

Bijlage 7 Zoekverantwoording

Search 1 – interventions for children in the palliative phase aged 0 to 18 years old

Clinical question

What is the effect of interventions for children in the palliative phase aged 0 to 18 years old?

P: Children in the palliative phase aged 0 to 18 years old

I: Palliative interventions

C: (not applicable)

O: (not applicable)

Search strategy

Search A

Search date October 5, 2018.

Databases OVID Medline, OVID PreMedline, Cochrane Library (CDSR & CENTRAL)

Search limits Publication date: 2010-present;

Language: English and Dutch;

Study design: Randomized Controlled Trials (RCTs), Clinical Controlled Trials (CCTs), and Systematic Reviews (of RCTs and/or CCTs).

Search B

Search date 24-01-2020

Databases PubMed (Medline)

Search limits Publication date: 2018 – present;

Language: English and Dutch;

Study design: Randomized Controlled Trials (RCTs), Clinical Controlled Trials (CCTs), and Systematic Reviews (of RCTs and/or CCTs).

Search results

Database	Number of hits
<i>Search A</i>	
OVID Medline	2045
OVID PreMedline	301
Cochrane Database of Systematic Reviews	246
CENTRAL	1496
<i>Search B</i>	
PubMed (Medline)	990
Total hits	5078
N excluded (language, year, duplicates)	573
Total unique eligible hits	4505

Inclusion criteria

Inclusion criteria	
Patient population	<ul style="list-style-type: none">• Children with a life threatening or life limiting disease aged 0 to 18 years old.• Patient population consisting of more than 10 patients.• 75% of the patient population consists of children aged 0 to 18 years old.
Intervention	<p>All palliative interventions on:</p> <ul style="list-style-type: none">• Recognition and treatment of symptoms: anxiety & depression, delirium, haematological symptoms (anaemia, thrombocytopenia, haemorrhages and thrombosis), coughing, rattling, skin complaints (itching, wounds and pressure ulcers), nausea & vomiting, pain, neurological symptoms (epilepsy, dystonia, dyskinesia and spasticity) and fatigue• Treatment of refractory symptoms at the end of life: palliative sedation and hydration & nutrition deprivation.• Psychosocial care: psychological interventions, social and practical support, cultural, spiritual and religious support.• Bereavement care.• Advance Care Planning and Shared decision making.• Organisation of care.
Study design	<ul style="list-style-type: none">• Randomized Controlled Trials (RCTs) or Controlled Clinical Trials (CCTs).• Systematic reviews (of RCTs and/or CCTs).
Study characteristics	<ul style="list-style-type: none">• English or Dutch language.• Minimum of two authors.• Abstract is available.

