

The state of Pediatric Palliative Care in Luxembourg: An Exploratory Mixed Methods Study

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What services are available for children with life-limiting or life-threatening conditions, and what is the status of pediatric palliative care in Luxembourg?



- Over **21** million children globally require a palliative approach. Of this, more than **8** million need specialized palliative care services for children. (Connor et al, 2017)
- Around 170,000 children will die every year in Europe with health-related suffering and no access to palliative care. (Arias-Casais, Garralda, & Rhee, 2019)
- In Luxembourg, the *National Cancer Plan* from 2014-2018 estimates that 8-10 children with cancer need end-of-life care, while 40-50 children require palliative care yearly. (Direction de Santé, 2014)

Pediatric Palliative Care Services

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Table 2 Availability of national pediatric palliative care activities and pediatric palliative care services per country^a

	national pediatric palliative care activities			pediatric palliative care services									
	plan/ strategy		networks	documents	PPHC	CCS	PPCU	ICAH	OCHS	nr (nr beds)		nr (nr beds)	
	exist	since	exist	exist	exist	nr	exist	nr	exist	nr (nr beds)	exist	nr (nr beds)	exist
Albania	●		●	●	●		●		●		●		●
Armenia	●		●	●	●		●		●		●		●
Austria	●		●	●	●	14	●		●	4(8)	●	1(4)	●
Belarus	●	2012	●	●	○		●		○		○	3(25)	○
Belgium	●		●	●	●	6	●	5	●		●		●
Bosnia and Hercegovina	●		●	●	●		●	11	●		●		●
Croatia	●		●	●	●		●	1	●		●		●
Czech Republic	●		●	●	●	3	●	3	●		●		●
Denmark	●	2014	●	●	●	5	●	5	●		●	2(4)	●
Estonia	●		●	●	●		●	2	●		●		●
Finland	●	2019	●	●	●	5	●	5	●		●		●
France	●	2010	●	●	●	22	●		●	2(15)	●	17(200)	●
Germany	●		●	●	●	26	●	15	●		●		●
Greece	●		●	●	●	1	●		●		●		●
Hungary	●		●	●	●	3	●	2	●		●	1(5)	●
Iceland	●		●	●	●		●	1	●		●		●
Italy	●	2010	●	●	●	7	●	7	●		●	9(40)	●
Lithuania	●		●	●	●		●		●	4(14)	●	1(6)	●
Luxembourg	●		●	●	●		●		●		●		●
Malta	●		●	●	●		●		●		●		●
Netherlands	●	2013	●	●	●	8	●	8	●		●	14	●
North Macedonia	●		●	●	●		●		●		●	2	●
Norway	●	2016	●	●	●	10	●	3	●		●		●
Poland	●		●	●	●	66	●		●		●	8(80)	●
Portugal	●		●	●	●	1	●	5	●		●	1(30)	●
Republic of Ireland	●	2010	●	●	●		●	2	●		●	1(8)	●
Republic of Moldova	●		●	●	●	1	●		●		●	1(16)	●
Slovenia	●		●	●	●	2	●	2	●		●		●
Spain	●	2007	●	●	●	22	●	30	●	1(7)	●	1(8)	●
Sweden	●		●	●	●	1	●	7	●		●	1(8)	●
Switzerland	●		●	●	●	2	●	3	●		●		●
Turkey	●		●	●	●		●		●	7 (100)	●		●
United Kingdom	●		●	●	●	11	●	11	●		●	54	●
total	exist= yes	9	18	19	21	183	20	96	5	18(144)	16	117(434)	11

● existent ● non-existent ● under development ○ not stated

^a Exist Existence of, nr Number of, PPHC Pediatric palliative home care, CCS Clinical consultation services, PPCU Pediatric palliative care unit, ICAH Inpatient children and adolescents' hospices, OCHS Outpatient children's hospice service

