-life care were considered with the same importance as new-born care by all actors (politicians, health managers, clinicians and overall population). This is a challenging objective due to the lack of awareness about end-of-life dignity. Beginning and ending of life should be protected as a **heritage of life** and it could be achieved with education.

Nevertheless, these issues are not included in **study programs** as a basic and solid ethical formation in all health degrees. It would be interesting to develop a more specific formation in this field through postgraduate degrees and health specialties.

Situation in Greece

According to the available data collected from all university institutions, Palliative Care is completely or almost absent from studies regarding the undergraduate medical school programs of all universities in the country (with the exception of two elective courses) but is included in all the university nursing programs. There are more than three postgraduate programs for Palliative Care and several seminars and workshops offered for payment. "PARHSYA", the Greek Association for Palliative Care offers some free seminars and workshops but this remains an exception. *"During our interaction with all health professionals at the beginning of the project, there were just a few who could give a description of what Palliative Care is when asked"* says the responsible for the implementation of the Greek pilot site in Thessaloniki.

Example of Amadora, Portugal

A descriptive observational study was carried out on the island of São Miguel, in the Hospital Divino Espírito Santo de Ponta Delgada (HDES) by applying an anonymous questionnaire to a convenience sample of doctors at the institution (Da Silva Aguiar, 2021) to assess the level of knowledge about palliative care. The study provided the following results:

- Most physicians did not have PC training but were aware of its importance and wished to acquire knowledge and competences in it.
- Specialties with more physicians trained in PC were the ones that referred more patients. The reasons being the perception of:
    - the added value of PC,
    - that investing in curative strategies is causing more unnecessary suffering to patients,
    - the need for support in symptomatic control.
- In general, most of the referrals are still conducted at an advanced stage of disease, still concern oncological patients, there is a high tendency for death soon after admission, and mainly in hospital settings.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

- There is a need for pre- and postgraduate PC training in order to ensure that the end of life is lived with the greatest possible comfort and quality of life, especially when it comes to chronic, progressive and suffering diseases.

2.2. Best practices and evidence from InAdvance

Empathy training for nurses and medical doctors developed in Thessaloniki

Palliative care should be delivered by all healthcare professionals who care for patients and requires a person-centred approach to improve quality of life through symptom management, focusing on psychosocial, mental, emotional, and spiritual needs.

To achieve these outcomes, healthcare professionals' palliative care education is an essential component to provide adequate care. Specifically, medical doctors and nurses need to acquire adequate communication skills to be able to initiate efficient conversations with their patients along with their families regarding patients' treatment preferences and overall needs. Patients' condition can rapidly change and, therefore, patient preferences and needs must be identified so that their wishes can be honoured and respected (Rosa, Ferrell, & Mazanec, 2021). Families are relying on medical staff to communicate with them regarding their family members' condition and to facilitate communication between the patient and family. This brings to light the importance of medical staff knowing how to announce and communicate difficult issues regarding patients' health to families. Nurses who have had palliative care education have reported being much more comfortable having difficult conversations (Mazanec, Ferrell, Virani, Alayu, & Ruel, 2020).

Following this perspective, the experiential empathy training conducted in the ''Healthcare Transitions Living Lab'' in the General Hospital of Thessaloniki "Ippokrateio" among nurses and medical doctors, allow for opportunities to open new services of palliative care in medical facilities. Additionally, the training seemed to enhance the knowledge and understanding of healthcare professionals with regard to effectively conducting important conversations with their patients along with identifying patients' families' needs and preferences on treatment, care, fast and adequate diagnosis. Healthcare professionals trained in palliative care are equipped to initiate and guide difficult conversations and to ensure patients and families are emotionally supported and encouraged to care for themselves during the loss process and bereavement. Empathy training also enhanced the psychological status of healthcare professionals and allowed them to confidently screen, intervene, consult specialists, and support patients accordingly. Additionally, nurses reported that the training will assist in improving their work environment in terms of enabling effective communication among colleagues and provide opportunities to share capacities amongst the different teams and faculties. These assets aim to improve the overall quality of life of patients, their families and healthcare professionals.

Virtual Reality (VR) application; scenarios for empathy training and 360° videos on stress and pain management:

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

The Virtual Reality scenarios for healthcare professionals' empathy training, developed in the context of the InAdvance project, aim to improve their empathic performance and communication skills. Specifically, pilot activities were conducted among nurses involving their empathy training through the VR interactive empathy scenarios implemented in the ''Healthcare Transitions Living Lab'' in the General Hospital of Thessaloniki "Ippokrateio". Overall, this innovative educational method can support the education and training in palliative care along with enhancing communication skills and gaining a greater understanding in terms of delivering efficient care. The benefits of this educational method also rely on learning with no restrictions, meaning that healthcare professionals have the opportunity to learn through the VR application in their own time.

They can exploit the VR scenarios within the living lab, which allows for their easy access and availability at any preferred time for as long as it is required. The VR headset is also considered a cost-effective digital tool, that enables the person-centred approach to teach and train healthcare professionals. These practices also apply in the exploitation of the VR 360° videos on stress and pain management, where healthcare professionals have the opportunity to interact with the 360° videos and, through mindfulness techniques, manage their work-related stress. This helps in minimising healthcare professionals' psychological distress and burden, resulting in more positive attitudes and relaxed work environment.

Adhera app: Reduction of the carer's burden through the improvement of the patient's quality of life.

Non-oncological palliative care patients do often face emotional challenges (e.g., stress, anxiety, fatigue). Available research suggests that such psychological burden might affect patients' Quality of Life (QoL), which impacts directly on their caregivers and care professionals' own quality of life. Adhera for InAdvance is a digital solution that aims to provide emotional and self-management tailored support to palliative care patients.

By reducing the psychological and health burdens experienced by palliative care patients and by supporting the professionals and caregivers in providing them support, the latter's overburden is reduced, and their work environment and conditions are improved.

Additionally, the solution makes available several modules of contents targeted to the caregivers themselves, in topics such as self-care and bereavement, more concretely:

- Caring for the carer (what it means to be a carer; principles of self-management; managing emotions; getting support),
- The carer's role (daily care; adapting the house; getting cooperation; pros and cons of a strong support network; when to ask for help),
- Preparing the final stages (spending the last weeks or days; planning for emergencies; what to do when someone dies; life after care).

« Living well » Course in Highland, UK

A remotely delivered course was developed to try to address some of the informational needs of the patients, to promote patient self-efficacy and peer support. The course consisted of eight one-hour weekly sessions:

- Introduction
- What is Chronic obstructive pulmonary disease (COPD)?

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

- What is breathlessness? How to manage my breathlessness
- Exercise and pulmonary rehabilitation
- How to speak to your doctor/ Planning for the future
- Funerals, wills, power of attorney
- Finances
- Day to day life. Goal setting, activities of daily living.

The qualitative feedback from the patients who attended the sessions was overwhelmingly positive. With support from the in-house technical team the remote delivery of the course was acceptable to patients over 60 with severe COPD and heart failure. The professionals involved felt that the course usefully complement existing respiratory services and the approach could be used for other disease groups. More work needs to be done to understand the barriers to participation.

In summary, patients and their families with serious, chronic disease do express a sense of fear and uncertainty about their future. They may worry about specific issues (e.g. symptoms, finances, family, bring prepared for death) or may find a lack of information on their prognosis to be unsettling. Patients and families are probably more willing to have the conversations that are part of good palliative care than healthcare professionals sometimes believe. While the term 'palliative care' can have negative connotations for some people, an increasing number or public awareness campaigns are challenging these. So, fear of misunderstanding should not cause health care professionals to delay the discussion of palliative care needs until a time of crisis. To do so risks missed opportunities to meet a person's needs and the inappropriate prioritisation of medical treatment over holistic needs.

Examples of initiatives aiming at improving public awareness of palliative care in Highland

There are several local, national and international initiatives aimed at improving public awareness of palliative care:

- In Highland, the Highland Hospice delivers the 'Last Aid' course, a small group, remotely delivered course on 'Death and Dying' using 'Last Aid' materials developed by the European Association for Palliative Care (Hospice, H., n.d.) (Care, E. A. o. P.,, 2022)
- In Scotland, the 'Good Life, Good Death, Good Grief' initiative "brings together people and organisations that are interested in improving people's experiences of death, dying and bereavement in Scotland" (Good Life, G. D. G. G.,, s.d.). This initiative (from Scottish Partnership for Palliative Care) raises awareness and provides advice aimed at individuals, communities and workplaces.
- Hospice UK is responsible for the UK wide 'Dying Matters Awareness Week' in May each year. This is part of the wider 'Dying Matters' public awareness campaign which aims to "break the stigma, challenge preconceptions and normalise public openness around dying" (Hospice UK, s.d.)
- Internationally, Death Café is a social franchise which aims to enable group directed discussions on death. The universal relevance of death is reflected in the fact that

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Death Cafes have now taken place in 83 countries, totalling 15369 events (Cafe, D., s.d.).

2.3. Recommendations to better educate

To ensure all citizens, included older people and health and social care professions have a common understanding of what palliative care is, policy makers and decision-makers should: **Invest in the education of older people and their relatives and caregivers.** Ensure that they have access to information by promoting and investing in the provision of information **earlier** and better. PC and end of life care need to be more openly discussed, as tabooing around the topic has negative consequences in the health of older people. As such, it is critical to provide extensive and **comprehensive** information about possible trajectories. Additionally, families and informal carers need to be made aware of the important role they play in demystifying and promoting adherence to palliative care, as well as afterwards, in supporting the patient's engagement to treatment.

Campaign media, TV programs, flyers, posters creating awareness on palliative care should be developed by Member States **as tools to reduce the stigmas**. Online sessions, MOOC, accessible and simple online videos should be developed to support informal carers e.g. "How to care for someone in need of PC at home?".

Invest in education and in continuous training for healthcare professionals, such as regarding basic PC knowledge and skills, and compassionate and patient-centred family focused care. On-going education and training should be offered to all healthcare professionals who should be familiar with PC principles and must be able to apply them. Principles of PC need to be embedded in standard medical practice to integrate PC into the whole care system and qualifications must be recognised equally in Europe. Such guidelines are being developed from the project InAdvance and will guide clinical professionals to deliver earlier palliative care for older people. Education needs to be provided with PC knowledge as a central component of learning objectives. Any professional working in the field of PC should possess a set of core competences enabling them to provide proper care and share a common language for practice and education including soft skills, such as empathy, aside from the specific palliative care training. Through these skills, namely empathy, the doctor-patient communication can be enhanced and improved, leading to more accurate diagnosis and predictions and supporting the decision-making progress for admission to PC.

Sharing of discipline-specific skills: Palliative Care should be taught as an autonomous course in all medicine schools, schools of nurses, schools of psychology and schools of social work. For example, Palliative medicine is recognised in the UK as a separate medical specialty. Physicians follow a specialised 4-year palliative medicine training curriculum following prior completion of both foundation and core medical training.

Similarly, Palliative Care Nurse Specialists may have undertaken a post-graduate diploma in palliative care nursing. Palliative care teams in Scotland are multi-disciplinary and include allied health professionals with additional palliative care training or experience.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Measure education: develop common standards and norms, learning objectives and curricula, as well as optimal way to teach and evaluate.

2.4. Specific recommendations with older adults

Addressing ageism in care provision through:

- Demystify what exactly palliative care is, by making the information available more accessible, readable and user-friendly, towards the older patients, the relatives and informal caregivers, including the understanding of the disease and how to provide adequate support.
- Guidelines for health professionals on the provision of palliative care to older people should consider that symptom management and needs assessment, diagnosis and medicalization of older patients should be done in an objective manner, without attributing pathologies solely to advanced age, without underestimating diagnoses because of age.
- Avoiding assumptions because of the older age of the patients: older patients receiving palliative care are older people suffering from different conditions, it is a heterogenous group of people, not all suffering with cognitive impairment leading automatically to functional impairment.
- Communication between health and social care professionals with older patients should be direct, using lay-language and avoid patronising tone (e.g. speaking slowly with exaggerated intonation, elevated pitch and volume, greater repetitions, using pet names) avoiding dependence-supporting responses and encouraging emotional expression by patients, responding with active listening and empathy by professionals.
- Empower older adults through the involvement of the patients in decision-making and design of their own pathway, respecting their decisions, limits and level of care they wish to receive or not, older people remain willing and legally entitled to make their own decisions in full autonomy.
- Avoiding self-ageism by allowing the patient to embrace positive health behaviours, take preventive actions or adhere to recommended treatments, building their confidence and empowering them to better self-manage their own care.

3. Non-person-centred care leads to late identification of needs

3.1. Person-centred care gaps in Europe

The responses received through the survey distributed to AGE members supported the perception that there are a lack of person-centred care and gaps in the timely provision of

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

care in Europe:

"They [palliative care services] do much depend on the good will of individuals and ideological rather than on receiving patient's desire and will" France.

"Care and treatments tailored on one's needs emerging in chronic or non-curable diseases and intended to preserve dignity and autonomy for as long as possible" Italy.

"Ensure the rights of the individual patient to palliative care of high quality" Sweden.
To the survey which has been circulated to AGE members and to the question "What would you consider as changes needed in palliative care in your area", most of the answers received (18) were to "Ensure a person-centred palliative care".