Flowchart

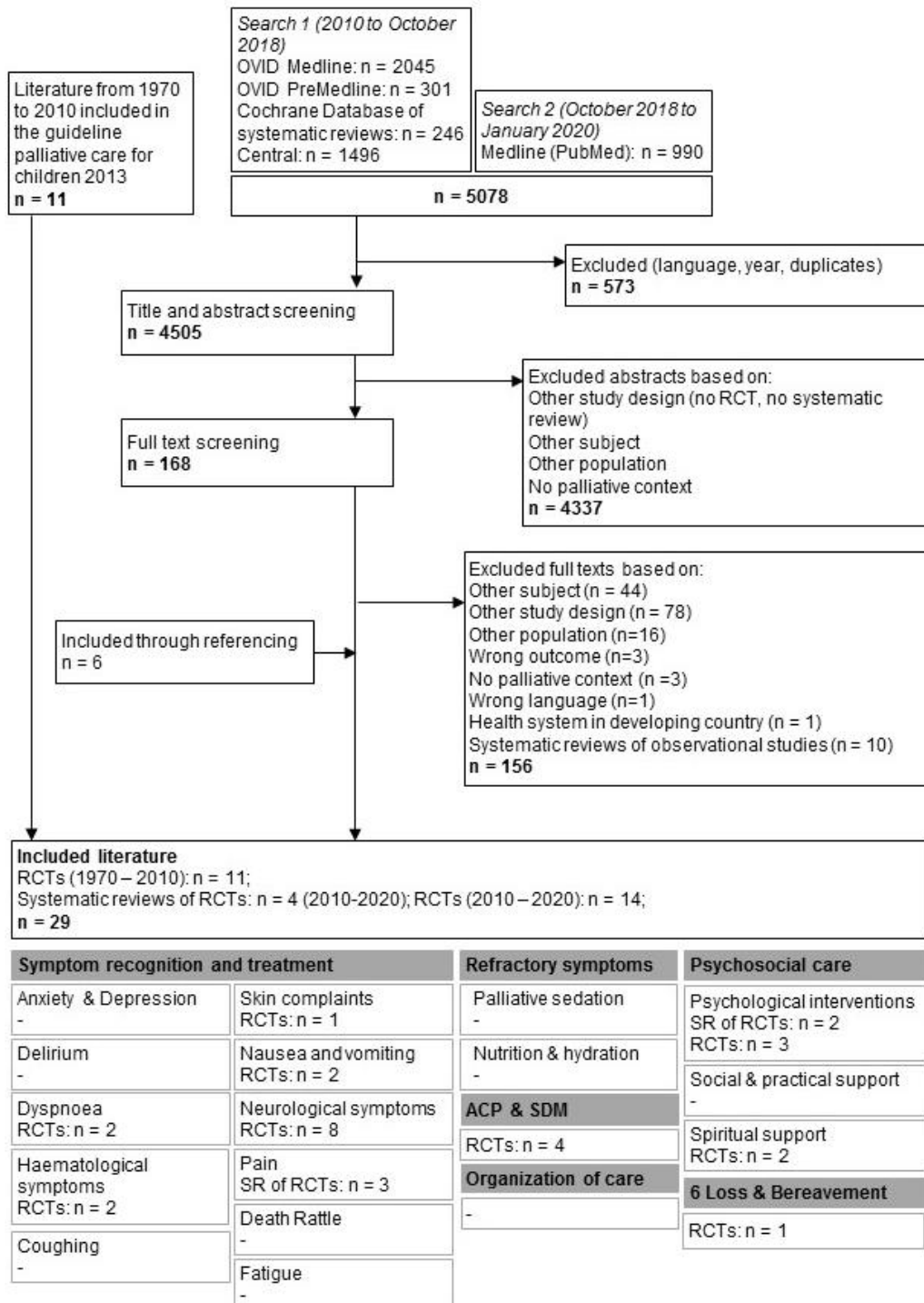


Figure 1. Flowchart Systematic Search Paediatric Palliative Care Interventions

Search strings

Search A

Name researcher:	Joan Vlaayen
Search date:	05-10-2018
Medline (OVID)	
Search 1: Intervention	1 exp Palliative Care/ (49362) or 2 palliat*.tw. (58051) or 3 advanced disease*.tw. (15975) or 4 (end-stage disease* or end stage disease* or end-stage illness or end stage).tw. (52291) or 5 Terminally Ill/ (6207) or 6 Terminal Care/ (25841) or 7 (terminal* adj6 care*).tw. (3554) or 8 ((terminal* adj6 ill*) or terminal-stage* or dying or (close adj6 death)).tw. (37618) or 9 (terminal* adj6 disease*).tw. (3457) or 10(end adj6 life).tw. (19644) or 11hospice*.tw. (9908)
Search 2: Population	12exp Infant/ (1075702) or 13exp Child/ (1789770) or 14Adolescent/ (1887787) or 15(minors* or perinat* or postnat* or kid or kids or neonat* or newborn* or infan* or child* or adoles* or paediatric* or pediatric* or baby* or babies or toddler* or teen* or juvenil* or boy* or girl* or underag* or youth* or kindergar* or puber* or pubescen* or schools or nursery school* or preschool* or primary school* or secondary school* or elementary school* or high school* or highschool* or school age* or schoolage*).mp. (3978287)
Search 3: Study design	16randomized controlled trial.pt. (468961) or 17controlled clinical trial.pt. (92654) or 18randomi?ed.ab. (442505) or 19placebo.ab. (175141) or 20clinical trials as topic.sh. (184906) or 21randomly.ab. (255868) or 22trial.ti. (163102) NOT 23(exp animals/ not humans.sh. (4501441))
Search 4: Study design	24meta-analysis.mp,pt. or review.pt. or search:.tw. (2504080)
Combined:	Search 1 AND Search 2 AND (SEARCH 3 OR SEARCH 4)
Total records:	2045 records
PreMedline (OVID)	
Search 1: Intervention	1 palliat*.tw. (7228) or 2 advanced disease*.tw. (1855) or 3 (end-stage disease* or end stage disease* or end-stage illness or end stage).tw. (6487) or 4 (terminal* adj6 care*).tw. (243) or 5 ((terminal* adj6 ill*) or terminal-stage* or dying or (close adj6 death)).tw. (3125) or 6 (terminal* adj6 disease*).tw. (237) or 7 (end adj6 life).tw. (2679) or 8 hospice*.tw. (944)
Search 2: Population	9 (minors* or perinat* or postnat* or kid or kids or neonat* or newborn* or infan* or child* or adoles* or paediatric* or pediatric* or baby* or babies or toddler* or teen* or juvenil* or boy* or girl* or underag* or youth* or kindergar* or puber* or pubescen* or schools or nursery school* or preschool* or primary school* or secondary school* or elementary school* or high school* or highschool* or school age* or schoolage*).mp. (195151)
Search 3: Study design	10randomized controlled trial.pt. (277) or 11controlled clinical trial.pt. (20) or 12randomi?ed.ab. (51918) or 13placebo.ab. (13994) or

