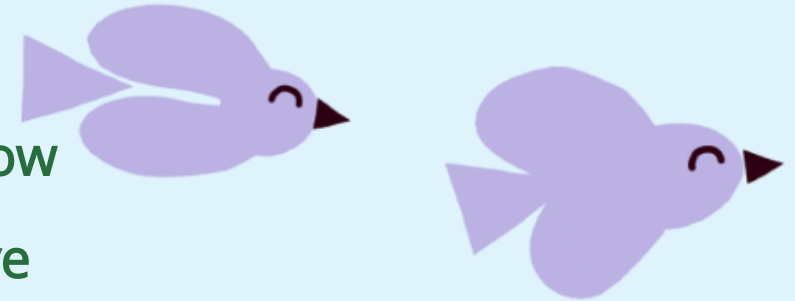




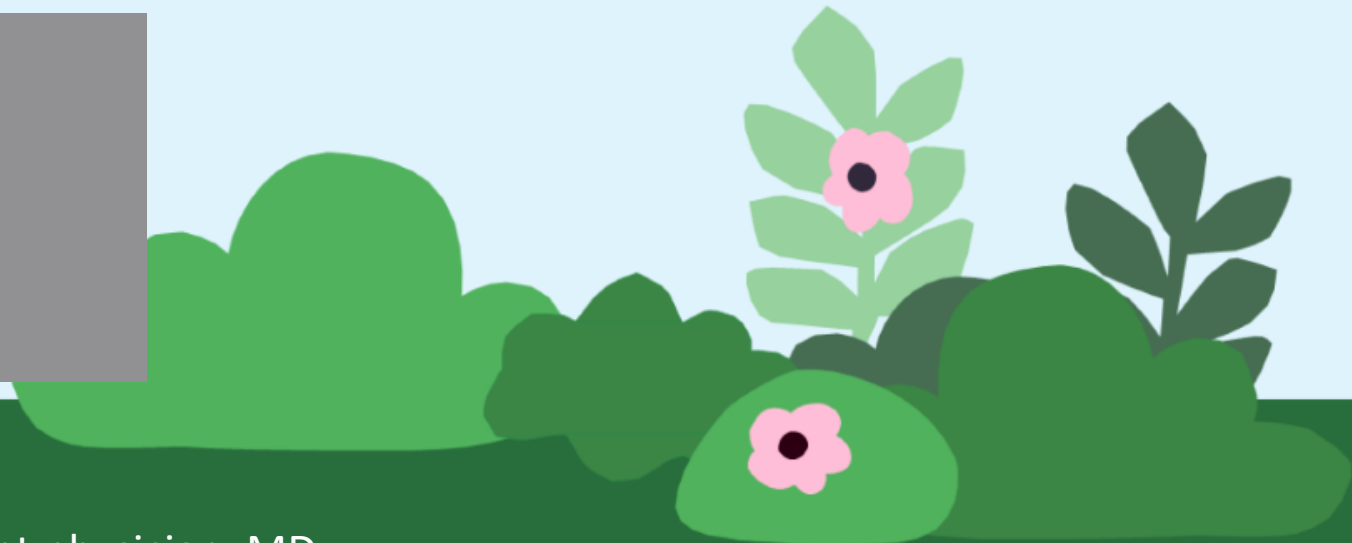
Nationwide 24/7 Paediatric Palliative Care in Denmark Data from 2016-2023

ROOTS & HORIZONS:
Learning from Yesterday, Living Today & Shaping Tomorrow

6th Maruzza International Congress on Paediatric Palliative
Care Rome 2024



Maja Abitz, teamleading consultant physician, MD
PPC team & Lukashuset, Copenhagen University Hospital
The Capital Region, Denmark



Jo før – jo bedre

Tidlig diagnose, bedre behandling
og flere gode leveår for alle



COWI



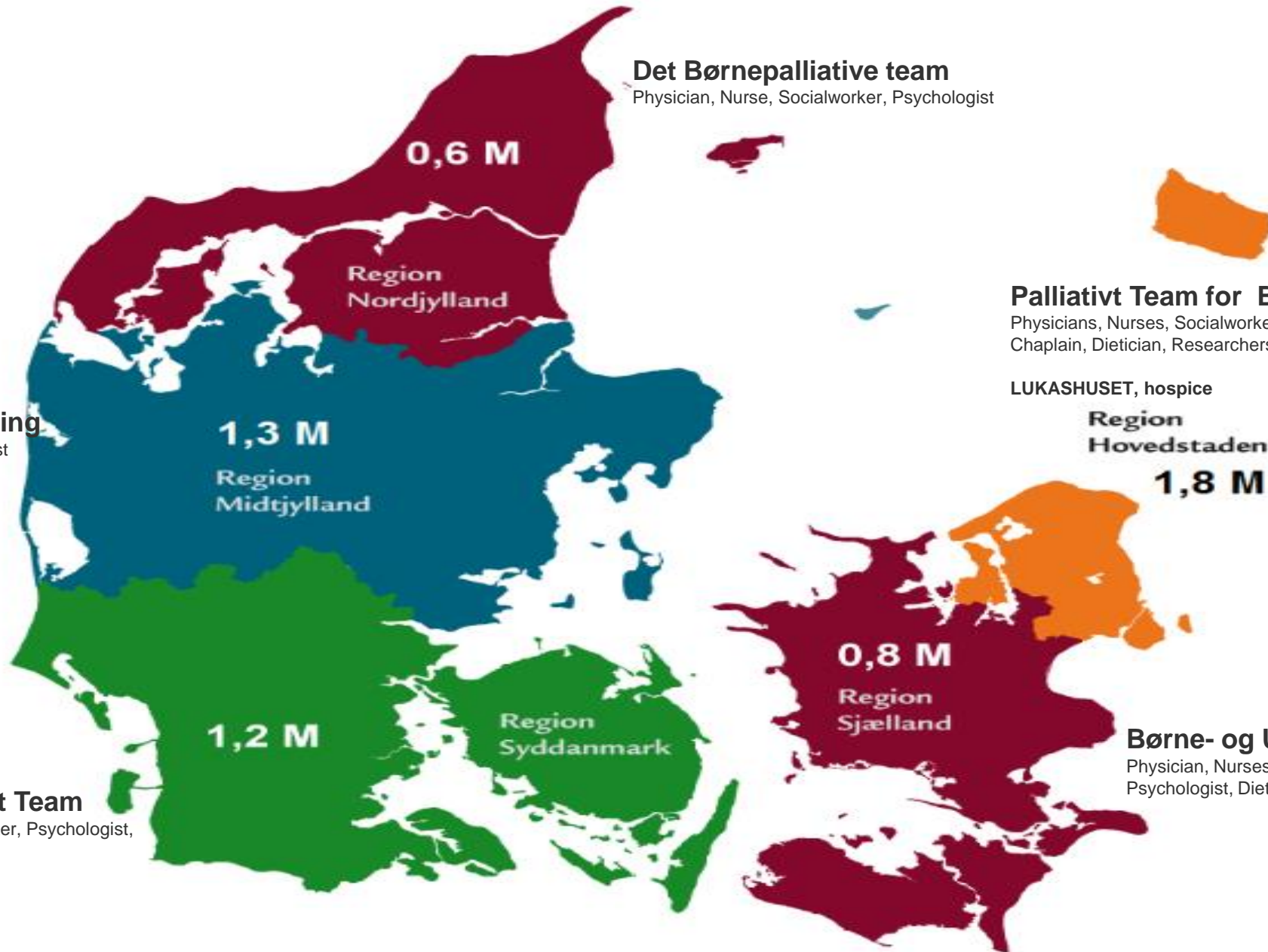
Familie**FOKUS**



**Hospital-Based
Paediatric Palliative Care
5 Regional Teams**



Region Hovedstaden



Det Børnepalliative team

Physician, Nurse, Socialworker, Psychologist

Palliativt Team for Børn og Unge

Physicians, Nurses, Socialworker, ,
Chaplain, Dietician, Researchers,, PhD student

