

# End of life care for infants, children and young people: planning and management

Appendices A–F and H–J

*NICE Guideline*

*Main appendix document*

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# Appendix A: Scope

## A.1 Guideline title

End of life care for infants, children and young people: The planning and management of end of life care for infants, children and young people with life-limiting conditions

### A.1.1 Short title

End of life care for infants, children and young people

## A.2 The remit

The Department of Health has asked NICE: 'To prepare a clinical guideline on the End of life care for infants, children and young people'.

## A.3 Need for the guideline

### A.3.1 Epidemiology

- a. The death of an infant, child or young person has become an uncommon event in the UK.
- b. The infant mortality rate in 2012 in England and Wales was the lowest ever recorded, at 4 deaths per 1000 live births. As recently as 1982 the infant mortality rate was 10.8 deaths per 1000 live births. This change can partly be explained by improvements in health care, particularly in midwifery, obstetrics and neonatal intensive care.
- c. Fair Society Healthy Lives: The Marmot review noted factors that were independently associated with an increased risk of infant mortality, including births outside marriage, maternal age under 20 years, and deprivation. Complications of pre-term birth particularly respiratory and cardiovascular conditions, account for about half of infant deaths. Congenital anomalies account for about a third of infant deaths.
- d. Between 1982 and 2012 the age-specific mortality rate in England and Wales for children and young people aged 1 to 14 years fell by 62%, from 29 deaths to 11 deaths per 100,000 people. The age-specific mortality rate for children aged 1 to 4 years fell by 66% over the same period, from 47 deaths to 16 deaths per 100,000 people. Over the past 30 years child death rates from respiratory and circulatory conditions in England and Wales have been falling, as they have for the whole population. This reflects general advances in medical care and preventative measures. In 2012, congenital conditions and cancers were the most common cause of death for children and young people aged under 16 years.
- e. The 2014 report, *Why children die: death in infants, children and young people in the UK* noted that, despite improving mortality rates, more than 2000 children and young people aged between 1 and 19 years died in England and Wales in 2012. From 1 to 15 years cancer and neurodevelopmental, respiratory, cardiovascular and congenital conditions (all of which tend to be chronic and progressive) account for about 60% of deaths. For young people aged over 15 years external causes (such as accidents) are more common, accounting for 42% of deaths. The proportion of young people aged over 15 years who die from chronic conditions falls to about 30%, although cancer and neurodevelopmental conditions continue to be common causes of death.
- f. Despite declining mortality rates, it is estimated that almost 50,000 infants, children and young people aged 19 years or under in the UK (40,000 of these in England) are living with a life-limiting condition and may need palliative care. They may have widely

1 varying needs, as there are over 300 conditions that could be classed as life-limiting or  
2 life-threatening in infants, children and young people. Some of these infants, children  
3 and young people also have severe disabilities and multiple complex health and care  
4 needs in addition to palliative care.

### 5 **A.3.2 Current practice**

- 6 g. In this guideline the term 'life-limiting condition' is used to refer to any condition which  
7 either generally or in a particular individual is thought likely to result in early death.
- 8 h. In this guideline end of life care will include care of the infant, child or young person  
9 and of their family members or carers from first recognition of the life limiting condition  
10 through to their care in the last days and hours of life and after death.
- 11 i. Children and young people and their family members or carers may have varied ideas  
12 about what, for them, would be good palliative and end of life care. However, most  
13 would place a high priority on being treated with dignity and respect and as an  
14 individual, and being involved in decision-making about their care. They would want to  
15 be without pain, or with as little pain or other distressing symptoms as possible. The  
16 Department of Health's End of Life Care Strategy Fourth Annual Report (2012) notes  
17 that 42.4% of people now die at home or in a care home.
- 18 j. Infants, children and young people with life-limiting conditions, including those who are  
19 approaching the end of their life, need high-quality treatment and care that supports  
20 them to live as well as possible and to die with dignity. Providing such treatment and  
21 care often involves decisions that are complex and emotionally distressing, especially  
22 towards the end of their lives. The GMC guidance Treatment and Care Towards the  
23 End of Life considered that patients were 'approaching the end of life' when they were  
24 likely to die within the next 12 months. However, a more flexible approach defining this  
25 phase of care is adopted for infants, children and young people in this NICE guideline,  
26 because they may have long-term life-limiting conditions. Together for Short Lives' A  
27 guide to end of life care states that most adults only need palliative care at the end of  
28 their lives, but many infants, children and young people with life-limiting conditions  
29 need palliative care over a much longer period. During this time their condition may  
30 fluctuate and there may even be times when it is difficult to determine if death is  
31 imminent.
- 32 k. Palliative care combines a broad range of relevant health and other care services.  
33 Good palliative and end of life care depends on establishing good communication and  
34 care coordination and this requires effective networking arrangements between the  
35 relevant services. These include the hospital, hospice, primary care and community  
36 professionals, ambulance services, other support providers, and dedicated palliative  
37 care teams.
- 38 l. Children's Palliative Care (CPC) aims to make infants, children and young people with  
39 a life-limiting condition as comfortable as possible by relieving pain and other  
40 distressing symptoms. It also provides them and their family members or carers with  
41 psychological care and social, spiritual and religious support as appropriate. CPC may  
42 be needed early in the course of an illness, together with other therapies to treat the  
43 condition. It may start from the antenatal stage, and may continue after the young  
44 person turns 18. It may be part of a plan for transition to adult care when appropriate.
- 45 m. CPC is delivered by various providers, including primary, secondary and tertiary  
46 services, community services and hospices. CPC can be commissioned from the NHS  
47 providers working collaboratively. CPC is also provided by the voluntary sector  
48 (including children's hospices), although there is geographical variation in this  
49 provision.
- 50 n. Some hospitals have specialist palliative care teams. Palliative care teams can provide  
51 care to infants, children and young people and their family members or carers (as  
52 appropriate) in hospitals, hospices and at home. However, not all palliative care teams  
53 currently provide care in all of these settings.

- 1 o. There is variation in palliative care practice, particularly in how services are delivered.  
2 Together for Short Lives has recommended that locally available community-led CPC  
3 should be central to the arrangements and should be supported by specialist medical  
4 input, community nursing teams, children's hospice services, specialist palliative care  
5 providers, access to secondary and tertiary care, community paediatrics, primary care,  
6 emotional and psychological care and support, and local authority children's services  
7 (social care, spiritual and religious support, education, housing and leisure). In contrast,  
8 NHS England in its 2013/14 NHS Standard Contract for Palliative Care recommends  
9 that multi-disciplinary palliative care teams led by clinical consultants should plan,  
10 deliver and evaluate palliative care services across a managed clinical network.

## 11 **A.4 The guideline**

12 The guideline development process is described in detail on the NICE website (see section  
13 6, 'Further information').

14 This scope defines what the guideline will (and will not) examine, and what the guideline  
15 developers will consider. The scope is based on the referral from the Department of Health.

16 The areas that will be addressed by the guideline are described in the following sections.

### 17 **A.4.1 Population**

- 18 • Groups that will be covered  
19 p. Infants, children and young people aged up to 18 who have a life-limiting condition and  
20 their family members or carers (as appropriate).

21 Subgroups for consideration will include:

- 22 o. Infants, children and young people with complex considerations that entail specific care  
23 needs, for example those with communication difficulties.  
24 o. Those with an antenatal diagnosis of a life-limiting condition.  
25 • Groups that will not be covered  
26 q. Adults aged 18 years and older.  
27 r. Infants, children and young people aged up to 18 years without a recognised life  
28 limiting condition who die unexpectedly (for example accidental death).

### 29 **A.4.2 Setting**

- 30 s. All settings in which NHS-commissioned healthcare is provided.

### 31 **A.4.3 Management**

- 32 • Key issues that will be covered  
33 t. Care of infants, children and young people with a life-limiting condition and their family  
34 members or carers (as appropriate) before death.  
35 u. Assessing needs and developing a personalised care plan, including parallel care  
36 planning. (Parallel planning refers to the development of plans that allow for  
37 unpredictability in the course of the condition.)  
38 v. Information and communication with children and young people and/or with the families  
39 and carers of infants, children and young people in relation to organ or tissue donation.  
40 w. Communicating and providing information, from recognition of a life-limiting condition  
41 until after death.  
42 x. Identifying the preferred place of care and the preferred place of death.  
43 y. The safe and effective management of distressing symptoms (such as pain and  
44 respiratory distress).

- 1 z. The role of oral and medically assisted hydration and nutritional support during end of  
2 life care.
- 3 aa. The psychological and emotional needs of infants, children or young people with life-  
4 limiting conditions.
- 5 bb. The psychological and emotional needs of the family members or carers (as  
6 appropriate) of infants, children and young people with life-limiting conditions.
- 7 cc. The support needs of infants, children and young people and their family members or  
8 carers (as appropriate), including social, practical, spiritual or religious.
- 9 dd. Recognising when infants, children and young people are likely to die within a few  
10 days or hours.
- 11 ee. Decisions regarding life sustaining interventions, including cardiopulmonary  
12 resuscitation.
- 13 ff. The organisation of services providing the end of life care of infants, children and  
14 young people with life-limiting conditions.
- 15 gg. The needs of family members or carers after the death of an infant, child or young  
16 person and bereavement support before and after the death.
- 17 hh. Care of the infant, child or young person's body after death.
- 18 • Issues that will not be covered
- 19 ii. The long-term specialist management of bereavement.
- 20 jj. Clinical management of the life-limiting condition.

#### 21 **A.4.4 Main outcomes**

- 22 kk. Quality of life of the child or young person and their family members or carers (as  
23 appropriate)
- 24 ll. Satisfaction of the child or young person with their care.
- 25 mm. Satisfaction with care of the family members, carers (as appropriate) to the infant,  
26 child or young person.
- 27 nn. Whether children and young people are able to die in a place they or their family  
28 members or carers (as appropriate) choose.
- 29 oo. Psychological well-being, for example resilience, depression or anxiety in the child or  
30 young person and their family members or carers (as appropriate).
- 31 pp. Preventing and managing pain and other distressing symptoms, for example  
32 restlessness or agitation.

#### 33 **A.4.5 Review questions**

- 34 Review questions guide a systematic review of the literature. They address only the key  
35 issues covered in the scope, and usually relate to interventions, diagnosis, prognosis, service  
36 delivery or patient experience. Please note that these review questions are draft versions  
37 and will be finalised with the Guideline Development Group.
- 38 qq. What symptoms, signs, or combinations of symptoms or signs indicate that infants,  
39 children or young people are likely to die within a few hours or days?
- 40 rr. What preferences do children and young people with a life-limiting condition and their  
41 family members or carers (as appropriate) have for place of care and for place of  
42 death, and what determines those preferences?
- 43 ss. What is the clinical and cost effectiveness of a home-based programme of care,  
44 compared with care in other settings?
- 45 tt. What service delivery arrangements (including neonatal intensive care and rapid  
46 transfer from intensive care units) can best provide for the needs of infants, children  
47 and young people with life-limiting conditions, and for the needs of their family  
48 members and carers (as appropriate) during this time and after death?

- 1 uu. What is the clinical and cost effectiveness of a defined multi-disciplinary team (MDT)  
2 of a particular composition compared with one of a different composition and compared  
3 with care without a defined MDT?
- 4 vv. What psychological and psychopharmacological interventions are clinically and cost  
5 effective for children and young people with life-limiting conditions, especially during  
6 the end of life, and for the family members and carers (as appropriate) of infants,  
7 children and young people with a life-limiting condition?
- 8 ww. What interventions are safe, and clinically and cost effective for managing pain and  
9 other distressing symptoms associated with life-limiting conditions?
- 10 xx. What is the effectiveness of medically assisted hydration in infants, children and young  
11 people during end of life care?
- 12 yy. What is the effectiveness of medically assisted nutrition support in infants, children and  
13 young people during end of life care?
- 14 zz. What aspects of communication and information provision do infants, children and  
15 young people with life-limiting conditions and their family members or carers (as  
16 appropriate) find helpful or unhelpful, especially as they approach the end of life?
- 17 aaa. What assessments are helpful in developing and reviewing the personalised care  
18 plan for infants, children and young people with life-limiting conditions?
- 19 bbb. What forms of social and practical support are helpful to infants, children and young  
20 people with life-limiting conditions and their family members or carers (as appropriate)?
- 21 ccc. What forms of spiritual or religious support are helpful to infants, children and young  
22 people with life-limiting conditions and their family members or carers (as appropriate)?
- 23 ddd. What information do infants, children and young people with life-limiting conditions  
24 and their family members or carers (as appropriate) need in order to be involved in  
25 advanced care planning, including if appropriate decisions about stopping life-  
26 sustaining treatment and attempting cardiopulmonary resuscitation?
- 27 eee. Before and after an infant, child or young person dies, what considerations do their  
28 family members or carers (as appropriate) consider important (for example,  
29 communication, emotional, spiritual and religious support, care of the body, and  
30 managing practical arrangements)?
- 31 fff. What aspects of communication and information provision help the family members or  
32 carers (as appropriate) of an infant, child or young person with a life-limiting condition  
33 to make decisions on organ or tissue donation?

#### 34 **A.4.6 Economic aspects**

35 Developers will take into account both clinical and cost effectiveness when making  
36 recommendations involving a choice between alternative interventions. A review of the  
37 economic evidence will be conducted and analyses will be carried out as appropriate. The  
38 preferred unit of effectiveness is the quality-adjusted life year (QALY), although this may not  
39 always be an appropriate measure for some analyses in this guideline. Costs considered will  
40 usually be only from an NHS and personal social services (PSS) perspective. Further detail  
41 on the methods can be found in The Guidelines Manual.

#### 42 **A.4.7 Status**

- 43 • Scope

44 This is the final scope.

- 45 • Timing

46 The development of the guideline recommendations will begin in January 2015.



## 1 **A.5 Related NICE guidance**

### 2 **A.5.1 Published guidance**

- 3 • Related NICE guidance
  - 4 ○ Pressure ulcers (2014) NICE guideline CG179
  - 5 ○ Neuropathic pain – pharmacological management (2013) NICE guideline CG173
  - 6 ○ Opioids in palliative care (2012) NICE guideline CG140
  - 7 ○ Patient experience in adult NHS services (2012) NICE guidance CG138
  - 8 ○ Organ donation for transplantation (2011) NICE guideline CG135
  - 9 ○ Acutely ill patients in hospital (2007) NICE guideline CG50
  - 10 ○ Improving outcomes in children and young people with cancer (2005) NICE cancer
  - 11 service guidance
  - 12 ○ Improving supportive and palliative care for adults with cancer (2004) NICE cancer
  - 13 service guidance
- 14 • Published quality standards
  - 15 ○ End of life care for adults (2013) NICE quality standard 13

### 16 **A.5.2 Guidance under development**

- 17 NICE is currently developing the following related guidance (details available from the NICE  
18 website):
- 19 ○ Transition from children's to adult services. NICE guideline (publication expected
  - 20 January 2016)
  - 21 ○ Care of the dying adult. NICE guideline (publication date to be confirmed)

## 22 **A.6 Further information**

- 23 Information on the guideline development process is provided in the following documents,  
24 available from the NICE website:
- 25 ○ How NICE clinical guidelines are developed: an overview for stakeholders the public
  - 26 and the NHS
  - 27 ○ The guidelines manual.
  - 28 ○ Information on the progress of the guideline will also be available from the NICE
  - 29 website.
  - 30

## Appendix B: Stakeholders

- 1
- 2 5 Boroughs Partnership NHS Foundation Trust
- 3 Acorns Children's Hospice
- 4 Action for Sick Children
- 5 Action on Hearing Loss
- 6 ALD Life
- 7 Alder Hey Children's NHS Foundation Trust
- 8 Allocate Software PLC
- 9 Amgen UK
- 10 AMORE health Ltd
- 11 AMORE Studies Group
- 12 Apetito Ltd
- 13 Aspen Medical Europe
- 14 Association for Continence Advice
- 15 Association for Dance Movement Psychotherapy UK
- 16 Association for Palliative Medicine of Great Britain
- 17 Association of Ambulance Chief Executives
- 18 Association of Anaesthetists of Great Britain and Ireland
- 19 Association of British Healthcare Industries
- 20 Association of British Neurologists
- 21 Association of Chartered Physiotherapists in Oncology and Palliative Care
- 22 Association of Chartered Physiotherapists in Respiratory Care
- 23 Association of Child Psychotherapists
- 24 Association of Child Psychotherapists, the
- 25 Association of Directors of Adult Social Services
- 26 Association of Hospice & Palliative Care Chaplains
- 27 Association of Paediatric Chartered Physiotherapists
- 28 Association of Respiratory Nurse Specialists
- 29 Barchester Healthcare
- 30 Barnardo's
- 31 Barnet and Chase Farm Hospitals NHS Trust
- 32 Barnsley Hospital NHS Foundation Trust

- 1 Basildon and Thurrock University Hospitals NHS Foundation Trust
- 2 Baxalta UK Ltd
- 3 Belfast Health and Social Care Trust
- 4 Bereavement Services Association
- 5 Betsi Cadwaladr University Health Board
- 6 Bevan Commission
- 7 Birmingham and Solihull Mental Health NHS Foundation Trust
- 8 Birmingham Children's Hospital NHS Foundation Trust
- 9 Birmingham St Marys Hospice
- 10 Birmingham Women's NHS Foundation Trust
- 11 Black Country Partnership Foundation Trust
- 12 Blackthorn Medical Centre
- 13 Bliss
- 14 Bloodwise
- 15 Bolton Hospitals NHS Trust
- 16 Bowel Cancer UK
- 17 Bradford District Care Trust
- 18 Brainstrust
- 19 Bristol Royal Hospital for Children
- 20 British Academy of Childhood Disability
- 21 British Acupuncture Council
- 22 British Association for Counselling and Psychotherapy
- 23 British Association for Music Therapy
- 24 British Association of Music Therapy
- 25 British Association of Prosthetists & Orthotists
- 26 British Association of Psychodrama and Sociodrama
- 27 British Association of Skin Camouflage
- 28 British Association of Social Workers
- 29 British Dietetic Association
- 30 British Heart Foundation
- 31 British Infection Association
- 32 British Liver Trust
- 33 British Lung Foundation

1	British Medical Association
2	British Medical Journal
3	British National Formulary
4	British Nuclear Cardiology Society
5	British Paediatric Neurology Association
6	British Pain Society
7	British Psychological Society
8	British Red Cross
9	British Renal Society
10	British Society for Antimicrobial Chemotherapy
11	British Society of Paediatric Gastroenterology Hepatology and Nutrition
12	British Specialist Nutrition Association
13	British Thoracic Society
14	BTG International Ltd
15	BUPA Foundation
16	Calderdale and Huddersfield NHS Trust
17	Cambridge University Hospitals NHS Foundation Trust
18	Cambridgeshire Community Services NHS Trust
19	Camden Link
20	Camden Provider Services
21	Camden, Islington ELiPSe and UCLH &HCA Palliative care service
22	Campaign for Better End of Life Care
23	Cancer Network User Partnership
24	Cancer Phytotherapy Service
25	Cancer Research UK
26	Cancer Voices
27	Cancer52
28	Caplond Services
29	Capsulation PPS
30	CARE NI
31	Care Council for Wales
32	Care England
33	Care Quality Commission

1	Carers Lewisham
2	Catholic Bishops Conference of England and Wales
3	Central London Community Health Care NHS Trust
4	Central Manchester University Hospitals NHS Foundation Trust
5	Chartered Society of Physiotherapy
6	Chelsea & Westminster Hospital NHS Foundation Trust
7	Child Bereavement Charity
8	Children's Heartbeat Trust
9	Children's Hospice Association Scotland
10	Children's Law Centre
11	Children's Liver Disease Foundation
12	Christian Medical Fellowship
13	Chroma
14	Church of England
15	Cicely Saunders International
16	Claire House Children's Hospice
17	Clatterbridge Cancer Centre
18	CLIC Sargent
19	College of Occupational Therapists
20	College of Paramedics
21	Community District Nurses Association
22	Compassion in Dying
23	Complementary and Natural Healthcare Council
24	Contact
25	Coordinate My Care
26	Cornwall Partnership NHS Foundation Trust
27	Covidien Ltd.
28	Croydon University Hospital
29	Cruse Bereavement Care
30	Cumbria Partnership NHS Foundation Trust
31	CVAA
32	CWHHE Collaborative CCGs
33	Cystic Fibrosis Trust