Services of Pediatric Palliative Care in Europe

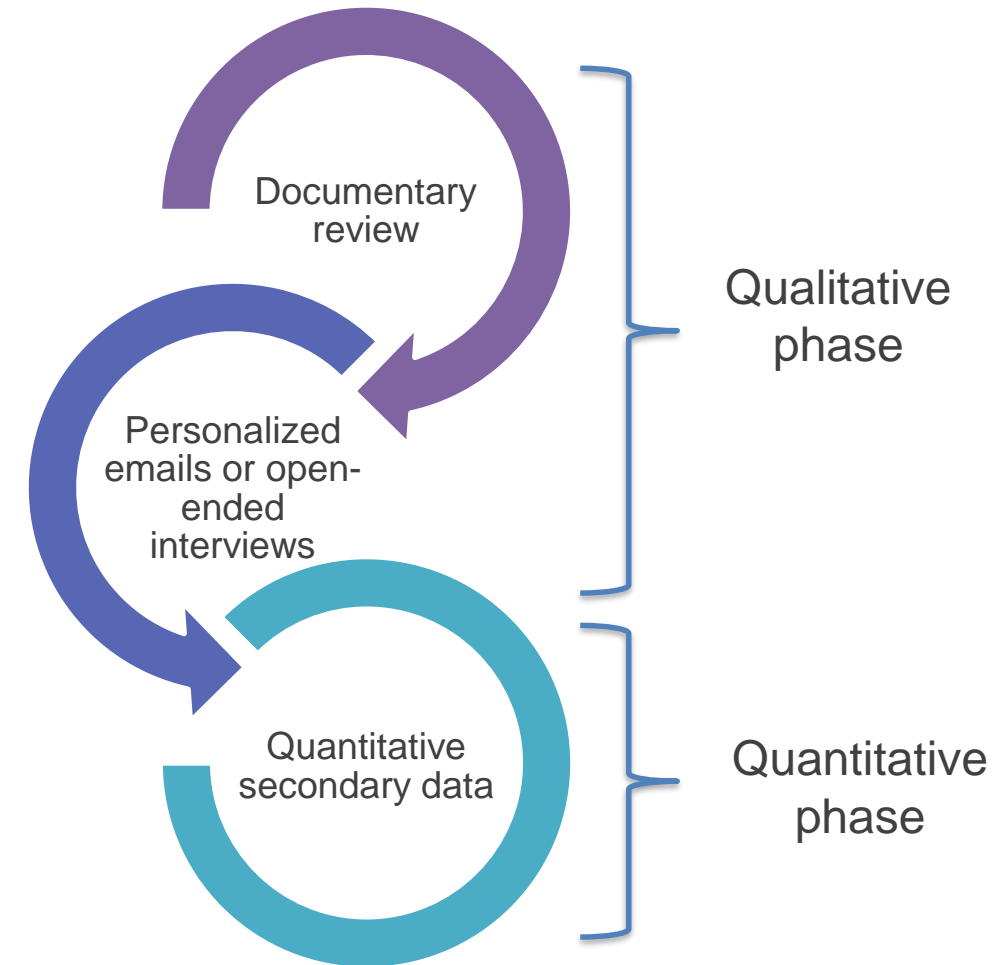
(Wager et al., 2022)



