

Organisational  
model of comprehensive  
care for children  
and young people  
with palliative and  
end of life needs

Comprehensive  
Paediatric Palliative  
Care Network

# Organisational model of comprehensive care for children and young people with palliative and end of life needs

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Care Network

Barcelona, 2020

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Jordi Amblàs Novellas

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Víctor Oliva

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Note: Throughout this document, the terms ***child and young people*** are used to refer to newborns, nursing babies, children and teenagers up to the age of 18 of both sexes.

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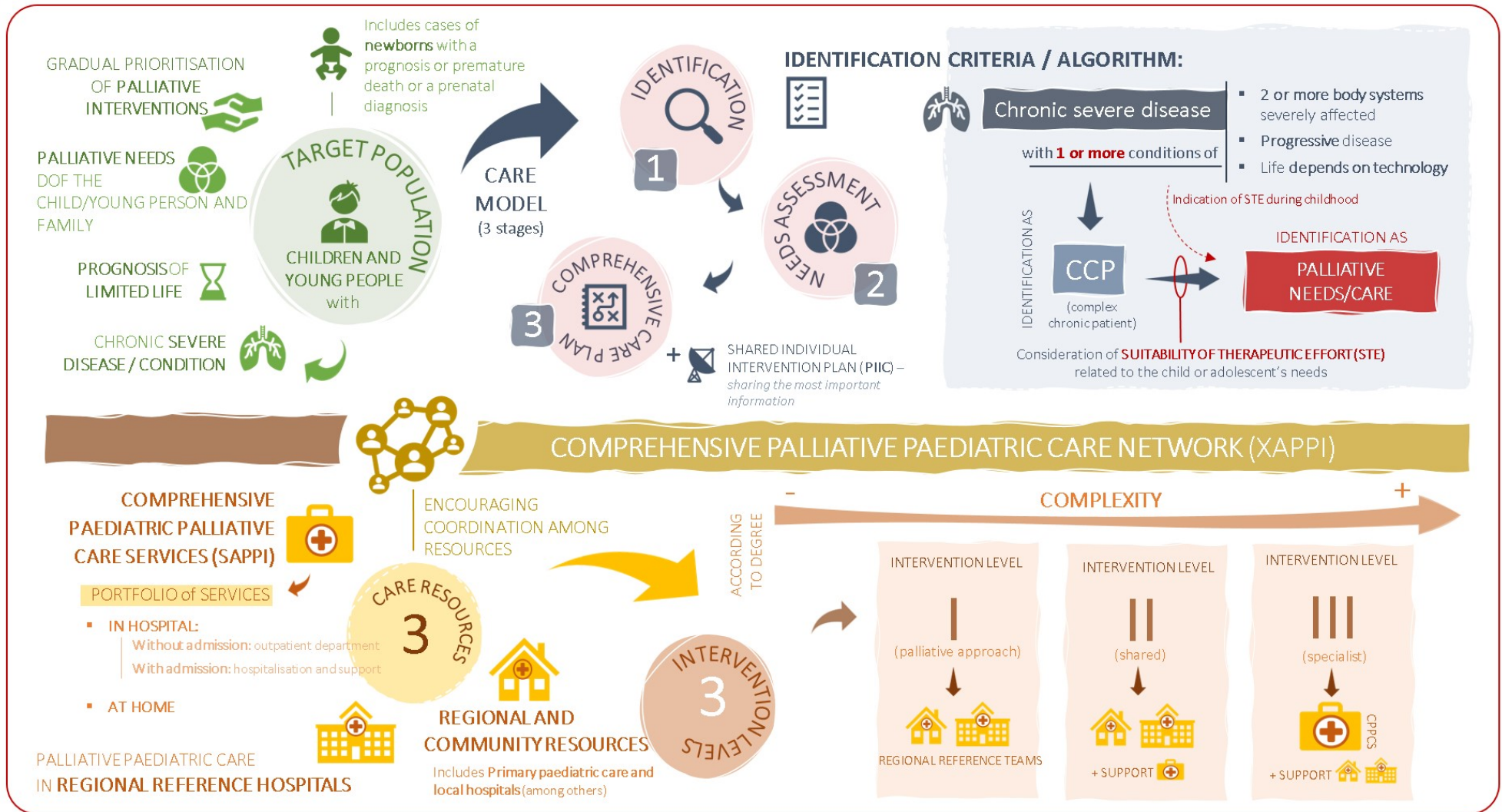
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# Visual summary

## CHILDREN AND YOUNG PEOPLE WITH PALLIATIVE NEEDS AND AT END OF LIFE

ORGANISATIONAL MODEL OF COMPREHENSIVE CARE FOR



# Prologue

After drafting the foundation for the organisational model of comprehensive care for children and young people with palliative needs, in late 2018, [Bases per al desenvolupament del model organitzatiu d'atenció integral a la població infantil i juvenil amb necessitats pal·liatives i en situació de final de la vida](#) (['Bases for the development of the organisational model of comprehensive care for children and young people with palliative and end of life needs'](#)), we have deemed it necessary to move forward with implementing it.

Paediatric palliative care requires collaborative work among the professionals in different caregiving fields, where it is essential to develop a comprehensive paediatric palliative care network (henceforth abbreviated XAPPI for its name in Catalan), which defines the conditions, characteristics and coordination circuits of each of the centres and services involved in caring for these children and young people.

Stemming from the organisational development of paediatric palliative care in the Catalan healthcare system and the concentration of knowledge in this field in certain hospitals in Catalonia, the priority was placed on starting to implement the network via three comprehensive paediatric palliative care services (henceforth SAPPis), with an initially tertiary focal point. Therefore, the purpose of this document is to start the organisational implementation of paediatric palliative care by outlining the minimum common requirements of these three services.

As actions are taken to train the regions on paediatric palliative care matters, the care will gradually be shifted in a complementary manner to the healthcare centres and services in the different health regions; the SAPPis will take only children and young people with a higher degree of complexity of care, and in this next phase the XAPPis will enter into full operation.

Therefore, this document focuses on the first of the different phases to come, in which the organisational model of paediatric palliative care in Catalonia will be established.



# Acronyms

STE	suitability of therapeutic effort
C2P2	paediatric palliative and complexity care
PCC	primary care centre
CIDIAP	child development and early care centres
MBDS	minimum basic data set
MBD	minimum basic data
CUAP	emergency primary care centre
HCCC	shared clinical record of Catalonia
LTE	limitation of therapeutic effort
ACD	advanced chronic disease
PCC	complex chronic patient
CP	cerebral palsy
PIIC	shared individual intervention plan
SAPPI	comprehensive paediatric palliative care services
SEM	emergency medical system
SISCAT	comprehensive public healthcare system of Catalonia
EOL	end of life
UEC	clinical expertise unit
UEH	hospital speciality unit
XAPPI	comprehensive palliative paediatric care network

# 1. Introduction

In recent decades, there has been a decrease in child mortality in our setting.<sup>1</sup> Furthermore, because of an increase in the survival rates of children and young people with severe diseases, there has been a parallel increase in the prevalence of children and young people, giving rise to a situation of vulnerability associated with their morbidity, oftentimes chronic comorbidity, which leads to more complex care.

The goal of paediatric palliative care is to optimise the quality of life of children, from the prenatal stage to adolescence, with severe – often incurable –, life-limiting or life-threatening conditions. It offers the patient and their family comprehensive care in different dimensions: physical, psychological, emotional, social, and spiritual.

Estimates of the prevalence of the population with paediatric palliative needs vary considerably depending on the methodology used and the population and regions analysed. On the one hand, figures from the European Association for Palliative Care (EAPC) estimate that at least 10 out of every 10,000 children and young people (ages birth to 19) have life-limiting or life-threatening diseases.<sup>2</sup> Studies published recently mention a prevalence of 20 out of every 10,000 children in countries like the United Kingdom.<sup>3</sup> According to the data on the population aged birth to 19 in Catalonia, making a minimal approximation it is estimated that there are 1,535 children with this condition. On the other hand, according to the mortality figures for Catalonia<sup>1</sup> in the past five years, there is an average of 400 deaths per year in the population aged birth to 19, approximately 65% of which had causes that made death predictable and were considered eligible for receiving palliative care (a percentage that ranges between 94% in the perinatal period to 54% in children over one year of age).<sup>4</sup>

Children and young people with life-limiting or life-threatening diseases require a comprehensive, integrated and interdisciplinary approach, with an expert team with the appropriate training, where the coordination and collaboration between specialist units and local paediatrics guarantee high-quality, early care.

- 
1. Death register of Catalonia, Information Management and Analysis Services for Strategic Planning, Directorate General for Health Planning, Ministry of Health. Government of Catalonia.
  2. EAPC Taskforce on Palliative Care in Children. Palliative care for nursing babies, children and young people: the facts. Rome: Fondazione Maruzza Lefebvre d'Ovidio Onlus; 2009.
  3. Connor SR, Downing J, Marston J. Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis. *J Pain Symptom Manage*. 2017 Feb;53(2):171-177. DOI:10.1016/j.jpainsymman.
  4. Navarro S, Ortiz J, Caritg J. Bosch. Estimació dels casos de mort tributàries de cures pal·liatives pediàtriques. *Pediatr Catalana*. 2015;75(1):12-8.

Action line 6.4 in the 2016-2020 Health Plan of Catalonia states the need to define and implement the organisational model of comprehensive care for children with palliative needs and at end of life. In February 2018, the Ministry of Health published the document [Bases per al desenvolupament del model organitzatiu d'atenció integral a la població infantil i juvenil amb necessitats pal·liatives i en situació de final de la vida](#) ('Bases for the development of the organisational model of comprehensive care for children and young people with palliative and end of life needs'). This document offered recommendations for the public healthcare system to organise and develop paediatric palliative care in accordance with the principles of equitable access and results, quality and efficiency, bearing in mind the resources available.

It has been determined that the organisation of care for children and young people with palliative and end of life needs should be based on a coordinated network of services and care in line with the degree of complexity required, which contributes to offering top-quality care and ensuring good results, the appropriate and equitable use of resources, and the sustainability of the public healthcare system. At the same time, it should facilitate innovation and improvements in knowledge transfer. Consequently, in order to improve the quality, clinical results and efficiency of the provision of paediatric palliative care, it is considered initially essential to concentrate this care in a limited number of reference hospitals with expert palliative care units with which professionals from hospitals, primary care centres and other services caring for children and young people can interact.

The purpose of this document is to frame the organisational model of palliative care in the paediatric population, the portfolio of services needed in the SAPPIS in Catalonia, and the functions and requirements of these palliative care services in order to implement the established model to meet the needs of children and young people and their families.

# 2. Conceptual framework and definitions

## 2.1 Definition of paediatric palliative care

According to the World Health Organisation (WHO), paediatric palliative care consists in the total active care of the body, mind and spirit of children or young people, and in providing support to their families. It begins when the disease is diagnosed and continues regardless of whether or not they receive treatment to combat it.

Likewise, the [2<sup>nd</sup> National Strategic Plan on Children and Young People \(abbreviated II PENIA\)](#) states that children and young people with advanced or terminal diseases require comprehensive care which is adapted to their situation at all times.

