KCE REPORT 394

Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

PROPOSITIONS FOR REINFORCING AND EXPANDING THE BELGIAN PALLIATIVE CARE OFFER: THE RIGHT CARE AT THE RIGHT MOMENT AT THE RIGHT PLACE





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HEALTH SERVICES RESEARCH

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2024 www.kce.fgov.be

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Acknowledgements: We would like to thank our colleagues at KCE for their inputs and support during this project: Carl Devos, Laurence Kohn, Roos Leroy, Jens Detollenaere, Céline Pouppez, Koen Van den Heede, Emily Van Coolput, Els Van Bruystegem and Andrée Mangin.

We would like to address a special thanks to the directors and staff of the three Federations of Palliative Care for their availability in answering our numerous questions and the fruitful discussions during this project. We also would like to thank the members of the patient umbrella associations and informal caregivers associations, the hospital federations, the professional associations of GP, specialists and nurses who commented on the proposal in September 2024.

Finally, last but not least, we would like to thank all the stakeholders, professionals and volunteers who participate to this study, especially those who welcomed our team in their service during our site visits.

Reported interests KCE members: KCE is a federal institution funded by INAMI-RIZIV, by the Federal Public Service of Health, Food chain Safety and Environment, and by the Federal Public Service of Social Security. KCE's mission is to advise policymakers on decisions relating to health care and health insurance on the basis of scientific and objective research. It is expected to identify and shed light on the best possible solutions, in the context of an accessible, high-quality healthcare system with due regard for growing demand and budgetary constraints.

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Reported interests: All experts and stakeholders consulted within this report were selected because of their involvement in the topic of palliative care. Therefore, by definition, each of them might have a certain degree of conflict of interest to the main topic of this report.

Layout: Joyce Grijseels, Ine Verhulst

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Publication date:	16 January 2025
Project number:	2022-02
Domain:	Health Services Research (HSR)
MeSH:	Palliative care; Palliative Medicine; Patient Preference; Hospice care; Belgium
NLM Classification:	WB 310 Hospice care. Palliative care. Terminal care
Language:	English
Format:	Adobe® PDF™ (A4)
Legal depot:	D/2024/10.273/63
ISSN:	2466-6459

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How to refer to this document?

Dauvrin M, Desomer A, Savoye I, Adriaenssens J, Ricour C. Propositions for reinforcing and expanding the Belgian palliative care offer: the right care at the right moment at the right place. Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE). 2024. KCE Reports 394. D/2024/10.273/63.

This document is available on the website of the Belgian Health Care Knowledge Centre.

https://doi.org/10.57598/R394C

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ACP	Advanced Care Planning
ADL	Activities of the Daily Life
AVIQ	*Agence pour une Vie de Qualité* (Walloon regional agency for health)
BFPZ-FBSP	*Brusselse federatie voor palliative en continue zorgen - Fédération bruxelloise de soins palliatifs et continus* (Brussels federation of palliative care)
CBPC	Community-Based Palliative Care
CNS	Clinical nurse specialists
DNR	Do Not Resuscitate
EAPC	European Association for Palliative Care
ED	Emergency Department
EOL	End-of-Life
EZL	*Eerste Lijn Zones* (primary care zones of the Flemish region)
Federal Cell	*Federale Evaluatiecel Palliatieve Zorg FEPZ –Cellule Fédérale d'Evaluation des Soins Palliatifs CFESP* (Federal Cell for Palliative Care Evaluation)
Fix payment for palliative care	*Palliatief forfait - Forfait palliatif*
FRZV-CNEH	*Federal Raad voor Ziekenhuisvereninigen - Conseil fédéral des Etablissements hospitaliers* (Federal Council for Hospitals)
FTE	Full Time Equivalent
FWSP	*Fédération wallonne des soins palliatifs* (Walloon federation of palliative care)
GP	Generalist Practitioner
Home care	*Thuiszorg - Soins à domicile*
Hospital at home	*Thuishospitalisatie (TH) - Hospitalisation à domicile (HAD)*

Hospital mobile palliative care team	*Palliatief supportteam (PST) - Equipe mobile de soins palliatifs*
ICU	Intensive Care Unit
Informal caregivers	*Mantelzorgers - Aidants proches*
KOTK	*Kom Op Tegen Kanker* (Flemish Fundation Against Cancer)
LoS	Length of stay
MRPA	*Maisons de Repos pour Personnes Agées* (Elderly home)
MRS	*Maisons de Repos et Soins* (nursing homes)
NHS	National Health Service
NIHDI	National Institute for Health and Disability Insurance (RIZIV-INAMI)
OCMW-CPAS	*Openbaar Centrum voor Maatschappelijk Welzijn - Centre Public d'Action Sociale* (Municipal welfare centre)
OLS	*Organisation Locorégionale de Santé* (Locoregional health organisation in the Walloon region)
Outreach multidisciplinary support team	*Multidisciplinaire begeleidingsequipes voor palliatieve verzorging (MBE) -Equipe de soutien de seconde ligne*
Palliative care networks	*Palliatieve netwerken en samenwerkingsverbanden - Plateformes de soins palliatifs*
Palliative care referent	*Referent in palliatieve zorg - Référent en soins palliatifs*
Palliative care unit (Sp4)	*Gespecialiseerde dienst voor palliatieve zorgen (Sp4) - Service spécialisé en soins palliatifs (Sp4)*
Palliative day care centres	*Dagverzorgingscentra voor palliatieve zorgen - Centres de soins palliatifs de jour*
PC	Palliative Care
PCU	Palliative care Unit
PICT-1	Palliative Care Indicators Tool-1

PMC	Palliative Middle Care
PPV	*Palliativ-Pflegeverband Ostbelgien* (Palliative care network of the Ostbelgien community)
PZV	*Palliatieve Zorg Vlaanderen* (Flemish federation of palliative care*)*
Qualified informal caregivers	*Bekwame helpers - Aidants qualifiés*
RD	Royal Decree
SDG	Sustainable Development Goals
SES	Socioeconomic Status
SHS	Serious Health-related Suffering
Supportive care	*Supportieve zorg - Soins de support*
Terminal care	*Terminale zorg - Soins de fin de vie*
UK	United Kingdom
VIVEL	*Vlaamse Instituut voor het Eerste Lijn* (Flemish Institute for First Line)
WHA	World Health Assembly
WHO	World Health Organisation
WHPCA	Worldwide Hospice Palliative Care Alliance
WZC	*WoonZorgCentrum* (nursing home)

SCIENTIFIC REPORT

1 INTRODUCTION

- ✓ Legal definition of palliative care was updated in 2016, resulting in an extended access to palliative care to "any person at an advanced or terminal stage of a serious, progressive, life-threatening illness, regardless of their life expectancy".
- ✓ The number of patients that need palliative care is likely to increase.
- ✓ Respecting patients preferences regarding end-of-life is an ethical duty.
- ✓ Most of palliative patients prefer to die in a familiar environment rather than in a hospital
- ✓ The Federal Cell for the Evaluation of Palliative Care emphasizes the need for an intermediary care offer called “palliative middle care” to complete the current offer of palliative care.

1.1 Context

Since 2002, the World Health Organisation (WHO) has adopted the following definition of palliative care: “*an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual*”.[1-3] Three key features can be found across the numerous definitions of palliative care: quality of life as the goal of care, inclusion of the relatives in the care, and multidisciplinary practice.

People affected by life-threatening conditions can experience serious health-related suffering (SHS) before the end of their life (see Appendix 1.1 for main life-threatening or life-limiting conditions and for the estimated proportion of SHS by condition).[4] Those people represents the target population of palliative care services.[5] The burden of SHS will increase worldwide by 87% to 2060, with the fastest increases occurring among older

people and people with dementia.[4] Estimation of PC population by country, region or continent can be done thanks to practical tools.[a]

Indeed, palliative care (PC) is no longer limited to people with terminal cancer.[6] It is also available to patients suffering from other incurable diseases. In addition, PC is not anymore delivered only in the few last days or weeks before death but also to patients whose life expectancy may exceed several months or even a few years. Globally, it is estimated that palliative care was needed in 40-60% of all deaths.[2, 4] In Europe, 4.4 million of the people who died in 2014 has experienced SHS and so were eligible for palliative care.[5] In 2019, the Parliamentary Assembly of the Council of Europe issued the following statement: "*palliative care should be available not just to the terminally ill, but also to those who are chronically ill […]. With an ageing population, living longer and with more years of chronic illness and pain, a substantial increase in palliative care needs can be anticipated over the coming years*".[7]

Although cancer is projected to remain the first cause of SHS, the majority of adults in need of palliative care worldwide have chronic diseases such as cardiovascular diseases, chronic respiratory diseases, AIDS and diabetes. Patients with many other conditions may require palliative care, including kidney failure, chronic liver diseases, rheumatoid arthritis, neurological diseases, dementia, congenital anomalies and drug-resistant tuberculosis. In 2014, worldwide, it was estimated that only 14% of people needing palliative care, actually receive it.[2] In Europe, "*the Assembly* [of the Council of Europe] *deeply regrets that […] hundreds of thousands of people in Europe still do not have access to appropriate palliative-care services. The Assembly is particularly concerned about the lack of access to appropriate pain relief, leading to situations in which patients suffer for months and even years, and die in pain that could be prevented.*[…] *The Assembly notes that the lack of appropriate palliative-care services not only increases suffering for patients and families, but also involves higher costs for the health-care system, as it leads to unnecessary hospital admissions, as well as inappropriate recourse to expensive emergency services and treatments*".[7]

Ensuring proper access to palliative care is one of the United Nation Sustainable Development Goals (SDG) as part of the universal health care, pressing States around the world to invest in an adequate health service organisation (SDG 3.8.). This was repeated by the World Health Assembly in its resolution WHA-67.19 who "urged" Member States to take the necessary actions to expand the access to palliative care, recalling that universal access to palliative care is an ethical imperative for government.[1] The Parliamentary Assembly of the Council of Europe also recognises in its resolution 2249 (2019) that palliative care is fundamental to human dignity and a component of the human right to health.[7] Those resolutions of the World Health Assembly and Council of Europe emphasize front-line access to Palliative Care in the community and at home.[1, 7, 8]

Pain is one of the most frequent and serious symptoms experienced by patients in need of palliative care. For example, 80% of patients with AIDS or cancer, and 67% of patients with cardiovascular disease or chronic obstructive pulmonary disease will experience moderate-to-severe pain at the end of their lives.[2] But the rationale for palliative care goes further to the need for relief from pain and other physical symptoms. As patients with life-threatening or terminal illness and their caregivers go through great stress, psychological support is another aspect of palliative care, requiring professionals to be adequately trained to help patients and relatives manage their stress. The health system and health facilities may also provide other end-of-life supports, such as spiritual, social, legal, and environmental.[2] All types of palliative care services should, at a minimum, identify patients who could benefit from palliative care; assess and reassess patients for physical, psychological, social and spiritual distress and (re)assess relatives for emotional, social, or spiritual distress; relieve pain and other distressing physical symptoms; address spiritual, psychological and social needs; and

[a] Interested readers are invited to consult the pages 85-86 of the report of Gomez-Batiste and Connor (2017) that details useful methods for calculating the need for palliative care.

clarify the patient's values and determine culturally appropriate goals of care.[2]

Palliative care enhance the quality of life, and may even influence positively the quantity of life. Patients are also helped to live as actively as possible until death.[2] Palliative care is not intended to hasten or postpone death, but uses ethical principles, shared decision making and advanced care planning to identify patients' priorities and goals for their care at the end of life. A team approach is used and many kinds of health and social care professionals, as well as volunteers, can be involved. A palliative support of good quality also offers help to the family to cope both during the patient's illness and during bereavement.[2]

According to the European experts consulted by the European Association for Palliative Care, only two care settings have been identified. On the one hand, the home and, on the other, the hospital. Specialised mobile teams are included in the home setting and residential hospices in the hospital setting.[5]

1.2 History of palliative care in Belgium

The first Belgian palliative care unit emerged in 1981, thanks to the efforts of an English woman living in Brussels. She organised and steered a team of caregivers to provide end-of-life care for patients in their own homes.[9] A few years later, due to a conference entitled "*When the Other One Dies...",* a number of units caring for the dying were set up. In 1985, the *Cliniques Universitaires Saint Luc* allocated four beds in the hospital's cancer department for the treatment of patients with terminal cancer. Three years later, a second academic hospital set up the first hospital mobile palliative care team. In the late 1980s, there came more specialised units, conferences and training courses for health professionals.[9]

In 1989, the first Belgian professional palliative care association was founded. Its creation was followed by the first two public authority interventions: financing by the Ministry of Public Health of field initiatives (already under way) and funding by the National Institute for Health and Disability Insurance (NIHDI) of hospital units providing quality care for cancer patients. Several groups of experts were then set up by the health authorities to study the problem of supportive care for the dying and to evaluate the needs of the Belgian population. The discussions resulted in a first coherent and comprehensive palliative care plan. This plan was improved in 2000 following the work of an inter-cabinet working group, and aimed to strengthen the culture of palliative care by increasing budgets, and to optimize care in the patient's own environment (at home or in residential institutions).[10]

Since 1997, palliative care networks have been established to foster a palliative care culture, organise trainings for care givers, coordinate services across different organisations and providers, and to evaluate the existing palliative care offer.[11] These networks covered the entire Belgian territory (15 networks in Flanders, 1 bilingual network in Brussels, 8 networks in Wallonia and 1 network in the German-speaking community).[12] This was followed, in 1998, by the creation of outreach multidisciplinary support teams to counsel healthcare professionals delivering palliative care at home within each network.[13] An organisation with networks allows a comprehensive integrated system of services where in- and out-patient services, home care services and other front-line or support services are connected to cover all care needs and treatment options.[14]

Belgium has a long-standing tradition of integrated palliative care in its legislation: access to palliative care has been enshrined in the Belgian laws for over 15 years. Already in 2002, three very important laws were passed as a whole- the law on euthanasia, the law on palliative care and the law on patients' rights. In this context, euthanasia is considered as part of the domain of palliative care expertise in Belgium.

In 2016, the legal definition of palliative care was updated, resulting in an extended access to PC to "any person at an advanced or terminal stage of a serious, progressive, life-threatening illness, regardless of their life expectancy".[15, 16] This enlargement of this definition induces a substantial extension of the target population eligible to benefit from palliative care.

Since 2018, the Royal Decree (RD) of 21.10.2018 related to the 2016 law on palliative care details which criteria a physician is supposed to use to identify a patient as palliative.[17, 18] These criteria are detailed in a specific

tool called the Palliative Care Indicators Tool-1(PICT-1) (see Appendix 2). The PICT-1 legally applies for the identification of palliative patients by individual physicians. But there is a mistake in the RD: the number of required frailty criteria is wrongly increased from minimum two to at least three. At the moment of report writing (2024), this tool is only linked to a benefit of the health insurance for the generalist practitioner (GP) and not the specialists, for example oncologists, psychiatrists or geriatricians.

Finally, in May 2022, the creation of one or more palliative status(es) has been endorsed by the federal government and has been incorporated as a principle into the law on compulsory health insurance (see Article 84 of the law of 18.05. 2022 containing various urgent provisions on healthcare, inserting a Chapter IIIquarter in the law of 14.07.1994 regarding the compulsory health and disability insurance). This law assigns to the King the task of defining one or more palliative status(es) linked to specific benefits. For the elaboration of this status or these statuses, the law provides that the life expectancy of the patient and/or the care needs of the patients shall be particularly considered. In this frame, KCE has led a research on how to align statuses and needs. This research concluded that no evidence-based tool are currently able to define such statuses. Solutions to define supports adapted to the needs of patients requiring palliative care in Belgium were suggested in the KCE report 367.[13]

Additional information over the evolution of palliative care can be found in previous KCE reports[12, 13]and in the reports of the Federal Cell for Palliative Care Evaluation.[10, 19-21]

1.3 Why this project?

1.3.1 A missing link in the Belgian palliative care landscape

In Belgium, the Federal Cell for Palliative Care Evaluation (*Federale Evaluatiecel Palliatieve Zorg –Cellule Fédérale d'Evaluation des Soins Palliatifs*), in short the Federal Cell, has the role of regularly and critically assessing palliative care needs and the quality of the response to them. In two evaluation reports, in 2017 and 2020, the Federal Cell highlighted the need of a robust palliative care offer between primary care and hospital care.

The Federal Cell designated this care offer as "palliative middle care" structures. Already in 2016, the Belgian National Council of Hospitals (*Federale Raad voor Ziekenhuisvoorzieningen - FRZV-Conseil Fédéral des Etablissements Hospitaliers - CFEH*) and the Belgian Federal Public Service of Public Health had published, a joint opinion where they stressed that "*the differentiation of the type of palliative care units (e.g. middle care units) could help to improve the allocation of resources according to the demands of care*".[22] Then in 2018, based on the 2017 report of the Federal Cell, the Chamber of Representatives (*Kamer van Volksvertegenwoordigers - Chambre des Représentants*) stated that palliative middle care is the link between home and hospital, allows for long stays and is defined according to needs (not age), place of residence or pathology.[23, 24]

In 2021, following the report of 2017, the Federal Cell published a specific report on "palliative middle care".[20] This report highlighted that the current palliative care system must evolve to keep pace with all the societal developments (e.g., aging of the population, changes in family structure), and to care for more and more patients with complex needs over a longer period. The Federal Cell concluded that there is an insufficient supply of palliative care structures, particularly "palliative middle care" structures.

At the end of 2020, the federal government included in its policy agenda the fact that palliative care must be introduced earlier in the patient's care pathway and that the necessary resources must be mobilised according to need. This decision aligns with the updated definition of the palliative patient published in 2016 in the Belgian legislation and led to the conclusion that the place of intermediate structures (the so-called "palliative middle care") should be studied by the KCE. In 2021, the Federal Cell introduced a research project proposal to KCE entitled "*Palliatieve 'Middle Care': een noodzakelijke nieuwe schakel in het Belgische palliatieve zorgnetwerk*" (transl. Palliative Middle Care: an essential link in the Belgian palliative care network).

In 2021, a multipartite meeting was organised at the initiative of the Office of the Minister of Public Health, gathering the Federal Cell for palliative care, the FPS Public Health and the NIHDI. This led to two KCE studies around palliative care: the identification of a palliative care needs assessment tool

(see KCE report 367 published in March 2023) and the current study on the organisation of palliative middle care (PMC).

1.3.2 An ethical duty to patient preferences

As suggested by WHO and several authors, one of the objectives of Member States' policymakers should be to pay greater attention to the preferred place of death of the patients.[1, 2, 25, 26] As PC aims at respecting as much as possible to the care needs and care preferences of the patients and their family, to choose one's place of death and the respect of that choice is an indicator of the quality of death for a State, like used in Belgium as a health system performance indicator.[11]

The preferred place of care and place of death should be acknowledged and discussed with the patient and family, and measures taken to comply with these preferences, wherever possible. It is important to elicit the preference of patients in regards to where they wish to receive care, and for this to be an on-going conversation between health professionals, patients and family members. Palliative treatment, care and support are provided at home, in nursing homes, in long term care facilities, in hospital and in hospice, or in other settings, if required.[14]

Some patients might prefer to die in a hospice or other institution but, in the vast majority, people appear prefers dying in their usual environment. Indeed, in a 2017 study[27], 56% of Anglo-Saxon people (living in London, Dublin and New York) aged over 65 who consulting an outpatient palliative care service identified their home as their most preferred place of death. However, it was not the case for all as 16 % preferred to die elsewhere than at home. In Belgium, according to a 2014 study which surveyed GPs knowledge about their patients' preferences, 9% of patients preferred a place other than their home to die, and 1.4% of people who died at home did not wish to do so. Data of 2013 reported by the Flemish Federation of Palliative Care indicated that 80% of the patients whose GP was aware of the preferred place of death died at the preferred place. This agreement was highest for people who died in the residential care home (93%), in hospital (94%) or palliative unit (83%). It was lowest for people who wished to die at home (72%).[28] In the Brussels region, the rate of those dying in their private home is particularly low at 15.1%.[29]

Table 1 presents an overview of the (in)congruence between the preferred and actual place of death, based on our literature review. Data is presented on the ranking of preferred place of death and the actual place of death (if reported). Table 1 only presents a ranking of the top 3 of preferred places of death, indicating a tendency in preference without detailing the heterogeneity between the included primary studies in the reviews and the potential bias linked to this simplified representation. Overall could be stated that the preferred place of death in palliative patients worldwide is the home setting, secondly hospital and thirdly hospice.

Table 1 – (In)congruence between the preferred and actual place of death in the retrieved literature reviews on preferred place of death

References	Participants	Preferred place of death	Actual place of death
Yamout, 2022[30]	Patients with terminal illness	1st: home 2nd: hospital 3rd: hospice/palliative care wards	Not reported
Garcia-Sanjuan, 2022[31]	Patients at the end of life, both oncological and non-oncological pathologies	1st: home 2nd: hospital 3rd: hospice/palliative care wards	In hospital: ranged from 6% to 74,3% At home: ranged from 13,4% to 88,9% In medium to long stay facilities: ranged from 0% to 50,9% In hospice or palliative care unit: ranged from 3,2% to 57,2%
Fereidouni, 2021[32]	Cancer patients	1st: home (in 55% of patients)	Not reported

		2nd: hospital (17%) 3rd: hospice (10%)	
Rainsford, 2016[33]	Rural, regional or remote palliative residents	1st: home 2nd: hospital 3rd: hospice (if available)	Most deaths in hospital Home death: 12% to 81,7% with 7 studies less than 25%, 10 studies 25-50% (including Belgium), 5 studies >50% Highest rates of home death in cancer patients (53-81%) Less than 10% of rural deaths occurred in nursing/care homes or hospices Rural patients are more likely to die in hospital or long-term care facility (in 4 studies) whereas other studies reported the change of dying at home to be greater in rural than urban locations
Costa, 2016[34]	Patients with an advanced, life-limiting condition	1st: home	Home death: in 21 to 78% of patients
Hoare, 2015[35]	Patients living in the UK	1st: home Patients in hospice: lower preference for home, with hospice as 2nd Patients in hospital: lowest % of preference for home	Not reported
Badrakalimuthu, 2014[36]	People living with dementia	1st: home 2nd: group home	1st: care homes Patient enrolled in home hospice program: increased number of patients died at their preferred place of death
Gomes, 2013[37]	Patients with advanced or severe stages of progressive disease (cancer or malignant)	1st: home	Not reported

A precise quantification of the preferred and actual place of death is not given in the retrieved systematic reviews as the range of rates are really broad when compiling within systematic reviews results from different primary studies : 6-74%,13-89%, 0-51%, etc. Precise numbering is so lacking from SR but interesting data is available on determinants to preferred place of death.

Across the retrieved reviews different types of **factors** were found associated with the preferred place of death (detailed results are presented in the evidence tables in the Supplementary report).

- Demographic predictors[30-32, 38 30]

Across the literature, gender, age, socio-economic status (including income, education level, living conditions), marital status were found as predicting factors for the preferred place of death. However the findings across these factors are inconsistent, therefore a clear conclusion is difficult to make on the importance of these factors on the choice of preference. For example some authors found contradictory results on the gender. In some studies women preferred home as preferred death as in other studies more men preferred home as preferred place of death. Some consistency can be found on the need for social support: patients with lack of social support will rather choose a nursing home or hospice as preferred place of death, whereas patients who live with their spouse or family will prefer home to die. Also higher income and higher educational level seemed to be associated with a preference to die at home.

- Availability of informal caregivers[30, 33, 38]

Being surrounded by informal caregivers was determinant in the preferred choice of the patient: the availability of informal caregivers made patients to choose to stay at home as long as possible. The lack of availability of the caregivers, due to employment (e.g. family members who are restricted in care time due to work regimens) or the inability of the informal caregivers to continue caregiving, made patients to choose for hospital at preferred place of death.

- Disease-related factors[30, 32, 36, 38]

A link was found between type of cancer ant the preferred place of death, e.g. patients with liver and pancreatic cancer and with lung or breast cancer were more likely to choose home as preferred place fo death. Also time since diagnosis may be determinant: patients in poor physical condition and who survived more than 6 months since diagnosis were more likely to choose home. Other disease-related factors made patients less likely to choose home as preferred place of death, such as being aware of the prognosis of the disease, having severe to moderate pain (however other findings show that patients using morphine to relieve pain were more likely to choose home), or patients with better and more independent functional status. If treatment becomes unbearable and/or when rapid deterioration of health makes patients to prefer to leave the house (and makes death at hospital more plausible). Being aware of their illness and/or being satisfied with their treament, made patients to chose for their home setting as their preferred place of death.

Some results were found on the actual place of death for people with dementia, but very little is known about the patients' preferences or the extent to which patients discuss their preferences with their families and healthcare professionals. In the only study (included in the review of Badrakalimuthu, 2014[36]) that looked at preferences it appears that preferences of proxy decision-makers are met more often than those of the patients with dementia themselves.

- Assumptions and beliefs of the patient[30]

Patient's assumption that home death is impossible because it is difficult to be cared for and die at home at end-of-life, made patients to choose another care setting as preferred place of death. The most frequent reason not to choose home as preferred place of death is that patients do not wish to be a burden on their family. They do not want to expect from their partner to take care of them and therefore prefer to go to a hospice at end of life rather than to stay at home. Also knowing that the family might witness suffering and having to manage pain and the dying body within the domestic space could affect the choice of the patient. The choice for hospital might be related to a strong and trusting relationship with healthcare professionals (especially in cancer patients undergoing chemotherapy for a period of time) and the preference of the patients to stay in a safer setting than can provide the necessary care. The authors found also that the choice for hospice care might be influenced by the awareness of the patient that hospice care is associated with a lower cost.

- Cultural factors[30, 37, 38]

In some cultures, relatives have permissions to make decisions for the older patients and this might affect the congruence between preferred and actual place of death. Also normative and moral values (i.e. cultural and religious belief involving death at home) and the culturally accepted involvement of

informal caregivers in the (intimate) care of the patient might influence the patients preferred place of death. The authors referred also to the differences between collectivistic and individualistic cultures and their determinant role in the preference of patients.

- Awaraness of healthcare professionals[30]

According to the findings in the reviews, most GPs and community nurses were aware that large number of patients would prefer to die at home. They were either informed by the patient themselves, or by a family member, relatives, a specialist or some other person. Also a linkage was found between the purpose of the care management and the awareness of preferred place of death: when care is more focused on comfort rather than on cure and/or included psychological and/or spiritual care, healthcare professionals were more aware of the patients preferred place of death. Cancer patients are more likely to discuss with their healthcare professionals compared to non-cancer patients. And healthcare professionals were more likely to refer cancer patients to palliative care.

- Health care availability and utilisation[30, 33-35, 38]

Some relationships were found between the type and place of care provision and the actual and/or preferred place of death, for example nurse and physician home visits and/or multidisciplinary palliative home care increased the likelihood of home death, while frequent hospital visits decreased the likelihood of home death (in patients receiving palliative care at home). Patients receiving palliative chemotherapy were more likely to die in an intensive care unit (ICU) and less likely to die in their preferred place of death. And in congruence with this finding was also found that cancer patients who received advanced home care that matched standards of hospital care were significantly less likely to die in hospital than those who received conventional hospital care. Admission to a hospital with palliative care services decreased the likelihood of home death. A previous hospice stay or admission is determinant in the choice made by the patient on their preferred place of death: 70% of patients with hospice experience preferred hospice as place of death versus 20% for those who had never been to a hospice. Inpatient hospices are also not always available in all locations, therefore requiring patients to travel outside their immediate community or were even not offered as an option.

The preference for place of death can also vary according to the care setting in which the patients is currently staying: nursing home residents preferred to stay in their nursing home, patients at home or in community preferred to die at home, whereas patients in hospice had a lower preference for home death and preferred to stay in hospice. Similar finding was found in patients in hospital (with the lowest preference for home death). In patients staying in multiple settings, home was their first choice as preferred place of death. The proximity to a hospital or hospice could also influence the decision to transfer from home, whereas the involvement of community nurses increased the likelihood of remaining home. While it is important to increase community services to support those who wish to stay at home, improvements in palliative care within community hospitals and residential aged care facilities should not be overlooked as these places are often substitute hospice and the only alternative to home.

However, as shown in Table 1 illustrating the preferred and the actual place of death, a **discrepancy** can be seen between both, whereas home is often expressed as the preferred place of death, the (limited available) data show rather a tendency towards more hospitals deaths. This discrepancy between preferred and actual place of death could be attributed to several factors influencing the choice of actual place of death.

- Changes in the preference of the patients over time

Across history a change over time was observed with in first period people often died at home due to poor access to health resources, secondly more deaths in hospitals due to advances in health system and in last decade preference to die at home, with emphasis on quality of end-of-life care and by developing home care.[32]

Not only availability and access to care services on population level, but mainly changes on individual level might determine the change in choice for preferred place of death. The direction of change varied between the studies but was most commonly from hospital to home, home to hospice and from home to hospital.[37] Several reasons for the change over time were found

across the different reviews related to (inter)personal changes in patient and/or family perception towards disease management or death (often through discussion between patient and the healthcare professional)[32], but also related to change in care management, social circumstances, availability of informal caregivers but also availability of care services. Gomes et al., 2013[37] found that preferences changed from home to institutions due to uncontrolled pain and other symptoms ("*she had terrible time breathing*", incontinence, mental impairment), acute events (e.g. falls, injuries), treatment of reversible conditions for comfort and to maximize length of life, imminent death, caregivers burden/inability to safely care at home, increased need for care and dependency ("*as I cannot go to the loo*", "*when he discovered he was incapable of being the host in his own home*"), "naivety" on what to expect ("*I've been watching too much TV, if I had known...*"), and possible traumatic effects on children. Preferences changed from institutions to home due to the recognition that "*prognosis was grim*", limited beds available ("*said she couldn't stay any longer*"), unsatisfactory/uncomfortable hospital experiences (e.g. fighting for adequate pain control in hospital), and when assured of support from services at home.[37]

Also in informal caregivers, the preference for place of death of their family member can change over time, however Gomes et al., 2013[37] found that only less than a third of the caregivers changed their preference (the direction of change was not reported).

- (Lack of) congruence between patient and family/informal caregiver

The preference for home as preferred place of death was in some situations a results of a 'mutual pact' or promise between the informal caregiver and the patients, in which the home death is considered as equally important to patients and informal caregivers. This promise is sometimes made in the context of hospital admission or involving reciprocate care.[37] However, an incongruence between the preferences of the patient and the informal caregivers might determine the actual place of death. Not always does the informal caregiver preference reflect the patient's preference and can affect the patient's choice as well if they are aware about the caregivers' choice.[30]

Caregivers found it also difficult to balance the patient and their own wishes.[37]

Badrakalimuthu et al., 2014[36] found that the preferences of the proxy decision-makers (often the informal caregivers) are more often met than those of the patients themselves.

Perceptions of family's ability to care impacted on place of care preferences, whereas consequences of witnessing death at home (e.g. for children) impacted on place of death preferences. Regardless of place of death, some surviving spouses said the value was frequently on the place where the majority of terminal care was provided and expressed satisfaction at having mastered the time spent at home.[37]

Some informal caregivers expressed a sense of achievement when the patient died at home, whilst others felt lack of choice, guilt and sorrow, depending on the outcome.[37] A "definite" or "desperate" desire to remain at home as long as possible, with the ultimate hope to die at home or until admission if required, was viewed as dignifying if by the time the move happened the person was not aware of it anymore.[37]

- "Missing" preferences

As shown in Table 1 on preferred and actual place of death, gaps in data are present and are sometimes not reported by the authors for the simple reason that these preferences were not asked or not expressed. Preferences may have been missing because participants may not have been given the opportunity to state their preferences, and so could reflect the difficulty healthcare professionals have in holding end of life care conversations. Preferences may also be missing because patients did not have a preference to give. Missing preferences like these suggest that patients prioritised other end-of-life issues such as pain and symptom management over place of death. Patients may also have been excluded from analysis because they were undecided about where they wished to die, did not wish to talk about preferences for place of death, were impaired cognitively or physically from communicating their preference or did not have their preference recorded.[35] This phenomenon of 'missing preferences' should be taken into account in the interpretation of the findings in this section, both on methodological level (with the bias of inflation of reported

preferences by the exclusion of missing preferences, i.e. when 'missing data' are included, they supress the proportion of preferences for all locations, therefore caution should be exercised if asserting that most patients prefer to die at home[35] as on patient level (with the need for direct communication with the patient on their preferences).

In conclusion, across the retrieved reviews, independently from variations in patient populations and care settings, it could be concluded that the majority of the patient with a terminal illness (cancer and non-cancer) would choose home as their preferred place of death.[30, 32, 38] Costa et al., 2016[34] found that some factors to improve the likelihood that the patient preferences will be met are related to the illness and may not be modifiable. But on the contrary more modifiable factors related to palliative care should be taken into account, such as the presence of a multidisciplinary palliative care team at home, the availability of palliative care services in nursing home, the provision of support to the patient and the caregivers, and a timely referral to palliative care services.

Considering that one of the goals of palliative care and end-of-life care program is to increase the quality of life of patients and their families, for this reason, guided policies to ensure death of patients in their desired place should be priority. Therefore, healthcare professionals should be aware of the palliative care preferences of their patients.[32] Also the potential incongruence between patients' and others' preferences show that neither the general public nor family caregivers appeared to be accurate proxies for patients' preferences for place of death.[35]

An important consideration has been elaborated by Garcia-Sanjuan et al., 2022[31] on the discrepancy between preferred and actual place of death: healthcare professionals try to ensure that people are cared for at home until the end of life, with dying at home being seen as an indicator of high-quality palliative care.[39] However, home is not the sole optimal option for providing quality end of life care, as other alternatives may be preferable such as hospitals, nursing homes, and hospices.[40, 41] Interpreting the proportion of deaths at home as the exclusive indicator of high-quality palliative care implies that not dying at home is a failure of care and ignores the possibility that the patient may wish to die in a different place.[42] For this very reason, congruence between the patient's preferred and actual place of death is increasingly being considered as a quality indicator of end of life care.

For patients preferring to die not at home, the Belgian palliative care landscape practically provides predominantly solutions in the hospital setting while other countries have developed, a long time ago, an alternative offer, usually called hospices (see Chapter 5). This situation could be one of the explanations that Belgium is in the top tier of countries that hospitalises patients at the end of life.[5, 11] The Belgian Health System Performance Reports highlight that around 60% of patients with cancer deceased in hospital.[11, 43]

Thönnes concluded in 2016 that European contemporary society is marked by the insufficient availability of hospice or palliative care services for the dying in many parts of Europe, both of the in-patient and out-patient services. This affects the rural population more strongly than the residents of urban agglomerations.[29]

1.4 Definitions, objective, scope and research questions

1.4.1 Definitions

In this report, the definitions used to describe palliative care patients and palliative care are the definitions used in the previous KCE report and based on Belgian legislation.

- A **palliative patient** is legally defined in Belgium as any patient in an advanced or terminal stage (in other words, no more possibility of remission, stabilisation or slowing down) of a serious, progressive and life-threatening disease regardless of life expectancy.[44, 45] To avoid that people are assimilated to the disease or their health situation, palliative patients are better described in this report as 'patients requiring palliative care'. Practically, according to the RD of 21.10.2018. related to the identification of palliative patient, a patient is identified as requiring palliative care in Belgium when he/she meets a list of criteria detailed in a specific tool called the PICT-1 (Appendix 2).

- **Palliative care** is legally defined in Belgium as all (multidisciplinary) care provided to palliative patients to support them physically, psychologically, socially, morally, existentially and, where appropriate, spiritually in order to offer the patient and his or her relatives the best possible quality of life and maximum independence. Palliative care can be initiated while treatment is still ongoing and is provided until the terminal phase and even beyond death for family members and caregivers.[44, 45]

Definitions of other terms also used in this report are those published by the Board of Directors of the European Association for Palliative Care (EAPC) based on a consensus of European experts in palliative care:

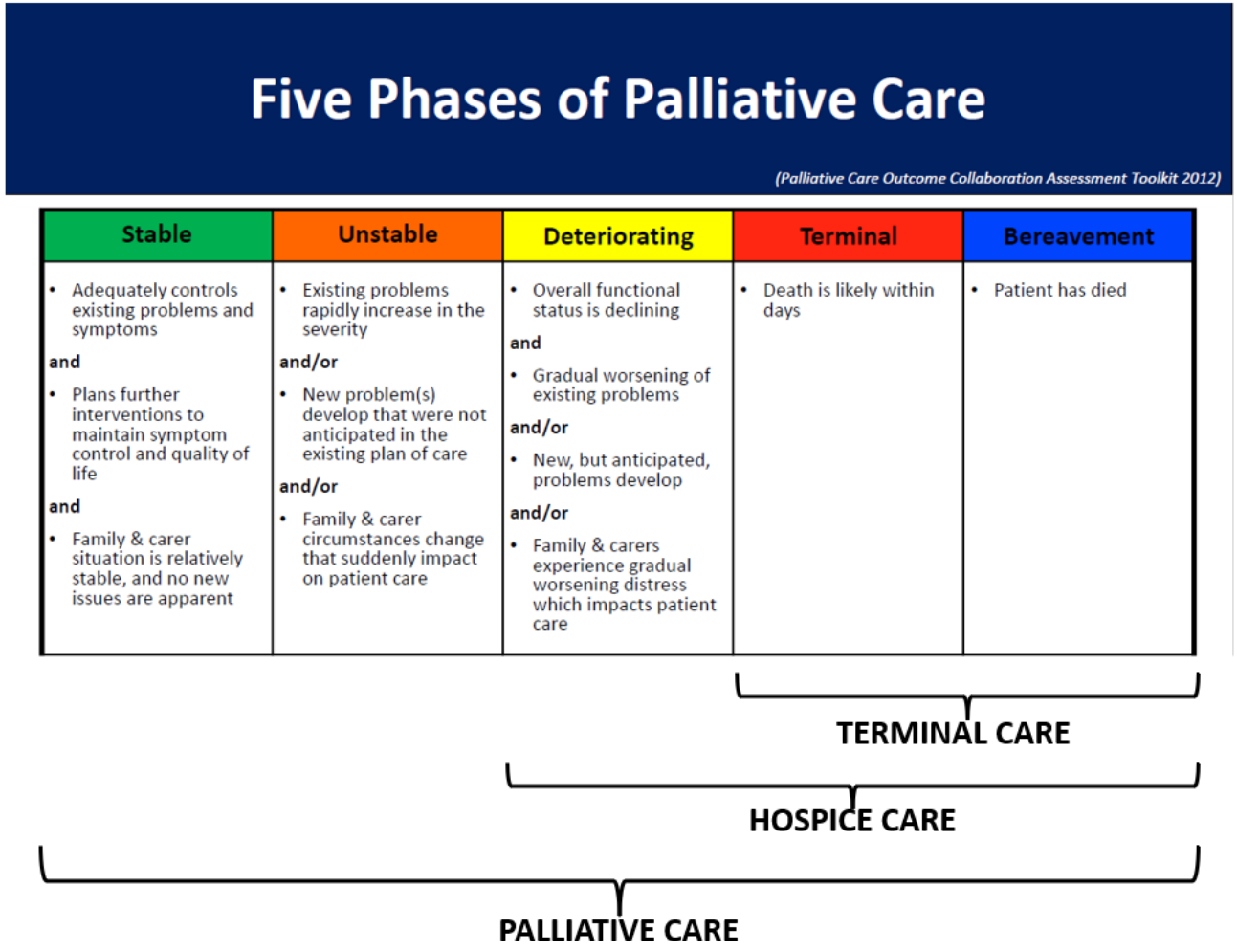
- **Palliative care approach (or palliative care culture[b])** is a way to integrate palliative care methods and procedures in settings not specialised in palliative care This includes not only pharmacological and non-pharmacological measures for symptom control, but also communication with patient and family as well as with other healthcare professionals, decision making and goal setting in accordance with the principles of palliative care. A palliative care approach applies to those with limited experience and knowledge in dealing with palliative care but can apply the basic principles of good palliative care.[14] As a reminder, the three key principles are quality of life as the goal of care, inclusion of the relatives in the care, and multidisciplinary practice.
- **General Palliative Care** applies to those who are frequently involved with palliative care and have some palliative care knowledge, such as primary care clinicians, oncologists, and geriatricians, but do not provide palliative care as the sole purpose of their work.[14]
- **Specialist Palliative Care** is provided by specialised services for patients with complex problems not adequately covered by other treatment options. Specialised palliative care services require a team approach, combining a multi- professional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care.[14]
- **Hospice care** is for the whole person, aiming to meet all needs - physical, emotional, social and spiritual. At home, in day care and in the hospice, staff and volunteers care for the patient who is facing the end of life and for those who love them. They work in multi-professional teams to provide care based on individual need and personal choice, striving to offer pain relief, dignity, peace and calm.[14]
- **Terminal care** may be understood as comprehensive care for dying patients in the last few hours, days or weeks of life.[14]
- **Supportive care** is the prevention and management of the adverse effects caused by treatment of life threatening and life limiting illnesses. This includes both physical and psychosocial symptoms, existential concerns and side effects across the entire continuum including the enhancement of rehabilitation and survivorship.[14]
- **Respite care** is aimed at family members or other primary caregivers caring for a palliative care patient at home who may suffer from the continuous burden of care. Respite care may offer a planned or unplanned break.[14]

The definition of hospice care is however open to variation. For example, the US database Medline defines Hospice Care as Mesh term by "*specialised health care, supportive in nature, provided to a dying person when death is likely within weeks. A holistic approach is often taken, providing patients and their families with legal, financial, emotional, or spiritual counselling in addition to meeting patients' immediate physical needs. Care may be provided in the home, in the hospital, in specialised facilities (hospices), or in specially designated areas of long-term care facilities. The concept also includes bereavement care for the family*" (Retrieved from: https://www.ncbi.nlm.nih.gov/mesh/?term=hospice+care).

[b] In this report, both terms are used interchangeably.

The several types of care (palliative care, hospice care, terminal care) defined above cover the same target population described in the definition of the palliative patient but seems to match with different stages of a palliative situation. The Australian *Fives Phase of illness* tool, also known as the *Palliative Care Phase*, makes it possible to link certain stages of the palliative situation with the definitions of some types of care.[46-48] **Terminal care** seems to correspond to the terminal phase described in the tool, which refers to the few days before death. **Hospice care** seems to be aligned with the deterioration phase, when functional status declines, while including terminal care. This type of care is usually available in the last few weeks or months of the patient's life. **Palliative care**, more broadly defined, covers all care that improves the quality of life of any patient suffering from a severe, progressive and life-threatening illness. During the course of a palliative situation, stable and unstable phases may alternate over a number of months or even years**. Palliative care also covers the same phase as hospice care and terminal care**. Figure 1 gives a rough overview of the possible relation between the different phases of a palliative care situation and the different types of care. The criteria for recognizing the different phases of the palliative situation are included in Figure 1.

Figure 1 – Five phases of palliative care related to forms of palliative care according to the status of the patients



Source: Adapted from the Palliative Care Outcomes Assessment Toolkit, 2012.

1.4.2 Objective

In Belgium, palliative care is routinely provided in patients' homes by front-line professionals and in hospital settings. This usual offer in the Belgian care landscape is reinforced by a more specific offer currently made up of outreach multidisciplinary mobile teams specialised in palliative care for the home and initiatives set up to fill gaps in current palliative care provision (Chapter 4). The research project presented in this report aimed to define and describe what should be intermediate services of palliative care that provide a link between palliative care at home and palliative care in hospital and that would enable palliative care to be delivered in the best possible way to all patients who need it, according to their preferences. With this aim, this project investigated the development of *palliative middle care* services in order to fulfil the potential gaps in palliative care by providing solutions for patients whose needs in palliative care are currently not met by the existing palliative care offer. Figure 2 depicts an a priori visualisation of how PMC could be positioned taken into account the current offer in palliative care.

Figure 2 – A priori visualisation of the positioning of "palliative middle care" in the Belgian landscape of palliative care



1.4.3 Scope

1.4.3.1 In scope

While drafting the first project form of this project, the scope was based on the definition of 'palliative middle care' like primarily formulated by the Federal Cell in its 2021 report and in its research proposal submitted to KCE in 2021, i.e. "*services which should make it possible to admit patients [requiring palliative care] whose state of health does not (or no longer) require hospitalization in an acute care bed or in a Sp S4 bed* [specialised palliative care bed in hospital] *but who, in the current situation, cannot stay either at home or in a nursing home*". This definition sounds to be very pragmatic to the Belgian situation but does not easily fit to international models of palliative care services development suggested by the WHO and other leading organisations like EAPC or experts.[2, 5, 49]

Indeed, internationally, following the expected expansion of palliative care delivery, it is suggested that countries need a care model that distinguishes generalist palliative care (basic skills that all healthcare professionals should have) from specialist palliative care (skills for managing more complex and difficult cases), so that they can coexist and support each other.[14, 49] In a coordinated view of such palliative care model, the GP or the treating specialist could manage many palliative care problems such as aligning treatment with a patient's goals and basic symptom management, and, if more complex or refractory problems such as negotiating a difficult family meeting, addressing veiled existential distress, or managing refractory symptoms appear, the treating doctor refers the patient to a specialist palliative care consultation.[49] Generalist-plus-specialist palliative care is the main model endorsed worldwide.[49] The two-step ladder of care can be extended to three steps: a palliative care approach, generalist palliative care and specialist palliative care.[14]

Consequently, when drafting the scope at the beginning of this project, the vision of the Federal Cell was combined with the international vision to allow for the larger scope possible to start the project. An emerging objective was then to define more and more precisely the scope throughout the research process with the aim to arrive at a pragmatic definition in line with the international scientific literature and the opinions of Belgian stakeholders in the palliative care sector.

At the starting phase of the project, "palliative middle care" was temporally defined as a service (*could be a provider (volunteer or professional) or a structure embedded several providers*) delivering palliative care (*generalist or specialist*) which is not a community-based front-line service composed of provider(s) not specifically trained in palliative care (*Palliative care knowledges acquired during basic cursus are not considered as a training in palliative care*) and not a hospital-based palliative care service composed of provider(s) specifically trained in palliative care. A community-based front-line service is for example palliative care delivered by a GP or nurses at home. A hospital-based palliative care service is, for example, a hospital unit specialised in palliative care. The refined and final version of the definition of palliative middle care is considered as a result of this project and is available in Chapter 9. Examples of services which could be included in the scope of this project are home-care hospice services, outreach multidisciplinary palliative care support teams, inpatients hospice services or day-care hospice services. Consequently, this report will focus on one aspect of the PC offer organisation, which can be placed at the intersection of the existing generalist palliative care at home (or at home substitute) and specialist palliative care delivered to patients admitted in hospitals (see Figure 2).

Textbox 1 – Working definitions of palliative middle care at the beginning of this study (2023)

Federal cell working definition of palliative middle care: services which should make it possible to admit patients [requiring palliative care] whose state of health does not (or no longer) require hospitalization in an acute care bed or in a Sp S4 bed [bed in a specialised hospital unit] but who, in the current situation, cannot stay either at home or in a nursing home.

KCE working definition of palliative middle care: a service (*could be a provider (volunteer or professional) or a structure embedded several*

providers) delivering palliative care (*generalist or specialist*) which is not a community-based front-line service composed of provider(s) not specifically trained in palliative care (*palliative care knowledges acquired during basic cursus are not considered as a training in palliative care*) and not a hospital-based palliative care service composed of professionals and volunteers specifically trained in palliative care.

1.4.3.2 Out of scope

The scope of this KCE project is limited to services delivering symptomatic care to patients with oncologic disease undergoing curative treatment in the hope to be cured. This report does not cover the services only delivering support to prevent and manage the adverse effects caused by oncological treatment from the diagnostic to the survivorship. Sciensano, the Belgian Scientific Institute for Public Health, is currently developing an online support BeONCOSup to improve the access to symptomatic care in haemato-oncology targeting chronic symptoms arising during and after anticancer treatments.[c]

The scope of this project is also limited to the delivery of palliative care to adults (aged of 18 years and above). As paediatric palliative care presents differences with adult palliative care, a separated KCE study is envisaged for paediatric palliative care (see Study 2023-06 (HSR) Paediatric palliative care).

[c] More information about this project – BeONCOSup – can be found on the website of Sciensano: https://www.sciensano.be/fr/projets/belgian-handbook-hemato-oncological-supportive-care

1.4.4 Research questions

The purpose of this report is to provide insights about and recommendations for the further development of palliative middle care in order to better respond to the needs of patients requiring palliative care and of their relatives taking into account the current landscape of palliative care in Belgium. These insights and recommendations will help to determine the priorities and the decision-making process when it comes to the implementation of palliative middle care in Belgium.

This project is organised around 3 interrelated research questions.

- **What are the most relevant palliative middle care models to cover the current gaps in the offer (and why)?**

  This question aims at identifying existing model(s) of palliative middle care and identifying which models can fill the gaps in the current landscape of palliative care in Belgium.

- **What are the most acceptable palliative middle care models in Belgium ?**

  This question aims at identifying the priority model(s) to be further developed in the Belgian context.

- **What are the conditions to make palliative middle care work in Belgium ?**

  This question aims at identifying the conditions of implementation related to the selected model(s) and – if possible - at reaching a consensus among stakeholders on the possible models for palliative middle care in Belgium.

Table 2 presents a summary view of the different research questions and the related methods: detailed methods are presented in the Chapter 2.

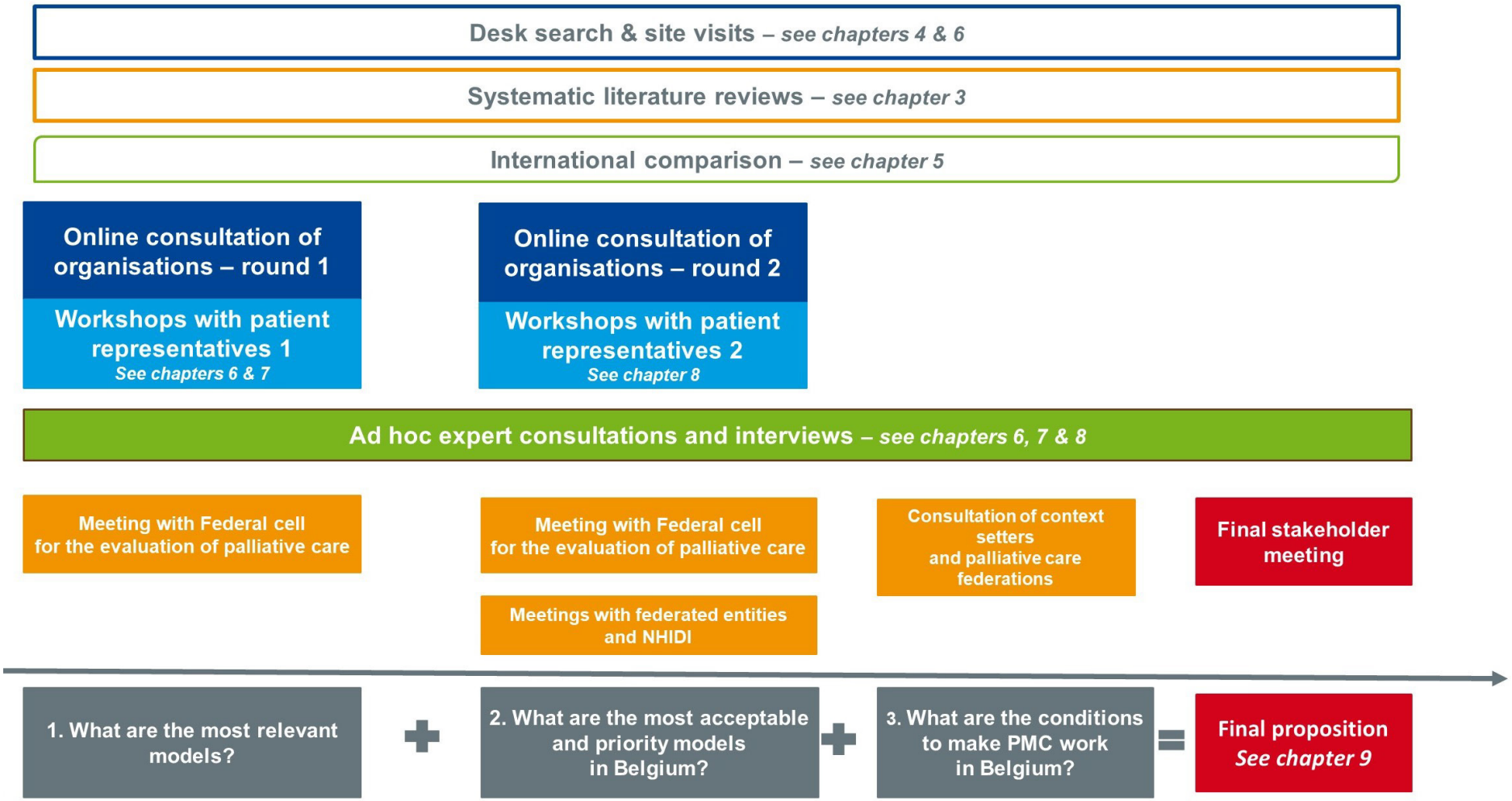
Table 2 – Overview of the research questions and the methods used

Research questions	Methods	Chapters displaying the results
What are the most relevant palliative middle care models to cover the current gaps in the offer (and why)?	• Desk search of existing documents related to palliative care and hospice care in Belgium • International comparison of existing models of palliative care • Site visits of existing initiatives offering "palliative middle care" in Belgium • Online stakeholder survey (round 1) • Workshops with patient representatives (round 1)	• Chapter 4 – How is palliative care organised in Belgium? • Chapter 5 - How is palliative care organised at international level? • Chapter 6 – What are the gaps and problems in Belgium?
What are the most acceptable palliative middle care models in Belgium ?	• Literature review on effectiveness and acceptability of palliative care • Online stakeholder survey (round 2) • Workshops with patient representatives (round 2)	• Chapter 3 – What is the effectiveness and acceptability of palliative care? • Chapter 7 – Which models are relevant to improve palliative care in Belgium? • Chapter 8 – Which models are acceptable and priority for improving palliative care in Belgium?
What are the conditions to make palliative middle care work in Belgium ?	• Ad hoc literature search • Expert consultations • Stakeholder meeting	• Chapter 9 – Propositions for reinforcing and expanding palliative care in Belgium

2 METHODS

This chapter aims at presenting the several research methods used in combination to triangulate different data sources. A stepped approach was used, each step being built on the results of the previous step. Figure 3 presents how these methods were articulated together and which data sources were used to answer the three research questions.

Figure 3 – Overview of the articulation between the methods and the research questions



2.1 Desk research & site visits

Desk search aimed at:

- Gathering international recommendations, guidelines, opinions and other policy documents related to palliative care: these help to better frame the Belgian challenges in palliative care and contribute to the identification of innovative practices when it comes to filling the gaps. They could elicit the policy arguments related to the potential need of further expanding palliative care. The starting point of this desk search was the Atlas of the European Palliative Care Association, the statements of the World Health Association and of the European Council.
- Describing the current landscape of palliative care in Belgium to better understand the challenges faced by professionals, patients and their relatives. Different sources were consulted: Belgian legislation, websites and documents of the authorities and organisations in charge of palliative care (e.g. activity reports or memorandums), websites and documents of the public health authorities (both federal and federated), reports of the Federal Evaluation Cell for Palliative Care, previous KCE reports on palliative care. A secondary objective was to identify emerging initiatives related to PMC (see below).
- Gathering data on the current problems and challenges related to palliative care in Belgium. Similar sources than for the description of the current landscape were used.

Site visits aimed at:

- Gathering data on existing initiatives identified as providing palliative middle care to understand their specificities in the Belgian landscape of palliative care;
- Gathering data on the challenges, problems and solutions regarding palliative (middle) care as experienced by these initiatives.

2.1.1 Identification of the initiatives

All the services delivering palliative care in Belgium that corresponded to the KCE working definition of palliative middle care were listed. Criteria for inclusion were (1) an inpatient or outpatient service delivering palliative care, that (2) was situated between generalist palliative care delivered at home (e.g. by GP and nurses) and specialist palliative care delivered in a hospital. Generalist palliative care at home and specialised hospital-based palliative care (palliative care beds and hospital mobile teams) were excluded. We also excluded the existing outreach multidisciplinary support teams, intervening in the context of home care as a form of specialised community-based palliative care as they already benefited from a structural framework and have a national coverage (the role and missions are discussed in the Chapter 4).

Identification of the initiatives was done through an Internet search, using the search engine of Google with a combination of the following key words (in Dutch and French): palliative care, hospice, day care, mobile palliative care team, respite. Additionally, initiatives of interest were identified through a snowballing approach, using the collaborations mentioned on the websites as a starting point. We also contacted stakeholders in the field of palliative care to triangulate our findings through the Internet search (e.g., palliative care networks*, Kom Op Tegen Kanker*, regional public health authorities). The search resulted in a list of 22 initiatives (14 located in the Flemish region, 6 in the Walloon region – including Ostbelgien and 2 in the Brussels region).

2.1.2 Site visits

All initiatives were contacted via email to organise a visit to better understand the functioning and apprehend the “atmosphere” of the service. As aspects pertaining to the environment and the infrastructure were often mentioned as of particular importance in the field of palliative care, site visits were preferred over online interviews.[50] Moreover, site visits allow for collecting data through observations, which complete the data collected through an interview.[51]

Preliminary information related to the initiative was collected through an online survey filled by a contact person of the organisation. The survey and the interview guide for the site visits were prepared by the research team (in Dutch, followed by a French translation), reviewed, and tested. As no

sensitive information was gathered and no patients were interviewed nor contacted, agreement of an ethical committee was not mandatory. Findings from the interviews were anonymised. Questionnaire and interview guides are available upon request to the research team.

Two KCE researchers (JEA – MAD) conducted the site visits between August 2023 and December 2023: JEA conducted the visits in Flanders while MAD conducted the visits in Brussels and Wallonia. Both researchers are trained as nurses. All interviews were recorded with the consent of the participants. All contacted initiatives – but one - accepted to participate. The initiative that did not participate never replied to the invitation, despite several reminders. There were 18 site visits with interviews of the professionals. Three interviews were held online as the projects were still under development at the time of interview for 2 of the initiatives (November 2023) and because of health problems of the researcher for the last one. Depending on the service, one staff member or several guided the visit: similarly, interviews afterwards were held with one person or with (a part of) the team (e.g. nurses, physicians, volunteers, psychologists, managers…).

2.1.3 Data analysis

Analyses were based on the notes taken during the visits and interviews: when needed, the audio recordings were used to complete the notes or elicit additional elements. Additional search on the website of the services, data included in the online survey and documents received during the visits were used to complete the data. Data were structured by means of a thematic grid, extracting the following elements: 1) description of the initiative (origin, care offer, target groups, admission criteria, human resources, fundings); 2) description of the infrastructure in itself (environment, furniture, and equipment); 3) problems encountered at patient / professional / service / context levels. A narrative synthesis was drafted per type of initiative and the findings were then triangulated with the information retrieved from the desk search. Chapter 4 and Chapter 6 present the findings related to the site visits and interviews.

2.1.4 Limitations

In the absence of formal definition of palliative middle care, the identification of the initiatives was complex and, to some extent, not respecting the exclusion criteria as 3 palliative care units were visited. Various sources mentioned these units as offering palliative middle care: it was therefore decided to meet them to better understand why they were designated as such. During the visit, the researcher confronted them with this appellation of being a PMC service. They expressed surprise of being identified as “middle care unit.” When asked to provide explanation, they suggested that it could be because they keep the patients for prolonged periods, that is more than one month of hospital stay contrary to other units where the length of stay is, according to the respondents, limited (also see Chapter 6).

> *« A la limite, ça nous coûte de garder le patient. Et donc on a la chance d'avoir la direction qui n'est pas super à cheval là-dessus et donc on a la possibilité, de temps en temps, quand, vraiment on ne voit pas de solution, de garder parce que on a toujours au moins un patient long séjour ». Respondent from the FR site visit - 1*

Another explanation provided by a respondent is that external professionals confounded their unit with the neighbouring nursing home. Other pointed out that the local environment played a role (e.g. being in a park and not in a hospital campus).

The absence of formal definition can lead to an underestimation of the existing initiatives. To counterbalance the absence of an official registry of palliative middle care, various sources were triangulated to identify these initiatives. The resulting findings reflect therefore the diversity of the possible forms of palliative middle care in Belgium. Visit were held between August 2023 and Decembre 2023. Since then, various reforms are ongoing and likely to influence the organisation of the field. Therefore, regular contacts with stakeholders, professionals and services helped to update the information. Additionally, at the moment of the interviews, several respondents were unsure about the future of their initiatives, regarding normative and financial aspects. Since then, there could have been changes to enhance the sustainability of the services or to put an end to their activities. Consequently, the data presented in the chapter 6 should be seen as a photography of different projects at a given time. Some initiatives were

more documented as they were older and / or more formalised (e.g. activity reports): it allowed to give more details on their activities when compared to others.

Site visits were conducted by a single researcher for practical reasons: therefore, being able to conduct such visits with 2 researchers could have led to additional questions and probes, aiming at eliciting some aspects that could be poorly understood. Hopefully, additional information was received by email.

2.2 Literature reviews

2.2.1 Effectiveness of palliative care services

Search strategy

A search strategy was developed by the KCE knowledge manager (NIF) based on a selection of key words (and their synonyms) suggested by 2 KCE researchers (AND & JEA), including: 'palliative,' 'hospice', 'terminal care', 'effectiveness', 'cost', 'reviews'. The research team decided to first apply an open search strategy without too many restrictions, to avoid missing relevant references. The restricted search period (2015-2024) and the focus on reviews were the two main restrictive criteria.

The search strategy was initially developed for MedLine and was then applied in following databases: Cochrane, Embase and CINAHL. The Supplementary Report present the details of the search strategies.

Manual selection of the retrieved references was based on a list of criteria, primarily focused on type of outcomes, to get an overview of effectiveness of different types of palliative care services on organisational outcomes, i.e. healthcare utilisation (see Table 3). The most important exclusion criteria applied during the selection were: 1) interventions in hospital setting (including intensive care units (ICU) and emergency department), 2) unclear reporting of the results on the outcomes in which no differentiation was made between types of interventions (e.g. general reviews on the effectiveness of all types of palliative care services compared to usual care in which the effect could not be attributed to one type of palliative care) and patient-centred outcomes (e.g. quality of life, patient satisfaction, etc).

Table 3 – Inclusion criteria for the literature search on effectiveness of palliative care services

Inclusion criteria for the literature search on effectiveness of palliative care services	
Type of intervention	Palliative care services provided in all types of settings, outside the hospital setting, including following types of services: - Palliative care in the usual place of residence (at home, in nursing home, in other types of home settings); - Specialised community-based palliative care services; - Interventions promoting collaboration between primary and secondary care, including multidisciplinary teams, outreach teams, GP involvement; - All types of ambulatory care settings: day care centres, day hospitals, ambulatory consultations; - More specific interventions: out-of-hours services, medicine access, focus on the specific role of one type of healthcare provider (e.g. nurse-led interventions); Comparator: usual care (mainly defined as care without palliative care components), other types of palliative care services
Type of participants	Adults (over 18 years) with advanced illness from malignant or non-malignant disease in the last year of life
Outcomes	Focus on organisational outcomes related to healthcare utilization including: - Hospital use: (re-)admission rate, length of stay, emergency department attendance, ICU visits - Primary care use: GP visits - Place of death (if available also preference for place of death) - Transfers to other care services: e.g. nursing homes, hospices - Cost-effectiveness Identification of characteristics of interventions related to - Composition of team members: profiles, competences - Setting - Collaborations between healthcare professionals - Perception of patients, informal caregivers on the experiences with the care service (including barriers and facilitators)
Search date	2015-2024, search performed on 21.02.2024
Type of included studies	(systematic) reviews, including meta-analyses, with clear reporting of outcomes per type of palliative care service
Languages	English, Dutch, French

Search results

A KCE researcher (AND) screened for 961 records for eligibility and included, after stepwise selection firstly on title and abstract followed by selection on full text, 34 reviews. Doubts about the inclusion or exclusion of references were discussed within the whole research team. The following categories of palliative care services were found: palliative care in the usual place of residence, specialised palliative care services in the community, additional services such as out-of-hours services, access to medicines in the community, different types of collaboration between primary and secondary care.

All included studies were summarised in an evidence table per reference, on a structured manner, which facilitates reading and comparison between the retrieved reviews. Next to the essential data on the comparators and the outcomes, also all data on the description of the intervention were included in these tables and interpretations by the authors were cited. All evidence tables are in the Supplementary Report. The full list of excluded studies is available on request.

2.2.2 Acceptability of palliative care services

Search strategy

A search strategy was developed by the KCE knowledge manager (NIF) based on a selection of key words (and their synonyms) suggested by the KCE researchers (AND & JEA), including: 'palliative', 'hospice', 'preference, 'expectation', 'reviews'. As for the review on effectiveness, an open search strategy was applied, with a restricted search period (2014-2023) and a focus on reviews.

The search strategy was initially developed for MedLine and was then applied in following databases: Cochrane, Embase, PsychInfo and CINHAL. These search strategies can be found in Supplementary Report.

Manual selection of the retrieved references was based on a list of criteria, primarily focused on type of outcomes, to get an overview of the perceived barriers related to hospice use by patients and informal caregivers (see Table 4). The most important exclusion criteria applied during the selection were: 1) evidence on therapeutic interventions, 2) children, 3) reviews on specific patient groups (e.g. prisoners), 4) acceptability of working in a hospice / in palliative care. The perception of healthcare professionals on the acceptability of hospice / palliative care was not primarily in the focus on this search strategy but during data extraction the outcomes related to healthcare professionals were also included, however some references could be missed due to the primarily selection on patient perceptions.

During data extraction, it was decided to perform an additional more specific search on preferred place of death. Similar inclusion and exclusion criteria were applied but focused on the preferred and actual place of death and barriers related to differences between both.

Table 4 – Inclusion criteria for the literature search on acceptability of hospice care

Inclusion criteria for the literature search on acceptability of hospice care	
Type of intervention	Access and / or use of hospice care, and even more in general palliative care, provided in all types of settings Comparator: access and / or use of usual care (mainly defined as care without palliative care components) or of other types of palliative care services
Type of participants	Adults (over 18 years) with advanced illness from malignant or non-malignant disease in the last year of life General adult population
Outcomes	Acceptability of access and / or use of services, with focus on facilitators and barriers including: - Sociodemographic characteristics - Societal awareness - Expectations before admission - Preferred place of death - Experiences during hospice stay - Values attributed to hospice care by informal caregivers and patients - Experiences perceived by informal caregivers - Barriers in access to hospice care related to healthcare professionals and health system
Search date	2014-2023, search performed on 22.05.2023
Type of included studies	(systematic) reviews, including quantitative data and qualitative data
Languages	English, Dutch, French

Search results

A KCE researcher (AND) screened for 1168 records for eligibility and included, after stepwise selection firstly on title and abstract followed by selection on full text, 20 reviews. Doubts about the inclusion or exclusion of references were discussed within the whole research team. The search on preferred place of death revealed 18 reviews of which 8 were included for data extraction.

All included studies were summarized in an evidence table per reference, on a structured manner, which facilitates reading and comparison between the retrieved reviews. All evidence tables are presented in the Supplementary Report. The full list of excluded studies is available on request.

2.2.3 Limitations

In some reviews the data on the actual place of death of the participants was not reported, in others a range of percentages per location was given, which hampers the interpretation of the findings. Some methodological limitations should also be taken into account in the interpretation of the findings: often the conclusions made by the authors of the reviews were based on very small number of primary studies, with poor reporting of results with limited transparency on quantitative data (e.g. percentages without total number of participants reported), and also a lack of reporting of further explanation behind predictive factors associated with preference which hampered translation to the Belgian palliative patients.

Palliative middle care is a terminology developed by the Belgian Federal Cell for the Evaluation of Palliative Care. Consequently, a large definition was

applied with a focus on out-of-hospital care as PMC was initially defined as "not in the hospital." This focus on community-based palliative care was also in congruence with the recommendation of the European Palliative Care Association.[5] This choice may have prevented us from identifying innovative effective hospital-based interventions. Therefore, when comparing the results of the literature review with those of the international comparison (see Chapter 5), the range of services identified in this review are congruent in both chapters.

It should also be noted that these interventions were developed in various contexts which can prevent the transferability of these interventions in the Belgian context, despite being identified as effective.

2.3 International comparison

International comparison aimed at:

- Giving an overview of the general context and organisation of palliative care in a selection of countries
- Describing the inpatient palliative care services developed in the selected countries in order to fulfil the needs of the palliative patients and of their relatives
- Identifying advantages and drawbacks of each service when compared to the Belgian situation

2.3.1 Selection of the countries

Three key publications regarding palliative care were used as a starting point of the international comparison: 1) the EAPC atlas of palliative care in Europe 2019[5], 2) the Quality of Death report of 2015[52d] and 3) the 2022 publication of Finkelstein and colleagues on a cross country comparison of the quality of death and dying in 2021.[53] These 3 publications served to make a first selection, based on the organisation and context of healthcare, which resulted in a list of 14 European countries presented in Table 5.

For each of the 14 countries, the following items were compiled to further describe the situation of palliative care from a policy perspective in each country:

- Score of quality of death: this score is based on the study conducted by Finkelstein et al. (2022). This score is calculated across 5 categories: Palliative and healthcare environment (20% weighting; 4 indicators); Human resources (20% weighting; 5 indicators); Affordability of care (20% weighting; 3 indicators), Quality of Care (30% weighting; 6 indicators); and Community engagement (10%; 2 indicators)
- Existence of a law specifically addressing palliative care,
- Existence of other relevant laws related to palliative care (e.g. related to patient rights)
- Existence of a specific budget at national level for the provision of palliative care
- Existence of a national palliative care plan guiding the organisation and the offer of palliative care
- Implementation of the plan in practice
- Evaluation of the plan (audit)
- Existence of national palliative care standards supporting the practices of healthcare professionals
- Existence of a national association for palliative care

[d] The Economist Intelligence Unit's Quality of Death Index highlights the public engagement and policy interventions to improve the quality of death through the provision of high-quality palliative care and the great strides made by some countries in improving affordable access to palliative care as well as the remaining challenges and gaps in policy and infrastructure.

Table 5 – Overview of the national characteristics of 14 European countries regarding palliative care

Country	Score of Quality of Death (2021)[1]	Law on PC*	Additional laws related to PC*	Specific PC national budget*	National PC plan*	Implementation of PC plan*	Audit of PC plan*	National PC standards*	National PC association*
Austria	74.8 (2015)	N	Y	Y	Y	Y	Y	Y	Y
Belgium	80.7	Y	Y	Y	N	N	N	Y	Y
Denmark	75.4	N	Y	Y	Y	Y	N	Y	Y
Finland	81.7	N	Y	Y	Y	Y	Y	Y	Y
France	82.6	Y	Y	Y	Y	Y	Y	Y	Y
Germany	86.9	Y	Y	Y	Y	Y	Y	Y	Y
Ireland	92.9	N	N	Y	Y	Y	Y	Y	Y
Italy	71.1 (2015)	Y	Y	Y	Y	Y	Y	Y	Y
Netherlands	80.9 (2015)	N	Y	Y	Y	Y	Y	Y	Y
Norway	87.9	N	Y	Y	Y	Y	Y	Y	Y
Portugal	49.9	Y	Y	Y	Y	Y	N	Y	Y
Spain	80.3	N	Y	Y	Y	Y	N	Y	Y
Sweden	85.3	N	Y	N	Y	Y	Y	Y	Y
United Kingdom	93.1	N/A	N/A	Y	N	Y	Y	Y	Y

[1]This score is retrieved from the study of Finkelstein et al., 2022.[53] Score is given for the year of reference 2021, unless stated otherwise.
**Data from these columns are retrieved from the Atlas of the European Association of Palliative Care (2019).[5]*
Legend: N:No; Y: yes, N/A: not applicable.

Alongside the policy framework, the following criteria related to the operationalisation of the palliative care in the country were included (Table 6):

- Proportion of palliative care services per 100 000 inhabitants,
- Number of palliative day care centres,
- Number of volunteer-led hospices,
- Distribution of the palliative care offer regarding inpatient hospital care, inpatient hospice care, outreach care, and mixed care supply

Table 6 – Overview of the offer in palliative care in 14 European countries

Country	Number of PC services /100000 inhabitants	Number of volunteer driven hospices	Number of PC day care centres	Proportion of PC units in hospitals	Proportion of inpatient hospices	Proportion of PC outreach teams	Proportion of hospital PC support teams	Proportion of PC mixed teams[1]	Ratio hospital/community services
Austria	2.2	184	2	22%(43)	6%(12)	35%(67)	37%(71)		59/41
Belgium	1.7	84	5	26%(51)	1%(2)	14%(28)	59%(116)		85/15
Denmark	0.9	28*	4*	17%(9)	35%(19)			48%(26)	Mixed
Finland	0.7	/	2*	26%(10)	10%(4)	59%(23)	5%(2)		31/69
France	1	/	15*	21%(139)	0%	14%(90)	65%(424)		86/14
Germany	1.1	1300	/	37%(336)	25%(232)	31%(283)	7%(63)		44/56
Ireland	1.9	/	9	2%(2)	12%(11)	37%(34)	49%(45)		51/49
Italy	0.9	/	/	0%	42%(240)	58%(330)	0%		0/100
Netherlands	0.9	91	29*	16%(24)	31%(46)	12%(18)	41%(62)		57/43
Norway	1.1	6*	5*	34%(21)	0%	0%	0%	66%(40)	Mixed
Portugal	0.9	2*	2*	18%(17)	14%(14)	22%(21)	46%(44)		64/36
Spain	0.6	/	2*	24%(63)	1%(1)	38%(100)	34%(88)	3%(8)	Mixed
Sweden	1.6	/	19*	6%(10)	15%(25)	73%(120)	6%(10)		12/88
United Kingdom	1.3	/	272*	0%	26%(223)	34%(291)	40%(346)		40/60

*Legend: Data indicated with a * are retrieved from the 2013 EAPC Atlas. The other data are from the 2019 EAPC Atlas: Data were directly extracted from the sources without to be checked further at the step of the selection of the countries to be compared. [1]Mixed team are teams that, generally from the hospital, provide care to patients in their homes and not only during hospital admission. Source: EAPC Atlas 2019[5], (ii) the Quality of Death report (2015)[52] and (iii) the 2022 publication of Finkelstein and colleagues on a cross country comparison of the quality of death and dying in 2021[53]*

Subsequently, a first quick search was done for each of the 14 countries to identify the items of interest on the organisation of inpatient PC and the availability of information related to this type of service. This search highlighted elements that helped to select countries for further description.

Criteria considered for definite selection were: 1) the "size" of the hospice offer in the country (no offer or diversified offer), 2) the existence of different types of palliative care provision, 3) the availability of performance assessments, 4) the scores of quality of death, 5) the availability of the information.

2.3.2 Data collection and analysis

Four countries were selected for further analysis: France, Germany, the Netherlands and the United Kingdom. Alongside the above mentioned selection criteria, these four countries were also selected because, together, they represent a diversified view of the current situation of palliative care across Europe and that information was easily accessible (from both practical and linguistic perspectives). For each country, the scientific literature and grey literature were search, with a focus on governmental and organisational websites (e.g. country's association of palliative care). More specifically, information on how hospice care is embedded in the whole context of palliative care services were searched. Data were categorised across the following dimensions: 1) context of palliative care in the country; 2) policy regulation and control; 3) access to palliative care; 4) palliative care offer; 5) target groups of palliative care; 6) staffing in palliative care; 7) role of volunteers; 8) financing and reimbursement; 9) umbrella organisations; 10) quality; 11) evaluation. Data were then triangulated between the different countries and compared with the existing situation in Belgium.

2.3.3 Validation process

A first draft of the results was sent to a national expert in each of the country studied for validation. Experts were identified through the desk search and previous KCE reports: their biography and publication list were verified to confirm their expertise. They were invited to comment and critically review the draft document for their country (see Colophon): these comments were integrated in an updated version of the results.

2.3.4 Limitations

The EAPC report only consulted one or a few experts per country: the results might be less accurate than a report using an in-depth analysis. Despite this potential limitation, it remains a good starting point for an international comparison. Similarly, only one reviewer was consulted per country which could led to a biased view. Therefore, as these experts were selected based on their contribution to the field of palliative care, they were likely to provide an informed view on the topic. As the EAPC was the guiding document for the selection of countries, this comparison did not consider non-European countries that may have developed interesting approaches regarding palliative care such as Australia.

2.4 Stakeholder consultation

A stakeholder consultation was chosen as the aim was to identify the possible orientations for the development of palliative middle care in Belgium when considering the current context and gaps. The approach taken was informed by previous KCE studies in which such approach has been successfully applied.[54, 55] In this study, the stakeholder consultation was organised in three interrelated steps, each step corresponding to a specific objective:

- Step 1: to identify which relevant options in palliative middle care can solve the current gaps in the Belgian context
- Step 2: to identify the acceptable options in palliative middle care
- Step 3: to identify the implantation conditions for the final options

Stakeholders are defined as "actors (persons or organisations) with a vested interest in the policy being promoted".[56] As stakeholders constitute a heterogeneous group, different methods of consultation were combined to better apprehend the perspectives of each group: an online consultation targeting professionals, workshops with representatives of patients and relatives, ad-hoc consultations with experts and stakeholder meetings.

2.4.1 Identification of the stakeholders

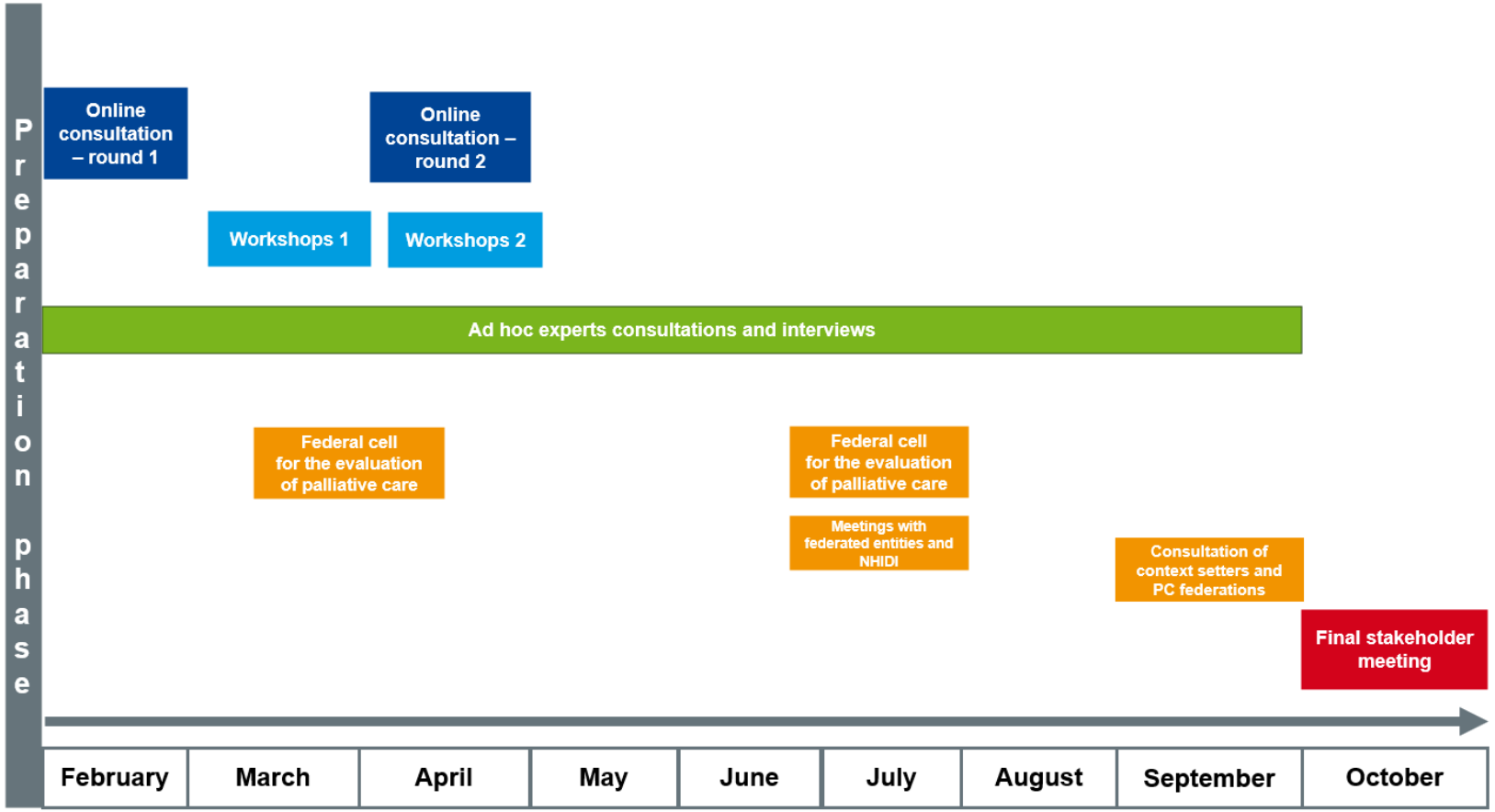
A broad list of all relevant stakeholders in the field of palliative care and health care policy in Belgium, including patients or their representatives was first drafted. Stakeholders were defined as those whose activities are related to palliative (middle) care or influenced by palliative (middle) care. They were identified through different channels: desk search, existing list of stakeholders available at KCE, previous KCE projects, and from the site visits.

The different stakeholders were categorised according to the following dimensions: key role in palliative care / health care policies, level of actions (federal / regional / provincial / local), linguistic regimen. This categorisation allowed to ensure a diversity in the profile of stakeholders.

Based on this categorisation, different strategies for collecting the stakeholder perspectives were combined as done by other researchers conducting stakeholder consultations.[57, 58] These different strategies are presented in the Figure 4 and are detailed in the sections below.

- **Workshops**: representatives of patients and relatives
- **Online consultations**: institutional members of the palliative care federations, professional associations, federations of hospitals, nursing homes and municipal welfare centres, sickness funds, primary care zones, coordination of home care services
- **Stakeholder meetings**: public authorities at federal and regional levels, federal cell for palliative care
- **Ad-hoc consultations**: academic and scientific experts, charities, field workers…

Figure 4 – Temporality of the stakeholder consultation on palliative care in Belgium, 2024



2.4.2 Online consultations of organisations

Recruitment process

In February 2024, invitations to participate were directly sent to 193 organisations previously identified. One questionnaire was expected by service / institution as this survey did not aim at collecting individual opinions. The invitation was also sent via the three federations of palliative care to disseminate the surveys among their members, especially the outreach multidisciplinary support teams, the hospital support teams and the palliative care units (because of the GDPR, the federations were not allowed to share the contact details of their members). From feedback received from some organisations, we were informed that our questionnaire was sent multiple times to some organisations which can be seen as an indicator of dissemination. Therefore, we are not able to report the number of organisations that received the questionnaire.

The same participants were invited to participate to the second online consultation in March 2024.

Tools for data collection

First round of consultation

Based on the data collected during the desk search, the site visits, and the literature, we developed an online close-ended questionnaire. The questionnaire was divided in 5 parts: 1) general information about the participants, 2) expertise and experience in the field of palliative care.[56], 3) gaps in the current offer, 4) characteristics of palliative middle care and 5) relevant options for developing palliative middle care in Belgium. Participants had the possibility of commenting their answers in open text boxes. Questionnaires are available upon request to the research team.
The questionnaire was first drafted in French then translated in Dutch. The questionnaire was assessed for language, content and practicability by KCE experts (CAD, CEP, EVC, ISS, KOV, LAK).

Second round of consultation

Based on the data collected during the first round, the literature reviews, the desk search of the Belgian context and the workshops with the representatives of patients, we developed a second online close-ended questionnaire. The questionnaire was divided in 5 parts: 1) general information about the participants, 2) transversal principles related to the organisation and the philosophy of palliative middle care, 3) proposals related to ambulatory offer, 4) proposals related to residential offer and 5) closing of the questionnaire. Participants had to choose between different options, with the possibility of commenting their answers in open text boxes. Questionnaires are available upon request to the research team.
The questionnaire was first drafted in French then translated in Dutch. The questionnaire was assessed for language, content and practicability by KCE experts (CAD, CEP, GUB, ISS, LAK).

Data collection

For the first online consultation, the questionnaire was launched on 05.02.2024, on the online platform Lime Survey. A reminder was sent on 19.02.2024. The questionnaire was closed on 05.03.2024.

For the second online consultation, the questionnaire was launched on 19.03.2024.on the online platform Lime Survey. A reminder was sent on 15.04.2024. The questionnaire was closed on 01.05.2024.

Analysis

Partial responses were included in the final sample if the organisations completed at least the third part of the questionnaire. Data were subjected to descriptive statistical analysis by a KCE researcher (ISS) using SPSS software, version 29, and graphical representations were created using Microsoft Excel. Whenever deemed appropriate, subgroup analyses were done by the region. Qualitative data were analysed by themes by another KCE researcher (MAD) and were used to nuance or develop the quantitative data.

Ethical aspects

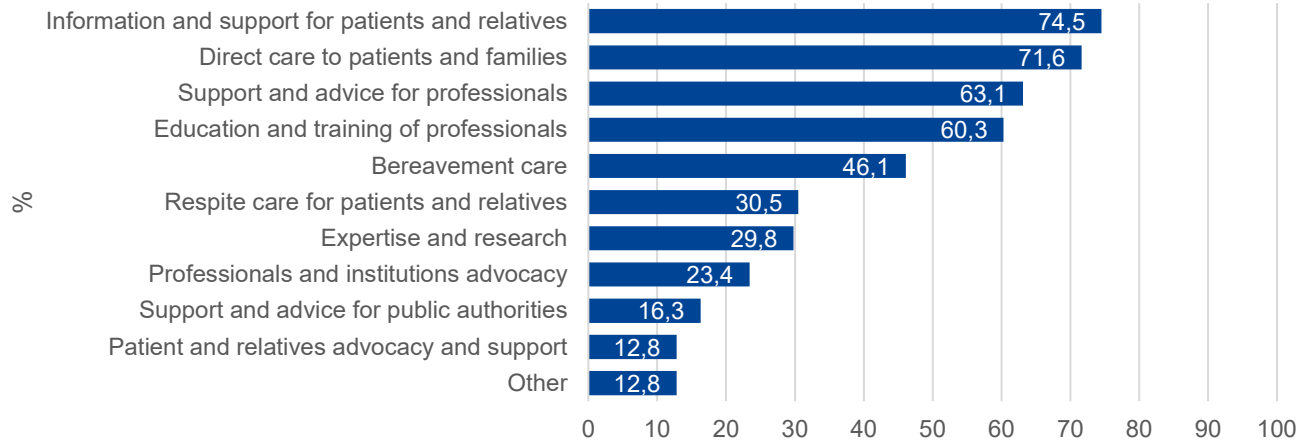
Participants gave their consent to participate to the study and were informed about the data privacy policy.

Participants

First online consultation

A total of 141 different organisations participated in the first online consultation. About 18% of the 141 organisations who participated to the survey are active at federal level (see Table 51 in Appendix 3). Among those who work at the regional or provincial level, they were overall evenly distributed over the Belgian territory. The panel of activities and services declared by the organisations was large and covered a lot of domains: more than 70% of the organisations provide information, advice and direct care to patients and relatives; more than 60% provide support and training to professionals; about a third provides respite for families, expertise and research; and about a quarter are representatives of professionals and health services (Figure 5).

Figure 5 – Repartition of activities of the participating organisations to the online consultation, 2024 (N=141)



Overall, the panel of organisations who participated to this survey seemed to have a lot or at last good expertise in several domains related to palliative care, such as ethical and deontological aspects (89.3% are (totally/very) expert), social care (88.0%), somatic care (87.3%), psychological care (84.5%), legal and regulatory aspects (83.6%), spiritual care (70.2%), financial aspects (66.7%), and political and strategic aspects (46.1%, see Table 52 in Appendix 3).

In concordance with their expertise, organisations declared having some to a lot of influence on the domains described above, especially regarding psychological, social and somatic care where more than 50% of the organisations declare to be influent (see Table 53 in Appendix 3).

Second online consultation

A total of 155 organisations participated to the second round of the online stakeholder survey. Among those, 96 had already participated to the 1st round of the survey.

2.4.3 Workshops with representatives of patients

Recruitment process

As the consultation aimed at collecting stakeholder perspectives and not individual experiences or preferences, we opted for a consultation of patient representatives. Patient representatives are defined as "*representatives of a patient organisation or patient population, not necessarily affected by the condition under consideration. Patient representatives are considered to be advocates defending specific interests of a specific patient group (e.g. patients with lung cancer) or a broader group of patients (e.g. cancer survivors). They have a broader perspective on the problems and experiences of the population than the individual expert by experience*" (retrieved from Cleemput et al. 2019, page 6).[59]

A call for interest was directly sent in January 2024 to a selection of patient associations whose objectives are likely to be connected to palliative care and / or end-of-life (e.g. associations related to cancer and oncology). To increase participation, the call for interest was also disseminated by the umbrella associations to their members.

The call for interest was accompanied by a description of the project and a short online questionnaire to elicit preferences regarding the practical organisation and the experience of the associations in the field of palliative care and / or end-of-life. Potential participants were informed about the sensitive aspect of the discussions. Participants were also invited to commit for 2 sessions in order to facilitate the continuity of the discussions.

Tool for data collection

A discussion guide was used to moderate the workshop.

For the workshop 1, the discussion guide was organised around 2 key questions: 1) to which extent the current palliative care offer matches the patient profiles; 2) what is / are the most relevant solution(s) to improve organisation of palliative (middle) care. The questions were adapted from the online survey questionnaire. The discussion guide was first drafted in French then translated in Dutch before being checked for structure and language by KCE experts (CEP – JED). Full discussion guide is available upon request to the research team. For the workshop 2, the discussion guide followed the structure of the online survey (see below). Probing questions were added to facilitate the discussion.

Data collection

Workshop 1 – March 2024

Based on the participants preferences, the research team opted for an online workshop. Online workshops allow for a participation of those with mobility problems although it requires that the participants have a performant Internet connection and have good digital skills.[60] Online discussion therefore appears to contribute to geographic and demographic diversity of the participants, with a low drop-out rate.[61]

One week before the workshops, the participants received a preparatory document describing in short, the current landscape of palliative care in Belgium and the key characteristics of patients in palliative care. Participants also received the questionnaire of the online survey.

The workshop was held online on 04.03.2024 (French workshop) and on 05.03.2024 (Dutch workshop). A total of 9 participants attended both

workshops, representing six different associations. Among the participants, four participants were salaried employees of the patient associations, and five participants were volunteers involved in associations. One salaried employee has a previous experience as coordinator of home care services. Three patient representatives were also involved as patient educators for healthcare professionals.[e] Representatives were involved in associations representing the following health problems and situations: Alzheimer Disease, scleroderma, amyotrophic lateral sclerosis (ALS), pulmonary hypertension, bladder cancer, and informal caregivers. Two representatives were not able to attend for personal reasons: it was proposed to organise a separate semi-structured interview, using the discussion guide as interview guide. But none of the representatives followed the demand.

Workshops were moderated by 2 KCE experts (MAD, a community health nurse, French native speaker– AND, a physiotherapist, Dutch native speaker) assisted by KCE experts acting as notetakers (CEP, a health economist – JEA, a nurse). MAD and AND are both members of the KCE qualitative research group and are experienced in conducting workshops. Workshop started by a round of presentations of participants before moving to the 2 key questions. To facilitate the discussion, a virtual whiteboard on Miro® was used. Sticky notes with existing services and patient characteristics were prefilled and empty sticky notes were available for additional variables. During the workshop, the notetaker simultaneously wrote the propositions of the participants on sticky notes and positioned it on the screen based on participants' inputs. This allowed for a direct validation of the findings by the participants.

Workshop 2 – April 2024

The second workshop was held online on 17.04.2024 (French workshop) and on 18.04.2024 (Dutch workshop). One patient association was not able to attend the workshop: a separate online meeting was organised with 3 members of this association.

Workshops were moderated by the two same KCE experts (MAD – AND) assisted by KCE experts acting as notetakers (ISS, a physiotherapist – EVB, a project coordinator). A total of 9 participants attended both workshops/ 6 participants joined the French speaking workshop (4 different patient associations) and 3 participants joined the Dutch speaking workshop (3 different patient associations). All participants to the second workshop participated in the first workshop.

Analysis

Workshops were audio recorded. For the first workshops, analysis was based on full verbatim transcriptions and on the notes taken during the workshop. For the second workshop, analysis was based on the notes taken during the workshop and completed by listening the recording of the meeting. One researcher analysed the entire corpus of data in both languages (MAD). Data of both workshops were analysed per category, following the question guide. Analyses were checked by a second researcher (AND) to ensure the validity and the consistency of the analysis before sharing and discussing the findings with the rest of the team (ISS, CER).

In a second step, data of the workshops were triangulated with the results of the online consultation.

It should be noted that not all findings pertain to the topic of palliative (middle) care: several elements mentioned during the workshops or in the online survey relate to the wider context of palliative care. Emerging issues

[e] Patient educators are patients or informal caregivers who are active in a patient association. They co-teach courses based on their expertise in cross-disciplinary themes: living with a chronic illness, patient rights, empowerment, therapeutic patient education, quality of care, and communication between caregivers and patients. (Definition adapted from: https://www.luss.be/wp-content/uploads/2021/08/projet-patients-formateurs-appel-a-candidatures-2021.pdf)

related to the healthcare system were brought by the patient representatives and the organisations who participated to the online survey. These are included in the Chapter 6 as palliative care should be considered in an integrative way but as they were out-of-scope of this report, they were not be further explored.

Quotes have been edited for length and clarity and kept in their original language.

Ethical aspects

Before participating to the workshops, participants disclosed their potential conflicts of interest. No further ethical approval was required as the participants were not expected to share their personal experience, sensitive or health data. Participants gave their consent for the recording of the workshops.

2.4.4 Stakeholder meetings

Work meetings with the Federal Cell

In addition to regular contacts to inform about the progression of the research, two formal work meetings were organised with the Federal Cell. The first meeting was held in March 2024, after the first round of online survey and the first workshop with patient representatives. During this meeting, a preliminary version of the results was presented and commented by the members of the Federal Cell. This helps to elicit some results and to further elaborate the elements that were integrated in the second round of the online survey and in the second workshop with patient representatives.

A second meeting was organised in June 2024, after the second round of the online survey and the second workshop with patient representatives. This second work meeting aimed at presenting a first proposal for the development of palliative middle care in Belgium. A work document was shared to the members of the Federal cell, with the possibility of sharing additional remarks and comments after the presentation of the meeting.

After each meeting, the remarks and comments were discussed by the research team to further improve the proposed model. Moreover, the Federal Cell was an important source of information for the Belgian context (see section on the desk search at the beginning of this chapter).

Work meetings with the federated and federal entities

In May 2023, several exploratory meetings were organised with the federated entities to present the objectives of the project and explore how the entity positions itself regarding palliative (middle) care. It was also useful to identify initiatives related to palliative middle care for the site visits (see above).

In June – July 2024, taking into account the current repartition of competences and the ongoing reforms in the different federated entities (see Chapter 4), four separate work meetings were organised with the administration of the federated entities: *Departement Zorg* for the Flemish region, regional and community services of the Brussels region, *Agence pour une Vie de Qualité* of the Walloon region and the German speaking community. Based on the preliminary results of this study (after the second online consultation and the second workshops), these meetings aimed at identifying the key elements of palliative middle care and how palliative middle care can be implemented in the regional context and in Belgium. Similarly to the approach with the Federal cell, each entity received a work document with the proposal for further commenting it.

A work meeting was held with the NIHDI with the same approach in July 2024.

Consultation of the palliative care federations

The 3 palliative care federations are key players in the Belgian landscape of palliative care. They are members of the Federal Cell but also have specific missions (Chapter 4). Because of this particular expertise, they were consulted during the process of the project for different purposes: contribution to the description of the Belgian context and of the challenges, dissemination of the online consultations, ad hoc questions regarding the development of palliative middle care …They were also consulted on an updated version of the model for palliative middle care in September 2024, similar to the context setters.

Consultations of the context setters

Context setters are stakeholders with a perceived high power on the topic but whose main interest is not the topic itself. These context setters were previously consulted during the online survey but not all of them participated. They were therefore important actors to consult: this is why an additional consultation strategy was developed to ensure that their perspectives were heard and, to some extent, considered in the model as it may influence its implementation. Specifically, this consultation aimed at collecting advantages and drawbacks about the feasible options in palliative middle care – including implementation conditions and contextual factors that need to be taken into account – and at identifying preferred options.

The following context setters were contacted: patient umbrella associations (n=6) and informal caregivers associations (n=2), hospital federations (n=7), professional associations of GP and specialists (n=9), professional associations of nurses (n=11).

The consultations were held online in September 2024: a work document was sent with guiding questions for facilitating the reviewing of the document. Context setters were invited to provide written answers and comments. Context setters were also invited online meeting to further discuss it with KCE researchers if they wished so. Three meetings were organised: 1) patient umbrella associations and informal caregivers' associations; 2) hospital federations; 3) professional associations of nurses, GP and specialists. Written comments were received from each category of context setters but not all replied.

Final stakeholders meeting

A final stakeholder meeting was organised on 17.10.2024. During this meeting, the results of this project were presented to the Federal Cell for the Evaluation of Palliative Care, the Palliative Care federations, the federal and federated entities, the Federal Council of Hospitals and the NIHDI. A total of 12 participants attended the meeting.

Participants had the possibility to share their last comments during this meeting, indicating facilitators and barriers at policy level that may influence the final recommendations. The final recommendations of this report are presented in the syntheses accompanying this report (in French and in Dutch).

2.4.5 Ad hoc consultations

Ad hoc consultations were organised on a punctual basis to further explore some elements identified in the online consultations or in the workshops. These consultations also served to get additional data when it comes to develop the proposals included in the models. Participants were selected based on their expertise and / or institutional appurtenance.

2.4.6 Limitations

There was no consensual definition of palliative middle care and its operationalisation in practice remained differently perceived by actors and organisations, as it was observed in the different interactions until the end of the project. For the first online survey, a broad definition of palliative middle care but this definition was perceived as too vague and some organisations expressed their difficulties in completing the survey. This was also reflected in the number of organisations that started the questionnaire but did not finish it. Organisations invited to the online survey had the possibility of commenting their responses thorough the whole questionnaire, which helped for the interpretation of their responses and to nuance some close-ended questions. Moreover, *palliative middle care* was translated in French and not kept in the English wording. This was a possible source of confusion for those familiar with the report of the Federal Cell where the term palliative middle care is used in English. It should also be noted that some also use the term "middle care" (or medium care) in the context of intensive care for patients who require a constant monitoring after a surgery or a major illness but in a less intense way than an intensive care unit where the

patients are, for example, intubated.[f] For the second online survey, building on the experience of the first survey, the vocabulary was carefully checked and the English wording was kept everywhere. The drop-out rate was lower by comparison and, surprisingly, some organisations who did not participate in the first survey participated to the second survey. The same database was used to contact organisations. One can hypothesise that these new organisations found the second survey easier to complete as it was shorter with more closed-ended questions.