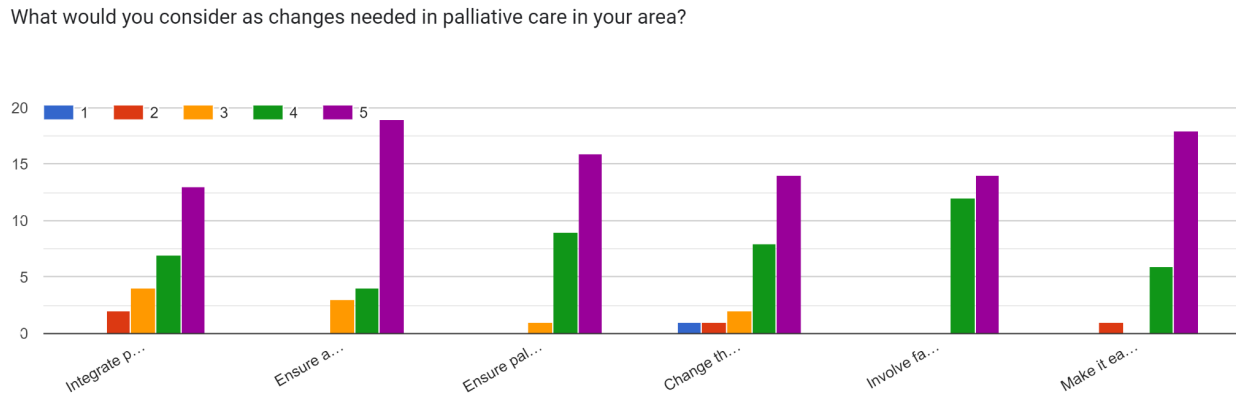

Figure 2 Results from the survey circulated among AGE members - Changes needed in palliative care

AGE members have been asked if they would be in favor of an earlier identification of needs of palliative and with 92.3% saying yes, the result is quite clear (See Figure 2, Figure 3).

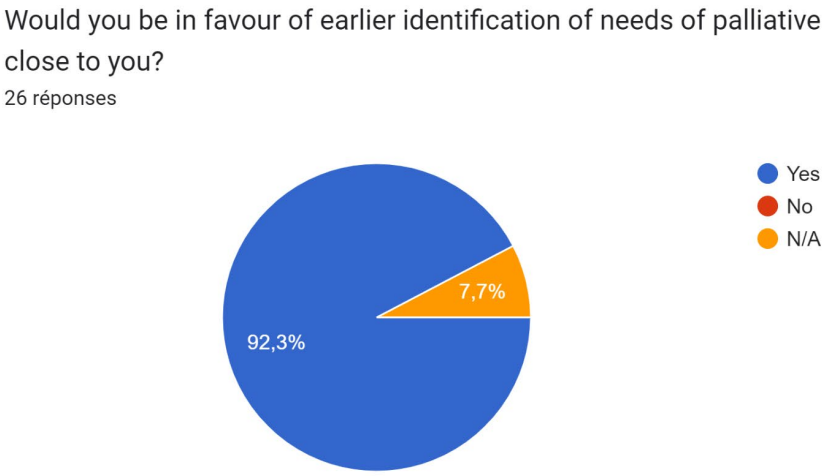

Figure 3 Results from survey circulated among AGE members - In favor of early palliative care

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Issues in Europe are fundamentally the same and share a lot of commonalities. In the following section common issues will be set out clearly with specific examples from the pilot regions of the project InAdvance.

- **Rural vs. Urban provision of palliative and consequences on patient centred care**

Situation in Highland, UK

In some respects, the impact of non-patient centred care may be felt more acutely in remote and rural areas of Highland than in more urbanised regions. In remote areas, logistical challenges may need to be overcome to deliver the right care, to the right person, at the right time. Where advance care planning fails to adequately assess individual wants, needs and capacity (or does not take place at all) **patients may be unable to access appropriate care that meets their needs or those of their families.** Additionally, limitations on service availability may be an obstacle to patient care, even where the needs of the patient are recognised.

Non-patient-centred care seen in Highland due to the lack of global geographical coverage

- Offering a face-to-face clinic appointment in Inverness to a patient dependent on family or friends for transport, or who has home-based responsibilities - especially when this is at short notice. The alternatives would include video consultations, home visits or hospital transport.
- Being cared for by ambulance staff from outside the local area, resulting in unnecessary hospital admission (patients in very remote areas often know their local ambulance crews personally). Examples have emerged through InAdvance of families who's loved one was able to remain at home due the personalised care of local ambulance crews.
- Admission for respite care to a facility several hours drive from the patient's home.
- Limitations on interventions that are offered at home – e.g., no service to set up syringe drivers out of hours.

- **Non-person-centred care and impact on well-being**

Non-person-centred services extend beyond health care and can have a significant impact on wellbeing. The impacts of non-patient centred care are:

- Wasted resources such as missed appointments or unnecessary clinic visits.
- Unnecessary use of acute care beds and medical interventions.
- Unmet needs with consequent health and emotional cost to patients.
- Financial costs to patients and family (particularly for time off work; or travelling to unnecessary appointments; or visiting relatives in an inpatient facility).
- Emotional distress of being cared for far away from loved ones.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

- Patients failing to seek timely care for fear of non-patient centred response, especially for Out Of Hours OOH (e.g. hospital admission or medical intervention).
- Lack of trust or patient / family frustration and anger.

Example in Highland, UK
One InAdvance participant's health was declined, he applied for a ramp to access his council owned property. This was declined. The participant was instead offered alternative housing in a different village a distance away from family and his trusted GP practice.

- **Non-person-centred care leads to late identification of needs**

The timely referral to PC, ideally conducted at the moment of diagnosis, has been shown to have a positive impact on the evolution of the patient's disease (and consequently on the life expectancy), quality of life, symptomatic control (particularly depressive symptoms), facilitating the communication with the patients and their family/caregivers, facilitating the discussion of end-of-life care preferences, reducing the number and length of hospital stays, reducing therapeutic futility, reducing costs with health resources, increasing patient participation in the decision-making process of their care pathway, and preventing caregiver burden and pathological grief (Alves, 2020).

Late identification of palliative care needs can result in suboptimal management of patient's needs at the time of acute deterioration. The delayed identification of palliative care needs results in missed opportunities to plan ahead and organise appropriate care. **Sadly, in the acute situation, it is not always possible to access the type of care which would have been most appropriate for that patient.**

In the decision-making related to the provision of PC and, especially, in terms of early provision of PC, **the patients' opinion should be considered always as the starting point.** However, the late provision of PC, the lack of primary resources, as well as the tabooing related to the PC concept complicate the fact that the patient is at the centre of the process when establishing a personalised PC scheme and the decision making in terms of care at the EoL (End of Life).

One of the specific issues related to the late provision of PC would be the **delay in the start of the follow-up program:** Sometimes, when the patient is admitted in the follow-up program, the illnesses are in an advanced stage so, probably, there is not enough time to establish trusting relationships with patients and caregivers. Therefore, it could be difficult to know in-deep the needs of both.

In some cases, **patients' referral is so late** that there is not enough time to respond on time to the referral and to take into account the patients' preferences. So they might end up dying in hospital when their wish was to stay at home.

The late provision of PC **may also involve costs.** Probably, before starting in the PC programme, some patients have received many health interventions (specialist referrals or

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

urgency episodes) that have provided little value to the patients' and caregivers' quality of life and have constituted a waste of resources.

Some patients probably start receiving PC as late as professionals could experience **a feeling of incapacity** to attend to them in higher conditions than if they would have been part of the PC programme before.

On the other hand, there is a **bad understanding of PC provision** among patients and relatives due to the late admission to PC program and the lack of enough time to plan the actions to take.

As a consequence of the previous points, the experience of some patients and caregivers might be negative, with a feeling of overwhelm, inability to cope and suffering.

- **Late identification leads to overburden of health and social care professionals**

On what concerns professionals' overburden, research so far has demonstrated that due to the chronic stress resulting from working alongside patients with complex diseases, palliative care professionals are especially vulnerable to burnout, with several countries also reporting increases in professionals' levels of stress, depression, drug/alcohol dependency and suicide. All of this can lead to absenteeism, ineffective communication, medical errors and job turnover. The factors that lead to this burnout are mostly associated with organisational factors rather than personal resilience issues, with organisational and leadership decisions affecting professional achievement (Alves, 2020).

The multidimensional role that professionals must assume when working in palliative care presents itself as very challenging and burdensome on said professionals, as they must possess a multitude of knowledge and competences to mitigate the holistic needs of the patients and their families/caregivers, whether they are physical, emotional, social or spiritual. Additionally, professionals report difficulties in sharing and discussing their vulnerabilities due to implicit pressure to be strong like the patients' families. All these factors raise concerns on the stability of the palliative care workforce, with increasing awareness being raised on the impact of this syndrome on professionals' quality of life and its consequences on the patients' care. As such, and in order to provide quality care, the wellbeing and quality of life of caregivers must also be ensured (Alves, 2020).

Some of the needs and concerns expressed by care professionals are:

- the need to set boundaries.
- the need to change the structure of the current palliative care practice (namely in what regards the pressure and burnout felt by professionals to fulfil multiple roles and cover multiple skill sets).
- the anxiety felt by having to respond to dimensions of care beyond their knowledge and skills.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

3.2. Best practices and evidence from InAdvance

The following best practices relate to the provision of person-centred care and were identified through the InAdvance project:

Implementing a formal assessment tool, such as the Needs Assessment Tool for Progressive Disease (NATPD) as used in InAdvance. This guides the Health Care Professionals (HCPs) to better understand the patient as a whole, as a person, not only as a patient and a diagnosis. The NATPD provides guidelines to HCPs to ask questions that usually they do not ask to patients and facilitates understanding of the values and preferences for each person.

Provide appropriate training to staff using needs assessment tools – the NATPD is an easy tool to be deployed and introduced into daily clinical care, but it is important to provide some training to HCPs and assure they do not implement it as a checklist.

Gather support of multidisciplinary teams prior to implementation of a new needs assessment tool - The use of the NAT: PD in normal clinical practice does not need any relevant change at institutional level, but it requires commitment and the investment of some time by multidisciplinary teams in charge of patients with chronic conditions and multimorbidity.

Discussion of needs assessments findings with multidisciplinary teams – in the InAdvance Clinical Trial results derived from the NATPD assessment were discussed in multidisciplinary teams which facilitated more appropriate referral to the most suitable service or professional. The referral process moved from more isolated decision-making to a joint and multidisciplinary decision.

Offering remote support - in terms of provision of information and knowledge, self-management, caregivers' skills, etc. This is achieved through the introduction and use of a variety of IT solutions.

Example in the Highlands, UK in the anticipation of PC planning

In the Highlands, there is an established process for Anticipatory Care Planning which is used by primary care physicians. Once an Anticipatory Care Plans has been completed there is a successful system in place for sharing this with out of hours primary care services and ambulance services. This allows for appropriate management of a person's needs and acknowledgment of their wishes should they acutely deteriorate. The Anticipatory Care Plans are typically updated on an annual basis if an earlier review has not been triggered by a change in circumstance.

However, when palliative care needs go unrecognised, Anticipatory Care Planning does not take place and patients are at increased risk of avoidable hospital admissions and overtreatment, including inappropriate cardiopulmonary resuscitation.

NHS Highland / Highland Hospice supports clinicians managing palliative patients in the community, especially out of hours, by providing the Palliative Care Helpline and the

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Palliative Care Response Service Both services may, to some extent, mitigate the negative effects of late identification of palliative care needs as they provide non-specialist clinicians with the information and support to provide good quality palliative care at home, avoiding hospital admission. Many examples were seen in InAdvance of good patient centred care in Highland, particularly in remote areas where patients and their families were well known to the healthcare professionals and social care staff.

Situation in HULAFE, Valencia around the earlier identification of needs

HULAFE aims to contribute to the shifting towards a value-based healthcare model through different actions planned. This model implies that the healthcare system focuses increasingly on quality of care rather than volume of care (Putera, 2017), and proposes a strategic framework with the aim to guide health services towards the provision of the highest value care for the patient at the best cost. Hence, this model combines three essential elements: Implementing systems for measuring health outcomes of value to patients, organising care practice around clinical processes or conditions, and calculating costs per patient throughout the process. Therefore, it measures outcomes in terms relevant to patients, as beneficiaries, so that healthcare institutions can reorient their response to their demand, ensuring a positive benefit-cost ratio (Porter, 2010).

La Fe Hospital is working to facilitate the introduction of **PROMS** (Patient-Reported Outcome Measure) and **PREMS** (Patient Reported Experience) collection. **PROMS** aim to determine whether a healthcare intervention has had an impact on patients' health status and quality of life. They consider the needs of patients and clinicians, as well as healthcare decision-makers and policymakers. **PREMS**, on the other hand, aim to gather the patient's point of view on the quality of healthcare services. This enables healthcare professionals and managers to know which services work best, or not, from the patient's point of view (Greenhalgh, et al., 2018).

HULAFE has a PC **organisation focused on processes management**. This methodology is based on planning the flow of patients through the hospital according to available resources and patient requirements. This ensures reproducible workflows and predictable, constantly improving results. It also brings benefits such as the optimised decision-making by social and healthcare professionals, reduced costs, and greater efficiency.