LUKASHUSET, hospice

Region
Hovedstaden

1,8 M

0,8 M

Region
Sjælland

Børne- og Unge Palliation

Physician, Nurses, Socialworker,
Psychologist, Dietician

Enhed for lindrende Behandling

Physicians, Nurses, Socialworker, Psychologist
Professor in Palliative Care

STRANDBAKKEHUSET, hospice

1,3 M

Region
Midtjylland

1,2 M

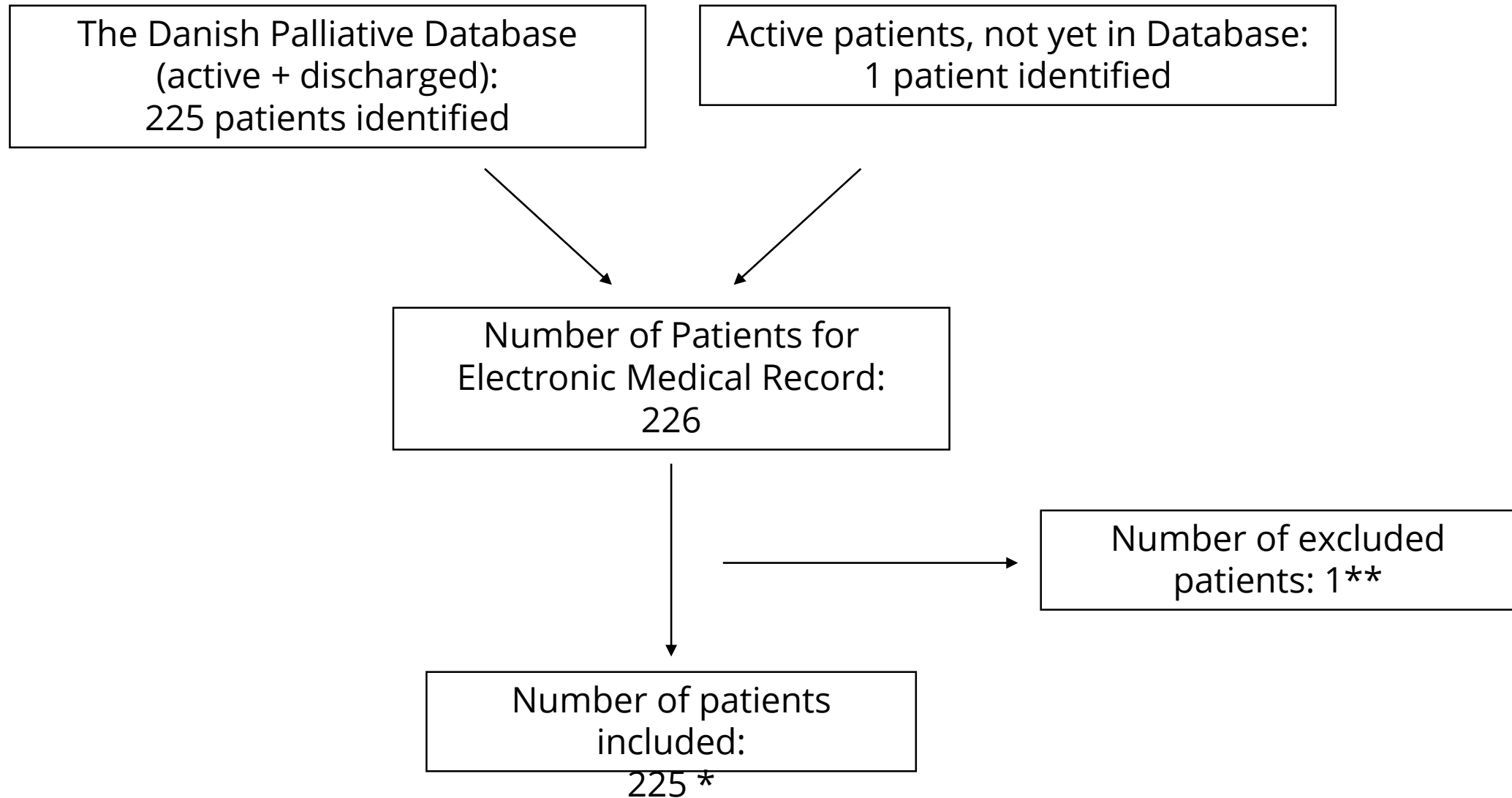
Region
Syddanmark

Pædiatrisk Palliativt Team

Physicians, Nurses, Socialworker, Psychologist,
Physiotherapist, Chaplain



9/3/23: NATIONAL INTERDISCIPLINARY MEETING for Clinicians working with Specialized PPC in Denmark