Based on patient representatives' preferences, the workshops were held online. Online workshops limit the interactions between participants and are likely to produce less in-depth data.[62] But, as some patient representatives already participated in previous KCE reports and / or know each other from other joint activities, interactions were therefore present. Despite not being familiar of the current organisation of palliative care, all patient representatives contributed to the discussion based on their experiences and knowledge. The diversity of the patient representatives was a strength of these workshops. Surprisingly, oncologic conditions and cancer were less present in the group: however, patient representatives were also able to voice their ideas about palliative care and cancer. Similarly, the online organisations were diverse. The online survey aimed at a diverse and heterogenous group of organisations with various experiences regarding palliative care and health care organisation. The final sample of the online survey reflected this diversity, contributing to the validity of the results. We do therefore acknowledge that more efforts were needed to better reflect the diversity of the Belgian society. Patient representatives insufficiently reflected the ethnocultural and socioeconomic diversity of Belgium: this is a recurring concern among patient umbrella associations.[63] As a way to better elicit this aspect, a work meeting with intercultural mediators could have been organised as they are regularly called to intervene for cultural issues related to end-of-life (see, i.e., Verrept 2019[64]).

This stakeholder consultation focused on key players and context setters with an emphasis on those involved in somatic and psychological care. Those involved in social care and spiritual care were not involved in the stakeholder consultation despite their essential role in delivering quality palliative care. Chaplains and priests play a major role in delivering spiritual care and not providing details about their role is lacking in our description (also the role played by social workers). Some respondents did mention them during site visits but no additional information was specifically searched to further complete the description. It was envisioned to involve in spiritual care counsellors in the consultation but their identification was problematic (not all religions and faiths have an organised association to represent them on the model of the Belgian Catholic Church) but, after considering the categories of stakeholders, they were identified as "subjects", that is those with a perceived high interest but low influence on the final outcomes. In that sense, they were not included. Further studies should therefore investigate how better support spiritual care for (palliative) patients.

As in other studies relying on stakeholder consultation, those interested in the topic are more likely to participate than those who have no interest in the issue. Consequently, the final outcomes could be more likely to reflect the preferences and priorities of those who support the development of PMC. But, to ensure a balanced view of the different opinions, we diversified the methods for consulting the stakeholders, with a specific targeting of the context setters. By opting for a stakeholder consultation, we also aimed at keeping track of the various reforms in the dynamic landscape of health care at federal and regional levels that could impact the development of a palliative care trajectory.

[f] See also the ongoing KCE study: https://kce.fgov.be/en/ongoing-and-planned-projects/ongoing-projects/study-2021-11-hsr-organisation-and-financing-of-intensive-care-introduction-of-medium-care

As explained above, few evidence is available for evaluating the effectiveness of palliative care interventions and data are still lacking for establishing a complete overview of the current offer of PC in Belgium. Stakeholder consultation was then the most appropriate option to identify options to be further developed to improve the health care trajectory of PC patients. It was envisioned to collect quantitative data related to the current initiatives identified as palliative middle care in order to draw a more accurate picture of the existing offer. Because of the diversity of the initiatives, the different registration systems and in the absence of a standardised data collection system, we decided not to use these data. Similarly, it was also envisioned to collect data about the current offer in palliative care in general to better identify the current gaps in the offer. But, after a rapid appraisal of the available data and considering the lack of data mentioned by the Federal Cell in their reports, we consensually decided not to further investigate these data as it would have required the development of additional indicators and a primary data collection.

Finally, as experienced in other previous studies, palliative care is not separated from the rest of the healthcare system: all transversal problems currently affecting the access, the quality and the availability of health care also affect palliative care, such as the shortage of nurses and medical doctors, the medical deserts in some areas, the closing of hospital beds... Similarly, social health inequalities play a role when it comes to accessing and receiving quality palliative care according to patient preferences.

To facilitate the identification of the data sources, the following language codes are used in the different chapters:

“Organisations” refer to the organisations which participated in the online surveys.

“Patient representatives” refer to the participants to the workshops.

“Umbrella associations” refer to the patient and relatives umbrella associations.

“Stakeholders” refer to those involved in the consultations and in the final stakeholder meeting.

3 WHAT IS THE EFFECTIVENESS AND ACCEPTABILITY OF PALLIATIVE CARE?

- ✓ Despite several methodological limitations in the analysis of the retrieved literature on effectiveness of palliative care, a potential positive tendency on healthcare utilisation was found (compared to usual care): reduced hospital use, less visits to the emergency department (in the last month of life), less referrals to non-palliative care services, and patient will more often die in their preferred place of death (with preference for home death).
- ✓ The economic evaluations could no demonstrate a consistent cost-saving effect of palliative care versus usual care.
- ✓ The effectiveness of a pallaitive care intervention can be impacted by several barriers, such as lack of knowledge, poor communication, restricted resource and financial capabilities of the care setting, small size of work force, and attitudinal and cultural barriers (such as culture of dealing covertly with death and dying).
- ✓ Patients (and their informal caregivers) preferred an easy access to desired care with frequent re-assessments of their needs, a 24H availability, the provision of respite care and access to appropriate durable medical equipment.
- ✓ The patients’ level of acceptance of palliative care is mainly determined by socio-demographic characteristics, their perception about the terminal nature of the disease, their attitude towards accepting care, their knowledge about the availability of services, financial concerns, and the presence (or absence) of advance care planning.
- ✓ The level of acceptance of palliative is determined by the patient’s own perceptions, by the people around the patient (such the informal caregiver, family and friends, professional caregivers) and by the healthcare system.

3.1 Aims of the literature reviews

This chapter presents the results of two literature reviews, one review on the effectiveness of community-based palliative care services and a review on the acceptability of palliative care from a patient perspective.

More specifically, the review on the effectiveness of palliative care services aimed at providing:

- An analysis of (potential) effect of any type of community-based palliative care service on healthcare utilisation, i.e. hospital use (admission, re-admission rates, length of stay), emergency department attendance, ICU visits, primary care use (GP visits), nursing home admission and place of death.
- An analysis of the cost-effectiveness of palliative care services (when data were available)
- Identification of key elements of palliative care interventions that can be source of inspiration for the development of a palliative care model in Belgium

The review on acceptability of palliative care from a patient perspective aimed at providing:

- An overview of barriers encountered by patients, informal caregivers, healthcare professionals, and health system in the decision-making to initiate palliative care
- Identification of the main values related to palliative care as perceived by patients and informal caregivers

As explained in the Chapter 2, this review included only systematic reviews. Overall, authors of systematic reviews had to make an amalgam between close concepts. As such, the concepts of specialised palliative care services and specialised palliative care interventions were considered as a similar entity, what is permissible as both concepts share similar target population and objective in the publications. Also, palliative care and hospice care, taken as type of intervention, were considered as synonyms when the results of several primary studies were aggregated by the authors of the reviews.

3.2 Effectiveness analysis of community-based palliative care services and interventions

3.2.1 Effectiveness of services and interventions per setting

3.2.1.1 Palliative care at home

The search strategy revealed only three, not so recent reviews on the effectiveness of home palliative care compared to usual care (including other types of palliative care): Gomes et al., 2013[37] on home palliative care services for adults with advanced illness and their caregivers, Nordly et al., 2016[65] on home-based specialist palliative care in patients with advanced cancer, and Bainbridge et al., 2016[66] on in-home end-of-life care programs in patients with advanced illness (Table 7).

Based on the findings across the three reviews, following **overall conclusions** can be drawn:

- Inconclusive findings were found on the effect of home PC on healthcare utilisation, in particular on ED and ICU visits, in which the primary studies, cited in Gomes et al., 2013[37], showed only a moderate or no significant effect on both ED visits and intensive care use.
- In the literature, a particular type of palliative care was compared to usual care, often referring to general GP care, without palliative care components. However, in Gomes et al., 2013[37] home palliative care was compared to other types of specialist (including palliative) care, such as primary or specialist care at home or in nursing home, hospital care or palliative or hospice care.The broadth of the comparative arm could be an explanation for the inconclusive or only moderate effects found, due to lack of specificity of home palliative care compared to other types of palliative care.
- A small difference was found on admission to nursing home (i.e. fewer home palliative care patients were admitted to a nursing home in the month before death as compared to those receiving usual care) but this effect disappeared when adjusted for other predictive factors (age, having home care at trial entry, living with a spouse and having a gastrointestinal or lung cancer diagnosis).[37]

- More robust evidence was found on place of death, with an increased chance of dying at home in home palliative care patients.[37, 65, 66] According to the authors of the reviews, these results provide clear and reliable evidence that home palliative care increases the chance of dying at home for patients with cancer. This justifies providing home palliative care for patients who wish to die at home.
- All authors agree that there is a lack of controlled clinical trials and organisational descriptions regarding home-based palliative care and more studies are needed on the cost-effectiveness of home palliative care, especially for people with non-malignant conditions.

Characteristics of the interventions

Home palliative care, within the Cochrane review of Gomes et al., 2013[37], was considered as a team delivering home palliative care with the presence of the following four elements:

- Primarily for patients with a severe or advanced disease (malignant or non-malignant), no longer responding to curative/maintenance treatment or symptomatic (or both), or their family caregivers, or both.
- Aiming to support patients and/or family caregivers outside hospital and other institutional settings (as far as possible) and to enable patients to stay at home.
- Providing either specialist or intermediate palliative/hospice care, as defined in a previous version of this systematic review[27]:
    - *Specialist palliative/hospice care* was defined as health and social care provided by one or more doctors who have undergone higher specialist training in palliative medicine, **and** one or more nurses who have undergone higher specialist training, **and** one or more professionals attached to the team from a profession allied to medicine who have had further training in palliative care.
    - *Intermediate palliative/hospice care* was defined as health and social care provided by professionals from differing clinical disciplines working full-time or most of the time in palliative/hospice care, who have not undergone any higher specialist training but developed much clinical experience over the years and had in-service training for their job, or a monodisciplinary team of professionals (e.g. nurses) working full-time or most of the time in palliative care, in which one or more members may have had some further training.
- Providing comprehensive care and aiming at different physical and psychosocial components of palliative care

Home palliative care was compared to usual care: community care (primary or specialist care at home and in nursing homes), hospital care (inpatient and outpatient) and in some instances other types of palliative or hospice care.[37]

Home-based specialised palliative care (only information found on patients with advanced cancer):[65]

- Across the 8 included primary studies, the composition of the team varied a little but the specialised palliative care team had to include at least a doctor or a nurse, and in most of the studies this team consisted of a multidisciplinary team of different healthcare professionals.
- The home-based specialised palliative care teams were issued either from the community or from the hospital.
- The studies reported the capacity of their home-based services reported a 24h, 7 day/per week availability of their service.
- The reasons for referral to home-based specialised palliative care were mainly caused by social issues or the combination of social problems and physical symptoms.

In-home EOL care program[66]

- The criteria of a program were: 1) the intervention had to deliver palliative, hospice, or EOL care directly to individuals at home; 2) the aim of the program was to support individuals to enable them to remain at home; 3) the program should involve one or more health professionals who care for the individual at home.
- Across the included studies, the EOL programs were provided by hospital-based outreach teams and community-based teams, often consisting of a multidisciplinary team of healthcare professionals. In some models a nurse coordinator monitored the needs and acted as a conduit between the individuals and the community services.
- The authors identified critical components of efficacious EOL in-home programs, grouped into five categories:
    - 1) Types of services offered (pain and symptom management, professional psychosocial support, ongoing assessment, physician home visits, practical support, bereavement support, spiritual support, visiting volunteer services, medical intervention); 2) availability (team contact on-call around the clock, around-the-clock home visits available, physician available around the clock, access to dedicated inpatient beds, one contact number, chart in the home, emergency response plan); 3) characteristics of the care model (multidisciplinary team, EOL care expertise or training, holistic care); 4) linkages to other resources (linkage with hospital, linkage between community services, expert consultation with other providers, linkage with residential hospice); and 5) process interventions (contact established with GP or specialist, customized care plan or needs-driven care mandate, case management or nurse navigation, patient and family education, team case rounds, individual-directed care or joint decision-making, advance care planning)
    - On average, each invention contained 11 components, with a maximum of 22. Seventy percent (n=21/30) of programs described at least one component from four of the five categories.
    - The six most common components were that the professionals had linkage with acute care, were multidisciplinary, had EOL expertise and training, provided holistic care (whole-person care that considered physical, emotional, and spiritual needs), provided pain and symptom management, and provided professional psychosocial support. Many programs also had linkages with existing community services, provided around-the-clock on-call for telephone contact and home visits, were linked to the individual's GP or specialist, included ongoing assessment of the individual's condition, and involved physicians who made home visits.

According to the authors, linkages with acute care and community formal or informal associations and channels of communication, help reduce the relational and bureaucratic barriers that service silos impose. This helps to increase interagency accountability and information transfer and to facilitate seamless transitions across settings. Also care that is multidisciplinary and holistic is more capable of meeting the diverse and individual needs of individuals at the end of life and their families, which often extend beyond the scope of medical interventions and include psychosocial and spiritual aspects. In addition, professionals with EOL expertise and symptom management training know what to expect as the individual declines, how to prevent symptom exacerbations, how best to resolve these crises when they occur, and how to broach sensitive EOL discussions with individuals and caregivers. It is likely that these components, and the others identified in the review, work synergistically to improve quality of life, satisfaction, and symptom management and ultimately to support individuals in dying at home and avoiding unnecessary late-life hospital use. However, in our analysis, these clear linkages between components of an EOL program and its impact could not be clearly stated and therefore should be interpreted with caution.

Table 7 – Comparison between the different forms of palliative care at home

Type of PC at home	Reference	Hospital admissions	ED visits	Admissions to other services	Place of death	Costs
Home PC	Gomes, 2013[67]	Inconclusive	Inconclusive	Decrease in admission to nursing home No difference in referrals to hospice care Inconclusive for other community services (physician visits, nursing care, social services, and home workers)	More likely to die at home	Inconclusive
Home-based specialised PC	Nordley, 2016[65]	*Not reported*	*Not reported*	*Not reported*	More likely to die at home	*Not reported*
In-home EOL care programs	Bainbridge, 2016[66]	*Not reported*	*Not reported*	*Not reported*	More likely to die at home	Reduction in costs

3.2.1.2 Palliative care in nursing homes

The literature search retrieved three recent reviews on the impact of palliative care services on healthcare utilisation in nursing home residents (with and/or without dementia): Buck et al., 2020[68] on specialist healthcare services on hospital admission and place of death in residents of care home, Spacey et al., 2020[69] on interventions to improve end-of-life care in residents in care homes and Carpenter et al., 2020 [70]on palliative care interventions in nursing home residents (see Table 8). We excluded other retrieved reviews based on older search date in the review, or no data reported on healthcare utilisation outcomes.

Across the three included reviews following **overall conclusions** can be drawn according to the impact of palliative care services on the following healthcare utilisation outcomes:

- Hospital admission: a tendency towards a decrease in hospital admissions could be found across the different types of palliative care services in nursing home residents, but in the majority of the included primary studies the statistically significant difference between the intervention group and comparator could not be proven. The initiatives on end-of-life care did not have a significant impact on the number of hospital admissions.[68,69]
- Emergency department visits: No consistent conclusion can be drawn across the different types of palliative care in nursing homes.[68] In initiatives focused on general physical health and on urgent care, a decrease in ED transfers could be found, however this decrease could not be shown in the other types of initiatives, such as initiatives focused on EOL care[69] and on improvement in prescribing. Multicomponent nursing home palliative care interventions showed a decrease in acute

care outcomes (reduced ED visits, rehospitalization, acute care admissions, days in acute care and in-hospital death), however this difference could not be found anymore in the last three months of life.

- Place of death: Conflicting evidence was found on home death and hospice use[70]
- Costs: this outcome was only mentioned in one primary study (on staff education combined with a clinical algorithm to identify residents' unmet PC needs), cited in Carpenter, 2020[70], and found lower mean cost per resident in the last three months and in the final month of life
- Referral to other care services: in nursing home palliative care practices retrieved in the review of Carpenter et al., 2020[70], greater physician involvement in residents' care during the last week of life, increased use of a pathway to assist staff in providing EOL treatments in nursing homes, and more discussion about hospice and higher hospice referral and enrolment rates were reported.

The lack of effect on outcomes may reflect intervention implementation failure rather than ineffectiveness (see below on the characteristics of the interventions)[70]

Looking into more detail on the impact of the **characteristics of the interventions** on these organisational outcomes, the authors of the included reviews found following findings:

- Initiatives focused on residents' general health[68]: strongest evidence on hospital admissions and ED transfers was found with multidisciplinary support services, or nursing interventions with more emphasis on training. Conflicting evidence was found in initiatives with involvement of nurses and (specialised) physicians.
- Initiatives focused on urgent care for acutely unwell residents[68]: 11 studies (n=13) reported decrease in hospital admissions and ED transfers, but no longer statistically significant after multiple testing. The initiatives comprised telemedicine services in which a nurse-doctor or a geriatrician performed assessment (and management) service, an assessment-based emergency practitioners service, a 'hospital in the home' assessment and management of admission-avoidance services, geriatric outreach services, predefined schedules of nurses visiting care homes and educational initiatives. These initiatives showed an overall tendency in positive effects on hospital admission and ED visits, but it was not possible to differentiate which type of service was more benefical compared to the others.
- Initiatives on EOL care[68, 69]: due to the weak quality of the evidence, the tendency to decrease the hospital admissions could not be proven, therefore no clear difference in hospital admission and ED transfers between the intervention group and the comparator could be stated.
- Multicomponent nursing home palliative care[70]:
  - Three major strategies were found across the included primary studies: advance care planning, staff education (e.g. general concepts taught in a class or seminar) or training (e.g. mentoring palliative care skills in practice), and integrating a palliative care team.
  - The most common strategy implied staff education and/or training, including audit and feedback strategy (shared results of bereaved family care evaluations with staff), staff champions or facilitators (to act as palliative care resources), staff training in EOL care alongside facility based palliative care teams or consultative teams.
  - The interdisciplinary palliative care team consisted of multiple disciplines (medicine, nursing, chaplains, social worker, and/or psychologist), by either creating palliative care teams from existing nursing homes staff or by implementation of consultation services.
  - Advance care planning strategies most often screened for individuals that would benefit from an ACP conversation (e.g. illness prognosis and acute changes in clinical status, resident, and surrogate interviews)
  - Within the multicomponent interventions it was difficult to assess which components were most effective and which did not provide benefit.

Spacey et al., 2020[69] reported mechanisms (including barriers) related to the intervention (i.e. the mechanisms contained in interventions that are designed to change the behavior of those at whom they are targeted), the context (i.e. the resources and restrictions embedded in the social and organisational context that might inhibit or promote the effectiveness of intervention mechanisms) and human agency (i.e. people's experiences and interpretations of, and responses to the intervention and contextual mechanisms) in end-of-life care for nursing home residents:

- Intervention: all interventions were related to education (EOL discussion with residents and relatives and ACP; leadership and communication with external services; overarching principles such as person-centred and dignified EOL care; education on identifying the signs and symptoms of EOL; dementia education; symptom and pain management), often combined. Education was hypothesised as the most effective mechanism to address common issues associated with EOL care, such as lack of knowledge and confidence to engage in ACP, and poor communication with residents with dementia due to staff's lack of knowledge of symptoms of dementia. Many interventions had also additional initiatives, to improve collaborations with external services (GP, hospice staff) via collaborative meetings; formalized reflective practice sessions; introduction of external professionals into care homes to help facilitate and support interventions (e.g. for training).
- Context: several contextual factors impacted the effectiveness of the EOL interventions, such as the restricted resource and financial capabilities of nursing homes, also lack of time (due to full-loaded work schedules of nursing home staff and staff often had to create time to engage with the intervention) was a common barrier for implementation and maintaining effective change. The effectiveness of education sessions could also not sustained if there is : 1) high staff turnover, 2) small size of workforce (knowledge lost when staff left care home), 3) only non-registered care home staff in care homes, who have increased reliance on GPs and registered nurses, and 4) lack of time of home managers to engage in the meetings.
- Human agency: the attitude and the culture in which the nursing home staff works, will have a (negative) impact on the effectiveness of educations sessions, such as variable level of cascade knowledge (too junior or a lack of motivation at senior level, EOL care lower priority for nursing home managers), culture of dealing covertly with death and dying, staff's personal background and experiences, conflicts with relatives who were "not ready", "not accepting", "not understanding" about approaching death, and would not "give up", conflict with external services (e.g. out-of-hours GPs unwilling to cooperate due to negative attitudes towards nursing home staff (overrode their decisions or tendency to admit residents to hospital at end of life).

Table 8 – Comparison between the interventions related to palliative care in nursing homes

Type of PC at home	Reference	Hospital admissions (in the last 8 weeks of life)	ED visits	Admissions to other services	Place of death	Costs
Initiatives focused on residents' general physical health	Buck, 2020[68]	Decrease	Decrease	Not reported	Not reported	Not reported
Initiatives focused on urgent care for acutely unwell residents	Buck, 2020[68]	Decrease	Decrease	Not reported	Not reported	Not reported
Initiatives focused on end-of-life care	Buck, 2020[68] Spacey, 2020[69]	No difference	No difference	Not reported	Not reported	Not reported
Initiatives to improve prescribing	Buck, 2020[68]	Weak evidence in favour (4/6 studies)	No difference	Not reported	Not reported	Not reported
Initiatives evaluating post-hospital discharge services	Buck, 2020[68]	Weak evidence in favour (5/6 studies)	No difference	Not reported	Not reported	Not reported
Training initiatives focused on specific outcomes (e.g. prevention of falls, pneumonia, provision of intravenous fluids, etc)	Buck, 2020[68]	Weak evidence in favour (3/5 studies)	No difference	Not reported	Not reported	Not reported
Multicomponent nursing homes PC	Carpenter, 2020[70]	Decrease	Decrease	Conflicting evidence on hospice use	Conflicting evidence on home death	Decrease

3.2.2 *Effectiveness of interventions promoting collaboration between primary and secondary care*

This section focuses on the collaboration between healthcare professionals to facilitate the provision of palliative care to their patients. This collaboration can comprise several types of engagement, including primary care involvement, interdisciplinary teams, transmural team-based palliative care, transitional care, and the involvement in clinical pathways.

3.2.2.1 *Involvement of primary care professionals*

The search strategy identified two reviews that focused on the involvement of primary care professionals in palliative care services and the impact of this involvement on healthcare utilisation outcomes: Kim et al., 2016[71] and Carmont et al., 2018[72].

Following overall **conclusions** can be drawn based on the findings reported per outcome (Table 9):

- Hospital (re-)admissions: a decrease was found in hospital admissions mainly in studies on case conferences and shared care. This decrease could not be confirmed by the review of Kim et al., 2016[71] due to conflicting results found for this outcome.
- Length of stay: a reduction of length of stay was reported in studies on cased conferences and shared care
- ED visits: in addition to the conflicting results found in the review of Kim et al., 2016[71], only one cohort study in the review of Carmont et al., 2018[72] showed a decrease in ED admissions, which hampers to draw a firm conclusion on the impact of primary care involvement on ED visits.
- Place of death: Nevertheless the often mentioned conflicting evidence found in the review of Kim et al., 2016[71], a consensus was found across the included primary studies on the positive effect of primary care involvement on the place of death, with participants in the interventions group who were more likely to die outside the hospital and more at home.

Both reviews described the **characteristics** of the interventions on how primary care professionals could be engaged in palliative care:

- GP engagement was defined as any organised cooperation between the GP and specialist secondary services in the care of the patient including shared consultations, case conferences that involved at least both the GP and the specialist clinician and/or other secondary services, and/or any formal shared care arrangements between the GP and specialist services. Interventions retrieved in the review of Carmont et al., 2018[72] included shared care, case conferences, home visits to the patient with both the specialist team and the GP and the use of a good practice framework (the Gold Standards Framework). The specialist secondary service is either a specialist palliative service or a service providing specialist care to a palliative population.

Next to healthcare utilisation outcomes, Carmont et al., 2018[72] analysed also the potential facilitators and barriers to engagement of GPs with specialist secondary services in integration of palliative care:

- Facilitators: 1) effective communication (including timely with an appropriate level of detail, digitalised patient information, communication should occur with the most relevant people involved); 2) clear role definition (roles should be clearly defined and understood by all involved); 3) availability of the GP (accessible through prompt appointments and telephone contact for medical care and referral, can provide emotional and family support); 4) family expectation that the GP will be involved; 5) the process should be organised and initiated by the secondary specialised service.
- Barriers: health system barriers (financial constraints for the GP and the hospital, workload, lack of standardised documents and systems, bureaucratic procedures, professional silos, lack of services and lack of infrastructure); communication barriers (poor communication creating personal issues (trust, poor relationships) between relatives and patients, lack of patient or family understanding of discussions with healthcare professionals, the quality of the relationship between the patient and the professionals, and a sometimes competitive or combative relationship between health professionals); process barriers (roles within integrated care not being clearly defined, barriers to

sharing information, health professionals' perceived lack of time, ambiguity around who should be involved, and communication and technology issues); engagement barriers (a lack of clarity of purpose (eg, future planning, acute medical issue), and participants being unprepared, either with not receiving information, or not reading the information prior to the meeting); other barriers (late referral, lack of understanding of patient prognosis by family, as well as medical professionals underestimating the seriousness of the patient's condition and therefore overestimating prognosis).

The involvement of primary care professionals was not uniformly operationalised across all primary studies in the review of Kim et al., 2016[71] but encompassed contacts at home, per phone or with outpatient primary care professionals during specific time frame, involvement of primary care professionals in different care settings, number of GPs involved, number of outpatient visits made.

Table 9 – Comparison between interventions facilitating collaboration between primary and secondary care

Type of PC	Reference	Hospital admissions	ED visits	Admissions to other services	Hospital LOS	Place of death	Costs
GP engagement	Carmont, 2018[72]	Decrease	Decrease	Not reported	Decrease	Not reported	Not reported
Primary care involvement	Kim, 2016[71]	Conflicting evidence	Conflicting evidence	Not reported	Not reported	Increase of home deaths	Conflicting evidence

3.2.2.2 Interdisciplinary teams

Throughout the selection process of the retrieved references, some reviews were found on different types of interdisciplinary collaboration: Leclerc et al., 2014[73] on interdisciplinary teams in a variety of care settings, Joseph et al., 2016[74] on interdisciplinary collaboration for palliative patients (but the selection procedure revealed no suitable studies that met the inclusion requirements), Fulton et al., 2019[75] on integrated outpatient palliative and oncology care and Senderovich et al., 2020[76] on early integrated palliative care.

The overall **conclusions** based on the results found in the reviews on the several types of interdisciplinary palliative care teams are as follows (Table 10):

- Hospital admission: across the several types of interdisciplinary collaborations, a decrease was found in hospital admissions in the intervention group, however these results are not based on a meta-analysis of the included primary studies, therefore the effect of this type of intervention on admission rate should be interpreted with caution.
- ED visits: like hospital admission rate, an overall decrease in ED visits could be observed across the included reviews.
- Admission to other services: the access to hospice care was only reported in one of the reviews and found no difference between interdisciplinary palliative care and usual palliative care.
- LoS: whereas the results on interdisciplinary teams in all types of care settings showed no difference in hospital length of stay, a decrease could be found in studies on early integrated palliative care. This outcome was not reported in the other types of interdisciplinary collaboration.
- Place of death: this outcome was not reported in all types of the intervention, however an increased rate of home deaths was found in interventions with interdisciplinary teams and integrated palliative care and oncology care.

- Costs: conflicting evidence was found on the effect of early integrated PC on costs with most studies proved integrated palliative care to be cost-effective by significantly reducing end-of-life care costs incurred in hospitals. However, noted that although PC is very effective, integration may lead to increased total inpatient spending, as county hospitals are required rather than town hospitals for the provision of palliative care services. The review on integrated PC and oncology care reported a lower mean total cost per day and lower chemotherapy costs in the last 30 days of life in the intervention group.
- Other: in the review on integrated palliative care and oncology care, the authors also reported some results on aggressiveness of care near the end of life. Three studies reported chemotherapy use at end of life, one of which showed an intervention effect (chemotherapy in the last 60 days of life). One study reported on the proportion of patients receiving chemotherapy at all, while the other reported receipt of chemotherapy in the last 60 days of life; neither showed an intervention effect.

The following **characteristics** of the interdisciplinary teams in palliative care were identified by the authors of the included reviews [73 75 74 76]:

- Palliative care from a team included members of at least three professions (consultants, associates, extended team members, and volunteers were not counted as team members; physicians, residents, and specialist doctors were all considered to belong to one discipline). The team involved as "interdisciplinary" or indicated that the team fulfilled at least two of these criteria: 1) meets regularly and has a designated leader or coordinator; 2) develops a common interdisciplinary plan for each patient; 3) provides care that considers the patient's physical, psychosocial, and spiritual needs (that is, takes a holistic approach); 4) identifies patients' goals of care; 5) involves patients and their families in decision making and care planning; 6) has team operating rules or policies, including formalisation of the collaboration; and 7) uses common evaluation tools.
- Interdisciplinary teams in hospice: Joseph et al., 2016[74] did not found any study that met the inclusion requirements, therefore no characteristics of such a collaboration with a hospice team providing home hospice services in the home care settings can be described.
- Integrated outpatient palliative and oncology care (Fulton et al., 2019)[75]:
  - Palliative care was delivered by a multidisciplinary team of two to five clinicians; all included nurses, five included a palliative care physician, three included a mental health professional, and two included chaplains. All studies provided services during outpatient visits; five also included telephone-based care, and three described delivery of written materials. The intensity of collaboration varied from basic collaboration on site to close collaboration on site with some systems integration. Palliative services were physically or virtually co-located in the same facility as oncology services, although not necessarily the same space. Standard communication about treatment issues, interactive communication, and routine communication exchanges between palliative and oncology clinicians occurred in at least half the studies.
  - All palliative care interventions addressed physical and psychological symptoms. Most interventions also addressed social, spiritual, ethical and legal, and end-of-life aspects of care. Structural issues (e.g. interdisciplinary team engagement with patients or families) were addressed explicitly in half the interventions, but cultural issues were not. The intensity of services varied greatly, ranging from four sessions weekly to contacts every 2– 4 weeks until death.
- Early integrated care: a variety of types of interventions were included in the review of Senderovich et al., 2020[76] on early integrated care, such as inpatient palliative care, weekly teleconsultation from a hospital-based specialised palliative care team, systematic versus on-demand early palliative care, integrated heart failure and palliative home care, early versus delayed palliative care, and integrated early palliative care with respiratory services. The authors did not differentiate the results on effectiveness per type of intervention, therefore it is not possible to conclude if one type of intervention is more beneficial compared to the others on organisational outcomes.

Table 10 – Comparison between interventions related to interdisciplinary teams

Type of PC	Reference	Hospital admissions	ED visits	Admissions to other services	Hospital LOS	Place of death	Costs
Interdisciplinary teams in all types of settings	Leclerc, 2014[73]	Decrease	Decrease	No difference in access to hospice	No difference	Increased deaths at home	Not reported
Interdisciplinary teams hospice and home PC care	Joseph, 2016[74]	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported
Integrated outpatient PC and oncology care	Fulton, 2019[75]	Decrease	Decrease	Not reported	Not reported	Increased death at home	Lower
Early integrated PC	Senderovich, 2020[76]	Decrease	Decrease	Not reported	decrease	Not reported	Conflicting evidence

3.2.2.3 Transmural team-based palliative care

Our search strategy looked at all types of palliative care services and, during the selection process, two reviews were retained on the effectiveness of transitional care, referring to collaboration between primary and secondary care: Flierman et al., 2023[77] on transmural team-based palliative care and Sezgin et al., 2020[78] on transitional care (also called intermediate care).

The overall **conclusions** based on the results found in the reviews are as following (Table 11):

- Hospital admission: the odds of hospital admission was significantly reduced, however with considerable heterogeneity in the meta-analysis (Flierman, 2023)[77]. A similar tendency could be found in Sezgin, 2020[78] with most studies reporting a significant decrease in readmissions. Interventions with collaborative teams and hospital-based teams resulted in fewer hospital admissions, but this effect was not observed in case-management interventions. Conflicting evidence was found on the mean number of admission days with no significant difference versus lower mean number of admission days in intervention group.[77] Sezgin et al., 2020 found only in one study results on length of stay and reported a reduced number of inpatient stays**,** however due to the very small number of studies this finding should be interpreted with caution.[78]
- Place of death: More home deaths, with larger effect in hospital-based teams than in collaborative teams (however high heterogeneity between two subgroups). In one study was reported that most patients died at their preferred place of death (but no control number reported).[77]
- ED visits: No clear conclusion can be drawn on the effect of transitional care on ED visits due to conflicting evidence showing no significant reduction in number of ED visits in palliative care patients.[78]

Characteristics of the transmural team-based palliative care, according to the authors of the review[77], were:

- Teams that provide continuous care for patients at the end of life while the patient moves between settings.
- Teams had to provide at least face-to-face consultations at home or in the hospital.
- The authors did not consider interventions to be transmural team based when teams were solely hospital based, for example, when they followed patients in the outpatient setting or were community/hospice

based with referrals from the hospital but no further or unclear collaboration with the hospital.

Three organisational models for the teams could be identified:

- Collaborative teams: These teams involve structural collaboration between professionals from both the hospital and community. They follow patients transitioning between care settings. They can provide medical care and symptom control at home.
- Hospital-based teams: These teams provide care for patients in the hospital and community setting (through home visits), without structural collaboration with primary care professionals. These teams are mostly responsible for all care and can treat patients at home.
- Case management: Case managers collaborate with hospital-based multidisciplinary teams. The main focus is on advance care planning and not on providing treatment at home.

The characteristics of transitional care were less detailed described in the review of Sezgin et al., 2020[78], but referred to care delivered by interdisciplinary teams, and consisted of technology-assisted interventions, including electronic health records and telephone calls. Also transitional care interventions should be implemented pre and post discharge, in order to improve communication between healthcare professionals. Relevant and accessible information has been highlighted as a key factor in patient's transition to palliative care. Other important factors included agreement, timing, and decision making amongst staff members.

Table 11 – Comparison between the interventions related to transmural team-based palliative care

Type of PC	Reference	Hospital admissions	ED visits	Admissions to other services	Hospital LOS	Place of death	Costs
Transmural team-based palliative care	Flierman, 2023[77]	Decrease	Not reported	Not reported	Conflicting evidence	More likely to die at home	Not reported
Transitional PC	Sezgin, 2020[78]	Decrease	Conflicting evidence	Not reported	Decrease	Not reported	Not reported

3.2.2.4 Pathways

The search in literature for effectiveness of palliative care services, revealed also five reviews on the impact of care pathways on clinical and organisational outcomes: Lewis et al., 2023[79] on models of care for people with dementia, Evans et al., 2019 [80] on care models for older people at end of life, and Siouta et al., 2016[81], Chan et al., 2016[82] and Husebo et al., 2017[83] on models of palliative care.

The **overall conclusions** based on the reported findings in the different reviews are as following (Table 12**)**:

- Hospital admission: Across the different types of care models, the primary studies showed conflicting evidence on hospital admissions.[79-81]
- ED visits: The care models on dementia found conflicting evidence on hospital admissions.[79]
- Place of death: Care models providing hospice care for people with dementia found that patients were more likely to die in their preferred place of choice.[79] Older people receiving care in a service model for older people at end of life were more likely to die at home[80], this finding was also confirmed for patients with cancer or chronic diseases.[81]

- Access to other healthcare services: An increased hospice use and increased number of referalls were found in models for people with dementia.[79] Care models for older people at end-of-life found that it was more likely to be discharged to home or nursing home after care provided within the care models[80] and Siouta et al (2016)[81] found in one of the included models an increase in GP visits
- Costs: Only one model (Programme Dignity from Singapore) on people with dementia reported cost-related outcomes and found that fully-enrolled patients had lower costs at 1, 3 and 6 months than partially or non-enrolled patients.[79] In one of the models on chronic disease (in particular on patients with multiple sclerosis) a reduction was found on inpatient and community costs.[81]

Across the different care pathways retrieved in in the five reviews, different types of care models were identified by the authors and their **characteristics** were shortly described:

- Twelve models of care for people with dementia[79] were identified but here only the four pathways with organisational outcomes were retained (more detailed information can be found in the evidence table in the Supplementary report):
  - Alzheimer's Disease and Related Dementias Palliative Care (ADRD-PC) programme (USA) including: palliative care consultation, phone support, informational booklet for families, individualised recommendations for palliative care domains, assistance with completing a Medical Orders for Scope of Treatment (MOST) order set, the North Carolina version of Physician Orders for Life Sustaining Treatment (POLST), recommended referrals to post discharge services, transitional care training session to palliative care physicians and nurse practitioners;
  - Challenge Pathway (Wales) including: specialist care, home-based hospice care, social workers, dementia day programmes, peer-support groups, training for health and social care workers, families and volunteers;
  - PEACE (US) including physical and psychological symptom management, advance care planning, education on the disease process, community resources, coordination of care, patient and carer-centred care, hospice services;
  - Programme Dignity (Singapore) including regular home visits and phone calls from multidisciplinary team, assessment and pharmacological interventions to manage pain and behavioural issues, carer education and support through counselling and referrals to other community services, after hours support, direct admission to ward or hospice as required;
  - Common elements found across the different models were related to
    - Referral and admission to care: admission based on criteria but none of the models reported analysis regarding accuracy of prognostication (if participants were appropriately identified for the intervention and if they were admitted at the appropriate time based on their level of need).
    - Integration of care: all models had elements of care coordination rule, interdisciplinary collaboration and person-centred care but level of integration varied considerably.
    - Evaluation of models of care: few models used large, robust study designs, most were feasibility studies.
    - Sustainability: some models ceased operation or it was unclear of they were still operating.
  - The authors mapped the included models of care against the nine domains of optimal palliative care for people with dementia (see the evidence tables in the Supplementary Report for information on the 9 domains) and showed that not all domains were consistenly met. The domain for which there was the least demonstrated evidence was ethical and practical issues, followed by psychosocial and spiritual support and person-centred care.

- The authors mentioned also some specificities related to dementia:
  - Given the variable disease trajectory of dementia, a longer-term palliative approach to care is needed for people with advanced dementia (in contradictory to some time-limited care models).
  - Models built around one care delivery location, for example residential aged care, run the risk of fragmenting care when transitions between care locations are required.

- Two overarching classification of service models were identified by Evans, 2019[80] on palliative care for older people at end-of-life, with common components such as person-centred care (focus on physical and psychosocial interventions), education (subdivided into its recipients: patients/caregiver with training on e.g. self-management; staff with training on palliative care by specialist palliative care teams) and workforce (workforce development programs to support EOL care in nursing homes).
  - Integrated geriatric care with a focus on physical function, concerned more in earlier stages of functional decline.
  - Integrated palliative care with a focus on symptom severity and psychosocial/spiritual concerns during the advanced disease stage up to death encompasses both specialised PC services provided by teams for patients with complex problems as well as generalist services from providers with a basic knowledge of palliative care and treating patients with chronic progressive conditions.
  - The authors found also that integration of care across services is determined by comprehensive assessment of patient's needs, case management and care coordination, and collaborative working in a multidisciplinary team

- Models on integrated palliative care[81, 83, 84]
  - One of the retrieved models (the Liverpool Care pathway) has been withdrawn and no longer used in cancer patients)[81, 83, 84]
  - Siouta et al., 2016[81] described different models of integrated palliative care models in patients with advanced cancer or chronic diseases and found thhree different collaboration strategies and their combinations: meetings of the team that is involved in the implementation of the model (model-responsible team), meetings between the model-responsible team together with experts from other disciplines involved in the treatment of the patient, and utilization of predefined protocols.
  - Based on their findings, the authors suggest a generic framework for the elaboration and implementation of a integrated care models for palliative patients, including focus of the intervention on symptom treatment, consulting of patients/family and training of personnel; application of the framework in every care setting; intervention initiated throughout the disease trajectory; a multidisciplinary composition of the team, and a collaboration strategy.

Table 12 – Comparison between different pathways for palliative care

Type of PC	Reference	Hospital admissions	ED visits	Admissions to other services	Place of death	Costs
Models of care for people with dementia*	Lewis, 2023[79]	Range from no difference to decrease	Range from no difference to decrease	Increased access to hospice use Increased referrals	More likely to die in their preferred place of choice	Decrease
Service delivery models for older people at end-of- life	Evans, 2019[80]	Conflicting evidence	Not reported	More likely to be discharged to nursing home, or home	More likely to die at home	Not reported
Models of integrated palliative care	Siouta, 2016[81] Chan, 2013[84] Husebo, 2017[83]	Conflicting evidence	Not reported	Increase in GP visits	More likely to die at home	Decrease

**Findings on the outcomes are summarized per type of model, this implies that not all outcomes were reported for every type of model. More detailed information can be found in the evidence tables in the Supplementary Report.*

3.2.3 *Effectiveness of specialised community-based palliative care services and interventions*

3.2.3.1 *Specialised community-based palliative care services*

Three specific reviews on the impact of specialised community-based palliative care services were found in our search strategy: Iupati et al., 2023[85], Vernon et al., 2022[86] and Hughes et al., 2023[86]. A fourth review focused on the effectiveness of nurse-led interventions in community-based palliative care: Salamanca-Balen, 2018.[87] Next to the specific reviews focused on specialised community-based palliative care services, in some additional, more general reviews, indications were found of effectiveness on healthcare utilization, however extracting the evidence on community-based palliative care services within the overall assessment of palliative care services in general was hampered and could be biased by the poorly reporting of the evidence in each of the primary studies. For clarity reasons, we did not merge these results with the main results found in the specific reviews and are reported separately as an addition to the conclusions drawn on the more specific reviews.

Overall **conclusion** across the diverse types of community-based palliative care services can be drawn on following healthcare utilization outcomes (Table 13):

- Hospital admissions: a positive effect of community specialist palliative care services can be seen on the number of hospitalisations in the majority of the included primary studies, however some conflicting evidence regarding this outcome was also found, therefore no strong conclusion can be drawn on the impact of community-based palliative care services on hospitalisation rates.
- ED visits: an overall decrease in number of ED visits was reported across the different types of community-based palliative care services, however also some conflicting evidence was reported by the authors of the reviews.
- Admission to other healthcare services: The review on comprehensive community-based palliative care programs and on clinical nurse specialists were the only retrieved sources of information that reported on the impact of such services on the use of healthcare services next to hospital use. In this review on comprehensive community-based palliative care programs an increased rate of hospice utilisation was found. The clinical nurse specialist interventions may be effective on

referrals, e.g. to other healthcare professionals, health services or clinics, however these findings are inconclusive. This review looked also in particular to medication prescription and medication uptake by patients and found an increase in both outcomes.

- Length of Stay (LoS): A tendency towards a decrease in hospital length of stay was found, however this outcomes was not reported for the simple components of community-based palliative care programs.
- Place of death: An increased number of home deaths (and a related decrease in hospital deaths) was found across all but one types of community-based palliative care services. This outcomes was not reported in the studies on clinical nurse specialists-led interventions.
- Costs: This outcome was reported in the review on comprehensive community-based palliative care programs and on the clinical nurse specialists-led interventions and found in the majority of the primary studies a decrease in hospital costs and in costs for the patients but conflicting evidence on the overall costs.

In addition to these reviews, some evidence was also found in more general reviews on the effect of all types of palliative care interventions:

- No difference in ICU LoS was found between outpatients with new diagnosis of life-limiting cancer with routine multicomponent PC consultation (4 weekly educational sessions) vs usual care (n=1 primary study).[88]
- A decrease in ED visits was observed in three US-based observational studies on hospice enrolment compared to nonhospice patients (reported in the review of DiMartino et al., 2014[89]) and a similar effect was seen in the non-US-based observational studies with reduced ED visits in patients who received palliative home care team services (2 studies), who received physicians palliative care assessments within 2 weeks of death (1 study), or who received PC Integration Project (PCIP) (1 study). Patients with no palliative care or late admission to palliative care were more likely to visit and ED in 90 days before death (1 study). Hospice care patients in this review were defined as patients who are no longer being actively treated for cancer and are required to have a life expectancy of less than 6 months to receive benefits.
- The review of Handley et al., 2018[90] reported some findings on the impact of early palliative care on unplanned acute care, but without differentiation between inpatient and outpatient services. Regarding ED visits and hospitalisation, conflicting evidence was reported. Re-admissions were only reported in one primary study which found a reduction in the rate of re-admissions to hospital. The authors identified several strategies to reduce acute care for patients with cancer, encompassing identification of patients at high risk for unplanned acute care: 1) enhancement of access and care coordination, 2) a standardized clinical pathway for symptom management, 3) the development of urgent cancer care tactics and 4) the use of early palliative care. The latter includes standardised symptom management teaching, standardised clinical teaching regarding end-of-life discussions, standardised and automated inpatient and outpatient consultation guidelines, embedded outpatient palliative care clinics, integrated inpatient palliative care/ oncology unit.
- Within the general review of Taylor et al., 2020[91] on different types of palliative care services, some studies were identified on palliative care support in the community (n=18 studies) including hospice at home services, hands-on nursing care, specialist advice from multidisciplinary teams and emergency intervention. Without differentiation in reporting of the results per type of interventions, the authors concluded that fewer patients died in hospital (in 6 studies), less patients were admitted to a hospital (n=14 studies), mixed results for reduction in ED attendance (in 8 of 10 studies a reduction, in 2 remaining studies no difference was found), and a shorter LoS (n=5 studies).

The following **characteristics** of the community-based palliative care interventions could be retrieved across the included reviews:

- **Support services** from community-based specialist palliative healthcare professionals: across the included studies in the review of Iupati et al., 2023[85] (strong) evidence of benefit was found for face-to-face patient care, while the evidence for consult/advice to other health professionals (including telehealth) is smaller. In the qualitative studies, the potential benefits experienced by patients and/or family and caregivers of this type of palliative care services encompassed:

- the benefits of **care coordination** which enabled patients to stay at home by providing adequate resources while creating partnership
- enhanced **emotional well-being or sense of relief**, which was achieved by witnessing patients' enhanced well-being, shared responsibility, ability and flexibility to stay at home, provided time and space to live through last stages of their relative's life in their own home, offered a sense of control, tailored to specific needs, and improved communication with other healthcare providers
- positive experience to various **practical help** they get from specialist palliative care services e.g., providing resources such as equipment, hands-on care by formal caregivers relieving care burden, continuity of care by the same individuals providing care, social services relieving financial burden, after-hours support, staff identifying and treating depression, assisting with medical tasks such as medications and access to medical services, medical crisis management

The same qualitative studies also reported barriers to those positive experiences, such as unmet need, failure of healthcare professionals to meet expectation or not listened to, and assumption of palliative care only providing end-of-life care resulting in late engagement.

- **Comprehensive** community-based palliative care programs (CBPC):
  - All programs were described in the review of Vernon, 2022[92] as interdisciplinary, with nurses as most common member of the team, followed by doctors and social workers, volunteers in 19% of the programs, spiritual care support workers and counsellors in 15% of the programs. Case coordinators, pharmacists and physical therapists mentioned as team member in more than one CBPC program. The programs encompassed various forms of symptom management and care coordination, patient and caregiver education, telephonic support services (most often provided by nurses) in 26% of programs (15% 24h / day), respite services in 9% of programs, other services mentioned in more than one program included advanced care planning support and domiciliary services.
  - The qualitative studies reported that drivers for satisfaction among patients and families was the flexibility and preference for place of death and among the providers, the strong team building. Also, these studies mentioned the importance of more communication on social and emotional issues and the need for education and training related to using technology. Patients emphasised the importance of adapting the community-based palliative care service to the personalised needs of the patient, also patient valued being treated with dignity and respect. The patients' desire to maintain a sense of independence and normalcy can be seen as a barrier to participation to this kind of palliative care programs.
- Single component community-based palliative care programs: The review of Hughes et al., 2023[86] reported the evidence on healthcare utilisation (and other outcomes) on following single components of a community-based palliative care program:
  - Early intervention (n=5 primary studies): lower ED visits and lower acute care stays in last 2 weeks of death were reported. Early was defined as in advance of a patient needing to make final decisions regarding PC. In 3 studies, it was 2-3 months before death, in 2 studies early intervention happened before the individual's disease continued to progress.
  - Education (n= 11 primary studies): no outcomes on healthcare utilisation reported, only on increased knowledge and competences or skills
  - Telehealth (n=7 primary studies): no results found on effectiveness, only some positive findings found on acceptability and feasibility
  - Standardised communication sessions among community-based palliative care team participants (n= 6 primary studies): an example of such a communication session is the interdisciplinary team meetings discussing patients. Most studies reported positive results on increase in respecting a patient's life will, home deaths and hospital utilisation rates.
  - Volunteers (n= 9 primary studies): no outcomes on healthcare utilisation reported, only on positive experience from perspective of

volunteers, patient/caregivers and involved healthcare professionals

- Innovative approaches including service provision (n=12 primary studies): overall positive results were reported on cost-effectiveness and hospitalisation rates across the innovative services. These services encompassed respite service, a screening tool for ageing patients needing palliative care, financial incentives for advanced care management, portable ultrasonography, palliative medication kit, community outreach, information sharing and education program) but differentiation in effectiveness or in description of characteristics per type of services was not possible due to poorly reporting in the review.
- Innovative approaches on professional roles (n= 8 primary studies): across the different types of professional roles (encompassing culturally tailored patient navigators, nurse-led collaborations and coordination, GP communication palliative care team facilitator), no consensus could be found on potential improvements of outcomes

- **Clinical Nurse Specialists (CNS)-led interventions:** this type of palliative care services was both reported in the review of Hughes, 2023[86] (see innovative approaches on personnel roles) and in the review of Salamanca-Balen, 2018[87]. Clinical nurse specialists are defined as a nurse prepared beyond the level of a generalist nurse and authorised to practice with advanced expertise in a nursing field. Specialist practice includes clinical, teaching, administration, research and consultant roles. CNS frequently work as part of multidisciplinary groups; this makes it difficult to evaluate their effectiveness as individual provider.

In general, interventions were complex and involved multiple interacting components, such as:

- **Interventions in which the clinical component was predominant** included activities directed to the diagnosis, treatment and control of the disease and were performed in hospitals, outpatient clinics or patients' homes
- **Supportive interventions** sought to increase patients' knowledge about their disease and its management, and at the same time aimed to give psychological/spiritual support
- **Care coordination** activities
- A **wide range of activities** were reported, including clinical consultations (in hospitals, at home, specialist clinics or via the telephone), the request of follow-up investigations, prescription or adjustment of medications, referrals to other agencies or staff, provision of support directed at overall well-being, and education to enhance self-management, as well as administrative work and liaison and communication with other professionals.

Table 13 – Comparison between the different interventions in specialised community palliative care

Type of PC at home	Reference	Hospital admissions	ED visits	Admissions to other services	Hospital LOS	Place of death	Costs
Support services from community-based specialist PC providers	Iupati, 2023[85]	Decrease (with conflicting results in reviews)	Decrease	Not reported	decrease	Increased home deaths	Not reported
Comprehensive community-based PC programs	Vernon, 2022[92]	Decrease (but conflicting evidence)	Decrease (but conflicting evidence)	Increase in hospice utilisation rates	Decrease	Increased home deaths	Decrease (but conflicting evidence)
Single components of community-based PC programs	Hughes, 2023[86]	Decrease	Decrease	Not reported	Not reported	Increased home deaths	NR
Clinical nurse specialists (CNS)-led interventions	Salamanca-Balen, 2018[87]	Decrease (but conflicting evidence)	Decrease (but conflicting evidence)	Decrease in doctor's visits	Decrease (but conflicting evidence)	Not reported	Decrease (but conflicting evidence)

3.2.3.2 Out-of-hours services

Only three reviews on out-of-hours services for palliative patients were found in our search strategy, with one reference excluded because of the design (i.e. research letter instead of a review): Johnston et al., 2020[93] on the (cost-)effectiveness of out-of-hours palliative care but found no studies of sufficient quality to analyse the effectiveness of these kind of services (therefore not reported in the table below); Firth et al., 2023[94] looked at different components of models of community-based out-of-hours care and Johansson et al., 2023[95] analysed more in detail the effectiveness of out-of-hours palliative care telephone advice lines (see Table 14).

Following **overall conclusions** were made based on the evidence found across the three included reviews:

- Hospital admissions: some tendency could be found on lower number of hospital admissions, but this finding was not reported in all included studies of Firth, 2023[94], which hampers the overall conclusion on the effect of out-of-hours services on hospital admission. Only one study reported on hospital admission and found that patients after an out-of-hours telephone call were less likely to be admitted to hospital in the last week of life and to die in hospital, but due to the very restricted number of studies, this finding cannot be generalised.[95]
- ED visits: confliting evidence was found in the review of Firth, 2023[94] with for some components of the care model a decrease in ED visits, but lack of effect in other types of care models (see below for description of these care models). Patients who used a telephone advice line were less likely to use emergency care services, or to visit ED, suggesting that hospitalisation if infrequent following out-of-hours calls and that patients remained at home after the call.[95]
- Access to other health services: some decrease was found on number of GP visits[94] and longer continuation of care at home[95] but due to this effect could not be seen across all included studies.
- Costs: mixed results were found in Firth et al., 2023[94] with some potential cost-savings estimated when specialised palliative care

service (free-of charge, round-the-clock, live-in support person) was provided. Also, conflicting evidence was found on potential cost-savings of telephone advice line by less use of avoidable emergency care however also slightly higher costs found regarding out-of-hours access to medicines for patients at home.

Nevertheless, the limited evidence on the potential impact of out-of-hours palliative care services on healthcare utilisation, some key **characteristics** of models of care could be identified:

- Out-of-hours was defined as outside of typical working hours (i.e. 9.00am–5.00pm, Monday to Friday) and therefore including overnight, weekends, and public holidays.[93]
- Within the community out-of-hours palliative care, Firth et al., 2023[94] identified 15 categories of components of models of care with three overarching dimensions (see evidence tables in the Supplementary Report for the full list of 15 categories):
    - **Service time** (if a service was provided during both daytime and out-of-hours or if it was only an out-of-hours service): the review of Firth et al., 2023[94] emphasised the importance of 24/7 care for palliative patients. The qualitative synthesis in the review highlighted the importance of patients and families feeling known to a service providing out-of-hours care. Shared patient records were deemed important, as were services giving consistent information to patients and families, and patients receiving responsive and appropriate care aligned with their priorities and preferences.
    - **Focus of staff delivering the care** (specialist palliative care/dedicated palliative care, generalist palliative care or integrated specialist and generalist palliative care): Although more research is specifically needed on effectiveness of the different categories of general palliative care and on models of integrated working out-of-hours between specialist and general services for palliative care, the authors highlighted the importance of a capable workforce that works collaboratively across disciplinary boundaries, in order to provide comprehensive and ongoing multidimensional assessment.
        - Specialist palliative care: hands-on clinical care was mainly for patients in last few days of life, mainly uni-disciplinary by specialist palliative care nurses and/or health care assistants, advisory care was more available to all patients receiving palliative care and not limited to the dying phase, mostly provided over the phone, with some also offering home visits. Patients and families reported a sense of comfort by always knowing care was available but integration and continuity were impeded with lack of access to shared patient records out of hours.
        - Integrated specialist and generalist palliative care: most studies found care delivered by multidisciplinary teams, and combination or advisory and hands-on clinical care, which enable the services to provide numerous interventions to patients and families out-of-hours.
        - Generalist palliative care: clinical care is more focused on personal and supportive care with a specific focus on meeting activities of daily living (including a sitting service) and care aids, with extended visits by care aids (healthcare assistants). Advisory care was provided by generalist services (multidiciplinary teams or services led by family physicians). Concerns were reported by patients and families of not feeling listened to and out-of-hours family physicians being little informed about the patient.
    - **Type of care delivered** (advisory only and/or hands-on clinical care): most evidence on improved outcomes for patients was for services, which provided a combination of both hands-on clinical care and advisory care. This also echoed patients and families assertion for high quality coordinated care that meets their needs (whether this be advisory or hands on clinical care) and ensure sense of comfort and safety.

- **A telephone advice line** was defined in Johanson, 2023[95] as availability through telephone calls, designated for providing palliative care support, help, and information, reactive, i.e., contact is patient/carer initiated, accessible during at least parts of the out-of-hours periods (weekdays between 6.00 pm-8.00 am, weekends, and public holidays). The most reported call reason was managing symptoms and/or medication, with other reasons involving health deterioration, nursing advice, requests for new or additional medication or equipment, or reporting that the patient had died. The most reported actions taken by responders involved providing support and nursing advice appropriate to their level of clinical training, and transferring or signposting callers to other services. Responders in some telephone advice lines also contacted on-call teams for urgent home visits, arranged next working-day follow-up at home or over the telephone, and, less commonly, helped with prescribing or collecting medication. Patients reported that the telephone advice lines provided valuable opportunity for patients and informal caregivers to ask about signs and symptoms and be informed about the disease trajectory or the dying process, so that callers can better understand whether these are 'normal' or expected. Receiving appropriate information was also reported to aid decision-making and help prevent unnecessary hospital admission and promote appropriate use of care services, as patients and informal caregivers noted that they might otherwise have contacted emergency care services. Callers perceived also a sense of comfort when responders were familiar to the patient's case. Similarly, access to patient records was described as valued by callers who did not have to re-explain the situation.

Table 14 – Comparison between out-of-hours services

Type of out-of-hours services	Reference	Hospital admissions (in the last 8 weeks of life)	ED visits	Admissions to other services	Place of death	Costs
24/7 specialist PC (hands-on clinical care only)	Firth, 2023[94]	Not reported	Decrease	Decrease in GP visits	More likely to die at home Less likely to die in hospital	Not reported
24/7 specialist PC (combination of advisory and hands-on clinical care)	Firth, 2023[94]	Decrease	Decrease	Not reported	More likely to die at home Less likely to die in hospital	Conflicting evidence
24/7 specialist PC (advisory care only)	Firth, 2023[94]	Not reported	No difference	Not reported	Not reported	Not reported
Telephone advice line	Johanson, 2023[95]	Decrease	Decrease	Enabled to continue caring at home	NR Less likely to die in hospital	Conflicting evidence

3.2.3.3 *Access to medicines in the community*

Our search strategy revealed only one review on the community access to palliative care medicines: Ogi et al., 2021[96], therefore the conclusions on this aspect of palliative care is rather limited and only based on the 10 primary studies included in this review.

The **overall conclusion** differs from the previous sections, since the authors mainly looked at outcomes related to medicine access and not to other outcomes of healthcare utilisation, such as hospital admissions or ED visits. Following main findings were reported:

- Lack of pharmacy stock of palliative care medicines: problematic stock, patients had to travel to more than one pharmacy before accessing medicine, reported delays in being able to provide palliative care medicines (even the pharmacies that were part of an enhanced commissioned service and specialist network)
- Lack of information provision: little contact with community pharmacist, poor overall knowledge of services (patients often acquiring knowledge in an unplanned way through family/friends or when in a crisis situation), patients and informal caregivers wanted a more proactive role from pharmacists regarding prescription and supply processes of controlled drugs or when a new medicine was prescribed, inadequate provision of information to manage their medications at home appropriately, pharmacists reported lack of information about the patient (disease status, awareness of illness and opioids), lack of room for private counselling.
- Influence on accessing medicines: problematic communication with pharmacy causing delays in supplying medicines through a mismatch between prescriptions received and stocks held and/or lack of information on palliative care status of the patient (due to unfamiliar patients who had been referred by another network pharmacist or health professionals' reluctance to share information), health professionals' lack of knowledge about enhanced or commissioned services, lack of awareness of more general pharmacy services, disrupted communication when patients transferred between secondary and primary care settings affecting prescriptions and the ability to swiftly supply medicines needed. These barriers could be solved by better training of counter staff, pre-emptive communication from community nurses about medicines likely to be required by patients, being part of a network of pharmacists where medicines and advice could be accessed.
- Practical problems with palliative medicine stock and couriering medicines: secure storage space, wide range of opioid dosage requirements for individual patients, delays in accessing stock, medicines not being on state reimbursement schemes, no one to courier prescriptions/ medication to and from GP, pharmacy and patient, a financial burden for some patients when delivery was not free of charge.
- Delay in access: median time for accessing urgent palliative care medicines was significantly longer for non-commissioned services pharmacists vs commissioned pharmacists to hold stock of palliative care medicines (5 hours vs 10 min), medicine access through GPs was often delayed due to the needs need to clarify the advice given by the home care team, inability of someone to collect the prescription, the patients being unable to attend the surgery. Access to a community specialist nurse showed most significant perceived benefit because it enabled patients to access medication quickly and no need to call and out-of-hours physician to prescribe.
- Hospital admission: kits averted use of other services (an emergency department visit or hospitalisation was avoided by having a kit in the home), increased both patient and nurse satisfaction, the after-hours nurses perceived caller (patient/family) satisfaction was significantly higher in pallaitive patients with a kit compared with both the non-kit palliative patients and the Hospice Emergency Medication Kit (HEKM) pallaitive patients without a kit, more patients with kits received symptom relief within 30min versus without kits.

The authors identified following **characteristics** of models of care:

- Medicine access was defined as prescribing, dispensing, supplying and providing associated information about medicines

- Some pharmacies provide enhanced or commissioned palliative medicine services (keeping a core stock of palliative medicines and extended opening hours for access)
- Patients and informal caregivers saw pharmacist as a source of medicine information (as well as GPs) if they had a previous relationship with them.
- Different service delivery modelswere found: community pharmacy, hospice emergency medication kits (HEMKs in the home), specialist community nurse prescribers, general practice, and multiple service delivery components. HEMKs are typically ordered by a physician on referral to home hospice service, and kept in the patient's home, to allow the patient access to small quantities of medication that can be administred immediately on nurse instruction. Emergency medication kits contain sufficient medications for 12–72 hours, thus avoiding the immediate need for pharmacy and physician involvement after hours.

3.2.3.4 Hospital at home

Only one review could be found on the impact of hospital at home services on healthcare utilisation in palliative care patients: Shepperd et al., 2021[97]

The **overall conclusion** was based on the single retrieved review, preventing the generalisation of the results (Table 15):

- Hospital admissions: conflicting evidence was found on (unplanned) admissions.
- Place of death: home-based end-of-life care increased the likelihood of dying at home compared with usual care (i.e. hospital or hospice).
- Costs: the reduction in total health service costs was not significantly different between particpants receiving EOL at home or in hospital or hospice.

Characteristics of the interventions, as described by Shepperd et al., 2021[97], were:

- Hopital at home is defined as end-of-life care at home and includes the provision of a service that provides active treatment for continuous periods of time by healthcare professionals in the patient's home for patients who would otherwise require hospital or hospice inpatient end-of-life care.
- In most studies EOL hospital at home care was multidisciplinary care which included specialist palliative care nurses, family physicians, palliative-care consultants, physiotherapists, occupational therapists, nutritionists and social care workers.
- One of the interventions was hospital-based in a specialised service of palliative care, which provided community outreach, including all inpatient and outpatient hospital services were provided at the unit unless care was required elsewhere for medical reasons. The unit served as a link to community services, and the PC physician and community nurse were defined as the main professionals. Predefined guidelines were used to keep optimal interaction between services, and community-based professionals were offered an educational program that included bedside training and 6-12 h of lectures every 6 month.
- Two trials described an educational component, either for participants and families on goals of care and expected course of disease and outcomes, or for community staff.

Table 15 – Hospital at home in the context of palliative care

Type of hospital at home care	Reference	Hospital admissions	ED visits	Admissions to other services	Place of death	Costs
End-of-life home-based care	Shepperd, 2021[97]	Conflicting evidence	Not reported	Not reported	More likely to die at home	No difference

3.2.4 Cost-effectiveness and resource utilisation

Three recent reviews could be identified in our literature search on resource utilisation, including analysis of cost-effectiveness and resource use: Luta et al., 2021[98], Mathew et al., 2020[99], Soltani et al., 2022[100]. Next to these reviews, another review was identified on human resource planning for palliative care personnel: Raine et al., 2020[101].

Following elements, described by the authors of the reviews, lead to the **overall conclusion** that currently no consistent evidence is available on substantial savings for the healthcare system:

- Methodological issues in the retrieved reviews (and their included primary studies) are major barriers for the interpretation of the results and to draw a concluson on the potential cost savings of palliative care services. For example, comparison was made between a mix of palliative care service across various settings versus usual care, but the differentiation in results per care setting lead to a significant attenuation of the potential costs savings to the health system. Also applicability and generalisability of evidence is uncertain due to small sample sizes, short duration, and limited modelling of costs and effects.[99]
- Characteristics explaining the potential cost-savings of a PC intervention were often not (detailed enough) described across the reviews. For example Luta et al., 2021[98] reported that home-based PC may lead to a reduction in costs, by reducing aggressive medicalisation at end-of-life. However, hospital-based PC could also be cost-savings by improved patient outcomes.
- Most studies in the review of Luta et al., 2021[98] overlooked important costs, including out-of-pocket, hospice and informal care costs.
- Although in some palliative care interventions some evidence could be found on cost-effectiveness, however there is still a great deal of uncertainty about these cost-savings when implementing these palliative care services in a healthcare system. Therefore more studies are neede in larger populations and over a longer period.[100]

Regarding human resource planning for palliative care personnel, Raine et al., 2020[101] found factors influencing the supply of hospice and palliative care professionals, such as lack of appropriate training, high rates of turnover in personnel, the fact that many palliative care professionals only work part time in that specialty. Also factors influencing the demand of hospice and palliative care professionals were identifed, such as more involvement at earlier stages to control pain or symptom management, the variation in setting, program structure and staffing structure means there is also variation in the number of patients seen per FTE, the experience level of the team has been shown to make a difference in the efficiency of the team. Based on these finding regarding the factors influencing the supply and demand of hospice and palliative care professionals (and the potential gap between both), the authors recommend to invest more in training of primary care professionals and other non palliative care specialists to perform basic hospice and palliative care, to make changes to the system to increase efficiency and to allow for mid-career specialist training.

3.2.5 Key elements from effectiveness analysis of palliative care services

This analysis of reviews aimed to give an overview of the effectiveness of **several types of palliative care services** provided to the palliative patients in their usual place of residence (e.g. at home, in a nursing home, or in a more temporary residential setting such as a hospice). Findings on the effectiveness of palliative care in a hospital setting were excluded from this analysis, to focus on extramural palliative care services. Nevertheless, the broad search on all types of palliative care services outside the hospital, the reported findings related to hospice care were only scarce and often included in a more general analysis on, for example, specialised palliative care services. Therefore, no firm conclusion can specifically be drawn on the effectiveness of hospice care in particular.

The search in literature was also focused on **organisational outcomes**, rather than on patient-centred outcomes, such as quality of life, patient satisfaction, etc. Organisational outcomes were defined as all types of outcomes related to healthcare utilisation, such as hospital (re-)admissions, visits to ED and/or ICU, LoS in hospital, costs, and place of death. This choice was made in the perspective of the hypothesis that the development

of an organisational palliative care model could decrease hospital use (hospital admissions in the last months of life and/or (undesired) decease at hospital) and therefore have a more cost-beneficial impact compared to usual care. Ideally the retrieved evidence on the effectiveness of palliative care services could then guide the choice for key-elements in the organisational palliative care model. However, several methodological limitations hampered the analysis of the retrieved evidence, and the reported findings should be interpreted with caution.

One of the major **methodological limitations** encountered during the analysis of the retrieved literature, was the lack of specificity in reporting of the results by the authors of the reviews. The lack of quantitative analysis of differences in outcomes (often without meta-analysis or statistically computing the difference in outcomes) lead to more general conclusions such as 'a certain decrease was found in healthcare utilisation,' but the amount of the difference neither the statistically relevance of this difference was difficult to retrieve. Ideally every included primary study should therefore be re-analysed and where possible a more quantitative analysis should be performed, but this approach was not considered feasible within the time span of this KCE project. The interpretation of the results was also hampered due to heterogeneity in primary studies related to multicomponent interventions. The lack of in-depth analysis of the effectiveness of each of these components (by the authors of the reviews) made it difficult to estimate which components are more effective compared to others and could therefore have a more important role in the elaboration of a palliative care model. In most studies palliative care was compared to usual care (which consisted in most cases of generic primary care without palliative care approach) but in some studies one type of palliative care services was compared to others. In most comparisons, no added value could be identified from one type of PC service compared to other types of PC services. Some primary studies and/or reviews were not restricted to quantitative reporting of differences in effectiveness but included also more qualitative approaches in which the patients and/or their relatives and/or healthcare professionals were questioned on their experiences related to the PC intervention and which barriers they encountered while receiving (or providing) the PC service. These results were also considered in this analysis and are considered as an important source of information in the further elaboration of the building blocks of the organisational PC model.

Across the reported results on effectiveness of the diverse types of palliative care services, a common finding can be stated: **no clear and consistent evidence** is currently present to show that the provision of palliative care could have more beneficial effects on healthcare utilisation compared to usual care. However, the lack of reported negative effects of palliative care and the lack of consistent dominating positive effects of usual care, may be interpreted as a (potentially) positive tendency in healthcare utilisation after (and during) the provision of palliative care. This positive tendency is illustrated by a decrease in ED and ICU visits, less hospital admissions, less referrals to (non-palliative) care services, more referrals to (and/or involvement of) hospice care and an increased change of dying at home (or in the preferred place of death). However, as mentioned previously in the methodological limitations, these findings should be interpreted with caution due to lack of statistical analysis.

The economic evaluations of palliative care services could not demonstrate a consistent cost-saving effect of PC versus usual care.

Next to the effectiveness of palliative care services, also an analysis was made on the **key characteristics** of the interventions. In the results section, these key characteristics were described per type of palliative care service. In this analysis, an overview is made across the different care services. For this overview, the theoretical model with 5 categories of 30 critical components of an efficacious EOL in-home programs[66] was used as basis and further completed with more concrete characteristics, as described in the interventions in the retrieved literature:

Types of services offered: pain and symptom management, professional psychosocial support, ongoing assessment, physician home visits, practical support, bereavement support, spiritual support, visiting volunteer services, medical intervention

- All types of services identified in this literature search share a common aim, i.e. to support patients and informal caregivers as far as possible and to enable patients **to stay at home**.

- Next to various forms of symptom management and care coordination, also **other services** were often encompassed in palliative care programs, such as patient and caregiver education, telephonic support services, respite services, advanced care planning support and domiciliary services.[92]
- According to patients and/or family caregivers, care coordination and practical help (such as the provision of equipment, hands-on care, social services, etc.) are considered as essential elements to guarantee the potential benefits of palliative care and to enhance **emotional well-being or sense of relief**, and in particular shared responsibility, ability and flexibility to stay at home and the provision of time and space to live through last stages of their relative's life in their own home.[85]
- **Innovative approaches** in service provision and personnel roles, such as portable utrasonography, palliative medication kit, culturally tailored patient navigators, nurse-led collaborations and coordinations were also reported in the studies, but the potential benefits on outcomes could not yet be demonstrated.[86]
- **Hospital at home** should be considered as an care option for palliative patients, however the underlying evidence is yet scarse and inconsistent.[97] In the single retrieved review[97] hospital at home is defined as a type of home-based end-of-life care that provides active treatment for continuous periods of time by healthcare professionals for patients who would otherwise require hospital or hospice inpatient end-of-life care. This type of service can either be delivered by a multidisciplinary outreach team or can be a outpatient hospital-based service in a palliative medicine unit.

Availability: team contact on-call around the clock, around-the-clock home visits available, physician available around the clock, access to dedicated inpatient beds, one contact number, chart in the home, emergency response plan

- A common element across the retrieved studies is the need for sufficient capacity of the palliative care service to provide a **24h, 7 day/per week availability** of their service.
- **Out-of-hours palliative care** should be available for all outpatient palliative patients. Out-of-hours was defined as outside of typical working hours (i.e. 9.00am–5.00pm, Monday to Friday) and therefore including overnight, weekends, and public holidays.[93] Some key elements related to an out-of-hours service were identified by Firth et al., 2023[94]: familiarity with the service by the patient and family, shared patient records in order to provide responsive and appropriate care aligned with the patient priorities and preferences, capable workforce who works collaboratively, the provision of hands-on and/or advisory palliative care ranging from general care, which is more focused on personal and supportive care to specialist hands-on clinical care in the last few days of life. The primary studies showed that responders in telephone advice lines provided not only support and nursing advice but also transferred or signposted callers to other services, contacted on-call teams for urgent home visits, arranged next working-day follow-up at home or over the telephone, and, less commonly, helped with prescribing or collecting medication.[95] The patients reported that receiving appropriate information was a facilitator for decision-making and prevented unnecessary hospital admission and promoted appropriate use of care services as patients noted that they might otherwise have contacted emergency care services.[95]
- Having **access to medicines in the community** has been described in literature[96], however in the Belgian context this was not considered as problematic. More information about this type of service can be found in the results sections and in the evidence tables.

Characteristics of the care model: multidisciplinary team, EOL care expertise or training, holistic care

- Across the retrieved studies, the composition of the PC teams varied a little but in general the team aimed to be multidisciplinary and consisted of at least a doctor or nurse, and in most studies the **multidisciplinary teams** consisted of different types healthcare professionals. To be labeled as a inter/multidisciplinary team, the team should fulfill at least two of the following criteria: 1) regular meetings, 2) development of a common interdisciplinary plan for each patient, 3) provision of comprehensive care, 4) identification of patients' goals of care, 5)

involvement of patient and their families in decision making and care planning, 6) team operating rules or policies, 7) use of common evaluation tools.[73]

Those teams were either home-based or either outreach teams from community or hospital, in some studies palliative services were physically or virtually co-located in the same facility as oncology services[73]. In nursing homes, the multidisciplinary teams were either created from existing nursing home staff or by implemenation of consultation services. In some cases a nurse coordinator acts as conduit between the patients and the community services. Volunteers are only included in a minority of palliative care programs.

- The **level of expertise** is determined by the level of specialised training in palliative medicine that a health professional had undergone. Health professionals who had undergone higher specialist training in palliative medicine were considered as specialists, whereas clinical experience over the years or a lower level of training has been considered as an intermediate level of expertise in palliative care.[37]
- **Staff education and training**, including audit and feedback strategy, staff champions or facilitators, staff training in EOL care alongside facility based palliative care teams or consultative teams, was also considered as one of the major strategies to implement a (multicomponent) palliative care program in a care setting, next to advance care planning and the integration of a palliative care team.[70]
- Independently from the level of expertise, or the healthcare setting, the common aim of palliative care is to provide **comprehensive care**, i.e. whole-person care that considered physical, emotional, and spiritual needs.

Collaborations with other resources (with variable degrees of formalisation) linkage with hospital, linkage between community services, expert consultation with other providers, linkage with residential hospice

- A collaborative network of palliative care services around the patients should also encompass the involvement of primary care professionals and in particular the GPs. **GP engagement** has been defined as any organised cooperation between the GP and specialist secondary services in the care of the patient including shared consultations, case conferences that involved at least both the GP and the specialist clinician and/or other secondary services, and/or any formal shared care arrangements between the GP and specialist services. Facilitators contributing to this engagement are effective communication, clear role definition, availability of the GP, family expectation that the GP will be involved and organisation and initiation of this collaboration by the specialist secondary service[72] Examples in the primary studies on GP engagement were telephone contacts with palliative care professionals during specific time frames, the involvement of palliative care professionals or volunteers in different care settings or outpatients visits made by the palliative care team.[71]
- While patients are moving between settings, a transmural team should be available for the coordination of care and to ensure the continuity of care. Three types of **transitional care** models were identified: collaborative teams from both the hospital and the community, hospital-based teams with outreach visits, and case management (with focus on advance care planning rather than the provision of care at home).[77] Key factor in transitional care is the the availability of relevant and accessible information for all involved healthcare professionals.[78]
- In line with one of the primary aims of palliative care (i.e. to enable the patient to stay at home), additional services were set up focused on **urgent care** in order to avoid hospital admissions and ED transfers. Those services comprised telemedicine services in which a nurse-doctor or a geriatric specialist performed assessment (and management) service, an assessment-based emergency practitioners service, a 'hospital in the home' assessment and management of admission-avoidance services, geriatric outreach services, predefined schedules of nurses visiting care homes and educational initiatives. However the evidence on the effectiveness of these services is still unclear.[68]

Process interventions: contact established with primary care or specialist, customized care plan or needs-driven care mandate, case management or nurse navigation, patient and family education, team case rounds, individual-directed care or joint decision-making, advance care planning

- The need for an early start of palliative care was also expressed across the retrieved studies. Early was defined as in advance of a patient needing to make final decisions regarding palliative care, varying in the studies from 2 to 3 months before death to the moment before the individual's disease continued to progress.[86]

One of the reviews on palliative care in nursing home residents identified three types of barriers **impacting the implementation and effectiveness** of a palliative care intervention.[69]

- Barriers related to the intervention

Common issues with end-of-life care are lack of knowledge and confidence to engage in ACP, and poor communication with residents with dementia due to staff's lack of knowledge of symptoms of dementia. The most effective approach to overcome these barriers, is the set-up of an educational intervention, e.g. EOL discussion with residents and relatives and ACP, leadership and communication with external services, overarching principles such as person-centres and dignified EOL care, education on identifying the signs and symptoms of EOL, dementia education, symptom and pain management, and combinations of the latter.

- Barriers related to the context

Contextual factors could also impact the effectiveness and the maintaining of an EOL intervention. Examples of those contextual factors are the restricted resource and financial capabilities of nursing homes and the lack of time due to full-loaded work schedules of nursing home staff, meaning that the staff often had to create time to engage with the intervention. Also the potential benefits of education sessions to overcome the barriers related to the EOL intervention could be hampered by contextual barriers, such as high staff turnover, small size of workforce (knowledge lost when staff left care home), only non-registered healthcare staff in nursing homes who have increased reliance on GPs and registered nurses, and lack of time of nursing home managers to engage in the meetings.

- Barriers related to the human agency

Next to barriers related the intervention and the context, the attitude and culture in which the staff works, could have a negative impact on the effectiveness and maintaining of an EOL intervention, e.g. variable level of cascade knowledge (too junior or at more senior level: lack of motivation, EOL care lower priority for nursing home managers), culture of dealing covertly with death and dying, staff's personal background and experiences, conflicts with relatives who were "not ready", "not accepting", "not understanding" about approaching death, and would not "give up", conflict with external services (e.g. out-of-hours GPs unwilling to cooperate due to negative attitudes towards nursing home staff (overrode their decisions or tendency to admit residents to hospital at end of life).

The author identified these barriers in particular in nursing home setting, but these barriers could be generalised to all types of palliative care settings and should be taken into account in the implementation of a palliative care intervention.

A recent review[102], retrieved via hand search, performed a similar exercise as in this chapter, i.e. determining the optimum service delivery model of specialised palliative care but whereas the focus in our literature overview was on organisational outcomes, these authors looked at the potential benefits on quality of life and emotional wellbeing. The analysis of RCTs on specialist palliative care (across settings) versus usual care revealed similar results as in ours: higher effect sizes were associated with multidisciplinary, multicomponent and multi-settings interventions. The sensitivity analyses showed a substantial benefit on quality of life and a moderate benefit on emotional wellbeing, but (also in line with our findings) the overall effectiveness is hampered by the large variation in intervention models and heterogeneity in outcome measures to measure quality of life and emotional wellbeing.

In conclusion, nevertheless the lack of consistent evidence on the effectiveness of palliative care interventions on healthcare utilisation, several key-elements related to the care offer needed in palliative care, but also more organisational and contextual factors could be identified as building blocks for the further development of a Belgian palliative care model.

3.3 Acceptability of palliative care to palliative patients, informal caregivers and healthcare professionals

3.3.1 Barriers encountered by palliative patients in the decision-making to initiate palliative care

Across the retrieved literature, several determinants were found which influenced the decision-making of palliative patients to initiate palliative care in their end-of-life care plan. These determinants are either non-modifiable characteristics, such as age, gender, or are more modifiable, such as knowledge about prognosis of disease, communication about patient preferences… Within the scope of this KCE report the focus was more on the modifiable determinants, and even more on how these determinants are often barriers for the patient to receive palliative care. Based on these findings, key-elements were determined to consider in the development of the Belgian organisational model and in particular how these determinants can either facilitate or hamper the implementation and use of this model.

The variety of determinants related to the perception of the palliative patient towards palliative care were grouped in the following categories: socio-demographic characteristics of the patient, patients' perception about the disease, public awareness about palliative care, patients' personal attitude towards accepting care, patients' knowledge about availability of services, financial concerns, and the role of advance care planning. An overview of these determinants and how they influence the acceptability of palliative care is presented in Table 16. Detailed information per retrieved review can be found in the evidence tables in the Supplementary Report. The following results should be interpreted with caution, due to poor reporting of quantitative data in which often a statistical analysis was lacking. Therefore, the findings should be considered as tendencies, rather than statements.

3.3.1.1 Socio-demographic characteristics

Differences in access and utilisation of palliative care were found between men and women. These **gender** differences could be related to care context: whereas women tend to receive care rather from generalists (versus more specialist care in men), have shorter hospitalizations and are more likely to die in a nursing home than at home. Also gender differences in care preferences determined the use of palliative care: women tend to be more positively towards palliative care, e.g. more women had a DNR order and fewer women received care in ICU. They expressed a higher preference for palliative care rather than for curative treatments. However they were less likely to benefit from early palliative care and were less likely to ask for informal care from family members. Women's living situation might also negatively affect end-of-life care: women were less likely to be married or more likely to be widowed, they are more likely to be living alone at end-of-life and to be older (with higher prevalence of chronic diseases and chronic pain conditions). The authors found also that women were more often found living in poverty.

The **socio-economic status** (SES) of the palliative patients determines the use of palliative care services, often leading to misuse and/or underuse of these services. Patients with low SES (lower income, lower education or no health insurance) were more likely to have high-intensity interventions (including chemotherapy, attendance at emergency departments or >14 days hospitalisation prior to death, intensive care admission, use of mechanical ventilation and cardiopulmonary reanimation), increased receipt of medication for pain, having dyspnoea and emotional distress, hospital admissions, ICU stays in last 30 days of life and were less likely to engage with palliative care or enter a hospice. Also an increased rate of transfers are seen from home or nursing home to secondary care in the last month of life. It was also reported that home was more diffcult due to home design obstacles (e.g. small rooms, lack of modern conveniences). In patients with financial strain (due to self-perceived poverty, disability or high medication cost) more reliance on practical or social support was found (e.g. transportation, help with navigating insurance policies or benefits, food stamps). However access to these sources of support were often perceived as challenging due to difficuties to naviguate between different types of supportive services. In patients with socio-economic deprivation, the financial distress was already common prior to diagnosis but got worsened after diagnosis, due to medical costs (with a larger proportion of family income to health expenses) and inability to work, but also feeling burdensome and useless and those patients are less likely to use (drug) reimbursement scheme. Patients with higher educational level tend to be more likely to choose supportive care and to accurately know their prognosis, which was associated with preference for comfort-orientated and hospice-based care at end-of-life). More inpatient hospice admissions were found in patients with higher income or living in a neighourhood with higher

SES. Also a higher availability of informal caregivers was seen and more unpaid caregiving hours were provided (6h versus 2h in patients with lowest SES).

The reported findings on the influence of **age** on access to palliative care were less consistent: older adults were less likely to use palliative/hospice care compared to younger counterparts versus older patients with cancer were more likely to use palliative/hospice care services than younger patients versus no significant association between age and use of PC services. In the advanced age more similar results were found, with an under-representation of the oldest old (over 85 years old) in palliative services, and centenarians seldom dying in (British) hospices, pointing out that advanced age might serve as a barrier to palliative or hospice care enrollment.

The **geographical location** of the hospice or palliative care services relative to the usual place of residence of the palliative patient determined its use. Patients living in more rural areas were less likely to use palliative or hospice care services compared to patients living in urban areas, mostly due to distance to those facilities and accessibility difficulties, such as lack of public transportation, lack of special needs or wheelchair accessible vehicles, lack of reliable drivers, often resulting in delayed or missed hospital visits. Also, the excessive cost of transportation services led to more transfers to bigger, urban hospitals in the last month of life, with high expenses for hotels, meals and parking. These transportation difficulties often result in isolation for older adults living in villages. Authors also mentioned the influence of poor road and weather conditions in the access to palliative care services. The remoteness of palliative care services also induced a limited choice in care services for the patients because they were limited to the facility closest to them, or they had to drive long distances and sought care outside of their community, often with no choice on the location of their death.

Characteristics related to the **disease** could lead to disparities in use of palliative care services. In general, it could be stated that cancer patients are more likely to be referred to hospices and to die in hospices compared to patients with non-malignant diseases (e.g. heart failure, non-cancer respiratory disease, renal and liver failure, mental health problems, cognitive problems, intellectual disability, dementia, and neurodegenerative diseases). Within the group of cancer patients, authors found that patients with gynaecologic, breast or stomach cancer were more likely to have access to palliative care services than patients with other types of cancer (or other diseases).

Vulnerable patient groups including minority groups (e.g. ethnic minority groups, racial disparities) and specific patient groups (e.g. patients with severe persistent mental illness) are less likely to receive (specialist) palliative care services, to see specialist healthcare professionals and they have lower rates of referrals to palliative care. Like patients with lower socio-economic status, vulnerable patients tend to have higher rates of ICU utilisation and were more likely to receive high-intensity interventions. Also, they are more likely to die in a nursing home. In patients with severe persistent mental illness, more visits were seen to the GPs and psychiatrists, but lower rates of seeing other specialists, receiving opioids for pain relief, or receiving palliative care. Inadequate coordination of care, a lack of clarity about patients' preferences and plans for care, and a discontinuity in service delivery (due to inconsistencies in how and what type of care is delivered), leading to a fragmentation of care and may hinder referrals to hospice and palliative care services.

3.3.1.2 Societal awareness of palliative care and hospice care

Studies on societal awareness showed that the perceptions about **palliative care in general** are low: the general public is unfamiliar with palliative care and even have a negative image or stereotype of palliative care. Often due to a lack of knowledge, and/or beliefs that palliative care required forgoing cancer therapy and often palliative care is equated with end-of-life/terminal care.

A higher public awareness and public favourability was seen related to **hospice care**. This higher level of awareness is mostly seen in patients with higher education or with personal experience with hospice care. However still some misconceptions were found, mostly beliefs that choosing hospice was tantamount to "giving up". Following factors were found influencing positively public perception, such as older, white females with higher education and socioeconomic status, a positive personal experience with a family member, trust in the health system and/or presence of a strong relationship with a primary care or other clinician. Barriers were reluctancy

to discuss serious illness, distrust of documents and/or mistrust in the healthcare system.

3.3.1.3 Patients' perception about the (terminal nature of) disease

In some patients (and families) a **denial** of the terminal nature of the disease is seen, characterised by a sense of urgency and desire to continue curative treatments and/or request to not be referred to palliative care.

Gender differences are also found in **symptom experience**, with a higher symptom burden in women (more pain, fatigue and nausea self-reported, however no difference in medical charts or documentation) and more undertreatment for pain in women because less heard by healthcare professionals. The latter was explained by the authors by the societal belief that pain is likely exaggerated by women and related to anxiety and emotional distress and natural process that do not need be treated. Also women tend to experience less improvement in quality of life when palliative care was initiated, due to difference in worries (unmet responsibilities for domestic and caring duties versus financial and legal duties in men). The authors found more depression in men at end-of-life and suggested that is is related to the expecation that men should be independent.

The relationship between socio-economic status and symptom experience was less clear. Some conflicitng evidence was found with socio-economic deprivation associated with lower functional, emotional and spiritual wellbeing vs less anxiety and depression versus very low illness burden versus higher hopelessness and depression rate.

Familial anxiety and patients' own illness-related anxiety were considered of high importance in influencing patients' symptom experience. Also feeling stigmatised by their social environment following the cancer diagnosis was a major determinant, next to patients worrying about pain and control of physical and emotional symptoms, experiences of depression, anxiety, spiritual distress, family breakdown, and the fear of losing personal autonomy, with the perception that dependency leads to loss of dignity and feeling of frustration.

3.3.1.4 Patients' personal attitude towards accepting care

Gender differences were found in **coping strategies** affecting patients' independence: women tend to be more able to express needs and ask for help, they have activated extended networks for support and valued and used physical appearance at end-of-life to retain control and agency (influence of culture and locations on value of appearance), whereas men felt the need to be strong and independent but relied more on their partners. No consistent evidence was found regarding coping ability and educational level: higher education was associated with better positive personal development and adjustment to trauma versus more likely to report feelings of having lost control and poorer coping with activities of the daily life (ADL).

Acceptance of palliative care was also determined by the **emotions** involved in cancer care pathways, such as emotions and psychological reactions experienced by patients/families, feelings of frustration and anger due to unpreparedness of family to patient transition to palliative care, fear of palliative care, and/or resistance or denial to accept actual medical condition and/or palliative care options. Also concerns becoming a burden to others and the wish to avoid creating hardship for their family and friends determined the acceptability of palliative care services.

The degree of **patient involvement** determined also the (non)acceptance of care: not feeling connected to their professionals hindered patient involvement or participation in decision making processes, and influenced communication. Also the feeling that they were not informed enough about available care choices (e.g., hospice transfer) or treatment options (e.g. palliative focused treatments) for their condition was perceived as a major barrier. On the contrary, patients reported feeling more secure when having drect access to care when needed.

3.3.1.5 Patients' knowledge about availability of services

The **misconceptions** about palliative care and its options is considered as one of the major barriers in accessibility of palliative care services, illustrated by uncertainty about the scope of palliative care, difficulty in defining palliative care, lack of patient education, lack of information on hospital and home services and difficulties in navigating between services. Also patient (and/or family) reluctance in accepting the terminal nature of the disease, is related to beliefs that palliative care being viewed as terminal care, beliefs

about losing hope, differing perspectives about hope (overoptimism versus hopelessness). The lack of adequate awareness or correct information about palliative care was reported regarding the definition and description of palliative/hospice care: some patients defined accurately hospice care and its components, but, for other patients, a lack of awareness about the advantages was mentioned, also misunderstandings about palliative and hospice care (e.g., hospice care provides services only for patients' relatives and for funeral arrangements; only for elderly, only in nursing homes or as home care for daily living activities and rehabilitation care). In some studies, patients had information about several components of palliative or hospice care (treatment management, nursing care, EOL care and pain relief), but limited information about pastoral care, social care and bereavement care. Less than half of the patients (reported in one of the included reviews) knew about healthcare professionals specialising in palliative care who could provide palliative care and even less of the patients knew that palliative care could be received in various settings.

In line with knowledge and misconceptions about palliative care, **patients' preferences** might also determine the acceptability of palliative care, e.g. some patients wish to receive care from family physicians or nurses rather than from unknown healthcare professionals in a palliative care unit.

3.3.1.6 Financial concerns

Economic barriers could be determinant the acceptability of palliative care services. Examples of such economic barriers, cited in the reviews, were: high expenses, lack of adequate healthcare insurance coverage, financial concerns due to an increase in out-of-pocket spending.

Also **logistic barriers** could impede the use of palliative care services, such as lack of palliative care professionals in the community, lack of time and difficulty in transportation, long wait times, and importantly lack of time during consultation to discuss or ask question about diagnosis/prognosis and to make informed decisions.

3.3.1.7 The role of advance care planning

No consistent impact was seen by **socio-economic status** on the (under)use of future care planning: having a higher household income increased the odds of having a legally designated power of attorney for healthcare, but no impact on EOL discussions or written instructions was found. Also no impact could be demonstrated of education level on advanced care planning behaviour.

In specific patient groups, such as patients with severe psychiatric mental illness, the **decisional capacity** is often questioned by family and/or healthcare professionals. Only very few individuals with severe psychiatric mental illness had discussed their preferences for EOL care and only 5% reported having had a conversation with their physicians about this. Also family communication problems and estrangement, guardianship status, and (false) assumptions regarding capacity to participate in EOL care decision-making made that the conversation about care preferences did not take place or only late in the course of illness.

A study on **life priorities** (based on the Life Priorities Survey) showed that 'live as long as possible, no matter what' was most frequently ranked in patient's top three goals, '(being) mentally aware' and '(being) independent' were 'somewhat to extremely important'.

The patients preference can also **change over time**. A study showed that the majority of patients requested themselves an end of life hospitalisation (even in the last few days or hours of life), because they felt safer in hospital, they wanted to be treated in hospital, were still hopeful of prolonging their life, and/or the hospital was considered as a safer place where they would receive the right treatment and care to sustain life.

Table 16 – Patient-related determinants related the acceptability of palliative care

Patient-related barriers	Influence on access problems and/or under/misuse of palliative care services
Socio-demographic characteristics[103-111]	Gender differences, lower socio-economic status, age differences (however with conflicting evidence), geographical aspects, vulnerable groups (including minority groups and specific patient groups) Cancer patients more likely to have access to PC services
Societal awareness of palliative / hospice care[103, 112]	Misconceptions and lack of knowledge about PC and hospice care
Perception about (terminal nature of) disease[105, 106, 110, 111, 113-115]	Denial of terminal nature of disease, desire to continue curative treatment, cognitive and emotional aspects (anxiety, guilt, fear of losing cognitive capacity, sadness), willingness to maintain personal autonomy,
Attitude towards accepting help/care[103, 105, 111, 115, 116]	Gender and educational differences in coping strategies affecting person's independence Emotions Patient involvement
Knowledge about availability of services[103, 104, 106, 107, 116, 117]	Lack of knowledge about palliative care, PC services and local services Misconceptions about care services Preference for hospital as safe place
Financial concerns[103]	(fear for) high expenses, lack of adequate insurance coverage Organisational barriers: lack of time for discussion during consultation, lack of providers in the community, long wait times
Advance care planning[105, 118-120]	Questioning of competency/ decisional capacity of the patient Life priorities Patient preferences change over time

3.3.2 Barriers encountered by the informal caregivers in the decision-making to initiate palliative care

The decision made by the patient to go to a hospice care facility, is not only determined by his personal preferences, beliefs, and characteristics, but also the perception by the family or informal caregivers in the entourage of the patient can have a significant impact on the acceptability of palliative and hospice care.

Table 17 presents an overview of the different barriers encountered by informal caregivers in the decision-making about the initiation of palliative care for their palliative relative. The following determinants were retrieved in the literature review: family perception about the (terminal nature of the) disease, the role of advance care planning, knowledge about the availability of services, personal attitude towards caring and practical concerns.

3.3.2.1 *(Family) Perception about (terminal nature of) disease*

The **denial of the terminal nature of the disease** by the family will hamper the use of palliative care: families did not want to disclose to the patient about the diagnosis, so that the patient would continue to fight the disease as if the diagnosis was not known, but also the denial by the family members themselves that the patient could die.

The **taboo of death** often impacted also the acceptability of palliative care, such as unrealistic family expectations, conflicting family opinions, patients and caregivers lack knowledge about available services and how to access them, lack of family participation in care planning, unrealistic expectations of death, family/patient denial of death, difficult to openly discuss death, may pressurize patients into accepting more aggressive forms of care.

3.3.2.2 *Role of advance care planning*

Family members perceived conversations with the patients about the terminal nature of the disease often as **emotionally difficult**. Some informal caregivers felt unable to discuss advance care planning (ACP) because it would cause the person to 'feel they were dying', too harsh or inhumane to set goals or document ACP preferences, might be perceived as 'putting the person with dementia to their death'. Next to this difficulty of signifying death, also the unpreparedness to face impending cognitive decline (in patients with dementia) determined the use of ACP: some informal caregivers and patients made an active decision not to participate in ACP (too 'frightening' to think about in advance), or 'no real urgency' for ACP and avoided the discussion, other informal caregivers regretted they had not completed ACP earlier (patient no able anymore to participate in the decision-making process).

The **lack of communication** with healthcare professionals implicitly reinforced the belief that death should remain unspoken.

The **fear of being responsible for cause of death** may also impact the acceptability of palliative care: even when ACP has occurred, operationalising goals for comfort into actions, which would lead to person's death, informal caregivers became less able to follow the preferences as they felt responsible for 'killing' the person, perceived this as too overwhelming, and ignore the preferences of the person in order to preserve their own peace of mind and maintain a clear 'conscience'.

To be obliged to make **uninformed choices** on behalf of the patient, negatively impacted the acceptability of palliative care and its use: some informal caregivers completed ACP on behalf of non-competent patient, felt that they had not made the best ACP plan, did not have enough time or received not enough support from clinicians to explore all options, they could have 'come up with a better plan' if they were better informed of the course of dementia and the treatment options. Informal caregivers and patients expressed a need for better education around the course of the disease and medical decisions, and ongoing communication and revisited to allow time to digest the relevant information.

3.3.2.3 *Knowledge about the availability of palliative care services*

A **lack of knowledge** about the provision of palliative care services was reported across the retrieved reviews, and related to access support services, the existence of palliative home support, and hospice involvement in palliative care, and more in particular about the services offered by hospice, a perceived uncertainty whether they had access to hospital if needed, and which roles the different palliative care professionals have.

The informal caregivers perceived this lack of knowledge (resulting in deprived hospice access and support and end-of-life) as **missed opportunities:** informal caregivers were disappointed by difficulties they experienced 'getting through the front lines' and accessing hospice and support. They believed it was a result of limited care options, high cost of services and inconsistent/lack of communication from healthcare professionals. Informal caregivers felt 'cheated' because palliative care was not offered until too late. Informal caregivers felt overwhelmed when patient was discharged or 'kicked out of hospice' because 'not dying fast enough' to qualify for hospice care.

3.3.2.4 Attitude towards caring

Some gender differences were found in **coping strategies** and, particularly, in the (under)use of financial support services: women perceived more mental and physical strain, lower self-esteem, higher levels of fatigue and greater expectations and responsibilities were placed on women as caregivers and increased burden on their own health (universal belief that women are natural caregivers of society), often also combined with heightened feelings of guilt or failure when unable to do so (due to diagnosis with multiple medical conditions). This gender difference in coping strategies resulted in that women were less likely to qualify for governmental financial support benefits (generally linked to employment) and received less money(related to lower income).

Following aspects were reported influencing **family decisions for hospital admission**: the informal caregivers' emotional and physical (in)ability to cope and to provide the care needed, also determined by their lack of knowledge, practical experience and skills required to look after the patient; multiple and conflicting caring roles by informal caregivers leading to the decision for hospitalisation so they could attend to other caring responsibilities; deteriorating symptoms (e.g., breathlessness); and/or an increase in physical care needs related to activities of daily living.

Family members (or informal caregivers) were less likley to request end of life hospital admissions if they had explored **end-of-life preferences and advance care planning** with a health professional. Informal caregivers who participated in ACP focused more on a 'good death' (in line with the preferences of the person with dementia), believed that aggressive treatment caused only prolonged suffering and were preferring 'to let nature takes its course', to have a 'natural death without machines'. However informal caregivers who did not participate in ACP struggled to understand dementia's dying process and felt obliged to treat what could be treated (e.g., pneumonia).

A **feeling of obligation** to facilitate care at home was also expressed by the informal caregivers. This moral duty or promise left caregivers with little choice but for home to be the place of care, had no choice but to care at home, and own preferences were unimportant and often ignored to facilitate the patient's preferences. Caregivers expressed some positive impact of facilitating home care, such as: allowing them to demonstrate love for their relative, experiencing the illness trajectory was beneficial, allowing families to feel greater sense of 'togetherness'. On the contrary, little escape from caregiving role, meaning of 'home' changed (becoming an impersonal and medicalised environment), feeling ignored and alone, sense of isolation were also expressed by the informal caregivers.

A similar feeling of obligation was expressed related to home death. Caring at home until death was of great significance for family caregivers, but managing or failing to do so, affected family caregivers before and after bereavement. Also facilitating home death was linked with feelings of accomplishment, and positively impacted bereavement experience, however in case of failure of home death, this had a substantial negative impact on family caregivers, and negatively impacted bereavement experience (ideas of failure and guilt).

