Which country are you answering the questionnaire for?
In the following, we will ask you about general information regarding national regulations for PPC in your country.
Do you have a national plan or strategy for PPC in your country?
1. Yes
2. No
<ul><li>3. Under developement</li><li>4. Other relevant plans or strategy</li></ul>
5. I do not know
1. When was the national plan or strategy published? Please indicate the respective year, if possible. In case you cannot make an educated guess, please enter "000"
Camillot make an educated guess, pieuse enter 1999
2. How long has the plan or strategy been in effect? Please report the approximate number of years. In case you
cannot make an educated guess, please enter "000"
What are the main objectives for PPC included in the plan or strategy?
4. De como insulant autation alon fonthe notice el alon en state en exist?
4. Does an implementation plan for the national plan or strategy exist?
1. Yes
2. No
3. I do not know
Do you have national networks, associations or taskforces specifically designated for PPC? (A national network of PPC
is formed by people interested in the advancement of PPC provision in a specific country and must be a registered
association)

Yes
 No

4. Other

3. I do not know

**Supplemental Material 1.** Online questionnaire on PPC structures in Europe used for the study purpose.

The network's name in your national language:
The network's name in English:
The network's internet address:
And the second s
At this point, participants could indicate additional networks.
Do you have regional networks, associations or taskforces specifically designated for PPC?
1. Yes
<ul><li>2. No</li><li>3. I do not know</li></ul>
3. Tue not know
The network's name in your national language:
The network's name in English:
THE NECWORK'S HUME IT ENGISH.
The network's internet address:

At this point, participants could indicate additional regional networks.

Do any published national documents regarding standards and norms for the provision of PPC exist in your country? Official documents specify requirements that PPC services should adhere to. They also demonstrate guidelines for the development, equipment and configuration of services required for adequate structural quality.

- 1. Yes
- 2. No
- 3. Under development
- 4. I do not know
- 5. Other

In the following, we will ask you about specific information regarding specialized PPC services available in your country. We will ask you about: Specialized Pediatric Palliative Home Care (SPHHC), Clinical Consultation Services, Pediatric Palliative Care Units, Inpatient children's and adolescents' hospices, Outpatient children's hospice Services.

Are Specialized Pediatric Palliative Home Care (SPHHC) Teams available in your country? The main objective of SPHHC teams is to provide and/or coordinate palliative care for children (0-18 years old) with life-threatening or life-limiting conditions at home. The team is managed by a professional and furthermore almost exclusively consists of professionals, though it may be supported by volunteers. Note: SPPHC may be offered by the clinical consultation service. If this applies to your country, please select "yes"; on this page and later on also provide information on clinical consultation services.

- 1. Yes, available in my country
- 2. No, not available in my country

Approximate number of SPPHC teams in your country:  This information is very important for us. If you do no	t know
the exact number of teams, please try to make an educated guess. Only in case you absolutely do not know, $\epsilon$	enter
"000"	

#### Are SPPHC teams and clinical consultation services unified in one team in your country?

- 1. Yes, each team functions as a SPPHC team and also provides clinical consultation services
- 2. Not always, combined and separate teams exist
- 3. No, the teams are never combined but are always separate

At this point, participants could indicate additional specialized pediatric palliative home care teams.

#### Where do SPPHC teams exist in your country?

- 1. Available in all regions
- 2. Availabe in most regions
- 3. Available only in a few regions
- 4. Other

#### How are the SPPHC teams mainly financed / funded?

- 1. Government funding
- 2. Health insurances
- 3. Donations

4. Other

Is there additional funding for the SPPHC team	ls there	additional	funding	for the	<b>SPPHC</b>	teams
--	----------	------------	---------	---------	--------------	-------

- 1. Government funding
- 2. Health insurances
- 3. Donations
- 4. Other

# Where are the SPPHC teams based?

- 1. Exclusively hospital-based
- 2. Mostly hospital-based
- 3. Exclusively community-based
- 4. Mostly community-based

Which professions are part of the SPPHC teams?

	Part of all	Part of some	Part of no	I do not
	teams	teams	team	know
Physicans				
Nurses				
Psychologists				
Social workers				
Volunteers				
Spiritual Support (e.g., chaplain, rabbi)				
Grief Counselor				
Others				

Who is mainly responsible for the management of the respective SPPHC teams?