- 1 Dementia UK
- 2 Department of Health
- 3 Department of Health, Social Services and Public Safety Northern Ireland
- 4 Difficult Conversations
- 5 Drinksense
- 6 Dudley Metropolitan Borough Council
- 7 East Anglia's Children's Hospices
- 8 East Cheshire NHS Trust
- 9 East Kent Hospitals University NHS Foundation Trust
- 10 East Lancashire Hospitals NHS Trust
- 11 East Midland Ambulance Services NHS
- 12 East Midlands Ambulance Service NHS
- 13 Equalities National Council
- 14 Equality and Human Rights Commission
- 15 Esoteric Practitioners Association UK/EU
- 16 Essex County Council
- 17 Ethical Medicines Industry Group
- 18 Europa Healthcare Solutions
- 19 Faculty of Dental Surgery
- 20 Faculty of Intensive Care Medicine
- 21 Faculty of Pain Medicine of the Royal College of Anaesthetists
- 22 Farleigh Hospice
- 23 Five Boroughs Partnership NHS Trust
- 24 Forgetmenot Childrens Hospice
- 25 Foundation Trust Network
- 26 Freshwinds
- 27 Genetic Alliance UK
- 28 Gentle Dusk
- 29 George Eliot Hospital NHS Trust
- 30 Glencare
- 31 Gloucestershire Hospitals NHS Foundation Trust
- 32 Gloucestershire LINK
- 33 Great Western Hospitals NHS Foundation Trust

1	Greater Manchester & Beyond Coalition of PLW & HIV
2	Greater Manchester and Cheshire Cardiac and Stroke Network
3	Greater Manchester Chaplaincy Collaborative
4	Greater Manchester West Mental Health NHS Foundation Trust
5	Greenwich & Bexley Community Hospice
6	Grunenthal Ltd
7	Harrow Council
8	Havens Hospices
9	Health and Care Professions Council
10	Health and Social Care Information Centre
11	Healthcare Improvement Scotland
12	Healthcare Quality Improvement Partnership
13	Healthwatch Bristol
14	Healthwatch Darlington
15	Healthwatch Halton
16	Heart of England NHS Foundation Trust
17	HEART UK
18	Heatherwood and Wexham Park Hospitals NHS Foundation Trust
19	Helen and Douglas House
20	Help the Hospices
21	Heritage Manor Ltd
22	Hertfordshire Partnership NHS Trust
23	Hindu Council UK
24	Hockley Medical Practice
25	Holisticedge
26	Home Instead Senior Care
27	Hospice of St Francis
28	Hospice UK
29	Humber NHS Foundation Trust
30	Hywel Dda University Health Board
31	ICU Steps
32	Impact of Neutropenia in Chemotherapy European study group
33	Independent Age

- 1 Institute of group analysis
- 2 Integrity Care Services Ltd.
- 3 International Brain Tumour Alliance
- 4 International Longevity Centre UK
- 5 Isabel Hospice
- 6 James Cook University Hospital
- 7 James Whale Fund for Kidney Cancer
- 8 Jessie May
- 9 JT Healing
- 10 KCI Medical Ltd
- 11 Kidney Cancer Support Network
- 12 Kidney Research UK
- 13 Lactation Consultants of Great Britain
- 14 Lancashire Care NHS Foundation Trust
- 15 Lancashire County Council
- 16 Lancashire Teaching Hospitals NHS Trust
- 17 Leeds Community Healthcare NHS Trust
- 18 Leeds Teaching Hospitals NHS Trust
- 19 Leicestershire Partnership NHS Trust
- 20 Lings bar hospital
- 21 Livability Icanho
- 22 Liverpool Heart and Chest Hospital NHS Trust HQ
- 23 Liverpool University
- 24 Liverpool Women's NHS Foundation Trust
- 25 London Ambulance Service NHS Trust
- 26 London Borough of Redbridge
- 27 London Cancer
- 28 London Clinic
- 29 London North West Healthcare NHS Trust
- 30 Luton and Dunstable Hospital NHS Trust
- 31 Macintyre
- 32 Macmillan Cancer Support
- 33 MacoPharma



1	Making Waves
2	MAP BioPharma Limited
3	Marie Curie
4	Martin House Children's Hospice
5	Mascot Child & Family Services Ltd
6	Mastercall Healthcare
7	Medicines and Healthcare Products Regulatory Agency
8	Medway Community Centre
9	Mencap
10	Mid Yorkshire Hospitals NHS Trust
11	Milton Keynes Hospital NHS Foundation Trust
12	Ministry of Defence
13	Motor Neurone Disease Association
14	Multiple Sclerosis Society
15	Multiple System Atrophy Trust
16	Murray Hall Community Trust
17	Muscular Dystrophy UK
18	Myeloma UK
19	Napp Pharmaceuticals Ltd
20	National Bereavement Alliance
21	National Cancer Action Team
22	National Cancer Peer Review Programme
23	National Care Forum
24	National Childbirth Trust
25	National Clinical Guideline Centre
26	National Collaborating Centre for Cancer
27	National Collaborating Centre for Mental Health
28	National Collaborating Centre for Women's and Children's Health
29	National Council for Palliative Care
30	National Deaf Children's Society
31	National Diabetes Inpatient Specialist Nurse
32	National End of Life Care Intelligence Network
33	National End of Life Care Programme

- 1 National Institute for Health and Care Excellence
- 2 National Institute for Health Research
- 3 National Institute for Health Research Health Technology Assessment Programme
- 4 National Patient Safety Agency
- 5 National Public Health Service for Wales
- 6 National Radiotherapy Implementation Group
- 7 Neonatal & Paediatric Pharmacists Group
- 8 Nester Healthcare Group Plc
- 9 Neurocentrx pharma ltd
- 10 Neuromodulation Society of UK & Ireland
- 11 Newcross Healthcare Solutions
- 12 Newlife Foundation for Disabled Children
- 13 NHS Barnsley Clinical Commissioning Group
- 14 NHS Blood and Transplant
- 15 NHS Bolton CCG
- 16 NHS Cambridgeshire
- 17 NHS Cambridgeshire and Peterborough CCG
- 18 NHS Central Lancashire
- 19 NHS Choices
- 20 NHS Chorley and South Ribble CCG
- 21 NHS Coastal West Sussex CCG
- 22 NHS Confederation
- 23 NHS Derbyshire county
- 24 NHS England
- 25 NHS England North
- 26 NHS Gloucestershire CCG
- 27 NHS Hardwick CCG
- 28 NHS Haringey CCG
- 29 NHS Health at Work
- 30 NHS Kidney Care
- 31 NHS National Specialised Commissioning Team
- 32 NHS Nene CCG
- 33 NHS North East Lincolnshire CCG

- 1 NHS Plus
- 2 NHS Sheffield
- 3 NHS Sheffield CCG
- 4 NHS Somerset CCG
- 5 NHS South Central
- 6 NHS South Cheshire CCG
- 7 NHS Trust Development Authority
- 8 NHS Wakefield CCG
- 9 NHS Warwickshire North CCG
- 10 NHS West Cheshire CCG
- 11 Norfolk and Norwich University Hospital
- 12 Norfolk and Suffolk Palliative Care Academy
- 13 Norfolk Hospice Tapping House
- 14 North East Autism Society
- 15 North East London Foundation Trust
- 16 North London Hospice
- 17 North of England Cardiovascular Network
- 18 North of England Commissioning Support
- 19 Northamptonshire Healthcare NHS Foundation Trust
- 20 Northern England Strategic Clinical Network
- 21 Northern Health and Social Care Trust
- 22 Northern Ireland Rare Disease Partnership
- 23 Northumberland, Tyne & Wear NHS Trust
- 24 Northumbria Healthcare NHS Foundation Trust
- 25 Northwest Children's Palliative Care Network
- 26 Nottingham Children's hospital
- 27 Nottinghamshire Healthcare NHS Foundation Trust
- 28 Nottinghamshire Hospice
- 29 Nursing and Midwifery Council
- 30 Nurtured Journey
- 31 Nutricia Advanced Medical Nutrition
- 32 Ovacome
- 33 Oxford Health NHS Foundation Trust

1	Oxford University Hospitals NHS Trust
2	Oxfordshire Clinical Commissioning Group
3	Paediatric Chaplaincy Network
4	Palliative care department, Eryri Hospital
5	Palliative Care Funding Review
6	Palliative Care Pharmacists Network
7	Pancreatic Cancer Action
8	Pancreatic Cancer UK
9	Papworth Hospital NHS Foundation Trust
10	Parkwood Healthcare
11	Patient information Forum
12	Paul Sartori Foundation
13	Peterborough and Stamford Hospitals NHS Foundation Trust
14	Pharmametrics GmbH
15	Picker Institute Europe
16	PICU Feeman Hospital
17	Pilgrim Projects
18	POhWER
19	Primary Care Cardiovascular Society
20	Primary Care Pharmacists Association
21	Primary Care Respiratory Society UK
22	Primrose Bank Medical Centre
23	Prison Reform Trust
24	Progressive Supranuclear Palsy Association
25	Prospect Hospice
26	Pseudomyxoma Survivor
27	Public Health England
28	Rainbows Children's Hospice
29	Rarer Cancers Foundation
30	Real DPO Ltd
31	Regard
32	Resuscitation Council UK
33	RioMed Ltd.

- 1 Roald Dahl's Marvellous Children's Charity
- 2 Rosie and Pete Maguire: Assessment & Consultancy for Children
- 3 Rotherham Hospice
- 4 Rowcroft Hospice
- 5 Royal Berkshire NHS Foundation Trust
- 6 Royal Brompton Hospital & Harefield NHS Trust
- 7 Royal College of Anaesthetists
- 8 Royal College of General Practitioners
- 9 Royal College of General Practitioners in Wales
- 10 Royal College of Midwives
- 11 Royal College of Nursing
- 12 Royal College of Obstetricians and Gynaecologists
- 13 Royal College of Ophthalmologists
- 14 Royal College of Paediatrics and Child Health
- 15 Royal College of Pathologists
- 16 Royal College of Physicians
- 17 Royal College of Psychiatrists
- 18 Royal College of Psychiatrists in Scotland
- 19 Royal College of Radiologists
- 20 Royal College of Speech and Language Therapists
- 21 Royal College of Surgeons of Edinburgh
- 22 Royal College of Surgeons of England
- 23 Royal Cornwall Hospitals NHS Trust
- 24 Royal Devon and Exeter NHS Foundation Trust
- 25 Royal Free Hospital NHS Foundation Trust
- 26 Royal Liverpool and Broadgreen University Hospitals NHS Trust
- 27 Royal Marsden NHS Foundation Trust
- 28 Royal Mencap Society
- 29 Royal National Institute of Blind People
- 30 Royal Pharmaceutical Society
- 31 Royal Society of Medicine
- 32 Royal Wolverhampton Hospitals NHS Trust
- 33 Sandoz Ltd

- 1 Sandwell and West Birmingham Hospitals NHS Trust
- 2 Sanofi
- 3 Scottish Directors of Public Health
- 4 Scottish Health Promotion Managers
- 5 Scottish Intercollegiate Guidelines Network
- 6 Sebastian's Action Trust
- 7 SeeAbility
- 8 Sheffield Children's NHS Trust
- 9 Sheffield Teaching Hospitals NHS Foundation Trust
- 10 Shooting Star Chase
- 11 Sirona Care & Health CIC
- 12 SNDRi
- 13 Sobell House Hospice Charity
- 14 Social Care Institute for Excellence
- 15 Society and College of Radiographers
- 16 Society of British Neurological Surgeons
- 17 Society of Homeopaths
- 18 Somerset County Council
- 19 Somerset, Wiltshire, Avon and Gloucestershire Cancer Services Operational Group
- 20 South Asian Health Foundation
- 21 South Central Cardiovascular Network
- 22 South Downs Health NHS Trust
- 23 South East Coast Ambulance Service
- 24 South Eastern Health & Social Care Trust Specialist Palliative Care Team
- 25 South Eastern Health and Social Care Trust
- 26 South Gloucestershire Council
- 27 South Tees Hospitals NHS Trust
- 28 South Wales Critical Care Network
- 29 South West Yorkshire Partnership NHS Foundation Trust
- 30 South Western Ambulance Service NHS Foundation Trust
- 31 Southern Health & Social Care Trust
- 32 Special Products Ltd
- 33 St Andrews Healthcare

- 1 St Catherine's Hospice
- 2 St Christopher's Hospice
- 3 St Gemma's
- 4 St Georges Healthcare NHS Trust
- 5 St Giles Hospice
- 6 St Helena Hospice
- 7 St Josephs Hospice
- 8 St Lukes Hospice
- 9 St Mary's Hospital
- 10 St Michaels Hospice
- 11 St Mungo's Broadway
- 12 St Oswald's Hospice
- 13 St Wilfrids Hospice
- 14 Staffordshire and Stoke on Trent Partnership NHS Trust
- 15 Stockport Clinical Commissioning Group
- 16 Stonewall
- 17 Sue Ryder
- 18 Surrey and Sussex Healthcare NHS Trust
- 19 Sussex Partnership NHS Foundation Trust
- 20 Sutton and Merton Community Services
- 21 Teenage Cancer Trust
- 22 Teenagers and Young Adults with Cancer
- 23 Tees, Esk and Wear Valleys NHS Trust
- 24 Teva UK
- 25 The Brain Tumour Charity
- 26 The British In Vitro Diagnostics Association
- 27 The Children's Trust
- 28 The College of Social Work
- 29 The Hindu Forum of Britain
- 30 The Intensive Care Society
- 31 The King's Fund
- 32 The Patients Association
- 33 The Peace Hospice

- 1 The Reiki Guild
- 2 The Rotherham NHS Foundation Trust
- 3 The Stroke Association
- 4 Together for Short Lives
- 5 Trafford Council
- 6 Trinity Hospice
- 7 Ty Hafan
- 8 UCL Partners
- 9 UK Clinical Pharmacy Association
- 10 UK Multiple Sclerosis Specialist Nurse Association
- 11 Unison
- 12 Unite the Union
- 13 United Kingdom Council for Psychotherapy
- 14 University College London Hospital NHS Foundation Trust
- 15 University Hospital Birmingham NHS Foundation Trust
- 16 University Hospital of North Staffordshire NHS Trust
- 17 University Hospital Southampton NHS Foundation Trust
- 18 University Hospitals Birmingham
- 19 University Hospitals Bristol NHS Foundation Trust
- 20 University Hospitals of Leicester NHS Trust
- 21 University of Bradford
- 22 University of Essex
- 23 University of Warwick Centre for Educational Development Appraisal and Research
- 24 University of York
- 25 Velindre NHS Trust
- 26 Vifor Pharma UK Ltd
- 27 Voyage Care
- 28 Wales Palliative Care Strategy Implementation Board
- 29 Warrington and Halton Hospitals NHS Foundation Trust
- 30 Way Ahead Care
- 31 Welsh Government
- 32 Welsh Scientific Advisory Committee
- 33 West Bromwich African Caribbean Resource Centre



- 1 West Midlands Ambulance Service NHS Trust
- 2 West Midlands Paediatric Palliative Care Network
- 3 West Sussex County Council
- 4 West Sussex Public Health
- 5 Western Health and Social Care Trust
- 6 Western Sussex Hospitals NHS Trust
- 7 Willowbrook Hospice
- 8 Wirral hospice
- 9 Wockhardt UK Ltd
- 10 Worcestershire Acute Hospitals Trust
- 11 Worcestershire LINK
- 12 York Hospitals NHS Foundation Trust
- 13 Yorkshire and Humber Strategic Clinical Network
- 14
- 15

## Appendix C: Declarations of interest

All Committee members' interests were recorded on declaration forms provided by NICE. The form covered personal, non-personal, specific or non-specific and non-financial or financial declarations. Committee members' declarations of interests are listed in this section. No conflicts were identified that required a Committee member to be asked not to participate in the relevant discussions. Details are available from the Committee minutes available on the NICE website where the policy can also be accessed (see <https://www.nice.org.uk/about/who-we-are/policies-and-procedures>).

This appendix includes all interests declared between the start of development and submission on 19 May 2016.

**Table 1: Declarations of interest**

Member	Interest declared	Type of interest	Decision taken
Peter Barry	No interests to be declared.	-n/a	Declare and participate
Karen Brombley	Masters dissertation on 'the factors that influence choices about place of care and death in children and young people.	Personal non-financial specific	Declare and participate
Karen Brombley	Submitted abstract to Cardiff about factors that influence choices about place of care and death in children and young people.	Personal non-financial specific	Declare and participate
Karen Brombley	Advisory volunteer role to Well Child charity - their remit is for recommendations on allocation of funding to nursing posts.	Personal non-financial non-specific	Declare and participate
Karen Brombley	Member and deputy chair of pain and palliative care MCRN group.	Personal non-financial non-specific	Declare and participate
Karen Brombley	Speaking at a regional study day on Advanced Care Planning - about the practical side of completing Advanced Care Plans (how, where, when etc.)	Non-Personal non-financial specific	Declare and participate
Karen Brombley	Contributed to a Delphi Study	Non-Personal non-financial specific	Declare and participate
Karen Brombley	I have contributed to a mini review paper (invited article for a special edition of Journal of Pharmacy & Pharmacology on the subject of Paediatrics), with 6 colleagues	personal non-financial non-specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	<p>(mostly from London School of Pharmacy). This deals with the complex issues faced in practically delivering medication to children in palliative care. This does not recommend specific treatments, it deals with the practical challenges related to the lack of paediatric formulations, in the hope of inspiring researchers to develop these.</p> <p>The title is 'Palliative Medicines for Children – a new Frontier for Research'</p> <p>If accepted this is likely to be published at the very end of 2016 / early 2017.</p> <p>I have not been paid to undertake this work, and do not express personal opinions about the choice of individual treatments.</p>		
Lucy Coombes	In April 2015, will commence a 3 year position as a palliative care research sister. The post is funded by the Caroline Menez Trust through the Royal Marsden Hospital.	personal financial non-specific	Declare and participate
Lucy Coombes	Part of a team developing a research protocol regarding the R&D/ethics on what symptoms life limited children experience towards end of life. Funding of £6000 received from Shooting Star Chase Hospice.	non-personal financial specific	Declare and participate
Lucy Coombes	Contributed to a journal article on 'Palliative and end of life care for children with diffuse intrinsic	non-personal non-financial specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	pontine glioma: results from a London cohort study and international survey'. The article is a retrospective cohort study of children with diffuse intrinsic pontine glioma (DIPG) aged 0-18 years who received treatment at Great Ormond Street or the Royal Marsden. An inventory of symptoms was compiled along with interventions received and a look at current service provision. The discussion is about the current state of palliative and end of life care for children with DIPG.		
Lucy Coombes	As part of current role in team, responsible for recruiting patients, ensuring the protocol is followed, taking PK studies etc. for a phase 1 open label drug study on Naloxegol which is an oral medication for opioid induced constipation.	Non-personal non-financial non-specific	Declare and participate
Lucy Coombes	Oral presentation accepted at the EAPC conference in Dublin in June 2016 with the title of 'the use of the 'surprise' question in paediatric palliative care. Aim to assess the sensitivity and specificity of the question 'would you be supposed if this patient dies within the next 12 months?'	Personal non-financial non-specific	Declare and participate
Lucy Coombes	Poster accepted on audit of resuscitation plans by ICPCN for conference in May 2016 in Argentina. Not attending meeting in person so no expenses.	Personal non-financial non-specific interest	Declare and participate
Lucy Coombes	Teaching at national study day on excess	Personal non-financial specific interest	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	respiratory secretions in March 2016.		
Lucy Coombes	The team she works with have received final approval to conduct a research study entitled 'Pain and symptoms in children with advanced cancer: A longitudinal study to develop a comprehensive symptom inventory'. She is named as chief investigator. They will be using a tool already validated in children with cancer (the memorial symptom assessment scale for 7-12 year olds and 10-18 year olds) to see whether there are any missing or redundant items when used in children with advanced cancer. They will also be comparing correlations between parent, child and nurse scores.	non-personal non-financial specific	Declare and participate
Lucy Coombes	Article entitled 'health related quality of life outcome measures in paediatric palliative care: a systematic review' accepted for publication in palliative medicine. Conclusion - there is currently no ideal measure - more research needed. Work was for MSc dissertation - funded in part by the NIHR collaboration for leadership in applied health research and care funding scheme (CLAHRC)	personal financial non-specific	Declare and participate
Elissa Coster	Works as the Children's and Families Worker at the Brain Tumour Charity	Personal financial non-specific	Declare and participate
Elissa Coster	Developing end of life resources for children, young people and young adults at the Brain Tumour Charity	personal non-financial specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
Elissa Coster	Member of the recently established national neuro-oncology nurses meeting.	Personal non-financial non-specific	Declare and participate
Stacey Curzon	No interests to be declared		Declare and participate
Sharon English	Author of chapter in textbook 'Neonatology at a Glance' on neonatal palliative and end of life care - due to be published in 2015.	Personal financial non-specific	Declare and participate
Sharon English	Member of guideline committee for British Association of Perinatal Medicine (BAPM) on perinatal palliative and end of life care. Published 2011 with no remuneration.	Personal non-financial specific	Declare and participate
Bobbie Farsides	Trustee of Medical Research Foundation - <a href="http://www.medicalresearchfoundation.org.uk">www.medicalresearchfoundation.org.uk</a>	Personal non-financial non-specific	Declare and participate
Bobbie Farsides	Member of UK Donation Ethics Committee and of sub-group considering Children and organ donation	Personal non-financial specific	Declare and participate
Bobbie Farsides	Member of the Nuffield Council on Bioethics until April 2015 and Chair of their working group on Children's Participation in Clinical Research report to be published April 2015.	Personal financial non-specific	Declare and participate
Bobbie Farsides	Part of the UK Donation Ethics Committee (they offer a stipend of £160 per day meeting and meets approximately four times a year). She was involved in drafting of the guidance on paediatric organ donation but has not spoken or written publicly on the matter.	Personal non-financial specific	Declare and participate
Bobbie Farsides	Member of the UK Donation Ethics Committee which has published a position paper on Children and	Personal specific non-financial	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	Organ Donation <a href="http://www.aomrc.org.uk/docman?gid=63&amp;view=category">http://www.aomrc.org.uk/docman?gid=63&amp;view=category</a> it has also commented UKDEC provides £160.00 per day to cover attendance at committee meetings (usually four per year) but does not pay for any work on projects between meetings		
Jane Green (Nee Morgan)	She is a co-applicant for 'Ambitions for palliative and end of life care'. A national framework for local action 2015 - 2020 that urges local leadership to be at the forefront of improvement in end of life care. (National palliative and end of life care partnership, <a href="http://www.endoflifecareambitions.org.uk">www.endoflifecareambitions.org.uk</a> )	personal non-financial specific	Declare and participate
Jane Morgan	Member of Together for Short Lives Parent Carer Advisory Group	Personal non-financial specific	Declare and participate
Jane Morgan	Community champion volunteer for Havens Hospices.	Personal non-financial non-specific	Declare and participate
Jane Morgan	Applied to study Child Nursing BSc (Hons) at Anglia Ruskin University in Chelmsford	Personal non-financial non-specific	Declare and participate
Jane Morgan	She reviewed a book called 'Luna's red hat' which relates to a child's grief after the suicide of a parent.	Personal non-financial non-specific	Declare and participate
David Hamilton	No interests to be declared.	-n/a	Declare and participate
Emily Harrop	Submitted abstract to Cardiff international conference (Summer 2015). This is on the subject of Buccal opioids for breakthrough. It's essentially based on a questionnaire result.	Personal non-financial specific	Declare and participate
Emily Harrop	Contributor to second addition of regional advance care planning	Non-personal non-financial specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	document (February 2015)		
Emily Harrop	A member of National Institute of Health Research (NIHR) medicines for children research network pain and palliative care clinical studies group. This is a multi-disciplinary group that supports and prioritises research in the area of palliative care and pain. This is an unpaid position, which was competitively gained (i.e. application process). The group looks at / discusses / evaluates studies on all areas of pain / palliative care.	Personal non-financial specific	Declare and participate
Emily Harrop	Contributor to APPM Master Formulary 3rd Edition in November 2014.	Personal non-financial specific	Declare and participate
Emily Harrop	Named Consultant for Advance Care planning at Children's Hospital in Oxford (part of the John Radcliffe). A teaching and coordinating role within current Honorary Contract. No change in remuneration or role description.	Personal non-financial specific	Declare and participate
Emily Harrop	Panel member on BBC Radio 4's 'Inside the Ethics Committee' which included a discussion on ethical issues related to a case of a child receiving end-of-life care.	Personal non-financial specific	Declare and participate
Emily Harrop	Met with neonatal ethics team for the palliative care funding review.	Non-personal non-financial specific	Declare and participate
Emily Harrop	Abstract written to be submitted to 3rd International Paediatric Palliative Medicine conference in Rome	Personal non-financial non-specific interest	Declare and participate