	14randomly.ab. (36549) or 15trial.ti. (20815)
Search 4: Study design	16meta-analysis.mp,pt. or review.pt. or search:.tw. (170831)
Combined:	Search 1 AND Search 2 AND (SEARCH 3 OR SEARCH 4)
Total records:	301 records
Cochrane library (Cochrane Database of Systematic Reviews and CENTRAL)	
Search 1: Intervention	1 MeSH descriptor: [Palliative Care] explode all trees (1454) OR 2 palliat*:ti,ab (4487) OR 3 advanced disease*:ti,ab (15208) OR 4 (end-stage disease* or end stage disease* or end-stage illness or end stage):ti,ab (8120) OR 5 MeSH descriptor: [Terminally Ill] explode all trees (80) OR 6 MeSH descriptor: [Terminal Care] explode all trees (407) OR 7 (terminal* NEAR/6 care*):ti,ab (110) OR 8 ((terminal* NEAR/6 ill*) or terminal-stage* or dying or (close NEAR/6 death)):ti,ab (1290) OR 9 (terminal* NEAR/6 disease*):ti,ab (143) OR 10(end NEAR/6 life) (1966) OR 11hospice*:ti,ab (529)
Search 2: Population	12MeSH descriptor: [Infant] explode all trees (15033) OR 13MeSH descriptor: [Child] explode all trees (1416) OR 14MeSH descriptor: [Adolescent] explode all trees (97673) OR 15(minors* or perinat* or postnat* or kid or kids or neonat* or newborn* or infan* or child* or adoles* or paediatric* or pediatric* or baby* or babies or toddler* or teen* or juvenil* or boy* or girl* or underag* or youth* or kindergar* or puber* or pubescen* or schools or nursery school* or preschool* or primary school* or secondary school* or elementary school* or high school* or highschool* or school age* or schoolage*):ti,ab (150225)
Combined:	Search 1 AND Search 2
Total records:	Cochrane Database of Systematic reviews: 246 reviews; CENTRAL: 1496