For InAdvance project, the register of patients' willingness in their medical record implemented as one of the 9 components in the second stage of the project, can be considered. Thanks to these registers, patients' relatives and health/social care professionals can take into account patients 'willingness to make important decisions, such as the place they wish to die or which types of care they prefer to receive in the last moments of their lives.

3.3. Recommendation: Patient should be at the centre of the process earlier

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Person-centred palliative care requires early identification of needs; which in turn requires early conversations about palliative care; which are stimulated by increased public and professional awareness and reduced taboos. Thus, ensuring person-centred palliative care is very much multifactorial and linked to recommendations made elsewhere in these guidelines.

In order to put the patient at the centre of their own palliative care policy makers and decision makers should:

Aim to decentralise palliative care service provision by developing **community-based interventions and resources, and making the access to early palliative care services less hospital-centric.**

Experience across the InAdvance **clinical sites suggests that community based palliative care services are well placed to provide timely access to palliative care**, which addresses the person's needs in a setting that is accessible and acceptable to the person and their family. Decentralisation of palliative care services may require the promotion of education and skill development for community-based health care professionals. There may also be a need to address resource provision in the community setting. **However, strengthening of community level services should go hand in hand with the development of specialist palliative care services which should disseminate knowledge and skills; developing advisory and outreach services and widen access to any centralised services.** Appropriate patient pathways should be developed to support the coordination of a person's care across all service providers.

In addition, policy makers should promote the active participation of the patients or their representatives in the decision-making process relating to their palliative care by ensuring that **person centred discussions relating to palliative care needs are an integrated part of standard care.**

They should establish local pathways and systems which allow care to be directed by individual needs and which ensure the patient is involved in their future care planning.

Policy makers should also take into consideration **the life-course perspective,** meaning that person-centred decisions should start early and continue throughout life. It underlines the need to consider the vast diversity of people, as well as changing needs and capacities with age.

Holistic, person-centred care should be delivered around a person's individual values, needs and preferences. This is best achieved when adequate time is allocated to explore those needs with the individual and their families and when these discussions are held out with times of acute need.

Tools such as NATPD PROMS and PREMS should be implemented by Member States in different health institutions, to make clinicians aware about the patients' opinion and experience on the quality of services as well as the patient's outcomes expressed after each

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

palliative care. This would allow us to assess and enhance the workflow and the processes carried out in the health institutions.

4. Fragmentation and discontinuity of care

4.1. Fragmentation and discontinuity of PC in Europe

Through the survey distributed to AGE members some answers were denouncing the discontinuity of care as well as the fragmented care with consequences on the quality and timely care received.
« We need a multidisciplinary and integrated care » Bulgaria.

"Palliative care should be part of a more complex idea of care, ranging from health care to LTC ect. and everyone in the EU, if in need, should be granted access to it" Italy.

"Investing more in a true network of continuous care with various levels of differentiation, prioritising proximity primary care or home care", Portugal.

These statements are reinforced by the recommendations from the WHO Strengthening of palliative care as a component of integrated treatment within the continuum of care published in 2014, "Realising the urgent need to include palliation across the continuum of care, especially at the primary care level, **recognizing that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care"** (Executive Board, World Health Organization, 2014)**.**

- **Older people with needs of PC require a multidisciplinary approach**

The coexistence of multiple healthcare professionals and settings is common in the care delivery of people with chronic diseases. This is due, in part, to the variety of needs and determinants of health that frequently converge such as pluri-pathology, severity of illnesses, behavioural and cognitive factors, geriatric syndromes, disability and negative socio-economic factors.

One of the consequences of the multiple professionals and care resources involved in responding to the needs of these people is the limited, discontinuous, episodic, and disorganised care delivery. Fragmentation of care is associated with reduced quality of life and negative health and social outcomes such as higher care interventions: readmissions, emergency department visits, non-value interventions, higher risk of complications (disability, pressure sores, delirium etc.), higher risk of mortality, higher costs of care, family exhaustion and overload and increased risk of caregiver burden, among others.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Continuity of care entails a collective action based on three basic pillars: patient centred care, the relation between different entities in the health and social sectors, and informational continuity.

Older people suffer from more than one condition towards end of life, and it leads to complex need for care and support; this needs a multidisciplinary approach answering to physical, emotional, spiritual and social needs. A combination of care trajectory may occur which leads to complex needs for care and support. In Europe there is a lack of coordination among multiple services providers in the public and private sphere and it may lead to inadequacy of care and discontinuity of services and, as a consequence, to reduce efficiency of care and services.

The population would highly benefit from a lifelong and integrated approach to care, which, being deployed, would allow for people to adjust their care-needs as they progress in their life and to detect any complications at an earlier stage, allowing for the timely activation and provision of care and the avoidance, or at least reduction, of exacerbations. The older generations may have a very clinical approach to wellbeing and quality of life, and the legal national context itself puts in place a heavily hospital-centric model, with the community-based responses made available providing predominantly social care and support.

Situation in Portugal

Portugal is facing an ageing population, an increase in multimorbidity and a lack of communication between primary care and hospitals. This communication problem, particularly between the private and public sectors, is leading to duplication of examinations and therapies. The government's over-centralisation on the care provided by the national health service leads to the neglect of the remaining entities operating at local and regional level, which does not contribute to the integration of care among the available resources.

- **Absence of medical digital records**

In some European countries, Greece, Portugal, there are still no digital medical records for patients, any patient having examinations or being hospitalised doesn't have this information available at their next visit in another setting or hospital. It is more likely that if they need hospitalisation again, they will end up in a different hospital (different hospitals are on duty every day) and their medical records will not have all needed information. PC is affected by this discontinuity. The digital records would contribute to the systematisation of the information and would facilitate in its communication and on the subsequent coordination of care, ensuring a continuum and integration among the relevant actors.

- **Lack of communication between professionals and between different PC settings**

Fragmentation of care could happen in different health settings but even in the same setting. The lack of communication between health professionals is very high depriving the patient from a holistic approach that could save time and money and would benefit the patient.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Situation in Greece
As mentioned before, PC in Greece is mainly offered by family members, paid caregivers, private care homes or pain clinics and less than a handful of PC organisations. Sometimes patients move from receiving PC at home to PC in hospitals and then come back home with public or private PC provision or back home with a paid caregiver that may change often. All these transfers are made with minimum interaction and communication between the health and social carers affecting the wellbeing of patients and their families. For families and carers, this can be a challenging and emotional time, and providing them with support and resources can help to alleviate some of the stress and burden that they may be feeling. This can include offering respite care, providing access to counselling services, and helping to coordinate care and support from other healthcare providers, friends, and community organisations.

Situation in Highland, UK
In initial interviews and focus groups performed for InAdvance, health care professionals and patients alike identified the importance of good communication between multidisciplinary services to optimise the delivery of palliative care to Highland patients. Health care professionals identified some well-established and functional informal and formal communication networks. But they also described how lack of integration of services impacts negatively on timely decision making and diminishes the effectiveness of specialist roles. They identified organisational structure as a barrier to developing integrated services.

Situation in Valencia, Spain
In Spain there is a fragmentation of clinical pathways due to the **lack of coordination between primary and specialised care**. In this sense, many patients with multiple chronic diseases are followed by different levels of care and services (hospitals, outpatient clinics, primary care and specialists). On the one hand, this is positive because each service can contribute from its knowledge and specialty to improve the patient's health status. However, this is often a **major obstacle to continuity of care due to the lack of communication and gaps between all the actors involved**. Often, this results in delays both in the referral process and in the Palliative Care Admission Triage. Effective and efficient communication together with continuity of care is crucial for delivering high-quality safe care in a cost-effective way.

- **Discontinuity of PC at home in rural areas**

In some European regions (the Highlands) there is also a real lack of local out of hours nursing care. This can result in patients being admitted for care where they could otherwise manage at home with nursing input. Even during daytime hours, the long travel distances can mean nursing resources are spread thinly and provision of care can be very challenging. This is also true for all health and social care professionals such as physiotherapists, otorhinolaryngologists, psychologists, therapists etc.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

4.2. Best practices and evidence from InAdvance

Concrete best practices to overcome care fragmentation for patients with chronic illnesses would be:

Promoting a sense of shared responsibility among all professionals and sectors involved. In the context of the InAdvance project, the actions that may have contributed favourably to this issue are:

- Regular joint multidisciplinary sessions focusing on frequent care fragmentation scenarios, such as care transitions after hospital discharge or transfer to nursing homes or long-term care institutions.
- To use the same assessment tools (e.g. NATP: PD or NECPAL - **Nec**esidades **Pal**iativas, which includes the Rockwood frailty index) as support for decision making and for reaching an agreement among professionals, such as the patients' inclusion in the PC programme.

Ensuring high-quality referrals. In the context of the InAdvance project, referrals and changes in the care plan have been based on a comprehensive assessment of each patient's needs through the NATP: PD and NECPAL tools. Thus, referrals and updates in the care plan have been more timely and responsive to patient and family needs and preferences.

Having the ability to track referrals and the relevant information related to care preferences. To achieve a coordinated health system in terms of PC providing, an important thing to consider is the patients' data sharing across care providers and health institutions. In this sense, it could be achieved through an information system which recorded important landmarks in the referral process (e.g., referral appointments made, patients' information received, appointments completed, consultation notes returned, etc.). Regarding this, a specific section in the electronic medical record for each patient including advanced care planning processes facilitated the access for professionals from different areas in order to know the patients' preferences (in terms of comfort care options, treatments and therapeutic intensities).

To assign a professional whose role focuses on acting as a communication nexus between patients and the healthcare professionals/health institutions. Another of the elements that may contribute to ensure a continuity of care, especially when new patients' needs have emerged, is the role of the nurse case managers. The establishment of a confident relationship between these professionals and patients allows them to know patients' preferences and needs in depth during their follow-up programme. In the context of the InAdvance project, these professionals have acted as transversal actors in the patients flow in the hospital and have had an important role when referral plan establishment.

Example of SCMA, Amadora, PORTUGAL

Integrated and Person Centred Care Model being the approach of InAdvance project, gaps in resources such as the inexistence of clinical staff, e.g. predominantly in social services as Homecare Support services or Day care centres, have been one of the biggest barriers faced. The absence of this social professional profile is due to the regulatory context, which does not contemplate clinical staff and does not support its funding. As the regulatory context

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

cannot be influenced at local level, the goal with InAdvance was to **emphasise the unattended needs and unmet challenges at organisational level, and in this way highlight** some major gaps. One of the key takeaways from InAdvance, is the need to have a Palliative Care Unit (PCU), as it was the case in the past, or develop a Palliative Care Community Team (PCCT), ensuring support and palliative care to patients throughout all services, mitigating the lack of human resources. Another key takeaway would be to restrengthen the collaboration with the public healthcare services, such as the Amadora Health Centres Cluster (ACES), in order to make the external referral process quicker and more efficient.

4.3. Recommendation to integrate health and social care services including Palliative care

To ensure integrated and avoid fragmentation of care having a direct impact on wellbeing and QoL of patients, families, health and social care professionals, policy makers and decision-makers should:

Boost the development of an organisational system that ensures coordination between the different medical and social resources aimed at the implementation of an interdisciplinary integrated care model for patients and their families. As mentioned in the previous section, it is necessary to provide an integrated assessment and for achieving this, coordination between all the parts involved in the PC providing should be primordial.

Establish common guidelines for specific interventions based on the available scientific evidence for aged patients with progressive chronic illnesses. These guidelines should focus on the coordination of the different medical and social resources involved at the primary care and hospital levels, ensuring consistent access to palliative care. It should also define care processes prioritising the integration of socio-health resources in such a way as to guarantee care coverage for patients 24 hours a day 7 days a week.

Shared information between professionals should be imperative to reach effective coordination of the different medical resources. To achieve that, it would be useful to develop accessible platforms which allow timely and accurate information sharing between health and social care professionals, relating to disease progression and palliative care decisions. Ideally, these should be integrated into existing standard electronic patient management systems.

In this sense, the development of an Observatory on palliative care and End of Life Care aimed at providing clear and accessible research-based information about care provision in the mentioned context would be another useful tool.

The existence of integrated and palliative care teams in the community would facilitate, in a decentralised approach, people's access to appropriate care, would avoid exacerbations and, in this way, decrease hospitalisations and prolonged stays at the hospital. However, the decentralised approach requires a legal framework that provides the resources needed to deliver this integrated, person-centred care, e.g. in Portugal, home care services and day

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

centres are owned by the Ministry of Social Security but must meet a clinical profile set by the Ministry of Health, which creates inconsistency in the provision of care.

Integrate patient and public involvement in national, regional, and local health care planning in order to understand and tackle the current barriers to timely palliative care planning. For this, it would be useful to establish a set of quality-of-care indicators explicitly related to palliative or end-of-life care, such as patient-reported quality of life, Palliative care education/training, International Classifications of Diseases, ICD codes, primary care providers management, specialist palliative care services referral, place of death, opioid utilisation, etc.