	All teams	Some teams	No team	I do not know
Physicans				
Nurses				
Psychologists				
Social workers				
Spiritual support (e.g., chaplain,rabbi)				
Others				

	All teams	Some teams	No team	I do not know
Care Coordination				
Medical Care				
Nursing Care				
Social Support				
Psychological counseling				
Psychotherapy (support for siblings/families)				
Legal consultation				
Grief counseling				
Bereavement support				
Spiritual guidance/support (e.g., chaplain, rabbi)				
24h/7d telephone consultation				
24h/7d outreach service				
Others				
Perinatal		teams		know
	By all teams	By some	By no team	I do no
Perinatal				
Neonatal				
Oncological patients, solid tumors				
Oncological patients, leukemia				
Non-oncological patients (not ventilated)				
Non-oncological patients (ventilated)				
Other				
hen may the services of the SPPHC teams be used?  1. From the diagnosis of a life-limiting/life-thread.  2. Only during the end-of-life period.  3. Other  ow is the access to the SPPHC teams regulated?		is onward, inc	luding the end	d-of-life po
Access only via referral				
2. Services may be privately arranged				
3. Other				
hat is the regular upper age restriction for the utilized	zation of SPPH	IC teams?		

Do you have further comments about the regular age restriction?
Is the utilization of SPPHC teams limited in time? (e.g., 4 weeks per year)
1. Yes, utilization is limited in time
2. No, utilization is not limited in time
Is the utilization of SPPHC teams free of charge for the families?
1. Yes
2. No
Do you have any further information on SPPHC teams in your country for us that we should consider when assessing
the state of PPC in the EU?
Are specialized pediatric palliative care clinical consultation services available in your country? Specialized pediatric
palliative care clinical consultation services work inside the hospital and support families and other physicians/nurs
when children and their families have palliative care needs, irrespective of their diagnosis.
1. Yes, available in my country
2. No, not available in my country
Approximate number of specialized clinical consultation services in your country. This information is very important
for us. If you do not know the exact number of teams, please try to make an educated guess. Only in case you
absolutely do not know, enter "000".
Where are the specialized clinical consultation services available in your country?

- 1. Available in all hospitals
- 2. Available in most hospitals
- 3. Available only in a few hospitals
- 4. Other

How are the specialized clinical consultation services mainly financed / funded?

- 1. Government funding
- 2. Health insurances
- 3. Donations
- 4. Other

Is there additonal funding for the specialized clinical consultation ser
--

- 1. No additional funding
- 2. Government funding
- 3. Health insurances
- 4. Donations
- 5. Other

Which	nrofessions are	nart of the s	pecialized clinica	I consultation	services?
VVIIICII		part or the 3	pecianzea eminea	i consultation	SCI VICCS:

	For all teams	For some	For no teams	I do not
		teams		know
Physicians				
Nurses				
Psychologists				
Social Workers				
Volunteers				
Spiritual Support (e.g. chaplain, rabbi)				
Grief Counselor				
Others				

How do the specialized clinical consultation services support the families?

	All teams	Some teams	No team	I do not know
Care coordination				
Medical care				
Nursing care				
Social Support				
Psychological counseling				
Psychotherapy support for siblings/families				
Legal consultation				
Grief counseling				
Spiritual guidance/support (e.g., chaplain, rabbi)				
Bereavement support				
24h/7d telephone consultation				
24h/7d outreach services				
Other				

# Which patients are cared for by the specialized clinical consultation services?

Triner patients are carea ior by the specialized chine				
	By all teams	By some	By no team	I do not
		teams		know
Perinatal				
Neonatal				
Oncological patients, solid tumors				
Oncological patients, leukemia				
Non-oncological patients (not ventilated)				