Member	Interest declared	Type of interest	Decision taken
	(Nov 2016) on antenatal paediatric palliative medicine		
Emily Harrop	Teaching session delivered on antenatal PPM and advance care planning to SpRs training in paediatric palliative medicine (National study day)	Personal non-financial specific interest	Declare and participate
Emily Harrop	Co applicant on NIHR RfPB application with Prof Ian Wong (London School of Pharmacy): 'Bridging the gap in pharmacological treatment for paediatric palliative care (PPC). A multicentre observational study'. (to be submitted 23rd March 2016) (1) What medications, formulations, dose regimens, method of administration and licensing status are being prescribed for symptom relief in children and adolescents with LLCs? (2) What adverse drug reactions have occurred and what is their frequency? We propose to conduct a multicentre, observational study to collect baseline information in regard to what medicines, formulations, dose regimens and method of administration are being prescribed for symptom relief in children and adolescents with LLCs and to identify and evaluate the nature and frequency of any adverse drug reactions. This is something that I have been less directly involved with for a number of years in an	Non-personal financial specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	indirect capacity since undertaking some additional training in clinical pharmacology. Even if funded, this work will not start until 2017.		
Emily Harrop	<p>I have contributed to a mini review paper (invited article for a special edition of Journal of Pharmacy &amp; Pharmacology on the subject of Paediatrics), with 6 colleagues (mostly from London School of Pharmacy). This deals with the complex issues faced in practically delivering medication to children in palliative care. This does not recommend specific treatments, it deals with the practical challenges related to the lack of paediatric formulations, in the hope of inspiring researchers to develop these.</p> <p>The title is 'Palliative Medicines for Children – a new Frontier for Research'</p> <p>If accepted this is likely to be published at the very end of 2016 / early 2017.</p> <p>I have not been paid to undertake this work, and do not express personal opinions about the choice of individual treatments.</p>	personal non-financial non-specific	Declare and participate
Paul Jacklin	Paid an honorarium to be on an eczema expert panel for Dr Tracey Sach's NIHR Career Development Fellowship.	personal financial non-specific	Declare and participate
Satbir Jassal	Having a paper published in Journal of Paediatric Health on 'Symptom	personal non-financial specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	management'. No recommendations are made and this was written before he joined the guideline.		
Satbir Jassal	Has been asked to do training for Paediatric specialist registrars in January. This will be relating to the prescribing of medication and the legal implications after the death of a child. The training will have no direct relevance to the guidelines.	personal financial non-specific	Declare and participate
Satbir Jassal	Child Health Lead for West Leicestershire CCG.	Personal financial non-specific	Declare and participate
Satbir Jassal	Medical Director of Rainbows Children's and Young Adult Hospice.	Personal financial non-specific	Declare and participate
Satbir Jassal	GP Palliative care lead for NHS England East Midlands	Personal financial non-specific	Declare and participate
Satbir Jassal	Member of the Association of Paediatric Palliative Medicine.	Personal non-financial specific	Declare and participate
Satbir Jassal	Honorary consultant at LOROS an adult hospice	Personal non-financial specific	Declare and participate
Satbir Jassal	Honorary lecturer at Cardiff University in palliative medicine	Personal financial non-specific	Declare and participate
Satbir Jassal	Writes the Rainbow manual which the WHO may adopt. This is the hospice's symptom control manual in paediatric palliative medicine.	Personal non-financial specific	Declare and participate
Satbir Jassal	Author and Editor for the APPM formulary.	Personal non-financial non-specific	Declare and participate
Satbir Jassal	Co-Author of the Oxford Handbook of Paediatric Palliative Medicine. Royalties of approximately £100 are received per annum.	Personal financial non-specific	Declare and participate
Satbir Jassal	Member of and has strong links with	Personal non-financial non-specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	Together for Short Lives.		
Satbir Jassal	Lecture in Moscow on Practical Pain management, DNAR and Criteria for admission to hospice.	Personal specific non-financial	Declare and participate
Satbir Jassal	Some of the papers used as evidence in a review for this meeting authored by Hunt contained perspectives from children who were cared for at Rainbows Children's and Young Adult Hospice where SJ is the Medical Director.	non-personal non-financial specific	Declare and participate
Satbir Jassal	That some of the papers used as evidence in a review for this meeting authored by Hunt contained perspectives from children who were cared for at Rainbows Children's and Young Adult Hospice where SJ is the Medical Director.	non-personal non-financial specific	Declare and participate
Satbir Jassal	Submitted a paper on symptom management in paediatric child health and rewrote a chapter in The Oxford Handbook in Palliative Care which focuses on the philosophy of care and principles of symptom management.	Personal non-financial specific	Declare and participate
Susan Lee	No interests to be declared.	-n/a	Declare and participate
Afia Manaf	No interests to be declared.	-n/a	Declare and participate
Paul Nash	Co-authored 'Multi-faith Care of Sick Children and their Families' JKP. London. June 2015. Royalties directly to employer.	non-personal financial specific	Declare and participate
Paul Nash	Tutor at Midlands Institute for Children, Youth and Mission	Personal financial non-specific	Declare and participate
Paul Nash	The lead for Red Balloon Resources, the publishing arm of	Personal financial non-specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	Birmingham Children's Hospital chaplaincy team. This organisation produce resources in paediatric spiritual and religious care for palliative, end of life and bereavement care. These are sold not for profit to other care professionals.		
Paul Nash	Presenting a paper on Palliative Spiritual Care at Paediatric Care Conference in Glasgow (October 2015). Payment was received but made directly to employer.	non-personal financial specific	Declare and participate
Paul Nash	Director of new research study and resource centre, Centre for Paediatric Spiritual Care encouraging research into the area of spiritual well-being in children.	non-personal financial non-specific	Declare and participate
Paul Nash	Vice chair of Trustees for Beyond the Horizon, a bereavement and loss support charity.	Personal non-financial specific	Declare and participate
Paul Nash	The co-convenor of the Paediatric Chaplaincy Network (GB&I), an informal support group for those offering religious and spiritual care in hospitals, hospices and in the community.	Personal non-financial specific	Declare and participate
Paul Nash	Co-authored 'Spiritual Care with Sick Children and Young People' JKP. London. September 2015	non-personal financial specific	Declare and participate
Paul Nash	"Presentation at RCPCH annual conference, Young people's health special interest group and ethics and law forum 'Resolving challenging issues in young people's health'	Personal financial non-specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	Religion, faith and culture. 26 April 2016		
Paul Nash	Chair for Islamic consultation for our two new resources to encourage families in further engagement with organ donation. 21 April 2016	Personal non-financial specific	Declare and participate
Fauzia Paize	A co-applicant for 'Ambitions for palliative and end of life care'. A national framework for local action 2015 - 2020 that urges local leadership to be at the forefront of improvement in end of life care. (National palliative and end of life care partnership, <a href="http://www.endoflifecareambitions.org.uk">www.endoflifecareambitions.org.uk</a> )	personal non-financial specific	Declare and participate
Zoe Picton- Howell	Given a talk about patient/parent perspective at the launch of 'NCPOD's' child health programme 22/10/15	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Chair of RCPCH Parent and Carer Advisory Group	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Member of RCPCH Ethics and Law Committee	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Member of Academy of Royal Colleges Lay Advisory Group	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Tutor at the NHS Leadership Academy	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Tutor on Health Inequality and Disability Stream at Edinburgh University Medical School	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Author of Edinburgh Law School's Course, Law, Rights and Ethics for Paediatrics	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Author of Paediatric Modules of Edinburgh Law School's LLM Compassionate Care	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Author of blog Triangulation of Thought	Personal non-financial non-specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
Zoe Picton-Howell	PhD Researcher Edinburgh University Law School researching how doctors make difficult medical decisions for disabled children with complex health needs.	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Author of chapter in disability matters e-learning platform launched in February 2015. The chapter's content was related to Choices and Decision Making and how to support children and young people in making decisions and how to advise those that are incapable of making decisions.	Personal financial non-specific	Declare and participate
Zoe Picton-Howell	Interview on Radio 2 programme for carer's week about the experience of caring for her son.	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Article published for Together For Short Lives newsletter in September 2015 about her son	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Lay member to the National Patient Enquiry into Patient Outcome and Death, Study Advisory Group	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Attended an event for UK Sepsis trust at reception at the House of Commons 08/09/2015	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Attendance as a delegate at 'Turn up the volume' conference as guest of conference organisers (carerightnow.co.uk)	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Attendance at Health Service Journals leaders' summit as a guest of Health Service Journal (HSJ, November 2015)	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	NHS Employers/ NHS Confederation/ Horizon Centre	Personal non-financial non-specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	naming their conference suite in Leeds Horizon Centre 'Adam's place' after her son Adam Bojelian and holding a reception to unveil a plaque on 18th December 2015		
Zoe Picton-Howell	NHS Employers/ NHS Confederation holding/hosting annual Adam Bojelian Memorial talk, 1st talk to be given by Kathy Evans of NHS England on 24/03/16	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	NCEFOD talk on Chronic Disability Programme (unpaid)	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Disability Matters talk at the RSM conference 'Patients and Families, the new doctors' (unpaid) - on co-production of Disability Matters. 20/10/15	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Talk on Disability Matters from parent perspective at Disability Matters Roadshow (2nd November)	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Will be speaking at the NHS leadership conference on the 02/02.16. Lessons from the life of Adam	personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	In December 2015, NHS confed/ NHS Employers hosted a reception and unveiled AdsPlace at their Horizon Centre	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	There was an article in the Yorkshire Post about Adam and his relationship with the NHS leaders	Personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Giving a paper 'in whose best interests' about paediatricians use of the term 'best interests' at Southampton University's 'Everyday ethics' conference at	personal non-financial non-specific	Declare and participate



Member	Interest declared	Type of interest	Decision taken
	RCN London on 10th May		
Zoe Picton-Howell	Will be guest of Young Epilepsy at their Champions Award 2016 on 18th May 2016	personal non-financial non-specific	Declare and participate
Zoe Picton-Howell	Received special recognition Award from the patient experience network 2015, February 2016	personal non-financial non-specific	Declare and participate
David Vickers	Works for East Anglia's Children's Hospices as Medical Director via a service level agreement with his NHS Trust	Personal financial non-specific	Declare and participate
David Vickers	Former Trustee, Together for Short Lives (until September 2013), remains a member and a member of Practice and Development Advisory Council	Personal non-financial non-specific	Declare and participate
David Vickers	Co-author of paper submitted to Cardiff International CPC Conference June 2015 on a mode of provision of out of hours care.	Personal non-financial non-specific	Declare and participate
David Vickers	Speaker on 'Palliative Care' at the BJHM conference (MA publications, palliative care 2016).	Personal non-financial specific	Declare and participate
Amy Volans	Coordinates a special interest group for psychologists working with infants, children and young people with palliative care needs. As part of this she co-chairs the London Children's Palliative Care Network.	Personal non-financial specific	Declare and participate
Amy Volans	Submitted application to organise a workshop at the 7th International Cardiff Conference on Paediatric Palliative Care (July 2015). The acceptance of the proposal is to be confirmed. The title is "Parents' narratives	Personal non-financial non-specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
	about compassion in children's palliative care: voices from the multicultural east end of London".		
Amy Volans	Contributed to the British Psychological Society and Together for Short Lives responses to the NICE consultation on the End of Life Care for infants, children and young people scope and to the same groups' responses to the House of Commons Select Committee on Palliative and End of Life Care in November 2014.	Personal non-financial specific	Declare and participate
Amy Volans	Employer's MDT service has applied to contribute data to the NHS England Palliative Care Funding Review Team's currency testing data collection point. This will involve submitting "activity" and "cost" data about patient care provided by the service to the Palliative Care Funding Team at NHS England who will analyse and interpret the data.	non-personal non-financial specific	Declare and participate
Amy Volans	Participated in interview with journalist writing an article for the Guardian on how school teachers can support each other and the wider community when a student has Palliative needs.	Personal non-financial specific	Declare and participate
Amy Volans	Invited to speak at the Barts Hospital Bereavement Conference on how healthcare staff can support each other and sustain themselves in work with bereaved families.	Personal non-financial non-specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
Amy Volans	Abstract accepted for the Cardiff International Children's Palliative Care Network Conference 'Parents narrative about compassion in Palliative care'	Personal non-financial specific	Declare and participate
Amy Volans	Invited to attend meeting with Together for Short Lives at the Houses of Parliament.	Personal non-financial non-specific	Declare and participate
Amy Volans	Gave brief presentation at Together for Short Lives regional network summit about the range of psychological services and models currently offered in different regions of the UK	Personal non-financial specific	Declare and participate
Amy Volans	Organised (booked rooms and registered delegates) for study day for children's palliative care psychologists. Did not make any presentations at the event.	Non-personal non-financial non-specific	Declare and participate
Amy Volans	"Gave 15 minute presentation of creative approaches to bereavement support for vulnerable children at Child Bereavement UK study day in East London in April 2016	personal non-financial non-specific	Declare and participate
Amy Volans	NB - covered bereavement care beyond the scope of this guideline"	Personal financial non-specific	Declare and participate
Claire Wensley	Author of a palliative care chapter in Paediatrics at a Glance – Miall, Rudolf and Smith	Personal non-financial specific	Declare and participate
Claire Wensley	Presented a poster at the RCPCH conference Glasgow 2013 and the Royal Society of Medicine meeting December 2012, "What delays discharge in children with life limiting conditions?"	Personal non-financial specific	Declare and participate

Member	Interest declared	Type of interest	Decision taken
Claire Wensley	Works as an ad hoc Bank Doctor at Martin House Children's Hospice	Personal financial non-specific	Declare and participate
Claire Wensley	Member of the steering group for the Yorkshire and Humber Children and Young Persons Paediatric Palliative Care network	Personal non-financial specific	Declare and participate
Claire Wensley	Member of the executive committee for the Yorkshire and Humber Children and Young Persons paediatric palliative care network (lead for the clinical subgroup)	Personal non-financial specific	Declare and participate
Claire Wensley	Wrote a chapter for an undergraduate paediatric text book	Personal non-financial non-specific	Declare and participate
Claire Wensley	Two articles published by the RCPCH - 'What delays discharge in children with life limiting conditions?' (2012) and 'Unannounced, single site, interprofessional real time simulation' (2015)	Personal non-financial specific	Declare and participate
Claire Wensley	Will be speaking at Yorkshire and Humber Children's and Young people's palliative care network annual conference on 10th March 2015 on symptom control specific symptom to be confirmed.	personal non-financial specific	Declare and participate
Claire Wensley	On the 20th of February 2016 she will be teaching at a workshop at APM medical students' conference in York on paediatric palliative care.	personal non-financial specific	Declare and participate

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# 1 Appendix D: Review protocol

## D.1.2 Information provision

Item	Details
<b>Key issues in the scope</b>	Communicating and providing information, from recognition of a life-limiting condition until after death. Care of the infant, child or young person's body after death.
<b>Related review question in the scope</b>	Before and after an infant, child or young person dies, what considerations do their family members or carers (as appropriate) consider important (for example, communication, emotional, spiritual and religious support, care of the body, and managing practical arrangements)?
<b>Review question:</b>	What information and information type (written or verbal) is perceived as helpful and supportive by children and young people (if appropriate), and their family or carer before and after an infant, child or young person dies including managing practical arrangements, and care of the body?
<b>Objective</b>	To identify the content and type of information that is experienced as helpful and supportive or a hindrance by the children or young people and their families or carers (as appropriate) before and after an infant, child or young person dies in relation the life limiting condition, likelihood of death and practical arrangements, and care of the body.
<b>Population</b>	Infants, children and young people (up to age of 18 years) with life limiting conditions, their families or carers (as appropriate) and healthcare professionals Population size and indirectness: <ul style="list-style-type: none"> <li>• No restrictions on sample size will be applied</li> <li>• Studies with indirect population will not be included</li> </ul>
<b>Subgroups and sensitivity analyses</b>	Important subgroups: <ul style="list-style-type: none"> <li>• people receiving information from interpreters</li> </ul>
<b>Setting</b>	Community, primary, secondary and tertiary care ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence
<b>Context and likely themes</b>	<b>Context</b> Information content and type with regards to life limiting conditions, likelihood of death, practical arrangements, and care of the body <b>Themes will be identified from the literature, but expected themes are:</b> <ul style="list-style-type: none"> <li>• Use of jargon and terminology</li> <li>• Uncertainty around likelihood of death</li> <li>• Methods of information provision (tools to facilitate) <ul style="list-style-type: none"> <li>○ Verbal</li> <li>○ Written</li> <li>○ Online</li> <li>○ Apps</li> <li>○ Play</li> </ul> </li> <li>• Choice and options (treatment related)</li> <li>• Direct practical information (how and when)</li> </ul>
<b>Study design</b>	Study designs to be considered:

Item	Details
	<ul style="list-style-type: none"> <li>• Qualitative studies (for example, ethnographic studies, interviews, and focus groups)</li> <li>• Mixed-methods observational studies where qualitative data were reported (for example, survey studies)</li> </ul> Exclude: <ul style="list-style-type: none"> <li>• Purely quantitative studies (including surveys with only descriptive quantitative data)</li> </ul>
<b>Population size and directness</b>	Population size and directness: <ul style="list-style-type: none"> <li>• No sample size specification.</li> <li>• Studies with indirect populations will not be considered</li> </ul>
<b>Search strategy</b>	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycInfo, CINAHL. Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters. Supplementary search techniques: No supplementary search techniques will be used. See appendix for full strategies (Appendix E:)
<b>Review strategy</b>	Appraisal of methodological quality <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by GRADE-CERQual approach for each identified theme.</li> </ul> Data synthesis: <ul style="list-style-type: none"> <li>• Thematic analysis of the data will be conducted and findings presented.</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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## D.2.1 Communication

Item	Details
<b>Key issue in the scope</b>	Communicating and providing information, from recognition of a life-limiting condition until after death.
<b>Review question in the scope</b>	What aspects of communication and information provision do infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) find helpful or unhelpful, especially as they approach the end of life?
<b>Review question:</b>	What are the barriers and facilitators to effective communication between the child or young person, the family or carer and the healthcare professionals about the life limiting condition and likelihood of imminent death?
<b>Objective</b>	To identify themes in the experiences, opinions and attitudes of the dying children or young people and the families or carers of infants, children or young people (as appropriate) on the factors that encourage and prevent good <i>communication</i> between them and the healthcare professional when talking about the life limiting condition or the likelihood they are entering the last days of life (as well as experiences, opinions and attitudes of the healthcare professional).
<b>Population</b>	Children and young people (up to the age of 18 years) with life limiting conditions; families or carers of infants, children or young people (as appropriate) and healthcare professionals Population size and indirectness: <ul style="list-style-type: none"> <li>• No restrictions on sample size will be applied</li> <li>• Studies with indirect population will not be included</li> </ul>
<b>Subgroups and sensitivity analyses</b>	<ul style="list-style-type: none"> <li>• Important subgroups: <ul style="list-style-type: none"> <li>• people with communication difficulties</li> <li>• people communicating through an interpreter</li> </ul> </li> </ul>
<b>Setting</b>	<ul style="list-style-type: none"> <li>• Community, primary, secondary and tertiary care ideally in a UK context, but</li> <li>• evidence from other countries will be considered if there is insufficient direct</li> <li>• evidence</li> </ul>
<b>Context and likely themes</b>	<p><b>Context</b></p> <p>Communication about the life limiting condition and likelihood of death</p> <p><b>Themes will be identified from the literature, but expected themes are:</b></p> <ul style="list-style-type: none"> <li>• Healthcare professionals' skill and experience and specialist training</li> <li>• Empathy and rapport (cultural and religious considerations)</li> <li>• Timing (when to initiate)</li> <li>• Resources (time spent with individuals and place of communication, that is, privacy in hospital)</li> <li>• Families' acceptance of prognosis</li> <li>• Translation services</li> <li>• Methods of communication (tools to facilitate) <ul style="list-style-type: none"> <li>○ Verbal</li> <li>○ Written</li> <li>○ Online</li> <li>○ Apps</li> <li>○ Play</li> </ul> </li> </ul>
<b>Study design</b>	Study designs to be considered: <ul style="list-style-type: none"> <li>• Qualitative studies (for example, ethnographic studies, interviews, and focus groups ;)</li> <li>• Mixed-methods observational studies where qualitative data were reported (for example, survey studies)</li> </ul>

Item	Details
	<p>Excluded</p> <ul style="list-style-type: none"> <li>• Purely quantitative studies (including surveys with only descriptive quantitative data)</li> </ul>
<b>Population size and directness</b>	<p>Population size and directness:</p> <ul style="list-style-type: none"> <li>• No sample size specification.</li> <li>• Studies with indirect populations will not be considered</li> </ul>
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycInfo, CINAHL.</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques will be used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy</b>	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by Grading of Recommendations Assessment, Development and Evaluation- Confidence in the Evidence from Reviews of Qualitative research (GRADE-CERQual) approach for each identified theme.</li> </ul> <p>Data synthesis</p> <ul style="list-style-type: none"> <li>• Thematic analysis of the data will be conducted and findings presented.</li> </ul>
<b>Equalities</b>	<p>No equality considerations over and above those stated in the equalities impact form are identified for this topic.</p>

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### D.3.2 Advance Care Planning

Item	Details
<b>Key issue in the scope</b>	<p>Assessing needs and developing a personalised care plan including parallel care planning</p>
<b>Review questions in the scope</b>	<ul style="list-style-type: none"> <li>• What assessments are helpful in developing and reviewing the personalised care plan for infants, children and young people with life-limiting conditions?</li> <li>• What information do infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) need in order to be involved in advanced care planning, including if appropriate decisions about stopping life-sustaining treatment and attempting cardiopulmonary resuscitation?</li> </ul>
<b>Proposed approach – qualitative</b>	<p>Rationale: This could both be tackled in one question since the overarching focus is on planning. It should also be highlighted that this is a process of shared decision making in planning (which not the main focus in the review questions in the scope)</p>
<b>Review question</b>	<p>What are the barriers and facilitators to the child or young person, the family or carer of the infant, child or young person and the multidisciplinary team in being involved in decision making to inform the development, assessment and reviews of personalised, parallel and advanced care planning (including if appropriate decisions about continuing or stopping life-sustaining treatment and attempting cardiopulmonary resuscitation)?</p>
<b>Objective</b>	<ul style="list-style-type: none"> <li>• To explore which positive and/or negative experiences and opinions of the child or young person with a life-limiting condition and the family or carer (as appropriate) of the infant, child or young person with a life-</li> </ul>



Item	Details
	limiting condition and the multidisciplinary team to facilitate or hinder the formulation of personalised (including parallel and advance) care plans for the last days of life and how they can be used to improve current practice.
<b>Population and directness</b>	Infants, children and young people (up to age 18) with a life limiting condition, their families or carers (as appropriate) and healthcare professionals Population size and indirectness <ul style="list-style-type: none"> <li>• No sample size specification.</li> <li>• Studies with indirect populations will not be considered</li> </ul>
<b>Subgroups and sensitivity analyses</b>	<ul style="list-style-type: none"> <li>• The following <b>groups</b> perspectives will be taken into consideration:</li> <li>• Parents/ carers and family members (that is, siblings)</li> <li>• Children or young person</li> <li>• Healthcare professionals</li> <li>• Important <b>subgroups</b>:</li> <li>• People with communication difficulties</li> </ul>
<b>Setting</b>	<ul style="list-style-type: none"> <li>• Community, primary, secondary and tertiary care ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence</li> </ul>
<b>Context and likely themes</b>	<p><b>Context:</b> Planning for the end of life</p> <p><b>Themes:</b> Themes will be identified from the literature, but expected themes are:</p> <ul style="list-style-type: none"> <li>• Reluctance to include the child or the family in all decisions in the development of plans</li> <li>• Timing of planning</li> <li>• Need for regular reviews</li> <li>• Assessments of needs</li> <li>• Professional roles</li> <li>• Cultural, religious and ethical differences</li> <li>• Dealing with uncertainty</li> <li>• emotional burden</li> </ul>
<b>Study design</b>	We will include: <ul style="list-style-type: none"> <li>• Qualitative studies (for example ethnographic studies, interviews, focus groups)</li> <li>• Mixed-methods observational studies where qualitative data were reported (for example survey studies)</li> </ul> We will exclude: <ul style="list-style-type: none"> <li>• Purely quantitative studies (including surveys with only descriptive quantitative data)</li> </ul>
<b>Search strategy</b>	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase. Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters. Supplementary search techniques: No supplementary search techniques were used. See appendix for full strategies (Appendix E:)
<b>Review strategy</b>	Appraisal of methodological quality: The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by GRADE-CERQual approach for each identified theme.

Item	Details
	Data synthesis: <ul style="list-style-type: none"> <li>• Thematic analysis of the data will be conducted and findings presented.</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

## D.4.1 Place of care and place of death

Item	Details
<b>Key issue in the scope</b>	Identifying the preferred place of care and the preferred place of death.
<b>Review question in the scope</b>	What preferences do infants, children and young people with a life-limiting condition and their family members or carers (as appropriate) have for place of care and for place of death, and what determines those preferences?
<b>Review question</b>	What preferences do children and young people with a life-limiting condition and their family members or carers (as appropriate) have for place of care and for place of death, and what determines those preferences?
<b>Objective (quantitative)</b>	To assess the preferences regarding place of care and place of death among children and young people who are approaching end of life and their family members or carers (as appropriate).
<b>Objective (qualitative)</b>	To examine factors that are associated with and/or influence preference of place of care or place of death among children and young people who access end of life care and their families or carers (as appropriate)
<b>Language</b>	English
<b>Study design (quantitative)</b>	<ul style="list-style-type: none"> <li>• Systematic reviews</li> <li>• Observational cohort studies (case-control, cross-sectional studies will be considered if there is limited availability of any other evidence).</li> <li>• Mixed method studies</li> <li>• Chart reviews</li> </ul>
<b>Study design (qualitative)</b>	<ul style="list-style-type: none"> <li>• Qualitative studies (for example, ethnographic studies, interviews, and focus groups)</li> <li>• Mixed-methods observational studies where qualitative data were reported (for example, survey studies)</li> <li>• Only published full text papers to be considered</li> </ul>
<b>Population and directness</b>	Infants, children and young people up to the age of 18 years who are approaching end of life and their families or carers of
<b>Setting</b>	Community, primary, secondary and tertiary care ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence
<b>Outcomes (quantitative)</b>	<ul style="list-style-type: none"> <li>• Availability of options</li> <li>• Circumstances that facilitate or hinder availability of choices (personal, social, practical)</li> <li>• Characteristics of acceptable place for care or to die</li> <li>• changes in the care and treatment (trajectory of care)</li> <li>• Cultural, ethnic or religious influences on choice of care</li> </ul>
<b>Importance of outcomes</b>	Critical:

Item	Details
<b>(quantitative)</b>	<ul style="list-style-type: none"> <li>• Availability of options</li> <li>• Circumstances that facilitate or hinder availability of choices (personal, social, practical)</li> <li>• Characteristics of acceptable place for care or to die</li> <li>•</li> </ul>
<b>Context and likely themes (Qualitative)</b>	<p><b>Context information</b> Preference and reasoning with regards to choices of place of care and death from the perspective of the child or young person or from the families of the infant, child or young person.</p> <p><b>Themes will be identified from the literature, but expected themes are:</b></p> <ul style="list-style-type: none"> <li>• Availability of options</li> <li>• Circumstances that facilitate or hinder availability of choices (personal, social, practical)</li> <li>• Characteristics of acceptable place for care or to die</li> <li>• changes in the care and treatment (trajectory of care)</li> <li>• Cultural, ethnic or religious influences on choice of care</li> <li>•</li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<p><b>Groups</b> that will be reviewed and analysed separately:</p> <ul style="list-style-type: none"> <li>• Neonates</li> <li>• all other age groups up to 18 years</li> <li>• In the event of heterogeneity, the following <b>subgroups</b> will be considered Socio-economic background</li> <li>• Cultural, ethnic or religious background</li> </ul>
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsychInfo, CINAHL.</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy (quantitative)</b>	<ul style="list-style-type: none"> <li>• Appraisal of methodological quality</li> <li>• For quantitative evidence, the methodological quality of each study will be assessed using NICE checklists and the quality of the evidence for an outcome (across studies) will be assess using GRADE.</li> </ul> <p>Data synthesis</p> <ul style="list-style-type: none"> <li>• Meta-analysis will be conducted if appropriate.</li> </ul>
<b>Review strategy (qualitative)</b>	<ul style="list-style-type: none"> <li>• Appraisal of methodological quality</li> <li>• For qualitative evidence, the methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by GRADE-CERQual approach for each identified theme.</li> </ul> <p>Data synthesis</p> <ul style="list-style-type: none"> <li>• Thematic analysis of the data will be conducted and findings presented.</li> <li>•</li> </ul>
<b>Equalities</b>	<p>No equality considerations over and above those stated in the equalities impact form are identified for this topic.</p>

## D.5.2 Organ and tissue donation

Item	Details
<b>Key issue in the scope</b>	Information and communication with children and young people and/ or their families and carers of infants, children and young people in relation to organ or tissue donation.
<b>Review question</b>	What aspects of communication and information provision facilitate or hinder discussions between children and young people with a life limiting condition and their family members or carers (as appropriate) with healthcare professionals to make decisions on organ or tissue donation?
<b>Objective</b>	The aim of this review is to identify what aspects of communication and information provision influence the attitudes of the child, young person, or the family or carers of an infant, children or young person with a life-limiting condition towards organ and tissue donation.
<b>Language</b>	English
<b>Study design</b>	<ul style="list-style-type: none"> <li>• Qualitative studies (for example, ethnographic studies, interviews, and focus groups;)</li> <li>• Mixed-methods observational studies where qualitative data were reported (for example, survey studies)</li> </ul> Exclude: purely quantitative studies, including surveys with only purely descriptive quantitative data
<b>Population and directness</b>	<b>Population</b> <ul style="list-style-type: none"> <li>• Parents or carers of an infant, child or young person with a LLC up to the age of 18 years</li> <li>• Children or young people with a LLC up to the age of 18</li> <li>• Health care professionals</li> </ul> Studies with indirect populations will not be considered. No restrictions will be made based on sample size.
<b>Stratified, subgroup and adjusted analyses</b>	Important subgroups <ul style="list-style-type: none"> <li>• Parents/carers</li> <li>• Those who have planned for an out of hospital death (this effects the type of donation – tissue donation is still possible)</li> <li>• Young people</li> <li>• Health care professionals</li> <li>• Children, young people, parents/carers with English not as a first language, those with communication difficulties and developmental difficulties</li> </ul>
<b>Setting</b>	Community, primary, secondary and tertiary care, ideally in a UK context. Evidence from other countries will be considered if there is insufficient direct evidence.
<b>Context and likely themes</b>	<b>Context</b> Information and communication regarding tissue and organ donation. <b>Themes will be identified from the literature, but expected themes are:</b> <ul style="list-style-type: none"> <li>• Bereavement experience (consolation)</li> <li>• Altruism</li> <li>• Organ donation as part of care plan</li> <li>• Religious beliefs</li> <li>• Family influences</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Impact on siblings</li> <li>• Cultural influences</li> <li>• Body integrity</li> <li>• Death rituals</li> <li>• Medical mistrust</li> <li>• Uncertainty about organs used for medical research instead of transplantation</li> <li>• Withdrawal of treatment in order to make donation possible</li> <li>• Lack of information about the donation process</li> <li>• Individual's knowledge about the process</li> <li>• Information about suitability</li> <li>• Family expectations about the possibility of transplantation</li> <li>• Feeling guilty about giving parts of the infant, child or young person's body away</li> <li>• Opting-out/ changing your mind</li> <li>• Healthcare professional attitude towards donation</li> <li>• Being approached at the right time, in the right way</li> <li>• Being approached by a professional that is specifically trained</li> </ul>
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycInfo, CINAHL.</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy</b>	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by GRADE-CERQual approach for each identified theme.</li> </ul> <p>Data synthesis:</p> <ul style="list-style-type: none"> <li>• Thematic analysis of the data will be conducted and findings presented.</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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### D.6.3 MDT

Item	Details
Key issue in the scope	The organisation of services providing the end of life care of infants, children and young people with life-limiting conditions.
Review question in the scope	What is the clinical and cost effectiveness of a defined multi-disciplinary team (MDT) of a particular composition compared with one of a different composition and compared with care without a defined MDT?
Review question	In infants, children and young people living with life limiting conditions, what is the clinical and cost effectiveness of receiving care from different models of MDT care including team composition and working arrangements?
Objective	To determine in infants and children up to and including the age of 18 years with a life limiting condition and in their families and carers, what is the clinical

Item	Details
	and cost effectiveness of receiving care from a defined multi-disciplinary team (MDT) of a particular composition compared with one of a different composition or receiving care without defined a MDT?
Language	English
Study design	<ul style="list-style-type: none"> <li>• Systematic reviews</li> <li>• Randomised controlled trials (RCTs)</li> <li>• Conference abstracts of RCTs (if full text papers are not available)</li> <li>• Cohort studies (if limited evidence from RCTs available)</li> <li>• Uncontrolled studies (only if no other evidence is found)</li> </ul> Exclude: <ul style="list-style-type: none"> <li>• Case series, commentaries, qualitative studies</li> <li>• Studies published before 1995 (the Committee considered that studies prior to this year would be too different in clinical practice and would therefore not be applicable).</li> </ul>
Population and directness	Infants, children and young people up the age of 18 years who are approaching the end of life and their families and carers Population size and indirectness: <ul style="list-style-type: none"> <li>• No restrictions on sample size will be applied</li> <li>• Studies with indirect population will not be included</li> </ul>
Stratified, subgroup and adjusted analyses	<b>Groups</b> that will be reviewed and analysed separately: <ul style="list-style-type: none"> <li>• None</li> <li>• In the event of heterogeneity, the following <b>subgroups</b> will be considered:</li> <li>• By condition (e.g., oncological versus others)</li> <li>• Need for certain HCP treatment (that is, some infants, children or young people may need a particular professional, for instance a physiotherapist whereas others may not)</li> </ul>
Intervention	Multi-disciplinary team in palliative care (for example, it could include palliative care consultation team, inter-disciplinary team, multi-professional team, trans-professional team, network meetings)
Comparison	<ul style="list-style-type: none"> <li>• Multi-disciplinary team care of different composition</li> <li>• No multi-disciplinary team care (individuals without a coordinated arrangement of care)</li> <li>• usual care</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>• Prevention of unplanned hospital admissions</li> <li>• Discharge time</li> <li>• Quality of life of the child, young person</li> <li>• Quality of life of the parent, carer</li> <li>• Satisfaction of the child, young person</li> <li>• Satisfaction with care of the parent or carer (for example level of care and Improved communication)</li> <li>• Control of symptoms (pain, dyspnoea, nausea/vomiting)</li> <li>•</li> </ul>
Importance of outcomes	Critical outcomes: <ul style="list-style-type: none"> <li>• Prevention of unplanned hospital admissions</li> <li>• Quality of life of the child, young person</li> <li>• Quality of life of the parent, carer</li> </ul>

Item	Details
Setting	Community, primary, secondary and tertiary care ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence
Search strategy	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycInfo, CINAHL. Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters. Supplementary search techniques: No supplementary search techniques were used. See appendix for full strategies (Appendix E:)
Review strategy	Appraisal of methodological quality: <ul style="list-style-type: none"> <li>The methodological quality of each study will be assessed using appropriate checklists and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> Synthesis of data: <ul style="list-style-type: none"> <li>Meta-analysis will be conducted if appropriate.</li> </ul> For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered. Other considerations if there is sufficient data: <ul style="list-style-type: none"> <li>Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> </ul> If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made
Equalities	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

## D.7.1 End of life care around the clock

Item	Details
Key issue in the scope	The organisation of services providing the end of life care of infants, children and young people with life-limiting conditions.
Review question in the scope	What service delivery arrangements (including neonatal intensive care and rapid transfer from intensive care units) can best provide for the needs of infants, children and young people with life-limiting conditions, and for the needs of their family members and carers (as appropriate) during this time and after death?
Review question	<ul style="list-style-type: none"> <li>What is the effectiveness of day and night specialist telephone health care professional support or parents/carers support, day and night</li> <li>community nursing support, and the combination of the two for the</li> <li>needs of infants, children and young people with life-limiting</li> <li>conditions, and for the needs of their family members and carers (as appropriate) during this time and after death as part of service delivery?</li> </ul>
Objective	<ul style="list-style-type: none"> <li>To assess the effectiveness of day and night specialist telephone support for health care professional or for parents/carers support in providing for the needs of infants, children or young people living with life limiting conditions, and their families/carers</li> <li>To assess the effectiveness of day and night community nursing support service in providing for the needs of infants, children or young</li> </ul>