Policy makers should push for an **open national dialogue** to understand the expectations from each stakeholder involved or impacting the accurate delivery of palliative care, including public and private actors, health and social care professionals, informal carers, patients representatives, public health institutions, older people and decision makers.

5. Cost-effectiveness of early admission to Palliative Care

Despite the human-rights based approach to care pursued by AGE members, which emphasises the right to care rather than following an economic logic, some responses acknowledged the relevance of cost in the provision of palliative care:

"[...] and more centres should be open, with regular funds from the government". from Poland

"We need more resources to widen scope of care", from the UK.

"More resources needed, more public attention and interest needed", from Finland

"to make sure that the service provided is up to a Standard and AFFORDABLE FOR EVERY BODY", from Cyprus

From the survey which has been circulated to AGE members and to the question "What would you consider as barriers to palliative care in your area?" 13 older people out of 26 consider that **the costs associated with palliative care is the main barrier (See figure 4).**

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

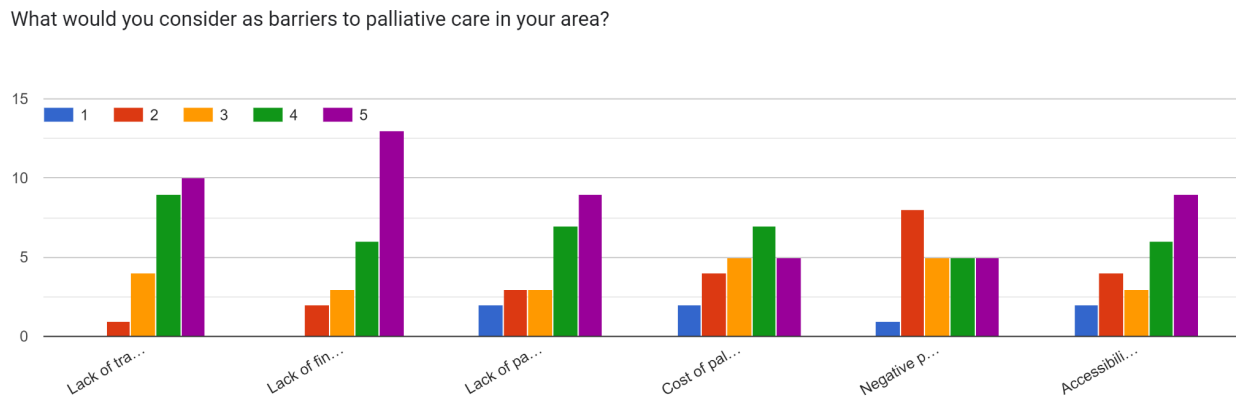

Figure 4 Results of the survey circulated among AGE members - Barriers to access palliative care

5.1. Costs associated with Palliative Care provision in Europe

Palliative care, as other health disciplines, is forced to compete with other areas of healthcare for limited financial resources. Demographic statistics indicate that the number of patients with palliative care needs are increasing every year. Dying in hospitals is often not a patient's preference and is costly to the health care system. As a result, healthcare decision makers need to maximise 'value for money' when authorising palliative care services, yet data which provide evidence to such decisions are lacking.

It is recognized that a relatively large share of healthcare resources is spent on end-of-life care (Smith, Brick, & O'Hara, 2014). A study reported that in the UK relatively 20% of hospital bed days are taken up by palliative care services (Hatziandreu, Archontakis, & Daly, 2008). However, the evidence base of cost-effectiveness evaluation to palliative care remains small (Bajwah, et al., 2020) (Gomes, Calanzani, Curiale, McCrone, & Higginson, 2013) (Johnston, et al., 2020). One literature review reported that palliative care services mostly cost less relative to comparator groups (i.e., standard hospital setting, acute care services), and in most cases, the difference in cost is statistically significant (Smith S. , Brick, O'Hara, & Normand, 2014). Another systematic review on the economic evaluations of palliative care models reported that within the five studies included in the review (covering the situations in the United States, England, Australia, and Italy), all studies suggested that palliative care was cost-effective compared to either usual care or absence of care (Mathew, et al., 2020) Three studies reported that the home-based palliative care model was cost-effective relative to usual/absence of care (Higginson, et al., 2009) (McCaffrey, et al., 2013) (Pace, et al., 2012). More cost-effectiveness evidence is needed in European countries with different health care systems or payer perspectives to support policy making.

As mentioned earlier, early palliative care can be defined as early and routine integration of a multi-professional specialist palliative care service. A study conducted in Italy reported that costs of early palliative home care for patients with hematologic malignancies are lower than standard hospital care costs. Domiciliary assistance may also be cost-effective by reducing

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

the number of days to treat infections (Cartoni & et al., 2021) Early use of palliative care may decrease overall healthcare costs, including improved ICU - Intensive Care Unit - utilisation, decreased emergency department utilisation, and reduced inpatient readmission rates (Milazzo, Hansen, Carozza, & A. Case, 2020).

- **Late identification of PC needs and related costs**

Results from economic evaluation of Palliative Care report that effective and timely implementation of PC interventions offers economic benefits, such as the optimization of the resources needed to get an effective PC provision (Effiong, 2012). According to these authors, this is possible only if PC is implemented in a comprehensive manner by improving, on the one hand, the budgetary forecast of public provision of this type of services and increasing the life span of patients and, on the other hand, by reducing the total and marginal costs of the intervention.
Due to the late provision of PC and, consequently, the lack of personalised assistance, patients under PC pathways might receive many health interventions (treatments, tests…) with no value added in their QoL. It would be a waste of resources and an increase in costs. Moreover, the late access to PC programs might result in a delay in the provision of public medical aid (both economic aid and social aid such as medium-long stay facilities, day care centres, paid caregivers, etc.). For cost analyses in the context of end-of-life care, it is common to analyse the costs associated with hospitalizations or emergency room episodes. However, it would be interesting to include the costs associated with caregiving at home. Caring for a relative at home might influence the family economy negatively due to the amount of time required and the use of resources that are not covered by the public health care system.

- **Costs vary according to the PC settings**

Cost analysis in each PC delivery setting is key for moving towards sustainable PC delivery (Yadav, et al., 2020). Cost-effectiveness reports of different modalities of PC interventions show the overall profit of PC when integrated at hospital, home and nursing home in terms of improved health services and reduced out-of-pocket costs (Smith S. , Brick, O'Hara, & Normand, 2014) In the case of early PC, the integration of PC in these settings after the diagnosis means even more savings in healthcare spending, especially in hospitals (Yadav, et al., 2020).
Generally, there is a consensus in the literature on the cost-effectiveness of PC, but there are significant differences depending on the mode and setting in which the PC is delivered. Regarding inpatient PC, studies reveal that early referrals of chronic inpatients improves and cost-effectively delivers PC (Fitzpatrick, Mavissakalian, Xu, & Mazurek, 2018). Considering the financial effects as a dependent variable, early PC in inpatient settings have greater economic benefits and better patient outcomes due to reduced length of stay in hospital (through earlier referral to outpatient care) without negatively affecting mortality (Fitzpatrick, Mavissakalian, Xu, & Mazurek, 2018). For instance, in the case of PC provided into the (intensive care units), early interventions generate greater savings in the use of healthcare resources in the hospital setting, both in terms of ICU and post-ICU (in terms of reduced in ventilator days, emergency department visits, tracheostomy performance and readmissions after hospital discharge and the same operational and pharmacy costs and

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

mortality (Ma, et al., 2019). For outpatient early PC, the evidence on its impact on costs is still insufficient. Evidence confirms that home-based early PC is cost-effective and has the ability to save both healthcare and patient expenditure by reducing the likelihood of hospitalizations, length of stay at hospital, visits to the emergency department and visits to clinicians (Behm, 2015).

- **Costs vary according to the patient conditions**

Going deeper to specific conditions or profiles of patients, economic studies demonstrate that early PC reduces the number of hospitalizations at the end-of-life for patients with cancer by reducing acute hospital care (hospitalizations and visits to emergency department) through increased home care (Seow, et al., 2022). Additionally, early PC has proven to be more cost-effective than standard PC as it generates less end-of-life care costs and savings in chemotherapy costs (Greer, et al., 2016). This trend has been also observed in other non-oncological conditions, such as dementia (Clarkson, et al., 2017) or haematological diseases (Cartoni, et al., 2021), where early home-based PC reduces costs at end-of-life. Finally, as part of another EU-funded project (PACE) focused on the provision of PC among older people, it was demonstrated that this intervention was cost-effective as a model of timely PC maintaining the patients' quality of life and significantly reducing medical costs at the end of their lives by reducing the number of nights hospitalised (Wichmann, et al., 2020).

- **Stigmas of PC and associated costs**

The taboo and stigma revolving around palliative care does have a direct impact on the cost of palliative care. These costs are both social and financial, namely by making the access to palliative care fall to later and more complicated stages of the morbidities, which implies more complex support and care needs; and by centreing the care model on hospital provided care. Also, the lack of sufficient beds in palliative care has a high impact on the general costs. Palliative care patients for lack of immediate adequate and proper responses to their needs, stay in general care occupying beds from other patients in need of immediate hospitalisation.

- **Scarce medical resources for PC patients**.

It is necessary to increase the number of medium-long stay hospitals and nursing homes in PC programs in order to reduce burnout in primary care and increase the QoL of patients and caregivers. It is worth mentioning that although during the worst part of the COVID 19 pandemic the healthcare workforce was reinforced temporarily by employing doctors and nurses, this was only a temporary solution.

Situation in Greece

In Greece, palliative care is not covered by the National Health System (ESY). However, there are private care homes that offer palliative care services, which may come at a cost to the patient or their family. It is important to note that the cost of palliative care can be substantial, particularly if it is provided in a hospital setting or if the patient requires a high level of care. This can place a significant financial burden on families, especially if they are already facing

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

other challenges such as loss of income or high medical expenses. To address this issue, some organisations and scientific communities in Greece are working to improve access to palliative care and to provide support and resources to those who need it, regardless of their ability to pay.

Situation in Highland, UK

Specialist palliative care services are well established in Highland. Nevertheless, the majority of palliative and end of life care is still delivered without specialist services, or with minimal specialist input. Recent work to quantify the cost of palliative and end of life care has been carried out by Highland Hospice. It is estimated that people in the final year of life account for:

- 1 in 3 hospital beds in use
- around 70% of emergency admissions to hospital
- around 50 % of care home and care at home costs.

In addition, persons with palliative care needs are also served by specialist palliative care services and by general practitioners, community and district nursing and allied health professional services. Taking into account the above level of service use, it is estimated that NHS Highland spends more than 15% of its total annual budget on persons with palliative care needs. This equates to £150 million annually by NHS Highland. However, this figure does not take into account the additional costs associated with informal / family care and third sector services which support patients and families. In particular, where family members are acting as carers (through choice or necessity) there may be associated loss of earnings and reduced economic activity, which may persist beyond the caring period. Good quality specialist palliative care which supports individuals, and their families has potential to reduce these costs. There is a need to adequately quantify these costs in the UK (Gardiner C, 2018).

5.2. Recommendation to increase funding for early palliative care

To ensure a better cost-effectiveness provision of palliative care policy makers and decision-makers should:

Member states should recognize the importance of early palliative care in improving patient outcomes and reducing healthcare costs and invest in research on the topic of cost-effectiveness in PC and ensure data availability to facilitate evidence-based decision making.

Policy makers should initiate national policies to address the workforce needs and payment models in palliative care services, facilitate the provision of palliative care by multiple private sectors and provide financial support to informal caregivers (families), as well as bereavement services as a preventive mental health approach.

Policies in the provision of palliative care and social protection associated should be developed hands in hands between the private providers and public health sector so to

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

ensure the most appropriate financial protection ensuring access to palliative care services for all.

Member states should implement cost analysis in all settings offering PC services. This cost analysis would be possible only with the implementation of a routine screening for palliative care needs to identify patients who could benefit from early palliative care, with the implementation of a monitoring of KPIs to perform quality assessments and optimise resources accordingly (for instance annually).

6. Diverse legal context in Europe

Through the survey distributed to AGE members some answers were supporting the lack of laws in Europe to support the accessibility of Palliative Care :

"In Poland, where I live, persons with dementia are not provided access to palliative care, simply because of the law, which is based on a limited list of diseases" Poland.

"*Performance indicators and evaluation of the Services provided must be available to the public.Legal support should be provided to be able to fine or close the premises not respecting the right of older persons"* Cyprus

"In Germany, there are a lot of regions without palliative care available (although we have a legislation for the right to palliative care)" Germany.

This section provides a European overview of the legal context of legislation around the provision of palliative care in Europe.

6.1. European overview of regulations around PC provision

- **Relationship between the existence of legal rulings and the healthcare system**

Currently in Europe there is no clear agreement on whether strict and formal regulations contribute to developing better PC services (EAPC, 2019). In this sense, a comparative study has been performed in the context of InAdvance, exploring the relationship between the existence of PC legal provision and consequences on PC implementation, with a special focus on early implementation of PC.