* 2 patients was found to have 2 different periods of connection to PABU

** not possible to identify patient because of non-existing cpr-number

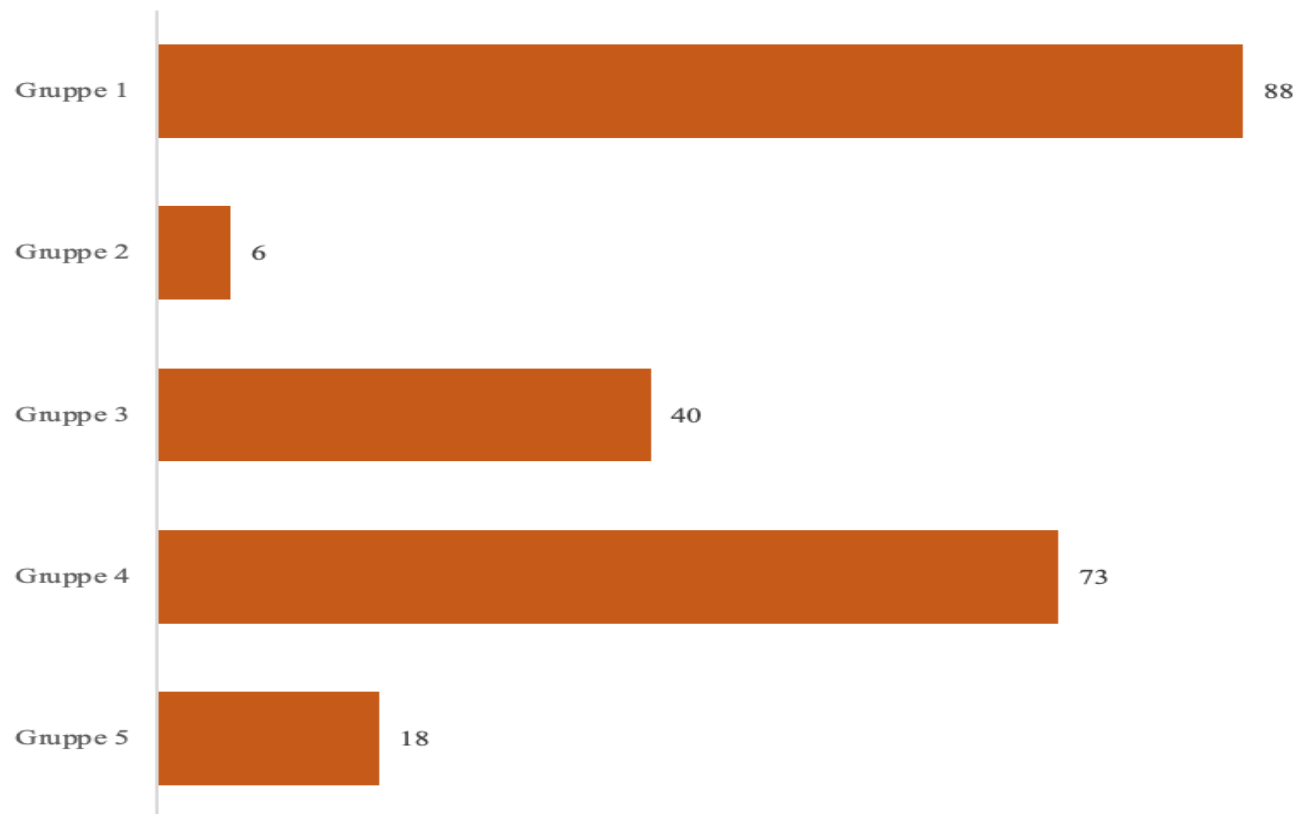
Figur 1: Flowchart, included data

Retrospective study Cohort 2016-2023

225 Patients

50 still active
by 31st Dec 2023

Forløb inddelt efter diagnosegrupper



Danish Palliative Database

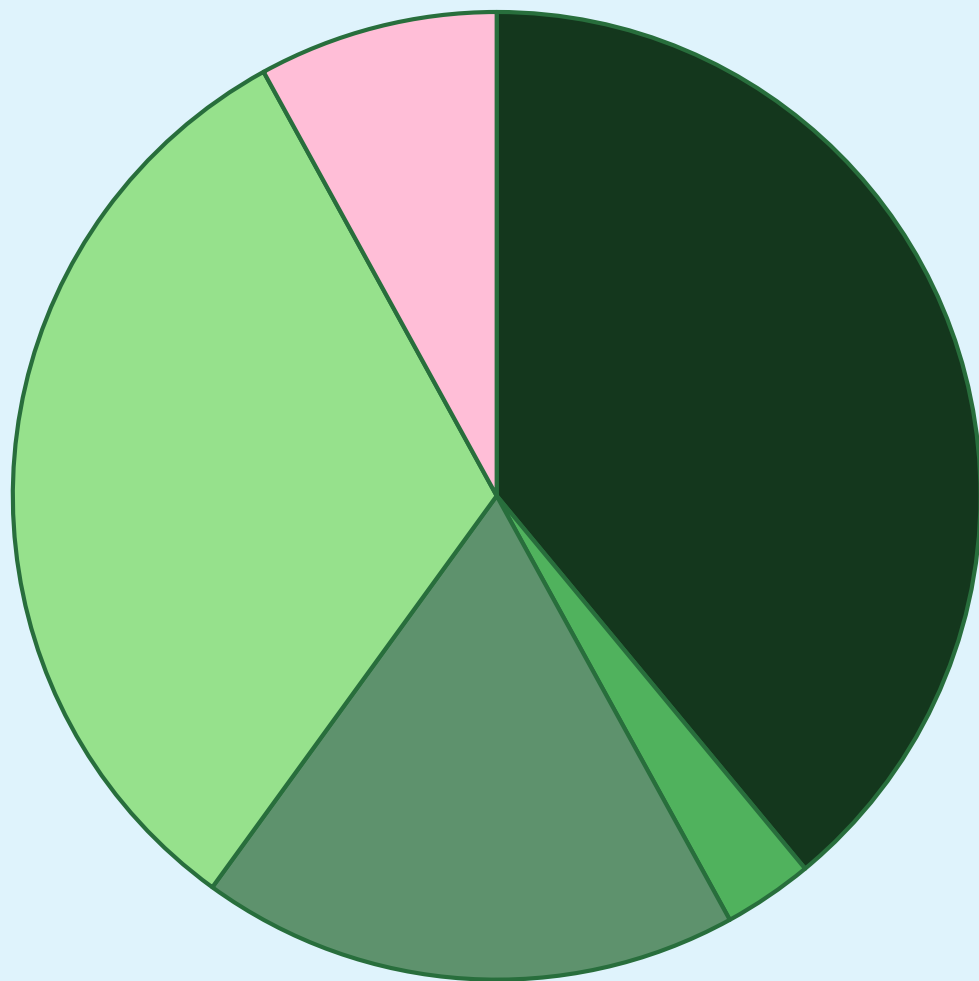
- Age + Gender
- Diagnosis (cancer, non-cancer)
- Length of follow up
- Referred, discharged, dead
- Date of Death + Place of Death

EPIC - Electronic Medical Record

- Referred from where
- Primary Diagnosis
- Interdisciplinary contacts
- Date of Discharge



Clinical categories



■ Group 1 ■ Group 2 ■ Group 3 ■ Group 4 ■ Group 5

Five Categories of Life-Limiting and Life-Threatening Conditions [Together for Short Lives 2018]

Group	Description
1	Life-threatening conditions for which curative treatment is possible but may fail. Access to palliative care services may be necessary due to the complexity of the patients' needs (e.g.: cancer, complex congenital cardiopathies, severe injuries resulting from trauma) There is no longer need for palliative care services upon achievement of long-term remission or following successful curative treatment
2	Conditions in which premature death is inevitable; however, long periods of intensive treatment aimed at prolonging life and allowing for a good QoL (e.g.: cystic fibrosis)
3	Progressive conditions without curative treatment options, for which treatment is exclusively palliative and may commonly extend over many years (e.g.: Batten disease, muscular dystrophy, chromosomopathies)
4	Irreversible but non-progressive conditions with complex healthcare needs leading to complications and, likely, premature death (e.g.: severe cerebral palsy and disabilities following brain or spinal cord injury) Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.
5	Unborn children with major health problems who may not live through birth, infants who may survive for only a few hours/days, infants with birth anomalies that may threaten vital functions, and infants for whom intensive care has been appropriately applied but developed an incurable disease