3.3.2.5 Practical concerns

Insufficient time (often due to job restrictions) was reported as a significant barrier and impaired their caregiving abilities. Insufficient time for self and stress between caring and other responsibilities were also common challenges. Also **financial difficulties** were associated with caregiver burnout and reduced quality of life. **Logistic barriers**, such as lack of availability of equipment to support families to care for patients at EOL and lack of integrated out-of-hours GP services could negatively impact the care provided by the informal caregivers.

Table 17 – Overview of informal caregiver-related determinants on the acceptability of palliative care

Informal caregiver-related determinants	Influence on access problems and/or under/misuse of palliative care services
(family) Perception about (terminal nature of) disease[113, 114, 120, 121]	Denial of terminal nature of disease, diagnosis and prognosis not disclosed to the patient Taboo of death
Role of advance care planning[121]	Reticence to discuss advance care planning Lack of communication with health professionals implicitly reinforced misbeliefs about death and lead to making uninformed choices Fear of being responsible for death, need for alleviation of decisional responsibility Struggling with unknown preferences (moral dilemma) vs carer advocacy
Knowledge about availability of services[121-123]	Lack of knowledge about palliative care, PC services and local services Perception that provision and duration of hospice access was inadequate Questioning the appropriateness of PC for their patient
Attitude towards caring[111, 120, 121, 123]	Insufficient coping strategies (feelings of guilt or failure, more mental and physical strain, higher expectations, and responsibilities) Lack of knowledge, practical experience and skills required to look after the patient Less likely to request hospital admissions if they've discussed EOL preferences and ACP with a health professional Feeling obliged to facilitate care at home (moral duty or promise)
Practical concerns[110, 120]	Job restrictions impair the caregiving abilities Insufficient time for self and stress between caring and other responsibilities Financial concerns Lack of availability of supportive equipment and/or integrated out-of-hours GP services

3.3.3 *Barriers encountered by the healthcare professionals in the decision-making to initiate palliative care for their patients*

Next to the patient preferences and the perceptions of the family, also the role of the healthcare professionals in initiating palliative/hospice care should not be underestimated.

Table 18 presents an overview of the different determinants encountered by healthcare professionals in the decision-making about the initiation of palliative care for their palliative patient. Following barriers were retrieved in the literature review: attitude and beliefs towards palliative care, communication with the patient, attitude towards the patient, attitude towards informal caregivers, lack of knowledge, need for collaboration and communication between healthcare professionals, and geographical challenges.

3.3.3.1 *Attitude and beliefs towards palliative care*

Similar to the patients and the informal caregivers, also healthcare professionals encounter **misbeliefs and misconceptions** related to palliative care, such the association of palliative care or hospice with death, the perceived inappropriateness of palliative care for complex problems if physical problems were not present, that the only goal of palliative care is symptom management, the incompatibility of palliative care and cancer therapy, that the development of PC services is specifically for solid tumour cancer rather than for blood cancer, and that palliative care is only suitable for certain types of cancer, for older patients, and not for onco-hematologic patients. The beliefs that patients or family might have inappropriate reactions to referral, that discussions or referral upset patients and families, and personal lack of interest in PC were also considered as major barriers towards the acceptability of palliative care.

The **lack of trust** in other (oncology) specialists was described as the preference to maintain control also on palliative care and the beliefs about losing patient care management, lack of trust in others professionals' oncology knowledge, felt compelled to fully exhaust disease-directed treatment options prior to referring patients to palliative care professionals, also the source of confusion over roles which is increasing care fragmentation and threat palliative care patient autonomy. Opportunities to discuss EOL preferences and plan with a palliative care professional are often not made available to patients and families.

Within a medicalised or curative model of care, characterised by cure-focused attitudes and over-emphasis on the treatment, palliative care or death is seen as **failure or giving up hope** (e.g. mistaken belief that referral to palliative services will shorten life because life-sustaining treatments are withdrawn), and the healthcare professional is unconsciously avoiding admitting failure. Often the lack of knowledge about the effectiveness and purpose of palliative care if determined in ignoring the introduction of palliative care to his patients.

3.3.3.2 *Communication with the patient*

Poor communication skills were reported as a major barrier in the acceptability of palliative / hospice care. This poor communication is due to cultural insensitivity, lack of clarity, poor use of translators, overuse of medical jargon. Lack of open communication can be due to absence of training in communication skills, problems with communication of bad prognosis, lack of communication skills, and difficulty discussing spiritual, psychosocial, or emotional issues.

Communication barriers could also be induced by a **low professional comfort level**, characterised by inadequate preparation for psychosocial care of terminally-ill patients, providers often not comfortable talking to patients and families about referral to hospice and palliative care services (and often deferring this type of conversations with their patient), or the feeling of having failed. Proactive communication by GPs often did not take place because they found it difficult to find the right moment to talk about dying (in particular in fast deterioration, patients who still seemed active and not very ill, or patients who are deteriorating slowly).

Long term relationships between haemato-oncologists and patients may result in difficulty conducting EOL discussions. Clinicians lack skills and confidence to tackle EOL discussions.

Several barriers were reported related to **advance care planning**: lack of ACP knowledge, delays in decision-making, doctor belief that other professionals are responsible for ACP, doctor doubts about content and practical aspects of living wills, staff lack of experience in using ACP,

clinician fear of upsetting patients/families by initiating discussion, nurses who may be closer to patients and families are often excluded from planning discussions, discussions are stressful and challenging, competing work demands, fear of talking about dying in nursing home, conflicting patient/organisation preferences, nonelectronic notes on plans may be lost in transitions.

3.3.3.3 Attitude towards the patient

Some **negative bias and stigmatisation** was reported from healthcare professionals towards patients in lower socioeconomic class. Also a reluctancy of professionals outside psychiatry or hospice to care for individuals with SPMI was mainly due to inexperience and discomfort. **Overconfidence** to manage a patient's symptoms and disease process and clinicians' own unrealistic expectation about patient's prognosis hampered the utilisation of palliative and hospice care. Healthcare professionals' **concerns** about competency and emotional vulnerability of patient, resulted often in an exclusion of the patient from EOL care decisions. **Personal preferences** of GPs might impact the utilisation of palliative care services, e.g. the preference for patients with distressing symptoms to be managed better in hospital.

3.3.3.4 Attitude towards informal caregivers

Sometimes a **distrust** between healthcare professionals and informal caregivers was shown, e.g. some informal caregivers perceived "medical uncertainty" among healthcare professionals, leading them to feel frustrated and lose trust in healthcare professionals, some believed that physicians lacked confidence in making clinical judgements and ACP process, or had actively "ignored" the informal caregiver's concerns, other informal caregivers considered healthcare professionals as "specialists" of dementia and chose not to "question clinicians decisions or actions about care".

A different **expectation** towards male and female informal caregivers could potentially lead to unequal use of care services: physical care was more delegated to women and decision making to men, more support was provided to male caregivers. Women were assumed to inherently be more compassionate, sensitive to others, and willing to put others before themselves, for men not the same standardwas applied. Healthcare professionals are often unaware of their unequal expectation of men and women and rendered women's work invisible and undervalued.

3.3.3.5 Lack of knowledge

One of the reasons behind a delayed referral to hospice or palliative care services was the persistence of **medical hierarchy** across specialties, with oncologists keeping their patient in the curative treatment model.

A lack of knowledge appeared also in the difficulty of delineating **referral criteria,** such as unfamiliarity with referral criteria, with basic concepts of what hospice care / palliative care services can offer, EOL not included in prelicensure programs, referral processes often led to organisational regulations that are aimed to guide providers, but do not individualise patient care.

Regulations lead to **limited scope of practice**, e.g. statutory laws limit nurses and physician assistants to admit patients into hospice (resulting in a deferred or delayed referral to care services), physician is still considered as gatekeeper and access to palliative care often only made possible if a patient has a terminal illness with less than 6 months to live.

Lack of formal training and education in palliative care is often mentioned across the retrieved literature. EOL care is not thoroughly taught in most undergraduate, graduate and medical schools and few formal education classes/continuing education is easily accessible.

Difficulty in prognostication and appropriate timing to introduce palliative care was reported to be a barrier in the accessibility of palliative care services: trajectories are unpredictable and estimating prognosis is difficult, more contact/familiarity with patients makes prognostication harder and less accurate, generalists/inexperienced staff struggle to estimate prognosis or identify EOL, in nursing homes: individuals do not take responsibility for recognising dying, health professionals often cannot recognise imminent death, which may lead to dying alone.

Time restraints, limited access to resources and limited computer skills, community clinicians may be unsure of procedures and available services, staff lack of education and experience in EOL discussions and care, nursing

home staff resistance to change, nurses have insufficient knowledge and training about clinical decisions at EOL including clinician reluctance to prescribe high dose analgesia, lack of understanding around care goals, insufficient medication knowledge, are examples, among others, of a **lack of staff experience and training**.

3.3.3.6 Lack of collaboration and communication between healthcare professionals

Lack of effective team communication, illustrated by poor information exchange, lack of clarity and consensus on palliative care initiation, lack of opportunity of conversations between cancer care and palliative care professionals and lack of trusted relationships between professionals, is a major barrier in the accessibility of palliative care services. A **lack of multidisciplinary collaboration** between care services, often lead to a lack of coordination of care, resulting in inappropriate hospital admissions at end of life and loss of medication or care preference details.

3.3.3.7 Geographical challenges

In rural areas there is often a physician shortage, nurse practitioners and physicians' assistants can partially fill the gap but there will still be a shortage of hospice and palliative care specialists. Also, the conditions in which care is provided may hamper the accessibility to palliative care: e.g. less professional support, consultation resources and time, more money needed to ship supplies and to drive far distances, inclement weather and poor road conditions, low staff retention and recruitment and a high burden on staff.



Table 18 – Overview of healthcare provider-related barriers on the access and utilization of palliative care

Healthcare provider-related characteristics	Influence on access problems and/or under/misuse of palliative care services
Attitude and beliefs towards palliative care[114, 116]	Misbeliefs and misconceptions related to PC Lack of trust in others oncology specialists PC or death seen as failure or giving up hope
Communication with the patient[103, 104, 106, 114, 116, 120]	Poor communication skills Low provider comfort level: feeling having failed, not comfortable talking to patients about referral to PC and HC services, having long term relationships between oncologist and patient Lack of discussions about EOL: lack of information about care, prognostic uncertainty often poorly communicated, shift needed from expectations of cure towards acceptance of EOL Lack of ACP knowledge
Attitude towards the patient[103, 105, 106, 116, 118]	Negative bias and stigmatization Overconfidence to manage patient's symptoms and disease process, unrealistic expectations about patient 's prognosis Concerns about competency and emotional vulnerability of patients
Attitude towards caregivers[111, 121]	Distrusting clinicians' mastery and knowledge: informal caregivers perceived medical uncertainty among HC professionals, informal caregivers believed physicians lacked confidence in making clinical judgements and ACP process Differences in attitude towards male and female caregivers
Lack of knowledge[103, 104, 106, 114, 116]	Medical hierarchy across specialties Difficulty delineating referral criteria Limited scope of practice Lack of formal training and education in PC Difficulty in prognostication Lack of staff experience and training
Collaboration and communication between healthcare professionals[114, 116]	Lack of effective team communication Lack of trusted relationships between providers Lack of multidisciplinary collaboration
Geographical challenges[106]	Physicians shortage in rural areas

3.3.4 Barriers related to the healthcare system

On a more organisational level, barriers could hamper the implementation of a palliative care model. Table 19 presents an overview of the different barriers related to the healthcare system which is responsible for the organisation of palliative care. Following barriers were retrieved in the literature review: organisational barriers, administrative barriers, reimbursement regulations, and policy barriers.

3.3.4.1 Organisational barriers

Across literature, a **lack of availability** and access to the different types of palliative care services (e.g. PC in community, PC specialist and services, outpatients PC programs, inpatients beds or resources to take referrals) was described.

Availability of palliative care services is also determined by the **training** of care professionals. However, in the literature, lack of in-service training in palliative care, unclear job description of the palliative care team, and a lack of a standard formal educational curriculum on palliative care were reported as organisational barriers.

Excessive demand, inadequate numbers of physicians/health professionals and allied health support, health system hierarchy (senior medical officer needed for palliative care referral), waiting times for palliative care appointments, poor infrastructure, lack of needed supplies, lack of institutional readiness and support for palliative treatments are some examples reported in literature of **institutional barriers.**

The **lack of care pathways and models of care**, with clear guidelines/protocols on timing of palliative care referrals, is linked to in poor prognostication, non-acceptance by healthcare team, insufficient resources and time for education and training, time restraints and time needed to follow care pathways.

Lack of physical space in hospitals to have family visits/discussions, insufficient physical space in hospitals to die privately, insufficient time and resources to care for patients in nursing homes, care home improvements are limited by time and available staff, staff have insufficient time to deliver effective EOL care in intensive care units, taking time with a dying patient is not prioritized or supported in busy settings, shortage of palliatieve care / hospice nurses and nurses experience fatigue in dealing with dying patients refer to a **lack of resources.**

3.3.4.2 Administrative barriers

A fragmentation of services is often due to administrative barriers, such as lack of advance directives and surrogate decision makers, advance directives and surrogate decision makers, continuity of care during transition, recognition among staff of the importance of optimal EOL care, available time due to high rate of consultations or heavy workload of oncologists, opportunities for support after highly emotional discussions, an adequate patient referral system due to structural problems. Procedures and authorizations required to access care, e. g. medications, appointments, procedures.

3.3.4.3 Reimbursement regulations

The financial organisation of a health system can lead to access disparities among their users. Following **health insurance-related barriers** were reported across the retrieved literature: insurance co-payments, reimbursement issues due to inadequate insurance coverage, expensive hospital bills, prospective payment systems of palliative care services and lack of financial resources for accessing palliative care. Also in some regulations there was an inability to receive payment to care for loved ones.

3.3.4.4 Policy barriers

Restricting criteria in healthcare policies could hamper the accessibility of palliative care services, e.g. Medicare policy states that patients need a 6-month until death certification from a physician and the hospice medical director, also the patient must withdrawn from curative treatment (not the case with PC) but patients and families are often not prepared to abandon curative treatments attempts.

A **need for supportive environments** was repeatedly reported in literature in order to enable changes in the currently lack of collaboration, the culture of medicalisation and 'striving to keep alive' towards systems that also reward supportive care.

Table 19 – Health system-related barriers on the access and utilization of palliative care

Health system-related barriers	Influence on access problems and/or under/misuse of palliative care services
Organisational barriers[103, 114]	Lack of availability and access to PC services Lack of in-service training in PC Institutional barriers Lack of resources
Administrative barriers[103]	Fragmentation of services: lack of advance directives and surrogate decision makers, lack of adequate patient referral system due to structural problems Procedures and authorizations required to access care
Reimbursement regulations[103, 106]	Health insurance-related barriers: co-payments, reimbursement issues due to inadequate insurance coverage, prospective payment systems
Policy barriers[106, 114]	Lack of policies and supportive environments

3.3.5 Main values perceived by patients and informal caregivers related to palliative care

Experiences of palliative patients, their informal caregivers and the involved healthcare professionals give an insight in the values attributed to palliative care. In the literature search, two key reviews were identified on the values regarding palliative care: Engbers et al., 2019[122] on informal caregivers' perception of needs from hospice professionals and Hughes et al., 2019[124] on what do patients and family caregivers value from palliative care.

Engbers et al., 2019[122] questioned informal caregivers about their experiences of home palliative care and came to the following findings:

- According to the informal caregivers, the provision of easy access to desired care (provided by palliative care professionals) should not only encompass prompt symptom management for the patient, but also frequent re-assessments (due to the changing nature of the patient), the security of having palliative care providers available 24h a day, an ease of having palliative professional be the point of contact for any healthcare question, the provision of respite care, the performance of tasks during the palliative care professionals' visits to ease the caregiving burden, and suggesting appropriate durable medical equipment.
- Emotional benefits of working with palliative care professionals, as experienced by the informal caregivers, were mostly related to becoming more confident caregivers and forming a relationship with the palliative care professionals.
- For building up this confidence (i.e. empowerment) the informal caregivers expressed the need for individualised training based on their specific abilities and patients'needs, including information on when and what to expect at time of death, also the need for encouragement and reassurance on their caring role and the need to be acknowledged by the palliative care professionals (wanting to remain primary caregivers, treated with respect, have their opinions valued).
- Forming a relationship with the palliative care professionals is considered as important for the continuity of care, e.g. to be able to relinquish care for their loved ones to palliative care professionals, during periods of isolation. Also after death, the need for closure with palliative care staff was expressed by the informal caregivers.
- However, also some missed opportunities were reported, such as the lack of awareness of all services offered by palliative care, healthcare professionals should be more direct and assertive when offering services, they experienced an uncertainty whether they had access to hospital if needed, and there was also a need for better explanation of particular roles of different healthcare professionals.

A similar review of surveys was performed by Hughes et al., 2019[124] on the patients' and their informal caregivers' views and experiences about palliative services in the UK. The following expectations were formulated by the participants across the included primary studies in the review:

- The importance of staff in the provision of high standard quality care:
    - This expectation covers different important attributes to a good death, such as the need for high quality of care (including high standard of care, with high levels of satisfaction), but also the need for availability of hospices and staff. Some additional expectations regarding staff were formulated, such as need for personal and professional traits (i.e. personal qualities of staff, their experiences and specialised knowledge and skills, development of a close rapport amongst staff-patients-their families ('turned out to be friends'), specialised knowledge and expertise in order to anticipate the changing needs of the patient and families and provide proactive responses, and regular contacts between staff and patients. Also the need for an adequate amount of staff, the possibility to reach palliative care team when necessary and the provision of requested help by the palliative team were considered as important attributes to palliative care.
    - Next to availability of staff, others attributes are related to the provision of high quality of care, such as sufficient provision of adequate information and being treated with respect and dignity.
    - More logistic expectations were reported regarding the availability of hospice transport, open visiting arrangements and the accessibility and quality of food.
- Regarding respite care, the opinions were more diversified among the participants, with a large proportion of informal caregivers finding it beneficial versus a similar rate of respondents showing improvement or even negative change in stress score. The need for respite care for the informal caregiver was one the reasons for referral to day care.
- The importance of the role of social engagement and participation in social activities in the maintenance of relationships and their sense of normality: in hospices the sense of community is highhly appreciated, and in particular to sit together and the frequent use of collective terms ('we, us'). Also peer support, e.g. to hold open discussion with each other, to share their stories and reduce social isolation, is considered as a major precondition for palliative care.
- The importance of the comfort gained from the availability and accessibility of the hospice. Three major attributes were identified: the sense of security (i.e. 24h support by staff, open visiting hours, access to wide range of staff and services), help for families in continuing their caregiving role (e.g. provision of phone support, addressment of worries, general support, reassurance, validation and help with practical tasks, provision of palliative night aids), and after death support (i.e. support following home death (arranging funerals, returning medical equipment, difficulties seeking bereavement support).
- The importance of the role of the hospice in helping promote patient and informal caregiver autonomy through the provision of various support mechanisms: a support mechanism for the informal caregivers' ability to cope encompasses physical, psychological, social and financial help, domestic-related support (also often done by night aides). Other support mechanisms are respite care, bereaevement support (e.g. monthly meomrial ceremonies, a volunteer bereavement support service).

Across the different expectations and attributes to a good death, some overarching findings on the experiences with these attributes were reported:

- Equity in the provision of support is an essential value to ensure patients and their family caregivers are receiving timely interventions day or night.
- Informal caregivers appeared to place high value on bereavement support but did not always receive it (mainly due to lack of contact from the hospice following the death of a family member).

- Informal caregivers appeared to place high value on proactive support but they did not always consistently receive it.
- Choice was a consistent value to patients thus creating a need for a wide range of activities: the patients valued having access to a wide range of activities but were less satisfied with the available activities.
- Informal caregivers valued the provision of social opportunities and could therefore benefit from access to official social support networks. The availability of social support was however often lacking.

Based on these findings the authors concluded that the concept of a good death can be complex and highly individual, therefore the importance of neglecting a "one size fits all" approach to care in favour of a system which offers continuous holistic assessments in response to the changing needs of both the patient and their family. A sidenote was also put by the authors on the role of hospice volunteers: "*There was a lack of evidence to demonstrate the importance of hospice volunteers in helping to deliver support, however could be due to patients and family caregivers having difficulty distinguishing between those who are staff and those who are volunteer*s". [124]

3.3.6 Key elements determining the acceptability of palliative care

The literature search on patients' perceptions about palliative / hospice care identified not only determinants encountered by the patient which hampered the acceptability of palliative care and more in particular related to hospice care, but also barriers perceived by the informal caregivers, the healthcare professionals and even at system level. In addition to these perceived barriers, some literature was also found on the values put on hospice care by the patients and informal caregivers. The triangulation of all these data on barriers and values, made it possible to identify some key elements to enhance the acceptability of hospice care and which elements are key in the development of an organisational palliative care model.

A stepwise approach is here suggested to improve the acceptability of palliative care, starting on the patient level, and further climbing up towards the social level (related to the informal caregivers), the care level (related to the healthcare professionals) ending in the macro level (healthcare system). At each level barriers were identified which hampered the acceptance, but switching them to facilitators, enables the identification of key attributes for acceptability of palliative / hospice care. In the development of an organisational palliative care model, the determinants on those different levels should be taken into account and additionally the interactions in between will demonstrate how dynamic the organisational model should be in adapting its system to the constantly changing needs on the different levels, and in particular to the rapidly changing needs of the palliative patient.

Rapid response to changing needs requires a shift from a historical cancer-appropriate 'one-size-fits-all' framework to a new model of hospice care whichever patients need it the most and better identify those patients with non-cancer illness who would benefit from hospice care. Innovative collaborative services based around patient, family, and wider community are needed to ensure optimal care for all.[107] This is in line with Bennardi, 2020[116] who emphasized the need from a change in model from a curative model in which palliative care is conceived only to address physical symptoms towards a more holistic approach addressing all care domains of the palliative patient.

Next to the need for change from a curative model to a patient-centred approach to ensure 'a good death,' more concrete actions were proposed by several authors, such as:

- Early identification of palliative care needs could be facilitated by effective communication, a gentle exploration of the topic, use of communication tools, 'reinforcing' the relationship with the patient.[116]
- The term palliative care was itself considered as a barrier to palliative care referral. A suggestion was made to reframe and better explain to patient and family, to use synonymous terms such as 'supportive care', 'comfort care'.[103]

- Unmet needs of family caregivers (communication, psychosocial issues, sense of isolation, feeling unprepared and unsupported) often leading to hospital admission. Informal caregivers should be made aware of the commitment and burdens of caregiving before agreeing to provide EOL care and support services should be available (with needs assessment tools and ACP documents).[123]
- Mandatory, ongoing training and education on end-of-life care is needed.[114]

4 HOW IS PALLIATIVE CARE ORGANISED IN BELGIUM?

- ✓ Palliative care is governed by both the federal and the federated entities. The Federal Cell for the Evaluation of Palliative Care oversees palliative care in Belgium.
- ✓ Three palliative care federations and 25 palliative care networks covering a determined territorial area play a major role in promoting and delivering quality palliative care.
- ✓ •Current offer is distinguished between specialised hospital-based inpatient palliative care (Sp4 beds) and generalist community-based outpatient palliative care delivered in the usual place of the residence of the patients (home, nursing home, institutions) by the usual healthcare professionals of the patients (mainly the GP and nurses). Patients staying at home can also attend a palliative day care centre.
- ✓ There are two types of mobile teams offering specialised palliative care: 1) the outreach multidisciplinary team intervening in outpatient settings such as home, nursing homes or institutions at the request of the generalist practitioner, and 2) the inpatient hospital mobile team supporting the healthcare staff of the different hospital wards where generalist palliative care is offered.
- ✓ Older patients have more possibility to receive palliative care as it is included in the nursing home offer (palliative care referent) and in geriatric units.
- ✓ Initiatives have been developed over the years to take care of palliative patients who do not fit in the current offer: hospicezorg in nursing homes in Flanders, volunteer-driven project offering non-medicalised support, stand-alone, residential service offering medicalised support, integrated palliative care project offering at the same place generalist and specialised outpatient and inpatient palliative care.

4.1 Introduction and aim

Palliative care has become an integral part of healthcare in Belgium, where the pursuit of a dignified and comfortable final phase of patients' lives is central. This chapter describes the organisation of palliative care in Belgium, focusing on the various actors involved in delivering this care. Around 110 000 persons die in Belgium annually.[125] Not all of these persons necessitate palliative care but, according to the same source, it is estimated that 45% to 75% of these persons are in need for palliative care, representing 44 000 to 82 500 persons per year.[28]. In 2015, almost half of the patients with a terminal cancer received palliative care (53.7%) but 19% of these patients die one week after palliative care has been started.[28] The proportion of cancer patients receiving palliative care rose to 57% in 2020 but regional variations were observed: cancer patients are more likely to receive palliative care in Flanders (62%) than in Wallonia (50%) or in Brussels (49%).[11] In 2020, 18.8% of the cancer patients receiving palliative care died within a week, supporting – again – the fact that palliative care is often started too late. It was also found that 1 out of 10 cancer patients received a chemotherapy in the 14 days before their death, which is considered as an indicator of inappropriate care.[11]

In Belgium, palliative care is currently delivered in various settings: in hospitals, at home, or in a place assimilated to the patient's home like nursing homes, homes for the elderly, other residential and/or care setting. Patients are oriented between settings depending on their situation, needs and wishes. Palliative care is also delivered by or with the support of various categories of caregivers or professionals: specialised healthcare professionals, general practitioners, informal caregivers, social workers, volunteers, etc. Consequently, the involvement of so many different actors in various settings across Belgium implies that many different competent authorities are involved in the palliative care process.

Consequently, this chapter aims at providing a description of the current landscape of palliative care in Belgium, albeit anticipating some of the ongoing reforms related to palliative care. As the KCE recently published a description of the landscape of palliative care in Belgium, some sections of the present description are based on this report. These sections have been edited and updated when needed.[13]

Despite our desire to draw up a clear and precise picture of current provision, consumption of care and the various options available, data is currently lacking. On several occasions, the Federal Cell for Palliative Care Evaluation (Federal Cell) has expressed its desire to obtain data relating to a whole series of indicators that would enable them to better assess the palliative care landscape and propose appropriate measures to improve it.[19] More recently, a group of experts gathered by the *PalliativPflegeverband Ostbelgien* (trans. palliative care network - PPV) undertook the exercise of drawing up an inventory of palliative care in the German-speaking community, and their findings are edifying in terms of the availability and quality of current data.[126] As stated on page 5 of the report: *"It should be emphasised, however, that the figures presented in this report in no way guarantee the accuracy of the actual (current) situation, but rather indicate trends, insofar as the figures and sources communicated to the PPV were in part incomplete or even contradictory*" (translated from PalliativPflegeverband Ostbelgien, 2023, page 5).

4.2 Legislation and governance

4.2.1 Legal framework

Three federal laws were issued in 2002 and governate to this day the Belgian approach to end-of-life and palliative care.

- **Law of 22.08.2002 related to patients rights**: This law frames patient rights and the relations between patients and all healthcare professionals. It includes, among others, the right to a clear and complete information about all aspects related to health, diagnosis, prognosis, therapeutic options and other procedures (including access to the patient health record), the free choice of the healthcare professional, the concept of informed consent and the possibility for refusing care, the respect of privacy and confidentiality and the designation of a trust person.[127, 128] In 2024, this law was updated to better frame the advance care planning (see article 8/2).

Textbox 2 – Advance Care Planning

For patients suffering from an incurable disease, Advance Care Planning (ACP) means being able to plan their future palliative care, in advance, with their general practitioner and in consultation with other people involved: informal caregivers, nurses, physiotherapists, other doctors, etc. As part of this planning process, the doctor and the patient engage in a dialogue to expectations and wishes regarding future care. The aim of this dialogue is to respect the patient wishes regarding the choice of care, whether curative or palliative. This planning process is open ended, the patient can always question and modify its choices and statements. In the context of palliative care, two possibilities of advance care planning are particularly of interest: the negative declaration, where the initiation of a new treatment aims at providing comfort rather than prolongating life, and the declaration related to euthanasia.

The right to advance care planning is already included in legislation addressing specific patient groups, such as residents of nursing and elderly homes (*Art. 5, 26, 30, 34 bijlage 11 Besluit van de Vlaamse Regering van 28 juni 2019 betreffende de programmatie, de erkenningsvoorwaarden en de subsidieregeling voor woonzorgvoorzieningen en verenigingen voor mantelzorgers en gebruikers, B.S. 2 augustus 2019; Chapitre 10 Arrêté du 16 mai 2019 du Gouvernement wallon modifiant le Code réglementaire wallon de l'Action sociale et de la Santé en ce qui concerne des dispositions relatives aux aînés, M.B. 4 novembre 2019) and palliative patients (Wet van 14 juni 2002 betreffende de palliatieve zorg, B.S. 26 oktober 2002*)"(Retrieved from Vinck et al. 2022, page 172).[129]

Additional information is available on the NIHDI website (in French and in Dutch):

https://www.inami.fgov.be/fr/themes/soins-de-sante-cout-et-remboursement/les-prestations-de-sante-que-vous-rembourse-votre-mutualite/soins-palliatifs/soins-palliatifs-en-parler-plus-tot-pour-une-meilleure-qualite-de-soins-et-de-vie-c-est-l-advance-care-planning

More information about 4 of the 5 possible declarations of advance care planning (in French):

https://docs.wixstatic.com/ugd/b61916_b41738afa05447e7ac349343181a3f42.pdf

- **Law of 28.05.2002 related to euthanasia:** This law regulates the conditions under which a person has the right to request euthanasia[130, 131]. It establishes the access criteria, such as unbearable suffering due to a serious and incurable condition, the patient's voluntary and repeated request, and the assessment by two doctors (one not being in a therapeutic relationship with the patient and independent from the treating medical doctor). Euthanasia practices are overseen by the Federal commission of control and evaluation of euthanasia.[g] It oversees the respect of the conditions of the law, based on the records sent by the doctors practicing euthanasia. It also reports twice a year to the Belgian Chambre of Representatives.
- **Law of 14.06.2002. related to palliative care**: This law frames palliative care in the Belgian healthcare system and regulates its organisation[44, 45]. It establishes guidelines for ensuring quality of care for patients in their final stages of life. The law emphasizes the multidisciplinary approach and the importance of psychosocial and spiritual support. The Law of 14.06.2002 was amended by the Law of 21.07.2016 in order to enlarge the definition of palliative care.[15, 16]

[g] See more about their activities: https://organesdeconcertation.sante.belgique.be/fr/organe-d%27avis-et-de-concertation/commission-federale-de-controle-et-devaluation-de-leuthanasie

Textbox 3 – Law of 21.07.2016. related to palliative care

Elke patiënt heeft, ongeacht zijn levensverwachting, recht op palliatieve zorg als hij zich bevindt in een vergevorderd of terminaal stadium van een ernstige evolutieve en levensbedreigende ziekte.

Een voldoende ruim aanbod van palliatieve zorg en de criteria voor de terugbetaling van die zorg door de sociale zekerheid, staan er borg voor dat dit soort zorg voor alle patiënten even toegankelijk is, binnen het geheel van het zorgaanbod.

Onder palliatieve zorg wordt verstaan: alle zorg die wordt verstrekt aan de patiënt die zich, ongeacht zijn levensverwachting, bevindt in een vergevorderd of terminaal stadium van een ernstige evolutieve en levensbedreigende ziekte. Voor een begeleiding van deze patiënten wordt multidisciplinaire totaalzorg gewaarborgd op fysiek, psychisch, sociaal, moreel, existentieel en desgevallend spiritueel vlak.

Palliatieve zorg biedt de zieke en zijn naasten een zo groot mogelijke levenskwaliteit en een maximale autonomie. Palliatieve zorg is erop gericht de kwaliteit van het leven van de patiënt en zijn naasten en mantelzorgers voor een zo lang mogelijke periode te waarborgen en te optimaliseren.

Palliatieve zorg wordt ingezet vanaf het ogenblik dat de patiënt als palliatief wordt geïdentificeerd tot en met de terminale fase.

Palliatieve zorg kan eveneens reeds ingezet worden wanneer er nog ziektebehandeling plaatsvindt tot en met de zorg voor naasten en mantelzorgers tot na het overlijden. De inzet van palliatieve zorg verloopt idealiter progressief in functie van de zorgnoden en -wensen, onafhankelijk van de levensverwachting.

Tout patient a droit à des soins palliatifs lorsqu'il se trouve à un stade avancé ou terminal d'une maladie grave, évolutive et mettant en péril le pronostic vital, et ce quelle que soit son espérance de vie.

Une offre de soins palliatifs suffisamment large et les critères de remboursement de ces soins par la sécurité sociale garantissent l'égalité d'accès aux soins palliatifs de tous les patients, dans l'ensemble de l'offre de soins.

Par soins palliatifs, il y a lieu d'entendre: l'ensemble des soins apportés au patient qui se trouve à un stade avancé ou terminal d'une maladie grave, évolutive et mettant en péril le pronostic vital, et ce quelle que soit son espérance de vie. Un ensemble multidisciplinaire de soins est garanti pour assurer l'accompagnement de ces patients, et ce sur les plans physique, psychique, social, moral, existentiel et, le cas échéant, spirituel.

Les soins palliatifs offrent au malade et à ses proches la meilleure qualité de vie possible et une autonomie maximale. Les soins palliatifs tendent à garantir et à optimaliser aussi longtemps que possible la qualité de vie pour le patient et pour ses proches et aidants proches.

Les soins palliatifs sont prodigués dès le moment où le patient est identifié comme palliatif jusqu'à et y compris la phase terminale. Les soins palliatifs peuvent également être entamés alors que des traitements sont encore en cours jusqu'aux soins liés pour les proches et aidants proches jusqu'après le décès. Idéalement, le recours aux soins palliatifs se fait de façon progressive en fonction des besoins et souhaits en matière de soins, quelle que soit l'espérance de vie.

4.2.2 Governance

Table 21 provides an overview of the repartition of competences related to palliative care in Belgium.

"*The federal State is competent for the social security, the regulation of health care practice and patient's rights, and the regulation and funding of certain aspects of in-hospital palliative care (programming the number of palliative beds, defining the basic rules and funding of in-hospital palliative care units and palliative functions* [multidisciplinary team within the hospital that works in support of all hospital units to treat palliative patients in other units than the palliative unit]*, excluding costs related to the infrastructure itself)*[Article 5, § 1er, I, 1°, of the special law on institutional reforms of 08.08.1980]*. In the field of palliative care, Communities (or Regions[h])[132] are fully competent for the programming (incl. ratio), regulation, authorisation, funding and control of nursing homes, of residential setting and day care setting and of ambulatory care services including those offering palliative services. […]*

A shift of competences between the federal and the federated levels occurred following the 6th State reform (2014). This shift includes the competences over palliative care platforms and multidisciplinary support teams for palliative care which were entirely transferred from the federal State to the federated entities. Communities are therefore competent for the regulation, authorisation, funding and control of palliative care networks and of multidisciplinary support teams for palliative care delivered outside the hospital.

The Communities are also partly in charge of in-hospital palliative care licensing rules (detailed quality rules in terms of equipment and staff, etc.), of palliative hospital beds and palliative functions in hospitals, and of controlling the compliance therewith. However, they cannot adopt quality rules that would increase the federal budget without the agreement of the federal government. Moreover, the financing of the hospital infrastructure (renovation / construction) is also a responsibility of the Communities" (section retrieved and adapted from Ricour et al., 2023).[13]

In Brussels, since 2023, the daily management and the health policies of the palliative care is organised by *Vivalis* (bicommunitarian administration of the Brussels region) while the management of the funding conventions via sickness funds is done by *Iriscare* (bicommunautarian institution of public interest ION-OIP) on behalf of *Vivalis*. In Flanders, palliative care regulation and funding is under the governance of *Departement Zorg* (formerly *Agentschap Zorg en Gezondheid*) while, in Wallonia, it is under the governance of the *Agence pour une Vie de Qualité* (AVIQ). In Ostbelgien, it is under the responsibility of the *Fachbereichsleiterin Gesundheit und Senioren*.

h In the French speaking Community, the exercise of certain competences, including health competences, has been transferred to the Walloon Region and to the 'Commission Communautaire française (COCOF)' in 1993, which is not the case in Flanders and in the German-speaking Community.

Table 20 – Overview of the distribution of competences for palliative care in Belgium, 2022

	Hospital	Nursing homes and other residential facilities	At home
FEDERAL LEVEL	**Regulation** • Requirement to have a palliative care unit and a palliative function (mobile team supporting palliative care in other care units of the hospital); • Programming of the number of palliative beds.	No federal competences at this level (except in the context of the competence to regulate health care practices, health professionals and patients' rights).	No federal competences at this level (except in the context of the competence to regulate health care practices, health professionals and patients' rights).
	Funding • All functioning & staff costs excl. infrastructure costs; • Reimbursement of the medical fees for the care delivered by healthcare professionals, of the costs of each day of hospitalisation and of the cost of reimbursable medicines and devices.	• Reimbursement of the cost of reimbursable medicines and devices, of the medical fees for the care delivered by healthcare professionals chosen by the patient (excl. collective care delivered by nurses, physiotherapists, etc. employed by the care / residential setting); • Co-payment abolition for GPs visits; • Oxygen therapy	• Reimbursement of medical fees for the care delivered by healthcare professionals (incl. general practitioners, nurses and physiotherapists) via compulsory health insurance. • Palliative lump sum; • Co-payment abolition for GPs, nurses and physiotherapists visit; • Oxygen therapy
	Compulsory health insurance, quality of health care practice, healthcare professionals and patient's rights		
COMMUNITIES & REGIONS	1. **Regulation** Licensing norms of the in-hospital palliative units and palliative functions (outside basic organisational rules)	All organisational rules incl. ○ Requirement to have a palliative function ○ Programming of the number of beds and settings ○ Licencing norm	Outreach multidisciplinary support teams (regulation & funding)
	Funding Infrastructure costs ("walls & equipment")	Financing of these structures (all costs excl. the ones funded by the federal according to their individual dimension)	
	Palliative care networks Regulation and funding of all possible alternatives (day centres, etc.). Social welfare including welfare services, in particular a specific allowance offered in Flanders only: the complementary (social and care) allowance (called *Vlaamse sociale bescherming* incl. *zorgbudget voor zwaar zorgbehoevende, zorgbudget voor ouderen met een zorgnood, zorgbudget voor mensen met een handicap*)*		

** Flemish social protection incl. care budget for severely care-dependent people, care budget for elderly people with care needs, care budget for people with disabilities*

4.2.2.1 Specific policies and reforms at federal level

In the frame of the Interfederal Plan on Integrated Health and Social Care of 2023[133], palliative care is directly concerned by the willingness of striving to more integration in the healthcare system as part of the continuity of care. Therefore, because of the current share of the competences, the policy related to palliative care is governate at the level of the federated entities. In this context, each federated entity has designed its own vision of palliative care for the future.

To date, one of the most visible aspects of the integration is the territorialisation of healthcare and integration of the first line of care (Table 22). Indeed, for some years now, we have been seeing the implementation of a policy of territorialisation of health and social services in the various Belgian regions, to encourage better integration of front-line services and, as a result, better meet the needs of residents. This territorialisation has taken different forms and is at different stages of progress depending on the regions.

In Flanders, the creation of *Eerste lijn zones* (ELZ – trans. primary care zones) started in 2019, under the coordination of VIVEL(*Vlaamse Instituut voor Eerste Lijn*).[134-136] An ELZ is a network of front-line professionals in a specific geographical area, that is professionals who are the first contact point of citizens. These professionals exchange knowledge and information and coordinate their actions, considering the local care and welfare needs with a view to improve the quality of healthcare. An ELZ includes one or more municipalities, covering around 75 000 to 125 000 inhabitants. It is coordinated by a "*zorgraad" (*trans. care council). There are currently 59 ELZ across Flanders and one for Brussels. ELZ are gathered in *zorgregio* (transl. healthcare region), constituting the meso level.[137] There are 15 *zorgregio* in Flanders.

In the Brussels regio, early 2024, there were 5 "*zorgzones" - bassins d'aide et de soins "* (transl. integrated care zones) created as part of the operationalisation of the *Geïntegreerd welzijns- en gezondheidsplan GWGP - Plan Social-Santé Intégré PSSI.*[138-140] An integrated care zone is a network of front-line professionals in a specific geographic area, covering 200 000 to 300 000 inhabitants. It aims at supporting knowledge, networking, coordination, and prevention / health promotion. Each integrated care zone has 3 health and social care coordinators and is subsequently divided in neighbourhoods (*wijk – quartier*), based on the current clusters of the regional survey on health and social care. Additional targeted activities will be organised in the neighbourhood under the coordination of the municipal centre for welfare (OCWM-CPAS). Established in January 2024, there are 5 integrated care zones and 47 neighbourhoods.[140]

In Wallonia, the is currently the creation of the "*organisations locorégionales de santé – OLS"* (trans. locoregional health organisations) as part of the Walloon Decree "ProxySanté." The locoregional health organisations cover 200 000 to 500 000 habitants, across several municipalities. A locoregional health organisation aims at integrating all the actors of the first line of its zone and organises the collaboration with the social services. The final text plans 10 locoregional health organisations (not yet in force at the moment of the finalisation of the scientific report on 18.10.24).[141]

Ostbelgien is not concerned by the Walloon reform. The Decree of the German Community establishes an Advisory Board (*Conseil consultatif pour le soutien aux personnes âgées*) in Ostbelgien (Chapter 8, Articles 70 and following). This advisory board has explicitly a role of counselling when it comes to develop health policies related to palliative care.

Table 21 – Summary information about the territorialisation of health in Belgium, 2024

	Belgian regions & communities			
	Brussels	Flanders	Wallonia	Ostbelgien[1]
Population (01.01.2024)[2]	1 249 597	6 821 770	3 692 283	79 479
Microlevel (number)	Neighbourhoods (n=47)	*Eerstelijnzones* (n=60)	*Bassins de vie* (number unknow)	/
Mesolevel (number)	*Bassins d'aide et de soins Zorgzones* (n=5)	*Zorgregio* (n=15)	*Organisations Locorégionales de Santé* (n=10)	/

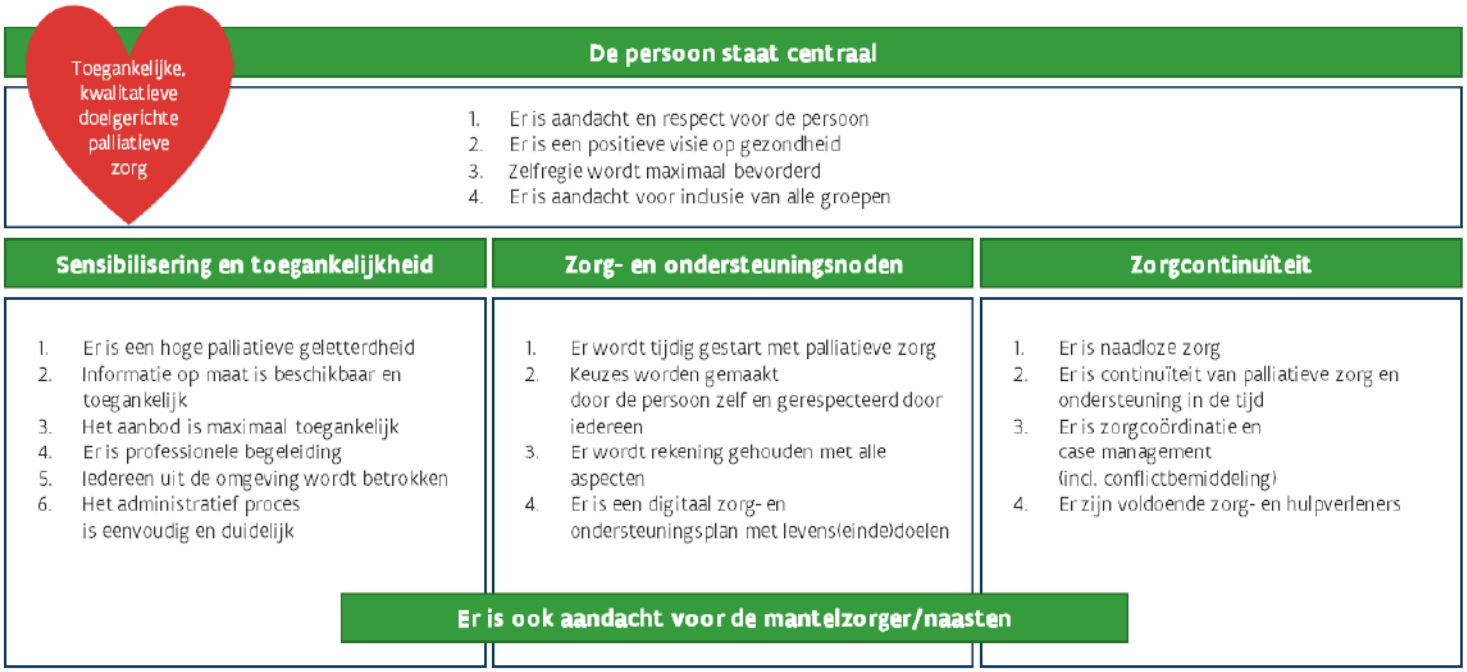
[1]Population of the Ostbelgien is also included in the Walloon regio. [2]Source: Statbel - https://statbel.fgov.be/fr/themes/population/structure-de-la-population

4.2.2.2 Policy plans in the Flemish region

We focus on 3 important policy plans for the Flemish region.

The first key policy plan is the vision document "*Hervorming van de palliatieve zorg in Vlaanderen*", published by the *Departement Zorg* in 2023.[142] This vision plan establishes guiding principles for a more integrated vision of palliative care, with a focus on the first line of care. The vision is organised around 6 key axes: the person is central; raising awareness and accessibility; care and support needs; continuity of care; attention to relatives and informal caregivers and focus on quality at all levels (see Figure 6). Of interest, this vision plan also includes priority groups for palliative care: persons living with chronic and/or life-threatening diseases (e.g. dementia, COPD…), hard-to-reach and vulnerable groups, persons outside the healthcare system, persons with low (health) literacy and children. This vision plan is supported by a "*actie-en-transitie plan 2023",* identifying actions to be put in place by professionals.[143]

Figure 6 – Vision plan for palliative care in the Flemish region, Department Zorg, 2023



Source: Departement Zorg, 2023, page 6[142]

The second key policy plan is the policy plan 2024-2029 of VIVEL – *Vlaams Instituut Voor de Eerste Lijn-* entitled *"DE TOEKOMST (van gezondheidszorg en welzijn) IS THUIS"* (transl. The future (of health and wellbeing) is home).[134] It points the importance of providing health care and social support in the place of living of the patients and of their entourage, also considering the role of informal caregivers, volunteers and of the neighbourhood as key components of a "*health in all policies"* approach. Front-line of care should be envisioned as integrated from preventive to palliative care and supported by a proactive collaboration between actors.

The policy plan also underlines the need for a *goal-oriented care*. Of particular interest, VIVEL aims at enforcing a "*person-en omgevingsreflex"* (trans. person-environment reflex) by 2026, implying that these will be part of the decision-making process when elaborating integrated care plans. This should be seen as a posture promoted by all actors rather than a checklist or a tool. Regarding palliative care, this policy plan is important as its implementation can have a positive influence on the development of palliative care at home.

"Tegen 2026 maakt het uitvoeren van een persoon en diens omgevingsreflex een integraal deel uit van onze besluitvormingsprocessen. Naast de reflex blijven we ook onze rol spelen in het betrekken van de persoon in de werking van de zorgraad". VIVEL, page 6

The third policy plan is the *Vlaams Mantelzorgplan 2022-2024*, published after the COVID pandemic.[144] This policy plan is organised around 2 key strategic objectives: the recognition and acknowledgement of informal caregivers and the support of the informal caregivers. Among other actions, there is a need for a better visibility of the informal caregivers through sensibilisation of healthcare professionals and the society but also a better identification of these informal caregivers to increase the recognition of their unique contributions. Regarding the support of informal caregivers, the focus is put on prevention of the burnout of these informal caregivers and on more attention to those with a professional activity.

To date, no equivalent policy plan has been issued regarding palliative care in the other Belgian regions. It does not imply that palliative care is not a matter of interest for these regions.

4.2.3 Official advisory bodies related to palliative care

4.2.3.1 Federal Cell for the Evaluation of palliative care

On 29.01.2003, the Federal Cell for the Evaluation of Palliative Care (*Federale Evaluatiecel Palliatieve Zorg - Cellule d'évaluation concernant les soins palliatifs*) was set up in implementation of the law related to palliative care of 14.06.2002. This cell is tasked with a regular critical assessment of "palliative care needs and the quality of the responses to them". It advises on what still needs to be examined or developed and how. Their evaluation report is submitted to the Chamber of Representatives every two years. The law on palliative care also stipulates that the ministers responsible for social affairs and public health must submit an annual progress report to the legislative chambers as an essential part of their policy memorandum.[145]

4.2.3.2 Palliative care federations

There are three palliative care federations in Belgium: *Palliatieve Zorg Vlaanderen* in the Flemish region, *Brusselse federatie voor palliative en continue zorgen - Fédération bruxelloise de soins palliatifs et continus* (BFPZ-FBSP) in the Brussels-Capital region and *Fédération wallonne des soins palliatifs* (FWSP) in the Walloon region. In coordination and collaboration with the palliative care networks, they foster cooperation between representatives of front-line social and health professionals, organisations, institutions, associations, and services for palliative care. Their missions are the promotion of communication between the actors of palliative care, the education and training and the development of (scientific) knowledge (Table 22). The three federations meet at the Interfederation of palliative care (*Interfédération des soins palliatifs*), a consultative body.

After the transfer of competences, the governance of the federations was endorsed by the federated entities: consequently, some variations can be observed between the federations although their core missions remain broadly similar.[21, 146] Alongside a common socle of interests, each federation can freely decide to develop particular projects, according to the needs and priorities of their members. As an example, the Flemish federation developed quality indicators.[i]

[i] See more here: https://palliatievezorgvlaanderen.be/zorgverlener/tools-en-documentatie/kwaliteitsindicatoren-palliatieve-zorg/

Table 22 – Overview of the key characteristics of the palliative care federations in Belgium

	Brusselse federatie voor palliative en continue zorgen - Fédération Bruxelloise Pluraliste de Soins Palliatifs et Continus (FBSP)	Federatie Palliatieve Zorg Vlaanderen (FPZV)	Fédération Wallonne de soins palliatifs (FWSP)
Missions	• Bringing together representatives of structures active in the palliative and continuing care sector in the Brussels-Capital Region, with a view to consultation in a spirit of openness and pluralism. • Organising think tanks on certain topics (training, ethical aspects, etc.). • Encouraging networking and effective collaboration between its affiliates. • Representing its affiliates, coordinate and promote their activities, and ensure the dissemination of information among and about them. • Promoting the development, recognition and funding of the various palliative and continuing care structures with the regional and federal authorities. • Acting as an interlocutor and spokesperson for the reality of palliative care in Brussels vis-à-vis local, regional, federal and international authorities, in collaboration with the other Belgian palliative care federations. • Helping improve the quality and skills of professionals in this field, particularly through training and research.	• Providing substantive advice and support to organisations and people responsible for palliative care. • Representing the interests of the palliative sector to the government and third parties. • Advising the government on how to optimally organise palliative care in Flanders. • Providing basic and specialised training for caregivers	• Ensuring consultation and cooperation between PC networks with a view to promoting and supporting the harmonisation of practices and the quality of activities ; • Coordinating the actions, objectives and evaluations carried out by the networks; • Representing its members in dealings with public authorities, administrative authorities and financial bodies; • Informing its members of advances and challenges in the palliative care sector; • Bringing together groups or individuals providing palliative care in order to develop exchanges and discussions between them; • Sharing its experience in palliative care and disseminate it in a variety of ways; • Where appropriate, establishing links with other federations with similar aims.
Funding	• COCOF (French speaking commission for Brussels) • Facultative subvention from the COCOM (bicommunautarian commission for the Brussels region) • Members financial contribution • Fondation contre le Cancer (exceptional funding)	• Vlaamse Overheid • Kom op Tegen Kanker • Members financial contribution	• Accredition by the Walloon region – 5 years subvention -

Informations retrieved and adapted from the websites of the 3 federations of palliative care

4.2.3.3 Palliative care associations / platforms / networks

The Royal Decree of 19.06.1997. established the criteria that a palliative care association must meet in order to be acknowledged.[147, 148] Over the time, the appellation « association » has evolved and, depending on the source, one will speak about « association », « platform » or « network », although these are the same organisations with the same missions.

A palliative care association aims at promoting the following missions (Art.2 §1):

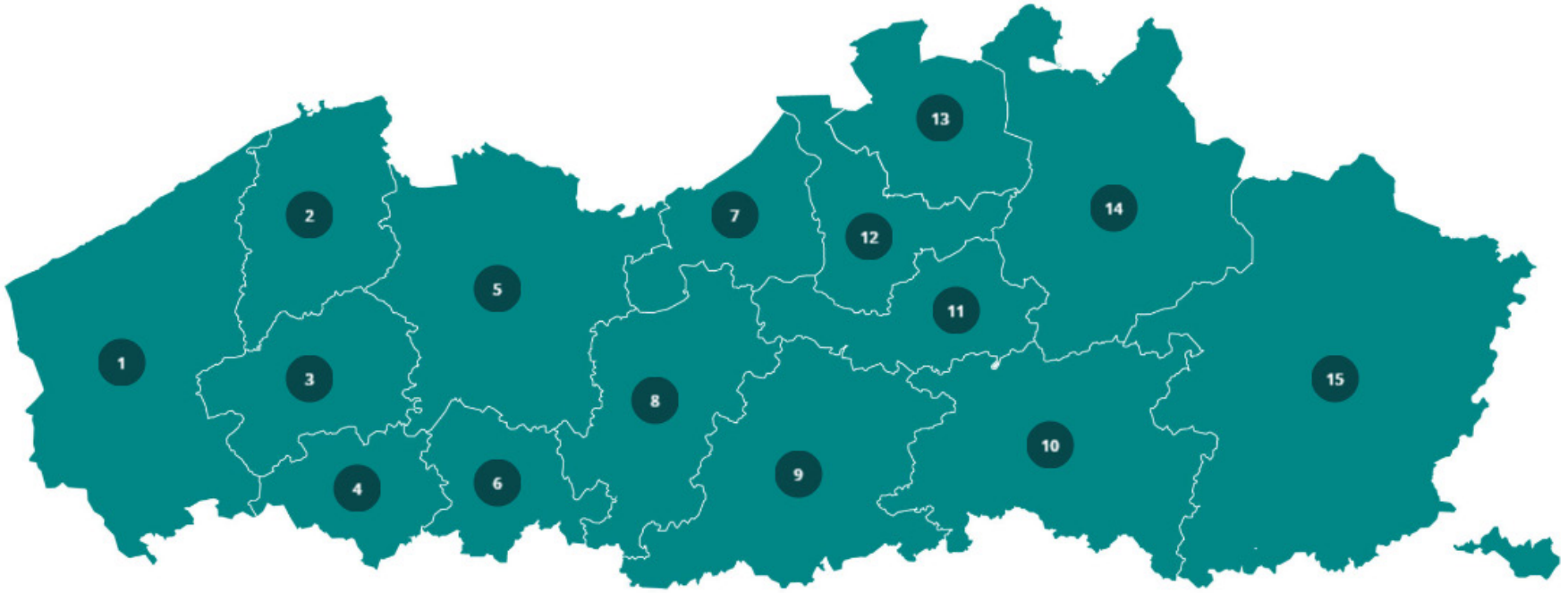
- Information and awareness of the population
- Update of knowledge related to palliative care of physicians, nurses and allied health professionals
- Coordination between the different activities, including establishment of collaboration protocols between different members of the network in order to maximise the complementarity between institutions and services
- Consultative function and logistic support to ensure the efficiency of the actions and the support of the patients
- Regular evaluation of the services, of the unmet needs and of the possible solutions to meet them
- Training and education of volunteers

Each palliative care association has a separate management (Art.4.) and, although expected to fulfil all missions, can decide to emphasize one of these missions, depending on the local context and needs. The palliative care association includes a wide range of actors: support services for patients and families benefiting from palliative care, home care services, local or regional GP or health professionals' associations, nursing homes, homes for the elderly, and hospitals. Actors can be affiliated to maximum 2 palliative care associations in their geographical zone.

A palliative care association should cover a territory whose population is between 200 000 and 1000 000 inhabitants, with a minimum of one palliative care association per Community (Art.3). Since 1997, the palliative care associations have been transferred to the Federated entities, but their missions and agreement criteria appear to remain identical. The Walloon region delegated additional missions to the networks, notably the possibility for psychological care (Table 23).

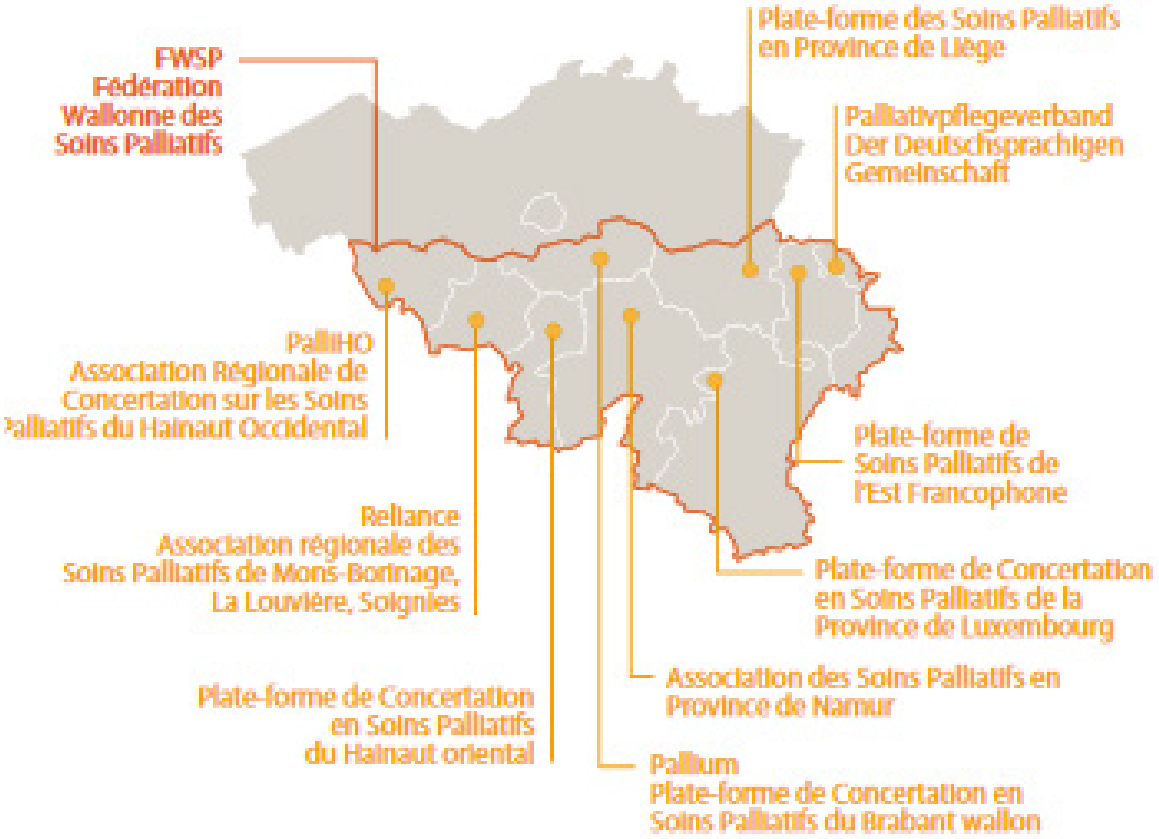
To date, there are 25 palliative care associations / networks / platforms in Belgium: 15 in Flanders (Figure 7), 9 in the Walloon region including the network of Ostbelgien (Figure 8) and 1 for the whole Brussels region where the network matches the regional frontier.

Figure 7 – Palliative networks in Flanders



Source: Website of Palliatieve Zorg Vlaanderen

Figure 8 – Palliative networks in Wallonia and Ostbelgien



Source: Website of the Fédération Wallonne des Soins Palliatifs, online

The RD of 1997 planned that each palliative care association has 1 FTE staff member per 300 000 inhabitants or more. If there are less than 300 000 inhabitants, the palliative care association has 1 FTE staff if the network is alone in the Community or in the province. In a Decree of 2019, the Walloon region lowered the recognition threshold to 200 000 inhabitants and added a function of coordinator and a 0.5 FTE psychologist to comply with their additional missions. The funding is also governed by the federated entities.[149-151]

Table 23 – Overview of the missions of the palliative care networks per region and community

	Brussels	Flanders	Ostbelgien	Wallonia
Mission 1	Information and awareness of the population	Inform the population about the provision and possibilities of palliative care in the region	Strengthen networks of the various professional groups and organisations by promoting communication such as working groups and meetings	Information of population and professionals
Mission 2	Update of knowledge related to palliative care of physicians, nurses and allied health professionals	Collaborate with different partners in the region and promote cooperation between them. These include residential care centres, hospitals, palliative care units, organisations of primary care professionals (general practitioners, home nurses, social workers, physiotherapists...), facilities for people with disabilities, care organisations for volunteers, families and informal caregivers.	Further training and updating of knowledge regarding palliative care for doctors, nurses, family support, nurses, paramedics, social assistants, etc.	Raising awareness of professionals regarding palliative approach in health care
Mission 3	Coordination between the different activities, including establishment of collaboration protocols between different members of the network in order to maximise the complementarity between institutions and services	Provide training for professionals and volunteers	Informing and sensitising the population to the topics of dying, death and mourning	Training of professionals

Mission 4	Consultative function and logistic support to ensure the efficiency of the actions and the support of the patients			Concertation with the palliative care network
Mission 5	Regular evaluation of the services, of the unmet needs and of the possible solutions to meet them			Psychological support upon request for palliative patients, their entourage, professionals involved in the end-of-life support, volunteers
Mission 6	Training and education of volunteers	Recruit and support volunteers		Training and education of volunteers
Mission 7		Collect and process numerical data	Periodic stocktaking of the association's successes and needs	Statistical data collection
Mission 8				Collaboration by supporting and encourage the participation of the staff to collaboration activities between networks

4.3 Overview of the offer

The organisation of palliative care in Belgium includes a varied network of institutions and professionals.

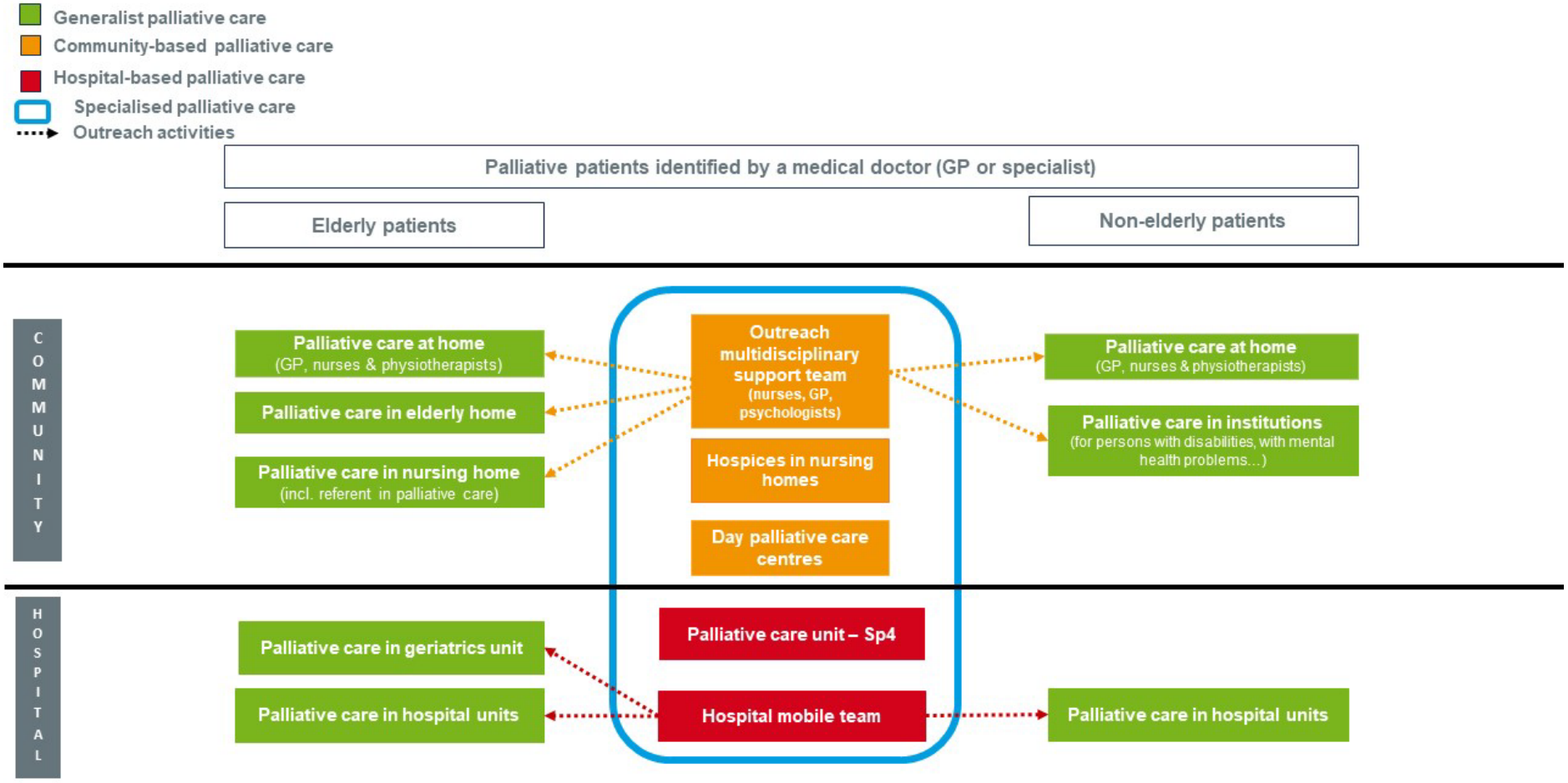
In Belgium, palliative care is either considered as part of mainstream health care, or as part of a specialised health care approach. Specialised professionals in palliative care include professionals working in palliative care units and in hospital palliative care mobile team, nurses, or other palliative care reference professionals in nursing homes and those making up home support teams. Other profiles also have a training in palliative care, to name a few: volunteers in palliative care, coordinating doctors in nursing homes, geriatricians, oncologists, neurologists, general practitioners who have focused their practice on palliative care, some psychologists, and some other allied health professionals.

Palliative care is not only provided by professionals specialising or trained in palliative care, but also by front-line or second-line professionals who are regularly confronted with palliative patients, such as emergency doctors and specialist hospital doctors, nurses, general practitioners, and physiotherapists who visit patients at home, and those working in nursing homes. But, over and above clinical skills and knowledge, palliative care is above all a posture and philosophy of care where the emphasis is on providing the best possible care in the time remaining to the patient, rather than on the goal of prolonging life. In no case is intensity the issue: palliative care can require as much intensity from those involved as guaranteeing and optimising quality of life without wishing to hasten or postpone death is an intensive task. (see also Chapter 1 Introduction).

This multiplicity of actors operates in different settings. At present, hospitals play a crucial role, with their hospital palliative care mobile team and their specialised beds for palliative care patients (Sp4). But there are also other organisational structures or healthcare professionals delivering palliative care (e.g., nurses taking care of patients at home, elderly homes).

Figure 9 presents the current offer in palliative care. Elderly patients are defined as those corresponding to the age and dependency criteria determined by the services (e.g. 65 years old and over, 70 years and over, 75 years old and over…). At present, age appears to be a determining factor in the orientation of patients to palliative care services within palliative care offer but “being elderly” is a vague and unclear concept.[152] Changes in the patient trajectories are defined by changes in the needs – somatic, psychological, social or spiritual. These variations could lead to a temporary adaptation of the health care provided, e.g. a short stay in a hospital unit to stabilise a pain treatment, or to a permanent adaptation as the situation is worsening, e.g. admission in a nursing home. The following sections provide a more detailed view of each offer – in theory. Exceptions to this theoretical presentation could occur in practice.

Figure 9 – Current offer in palliative care in Belgium, 2024



Note: distinction between nursing homes and elderly homes no longer exist in Flanders

4.3.1 Palliative care at home

Around 23% of cancer patients die at home and 7% die in community residential care.[11] There is some regional variation in the place of death. In Flanders generally more people die at home (30.8% in 2020) compared to Wallonia (27.1%) and Brussels (19.1%).[11]

4.3.1.1 Palliative care provided by non-specialised healthcare professionals

Available offer

- Role of the GP

GP endorse several tasks and roles when it comes to palliative care. In addition to the direct palliative care at home as part of the generalist offer, GP could attest of the palliative status of the patients to allow them to palliative care benefits (see above). GP have also a role in conducting the advance care planning (ACP) consultation. Since the broadening of the definition of palliative care in 2016, access to quality palliative care should longer be based solely on life expectancy, but also on the stage of the illness and the level of care required by the patient. As part of the reimbursement of the ACP consultation, the PICT-1 scale (Palliative Care Indicator Tool) enables GPs to identify a patient as palliative at an earlier stage, based also on their vulnerability and the severity of their needs.[153-155] When taking care of a palliative patient, GP have to be available on a 24/7 basis.[156]

- Palliative care as part of nursing care at home

Nurses and midwifes are allowed to provide palliative care at home for patients whose palliative status has been granted. It implies that the nurses should be available 24/7 for the palliative care patients and can refer to a specialised nurse in palliative care in case of needs, e.g. a nurse of the outreach multidisciplinary support team. Nurses should complete the patient health record with the following data: recording of the symptoms, pain scale, contacts with the patient family, and outcomes of the coordination meetings. They have to attest – for each lump sum – the general and palliative pseudocodes corresponding to the health care acts provided to the patients.[157]

Textbox 4 – When nursing care is not possible at home: Cité Sérine, a therapeutic hotel for chronic and palliative care patients

Launched in 1988, *Cité Sérine* started on the initiative of a Brussels doctor whose friend had HIV and did not wish dying at hospital. At the beginning, in a time where people with HIV were socially and medically rejected, *Cité Sérine* was a place where presence and medical care were provided firstly to HIV patients. Over the years, the project evolved and is now hosted in Schaerbeek. The infrastructure is shared with Aremis (hospital at home) and Semiramis (outreach multidisciplinary support team in palliative care). They are three distinct nonprofit associations, but they share a common socle of values.

Patients hosted in *Cité Sérine* are patients in need for palliative support with a certain degree of medical attention. It is not necessary to have a palliative care status. There is no restriction regarding age: mean age range is 40-55, range is from 1 month of life up to 80 years.

Patients can access by different channels: on their own initiative, via the patient's GP, via hospitals, via Aremis (hospital at home), or via the outreach multidisciplinary support team. Admission interview is done by a duo of social worker and nurse at the place where the patient is staying before arriving to *Cité Sérine* (house, hospital, …) to initiate the therapeutic relationship and to facilitate the transition with the previous place of stay. Medical file is also assessed to ensure that the patient's needs correspond to the available interventions. GP, physiotherapists, and other health professionals are external to the project: the patient has already a health care team or *Cité Sérine* helps them to connect. If the patient already has a GP, they can keep it: some GP accept to do it but, for some, this is not possible (distance). When a GP is needed, *Cité Sérine* staff has contact with GP in the neighbourhood: they choose the GP according to the pathology, the age, or the palliative situation. If the

GP has no training in palliative care, the referent medical doctor is available for supporting them 24/7.

There are 25 studios, among which around 15 are dedicated to palliative care patients (the number can vary according to the demands). On average, the length of stay is around 5 months, ranging from less than 24h to several years.

At the time of the visit (2023), the status of *Cité Sérine* was not yet determined: according to the respondents, various possibilities have been envisioned over the years without leading to a defined solution. They benefited from a funding of the Brussels French speaking community (CoCof) as part of the *Décret ambulatoire de 2009 "subsides initiatives complémentaires"*. Other sources of fundings are cumulated to cover various fees (e.g. charity funds to pay for the electric armchairs).

More information on *Cité Sérine* (in French and Dutch): https://www.serine.be/

- Other health care professions

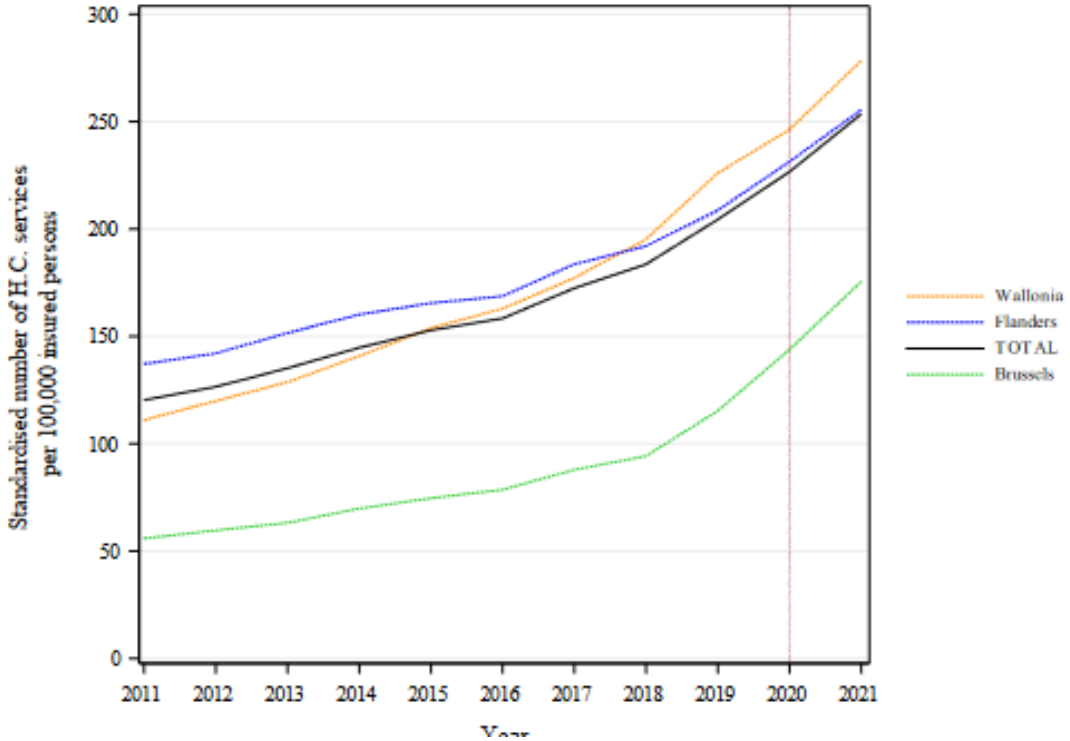
Physiotherapists, psychologists and pharmacists can also play a role as part of the generalist palliative care offer.

Use

According to the Federal Cell, it is estimated that GPs manage around 10 palliative care situations per year.[19] In 2021, GPs represented 20.82% of the prescribers for palliative care at home delivered by nurses.[158] In 2021, per 100 000 patients, there were 254 nursing interventions related to palliative home care.[158]

Over the years, it is interesting that the use of palliative nursing home care increases in all the region, Wallonia having the highest rate in 2021 (Figure 10). Additional data regarding palliative care delivered by nurses at home are available at the NIHDI.

Figure 10 – Evolution of standardised rate of use of palliative nursing home care per 100,000 insured persons by region



Source: Meeus et al. 2022, page 20[158]

Content of care

Health care provided by GP and nurses in the context of the home is envisioned as generalist palliative care, as provider's knowledge comes from general education of these healthcare professionals. The main difference between classic/usual care and palliative care at home appears to lie on a financial valorisation of the additional time devoted to care for palliative care patients: for example, home nurses can attest pseudo-codes for patients eligible for the palliative lump sum covering additional visits during working hours or out-of-hours visits (nights and weekends).[157]

Palliative federations provide guidelines to healthcare professionals to help to adapt the content of care to the needs of palliative care patients such as pain management, sedation and other symptoms.[159] And healthcare professionals can also benefit from the support of providers specialised in PC coming at home, the outreach multidisciplinary support team.

Funding mechanism & financial benefits for the patients

Table 24 present an overview of the financial benefits for patients in need for palliative care in the context of the home setting. For an exhaustive description on the financial benefits for patients in need of palliative care, we kindly invite the readers to consult the KCE report 367 (pages 22 to 36).

Table 24 – Overview of the financial benefits for patients in need of palliative care at home

	At home
Palliative lump sum	✓
General practitioner's visits **No co-payment for visits**	✓
Nursing visits **No co-payment for specific palliative care services**	✓
Physiotherapist visit **No co-payment for specific palliative care provisions**	✓
Oxygen therapy (short term) **Entirely reimbursed**	✓
Oxygen therapy (long term) **Reimbursed under the condition of the NIHDI convention**	✓
Support of a multidisciplinary support teams for palliative care **Entirely reimbursed**	✓

Source: Ricour et al., 2023, page 23[13]

To financially support patients in need of palliative care wishing to die at home, a specific lump sum was created to cover part of the out-of-pocket expenses related to drugs and equipment in the terminal phase. To be eligible for this "palliative lump sum", the patient at home must fulfil 7 criteria defined in the Royal Decree of 02.12.1999, including a certain degree of dependency, an illness that no longer responds to treatments, a wish to die at home and a life expectancy of less than 3 months (see Table 25). To certify this status, the general practitioner must fill out a form and send it for approval to the sickness fund's medical advisor (Table 25). The lump sum is granted a maximum of two times. The abolition of co-payment for some services (GP, nurse, physiotherapists) lasts till the end of life, even if the patient lives many years after the declaration. Currently more than 10% of the palliative patients still live a year after the medical declaration despite the presence of a criterion on a life expectancy of less than 3 months.[160]

It was also decided to abolish the co-payments for specific care services delivered by nurses and physiotherapists to patients fulfilling the condition to obtain the lump sum. However, the co-payment of GP visits was abolished within the same seven condition but also when only 5 of the 7 conditions are met (see Table 25).

As mentioned in the previous section, these specific benefits (palliative lump sum and co-payment abolition) specifically target patients staying at home in the terminal phase.[161] They constitute one of the possible palliative interventions reimbursed at a certain point in the progressive course mentioned by the law of 2002 on palliative care.

Table 25 – Lump sum (7 criteria) vs. co-payment abolition for GP visits (5 criteria)

To be entitled to the palliative lump sum a palliative patient at home must fulfil the following 7 criteria	To be entitled to the abolition of co-payment for GP (at home or in any residential setting), a palliative patient must fulfil the following 5 criteria
1° irreversible condition(s)	1° irreversible condition(s)
2° evolution is unfavourable, with a generalised severe deterioration of his/her physical/psychic situation	2° evolution is unfavourable, with a generalised severe deterioration of his/her physical/psychic situation
3° therapeutic interventions and revalidating therapy no longer influence this unfavourable evolution	3° therapeutic interventions and revalidating therapy no longer influence this unfavourable evolution
4° the prognosis of the condition(s) is poor, and death is expected within a relatively short time (life expectancy of more than 24 hours and less than three months);	4° the prognosis of the condition(s) is poor, and death is expected within a short period of time (life expectancy of more than 24 hours and less than three months)
5° important physical, psychological, social, and spiritual needs requiring a sustained and long commitment; if necessary, the services of specially qualified staff and appropriate technical means are used;	5° significant physical, social, and spiritual needs requiring a sustained and long commitment; if necessary, the services of specially qualified staff and appropriate technical means are used.
6° patient intends to die at home;	
7° patient meets the conditions mentioned in the form attached to the royal decree	
The evaluation of those conditions requires the confirmation by the general practitioner and the approval of the sickness fund's medical advisor.	*This status can be confirmed by the GP.*
NB: Palliative patients entitled to the lump sum are also entitled to specific palliative nursing care and physiotherapy at home without co-payments. If the patients do not meet those 7 criteria, they are entitled to regular nursing and physiotherapy visits at home with co-payment and, possibly, extra-billing.	NB: If the patients do not meet those 5 criteria, they are entitled to regular GP visits at home with co-payment and, possibly, extra billing.

Table 26 presents the standardised health expenditures regarding nursing care delivered to palliative patients at home: these data confirm the importance of the palliative care delivered in the home context. And several sources tend to confirm that the number of interventions will increase in the coming years.[11, 21, 162]

Table 26 – Standardised health care expenditures for 2020 in palliative nursing care at home covered by the NHIDI,

	Total
Average number of interventions per year	29.064
Average annual expenses (€)	218.504.666
Average cost per intervention (€)	7518,08
Average annual expenses per insured patient (€)	19,06

Source: Adapted from NIHDI data, 2020 – retrieved from Meeus et al. 2022, page 29[158]

4.3.1.2 Outreach multidisciplinary support teams

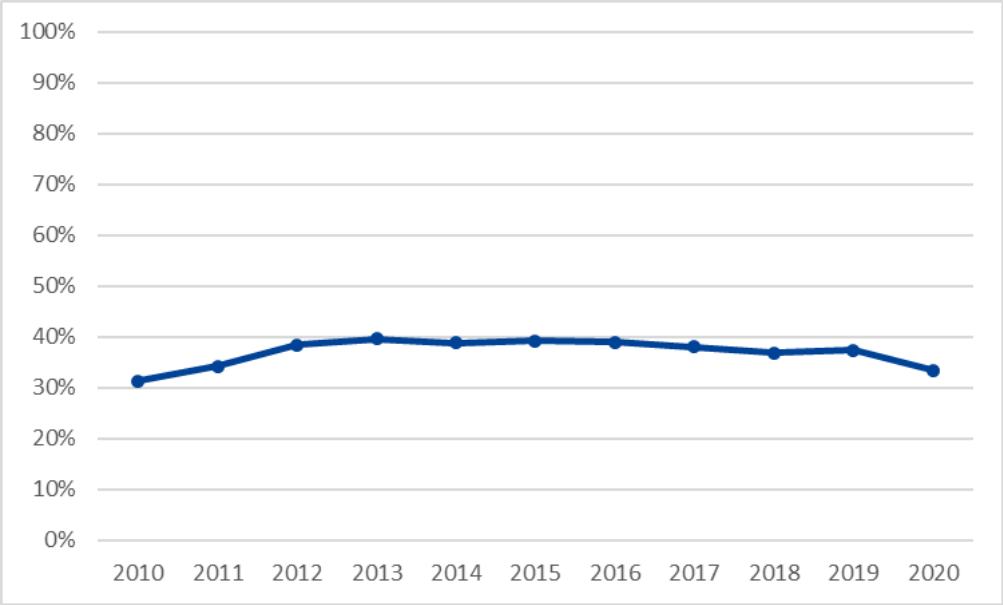
Available offer

Healthcare professionals delivering generalist PC at home can be supported by an **outreach multidisciplinary support team** (*multidisciplinaire begeleidingsequipe MBE - équipes d'accompagnement multidisciplinaire de soins palliatifs EAMSP*). According to law, each palliative care network must include one or more teams. The teams intervene on the request of the GP of the palliative care patients. In 2024, there were 15 outreach multidisciplinary support teams for the Flemish region, 9 in Wallonia (including the German speaking teams) and 4 for the Brussels region.[163, 164] Since the transfer of the competences of palliative care to the federated entities, these teams are governed by a regional legislation (although the federated entities mostly preserved the legal framework as established by the RD of 13.10.1998).[165-169]

Use

From 2010 to 2020, there were – on average - 36.89% of the patients with at least one palliative benefit who benefitted from the services of an outreach multidisciplinary support team (see Figure 11).

Figure 11 – Evolution of the proportion of patients with at least one palliative benefit billed in contact with the outreach multidisciplinary support team (2010-2020)



Source: Ricour et al., 2023[13]

Eligibility criteria

To benefit from the support of such a team, eligible patients are patients who had reached the terminal stage of an incurable disease and who met the following conditions:

- the general state of health must be poor; the patient will therefore be mostly dependent on others for the activities of daily living
- any treatment of the patient that is not purely symptomatic is superfluous;
- no remission is foreseen for the patient;
- the care of the patient requires an intensive commitment of time and is supported by caring staff with specific qualifications (general practitioners, nurses, etc.) and in some cases also with appropriate technical means.

Similar conditions are currently applied by the federated entities in the contracts they currently conclude with these teams, but a more in-depth analysis of this specific offer should be carried out in order to know exactly the profile of the patients entitled to these intervention (and those who are not). Some specific conditions (different in each federated entity) can apply, for instance a limited duration.

This team can also intervene in nursing homes, elderly homes, institutions for persons living with disabilities or with mental health problems, or any other residential facility. It is therefore important to recall that the team acts as a complement to the existing healthcare professionals and not as a substitute. The nature of their involvement in these facilities and how it is organised in practice is subject to a discussion between the team and the facilities.

Textbox 5 – Focus on patients in need of palliative psychiatric care: *crustatieve zorg*

Crustatieve zorg (trans. oyster care)[170] is a form of care developed for people with severe persistent psychiatric disorders. This form of care comprises an integrated approach that aims to increase quality of life, autonomy, and a person-centred approach. Here, the shell is a metaphor for external support and comfort and can be more or less protective depending on the situation. It is a dynamic approach, responding to the needs, abilities, and pace of each patient.

Like palliative care, *crustatieve zorg* rests on 4 pillars: somatic care, psychological and emotional care, social care and spiritual care, with a personalised approach to each patient.

Translated and adapted from: https://www.crustatievezorg.be/

Content of care & missions

As part of their mission of delivering specialist palliative care, outreach multidisciplinary support teams have as core missions:

- the liaison with the healthcare professionals around the palliative patients by providing advices on the different aspects of palliative care, such as pain management, relief of a range of symptoms, the use of specialist equipment (e.g. pain pumps), psychological and emotional support, the information for the patients and the families, including providing information about diagnosis, treatment and prognosis. A telephone hotline for the professionals is therefore required;
- the assurance that palliative care is well organised and coordinated, by means of agreements with GP, healthcare professionals, social and support services
- the assurance that the equipment needed for palliative care is always available in good time at the patient's place of residence
- the delivery of psychological and moral support to the healthcare professionals accompanying palliative care patients at home[19]

The operationalisation of these missions is let at the discretion of the teams: some will directly provide care – in agreement with the usual healthcare professionals - while other will remain in an advisory position.

After the transfer of competences to the authorities of the federated entities, some additional missions have been added to the teams. For example, in Wallonia, teams are expected to provide advices to patients and families by the means of a telephone hotline and to train and accompany volunteers.[171] In Brussels, training of the volunteers is coordinated by Brusano, a regional coordination platform which also includes the palliative care network of the Brussels region. No additional missions have been devoted in Flanders but the teams develop additional activities if it helps to improve the quality of palliative care.[164, 165]

Human resources

A team necessarily consists of nurses and physicians and, on a local basis, of other professionals such as psychologists, paramedics and volunteers. The staffing of the team should allow for the 24/7 permanence, implying at minimum 3 FTE nurses with a training in palliative care. Medical presence is usually ensured by a GP with a training in palliative care, with a minimum of 4 hours per week. In each region, the staffing is calculated based on the number of inhabitants in the area of activity of the team.

Infrastructure

The team is expected to have an infrastructure and equipment allowing for receiving visitors, managing administrative tasks, and organising. This can be shared with the palliative care network.

Funding mechanism & financial benefits for the patients

The support provided by this team is fully reimbursed, no fee is invoiced to the patients and their families. However, some additional costs may be charged (for example: the co-payment fee for some medication used). The team should always inform the patient or a relative about potential extra-costs in advance. The interventions of the multidisciplinary support teams were initially managed by private associations contracting with the NIHDI. Until the transfer of this competence to the federated entities, the applicable contracts reserved the intervention of these teams to patients described as terminal. The duration of the team's interventions was evaluated of one month on average on an annual basis.

Evaluation

Each federated entity requires activity reports but, to our knowledge, no formal evaluation has been conducted.

Textbox 6 – When home is no longer a place to stay – Pass-Ages, a home-like initiative driven by volunteers

Pass-Ages is a home-like facility rooted in an intergenerational housing project. Isabelle (palliative care nurse) and Thérèse (midwife) had the project of creating a place where birth and death will be joined as it is part of a continuum. They were inspired by the approach developed by Lydia Müller (a Swiss psychotherapist): she came to discuss with the funders and helped them to develop the Brussels project. The project exists since 10 years but the service in itself has been officially inaugurated in May 2022. In the philosophy of the project, everybody is welcome as long as the project matches with values of Pass-Ages. Patients can bring their own decoration and furniture (including to decorate common spaces to create a warming and caring environment familiar for the patients and relatives).

Pass-Ages is organised on collective intelligence: there is an administration council, gathering representatives of the 3 projects hosted in Pass-Ages (birth house, death house, housing). Habitants are active in the different working groups alongside volunteers: there are various working groups to develop the different aspects of the project (e.g. working group "Mourance", working group "Rituels" where they develop support for those in demand for spiritual support in an open way without references to a religion or a belief).

Before the admission, the project of the patient is discussed with the volunteers of Pass-Ages in order to keep it in the limits and possibilities of the structure (e.g. situations where there is a need for highly complicated care that are not usually performed in the context of home care are not accepted). The same care that a patient can receive at home is organised at Pass-Ages: patients came with their own healthcare professionals (e.g. pre-existing GP, outreach multidisciplinary support team, home nurses…). If it is not possible to deliver the health care at home, it is not possible in Pass-Ages: they organise transport to the hospital if needed (e.g. in case of chemotherapy, ascites punction…). Families and relatives are welcome to come back after the death of the patients. This is related to the concept of "ambassadors", implying that these families can contribute to a better understanding of palliative care and death in the society.

To date, there is no official agreement for Pass-Ages. They receive a mix of subventions to cover their activities: subventions from the European Union for the infrastructure, subventions from the Brussels region for hiring the coordinator as part of a pilot project (until December 2025), subventions from the Funds King Baudouin for investments (e.g. mobilier, chairs,…), subventions from the Brussels Institute for Research and Social Innovation (INNOVIRIS) and subventions from the *Fonds du Logement Bruxellois* (Brussels Housing Funds).

Around 30 volunteers are involved in the activities of Pass-Ages. Inhabitants of the intergenerational housing project have 5 hours per week of volunteer work in the project (birth and/or dead). There is only one salaried staff member, the coordinator.

More information on Pass-Ages (in French and in Dutch): https://www.pass-ages.be/

4.3.2 Day care centres for palliative care

From 2002 to 2004, the NIHDI piloted ten projects for palliative day care centres. After evaluation, these pilot projects were no longer funded: only 5 remained, all in the Flemish region, thanks to funding from the Flemish government and charities funds. After a transition phase where the federal authority issued specific agreement criteria, the competence over palliative day centres was fully transferred to the Flemish region. To date, no palliative day care centre exists in Wallonia and Brussels. There are two day centres offering wellbeing and non-medical activities in Brussels, led by volunteers (such as OASE).[j]

Despite the absence of palliative day care centres, in Wallonia, there are day care centres for persons with serious illness. These day care centres, offers support for: pain and symptom control in the event of mental or physical suffering resulting from the progression of the disease or related treatments; adapted and complementary care and revalidation and, in particular, learning specific skills for the everyday life. These centres must have a formal collaboration with a hospital with a Sp4 unit, a hospital with a function for emergency care and intensive care, the palliative care network, the outreach multidisciplinary support team, and an elderly home / a nursing home. Medical supervision is provided by a GP or specialist with particular experience in palliative care (no requirement in palliative care is mentioned for the nurses and care assistants).[171]

The following section describes the situation of palliative day care centres in Flanders only. It is worth mentioning that the oldest palliative day care centre was started in 1987 (Heidehuis, Brugge) while the most recent one – to date – is De Kade in Roeselare, attesting of the longstanding existence of such ambulatory offer.

Available offer

The Flemish Decree of 15.02.2019 (Chapter 3 – Appendix 7) regulates the agreement criteria and the offer for palliative day care centres (*Centra voor dagverzorging met een bijkomende erkenning voor gebruikers met een ernstige ziekte* previously called *dagverzorgingscentra voor palliatieve verzorging*). Number of places vary across centres, from 5 to 11 persons per day. Before being acknowledged as palliative day care centres, these centres need to be recognised as day centres that must meet the conditions for approval of day centres as described in the Flemish Decree of 28.06.2019.[172] It implies that, in practice, there is a mix of patients in the day care centre and not only palliative care patients.

A palliative day care centre is a day-care centre that has additional accreditation for offering a care structure for accommodating patients suffering from a serious illness requiring adapted care during the day. A palliative day care centre also provides the necessary support for maintaining those patients in their home environment (Art. 46 of the *Woonzorgdecreet* of 15.02.2019).

The number of **day care centres** shall be at least one per municipality (not specific to palliative care patients). The programming of the number of places is based on the following figure (Art. of the *Woonzorgdecreet*): 1° 0.1 centre per 3,000 elderly people of the age group of 65 to 69 years; 2° 0.4 centre per 3,000 elderly persons of the age group of 70 to 79 years; 3° 0.8 centre per 3 000 elderly people of the age group of 80 to 89 years; and 4° 1.5 centre per 3,000 elderly people of the age group of 90 years and over.

j https://www.reseau-sam.be/fr/prestataires/oase

Art. 52 of the *Woonzorgdecreet*also states that day care centres with additional approval for persons suffering from a serious illness with fewer than seven places may be granted additional approval up to a maximum of seven accommodation units per day-care centre, within the available budget appropriations.

Admission criteria and length of stay

Palliative day care centres are intended for patients who meet the dependency category Fp, mentioned in Art. 427 of the Flemish Government Decree of 30.11. implementing the Decree of 18.05.2018 on Flemish social protection (Art. 55).

From the interviews, it also appears that the centres can have additional admission criteria. Among the 6 visited centres, only one specifically mentioned children as part of their target population. Although accessible to adults aged of 18 years and more, the day care centres mostly welcome patients aged of 65 years old and more.

According to the legal framework, to be admitted, patients need to suffer from a life-threatening degenerative disease. However, it oftens appears – from the interviews - that, in practice, most of patients attending these centres suffer from cancer and, to a lesser extent, of multiple sclerosis or amyotrophic lateral sclerosis. Dementia and other behavioural problems were often mentioned – in the interviews - as exclusion criteria, as well as severe mobility problems. During the site visits, some centres explained that they admitted only patients with an estimated 3 months life expectancy. Therefore, based on the interviews, it appears that the personal situation of each patient was considered before admission.

Care offer

The day care centre in palliative care offer care for patients with life-threatening conditions who wish to stay at home and will to avoid an admission to a hospital or in a nursing home. As described in the Art. 58 of the *Woonzorgdecreet*, the palliative day care centre provides : pain and symptom control in the event of psychological or physical suffering due to disease progression or related treatments; adapted, complementary care; psychosocial support of the user and relatives to maintain or increase their coping capacity, as well as learning specific skills; resocialisation or rehabilitation through adapted daytime activities and relaxation. The same decree also specifically requires that each patient file includes advance care plan, drawn in collaboration with the patients, their informal caregivers and the GP (Art.59).

A palliative day care centre provides adapted and / or specialist palliative care that is impossible or difficult to provide at home. This aims at increasing the patients person's physical and psychological comfort and at preventing unnecessary hospitalisation. The care provided also focus on the improvement of the patients' autonomy and psychological well-being through adapted activities and social contacts: this is envisioned as a way to increase their ability to cope and reducing any tensions in the home environment. It also aims at reducing the burden on informal caregivers (and possibly also on the primary caregivers involved), as the person spends certain days at the day centre.[k]

Human resources

Each palliative day care centre should have an appointed medical doctor with a specific training in palliative care. This medical doctor has to coordinate the medical activities, the medical follow-up of the patients and their medical files. The medical doctor shall be present for at least five hours per week per 15 users (Art.56). Additionally, per 15 patients, there should

[k] Information translated and adapted from https://www.vlaanderen.be/gezondheid-en-welzijn/overlijden-en-erfenis/palliatieve-zorg/dagcentra-voor-palliatieve-verzorging

be 2.5 FTE nurses, 2 FTE care assistants, 0.5 FTE salaried clinical psychologists; 1 FTE other reactivation staff[l] (Art. 57).As an example, in the interviews, centres mentioned that they have occupational therapists (e.g., for art-based activities), physiotherapists, social nurses, social workers and spiritual counsellors. Some also report having a (administrative) coordinator.

Each palliative day care centre must have a formal collaboration with a specialised palliative care unit (Sp4) in a hospital and with the palliative care network of their area (Art. 61). Moreover, the patient keeps its usual healthcare professionals, e.g. the GP or the specialists.

Alongside the staff required by law, as explained in the interviews, day care centres also involved volunteers who contributed to the daily activities, with variations in their number per centre (from 3 to 68 volunteers) In some day care centres, these volunteers were also participating to the activities of the Sp4 unit of a neighbouring hospital.

Infrastructure

The *Woonzorgdecreet* establishes all the requirements concerning the infrastructure (*Afdeling* 5 – Art. 45 to 49). It emphasizes the need for a safe, cosy, practical and adapted infrastructure so that patients, families, and professionals can function adequately.

In practice, day care centres can be integrated in a hospital building: this is, e.g., the case for Ikaria (Morstel[m]) and *De Kade* (Roeselaere) which both were created on the initiative of a hospital. It can also be a separate infrastructure, often in a green and quit environment, making it more "like-home" and less "medicalised": this is the case, e.g., for *De Kust* (Oostende), *Heidehuis* (Brugge), CODA (Wuustwezel) or Topaz (Wemmel).

Funding and patient financial contributions

Each centre determines the daily fees (or the per-hour fee) that will be paid by the patients: some sickness funds intervene partly or totally to cover the patient personal expenses. There is no restriction for the length of stay.

The palliative day care centres benefit from a Fp lump sum from the Flemish health department: they can combine this public funding with other sources of fundings (e.g. subsidies from *Kom Op Tegen Kanker*, charities, local subventions from the municipalities, gifts and legacies…).

Evaluation

All (palliative) day care centres must comply with a regular evaluation of their activities, as defined by the Art. 5 of the *Woonzorgdecreet*.

4.3.3 Palliative hospices integrated in nursing homes

Available offer

Since less than a decade, palliative hospices integrated in nursing homes appear to be a growing care model in Flanders: 4 hospices are currently in activity in 2024 (*Aulighem* in Avelgem[173, 174]; *De Klaproos* in Tienen; Asteria in Elverdinge, Ieper[n]; *Avondlicht* in Koksijde) while 4 are expected to be launched before the end of the year in 2024 (*De Vliet* in Zele; *Samen Ouder* in the nursing home *De Ark* in Sint-Niklaas, the nursing home *Grootenbosch* in Beveren, and *De Bron* in Zottegem). To date, no equivalent model appears to exist in Brussels and Wallonia. On average, these hospices have two beds.

[l] Reactivation staff is a member of the multidisciplinary team: it can be a physiotherapist, occupational therapist, animator, etc.). This professional provides customised services for residents who need care and/or residents with a starting care situation. It should also be noted that not all reactivation staff has a background as healthcare professional.