	Non-oncological patients (ventilated)				
	Other				
		_	_	_	
When	may the services of the specialized clinical con	sultation serv	ices be used?		
1.	From the diagnosis of a life-limiting/life-threa	tening diagnos	sis onward, ind	luding the en	d-of-life period
2.	Only during the end-of-life period				
3.	Other				
	specialized clinical consultation service a fixed		f the care child	dren with life	-limiting conditions/
	ening conditions and their families receive in t	the hospital?			
	Yes				
	No				
3.	Other				
Do any service	$v$ age restrictions regarding the affected child $\epsilon$ es?	exist for the ut	ilization of sp	ecialized clini	cal consultation
1.	Yes				
2.	No				
a <b>+ h</b> a .	stilination of annaiglinad aliminal approximation a	omicos fues of	charge for the	s formilias?	
	utilization of specialized clinical consultation so Yes	ervices free of	charge for the	e tamilies?	
	No				
۷.	NO				
PPC pa consid 1.	diatric Palliative Care (PPC) units available in y itients. PPC units do not provide respite care. I ered a PPC unit. Yes, available in my country No, not available in my country	•		-	•
• •	ximate number of PPC units in your country. T number of teams, please try to make an educa				•
not kn	kimate total number of beds of all PPC units in ow the exact number of teams, please try to n solutely do not know, enter "000".	-		-	•
,					

Please provide the internet address of the PPC unit:				
At this point, participants could indicate the internet	address of ad	ditional pedia	tric palliative	care units.
Where do PPC units exist in your country?				
1. Available in all regions				
2. Available in most regions				
3. Available only in a few regions				
4. Other				
How are the PPC units mainly financed / funded?				
<ol> <li>Government funding</li> </ol>				
2. Health insurances				
3. Donations				
4. Other				
Is there additional funding for the PPC units?				
<ol> <li>Government funding</li> </ol>				
2. Health insurances				
3. Donations				
4. Other				
Which professions, besides physicians and nurses, w	ork on the PPC	units?		
	On all units	On some	On no unit	I do not
		units		know
Psychologists				
Social workers				
Volunteers				
Spiritual Support (e.g., chaplain, rabbi)				
Others				
How do the PPC units support the families, besides the	he provision o	f medical and	nursing care?	
	All units	Some units	No unit	I do not
				know
Case management				
Social support				
Legal support				
Psychological counseling				
Grief counseling				
Psychotherapy for siblings/families				
Spiritual support (e.g., chaplain, rabbi)				

Other

#### Which patients are treated on the PPC units?

	On all units	On some	On no unit	I do not
		units		know
Neonatal				
Oncological patients, solid tumors				
Oncological patients, leukemia				
Non-oncological patients (not ventilated)				
Non-oncological patients (ventilated)				
Other				

#### When may the services of the PPC units be used?

- 1. From the diagnosis of a life-limiting/life-threatening diagnosis onward, including the end-of-life period
- 2. Only during the end-of-life period
- 3. Other

#### How is the access to the PPC units regulated?

- 1. Access only via referral
- 2. Services may be privately arranged
- 3. Other

Do any age restrictions regarding the affected child exist for the utilization of the PPC units?

- 1. Yes
- 2. No

### Is the utilization of PPC units limited in time? (e.g., 4 weeks per year)

- 1. Yes, utilization is limited in time
- 2. No, utilization is not limited in time

#### Is the utilization of PPC units free of charge for the families?

- 1. Yes
- 2. No

Do you have any further information on the PPC units in your country for us that we should consider when	assessing
the state of PPC in the EU?	

the state of the and the Lo.		

Are Inpatient Children's and Adolescents' Hospices available in your country? Children's and Adolescents' Hospices are inpatient institutions that are managed by a professional. They provide respite care as well as terminal care to children and their families. For respite care, children may spend time in the hospice, with or without the family being present. For terminal care, children and their family, if desired, stay in the hospice until death.

- 1. Yes
- 2. No

Approximate number of pediatric hospices in your country: This information is very important for us. If you do know the exact number of teams, please try to make an educated guess. Only in case you absolutely do not know enter "000".	
Approximate total number of beds of all pediatric hospices in your country (rough estimation ok)This informativery important for us. If you do not know the exact number of teams, please try to make an educated guess. Coase you absolutely do not know, enter "000".	

## Where do pediatric hospices exist in your country?

- 1. Available in all regions
- 2. Available in most regions
- 3. Available only in a few regions
- 4. Other

## How are the pediatric hospices mainly financed/funded?

- 1. Government funding
- 2. Health insurances
- 3. Donations
- 4. Other

## Is there additional funding for the pediatric hospices?

- 1. Government funding
- 2. Health insurances
- 3. Donations
- 4. Other

## Which professions are employed in the pediatric hospices?

processors and employee in the promise in				
	In all	In some	In no hospice	I do not
	hospices	hospices		know
Physicans				
Nurses				
Psychologists				
Social workers				
Volunteers				
Spiritual Support (e.g., chaplain, rabbi)				
Others				

How do pediatric hospices support the families?