	2016-2019	2020-2023	Alle
Køn			
Alle	132	93	225
Dreng	75 (58,8%)	51 (54,8%)	126 (55,7%)
Alder ved henvisning			
Medianalder (år)	5,4	2	3
Spædbørn (0 år)	27 (20,5%)	31 (33,3%)	58 (25,7%)
Småbørn (1-5 år)	40 (30,3%)	30 (32,3%)	70 (31,3%)
Skolebørn (6-13 år)	36 (27,3%)	17 (18,2%)	53 (23,6%)
Unge (> 14 år)	29 (21,9%)	15 (16,2%)	44 (19,4%)
Bopælsregion			
Region H	111 (84,1%)	86 (92,5%)	197 (87,6%)
Anden region i DK	21 (15,9%)	5 (5,4%)	26 (11,5%)
Færøerne/Grønland	-	2 (2,1%)	2 (0,9%)
Diagnose			
Kræftdiagnose	51 (38,6%)	25 (26,9%)	76 (33,7%)
Anden diagnose	81 (61,4%)	68 (73,1%)	149 (66,3%)

Preliminary descriptive data, Errebo-Jacobi, M & Abitz, M 2024



	Alle	Gruppe 1	Gruppe 2	Gruppe 3	Gruppe 4	Gruppe 5
Forløb						
Henviste familier	225	88	6	40	73	18
Tid fra henvisning til forløbsstart	14 (0-728)	9 (0-317)	31 (0-175)	11 (0-174)	26 (0-728)	1 (0-14)
Forløbslængde i dage	374 (1- 1829)	317 (1-1663)	566 (1-1102)	495 (1-1729)	442 (1-1829)	140 (0-811)
Aktive forløb	50	15	1	8	25	1
Forløbsafslutning						
Afsluttet i alt	175 (100%)	73 (100%)	5 (100%)	32 (100%)	48 (100%)	17 (100%)
Afdøde	118 (69,9%)	56 (76,7%)	3 (60%)	24 (75,0%)	21 (43,8%)	14 (82,2%)
I live	57 (30,1%)	17 (23,3%)	2 (40%)	8 (25,0%)	27 (56,2%)	3 (17,8%)
Dødssted						
Afdøde	118 (100%)	56 (100%)	3 (100%)	24 (100%)	21 (100%)	14 (100%)
I hjemmet	66 (55,9%)	36 (63,2%)	2 (66,7%)	15 (62,5%)	7 (33,3%)	6 (42,9%)
I palliativ enhed (inkl. Børnehospice)	7 (5,9%)	2 (3,5%)	-	1 (4,2%)	3 (14,3%)	-
På sygehusafdeling	43 (36,4%)	17 (29,8%)	1 (33,3%)	8 (33,3%)	10 (47,7%)	7 (50,0%)
Ukendt	2 (1,8%)	2 (3,5%)	-	-	1 (4,7%)	1 (7,1%)
Sorgstøtte						
Antal forløb med sorgstøtte	69	30	2	17	18	7
Antal forløbsdage efter død (i dage)	185 (1-722)	115 (1-632)	72 (49-99)	150 (1-586)	167 (1- 1273)	114 (1-451)

- Referred families
- Duration of care
- Discharge from PPC team
- Place of Death
- Bereavement support



Cancerdiagnoser	Organspecifikke diagnoser	Andre diagnoser
<p>DC56 Kræft i æggestok (1) DC222 Hepatoblastom (1) DC227 Anden kræft i leveren (1) DC410A Kræft i kranieknogle (2) DC414 Kræft i bækken, korsben eller haleben (1) DC420A Kræft i ledbrusk på lang rørknogle i underekstremitet (1) DC420B Kræft i lang knogle i underekstremitet (2) DC451 Malignt mesoteliom i bughinden (1) DC490 Kræft i bindevæv og bløddelsvæv i hoved, ansigt og hals (1) DC490C Kræft i bindevæv og bløddelsvæv i ansigtet (2) DC492 Kræft i bindevæv og bløddelsvæv i underekstremitet (1) DC493 Kræft i bindevæv og bløddelsvæv i thorax (2) DC494 Kræft i bindevæv og bløddelsvæv i abdomen (1) DC496 Kræft i bindevæv og bløddelsvæv i truncus (1) DC498 Kræft i bindevæv og bløddelsvæv overgribende flere lokalisationer (1) DC499 Kræft i bindevæv og bløddelsvæv (1) DC649 Nyrekræft med metastaser (1) DC700 Kræft i hjernehinde (1) DC710B Supratentoriel kræft i storhjernen (4) DC710C Infratentoriel kræft i hjernen (2) DC712 Kræft i hjernens tindingelap (1) DC713 Kræft i hjernens isselap (2) DC716 Kræft i lillehjernen (2) DC717A Kræft i 4. ventrikel (3) DC717B Kræft i hjernestammen (7) DC718 Kræft i hjernen overgribende flere lokalisationer (2) DC71 Kræft i hjernen (3) DC720 Kræft i rygmarven (2) DC741 Kræft i binyremarv (2) DC753 Kræft i corpus pineale (1) DC755 Kræft i corpus para-aorticus eller andet paraganglion (1) DC910 Akut lymfoblastær leukæmi (2) DC920 Akut myeloblastær leukæmi (2) DC933 Juvenil myelomonocytær leukæmi (1) DD180F Kapillært hæmangiom (1) DD330 Supratentoriel godartet tumor i hjernen (2) DD332 Godartet tumor i hjernen (1) DD353 Godartet tumor i ductus craniopharyngeus (1)</p>	<p><u>Neurologiske sygdomme</u> DE713A Adrenoleukodystrofi (Addison-Schilder) (1) DE750C Sandhoffs sygdom (type 2) (2) DE750E Tay-Sachs' sygdom (2) DE752A Nonketonisk hyperglycinæmi (1) DE752E Metakromatisk leukodystrofi (4) DE770A Mukolipidose II (1) DF842 Retts syndrom (1) DG379 Demyeliniserende sygdom i centralnervesystemet (1) DG404 Epileptisk encefalopati (10) DG712D Medfødt centronukleær myopati DG713 Mitokondriel myopati (3) DG800 Spastisk tetraplegisk cerebral parese (3) DG809 Cerebral parese (6) DG919 Hydrocefalus (2) DG931 Anoksisk hjerneskade (4) DM414 Neuromuskulær skoliose (1) DP910 Hjerneiskæmi hos nyfødt (1) DP210 Svær neonatal asfyksi (2) DP371 Medfødt toxoplasmose (2) DQ029 Mikrocefali (4) DQ048C Cerebellar hypoplasia (2) DQ049 Medfødte misdannelser i hjernen (1) DQ128 Spinal muskeltrof (2) DQ283E Medfødt cerebral arteriel misdannelse (1) DQ238 Anden degenerativ sygdom i basalganglier (1) DQ31C Dandy-Walkers syndrom (1) E754E Neuronal ceroid lipofuskinose type 3 (1) ZM91210 Kavernøst hæmangiom (1)</p> <p><u>Nyresygdomme</u> DD593 Hæmolytisk-uræmisk syndrom (1) DN184 Kronisk nyreinsufficiens (1) DN289A Nefropati (1) DQ61 Cystenyre (1)</p> <p><u>Hjertekarsygdomme</u> DI420 Dilateret kardiomyopati (5) DQ20 Medfødte misdannelser af hjertekammer (1) DQ200 Truncus arteriosus communis (1) DQ213 Steno-Fallots tetralogi (1) DQ230 Medfødt aortastenose (1) DQ234 Hypoplastisk venstre hjertesygdom (1) DQ251 Coarctatio aortae (1)</p> <p><u>Lungesygdomme</u> DE84 Cystisk fibrose (1) DP271 Bronkopulmonal dysplasi opstået i perinatalperioden (1) DQ336B Medfødt lungehypoplasia (1)</p>	<p><u>Andre diagnoser</u> D821 Di Georges syndrom (1) DD669A Hæmofili (1) DD719C Kronisk granulomatøs sygdom (1) DD809 Immundefekt med overvejende antistofmangel (1) DD819A Svær kombineret immundefekt (SCID) (2) DE752D Krabbes sygdom (1) DE752H Niemann-Picks sygdom (1) DE760B Hurlers syndrom (1) DF731 Mental retardering i sværeste grad med væsentlig adfærdspåvirkning (1) DG318A Alpers' sygdom (1) DP073 Præmaturitet (1) DP351 Medfødt cytomegalovirusinfektion (2) DQ44 Medfødte misdannelser i galdeblære, galdegange og lever (1) DQ743 Arthrogryposis multiplex congenita (1) DQ750D Trigenocefali (1) DQ751 Kraniofacial dysostoses (1) DQ777 Spondyloepisyseal dysplasi (1) DQ796 Ehler-Danlos' syndrom (1) DQ808 Ichthyosis circumflexa (1) DQ812 Dystrofisk bulløs epidermolyse (2) DQ850 Ikke-malign neurofibromatose (1) DQ871 Noonans syndrom (1) DQ872D Rubinsteins-Taybis syndrom (1) DQ878 Andet medfødt misdannelsessyndrom (2) DQ910 Trisomi 18, meiotisk nondisjunktion (1) DQ913 Edwards' syndrom (1) DQ917A Trisomi 13-15 (1) E711 Anden forstyrrelse i omsætningen af forgrenede aminosyrer (1)</p> <p><u>Tilstande uden diagnosekode</u> Aicardi-Goutierre (1) Yunis-Varon syndrom (1) Giant axonal neuropati (1) Pelizeus-Merchbacher (1) Eye-muscle-brain-disease (1) Myotubulær myopati White matter disease (1) Leighs syndrom (1) Karaboga sygdom (1) Danon sygdom (1) Lafora syndrom (1) Treacter Collins Syndrom (1) Nijmegen breakage syndrom (1) Calfan syndrom (1) Molybdenum Cofactor mangel (1) 22q11 duplikationssyndrom (1)</p>