[m] Example of a day care centre in palliative care (in Dutch): https://www.zas.be/diensten/palliatieve-zorg/dagcentrum-ikaria

[n] More information on Asteria (in Dutch): https://www.homevrijzicht.be/hospiceasteria

Currently, these hospices are regulated by the legal framework pertaining to the centres for short stay in nursing homes (*centrum voor kortverblijf CVK type 1)* as framed by the Flemish Government. A centre for short stay is defined as a: "*een voorziening waar aan gebruikers van 65 jaar of ouder ofwel gedurende een beperkte periode dag en nacht ofwel alleen 's nachts huisvesting en ouderenzorg wordt aangeboden*" (Article 30) (trans. 'a facility where users aged 65 or over are provided with accommodation and elderly care either day and night or only at night for a limited period of time').[175]

In July 2024, the Flemish Federation of Hospital Federations – ZorgNetIcuro – published a proposal for the recognition and funding of *hospicezorg*.[176]

Admission criteria and length of stay

As there is not yet formal criteria for the "hospice" part, admission follows the rules for being admitted in a short-stay centre (age condition – being older than 65 years). Additional admission criteria are based on the PICT1 and PICT2 and, in some hospices, also the Palliative Scan developed by the Flemish Federation of Palliative Care. As an illustration, in Hospice Asteria, this evaluation before the admission is conducted by a multidisciplinary team of in-house staff and volunteers, supported by professionals from Jan Yperman Hospital and from the Westhoek Oostende palliative network. Based on this evaluation, the staff decides, in consultation with the family and GP, whether the patient is eligible for admission to the hospice[o]. The maximal length of stay is of 3 months (criteria of the "short stay").

Textbox 7 – PICT-1 & PICT-2

The PICT-1 is a tool allowing the identification of a PC situation for a patient with life-threatening condition. It is based on the life expectancy (surprise question on 6 to 12 months), frailty criteria (at least 2 among 7) and incurability criteria (1 among 9). The PICT-2 is a categorisation tool allowing to sort identified palliative patient in three categories (Appendix 2.1 Appendix 2.2). There are 11 "extraordinary" treatment among the 24 complex needs listed in the PICT-2.[177] Patients with less than 3 months of life expectancy are eligible for the category 'full palliative status'; patients with, at least, one complex need are eligible for the category 'enhanced palliative status' and the remained patients are eligible for the 'simple palliative status'. While the PICT-1 is recognised as a legal tool for the identification of palliative patient in Belgium, the PICT-2 is not legally recommended to categorize palliative patient in Belgium although this is not an obstacle to its use as admission criteria by palliative care services.

Care offer

Hospice care consist in integrating specialist palliative care offer in a nursing home infrastructure with some limitations as short-stay centre (*centrum voor kortverblijf* CVK) type 1 can only provide care and support to people aged 65+ for a limited period of time (day and night or only overnight for a period of up to 60 consecutive days and up to 90 days per year). A type 1 short-stay centre is always attached to a nursing home or a recovery stay centre. When a day care centre is present in the nursing home / home for the elderly, patients can also attend the activities of the day care centre, if they wish.

Technical acts like those listed as "extraordinaire" in the tool PICT2 cannot all be offered in hospices. As explained by a hospice staff, in PC focuses mainly on "full palliative status" according to the PICT-2 categorization, which, in their perspective, eliminates the need for many of these acts. They also explained that patients with "enhanced palliative status" were also eligible for admission, however, provided there was no need for "technical medical care " (e.g. pleural or ascites puncture, blood transfusion, dialysis…) and that a lot of "extraordinary" mentioned in PICT2 were mainly available in a "high-care" setting (SP4 unit).

[o] Information retrieved from the website https://www.homevrijzicht.be/hospiceasteria

Human resources

Patients can continue being cared by their usual GP while receiving nursing care provided by the nursing care team of the hospice. Depending on the nursing home, physiotherapy is also provided by an in-house physiotherapist or an external physiotherapist.

As these hospices are integrated in a nursing home, the staff usually circulates among the different services. Depending on the hospice, as explained during the interviews, there are sometimes possibilities of having specialised doctors on site.

Infrastructure

Infrastructure is comparable to the ones of the nursing homes: therefore, from the visits, it was observed that hospices tend to have a separate entrance, allowing families and friends to visit at any hour. Similarly, it was observed that the focus is put on creating a comfortable and cosy environment.

Funding and patient financial contributions

Currently, the stay are funded through the short-stay centre lump sum. Patients have some out-of-pocket expenses to cover per day with amounts similar to the out-of-pocket expenses in a nursing homes (e.g. hairdressers, laundry) and the patient personal contribution (*remgeld* – ticket modérateur) for medications and medical fees.[p]

As observed in other settings, additional funding sources are obtained through charities and subventions (e.g. *Kom Op tegen Kanker*).

[p] Information found on the website of Hospice Aulighem: https://www.vincentiusavelgem.be/nl/prijzen/hospice-aulighem

Evaluation

To date, no formal evaluation has been conducted. On the initiatives of the hospices themselves, there is a willingness to develop a common evaluation framework across the different hospices in the coming months.

Textbox 8 – Centre for short stay type 2 in Flanders

Since the *Woonzorgdecreet* of 2019, a new day care possibility has been launched: the centre for short stay type 2 (*centra voor kortverblijf type 2*). These centres aim at providing respite for adult patients with young dementia or a life-threatening condition. To date, no centre has applied for acknowledgement.[175]

4.3.4 Palliative care in nursing homes

In 2017, the Federal Cell estimated, based on the PICT-1, that there were around 14% of palliative patients in nursing homes.[19] The Flemish palliative care federation, based on the data of the *Agentschap Zorg en Gezondheid* (AZG – trans. Agency Care and Health), pointed that "*the proportion of hospital deaths has declined in the last 15 years. Among men, the proportion fell from 57% in 2000 to 50% in 2015. Among women, the proportion fell from 50% in 2000 to 42% in 2015. In contrast, the proportion of deaths in residential care homes has increased in the last 15 years. Among men the share rose from 11% in 2000 to 20% in 2015. Among women, the share rose from 28% in 2000 to 38% in 2015*".[178]

Current offer

Nursing homes are governed by the federated entities, implying that each federated entity edited its criteria for the organisation and delivery of palliative care in nursing homes. No detailed data on the delivery of PC

within nursing homes are available.[126] In Flanders, the term *Woonzorgcentra* (WZC) is now used to designate nursing homes, hosting elderly residents with various degrees of dependency. In Brussels and Wallonia, the distinction between nursing homes and homes for the elderly still persists although stand-alone elderly homes are less and less frequent: most of the nursing homes include beds for patients corresponding to a less dependent profile (those targeted by elderly homes).

Care offer

To obtain and keep their licence, nursing homes must offer palliative care for residents who need it as part of the generalist care offer. It implies covering the 4 pillars of palliative care, including attention to the families and relatives of the residents.

Each nursing home should have a coordinating and counselling GP[179](*coordinerend en raadgevend arts - médecin coordinateur et conseiller*), who must be trained in palliative care, ethical aspects related to end-of-life, euthanasia and advance care planning.[171] They are also expected to participate to the meetings of the palliative care network and to implement the institutional policies related to palliative care – in collaboration with the nursing staff. They also contribute to the training of the healthcare professionals (nurses, allied health professionals, healthcare staff) in palliative care and end-of-life care. [171] [180] Similarly, elderly homes, without acknowledgement as nursing homes, should rely on a referent medical doctor, that is expected to take initiatives related to end-of-life care.

Additionally, each nursing home must appoint a staff member specialised in palliative care; this person oversees increasing the caregivers' awareness and provide them with education on palliative care. This function consists 10% of a full-time equivalent for 30 residents.[181]

Nursing homes must have a functional link with an in-hospital palliative care unit (Sp4) and a hospital geriatrics unit as well as a collaboration in place with the palliative care network in its geographic area. The functional link implies at minimum one concertation meeting per year. Functional link implies that, when a hospitalisation is needed, the hospital units are the privileged destination (considering the availability of beds, the patient preferences, and the medical diagnosis) and that the patient will be returning to the nursing home after the hospitalisation. If the hospital units need a place for a patient, the nursing home is expected to prioritise the patient oriented from the hospital. This functional link can take place with several hospitals. The collaboration with the palliative care network implies that the nursing home commits to the development of palliative care (through training, referent person, collaboration, …) while the network commits to provide the resources to help the nursing home to develop palliative care.

Finally, it is worth reminding that specialists can visit residents in a nursing home. In 2024, an additional budget has been planned to improve the financial compensation for geriatrists, psychiatrists, neurologists, and neuropsychiatrists visiting their patients in a nursing home.

Funding mechanisms

The nursing care, physiotherapy as well as equipment in nursing homes are provided by the institution and included in the daily fees (Table 27). The palliative patients residing in nursing homes or other residential facilities have no access to the palliative lump sum (since this is intended to cover the costs of receiving palliative care at home). These patients are also not entitled to the abolition of co-payments for physiotherapy and nursing care (since these are only granted to patients who meet the conditions for the lump sum).

However, they have access to the following benefits to complete the residential offer:

- the elimination of the co-payment for visits by the general practitioner
- oxygen therapy

The outreach multidisciplinary support teams can also intervene as a second line in nursing homes or other residential facilities, under conditions agreed in advance with the institutions.

Table 27 – Overview of the financial benefits for patients in need of palliative care in nursing homes

	Nursing homes
Palliative lump sum	⊘
General practitioner's visits **No co-payment for visits**	✓
Nursing visits **No co-payment for specific palliative care services**	Not applicable: this care is delivered as part of care in nursing homes
Physiotherapist visit **No co-payment for specific palliative care provisions**	
Oxygen therapy (short term) **Entirely reimbursed**	✓
Oxygen therapy (long term) **Reimbursed under the condition of the NIHDI convention**	✓*
Support of a multidisciplinary support teams for palliative care **Entirely reimbursed**	✓**

**Palliative patients staying in certain residential facilities are entitled to the benefit of the convention on long term oxygen therapy at home (see Art. 4, §1 of the agreement for long-term oxygen therapy at home). They are also entitled to the reimbursement of short-term oxygen therapy with certain nuances. ** Multidisciplinary support teams for palliative care are different from the mobile team that is part of the palliative function in nursing homes). In Wallonia, support teams must counsel the healthcare professionals of residents of residential facilities if the request is made in agreement with the GP and the patient meets the criteria.*
Source: Table retrieved from Ricour et al. 2022, page 23

Human resources

Table 28 presents the repartition of staff per 30 residents in nursing homes, per federated entity and per qualification. As part of the continuing education, staff in nursing homes is expected to regularly receive training related to palliative care and end-of-life care.

Table 28 – Repartition of staff per 30 residents in nursing homes, per federated entity and per qualification

	Flemish Community	Walloon Region	Brussels-Capital Region	German-speaking Community
Nurses	5 FTE/30 residents At least one nurse on duty 24/7	5 FTE/30 residents At least one nurse on duty 24/7 1 FTE nurse may be replaced, in proportion to a maximum of 1 FTE/30 residents, and provided that the 24/7 nurse on duty is respected, by a reactivation staff member	5 FTE/30 residents	5 FTE/30 residents At least one nurse on duty 24/7 1 FTE nurse may be replaced, in proportion to a maximum of 1 FTE/30 residents, and provided that the 24/7 nurse on duty is respected, by a reactivation staff member
Team manager	1 FTE/30 residents 1 additional FTE when the resident count exceeds half of 30 residents	1 FTE/30 residents 1 additional FTE when the resident count exceeds half of 30 residents		1 FTE/30 residents 1 additional FTE when the resident count exceeds half of 30 residents
Caring staff	5 FTE/30 residents (at least 95% care assistants)	5 FTE/30 residents	B:5 FTE/30 residents C: 6 FTE/30 residents Cd: 6.5 FTE/30 residents	5 FTE/30 residents
Physiotherapist and/or occupational therapist and / or speech therapist	1 FTE/30 residents	1 FTE/30 residents	B, C, Cd: 1 FTE/30 residents	1 FTE/30 residents
Reactivation staff with a qualification in palliative care for support of residents in terminal phase	0.1FTE/30 residents	0.1FTE/30 residents	B:/ C:0.5/30 residents Cd: 0.5/30 residents	
Coordinating and advisory physician	1 per residential care centre	1 per residential care centre		1 per residential care centre
Coordinating head nurse		If more than 75 places, one of the head nurses is appointed as coordinating head nurse		

Legend : B, C, Cd refer to the KATZ dependency care profiles as defined in the RD of 03.07.1996. Source: Adapted from Dejonghe, Ricour et al. 2022[182]

Evaluation

An assessment tool has been developed in Flanders: https://palliatievezorgvlaanderen.be/zorgverlener/tools-en-documentatie/woonzorgcentra/

4.3.5 Palliative care in hospitals

In 2017, the Federal cell estimated that one patient out-of-five could benefit from palliative care when staying at hospital.[19] The majority of cancer patients dies in the hospitals (2 out 3).[11]

Palliative care is a hospital function, as referred to in article 76bis, inserted by the Law of 30.12.1988 into the Law on hospitals, coordinated on 07.08.1987.

The Royal Decree of 15.07.1997 establishes the criteria that a hospital function in palliative care has to meet[183, 184]:

- A functional link with a specialised treatment and rehabilitation unit (Sp) intended for patients requiring palliative care, when the hospital has no palliative care unit
- A collaboration with the palliative care network of the geographic area
- A functional link with home care services delivering palliative care if these services are members of the network
- A regular registration of their activities according to legal requirements

The function is endorsed by a multidisciplinary team whose members have received a specific training in palliative care.[183, 184] The team should include medical doctors (GP and/or specialists), nurses, allied healthcare professionals, psychologist and social workers. A hospital pharmacist can participate to the activities. [19] This multidisciplinary team is not directly involved in the everyday treatment and care (Art.4. §1 §2): it has a role in introducing and promoting a culture of palliative care, making the hospital staff aware of the need for it, in formulating advice on palliative care for all healthcare professionals of the hospital and advising the hospital's management on the policy to be pursued in this area; providing ongoing training in palliative care for hospital healthcare professionals and ensuring continuity of care when terminally ill patients are discharged to their home or any other place of residence (nursing home, home for the elderly, institutions).

4.3.5.1 Hospital mobile team in palliative care

Available offer

In each general hospital, a mobile team (that is part of the palliative function) specialised in palliative care visits the other care units upon request. This team does not provide palliative care itself, but provides advice, continuous training, and awareness-raising on palliative care to the care teams, to the patient and their relatives. It also coordinates the liaison between hospital and home, ensuring the continuity of care in and out of hospital. All Belgian general hospitals' departments have a mobile palliative care team.[185, 186] The intervention of that team is fully covered by the compulsory health care insurance (included in the day of hospitalisation).

Human resources

A mobile team includes – at least – a 0.5 FTE medical doctor (GP or specialist), a 0.5 FTE nurse and a 0.5 FTE psychologist. For hospitals with 500 beds or more, the mobile palliative care team is strengthened by a 0.5 FTE specialist doctor, a 0.5 FTE nurse and a 0.5 FTE psychologist for each additional 500 beds, in proportion to the number of additional beds. In 2024, the Walloon federation of PC established the function profiles of the medical doctor, the nurse and the psychologist involved in the mobile team.[187-189]

Funding mechanism

The Article 65 of the RD 25.04.2002 regulates the funding of hospital palliative care mobile teams.

The costs relating to hospital mobile team for the palliative function are covered by the Subpart B4 of the budget for financial resources. The amount varies according to the number of beds of the hospitals: 1) an amount determined by law for general hospitals with less than 500 beds,

corresponding to the occupation of 1/2 FTE doctor with the required training and/or experience in palliative care, 1/2 FTE graduate nurse and 1/2 FTE psychologist; 2) for general hospitals with 500 beds or more, by an amount determined by law multiplied by the number of beds in the hospital and divided by 500.

4.3.5.2 Residential units in palliative care

The RD of 23.10.1964 determines the agreement criteria for a residential palliative care unit (PCU). All the residential PCU are part of the palliative care network covering the geographical area concerned.[190]

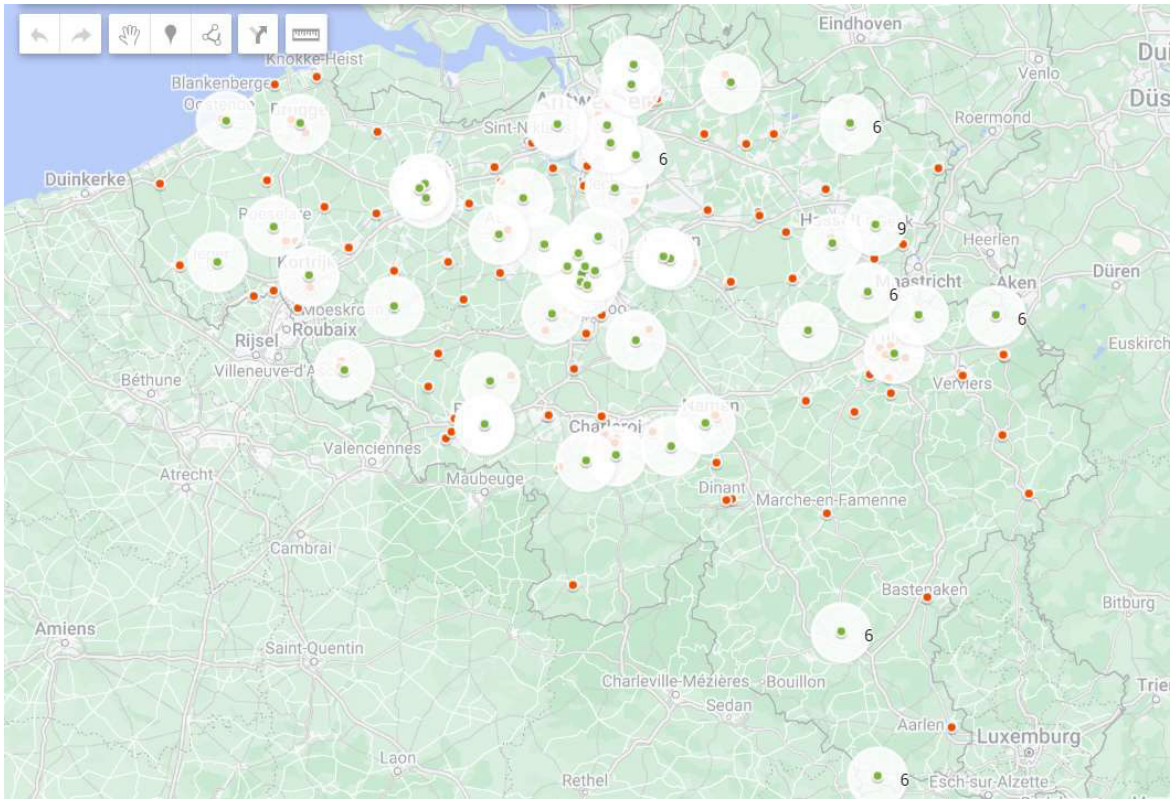
Available offer

Palliative care units in hospitals are part of the category of specialised units for the treatment and functional rehabilitation (*Gespecialiseerde dienst voor behandeling en revalidatie - Service spécialisé pour le traitement et la réadaptation*). The beds within the palliative care units are identified by the letters Sp (specialised) followed by the mention 'palliative' or by a number corresponding to the specialty concerned. In the case of the palliative care units, it is the number 4: Sp4 beds.[q] In Belgium, there are currently, 379 Sp4 beds. In 2018, there was 1.7 Sp4 beds per 100 000 inhabitants, which is above the European median (0.8/100 000 inhabitants).[185, 191]

Figure 12 presents the repartition of palliative care units across Belgium. These beds are clustered in 51 Palliative Care Units with (minimum) 6 to (maximum) 12 beds and can be spread over several hospital units (e.g. in geriatrics), or gathered in a palliative care unit itself. The Sp4 beds are foreseen for patients with an incurable disease in terminal phase and who require palliative care.[190]

[q] There are 6 categories of Sp beds: Sp1 – cardiac and pulmonary readaptation; Sp2 – locomotor readaptation; Sp3 – neurological readaptation; Sp4 – palliative care; Sp5 – chronic; Sp6 - psychogeriatrics.

Figure 12 – Repartition of the hospital palliative care units (Sp4) units in Belgium



Dots on the map indicate the campus of a general hospital. Green dots indicate a hospital campus with Sp4 beds, red dots indicates hospital campus without acknowledged Sp4 beds. Source : liste d'adresses 09_2023 de l'AZ et du PZ - SPF Santé publique, Sécurité de la chaîne alimentaire et Environnement - DG GS - Data & Policy Information Service ; visualisation via Google My Maps. Source : Federal Council of Hospitals, 2024, page 10[162]

Textbox 9 – Residential units outside hospital campus

A legacy of the past, when hospitals were sometimes isolated structures offering a single type of care, there are still palliative care units located outside a hospital building or campus. They have the same norms of agreement and recognition than the other palliative care units. Their originality lies on the fact that they are decentralised: they are not located on the same campus than the rest of the hospital. The reform of the hospital landscape has enabled these structures to continue to operate, provided they join a hospital network or any other care structure. This type of grouping also appears necessary to guarantee the financial viability of PC units. From our visits, we can observe that this decentralisation gives a feeling of "not being in a hospital" which is often, according to the respondents, primed as important by the patients and their families. Inside the unit, the organisation of the space and the equipment are therefore based on hospital norms: a specific attention is paid to the atmosphere and embellishment as we can also observe in other palliative care units (flowers, coloured walls, wooden furniture…).

Foyer Saint-François and *Le Goéland* are examples of such decentralised palliative care hospital units. *Foyer Saint-François* is located in the campus Saint-Jean de Dieu (Salzinnes) where other facilities are located such as a day care centre for children and a nursing school. *Le Goéland* (Soignies) is located in the vicinity of a nursing home and a rehabilitation centre in the countryside. Architecturally speaking, these units are built as a separate pavilion, inserted in a garden or a park. This current appearance is inherited from the past: for example, Foyer Saint-François was previously a nursery.

In 1989, les *Soeurs de la Charité* opened a palliative care unit "Foyer Saint-François". In 1995, it was acknowledged as an isolated hospital with agreement for palliative beds. In 2006, it was included as part of a local hospital, under the condition that the pavilion remains at its current location. It was progressively included as part of hospital, allowing the pavilion to benefit from all the transversal services of the hospital (hospital hygiene, logistics,…). In 2015, a new fusion project of the hospital led to change in the governance but not in the daily organisation. A massive renovation was held in 2015-2016. To date, the Belgian Church is still member of the Administration Council.

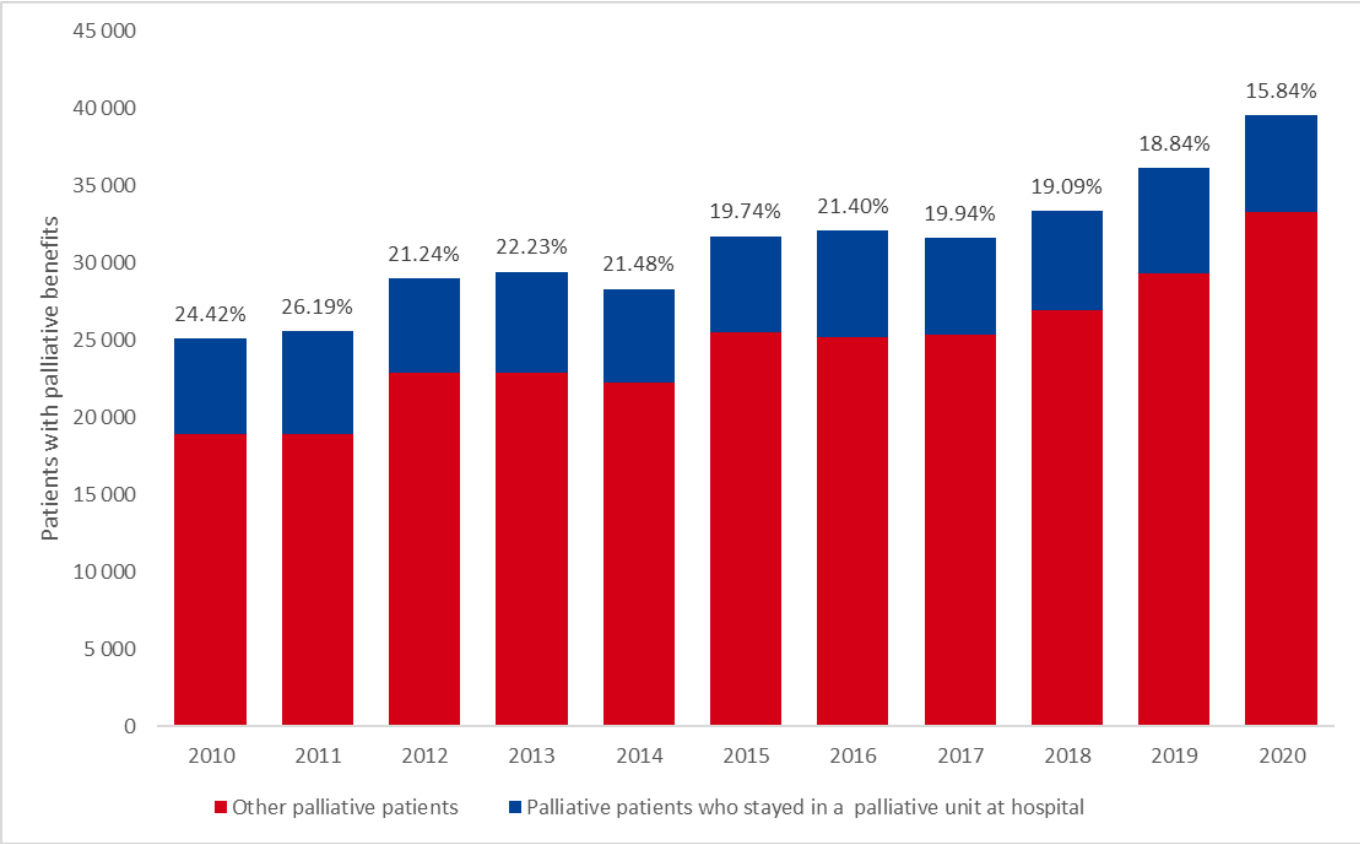
In 1994, the non-profit association *Maison Marie Immaculée* (MMI) decided to create a palliative care unit "*Le Goéland*" located close to the nursing home "*Le Grand Chemin*" in Neufvilles on their own funds. They then obtained an agreement as hospital with only palliative care beds. A few years later, as it was too costly to function alone, the palliative beds were integrated in the *CHR Haute Senne* but the rest of the MMI services remained independent. They signed an agreement that the pavilion will always stay on the premises of the *Grand Chemin* to preserve the familial and rural aspect of the project. According to the respondents, there is therefore a project of displacing the unit inside the new hospital complex (but not before 10 years- other sites are priority): they will keep it separated and close to a wooden area. The respondents anticipated it and already made some proposals for the further management qua infrastructure. As part of this agreement, the MMI is member of the administration council of the hospital and vice-versa.

Use

Among the patients who received palliative care benefits between 2010 and 2020, 20.62% have had an admission at hospital in a palliative care unit. Figure 13 illustrates that proportion; the number of palliative patients who stayed in a palliative care unit at hospital is relatively constant over time (between 6120 and 6860 patients per year), while the number of palliative patients increases from 25 060 in 2010 to 39 520 in 2020 (estimated numbers based on EPS data).

According to the Federal Council of Hospitals (FRZV-CFEH), only 13% of deaths occur in a palliative care unit : the majority of deaths occurs in type C units (chirurgical diagnosis and treatment) and type D units (medical diagnosis and treatment), with a raising number of deaths in geriatric wards type G2.[162]

Figure 13 – Proportion of patients with palliative benefits admitted in a palliative care unit at hospital



Source: Ricour et al., 2023, page 25[13]

Admission criteria and length of stay

To our knowledge, there are no strict admission criteria: the multidisciplinary team will examine each situation on a case-by-case basis, taking into account various vulnerabilities factors (e.g. stability of the patient, comorbidities, prognosis, type of care needed…). The patients staying in a palliative care unit at hospital stayed on average 16.14 days (STD=20.18 days, median=9 days, IQR=17 days), in one or several stays.[11, 13]

Care offer

The care delivered in those units focusses on the control of symptoms, the psychological accompaniment of the patient and the family, and the preparation for and accompaniment during mourning. Specifically, the Sp4 must have the necessary technical resources to proper pain management. Visits from family members and close friends must be possible 24 hours a day. Some Sp4 have the equipment allowing for families to sleep in the same room than the patients or have separate rooms for the families.

The activities of these units should be regularly evaluated, and hospitals are required to record the medical, medico-technical and nursing procedures performed. According to the licencing rules, this registration should show that the care provided is relevant and limited and that 'the patient's stay in the unit is short'.[190] The unit recording should indicate the patient's destination after leaving the unit.

Some Sp4 also organise activities for families (e.g. relaxation, massages).

Infrastructure

Sp4 beds can be spread over several hospital wards or form a distinct and identifiable architectural entity. By way of derogation from section I ("Architectural standards"), 1, a), the department may be located outside the site of an acute hospital, provided that it is the result of the conversion of C, D, H or G beds.

Sufficient floor space must be provided per bed. Rooms must be spacious and intimate, with a toilet and appropriate furniture, including a height-adjustable bed.

At least half of the rooms will be single rooms, the others may be twin rooms. The SP4 must have a sufficient number of bathing facilities to enable patients to be placed in a supine position. It also must have the following communal areas: a family room; a kitchen that is also accessible to the family and an office for the nursing team. The Sp4 must be designed in such a way that it is possible to maintain a calm atmosphere, organise meetings and look after family members. Each Sp4 should also be organised in a way that family members can spend the night.

Human resources

The unit is under the coordination of a medical doctor – GP or specialist – with an expertise in palliative care. In case of needs, it should be possible to benefit from the expertise of an oncologist, an anaesthetist, or a geriatrician, with an expertise in palliative care.

Two thirds of the nursing staff in palliative care units must be graduated / bachelor nurses. At least 66% of the graduate nurses must be nurses with the specific professional qualification of palliative care nurse. It should be planned 1.5 FTE nurse per bed.

Alongside nurses, it should be possible to benefit from the interventions of a physiotherapist, a social worker, a spiritual advisor, and consultants, including a psychologist and a psychiatrist or neuropsychiatrist.

Interdisciplinary team meetings must be held every week and a continuing education session for all healthcare professionals is planned every year for at least two days.

Each palliative care unit can also integrate volunteers in daily functioning: there are no official requirements regarding the presence of volunteers, their qualification, and their role.

Funding mechanism & financial benefits for the patients

The costs of hospitalisation are covered in the same way as any other hospitalisation: to date, there is no abolition of the co-payments or prohibition of extra billing for single rooms (Table 29).

Table 29 – Overview of the financial benefits for patients in need of palliative care at hospital

Palliative lump sum	⊘
General practitioner's visits **No co-payment for visits**	Not applicable: this care is delivered as part of hospital care
Nursing visits **No co-payment for specific palliative care services**	
Physiotherapist visit **No co-payment for specific palliative care provisions**	
Oxygen therapy (short term) **Entirely reimbursed**	
Oxygen therapy (long term) **Reimbursed under the condition of the NIHDI convention**	✓
Support of a multidisciplinary support teams for palliative care **Entirely reimbursed**	✓ **

*** In some hospitals, the palliative function includes a hospital mobile team supporting palliative care in other, non-palliative, hospital units.*
Source: Table retrieved and adapted from Ricour et al. 2023, page 23[13]

Textbox 10 – Coda, a unique palliative care model in the Belgian landscape

Building up on her professional experience at the Klina hospital in Brasschaat, Adrienne Kenis developed the project Coda, after facing a confronting experience. One of her patients, living in a nearby village, expressed her wish to die at home with dignity instead of dying at the hospital: Adrienne took her home and guided her through the end of her life. This decision leads her to develop a palliative care model based on the idea of organizing palliative care in a homely atmosphere. Supported by the Klina Hospital, Dr Van Peel from Kalmthout, Dr Van Imschoot from Loenhout and her ex-husband, Adrienne Kenis was allowed to use an old farmhouse near the monastery of a catholic congregation in a rural environment with a surrounding forest and fields. In February 1996, Coda Hospice was able to open with 6 beds.

Currently, Coda is an umbrella organisation that includes a palliative care unit with 8 Sp4 beds (part of the palliative function of Klina), a palliative day care centre, a CADO (collective autonomous day care), a bereavement service, and an outreach multidisciplinary support team (MBE). The equipment allows for the delivery of complex care like in SP4 unit in a hospital building. Specifically for the Sp4 beds, patients have to have an estimated life-expectancy of around 3 months. All age profiles are admitted, at the exception of patients already in a nursing home. The average length of stay is around 16 to 18 days.

Coda is the host place of the palliative care network *Palliatieve Zorg Noorderkempen*. They also have local service centre (*dienstencentrum*) with a café, a LEIF-Point, providing information and support for patients, informal caregivers, and volunteers. This centre also offers training and support for informal caregivers. Coda has a partnership with *Handicar* and *de Minder Mobiele Centra* for travel accommodations to the day care centre. Additional activities are organised in partnership with the municipality and the *Eerste Lijn Zones*. This model of "all services under the same roof" appears to be quite unique in the Belgian landscape of

palliative care and is perceived of added value for the continuity of care for the patients and the entourage.

Because of these multiple activities, Coda relies on different forms of fundings. A stay in the residential unit follows the funding rule for a stay in a palliative care unit (Sp4), with out-of-pocket expenses for the patients (in 2023: 38 € (first day) + 16-18 €/day for next days). Activities of the day care centre are covered by the Flemish government (Fp lump sum), as well as the activities of the outreach multidisciplinary support team and the palliative care network. Other activities, such as bereavement care, are funded through own fundings gained via fundraising events or charities.

More information on Coda (in Dutch): https://coda.care/palliatieve-zorg

4.3.6 *Emerging initiatives in palliative care outside a regulatory framework*

In the current Belgian landscape, additional initiatives emerged to fulfil the unmet needs of patients in palliative care. The common dimension in these initiatives is that they are currently not integrated in an existing regulatory framework, contrary to the above-mentioned services.

Available offer

Six initiatives corresponding to this situation were identified across Belgium. Three of them are currently functioning (*Zorghuis Ostende, Zorghuis Koersel* and *Pass-Ages*) while 3 others are still under development (*l'Autre Maison, la Maison Coquelicot* and a project supported by the palliative care network of the province of Luxembourg). *Zorghuis Oostende* (2009), *Zorghuis Koersel* (2016, and *Pass-Ages* (2020) are citizen-based initiatives, either because of a personal experience of end-of-life, either because of personal convictions. *L'Autre Maison*, la *Maison Coquelicot* and the project in the Luxembourg province are at the initiatives of healthcare professionals – supported by citizens and volunteers -: an outreach multidisciplinary support team, a palliative care network and a hospital, aiming at better meeting the needs of their patients. These initiatives are all supported by charities and other non-profit organisations, e.g., the 2 *zorghuizen* are financially supported by *Kom Op Tegen Kanker* while the *Fondation Ginette Louviaux* is involved in the development of initiatives in Wallonia.

From the interviews, it appears that a common feature across these different initiatives is the observations made by citizens and / or professionals that the current offer does not meet the needs of the patients in need for palliative care. Among those unmet needs were pointed: the lack of possibilities for respite care, the absence of facilities for active adults, the lack of palliative residential structures in the area and the need for flexible support allowing to preserve social network and occupations.

Each project also looked for inspiration sources to further develop their idea. For example, one project was inspired by different existing initiatives at international level such as the palliative houses in Canada (3 months of stay), by a palliative initiative *La Maison de Gardanne* in Aix-en-Provence (France) and by a palliative house in the city centre of Nantes. They also considered existing Belgian initiatives: the *Villa Indigo* which offers respite stay for families and children with severe diseases and *La Vie-là*, a house for patients with cancer.

Textbox 11 – Villa Indigo: a respite offer for families of children suffering from serious illnesses

The Villa Indigo project was born out of the realisation that the families of children and teenagers suffering from serious illnesses are very exhausted, and that they need to be offered moments of respite outside the immediate family circle. A child's illness has a major impact on the whole family and those around them. Often, dealing with the illness requires a total commitment from the family, day and night, throughout the years. Care is provided by a multidisciplinary team present 24h/day. On medical advice and with the agreement of the sickness funds, Villa Indigo offers two types of care: residential care (one or more nights) and day care (between 1 and 5 times a week from Monday to Friday, and outside weekends and school holidays).

Information retrieved and adapted from: https://villaindigo.be/notre-offre/

Textbox 12 – La vie-là: supporting patients after cancer

Close to the hospital, *La Vie-là* is accessible during cancer treatment and during the following year: it offers various activities, psychological and spiritual support. Everything is managed by volunteers with a symbolic financial participation.

Information retrieved and adapted from: https://www.lavielaottignies.org/

One project started from the three models of the report of the Federal Cell but decided to think creatively and make their own model to better fit the realities. They mentioned that there is a need for alternative care models (e.g. shared housing models): they then crossed the different models of the Federal Cell to make their own. They also reported that nursing homes have their limits when it comes to taking care of people with needs in palliative care. They explained that their project aims at filling the link missing in the current offer for palliative care. To them, the missing link takes the form of a residential structure.

Care offer

Zorghuizen mostly aim at supporting patients during or after their cancer treatment: it is not directly aiming at patients in needs of palliative care: they are considered as low care facilities as there is no specific palliative care delivered in the settings. Patients can still receive care from their usual healthcare professionals, as part of home care. Therefore, from the interviews, it appeared that patients needed to have a certain level of autonomy as there was no permanent presence of professionals. This also implied that the patients could not elect the *zorghuizen* as place of death.

From the interviews, the three other initiatives under development were more positioned as health care facility where there is possibility for receiving generalist or specialist palliative care (e.g. support from the outreach multidisciplinary support team). These initiatives are intended for patients in palliative situations, with or without a social network to support them, and can be elected as place of death (and, if the person expresses the wish during the stay, euthanasia could be possible). Having a palliative status was envisioned by some initiatives as an admission criterion (but not the imminence of death or the “last month of life”).

All these initiatives were aiming at respite care and therefore are / will be organised to ensure that families and relatives can spend quality time, with some privacy, with the patients.

Human resources

The *zorghuizen* have a salaried coordinator, the rest of the staff being volunteers. In the initiatives under development, the overall idea was combining volunteer work for the daily and occupational activities and professionals for the health care delivery.

Infrastructure

In all the interviews, the respondents stressed the need for a warm and cosy environment: this was the case in the *zorghuizen* and the initiatives under development were also thinking about finding a place where nature is surrounding the facility. It was therefore raised, by a respondent, to pay attention to the insertion of the facility in an easy-to-reach area and to the visibility of the service. Keeping it “hidden” was perceived as counterproductive as one idea was also to contribute to a better visibility of the palliative care. As also mentioned by other respondents in the interviews, these “alternative” should also contribute to the demystification of death and palliative care. To this aim, some envisioned offering the possibility to welcome activities with the neighbourhood on the premises of the facility.

4.4 The volunteers, a must-have in the field of palliative care

Site visits evidenced the key role played by volunteers when it comes to palliative care, whatever the service or the complexity of the care provided. Based on the experiences of the respondents, it appears that these volunteers are often driven by a personal loss of a relative. It is also interesting to mention that it seems that organisations can rely on an important number of (retired) healthcare professionals as volunteers. To date, it is not therefore possible to depict a clear overview of the profile, number and missions of volunteers active in palliative care but, with some exceptions, in almost all the services that we met, these volunteers appear to be indispensable to ensure the quality of care.

Some organisations had more than 150 volunteers at the moment of the visits. All volunteers undergo an intake process, are trained (internally or externally i.e. in Brussels, training is done by Brusano, the palliative care network) and are covered by an insurance of the organisations. Usually, the organisation requires a minimum of weekly involvement to facilitate their integration and the continuity, especially for those with direct activities with the patients. It also appears that most of the organisations formalise the involvement through a "contract" with the volunteers.

Volunteers, as explained by respondents, have a complementary role alongside the professionals as they can endorse tasks and missions for which the staff has not enough time. As pointed by a respondent during a visit, a lot of tasks in palliative care can hardly be done by paid professionals as these tasks would be too expensive (e.g., talking and socializing with the patients, staying up all night to hold a hand).Moreover, as explained by a respondent in an emerging initiative, as volunteers are trained, they may use these skills for their own families and relatives and then contribute to the quality of life when these relatives are in need of accompaniment.

Overall, volunteers mostly play a role in the psychosocial, spiritual and emotional support: ensuring a presence, providing spiritual comfort according to the beliefs of the patients, taking the person for a walk with the wheelchair…Not all volunteers directly intervene at the patient bedside as they can contribute to various tasks and activities aiming at contributing to the warm and cosy environment by taking care of flowers, decoration, charity events…Usually, activities performed are chosen by the volunteers, sometimes also taking into account their profile (e.g. kitchen help, healthcare professional, gardener, previous informal carer). In one organisation, the respondents explained that they do not encourage the direct contacts with the patients as it may be too difficult to bear. Activities can address all the patients (e.g. making waffles or crepes) or be provided in a one-to-one interaction (e.g. playing a board game).

From the interviews, we also found that volunteers also participated in the activities of the outreach multidisciplinary support team. As explained, volunteers always work in pair with a nurse: they never go to see a patient if there is no previous contact with a nurse, but they can also intervene once the patient is deceased to support the family. Additionally, outside the palliative care sector, some municipalities organise volunteer services of caregivers – such as the *thuisoppasdiensten*[r] or the *Baluchon Alzheimer*[s]- where volunteers can stay at home with the patients when the family cannot do it. Depending on the services and the sickness funds of the patients, these services are free of charge or (partly) reimbursed.

Volunteer work is entirely free: depending on the services, volunteers receive a meal, the reimbursement of their travel expenses or a financial intervention for the training. No uniform approach was found between the different facilities and projects. Similarly, various practices were observed to cover these expenses and the equipment needed to organise activities (e.g. charities, punctual subventions from public authorities, donations, internal budget of the institutions…).

[r] More information on *thuisoppasdiensten* (in Dutch): https://www.oud-heverlee.be/product/204/thuisoppasdiensten

[s] More information on Baluchon Alzheimer (in French): https://baluchon-alzheimer.be/

During the site visits, this key role of volunteers particularly emerged in the non-medicalised projects as Pas-Ages, the *Zorghuizen* and emerging projects in Wallonia. For example, in Pas-Age, they explained that they first envisioned to work only with volunteers, but they decided to have a permanent staff member to ensure the continuity of work. Similarly, when presenting the project *L'Autre Maison*, respondents explained that they already have positive experience with volunteers as part of the activities of the mobile palliative care team. This is why, in this new project, volunteers are expected to ensure the presence at the bedside and to offer support in daily activities (not for health care).

4.5 Discussion

Belgium has already a quite developed offer when it comes to palliative care in comparison with other countries (see Chapter 5). Both generalist and specialist care are offered to patients, relying on the expertise of interdisciplinary teams in residential and ambulatory settings. The transfer of the competences after the 6th State Reforms lead to various approaches to palliative care across the different regions: therefore, this can also be seen as an opportunity to better integrate the needs and the resources at micro and / or meso levels. But, despite this apparent extensive and complete offer, gaps and problems can occur: these aspects will be developed in the Chapter 6.

5 HOW IS PALLIATIVE CARE ORGANISED AT INTERNATIONAL LEVEL?

- ✓ Three levels of palliative care are distinguished: the palliative approach, the generalist palliative care and the specialised palliative care.
- ✓ Two main aspects allow to identify the level of palliative care delivered by a palliative care service: the training of the providers and the proportion of working time devoted to palliative care.
- ✓ The WHO identifies 6 types of specialised PC services: inpatient palliative care units, inpatient hospice, hospital palliative care support team, palliative care outreach team, day hospice or care centre, and palliative care outpatients clinics.
- ✓ The term 'Palliative Middle Care' is not used at international level in the scientific literature on palliative care services organisation. However, the term 'hospice' is used recurrently.
- ✓ The organisational models of 'Palliative Middle Care' services proposed by the Belgian federal cell of palliative care evaluation share similarities with the inpatient hospice services. Inpatient hospice services function as a link between hospital palliative care and generalist palliative care delivered at home.

'Palliative Middle Care' should deliver specialised palliative care service rather than an intermediate level that is difficult to distinguish from general palliative care services. It could deliver technical care or hospital treatment outside a hospital building, as in France and the United Kingdom. It would be more akin to residential care, with similarities to nursing homes, which combined living and caring aspects. The ideal Palliative Middle Care' model would be able to manage unstable (or crisis) situations, as in the Dutch system.

5.1 Aims of the international comparison

When it comes to improve the organisation of health care services at a country level, international recommendations and examples from foreign countries help to give a framework and to learn from other experiences in developing or improving a health care organisation. For palliative care services organisation, WHO has published in 2016 a clear framework on which state members are invited to align if appropriate. The European region also benefits from guidelines adapted to the European context. Border countries of Belgium are currently developing their own palliative care services organisation. Although each country evolves in its own context of care system, comparing the characteristics of palliative care services with each other and between countries allows to identify strengths and weaknesses faced by one or another and to learn from others experience. **This chapter first describes international recommendations to compare Belgium palliative care services organisation with the theoretical framework and analyses the place of PMC within this framework. Secondly, it presents a comparative analysis of palliative care services organisation between five countries**: **The Netherlands, Germany, the United Kingdom, France and Belgium. Those two analysis aim finally at the identification of criteria allowing to distinguish palliative middle care services from other types of palliative care services.**

5.2 Current international recommendations to organise a global palliative care offer at a country level

5.2.1 Categories of palliative care services

Table 30 presents the WHO classification of palliative care services according to care situations and providers training, whether professionals or volunteers.[2] Three care situations are distinguished: the ambulant care for those who live at home, the residential long-term care for those who live in community because of their functional limitations and the residential acute care for those whose health state is acutely impacted and requires immediate and intensive care.[2]

Internationally, the usual approach is to divide palliative care in two levels of care: non-specialist and specialist palliative care. Specialised palliative care services are organised in interdisciplinary teams, with advanced training and full dedication on relieving the serious health suffering that is associated with life-threatening conditions or the end of life.[5] According to the level of training in palliative care of the professionals or volunteers, non-specialist palliative care is also divided in two levels: generalist palliative care delivered by professionals and volunteers with a mid-level training and palliative care approach that can be delivered by professionals and volunteers with basic training (Textbox 13). For its part, specialist palliative care are divided in two levels according to the assigned mission. On the one hand, services where specialised professionals or volunteers give advice and support to non-specialist professionals or volunteers represent one type of specialised services. On the other hand, services where specialist professionals deliver front-line care represent a second type of specialised services. In both types of services, specialist palliative care should always be delivered by fully trained professionals and volunteers (Textbox 13).[2]

In the perspective of caring the extended target population to palliative care (i.e. not only the dying persons but also the people living with SHS due to life-threatening condition), a major part of palliative care will be provided by non-specialist professionals or volunteers. Services or professionals working on their own that are not specialised in palliative care will use the palliative care approach or deliver generalist palliative care, even when done by one professional category (see section 1.4.1 in the Chapter 1). Consequently, non-specialist professionals must have easy access to specialist consultation for advice and support.[14]

Table 30 – Categories of palliative care services according to the World Health Organisation

	PALLIATIVE CARE				
	Non-specialist palliative care		Specialist palliative care		
	Palliative care approach	**General palliative care**	**Specialist support to non-specialist providers**		**Front-line specialist palliative care**
Residential acute care	General inpatient service	Geriatrics unit, Oncology unit	Community-based /volunteer hospice team	Hospital palliative care support team	Inpatient palliative care unit
Residential long-term care	Nursing home, Residential home	Palliative care referent		Home palliative care team,	Inpatient hospice
Ambulant care	GPs, Community-based / ambulatory nursing service	Experienced GPs Community-based / ambulatory nursing services		Palliative care clinics, Day care centre	Home palliative care team (incl. services delivering hospital at home), Palliative care outpatient clinics, Day hospice

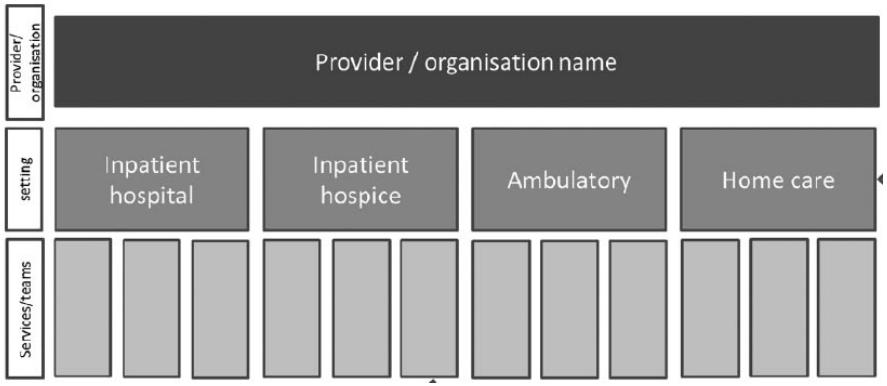
Source : Table adapted from WHO, 2016[2]

Textbox 13 – Levels of training in palliative care according to the World Health Organisation

Different levels of training in palliative care correspond to the different levels of care. WHO recommends in its 2016 guide, 3 to 10 days of palliative care courses for doctors and nurses to obtain a basic level. Community health workers and volunteers should follow minimum 3 hours introductory palliative care course to obtain a basic level in palliative care, covering communication skills, emotional support, patient assessment and reporting to higher level. Basic training in palliative care allows to develop a palliative care approach. To deliver generalist palliative care, doctors and nurses should follow at least 6 weeks of residential courses while community health workers should be trained to palliative care during at least 400 hours and volunteers during 16 hours + 4 clinical sessions, covering communication skills, emotional support, patient assessment, basic nursing tasks, home care, basic of symptom management and reporting to high level. Those courses allow to get a mid-level training. To get an advanced level and delivering specialist palliative care, doctors should obtain a fellowship/postgraduate qualification in palliative care (1 to 3 years), nurses a certificate course of 4 months or a fellowship of 1 year. Community health workers should be trained to advanced communication skills and lymphoedema management, and volunteers to advanced communication skills and train-the-trainer course.[2]

While the WHO has defined all levels types of palliative care services (palliative approach, generalist and specialist palliative care), Firth and colleagues have developed a template to describe the different types of specialised palliative care services within an institution in the UK. Figure 14 enables any specialist palliative care organisation in the UK to determine its organisational model.[192] This tool shares similarities with the categorisation proposed by the WHO for the part devoted to specialised palliative care services. A difference is the categorisation into 4 settings instead of 3: inpatient hospital, inpatient hospice, ambulatory and home care.[192]

Figure 14 - Tool for defining the specialised palliative care services in an organisation



Source: Figure retrieved from Firth et al. 2019[192]

5.2.2 *Different kinds of specialised palliative care services: international norms and standards*

Specialist palliative care delivery requires a multiprofessional team with an interdisciplinary work style. The core palliative care team should consist of nurses and physicians with special training as a minimum, supplemented by psychologists, social worker, and physiotherapists if possible. Other professionals can be members of the core team or be punctually associated to the care according to needs. Those can be professionals skilled in psychosocial support and/or bereavement support, dieticians, pharmacists, wound management specialists, coordinators for spiritual care and/or for voluntary workers, chaplains, and adequate number of office workers. Specialised palliative care services should include volunteers or collaborate with volunteer services.[14]

The EAPC Board of Directors has recommended, based on a recent European experts' consensus (2022), standards and norms for each kind of specialised palliative care services. Table 31 presents a summary of these standards and norms that will be detailed in the next sections.

Table 31 – Summary of standards and norms of specialised palliative care services

	Standard	Norm
Outreach palliative care teams	Minimum 4 to 5 FTE of specialist nurses and physicians + 1 social worker + administrative staff	1/100 000 inhabitants
Hospital palliative care support team	Minimum 1 physician and 1nurse specialised in PC	1/general hospital
Inpatient palliative care units or hospice	Minimum 8 beds, 1 to 1.2 nurses/beds	1/100 000 inhabitants
Day centre and day hospice	Minimum 2 FTE health or social care professionals with at least 1 trained in PC	1/100 000-150 000 inhabitants

5.2.2.1 Inpatient palliative care units

Palliative care units (PCU) provide specialist inpatient care. A palliative care unit is a place specialised in the treatment and care of palliative care patients. It usually is a ward within or adjacent to a hospital but can also exist as a stand-alone structure. In some countries palliative care units will be regular units in hospitals, providing crisis intervention for patients with complex symptoms and problems, in other countries PCU can also be freestanding institutions, providing end-of-life care for patients where home care is no longer possible. The aim of palliative care units is the alleviation of disease- and therapy-related discomfort and, if possible, to stabilize the functional status of the patient and offer patients and relatives psychological and social support in a way that allows for discharge or transfer to another care setting.[14] A palliative care unit first aims to improve patient outcomes. The on-site availability of various specialities and diagnostic/technical procedures makes the care more comprehensive and makes it easier to control symptoms. PCU also facilitates the discussion of the patient's values, diagnosis, prognosis, and agreement about the goals of care. A PCU, in fact, generally reduces a patient's length of stay in hospital and enables a smooth transition to care in the community.[2] The EAPC Board of Directors recommends, based on the recent European experts consensus (2022), as aspirational norm and standard, that there should be 80-100 PCU and hospice beds per 1 000 000 inhabitants. Using an 8-12 bed PCU as an example, this would correspond to 8-10 PCUs per million inhabitants. However, this estimation should also consider local demand and institutional structure. PCUs require a highly qualified, multidisciplinary team. Staff members in palliative care units are supposed to have specialist training. The core team consists of physicians and nurses. The extended team comprises relevant associated professionals, such as psychologists, physiotherapists, social workers, or chaplains. There should be regular multidisciplinary team meetings (minimum weekly) to review palliative care patient's referrals and care plans. Qualified nursing staff should encompass a shift ratio of at least one nurse per bed, and preferably 1.2 nurses per bed. PCUs require 1 physician with special training per 5-7 beds. PCUs should offer a homelike atmosphere with quiet and private areas. They should be separate areas with a capacity of 8 to 15 beds. The units should be equipped with single or double patient rooms, facilities for relatives to stay overnight and rooms for social activities, such as kitchens or living rooms.[14]

5.2.2.2 Inpatient hospice

An inpatient hospice admits patients with palliative care and end of life care needs when treatment in a hospital is perceived as not necessary or desired, and care at home or in a nursing home is not possible. An inpatient hospice requires a multiprofessional team that cares for patients and their relatives using a holistic approach. Qualified nursing staff should encompass at least one, preferably 1.2 nurses per bed. A physician specialised in palliative care

should be available 24 hours a day and be on site within 30 minutes. There should be dedicated input from healthcare professionals that can provide support for the patient's physical, psychosocial, and spiritual needs. A team of volunteers should support the staff. An inpatient hospice requires a homelike atmosphere with access for people with disabilities, single or double patient rooms and a capacity of at least eight beds. The hospice should be equipped with rooms for social and therapeutic activities.[14]

5.2.2.3 Hospital palliative care support team

Hospital palliative care support teams provide specialist palliative care advice and support to other clinical staff, patients, relatives and informal caregivers in the hospital environment. They offer formal and informal education and link with other services in and out of the hospital. One central aim of a hospital palliative care support team is the assessment of palliative care needs and alleviation of symptoms of patients on different hospital wards. Also, the team offers mentoring of the regular staff and support to patients, their relatives and their informal caregivers. The team educates other staff on pain management and palliative care. The aims of a hospital palliative care support team are the improvement of palliative care in their institution and to foster discharge from an acute hospital unit by facilitating the transfer between inpatient and outpatient care. A hospital palliative care support team should be affiliated to every PCU and should be available for every general hospital. There should be at least one team available for a hospital with 250 beds. A hospital palliative care support team is composed of a multiprofessional team with at least one nurse and one physician with a training in specialist palliative care. The team should have a room for staff meetings and administrative support at its disposal.[2, 14]

5.2.2.4 Palliative care outreach team

PC outreach team is a mobile service that brings care to patients who are not able to travel to seek treatment. This kind of service requires little infrastructure. The important features of an outreach service is that it harnesses the strengths of family caregivers.[2]Two kind of outreach teams are described: home palliative care team and community/volunteer hospice team.

Home palliative care team

Home palliative care teams provide specialist palliative care to patients who need it at home and support to the relatives and informal caregivers at the patient's home. They provide specialist advice to general practitioners, family physicians and nurses caring for the patient at home. The home palliative care team also assists the transfer between hospital and home care. There should be one home palliative care team available for 100 000 inhabitants. The team should be accessible 24 hours a day. The core team of a home palliative care team consists of 4 – 5 FTE professionals and comprises nurses and physicians with specialist training, a social worker, and administrative staff. The home palliative care team works in close collaboration with other professionals so that the full range of multiprofessional teamwork can be realised in the home-care setting. Home PC team collaborates with other professional services, such as specialised nursing services and general practitioners. Their activities include regular meetings at the patient's bedside with all people involved. The home palliative care team requires a working room at its disposition for nurses, physicians and social workers, as well as a meeting room and a storage for medical equipment and supplies.[14]

Community/volunteer hospice team

A volunteer hospice team offers support and befriending to palliative care patients and their families. The volunteer hospice team is part of a comprehensive support network and collaborates closely with other professional services in palliative care. Rates of volunteering vary significantly across Europe due to cultural, financial, and institutional reasons. As a result, norms and standards vary. The EAPC suggests that a volunteer hospice team providing direct support should consist of at least 10 to 12 hospice volunteers and one dedicated professional (or volunteer) coordinator. The coordinator should have expertise in the social- and/or health sector with additional specialist training in palliative care. The volunteers should have participated in an accredited instruction course and take part in regular supervision and self-reflection, as well as continuing education.[14]

5.2.2.5 *Day hospice and day care centre*

Day hospice and day care centre are spaces in hospitals, hospices, palliative care units or the community especially designed to promote recreational and / or therapeutic activities among palliative care patients. Central aims are social interaction and therapeutic care, to avoid social isolation as well as to relieve the burden of care on relatives and caregivers.

A day care centre is defined as a centre specialising in holistic and psychosocial palliative care. It is staffed by a multiprofessional team supplemented by volunteers with at least two health or social care workers present during opening hours. One of them is a palliative care specialist professionals able to assess patients and who can seek further medical assistance if required. A qualified physician should be directly accessible in case of need. Direct access to other professionals, such as physiotherapists, social workers, or spiritual care workers, is planned. A day care centre is a unit with a minimum of four places. It is preferably composed of patient rooms, a therapy room, staff rooms, a bathroom, a kitchen, and a recreation room. All rooms should have access for people with disabilities. A day care centre may be associated or located within an inpatient hospice, palliative care unit or other care facility.

A day hospice is defined as a palliative care centre providing specific medical management/treatment. It offers stabilisation of symptoms, respite care, counselling of both patient and families. It also deals with longer technical procedures such as draining ascitic fluid and wound care, as well as injections. There should be a day hospice available for 100 000 to 150 000 inhabitants.[2, 14]

5.2.2.6 *Palliative care outpatients clinics*

Palliative care outpatient clinics are an important component of a community palliative care programme. Usually, outpatient clinics are affiliated to PCUs, inpatient hospices or specific community services. These aims to provide continuity and support to those living in the community. Care can be provided by a nurse, social worker, or doctor or ideally a team including all three. Psychologists and spiritual counsellors also perform important roles in some settings. Patients may be referred to the clinic for pain management, symptom control, nursing needs or psychosocial support. However, patients must be mobile to attend the clinic. Palliative outpatient clinics should be integrated in regional networks, in order to coordinate with inpatient services, home palliative care team or the primary care team.[2, 14]

5.2.3 *Access to palliative care services*

It is important that palliative care should not be considered as something that only hospitals can do. It can be provided in any healthcare setting and also in patients' homes and can be successfully implemented even if resources are limited.[3] Palliative care services should be available to all patients, wherever and whenever, without delay. In 2022, the EAPC recommended that the equity of access to PC should be guaranteed, assuring provision of PC according to needs and regardless of cultural, ethnic or other background.[14] Access to high-quality palliative care should not depend on the ability of patients or informal caregivers to pay. Considering the reduced life expectancy of palliative care patients, fast-tracking care pathways should be implemented in medical services, ensuring adequate priority for these patients, to prevent disproportional burden from lost time.[14] There should be unrestricted open hours for the relatives of dying patients. Opioids and other essential medicines routinely used in palliative care should be available in all settings. Specialist equipment (e.g. anti-decubitus mattresses, aspiration material, stoma care, oxygen delivery, special drug hospital beds) should also be available for the care of palliative patients in each specific setting.

5.2.4 *Coordination of palliative care services*

Palliative care networks are networks integrating a broad spectrum of institutions and services in a delimited healthcare services area. A network is not only a list of providers but is defines by the effective coordination which exist between them. The mission of the network is to improve access to palliative care and increase quality and continuity of care. There should be at least one PCU within each network. Effective coordination within the network is best achieved with a case manager who can transfer information and support continuity of care across different settings. To be effective, these coordination services must be available 24 hours a day, 7 days a

week. Coordination can be accomplished by a team or a person. An effective coordination of services will allow a higher proportion of people to die at home if they so wish. The network has different missions: (i) to define consensual definition of goals and quality standards; (ii) to uniform criteria for admission and discharge at all levels of care; (iii) to use common evaluation methods; and (iv) to implement common therapeutic strategies based on available evidence.[14]

Patients and their relatives should have access to a national directory of palliative care professionals, local caregivers and other relevant organisations that can have a role in palliative care. All palliative care services should have a website. There should be a process to support the exchange of information across professionals, disciplines, and settings. All professional caregivers involved in the care of palliative care patients should have access to the digital patient health record whatever the care setting.[14]

5.3 Place of palliative middle care services in the global palliative care context

5.3.1 Hospices versus palliative middle care services

An aim of this report is to define what should be Palliative Middle Care services in Belgium. When looking at the description of international categories and norms and standards of palliative care services given above, the term PMC is not used once. Indeed, as explained in the introduction of this report (section 1.4.1), the term Palliative Middle Care is not used at the international level. And when looking at the KCE scoping definition of PMC given in the introduction, one can wonder to which types of palliative care services PMC services can be assimilated.

- Palliative Middle Care: "*any service (could be a provider -volunteer or professional, or a structure embedded several providers) delivering palliative care (generalist or specialist) which is not a community-based front-line service composed of provider(s) not trained in palliative care (palliative care knowledges acquired during basic cursus are not considered as a training in palliative care) and not a hospital-based palliative care service composed of provider(s) specialised in palliative care" (see section 1.4.1).*

The term 'hospice' used recurrently in the international description in previous sections seems to match with the scoping definition of Palliative Middle Care service chosen as starting point of this project. Indeed, some similarities can be found with the definition of a hospice given by the EAPC:

- Hospice: "*a stand-alone facilities providing palliative care outside hospitals, present more frequently in Anglo-Saxon countries. The hospice concept almost always designates an intermediate care resource between the hospital and the home*."[5]

So, the definition of a hospice is close to the KCE scoping definition of PMC as both concepts of services (PMC and hospice) provide palliative care outside hospital setting. The exclusion of services delivering a palliative care approach (basic trained providers) is also common to both concepts. But the stand-alone aspect of a hospice differs from the scoping definition of PMC.

While looking at the concept of PMC[20] as described by the Federal Cell (see Textbox 1), and by contrast with the KCE working definition of PMC, PMC services designated inpatient hospice services. So even when focusing on the more limited definition of the Federal Cell, the hospice concept still matches to PMC concept. A deeper analysis of what hospice means theoretically at the international level and in other border countries to Belgium is led in the following sections to better understand the possible match between PMC and all aspects of hospices.

5.3.2 International history of hospices

Palliative care hospices have a rich international history that spans several decades. The current hospice movement originated in the mid-20th century and has since then evolved and expanded across the globe. The hospice movement can be traced back to the efforts of Dame Cicely Saunders, a British physician, in the sixties.[193] She established Sint Christopher's Hospice in London in 1967, which became a pioneering model for the holistic care of terminally ill patients. Saunders emphasized the importance of pain management, emotional support, and spiritual care in addition to medical

treatment. The success of Sint Christopher's Hospice led to the establishment of numerous hospices across the United Kingdom. These hospices provided palliative care (almost) free of charge to patients and their families. The concept of hospice care gained recognition and support from the British government, leading to the creation of National Health Service (NHS) hospices. Differences between hospice care and palliative care are tenous, and mainly concern the disease phase during which the care are delivered: the end of life for hospice care and the moment a disease is categorised as non curable for palliative care (Textbox 14).

The hospice movement gradually spread to other countries[194], with various organisations and individuals that adopted the goals and approaches of palliative care. In the 1970s and 1980s, hospices were established in a lot of regions such as the United States, Canada, Australia, and also in Europe, following the British model. These hospices focused on providing comprehensive care for patients with life-limiting illnesses, aiming to improve their quality of life and alleviate suffering. Recognizing the importance of palliative care, the WHO has played a significant role in promoting and advancing the hospice movement. In 1990, the WHO published its first guide on palliative care, encouraging member states to integrate palliative care into their healthcare systems.[8] This guide served as a catalyst for the development of hospices in many countries. Hospice and palliative care models have been adapted and tailored to suit the cultural, religious, and healthcare systems of different countries but the basis principles always remained the same.[195]

Textbox 14 – Definitions of hospice care and palliative care

Hospice care: Hospice Care is for the whole person, aiming to meet all needs - physical, emotional, social and spiritual. At home, in day care and in the hospice, hospice care providers care for the person who is **facing the end of life** and for those who love them. Staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice, striving to offer pain relief, dignity, peace and calm.[14]

Palliative care: Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological, and spiritual **problems** is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the **best possible quality of life until death**.[14]

5.3.3 International description, norms and standards of a hospice

The following theoretic description of what a hospice should be is extracted from the guide for programme managers published in 2016 by the WHO on how to plan and implement palliative care services.[2] In this guide, a hospice is defined as a stand-alone centre delivering the basic elements of palliative care (medical, nursing, psychological, social and spiritual support) in which the level of care depends on local resources, availability and capabilities of staff, and their training. The scope of the care depends on the target group of patients. As such, the care provided may need to include financial support and basic necessities, such as food, utilities, mobile telephone, travel subsidy and the lending of equipment. The reader should be careful that this worldwide definition is quite different from the European definition given by the EAPC (see section 1.4.). According to worldwide guidelines, the different services that a hospice can provide are (i) hospice home-care service; (ii) hospice inpatient service; (iii) hospice day-care service; (iv) education centre; and (v) research centre (Textbox 15).[2]

Textbox 15 – Types of hospice services according to the World Health Organisation, 2016

Hospice home care service: Patients are cared for by their families at home. The hospice team visits patients to provide medical care, nursing advice and psychosocial support. A 24-hour telephone support service is essential. A nurse is often the main care manager, calling in any member of the interdisciplinary team when needed. The nurse has special training

in symptom assessment and case management in addition to nursing expertise.

Hospice inpatient service: Patients receive care while staying in the hospice. The level of care depends on the capabilities of the staff, and how the hospice is viewed in the spectrum of healthcare services. This may range from highly skilled medical and nursing care (similar to those hospitals but in a more peaceful environment) to very basic medical care with the hospice acting as a shelter for terminally ill patients with no home or informal caregivers. Staffing is mainly a nursing staff with different levels of expertise, present 24 hours a day. Nurses will form the largest group of the interdisciplinary team.

Hospice day-care service: Patients stay in their own homes and travel to the hospice centre during the day for medical consultation, nursing care, rehabilitation and/or social activities. This service is possible only if the patient is sufficiently fit to travel. An outpatient clinic may be added to the day-care service. An occupational therapist, a physiotherapist or a nurse manager may manage a day-care service.

Source: World Health Organisation, 20162

Each hospice needs clarity on the profile of patients that it will accept to determine the type of care to provide. The focus of the hospice may be on a type of disease (HIV, cancer, chronic life-limiting conditions), the prognosis or the needs whatever the prognosis, the issue (death or discharge after stabilization), the geographic zone (particularly for hospice home-care service), the socioeconomic condition of the patient (e.g. priority on the very poor and the homeless) or the allowed duration of family members presence (full stay to limited visit time).[2]

When planning to set up a hospice, it is important to be clear whether essential medications (including oral morphine) are available, and whether long-term funding (public and private) can be assured. The systems for referrals and management of information must be planned. And integration of care between the hospital, hospice home care, inpatient care and day care is essential. Attention must be given to patients pathway, easing the transition from one service to another, so that no patient is overlooked.[2]

The best mix of paid staff and volunteers must be analysed before implementing a hospice. The amount and level of input from different disciplines to form the interdisciplinary team will depend on the care envisaged and the availability of staff. To attract enough volunteers, it is important to conduct publicity and promote community involvement in the hospice activities. In addition, as staff need special training, it is necessary that providers can access continuing education. The amount of medical input may depend on the resources available. It may be provided either by a specialist in palliative care or by GP with training in palliative care. As it is difficult to recruit and retain highly trained palliative care specialists, agreements for staff from hospital palliative care services may be necessary.[2]

Social workers; occupational, physio- and speech therapists; and counsellors are core members of the interdisciplinary hospice team (part-time or full-time). They will require training in handling patients with advanced disease whose conditions are expected to deteriorate and where the aim of care is to maximize function and quality of life.[2]

The role of volunteers must be carefully considered. Volunteers often enrich a hospice service and sometimes are the mainstay of workforce, but training and coordination are essential, so they are not without cost. Volunteers' tasks often mix care for patients, governing boards, raising funds and awareness, and helping with organisation, administration and maintenance of the hospice srevice.[2]

Financing of a hospice can arise from foundations, donations from the public, legacies, subsidies from the government and co-payment by the end-users, or a combination of these. Many hospices start off as community projects, often funded by charitable bodies, and then, for sustainability, government funding should cover part or all of the intervention provided.[2]

5.4 Comparison of the palliative care organisation in four border countries of Belgium

Over time, the importance of palliative care and hospice services has been increasingly recognized by a broad range of governments, healthcare organisations, and the general public. However, not every country or region implemented and integrated hospice services in their healthcare system in the same way. For that reason, it is interesting to analyse hospice services organisation in a few countries to gain knowledge about the advantages and drawbacks.

Four countries were selected for analysis: the Netherlands, Germany, the United Kingdom, and France (see Chapter 2 for the method). Each description includes the model of care, the type of hospice service, the providers involved, the admission criteria, the financing, and the available interventions. A focus was made on hospice inpatient services, given the absence of this type of service in Belgium. The four detailed descriptions of the PC offer with a focus on inpatient hospice services in the Netherlands, are available in the Supplementary Report, including the references documenting the sources of the extracted information.

5.4.1 Detailed analysis of palliative care offer in four foreign countries

The organisational model for palliative care in the four countries studied is broadly like the current model used in Belgium. In these four countries, palliative care is either provided by professionals who do not specialise in palliative care, or by professionals or volunteers who specialise in palliative care. So everywhere there is a generalist and a specialist palliative care offer. In each country, there is also a link between hospital care and care in the home. These intermediate services seem to take different forms and be flexible in order to meet the diversity of palliative situations experienced by the patients and their families. All the countries studied base their overall approach on the WHO definition of palliative care and therefore try, in their organisation of palliative care, to empower the patients, to take account of the four pillars of palliative care and to include relatives and families.

This section is structured in six parts. First, a comparison is made of overall palliative care policy. This is followed by a comparison of the generalist provision and the various specialised palliative care services, followed by a discussion including data from the analysis of foreign countries concerning the development of the PMC concept, at the centre of this report. Finally, a comparison of the characteristics of inpatient hospice services finalises this systematic comparison.

5.4.2 Overall palliative care policy

The Netherlands has a well-established and integrated palliative care system; palliative care becoming recently but rapidly part of the regular care process. Community-based palliative care services are well-developed, and there is a strong emphasis on involving general practitioners (GPs) in palliative care provision. Compared to most other European countries, there is a higher proportion of patients dying at home (between 30.5% and 42.6%). The focus of the Dutch government is on the collaboration / coordination between services, and innovations in care quality. The Dutch government set up *Palliatieve Zorg Nederland*, becoming *PZNL Stichting*, an platform made of a network of organisations involved in palliative care and that focuses on promoting and improving palliative care through coordinating regional PC networks and improving information exchange. Health care policy in the Netherlands foresees and finances integrated care between hospitals, hospices, and home care: consultation and coordination between care staff (including volunteers) and transmural collaboration (between community and hospital providers). The Dutch system invests in efficiency by monitoring the impact of the ongoing programmes on patients and families, on the collaborative process and on the organisational structure. The development of strategic plans (NPPZ I and II) which, as well as being implemented, are also monitored. The global evaluation of palliative and hospice care in the Netherlands is at the forefront of the palliative care movement.

In Germany palliative care provision is characterized by a dual development. Hospice care developed, almost independently of palliative medicine, as a civil society movement. While the medical corporation developed palliative medicine to relieve physical symptoms, the community

developed hospice care aimed at providing psychosocial support as psychosocial care are not publicly financed. Since 2007, the German government financially supports specialised outpatient palliative care to create synergies between the two complementary sectors (hospice care and palliative medicine). In Germany, it is estimated that 21% of the people died at home with a trend of few less death at home, compared to 6 years before, to the profit of hospices and nursing homes. Germany stands out for having a longer duration of palliative care follow-up than other European countries, which is an indication of awareness to the concept of palliative care not linked to life expectancy. In 2015 a study was conducted to evaluate outpatient and inpatient palliative care by employees and relatives of deceased patients. The assessment by the relatives was positive and largely agreed with the one of the employees. The highest satisfaction rates occurred for relatives of palliative patients with a stay of over 8 days in palliative care units.

The United Kingdom (UK) is the country where the current palliative care and hospice movement started**.** It has developed into a full medical and healthcare multidisciplinary specialism that not only focuses its expertise on symptom management of life-limiting illnesses but also in the holistic provision of comfort and support in psychological, social, and spiritual care at the end of life. Before the launch of the NHS End of Life Care Programme, research showed that most people wanted to die at home in the UK yet most, in fact, died in hospital. NHS program aiming at reducing the number of unnecessary emergency admissions and improving the skills of the workforce led to the following observations: primary care staff has the central role in establishing high quality, well-coordinated, patient-centred services and success of palliative care organisation depends on effective use of resources and good communication and coordination between professionals. The next programme of the UK government, named End-of-Life Care Strategy (EOL Care Strategy), aims to improve the PC organisation in the UK with a whole system approach of a good death, irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. It aims to enable individuals to express their preferences and make decisions about their care. Two key features can be highlighted: 1) the effectiveness of establishing a central coordinating facility providing a single point of access through which all services can be coordinated and 2) the importance of 24/7 services provision to avoid unnecessary emergency admissions to hospital. In the UK, it is estimated that 26.7% of the people died at home. This quite good proportion is reinforced by the fact that the percentage of people which had three or more emergency admissions to hospital in their last 90 days of life is lower in 2022 than every other reported year (6.2%). Inpatient hospice is usually the second most frequently chosen place to die in the UK. Older people are more likely to choose inpatient hospice than their younger counterparts although currently they are the group less likely to die there.

In France, the development of palliative care has been influenced by three legislations that have provided a legal framework for the development and provision of palliative care services. They have emphasized the importance of pain management, symptom relief, patient autonomy, and respect for patients' dignity and wishes at the end of life. The implementation of legislations has been accompanied by national plans to structure and support the development of palliative care. The fifth French national plan on the development of palliative care and end-of-life support aims to guarantee access to graduated, appropriate and local palliative care for all citizens, throughout the country and in all areas of life. In this aim, specialised palliative care professionals must coordinate with the front-line, and to provide front-line professionals with the necessary support and expertise. The graduated vision of palliative care supply supported by the government should balance the actual hospital-based organisation of PC in France where 86% of the offer depends on hospital establishments (2019 data). Graduated care is organised according to the setting of care (in an institution or at home) and to the choices of the person, also considering the level of complexity of the situation, the intensity of care required and the providers who can be mobilised. There are three levels of care: 1) level 1 corresponds to stable, non-complex situations and/or situations requiring occasional adjustments; 2) level 2 corresponds to situations of intermediate medico-psycho-social complexity; 3) level 3 corresponds to situations of high or unstable medical, psychological, and social complexity. All three levels must be accessible at home and in hospital. Statistics show that 60% of the French population die in a healthcare institution (less than 3% of these dies in a palliative care unit), 10% die in a nursing home and less than 30% dies at home. Access to palliative care in France typically involves a collaborative

process between healthcare professionals, patients, and their families. The number of steps to access palliative care services might depend on the type of service and the region or geographical distribution.

5.4.3 Generalist palliative care offer

In all the countries studied, non-specialist professionals provide palliative care either at the patient's home, at a substitute home, on an outpatient basis (the patient visits the professional but does not stay there), or during a hospital stay. This generalist provision has been little studied in this chapter, given the focus on the link between technical provision in hospital and generalist provision at home. In the four countries, generalist palliative care at home is provided by the patients' GP, the home care nurse (or a nursing care service), healthcare assistants, social workers, professionals responsible for housekeeping and informal caregivers. The healthcare professionals are considered to be able to deliver generalist palliative care as they received a mid-level PC training during their basic training, meaning to have acquired good fundamental knowledge and good basic skills in palliative care. At hospital, generalist PC are delivered by specialists like oncologists, or geriatricians.

In the Netherlands, there are groups named PaTz (*Palliatieve Zorg Thuis* – transl. palliative care at home) where the GPs and community nurses proactively discuss the expected palliative care needs of patients and their relatives with the support of palliative care consultants (experienced general practitioners, experienced geriatric specialists, or experienced home care nurses). The Netherlands stands out for its better ability to identify patients eligible for palliative care through the first line of care than other countries.

In Germany, the generalist palliative care is often focused on maintaining the physical functions by performing or providing assistance with personal hygiene, dressing or administering medication. The care delivered does not always cover psychosocial needs, information for the family members or social interactions. Generalist palliative care services can struggle to ensure 24-hour pain management or to provide the necessary technical medical services during the process of dying.

In the UK, generalist palliative care services are delivered by any healthcare professional not involved in multidisciplinary palliative care team of NHS or hospice staff with the requisite qualifications, expertise, and experience. Generalist healthcare staff also visits patients in hospice.[t]

In France, generalist palliative care is provided at home if the patient's medical condition, their preference, and the availability of resources are sufficient. Although an increasing number of doctors and nurses working in home care have quite advanced training in palliative care, they can always call on mobile palliative care teams to help them. Generalist palliative care can be delivered in different residential places: the nursing homes, the follow-up care and rehabilitation services for medium stays and the long-term care units offering long term care to patients who are quite stable and do not have too complex palliative care needs. France has numerous follow-up care and rehabilitation services which welcome many patients requiring generalist palliative care for stays of 1 to 3 months. Long-term care units are included in general hospitals and intended for patients who require ongoing medical care and monitoring but do not necessarily have a terminal illness. The focus is on medical management, rehabilitation, and prolonged hospital-based care for patients with chronic conditions or complex medical needs. Long-term care units are reserved for people aged over 60 years and 77 % of the admitted patients were older than 75 years. The setting is comparable to a traditional hospital environment. The duration of stay can vary depending on the patient's condition and needs, but it typically involves months or even years of hospital-based care. In 2019, 19 800 patients were admitted to long-term care units.

[t] Data from a survey led by Hospice UK including 80% of the 204 Hospice UK members as respondents.

Table 32 – Summary table of key elements of palliative care per country

	The Netherlands	Germany	UK	France	Belgium
Death at home rate	30.5 – 42.6%	21%	26.7%	< 30%	23%
Approach	Community approach	Dual approach	Whole system approach	Graduated approach	Dual approach
Identified strengths	Primary care • identification • group discussions Research Monitoring	Outreach teams Awareness Training Quality of care in PCU	Availability 24/7 Centralisation Charities	Hospital-based expertise (+ hospital at home) Medium and long term residential offer • generalist PC • available technical interventions	Hospital-based expertise combined with outreach multidisciplinary support team at home Palliative care networks as exchange platforms between generalist and specialist palliative care professionals and volunteers
Identified weaknesses	Hospital-based services	Financing of psycho-social care Lack of PC knowledge in nursing homes	Lack of public legislation Weak public financing	Incomplete territorial coverage by outreach teams	Incomplete territorial coverage by outreach teams and hospitals

5.4.4 Specialist palliative care offer

Professionals and volunteers specialising in palliative care provide this care in the same four settings (the patient's home, a place replacing their home, on an ambulatory basis, a hospital stay) as non-specialist providers, but a fifth place is setting. This is non-hospital residential palliative care setting, which is not long-term. In most countries, these services are called hospices. Characteristics such as holistic care, training in specialist palliative care and use of multidisciplinary teams in delivery of care are not considered as differentiating criteria between services because there are core to the definition of specialised palliative care. Indeed, in all the assessed countries, palliative care is multidisciplinary. A broad range of professionals is involved. As based on the four pillars of palliative care (physical, psychological, social, and spiritual/existential care) all these professionals enrich the palliative holistic care with their expertise and skills. In most cases (except the initiatives that are completely ran by volunteers), nurses and other physical caring staff is financed by the government. But often, involvement of other healthcare professionals depends on the financial reserves of the service, i.e., the organisation pays by its own for the supplementary skilled person (e.g., psychologist, spiritual/existential supporter…). Table 33 – below - gives an overview of specialised palliative care offer by country.

In the Netherlands, specialised palliative care service at home consists of receiving care from a 'home specialised palliative care team'. The outpatient hospice teams (volunteers-based) come from the *Bijna Thuis Huizen* (BTH – transl. almost home house), that is a type of volunteer-led inpatient hospice service, and support people in the terminal phase at home. Nurses specialised in PC can also care for patients at home with more complex palliative care nursing needs. In nursing homes, many staff is trained in palliative care. In hospital, patients may either be admitted to a palliative care unit (PCU) or be followed by an intra-hospital mobile team when staying in any other care unit. Inpatient hospital palliative care is rare in the

Netherlands and focuses on patients with overly complex needs and/or requiring highly technical care at the last phase of life. Also, day centres are rare: only one clinical day treatment centre and five non-clinical day treatment centres (only supportive care) are identified. Differently to other countries, the Dutch legislation foresees and funds transmural palliative care consultation (*Transitie Consultatie*). This specialised palliative care service strives for proactive deployment of care provider specialised in palliative care for every patient, family member and his first line care provider who needs it at the right time and in the right place, appropriately and regularly. So, primary healthcare professionals can consult specialist healthcare professionals (often from a hospital) to receive information, guidance, or practical support. Most consultations are by phone (90%) and take place during office hours (20% outside office hours). An important characteristic of this care is that the regular care provider maintains the treatment relationship, but with the support of a specialised professional to achieve a better quality of palliative care. The specialised palliative care offer in the Netherlands is supplemented by three types of inpatient services located in the community: the *Bijna Thuis Huizen – BTH*, hospices run by volunteers; the *High Care Hospices – HCH*, hospices run by professionals, and the palliative units in nursing homes.

In Germany, the types of specialised palliative care services is very similar to those in the Netherlands although some differences exist. In Germany, mobile teams form the basis of specialist palliative care in the community. Staff of mobile teams named *Spezialisierte ambulante Palliativversorgung* (SAPV) (n=400) provide comprehensive medico-psycho-social services and are supported by the government. They are not part of the 'hospice' sector. *SAPV* teams work closely with other service providers such as community-based doctors, nursing services, hospitals, residential care facilities, hospice services and pharmacies. Patients in palliative situation can access a legal entitlement to *SAPV* team if generalist palliative care is no longer able to meet their needs. In accordance with statutory health insurance agreements, *SAPV* teams are available whether the patient lives in a home environment or in a residential care facility. The palliative medicine sector also offers the services of specialist nurses who go into people's homes, but this service is disappearing in favour of the *SAPV*. In addition, many volunteers-led outpatient hospice teams (n=1500) provide support for day-to-day concerns to palliative patients wherever they are, including in inpatient hospice services. Globally, the main task of hospice outpatient services is a psycho-social support provided by volunteers to patients and their families, mainly delivered at home but also in hospitals, care homes or inpatient hospices. Despite their large numbers, there are gaps in outpatient palliative care provision in rural areas. Inpatient hospice services (n=250) do not seem to be automatically linked to the outpatient hospice teams and seem to be 'stand-alone'. While a number of nursing homes offer palliative care as part of their care package, other funding agencies and institutions have done little or nothing about the palliative care in nursing homes. It would seem that only 20% to 40% of nursing home staff are trained in palliative care and it is reported that the collaboration of nursing homes with mobile palliative care teams is only occasional. Hospital PCUs (n=340) aim to provide care in crisis situations, improving or stabilizing the condition and quality of life of individual patients. The length of stay is often short, averaging 9 to 10 days, and in 50% of cases, patients are redirected to home or to a hospice inpatient service. Hospital palliative care support teams complete the hospital palliative care offer. Hospital-based palliative care units may provide similar services as hospices, but they are typically integrated into large hospital system and offer more specialised medical care. Finally, there are only a few day-care centres in Germany, most running as a pilot service and without regular funding. Day-care services are linked to institutions such as inpatient hospices and palliative care units at hospitals; however, they may also operate independently.

In the UK, at hospital, short term palliative care is delivered until a discharge plan is in place. Hospital palliative care teams arrange for patients to be transferred to receive palliative care in hospices, nursing homes or at home. Depending on the condition and the needs, support is overseen either by specialist teams or a single nurse. At home, palliative home care enables individuals to remain in their own homes to receive end-of-life care. Nurses, specially trained in palliative nursing, will move into the home of the patient to provide round-the-clock support. It is referred to as hospice at home. In 2022-2023, 18% of hospices' total service activity was delivered in an inpatient unit and 55% of hospices' total activity was delivered at the person's place of residence. A trained palliative carer (not related to a hospice) can also perform home visits at arranged times of the day and even

overnight. Homecare visits can be used to provide breaks for family members or other professionals, or to assist with personal care. Hospice patients' home services offer companionship and practical support services by a member of the hospice staff or a team for those living at home. In 2022-2023, 880 000 visits were made by specialist palliative care nurses and doctors to palliative patients at home. Not all residential nursing homes can provide palliative care; only those with specially trained staff. For those who already live in those nursing homes, remaining there to receive end-of-life care is a more comfortable option than having to move to a hospital ward. Hospices are like residential nursing homes in some ways. They deliver palliative nursing and rehabilitation. Individuals may be referred to an inpatient hospice if they require end-of-life care and support that cannot be adequately provided in their current setting, such as at home or in a nursing home. In the UK, outpatient service refers to a patient living at home which travels to the hospice for care: consultations services and day therapy services are examples of this kind of services. Day therapy services deliver palliative nursing and rehabilitation to people which do not reside there permanently. The patient attends for the day then returns home. In 2022-2023, 820 000 outpatient appointments were made by hospices for physiotherapy, counselling, and other support services. Day care services provide specialist palliative care within a group context, where meaningful relationships are paramount. In addition, hospices in the UK also offer community-based services including activities in community hubs such as a village hall or library and outreach work, online services and education and local service developments. Two types of nursing services deserve to be highlighted for their particular profile: the Macmillan and the Marie Curie services. Macmillan nurses are specialist nurses that work in different areas of cancer care and treatment. They work in hospitals, hospices and in the community. While some of them are specialised in supportive care during cancer treatment, others are PC nurses. Some palliative care nurses are based in hospital. They are experts in managing symptoms and medications. They work with members of the multidisciplinary team to help plan care in hospital. They also refer patients to the palliative care team in the community at discharge. Other specialist palliative care nurses are based in the community and visit patients at home. They work as part of a community palliative care team and may be connected to a hospice. Community palliative care nurses work with the GP and district nursing care team to give them specialist advice on treating symptoms, medicines, emotional support, or any other support needed but they do not usually give direct somatic nursing care. Access to Macmillan nurse requires a referral by a doctor or another nurse. Marie Curie nurses offer specialist palliative care, whatever the illness. They provide one-to-one nursing care and support overnight at home, usually for eight or nine hours. In some areas, it is possible to be cared for a shorter period, or during the evening or daytime, as well as care at very short notice in a crisis. Marie Curie nurses deliver hospice care in partnership with the NHS. The type of service provided by the nurses vary in each area, according to what support the local NHS trust has decided.

In France, palliative care unit (PCU) can be located in a hospital or as stand-alone facility. PCUs are both a place of care and a place of life for patients and their families, whose beds are entirely dedicated to palliative care and support at the end of life. The PCU provides temporary or permanent care when patients can no longer be cared for at home, in a medico-social establishment, or in their original hospital department, meaning patients with complex palliative care needs. The PCU has a triple mission of care, research, and training for professionals. In 2019 there were 164 PCUs in France, however the geographical distribution of palliative beds (primordially in-hospital beds) in France seems to be suboptimal as 26 counties (*départements*) lack of PCU beds. Hospital-based PCUs are located within larger general hospitals. They collaborate closely with other hospital departments. They may have a homelike environment, offering a comfortable and supportive setting for patients and their families. Patients in PCUs generally have shorter stays, usually during the end-of-life phase. Stand-alone PCUs are quite rare in France. They are designed to create a home-like environment, focusing on comfort, support, and quality of life for patients nearing the end of life. These services offer a range of services, including medical care, pain management, psychological support, and family counselling. They do not seem to be recognized by French policy. In fact, these structures are considered palliative care units and not as hospice services although they seem like hospices. Indeed, hospice services are not mentioned in policy papers and are not listed as recognised palliative care services by French authorities. A national expert explained that, at present,

there is no hospice except some sparse private initiatives in France. An innovative type of specialised palliative care services is the identified palliative care beds, offering specialist palliative care in a hospital ward that is frequently confronted with end-of-life situations, but whose activity is not exclusively devoted to palliative care. The individualisation of identified palliative care beds within a hospital ward makes it possible to provide appropriate palliative care thanks to a specific organisation and the reinforcement of the palliative care skills of the healthcare teams although medical and supportive care is generally provided by the same team that took care of the initial illness, meaning they provide an intermediate level of care. In 2019, there were 901 organisations with identified palliative care beds in France. Palliative Care Outreach Teams is usually named mobile palliative care teams. It is made up of doctors, nurses, psychologists, and social workers whose role is not primarily to provide care but to support and provide expertise to the front-line healthcare teams and professionals. They visit patients and provide specialist palliative care advice and support in the setting of the patient (hospitals, social and medico-social establishments (nursing homes, etc.) or at home). It may be attached to a health establishment or to a territorial coordination structure. Mobile teams collaborate closely with the patient's primary healthcare provider and specialists to ensure graduated, coordinated and integrated care. The mobile PC team can be requested by patients, their families, or primary care professionals. As part of its remit, the mobile team helps to raise awareness among professionals and train anyone involved in palliative care and end-of-life support. In 2019, 405 mobile teams were active in France. Another innovative service available in France is the palliative hospitalisation at home (PHAH). This is full-time hospitalisation during which care is provided in the patient's own home (at home or in a social or medico-social establishment). PHAH staff has the necessary skills to provide palliative care at home otherwise it relies on a mobile palliative care team. PHAH is requested when the patient requires complex medical, psychological, and social care, specific technical skills, particular medical instability or when the health care load is high. As it ensures that the patient's regular care healthcare team remains, it operates in addition to the home nursing care. To receive PHAH, patients must have a life-limiting illness and meet certain criteria established by the healthcare system. Hospital-at-home services devote 40% of their activity to palliative care. In addition, hospital can also sometimes provide palliative day hospital designed to provide a range of specialised PC interventions and support to patients with life-limiting illnesses who do not require 24-hour inpatient care. In a future strategy (2024-2034), French authorities plan a larger and more variated specialised PC offer with mobile teams covering all living and care places, access to specialist palliative care consultations, day hospital, regional telephone support service for palliative care 24/7, multidisciplinary consultation meetings, management of palliative emergencies, bereavement support for the relatives and training for volunteers, professionals and staff. Specialised palliative care services are often accessed through referrals from healthcare professionals involved in the care of the patient. This can include general practitioners, oncologists, palliative care specialists, hospital-based teams, or home care teams. Palliative care institutions often have a limited number of beds, and availability can vary depending on the specific type and its capacity. The placement process considers the availability of beds and prioritizes patients based on their needs and urgency. In some cases, there may be a waiting period before a bed becomes available, and interim care may be provided in other settings, such as hospitals or the patient's home, until a bed becomes available.

Table 33 – Characteristics of the specialised palliative care services per country

	The Netherlands	Germany	United Kingdom	France	Belgium
Outreach teams	Volunteers-led home specialised PC team Specialised PC nurses	SAPV teams (n=400) • Medico-psycho-social • doctors and nurses • At home or in residential facility Specialist nurses teams (disappearing) Volunteers-led outpatient hospice teams (n=1500) • Any setting (including hospital and hospice) Coverage gaps in rural area	Hospice at home (75% of the activity of hospices) • nurses specially trained in palliative nursing • round-the-clock support Trained palliative carer not related to a hospice • MacMillan or Marie Curie nurses • day and overnight • direct care or respite care	Mobile palliative care teams (n=427) • doctors, nurses, psychologists and social workers • no direct care but support and expertise • any setting • attached to health establishment or to territorial coordination structure • requested by patients, their families or informal caregivers Palliative hospitalisation at home • Any place in the community • in addition to home nursing care • complex medical, psychological, and social care • technical skills, medical instability, or high care load	Multidisciplinary palliative support teams • nurses, psychologists and doctors • attached to a territorial zone • home and other outpatient residential settings (e.g. nursing homes) • direct care OR support to professionals OR both
Nursing homes	Vast majority of staff trained in PC Palliative Units (a type of hospice service) (n=62)	Only 20% to 40% of staff trained in palliative care Need to have a formal collaboration agreement with a volunteer's organisation	No specialised PC except in those with specially trained staff	No specialised PC included	Palliative care referent (0.10 ETP per 30 residents)
Hospital	Rare PCU • overly complex needs • highly technical • last phase of life Intra-hospital mobile team	PCUs (n=340) • Crisis situations • Short length of stay (9 to 10 days) • 50% discharged. Hospital PC support teams	Short term PC units • discharge plan. • Mobile teams • specialist teams or single nurse	PCU (n=164) • specialised care and support in the final weeks or months of life (place of care and life) • triple mission of care, research, and training	PCU (n=52) • specialised care and support • 6 to 12 beds in a single unit or dispersed in the hospital. Hospital PC support teams

Day centres	Rare (n=6)	Few pilot service Without regular funding Linked to • inpatient hospices • palliative care units at hospitals independently	Related to hospices (85% of hospices) Palliative nursing and rehabilitation Meaningful relationships	Palliative day hospital • in hospital setting	Rare and only in Flanders
Stand-alone inpatient hospice service	*Bijna Thuis Huis* (n=120) High Care Hospice (n=41)	Inpatient hospice services (n=250)	Hospices (n=220) • palliative nursing • rehabilitation	Rare palliative care unit • not recognized by French authorities No hospice	Inexistant, apart from local citizen-based initiatives
Innovation	Transmural palliative care consultation • for primary healthcare professionals • by specialist from the hospital • by phone (90%) • 20% outside office hours			Identified palliative care beds (n=901) • in a hospital ward frequently confronted with end-of-life situations • same teams that took care of the initial illness • more familial environment • intermediate level of care	Hospice care in nursing homes in Flanders

According to the EAPC, the level of development of palliative care in a country can be assessed by studying around twenty indicators. Five of these indicators relate to the provision of palliative care services: number of outreach PC teams, number of PCU in hospital, number of hospices, number of in-hospital palliative care support teams and total number of specialised palliative care services/population. EAPC obtained data from each European country via an online survey conducted in 2018-2019 with national experts. In addition to the five above-mentioned indicators, this survey also collected data on the number of day centres and the number of volunteer-run hospices.

According to the EAPC study, of the five countries studied, Belgium is the country with the most specialist palliative care services in relation to the number of inhabitants. However, this number does not consider the size of each service, which means that this indicator alone cannot really be considered as a reflection of the level of development of specialist palliative care provision in a country. Also, the EAPC points out that the consensus of experts considered that the ratio of outreach palliative care teams per population is a better indicator of the development of palliative care in a country than other indicators (even the total number of services). So, the EAPC recommends, for an adequate coverage of population PC needs, a minimum of one outreach PC team per 100 000 inhabitants. According to this recommendation, the UK and Germany would therefore rank better on the development level of their palliative care offer compared to Belgium, which seems to be reflected in their Quality of Death score published in 2022. According to these data based on expert opinion, Belgium should further develop its outreach palliative care services. This seems to be in line with the preferences of Belgians, of whom around 70% want to die at home (2012 data in Flanders). The EAPC recommended as aspirational norm and standard, that there should be 80-100 PCU and hospice beds per 1 000 000 inhabitants.[14] Using an 8-12 bed PCU as an example, this would correspond to 8-10 PCUs per million inhabitants. Therefore, Belgium would need around 1100 inpatient PC beds in Belgium to distribute between PCUs and inpatient hospice services. Finally, the EAPC recommends two specialised palliative care services every 100 000 inhabitants (1 community-based team and 1 hospital-based team).[5, 196]

In summary, there is no single way of supplying palliative care provision in any one country, but among the countries selected, there is not much variation in this either as pretty much all types of specialised palliative care services are present. Germany, the UK and the Netherlands seem to have distinguished the criteria for admission and length of stay between their hospital and hospice services. The hospital is reserved for periods of crisis or complex technical needs, while the hospice is used more for the end of life. In nursing homes, the Netherlands seem to have developed their offer well, but less so in the UK, Germany, or France. However, France offers long-term stay in hospital setting for those needing technical care. The role of day centres was little described in our analysis. This type of service seems to be more frequent in the UK. Finally, France stands out for its the services of hospital at home, which enable technical care to be delivered in community settings. Outreach palliative care teams' development vary a lot between countries. Those are numerous in Germany and France although it is not clear which country succeeds to cover all community settings and all geographical areas. Like in Belgium, outreach palliative care teams are multidisciplinary. In Germany and the Netherlands, outreach teams are composed of volunteers. In the UK and the Netherlands, there are also nursing services specialised in palliative care, allowing sometimes around the clock interventions. Finally, The Netherlands offers transmural palliative care consultation to support first line professionals in the community.

5.4.5 Networks

As in Belgium, The Netherlands, Germany, and France have structured the palliative care supply within networks. However, in the UK, palliative care networks are unequally developing according to NHS area. Setting-up networks is a way to integrate all types of PC services in a given area.

In the Netherlands, there are 65 palliative care networks, defined as a formal and long-term partnership of independent organisations involved in palliative care in a specific region. They aim to promote cohesion in interdisciplinary care thanks to a government financial and organisational support. Some plead to choose a geographical scale of operation for the networks in which all healthcare and social care staff involved in palliative care can (get to) know each other personally. There is an integrated care

project in the Netherlands that aimed at strengthening the front-line in which participation is open-ended so that some regions participate, and others do not. Since the end of 2023, 43 regions (approximately 85% of the Netherlands) have begun to anticipate and prepare plans to strengthen primary care and to bring together (where appropriate) existing primary care partnerships and networks, including palliative care networks. The programme aims for national coverage. For this programme, the region is defined as the (sub-region of the) region of the care office. This corresponds to the region in which the regional GP organisations operate.

In Germany, since 2015, the network of palliative care service providers is constantly expanding, but has not yet reached all parts of Germany, and its density varies from one region to another. Regional palliative care and hospice networks receive financial support from the federal authorities. But one of the difficulties in achieving balanced collaboration is the regionalisation of healthcare in Germany. It must be stated that, as the German regions (*Bundesländer*) are quite independent, some regulation may not apply or in a slightly different way in certain areas. However, the federal government promotes the setup of palliative care networks. Over the last years the Health Ministry fostered the establishment of regional hospice and palliative care networks through a pilot project, and networks could introduce themselves to the public on the Ministry's website.