Search B

Name researcher	Kim van Teunenbroek
Search date:	24-01-2020
PubMed (Medline)	
Search 1: Intervention	palliative care OR Care, Palliative OR Palliative Treatment OR Palliative Treatments OR Treatment, Palliative OR Therapy, Palliative OR Palliative Therapy OR Palliative Medicine OR Medicine, Palliative OR OR pediatric palliative care OR children's hospice OR Hospice care OR Terminal care OR "end life"
Search 2: Population	infant OR infan* OR newborn OR newborn* OR new-born* OR baby OR baby* OR babies OR neonat* OR perinat* OR postnat* OR child OR child* OR schoolchild* OR schoolchild OR school child OR school child* OR kid OR kids OR toddler* OR adolescent OR adoles* OR teen* OR boy* OR girl* OR minors OR minors* OR underag* OR under ag* OR juvenil* OR youth* OR kindergar* OR puberty OR puber* OR pubescen* OR prepubescen* OR prepuberty* OR pediatrics OR pediatric* OR paediatric* OR peadiatric* OR schools OR nursery school* OR preschool* OR pre school* OR primary school* OR secondary school* OR elementary school* OR elementary school OR high school* OR highschool* OR school age OR schoolage OR school age* OR schoolage* OR infancy OR schools, nursery OR infant, newborn
Search 3: study design	(systematic review[tiab] OR review literature[mh] OR review[tiab] OR reviews[tiab] OR review[pt] OR systematic literature review[tiab] OR systematic literature review[tiab]) OR (meta analysis[pt] OR meta analysis[mh] OR meta analysis[tiab] OR metaanalysis[tiab] OR meta analyses[tiab]) OR (guidelin*[tiab])

Search 4: Study design	(randomized controlled trial [pt] OR controlled clinical trial [pt] OR randomized [tiab] OR placebo [tiab] OR drug therapy [sh] OR randomly [tiab] OR trial [tiab] OR groups [tiab]) NOT (animals [mh] NOT humans [mh])
Combined:	Search 1 AND Search 2 AND (Search 3 OR Search 4)
Total records:	990

Search 2 – Barriers and facilitators of Advance Care Planning and Shared Decision making.

Clinical question

What are the barriers and facilitators for Advance Care Planning and shared decision making to children aged 0 to 18 years in the palliative phase, their parents, carers and family members and their health care professionals?

- P: Children aged 0 to 18 years in the palliative phase.
Parents, carers and family members of children aged 0 to 18 years in the palliative phase.
Health care professionals of children aged 0 to 18 years in the palliative phase.
- I: Advance Care Planning, development, assessment and reviews of personalised and parallel Advance Care Planning),
Shared decision making.
- C: -
- O: Barriers and facilitators

Search strategy

Included literature from the NICE-guideline

We used the literature as cited in the NICE-guideline 'End of life care for infants, children and young people with life-limiting conditions: planning and management'. The original search strategy, inclusion criteria and excluded studies can be found in [Appendix A – F and H – J](#).

Search

- Search date 16-09-2020
- Databases PubMed (Medline)
- Search limits Publication date: 2016 - present;
Language: English;
Study design: Qualitative studies, Mixed-methods observational studies where qualitative data were reported, Systematic reviews of qualitative and mixed-methods observational studies.

Inclusion criteria

Inclusion criteria	
Patient population	<ul style="list-style-type: none"> • Children with a life threatening or life limiting disease aged 0 to 18 years old. • Parents, carers and family members (brothers and sisters) of children with a life threatening or life limiting disease aged 0 to 18 years old. • Health care professionals of children with a life threatening or life limiting disease aged 0 to 18 years old.
Subject	<ul style="list-style-type: none"> • Advance Care Planning. • Shared Decision Making.
Outcome measure	<ul style="list-style-type: none"> • Barriers and facilitators.
Study design	<ul style="list-style-type: none"> • Qualitative studies (for example ethnographic studies, interviews, focus groups) • Mixed-methods observational studies where qualitative data were reported (for example survey studies) • Systematic reviews of qualitative and mixed-methods observational studies.
Study characteristics	<ul style="list-style-type: none"> • English or Dutch. • Minimum of two authors. • Abstract is available.

