KCE REPORT 430

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HOW TO IMPROVE THE ACCESS TO PAEDIATRIC PALLIATIVE CARE IN BELGIUM?



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COLOPHON

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ACCAPED	Assessment of Complex Clinical Assistance needs in PEDiatrics
ACP	Advance Care Planning
ACT-RCPCH	Association for Children's Palliative Care/Royal College of paediatrics and Child Health
ADL	Activities of the Daily Living
ASD	Aide et Soins à Domicile
AVIQ	Agence pour une Vie de Qualité (Walloon regional agency for health)
AYA	Adolescent and Young Adult
BFM	Budget of Financial Means
BFPZ-FBSP	Brusselse federatie voor palliative en continue zorgen - Fédération bruxelloise de soins palliatifs et continus (Brussels federation of palliative care)
BIHR	Belgian Integrated Health Record
BPPC	Belgian Paediatric Palliative Care
CAPC	Center for Advancement of Palliative Care
CCC	Complex Chronic Conditions
CHC	Groupe santé CHC (previously Centre Hospitalier Chrétien)
CHR	Centre Hospitalier Régional (Regional hospital)
CHU	Centre Hospitalier Universitaire (University hospital)
CM/MC	Christelijke Mutualiteit - Mutualité Chrétienne
COCOF	French community Commission
EAPC	European Association of Palliative Care
EHD	Ecole Hôpital et Domicile
EOL	End-of-Life
EPR	Electronic Patient Record
FPS	Federal Public Service - Federale Overheidsdienst (FOD) - Service Public Fédéral (SPF)
FTE	Full Time Equivalent
FWSP	Fédération wallonne des soins palliatifs (Walloon federation of palliative care)
GO-PPaCS	Global Overview- Pediatric Palliative Care Standards
GP	General Practitioner
HAD	Hospital at home - Thuishospitalisatie (TH) - Hospitalisation à domicile (HAD)
HCP	Health Care Professionals
HSR	Health Service Research

HUDERF	Hôpital Universitaire des Enfants Rein Fabiola
ICD-10	International Classification of Disease - 10
ICPCN	International Children's Palliative Care Network
ID	Intellectual Disability
IFIC	Instituut voor Functieclassificatie - Institut de Classification de Fonctions
IZP	Individueel ZorgPlan
KBS-FRB	Koning Boudewijn Stichting - Foundation Roi Baudouin
KCE	Belgian Health Care Knowledge Centre
KITES	Kinderen In Thuis en Supportieve zorg
KOESTER	Kinder Oncologische Eenheid voor Specifieke Thuiszorg en Rehabilitatie
KOTK	Kom Op Tegen Kanker (Flemish Fundation Against Cancer)
LLC/LTC	Life-limiting Condition/Life-Threatening Condition
MAF - MàF	Maximum Factuur (MAF)- Maximum à Facturer (MàF) (Maximum bill)
MD	Medical Doctor
MOC	Multidisciplinary Oncological Consultation
MZG-RHM	Minimal Hospital Data
NIHDI	National Institute for Health and Disability Insurance (RIZIV-INAMI)
OCMW-CPAS	Openbaar Centrum voor Maatschappelijk Welzijn - Centre Public d'Action Sociale (Public welfare centre)
OPZ	Openbaar Psychiatrische Zorg (Public mental healthcare)
PaPaS	PAediatric PAlliative Screening
PaPCANZ	Paediatric Palliative Care Australia and New Zealand
PC	Palliative Care
PCA	Patient Controlled Analgesia
PLT	Paediatric Liaison Team
PPC	Paediatric Palliative Care
PPCN	Paediatric Palliative Care Network
PZV	Palliatieve Zorg Vlaanderen (Flemish federation of palliative care)
QuoCCA	Quality of Care Collaborative Australia
RD	Royal Decree
RQ	Research Question
RVA-ONEM	Rijksdienst Voor Arbeidsvoorziening - Office National de 'Emploi
SC	Supportive Care
SHS	Severe Health-related Suffering
SIO	Synchroon Internet Onderwijs (synchronous online education)

START	Screening Triage Assessment and Re-evaluation tool
TCT	Technical Cell - cellule Technique
TOAH	Tijdelijk Onderwijs Aan Huis (Temporary education at home)
UK	United Kingdom
USA	United States of America
UZ	Universitair Ziekenhuis (University hospital)
UZA	Universitair Ziekenhuis Antwerpen (Antwerp University Hospital)
VAPH	Vlaams Agentschap voor Personen met een Handicap (Flemish agency for persons with a disability)
vzw-asbl	vereniging zonder winstoogmerk - association sans but lucratif (non-profit organisation)
WHO	World Health Organisation
YA	Young Adult

SCIENTIFIC REPORT

1 INTRODUCTION

1.1 What is paediatric palliative care?

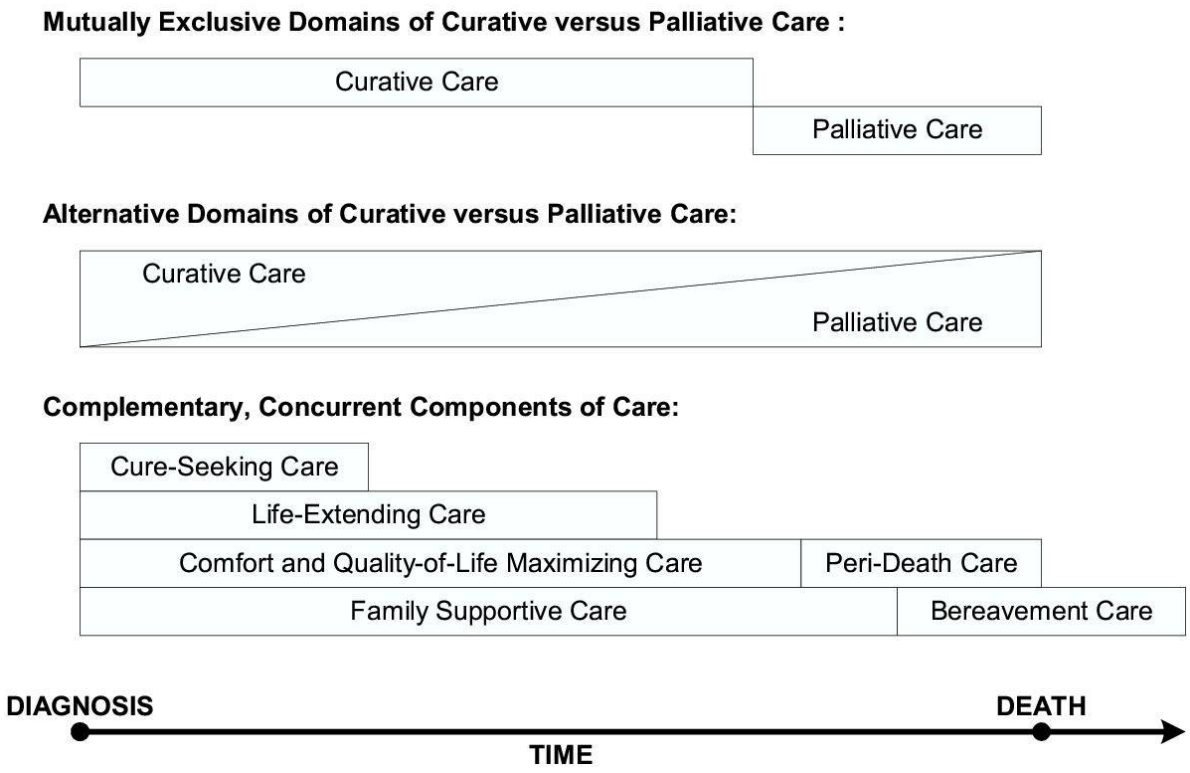
In 2022, the GO-PPaCS project (Global Overview – Paediatric Palliative Care Standards) led by an international group of experts in paediatric palliative care (PPC) has considered two definitions of the World Health Organization (WHO) as valid to define paediatric palliative care[1]:

- Palliative care as *'an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. This requires 'a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited'.*[2]
- Palliative care for children as '*the active total care of child's body, mind, and spirit, and also involves giving support to the family.*'[3,4]

Paediatric palliative care is very specialised and very complex. PPC begins when an illness is diagnosed and continues regardless of whether or not a child receives treatment aimed at treating the disease. PPC is not restricted to the end-of-life period.[1] So, PPC extends well beyond terminal care, serving as a complement of curative care while also including respite care and bereavement care.[5,6] It can be provided in tertiary care facilities, in community health centres, and even in children's homes.[3,4]

As illustrated in Figure 1, PPC is a part of integrated care and complete curative care.[7]

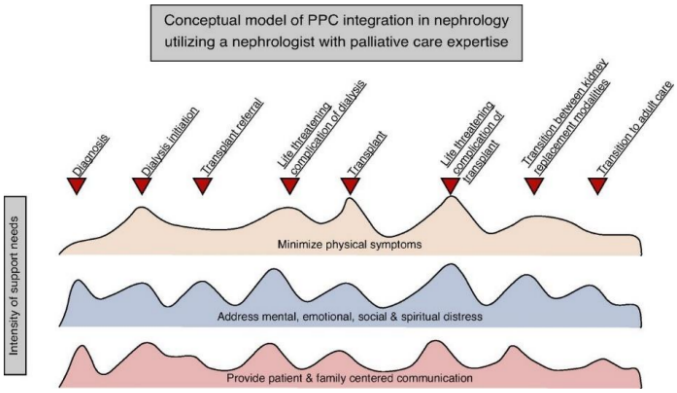
Figure 1 – Complementary and concurrent components of care



Source: Feudtner et al., 2003[7]

An unexpected example of a condition which may require PPC is chronic kidney disease.[10] This example allows to illustrate the gap between the theoretical definition of PPC and the perception of PPC by the public and the HCPs (see Figure 2). Indeed, there is often a misunderstanding between palliative care and terminal care.

Figure 2 – Conceptual model of PPC integration in paediatric nephrology



Adding Life to Their Years: The Current State of Pediatric Palliative Care in CKD. T.R. House and A. Wightman. Kidney360 June 2021, 2(6) 1063-1071.

Source: T.R. House and A. Wightman. Kidney360, June 2021, 2(6) 1063-1071.[10]

As explained by experts in PPC, "*Paediatric palliative care begins when illness is diagnosed and continues regardless is treated for the disease or not. This means that young patients and their families may require care and support for a prolonged period, sometimes more than 20 years.*"[8,9] In contrast, the Belgian law states that *"Every patient is entitled to palliative care when they are at an advanced or terminal stage of a serious, progressive and life-threatening illness, regardless of their life expectancy*". There is therefore a misalignment between the Belgian law and this aspect of PPC.[11]

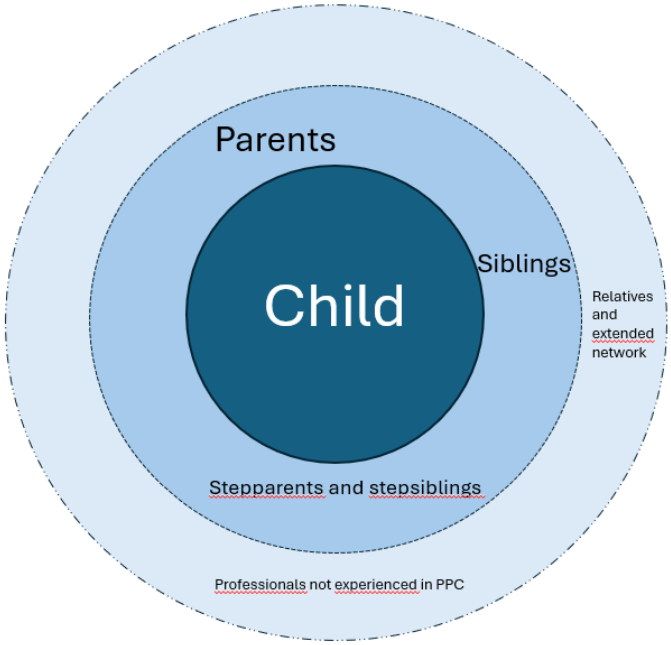
1.2 Scope of the research

1.2.1 Which population was studied?

Children and adolescents are the main target population of the study. The term 'children' includes neonates (0-28 days), babies (1-24 months), toddlers (2-5 years), children (6-14 years) and adolescents (15-18 years). In this study, the question was raised to extend the target population to young adults lacking financial and decisional autonomy (18-24 years), as well as adults aged 25 years and older who have been in a palliative situation since childhood and lack decisional capacities (i.e., psychiatric or intellectual disabilities).[12] In this report, the term 'young patient' will be used to include all age ranges of patients.

As the quality of life of young patients is highly dependent on the well-being of their family (parents and siblings) but also of relatives and close caregivers, the question was also raised to extend the target population of the study to relatives and close caregivers, as suggested in the recent report of the King Baudouin Foundation.[13] In the current practice in Belgium, HCPs without or with limited experience in PPC already benefit from the support of professionals with experience in PPC. Figure 3 gives an overview of the likely target population of the study. Additional information on the target population is available in Chapter 3.

Figure 3 – Schematic overview of the target population



Not all young patients are included in the scope of this study. Only those suffering from serious health conditions such as life-threatening conditions, life-limiting conditions and complex chronic conditions are in-scope. Serious health conditions that may threaten or shorten young patients' lives represent many different types of conditions, often rare and always complex.[5,6]

As the target population of this study may include relatives and carers of the young patient, e.g., pregnant women whose foetus presents a serious health condition, the authors have decided to use the wording "paediatric palliative situation" instead of the expression "children with PPC needs" or "children requiring PPC". Within the context of paediatric care, it would have been against principles of PPC and family-centred care to only focus on the needs of the child. The reader will find more information on the family-centred approach in Chapter 5.

Additional insights, based on a primary data collection, on the identification of a paediatric palliative situation are given in Chapter 3 because definitions and perceptions of such situation vary a lot in the literature and the practice.[15]

1.2.2 Which public health problem was studied?

This study has focused on the under-use of PPC in case of paediatric palliative situations.

This issue about PPC access was raised by the Belgian compulsory insurance institution (RIZIV-INAMI) and also by other stakeholders such as the federal public service health, food chain safety and environment (FOD *volksgezondheid, veiligheid van de voedselketel en leefmilieu* - SPF *santé publique, sécurité de la chaine alimentaire et environnement*), and the King Baudouin Foundation (Koning Boudewijnstichting - Fondation Roi Baudouin).

In 2019, Friedel et al. (2019) reported that only 384 (1.7%) of the 22 533 young patients up to 19 years of age eligible for PPC had been, in fact, referred to specialised PPC teams in the Brussels capital region, between 2010 and 2014.[16]

1.3 Research objectives and questions

1.3.1 Research objective

This study aims to propose organisational solutions to improve referral and access to PPC for young patients and their families in a paediatric palliative situation.

1.3.2 Research questions (RQ)

RQ1: How to identify a paediatric palliative situation?

RQ2: What are the categories of PPC needs and how do they differ from those in adults?

RQ3: How can the needs of close relatives, informal caregivers and professionals not experienced in PPC influence the access to PPC of children in palliative situations?

RQ4: What is the current offer of PPC in Belgium and what are the gaps?

RQ5: Which good practices in other countries can inform access improvements to PPC in Belgium?

RQ6: What are the perceived barriers reported by professionals to access PPC in Belgium?

RQ7: Which solutions could reduce the unmet PPC needs and improve access to PPC? How far are those solutions acceptable and feasible according to Belgian stakeholders?

1.4 Lexicon

In this report working definitions are used. Table 1 presents those definitions.

Table 1 – Working definitions of terms frequently used across the report

Terms	Working definition
Advance care planning (adapted from Rietjens et al., 2017.[17])	A decisional process enabling individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate.
Care pathway (adapted from Gartner et al., 2022[18])	An integrative framework for organising and coordinating clinical, administrative and organisational practices around the needs of a well-defined group of patients and their carers during a well-defined period. A care pathway considers healthcare professionals, the healthcare system, coordination mechanisms and information systems.
Care plan	A personalised and regularly updated document developed collaboratively with the patient, family, and multidisciplinary team, which identifies the needs, establishes goals of care, specifies planned interventions, and coordinates care across healthcare, social, community, and other relevant settings.
Complex chronic condition (CCC)	Any medical condition expected to last at least 12 months (unless death intervenes) and involving either multiple organ systems or a single organ system to a severity that requires specialty paediatric care and likely hospitalisations in a tertiary care setting.
Family	The nuclear family unit, composed of the parent(s), the siblings, and if applicable also the stepmother, stepfather, and stepsiblings living with the young patient.
Life-limiting conditions (LLC)	Conditions for which there is no reasonable hope of a cure, and the young patient will die from this condition.
Life-threatening conditions (LTC)	Conditions for which curative treatment may be feasible but may fail.
Paediatric palliative situation	A care situation in which a young patient or any person caring for him/her presents PPC needs.

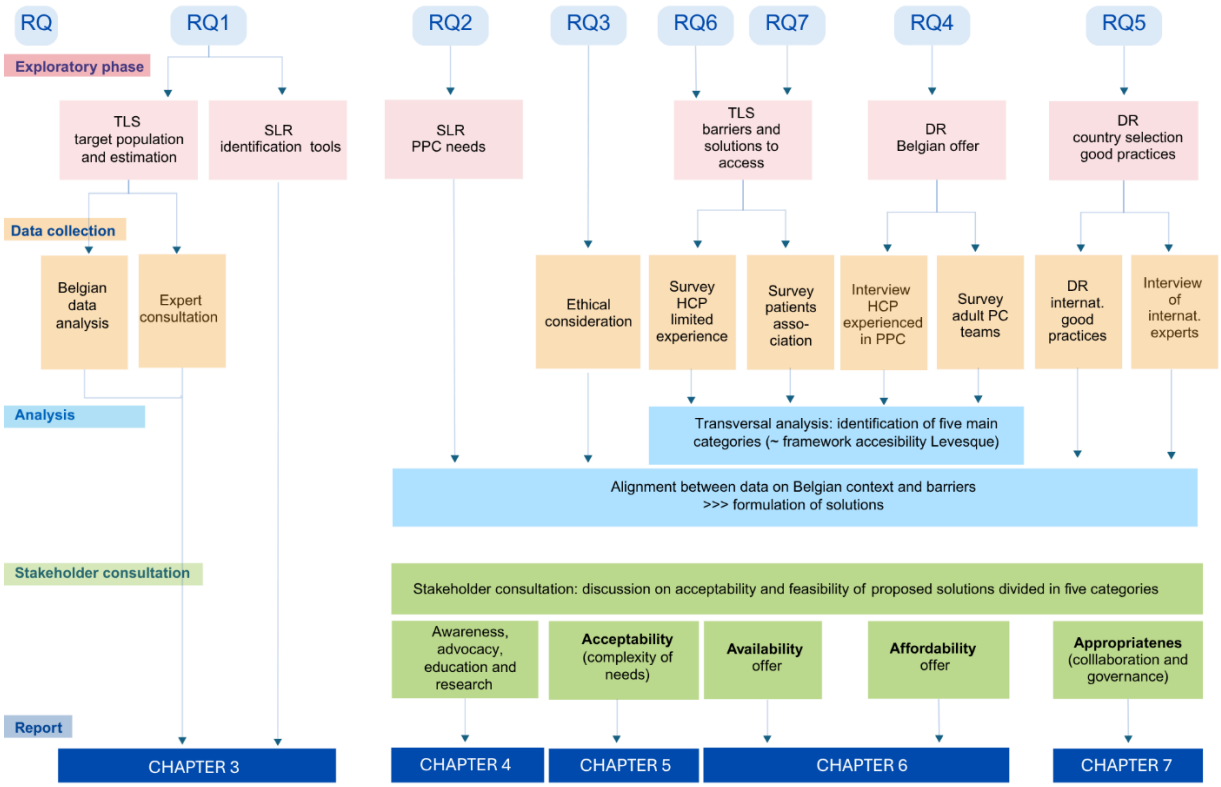
Parent(s)	One or both parents or legal guardians directly involved in decisions and daily care of a child.
Patient journey (adapted from Bulto et al., 2024[19])	Barriers, facilitators, experiences, interactions with services and/or outcomes for individuals and/or their carers and family members as they enter, navigate, experience and exit one or more services in a health system.
PPC needs	Any basic conditions required to ensure the physical, psychological, social and spiritual well-being of someone that can be met through the provision of PPC by a professional.
Professional experienced in PPC	Professional with explicit PPC training and role.
Professional not experienced in PPC	Professional without specific PPC expertise (e.g., general paediatrics, oncologist, home care nurses) and no prior involvement in a paediatric palliative situation.
Professional with limited experience in PPC	Professional who has been involved at least once in his/her practice in a paediatric palliative situation.
Relatives and extended network	Other family members compared to those mentioned under 'Family' or significant others (friends, community figures) caring for the young patient.
Serious health condition	A condition associated with a high burden of illness, significant impairment of health or functioning, and an increased risk of adverse outcomes, including premature death.
Treating physician	The physician, general practitioner or specialist, who has the most in contact with the patient and knows him/her and his/her main condition the best.
Young patient	A foetus (pregnant woman), a child, an adolescent or a young adult

2 METHODOLOGY

Health services research requires combining data from a range of investigative strategies. Generally, it includes reviews of literature, analysis of health care utilisation databases, analysis of policy and legal documents, comparison between countries and qualitative methods to identify facilitators and/or barriers.

Our research strategy followed a sequential plan. First, exploratory searches were conducted to inform a second step aimed at collecting primary data and evidence on key topics. The third step included combining primary data about barriers, categorising those barriers using an accepted framework on care access, identifying similarities between barriers categories, and identifying possible solutions suitable to the Belgian context, supplemented by data on specific needs, ethical issues, and international examples. In the final phase a panel of Belgian stakeholders was involved to comment on the acceptability and feasibility of the proposed solutions. Figure 4 shows the sequential methodological steps followed by the authors.

Figure 4 – Sequential methodological steps followed by the authors



RQ=Research question; TLS=Targeted literature search; SLR=Scoping literature review; DR=Desk research; PC= Palliative care; PPC=Paediatric palliative care; HCP=Health care professional

2.1 First step – literature reviews

2.1.1 Targeted search on population estimations and target population (RQ1)

The objective was to identify the usual age range of the target population and to explore which population-identification tool(s) are being used to estimate the number of paediatric palliative situation in the peer-reviewed literature. This information was used to inform a data analysis conducted in a second step (see 2.2.1). The exploratory search has followed a snowballing process of peer-reviewed

literature, starting with hand-searching the reference lists of the Belgian reference manual for PPC, looking for studies that estimated the number and age of young patients in a palliative care situation.[20,21] The search was performed in October 2024. An update was done in June 2026 to check if new studies were published since the first search.

2.1.2 Scoping literature review on identification tools (RQ1)

An identification tool can be defined as a standardised instrument, checklist, questionnaire, or algorithm designed to support the early recognition of individuals who may have specific healthcare needs, conditions, or risks requiring further assessment or intervention.

First, an exploratory search of the literature was conducted to map the usual key words and the tools usually used to identify paediatric palliative situations. This exploratory step was necessary to build the search strategy of the next step, a scoping literature review on identification tools.

For the scoping literature review, a search was carried out in MEDLINE (OVID) for peer-reviewed publications using a combination of keywords focusing on publications in English over the past 15 years (2010-2025) (latest update on 26th of March 2026) (see the search strategy in Appendix 1 of the Supplement). We searched for good quality systematic reviews first, which were subsequently updated with more recent primary studies.

Grey literature (reports and policy documents) were analysed on the websites of key international organisations involved in PPC (i.e., International Children's Palliative Care Network (ICPCN), Together for Short Lives, European Association of Palliative Care (EAPC), WHO) as well as the websites of the national PPC organisations and key providers in the countries that were reviewed to answer RQ5 on PPC initiatives abroad (see section 7 of the supplementary data for more information). Additionally, national experts that were interviewed for the PPC initiatives were also asked specifically for PPC identification/referral tools used in their country (see also section 7 of the supplementary data for more information).

2.1.3 Scoping literature search on PPC needs (RQ2)

A preliminary search was conducted in MEDLINE with the following two objectives. First, it sought to provide an exploratory overview of the needs and experiences of young patients requiring paediatric palliative care (PPC), their families, and the healthcare professionals involved in their care, while also identifying differences from the needs observed in adult palliative care. Second, it aimed to explore how these needs could be categorised. The analysis of need categories was initially intended to support the identification of strategies to improve access to care, based on the hypothesis that young patients with specific needs would benefit from tailored care packages and corresponding funding mechanisms. However, as the project progressed, the feasibility of a care package-based approach appeared limited. Consequently, the literature search was refocused on the specific needs associated with PPC and the ways in which these needs may influence the accessibility of PPC services.

The following eligibility criteria were applied:

- population: young patient, family members, and professional caregivers;
- health condition: life-limiting or life-threatening illnesses, complex chronic conditions, or medical complexity;
- intervention: paediatric palliative care (PPC), end-of-life care, supportive care, complex care;
- outcomes: needs, experiences, perceptions, and perspectives;
- study design: review studies without restrictions on the designs of the included primary studies, encompassing both quantitative and qualitative evidence.

The search was performed in April 2025 and covered publications from 2020 to 2025. Following title and abstract screening, 16 reviews met the eligibility criteria and were retained for further analysis. No

formal quality appraisal of the included literature was undertaken. As the searches were limited to a single database and were not supplemented by systematic searches of additional databases or grey literature sources, the degree of literature saturation could not be formally assessed. Nevertheless, findings through the reviews retrieved showed a high level of consistency regarding PPC needs. Reviews on the effectiveness of PPC were not retained. No restrictions were applied within the target population of this literature search, allowing the identification of needs and experiences specific to particular subgroups. These included, among others, migrants, families experiencing financial or other forms of socioeconomic disadvantage, adolescents, children with intellectual disabilities, and young adults transitioning from PPC to adult palliative care services.

In addition, a targeted search was conducted on the concept of complexity in palliative care. The primary objective of this search was to explore how complexity is conceptualised and integrated within care models, given that this report focuses on organisational factors influencing access to PPC. Because few publications addressed complexity within PPC-specific care models, literature from adult palliative care was also reviewed. However, it is important to acknowledge that adult care models are not fully transferable to PPC, as paediatric care places greater emphasis on the family unit, whereas adult models tend to centre primarily on the individual patient (a more in-depth analysis of the differences between PPC and adult PC can be found in Chapter 5). The search was carried out in MEDLINE (June 2026) using broad terms such as “complexity” and “care model”. In addition, reference lists of relevant publications were screened to identify additional studies, following a snowballing approach. Given that the concept of complexity in palliative care remains relatively novel and is still being developed in primary research, achieving literature saturation was not the goal. Rather, the search was intended to provide conceptual insights and support subsequent project analyses, particularly regarding how the complexity of care needs might be captured in the access to PPC.

2.1.4 Targeted search on perceived barriers and solutions in the access to Belgian PPC (RQ6 and 7)

The aim of this targeted literature search was to identify surveys that explored barriers to accessing specialised paediatric palliative care as perceived by healthcare professionals. The search was conducted in MEDLINE in August 2025 using broad search terms such as “survey”, “paediatric palliative care”, and “provision of care”. The primary objective was to assess the feasibility of the planned online survey (using LimeSurvey©) by examining how similar studies had formulated, structured, and presented survey questions. The retrieved publications served as a source of methodological inspiration for the design of the questionnaire, including the wording and organisation of items. The results reported in these studies were also used to complete the content of the online survey.

2.1.5 Desk research on PPC offer in Belgium (RQ4)

We conducted desk research of the (grey[a]) literature to map the available information on Belgian PPC offer. Three key publications were identified during the scoping phase of this project with the help of involved stakeholders: the BPPC manual[20], a recent report from the King Baudouin Foundation[5,6] and a peer-reviewed paper on PPC in Belgium based on the annual paediatric liaison team reports from 2010 to 2014 by Friedel et al. (2018) [22]. These publications formed the basis for further research, which involved checking the reference lists and using a snowballing approach. Selected items concerning paediatric palliative care offer in Belgium were sought from websites of federal and federated authorities, RIZIV-INAMI and identified private initiatives. Additional information was

[a] Grey literature review consists in searching data on a topic in extra sources than indexed scientific articles. According to the KCE process note, the number of sources needed to search is dependent on the research topic and time/resources available.

retrieved from legal text databases, HCP professional websites and using Google as a search engine. Where appropriate, grey literature information was supplemented by targeted searches of the scientific literature using the MEDLINE (OVID) database and specific keywords, with the most relevant publications being selected. Searches continued until either additional source could not provide new data.

2.1.6 Desk research on PPC initiatives in other countries (RQ5)

The aim was to identify good practices abroad that could help bridge the gap between the existing services and the actual care needs in our country. We initially selected countries based on their high level of PPC provision, as rated by the ICPCN, and because their healthcare systems share certain characteristics with the Belgian system.[23] Following a preliminary review of the (grey) literature and a broad assessment of paediatric palliative care provision, we retained eight countries whose models offered added value and/or organisational features considered sufficiently transferable to the Belgian context: Australia, Canada, Germany, Italy, Spain, Switzerland, the Netherlands and the United Kingdom.

For each country, we carried out a search of grey literature, government agency websites and parents or professional associations dedicated to PPC, between July 2025 and November 2025. Where relevant, we also examined the websites of university paediatric hospitals and paediatric hospices. In addition, we searched the MEDLINE (Pubmed) for scientific articles on innovative PPC practices in these eight countries. Artificial intelligence tools (e.g., ChatGPT and Copilot) were used to support the review process by translating webpages, providing preliminary overviews of PPC organisation in the selected countries, and helping to identify potentially relevant PPC initiatives. All information was subsequently verified. Identified initiatives were then classified according to the five priority actions identified by the King Baudouin Foundation (KBF)[b] in its overview of paediatric palliative care in Belgium: education and training, access to care, research, and support for siblings, and communication (further developed in awareness and advocacy).[5,6]

We considered that good practices in PPC are initiatives that enhance the organisation and delivery of services, with the focus on improving access to care. They may consist of a coordinated set of services within a national territory at a local level, or a formal national plan. We did not aim at exhaustivity but rather were looking forward to innovative initiatives that could be a source of inspiration to improve access to PPC in Belgium.

2.2 Second step – primary data collection

2.2.1 Patients' data analysis of administrative Belgian data (RQ1)

The aim was to estimate the number of young patients in a paediatric palliative situation in Belgium.

2.2.1.1 Data sources

Three administrative Belgian databases were used for the analysis: the minimal hospital data (MZG – RHM), the technical cell data (TCT) and the hospital billing data (AZV – SHA and ADH – HJA).

All general hospitals in Belgium are required to submit a large set of data twice a year on all inpatient and day-care hospital stays and emergency room contacts: the Minimal Hospital Data (MZG – RHM defined in the Royal Decree of 27-04-2007). This et of data is transferred to the Federal Public Service (FPS) for Health, Food Chain Safety and Environment. Day-care stays include all surgical stays, and

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[b] The King Baudouin Foundation is an independent Belgian foundation that supports projects and initiatives seeking to improve living conditions and promote social cohesion, inclusion, and well-being.

non-surgical day-care stays for which day-care lump sum can be charged, or are of a specific type (e.g., geriatric, paediatric, oncological).

The "Technical Cell – Cellule Technique" is a common service of the RIZIV–INAMI and FPS Public Health, Safety of the Food Chain and Environment. Its mission is to collect, link, validate, anonymise data related to care provided within hospitals. Each year, the TCT links the Minimal Hospital Data (MZG-RHM) to the Sickness Funds reimbursement data in hospital (the Hospital Billing Data) for the analysis of links between the expenditures of the health care insurance and the treated condition and for the elaboration of financing rules, accreditation standards and quality conditions in the context of an effective health policy. The data originating from the TCT will be referred to as TCT data.

The Hospital Billing Data includes all reimbursements by the RIZIV – INAMI related to hospital stays: fees charged by physicians and other healthcare providers, pharmaceuticals and implants, per admission and per diem lump sum payments, etc. In practice, hospitals bill the patient's sickness fund for the provided services for the part covered by the health insurance based on the RIZIV – INAMI nomenclature. A subset of the data available on these transactions is passed yearly from the sickness funds to the RIZIV – INAMI: Anonymous Hospital Stays for inpatient stays and Anonymous Day-care Stays for day-care stays.

2.2.1.2 Data selection

All patients ≤25 years old with a hospital discharge between 2016 and 2023 with at least one of the ICD-10 diagnostic codes listed in the CCC table V3 were selected[c]. For each patient, the first hospital discharge year between 2016 and 2023 was used as the year of inclusion. The age of the patient was the age in years at the moment of hospital admission.

2.2.1.3 Data analysis

Frequencies were calculated on the selected data per year and per age group.

2.2.2 Expert consultation about the target population: Surveys; Round tables and Nominal group technique (RQ1)

Two groups of Belgian experts were consulted: one group of content experts on paediatric palliative care were consulted on their opinion on the ideal target population for PPC in Belgium and another group of clinical experts in paediatric palliative care were consulted on their perception of what is a paediatric palliative situation.

2.2.2.1 Content experts' consultation on the ideal target population

The experts were consulted in two sequential parts: first we sent out a written survey followed by a round table discussion. Both consultations took place in September 2025.

Potential participants were

- members of the paediatric liaison teams,
- field professionals experienced in PPC: such as teachers of the certificate in PPC, academic MD involved in publication about PPC, HCP from the community involved in PPC
- associations experienced in PPC which offer support to patients/parents
- researchers specialised in PPC

[c] The list of CCC is available by the following URL: https://www.childrenshospitals.org/content/analytics/toolkit/complex-chronic-conditions

- regional PC federations
- PC second-line support team for adults
- Federal cell for the evaluation of PC
- specialists of AYA care

Sixty-two potential participants were invited by email to the written and the oral parts. As the participants are professionals who are surveyed about their experiences, no assessment by an ethical committee was required. All eligible participants who had accepted to participate, were asked to fill in a declaration of conflict of interest and confidentiality. When signed, they received the survey by email (written part). In total, 40 content experts took part in the survey and 36 took part in the round table discussion (31 participants took part in both).

Table 2 shows the profile of the participants which took part in the consultation.

Table 2 – Profile of the participants to the survey 'target population' and the round table

Characteristics	Survey (n=40)	Round table (n=36)*
Region	Flanders: 19; Brussels: 14; Wallonia: 7	Flanders: 17 ; Brussels: 14; Wallonia: 5
Background	Paediatrician: 14; Nurse: 11; Psychologist: 5; Life expert: 3; Ethicist: 3; General practitioner: 2; Social worker:1; Economist: 1	Paediatrician: 9; Nurse: 8; Psychologist:5; Life expert: 3; Ethicist:3; General practitioner:1; Social worker:1; Economist:1
Work setting	Hospital: 22; Community: 8; Home care: 7; Academic: 3	Hospital: 17 Community: 10 Home care: 3 Academic: 6
Clinical PPC expertise level	High: 19; Intermediate: 4; Low: 17	High:15; Intermediate: 4; Low: 12

**missing data for 5 participants to the round table about background and expertise level*

The survey included a first section on informed consent, a second section on participants profile, a third section with information on a theoretical target population of PPC and a fourth section with the core questions. The survey is available on request. The participants had 10 days to answer the survey.

Participants were asked to define the target population by including or excluding population subgroups sorted by age and social roles (parents, teacher, first line HCP, etc) (see Figure 3 in Chapter 1 of the report). Free text fields allowed the experts to nuance/justify their choice. The frequency and the proportion to include or exclude each subgroup were calculated. The cut-off for a consensus was set at 90% of agreement between the participants. Nuances and justifications (free text) were used to interpret the results about the subgroups which have not reached a consensus, with the aim to better redefine and reorganise the subgroups in preparation for the oral consultation.

Subsequently, 36 experts participated in the round table with the aim to discuss the subgroups for which no consensus was reached.

Two round tables were organised with 18 participants each, according to the availability of the participants and the ideal number of participants to conduct a round table (ideally maximum 20 participants).

The meetings were preferably held in English, but any national language was allowed. The meeting was held in hybrid mode (in person or using Zoom©) and audio recorded. The recording was only used if further clarifications were needed during the analysis phase. The participants were first informed about the quantitative and qualitative results of the written consultation A voting system (Wooclap©) was used to define the target population by including or excluding population subgroups. Only the subgroups for which no consensus was reached during the written phase were submitted to the vote.

Again, agreement with the statement of more than 90% (or below 10%) was considered as a consensus. If no consensus was reached, KCE set the final target population based on experts' opinions (major opinion with the nuance brought by participants who did not agree) and grey/peer-reviewed literature.

2.2.2.2 Clinical experts' consultation on the definition of a paediatric palliative situation

In order to grasp the clinical reality of how a paediatric palliative situation is currently identified, we consulted a second group of experts who have clinical experience with paediatric palliative situations. A list of clinicians was established by consulting the professional associations of paediatricians, the website of the liaison teams. Belgian clinicians with at least one peer-reviewed publication on PPC and all clinicians identified by peers as having experienced at least one paediatric palliative situation were eligible. Only candidates with an online available email address were selected.

The list finally included 135 clinicians (MD, nurse, physiotherapists and clinical psychologist). All contacts were conducted by email in October 2025. The first email introduced the research and invited participants to sign a conflict of interest and confidentiality declaration. Thirty-four participants signed the declaration and received the survey which they were required to fill in and return within seven days.

Characteristics from the 22 participants who returned the survey are listed in Table 3.

Table 3 – Profile of the participants to the survey on the definition of a paediatric palliative situation

Characteristics	Number of participants (n=22)
Region	Flanders: 5; Wallonia: 5; Brussels: 12
Background	Physician: 15; Nurse: 6; Psychologist: 1
Work setting (subspeciality)	Hospital: 20 (neuropaediatry: 5; NICU/PICU: 5; haematology/oncology: 4; paediatric liaison team: 4; cardiology: 2); Primary care: 2
Clinical PPC expertise level	Major: 8; Moderate: 3; Minor: 7;

	Rare: 4; None:0

NICU/PICU= neonatal intensive care unit/paediatric intensive care unit

All academic centres were represented in the written part: *HUDERF*, *UCL*, *UZA*, *CHU-Citadelle*, *UZ Leuven*, *UZ Gent*, *UZ Brussels*. Other hospitals are *CHC Mont-Legia*, *Helora Jolimont*. Other institutions represented are *Cité Sérine* (respite and EOL care), *Arémis* (home care specialised in PC) and *Villa Indigo* (respite care).

The survey included a first section on informed consent, a second section on participants profile, and a third section with the core questions. Theoretical information with comprehensive definition and a lexicon was provided as an annex document. The survey is available on request.

The core questions were divided in five sections. Section one was about definitions and identification tools; section two was about symptoms and communication; section three was about treatment options; section four was about suffering; and section five was about prioritisation. Participants had to score elements from one to four. They scored one if the element could strongly influence a referral to PPC and they scored four if the element could not influence a referral to PPC. A box 'I do not know' is foreseen. Mean scores were then calculated for section one to four. For section five, frequency was calculated.

Subsequently, all coordinators of the 23 Belgian liaison teams, which are specialised services of PPC, were invited to participate in a group discussion, using the nominal group method[d].

Two nominal groups were organised according to the availability of participants. Fifteen PPC experts have finally participated in the nominal group. All liaison teams were represented.

The meeting was held in French and Dutch. The meeting was audio recorded in case clarifications were needed later. Data was collected directly during the meeting with the support of the Miro© programme and by hand. It was asked to participants to have access to a computer with the Google chrome navigator to access the Miro© platform. A password allowed the participants to see and to edit the content of the Miro board of the KCE. The objective was the share of opinions and knowledge directly online through a visual and collaborative mean, simultaneously visible by all the participants and the researchers. However, the Miro© program was only used for the first meeting. This option was abandoned because of the waste of time as the tool was too complicated to be handled by non-trained users although a feasibility test of the Miro program was conducted with success during the scoping phase. For the second meeting written comments were collected in a Zoom© *chat*.

During the oral part, the participants were first informed about objectives and instructions of the oral part. Then results of the written part about the definition of a paediatric palliative situation were presented. Then questions still pending after the written consultation analysis were addressed to the participants. Those questions were: "*Does palliative care involve the same interventions than supportive care?*" and "*How can the elements influencing a referral to PPC services serve as decision-making tool?*". Finally, an agreement on a working definition of a paediatric palliative situation was searched. The oral consultation guide is available on demand.

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[d] A nominal group is a structured method for group brainstorming that encourages contributions from everyone and facilitates quick agreement on the relative importance of issues, problems, or solutions. The primary purpose of the discussion is clarification (not to resolve differences of opinion). It does not aim to reach a consensus but can reach it. The topics to be discussed are of interest to the participants and participants have expertise in the topics. Discussion is equally balanced among all ideas.

2.2.3 Ethical considerations

2.2.3.1 Descriptive, coding and interpretative phases (RQ3)

First a descriptive phase aimed to identify situations of tension or conflict influencing access to paediatric palliative care as reported in the literature was conducted. Any situation in which needs, preferences, or expectations between stakeholders generated tensions that could affect referral, acceptance, or continuity of paediatric palliative care, including decision-making impasses, communication breakdowns, relational difficulties, or structural constraints, was defined as an item.

The documentary sources combined peer-reviewed PPC literature, clinical studies, grey literature (guidelines, policy frameworks, professional reports), and ethical or clinical monographs addressing decision-making, parental experience, and illness trajectories. Sources were identified through expert-driven selection and iterative reference-chaining. They include reference textbooks in PPC and specialised literature (e.g., neonatology, intensive care, oncology, complex chronic conditions) (listed in Appendix 6 of the supplementary data).

Initial identification of itemse was conducted through manual screening of three reference textbooks in paediatric palliative care [24–26]. Items were recorded using a structured coding grid including: (1) a short description of the situation, (2) the underlying need or preference expressed, (3) the type of conflict generated, (4) its potential effect on PPC access, and (5) the typical moment of emergence along the illness trajectory.

This initial manually coded dataset was then used as an in-context reference framework to guide a dedicated generative GPT-assistant operating in a closed environment restricted to the documentary corpus. The manually extracted items were provided to the assistant in order to guide the identification and classification at this step of additional situations across the corpus. As the analysis progressed, updated item lists were periodically reintegrated into the assistant dataset (“knowledge”) with the aim to refine its analytical sensitivity and maintaining internal consistency. All AI outputs were systematically reviewed and validated by the researcher.

Item identification continued iteratively until qualitative saturation was reached, resulting in approximately 2,600 items. A final refinement step ensured analytical coherence through removal of duplicates, consolidation of near-duplicates, and grouping of semantically similar situations while preserving contextual nuances.

Second, the coding phase consisted in coding each item in a consistent way in order to identify recurrent ethical dynamicsf influencing access to paediatric palliative care (PPC) and to transform the descriptive dataset into a coded usable basis for interpretative typology.

The coding phase examined the items through an ethical framework, a structured coding system organised as a multidimensional coding grid including: actors involved (young patient, parents, family, relatives, PPC and non-PPC professionals); ethical theories (principlism, narrative ethics/medicine, ethics of care); theory-derived ethical determinants (principles, virtues, narrative and relational dimensions); conflict types (value, role, temporal, informational, systemic, relational); effects on PPC access (facilitation, delay, barrier, misidentification, discontinuity, repair); and temporal zones along the care trajectory (See details about the ethical framework in Appendix 4 of the supplementary data)

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[e] Each item corresponded to a situation in which needs, preferences, or expectations expressed by stakeholders could generate ethical tension affecting access to PPC was included.

[f] Ethical dynamics describe how determinants interact across actors, situations, and stages of the care trajectory. Through systematic comparison of coded items, recurring configurations of determinants were identified across sources. These dynamics capture the prevalence and intensity of ethical tensions, the complexity of situations involving multiple actors or determinants, the recurrence of similar configurations across literature, and their temporal consistency along the illness trajectory.

Third, the interpretative phase translated the coded items and ethical dynamics identified during the coding phase into a typology of principal patterns of conflict influencing access to paediatric palliative care. The transition from ethical dynamics to formal patterns was guided by the recurrence of similar configurations across the dataset, the stability of their effects on access to PPC, and their occurrence across diverse clinical and relational contexts rather than by automated clustering procedures.

Each pattern represents a stable mechanism linking a configuration of determinants to a characteristic effect on PPC access. Patterns were defined to be sufficiently broad to encompass a diversity of situations, sufficiently precise to preserve the internal coherence of the mechanisms they represent, sufficiently nuanced to accommodate variation across sources, and sufficiently open to allow overlap when situations engage several ethical dynamics simultaneously.

Finally, patterns of conflict sharing similar mechanisms were grouped into broader macro-categories, providing an interpretative synthesis of the coded dataset while preserving the contextual variability of individual situations (Illustrative examples provided in Appendix 8 of the supplementary data).

2.2.3.2 Transversal analysis phase; re-categorisation of the pattern of conflict and field consultation (RQ3)

In order to prepare the field consultation, a transversal analytical step was conducted in order to examine conflict patterns beyond their initial macro-categorical classification. While macro-categories provided an empirical organisation of the patterns, they did not fully capture the intersectional dynamics through which ethical tensions unfold along the care trajectory.

The transversal analysis re-examined the patterns through a temporal lens, focusing on the moments of the care trajectory to which they referred and on the interactions between ethical determinants across different stages of care.

Rather than analysing patterns primarily as thematic entities, this step aimed to situate them within the lived temporality of paediatric care trajectories. Conflict patterns were thus reorganised according to the moments and transitions of care in which they tend to emerge, as well as the types of ethical determinants they mobilise across time.

Then a field consultation was conducted with PPC professionals from Belgian paediatric liaison teams to assess the practical resonance of the identified patterns of conflict. A structured survey was disseminated, followed by multidisciplinary roundtable discussions in French and Dutch where aggregated results were collectively discussed and interpreted. The consultation examined professionals' perceptions of the relevance, frequency, and complexity of the patterns in practice and explored whether additional patterns were missing (see survey in Appendix 11 of the supplementary data). Out of the eight paediatric liaison teams (PLTs), ten surveys were received. Fo the oral part, four French-speaking and five Dutch-speaking members of PLTs have participated.

An ethical and philosophical analysis was finally performed to discuss the findings and to suggest some perspectives of improvement.

2.2.4 Online survey of health care professionals with limited experience (RQ1, 2, 4, 6, 7)

Health care professionals with limited experience in PPC were consulted to explore perceived barriers to access and identify possible solutions for the different aspects as well as about their professional experience about identification, referral, types of interventions, collaboration, unmet needs, and needs assessment.

A document listing the questions, explanations and types of questions (open, closed, rating scale) was produced by the team members in two languages: Dutch and French. The questions were then encoded in the online survey software. Two KCE colleagues, external to the research project, reviewed the language and the quality of the questionnaire, one for each language (Dutch and French).

Some limitations of access were introduced in the online survey software to avoid participation of non-professionals, of people without any experience or no recent experience (more than 15 years). As we aimed to collect the views of health care professionals with limited experience in PPC, people with a lot of expertise in paediatric palliative care were excluded from this step. Patients, parents, family, and members of patient associations were not eligible for practical and ethical reasons: (i) the resource to handle very sensitive consultation of patients or parents in paediatric palliative situations was not present at KCE; (ii) the facilitator to recruit participants which is to have a close contact with potential participants was lacking for KCE researchers; and (iii) the chance to obtain an agreement for a study on PPC from an ethical committee for researcher in public health was weak.

Institutions and associations (where professionals from the health, social or youth sector are working or are affiliated) have served as an intermediary to distribute the survey amongst their members or staff.

The consent of participants was requested at the starting page of the questionnaire, then some personal information was collected about training, work setting and level of experience.

To maximise the data collection about the barriers and solutions, the survey was divided into two sections, the second one being optional. Each section was planned to take around 15 minutes. The participants had 6 weeks to respond.

At the moment of closure on the 15th of January 2026, 267 respondents had accessed the survey, of whom 61 did not fill in any question. Of the remaining 206 respondents, 37 did not meet the inclusion criteria and 33 did not complete any of the questions on barriers or solutions. Finally, two questionnaires were filled in by the same participant, leaving 134 unique respondents. Forty-six participants are medical doctors, 64 participants are nurses or midwives, and 24 participants work as social workers, psychologist, domestic helper, nursing assistant, massage therapist or coordinators. Most respondents had regularly encountered a paediatric palliative situation (n=58), whereas fifteen respondents had only encountered one paediatric palliative situation in the last 15 years. The remaining 61 respondents had limited experience of paediatric palliative situation. Table 4 presents their characteristics according to the region where the participants had their main professional activity.

Table 4 – Proportion of participants across regions at the online survey of professionals with limited experience in PPC (n=134)

Profile		Flanders (n=68)	Brussels (n=36)	Wallonia (n=30)
Background	Nurse or midwife	65%	36%	28%
	Medical doctor	23%	44%	22%
	Other profile	12%	20%	50%
Level of experience of paediatric palliative situation	Once	16%	0%	19%
	Few	51%	33%	44%
	Often	33%	67%	37%

The second, optional part of the survey was filling in by ninety-three participants (47 French-speaking and 46 Dutch-speaking; 45 from Flanders, 25 from Brussels regio and 23 from Wallonia). Their profiles were varied. The majority was nurses (n=43) and physicians (n=33) but social workers, massotherapists, psychologists, care helpers, physiotherapist, orthopedagogist and midwife have also participated. They were working in as varied settings as hospitals, home care, respite care and

disability institutions. Nine of them had only one experience of paediatric palliative situation, forty-one of them some experiences of paediatric palliative situations and thirty-three had regular experiences.

The analyses were quantitative and qualitative. The quantitative analyses comprised the questions answered with a Likert scale or by a numerical rating: average and median score were calculated in Excel. The qualitative analyses were performed on the data collected via open questions: quotes were sorted by thematic categories based on key words in Excel.

2.2.5 Survey of patient associations (RQ6)

The aim of this survey was to collect the opinion of head of patient associations representing young patients (up to 25 years of age) and their families on the optimal timing and manner of offering paediatric palliative care. Of the 46 associations contacted, 36 did not respond to our invitation by email. Three declined to participate, two expressed initial interest but did not follow up, five requested a copy of the questionnaire, and two completed and returned it. The two respondents who completed the questionnaire had already participated in the expert round tables organised at the beginning of the project about the ideal target population. They represented bereavement support organisations rather than associations linked to a specific condition or group of conditions.

2.2.6 Survey of adult PC support teams (RQ4)

This survey was conducted to explore potential solutions for the gaps in the current PPC offer (see 2.1.5). Eligible participants, i.e., the twenty-five adult palliative care support teams, were contacted by email with an invitation to answer three questions about their involvement in PPC. Of the 25 teams that received the questionnaire, five responded: three from Flanders and two from Wallonia.

2.2.7 Semi-structured interviews of national experts from other countries (RQ5)

For RQ5, national experts from selected countries were consulted through semi-structured online interviews. Following the desk research described in section 2.1.6, one or more PPC experts from each of the eight selected countries were invited to share their insights and experiences. An interview guide, developed from a generic template and subsequently adapted to each country (see section 7 of the supplementary data), explored the general context of PPC, and examples of good practices that improve PPC, addressing subtopics such as access to care, education and training, support for siblings, psychosocial and spiritual care, research, awareness and advocacy, and available resources and tools. These interviews were designed to enable us to refine our findings, gather additional information on specific initiatives, and, where applicable, identify further examples of good practice.

Seven[g] interviews were conducted in March 2026, each lasting approximately one hour. Two researchers attended each interview, took notes, and audio-recorded the discussion to facilitate any subsequent review. Findings from the document review and expert interviews were combined to identify examples of good practice potentially applicable to the Belgian context (see section 7 of the supplementary data).

2.2.8 Semi-structured interviews of HCP experienced in PPC (RQ1, 4, 6, 7)

Members of the paediatric liaison teams (PLTs) were interviewed through semi-structured group interviews. These group interviews aimed to gain insight into the functioning of Belgian paediatric liaison teams, explore their perceptions of barriers to accessing paediatric palliative care, and assess the feasibility of potential solutions. Nearly all Belgian PLTs participated (except one, 7 interviews in total). Interviews were conducted interactively using an open-ended interview guide and visual aids illustrating key PPC concepts (see interview guide in the section 5.6 of the supplementary data). Meetings typically took place in hospital settings, lasted around two hours, and were held in the

[g] All countries except Italy agreed to participate in this online interview.