The Netherlands – Best practices of National guidelines for Palliative care
The Atlas of Palliative care published by the WHO, points out that it is one of the few countries across Europe which has not enacted any legal ruling on PC service implementation (EAPC, 2019). Furthermore, it is also one of the countries featuring modern and advanced euthanasia bills, which has been seen as a source of discussion for academia (Gordijn & Janssens, 2004). The provision of palliative care in the Netherlands follows the guidelines of

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

"**Netherlands Quality Framework for Palliative Care"** (IKNL/Palliactief. , 2017), which seeks to develop a set of quality standards to be implemented by both GPs and PC specialised teams. These guidelines cover the different domains to be considered when implementing PC: core values and principles; structure and process; physical, psychological, social and spiritual dimension; end-of-life care; loss and bereavement; cultural aspects; ethical and legal aspects. Guidelines also consider early identification and advance care planning. Nevertheless, there is no formal mechanism to get the guidelines effectively implemented. The dutch healthcare system is governed by five general laws (the Public Health Act, the Long-Term Care Act, the Social Support Act and the Youth Act), as well as regulatory frameworks on specific aspects (Individual Healthcare professions act, the Health Insurance Act and the Care Quality, Complaints and Disputes Act). Despite these legal provisions, references to PC are absent, and they should be interpreted as belonging to more general terms e.g.PC services are included within the "agreement regarding medical treatment" (*overeenkomst inzake geneeskundige behandeling*), which is contained in Article 446 of the Dutch Civil Code Book.

United Kingdom with a focus on England and Scotland

Situation in England, UK

Significant inequalities regarding the access to PC services have been reported across England. There is an exclusion phenomenon considered as "postcode-lottery", since the inequalities could be easily retraced according to the geographical area (Cicely Saunders International, 2022).

Despite those issues, England has been acknowledged as one of the top-ranking countries on PC provision, since it belongs to the list of the 30 countries equipped with "Palliative care at advanced stage of integration", as classified by (Clark, et al., 2020). This good performance from the UK, as for the Netherlands, has not been based on an extensive legal PC framework. The Health Committee of the House of Commons pointed out that provisions contained in the 2005 Mental Capacity Act were not meeting the expected quality goals (House of Commons., 2015)and particularly for Advanced planning, which should be one of the essential aspects of end-of-life treatments, since it requires healthcare professionals to implement decision-making processes based on prognosis reports. After receiving some criticism, the Health and Care Act 2022, which came into force last 28th of April 2022, amended the general functioning of the NHS Commissioning Board. From now on the legal body "NHS England" is responsible to "*Arrange for the provision of services for the purposes of the health service in England in accordance with this act, and Exercise the functions conferred on it (…) in relation to clinical commissioning groups so as to secure that services are provided for [those] purposes in accordance with [this Act]*", and that encompass PC. PC provision is now legally integrated into the general health service to be provided "*such other services or facilities for palliative care as the board considers are appropriate as part of the health service*".

Therefore, the United Kingdom will be a research area of the utmost interest, since such a normative up-scaling can be the starting point of new studies focusing on how it has impacted the implementation stage of an already leading PC policy.

Situation in Scotland, UK

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Palliative care is embedded in the Scottish government's National Health policy and, in recent years, has been guided by the Scottish Government's 2015 "Palliative and end of life care: strategic framework for action" (Government, S., 2015). The strategy's guiding vision is to achieve access to palliative care for all who need it. Of particular relevance to the InAdvance project are the commitments within the strategy to improve identification of those who can benefit from palliative and end of life care; and to ensure access is available to all who need it, regardless of diagnosis . Furthermore, the strategy recognises the need to improve care coordination and to improve education of health care professionals. It also commits to facilitate public and personal discussion of death, dying, bereavement and end of life care.
These priorities reflect those which have been identified through the implementation of the InAdvance project activities in Scotland. Encouragingly, the strategy also places significant emphasis upon the gathering and evaluation of evidence relating to all aspects of current SPC provision and the establishment of a "Scottish Research Forum for Palliative and End of Life Care".

Specialist palliative care services in many areas of Scotland are delivered by independent Hospices which operate out with the National Health Service (NHS).

Such independent Hospices are regulated by Healthcare Improvement Scotland which inspects services to ensure compliance with relevant legislation and guidelines, including The Health and Social Care Standards (Scotland, H. I., n.d.).

Example of Greece and absence of regulations
Greece has obtained a poor score in PC-related rankings such as the Quality of Death (Economist Intelligence Unit, 2010), where it is ranked at the 29th position (right above South Africa) and as the second worst Western European country.

According to the Stavros Niarchos Foundation, (Stavros Niarchos Foundation, 2019), around 135,000 people are calculated to be in-need for PC services before and at the end of life in Greece. This issue has not received any institutional response yet and can be partially due to "*the lack of a suitable legislation that would recognize the need for adult, and childhood PC services both within the community and the health care system*"). Indeed, there is no legal structure in the country for the delivery of palliative care. The existing legal framework makes it very difficult and costly to establish hospices or other palliative care institutions like day care facilities. It is crucial that a legal framework will be established collaborating with the primary care and hospital care systems that are already in place. There should also be an allocation of budget for palliative care specifically.

Therefore, the legal framework governing PC in Greece should be approached in order to identify and characterise the setbacks it may produce. According to the regulatory outlining of the report PC rules could be summarised within two legal provisions. First, the reorganisation of the National Social Care System should provide the legal basis so public bodies and civic society can create and run proper palliative facilities. Currently the provision allows establishing such facilities, but not specifically for PC provision. Then the Code of Medical Ethics enacts the mandatory requirement aimed at healthcare professionals to include treatment responses to patients' psychosomatic pain. This wide-scoping definition

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

also encompasses the provision of PC services to ensure dignity and quality of life until the end of the patients' life. These "regulations" are neither sufficient nor suitable to respond to the needs. Despite attempts to develop a statutory framework for PC, through the Inter-ministerial Decision - regarding the conditions and specifications for the development of PC services, ministerial decisions never have been implemented.
There should be clear regulations and procedures for the organisation and operation of: outpatient clinics and day centres; departments with available beds for Palliative Care in hospitals; advisory groups within hospitals, including health and social care professionals specialised in the provision of Palliative Care.
Private facilities should be provided with licences and regulations to provide palliative care, in collaboration with hospitals to ensure the excellence of these services for the patients.

In accordance with the existing legal framework, patients do not have the option to express their wish to not be resuscitated without criminal consequences. There is also no statutory framework for issues related to advance wishes regarding care (mental capacity to make decisions, proxies for decision-making, futile treatment, terminal sedation). Issues like disclosing bad news, understanding the wishes of patients and their families for care, especially at the end-stage care, procedures that ensure pain reduction, patient autonomy, and self-respect. Issues related to the most common bioethical dilemmas in palliative care need to be highlighted, debated and addressed with due care, such as disclosing unpleasant news, understanding the wishes of patients and their families for care, especially end-stage care. and procedures that ensure pain reduction, patient autonomy and dignity.

Portugal
The Portuguese care system could be seen as an interesting case study of PC regulation and this country has one of the most developed legal frameworks for PC provision across all Europe. However, Portugal has deployed a significantly poor performance in the last years, as registered by the Economist Intelligence Unit (Economist Intelligence Unit, 2010), despite its satisfactory institutional design. This weakness has been widely exposed by different authors (Duarte, Guedes, Miranda, & Fonseca, 2018) (Gomes, Brito, Lacerda, & A., 2020).

PC was firstly introduced through 2006 Decree Law 101/2006 as an essential component of integrated continuous care (article 5.2). Furthermore, its provisions are explicitly aligned with the 'National Palliative Care Program', which was also based on the European Association of Palliative Care recommendations.

The Portuguese Assembly of the Republic published Law No. 52/2012 which established the right and regulated citizens' access to palliative care, defined the State's responsibility for palliative care and created the National Palliative Care Network (RNCP), to operate under the Ministry of Health. Additionally, this Law advocates for a comprehensive definition of PC:

Palliative care is active, coordinated and comprehensive care provided by specific units and teams, in hospital or at home, to patients suffering from incurable or serious illness in advanced and progressive stages, as well as to their families, with the main objective of promoting their wellbeing and quality of life, through the prevention and relief of physical, psychological, social

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

*and spiritual suffering, based on **early identification**.*

However, there is a gap between what is contemplated by law and what happens on the field, as practical implementation presents its barriers. This is visible mainly through the lack of human resources available, due to the scarcity of specific training, to the lack of conditions for the provision of care in the Palliative Care area and the economic barriers preventing the teams from fully functioning.

Spain with a focus on the Valencia region

The access to Palliative Care as well as the rights involving a dignified death is regulated at different levels in Spain and in the Valencian Community. **PC is covered by the national healthcare system**; this is supported, among other regulations, by the following regulations: Law 14/1986, April 25, General Health Royal Decree 1030/2006, September 15, which establishes the portfolio of common services of the National Health System and the procedure for updating it[3]. When analysing the specific content of this Royal Decree, two references to PC can be found. Both mentions share a common PC definition:

*PC includes comprehensive, individualized and continuous care for people with advanced illnesses, who are not susceptible to curative treatment and have a limited life expectancy (generally **less than 6 months**), as well as the people around this situation. Its therapeutic objective is to improve their quality of life, respecting their belief systems, preferences and values.*

This definition lacks essential aspects of the current definition and approach to PC, which is, mainly, the provision of care regardless of the patient's life expectancy.

From the beginning of the InAdvance project, different regulations have been published in this context: Euthanasia has been legalised in Spain from June 25, 2021, when the Organic Law for the Regulation of Euthanasia came into force. The law responds to the demands of Spanish society. The Spanish law 3/2021 [4]permits two voluntary means of allowing a person to end their own life: euthanasia and assisted suicide. To request either, the person must (i) suffer a "serious or incurable illness" or a "chronic or incapacitating condition" that causes "intolerable suffering" (ii) be an adult Spanish national or a legal resident (iii) be "fully aware and conscious" when they make the request.

Thus, the new law recognises the right to people to end their own life in the above-mentioned circumstances and establishes the process to be followed for patients and professionals.

At an Autonomous community level: in 2021, the Royal Decree 180/2021 [5]was published aiming at updating the principles that must govern the advance directive of each person. It establishes for the first time the requirements for the Advance Care Planning Procedure.

[3] Royal Decree 1030/2006, September 15, Establishment of the portfolio of common services of the National Health System and the procedure for updating it.

[4] Organic Law 3/2021, March 24, Euthanasia regulation.

[5] Royal Decree 180/2021, November 5, regulation and updating of the advance directive in the Advance Care Planning procedure into the Valencian Community.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Within the package of actions foreseen in the 2nd intervention, action number 9 aims to *"Establish standardized action protocols to manage complicated situations such as: comfort care options, treatments or therapeutic intensities"*, which is fully related to Advanced Care Planning processes.

As a conclusion, there is no strict causality pathway between the development of legal frameworks and the actual performance and provision of PC services. Strong legal frameworks have been detected in Portugal, but there is a clear deficiency in the provision of these services towards the population. And, on the contrary, there are cases with excellent performance indicators on PC provision that are not accompanied by well-established legal regulations, as proven in the Dutch and British cases. However, the relative importance of legal provisions when it comes to organising healthcare assets and facilities should not be disregarded. Considering a comprehensive PC approach, it should be also assessed how stages prior to the implementation of legal frameworks are actually designed.
Therefore, legal frameworks remain relevant to setting the basis for specific implementation programmes, which could be shaped as National Plans or Quality Frameworks. This is especially useful when approaching multilevel or decentralised governments, where healthcare policies may not be designed by the same offices/ministries all over the country, as in the Swiss case.
The development of a legal basis for PC might not derive on outstanding effects by itself, as shown in the Portuguese case. However, it may be an interesting starting point for systems lacking strong institutional support, as in Greece.

Going to the specific InAdvance approach to implement PC, not all the countries analysed contemplate the early provision of PC. The Netherlands and Portugal consider this early-stage identification, as well as Belgium also adding the importance of providing this type of care regardless of patients' life expectancy. On the opposite side, Spain remarks that PC should be addressed to persons with limited life expectancy, and even suggests a very limited timeframe for that referral (usually less than 6 months).

6.2. Recommendation to regulate the provision of PC

In the field of recommendations to regulate the provision of PC, it is strongly recommended to act in two main areas. First, policy and decision-makers should **support and set the necessary laws, standards and guidelines for PC**, including early-stage attention and the recent definition of PC. In this regard, laws should be drafted with public participation and dissemination, complying with society's and healthcare professionals' needs. Furthermore, laws should not be considered stand-alone. On the contrary, they should be accompanied by indicators, pathways, trajectories, provisions, monitoring plans, and tools to ensure success.

Secondly, it is paramount to **integrate PC into care plans and regulations towards non-communicable diseases**. This is especially relevant in decentralised healthcare systems to avoid geographic inequalities. Efforts should be directed to embed PC in all acts, strategies, treaties, regulations, and laws involving healthcare systems and older people.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

On the other hand, it will be effective to have a common EU Palliative Care Platform. Following the Swiss model (OFSP, s.d.), the EU Palliative Care Platform would promote the debate, best practices and exchanges between crucial actors and networking, also identify relevant themes and current challenges. It would also be focused on coordinating the ongoing work to bring together the relevant actors, ensure knowledge transfer, draft recommendations, and make basic knowledge available.

An implementation and assessment framework should accompany previous recommendations to ensure PC is correctly provided in time and manner. For this, national, regional and local decision-makers should develop the laws, regulations, guidelines and indicators to ease the PC implementation and the mechanisms to assess and regulate this implementation qualitatively and quantitatively.

