

Box 1. Search terms

1. exp advance care planning/ OR exp attitude to death/ OR exp bereavement/ OR exp terminal care/ OR exp hospices/ OR exp life support care/ OR exp palliative care/ OR exp terminally ill/ OR death/ OR palliate\$.mp OR hospice\$.mp OR terminal care.mp
2. (dying.mp OR death.mp OR end of life.mp) AND (imminen\$.mp OR nearing.mp OR last day\$.mp OR last week.mp OR last hour\$.mp OR final day\$.mp OR final week.mp OR final hour\$.mp OR critical pathway\$.mp)
3. 1 OR 2
4. exp delivery of health care/ AND (exp models, theoretical/ OR exp models, economic/)
5. 3 AND 4
6. child, children, infant, preschooler, school age, adolescent, young person, young people (all searched independently with 'OR')
7. 5 AND 6
8. Limit '7' with 2000 – current and English language

Figure 1: Flowchart of search results

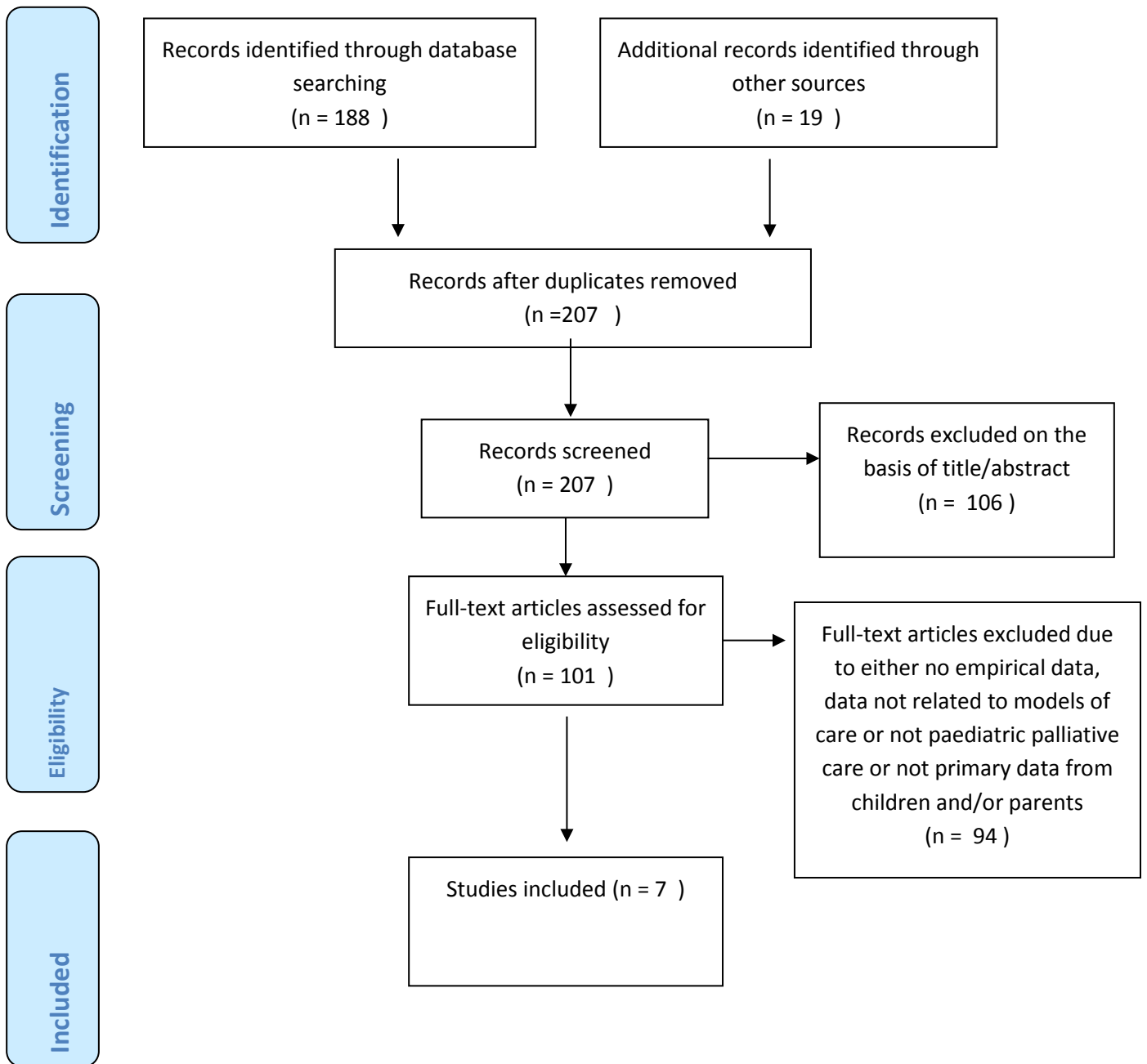


Table 1 – Quality appraisal of included articles

Article	(Noyes et al., 2013)	(Amery, Rose, Holmes, Nguyen, & Byarugaba, 2009)	(Kirk & Pritchard, 2012)	(Knapp et al., 2008)	(Vickers et al., 2007)	(Monterosso, Kristjanson, Aoun, & Phillips, 2007)	(Steele, 2000)
Level (as per NHMRC)	IV	IV	IV	IV	IV	IV	IV
Quality of methods	2	3	3	2	3	2	4
Relevance to question	4	3	4	3	3	3	3
Evaluator / s:	CV/ TL	CV/ TL	CV/ TL	CV/ TL	CV/ TL	CV/ TL	CV/ TL

Table 2: Study characteristics

Author	Focus	Study design	Participants	Diagnoses	Optimal elements of paediatric palliative care
(Noyes et al., 2013) United Kingdom	Determine child and parent preferences for end of life care	Mixed methods (interview)	17 parents (12 mothers/ 5 fathers); 11 children aged 0 – 19 years (3 active / 8 passive)	Oncological and non-oncological conditions	Parents and children valued: <ul style="list-style-type: none"> • 24 hour specialist support • Home care support • Psychosocial support • Flexibility in location of care • Bereavement support
(Kirk & Pritchard, 2012) United Kingdom	Describe parent and child perspectives on a children's hospice	Mixed methods: survey and interview	108/217 parents survey (RR: 49.8%) Interview: 12 parents & 7 children (age M = 14.94 years SD = 7.54)	Non-oncological conditions (97%)	Parent supported by: <ul style="list-style-type: none"> • A break from caring / respite • Enabling time for other children • Access to trusted staff • Bereavement support • Activities for other children
(Amery et al., 2009) Uganda	An evaluation of a nurse led and volunteer supported children's palliative care service	Mixed methods: chart audit and semi-structured interview	12 parent/guardians and 11 children (age not reported)	Oncological and non-oncological conditions	Parent & child perspectives of service strengths: <ul style="list-style-type: none"> • Symptom control (100%) • Play and education (80% children; 58% caregivers) • Supportive staff (80% of children)