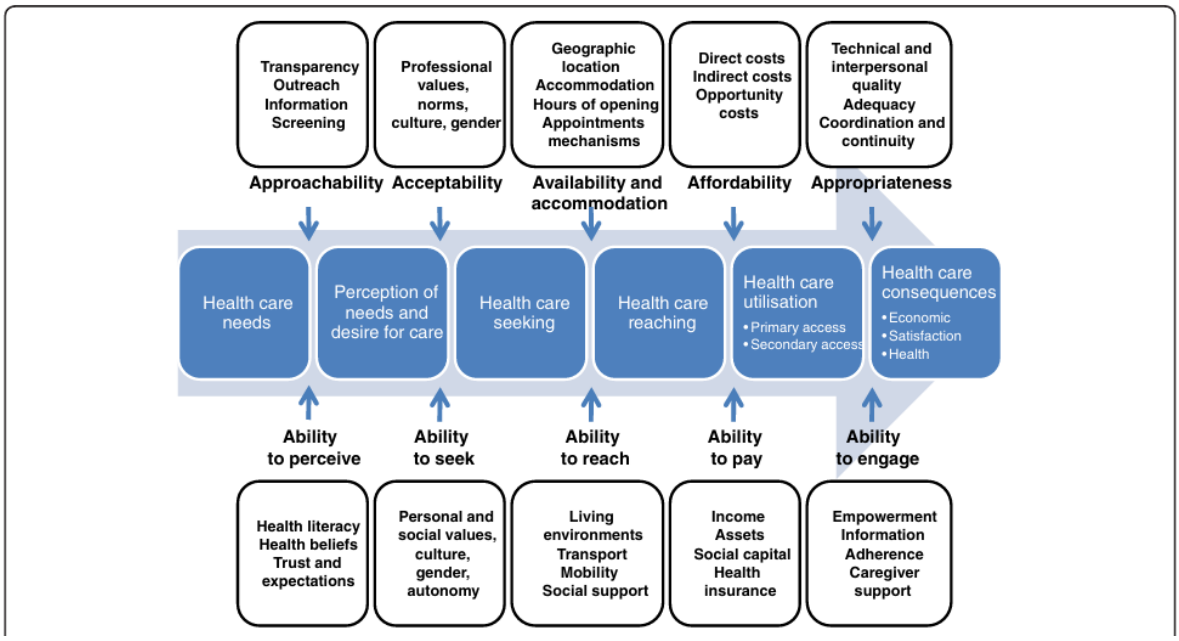
participants' native language by a native-speaking interviewer supported by a KCE researcher. Interviews were audio-recorded with consent, and participants did not receive remuneration.

Following transcription, correction, and anonymisation of the recordings, the data were analysed according to four accessibility domains: acceptability, availability, affordability, and appropriateness. Findings were first examined for each PLT and then synthesised to identify common barriers and solutions across teams. Microsoft Copilot was used to support thematic analysis, but all AI-generated results were independently verified by KCE researchers through traditional qualitative thematic analysis methods. The findings are presented as perceptions rather than facts and should not be interpreted as validated evidence. Limitations of these group interviews and the analysis include the challenges of categorising findings within accessibility domains, overlap between categories, and the relatively novel use of AI-supported qualitative analysis, which necessitated careful human validation to ensure credibility and accuracy. The tables with the findings per accessibility domain can be retrieved in the section 5 of the supplementary data.

2.3 Third step – integrative analytical process

In this step, we organised all information that was obtained in the surveys, round tables, interviews and literature reviews in an existing framework on health care services access. Figure 5 illustrates this framework.[27]

Figure 5 – Conceptual framework of access to healthcare



Source: Levesque et al. (2013).[27] The linearity of the representation of the steps to succeed in accessing adequate healthcare does not reflect the reality of the variation of real care pathways experienced by patients and families.

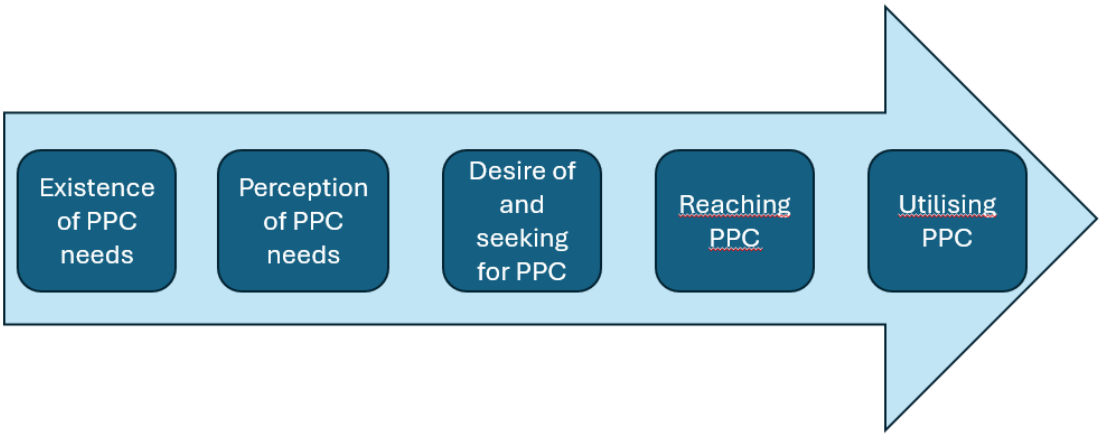
According to Levesque et al (2013), access to healthcare services can be achieved in six steps[27] (see Figure 5):

- The existence of healthcare needs
- The perception of healthcare needs and desire for care
- Health care seeking
- Healthcare reaching
- Healthcare utilisation

- Healthcare consequences

This report will consider the five first steps of this framework, as illustrated in Figure 6, a freely adapted version of the framework to the context of PPC.

Figure 6 – Adapted version of the framework to the context of PPC



2.4 Fourth step – stakeholder consultation

Finally, we presented our findings and conclusions to the relevant stakeholders during a meeting. Stakeholders were invited from a variety of institutions and associations to ensure representation all aspects of PPC in Belgium, to discuss the acceptability and feasibility of suggested solutions during five thematic sessions.

The list of stakeholders identified to be consulted is available in Appendix 3 of the supplementary data.

Themes were:

1. Availability (in terms of opening hours and geographical coverage) of paediatric palliative care services and types of services provided
2. Services tailored to complex situations: ethical, cultural, and socio-economic challenges
3. Coordination, collaboration and consultation across levels of care and sectors (medical, psychological, social, and spiritual)
4. Funding of paediatric palliative care services
5. Research, education, awareness and governance

A data sheet was developed for each theme, accompanied by a list of barriers associated with that theme. A table with the sources used in each of the five questionnaires is available in section 13 of the supplementary data. Data sheets are available on demand.

Firstly, all stakeholders were sent all data sheets by email asked to rate the acceptability and feasibility and return their assessment to the researchers before the meeting. Secondly, responses were discussed alongside the overall findings of the research project.

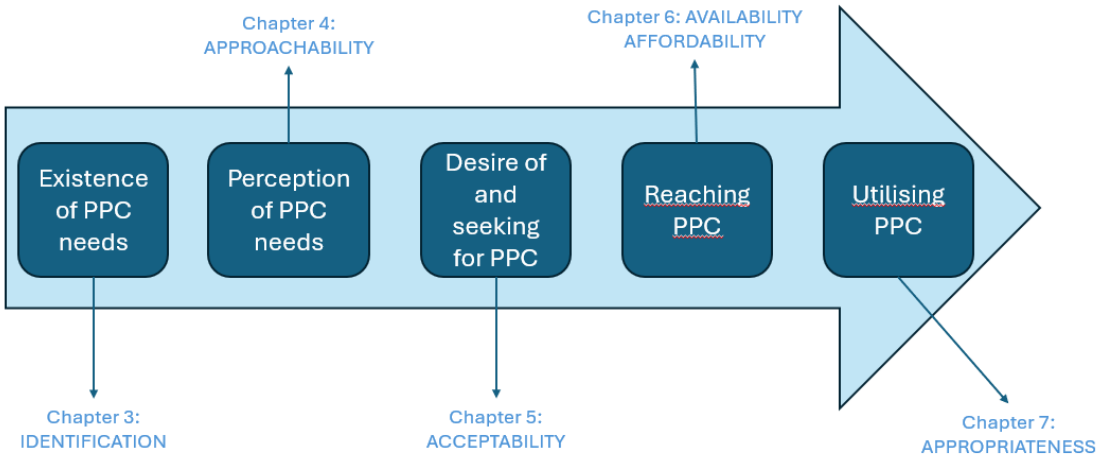
Notes were taken and the meetings were audio recorded to help solving potential misunderstanding during the analysis of the content of the discussion.

Analysis was quantitative with frequency calculation about acceptability and feasibility and qualitative on the content of the free text in the open fields.

2.5 Structure of the report

The following chapters present all the result of all the methods in an integrated way to avoid repetitions and respond more directly to the concern of the authorities about the lack of access to PPC in Belgium. Figure 7 illustrates the project flow from the research questions to the chapters.

Figure 7 – Overview of the report structure



Chapter 3 is about the identification of a paediatric palliative situation (RQ1).

Chapter 4 is about awareness, advocacy, training and research highlighting how to grant a place to PPC in the society and the health system (related to RQ4, 5, 6 and 7).

Chapter 5 is about the complexity of needs and ethical tensions occurring in palliative situations (RQ2, 3, 4, 5, 6 and 7).

Chapter 6 is about the current offer in PPC in Belgium, the gaps and the ideal offer in the future (RQ4, 5, 6 and 7).

Chapter 7 is about collaboration and governance to build an ideal care journey for young patients in palliative situations and their family (RQ4, 5, 6 and 7).

3 TO IDENTIFY A PAEDIATRIC PALLIATIVE SITUATION

KEY POINTS

To identify paediatric palliative situations at the population level

The ideal target population according to Belgian experts in PPC, includes children from birth to 18 years of age, young adults until 25 years of age and foetuses as soon as they are diagnosed with a LLC/LTC. For unknown conditions, the following elements would help for inclusion: a wish to receive PPC, signs of EOL, physical or psychological suffering, absence of curative treatment, perception or knowledge of an association between the clinical picture and early death, and the possibility of relieving symptoms.

While keeping the child or young adult at the centre of the care, the nuclear family (parents, siblings, stepparents and stepsiblings living with the patient), close relatives and informal caregivers (extended network), and close professionals without or with limited experience in PPC should also be included in the target population of the PPC offer.

As the target population of PPC goes farther away than only the young patient, the authors will refer to a paediatric palliative situation rather than to refer to a child with PPC needs in this report.

Belgian experts' perception of PPC aligns with the usual definitions of PPC (WHO, GO-PPaCT) but not with the Belgian law of PC 2016 because of the reference to an advanced stage of the condition.

Three main tools are available to estimate the target population at a population level: the CCC list, the LLC directory and the LLC list.

It is estimated that there is a maximum of 20,000 individuals per year eligible for PPC in Belgium annually.

Transition to adulthood

Experts' consultation highlighted that the presence of an adult (25y+) in the paediatric system means that the transfer to the adult care sector did not occur (yet). Although transitional care requires effort and appropriate support because of its complexity, this was highlighted as a failure in the Belgian care system.

To identify a paediatric palliative situation at the individual level

Several standards, frameworks and scales are available, but no consensus exists on the instrument of choice.

Main finding is that the identification of a paediatric palliative situation in a patient is a longitudinal process, by means of a comprehensive, individualised, continuous assessment of needs, including the complexity aspect of those needs.

Beyond the identification role, tools allow to support clinical decision-making and timely recognition of needs to be addressed by PPC services.

3.1 Introduction

This chapter mainly presents the findings related to research question one: “How to identify a paediatric palliative situation?”.

3.1.1 Working definitions

A paediatric palliative situation is a care situation in which a foetus or a young patient or any person caring for them presents PPC needs.

Paediatric palliative care needs are defined as “Any basic conditions required to ensure the physical, psychological, social and spiritual well-being of someone that can be met through the provision of PPC by a professional”.

3.1.2 Methodological sources

The methods used in this chapter are:

- Exploratory phase:
  - Targeted search on population estimation and target population
  - Targeted search on identification tools
- Primary data collection:
  - Patients’ data analysis of administrative Belgian data
  - Expert consultation about the target population: surveys, round tables and nominal groups
  - Scoping literature review on identification tools
- Integrative analytical process also included data from
  - Online survey of HCP with limited experience
  - Semi-structured interviews of HCP experienced in PPC
- Stakeholders consultation

3.1.3 Context

To identify a paediatric palliative situation is important because it enables the identification and timely provision of PPC at the individual level, and allows to estimate the population who needs PPC so that PPC services can be organised and planned accordingly.[28]

Nonetheless, defining identification criteria of a paediatric palliative situation is difficult and complex for the following reasons:

- The range of conditions that could make a young patient eligible for PPC is broad and diverse including neurological, neuromuscular, oncological, respiratory, cardiac, metabolic, chromosomal, syndromic and congenital malformation disorders, infectious diseases, post-anoxic conditions, and many “undiagnosed” conditions.
- Eligibility to PPC is not based only on diagnosis but also on care complexity consisting of clinical, psychological, social, organisational, spiritual and ethical problems experienced by the different actors involved
- The population in need of PPC is dynamic due to advancements in medicine and technology that have reduced neonatal and paediatric mortality but have increased survival of paediatric patients with increased health and care needs.[28]

- Using death record data alone to identify children and young people with life-limiting condition would underestimate the numbers of children and young people requiring PPC.[29]

3.2 To identify a paediatric palliative situation at the population level

In most European countries, comprehensive epidemiological data on paediatric palliative situations are rarely available. They are either collected using diverse methods (with varying criteria) or not collected at all. Existing data are limited to two types of statistics: mortality rates due to life-threatening or life-limiting conditions (LTC/LLC), and the prevalence of cases of life-threatening or life-limiting conditions.[30] But there is no universal agreement on how paediatric palliative situations have to be defined within population-level policy. In most cases, the method used to quantify population-level PPC need is based on the content of the available data within each country.[28]

To identify the people in a paediatric palliative situation at the population level is challenging.[15] It requires to state the profile of the target population and to determine the elements in databases allowing to determine a paediatric palliative situation. As healthcare professionals providing paediatric or palliative care in Belgium or members of associations involved in PPC, their view on the target population for PPC in Belgium complement the evidence available in the literature and helps to contextualise it within the Belgian setting.

3.2.1 The ideal age of the patients to be included in the target population

By target population of PPC we mean people living in Belgium who could, at one moment in their life, require the intervention of professionals/volunteers who deliver paediatric palliative care and/or support. In the introduction, it was highlighted that children and adolescents are the obvious target population of the study, but the question was also raised to extend the target population of the study to relatives and close caregivers.

In a previous KCE report on hospitalisation in paediatric units, four coherent groups of children were identified for epidemiological analyses of the hospital at home offer: infants (0 to 1 year old), toddlers and preschoolers (2 to 5 years old), school-aged children (6 to 14 years old), and adolescents/ young adults (15 years or older).[31] Recent publications (2012-2026) on PPC population estimates mostly use the age ranging from 0 to 19 years old to define their study population. However, some use a narrower range (1-17 years) and some a wider (0-25 years) (see Section 1 of the supplementary data for more details). Friedel et al. (2019) have previously published epidemiological data for Belgium and had used the age range of 0-19 years.[16] In the Netherlands, young adults until 23 years of age are included in the target population of PPC.[32]

The scoping phase highlighted the relevance to include young adults living with their parents (or other referent adults) because they are still in the process of gaining autonomy (18-24 years), based on the reflection that the living environment and the interactions between the protagonists involved in a palliative situation concerning such young adults can share similarities with those of a child. Following the same idea, young adults (25+) lacking decisional capacities (i.e., because of a situation of psychiatric or intellectual disability) would also be eligible to PPC, notably if a chronic disease, and even more a palliative situation, had existed since childhood.[12]

In the absence of a consensus, we consulted 45 Belgian content experts (see 2.2.2.1).

All experts were in favour of including children aged 0-18 years. There was no consensus (less than 90% agreement) on the inclusion of young adults or adults with intellectual disability (five and fourteen disagreed to include these groups respectively).

The arguments to exclude young adults or adults with ID from the target population are related to (i) different needs that could be more difficult to meet by paediatric teams (lack of knowledge and experience of the paediatric professionals with conditions of young adults and of adults with ID), (ii) the societal emphasis of acknowledging and promoting the autonomy of young adults and of adults with ID, (iii) the current organisation of the health system based on an age cut-off between paediatric

and adult care and (iv) the will to stay focused on children and avoiding to stretch the definition too much.

However, the same respondents who did not advocate for the inclusion of young adults are concerned by (i) the lack of adapted structure for YA and adults with ID in the adult sector, (ii) the necessity to accompany the transfer to the adult care and transition to adulthood, (iii) the fact that specific communication skills and parents' involvement are required in the care of YA and adults with ID like in paediatric model of care, and (iv) the distinction between YA cared for in paediatrics for a long time and YA whose PC needs were identified after 18y.

Four respondents, who participated in the survey, suggested adding another age category, i.e., children before birth, the foetus. This kind of care, named the perinatal palliative care, mainly targets the parents and occurs when a severe condition was detected before birth and/or a medical abortion was planned.

During the round table, more than 80% of the participants have agreed to include foetus in the target population.

Most participants of the round table discussions agreed that the onset age of the palliative situation influences whether a young adult should be included in the paediatric or adult service, rather than their actual age. Participants also agreed that adults with ID should be cared for in the adult sector with care inspired by the paediatric model but excluding them from the paediatric target population. The presence of a young adult patient (25y+) in the paediatric system means that the transition did not occur (yet), which was considered as a failure in the Belgian care organisation.

Participants explained that age alone is an arbitrary criterion; other factors should also be considered like developmental stage, life expectancy, clinical context, disease trajectory. Regardless, adolescent and young adults (AYA) should always be given a voice. Participants have expressed felt that age-based protocols should be avoided. Instead, transition processes should be tailored to individual circumstances and the needs of each child with role distribution between adult and paediatric PC teams.

According to participants, the major issue with transition is that it requires effort and appropriate support as it is very complex. First, the multidisciplinary teams specialised in PPC, the Paediatric liaison teams (PLTs), often experience difficulties transferring the care of patients and families with whom they have developed long-term relationships. Second, adult PC teams function differently than PLTs (less collaboration, less people involved, less support for families). Third, it is difficult to find treating physician (internist for example) or hospital units, in the adult system, able to meet the needs of young adults with chronic diseases or even accepting to take the lead of the care. Fourth, GPs lack experience in PPC and severe chronic conditions of young adults. Fifth transition requires time to allow patients, parents and care givers to become adapted to the new situation. To increase the success of a transition process, adult PC services, all types of HCP from paediatric services (not only MD and nurses), and staff from centre for disabled children should be involved.

In conclusion, the ideal age range for patients eligible to benefit from PPC and also to represent the target population for patient data analysis, is from birth to 24 years old.

3.2.2 The inclusion of other people than the patient into the target population

As the quality of life of young patients is highly dependent on the well-being of their family and their close caregivers, they are usually also included in the target population of PPC services. Based on the results of a survey, all content experts agreed that the target population should include the parents, the siblings and the HCP not experienced or with limited experience in PPC. There was no agreement on the inclusion of co-habitants and informal caregivers.

Some suggested the inclusion of co-habitants who have a very close relationship with the young patient, such as stepfathers, stepmothers, half-brothers and half-sisters, family members and informal caregivers. Others proposed to also add people with different roles in relation to the young patient,

such as friends, a girl- or boyfriend, a teacher, staff and volunteers of respite house, day care and centres for disabled children, and even professionals with experience in PPC.

During the round table discussion, it was suggested to consult the nuclear family to define the group that requires PPC support, while keeping the nuclear family at the centre and respecting budgetary constraints.

In conclusion, around each patient eligible for PPC, a lot of other people may also benefit from the PPC like the pregnant woman (inclusion of foetus in the target population), the nuclear family, the extended network including the professionals without or with limited experience in PPC. As the target population of PPC goes farther away than only the young patient, the authors will refer to a paediatric palliative situation rather than to refer to a child with PPC needs in this report.

3.2.3 The elements in databases allowing to determine a paediatric palliative situation

Several lists of diagnoses and conditions eligible for PPC have been developed based on the International Classification of Disease (ICD-10). ICD codes can be available in administrative databases.

3.2.3.1 Paediatric Complex Chronic Conditions (CCC) classification

Version 1 introduced a list of CCCs, defined as any medical condition expected to last at least twelve months (unless death intervenes) and involving either multiple organ systems or a single organ system to a severity that requires specialty paediatric care and likely hospitalisations in a tertiary care setting.[33] This classification includes more than a thousand diagnoses in ten CCC categories: cardiovascular, respiratory, neuromuscular, renal, gastrointestinal, hematologic or immunologic, metabolic, other congenital or genetic, malignancy and perinatal conditions.

Version 2 expanded the classification system to include diagnostic and procedural codes, added a neonatal CCC category, and incorporated complexity domains such as medical technology dependence or organ transplantation.[34] Version 3, published in 2024 reflects updates aligned with the evolving ICD-10-CM coding system.[35] The version 3 of the CCC list is easily available online[h].

3.2.3.2 Directory of life-limiting conditions (LLCs)

This directory was developed by mapping the categories developed in 1997 by the Association for Children's Palliative Care/Royal College of paediatrics and Child Health (ACT/RCPCH) into diagnoses (ICD-10 codes) of patients admitted to PPC services in the UK.[36,37] The resulting list includes 376 diagnostic labels.[38] Similar to the CCC classification, the list requires periodic updating as new diagnoses and conditions emerge and some may disappear thanks to curative treatment development.

3.2.3.3 List of Life-Limiting Conditions (LLCs)

Based on the Directory of life-limiting conditions (see above) and the diagnoses of children accepted for care at a UK hospice, a list of 777 ICD-10 diagnosis codes was developed.[39] The list includes diagnoses where most children were life-limited/threatened, and also if a diagnoses of the ICD-10 code was life-limiting/threatening, along with all malignant oncological codes. The LLC list has been used to estimate the number of children with LLCs in England, Scotland and Wales.[39–42]

The most recent version [42] further explores how to capture the complexity of needs by applying a framework of medical complexity based on the conceptualisation proposed by Cohen et al. (2011)[43], which in turn builds on a previous systematic review of chronic health conditions in childhood[44].

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[h] Available at: https://www.childrenshospitals.org/content/analytics/toolkit/complex-chronic-conditions

A targeted search in the literature (see section 1 of the supplementary data for details) illustrated the use of those lists to estimate the number of paediatric palliative situations in some countries. Fraser et al. (2021) showed that the prevalence of LLCs has progressively increased over the past 15 years in the UK, currently estimated at 66 per 10,000 children aged 0-19 years. A projection foresees between 67 and 84 children with LLC per 10,000 children by 2030.[9] In the USA, patients with CCC constitute approximately one third of all hospitalised young patients, with also an increasing trend.[34,35] A recent publication based on the concept of severe health-related suffering (SHS)[i] taking into account the burden of suffering from each disease, estimates that 10,600,000 children experienced SHS in 2023 worldwide.[45]

Incorporating information on the complexity of need is seen as essential for identifying the population-level need for PPC that goes beyond a diagnosis-based list. However, this approach requires the availability and integration of broader datasets in addition to mortality and disease prevalence data, including hospital admissions, paediatric intensive care data, outpatient and general practice data, prescribing data, etc.

3.2.4 Estimation of the Belgian population

Based on the ideal range age for patients eligible for PPC and on the available online list of ICD-codes identifying a paediatric palliative situation, we estimated the number of young patients eligible for PPC in Belgium using the CCC list.[16]

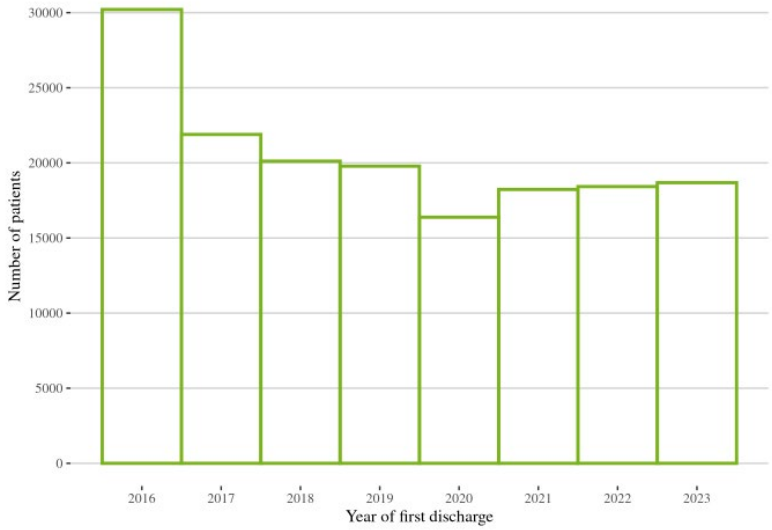
Between 2016 and 2023, 163;712 unique patients (0-25 years) were discharged from hospital (one-day or longer stay) with one of the selected diagnoses or procedures from the CCC list, of which 84% by diagnosis, 8.8% by a procedural code and 7.2% by both diagnosis and procedure codes.

Based on the analysed data, a maximum of around 20 000 young patients with a CCC diagnosis had a first hospitalisation annually. However, the CCC list selects young patients *at risk* of a paediatric palliative care situation. The number of young patients with an actual need of PPC is likely to be smaller.

Figure 8 shows that numbers were stable across the time period. In 2016, the number of patients was somewhat larger than the other years: this is mostly due to the fact that patients included in 2016 can have a hospital discharge in earlier years as well as in 2016, but as these prior data are outside the available data period, they are included in 2016.

[i] It refers to pain, distress, and suffering that could be physical, psychological, social, and spiritual, linked to life-threatening or life-limiting conditions, including end-of-life situations, that require medical intervention and can be alleviated through palliative care.[15]

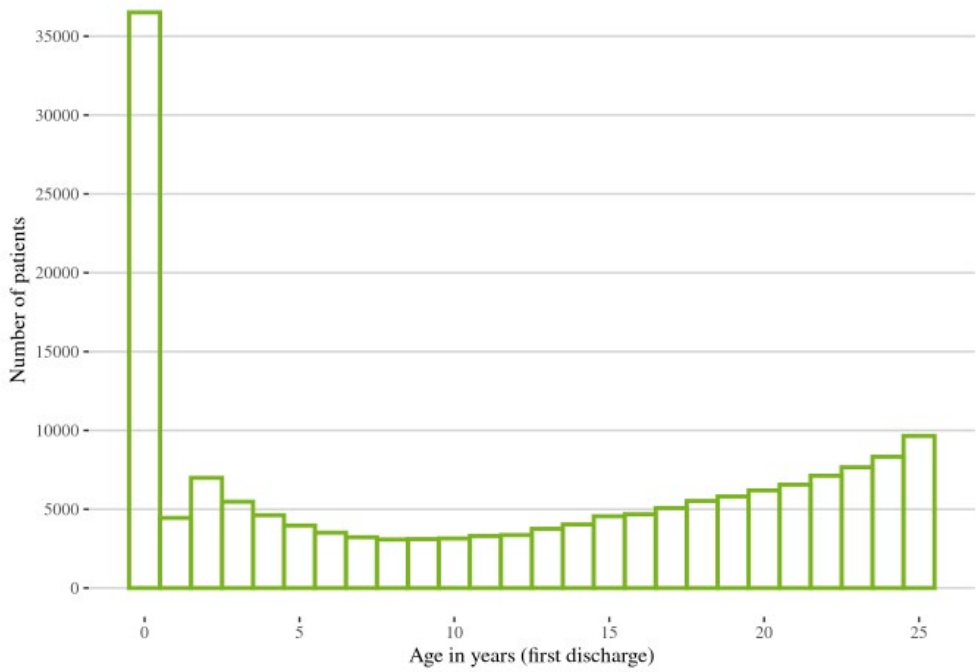
Figure 8 – Number of patients by year between 2016 and 2023



The distribution of the patients according to their age is illustrated in Figure 9.

Over a seven-year period, Figure 8 shows that more than 35,000 babies less than 1 year old were identified with a CCC in the Belgian hospital database. The other age categories include approximately 5000 young patients affected by a CCC over a seven-year period. Within the young adult population, there is a gradual increase in the number of affected patients. Between 2016 and 2023, the age profile of newly identified patients is very similar. Based on this analysis, no change in the age profile would be expected in the future (figure on request). However, it is known from epidemiological data at international level that the prevalence of CCCs in adolescents and young adults will increase over time as the survival rates of complex, often life-limiting conditions increased substantially over the past decades thanks to medical advancements. The expectations therefore are that more AYAs will be present in our healthcare systems in future decades.

Figure 9 – Number of patients by age during the period 2016-2023

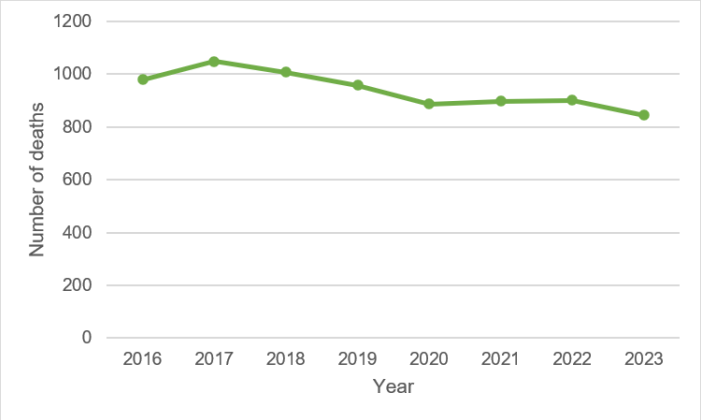


A recent study demonstrated that it is possible to extrapolate prevalence estimates of LLCs from one European country to another (UK to Germany).[46] If this exercise was applied to Belgium, assuming that the comparability criteria are met, the number of young patients with LLCs in the Belgian population aged 0 to 19 years could range between 15,865 and 17,165. This number is quite aligned with the estimation made by using the CCC list.

This estimation is probably overestimated as CCC is a proxy for palliative situation and that all young adults may not be included in the target population. However, it could be used as a starting point to estimate the needs of PPC offer by the authorities. The 163 712 unique patients (0-25 years) identified in this analysis represent the population over a period of seven years. It is also important, in the estimation of the target population, to take into account the expected mortality rate among children aged 1 to 17 years with LLCs of approximately 36% in Belgium.[47]

In the same period (2016-2023), 7522 people; aged 0 to 24 years old died in Belgium (Figure 10).[48] When comparing this data with the Belgian data on mortality rate for the age range 0-24 years, the difference is important, showing that the number of death is not a good proxy to determine the target population for PPC, as shown by Jarvis and Fraser (2018).[29]

Figure 10 – Total deaths among people aged 0–24 years, all causes, 2016-2023



In conclusion, three main tools are available to estimate the target population at a population level: the CCC list, the LLC directory and the LLC list. An analysis of patients database estimated that there is a maximum of 20,000 individuals per year eligible for PPC in Belgium annually.

3.3 To identify an individual patient in a paediatric palliative situation

The online survey of professionals with limited experience and the survey of content experts showed that understanding a paediatric palliative situation is complex due to heterogeneous perceptions of the field (see sections 2 and 4 in the supplement). According to interviews with HCP experienced in PPC, PPC is commonly perceived as a service primarily intended for children with incurable cancer; however, this perception overlooks the broad spectrum of life-limiting and life-threatening conditions for which palliative care is equally relevant and beneficial (see section 5 in the supplement).

PPC is also still perceived as end-of-life care rather than a part of integrated care starting with the diagnostic. An example is the Belgian administrative rules that have maintained for years the vision of PC as being associated to a life expectancy of less than 3 months despite a change in the respective law since 2016.[49]

As definitions and perception of a paediatric palliative situation vary between the literature and the practice, a consultation of healthcare professionals providing paediatric palliative care in Belgium was conducted. Their view on the way to perceive a paediatric palliative situation in their every-day practice in Belgium aimed to complement the evidence available in the literature and to help contextualising it within the Belgian setting.

Clinical experts shared their experience with common definitions and on elements which could influence a referral to PPC.

3.3.1 Alignment with common definitions of PPC

Clinical experts (n=22) have expressed their views on how well definitions of PPC align with their perception of a paediatric palliative situation in clinical practice. The definitions were the following:

Belgian law on palliative care (21 July 2016)[j]: « *All patients have the right to palliative care when they are in the advanced or terminal stages of a serious, progressive, life-threatening illness, regardless of their life expectancy.* »

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[j] Loi du 21 Juillet 2016 modifiant la loi du 14 juin 2002 relative aux soins palliatifs en vue d'élargir la définition des soins palliatifs. *M.B. 29 août 2016.* https://etaamb.openjustice.be/fr/loi-du-21-juillet-2016_n2016024163.html ; Wet tot wijziging van de wet van 14 juni 2002 betreffende de palliatieve zorg, tot verruiming van de definitie van palliatieve zorg. *BS 29 augistus 2016.* Wet van 21/07/2016 tot wijziging

WHO definition (1998): Paediatric palliative care is defined as "*the active, comprehensive care for the body and mind of a child suffering from a life-limiting or life-threatening illness, as well as support for the child's family*".[3]

WHO definition (2020): "*Palliative care is 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.*"[50]

The definition of PPC by the GO-PPaCT[k] consortium of experts (2022) highlights the following fundamental points: *PPC is a right for all children with a life-threatening or life-limiting illness and their families. All children with a life-limiting, life-threatening or terminal disease are eligible for PPC.*[1]

All participants agreed with all the definitions listed above, except with the definition included in the Belgian legislation (2016). This non-alignment was related to the 'advanced or terminal stage' aspect expressed in this legal definition. Indeed, all participants expressed that the terminal phase is far too late to start palliative care in young patients and that palliative care is not synonymous to terminal care.

Although the diagnosis of LLC/LTC as part of the definition was not questioned, the possibility of an unknown condition causing the palliative situation should be considered. Several participants expressed the importance that PPC is provided alongside curative treatment.

Finally, the concept of a severe illness appears more relevant than that of incurability, as the latter is not well suited to health conditions that are, although life-threatening, may still be theoretically curable.

In conclusion, Belgian clinical experts mostly agree with the content of common definitions of PPC (or PC). One point of disagreement is when a link is made between PC and the advanced or terminal stage of a serious illness.

3.3.2 Transition between supportive care and palliative care

Clinical experts from the Paediatric Liaison Teams (PLTs) (n=15), expressed their views on the transition between supportive and palliative care in the nominal group discussions (see details of the methods in Chapter 2 and section 3.3.2. of the supplementary data).

As curative care is delivered concurrently with PPC, the question has emerged how to determine the difference between supportive care and palliative care. Indeed, both aims to increase the quality of life of patients with severe conditions[l]. Theoretically, supportive care encompasses interventions aimed at preventing, reducing, or managing the physical, psychological, social, and practical consequences of disease and its treatment throughout the illness trajectory (often oncological illness), while palliative care focuses more on the prevention and relief of suffering and on also improving the quality of life of the family.[51] While the two concepts overlap substantially, the authors postulated that supportive care generally represents the broader framework, within which palliative care constitutes a specialised approach for addressing complex symptoms, psychosocial needs, and decision-making challenges as illustrated in Figure 11.

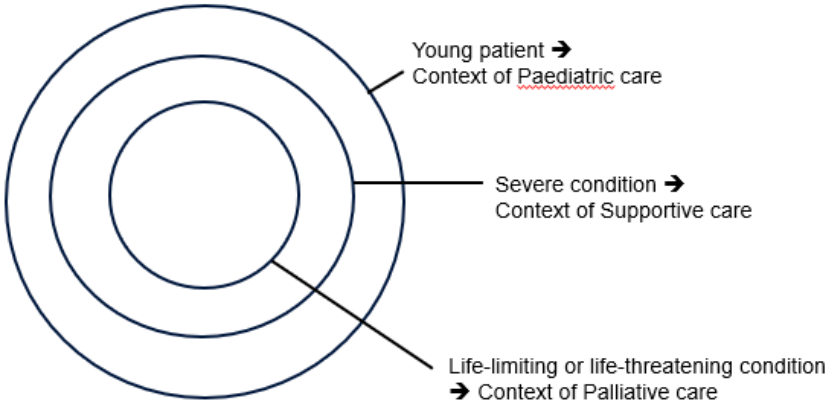
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van de wet van 14 juni 2002 betreffende de palliatieve zorg, tot verruiming van de definitie van palliatieve zorg

k GO-PPaCS project (Global Overview – Paediatric Palliative Care Standards) was a project led by an international group of experts in paediatric palliative care (PPC). The results of the project were published in 2022.[1]

l A severe condition is a condition associated with a high burden of illness, significant impairment of health or functioning, and an increased risk of adverse outcomes, including premature death

Figure 11 – Gradual refinement of the target population



3.3.2.1 The mindset progression

The findings from the consultation of clinical experts from PLTs have shown that the mindset progression of HCPs from a supportive care situation to a palliative care situation depends on several elements.

In summary, the major impact of the mindset change seems to result from the combination of several elements with the most impactful are: the wish to receive PPC, signs of end-of-life (EOL), physical or psychological suffering, absence of curative treatment, perception or knowledge of an association between the diagnosis (or clinical picture) and premature death, and the possibility of relieving symptoms. When looking into the common definitions of PC, one can notice the similarity with those key elements and the content of the definitions.

3.3.2.2 The difference between the interventions

Clinical experts from PLTs were also asked to sort care interventions as related to supportive care or to palliative care.

In a model developed by Lacerda et al (2023), paediatric oncological care already includes EOL care, psychosocial care and symptoms control. Spiritual care, family support and ACP are the additional interventions brought by PPC within paediatric oncological care according to the authors.[52]

Several clinical experts from PLTs expressed their understanding or interpretation that supportive care (SC) and palliative care (PC) are the same. Both types of care aim to provide comfort to patients with severe conditions.

It was also said that separating SC and PC in two categories could induce the risk that people assimilate PC and terminal care. One participant also evoked that the difference between SC and PC is less in the types of interventions delivered than in the philosophy of care: in PC, *primum non nocere* is central: relieving symptoms carries more weight in decision-making than curing or slowing the disease. PC consider quality of life as the main objective of care provided.

According to the participants, PC interventions differ from SC interventions by

- the importance placed on the views of the patient and their family;
- the support provided to families, informal caregivers, and healthcare professionals less experienced in PPC;
- the expertise in discussing end-of-life issues, treatment preferences, and existential questions (including openness to spirituality);

- the support offered in the decision-making process, particularly when ethical tensions arise;
- the establishment of connections between the patient, their family, loved ones, healthcare professionals, and other involved providers;
- the gradual and individualised development of advance care planning;
- the expertise in protocols for distress management, palliative sedation, and euthanasia
- and the bereavement support if necessary.

This list is aligned with the publication of Lacerda et al. (2023) about the integration of PC into paediatric oncological care.[52]

3.3.2.3 Key elements as trigger for identifying a paediatric palliative situation

Most participants to the nominal group expressed the absence of clear-cut element when deciding to start PC due to the difference of every context and the fluctuating and progressive nature of severe conditions. Some participants expressed the need for the right care at the right moment in the right place independently of a decisional algorithm determining when to start PC.

The presence of LLC, LTC or an unknown condition was clearly expressed as a mandatory element to wonder if there is a palliative situation, even if the life expectancy is not estimated to be (rather) short. This confirms the content of Figure 11 where the clear-cut element between SC to PC is the presence of LLC/LTC.

Some participants to the nominal group have again illustrated that PC is started when different key elements cumulate. The elements “impact on the quality of life”, “duration of the suffering”, “incurability”, and “short life expectancy” were again mentioned. Also, the presence of multiple needs was reported. Unstable phases (e.g., GPs change, surgery, change in family situation, unexpected complication, new symptom) were also reasons to consider the start of PC.

But in practice, PLTs are mainly called when the deteriorating phase occurs. One participant says that the early integration of PC is easier in metabolic and neurologic diseases than in oncology. The importance of initiating palliative care as early as the time of diagnosis was, however, consistently emphasised throughout the nominal group. It was explained that the early involvement of a paediatric liaison team (PLT) is very important to build trustful relationships with parents and the young patient.

Some clinical experts from PLTs explained that the start of PC also depends on family decision, particularly when the family is exhausted. One clinical expert stated that deciding on limitations of care often marks the start of palliative care, highlighting the close link with advance care planning (ACP).

Complexity was also mentioned as a reason to ask for the support of PLTs, notably when an important number of actors was involved and therefore coordination is needed. In this way, a first concertation meeting around the ACP may be the starting point of PPC.

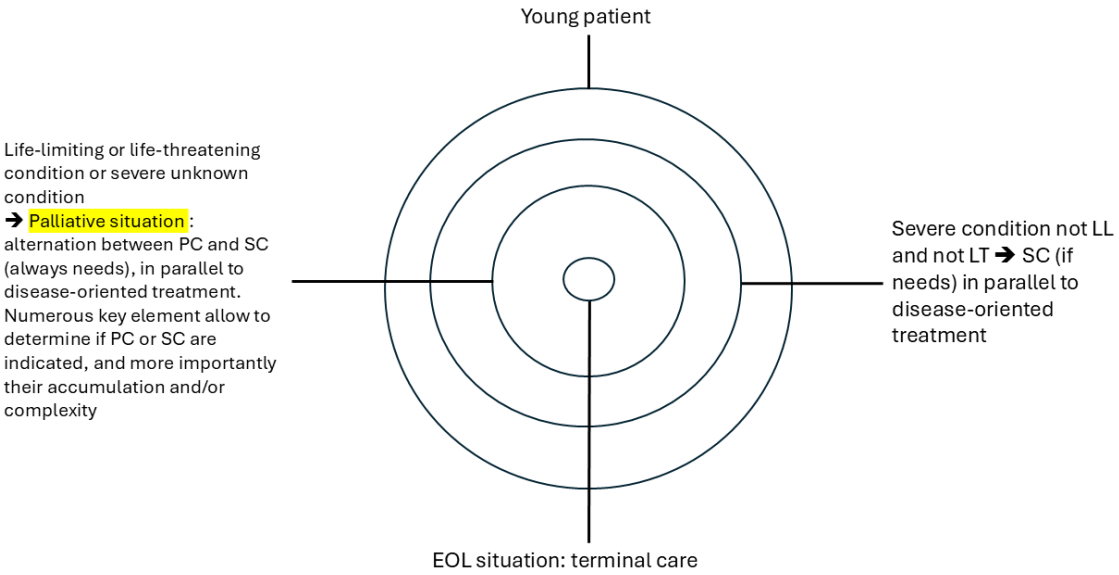
Finally, one participant suggested to use the PaPaS scale as a decision-making guide (see 3.3.3.2).

3.3.2.4 Summary of and discussion about the findings about the transition between supportive care and palliative care in the paediatric context

One recurrent point across the consultations is the context of LTC or LLC highlighted by experts and also by clinicians with limited or extended experience in PPC (see section 4 on the online survey results of the supplementary data). The presence of LLC, LTC or an unknown condition was clearly expressed as a mandatory element to wonder if there is a palliative situation.

The model presented in Figure 11 was updated in Figure 12 with the insights gained from the clinical experts’ consultation.

Figure 12 – Model of PPC target population



In this model, supportive care should be delivered to young patients with severe conditions, not necessarily life-limiting and not life-threatening, while palliative care should be offered to young patients and their family in the presence of LLC/LTC. According to the clinical experts, supportive care interventions differ from PC by the place given to communication about spirituality, patients and family wish, ACP, and family support.

Beyond the presence of a LLC/LTC, the accumulation of different key elements, in addition to the wish for PPC or the exhaustion of the family, makes the mindset of professionals progressing to the start of PPC.

PPC finally seems mainly to be patient/family-centred care than care mainly oriented on comfort, as is the case in adult palliative care. Moreover, as the trajectories of LLC and LTC fluctuate, supportive care and palliative care can alternate to relieve the suffering of the patient in parallel to curative or disease-directed treatments if those are available. In this case, the philosophy of care will also fluctuate according to the disease phase. There is no single transition into a "palliative phase"; rather, palliative care needs emerge and recede over time within a palliative situation defined by the presence of LLC/LTC or an unknown condition. Those needs may be met by coordination, communication, spiritual care, support for the family and wider social network, and support for healthcare professionals without or with limited experience in PPC.

3.3.3 Identification of paediatric palliative situation and referral tools to PPC services

An extensive search using a scoping review method was conducted to determine the availability of identification and referral tools to help the clinicians in the difficult exercise of identifying a paediatric palliative situation (see details and full search results in section 6 of the supplementary data).

The result of that search is presented below according to two categories:

- International standards and national referral frameworks
- Identification scales
  - Scales developed for paediatric population
  - Scales adapted from adults' palliative care

3.3.3.1 International standards and national referral frameworks/eligibility criteria

ACT/RCPCH categories of life-limiting and life-threatening conditions (1997)

The four categories of disease trajectories of life-limiting and life-threatening conditions were developed by The Royal College of Paediatrics and Child Health (RCPCH) and the Association for Children's Palliative Care (ACT) in 1997.[36] They have been and continue to be the conceptual basis for international PPC standards and policies.
These four categories of disease trajectories were developed based on expert opinion aiming to avoid an inappropriate focus of PPC on malignant/oncologic diseases. These categories of disease trajectories are based on the high probability that the child will not survive into adulthood as expressed by the 'surprise' question: 'Would you be surprised if this child were to survive into adulthood?'.[37]

Figure 13 – ACT/RCPCH categories of life-limiting and life-threatening conditions

Table 1 ACT/RCPCH Categories [6]

Category	Key characteristic	Description	Examples
I	**Potential for cure** - life is threatened, not necessarily limited.	Conditions for which treatment may be feasible but can fail	Cancer Some cardiac anomalies
II	**Period of normality** despite having fatal diagnosis.	Conditions where premature death is inevitable but where there may be long periods of participation in normal activities	Duchenne Muscular Dystrophy
III	**Relentless deterioration** from, or before, time of diagnosis.	Progressive conditions without curative treatment options, where treatment is exclusively palliative and commonly extends over many years	Metabolic or neurodegenerative conditions
IV	**Unpredictable** course whose progression is not easily judged from natural history.	Irreversible but non-progressive conditions causing likelihood of premature death through complications	Severe cerebral palsy Traumatic brain injury Septic brain injury

Source: Hain et al 2013[37]

The goal of these categories of disease trajectories is to identify children who need PPC interventions. The four categories of disease trajectories illustrate the wide range of conditions that may benefit from PPC at different levels of provision (PPC approach, general PPC, and/or specialist PPC services). The examples of conditions provided in each disease trajectory category are illustrative rather than exhaustive. Children may move between the categories over time or meet the criteria for more than one category simultaneously. Furthermore, only a proportion of children within these categories will have active palliative care needs at any given time.[1]

Together for Short Lives Guide for PPC (2018)

This guide published in 2018 by Together for Short Lives in the UK[m] confirmed the four categories of life-threatening and life-limiting conditions and stated that, besides diagnosis, other factors of care complexity should have been considered such as: spectrum and severity of disease, complications, needs of the child and family.[53]

WHO's Guide on integrating PC into Paediatrics (2018)

The WHO's guide presents groups of populations and conditions (details in section 6.3.1.1. of the supplementary data) that generate a need for PPC.[54] The groups of populations of children that need PPC are based on the four groups of ACT/RCPCH with two new groups: neonates who are severely premature or with severe congenital conditions, and family members of a foetus/child who dies

[m] A new referral framework for PPC has been recently developed and published by Together for Short Lives (May 2026) and is presented below under 3.1.1.11

unexpectedly. The groups of conditions include malignancies, perinatal conditions, injuries, serious infections, genetic conditions, malnutrition and pain.

GO-PPaCS (Global Overview- Pediatric Palliative Care Standards) (2022)

These standards for PPC were developed by a group of international experts in PPC. GO-PPaCS replaced the first version of the guidelines, IMPaCCT[55] and were endorsed in the 2022 European Charter on Palliative Care for Children and Young People.[1,56] The GO-PPaCS are based on a literature review (updated until April 2021) and consensus through open discussion.[1] According to GO-PPaCS, there is a general agreement that children with life-threatening or life-limiting conditions, as well as those with terminal illness (i.e., a condition in which death has become inevitable) may need PPC (see Figure 14).

Figure 14 – Classification of conditions where the child may need PPC

Conditions for which the child may need PPC can be classified as life-threatening, life-limiting (both also refer to serious illness), or terminal (see Table 1).

Table 1. Classification of Conditions Where the Child May Need PPC

Category	Description
Life-threatening condition	A condition with a high probability of premature death due to severe illness, but also a chance of long-term survival to adulthood for example,: children receiving cancer treatment, children with severe neurological impairment, children in intensive care due to acute injury, children with technology dependency
Life-limiting condition	A condition where there is no reasonable hope of cure: premature death is expected, for example: Duchenne muscular dystrophy, Tay Sachs Disease, Trisomy 13, Trisomy 18
Terminal illness	A condition in which death becomes inevitable in children with life-limiting or life-threatening illnesses

Source: Table taken from International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS.[1]

The medical conditions eligible for PPC were classified in five categories based on disease progression/trajectory (four categories of ACT/RCPCH plus a fifth group relating to perinatal/neonatal conditions). The description of the five categories is available in section 6.3.1.1. of the supplementary data.

The GO-PPaCS emphasise that both the child's diagnosis and the complexity of the needs of child and family should be considered when determining eligibility to PPC. They also highlight the importance of standardising PPC eligibility criteria. To this end, GO-PPaCS endorse the list of eligibility criteria presented by a group of PPC experts, in Italy, which integrated the findings of a review of literature (Medline, CINAHL, Cochrane, Trip Database) with the clinical experience of the members.[1,57] The GO-PPaCS recommend that PPC should be provided when any of these criteria are met. The list of the eligibility criteria is shown in Figure 15. These criteria include the presence of a **life-limiting/threatening condition**, as well as indicators of **care complexity**, such as recurrent or severe hospitalisations, dependence on invasive medical devices, conditions associated with difficult symptom/pain management, complex psychosocial and/or spiritual needs, and difficulties in making significant care decisions.

Figure 15 – GO-PPaCS criteria for PPC

Table 3. Eligibility Criteria for PPC (Modified From [Jankovic 2019]). PPC should be Provided when Any of the Following Eligibility Criteria are Met

- **Diagnosis of a life-limiting/threatening condition**
- **Serious episodes of hospitalizations:**
  - **at least three hospitalizations for serious clinical crises over a period of 6 months;**
  - **hospitalization of over 3 weeks without clinical improvement according to the medical team;**
  - **admission to intensive care of over 1 wk without clinical improvement**
- **Use of invasive medical devices for life support**
- **Life-threatening condition that causes difficulties in the management of pain or other symptoms**
- **Life-threatening conditions and complex psychosocial and spiritual needs of the child and family, including, but not limited to:**
  - **limited social support**
  - **the simultaneous need for more than three specialized services**
  - **a child with difficult and complex management of care handover between the hospital setting and the home**
- **Difficulties in making significant decisions for children and/or family:**
  - **difficulties in achieving consensus between the child, family and medical team on treatment and goals of care (e.g., resuscitation, use of parenteral nutrition/IV hydration or continuation of chemotherapy in the terminal stages)**
- **The anticipation of special support during the mourning period**

Source:Table taken from International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS.[1]

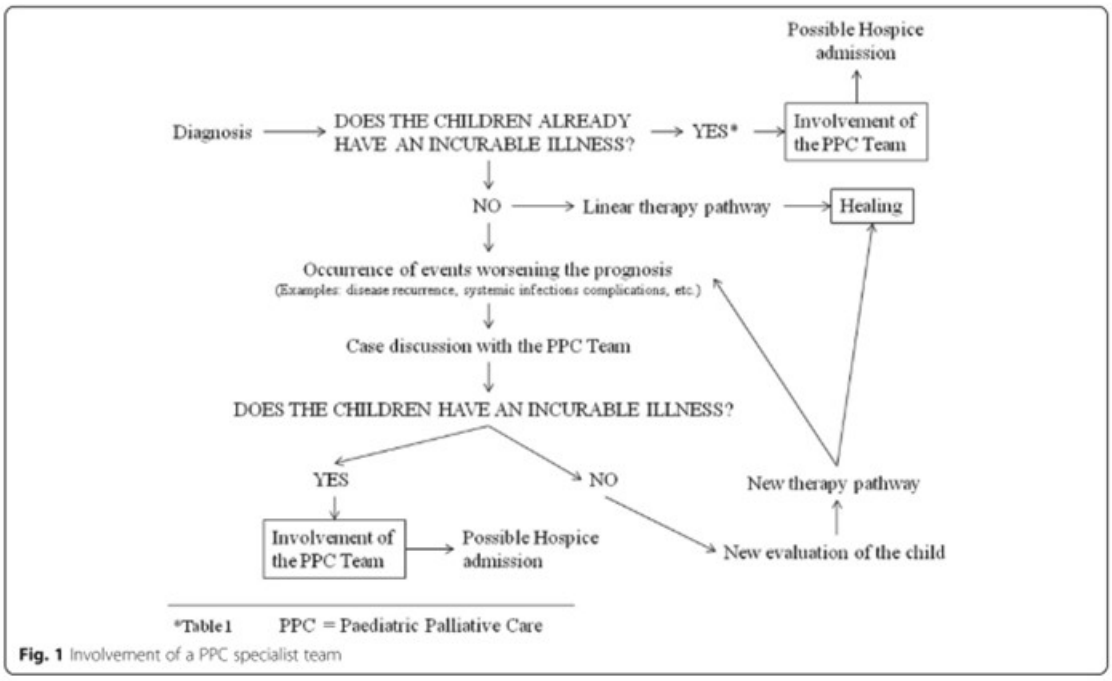
The list of eligibility criteria (green lights) for PPC

The list of 'green lights' to consider a PPC consultation for a child with and without cancer from the community presented by Kaye et al. in 2015 [58] and the referral criteria for PPC of the Center to Advance Palliative Care in USA[59], have served as a basis to the set of 'green lights' for considering a child eligible for PPC published by the consensus group of PPC experts in Italy and endorsed by GO-PPaCS.[1,57] The lists are available in section 6.3.1.1. of the supplementary data.