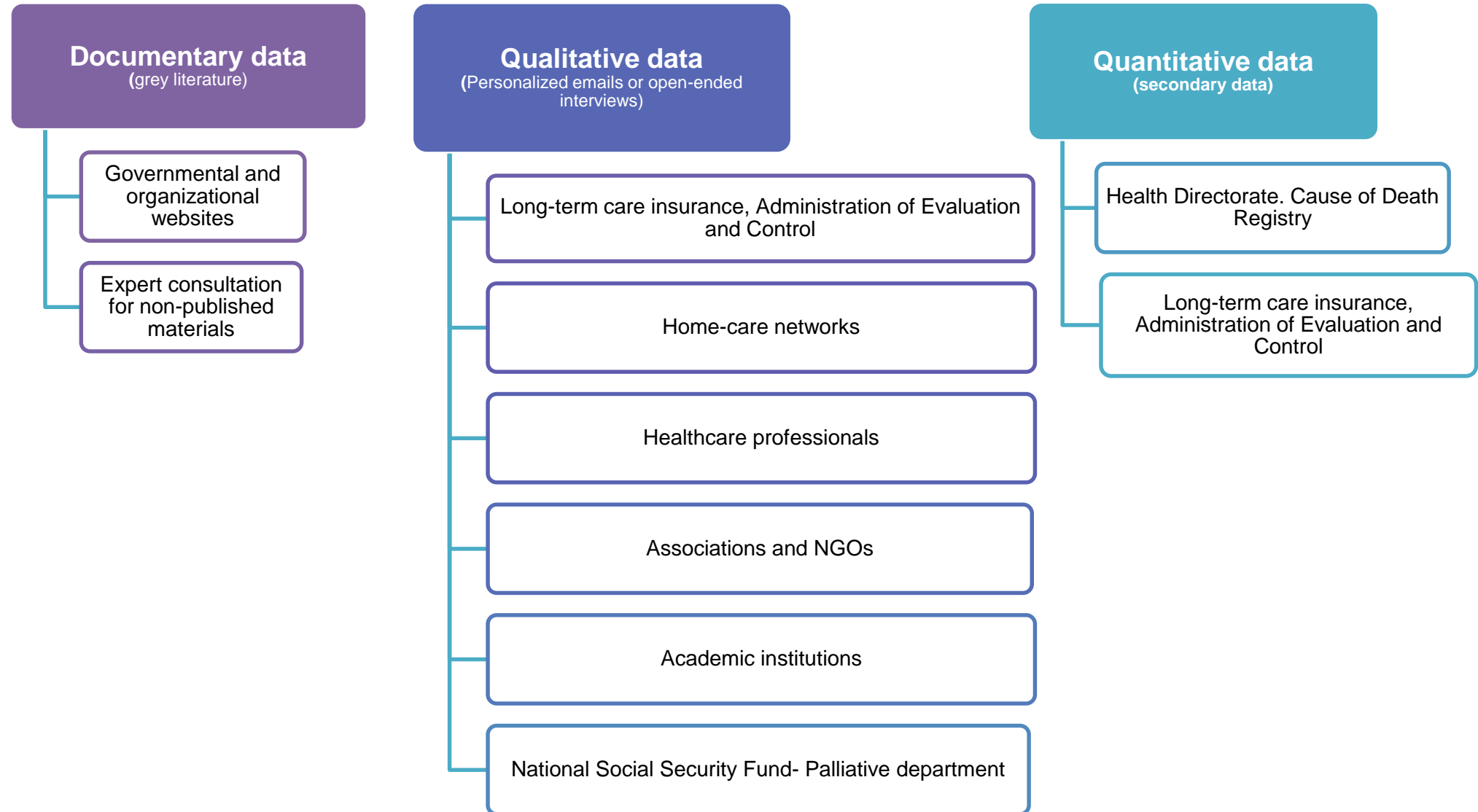
Source PowerPoint

*Building Upon Existing Knowledge, Our State-of-play
Sheds Light On Various Perspectives...*

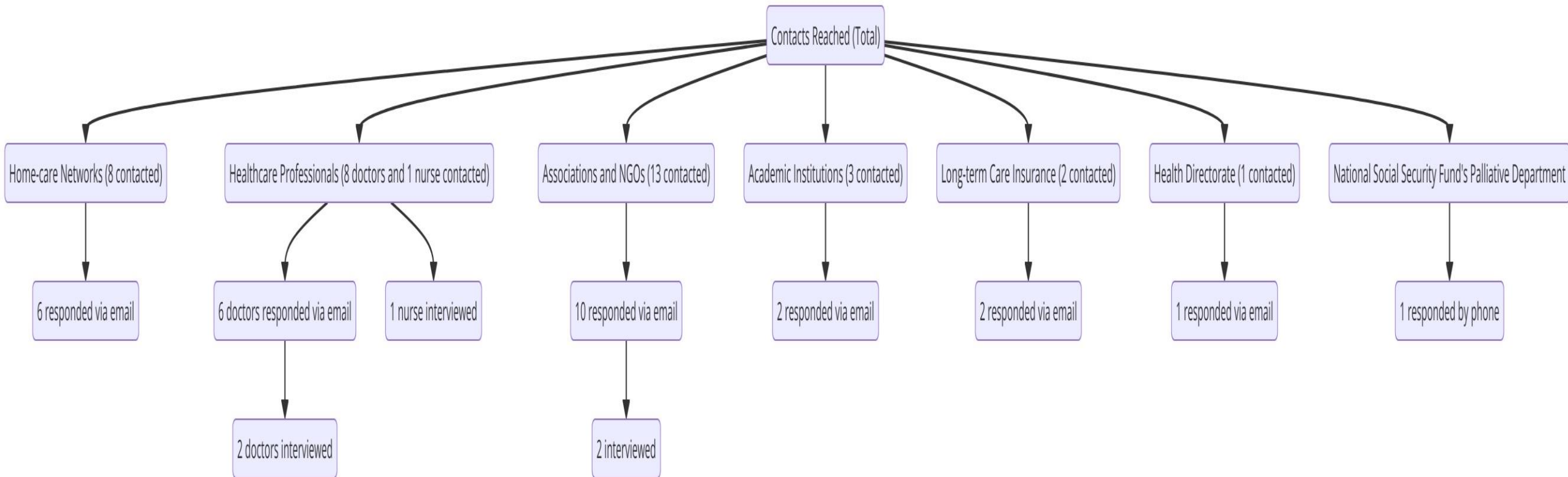
- January 2024 until May 2024
- *Design:* Exploratory Sequential mixed methods with a two-phase approach (Creswell & Clark, 2017)
- *Sampling:* Snowball and purposive
- *Recruitment:* Participants chosen for their experience, roles, and care for children with serious illnesses
- *Analysis:* Qualitative phase: Documentary analysis & Thematic analysis
Quantitative phase: Description of secondary data



Methodology: Data Collection



Methodology: Key Persons and Contact Response Overview



- Total responses via personalized emails: 27
- Total interviewed: 5
- Phone call: 1