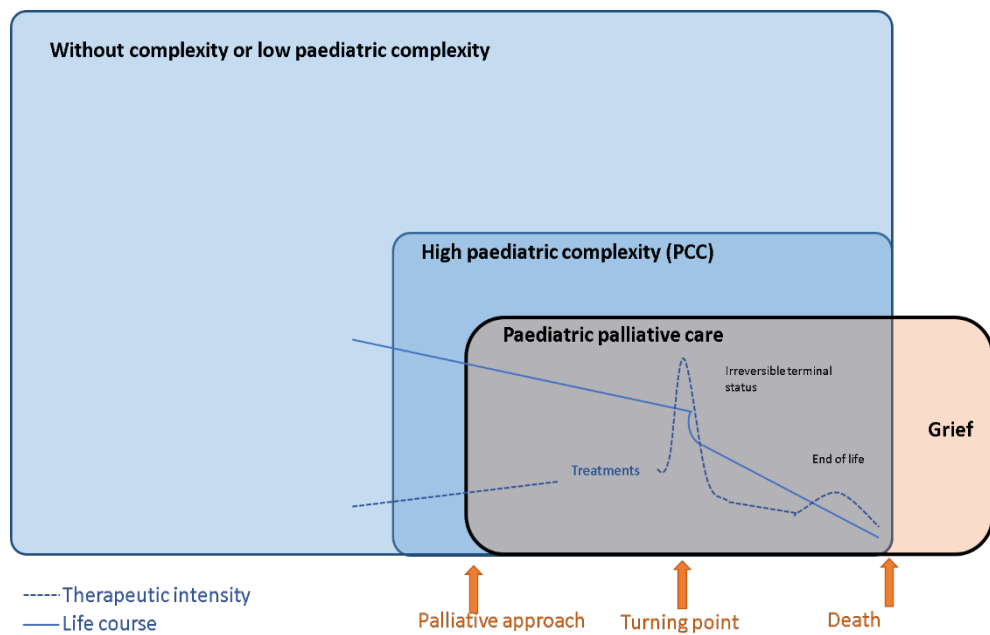
The Association for Children's Palliative Care of the United Kingdom (ACT) defines palliative care for children and young people with limiting or life-threatening conditions (with the risk of dying) as an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements, and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management, monitoring and treatment of (often) distressing symptoms, provision of short breaks and care through death and bereavement.

According to the WHO'S position, the concept of *palliative care* encompasses an early, broad perspective. Consequently, it includes not only the paediatric population with a terminal disease (past the turning point)\*<sup>5</sup> and at end of life (EOL) but also children and young people with life-limiting or life-threatening condition, whose hopes of living may be relatively longer yet uncertain. This usually corresponds to cases in which a palliative approach has been taken or measures targeted at adapting the therapeutic effort have been determined (Figure 1).

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5. Martino R. El proceso de morir en el niño y el adolescente. *Pediatría Integral*. 2007; 11:926-34.

**Figure 1.** Representation of complexity and palliative care in paediatrics.



Source: Authors

\* *past the turning point* refers to the period of time when a change has been identified in the clinical course of the disease, with an acceleration in clinical decline, a decrease in symptom-free intervals, an increase in hospital admissions, a lack of response to an escalation in treatments or repeated relapses to the baseline process.

Paediatric palliative care is associated with paediatric complexity; this is why the abbreviation P2C2 (paediatric palliative and complexity care) is mentioned. Some of the features which make paediatric palliative care more complex are the low prevalence of cases, the wide variety of underlying diseases, the limited availability of specific medication, the lack of specific training among professionals, the repercussions on family dynamics and the emotional and social impact, among others.

## 2.2 Model of palliative care

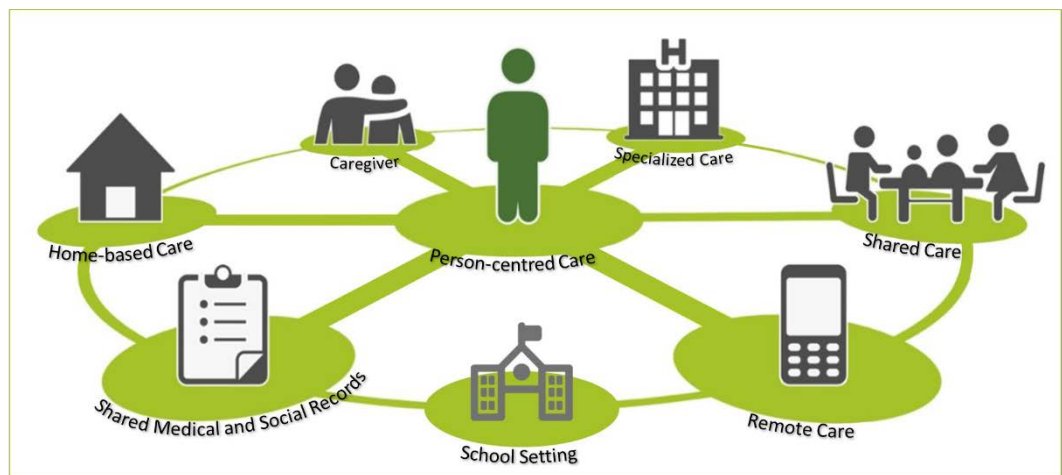
The care model of children and young people with complex needs includes care for the complex paediatric population (in the Catalan model of complex chronicity, the acronym PCC is used to refer to complex chronic patients)<sup>6</sup> and the paediatric population with a palliative approach or palliative needs (ACD or MACA in the Catalan model of complex chronicity).<sup>5</sup>

6. Blay C, Limón E (coord.). Bases per a un model català d'atenció a les persones amb necessitats complexes. Conceptualització and Introduction als elements operatius. Versió 6.0 from 27 March 2017. [cited 15 July 2019]. Available from: [https://scientiasalut.gencat.cat/bitstream/handle/11351/3305/bases\\_model\\_catala\\_atencio\\_persones\\_necessitats\\_complexes\\_2017\\_ca.pdf?sequence=4&isAllowed=y](https://scientiasalut.gencat.cat/bitstream/handle/11351/3305/bases_model_catala_atencio_persones_necessitats_complexes_2017_ca.pdf?sequence=4&isAllowed=y)

The organisational model of paediatric palliative care should be interdisciplinary, integrated and collaborative among the different caregiving services and levels (it should also consider other devices in the educational, social, third sector and other spheres) which come into play throughout the caregiving process. The model is grounded upon three cornerstones:

- Identifying children and young people with palliative needs.
- Evaluating the child’s or adolescent’s needs and those of the people in their caregiving environment.
- Making a comprehensive care plan, which includes support and assistance for the children and young people and their families throughout the entire caregiving process (and grief care as well), in which the most appropriate level and sphere of care are determined according to the complexity of the needs (Figure 2).

**Figure 2.** Comprehensive care model



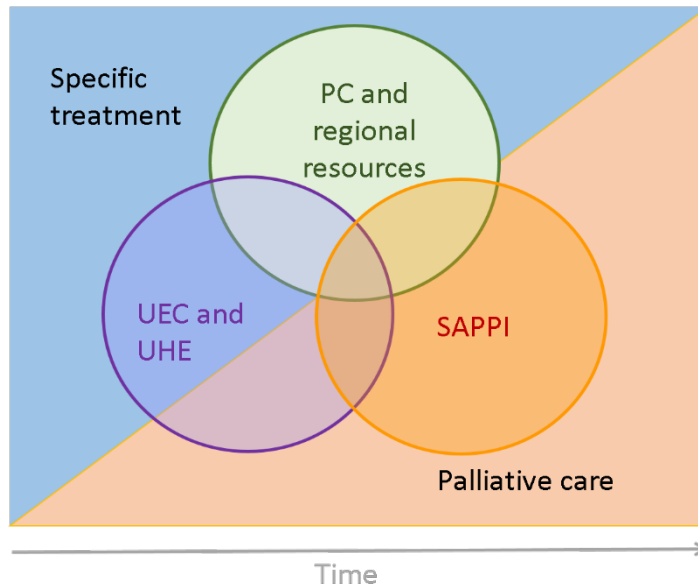
Source: adapted from TERMCAT.

Given the low prevalence of children and young people with palliative needs, a particular concentration of resources and knowledge is needed in certain specific units, which can lead and organise the networked efforts. This model aims to provide the maximum value and to optimise the resources available and the appropriateness of care by establishing caregiving levels and circuits that guarantee the quality and efficiency, continuity of care and assistance of the ill child and their family through the different episodes of the disease.

Given that a high percentage of children and young people who require palliative care have a rare disease, it is essential to ensure the continuity of care needed among the reference units (UEC or clinical expertise units, and UEH or hospital speciality units), the paediatric primary care and the paediatric palliative care services (Figure 3). The paediatric primary caregiving teams and the teams at the healthcare centres around the region play a constant role

throughout the entire caregiving process as local resources and services. In the population group that does not have a UEC for the baseline disease or situation, such as children or young people with cerebral palsy (CP), a reference professional (primary care paediatrician or a paediatrician from a hospital unit, depending on the main health problem) should coordinate with the SAPPI.

**Figure 3.** Continuity among caregiving areas and units



Source: Authors.

UEC: clinical expertise units; UEH: hospital speciality units; SAPPI: comprehensive paediatric palliative care services; PC: primary care.

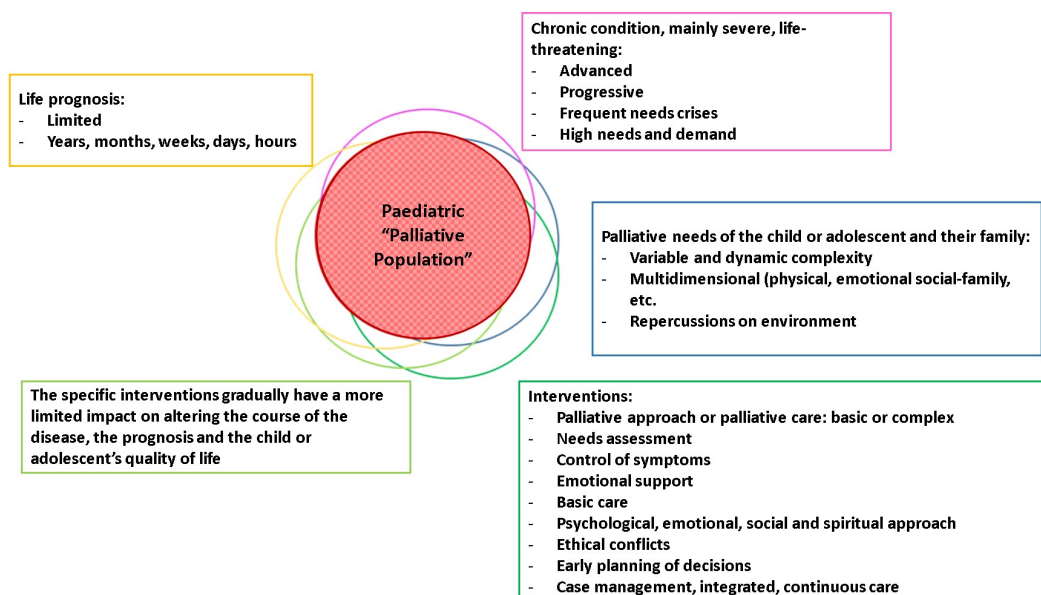
# 3. Target population of palliative paediatric care

Paediatric palliative care is targeted at children and young people (in some cases prenatal babies and teenagers – up to age 20 – are included) with different diseases, often rare diseases, which entail different life course in terms of the type, intensity and length of their care – from just a few hours or days to several years. It also encompasses babies who have a prognosis of premature death stemming from a prenatal diagnosis.

They are often cases in which there is a suitability of therapeutic effort (STE) approach in both diagnostic and therapeutic measures. The needs of this paediatric population are manifold and complex, primarily determined by age, the course of the disease and the social-family and cultural milieu.

Consequently, this paediatric population is considered to need a comprehensive model of palliative care with professionals who have capacity and expertise on this matter (Figure 4).

**Figure 4.** Factors that define the target population



Source: Translated and adapted from Building Integrated Palliative Care Programs and Services.<sup>7</sup>

7. Gómez-Batiste X, Connor S. Building integrated palliative care programs and services. Chair of Palliative Care. WHO Collaborating Centre Public Health Palliative Care Programmes. Worldwide Hospice Palliative Care Alliance. "la Caixa" Banking Foundation. Barcelona; 2017. ISBN: 978-84-9766-602-2.