7. Societal benefits if policy action is taken

Caring for those nearing the end of their lives in a respectful and individualised manner is one of the ways that a state can, and should, demonstrate its humanity.

Should the recommendations have been implemented, the following benefits for society will arise:

Rights of older people are respected: older people will have access to better and more targeted services, tailored specifically to their needs. No one will be left behind. The right to receive appropriate health and social care provision will be respected: the user of health services is entitled to receive, promptly or within a period considered clinically acceptable, depending on the case, the health care needed. The user of health services is entitled to the provision of the most appropriate and technically correct health care. Finally, health and social care must be provided humanely and with respect for the user.

Decrease of costs with care: supporting the patient's emotional wellbeing should increase their quality of life and empower health self-management, improving the adherence to the treatments and avoiding costly exacerbations. Addressing individual priorities makes **better use of resources and improves efficiency within health and social care services.** Providing personalised care which meets individual needs **reduces economic impact for families and wider community** related to supporting a patient with palliative care needs.

Improve professional well-being with **better working environments and conditions** for health care professionals. Providing holistic and early palliative care which is tailored to individual needs not only supports the patient themselves, but **also benefits the emotional and physical wellbeing of carers.** HCPs will be equipped with better tools **to timely and accurately refer patients to PC care**. Providing adequate and timely palliative care which addresses a person's needs and priorities, reduces moral injury in health care practitioners (this occurs when HCPs are aware of their inability to provide the care that the patient really needs and that they want to give). This would impact directly in the delivery of quality public

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

health services that would be translated to a satisfaction of professionals and the population involved.

Measuring Quality of Life: Patients and their caregivers will be more empowered and will be able to take part in the decision-making process, **increasing the QoL of patient and carers,** which will be measurable through real-world comparisons between palliative and standard care. A standardisation of common criteria to include patients in PC programs, that can mean a decreased use of acute healthcare services, such as visits to emergency departments. This strandardisation will improve practices in Europe through peer sharing.

8. Methodology used to draft these policy recommendations

During the last two years, various stakeholders contributed to the production of these policy recommendations.
The drafting of the recommendations started from the analysis of the results of FG conducted at the very beginning of the project in each of the pilot sites with health and social care professionals directly in contact with patients in need of palliative care.

During the second semester of 2022, an internal workshop with InAdvance project partners presented the draft recommendations to different 22 healthcare institutions, thus involving different professionals in contact with older people in palliative care. The workshop helped consolidate the common challenges encountered at the various pilot sites with the reality on the ground varying according to the pathologies and the settings where palliative care services are provided, and helped exchange good practices and evidence to bring solutions at national level.

In parallel, AGE Platform Europe launched a consultation with its members and particularly with the members of the Task Force on Dignified and Healthy Ageing. A survey both on paper and in an online format, was circulated in 2022 to understand the main barriers and facilitators in accessing palliative care for older people in their respective countries. 26 completed surveys were received representing 17 different European countries.

The results of these 3 contributions (pilots' focus groups, consultation of European stakeholders, survey to European older people) made possible the identification of the main issues for the different stakeholders:

1. Palliative care is neither available nor accessible for all.
2. Education and public awareness about Palliative Care is lacking.
3. Non-person-centred care leads to late identification of needs.
4. Fragmentation and discontinuity of care.
5. Cost-effectiveness of early admission to Palliative Care.
6. Diverse legal context in Europe.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Moving from the challenges to the solutions, each clinical sites contributed with good practices at local level and the recommendations; partners also worked on the benefits to society if action is taken. AGE Platform Europe consolidated such work into the policy recommendations presented in this deliverable.

The methodology followed in the drafting of the recommendations ensures the reflection and inclusion of suggestions from different points of view, creating a first attempt and hopefully can be the basis of an open dialogue at national level.

9. Dissemination of the policy recommendations

The short version of the policy recommendations available in annexes has been disseminated to all stakeholders involved in the project and more specifically the ones involved in the consultative workshop and the project's final event.

The short version was published through different channels: social media of the InAdvance project and from all partner organisations. At European level, AGE share these policy recommendations in its newsletter and website, reaching over 2000 stakeholders. The blogpost of InAdvance dedicated a full article on the recommendations, reaching around 110 views. At national level, partners translated and disseminated the short version of the recommendations to their affiliated organisations working on the field of palliative care or with older patients in general, informing and disseminating the need of early PC.

The consultative workshop (March 2022) was an opportunity to bring together stakeholders interested in the early provision of palliative care for older people, who also wanted to highlight the need for palliative care in advance. This workshop (see report in annexes of this document), with AGE, UV, EMC, NHS HIGHLAND and AUTH as project speakers, took place at the European Economic Social Committee (EESC) and brought together representatives of European networks- representatives (members of the coalition on Long Term Care - see above) and AGE members. More specifically, the organisation represented were:

- Trade Unions, with the participation of UNI Europa and EPSU the European Federation of Public Service Unions.
- Organisation representing carers, with the participation of Eurocarers, the European Hospital and Healthcare Federation (HOPE) and the European Ageing Network.
- Scientific community, with the presence of the End of Life Care Research Group.
- Organisation representing citizens, with the participation of Caritas Europa and the European Network on Independent Living representing people living with disabilities in Europe.
- Oranisations representing older people in Europe, and AGE members: Association des retraités d'Airfrance, Pensionisten Verband, FNAR Association Nationale des Associations des Retraités Older Women Network and the Union Française des Retraités.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

As a result of the various discussions and opinions coming from a variety of stakeholders in the EU, over 120 comments and suggestions received during the workshop were considered and a new version of the recommendations was produced. The event was disseminated through InAdvance social media channels (LinkedIn post and Twitter) and through a blog article on the website of the project. The event was also disseminated through social media channels of the project partners (AGE, Polibienestar). Visibility was provided also through AGE newsletter and website, reaching over 2000 stakeholders. A report has been shared to the EESC to be disseminated on their website and social media channels.

The policy recommendations were moreover presented at the project's final event which took place on 10th of May 2023 in Brussels. The conference was held in person and gathered 28 representatives from social and health care, academia, patient associations, policy makers and the general public with an interest in palliative care. On this occasion, the policy recommendations were disseminated again through social media channels and shared by project partners.

The work of disseminating the recommendations will continue after the end of the project, as several key political events are scheduled in the EU in the following months, specifically in the context of EU Care Strategy. Seeking a larger impact in the advocacy work from civil society to be fairly represented in the EU Care Strategy, AGE is leading the Civil Society Organisation (CSO) coalition on Long Term Care (LTC). This coalition is an ad-hoc coalition of organisations representing:

- Persons in need of care: European Disability Forum (EDF), AGE Platform Europe, the Platform for International Cooperation on Undocumented Migrants (PICUM), European Women's Lobby, European Anti-Poverty Network (EAPN), COFACE Families Europe, Make Mothers Matter, Social Platform, UNI Europa, European Association of Paritarian Institutions (AEIP), European Roma Grassroots Organisations Network (ERGO), Caritas Europa.
- Informal carers and care workers, care providers (public, not-for profit and cooperative): Eurocarers, European Association of Service providers for Persons with Disabilities (EASPD), Eurodiaconia, European Public Service Union.
- Not-for profit insurers: The International Association of Mutual Benefit Societies (AIM),
- Public health and health promotion actors: The European confederation of industrial and service cooperatives (CECOP), EuroHealthNet.

The members of this civil society coalition were mobilised to ensure the success of the European Care Strategy, leading to the development of universal and better-quality long-term care systems, rooted in the right to independence, people's preferences, dignity, affordability, accessibility, and universality. The coalition also believes that improved working conditions for care professionals and better recognition and support for informal carers and families are a prerequisite to ensure universal and quality social protection against long-term care risks.
A letter was addressed to the European Commission in July 2022 calling for the resolution of the European Parliament towards a common European action on care.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

The Council adopted the recommendations in December 2022. Unfortunately access to palliative care is not yet encompassed by the strategy. Member states are now expected to provide their national action plans, responding to the recommendations adopted. National long-term care coordinators (LTC) and contact points were appointed by Member States for the implementation of the Council Recommendation on access to affordable high-quality long-term care. Long-term care coordinators kick-off meeting was held the 19th of June 2023 where most mentioned challenges were discussed. The "development and/or modernisation of needs assessment tools" was listed as the second priority, on the eight challenges highlighted. This is a great opportunity for InAdvance to be presented as a best practice to be replicated in the EU and be part of the national action plans of member states.

To pursue this advocacy work, the project can count on the following occasions, beyond its life-span:

1. AGE members part of the Task Force on Active and Healthy Ageing will meet in December 2023, and InAdvance policy recommendations will be an agenda item, for investigating further action for their implementation at national level. InAdvance recommendations are a best practice which can be used at local level from AGE members. The "easy to read" version is freely available for translation in local language.
2. InAdvance partners can contact their attributed national Long-Term Care coordinator, appoint by Member States, and follow-up.
3. AGE co-ordinate part of the actions of the CSO coalition on LTC. InAdvance recommendations are kept on the agenda of the Task Force's meetings thanks to the involvement of AGE together with The Social Platform Task Force (TF) on the EU Care Strategy, of which AGE is member,

Another opportunity for the dissemination of the recommendations is a possible exchange between the TF on EU Care strategy and the Social Protection Committee (SPC) Indicators Subgroup. This subgroup is in charge to develop and define EU social indicators to monitor member countries' progress towards the commonly agreed objectives underpinning the Open Method of Coordination for social protection and inclusion. The exchanges will be an opportunity to push the process to have indicators specifically developed for the EU Care strategy, including indicators for Quality, Affordability, Accessibility but also Capacity. AGE will push to include indicators on palliative care provision.

Two upcoming events will be particularly important for the dissemination of the policy recommendations for 2023.

The European Economic Social Committee will hold a conference in the framework of the Spanish Presidency of the EU to discuss and present the political avenues for a European strategy for older people, drawing on the lessons and policy tools that have succeeded in supporting other groups at risk of exclusion across Europe over the years. This event will be open by AGE president, Heidrun Mollenkopf, and followed by several policy makers (commissioners, EESC rapporteurs, members of the EC cabinets). A session on Future of EU policy on older people is dedicated to what policy tools can be designed to generate/foster a

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

society of active and healthy older people. AGE will be participating and provide participants with easy-to-read InAdvance recommendations.

The World Bank is organising a Workshop on transition to community-based care in Poland early December. AGE will be in the organisation and will take the opportunity to share the policy recommendations.

AGE is also planning to answer to a written contribution and stance for oral statements to the Open-Ended Working Group on the right to health and health services and to contribute to the WHO Europe consultation on the forthcoming 'Framework of Action for Healthy Ageing'. Consultation will include recommendations from InAdvance, whenever it is possible.

Dissemination work will continue in line with the European political agenda. Disseminating the recommendations is a long-term project, and is also part of AGE's advocacy work. As such, the recommendations will be promoted at policy development events, consultations, events or any other opportunity to push for early provision of palliative care, especially for older people.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

10. Conclusion

In conclusion, InAdvance policy recommendations provide policymakers with the tools and action to be taken to make change happen for early detection of palliative care for older people. Thanks to the inputs from activities realised at pilot sites level for InAdvance and the feedbacks received through the consultations made during the project, the following policy recommendations for early palliative care for older people are proposed:

1. **Improve the adequate provision of Palliative care in Europe:** Develop policies that ensure the accessibility of PC services for anyone, especially for older people suffering from chronic diseases and non-oncological patients. This should be done with a better and earlier assessment of the needs to provide care in adequacy.
2. **Education and Training, Public Awareness Campaigns**: Develop policies to enhance the education and training of health and social care professionals, including informal carers; Offer specialised training, programs, master's degree and continuing education opportunities to improve the knowledge and specific skills needed when working for older people; e.g empathic skills. Launch public awareness campaigns to educate citizens, older people, their relatives and families about the benefits of early palliative care. Address misconceptions and promote open discussions about preferences, advance care planning and the importance of quality of life until the end.
3. **Timely Person-centred care**: Develop policies that encourage professionals to assess patients palliative care needs during routing evaluations, taking into account physical, psychological and spiritual aspects. Support a community-based approach ensuring the promotion of education and skills for development for community-based health care professionals. Foster policies that emphasise the integration of palliative care into the standard care pathways for older people across various health care settings, including hospitals, long-term care facilities and community-based care.
4. **Continuous and holistic approach in the provision of palliative care:** Implement policies to ensure continuity of care between different PC settings, ensuring the coordination and implementation of integrated models for patients and relatives. Open a dialogue involving all stakeholders to understand expectations improving quality of life of patients, health and social care professionals and families.
5. **Fundings and cost-effectiveness of early palliative care**: Advocate for policies that ensure adequate funding and reimbursement mechanisms for palliative care services targeting older people. Support cost-analysis in all PC settings when implementing the screening routine of early identification of palliative care needs, monitoring the performance and optimising the resources accordingly.
6. **Legal provision and regulations:** Support and set the necessary laws, standards and guidelines for the early-stage attention of PC. Integrate PC into care plans and regulations towards non-communicable diseases.