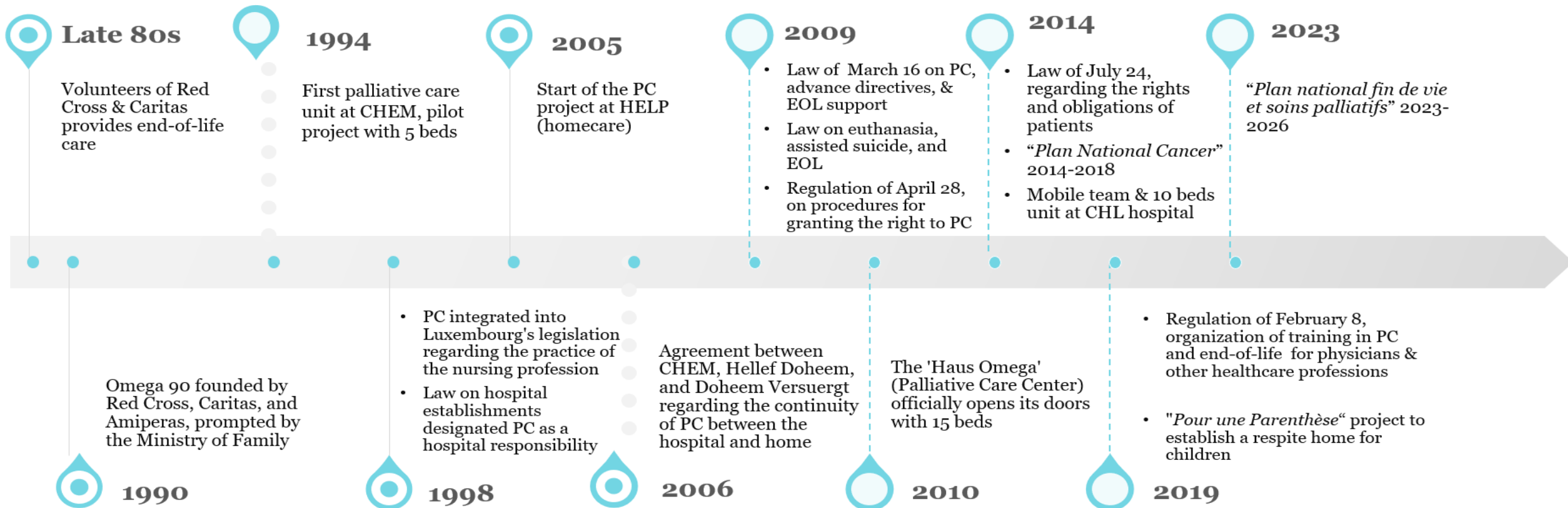
Qualitative data: Regulations and Services Overview

Progress of adult and pediatric palliative care in Luxembourg

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History timeline of palliative care in Luxembourg



■ The National Plan for End of Life and Palliative Care 2023-2026:

Axis 4: New care concept development specific to children

Organizing Pediatric Palliative Care

- Mobile expert team
- At diagnosis time, continues after age 18 up to age 27

➤ Providing Training In Pediatric Palliative Care

- PPC training into the nursing curriculum at UniLu (40 hours)
- General training on PPC

➤ Addressing The Issue Of Euthanasia And Assisted Suicide In Minors

- Prioritize PPC and psychological support for the family
- Adapt the legal framework

Establishment of a Respite Facility

- Offer tailored palliative care services to children and families



Accompanying leave

- 5 working days per case per year
- Terminally ill, first-degree or second-degree relatives