Item	Details
	<p>people living with life limiting conditions, and the needs of their families/carer</p> <ul style="list-style-type: none"> <li>• Or to assess the effectiveness of the combination of telephone support and community nursing support, in providing for the needs of infant, child or young person living with life limiting conditions, and their families/carers?</li> </ul>
<b>Language</b>	English
<b>Study design</b>	<ul style="list-style-type: none"> <li>• Systematic reviews</li> <li>• Randomised controlled trials (RCTs)Conference abstracts of RCTs (if full text papers are not available)</li> <li>• Cohort studies (only if RCTs unavailable or limited data to inform decision making)</li> <li>• Uncontrolled studies (only if there is no other evidence found)</li> </ul> <p>Sample size: No sample size restrictions</p>
<b>Population and directness</b>	<p>Population: infants, children and young people with life limiting conditions (up to age 18)</p> <p>Directness: ideally representative population sample from UK national data registry or regions where relevant services are readily available (evidence from other settings could be considered if relevant);</p>
<b>Stratified/ subgroup and adjusted analyses</b>	<p><b>Groups</b> that will be reviewed and analysed separately:</p> <ul style="list-style-type: none"> <li>• neonates</li> <li>• infants/children and young people discharged from intensive care services</li> <li>• conditions, e.g. cancer</li> <li>• locations where services are delivered (home versus hospice)</li> <li>• regions where the availability of relevant EOLC services differ</li> <li>• <b>Important confounders</b> need adjusted for in comparative studies:</li> <li>• age, conditions</li> <li>• community support services available, other medical and social support services, and palliative care in place</li> <li>• socio-economic, cultural background of the family</li> </ul>
<b>Intervention</b>	<p><b>For day and night remote access to specialist advice, (for example email, telephone, or video conference ):</b></p> <ul style="list-style-type: none"> <li>• parents/carers day and night telephone access to health care professional advice</li> <li>• nurses' telephone access to 24/7 specialist medical advice</li> <li>• <b>For day and night nursing support:</b></li> <li>• standard community nursing</li> <li>• specialist (palliative care) nursing</li> <li>• or combination of day and night of both</li> <li>• <b>Exclude:</b></li> <li>• day and night service delivery related to the longer term management of the life limiting condition rather than related directly to 'end-of-life' care.</li> </ul>
<b>Comparison</b>	<p><b>For day and night specialist telephone advice, day and night nursing support interventions, and the combination of the two:</b></p> <ul style="list-style-type: none"> <li>• No day and night specialist telephone advice;</li> <li>• No day and night community nursing support;</li> <li>• No day and night specialist telephone advice or day and night community nursing;</li> <li>• Practices without routine access to day and night services</li> </ul>



Item	Details
	<ul style="list-style-type: none"> <li>• Convention/standard or usual home/hospice care without the additional/complementary support of day and night specialist tele support or/and community nursing support</li> <li>• Other medical and community support/services with different packages or configurations</li> <li>• Standard community care (more relevant to day and night nursing support intervention)</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• Quality of life of the infant, child or young person and their families/carers (as appropriate), e.g. anxiety in child and families/carers</li> <li>• Satisfaction with the care on the part of the infant?, child or young person and/or their families/carers (as appropriate)</li> <li>• Change in health resources utilisation (e.g., reduction in unintended hospital re-admission rates, reduction of hospitalisation, reduction in length of hospital stay)</li> <li>• Change in level of distressing symptoms such as pain, agitation</li> <li>• Change in home visits by nurses (mainly relevant to day and night specialist advice support)</li> <li>•</li> </ul>
<b>Importance of outcomes</b>	<p>Preliminary classification of the outcomes for decision making – Critical outcomes:</p> <ul style="list-style-type: none"> <li>• Quality of life of the infant?, child or young person and their families/carers (as appropriate), e.g. anxiety in child and families/carers</li> <li>• Satisfaction with the care of the infant?, child or young person and their families/carers (as appropriate)</li> </ul>
<b>Setting</b>	All settings in which NHS-commissioned healthcare is provided.
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy</b>	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using appropriate checklists and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> <p>Data synthesis:</p> <ul style="list-style-type: none"> <li>• Meta-analysis will be conducted if appropriate.</li> </ul> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p> <p>Other considerations if there is sufficient data:</p> <ul style="list-style-type: none"> <li>• Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>

Item	Details
Equalities	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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### D.8.3 Rapid transfer

Item	Details
<b>Key issue in the scope</b>	The organisation of services providing the end of life care of infants, children and young people with life-limiting conditions.
<b>Review question in the scope</b>	What service delivery arrangements (including neonatal intensive care and rapid transfer from intensive care units) can best provide for the needs of infants, children and young people with life-limiting conditions, and for the needs of their family members and carers (as appropriate) during this time and after death?
<b>Review question</b>	Discussed: What service delivery arrangements can best provide for the needs of infants, children and young people with life-limiting conditions, and for the needs of their family members and carers (as appropriate) during this time? The following topics were prioritised to provide an adequate service. <ul style="list-style-type: none"> <li>• New:</li> <li>• What services have to be in place to make rapid transfer available to take infants, children and young people with a life limiting illness to their preferred place of care in their last days of life as part of service delivery?</li> </ul>
<b>Objectives</b>	<ul style="list-style-type: none"> <li>• To determine the clinical effectiveness of a rapid transfer programme (including from neonatal intensive care) compared with standard transfer programme or care without such arrangement in facilitating the infant, child or young person with a life-limiting condition to die in their preferred place of care.</li> <li>• As an integrated part of the rapid transfer programme, particular consideration will be given to infants, children or young people with a life-limiting condition who need compassionate extubation in the preferred place of care (what services should be in place to facilitate)</li> </ul>
<b>Language</b>	English
<b>Study design</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>• Systematic reviews</li> <li>• Randomised controlled trials (RCTs) (RCTs are not expected to be found due to the nature of the question)</li> <li>• Conference abstracts of RCTs (if full text papers are not available)</li> <li>• Cohort studies (only if RCTs unavailable or limited data to inform decision making)]</li> <li>• Uncontrolled studies (only if there is no other evidence found)</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>• Case series and case studies</li> <li>• Qualitative studies</li> </ul>
<b>Population and directness</b>	<p>Infants, children and young people (up to age 18) with life limiting conditions who are approaching the last days of their life</p> <p>Population size and indirectness:</p> <ul style="list-style-type: none"> <li>• No restrictions on sample size will be applied</li> <li>• Studies with indirect population will not be included</li> </ul>
<b>Stratified, subgroup and</b>	<p><b>For both parts of the question:</b></p> <ul style="list-style-type: none"> <li>• <b>Groups</b> that will be reviewed and analysed separately:</li> </ul>

Item	Details
<p><b>adjusted analyses</b></p>	<ul style="list-style-type: none"> <li>• Neonates – transferred from neonatal intensive care</li> <li>• All other infants, children and young people discharged from paediatric intensive care</li> <li>• Those who may not be in intensive care but are expected to deteriorate and die within hours/days</li> <li>• Important <b>confounders</b> (when comparative observational studies are included for interventional reviews):</li> <li>• Age of the infant, child or young person</li> <li>• Infants with anticipated early death</li> <li>• Advanced care planning</li> <li>• Support from community services</li> </ul>
<p><b>Intervention</b></p>	<p><b>For the first part of the question: rapid transfer</b> from hospital care, e.g. to home or to hospice care or to alternative setting, components/elements of the programme could include:</p> <ul style="list-style-type: none"> <li>• Advanced care planning</li> <li>• Ambulance</li> <li>• Other transport</li> <li>• Staffing</li> <li>• Medications</li> <li>• Equipment and other necessary supplies</li> <li>• Availability of home / hospice extubation</li> <li>• care plan after death</li> <li>• carrying out any necessary regulatory or legal obligations (for example, Informing coroner of death within 24 hours)</li> </ul> <p><b>For the second part of the question: home/hospice extubation</b>, components/elements of the programme could include:</p> <ul style="list-style-type: none"> <li>• HCP support in the preferred place of dying (for example, nursing support)</li> <li>• Specialist support to HCPs and parents</li> <li>• Advanced care planning specific to compassionate extubation</li> <li>• communication between HCPs and parents (for example discussion of the process and readiness to proceed)</li> <li>• Care plan after death</li> <li>• We will exclude:</li> <li>• Interventions that are part of the longer term management of the life limiting condition rather than directly related to ‘end-of-life’ care.</li> </ul>
<p><b>Comparison</b></p>	<p><b>For the first part of question: rapid transfer</b></p> <ul style="list-style-type: none"> <li>• Standard transfer programme</li> <li>• No transfer programme</li> <li>• Transfer programme with different components/elements</li> </ul> <p><b>For the second part of the question: home/ hospice extubation</b></p> <ul style="list-style-type: none"> <li>• Extubation programme/preparation with different components</li> </ul>
<p><b>Outcomes</b></p>	<p><b>For the first part of question: rapid transfer</b></p> <ul style="list-style-type: none"> <li>• Infant, children or young person quality of life/ death</li> <li>• Parents or carers’ quality of life before and after death</li> <li>• Infant, child or young person satisfaction with the care</li> <li>• Parents or carers’ quality of life satisfaction with the care</li> <li>• Transfer time</li> <li>• Waiting time prior to home/hospice discharge</li> <li>• Unexpected hospital re-admission</li> <li>• Access of family to the patient infant, child or young person in both settings</li> </ul>

Item	Details
	<p><b>For the second part of the question: home/ hospice extubation</b></p> <ul style="list-style-type: none"> <li>• Infant, child or young person quality of life/ death</li> <li>• Parents or carers' quality of life before and after death</li> <li>• Infant, child or young person satisfaction</li> <li>• Parents or carers' quality of life satisfaction</li> </ul>
<b>Importance of outcomes</b>	<p><b>Critical</b> outcomes for decision making:</p> <ul style="list-style-type: none"> <li>• Quality of life of the infant , child or young person or/and their families/carers, e.g., pain of the infant, child or young person, release of distressing symptom of the infant, child or young person, and anxiety of infant, child or young person and parents or carers</li> <li>• Satisfaction of the infant , child or young person and their families/carers with the care</li> <li>• Waiting time prior to home/hospice discharge</li> </ul>
<b>Setting</b>	All settings in which NHS-commissioned healthcare is provided.
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy</b>	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using the appropriate checklist and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> <p>Synthesis of data:</p> <p>Meta-analysis will be conducted if appropriate.</p> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p> <p>Other considerations if there is sufficient data:</p> <ul style="list-style-type: none"> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• State how outcomes will be recorded, e.g. If studies only report p-values, this information will be entered in GRADE tables and will be downgraded for imprecision due to the imprecision in reporting.</li> <li>• State analysis considerations, e.g. If cohort studies are included, the minimum number of events per covariate to be recorded to ensure accurate multivariate analysis.</li> <li>• State the MIDs, e.g. default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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### D.9.3 Care based in the child or young person's home

Item	Details
<b>Key issue in the scope</b>	The organisation of services providing the end of life care of infants, children and young people with life-limiting conditions.

Item	Details
<b>Review question in the scope</b>	What is the clinical and cost effectiveness of a home-based programme of care, compared with care in other settings?
<b>Review question</b>	<p>In infants, children and young people who are recognised to have a life-limiting condition, what is the effectiveness of a home-based programme of care compared with care in other settings?</p> <p>There is uncertainty around this timeframe, but it is aimed that the evidence would look at home care providing 'end-of-life' care rather than care related to the life limiting condition. Therefore it was decided to take a pragmatic approach by which we would use:</p> <ul style="list-style-type: none"> <li>• 2 months as a direct population</li> <li>• Could have 2 -6 month indirect population</li> <li>• Over 6 months would be excluded since this would not refer directly to palliative 'end-of-life' care.</li> </ul>
<b>Objective</b>	<ul style="list-style-type: none"> <li>• To determine the clinical and cost effectiveness of a home-based programme of care compared with care in other settings in infants, children and young people with a life-limiting condition who are approaching the last days of their life.</li> </ul>
<b>Language</b>	English
<b>Study design</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>• Systematic reviews</li> <li>• Randomised controlled trials (RCTs)</li> <li>• Conference abstracts of RCTs (if full text papers are not available)</li> <li>• Cohort studies (if no or few appropriate RCTs found)</li> <li>• Uncontrolled studies (only if no other evidence is found)</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>• Case series, case studies</li> <li>• Qualitative studies</li> </ul>
<b>Population and directness</b>	<p>Infants, children and young people (up to age 18) with a life-limiting condition and who are within the last two months of their life.</p> <p><u>Population size and indirectness:</u></p> <ul style="list-style-type: none"> <li>• No restrictions on sample size will be applied</li> <li>• 2 months – direct population</li> <li>• 2- 6 months – indirect population</li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<p><b>Groups</b> that will be reviewed and analysed separately:</p> <ul style="list-style-type: none"> <li>• Oncology (has an established care path from hospital to home care) however this is not as well established in other LLCs which are likely to benefit more from new recommendations</li> </ul> <p>In the event of heterogeneity, the following <b>subgroups</b> will be considered:</p> <ul style="list-style-type: none"> <li>• Type of home care programme (including length or intensity of programme)</li> </ul>
<b>Intervention</b>	<p>Provision of comprehensive (holistic care) at home that fulfils the following (this list has been adapted from the description of a home palliative care service for adults Cochrane review (Gomes 2013)):</p> <ul style="list-style-type: none"> <li>• Children with advanced terminal conditions who have been identified as likely to be in their last weeks or days of life</li> <li>• The majority of services are provided at home with the aim of enabling the child to stay at home</li> <li>• Specialist care provision by staff with experience in palliative / hospice care</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Care that aims to deliver different physical and psychological components</li> <li>• All environments where the home care needs are provided</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>• Interventions not directly delivering care to children and their families (i.e. training in delivery of home care, coordination of services, interventions related to assessments of care needs only)</li> <li>• Evaluations of home care differing in only one component of care (e.g. medication regimen)</li> <li>• Interventions that deliver only one physical or one psychological component of palliative care (as this does not address the holistic nature of palliative care). This could include effectiveness of home psychotherapy, pain medication etc.)</li> <li>• For each study extract the data that indicates the particular type of homecare and it can then be decided on a case by case basis whether it can be classified a defined programme.</li> </ul>
<b>Comparison</b>	<ul style="list-style-type: none"> <li>• Inpatient hospital or hospice care</li> <li>• Different types of home-based care</li> <li>• Usual care</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• Unplanned/precipitous admission to hospital</li> <li>• Family or care giver stress and distress</li> <li>• Infant, child or young person’s satisfaction/comfort</li> <li>• Parent/ carer satisfaction/comfort</li> <li>• Control of symptoms (pain, dyspnoea, nausea/vomiting)</li> <li>• Infant, child or young person’s health related quality of life – levels of comfort, lack of distress</li> <li>• Parent/ carer health related quality of life</li> </ul>
<b>Importance of outcomes</b>	<p><b>Critical</b> outcomes for decision making:</p> <ul style="list-style-type: none"> <li>• Symptom control</li> <li>• Family or caregiver stress and distress</li> </ul>
<b>Setting</b>	<p>Community, primary, secondary and tertiary care ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence</p>
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycInfo, CINAHL.</p> <p>Limits (e.g. date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy</b>	<p><u>Appraisal of methodological quality:</u></p> <p>The methodological quality of each study will be assessed using the appropriate checklist and the quality of the evidence for an outcome (i.e. across studies) will be assessed using GRADE.</p> <p><u>Synthesis of data:</u></p> <p>Meta-analysis will be conducted where appropriate.</p> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p> <p><u>Other considerations if there is sufficient data:</u></p>

Item	Details
	<ul style="list-style-type: none"> <li>• Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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## D.10<sub>2</sub> Emotional and psychological support and interventions for children and young people

3

Item	Details
Key issue in the scope	<ul style="list-style-type: none"> <li>• The psychological and emotional needs of infants, children or young people with life-limiting conditions.</li> </ul>
Review question in the scope	<ul style="list-style-type: none"> <li>• What psychological and psychopharmacological interventions are clinically and cost effective for children and young people with life-limiting conditions, especially during the end of life, and for the family members and carers (as appropriate) of infants, children and young people with a life-limiting condition?</li> </ul>
<b>Review question</b>	<ul style="list-style-type: none"> <li>• Are psychological interventions effective for infants, children and young people with life-limiting conditions and what factors influence the attitudes of children and young people and the family's involvement and decisions about choices of those interventions?</li> </ul>
<b>Objectives (quantitative)</b>	<ul style="list-style-type: none"> <li>• To assess the effectiveness of psychological interventions/therapies for improving psychological well-being (such as resilience, depression, fear, or anxiety) in infants, children or young people living with life-limiting conditions (LLC) and approaching the end of life</li> <li>• To assess the effectiveness of psychological interventions/therapies for reducing physical symptoms (such as pain) associated with LLC in infants, children or young people who are approaching the end of life</li> </ul>
<b>Objectives (qualitative)</b>	<ul style="list-style-type: none"> <li>• To identify and describe the factors that influenced children, young people, and their parents/carers' attitudes in making choices about psychological therapies, who are living with LLC and approaching the end of life;</li> <li>• To identify and describe children, young people, and their parents/carers' experiences with psychological therapies</li> </ul>
<b>Language</b>	English
Study design (quantitative)	<ul style="list-style-type: none"> <li>• Systematic reviews</li> <li>• Randomised controlled trials (RCTs)</li> <li>• Cohort studies (only if RCTs unavailable or limited data to inform decision making)]</li> <li>• Uncontrolled studies (only if there is no other evidence found)</li> <li>•</li> </ul>
<b>Study design (qualitative)</b>	<ul style="list-style-type: none"> <li>• Qualitative studies (for example, ethnographic studies, interviews, and focus groups)</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Mixed-methods observational studies where qualitative data were reported (for example, survey studies)</li> <li>• Exclude:</li> <li>• purely quantitative studies (including surveys with only descriptive quantitative data)</li> </ul>
<b>Population and directness</b>	<p><b>Population</b></p> <ul style="list-style-type: none"> <li>• Infants, children or young people up to the age of 18 years with a LLC and/or are approaching the end of life</li> <li>• <b>Population size and indirectness</b></li> <li>• No sample size specification</li> <li>• Studies with indirect populations will not be included</li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<ul style="list-style-type: none"> <li>• <b>Groups that will be reviewed and analysed separately:</b></li> <li>• None <ul style="list-style-type: none"> <li>◦ <b>In the event of heterogeneity, the following subgroups will be considered:</b></li> <li>• By age</li> <li>• By mental development stage (including communication difficulties)</li> <li>• By specific conditions (oncology, neuromuscular, degenerative, neurodisability, DMD, significant technology dependents)</li> <li>• By time point and trajectory of the illness when psychological therapies were employed</li> <li>• gender of the infant, child or young person</li> </ul> </li> <li>• <b>Important confounders:</b> (for observational comparison studies)</li> <li>• Age (mental development stage of the infants, children or young people ) and stage of the disease of the infants, children or young people (the most important confounders that should be controlled for) conditions,</li> <li>• socio-economical status of the infants, children or young people</li> <li>• cultural, religious background of infants, children or young people</li> </ul>
<b>Intervention</b>	<ul style="list-style-type: none"> <li>• Any psychological approaches that are primarily psychological, and</li> <li>• have credible recognisable psychological/ psychotherapeutic content (as</li> <li>• defined in <b>Eccleston 2015 Cochrane review</b>), for example:</li> <li>• Behavioural therapy: relaxation based</li> <li>• Cognitive behaviour therapy (CBT): cognitive coping; cope skills training; parent operant strategies;</li> <li>• Group psychotherapy</li> <li>• Exclude:</li> <li>• studies that compared psychological with pharmacological interventions</li> <li>• Case studies</li> <li>• Note. At times the parents are those that are trained in and apply the therapy to their child.</li> </ul>
<b>Comparison (quantitative)</b>	<p><b>Mainly relevant to the quantitative part of the review:</b></p> <ul style="list-style-type: none"> <li>• No psychological intervention (Waiting list/usual care )</li> <li>• Alternative psychological interventions</li> </ul>



Item	Details
<b>Outcomes (quantitative)</b>	<ul style="list-style-type: none"> <li>• Psychological well-being (for example resilience, depression, fear, anxiety, mood change) of infants, children or young people</li> <li>• Quality of life of infants, children or young people</li> <li>• Satisfaction infants, children or young people /parents/carers</li> <li>• Changing clinical symptoms (for example pain and agitation)(agitation)</li> <li>• Adherence to care plan or management of condition</li> </ul>
<b>Importance of quantitative outcomes</b>	<ul style="list-style-type: none"> <li>• Critical outcomes</li> <li>• Psychological well-being (for example resilience, depression, fear, anxiety, mood change) of infants, children or young people</li> <li>• Quality of life of infants, children or young people</li> <li>• Changing clinical symptoms (for example pain and agitation)(agitation)</li> </ul>
<b>Context and likely themes (qualitative)</b>	<p><b>Context:</b></p> <ul style="list-style-type: none"> <li>• psychological therapies after the illness is diagnosed, during the process of dying</li> <li>• <b>Themes will be identified from the literature, but expected themes are:</b></li> <li>• Patients perceptions of treatments effectiveness, for example for anger, sadness, depression, trauma, isolation, stigma and so on.</li> <li>• Their attitudes toward psychological therapies (personal values, cultural differences; therapies deemed helpful or not helpful);</li> <li>• Their experiences with psychological therapies (perceptions; cultural differences; experiences with the therapist; helpful or unhelpful);</li> <li>• Unmet needs (access, early access, availabilities, flexibilities, resources; burdens due to the lack of psychological therapies);</li> <li>• Timing of the access to psychological intervention (Tier 1 to 4 interventions, which tier of intervention should be offered)</li> <li>• Challenges experienced (coping of infants, children or young people during the process; skills of therapist, misconceptions; referrals);</li> <li>• Factors related to the therapist (skills / experience, time)</li> <li>• Parents attitudes related to consent to psychological therapy (with regards to disclosure of prognosis diagnosis)</li> <li>• Parents experience of being involved in providing therapies and participating in the therapy for the child</li> </ul>
<b>Setting</b>	Community, primary, secondary and tertiary care funded by the NHS (hospices too if evidence available); if no direct evidence from the UK, findings from other countries will be considered
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycInfo.</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy (quantitative)</b>	Appraisal of methodological quality:

Item	Details
	<ul style="list-style-type: none"> <li>The methodological quality of each study will be assessed using appropriate checklists and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> <p>Synthesis of data:</p> <ul style="list-style-type: none"> <li>Meta-analysis will be conducted if appropriate.</li> </ul> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p> <p>Other considerations if there is sufficient data:</p> <ul style="list-style-type: none"> <li>Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>
<b>Review strategy (qualitative)</b>	<p>Appraisal of methodological quality</p> <ul style="list-style-type: none"> <li>The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by GRADE-CERQual approach for each identified theme.</li> <li>Data synthesis:</li> <li>Thematic analysis of the data will be conducted and findings presented.</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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### D.11 **Emotional and psychological support and interventions for parents and carers**

4

Item	Details
<b>Key issue in the scope</b>	<ul style="list-style-type: none"> <li>The psychological and emotional needs of the family members or carers (as appropriate) of infants, children and young people with life-limiting conditions.</li> <li>The needs of family members or carers after the death of an infant, child or young person and bereavement support before and after the death.</li> </ul>
<b>Review questions</b>	<ul style="list-style-type: none"> <li>Are psychological interventions (including short term bereavement therapies) effective for family members and carers of infants, children</li> <li>and young people living with LLCs? and what factors influence their</li> <li>attitudes about those interventions before and after the death of an infant, child or young person with a life-limiting condition?</li> </ul>
<b>Objectives (quantitative)</b>	<ul style="list-style-type: none"> <li>To assess the effectiveness of psychological interventions/therapies for</li> <li>improving psychological well-being such as resilience, depression,</li> <li>fear, or anxiety in carers/families (including siblings) of infants, children</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• or young people with life-limiting conditions (LLC) before and after the</li> <li>• child's death</li> </ul>
<b>Objectives (qualitative)</b>	<ul style="list-style-type: none"> <li>• To identify and describe factors that influenced carers/families' (including siblings) attitudes towards psychological therapies, whose child (or sibling) living with LLC and/or approaching the end of life, before and after the child's death</li> <li>• To identify and describe carers/families' (including siblings) experiences with psychological therapies, challenges faced, and unmet needs (such as access, resources, burdens due to the lack of adequate psychological therapy either provided to them or to their child (sibling) with LLC)</li> </ul>
Language	English
<b>Study design (quantitative)</b>	<ul style="list-style-type: none"> <li>• Systematic reviews</li> <li>• Randomised controlled trials (RCTs)</li> <li>• Cohort studies (only if RCTs unavailable or limited data to inform decision making)]</li> <li>• Uncontrolled studies (only if there is no other evidence found)</li> <li>•</li> </ul>
<b>Study design (qualitative)</b>	<ul style="list-style-type: none"> <li>• Qualitative studies (for example, , ethnographic studies, interviews, and focus groups)</li> <li>• Mixed-methods observational studies where qualitative data were reported (for example, survey studies)</li> <li>• Exclude:</li> <li>• purely quantitative studies (including surveys with only descriptive quantitative data)</li> </ul>
<b>Population and directness</b>	<p><b>Population</b></p> <ul style="list-style-type: none"> <li>• carers/families (including siblings) of infants, children or young people up to the age of 18 years with a LLC approaching the end of life, and before and after the child's death</li> </ul> <p><b>Population size and indirectness</b></p> <ul style="list-style-type: none"> <li>• No sample size specification</li> <li>• Studies with indirect populations will not be included</li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<p><b>Groups</b> that will be reviewed and analysed separately:</p> <ul style="list-style-type: none"> <li>• None</li> <li>• In the event of heterogeneity, the following <b>subgroups</b> will be considered:</li> <li>• Gender</li> <li>• Cultural background, ethnicity, spirituality</li> <li>• Sibling's age</li> <li>• By infants, children or young people's age</li> <li>• By infants, children or young people's mental development stage</li> <li>• By infants, children or young people's specific conditions (neuro-disability, cancer and so on)</li> <li>• Grandparents</li> <li>• By time point and trajectory of the illness when psychological therapies would be needed:</li> <li>• <b>Important confounders (for observational comparison studies):</b></li> <li>• Age (mental development stage of the infants, children or young people conditions,</li> <li>• stage of the disease of the infants, children or young peoples</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• socio-economic status of parents/carers</li> <li>• cultural, religious background of parents/carers (siblings, grandparents)</li> </ul>
<b>Intervention</b>	<p><b>Any psychological approaches that are primarily psychological, and have credible recognisable psychological/ psychotherapeutic content ( Eccleston 2015), for example:</b></p> <ul style="list-style-type: none"> <li>• CBT;</li> <li>• Family therapy;</li> <li>• Problem solving therapy;</li> <li>• Multi-systemic therapy;</li> <li>• Exclude:</li> <li>• Studies that compared psychological with pharmacological interventions</li> <li>• Case studies</li> </ul>
<b>Comparison (quantitative)</b>	<ul style="list-style-type: none"> <li>• No psychological intervention (Waiting list/usual care )</li> <li>• Alternative psychological interventions</li> </ul>
<b>Outcomes (quantitative)</b>	<ul style="list-style-type: none"> <li>• Psychological well-being (for example resilience, depression, fear, anxiety, mood change) of carers/families (including siblings) before and after the infant, child or young person's death</li> <li>• Quality of life of carers/families (including siblings)before and after the infant, child or young person's death</li> <li>• Satisfaction of carers/families (including siblings) before and after the infant, child or young person's death</li> <li>• Coping of carers/families (including siblings)before and after the infant, child or young person's death</li> <li>• Activity of daily living and parenting; before and after the infant, child or young person's death?</li> <li>• Family function before and after the infant, child or young person's death</li> <li>•</li> </ul>
<b>Importance of quantitative outcomes</b>	<ul style="list-style-type: none"> <li>• Critical outcomes:</li> <li>• Psychological well-being (for example resilience, depression, fear, anxiety, mood change) of carers/families (including siblings) before and after the child's death</li> <li>• Quality of life of carers/families (including siblings)before and after the child's death</li> <li>• Family function before and after the child's death</li> <li>•</li> </ul>
<b>Context and likely themes (qualitative)</b>	<p><b>Context:</b> <b>psychological therapies after the illness is diagnosed, during the process of dying, and after the infants, children or young people's death</b></p> <p><b>Themes: will be identified from the literature, but expected themes are:</b></p> <ul style="list-style-type: none"> <li>• Bereavement for carers/families (including siblings) before and after infants, children or young people's death (perceived benefits from the intervention)</li> <li>• Carers/families' (including siblings) perceptions of treatments effectiveness, for example for anger, sadness, depression, trauma, isolation, stigma, feelings of guilt, and so on.</li> <li>• Carers/families' (including siblings) attitudes toward psychological therapies (personal values, cultural differences; therapies deemed helpful or not helpful);</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Carers/families' (including siblings) experiences with psychological therapies (stigma associated with treatment; perceptions; cultural differences; experiences with the therapist; helpful or unhelpful);</li> <li>• Unmet needs (access, availabilities, flexibilities, resources; burdens due to the lack of psychological therapies);</li> <li>• Challenges experienced (coping of carers/siblings during the process, preparing for bereavement and going on after death of the infants, children or young people's; skills of the therapists; misconceptions; referrals);</li> <li>• Factors related to the therapist (skills / experience, time)</li> <li>• Parents' attitudes about disclosure to the siblings (psycho-education: normalising and validating experience)</li> </ul>
<b>Setting</b>	Community, primary, secondary and tertiary care
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycInfo.</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy (quantitative)</b>	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using appropriate checklists and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> <p>Synthesis of data:</p> <ul style="list-style-type: none"> <li>• Meta-analysis will be conducted if appropriate.</li> </ul> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p> <p>Other considerations if there is sufficient data:</p> <ul style="list-style-type: none"> <li>• Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>
<b>Review strategy (qualitative)</b>	<ul style="list-style-type: none"> <li>• Appraisal of methodological quality:</li> <li>• The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by GRADE-CERQual approach for each identified theme.</li> <li>• Data synthesis:</li> <li>• Thematic analysis of the data will be conducted and findings presented.</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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## D.12<sub>1</sub> Social and practical support

Item	Details
<b>Key issues in the scope</b>	The support needs of infants, children and young people and their family members or carers (as appropriate), including social, practical, spiritual or religious. Care of the infant, child or young person's body after death.
<b>Review question in the scope</b>	l) What forms of social and practical support are helpful to ICYP with LLC and their family members or carers (as appropriate)? o) Before and after an infant, child or young person dies, what considerations do their family members or carers (as appropriate) consider important (for example communication, emotional, spiritual and religious support, care of the body, and managing practical arrangements)?
<b>Review question</b>	What factors of social and practical support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death?
<b>Objectives (quantitative)</b>	<ul style="list-style-type: none"> <li>• To assess the effectiveness of social and practical support interventions</li> <li>• for infants, children or young people who are approaching the end of life and their family members or carers.</li> </ul>
<b>Objectives (Qualitative)</b>	<ul style="list-style-type: none"> <li>• To identify and describe factors that influence infants, children and young people and their families' or carers' attitudes towards social and practical support interventions</li> <li>• To identify and describe infants, children and young people and their family or carers' experiences with social and practical support interventions, challenges faced and unmet needs.</li> </ul>
<b>Language</b>	English
<b>Study design (Quantitative)</b>	<ul style="list-style-type: none"> <li>• Systematic reviews</li> <li>• Randomised controlled trials (RCTs)</li> <li>• Cohort studies (only if RCTs unavailable or limited data to inform decision making)]</li> <li>• Uncontrolled studies (only if there is no other evidence found)</li> <li>• We will exclude case studies</li> </ul>
<b>Study design (Qualitative)</b>	<ul style="list-style-type: none"> <li>• Qualitative studies (for example, ethnographic studies, interviews, and focus groups)</li> <li>• Mixed-methods observational studies where qualitative data were reported (for example, survey studies)</li> </ul>
<b>Population and directness</b>	<ul style="list-style-type: none"> <li>• Infants, children or young people with a LLC</li> <li>• Parents or carers of infants, children or young people with a LLC approaching the end of life, and before and after death</li> </ul> <p><b>Population size and indirectness:</b></p> <ul style="list-style-type: none"> <li>• No sample size specification</li> <li>• Studies with indirect population will not be considered</li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<p><b>Groups</b> that will be reviewed and analysed separately:</p> <ul style="list-style-type: none"> <li>• None</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• In the event of heterogeneity, the following <b>subgroups</b> will be considered:</li> <li>• Cultural background</li> <li>• Ethnicity</li> <li>• Spirituality</li> <li>• Time point of the illness</li> </ul>
<b>Intervention (Quantitative)</b>	<p>Practical and social interventions – in addition to usual care – to support infants, children and young people with a LLC and their families or carers including, but not only:</p> <ul style="list-style-type: none"> <li>- Peer support groups</li> <li>- (Community) support groups</li> <li>- Respite care</li> <li>- Assistance with day to day care</li> <li>- Domestic services</li> <li>- Help with getting house arrangements (for example documentation)</li> <li>- Joint clinics</li> <li>- Transport arrangements</li> <li>- Equipment supply</li> <li>- Advice on financial support (by hospital social worker)</li> <li>- Advice and information about funeral arrangements</li> <li>- Legal and regulatory requirements</li> <li>- Practical advice regarding any of the above</li> <li>- Care of the body – for example bathing, cooling arrangements</li> <li>- Exclude interventions that are required by the condition itself – for example home oxygen</li> </ul>
<b>Comparison (quantitative)</b>	<ul style="list-style-type: none"> <li>• Usual care</li> </ul>
<b>Outcomes (quantitative)</b>	<ul style="list-style-type: none"> <li>• Infants, children or young people’s well-being, including psychological well-being, common mental disorder or death distress</li> <li>• Infants, children or young people’s coping</li> <li>• Parents or carers coping</li> <li>• Infants, children or young people’s quality of life</li> <li>• Parents or carers quality of life</li> <li>• Family functioning</li> <li>• Infants, children or young people’s and their families’ or carers’ health service use</li> <li>• Facilitating preferred place of care</li> <li>•</li> </ul>
<b>Importance of outcomes (quantitative)</b>	<p>Critical:</p> <ul style="list-style-type: none"> <li>• Infants, children or young people’s well-being, including psychological well-being, common mental disorder or death distress</li> <li>• Infants, children or young people’s coping</li> <li>• Parents or carers coping</li> </ul>
<b>Context and likely themes (Qualitative)</b>	<p><b>Context:</b> Social and practical support during for end of life care and after the death of the Infants, children or young people’s</p> <p><b>Themes</b> will be identified during the literature, but expected themes are: Social support</p> <ul style="list-style-type: none"> <li>• Value of contact with people who have similar experiences</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Value of (community) support groups</li> <li>• Value of hospital volunteers</li> </ul> <p>Practical help</p> <ul style="list-style-type: none"> <li>• Family or carers coping with their caregiver role</li> <li>• Family functioning</li> <li>• Infants, children or young people's health service use</li> <li>• Financial stress</li> <li>• Provision of equipment</li> <li>• Time spent on caregiving activities</li> <li>• Need for a break</li> <li>• Lack of coordination for hospital appointments</li> <li>• Lack of time with partner or other children</li> <li>• Lack of time for self-care</li> <li>• Care of the body after death</li> <li>• Family's preferences immediately after the child's death with regards to the body</li> <li>• Transfer of the body to mortuary or funeral directors,</li> <li>• Effect of need to maintain cool environment for body</li> <li>• Practical arrangements with regards to funeral directors</li> <li>• Preferences with regards to clothes or artefacts (favourite outfit or toy)</li> <li>• Fear about changes in the body</li> <li>• Cultural differences with regards to care of the body</li> </ul>
<b>Setting</b>	Community, primary, secondary and tertiary care ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy (quantitative)</b>	<p>For the quantitative review:</p> <p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using appropriate checklists and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> <p>Synthesis of data:</p> <ul style="list-style-type: none"> <li>• Meta-analysis will be conducted if appropriate.</li> </ul> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p> <p>Other considerations if there is sufficient data:</p> <ul style="list-style-type: none"> <li>• Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> </ul> <p>If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</p>



Item	Details
<b>Review strategy (qualitative)</b>	<p>For the qualitative review:</p> <ul style="list-style-type: none"> <li>The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by GRADE-CERQual approach for each identified theme.</li> </ul> <p>Data synthesis:</p> <ul style="list-style-type: none"> <li>Thematic analysis of the data will be conducted and findings presented.</li> </ul>
<b>Equalities</b>	None that are not already considered in the equalities impact form.

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### D.13<sub>3</sub> Spiritual and religious support

Item	Details
<b>Key issues in scope</b>	<ul style="list-style-type: none"> <li>The support needs of infants, children and young people and their family members or carers (as appropriate), including social, practical, spiritual or religious.</li> <li>Care of the infant, child or young person's body after death.</li> </ul>
<b>Review questions in the scope</b>	<ul style="list-style-type: none"> <li>What forms of spiritual and practical support are helpful to infant, child or young people with life-limiting condition and their family members or carers (as appropriate)?</li> <li>Before and after an infant, child or young person dies, what considerations do their family members or carers (as appropriate) consider important (for example communication, emotional, spiritual and religious support, care of the body, and managing practical arrangements)?</li> </ul>
<b>Review question</b>	What factors of spiritual or religious support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death?
<b>Objectives (quantitative)</b>	<ul style="list-style-type: none"> <li>To assess the effectiveness of spiritual and religious support for infants, children or young people with a life-limiting condition who are approaching the end of life and their family members or carers</li> </ul>
<b>Objectives (qualitative)</b>	<ul style="list-style-type: none"> <li>To identify and describe the factors that influence children and young people living with a life-limiting condition and their families or carers attitudes towards religious and spiritual support.</li> <li>To identify and describe the experiences of children and young people living with a life-limiting condition and their families or carers, with religious and spiritual support, challenges faced and unmet needs.</li> </ul>
<b>Language</b>	English
<b>Study design (quantitative)</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>Systematic reviews</li> <li>Randomized controlled trials (RCTs)</li> <li>Conference abstracts of RCTs (if full text papers are not available)</li> <li>C studies (only if RCTs unavailable or limited data to inform decision making)]</li> <li>Uncontrolled studies</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>Case series and case studies</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Qualitative studies</li> </ul>
<b>Study design (qualitative)</b>	<ul style="list-style-type: none"> <li>• We will include:               <ul style="list-style-type: none"> <li>• Qualitative studies (for example, ethnographic studies, interviews, and focus groups)</li> <li>• Mixed-methods observational studies where qualitative data were reported (for example, survey studies, interviews, focus groups, observations )</li> </ul> </li> <li>• We will exclude:               <ul style="list-style-type: none"> <li>• Purely quantitative studies (including surveys with only descriptive quantitative data)</li> </ul> </li> </ul>
<b>Population and directness</b>	<ul style="list-style-type: none"> <li>• Infant, child or young people (up to age 18) with a life-limiting condition approaching the end of life</li> <li>• Parents or carers of Infant, child or young people (up to age 18) with a life-limiting condition approaching the end of life, and before and after death</li> </ul> <p>Population size and indirectness:</p> <ul style="list-style-type: none"> <li>• No sample size specification</li> <li>• Studies with indirect population will not be considered</li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<p><b>Subgroups:</b></p> <ul style="list-style-type: none"> <li>• Cultural background, ethnicity, spirituality, religion/ faith</li> <li>• Time point of the illness</li> </ul>
<b>Intervention</b>	<p>Any spiritual or religious intervention.</p> <p>As defined by the Cochrane review (Candy 2012): by spiritual or religious interventions we mean “those that contain at least some reference to beliefs and/or experiences in a realm that transcends the material world and/ or daily experiences” (King 2009).</p>
<b>Comparison (quantitative)</b>	<ul style="list-style-type: none"> <li>• Usual care</li> </ul>
<b>Outcomes (quantitative)</b>	<ul style="list-style-type: none"> <li>• Infant, child or young person’s well-being, including psychological well-being, common mental disorder or death distress</li> <li>• Infant, child or young person’s physical symptoms, such as pain, fatigue, hypersomnia and breathlessness</li> <li>• Infant, child or young person’s coping</li> <li>• Family or carers’ coping</li> <li>• Infant, child or young person’s quality of life</li> <li>• Family or carers’ quality of life</li> <li>• Family functioning</li> <li>• Infant, child or young person’s health service use</li> </ul>
<b>Importance of outcomes (quantitative)</b>	<ul style="list-style-type: none"> <li>• <b>Critical</b> outcomes for decision making:               <ul style="list-style-type: none"> <li>• Infant, child or young person’s well-being, including psychological well-being, common mental disorder or death distress</li> <li>• Infant, child or young person’s physical symptoms, such as pain, fatigue, hypersomnia and breathlessness</li> <li>• Infant, child or young person’s coping</li> </ul> </li> </ul>
<b>Context and likely themes (qualitative)</b>	<p><b>Context:</b></p> <p>Spiritual and religious support during end of life, and after the infant, child or young person’s death</p> <p><b>Themes:</b></p> <p>Themes will be identified from the literature, but expected themes are:</p> <ul style="list-style-type: none"> <li>• Wellbeing of infant, child or young person</li> <li>• Wellbeing of family</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Comfort of family</li> <li>• Comfort of infant, child or young person</li> <li>• Relationship with God or a higher being, transcendence</li> <li>• Relationship with self</li> <li>• Relationship with others</li> <li>• Relationship with nature and music</li> <li>• Hope</li> <li>• Meaning and purpose in life</li> <li>• Need for positive outlook</li> <li>• Fear</li> <li>• Institutional support</li> <li>• Staff awareness and training</li> <li>• Time and timing (having quality time at the right moment)</li> <li>• Assessment of spiritual needs</li> <li>• Unmet spiritual needs</li> <li>• Themes related to care of the body after death</li> <li>• Professionals' awareness of religious preferences/ practices</li> <li>• Spiritual or religious rituals with regards to care of the body</li> <li>• Choice of cremation or burial</li> <li>• Choice of music</li> <li>• Spiritual feelings with regards to 'green/environment' issues (green burials do not permit the child to be embalmed)</li> <li>• Incense and aromatherapy</li> <li>• Washing of the child after death</li> <li>• Disposal of ashes</li> </ul>
<b>Setting</b>	Community, primary, secondary and tertiary care.
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E: add link)</p>
<b>Review strategy (quantitative)</b>	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using the appropriate checklist and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> <p>Synthesis of data:</p> <p>Meta-analysis will be conducted where appropriate.</p> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p> <p>Other considerations if there is sufficient data:</p> <ul style="list-style-type: none"> <li>• Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>