Four groups who require palliative care are defined within the paediatric population according to the course of the disease:<sup>8</sup>

Group 1: Children or young people with life-threatening conditions for whom curative treatment may be feasible but can fail (such as: cancer, infections or organ failure of the heart, liver or kidney).

Group 2: Children or young people with conditions requiring long periods of intensive treatment aimed at prolonging life, but where premature death is still possible (such as: cystic fibrosis, HIV/AIDS, cardiovascular anomalies, Duchenne muscular dystrophy).

Group 3: Children or young people with progressive conditions without curative treatment options, with palliative treatment starting from the diagnosis (such as: neuromuscular or neurodegenerative disorders, progressive metabolic disorders, chromosomal anomalies, advanced metastatic cancer at the time of diagnosis).

Group 4: Children or young people with irreversible but non-progressive conditions causing severe disability, leading to extreme susceptibility to health complications (such as: severe CP, genetic disorders, congenital defects, newborns with extremely low birth weights, brain or spinal cord injuries).

Parallel to these four groups, it should be borne in mind that newborns, children, preteenagers and teenagers have very different characteristics. Additionally, due to the specific characteristics and care they receive, newborns (and those in the perinatal stage) are considered to have distinct characteristics as a group eligible for palliative care. This primarily includes fetuses whom we know will be born with life-limiting problems or lifeless, such as: fetuses at the threshold of viability (less than 23 weeks of gestation or less than 500 grams at birth), newborns with congenital malformations (trisomy 13-15 or 18, anencephaly, inoperable heart anomalies, etc.) or newborns with severe perinatal brain damage who do not respond to intensive care interventions, among others.

### 3.1. Criteria for identifying the population with palliative needs

Children and young people with palliative needs should be identified by the caregiving team in the different areas:

- Primary care
- Hospital

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8. Association for Children's Palliative Care (ACT). A Guide to the Development of Children's Palliative Care Services. ACT. 3rd ed. Bristol; 2009.

On an exceptional basis, the families themselves or professionals from non-healthcare institutions may also identify and suggest the need to shift the therapeutic approach towards palliative care. Examples of these teams include:

- Child development and early care centres (CIDIAPs): If the staff at these facilities identify a child with palliative needs, they should refer to them to the appropriate healthcare system personnel so they can be registered in the information systems and the palliative care model can be applied.
- Special education centres: There are professionals at these centres with considerable expertise in children with palliative needs. They should proceed the same as the staff at CIDIAPs.

In these cases in which there is no caregiving team that detects the need to start a palliative approach, in order to ensure that the child or young person receives palliative care, they should notify the appropriate public healthcare teams (primary or hospital care) of the situation and the child or adolescent's needs.

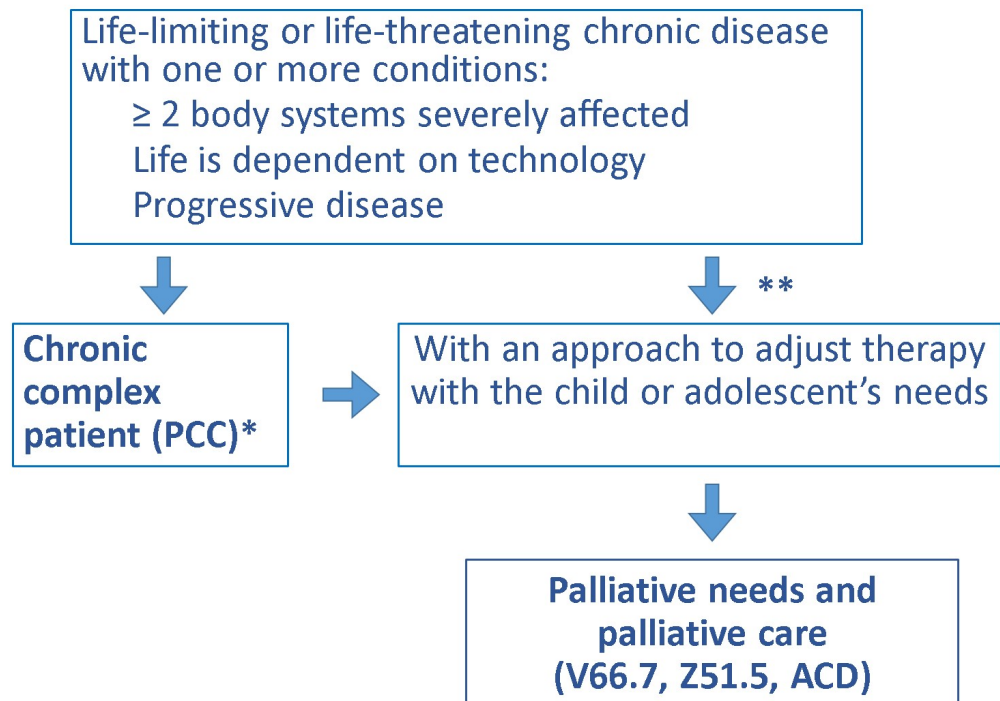
Bearing in mind that the majority of the paediatric population with palliative care needs is very small, the clinical expertise units are expected to play a prominent role in this identification process.

The population with palliative needs requires decisions to be made related to STE (both diagnostic and therapeutic measures), and should meet one or more of the following criteria (Figure 5):

1. Burden of disease (condition or major health problem) with significant, major or severe effects on at least two of the body systems:
  - Cardiac
  - Respiratory
  - Gastrointestinal
  - Renal
  - Haematological
  - Endocrine/metabolic
  - Neurological
2. Progressive, advanced disease associated with a deterioration in health. Examples: oncological disease and other rare diseases, degenerative neuromuscular diseases, complex heart diseases, etc.
3. Life or functional dependency on technology (the patient's life depends on the device).  
Examples: conventional mechanical ventilation, non-invasive ventilation for more than 12 hours, continuous drug infusion with an intrathecal pump, parenteral nutrition at home, tracheotomy, etc.

Despite their importance in comprehensive care, the needs in the psychosocial and spiritual spheres are not considered core criteria for identification, even though they should be evaluated as they affect the complexity of the situation.

**Figure 5.** Algorithm to identify children and young people with palliative needs



Source: Authors.

\* Documentation on paediatric complex chronicity has yet to be developed.

\*\* Situations in which the evolution and progression of the situation or the disease is quick and requires the start of palliative care (per example, anencephaly).

## 3.2. Epidemiological figures on paediatric palliative care

To estimate the paediatric palliative care needs and help ascertain the magnitude of this need in Catalonia, calculations can be made in two complementary ways:

- Based on the general population and applying the prevalence figures found in the literature.
- Based on the mortality of the paediatric population and choosing the causes of death eligible to receive palliative care.

### 3.2.1. Estimates of the prevalence of life-limiting conditions in the paediatric population

According to CatSalut's Central Registry of Insured Persons (RCA), Catalonia had 7,570,452 inhabitants in 2019; 1,384,711 (20.28%) are under the age of 18, 713,816 of whom are males and 670,895 females.

Bearing in mind the minimum prevalence figures<sup>2</sup> (10/10,000 children and young people, age birth to 19), there are estimated to be 1,535 children and young people in Catalonia with paediatric palliative care needs. It should be borne in mind that this is a slight overestimation of the prevalence, as the population under the age of 20 is included in this calculation given that there are no prevalence figures with the age ranges of paediatric care in Catalonia (until age 18).

Based on these figures, when we examine the regional distribution of estimated cases (Annex 1), we can see that there are Health Sectors with very few cases (1 or 2 cases) of children or young people with these characteristics (Aran and Alt Pirineu), while other zones may have more than 80 prevalent cases (Regional Management Areas of Vallès Occidental Oest, Baix Llobregat Centre and Font Santa-l'Hospitalet Nord, Barcelonès Nord and Baix Maresme). This distribution of cases should be considered when developing paediatric systems at the level of primary care<sup>9</sup>.

### **3.2.2. Estimates of palliative needs based on mortality**

According to the figures in the Death Registry from the past five years, there is an average of 301 deaths per year of the population under the age of 18 in Catalonia (174 boys and 130 girls), 70.5% of which are for causes eligible for paediatric palliative care (70.2% in boys and 71% in girls). Approximately 57.42% of annual deaths occur in the population under one year of age (approximately 175 cases per year; 43% girls and 57% boys), where the percentage of causes eligible for paediatric palliative care is 81.09%, specifically 90.3% in the first week of life. In children over one year old, this percentage drops to 56.17% (Annex 2).

In this period, there was an average of 261 cases of stillborn children (53.26% boys).

In 2017, the death rate in this age group was 0.2 per 1,000 inhabitants (0.18 per 1,000 girls and 0.22 per 1,000 boys) and ranged between 2.36 per 1,000 inhabitants in children under one year old and 0.06 per 1,000 inhabitants in children aged 10 to 14 years old. Applying these rates, and based on mortality, it is estimated that there will be 281 deaths in 2019, approximately 70% of which will be for causes eligible for care (Annex 3).<sup>10</sup>

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9. Agreement 13/2018, dated 29 November 2018, of the Administrative Council of the Catalan Health Institute, creating new regional paediatric primary care centres and amending point 1 in Agreement 11/2012, dated 28 June 2012, creating regional paediatric primary care centres. Official Gazette of the Government of Catalonia (DOGC) 7911, dated 5 July 2019.

10. Cuidados paliativos pediátricos en el Sistema Nacional de Salud: criterios de atención. Madrid: Ministerio de Sanidad, Servicios Sociales e Igualdad; 2014.

### 3.2.3. Analysis of paediatric palliative care activity in SISCAT hospitals

Based on the current information systems, it is complex to analyse the paediatric palliative care both of children and young people identified who have received this care, and of those who could benefit from receiving it but whose palliative needs have not been adequately identified.

In 2017, there were 62 children and young people in Catalonia identified with the MACA codes in the primary care information systems based on the complex chronicity policies promoted in recent years, even though they have not been implemented in the field of paediatric care.

The most approximate information on palliative care in the healthcare system stems from the analysis conducted in the period 2017-2018, when four hospitals (Table 1) were asked to provide data on the patients who required paediatric palliative care and complex chronicity (P2C2). Some noteworthy figures are:

- In this period, 461 children and young people with Catalan public health coverage were served, 108 of whom died during the period analysed.
- The percentage of deaths among the hospitals studied ranged between 18% and 34.2%, which suggest that they care for children and young people in different developmental stages of the disease.
- Almost three-fourths of the population served in these hospitals was from the Barcelona Health Region.
- 98.3% of the children and young people suffered from a rare disease.
- 91.6% of the children and young people served and 96.4% of those who ultimately died suffer or suffered from a disease which is classified within the following major groups of diseases:
  - Certain disorders originating in the perinatal period.
  - Diseases of the nervous system.
  - Endocrine, nutritional and metabolic diseases.
  - Congenital defects and congenital deformities and anomalies (28% of the cases seen by the P2C2 units).
  - Neoplasia (they account for 22.3% of the cases seen by the P2C2 units).

- During the period studied, 91.7% (423 children and young people) visited primary care 20,770 times for a wide variety of reasons (average of 28-29 visits). Almost two-thirds of the appointments were with doctors and one-third with nurses.
- With regard to hospital activity, 390 children and young people (84.6%) had 2,837 admissions (average of 3.6 admissions/year); 450 (97.6%) received outpatient care with 27,068 visits (average of 30 visits/year); 397 children and young people (86.1%) visited emergency services 3,015 times (average of 4 emergencies/year). Most of them received hospital care in the same hospital that offered them P2C2.
- Only seven cases received care from health and social resources (five cases in the Home Care and Support Teams Programme (PADES) and two cases in interdisciplinary social and health functional units (UFISS).
- 81.1% took medication (295 outpatient-dispensed hospital medication) with an average cost per patient per year of 8,393 euros.