These "green lights" or eligibility criteria for PPC are not intended to serve as mandatory referral criteria but rather as signposts to prompt consideration of PPC referral.[58] They reflect the broad range of clinical situations that PPC experts consider appropriate for community-based paediatric palliative care and support timely identification of children who may benefit from these services.[58]

The consensus group of PPC experts in Italy also developed a flowchart (see Figure 16) to guide the involvement of the specialised PPC team, based on the presence of an incurable illness and evidence of disease progression or a worsening prognosis.(Jankovic et al., 2019)

Figure 16 – Flowchart to guide the involvement of the specialised PPC team



Source: Flowchart taken from "A consensus conference report on defining the eligibility criteria for pediatric palliative care in Italy" [57]

PPC referral criteria of the Center for Advancement of Palliative Care

These widely cited referral criteria were developed in 2009 by Friebert & Osenga (last version reviewed in October 2025 and used with permission from CAPC) and include general and specific criteria for twelve specific groups of children with complex chronic or life-threatening/life-limiting conditions: malignant disease, pulmonary, genetic, neurologic, metabolic, infectious, orthopaedic, renal, GI, neonatal, cardiac and intensive care. Each set of criteria is divided into those leading to automatic and suggested referral.[59] (See Figure 17)

Figure 17 – PPC referral criteria of the CAPC



Source: Taken from Pediatric Palliative Care Referral Criteria [59] (used with permission)

The Standards of Practice for PPC, National Hospice and Palliative Care Organization, USA (2022)

These standards adopt the four diagnostic categories developed by ACT/RCPCH as examples of children who should be considered for palliative care or hospice services, with or without ongoing curative or disease-modifying treatments. They further suggest that, when determining whether to recommend palliative care or hospice services while disease-modifying treatment continues, one approach would be to ask the question: "Do you expect this child to live to adulthood?" or "Would you be surprised if this child died in the next year?".[60]

The Core Care Pathway for PPC, Pediatric Palliative Care Alliance, Canada (2025)

The Core Care Pathway for PPC includes a guide on "How to identify if an infant, child, or youth has palliative care needs" which is based on a synthesis of best available evidence for identifying children who may benefit from PPC.[61,62]

The pathway states that a child with serious illness may be identified by either a family member or healthcare professional. Serious illness is defined as a life-threatening/life-limiting condition associated with a high likelihood of death before full adulthood that negatively impacts a child's daily function, quality of life, or places substantial stress on caregivers. Additional indicators may include prognostic uncertainty, prolonged/recurrent hospitalisations/intensive care unit admissions, medical fragility or instability, and dependence on medical technology.[61,62] Details are available in the section 6.3.1.1. of the supplementary data.

The Canadian Core Care Pathway for PPC outlines four categories of criteria that can be used to guide decisions about which child may benefit from PPC:

- Illness trajectories: the conditions where a child and their family may benefit from PPC can be grouped in five trajectories (based on GO-PPaCS)
- Functional and clinical indicators: these indicators are guides to recognise when PPC is needed and when a referral to specialist PPC may be appropriate.

- Triggers like concerns about caregiver or HCP; psychosocial or spiritual cues; acute care episodes, diagnosis with poor prognosis or high symptom burden
- Fragility, Instability, and the 'Gut check'

Canuck Place Children's Hospice in Canada has adapted the Canadian Core Care Pathway of PPC into five steps of identifying a child/youth with a serious illness or palliative care needs.[63]

- Step 1: Assess presence of serious Illness
- Step 2: Consider the possible category
  - Category 1 - Life-threatening curative treatment available but may be unsuccessful
  - Category 2 - Long period of treatment which aims to prolong life, but premature death is anticipated
  - Category 3 - Progressive conditions where treatment is palliative from diagnosis (no cure but symptoms can be managed
  - Category 4 - Severe disability that leads to extreme vulnerability to complications and premature death is expected
- Step 3: Consider the fragility and instability of the child's health condition: health zones as an intersection of fragility and instability
- Step 4: Consider the 'surprise question': Would you be surprised if this child or young adult were to die in the next 12 months or would you be surprised if this child or young adult were alive in the next 12 months?
- Step 5: If the child/young adult meets any of the above criteria contact the Hospice team to discuss possible referral or consultation.

The PPC Referral Decision-Making Guideline Tool for Health Professionals, Australia (2025)

This tool aims to support health professionals in identifying the appropriate time to refer children, young people, and their families to PPC.[64]

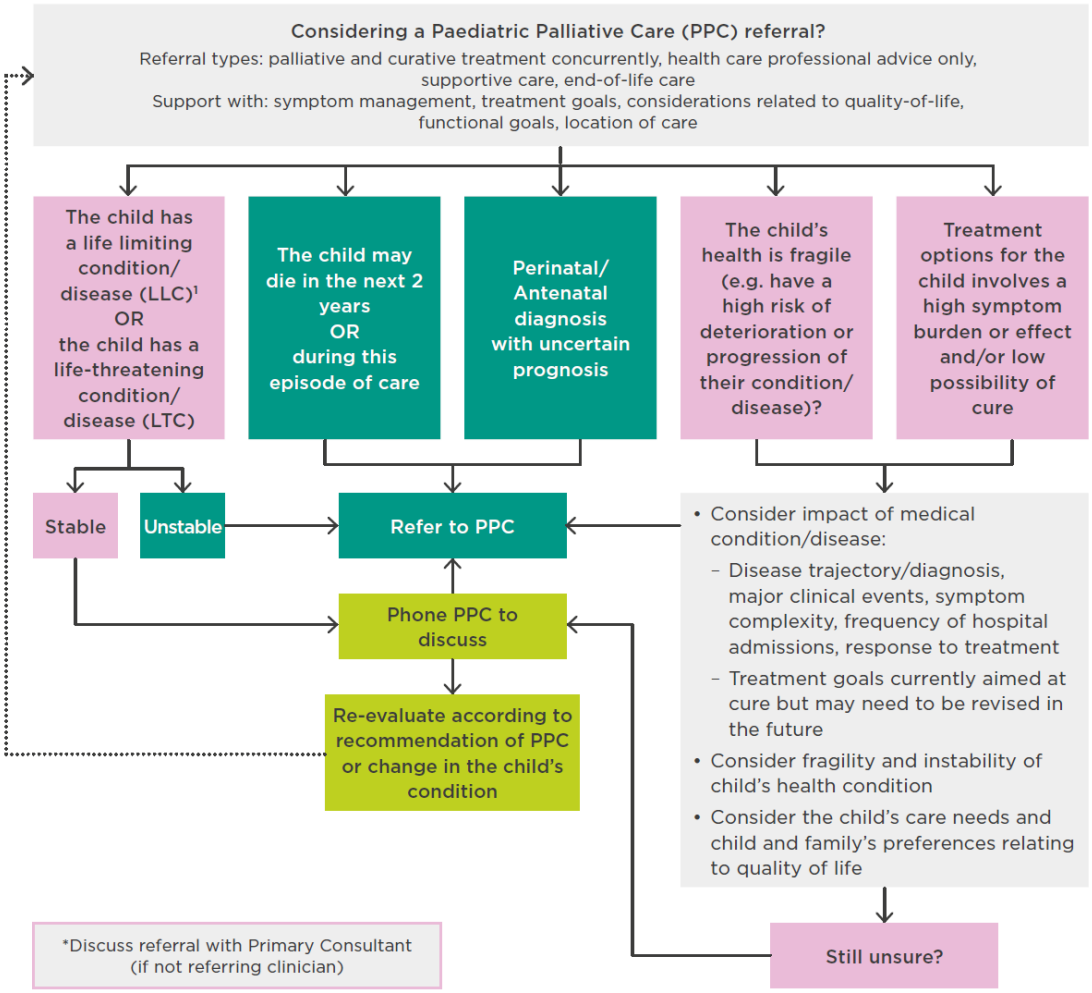
The tool encourages the provider not to rely solely on a set of indicators, but to consider the overall picture of unmet needs or increasing challenges, such as:

- Escalating symptoms or emotional distress in child or family
- Functional decline or change in quality of life
- Conflicting views about care goals or treatment pathways
- Gaps in psychosocial support, understanding of prognosis or system navigation
- Clinician uncertainty or concern about the future

The tool is designed for treating specialists, such as oncologists, neurologists, cardiologists, neonatologists, paediatricians, and other healthcare professionals, working with children with life-limiting conditions. It is also intended to support nurses and palliative care teams by complementing their expertise and promoting timely, multidisciplinary collaboration in referral decisions.

The decision-making guideline for PPC referrals includes a flowchart to help healthcare professionals determine whether referral to PPC is appropriate (see Figure 18). It facilitates a reflective process that considers the child's medical condition, prognosis, symptom burden, and family preferences.

Figure 18 – Flowchart of the decision-making guideline tool



Source: Flowchart taken from Referral to Paediatric Palliative Care: Decision Making Guideline Tool for Health Professionals [64]

The Decision-Making Guideline Tool includes a set of 30 questions designed to help explore and understand the overall situation of the child and family. These questions are organised into five key areas:

- Questions 1-3 are assessment questions on condition and referral types using the life-limiting and life-threatening conditions and the four categories of their trajectories, and a version of the surprise question
- Questions 4-12 are reflective questions on progression and management of conditions
- Question 13-19 are reflective questions on child and family needs
- Question 20-23 are reflective questions on service considerations
- Question 24-30 are reflective questions on health professional considerations

By working through these reflective questions, healthcare professionals determine whether referral to PPC should be immediate, soon or at a later stage. This process also helps ensure that families are introduced to PPC in a manner that supports informed choice and coordinated care.[64]

The new framework for recognising children's palliative care needs, Together for Short Lives (2026)

The new framework in the UK[n] is designed to reflect the complexity, uncertainty and variation seen across services in real-world practice and is aligned with national guidelines and standards. The new toolkit is intended as a recognition tool rather than a referral threshold. Decisions regarding referral to specialist services will continue to depend on local service configuration, service availability, professional judgement, and individual family circumstances.[65]

The new framework shifts the focus away from identifying children needing PPC based solely on medical diagnosis, toward assessing the individual needs of the child and family. It emphasises **complexity and vulnerability as key determinants of need rather than diagnosis alone**. It also recognises that paediatric conditions often follow non-linear trajectories and change over time, thereby shifting attention from prognosis to dynamic and evolving care needs.[65]

In addition, the framework supports the involvement of PPC from the point of diagnosis, including prenatal and perinatal stages of life. It is designed to be applied across the three levels of PPC - universal, core and specialist- thereby promoting a whole-system approach rather than a model focused on specialist services.[65]

To ensure a standardised approach across different healthcare settings, the new framework encourages professionals to use a four-step checklist during routine reviews or when a child's condition changes:

Step 1: Assign a category of care: identify the pattern of vulnerability (category A, B, or C) that best describes the child's underlying condition.

- Category A: Life-threatening conditions

  Conditions for which disease-modifying or life-prolonging treatment may be available but may fail, or where intensive therapies and interventions are required to sustain or prolong life. These conditions carry a significant risk of premature death even if treatment is pursued.

- Category B: Life-shortening conditions

  Conditions where death in childhood or early adulthood is likely due to the progressive nature of the condition or the absence of effective disease-modifying or curative treatment.

- Category C: Severe medical complexity

  Children with severe medical complexity and vulnerability, including multi-system involvement, profound neurological impairment, technology dependence, or extreme frailty, where there is a significant risk of life-threatening events.

Children and young people may move between categories over time.

Step 2: The graded surprise question: use prognostic horizons to gauge risk and trigger appropriate discussions and planning. Where the answer to the question is 'no' and it would not be a surprise if the child died that should prompt the team to actively consider/discuss a palliative approach to care with the child (if appropriate) and their family.

Step 3: Consider the current phase of care: determine the child's clinical state to decide what actions and resources may be needed.

The phases of care needs describe a child's current care requirements rather than their long-term prognosis. A child can be in any phase regardless of their diagnostic category and may move between phases of care needs in a non-linear way. Phases are intended to support planning, not act as

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[n] The charity Together for short life asked KCE to keep the description of the framework as close as possible to the one published on their website.

thresholds. Use of phases should always involve clinical judgement and family discussion. A description of the different phases including the types and intensity of the required PC for each phase is available in section 6.3.1.1. of the supplementary data.

Step 4: Identify triggers for specialist input: decide if the child's needs (such as complex symptom management or complex ethical decisions) now exceed the capability of the local core team.

While many needs are met by universal and core teams, a specialist PPC referral should be triggered when clinical or ethical complexity increases.

Key triggers can include:

- refractory symptoms that are difficult to manage with standard medications.
- complex ethical disputes regarding the withholding or withdrawal of life-sustaining treatment.
- end-of-life care at home, where 24/7 specialist advice and nursing support are required to maintain comfort.

3.3.3.2 Screening/Identification Scales developed for paediatric population

PaPaS (PAediatric PAlliative Screening) scale

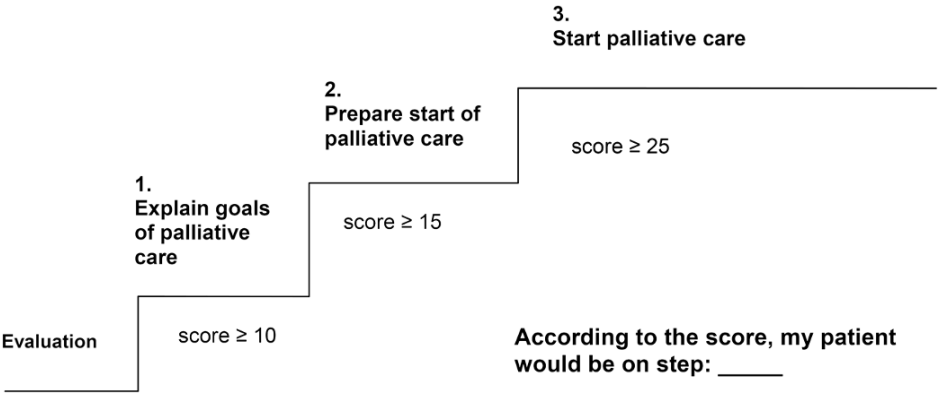
This scale is based on five domains and intended to facilitate appropriate and timely involvement of specialist PPC teams/services.[66,67]

- Disease trajectory and impact on daily activities
- Expected outcomes and treatment burden directed at disease and burden of treatment
- Symptom and problem burden
- Preferences of the child, parents and health professionals
- Estimated life expectancy

Each domain is scored using yes/no questions/items, with a total of thirteen items weighted from 0 to 4 points (see Figure 19). Based on the total score, the child is assigned to one of the three steps of the graduated PPC referral process:

- Explain goals of PC (introduction of PC)
- Prepare start of PC (basic symptom management alongside disease-specific treatments)
- Start PC (PC becomes the focus of care)

Figure 19 – Steps determined by PaPaS scale score



Source: Taken from The development of an instrument that can identify children with palliative care needs: the Paediatric Palliative Screening Scale (PaPaS Scale): a qualitative study approach [66]

The scale is available in the section 6.3.1.1. of the supplementary data.

The PaPaS scale has evolved into an international screening tool for PPC. It has been translated and adapted for use across different healthcare settings and languages. It is available in English (original), German[68], Korean[69], Portuguese[70], Chinese[71], Italian[72] and Spanish[73]. It has been applied in PPC research studies in Singapore[74], India[75], South Korea[69] and Peru[76]. It is also recommended for use within the Canadian Core Care Pathway for PPC (see 7.6.3.4).[62] A neonatal version of the PaPaS scale is currently in process of publication, as explained by the Swiss expert during the interview (see section 7 of the supplementary data).

An adaptation of the PaPaS scale for the paediatric intensive care unit has also been developed and validated: the Pediatric Intensive Care-Pediatric Palliative Care Screen (PIPPS).[77] PIPPS is seven-item screening tool consisting of true-or-false questions. It comprises of two parts:

- Part 1 identifies patients who may benefit from a PPC consultation,
- Part 2 assesses five domains of potential palliative care needs, reflecting the domains of the PaPaS scale. The screen is considered positive when at least one statement in each part is endorsed as true.

The tool is available in section 6.3.1.2. of the supplementary data.

ACCAPED - Assessment of Complex Clinical Assistance needs in PEDiatrics

This tool aims to assess the complexity of care needs in children with incurable or chronic conditions. It is designed for use by healthcare professionals across different settings and focuses on clinical and supportive care needs to identify children and adolescents who need different levels of PPC.[78–80] It covers medical (clinical) and supportive (assistance) needs in ten areas:

- Respiration
- Feeding
- Convulsive crisis or altered state of consciousness
- Skin and tissue integrity
- Mobility
- Communication
- Sleep and rest
- Continence and elimination
- Administration of medications
- Pain
- Risk of clinical instability/premature death
    - no risk of progression or early death
    - risk of progression/deterioration
    - not surprised if this patient dies within 12 months

Points (0-50) are assigned to each area depending on the level of care complexity. The scale also includes a modified version of the ‘‘surprise question’’ (‘‘Would you be surprised if this patient died within the next 12 months?’’), which is used as a trigger for referral to specialist palliative care and accounts for up to 50 points. Scores across all areas, including the surprise question, are then summed up. Based on the total score, the level of care complexity and corresponding level of PPC provision needed are categorised in three levels as shown in Table 5.

Table 5 – ACCAPED – Three levels of complexity of care needs

Total ACCAPED score	Level of complexity of care needs	Level of PPC services and providers
≤29	Basic	Level 1: PPC approach Primary care providers: GP, general paediatrician, community healthcare facilities
30-49	Moderate	Level 2: General PPC Secondary care: hospital, medical specialties
≥50	High	Level 3: Specialist PPC Specialised PPC centre/team

The severity of the care needs determines the level of PPC service provided within community care, general PPC (delivered by specialists managing the underlying disease with training in PPC), or specialist PPC (delivered in dedicated settings by a multidisciplinary team of PPC experts).

ACCAPED was originally developed in Italian and has recently been translated and validated in a modified English version.[81] The English version of ACCAPED is available in section 6.3.1.2. of the supplementary data.

START (Screening Triage Assessment and Re-evaluation tool)

START is a tool developed and used by the Pediatric Advanced Care Team (PACT) at the East Switzerland Pediatric Hospital. The tool begins with a quick test (a shortened version of the PaPaS scale), followed by the main assessment part. The tool is currently only available in German.[82] A translation of the two parts in English is available in the section 6.3.1.2. of the supplementary data.

Like the PaPaS scale, the START scale uses the overall score to guide the choice of the three levels of PPC interventions. Details are available in section 6.3.1.2. of the supplementary data.

A neonatal START questionnaire has also been developed.[83]

3.3.3.3 Screening/Identification Scales developed for paediatric population

PALLIAPED 10

PALLIAPED 10 is a paediatric adaptation of PALLIA-10, a multidimensional questionnaire addressing medical, psycho-social and ethical issues. It was developed and proposed by SFAP (*Société Française d'Accompagnement et de Soins Palliatifs* - French Society for Palliative Support and Care) in 2010.[84] PALLIAPED 10 is designed for use by any professional, including nurses, physicians, and educational or social professionals, to initiate referral to PPC. The tool comprises ten key areas/domains for a global assessment, with each item as a Yes/No question. If three or more answers are 'Yes', referral of the child to a PPC team is considered appropriate.[85] The tool in French is available in section 6.3.1.2. of the supplementary data.

PALLIAKID Early Detection System

PALLIAKID is an EU-funded [o], interdisciplinary project aiming to evaluate the feasibility, effectiveness, and cost-effectiveness of novel interventions for children, adolescents and young adults with palliative and end-of-life care needs in different healthcare systems across Europe. The project started in 2023 and is expected to finish in 2028.[86]

One of the goals of PALLIAKID project is to develop the PALLIAKID early detection system using advanced technology to identify, in an early-stage, children and young adults with serious illness who

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[o] 19 organisations from 10 European countries coordinated by *Fundacio Privada Per a la Recerca I la Docencia Sant Joan de Deu* in Spain

need palliative care. The Early Detection System will be developed in collaboration with healthcare, data management, ethics, and data protection experts. It will identify variables that correlate with the need for palliative care, apply exploratory data analytics and bio-computational engineering techniques, and develop predictive machine-learning models using a retrospective clinical dataset and will be prospectively validated at four clinical sites to evaluate its feasibility, predictive performance, and cost-effectiveness.[87]

3.3.3.4 Summary of the findings about identifications tools and referral frameworks

In conclusion, the above mapping of the available identification tools for PPC demonstrate that, over the past 30 years, the focus has gradually shifted from the diagnosis- and disease trajectory-based approaches toward assessing the complexity of care needs. This shift provides a more accurate reflection of the real-world needs of young patients, families, and the professionals involved in their care, and aligns more closely with the comprehensive definition of PPC.

Assessment of eligibility and referral for PPC should also be viewed as a longitudinal process rather than a one-time event. Because the needs of young patients and their families are dynamic and may change throughout the disease trajectory, regular reassessment is essential to identify evolving PPC needs and to adjust accordingly the level of PPC provided. This finding aligns with the consultation of Belgian professionals which has shown that a part of them have agreed that an assessment tool can help but that the most useful ways to identify a palliative situation, according to them, are multidisciplinary consultation, knowledge and time.

Regarding the most appropriate tool for early identification of young patient who need PPC, there is currently no consensus. The PaPaS scale was developed on a strong foundation of literature review and consultation with international PPC experts and has since been translated and validated across several languages and PPC settings including paediatric intensive care.[69,74,77] It is a structured tool that supports clinicians in objectively assessing the need for PPC and facilitating timely referrals. However, its limitations include variability in scoring between clinicians and limited correlation with quality-of-life measures.[69,75] Furthermore, its comprehensive, multi-domain structure requires training and familiarity with PPC, which may limit its feasibility in non-specialist settings. The ACCAPED scale determines eligibility for different levels of PPC by assessing the complexity of medical needs and the risk of life-threatening events.[79–81,88,89] However, it is primarily focused on clinical complexity and does not comprehensively assess other important dimensions of complexity of care, such as psychosocial and spiritual needs of the young patient and family. Therefore, a broader, multidimensional assessment remains necessary to ensure that all aspects of the young patient's and family's palliative care needs are identified and addressed.

Although screening tools are valuable for identifying young patients who may benefit from PPC, they should not replace comprehensive, individualised, continuous assessment by healthcare professionals involved in the young patient's care. Rather, they should be used to support clinical decision-making and facilitate timely recognition of needs that can be addressed by PPC services.

3.4 Conclusion of the chapter

According to the framework of Levesque et al. (2013), the first step of the journey of a patient needing to access adequate healthcare service is the presence of care needs.[27]

In Belgium PPC needs exist. An estimation of the number of young patients who are likely to be in a palliative situation gives an approximation of 20 000 eligible patients for PPC every year. This number is likely an overestimation as the young adults from 18 to 25y were all included in the calculation (while only the ones whose condition started before 18 should be included) and the complex chronic conditions which allow to determine the eligible population are not all life-limiting or life-threatening conditions. However, as the target population also includes parents, siblings, informal caregivers and professionals, the population in paediatric palliative situation is larger than the number of eligible young patient. Improvements in routine data collection of a wide range of care complexity factors could

facilitate estimation of population-level PPC need and ensure greater alignment with how need for PPC is defined at the individual level in the clinical setting.

In addition, this chapter brings clarification on key elements like suffering, patients/parents wish or incurability, allowing to distinguish, for unknown conditions, which one could be in a paediatric palliative situation. Many tools are available to help HCPs assess the healthcare situation of young patient and their families. However, none of them is more recommended than another and all seem to evolve by taking into account complexity of the situation in addition to clinical aspects.

4 AWARENESS, ADVOCACY, EDUCATION AND RESEARCH IN PAEDIATRIC PALLIATIVE CARE

KEY POINTS

Awareness

Awareness of paediatric palliative care, among both the general public and some professional groups, remains limited and largely dependent on fragmented local initiatives.

Therefore, improving awareness of PPC requires a coordinated national approach combining public awareness, targeted information, stakeholder collaboration, and stronger engagement of patient and family organisations.

Advocacy

Advocacy for PPC remains underdeveloped, with constrained capacity among key stakeholders and limited visibility in broader policy processes.

Strengthening advocacy requires better-supported organisations, stronger coordination, and clearer recognition of PPC within policy and children's rights frameworks.

Training

Training in PPC is underdeveloped, heterogeneous and not yet organised within a coherent educational continuum, in general education and in continuing education.

A graduated and competency-based training model is proposed, ranging from public awareness to specialist PPC expertise, reflecting the rarity of PPC cases and the need for proportionate, role-based education embedded in a broader strategic framework.

Research

PPC research in Belgium remains scarce and dispersed, with limited coordination, prioritisation and integration into national knowledge development structures.

Strengthening PPC research requires coordinated priorities, sustainable funding, stronger collaboration, and better use of national data to support evidence-informed policy and practice.

4.1 Global context: the perception of healthcare needs

As outlined in section 2.3, the second step in a patient's journey to accessing appropriate healthcare services is the perception of care needs.[27]

The dimension underlying the ability to perceive healthcare needs is the approachability of the service. To access paediatric palliative care, people facing paediatric palliative care needs must be aware that PPC services (i) exist, (ii) are accessible, and (iii) can effectively address the child's and family's needs. Various elements such as transparency, outreach activities, and information regarding available

treatments and interventions could contribute to improve the health care system and to make the services more or less approachable.[27] However, these factors alone are not sufficient. The patients, families and HCPs not experienced in PPC have to be able to perceive PPC needs. This depends on factors such as health/death literacy, and knowledge and beliefs about palliative care.

This chapter mainly presents the findings related to the research question five: "What are good practices in other countries able to serve as good examples to improve the access to PPC in Belgium?" The methods used in this chapter are a scoping review of the scientific and grey literature on awareness, advocacy, education, and research in Belgium and internationally, complemented by consultations with Belgian professionals and international experts through questionnaires and interviews. Details of the methodology are provided in Chapter 2.

4.2 Raising awareness on PPC

This section examines awareness-raising activities related to PPC. Several sources have identified increased awareness of PPC as an important facilitator of access to care, both in Belgium and internationally.[5,6,90,91] Indeed, increasing awareness requires challenging persistent misconceptions and promoting a broader understanding of PPC as an approach to care centred on quality of life, rather than being associated solely with end-of-life care.[90]

This section is organised into three parts. First, it examines **awareness-raising activities** targeting the general population. Second, it explores how **organisations** such as charities, institutions and centres of expertise can raise awareness among the general population. Third, it reviews initiatives aimed at strengthening **awareness of PPC among healthcare professionals** as part of a broader professional culture (i.e., a core level of awareness that all healthcare professionals should possess, irrespective of their involvement in the care of children with palliative care needs and their families).

By awareness, we mean that PPC should be better known, by the general public and by HCPs, in order to help remove certain taboos and to provide these services from the time of diagnosis.

4.2.1 Awareness-raising activities

4.2.1.1 In Belgium

A web-based ad hoc search of current awareness-raising initiatives in Belgium showed that there is currently **no structured national awareness campaign**, **nor any other nationwide awareness-raising initiative**, specifically focused on PPC.

Nevertheless, some **local initiatives** that may contribute to raising awareness of PPC were identified. The *Koester Week* is organised each year in December to raise public awareness and encourage greater social support for bereaved parents.[92,93]. *Berrefonds vzw* has developed a range of activities aimed at increasing awareness of the need for bereavement support for parents and families who have lost a child.[94] Although not specifically focused on PPC, these initiatives help foster public discussion about child death and the support needs associated with it. Examples include an information website for parents and families, HCPs, schools and other stakeholders; World Candle Lighting Day (*Wereldlichtjesdag*), held annually on the second Sunday of December, during which people are invited to light a candle in memory of a deceased child.

Local municipalities can also obtain the status of **Compassionate Municipality** (*troostgemeente*), indicating that they have implemented initiatives addressing bereavement, loss and loneliness. Examples include remembrance or consolation concerts, educational activities and training for schools, and public information sessions on these themes.[95]

4.2.1.2 Examples from abroad

The examples from the countries we investigated show that awareness-raising activities related to PPC can take various forms. Many countries organise dedicated **awareness weeks** or **national campaigns** (e.g., Children's Hospice Week), often combining public events, fundraising activities, educational initiatives and media coverage. They seek to improve public understanding of PPC and challenge misconceptions.[96]

The formats of the initiatives vary, including audiovisual resources (e.g., short animated film *Nano y Choco* in Spain, or an animated information video that provides accessible information on available support, how and when services can be accessed, and the professionals involved in care in Germany), documentaries and communication campaigns targeting the general population. These may be embedded in the worldwide "Hats On" initiative.[97–100]

Other actions focus on **supporting communication** about PPC by providing guidance and tools for families, healthcare professionals, associations and media professionals (HEARD, IMA-GO!).[101,102]

Finally, broader palliative care initiatives, particularly those aimed at improving **health literacy and death literacy** among the general population, may contribute indirectly to increasing awareness and acceptance of PPC within society (Last Aid® Courses).[103]

Details of the activities, events and initiatives are available in section 7.3.1. of the supplementary data.

4.2.2 Contribution of organisations such as charities, institutions and centre of expertise on PPC

4.2.2.1 In Belgium

In Belgium, **non-profit organisations** exist to support parents and children living with serious illnesses. These organisations are generally created on the model of patient associations and provide support across a range of health conditions or for specific group ages. For example, some have developed activities focused on newborns and the perinatal period, while others support children with specific conditions. Some are also related to particular moments in life, such as bereavement. In addition to providing practical and emotional support to families, these organisations may play a role by raising awareness on childhood illnesses, PPC, and/or bereavement. Examples include *Stichting tegen kanker/Fondation contre le cancer*, *Kom op tegen Kanker, Berrefonds vzw*, *parents désenfantés asbl* and *Vilomah vzw*. However, the visibility of these organisations within the general population remains limited.[94,104–106]

Patient representatives emphasised the importance of informing parents about the existence of PPC teams, as families need a designated point of contact for issues related to quality of life. However, they reported that this information, which they considered should be provided by the treating clinical teams, is not being communicated effectively. According to the stakeholder consultation, first- and second-line healthcare professionals still appear to have limited awareness of PPC teams and their role. Patient representatives therefore questioned whether adequate mechanisms are in place to ensure that parents are informed about the existence and remit of PPC teams. (see section 8 of the supplementary data)

Several **organisations active in PPC**, other than patients' organisations, were also identified. For example, Hospichild.be, a platform supported by the Brussels regional authorities, provides information and practical resources related to the care of children with illnesses in the Brussels region. The platform is intended to support both families and professionals involved in the care of children.[107]

Stakeholders explained that adult palliative care federations include awareness-raising among their core functions, including about paediatric palliative care.

4.2.2.2 *Examples from abroad*

Across the countries reviewed, charities, foundations, professional networks and centres of expertise play a **central role in raising awareness of PPC**. Beyond their functions in family support, service development and professional education, these organisations contribute to improving public understanding of PPC through **websites, educational resources, campaigns, testimonials, videos and other communication tools**. Examples include the *Fondazione Maruzza Lefebvre D'Ovidio* in Italy, *Fundación porqueViven* in Spain, *Pro Pallium* in Switzerland and *Together for Short Lives* in the UK.[108–111]

In some countries, awareness-raising activities are also coordinated through **national organisations** that bring together multidisciplinary and multi-perspective stakeholders. For example, the Dutch *Kenniscentrum Kinderpalliatieve Zorg* (see Textbox 1) acts as a national reference centre for knowledge dissemination, coordination and policy development, while the Canada's Pediatric Palliative Care Alliance and the Canadian Network of Palliative Care for Children bring together healthcare professionals, organisations, and families to promote coherent, equitable, and high-quality PPC across the country.[112–115] In Australia, awareness-raising forms part of a broader national strategy, the National Action Plan for Paediatric Palliative Care (2023 – see Textbox 4 in Chapter 6), with dedicated actions.[116]

These examples illustrate the role of dedicated organisations and coordinated national structures in promoting awareness and visibility of PPC.

Details are provided in section 7.3.1. of the supplementary data.

Textbox 1 – *Kenniscentrum Kinderpalliatieve Zorg* (The Netherlands)

The *Kenniscentrum Kinderpalliatieve Zorg* (Dutch Centre of Expertise for Paediatric Palliative Care) is the national knowledge and expertise centre dedicated to improving paediatric palliative care across the Netherlands. It works to ensure that children and young people with life-limiting or life-threatening conditions, and their families, receive high-quality, coordinated and compassionate care.

Missions:

- Advancing knowledge and best practice, by developing national recommendations and clinical guidelines, generating, disseminating, and translating scientific knowledge into practice, and supporting research and innovation in PPC.
- Education, training, and professional support, by designing and delivering educational and training programmes, providing specialised clinical expertise, and offering consultation and advisory services to healthcare professionals and multidisciplinary teams.
- Strengthening care coordination, e.g., developing and facilitating collaborative care networks, promoting continuity of care across hospital, community, and home-based settings, supporting initiatives aimed at improving the organisation and integration of care pathways.
- Shaping the national PPC system, e.g., contributing to the development of health policy and strategic frameworks, coordinating with expert advisory bodies and national stakeholders, identifying emerging needs and promoting continuous service improvement.
- Supporting regional care networks, by facilitating integrated regional paediatric care networks, supporting specialised regional PPC teams (*Kinder Comfort Teams*), enhancing interprofessional and cross-sector collaboration.

The Centre promotes a child- and family-centred approach to PPC by addressing the medical, psychological, social, and spiritual dimensions of care, providing support to parents, siblings, and

other family members, and enhancing quality of life while ensuring, where appropriate, high-quality end-of-life care and bereavement support.

Source: Kenniscentrum Kinderpalliatieve Zorg(Kenniscentrum Kinderpalliatieve Zorg, n.d.-e, 2021)

4.2.3 Raising awareness of PPC among healthcare professionals

4.2.3.1 In Belgium

Existing awareness-raising activities targeting healthcare professionals appear to be **limited in Belgium**. One example is the Palliapro platform, developed by the Brussels Federation for Palliative Care and Continuing Care.[117] This online platform provides information, resources, training opportunities and practical tools related to palliative care for healthcare professionals. Although not exclusively dedicated to paediatric palliative care, it includes a specific paediatric section and contributes to increasing the visibility of PPC among healthcare professionals.

The **Belgian Paediatric Palliative Care** (BPPC) group was established to support the development of PPC in Belgium through activities such as networking, the development of recommendations and the dissemination of knowledge and good practices[118]. This network of healthcare professionals from paediatric liaison teams developed a handbook on paediatric palliative care and meets regularly to discuss needs and priorities in the field.[20,21]

4.2.3.2 Examples from abroad

Several countries have developed initiatives aimed at increasing awareness and understanding of PPC among healthcare professionals. These activities are often led by **charities, national PPC organisations or centres of expertise** and may take the form of **scientific conferences, webinars, informational resources, websites, flyers or introductory educational activities**. In particular, the Dutch *Kenniscentrum Kinderpalliatieve Zorg* develops and disseminates practical tools to support healthcare professionals' understanding of PPC and appropriate referral pathways.[119]

At the organisational level, the Swiss experience illustrates how awareness and visibility of PPC services can be strengthened through the participation of PPC teams in clinical rounds across various paediatric departments, including intensive care, general paediatrics and paediatric cardiology.

Details are provided in section 7.3.1. of the supplementary data.

4.2.4 Barriers to awareness raising in Belgium

As described in the methodology (Chapter 2), HCPs with limited experience in PPC were invited to complete an online questionnaire. Twenty-one respondents identified raising awareness as a priority for improving the quality of care. In open fields, respondents reported that a **lack of understanding of what PPC is**, according to the World Health Organisation definition, constitutes a barrier to access. They also highlighted that, among the general public and some non-specialist professionals, palliative care is often perceived as synonymous with end-of-life care and death, also constituting a barrier to accessing care. Some respondents reported the term “palliative” as being **taboo**. These findings are consistent with Bailey et al.(2025), who report that such misconceptions delay timely access to PPC services and make PPC appear intimidating to families and generalist healthcare professionals.[90]

The reasons why no coordinated approach to raising public awareness of PPC currently exists have not been deeply investigated. Although many patient organisations exist, they appear to play only a **limited role in awareness-raising activities** and generally have **low visibility**. This may be explained by their small scale, reliance on volunteers, and limited, non-recurring funding, which restrict their capacity to sustain awareness-raising activities. As a result, they may lack the financial resources, workforce capacity and expertise required to undertake sustained awareness-raising activities.

Professionals experienced in PPC expressed, during the interviews, that the limited role of patient organisations and professional associations, together with the absence of public awareness initiatives, may also contribute to low awareness of PPC among non-specialist healthcare professionals, including paediatric hospital departments. This limited awareness encompasses a broad spectrum, ranging from a lack of understanding of what paediatric palliative care entails to limited knowledge of the services available to support children, their families, and healthcare professionals (see section 5 in the supplementary data).

As a result, PPC remains largely invisible to the general public, contributing to poor understanding of its role and the services available. A key challenge in Belgium is therefore the absence of a coordinated and strategic approach to awareness-raising.

4.2.5 Solutions to raise awareness on PPC

The proposed solutions to increase awareness focus on collective literacy and social acceptability, including health and death literacy. They include public awareness campaigns, thematic awareness days, and information resources for the general population, with the primary aim of destigmatising palliative care.

Achieving this requires a **coordinated and strategic approach**. Given the sensitive nature of PPC, awareness activities should be developed carefully, in close collaboration with family representatives, healthcare professionals, and communication specialists.

Public awareness could be strengthened by **expanding existing local initiatives**, such as the *Koester Week*, to all regions, while **building on international initiatives** such as the "Hats On" campaign. National campaigns could also address broader themes that resonate with the public, such as the experiences of families caring for a child with a serious illness, the importance of support and comfort, or the challenges of life-limiting conditions. Stakeholders also suggested that palliative care federations could contribute through annual PPC campaigns using videos, awareness weeks, and digital communication tools. Federal coordination, for example through the FPS (FOD-SPF), could improve coherence and visibility.

Stakeholders stressed the importance of **assessing the feasibility and cost-effectiveness of proposed actions and coordinating them with existing initiatives**, particularly in Flanders, to avoid duplication. Examples include Compassionate Communities, the future Flemish Centre of Expertise for Palliative Care, and the PalliaPro website.

They also emphasised **tailoring awareness campaigns to different target audiences** and **providing information in multiple formats**, including practical toolkits for families and professionals. Health insurance funds and hospitals could also support dissemination.

Regarding campaigns targeting the general public, stakeholders highlighted the importance of **collaboration** with the federated entities and all relevant partners, including patient representatives. The respective roles of PLTs, the BPPC and palliative care federations in awareness-raising should also be reinforced.

Awareness among those directly involved in the care and support of children, including parents, extended family members and schools, could be improved through **audience-specific information** delivered via websites, videos, flyers, and face-to-face explanations. Regional authorities could coordinate these activities with patient organisations, palliative care federations, and the BPPC, while further strengthening existing international initiatives.

Patient, parents, and disease-specific organisations currently play a limited role in PPC awareness. International experience demonstrates that many significant advances in PPC awareness and policy development have been initiated and driven by non-governmental organisations (patients-, parents-, professional associations). **Supporting these organisations to become more visible** and communicate more actively about PPC could strengthen awareness in Belgium.

Proposed solution: reflection on an organisational model

A potential proposal for strengthening PPC awareness and coordination would be to reinforce and structurally fund the BPPC as a national umbrella organisation. This body could include a formal advisory structure bringing together parents, patient organisations, healthcare professionals, and providers already involved in paediatric palliative care, thereby avoiding the creation of an additional structure. International models, such as those in the UK and Canada, illustrate the value of such umbrella organisations acting as centres of expertise, information platforms, and key partners for public authorities.

In this model, the BPPC could have a strengthened mandate including:

- raising public awareness of PPC and the needs of affected children and families
- providing reliable, accessible, and tailored information and resources for different audiences
- offering peer support and facilitating referral to appropriate services
- advocating for the rights, needs, and interests of children with life-limiting or life-threatening conditions and their families
- contributing to policy development and strategic planning in PPC
- participating in consultations with health authorities
- supporting the implementation of national PPC strategies.

RAISING AWARENESS ON PPC

Improving awareness of PPC requires a coordinated set of actions at different levels of intervention

Implement a coordinated and strategic approach to PPC awareness, developed in collaboration with families, healthcare professionals, and communication experts.

Scale up existing local initiatives and strengthen national and international awareness campaigns using diverse formats (videos, awareness weeks, digital tools).

Ensure coordination and coherence of existing initiatives, including assessing feasibility and cost-effectiveness to avoid duplication.

Tailor campaigns to different target audiences and provide multi-format information (toolkits, digital and print materials), supported by hospitals and health insurance funds.

Develop targeted, accessible information for families, schools, and carers, delivered through multiple coordinated channels at regional and sectoral levels.

Support and increase the visibility of patient and family organisations to strengthen their role in PPC awareness and advocacy.

A strengthened, well-funded umbrella organisation could provide national leadership and coherence in PPC awareness, information, and policy support without creating new structures.

4.3 Advocacy

Advocacy is also recognised as a key pillar in improving access to PPC. Indeed, advocacy organisations help to change attitudes through the initiatives they undertake. In addition, they can play a significant role in driving organisational or legislative changes through their work and activities.[120]

Advocacy initiatives are also recognised by the International Children's Palliative Care Network (ICPCN) at regional and national levels, using a set of WHO-approved advocacy resources.[121]

4.3.1 In Belgium

In Belgium, the most recent initiative to draw the attention of public authorities to paediatric palliative care was launched in March 2026 by the BPPC. It took the form of an **open letter addressed to policymakers**. The letter highlighted key challenges in the current organisation of PPC and outlined a range of proposed improvements[122] This letter is set within the context of the conference entitled *"Paediatric palliative care: breaking taboos and strengthening support for children and their families"*, organised by the King Baudouin Foundation.[123]

To date, no advocacy initiatives on PPC led by **families, parent or patient organisations** have been identified. This contrasts with the situation in several other countries, where family- and patient-led organisations (charities) have played an important role in raising awareness, influencing policy development and advocating for improved access to PPC services. Patient organisations, parent associations and disease-specific organisations currently appear to have a limited role in PPC-advocacy activities. In addition, advocacy efforts directed towards policymakers remain relatively limited, with professional organisations playing only a limited role in this area.

4.3.2 Examples from abroad

We identified several initiatives aimed at advocating for PPC among policymakers. In the UK, reports such as *Short Lives Can't Wait* (2024) and *Built to Last?* (2025), led by Together for Short Lives, have **documented inequalities in access to PPC, identified funding and organisational gaps, and informed parliamentary discussions**. These advocacy efforts have contributed to securing dedicated funding for children's hospices up to 2029.[124–126]

In Italy, the National Bioethics Committee has described PPC as an **ethical and public health priority**, highlighting structural gaps in access, workforce training and service provision, and calling for urgent policy action and system-level reform[127]

In Spain (Catalonia), families and PEDPAL (the professional association of PPC), have been directly **involved in the policy process**, including the presentation of a draft PPC law and formal hearings in Parliament.[128–130]

At the international level, the ICPCN's recent "Close the Gap" campaign advocates for equitable access to PPC and calls for stronger integration of PPC within health systems.[131]

Details are provided in section 7.3.2. of the supplementary data.

4.3.3 Barriers to advocacy in Belgium

In Belgium, the development of advocacy in paediatric palliative care remains limited for several structural and organisational reasons. First, PPC is a relatively **low-visibility field** in the public and policy sphere, partly due to the small number of children concerned and the wide heterogeneity of clinical situations. This makes the issues less immediately legible and more difficult to translate into clear policy priorities. In addition, stakeholders explained that the **institutional fragmentation** of the Belgian healthcare system, with responsibilities distributed across multiple levels of governance and a dispersed range of actors, does not facilitate the emergence of a single, coordinated voice or a unified advocacy strategy.

Furthermore, stakeholders with the potential to engage in advocacy, including patient organisations and professional associations, often have **limited resources**, rely heavily on volunteer work, and operate with non-recurring funding. This constrains their ability to develop sustained and structured advocacy activities. The professionals experienced in PPC highlighted that the field is also characterised by **strong clinical engagement**, with professionals primarily focused on direct patient care, leaving limited time and capacity for policy engagement and advocacy work. Finally, the **lack of consolidated epidemiological data and robust indicators** on PPC needs further reduces the visibility of the issue and weakens the evidence base available to support policy arguments and decision-making.

4.3.4 Solutions

Experiences from other countries highlight the important role of advocacy in placing paediatric palliative care on the political agenda. In countries such as the UK, Spain and Italy, advocacy by professional, patient and family organisations has contributed to significant developments in PPC policy, service provision and funding. As previously mentioned, **supporting patient, parent and professional organisations in Belgium to increase visibility and to communicate more actively** about PPC (what it is and is not), as well as about the needs of children requiring PPC, could strengthen advocacy and promote policy development. To achieve this, recognised PPC organisations in Belgium should be provided with the resources, skills and opportunities needed to engage effectively in communication and advocacy. Strengthening advocacy capacity may therefore require adequate support, enabling these organisations to better represent the interests of children and families, and contribute to policy discussions and awareness-raising. These organisations may include the BPPC, as well as patient organisations and palliative care federations.

Stakeholders highlighted the challenges faced by patient organisations in advocacy, particularly due to the emotional burden associated with their work. They therefore stressed the importance of enabling a more **professional and sustainable approach**. Adequate funding was identified as a key enabling factor, reducing vulnerability linked to reliance on external funding and potential conflicts of interest.

It was also suggested that the BPPC could play a coordinating role in advocacy and stakeholder engagement. However, if such responsibilities were formally assigned, some stakeholders raised concerns regarding the sustainability of its current funding model. Others noted that the BPPC already partially fulfils this role.

At a policy level, the explicit **recognition of PPC within a children's rights framework** could be considered. Stakeholders questioned the feasibility of this, given international legal and institutional constraints. However, it was suggested that the issue could be brought to the attention of the Children's Rights Commissioner, who could then communicate it to relevant authorities. Stakeholders also noted that the right to PPC could more feasibly be incorporated into the Charter of Rights of Hospitalised Children, which is easier to amend.

ADVOCACY

Strengthening advocacy for paediatric palliative care

Support and empower key organisations to become more visible and active in PPC advocacy, through adequate resources, skills, and opportunities for engagement.

Promote a more professional, sustainable and well-funded approach to advocacy.

Consider a coordinating role for the BPPC in advocacy and stakeholder engagement, with a clear and sustainable mandate.

Explore the recognition of PPC within a children's rights framework.

4.4 Education

A recent rapid review synthesising international PPC programmes and services to inform system-level change in Canada identified a shortage of PPC expertise as a key barrier. This was attributed both to an insufficient number of specialised PPC professionals and to a lack of generalist HCP confident in delivering PPC. The latter issue was explained by the relatively small number of children with palliative care needs encountered by generalist practitioners, as well as by a broader discomfort with providing palliative care to children. Moreover, the very concept of PPC remained poorly understood in some areas.[90]

These findings were largely confirmed through expert and stakeholder consultations via interviews of professionals experienced in PPC, online survey of professionals with limited experience in PPC and stakeholders conducted as part of the present study. The King Baudouin Foundation also recognised training as one of the five priority areas for action.[5,6] Although Bailey et al. 2025 was developed within the Canadian context, the key recommendations proposed to address these barriers are highly relevant to the Belgian setting. On the one hand, they emphasise the importance of training through consistent training opportunities, strengthened communication strategies, and standards of practice. On the other hand, they highlight the need to enhance the perception of palliative care as a holistic approach focused on quality of life and compassion among the general population, families, and healthcare professionals.[90] Issues related to raising awareness for HCP as part of general professional culture are addressed in section 4.2.3. In the present section, the focus is placed on training opportunities. Standards of practice are not addressed, as they fall outside the scope of this study: the European project Hope4kids is currently developing guidelines in PPC at the European level.
Drawing on experiences from other countries, three levels of training were identified, ranging from basic PPC training for the wider care network to advanced specialist training. Table 6 summarises the target audience and primary objective associated with each training level. This table also includes awareness-raising activities, which may be considered as the foundation upon which training and competency development can build.

Table 6 – Level of awareness and education, based on literature and experiences abroad

Level	Target audience	Purpose	
Public awareness initiatives	General population	Improve understanding and acceptance of PPC	See 4.2.3
Education for the wider care network	Teachers, psychologists, social workers, volunteers, family caregivers, etc.	Support children and families within their environment	See 4.4.1
Core PPC education	Generalist healthcare professionals	Deliver primary-level PPC and identify referral needs	See 4.4.2
Advanced PPC education	PPC specialists	Develop expert clinical competencies	See 4.4.3

4.4.1 PPC training for the wider care network

This level targets non-medical and community-based actors who contribute to the support of children with life-limiting conditions and their families. It includes professionals and individuals who are not specialised healthcare professionals, such as teachers, psychologists, social workers, allied health professionals, spiritual care providers, volunteers, funeral service professionals, family caregivers, and families themselves. Rather than developing specialist clinical expertise, this level aims to strengthen the knowledge, skills, and confidence of those involved in the child's wider support network, thereby building capacity around the child and family and promoting coordinated, family-centred care. This may also include information to help young patients and their family understand what paediatric palliative care is and what it means in practice (e.g., support, pain management, and other aspects of care), provided at the appropriate time.

4.4.1.1 What exists in Belgium

Based on our findings, there **does not appear to be any structured training or dedicated tools** for this population group, which has more specific needs than the general population, while not requiring a high level of skills or knowledge. One respondent to the online survey reported having followed an

eight-day (adult) palliative care training programme for volunteers organised by Brusano. Targeted, needs-based information, mainly delivered by PLTs, could help address these needs.

4.4.1.2 Examples from other countries

Abroad, training initiatives extend beyond healthcare professionals to include the wider care network supporting children with life-limiting conditions. In Australia, organisations such as Palliative Care Australia provide practical, non-clinical resources for families and communities, offering guides and toolkits for parents, carers and teachers, while in Switzerland Pro Pallium provides basic training for volunteers supporting families.[110,132–135] These kinds of initiatives illustrate different ways of extending learning beyond specialised clinical settings.

Details are provided in section 7.3.3. of the supplementary data.

4.4.2 Core PPC training for non-specialist HCP

These trainings target non-specialist HCP, such as GP, primary care professionals, and hospital-based paediatric staff who may be involved in the care of children with life-limiting or life-threatening conditions but are not experts in PPC due to the limited number of such cases encountered in their professional practice.

4.4.2.1 What exists in Belgium

An exploratory review of current training opportunities in Belgium indicates that there is **no systematic or standardised PPC module** within the core education programmes of healthcare professionals (during initial training). Each university or university college independently determines whether to include PPC in its curriculum and, if so, how it is organised and delivered (e.g., number of teaching hours and placement within the curriculum).

Regarding **continuing education**, some training modules and sessions are delivered by paediatric liaison teams or by other organisations, including palliative care networks, hospitals, universities, and university colleges. These initiatives are generally introductory in nature and are not intended to provide specialist-level training. They are typically short in duration and may focus primarily on practical clinical skills.

Several continuing education and postgraduate programmes related to paediatrics and palliative care were identified in Belgium in the grey literature and via the online survey of professionals with limited experience in PPC. Examples include the multidisciplinary continuing education programme *Les soins continus et palliatifs de la naissance à l'adolescence – Compétences-clés pour un accompagnement de qualité*, delivered at *Haute École Léonard de Vinci* in Brussels; the continuing education programme in perinatal palliative care offered by the *Université libre de Bruxelles*; the *Basic Training in Palliative Care for General Practitioners* (*Basisopleiding Palliatieve Zorg voor Artsen* – BOPZA), organised jointly by *Panal vzw*, *Palliatieve Zorg Vlaanderen*, and *UZ Leuven*; and the *Postgraduaat Rouw- en Verliesconsulent* offered by Artevelde University of Applied Sciences (Ghent).[136–139] For programmes covering palliative care more broadly, the proportion of teaching specifically dedicated to paediatric palliative care is generally not clearly defined.

In March 2026, a national symposium on paediatric palliative care, *Breaking taboos and strengthening support for children and their families*, was held under the auspices of the King Baudouin Foundation.[123]

Some respondents to the online survey also reported having undertaken training in France or the Netherlands.

Furthermore, on-the-job training is provided by paediatric liaison teams to healthcare professionals involved in the care of children with palliative care needs, allowing learning to take place within the context of direct patient care. This individualised approach enables healthcare professionals to

address knowledge and skills gaps specific to the needs of the child and family under their care, consistent with the "**pop-up model**" (see Chapters 6).

4.4.2.2 Examples from other countries

Several examples can be presented: a four-day multidisciplinary *Basistraining Kinderpalliatieve Zorg* developed by the national *Kenniscentrum Kinderpalliatieve Zorg* and online modules hosted on the Palliaweb platform in the Netherlands, and the Quality of Care Collaborative Australia (QuoCCA) in Australia.[140–142].

Details are provided in section 7.3.3. of the supplementary data.

4.4.3 Advanced training in PPC

This level represents the most specialised form of training in PPC. Given their professional background and clinical responsibilities, these training programmes are primarily intended for healthcare professionals working in paediatrics, including paediatricians, paediatric nurses and members of specialised PPC teams.

4.4.3.1 What exists in Belgium

No formal training pathway leading to recognised expertise in paediatric palliative care currently exists in Belgium. Stakeholders interviewed for this study consistently reported that, after completing introductory or intermediate-level training, they developed their expertise primarily through experiential learning. This included on-the-job learning, participation in national and international conferences, and/or attendance at specialised training programmes abroad (e.g., France, the Netherlands). Similarly, within paediatric liaison teams, newly recruited professionals are mentored and trained by more experienced colleagues, allowing specialist knowledge and skills to be transferred through clinical practice and peer learning.

As part of **continuing education**, healthcare professionals (mostly from paediatric liaison teams) also attend specialised training programmes and conferences abroad.