In the UK, the palliative care network of East of England was identified. This network provides strategic leadership and expert clinical support to integrated care boards of and providers of palliative and end-of-life care in the East of England. The network is focused on a number of local priorities, as well as supporting the national palliative and end of life care strategy and the NHS long term plan.

In France, there is a nationwide network of palliative care services. These are regional subdivided in territorial networks. They coordinate and improve the provision of palliative care services in a given area. They facilitate collaboration and communication among various healthcare professionals, including hospitals, home care services, and community facilities, to ensure continuity and quality of care for patients in different settings. Within the network, the role of each provider is defined in a formal agreement with all the providers involved in the network and is based on a set of guidelines.

5.4.6 Volunteers

In each country, in all settings, volunteers can offer (i) companionship, listening ear and emotional support for patients and families, (ii) practical assistance (light housekeeping, meal preparation, gardening, shopping or administration, offering respite to families), (iii) recreational activities, (iv) end-of-life support (sit vigil with patients, offer comfort measures, help create a calm and peaceful environment), and (v) bereavement support (emotional support, participate in group talks). Their presence can help alleviate feelings of loneliness and isolation, which are common in individuals facing serious illnesses. Volunteers also often serve as a bridge between the healthcare system and the community. They may organize support groups, awareness campaigns, or fundraising events to promote the importance of palliative care. Volunteers are a vital part of the palliative care team, working in collaboration with healthcare professionals to ensure that patients receive comprehensive and person-centred care without hierarchical distance. Moreover, from a financial viewpoint, the roles that they assume cannot be done by professionals. Nevertheless, volunteers may not be seen as a cheap alternative for health professionals. Their dedication and willingness to give their time and support can significantly improve the overall well-being of individuals receiving palliative care and their families.

Volunteers coordinators play several roles as coordinating, training, and supervising the volunteers. They also collaborate with patients and families and can be involved in policy making, public relations, organising collaboration and mediation.

In the Netherlands, volunteers play a key role in BTH and HCH and less in PC in nursing home or hospitals. However, there involved in outreach teams issued from BTH. In 2024 16 692 patients were supported by 14 533 volunteers (a ratio of one patient attended for every volunteer involved). About 7 hours of volunteer support were spent in hospices per patient each day. Eighty-five percent of volunteer work is care-focused role and 15% of time is dedicated to administrative tasks and fundraising. The success of

volunteers in the Netherlands is explained by their clearly defined position between families and professionals, the Dutch model of small-scale community-based hospice, the power of the federations representing them with a broad range of activities (e.g., advocacy, education, training), and the financial support of the Dutch government.

In Germany, the number and role of volunteers in the palliative care sector are important. In 2022, more than 120 000 people were involved on a voluntary, civic, and full-time basis. The volunteers take on a wide range of practical support services which are intended to make it easier for those affected to cope with day-to-day concerns. In Germany, the volunteers provide the psycho-social support for patients and their families as this care is not well covered by the compulsory health insurance. They also offer bereavement services for which they are often specifically trained. The work of volunteers is coordinated by professional coordinators, funded by the German authorities. They support and assist the volunteers in their work and may take responsibility for coordinating hospice outpatient volunteers' services and any other types of palliative care services involving volunteers. The German Hospice and Palliative Care Act clarifies that volunteering is an important part of palliative care: for example, nursing homes need to have a formal collaboration agreement with a volunteer's organisation. The Charter for the Care of the Critically Ill and the Dying in Germany acknowledged that volunteering is a core element of hospice work and care for patients and their families. A total of 100 to 120 hours of training is recommended.

In the UK, volunteers are inextricably linked with the history and development of hospice care. Most of the charity hospices were founded by volunteers. Volunteers work hard to the awareness raising of the general population on the vision and aims of the hospice movement and the needs of palliative care. Volunteers and volunteering are not defined in the law within the UK. Some perceive this as a positive situation (volunteering can flourish without restrictions) while others see this as a negative situation (denial of volunteer rights). In the UK, about 160 000 volunteers give around 23 million hours of time every year. Besides voluntary sector hospices, volunteers are also involved (to a smaller extent) in NHS funded hospices. The role of volunteers changes depending on the stage of development of the hospice. In the founding stages, volunteers within the local community drive the idea forward. Once paid staff are employed the role changes to a more supporting role (except the hospice board where volunteers remain to have the lead). Volunteers in the UK have three roles in hospice services: direct support, organisational support, and income generation and awareness raising. Success factors for palliative hospice volunteering are, among others, sufficient training, staff acceptance, description of roles and boundaries, effective recruitment, support and supervision, integration of volunteers and professional staff, clear structures and policies, valuing and empowerment of volunteers, shared leadership, flexibility, mentoring, and strong partnerships with local players. All hospice volunteers in the UK undertake training but the content and the intensity of the training depends on the local service. However, a common ground can be found in almost every service (e.g., needs of patients and families, understanding death and dying, bereavement, responsibilities and boundaries).

In France, volunteers can play quite a key role in palliative care. While healthcare professionals provide the necessary medical treatments, volunteers offer additional assistance, companionship, and emotional support. They work closely with healthcare professionals, such as doctors and nurses within specialised palliative care services, hospices, or home care settings. The volunteers are trained, coordinated, and supervised by healthcare organisations or nonprofit associations specialised in palliative care to ensure that volunteers can effectively contribute to the well-being of patients and their families. They undergo training programs to develop the necessary skills and knowledge for their roles.

5.4.7 Inpatient hospice services

In this chapter, different organisational models of PMC services were identified. Starting from the worldwide framework for the global organisation of palliative care offer at a country level, the focus was then placed on different types of specialised palliative care services and in particular on hospice services.

5.4.7.1 Global concept and localisation

In the Netherlands, hospices are mostly citizen initiatives and sometimes nursing home initiatives They are quite well spread over the country with a predominance for the western part and for large cities**. In Germany,** the all-hospice care sector is a citizen-led volunteer movement. Hospice work, developed as a community movement, depends strongly on volunteer engagement. Hospices in Germany are generally well spread across the country, although their availability may vary depending on the region with more gaps in provision in rural areas. **In the UK**, hospices are the pillar of the palliative care offer and depends strongly on charities. The hospices can be large institutions offering frequently different types of palliative care services but always inpatient services. **In France**, hospices are rarely citizen initiatives, and the term 'hospice' is used very sparse as it has a different connotation, related to poverty and low socio-economic situations.

5.4.7.2 Types of inpatient hospice services: structural description and available interventions

In the Netherlands, as already explained, three different types of hospice services were identified.

- *Bijna Thuis Huis (BTH)* are volunteer-driven hospice delivering care to patient usually till the end of life but occasionally providing also respite care or symptomatic care. Unstable or deteriorating patients can be cared for by highly trained volunteers whose role is being there for the patients and their relatives. Volunteers take up the complete assistance for daily living (non-medical tasks). Volunteers are supported by one or more home care organisations or independent contractors for cleaning, catering, etc. External healthcare professionals (home care nurses and GP) are responsible of the medical, paramedical and nursing care. Possible nursing-related tasks are washing, medication therapy, wound care, etc. Senior palliative care physician can be involved as an external consultant (transmural care). The care is completely moved from home to *BTH*. Most of the day and evening care is provided by informal caregivers, i.e., family caregivers and trained volunteers. Volunteers run the household daily between 7.00am-11.00pm in shifts of 4 hours and sometimes during night shifts (11pm-7am). Otherwise a nurse is often present during the night. The building is stand alone and of small-scale (4 to 6 rooms and guest rooms).
- *High Care Hospices (HCH)* result from a collaboration between citizens and healthcare professionals. The structure usually grows into small-scale (6 to 10 rooms and guest rooms) independent care organisations specialised in palliative terminal care. It offers expertise for complex palliative terminal care. It hires permanent staff like coordinators, nurses, volunteers and spiritual counsellors. In addition to the permanent nursing staff, specialised nursing and care team (e.g. assistant nurses) of a home care organisation collaborate to the care. Medical care are under the responsibility of a GP, either the own of the patient or a dedicated hospice GP specialised in palliative care. Physiotherapists and other specialists are also involved. HCHs cooperate with trained volunteers' organisations. In HCH, volunteers support professionals. They help with care tasks and are present with the patients in shifts of four hours between 7.00am -11.00pm.

Palliative Units in nursing homes are professional driven hospice, initiated by nursing homes. It is composed of few rooms in a care unit but can be a separate accessible unit with its own living environment. A specific care and nursing team delivers palliative care. The allied health professionals are the same than for the rest of nursing home residents. The medical responsibility is under a geriatrician or a palliative care specialist. Volunteers are in limited numbers.

Overall, in the Netherlands, staffing often depends on the financial capacity of the organisation. Still all disciplines (for multidisciplinary palliative care) can be used in all hospice types.

In **Germany**, hospice care is provided by specialised services that offer inpatient or outpatient care. There are significant differences between hospice services concerning the type of interventions. Certain inpatient hospices focus on complex medical care. This type of hospices delivers comprehensive palliative care, including pain and symptom management, emotional and spiritual support, and assistance with activities of daily living. Other hospices (more specifically those ran by a small professional team

and more volunteers) provide more psychosocial care but less medical or nursing care. Hospice inpatient services allows people to stay there until they die. Medical care is provided by GP or palliative care specialists, often external to the institution. Inpatient hospices in Germany do not have doctors on their payroll. This is the only type of service for which there is an admission criterion linked to life expectancy, which must be less than 6 months. Inpatient hospices are facilities with a family-like atmosphere, not connected to a hospital or nursing home, which deliver palliative care where such care cannot be provided in the home environment and do not require hospital treatment. Volunteer outpatient hospice services can visit patients in inpatient hospice services to deliver psychosocial support. Inpatient hospices need to have a formal collaboration agreement with a volunteer's organisation.

In the UK, almost all hospices offer inpatient service. This type of service offers a calmer environment in which to receive the medical support required. Around 75% of the hospices provide patients' home service. Around 85% of the hospices provide day service. Common interventions provided in hospices are pain and symptom control, wound care, nutritional support, intravenous therapy (in most cases), assistance with daily activities, psychological support, physiotherapy and rehabilitation (in most cases), end of life care planning, respite care, spiritual care, and often also bereavement support, social support, specialist occupational therapy, and complementary therapies such as massage and aromatherapy. The specific medical and non-medical technical interventions offered can however vary among hospice services. Hospices provide 24-hour interventions, for example, in case of terminal care or emergency care. The size of hospice may significantly vary, with one hospice received 171 patients in a year while another received 4 255 patients. Staffing of hospices depends on the financial means of the institution, but nursing care and medical support is always available. Other professionals are also involved when possible. In 2022-2023, 16 000 clinical and healthcare staff were employed by hospices in the UK. Of these, 12 200 were nurses and healthcare assistants and 950 were doctors.

5.4.7.3 Access to inpatient hospice services and patients' profile

Life expectancy was usually used as an admission criterion but it is progressively abandoned because it is difficult to assess with certainty life expectancy, it is patient-unfriendly and it causes unnecessary administration tasks. However, the underlying disease or condition of the patients must always be life limiting. Only Germany kept an admission criterion related to life expectancy: there is a 6-months life expectancy criterion for entry into an inpatient hospice service but for accessing other types of specialised palliative care service in Germany, there is no criterion linked to life expectancy. In Belgium, the RD of 2018 introduces the notion of a life expectancy around 6 to 12 months to identifying patient requiring PC although it is opposite to the content to the 2016 law on palliative care. However, in every analysed country, including Belgium, the decision to enter an inpatient hospice service follows a discussion between the patient, the relatives, the informal caregivers and the healthcare professionals. Referral by a doctor (GP or other) is the standard in all the countries but in some cases other healthcare professionals or instances can also refer patients (community nurses in the UK). In the UK, there is, in some cases, even a possibility for self-referral.

In the Netherlands, a *Palliatieve Terminale Zorg* (*PTZ)* statement (3 months life expectancy) was in force till 2019. Since then, admission criteria are variable, depending on the circumstances and the policies of the hospice but an admission always results of a collaborative process involving individuals and healthcare professionals. The possible admission criteria are: 1) the presence of a terminal or life-limiting illness where curative treatment is no longer the primary focus; 2) a few months or less of life expectancy; 3) the presence of complex palliative care needs; and 4) the informed understanding of the condition, prognosis, and the goals and nature of hospice care. Eighty-four per cent (84%) of the patients admitted in any type of hospices in the Netherlands had cancer. Fifty-two per cent (52%) were transferred from hospital. Their age was around 75. They were from Dutch origin, married or widowed and received support of informal caregivers. All of them (100%) had physical needs, 50% psychological needs, 33% social needs, and 25% spiritual needs at the admission time. According to the PALCOM tools[13], 50% of the admitted patients presented

a palliative situation of low complexity, 25% of medium complexity, 7% of high complexity. The reasons expressed to be admitted were in 70% of case to die in hospice, in 52% to receive intensive care, in 43% for respite care, and, in 40%, to stabilize symptom. The patients' profiles were the same when admitted to any hospice meaning that a particular type of hospice is not linked to specific care needs.

In Germany, there is a 6-month life expectancy criterion for entry into a residential hospice. Patients with a life-limiting illness can be referred to hospice services by their GP, ambulatory specialist doctor, or by a doctor of the hospital. The decisive factor for admission to a residential facility (hospital or hospice) is the patient's choice. Patients in Germany have the freedom to choose between receiving palliative care in a hospice or in a hospital setting. In theory, both options are available and can be chosen based on the individual needs and preferences of the patient and their family. The patient and their family are expected to work closely with their healthcare professionals to determine the best option for their situation. There are only small differences in admitted patients' characteristics between inpatient hospital units and inpatient hospice services.

In the UK, hospices are generally accessible to patients who meet the criteria for palliative care and require specialised support that cannot (or difficultly) provided at home. Access to hospice services is not limited to a specific group of people but is based on the individual's clinical needs. Referral can be done by healthcare professionals (GP, hospital doctors, community nurses, or specialist palliative care teams), social workers/local authorities or the patient / relative. The hospice staff assess the patient needs and determines if their services are appropriate. Access is greater in the UK for those living in urban areas, with closer proximity to a hospice and/or to associated services (e.g. day centres, home care). Hospices with 4–5 FTE doctors was associated with earlier admission compared with hospices with 0–3 FTE doctors. Delay before admission also vary between part of UK ranging from 56 days in Scotland to 17 days in Wales. Significant differences were found across age groups, with fewer days between referral and death as age increases. Compared to adults aged of less than 50 years, adults between 50 and 74 years old had 7% fewer days of hospice-based palliative care. This relationship was amplified for adults aged 75 years and over who had 18% fewer days of hospice-based palliative care compared to adults aged less than 50 years old. Also, patients with liver failure, kidney failure, non-cancer lung disease, liver cancer or rare cancer are more likely to be referred to hospice later. Of the 29 428 deaths in hospices in 2019, 24 925 (84.7%) were from cancer. The proportion of non-cancer deaths occurring in hospice in England and Wales has increased over the past decade, from 7.8% in 2010 to 12.4% in 2015 and 15.3% in 2019.

5.4.7.4 In short

Table 34 summarises the findings about the inpatient hospice services in the four analysed countries. Inpatient hospice services are indeed an intermediate residential care resource between the hospital and the home. Hospices in the three countries that have developed this type of service allow their patients to die there. Referral to an inpatient hospice service seems to be guided by patient choice in all three countries. In the Netherlands, hospices are defined as residential end-of-life care provided in three different settings: *BTH*, *HCH*, palliative unit in nursing homes. Some initiatives in Belgium draw heavily on Dutch models (palliative beds in *woonzorgcentra*, the *zorghuis* of *Kom op Tegen Kanke*r, the *Cité Sérine* - Textbox 4)). In Germany, inpatient hospice services can deliver various interventions defined historically. The interventions may be solely psychosocial. In the UK, hospices offer holistic palliative care expertise within facilities whose interventions vary according to funding. In France, there are no hospices. A French initiative described in the Supplementary Report is an illustrative example revealing many similarities with an initiatives currently being developed in Belgium: *La Maison Gardanne* in France and Coda in Belgium (see Textbox 10 in Chapter 4).

Table 34 – Characteristics of inpatient hospice services per country

	The Netherlands	Germany	United Kingdom	France
Concept	Citizen initiatives Nursing home initiatives	Citizens' led volunteer movement (not connected to a hospital or nursing home)	Pillar of the PC offer • Charity-led • NHS-led	Rare initiatives
Types	*Bijna Thuis Huis* • small scale • terminal care, respite care, symptomatic care • highly trained volunteers (non-medical tasks) • External generalist and specialised HCP (medial tasks) High Care Hospice • small scale • complex palliative terminal care • collaboration between volunteers and healthcare professionals Palliative Unit in nursing homes • small scale • mainly healthcare professionals	Depends on the interventions available: • terminal care and psycho-social support (and/or) • comprehensive palliative care (and/or) • complex medical care Agreement with a volunteer's organisation	Depends on • specific medical and non-medical technical interventions can vary among services. • staffing (depends on financing) • size (<200 to >4000)	
Profile	Patients' profiles similar in any hospice types: • Unstable or deteriorating patients	Only small differences in patients' profile between inpatient hospital units and inpatient hospice services	Age, disease, staffing and geographical parameters influence on the timing to be admitted	
Admission criteria	Life-limiting illness, complex palliative care needs A few months or less of life expectancy	Life-limiting illness, do not require hospital treatment 6-month life expectancy Patient's choice + Discussion between the patient, the loved	Life-limiting illness, require specialised support that cannot (or difficultly) provided at home Not related to life expectancy	

	Patient's choice + Discussion between the patient, the loved ones, the informal caregivers, and the healthcare professionals GP's referral	ones, the informal caregivers, and the healthcare professionals GP or specialist referral	Discussion between the patient, the loved ones, the informal caregivers, and the healthcare professionals Referral: • healthcare professionals (GPs, hospital doctors, community nurses, or specialist palliative care teams • social workers/local authorities or • the individual/ family

5.5 Lessons learned from the international comparison and the analysis of international standards and frameworks

5.5.1 Precision about the concept of palliative middle care and the similarities with the inpatient hospice services

Facing a discrepancy between the term PMC emerging in the Belgian context and its absence from international framework and standards, a first result of this chapter is the identification of the similarities between the organisational models of PMC services proposed by the Belgian Federal Cell and the inpatient hospice services described in international frameworks. The results from the previous section show that, indeed, inpatient hospice service present numerous similarities with the concept of PMC as designed by the federal cell. And inpatient hospice services developed in some countries (The Netherlands, Germany and, to a much lesser extent France and Belgium) seem indeed to function as a link between hospital palliative care and generalist palliative care delivered at home. However, in the UK, hospices look more like pillars of the system than a link in the chain. Another point of attention is related to the level of delivered palliative care. While generalist and specialist palliative care was primarily included in the scoping definition of PMC, the first look at hospice services in the 4 studied countries indicates that hospice services are more related to specialised palliative care than to generalist palliative care. So, at this stage of the study, one can conclude that the concept of PMC as defined by the KCE research team in its working scope can be slightly reduced to: "any service (*could be a provider -volunteer or professional, or a structure embedded several providers*) delivering rather specialist palliative care. The service is not a community-based front-line service composed of provider(s) not trained in palliative care (*palliative care knowledges acquired during basic cursus are not considered as a training* in palliative care) and not a hospital-based palliative care service composed of provider(s) specialised in palliative care." With that evolving definition, PMC can still be assimilated to the concept of hospice with a broader scope for PMC services than hospice services. The following paragraphs highlights how the comparative study of four border countries of Belgium allow to precise the concept of PMC.

5.5.1.1 The WHO model

The WHO defines a hospice as "*a stand-alone centre delivering the basic elements of palliative care (medical, nursing, psychological, social, and spiritual support) in which the level of care depends on local resources, availability and capabilities of staff, and their training. The scope of the care depends on the target group of patients. As such, the care provided may need to include financial support and basic necessities, such as food, utilities, mobile telephone, travel subsidy and the lending of equipment*."[2]

This first PMC model is based on a structure that is isolated from the point of view of its legal status, not dependent on an existing structure. This type of model can be found in the various countries studied, as well as in Belgium, in the form of initiatives such as *Pass-Ages* and *Cité Sérine* in Belgium, and *La Maison Gardanne* in France, and the charities-led hospices or the citizen-led hospices in Germany and the UK. In the UK, 88% of inpatient hospice services were charitable organisations-led and only 12% were NHS units. The stand-alone aspect can also be understood as isolated geographically (and not statutorily). This is the case of *BTH* and *HCH* in the Netherlands and of the *Zorghuis van Kom op tegen kanker* in Belgium. This is also the case for several Sp4 services in Belgium (*Foyer Saint-François*, *Le Goéland, Foyer Horizon, CODA* …), that are Belgian PCU.

Based on this definition, one can also discuss the fact that the level of care in an PMC service may depend on the resources, availability, expertise, and skills of the professionals and volunteers. In terms of resources, this is the case for most of the services studied. In Germany, the state funds up to 95% of costs (but not the costs of psycho-social care) and 5% depends on fundraising. In the UK, the split of 35% state and 65% fundraising demonstrates the dependence of hospices on charities and donors. In the Netherlands, coverage by the State is on the way to being improved, with a programme to cover accommodation as well as care in all four pillars of palliative care. In Belgium, isolated initiatives split the costs between occasional subsidies from the authorities and co-payment from individuals. Regarding the expertise and capacity of professionals and volunteers, the level of training required varies greatly from one country to another, although one constant is the training and supervision of volunteers. In the Netherlands, it is clearly stipulated that volunteers are capable of managing palliative crisis situations. Germany stands out for its well-defined and compulsory training programme, which has enabled the country to reach the recommended minimum number of doctors specialising in palliative care according to the quotas set by the EAPC.

As far as the target population is concerned, in the countries studied, all from Europe, there seems to be a consensus on the pathological aspect, i.e. that hospices accept anyone with an incurable, severe and life-limiting pathology. There also seems to be a clear theoretical trend towards the absence of age criteria, at least for adults; however, in the fact, the older the patient is, the later he is referred to inpatient hospice services. Furthermore, none of the models studied showed selection based on socio-economic status. However, the need to finance accommodation or meals could be a barrier for some patients in certain models, such as in the Netherlands (*BTH*, *HCH*) or Belgium (*Cité Sérine*), and the same problem of co-payment is also present in Germany for the psycho-social support. Although the life expectancy criterion has lost much of its credibility in recent years (abolished in 2019 in the Netherlands, for example), it remains in force in Germany for access to inpatient hospice services (max 6 months) and in Belgium (max. 12 months to be identified as a palliative patient). It should be noted, however, that despite the absence of strict numerical criteria, the concept of hospice care still tends to focus on people at the end of their lives. Inpatient hospice services in the Netherlands tend to admit patients who wish to die in situ; the median length of stay in *BTH* is 14 days. This is also the trend in the profile of patients in the UK.

5.5.1.2 The EAPC model of hospice

The EAPC defines a hospice as : "*a stand-alone facilities providing PC outside hospitals, present more frequently in Anglo-Saxon countries. The hospice concept almost always designates an intermediate care resource between the hospital and the home*".[5] In this model, the stand-alone aspect is again clearly expressed. In addition, there are two further aspects that advance our perception of PMC. Firstly, it is interesting to note that hospices are mainly found in Anglo-Saxon countries. This statement is borne out by this international comparison, where the only Latin country, France, offers only anecdotal evidence of hospices. When considering how few 'hospice-like' initiatives are currently existing in Belgium, and by comparing this findings with the hundreds of inpatient hospices in the Netherlands (n=225), Germany (n=250) and the UK (n=220), it becomes clear that the difference with Belgium and France may indeed be cultural in origin. Moreover, a historical analysis of the development of palliative care services in the various countries shows that since the beginning of the palliative care movement, France and Belgium have primarily developed hospital-based services in the form of hospital PCUs, which were the only type of PC service

at that time. In the UK, on the other hand, the very concept of hospice care had been created 20 years earlier, at the origin of palliative care. This offer was directly set up in the community and with associated inpatient and outpatient services from the outset. The time that has elapsed since their creation has enabled British hospices to become sometimes very large structures with many different types of services. The Netherlands was much later in developing its hospice services, which differ from those in the UK in that they have much smaller accommodation structures but are similar in that they offer outpatient home care services provided by volunteers from inpatient hospices. In Germany, outpatient care is in the majority, with more than 1 500 teams of volunteers visiting palliative patients wherever they live, although residential care is also well represented.

On the other hand, the EAPC definition perfectly illustrates the concept underlying the proposal to make PMC the link between palliative care delivered in hospital and that delivered by the front-line healthcare professionals in the community. While the Federal Cell behind the proposal did not really distinguish specialist care from generalist care, the study of the international framework and international comparison indicated the relevance of taking account of these two levels of care.

5.5.2 How to distinguish palliative middle care services from other types of palliative care services?

The PC offer at a country level can be organised according to settings, care situations and providers training. Authorities in charge to plan healthcare offer can define/sort existing and new palliative care services by answering the following questions:

- Is the service provided by one or more specialised providers (professionals and / or volunteers), or not? Specialised status depends on the level of training and experience of the providers. Some countries define the required levels quantitatively and qualitatively. The WHO gives training level guidelines (Textbox 13).
- Is the service hospital-based or not?
- Does the service offer accommodation or not, and for how long?
- Does the service target patients whose palliative situation is stabilised or crisis situations? The 'Phase of illness' tool can be used to identify unstable situations (Figure 1).

Depending on the answer to these different questions, different types of palliative care services are can be characterised. Such an exercise was carried out in 2019 in the UK by Firth and colleagues [192](see Supplementary Report). The four countries studied in the international comparison, as well as Belgium, have adopted organisational models for palliative care provision that include similarities and differences (see Table 32 and Table 33).

First, the level of competence (a combination of training and experience) of the providers (volunteers or professionals) makes it possible to distinguish between specialised and generalist palliative care services. Recourse to one or the other depends on the level of complexity of the palliative situation. Complex situations are referred to specialised services, while non-complex situations (the majority) can be managed by generalist services. The four countries studied and Belgium currently offer both levels of care. However, the aim of the present study was to identify whether an intermediate type of service (PMC) should be developed in Belgium. According to these results, binding PMC services to an intermediate level of competence of professionals delivering an intermediate care level could theoretically be made (Textbox 13) but this type of model has not been identified in any of the countries studied. Furthermore, Belgium has, indeed, even not yet defined the levels of training and competence legally required to simply distinguish specialist from generalist providers (professionals and / or volunteers). To date, only nurses have access to higher education training program in palliative care, leading to an official recognition of a professional qualification.

Secondly, the hospital or community context enables to identify services that can deliver highly technical care or treatments available only from the hospital environment (transfusion, radiotherapy, scanner, etc.). Indeed, some palliative situations require this type of technique or treatment, while remaining consistent with the definition of palliative care if these procedures are aimed at the patient's quality of life. The notion of intermediate care does not seem to fit here. In the Belgian healthcare

system, care is generally divided into first, second and third lines. The second and third lines are both hospital-based, with the only difference being that the third is university-based. The situation in Germany illustrates well the problems related to manage an additional sector. There, a hospice sector was historically developed to provide psycho-social care to compensate the lack of such care in the medical sector. The creation of a new sector prevented to adhere with the concept of palliative care, which calls for simultaneous holistic care (medico-psycho-social-spiritual) and now, Germany struggles with the merge of palliative medicine and volunteer-led psychosocial PC. This type of division of the holistic vision of palliative care does not seem relevant, and the creation of a middle level of care should be consider with caution. In France and UK, the delivery of hospital-related interventions is possible in the community. In France, hospital at home service is in charge and in the UK, technical intervention are available in inpatient hospices in which medical staffing can be important. So instead of the creation of an additional sector, a model of palliative care service in the community allowing the access to hospital-related treatments and technics in palliative situation could be suggested.

Thirdly, the residential aspect of the service distinguishes the offer dedicated to people who can continue to live in their usual living environment from those who require accommodation in a residential facility, whether in a hospital, nursing home, hospice or social institution (psychiatric care homes, homes for the elderly, the disabled or those in precarious situations). A crucial element is the authorized length of stay within residential facilities. Hospital-based residential palliative care services allow usually short-term stays like in Germany (median length of stay of 9 days). In most cases, medium- or long-term residence is not possible in the hospital context as they are not living facilities. However, two exceptions are identified: PCUs and medium- and long-stay wards in France, and some Sp4 wards in Belgium. Nursing homes always allow long-term stays but medium-term stay is also possible in Belgium. However, hospices are used for short- to medium-term stay rather than long-term stays although no clear-cut length of stay are mentioned. In the Netherlands, median length of stay in *BTH* is 14 days and in the UK, median length of stay is around 7 weeks. In Germany, the life expectancy is still used to be admitted in inpatient hospice service (max. 6 months). Moreover, intermediate palliative care services in term of accommodation also exist like day care services where patients spent a part of their time at home and another part in a care facility. Respite place can also be seen as partial accommodation where the patient lives alternating at home and in a facility full time but during a limited period. Some inpatient hospice services offer this possibility, for example *BTH* in the Netherlands.

Finally, the service's ability to manage unstable palliative situations is the last criterion for distinguishing between types of service. Amongst residential facilities identified to accommodate people in palliative situation, some are well equipped to manage unstable situations, while others are barely equipped at all. Indeed, three different types of residential facilities can be distinguished. First, hospital-based residential palliative care services are adapted to unstable palliative situation. Second, institutions that serve as home (psychiatric care homes, homes for the elderly, people with disabilities or those in precarious situations, forensic places) are living facilities. Their purpose is to provide accommodation rather than care. This type of residential facilities are rarely able to manage unstable palliative situations. And third, intermediate establishments like nursing homes are both living facilities and places of care. In those last, the capability to manage unstable situation vary a lot, according to the level of training and the staffing in volunteers and professionals. In the Netherlands, some nursing homes include palliative care units. Those are more able to manage crisis. To solve the problem of crisis management, whether at home or in residential facilities, countries, including Belgium, have supplied the health offer with specialist palliative care mobile teams or specialised crisis service (Marie Curie nurses in the UK) providing support for front-line professionals. In France, the organisation of palliative care takes clearly into account the factor instability with its graduated palliative care supply. It is when the collaboration between front-line and second line teams fails that the emergency services are called in. For example, in Germany, France and Belgium, nursing home staff are rarely sufficiently competent, or sometimes not sufficiently numerous, to be able to manage unstable palliative situations without the help of a specialist team. In Germany, 1 500 outpatient hospice teams staffed by volunteers care for palliative patients on call whatever the place of residence, even in the hospital. In Belgium, outreach community teams are allowed within nursing homes. Although the 'Phase of illness' tool

can be used to determine the phase of the palliative situation (stable, unstable, deteriorating, terminal or bereavement –Figure 1), this criterion is not currently clearly used to distinguish between types of service. The inability for a service to manage unstable situations usually results in an emergency transfer to a residential facility: an hospital in the case of medical instability, and other types of residential facilities in certain cases of behavioural or social instability. Currently, the phases of illness determine rather when needs, resources and preferences are reassessed, and guide transfers between care settings. It should be noted, however, that this process does not fall within the concept of palliative care (see section 1.4.1), which requires anticipating new needs as far as possible thanks to a care plan to avoid the discomfort associated with instability. Everywhere, hospital PCU are described as the type of service designed to manage unstable situations. But also, inpatient hospice services can, like *BTH* and *HCH* in the Netherlands which are described as places capable of managing crisis situations.

As possible new palliative care service in Belgium, PMC could be defined differently according to the above characteristics but certain aspects seem to be becoming clearer. PMC should deliver specialist palliative care, rather than an intermediate level that is difficult to distinguish from general palliative care services. PMC could deliver technical care or hospital treatment outside a hospital building, as in France and the UK. PMC would be more akin to residential care, with similarities to nursing homes, which combined living and caring aspects. The ideal PMC model would be able to manage unstable (or crisis) situations, as in the Dutch system. However, it is worth to notice that, in two sections of this chapter, the term intermediate (close to 'middle' in PMC) was used. In the definition of a hospice proposed by the EAPC in 2019 (section 1.4.1), the term intermediate is used to explain that a hospice designates an intermediate care resource between the hospital and the home.[5] In the description of the French palliative care offer, palliative care delivered to patients hospitalised in identified palliative care beds within a general care ward and provided by the same team that took care of the initial illness, are appropriate palliative care thanks to the reinforcement of the palliative care skills of the healthcare teams, able to provide an intermediate level of palliative care. But, considering the Belgian context and the repartition of competences, one could question whether it is more appropriate to conceive PMC as simply as the missing links in the current offer, without giving it a label "middle". In the next chapter, we report the gaps and problems as experienced in the Belgian context.

When the authorities will decide the organisation of the palliative care offer within their country, it is important remembering that the final decision to refer palliative patients and their family to a particular type of service will depend not only on the characteristics of that service, but above all on the assessment of the preferences, needs and resources of the patients and their relatives. The step of needs assessment should therefore be at the centre of any palliative care offer development, especially as the availability and characteristics of the palliative care services around the patients are included in the assessment of resources.

6 WHAT ARE THE GAPS AND PROBLEMS IN BELGIUM?

- ✓ Preferences and needs of patients and relatives are insufficiently considered.
- ✓ Relatives and informal caregivers are at risk of exhaustion and burnout and lack of support and respite solutions.
- ✓ Population in need for palliative care is currently underestimated in Belgium
- ✓ The existing offer in palliative care is not sufficient to meet its objectives: shortage of (qualified) staff, unequal distribution of specialised services in palliative care across the territory, lack of knowledge and competences related to palliative care, …
- ✓ There are patients for whom the current offer does not meet the needs and for whom current palliative care offer needs to be further enhanced.

6.1 Introduction and aim

Although it offers a wide range of possibilities for supporting patients, current palliative care provision in Belgium is not free of gaps and problems, whether for patients and their families, for healthcare professionals and services specialising in palliative care or not, or for society as a whole.

This chapter aims at highlighting the gaps and problems in Belgium by triangulating different sources of information (see Chapter 2 for more details). In doing so, many problems are presented, although the ambition is not to make an exhaustive list of all the difficulties surrounding palliative care. However, not all these problems will be solved by palliative middle care: that is why, at the end of this chapter, readers will find the gaps for which middle care palliative care could provide some form of response.

This chapter is organised around three key actors in palliative care: the patients and their families, the informal caregivers and the volunteers and the healthcare professionals. The term "respondents" refers to the people met during the site visits (whether the visits were held on site or virtually). “Organisations" refers to participants in the online survey. “Patient representatives" refers to participants in the workshops. “Experts” refer to the persons met during ad hoc meetings.

6.2 Problems for patients and families

6.2.1 Personal barriers : acceptability, attitudes, language and culture

According to the organisations, the most frequent personal barrier experienced by patients and relatives is linked to the knowledge and representation of palliative care (which is “often/always” a barrier according to 43% of the organisations and “regularly” according to 38% of them), followed by acceptance and understanding of issues related to end of life by the patient, beliefs of the family, cultural aspects, and personal beliefs of the patient (Figure 15).

This was also mentioned by some respondents during the site visits. Not all patients and families appear to understand what end-of-life means. In their view, it is difficult for the patients to hear or to learn that the chemotherapy is stopped, and that the treatment is not longer to cure but to care. Moreover, other respondents explained that it is difficult to envision what does it mean “dying at home.” According to them, dying at home could be the preferred option but patients cannot imagine the impact of dying at home on their relatives (e.g. dying because of a respiratory distress). Patient representatives also pointed that patients and relatives are not prepared to discuss palliative care which prevent them from getting access to palliative care and additional form of support such as psychological support or financial aid.

> *J'avais aussi relevé que le fait de parler des soins palliatifs annonce aussi la fin de vie et que cela pouvait être tabou, surtout pour les familles en fait. J'ai l'impression qu'elles ne sont pas aussi préparées à entendre et sont comme dans une sorte de déni, si on peut l'appeler comme cela, de l'annonce de la fin de vie. Il y a aussi une problématique au niveau des familles et parfois aussi des aidants qui ne sont peut-être pas prêts à entendre la fin de vie et donc ils peuvent être réticents […]. Patient representative 3 – FR workshop*

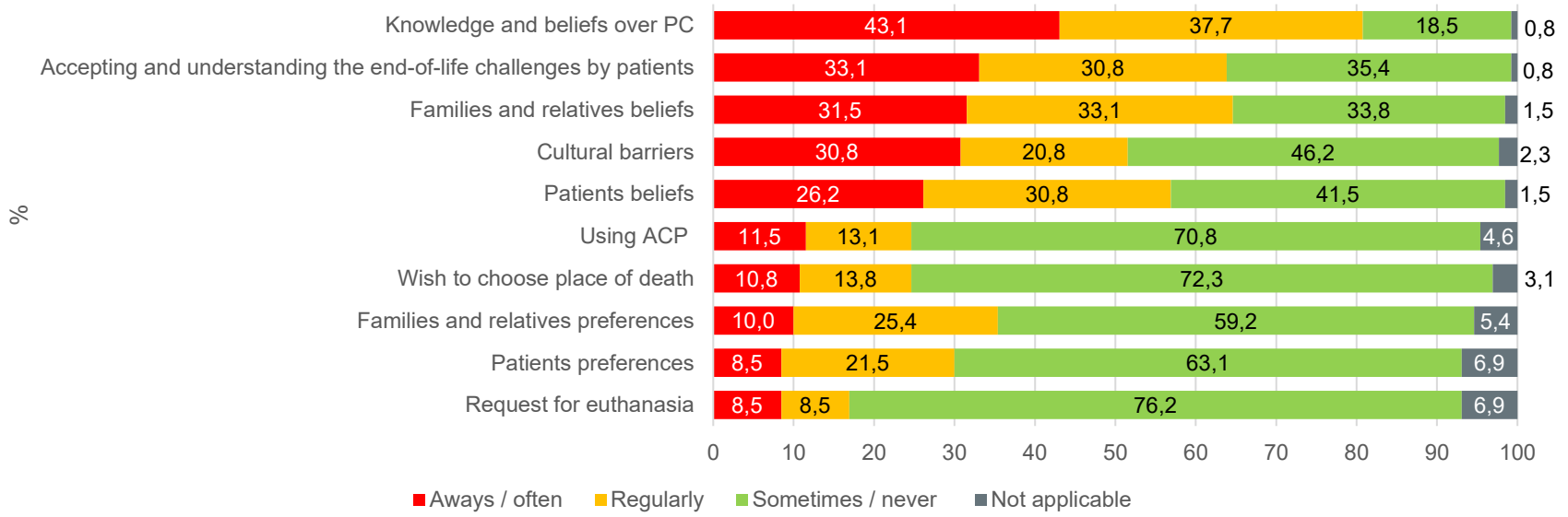
Several patient representatives explained that themselves were not aware that palliative care can be accessible to a wider patient population, not only to patients suffering from a cancer in a terminal phase. Patient representatives also observed that some healthcare professionals lack of knowledge about who can be benefit from palliative care.

> *[…] En fait, les soins palliatifs n'étaient pas seulement destinés aux personnes qui étaient vraiment proches de la mort mais plutôt aussi qui, sachant qu'il n'y avait pas de guérison, pas de traitement curable, devaient dégager pour eux-mêmes mais aussi pour les soignants, une perspective de vie de qualité autant que possible. Patient representative 1 – FR workshop*

Culture and ethnicity also play a role in the understanding of the challenges related to the end-of-life and palliative care, supporting the need for more attention in the delivery of palliative care.[19, 197]

It was also mentioned during the workshops that the patients, but also the general population, do not understand the added value of palliative care, which, according to patient representatives, can explain the poor acceptability of palliative care.

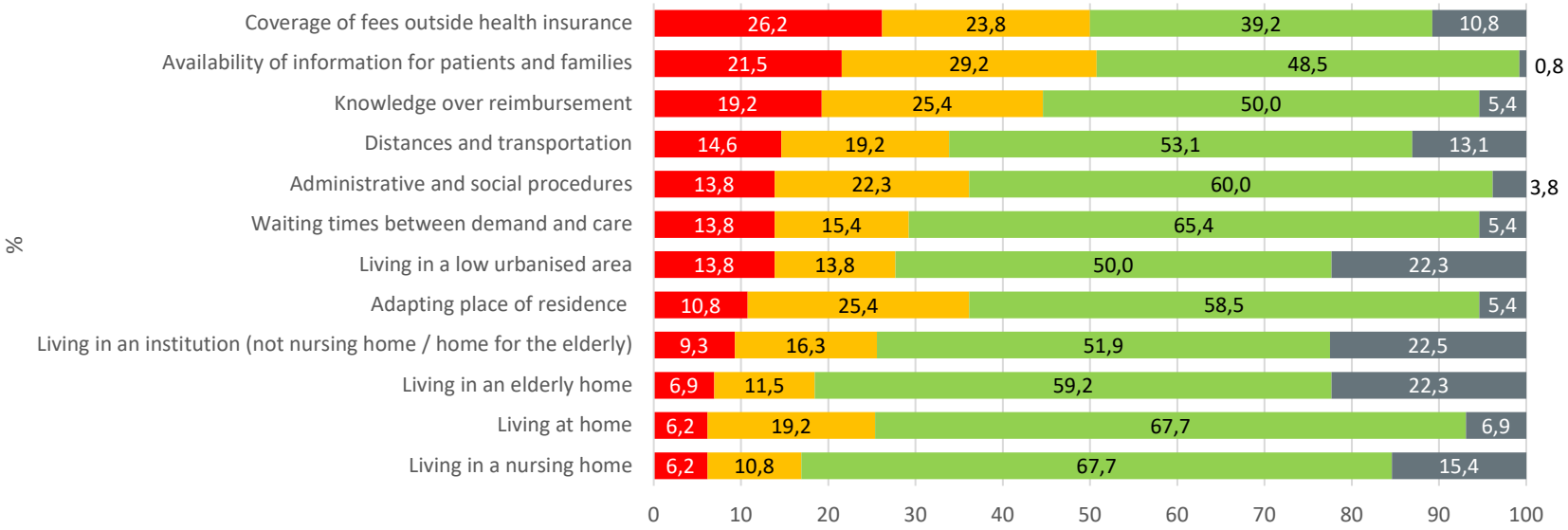
Figure 15 – Personal barriers experienced by patients and relatives when needing palliative care in Belgium (N=130)



6.2.2 *Personal barriers: administrative, socioeconomic, and financial barriers*

Among the social and financial barriers, the most frequent barriers were the availability of information on palliative care and end of life and the coverage of non-reimbursed costs, which were reported by about half of the organisations (Figure 16). This was also a major concern raised by patient representatives. Next to this, lack of knowledge of reimbursement possibilities was also reported as an important barrier for the patients by organisations.

Figure 16 – Social and financial barriers to palliative care according to organisations (N=130)



6.2.2.1 *Patients and relatives experience information and communication problems*

As stated by patient representatives, this lack of information can be related to a lack of information of the professionals themselves. Patient representatives explained that there are still misinformation and lack of information about end-of-life, patient rights, palliative care, euthanasia, as well as forms of support that can be received, leading to an underuse of the existing resources.

> *C'est ce sujet-là qui fait en sorte que les familles pensent moins, c'est un évitement, c'est presqu'un déni de fin de vie. On n'aborde pas le sujet parce qu'on a l'impression qu'il n'y a pas vraiment une aide très concrète à domicile et les soignants nous expriment les mêmes problèmes ou les mêmes inquiétudes. Patient representative 1 – FR workshop*

For some patient representatives, the terminology around palliative care often lead to confusion as they perceive that professionals themselves do not speak the same language when it comes to palliative care, end-of-life care, or terminal care. The meaning of the words themselves in French or Dutch were also pointed by some patient representatives as hurtful, distressing or confounding.

As pointed by a patient representative, this lack of proper information about palliative care and available support was exacerbated for those in poor socioeconomic conditions. Patient representatives therefore expressed that those in poor socioeconomic are those with the higher needs for support.

A patient representative also mentioned the need to anticipate discussion about topics such as euthanasia, as, in some diseases, it appears no longer discussed when the patients are likely to have incapacity to express their decisions.

> *Moi je voulais réagir parce que j'ai entendu parler au début d'euthanasie et bien souvent dans le trajet de soins, quand il commence à y avoir démence ou problèmes cognitifs, on n'en parle pas. Patient representative 5 – FR workshop*

Among the topics that are poorly discussed, the advance care planning appears to be insufficiently known by patients.[198] The overall poor implementation of ACP was previously identified.[129, 199, 200] But, more generally, in 2022, only 33.9% of the patients in Belgium reported having a health care plan, gathering their needs regarding health and well-being: an age gradient was found (older patients having more often this health care plan) and a socioeconomic gradient was also evidenced (patients with lower SES having one more often).[11]

6.2.2.2 *Financial barriers prevent receiving adequate support*

Despite existing financial support, patient representatives mentioned that financial aspects influence the care trajectory, particularly when the patient wish to stay home.

> *Ik denk dat het financiële kunnen van een patiënt heel zeker een zwaar bepalende factor is in… Of juist bij die zorg terechtkomt of niet want… Of dat je kan verblijven op een andere plek dan thuis. Patient representative 1 – NL workshop*

For patients, whose financial resources are not sufficient to cover the fees, a financial support from the municipal welfare centre (OCMW-CPAS) can be needed but, according to some respondents, the length of the procedures is not adapted to the situation of dying patients. As explained by a respondent, it took 30 days to know if the municipal welfare centre accepts to cover the fees, without guarantee of a positive decision, meaning they may have to apply against a negative decision. A respondent explained that they had a dying patient waiting at the hospital, they applied in July at the municipal welfare centre, they received the answer in September and the patient died one week after arriving in the service. This situation can be seen as illustrative of several problems related to cost issues. The patient stayed several months in a hospital where the daily fees are expensive, he was not in need of the hospital care but, if the patient had been transferred before the agreement of the municipal welfare centre, the service may not have been paid. Some respondents explained that they can have an agreement with the municipal welfare centre where they are located but that problems occur when the patients come from another municipality as each municipal

welfare centre has different procedures. As explained by patient representatives, asking for financial support can be difficult for some patients and is considered by some as taboo, which reinforce the financial barriers.

> *Zo ne stap naar het OCMW, dat is ook weer een grens voor veel mensen. […] Ik denk dat een financieel aspect toch iets serieus tegenhoudt. Dat je bij bemiddelde patiënten, dat het toch iets gemakkelijker gaat, dan bij niet-bemiddelde patiënten, denk ik. Ik denk dat er, dat dat toch ook zowat een taboe is. Het ja, financiële: als je het financieel moeilijk hebt om bepaalde zaken in orde te krijgen, om ergens bij te horen, om het gemakkelijk te hebben, denk ik… Ik heb zo in… Bij ons is er zo één patiënt die het financieel moeilijk heeft. En je ziet dat aan alles. Die moet precies meer hare plan trekken dan iemand anders. Patient representative 3 – NL workshop*

Patient representatives pointed the lack of material and financial resources as a barrier to receiving adequate palliative care. For some patients, it implies not being able to afford adapted furniture or comfort therapies. For others, the situation appeared to be more complex, as for those in poor housing and living conditions, what means that they will be oriented to health care structures despite not needing it from a clinical point of view.

> *Il y a aussi les conditions. C'est un public qu'on oublie souvent un peu mais il y a parfois des domiciles qui sont très précaires, limite insalubres. Fournir des soins de qualité dans ce type d'environnement est très compliqué et donc j'imagine que ce public bascule plus facilement en maison de repos ou à l'hôpital quand déjà la précarité est présente. Ce public précaire financièrement et socialement, je ne sais pas comment cela peut se goupiller à domicile. C'est un public avec lequel malheureusement à l'ASBL on est assez peu confronté, pourtant il doit vivre tout autant et ce n'est pas plus la maladie et la fin de vie. C'est vrai que ce public est moins informé de ce qui existe et moins en capacité d'être soutien des personnes malades peut-être. Patient representative 2 – FR workshop*

Moreover, some costs are not covered by the sickness funds as reported by some respondents: they saw that more and more patients have problems to pay. In other situations, the family does not want to pay when the patient is deceased.

> *En soins palliatifs, bah généralement, soit les gens payent, ils ont les moyens, ils payent, la famille paye. Soit on a quand même une part de la population de plus en plus, qui augmente chaque année, de patients avec beaucoup de tensions dans les familles des gens qui ont des dettes et dont les familles refusent les successions et donc les dons couvrent alors l'impayé, mais ce n'est quand même pas rare du tout. A Sp4 unit*

Similarly, some respondents explained that patients and families cannot afford all facilities: this was the case when the patients were oriented to a nursing home but still had their mortgage loans to cover. Although patients can receive a replacement income from their sickness funds, this may be not sufficient to cover the costs they have to face.

> *On accueille de plus en plus qui ont 40, 45 ans. Vous êtes dans une famille avec un conjoint actif, des enfants en bas âge à l'école, si on doit vous placer en maison de repos, ce n'est pas sur base de toutes les économies que vous avez fait dans la vie ou du fait que vous vendiez votre maison. Ce qu'on voit, les enfants, ils restent dans la maison. Qui paie votre maison de repos ? Ce n'est pas la bonne structure de toute façon en plus mais c'est la seule structure, mais je veux dire, quand on est âgé, on peut revendre ses biens, utiliser sa pension pour payer une maison de repos. Quand on a 40 ans et qu'on est gravement malade, on n'est pas dans la même position. Et donc il y a comme ça beaucoup de contradictions, des choses très difficiles à gérer. A Sp4 unit*

Finally, it was also pointed that administrative criteria also prevent patients from receiving additional (financial) support. In Flanders, citizens can benefit from a "*persoonsvolgend budge*t" (transl.: budget related to the person) which aims at covering extra support for those with a handicap.[201] Therefore, it appeared that young patients have more difficulties to receive help and

that they cannot benefit from this budget, limiting the support they can choose themselves.

> *Overheidsgewijs wordt daar ook al een beetje een... De schifting in gemaakt en dat zit je met die leeftijdsgrens van 65 jaar, waar dat mensen ja, meer en minder ondersteuning hebben. Ik denk in het kader bijvoorbeeld van mensen die een persoonsgebonden budget kunnen hebben, denk ik dat zich wel lang thuis kunnen redden door… Als ze misschien zelfs niet op hun eigen netwerk kunnen rekenen, wel professionele ondersteuning in te schakelen, assistenten in te schakelen, thuiszorg in te schakelen… Dan kan er best veel in die thuissituatie. Maar ik denk als er heel veel zorg komt kijken wat dat doorsnee… Wat een financiële last met zich meebrengt, en daar is geen extra gedragenheid of niet voldoende gedragenheid, want nul is het zelden, maar niet voldoende om de lading te dekken, dan denk ik dat mensen wel meer in de problemen komen. En misschien ook als er geen netwerk is, minder gemakkelijk hunne weg vinden naar wat er misschien nog wel bestaat, want oké, palliatieve thuiszorgequipes… De ondersteuning is gratis, maar hebben ze dan genoeg begeleiding om hunne weg daar naartoe te vinden, als er geen netwerk is om hun daarin te ondersteunen? Patient representative 2 – NL workshop*

6.2.2.3 *Not all home can be adapted to the needs of the palliative patient*

Patient representatives and respondents pointed several problems when it comes to adapt the home of patients. Respondents mentioned that not all houses are adaptable for delivering palliative care (e.g. not possible to install a medicalised bed, no spare room for the patient…). Patient representatives identified additional problems. Firstly, not all aids are accessible to patients: they need to comply to several criteria such being acknowledged as a disabled person to benefit from adaptation of their home. This cannot be the case for all palliative patients. Secondly, it appeared that it took time to have a home visit from a counsellor to identify which adaptations are suitable for the home. These services are free but, again, limited to those acknowledged as disabled (independently of their age). Thirdly, the overall process for being granted some aids takes too long with some dramatic consequences for the families. And only those with sufficient financial means appear to be able to afford equipment and furniture to make palliative care at home easier.

> *Je pense que, dans des situations de soins palliatifs, malheureusement il faudrait une dérogation, mais le nombre de témoignages qu'on a de proches qui ont fait une demande d'aménagement de l'escalier, de placement d'un monte-escalier, les sièges, et l'accord intervient après le décès du patient. C'est innombrable. En plus, ils reçoivent des relances : vous avez reçu le droit alors que le patient est décédé depuis six mois, un an, deux ans, trois ans. C'est horrible pour les proches. C'est un vrai bémol, les demandes de chaises roulantes, d'aide à la mobilité, etc., arrivent beaucoup trop tard et donc les familles qui peuvent se le permettre investissent mais sur leurs propres deniers parce que tant qu'il n'y a pas d'accord, ce ne sera pas remboursé. C'est quand même un gros écho qu'on reçoit des proches. Patient representative 2 – FR workshop*

6.2.2.4 *Administrative procedures are burdening*

Despite in palliative care, patients and their families still have to do some administrative procedures that, according to some respondents, can be suppressed: they gave the examples that the hospital invoices cannot be sent directly to the sickness funds for the costs covered by the national health insurance. This can have negative consequences for the professionals as they are not paid.

> *Une dame […] elle avait la mutuelle, mais elle ne rentrait pas ses papiers. Elle avait une situation de vie difficile, etc, sauf que nous, [les soignants] on n'a jamais été payés parce que l'hôpital ne peut pas envoyer à la mutuelle. Elle ne rentrait pas ses papiers ou quand elle rentrait, elle gardait l'argent. A Sp4 unit*

Similarly, patient representatives pointed this administrative burden which appears time-consuming and without any meaning. It adds to the mental and psychological distress of the patients and their families. Again, patients with personal resources appear to be more likely to find support, even they experience it as against their principles ("piston").

Il a fallu que je fasse intervenir une personne que je connaissais bien alors que je déteste cela et en quatre jours, cela a été bouclé. Quatre jours, cela veut dire que c'est quand même possible. Moi je me pose toujours des questions de savoir comme cela se fait que cela mette autant de temps, que c'est vraiment très fonctionnaire, paperasserie et tout, et c'est vrai que la simplification pour des patients comme nous qui sont chroniques et qui vont vers du palliatif à 80-95 %, ce serait bien un peu de s'alléger parce que la lourdeur administrative nous pèse aussi énormément psychologiquement. C'est vraiment très, très pesant de demander la continuation de médicaments et de se demander si la personne va bien le mettre dans la bonne case ou va cocher les bons trucs parce que, sinon, cela va être refusé, on n'aura pas son médicament. On n'a pas besoin de ce stress-là et de ce poids psychologiques-là. On est déjà malade et on demande juste de continuer un trajet de vie le plus dignement possible. Patient representative 5 – FR workshop

Procedures allowing patients to certain benefits were perceived by patient representatives as heavy and adding to the overall burden of the patients and their relatives.

Je moet stap voor stap alles zelf uitzoeken. Je moet stap voor stap voor elk dingetje andere documenten aanleveren. Ja, van het moment dat er één lettertje verkeerd staat op een document wordt het teruggestuurd. Dat is, ja, daar is mijns inziens nog heel veel werk aan de winkel. Patient representative 1 – NL workshop

Social services of hospitals and sickness funds were mentioned as poorly contributing to the social support of the patients and families, although, according to some patient representatives, it should be their role.

6.2.2.5 *Assessment criteria lack of contextualisation and integration*

During the workshops, two assessment grids were discussed and pointed as problematic by the patient representatives. The first assessment concerned the evaluation of the autonomy of the patients, especially for those willing staying at home. The second assessment concerned the evaluation of the palliative care status. From the discussions, it appeared that these assessments are too restrictive and not enough related to the context of the patients.

When assessing the autonomy, it was pointed that the current evaluation does not consider the living context and the interaction between the different activities.

Participant 1: Ja, want ik denk dat nu heel vaak nog de criteria om ergens binnen te geraken, tussen aanhalingstekens, ja, heel hoog liggen. Ik ga u het voorbeeld geven van wat bij mij posttransplant voorvalt: voor één of andere kleine tegemoetkoming krijg ik een onderzoek of iemand van de mutualiteit bij mij om vragen te stellen. En de vraag die gesteld wordt is van: kan jij zelf een boterham smeren?

Participant 3: Of kan je douchen?

Participant 1: Kan je douchen vind ik al… Maar kan je zelf een boterham smeren? Ja, ik kan die boterham smeren. Maar kan ik zelf uit mijn bed naar de koelkast stappen, alles op tafel zetten, een bord nemen, een mes nemen en dan mijn boterham smeren? Nee. Ah, maar ik kon een boterham smeren, dus dan kreeg ik geen puntje op de lijst. Ik denk… Wie moet in zo'n palliatief huis terecht kunnen? Iemand die een ja, een diagnose krijgt van: je kan niet meer beter worden. Ik denk dat sowieso iedereen die nog thuis kan blijven, die zal thuis willen blijven. Maar op het moment dat dat niet meer lukt, ja, dat je dan wel op die plek terecht kan. En niet lukken wil niet zeggen dat het over de ganse lijn niet lukt. Jij kan palliatief zijn of ziek zijn in ruime zin ook en bepaalde dingen niet meer kunnen, maar daarvoor andere dingen nog wel heel goed kunnen. En ja, dat het feit dat je, ja, één ding, twee dingen, drie dingen nog wel

goed kan, geen belemmering mag zijn om dan wel daar terecht te kunnen. NL workshop

Moreover, the patient representative explained that these assessments poorly consider the impact of fatigue on the ability to perform multiple daily activities in a row, which may lead to an inappropriate response when it comes to receive support.

Niks mis mee, maar ik was zo vermoeid dat ja, naar den bakker om brood lopen voldoende was… En dat is letterlijk hier een halve straat verder, voldoende was om daarna een half uur te moeten platliggen. Dat een maaltijd bereiden een half uur rust vooraf en een uur rust daarna betekende. Dus ja, kan je dan nog voor jezelf zorgen? Ja, als je een heleboel andere dingen niet meer doet. Wat erop neer komt dat je op een bepaald moment in uw leven enkel nog doet wat dat er moet gebeuren om ja, gewoon de pure basisbehoeftes… Maken dat je gewassen bent, maken dat je gegeten hebt. En ja, voor de rest nog wat uwe boel op orde houden en daartussen, ja, continue moet rusten. Dus ja, zou dat een hulp geweest zijn in die fase van mijn leven mocht ik ergens terecht gekunnen hebben? In bepaalde periodes zeker wel. Patient representative 1 – NL workshop

When it comes to assessing the needs for palliative care (and thus granting a "palliative care status"), the problem appeared to lie on the tension between the assessment done by the doctor and the moment where the support is granted. Doctors must answer the following question: "*would you be surprised if the patient dies within one year?*" Support, according to patient representatives, is granted for the 3 last months of life. Consequently, several patient representatives mentioned that there are more patients in palliative situation than those currently benefiting from palliative care support, that is those with an official status of palliative patients.

I faut distinguer les personnes qui vivent, dans les faits, une situation médicale de soins palliatifs et les personnes qui sont reconnues en soins palliatifs parce que c'est peut-être la pointe de l'iceberg, pour certaines pathologies en tout cas. Je pense à des pathologies comme Parkinson, comme Alzheimer et démence associée. Patient representative 2 – FR workshop

Patient representatives also discussed the length of the palliative phase or the moment where palliative phase starts. No defined length or moment emerged as it depends on the nature of the disease, its evolution, and other non-medical aspects (i.e., personal goals, family context, housing conditions…). As explained by a patient representative, some diseases, such amyotrophic lateral sclerosis (ALS), imply that patients are directly considered as palliative patients because of their short-term life expectancy.

Researcher: Bij ALS ben je dan direct palliatief?

Participant 2: Ja, klopt. Omdat je met een ongeneeslijke ziekte zit. Mensen overlijden gemiddeld binnen 33 maanden na start van symptomen. Dus zij hebben sowieso al een heel korte levensverwachting en geen hoop op genezing. Zij kunnen meteen beroep doen op palliatieve begeleiding, los van de terminale begeleiding. […] – Patient representative 2 – NL workshop

Related to this, some patient representatives discussed the concept of life expectancy, pointing the difficulty to estimate it. As perceived life expectancy is a key criterion of the PICT scale, one may question its relevance. These concerns were also raised on different occasions during the whole project.

Persoonlijk denk ik dat het heel lastig is om daar een specifieke termijn op te zetten. Patient representative 1 – NL workshop

Ik vind zo de beperking van die levensverwachting te kort door de bocht om te beantwoorden aan het scala van factoren, die dat in de context ne rol kunnen spelen wanneer iemand daar beroep op kan doen, of zou moeten kunnen doen op basis van de noden die dat er ook zijn op dat moment. Patient representative 2 – NL workshop

6.2.3 Who benefit from palliative care in Belgium?

Organisations were also questioned about the patients who benefit from palliative care in Belgium, according to different characteristics; age, life expectancy, clinical status, living place, as well as social and financial aspects. First of all, older patients seem to benefit more often from palliative care than youngers, especially those aged less than 18 years old (Table 54 0). Patients with a shorter life expectancy, unstable clinical status, needing complex care or having complex needs also seem to benefit more often from palliative care, as compared with patients with a better life expectancy or a more stable clinical status. These results are consistent with the current organisation of palliative care in Belgium with an emphasis on hospital-based care. Moreover, it was expected that older patients will benefit more of palliative care as the average year of palliative care patients is around 80 years.

During the site visits, several respondents mentioned the lack of palliative care for children and adolescents as a growing problem. Some mentioned the adolescents of 16-18 years as lacking possibilities for accompaniment while other pointed out the adults aged of 40-45 years with children as lacking of appropriate solutions. Now, some of these patients are accommodated in nursing homes but some respondents pointed that it is not suitable for them.

> *La question des gens plus jeunes qui ne pourraient pas rester à domicile mais qui n'ont pas leur place [à l'hôpital] et meurent en maison de repos. Et c'est pas que ne pas avoir leur place hein. Vous vous rendez compte ? Vous avez 45 ans, ça n'allait plus de rester à la maison et on vous met en maison de repos avec toutes les personnes âgées. C'est quand même horrible. A Sp4 unit*

Most importantly, organisations reported that the patients who most rarely benefit from palliative care are those with mental health problems, intellectual disability, or dementia, those with poor social network or homeless patients. A quarter also reported that patients with financial difficulties rarely benefit from palliative care. Some organisations also stressed that palliative care is less accessible for patients with chronic diseases. This overall lack of attention / resources for vulnerable groups because of culture, socioeconomic aspects and mental health was also pointed by the Flemish Palliative Care Federation.[202]

> *Vooral mensen met chronische ziekten hebben weinig toegang tot palliatieve zorg. Zolang oncologische patiënten bezig zijn met behandeling (o.a.. 'comfort' chemotherapie) wordt niet gepraat over/of verwezen naar palliatieve. Gedetineerden en mensen zonder papieren hebben amper toegang tot palliatieve zorg. Palliative care unit 4 – Online survey*

> *Personen met een beperkt netwerk, die geen personen hebben die advocaat voor hen zijn om te bekomen wat er nodig is, vallen vaak door de mazen van het net. Hospice 2 – Online survey*

From the desk search, it appears that other residential facilities, such as psychiatric care homes or institutions for persons with (intellectual) disabilities, are not required to have staff member specialised in palliative care. To date, no specific information was found regarding the offer of palliative care in specific settings such as inpatient psychiatric services, residential services for persons with disabilities, prisons, or reception centres for asylum seekers, to name a few. It appears that the offer is organised on a local basis, in collaboration with healthcare professionals of the home services and the palliative care network.

This was confirmed by some respondents who explained that, for some profiles, it is even more complicated to receive quality palliative care. Some respondents explained that they frequently receive calls from institutions for people with intellectual disability with questions related to end-of-life care or from psychiatric institutions.

> *"Les psychiatres ont horriblement peur de la mort et nous [les médecins de soins palliatifs], on a peur des fous » - Respondent from FR site visit 5*

Surprisingly, only 70% of the organisations reported that patients hospitalised in palliative care units received palliative care. This finding was no further explained in the comments let by the organisations. One may hypothesise that, in a global context of shortage of healthcare professionals and pressures on the health services to be more efficient by shortening the

length of hospital stay, some organisations feel that this is likely to negatively impact the quality of care provided to the patients. This needs to be further explored in a different study.

For patients in nursing homes, half of the organisations reported that patients 'sometimes' receive palliative care. This finding appears as less surprising as some respondents – during the interviews - commented about the shortage of (qualified) staff in nursing homes and the limits of the health care that can be provided in a nursing home. It was also mentioned that palliative care is organised too late in institutions, preventing residents of these structures to access palliative care in a timely manner.

6.3 Problems and gaps for informal caregivers and volunteers

In addition to the barriers that families can share with the patients, during the desk search, the site visits, and the workshops with patient representatives, we identified some barriers specific to the informal caregivers. We decided to present it in a separate section as informal caregivers have their own needs and preferences, which should not be confounded with those of the patients. In the same section, we also included volunteers as they are at the intersection between professionals and families.

6.3.1 Relatives are highly solicited to take care of palliative patients

Patient representatives underlined the importance of the presence of a supporting entourage, as it is considered as a predictor of a good end of life.

> *Er kan niet zoveel gebeuren medisch, maar je bent niet goed genoeg om thuis te zijn, voor jezelf te zorgen, of je bent niet genoeg omringd om thuis te zijn, en daar een stuk verzorgd te worden. […] Als er goeie mantelzorg is, of dat dat nu, ja, binnen het gezin is, of binnen de familie, of ja, toch eerdere professionele mantelzorg… Maar als er ja, goeie mantelzorg is, dan denk ik ja, is die persoonlijke zoektocht waarover dat we het net hadden, ja, zou die denk ik wel een stuk gemakkelijker verlopen. 't Is sowieso soms gemakkelijker als je dingen met twee kan bekijken, zeker als je je fysiek of mentaal niet goed voelt, van… Dat iemand mee met u kijkt en zoekt en zorgt, ja, kijkt en zoekt naar wat mogelijk is, wat er bestaat. En zorgt dat je, ja, op de juiste plek terechtkomt of bij de juiste mensen terechtkomt die je verder kunnen helpen. Patient representative 1 – NL workshop*

It was also reported that the fatigue of informal caregivers is often the trigger for a decision to transfer the patient to a health care setting or to increase the help at home. The complexity of care appeared not determined by the technical medical interventions - therefore sufficient professional help can be called for- but the continuous caring for a sick person in home environment put a lot of weight on the informal caregivers/relatives. Respite solutions for relatives appear to be lacking, which was also mentioned by respondents during site visits.

Patient representatives and respondents explained that one needs to be cautious when relying on relatives to provide support for palliative patients. It was pointed that not all relatives are able to take care of a palliative care patient for various reasons (education, socioeconomic resources, literacy, social support), some being implicit and rooted in a complex familial history. This requires that professionals take the time to assess the willingness and capacities of the relatives to endorse this role.[203]

> *On fait comme si c'était tous les mêmes proches mais chacun a ses ressources personnelles de nouveau en termes socio-éducatif, en termes de réseau élargi, de pouvoir faire appel que ce soit à un voisin surtout quand les crises se passent la nuit, c'est effrayant pour le patient, c'est effrayant pour les proches aussi. Patient representative 4 – FR workshop*

A patient representative expressed his feeling that the medical sector uses relatives as substitute for delivering health care, without taking in consideration that the relatives do not know how to do it. It appears that some professionals consider that being a family member automatically implies that the relative is ready to endorse a role of informal caregiver without looking at the consequences for the relatives.

Parfois, le corps médical peut se substituer en disant « vous allez bien vous occuper de lui parce que vous êtes le proche » mais on est complètement démuni. Patient representative 5 – FR workshop

This implicit assumption by professionals and – to some extent – by the society that relatives should become the first caregivers of patients can explain why some informal caregivers have difficulties to ask for help or feel guilty to ask for help.

Effectivement, le proche s'épuise et c'est aussi un très gros problème. Il n'a pas le droit de le dire stop ou il ne veut pas ou culpabilise parce que ce n'est pas lui le malade. Donc il va au bout de ses forces et après, il craque. C'est déjà aussi une autre problématique mais je pense qu'avant toute chose, moi, tout ce que je vois ce sont des mamans d'amis qui ont fait tout ce qu'elles pouvaient pour les garder à la maison. Patient representative 5 – FR workshop

For some respondents, the burden increased for the families because of an overall lack of support for palliative care patients. These respondents stressed that palliative care / having a relative in a palliative stage is a financial and a mental burden for the families. Respondents working in rural context mentioned that as the rural environment slightly disappears, the familial solidarity disappears too, and patients find themselves alone. This contributes to the increase in the demands for home assistance and home care but also in respite care, which is perceived by some respondents, as lacking.

Patient representatives also explained that relatives often must take the difficult and / or urgent decisions, especially when the patient is staying at home or is no longer able to express its willingness, adding to their psychological burden. This can be even more stressful when the relatives lack of proper information or have a poor understanding of the situation and of the consequences of the decision.

Les décisions difficiles et les décisions d'urgence, ce sont souvent les proches qui doivent les prendre. Patient representative 2 – FR workshop

Therefore, despite their importance as partners in the care trajectory, it appears that relatives still feel not respected by the healthcare professionals.

Moi, je trouve que le proche n'est pas du tout respecté. On parle au patient et le proche, on l'ignore. Patient representative 4 – FR workshop

For some patient representatives, medical paternalism remains a problem, which contribute to a poor consideration of the patient and relatives' voices.

[…] Ce paternalisme du médecin, il est grand temps que ce paradigme disparaisse. […] le médecin a l'expertise médicale mais les proches et les patients, ils ont l'expertise du vécu avec la maladie 24 heures sur 24. On n'a pas de jours fériés, on n'a pas de vacances, on n'a rien. Qui de mieux que nous savons ce qu'il en est pour nous et c'est un médecin qui va encore voir deux à trois fois par an pendant un quart d'heure qui va décider de notre avenir. Cela ne me convient pas du tout. Patient representative 5 – FR workshop

6.3.2 Caring for a relative is emotionally and physically burdening

Several Belgian studies documented the problems as experienced by informal caregivers.[204-210] Around 33% of the Flemish adult population was involved as an informal caregivers during year 2020.[211] Seven out of ten informal caregivers were still professionally active. The same study also showed that 50% of informal caregivers experienced it as emotionally burdening and 24% experienced it as physically burdening. They also reported that 6% of the informal caregivers with a professional activity got sick because of the burden of the health care giving. Alongside those working while caring for a relative, several most vulnerable groups emerged: older informal caregivers, young caregivers, those with a migration background or with a poor socioeconomic status, those caring for a patient with physical and mental vulnerabilities or dementia, and parents of a child with disability or chronic disease.[144]

The burden is also evolving over time and over the course of the day, supporting the need for flexible solutions as well. As explained by a respondent, the burden for the families is especially high during the nights.

« Moi je pense que pour les proches ça reste quand même toujours très compliqué quand les nuits, quand le patient est agité, vous passez pas une seule bonne nuit, vous pouvez tenir. Oui une semaine 2 semaines mais après ? C'est quand même. Compliqué, hein ? Alors il faut vraiment que les patients soient stables" – Respondent from FR site visit 5

When a presence is needed, patients and families can call for a professional caretaker, but some respondents explained that there is a shortage of caretakers. They also reported that the level of competence is highly heterogeneous and that there are numerous caretakers who are not legally registered workers, which jeopardise both patients and caretakers. Moreover, these services are not financially accessible.

The burden can also be related to the multiplication of the services necessary to maintain the patient at home: as experienced by some respondents, in some case, the patients and their families feel invaded in their intimacy because of a lack of coordination (e.g. all professionals arriving at the same moment), the multiplication of the professionals or the lack of continuity (having a different nurse every day, lack of transmission of the information..).

6.3.3 Volunteers in palliative care

As mentioned in the section 4.4 in the Chapter 4, volunteers play an important role in the palliative care sector, mostly contributing to the social and spiritual care. Like other sectors, the COVID-crisis impacted the retention of the volunteers and some respondents explained facing difficulties to find volunteers. Some moments of the week are more difficult to cover as explained by a respondent, particularly weekend and nights but also some periods of the year (school holidays).

From the site visits, it emerged that there is no common approach of volunteer work across the different services and facilities. Large organisations appeared to have a more professional approach of the volunteers with a well-established procedure for involving, training and supervising them while smaller organisations appear to have a more person by person approach. Some respondents identified areas for more training such as manutention, legal aspects or the culture of palliative care. For some respondents, the training is time-consuming, especially if there is no guarantee that the volunteers will stay. Moreover, if a large number is positive, it also requires more time for the management by the coordinators.

Various practices regarding compensation were observed: usually only lunch is provided, not all organisations reimburse transportation fees.

It was also observed, from the different site visits, that volunteers perform a wide range of tasks and activities: not all volunteers have direct contacts with the patients (e.g. management of the website, gardening, organising charity events) while, in some organisations, volunteers appeared to participate to the health care delivery. This observation raises some ethical concerns about the limits of the investment of the volunteers and the risk of having volunteers doing professional work. Respondents from a Sp4 explained that the status of their volunteers was discussed with the unions to avoid "illegal" or "false" work and using people instead of salaried staff (the law of 03.07.2005. frames the statutes of volunteers: volunteer work is free and unrestricted, with any salary paid, it should be done for a third person outside the private sphere – i.e. helping a neighbour is not volunteer work-, in a non-profit organisation and is performed outside an employment contract).

Some respondents pointed the lack of clarity about the patient confidentiality and to which extent the medical information can be shared with the volunteers (e.g. when a patient is deteriorating or when an euthanasia is planned).

Therefore, not all organisations reported positive experiences when involving volunteers. Some respondents explained that it requires lots of work to manage them and that the experience was complicated at some point because of the profiles of the candidates. They mentioned people who wanted to become psychologists but are not and are frustrated, people pretending having gifts to help patients to go to the "*au-delà*" or people wanting to convert patients. According to the respondents, this leads to the discouragement of the team and the project was no more invested.

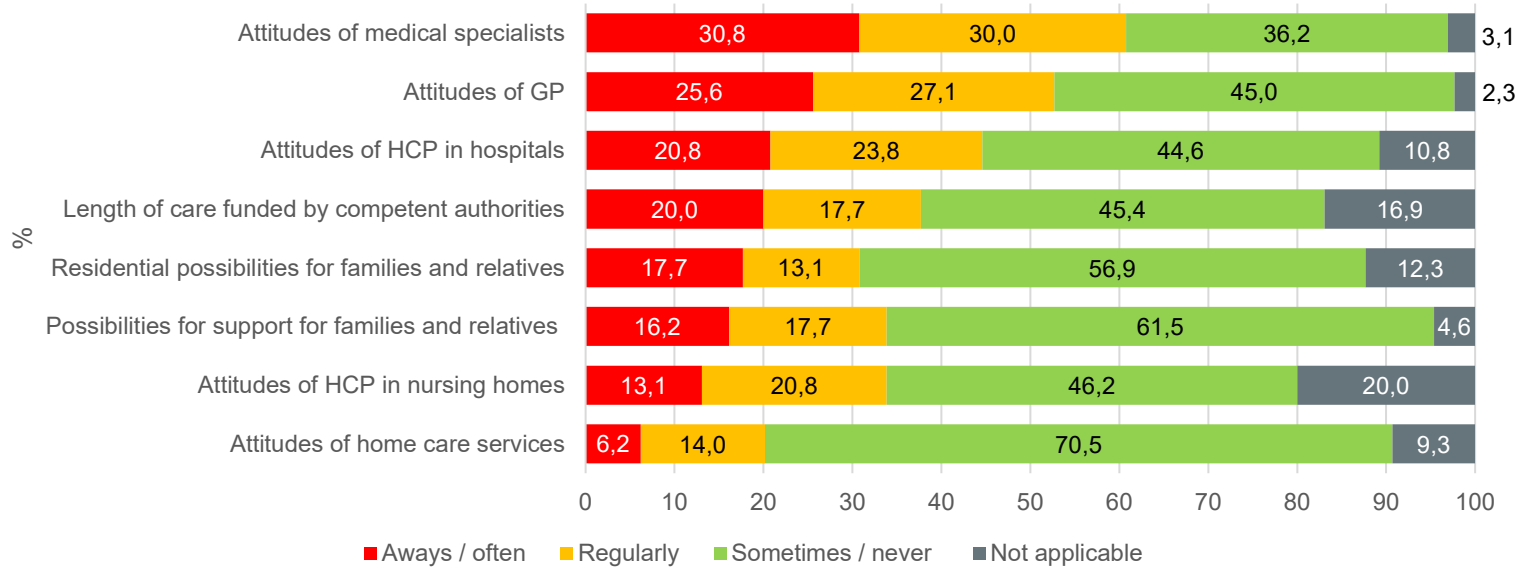
Finally, from the site visits, as there is no recognition of the value of the work done by volunteers in end-of-life and palliative care, this can lead to discouragement: volunteers and informal caregivers play a major role but, according to respondents, this is still undervalued by the society. Some respondents, highly relying on volunteers involvement, questioned how volunteering work can be better valued, by suggesting that these volunteers may be entitled to the same status that informal caregivers. For some respondents, valuing volunteers is not only a question of remuneration but also possibility to be trained.

6.4 Problems and gaps for healthcare professionals and services

6.4.1 Barriers related to health services impacting access to PC for the patients

From the online survey, attitudes of specialists were always/often a barrier for the patients when they need to access palliative care according to 60% of the organisations, followed closely by attitudes of GP and of hospital teams (Figure 17). “Attitudes” corresponds to the knowledge, competences and skills related to palliative care.

Figure 17 – Barriers related to health services impacting access palliative care for patients according to organisations (N=130)



From the site visits and the workshops, it also emerged that **healthcare professionals need to shift from curing to caring as a starting point for more accessibility of palliative care.** Some respondents with a longstanding experience in palliative care explained that delivering palliative care is more than competences, it is a posture. This change in posture appears difficult to adopt for some professionals, especially those whose primary mission is to treat a disease (i.e. oncologists and GP were mentioned). But not all diseases are curable and may therefore require this palliative approach. According to patient representatives, some healthcare professionals do not think about palliative care for patients with a chronic disease / a rare disease as the evolution is different, even though palliative care can help patients to improve their quality of life.

Est-ce que les médecins, etc. pensent à un moment à évoquer ce volet soins palliatifs qui permet quand même un soutien supplémentaire à domicile, un soutien financier aussi parce qu'on y pense très fort et très vite dans des situations de cancer, d'onco, etc. mais peut-être beaucoup moins vite dans certaines pathologies, dont certaines maladies rares qui, pour moi, font partie des maladies chroniques mais qui ont une spécificité. C'est qu'elles sont très peu connues des médecins, que l'évolution est souvent peut-être encore moins prévisible. Patient representative 2 – FR workshop

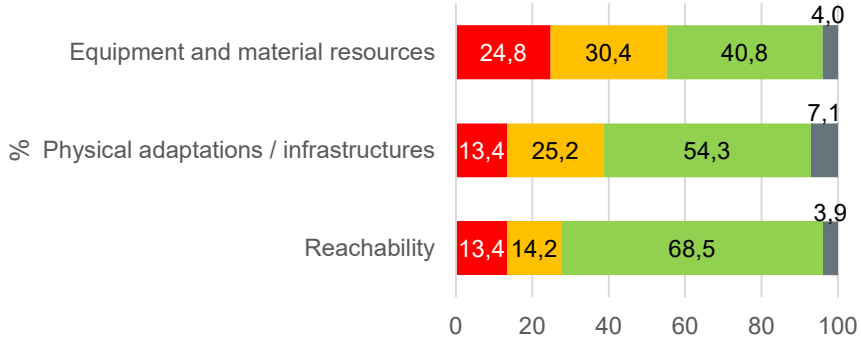
6.4.2 Barriers experienced by healthcare professionals and health services

6.4.2.1 Barriers related to reachability and equipment

Having the proper equipment and material resources to deliver quality palliative care seemed to be a more important barrier than having the proper infrastructure to deliver palliative care (e.g. having a residential facility devoted to palliative care) or the reachability of the existing services, that is the geographic accessibility, with a quarter of the stakeholders experiencing it always/often (Figure 18). Therefore, some respondents perceived that the hospital context is too impersonal: according to them, there is a need for small and flexible structures, allowing for a warm and comfortable environment for the patients and the families but also for the healthcare professionals.

Examples of the lack of appropriate equipment or material resources were shared during the site visits such as access to some medications through the community pharmacy, availability of syringe pumps, medical equipment for dialyse at home, blood transfusions in some nursing homes…but also problems related to the patient 'environment such as the absence of a functioning fridge to store medications or no room in the house for a medical bed.

Figure 18 – Barriers for professionals related to reachability and equipment when providing palliative care in Belgium (N=127)



The results related to reachability must be nuanced as, from other different data sources consulted, it therefore appeared that access to specialist palliative care is unequal across Belgium. The most apparent inequality in the access and availability concerned the Sp4-beds as pointed – among others - by the Federal Cell, the Federal Council of Hospitals, and the *Palliativ-Ppflegeverband Ostbelgien* (PPV).[21, 126, 162] An interesting illustration is reported by the PPV: a patient living in Sint-Vith needs to travel to Moresnet (75km distance) or Hermalle-sous-Argenteau (76 km) to find a PCU. Indeed, there are no palliative beds in Sint-Vith or Malmedy (25km). When visiting decentralised PCU, respondents also confirmed that palliative patients often travel long distances to receive palliative care: it can be because of a lack of availability at local level (see section 6.4.2.3) but also for more personal reasons such as being closer to family, philosophical preferences or being in a more natural environment.

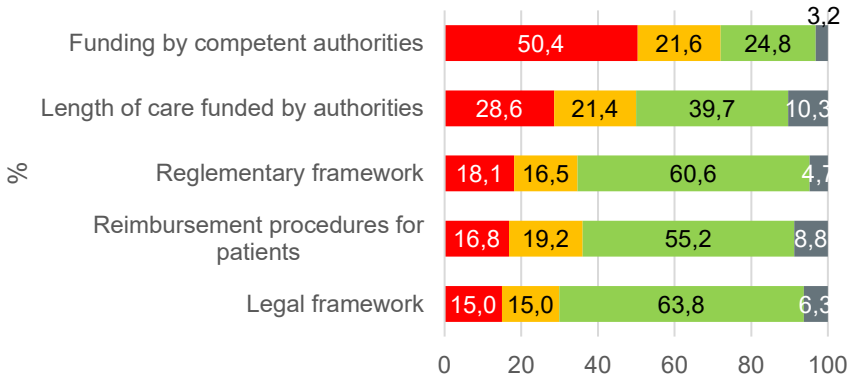
When it comes to the content of palliative care itself, differences in practice were also found. As observed in the interviews, it appeared that not all day care centres provided the same complexity of care: being located in a hospital or in its close environment appears to be a facilitator for the delivery of complex care while, in some centres, patients whose condition was deteriorating or too complex were oriented to another health care facility.

The same concern regarding hospital services organised in different campus was raised by the Federal Cell (2017): there should be a guarantee that a patient in need of palliative care on every campus can effectively be cared for.[19]

6.4.2.2 Barriers related to legal framework and affordability

Duration of care financed by the competent authorities was also often/always a barrier for the patients, according to 20% of the organisations (Figure 19) but is also a problem for professionals according to the organisations. However, barriers that stakeholders experience most often were related to the financing by the competent authorities (50%, Figure 19): funding problems were previously mentioned.[202]

Figure 19 – Barriers related to legal framework and affordability experienced by professionals when providing palliative care in Belgium (N=127)



Funding and financial issues

Financial difficulties were a recurring problem for the respondents met during the site visits: some recalled that without agreement, no clear funding mechanism exist. During the site visits, some initiatives promoting PMC were stopped because of financial problems. One of the visited PCU previously had a day centre that was stopped because of a lack of funding. It was perceived as a key component for respite care but as they had situations where the patients died, it implied having healthcare professionals to manage it and not only volunteers. This led to an increase of the overall costs.

Some respondents pointed out the overall increase of the costs: a respondent explained that the salary mass has been indexed but that the subventions were not. All palliative day care centres, except one, mentioned they had a financial deficit of at least 50 000 to 100 000€/year (despite their efforts to search for additional private or charity funding). Several stated that they survived with material and financial support of another funder (e.g., the hospital nearby). Due to the yearly financial deficit of some centres, the future of these facilities remains insecure according to respondents. Most of the respondents stated that they already invested a lot of time to lobby and plead for a different governmental recognition (but up till now there is no solution). Another perceived threat by the respondents when it came to their future is the higher out-of-pocket payment for the palliative patients (what might hamper potential patients to choose for the facility). Some respondents also emphasised that the total cost for this kind of palliative stay was a lot cheaper than the cost of a palliative hospital stay.

As explained by respondents working in hospices, out-of-pocket expensed for the patients are 50 – 70€ per day (the same price as for other elderly home residents). This is perceived significantly higher than the cost people pay in the hospital. Respondents also often rose problems regarding reimbursement of the hospice stay. For the sickness funds the facility was not considered as "short stay" if the patients died in the hospice. Although they stayed in a recognized short stay bed, this was regarded as an effective inclusion in the elderly care home. According to the respondents, the reason was that regulations state that a “short stay” can only occur if there actually

was a discharge home, which was not the case in 99% of hospice admissions. As a result, they lost the allowance for admission to short-term accommodation, which is granted by many health insurance companies. Moreover, as these people were not cared for in a home environment but in an elderly home, respondents expressed their fear that the patients were at risk of losing their 'palliative home care lump sum.'

Most of the services – including Sp4 units - benefit from charity or sponsoring to cover additional activities. But, for some respondents, the money received from charities, although important, did not allow them to cover for the expenses that are not covered by the public subventions. Moreover, these sources of revenues were not sustainable over time.

The absence of a clear funding mechanism lead to various practices when it came to the patient personal contributions.

As funding sources were multiple, this added to the complexity of the management and lead to complicated financial situations according to several respondents. The lack of a sustainable funding created lot of uncertainties: some respondents explained that the staff was not always aware of it as the management tried to preserve them, but this created stress. Some respondents managing innovative projects explained that without agreement, sickness funds and private insurance did not want to intervene in the costs. During a site visit, a respondent explained that they negotiated for years with some sickness funds and private health insurances: some accepted to cover for the fees but not all sickness funds or health insurances accepted. These differences in the cost coverage created inequalities between patients, depending on their insurance status and their financial resources. As there is no funding by the competent authorities, "*monsieur et madame tout le monde*" cannot access the initiatives as they need to be able to cover for the costs.

Barriers regarding legal and regulatory framework

Regarding the legal and reglementary framework, during the site visits, respondents shared that the current agreement system is complex and not flexible. Some requirements and obligations were difficult to achieve for small organisations. A respondent gave the example of hiring professional staff, which is costly but not needed in their model of home-like palliative care where the patients keep their usual healthcare professionals. The current norms for health services do not allow for flexible models supported by small non-profit organisations or citizen-led initiatives, although these models were perceived by some respondents as more able to meet the patients and family's needs.

Even large organisations appeared to face problems when it came to the legal and regulatory framework. It was mentioned that the current regulation for the length of stay in a palliative care unit is not appropriate and does not take into account the uncertainty of the death. Consequently, several respondents reported the violence of saying to the patient who is not dead after the stay in palliative care unit "now you go back home". For some respondents, asking the patients to leave created misunderstanding and anxiety but also led to violent and aggressive reactions from the families (i.e. a family lawyered up against a discharge decision).

> *« Pour ces patients-là de se dire en fait je suis palliatif mais au fait on veut plus de moi, c'est vraiment ça qu'ils sentent hein. On veut plus de moi, je peux pas rester ici et pourtant. Et alors souvent la famille vous dit mais il est palliatif quand même. Pourquoi est-ce qu'il peut pas rester dans une unité palliative ? » - Respondent from a Sp 4 unit, FR site visit*

Considering the opportunities of hospitalisation at home, some respondents stressed that there is no need for additional medicalised structures: they expressed that hospitalisation at home already exists and can care for those in need for specialised care, under the conditions that the care offer is expanded, meaning the legal and regulatory framework needs to be adapted.

Also facing an increase of their workload, the hospital mobile teams are insufficiently funded. The current funding mechanism is perceived as insufficient to cover the current activities by the Federal Council of Hospitals (Advice FRZV/D/594-3 – January 2024)[162]. In his reply, the Federal ministry of public health agreed on the necessity to reinforce these teams (budget of 5.3 million) but the budget was not available at the moment.

On their side, patient representatives explained that patients underused the possibility of attending a day centre related to a nursing home because the admission criteria do not allow young patients to access it (less than 70 years old), pointing the problems related to the reglementary framework. For short stay in nursing homes, according to patient representatives, patients were supposed to stay for a minimal number of months, which is not always adapted in end-of-life. For people with disabilities, a patient representative pointed that there is a lack of day care centre for people with disabilities, on the model of the existing day care centres for elderly.

From the discussion with the patient representatives, it appeared that the current offer has not considered the evolution of the needs, implying that the current reglementary framework is no longer relevant. Some specific groups are ageing while a decade ago, their life expectancy was shorter. Consequently, the institutions where they live also need to evolve with them. On the contrary, some diseases are more quickly diagnosed at a younger age and patients may live longer than before but will need other health care structures.

> *Les structures handicap ne sont pas adaptées au vieillissement et aux besoins médicaux, aux besoins de soins des personnes et les structures maisons de repos ne sont pas adaptées à des personnes plus jeunes. Patient representative 2 – FR workshop*

According to the patient representatives, it appeared that the current offer still struggles to accommodate for chronic and acute needs at the same place (e.g., residents of nursing home are sent to hospitals when in acute situation) or to cope with the instability of the patients. It also emerged that the offer is still limited in its ability to integrate the 4 pillars of palliative care, the focus being mostly on somatic and psychological care. This was also reported as an unmet need of palliative care patients: some respondents pointed the lack of integration of spiritual needs although it should be done according to the law on palliative care.

This inadequacy of the current offer seemed even more pronounced when it came to younger patients, at the intersection of home care and hospital care, who appeared to struggle when looking for an adequate (residential) offer in palliative care.

> *Enerzijds ben je goed genoeg en wacht je thuis af. Er is een andere groep ja, die absoluut niet goed genoeg is en dat die dan ja, heel lang periodes in het ziekenhuis verblijven. Zeker ook omdat er ja, voor mensen met leverziektes vaak geen mogelijkheid is om op een andere plek terecht te kunnen. Ook niet in die RVT's [Rust -en verzorgingstehuis]. Niet in de revalidatiecentra, niet in ja, wat er op dit moment is aan… Het is ofwel thuis ofwel ziekenhuis, omdat je niet binnengeraakt ook in dat middensegment van ja, van opvang van zorg, van… Patient representative 1 – NL workshop*

Consequently, it appeared that young palliative patients ended up in nursing homes where they did not feel belonging.

> *Maar die jongere generatie, zelf van bij ons, dan kunnen die soms terecht in woonzorgcentra, die voelen zich daar doorsnee absoluut niet op hun plaats omdat die geen voeling hebben met de leefwereld van een generatie die veel ouder is dan zichzelf. Patient representative 2 – NL workshop*

> *Maar de realiteit vandaag is nog altijd, ja, een woonzorgcentrum, dat is voor echt oudere ouderen, en daar ga je alleen maar naartoe als je niet echt anders kan. En dat je daar zelfs als vijftigjarige compleet uit de boot valt. Patient representative 1 – NL workshop*

Assessment criteria and procedures

A particular aspect in the regulatory framework was related to the assessment of the patient's status in order to grant them palliative care benefits. In practice, it appeared that the evaluation of a life expectancy of less than 3 months appears to be a difficult exercise for the GP. While this criterion is explicitly mentioned in the mandatory declaration forms to be used by the GP, the application of this criterion appears - in practice - complex to assess. Organisations, in the online survey reported these difficulties for professionals when it comes to assessing the palliative status and the needs of the patients, delaying the moment where palliative care is offered to the patients (and their relatives).

L'estimation de l'espérance de vie des patients est souvent mauvaise ou erronée. La prise en charge précoce des patients est encore rare pourtant recommandée. l'évaluation de la complexité des besoins des patients n'est pas faite. Palliative care unit 5 – Online survey

[…] L'espérance de vie est souvent un frein à la mise en place pour les médecins traitants et cela complique la prise en charge des autres intervenants dans certains cas. […]. On constate un frein très régulier des médecins traitants : est-ce par peur de devoir intervenir plus souvent (vu leur charge de travail déjà importante ?), j'ai du mal à comprendre et pourtant cela arrive très, très souvent ! Home care service 2 – Online survey

It is noticed here that the general documentation made available by field actors regarding the palliative lump sum and co-payment abolition did not always refer to this criterion explicitly (see for instance the leaflet of the Flemish association for palliative care which summarises this requirement).[212,13] In an ideal world, some respondents suggested that the palliative care staff goes to see the patient before admission to perform a first assessment but, in practice, it appeared that it is only possible if the patient is already in an partner institution (hospital unit or nursing home of the hospital network).

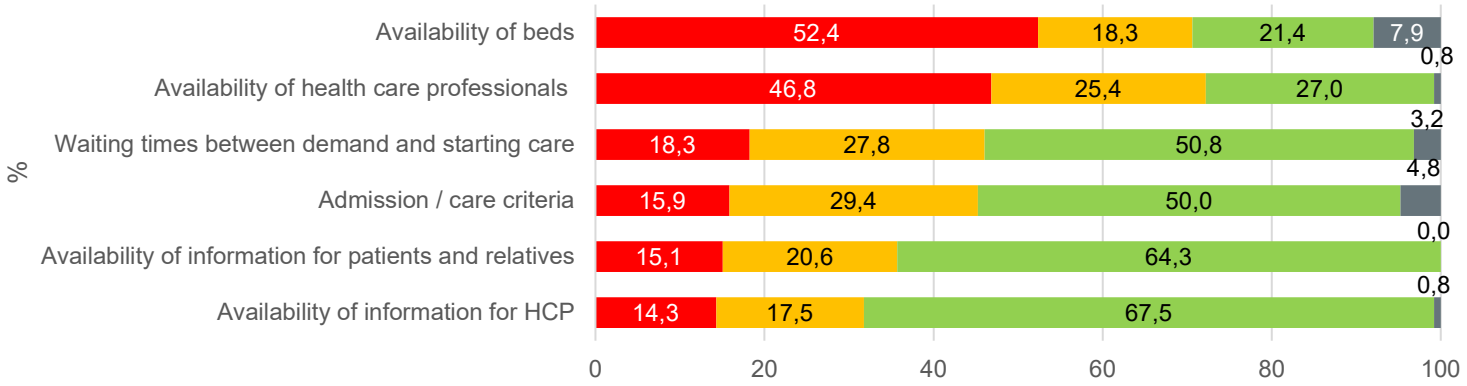
Finally, from the site visits, it emerged that there is a need for a political decision to better frame the current offer of PMC as some respondents were afraid that local initiatives spontaneously emerge, using the same appellation of middle care but covering different services. This was also mentioned by the Flemish PC federation in its 2024 memorandum: "*at the moment, intermediate palliative structures such as "care hotels" or other extra out-hospital accommodations are in a grey zone: they are not structurally regulated and financed*".[202] This was perceived as a risk of adding confusion for both patients and professionals. In that sense, some respondents suggested determining a defined number of beds per province, as done for palliative beds at hospitals, to help framing the offer in palliative middle care.

Similarly, during the site visits, we observed that different admission criteria were applied for services belonging to the same category (for example, the age range is different, dementia patients are excluded/included, etc.). For example, in one "hospice", people from nursing homes were not admitted as patients, because the management of the centre was convinced that nursing homes can also take on the role of palliative care in their establishment. Some of these criteria were explicit, others implicit: if not all services face the same local reality, the lack of uniformity can be seen as working to the detriment of patients requiring palliative care.

6.4.2.3 Barriers related to availability

When it comes to barriers related to availability, availability of beds (52%) and of nursing staff (47%) were the most frequent barriers identified by organisation (Figure 20).

Figure 20 – Barriers related to availability according to organisations (N=127)



Legend: HCP stands for healthcare professionals

Availability of PC beds and residential services

Problems related to the availability of Sp4 beds were previously documented. According to the Federal Council of Hospitals, based on data retrieved in 2023 by Zorgnet-Icuro in 28 Flemish hospitals, no solution was found for 42% of palliative patients in need for an admission in a palliative bed during the five last years. Similarly, they found that 27% of the patients died in a hospital ward before being admitted in a palliative bed. The same report stressed that some geriatrics wards prefer organising palliative care themselves. Also reported by the Federal Council of Hospitals, "*some hospitals report that patients with an unfavourable prognosis are not even asked to be admitted to a palliative care unit. For example, non-oncology patients and patients whose life expectancy is greater than 2 - 3 months, or whose life expectancy is unclear, are often not considered*" (translated from the FRZV-CFEH, page 6).[162] During the site visits, whatever the type of service visited, it was often reported by respondents that there are waiting lists or "triage" when it came to orient patients in need of PC, forcing patients to stay in a service that is not adapted to their needs. Some respondents also testified that often patients die before they can be admitted to a P(M)C service. These findings were previously observed by the palliative care federations who found a saturation of some PCU at some points.[19] To compensate, some hospitals created beds outside the legal and regulatory framework.[19]

Some respondents in palliative units explained that every week they have situations where the patients cannot stay in the palliative care unit for which they need to find a solution (either patients already in the service / either requests by phone that need to be reoriented). Moreover, respondents working in palliative care units also reported that they observe growing needs in palliative (middle) care and that they must refuse a lot of patients per year (no objective data were communicated).

> *[…] C'est pour ça qu'on voit qu'il y a un manque au niveau justement de ces services un peu intermédiaires parce qu'en fait, nous, c'est une énorme partie de notre travail. Il n'y a pas un moment où on n'a pas un patient qui est dans cette situation-là, on a tout le temps au moins un patient. Qui devrait sortir de chez nous, mais en mode « voilà tout ce que tu as expliqué ». En même temps, on ne sait pas trop et donc c'est beaucoup de négociations pour leur faire comprendre, pour leur faire*

accepter [de partir]. Parce que, souvent, c'est un choc. Les familles ne sont pas contentes pour trouver une solution qui nous semble aussi acceptable parce que nous, on n'a pas juste envie de dire « Bah vous devez sortir parce que vous êtes trop stable pour être ici ». Et en même temps on est entre guillemets « super paternalistes » parce que on n'est pas à les laisser juste leur dire « bah voilà vous sortez telle date ». Nous, on va passer énormément de temps à trouver une solution. Respondent form a Sp4 unit, FR site visit

For some respondents, this was related to the difficulty to anticipate the prognosis of dying patients: some patients, when their pain was properly managed, survived several months and experienced a more relaxed end-of-life.

Nous, on n'envisage pas vraiment la fin de vie comme ça, mais c'est clair qu'un patient bien pris en charge, il est ici. Il revit 15 jours. Ils viennent, on pourrait imaginer qu'ils vont mourir le lendemain, ils meurent 15 jours plus tard, mais ils ont pu dire au revoir à leur famille. Enfin quand même que c'est ce qu'on doit faire ou pire, les gens qui arrivent vraiment me rendent. Et puis avec tout le cadre, tout ce qu'on met en place, les petits plus, ils se restabilisent. Et alors là c'est la catastrophe, ils ne meurent plus et on doit les faire sortir dans après un mois après, ils étaient vraiment très moches. À l'entrée, c'est quasi avec ces patients-là qu'on a le plus de mal. Respondent from a Sp4 unit, FR site visit

When it came to the waiting times between the demand and the initiation of palliative care, based on the site visits and the desk search, it appeared that these waiting times highly depended on the nature of the palliative care needed, the patient profile, the geographical area and other characteristics related to the context. No objective data was further found about the waiting times and the waiting lists. It was observed from the site visits that most of the professionals displayed a large set of creative skills to ensure that the patients received the palliative care they need in the absence of solutions: loaning material from the hospital to accommodate patients at home, keeping the patient longer in a facility, accepting patients for respite stay in hospital units, admitting patients not corresponding to the criteria for a funded stay / care, organising extra outreach support…Therefore, these solutions appeared being not sustainable at long term and could create sources of tensions with the management, other facilities, authorities, sickness funds...On top of that, as experienced by some respondents, not all palliative patients are bedridden: some patients with a high PICT score are still able to walk and move, meaning that highly medicalised services are not the solutions. But, as explained by some respondents, in the absence of palliative middle care, they must do "medical shopping" to find solutions for the patients.