Flowchart

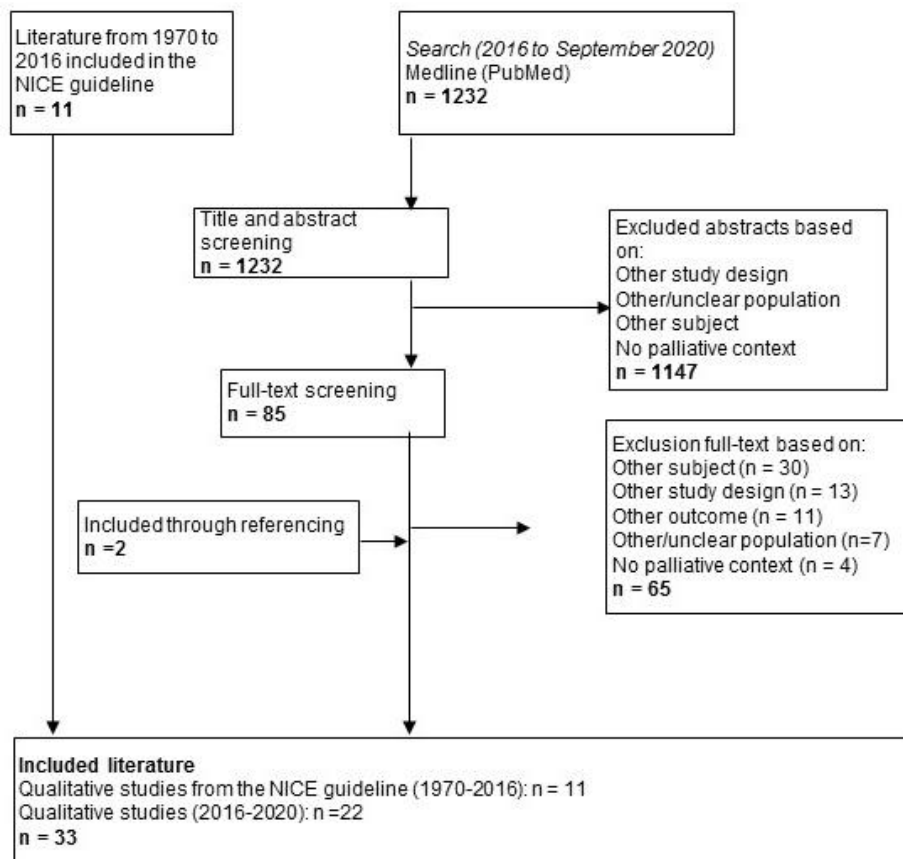


Figure 2. Flowchart Systematic Search Barriers and Facilitators on ACP and SDM

Search strings

Search A

Original search strings performed by the National Institute of Health Care excellence are reported in [Appendix E3: Search strategies, Advance Care Plan](#) (p.127-130) of the NICE-guideline 'End of life care for infants, children and young people with life-limiting conditions: planning and management'.

Search B

Name Researcher	Kim van Teunenbroek and Dayna van Heel
Search date	16-9-2020
PubMed (MEDLINE)	
Search 1: Patient	infant OR infan* OR newborn OR newborn* OR new-born* OR baby OR baby* OR babies OR neonat* OR perinat* OR postnat* OR child OR child* OR schoolchild* OR schoolchild OR school child OR school child* OR kid OR kids OR toddler* OR adolescent OR adoles* OR teen* OR boy OR boys OR girl* OR minors OR minors* OR underag* OR under age OR juvenil* OR youth* OR kindergar* OR puberty OR puber* OR pubescen* OR prepubescen* OR prepuberty* OR pediatrics OR pediatric* OR paediatric* OR peadiatric* OR schools OR nursery school* OR preschool* OR pre school* OR primary school* OR secondary school* OR elementary school* OR elementary school OR high school* OR highschool* OR school age OR schoolage OR schoolage* OR infancy OR schools, nursery OR infant, newborn
Search 2: Patient	palliative care OR Care, Palliative OR Palliative Treatment OR Palliative Treatments OR Treatment, Palliative OR Therapy, Palliative OR Palliative Therapy OR Palliative Medicine OR Medicine, Palliative OR pediatric palliative care OR children's hospice OR Hospice care OR Terminal care OR "end life"
Search 3: Intervention	"patient care planning"[MeSH Terms] OR Patient care planning[tiab] OR "advance care planning"[MeSH Terms] OR advance* care plan*[tiab] OR "Advance Directives"[Mesh] OR advance directive*[tiab] OR "living wills"[MeSH Terms] OR living will*[tiab] OR "Case Management"[Mesh] OR case management [tiab] OR "critical pathways"[MeSH Terms] OR critical pathways*[tiab] OR critical path*[tiab] OR parallel plan*[tiab] OR "resuscitation orders"[MeSH Terms] OR resuscitation order*[tiab] OR resuscitat* order*[tiab] OR resuscitat* policy[tiab] OR resuscitat* policies[tiab] OR resuscitat* decision[tiab] OR resuscitat attempt*[tiab] OR "withholding treatment"[MeSH Terms] OR withhold* treatment*[tiab] OR withdraw* treatment [tiab] OR "euthanasia, passive"[MeSH Terms] OR passive euthanasia[tiab] OR "Decision Making, Shared"[Mesh] OR "Clinical Decision-Making"[Mesh] OR shared decision making[tiab] OR shared decision-making[tiab] OR clinical decision-making[tiab] OR clinical decision making[tiab] OR medical decision making[tiab] OR medical decision-making[tiab] OR decision*[tiab] OR "Decision Making"[Mesh] OR decision making[tiab] OR "Advance Directive Adherence"[Mesh] OR directive* Adhere*[tiab] OR directive* compl*[tiab]
Search 4: Study design	"Letter"[Publication Type] OR "Editorial"[Publication Type] OR "News"[Publication Type] OR "Historical Article"[Publication Type] OR "Anecdotes as Topic"[Mesh] OR "Comment" [Publication Type] OR "Qualitative Research"[Mesh] OR "Interviews as Topic"[Mesh] OR "Focus Groups"[Mesh] OR "Case Reports"[Publication Type] OR qualitative stud*[tiab] OR qualitative[tiab] OR qualitative research[tiab] OR interview*[tiab] OR Case Report*[tiab] OR focus group*[tiab]
Search 5: Study design	"Randomized Controlled Trial" [Publication Type] OR random*[tiab]
Combined:	Search 1 AND 2 AND 3 and (4 NOT 5)
Total eligible records	1232