4.4.3.2 Examples from other countries

Advanced training in PPC is most developed in countries where PPC is recognised as a **subspecialty or structured field of practice**. In the UK, paediatricians can undertake a two-year GRID training programme or a SPIN pathway.[143,144] Canada offers a recognised two-year PPC residency programme, supplemented by certificate courses and national communication tools.[145] In Spain, organisations such as PEDPAL and the Dignia Foundation have developed training programmes, including ESPEDPAL, which combines clinical practice and learning in accredited units.[146]. In Germany, the *Multiprofessional Curriculum in Paediatric Palliative Care*, provides 200 hours of training for paediatricians, nurses and psychosocial professionals, based on the twelve core competencies defined by the European Association for Palliative Care (EAPC).[147,148] Similar opportunities exist for paediatric nurses, for example through level-based courses and a Certificate of Advanced Studies in PPC in Switzerland.[149] These programmes provide recognised qualifications and support the development of advanced PPC expertise.

The **Education in Palliative and End-of-Life Care (EPEC) Pediatrics** is an international structured, modular curriculum designed to strengthen core competencies in palliative and end-of-life care among HCP. EPEC serves as a recognised reference framework.[150,151]

Details are provided in section 7.3.3. of the supplementary data.

4.4.4 Practical and organisational considerations for PPC education, across all levels of training

4.4.4.1 In Belgium

Training opportunities in paediatric palliative care remain limited in Belgium, both within basic and continuing education. Nonetheless, existing training initiatives take a variety of forms but are generally of short duration and delivered on an ad hoc basis. Furthermore, there is no standardised national curriculum to ensure consistent PPC education across institutions and professional groups. The competencies to be developed are broad and multidisciplinary, encompassing clinical, psychosocial, communication, ethical, and technical aspects of care. The role of professional associations in training is limited.

4.4.4.2 Examples from other countries

PPC education is delivered through a range of **formats**, from undergraduate teaching to specialist and continuing professional development. Undergraduate exposure to PPC varies across countries but is increasingly guided by national frameworks, such as the UK Children's Palliative Care Education and Training Standard Framework and the Royal College of Nursing's competency framework, which define progressive levels of knowledge and expertise.[152,153]. In Spain, PPC content is also incorporated into some undergraduate nursing programmes.[154]

Continuing professional education is widely available through short courses, certificates, online platforms, and blended learning programmes. Examples include LEAP Paediatric in Canada, QuoCCA in Australia, Palliaweb in the Netherlands, PPCEducate in the UK, and PEDPAL courses in Spain.[142,155–158] Community-based initiatives such as Pediatric Project ECHO® in Canada further support knowledge sharing and mentorship between specialist and local healthcare professionals.[159] The International Children's Palliative Care Network (ICPCN) also provides free educational resources for healthcare professionals, including e-learning courses and regular webinars on various aspects of children's palliative care, supporting continuing professional development.[160,161]

Training programmes primarily focus on clinical **competencies**, including symptom management, pain control, advance care planning, end-of-life care, and continuity of care. They also emphasise transversal skills such as communication, shared decision-making, and psychosocial support, as illustrated by programmes such as IMPACT and CONNECT in the Netherlands, MAPPS in Germany, and LEAP Paediatric in Canada.[157,162–165]

Professional associations play an important role in education and knowledge dissemination. Organisations such as the Canada's Pediatric Palliative Care Alliance, the UK Association for Paediatric Palliative Medicine (APPM), and PEDPAL in Spain provide educational resources, training opportunities, professional networks, and support for the implementation of best practices in PPC.[112,158,166]

Details are provided in section 7.3.3. of the supplementary data.

4.4.5 Barriers to develop education and training on PPC, across all levels of expertise

When asked about their priorities for improving the quality of care in the online survey, 25 professionals with limited experience in PPC amongst 52 cited training as a key priority.

Participants to the online survey highlighted **gaps in knowledge and competencies** related to paediatric palliative care, including clinical aspects of care, communication skills, and the emotional support of children and their families. The findings also underscored the importance of the specific characteristics of paediatric care, which are closely linked to the developmental stages and evolving needs of each child. It was on this basis that respondents emphasised the distinction between paediatric and adult palliative care, thereby supporting the need for dedicated training in PPC.

In Belgium, the **absence of a standardised curriculum** and the **insufficient integration of paediatric palliative care modules into both undergraduate and continuing professional education** remain significant barriers to access to PPC. This gap is recognised as an obstacle to ensuring equitable access to paediatric palliative care services by the professionals with limited experience. In addition, **limited awareness regarding the existing PPC services and structures** (including the very existence of paediatric liaison teams), was reported, by stakeholders and professionals with limited experience, as a key factor contributing to missed or delayed referrals to appropriate care, unnecessary hospitalisations, avoidable use of emergency services, and insufficient support for families in the home setting. Stakeholders also highlighted that healthcare professionals working in hospitals without a paediatric liaison team often have limited knowledge of the available PPC services and referral pathways, further hindering timely access to appropriate care. This limited awareness also affects children and their families, resulting in delayed access to PPC or a lack of engagement with PPC services.

Stakehodlers explained that the **inclusion of additional PPC content** may be challenging due to the already substantial volume of material covered in undergraduate curricula. Nevertheless, some nursing schools have implemented a progressive approach to introducing PPC concepts throughout the programme.

4.4.6 Solutions for all levels of training

The importance of training has been widely emphasised. Rather than offering mass training for all HCP, the proposed model is based on a **tiered approach**, whereby increasing levels of training correspond to progressively advanced competencies and responsibilities in PPC, as illustrated by the CPCET (Children's Palliative Care Education and Training) Education Standard Framework in the UK and Ireland.[167] Based on the stakeholder consultations, four levels of education are proposed in Table 7[p]:

Table 7 – Proposition of levels of awareness and education, based on stakeholder consultations

Level	Target audience
Awareness and understanding	Wider care network
Foundational PPC	HCPs who may encounter children with life-limiting or life-threatening conditions on an occasional basis
Intermediate PPC	HCPs who are regularly involved in the care of children with serious or complex chronic conditions (e.g., paediatric oncology, neurology, metabolic diseases, and related specialties), requiring a solid working knowledge of PPC principles, communication, and anticipatory care
Specialist/expert PPC	Highly specialised healthcare professionals whose primary clinical role is dedicated to paediatric palliative care (e.g., paediatric liaison teams, dedicated PPC physicians, specialist nurses, and psychologists)

This model takes into account the rarity of paediatric palliative care situations. Indeed, most healthcare providers, particularly those in primary care, will only occasionally encounter paediatric palliative care needs during their professional careers. As basic competencies acquired through undergraduate education or continuing professional development tend to decline rapidly in the absence of regular practice, it is therefore not considered appropriate to include overly detailed clinical or organisational content at non-specialist or lower levels of training.

[p] Instead of the three initially presented in Table 6.

The first level, "**awareness and understanding**", refers to a level of education that goes beyond general public awareness, which aims to inform the general population about what PPC is in an accessible language (see Section 4.2). This level targets individuals who, through their professional or personal activities, may come into contact with children with palliative care needs and their families, i.e., non-health and non-specialist actors involved in the child's environment and support system. These individuals (such as funeral service providers, siblings' babysitters, etc.) do not require clinical knowledge but should have access to practical tools, available for example online or through adult palliative care federations and/or Sickness funds, to communicate appropriately about these situations without being personally overwhelmed. This "community training" level may, to some extent, be linked to the concept of "compassionate communities".

The "**foundational PPC**" level targets healthcare providers who are in contact with children with illness, such as community-based general paediatricians, paediatric nurses working in general paediatric wards, general practitioners, and other allied health professionals such as physiotherapists involved in the care of children. These professionals require an enhanced level of general awareness of PPC, without entering into technical, clinical or organisational detail.

It is within this group of professionals that, in the context of the care of a specific child and family at home, paediatric liaison teams may intervene to further develop the knowledge and competencies of the professionals involved in care delivery (notably home care nurses), in relation to the needs of the child and family. This constitutes an individualised, ad hoc form of training (see Chapter 7).

Stakeholders involved in education highlighted the difficulty of adding new content to already crowded curricula, despite recognising the relevance of PPC. Some suggested that this topic could be offered in response to demand and at a later stage of training, when healthcare professionals are more likely to perceive its relevance to their practice. Stakeholders also supported the proposed approach of avoiding in-depth training for all healthcare professionals, given the limited number of PPC cases that most non-specialist professionals in palliative care will encounter during their careers.

Another stakeholder pointed to the difficulty of obtaining a comprehensive overview of curricula across different disciplines and educational levels, while also highlighting the need for greater consistency between programmes, albeit acknowledging the challenges associated with such harmonisation.

Continuing professional development was also identified as an important component that should not be overlooked and should be available across the different levels of training. Stakeholders further emphasised the importance of coordinating new initiatives with existing training opportunities.

Nevertheless, one stakeholder involved in Belgian nursing education described experience with palliative care and paediatric palliative care teaching programmes in which knowledge is developed progressively over time, in line with the approach proposed in this report. This indicates that such an approach may be feasible in the Belgian context.

The "**intermediate PPC**" level targets professionals who are in regular contact with children with serious illnesses and who are likely to encounter PPC needs in the course of their professional activities. However, although a relatively high level of expertise is expected, this level does not correspond to expert practice and does not include responsibilities such as supporting or advising less specialised teams. Examples of professionals within this category include the designated PPC local teams in hospitals without a paediatric liaison team (the PPC referent tandem as proposed in chapter 6), healthcare professionals working in paediatric oncology, neurology, metabolic diseases or perinatal care, as well as individuals providing respite care or tailored leisure activities. The latter two groups were included at this level rather than within the "awareness and understanding" category following consultations with experts and stakeholders. This reflects the close relationship these individuals develop with children and families, as well as the level of trust placed in them when providing care, support or activities. These professionals require a more in-depth understanding of PPC principles and concepts of PPC, although not necessarily in its more specialised technical or clinical aspects.

With regard to the specialised level of training, one stakeholder highlighted the value of integrating PPC into existing educational programmes. Dedicated training days could also be developed, particularly in collaboration with paediatric liaison teams.

The "**specialist/expert PPC**" level refers to specialised training aimed at developing advanced expertise in paediatric palliative care. It targets professionals whose core professional activity is centred on the care and support of children with palliative care needs and their families. Examples include paediatricians, paediatric nurses, psychologists and other professionals working within paediatric liaison teams.

Regarding the expert level, stakeholders noted the limited demand for highly specialised training and highlighted the potential value of developing inter-university programmes and, where appropriate, integrating PPC into existing adult palliative care qualifications. Stakeholders also emphasised the benefits of strengthening collaboration between the paediatric and adult palliative care sectors.

The proposal to fund training activities delivered by members of paediatric liaison teams was considered by some stakeholders to be difficult to implement in the current financial context. Similarly, regarding the organisation of activities aimed at sharing good practices, research findings and specialised training between paediatric liaison teams, funding constraints were raised as a potential barrier. In this context, some stakeholders suggested that remote or online formats could represent a more feasible alternative.

This tiered model applies both to **initial qualification programmes and to continuing professional development** throughout the professional career. Training opportunities may take various forms, including formal educational programmes, symposia, conferences and other continuing education activities organised in collaboration with, among others, the palliative care federations and the Belgian Paediatric Palliative Care (BPPC) group.

Training curricula such as EPEC could be used in Belgium.[150] This would support the progressive development of knowledge and skills, beginning with foundational topics such as the definition of PPC, the existence of paediatric liaison teams, and the organisation of PPC in Belgium, before gradually incorporating more advanced concepts, including the different dimensions of PPC needs and the principles and tools of advance care planning (ACP).

The EPEC curriculum is based on a "train-the-trainer" model, which is consistent with the approach underpinning the present proposal.[150] Within such a framework, the Belgian Paediatric Palliative Care (BPPC) group, paediatric liaison teams and palliative care federations could play an active role in supporting the training of less specialised professionals through seminars, conferences and other educational activities.

In Belgium, only a limited number of professionals would ultimately require expert-level training each year, for example to address staff turnover within paediatric liaison teams. Developing dedicated training programmes in both Dutch and French for such small numbers would therefore be unlikely to represent an efficient use of resources. It is therefore proposed that the training of these highly specialised professionals be supported through access to programmes offered by other European organisations, with particular attention paid to overcoming potential language barriers.

The UK experience illustrates the feasibility of a tiered approach to paediatric palliative care education, in which progressively advanced levels of training correspond to increasing clinical responsibilities, and may therefore serve as a useful model for the development of a tiered competency framework in Belgium.

With regard to **organisational aspects**, training opportunities could be delivered through different formats according to the level concerned, including toolkits and practical resources for the "awareness and understanding" level, online and face-to-face training for the intermediate levels, and partnerships with organisations in other countries for the most advanced levels of training. These training resources and programmes could be made available in the national languages. One stakeholder highlighted the value of involving patient experts in training activities.

In this context, experiences and expertise in training organisation could be shared between adult and paediatric palliative care services. Professional organisations outside the field of palliative care, such as Domus Medica, the Belgian Academy of Paediatrics (BAoP), nursing associations and associations representing other allied health professions, could also be invited to contribute through the sharing of educational platforms and/or the co-development of training programmes. Encouraging these collaborations was also reported by some stakeholders.

The time invested in training could be recognised using the mechanisms already existing for each profession, such as accreditation points for physicians or professional portfolios for nurses and physiotherapists. This recognition was also highlighted by some stakeholders.

Financial support could be provided to training teams to cover the costs associated with the delivery of educational activities.

Particular attention could be paid to strengthening knowledge-sharing networks through:

- the regular organisation of conferences and symposia accessible to all healthcare professionals by paediatric liaison teams and the Belgian Paediatric Palliative Care (BPPC), with the necessary financial support and the involvement of patient and family organisations;
- the organisation of regular exchange and consultation meetings between paediatric liaison teams to share good practices, discuss experiences, disseminate research findings, and jointly organise continuing professional development activities.

Awareness-raising activities, including education and training, are likely to be effective when embedded within a **broader strategic action plan for PPC**.[168] Such a framework would include the implementation of a clear model of care, encompassing defined roles and responsibilities, guidance on care approaches, sustainable funding mechanisms, and appropriate education and training pathways for all stakeholders involved (see Chapter 7).

EDUCATION

A tiered model for PPC training

A tiered training model is proposed, with four levels of increasing depth of knowledge and responsibility: awareness and understanding, foundational PPC, intermediate PPC, and specialist/expert PPC. The model reflects the low prevalence of PPC cases and the need to avoid overly detailed training for professionals with limited exposure, while ensuring progressive skill development.

Training should be implemented through multiple formats and existing educational structures, including continuing professional development, inter-university collaboration, and European training programmes where relevant.

A train-the-trainer approach and knowledge-sharing networks (including the BPPC and paediatric liaison teams) are considered important to support dissemination and sustainability.

The training system should be embedded within a broader strategic PPC framework, ensuring coherence with service organisation, roles, and care pathways.

4.5 Organisation of research on PPC

Research and data collection are increasingly recognised as key components of paediatric palliative care development. They provide the evidence required to assess population needs, evaluate the quality and organisation of services, and support evidence-based planning and policy-making.[28,169]

According to a study on paediatric palliative care in Europe, research in this field has grown considerably. Nonetheless, the evidence base remains limited in several core areas, including decision-making, communication, and clinical issues related to pain and symptom management. Strengthening research in these domains is essential to support the delivery of high-quality, evidence-informed care in PPC.[170] The necessity to increase research was also mentioned as a key priority in the King Baudouin foundation report.[5,6]

4.5.1.1 In Belgium

Research in paediatric palliative care in Belgium remains limited and is conducted primarily within **academic institutions and specialised clinical services**. These institutions also aim to foster collaboration between researchers and healthcare professionals from different disciplines. The End-of-Life Care Research (EOL) Group, a collaboration between *the Vrije Universiteit Brussel* and Ghent University, is the principal research centre in this field and has contributed to the evidence base on paediatric end-of-life care, quality indicators, quality of life, and the organisation of PPC services.[171–174] The *Institut de recherche santé et société (IRSS)* at the *Université catholique de Louvain (UCLouvain)* has also conducted interdisciplinary research in paediatric palliative care. Ethical research is also conducted at academic institutions such as KU Leuven and the Université libre de Bruxelles (ULB).

Studies at the **national level** have examined the organisation and outcomes of PPC services, including analyses of the activities of paediatric liaison teams and assessments of quality of life among children with life-limiting conditions and their families. These studies have highlighted the need for improved data collection, outcome measurement, and evidence-based evaluation tools.[5,6,22,175]

Belgian teams have participated in several **European initiatives** in paediatric palliative care. They are currently involved in the European HOPE4Kids and PALLIAKID projects, which aim to strengthen paediatric palliative care through guideline development, education, family-centred care, and advance care planning.[176,177]

According to experts consulted in this KCE project, important gaps remain regarding **clinical practice data, identification tools, and evidence-based guidelines**, which limits the capacity to monitor needs, evaluate services, and support policy development.

Regarding research organisation, the *Departement Zorg*, a public body of the Flemish Community, is currently developing a **palliative care expertise centre** at the regional level, as part of the ongoing reform of palliative care services in Flanders.[178] However, no national structure currently exists to coordinate PPC research, establish a national research agenda, or systematically collect and report PPC data.

4.5.1.2 Examples of research organisation in other countries

Research initiatives address needs assessment, service mapping, quality evaluation, symptom management, communication, and care coordination. Examples include Italy's PalliPed project, which provides national epidemiological data and quality indicators on PPC provision, and research programmes at Germany's *Datteln* Centre, focusing on care pathways, quality of care, symptom assessment, communication, and outcomes of specialised services. Other notable initiatives include the Swiss PELICAN and SPhAERA studies and the European PALLIAKID project, which evaluates a family-centred intervention across multiple countries.[176,179–183]

Four of the eight countries included in the review had developed national structures to coordinate PPC. In the UK, the model combines a **research network** (coordination, capacity-building) and a

national academic centre (high-level research, leadership and involvement in clinical and policy decisions), with research being supported through both the Collaborative Paediatric Palliative Care Research Network (CoPPAR) and the National Centre of Excellence for Paediatric Palliative Care, which provides academic leadership and conducts original research.[184–188]. In the Netherlands, the National Expertise Centre for PPC acts as a **central hub** coordinating research activities, supporting guideline development, maintaining research platforms, and contributing to a national research agenda; the *KennisHub Palliatieve Zorg*, a national platform brings together ongoing and completed research projects to facilitate access to the data for researchers, decision-makers, and other professionals.[189] In Canada, pan-Canadian **alliances and research networks** facilitate collaboration across provinces, harmonise terminology, map services, and support multi-site studies.[61] In Australia, research is embedded within the **National Action Plan for Paediatric Palliative Care**, with a strong focus on epidemiological data, outcome measurement, benchmarking, and service planning.[116]. **Data collection** is also embedded within this National Action Plan. The 2023 national needs assessment highlights the importance of population-level data to inform service planning, policy, and quality improvement.[190,191]

Overall, these examples illustrate different models of research organisation, ranging from dedicated academic centres and collaborative networks to nationally coordinated knowledge hubs and policy-driven research programmes. Despite their differences, all aim to strengthen the evidence base, support service development, improve care quality, and inform policy and planning in PPC.

Details are provided in section 7.3.4. in the supplementary data.

4.5.1.3 Barriers related to research and in organising research in Belgium

Several barriers to research on PPC in Belgium were identified in this study. The **lack of data** was mentioned by experts and stakeholders. Standardised data collection systems and paediatric-specific quality indicators remain underdeveloped, making it difficult to monitor needs, evaluate services, and compare practices across settings. In addition, they reported that the identification of children who could benefit from PPC may be hindered by the limited availability and use of validated identification tools.[192]

Furthermore, **evidence-based tools and guidelines** remain limited in some areas of PPC, as mentioned in the online survey by professionals with limited experience, what may constrain the development of robust research programmes.

Methodological challenges are also important. PPC concerns a relatively small patient population with highly diverse diagnoses, disease trajectories, and care needs. This heterogeneity can make it difficult to recruit sufficiently large study populations, compare findings across studies, and evaluate the effectiveness of interventions.

Resource-related barriers may affect research capacity. Stakeholders explained that clinical teams often operate with limited resources and prioritise direct patient care, leaving little protected time for research activities. Funding opportunities specifically dedicated to PPC research are limited, and the number of researchers specialising in this field remains relatively small. Together, these factors may restrict the scale, continuity, and impact of research efforts in Belgium.

The **absence of a structured research organisation** may also be a barrier. Unlike some countries that have established national research networks, expertise centres, or coordinated research agendas, Belgium does not currently have a national structure dedicated to coordinating PPC research. Research activities are conducted by individual academic institutions and clinical teams, which may lead to fragmentation and limit opportunities for large-scale collaboration. The organisation of the Belgian healthcare system across different levels of governance may further complicate the development of national initiatives and data collection mechanisms.

Stakeholders also highlighted the **absence of a dedicated academic chair** in paediatric palliative care, which they perceived as further contributing to the limited visibility and recognition of the field.

4.5.1.4 Solutions

Several challenges have hindered the development of PPC research in Belgium. We propose the following solutions to strengthen research, and therefore to support evidence base and improvement of access to care.

To address the limited availability of validated tools, outcome measures, and clinical guidelines adapted to the Belgian context, **the participation of Belgian teams should be encouraged in European and multicentre research initiatives**, which facilitate access to internationally developed tools and methodological expertise. Efforts should also be pursued to translate, culturally adapt, and validate existing instruments and guidelines in the national languages and within the Belgian healthcare context. This would also address the methodological challenge related to the small patient population.

A publicly funded **research prioritisation process** should be established, based on the needs identified by key stakeholders, including healthcare professionals, researchers, children, young people and families. National funding bodies such as the *Fonds Wetenschappelijk Onderzoek* (FWO), *Fonds de la Recherche Scientifique* (FNRS) and KCE should be encouraged to dedicate a proportion of their research funding to paediatric palliative care. In this context, some stakeholders highlighted the need to increase awareness among proposal reviewers of the specificities and importance of paediatric palliative care research. PPC research is often multidisciplinary in nature and does not fit easily within traditional biomedical or social science categories, which may create challenges when seeking funding and undergoing scientific review.

Drawing inspiration from the Dutch National Centre for Expertise in Children's Palliative Care, the Belgian Paediatric Palliative Care (BPPC) group could be entrusted with a **coordinating role** in the field of PPC research and knowledge dissemination, provided that adequate resources are allocated[q]. With regard to the proposed role of the BPPC as a centre of expertise and reference for PPC, stakeholders emphasised the importance of both centralising knowledge, standardise indicators collection, and harmonising good practices. They also highlighted the need to communicate and disseminate research findings effectively, in collaboration with paediatric liaison teams, to frontline professionals and other relevant stakeholders, including professional associations acting as dissemination channels. However, as previously reported, some stakeholders expressed concerns regarding the financial feasibility of assigning such an extensive coordination role to the BPPC.

Whatever the organisation of research, **research priorities have to be defined through consultation** with a multi-stakeholder group, including, where possible, children, families and their representatives, as well as experienced researchers, such as those involved in the End-of-Life Care (EOL) Research Group.

The limited volume of PPC research currently conducted in Belgium and the resulting lack of visibility of the field could be addressed through the development of a future **national plan** for **palliative care** (see Chapter 7). The coordination of PPC research would be explicitly included as a strategic objective.

According to some stakeholders, collaboration should also involve the future Flemish Centre of Expertise for Palliative Care. It was further noted that a single centre of expertise could improve the visibility of ongoing research activities, as well as educational initiatives and clinical practices, thereby helping to break down silos between disciplines. The creation of awards for Master's dissertations or doctoral theses related to PPC was also mentioned as a potential incentive to stimulate research activity.

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[q] The BPPC is hosted by Sciensano and currently contributes to Belgium's participation in the European HOPE4KIDS project, providing a potential foundation for a broader national research coordination function.

Stakeholders also proposed **strengthening research links between universities and university colleges**. Such partnerships could facilitate collaborative research projects and create opportunities for Master's dissertations and other student research initiatives in the field of paediatric palliative care.

The lack of **robust epidemiological data** on children with paediatric palliative care needs in Belgium has to be addressed with reliable data for estimating needs, monitoring service provision, informing policy decisions, and supporting research activities. In this regard, the ongoing eHealth project being developed within the RIZIV-RIZIV represents an important opportunity (see Chapter 7). Consideration would be given to ensuring that activity data routinely collected by paediatric liaison teams can be used for research purposes, subject to the anonymisation and data governance procedures currently being developed. Such an approach would facilitate the generation of national epidemiological data and the collection of patient-reported outcomes (PROs) while minimising additional administrative burden for healthcare professionals.[193]

Regarding the **use of activity data** collected by paediatric liaison teams for research purposes, one stakeholder emphasised the importance of ensuring full compliance with applicable legislation and General Data Protection Regulation (GDPR) requirements.

Some stakeholders emphasised the need for **greater policy attention** to paediatric palliative care and for the systematic evaluation of policy developments and service reforms. They highlighted the importance of strengthening research capacity in order to increase the visibility and accessibility of evidence in the field. In particular, they suggested making greater use of RIZIV-INAMI databases to evaluate the impact of policy measures and service developments, while ensuring that researchers are involved throughout the process to support evidence-informed decision-making.

RESEARCH ON PPC

Strengthening research in paediatric palliative care

The analysis highlighted several areas requiring further development to strengthen research in paediatric palliative care in Belgium:

- The importance of greater Belgian participation in European and multicentre research was highlighted, including the adaptation and validation of research tools, outcome measures and clinical guidelines to the Belgian context.
- The need for a national research agenda for PPC was identified, reflecting the priorities and needs of healthcare professionals, researchers, children, young people and families, and supported by dedicated research funding.
- The importance of stronger coordination and knowledge dissemination was highlighted, including the potential contribution of the BPPC.
- The importance of collaboration between universities, university colleges and clinical services was identified as a means of strengthening research capacity.
- Gaps in the availability and use of national epidemiological and activity data were identified, limiting their potential contribution to research, policy evaluation and service planning.
- The importance of systematically evaluating PPC policies and service developments was highlighted to strengthen the evidence base for decision-making.

4.6 Discussion

This chapter highlights important gaps in the development of awareness, advocacy, training, and research in paediatric palliative care in Belgium. Across these four domains, initiatives remain limited in scope and unevenly developed, with no clear evidence of a comprehensive or coordinated national approach. Given this underdeveloped state, experiences from other countries may provide useful reference points to inform reflection on possible directions for future development.

Awareness of PPC appears relatively low and is largely dependent on isolated initiatives, with limited structured communication targeting either the general public or specific groups involved in the care of children. Advocacy efforts are also still in an early stage of development, with constrained capacity among key stakeholders and limited visibility in broader policy processes. Similarly, training opportunities are fragmented across different levels of education and professional groups, without a fully established and coherent pathway ensuring continuity from basic awareness to specialist expertise. In the field of research, activities remain relatively scarce and dispersed, with limited coordination and prioritisation at national level.

Overall, the findings suggest that the limited development and fragmentation across awareness, advocacy, training and research may indirectly affect access to PPC. Insufficient awareness among both the public and some professional groups, uneven training opportunities, limited advocacy capacity, and a lack of coordinated research structures may contribute to delays in identification, referral and appropriate support for children with palliative care needs and their families. Strengthening these four domains in a more coherent way therefore appears important to support earlier access to PPC and improve its overall visibility.

5 ACCEPTABILITY OF PAEDIATRIC PALLIATIVE CARE: A COMPLEX, MULTIDIMENSIONAL CONCEPT

KEY POINTS

Acceptability is a dynamic process

- Acceptability of paediatric palliative care emerges from a dynamic interplay between the child, the family, healthcare professionals, healthcare organisations, and society. Rather than being determined by a single factor, acceptability is shaped by cumulative and evolving interactions involving communication, trust, uncertainty, developmental processes, family dynamics, cultural values, practical circumstances, and organisational conditions.

The child seeks autonomy, participation, and normality

- Children and adolescents want to be involved in decisions affecting their lives. Their desire for participation increases with age, maturity, and illness experience. Maintaining normality (school, friendships, leisure activities, family life) is a major priority.
- PPC should support dignity, identity development, and developmentally-appropriate autonomy.

Families are central but experience major burdens

- Parents act as caregivers, care coordinators, advocates, and decision-makers. Family members may have differing values, preferences, and understandings of the child's needs. Families face significant emotional, psychological, practical, financial, and physical burdens. Decision-making is particularly stressful when choices involve life-sustaining treatments or end-of-life care.

Communication and trust are fundamental in a family-centred care model

- Trusting relationships between families and healthcare professionals are the strongest facilitators of PPC acceptability. Honest, respectful, consistent, and developmentally-appropriate communication is essential. Trust improves engagement in care, shared decision-making, and acceptance of palliative care interventions. Fragmented communication and inconsistent messages can undermine trust and delay PPC integration.
- Successful paediatric palliative care depends on building trustful relationships, empowering children and families, supporting healthcare professionals, addressing cultural and social diversity, and adopting a flexible family-centred approach that recognises the inherent complexity of caring for seriously ill children.

Summary of solutions to improve acceptability of PPC

- Embracing complexity through a child-and family centred care approach, by:
  - valorisation of the time needed for building trusting relationships with children and families;
  - introduction of PPC services as early as possible in the care trajectory;
  - continuity of time of the established trusting relationship by reducing staff turnover in PLTs.
- Empowerment of the child/adolescent
  - A child-centred, individualised care plan that prioritises the child's preferences, values and needs (with regular re-assessment of these preferences and needs), adapt the care plan and communication to the developmental needs of the child/adolescent, and take into account the socio-cultural background of the child and family (including social vulnerability).
  - Preconditions to enhance developmentally-appropriate shared decision-making and advance care planning are: a child-friendly environment, use of age-adapted communication tools, expertise of PPC services to use these tools, initiation and coordination of ACP by PLTs, and the provision of opportunities for active involvement of adolescents.
- Empowerment of the parents/family
  - Active participation in decision-making by recognising the central role of the parents as one of the experts of their child and by setting up a supportive environment around the family unit.
  - Facilitators to stimulate communication between family and HCPs: availability of interpreters, intercultural mediators (via a centralized pool or database) or translation tools, continuity of time through the involvement of the same interpreter/intercultural mediator, introducing the wording of "palliative care" depending on the child and family readiness, ethicist involvement.
- Empowerment of the healthcare professionals
  - Strengthen the role of PLTs in the development of an ACP plan.
  - Enhance cultural sensitivity among HCPs.
  - Empower HCPs to guard child's safety.
- A need for a shift in societal attitude towards PPC with more emphasis on the set up of a nurturing environment for the child and the family.

5.1 Acceptability as one of the dimensions of patient-centred access to care

Within the Levesque Framework[2i] on patient-centred access to health care, one of the dimensions which determine the accessibility of care, is the dimension on acceptability, defined as:

> *Acceptability relates to cultural and social factors determining the possibility for people to accept the aspects of the service (e.g., the sex or social group of providers, the beliefs associated to systems of medicine) and the judged appropriateness for the persons to seek care. Ability to seek health care relates to the concept of personal autonomy and capacity to choose to seek care, knowledge about health care options and individual rights that would determine expressing the intention to obtain health care.*

As reflected in this definition, the acceptability dimension is determined by both **individual and systemic factors**. On the one hand, it is shaped by personal characteristics such as individual and social values, cultural background, gender, and the degree of autonomy a person has in making decisions about their own care, all of which influence the person's ability and willingness to seek care. On the other hand, it depends on the extent to which the healthcare system, and society more broadly, can recognise and respond to these preferences and values, thereby facilitating access to the most appropriate and acceptable care options.

Conversely, poor acceptability may be reflected in **patients' perceptions** that the provided care, HCPs or proposed treatments are not aligned with their values, beliefs, expectations, identity or preferences. Beyond patients' attitudes and perceptions, acceptability can also be impacted by (no) **care-seeking behaviour** (e.g., refusal of treatment, preference for traditional healing, declining appointments, etc.) and by a low level of a (trustful) **communication** between patient and providers (e.g., feeling (un)heard during consultations, reluctance to ask questions, reporting that explanations were unclear or not meaningful, etc.). Adherence to treatment is related to appropriateness of care (i.e., the fit between services and patients' needs, quality of care, continuity and expected outcomes of care) and to the patients' ability to engage with care, which encompasses also empowerment, participation in decision-making and engagement with care. However, when a patient does not adhere to treatment because the proposed treatment is not perceived as acceptable for him (for example due to cultural beliefs, distrust, dissatisfaction, etc.), then non-adherence may also be considered an indicator of poor acceptability.

This dimension of patient-centred access to care highlights the importance of the relational interactions between patients, healthcare providers and the healthcare system. It is largely determined by the presence of trustful and effective communication, through which the values, preferences and expectations of all actors are acknowledged and respected. Such mutual understanding is essential for aligning care with patients' needs and ensuring access to the most appropriate and acceptable care options.

5.2 Acceptability in the context of paediatric palliative care

The application of the Levesque framework to paediatric palliative care aims to provide a deeper understanding of the specific features and challenges associated with access to care. In this chapter, the objective was to identify the factors that shape how PPC is perceived, received and experienced by children, their families and the involved care professionals.

The exploratory analysis integrates two research questions addressed by this KCE report, namely:

- Research question two: What are the categories of PPC needs and the difference with adult PC needs categories?

  An exploratory search in literature was performed to retrieve (systematic) reviews on factors determining the acceptability of PPC, with a focus on barriers and facilitators related to access to PPC and PPC needs in children, families and HPCs (see 2.1.3 in Chapter 2). The complete results are presented in section 9 of the supplementary data.

- Research question three: How can the needs of the close relatives, informal caregivers and professionals not trained in PPC influence with the access to PPC of children in palliative situations?

The analysis was conducted using a multi-method approach comprising a targeted literature review of ethical issues and tensions, a theory-informed interpretative analysis, and a stakeholder consultation process with representatives of the Belgian PLTs (see 2.2.3 in Chapter 2). The complete results are presented in section 10 of the supplementary data.

Inspired by dynamic models of complexity [194–196], this chapter is structured around the characteristics and determinants operating at different system levels (micro, meso, and macro), as well as the interactions and dynamics between these levels. It first examines the characteristics, preferences, and PPC needs of the child or adolescent, situated within the microsystem. The family is considered a second microsystem surrounding the child and is explored through its characteristics and circumstances. Attention is also given to the dynamics within the family unit, including interactions between the child, parents, siblings, and other relatives. At the mesosystem level, the chapter addresses the characteristics of health care professionals (such as their needs, preferences, and attitudes towards PPC) as well as the care services they deliver. It further examines the dynamic interactions between children and families on the one hand, and care providers on the other. Finally, at the macrosystem level, the chapter considers broader societal attitudes towards the death of a child and their influence on paediatric palliative care experiences and practices.

5.2.1 Interpersonal dynamics influencing the acceptability of PPC from the perspectives of children, families and healthcare professionals

Figure 20 presents an overview is of the literature review findings on the individual factors determining the perspective of the child, the family and HCPs. Figure 21 presents the interpersonal dynamics within the family unit and with the HCPs. The narrative description below provides only a focused synthesis, intended to enhance readability and facilitate understanding. All findings are in detail reported in section 9 of the supplementary data.

Figure 20 – Schematic overview of the individual factors determining the perspectives of the child, families and HCPs

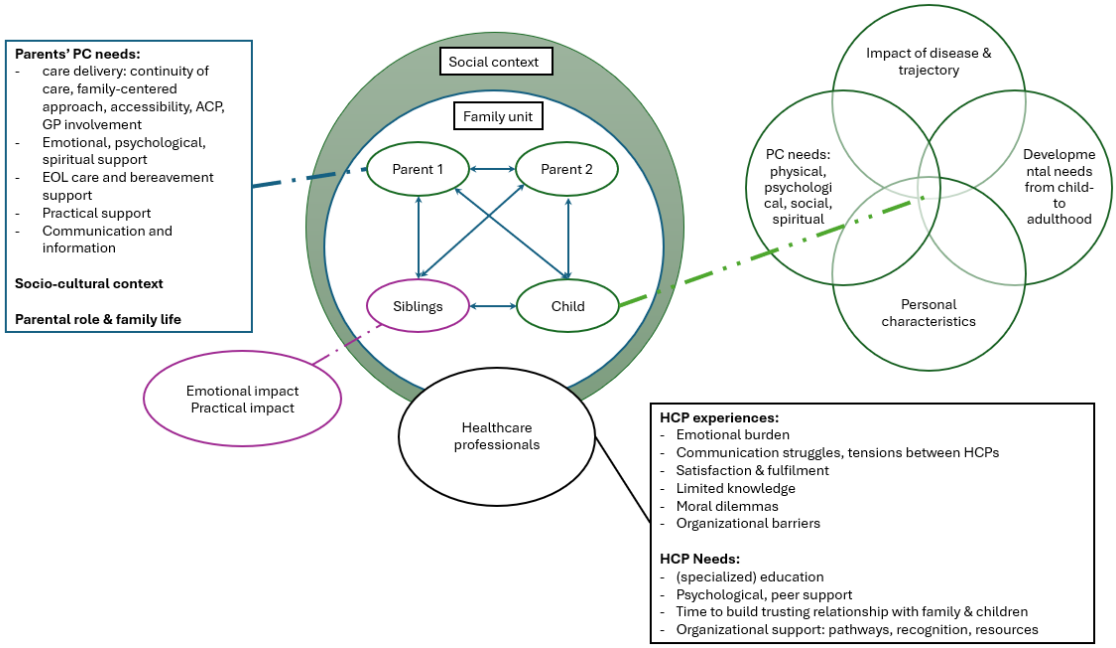
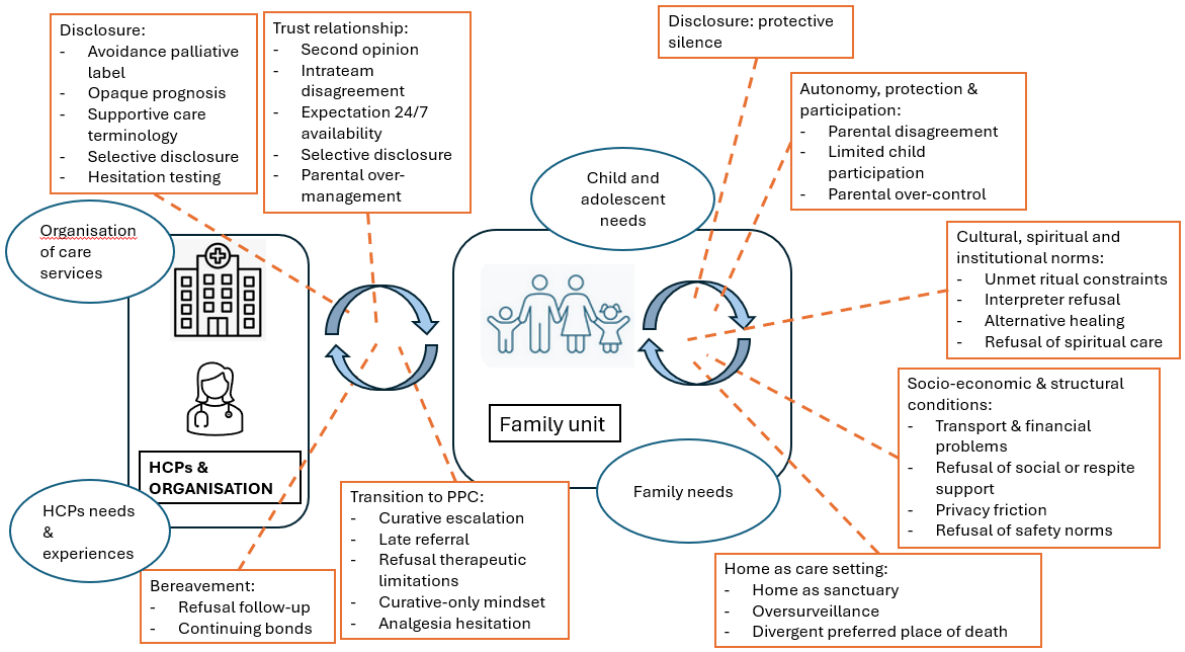


Figure 21 – Overview of the dynamics within the family unit and in interaction with the HCPs



Schematic overview of the dynamics between child, family, HCPs and society (not visualized on this figure), each with their specific characteristics and needs. PPC=paediatric palliative care; HCP= health care professional

5.2.1.1 The child's perspective: from dependency towards autonomy and a desire for normality

The child's perspective evolves throughout the illness trajectory and is shaped by the interaction between diagnosis, prognosis, developmental stage, personal characteristics, and palliative care needs. While children with life-limiting or life-threatening conditions often experience prolonged periods of dependency on parents and healthcare professionals, their growing cognitive, emotional, and social development simultaneously fosters a desire for greater **autonomy and participation** in decisions affecting their lives.[197]

As children mature, they progressively develop a better understanding of their illness, treatment, and future implications. Serious illness can influence this developmental process in different ways, but increasing age, illness experience, and exposure to healthcare settings may strengthen children's confidence and capacity to express preferences and engage in decision-making.[198 199] Adolescents, in particular, often seek greater control over their care, access to honest and developmentally-appropriate information, and opportunities to actively participate in discussions about treatment and future care goals.

Across developmental stages, children and adolescents consistently express a strong desire to maintain a sense of **normality**.[197] They wish to participate in everyday activities, preserve peer relationships, and be perceived as individuals rather than being defined by their illness. Changes in appearance, functional limitations, repeated hospitalisations, and dependence on others can challenge this sense of normality and may lead to feelings of frustration, exclusion, or loss of identity.[200] At the same time, children strive to maintain meaningful roles within their family, school, and social environment.[198,201]

The literature further highlights the importance of **dignity**, respect, and recognition of the child as a developing person.[202] Even within the context of serious illness and increasing care needs, children continue to grow towards adulthood. Consequently, paediatric palliative care should not only address

symptom burden and support needs but also create opportunities for autonomy, participation, identity development, and the pursuit of a normal life as much as possible.[197,203]

5.2.1.2 *The family's perspective: the central caregiving role within family life and cultural diversity*

In paediatric palliative care, the family occupies a central role, not only as decision-makers but also as active caregivers throughout the child's illness trajectory.[204](see also figure in section 9.3.2. of the supplementary data) As care increasingly shifts from hospital to home, parents often become the **primary coordinators of care**, taking on complex caregiving responsibilities, managing medical treatments, navigating healthcare services, and advocating for their child.[203] This caregiving role places a considerable emotional, practical, financial, and psychological burden on the family, while also affecting siblings and the wider family network.[205,206] The health consequences for parents who provide intensive care at home for their child, including physical pain, sleep disruption, and the neglect of their own well-being, should not be underestimated. Yet these effects remain widely misunderstood and often neglected.[200,207]

The family context also shapes the child's opportunities for participation in care and decision-making. While parents often act as protectors and advocates, tensions can arise between parental responsibility to protect the child and the child's evolving wish for autonomy, information, and involvement in decisions. Differences may emerge regarding disclosure of prognosis, participation in advance care planning, treatment preferences, or the balance between maintaining hope and discussing end-of-life issues. **Family dynamics** can both support and constrain the child's voice, particularly during adolescence, when growing independence and self-determination may conflict with parental concerns and protective instincts.

Families' experiences and needs are further shaped by their **cultural, linguistic, religious, and socio-economic context**. Cultural beliefs and practices may influence communication about illness, decision-making, preferences for care, spiritual care, and attitudes towards death and dying. Families from migrant backgrounds may face additional challenges, including language barriers, limited health literacy, unfamiliarity with healthcare systems, financial hardship, and reduced social support networks.[208] A culturally sensitive and family-centred approach is therefore essential to build trust, address tensions within the family, acknowledge diverse values and beliefs, and ensure equitable access to paediatric palliative care.

5.2.1.3 *The HCP's perspective: building trusting relationship with children and families in contexts of uncertainty*

Paediatric palliative care unfolds in a context of ongoing uncertainty related to diagnosis, prognosis, disease progression, transitions between care settings, and the child's transition towards adulthood. Building and maintaining a trusting relationship between healthcare professionals, children, and families is therefore a central condition for the acceptability and quality of care. Trust is shaped by open, honest, and developmentally appropriate communication, while also recognising that children and families may differ in their readiness to receive information and engage with discussions about future care planning. HCPs consistently describe trusting relationships as essential for understanding family circumstances, assessing needs, supporting shared decision-making, and ensuring that care remains responsive to the child's and family's evolving situation.[209]

Healthcare professionals often accompany families through an evolving process, from seeking cure and maintaining hope to gradually recognising palliative care needs. During this trajectory, tensions may arise around disclosure of prognosis, continuing curative treatment, advance care planning, and the timing of introducing palliative care. HCPs report difficulties balancing honesty with maintaining hope, responding to difficult questions from children and parents, supporting emotionally distressed families, and navigating cultural expectations surrounding disclosure of diagnosis and prognosis. Prognostic uncertainty, conflicting information from multiple professionals, and transitions between services can further challenge mutual trust and shared understanding.[210–212]

Building these relationships can be particularly demanding because PPC is emotionally intensive. HCPs often develop close and long-term relationships with children and their families, which can blur professional boundaries and increase emotional vulnerability. While these relationships enable personalised, family-centred care, they also contribute to grief, sadness, moral distress, and emotional burden when a child's condition deteriorates, or death occurs. Professionals frequently describe caring for dying children as emotionally exhausting and report feelings of helplessness, guilt, frustration, professional inadequacy, compassion fatigue, and burnout.[209–212] Nevertheless, many also describe PPC as deeply meaningful, finding professional fulfilment in reducing suffering, supporting families, and helping children achieve a peaceful and dignified death.[212]

HCPs report that staffing shortages, heavy workloads, lack of time, inconsistent communication between services, and uncertainty regarding roles and responsibilities can hinder their ability to build and sustain relationships with families.[210–212] In home-based PPC, these challenges are compounded by the need to work independently in unfamiliar and unpredictable environments, often with limited resources and equipment.[209] HCPs emphasised that being perceived as knowledgeable, prepared, and responsive is critical for maintaining families' confidence and trust.[209]

A trust-based relationship is essential to navigate uncertainty, support shared decision-making, but also for enabling healthcare professionals to provide compassionate, coordinated, and individualised care. Such relationships help facilitate transitions across care settings and developmental stages, create a secure environment in which both children and families can express their perspectives, and allow HCPs to respond proactively to changing physical, psychosocial, and emotional needs over time. However, sustaining these relationships requires adequate organisational support, ongoing professional development, emotional support systems, and effective interdisciplinary collaboration.[209–212]

5.2.1.4 Societal attitude towards the death of a child

At the macrosystem level, the acceptability of paediatric palliative care is influenced by broader societal attitudes towards serious childhood illness, death, and dying.[194,196] In many societies, childhood is associated with growth, future opportunities, and the expectation of a long life. Consequently, the possibility of a child's death challenges deeply held social and cultural beliefs, making discussions about palliative care particularly difficult for families, healthcare professionals, and the wider community.

This **discomfort** is reflected in the persistent association of palliative care with imminent death or therapeutic failure. As a result, professionals and families may avoid the term palliative care or prefer alternative terminology such as supportive care. While such semantic strategies may facilitate initial engagement, it can also contribute to misunderstandings about the scope and benefits of paediatric palliative care, potentially delaying its timely introduction. **Societal expectations** that medicine should prioritise cure and life prolongation may further reinforce reluctance to discuss treatment limitations, advance care planning, or care goals focused on quality of life and comfort.

In addition, **societal taboos** surrounding death and grief can hinder open communication about the child's prognosis, future care needs, and end-of-life preferences. This may limit opportunities for children and families to express their values, fears, and wishes, and can reduce acceptance of palliative care. Promoting greater public understanding of paediatric palliative care as a comprehensive approach that supports quality of life throughout the illness trajectory, rather than only at the end of life, may help foster earlier engagement and improve its acceptability.

5.2.2 Transversal analysis of the determinants influencing the acceptability of PPC

The analysis of the retrieved literature demonstrates that the acceptability of paediatric palliative care (PPC) is shaped by a complex interaction of factors operating across the child, family, healthcare professional, and societal levels. In line with the Levesque framework[27], acceptability is not a fixed characteristic of a service but rather a dynamic process that reflects whether PPC aligns with the

values, beliefs, needs, expectations, and life circumstances of the various stakeholders involved. Several overarching determinants emerged across the different system levels, including the child-and-family-centred nature of care, temporality, communication and trust, ethical tensions surrounding hope and acceptance, complexity, and ethical perspectives. A more detailed analysis can be found in section 10 of the supplementary data.

A key characteristic of PPC is its inherently **child-and-family-centred** nature. Unlike adult palliative care, the child cannot be considered separately from the family system. Family members strongly influence communication, care decisions, symptom management, care coordination, and end-of-life planning. Acceptability therefore depends not only on the child's preferences and experiences but also on parental beliefs, emotional wellbeing, coping strategies, cultural values, and practical capacities. Tensions may arise when parents prioritize protection over participation, when adolescents seek greater involvement in decision-making, or when family members hold different views regarding treatment goals, prognosis, or end-of-life care.

The findings further suggest that acceptability should be understood as a **dynamic and evolving** process that changes throughout the illness trajectory. Children's and families' needs, preferences, coping strategies, and readiness to engage with palliative care evolve over time. The **diagnostic phase** often represents a period of uncertainty, shock, and information overload, during which preserving hope and pursuing treatment remain dominant priorities. As illness progresses, families and professionals may gradually re-evaluate goals of care and engage with discussions about advance care planning, treatment proportionality, preferred place of care, and end-of-life decisions. However, this process rarely occurs in a linear manner. Different actors frequently move through these transitions at different rates, resulting in **asynchronous** understandings of prognosis and palliative care needs. Delayed recognition of palliative care needs may compress PPC integration into crisis situations where options become more limited and suffering more difficult to anticipate.

The analysis also highlights the **multidimensional nature of complexity** within PPC. Complexity frequently exists before palliative care is introduced, as many families are already experiencing social, psychological, financial, or practical vulnerabilities. Additional complexity arises through the accumulation of multiple interacting challenges, such as prognostic uncertainty, communication difficulties, emotional distress, caregiver burden, financial pressures, cultural differences, and fragmented service delivery. Importantly, complexity changes over time as disease trajectories, family circumstances, and care needs evolve. Consequently, PPC needs continuous reassessment rather than one-time evaluation.

Across all system levels, **communication and trust** emerged as the most consistent determinants of acceptability. Families are more likely to engage with PPC when communication is perceived as honest, respectful, understandable, and emotionally sensitive. Challenges related to prognosis disclosure, advance care planning, treatment limitations, symptom management, and end-of-life discussions frequently reflect difficulties in establishing shared understanding. Trust functions as the mechanism through which communication influences acceptability. When trust is established, families may be more willing to discuss difficult topics, participate in shared decision-making, and accept palliative interventions. Conversely, fragmented communication, inconsistent messages, lack of continuity, or perceived disregard for family values may reduce trust and contribute to resistance toward PPC.[196]

Another overarching theme is the **tension between hope and acceptance**. Many barriers to PPC integration, such as avoidance of the term palliative care, pursuit of additional treatments, reluctance to discuss prognosis, and resistance to treatment limitations, can be understood as attempts to preserve hope and maintain meaning in the face of uncertainty. These responses should not necessarily be interpreted as denial but rather as coping mechanisms. The challenge for PPC is therefore not to replace hope with acceptance, but to support a gradual reframing of hope from cure towards comfort, quality of life, meaningful experiences, symptom relief, family connection, and dignity.

The findings additionally underscore the importance of **developmental and relational autonomy**. Children's ability to participate in decision-making varies according to age, maturity, cognitive capacity, communication abilities, and illness burden. Adolescents often express a strong desire for information, involvement, independence, and control over decisions affecting their care. However, decision-making in PPC remains fundamentally relational, involving children, parents, and healthcare professionals. Acceptability therefore depends on achieving an appropriate balance between child participation, parental responsibility, and professional guidance.

Finally, the review demonstrates that acceptability extends far **beyond clinical** and medical decision-making. Families evaluate PPC according to its influence on everyday life, family functioning, spiritual meaning, social participation, and practical feasibility. Factors such as respite care, financial support, transportation, home adaptations, sibling support, cultural sensitivity, continuity of care, preferred place of care, and preferred place of death all contribute to whether PPC is perceived as acceptable. Ultimately, acceptability is closely linked to the capacity of healthcare systems to respond flexibly to changing and multidimensional needs while ensuring continuity, coordination, and person- and family-centred care across the entire illness trajectory.

From an ethical perspective

Beyond organisational explanations, the findings support a broader ethical interpretation of delayed access to paediatric palliative care. Many barriers appear linked to the difficulty of confronting what remains, in many societies and institutions, an “unthinkable” horizon: the severe illness and possible death of a child. Delays should therefore not be interpreted merely as denial or communication failure but as ethically intelligible mediations through which actors attempt to maintain meaning, responsibility, and moral orientation in situations that profoundly destabilise expectations.

In paediatrics, the possibility that a child may die challenges deeply rooted moral assumptions: childhood as promise, medicine as restoration, and parenthood as protection. When these expectations are disrupted, actors may maintain curative frames longer than proportionality would suggest, postpone irreversible decisions, or redirect distress toward technical debates. Such responses can be understood as attempts to reconstruct moral intelligibility in situations that threaten established ethical categories.

From a principlist perspective, many barriers reflect tensions in redefining benefit, harm, and justice when cure is no longer a credible horizon. Non-maleficence may justify limiting burdensome treatments, yet it may also motivate continued escalation to avoid the perceived harm of “giving up.” Beneficence may shift toward comfort and relational integrity, but this transition rarely occurs synchronously across actors. In paediatrics, autonomy is mediated through parents and professionals, while justice involves both resource distribution and recognition of whose interpretation of good care is legitimised.