(Knapp et al., 2008) USA	To describe a new program of palliative care for children with life-limiting diagnosis	Descriptive study: Retrospective telephone survey	Parents of children enrolled in hospice service (n=468) RR: 53% and 40% of two consecutive years	Oncological and non-oncological conditions	Parents highly satisfied with service (83-85%). Services children received include: <ul style="list-style-type: none"> • Support counselling 42-49% • Respite 20-23% • Activity therapies 8-20% • Nursing care 13-17%
(Vickers et al., 2007) United Kingdom	Describe effectiveness of an outreach model of paediatric palliative care	Descriptive study: Prospective questionnaire survey	Parents of 164 children (age M= 8.9, range 4 months – 18 years) from 20 centres	Oncological conditions	<ul style="list-style-type: none"> • Preferred location for death: Home (68%) at outset of diagnosis; Home (80%) within a month of death. • Child died in preferred location: 86% • 24 hour on-call support provided • Multidisciplinary care provided • Complementary therapies used by 66% of sample • Bereavement support provided by outreach nurses
(Monterosso et al., 2007) Australia	Parent perspectives on extent of service provision, and facilitators and barriers to supportive palliative care	Mixed methods: Questionnaires and semi-structured interviews	257 eligible parents approached and 129 consented (RR- 50%) 110 parents of children with non-oncological condition: M = 1.8 years (SD ±2.96)	Oncological and non-oncological (85%)	<ul style="list-style-type: none"> • Parents prefer to care for children at home. • Parents of children with cancer felt well informed. Parents of children with non-oncological condition did not. • Palliative care not well understood. • Parents expect professionals to have specialist paediatric knowledge and experience.

			19 parents of children with cancer: M = 6 years (SD: 4.54)		<ul style="list-style-type: none"> • Respite care insufficient
(Steele, 2000) Canada	To enhance understanding of the experiences of families with a child with a neurodegenerative life threatening illness (NLTI)	Qualitative Study: grounded theory	8 families (comprising 29 members) of 10 children (6 boys and 4 girls aged 3- 13 years) with a NLTI	Non-oncological	<ul style="list-style-type: none"> • Key themes including entering unfamiliar territory, shifting priorities, creating meaning and holding the fort. • Experiences took place in contexts of acute care and the family's sociocultural environment. • The experience was moderated by their relationships with health care providers, availability of information, gender differences and communication between parents.

Acronyms used within Table 1: RR = response rate; M = Mean; SD = Standard deviation