Availability of outreach multidisciplinary support teams

Availability problems were also raised concerning the outreach multidisciplinary support teams. Over the years, their workload has increased because of the complexification of the palliative care situations, the reduction of the length of the hospital stays and the shortage of qualified professionals in first line. But their resources have been not adapted to cope with this complexity. Registered activities are perceived as underestimating the real volume of activities and the funding system is said as no longer appropriate.[19] In its last report, the Federal Cell underlined the overload and under funding of these outreach teams.[21] In 2018, the Walloon Federation for Palliative Care estimated that 6.56 FTE nurses were needed to help the outreach team to fulfil their missions (since then an upgrade has been done but is not yet sufficient to cover the needs).[213] In each region, the staffing is calculated based on the number of habitants in the area of activity of the outreach team. These standards are calculated on the basis of the resident population, but not on the basis of the resident population who may require palliative care: this phenomenon was mentioned as problematic in areas where a large number of retired people come to live but remain resident elsewhere (one example cited by a respondent concerned people domiciled in Brussels but living on the Belgian coast). Other respondents pointed that the palliative care networks and the multidisciplinary outreach palliative teams must cover a too wide geographic zone, preventing them to cover the needs. Some respondents also mentioned that the networks lacked of staff, could not follow the demands, did not provide direct care although needed, only advised by phone and were not with the patients every day.

Availability of healthcare professionals

Patient representatives pointed out that some hospital doctors and GP are not anymore available, implying that the patients have a lot to do by themselves or that the patients have not time to discuss about emotional and psychological burden of the disease but also about the practical and organisational aspects of the end-of-life.

> *Maar ik denk dat we ook echt wel eens mogen kijken, ja, intern de ziekenhuizen, beginnend met de artsen. En niet dat zij u alles moeten aanreiken want, ja, daar hebben zij de tijd niet voor. Maar wel dat zij u onmiddellijk kunnen doorverwijzen naar een persoon binnen het, de ziekenhuiscontext, die met jou een stukje ja, bekijkt, bewandelt wat dat de mogelijkheden zijn. Patient representative 1 – NL workshop*

Some respondents also experienced that home care is currently unable to cover the needs of patients in general and it appeared to be even more pronounced when it comes to palliative care. In their view, each region did not have the same competences available for home care, meaning that, in some areas, the home nurses and / or the GP have an extensive expertise in PC while in other areas, it is absent. One explanation of these differences regarding the availability of expertise was the lack of (financial) acknowledgment / lack of obligation of having a training in palliative care for nurses in nursing homes and home care. Indeed, for some respondents, the home nurses were particularly lacking a proper training in palliative care. Some respondents reported that no specific training is expected from home care nurses delivering palliative care, although this could contribute to the quality of palliative care. The ministerial decree of 08.07.2013. established the agreement criteria framing the professional qualification in palliative care for nurses.[214] This led to an acknowledgement of their expertise in hospitals through a financial compensation if the norms of the service, the function or the health care program include palliative care. [19] But, to date, according to respondents, in other settings, this qualification has no formal recognition, implying that if nurses decide to get this qualification, this will not affect their salary. Moreover, as explained by an expert, this contributed to a form of concurrence between palliative care at home and palliative care in hospitals, the nurses preferring working in a hospital setting at it is more financially rewarding.

The lack of availability appears even more problematic during out-of-office hours and over weekends. As explained by the patient representatives, GP are no longer available for emergency and home nurses appear not have a 24/24 watch for emergency despite the legal obligation.

> *Mais on sait qu'au niveau des équipes infirmières ou du médecin-traitant, quand la personne est déclarée en soins palliatifs, ils sont censés pouvoir intervenir 24 heures sur 24, mais est-ce que dans les faits, c'est réel ? J'imagine le médecin qui est appelé en pleine nuit. Il va dire au patient ou à ses proches : écoutez, passez aux urgences. Patient representative 2 – FR workshop*

But some patient representatives also acknowledge that home nurses are also under pressure which can be explained by the current funding system.

> *Zeker. Al kan ik niet klagen, want ik heb een fantastische overbuurvrouw thuisverpleegkundige, die nam wel haar tijd. Maar het is wel een gegeven: zij worden per prestatie betaald. En zij hebben een agenda af te werken, en op dat, dit uur daar en dat uur ergens anders. Ik hoor bijvoorbeeld van haar ook van ja, dat van de patiënten uit die heel erg op uur staan, als ze vijf minuten te laat zijn, ja, dat ze al gebeld worden en zo. Ja, een thuisverpleegkundige kan ook maar zoveel doen. Patient representative 1 – NL workshop*

Some respondents also pointed the limits of the home care as some self-employed nurses do not accept to cover some shifts (e.g. nights or weekends). Some respondents and experts mentioned that, although they are paid for, some home nurses do not provide the services that they are expected to (e.g. 3 visits per day).

> *"Passage 3 fois de l'infirmière ? Ils vous expliquent toujours qu'ils ont une bonne raison pour jamais passer 3 fois. » - Respondent from FR site visit 1 -*

During the site visits, several respondents pointed that the nursing shortage negatively impacts the ability of the healthcare system to respond to the

needs of palliative care patients but also affect the whole health care offer (e.g. hospital beds are closed). Some respondents were expecting that the shortage will increase as they knew that the number of nursing students also decreased (a respondent stated that there is a decrease of 30% of inscriptions). Consequently, some respondents mentioned that they needed to rely more on interim which generate additional fees and offered not guarantee of having qualified nurses in palliative care. Some respondents also expressed that they had no choice but hiring nurses that were less suitable for the job. For some respondents, as these nurses were not enough qualified, they rapidly quitted as they were struggling to meet the requirements of caring for palliative care patients and they must be replaced, adding to the burden on the service. Because of a lack of (human) resources, a respondent in a palliative day care centre even mentioned that they were not able to open the number of places for which they have an agreement. Besides, as pointed by an expert, shortage of nurses, in some nursing homes, led to the decision of no longer being accredited as "nursing home" but as an "elderly home" for less dependent patients, reducing the available places for a long-term stay.

Problems of professionals' availability also concerned other professionals than nurses. Some respondents explained facing problems when recruiting some healthcare professionals such as external physiotherapists that work in palliative care units as part of a complementary activity and for whom it was difficult to involve them in the multidisciplinary team.

Availability of expertise for rare diseases

In addition to unmet needs in palliative care, representative of patients with rare diseases stressed out that their needs for preventive and curative care were not covered by the healthcare system. It was planned to develop reference centres but, to date, they are not yet implemented. Despite sharing some common needs with chronic patients, the participant recalled that patients with rare diseases also have specific needs, i.e., some analgesic treatments were not effective because of the pathophysiology of the underlying disease.

> *Je pense que ce qu'il y a toujours dans les cas des maladies rares, c'est l'offre de soins qui n'est forcément totalement pas la même d'une partie du pays à l'autre. Comme disait tantôt [autre participant], si on a la chance d'être par rapport à un centre de référence en Wallonie, vous savez très bien où on en est dans les centres de référence de maladies rares, je ne vais pas retaper le clou, cela fait 12 ans qu'on les attend nous patients. Cela a été voté en 2012 donc vous voyez que le temps passe et qu'il n'y a pas grand-chose qui se fait. Parfois j'ai envie de secouer le cocotier parce que, pour nous, ce serait vraiment une grande fête. Besoins spécifiques, c'est clair, on est encore toujours assimilé à des malades chroniques, je crois que c'est Madame [nom] qui le disait et on n'a pas du tout les mêmes besoins. Patient representative 5 – FR workshop*

Availability of palliative care

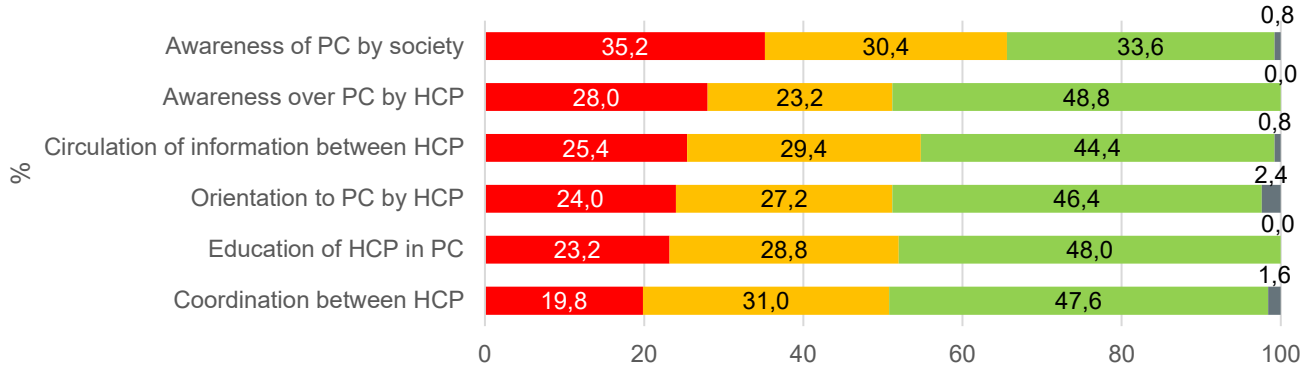
Furthermore, from the desk search and during the site visits, we identified that, despite a general framework, outreach multidisciplinary support teams were differently organised and the extent to which they invest in their missions can vary, leading to a diversity of practices. On the one hand, this was positive if these variations aim at making the most efficient use of the local resources. For example, a number of multidisciplinary outreach teams are not supporting the idea of intervening in nursing homes, just as, conversely, a number of nursing homes are not willing their support, believing they have sufficient palliative expertise in-house. In other regions, outreach multidisciplinary support teams frequently enter the nursing homes. Sometimes this was at the expense of developing sufficient basic palliative care internally.[178] On the other hand, this can be seen as complexifying the practices as some professionals and institutions interact with different outreach multidisciplinary support teams from which they cannot expect the same availability of services. As an illustration, during a site visit, a respondent explained working with two networks: one promoting direct patient care and the other focusing on the communication to the main public about palliative care. According to the respondent, it can negatively impact the local offer of palliative care and then the unmet needs of the palliative care patients.

Additionally, during the site visits, it appeared that not all facilities accepted patient with a euthanasia project, and not all facilities accepted patients who wished to die there. In the later, this led to a transfer to another place in the last days of the patients. This practice can be perceived as having a negative impact on patients' quality of life, as well as that of their families. This type of 'emergency' transfer can also be perceived as a negative impact on the teams who receive a patient 'just to die' and increases the risk that patients will be transferred to any hospital care unit, or even end up dying in the emergency room, while waiting for a place. Similarly, differences were observed in length of stay, where it appeared that the length of stay was the result of a discretionary decision of the doctors, sometimes influenced by the "pressures" exerted by the management of the service.

Barriers related to information and training

Several barriers related to information and training were also reported as being always/often experienced by the respondents, such as recognition of palliative care by society (35%) and by health professionals (28%), sharing of information between professionals (25%), referral to palliative care by health professionals (24%) and training of health professionals in palliative care (23%, Figure 21).

Figure 21 – Barriers related to information and training experienced by professionals when providing palliative care in Belgium (N=127)



Legend: HCP stands for healthcare professionals

Barriers to awareness impacting the beliefs around death and end-of-life

Respondents and patient representative acknowledged that the society is not organised to “welcome death”, meaning that death and end-of-life are hidden. Some explained that there is a need for a societal questioning about the relation to the death and the end-of-life, to make palliative care more visible. There are misconceptions in society about palliative care and who can benefit from it, leading to an underuse of the existing services and benefits.

> *De nouveau, le grand public connaît cette notion de soins palliatifs mais qui est encore dans la tête des gens très liée aux situations d’oncologie. Patient representative 4 – FR workshop*

> *En daarnaast, anderzijds, ik denk als je aan de gemiddelde Belg vraagt: wat is palliatieve zorg? Dat daarvan 90% zegt van: ah, dat is voor die laatste dagen of laatste weken. Dat palliatief heel erg gekoppeld wordt aan die laatste fase waar dat je echt weet van binnen de zoveel tijd zal ik, ja, zal ik sterven, zal ik overlijden. Maar het zou heel mooi zijn mocht dat, ja, dat idee-fixe ja, een stukje doorbroken kunnen worden, dat mensen effectief weten en beseffen dat palliatief ruimer is dan dat. Dat het gaat over bespreekbaar maken, ja, over wat je wil in die tijd dat je nog hebt. En ook wat je wil, wat je zelf wil op het moment dat het niet meer gaat, of dat uw situatie/gezondheid achteruitgaat. Patient representative 1 – NL workshop*

Some respondents also explained that the general population -and the policymakers - does not understand the nature and objectives of palliative care: this can be seen as a barrier to the development of services.

> *Même si on en parle depuis des années et des années, je pense que c'est toujours un travail à remettre sur la table. C'est méconnu, il y a beaucoup de fausses croyances par rapport à la fin de vie, aux soins palliatifs, par rapport au centre où les gens pensent que ce sont des mouroirs […] gens se trompent souvent, mettent des étiquettes et s'il en est du même de nos instances qui nous gouvernent, ça veut dire qu'on ne sait pas très bien ce qu'on fait ici – Sp4 unit*

For respondents, there was a need for a better visibility of existing projects in palliative care – including alternatives- and offer to demystify it.

Some respondents also explained that, for some professionals, not caring correctly for a patient accelerates the end of life and is thus less costly for the society.

> *Tout parce qu'ils vont être beaucoup plus efficaces et beaucoup plus rationnels que nous pour un certain nombre de choses, c'est qu’il ne faut pas que ça dure trop longtemps, hein. Les maladies neurologiques dégénératives ? Je ne vais pas dire que moins on s'en occupe, plus ça va vite – FR Site visit 3*

All palliative day care centres mentioned that a persisting taboo regarding palliative care, despite the efforts made to inform people about their wrong perception. During an interview, the respondent mentioned that people in the neighbourhood thought that ‘*the hearse will come by every day*.’ The respondents stated that this taboo, together with the fact that palliative day care centres were not well known, resulted in quite low occupancy figures and absence of waiting lists. Nevertheless, in all interviews it was mentioned that patients attended palliative care too late. From that viewpoint, there are unmet needs in the palliative care population for those people staying (too long) at home (e.g., demanding situation at home, lack of supportive resources) or in hospital (e.g., prolonged stay in a clinical environment).

As reported by the National Bioethics committee, efforts were made for demystifying palliative care and end-of-life care but the COVID19 negatively impacted these initiatives, implying that additional actions are still needed.[199]

Barriers related to competences in palliative care impacting quality of care

Patient representatives mentioned that there is a lack of training in palliative care for healthcare professionals, especially when patients cumulate several factors of vulnerabilities that complexify the management of the situations by the professionals. These factors of vulnerabilities can be multimorbidity, double diagnosis, presence of a sensorial limitation but also social, cultural, or economic factors.

Le problème est quand il y a la conjonction de pathologie entre guillemets, ce qui est à la fois une notion de soins palliatifs et de troubles cognitifs ou soins palliatifs et handicap mental. Patient representative 2 – FR workshop

Regarding the competences of the healthcare professionals intervening at home, respondents explained that both the families and the professionals express their concerns about the lack of competences. This lack of competences appeared to be related to palliative care and the management of situations such as dementia. One should note that being aware of its limitation is often considered as the first step to gain further education or asking for help: the challenge being to provide adequate support to help professionals to gain these additional competences to reassure the relatives.

Ce sont souvent les aidants qui expriment la crainte que l'aide qu'on peut avoir au domicile ne soit pas assez compétente. C'est-à-dire l'information comment approcher une personne avec une démence en fin de vie ou déjà dans une dégradation au stade avancé de la maladie, comment communiquer avec elle, etc. semble être une crainte de la part des familles mais aussi une crainte de la part des soignants que nous voyons qui ne se sentent pas assez formés, n'ont pas la connaissance relationnelle avec les personnes. Patient representative 1 – FR workshop

Vaak vanuit: wij hebben niet de kennis daarrond wat we moeten doen met dat soort patiënten. Patient representative 1 – NL workshop

Some respondents expressed that they feel that the GP distance themselves from the palliative care and the support of their dying patients. These respondents explained that some GP appeared not understand their role when facing end-of-life, leading to a lack of support. This, according to some respondents, translated in inappropriate care: in their experience, it seemed that some healthcare professionals did not find it shocking to organise transfers for dying patients every 2-3 days. Moreover, some respondents pointed out that, despite having a nomenclature code, not all GP came to visit their palliative patients at home. But some respondents also explained that when patients have a cancer, they stopped seeing their GP to be followed by their oncologist and only went back to the GP when the oncologist said that the treatment was not working anymore. According to some respondents, it also appeared that it was not always visible that there is a therapeutic project planned in the patient health record. Moreover, it appeared that GP had no access to the patient health record from the hospital. Consequently, some respondents found that health care was over medicalised at the end of life, meaning that the patients received inappropriate care without a positive effect on their wellbeing.

Some respondents reported that the palliative care treatment initiated by GP were not always adapted to the needs of the patients because of a lack of knowledge. A respondent gave the example of GP prescribing morphine patch, believing that it was easier to use but underestimating that the patient received a triple dose because of the cachexia. Some respondents explained that some GP did not want to call the palliative care network to have an additional opinion. Other respondents mentioned that there was lack of availability and support from GP for follow up at home, explaining that the patients waited and suffered a few days before being treated. Moreover, a patient representative explained that some GP refused to declare the patient as palliative patient, limiting the help that the patients received.

J'ai connu des situations catastrophiques de personnes avec des difficultés respiratoires majeures mais le médecin refusait de déclarer la personne en soins palliatifs et du coup cette personne n'avait pas accès au matériel, au passage infirmier, kiné, médecin gratuit au forfait palliatif. Tant que le médecin ne dit pas oui, l'équipe de soutien ne peut pas intervenir. […] Il est un peu tout puissant par rapport à cela, c'est assez effrayant. Patient representative 2 – FR workshop

Several respondents explained that there was a lack of medical training / education targeting palliative care. According to them, this explained why it is complicated to have palliative care at home, as the trainings were not sufficient for GP and specialists. Some respondents did therefore acknowledge that the youngest generation of medical doctors were more networking doctors: this attitude was perceived as supporting collaboration and, by consequence, improving the quality of care. Patient representatives expressed the same positive report: they also mentioned that the new

generation of medical doctors were more and more developing soft skills and competences allowing them to provide better care, which is an asset for improving palliative care in general. However, some respondents declared that even GP considered as competent and committed needed more training and resources to deliver quality palliative care.

> *Globalement, je pense que les jeunes médecins sont beaucoup plus ouverts au travail pluridisciplinaire, aux compétences de leurs collègues qui ont peut-être d'autres profils de formation surtout à domicile, je pense. À l'hôpital, il reste sans doute encore un peu cette suprématie du médecin spécialiste qui sait tout et qui écoute très peu le patient, les proches, les infirmiers, etc. Patient representative 2 – FR workshop*

Regarding the competences of the outreach multidisciplinary team, the cumulation of vulnerabilities also impacted them, according to patient representatives, as they may need additional competences to properly address these situations.

> *Maintenant les équipes de deuxième ligne soins palliatifs sont clairement des équipes de deuxième ligne qui viennent en soutien aux patients, aux proches mais aussi aux professionnels. Eux amènent leur expertise soins palliatifs, mais c'est vrai que, quand c'est du handicap mental lourd, où les personnes parfois ne parlent pas, les troubles cognitifs à un stade avancé où, de nouveau, le contact avec la réalité est compliqué….ce sont des profils particuliers. Je pourrais imaginer aussi les personnes d'origine étrangère qui ne parlent pas français. Il y a, sans doute, comme cela toute une série de situations…les personnes sourdes…Le volet soins palliatifs évidemment arrive chez toute la population, enfin, potentiellement et donc il y a parfois une situation préexistante qui fait un cumul, qui est peut-être difficile à prendre en charge pour les équipes du domicile mais aussi pour les équipes en maison de repos, quelles que soient les équipes, cette conjonction de facteurs. Patient representative 2 – FR workshop*

Barriers related to communication impacting the relationships and the awareness regarding palliative care

But, before being able to take care of complex situations, one can also stress that healthcare professionals need to be able to engage in dialogue about palliative care: some patient representatives mentioned that this remains difficult for some healthcare professionals and that some of them lacked empathy and communication skills.

> *Par exemple, il y a une aidante qui m'avait dit qu'ils arrivaient auprès du médecin et celui-ci lui avait dit « il faudra peut-être penser à la fin de vie, il n'y a plus rien à faire ». Cela m'avait quand même assez choqué et la dame aussi. Elle se disait : « il ne me donne aucune information, il me dit ça comme ça, moi je n'ai pas été préparée à une annonce comme ça ». Je sais qu'il y avait un souci à ce niveau-là, donc vraiment la bonne utilisation des mots et l'empathie surtout qui peut aussi poser un problème à ce niveau-là. Patient representative 3 – FR workshop*

> *En dat ge misschien ook wel vanuit het zorgverleningsveld ook wel wat expertise daarin nodig hebt. Ik zeg niet dat iedereen dat moet hebben, maar dat er misschien wel een aanbod is binnen het palliatieve landschap die ook wel een beetje kennis hebben van: hoe ga ik met dit type situatie om? Hoe ga ik dat gesprek aan? Wat is de beleving van mensen die daar mee geconfronteerd worden? Patient representative 2 – NL workshop*

Communication problems can also be related to a form of anticipation of the (negative) impact of the topic on the mental health and on the family dynamics: this was mentioned when it comes to explaining what euthanasia is.

> *On a parlé d'euthanasie tout à l'heure et c'est vrai qu'encore trop souvent, l'euthanasie est un peu opposée aux soins palliatifs alors qu'elle pourrait tout à fait faire partie de l'offre. C'est une porte qui doit, même quand les personnes sont prises en charge par des soins palliatifs, être ouverte. De nouveau, c'est difficile à entendre pour les proches. C'est parfois plus une demande des patients mais pouvoir*

avoir ce discours de la part des professionnels, c'est que, dans ce type de situations, parfois des patients pourraient être amenés à demander l'euthanasie. Ce mot du coup, il est prononcé et cela fait alors son chemin chez les proches. Ce n'est pas dire « est-ce que vous avez pensé à l'euthanasie ? ». C'est assez violent mais, dans ce type de situations, des patients ont fait la demande d'euthanasie et cela pourrait être tout à fait entendu. C'est une manière pour les professionnels d'amener…De nouveau, c'est quelque chose de difficile pour les proches. Patient representative 2 – FR workshop

There were also communication problems arising from the vocabulary and terms used in palliative care. Some respondents reported that there was no uniform discourse in palliative care, leading to confusion and inappropriate decisions (i.e. what does it mean "sedation"). For some patient representatives, the vocabulary around palliative care was not clear and contributed to the misunderstanding about its added value. Using "supportive" care instead of palliative care can contribute to broaden its spectrum in the society. Some patient representatives also discussed the difference between palliative care and terminal care, highlighting, again, that it also added to the confusion and the lack of awareness about the added value of palliative care. Also, mixing palliative care with terminal care can contribute to a negative connotation of what palliative care is.

Omdat we volledig volgen dat palliatief nog binnen de maatschappij heel erg gelijkgesteld wordt aan terminaal, en dat dat vaak dienen drempel creëert effectief, waardoor wij al vrij lang gepleit hebben van: zou het niet beter zijn om misschien zoals je zelf zegt… Misschien beter te spreken over supportieve zorg, om dat het daar ook wel in essentie over gaat: de ondersteuning die er is, gedurende de tijd die er is. Patient representative 2 – NL workshop

Barriers related to collaboration impacting continuity of care

Communication appeared even more complex when the information must circulate between professionals that were not directly involved in palliative care. A respondent explained that the large interdisciplinary concertation with all actors was positive, but it was not useful if the information is not shared among doctors. The respondent gave the example of a patient decompensating at home, the family called 112 and the emergency doctor did not know that, in this situation, he had to start a sedation. Instead, he started a cardiopulmonary resuscitation (CPR).

Problems related to collaboration also concern professional-to-professional interactions: since the COVID pandemics, some respondents experienced more difficulties to have direct contact with other health professionals, even by phone.

Avoir un médecin au téléphone depuis le COVID, on oublie parce que c'est vraiment compliqué. Moi, j'ai toujours des secrétariats, ils vont me rappeler. Je veux dire que j'ai un patient qui est en détresse, une famille qui doit appeler… […] J'ai un secrétariat « on va vous rappeler ». Pour finir, j'annonce les décès à des secrétaires. Je n'ai plus jamais un médecin à qui je pourrais expliquer comment ça s'est passé, s'il y a eu un souci avec la famille. J'ai beau dire, s'il veut plus d'informations, qu'il n'hésite pas à m'appeler, il n'y a plus personne qui appelle après 17 h, il ne faut même plus espérer avoir un médecin au téléphone. A medical doctor in a Sp4 unit, FR site visit

From the different visits, it was also observed that the degree to which services collaborate varied across the different settings: some collaborations appeared to be intensive while others almost non-existent. This was mentioned, for example, in palliative day care centres, where the collaboration with the primary care zone was perceived as low (but also that the primary care zone was still not completely deployed and too premature to function for the full 100%).

Some respondents, active in palliative care units, pointed a lack of follow-up after discharge to nursing homes. The lack of continuity was reinforced by the fact that, according to some respondents, GP were not always available to support the launch of a proper palliative care treatment when the patients were returning to the nursing homes. They expressed that they felt unsure that the nursing homes will call in case of needs or that the patients will receive the care they need. They stressed the shortage of (qualified) nurses, some shifts being only managed by nursing assistants which rose questions

about the quality and the security of care. They also reported that there was not enough staff for overseeing agitated patients or stressed patients.

As explained by some respondents, staff in nursing homes appeared not able to manage unexpected events and transfer the patients to the emergency department. But, as experienced, when patients were admitted through the emergency department at the hospital, they underwent additional and unnecessary exams while if they were properly oriented to the palliative care doctor, they would have been correctly treated. Some respondents also pointed that the referents in palliative care were not always trained or had the resources to work in efficient conditions, some felt that the expectations are too high for referent palliative care. These transfers at the end of life were perceived by professionals as opposed to the patients desire of dying in the nursing home.[215]

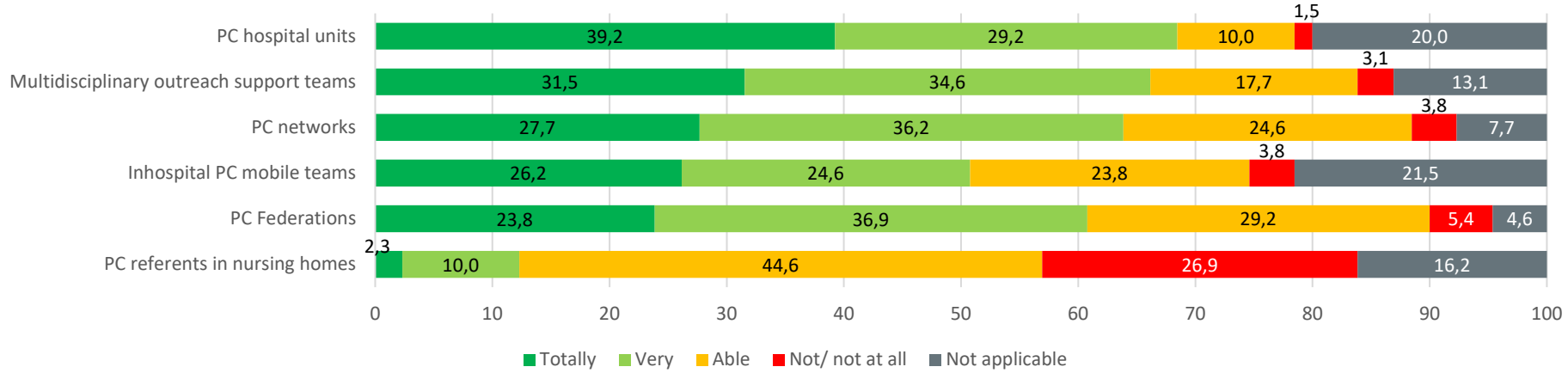
As pointed by the National Bioethics committee, nursing homes and elderly homes lacked of preexisting collaboration with Sp4 units when the COVID19 pandemic started, which led to several problems and shortcomings when it came to provide palliative care.[199] A respondent reported that referents were not interested in learning from palliative care units: this was also pointed by Scacchitti et al. 2021.[215]

> *[…] En fait, ça ne les intéresse pas même de savoir comment on travaille, ça ne les intéresse absolument pas d'apprendre des choses, ils savent tout faire. Le référent palliatif OK et donc ça, c'est ma crainte aussi si vous faites des middle care avec des maisons de repos. Pas suffisamment de présence médicale ou des médecins qui ne sont pas formés ou gardant le médecin traitant du patient. A medical doctor from a SP4 unit, FR site visit*

6.4.3 Capacities of the existing palliative care sector

During the online survey, organisations positively assessed the ability of the existing actors to fulfil the missions of palliative care. Indeed, almost 40% declared that hospital units in palliative care were totally able to fulfil these missions (Figure 22). Multidisciplinary outreach palliative care teams, palliative care networks, and the federation of palliative care were also rated positively (more than 80% of the organisations believe in their capacity). However, the referent function in nursing homes had poorer results, since a quarter of the participants reported that they were not able to fulfil these missions.

Figure 22 – Capacities to fulfil the missions by existing actors of palliative care in Belgium (N=130)



According to some respondents, nursing homes were not organised and equipped to accompany the end-of-life: they lacked of staff and competences to properly manage it although more and more nursing homes had now the proper equipment to provide quality care.[178] The fact that there is no medical doctor all the time was pointed as problematic by some respondents, trained as medical doctors themselves. These shortages of staff and competences were also pointed by the Belgian National Bioethics Committee and the Federal Cell which both stressed the disparity in the quality of palliative care across nursing and elderly homes.[19, 199, 216] The Bioethics Committee mentioned an overall lack of training in nursing homes.[216] A study conducted in the Brussels region in 2021 seemed to led to a more positive situation but these results should be taken with caution as these were self-reported data and a bias of social desirability could occur.[215] In one site visit, a respondent expressed that some referents in palliative care appeared to overestimate their abilities to take care of complex situations: referents had a training but they had less resources than those working in a highly specialised setting such as a Sp4 and therefore appeared to be reluctant to organise a transfer or call for help when needed.

Et puis la qualité des soins, ce n'est pas absolument pas la même chose si vous avez quand même des infirmiers spécialisés : en maison de repos, vous avez des aides-soignantes. Si on en trouve encore. Au jour d'aujourd'hui - je suis dans le CA d'une maison de repos - la situation est quand même vraiment critique. Ici, on a un médecin, qui est là 10h par jour. C'est ce qu'il faut aussi : la qualité. A medical doctor from a SP4 unit, FR site visit

Ils [les maisons de repos et soins] ont des référents palliatifs. Ils ont 0,27 équivalent temps plein par patient. Et, ici, dans l'unité, on a un équivalent et demi temps plein par patient, mais ils considèrent - et moi je trouve que c'est de l'orgueil mal placé - que ça fait la même chose mais c'est impossible. Vous n'avez pas les moyens de faire la même chose, vous n'avez pas la même surveillance, ce n'est pas qu'ils ne sont pas compétents, c'est qu'ils n'ont pas les moyens et donc je trouve toujours ça tellement dommage de dire « on a un référent palliatif donc on garde bien nos patients palliatifs, même si c'est pas l'idéal ». A medical doctor from a SP4 unit, FR site visit

It should be noted that there is no legal definition of the "palliative care referent" in nursing homes: not only nurses can take this role but also other professional profiles, some even without a background as healthcare professionals (medical doctors, psychologists, physiotherapists, art therapists…).[u] To date, there is no defined profile or no compulsory training, unlike what is required for "dementia referents".[181] In the Brussels region, it also appears that nurses can no longer be the referent persons for palliative care: this referent person should be identified among the reactivation staff, at the expenses of nurses who already endorsed this role.

It also happened, according to patient representatives, that nursing homes refused palliative patients because the staff of the nursing home said that they were not competent to take care of these patients, especially when there was a cumulation of (health) problems.

> *Ah nee, mensen met leverproblematiek aanvaarden wij niet. Dat heeft een stuk te maken denk ik met, ja, er is geen overaanbod. De kamers staan niet leeg te wachten tot iemand komt. Maar ook misschien wel een stukje de schrik dat ja, dat ze dan bijvoorbeeld vanuit een RVT niet voldoende die medische zorg kunnen geven. Patient representative 1 – NL workshop*

6.5 Discussion

There were two interconnected major gaps when considering the Belgian landscape of palliative care.

First, the existing offer in palliative care is not sufficient to meet its objectives: outreach multidisciplinary support teams and hospital mobile teams are understaffed, Sp4 beds are lacking in some regions of Belgium, expertise in palliative care in nursing homes and institutions is unequally available…The limitation of the current offer is even more pronounced during evenings, nights and weekends. Outside the specialised palliative care offer, nurses and GP lack of training to take care of patients at home. The issue of training professionals comes up repeatedly: beyond training in skills and knowledge, it appears necessary - as a premise - to work towards greater awareness of the added value and complementary nature of the palliative approach, regardless of the health profession or medical speciality concerned. The complicating factor is that there is currently no comprehensive view of the quantity and quality of palliative care on offer: it is not possible to know how many professionals and volunteers are trained in palliative care and whether they have the capacity to apply these skills in the field. It is not possible to know to what extent the palliative care provided in nursing homes is able to meet the complexity of situations.

Second, there are patients for whom the current offer does not meet the needs and for whom current palliative care offer needs to be further enhanced.

- There are patients who prefer to stay in their usual place of stay as long as possible but lack of possibilities for receiving complex and / or technical specialist palliative care.

[u] See here the list of the professional profiles entitled to work as reactivation staff in nursing homes in the Brussels region (in French): https://www.iriscare.brussels/fr/2023/09/22/du-personnel-supplementaire-pour-nos-maisons-de-repos/

- There are patients who cannot stay in their usual place of stay as it is not possible to deliver quality palliative care (generalist or specialist palliative care). This can also patients who do not have a place to stay.
- There are patients who prefer to leave their usual place of stay and do not require complex / highly technical palliative care. If they are considered “too young” , they cannot access nursing homes.
- The patients also want to be able to navigate across the different options as, for some, leaving their usual place of stay can be temporary, e.g., to provide some respite for their relatives.
- Some may prefer to leave their usual place of stay accompanied by their significant other or a close friend.

On top of these problems, the current shortage of nursing staff in nursing homes and hospital was regularly mentioned as a preoccupying issue for the future of the healthcare system. Similarly, the shortage of GP and home nurses, the difficulties in nursing homes, the lack of awareness of healthcare professionals regarding palliative care, the inadequacy of the funding system for nursing home care or the burdening of social welfare centres in a post-pandemic context, characterised by an economic crisis were also identified as contributing to the overall problem of access to palliative care. It should be also pointed that palliative care lies, for an important part, on the commitment of the relatives and of volunteers to provide quality care to the patients. Informal caregivers need to be adequately supported as providing palliative care to a relative is mentally and physically burdening. Similarly, volunteers need to be trained and supported adequately.

This project did not aim at solving all these problems and gaps, but these are important elements that need to be taken into account.

7 WHICH MODELS ARE RELEVANT TO IMPROVE PALLIATIVE CARE IN BELGIUM?

- ✓ The absence of a consensual definition of palliative middle care is a major limitation.
- ✓ Existing services can be used to further develop palliative middle care but, to some extent, alternative models are also needed.
- ✓ The ongoing reforms of primary care and territorialization of health can influence the future of palliative care.
- ✓ Advanced care planning is a facilitator for orienting patients to solutions corresponding to their preferences and needs.

7.1 Aim of the first consultation

In the absence of an existing framework – including a consensual definition – related to palliative middle care, this chapter aims at collecting elements related to both the definitions and the characteristics of such an offer but also to evaluate the relevance and the acceptability of the feasible options to further develop palliative middle care. This chapter is built upon the contributions of organisations – consulted during an online survey, patient representatives met during two workshops and elements gathered during the site visits (Chapter 2).

7.2 What is palliative middle care?

Definitions of palliative middle care were found in the reports of the Federal Council of Hospitals (FRZV-CNEH) of 2016 and of the Federal Cell of 2021 where palliative middle care is defined by its objectives.

> *Lieu de séjour où les patients peuvent recevoir des soins techniques spécialisés et/ou complexes habituellement réservés au milieu hospitalier. Leur état est stable et le plan de soins intègre les différentes*

évolutions possibles en précisant les décisions et attitudes éventuelles qui en découleraient. Pour des raisons organisationnelles, logistiques ou autres, le retour à domicile est temporairement ou définitivement impossible. L'environnement d'un hôpital aigu n'est pas requis.[22]

- *Palliatieve Middle Care zou zich moeten richten tot patiënten die voldoen aan de criteria van het Koninklijk Besluit van 21 oktober 2018 (Belgisch Staatsblad. 20 november 2018) en voor wie het zorgproject uitsluitend of prioritair gericht is op het comfort van deze patiënten met specifieke behoeften, zoals hierboven beschreven. Patiënten zouden baat hebben bij medische verzorging en psychologische en sociale ondersteuning door een multidisciplinair team en vrijwilligers opgeleid in de palliatieve zorg. Familie en vrienden zouden 24 uur per dag welkom moeten zijn en zouden over een ontspanningsruimte moeten beschikken. Er zou een formele en functionele link moeten bestaan met de andere structuren van het palliatieve zorgnet. De verblijfsduur zou beperkt worden, maar zou verlengbaar zijn indien nog steeds aan de toelatingscriteria wordt voldaan.*[20]

A first observation is that both definitions seemed to pertain to the idea that "palliative middle care" is limited to a residential offer (see also the Chapter 1 and the section 5.5.1 in the Chapter 5).

A second observation is that there is no definition of palliative middle care in the scientific literature: the concept of "palliative middle care" appeared to be a hybrid of palliative care and middle care. Strictly speaking the MeSH database defines palliative care as "*care alleviating symptoms without curing the underlying disease* (Stedman, 25th ed)" while proposing a definition of hospice and palliative care nursing as "*a nursing specialty concerned with care of patients facing serious or life-threatening illnesses. The goal of palliative nursing is to prevent and relieve suffering, and to support the best possible quality of life for patients and their families. Hospice nursing is* ***palliative care*** *for people in their final stages of life*" and palliative medicine "*a branch of medicine concerned with preventing and relieving the suffering of patients in any stage of disease. Its focus is on comprehensive care and improving the quality of all areas of the patient's life*" (definitions retrieved from the MedLine database of MeSH – consulted in November 2023).

Middle care – in the context of this report – should be understood as "intermediate care". But, similarly to the definition of palliative care, a wide range of definitions exists.[217] As an illustration, CINHAL defines "intermediate care" as "*intermediate care (see subacute care) is care provided to acute care patients who are medically stable but too unstable to be treated in alternative healthcare settings such as home, ambulatory, or traditional skilled long term care*" while the British Society of Geriatric defines it as "*an approach to health care intended to facilitate patients' transitions from illness to recovery, or to prevent their transition from home managed chronic impairment to institution-based dependence, or to help terminally ill people be as comfortable as possible at the end of their lives*".

A third observation is that the care delivered appeared to be confounded with the facility (a built infrastructure), contributing to the confusion between the nature of the care dispensed to the patients and the place where this care can be delivered. Considering the objectives of the "palliative middle care" as reported in the two Belgian reports on the topic, "palliative middle care" can be envisioned as a "hospice care." Hospice Care is defined as a *"specialised health care, supportive in nature, provided to a dying person. A holistic approach is often taken, providing patients and their families with legal, financial, emotional, or spiritual counselling in addition to meeting patients' immediate physical needs. Care may be provided in the home, in the hospital, in specialised facilities (HOSPICES), or in specially designated areas of long-term care facilities. The concept also includes bereavement care for the family". (From Dictionary of Health Services Management, 2d ed) – MeSH.* This definition implies that hospice care is more than a residential offer (and, inside the residential offer, it can take several forms of operationalization, meaning that there is not a defined model of "hospice care"). Hospices are defined in MeSH as "*facilities or services which are especially devoted to providing palliative and supportive care to the patient with a terminal illness and to the patient's family*".

In the absence of a consensual definition and criteria, during the site visits, respondents also suggested various definitions of palliative middle care in Belgium. These definitions appeared to reflect different profiles of patients, leading to different perceptions about the content of the offer and the profile of the patients. This heterogeneity could be seen as reflecting the need for a diverse offer to cover the patient needs.

From the workshops, it appeared that giving a clear definition of palliative middle care remains difficult for the patient representatives. Therefore, some elements of this definition can be highlighted. Patient representatives firstly explained that, for them, palliative middle care was at the intersection between home care and hospital care. According to some of them, solutions directly provided at home are not considered as part of the palliative middle care (e.g., the multidisciplinary outreach palliative care teams). But palliative middle care was not only residential in their views: it can be ambulatory as a day care centre.

> *C'est hors du domicile, c'est hors de l'hôpital et hors des maisons de repos. Sinon, c'est ce qui existe déjà et on n'est pas sur de l'intermédiaire ou de l'alternative. Patient representative 2 – FR workshop*

A second element is that the middle care should provide a certain degree of medicalised (respite) care.

> *Ce sont des structures de soins et de répit qui puissent être médicalisées parce que les patients en soins palliatifs ont parfois des besoins de soins et de techniques spécifiques mais qui ne soient pas identifiés uniquement soins palliatifs. Je pense que le répit par rapport à des patients chroniques pourrait être un répit large et des structures qui en effet auraient un point d'attention sur le lien social et qui pourraient accueillir à la fois soit uniquement les patients parce que la demande de l'aidant, ce serait de souffler et que son proche soit pris en charge mais pas forcément lui présent mais aussi des structures qui pourraient accueillir l'un ou l'autre proche et donc lui aurait l'occasion d'être aussi accompagné en termes de pouvoir parler, de rencontrer d'autres proches. Patient representative 2 – FR workshop*

But, from the site visits, it was not possible to clearly identify the type of care that should be delivered in a palliative middle care service. Some respondents suggested that there should be a mix of "regular" palliative patients and intermediate palliative patients and the norms of an existing palliative care unit should be applied to the middle care unit. To achieve this additional mission, they suggested that extra staff could be envisioned but as these patients need less monitoring, it may be not needed. It will therefore require expanding the support for occupational activities (hypnosis, music...). In this view, a respondent suggested to consider the agreement criteria of a rehabilitation unit. Other insisted on a model delivering the same health care than those possible at home. It also emerged from the site visits that "low care", "highly medicalised care", …were differently perceived by the respondents, stressing the need for defining clearly the content of the health care offer.

7.3 Do we need palliative middle care?

In the online survey, 89% of the organisations declared that having palliative middle care in Belgium is needed (Figure 23), as it can fill a gap between home care and hospital care for some patients.

> *Les initiatives de soins intermédiaires sont indispensables dans le paysage médico-social actuel. Elles seront riches de diversité et inventives. Elles devront être encadrées et soutenues par des organes garants de la qualité des soins et de la sécurité des patients. Leur fonctionnement soulagera les pratiques de soins palliatifs qu'elles soient spécialisées ou occasionnelles. Elles éviteront nombre de souffrances et d'hospitalisations intempestives. Elles seront économes des moyens consacrés actuellement à la fin de vie et participeront bien plus efficacement à la culture palliative par leur ouverture sur la société. Palliative network 2 – Online survey*

It can also help to better orient patients according to their needs, e.g. orienting those with the more complex care needs to palliative care units.

> *De dure palliatieve bedden op een palliatieve eenheid dienen benut te worden voor de patiënten die de zorg die ze nodig hebben elders niet kunnen krijgen. De opnamecriteria voor de palliatieve eenheden moeten uitgezuiverd worden. Een patiënt die 3 maanden op een palliatieve eenheid verblijft, is veel te lang. En nu liggen er vaak patiënten een half jaar of langer waardoor de patiënt die het echt nodig heeft er niet terecht kan. Hospice 1 – Online survey*

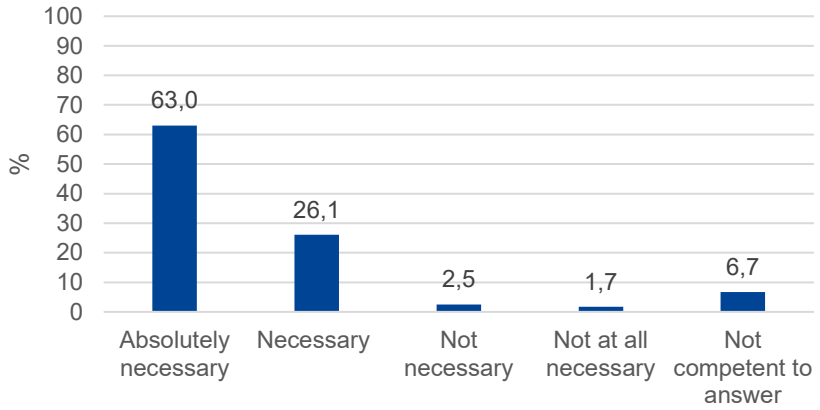
> *Nous avons souvent dans les unités de soins palliatifs des patients qui, après la prise en charge, sont confortables et relativement stable. Ils ne sont cependant pas assez stables ou la prise en charge reste trop lourde pour un retour au domicile ou un placement en MRS (plaie, risque de dyspnée aiguë, risque d'hémorragie, traitement en intraveineux...;) ou l'entourage n'est pas suffisant pour permettre un retour à domicile. Palliative care unit 6 – Online survey*

> *Voor patiënten en families waarbij de zorgnood te zwaar is of de draagkracht overschreden, zijn intermediaire zorgvormen buiten het ziekenhuis een populatiegericht antwoord. Professional Association 1 – Online survey*

If, for some organisations, new structures can be created, other stressed that the existing services can be adapted for accommodating these patients.

> *Renforcer l'offre existante, adapter les structures actuelles en différenciant les services/missions/encadrement et ne pas forcément créer des nouvelles structures. Hospital federation 3 – Online survey*

Figure 23 – Necessity of having palliative middle care in Belgium according to organisations (N=119)



Those mentioning that it was not necessary to develop a new offer worked in different settings: home care, hospital care or palliative network. These organisations stressed that there were already numerous services able to deliver quality care and adding to the current offer complexified the landscape instead of smoothing it. Better informing the professionals about their role and their added value was, according to those respondents, a more effective way of improving palliative care.

> *De huidige MBE-werking kan al een deel van deze intermediaire functie opvangen, mits duidelijk (transmuraal) mandaat en verdere optimalisatie. Wel is er nood aan meer medium palliative care. Voornamelijk sociale aspecten maken een overlijden thuis niet altijd mogelijk terwijl de ingeschatte prognose soms te onvoorspelbaar is tgv aandoening om op een gespecialiseerde palliatieve unit/ hospice te kunnen komen. Mensen die nog niet (hoog)bejaard zijn voelen wel een drempel om opgenomen te worden in WZC [woonzorgcentra]. Soms kan een tijdelijke ontlasting van de draagkracht van mantelzorg wel een overlijden thuis doen slagen, maar een goed uitgebouwde respijtzorg ontbreekt momenteel. Palliative network 1 – Online survey*

[…] Il s'agit avant tout de mettre en place les soins palliatifs à domicile dès que c'est nécessaire. Informer et réinformer les médecins traitants, les infirmiers et même les kinés du secteur de l'aide à domicile. Créer du lien entre l'hôpital et le domicile. Être dans la prévention et non dans l'urgence. Home care service 1 – Online survey

This needs for reinforcing instead of creating also emerged during the site visits. As an illustration, considering the opportunities of hospitalisation at home, some respondents stressed that there is no need for additional medicalised structures: they expressed that hospitalisation at home already exist and can care for those in need for specialised care, under the conditions that the care offer was expanded.

During the workshops, patient representatives acknowledged that there were already a lot of services, but their existing rules or norms needed adaptations to make them accessible to palliative patients. The focus can be put, as suggested by a patient representative, on the rapidity of the response for these patients. For a patient representative, if one decided to use existing services and "just" adapted the rules to make it more relevant in the current context, it can be easier to accept for the public authorities. Indeed, the patient representatives perceived that, for the public authorities, if they already knew the service, it was a more efficient way of working.

Mais, en tout cas, ne pas réinventer, on ne part pas de rien, il y a des choses qui existent et ce sont ces choses-là qu'il faut peut-être un peu plus ouvrir, peut-être au niveau palliatif. Il y a une notion un peu d'urgence et de priorité peut-être qui devrait être mise. Mais il faut plus de dispositifs quand même mais il y a des choses qui existent. Patient representative 2 – FR workshop

Je crois qu'il y a déjà pas mal de choses et ce qui rend peut-être la réalisation plus facile, c'est que ces concepts sont aussi déjà conçus d'un point de vue financier, intervention des pouvoirs publics et autres. Ne cherchons pas à créer quelque chose tout à fait extraordinaire, on peut le faire mais peut-être aussi optimiser ce qui existe, mieux le faire connaître, donner aux personnes qui aménagent ou qui travaillent dans ces centres de vacances l'occasion d'être plus à l'aise en leur proposant de la formation, etc. mais d'en faire des lieux de vie et pas des lieux de soins. Patient representative 1 – FR workshop

During the workshops; it was suggested to increase the possibilities of respite stay for the patients in existing palliative care units, as an existing solution that can be brought to the patients via the outreach multidisciplinary palliative care teams.

Je pense que c'est une forme de répit possible [les unités de soins palliatifs], qu'il faut pouvoir activer et que les unités mobiles de soutien deuxième ligne à domicile doivent pouvoir informer, en effet, les patients et les proches sur ce qui existe déjà. Patient representative 2 – FR workshop

Another adaptation concerned the holidays camps and recovery centres, managed or not by sickness funds, where additional support for the health care can be integrated (i.e., external healthcare professionals, mobile team in palliative care).

Des camps de vacances pour personnes dans lesquels les personnes avec un handicap ou une difficulté sont accompagnées adéquatement, dans lesquels on peut, le cas échéant, si la situation s'aggrave, on peut faire appel à de l'aide extérieure. Moi je trouve qu'il faut favoriser ce genre de séjour. Patient representative 1 – FR workshop

C'est vrai que ces lieux de convalescence [des mutuelles] peuvent servir de répit [et] sont souvent dans des cadres assez sympas. Patient representative 2 – FR workshop

A patient representative therefore pointed that these options can be not affordable for all patients, that not all these services have a medicalised offer and that the admission criteria can be strict.

Responding the lack of ACP and of proper information, a patient representative suggested to use the possibility of short stay in nursing homes as a moment for informing and planning end-of-life but also for starting what one calls a personalised health care plan starting from the needs and preferences of patients.

Les court-séjours en maison de retraite qui sont agréés pour ce genre d'accueil pourraient être aussi un lieu d'information mais aussi d'explication par rapport à la personne elle-même ou pour déjà dessiner un peu les possibilités qu'elle aurait plus tard en fin de vie parce que les court-séjours ne sont pas proposés pour les personnes très, très avancées ou proches de la mort mais cela pourrait aussi être un endroit, une maison de repos et de soins qui propose ce genre d'accueil court-séjour pour informer mais aussi pour pratiquer déjà ces soins de confort et faire connaissance des besoins, des attentes de la personne elle-même parce que je trouve que dans la réflexion que nous faisons, nous devons distinguer, même si c'est lié, mais distinguer quand même les besoins de la personne elle-même et les besoins des proches qui ne sont pas forcément identiques mais il y a une interdépendance évidente. Patient representative 1 – FR workshop

Finally, a patient representative suggested that there were already a lot of positive initiatives than can be a source of inspiration.

Je pense que là aussi, il existe déjà des initiatives dont on peut s'inspirer et je pense qu'on ne se fait pas du bien en ne mettant en avant que les déficits et les manquements. C'est un peu comme la visite chez le médecin qui demande ce qui ne va pas mais moi j'ai envie de dire aussi ce qui va. Patient representative 1 – FR workshop

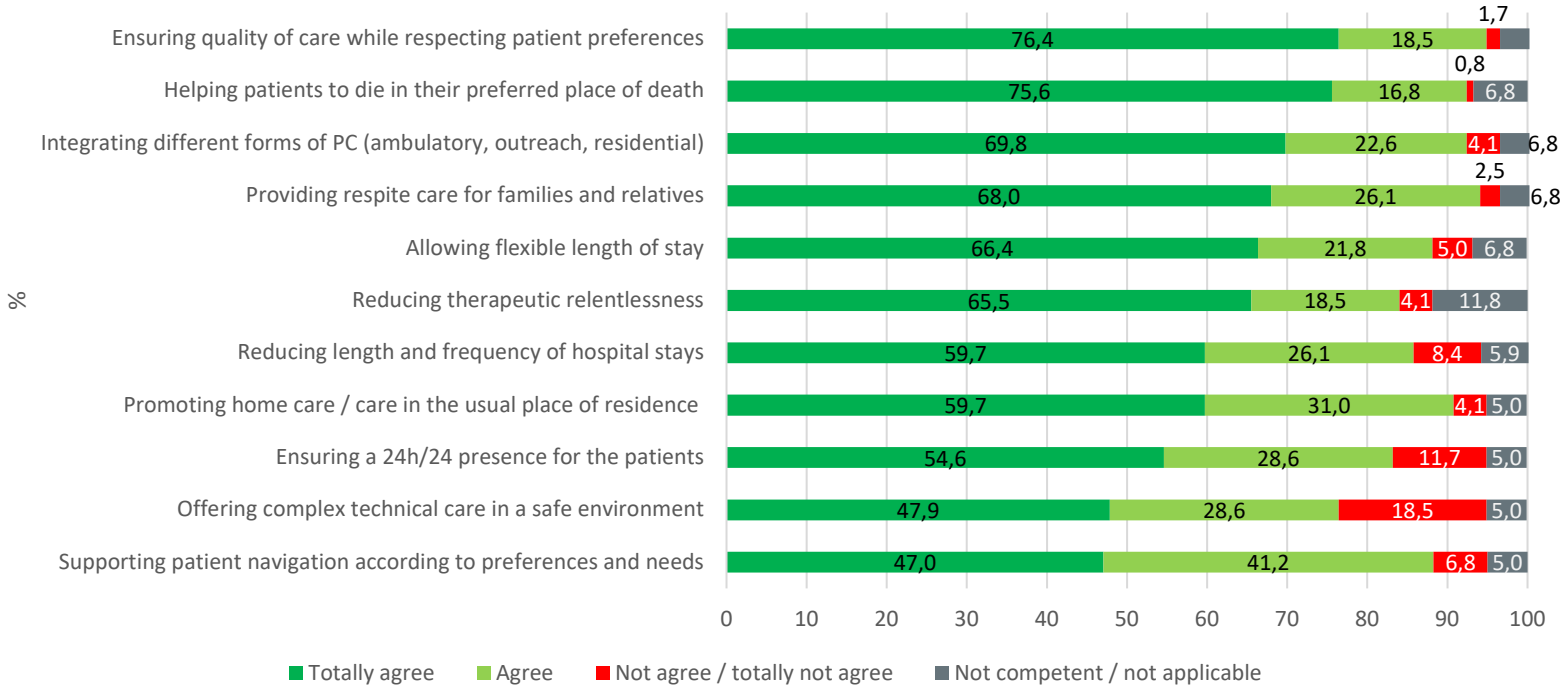
7.4 Objectives of palliative middle care

In the online survey, more than 90% of the organisations agreed that the objectives of PMC should be to guarantee quality of care while respecting patient preferences; to provide respite to families; to allow patients to die in the place of their choice; to integrate different forms of palliative care (ambulatory, mobile team, residential); and to promote staying at home/in the usual living place (Figure 24). Allowing patients to die in their preferred place was also mentioned during the site visits as a key objective for the palliative day care centres. In their respective experiences, many palliative patients wanted to stay (and die) at home but were often socially isolated and / or could take care for their needs. According to them, PMC under the form of a palliative day care centre could help these patients and increase their quality of life, particularly when an informal caregiver was not present for the patient 24/7.

For the other objectives, the proportion of organisations who agreed ranked between 76.5% (for delivering of complex technical care in a safe environment) and 88.2% (for allowing flexible lengths of stay and promoting patient circulation according to their preferences and needs).

It was suggested, as additional objective, to allow for more patient participation and goal-oriented care, which can be understood as respecting the patient preferences.

Figure 24 – Objectives of palliative middle care according to organisations (N=141)



Patient representatives firstly mentioned that patient preference is staying at home as long as possible as the hospital is not the place where patients wish to die.

> *Of misschien iemand wel in een ziekenhuis terecht zou kunnen, en ik spreek dan misschien over de meest extreme situaties waar dat het een noodzaak is, maar geen optie is, wil misschien zelfs niet iedereen naar een ziekenhuis gaan omdat een ziekenhuis nog altijd die connotatie heeft van: ik ben in een ziekenhuis. En waar dat dat zo'n residentiële setting misschien meer geschikt zou zijn als er… De thuiszorg ook echt niet meer gaat, maar dat een zekere huiselijkheid wel bewaard blijft. Patient representative 2 – NL workshop*

Although navigation between different options could be an asset for some patients, some patient representatives also pointed out that stability of the place of life / place of care can be equally important for some patients and that transfer between (health) facilities can be difficult for some patients.

> *Changer de lieu de vie pour ces personnes [avec un handicap mental], c'est encore plus difficile que pour n'importe qui, tout comme pour les personnes qui ont des troubles cognitifs. Patient representative 2 – FR workshop*

When it was no longer possible to stay at home, patient representatives also insisted that decision of transferring patients to another place should not be taken in last minute. This was also mentioned regarding transfer from nursing home to hospital or hospital to home.

A last objective that was mentioned during a site visit was the possibility for patients and families to put aside time pressure, which is be with the relatives in a peaceful setting for the time remaining without thinking about length of stay.

> *C'était trouver un endroit, ou une structure, ou une forme de structure où on peut poser ses valises sans se dire si je ne suis pas mort dans les 28 jours, je dois retourner chez moi. Avoir un endroit où on peut dire là maintenant je vis la fin de ma maladie et la fin de ma vie dans de bonnes conditions, y compris pour ma famille. Donc c'est ma vision de l'intermédiaire, donc je n'ai pas de notion de temps en fait, c'est entre la fin du curatif et la phase terminale, mais justement de ne pas avoir cette pression de temps, c'est plus lié à l'environnement qui fait qu'on ne sait pas le faire dans de des conditions optimales. Project leader – FR site visit 3*

7.5 Perceived impact of palliative middle care

Overall, the feedback from the organisations regarding the potential impact of PMC on the barriers experienced by patient and relatives was quite positive. Indeed, between 70% and 80% of the organisations declared that PMC could have a positive impact on the personal barriers of the patients, except for euthanasia where the impact would be less important (Figure 37a in Appendix 5).

Regarding social and financial barriers, the perceived positive impact varied between 40% and 80% for most barriers, with a maximum for the availability of information about palliative care and end of life, for which almost 80% of stakeholders assessed that the impact would be positive (Figure 37b in Appendix 5). During the site visits, PMC was mentioned several times as a cheaper organisational model when compared to hospitals, based on the respondents' estimates.

The perceived impact on professional barriers experienced by the patients was also positive, according to the organisations. Almost 90% of the organisations estimated that PMC could have a positive impact on the respite and support care for the families. Results were also encouraging regarding the potential impact on attitudes of general practitioners (80% estimated a positive impact), stay options for families (76%), attitudes of home care services (75%), hospital teams (70%), specialists (69%), and nursing home teams (60%), and on the length of stay funded by the authorities (55%) (Figure 37c in Appendix 5).

> *Les endroits type middle care permettraient aussi d'accueillir toutes ces personnes qu'on refuse en unités de soins palliatifs car « pas assez mal » et qu'on doit orienter vers des maisons de repos alors qu'on sait pertinemment que les soins n'y seront pas optimaux. Palliative care unit 7 – Online survey*

Some organisations perceived that palliative middle care could be more accessible, implicitly implying that admission criteria will be less restrictive than those of palliative care units.

> *Intermediaire palliatieve zorg gaat veel laagdrempeliger zijn voor patiënten en families. Hospice 1 – Online survey*

But, the impact of PMC was also to be taken into a wider context of palliative care as stressed by an organisation:

> *Zolang de perceptie blijft bestaande dat palliatieve zorg gelijk is aan terminale zorg zal er niets veranderen aan de mindset van veel betrokken hulpverleners, artsen, overheden, ... kortom iedereen in onze samenleving. Palliative day care centre 1 – Online survey*

The perceived impact of PMC on the barriers experienced by professionals also showed very encouraging results. The barriers that received the highest 'positive impact' score are related to availability, information, and training. Indeed, around 80% of the organisations perceived that PMC would have a positive impact on the waiting times, admission criteria, recognition of palliative care by society and by health professionals, and on referral to palliative care by healthcare professionals (Figure 38 in Appendix 5). When looking at the most important barriers declared by the organisations (also see Chapter 6), the potential positive impact also reached high scores, whether for the financing by the authorities (59% declared a positive impact), for beds availability (76.3%) or health professionals availability (61.9%). Finally, around 70% of the organisations estimated that the impact would also be positive regarding reachability.

But, as stressed by several organisations, to date, envisioning the impact of PMC remained a theoretical exercise, conditioned by the final options and their implementation.

> *Idem kwaliteit van leven; financiering hangt af van het regelgevend kader. als intermediaire zorg als volwaardig zorgalternatief wordt uitgewerkt door de overheid, kan dit op verschillende vlakken positief uitdraaien voor mens en maatschappij; op voorwaarde dat het financieringsmodel een volwaardige uitbouw toelaat. Expertise centre 1 – online survey*

Some also suggested that the impact of PMC could be positive if this offer was developed as a complement to the existing offer, considering the other challenges that the health care sector has to face.

> *[…] Ils seront positifs si le middle care vient en complément et pas à la place de ce qui existe déjà (sachant que le secteur lui-même doit être renforcer pour répondre aux besoins palliatifs actuels). Palliative care network 3 – Online survey*

From the workshop with patient representatives, it appeared that palliative middle care could contribute to fill two gaps in the current offer of palliative care and can be thus considered as necessary to develop in the current context of palliative care. The first gap consisted in the lack of residential structures, outside home care and hospital care, especially for the young patients and those in precarious social and / economic contexts.

> *Of misschien iemand wel in een ziekenhuis terecht zou kunnen, en ik spreek dan misschien over de meest extreme situaties waar dat het een noodzaak is, maar geen optie is, wil misschien zelfs niet iedereen naar een ziekenhuis gaan omdat een ziekenhuis nog altijd die connotatie heeft van: ik ben in een ziekenhuis. En waar dat dat zo'n residentiële setting misschien meer geschikt zou zijn als er… De thuiszorg ook echt niet meer gaat, maar dat een zekere huiselijkheid wel bewaard blijft. Patient representative 1 – NL workshop*

> *Qu'il y a un besoin criant pour les personnes plus jeunes, moins de 60 ans, 65 ans pour des lieux de vie en dehors du domicile mais résidentiels quand même. Patient representative 1 – FR workshop*

> *Maar ik denk meer een residentiële setting gericht op palliatieve, denk ik dat voor het segment van alleenstaanden, wel echt ook een enorme meerwaarde kan zijn nog. Patient representative 1 – NL workshop*

A second gap that needed to be filled was the lack of respite care. PMC services could be places where the patients could stay for a brief period before going back home (or another place), similar to the model of the short stay in nursing homes or recovery homes.

(…) Il y a peut-être un petit maillon manquant d'une bonne prise en charge quand le proche veut prendre du repos, parfois juste pendant 8-15 jours, souffler un peu et que, du coup, cela se passe à l'extérieur du domicile. Patient representative 2 – FR workshop

Je pense qu'on aurait plus d'intérêt à travailler là-dessus avec de la prévention que, encore une fois comme le fait souvent la Belgique, de travailler avec du curatif une fois qu'ils [les proches] ont craqué. C'est un changement de mentalité qui doit intervenir encore. Patient representative 5 – FR workshop

7.6 Priority target groups

Organisations were also asked to select three priority groups of patients for the development of PMC. More than half of the organisations (58%) think that PMC should not be targeting priority groups**.** This was also stressed by some respondents during the site visits. For some respondents, it was difficult to draw the frontier between middle care and palliative care as the situation could quickly evolve or some patients presented as terminal can still live a few months once their symptoms are correctly treated (e.g. pain management). In that sense, having a target group appeared as a complex exercise to perform for clinicians.

Among groups which were most often selected were patients with complex needs, patients with poor social network, and patients with a life expectancy longer than 6 months (Table 55 in Appendix 5). But what some organisations stressed, it is the need for a need-based approach, integrating different criteria of vulnerabilities.

Mensen die door hun aandoening tijdelijk of permanent niet thuis kunnen verblijven, bv. jonge papa met glioblastoom die verwardheid vertoont maar wel nog bezig is met zijn behandeling en hier mogelijks nog even door kan opklaren. Palliative care unit 8 – Online survey

Plusieurs critères, pris ensemble ou non, sont nécessaires afin de déterminer les patients pouvant potentiellement bénéficier de soins palliatifs intermédiaires. Un des critères majeurs est sans aucun doute la stabilité clinique (les patients instables ayant alors leur place en aigu en milieu hospitalier). Il est primordial de pouvoir, par exemple, distinguer parmi les patients stables : 1) les personnes (jeunes ou âgées) avec des soins complexes chez qui, ni le milieu hospitalier, ni les maisons de repos et soins – ni les maisons de repos pour personnes âgées, ne sont adéquates ; 2) les personnes jeunes sans soins complexes mais avec des besoins complexes (isolement social par exemple) chez qui une structure intermédiaire a tout son sens. (Les personnes âgées avec ces besoins complexes mais sans soins complexes ont le profil pour aller en maison de repos pour personnes âgées ou maisons de repos et soins) Discriminer uniquement en fonction de l'âge, de la stabilité clinique sans tenir compte de l'environnement psycho-socio-économique nous semble compliqué. Hospital palliative support team 2 – Online survey

Also, some organisations suggested to consider the degree of fatigue of the informal caregivers as a predisposing factor for admission or orientation to PMC.

For the patient representatives, two distinct target groups emerged from the discussions: 1) the patients and 2) the relatives involved in the care of palliative care patients (informal caregivers and qualified informal caregivers).

Patient representatives pointed that the priority should be given to those who were no longer able to stay at home. Socioeconomic context needed to be considered into the priority orientation, such as single mother with young children or isolated person without close family able to provide extra support. Alongside those in complex social situations, patient representatives also explained that the presence of cognitive problems or dementia limited the capacity to stay at home.

Mais, à partir du moment où les problèmes cognitifs sont là, où la police les retrouve à 3 heures du matin dans la rue. À un moment, il y a une limite humaine à aider. Je pense que le début de démence et les problèmes cognitifs sont vraiment un obstacle au fait de pouvoir garder sereinement quelqu'un à son domicile. Patient representative 5 – FR workshop

From the workshops, it emerged that palliative (middle) care should not only be limited to those with a terminal disease such as cancer but also those with a chronic or rare disease. These distinct groups could be, according to some patient representatives, mixed in the same health care facilities, as they may have congruent needs and preferences. Another aspect that was discussed was mixing the patients at distinct stages of their disease: it could be experienced as confronting for some patients and, consequently, adding to the distress instead of providing support.

Ik denk dat dat een voor- en nadeel terzelfdertijd is. Dat merk je heel erg bij lotgenotencontacten van enerzijds, ja, heb je bij lotgenoten maar een half woord nodig om elkaar te begrijpen. Ik denk dat er heel veel begrip is onder lotgenoten. Maar dat er wel een fundamenteel verschil is tussen ja, lotgenotencontacten waarbij dat er een ja, nog hoop op genezing is van… Of dat je nog x-aantal behandelingen kan gaan toepassen of uitproberen. En anderzijds ja, lotgenoten die terminaal zijn. Ik denk dat dat heel steunend kan zijn voor sommige mensen, maar het kan ook wel heel confronterend zijn. Zeker als er dan een aantal mensen beginnen weg te vallen. Patient representative 1 – NL workshop

In that sense, some patient representatives suggested to have generalist structures based on patient needs, independently of their disease / diagnosis: by putting patients into categories, there was a risk of increased fragmentation of the offer and, consequently, patients could fall between gaps.

Peut-être qu'il faut des structures un peu plus généralistes et pas uniquement limitées parce que c'est un peu le problème au niveau institutionnel chez nous, c'est qu'il y a souvent tellement des critères spécifiques et qu'il y a des gens qui sortent des cases, peut-être qu'il ne faut pas des structures spécifiques soins palliatifs mais que les personnes en soins palliatifs aient une certaine priorité. Patient representative 2 – FR workshop

From a practical point view, a patient representative reported that equal health care needs could facilitate the organisation of the services: this may be seen as an argument for an offer based on patients (care) needs.

Naar praktische medische zorg… Naar het praktisch kunnen geven van een uitgebreide medische zorg, die vraag van daarnet, is dat wel gemakkelijker als je allemaal mensen hebt met min of meer dezelfde zorgnood, ja, dan kan je dat wel gemakkelijker organiseren. Maar ik denk dat het ook een meerwaarde kan zijn als het niet zo strikt opgedeeld. Patient representative 1 – NL workshop

But, as pointed above, the needs and preferences of the patients must as much as possible guide the nature of the services provided. In any case, patient representatives reported that support was needed to accompany the patients over time.

Some respondents stressed that palliative middle care should aim at patients with higher care / medical needs than those possible to be managed at home or in a nursing home. These patients were described as in need of constant medical attention (e.g. when there is a need for a daily adaptation of pain treatment). Some respondents suggested that the palliative middle care could be beneficial for stable patients at risk of complications (dyspnoea, haemorrhage) and with multiple problems *(e.g.* comorbidities, metastases*…)*. It was also stressed that, for these patients, they needed more than the 30 days of stay as, according to them, it is the current length of stay funded in palliative care unit.

Les soins palliatifs intermédiaires, ce sont vraiment tous ces patients palliatifs au-delà du mois d'hospitalisation, qui ont des besoins plus importants des patients classiques qu'on peut facilement renvoyer à la maison avec la prise en charge palliative globale interdisciplinaire avec la présence du médecin généraliste et la première et potentiellement la 2e ligne, donc des besoins au niveau médical, au niveau soins avec des médications souvent qu'on ne peut pas trouver à domicile. Des patients qu'on ne peut pas renvoyer en maison de repos parce que le la maison de repos est inadaptée, soit par rapport à l'âge des patients, soit par rapport à la pathologie du patient, soit à la charge de travail du patient. Respondent from a Sp 4 unit – FR site visit

Another dimension emerging from some site visits was the fact the housing or the nursing home was not suitable for the patient's needs. It was, among others, stressed by several respondents that some patients were too young to enter nursing homes but had a family with young children, making a stay at home difficult to organise. Financial accessibility of the nursing homes was also pointed as a barrier for some patients.

> *Des patients qui souffrent d'une maladie incurable mais qui ne sont pas forcément symptomatiques, mais dans l'état, requièrent un environnement plus adapté que ce que le domicile ou la maison de repos. Respondent form a Sp4 unit – FR site visit 2*

> *On s'est rendu compte quand même que la plupart, qu'une partie des patients ne trouvaient pas, je dirais chaussure à leurs pieds, dans des soins qui étaient proposés. Et il y a une partie de patients dont les soins à l'hôpital ne sont plus nécessaires, donc des médecins leur disent clairement qu'il n'y a plus de possibilité pour eux de traitement en milieu hospitalier, ils n'ont pas l'âge pour rentrer dans une maison de repos, mais le maintien à domicile est parfois très difficile parce qu'ils sont seuls ou parce que l'entourage est épuisé, parce qu'il y a des petits enfants à la maison. Project leader – FR site visit 3*

Some respondents also reported that some symptoms were burdening for the families (e.g. severe dyspnoea, patients agitated…), making the stay at home difficult to experience. It was also reported that the lack of entourage, the difficulties for adapting the home (or the absence of home) reinforced the need for palliative middle care like home. These respondents supported a model of middle care targeting basic medical care without complex technical care, aiming at patients whose living place is not suitable rather than for those with an unstable clinical condition / in need of complex technical care.

7.7 Possible options for developing palliative middle care

In the online survey, organisations estimated the relevance of a set of criteria regarding admission; offer and organisation; and infrastructure and furnishing of PMC.

7.7.1 Transversal elements for the development of PMC

Thorough the discussions, patient representatives pointed out several attention points for the development of palliative (middle) care. These elements, although not specific to palliative middle care, were envisioned as preliminary guiding principles when developing a new health care offer or enlarging existing services.

Patients' needs and preferences evolve over time

Patient representatives stressed that the needs and preferences of patients evolve with their disease: consequently, several solutions were needed to comply with their needs and preferences while respecting care continuity. The stage of the disease also played a role in deciding the most appropriate solution for the patients.

> *Donc il n'y a pas d'évolution classique pour tout le monde, la même, mais cela dépend aussi à quel moment, à quel âge ces maladies commencent et comment ils se déroulent. Patient representative 1 – FR workshop*

Needs of the patients should be distinguished from those of the relatives

Patient representatives also reported that the needs of patients should not be confounded with the needs of the relatives, meaning that the professionals should be able to hear and listen patients and relatives to find the most appropriate solution.

J'adhère tout à fait à l'idée de distinguer – et ce n'est pas évident – les besoins du patient et les besoins des proches. Par exemple, par rapport au relais hospitalier, au relais en maison de repos, parfois la personne malade y est très, très opposée, réticente. Ce n'est pas facile en tant que professionnel de pouvoir entendre les besoins de la personne et ceux des proches. Patient representative 2 – FR workshop

A major improvement noted by some patient representatives is the officialization of the status of qualified helper (*bekwame helper - aidant qualifié*), contributing to the provision of additional care to the patients wishing to stay at home. Therefore, the qualified helpers will not be able to perform all (complex) care that may be needed in palliative status, implying that they will always be dependent on professional help while remaining constantly aware for the patients.

Une autre chose, au niveau des manques et du domicile, c'est parfois quand il y a justement des soins techniques un peu plus complexes. Je pense à des patients qui sont trachéotomisés à domicile, des patients qui souffrent au niveau alimentation, de risques de fausse déglutition. Les proches peuvent être formés pour pouvoir réaliser ces soins mais, de nouveau, cela veut dire qu'à part quand il y a un relais infirmier et qu'on ne sait pas à quelle heure le passage infirmier va arriver, qu'en général, il reste un quart d'heure ou 20 minutes, ces proches, même quand il y a vraiment une volonté d'accompagner le patient le plus longtemps à domicile, sont indispensables 24 heures sur 24. Parce que s'il y a un relais d'une aide familiale, l'aide familiale ne peut pas réaliser ce type d'acte à domicile. Même s'il y a une législation en cours sur les aidants qualifiés, je pense que, pour les aidants qualifiés, ces actes précis d'alimentation en cas de risque de fausse déglutition, d'aspiration en cas de trachéotomie, resteront exclus des actes qui peuvent être délégués et donc ce sont des proches qui sont réquisitionnés 24 heures sur 24, qui ne peuvent pas avoir une nuit complète parce que la machine sonne, il y a une obstruction… Patient representative 2 – FR workshop

Solutions need to be affordable and known by patients and relatives

The offer of PMC must be affordable and known to the patients and their relatives.

Malheureusement tout le monde n'a pas les mêmes ressources et les mêmes capacités de formation et, de nouveau, je pense au public plus précarisé en termes financiers mais aussi de précarité sociale. Patient representative 2 – FR workshop

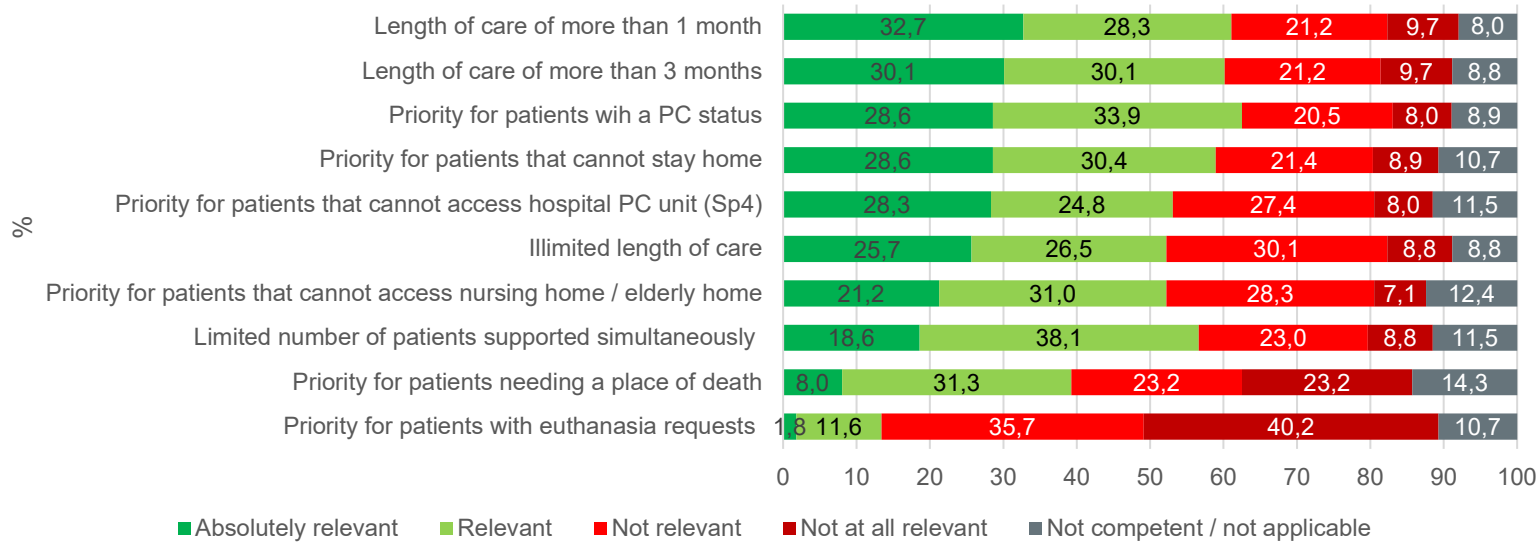
A feasible option to make is affordable can be the use of a convention system, like what exists for some rare diseases or complex health conditions.

Conventies voor bepaalde ziektes. D'r is onder… De ALS Huntington conventie waar dat ook wel woonzorgcentra onder gekoppeld zijn, waar dat mensen terecht kunnen die niet meer thuis kunnen verblijven, waar dat het niet meer gaat Patient representative 2 – NL workshop

7.7.2 Propositions for the admission criteria

Regarding admission in PMC, no criteria really standed out compared to the others, although admission for a stay of more than one or three month(s) and having a palliative 'status' had the highest scores of relevance (more than 60% of the organisations declared those were relevant criteria) (Figure 25). In contrast, most organisations did not think that PMC should be limited to patients asking for euthanasia. This was also mentioned during the site visits: euthanasia was perceived by the respondents as an element of the therapeutic project of the patients and not as a guiding criterion for admission. As experienced by some respondents, there was a pressure for admitting non-Belgian patients, mainly French citizens, asking for euthanasia as it is not legally allowed in France. Several respondents expressed their desire to avoid transforming their service into a *mouroir* (lit. a place to die), where patients were admitted just for "being killed".

Figure 25 – Relevant criteria for admission in a palliative middle care service according to organisations (N=113)



To be adequate, the offer should remain flexible regarding the admission criteria of residential possibilities: according to patient representatives, patients should have access already at initial stages of their diseases, as it could help to gain familiarity with the services and staff. Patient representatives also reported that offer should allow for short and / or temporary stays, meaning that patients should not be forced to stay in the residential service. They finally stressed the added value of having the possibility to leave and return, upon their needs and preferences.

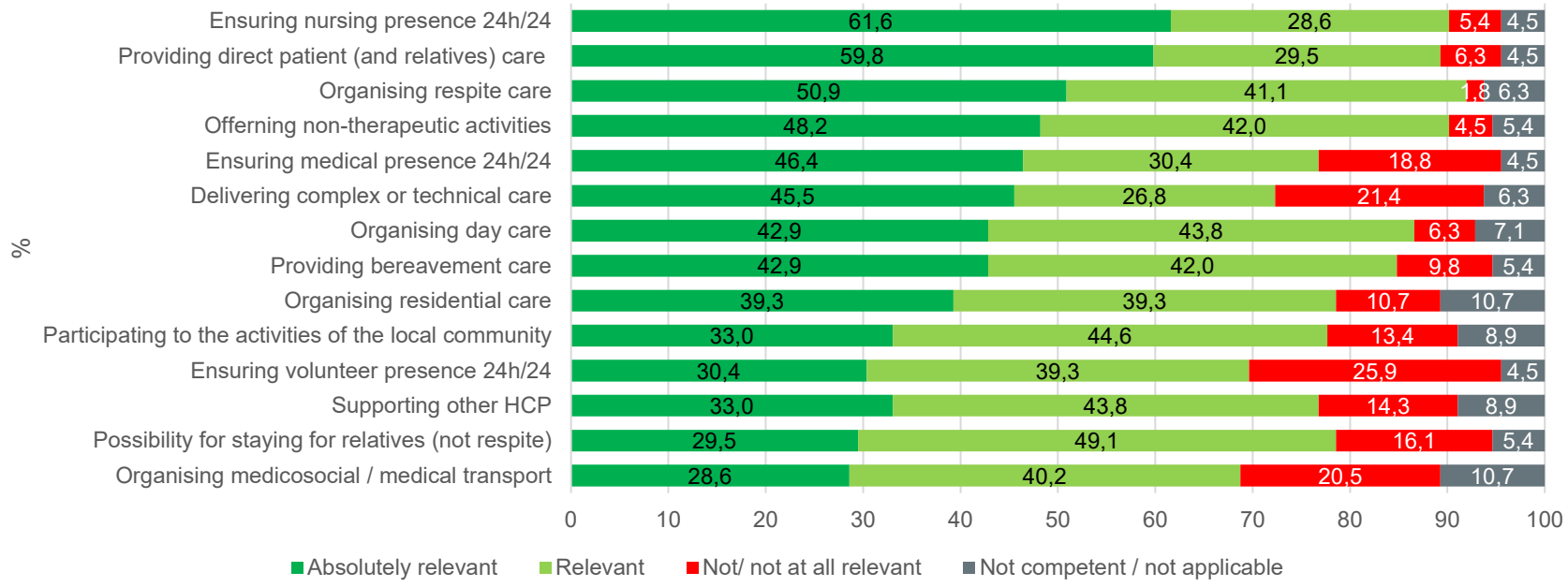
7.7.3 Options for the offer and organisation

Regarding the offer and organisation of PMC, the most relevant criteria according to the organisations were: organising respite care, ensuring nursing availability 24 hours a day, organising non-therapeutic activities, and providing direct care to patients and their relatives (Figure 26). Still, at least 70% of the organisations agreed with the relevance of all the other criteria related to offer and organisation.

A palliative care network suggested that the organisation should ensure that in every palliative network a (similar) range of care services should be set up.

> *In Vlaanderen zijn er 15 netwerken palliatieve zorg. Per netwerk zou er minstens 1 palliatief dagcentrum en meerdere hospices (in woonzorgcentra) moeten operationeel zijn. De armtierige financiering van de intermediaire zorg is een belangrijke verklaring en is een zorgstaat onwaardig! Palliative care network 4 – Online survey*

Figure 26 – Relevant criteria for offer and organisation of a palliative middle care service according to organisations (N=112)



Offer needs to be diverse

As the needs and preferences are evolving over time, often over a short period, the offer needs, according to patient representatives, to propose several options, not only limited to medical care but also to social and leisure activities for both patients and families. This requires more than a healthcare team but also professionals and/or volunteers able to organise social and occupational activities.

> *Je pense qu'il faut différentes choses et des structures. Monsieur parlait de sa marche. En effet, et ce n'est pas du tout lié au fait que vous étiez aidant proche ou au fait que votre proche était en soins palliatifs. Ce sont vraiment les structures généralistes mais, pour que le proche puisse participer à ce genre d'activités qui lui fait du bien, et qui, en effet, si cela peut déjà se mettre en marche avant que le patient ne décède, c'est déjà un accrochage et cela va être une forme de soutien et de passage un peu plus en douceur. Pour l'un, ce sera un peu d'écoute, pour l'autre, ce sera une activité hors de la maison, pour une troisième, ce sera rester avec son proche mais que le proche soit pris en charge. […] Il faut une multitude de choses, mais essayer de ne pas faire des spécificités par pathologie ou par notion de soins palliatifs, par exemple, que cela puisse être ouvert et, du coup, il faut une équipe qui soit suffisamment souple, que ce soit une équipe aide, que ce soit une équipe soins ou que ce soit une équipe vraiment accompagnement et volet soutien psychologique. Patient representative 2 – FR workshop*

For some patient representatives, it appeared important to preserve their personal social life by having opportunities to leave their place of stay, e.g., to visit a friend or to go to the cinema on their own. The patient representatives also suggested to organise the offer according to the age of the patients, implying that young patients may have different needs and rhythms than older ones.

> *Ja, of eens naar een vriendin of een… Of eens toch nog zelf naar een winkel of toch nog eens ergens één of andere activiteit gaan meepikken. Het is niet omdat je palliatief bent en zorg nodig hebt en niet meer zelfstandig kan wonen, dat het ja, dat het niet meer mogelijk mag zijn of moet zijn om ook nog eens iets anders te doen dan enkel met uw ziek zijn, of uw eindigheid van het leven bezig te zijn. Dus dat. Ja, dat mensen ja, nog een zo normaal mogelijk leven kunnen hebben op het moment dat ze kunnen, op betere dagen, ja, dat er toch nog wel de mogelijkheid is om ja, dingen te gaan doen waar dat… Die ze graag doen, waar dat ze zich goed bij voelen, waar dat ze gelukkig van worden. Patient representative 1 – NL workshop*

> *Ja, ik vind dat heel mooi, ik vind dat…. En ik denk dat je dan weer voor een stuk bij de vrijwilligers komt, die dan bijvoorbeeld als… Zo naar een vriendin gaan, dat er dan een vrijwilliger wordt gevraagd om persoon, om die persoon van punt A naar punt B te brengen, en dan een uur of twee nadien weer terug op te halen. Patient representative 3 – NL workshop*

But, as already mentioned, the diversity of the offer can reach its objectives if the patients (and their relatives) are aware about it and were informed to make decisions in accordance with their preferences and needs.

> *Dat is ook weer iets heel persoonlijk. Ik denk dat dat ook wel mee een stuk kan beslissen van, of iemand dan kiest om in zo'n collectieve setting te gaan, ja, verblijven of niet. Iemand die d'r niet mee geconfronteerd wil worden, zal wellicht ook niet kiezen voor een collectieve setting. Patient representative 1 – NL workshop*

> *Dat is misschien een stukje waarom het interessant is om die verschillende mogelijkheden te hebben. Dat mensen gericht kunnen kiezen van: dit is wat bij mij past. Patient representative 3 – NL workshop*

Solutions need to be close to patient home and accessible geographically

Whatever the offer in palliative middle care, some patient representatives insisted on the reachability of such solutions. It implied an adequate geographic repartition across the territory and an affordable transportation service. Ideally, according to participants, offer should be as close as possible to patient home: it facilitated the possibility of short stay.

> *Zeker voor dagcentra-gewijs of kort verblijf, om daar een vervoersdienstovereenkomst of zo in te vervatten Dat, ik denk dat dat vaak ook nen drempel is. Zeker mensen die dat niet de nodige financiële middelen hebben of zo om ook nog eens bijvoorbeeld aangepast vervoer, of ne partner dat fulltime werkt en dat zegt: allemaal goed en wel, maar ik heb niet de tijd om u op en af te voeren. Of een beperkt netwerk. Dat er ergens een samenwerking met een bepaalde vervoersdienst of regionaal, dat dat geïntegreerd is in het pakket van wat dat er wordt aangeboden… Denk ik dat interessant kan zijn voor sommige mensen. De mogelijkheid om daar beroep op te doen. Niet standaard per se. Ja, dat is nog iets praktisch. Patient representative 2 – NL workshop*

> *Los van dat er thuis, maar structurele residentiële ondersteuning, denk ik aan nabijheid: hoever moet iemand gaan om daarin terecht te kunnen? Dat dat een belangrijke rol gaat spelen, want ik weet de dagcentra hebben een supermooie werking, maar als ik mij niet vergis, zitten die zowat meer in de uithoeken. En dat maakt dat mensen in sommige stukken van het land geen beroep op doen, omdat dat te gek is om 70 km te rijden om daar nen dag te zijn. En als je dat structureler gaat uitbouwen, denk ik wel dat dat een belangrijk facet gaat zijn. Patient representative 2 – NL workshop*

> *On a parlé de mobilité et d'accessibilité en terme territorial, pour en avoir un peu partout sur le territoire et que le proche, s'il n'est pas aussi hébergé dans ces structures puisse continuer à aller voir son patient régulièrement et ne doit pas 120 ou 150 km fois deux. Patient representative 2 – FR workshop*

> *Il en faut plusieurs sur le territoire, idéalement une par province mais peut-être avec une espèce de priorité pour les patients palliatifs mais qui ne sont pas uniquement accessibles aux patients palliatifs. Patient representative 2 – FR workshop*

Volunteers play a central role in delivering *warme zorg*

The focus was put, by patient representatives, on the need for *warme zorg* (litt. warm care), implying that it was more important to have time, opportunities for socially meaningful contacts and space than receiving medical care. In that sense, volunteers were mentioned by patient representatives as playing a key role in the palliative middle care offer, including by triggering specialised help in case of needs or holding permanencies. Patient representatives explained that these volunteers needed to be trained and supported to be able to act in the respect of their limits.

> *Ik denk wel dat… Goh, als je ziet hoeveel vrijwilligers zijn, zowel in de lotgenotengroepen als daarbuiten en in de ziekenhuizen, dan denk ik dat dat toch wel een heel belangrijke rol is dat vrijwilligers kunnen spelen in zo'n middle care centrum. Dat die even belangrijk zijn dan… Zelfs misschien nog veel belangrijker, voor een praatje te komen slaan, om de simpele dinges als… Dat er iemand is: kunt je voor mij een tas thee maken of…? Zo'n zaken, denk ik dat de vrijwilligers altijd heel belangrijk zijn. Patient representative 3 – NL workshop*

> *We spraken daarnet over het permanent aanwezig zijn van iemand. Dat vrijwilligers met een bepaalde opleiding zelfs daar een stuk permanentie kunnen opnemen, naast het sociale aspect wat vrijwilligers kunnen bieden: er zijn, luisteren, een babbeltje doen, een koffietje drinken, klein wandelingetje maken, noem het op. Met de persoon misschien zich toch nog naar de externe kiné te begeven. Als dan toch die verplaatsing naar een ziekenhuis moet gebeuren, misschien… Dat die daar een link kan blijven vormen van: hij kent die persoon van in het palliatief huis, die is tijdelijk in het ziekenhuis, ik ga daar dan toch eens op bezoek. Ik denk dat dat allemaal… Dat hoort allemaal in dat sociale aspect. Patient representative 1 – NL workshop*

Nee, ik denk dat ze, ja, een zeer belangrijke rol kunnen spelen, net als de thuissituaties. Vaak gaat het om dat gezelschap. Iemand komt een babbeltje doen. Een bekend gezicht. Iemand om een beetje permanentie te houden in… Iemand die dat desnoods aan de alarmbel kan trekken als er iets is, zodat dan de gespecialiseerden kunnen inspringen. Ik denk dat daar zeker… En ook naar praktische haalbaarheid, van daar altijd mensen paraat te hebben. Ik denk dat als je met betaalde krachten en zorgverleners moet doen, dat da2 al een heel ander plaatje is dan dat je dat, ook onder andere met vrijwilligers kunt werken en… We hebben zelf binnen de organisatie ook heel veel vrijwilligers. Dus ik kan alleen maar achter het gegeven d'r van staan. Het is een grote meerwaarde. Patient representative 3 – NL workshop

A collaborative team of health and social care professionals delivers multidisciplinary and integrated care

When medical care is needed, patient representatives pointed out that it should be a multidisciplinary approach, shared by different health professionals such as occupational therapists, physiotherapists in collaboration with the GP of the patients and the existing healthcare team (e.g., home nurses). Although not specific to palliative middle care, participants recalled the importance of the communication between healthcare professionals as a guarantee for quality care and coordination.

The need for a presence must be carefully appraised according to patient representatives: even it was considered as a key need by some patient representatives, it may not be necessary to have a permanent (professional) presence at the patient's side. For example, it was explained that there was no need to have a GP 24/7 in the residential structure but that the GP needed to be accessible per phone. The focus appeared to be having the possibilities to activate an ambulatory support in a timely manner, especially during out-of-office hours and weekends.

A dedicated support is organised for the informal caregivers

As mentioned above, next to care for the patients, the palliative middle care offer should also provide a range of (respite care) services for the informal caregivers. Indeed, it was stressed that there was a need for a specific offer tailored to their needs and preferences, with dedicated services for them because they are informal caregivers, qualified helpers, or relatives of palliative care patients. Support can consist in administrative support, psychological and social help, respite care…Whatever the nature of the support provided, it was important that the support was rapidly identified, easily accessible and timely provided. In case of additional needs, there was also a need for a quick reorientation to the most adequate healthcare professionals. Bereavement care, including support for administrative aspects, for the relatives also helped for the transition when the patient deceased, as it was perceived that the help was stopping abruptly and that it added to the loneliness of the relatives.

Participant 1: Ja, ik denk dat er zeker een plek - daarmee bedoel ik niet een fysieke plek - kan zijn voor mantelzorgers binnen dat gegeven van een palliatief huis. Dan denk ik vooral vanuit, ja, dat mantelzorgers met vragen of met, ja, met prakticiteiten of wat dan ook, ook een stuk terecht zouden kunnen bij de ja, permanente zorgverleners die daar aanwezig zijn van… Dat die permanente zorgverleners ja, dan ook opgeleid zijn, kennis hebben waarmee zij dan ja, mantelzorgers een stuk kunnen steunen of een stuk in de juiste richting kunnen sturen, bijvoorbeeld ook misschien naar externe organisaties die dat misschien mantelzorgers bij elkaar brengen. Of naar ja, naar ja, ja, dingen die bestaan vanuit de overheid of… Dat zij dan ook de weg weten, ja, een beetje het gegeven wat dat een sociale dienst in principe doet of zou moeten doen binnen een ziekenhuis. Dat dan ook een stukje vanuit het permanente kader van dat palliatief huis, ja, wel kan ondersteunend zijn voor die mantelzorgers.

Participant 2 praktische informatie waar dat ze terecht kunnen en dan psychologische begeleiding als ze daar nood aan hebben.

Participant 1 Niet alle zorg hoeft daar permanent aanwezig te zijn, maar wel van dat je vanuit die centrale persoon, dat je aan die persoon kan

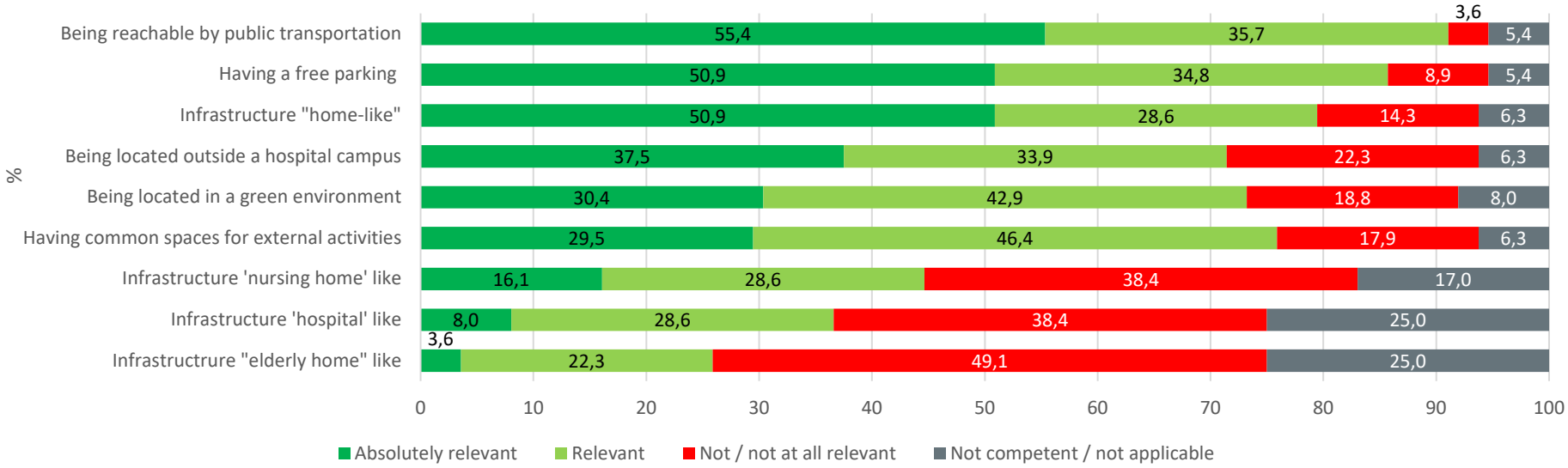
aangeven van: ik zit hier of daar mee. Ik "struggle" daar of daar mee. Oké, je kan terecht bij die en die. En ook op korte termijn terecht. Patient representative 1 and 2 - NL workshop

De nouveau, il y a des pathologies où l'évolution est plus lente. Il y a des pathologies où il faut une prise en charge médicale assez importante mais ce qu'on a mis surtout en évidence, c'est le besoin d'accompagnement, y compris psychologique, que ce soit pour le patient ou ses proches, le besoin de lien social à travers des activités peut-être de détente, des activités de bien-être, que les patients puissent créer du lien social et qu'idéalement cette structure puisse aussi accueillir mais que ce soit au choix de l'aidant, l'aidant qui pourrait du coup rencontrer d'autres aidants, qui pourrait avoir du soutien psychologique mais ne pas vivre… Certains aidants vivent peut-être la culpabilité de je place, entre guillemets, mon proche pour 15 jours parce que j'ai besoin de souffler. Je pense que cela peut être assez culpabilisant pour les aidants. Donc accompagner son proche dans une structure où le proche sera pris en charge de son côté et lui pourra trouver peut-être un cadre dépaysant, au milieu un peu de la nature quand même, rencontrer d'autres proches, avoir s'il le souhaite des informations sur la pathologie, sur l'évolution mais aussi un accompagnement un peu psychologique et être préparé justement au deuil, à la vraie fin de vie. Pour les proches, même s'ils le perçoivent et ils savent que cela va s'arrêter un jour, comment appréhender le jour où tout va s'arrêter. Quand l'accompagnement se fait à domicile, il y a énormément d'interventions professionnelles et quand tout s'arrête, ce n'est pas seulement le décès du proche, c'est l'arrêt de ce va-et-vient professionnel à domicile, le vide. Il y a beaucoup de proches qui nous en parlent, le vide est très violent parce qu'il y a ces deux dimensions. Le décès du proche et donc cette seule issue, le proche était souvent le conjoint et donc aussi un confident, etc. et l'arrêt brutal de tous les intervenants du domicile. Je pense que le proche doit pouvoir être pris en charge aussi s'il le souhaite. Patient representative 2 – FR workshop

7.7.4 Options for infrastructure and furnishing

Lastly, regarding infrastructure and furnishing, being reachable by public transportation and having a free parking were the most relevant criteria for the organisations (Figure 27). In addition, more than 70% of the organisations ranked the following criteria as relevant: organisation like a private house, having common spaces for external activities, localisation in a green/wooded environment, and being located outside the hospital campus. In contrast, having an infrastructure with standards corresponding to hospital units, nursing homes or elderly homes seemed less relevant.