Search 3 – Guidelines on palliative care for children

Clinical question

Which guidelines on palliative care for children are published from 2010 and onwards?

P: Children aged 0 to 18 years in the palliative phase

I: (not applicable)

C: (not applicable)

O: (not applicable)

Search strategy

Search date 24-01-2020

Databases Guideline International Network (GIN), IPOG, NICE, NVK en Pallialine.

Search limits Publication date: 2010-present;

Language: English and Dutch only.

Inclusion criteria

Inclusion criteria	
Patient population and study design	<ul style="list-style-type: none">Guidelines on palliative care for children aged 0 to 18 years with a life threatening or life limiting disease.Guidelines on palliative care for adults with separate recommendations on palliative care for children.
Subjects	Guidelines on: <ul style="list-style-type: none">Recognition and treatment of symptoms: anxiety & depression, delirium, haematological symptoms (anaemia, thrombocytopenia, haemorrhages and thrombosis), coughing, rattling, skin complaints (itching, wounds and pressure ulcers), nausea & vomiting, pain, neurological symptoms (epilepsy, dystonia, dyskinesia and spasticity) and fatigue.Treatment of refractory symptoms at the end of life: palliative sedation and hydration & nutrition deprivation.Psychosocial care: psychological interventions, social and practical support, cultural, spiritual and religious care.Bereavement care.Advance Care Planning and Shared decision making.Organisation of care.
Exceptions	<ul style="list-style-type: none">When guidelines on symptom recognition or treatment for children in the palliative context were not available or inadequate, guidelines on symptom recognition or treatment for children in the non-palliative context* were included.When guidelines on (refractory) symptom recognition and treatment, psychosocial care, bereavement care, Advance Care Planning & Shared decision making and organisation of care for children in the palliative phase were not available or inadequate, guidelines on palliative care for adults* were included.
<i>*Guidelines are only included if the recommendations were considered relevant for children in the palliative phase</i>	