Narrative ethics highlights how access to PPC is shaped by framing and storytelling. When “palliative” is equated with death, the term itself can threaten identities, parents as protectors, clinicians as healers, institutions as sites of therapeutic progress. Delayed disclosure, semantic reframing, or protective silence may therefore function as narrative strategies aimed at preserving a livable story until new meanings can emerge.

Care ethics reframes resistance as a relational response to vulnerability. In contexts of uncertainty and impending loss, maintaining agency, “doing something”, can be ethically protective for parents and professionals alike. These responses express efforts to preserve responsibility, relational bonds, and hope. At the same time, care ethics draws attention to systemic vulnerabilities, burnout, time pressure, fragmented services, that shape whether accompaniment remains sustainable.

5.3 Acceptability in Paediatric Palliative Care: embracing complexity through a family-centred care approach

5.3.1 A child and family-centred care in PPC: conceptual model

The analysis of the perspectives of children, families, healthcare professionals, and society indicates that the needs of children with serious illness extend far beyond the physical domain. Consistent with a biopsychosocial-spiritual model of care, these needs encompass psychological, social, and spiritual dimensions alongside physical well-being.[213] Another important finding is that the child cannot be viewed as an isolated individual; rather, the child's experiences, needs, and decision-making processes are closely intertwined with those of the family. Consequently, a child- and family-centred care model appears more appropriate for PPC than a strictly patient-centred approach, which is more commonly applied in adult palliative care. Such a model acknowledges the central role of the family in the child's life and aims to address the needs of both the child and family as an integrated unit.

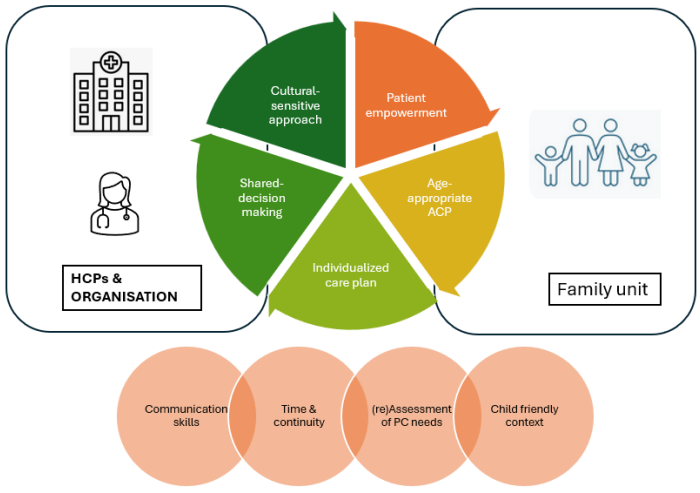
A concept analysis of child and family centred care (CFCC) came to the following definition [214]:

> *A flexible approach to delivering holistic care to children and their families, while placing the child at the core of care. Children are acknowledged to have rights, preferences, and perspectives. CFCC is generally achieved through collaborative processes involving individualised partnerships with children and their families, guided by the principles of collaboration, participation, communication, and dignity/respect*

As the definition already stated, main component of this model of care is the place of the child (rather than their illness) at the centre of holistic care, working in partnerships with the child and parents/caregivers and to consistently consider the contextual wishes of the child, family and community. These partnerships help to develop relationships that engender trust between the child, their parents/caregivers and the HCPs, which will in turn increase the efficacy of care. Children are considered as active partners alongside their families in all areas that impact their health.[214] CFCC conceptualises the whole family as recipients of care and is considered fundamental for improving quality of life of families in a paediatric palliative care situation.[206]

Figure 22 presents an overview is of elements related to CFCC, based on the analysis of the perspectives of the child, family and HCPs

Figure 22 – Overview of the core-elements to build a trust relationship between HCPs and child and family within a family-centred care approach



HCP= health care professional

The analysis of the different perspectives and ethical tensions is used as input for the elaboration of solution to improve the acceptability of PPC. Findings from the different research methods, such as the interviews with PLT members, description of initiatives abroad, and ad hoc searches in literatures served as basis for the elaboration of the solutions. In a next step these solutions were discussed with a panel of stakeholders and the input from these discussions was taken into account for the final formulation of the solutions. The aim of the solutions in this chapter is to indicate the main principles to improve acceptability of PPC in Belgium, more concrete action points are identified and elaborated more in detail in the Chapter 6 of this report.

5.3.2 Building a trustful relationship with the child and family

5.3.2.1 Concept of a trustful relationship

According to Dickens et al. (2025)[215], building a trustful relationship between healthcare professionals and children is a complex process influenced by antecedents, key relational attributes, and resulting consequences.

Trust is more likely to develop when children are well prepared for healthcare encounters, supported by their parents, and cared for by skilled professionals who have strong communication and relationship-building abilities. Organisational factors such as sufficient staffing, continuity of care, opportunities to see the same healthcare professionals repeatedly, child-friendly environments, and supportive policies (e.g., children' rights, cultural norms, legal frameworks) also create conditions that facilitate trust.

The development of trust relies on several interpersonal, communication-related and contextual **attributes**. Healthcare professionals foster trust by demonstrating empathy, genuineness, respect, friendliness, and emotional presence, while making time to engage meaningfully with the child. Effective communication is essential and includes using developmentally-appropriate language, providing honest information, maintaining a calm tone, and displaying positive non-verbal behaviours (e.g., eye-level contact, smiling, etc.). Trust is further strengthened when professionals acknowledge children's emotions, involve them in decision-making, support their autonomy, and use therapeutic approaches such as play, storytelling, distraction, and gradual familiarization with (medical) procedures to help reduce anxiety and create positive experiences. Continuity of care, professional competence, parental involvement, and a child-centred approach contribute to children feeling safe, respected, understood, and empowered to engage in their healthcare.

Trustful relationships generate positive **outcomes** for children, parents, healthcare professionals, and healthcare organisations. For children, trust improves emotional well-being, self-confidence, coping abilities, satisfaction with care, and cooperation during procedures, while reducing fear, anxiety, and distress. Parents experience greater confidence (and satisfaction) in healthcare services when their child trusts healthcare professionals. Professionals benefit through stronger relationships, increased job satisfaction, and reduced stress. At an organisational level, trust can improve efficiency, reduce hospital stays, facilitate future healthcare interactions, and lower the risk of errors and malpractice. In contrast, a lack of trust may result in emotional distress, poorer cooperation, family conflict, and less effective care.

Overall, Dickens et al. (2025)[215] highlight that trust between children and healthcare professionals is shaped by multiple interacting factors and depends heavily on empathy, effective communication, and a child-centred care environment. The review also emphasises the importance of developing specific, teachable competencies (particularly communication and trust-building skills) to enhance child–provider relationships, improve treatment outcomes, and support compassionate healthcare delivery.

For the implementation of building a trusting relationship with the child and families in the Belgian care context, two main elements were identified, i.e., time to build such a relationship and the provision of coherent (to the child and family) communication.

5.3.2.2 *Building trusting relationships within the Belgian care context*

According to the interviewed (Belgian) PLTs, parental resistance to palliative care was a common challenge. Parents were often reluctant to involve additional care teams and expressed a strong preference for maintaining continuity with familiar caregivers. To address this, interviewees emphasised the importance of fostering open and honest dialogue to develop a shared understanding of the child's needs and to build trust with families. They highlighted the need for a gradual, family-centred approach, adapted to each family's pace and readiness to engage with palliative care services. Establishing long-term, trusting relationships and ensuring continuity of care, through sustained involvement of the same caregivers over time, were considered essential. Building this trust required significant time, patience, and multiple recurring conversations throughout the care trajectory.

Based on these findings and in accordance with the principles of family-centred care, four objectives addressing the key modalities involved in building trusting relationships were formulated and subsequently discussed with a broad panel of Belgian stakeholders. A summarising overview of the objectives and the related solutions are presented in the summary box below the text.

Objective 1: Improve the recognition and valuation of the time healthcare professionals dedicate to building trusting relationships with families by implementing reimbursement mechanisms that adequately compensate for the time needed for communication, relationship-building, and continuity-of-care activities.

Organisational modalities focused on adapting the reimbursement system to better acknowledge the time healthcare professionals invest in building relationships with children and families in paediatric palliative care. Proposed approaches include

- the introduction of hourly rates, the creation of nomenclature codes that specifically value communication and consultation time, and greater use of salaried employment models
- the systematic registration of PLT activities to better understand the time investment and care provided, thereby informing future financing models.

Stakeholder consultation strongly supported the principle of valuing relationship-building time within the reimbursement system. Stakeholders emphasised that consultation time should become an explicit factor in assigning value to healthcare services during nomenclature reform. They also referred to recent initiatives aimed at facilitating and reimbursing longer consultations, as well as the introduction of new palliative support fees for general practitioners (see section 11 of the supplementary data). In addition, stakeholders highlighted the importance of strengthening PLTs as a mechanism to support trust-building and continuity of care. Stakeholders generally supported activity registration but identified several implementation challenges. Stakeholders stressed the need for a user-friendly digital tool integrated into electronic patient records, while avoiding additional administrative burden. Concerns were raised about the feasibility of accurately capturing the complexity of PPC activities, clarifying responsibilities for data governance, and ensuring that qualitative aspects of care are measured alongside quantitative indicators. Participants also emphasised the need to clearly define whether the purpose is to record time spent or to document the actual care and support delivered.

Objective 2. Extend the duration and continuity of professional involvement with children and families by introducing PPC at an earlier stage of the care trajectory

Organisational modalities include early identification of PPC needs and immediate involvement of palliative care services to facilitate earlier relationship building between families and professionals.

Stakeholder consultation showed strong agreement on the importance of early identification and early involvement of PPC services. Stakeholders indicated, however, that successful implementation requires sufficient human resources, validated identification tools, training for healthcare professionals, clear referral criteria, defined responsibilities, and established care pathways. Participants noted that early identification can help anticipate psychosocial, cultural, and family-related

challenges and support proactive care planning. They also highlighted the need for service mapping and wider involvement of healthcare professionals in recognising PPC needs. Recent policy developments (see section 11.3.1.2. of the supplementary data), including new palliative support fees and expanded advance care planning initiatives, were viewed as supportive measures that could facilitate earlier integration of PPC.

Objective 3. Ensure continuity and stability of the established trusting relationship over time

Organisational modalities aim to promote long-term continuity by assigning one or several fixed PLT members as trusted points of contact throughout the care trajectory, in line with the concept of a reference person in palliative care, and propose measures aimed at reducing turnover and preserving continuity in therapeutic relationships.

Stakeholder consultation strongly supported this objective and emphasised the need for additional human resources to make it feasible. Stakeholders highlighted that continuity should be balanced with sufficient team involvement to guarantee availability, particularly within 24/7 care models. Participants stressed that PLTs should be involved early in the care trajectory to facilitate relationship building and that a trusting relationship is fundamental for effective coordination and long-term follow-up. PLT members were considered essential reference persons not only during care but also during bereavement support following a child's death. Stakeholders further noted that the intensity of support should reflect the complexity and duration of care needs.

Staff retention was considered as highly important because trustful relationships are central to PPC. However, stakeholders acknowledged that there is no simple solution to predict or prevent turnover. Participants emphasised that turnover reflects broader workforce challenges within healthcare and is influenced by the emotionally demanding nature of palliative care, availability of team support, adequate work organisation, and individual factors. Stakeholders advocated for structural support measures such as supervision, debriefing opportunities, professional recognition, meaningful job content, and appropriate work organisation. Training and education were also identified as important strategies to prepare professionals for the emotional demands of palliative care and improve retention.(see also Chapter 6)

Objective 4. Ensure coherence in communication and information provided to the child and their family

This objective is discussed in more detail in Chapter 7.

TRUST BUILDING: TIME

Improve the recognition and valuation of the time healthcare professionals dedicate to building trusting relationships with families by implementing reimbursement mechanisms that adequately compensate for the time needed for communication, relationship-building, and continuity-of-care activities.

Suggested organisational modalities to facilitate this process of trust-building

- The integration of time-value in the reimbursement system with the introduction of hourly rates, the creation of nomenclature codes that specifically value communication and consultation time (within the ongoing reforms of the NIHDI nomenclature code), and greater use of salaried employment models.
- The systematic registration of PLT activities to better understand the time investment and care provided, thereby informing future financing models (see Chapter 6).
- As an alternative to adapting existing reimbursement mechanisms, increased investment in PLTs could provide the capacity needed for HCPs to spend sufficient time with families, facilitating trust-building and long-term relational continuity.

Extend the duration and continuity of professional involvement with children and families by introducing PPC at an earlier stage of the care trajectory

- Provide sufficient resources (human, validated identification tools, training, clear referral criteria, service mapping) embedded in the development of a care pathway.
- Early identification of PPC needs may be facilitated by engaging a wider range of HCPs in recognising when palliative care support is required.

Ensure continuity and stability of the established trusting relationship over time

- Identify one or more PLT members as trusted point(s) of contact as early as possible and maintain their involvement throughout the entire care trajectory.
- Actively prevent staff turnover within PLTs, by providing structural support measures (e.g., appropriate work organisation, training in coping strategies for the emotional demands of PC, professional recognition, meaningful job content, peer support (debriefing, team support)) (see Chapter 6 for further details).

TRUST BUILDING: COMMUNICATION

Ensure coherence in communication and information provided to the child and their family

- See Chapter 7.

5.3.3 Empowerment of the child/adolescent

Within the framework of child-and family-centred care, the child's voice is acknowledged and respected through the establishment of an individualised care plan that prioritises the child's preferences, values and needs, as well as through the active involvement of the child in shared decision making and advance care planning processes.

An overview of the key findings and the solutions is presented in the summary box below each text section.

5.3.3.1 A child-centred, individualised care plan

DEVELOPMENTAL NEEDS AS ONE OF THE KEY DRIVERS IN THE CARE PLAN

Core principles of a PPC plan include symptom management, management of psychological, social, spiritual needs, assessment of quality of life, communication, family support and coordination activities.[201] In addition to these core principles, the analysis of the perspective of the child (see above) identified the importance to take into account the developmental needs of the child, not only in developmentally-appropriate involvement in decision-making but also the need for normalcy with contact with other children, leisure activities and a child-friendly environment.

These findings are also in in line with other publications on the importance of taking into account the developmental needs of the child/adolescent. The review of van Driessche, 2025[197] concluded that a significant gap still exists in understanding factors that impact the development of children with a serious illness and therefore a continuous monitoring of the development of the child throughout the illness trajectory is needed as key driver to support the child's engagement and to adapt the care plan in a developmentally appropriate way. The review of Verma et al, 2026[198] found that developmentally-appropriate psychological interventions such as play therapy, art therapy, and counselling were beneficial but were inconsistently implemented.

During the consultation with Belgian stakeholders, two organisational modalities were discussed, i.e.:

- Contact with siblings, friends, school, and leisure activities should be maintained as much as possible
- Initiatives aimed at leisure activities and maintaining school participation should be supported.

Stakeholders broadly agreed on the importance of supporting leisure activities and maintaining access to education for children receiving PPC, as these contribute to quality of life, normality, and ongoing development. A recurring theme was the need for sustainable and structural funding (rather than project-based financing alone) for both the development of new initiatives and the visibility of existing services. According to the interviewed PLTs, also more structural development of recreational care offer is needed. This recreational care offer should be accessible for all children (see Chapter 6 offer section 6.2.2.6).

Stakeholders also highlighted the need to support and guide professionals involved in facilitating school attendance and leisure participation. It was suggested that this could become an additional mission for the PLTs. Several stakeholders stressed that participation in school and leisure activities should always be individualised and adapted to the child's health condition. The continuation of schooling and leisure activities was considered important for preserving a sense of normality and for maintaining quality of life.

AN ONGOING PROCESS OF NEEDS ASSESSMENT OF THE CHILD AND THE FAMILY UNIT

Across the retrieved literature on paediatric palliative care needs (see analysis above), all authors agreed on the necessity to regularly assess the needs of the child and the family. In some reviews assessment tools and instruments were listed, but the exhaustive search for appropriate tools (and their psychometric properties for accuracy and reliability) was considered out-of-scope for this project. More profound research is needed to determine which tool(s) are the most appropriate and fitted to a child with an advanced disease and their family. Nevertheless, the lack of a clear conclusion on the appropriateness of assessment tools, it is recommended in clinical practice to regularly assess all domains of care needs.

Very recently the UK organisation Together for Short Lives published an updated version of the categories of care needs, adapted to increasing complexity, longer survival and variation in access across the system, and a support checklist to identify which children may benefit from a palliative care approach.[216] This checklist consist on a red/amber/green rating tool covering the child and family needs, support networks, and practical needs such as finance, transport and education. The rating

with colours helps to identify the urgency of a family's need and signpost them to the correct level of support (i.e., universal resources, core services or specialist clinical input)

- The domain of the child and family needs focuses on the immediate wellbeing and identity of the child and their closest caregivers, by assessing the physical and clinical needs (management of pain, distressing symptoms, and ensuring the child and family get enough rest and sleep), emotional wellbeing (supporting the mental health and resilience of the child, parents and siblings), identity, spiritual and cultural needs (respecting the family's values, beliefs and cultural preferences to ensure care "fits" their unique identity), planning (offering memory-making opportunities and preparing families for death of their child with compassion)
- The domain of support networks looks at the wider 'team' around the child and their social integration, with wider family and friends (assessing the needs of siblings, and the support available from extended family and the local community), faith and community (connecting families with their faith groups or local community-led support initiatives), respite and leisure (ensuring access to short breaks (respite care) and supporting the child's right to play and social interaction), education and work (helping the child stay in child care, school or college and supporting parents with their employment needs)
- The domain of practical needs, in which the practicalities and financial security is assessed to maintain a safe home environment, with finance and benefits (ensuring the family is accessing all available support and grants), living environment (checking that housing is suitable, accessible, and safe to the child and family's needs), equipment and transport (coordinating the medical technology, home adaptations, and transport needed for safe care), food and nutrition (ensuring the family can access appropriate nutrition to meet the child's specific medical needs)

The assessment of the needs should also take into account the fluctuating evolution of the condition, which may result that the child moves between phases of care needs in a non-linear way. These phases of care needs include the stable phase (in which the child' overall condition is relatively stable and predictable), the unstable phase (in which the child's condition is fluctuating, unpredictable or changing, requiring closer review and adaptation of care), deteriorating phase (in which the child's condition is showing a pattern of progressive decline, with increasing vulnerability and reduced response to interventions), dying phase (in which the child is recognised to be approaching the end of life, where death is likely in the coming days or weeks).

The above-mentioned checklist is mentioned here as an illustration of an assessment tool, covering all domains of care needs of the child and the family.

Another example found in the international search, was the Dutch initiative called the *Individueel Zorgplan* (IZP) (see section 7.3.5.9. of the supplementary data).[217] It is a structured, personalised care planning tool to support children with life-limiting or complex conditions and their families. It provides a comprehensive, multidisciplinary framework for assessing needs, agreeing shared goals, coordinating interventions and documenting care delivery across settings. The *IZP* emphasises collaboration between clinicians, specialists, home care nurses and families, ensuring that the child's preferences and family context are central to care decisions. By formalising key aspects such as symptom management, psychosocial support and practical arrangements, the *IZP* promotes continuity, transparency and proactive planning throughout the illness trajectory.

In the **interviews with the PLTs** the participants were not in favour of using an assessment instrument. They cited a perceived absence of assessment instruments, and they preferred ongoing conversations with the child and family. According to the interviewees, the use of formal assessment instruments is not considered necessary as such tools are often perceived as impersonal and time-consuming. Furthermore, the highly diverse and complex characteristics of the patient population make it difficult to develop a single instrument that is appropriate and applicable across all cases.

ADAPTING THE CARE PLAN TO THE SOCIO-CULTURAL BACKGROUND OF THE FAMILY UNIT

An example of impact of socio-cultural background of the family, is the review on forced migrant parents in PPC.[208] They often experienced cultural and language barriers, including feeling ignored, excluded from decision-making, fearful of misusing services, and encountering cultural misunderstandings, discrimination, or racism. A **collaborative care approach** that respects divergent beliefs and supports parental advocacy was found to address these needs, although it requires additional time.[208] Key facilitators included clear communication strategies (simplified language, interpreters, visual aids, and non-verbal communication), building trust through empathy and understanding families' migration experiences, and improving access to services through care navigators, community support, and specialist healthcare providers.[208]

The review proposed a framework for **culturally sensitive care**, defined as effective and appropriate interactions, with a mutual understanding and respect of culture, to promote equity and meet individual need.[208] Essential elements include:

- on individual level: compassionate, empathetic non-judgemental approach (a philosophy of cultural humility), good parental coping mechanisms and support systems
- on relational level: mutually respectful relationships, individualised collaborative care with balancing of safety versus preference/comfort
- on structural level: access to professional interpreters and language aids, community and respite services, culturally informed HCPs, parental health literacy support, additional time with families, and linking of staff with similar cultures and ethnicities to families

When implemented, culturally sensitive care can increase parents' confidence, reduce anxiety and uncertainty, improve service access and advocacy, strengthen trust and mutual understanding, and enhance shared decision-making and care planning.

In interviews with the Belgian PLTs, cultural and religious aspects were identified as potential barriers to the acceptability of PPC (in line with our findings above). These included beliefs that influence the acceptance of care decisions, cultural differences in perceptions of death (and death at home) and challenges in communicating prognosis or discussing the child's condition openly due to cultural norms and values. Potential solutions highlighted the importance of providing culturally sensitive psychosocial and spiritual support, including the involvement of intercultural mediators and psychologists. Interviewees also emphasised the need to strengthen cultural sensitivity among HCPs to facilitate communication, enhance mutual understanding, and ensure care that is respectful of families' cultural and religious backgrounds.

Social vulnerability: financial support

In the interviews with the PLTs, the socio-economic circumstances of families emerged as an important factor influencing the acceptance and engagement with PPC. Complex family situations, such as parental separation or divorce, may complicate the delivery of standard home-based care and, in some cases, render it difficult or even not feasible. Housing instability, including the absence of a fixed residence, and socio-economic vulnerability (e.g., financial hardship) were identified as additional barriers to access to PPC. Furthermore, families may be reluctant to disclose socio-economic needs due to feelings of shame or stigma, which can result in resistance to the involvement of external social support services.

Stakeholders generally agreed that **financial support** should be targeted toward families with the greatest needs, while recognising the challenges associated with defining and operationalizing such an approach. Several participants noted that certain forms of financial assistance already exist through patient organisations and support schemes, particularly in end-of-life situations, but concerns were raised about potential inequities between different disease groups. Stakeholders highlighted the difficulty of determining who should qualify for additional support, with suggestions including consideration of the family's cumulative income and overall socioeconomic situation. There was strong

support for using clear, proactive eligibility criteria to ensure that vulnerable families receive the assistance to which they are entitled and to reduce the risk of non-take-up of benefits. At the same time, participants emphasised that financial hardship often results from the cumulative impact of a long illness trajectory, including loss of income, caregiving responsibilities, and other sacrifices made by families. To balance equity and universality, some stakeholders suggested a model combining a basic level of support available to all eligible families with additional, needs-based assistance for those facing greater financial challenges.

Stakeholders recognised the potential value of **including a social worker within PLTs**, particularly to support families facing social or financial vulnerability and to help navigate administrative procedures, benefits, and available support services. More details about the involvement of a social worker in the Belgian context can be found in the Chapter 6.

Empowerment of the child: a child-centred, individualised care plan

A child-centred, individualised care plan, adapted to the regular assessment of palliative care needs of the child and the family, and taking into account the developmental phase of the child and the socio-cultural background of the family unit.

- Developmental needs as one of the key drivers in the care plan
  - Contact with siblings, friends, school, and leisure activities should be maintained as much as possible.
  - More details about the implementation of such initiatives in the care offer is presented in Chapter 6.
- An ongoing process of needs assessment of the child and the family unit
  - Comparison of available tools was not conducted within this project.
  - Complexity is increasingly acknowledged as a core element in the assessment of children's and families' care needs (e.g., checklist by UK Together for Short Lives with an updated version of the categories or the *Individueel Zorgplan* from the Netherlands).
- Adapt the care plan to the socio-cultural background of the family unit
  - Improve culturally sensitive care
    - Every hospital should ensure access to intercultural mediators for its patients (see Chapter 6).
      - Every hospital should play a role as intermediator to ensure building a trust relationship between HCPs and patients.
      - See also section on empowerment of the HCP: strengthen cultural sensitivity among HCPs.
  - Take into account social vulnerability
    - Provide financial support to families with greatest needs: criteria to determine these needs should be further specified.
    - At least one social worker should be included in the multidisciplinary network of care providers surrounding the child and family. A key responsibility of the social worker is to alleviate the administrative burden on families and to facilitate equitable financial access to PPC and related support services.
    - See also section on guarding child' safety.

5.3.3.2 *Developmentally -appropriate shared-decision making and advance care planning*

Empowering children and adolescents to have their voices heard requires a patient-centred communication approach with comprehensive understanding of their needs, values and context. This communication model aims to promote autonomy, trust and adherence to the care plan. The effectiveness of such a communication model depends on the capacity to be adapted to the particularities of the age group, and involves active listening, frequent and structured conversations, sensitivity and affection.(Naughton, 2018, Street, 2009 and Rabin, 2011 in [199]) Within the family dynamics, a triadic communication will occur, in which adolescents, parents or caregivers and health professionals are involved.

Developmentally-appropriate advance care planning

Advance Care Planning (ACP) is a dynamic, person-centred communication process that aims to explore the values, preferences, and care goals of the child/adolescent and their family throughout all stages of illness. It provides an opportunity to address a wide range of topics, including quality of life, expectations, fears, treatment preferences, and future scenarios. Although evidence of effectiveness from randomized controlled trials remains limited, particularly for holistic and early ACP approaches, ACP can provide families with relief and a greater sense of control, help them prepare for future situations, and facilitate the gradual and appropriate discussion of difficult topics.[218]

Recently a Dutch guideline was published on advance care planning and shared decision-making in paediatric palliative care (children aged 0-18y with LTC and LLC, their families and HCPs).[219]

Advance care planning and shared decision-making are conversational approaches that can be used to give substance to care and treatment together with child and family. These approaches focus on open and equivalent exchange of knowledge, experiences, values, goals, and preferences between children, families, and health care professionals.(Fahner, 2020 and Rietjens, 2017 in van Teunenbroek, 2024[219]) Advance care planning enables individuals to define goals and preferences for future medical care and treatment, to discuss these goals and preferences with the child, its family and health care professionals, to record these, and review these if appropriate.(Rietjens, 2017 in van Teunenbroek, 2024[219]) The outcomes of an advance care planning conversation can guide the child, family, and health care professionals in determining what treatment policy supports the best interest of the child and aligns with the family's values and preferences. In this way, advance care planning is extremely helpful when a decision on the treatment is needed.

In PPC many decisions need to be made, due to the uncertainty of prognosis and the variability in treatment options (varying from no treatment to different options). Shared decision-making is a collaborative process in which the child, family and HCPs are working together to make joint decisions. However, involving children in shared decision-making remains challenging due to their developmental stage, the associated cognitive abilities required for decision-making, and the impact of illness on their overall development.

Key elements highlighted in recommendations for advance care planning (ACP) include viewing ACP as an ongoing and dynamic process that should begin early in the course of the disease. Information materials should be provided to support discussions, and all ACP conversations should be thoroughly documented in the medical record. The use of a structured conversation guide may facilitate the integration of ACP into clinical practice and help organise the planning process. Furthermore, conducting ACP conversations requires specific communication competencies, including the ability to explore the perspectives of children and families in a neutral manner, respond empathetically to emotional concerns, and present own professional perspectives grounded in scientific evidence and clinical expertise. A Belgian example of an ACP tool is presented in Textbox 2.

Textbox 2 – A Belgian example of an ACP tool

The development of CareSets is part of the Be-SafeShare project (Belgian Coordination Authority for Secure Standardized Multidisciplinary Health Data Exchange), which aims to develop and implement solutions for secure, standardized multidisciplinary electronic health data exchange.[220]

A CareSet is a reusable block of information that provides a single, patient-specific version of a given set of information, shared consistently among all healthcare professionals involved in the patient's care.

The "PatientWill" CareSet enables the recording of a patient's wishes regarding:

- an advance directive concerning euthanasia;
- a negative advance directive (treatments and/or examinations that the patient does not wish to receive);
- an advance directive concerning organ donation;
- an advance statement of end-of-life wishes and/or preferences regarding funeral rites;
- an advance declaration concerning body donation to science.

Active participation in decision-making

Braybrook (2025) examined the perspectives of children, young people, and parents regarding the characteristics of high-quality PPC.[194] At the microsystem level, active involvement of children in decision-making was identified as a key factor in strengthening positive relationships and interactions between children and health and social care professionals. Various ways to achieve the active involvement of children was proposed, such as 'telling children about their condition', 'asking children questions about their condition and care', 'enabling children to ask questions about their condition and care', 'exploring and incorporating activities that are important to the child'. Alongside discussion about their health, children of all ages described the importance of professionals getting to know them and their interests and support them to do things they enjoy. Children valued a space with home comfort or activities that enabled them to stay in touch with things or people that mattered to them, and opportunities to be distracted within the care setting (e.g., hydrotherapy pool, computer games).

Children's ability to make health decisions is not only shaped by their developmental stage (see above) but also by their experiences with the illness, and interactions with the attitudes of parents and healthcare professionals towards their decisional capacity.(Feenstra, 2014 in [197]) Since no agreement is yet found on the **biological age of competence for decision-making** (some studies suggest the age of 12y as appropriate), the ability of the child for decision-making should rather be considered and not their calendar age, and should therefore individually be determined. The competence for decision-making does not only depend on a certain level of maturity of neurological capacity, but also on several other factors, such as socio-economic status, culture, peer environment, etc. Whereas neurocognitive development in healthy children can already vary due to the interaction of these factors, an additional layer of complexity is added by the impact of serious illness on the development of the child.[197]

During **adolescence**, the desire to participate in decisions about their care aligns closely with a growing need for independence and active involvement in managing their own health.[199] Supporting **teen autonomy** consist of strategies of good communication and emotional support and can help the adolescent to feel more in control and respected. Empowerment of adolescents is a multifactorial process, influenced by positive interpersonal relationships, access to accurate information and opportunities to make decisions about their care. The authors of this review [199] identified several advanced care planning tools for promoting autonomy of adolescents, such as the Family-Centred Advance Care Planning model (FACE). These tools aim to increase the congruence between the preferences of the adolescent and their family and to facilitate open communication about complex

topics, contributing to a greater satisfaction of adolescents and their family with the care plan, and by reducing the stress and anxiety associated with end-of-life decisions.

Questions about the legal age of decision-making are recurrent and conflict with the gradual and highly variable developmental process of each individual. There is often an overrepresentation of the parental voice. It is important that both parents and children have a voice, while maintaining emotional security and family coherence. However, legal experts should be available to guide healthcare professionals in legally and ethically complex situations. At present, legal frameworks appear to be insufficiently developed according to stakeholders, and healthcare providers often find themselves operating in a grey area.

Healthcare professionals should be familiar with, provide access to, and use tools that facilitate the inclusion of adolescents and young adults (AYAs) in discussions from the time of diagnosis, including tools that can also be used by parents. Professionals should have the time and resources to centralize these tools and to train, or at least raise awareness among, families and healthcare providers regarding their use. In Australia, the tool Voicing My CHOiCES is used in adolescent and young adult care. Developed in the United States, it is an advance care planning tool designed to help young people with serious illnesses articulate their values, preferences, fears, and hopes in a developmentally appropriate way, going beyond traditional advance directives. It also supports continuity of care by ensuring that these preferences are clearly documented and can be carried forward across different stages of care and between services.[221]

Evidence on the FACE intervention in adolescents with cancer or HIV, compared with usual care, was based on low- to very low-quality evidence. The findings suggest that adolescents who participated in the FACE intervention were more likely to complete a legal statement of treatment preferences, demonstrated greater concordance regarding treatment preferences and treatment restrictions, and showed greater agreement in granting family members decision-making flexibility (cfr. family leeway). Among adolescents with cancer, the intervention was also associated with a lower risk of depression and higher levels of spiritual well-being. However, no significant effects were observed on anxiety or overall quality of life.[219]

Key elements in the **recommendations** by the Dutch guideline on (advance-care planning and) decision-making in PPC [219] include recognising when a decision is required, presenting treatment options with their advantages and disadvantages, exploring the preferences and circumstances of the child and family, and reaching a joint treatment decision (cfr. four steps structure in a shared decision-making process). Effective implementation requires advance preparation, the use of structured conversations, clear and balanced communication, opportunities for questions, and attention to the child's and family's preferences. The process should also account for legal and ethical considerations, recognise that multiple discussions may be needed, and be adapted to the child's desired level of involvement and the clinical context, as shared decision-making may not be feasible nor appropriate in emergency situations. The involvement of the child should always be in a developmentally appropriate way, with use of accordingly adapted language by the healthcare professionals.

During the stakeholder consultation following comments were given concerning the following organisational modalities:

- Use of adapted communication tools

Several tools already exist but need to be adapted to context of PPC. The search for an exhaustive list of available tools was not feasible within the scope of this project; however some examples were cited by stakeholders or came across the research process. The BOOST tool, which has been validated by the End-of-Life Care Research Group, is an example of a communication support instrument. Communication with babies and infants remains particularly challenging because of their limited communication abilities. They suggested exploring whether specific training approaches, potentially inspired by programmes such as FINE (Family and Infant Neurodevelopmental Education), could help professionals further develop communication skills for this population.[218]

- Participation of AYAs in decision-making

Stakeholders emphasised that the participation of adolescents and young adults (AYAs) in decision-making should be supported within a child- and family-centred care approach that takes into account both the perspectives of the young person and those of their parents. HCPs play a key role in facilitating open dialogue and ensuring that all voices are heard throughout the decision-making process. At the same time, **participation must be carefully balanced with protection**. Children and AYAs should not be placed in situations of divided loyalty between their own preferences and those of their parents, nor should they be burdened with excessive decision-making responsibilities. Safeguarding emotional well-being and maintaining family cohesion remain important considerations. Effective implementation of shared decision-making therefore requires healthcare professionals with strong communication skills and specific expertise in engaging children, adolescents, and families in sensitive discussions, with experienced professionals being particularly valuable in complex situations. Stakeholders also highlighted ongoing **legal and ethical uncertainties** regarding the decision-making authority of minors and AYAs, especially when their wishes diverge from those of their parents. To address these challenges, healthcare professionals should have access to **practical support mechanisms**, such as ethical-juridical consultation services and clear guidelines for navigating complex decision-making processes. Particular attention is also needed during the **transition to adulthood**, as continuity of care and established therapeutic relationships may be disrupted when young people reach the age of 18. Finally, stakeholders stressed the importance of effective coordination between federal and regional authorities in areas such as palliative care, education, and psychosocial support to ensure coherent, continuous, and integrated services for AYAs and their families.

- Collaboration PLT-AYA teams

Stakeholders highlighted the importance of strengthening collaboration between PLTs and AYA teams, while noting that the organisation, scope, and day-to-day functioning of AYA teams remain insufficiently understood. Current AYA initiatives appear to focus primarily on oncology populations, raising questions about their role in supporting young people with other life-limiting conditions. To facilitate effective collaboration, stakeholders emphasised the need for a clear delineation of roles and responsibilities between PLTs and AYA teams, ensuring complementary rather than overlapping care provision. They further stressed that multidisciplinary consultations, coordination activities, and joint care planning require dedicated resources and appropriate financing. Structural mechanisms for coordination and expertise exchange were considered essential, enabling effective knowledge-sharing between AYA teams and PPC services and supporting the provision of integrated, developmentally appropriate care for adolescents and young adults with palliative care needs.

Empowerment of the child/adolescent: developmentally-appropriate advance care planning and active participation in decision-making

- Create a child-friendly environment in which the child can openly express his preferences, needs and values regarding his care plan, ACP, and other aspects related to PPC.
- Preconditions for such a child-centred environment are:
  - Use developmental age-adapted communication tools.
  - PLTs should have expertise in these tools, provide access to them, and promote their use to facilitate the child's active involvement alongside families and healthcare professionals.
  - The age appropriateness is influenced by the willingness to participate, the ability to participate (including decision-making capacity, a child's understanding of their own medical process, cognitive impairment), developing social identity and legal responsibilities. These factors should be carefully considered when tailoring

communication and advance care planning (ACP) processes to the individual child's needs and circumstances.

- Provide opportunities for adolescents and young adults (AYAs) to participate in decision-making themselves, alongside simultaneous support for parents.
- Experience with shared decision-making and advance care planning (ACP) in other settings, such as adolescent and young adult (AYA) services and adult palliative care teams, can provide valuable insights and inform ACP practices for children and adolescents.
- The initiation of paediatric ACP should not depend on a single healthcare professional. Rather, it should be regarded as a shared responsibility, with all members of the multidisciplinary team feeling empowered and supported to contribute to the process. Elements that can support HCPs in conducting ACP include formal ACP training, incorporating communication skills development, ensuring that parents have a clear understanding of ACP and that their readiness to participate is assessed before ACP conversations begin, and providing access to an appropriate physical environment where conversations with the child and family can take place in privacy and away from busy clinical settings.
- The timing of initiation should be as early as possible, ideally close to diagnosis.

5.3.4 *Empowerment of the parents and family*

The analysis of parents' needs and of the dynamics within the family unit and between parents and healthcare professionals shows that parents are often caught between their own preferences, values, and needs (which are frequently influenced by the family's sociocultural background), their central role as (co-)decision-makers regarding the child's care plan, the child's needs and preferences (which may differ from their own), the uncertainty surrounding the prognosis and course of the illness, and their dependence on the information provided by healthcare professionals in order to make informed decisions. In the interviews with the PLTs, it was also cited that parents often experience a substantial emotional and practical burden when caring for a seriously ill child. Decision-making can be particularly distressing, especially when parents are asked to participate in choices with potentially life-or-death consequences. This burden extends beyond individual parents and affects the entire family unit, as ongoing discussions about care involve balancing the preferences, values, and needs of the child, parents, siblings, and other close family members. In addition, families may face limitations in their caregiving capacity due to organisational and practical constraints, such as employment obligations or the inability to be constantly present with the child, which can hinder the implementation of home-based care plans. Home care itself may also place a heavy burden on families because of increasing medicalization, requiring parents to take on quasi-professional roles, including managing medical devices and administering medications.

One of the key elements of a family-centred care model, is the supportive attitude towards the parents (and the child), including the active involvement of parents in decision-making and the provision of information.

5.3.4.1 *Active participation in decision-making*

Advance care planning assists parents in thinking now about what health care they would want their child to have in the future and communicating these wishes to their healthcare team. It allows families the opportunity to discuss their beliefs and values, with the overarching goal that the child/young person will receive the "right care, at the right time, in the right place".[222]

Key elements from the Dutch guideline on the roles of the child, family and HCP in ACP and decision-making include the substantial variation in preferences regarding the involvement of parents and children in advance care planning and shared decision-making. Parents may prefer to act as the final decision-makers, share decisions with healthcare professionals, defer decision-making to clinicians,

or, at times, feel unable to make a decision. Similarly, the desired level of child involvement varies according to the child's age, developmental stage, clinical situation, and the nature of the decision. Consequently, recommendations emphasise that the involvement of both the child and family should be tailored to their individual needs and preferences. Healthcare professionals are strongly encouraged to actively involve children and families in ACP and shared decision-making conversations, ensuring that the child's perspective is considered in a manner appropriate to their developmental age. Furthermore, parents should be recognised and valued as experts on their child, given their unique knowledge of the child's needs, values, and preferences.[219] This was also confirmed during the interviews of professionals experienced in PPC and the stakeholder consultation. A potential solution mentioned during stakeholder consultation would be to raise awareness among healthcare professionals during their training about the importance of acknowledging and supporting parents in this role.

A variety of practical approaches can also help involve parents in decision-making. Two examples were mentioned by stakeholders. First, the use of Advance Care Planning (ACP) can promote consistency in care and facilitate the participation of both families and children. Second, the access to secure digital platforms, such as CoZo, can help patients and their families gain a better understanding of their care plan and become more actively involved in the care trajectory. The search for initiatives from abroad revealed also an example of a comprehensive tool for shared decision-making from the Netherlands (see Textbox 3).

The analysis of potential ethical tensions further suggests that the considerable responsibility borne by parents may sometimes lead to overprotective attitudes towards their child, resulting in reluctance to accept support or care coordination from the PLT or other healthcare providers. In such situations, peer support is particularly valuable. Parent and patient associations may play an important role in providing this support, but these organisations require adequate logistical resources to carry out this function.

Textbox 3 – Illustration of a comprehensive tool for shared decision-making across the care trajectory

The Experience Meter (*Ervaringsmeter*) is a digital tool developed in the Netherlands to systematically capture the experiences and perspectives of children receiving palliative or long-term care, their families and care professionals. It enables regular, structured feedback on care quality, symptom burden, support needs and satisfaction with services, using developmentally-appropriate questionnaires and visual scales. The tool can be used across care settings (hospital, home and community) to monitor outcomes, inform care adjustments and identify areas for improvement. By integrating real-time experience data into clinical practice and organisational learning, the Experience Meter supports responsive, person-centred care and contributes to quality improvement at both the individual and service levels.

Source: Kenniscentrum Kinderpalliatieve Zorg)[223]

5.3.4.2 Communication between family and HCPs

Use of an interpreter

Stakeholders agreed that language barriers can significantly hinder communication in PPC, particularly during urgent, complex, or emotionally charged situations. Human interpreters and intercultural mediators were generally considered the preferred option because they are better able to convey cultural context, emotions, and nuanced information than AI-based translation tools. However, accessing qualified interpreters is often challenging, even for planned consultations, and becomes even more difficult during unplanned care or emergency situations. As a result, AI translation tools were seen as a useful backup solution when no interpreter is immediately available, although stakeholders raised concerns about translation accuracy, confidentiality, and the risk of misunderstandings.

Several participants emphasised that language support is needed not only in hospitals but also in home care settings, where PLTs frequently encounter families with limited knowledge of the local language and little social support. Stakeholders stressed that family members should be avoided as interpreters whenever possible because of the risk of inaccurate translation, loss of important nuances, and the emotional burden placed on relatives. There was broad recognition that interpreters and intercultural mediators require specific training and supervision to adequately support discussions about serious illness, palliative care, and end-of-life issues.

To improve access to expertise, stakeholders suggested developing a centralized pool of intercultural mediators that could support PLTs and other healthcare professionals across settings. In addition, peer supporters or expert patients who share the family's language, culture, or lived experience were identified as valuable complementary resources. Finally, stakeholders highlighted the importance of continuity, noting that involvement of the same interpreter, mediator, or support person over time can help strengthen trust, facilitate communication, and support relationship-building with families.

Introducing the term "palliative care"

Stakeholders supported the idea of introducing the term "palliative care" progressively and sensitively, adapting communication to the child's condition, the family's readiness, and the stage of the illness. Several participants emphasised the importance of framing palliative care initially in terms of comfort, quality of life, symptom management, and support, helping families understand its benefits before focusing on the terminology itself. Stakeholders noted that HCPs require adequate training and communication skills to introduce the concept appropriately and avoid misconceptions.

EMPOWERMENT OF THE FAMILY

Active participation in decision-making

- Recognition of the parents as central actor, expert of the child.
- Organisation of a supportive environment around the family unit.
    - PLTs should involve psychologists, spiritual counsellors and ethicists in the care plan to support parents, and may seek legal advice to clarify legal boundaries in decision-making (more details are described in Chapter 7).
    - PLTs can refer parents to appropriate patient or parent associations (more details are described in Chapter 7).

Facilitating communication between family and HCPs

- Human interpreters and intercultural mediators were the preferred option, however in case of unplanned or emergency situations, the use of AI-based translations tools can be considered.
- Establishing a centralized pool or database of intercultural mediators may enhance access to support services and facilitate the provision of culturally and linguistically appropriate care by PLTs and other healthcare professionals across settings.
- Maintaining continuity over time through the ongoing involvement of the same interpreter, intercultural mediator, or support person may facilitate effective communication and contribute to the development of trusting and supportive relationships with families.
- A key factor influencing the acceptability of the term "palliative care" is the readiness of the child and family to engage with the concept. To support this readiness, alternative terms such as supportive care, comfort care, or quality-of-life care may help families better understand the goals and benefits of paediatric palliative care. Healthcare professionals require appropriate training and strong communication skills to introduce these concepts sensitively and effectively, while addressing concerns and minimizing misconceptions.

5.3.5 Empowerment of the HCPs

According to professionals experienced in PPC, healthcare professionals with limited experience in PPC play a crucial role in shaping the acceptability of paediatric palliative care, yet they face significant emotional and professional challenges. Many experience a substantial emotional burden when caring for children with life-limiting conditions, often without adequate structural support for their own wellbeing, such as regular supervision, debriefing opportunities, or psychological support. The emotionally demanding nature of PPC can contribute to moral distress, grief, compassion fatigue, and burnout. In addition, some healthcare professionals may be reluctant to initiate advance care planning (ACP) discussions or refer children and families to PLTs, partly because palliative care remains difficult to integrate within a predominantly curative medical mindset. Professional experienced in PPC explained that emotional resistance may arise from concerns about diminishing hope, uncertainty regarding prognosis, or the perception that referral signals therapeutic failure. Misunderstandings, conflicting messages, or breaches of trust between families and healthcare professionals can further complicate these discussions and, in some cases, may even lead families to seek care in another hospital. These findings highlight the need for better support, training, and guidance for healthcare professionals, enabling them to navigate difficult conversations, manage their own emotional responses, and engage confidently in timely palliative care integration.

Internationally, it has been reported that the use of tools such as the *Serious Illness Conversation Guide Pediatrics*© helps to prevent mental overload among healthcare professionals. During the stakeholders' and professionals' consultations, it was emphasised that documenting ACP decisions is perceived as a form of emotional support, enabling healthcare providers, particularly in primary care, not to feel solely responsible for ethically sensitive decisions. The model of multidisciplinary oncology consultations is cited as an example.

5.3.5.1 HCPs' leading role in advance care planning

Recommendations from the Dutch guideline on communication during advance care planning (ACP) and shared decision-making [219] emphasise the importance of providing clear, honest, and transparent information about diagnosis, prognosis, treatment options, and associated uncertainties. Healthcare professionals should employ effective communication skills, including the use of concrete and developmentally-appropriate language, active and exploratory listening, and empathetic acknowledgment of emotions. Communication should also be tailored to the preferences of the child and family, while respecting their cultural, religious, and philosophical beliefs. In addition, professionals should recognise that parents may experience significant challenges during ACP and decision-making, including feeling unprepared to make decisions, difficulty anticipating consequences, and emotional conflict between minimizing their child's suffering and prolonging life. These challenges should be acknowledged and addressed when preparing for and conducting ACP and shared decision-making conversations.

Healthcare professionals often avoid or delay the initiation of paediatric advance care planning (see also description of the dynamics between family unit and HCPs).[224]

Although healthcare professionals generally agreed that ACP discussions should begin early, ideally soon after diagnosis of a life-limiting condition, these conversations often occurred much later, frequently during crises or when death was imminent. Delays were commonly linked to prognostic uncertainty, concerns about parental readiness, fear of causing distress or diminishing hope, and uncertainty about who should lead the discussions.

Effective initiation was associated with professionals who had established trusting relationships with families, possessed strong communication skills, experience, and ACP knowledge. Important prerequisites included professional training, parental understanding and readiness, open discussions about prognosis, multidisciplinary support, and an appropriate environment for conversations. Overall, the review concluded that personal, social, cultural, and organisational factors all influence ACP initiation, resulting in inconsistent practice and delayed discussions, highlighting the need for

standardized approaches, education, and tools to support earlier and more effective paediatric ACP conversations.[224]

In line with Carr et al. (2021)[224], PLTs were identified as the healthcare professionals best positioned to initiate ACP conversations and oversee the ACP process, given their expertise in paediatric palliative care and their close involvement with children and families.

Examples from other countries are available, such as the ACP framework developed in the Netherlands, which could serve as a source of inspiration for the development of a Belgian Advance Care Planning (ACP) approach in paediatric palliative care.

5.3.5.2 Shared knowledge and experiences between professionals

This element is in detail described in the Chapter 7.

5.3.5.3 HCPs intercultural sensitivity

Stakeholders acknowledged that improving healthcare professionals' intercultural sensitivity is important but remains challenging in practice due to limited knowledge, the complexity of cultural and religious diversity, and insufficient training opportunities. Many participants emphasised the need for dedicated education and training on culturally sensitive care, including the integration of cultural, spiritual, and philosophical aspects into undergraduate curricula and continuing professional development programmes. Several stakeholders suggested that such training could be supported through accreditation systems and highlighted existing examples, such as PalliaCare initiatives and communication guides for complex conversations.

Stakeholders also stressed that intercultural competence requires sufficient time and resources, allowing professionals to reflect on their own assumptions and develop a better understanding of the perspectives of children and families from diverse backgrounds. There was support for increasing workforce diversity and involving more healthcare professionals with different cultural backgrounds. In addition, participants highlighted the importance of knowledge sharing, experiential learning, and ensuring that professionals do not make assumptions on behalf of families but instead actively explore their individual values, preferences, and needs. Some stakeholders proposed a stepped-care model, whereby professionals could first seek remote intercultural expertise and escalate to on-site support when needed. Finally, attention was drawn to the close relationship between cultural sensitivity, spiritual care, and person-centred care, emphasising that culturally sensitive practice requires both communication skills and competence in addressing existential and spiritual concerns.

5.3.5.4 Guarding child' safety

Stakeholders acknowledged that situations may arise in which a child receiving PPC cannot safely remain at home because of unsuitable living conditions, lack of caregiver capacity, or concerns related to the home environment. In such cases, there was cautious support for exploring alternative residential care arrangements, although participants stressed that these should remain exceptional and be tailored to the child's needs. Residential disability services, respite care facilities, or other specialized settings were mentioned as potential options, provided that they receive support from nursing services and specialized PPC teams. Stakeholders emphasised the importance of ensuring that staff in such facilities are appropriately qualified and that the child's psychological well-being and family relationships are protected. Concerns were also raised about the limited availability of respite care places, the lack of accommodation options for unaccompanied minors, and the risk of family disruption. Several participants suggested exploring partnerships with youth care services, disability services, patient organisations, and initiatives such as the Ronald McDonald Foundation. Strong intersectoral collaboration, involving health, welfare, youth care, and justice sectors, was considered essential, with clear agreements on roles and responsibilities.

Stakeholders also agreed that mental health professionals and youth support services should be involved when there are concerns about the safety or suitability of the home environment, while noting

that such situations are relatively rare and that existing mechanisms can often be mobilized when needed. However, participants stressed that interventions should avoid unnecessarily multiplying professionals involved in the family's care and should aim to preserve the child's trust and, whenever possible, maintain family relationships. Some stakeholders highlighted practical limitations, including shortages of services and available placements, which can restrict the range of feasible solutions.

Regarding the use of the hospital as a temporary accommodation solution, stakeholders generally viewed this as a measure of last resort. While temporary hospitalisation may sometimes be necessary to ensure the child's safety and continuity of care, many participants questioned whether the hospital represents the most appropriate environment for prolonged stays. Concerns were raised about costs, bed capacity, staffing availability, and the risk of using healthcare settings to compensate for broader social, housing, or welfare shortcomings. Nevertheless, stakeholders acknowledged that hospitals can provide a temporary option when no suitable alternatives are available, particularly if specialised paediatric staff are present. Overall, participants emphasised that hospitalisation or residential placement should not replace structural solutions addressing housing, social support, and family needs.

EMPOWERMENT OF THE HEALTHCARE PROFESSIONALS (HCPS)

HCPs leading role in advance care planning

- Strengthen the role of PLTs in the development of an ACP plan, in particular through:
  - the early initiation of ACP discussions;
  - the use of a shared ACP tool;
  - the centralization of all relevant information in a shared patient record;
  - pending the implementation of such a shared record, the designation of a healthcare professional responsible for documenting all information regarding the child's and family's ACP preferences and values, and for sharing this information with all relevant healthcare providers;
  - the provision of sufficient support (time and resources) to enable PLTs to regularly review and update the preferences and values of the child and their parents.
- Provide training on communication and relationship building skills for all HCPs.
- Legal experts should be available to guide HCPs in legally and ethically complex situations.
- Initiatives from abroad are available as source of inspiration for the development of a coordinated approach on ACP in Belgium.

Enhancing cultural sensitivity among HCPs

- Map and identify all care-related initiatives within the family's socio-cultural context, enabling healthcare professionals to draw upon this network and tailor care as closely as possible to the specific needs, values, and circumstances of the child and family.
- Share best practices and tips between services and experienced professionals by facilitating networking and the exchange of best practices.
- Improve the availability and implementation of intercultural mediators and spiritual counsellors in hospitals and in the community (see Chapter 6).
- Also, patient organisations may play an important role as source for information and peer-support for families with more specific socio-cultural needs.

Guarding child' safety

If the child is not safe at home:

- PLTs appear well suited to take on a mediating role and, thanks to their communication expertise, help find the best solution for the child and family.
- PLTs can receive support from mental health professionals and from existing social and judicial youth care services.
- If placement of the child is unavoidable, temporary hospitalisation may be considered. Institutions that care for children with medical needs should be authorised to also accommodate children with paediatric palliative care needs and a long-term, highly precarious social situation. For AYAs, residential options within adult palliative care may also be considered.