In parallel, an ad-hoc cross-section in July 2019 found that in these four Catalan hospitals that offer P2C2, these units cared for 311 children and young people, two-thirds of whom are considered in need of palliative care, and the other one-third with complex care needs yet without a palliative approach (Table 1).

**Table 1.** Paediatric population served in hospitals which offer palliative care and complex chronicity care

	LTE	LTE approach	No LTE	Total
Hospital 1	6	16	7	<b>29</b>
Hospital 2	16	10	16	<b>42</b>
Hospital 3	3	10	37	<b>50</b>
Hospital 4	76	51	63	<b>190</b>
<b>Total</b>	<b>101</b>	<b>87</b>	<b>123</b>	<b>311</b>

Source: Authors.

LTE: limitation of therapeutic effort.

LTE approach: indication of LTE by the caregiving team, although this has not been agreed upon with the family.

The information collection and mining system in relation to paediatric palliative care must be further developed so it allows the activity performed in this field within the healthcare system as a whole to be analysed, beyond any specific studies which have been conducted.

## 4. Organisation for comprehensive paediatric palliative care (care network) according to complexity

Because a high degree of clinical expertise is needed to assess, treat and support a comprehensive care network by a multidisciplinary team specific for paediatric palliative care, it is essential to have such a network grounded on participation and formalised agreement among the centres and services involved.

In the initial phase, the XAPPI is based on identifying the centres with SAPPs (with a structure, operations and portfolio of services defined by the region and reference population). The NCPCC will gradually expand to local hospitals with specific reference palliative care professionals, with which associations will be reached via formal cooperation agreements that define the circuits patients have to follow and the shared responsibilities. The full implementation of the NCPCC also entails the essential involvement and participation of the professionals closest to the child or adolescent's males, primary paediatric care, hospitals that offer basic paediatric care and health and social care services offering palliative care.

The XAPPI has three levels of care:

- SAPPs. They offer the most expert, specific palliative care concentrated in a handful of healthcare centres. It is offered in in-patient centres, solely paediatric or not, which seek to solve all health problems and have what are called highly specialist and supra-specialist services and diagnostic technologies – advanced therapies, tertiary care and clinical expertise units in rare diseases.
- Paediatric palliative care in benchmark regional hospitals. This is provided in hospitals which seek to solve almost all health problems except for those that require a highly specialist practice (tertiary care and clinical expertise

units in rare diseases). They have one or more professionals who do not work full-time in palliative care but have some training in paediatric palliative care.

- Regional and community resources near the home of the child or young person with palliative needs. This includes primary paediatric care and other regional health resources and services, especially in local hospitals which meet the population's usual needs. Healthcare professionals offer basic palliative care in these centres and services. At this level of care, it is essential to also coordinate with local social, educational and third-sector services which offer the child or young person care.

## 4.1. Objectives of the XAPPI

The objectives sought by organising a comprehensive paediatric palliative care network are:

1. To identify patients with diseases that threaten or limit life who have palliative needs.
2. To guarantee comprehensive, integrated care with multidisciplinary teams that include psychosocial and spiritual care, in conjunction with health and social care, psychology and other professionals that meet these needs.
3. To organise and implement paediatric palliative care in the comprehensive public healthcare system in Catalonia (SISCAT) by territorialising the Catalan paediatric population and the different levels of paediatric palliative care centres and services to guarantee quality care and keep the Catalan healthcare system efficient and sustainable. The ultimate goal is to guarantee territorial equity and to avoid reduplications by establishing care protocols following the same criteria as the entire Catalan healthcare system.
4. To create a care network among the specific paediatric palliative care services and hospital specialists, the other SISCAT centres (primary care, hospitals at different levels, etc.) and other services (education, social welfare, etc.), incorporating the family into the care process and guaranteeing coordinated, constant care.
5. To establish the Individual and Shared Intervention Plan (PIIC) in paediatrics as a tool to coordinate the different care levels.
6. To establish a framework of cooperation among the different areas of care which enable supra-territorial circuits to be developed that provide in-person care by the local teams in the child or adolescent's region (especially at home), taking advantage of the opportunities afforded by the new technologies and the support and advice that the specific palliative care teams can offer (in person and remotely) in ongoing care.



7. To design and implement training and coordination tools for the professionals from the services and resources that provide paediatric care in the SISCAT on care for patients with diseases that threaten or limit their lives who have palliative needs.
8. To systematically evaluate the implementation and quality of the organisational model of palliative care so that the Catalan Health Service and the Ministry of Health can have the information they need to better plan the care provided to this group.
9. To create evidence of the results of this model and draw best practices from it.

## 4.2 Intervention levels and prioritisation based on complexity criteria

### 4.2.1. Complexity criteria in paediatric palliative care

Once the child or young person with palliative needs has been identified, the care team has to conduct a comprehensive assessment to determine the degree of complexity of their needs.

The conditioning factors and physical and physiological needs are the main focal point when evaluating the complexity of each case, and as mentioned above, the psychosocial and spiritual situation adds complexity to the caregiving process.

In a disease that is usually incurable or has an irreversible clinical outlook with health deterioration and a lower life expectancy, making it unlikely for the patient to reach adulthood, the general criteria defining a higher degree of complexity in paediatric palliative care are:

- Disease with a poor short-term life prognosis (death is predicted in less than two years).
- Constant dependency on technology to live (tracheotomy, ventilation more than 12 hours a day, artificial nutrition).
- Symptoms which are difficult to control or refractory.<sup>11</sup>
- Advanced disease in palliative stage (PaPaS stage > 25,<sup>12</sup> it should be individualised if the PaPaS scale is 15-25) or past the turning point.
- Assistance is needed in decision-making to assess the suitability of the diagnostic and therapeutic measures (ATE or LTE).
- Last days of life.
- Prediction of hospital release in highly complex patient (who depends on

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11. Iglesias ML, Echarte JL. Asistencia médica y de enfermería al paciente agónico que va a fallecer en urgencias. *Emerg.* 2007;19(1):201-10.

12. Bergstraesser E, Hain RD, Pereira JL. The development of an instrument that can identify children with palliative care needs: The Paediatric Palliative Screening Scale (PaPaS Scale): A qualitative study approach. *BMC Palliative Care.* 2013;12(1):20.

technology to live, with a risk of severe decompensation or high psychosocial vulnerability that impacts care).

There are also high complexity criteria related to the different groups of diseases that require palliative care:

— **Neoplasia:**

- Diagnosis of neoplasia in which there is no curative treatment.
- Diagnosis of neoplasia with survival rates under 20% in five years.
- Entry in phase 1-2 clinical trial.
- Relapse or progression of the disease and worsening of the clinical condition despite receiving the first-line treatments prescribed and the use of salvage treatments.

— **Organ failure:**

- Progression of the disease and worsening of the clinical condition despite receiving optimised treatments that require a higher use of healthcare resources (meaning an unscheduled admission to the intensive care unit, or ICU; an admission lasting more than two months with intense changes in the patient care or more than two admissions to hospital for the same health problem or due to decompensation of the baseline disease).

— **Irreversible incurable diseases, either progressive or stable, but with inevitable premature death:**

- These are severe diseases whose treatments can exacerbate or gradually weaken the patient (neurodegenerative), which require a high use of healthcare resources to treat and control the symptoms.

- It is considered a situation of high complexity when two or more the following criteria are present:

— Respiratory:

- Oxygen therapy more than 12 hours at home
- Non-invasive mechanical ventilation than 12 hours at home
- Tracheotomy
- 24-hour mechanical ventilation

— Food:

- Weight loss due to eating difficulties
- Pain or gastrointestinal symptoms which force the amount of food to be gradually reduced

— Convulsions:

- Frequent use of salvage medication
- Epileptic episodes which require intensive treatment

— Locomotor:

- GROSS Motor Function (GMF) V

— Other:

- Severe bulbar affect (worsening of dysphagia, cough and nausea)
- Baclofen pump (as a marker of the severity of spasticity)
- Ventriculoperitoneal shunts (especially if frequent checks are needed)

The criteria used to identify complexity based on physical needs are joined by others on psychological complexity when one of the following items is found:

— **Psycho-emotional vulnerability.**

- Emotional distress in the family and/or people near the caregiver that interfere with the care of the child or adolescent.
- Inability to accept the disease.
- Diagnosed psychopathology without specific follow-up.
- Family members not integrated with emotional distress (such as siblings).
- Previous unresolved mourning over disease or loss.

— **Communication problems**

- Family members with difficulties interacting.

Social complexity criteria are defined when three or more high vulnerability criteria or one risk criterion are met:

— **High vulnerability criteria**

- Physical or emotional overload of the main caregiver, the family and/or the caregiving environment, with a lack of support.
- Insufficient socioeconomic and/or job situation of the parents.
- Lack of minimum conditions at home: job, eviction, undocumented (legal-administrative process that does not allow the child or young person to access comprehensive healthcare).
- Difficulties bonding with or taking responsibility for the child or young person due to a lack of parenting skills.
- Linguistic or sociocultural barriers leading to severe difficulty in treatment adherence.

— **Risk criteria**

- The main caregiver giving up.
- Addiction or antisocial or criminal behaviours.
- Suspicion of risk of maltreatment (in the couple or towards the child or adolescent).
- Normalised severe problems in the upbringing or care of the child or young person due to their severe or chronic health, physical or intellectual disability, etc.
- Nonadherence to treatment or noncompliance with medical prescriptions, appointments, etc.

The spiritual and existential complexity criteria are defined by the following items:

- Expression of the absurdity of life or total loss of the meaning of life.
- Sense of guilt and lack of coherence with the life they have lived.
- Inability to find peace and persistent expression of despair.
- Social isolation and prevailing sense of loneliness.
- Despair towards death for fear of disappearing or disintegrating due to the difficulty of finding a transcendent space.
- Ruminative sense of guilt and inability to repair broken relations with people who had been important to them.
- Expression of the conviction of guilt or deserved punishment.

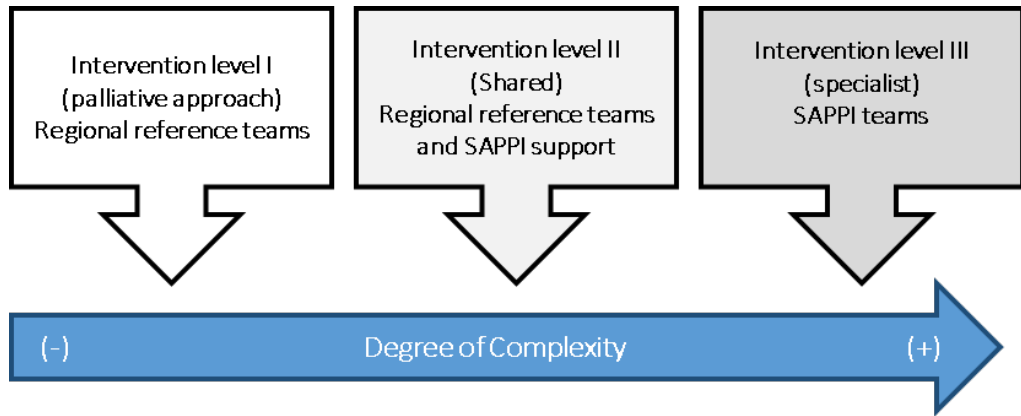
#### **4.2.2 Intervention levels**

The identification of a child or young person with palliative needs implies at least a palliative approach by the caregiving team treating them. Nonetheless, according to the child or adolescent's needs, and bearing in mind the complexity criteria, three intervention levels are established, which are, in turn, dynamic. A patient can go from one level to another depending on their needs or perhaps their family situation:

- Level I, palliative approach: Child or young person whose care can be provided by the reference or regional units and teams, primarily paediatric primary care, without the intervention of (or occasional inter-consultations with) the SAPPI.
- Level II, shared: child or young person whose care can be provided by the reference or regional units and teams, but with the support and periodic collaboration of the SAPPI (either virtual or in-person).
- Level III, specialist care by the SAPPI: High complexity requiring the management of an expert multidisciplinary team until death, the transition to adulthood or a decrease in complexity. The objective of the expert unit is direct interdisciplinary care of the child or young person and their family; physical, psychosocial and spiritual evaluation; the development of a shared functional plan; and multidisciplinary coordination.