Figure 27 – Relevant criteria for infrastructure and furnishing of a palliative middle care service according to organisations (N=112)



The focus on the environment and the infrastructure was also stressed by the respondents during the site visits: some considered that it should be part of the recognition as a palliative middle care offer.

> *Quand on a passé 6 mois au 5ème étage d'un hôpital, ça fait du bien de voir le ciel et le dehors. Quand ils arrivent, les patients demandent qu'on ouvre les fenêtres » - A professional during the FR site visit 2*

Some of the visited initiatives were located outside of a hospital campus which was perceived by respondents as a key characteristic of the palliative middle care service. This also played a role in the transition from "being treated for a disease" to "being supported at the end of life".

> *Moi j'ai l'impression que, pour les patients, pour leurs proches, ça permet de faire la distinction entre l'hôpital, la maison de repos ou le lieu de vie et d'avoir cet intermédiaire en se disant mais on est dans quelque chose d'intermédiaire. A professional during the FR site visit 1*

> *La structure extra hospitalière, elle est très intéressante pour beaucoup de choses. Il y a la transition, le fait d'arriver ici, c'est une chose, ça nous permet de mettre autre chose en place aussi. Je pense que dans les hôpitaux, c'est quand même beaucoup plus difficile de créer tout ce qu'on met en place. A professional during the FR site visit 2.*

Respondents still discussing their PMC project appeared to devote lots of time to think and develop the infrastructure. Respondents from an initiative under construction explained that they wanted to be in a green zone with small studios where patients had their intimacy while being able to access collective infrastructure. They took their inspiration by the current norms for nursing homes, but they explained that they did not want to fall in the hospital / nursing home model for the infrastructure. According to the respondents, it was important that the patients felt cosier and more comfortable. The building needed to have terrace large enough to put a bed (and all the space needed to be developed to ensure that the beds are easily moved). The

service must be kept small with 10 to 12 beds maximum. They also expressed that if the building was geographically part of a hospital complex, there was something lost. Another project underdevelopment envisioned an infrastructure consisting in 3 to 4 small houses where it was possible to accommodate a family with a severely ill patient. There will be a concierge on site, allowing for orienting and reorienting the patients and the families.

In terms of infrastructure, according to some patient representatives, there was a balance needed between respecting the privacy and intimacy of the patients while enjoying the company of other patients and families. Patient representatives mentioned that patients should be able to choose when to stay alone and when engaging with others. It implied that the residential services should both offer personal and private rooms while offering spaces for common activities. All patient representatives agreed on the fact that the infrastructure should not look like a hospital, implying a cosy and warm atmosphere, a garden, etc. It could be on a hospital campus or a nursing home campus for practical aspects, but it should be a small size structure.

7.7.5 *Leading institutions for delivering or organising palliative middle care*

Palliative hospitals units were identified by the organisations as the most relevant ones for the development of the residential offer when considering the existing services (Figure 28). For the offer of PMC at home, palliative care networks and outreach palliative care support teams were the most relevant according to the organisations (Figure 29). Regarding the day care offer, opinions of the participants were less clear-cut: 32% and 25% declared that palliative care units and palliative care networks, respectively, are relevant options, without any change, although day care centres, outreach palliative care support teams, nursing homes, and home care services were also perceived as relevant (Figure 30).

For some organisations, residential PMC need to be organised outside hospitals.

> *Intermediaire palliatieve zorg MOET buiten de ziekenhuizen blijven. Een ziekenhuis is niet de juiste setting om maanden en maanden te verblijven en de kostprijs is veel te hoog voor de maatschappij. Intermediaire palliatieve zorg is zorg voor personen die normaal gezien gewoon thuis kunnen verblijven maar omwille van sociale, infrastructuur, psychische redenen dit niet kunnen. In de ziekenhuizen moeten patiënten verblijven die acute medische zorg nodig hebben. Hospice 1 – Online survey*

Moreover, as mentioned by some organisations, local initiatives already exist and can be better supported and developed to improve availability of residential offer.

> *Ik verwijs graag naar de mooie voorbeelden van hospices in Tienen (de Klaproos) en Avelgem (Aulighem). Degelijke en structurele financiering voor dit soort van pilootprojecten ontbreekt. Steeds meer patiënten blijven onbediend als het om palliatieve zorg gaat terwijl dit een (wettelijk) recht is in België. Nursing home 1 – Online survey*

> *We zijn een grote voorstander van de ontwikkeling van palliatieve intermediaire zorg als tussenschakel tussen eerstelijnszorg en zorg in ziekenhuis, zowel als dagopvang als respijtzorg en residentieel verblijf. Nursing home 2 – Online survey*

> *Palliatieve zorg moet laagdrempelig zijn, door de te grote onwetendheid bij zorgontvanger en diens familie, maar ook bij huisartsen als zorgpersoneel, ontstaan er misverstanden. Een eenvoudige duidelijk taal de juiste informatie doorgeven is hierbij cruciaal. Het organiseren van palliatief zorgen binnen de verschillende settings kan enkel door expertise op de werkvloer te voorzien, en hen de tijd en ruimte geven om aan kruisbestuiving te doen naar alle andere collega's. Palliatieve zorg dat doe je niet alleen, maar met alle zorgaanbieders om de persoon heen. Nursing home 3 – Online survey*

Figure 28 – Relevant options for the development of residential offer of palliative middle care services according to organisations (N=112)

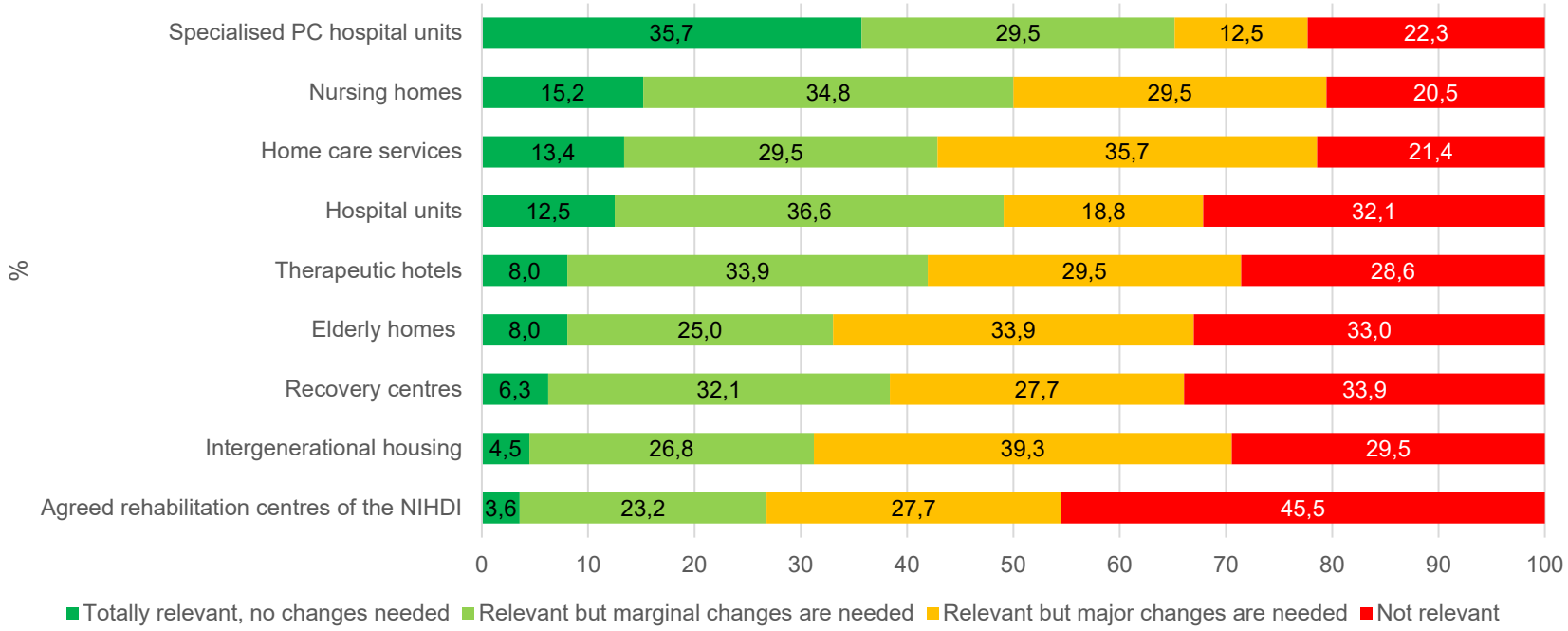


Figure 29 – Relevant options for the development of a palliative middle care offer at home according to organisations (N=111)

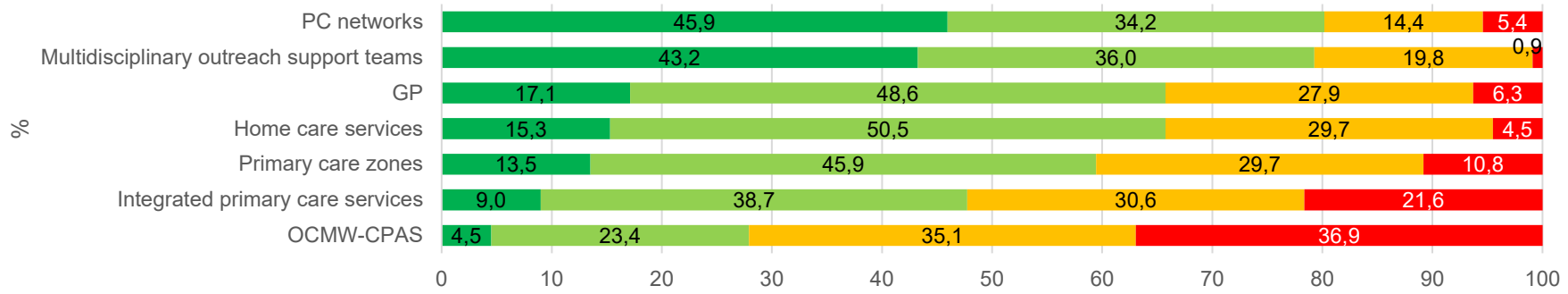
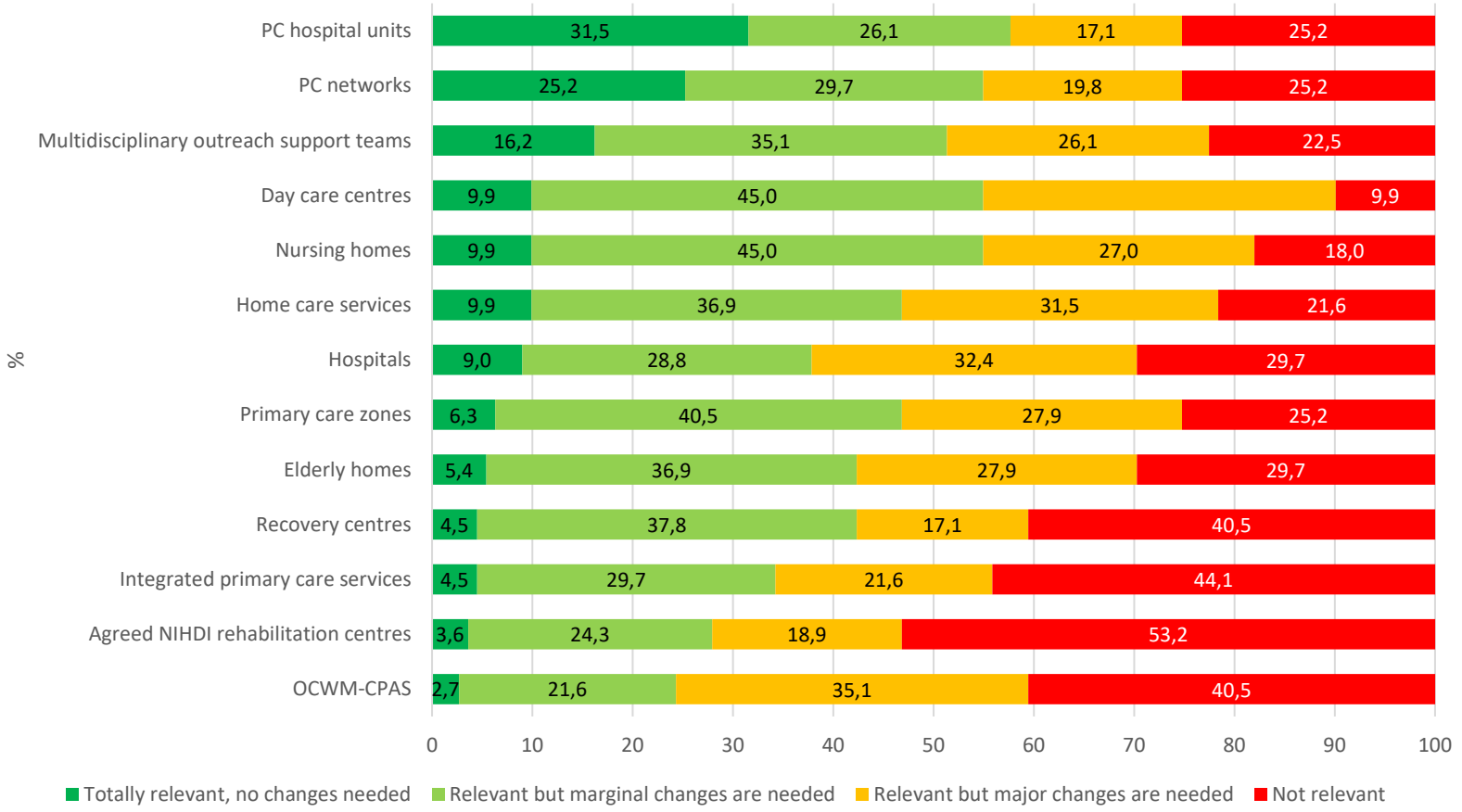


Figure 30 – Relevant options for the development of a day care offer of palliative middle care according to organisations (N=111)



7.8 Preliminary conclusions after the first consultations and elements for acceptability of solutions

7.8.1 Key elements

Patient representatives, organisations and respondents stressed the need for a large offer of palliative middle care: it needed to be both ambulatory and residential as the gaps between palliative care delivered at home (including institutions) and hospital-based palliative care are heterogeneous and cover a wide range of needs. This emerging result was congruent with the position of the experts of the WHO, WHPCA and of the EAPC.[1-3, 218-221] By contrast with the report of the Federal cell which was limited to options in a residential model, this implies the creation and / or the development of ambulatory forms of palliative care to achieve the objectives of PMC.

But, from this first step, no clear option for the creation/development emerged, which could be explained by the lack of consensual definition (see also section 2.4.6 Limitations). As organisations were allowed to choose multiple options and patient representatives were not required to reach a consensus, this was somehow an expected result, although more clear-cut directions were possible when considering the previous reports on PMC.

After this first step, distinction between palliative care at home, palliative middle care and palliative care at hospital remained complex. But these problems of distinction undoubtedly reflected the problems of understanding that persist when the issue of palliative care is raised. These problems were highlighted in the Chapter 6, whether between professionals, towards patients and their families, or in relation to society as a whole. Each stakeholder therefore, depending on its perspective, proposed its own definition of PMC, with its target groups (if any), its characteristics, its care offer...If an appellation “palliative middle care” is perceived as necessary, there is a need for a clear and consensual definition, stressing the difference with the existing services.

It was therefore the choice of the research team to have an open definition of palliative middle care. By opening the field, the participants were given the opportunity to reflect on a trajectory around palliative care (middle care) within a continuity of care rationale rather than opting for an approach limited to a certain - potentially predefined - form of response to complex needs. In addition, this openness made it possible to collect elements that could be used to develop a definition. Further discussions are needed regarding the degree of medicalisation of the PMC: some complex care appear to be difficult to organise in all (care) settings. What is low-intensity and/or low-complexity care? How can we distinguish between different levels of care? What should be made possible and in what setting, under what conditions (staff, equipment, funding)?

At this stage of the study, all the participants consulted (patient representatives, respondents, organisations and experts) also converged to point that existing services can be used to further develop palliative middle care but, to some extent, alternative models are also needed. This element was also mentioned by the experts of the WHPCA: in their view, no new models are currently needed but a development of existing models.[221]

Finally, some participants pointed that the ongoing reforms of primary care and territorialization of health could have an impact on the future of palliative care. But, as presented in the Chapter 4, only the Flemish region has developed a policy plan related to palliative care.

An interesting point raised by the patient representatives was the need for more advance care planning. This was previously recommended in another KCE report as a key element for enabling patient decisional capacity.[129] Although this was not specific to palliative middle care, this was envisioned as a supporting condition for better quality of the end-of-life trajectory. Additional suggestions were made and not specific to palliative middle care. Other suggestions, as the automatic activation of rights, which is granting directly the social and health benefits to the patients once identified as palliative, were not specific to palliative (middle) care and deserve a specific study to investigate the possibilities to make it effective.

7.8.2 Updated model of palliative middle care

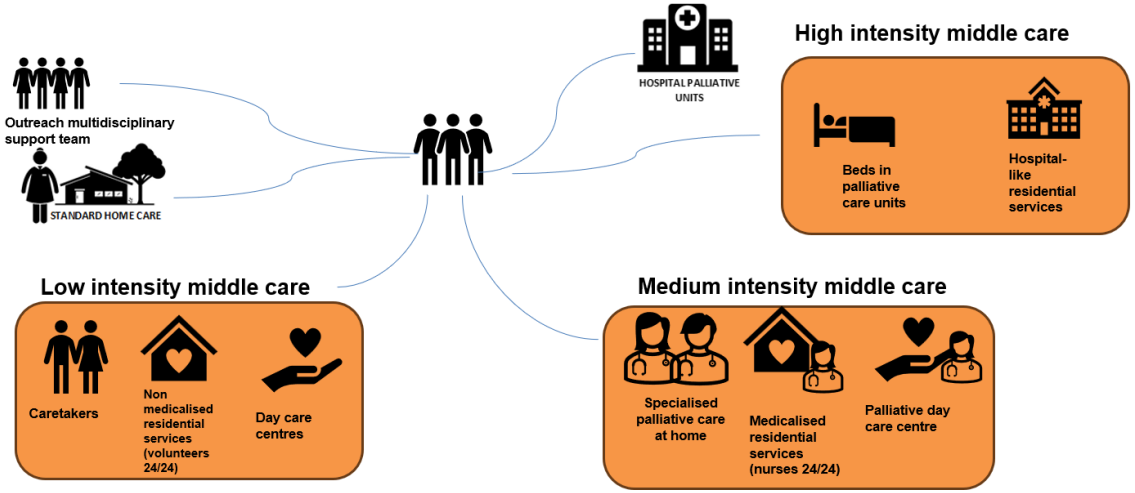
Based on these different elements, a proposal for the development of PMC was drafted (Figure 31) as a basis for discussion for the Federal cell of palliative care. In this model, PMC offer was divided in 3 levels of intensity, based on the heterogeneity of the needs of the patients alongside a continuum from low care to high care. At the centre of the Figure, were the patients and the relatives, as the offer needed to be flexible and circular by opposition to an offer that is envisioned as linear and progressive.

Low intensity middle care corresponded to a care offer with low medical attention. For the ambulatory form, it could be a service of trained caretakers, going at home to provide respite care (also during out-of-office hours), or a day care centre with a focus on occupational activities. Residential offer was envisioned as a non-medicalised service where volunteers were present 24h/7d. This model corresponded to a form of “home-like” service, where the focus was providing a presence and a house to the patients.

Medium intensity middle care corresponded to a care offer with nursing care on a semi-permanent basis. For the ambulatory form, it consisted in a nursing team intervening at home to directly deliver specialist palliative care (instead of the home nurses). It could also be a palliative day care centre. Regarding the residential offer, it was a nursing based medicalised service where trained nurses were present 24h/7d. This model corresponded to a form of “nursing-home like”, where the focus was to provide PC nursing.

High intensity middle care corresponded to a care offer where there was no possibility for ambulatory care but only residential care. It could be reserving beds inside Sp4 for patients with longer financed length of stay than “regular” palliative patients. But it could be also creating residential structures with a medical presence, corresponding to a form of “hospital-like” service.

Figure 31 – Proposal for the development of palliative middle care after the first round of consultation



During the work meeting with the Federal cell, this proposal was therefore perceived as adding more complexity than simplifying and smoothing the current trajectory. Based on the discussion, 4 key points emerged:

- It is needed to determine the objective and the target group(s)
- It is needed to determine the governance level
- It is needed to determine the repartition of the offer
- It is needed to determine the norms and infrastructures

8 WHICH MODELS ARE ACCEPTABLE AND PRIORITY FOR IMPROVING PALLIATIVE CARE IN BELGIUM?

- ✓ Organisational solutions need to fill the gap between home-based palliative care and hospital-based palliative care: it needs to be both residential and ambulatory.
- ✓ Palliative care networks are identified as the key actors for the coordination of new organisational solutions. Their area of action is a relevant territorial zone for the organisation of these services.
- ✓ Day care centres are identified as the most acceptable option for improving the offer of ambulatory palliative care.
- ✓ Residential alternatives need to be created according to the stakeholders (organisations and patient representatives).

8.1 Aim of the second consultation

Based on the results of the first consultations, and in the absence of an emerging relevant solution, the second consultation aimed at choosing the most acceptable options in the current context. In that view, organisations – through the online survey - and patient representatives – during a second workshop - had to choose between different options. This chapter aims at presenting the acceptable and priority organisational aspects necessary to improve palliative care and / or to develop a specific offer of PMC.

8.2 Objectives of palliative middle care

First, organisations and patient representatives were asked to choose the priority objectives of PMC.

About 66% of the organisations expressed that one of the main objectives of palliative middle care should be to fill a gap between the current palliative care offer at home and the palliative hospital offer (Figure 32). Patient representatives also opted for this objective but to a lesser extent as they explained that, in the absence of a clear view on the current offer in palliative care, it was difficult to identify the magnitude of the gaps. Similarly to the responses provided during the first round, the other objectives most often selected by the organisations were related to the quality of care (42%) and the presence (professional or voluntary) 24/7 (37%).

Patient representatives also highlighted the possibility of having a presence 24/7 as one of the main objectives for PMC. This presence could be done by volunteers and did not have to be permanent (meaning that this person could be elsewhere but quickly arriving at the patient request): therefore, PMC should make it possible according to patient preferences.

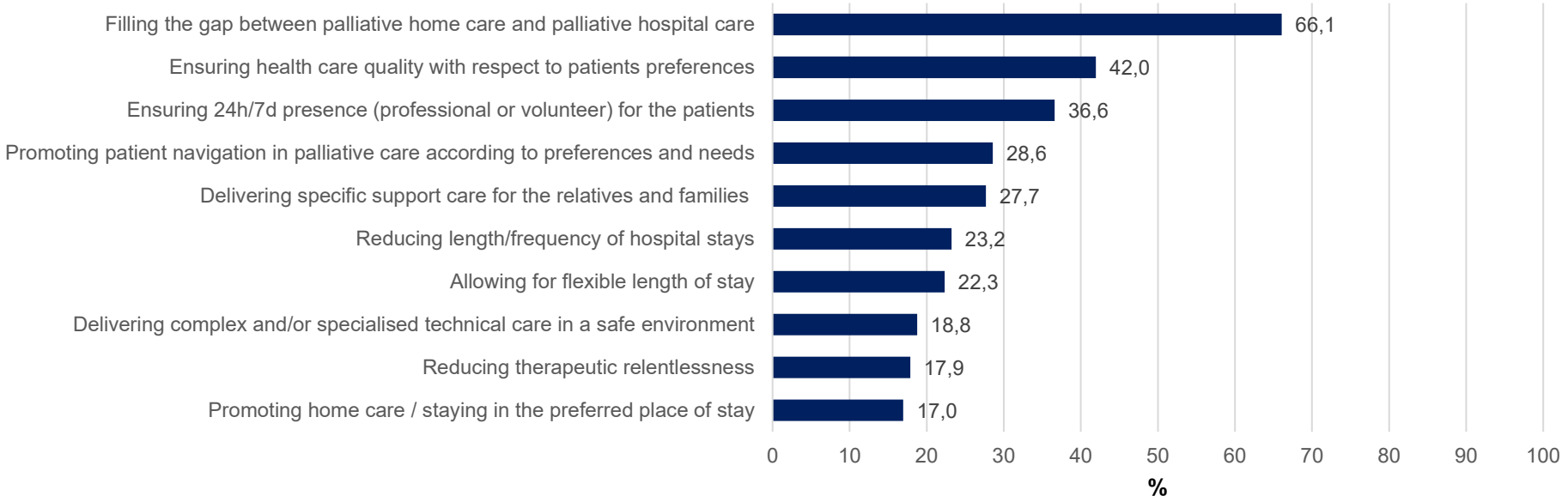
One key objective for the patient representatives appeared to be quality of care in the respect of the patient preferences. Some insisted on the concept of “patient preferences”, that was also related to the possibility of circulating between the different forms of care and the flexibility of the length of stay.

Patient representatives also suggested that one of the objectives of the PMC could be supporting the shared decision making, by giving time to discuss the needs and preferences of both patients and informal caregivers, including the pros and cons of the different possibilities and identifying the resources that are needed.

Finally, patient representatives also stressed that respecting choices and preferences should also consider the healthcare professionals: the preferences of the patients should not be harmful for the healthcare professionals, especially in primary care in a context of shortage of staff (nurses and GP).

> *L’objectif en soi, c’est de respecter le choix du patient sans ce que ce soit au détriment des proches et des équipes de première ligne, tout en offrant une diversité dans l’offre. Patient representative 1 – FR workshop*

Figure 32 – Main objectives of palliative middle care according to organisations



The need for respite care emerged from the first consultation. Participants were then asked about the necessity of formalising the offer in respite care: 78% of the organisations agreed that all residential PMC services should have a minimal number of beds in respite care. Therefore, an organisation pointed that respite care should not be limited to palliative units, leaving the room for respite care initiatives outside hospital context. Patient representatives also insisted that respite care is more than providing a residential offer and that informal caregivers need to be better supported, especially when the patients wish to stay at home.

Niet elke palliatieve zorginstelling zou over respijtbedden moeten beschikken, tenminste als dit zou betekenen dat hierdoor geen ruimte voor andere initiatieven zou komen. Niet elke SP4 eenheid bv moet over respijtbedden beschikken...Deze respijtbedden kunnen perfect toegewezen worden aan bv woonzorgcentrum in plaats van aan ziekenhuis. Palliatieve respijtbedden zouden ook aan "niet palliatieve zorginstelling" toegewezen kunnen worden. Hospice 1, online survey

Dit [respite stay] opent deuren op korte termijn, en dat betekent dat je op lange termijn langer thuis kan blijven. Niet elk WZC [woonzorgcentrum] is uitgerust om een patiënt in respijtzorg op te nemen. Patient representative 1 – NL workshop

Importantly, the majority of the organisations (90%) agreed with the proposition that "*palliative middle care should be accessible both to people at the end of life and to people living with a serious chronic illness, i.e. whose state of health requires care focused on preserving the quality-of-life and comfort rather than curative care because of the experience of a serious chronic suffering*". Patient representatives also supported this statement as the needs of palliative patients and of (some) patients with severe rare or chronic diseases can be similar although the needs for such care can be more limited in time.

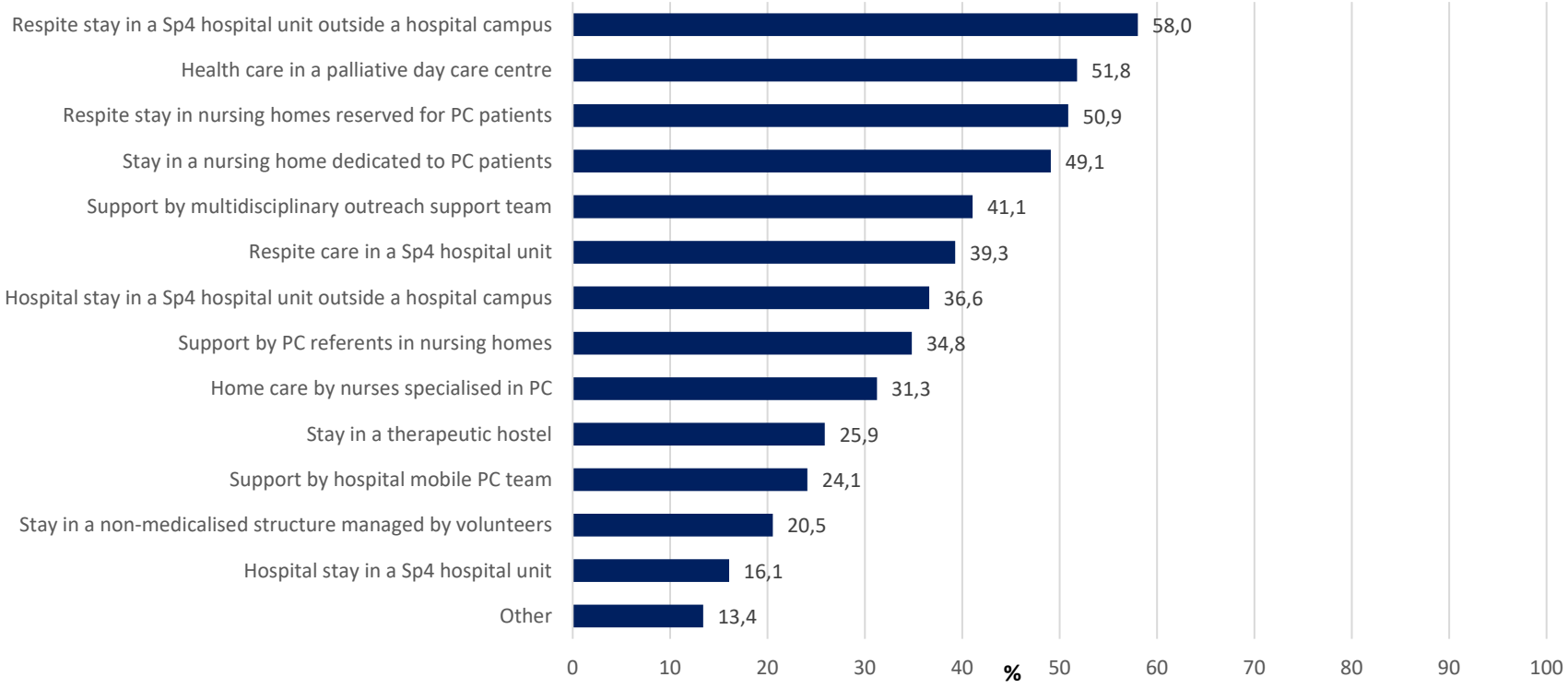
> *Misschien is dit meer tijdelijk, maar er zit zeker een meerwaarde voor chronische zieke patiënten. Als je meerdere mensen samen laat wonen, de ene kan misschien de andere nog op een bepaalde manier helpen. Mensen kunnen voor een stukje voor elkaar zorgen. In de kleine dingen, niet in de medische aspecten. Misschien kan er iemand iets meebrengen uit de winkel of een tas thee brengen, om de patiënt even in de tuin zetten. Patient representative 2 – NL workshop*

8.3 Need for a diversified offer of services within PMC

Organisations had to identify, in the current offer, which existing services are likely to correspond to PMC. Organisations mostly selected: respite stays in palliative care hospital units outside hospital campuses (58%), care in palliative day care centres (52%), as well as stays (including respite stays) in nursing homes where there should be beds reserved for palliative care patients according to half of the organisations (Figure 33).

Most of the organisations (n=87, 82%) proposed that the PMC offer should be both ambulatory and residential, while 17% (n=18) declared it should be limited to residential offer and only one respondent (0.9%) that it should be limited to an ambulatory offer. Similarly, patient representatives were in favour of a mixed model, as it supported a more integrated view of palliative middle care.

Figure 33 – Existing services corresponding to a palliative middle offer according to organisations



Additionally, organisations suggested that respite stay in palliative care units correspond to their view of palliative middle care, as well as (short) stays in convalescence centra or initiatives "home-like." An organisation also mentioned that palliative middle care should be envisioned as a function – like the palliative care function in hospitals – meaning that it is not only a "place" but also competences and expertise.

Patient representatives expressed more difficulties to identify which services corresponded to PMC in the current offer. They therefore found that therapeutic hotels could be a form of PMC, under the conditions that all patients should be able to access it. Indeed, they felt that this kind of services was like recovery institutions managed by sickness funds and reserved to the members of the sickness funds.

Misschien moet er meer geïnvesteerd moeten worden in zorghotels, waar iedereen terecht kan, met een bepaalde afdeling voor palliatieve middle care. Patient representative 3 – NL workshop

Also, patient representatives stressed that services managed by volunteers were only effective if they were in the close vicinity of the patient's home.

According to 30% of the organisations, **it was necessary to create new structures** (residential and/or ambulatory), while another 30% declared that it was necessary **to strengthen the existing offer** (residential and ambulatory) in palliative care approved by the public authorities. Next to this, a quarter think that ambulatory and/or residential middle care initiatives should be integrated into the existing offer. When looking at the comments of the organisations, they mostly insisted on a combination of the different propositions, mostly reinforcing existing offer and integrating initiatives. Moreover, from the comment, it emerged that the offer of palliative care (without considering middle care) was unequally organised, which was already mentioned in the previous consultation round and of the analysis of the Belgian context (Chapter 6).

Il est possible d'utiliser les structures existantes, il est possible de créer de nouvelles structures MAIS SURTOUT il faut équiper médicalement ET en personnel QUALIFIE et en nombre les structures qui deviendront du middle care. Palliative care unit 1 – Online survey [Uppercase is used by the participant in the original quote]

Il nous semble essentiel de renforcer l'aide existante par la création d'USP supplémentaire. Par exemple, le nombre de lits nous paraît insuffisant pour notre région (Borinage/Haut-Pays et Ath). Il est fréquent de ne pas pouvoir transférer nos patients faute de place. De plus, la création de centre de jours et de services résidentiels (middle care) devraient compléter cette offre. Palliative care unit 2 – Online survey

Er zijn ongetwijfeld een heel aantal goede initiatieven, maar onvoldoende en niet steeds van goede kwaliteit - dus én uitbreiding, versterking, intensificatie én vernieuwing Palliative care unit 3 – Online survey

A hospital – without a palliative care unit – suggested to work based on a "call for interest" for developing new services in PMC. They also stressed that these services needed to be accessible to all patients.

Nous pensons que, dans l'idéal, les centres de jours (mais également les services résidentiels) devraient faire l'objet d'un appel à projets et pas gérés nécessairement par des institutions disposant ou non d'une USP [unité de soins palliatifs]. Toutefois, nous aimerions souligner notre crainte que les institutions qui obtiendraient un éventuel agrément ne respectent pas les règles du jeu et s'octroient toutes les places pour leurs propres patients sans ouverture pour ceux des autres institutions ; comme nous le vivons actuellement avec certaines USP ! Hospital without Sp4 beds 1 – Online survey

Patient representatives also reported that the three possibilities should be envisioned in order to meet the needs and preferences of the palliative patients and of their relatives. Moreover, they also stressed that the key point should be the availability and accessibility of the offer across the Belgian territory. In that sense, they insisted on the necessity of examining the gaps at local level and to provide the most appropriate solution(s) according to the local reality. Patient representatives also mentioned integrated services as a positive model, taking as example Coda, a facility where a various range of palliative care services is available (Textbox 10).

8.4 Coordination and organisation of palliative middle care

About half of the organisations declared that PMC should be coordinated (60%) and organised (48%) by the palliative care networks (Table 35). The patient representatives also preferred this option. Therefore, they also stressed that the coordination and the organisation should aim at equity between patients across Belgium, supporting the idea of a federal-led coordination / organisation.

Het voor gans België te doen is beter. Er zit zoveel verschil tussen het zorglandschap van Vlaanderen en Wallonië, je moet gelijkheid kunnen creëren. Patient representative 1 – NL workshop

Not all organisations explained their additional ideas when choosing "Other." It was therefore suggested that, for the coordination, palliative care networks should work in collaboration with the primary care zones. Other organisations proposed that the outreach multidisciplinary support team should coordinate as some emerging initiatives were created by these outreach multidisciplinary support teams. Some stressed that the coordination will depend on the chosen model while an organisation said that the coordination and organisation should be autonomous. It was therefore not further explained.

Table 35 – Coordination and organisation of palliative middle care services according to organisations (N=107)

	N	%
Palliative middle care services should be coordinated by:		
Palliative care networks	64	59.8
Primary care zones (health and social zones in Brussels, primary care zones in Flanders, locoregional health organisations in Wallonia and the entire German speaking Community)	21	19.6
Other	10	9.3
Existing palliative care units (Sp4)	9	8.4
Nursing homes	3	2.8
Palliative middle care services should be organised by:		
Palliative care networks	51	47.7
Primary care zones (health and social zones in Brussels, primary care zones in Flanders, locoregional health organisations in Wallonia and the entire German speaking Community)	29	27.1
Hospital networks	10	9.3
Regions	7	6.5
Other	6	5.6
Provinces	4	3.7

When choosing the patient characteristics to consider in the offer of PMC, organisations most often selected: the complexity of needs (69%) and of care (58%), the clinical status and symptoms of the patient (54%), followed by the life expectancy (27%) and socioeconomic aspects (25%) (Table 36). For patient representatives, socioeconomic status can even be considered as a multiplying factor of vulnerability. An organisation pointed explicitly the absence of informal caregivers as a key factor for orienting patients to PMC. Patient representatives also pointed the risk of burnout of the informal caregivers.

Most organisations declared that the offer of PMC should be adapted according to the living place (home, institution for people with disabilities or mental health problems, rest homes, residential centres, etc., 91%), the complexity of needs and care (82%), the clinical status (77%), socio-economic aspects (70%), and the estimated life expectancy (70%). Also, 43% estimated that a distinction should be made based on the age, with an offer for the 18–65-year-olds and an offer for the over 65-year-olds). Patient representatives nuanced this criterion by pointing out the necessity of considering the needs of the patients, which can be not related to the age of the patients. Regarding life-expectancy, an organisation suggested to consider an estimated life expectancy above 1-month and below 3-months, but patient representatives found this criteria difficult to assess and suggested to leave it out.

Some organisations and the patient representatives also insisted that these factors should be considered in interaction. Moreover, an organisation stressed that the criteria need to be similar across the offer of PMC and not generate numerous services with limited specificities.

> *L'offre doit pouvoir répondre aux besoins des patients mais il ne faut pas créer une multitude de structures à spécificités réduites ; toutes les structures doivent avoir la capacité de répondre aux besoins correspondant à la définition des structures intermédiaires. Hospital federation 1 – Online survey*

Patient representatives also pointed that PMC should not become a “mini-ziekenhuisje” (transl. a small hospital), implying that the most complex clinical situations should stay in a hospital. They insisted on an offer that considers the heterogeneity of the needs and preferences but ensure a form of compatibility when it comes to caring for a group of patients.

> *Er zijn bepaalde zorgnoden die niet meer compatibel met anderen. In leefgroepen wordt dit ook gedaan. Ik ben geen fan van hokjesdenken, maar het is een voordeel dat er onderling gepraat kan worden dat het elkaar aanvult. Dat er een mogelijkheid is om voor elkaar te zorgen. Leefgroepgewijs kan er wel een verdeling gemaakt worden. Op basis waarvan je de verdeling doet is niet per se je fysieke capaciteiten. Heterogeen maar wel compatibel. Patient representative 1 – NL workshop*

> *De factor “kiezen” is belangrijk. Er zou moeten beschikbaar zijn over welke groep het gaat, en of je jezelf ziet in die groep. Dat er ook een keuze-aspect is. Patient representative 2 – NL workshop*

Table 36 – Aspects to consider in a palliative middle care offer according to organisations

Aspects to be considered	N	%
Complexity of needs	77	68.8
Complexity of care	65	58.0
Clinical status and symptoms	61	54.5
Life expectancy	30	26.8
Socioeconomic factors	28	25.0
Place of residence before entering the service	19	17.0
Age	10	8.9
Others	4	3.6

Note: multiple choice allowed

According to the organisations, the referral of the patient to PMC should be decided by general practitioners (according to 71%), outreach multidisciplinary support team (57%), doctors with a training in palliative care (40%), patients (37%), or specialists (35%) (Table 37). Some suggested that not only social workers from the municipal welfare centre (OCMW-CPAS)

could contribute to the orientation of patients to PMC but other social workers (e.g. those located in hospitals).

The patient representatives discussed the role of the GP. Generalist practitioners were perceived as supportive by some representatives and should be the central actor while other representatives feared that not all GP were competent to engage in a dialogue around palliative care. A patient representative reported situations where the GP was opposed to the initiation of a palliative care treatment: in that sense, a multidisciplinary dialogue was preferred to bypass the potential resistances.

> *J'ai toujours cette idée un peu idéale, peut-être, c'est que le médecin généraliste est aussi le médecin de la famille et il pourrait entendre aussi bien les demandes que les besoins des proches. Donc je crois que c'est lui qui pourrait aussi favoriser un échange et trouver peut-être un consensus pour couvrir les besoins ou les attentes aussi bien des aidants mais d'abord du patient. Patient representative 4 – FR workshop*

> *Intuïtief: een huisarts. Maar er zijn huisartsen die aangeven dat er geen beroep moet gedaan worden op palliatieve care. Patient representative 1 – NL workshop*

Several organisations and the patient representatives insisted that the decision should be done in concertation with the patients, the relatives and all the professionals involved in the therapeutic accompaniment. A participant pointed that it should be the team that cares for the patient at the moment of the demand. One participant distinguished the orientation to PMC from admission to PMC. Proposing that the patient needed to be oriented to a PMC service could be done by any actor. Deciding if the admission was acceptable should be limited to specialised healthcare professionals, such as doctors with a specialization in palliative care and the outreach multidisciplinary support team.

> *La décision d'admission en middle care doit être du ressort des médecins formés en soins palliatifs et des équipes de soutien de seconde ligne mais la décision d'orienter peut être prise par n'importe quel intervenant. Palliative care unit 2 – Online survey*

Table 37 – Referral to palliative middle care according to organisations

Actors leading the referral	N	%
Generalist practitioners	80	71.4
Physicians with a training in palliative care	45	40.2
Outreach multidisciplinary support team	64	57.1
Patients	41	36.6
Specialists	39	34.8
Other	10	8.9
Relatives	9	8.0
Social workers of the OCMW-CPAS	3	2.7

Note: multiple choice allowed

8.5 Ambulatory offer

About 44% of the organisations chose that the offer of ambulatory PMC should be organised similarly as day care centres, while others preferred an organisation under the form of specialised teams (27%). Around 19% therefore proposed that an alternative should be created. An organisation stressed that PMC should be more envisioned as a function to better encompass different forms of care.

> *Ambulante palliatieve middle care kan al de hierboven vernoemde mogelijkheden inhouden. Eerder denken aan een 'functie middle care' die verschillende vormen kan aannemen en op verschillende plaatsen kan worden verleend. Hospital federation 2 – Online survey*

This proposal is congruent with a proposal made by patient representatives stressing that PMC could include a liaison between hospitals and middle care, whatever its form.

Een soort liaison functie tussen ziekenhuis en middle care. Overdracht van informatie ook bvb. Begeleiding naar andere types of zorg. Patient representative 1 – NL workshop

According to the organisations, an offer like day care centres should be managed mainly by day care centres (37%) or an alternative to create (24%). Only 15% and 7% think that it should be managed by hospital palliative care units or hospitals without palliative care units, respectively. Palliative day care centres already exist in Flanders, some being considered as PMC services (see section 4.3.2). On the Walloon side, there is no palliative day care centres to date.

Deze zouden idealiter georganiseerd worden volgens model van hopice-care. Hospices op wijk/gemeenteniveau die sterk geïntegreerd worden met de lokale samenleving. Draagvlak creëren voor vrijwilligerswerk. Deze kunnen eventueel verbonden zijn aan een WZC met ondersteuning van een MBE of palliatieve zorgeenheid van een ziekenhuis. Palliative care network 5 – Online survey

L'organisation devrait se calquer sur celle des centres de jour mais avec des équipes spécifiquement formées aux soins palliatifs à la fois sur le plan médical (thérapeutiques spécifiques par exemple) mais aussi sur le plan de l'accompagnement des personnes en fin de vie et de leurs proches (notions de finitude, incertitude…). Palliative care unit 10 – Online survey

This could also be helped by the existing home care services, as suggested by an organisation.

Les équipes salariées de soins à domicile pourrait envisager de mettre du personnel à disposition de ce type de structure. Home care service 3 – Online survey

Regarding the specialised teams, most organisations (57%) preferred that it should be like the existing outreach multidisciplinary support teams, while others envisioned these teams as primary care teams as part of home care (11%) or as part of hospital at home (11%). A small number of organisation suggested to create an alternative but did not further explain how they envision it (3.6%). Patient representatives suggested that these specialised teams can be a solution to bring additional specific expertise at the patient bedside (e.g. patients with autism, intellectual disability, or psychiatric troubles).

Selon les besoins en soins palliatifs, les équipes spécialisées en soins palliatifs peuvent être 1/ la première ligne (cf. soins palliatifs hospitaliers ou soins palliatifs en hospitalisation à domicile qui n'existent pas encore actuellement), 2/ une deuxième ligne sur le terrain : équipes mobiles hospitalières ou à domicile ou en maison de repos et soins ou 3/ une équipe qui gère des consultation en ambulatoire de suivi en collaboration avec la deuxième ligne du domicile. Palliative care unit 1 – Online survey

Regarding the possibility of having a palliative telemedicine offer, none of the organisations and none of the patient representatives found it a valuable solution to be develop as part of the PMC (Table 38).

For patient representatives, a service of professional or volunteer caretakers (*garde-malades*) could be envisioned as part of the ambulatory PMC offer: this service could support the informal caregivers, ensure a presence at home also to support the home care team. This was related to a proposal made by an organisation: it was suggested to develop night care centres to compensate the lack of offer for night surveillance at home. A palliative care unit suggested that all options should be made available to ensure continuity of care.

Alle opties beschikbaar maken, dagzorg, nachtzorg, inbellen voor hulp en vragen, contact met gespecialiseerd team, continuïteit van opvolging en trapsgewijs meer zorgnoden tegemoetkomen. Palliative care unit 9 – Online survey

Patient representatives also recalled that the ambulatory solutions needed to consider the mobility of the patients: for some palliative patients, the added value of an ambulatory solution was null as the transportation could be difficult to organise and / or painful. This concern was also raised by some organisations: not all palliative patients are eligible for such care.

Dagcentra vinden we ok voor bepaalde doelgroep , niet geschikt voor iedereen, gespecialiseerde teams ook ok, maar thuis situatie laat dit

niet altijd toe, alternatief denken we aan mogelijkheid bieden tot zorg op maat en ook de doelgroep personen met dementie niet vergeten, Locatie meer in natuurlijke omgeving, interactie met familie, een samensmelting van dag centra en verblijf waarbij comfort centraal staat voor alle betrokken partijen. Palliative care unit 3 – Online survey

Table 38 – Preferred options for developing ambulatory services of palliative middle care according to organisations (N=86)

	N	%
Day care centres	38	44.2
Specialised health care teams	23	26.7
Alternative to be created	16	18.6
Other	6	7.0
Not competent to answer	3	3.5
Telemedicine	0	0.0

Some organisations insisted that "just creating" a day care centre was not enough to fill the gap but that the organisation of PMC should ensure the smooth transition of patients across different care alternatives.

Palliative middle care hoort niet thuis in een ziekenhuis, maar enkel een dagcentra gaat dit gemis in het zorglandschap ook niet invullen. De middle care patiënt, zijn vaak patiënten die psycho-sociaal onvoldoende omkadering hebben, weinig tot geen fysieke zorg nodig hebben, maar zich alleen thuis ook niet veilig voelen. Er is een goede samenwerking met de palliatieve zorgeenheden en MBE's [outreach multidisciplinary support team] nodig zodat heroriëntatie naar een andere palliatieve setting vlot kan gebeuren. Hospice 2 – online survey

Moreover, it was also recalled that not all solutions could match the needs of the patients in each context and that the rural versus urban character needed to be taken into account.

Garder une souplesse dans la réponse aux besoins des patients, aux possibilités d'accueil dans des régions rurales, sans exclure les autres propositions mais en les ouvrant à d'autres opportunités ; l'essentiel sera de garder un accompagnement au moins supervisé par des professionnels des soins palliatifs. Palliative network 2 – Online survey

8.6 Residential offer

First, it was interesting to note that an organisation recalled that "*Thuis moet indien haalbaar de eerste optie zijn*" (*home care service 1 – Online survey*), being congruent with the findings of the workshops with the patient representatives.

Most organisations chose the creation of an alternative residential offer to improve PMC (Table 39). Some selected hospital palliative care units (Sp4), an organisation suggesting improving the number of beds per unit. Some participants suggested that PMC could be integrated in hospitals without palliative care units. Other organisations selected nursing homes and therapeutic hotels as options for the development of residential PMC. However, some organisations also stressed that integrating PMC in nursing homes required to improve staffing norms and training requirements.

It was worth noting that 19 organisations opted for the option Others. Some justified their choice by explaining that the place was not the most important aspect when it came to residential offer but rather the care that will be provided.

Le lieu n'est pas primordial dans le projet, il doit offrir du matériel médical adéquat, et du personnel soignant en nombre et compétent et qualifié. Des nouvelle structures offrant une attention aux aidants proches, aux "loisirs" des patients, à un cadre plus proche de la vie que de la médicalisation seraient de beaux projets. Inpatient palliative support team 1 – Online survey

Plaatsen waar patiënt met zijn specifieke behoefte de juiste zorg kan krijgen vanuit de visie totaalzorg. Primary care zone 1 – Online survey

Peu importe le lieu, ce qui importe c'est l'accès au personnel qualifié et compétant en nombre adéquat et au matériel nécessaire. Ce qui importe est également de respecter des normes de qualité et de travail en coordination avec le réseau de soins palliatifs. La structure middle care doit intégrer le projet de soins autour du patient. Hospital federation 1

Therefore, some participants highlighted the need for having said that the offer should be outside a hospital building, need that was also mentioned by the patient representatives.

Voorkeur voor palliatieve zorgeenheden, buiten het gebouw van het ziekenhuis, wel op de campus en met inzet van een aantal vrijwilligers. Palliative care unit 3 – Online survey

Among organisation who selected nursing homes for the development of residential PMC, all except one agreed that the residential offer in nursing homes should include beds reserved for patients coming from homes for the elderly with palliative care needs.

Among those choosing the creation of residential structures, 21 organisations (51%) preferred the creation of new standards while 10 (24%) preferred to rely on existing standards of palliative care units Sp4 (approval, staff, infrastructure, etc.). Eight organisations (20%) preferred standards based on a "home-like approach" where the structure must comply to the rules in force for a private housing (e.g. energy performance, electrical compliance, etc.). Only two respondents (5%) selected the standards of the nursing homes.

Some organisations and the patient representatives stressed that it should be possible to combine all forms of residential services.

Plusieurs endroits devraient être adaptés en fonction de la complexité des soins et des besoins de chaque patient. Inpatient palliative support team 2 – Online survey

Table 39 – Preferred options for the development of a residential offer of palliative middle care according to organisations (N=104)

	N	%
Residential alternatives to be created	43	41.4
Others	19	18.3
Palliative care units (Sp4)	13	12.5
Nursing homes	12	11.5
Therapeutic hotels	12	11.5
Non-medicalised services managed by volunteers	4	3.9
Not competent to answer	1	1.0

8.7 Preliminary conclusions after the second consultation

From the second consultation, the following key aspects emerged to develop and complete the current palliative care offer. This second round confirmed the need for ambulatory services and residential services. The coordination team of the palliative care network was perceived as a relevant actor to ensure the coordination of the palliative middle care offer. This was coherent with the finding that the area of action of a palliative care network was the most appropriate repartition key. Palliative day care centres were identified as a relevant option for further developing ambulatory care while creating new services was identified as the solution for residential offer.

9 PROPOSITIONS FOR REINFORCING AND EXPANDING PALLIATIVE CARE IN BELGIUM

- ✓ • The following key principles are transversal to the reinforcement and the development of palliative care in Belgium:
  - Respect patients' end-of-life preferences as far as possible.
  - Support the delivery of care in the community with a view - in particular - to demystifying the end of life and palliative care.
  - Allow patients to navigate between different care options.
  - Organise care based on needs and preferences rather than on patients' age (before or after 65) or life expectancy.
  - Reinforce the current offer to cope with the increase of the needs for palliative care
  - Develop new options to diversify the possibilities for palliative care in the community, particularly for the delivery of technical care and for unstable patients who do not require a hospital environment
- ✓ Five existing services delivering palliative care need to be reinforced: outreach multidisciplinary support team, palliative day care centres, hospital mobile teams, specialised palliative care units (Sp4)
- ✓ Five possibilities for further developing palliative care are identified: non-medicalised residential service, medicalised residential service, palliative care via hospital at home, palliative care via day hospitals and transmural consultations.
- ✓ The current palliative care function in hospital can be expanded to include all forms of palliative care in hospital setting
- ✓ Offer needs to be available, affordable and reachable for all patients and families in a defined territorial zone.
- ✓ It is required to have a clear a clear view of the needs and resources per geographical zone and to bring the adequate response, based on this proposal.
- ✓ The centralisation of the health data is a key element for better meet the patient preferences and needs.

9.1 Aims of this chapter

This final chapter aims at presenting the different elements that are needed to improve palliative (middle) care, the gaps that can be solved, and attention points (Chapter 2).

Palliative care in Belgium has continuously evolved over time with the aim of developing an integrated and coherent health care offer meeting the needs of palliative patients and their relatives. Palliative care was one of the policy priorities of the Federal government, as mentioned in health objectives, and a strong emphasis was put on the development of evidence-based practice guidelines to improve palliative care (see Chapter 4).

Palliative middle care, trigger element at the initiation of this report, has been under discussion for many years: as early as 2008, the need for it was discussed by the Federal Cell for the Evaluation of Palliative Care with a view to supplementing the available provision of palliative care. Other organisations and institutions have commented on its relevance and potential added value in terms of greater accessibility and availability of palliative care in Belgium.[20, 22, 162, 178]

While the relevance of palliative middle care as an additional care offer seemed to be beyond doubt for many palliative care stakeholders, others felt that there is no need to create an additional service with a specific term to identify it, at the risk of adding confusion to the current landscape. In our survey, the diverse panel of organisations active in the field of palliative care, 89% of the organisations (n=119) felt that there is currently still a need for a palliative middle care offer in the current landscape of PC services, whatever the term used to designate it.

The proposals set out in this chapter can only help to resolve a part of the problems and shortcomings relating to palliative care (see Chapter 6) as these proposals will only be fully effective if, at the same time, efforts are made to strengthen the palliative culture, the generalist and the specialist palliative care offer in the whole healthcare system. We refer readers to the recommendations made in this respect by the Federal Cell for the Evaluation of Palliative Care, the Federal Council of Hospitals, the Federations of Palliative Care and the National Bioethics Committee.[10, 19-22, 162, 178, 199, 213, 216] We would also point out that previous KCE reports have studied some issues of palliative care in Belgium and have developed a series of recommendations based on the research carried out[12, 13, 222]: some of these recommendations are currently being discussed, while others have yet to be decided on by the authorities concerned. Finally, these proposals are not based on quantitative and economic data: as our review of the literature on the effectiveness of palliative care shows, there are few high-quality data available (Chapter 2 and Chapter 3).

9.2 Palliative middle care: a needed concept?

From our research, we could propose the following definition of *palliative middle care*:

- Palliative middle care services are a range of residential and ambulatory care services for patients identified as palliative according to the PICT-1 criteria who, because of their clinical condition and/or resources and/or needs, require palliative care provided by professionals and volunteers specialising in palliative care, but who do not require admission to a hospital unit specialising in palliative care (Sp4).
- Palliative middle care services provide high-quality somatic, psychological, social, and spiritual palliative care that takes into account the preferences, needs and resources of patients and their families. It accompanies patients until they die. As palliative care also concerns patients' relatives, informal caregivers and qualified caregivers, providers active in palliative middle care services also provide specific services to meet their needs and preferences, including beyond the patient's death (bereavement support).
- The provision of palliative middle care services is a flexible care offer that extends the existing offer available in a delimited territorial area, (i.e. the area covered by a PC network) in the community or in the hospital context, when this offer is unable to meet the needs of patients and their relatives. Palliative middle care is integrated into existing services.

But it appears that the only element which distinguishes palliative middle care service from that provided in hospital (Sp4 unit) and could justify its being called “middle care”, appears to be linked to the legal barrier preventing certain technical procedures or treatments from being provided outside the hospital environment in Belgium.

At this stage of the research, we could question the need to add a new name to designate services specialised in palliative care. This questioning does not call into question the need to complete the offer, but rather the need for another name that could be a source of confusion. As highlighted in the previous stages of the research, both professionals and patients find already difficult to understand what palliative care is and how it is organised, including how to benefit from it. In that sense, several stakeholders commented that, in their view, there is no need for a new appellation for a service: the most important aspect, in their view, is to reinforce and / or to complete the existing offer to better meet the patient needs.

> *L’appellation en soi est secondaire et reflète simplement une réalité de terrain : certains patients ne peuvent pas rester à domicile (pour des raisons sociales ou en raison de leurs besoins), mais ne sont pas non plus candidats pour une MRS (par exemple, en raison de leur âge ou de leur choix) ou pour une unité de soins palliatifs (parce que leur espérance de vie est trop longue ou qu'ils n'ont pas besoin d’une structure hospitalière). Ces patients se retrouvent souvent sans solution d’accueil adaptée. Il est donc urgent de créer des structures pour répondre à ce besoin manifeste, que ces établissements s’appellent maisons de soins palliatifs, maisons palliatives communautaires, middle care palliatif ou autre. L’important est qu’ils existent et répondent à ces besoins. Hospital federation - 1*

Ik wil vooral oproepen voor duidelijkheid. Het is vaak al heel complex om door het bos te bomen te zien. […] Een goed uitgebouwde palliatieve zorg is essentieel, dat staat buiten kijf. Maar zorg ervoor dat personen en mantelzorgers door het bos de bomen zien en zo maximaal ondersteun kunnen worden. Patient umbrella association – 1

Two stakeholders however mentioned that this appellation could have an added value as it can help to identify these services and allocate the proper funding.

De naam palliatieve middle care: we denken dat dit een mooie verbinding zou kunnen maken met de PICT-schaal deel 2 nl. dat dit een plaats is waar mensen terecht kunnen/recht op hebben, wanneer ze wel hogere zorgnoden hebben maar nog niet in het 'volledig' palliatief statuut vallen. (Dus voor het 'eenvoudig' en het 'verhoogd' palliatief statuut). Professional association – 1

Het geven van een naam aan een nieuw organisatorisch element geeft het een identiteit waardoor het kan besproken worden, waardoor het een identiteit kan krijgen en waardoor het gefinancierd worden. Valkuil hierbij is dat het dan een geïsoleerd element gaat worden dus de uiteindelijke doelstelling van stimuleren integrated care mag nooit uit het oog verloren worden. Professional association – 2

A good identification of the services is indeed essential and not only for new types of services but for all types. And one objective of this report is to clarify the current offer and the place of new services in the current landscape. Figure 35 and Figure 36 aim at working at this clarification. On the contrary, as explained in the conclusion of the Chapter 5 on the models, the term 'middle' has several meanings in the field of palliative care services and can be understood in too many ways to be clear enough (see Chapter 6 and Chapter 7). **We therefore would like to propose not further use the appellation "palliative middle care" but rather to insist on the generalist or specialist palliative care offer, as used at international level**.

9.3 Transversal key principles to a patient-centred approach in palliative care

Several transversal key principles underly the offer to be further developed or created. These principles underline all the solutions further proposed in this chapter and should be kept in mind when reading it.

9.3.1 Respecting as much as possible the patient preferences regarding their end-of-life

Dying with dignity is at the heart of the palliative care approach.[1, 3, 6, 142] Patient preferences concern the preferred place of death but also the intensity and the complexity of the support that they can receive as well as the setting where they wish to be cared for (staying at home, going to a hospice or a nursing home). This strong emphasis on the patient preferences is a common feature among the different health policies and guidelines when it comes to palliative care but also emerged from the different consultations with stakeholders during this study. It also implies ensuring that the patient rights, the possibility for euthanasia and the right to palliative care are respected in accordance with the legal framework. The literature on the preferred place of death and on patient acceptability of palliative care interventions also supports this key principle. As pointed by several authors, respecting preferences could contribute to more equity in the provision of palliative care (see Chapter 3).

9.3.2 Promoting palliative care in the community

Promoting palliative care in the community contributes to the respect of patient preferences as most of the patient wish to die in a familiar place and not in a hospital. Although hospitals offer high-quality care in a safe environment, they are still not very popular when it comes to choosing a place to die, even though in practice most patients die in hospital. The patients' desire to maintain a sense of independence and normalcy can be seen as a barrier to participation to hospital-based palliative care. In the literature, we found that patients emphasised the importance of adapting the community-based palliative care service to the personalised needs of the

patient, also patient valued being treated with dignity and respect (see also Chapter 3).

Promoting palliative care in the community is linked to various health policies in Belgium and internationally, particularly regarding long-term care. One should however not forget that, for some patients, dying at home is not their preferred place of death.

This principle also aims at reinforcing the availability and the accessibility of palliative care in various settings such as institutions for persons with disabilities or with psychiatric problems.

Promoting palliative care in the community can contribute to the demystification of palliative care and end-of-life. To date, aging, death, end-of-life, and palliative care remain taboo topics at societal level. As suggested by a patient representative, aging and end-of-life are part of the life and cannot be avoided: by socially acknowledging aging and end-of-life as part of the circle of life, this can help to develop adequate solutions.

9.3.3 Ensuring patient circulation across the different palliative care services

Any improvement in the provision of care, either by strengthening what already exists or by developing new options in the offer, must aim to ensure that the trajectory gains in continuity of care and integration. It is important that patients can navigate from one option to another without having to go through a whole series of administrative procedures and/or to repeat clinical evaluations. Often care transitions are delayed or even not executed due to the administrative burden before accessing another type of care service. Also particular to disease trajectory of palliative care patients is the rapid evolving of the clinical status to an unstable health situation with the need for rapid responses of the appropriate care services.[223]

As much as possible, patients (and families) need to be able to navigate across the different palliative care services as their needs and preferences can evolve over time. Because it is difficult to anticipate how a defined situation will evolve and to which extent it is possible to regain a form of stability, administrative procedures should be kept as simple as possible and be as fast as possible to prevent any administrative related delay in the response to the needs of the patients. In this respect, it should be remembered that all too often patients (and professionals) come up against time-consuming and complex administrative procedures, which - in an end-of-life context - sometimes succeed after the patient has died. In that sense, sickness funds, public welfare centres and other administrative services have a role to play to accelerate and simplify the procedures. Patient representatives suggested to develop the automatic activation of the rights, meaning that the patients do not have to apply at regular intervals to receive a benefit once they are considered as palliative. The automation of the rights needs also to be combined with a fast completion of the procedure. Some suggested a sort of “priority” system / “fast-track” once the patients are acknowledged as palliative to have reduced length for the procedures and granting of benefits. In that sense, sickness funds, according to patient representatives, can also be more proactive to support the patients and their families in case of severe (terminal) diseases. Sickness funds are informed about the “palliative status” of a patient and can provide information and support without waiting that the patients ask for it.

A better patient navigation also requires a better and a repeated[v] information of both patients and relatives, for example about the rights and the benefits that one may receive, including how to get access to these benefits and at which stages of diseases they can obtain it.

[v] Patients and relatives can feel overwhelmed when receiving much information at a very early stage of the disease / when these information are provided at the same moment than “bad news”. In that sense, repeating it is a good practice, as pointed by patient representatives.

9.3.4 Organising palliative care offer according to needs and preferences rather than based on age or life expectancy

Age is often used as an administrative criterion for determining the orientation to certain form of care, implying that “elderly patients” have access to different facilities than “young patients”. But, the very concept of “elderly” is a fluctuant and subjective concept.[152] Similarly, in the field of palliative care, the estimated life expectancy is one of the criteria that is used to initiate the access to some benefits (Chapter 4). But, as mentioned in the KCE report 367[13], life expectancy is complex to assess and, as seen in the international comparison (Chapter 5), is less and less used as a determining criteria when it comes to palliative care. In that context, needs and preferences appear to be more relevant criteria when it comes to the organisation of the care offer. Patients above and below the “administrative” limit of 65 years may share similar needs but also be different in their preferences.

9.3.5 Reinforcing the palliative culture among healthcare professionals

The palliative culture (or approach) is not the preserve of a small number of hand-picked professionals and services with a monopoly on knowledge and skills. All professionals, regardless of their area of expertise or speciality, are confronted at one time or another with palliative situations, i.e. situations where the emphasis must be placed on the quality of the life that remains rather than on prolonging life. Implicitly, in these situations, professionals must move away from the objective of "curing" at all costs to promote comfort and quality of life. It is also worth reminding that, as for other patients and situations, time and (mental) availability of healthcare professionals is key to nourish the dialogue between patients, professionals and families.[224]

Strengthening the palliative culture across the various care lines between all the actors in the healthcare system requires a better understanding of the added value of the palliative approach and palliative care, whether generalists or specialists. Initial or continuing training, exchanges between professionals, the development of a common language, etc. are ways to extent the palliative culture amongst all providers of help and care. This is essential to succeed in offering patients truly integrated palliative care services. As showed in the Chapter 3, interventions based on training showed positive impact on different organisational outcomes.

Strengthening the palliative culture helps patients and their families to understand it better, making it easier to implement and demystifying palliative care. A well-developed palliative culture improves the chance to identify a palliative situation and the use of identification tools like the PICT-1. It can also help to start earlier the dialogue around the advanced care planning (ACP), especially when cognitive impairments may impede the decisional capacity in a later stage.[129] ACP can involve discussing over the preferences for health care and end-of-life but also about more practical aspects and activities.

Finally, at local level, the palliative culture would benefit from a better mobilisation of the social network around the patient and their families, by relying more on the municipalities and their social activities. In other words, this can result in the broadening of the actors involved in social support: not only healthcare professionals but also volunteers without any kind of training in health care. Initiatives already exist and be further expanded. This can be seen also as a way to contribute to the demystification of end-of-life and aging.

9.3.6 Ensuring effective collaboration and communication between professionals, patients, relatives and informal caregivers

Collaboration is a major principle to improve the accessibility and the quality of palliative care. Professionals need to trust each other and to exchange information about their patients for ensuring continuity of care. This collaboration should transcend the gap between disciplines and between the community and the hospital. Digital shared health records are an asset to reinforce collaboration, alongside opportunities for exchanging and discussing cases between professionals.[199, 216] As part of the collaboration, patients and the informal caregivers should be fully involved in the decision making process and the elaboration of the health care plan.

Communication implies providing clear, up-to-date, and complete information to the patients and their relatives to allow them making informed decisions with respect to the legal framework related to patient rights (including the notion of trust person), palliative care, advanced care planning (including refusal of care and euthanasia). It would also be relevant to provide specific information for trusted persons to better prepare them for their role.

But not only patients and relatives need to receive adequate information. Healthcare professionals also need to receive this information so that they can properly inform their patients and refer them to the most appropriate support. As found in the literature, proper information influences the acceptability of palliative care for informal caregivers (see also the Chapter 3).

Finally, citizens are insufficiently aware of their rights regarding palliative care, especially when considering serious situations, such as euthanasia or refusal of care. Awareness-raising is essential to ensure that each person is well informed about their choices. It is then crucial to provide clear and accessible resources on the rights of palliative patients, with a focus on the 2002 law on euthanasia and the eligibility conditions. Relevant sources of information can be the treating doctor (GP or specialist), sickness funds, some previous KCE reports[13, 129] as well as Belgian associations that specifically deal with these issues, such as Domus Medica, *Association pour le Droit de Mourir dans la Dignité*, or patient associations concerning specific pathologies such as Huntington's disease, multiple sclerosis, amyotrophic lateral sclerosis, etc.. There are already initiatives ongoing, and these initiatives should be repeated regularly.

9.3.7 Integrating specific support for the informal caregivers and qualified caregivers

Consultations with the stakeholders highlighted the need for respite care for informal caregivers and qualified caregivers as they play a key role in the support of the palliative patients. For example, they coordinate the different services involved, they deliver direct care, they arrange for a permanent presence, they manage the administrative tasks, they take care of the household by doing the domestic chores....But, from the literature (Chapter 3), we also found that informal caregivers placed high value on proactive support but they did not always consistently receive it. Similarly, informal caregivers were found to value the provision of social opportunities and could therefore benefit from access to official social support networks, but the availability of social support was however often lacking. And, once their loved one is dead, informal caregivers did not always receive bereavement support (due to lack of contact from the palliative care service following the death of a family member).

The needs of the informal caregivers / qualified caregivers should be assessed separately of the needs of the patients while considering the interactions of the (unmet) needs of both the patients and the caregivers. This calls for a differentiated response and support in a perspective of prevention of the burnout and exhaustion of these caregivers. Besides, as pointed by Woodman 2016[123], informal caregivers should be made aware of the commitment and burdens of caregiving before agreeing to provide EOL care and support services should be available.

For patients staying at home with informal / qualified caregivers, it then appears of the utter most importance to improve the possibilities for benefiting of respite care. Facing (imminent) death, accompanying a dying relative generate lots of fear and anxiety for patients and relatives but also a physical and mental burden. This triggers, according to patient

representatives, the need for (immediate) emotional support at home because of the stress related to end-of-life. This is related to the need for more support for the relatives, by better involvement in the decisions but also by providing effective support in various forms: material, social, psychological, financial…Providing support should include practical help, e.g. providing resources such as equipment, relieving care burden through hands-on care by formal caregivers, ensuring continuity of care by the same individuals, relieving financial burden with the help of social services, receiving after-hours support, identifying and treating depression, assisting with medical tasks such as medications and access to medical services, manging medical crisis (see Chapter 3).

As stated by Rao et al. (2021)[225], respite care is defined as both a service and an outcome. When defined as an outcome of an intervention, respite care aims at providing relief, comfort, and "time-outs" from the caregiving activities. When defined as a service, it can take different forms like day care centres, a stay in a facility such as a nursing home or a hospital as well as day care or overnight care at home.[225] It can consist in a form of outreach support where a professional comes at the patient place to act as a substitute for the informal caregiver such as the project *Baluchon Alzheimer*.

9.4 Assessment of the preferences, needs and resources of patients, relatives and professionals

9.4.1 Preferences, needs and resources

Patient preferences are defined as "the choices of individuals to make decisions about health and medical treatment by using their own experiences, beliefs, and values".[226]

Patient needs are articulated across the four pillars of palliative care, namely somatic care, psychological and emotional care, spiritual care and social care. The KCE report 367 previously investigated the needs of palliative care patients and of their families.[13] Textbox 16 presents a summary of the key findings.

Textbox 16 – What are the needs of palliative patients and of their relatives?

- **Medical needs** which requires the use of therapies, medicines and technical health materials and the involvement of physicians, nurses, allied health professions and psychologists to be met. Needs like pain, shortness of breath, fatigue, nausea, bowel problems, sleeping problems, loss of appetite, restlessness, agitation, etc. of the patients are included in this domain. Symptoms of the informal caregivers should also be included.
- **Psychological, emotional and spiritual needs** which requires providers (e.g. psychologist, spiritual counsellor, trained volunteers, trained health care professionals, etc.) with an expertise in listening, advising and supporting patients, informal caregivers and professionals delivering palliative care. Needs like loneliness, stress, depressive feelings, anxiety, feeling like a burden on families, 'thoughts about ending it all', 'desire for death', 'requesting a hastened death', bereavement support needs, loss of life worthwhile or self-worth, etc. are included in this domain.
- **Social needs** which requires financial, legal and practical support of the patient and the informal caregiver should involve social assistants, help and care coordinators, etc. This domain is of main importance for isolated patients. Needs like support for the instrumental activities of daily life, working and financial issues (out-of-pocket expenses related to travel, energy cost, etc.) are included.
- **Daily life/personal care needs** which requires nursing assistant or nurse help, financial support for personal care furnishings and home accommodations, tailored physical environment and support in communication and behavior management for demented patients. Lack of autonomy in the bathing, eating, transfer, dressing, etc. are the needs included in this domain. The focus is on the patient.
- **Relationship/respite needs** which requires direct financial support and social services to alleviate the burden of care (e.g. volunteers,

respite care, day care) and requires healthcare professionals with more time, more communication skills and more human connections. Needs like loss of and decrease in caregivers' social contacts, exhaustion of the relatives, or the experience of isolation from friends, neighbours and the community, lack of the three last steps of the Maslow pyramid for the patient and the informal caregiver are included. It requires improvement in the organisation and supply of the health and social systems.

- **Coordination needs** which requires multidisciplinary onsultations including all providers and the patient and informal caregivers and the involvement of specialist palliative care providers (professionals and volunteers). Needs like highly complex case and unnecessary hospitalisation and procedure are included.
- **Knowledge and skills needs** which requires a common will of all actors involved in palliative care situations from the patients to the authorities. Needs like lack of information on disease, treatment, benefits, reimbursement procedures, administrative aspects, accommodations, legal issues, etc., lack of training of the social and non-specialised providers, too little involvement in decision-making of patients and informal caregivers (preferences and values), lack of cultural adequation consultations including all providers and the patient and informal caregivers.

Retrieved and adapted from Ricour et al. 2023, page 132

Patient resources include the attitudes of the patient regarding health and death (including beliefs, sense of control, knowledge about the disease, …), acceptability of the responses proposed to its needs, the ethnocultural resources (including religion, familial support, traditions, …) and the education and income (including the health literacy). Income can be further developed in the type of housing (including the degree of cleanliness, the equipment, the financial means to afford additional health and social services (e.g. being able to hire a caretaker). Patient resources also include the support received from the relatives and caregivers.

Like patient resources, the **resources of the relatives** include their attitudes regarding health and death, the acceptability of the responses proposed to its needs, the ethnocultural resources and the education and income. It is also important to consider the needs of the relatives (Textbox 16). The resources and needs of relatives should also be recorded in the patient's shared health record. If necessary, it is recommended to have separate shared health record for relatives, particularly for those intervening as informal caregivers or qualified helpers. This can help to better identify their specific needs and resources and make them aware of the risks of decompensation.

Professional resources refer to the capacities of the professionals to deliver palliative care according to patient needs. It first concerns the knowledge, skills, competences and availability of the professionals themselves. It also includes the existence of resources to support the professionals in their activities: hotline, expertise of more specialised professionals, procedures, medical equipment, medications, referent persons…

9.4.2 Current situation

To date, it appears that the patient preferences are not enough taken into account when discussing over palliative care and that advance care planning is insufficiently implemented. As showed in the literature (Chapter 3) and voiced during the workshops with patient representatives (Chapter 6), most of the patients prefer dying in a familiar environment and only a minority prefer dying at hospital. Moreover, as recommended by the participants in our study, it is necessary to have an open discussion with the patients and their family about the preferences regarding palliative care and end-of-life, including refusal of care by the patient, diversity of the therapeutic options, palliative sedation, and euthanasia.

Additionally, alongside the preferences, patients in need of palliative care are insufficiently identified. It could be explained by a lack of awareness and training of health care professionals but also a difficulty, for some professionals, to shift from a curative approach to a palliative approach. There is also a challenge for the health care professionals to initiate a

dialogue around palliative care when the patients (and their relatives) are still in denial of their bad prognosis and upcoming death. It is then necessary to raise awareness among health care professionals regarding palliative care approach. Moreover, currently in Belgium, the administrative recognition of palliative situation is notably based on an estimated expectancy of less than 3 months. This outdated view of the palliative care prevents healthcare professionals to timely identify palliative situation (Appendix 2.2).

When an assessment is conducted, it also appears that this assessment still lacks comprehensiveness. Preferences, needs, and resources need to be envisioned from a larger perspective than only a medical or somatic one. It also needs an interdisciplinary perspective: for some professionals, this could represent an additional challenge.

Finally, for the patients and the relatives, when there is no coordination between the professionals involved in the different assessments, these assessments could be perceived as redundant and not useful while some aspects are forgotten.

9.4.3 Assessment characteristics

A comprehensive assessment of the patient preferences, needs and resources has to be conducted by a professional with the patient. If the patients so wish, their trusted support person or relatives take part in this discussion. If the patients do not have the capacity to take part in the assessment, the assessment may be conducted with their trusted support person, as provided for by law.

A dedicated time is necessary to conduct the assessment. It is planned in agreement with the patients and their relatives (when they are present). Sufficient time is allowed and, if necessary, the assessment can be conducted at different times. The assessment can be carried out in the patient's place of residence or place of care (including hospital), according to the patient's preference. A comprehensive assessment of the preferences, needs and resources of the patients and the relatives takes time, particularly for the professional in charge of this assessment: the KCE report 367 recommended planning a specific funding for doing it.

This assessment must be carefully conducted and regularly updated, particularly considering the turning points in the patient's end-of-life trajectory. A turning point can be a sudden deterioration in the patient's clinical condition, a return from hospital, but also an external event: the informal caregiver is hospitalised, there is a change in the care team, or the home is no longer adapted to the complexity of the palliative patient's needs.

Several tools already exist to support professionals when assessing patient needs, resources and preferences (see, among others, the analysis conducted in the KCE report 367).[13] Validated assessment tools are used to conduct this assessment as fully as possible.

This assessment needs to include the elicitation of the advance care directives of the patient (ACP) and the identification of the palliative situation based on the PICT-1. It is necessary to consider the sociodemographic characteristics of the patients influencing access and utilisation of palliative care as illustrated in the Chapter 3.

In the context of palliative care, the medical needs can be assessed by healthcare professionals, with attention to the degree of the stability of the palliative situation as it intervenes in the orientation to an appropriate care setting (Textbox 7 - Appendix 2.1 - Appendix 2.2). As presented in the introduction, depending on the phase of illness the patient is in, variable intensity of palliative care is required (Figure 1). The medical assessment needs to include the technical acts necessary to the comfort of the patient. The extraordinary treatments included in the PICT-2 can help the healthcare professionals to identify those needs (Appendix 2.2.).

The patient preferences / resources / needs need to be recorded in a shared patient health record. As recommended in the literature[14, 192], shared patient records are essential elements contributing to the quality of (palliative) care. The patients can consult the assessment and receive a copy. They can (ask to) add, remove, or modify elements from the assessment at any moment. The other professionals involved in the patient's healthcare are informed of the content of the assessment, as is the trusted support person designated by the patient, where appropriate.

Putting the results of the assessment in practice needs to be coordinated by the professional/team who conducted the assessment, in collaboration with the professionals and informal caregivers / qualified helpers involved in the care. Where appropriate, other healthcare and support professionals are also involved.

9.4.4 Possible actors of the assessment

To properly orient the patient to the most appropriate palliative care services, it is necessary to start by a comprehensive assessment of the needs, resources and preferences of the patients. It is necessary to have a clear identification of the professional(s) who can orient a patient to palliative care as this professional(s) will endorse a role of referent and coordinator of the palliative care pathways of the patient. A clearly identified professional endorsed with such mission improves the coordination, facilitates communication and continuity of care. Different healthcare professionals / teams can carry out these assessments. Table 40 presents the advantages and drawbacks of each possible option.

Table 40 – Advantages and drawbacks of possible professionals / teams eligible for conducting a comprehensive assessment of the preferences, needs and resources

	Advantages	Drawbacks
Generalist practitioners	Referent person for the patients ACP consultation is already funded for GP In charge of the PICT-1 and of the global medical file Support the continuity of care	Not possible for hospitalised patients Shortage of GP Not all GP are trained in palliative care or feel comfortable to engage in a dialogue around end of life care Not all GP are able to assess social, psychological and spiritual resources and needs Not all patients have a GP Takes time
Outreach multidisciplinary support team (patients in the community) OR hospital palliative care mobile team (hospitalised patients)	Have expertise in palliative care Knowledge of the network and resources Is multidisciplinary, which facilitates the inclusion of the different dimensions of palliative care	In the community: need to be called by the GP Insufficient staffing Not all outreach team directly intervene at the patient bedside. Can be difficult to initiate the discussion on palliative care
Any healthcare professional who is already taking care of the patient (e.g. specialist doctor, home care nurse, social worker, psychologist…)	Prior knowledge of the patient facilitating the dialogue, continuity of the relationships, move from cure to care Possible to be conducted in all settings, including hospitals Increase the possibilities for assessment taking into account the specificities of patients living with chronic and/or rare diseases	Uncertainty about the availability of the expertise for conducting the assessment Risk of redundancies of the assessment ACP is only funded for the GP Palliative culture is lacking
A multidisciplinary team who is already taking care of the patient (e.g. oncology team, primary care team, nursing home team…)	Know the patients Facilitate the continuity of care for some patients (e.g. oncology patients) Prior knowledge of the patient facilitating the dialogue, continuity of the relationships, move from cure to care Possible in all settings, including hospitals Possible for chronic diseases patients / rare diseases Bring the specific expertise in case of comorbidities	Uncertainty about the availability of the expertise for conducting the assessment, particularly concerning ACP Risk of redundancies of the assessment ACP is only funded for the GP Lack of palliative culture

What emerges from the stakeholder consultation, is that **the GPs are essential players and that they must be involved in one way or another in this assessment.** However, it does not seem relevant to leave them alone to make this assessment as it takes time (sometimes being organised in different moments) and needs to be repeated.

It should also be remembered that, in some cases, the GP "finds back" their patients when the specialists "hand over", once the "curative" treatment has come to an end. In this case, the GP may be less familiar with their patients' experience. The same goes for patients with a rare disease whose main follow-up could be provided by a specialist doctor (or a team), even for health problems that are not related to the rare diseases. Finally, some patients do not have a general practitioner and having to find a GP remains a challenge.

For the first assessment, **we propose that this assessment be conducted by the GP supported by a multidisciplinary team that already knows the patients and their relatives**. However, there is uncertainty about the expertise available to do this if no one is trained / aware in palliative care and ACP. In this sense, the specialised palliative care teams (hospital mobile team or outreach multidisciplinary team) can play a coaching role to support the GP / the team to conduct this first assessment. However, if necessary, the following assessments could be performed by specialised palliative care teams (hospital mobile team or outreach multidisciplinary support team). As instruments, the BelRAI[w] remains essential - at a minimum. Other instruments can be mobilised but a common of assessment tools set is also needed for communication and collaboration purposes.

A key element remains that **this assessment needs to be centralised** in one way or another. In this sense, the coordination team of the palliative care network could play a key role in carrying out this centralization mission. This could also contribute to better monitoring the orientation to the most appropriate PC services at the level of a palliative care network (see below).

9.5 Current offer in palliative care in a nutshell

Figure 34 presents the current offer in palliative care in Belgium in a simplified and theoretical way.

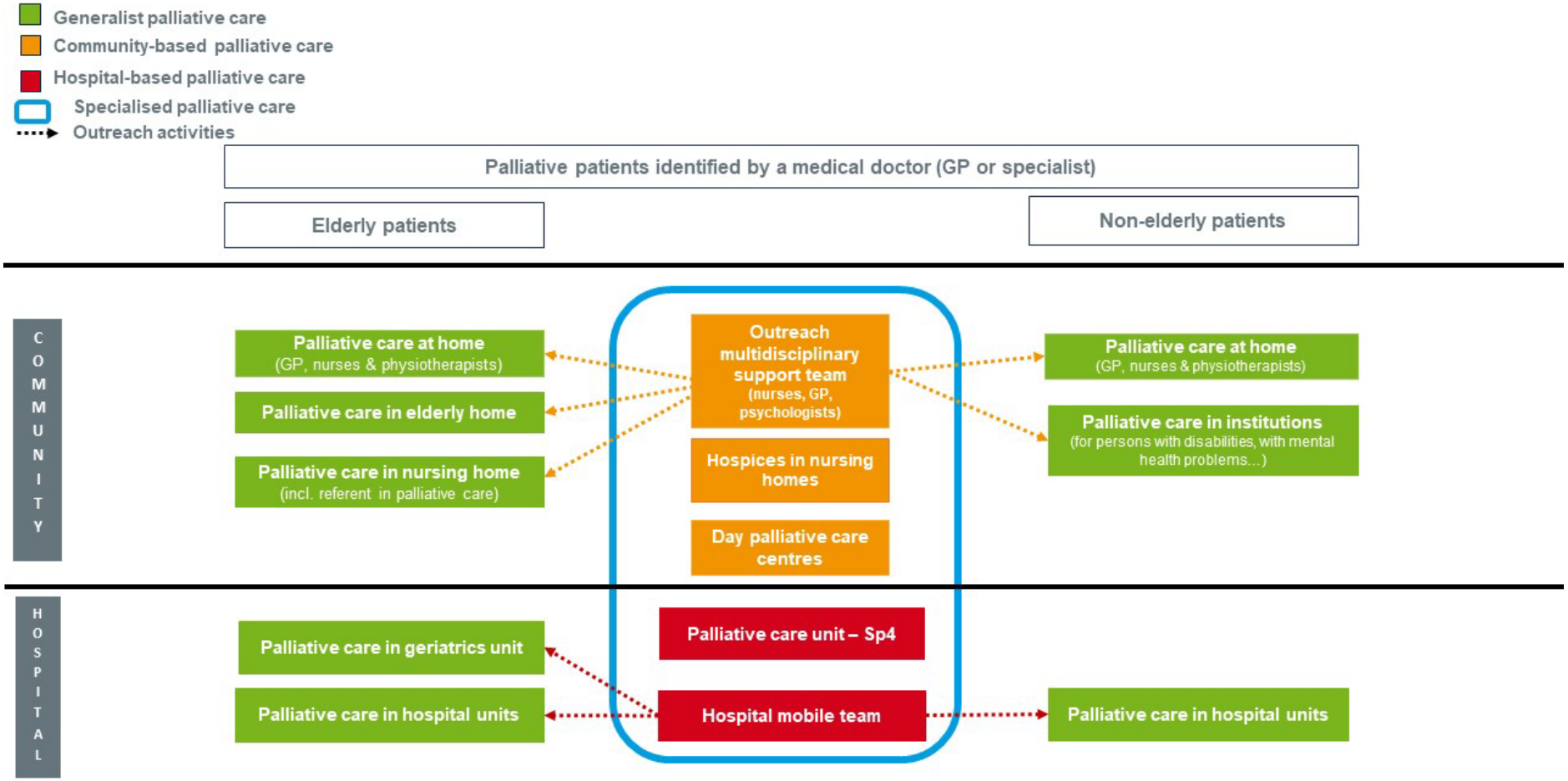
Boxes in green indicate a generalist palliative care offer. Generalist palliative care applies to professionals and volunteers who are frequently involved in palliative care and who have some knowledge of palliative care, such as general practitioners, nurses, specialist doctors (all disciplines) and paramedics (psychologists, physiotherapists, etc.), but who do not have palliative care as their sole care activity.[14]

Boxes in red indicate a hospital-based palliative care offer where professionals are specialised in palliative care while boxes in orange indicate community-based palliative care where professionals are specialised in palliative care. Both orange and red boxes constitute the specialist palliative care offer. Dotted arrows indicate an outreach function, implying that the professionals bring their expertise where the patients are staying. Specialist palliative care is delivered by specialised services for patients with complex needs that are not adequately met by other treatment options. Specialised palliative care services require a team approach, combining a multi-professional team and an interdisciplinary way of working. Team members must be highly qualified in palliative care, i.e. have both training and experience in palliative care, and their main activity must focus on palliative care.[14]

From this figure, one can observe that the current offer in palliative care in Belgium is currently divided between “elderly” patients and “non-elderly” patients. “Elderly” is frequently defined according to an age criterion varying according the facilities (above 65 years old, above 70 years old…). No common or consensual approach for defining elderly applies. This figure does not aim at reflecting all the possible situations as it can occur than some “non-elderly” patients find a place in a nursing home. Additionally, there are variations at local level regarding the availability and the reachability of the different forms of palliative care services contributing to a risk of interrupted palliative care trajectory (see Chapter 6).

[w] See more on the BelRAI (in Dutch and in French): https://www.belrai.org

Figure 34 – Overview of the current offer in palliative care in Belgium, 2024



Note: distinction between nursing homes and elderly homes no longer exist in Flanders

9.6 Services to be created to support the existing palliative care offer in Belgium

After identifying the patient's palliative situation and analysing their needs, resources and preferences, as well as those of their professional and informal caregivers, the patient is oriented towards the most appropriate palliative care service.

Palliative care can be characterised according to the following dimensions:

- **Level of care:** 1) palliative culture, 2) generalist palliative care, 3) specialist palliative care (see section 1.4.1)
- **Context of care**: 1) inpatient / residential; 2) outpatient / ambulatory
- **Setting of care:** 1) community-based; 2) hospital-based
- **Medical stability:** 1) stable; 2) unstable
- **Degree of technicity required by the medical treatment**: 1) limited technical needs; 2) extended technical needs

These dimensions have different implications for the patients, their relatives, and the professionals when considering the matching between the characteristics of a palliative care service and the results of the assessment of the preferences, needs and resources of the patient.

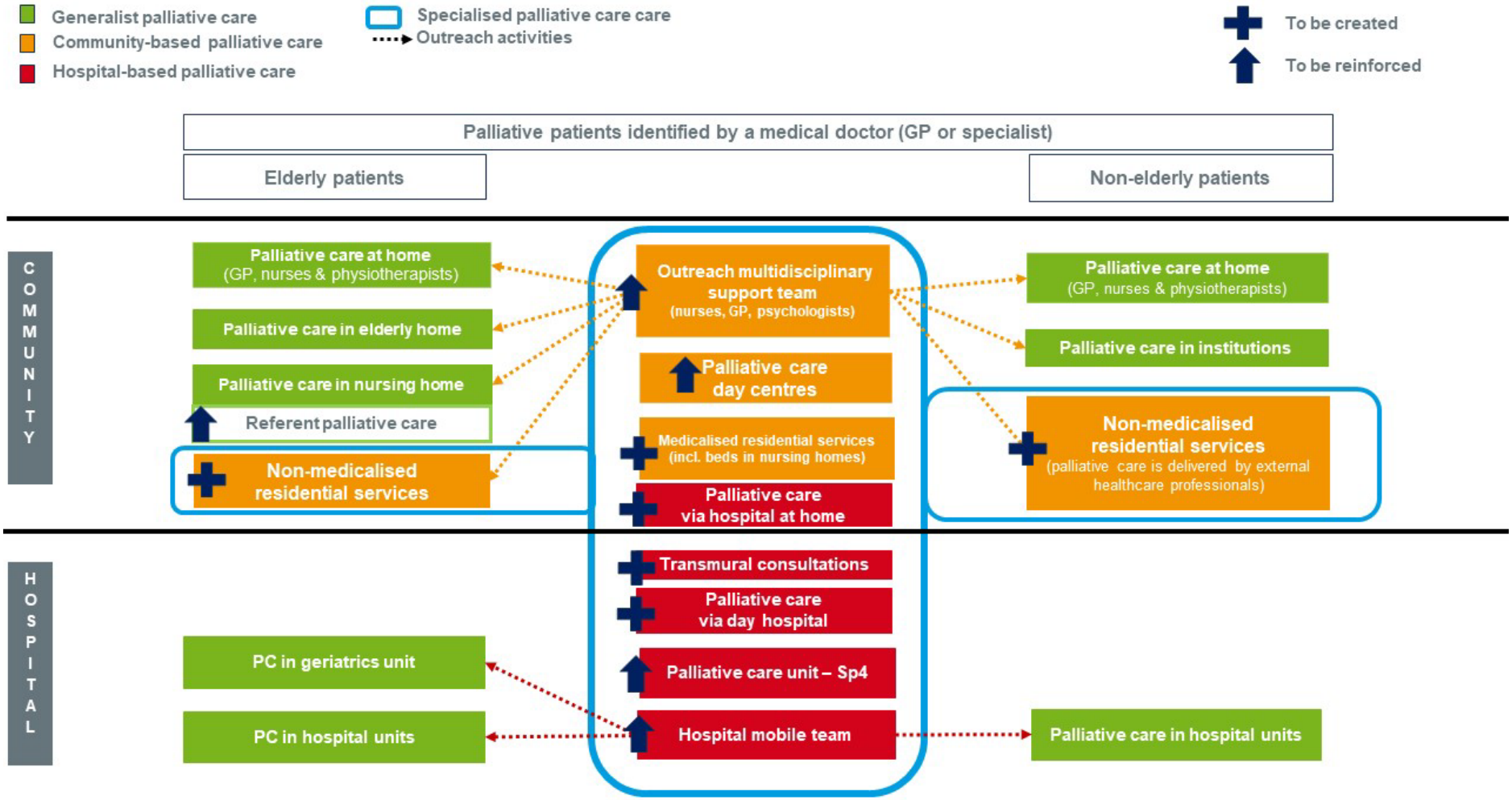
- Outpatient services are addressed to patients remaining in a place of residence for which they have the resources to maintain this residential situation (home, nursing home, institution for people with disabilities, etc.). This implies that **the place of residence must enable palliative care to be provided in complete safety, with respect for the quality of care and with adequate support**.
- Outpatient services also mean that **professionals are able to travel to patients**. However, it should not be overlooked that, for some patients, staying in their usual place of residence is a default choice, due to a lack of (financial) resources to access other places.
- Outpatient services imply that the **patients need to be able to travel in a safe manner**. A safe travel requires that the patients are physically and psychologically able to travel. When the patients (or their relatives) have no private transport, transporation services should be adapted to the transport of palliative care patients, affordable and reliable.
- Palliative care in the community is based on the principle that patients **can receive generalist palliative care from health professionals who do not specialise in palliative care in all types of residence**. This place of residence may be a private home, an institution for people with (intellectual) disabilities or psychiatric problems, a rest and care home, a collective residential structure such as a reception centre for asylum seekers or homeless people, a prison, etc.
- **Community-based inpatient services are addressed to patients who can no longer remain in their usual place of residence due to a lack of resources to manage their residential situation**, including the exhaustion of informal caregivers and family and friends. Some patients may also express a preference not to remain in their usual place of residence for a variety of reasons: limiting the burden on the family, feeling insecure, needing a permanent presence, wishing to be geographically closer to loved ones, etc. Their new place of residence or care may be close to their home, or it may be in another province. This need for a residential solution may therefore be temporary as, in certain situations, it may be possible to improve resources to enable patients to return to their usual place of residence.Patients may also decide to make a temporary stay in a residential palliative care service to offer their informal caregivers a little respite. For other patients, a temporary stay may be necessary before making the decision to stay permanently in the residential service (and ultimately die there). This means that every form of residential palliative care service must offer both a short stay and a long stay.

- **Unstable patients require the presence of healthcare professionals**: it can be a permanent presence at bedside (e.g. nurses on a night shift) and / or a on-call system where the professionals are available around the clock and can be at the patient bedside in a timely manner (e.g. a medical assistant covering several wards in a hospital or the GP coming at home).
- **Most of the technical acts** are performed in a hospital setting, as they require specific equipment and devices to be done.

Currently, some patients do not find a palliative care service corresponding to the result of their assessment of preferences, needs and resources. The palliative care offer must be diversified. Moreover, in order to provide palliative care in line with the expected growth of the palliative population resulting from the amendment adopted in 2016 to the law of 2022 on palliative care (no life expectancy limitation) and to the adoption of the Royal Decree of 2018 on the identification of palliative patients (including an estimated life expectancy of 6 to 12 months), the palliative care offer must be developed. As already pointed in the Chapter 3, rapid response to changing needs requires a shift from a historical cancer-appropriate 'one-size-fits-all' framework to a new model of palliative care whichever patients need it the most and better identify those patients with non-cancer illness who would benefit from palliative care. Innovative collaborative services based around patient, family, and wider community are needed to ensure optimal care for all.[107] This is in line with Bennardi, 2020[116] who emphasized the need from a change in model from a curative model in which palliative care is conceived only to address physical symptoms towards a more holistic approach addressing all care domains of the palliative patient.

In this aim, services specialised in palliative care should be strengthened, and others created. Figure 34 presents a simplified view of the current palliative care offer in Belgium. The offer is presented according to whether patients are considered 'elderly' or 'non-elderly' based on an age criterion. As there is no consensus on this criterion, we will not specify a threshold at which patients become 'elderly.' Figure 35 illustrates the types of specialised services to be created and those to be strengthened. Services to be created are indicated by a cross (+), while existing services to be strengthened are indicated by an arrow. Each element to be created in Figure 35 is detailed in the next sections: services to be strengthened are not dealt with as previous recommendations have been issued. This proposition focuses on specialised palliative care services: readers are therefore invited to keep in mind the transversal key principles of any palliative care organisation as described in section 9.3.

Figure 35 – Services that need to be created or expanded to complete the current palliative care offer



Note: Distinction between nursing homes and elderly homes no longer exist in Flanders

9.6.1 *Inpatient palliative care service in the community: non-medicalised residential service*

Non-medicalised residential services need to be created for **stable** palliative patients, who cannot / do not want to stay in their usual place of residence.

9.6.1.1 *Current situation of non-medicalised residential service*

To date, although local private initiatives exist, at the initiative of charities or non-profit associations, there is no formal acknowledgement of palliative community house.

During this project, we identified 2 distinct existing projects, fitting the objectives of a palliative community house.

The first project are the *zorghuizen* supported by *Kom op Tegen Kanker*. These are small residential structures where patients stay after a cancer treatment or when in palliative situation because of a cancer. Volunteers manage the structures. Patients need to be autonomous in their daily activities. Patients are not expected to elect this place as place of death (see section 4.3.6).

The second project is Pass-Ages in Brussels, an intergenerational co-housing project. This small residential structure receives patients in need of social and emotional support. Volunteers manage the structure. External healthcare professionals deliver generalist palliative care to the patients. Patients can elect this place as place of death (including via euthanasia) (Textbox 6).

At international level, this form of non-medicalised residential service can be found in the Netherlands: the *Bijna-Thuis Huizen* (section 5.4.7). A *Bijna-Thuis Huis* is a house with about 4 to 6 rooms and guest rooms for family and other loved ones. Patients can stay until their death or use it as a place for a short stay. Generalist palliative care is provided by the usual healthcare professionals of the patients (patient keeps their GP) while the daily management is overseen by trained volunteers, professionally supported by one or more home care organisations, external healthcare professionals and independent contractors (e.g. cleaning services, catering).

9.6.1.2 *Proposed organisation of a non-medicalised residential service*

Referral

Referrals to a non-medicalised residential service may be made at the request of patients, a general practitioner or the patient's treating doctor (e.g. hospital specialist), the hospital mobile palliative care team, the outreach multidisciplinary support team.

Admission criteria

The non-medicalised residential service is intended for adult patients in a palliative situation (PICT-1 +) whose needs correspond to those of patients staying at home or in a nursing home (simple medical needs). The non-medicalised residential service also welcomes the relatives of these patients. The non-medicalised residential service can be a temporary (short stay) or permanent place of residence.

Staff

The permanent staff includes a coordinator, volunteers and/or non-medical staff (e.g. social workers, educators, etc.). Volunteers and staff are trained in palliative care.