“It is far more important to know what sort of person has a disease than to know what sort of disease a person has”

Hippocrates





225 Patients
126 different diagnoses

1. Epileptic Encephalopathy (10)
2. Pontine glioma (7)
3. Cerebral Palsy, GCMS 5 (6)
4. Dilated CardioMyopathy (5)

Length of follow up
374 days (1-1829)

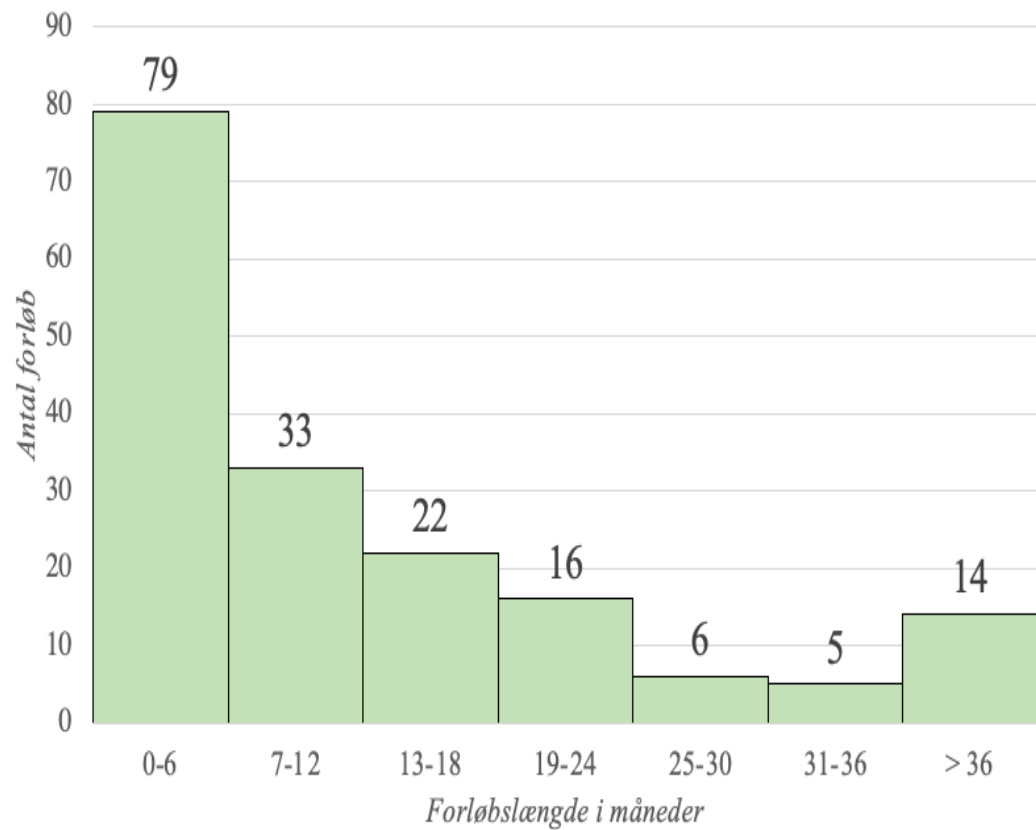
Bereavement support
185 days (1-722)

Interdisciplinarity in 94% of cases

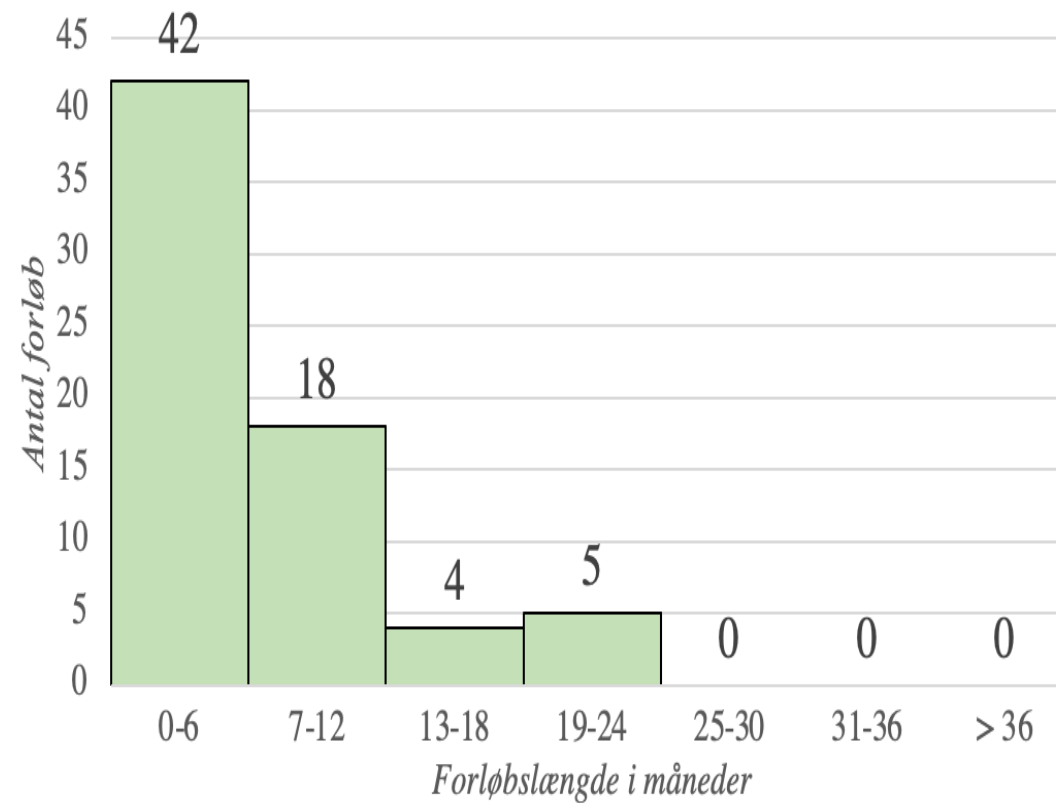
400 Homevisits per year
24/7 Telephone service