Leave for family reasons in the event of a child's illness

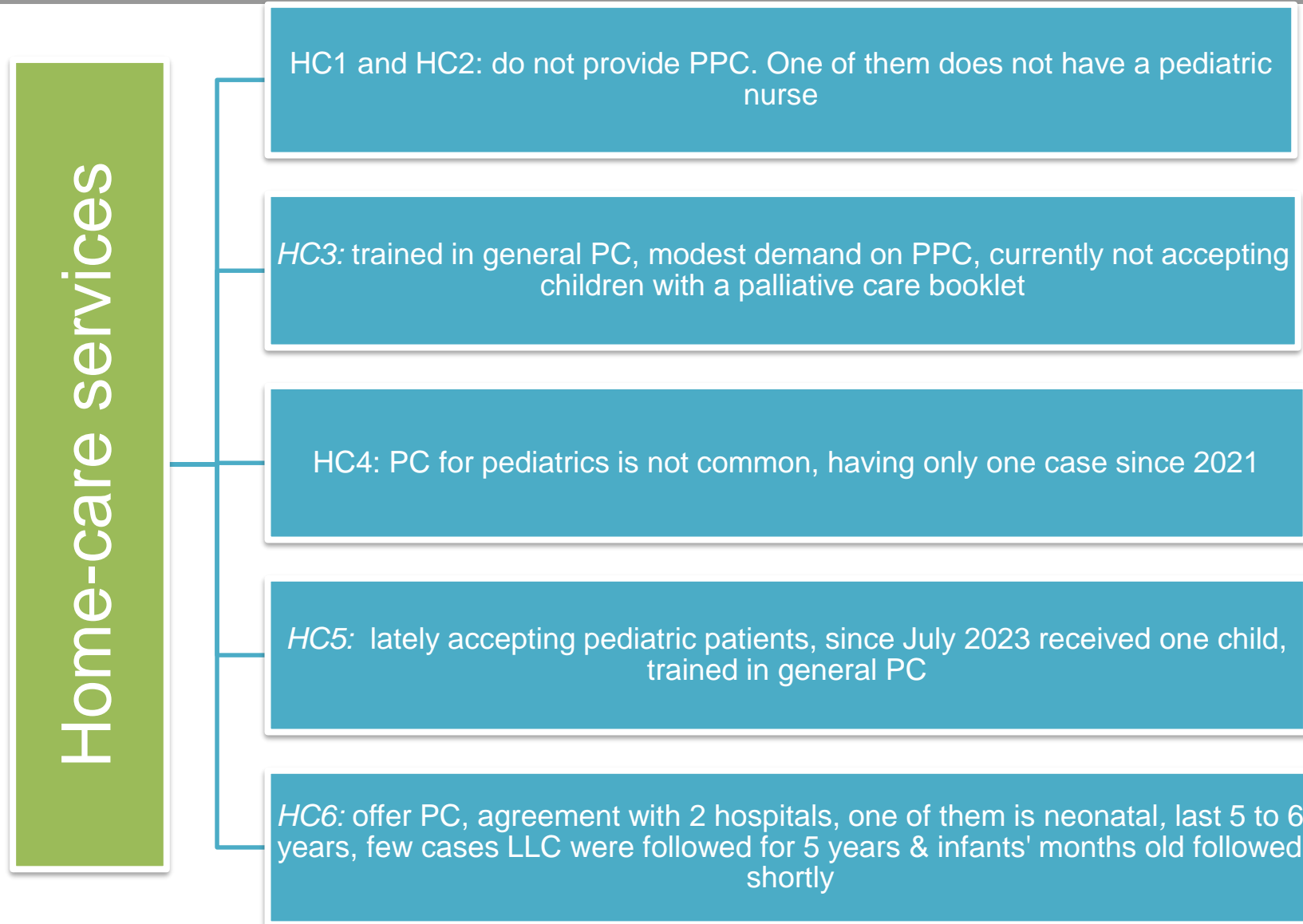
- Child under 18
- 0-4: 12 days off per child, 4-13: 18 days, 13-18: 5 days
- Maximum of 52 weeks

Supplementary allowance for children with a disability

- Cash assistance EUR 200

Night supervision

- Right for 10-day annual fee for night care



■ Hospitalization:

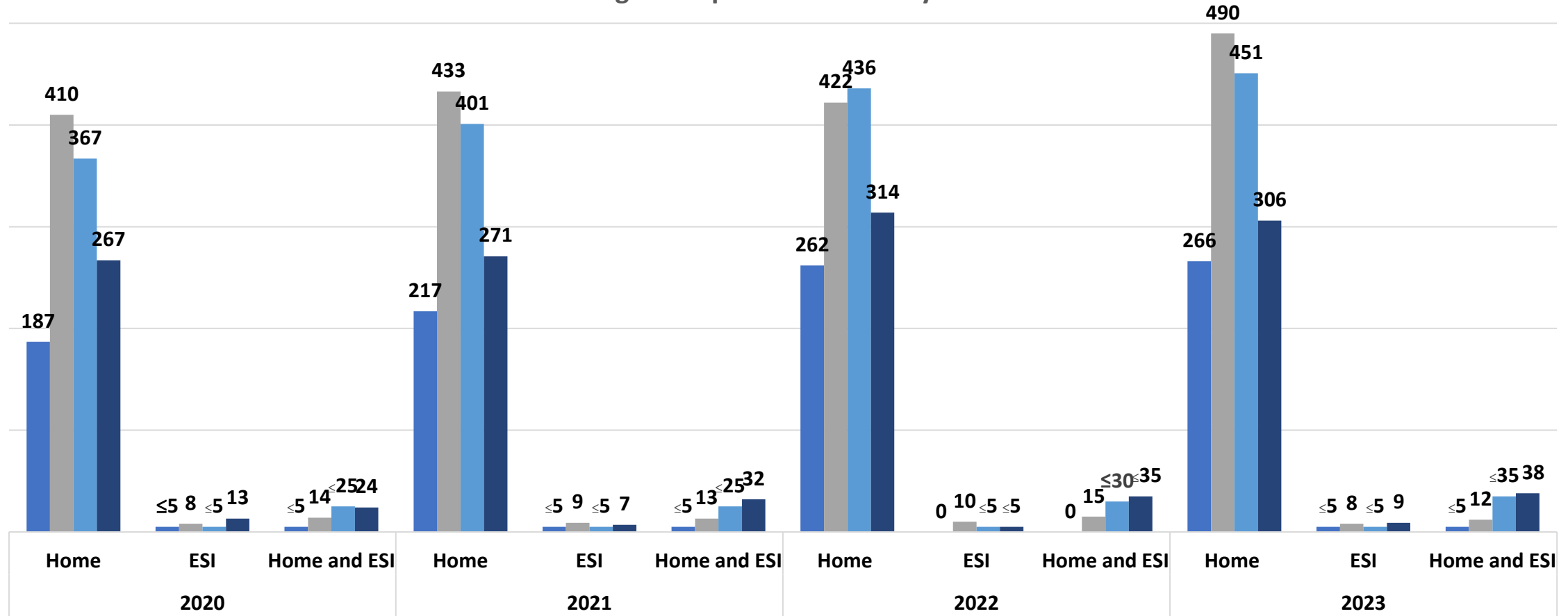
- At the Centre Hospitalier de Luxembourg (CHL) *KannerKlinik* in the general pediatric ward or the intensive care unit.
- Transferred to neighboring countries where enhanced expertise and resources are available