Several aspects peripherally related to the early provision of palliative care emerged over the course of the InAdvance project and the elaboration of this policy recommendations. They were not at the core of the project but may provide food for thought for further research. The

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

ecological approach could be interesting to address to improve the management of the waste generated by health-care activities at home. The gender perspective for caregiving. Historically, relative's caregiving has been associated with women; however, as a consequence of demographic and sociocultural changes, men are increasingly taking on the role of a family caregiver. All this suggests the need of studying in-depth gender differences regarding informal caregiving, especially in the end-of-life stages, when the burden of care is usually heaviest. It might be interesting to reflect carefully on historically widespread beliefs. For example, to consider that the home is the best place to die or to tie in dying in the hospital with an undignified death.

Through the recent publication of recommendations from the Council of Europe following (Commission, 2022) the communication from the European Commission of the European Care strategy, member states should provide action plans for the upcoming years. These recommendations could be used as a tool to implement best practices at national level and could be included in the national action plans.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Annexes

Easy-to-read version of policy recommendations

EARLY INTEGRATED PALLIATIVE CARE
For older non-cancer patients
POLICY RECOMMENDATIONS

InAdvance

*"We deserve to live in dignity whatever our age, until we die, including during the last years of our lives" **

Only 19.2% of older people consulted are aware of the palliative care services they could receive*.

What are the gaps ?

Adequate palliative care in Europe **is not always accessible or affordable,** especially for older palliative care patients (for instance, due to ageism) suffering from complex chronic diseases other than cancer. **Education and public awareness** are lacking behind and lack of **integrated and person-centred palliative care** increase costs substantially due to **the late identification of palliative care needs.**

Where do we want to go?

Removal of taboo and stigma around palliative care. Living with dignity until the end would become the norm.

Informe the general public of possible options and the **benefits of early detection of palliative care needs,** including health and social care professionals, patients and their families.

Implementing a **holistic, integrated and early approach to palliative care.**

Empowerment of older people, health and social care professionals, including informal caregivers, through **clearer information and supporting solutions** (eg. guidelines or technologies).

**Conclusion from a consultation conducted with AGE Platform Europe members on the earlier provision of palliative care through InAdvance project.*

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

InAdvance

Recommendations to get there

Invest in early and broader palliative care education

1

- Raise public awareness through campaigns to reduce the stigma around palliative care and the taboo around death.
- Invest in the education for older people, their relatives and caregivers providing information about symptoms, prognosis and care options earlier and better.
- Invest in continuous training for healthcare professionals, including compassionate skills and older patient-centred family focused care.

Empower older people and their families

2

- Promote the active participation of patients and informal carers in the decision-making process, establishing personalised future local pathways and plans.
- Provide financial support to informal caregivers (families), as well as bereavement services as a preventive mental health approach.

Coordinate and Integrate Care

3

- Boost the development of an organisational system that ensures coordination between health and social care professionals.
- Implement a routine screening for needs to identify patients who could benefit from early palliative care, moving from an isolated decision-making to a joint and multidisciplinary referral process.

Set legal provision and indicators

4

- Develop laws, regulations, guidelines and indicators in line with these recommendations to facilitate palliative care implementation.
- Create mechanisms to assess and regulate qualitatively and quantitatively the provision of palliative care

Cost-effectiveness of early identification

5

Early palliative care does not only improve patient outcomes but also reduces health care costs. Member States should implement cost analysis in all settings, recognizing the importance of early palliative care in improving patient outcomes and decentralising costs.

Member states should share practices

6

Create an EU Palliative Care Platform aimed at providing clear and accessible research-based information about care provision, to promote the debate, encourage the sharing of best practices and exchanges between crucial actors and networking

To access additional information, please visit InAdvance website
https://www.inadvanceproject.eu/

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

InAdvance policy recommendations

Workshop with EU stakeholders

Report EESC

On 14 March 2023, the EU-funded InAdvance project organised in partnership with the European Economic and Social Committee (EESC) a workshop with 22 people on the project's policy recommendations with EU stakeholders. The InAdvance project proposes a new model of palliative care based on early detection and personalised care pathways addressed specifically to older people with complex chronic conditions.

The first draft of the policy recommendations aims to create awareness of the need to provide earlier palliative care to older people who need it. It is based on the firsts results of the InAdvance project with a specific focus on the results obtained in the pilot sites. An excerpt of this draft focusing on the recommendations formed the basis for discussions at the workshop.

The InAdvance palliative care policy recommendations are drafted in the EU Care strategy context and its recommendations on affordable high-quality long-term care adopted by the Council in December 2022. The long-term care recommendation proposes to Member States actions to make care more accessible, affordable and of better quality but does unfortunately not mention palliative care specifically.

Ms Zoe Tzotze-Lanara, Greek member of the EESC and rapporteur of the EESC's Own-Initiative Opinion on the "Health Workforce and Care Strategy", as well as co-rapporteur on the "European Care Strategy", provided in her speech the framework for the workshop and highlighted how the European Care Strategy's cohesive framework for EU Member States will lead to upward convergence. She also emphasized that providing accessible, available, affordable & inclusive high quality care is a litmus test for social rights, for human rights in Europe and the success of the EU Care Strategy.

The policy recommendations drafted by the InAdvance project are very well in line with the points highlighted by Ms Zoe Tzotze-Lanara and are structured according to the following topics:

1. Palliative care is neither available nor accessible for all;
2. Education and public awareness about Palliative Care is lacking;
3. Non-person-centred care leads to late identification of needs;
4. Fragmentation and discontinuity of care;
5. Cost-effectiveness of early admission to Palliative Care;

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

6. Diverse legal context in Europe.

The recommendations were discussed in small groups in a round table format, allowing every participant to provide their feedback on each topic.

On the recommendations for an adequate provision of Palliative Care for older people (Topic 1. Palliative care is neither available nor accessible for all), participants highlighted that (social care aspects of) palliative care is often not covered by insurance when it should be integrated into public health systems. The lack of professional care workers and clinicians who are key in the early identification for the need of Palliative Care, as well as missing social schemes for informal carers to support their needs, were also discussed.

Concerning education (Topic 2: Education and public awareness about Palliative Care is lacking), participants agreed that generalists and specialist HCPs require regular Palliative Care trainings (including communication and empathy skills) and students in medical professions need to be taught empathy and soft skills. Education should also target the public in general, in addition to older people and their carers and families, to alleviate fears that may be connected to the topic of palliative care.

The discussions on early person-centred care (Topic 3. Non-person-centred care leads to late identification of needs) revolved around the different issues that are obstacles to person-centred care (lack of resources, coordination, quality, time, money, workers, empathy etc.) and participants shared their personal experiences and examples (good and bad practices in early person-centred palliative care provision) from different countries. In this context, a reference was also made to Article 18 on long-term care of the European Pillar of Social Rights. Decentralisation as a recommendation to implement early person-centred care was met with some scepticism, as participants doubted the feasibility.

In terms of integrated care (Topic 4. Fragmentation and discontinuity of care), many points were already discussed in the context of person-centred care. Participants agreed that here the focus needs to be on the national and regional level but that qualifications should be recognised across countries.

Concerning cost-effectiveness (Topic 5. Cost-effectiveness of early admission to Palliative Care;), a number of participants emphasised that cost reduction should not be the main objective in palliative care but rather to focus on other objectives such as quality.

Discussions on the legal basis for Palliative Care (Topic 6. Diverse legal context in Europe) looked at Palliative Care in the context of long-term care – in particular the EU Care strategy – and at strengthening existing national frameworks and their implementations (recognition, training, quality, monitoring, workers' rights).

The active participation of EU stakeholder provided valuable feedback and insights on palliative care from different perspectives which will be integrated in the further elaboration of the InAdvance policy recommendations.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Before and After InAdvance results from the FG interviews from HULAFE pilot sites

Before InAdvance	After InAdvance
Information for patients and families when initiating follow-up in the clinical area	
We used sheets designed when the unit was created (approximately 1991) with very brief information (telephone numbers, schedules, various information organized without clear criteria). Poorly printed sheets.	We updated and agreed on the basic information content for patients and families in the following scenarios: admission to the hospital at home unit, follow-up in case management programs (CMP complex chronic conditions, CMP chronic conditions with palliative care needs). Both editing and content writing are clearer and friendlier, facilitating the information process. These leaflets have been included in the welcome pack (together with the Caregiver's support kit/leaflets).
Assignment of the case management program (CMP). Possibilities: CMP complex chronic conditions or CMP chronic conditions with palliative care needs	
Usual routine: individual criteria of each team/physician.	The use of standard tools (in our case, the NECPAL tool which includes, among many criteria, the Rockwood Frailty Scale) has contributed to a more accurate/homogeneous selection of patients to be referred to the CMP chronic conditions with palliative care needs between all unit teams.
Management of complicated situations such as: comfort care options, treatments (CPR, ventilation, artificial nutrition and hydration) or therapeutic intensities.	
Decision-making processes related to specific care scenarios (comfort care options, treatments and therapeutic intensities) were carried out at the discretion of the individual physician/team. The records related to this decision making were made in the standard daily chart (this makes it difficult to locate this information after a certain period of time) or in sections of the medical record not intended for this purpose (administrative sections, sections for general notes, etc.).	A specific section in the electronic medical record for advanced care planning processes is available. This section has a linked alert to facilitate access to this information. The registries related to advanced care planning processes include: the criteria of therapeutic intensity (defined by the Rogers Memorial Veterans Hospital), specific treatment measures, preferences for place of care, among others. In order to homogenize the decision-making processes with patients and families among teams, we have used
Personalized follow-up of patients and caregivers reinforcing several issues such as symptom assessment, clinical swing phase changes, caregivers' skills and caregiver well-being.	
In the case of chronic patients, there was usually an initial handover between the HaH and the nurse case managers. After that, patients were not usually reviewed together, periodically and proactively (it used to be done reactively, after some severe clinical episode).	As a result of the RCT, and in particular the need to complete the NAT:PD, multidisciplinary meetings have been held between the HaH unit and the nurse case managers. These meetings have helped us to review and update the needs of each patient, as well as to agree/validate the care plan to be followed.
Provide support to Caregiver's	
Each professional/team was looking for material on their own to reinforce the educational interventions. This was sometimes shared with the rest of the unit or not, much variability among the sources consulted.	Support kits/leaflets with practical caregiving information related to the most common problems/ geriatric syndromes/ care needs as well as caregiver self-caring have been welcomed both caregivers/patients and professionals.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

GLOSSARY

PALLIATIVE CARE

Palliative care, according to the WHO, is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care; • offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

END OF LIFE CARE

According to Mariecurie.org.uk:

End of life care is an important part of palliative care for people who are nearing the end of life. End of life care is for people who are considered to be in the last year of life, but this timeframe can be difficult to predict.

End of life care aims to help people live as well as possible and to live with dignity until the end of life. It also refers to treatment during this time and can include additional support, such as help with legal matters. End of life care continues for as long as you need it.

According to the National Institute on Aging:

End-of-life care is the term used to describe the support and medical care given during the time surrounding death.

ADVANCE CARE PLANNING

According to the European Association for Palliative Care:[6]

[6] https://www.acp-i.org/wp-content/uploads/2018/07/Rietjens-1.pdf

Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.

PERSON CENTRED CARE

Person-centred care[7] , according to Health Innovation Network in London, is a way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs. This means putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome.

QUALITY OF LIFE

WHO defines Quality of Life[8] as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

AGEISM

According to the WHO[9]Ageism refers to the stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) towards others or oneself based on age.

EARLY PALLIATIVE CARE

Early Palliative Care is initiated much earlier in the disease trajectory, and it is not bound to the non-response to curative treatment or evident anticipation of death.

7 https://healthinnovationnetwork.com/system/ckeditor_assets/attachments/41/what_is_person-centred_care_and_why_is_it_important.pdf

8 https://www.who.int/tools/whoqol

9 https://www.who.int/news-room/questions-and-answers/item/ageing-ageism#:~:text=Ageism%20refers%20to%20the%20stereotypes,or%20oneself%20based%20on%20age.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Bibliography

EAPC. (2019). *EAPC Atlas of Palliative Care in Europe.* EAPC Press. Retrieved from https://dadun.unav.edu/handle/10171/56787

Hospice UK. (n.d.). *Dying Matters.* Retrieved from https://www.hospiceuk.org/our-campaigns/dying-matters

Alves, E. M. (2020). *O impacto da resiliência e do ambiente ético hospitalar na perceção de burnout nos profissionais de cuidados paliativos.* U.PORTO.

Bajwah, S., Oluyase, A., Yi, D., Gao, W., CJ, E., G, G., . . . Higginson, I. (2020). The effectiveness and cost-effectiveness of hospital-based specialist palliative care for adults with advanced illness and their caregivers. *Cochrane Database Syst Review*. doi:10.1002/14651858.CD012780.pub2

Behm, B. (2015). *A synthesis of home-based palliative care on clinical effectiveness, cost-effectiveness and quality of life: Policy implications explored.* Georgia State University. doi:doi: https://doi.org/10.57709/7030577

Cafe, D. (n.d.). *Death Ca/fe.* Retrieved from https://deathcafe.com/

Care, E. A. o. P.,. (2022). *Last Aid and Public Palliative Care Education.* Retrieved from https://www.eapcnet.eu/eapc-groups/task-forces/last-aid/#

Cartoni, C., & et al. (2021). Early Palliative Home Care versus Hospital Care for Patients with Hematologic Malignancies: A Cost-Effectiveness Study. *Journal of Palliative Medicine.*, 887-893.