5.3.6 A need for a shift in societal attitudes toward a nurturing environment

At the societal level, the acceptability of paediatric palliative care is influenced not only by the characteristics of children, families, healthcare professionals, and services, but also by broader societal attitudes towards serious childhood illness, death, and dying. These societal beliefs shape how palliative care is perceived, discussed, and integrated into the care trajectory.[194,196]

One of the most prominent manifestations of societal attitude towards PPC is the avoidance of the term "palliative care." (as shown in our ethical analysis). The word "palliative" is often strongly associated with imminent death, therapeutic failure, or the abandonment of curative efforts. As a result, families and professionals may prefer alternative terminology such as "supportive care" or may postpone conversations about palliative care altogether. While such semantic strategies may initially help preserve hope and facilitate discussions about supportive interventions, they may also obscure the broader goals and benefits of PPC. This semantic avoidance can delay the recognition of palliative needs, hinder timely referral to specialised services, and contribute to the late integration of PPC into the child's care trajectory.

Stakeholders, experts and professionals report that, in the case of life-threatening but potentially curable conditions, the term “palliative” constitutes a major barrier to the early introduction of PPC by professionals although PPC is not restricted to the end-of-life phase. Members of PLTs must reiterate this message almost daily. Some professionals experienced in PPC even propose using multiple terms (palliative care, continuous care, comfort care, supportive care) to facilitate its acceptance by families and professionals.

Societal attitudes may also reinforce a predominantly curative orientation of healthcare (cfr. ethical tensions on ‘refusal of therapeutic limitations’, ‘curative-only mindset’, ‘curative escalation’). The expectation that medicine should primarily aim to cure and prolong life can make it difficult to shift toward goals focused on comfort, quality of life, and psychosocial support. Families may feel social pressure to continue pursuing active treatment, while healthcare professionals may hesitate to introduce palliative care for fear of being perceived as giving up. Such dynamics can contribute to delayed discussions about proportionality of treatment, advance care planning, and symptom-focused care.

Furthermore, societal taboos surrounding death and grief may limit opportunities for open communication about the child's prognosis, future care needs, and end-of-life preferences. When discussions about death are avoided or considered inappropriate, children and families may receive less support in expressing fears, hopes, values, and wishes. This can affect the development of a shared understanding of the illness trajectory and reduce the acceptability of palliative care interventions.

Participants in the stakeholder consultation stressed the need for broader societal awareness and education about palliative care, including integration into educational programmes and professional training. Stakeholders highlighted that death, grief, and loss are still often viewed in society through a

lens of avoidance and deficit rather than as natural aspects of life. This challenge is even greater in the context of paediatric palliative care, as the death of a child is frequently perceived as particularly distressing and "against the natural order". Stakeholders therefore advocated for better public understanding of what paediatric palliative care truly entails, similar to efforts made in adult palliative care, emphasising its role in improving quality of life rather than focusing solely on end-of-life care.

A shift in societal attitude

- The gradual introduction of the term "palliative care" across all system levels: at individual level, based on child and family readiness; more awareness and training for HCPs and more awareness at societal level (see Chapter 4 for more concrete action points)
- In addition to empowerment at the individual level (of the child, the family, and healthcare professionals) support is also needed at the societal level. This requires the development of a broad support network that accompanies and supports families throughout the care trajectory as well as after the child's death. Such a network extends beyond the healthcare sector and includes supportive attitudes and policies from employers, understanding and flexibility within school environments, adequate support for siblings, and greater recognition and space for grief within society as a whole.

5.4 Conclusion on the acceptability in PPC

The acceptability of paediatric palliative care is not a fixed concept but a dynamic process that evolves through the interactions between children, families, healthcare professionals, care organisations, and society. Children seek participation, autonomy, and the possibility to maintain a sense of normality, while families occupy a central role as caregivers, advocates, and decision-makers, often carrying substantial emotional, practical, and financial burdens. Across all stages of care, trusting relationships and open, respectful communication emerge as key determinants of acceptability, supporting shared decision-making and facilitating the timely integration of PPC.

Improving acceptability therefore requires a comprehensive child- and family-centred approach that acknowledges the complexity of PPC. Key enablers include early introduction of PPC, continuity of care and relationships (by valorising the time needed to build trusting relationships), a child-centred, individualised care planning, developmentally appropriate communication, active involvement of children and families in decision-making, and support for cultural and linguistic diversity. Healthcare professionals also require sufficient expertise, support, and empowerment, particularly regarding advance care planning and culturally sensitive care. Ultimately, enhancing the acceptability of PPC extends beyond healthcare services and calls for a broader societal shift towards creating a nurturing and supportive environment for seriously ill children and their families.

6 AVAILABILITY AND AFFORDABILITY OF PAEDIATRIC PALLIATIVE CARE IN BELGIUM

KEY POINTS

Possible solution to improve the availability and affordability of paediatric palliative care services in Belgium include:

Regarding the PLTs

- Updating the Royal Decree specifying the standards, staffing levels and duties of the 'paediatric liaison function'.
  - Including sufficient/appropriate administrative and social support.
  - Including a broad target population not limited to haemato-oncology patients.
  - Including potential new tasks such as registration of patients in palliative situations.
- Maintaining the curative and palliative mission within one paediatric liaison team.
- Better financing of the paediatric liaison teams, at least partly based on activity.
- Increasing the job attractiveness for paediatric liaison team members to increase human resources.
- Improving the geographical distribution of services directly or indirectly by involving a 'tandem referent' in hospitals without PLTs, and by supporting the transport of patients, medication and equipment.

In all settings (home, respite care, hospital with and without PLT)

- Providing psychological support for all HCPs involved in PPC.
- Involving spiritual care providers in all settings.
- Providing legal and ethical support for all HCPs involved in PPC.

In home setting

- Developing a network of paediatric nurses (or a multidisciplinary network also including psychologists) in primary care.
- Reviewing the financing of primary care nurses and psychologists in PPC.
- Supporting GPs with home visits from general and specialised paediatricians.
- Increasing the visibility of and promote collaboration between private initiatives that support wellbeing, recreation or bereavement support of children, siblings and family.
- Developing a strategy to access long term bereavement support by patient/parent organisations and other private initiatives after initial bereavement support from PLTs.
- Adapting eligibility criteria for children to receive the palliative lump sum.
- Reimbursing travel costs between hospital and home.
- Increasing awareness about paediatric palliative care in residential care setting.

In respite care

- Developing and (financially) supporting existing residential respite care facilities.

- Developing mobile respite care services network with corresponding financial support.

In hospital setting and respite care setting

- Accepting hospital with adapted infrastructure or residential respite care facility as a place to die if required or desired and in collaboration with PLTs.

In hospital without PLT

- Creating a position of PPC 'referent tandem' in hospitals without PLTs to collaborate with PLTs.

6.1 Global concept

Once the patients and their family have recognised their needs in PPC and when they have agreed to receive PPC, the next step, in a patient journey to access healthcare, is to **reach the relevant services**. The dimensions that underlie the success of reaching the relevant services within the healthcare system are related to **availability and affordability of those services**. It requires that the people involved can reach and to pay for the offer. This means they must live in a place with an offer and/or are able to travel, receive social support, have occupational flexibility and/or enough income or insurance. Barriers to the availability and affordability of healthcare can include an unequal distribution of resources (geographically or across levels of care), a restricted mobility due to age or handicap, or the inability to be absent from work to consult medical providers.[27]

In this chapter we will discuss the current offer in PPC in Belgium and identify the barriers (or gaps) in this offer that jeopardize the access to PPC. We will look both at availability and affordability of the services. Finally, several solutions will be proposed to remove these barriers and improve access.

This chapter mainly presents the findings related to research question four: "What is the current offer of PPC in Belgium and what are the gaps?". The findings presented in this chapter are based on grey literature on the Belgian PPC offer, supplemented with international scientific literature where appropriate to describe the current offer. This has been combined with information retrieved during the different phases of our project, including the questionnaires, interviews with experts, interviews with PLTs, and stakeholder consultations to discuss the barriers and propose solutions. Chapter 2 provides details of the methodology.

6.2 Current situation

6.2.1 The Paediatric Palliative Care pop-up model in Belgium

Paediatric palliative care in Belgium is organised according to the 'pop-up model of care'. This means that specialist paediatric care services, known in Belgium as paediatric liaison teams (PLTs), coordinate and provide palliative care when required in any facility and in close collaboration with local healthcare providers, primarily home nurses and GPs. This concept includes timely training and education of the local healthcare professionals.[5,6,225]

The Royal Decree of 15 November 2010 specifies standards, staffing levels and duties of the paediatric liaison function. This function was designed for children with severe chronic pathology that developed before the age of 18. It can offer curative, palliative and terminal care and it should be available 24/7. The function can be established in a hospital treating severely ill paediatric patients, with at least fifty new cases each year under 16 requiring complex treatment for haematological-oncological or serious non-oncological blood conditions.[226]

The team should consist of at least one paediatrician (0.5 Full Time Equivalent (FTE)) with experience in pain management, four nurses (4 FTE) including one specialised in paediatrics and neonatology, and a psychologist (0.5 FTE). Additionally, 0.5 FTE administrative assistant was included.[226]

Currently in Belgium, eight paediatric liaison teams have been recognised and licenced. The first six were recognised by the Federal Authorities in 2010 and 2022.[31] These are:

- *Kinderen in Thuis en Supportieve Zorg (KITES)* linked to UZ Leuven (2010)
- *Kinder Oncologische Eenheid voor Specifieke Thuiszorg en Rehabilitatie (KOESTER)* linked to UZ Gent (2010)
- *Equipe de liaison pédiatrique Globul'Home and équipe mobile de soins palliatifs linked to Hôpital Universitaire des Enfants Reine Fabiola (HUDERF)/*Universitair Kinderziekenhuis Koningin Fabiola (2010)
- *Equipe Interface (soins palliatifs à domicile) pédiatrique l*inked to Cliniques universitaires Saint-Luc (2010)
- *Equipe des Soins Continus Pédiatriques* linked to CHR la Citadelle et du CHU de Liège (2010)
- *Equipe de liaison pédiatrique* linked to la Clinique CHC MontLégia à Liège (2022)

Following the 6th State Reform in Belgium (2014), responsibility for the recognition of paediatric liaison teams has been transferred to the federated authorities. Two other teams were recognised in 2024 by the Flemish authorities (*Vlaams Ministerie van Welzijn, Volksgezondheid en Gezin, Departement Zorg*)

- *ComfortKIDZ* in *UZ Brussels* (2024) [227]
- *Paediatrische liaison* (Oever) in *UZ Antwerp* (2024)[228]

The paediatric liaison teams are currently financed by the hospital budget (Budget of Financial Means BFM, part B4, as a part of the financing for the cancer plan).[229] They receive a fixed amount of money each year, which was calculated based on the number of patients cared for at the start of structural financing in 2013 and remained unchanged since then. The two latest recognised teams have not received any financing yet. Depending on the hospital where they are localised, they rely on other sources such as charity donations (e.g., Children's Cancer Fund) or other parts of the hospital budget.[31]

6.2.2 Paediatric palliative care in the home setting

A large part of the palliative phase will be spent at home, and it may be the preferred place to die for children and their parents. The paediatric liaison teams serve as a critical link between the hospital where they are localised and the home setting. They coordinate care and ensure the continuity of care between the hospital and the home environment.[226] Home is actually a concept that should be interpreted broadly and that can include residential and semi-residential care settings for children with complex chronic disorders. A child is mostly referred to the paediatric liaison team by the treating physician from the hospital, but they are also contacted by other healthcare providers (GP, home nurses, etc) and occasionally by parents themselves.[31] This information was confirmed by the professionals with limited experience consulted by online survey and by professionals experience in PPC during the interviews. The needs of patient and family are evaluated and taken into account when developing a network of healthcare providers and other professionals around the child for providing individualised and patient-centred care, focusing on comfort and quality of life.[5,6,20–22]

6.2.2.1 Physical care

It is essential that a GP and a home nurse are involved if a child is to be cared for safely at home.[20,21] The GP and/or home nurse should be able to visit the child quickly and 24/7 in case of an emergency. Their main task will be the physical care that includes **symptoms and pain management** including prescribing, administrating and evaluating the effect of medication. They are supported by the community pharmacist and if needed by a physiotherapist, e.g., for respiratory physiotherapy or therapeutic massages. The nurses will also perform simple and more complex technical nursing tasks,

like hygiene care (bathing the child), monitoring parameters, support with enteral nutrition/tube feeding, taking care of a central venous catheter, and administration of IV medications. Because the experience of primary caregivers in paediatric palliative care is very often limited, the paediatric liaison team remains available for education and coaching when needed.[20,21,31] Two examples of primary care teams that include home nurses with experience in (paediatric) palliative care and working in close collaboration with the paediatric liaison teams include Arémis (in Brussels) and *L'Etoile des Enfants* (multidisciplinary team in the provinces Hainaut and Walloon Brabant).[5,6] Professionals experienced in PPC explained that the latter seems to be more involved in second line care providing coordination and advice.

To take care for a child in a palliative situation at home, families need specific **equipment and material**. The equipment can include an adjustable hospital bed, a pressure-relief mattress, a wheelchair, a toilet chair, an infusion stand, a syringe pump, etc. The Red Cross and different sickness funds dispose of a lending service for equipment. Some materials, especially if they are personalised, need to be bought by the parents. Some paediatric liaison teams explained that they often have a certain amount of equipment that they can lend temporarily to their patients such as patient controlled analgesia (PCA) pumps used in the terminal phase. Disposable materials can include incontinence material, wound dressings, syringes, stoma care products, etc. This material needs to be purchased by the parents at the pharmacy or home care stores of the sickness funds. The paediatric liaison Team also regularly offers material, free of charge, especially to parents with financial problems.[20,21]

6.2.2.2 Psychological support

Paediatric liaison teams rely on the **psychologist** from their own team or another multidisciplinary team, e.g., the one from the RIZIV-INAMI convention[r] that has already built a relationship with the patient and their parents. Psychologists from the hospital occasionally pay a home visit in selected cases.[20,21] Whilst confirming the previous information, consulted professionals experienced in PPC and stakeholders also explained that some paediatric liaison teams work together with psychologists from adult palliative care teams (such as Brusano[231] Reliance [232] and Domus)[233]. Psychologists working privately or in a local multidisciplinary practice are rarely involved in paediatric palliative care.

6.2.2.3 Social support

During interviews, PLTs explained that social support includes providing information on, and administrative support to help parents file for certain available benefits. It also includes contacting schools or recreational organisations, organising domestic help, and arranging other services for family assistance or care such as 'Familiehulp'[234] and '*Aide & Soins à Domicile* (ASD)[235]. (see section 11 of the supplementary data for more information)

The **benefits** for palliative children and their parents include the palliative lump sum, palliative care leave, *Flemish incentive bonus* (*Vlaamse aanmoedigingspremie*), or an incentive bonus from specific employment sector (e.g.the Social Fund of Service Voucers) and more general benefits like the maximum billing system (*Maximumfactuur – Maximum à facturer*), and financial support from *Vlaams Agentschap voor Personen met een Handicap* (VAPH), Agence pour une Vie de Qualité (AVIQ) or (Persons with Disabilities seeking Autonomy) PHARE for purchasing material or equipment.[20,21,236,237] (see section 11 of the supplementary data for more information) Some private organisations provide additional financial support, e.g., '*De Kleine Prins*',[238] or TUKI.[239]

During interviews, PLTs explained that the involvement of a social worker facilitates access to available benefits and reduces the administrative burden for parents. Several paediatric liaison teams have already integrated a social worker or social nurse into their teams out of necessity, although this

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[r] Conventions are agreements between NIDHI (RIZIV-INAMI) and one or more care institutions, in which the care provision to a certain group of patients (target group) and the method of financing are regulated.[230]

is not mandated by Royal Decree. However, in many cases, multiple social workers and support professionals are already involved in the care pathway of patients with severe and chronic conditions, through hospital treatment teams, health insurance funds and other institutions.

6.2.2.4 Spiritual care

Spirituality has been defined by the European Association of Palliative care (EAPC) as '*the dynamic dimension of human life that relates to the way persons (individuals and community) experience, express and/or seek meaning, purpose, and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and//or the sacred.*[240] Existential questions such as 'Why is this happening to me?', 'What will happen after I die?' tend to surface when people are faced with a life-threatening diagnosis. '' [241] Spirituality can be a coping mechanism [242] and can impact decision-making.[243]

For spiritual care a distinction has to be made between '**generalist' or 'primary' spiritual care** that can be provided by any healthcare provider or person (professional or volunteer) that encounters patients and parents with existential questions or spiritual needs (see Chapter 5 and section 11 of the supplementary data) and '**specialist' spiritual care**'.[244] Stakeholders and professionals experienced in PPC highlighted that paediatric liaison team members will address existential questions to the best of their abilities and some have already done additional training for this.

However, if the involved caregivers are unable to address the spiritual needs, due to restrictions in time or a lack in knowledge or expertise, then referral to 'a chaplain' or '**spiritual care provider'** is recommended.[245].

The term "spiritual care provider" refers to any professional working in the health and welfare sector who, guided by one of the recognised philosophies of life in Belgium, provides spiritual care to care recipients and care providers.[246] Although originally rooted in the Christian tradition, the term 'chaplain' can also be used for 'spiritual care providers' from any faith or background including moral counsellors with a liberal-humanist background and Islamic counsellors. Independ of their background, chaplains strive to be there for everyone including believers, people of other faits and non-believers. Moreover, it has been shown that the effectiveness of care does not depend on faith-concordance between the chaplain and the patient.[245] During their training they learn to deal with their own spirituality in a professional manner, thus not trying to convert people or convince them of their own insights regarding spirituality.[247]

6.2.2.5 Bereavement support

As explained during interviews with professionals experienced in PPC, after the death of a child, PLTs currently provide intermittent spiritual and emotional follow-up, structured around key dates in the child's life. This is subsequently followed by a gradual handover to specialised bereavement organisations such as, (*Parents désenfantés*,[248] *Berrefonds*, [249] *Vilomah* [106] and others, in order to ensure sustained support for bereaved parents and, in some cases, siblings. The available offer of these private patient or parent organisations varies between organisations and regions, and can consist of providing information, organising lectures, peer support, creative workshops, walks, yoga etc. Some organisations provide administrative and financial assistance and/or provide tangible mementoes.[106,248,249] However, stakeholders warned that PLTs are not equipped to treat pathological grief. Pathological grief requires specialised follow-up by psychiatrists or psychologists. The GP can also play a role in referral to mental healthcare.[5,6]

6.2.2.6 Developmental support (school, recreation and wellbeing)

If a child is unable to go to school, initiative exist for them to go to school at the hospital (Special education type V)[250,251] or follow school at home by *tijdelijk onderwijs aan huis* (TOAH)[252] or *École Hôpital et Domicile* (EHC)[253], or by synchronous online education (*synchroon internetonderwijs* (SIO)) such as 'Bednet' in Flanders[254] and 'ClassContact' in Brussels and Wallonia[255], or private initiatives (see section 11 of the supplementary data for more information).

PLTs explained, during interviews, that the availability of privately organised wellbeing activities (non-pharmacological interventions) at home, such as music-, art-, and play- therapy (e.g., *Ponts des arts*[256], *Troubadour sur Mesure*, clowns (e.g., docteur Zinzin)[257] and massage (e.g., KIDScare[258]), varies by region and depends heavily on charity and volunteers. Some interventions target not only the child but also their siblings and parents.

Several private initiatives organise holidays for families with sick children such as Beyond the Moon (*severe illness*), *Menno's droom* (cancer), *Château Cousin* (Complex chronic disorders), Noctiluca (cancer), etc. …).[20,21]

Textbox 4 – Lifelites (UK)

Lifelites is a UK charity that provides assistive technology and digital resources to children with complex and life-limiting conditions, supporting communication, learning, play, and social participation as an essential adjunct to clinical PPC. For example, they provide eye-gaze communication devices that allow children with severe motor impairments to express choices, participate in educational activities, or interact with family and peers, helping to improve engagement, autonomy, and overall quality of life.

Source: Lifelites: Inclusive Technology - Assistive Technology[259]

A special form of holistic care (including physical care, psychosocial care and developmental care) is respite care. Respite care includes different initiatives that relieve the parents (and the family) for a while of their caring role, leaving the child the hands of a substitute formal or informal caregiver whilst the family 'takes a break' (see section 11 of the supplementary data).

In Belgium, there are five paediatric residential **respite care facilities** that offer care and support in a home-like setting to children with complex chronic care: 'Villa Indigo'[260] and 'Cité Sérine' in Brussels[261], 'Villa du Phare'[262](will open in 2029) in Wallonia and 'Villa Rozerood'[263] and 'Limmerik'[264] in Flanders. These respite care facilities are not intended for dying but it happens occasionally or on request of parents and in collaboration with the PLT.[5,6,20,21]

In Flanders children are granted up to 60 days of respite care, while in Brussels and Wallonia they are granted only up to 32 days. Usually, parents must only pay a small part out-of-pocket for their children. The respite care facilities themselves are partly financed by the federated authorities and partly by donations and charities. The multidisciplinary teams are supported by volunteers.[5,6,20,21,265]

Mobile respite care services, which provides respite care at home is not systematically developed in Belgium. The above-mentioned Villa du Phare has a mobile team that is already active in the region of Liège. Babysitting for children with chronic disorders or complex care needs is also offered by sickness funds such as '*de Christelijke Mutualiteit/Mutualité Chrétienne*' (CM/MC)[266] and independent care organisations such as I-mens.[267]. Private initiatives are, e.g., Casa Magnolia (informal mobile respite) in Flemish Brabant and Casa Corlien (medical and nursing mobile respite care) in Limburg, and Les Tof services.[20,21,268]

6.2.3 Paediatric palliative care in the hospital setting

As explained by PLTs during interviews, children in a palliative situation will be in the hospital from time to time for shorter or longer periods for medical and/or social reasons. Some will prefer to die in the hospital, while some will die in hospital because the situation is unstable and/or parents may not feel safe to take care of their children at home. There are no specific paediatric palliative wards. The on-site availability of palliative care will depend on the presence (or not) of a paediatric liaison team, although paediatric liaison team can provide support in hospitals without a paediatric liaison team.[20,21]

6.2.3.1 Hospital with paediatric liaison team

In the hospital with a paediatric liaison team, the paediatric liaison team has an internal task to provide multidisciplinary support to the hospital "curative" team caring for the hospitalised child.[226]. In the hospital they work in close collaboration with different care givers and professionals providing different aspects of palliative care according to the needs of the patient and their family.[20,21] This information was confirmed during the interviews of PLTs.

In hospitals with a paediatric liaison team, physical care is provided by the 'curative' multidisciplinary treatment teams consisting of paediatricians, nurses, physiotherapists, dieticians, pharmacists etc. depending on the needs of the child. In fact, the paediatric liaison teams explained that they have a wide offer of healthcare professionals available with whom they collaborate. Psychosocial support will be provided also by the multidisciplinary treatment teams or by members of the paediatric liaison team (nurses, psychologists and social workers). If the hospital employs a spiritual care provider, he or she can provide specialised spiritual care, otherwise the spiritual care will be limited to a generalist level of spiritual care, or the parents may depend on their own resources. The paediatric liaison team supports also the organisation of bereavement care in the hospital including support groups for siblings and parents and structured meetings for different health care professionals involved, such as debriefing meetings after death and supervised intervision. Hospitals with a paediatric liaison team provide developmental support such as school, clowns, art-, music- or play therapy, through professionals, volunteers and private organisations. The offer can vary between hospitals. Hospitals without paediatric liaison team

The physician, nurses, psychologists, social workers, etc. of a general hospital without paediatric liaison team in general have limited experience in paediatric palliative care, although a team responsible for palliative care should be available (adult palliative support team). The paediatrician as well as other health providers can ask for support from a paediatric liaison team. The paediatric liaison teams will provide the same services as they would do in a home setting.[20,21]

6.3 Barriers to the access of paediatric palliative care identified in the offer

6.3.1 Paediatric liaison teams

6.3.1.1 The Royal decree of 15 November 2010 is outdated

Our research, through stakeholders and experts' consultations, shows that some aspects of the Royal Decree of 15 November 2010 regarding the paediatric liaison function are no longer aligned with current needs and practices. In particular, the link to paediatric haematological-oncological services and the presence of administrative support rather than a social worker within the team composition was considered outdated. The whole palliative target population should be considered and not only the oncology patients. Some hospitals with paediatric liaison teams do not even have a haemato-oncological service anymore. Furthermore, the spiritual domain of palliative care was not addressed in this decree. The composition of the team, including the 0.5 FTE psychologist and 0.5 FTE coordinating physician was questioned by the stakeholders, because of growing caseload, as well as the imbalance in paediatric expertise within the team.

6.3.1.2 Discontinuity between curative and palliative care

Access to palliative care is facilitated by the triple role of the paediatric liaison team, in curative and palliative care and in pain management, as explained by professionals experienced in PPC. This enables them to be involved and build relationships of trust with the child, the family, the healthcare professionals in hospital and primary care, when curative treatment is still being pursued, or when parents have not yet accepted the palliative situation of their child. Most paediatric liaison teams combine their function in palliative care with a broader hospital at home function for children without underlying complex chronic disease. However, in HUDERF, two separate teams exist for hospital at home (*Equipe de liaison pédiatrique Globul'Home) and for palliative care (équipe mobile de soins palliatifs*). The existence of two separate teams may pose a barrier to the access of palliative care.

6.3.1.3 Systematic underfinancing of the paediatric liaison teams

The current fixed yearly amount of money paediatric liaison teams received from the hospital financing was calculated based on the number of patients cared for in 2013 and has never been adapted since. The financing is not sufficient to perform all their tasks. The costs of a 0.5 FTE coordinating physician was not provided for in the financial breakdown of the Royal decree. Nor were the operating costs, including material for home care, taken into account. The paediatric liaison teams rely heavily on donations and charities.[5,6]

6.3.1.4 Lack of stable human resources

A key factor in facilitating access to paediatric palliative care, is the 24/7 round-a clock availability of the paediatric liaison team because it can reassure both primary care providers and families when patients return home. This 24/7 availability is sometimes restricted after triage by a nurse on the hospital ward. However, stakeholders and professionals experienced in PPC explained that the 24/7 availability, the high emotional burden of palliative and terminal situations, and limited available emotional support, poses a risk of burnout and high staff turnover.[269] The general shortage of nursing staff, coupled with the lack of paediatric nurses with expertise in paediatric palliative care, exacerbates the problem of having a sufficient and stable workforce.

During the interviews, PLTs also stated that a part of the workforce that contributes to the function of the small paediatric liaison teams is hidden. This consists of healthcare professionals and specialists who contribute ad hoc, depending on specific needs.

They also explained that a lack of resources can cause conflicts between different tasks for the paediatric liaison teams, resulting in less time being spent on bedside care delivery (versus coordination of care), curative care (versus palliative care), proactive follow-up such as home visits and school contacts, preventive support, and more in-depth psychosocial support.

6.3.1.5 Limited involvement of spiritual care providers

Spiritual care is an essential part of palliative care. While general spiritual care can be provided by the nurses of the paediatric liaison teams and other caregivers, specialist spiritual care is not always available in all hospitals and is completely absent from primary care. Spiritual care providers are specialists in existential questions and receive extensive training, but their profession is not (yet) officially recognised (as a health care profession) and thus not protected, as explained by a stakeholder. This recognition would be a benefit for the spiritual care provider regarding job-security, and for the patient to ensure quality and protect against incompetence. Hospitals are currently not obliged to hire a spiritual care specialist.

6.3.1.6 Unequal geographical distribution

The geographical distribution of paediatric liaison teams is unequal, especially in Wallonia, where both teams are in Liège. In Brussels three teams are available. In Flanders, the distribution of the four available teams is more geographically balanced. Nevertheless, professionals experienced in PPC explained, during interviews, that PLTs travel to wherever their patients are, regardless of the distance, especially if no paediatric liaison team is available in certain regions. These journeys are often necessary to provide training and coaching to primary care providers. On the other hand, the large distance can be a burden to the parents as well, who do not receive any financial compensation if their child's diagnosis is not cancer or another disease with a RIZIV-INAMI convention.

6.3.2 Home setting

6.3.2.1 Lack of expertise in paediatric palliative care in primary care

Both stakeholders and professionals with limited and extended experience in PPC agreed that there is a lack of paediatric nurses performing home care. This can be explained by the lack of paediatric patients in the home setting and no distinction being made between a home nurse with and without paediatric training (thus no benefit of additional training). This may also lead to unfamiliarity with medical equipment which is often hospital specific.

On the other hand, participants to the consultation highlighted that the health care professionals in primary care lack knowledge in paediatric palliative care and awareness of the existing services. This is further explained in Chapter 4 on awareness-training.

The rarity of paediatric palliative care situations among non-specialist care providers makes building up **experience** difficult. Therefore, it is not unexpected that home nurses rely on training and coaching by the paediatric liaison teams. Moreover, the GP accepting the care and responsibility for the child in a palliative situation is not always familiar with the child and/or the (complex) pathology. Support at home from a paediatrician would be welcomed, but a home visit of a paediatrician is not appropriately reimbursed. This information was confirmed by stakeholders and professionals with limited and extended experience in PPC.

6.3.2.2 Refusal of health care professionals in primary care to be involved in paediatric palliative care

Professionals experienced in PPC and stakeholders explained that health care professionals in primary care, mainly GP and home nurses regularly refuse to care for children in palliative care situations. This can be explained by their lack in expertise (see section 6.3.2.1), the expected burden/workload, emotional factors, legal uncertainties or financial reasons.

The round-the-clock availability that is necessary to provide high quality and safe continuous care for a child in a palliative situation can increase the workload for GP and home nurses and lead to a refusal to take care of the child. However, their engagement facilitates the access to palliative care for the child. On the other hand, time lost due to travel can have an impact too, as health care professionals in rural areas may be unwilling to make longer (non-reimbursable) journeys several times a day. This information was confirmed by stakeholders and professionals experience in PPC.

Additionally, professionals experienced in PPC and stakeholders highlighted that emotional factors and mental overload due to liability issues and other legal uncertainties around home-based palliative interventions can have impact on the willingness of health care professionals to be involved in paediatric palliative care.

A previous KCE report already highlighted the inappropriate financing of home care nursing for children because of not taking differences with adult care into account (time, workforce, equipment, approach). The lack of nomenclature for specific tasks (administration of medication, teaching of parents) together with the need for more frequent visits that cannot be billed and problems with

reimbursement for hygiene care (because of a natural independence) add to this problem.[31] This information was confirmed by stakeholders and professionals experience in PPC.

In practice, stakeholders and professionals experience in PPC explained that it is usually only nurses employed by an organisation who are willing to care for children in a palliative situation at home or in a facility at the request of the paediatric liaison teams. In certain regions of Belgium, where there is a high concentration of paediatric liaison teams and residents (Brussels, Liège), the paediatric liaison teams have a list of home nurses who are willing to provide the necessary care.

6.3.2.3 Limited availability of psychosocial support and spiritual care in home setting

Stakeholders and professionals experience in PPC explained that the involvement of psychologist working in mono- or multidisciplinary private practices in primary care in paediatric palliative care is currently limited. This can be probably explained by fixed agendas, high demands with waiting lists and not taking on the care for any new patient, and no 24/7 'on call' availability. Psychologists from the hospital often have already a trusting relationship with the patient and their parents. They can contact them at home or occasionally pay a home visit, but possibilities there are often limited and depend on the willingness of the hospital to allow this, mostly because of the time investment. Some paediatric liaison teams work together with psychologists from adult palliative care teams if needed.

The availability of a social worker or spiritual care provider in the home setting is perceived less as a problem by consulted stakeholders. However, if several social workers (from the treatment team in the hospital, from the paediatric liaison team and from primary care such as the sickness fund) are involved it is important to clarify the role of each of them. Spiritual care providers work in hospitals and other care institutions and do not pay home visits. To obtain specialist spiritual care, parents often rely on their own network. A stakeholder explained that the status of a spiritual care provider also does not allow them supporting health care professionals in the community.

6.3.2.4 Support provided to siblings is limited and fragmented

Having a brother or sister in a palliative situation can have a major impact on the other siblings. The needs and experiences of siblings need to be taken into account when taking care of a severely ill child to prevent problems in the future. Active involvement of siblings in the care trajectory is needed as well as listening and providing reassuring presence. There is a need for spaces close to but outside the hospital where the siblings can meet and express themselves. This should not be an additional burden for parents.[5,6]

However, currently private initiatives organising recreational activities and psychosocial support for siblings including bereavement support are often disease-specific and/or linked to RIZIV-INAMI conventions, e.g., cancer, epilepsy etc. or regional. Stakeholders highlighted that private initiatives also have limited resources, often depending on volunteers and donations, and have a variable offer (websites private initiatives).

6.3.2.5 Lack of visibility and financing of private initiatives

Mapping of the different private initiatives in different domains (recreational and wellbeing, support for siblings, bereavement support, etc.) is very difficult as they often lack visibility unless they are supported or promoted by the multidisciplinary treatment team from the hospital or the paediatric liaison team. Moreover, private initiatives from patient associations or charities are often dependent on volunteers and donations, which makes it difficult for them to survive long term. This information was confirmed by stakeholders and professionals experience in PPC.

6.3.2.6 Access to the palliative lump sum is inappropriate

Criteria to have access to the palliative lump sum are not well aligned to the situation in children. Mainly the limited life expectancy (currently three months, in future one year) for access to the palliative lump sum is not in line with the average duration of seven years for paediatric palliative care pathways.

Moreover, the exact life expectancy in case of a chronic disease is difficult to predict, and thus a barrier to access, as explained by stakeholders and professionals experience in PPC.

Stakeholders highlighted the need for an additional financial support by means of a palliative lump sum to use for medication, material and equipment that is often already provided by the paediatric liaison teams or social services was initially questioned, but RIZIV-INAMI confirmed that this lump sum could also be used to pay respite care.

6.3.2.7 Lack of material and medication in the home setting

In Belgium, the legislature has restricted access to certain medicines to hospital settings. As part of the roll-out of transmural care (via hospital at home HAD), it is now possible for certain medicines to become more widely available for use at home. However, professionals experienced in PPC explained that providing these medicines sometimes requires close collaboration between the PLTs and a local hospital or community pharmacy. Additionally, some medical equipment (infusion stands, syringe pumps, catheters, etc.) is difficult to obtain in paediatric versions. The paediatric liaison teams usually take on the responsibility of making this equipment available or bringing medicines to patients in their home. This creates, on the one hand, a dependence on hospitals and, on the other hand – once again – on the paediatric liaison teams for the provision of care outside the hospital.

6.3.2.8 Limited access to paediatric palliative care in residential care

In residential and semi-residential care homes for children with disabilities, carers are the primary care providers. There are only few healthcare professionals on site and multidisciplinary care is not always clear to those concerned. In the online survey, professionals with limited experience in PPC explained that some care homes accommodate several seriously ill residents, and that partnerships may be established with the paediatric liaison teams, provided that the care home staff are aware of this service. However, organisations for children with disabilities highlighted that information they receive about the child's disease is mainly passed on via the parents and that they lag behind in providing care for children in a palliative situation.

6.3.3 Shortage in respite care

A significant shortage of respite care was identified during the interviews with professionals experienced in PPC. The offer in respite care, both residential and at home, is currently very limited and not prioritised for palliative care. Parents are confronted with waiting lists and administrative delays. Only five respite care facilities (see section 6.2.3) are available, and a network of mobile respite care is not systematically developed. Although it is perceived as very much needed, parents find it very difficult to hand over the care of their children to others and be separated from their child.

Stakeholders highlighted that only residential respite care is reimbursed, but there is a difference in the number of days residential respite care that are granted in Flanders compared to Brussels and Wallonia. Mobile respite care teams are private initiatives that depend heavily on volunteers and charity. There is a difference (but also overlap) with services providing family care.[5,6]

6.3.4 Hospitals with a paediatric liaison team

6.3.4.1 Lack of paediatric palliative wards (and hospice care)

Stakeholders and professionals experienced in PPC expressed that the rarity of deaths and the desire to return home are probably the reasons why there are no paediatric palliative wards or hospices for children in Belgium. Paediatric beds are not integrated into adult palliative care wards either, partly due to negative past experiences (seriously ill children and their families have very different needs compared to adults in the final stages of life). Furthermore, families and children often have established routines within 'traditional' paediatric wards, where a relationship of trust has been built up. However, hospitals that are tasked with (and financially rewarded for) delivering care to uninsured

patients indicate that there is a need for paediatric palliative care beds for children from a low socioeconomic background. Adolescents sometimes go to an adult palliative care ward or adult hospice.

6.3.4.2 (Bereavement) support provided to siblings (and parents) in hospital is limited

Stakeholders and professionals experienced in PPC also explained that hospitals organising recreational activities and psychosocial support for siblings are often disease-specific and/or linked to RIZIV-INAMI conventions, e.g., cancer. They potentially involve psychologists, music therapist, play therapist, etc.. These activities are often co-financed by charities.

Experts, stakeholders, and parents report that bereavement support is very challenging. Grief is highly individual and needs to be tailored to each family's emotional, cultural and spiritual need. Some parents decline support, while paediatric liaison teams often lack sufficient time and resources to provide comprehensive, long-term follow-up.

6.3.4.3 Psychological and spiritual support provided to health care professionals in hospital is limited

Stakeholders and professionals experienced in PPC also highlighted that there is a need for more psychological and spiritual support, mostly linked to the high emotional burden for health care professionals working together with the paediatric liaison teams in the hospital.

6.3.5 Hospitals without paediatric liaison team

6.3.5.1 Lack of expertise in paediatric palliative care in hospitals without paediatric liaison team

Some children in palliative care situation are cared for in hospitals without paediatric liaison team. This can be the explicit choice of the parents for proximity or other reasons. As explained by stakeholders and professionals experienced in PPC, the treating physician may not refer to a paediatric liaison team, because they have not identified the palliative care needs of the child, because they are not aware of the possibility to involve a paediatric liaison team for advice or because they are afraid to that the paediatric liaison team will take over completely. Not involving the paediatric liaison team does not mean the child is not well taken care of, but in case of a lack in expertise in paediatric palliative care of the treating physician, this might lead to missed opportunities to improve quality of life.

Health care professionals in a hospital without paediatric liaison team may have little expertise (training and/or experience) in paediatric palliative care situations and may not be familiar with the child and/or the pathology, especially in urgent situations. Though the paediatric liaison team can be asked for support, this leads to increased travel and time investments from their part. Sometimes they are unable to attend these children because of logistical restraints, e.g., limited number of cars.

6.4 Possible solutions

6.4.1 Paediatric liaison teams

6.4.1.1 Update of the (or drawing of a new) Royal Decree

During discussions, the involved stakeholders agreed that an updated version (or drawing of a new) Royal Decree regarding the paediatric liaison function could broaden the target population, including not only children with cancer, and expand on the roles and responsibilities of paediatric liaison team members. It could also integrate better all four domains of palliative care: physical, psychological, social and spiritual care.

They suggested the paediatric liaison team could be composed of a full-time coordinating paediatrician specialised in paediatric palliative care, nurses (amount of FTEs dependent on the number of patients cared for), a dedicated psychologist, a social worker or social nurse and an administrative assistant. A specialist in spiritual care should at least be involved (for more information see section 6.4.2.2) to support the paediatric liaison team.

The initial solution proposed here was the inclusion of a social worker within the paediatric liaison team. However, discussions regarding financing of a social worker within the PLT (see 6.4.1.3) and questions regarding the need for an additional social worker around the patient (see also section 6.2.2.3 and 6.3.2.3) led to reformulation suggesting a social nurse instead of a social worker because of their double function.

During discussions with the stakeholders the inclusion of one full time coordinating paediatrician specialised in paediatric palliative care was preferred over dividing the work over several paediatricians with different subspecialties (neurology, oncology, etc.). However, strong collaboration with the treating paediatricians from different subspecialties was emphasized (see Chapter 7).

Responsibilities and tasks could include (among others) the standardised registration of patients and activities, 24-hour availability, organising debriefing moments for health care professionals after death of a child, continuity of care and possible home visits from all team members. Because of limited resources, choices (shifts in tasks) may be necessary and/or the use of an adaptive intensity model may be promoted.

This item (update of the Royal Decree) can be further discussed within a working group composed of members from different paediatric liaison teams and other stakeholders including the federal authorities (who are competent in this matter) and the federated authorities. Inspiration could be drawn from the German quality standards for funding an interdisciplinary PPC team.[270] A lack of clarity in the allocation of responsibilities between different levels of government regarding social workers constitutes a barrier to the delivery of high-quality palliative care. Stakeholder consultations indicated that neither the federated entities nor the federal level consider themselves competent for funding in this area.

6.4.1.2 Maintain the curative and palliative mission within the paediatric liaison team

The combination of curative and palliative (and terminal) care within the function of paediatric liaison teams was perceived by most stakeholders as a benefit, because of the positive impact on building trustful relations (section 6.3.1.2 and see also Chapter 5).

Because pain management is an important part of palliative care, the question was raised whether the currently existing ‘in hospital pain referent function’ (competence FPS (FOD-SPF) could be integrated into the paediatric liaison teams. The answer was not clear. Stakeholders argued that the type of pain management seems to be different: acute and procedural versus chronic pain management. Expanding this mission would result in a significant increase in the patient population, particularly at the hospital. However, this is not recommended given the current limitations of the workforce.

More ‘hospital at home’ care is expected in the future, but it is also not clear if all this care would be coordinated by the paediatric liaison teams. This would even further increase the workload. For this project we are restricted to the population of children with life-limited and life-threatening diseases. More information about the hospital at home function of the PLTs is available in KCE report 358.(Lefevre, 2022)

6.4.1.3 More financial and human resources for paediatric liaison teams

Data from the consultation of professionals with limited experience in PPC and of professionals experienced in PPC converge in highlighting the need for increased human resources and financial support to enable paediatric liaison teams to further develop their organisational role, particularly with regard to:

- initiating (and continuously supporting parents in) administrative procedures aimed at securing the benefits to which patients and their families are entitled;
- establishing and facilitating collaboration among all relevant stakeholders, as well as organising interdisciplinary meetings across different levels of care;
- providing ad hoc training for parents, non-specialist healthcare professionals, and qualified caregivers;
- implementing technological solutions to support ongoing coordination among involved healthcare providers through digital communication tools (e.g., messaging applications).

Better financing of the paediatric liaison teams

The stakeholders agreed that financing of the paediatric liaison teams could be at least partly based on their activity. This activity could be based for example on the number of patients and/or the profile of the children and/or the distances travelled and/or complexity of support needs and/or frequency of visits and/or time invested, etc. Inspiration could be drawn from the *Registratiewijzer Kinderpalliatieve Zorg* in The Netherlands (see Textbox 5). Providing each paediatric liaison team additionally a basic lump sum could prevent a performance-driven model. Information could be gathered from the registered activities with support from the administrative assistant (see 6.4.1.1) to reduce the administrative burden on the other paediatric liaison team members.

To reduce the administrative burden, the use of a limited number of simple items that could affect the costs of care could be envisaged, e.g., the number of patients and the score on the PaPaScale that reflects the intensity of paediatric palliative care. This could be further discussed within a working group. The automatic involvement of a palliative care team for every child requiring palliative care would facilitate the (centralised) recording of the number of children affected in Belgium, thereby providing a more accurate picture of the target population

Textbox 5 – Registratiewijzer Kinderpalliatieve Zorg (The Netherlands)

Registratiewijzer Kinderpalliatieve Zorg, version 3.0 (January 2025) is a technical guide used in the Netherlands to standardise the documentation and coding of PPC activities for funding and reporting purposes. Developed by the national PPC expertise centre, it defines multidisciplinary care activities, minimum team compositions, and criteria for classifying care events into specific reimbursable care products. The guide ensures consistent registration of hospital-based consultations, clinical admissions, and other interventions provided by paediatric palliative care teams, facilitating accurate cost attribution and reimbursement under the Dutch healthcare system. By providing a structured framework, it supports both clinical teams and hospital administrators in maintaining standardised records while promoting transparency and accountability in paediatric palliative care delivery.[271]

The financing of the paediatric liaison team would have to consider changes in the Royal Decree (section 6.4.1.1) and cover increasing need for human resources.

One of the initially suggested solutions included the addition of a social worker in the paediatric liaison team, however financing them was perceived as a problem. A stakeholder highlighted that any request for funding for a social worker would therefore be submitted to the Council of State, if necessary. However, the Council of State previously argued against this in another case, because funding must be linked to the provision of care. To overcome this problem, the solution was revised to the inclusion of a social nurse in the paediatric liaison team.

This item can be further discussed within a working group composed of members from different paediatric liaison teams and other stakeholders including the federal authorities (who are competent in this matter). Budgetary constraints must be considered. Activity reports from 2010-2014 might be used as a starting point, however, these cannot be used from the new paediatric liaison teams.

Increase the job attractiveness for paediatric liaison team members to prevent high staff turnover

To attract new personnel and guarantee a sufficient and stable workforce within the paediatric liaison teams, different structural support measures and incentives were discussed with the stakeholders.

Time for education and training (general and continuing) could be provided, resulting in an appropriate salary (IFIC-classification www.if-ic.org) considering the extra technical and social qualifications, and ensuring professional recognition. More information on education and training can be found in Chapter 4. Additionally, psychological and spiritual support could be offered, including debriefing sessions and team support, because of the high emotional burden of the function (see sections 6.4.2.1 and 6.4.2.2). The stakeholders considered financial incentives not the most important and durable solutions. Time to recuperate after an on-call duty was deemed essential and legally required.

6.4.1.4 Better geographical distribution

To improve geographical distribution, possible solutions may include a redistribution of paediatric liaison teams, adding an additional team for example in the province of Luxembourg, or more a territorial organisation with better alignment between care proximity and efficiency (see 6.3.1.6). During interviews with professionals experienced in PPC, it was mentioned that, to do so, it may be needed to develop inter-hospital or regional models instead of hospital-bound PLTs. Patient representatives were found to be in favour of non-hospital bound PLTs.

Additionally, an increase in the visibility and awareness about PCC and PLTs across all hospitals in Belgium may compensate partially for the unequal distribution of paediatric liaison teams, as explained by PLTs

A better geographical distribution of paediatric palliative care can also be achieved by involvement of referent tandems in the hospitals without a paediatric liaison team (see section 6.4.6.1) and by supporting transport of patients, material and medication (see section 6.4.1.5 and 6.4.3.7).

6.4.1.5 Support medication and material provision in the home setting

In interviews with PLTs, different solutions were reported regarding availability of medication and equipment in the home setting including a direct provision or stock of essential drugs and equipment, anticipatory planning on medication with pharmacy coordination and a protocol with prescriptions, explanations on doses and phone numbers in case of questions. Within the care network established by the PLTs around each child, collaboration with a regional hospital and a local pharmacy is necessary to ensure the rapid availability of medications. To enhance feasibility, stakeholders suggested raising awareness among pharmacists and integrating them into the care pathway. Stakeholders noted that community pharmacies and those in regional hospitals do not always have the medications required for comfort care and available all the time in the expected quantities. For this reason, it is also important for PLTs to maintain very close collaboration with the pharmacy of the hospital in which they are based.

Most paediatric liaison teams have implemented these solutions already, but a more standardised way to deal with specific issues may be beneficial. Alternatively, a taxi service or existing delivery services could be used to reduce the distance travelled by the paediatric liaison team in case no HCP is required. The stakeholders commented that this hardly ever happens, and delivery visits are, if not possible and not urgent, combined with care visits that would be performed anyway. Anticipation of potential future scenarios and what may be required to ensure the patient's comfort, is considered key by PLTs to ensure safe care 24 hours a day, 7 days a week, but need time and preparation. If a taxi or deliver service would be considered, legislation would need to be reviewed in detail, and protocols and agreements developed.

Another solution to avoid constant travel for the distribution of medication or equipment would be extending collaboration with regional hospitals, as suggested by stakeholders.

6.4.1.6 Develop a strategy to access long term bereavement support from patient/parents organisations and other private initiatives

Long-term bereavement support is often needed. Although the paediatric liaison teams feel that providing bereavement support is an important task, they admit that they do not have enough time and resources to provide this long-term comprehensive support for parents, siblings, but also other family members close to the child. Therefore, a strategy could be imagined where responsibility for ongoing support (after 6-12 months) could be assumed by private bereavement initiatives, with appropriate referral and signposting from the paediatric liaison teams.

The psychologist from the paediatric liaison team could still be responsible for identifying the needs regarding bereavement support. A more structured pathway after death to guide parents and family in the bereavement process could be developed or bereavement support could be included in the integrated care programme. A funding model based either on a fixed number of consultations or on a global budget allocated for the entire course of consultations has been proposed by stakeholders.

6.4.2 All settings: home setting, respite care setting, hospitals with and without paediatric liaison team

6.4.2.1 Provide psychological support for health care professionals involved in paediatric palliative care

According to the stakeholders, psychological support of paediatric liaison team members and other healthcare professionals involved in paediatric palliative care (including in hospital without paediatric liaison team and primary care) should include the organisation of a debriefing session after the death of a child among other support from a psychologist and/or spiritual care provider (see also section 6.4.2.1 and 6.4.2.2). These debriefing sessions are nothing new, but sometimes the necessary resources (time and financial compensation) are lacking for a proper organisation. Increasing opportunities to express psychological and existential needs has been proposed as a way to sustain staff engagement over time.

Internationally, it has been reported that the use of tools such as the *Serious Illness Conversation Guide Pediatrics*© helps to prevent mental overload among healthcare professionals (see Chapter 5). During the stakeholders consultations, it was emphasised that a record in which decisions relating to ACP are documented is perceived as a form of emotional support, enabling HCPs, particularly in primary care, not to feel solely responsible for ethically sensitive decisions.

6.4.2.2 Involve spiritual care providers in different levels of paediatric palliative care

While stakeholders agree there is certainly a need for a specialist in spiritual care (spiritual care providers) to be involved in paediatric palliative care, the question remains whether they should be part of the paediatric liaison team. Each hospital, with or without a paediatric liaison team, could be encouraged to employ at least one spiritual care provider. Their support is, as it should be, independent of their own religious or spiritual background. This person could be available to support patients, their family and the (healthcare) professional working in the hospital. The spiritual care provider can also train these (healthcare) professionals in 'primary' spiritual care. According to the stakeholders consultation, ideally, a spiritual care provider would be available in each primary care organisation as well. Their task can be broader than paediatric palliative care. Regional collaborations may be possible to ensure availability of spiritual care. Having the same spiritual care provider following the patient and their family throughout the whole disease trajectory could be an advantage (promote integrated care).

Since the profession is still 'under evolution' in Belgium (recognition, training, etc.) no final consensus was reached on this topic. Mainly the involvement in primary care and future financing is unclear and would require gathering evidence on the impact of spiritual care on quality of life. A possible solution suggested by stakeholders would be the recognition of an official training programme, shorter than

the current 5 year-long theology studies, that would enable current paediatric liaison team members to be additionally trained as specialist spiritual care providers.

6.4.2.3 *Provide legal and ethical support to physicians (and other HCPs) involved in a palliative care situation*

In case of legal questions or ethical conflicts, our consultations also highlighted the need for physicians (and, more broadly, for all relevant HCPs) to have access to legal or ethical support. This support may take various forms, such as 24/7 telephone availability, support provided by the head of the local hospital department, or the development of protocols and guidelines for ethical decision-making. Each hospital in Belgium is also required to have a local ethical committee to provide advice and guidance on the ethical aspects of hospital care and support in decision-making on individual ethical cases.[272]. Other suggestions from stakeholders included a role for the Order of Physicians in this matter. Once again, few resources available at the primary care level were identified in our research. One proposition is the development of psychological, spiritual, legal and ethical support mechanisms for healthcare providers in the community. Another is to increase the visibility of existing resources.

In the Netherlands, the *Artsensteunpunt Levenseinde Kinderen* (End-of-Life Support for Children Physicians' Service) is a national support service for physicians involved in end-of-life care for children. It provides clinical advice, ethical guidance and case consultation to doctors facing complex decisions about symptom control, life-prolonging treatment withdrawal, comfort care and communication with families. The service is staffed by experts in paediatric palliative medicine, ethics and law, and is accessible for consultations at critical decision points. By offering evidence-informed and case-specific support, the *Artsensteunpunt* aims to improve care quality, consistency and physician confidence in managing end-of-life situations, while respecting the best interests of the child and supporting family-centred care.[273]

Stakeholders suggested that GPs refusing care for legal reasons could be offered legal advice to provide clarity about responsibilities and liabilities. Clarification about responsibility could be added in the Royal Decree update.

6.4.3 *Home setting*

6.4.3.1 *Development of a (multidisciplinary) network of paediatric nurses in primary care including psychologists and spiritual care provider*

The initial solution proposed was inspired by a Swiss practice example (*KinderSpitex* services - more information in section 7 of the supplementary data).[274] Translating this example to the Belgian context, the home nurses working within this paediatric palliative care network would also provide hospital at home services and mobile basic psychological support because paediatric palliative care is rare. Meanwhile, they would be supported by the paediatric liaison teams, acting as second line. Including a clinical psychologist with appropriate training and coaching and a spiritual care provider (see section 6.4.2.2.) would be beneficial. For a balanced geographical distribution, a network would need to be developed in each Belgian region and nurses selected on their location. Each network would then be coordinated by the regional palliative care federation or similar.

Stakeholders questioned the feasibility of this solution because of general shortages in nurses and psychologists, the need for appropriate training modules and limited resources for financing the coordination by the regional authorities. They mostly supported the idea of combining the functions of hospital at home and palliative care in primary care but were more hesitant about the combination with mental care. They considered the **collaboration between primary care nurses and the paediatric liaison** team crucial (see Chapter 7) with appropriate intermediate level training and ongoing support. The development of a shared database of health care professionals with some previous experience in paediatric palliative care was also mentioned during the interviews with professionals experienced in PPC.