The intervention level should be determined based on the needs of the child or young person and their family, but the training of a reference caregiving team on paediatric palliative care is essential.

The gradual development of the XAPPIS, especially in the sphere of training, will enable us to have professionals with more training in paediatric palliative care in the Catalan healthcare system, in both primary care centres and hospitals. This will allow the children and young people at levels I and II who are currently referred to the SAPPIs to be cared for by reference teams in the middle term.



# 5. Comprehensive paediatric palliative care services

SAPPs are expert services in paediatric palliative care which provide care in cases in which level II or III is determined, according to the characteristics and the complexity criteria. At the same time, these services are also the first link in the development of the XAPPs via the establishment of accessibility and sectorisation criteria which are needed to train professionals around Catalonia.

## 5.1. Accessibility and sectorisation

Palliative care should be provided by all professionals in SISCAT, and the accessibility criteria and circuits to units or services with greater therapeutic intensity must be determined according to the complexity of the needs of the child or young person and their family.

The SAPPs offer care to children and young people and their families with public health coverage.

Access to SAPPs, regardless of the service, resource or centre where the request reaches, is provided via a specialist consultation request which should state:

- Information on the child or young person (administrative and relevant clinical data, such as weight).
- Proposed level of prioritisation (normal, preferential or urgent).
- Relevant diagnoses.
- Medication plan (magistral formulas should be included).
- Allergies and adverse reactions.
- Multidimensional assessment (state of the situation and functional, nutritional, cognitive, sociocultural and family needs).
- Aspects on communication and information with the child or young person and their family.
- Patient care (the resources and care services which are caring for the child or young person should be described).
- Reason for the consultation and/or referral.
- Additional information of interest related to their care.
- Signature and information on the referring professional referent, the service and the home centre.

The SAPPI will assess the specialist consultation to establish the prioritisation criteria according to the criteria established in section 5.1.2 of this document. Any child or young person with palliative needs, their family and the caregiving team in Catalonia should have a reference SAPPI.

Bearing in mind the regional areas of influence of the hospitals of Catalonia which care for children, and with the goal of establishing the XAPPI gradually, the reference population for each of the SAPPis will be defined.

The complexity of managing the hospitals with SAPPis should be borne in mind, as they offer care to the population in their region while also serving children and young people with more complex situations in a broader geographic area.

We should highlight that in accordance with CatSalut Instruction 12/2015, which amends Instruction 12/2014 on the development and implementation of the care model for rare diseases (RD) in Catalonia, organisation of clinical expertise units (UECs) for RD or thematic groups of RD, and bearing in mind the high prevalence of children with rare diseases who are cared for by the SAPPI, there is concurrence that palliative care should be offered at the hospital where the child is being treated for their baseline condition, even if this is not the centre they are assigned by their home address according to this territorialisation. This condition should also be borne in mind for other instructions which suggest a territorial distribution different to the one outlined. This situation means that in some cases, the SAPPI team has to coordinate with the resources in other regions which are not referents for paediatric palliative care.

### **5.1.2. Prioritisation care criteria at the SAPPis**

In the groups of patients with complexity criteria that require the intervention of the SAPPI to a greater or lesser extent, it is essential to agree upon the prioritisation of the intervention by these specific paediatric palliative care services with the other specialists.

Generally speaking, given the possibility that the SAPPis have different cases in which they have to intervene at the same time, three priority levels are established:

- Urgent:
  - Death throes/EOL.
  - Death predicted within the next month.
  - Symptoms that are difficult to control or refractory.
  - Complex, urgent decision-making.
  - Situations which cannot be referred to the SAPPI because of the urgency of the case, but in which this service will offer support and advice to the professionals that need it.

In these cases, the response time of the visit should be between 24 and 48 hours if the patient is admitted into the hospital and less than three days if they are at home.

When it is impossible to offer direct, in-person care due to the urgency of the case, it is essential to provide advice, and responses should be given to the referring team urgently either remotely or virtually in order to meet the most immediate and intense needs, which will allow the patient to overcome the access time to the SAPPI.

— Preferential:

- Terminal stage.
- Death predicted within the next 6-12 months.
- Complex decision-making.
- Cases in which hospital release is prioritised to focus the care at home, especially when there is no referent or coordination with the region.

In these cases, the response time of the visit should be one week if the patient is admitted to the hospital and less than 15 days if they are at home.

As long as it is impossible to provide direct, in-person care, it is essential to provide the possibility of remote or virtual contact to meet the needs that will enable the patient to overcome the access time to the SAPPI.

— Ordinary:

- Stability.
- There is minimum coordination of care and a referent professional or team.
- Life prognosis over 12 months.

In these cases, the response time of the visit should be less than one month.

As long as it is impossible to provide direct, in-person care, it is essential to provide the possibility of remote or virtual contact to meet the needs that will enable the patient to overcome the access time to the SAPPI.

The start of the specialist psychosocial intervention may not dovetail with the priority levels described and should happen according to its own prioritisation criteria and suitable resources.



## 5.2. Portfolio of services

At least one member of the SAPPI should be the care referent of the child or adolescent, and the family should identify them as such. At the same time, this coordinating referent should ensure that the service that best meets their needs is offered at all times, and they should work actively to ensure the continuity of care both at home and in the hospital.

In terms of care, the objectives of the SAPPIs are the following:

- Holistic assessment of the case which enables the needs and the interventional level required to be identified.
- Creation of shared individual care plans (PIIC) based on the assessment of the needs of the child or adolescent, their family and their environment; shared decision-making between the broad multidisciplinary team (palliative care team plus the professionals involved in comprehensive care), the family and the child or adolescent, if possible; and their desires and preferences, according to the case conference methodology.<sup>13</sup>
- Management of the case, meaning advanced caregiving practice which plans and executes an individualised care plan based on coordination among organisations and professionals, with the goal of meeting the social or health needs of people or their environments.<sup>14</sup> The purpose is to guarantee the continuity of care, the coherence of a complex care process and the coordination of the interventions of the professionals involved in caring for the child or young person health-wise or socially, and educationally, if needed, to overcome the fragmentation and compartmentalisation of services, levels, departments and people. In cases at level III, the SAPPI should lead the case management. In cases at levels I and II, the SAPPI should communicate and coordinate with the case management (primary or hospital care) acting as the referent of the child or young person and coordinate the actions of all the primary care professionals and the hospital services involved in the case: diagnostic services, clinical services and support services (and health and social services, if applicable).
- Specific multidisciplinary advice in paediatric palliative care.
- Coordination of care to prevent the child or young person and their family from suddenly losing contact with the reference specialists and professionals, regardless of whether they are intra-hospital referrals or referrals between the hospital and the primary care centres, or the transition between paediatric and adult services.
- Health education and psychosocial assistance of the child or young person and families to train them in self-care or caring for their children,

13. “Model de conferència de cas”. Departament de Salut. Generalitat de Catalunya. Forthcoming 2019 [Forthcoming].

14. TERMCAT. <https://www.termcat.cat/ca/diccionaris-en-linia/160/ca/G>

especially in cases in which the family is being prepared to take over care at home. Early prevention and detection of new symptoms and possible complications.

- Disease management and symptom monitoring, with both pharmacological and non-pharmacological therapies, adapting the treatment to the course of the disease and situation at all times, along with managing the information and decision-making this entails.
- Psychosocial and spiritual care to jointly meet these dimensions, which includes specific psychological support, specific social support and specific spiritual support, as needed. This also includes support groups targeted at children, young people, siblings or caregivers to prevent exhaustion and the risk of giving up.
- Attention to the grieving process with both individual and group grief therapy, as needed. This care is crucial not only in the dying process but also during the course of the disease, for both the child or young person and the people closest to them, and ensuring the coordination and comprehensive monitoring with the mental health services in the region in cases of complicated grief.
- Specific paediatric palliative care telephone support to ensure continuous care 24/7 throughout the process for both the children or young people and their families and the internal professionals at the hospitals, in the paediatric primary care service or the paediatric coordinator of the emergency medical system (SEM) which provide direct care.

The activity primarily takes place in in-person (or remote) visits in outpatient, hospital and home care. The portfolio of services of the SAPPis include:

### **5.2.1. In hospitals**

In hospitals, the SAPPis offer services that do not require admission when the child or young person is at home and the visit to the hospital is outpatient, as well as in-patient visits that entail admission.

#### **5.2.1.1. Without admission (external offices and inpatient hospital visits)**

A multidisciplinary team specialised in palliative care provides outpatient care at the hospital. The portfolio of services is primarily meant for children and young people with palliative needs who:

- Require an initial comprehensive evaluation by a specific paediatric palliative care team.
- Require specialist follow-up by a specific paediatric palliative care team.
- Have been released from a hospital service and need specialist follow-up by a specific paediatric palliative care team.

Care by these teams is based on care of children and young people with palliative needs. Once identified, a situational diagnosis will be made based on a

comprehensive assessment and a needs assessment in order to come up with the best comprehensive care plan determined by the intervention level.

Following up and sharing this care plan within the healthcare system around Catalonia should be done via an PIIC, which should be available in the shared clinical record of Catalonia (HCCC).

Specialised, planned follow-up should be provided in coordination with the professionals in the different fields and services established, with the creation of specific care pathways which encompass the care circuits and collaborative practices needed to ensure quality care with the local paediatric primary care professionals and hospital professionals (and health and social professionals, if needed) near the child or adolescent's home.

These teams primarily do two types of activities:

- Evaluation and/or follow-up appointments: This consists in providing specialist evaluation and follow-up by one, several or all the members of the team of pediatricians (doctors and nurses), social and health workers and psychologists with training in paediatric palliative care.
- Multidisciplinary evaluation: This includes conducting a comprehensive paediatric evaluation by a team of pediatricians (doctors and nurses), health and social workers and psychologists with training in paediatric palliative care, as well as drafting a final report, which should be sent to the paediatrician who originated the consultation with the goal of guiding them on the needs associated with the child or adolescent's life-limiting condition and their family and the care level they will be given.

An essential factor is having the technical capacity to diagnose, with in-house means or outsourced to another entity, which guarantee sufficiently quick action to ensure efficient service.

### 5.2.1.2 Admission: Hospitalisation

Hospital care by the specific paediatric palliative care team is meant primarily for children or young people with life-limiting or life-threatening conditions, including advanced and end-stage diseases and acute hospital admissions requiring management of specific symptoms by an expert palliative care team (level III).

It offers comprehensive care, and the palliative care team follows up throughout the admission, while the medical leadership and responsibility are held by the SAPPI doctor. The nursing staff in the unit where the child or young person is admitted offers them ongoing hospital care.

The care is grounded on the global intervention plan based on the initial comprehensive assessment, which makes a diagnosis of the situation and the child or young person and their family's needs and determines the intervention

level for follow-up. The transition to release is prepared in coordination with the professionals in the different areas and services at the destination, working proactively and creating a network with the local primary care and hospital paediatric professionals (and social and health professionals, if needed) near the child or adolescent's home.