Flowchart

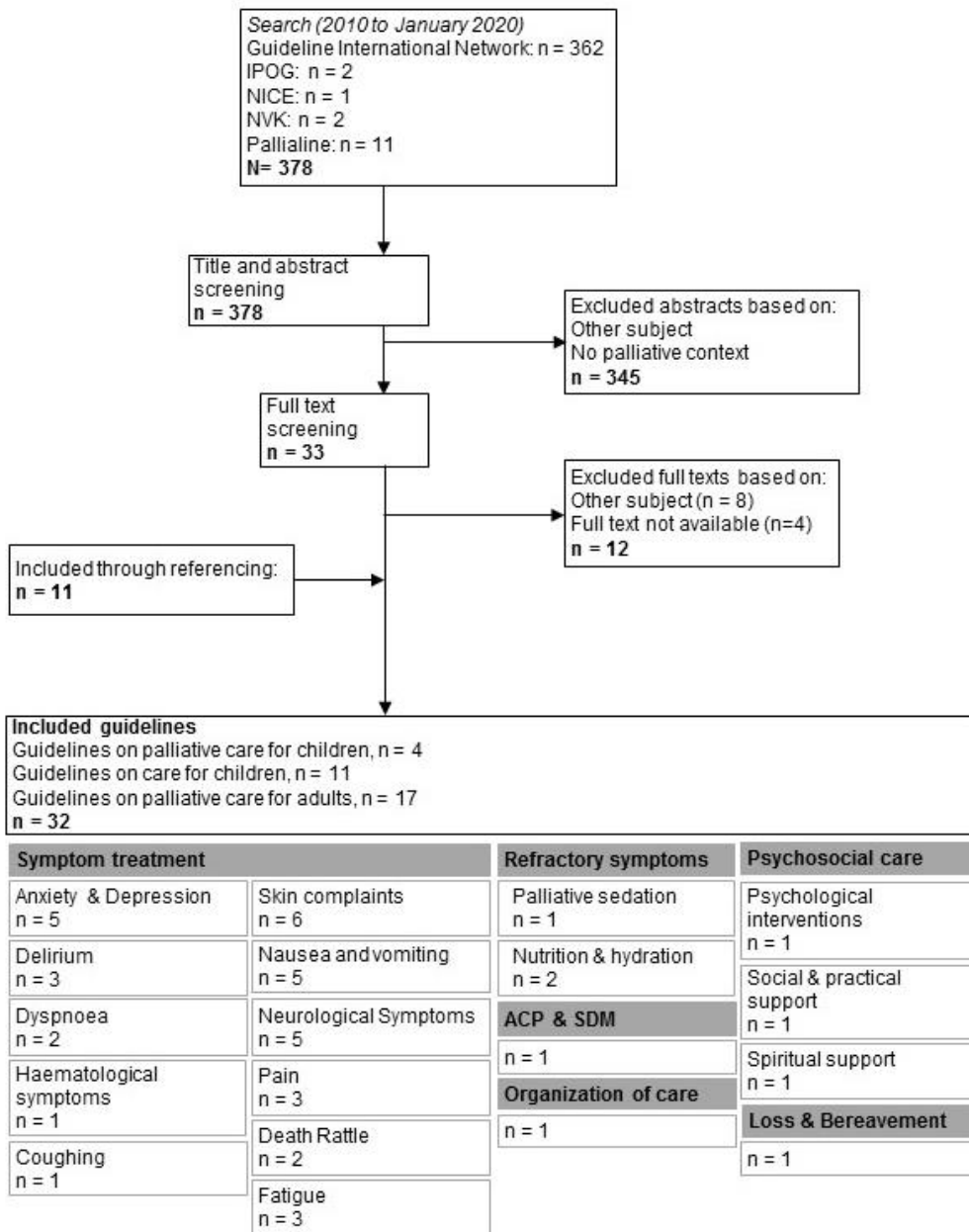


Figure 3. Flowchart Systematic Search Paediatric Palliative Care Guidelines

Search strings

Name researcher:	Kim van Teunenbroek
Search date:	24-01-2020
Search in GIN	
Search 1: Intervention	palliative care OR pediatric palliative care OR children's hospice
Search 2: Population	child OR child* OR children*
Combined:	Search 1 AND Search 2
Total records	362
Search in databases of NICE, IPOG, NVK and Pallialine	
Search NICE database	Guidelines on care for children, n = 1
Search IPOG database	Guidelines on palliative care for children, n = 2
Search NVK database	Guidelines on care for children, n = 2
Search Pallialine database	Guidelines on palliative care for adults, n = 11
Referencing	Guidelines on palliative care for children, n = 1 Guidelines on care for children, n = 6 Guidelines on palliative care for adults, n = 4
Total records:	27