■ Key Associations

- Supporting children with serious illnesses and providing grief support for their families.

Quantitative Data: Long-term care insurance

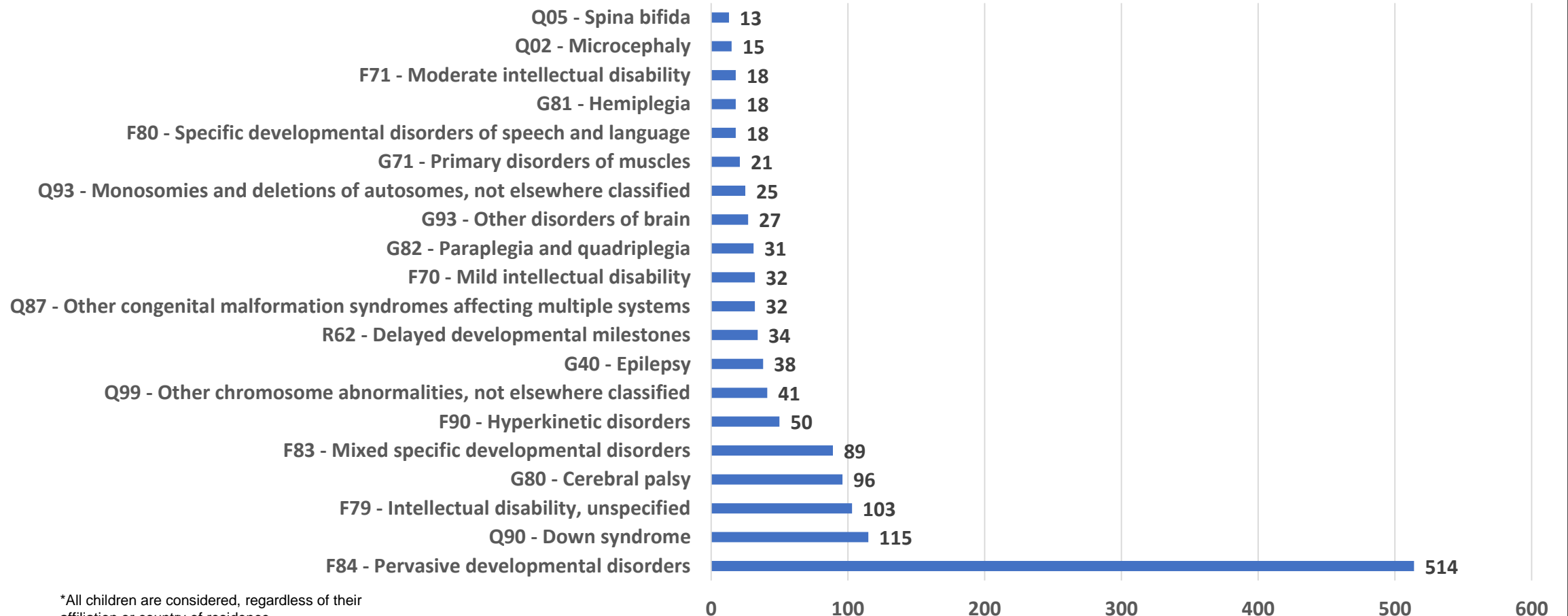
Annual Evolution Of Children's Care Coverage By Long-term Care Insurance (2020-2023): Age Groups & Place Of Stay