Item	Details
<b>Review strategy (qualitative)</b>	Appraisal of methodological quality: The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by GRADE-CERQual approach for each identified theme. Data synthesis: Thematic analysis of the data will be conducted and findings presented.
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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### D.14<sub>3</sub> Managing pain

Item	Details
<b>Key issue in the scope</b>	The safe and effective management of distressing symptoms (such as pain and respiratory distress)
<b>Review question in the scope</b>	What interventions are safe, and clinically cost-effective for managing pain and other distressing symptoms associated with life-limiting conditions?
<b>Review question</b>	What pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of pain in infant, children or young people with a life-limiting condition?
<b>Objective</b>	<ul style="list-style-type: none"> <li>The aim of this review is to assess the clinical effectiveness, the safety and the cost-effectiveness of pharmacological and non-pharmacological treatments for the management of pain in infant, children or young people with a life-limiting condition.</li> </ul>
<b>Language</b>	English
<b>Study design</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>Systematic reviews of RCTs</li> <li>Randomised controlled trials (RCTs), including cross-over RCTs</li> <li>Conference abstracts of RCTs (if full text papers are not available)</li> <li>Cohort studies (only if RCTs unavailable or limited data to inform decision making)</li> <li>Uncontrolled studies (only if not other evidence is found)</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>Qualitative studies</li> <li>Case reports and case series</li> </ul>
<b>Population and directness</b>	<p>Infant, children or young people (up to age 18) with a life-limiting condition and with pain due to:</p> <ul style="list-style-type: none"> <li>Noiceptive pain</li> <li>bone pain (due to cancer)</li> <li>headache (related to raised intracranial pressure)</li> <li>neuropathic pain</li> <li>visceral pain</li> </ul> <p>Population size and indirectness:</p> <ul style="list-style-type: none"> <li>No sample size specification</li> <li>No restrictions on year of publication</li> <li>Studies with indirect population will not be considered</li> </ul>

Item	Details
<p><b>Stratified, subgroup and adjusted analyses</b></p>	<p><b>Groups</b> that will be reviewed and analysed separately:</p> <ul style="list-style-type: none"> <li>• None</li> </ul> <p>In the presence of <b>heterogeneity</b>, the following subgroups will be considered:</p> <ul style="list-style-type: none"> <li>• By individual drugs within drug classes</li> <li>• Route of administration: <ul style="list-style-type: none"> <li>○ Oral, enteral, nasogastric (NG) tube, orogastric (OG) tube, percutaneous endoscopic gastrostomy (PEG)/ gastrostomy</li> <li>○ Transmucosal (includes sublingual, buccal, nasal, rectal)</li> <li>○ Subcutaneous</li> <li>○ Intramuscular</li> <li>○ Intravenous</li> <li>○ Transdermal</li> <li>○ Inhalation</li> <li>○ Epidural</li> <li>○ Topical</li> </ul> </li> <li>• Delivery system: <ul style="list-style-type: none"> <li>○ Bolus injection</li> <li>○ Continuous infusion (SC or IV)</li> <li>○ Patients controlled analgesia (PCA)</li> <li>○ Nurse controlled analgesia (NCA)</li> </ul> </li> <li>• Type of pain: <ul style="list-style-type: none"> <li>○ Location</li> <li>○ Intensity</li> <li>○ Duration</li> </ul> </li> </ul> <p>Important <b>confounders</b> (when comparative observational studies are included for interventional reviews)</p> <ul style="list-style-type: none"> <li>• Age</li> <li>• Severity of pain</li> </ul>
<p><b>Intervention</b></p>	<p><b>Pharmacological interventions</b>, including:</p> <p>Non-opioids:</p> <ul style="list-style-type: none"> <li>○ Paracetamol</li> <li>○ Sucrose</li> <li>○ NSAIDs: ibuprofen, diclofenac, ketorolac,</li> <li>○ Nitrous oxide</li> <li>○ Ketorolac (IV)</li> <li>○ Diclofenac</li> <li>○ Naproxen</li> </ul> <ul style="list-style-type: none"> <li>• Opioids: <ul style="list-style-type: none"> <li>○ Morphine</li> <li>○ fentanyl</li> <li>○ Tramadol</li> <li>○ Buprenorphine</li> <li>○ Hydromorphone</li> <li>○ Oxycodone</li> <li>○ Diamorphine</li> </ul> </li> <li>• Local anaesthetics: <ul style="list-style-type: none"> <li>○ Lidocaine patches</li> <li>○ Ametop</li> <li>○ Topical lidocaine (EMLA)</li> <li>○ Topical diamorphine</li> </ul> </li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Adjuvants (drugs with a primary indication that is not for pain but that nevertheless have analgesic properties are explicitly administered for pain relief)               <ul style="list-style-type: none"> <li>○ Antidepressants:                   <ul style="list-style-type: none"> <li>- amitriptyline (can also be used for neuropathic pain)</li> <li>- nortriptyline (can also be used for neuropathic pain)</li> </ul> </li> <li>○ Adjuvants for neuropathic pain:                   <ul style="list-style-type: none"> <li>- Amitriptyline</li> <li>- Nortriptyline (used for neuropathic pain but dosing only available for older children)</li> <li>- Anticonvulsants</li> <li>- Gabapentin</li> <li>- Pregablin</li> <li>- NMDA antagonist ketamine</li> <li>- Corticosteroids</li> </ul> </li> <li>○ Adjuvants for bone pain:                   <ul style="list-style-type: none"> <li>- Bisphosphonates</li> <li>- Calcitonin</li> <li>- Corticosteroids</li> </ul> </li> <li>○ Adjuvants for bowel spasm:                   <ul style="list-style-type: none"> <li>- Anticholinergic</li> <li>- Hyoscine butylbromide</li> <li>- Octreotide</li> </ul> </li> <li>○ Adjuvants for muscle spasm                   <ul style="list-style-type: none"> <li>- Benzodiazepine</li> <li>- Botulinum toxin A</li> <li>- Baclofen</li> <li>- Tizanidine</li> <li>- Dantrolene</li> <li>- Clonidine</li> </ul> </li> </ul> </li> <li>• Palliative chemotherapy</li> <li>• Palliative radiotherapy (bone pain and raised intracranial pressure)</li> <li>• Steroids (indicated for headache related to brain tumour and liver capsule pain and bone pain sometimes)</li> <li>• Medical formulations of cannabis: sativex</li> <li>• Chronic pain rehabilitation strategies (includes both pharmacological and non-pharmacological)</li> <li><b>Non-pharmacological interventions</b>, including (but not only):               <ul style="list-style-type: none"> <li>• Acupuncture/ acupressure</li> <li>• Cold/ heat</li> <li>• Massage</li> <li>• Music therapy</li> <li>• Physiotherapy</li> <li>• Reflexology</li> <li>• Transcutaneous electrical nerve stimulation (TENS)</li> </ul> </li> <li>We will exclude:               <ul style="list-style-type: none"> <li>• Interventions for pain not related to end of life care</li> </ul> </li> </ul>
<b>Comparison</b>	<ul style="list-style-type: none"> <li>• Any other pharmacological (within group and between group)</li> <li>• Any other non-pharmacological intervention</li> <li>• Combinations of the above</li> <li>• Routes of administration (same drug or same drug class)</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>NOTE Different dosages is not seen as a comparison of interest, given that dosages vary often</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>Pain (measured by a validated scale, such as FLACC, NIPS)</li> <li>Infant, children or young person's levels of distress</li> <li>Parents or carers' levels of distress</li> <li>Adverse events, particularly opioid related:               <ul style="list-style-type: none"> <li>Constipation</li> <li>Nausea / vomiting</li> <li>Itching</li> <li>Urinary retention</li> <li>Fatigue</li> <li>Confusion</li> <li>Respiratory depression</li> <li>Unwanted levels of sedation</li> </ul> </li> <li>Infant, children or young people quality of life (validated instrument, such as PedQL)</li> <li>Parents or carer's quality of life</li> <li>Control of other distressing symptoms (agitation, breathlessness, and so on)</li> <li>Proportion of children taken home/ re-admission to hospital/ admission to hospice</li> </ul>
<b>Importance of outcomes</b>	<ul style="list-style-type: none"> <li><b>Critical</b> outcomes for decision making:</li> <li>Pain (different ways of measuring pain depending on the age of the child)</li> <li>Adverse events</li> <li>Infant, child or young person and Parents or carer's quality of life(validated instrument)</li> </ul>
<b>Setting</b>	UK, primary, secondary care and tertiary care
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase.</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy</b>	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>The methodological quality of each study will be assessed using the appropriate checklist and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> <p>Synthesis of data:</p> <p>Meta-analysis will be conducted where appropriate.</p> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p> <p>Other considerations if there is sufficient data:</p> <ul style="list-style-type: none"> <li>Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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## D.15<sub>2</sub> Managing agitation

Item	Details
<b>Key issue in the scope</b>	The safe and effective management of distressing symptoms (such as pain and respiratory distress)
<b>Review question in the scope</b>	What interventions are safe, and clinically cost-effective for managing pain and other distressing symptoms associated with life-limiting conditions?
<b>Review question</b>	What pharmacological and non-pharmacological interventions (excluding psychological) are effective for the management of agitation in infants, children or young people with a life-limiting condition who are approaching the end of life?
<b>Objective</b>	<ul style="list-style-type: none"> <li>The aim of this review is to assess the clinical effectiveness, the safety and the cost-effectiveness of pharmacological and non-pharmacological treatments for the management of agitation in infants, children or young people with a life-limiting condition who are approaching the end of life.</li> </ul>
<b>Language</b>	English
<b>Study design</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>Systematic reviews of RCTs</li> <li>Randomised controlled trials (RCTs) - including cross over RCTs</li> <li>Conference abstracts of RCTs (if full text papers are not available)</li> <li>Cohort studies (only if RCTs unavailable or limited data to inform decision making)</li> <li>Uncontrolled studies (only if not other evidence is found)</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>Before and after implementation or evaluation studies</li> <li>Qualitative studies</li> <li>Case series and case reports</li> </ul>
<b>Population and directness</b>	<p>Infants, children and young people (up to age 18) with a life-limiting condition who are approaching the last days of their life and who are experiencing agitation.</p> <p>This is aimed at the very end of life (days), (as recognised from the signs and symptoms – in another review topic).</p> <p>Population size and indirectness:</p> <ul style="list-style-type: none"> <li>No sample size specification</li> <li>As highlighted in the signs and symptoms protocol: <ul style="list-style-type: none"> <li>up to 5 days will be direct population</li> <li>6 days to 2 weeks will be indirect</li> <li>2 to 4 weeks very indirect and will be considered on a case by case basis only</li> </ul> </li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<p><b>Groups</b> that will be reviewed and analysed separately:</p> <ul style="list-style-type: none"> <li>Neonates</li> <li>All other age groups</li> </ul> <p>In the event of heterogeneity, the following <b>subgroups</b> will be considered:</p>



Item	Details
	<ul style="list-style-type: none"> <li>• Mechanisms/ causes of agitation</li> <li>• Delivery system</li> <li>• Route of administration</li> <li>• Type of agitation</li> </ul> <p>Important <b>confounders</b> (when comparative observational studies are included for interventional reviews)</p> <ul style="list-style-type: none"> <li>• Severity of agitation</li> <li>• Age</li> <li>• Time before death</li> </ul>
<b>Intervention</b>	<p><b>Pharmacological interventions</b>, including:</p> <ul style="list-style-type: none"> <li>• Benzodiazepines               <ul style="list-style-type: none"> <li>○ Midazolam</li> <li>○ Lorazepam</li> <li>○ Diazepam</li> <li>○ Clonazepam</li> </ul> </li> <li>• Benzodiazepines               <ul style="list-style-type: none"> <li>○ Midazolam</li> <li>○ Lorazepam</li> <li>○ Diazepam</li> <li>○ Clonazepam</li> </ul> </li> <li>• Neuroleptics               <ul style="list-style-type: none"> <li>○ Haloperidol</li> </ul> </li> <li>• Levomepromazine</li> <li>• Other sedatives               <ul style="list-style-type: none"> <li>○ Phenobarbital</li> <li>○ Chloral hydrate</li> </ul> </li> <li>• Beta-blockers/ Propanolol?</li> </ul> <p><b>Non-pharmacological interventions</b>, including:</p> <ul style="list-style-type: none"> <li>• Soothing / comforting methods such as, calming voice, gentle touch or provision of familiar objects</li> <li>• Music</li> <li>• Communication aids</li> <li>• Massage</li> <li>• If in danger of harming himself / herself- physical restraints (such as when agitated movements might dislodge a central line or a tracheal airway)</li> <li>• Other methods of distraction</li> <li>• Play</li> <li>• Functional assessment of environmental trigger</li> </ul>
<b>Comparison</b>	<ul style="list-style-type: none"> <li>• Placebo</li> <li>• No treatment / usual care</li> <li>• Cross comparisons between any of the above (within group and between group)</li> <li>• Combinations of the above</li> <li>• Routes of administration (same drug or same drug class)</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• Reduction of agitation</li> <li>• Infant, child or young person's levels of distress alleviated</li> <li>• Parents or carers' levels of distress alleviated</li> <li>• Infant, child or young person's (health-related) quality of life</li> <li>• Parents or carers' quality of life</li> <li>• Infant, child or young person's satisfaction</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Parents or carer's satisfaction (also retrospective)</li> <li>• Adverse events, including unwanted levels of sedation                             <ul style="list-style-type: none"> <li>◦</li> </ul> </li> </ul>
<b>Importance of outcomes</b>	<p><b>Critical outcomes</b> for decision making:</p> <ul style="list-style-type: none"> <li>• Reduction of agitation</li> <li>• Infant, child or young person's levels of distress</li> <li>• Infant, child or young person's (health-related) quality of life</li> </ul>
<b>Setting</b>	UK, primary, secondary care and tertiary care
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase.</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy</b>	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using the appropriate checklist and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> <p>Synthesis of data:</p> <p>Meta-analysis will be conducted where appropriate.</p> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p> <p>Other considerations if there is sufficient data:</p> <ul style="list-style-type: none"> <li>• Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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### D.16<sub>3</sub> Managing respiratory distress

Item	Details
<b>Key issue in the scope</b>	The safe and effective management of distressing symptoms (such as pain and respiratory distress)
<b>Review question in the scope</b>	What interventions are safe, and clinically cost-effective for managing pain and other distressing symptoms associated with life-limiting conditions?
<b>Review question</b>	What pharmacological and non-pharmacological interventions (excluding psychological) are effective for the management of respiratory distress in infants, children or young people with a life-limiting condition who are approaching the end of life?
<b>Objective</b>	<ul style="list-style-type: none"> <li>• The aim of this review is to assess the clinical effectiveness, the safety and the cost-effectiveness of pharmacological and non-pharmacological</li> </ul>

Item	Details
	treatments for the management of respiratory distress in Infant, child or young people with a LLC who are approaching the end of life.
<b>Language</b>	English
<b>Study design</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>• Systematic reviews of RCTs</li> <li>• Randomised controlled trials (RCTs) - including cross over RCTs</li> <li>• Conference abstracts of RCTs (if full text papers are not available)</li> <li>• C Cohort studies (only if RCTs unavailable or limited data to inform decision making)]</li> <li>• Uncontrolled studies (only if not other evidence is found)</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>• Qualitative studies</li> <li>• Case series and case reports</li> </ul>
<b>Population and directness</b>	<p>Infant, child or young person (up to age 18) with a life-limiting condition who are approaching the last days of their life and who are experiencing respiratory distress.</p> <p>This is aimed at the very end of life (days), (as recognised from the signs and symptoms – in another review topic).</p> <p>Population size and indirectness:</p> <ul style="list-style-type: none"> <li>• No sample size specification</li> <li>• As highlighted in the signs and symptoms protocol: <ul style="list-style-type: none"> <li>○ up to 5 days will be direct population</li> <li>○ 6 days to 2 weeks will be indirect</li> <li>○ 2 to 4 weeks very indirect and will be considered on a case by case basis only</li> </ul> </li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<p><b>Groups</b> that will be reviewed and analysed separately:</p> <ul style="list-style-type: none"> <li>• Neonates</li> <li>• Infants (&gt; 28 days), children and young people</li> </ul> <p>In the event of heterogeneity, the following <b>subgroups</b> will be considered:</p> <ul style="list-style-type: none"> <li>• Mechanisms/ causes of respiratory distress</li> <li>• Type of respiratory distress (dyspnoea...)</li> <li>• Prior conditions leading to shortness of breath (such as asthma, cystic fibrosis...)</li> <li>• Delivery system</li> <li>• Route of administration</li> </ul> <p>Important <b>confounders</b> (when comparative observational studies are included for interventional reviews)</p> <ul style="list-style-type: none"> <li>• Severity of respiratory distress</li> <li>• Time before death</li> <li>• Age</li> </ul>
<b>Intervention</b>	<p><b>Pharmacological interventions</b>, including:</p> <ul style="list-style-type: none"> <li>• Diuretics for fluid overload/ pulmonary oedema <ul style="list-style-type: none"> <li>○ Furosemide</li> </ul> </li> <li>• Anti- secretory agents <ul style="list-style-type: none"> <li>○ Hyoscine hydrobromide/ Scopolamine hydrobromide</li> <li>○ Atropine</li> <li>○ Glycopyrronium Bromide (previously known as Glycopyrrolate)</li> </ul> </li> <li>• Bronchodilators <ul style="list-style-type: none"> <li>○ Salbutamol</li> <li>○ Ipratopium bromide</li> </ul> </li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Inhaled steroids</li> <li>• Nebulised saline</li> <li>• Sedative and anxiolytic agents:               <ul style="list-style-type: none"> <li>○ Opioids</li> <li>○ Benzodiazepines</li> </ul> </li> <li>• Oxygen</li> <li><b>Non-pharmacological interventions</b>, including:               <ul style="list-style-type: none"> <li>• Repositioning</li> <li>• Fans and opening windows</li> <li>• Square breathing (breathing techniques)</li> <li>• Chest physiotherapy</li> <li>• Mechanical airway suctioning</li> <li>• Non-invasive ventilation (BIPAP, CPAP)</li> </ul> </li> </ul>
<b>Comparison</b>	<ul style="list-style-type: none"> <li>• Placebo</li> <li>• No treatment/ usual care</li> <li>• Cross comparisons between any of the above (within group and between group)</li> <li>• Combinations of the above</li> <li>• Routes of administration (same drug or same drug class)</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• Objective and subjective signs of respiratory distress alleviated</li> <li>• Infant, child or young person's levels of distress alleviated</li> <li>• Parents or carers' levels of distress alleviated</li> <li>• Infant, child or young person's (health-related) quality of life</li> <li>• Parents or carers' quality of life</li> <li>• Infant, child or young person's satisfaction</li> <li>• Parents or carers' satisfaction (also retrospective)</li> <li>• The number of different types of interventions (including varying doses and types of anticholinergics) needed to change noise intensity.</li> <li>• Adverse effects, including unwanted levels of sedation</li> </ul>
<b>Importance of outcomes</b>	<ul style="list-style-type: none"> <li>• <b>Critical outcomes</b> for decision making:               <ul style="list-style-type: none"> <li>• Infant, child or young person's subjective distress alleviated</li> <li>• Objective and subjective signs of respiratory distress alleviated</li> <li>• Parents or carers' distress alleviated</li> </ul> </li> </ul>
<b>Setting</b>	UK, primary, secondary care and tertiary care
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase.</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy</b>	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using the appropriate checklist and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> <p>Synthesis of data:</p> <p>Meta-analysis will be conducted where appropriate.</p> <p>For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</p>

Item	Details
	<p>Other considerations if there is sufficient data:</p> <ul style="list-style-type: none"> <li>• Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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### D.17<sub>3</sub> Managing seizures