	All hospices	Some hospices	No hospice	I do not know
Medical Care				
Nursing Care				
Case management				
Social support				
Legal support				
Psychological counseling				
Psychotherapeutic support for siblings/families				
Grief counseling				
Bereavement support				
Spiritual support (e.g. chaplain, rabbi)				
Educational support				
Cold room				
Other				

Which patients are accommodated in the pediatric hospices?

·	_ •	,	,	
	On all	On some	On no	I do not
	hospices	hospices	hospice	know
Neonatal				
Oncological patients, solid tumors				
Oncological patients, leukemia				
Non-oncological patients (not ventilated)				
Non-oncological patients (ventilated)				
Other				

## When may the services of the pediatric hospices be used?

- 1. From the diagnosis of a life-limiting/life-threatening diagnosis onward, including the end-of-life period
- 2. Only during the end-of-life period
- 3. Other

#### How is the access to pediatric hospices regulated?

- 1. Access only via referral
- 2. Services may be privately arranged
- 3. Other

## Do any age restrictions regarding the affected child exist for the utilization of pediatric hospices?

- 1. Yes
- 2. No

## Is the utilization of pediatric hospices limited in time? (e.g., 4 weeks per year)

- 1. Yes, utilization is limited in time
- 2. No, utilization is not limited in time.

1. 165		
2. No		
How is the pediatric hospice operation	on regulated by the local/national health authorities?	
The pediatric respice operation	in regulated by the local, national neutrin authorities.	
Do you have any further information of assessing the state of PPC in the EU?	on pediatric hospices in your country for us that we should co	onsider when
services usually almost exclusively con support the family at home temporar 1. Yes, available in my country	vices (hospice-at-home) available in your country? Outpatient nsist of volunteer workers who provide respite and psychosocily during the day and thereby allow for more free time in dai	cial support. They
2. No, not available in my country	У	
	hildren's hospice services in your country: This information is ber of teams, please try to make an educated guess. Only in c	
Where do outpatient children's hospi	ce services exist in your country?	
<ol> <li>Available in all regions</li> <li>Available in most regions</li> </ol>		
z. Avaliable III IIIOSI (ESIONS		

How are the outpatient children's hospice services mainly financed / funded?

Is the utilization of pediatric hospices free of charge for the families?

1. Government funding

3. Available only in a few regions

- 2. Health insurances
- 3. Donations
- 4. Other

4. Other

Is there additional funding for the outpatient children's hospice services?

- 1. Government funding
- 2. Health insurances
- 3. Donations
- 4. Other

	For all teams	For some	For no team	I do not
		teams		know
Volunteers				
Professional manager				
Other employees				
do the outpatient children's hospice service	s support the fam		No toom	I do not
	All teams	Some teams	No team	know
Spending time with the affected child				
Spending time with healthy siblings				
Nursing support				
Helping with household chores				
Dayahalagigal support				
Psychological support	_			
Other  you have any further information on outpatie	ent children's hosp	ice services in	your country	for us that
	ent children's hosp EU? etric Palliative Hom	ice services in ne Care (SPHH d adolescents	your country IC), Specialized	for us that d Clinical Co utpatient ch
Other  you have any further information on outpatie is ider when assessing the state of PPC in the E  have now asked you about: Specialized Pedia vices, Pediatric Palliative Care Units (PPC)Inpa is pice services. Are there other specialized pedia assess in this questionnaire?	ent children's hosp EU? etric Palliative Hom	ice services in ne Care (SPHH d adolescents	your country IC), Specialized	for us that d Clinical Co utpatient ch

- 2. Nurse
- 3. Psychologist
- 4. Social worker
- 5. Other

## How are you involved in PPC?

- 1. Actively providing care
- 2. Administrative services
- 3. Active membership in PPC networks/associations
- 4. Passive membership in PPC networks/associations
- 5. Other

# Would you like to become a member of the European Network for Pediatric Palliative Care that we aim to establish with the collected data?

- 1. Yes, please keep me updated.
- 2. No, thank you.

This is the end of the questionnaire. Thank you very much for providing us with data on specialized pediatric palliative care in your country!