■ 0-4 ■ 5-9 ■ 10-14 ■ 15-19

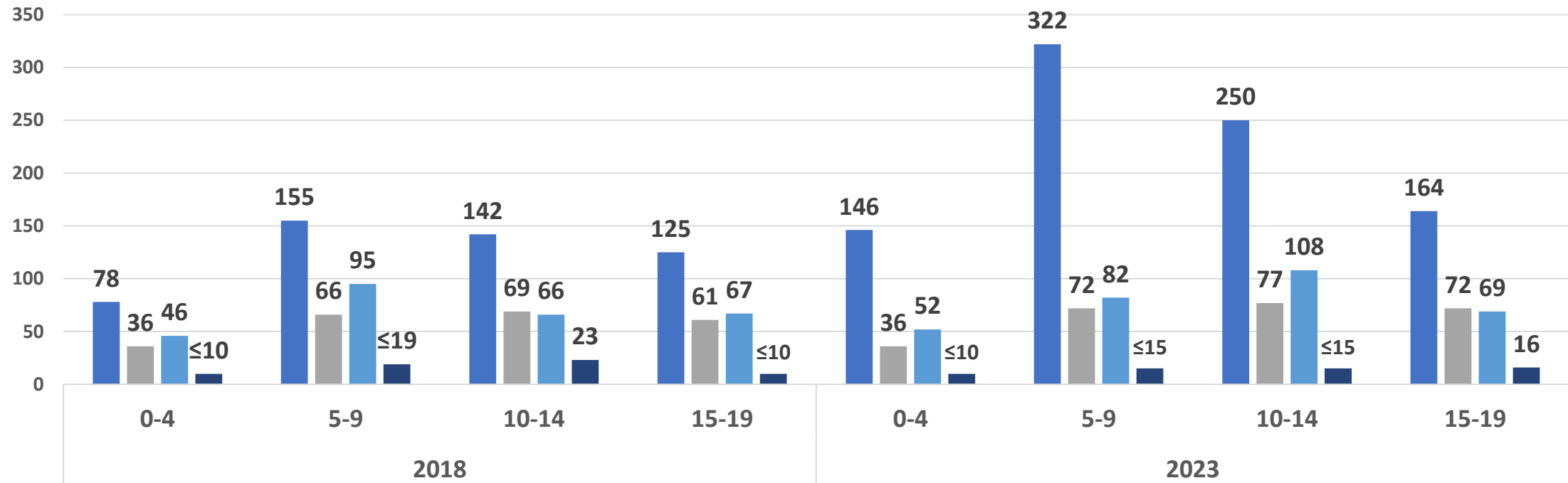
*Intermittent Stay and Care Establishments (ESI) *
* All children are considered, regardless of their affiliation or country of residence.

Top 20 Most Common Dependence Causes By ICD-10-CM For Children Benefiting From Care Synthesis By Long-term Care Insurance In 2023



*All children are considered, regardless of their affiliation or country of residence.

Comparison of 2018 and 2023 for Children Receiving Care Synthesis by long-Term Care Insurance: Age Groups and Across Four Main ICD-10-CM Chapters



- Mental and behavioral disorders
- Diseases of the nervous system
- Congenital malformations and chromosomal abnormalities
- Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified

*All children are considered, regardless of their affiliation or country of residence.