Forløbslængder



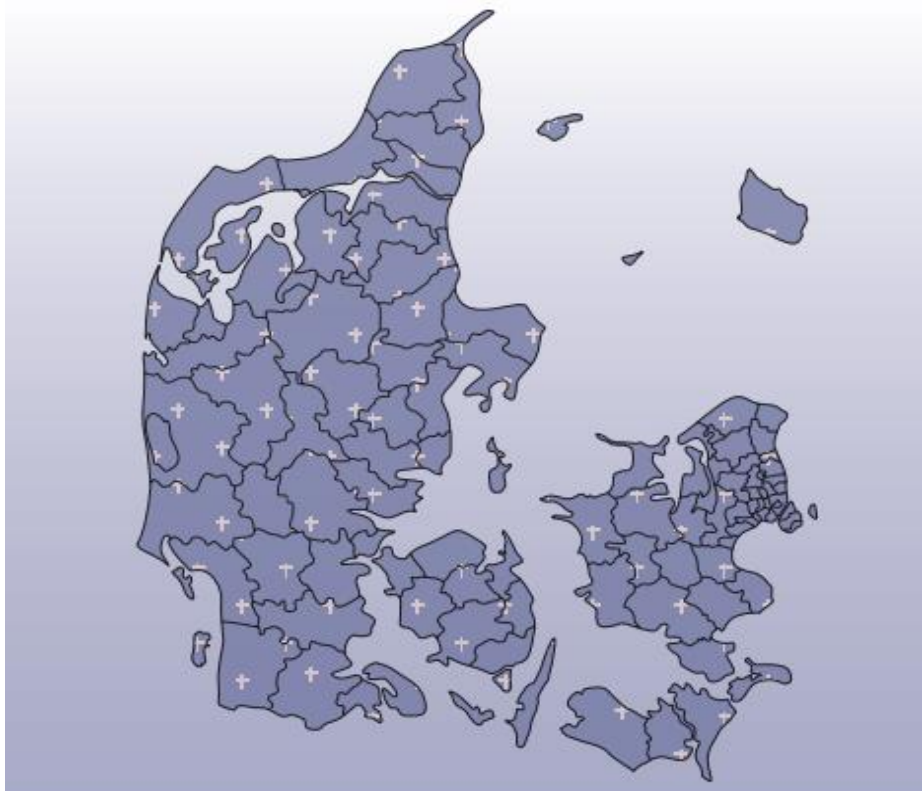
Forløbslængde efter livsafslutning



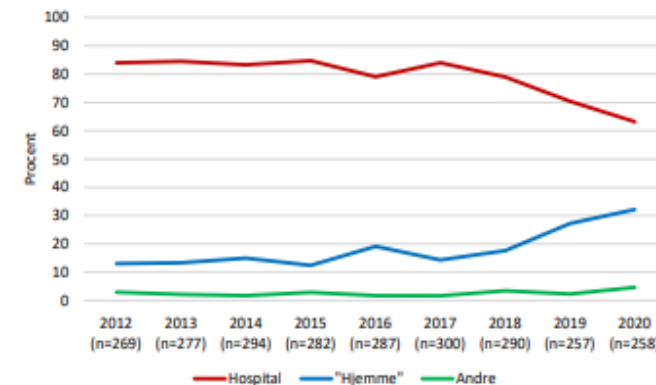
REHPA

Videncenter for
Rehabilitering og Palliation

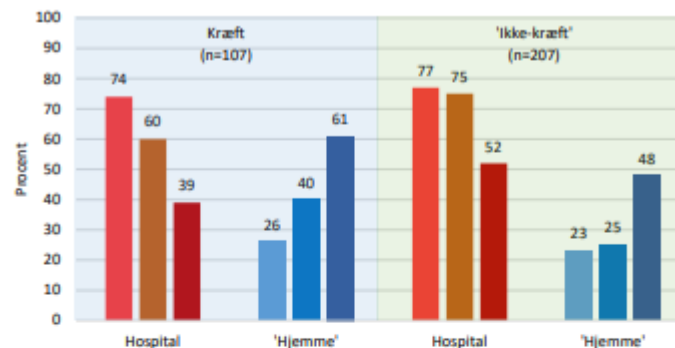
**Dødssted og dødsårsager
blandt børn og unge i Danmark
– i perioden 2012-2020**



Figur 3. Udviklingen i dødssted blandt børn og unge (0 år til ≤18 år), som er døde af naturlige årsager i årene 2012-2020 i Danmark

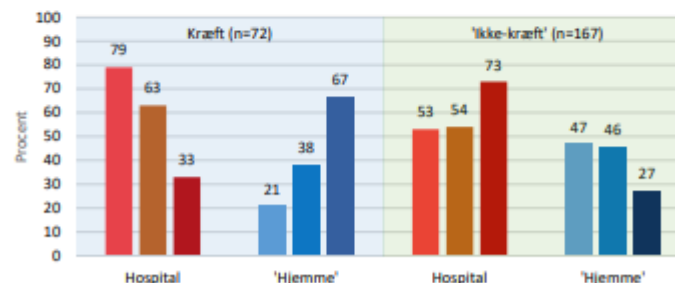


Figur 11. Dødssted (hospital og 'hjemme') for dødsfald som skyldes henholdsvis kræft og andre diagnoser ('ikke-kræft') hos større børn (2 år - <12 år), fordelt på perioder*



Note: *De tre søjler repræsenterer de tre perioder: 2012-2014, 2015-2017, 2018-2020.