If it would not be feasible to include a psychologist in the multidisciplinary team, other solutions could improve psychological support at home. For example, stakeholders suggested to allow either home visits and/or teleconsultation by hospital psychologists from PLTs or other multidisciplinary teams for palliative care, or the structural involvement of psychologists from other services such as adult second line palliative care support team, or the involvement of so-called 'first line psychologists' who signed a NIDHI (RIZIV-INAMI) convention with a mental health network.[s] [275] However, regarding the involvement of first-line psychologists, one might question whether these first-line psychologists, who usually deal with primary care issues, such as alcohol abuse, depression and anxiety disorders in adults, are the best placed for providing psychological support in a paediatric palliative situation.

6.4.3.2 Review financing for home nurses involved in paediatric palliative care

The costs, feasibility and requirements to develop a multidisciplinary network of home nurses working in paediatric palliative care and hospital at home could be further investigated. The best practice example that was identified in Swiss pays the home nurses **a fixed monthly salary** and could be used in Belgium. However, stakeholders argued that this might not reflect differences in complexity and duration of care tasks performed.

- A pilot project in Belgium on **hourly rates** for paying home nurses is currently ongoing, but results will only be available in 2029.[276] Although hourly rates can have advantages such as reducing the pressure on home nurses and improving the quality of care, attention should be paid to maintaining efficiency, as mentioned by stakeholders.
- The development of **additional nomenclature** for paediatric home nursing care could be considered, but the impact on budget may be a limiting factor, according to stakeholders. This nomenclature could be linked to graduation as a paediatric nurse, but this may not be in line with the reality of the low number of paediatric nurses in primary care. On the other hand, appropriate valorisation of their work may incentivize paediatric nurses to work in home care.

6.4.3.3 Review the financing for psychologists in primary care

Psychologists working in multidisciplinary teams together with home nurses for providing palliative care and hospital at home services could receive a fixed monthly salary.

In case multidisciplinary teams are not feasible and psychologists from the paediatric liaison teams are allowed to pay home visits or do teleconsultation, this would not change the salary they already receive. The costs would be absorbed by the hospital.

Regardless of the remaining questions regarding organisational clarity about the first-line psychologists' involvement in paediatric palliative situations, the current budget of the RIZIV-INAMI agreement is currently probably insufficient, as mentioned during the stakeholder consultation.

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[s] The RIZIV-INAMI "Eerstelijns psychologische zorg met de netwerken geestlijke gezondheid/ soins psychologique de première ligne avec les réseux de santé mentale" agreement enables clinical psychologists and orthopedagogues to provide accessible, reimbursed mental health care through regional mental health networks. The programme focuses on early intervention, prevention, resilience-building, and treatment of mild to moderate psychological difficulties, with direct access for patients and special attention to vulnerable groups including children and adolescents. Care is fully reimbursed for children and young adults up to 23 years, while adults pay a limited personal contribution, with the remainder covered by health insurance. The number of reimbursed sessions depends on network (children and adolescents or adults) and the type of intervention: community-based interventions (group sessions), first-line psychological support or first-line psychological treatment.

6.4.3.4 Support GPs by home visits by paediatricians

The GPs accepting responsibility to take care of a child in a palliative situation would occasionally need the support of a paediatrician (from the paediatric liaison team, from the treatment team or from a local hospital) to pay a home visit. Because of impact on the hospital organisation, a home visit could be replaced by a teleconsultation if appropriate (see also Chapter 7). As highlighted by stakeholders, the home visit should be organised only at the explicit request of the GP in very specific and rare circumstances. Currently, home visits by paediatrician are possible, but depend strongly on their willingness and availability. The existing nomenclature for home visits by a paediatrician (103736 and 103014) could be reviewed to allow compensation for extra costs involved.

6.4.3.5 *Increase the visibility of and promote collaboration between private initiatives for wellbeing, recreation and bereavement support*

To ensure the visibility of private initiatives for recreational and wellbeing and for psychosocial support including bereavement support for patients, parents and siblings, the paediatric liaison teams could provide practical support: mapping the regional offer, advertise activities, liaise with charities.

The hospital initiatives for support of siblings and private initiatives in wellbeing, recreation and bereavement support for patients and their family could benefit from a clarification of the involved professionals: psychologists, pedagogues, social workers, play therapist, … and inclusion in the Royal Decree concerning the paediatric care programme.

A more structured financing of the initiatives from federated entities would of course be beneficial but is maybe not realistic. Stakeholders suggested bringing separate private initiatives together and encourage collaboration.

The stakeholders suggested other possibilities to organise support for siblings such as organising it at a regional level or linking it to existing networks of psychopaediatrics.

6.4.3.6 *Review eligibility criteria to receive the palliative lump sum*

The stakeholders agreed that the current criteria for receiving the palliative lump sum do not reflect the reality of a child in a palliative situation, especially with regard to a defined life expectancy, as prognosis for children with chronic life limiting diseases is very difficult to determine. Other criteria could be the same criteria as used for the definition of 'palliative status', which currently does not exist. It would also be beneficial to be able to switch this status 'on' and 'off' to remain within the reality of the child, for example if it were to be cured. Criteria as age, pathology and other may be used to create different categories with different lump sums. The palliative lump sum could also be reserved for those families who need it the most as many of the costs are provided for by the paediatric liaison teams and other social services like the maximum to bill system. However, criteria to determine this would need to be further discussed.

Currently there is no systematic financing for mobile respite care, parents must pay for this themselves. Since parents receive the lump sum on their account and no justification of expenses is needed, stakeholders explained that this could be used for respite care as well as for medication that is not reimbursed in the home setting.

6.4.3.7 *Compensate travel costs between hospital and home*

A reimbursement of travel costs made could be foreseen for all parents of young patients in a paediatric palliative situation, using the same criteria as for receiving a palliative lump sum, and similar to cancer patients and patients within specific NIDHI (RIZIV-INAMI) conventions, to compensate for travel costs between hospital and home. On the other hand, parents should also be able to stay close to their child when admitted to hospital.

6.4.3.8 Increase awareness about paediatric palliative care in residential care setting

Stakeholders highlighted that to increase the awareness about paediatric palliative care in residential care settings, clear referral criteria could be formulated and the visibility of the paediatric palliative care offer, could be improved.

For more information regarding referral criteria and increasing visibility see Chapter 2 and Chapter 4.

6.4.4 Respite care

6.4.4.1 Development and (financial) support of existing residential respite care facilities

During the stakeholders consultation, it was suggested that existing residential respite care facilities could be supported and new facilities developed, linked to specific quality criteria, e.g., a minimum number of beds available for children and their close family members, a balanced geographical distribution across Belgium, a cooperation agreement with the paediatric department of the local hospital, and the availability of the four domains of palliative care. Residential respite care includes three types of stays: day care, a stay without family and a stay with family members.

When discussing this solution, stakeholders rightly pointed out that the primary function of respite is not to take care of dying children (hospice care), although it can occur if needed in exceptional cases. In that case a close collaboration with a paediatric liaison team is advisable. Legal and administrative points need to be addressed in more detail. The purpose is not to develop hospice care for children.

During interviews with PLTs, day care centres were not considered good alternatives for children, because children would prefer to go to school and have leisure activities with peers.

Questions remain regarding financing. Inter-ministerial consultation could help to streamline funding (costs for functioning and costs for care) and the policy plan across the various policy levels. The palliative lump sum could be used by parents to pay for respite care.

6.4.4.2 Development of mobile respite care services with corresponding financial support

The respite care offer could be diversified by the development of a network of mobile respite care teams. Currently there are only a small number of private initiatives offering a spectrum of mobile respite care from informal services working with volunteers or informal caregivers over formal services working with professional. Informal caregivers should ideally have the possibility to seek advice from the health care professionals involved including the paediatric palliative care team. The choice for informal or formal services can depend on the needs of the young patient, though some stakeholders mentioned that the real respite care in need of proper financing are the formal services with educated and legally recognised professionals working in close collaboration with the paediatric liaison teams.

When informal caregivers are involved, they need sufficient background and a level of education to do this safely. PLTs often come up against the limitations of the current legislative framework for qualified carers, as children with palliative care needs require often high level of care. According to the PLTs uncertainty regarding the scope of a qualified carer's responsibilities in paediatric palliative care acts as a barrier to access. Stakeholders highlighted that greater clarity and precision are needed, particularly regarding the legal framework. The federal authorities are considering revising certain definitions as part of the nomenclature reform.

Quality criteria for mobile respite care teams could be thought of but might be more difficult to achieve especially in the beginning according to stakeholders. A gradual achievement plan of these criteria could be considered.

Many consulted stakeholders, including patient representatives, and also professionals with limited experience and professionals experience in PPC, emphasise that the primary need lies in managing administrative workload rather than in information provision or guidance by social worker. The expressed need is for practical, home-based support to handle administrative tasks, thereby relieving

parents of this burden. Therefore, mobile respite care may include additional administrative support, if this is not provided elsewhere by other professionals involved and if the person providing the respite care has sufficient knowledge about this.

Questions remain regarding financing and responsibilities. This item (mobile respite care teams) could be included in the KCE's research on informal carers and the Flemish Region's research on respite care, as well as in the ongoing reforms of the organisation of palliative care (at federal level and in the federated entities).

6.4.5 Accept a hospital or a respite care facility as a place to die for the child if required or desired

The lack of paediatric palliative care wards was discussed during interviews with PLTs but was perceived as a problem in only one hospital. Because of a lack of paediatric palliative wards, it may be considered to develop adapted infrastructure on the paediatric ward such as family rooms or spaces for palliative and terminal care.(see also chapter 5) Examples of paediatric palliative care wards exist in Germany and Switzerland (see section 7 of the supplementary data).

Hospice care for children was not really discussed, because the absence in Belgium was not perceived as a problem or a need by the experts and stakeholders. This intermediate care setting was mentioned to be different from respite care because the hospice is considered as an alternative place to die and respite care normally is not. However, in exceptional cases residential respite care facilities accept patients in the end-of-life phase in close collaboration with PLTs.[20,21] Conversely, a hospice can function as a space for respite, among other functions (see section 7 of the supplementary data). Examples of paediatric hospice care were identified in Spain (see section 7 of the supplementary data).

6.4.6 Hospital without paediatric liaison team

6.4.6.1 Create a position of paediatric palliative care 'referent tandem' in hospitals that do not have a paediatric liaison team

The hospitals without paediatric liaison team could benefit from the creation of a (paediatric) palliative care 'referent tandem' consisting of a nurse and a paediatrician with 'intermediate' level of training and experience in paediatric palliative care. This could solve the lack of expertise in paediatric palliative care in hospitals without a paediatric liaison team and could compensate the unequal geographical distribution of the paediatric liaison teams.

The tasks of the paediatric palliative care 'referent tandem' could include:

- sensibilisation of the hospital staff for paediatric palliative care
- contacting the paediatric liaison team when a palliative care patient is admitted whether they are already being cared for by a paediatric liaison team or a new patient who need to be referred to a paediatric liaison team
- provide (first level) support to the care team (ED, inpatient ward or other departments)
- involvement in advanced care planning (if needed in discussion with paediatric liaison team)
- provide medication and material/equipment to family and primary care providers if appropriate
- pay home visits to the child at request of the GP, if appropriate (referring paediatrician too far or not available)

The referent tandem and their tasks may be included in the new paediatric care programme. The model of 'pain referent', an already existing function supported by FPS (FOD-SPF) could be used, but not by combining the two functions. Further discussions are needed. This function would require time, formal training and official recognition. If necessary, the nomenclature for the paediatrician must be

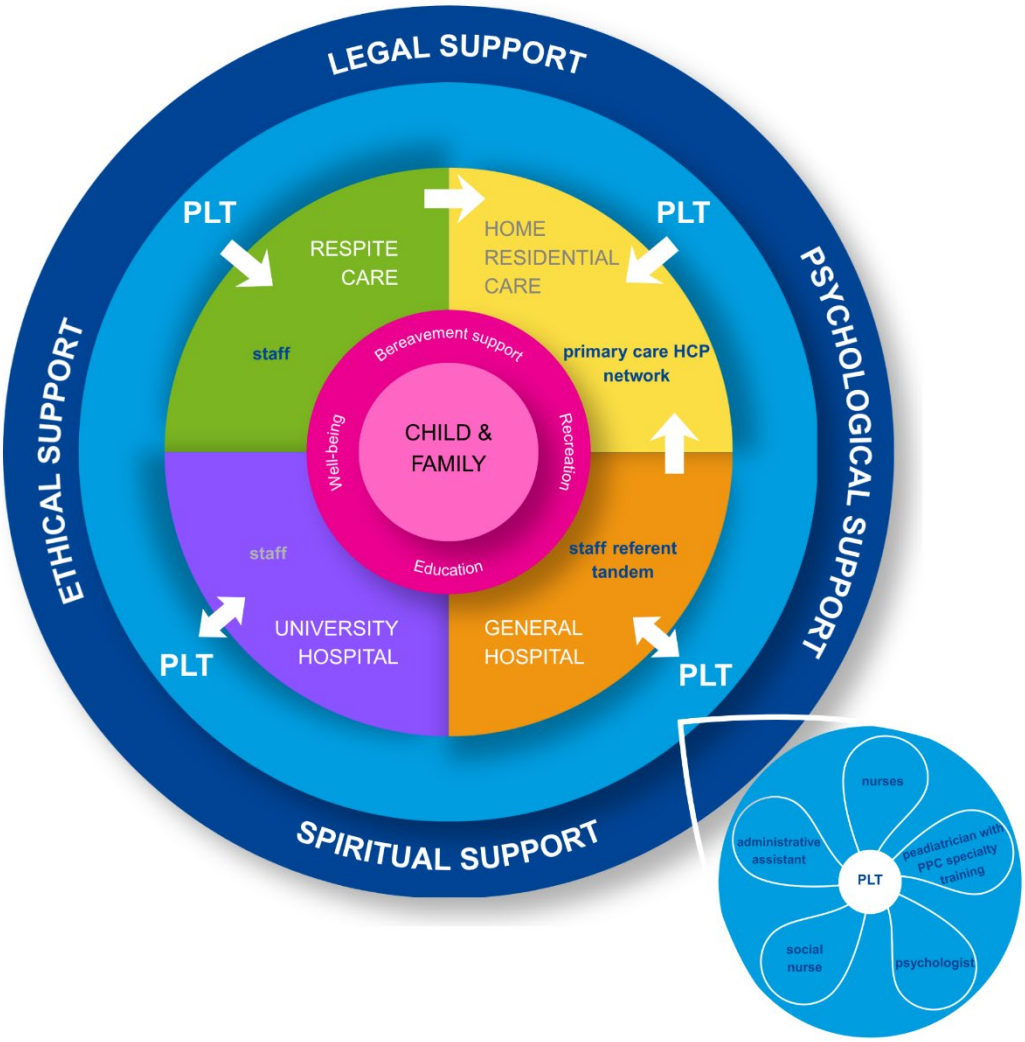
adapted. Stakeholders also mentioned that an equal geographical distribution must be considered. An alternative solution suggested was the involvement of 'palliative support teams' of the hospital.

6.5 Conclusion

In this chapter we describe the current offer of PPC in Belgium, the perceived gaps in the existing offer and the solutions as they were proposed and discussed during the stakeholders' meetings to improve the availability and affordability of PPC services. A schematic overview of the suggested solutions to improve the availability of services is presented in Figure 23.

In Belgium, currently eight multidisciplinary paediatric liaison teams play a central role in coordinating and providing PPC in close collaboration with treating paediatricians and other healthcare providers in hospital, as well as with local healthcare providers, primarily home nurses and GPs, in the home setting or equivalent.

Figure 23 – Schematic overview of suggestions to improve availability of PPC services



Unfortunately, the Royal Decree that specifies the licensing standards, staffing and duties of the paediatric liaison function is no longer aligned with the current needs and practices, and an update of the RD needs to be considered.

The PLTs are distributed unevenly across the country, resulting in long travel distances, especially for providing material and medication. Several ways to improve geographical distribution, directly or by involvement of a 'referent tandem' in hospitals without PLT have been discussed.

Additionally, PLTs suffer from insufficient human and financial resources. The current and future responsibilities of the PLTs would require additional human and financial resources, and could also include a partly activity-based financing aligned with any changes to the RD.

Moreover, the PLTs struggle to find HCPs in primary care willing to be involved in palliative situations due to a lack of expertise and other reasons, such as financial and emotional ones. Strengthening PPC in the community would benefit from a primary care network with appropriate training and financing of nurses (and psychologists). GPs would appreciate (exceptional) home visits from paediatricians.

HCPs that are involved in paediatric palliative situations currently have limited access to psychological, spiritual, legal and ethical support. Organising these types of support around all HCPs involved in a palliative situation would be considered a major benefit.

The limited availability of psychological, social and specialist spiritual care for children, their siblings and families at home and lack of awareness on PPC in residential care needs further attention, as well as the fragmented provision of well-being and recreational activities, respite care and bereavement support. These types of support are often provided by private initiatives that lack visibility among parents and rely heavily on volunteers and charitable donations. Improvement to access could be achieved by increasing visibility, collaboration and other strategies to support these initiatives.

To support parents in their role as primary carers for their child and to prevent parental burn-out, respite care could be further expanded through additional residential facilities and mobile respite care teams. Although there was no identified need to develop paediatric palliative care wards or hospices, considerations could be given to ensuring appropriate alternatives for exceptional situations where end-of-life care at home is not feasible or preferred. Parents could be further supported financially by amending the eligibility criteria for the palliative care lump sum for children and travel cost compensation.

7 ADEQUACY OF PAEDIATRIC PALLIATIVE CARE AND NEEDS

KEY POINTS

Conditions for timeliness

First, raise public awareness of palliative care and promote a culture of ACP among both the public and healthcare professionals.

Second, communicate clearly and widely about the roles and missions of PLTs and maintain the dual function of PLTs.

Third, incorporate referral criteria to PLTs into care protocols and care pathways for LLC and LTC.

Fourth, formalise regular contact between PLTs and key personnel from specialist services within paediatric departments.

Coordinated care

First, spend time to assess needs and determine correct interventions.

- ⇨ The assessment of needs - Continuous reassessment of the needs - Early identification of changes in palliative care needs.

Second, develop a flexible, individualised care plan with care location adapted to each family aligning interventions and persons' needs.

- ⇨ The care plan - takes into account a timeline adapted to the type of disease – developed with a multidisciplinary decision-making process.

Third, organise cross-disciplinary, cross-unit meetings leading to collaboration agreements.

- ⇨ The collaboration agreements – kind of contract between HCPs which clearly define the roles.

Fourth, plan and implement the patient pathway across the different sectors involved in the child's life.

- ⇨ The patient journey - the links allowing quality care delivering between the child's various living and care settings.

Conditions for ensuring access to high-quality PPC services

First, increase the human and financial resources of PLTs to enable them to fulfil coordinating role, supporting and training parents, carers and helpers, and providing direct highly specialised care.

Second, strengthen PLTs' communication skills and increase the visibility of communication support tools.

Third, simplify or clarify the regulations defining the nursing acts permitted for qualified helpers and facilitate contact of PLTs with relevant authorities.

Fourth, recognise and value paediatricians who provide home visits.

Fifth, provide financial and practical incentives for professionals to participate in cross-disciplinary meetings.

Sixth, coordinate according to a patient-centred model by the roll-out of the shared patient record (BIHR) across the different care settings and of secure messaging applications between healthcare professionals and parents.

Seventh, organise consultation meetings with professionals from other sectors, attended by parents.

Political commitment to improving access to PPC

First, a genuine effort must be made to combat the stigma surrounding palliative care in paediatrics.

- Develop generic models for cross-sectoral and cross-disciplinary care pathways.
- Incorporate PPC into clinical protocols and guidelines for life-threatening or life-limiting conditions.

Second, the paradigm shift from the separation between curative and palliative care to embedding PPC within existing and future care models requires interfederal discussions.

- Inclusion of paediatric palliative care in care plans for children and young adults, including the rare diseases plan.
- Integration of paediatric palliative care into the future children's care programme.
- Ensuring that families affected by paediatric palliative care benefit from the integrated care model.

Third, strengthen the contact between paediatric and adult PC.

- Support regional palliative care federations to become the hub for linking paediatric palliative care with adult palliative care. Palliative care federations should incorporate paediatric aspects more systematically into their projects.
- Provide financial and staffing support to the BPPC to enable them to play a role in fostering collaboration between PLTs and confirm them as the knowledge centre of PPC in Belgium.
- The BPPC and the palliative care federations could jointly organise symposia and joint training sessions to facilitate meetings between PLTs and mobile adult palliative care teams.
- Develop/perform HSR research concerning the transition between paediatric and adult care provision.

Reinforcement of the capacity and motivation to participate in care and to commit to its completion

- In order that parents can fill their key role, emotional and psychological support must be available and offered to them on a regular basis.
- The legal framework governing medical (and paramedical) interventions in paediatric palliative care, both in hospital and at home, must be clarified and better understood to support the commitment of frontline carers.

7.1 Global concept: the appropriateness of PPC services

Within Levesque's conceptual framework of access to healthcare tailored to needs, the final stage is healthcare utilisation. This stage relates to the **dimension '*appropriateness of services*'**, reflecting the adequacy between services and needs but also its timeliness, the amount of care spent assessing health problems and determining the correct treatment, the involvement of people in decision-making and treatment decisions, the technical and interpersonal quality of the services provided and, the coordination and continuity of care.[27] In addition to those aspects related to the organisation, success in accessing healthcare services adapted to needs also requires, from patients and professionals, **the ability to engage in healthcare**. This ability is strongly determined by capacity and motivation to participate in care and to commit to its completion. It is also strongly related to the capacity to communicate as well as notions of self-efficacy and self-management.[27]

With the overall aim of identifying barriers to and potential solutions for improving PPC **utilisation**, this last chapter mainly presents the finding related to research questions six and seven: "What are the perceived barriers reported by professionals to access PPC in Belgium" and Which solutions could reduce the unmet PPC needs and improve access to PPC? How far are those solutions acceptable and feasible according to Belgian stakeholders?". The methods used in this chapter comprise literature searches and consultations with experts and stakeholders (round tables, surveys and interviews) on the barriers to and potential solutions for improving **healthcare utilisation**. Details of the methods are provided in Chapter 2.

7.2 Adequacy of interventions to patients' needs

The dimension 'appropriateness of services' includes the adequacy of the time and care devoted to assessing needs and determining appropriate care plan.[27]

The care plan of a patient in a paediatric palliative situation has to plan interventions (care and support), tailored to the needs as shown in Chapter 5 on the complexity of PPC situations. professionals with limited experience in PPC expressed, in the online survey, that a flexible, individualised care plan, with the place of care tailored to each family's needs and preferences, is key component of the appropriateness of care. They also pointed out that palliative care covers the psycho-socio-spiritual domains, requiring a multidisciplinary decision-making process to develop an individualised care plan adapted to all types of needs.

Both professionals with limited and extended experience in PPC highlighted that, as the needs of the young patients and their families evolve over time, continuous reassessment is required. In this context, early identification of changes in palliative care needs has been highlighted as a key facilitating factor during the interviews with the PLTs, enabling the care plan to be adapted in a timely manner to the evolving situation of the young patient (and/or the family). According to the stakeholders, the care plan should take into account a timeline adapted to the type of disease. For example, during the initial phases of neuromuscular disorders, contact with the PLT may be limited to once or twice a year, whereas in the subsequent, more unstable phases of the disease, more frequent contacts may be planned.

When consulted by the semi-structured interview method, PLTs have also highlighted that they do not use instruments to assess PPC needs. They have rather a preference for ongoing conversations with the child and family. They explain that instruments are perceived as impersonal and their use is time-consuming. In addition, they mentioned the highly variable profile of patients as a barrier to the development of a tool adapted to all.(see section 5 of the supplementary data)

In the Netherlands (see section 7.3.5.9. in the supplementary data), the *Individueel Zorgplan (IZP)* is a structured, personalised care planning tool to support children with life-limiting or complex conditions and their families.[277] It provides a comprehensive, multidisciplinary framework for assessing needs, agreeing shared goals, coordinating interventions and documenting care delivery across settings. The *IZP* emphasises collaboration between clinicians, specialists, home care nurses and families, ensuring that the child's preferences and family context are central to care decisions. By formalising key aspects such as symptom management, psychosocial support and practical arrangements, the *IZP* promotes continuity, transparency and proactive planning throughout the illness trajectory.[278]

ADEQUACY BETWEEN INTERVENTIONS AND NEEDS

The adequacy between the interventions in the care plan and the patients' and family needs requires

a multidisciplinary decision-making process to develop a care plan including the four domains (physical psychological, social and spiritual);

a flexible, individualised care plan with the place of care adapted to each family;

continuous reassessment of the needs, including early identification of changes in palliative care needs;

to take into account disease trajectory of each type of disease.

7.3 Timeliness

Appropriateness of a service includes to reach that service at the good moment.[27]

7.3.1 The early start of PPC needs

Early identification of PPC needs facilitates access to appropriate care.[1] Professionals experienced in PPC explained that early identification of PPC needs allows for the gradual introduction of concepts related to palliative care and advance care planning. Professionals delivering bereavement support to parents expressed that the advantage of a gradual introduction is to avoid a sudden transition occurring at the very end of life. In addition, early involvement enables the establishment of a long-term relationship of trust between patient/parents and healthcare professionals, as explained in Chapter 5. Early identification was considered important by patients/parents representatives during the stakeholder consultation.

Our findings from surveys and interviews show that PLTs are often mobilised relatively late although PLTs reported that they should be involved as early as possible in the child's care pathway (see section 4, section 5 and section 8 in the supplementary data).

Several causal factors of this delay in early involvement of PLTs were identified:

First, according to professionals with limited experience in PPC, to stakeholders and to experts, some (perhaps many) primary and secondary care professionals, as well as parents, are unaware of the existence of PPC and PLTs. The improvement of the visibility of the PPC offer was positioned as first priority by professionals non experienced in PPC during the online survey.

Second, professionals experienced in PPC explained that some physicians are reluctant to initiate palliative care early in parallel with curative treatments. Consequently, even healthcare professionals who are well acquainted with PLTs do not always refer patients to them.

Third, stakeholders have highlighted that the end-of-life image often associated with PLTs contributes to delaying initial contact. However, they also recognise that, given their high level of expertise, PLTs are still the most appropriate service.

Fourth, the absence of clear criteria indicating when a PLT should be involved hinders professionals with limited experience to engage in a referral process. In addition, the lack of standardised definition of a palliative situation (see Chapter 3), shared across specialties, leads to variety of timing in referral to PLTs.

So, the timing of involvement of PLTs is often inconsistent and person-dependent and relates to individual clinicians recognising the need and knowing the PLT.

However, the lack of availability of PLTs was never mentioned in the data. Instead, clinical experts' concerns during the nominal group, rather tend to oscillate between the risk of excluding a child and their family (based on restrictive access criteria) or the risk of including children who will never require PPC. Some clinical experts pointed out that including all children with LLC/LTC from the time of diagnosis would represent many patients, with a risk of reduced availability (see also Chapter 2). In addition, stakeholders highlighted that treating physicians may perceive a systematic contact with PLTs when caring for a child with LLC/LTC as overly burdensome.

7.3.2 Prerequisites for delivering PPC at the appropriate time

The first prerequisite for delivering PPC at the appropriate time is to strengthen awareness (see Chapter 4). The general population must be significantly better informed about the concept of palliative care, including paediatric palliative care. According to the results of the online survey of professionals with limited experience in PPC (n=94 with the possibility of multiple answers), multiple actors are involved in the request of PPC (see section 4 of the supplementary data): families were mentioned 51 times, followed by paediatric liaison teams (42 times), specialist physicians (37 times), general practitioners (30 times), self-referrals (26 times), and patients (24 times). Less frequently mentioned referral sources included social workers, schools, employers, colleagues, centres for children with disabilities, hospital psychologists, home-care nurses, and hospital nurses. Many kinds of people profile could be involved in the referral to a PLTs in the real life.

The second prerequisite is about HCPs knowledge. Stakeholders highlighted that established habits constitute a barrier to the integration to PPC. Physicians who have been providing paediatric care for many years without the involvement of PLTs do not always perceive their added value or tend to associate them with end-of-life care. Increasing knowledge of what PLTs can offer would facilitate timely access to PPC. Clear communication regarding the roles of PLTs is essential, notably about the notion of complementarity. Indeed, there are concerns among paediatricians about losing their patient, or rather losing oversight of the patient's care pathway in case of PLTs involvement. However, stakeholders further explained that one advantage of the PLT model is that it enables the treating physicians (a paediatrician most of the time) to remain in charge, as their continued involvement in care is required while the PLT assumes an advisory and supportive role. According to stakeholders, sharing positive experiences would help to reduce reluctance towards PLTs. The creation of the role of "PPC reference tandem" in hospitals without a PLT would also increase the visibility of PLTs (see Chapter 6).

A third prerequisite is the maintenance of the dual function of the PLTs. During the interviews, professionals experienced in PPC explained that the function 'hospital at home' and the function 'PPC'. helps to build early connections both with patients and their families and with healthcare professionals. They note that they did not always succeed in clearly conveying that their teams were never intended solely for palliative care but also for care pathways linked to the home setting. Moreover, they admitted that, in practice, they do not always think in terms of 'palliative' and 'not-palliative' patients. The distinction is sometimes difficult and dependent of the definition used (see Chapter 3). Nevertheless, they described this dual mission as has always been their guiding principle. Furthermore, the integration of these two functions (hospital at home and PPC) is described as effective by the teams that implemented it.

A fourth prerequisite is the development of clear referral criteria within a pathway to enhance the early involvement of the PLTs as mentioned by experts and stakeholders. The reader can find more information about referral tools or targeted referral-based approaches in Chapter 3 and in section 7 of the supplementary data. The Swiss expert, interviewed about good practice in his country, explained that, in Switzerland (Zurich), specialised PPC team has established a clear pathway to PPC by developing referral criteria for paediatric cardiac patients in collaboration with the hospital's paediatric cardiology team. They agreed on five specific diagnoses for which referral to PPC is mandatory. According to the Canadian expert, a similar approach is used in Canada: once certain predefined diagnoses are confirmed, this automatically triggers contact with the PPC team. The Belgian professionals experienced in PPC suggested that a possible solution in Belgium could also be a better integration of referral systems. However, the views of stakeholders and experts are somewhat contradictory. On the one hand, they warned against rushing the introduction of referral criteria, as prerequisites must first be met in order to accommodate the arrival of a large number of patients to be cared by the PLTs. On the other hand, they indicated that, without a shift in mindset among those accustomed to managing complex chronic conditions, it seemed unlikely that referral criteria alone would lead to an increase in the number of cases referred to PLTs.

A fifth prerequisite is about the strengthening of PLTs' human and financial resources. Stakeholders expressed that adherence to the definition of young patients in paediatric palliative situation, i.e. young patients with LTC/LLC/unknown serious condition (as described in Chapter 3), would result in a substantially larger group of patients being referred to PLTs. Details on the offer are provided in Chapter 6 and on the PC definition in Chapter 3.

A sixth prerequisite consists of the implementation of ACP in routine practice. Stakeholders and experts highlighted that ACP should be an integral part of the entire care pathway of young patients seriously ill rather than being limited to the end-of-life phase. ACP could even be initiated outside a palliative context. Some stakeholders further argue that the implementation of advance care planning may be even more important than the early involvement of PLTs in ensuring access to PPC (see details on ACP in Chapter 5). Barriers to the implementation of ACP include a lack of time to regularly review and reassess the young patient's and parents' preferences and values; professionals' discomfort with conducting such discussions; and the perceived reluctance of families.[218] According to experts, ACP requires, above all, a shift in mindset among physicians and healthcare providers.

TIMELINESS

Key enablers for ensuring timely access to PPC

Raise public awareness of palliative care, including PPC.

Communicate clearly and widely about the roles and missions of PLTs.

Maintain the dual function of PLTs in 'hospital at home' and PPC.

Incorporate referral criteria to PLTs into care protocols and care pathways for eligible conditions (LLC/LTC/unknown serious conditions.

Strengthen PLTs in line with the estimated increase of the target population.

Promote a culture of ACP among both the public and healthcare professionals.

7.4 Involvement of patients and their families in decision-making and treatment decisions

Appropriateness of services includes the involvement of patients and their families in decision-making and treatment decision. This aspect is already widely discussed in Chapter 5 on the acceptability.[27]

According to the results of the online survey of professionals with limited experience in PPC, families were identified as the actors most frequently involved in initiating PPC (opinion expressed by 51 participants amongst 65). According to the same data source, children were also involved (opinion expressed by 24 participants amongst 65) (see section 4 in the supplementary data about the online survey).

Experts highlighted that parents of a child with a severe illness develop, in addition to the knowledge that any parent naturally has of their child, expertise regarding the child's health condition. This expertise is not always recognised by healthcare professionals, even though a high level of respect for parental choices within PLTs was reported by the PLTs themselves. During the stakeholder consultations, it was suggested that the status of parent-caregiver could be formally and structurally integrated into the care process. However, there is currently no regulatory framework in Belgium that formally recognises this role or provides dedicated funding for it. Our findings have highlighted a need for greater recognition of parents in their caregiving role. Furthermore, the importance of involving parents in care-related decision-making was repeatedly emphasised, see Chapter 5. A stakeholder suggested that one possible avenue for improvement would be to raise healthcare professionals' awareness during their training of the importance of recognising and supporting parents in this role.

Many practical approaches exist to facilitate parental involvement in decision-making. Two examples were mentioned by stakeholders. First, the use of Advance Care Planning (ACP) which promotes consistency in care and encourages the participation of families and children. Second, the development of secure digital platforms, such as *CoZo*, which can help patients and their families gain a better understanding of their medical issues and become active participants in their care journey.

Patient representatives also highlighted, during the stakeholder consultation, the importance of informing parents about the existence of PPC teams, as families notably need a designated resource person for issues related to quality of life. However, this information, which should ideally be communicated by the young patient's treating paediatrician, does not circulate effectively enough. It appears that many paediatricians are still insufficiently familiar with PPC teams and their missions. Patient representatives therefore question whether adequate mechanisms are in place to ensure that parents are aware of the existence and role of PPC teams.

Professionals experienced in PPC also mentioned the risk of psychological and emotional burden among parents. Therefore, alongside recognition of their central role, it is essential to provide parents with sufficient information, training, and support to enable them to fulfil this role effectively (see the section 7.7).

Finally, stakeholders expressed the view that decisions made through ACP should be regarded as shared decisions rather than being seen solely as the responsibility of a parent or an HCP. Even more importantly, attention should be taken not to place an excessive decision-making burden on the young patient.

7.5 Interpersonal and technical quality

Only limited data were collected on the quality of interpersonal relationships during service delivery, and no data were collected on the technical quality of the services as this report focused primarily on access to services rather than on the evaluation of service quality. In addition, participants to the survey of professionals with limited experience in PPC estimated that the quality of PPC is sufficient. Some aspects of quality that may contribute to improving access to PPC are presented below.

7.5.1 Communication skills of PLTs

PLTs explained that, to carry out their work effectively, they require the trust of primary care professionals, the trust of the family and the young patient, and the trust of treating teams. To establish these relationships of trust, they naturally need time (see Chapter 5) and opportunities to meet (see section 7.6.1.1), but they also require a high level of communication skills. The ability to communicate appropriately is essential in the context of PPC, which is always sensitive and carries a risk of ethical tensions (see Chapter 5). For this reason, members of PLTs must, on the one hand, possess an inherent aptitude for communication and, on the other hand, be able to maintain, or if necessary, further develop, this competence through training (see Chapter 4).

7.5.2 Capacity of PLTs to train unexperienced people

PLTs make use of their communication skills and technical expertise when training **parents** in the technical care required by their child. Indeed, parents play a crucial role in the day-to-day management of their child's condition.

In addition to parents, **non-healthcare professionals** may also participate in the delivery of technical care. Since 2024, the Belgian legislation has allowed professionals outside the healthcare sector to perform nursing acts after receiving appropriate training from a healthcare professional. PLTs can therefore train educators working in institutions for children with disabilities, childcare workers, teachers, and "*persoonlijk Assistentiebudget*" assistants supporting, in Flanders, children at home. During the stakeholder consultation, professional experienced in PPC explained that organising this training is highly time-consuming because the regulatory framework is complex and requires significant effort to determine what qualified caregivers are authorised and competent to perform

specific tasks. PLTs frequently encounter the limits of the current framework because young patients in paediatric palliative situation often require intensive and complex care. They explained that uncertainty about the competencies of qualified caregivers in paediatric palliative care remains a barrier to access. Stakeholders explained that greater clarity and specificity, particularly regarding the legal framework, are needed, and federal authorities are considering revising certain definitions through the ongoing nomenclature reform.

As previously mentioned, there is a lack of expertise in home care services like skills to control complex symptoms or to deliver complex treatments. The training of **HCP with limited experience in PPC** is another mission of the PLTs. Details on the training of HCP by PLTs are available in Chapter 6. In Canada, PPC delivery is shaped by partnerships between specialised PPC teams and community providers, based on willingness and local engagement. This model is inherently capacity building: community professionals contribute, according to their existing skills, while specialist teams provide mentorship, coaching, and ongoing support to expand competencies over time. Relationship-building is central to this approach, as explained by Canadian experts in PPC, with practices such as in-person meetings in family homes and "warm handovers" facilitating trust, reducing anxiety, and clarifying roles among families and care providers (see also chapter 5 on trust building). Continuous communication through phone calls, messaging, and informal exchanges further reinforces this collaborative framework. However, the effectiveness of this pop-up model, shared by Canadian experts during interviews, remains uneven as it depends heavily on the availability, readiness, and geographic proximity of local providers. Other countries also value this type of model.

7.5.3 Support provided by paediatricians to GPs

Maintaining the quality of care when a child returns home or remains at home requires significant effort from primary care providers and the young patient's immediate environment to create a care setting adapted to the young patient's needs. In the online survey, some professionals with limited experience in PPC highlighted that the GP who assumes responsibility for the care of a young patient in a palliative situation may occasionally need the support from a paediatrician (from the paediatric liaison team, from the treating team or from a local hospital) to pay a home visit. Currently, home visits by paediatricians are possible but depend strongly on their willingness and availability.

Stakeholders explained that, while a RIZIV-INAMI service code for paediatric home visits exists (code 103736 and 103014), its remuneration has not kept pace with inflation and does not adequately compensate for the time, travel, and organisational impact on hospital and private practices, limiting its use. Although such visits remain uncommon, they are available through most PLTs and can be valuable in supporting community-based care. To facilitate paediatricians' involvement, improved reimbursement is needed, while teleconsultations may offer an appropriate alternative in some situations. In contrast, professionals experienced in PPC stated that telephone support from PLTs is widely available, provided free of charge, and highly valued by GPs.

Stakeholders and experts could accept this practice only if this practice of home visit must remain an exception: (i) it must always be initiated by a GP; (ii) it must always follow an attempt at resolution via written and/or verbal remote contact (messages, telephone, video call); (iii) it must have been explained to and agreed upon with the patient and their family; (iv) it must result in a written report from the paediatrician to the GP, included in the patient's (shared) medical record; (v) without extra charge for the patient's family.

TO ACCESS QUALITY

Key enablers for ensuring access to high-quality PPC services

Involve patients and their families in decision-making. Provide them with clear information, offer technical training, and support them notably by granting access to their medical records (e.g., through *CoZo*).

Strengthen PLTs' communication skills.

Support the efforts made by PLTs in training non-healthcare professionals (qualified helpers) by facilitating their contact with relevant authorities.

Financially value paediatricians who provide home visits at the request of a GP in exceptional cases.

7.6 Coordination and continuity of care

Appropriateness of healthcare includes the continuity of care and therefore the examination of coordination issues.[27]

Intensive collaboration already exists in PPC offer. Amongst the 90 professionals with limited experience in PPC surveyed on the question of collaboration, 59 have declared an intensive collaboration with PLTs, 52 with the first line and 39 with the second line. Only 13/90 did not collaborate with PLTs, 10/90 with second line and 8/90 with first line. However, some participants have mentioned undesirable collaboration: nine with spiritual counsellors, three with PLTs or second line and two with first line. So, difficulties in collaboration may occur at the individual level. At an intermediate level, challenges emerge when care teams face issues related to collaboration and communication, and at the system level, fragmentation may further exacerbate access to care.

7.6.1 Coordination within the healthcare sector

7.6.1.1 Coordination of care between healthcare lines

A question of information flow

Professionals with limited and with extended experience in PPC agreed in highlighting that poor or fragmented information flow between hospital teams, primary care and families leads to misunderstandings and unsafe situations. In PPC, shared information about ACP discussions is particularly crucial. Yet ACP are not systematically (even, rarely) documented in the patient's record, according to PLTs during the interviews. Adequate collaboration between different types of HCPs, from an early stage in the patient journey, has been identified as an important facilitating factor for the development of a common language between PLTs and professionals with limited experience in PPC. Consistency in the information provided and exchanged is essential for establishing relationships of trust (see Chapter 5). Patients/parents' representatives identified this aspect of the healthcare system as particularly important during the stakeholder consultation

The electronic patient record (EPR):

Professionals experienced in PPC explained that to ensure continuous support across the continuum of care, in both acute and chronic phases, healthcare professionals should be able to rely on a shared electronic patient record across the different levels of care. In Belgium, there is no national system for sharing data between healthcare settings. While each hospital has an EPR system accessible to all healthcare professionals within that hospital, as well as an internal messaging system, the global Belgian healthcare system lacks a centralised data-sharing system outside each hospital setting.

According to PLTs, the quality of PPC between different levels of care and among different types of providers would benefit from a shared and accessible EPR. Ideally, this should include medical, psychosocial, and spiritual information, including an ACP. Due to a lack of shared ACP, in case of urgency/crisis, emergency services do not obtain the correct information and may perform inappropriate interventions. Also, stakeholders expressed that, in the absence of a shared EPR and shared ACP, families are required to repeatedly provide information relating to their child's illness and care decisions, that some of them experience as highly distressing psychologically. In addition, at the

end of life, experts indicate that a shared EPR linking the PLT, community nurses, and the GPs would be highly valuable to ensure optimal management of pain and other symptoms.

In Belgium, numerous EPR have emerged across care settings, often using incompatible formats. In addition, access is frequently restricted to specific providers. Stakeholders explained that, from a technical perspective, a shared EPR is feasible in Belgium, but it depends on interoperability between existing electronic records and on how it is, or will be, implemented within the eHealth framework. A proposed solution by a stakeholder is to continue the deployment of the Belgian Integrated Health Record (BIHR)[t] across care settings, in line with the eHealth Action Plan 2026-2029[u]. Raising patient awareness of the benefits of a wider shared EPR is also proposed by a stakeholder as a facilitator for broader uptake among HCPs. Patient representatives further note that healthcare professionals do not always have sufficient time to complete records thoroughly, and that parents should be allowed to review essential elements of the EPR.

According to experts and stakeholders, the inclusion of an ACP module within the EPR is essential for ensuring quality and coordination of care. During the stakeholder consultation, the following information was shared: Aa module entitled 'advance life and care plan' (PAVS – *projet anticipé de vie et de soins*) is already available within the 'Wallonia Health Network' (*Réseau Santé Wallon)* , and a dedicated 'careset' for advance directives is currently being developed within the federal 'Be-SafeShare project'[v] Some stakeholders consider it unnecessary to develop a new ACP tool, as functional models already exist internationally. A facilitating factor identified by stakeholders is the training of HCPs to integrate ACP into routine practice. Patient representatives, however, emphasise the need for a gradual and supportive approach to discussions with families about ACP, with careful attention to cultural sensitivity.

Digital communication channels:

Stakeholders highlighted that digital communication tools like messaging applications are improving the share of information between healthcare professionals, carers, patients and families. The AVIQ (*Agence pour une Vie de Qualité* – Wallonia health administration) supports the use of digital communication tools (e.g., messaging apps) to improve the coordination. In Wallonia, it will be soon possible to use the new module of the Walloon Health Network, called OASIS, which is dedicated to care coordination. In Flanders, the Siilo app is considered as a safe app for messaging by Domus Medica, a representative association of general practitioners in Flanders.[281]

Several experts from Canada, Australia, and Germany reported, during interviews, that commonly used communication tools and applications (such as phone calls, simple messaging and FaceTime) have been frequently utilised to respond and support parents and professionals and maintain continuity of contact. They are reported to be often more effective than formal platforms by facilitating accessible, relationship-based communication. Initiatives developed abroad can serve as a source of inspiration for the future development of shared communication in PPC. For example, in the UK, *My Care Transfer*, developed by the charity *Together for Short Lives*, is a family-centred digital tool that allows key clinical and personal information to be recorded, shared, and updated across settings, supporting continuity and coordinated PPC.[282] It facilitates secure transfer of clinical information

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[t] The BIHR (Belgian Integrated Health Record) is an initiative aimed at creating a digital ecosystem in which citizens can easily access and consult their health and well-being data, and in which all healthcare professionals with whom they have a therapeutic relationship have access to all the information necessary to provide high-quality care.[279]

[u] The 2026–2029 eHealth Action Plan fully supports a sustainable and long-term ecosystem for prevention, well-being, and healthcare in Belgium by providing the necessary eHealth systems, tools, and solutions.[280]

[v] The Be-SafeShare Project (Belgian Coordination Authority for Secure Standardized Multidisciplinary Health Data Exchange) aims to develop and implement solutions for secure, standardized multidisciplinary electronic health data exchange.F

between healthcare settings, supporting continuity across hospital, hospice, and home care. In the Netherlands, the secure digital platform *MyKinderComfortNet* (*mijnKinderComfortNet*) enables families and professionals to monitor symptoms, communicate with care teams, and access personalised care plans.[283]

However, stakeholders raised GDPR issues, ever-present when it comes to the use of messaging services. Another issue raised is that of linguistic, cultural and socio-economic barriers, when using digital communication tools. There is also a risk of unrealistic expectations on the part of parents/patients regarding response times from healthcare professionals.

A question of role distribution

The online survey of professionals with limited experience in PPC highlighted a lack of clarity regarding the distribution of roles among the actors involved, notably when interdisciplinary consultations are absent. As many actors are necessary to deliver the different interventions of the care plan and as those actors originate from different care lines, strong coordination of every care role is necessary, moreover regarding the need for coherency.

PLTs as central coordinators:

In Belgium, PLTs are responsible of paediatric healthcare coordination across the different levels of the healthcare system through the transmural care they provide[w]. PLTs explained that setting up a network of caregivers around the family in hospital and in the home setting requires a huge time-investment from them. However, this coordinating role is not formally recognised in the Royal Decree defining the missions of PLTs (see section 11 of the Supplement). The central role of PLTs in coordinating care across sectors, as well as their multiple missions encompassing direct care, the establishment of collaborations, and support for healthcare providers and parents, is sometimes compromised by a lack of resources. All stakeholders consulted agree that this essential function can only be fulfilled by PLTs if their staffing levels (in terms of full-time equivalents) and financial resources were increased.

Stakeholders suggested that PLTs should be able to draw on existing networks, but PLTs have sometimes limited knowledge of the local care and support services available, particularly in regions that are geographically distant from hospitals with PLT. For this reason, early involvement of the GP is a crucial element in ensuring effective coordination of care across the different levels of the healthcare system (see Chapter 6). During the stakeholder consultation, tit was mentioned that the early involvement of the GP is encouraged by the NIDHI (RIZIV-INAMI) within the reform of the honorarium. In the future, GPs interventions for patients aged less than 18 years with palliative needs will be better financed by new honoraria but only if a paediatric team specialised in PC is involved and includes the GPs in the care plan.

Multidisciplinary meetings:

A means used by PLTs to coordinate the interventions of the care plan is the organisation of multidisciplinary meetings. According to PLTs, such coordination meetings are essential for ensuring quality of care. Patient representatives view this coordination approach as an important lever for improving continuity of care and patient-centred care.

The objective of these meetings is to define each actor's roles aligned with the care plan. To improve the benefit of the multidisciplinary meetings, consensus about roles could be formalised into a collaborative plan.

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[w] In continuity with the KCE report on the organisation of paediatric hospital care, the same definition of transmural paediatric care is used: "Transmural paediatric care encompasses all forms of acute, chronic, palliative or end-of-life care provided to children, based on collaboration and coordination agreements between healthcare providers, across the different levels and organisations of care."

The involvement of all healthcare providers in multidisciplinary meetings is necessary: treating paediatrician(s), GP(s), home nurse(s), psychologist(s), social worker(s) and the members of the PLT. Patient representatives indicate that the presence of parents is essential, although other stakeholders point out that not all parents wish to attend. It was also highlighted, by PLTs, that there is a need for discussions both with and without the families present. They have explained that the role of the PLTs is to understand the families' views, choices, and preferences before the meeting, to represent them during the meeting, and then to communicate the key outcomes and important discussion points back to the families afterwards.

The opinions collected suggest that a multidisciplinary meeting could systematically take place as soon as a specialised PPC team was involved. Subsequently, a multidisciplinary meeting could be organised whenever the care plan is modified, for example, after a period of instability. The conclusions and decisions should ideally be documented in the shared medical record, with the ACP section completed. A stakeholder has suggested that adult palliative care networks could represent a possible alternative for organising and facilitating interdisciplinary meetings across care levels.

The feasibility of these meetings is nevertheless questioned by some stakeholders. For example, the uneven distribution of PLTs in Wallonia, where both teams are in Liège, creates challenges related to travel time. The relevance of videoconferencing for such meetings was raised by stakeholders and was illustrated by examples from abroad. In Australia, where travelling distances are huge, telemedicine is used when direct attendance is not feasible.[284]

Outside of the travel time itself, professionals with limited experience in PPC, as well as stakeholders, highlighted that the time required to attend such meetings constitutes a significant barrier to HCPs participation. According to free text from the online survey, participation in these meetings relies on goodwill at the present time. The question of remunerating participants at multidisciplinary meetings has been raised in the online survey, like providing a fee per meeting to primary care providers for their effective participation. Stakeholders have considered a structured framework for remunerating participation in such meetings to be necessary. In response to the concerns raised, several measures could be envisaged to avoid over-participation, prevent passive attendance and ensure the genuine involvement of each HCPs involved.

The NIDHI (RIZIV-INAMI) has referred to preparatory work in the frame of the reform of the nomenclature to determine how to appropriately remunerate HCPs for their participation in multidisciplinary consultations. The principle of a compensation could also have an impact on organisational aspects: given the differing schedules across professions, meetings are sometimes postponed by as much as a month due to organisational constraints.

An example of coordination between healthcare lines from abroad:

An example of an initiative addressing the question of PPC coordination between healthcare lines is the 'Kentown Model', developed by the charity 'Kentown Support', in the UK. This model was designed in response to the traditionally fragmented and poorly coordinated delivery of PPC in the UK. The Kentown Model aims to reshape how children with life-limiting conditions and their families are supported, by integrating and coordinating services more effectively around the needs of the child and family. A central feature of the model is the establishment of structured coordination mechanisms that align hospital services, hospice provision, and community care already existing in the community into a more coherent care pathway. A key characteristic of the model is its modular and flexible design. The Kentown Model provides a set of interlinked components of support that can be adapted according to the evolving needs of each family. The programme includes integrated community-based support services, such as clinical care and PPC education within local teams (community children's nurse), practical and emotional home-based support such as transport, school pickups, and activities for siblings (family support workers), structured psychological and bereavement support for children and families, including sibling-focused interventions (therapeutic counsellors), and coordination and navigation of local services, financial assistance, and equipment access (care navigators/coordinators). Importantly, these elements are not delivered as a standardised bundle but

are adjusted dynamically over time. The principal innovation of the Kentown Model does not lie in the creation of new types of services, but in the systematic integration and coordination of the ones existing in the community.[285] An evaluation of the pilot project showed that "*the Kentown model filled a critical gap in statutory provision by offering holistic support, relational continuity, and earlier access to palliative care than families had previously experienced*".[286] This programme is being evaluated, including a health economic evaluation.

7.6.1.2 Coordination of care with paediatric departments

The degree of interaction and collaboration between PLTs and various paediatric departments varies considerably from one hospital to another as it often depends on the professionals involved. According to professionals experienced in PPC, contacts with neonatology units appear to be even more inconsistent: such units have sometimes developed their own PPC provision as they are more frequently confronted with palliative situations than other services. The situation is even more inconsistent between departments that are not located within the same hospital or hospital network.

Some experts and stakeholders suggested that scheduling regular contacts between the PLT and a key contact person within the various paediatric departments (e.g., neurology, neonatology, metabolic medicine, oncology), in the form of case conferences, constitutes a potential solution based on the data collected. The conclusions and decisions arising from these case conferences would benefit from being systematically documented in the shared medical record, as well as in the ACP section where appropriate. For example, the Swiss expert explained, during the interview, that to address the limited awareness about PPC services and to promote collaboration with paediatric departments, PPC teams, in Switzerland, participate in clinical rounds across various paediatric departments.

Stakeholders highlighted that, periods of instability, during which the care plan may need to be revised repeatedly, require even closer collaboration between HCPs despite the greater difficulty of organising multidisciplinary meetings. This ensures that all necessary information regarding the child is transferred efficiently, particularly during transfers between care settings. Stakeholders and experts emphasised the importance of establishing prior, close working relationships between PLTs and other care teams, to enable a rapid and coordinated response in situations of instability.