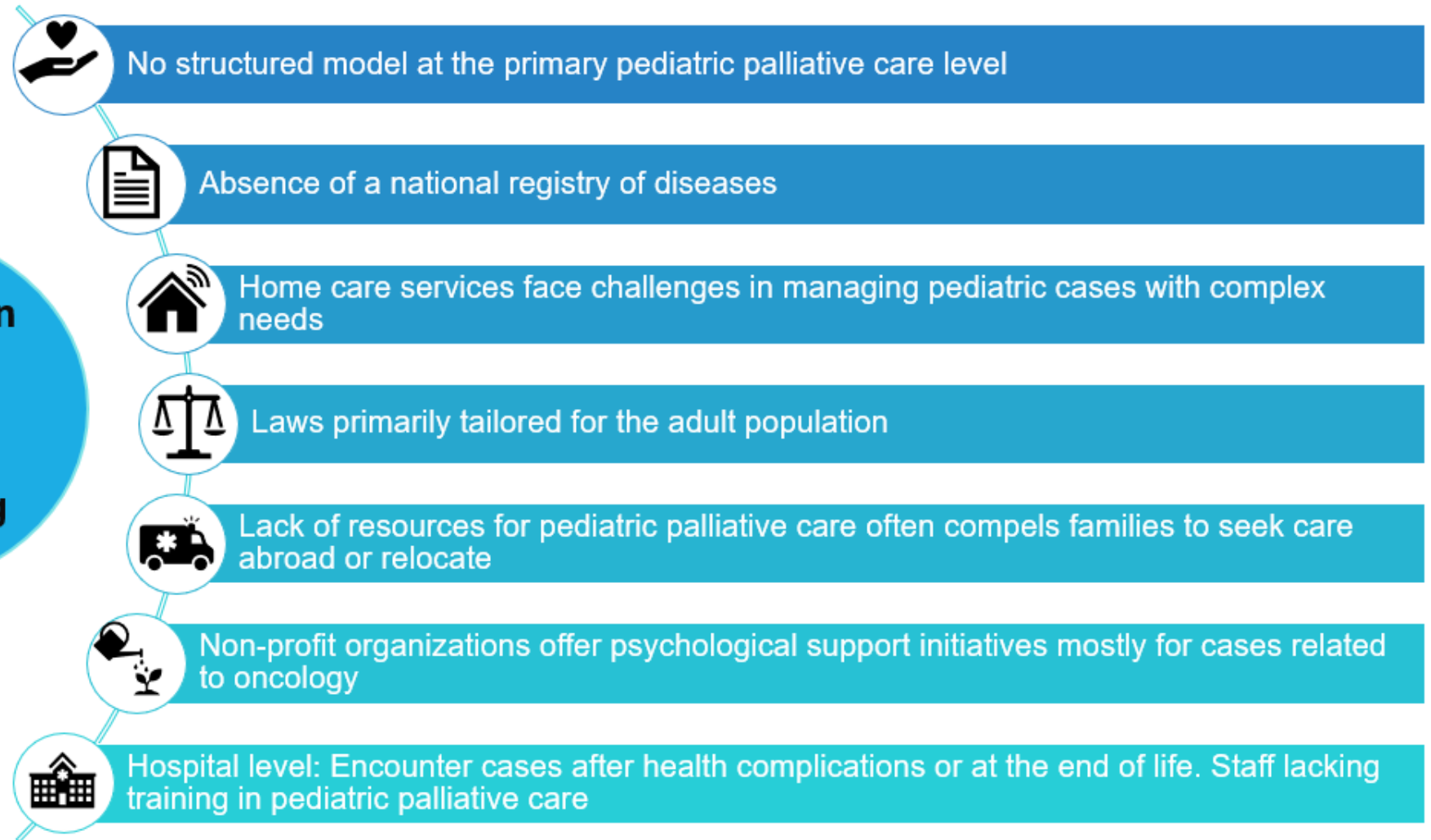
Challenges And Recommendations

Limitation

The **lack of a national registry** in Luxembourg limits the ability to accurately estimate needs, track changes over time, and plan and allocate services effectively



Challenges in Pediatric Palliative Care in Luxembourg



Recommendation

- Implement the National Plan for End of Life and Palliative Care 2023-2026
- Establishment of a mobile pediatric palliative care team within hospitals
- Provide general and specialized training within academic institutions and continuous education
- Adjust regulations for the pediatric population in PC
- Create a respite care facility
- Raise community awareness
- Provide psychosocial support services
- Review and adjust the eligibility criteria for long-term care insurance
- Expand medical coverage
- Establish and/or support associations dedicated to pediatric palliative care

- Connor, S. R., Downing, J., & Marston, J. (2017). Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis. *Journal of Pain and Symptom Management*, 53(2), 171–177. <https://doi.org/10.1016/j.jpainsymman.2016.08.020>
- Arias-Casais, N., Garralda, E., & Rhee, J. (2019). EAPC atlas of palliative care in Europe. Romania, 122, 0-6.
- Wager, J., Kubek, L. A., Brenner, M., Calmanti, S., Doyle, C., Lövgren, M., Kreicbergs, U., Kremer, L., Le Moine, P., Robert, G., Schuiling-Otten, M., Schröder-Bäck, P., Verhagen, E., & Zernikow, B. (2022). Expert survey on coverage and characteristics of pediatric palliative care in Europe – a focus on home care. *BMC Palliative Care*, 21(1), 185. <https://doi.org/10.1186/s12904-022-01078-0>
- Creswell JW, Clark VL. Designing and conducting mixed methods research. Sage publications; 2017 Aug 31.
- Grand-Ducal Regulation of 28 April 2009 determining the form and content of the care booklet for patients treated at the end of life. (Memorial A No.91 of 2009)
- Direction de Santé. (2014). Plan National Cancer Luxembourg 2014-2018. Concept de soins palliatifs pédiatriques validé le 30-09-2015 par la Plateforme Nationale Cancer.
- Direction de la Santé. (2023, June 30). Plan national fin de vie et soins palliatifs (2023-2026).
- Le gouvernement du Grand-Duché du Luxembourg. (2022, Juin 14). Allocation supplémentaire pour enfant vivant avec un handicap. Retrieved from: <https://guichet.public.lu/fr/citoyens/aides/famille-education/allocations-naissance/allocation-supplementaire-enfant-handicape.html>
- Law of 16 March 2009 on palliative care, advance directives, and end-of-life care. (Memorial A No. 46 of 2009)
- Grand-Ducal Regulation of 8 February 2019 on the organization of training in palliative care and end-of-life care for doctors, other health professionals, and staff in care services for the elderly. (Memorial A No.109 of 2019)



Thank you!