Figur 12. Dødssted (hospital og 'hjemme') for dødsfald som skyldes henholdsvis kræft og andre diagnoser ('ikke-kræft') hos unge (12 år til ≤18 år), fordelt på perioder*



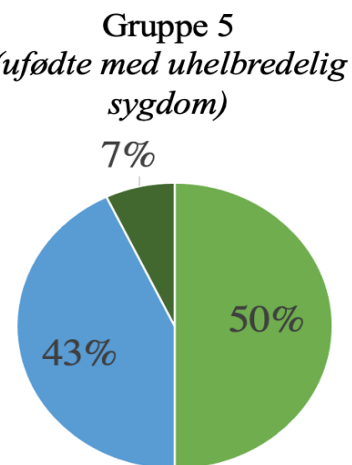
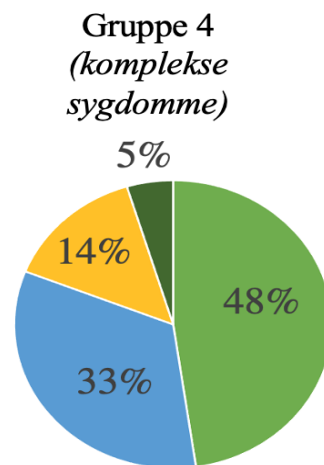
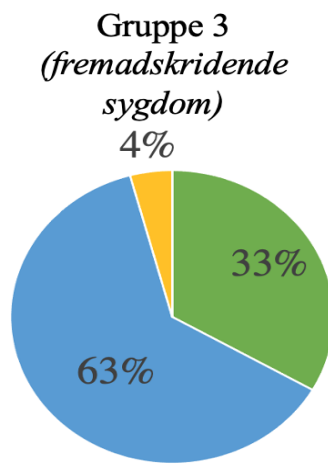
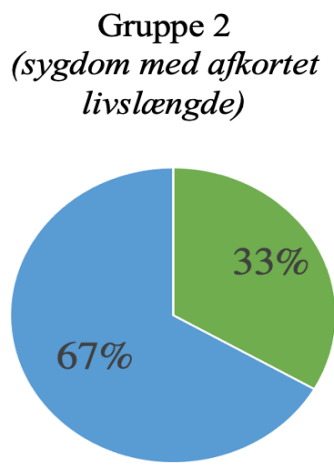
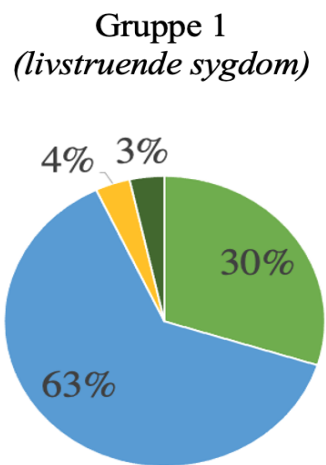
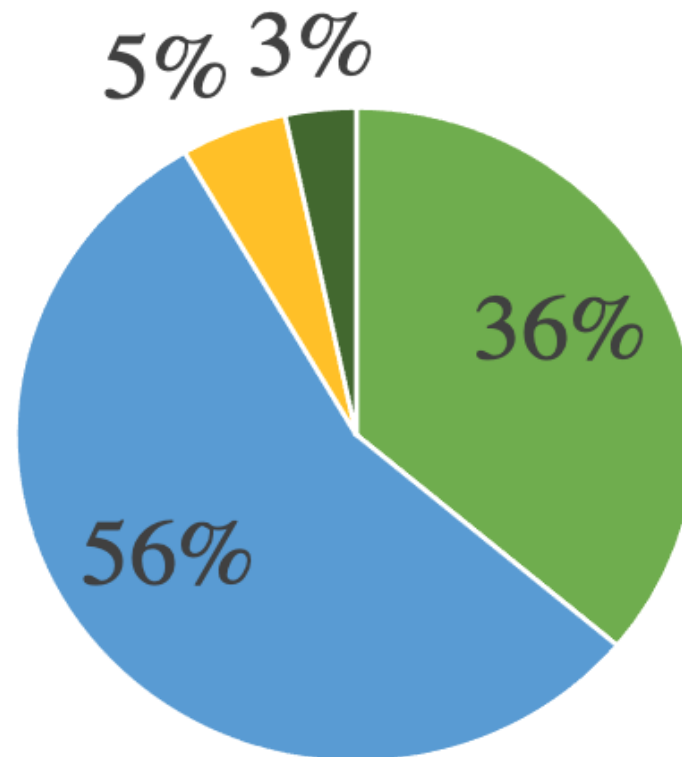
Note: *De tre søjler repræsenterer de tre perioder: 2012-2014, 2015-2017, 2018-2020. Dødssted: hospitalet - røde søjler, hjemme - blå søjler, og rækkefølgen er perioderne 2012-2014, 2015-2017 og 2018-2020 for hvert dødssted.

- Death at home increases substantially after PPC was introduced
- Patients with cancer die at home more often than non-cancer patients





»Døden er uretfærdig, når det er et barn. Men det var fint og roligt«

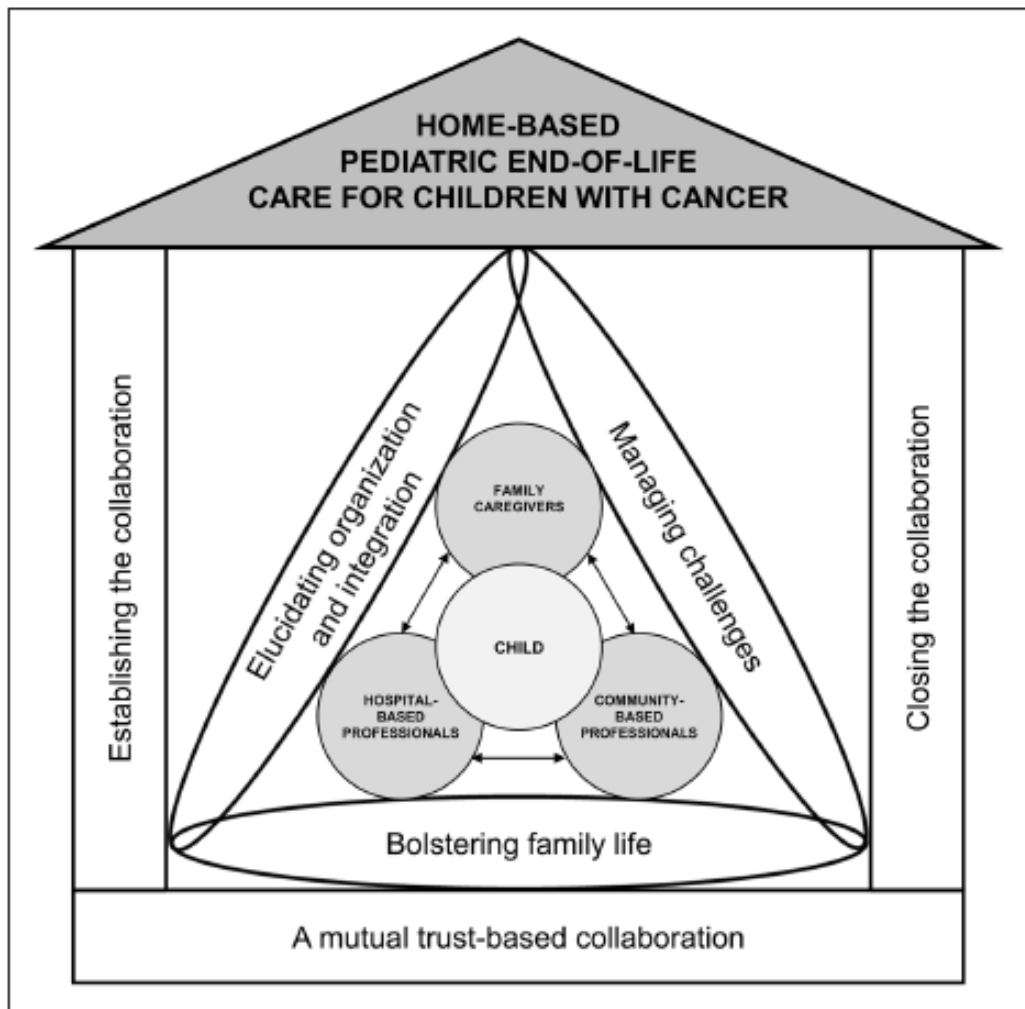


■ Sygehusafdeling ■ I hjemmet ■ Palliativ enhed (børneshospice) ■ Ukendt



”Hvis børn er lindret godt, så leger de på dødslejet”: I børnepalliationen gør man det, der mangler for de voksne