These teams primarily do the following activities:

- Direct care of the child or young person and their family: specialist follow-up by a team of paediatric medicine, paediatric nursing, social work and psychology professionals trained in palliative paediatric care.
- Comprehensive, interdisciplinary evaluation: evaluation of the different dimensions of the child or young person by the multidisciplinary team.
- Case management: Leading the process of evaluating, planning, facilitating and defending the options and services which meet the child or young person and their families' health needs by organising the available resources and promoting high-quality, efficient results.
- Planning the release with the requirement of continuation of the palliative care by the local paediatric primary care and community, hospital or health and social care services.

#### 5.2.1.3. Admission: Hospital support

The hospital support care by the specific paediatric palliative care team is meant primarily for children or young people with life-limiting or life-threatening conditions, including advanced and end-stage diseases and acute hospital admissions requiring a comprehensive evaluation, comprehensive follow-up or preparation and coordination of the hospital release by a specific palliative care team.

It offers comprehensive care in coordination with the respective paediatric services in the hospitalisation units. The nursing staff in the unit where the child or young person is admitted offers them ongoing hospital care.

The care is grounded on the global intervention plan based on the initial comprehensive assessment, which makes a diagnosis of the situation and the child or young person and their family's needs and determines the intervention level for follow-up.

The specific palliative care team is responsible for follow-up throughout the admission, with the intensity and leadership required in each case. The transition to release is prepared in a coordinated, collaborative fashion with the professionals in the different areas and services at the destination, working proactively and creating a network with the local primary care and hospital paediatric professionals (and health and social professionals, if needed) near the child or young person's home.

These teams primarily do the following activities:

- Direct care of the child or young person and their family: specialist follow-up by a team of paediatric medicine, paediatric nursing, social work and psychology professionals trained in palliative paediatric care.
- Comprehensive, interdisciplinary evaluation: evaluation of the different dimensions of the child or young person by the multidisciplinary team.
- Proactive hospital action: identification of the paediatric population with palliative needs admitted to the hospital by establishing criteria, incorporating systematic identification procedures and working jointly and closely with the professionals in the other services and units.
- Case management: participation (levels I and II) and leadership (level III) in evaluating, planning, facilitating and defending the options and services which meet the child or young person and their families' health needs by organising the available resources and promoting high-quality, efficient results.
- Coordinating the resources among care levels: establishing specific care pathways, care circuits and collaborative practices.
- Planning the release with the requirement of continuation of the palliative care by the local paediatric primary care and community, hospital or health and social care services.
- Support for the respective teams in the different hospital paediatric services: advice to hospital professionals on palliative care matters, and providing support in training, teaching and research.

### **5.2.2. At home (support from the SAPPI)**

Home care by the paediatric palliative care team is meant primarily for the following patients:

- Children and young people with life-limiting or life-threatening conditions, including advanced and end-stage diseases, who do not require hospital admission but, because of their dependency level and health and social needs, require a comprehensive evaluation, care and follow-up by a specific palliative care team at differing levels of intensity.

Home coverage of the team caring for children and young people with palliative needs is based on the sectorisation of the sphere of influence. This care should be integrated with the regional paediatric primary care team which the child and young person is assigned and the local hospital resources to guarantee optimal care for their needs, as well as with the local social and educational services, when needed.

The palliative care team should also ensure continuity of the care and draw from the paediatric professionals in the primary care, hospital and health and social resources, if needed, in the region where child or young person and their family live. Likewise, the use of previously defined tools and the design of appropriate care pathways should guarantee a safe, quick transfer to the referent hospital where the specialist team is located in a situation of crisis of the child or young person with palliative needs, in light of the complex characteristics or needs they may have.

It may be necessary for one or several professionals to make home visits depending on the needs. The intensity or frequency and the type of visit will depend on the needs of the child or young person and their family and the resources and implementation of the XAPPs. Home care can also take place remotely via remote visits (telephone, video conference, etc.).

In order to provide the aforementioned portfolio of care services, the SAPPs also conduct a series of activities involving indirect care which provide an entire range of tools aimed at facilitating communication between primary care, support services and specialist care, and enabling information on the ill child or young person to be shared, the clinical and epidemiological information on the paediatric palliative care to be updated and the expert services to be defined. Ultimately, these are tools that facilitate networking to improve the interdisciplinary care of a child or young person with palliative needs, including the participation of professionals from the educational and social systems.

These indirect activities associated with the portfolio of services include specialist consultations, coordination actions and advice, and support for other professionals, either at the same hospital or at other centres, including:

- Medical, nursing, social work or psychological advice, when needed.
- Multidisciplinary meetings and periodic sessions (both in-person and with the option of virtual follow-up) to discuss cases with regional specialists and professionals.
- Coordination meetings with the professionals from the reference region, from both the health services and social services and education.
- Participation on multidisciplinary intra-hospital committees and commissions which consider cases and jointly decide on the most suitable therapeutic approach among the different specialists and professionals participating in them. It is strongly recommended that the regional professionals also participate on these committees (local paediatric primary care, hospital and health and social care services, if needed).

### 5.2.3. Teaching

Studies of the care needs and expectations of the paediatric population with palliative needs highlights the need for the majority of professionals (both community and hospital) to undergo further clinical training in basic paediatric palliative care in order to overcome the fragmentation of services between levels, departments and centres and to move towards innovation and definitions of the role of everyone who participates in the care to achieve a continuous clinical pathway for the child or young person and their family when seeking an integrated diagnosis, care plan and treatment.

Identification of the centre and service that will lead the caregiving process is a bond and an important dependency for the child or young person with palliative needs and their family, in this case the SAPPI. At the same time, the lack of coordination or detachment with community social, educational and healthcare resources near their home means squandered opportunities to improve the care and quality of life of the patient and their families. In this sense, tools should be offered to improve the knowledge, techniques and tools of the professionals caring for the child or young person in order to progress in clinical practice and interdisciplinary case management. Beyond clinical and technical knowledge of palliative care, the professionals should also have a global picture of the issues dealt with and of the model, and they should gain skills and attitudes that enable them to understand the reality of the work environment and detect intervention opportunities.

The objective is to train paediatric professionals in primary, hospital, urgent and outpatient care according to the degree of intensity with which they care for the paediatric population with palliative needs.

In addition to the caregiving activity, paediatric palliative care services should participate in training programmes and offer regularly classes for medical (MIR) and nursing (EIR) professionals, and it is also recommended for psychology professionals (PIR), as well as for specific residents (post-graduate training).

There are two key training areas:

- Ongoing training to train paediatric professionals in good practices according to the field of care and the care offered, which should provide technical updates in the detection, diagnosis and therapy processes, as well as in follow-up and assistance throughout the process.
- Continuous management training (through the shared clinical record, the care circuits, the referral criteria, etc.) with ongoing training in the form of training and coordination sessions which share working tools and methodologies with professionals with other services, resources and care levels.

### 5.3. Structural and functional requirements of the XAPPI

The development of the XAPPI is considered a Catalonia-wide programme with the aim of developing comprehensive paediatric palliative care which is high quality and equitable everywhere. It starts with the creation of SAPPis in three centres which work closely together, enriching each other with mutual knowledge, establishing standard operating circuits and criteria and participating in joint service evaluation and research projects. Consequently, a formalised agreement among the three centres that are initially involved is needed.

In order to guarantee the steady, standard development of the XAPPI, a coordinator is needed, who should be a professional from one of the three SAPPis (with at least two years and in rotation). Their main functions are:

- To be a clinical referent in the Catalan healthcare system and an interlocutor with the administration on paediatric palliative care matters.
- To coordinate with the heads of the three SAPPis to ensure that they operate as a single functional unit.
- To bring together and disseminate knowledge on the paediatric palliative care model and its operational implementation in Catalonia.
- To ensure that the objectives set for the SAPPis are met.
- To promote the development of joint protocols to achieve homogeneous operations and care levels among the three SAPPis and throughout the entire XAPPI. Important aspects include:
  - Caregiving processes of the main health problems (CP, oncology, neurology, advanced chronic organ failure neonatology, etc.).
  - Specific psychosocial intervention criteria.
  - Intervention in the grieving process.
- To plan the training strategies that the SAPPis should carry out in their regions to gradually train the professionals in the XAPPI.
- To plan the training strategies to be received by the professionals in the SAPPis to ensure they have the training needed and are abreast of paediatric palliative care.
- To participate in the periodic evaluation and dissemination of the results of paediatric palliative care in the Catalan healthcare system. To coordinate the work that enables the content of the annual report on services to be drafted, and, as part of the follow-up, to draft an annual activity and results report.
- To promote research within the XAPPI and to learn about the studies on paediatric palliative care that are being conducted.



At the same time, the SAPPIs are included in the paediatric services which provide care to children and young people with complex chronic diseases, are dependent on these services or have close ties with them. They should also work with the different paediatric services and specialities, primarily with the UECs and UEHs in neurology, oncology, neonatology and intensive care, as well as with the centres and professionals in the region closest to the child or adolescent.

To ensure this coordination, the SAPPIs must reach joint work and cooperation agreements with other services and entities, at least with regard to the aspects discussed in this document. A timeframe is needed so that cooperation agreements and responsibility criteria of the care included are reached and the portfolio of services among the different centres involved are defined depending on the situation in each territorial region.

### **5.3.1. Teams and professionals**

The SAPPIs are considered interdisciplinary services for paediatric palliative care which have all the professionals needed to guarantee high-quality, expert comprehensive care (physical, psychological, emotional, spiritual and social needs) to the paediatric population with palliative needs and their families.

The minimum team of doctors, nurses, psychologists and social workers with specialist training in paediatrics (in the existing disciplines), and specifically in palliative care (post-graduate and in-service training, attendance at conferences, etc.), is established. At the same time, the team members' knowledge and experience in paediatric palliative care is invaluable (years of experience providing care in this field) and the team's common history and degree of consolidation (especially important in alliances between organisations).

All the professionals working in paediatric palliative care have to have specific training in this field, and in communication and emotional management, and they should receive support and individual and team supervision. One requirement of the SAPPIs is to ensure that the professionals in these services have the most recent information available in training and needs for daily caregiving practice.

Each SAPPI should have a coordinator in charge of directing, implementing, coordinating and overseeing the work of the service.

It should be borne in mind that that service also needs a professional to provide administrative support, as well as others who can intervene as cultural mediators and help cover spiritual needs (spiritual agent).

With the goal of meeting the palliative care needs of the paediatric population, there is also the possibility that SAPPis may have the support of third-sector entities through agreements and other formulas of cooperation, which will allow the activity of the public healthcare system and the complementary activities performed by these organisations, especially at home, to align.

### **5.3.2. Information and registration systems**

With the goal of improving the information available on the children and young people served by the SAPPis and the healthcare resources used to attend to them, the use of the ICT tools currently available will be promoted, such as the shared clinical record (targeted at professionals) and La Meva Salut (targeted at users). At the same time, as the Systems Plan of the Ministry of Health incorporates other IT tools, CatSalut will make them available for use.

Likewise, the existing records and databases available in the healthcare system will also be used. If new records are needed to evaluate the palliative care of the SAPPis, it will be essential to align and to link the new records to the existing ones, if possible, to ensure data security and avoid duplicating information sources. Annex 5 describes the Guidelines for registering and reporting caregiving activity.

# 6. Follow-up and evaluation

It is considered essential to establish a regular frequency of biannual meetings (initially) with the Ministry of Health, CatSalut and the coordinator of the XAPPI in order to follow up and evaluate the functioning of these services and the development of the network.

In order to follow up on and evaluate the children attended by the SAPPis, based on the cases entered in the Registry of Rare Diseases, the data available in the different databases in the healthcare system (MBDS, invoicing, pharmacy, etc.) will be analysed.