Cartoni, C., Breccia, M., Giesinger, J. M., Baldacci, E., Carmosino, I., Annechini, G., . . . Efficace, F. (2021). Early palliative home care versus Hospital Care for Patients with hematologic malignancies: a cost-effectiveness study. *Journal of Palliative Medicine*, 24(6), 887-893.

Cicely Saunders International. (2022, March 3). *New UK legal right to Palliative Care. Cicely Saunders International*. Retrieved from https://cicelysaundersinternational.org/new-uk-legal-right-to-palliative-care/

Clark, D., Baur, N., Clelland, D., Garralda, E., López-Fidalgo, J., S., C., & Centeno, C. (2020). Mapping Levels of Palliative Care Development in 198 Countries: The Situation in 2017. *Journal of Pain and Symptom Management*, 59(4), 794-807.

Clarkson, P., Davies, L., Jasper, R., Loynes, N., Challis, D., in Dementia, H. S., & Group, P. M. (2017). A systematic review of the economic evidence for home support interventions in dementia. . *Value in Health*, 20(8), 1198-1209.

Comissão Nacional de Cuidados Paliativos. (2021-2022). *PLANO ESTRATÉGICO PARA O DESENVOLVIMENTO DOS CUIDADOS PALIATIVOS 2021-2022.*

Commission, E. (2022). *COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS on the European Care Strategy.* European Commission.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Council of Europe. (2014). Section D, Palliative Care. In *Promotion of Human Rights of Older Persons - Recommendation CM/Rec(2014)2 and explanatory memorandum* (pp. 25-26).

Cruz Rodrigues, H. M. (2014). *Os cuidados paliativos e a intervençao social.* Instituto Politécnico de Viana de Castelo.

Da Silva Aguiar, R. A. (2021). *Reference for Palliative Care (PC) in a differentiated hospital: motivation, challenges and obstacles.* Repositório científico da UC.

Duarte, S., Guedes, M., Miranda, M., & Fonseca, A. (2018). *Direitos dos Doentes em Cuidados Paliativos – da legislaçao à realidade no terreno. .* Ordem dos Médicos. Retrieved from https://ordemdosmedicos.pt/direitos-dos-doentes-em-cuidados-paliativos-da-legislacao-a-real

Economist Intelligence Unit. (2010). *The quality of death. Ranking end-of-life care across the world.* The Economist Intelligence Unit. Retrieved from http://www.lienfoundation.org/sites/default/files/qod_index_2.pdf

Effiong, A. (2012). Palliative care for the management of chronic illness: a systematic review study protocol. *BMJ open*, 2(3), e000899.

EUGMS - EAPC - Fondazione Maruzza. (2021). *Manifesto Better Palliative Care for Older People.* Retrieved from https://www.fondazionemaruzza.org/wp-content/uploads/2021/08/Manifesto-Eng.pdf

European Comission. (2022, September 7). *A European Care Strategy*. Retrieved from European Comission: https://ec.europa.eu/commission/presscorner/detail/en/ip_22_5169

Executive Board, World Health Organization. (2014). Strengthening of palliative care as a component of integrated treatment within the continuum of care. (EB134.R7).

Feedback from Member States in response to WHO Director-General's call to strengthen palliative care services. (2022, June 9). Retrieved from World Health Organization: https://www.who.int/news/item/09-06-2022-feedback-from-member-states-in-response-to-who-director-general-s-call-to-strengthen-palliative-care-services

Fitzpatrick, J., Mavissakalian, M. L., Xu, Y., & Mazurek, A. (2018). Economic impact of early inpatient palliative care intervention in a community hospital setting. . *Journal of Palliative Medicine*, 21(7), 933-939.

Gardiner C, R. T. (2018). What is the cost of palliative care in the UK? A systematic review. . *BMJ Supportive & Palliative Care*, (8), 250-257.

Gardiner, C., Cobb., M., Gott, M., & Ingleton, C. (2011). Barriers to providing palliative care for older people in acute hospitals. *Age and Ageing*, 40(2): 233-238.

Gomes, B., Brito, M., Lacerda, F. d., & A., S. D. (2020). *Portugal needs to revolutionise end-of-life care.* The Lancet 395, 495-496. doi:https://doi.org/10.1016/S0140-6736(19)32969-1

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Gomes, B., Calanzani, N., Curiale, V., McCrone, P., & Higginson, I. (2013). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. . *Cochrane Database Syst Rev.* .

Good Life, G. D. G. G.,. (n.d.). *About Us.* Retrieved from https://www.goodlifedeathgrief.org.uk/content/about/

Gordijn, B., & Janssens, R. (2004). Euthanasia and Palliative Care in the Netherlands: An Analysis of the Latest Developments. *Health Care Analysis*, 12(3), 195-207. doi: https://doi.org/10.1023/B:HCAN.0000044926.05523.ef

Gott, M., Ibrahim, A., & Binstock, R. (2011). The disadvantaged dying: Ageing, ageism, and palliative care provision for older people in the UK. In *Living with ageing and dying: international perspectives on end of life care for older people* (pp. 52-62). Oxford : University Press.

Government, S. (2015). *Palliative and end of life care: strategic framework for action.* Retrieved from https://www.gov.scot/publications/strategic-framework-action-palliative-end-life-care/

Greenhalgh, J., Gooding, K., Gibbons, E., Dalkin, S., Wright, J., Valderas, J., & Black, N. (2018). How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. *J Patient Rep Outcomes.*, 2:42. doi:10.1186/s41687-018-0061-6

Greer, J. A., Tramontano, A. C., McMahon, P. M., Pirl, W. F., Jackson, V. A., El-Jawahri, A., . . . Temel, J. S. (2016). Cost analysis of a randomized trial of early palliative care in patients with metastatic nonsmall- cell lung cancer. *Journal of palliative medicine*, 19(8), 842-848.

Hatziandreu, E., Archontakis, F., & Daly, A. (2008). *The potential cost saving of greater use of home - and hospice-based end of life care in England.* RAND Corporation.

Higginson, I. J., Paul, M., R., H. S., Rachel, B., Eli, S., & M., E. P. (2009). Is Short-Term Palliative Care Cost-Effective in Multiple Sclerosis? A Randomized Phase II Trial. *Journal of Pain and Symptom Management*, Pages 816-826.

Hospice, H., n.d. . (n.d.). *Last Aid.* . Retrieved from https://highlandhospice.org/what-we-do/education-learning-development/last-aid

House of Commons. (2015). *End of Life Care. Fifth Report of Session 2014-15.* Health Committee. Retrieved from https://publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/80502.html

IKNL/Palliactief. . (2017). *Netherlands Quality Framework for Palliative Care.*

Johnston, B., McCauley, R., McQuillan, R., Rabbitte, M., Honohan, C., Mockler, D., . . . May, P. E. (2020). Effectiveness and cost-effectiveness of out-of-hours palliative care: a systematic review. *HRB Open Res*, 3-9.

Ma, J., Chi, S., Buettner, B., Pollard, K., Muir, M., Kolekar, C., . . . Dans, M. (2019). Early palliative care consultation in the medical ICU: a cluster randomized crossover trial. *Critical care medicine*, 47(12), 1707.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Mathew, C., Hsu, A., Prentice, M., Lawlor, P., Kyeremanteng, K., Tanuseputro, P., & Welch, V. (2020). *Economic evaluations of palliative care models: A systematic review.* Palliative Medecine. doi:doi: 10.1177/0269216319875906. Epub 2019 Dec 19. PMID: 31854213.

Mazanec, P., Ferrell, B., Virani, R., Alayu, J., & Ruel, N. (2020). *Preparing new graduate RNs to provide primary palliative care.* 51(6), 280–286.: The Journal of Continuing Education in Nursing. doi: 10.3928/00220124-20200514-08

McCaffrey, N., Agar, M., Harlum, J., Karnon, J., Currow, D., & Eckermann, S. (2013). Is home-based palliative care cost-effective? An economic evaluation of the Palliative Care Extended Packages at Home (PEACH) pilot. *BMJ Support Palliat Care.*, 3(4):431-5.

Milazzo, S., Hansen, E., Carozza, D., & A. Case, A. (2020). How Effective Is Palliative Care in Improving Patient Outcomes? *Springer*.

OFSP, O. f. (n.d.). *Plateforme des soins palliaitifs*. Retrieved from https://www.plateforme-soinspalliatifs.ch/

PACE project. (2019). *Palliative care for dignity in old age - Adressing the needs of Older People in Long-Term Care Facilities in Europe.*

Pace, A., Di Lorenzo, C., Capon, A., Villani, V., Benincasa, D., Guariglia, L., . . . Pompili, A. (2012). Quality of care and rehospitalization rate in the last stage of disease in brain tumor patients assisted at home: a cost effectiveness study. *Palliative Medicine*, 15(2):225-7.

Porter, M. (2010). What is value in health care? *The New England Journal of Medicine*, 2477-2481. doi: 10.1056/NEJMp1011024

Putera, I. (2017). Redefining Health: Implication for Value-Based Healthcare Reform. *Cureus*, 9(3): e1067. doi:doi:10.7759/cureus.1067

Recommendation Rec 24. (2003, November 12). Retrieved from Council of Europe: https://www.coe.int/t/dg3/health/Source/Rec(2003)24_en.pdf

Rosa, W., Ferrell, B., & Mazanec, P. (2021). *Global integration of palliative nursing education to improve health crisis preparedness.* 1;52(3):130-5.: The Journal of Continuing Education in Nursing.

Scotland, H. I., n.d. . (n.d.). *The regulation of independent healthcare in Scotland.* Retrieved from https://www.healthcareimprovementscotland.org/our_work/inspecting_and_regulating_care/independent_healthcare.aspx

Seow, H., Barbera, L. C., McGrail, K., Burge, F., Guthrie, D. M., Lawson, B., . . . Sutradhar, R. (2022). Effect of Early Palliative Care on End-of-Life Health Care Costs: A Population-Based, Propensity Score–Matched Cohort Study. *JCO Oncology Practice*, 18(1), e183-e192.

Shen, M., & Wellman, J. (2019). Evidence of palliative care stigma: The role of negative stereotypes in preventing willingness to use palliative care. . *Palliative and Supportive Care*, 17, 374–380.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

Smith, S., Brick, A., & O'Hara, S. (2014). Evidence on the cost and costeffectiveness of palliative care: A literature review. *Journal of Palliative Medicine*, Vol 28(2) 130-150.

Smith, S., Brick, A., O'Hara, S., & Normand, C. (2014). Evidence on the cost and cost-effectiveness of palliative care: a literature review. . *Palliative medicine*, 28(2), 130-150.

Smith, T., Temin, S., Alesi, E., Abernethy, A., Balboni, T., Basch, E., . . . Von Roenn, J. (2012). American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *Journal of Clinical Oncology*, 30(8), 880–887.

Sousa, J., Filipe, C., Ilinca, S., Buttigieg, S., & Larsson, A. (2019). Ageism in Health Care : A Systematic Review of Operational Definitions and Inductive Conceptualizations. *The Gerontologist*, 59(2): e98-e108.

Stavros Niarchos Foundation. (2019). *Palliative Care Feasibility. Study for Greece. Ministry of Health. National Committee for the Development & Implementation of a Palliative Care Strategy in Greece.* Ministry of Health. National Committee for the Development & Implementation of a Palliative Care Strategy in Greece. doi: http://www.thewhpca.org/resources/item/greek-palliative

Van den Block, L. a. (2015). Palliative care for older people: A public health perspective. *Oxford*, online edition.

Wichmann, A. B., Adang, E. M., Vissers, K. C., Szczerbińska, K., Kylänen, M., Payne, S., . . . Engels, Y. (2020). Decreased costs and retained QoL due to the 'PACE Steps to Success' interventions in LTCFs : cost-effectiveness analysis of a randomized controlled trial. *BMC Medicine*, 18(1), 1-9.

World Health Organisation Europe. (2004). *Better Palliative Care for Older People.* Copenhagen: WHO Regional Office. Retrieved from World Health Organisation Europe: https://apps.who.int/iris/bitstream/handle/10665/107563/9789289010924-eng.pdf?sequence=1&isAllowed=y

World Health Organization Europe. (2011). *Palliative Care for Older People : better practices.* Copenhagen: WHO Regional Office.

Wyman, M., Shiovitz-Ezra, S., & Bengel, J. (2018). Ageism in the health care system: providers, patients and systems. In L. Ayalon & C. Tesch-Römer (Eds.), *Contemporary Perspectives on Ageism.* (pp. 193-212). Springer .

Yadav, S., Heller, I. W., Schaefer, N., Salloum, R. G., Kittelson, S. M., Wilkie, D. J., & Huo, J. (2020). The health care cost of palliative care for cancer patients: a systematic review. *Supportive Care in Cancer*, 28(10), 4561-4573.

Zimmermann, C. S., & Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. *Canadian Medical Association Journal*, 188(10), E217–E.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825750