Maja Funch



Original Article

Intersectoral collaboration in home-based end-of-life pediatric cancer care: A qualitative multiple-case study integrating families' and professionals' experiences

Nanna Maria Hammer^{1,2}, Helena Hansson^{1,2}, Line Hjöllund Pedersen^{1,3}, Maja Abitz¹, Per Sjøgren⁴, Kjeld Schmiegelow^{1,2}, Pernille Envold Bidstrup^{5,6}, Hanne Bækgaard Larsen^{1,2*} and Marianne Olsen^{1,7*}

Palliative Medicine
1–14
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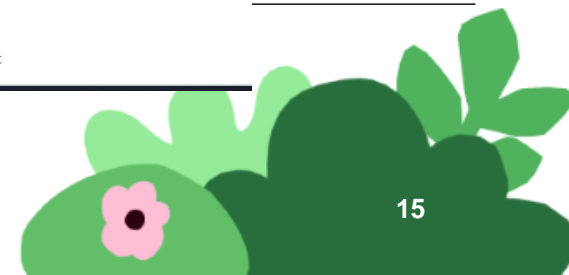


20/07/2024 KL 08:10 | FOR ABONNENTER

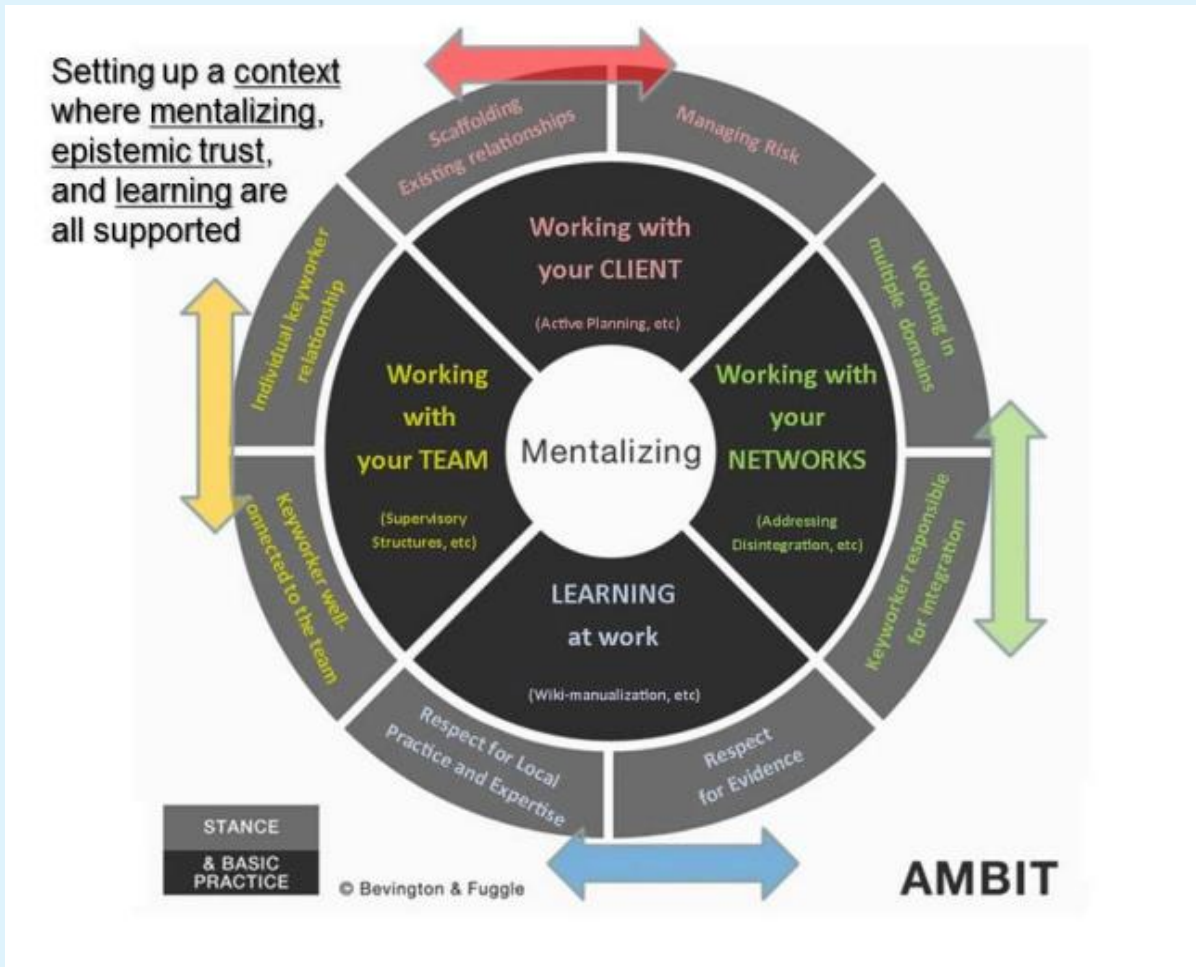
»Det giver kræfter at måtte bære«

Freja gjorde sin entré i Anja Gerdes Duch og Kasper Rømer-Bruhns liv den 14. februar 2021. Et halvt år efter fandt forældrepæren ud af, at deres datter ikke var kommet for at blive.

...of-life care and to die at
...l-functioning collaboration
...cancer, as experienced by
...and written responses to
...ancer at home. Cases were
...professionals (n = 16). Also,
...o interviews.
...blishing the collaboration,
...llaboration. These themes
...the "Home-Based Pediatric
...t-of-life care collaboration,
...her optimization of home-
... , qualitative research



Moving from an Interdisciplinary Team to *Collective Trans-Professionalism* – a way of working in highly complex contexts with substantial suffering



AMBIT - Adaptive Mentalization-Based Integrative Therapy

Epistemic trust:

an individual's willingness to consider new knowledge as trustworthy and relevant, and therefore worth integrating into their lives





And tomorrow...

- **Danish Network for Paediatric Palliative Care** start mapping and strategic planning across Denmark - both improving quality of care and policy making
- Create a **PPC & Chronic Complex Children Unit** connected to PICU & Paediatric Home Care at Rigshospitalet
- **Perinatal Palliative Care** has to be prioritized
- Copenhagen is hosting the next **International Meeting** in the EU-Horizon-2020 financed **PALLIAKID**



Thank you

Acknowledgement
to my PPC team in Copenhagen and to
Martha Errebo-Jacobi, MD for helping
with data collection