Services offered to the patients

This service includes 6 to 12 beds, managed by a team of trained volunteers and/or non-medical staff (e.g. educators, social workers). The service is available 24 hours a day, 7 days a week.

Non-medical staff and volunteers do not provide health care to palliative patients but may contribute to activities of daily living if these do not fall within the scope of services reimbursed by the NIHDI. They provide social, emotional, and spiritual support. They accompany patients until they die in addition or instead of informal caregivers or relatives. The legal framework related to euthanasia is in force like at home.

Services offered to the relatives

The non-medicalised residential service provides social, emotional, and spiritual support as well as bereavement care to the relatives.

Relatives can stay 24 hours a day, 7 days a week. They can access the non-medicalised residential service day and night. They can have a phone contact at any time with the non-medicalised residential service.

Coordination

A coordinator oversees the overall management of the service. The coordinator and staff can be hired by a palliative care network, a hospital or group of hospitals, a nursing home, a public social welfare centre (OCMW-CPAS) or any other relevant service (e.g. citizens' initiatives or charities).

Collaboration with other services

The non-medicalised residential service works with patients' usual healthcare professionals (e.g. GPs, home nurses, physiotherapists, etc.). The patient's health record is kept up to date by each professional involved in the care. The coordinator is responsible for ensuring that every member of staff and volunteer receives the information they need to care for patients in the respect of the privacy protection laws.

If necessary, the non-medicalised residential service staff organises appropriate medical support (e.g. making sure the patient has a GP, finding home nurses).

The outreach multidisciplinary support team can visit patients in the non-medicalised residential service to provide advice to the external healthcare professionals, staff and volunteers, and patient and relatives. If necessary, the outreach multidisciplinary support team can also provide direct care to the patients and the relatives. The staff can directly contact the outreach multidisciplinary support team, including during out-of-office hours.

The non-medicalised residential service is a member of the local palliative care network and participates in its activities. The palliative care network coordination team provides training and supervision for staff and volunteers.

The non-medicalised residential service has an agreement with a Sp4 palliative care unit, a medicalised residential palliative care service (see below) and a nursing home in its geographical area. If the patient's needs exceed the health care offer that can be delivered in the non-medicalised residential service, the patient is referred to the most appropriate service.

Infrastructure

The infrastructure of the non-medicalised residential service is organised to provide generalist palliative care like that provided at home. The non-medicalised residential service is accessible to patients with mobility problems. The non-medicalised residential service may be a stand-alone facility or part of an existing institution. It can be combined with a medicalised residential palliative care service.

Geographical distribution

There is at least one non-medicalised residential service per palliative care network.

9.6.1.3 Added value of and attention points

In addition to the care of stable palliative patient, the creation of non-medicalised residential services in the community, especially for non-elderly patients, for patients whose place of stay is not adapted for delivering quality care, for patients without informal caregivers and for homeless persons. This new offer will also contribute to respite care and specific support for the relatives by offering dedicated services to them.

However, it is necessary to have front-line professionals trained and available to provide general palliative care in this type of facility (general practitioners, nurses, psychologists, etc.). As explained in the introduction of this chapter, the creation of non-medicalised residential services will only be fully effective if, at the same time, efforts are made to strengthen the generalist offer in palliative care. Also, if the facility is far from the patient's home, it will be difficult to keep the patient's usual healthcare professionals and informal caregivers. To date, there is no clear vision for quantifying the needs of such a structure and its distribution.

Also, the creation of non-medicalised residential services requires financial and human resources. However, funding mechanism for this type of structure is not yet identified and there is a shortage of staff in the care sector, such as family assistants, educators, social workers, etc.

Concerning the involvement of volunteers, a model based solely on volunteers is seen as unsustainable because of the fluctuations in the volunteers' commitment. And volunteers need to be recruited, trained and retained, which requires additional professional resources. Finally, there is a need to define the scope of sharing potentially sensitive information (health data) with volunteers.

9.6.1.4 Key actions and actors to be involved

Table 41 gives an overview of the actions to be conducted and actors to be held accountable to create and sustain non-medicalised residential services in the Belgian palliative care offer.

Table 41 – Overview of the actions to be conducted and actors to be held accountable for non-medicalised residential service

Key actions	Key actors
Opening a non-medicalised residential service in the geographic zone of a palliative care network	• PC network • Outreach multidisciplinary support team • Hospital / hospital group • Municipal welfare centres (OCMW/CPAS) • Nursing homes • …
Ensuring that the staff (including volunteers) is trained and supervised	• Coordination team of the PC network
Coordinating the offer of non-medicalised residential service in the geographic area of the palliative care network	• Coordination team of the PC network
Reinforcing the coordination team of the PC network	• Federated entities
Funding of the non-medicalised residential service offer: infrastructure, equipment, daily fees (catering, laundry and other costs) and salaried of the permanent staff.	• Federated entities
Funding of the non-medicalised residential service offer: health care costs via the nomenclature	• NIHDI
Supporting the displacement of healthcare professionals in non-medicalised residential service houses via the nomenclature in force for the consultations of specialists in nursing homes	• NIHDI
Establishing the accreditation norms for a non-medicalised residential service, including the budget, the staffing number and qualification, and the planning	• Federated entities • PC federations

9.6.2 *Inpatient palliative care service in the community: medicalised residential services*

Medicalised residential services need to be created in the community for unstable palliative patients who cannot / do not want stay in their usual place of residence.

9.6.2.1 *Current situation of medicalised residential services in the community*

To date, there is no formal acknowledgement of this kind of structure in Belgium. However, there exist already initiatives that could correspond to medicalised residential services in the community.

The first initiatives are the *hospicezorg*, currently under development in Flandres (section 4.3.3). *Hospicezorg* is aimed at patients in the last weeks of life:

- for whom dying at home is not or no longer feasible due to circumstances.
- for whom their informal carers are at risk of becoming chronically overburdened. A temporary relief from care is then needed to allow the informal caregiver to regain strength (respite care).
- in vulnerable and unstable situations that require targeted integral care and support by an interdisciplinary team of care professionals and volunteers with generic and specialist competences.
- who are at risk of being hospitalised in a crisis.[176]

It is worth mentioning that ZorgNetIcuro published a report in July 2024 with their proposal for a recognition and a funding of *hospicezorg* in Flandres.[176]

The second initiative is the *Cité Sérine*, a therapeutic hotel, receiving chronic patients and palliative care patients for short and long stay. *Cité Sérine* can be chosen as a place of death. There is a nursing staff, 24h/7d, trained in palliative care, with a referent medical doctor. External health care professionals such as the patient GP also contribute to the health care (Textbox 4).

At international level, in Germany, the inpatient hospices (*stationäre hospize*) are stand-alone facilities, not connected to a hospital or elderly home, which ensure that people with incurable, life-threatening diseases receive palliative care where such care cannot be provided in the home environment and do not require hospital treatment.[227] Inpatient hospices are institutions with a family-like atmosphere, which are generally part of a networked care structure within the regional health and social welfare system. Patients usually stay there until the end of their life.[228] Inpatient hospices do not have physicians on their payroll.[228] Medical care is provided within the contractual healthcare system by an external accredited GP or by a physician with a sub-specialisation in palliative medicine.[227] In 2022 Germany counted about 250 hospice inpatient hospices for adults and 19 inpatient hospices for children, adolescents, and young adults.[229] (see section 5.4.7).

9.6.2.2 *Proposed organisation of a medicalised residential service*

Referral

Referral to the medicalised residential service is made at the request of the general practitioner/ treating doctor (hospital, nursing home, etc.), the hospital mobile team or the outreach multidisciplinary support team.

Admission criteria

The medicalised residential service is intended for adult palliative patients whose needs require constant monitoring and nursing expertise, but who do not require a hospital environment. The hospice also welcomes the relatives of these patients.

The medicalised residential service welcomes patients who cannot stay at home / who do not wish to stay at home. The medicalised residential service can be used as a permanent or temporary place of residence (short stay).

Staff

The care team consists of specialist palliative care nurses, under the supervision of a nurse coordinator, and volunteers. The staff may be employed by a palliative care network, an outreach multidisciplinary support team, a hospital or group of hospitals, a nursing home, a public social welfare centre (OCMW-CPAS) or any other competent service.

Services offered to the patients

This facility includes 6 to 12 beds and is run by a team of nurses qualified in palliative care. The nursing staff are present 24 hours a day, 7 days a week. The nurses provide somatic, social, psychological, and spiritual support - assisted by external service providers depending on patients' needs (psychologist, spiritual counsellors). They accompany patients until they die and support relatives after their death. The patient's general practitioner may continue to monitor the patient.

Patients can elect the medicalised residential service as place of death, including via euthanasia.

Volunteers may also contribute to social, emotional, and spiritual support and any other activity that helps the service to run smoothly, except for providing healthcare to patients.

Services offered to the relatives

The medicalised residential service provides social, emotional, and spiritual support as well as bereavement care to the relatives.

Relatives can stay 24 hours a day, 7 days a week. They can access the palliative care house day and night. They can have a phone contact at any time with the medicalised residential service.

Coordination

A nurse coordinates the overall management of the service, in collaboration with a doctor with specialist skills and regular practice in palliative care.

Collaboration with other services

The medicalised residential service collaborates with patients' usual healthcare professionals where they are present (e.g. GPs, physiotherapists, etc.). If, on admission or during the stay, other professionals are required, the medicalised residential service is responsible for organising support. The patient's file is kept up to date by the carers involved in the care.

The outreach multidisciplinary support team could intervene to provide support to the nursing team, volunteers and other professionals involved.

The medicalised residential service is a member of the palliative care network and participates in its activities (e.g. training, exchange meetings, events, etc.).

The medicalised residential service has an agreement with an Sp4 unit, a non-medicalised residential service and a nursing home. If the patient's needs exceed the capacity of the medicalised residential service, the patient is referred to the most appropriate service.

Infrastructure

The medicalised residential service may be integrated into an existing residential service (e.g. in the form of integrated hospice beds in a nursing home or institution) or may be a stand-alone residential service. The medicalised residential service may be combined with a non-medicalised residential service.

The medicalised residential service is set up to provide care in the same way as a nursing home. The medicalised residential service is accessible to patients with mobility problems. The infrastructure of the medicalised residential service allows relatives to stay overnight.

Geographical distribution

There is at least one medicalised residential service in each palliative care network.

9.6.2.3 Added value of and attention points

In addition to the care of unstable palliative patient, the creation of medicalised residential services will complete the residential offer in the community, especially for non-elderly patients. Medicalised residential services allow for long term stay for those in need of medical attention but who do not need a hospital environment. This new offer will also contribute to respite care and specific support for the relatives by offering dedicated services to them.

However, the creation of medicalised residential services requires financial and human resources. To date, funding mechanism for this type of structure is not yet identified. Moreover, stand-alone structures are rarely financially viable and there is a general shortage of nurses. In addition, there is little formal recognition of palliative care training for nurses working outside hospitals, except for those who have a palliative care referral function in nursing homes and although training in palliative care has existed for a long time. Finally, a scientific consensus is needed on the technical acts that can be delivered in this type of facility, in particular by referring to the extraordinary treatments listed in the PICT-2.

Concerning the integration of this offer into nursing homes, it requires adapting the admission criteria for non-elderly patients alongside working on the representations associated with nursing homes to make them more culturally and socially accessible. At the moment, there is no clear vision for quantifying the needs of such a structure and its distribution. It should also be noted that the general shortage of nurses currently leads to the decision of closing beds in nursing homes in some areas, reducing the possibility for integrating this offer in nursing homes.

9.6.2.4 Key actions and actors to be involved

Table 42 gives an overview of the actions to be conducted and actors to be held accountable to create and sustain non-medicalised residential services in the Belgian palliative care offer.

Table 42 – Overview of the actions to be conducted and actors to be held accountable for medicalised residential services

Key actions	Key actors
Opening a medicalised residential service in the zone of a palliative care network	• PC network • Outreach multidisciplinary support team • Hospital / hospital group • OCMW-CPAS • Nursing home • …
Coordinate the supply of medicalised residential services in the geographical area of the palliative care network	• Coordination team of the PC network
Strengthen the palliative care network coordination teams	• Federated entities
Ensure that the team (including volunteers) is trained and supervised	• Coordination team of the PC network
Fund the medicalised residential service: infrastructure, equipment, daily expenses (catering, laundry and other costs) and salaried of the permanent staff.	• Federated entities
Financing health care: application of the NIHDI nomenclature	• NIHDI
Establishing accreditation standards for medicalised residential services, including the budget, the staffing number and qualification, and the planning	• Federated entities • PC federations

9.6.3 Outpatient hospital-based palliative care in the community: palliative care via hospital at home

Specialised technical palliative care is delivered via hospital at home to stable and unstable palliative patients to cover their technical medical needs in their place of residence.

9.6.3.1 Current situation of hospital at home

Scope of hospital at home

Hospital at home care consists in specialised medical care that usually is given in a hospital environment, but now is given in the home environment. The intervention can be both of the early discharge type or admission avoiding type.[230] In the context of palliative care, hospital at home is defined as a type of home-based end-of-life care that provides active treatment for continuous periods of time by healthcare professionals for patients who would otherwise require hospital or hospice inpatient end-of-life care. This type of service can either be delivered by a multidisciplinary outreach team or can be an outpatient hospital-based service in a palliative medicine unit (Chapter 3).

In Belgium, the NIHDI defines hospital at home as "*situations in which care can be administered in the living environment of the patient in compliance with the applicable regulations and quality and safety criteria, and which, if these criteria cannot be applied, must be administered in the context of standard hospitalisation or day hospitalisation*".[231]

To date, in Belgium, hospital at home includes:

- intravenous antibiotic, antimycotic or antiviral treatment lasting at least 5 days
- parenteral administration as part of anti-cancer treatment lasting at least 3 days
- only medicines listed in the list of reimbursable pharmaceutical specialities

Hospital at home is available at the patient private place of stay but also in nursing homes, psychiatric institutions or recovery centres.

Procedure

Hospital at home can only take place if a number of conditions are met in terms of quality and safety of care. It involves collaboration between several care professionals: the hospital care team, the home nursing team, doctors and pharmacists.

- The treating doctor (e.g. hospital specialist) or nursing team discusses the possibility of hospitalisation at home with the patient. The GP is also involved. The hospital's specialist doctor makes the final decision.
- When a decision is made to admit a patient to hospital at home, all the parties involved agree on a care plan. Coordination takes place in consultation between the hospital care team and the home care nurses.
- In the case of long-term antibiotic treatment, coordination also takes place with the hospital doctor responsible for infectiology/microbiology.
- The hospital pharmacist is responsible for preparing, transporting, and delivering the medication.
- If the patient has a reference pharmacist, he or she will also be kept informed.
- Organising the collection of high-risk medical waste is the responsibility of the hospital.

Funding and costs

As well as being reimbursed by the health insurance scheme, the patient pays no co-payment either for medicines or for the health services provided under the agreement. The patient may have to pay a co-payment for additional nursing services or for drugs and medical devices dispensed by the hospital pharmacist and required to administer an oncological or antimicrobial drug.
The NIHDI intervenes for several services:

- Lump-sum payments for the initiation of hospitalisation at home, for the hospital, the specialist doctor, the general practitioner, and the home nurses.
- Fees for monitoring by the specialist doctor.
- Fees for the coordination of care by the hospital nurse and the home care nurse.
- Lump sum for the preparation and dispensing of medication by the hospital pharmacist.
- Additional flat-rate fee for the home care nurse who administers anti-cancer drugs by the intramuscular, subcutaneous, or hypodermic route.
- Lump sum for medical equipment.
- Flat-rate fee for the GP who provides advice in the event of a worrying situation in the home.
- Funding for the administration of the medication itself will be based on the existing nomenclature for home nursing care.

Future

An evaluation of the existing offer is foreseen by the NIHDI.

9.6.3.2 *Proposed organisation for palliative care via hospital at home*

Referral

Referral for palliative care via hospital at home may be made by the treating specialist (oncologist, geriatrician, cardiologist, neurologist, etc.), the doctor from the palliative care consultation team (see below), the doctor from the hospital mobile palliative care team or the doctor from the palliative care day hospital (see below).

Admission criteria

The patient has the necessary resources to receive technical medical treatment at home (for example, a refrigerator for storing medicines). The resources also include those of the patient's informal caregivers if they are involved in the care.

The patient may also be eligible for receiving palliative care via hospital at home if the appropriate resources can be put in place quickly.

Services offered to the patients

Palliative patients who need technical medical care can receive it via hospital at home. Palliative care via hospital at home implies that technical medical care can be delivered at home in complete safety for patients, relatives, and professionals. These treatments complement the generalist and / or specialist palliative care that patients receive in their usual place of residence. Professionals are responsible for keeping the patient's health record up to date and making it available to other healthcare professionals and patients. Professionals administrating the treatment communicate all relevant information to the patient's usual healthcare professionals and to the doctor specialising in palliative care who prescribed the treatment. Outside office hours, patients can contact the outreach multidisciplinary team.

Services offered to the relatives

If necessary, the professionals provide training for the relatives involved in the health care as part of the framework of qualified caregivers.

Staff

The team delivering palliative care via hospital at home is made up of nurses, some of whom specialise in palliative care, working in collaboration with specialist doctors.

Coordination

Treatment for palliative patients via hospital at home is prescribed by a doctor specialising in palliative care. This doctor is the point of contact for the team administrating palliative care via hospital at home and works with the patient's GP.

The team administrating palliative care via hospital at home has access to the information in the patient's hospital record that is necessary for the patient's care, and vice versa. The patient is informed of this sharing of information.

Collaboration with other services

The prescribing doctor collaborates with the patient's GP to ensure the continuity and the quality of care.

The nurses delivering hospital at home works with the patient's GP, the home care nurses and other professionals involved in the patient's care

There is a formalised collaboration with a hospital that has an Sp4 palliative care unit, with the palliative care network and with the outreach multidisciplinary support team. If necessary, the nurses intervening in the context of hospital at home are supported by the outreach multidisciplinary support team or the hospital mobile palliative care team.

There is an agreement with a hospital for the disposal of medical waste.

The hospital pharmacy supplies treatments, medical products and technical equipment for the PC delivered as part of hospital at home.

Infrastructure

The team could be integrated into a hospital or may be a specialist team integrated in a home care service.

Geographical distribution

There is at least one offer of PC via hospital at home service per palliative care network. PC hospital at home should ideally be managed by professionals already involved in hospital at home, with appropriate training for nurses.

9.6.3.3 Added value of and attention points

Palliative care via hospital at home service complete the current offer in specialised nursing care at home for palliative patients who wish to stay in the community. It reduces the need for transportation of the patients as health care is provided in their place of residence and allows for reaching patients in less urbanised areas. It also allows for providing specialist palliative care in residential facilities such as institutions for persons with disabilities, psychiatric institutions, receptions centres for asylum seekers. Importantly, it increases the likelihood of dying at home compared with usual care and could reduce (unplanned) admissions at hospital[97, 232]

However, currently, hospital at home is differently organised across the Belgian territory as there is no clear organisational framework and hospitalisation at home is unequally implemented in the different settings (e.g. home, nursing home, psychiatric institutions…). And sharing information between the first line of care and the second line of care is complicated: transmural communication is not yet effective. Also disposing of care waste is a challenge.

For the moment, hospitalisation at home is only limited to chemotherapy and intravenous antibiotics. So, there is no list of technical services related to palliative care that can be performed by nurses in the context of hospitalisation at home. A scientific consensus needs to be reached on the technical acts that can be provided, in particular by referring to the extraordinary treatments listed in the PICT-2. However, the addition of new technical procedures related to palliative care in the context of hospital at home must not be to the detriment of the other pillars of palliative care.

The number of patients who could benefit from extending hospitalisation at home to include palliative care is not known: it needs to be quantified, as does the care that would be required. Moreover, if hospitalisation at home is extended, the division of legal responsibility between professionals (nurses and doctors) must be clarified and the nursing care nomenclature will have to be adapted. The extent to which nursing home nurses perform technical acts vary across nursing homes. Although home nurses have the opportunity to receive training in palliative care, this training is insufficiently recognised and valued.

9.6.3.4 Key actions and actors to be involved

Table 43 gives an overview of the actions to be conducted and actors to be held accountable to include the delivery of technical palliative care interventions via hospital at home in the palliative care offer in Belgium

Table 43 – Overview of the actions to be conducted and actors to be held accountable for the development of palliative care via hospital at home

Key actions	Key actors
Establishing an evidenced-based list of additional interventions that can be safely performed at home by nurses	• Evikey • Federal Cell of PC, in collaboration with the professionals specialised in palliative care • Professional associations of medical doctors • Federal Council of Nursing Art
Establishing national protocols to harmonise and standardise the procedures	• Evikey • Federal Cell of PC, in collaboration with the professionals specialised in palliative care • Professional associations of medical doctors • Federal Council of Nursing Art
Establishing the fees to cover the additional interventions	• NIHDI • Hospital federations, • Federal Council of Nursing Art
Clarifying the legal responsibilities in case of task delegation and differentiation	• Professional associations of medical doctors • Federal Council of Nursing Art • FPS Public Health • Hospital federations
Planning the budget to cover the additional interventions	• NIHDI
Establishing national protocols for waste disposal	• FPS Public Health

9.6.4 Outpatient hospital-based palliative care in hospitals: palliative care in day hospital

The possibilities for palliative care in day hospital need to be developed / enhanced to take care of stable palliative patients who have complex medical needs, that do not require a hospitalisation.

9.6.4.1 Current situation of day hospitals

Scope of day hospitals

Day hospital is defined by the Federal Council of Hospitals as "an *admission and a stay in an agreed hospital without overnight stay, where the patient receives one or more planned interventions. These interventions require established procedures for the selection of the patients, the safety, the quality control, the continuity, the health care after discharge, the redaction of reports and the cooperation with various medical and technical services, under the supervision and the management of a specialist doctor belonging to the hospital, with an adequate monitoring and delivery of health care".*[233] It includes both surgical and non-surgical interventions, as long as the patient leaves the hospital the same day. A day hospital is a hospital function / activity and not necessarily a distinct architectural unit within the hospital.

Costs and funding

Currently, the intervention is covered by the nomenclature while a lump sum is attributed to the hospital for covering the deployment of the staff and resources needed to ensure the quality of care and maintenance of day hospitalisation procedures, which are not covered by the nomenclature. To date, the funding is covered by the financial resources budget (*Budget Financiële Middelen - Budget des Moyens Financiers*) of the hospitals[x] and several lump sums of the NIHDI.

Among the existing lump sums for non-chirurgical interventions, we can point the lump sum for the pain clinics, for oncologic day hospitals or for implantable perfusion pumps.

Future

In 2019, the Federal Council of Hospitals and the NIHDI issued a conjoint statement related to a revision of the organisation, functioning and funding of the day hospital.[233]

[x] More on the financial resources budget (in English): https://www.healthybelgium.be/en/key-data-in-healthcare/general-hospitals/funding/the-financial-resources-budget

9.6.4.2 *Proposed organisation for palliative care via existing day hospitals*

Referral

Referral to the palliative day hospital may be at the request of the general practitioner, the treating specialist (e.g. oncologist, geriatrician, specialist doctor, etc.), the outreach multidisciplinary support team or the multidisciplinary palliative care consultation team (see below).

Admission criteria

Palliative patients requiring specialist and/or technical care may be admitted to the day hospital, provided they are still able to attend hospital**.**

Staff

The multidisciplinary day hospital team is made up of doctors, nurses, psychologists, volunteers, social workers and other professionals with specific expertise in palliative care. The team may be made up of the hospital mobile palliative care team and/or staff of the SP4 palliative care unit team.

Services offered to the patients

The palliative day hospital offers specialised technical treatments that cannot be provided at the patient's home but do not require a hospital stay. These treatments complement the generalist and / or specialist palliative care that patients receive in their usual place of residence. During their stay at the day hospital, patients can also receive psychological, spiritual, or social support. The day hospital is responsible for updating patient records and making them available to the other healthcare professionals involved and to patients.

Services offered to the relatives

Relatives are allowed to accompany patients and may also receive psychological, spiritual, or social support on their own. After the death of the patients, the relatives can still benefit from these different supports and from bereavement care.

There is attention for preventing relatives' exhaustion and burnout.

Coordination

The care of palliative patients in the day hospital is supervised by a doctor specialising in palliative care. A nurse coordinates the overall management of the service, in collaboration with the doctor specialising in palliative care.

Collaboration with other services

The palliative day hospital communicates all relevant information to the patient's usual healthcare professionals. A specific period is set aside for external professionals to facilitate communication and the sharing of information.

The palliative day hospital works in collaboration with the hospital mobile palliative care team. If necessary (for example, if the patient is too unstable to return home), the day hospital organises the transfer the patient, preferably to a SP4 palliative care unit. If the patient is oriented to another hospital unit, the team of the day hospital informs the hospital mobile team as part of the continuity of care.

The palliative day hospital has an agreement with a medico-social transport service for patients who are unable to travel on their own.

Infrastructure

The palliative day hospital is integrated into an existing day hospital, with appropriate training for professionals.

Geographical distribution

There is at least one palliative day hospital - integrated into an existing day hospital - per palliative care network.

9.6.4.3 Added value of and attention points on palliative care via day hospital

In addition to care of stable palliative patients with complex medical needs, the enhancement of specialist palliative care in day hospitals reinforces the continuity of care when the patient was previously receiving curative treatment in the day hospital. It also increase the possibility for early integrated palliative care[76] and it contributes to the specific support for the relatives by offering dedicated services to them

The diversification of the specialist palliative care offer through an ambulatory service strengthen the possible interventions delivered in hospitals, facilitating the patient's return to the community through the possibility of an ambulatory follow-up. Different combinations with other new hospital-based palliative care such as the transmural consultations (see below) are also foreseen for patients presenting difficulties to travel.

However, not all day hospitals have the capacity to expand their services. Hospital mobile PC teams are not sufficiently staffed to also provide day hospital services especially since palliative care in day hospitals must include the 4 pillars of palliative care and not only technical care. More day hospital staff are needed to take better care of family carers (e.g. specific consultations, discussion groups, social support, etc.).

Day hospitals are unevenly organised across the country. As distance may be large, transport must be organised and affordable for patients and their families.

Day hospital procedures include the possibility to be transferred to a SP4 palliative care unit if necessary, what seems unrealistic, given the current shortage of beds and the uneven distribution of palliative beds across Belgium (some hospitals do not have any palliative beds).

9.6.4.4 *Key actions and actors to be involved*

Table 44 gives an overview of the actions to be conducted and actors to be held accountable to enhance specialised PC within day hospitals in Belgian hospitals.

Table 44 – Overview of the actions to be conducted and actors to be held accountable for the development of palliative care via day hospital

Key actions	Key actors
Integrate specialist palliative care in day hospital into the hospital palliative function	• FPS Public Health • Federal Council of Hospitals (FRZV-CFEH) • NIHDI
Determine the PC interventions that can be provided in day hospitals	• Federal Cell for PC
Determine the budget needed to cover the 4 pillars of palliative care in the activities of the day hospital, including an increase in available staff	• FPS Public Health • FRZV-CFEH • NIHDI

9.6.5 *Outpatient hospital-based palliative care in hospitals: transmural palliative care consultations*

Stable and unstable palliative patients staying in their usual place of residence can benefit from transmural palliative care consultations to further investigate punctual complex (medical) problems.

9.6.5.1 *Current situation of transmural palliative care consultations*

There are no transmural palliative care consultations in Belgium. This form of palliative care exists at international level and is particularly developed in the Netherlands (see section 5.4.4 in Chapter 5). Transmural PC consultation (*Transitie Consultatie*) allows for the primary healthcare professional to consult a specialised healthcare professional (often from a hospital, not limited to medical doctors) to receive information, guidance, or practical support. This consultation is characterised by the continuity of the therapeutic relationship with the regular healthcare professionals care provider maintains the treatment relationship, but with the support of a specialised professional to achieve a better quality of palliative care.

9.6.5.2 *Proposed organisation for transmural palliative care consultations*

Referral

Referral to the consultations may be at the request of the general practitioner, the treating specialist (e.g. oncologist, cardiologist, geriatrician, etc.), the hospital mobile palliative care team (e.g. after hospitalisation) or the outreach multidisciplinary support team.

Admission criteria

Palliative patients requiring a specialised expertise and/or specialist care may be admitted as part of transmural consultations.

Staff

The transmural consultations are ensured by a multidisciplinary team made up of doctors, nurses, psychologists, psychiatrists, social workers, volunteers, and other professionals specialised in palliative care. The team may be made up of the hospital mobile palliative care team and/or staff of the SP4 palliative care unit team.

Services offered to the patients

These consultations are aimed at patients living in the community who have specific palliative care needs, requiring an additional expertise. These consultations meet the somatic, psychological, social, and spiritual needs of patients and their families. These consultations complement the generalist palliative care provided in the community. Patients can consult with one professional or with several professionals, depending on their needs. If necessary, a joint consultation can be organised (e.g. nurse and occupational therapist, pharmacist and medical doctor…).

The consultation team is responsible for communicating treatment adaptations and other relevant information to the usual healthcare professionals. The consultation team is responsible for keeping the patient's file up to date and making it available to external healthcare professionals and patients.

If medication is required, the team must ensure that it is available in the community. If this is not the case, the team must organise a pharmacy service to guarantee the availability of medicines or organise care with a home hospitalisation team.

The consultation can also take place at the patient’s usual place of stay or be provided by teleconference.

Services offered to the relatives

Relatives can also attend the consultations on their own to meet their psychological, social and spiritual needs. These consultations should aim at preventing relatives’ exhaustion and burnout.

The consultations should also include bereavement care after the death of the patients.

The consultations can also take place at the relatives’ usual place of stay or be provided by teleconference.

Coordination

The team is supervised by a doctor specialising in palliative care. A nurse coordinates the overall management of the service, in collaboration with the doctor specialising in palliative care. The team holds weekly multidisciplinary meetings.

Collaboration with other services

The consultation team collaborates with the general practitioner, the treating specialist (e.g. oncologist, geriatrician, other specialist), the outreach multidisciplinary support team and other professionals involved in care.

The consultation team is available for the other healthcare professionals for a joint consultation or for teleconferencing. A specific period is set aside for external professionals to facilitate communication and the sharing of information during working hours.

With the patient's agreement, a consultation report is sent to the professionals involved in the care, particularly the GP and the outreach multidisciplinary support team.

The consultation team has an agreement with a medical-social transport service for patients who are unable to travel themselves, if travelling is necessary.

Infrastructure

Consultations take place in the hospital's existing consultation rooms. These consultations can also be integrated into the activities performed in a day hospital.

The consultation can also take place at the patient’s usual place of stay or be provided by teleconference.

Geographical distribution

Transmural palliative care consultations are organised in each hospital network. In the case of multi-site hospitals, a rotation between sites is organised to improve the accessibility of consultations.

9.6.5.3 Added value of and attention points on transmural palliative care consultations

In addition to care of stable and unstable palliative patients with complex (medical) needs, the creation of transmural palliative care consultation based in the hospital setting reinforces the continuity of care when the patient was previously receiving curative treatment in hospital. It also contributes to the specific support for the relatives by offering dedicated services to them

The diversification of the specialist palliative care offer through an ambulatory service strengthen the possible interventions delivered in hospitals, facilitating the patient’s return to the community through the possibility of an ambulatory follow-up. Different combinations with other new hospital-based palliative care such as palliative care in day hospitals (see above) are also foreseen for patients presenting technical medical needs.

This new palliative care offer allow to bring additional expertise for specific problematics through the involvement of experts in various fields (e.g. for cognitive troubles, psychiatric problems, rare diseases…). It may also bring the expertise to the patients and the relatives in their usual place of stay and to the front-line professionals in their current practice.

As transmural consultations can be delivered by nurses, this new offer represent an opportunity for integrating emerging functions such as advanced practice nurses.

However, financial and human resources have to be carefully foreseen. Indeed, mobile teams working within hospitals are not sufficiently staffed to be able to carry out transmural consultations. And these consultations should last a long time (around 1 hour) as they focus on the needs of patients and their families. Further discussions and researches are needed to clarify the content of these consultations. New funding mechanisms have to

develop even more than some non-medical consultations have no funding mechanisms yet.

There is a risk of GPs bypassing or losing interest if the team of the transmural consultations does not sufficiently involve them. So the coordination with healthcare professionals working in the home setting needs to be carefully organised. Also transport must be organised and affordable for patients and their families.

9.6.5.4 Key actions and actors to be involved

Table 45 gives an overview of the actions to be conducted and actors to be held accountable to create transmural palliative care consultation based in Belgian hospitals.

Table 45 – Overview of the actions to be conducted and actors to be held accountable for the creation of transmural consultations

Key actions	Key actors
Integrate transmural PC consultations into the hospital palliative care function	• FPS Public Health • FRZV-CFEH • NIHDI
Determining the profile of professionals who should conduct these transmural consultations	• Federal Cell for PC
Determine the budget needed to cover the activities of multidisciplinary consultations	• FPS Public Health • FRZV-CFEH • NIHDI

9.7 Key elements for an integrated approach of palliative care

This section presents information on key elements underlying the creation of new types of palliative care services in Belgium. As mentioned above, these new services cannot be developed without the improvement of the whole PC system. Each individual service is a link in the chain of the palliative care offer ranging from generalist care at home to residential care at the hospital and service delivery depends on solid legal and administrative base. It is so necessary, before creating the new palliative care services, to:

1. Correct the inconsistency between the eligibility period for palliative care benefits as currently applied by the NIHDI and the legal framework relating to the Law on palliative care revised in 2016, in accordance with article 84 of the Law of 18.05.2022. containing various urgent provisions relating to health, inserting a chapter III quater into the law relating to compulsory health care and compensation insurance, coordinated on 14.07.1994 (published on 30.05.2022), which refers to the establishment of one or more palliative status(es). The correction of this inconsistency must be accompanied by the correction of the number of frailty criteria of the PICT-1 tool in the annex to the Royal Decree of 21.10.2018 laying down the criteria for identifying a palliative patient (published on 20.11.2018).
2. Reiterate that existing palliative care provision needs to be strengthened to ensure adequate provision (indicated by an arrow in Figure 1) according to the growing population eligible for palliative care. This concerns:
    - Reinforcing the staffing and funding of the outreach multidisciplinary support team (see, i.e., the recommendations of the Palliative Care Federations and the Federal Cell).
    - Improving the distribution and funding of day care .centres for palliative care patients as emerging from this research.
    - Reinforcing the staffing and funding of the hospital mobile palliative care team as evidenced by the Federal Cell and Federal Council of Hospitals.[162]

- Improving the distribution and funding of Sp4 beds as also pointed by the Federal Cell and Federal Council of Hospitals.[162]
- Reinforcing the function of palliative care referent in nursing homes as stressed by organisations and stakeholders during this research. The function can also be organised as an internal cell where several staff members are trained in palliative care and contribute to the diffusion of the palliative care culture.

3. Change the hospital palliative care function into a '**palliative care programme'** to ensure integration and coordination of hospital provision in its extended version. This palliative care programme would include in-hospital mobile palliative care teams, specialised palliative care units (Sp4), palliative care in day hospitals, transmural palliative care consultations, and hospitalisation at home[y].

   Care programmes can be defined as an organisational framework for implementing 'care pathways' for a specific target group. They are the result of an arrangement between the hospitalisation services, medical or medico-technical services and functions that are necessary in order to provide high-quality care.[11] There are currently various care programmes: 'cardiac pathology', 'reproductive medicine', cancer patients, children, geriatric patients and 'stroke care'.

   Care programs support the multidisciplinary and integrated approach, with the aim of improving quality of care. It can contribute to the reinforcement of the expertise of the healthcare professionals but also to a better visibility of palliative care. From the literature, despite some conflicting evidence, pathways in palliative care appear to be of added value: reduction of costs was found, as well as an increased likelihood to die at home or in the preferred place of choice (section 1.1.1.1).

4. Improve **palliative care training** for healthcare professionals, both in initial and continuing training. Consideration should be given to the normative framework defining what constitutes **specialisation in palliative care for doctors**. Consideration should also be given to a **specific professional title** in palliative care for nurses, particularly in connection with the development of the nursing function scale (e.g. advanced practice nurse in palliative care). Enhanced training should also include greater attention to people in vulnerable situations, such as people with (intellectual) disabilities or living with mental health problems as well as the influence of the sociodemographic and ethnocultural characteristics on access and utilisation of palliative care (see section 3.3.1.1). As found in the literature, several barriers related to access and utilisation of palliative care could be, to some extent, solved by training and educating healthcare professionals. It can help them to change their attitudes and beliefs regarding palliative care but also with the patients and the informal caregivers., to gain more knowledge about palliative care and improve their communication skills with patients, relatives and other professionals (see barriers in the Table 18). In the literature (see Chapter 3), we could observe that interventions focusing on the training of the healthcare professionals have a positive impact. Threapleton (2017)[114] even suggested to have mandatory, ongoing training, and education on end-of-life care.

5. Improve the **centralisation and the exchange of information** related to palliative care needs and resources in a determined geographic zone. In our study, participants identified palliative care networks as the relevant actors to centralize and coordinate what is done in terms of palliative care in their territory. At the same time, reforms are underway, particularly with a view to better integrating the first line. It is needed to identify a relevant territorial area for a better understanding of the needs and resources of patients and their families. This will also allow for a better consideration of the sociodemographic characteristics of the patients influencing the access and utilisation of palliative care services, such as gender, socioeconomic status, age, geographical location,

[y] This does not exclude the possibility of having an external home care service delivering the health care

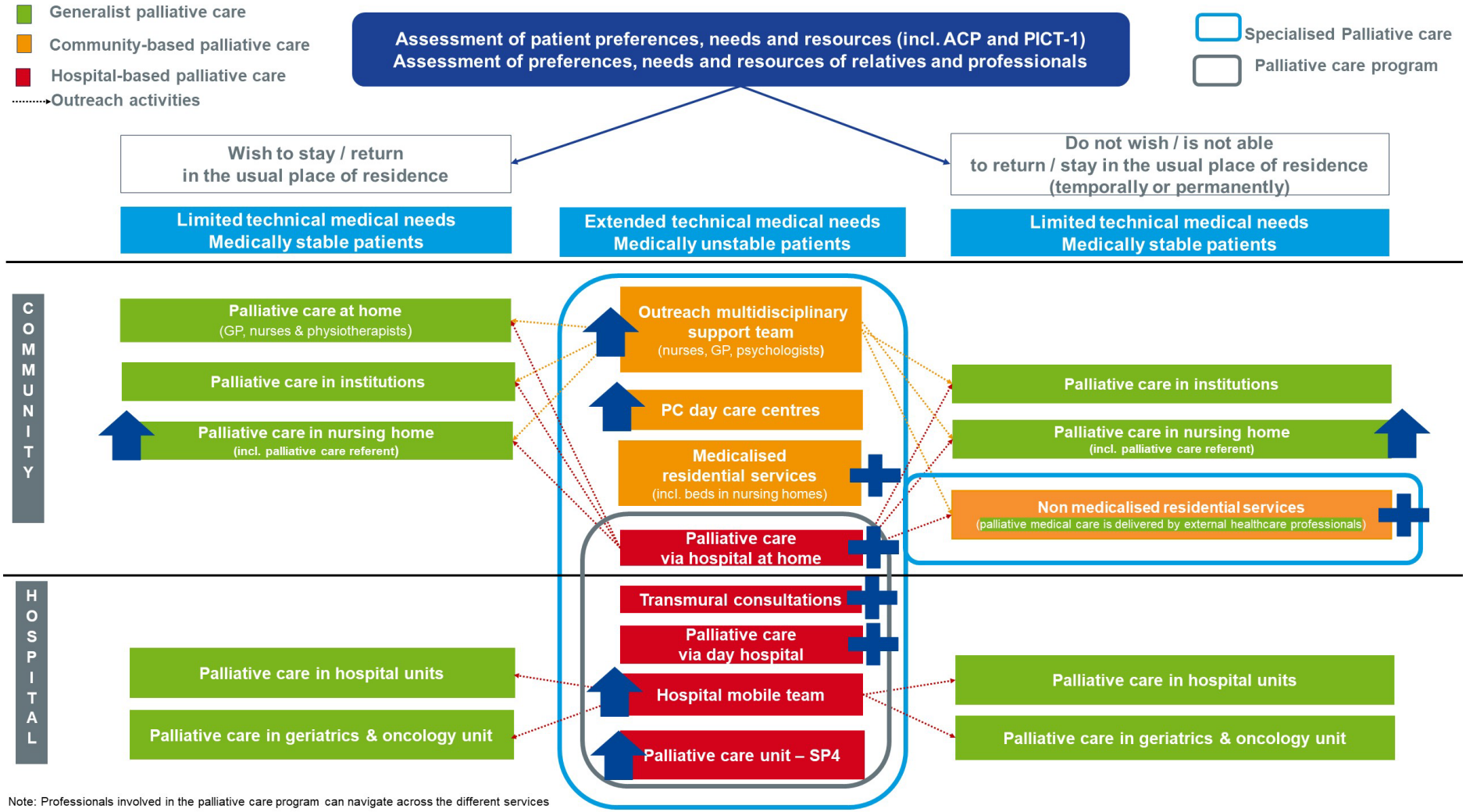
disease, ethnicity and culture, comorbidities…(see section 3.3.1.1). This territorial area can be used to determine the necessary resources.

9.8 Final proposition

Figure 36 presents the final proposition for better meeting the preferences of palliative patients by reinforcing and expanding the Belgian palliative care offer. In this figure, the dotted arrows indicate an outreach flow of professionals who deliver direct care to the patients and / or provide support to the patients or the professionals.

It should be possible to combine the different offers throughout the course of care or, where appropriate, during an episode of care. For example, the patient receives care via a hospital-at-home service and goes to hospital to receive multidisciplinary consultation services. Inside each care offer, attention should be paid to the 4 pillars of palliative care: somatic, psychologic and emotional, social and spiritual, for both the patients and their relatives. As mentioned above, a specific offer should target the relatives, even after the death of the patients. We also want to stress that there is a need for formal collaboration between the different care offers for facilitating transmission of information, patient referrals, exchange of expertise and best practices between professionals. As mentioned in the literature, (formal) linkages between services contribute to the reduction of relational and bureaucratic barriers and, consequently, contribute to a seamless transition between services (section 3.2.2).

Figure 36 – Overview of the future offer of palliative care in Belgium



Note: Professionals involved in the palliative care program can navigate across the different services

Table 46 presents the 5 services of palliative care that need to be reinforced while Table 47 presents the 5 models that need to be created according to a selection of the criteria proposed by Firth et al. (2019).[192] These criteria were adapted to the Belgian context and completed by additional criteria. These two tables aim at illustrating to which extent the propositions complete each other to ensure a comprehensive health care pathway.

In Table 46, presenting the existing offer, the criteria reflect the current theoretical situation (without any improvement or change in the existing organisation). In practice, there are variations in the way these aspects are operationalised. For example, not all outreach multidisciplinary support teams provide direct palliative care.

In Table 47, the characteristics are theoretical and require additional research to be further put in practice.

From these 2 tables, we can highlight the following key points:

- The creation of additional offer aims at diversifying the possibilities for **specialist palliative care based in a hospital setting for patients staying in the community** (hospital at home, palliative care in day hospital and transmural consultations).
- The additional offer also diversifies the possibility for **long term stay** in the community for medically stable patients (community houses) and medically unstable patients (palliative care houses).
- The reinforcement of the current offer and the development of an additional offer can contribute to diversify the **possibility for out-of-hours support**. As pointed in the literature (section 3.2.3.2) , out-of-hours services are perceived of added-value for patients and their relatives, especially for those endorsed as informal caregivers. At international leve, the UK has particularly invested in developing out-of-hours support to facilitate staying in the community as long as possible.
- The inpatient servivces to be created include the **out-of-hours availability of a medical doctor specialised in palliative care**. To date, there is no out-of-hours availability of medical doctor specialised in palliative care: medical presence outside working hours is ensured by GP in the community or medical residents in hospitals, without specific requirement for being specialised in palliative care. In their recommendations of 2022, the EAPC therefore advised that “a physician specialised in palliative care should be available 24 hours a day and be accessible within 30 minutes” for inpatient specialised pallaitive care services in the community.[14] In the Belgian context, it can envisioned as a transversal function at the level of a palliative care network where the on-duty medical doctor can be a referent for inpatient services in hospitals or in the community (e.g. Sp4 units, nursing homes, medicalised residential services and non-medicalised residential services).
- When comparing the number of disciplines available in the different offers, transmural consultations contribute to the improvement of the availability of the expertise. In the current offer, palliative care units represent the health care offer where the most diverse specialised staff is present (11 different disciplines) but this expertise is limited to hospitalised patients. Transmural consultations can expand the **availability to 14 different disciplines** (see Table 48).
- Sp4 units and the hospital support team can perform the higher number of interventions related to palliative care (13 different interventions – Table 49). In day hospitals, it appears that a large range of interventions could be performed. In the framework of hospitalisation at home, 10 interventions could be performed (all interventions apart medical imagery). In a next step, it can be interesting to consider the list of extraordinary treatments (technical medical acts) as included in the PICT-2 scale in order to identify which treatments can be performed safely outside the hospital.
- But the most important aspect is to note that the current Sp4 units and the palliative care houses have the same number of care objectives, implying that the intensity of care – but not the technicity – appears to be similar (Table 50).

- **It should be noted that there are no details in the possibilities for funding a new offer** and that further investigation could have been of added value. The practical aspect of implementing measures (and the difficulties that might be encountered in doing so) were outside the scope of this KCE project. At the moment, it is not possible to conduct an indepth analysis of the financial data because of their fragmentation and the fact that they are only partially linked to activity. It makes it thus difficult to obtain an accurate picture of the budget currently invested to cover the needs of the palliative care population and even less the costs involved in a new offer. As mentionned in the introduction of this chapter, previous reports attempted to define what is needed and in which magnitude for the existing offer. But regarding the offer to be created, the estimation of a necessary budget was impaired by limited data and limited scope of the project and of the remit of KCE. The KCE report 367 already pointed the lack of comprehensive financing system of palliative care in Belgium as in a lot of countries except Australia.

Characteristics of the existing services delivering palliative care in Belgium

The current offer is divided in community-based and hospital-based services. Hospital-based services are limited to inpatient services for unstable patients in need for complex technical care while community-based services are outpatient services intended for stable patients who do not require complex technical care. Hospital-based services are funded by the federal authority while community-based services are funded by the federated entities.

Table 46 – Key characteristics of the existing palliative care offer

	Existing palliative care offer - theoretical situation in 2024				
				Hospital palliative function	
	Outreach multidisciplinary support team	**Day palliative care centres**	**PC referent in nursing homes**	**Hospital mobile palliative care teams**	**Specialised palliative care units (Sp4)**
Criteria to organise palliative care services[1]					
• Context	Outpatient	Outpatient	Inpatient	Inpatient	Inpatient
• Setting	Community	Community	Community	Hospital	Hospital
• Degree of medical stability[2]	Unstable	Stable	Stable	Combination	Unstable
• Direct care or advisory	Combination	Direct care	Combination	Advisory	Direct care
• Possibility for technical care	Limited	Limited	Limited	Extended	Extended
• Purpose of the care provided	6	5	7	5	9
• Possibility for the patient to apply for euthanasia[2,3]	Yes	Yes	Yes	Yes	Yes
• Length of stay[2]	N/A	N/A	unlimited	N/A	limited
• Care until the death of the patient	Yes	No	Yes	Yes	Yes
• Number of disciplines permanently included in the offer[2]	5	5	3	3	11
• Mode of care (face-to-face or remote)	Combination	Face-to-face	Face-to-face	Face-to-face	Face-to-face
• Number of available interventions done by the staff	4	2	2	13	13
• Admission criteria[2]	Any life-limiting condition	Any life-limiting condition	Geriatric patients	Any life-limiting condition	Any life-limiting condition
• Possibility for self-referrals by patient or family	No	No	No	No	No
• Can admissions be made and seen out of office hours?	No	No	No	No	Yes

• Presence of a medical doctor specialised in palliative care during working hours[2]	Team member	Team member	Team member	Team member	Team member
• OOH availability of a medical doctor specialised in palliative care	None	None	None	None	None*
• OOH mode of the medical doctor (face-to-face or remote)	N/A	N/A	N/A	N/A	N/A
• OOH type of the medical doctor (advisory or direct care)	N/A	N/A	N/A	N/A	N/A
• OOH nursing availability of a nurse specialised / qualified in palliative care	Via usual HCP	None	None	None	Yes
• OOH mode of the nurse (face-to-face or remote)	Combination*	None	None	None	Face-to-face
• OOH type of the nurse (advisory or direct care)	Combination*	None	None	None	Combination
• Existence of a standardised evaluation of outcomes of activities and interventions	Unknown	Unknown	Unknown	Unknown	Unknown
• Existence of a standardised evaluation of experience of patients, relatives, and staff (including volunteers)	Unknown	Unknown	Unknown	Unknown	Unknown
• Service funded by	Federated entities	Federated entities	Federated entities	Federal	Federal

*[1]adapted from Firth et al. 2019 [2]Criteria added [3]It does not imply that euthanasia should be an admission criterion. *Some hospitals have organised a OOH permanence of a medical doctor specialised in palliative care*
*Legend: OOH – out-of-hours *local variations can occur*

Characteristics of the services to be created

By creating additional services, the current offer will notably be completed with outpatient hospital-based services, which can be integrated in a "palliative care program" and benefit from a funding of the federal level. The new offers also aims at diversifying the inpatient community-based service, by developing 2 inpatient community-based services: 1) the non-medicalised service for medically stable patients; 2) the medicalised service for medically unstable patients.

Flexible length of stay implies the possibility for short term stay, respite stay or unlimited stay, depending on the patient preferences.

Table 47 – Key characteristics of the palliative care offer to be created

	Palliative care offer to be created - projection of characteristics				
				Palliative care program	
	Non-medicalised residential service	**Palliative care house & beds in nursing homes**	**Palliative care via hospital at home**	**Palliative care via day hospital**	**Transmural consultations**
Criteria to define models of palliative care[1]					
• Context	**Inpatient**	Inpatient	Outpatient	Outpatient	Outpatient
• Setting	Community	Community	Community	Hospital	Both
• Degree of medical stability[2]	Stable	Unstable	Combination	Stable	Combination
• Direct care or advisory	Combination	Combination	Direct care	Combination	Advisory
• Possibility for technical care	No	Extended	Extended	Limited	Limited
• Purpose of the care provided	6	9	1	8	8
• Possibility for the patient to apply for euthanasia[2,3]	Yes	Yes	Yes	Yes	Yes
• Length of stay	Flexible	Flexible	N/A	N/A	N/A
• Care until the death of the patient	Yes	Yes	Yes	Yes	Yes
• Number of disciplines permanently included in the offer[2]	3	6	3	9	14
• Mode of care (face-to-face or remote)	Face-to-face	Face-to-face	Face-to-face	Combination	Combination
• Number of available interventions done by the staff	1	5	10	13	4
• Admission criteria[2]	Any life-limiting condition	Any life-limiting condition	Any life-limiting condition	Any life-limiting condition	Any life-limiting condition
• Possibility for self-referrals by patient or family	No	No	No	No	No
• Can admissions be made and seen out of office hours?	No	No	No	No	No

•	Presence of a medical doctor specialised in palliative care during working hours[2]	External consultant	External consultant	External consultant	Team member	Team member
•	OOH availability of a medical doctor specialised in palliative care	On call	On call	None	None	None
•	OOH mode of the medical doctor (face-to-face or remote)	None	Combination	None	None	None
•	OOH type of the medical doctor (advisory or direct care)	None	Combination	None	None	None
•	OOH nursing availability of a nurse specialised in palliative care	Through multidisciplinary outreach support team	Yes	Through multidisciplinary outreach support team	None	None
•	OOH mode of the nurse (face-to-face or remote)	None	Face-to-face	None	None	None
•	OOH type of the nurse (advisory or direct care)	None	Combination	None	None	None
•	Existence of a standardised evaluation of outcomes of activities and interventions	Compulsory	Compulsory	Compulsory	Compulsory	Compulsory
•	Existence of a standardised evaluation of experience of patients, relatives, and staff (including volunteers)	Compulsory	Compulsory	Compulsory	Compulsory	Compulsory
•	Service funded by	Federated entities	Federated entities	Federal	Federal	Federal

[1]Adapted from Firth et al. 2019 [2]Criteria added [3]It does not imply that euthanasia should be an admission criterion.
Legend: OOH – out-of-hours

Permanent staff

As presented in the Chapter 3, multidisciplinary teams are a key component of quality palliative care. In that sense, a minimum of different disciplines is to be expected in the services to be created. Professionals and volunteers need to be trained in palliative care to perform effectively but they also need to be able to work together. Across the different palliative care offer, there is a need for a permanent collaboration to support knowledge exchanges.

Table 48 – Permanent members of the staff specialised in palliative care per existing offer and per offer to be created

	Palliative care offer to be reinforced					Palliative care offer to be created				
	Outreach multidisciplinary support team	Day palliative care centres	PC referent in nursing homes	Hospital mobile palliative care teams	Specialised palliative care units (Sp4)	Palliative community house	Hospital at home	Day hospital	Transmural consultations	Palliative care house
Doctors	1	1	1	1	1	0	1	1	1	0
Nurses	1	1	1	1	1	0	1	1	1	1
Healthcare Assistants	0	0	0	0	1	0	0	0	0	0
Social Workers	0	0	0	0	1	0	0	1	1	0
Pharmacists	0	0	0	0	1	0	1	1	1	0
Physiotherapists	0	0	0	0	1	0	0	0	1	0
Occupational Therapists	0	0	0	0	0	0	0	0	1	0
Speech & Language Therapists	0	0	0	0	0	0	0	0	1	0
Dietitian	0	0	0	0	1	0	0	0	1	0
Psychiatrists	0	0	0	0	0	0	0	0	1	0
Psychologists	1	1	0	1	1	0	0	1	1	1
Spiritual Workers/Chaplains	0	0	0	0	1	0	0	1	1	1
Volunteers	1	1	0	0	1	1	0	1	1	1
Administration / coordinator	1	0	0	0	1	1	0	1	1	1
Reactivation staff	0	1	1	0	0	1	0	1	1	1
Total (n)	**5**	**5**	**3**	**3**	**11**	**3**	**3**	**9**	**14**	**6**

Legend: 1 indicates that the professional is present – 0 indicates that the professional is not present as permanent member of the staff

Possible interventions

Table 49 presents the interventions per type of palliative care service. For services to be created, the proposed interventions are based on the opportunities that represent these offers. It will however require an in-depth analysis of the scientific literature to ensure that these interventions can be performed in a safe way, in the respect of the quality standards. It will be also needed to develop standardised clinical guidelines for framing the delivery of the interventions and the related processes. As already mentioned, the “extraordinary treatments” based on the PICT-2 scale can serve as a basis for developing technical care for palliative care patients. An evidence-based consensus on the interventions is therefore needed, before establishing standardised care protocols for the operationalisation in practice. Moreover, for being able to deliver some of the interventions reported in both tables, professionals will need a specific training, with regular updates to ensure that the quality of care persists over time.

Table 49 – Interventions per type of palliative care offer to be reinforced or to be created

	Palliative care offer to be reinforced					Palliative care offer to be created				
	Outreach multidisciplinary support team	Day palliative care centres	PC referent in nursing homes	Hospital mobile palliative care teams	Specialised palliative care units (Sp4)	Palliative community house	Hospital at home	Day hospital	Transmural consultations	Palliative care house
Interventions										
Sitting service (staying with patients for planned periods of time)	1	1	0	1	1	1	1	1	0	1
Subcutaneous infusions by syringe driver	1	1	1	1	1	0	1	1	0	1
Blood tests	0	0	0	1	1	0	1	1	1	1
Ultrasounds	0	0	0	1	1	0	0	1	1	0
X-rays	0	0	0	1	1	0	0	1	1	0
Other medical imaging	0	0	0	1	1	0	0	1	1	0
Ascites drainage	0	0	0	1	1	0	1	1	0	1
Pain intervention procedures	1	0	1	1	1	0	1	1	0	1
Intravenous fluid infusions	0	0	0	1	1	0	1	1	0	0
Blood transfusions	0	0	0	1	1	0	1	1	0	0
Bisphosphonate infusions	0	0	0	1	1	0	1	1	0	0
Other blood product transfusions	0	0	0	1	1	0	1	1	0	0
Intravenous antibiotics	0	0	0	1	1	0	1	1	0	0
Total	**3**	**2**	**2**	**13**	**13**	**1**	**10**	**13**	**4**	**5**

List of interventions based on Firth et al. 2019.

Care objectives

Palliative care includes four distinct pillars of care: somatic, psychological, and emotional, social and spiritual. In that sense, one could expect that a minimum each offer has at least four care objectives, covering the four pillars. But, when looking more closely to the repartition of care objectives, not all existing services and services to be created are likely – on their own – to achieve the four pillars of palliative care. In that sense, it should

envisioned as a supporting point for combining the different palliative care offer.

We do acknowledge that providing palliative care via hospital at home appears to be limited in its care objectives as hospital at home focuses on the delivery of technical care in the home environment. It does not imply that the nurses performing technical care aiming at controlling symptoms do not contribute to emotional care or social care. Nevertheless, the main care objective of hospital at home is providing symptom control.

Table 50 – Overview of the care objectives per palliative care offer to be reinforced and to be created

	Palliative care offer to be reinforced					Palliative care offer to be created				
	Outreach multidisciplinary support team	Day palliative care centres	PC referent in nursing homes	Hospital mobile palliative care teams	Specialised palliative care units (Sp4)	Palliative community house	Hospital at home	Day hospital	Transmural consultations	Palliative care house
Symptom control	1	0	1	1	1	0	1	1	1	1
Family and carer support	1	1	1	1	1	1	0	1	1	1
Psychological care	1	1	0	1	1	0	0	1	1	1
Bereavement care	1	0	0	1	1	1	0	1	1	1
Care of the dying (last few days of life)	1	0	1	1	1	1	0	0	1	1
Respite care	0	1	1	0	1	1	0	1	0	1
Spiritual care	0	0	1	0	1	1	0	1	1	1
Rehabilitation	0	1	1	0	1	0	0	1	1	1
Social care	1	1	1	0	1	1	0	1	1	1
Total	**6**	**5**	**7**	**5**	**9**	**6**	**1**	**8**	**8**	**9**

9.9 Conclusion

Improving palliative care in Belgium requires **both the reinforcement of the existing offer and the creation of an additional offer**. The different propositions mentioned in this chapter need to be combined as together they are intended to meet the diversity of the preferences of the patients and particularly the preference for dying in a familiar environment. But it is also needed to integrate the preferences of those who wish to die in a medical environment. In that sense, palliative care offer should include a wide range of services and activities, as it is likely to better meet the preferences and needs of patients and their families. The “one size fits all” makes no sense as “having a good death” is complex, dynamic, and highly individual, stressing the need for a system which offers continuous holistic assessments in response to the changing needs of both the patient and their family.

It is necessary to ensure that the offer of palliative care should be **available, affordable, and reachable** for all patients and families in a **defined territorial zone**. This zone needs to make sense for the patients, the relatives and the professionals and be aligned with the ongoing discussions related to the territorialisation of health and integration of care. But, at the level of a zone, it may be not necessary to develop the same number of each form of palliative care offer as the preferences, the needs and the resources could vary. In that sense, it is important to have a clear view of the needs and resources per geographical zone and to bring the adequate response, based on the proposals above. This is why the **centralisation of the health data** appears as a key element for better meet the patient preferences and needs. From an organisational perspective, the different services proposed can be integrated at the same place and managed by a single organisation. But different organisations can also manage different services with respect to their relative expertise and experiences. Centralisation should not imply that patients remain in their hometown to benefit from palliative care as some could also prefer being cared in another place, closer to their family or friends.

To support the development of palliative care in Belgium, in the next steps, it will be needed:

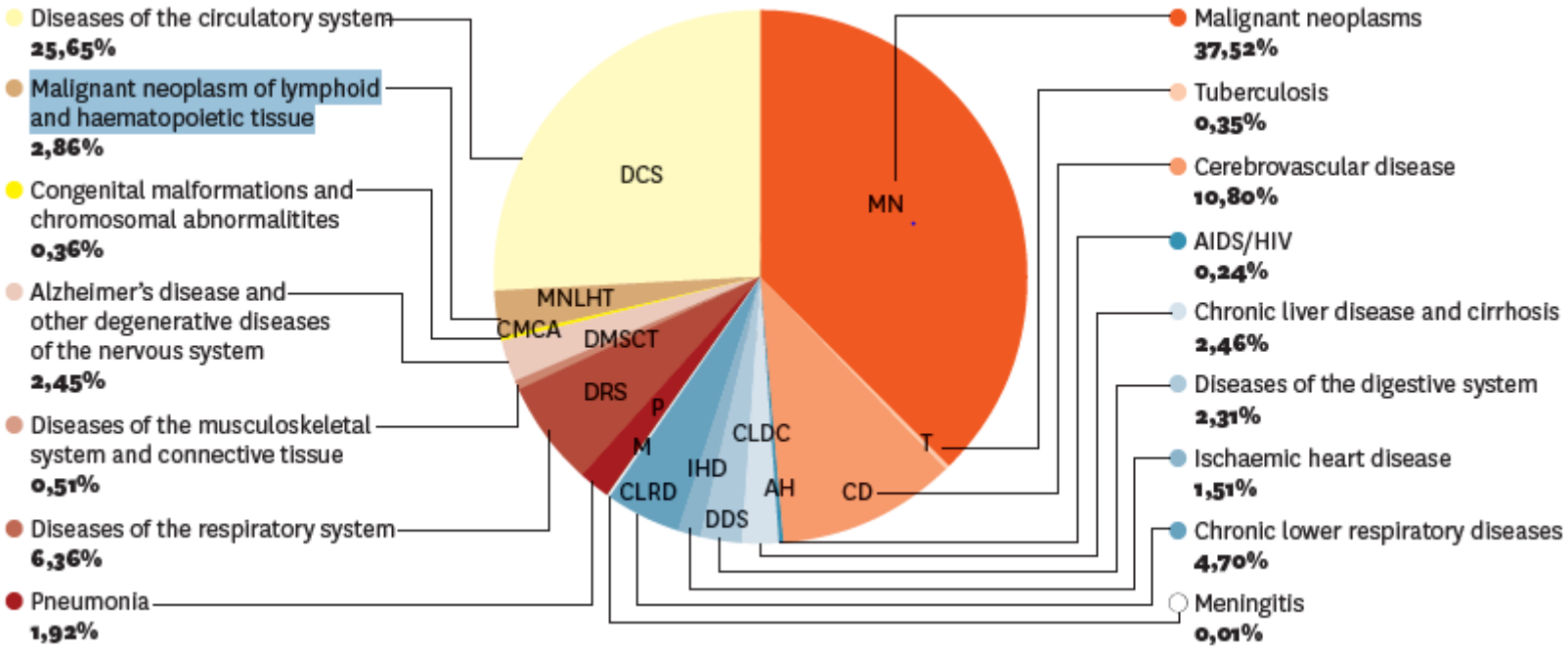
- To properly monitor the existing resources, including the documentation of the local variations in the offer. The criteria proposed by Firth et al. (2019)[192] could serve as a template to conduct such monitoring.
- To estimate per territorial zone the needs in palliative care services with attention to socioeconomic and ethnocultural factors;
- To monitor the costs of the existing initiatives similar to palliative community houses and to palliative care houses;
- To allocate a budget per territorial zone to support the reinforcement and the creation of the resources that are needed in palliative care to better meet the patient preferences.

This is why we would suggest a stepwise approach to improve the offer of palliative care in Belgium, starting on the patient level (identifying their preferences, needs and resources), and further climbing up towards the social level related to the informal caregivers (also identifying their preferences, needs and resources), the care level related to the healthcare professionals (with a view to the development and reinforcement of competences related to palliative care) ending in the macro level, that is the healthcare system. In the future development of an organisational palliative care model, the determinants on those different levels and their interactions need to be considered as it is necessary to develop a dynamic organisational model, continuously adapting the constantly changing needs on the different levels, and in particular to the rapidly changing needs of the palliative patients.

APPENDICES

APPENDIX 1. LIFE-THREATENING AND LIFE-LIMITING CONDITIONS

Appendix 1.1. Types and proportion of life-threatening and life-limiting conditions with serious health-related suffering in people who died in 2014 in Europe



Source: Retrieved from Arias-Casais et al. (2019), page 33 [5]

Appendix 1.2. Life-threatening and life-limiting conditions according to the PICT-1

- ☐ **1. Pathologie oncologique ou hématologique**
  - ☐ Déclin fonctionnel lié à l'évolution tumorale ou à une complication médicale ou chirurgicale
  - ☐ Refus ou contre indication à poursuivre un traitement oncologique, ou poursuite du traitement à visée purement symptomatique
  - ☐ Syndrome myélodysplasique à haut risque de transformation leucémique avec contre-indication à la greffe médullaire, ou syndrome myélodysplasique compliqué d'une neutropénie ou d'une thrombopénie sévère et persistante.
- ☐ **2. Pathologie cardiaque ou pathologie vasculaire périphérique**
  - ☐ Insuffisance cardiaque NYHA IV ou maladie des coronaires étendue et non traitable, accompagnée de symptômes présents au repos et aggravés au moindre effort
  - ☐ Maladie vasculaire périphérique sévère et inopérable
- ☐ **3. Pathologie respiratoire**
  - ☐ Maladie respiratoire chronique sévère et accompagnée d'une dyspnée au repos ou au moindre effort entre les périodes d'exacerbation
  - ☐ Besoin d'une oxygénothérapie au long cours, ou d'une ventilation (invasive ou non invasive), ou contre indication à ces traitements
- ☐ **4. Pathologie rénale**
  - ☐ Maladie rénale chronique de stade 4 ou 5 (ou FG < 30 ml/min), traitée ou non par dialyse et accompagnée d'une détérioration de l'état de santé
  - ☐ Contre-indication, arrêt ou refus de dialyse
  - ☐ Insuffisance rénale aigue compliquant une maladie incurable ou un traitement chez un malade dont le pronostic de vie est limité
- ☐ **5. Pathologie digestive ou hépatique**
  - ☐ Cirrhose grave ou décompensée avec échec du traitement médical et contre indication à la transplantation hépatique
  - ☐ Hémorragie, occlusion ou perforation du tube digestif d'origine non néoplasique avec échec ou contre-indication à un traitement médical et/ou chirurgical
- ☐ **6. Pathologie neurologique**
  - ☐ Altération irréversible et sévère des capacités fonctionnelles et/ou cognitives et/ou de l'état de conscience, malgré une thérapie optimale
  - ☐ Dysarthrie progressive rendant la parole difficile à comprendre, ou dysphagie irréversible et responsable de pneumonies d'aspiration récurrentes
- ☐ **7. Syndrome gériatrique**
  - ☐ Incapacité de se déplacer, de s'habiller, de se laver et de manger sans l'assistance d'un tiers, associé à ≥ 1 des 6 critères suivants :
  - ☐ Incontinence urinaire et fécale
  - ☐ Refus alimentaire et/ou refus de soins persistant
  - ☐ Perte définitive de l'appétit, ou perte de poids ≥ 10 % en 1 mois, ou indice de masse corporelle < 18, ou albuminémie < 30 gr/litre
  - ☐ Incapacité à parler, à communiquer et à reconnaitre ses proches
  - ☐ Antécédent de chutes répétées ou d'une chute compliquée
  - ☐ Dysphagie irréversible et pneumonies d'aspiration récidivantes
- ☐ **8. Pathologie infectieuse**
  - ☐ Infection ne répondant pas aux traitements
- ☐ **9. Autre pathologie incurable et évolutive sans possibilité de rétablissement ou de stabilisation**

Source: Retrieved from Desmedt (2015), page 64.[177]

Appendix 1.3. Overview of the proportion of serious health related suffering by life-threatening/life-limiting conditions

	ICD-10 codes used to identify number deaths	Multiplier (%)
Haemorrhagic fevers	A02, A05, A20–28, A31, A32, A38, A40–49, A65–70, A74–79, A80–81, A87–89, A92–99, B0–04, B06–15, B25–49, B58–60, B64, B66–72, B74·3–74·9, B75, B78, B80–89, B91–99 (except B94·1)	All 5%
Tuberculosis	A15–19	Drug-resistant tuberculosis 100%, other types 90%
HIV	B20–24	All 100%
Malignant neoplasms (except leukaemia)	C0–97 (except C91–95)	All 90%
Leukaemia	C91–95	All 90%
Dementia	F01–03, G30, G31	All 80%
Inflammatory CNS diseases	A33–35, A39, A50–53, A82, A83–86, B05, B56, B94·1, G0, G03, G04	Syphilis 70%, measles 50%, tetanus 100%, meningitis 30%, encephalitis 30%, trypanosomiasis 100%, rabies 90%
Degenerative CNS diseases	G06–12, G20–21, G23–25, G35–37, G40–41, G45–98 (except G72·1)	Parkinson's disease 65%, epilepsy 50%, multiple sclerosis 100%, other neurological conditions 65%
Cerebrovascular diseases	I60–69	All 65%
Non-ischaemic heart diseases	B57, I01–15, I30–33, I38, I40, I42	Rheumatic heart disease 65%; hypertensive heart disease 70%; cardiomyopathy, myocarditis, and endocarditis 40%; Chagas disease 30%
Chronic ischaemic heart diseases	I20–25	All 5%
Lung diseases	J30–98	COPD 80%, other respiratory diseases except asthma 50%
Liver diseases	B65, K20–K22, K28–K31, K38–K66, K70–92	Cirrhosis of the liver 95%, other digestive disease 30%, schistosomiasis 70%
Renal failure	N0–19	All 45%
Birth trauma, low birth weight, and prematurity	P03, P05, P07, P10–P15, P20–22, P24–29	Preterm birth complications 75%, birth asphyxia and birth trauma 40%
Congenital malformation	Q0–99	All 60%
Injury	V01–Y98	All 30%
Atherosclerosis	I0, I26–28, I34–37, I44–51, I70–99	All 35%
Musculoskeletal disorders	M0–99	All 70%
Malnutrition	E40–46	All 10%

International Classification of Diseases, tenth revision (ICD-10) code breakdown corresponds to the WHO's Global Health Estimates for 2016. COPD=chronic obstructive pulmonary disease.

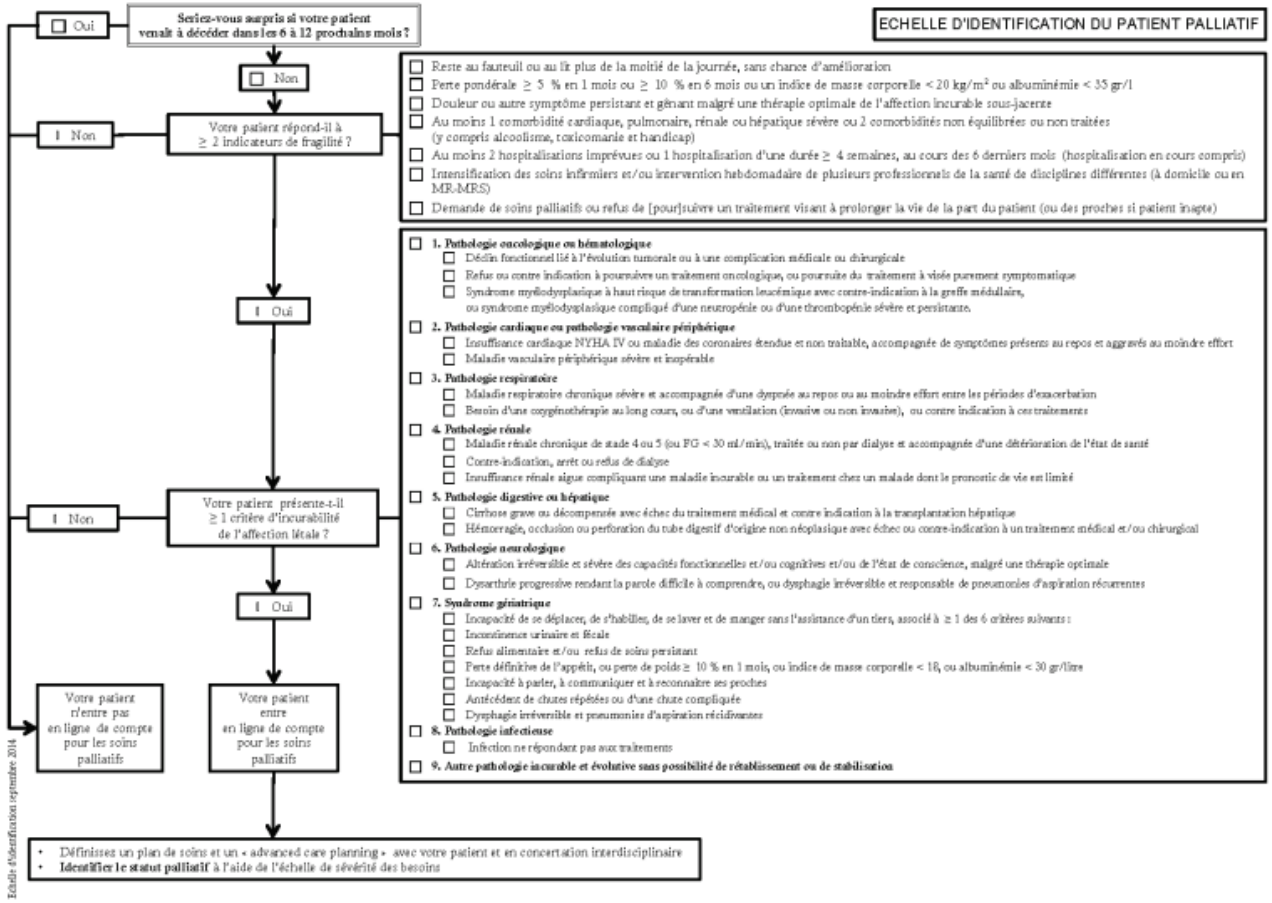
Table 1: Health conditions (according to the International Classification of Diseases, tenth revision) that most often generate a need for palliative care with associated multiplier, based on methods of the *Lancet* Commission on Palliative Care and Pain Relief

Legend: Multipliers estimate the proportion of people with each condition likely to experience serious health-related suffering. Multipliers were based on empirical evidence of the prevalence of 11 physical and 4 psychological symptoms frequently associated with the need for palliative care

Source: Table retrieved from Sleeman et al. (2019), page e885[4]

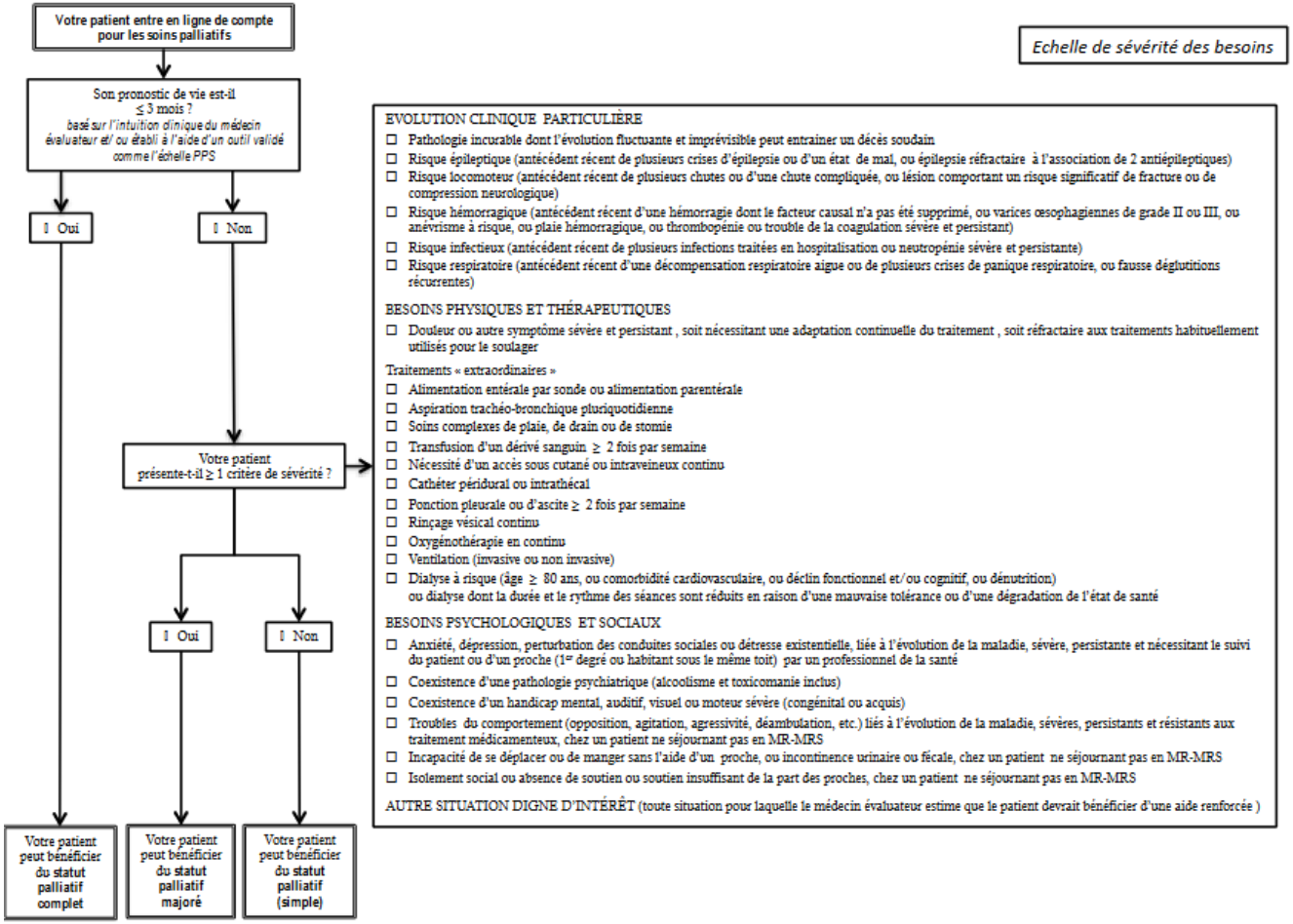
APPENDIX 2. CRITERIA FOR IDENTIFYING A PALLIATIVE PATIENT

Appendix 2.1. Criteria for identifying a palliative patient – PICT-1



Source: Retrieved from Desmedt, 2015, page 64[177]

Appendix 2.2. Severity scale based on the Palliative Care Indicators Tool-2 – PICT-2



Source: Retrieved from Desmedt, 2015, page 65[177]

APPENDIX 3. CHARACTERISTICS OF PARTICIPANTS OF THE FIRST STAKEHOLDER SURVEY

Table 51 – Level of activity (N=141)

Level	Frequency (%)*
Federal	**26/141 (18.4)**
Regional	**57/141 (40.4)**
• Brussels	18/57 (31.6)
• Flanders	30/57 (52.6)
• Wallonia	22/57 (38.6)
Provincial	**48/141 (34.0)**
• Antwerp	8/48 (16.7)
• Flemish Brabant	6/48 (12.5)
• Walloon Brabant	8/48 (16.7)
• Western Flanders	4/48 (8.3)
• Eastern Flanders	9/48 (18.8)
• Hainaut	11/48 (22.9)
• Liège	8/48 (16.7)
• Limburg	6/48 (12.5)

Level	Frequency (%)*
• Luxemburg	6/48 (12.5)
• Namur	9/48 (18.8)
Municipal	**38/141 (27.0)**
Not applicable	**26/141 (18.4)**

** Proportions do not add up to 100% because multiple choice was allowed.*

Table 52 – Perceived expertise of participating organisations (N=141)

	Absolutely expert	Very expert	Expert	Poorly expert	Not at all expert	Not applicable
Ethical and deontological aspects	31 (22.0%)	47 (33.3%)	48 (34.0%)	11 (7.8%)	3 (2.1%)	1 (0.7%)
Financial and budgetary aspects	13 (9.2%)	32 (22.7%)	49 (34.8%)	32 (22.7%)	6 (4.3%)	9 (6.4%)
Legal and normative aspects	23 (16.3%)	48 (34.0%)	47 (33.3%)	15 (10.6%)	3 (2.1%)	5 (3.5%)
Political and strategical aspects	6 (4.3%)	23 (16.3%)	36 (25.5%)	40 (28.4%)	14 (9.9%)	22 (15.6%)
Psychological care	38 (27.0%)	42 (29.8%)	39 (27.7%)	17 (12.1%)	2 (1.4%)	3 (2.1%)
Social care	28 (19.9%)	49 (34.8%)	47 (33.3%)	11 (7.8%)	2 (1.4%)	4 (2.8%)
Somatic care	50 (35.5%)	40 (28.4%)	33 (23.4%)	11 (7.8%)	3 (2.1%)	4 (2.8%)
Spiritual care	22 (15.6%)	37 (26.2%)	40 (28.4%)	34 (24.1%)	4 (2.8%)	4 (2.8%)

Table 53 – Perceived influence of participating organisations (N=141)

	Absolutely influent	Very influent	Influent	Poorly influent	Not at all influent	Not applicable
Ethical and deontological aspects	7 (5.0%)	14 (9.9%)	47 (33.3%)	50 (35.5%)	16 (11.3%)	7 (5.0%)
Financial and budgetary aspects	4 (2.8%)	9 (6.4%)	29 (20.6%)	66 (46.8%)	26 (18.4%)	7 (5.0%)
Legal and normative aspects	3 (2.1%)	11 (7.8%)	31 (22.0%)	70 (49.6%)	18 (12.8%)	8 (5.7%)
Political and strategical aspects	2 (1.4%)	9 (6.4%)	34 (24.1%)	60 (42.6%)	25 (17.7%)	11 (7.8%)
Recommendations and guidelines for psychological care	5 (3.5%)	15 (10.6%)	52 (36.9%)	51 (36.2%)	12 (8.5%)	6 (4.3%)
Recommendations and guidelines for social care	1 (0.7%)	26 (18.4%)	46 (32.6%)	51 (36.2%)	13 (9.2%)	4 (2.8%)
Recommendations and guidelines for somatic care	6 (4.3%)	27 (19.1%)	49 (34.8%)	40 (28.4%)	12 (8.5%)	7 (5.0%)
Recommendations and guidelines for spiritual care	3 (2.1%)	15 (10.6%)	41 (29.1%)	57 (40.4%)	18 (12.8%)	7 (5.0%)

APPENDIX 4. WHO BENEFIT FROM PALLIATIVE CARE IN BELGIUM?

Table 54 – Profile of patients perceived as benefiting from palliative care in Belgium according to organisations

	Always	Often	Sometimes	Poorly	Never	Missing*
Adults (65 years old and more)	6 (4.8)	82 (66.1)	32 (25.8)	2 (1.6)	2 (1.6)	17 (12.1)
Adults (less than 65 years old)	5 (4.0)	47 (37.9)	66 (53.2)	4 (3.2)	2 (1.6)	17 (12.1)
Children and youths under 18 years	6 (4.8)	12 (9.7)	42 (33.9)	58 (46.8)	6 (4.8)	17 (12.1)
Patients whose life expectancy is estimated of less than 3 months	11 (8.8)	91 (72.8)	22 (17.6)	1 (0.8)	0 (0.0)	16 (11.3)
Patients with an estimated life expectancy of 3 months	6 (4.8)	72 (57.6)	42 (33.6)	5 (4.0)	0 (0.0)	16 (11.3)
Patients with an estimated life expectancy of 6 months	4 (3.2)	22 (17.6)	60 (48.0)	35 (28.0)	4 (3.2)	16 (11.3)
Patients whose life expectancy is estimated of more than 6 months	3 (2.4)	8 (6.4)	52 (41.6)	50 (40.0)	12 (9.6)	16 (11.3)
Patients whose clinical status is unstable	2 (1.6)	40 (32.0)	62 (49.6)	21 (16.8)	0 (0.0)	16 (11.3)
Patients whose clinical status is stable	2 (1.6)	7 (5.6)	43 (34.4)	66 (52.8)	7 (5.6)	16 (11.3)
Patients needing complex care / acts	1 (0.8)	34 (27.2)	55 (44.0)	34 (27.2)	1 (0.8)	16 (11.3)
Patients with complex needs	2 (1.6)	35 (28.0)	55 (44.0)	2 (1.6)	2 (1.6)	16 (11.3)
Persons with mental health problems, intellectual disability or dementia	1 (0.8)	14 (11.2)	43 (34.4)	65 (52.0)	3 (2.4)	16 (11.3)
Persons whose social network is absent / unable to participate to	2 (1.6)	25 (20.0)	42 (33.6)	48 (38.4)	8 (6.4)	16 (11.3)
Persons whose home is not adapted	4 (3.2)	23 (18.5)	46 (37.1)	44 (35.5)	7 (5.6)	17 (12.1)
Homeless persons	5 (4.0)	6 (4.8)	14 (11.3)	56 (45.2)	43 (34.7)	17 (12.1)
Persons with limited financial resources	5 (4.0)	17 (13.7)	67 (54.0)	30 (24.2)	5 (4.0)	17 (12.1)
Hospitalised patients outside palliative care units	1 (0.8)	30 (24.2)	62 (50.0)	29 (23.4)	2 (1.6)	17 (12.1)
Hospitalised patients in palliative care units	83 (66.9)	31 (25.0)	5 (4.0)	3 (2.4)	2 (1.6)	17 (12.1)

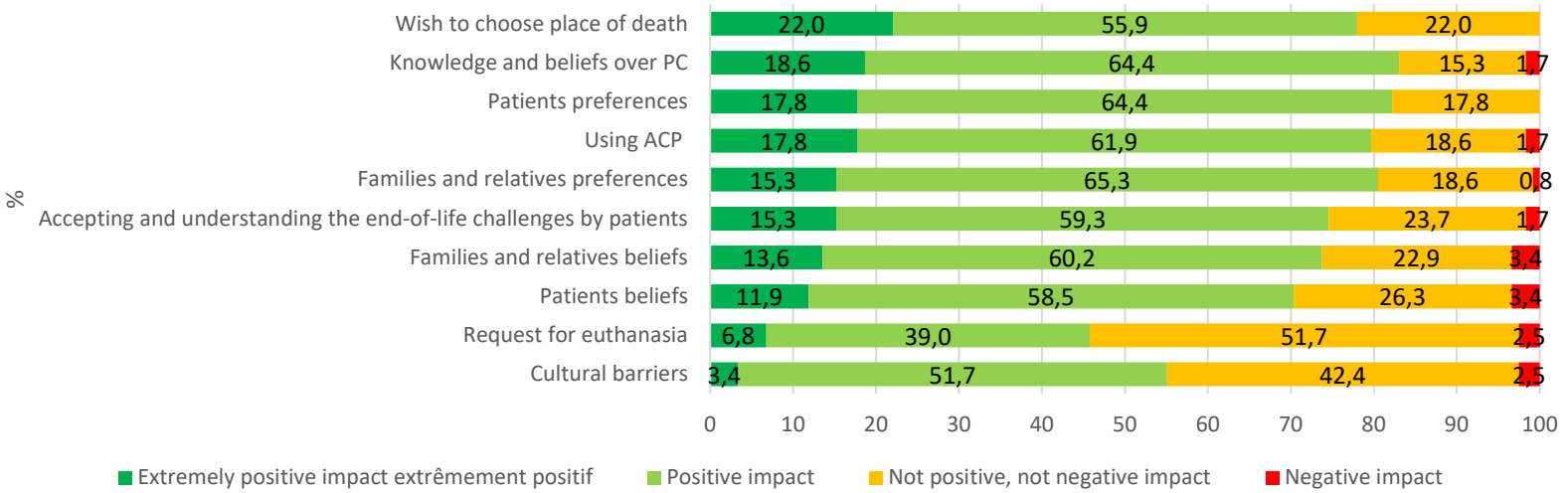
	Always	Often	Sometimes	Poorly	Never	Missing*
Persons staying at home	4 (3.2)	53 (42.7)	56 (45.2)	11 (8.9)	0 (0.0)	17 (12.1)
Residents in institutions (but not elderly homes / nursing homes)	5 (4.0)	18 (14.5)	51 (41.1)	47 (37.9)	3 (2.4)	17 (12.1)
Residents in elderly homes	7 (5.6)	23 (18.5)	58 (46.8)	33 (26.6)	3 (2.4)	17 (12.1)
Patients in nursing homes	9 (7.3)	35 (28.2)	63 (50.8)	15 (12.1)	2 (1.6)	17 (12.1)

**not included in the % calculation of the other columns.*

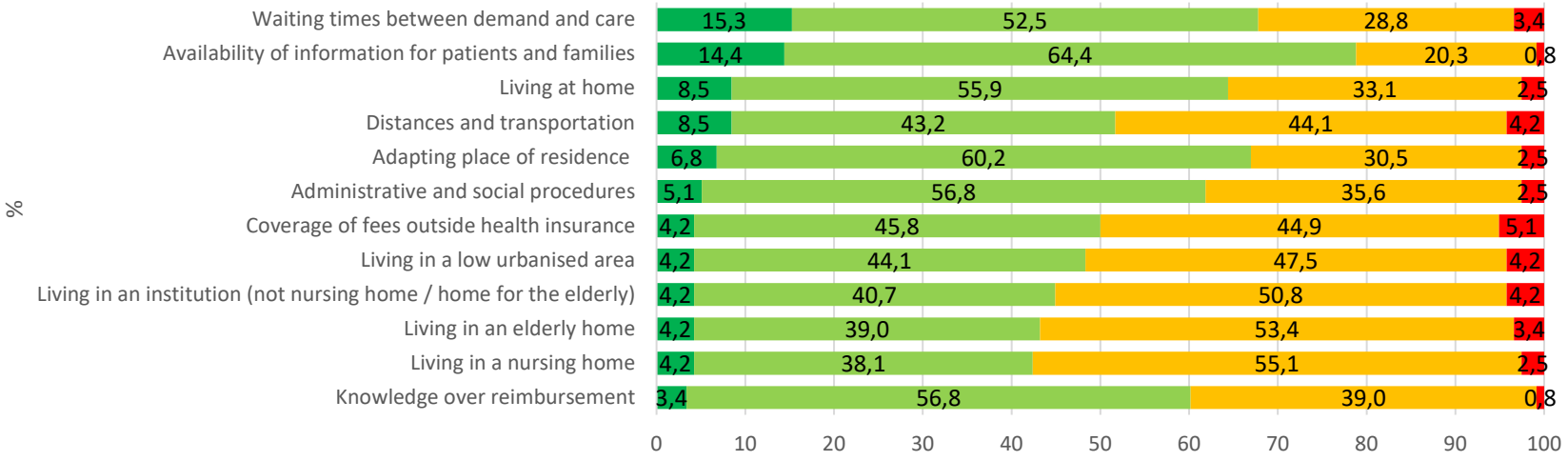
APPENDIX 5. WHICH BARRIERS CAN BE SOLVED?

Figure 37 – Perceived impact of a palliative middle care service on barriers experienced by patients and relatives according to organisations (N=118)

a) Personal barriers to palliative care



b) Social and financial barriers to palliative care



c) Professional barriers to palliative care

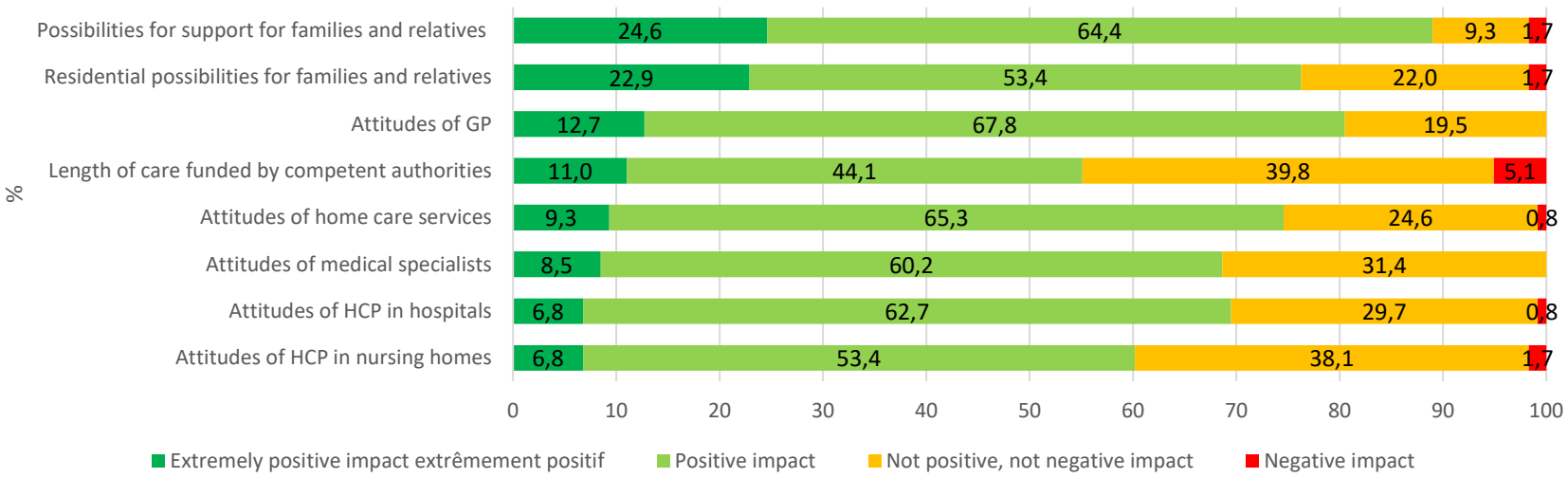
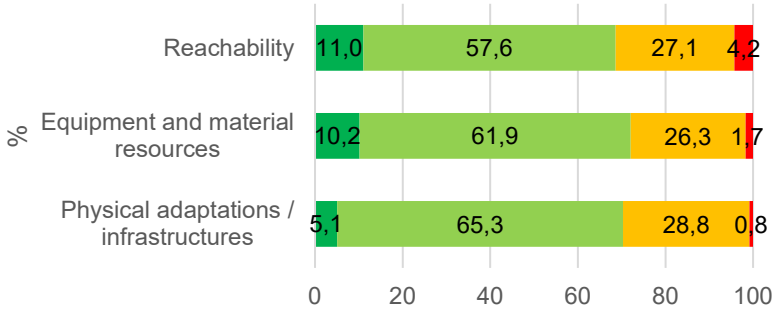
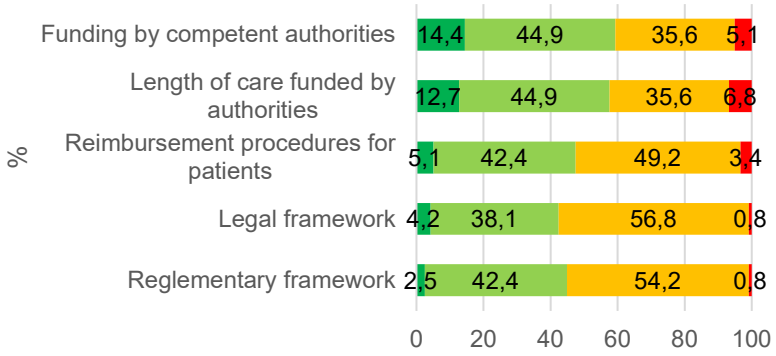


Figure 38 – Perceived impact of palliative middle care services on barriers experienced by professionals according to organisations (N=118)

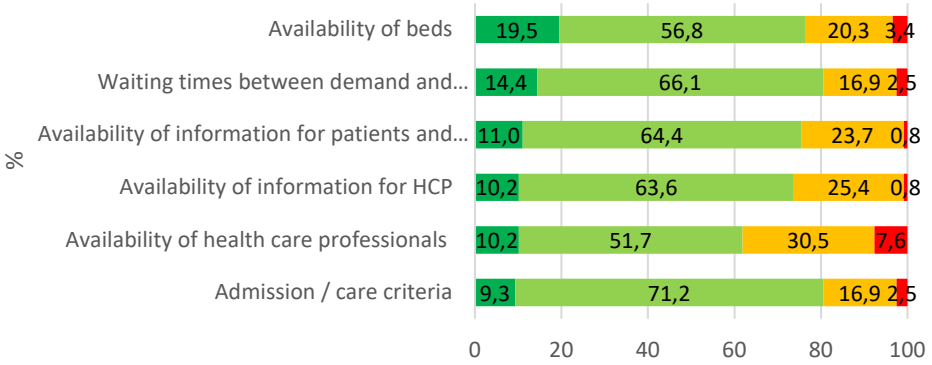
a) Barriers related to reachability



b) Barriers related to affordability and legal framework



c) Barriers related to availability



d) Barriers related to information and training

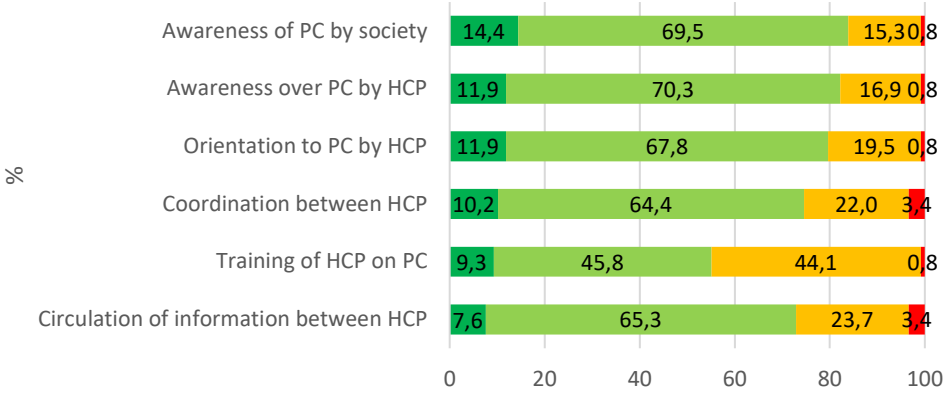




Table 55 – Priority groups of patients for the development of palliative middle care services according to organisations (N=119)

	Yes	No
No priority group need to be defined	**50 (42.0)**	**69 (58.0)**
Adults (65 years old and more)	6 (5.0)	113 (95.0)
Adults (less than 65 years old)	14 (11.8)	105 (88.2)
Children and youths under 18 years	2 (1.7)	117 (98.3)
Patients whose life expectancy is estimated of less than 3 months	8 (6.7)	111 (93.3)
Patients with an estimated life expectancy of 3 months	2 (1.7)	117 (98.3)
Patients with an estimated life expectancy of 6 months	20 (16.8)	99 (83.2)
Patients whose life expectancy is estimated of more than 6 months	23 (19.3)	96 (80.7)
Patients whose clinical status is unstable	11 (9.2)	108 (90.8)
Patients whose clinical status is stable	11 (9.2)	108 (90.8)
Patients needing complex care / acts	15 (12.6)	104 (87.4)
Patients with complex needs	30 (25.2)	89 (74.8)
Persons with mental health problems, intellectual disability or dementia	4 (3.4)	115 (96.6)
Persons whose social network is absent / unable to participate to	37 (31.1)	82 (68.9)
Persons whose home is not adapted	12 (10.1)	107 (89.9)
Homeless persons	5 (4.2)	114 (95.8)
Persons with limited financial resources	4 (3.4)	115 (96.6)
Hospitalised patients outside palliative care units	4 (3.4)	115 (96.6)
Hospitalised patients in palliative care units	1 (0.8)	117 (98.3)
Persons staying at home	9 (7.6)	110 (92.4)
Residents in institutions (but not elderly homes / nursing homes)	(0.0)	119 (100.0)
Residents in elderly homes	(0.0)	119 (100.0)
Patients in nursing homes	1 (0.8)	118 (99.2)

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