COORDINATION WITHIN THE HEALTHCARE SECTOR

Coordination to ensure access to a high-quality service can be done through

The development of the shared patient record (BIHR) across the different care settings

The use of a secure messaging applications between healthcare professionals and parents/patients.

The increase of the human and financial resources of PLTs to enable them to fulfil coordinating role, in addition to their role in supporting and training parents, carers and helpers, and the direct care they provide.

The organisation of multidisciplinary meetings:

- at the start of specialised paediatric palliative care
- whenever there is a change to the care plan following a period of instability.

The provision of financial and practical incentives for professionals to participate in multidisciplinary meetings.

Regular contacts between PLTs and key personnel from specialist services within paediatric departments.

7.6.1.3 Collaboration between PLTs

From our consultations of the PLTs, it seems that a structured system of clinical collaboration between PPC teams currently does not exist. PLTs work in parallel rather than collaboratively. This limited collaboration may represent an obstacle to the development of PPC in Belgium. From the perspective of patient representatives, closer collaboration between PLTs would enable better sharing of expertise regarding the management of pain, complications and psychosocial issues.

Since 2012, there has been a group bringing together representatives from the various PLTs, known as the Belgian Paediatric Palliative Care Consortium (BPPC). At this time, working groups were set up by the BPPC to develop a paediatric palliative care manual tailored to the Belgian context. This manual was published in 2021.[20,21] As explained by some of their members, since the publication, the BPPC is not very active and struggles to recruit new members. The lack of structure, resources and recognition from the authorities has led to a sense of discouragement. With minimal financial and staffing support, the BPPC could play an important role in fostering collaboration, notably by bringing all PLTs together, at least once a year, and drawing up a number of common protocols. According to a stakeholder, an extensive structure in the Netherlands including numerous experts represents a good example for Belgium (see also Textbox 1n Chapter 4).

In Switzerland, the Paediatric Palliative Care Network (PPCN) Schweiz, is an example of what could be developed by the BPPC under the condition that they would receive adequate support.[287] (see Textbox 6)

Textbox 6 – Paediatric Palliative Care Network (PPCN) Schweiz (Switzerland)

The Paediatric Palliative Care Network Schweiz (*PPCN Schweiz*) is the national coordination network for PPC.

It connects university hospitals, regional hospitals, hospices, and local care teams. The network is designed to reflect the full spectrum of the care system, including hospital services, outpatient home care providers, volunteer-based organisations, and specialists in psychology, and education. It also integrates chaplains, social workers, funeral directors, bereavement support workers, and researchers.

PPCN Schweiz develops and disseminates national guidelines, protocols, and best practices, while facilitating knowledge exchange and professional collaboration across healthcare teams. Although it does not provide direct care to children, the network plays a central role in coordinating services, supporting regional teams, and promoting continuity and multidisciplinary integration, by aligning practices at the national level while allowing local adaptation.

Source : Le réseau national pour soins palliatifs pédiatriques[287]; interview with Swiss expert

The BPPC website could be the resource hub for PPC in Belgium as the Australian website *PaediatricPalliativeCare.org.au* does, offering a wide range of evidence-based tools, guidelines, educational materials, clinical resources, toolkits and support documents tailored to both health professionals and families.[288] Professionals can access clinical tools, assessment instruments, workforce resources, and training modules, while families can find information for understanding palliative care, preparing for care transitions, navigating care options, and accessing psychosocial support. For example, the "Green Book" (a Practical Guide to Palliative Care in Paediatrics - 4th Edition) is a key clinical resource for healthcare professionals. It provides structured tools for assessment, symptom management, care planning, and documentation, promoting consistent, evidence-based, and family-centred care across settings.[289]

Experts and stakeholders also highlighted that another factor complicating collaboration between PLTs in Belgium is the language issue, as well as persistent cultural differences regarding palliative care and end-of-life decisions. An initiative has been launched in Flanders to bring together Flemish teams and explore how they can support one another as PLTs. PLTs explained during the interviews

that an opportunity to forge links raised when new PLTs were set up, with an established PLT sharing its experience and knowledge with the new one.

7.6.1.4 Collaboration between the paediatric and the adult health care services

PLTs and AYA teams: the problems of the transition to adulthood

The findings of our research into the transfer from paediatric palliative care to adult palliative care revealed that this issue was at the heart of many concerns held by experts and authorities in Belgium and abroad. At present, PLTs explained that there is little continuity of care at the point of transition to adulthood in Belgium. This is a significant gap identified in the provision of care, for which the solutions identified during consultations with Belgian and international experts extend well beyond paediatric palliative care services. This gap should be the subject of in-depth and targeted research focusing on this period, without being restricted to palliative care situations.

Our project has nevertheless highlighted several points requiring particular attention:

- **A lack of appropriate services**: recent new conventions aiming at providing adolescent and young adults (AYA) (16-35 years) with quality care specifically designed for people of their age, were never fully operational due to recognition complaints. PLTs expressed that, although the missions of AYA teams were not oriented towards the palliative dimension, once reactivated, these hospital-based AYA teams could serve as a starting point for disseminating best practices in AYA care among professionals across all specialties, not limited to oncology. The acquisition of PPC-related expertise would enable them to become a key pillar for transfer and transition in palliative contexts. Some PLTs have already collaborated with AYA teams and have reported that the formalisation of such collaborations will depend on the time and funding that can be allocated.
- **End-of-life phases and oncologic situations are not suitable to transition processes**: Professionals experienced in PPC highlighted that transfers primarily concern patients with chronic life-limiting conditions and only rarely those with oncological diseases.
- A **transition period of approximately 10 years** (between the ages of 15 and 25) is considered sufficient by content experts during the round table, to move from paediatric to adult care provision (see section 2 of the supplementary data).
- **Variability among adult palliative care support teams**: some adult PC support teams surveyed are willing to develop competencies to care for AYAs while others consider such care to be too far removed from their usual practice (see section 12 of the supplementary data).
- **The development of a structured transfer programme is proposed as a solution by PPC experts**: experiences from transfer pathways in chronic care, such as joint consultations involving internists and paediatricians in transplantation or genetics départements, are viewed as a valuable source of inspiration for transfer and transition in palliative care contexts. The Australian PPC National Action Plan does explicitly address transfer from paediatric to adult services and transition to adulthood.[290] This acknowledges that many children and young people with life-limiting conditions will continue to require care into young adulthood, and that their transfer should be planned early and managed collaboratively to reduce stress, maintain continuity, and support ongoing needs as care models differ between paediatric and adult teams. In particular, Action 2.1 of the plan proposes the development and implementation of an optimal PPC pathway that includes a transition pathway between paediatric and adult palliative care services. The 'Shaping the Future of Paediatric Palliative Care Project' identifies '*developing a transition pathway between paediatric and adult palliative care services*' as a specific focus area. This project includes tools and resources to help young people and families prepare for and navigate the move (i.e., the transfer of care) to adult palliative settings.[291] This fully codified national transition pathway is still under development (see section 7 in the supplementary data). Developed in the context of the PPC National Action plan, the "*Transitioning to the Adult Health Care System: A Starter Toolkit*" provides a structured, practical framework to support young

people with chronic or complex conditions, their families, and healthcare professionals in planning and navigating this transfer from paediatric to adult services and accompanying transition to adulthood.[292]

PLTs and second-line PC support teams for adults

From the interview of PLTs, the survey of adult PC teams and the online survey of professional with limited experience in PPC, a potential risk of reduced quality of care was highlighted when two coordinating teams are involved in the care for the same patient, specifically a PLT and a second-line adult palliative care support team. Still one respondent to the online survey of professionals with limited experience in PPC noted that collaboration between adult and PLTs can function effectively, provided there is good communication, trust, strong interpersonal relationships, and mutual support.

Experts and stakeholders emphasised that, while children and adults in palliative situations do have distinct needs, there are also important commonalities. Situations involving discontinuity of care and significant psychological vulnerability among relatives would greatly benefit from the sharing of best practices between adult and paediatric teams.

The BPPC and regional palliative care federations could play a role in fostering collaboration between specialised adult and paediatric services. At present, a PPC working group is being developed within the Flemish and the Brussels PC federations. Opportunities for interaction, such as symposia and joint training sessions, have also been proposed as ways of improving collaboration by stakeholders.

The principal barrier identified by stakeholders relates to the limited human and financial resources available to regional federations and the BPPC. Some stakeholders have also expressed concerns about the risk of "diluting" PPC within the adult care sector and thereby losing its specific characteristics. Conversely, other stakeholders support the inclusion within palliative care federations of professionals trained in paediatrics to facilitate adaptation to the specific needs of children.

COLLABORATION BETWEEN SPECIALISED SERVICES

Collaboration as a guarantee of access to a high-quality service can be improved by

Providing financial and staffing support to the BPPC to enable it to play a role in fostering collaboration, by bringing together all the PLTs at least once a year and by drawing up joint protocols.

Investing in HSR research concerning the transfer between paediatric and adult care provision and transition to adulthood.

Incorporating paediatric aspects more systematically into the project of the palliative care federations.

Organising joint symposia and training sessions by the BPPC and the palliative care federations to facilitate meetings between PLTs and mobile adult palliative care teams.

7.6.2 Coordination between the healthcare sector and other sectors

Professionals with limited experience in PPC and stakeholders explained that providing care for children and young adults with severe and complex conditions, as well as their families, requires collaboration with professionals from the social sector, early childhood services, education, well-being services and disability sectors. Results from the online survey indicate that there is a lack of communication between the healthcare sector and these other sectors.

Patient representatives and professionals with limited experience in PPC viewed the implementation of a structured patient journey very positively. It could ensure a better continuity of care across the various settings the young patient frequents, thereby reducing disruptions in care delivery. They

emphasised the added value of having a single designated coordinator responsible for overseeing the entire patient journey and serving as a consistent point of reference for parents.

According to professionals experienced in PPC, the main facilitator for improving collaboration among all stakeholders is the organisation of meetings with professionals involved in the young patient's care at school or during leisure activities, for example. However, it is essential to define, in consultation with the parents, which (personal) information may be shared outside the healthcare sector, and to ensure that parents themselves are present at these meetings. Owing to their coordinating role and communication expertise, PLTs appear best positioned to organise and lead such intersectoral meetings.

Some examples from abroad, collected by interviews with national experts, illustrate the tendency for case management to go outside the healthcare sector and to include other aspects of a young patient's life. In Germany, *Bunter Kreis* provides case management to children with life-limiting or complex chronic conditions.[293] The organisation provides each child and family with a dedicated case manager, typically a specialised nurse or trained professional, who coordinates all aspects of care across settings, including hospital, home, community services, and hospice when available. The case manager ensures continuity of care, integration of medical, psychosocial, and educational support, and guidance through administrative processes, while also providing family-centred support throughout the illness trajectory, including end-of-life care. *Bunter Kreis* emphasises individualised follow-up, tailoring interventions to the specific needs of each child and their family.

In the Netherlands, the *Netwerken Integrale Kinderzorg* (NIK) are regional, multidisciplinary networks designed to coordinate and integrate care for children with complex or life-limiting conditions.[294] These networks bring together stakeholders across hospital, community, home care services and social care sectors to facilitate collaboration across medical, psychosocial, and educational domains and to improve continuity of care. Their role is primarily organisational, focusing on aligning services, supporting care planning, and enhancing communication between professionals and institutions involved in a child's care. Each NIK has an independent coordinator employed by the PPC centre and is connected to hospital services through the Kinder Comfort Teams (PPC-teams providing care in the hospitals and acting as bridges with home care). This model has a high level of standardisation (shared methods used), resulting in a high degree of consistency in practice across the country.

COLLABORATION BETWEEN THE HEALTHCARE SECTOR AND OTHER SECTORS

Cross-sector collaboration through a coordinated pathway centred on the sick young patient and their parents can be made by

The development of a structured patient journey that clearly defines everyone's roles and the links between the child's various living and care settings.

The consultation meetings with professionals from other sectors, attended by parents and organised by the PLTs.

7.6.3 Collaboration between the different levels of authorities

One of the challenges relating to access to paediatric palliative care identified in the review by Bailey et al. (2025), concerns "*the experience of people navigating a fragmented healthcare system*".[90] Our findings showed that the fragmentation of the system occurred at various levels in Belgium but that solutions are available.

7.6.3.1 Weak link between adult and paediatric health systems

One of the recurring findings in the data collected from content experts, stakeholders and professionals experienced in PPC is the lack of links between the adult palliative care sector and the PPC sector. Since the 1990s, Belgium has introduced several pieces of legislation concerning palliative care for adults and one piece of legislation concerning the PPC. At present, legislation on PC for children and adults is evolving in parallel.

During this project, the question arose on the added value of integrating adult and paediatric palliative care services and models into a single, unified system with shared resources, infrastructure, and services. Our data demonstrated the relevance of this approach for certain components of the system, particularly in strengthening continuity of care and improving the transfer to adult services.

Across the previous KCE reports on PC, several fundamental principles common to palliative care, irrespective of patients' age, can be identified.

- The palliative approach is intrinsically multidimensional, encompassing physical, psychological, social, and spiritual domains, with a central focus on quality of life.
- Early initiation of palliative care is essential.
- Palliative care should be delivered as integrated and continuous care, concurrent with curative treatments.

However, several characteristics specific to paediatric palliative care limit the feasibility of fully integrating paediatric and adult palliative care models into a single unified framework (see also Chapter 5).

- In the Belgian system, the majority of the HCPs delivers care to either children or adults but not both. They develop an expertise for one or the other target group.
- Children are continuously developing, and this dynamic must be considered in any care plan. Numerous non-medical domains must be involved, including education, leisure activities, and social services.
- Parents play a central role, both as primary caregivers and as decision-makers for their minor child.
- The palliative situation has a profound impact on the entire family context and on daily family life.
- Whereas the palliative phase in adults is theoretically limited to less than one year (PICT-1), paediatric palliative care generally involves long and intensive trajectories, during which sustained relationships of trust are built between healthcare professionals, the child, and the family.

Considering both these shared principles and specific characteristics, the Belgian care model could be based on a common vision (and potentially shared infrastructure), particularly for aspects such as awareness-raising, training, public engagement, research, and ethical, spiritual, and legal support. Regional palliative care federations appear to be an ideal anchor point for connecting PPC and adult palliative care. However, stakeholders involved in these federations emphasise that this will only be feasible provided that sufficient resources are available.

7.6.3.2 Division of responsibilities between federal and regional levels

Previous KCE reports showed the fragmentation in the organisation of care policies, notably due to the division of responsibilities between the federal level and the regional levels.[49,295] Other countries have developed legal frameworks or national strategies to structure and support paediatric palliative care, reflecting different approaches to policy integration (see section 7 of the supplementary data):

- Australia has adopted a national PPC action plan (see Textbox 7), structured around key priorities such as quality of care, access, information sharing, and research. This plan emphasises equity (both geographical and cultural), a life-course approach (rather than one focused solely on end-of-life), and the strengthening of community-based care.
- The Netherlands has developed a coordinated national policy agenda involving multiple stakeholders, focusing on concrete priorities such as accessibility, the organisation of care and daily life, financing, and the development of knowledge and expertise based on identified needs.

Textbox 7 – National Action Plan on Pediatric palliative care (Australia)

The Australian Paediatric Palliative Care National Action Plan, launched in July 2023, is a nationally coordinated framework aiming at strengthening PPC provision for infants, children and young people with life-limiting conditions. Supported by the Australian Government Department of Health and Aged Care, the plan establishes a strategic foundation for system-wide improvement.

The overarching objective of the Action Plan is to ensure equitable access to timely, high-quality PPC that optimises quality of life for patients while providing comprehensive support to families and carers across the illness trajectory. The Plan considers that PPC should be integrated from the point of diagnosis, rather than being confined to end-of-life care.

The Action Plan is structured around four priority domains: quality of care, access to services, information sharing and collaboration, and data, evidence, and research. Within these domains, the plan emphasises the need to standardise care delivery, reduce geographical and socio-demographic inequities in access, and enhance interdisciplinary and cross-jurisdictional coordination. Furthermore, it identifies significant gaps in national data infrastructure and research capacity, highlighting the necessity for improved evidence to inform policy and clinical practice.

Key strategic actions include the development of targeted education and training initiatives to build workforce capability, the establishment of clearer and earlier referral pathways, and the promotion of public and professional awareness regarding the scope and benefits of PPC. The plan also underscores the importance of delivering care that is family-centred, culturally responsive, and adaptable to local contexts while maintaining national consistency.

Implementation is supported by Australian Government funding of approximately AUD 1.25 million over the 2023-2026 period, intended to facilitate capacity-building activities, resource development, and improvements in service coordination.

Source: Pediatric palliative care Australia(Paediatric Palliative Care (Australia), n.d.)

7.6.3.3 Existing coordinated plans and programs

Suggested solutions to improve the coordination of PPC at the system level is the opportunity to embed PPC policy within various already existing national plans and care programmes. Indeed, PLTs highlighted a lack of integration of paediatric palliative care within both current and future care models. Rather than developing a separate palliative care plan, PPC could be regarded as a cross-cutting principle, being systematically incorporated into existing and future care plans. Such an approach may help to prevent the late initiation of palliative care, which is still too often introduced only after the "failure" of curative treatments.

Several plans, programmes, models, and policies relevant to children and young adults with severe illness already exist in Belgium, including:

- the paediatric care programme[x],
- the integrated care plan for vulnerable populations[296,297],
- the rare diseases plan (see Textbox 8)[298],
- AYA conventions[299,300],
- conventions for neurological, metabolic, and genetic conditions in children,
- different social policies (well-being, education, youth care, bereavement support),
- regional policy plans (e.g., the reform of palliative care in Flanders).

Textbox 8 – Rare disease plan (Belgium)

The Rare Diseases Plan 2026-2030 is a national strategy developed to improve the quality of life of people living with a rare disease, as well as that of their families and carers.[298] The objectives of this plan include:

- Ensuring coherent, continuous, and person-centred care
- Promoting networks between highly specialised care services and hospitals, as well as across different levels of care
- Achieving optimal coordination of care
- Paying particular attention to the transition from paediatric to adult care
- Improving data registration and monitoring
- Facilitating rapid and accurate diagnosis
- Simplifying administrative procedures
- Etc.

Numerous similarities are identified between the needs and solutions in the field of rare diseases and those identified for PPC. Several objectives of the 'Rare Diseases Plan' are shared with objectives allowing to improve access to paediatric palliative care. This plan therefore represents an ideal example in which the integration of PPC would have been highly relevant.

Authorities responsible for updating this plan could include representatives of the BPPC within working groups in the future, to ensure that children with life-threatening or life-limiting rare diseases can benefit from PPC. Relevant stakeholders have indicated that PPC could still be incorporated during the implementation phase of the plan, even if modifications to the plan's text are no longer possible.

A second opportunity for PPC is 'The integrated care program.' Indeed, our findings highlighted a lack of integration across the different domains of palliative care provision, particularly about psychological,

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[x] AR-KB 13-07-2006. *Arrêté royal fixant les normes auxquelles un programme de soins pour enfants doit répondre pour être agréé et modifiant l'arrêté royal du 25 novembre 1997 fixant les normes auxquelles doit répondre la fonction 'hospitalisation chirurgicale de jour' pour être agréée - Koninklijk besluit houdende vaststelling van de normen waaraan het zorgprogramma voor kinderen moet voldoen om erkend te worden en tot wijziging van het koninklijk besluit van 25 november 1997 houdende vaststelling van de normen waaraan de functie "chirurgische daghospitalisatie" moet voldoen om te worden erkend*. MB – BS 16/08/2006

social, spiritual, and respite care (see Chapter 6). Given the high proportion of chronic conditions in paediatric palliative situations, and the vulnerability of families due to the psychosocial impact of these conditions (see Chapter 5), one potential solution would be to extend access to the integrated care program developed by the Federal Public Service for Public Health to families with a child in a palliative situation but at present, some uncertainty remains regarding the eligibility criteria for inclusion in this programme. Internationally, England has developed a system integrating PPC into its healthcare framework. Stakeholders note that post-bereavement care fits particularly well within the concept of integrated care. Patient representatives emphasise that an integrated approach is crucial for families facing a high burden related to care needs, repeated hospitalisations, and socio-economic impacts. According to stakeholders, feasibility will depend on clearly defined inclusion criteria, the availability of resources and openness to spiritual and respite care.

Some stakeholders indicated that it was both appropriate and feasible to integrate PPC into the future paediatric care programme and into the future Cancer Plan, particularly regarding AYAs. With respect to the paediatric care programme, one stakeholder highlights the importance of adopting a broad, cross-cutting vision in which PPC is accessible to all children (including those with oncological, rare, or complex conditions), and of avoiding fragmentation through condition-specific agreements or silos. However, some stakeholders raised concerns regarding the potential time required before such a new programme can be established.

7.6.3.4 Care pathways combining palliative and curative care

Echoing this perspective expressed by stakeholders, professionals experience in PPC explained that the integration of PPC within other plans and programmes requires a paradigm shift in the conception of healthcare, namely towards an approach based on the life course and care trajectory, in which palliative care is no longer confined to the terminal phase but is incorporated into care pathways that may extend over several years. Many patients requiring PPC are already engaged in care pathways related to a specific condition in which PC and curative care can be combined. However, as already mentioned, the data collected in the online survey and in the stakeholders consultation indicate a lack of awareness among healthcare professionals, patients, families, and policymakers that these trajectories and care pathways could include a palliative component.

The development of a care pathway relies on coordination across different levels of care; effective collaboration between providers; integration of medical, paramedical, social and spiritual care; inclusion of transfer to adult services; continuous evolution and adaptation to medical advances with ongoing evaluation of quality and effectiveness; as well as a central role for multidisciplinary consultations organised by treatment teams. Patient representatives warn of the risk that some parents may not feel ready, at the early stages of their child's illness, to engage in discussions about a structured care pathway. One stakeholder suggests that defining such a pathway could be facilitated through discussion with the patient and the family.

Existing national and international models could serve as a basis and be adapted to the Belgian context. One example is the 'Care Pathway' developed in Canada, which has recently been implemented but has not yet been evaluated.[301] That 'Core Care Pathway for Paediatric Palliative Care' outlines key stages from diagnosis to end-of-life and bereavement, promoting the early integration of palliative care and continuity across settings. It emphasises multidisciplinary collaboration, advance care planning, symptom management, psychosocial support, and family-centred care. That pathway also supports coordination between hospital, community, and home-based services, while clarifying roles and responsibilities among professionals. It aims to enhance consistency, quality, and equitable access to care, providing a structured framework to guide clinical practice and service organisation.[61] (see section 6 and 7 of the supplementary data)

A potential solution within the Belgian context is therefore to develop generic care pathways, for example by drawing inspiration from the model of generic care pathways proposed in the Rare Diseases Plan.[298] A generic care pathway is a standardised care protocol that serves as a model for

a specific group of patients (or a given medical condition). It is then adapted to the specific needs of each individual to create a personalised care plan. Such pathways should, at a minimum, include:

- identification of patients
- referral to PLTs
- assessment of needs at initiation and during periods of instability
- collaboration across different levels of care (care pathway continuity)
- effective coordination between providers (multidisciplinary case conferences)
- integration of medical, paramedical, and social care
- inclusion of transfer to adult services and transition to adulthood
- continuous evolution and adaptation to medical advances
- evaluation of quality and effectiveness of practices.

A stakeholder expressed concerns regarding the complexity of such a project, given regional variations in approaches, but acknowledged its clear added value if successfully implemented. Stakeholders emphasise the importance of embedding care pathways within the ongoing reforms taking place in the federated entities, referring in particular to the primary care reform in Wallonia and suggesting that the ASCOP (*Aide et Soins Centrés sur les Objectifs de la Personne* - person-centred support and care focused on the individual's goals) approach could serve as an achoring point. Coordination between the different levels of government therefore appears necessary.

Stakeholders expressed that the development of generic pathways should include the participation of expert patients. The relevance of a care pathway approach is also recognised by representatives of palliative care federations for the sector as a whole.

Finally, the integration of PPC into care pathways should not be limited to policy and clinical dimensions but could also extend to the scientific level, through the incorporation of PPC into care protocols and clinical guidelines relating to life-threatening and life-limiting conditions.

7.6.3.5 Need for an interministerial committee

Changes of this magnitude (i.e., a paradigm shift where palliative care would systematically be integrated into care pathways of severe conditions) could require the establishment of an interministerial committee in which:

- a shared vision is developed between federal and regional levels of responsibility
- existing tensions surrounding the integrated and shared patient record (BIHR) are resolved in the interest of patients.

GOVERNANCE

Collaboration between different levels of political competencies

Regional palliative care federations as ideal hub for linking paediatric palliative care with adult palliative care.

Combat the stigma surrounding palliative care in paediatrics to embed PPC within existing and future care models.

Inclusion of paediatric palliative care in care plans for children and young adults, including the rare diseases plan.

Integration of paediatric palliative care into the future children's care programme.

Ensuring that families affected by paediatric palliative care benefit from the integrated care model.

Develop generic models for cross-sectoral and cross-disciplinary care pathways.

Establishment of an interministerial committee to align decisions about the integration of PC into care pathways of severe conditions.

Incorporate PPC into clinical protocols and guidelines for life-threatening or life-limiting conditions.

7.7 Ability to engage in healthcare

This is the capacity and motivation to participate in care and to commit to its completion. It requires the capacity to communicate as well as notions of self-efficacy and self-management. It is the last stone necessary to build an ideal access to health care. Patients, families and professionals can be concerned.[27]

7.7.1 The patients and parents' ability to engage

Stakeholders highlighted that the emotional burden borne by parents of a child with severe, chronic illness and by the young patient him/herself is substantial. They carry significant responsibilities when making decisions regarding their child's quality of life and the care provided daily. This requires sustained skills in emotional regulation and decision-making. Some stakeholders recommended establishing a structured network providing psychological support for parents to help them cope with these challenges. PLTs explained that, in principle, most parents receive emotional support from direct care providers such as GP and home nurses. In many cases, they can also rely on the psychologist attached to the PLT and/or the specialised care service. Patient representatives emphasise the importance of aligning with the parents' pace when offering psychological support. While this support should remain optional, they considered it should be included in the care plan and proposed regularly until the appropriate moment was identified. Professionals experienced in PPC and stakeholders highlighted that regular psychological support was essential to prevent burnout and family isolation.

Support for parents may include mechanisms that facilitate access to second opinions. The analysis of potential ethical tensions indicates that the heavy responsibility carried by parents may sometimes lead to overprotective attitudes toward their child, resulting in reluctance to accept support or care coordination from the PPC team or other healthcare professionals (see also Chapter 3). Professionals with limited experience in PPC and stakeholders highlighted that, in such situations, peer support is crucial. Parents and patients associations can provide this support, although they themselves require logistical support to fulfil this function effectively.

7.7.2 Ability to engage of the HCP with limited experience in PPC

PLTs explained that early detection of changes in palliative care needs depends on the involvement and vigilance of primary care professionals. Ad hoc training delivered by PLTs equips first-line carers with the tools required to identify problems and initiate necessary changes promptly, while maintaining contact with the PLTs, which can subsequently assume responsibility if needed.

Data from the online survey and the interviews with PLTs suggested that some primary care providers are hindered, in their decision-making and even in their willingness to engage in palliative care, by a lack of clarity in the legislation, particularly regarding medical and paramedical procedures authorised in home settings or residential institutions. Some professionals with limited experience reported being insufficiently informed about interventions that are legally permitted. Stakeholders indicated that, in the absence of a legal framework providing clearer guidance on care practices, a degree of apprehension would persist about whether to act or refrain from acting. However, professionals experience in PPC stated that there would always be grey areas within situations that are ethically

challenging, and, at times, also legally complex. This underscores the importance of having access to an ethics committee. A proposed solution by stakeholder was that medical councils (*Ordre des médecins - Orde der artsen*) could organise training on this topic, either as part of undergraduate education or within a broader module on medical liability.

ABILITY TO ENGAGE IN HEALTHCARE

To access to PPC, some conditions and skills are required like

Providing emotional and psychological support to parents on a regular basis in order that they can fill their key role.

Orienting patients and families to patient associations which can play a key role in providing peer-support.

Clarifying the legal framework governing medical (and paramedical) interventions in paediatric palliative care and support the commitment of professionals with limited experience in PPC by training them in legal issues.

7.8 Conclusion

This chapter explored the final step in the journey to accessing healthcare services through the lens of healthcare utilisation, which relates to the dimensions of 'appropriateness of services' and the ability to engage in healthcare. Although that step is not traditionally considered part of barriers to access, the findings provide valuable insights for the development of the care pathway envisaged by the project submitters.

8 STRENGTHS AND LIMITATIONS

8.1 Strengths

8.1.1 Societal expectations for enhanced care management of young patients in paediatric palliative situation

In the absence of a clear international consensus and considering the cultural sensitivity of the topic, the study adopted a context-specific approach rooted in the Belgian healthcare setting. This approach was further strengthened through a consultation of Belgian healthcare system stakeholders about the acceptability and feasibility of potential solution, ensuring that the findings and recommendations reflected the realities of the national context.

This ambitious scope and strong anchoring in the Belgian healthcare context, exploring important expectations expressed by both care professionals and policy makers. The study generated considerable interest among healthcare professionals, including those less familiar with paediatric palliative care. Despite the low frequency of paediatric palliative situations, participation in the online survey far exceeded expectations. In addition, experts and stakeholders were highly committed, providing extensive input through both written and oral consultation processes. Consequently, the research process has already initiated a process of reflection and change among those involved.

8.1.2 Tailored methodological approaches to address the multidimensional research questions

Given the multidimensional nature of accessibility to paediatric palliative care, which involves elements such as the timely identification of young patients requiring palliative care, the alignment of care provision with identified needs, and the coordination between the various actors involved, multiple methodological approaches were combined. This mixed-methods strategy was adopted to generate

the most comprehensive evidence base for addressing the report's central research question: how can access to paediatric palliative care in Belgium be improved?

For instance, the review of scientific literature on **tools for identifying young patients** with palliative care needs revealed relatively few relevant publications. In contrast, the inclusion of grey literature through snowballing and targeted web searches uncovered a wider range of identification tools. The triangulation of these sources provided a more complete overview and supported the identification of the tool(s) most suitable for recognising young patients in a palliative care situation (within the Belgian context).

While tailoring care to **patients' needs** is a core principle of palliative care, it represents a particular challenge in PPC because of the wide range of actors involved. Beyond addressing the needs of the young patient, PPC must also consider those of parents, siblings, extended family members, peers, and other individuals forming the young patient's social network. The resulting complexity of relationships and care needs was explored through a literature review examining the perspectives of these different groups. Triangulating these findings with an analysis from an ethical point of view of the interactions between the different actors enabled a more nuanced understanding of how these relational dynamics may facilitate or hinder access to PPC.

Mapping the **Belgian PPC offer** required the integration of multiple sources of information. In addition to a review of grey literature, such as websites of hospitals, organisations, and public authorities, expert consultations were conducted to complement and contextualise the available information. This triangulation of evidence enabled the identification of gaps, unmet needs, and barriers to access that may not be apparent from documentary sources alone, thereby providing a more comprehensive overview of the current PPC landscape in Belgium.

8.1.3 Insights from initiatives from abroad for the Belgian context

The exploration of international paediatric palliative care initiatives provided an important opportunity to broaden the range of potential solutions considered in this study. By building on experiences and practices already implemented in other countries, the study avoided a "reinventing the wheel" approach and benefited from existing knowledge, expertise, and lessons learned. The analysis of international experiences also highlighted the variety of ways in which healthcare systems address similar challenges. This enabled the identification of a range of promising practices and innovative approaches that could potentially be adapted to the Belgian context. Furthermore, these examples served as concrete discussion material during stakeholder consultations, thereby stimulating reflection and supporting the development of solutions to address existing gaps in Belgian PPC provision.

The interviews with international experts complemented the exploration of initiatives by providing a deeper understanding of the contextual factors underpinning the identified practices. These discussions helped to clarify the rationale behind specific approaches, the circumstances in which they were developed, and the way they operate in real-world settings. These interviews also enabled the identification of additional relevant initiatives that had not emerged from the literature searches or publicly available documentation, thereby enriching the range of practices considered.

8.1.4 Extensive stakeholder involvement across all stages of the research process

A major strength of this study was the extensive consultation of stakeholders from across the PPC landscape. The study successfully engaged a wide range of actors, including 45 PPC content experts, 29 clinical experts, 134 professionals with limited experience in PPC, 65 stakeholders including representatives of public authorities, healthcare professional organisations, the adult palliative care sector, and patient organisations. This broad consultation ensured that the findings were informed by diverse perspectives and experiences across different levels of care and policy.

Stakeholder input was gathered on key aspects of PPC, including the definition of the target population, the organisation of the PPC offer, barriers to accessing PPC, and potential strategies to

improve accessibility. The inclusion of participants with differing backgrounds, roles, and levels of expertise enriched the analysis by capturing complementary and sometimes contrasting viewpoints, thereby strengthening the comprehensiveness, relevance, and validity of the study findings and recommendations.

8.1.5 *Incorporating an ethical perspective as an innovative component in health services research*

In addition to the standard methods used to conduct HSR studies, an ethical examination of the tensions that may exist between the actors involved has enabled the research to be grounded in the reality of many paediatric palliative care situations. The method used is innovative as it lies at the intersection of a scientific and a philosophical approach. The inclusion of an ethicist in the research team provided a different and important perspective, given the subject matter.

8.2 Limitations

This KCE study adopted a mixed-methods strategy, enabling the strengths of complementary methodological approaches to be combined, while acknowledging the inherent limitations associated with each method.

8.2.1 *Literature searches*

Targeted searches were chosen over a systematic review methodology for pragmatic and contextual reasons since access to care depends on the local care offer which varies from one place to another. Furthermore, the range of subthemes was very broad, from advance care planning and spiritual care to public awareness campaigns. Given this breadth, conducting systematic searches in so many areas was not feasible.

For the inventory of identification tools, we identified three reviews published in 2023, which were subsequently updated in a scoping review. In addition, several of the tools presented were identified in the grey literature and from interviews with national PPC experts. We also did not perform a formal assessment of the quality of the tools that were identified: the heterogeneity of their structure and scope of use prevent any comparison. Our aim was not to provide an exhaustive systematic review of validated tools, but to map the tools and criteria for eligibility to PPC that are available internationally (in key countries considered as providers of high level of PPC) that can be useful for the stakeholders in making decision regarding the improvement of access to PPC in Belgium.

Information gathered from grey literature is fragmented and scattered across many different websites and webpages. Systematic searching is challenging due to inconsistent search functionalities and the absence of comprehensive databases that collate and index relevant information. This increases the risk of selection bias. Important information can remain hidden if the right term is not used or the correct link is not followed. The quality, accuracy, and completeness of the retrieved information cannot always be guaranteed because grey literature is generally not subject to peer review. The dynamic nature of online content, which may be modified, relocated, or removed over time, also limits the reproducibility of searches.

To mitigate these risks, we combined information from the literature with information from experts and stakeholders.

8.2.2 *Methodological reflexions on stakeholder consultations and surveys*

The analyses of the **stakeholder consultations and surveys** were primarily qualitative rather than quantitative. Variations in response rates across questions and the frequent use of open-ended responses limited the feasibility and relevance of statistical analyses. As several barriers related to access to PPC emerged from free-text comments rather than direct survey questions, their identification relied on qualitative interpretation during the analysis phase. Consequently, the findings

should be viewed as exploratory and are not intended to be statistically representative of the broader population. Similarly, stakeholder consultations generated rich qualitative insights, with participants often providing nuanced comments instead of using predefined response options. While this approach yielded valuable contextual information and a deeper understanding of stakeholders' perspectives, it limited the opportunity for quantitative comparisons across participants.

A limitation of this study is that primary data were not collected directly from **young patients, parents, or families**. This decision was taken based on practical and ethical challenges, including the sensitive nature of paediatric palliative care, the lack of established recruitment channels for engaging with families in such situations, precluded their participation. To nevertheless incorporate their perspectives, the study relied on evidence from the literature and sought input from patient representatives where possible (with only two out of forty contacted patients' associations participated). While this approach provided valuable indirect insights into the experiences and needs of patients and families, it did not allow for the direct collection of their views within the Belgian context.

Some **overlap** occurred between stakeholders, professionals with limited PPC experience, and PPC experts. In particular, certain organisations designated PPC experts to represent their views during stakeholder consultations, which may have biased assessments of feasibility and acceptability. In addition, although measures were taken to prevent PPC experts from participating in the anonymous online survey, some uncertainty remains regarding their participation. To mitigate the potential impact of these overlaps, findings from the consultations were put in perspective with evidence from the literature.

8.2.3 Transferability of findings from initiatives from abroad to the Belgian context

The international comparison was based on a review of literature from different sources and interviews with national experts from abroad. As a result, some initiatives may not have been identified, particularly those that are recent, locally implemented, poorly documented or located in a country not retained by the selection criteria (see Chapter 2 – section 2.1.6.). The findings also reflect the perspectives of individual experts and may not capture the full diversity of practices within each country. Moreover, the information collected on national initiatives remains largely descriptive and based on available documentation and expert input, without direct verification of their implementation in practice. As a result, the findings should be interpreted as a theoretical overview rather than an assessment of real-world application. Finally, the content related to each country was not reviewed or validated by the respective national experts after drafting. Consequently, potential inaccuracies or misinterpretations may remain, and the responsibility for the synthesis and interpretation of the information lies with the authors of this report.

8.2.4 Data availability in Belgian administrative databases

The hospital database used to estimate the number of young patients in a paediatric palliative care situation included some records without a Belgian identification number. These mainly concerned foreign patients or newborns registered under their mother's identity and were therefore excluded from the analysis. As most of these cases related to routine birth-related admissions or minor health issues (often taken care in day hospital), their exclusion is unlikely to have affected the estimation of the target population. In addition, an apparent increase in the number of identified patients in 2016 reflects a database artefact linked to the start of the available observation period rather than a true increase in prevalence. As the database analysis was intended to provide an approximate estimate of the population size, these limitations are not expected to affect the study conclusions.

8.2.5 Challenges related to the development of an ethics-based typology

This component of the study employed a multi-layered approach combining literature mapping, AI-assisted and researcher-led interpretative coding, expert consultation, and a secondary review of paediatric ethics literature. While this enhanced the conceptual robustness of the analysis, some limitations should be considered. The literature search was targeted rather than systematic, limiting

reproducibility and potentially introducing selection bias, although the risk for this kind of bias was minimized by the use of a second-cycle screening of the literature.

The identification and categorisation of ethical determinants and conflict patterns relied on interpretative judgement, without formal inter-rater reliability assessment. Model hyperparameters were not systematically documented or openly accessible in ChatGPT. As probabilistic systems may generate slight analytical variations, the stability of the coding process relied primarily on iterative prompt-guided structuring, researcher supervision, and progressive refinement rather than formal statistical concordance or strict reproducibility. The resulting typology of conflict patterns reflects analytical consolidation rather than statistical validation, and alternative classifications may be possible.

In addition, stakeholder consultations involved a limited number of participants and should be viewed as providing contextual insights rather than formal validation. Finally, the chosen ethical framework shaped the interpretation of findings and may have underrepresented alternative theoretical perspectives (e.g., sociological, political). Consequently, the typology should be understood as an interpretatively developed model of ethical mechanisms affecting access to paediatric palliative care rather than a statistically generalisable taxonomy.

9 CONCLUSION - HOW TO IMPROVE ACCESS TO PPC IN BELGIUM?

Our findings suggest that several steps could be taken to improve the access to paediatric palliative care in Belgium.

In a first step, the identification of young patients in a paediatric palliative situation could be improved.

The target population includes foetuses, children and young adults, who are referred to as 'young patients'. However, young patients are not the sole target group of PPC. The nuclear family, relatives, extended networks and professionals with no or limited experience in PPC should also benefit from the PPC offer.

The WHO definition (2020) of palliative care is considered appropriate by Belgian clinical experts. They particularly highlight the key role of a life-limiting or a life-threatening condition when identifying a paediatric palliative situation.

Professionals caring for young patients with serious health problems should always determine if their patient's health problem is a life-limiting or a life-threatening condition and check for a possible paediatric palliative situation. When no definitive diagnosis is set, other indicators may support the identification of a paediatric palliative situation, such as the absence of curative treatment options or the recognition that symptom burden can be alleviated through palliative intervention.

Professionals could be helped by one of the many existing identification and referral tools. A wide range of identification scales and referral frameworks developed worldwide were identified. However, no consensus exists regarding the instrument of choice. However, beyond their identification role, instruments also allow to support clinical decision-making and timely recognition of needs to be addressed by PPC services. The identification of a paediatric palliative situation in a young patient is a longitudinal process, by means of a comprehensive, individualised, continuous assessment of needs, including the complexity aspect of those needs. Indeed, discussions with the patient and the family seem more used in practice by health care professional to identify a paediatric palliative situation than tools.

Based on an analysis of Belgian data, approximately 20 000 young patients are at risk of being in a paediatric palliative situation annually. This latter estimate is consistent with estimates reported in other countries.

Secondly, the societal perception of paediatric palliative care may require modification

A significant challenge in improving access to PPC in Belgium concerns perceptions and attitudes toward paediatric palliative care. The findings highlighted the importance of coordination and support for awareness-raising, advocacy, education, and research initiatives in supporting a shift in these perceptions and attitudes. Increasing the visibility of paediatric liaison teams, engaging patient and family organisations, and strengthening healthcare professionals' communication skills when discussing palliative care with young patients and their families were identified as important enabling factors.

The findings also highlighted the potential contribution of a tiered approach to education, and structured coordinated care pathways, supported by clear referral mechanisms, communication tools and collaboration among the professionals involved in care. Different models for organising PPC research were also identified, including coordinated research agendas, dedicated research structures and data collection, which can support planning, quality improvement and policy development. Patient and family organisations may further contribute, particularly through awareness-raising and advocacy.

The analysis of practices implemented in other countries provided a range of examples that may inform the cultural and organisational development of PPC in Belgium. Among these, expertise centres represent one model in which knowledge, training, awareness-raising, advocacy and support are centralised and more visible.

Thirdly, the healthcare system needs to adapt to the complexity of paediatric palliative situations

The acceptability of paediatric palliative care depends on a dynamic interplay between the young patient, the family, healthcare professionals, healthcare organisations, and society. Acceptability is shaped by cumulative and evolving interactions involving communication, trust, uncertainty, developmental processes, family dynamics, cultural values, practical circumstances, and organisational conditions.

The findings highlighted the importance of involving young patients in decisions affecting their lives, taking into account their age, maturity, and illness experience, as well as their need to maintain normality in areas such as school, friendships, leisure activities, and family life. At the same time, families face significant emotional, psychological, practical, financial, and physical burdens. Decision-making was identified as particularly stressful when choices involve life-sustaining treatments or end-of-life care. The findings also highlighted the importance of a flexible family-centred approach that considers cultural and social diversity and recognises the inherent complexity of caring for seriously ill young patients.

Trusting relationships between young patients, families and healthcare professionals were identified as important facilitators of PPC acceptability. Honest, respectful, consistent, and age-appropriate communication was highlighted as central to the development of trust, while fragmented communication and inconsistent messages may undermine trust and delay PPC integration.

The time required to develop trust highlighted the potential value of introducing palliative care early in the disease trajectory and involving paediatric liaison teams as early as possible, following the diagnosis of a LLC/LTC. The findings also highlighted the importance of recognising and valuing the time spent by professionals and of limiting staff turnover in supporting the development of trusting relationships with young patients and families.

The potential contribution of multidisciplinary support from ethicists, spiritual care providers, psychologists, social workers, and, when necessary, legal experts was identified in addressing relational and ethical challenges that may emerge during periods of instability. A wide range of identification scales and referral frameworks developed worldwide were identified; however, no consensus exists regarding the instrument of choice.

The findings highlighted the importance of individualised care that prioritises the young patient's preferences, values and needs, with regular re-assessment when these evolve. Care should also take account of the young patient's developmental needs and the family's socio-cultural background. The central role of the parents as experts in their child's care, together with the value of a supportive environment around the family unit, was also highlighted.

Fourthly, the provision of paediatric palliative care in Belgium may require adaptations

The challenge lies in ensuring that PPC is delivered at the right time and in the right place. In Belgium, PLTs currently provide high quality level of specialised PPC. Liaison teams were found to have strong coordination and communication skills, 24/7 availability, and a strong commitment to respecting the values and preferences of young patients and their families.

Additional services are available, including respite care facilities and organisations offering psychosocial, well-being, recreational and bereavement support to young patients with serious illnesses. Nevertheless, important gaps remain in both community-based and hospital-based paediatric palliative care provision.

In the home setting, the current financing system for home nursing care was identified as being insufficiently adapted to the specific requirements of PPC, notably the time to build trusting relationships. The findings highlighted the need for a sustainable approach to paediatric home care, particularly in terms of access to adequately trained professionals and appropriate resources. The availability of dedicated paediatric home nurses and first-line psychologists, supported by appropriate funding mechanisms, was identified as a potential component of such an approach. The current reimbursement framework may also not adequately reflect the complexity and intensity of paediatric home care. The responsibilities endorsed by GPs when caring for a young patient in a palliative situation at home may occasionally require support from paediatricians in the home setting. Although PLTs ensure national geographical coverage, this often involves considerable travel distances, which can be burdensome for both families and professionals. The potential value of designated referent (paediatric palliative care) tandems within hospitals without PLTs was identified as a means of facilitating local support, reducing travel time and improving continuity of care.

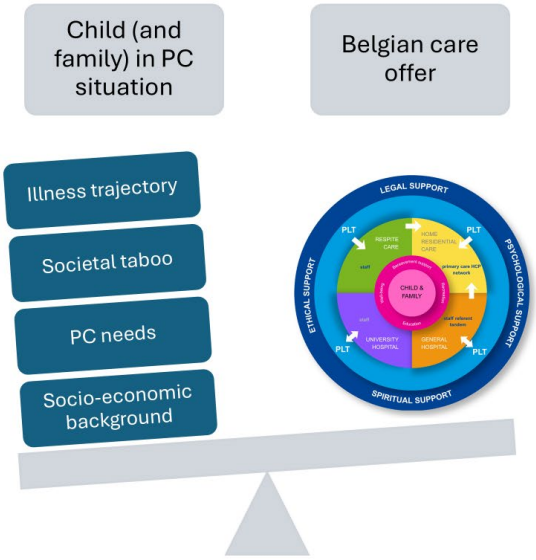
While the current care system generally responds well to the physical and psychological needs of the young patient, the needs of parents and siblings remain insufficiently addressed. The importance of developing respite care, psychological support, social assistance, spiritual care, and bereavement services in a more structured, specialised and sustainable manner was highlighted, together with the need for adequate support for the organisations that provide these essential services.

Finally, the analysis indicated that the consistent application of palliative care definitions and referral criteria would result in a substantially greater number of young patients and families becoming eligible for PPC services. This would have implications for the workload of PLTs, which already face limitations in staffing and financial resources, as reflected in their dependence on charities support. The need for the authorities to provide additional human, material, and financial resources to ensure equitable and high-quality care for all young patients with palliative care needs was highlighted.

The findings also identified alternative approaches to PLTs financing, including models that take account of activity levels, such as the number of young patients supported and the intensity of PPC provided, in addition to existing lumpsum financing. The standardisation of the documentation and coding of PPC activities in the Netherlands was identified as an example that may provide useful insights into the development of activity-based coding for funding and reporting purposes in the Belgian context.

The Figure 24 summarises the major finding about the offer and its alignment with the needs.

Figure 24 – The balance between the PPC offer and the PPC needs



Finally, the care that is delivered by all involved actors may require coordination

The appropriateness of PPC services encompasses the timeliness, coordination and quality, as well as the commitment of the authorities. Although the quality of PPC provided in Belgium is generally high, the finding identified scope for improvement in organisational aspects. One major limitation is the absence of a national shared electronic patient record, which hinders effective information exchange and continuity of care across settings and providers. The ongoing Belgian Integrated Health Record (BIHR) project was identified as having the potential to enhance coordination and improve care for young patients and families facing paediatric palliative situations.

The coordination of PPC, and in particular the comprehensive assessment of needs, the development of a family-centred care plan and its regular updating, is currently ensured by PLTs, which already organise multidisciplinary meetings in the home setting. The findings highlighted the importance of adequate financial and logistical support to facilitate participation in these meetings and support meaningful outcomes. The involvement of professionals from different levels of care, together with young patients, where developmentally appropriate, and parents, was identified as an important element in strengthening collaboration. In the hospital setting, joint consultations involving the treating physician and a member of the PLT were identified as a potential approach to supporting the early integration of PPC.

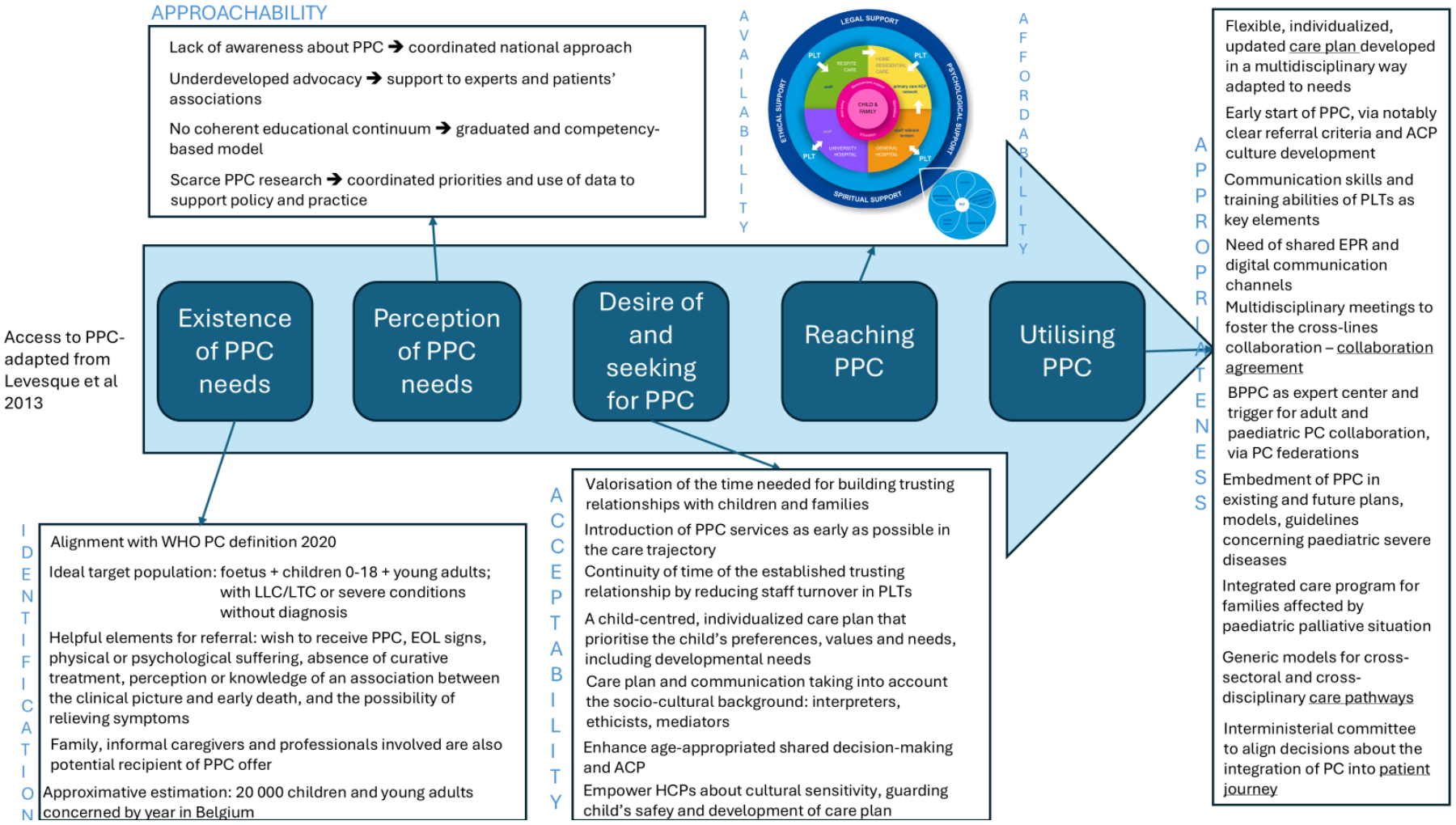
A gap was also identified between multidisciplinary teams delivering PPC and those delivering palliative care to adults. Palliative care federations were identified as potential partners for strengthening connections between these groups, for example, through joint training initiatives.

A broader challenge identified by the analysis concerns the systematic integration of PPC into existing and future care models, plans, and guidelines for young patients with serious and complex illnesses. Such integration may support better alignment between curative and palliative approaches, in line with international recommendations advocating for early and concurrent palliative care. The analysis also highlighted the persistent societal and professional taboo surrounding the death of young patients as a factor influencing this integration.

The potential value of generic, cross-sectoral and multidisciplinary care pathways in providing a framework for more coordinated and family-centred care was highlighted. Examples from abroad provided different models and experiences that may inform the development of such pathways in Belgium. The analysis also highlighted the importance of coordination across relevant policy areas to support the integration of palliative care throughout the care pathway of young patients with serious conditions. Such a committee would bring together decision-makers from all relevant sectors, including health, social services, education and youth care, to address the fragmentation that characterises the Belgian system and support coherent, equitable and integrated care for young patients and their families.

The Figure 25 summarises the main findings of this report.

Figure 25 – Summary of the main findings



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