Indicators will be used to track and follow up on the SAPPis, which will also be associated with the development of the XAPPI. The indicators that can currently be measured feasibly are related to:

- Identification of children or young people with palliative needs
  - Children and young people with codes V66.7, Z51.5 and/or ACD (age, sex, main diagnosis category [MDC], region of residence [health management area [HMA] and health region [HR]).
- Accessibility to the SAPPis
  - Children and young people attended by the SAPPis (age, sex, hospital, MDC, region).
  - Children and young people not attended by the SAPPis who have died during the year (age, sex, hospital, MDC, region).
  - Time elapsed from entry into the SAPPis until the child or adolescent's death (age, sex, hospital, MDC, region).
- Care load of the children and young people served by the SAPPis
  - Care from the SAPPis (age, sex, hospital, MDC, region, type of visit [hospital, home, outpatient, telephone], attending professional).
  - Paediatric primary care (age, sex, hospital, MDC, region, type of visit [home, telephone], attending professional, reason for the visit, etc.).
  - Hospital care (age, sex, hospital, MDC, region, type of visit [hospital, outpatient, etc.]).
  - Health and social care (age, sex, hospital, MDC, region, line of assistance, etc.).
  - Emergency care (age, sex, hospital, MDC, region, type of activity (hospital, SEM, CUAP, etc.))

- Pharmacy (age, sex, hospital, MDC, region, prescriptions, outpatient-dispensed hospital medication, etc.).
- SAPPI results
  - Children and young people attended by the SAPPIs who have died during the year (age, sex, hospital, MDC, region).
  - Place of death of the children and young people attended by the SAPPIs (age, sex, hospital, MDC, region).

In parallel, to complement the information in the information systems available to CatSalut and the Ministry of Health, the coordinator should submit an annual report of the SAPPIs which includes the following information:

- Description of the professional staff of the SAPPIs (number of professionals, profiles, full-time/part-time, timetables, etc.).
- Description of the population attended by the SAPPIs that year according to the intervention levels defined in the section.
- Consensus protocols and common criteria agreed upon in terms of processes and operation of the SAPPIs.
- Training activities that the SAPPI professionals have done.
- Intra-hospital and extra-hospital training actions with the other caregiving areas.
- Layout of regional care pathways or other coordination tools with other care levels (PC, health and social care, emergencies, etc.).
- Intra-hospital and extra-hospital coordination sessions.
- Intra-hospital and extra-hospital discussion sessions or activities.
- Studies or research projects underway.
- Support or grief therapy groups for families.
- Measures to evaluate the satisfaction and experience of the children and young people and their families.
- Other relevant information that brings value to the follow-up and evaluation of the SAPPIs.

# Annex 1

## Estimate of children and young people with palliative needs

Estimate of the minimum number of children and young people with palliative needs by region based on reference figures in the literature

Health region	Health sector	Health management area (HMA)	Population age birth to 19 (RCA 2019)			Min. estimate of CPC
			Male	Female	Total	
Lleida	Lleida	Lleida	37,856	35,376	73,232	<b>72</b>
Camp de Tarragona	Alt Camp - Conca de Barberà Tarragonès - Baix Penedès Baix Camp –Priorat	Alt Camp and Conca de Barberà	6,549	6,139	12,688	<b>13</b>
		Baix Penedès	9,752	9,116	18,868	<b>18</b>
		Tarragonès	28,915	27,020	55,935	<b>55</b>
		Baix Camp and Priorat	22,400	21,222	43,622	<b>43</b>
Terres de l'Ebre	Terres de l'Ebre	Altebrat	2,906	2,625	5,531	<b>6</b>
		Baix Ebre	7,831	7,241	15,072	<b>16</b>
		Montsià	7,064	6,369	13,433	<b>14</b>
Girona	Girona Nord	Alt Empordà	14,964	14,374	29,338	<b>29</b>
		Baix Empordà	13,689	12,757	26,446	<b>27</b>
		Garrotxa	5,866	5,403	11,269	<b>11</b>
		Ripollès	2,175	1,959	4,134	<b>5</b>
	Girona Sud	Alt Maresme	12,468	11,735	24,203	<b>25</b>
		Selva Marítima	8,311	7,656	15,967	<b>16</b>
		Gironès Nord and Pla de l'Estany	18,496	17,276	35,772	<b>35</b>
		Gironès Sud and Selva Interior	17,752	16,608	34,360	<b>35</b>
Catalunya Central	Anoia Osona Solsonès-Bages-Berguedà	Anoia	12,858	11,847	24,705	<b>25</b>
		Osona	17,831	16,606	34,437	<b>36</b>
		Bages and Solsonès	22,775	21,185	43,960	<b>45</b>
		Berguedà	3,486	3,089	6,575	<b>7</b>

Alt Pirineu i Aran	Aran	Aran	893	826	1,719	<b>2</b>
	Alt Pirineu	Cerdanya	1,689	1,599	3,288	<b>3</b>
		Alt Urgell	1,885	1,781	3,666	<b>4</b>
		Pallars	1,665	1,594	3,259	<b>3</b>
		Alta Ribagorça	330	303	633	<b>1</b>
Barcelona	Baix Llobregat Nord	Baix Llobregat Nord	19,352	18,080	37,432	<b>38</b>
	Vallès Oriental	Baix Montseny	6,478	6,022	12,500	<b>12</b>
		Baix Vallès	18,358	17,203	35,561	<b>35</b>
		Vallès Oriental Central	26,133	24,432	50,565	<b>49</b>
	Vallès Occidental Oest	Vallès Occidental Oest	51,818	48,727	100,545	<b>100</b>
	Vallès Occidental Est	Vallès Occidental Est	43,479	41,119	84,598	<b>84</b>
		Barcelona Nord	4,112	3,744	7,856	<b>8</b>
	Barcelona Ciutat Vella	Barcelona Litoral Mar	7,723	7,037	14,760	<b>15</b>
	Barcelona Sant Martí	Barcelona Dreta	3,038	3,018	6,056	<b>6</b>
	Barcelona Sant Martí	Barcelona Litoral Mar	18,410	17,274	35,684	<b>36</b>
	Barcelona Les Corts	Barcelona Esquerra	6,362	6,155	12,517	<b>1</b>
	Barcelona Sants-Montjuïc	Barcelona Esquerra	14,774	13,917	28,691	<b>29</b>
	Barcelona Sarrià-Sant Gervasi	Barcelona Esquerra	11,569	11,003	22,572	<b>22</b>
		Barcelona Nord	3,227	3,250	6,477	<b>6</b>
	Barcelona Eixample	Barcelona Esquerra	10,428	9,957	20,385	<b>20</b>
		Barcelona Dreta	9,254	8,709	17,963	<b>19</b>

Barcelona	Barcelona Gràcia	Barcelona Nord	1,975	1,847	3,822	<b>4</b>
		Barcelona Dreta	7,878	7,366	15,244	<b>16</b>
	Barcelona Horta-Guinardó	Barcelona Nord	8,506	8,075	16,581	<b>16</b>
		Barcelona Dreta	5,881	5,613	11,494	<b>12</b>
	Barcelona Nou Barris	Barcelona Nord	15,409	14,957	30,366	<b>30</b>
	Barcelona Sant Andreu	Barcelona Nord	7,803	7,397	15,200	<b>15</b>
		Barcelona Dreta	5,712	5,257	10,969	<b>10</b>
	Alt Penedès – Garraf	Alt Penedès	11,208	10,481	21,689	<b>22</b>
		Garraf	16,663	15,987	32,650	<b>32</b>
	Baix Llobregat Centre-Litoral and l’Hospitalet de Llobregat	Baix Llobregat Centre and Fontsanta - l’Hospitalet	44,887	42,383	87,270	<b>87</b>
		L’Hospitalet Sud and el Prat de Llobregat	19,601	18,624	38,225	<b>38</b>
		Baix Llobregat Litoral and Viladecans	21,417	20,032	41,449	<b>42</b>
		Baix Llobregat Litoral and Sant Boi	13,628	13,114	26,742	<b>27</b>
	BARCELONÈS NORD and MARESME	Barcelonès Nord and Baix Maresme	44,521	41,502	86,023	<b>85</b>
		Maresme Central	29,516	27,483	56,999	<b>57</b>
		Barcelona Litoral Mar	2,085	1,922	4,007	<b>4</b>
			Unspecified	--	2	2
<b>Total</b>			<b>791,611</b>	<b>743,395</b>	<b>1,535,006</b>	<b>1,535</b>

# Annex 2

## Estimate of deaths and deaths from causes eligible for PC

Estimate of deaths due to causes eligible for paediatric palliative care by region, based on the rates and causes of death in the population aged birth to 17 in Catalonia.

Health region	Health sector	Health Management Area (HMA)	Population age birth to 17 (RCA 2019)			Estimate of deaths	Deaths eligible for palliative care
			Male	Female	Total		
Lleida	Lleida	Lleida	34,092	32,025	66,117	14	7
Camp de Tarragona	Alt Camp -Conca de Barberà	Alt Camp and Conca de Barberà	5,882	5,558	11,440	2	1
	Tarragonès - Baix Penedès	Baix Penedès	8,830	8,225	17,055	4	2
		Tarragonès	26,271	24,456	50,727	11	6
	Baix Camp - Priorat	Baix Camp and Priorat	20,347	19,221	39,568	6	5
Terres de l'Ebre	Terres de l'Ebre	Altebrat	2,604	2,352	4,956	0	0
		Baix Ebre	7,035	6,542	13,577	2	2
		Montsià	6,336	5,723	12,059	2	2
Girona	Girona Nord	Alt Empordà	13,515	12,956	26,471	5	2
		Garrotxa	5,276	4,868	10,144	1	1
		Ripollès	1,970	1,768	3,738	0	0
	Girona Sud	Alt Maresme	11,227	10,613	21,840	5	4
		Selva Marítima	7,416	6,912	14,328	3	2
		Gironès Nord and Pla de l'Estany	16,668	15,572	32,240	6	4
		Gironès Sud and Selva Interior	16,074	15,112	31,186	5	3



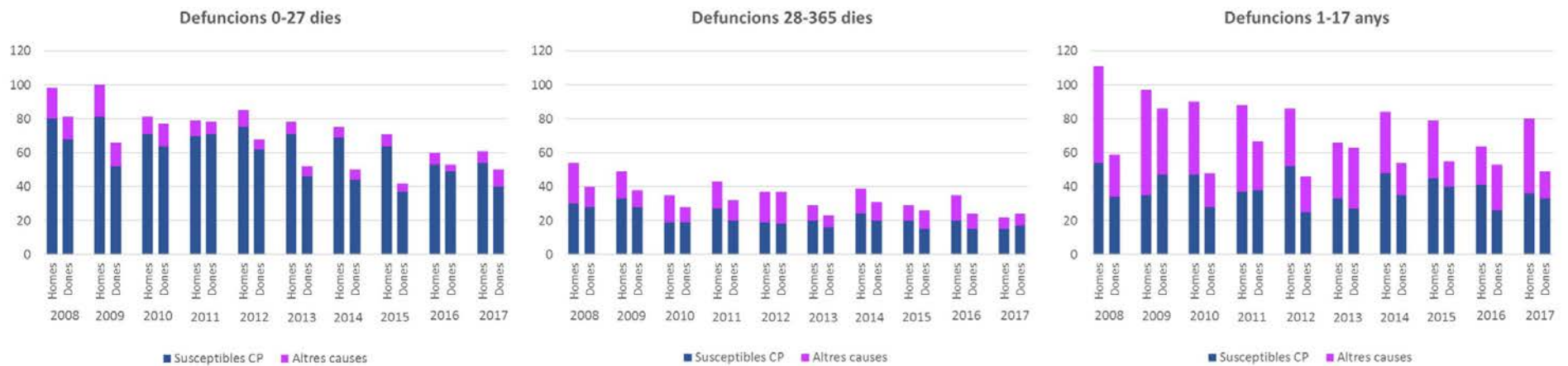
Catalunya Central	Anoia	Anoia	11,612	10,782	22,394	4	3
	Osona	Osona	16,072	15,004	31,076	5	3
	Solsonès-Bages-Berguedà	Bages and Solsonès	20,561	19,130	39,691	8	4
Berguedà		3,157	2,768	5,925	1	1	
Alt Pirineu i Aran	Aran	Aran	803	750	1,553	0	0
	Alt Pirineu	Cerdanya	250	249	499	0	0
		Alt Urgell	2,952	2,776	5,728	2	0
		Pallars	1,512	1,451	2,963	0	0
Alta Ribagorça		298	268	566	0	0	
Barcelona	Baix Llobregat Nord	Baix Llobregat Nord	17,548	16,434	33,982	6	5
	Vallès Oriental	Baix Montseny	5,846	5,427	11,273	2	2
		Baix Vallès	16,400	15,419	31,819	8	5
		Vallès Oriental Central	23,584	22,106	45,690	8	7
	Vallès Occidental Oest	Vallès Occidental Oest	46,852	44,066	90,918	17	13
	Vallès Occidental Est	Vallès Occidental Est	39,375	37,140	76,515	18	11
		Barcelona Nord	3,689	3,404	7,093	1	1
	Barcelona Ciutat Vella	Barcelona Litoral Mar	6,854	6,339	13,193	3	1
	Barcelona Sant Martí	Barcelona Dreta	2,707	2,731	5,438	1	0
	Barcelona Sant Martí	Barcelona Litoral Mar	16,637	15,594	32,231	7	5
	Barcelona Les Corts	Barcelona Esquerra	5,687	5,502	11,189	3	2
	Barcelona Sants-Montjuïc	Barcelona Esquerra	13,185	12,451	25,636	6	3
	Barcelona Sarrià-Sant Gervasi	Barcelona Esquerra	10,299	9,839	20,138	4	4
		Barcelona Nord	2,872	2,917	5,789	1	1
	Barcelona Eixample	Barcelona Esquerra	9,394	8,904	18,298	4	4
		Barcelona Dreta	8,277	7,785	16,062	5	2
	Barcelona Gràcia	Barcelona Nord	1,777	1,661	3,438	1	0
		Barcelona Dreta	7,155	6,656	13,811	4	2
	Barcelona Horta-Guinardó	Barcelona Nord	7,622	7,281	14,903	4	2
		Barcelona Dreta	5,298	5,033	10,331	3	1
Barcelona Nou Barris	Barcelona Nord	13,816	13,351	27,167	6	2	

Barcelona	Barcelona Sant Andreu	Barcelona Nord	7,027	6,690	13,717	3	2
		Barcelona Dreta	5,118	4,670	9,788	2	2
	Alt Penedès - Garraf	Alt Penedès	10,153	9,512	19,665	4	4
		Garraf	14,980	14,388	29,368	7	6
	Baix Llobregat Centre-Litoral and l'Hospitalet de Llobregat	Baix Llobregat Centre and Fontsanta - l'Hospitalet N.	40,475	38,157	78,632	18	14
		L'Hospitalet Sud and el Prat de Llobregat	17,690	16,824	34,514	8	7
		Baix Llobregat Litoral and Viladecans	19,452	18,100	37,552	7	7
		Baix Llobregat Litoral and Sant Boi	12,281	11,803	24,084	4	4
	Barcelonès Nord and Maresme	Barcelonès Nord and Baix Maresme	40,249	37,510	77,759	18	14
		Maresme Central	26,553	24,784	51,337	12	8
		Barcelona Litoral Mar	1,873	1,769	3,642	1	1
		Unspecified	--	2	2		0
<b>Total</b>			<b>713,816</b>	<b>670,895</b>	<b>1,384,711</b>	<b>287</b>	<b>197</b>

# Annex 3

## Child and youth deaths eligible for PC

Data on child and youth deaths for causes eligible for palliative care. Catalonia, 2008-2017



Source: Death Registry of Catalonia. Information Management and Analysis Services for Strategic Planning. Directorate-General for Health Planning. Ministry of Health. Government of Catalonia.

Death rates by age groups. Catalonia, 2017

	Deaths				Population			Rates x 1,000 inhab.		
	Females	Males	Total	Percentage (%)	Females	Males	Total	Females	Males	Total
<b>Catalonia</b>	<b>32,825</b>	<b>32,684</b>	<b>65,509</b>	<b>100</b>	<b>3,836,279</b>	<b>3,683,602</b>	<b>7,519,881</b>	<b>8.56</b>	<b>8.87</b>	<b>8.71</b>
Age group										
<1	74	83	157	54.89	33,162	35,201	68,363	2.23	2.36	2.30
1- 4	12	21	33	11.54	142,679	151,802	294,481	0.08	0.14	0.11
5- 9	16	17	33	11.54	202,538	216,173	41,711	0.08	0.08	0.08
10-14	12	15	27	9.44	196,549	209,723	406,272	0.06	0.07	0.07
15-17	9	27	36	12.59	108,063	114,951	223,014	0.08	0.23	0.16
<b>0-17</b>	<b>123</b>	<b>163</b>	<b>286</b>	<b>100</b>	<b>682,991</b>	<b>727,850</b>	<b>1,410,841</b>	<b>0.18</b>	<b>0.22</b>	<b>0.20</b>

Source: Death Registry of Catalonia. Information Management and Analysis Services for Strategic Planning. Directorate-General for Health Planning. Ministry of Health. Government of Catalonia.

# Annex 4

## Guidelines for registration and reporting caregiving activity

It is essential for the SAPPIs to enter the information on the children who have required this kind of care in the Registry of Minority Diseases. The information that must be included is:

- Patient identifier
- Name of disease
- Diagnosis date
- Date added to the SAPPI (variable yet to be created)

In parallel, hospitals with a SAPPI will create the hospital care service called “Paediatrics: palliative care” (code yet to be created).

The report of the caregiving activity provided by these units should be made in the MBDS according to the type of activity (following the regulations and the CatSalut reporting manuals). Based on standard criteria that allows this information to be integrated and compared, it should be used for:

- Planning healthcare services: identifying needs given the attended morbidity, developing certain health profiles among the population attended, analysis of the use of services, etc.
- Evaluating healthcare interventions: evaluating interventions prioritised by the Health Plan and evaluation of other situations within the sphere of health policy for attending to certain health problems and/or population groups.

The hospital admission generated in which the doctor in the SAPPI is the referral for the admission in the MBDS of acute hospitals (MBDS-AH should be reported). The goal of the MBDS-AH registry in its entirety is to have information on the morbidity attended to in admissions, in resources associated with hospitals, and in the case of the SAPPIs, to register information on the conventional hospitalisation activity of these units. In order to ensure that the MBDS-AH is fulfilled properly, the instructions and recommendations described in the CatSalut General Acute Hospital Reporting Manual should be followed.

Specialist outpatient activity and home visits must be reported in the MBDS on specialist outpatient care (MBDS-SOC), as the unit of information collection of the registry is the patient visit. In order to properly comply with the MBDS-SOC, the instructions and recommendations described in the CatSalut Specialised

Out-Patient Care Reporting Manual should be followed, bearing in mind the following considerations:

- Out-patient visits to external offices should be reported following the MBDS-SOC as:
  - Type of activity: external appointment (135).
  - Means of the visit: in-person in a healthcare centre (presence of one professional [10] or presence of more than one professional [11], as appropriate).
- A thematic consultation with the child or young person or their family or via any remote means (telephone, video conference, email, etc.) should be reported as:
  - Type of activity: external appointment (135).
  - Means of the visit: not in-person (synchronous [20] or asynchronous 21], as appropriate).
- A visit by the child or young person in the hospital (as a support visit for another hospitalisation service) should be reported as:
  - Type of activity: external appointment (135).
  - Means of the visit: in-person in a healthcare centre (presence of one professional [10] or presence of more than one professional [11], as appropriate).
- An in-person home visit should be reported as:
  - Type of activity: external appointment (135).
  - Means of the visit: in-person at home (presence of one professional [12] or presence of more than one professional [13] as appropriate [these values of this variable have yet to be created]).

Currently, the professionals at the SAPPIs may make reports that are shared in the child or adolescent's HCCC, even though they may not create the PIIC.

In cases in which the SAPPIs are established as the referents in the child or adolescent's care, they should write a report with the therapeutic plan and factors of interest to ensure continuity of care. That is, they should draw up a plan with the specific, exhaustive care plan for a person with one or more chronic health problems which bears in mind their physical, psychological, social and spiritual needs, and which must be agreed upon by the different health and social professionals and the child or adolescent, or their family, if appropriate.

It should also mention the instructions to be followed if the child or young person is attended by a team other than the usual one, which identifies their values and preferences, or those of their family, if applicable, in order to prepare the care objectives and resources needed to attend to them.

This report must include:

- Patient data (administrative and relevant clinical data, such as weight)
- Data on the reference professionals (from primary paediatric care and from the SAPPI).
- Relevant diagnoses.
- Medication plan (magistral formulas should be included) and non-pharmacological measures.
- Allergies and adverse reactions.
- Recommendations in case of crisis or decompensation:
  - Specific recommendations (including the most frequent or likely ones in each case (fever, shortness of breath, pain, epileptic fits, etc.); the care level to which they are referred should be appropriate (reference hospital [specify which one]; primary care centre or emergency primary care centre; immediate home care; non-immediate home care; telephone consultation [specify where]).
  - Generic recommendations and comments on communication and information with the child or young person and their family.
- Early decision planning: other relevant information (desired place of death, etc.).
- Relevant information from the multidimensional assessment (state of the situation and functional, nutritional, cognitive, emotional, social and spiritual needs).
- Information on the care resources involved (describe which ones and the timetables of the resources, as well as the care services attending to the child or adolescent).
- Additional information of interest on their care.
- Relations (information on the main caregiver, legal guardian, custody holder or other relevant information).
- Data on the referent professional in the PIIC.

This report should be updated whenever there are important clinical changes (turning point, change in therapy, changes in location or important family members, etc.), and least once a year in the most stable cases.

It is essential to share the report with all the professionals in the network to facilitate continuous and integrated care. It is important to ensure that the hospitals involved publish the report on the HCCC no more than 24 hours after it is created to guarantee its usefulness. At the same time, it is recommended that this report be conveyed to the child or adolescent's primary care team so that they can create the PIIC in the HCCC in order to make it easily visible throughout the entire healthcare system.

The document code and description shall be as follows:

Document code	Document description
114551000135106	shared individual intervention plan



# Annex 5

## **Working groups in alphabetical order**

Herminia Biescas  
Íngrid Bullich  
Cristina Casanovas-Guitart  
Carla Cusó  
Roser Francisco  
Olimpia Garcia  
Teresa Gili  
Gemma Gómez  
Àlex Guarga  
Soraya Hernández  
Andres Morgenstern  
Sergi Navarro  
Sebastià Santaeugènia  
Daniel Toro

## **Other participants in alphabetical order**

Jordi Amblàs  
Paloma Amil  
Ignasi Bocanegra  
Joan Carles Contel  
Esther Gil  
Gemma Giráldez  
Cristina Mallol  
Maria Rosa Martínez  
Eva Maria Melendo  
Victòria Mir  
Marta Palomares  
Alfonso Pozuelo  
Glòria Ribas  
Xavier Salvador  
Elisabeth Vallès  
Emili Vela  
Lluís Vilardell

## **Reviewers in alphabetical order**

Anna Mompart  
M. Jesús Pueyo