Item	Details
<b>Key issue in the scope</b>	The safe and effective management of distressing symptoms (such as pain and respiratory distress)
<b>Review question in the scope</b>	What interventions are safe, and clinically cost-effective for managing pain and other distressing symptoms associated with life-limiting conditions?
<b>Review question</b>	What pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of seizures in infants children or young people with a life-limiting condition who are approaching the end of life?
<b>Objective</b>	<ul style="list-style-type: none"> <li>• The aim of this review is to assess the clinical effectiveness, the safety and the cost-effectiveness of pharmacological and non-pharmacological treatments for the management of seizures in infant, children or young people with a life-limiting condition who are approaching the end of life.</li> </ul>
<b>Language</b>	English
<b>Study design</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>• Systematic reviews of RCTs</li> <li>• Randomised controlled trials (RCTs) - including cross over RCTs</li> <li>• Conference abstracts of RCTs (if full text papers are not available)</li> <li>• C Cohort studies (only if RCTs unavailable or limited data to inform decision making)]</li> <li>• Uncontrolled studies (only if not other evidence is found)</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>• Qualitative studies</li> <li>• Case series and case reports</li> </ul>
<b>Population and directness</b>	<p>Infant, children or young people (up to age 18) with a life-limiting condition who are approaching the last days of their life and who are experiencing seizures</p> <p>This is aimed at the very end of life (days), (as recognised from the signs and symptoms – in another review topic).</p> <p>Population size and indirectness:</p> <ul style="list-style-type: none"> <li>• No sample size specification</li> <li>• As highlighted in the signs and symptoms protocol: <ul style="list-style-type: none"> <li>○ up to 5 days will be direct population</li> <li>○ 6 days to 2 weeks will be indirect</li> </ul> </li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>○ 2 to 4 weeks very indirect and will be considered on a case by case basis only</li> </ul>
<p><b>Stratified, subgroup and adjusted analyses</b></p>	<p><b>Groups</b> that will be reviewed and analysed separately:</p> <ul style="list-style-type: none"> <li>● Neonates</li> <li>● All other age groups</li> </ul> <p>Both the beneficial and adverse effects of interventions may differ depending on age group</p> <p>In the event of heterogeneity, the following <b>subgroups</b> will be considered:</p> <ul style="list-style-type: none"> <li>● Mechanisms or causes of seizures</li> <li>● Delivery system</li> <li>● Route of administration</li> </ul> <p>Important <b>confounders</b> (when comparative observational studies are included for interventional reviews)</p> <ul style="list-style-type: none"> <li>● Severity of respiratory distress</li> <li>● Age</li> </ul>
<p><b>Intervention</b></p>	<ul style="list-style-type: none"> <li>● <b>Pharmacological interventions</b>, including: <ul style="list-style-type: none"> <li>● Midazolam</li> <li>● Clobazam</li> <li>● Clonazepam</li> <li>● Levetiracetam</li> <li>● Phenobarbital</li> <li>● Diazepam</li> <li>● Lorazepam</li> <li>● Paraldehyde</li> </ul> </li> <li>● NOTE: Some of these drugs are available in more than one form. Doses and onset of action can vary depending on route.</li> <li>● <b>Non-pharmacological interventions</b>, including: <ul style="list-style-type: none"> <li>● Trigger avoidance – by altering environment</li> <li>● Music therapy</li> </ul> </li> </ul>
<p><b>Comparison</b></p>	<ul style="list-style-type: none"> <li>● Placebo</li> <li>● No treatment / usual care</li> <li>● Cross comparisons between any of the above (within group and between group)</li> <li>● Combinations of the above</li> <li>● Routes of administration (same drug or same drug class)</li> </ul>
<p><b>Outcomes</b></p>	<ul style="list-style-type: none"> <li>● Reduction of seizures</li> <li>● Infant, child or young person’s levels of distress alleviated</li> <li>● Parents or carers’ levels of distress alleviated</li> <li>● Infant, child or young person’s (health-related) quality of life</li> <li>● Parents or carers’ quality of life</li> <li>● Infant, child or young person’s satisfaction</li> <li>● Parents or carers’ satisfaction (also retrospective)</li> <li>● Adverse effects <ul style="list-style-type: none"> <li>○ Unwanted levels of sedation</li> </ul> </li> </ul>
<p><b>Importance of outcomes</b></p>	<p><b>Critical outcomes</b> for decision making:</p> <ul style="list-style-type: none"> <li>● Reduction of seizures</li> <li>● Infant, child or young person’s (health-related) quality of life</li> <li>● Parents or carers’ satisfaction (also retrospective)</li> <li>● Infant, child or young person’s levels of distress</li> </ul>

Item	Details
<b>Setting</b>	UK, primary, secondary care and tertiary care
<b>Search strategy</b>	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase. Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters. Supplementary search techniques: No supplementary search techniques were used. See appendix for full strategies (Appendix E:)
<b>Review strategy</b>	Appraisal of methodological quality: <ul style="list-style-type: none"> <li>The methodological quality of each study will be assessed using the appropriate checklist and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> Synthesis of data: Meta-analysis will be conducted where appropriate. For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered. Other considerations if there is sufficient data: <ul style="list-style-type: none"> <li>Default MIDAs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

1

## D.182 Managing hydration

Item	Details
<b>Key issue in the scope</b>	The role of oral and medically assisted hydration and nutritional support during end of life care.
<b>Review question in the scope</b>	What is the effectiveness of medically assisted hydration in infants, children and young people during end of life care?
<b>Review question</b>	What is the effectiveness of medically assisted hydration in infants, children and young people living with LLCs in the last days of life?
<b>Objective</b>	To determine the effectiveness of medically assisted hydration in infants and children up to and including the age of 18 years with LLC during end of life care
<b>Language</b>	English
<b>Study design</b>	<ul style="list-style-type: none"> <li>Systematic reviews</li> <li>Randomised controlled trials (RCTs)</li> <li>Conference abstracts of RCTs (if full text papers are not available)</li> <li>Cohort studies (if no appropriate RCTs found)</li> <li>Uncontrolled studies (only if not other evidence is found)</li> </ul>
<b>Population and directness</b>	Infants, children and young people up to and including the age of 18 years who have a life-limiting condition and are approaching the end of life (likely to be in the final days)

Item	Details
	Population size and indirectness: <ul style="list-style-type: none"> <li>• No restrictions on sample size will be applied</li> <li>• Studies with indirect population will not be included</li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<b>Groups</b> that will be reviewed and analysed separately: <ul style="list-style-type: none"> <li>• Neonates</li> <li>• All other age groups up to age 18</li> <li>• In the event of heterogeneity, the following <b>subgroups</b> will be considered: Routes of administration : <ul style="list-style-type: none"> <li>• intravenously,</li> <li>• enteral tube feeding,</li> <li>• subcutaneous</li> </ul> </li> </ul>
<b>Intervention</b>	<ul style="list-style-type: none"> <li>• Medically assisted administration of non-nutritional fluids (water or electrolyte solutions)</li> </ul>
<b>Comparison</b>	<ul style="list-style-type: none"> <li>• No intervention</li> <li>• Usual treatment/Supportive care fluids that are provided non-medically assisted, that is, cups, straws, spoons and so on)</li> <li>• Alternative administration routes (for example, intravenously versus enteral tube feeding)</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• Satisfaction of family members or carers</li> <li>• Comfort or distress of the patient (or relevant proxy outcomes)</li> <li>• Adverse events including vomiting, respiratory distress, abdominal pain</li> </ul>
<b>Importance of outcomes</b>	Preliminary classification of the outcomes for decision making: <ul style="list-style-type: none"> <li>• critical (up to 3 outcomes): <ul style="list-style-type: none"> <li>• Comfort or distress of the patient (or relevant proxy outcomes)</li> <li>• Satisfaction of family members or carers</li> </ul> </li> <li>• Important but not critical (up to 3 outcomes)</li> <li>• Adverse events including vomiting, respiratory distress, abdominal pain]</li> </ul>
<b>Setting</b>	All settings
<b>Search strategy</b>	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, CINAHL. Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters. Supplementary search techniques: No supplementary search techniques were used. See appendix for full strategies (Appendix E:)
<b>Review strategy</b>	Appraisal of methodological quality: <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using appropriate checklists and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> </ul> Synthesis of data: <ul style="list-style-type: none"> <li>• Meta-analysis will be conducted if appropriate.</li> </ul> For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered. Other considerations if there is sufficient data: <ul style="list-style-type: none"> <li>• Default MIDs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> </ul>



Item	Details
	<ul style="list-style-type: none"> <li>If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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### D.19<sub>3</sub> Managing nutrition

Item	Details
<b>Key issue in the scope</b>	The role of oral and medically assisted nutrition and nutritional support during end of life care.
<b>Review question in the scope</b>	What is the effectiveness of medically assisted nutrition in infants, children and young people during end of life care?
<b>Review question in the protocol</b>	What is the effectiveness of medically assisted nutrition in infants, children and young people with life-limiting conditions in the last days of life?
<b>Objective</b>	<ul style="list-style-type: none"> <li>To determine the effectiveness of medically assisted nutrition in infants, children and young people with a life-limiting condition during end of life care.</li> </ul>
<b>Language</b>	English
<b>Study design</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>Systematic reviews</li> <li>Randomised controlled trials (RCTs)</li> <li>Conference abstracts of RCTs (if full text papers are not available)</li> <li>Cohort studies (only if RCTs unavailable or limited data to inform decision making)</li> <li>Uncontrolled studies (only if not other evidence is found)</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>Qualitative studies</li> <li>Case series and case reports</li> </ul>
<b>Population and directness</b>	<p>Infants, children and young people (up to age 18) who have a life-limiting condition and are approaching the end of life (likely to be in the final days)</p> <p>Population size and indirectness:</p> <ul style="list-style-type: none"> <li>No restrictions on sample size will be applied</li> <li>Studies with indirect population will not be included</li> </ul>
<b>Stratified, subgroup and adjusted analyses</b>	<ul style="list-style-type: none"> <li><b>Groups</b> that will be reviewed and analysed separately: <ul style="list-style-type: none"> <li>Neonates</li> <li>All other age groups up to age 18</li> </ul> </li> <li>In the event of heterogeneity, the following <b>subgroups</b> will be considered: <ul style="list-style-type: none"> <li>Routes of administration: <ul style="list-style-type: none"> <li>intravenously</li> <li>enteral tube feeding</li> </ul> </li> </ul> </li> </ul>
<b>Intervention</b>	<p>Administration of nutrients administered:</p> <ul style="list-style-type: none"> <li>enterally (nasogastric, percutaneous endoscopic gastrostomy, percutaneous endoscopic gastrostomy jejunostomy, or gastrojejunostomy tubes) or</li> <li>parentally (intravenously)</li> </ul>
<b>Comparison</b>	<ul style="list-style-type: none"> <li>No intervention</li> <li>Usual treatment/ supportive care (nutrients that are provided non-medically assisted, that is, spoon feeding and so on)</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Alternative administration routes (for example enterally or parentally)</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• Satisfaction of parents or carers</li> <li>• Comfort or distress of the infant, child or young person (or relevant proxy outcomes)</li> <li>• Adverse events, including vomiting, respiratory distress, abdominal pain</li> </ul>
<b>Importance of outcomes</b>	<p><b>Critical</b> outcomes for decision making:</p> <ul style="list-style-type: none"> <li>• Comfort or distress of the infant, child or young person (or relevant proxy outcomes)</li> <li>• Satisfaction of parents or carers</li> </ul>
<b>Setting</b>	All settings
<b>Search strategy</b>	<p>Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase.</p> <p>Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques were used.</p> <p>See appendix for full strategies (Appendix E:)</p>
<b>Review strategy</b>	<ul style="list-style-type: none"> <li>• Appraisal of methodological quality:</li> <li>• The methodological quality of each study will be assessed using the appropriate checklist and the quality of the evidence for an outcome (that is, across studies) will be assessed using GRADE.</li> <li>• Synthesis of data:</li> <li>• Meta-analysis will be conducted where appropriate.</li> <li>• For non-randomised studies, evidence from studies using multivariable analysis will be considered in the first instance and only if there are none available will studies with univariate analysis be considered.</li> <li>• Other considerations if there is sufficient data:</li> <li>• Default MIDAs will be used: 0.75 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes.</li> <li>• Record any considerations for continuous data for example if final and change scores will be pooled and if any study reports both, the method used in the majority of studies will be analysed.</li> <li>• If studies only report p-values, this information will be entered into GRADE tables without an assessment of imprecision possible to be made</li> </ul>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

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2

### D.20<sub>3</sub> Recognising the last days of life

Item	Details
<b>Key issue in the scope</b>	Recognising when infants, children and young people are likely to die within a few days or hours.
<b>Review question in the scope</b>	What symptoms, signs, or combinations of symptoms or signs indicate that infants, children or young people are likely to die within a few hours or days?
<b>Review question</b>	What signs and symptoms, individually or in combination help to recognise that infants, children or young people are likely to be in their last days of life and which of them are considered most informative by healthcare professionals?

Item	Details
<b>Objective</b>	<ul style="list-style-type: none"> <li>Identify signs and symptoms that help recognise that infants, children and young people are likely to be in their last days of life.</li> </ul>
<b>Population size and directness</b>	<p>Infants, children and young people (up to age 18) with life limiting conditions and who are approaching the last days of their life.</p> <p>Population size and indirectness:</p> <ul style="list-style-type: none"> <li>Small surveys– no participant limit</li> <li>Studies with indirect populations will not be considered</li> </ul>
<b>Language</b>	English
<b>Subgroups and sensitivity analyses</b>	<ul style="list-style-type: none"> <li><b>Groups</b> that will be reviewed and analysed separately: <ul style="list-style-type: none"> <li>Neonates</li> <li>Infants</li> <li>Children and young people</li> <li>Children with neuro-disability</li> </ul> </li> </ul> <p>Important <b>confounders</b> (when comparative observational studies are included for interventional reviews)</p> <ul style="list-style-type: none"> <li>Age</li> <li>Condition</li> <li>Pre-verbal versus those who can comprehend and express their symptoms</li> </ul>
<b>Signs and symptoms (quantitative review: prognostic / diagnostic)</b>	<p>Signs and symptoms in at least one of the following categories:</p> <ul style="list-style-type: none"> <li>deterioration in level of consciousness</li> <li>deterioration in cognition</li> <li>change in skin (for example colour or temperature)</li> <li>loss of willingness to take oral fluids</li> <li>loss of willingness to eat</li> <li>ability to tolerate feeding</li> <li>altered behaviour or emotional state (for example agitation or anxiety)</li> <li>social withdrawal (for example cessation of talking)</li> <li>loss of urine output change in vital signs (heart rate / pattern and respiratory rate / pattern)</li> </ul>
<b>Study design (quantitative review: prognostic/ diagnostic)</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>Systematic reviews of prospective or retrospective cohorts</li> <li>Prospective or retrospective cohorts</li> </ul> <p>We will exclude:</p> <ul style="list-style-type: none"> <li>Editorials, commentaries, opinion pieces (other than large survey related to consensus)</li> </ul>
<b>Study design (qualitative review)</b>	<p>We will include:</p> <ul style="list-style-type: none"> <li>Consensus survey of health care professionals' global assessment:</li> <li>Delphi consensus surveys</li> <li>Representative surveys of healthcare professionals experienced in paediatric palliative care</li> </ul>
<b>Outcomes (quantitative review: prognostic / diagnostic)</b>	<ul style="list-style-type: none"> <li>For <b>diagnostic</b> information: <ul style="list-style-type: none"> <li>sensitivity</li> <li>specificity</li> <li>positive predictive value</li> <li>negative predictive values</li> <li>positive likelihood ratios</li> <li>negative likelihood ratios</li> </ul> </li> <li>For <b>prognostic</b> information:</li> </ul>

Item	Details
	<ul style="list-style-type: none"> <li>• Dying within the next days (0-5 days direct evidence and up to 2 weeks indirect)</li> <li>• Note: longer-term (5+ days) prognostic factors would be less accurate in predicting death, and therefore this evidence should be downgraded</li> <li>• If thresholds are established/pre-defined or for prognostic information:</li> <li>• Relative risk (RR), odds ratio (OR), hazard ratio (HR) (and ultimately risk difference).</li> <li>• The expected effect of the classification strategies on clinical outcomes will be extracted if this information is reported</li> </ul>
<b>Importance of outcomes (quantitative review)</b>	<ul style="list-style-type: none"> <li>• <b>Critical</b> outcome for decision making:</li> <li>• Dying within the next days</li> </ul>
<b>Themes (qualitative review)</b>	Healthcare professionals' views on which signs and symptoms, prognostic tools, scores or indices, and laboratory or biological information are most useful. These would be extracted by theme and agreement about signs/symptoms that may indicated that an infant, child or young version is in the last days of life.
<b>Setting</b>	Community, primary, secondary and tertiary care
<b>Search strategy</b>	<ul style="list-style-type: none"> <li>• Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase.</li> <li>• Limits (for example date, study design): All study designs. Apply standard animal/non-English language filters.</li> <li>• Supplementary search techniques: No supplementary search techniques were used.</li> <li>• See appendix for full strategies (Appendix E:)</li> </ul>
<b>Review strategy (quantitative)</b>	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> <li>• The methodological quality of each study will be assessed using the appropriate checklist and the quality of the evidence for an outcome (that is, across studies) will be assessed using a modified GRADE approach.</li> <li>• Synthesis of data:</li> <li>• Meta-analysis will be conducted where appropriate.</li> <li>• For the quantitative part of the review preference would be given to studies accounting for possible baseline characteristics that may impact on life expectancy, if none of these are found then other studies may be considered.</li> <li>• When the studies report the raw data of outcome of interest the data will be summarised in RR/ OR and corresponding absolute effect measures or sensitivity / specificity where applicable.</li> </ul>
<b>Review strategy (qualitative)</b>	<p>Appraisal of methodological quality:</p> <p>The methodological quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies and the quality of the qualitative evidence will be assessed by GRADE-CERQual approach for each identified theme.</p> <p>Data synthesis:</p> <p>Thematic analysis of the data will be conducted and findings presented.</p>
<b>Equalities</b>	No equality considerations over and above those stated in the equalities impact form are identified for this topic.

# 1 Appendix E: Search Strategies

## E.1.2 Providing information

### E.1.13 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	INFORMATION SEEKING BEHAVIOR/
35	exp CONSUMER HEALTH INFORMATION/
36	PATIENT EDUCATION AS TOPIC/

#	Searches
37	PARENTS/ed
38	PUBLICATIONS/
39	PAMPHLETS/
40	INTERNET/
41	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (information\$ or educat\$)).ti,ab.
42	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 (information\$ or educat\$)).ti,ab.
43	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
44	(information\$ adj3 (help\$ or support\$ or benefi\$ or hinder\$ or hindran\$ or barrier? or facilitat\$)).ti,ab.
45	(information\$ adj3 (program\$ or need\$ or requirement\$ or seek\$ or access\$ or dissem\$ or shar\$ or provision)).ti,ab.
46	(information\$ adj3 (type? or content? or method? or practical\$)).ti,ab.
47	((additional or extra) adj3 information).ti,ab.
48	or/34-47
49	9 and 33 and 48
50	limit 49 to english language
51	LETTER/
52	EDITORIAL/
53	NEWS/
54	exp HISTORICAL ARTICLE/
55	ANECDOTES AS TOPIC/
56	COMMENT/
57	CASE REPORT/
58	(letter or comment*).ti.
59	or/51-58
60	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
61	59 not 60
62	ANIMALS/ not HUMANS/
63	exp ANIMALS, LABORATORY/
64	exp ANIMAL EXPERIMENTATION/
65	exp MODELS, ANIMAL/
66	exp RODENTIA/
67	(rat or rats or mouse or mice).ti.
68	or/61-67
69	50 not 68

### E.1.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.

#	Searches
4	(p?ediatic\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (information\$ or educat\$)).ti,ab.
24	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 (information\$ or educat\$)).ti,ab.
25	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
26	(information\$ adj3 (help\$ or support\$ or benefi\$ or hinder\$ or hindran\$ or barrier? or facilitat\$)).ti,ab.
27	(information\$ adj3 (program\$ or need\$ or requirement\$ or seek\$ or access\$ or dissem\$ or shar\$ or provision)).ti,ab.
28	(information\$ adj3 (type? or content? or method? or practical\$)).ti,ab.
29	((additional or extra) adj3 information).ti,ab.
30	or/23-29
31	5 and 22 and 30

### E.1.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.

#	Searches
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab,kw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti,kw.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	INFORMATION SEEKING BEHAVIOR/
35	exp CONSUMER HEALTH INFORMATION/
36	PATIENT EDUCATION AS TOPIC/
37	PUBLICATIONS/
38	PAMPHLETS/
39	INTERNET/
40	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (information\$ or educat\$)).ti,ab,kw.
41	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 (information\$ or educat\$)).ti,ab.
42	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
43	(information\$ adj3 (help\$ or support\$ or benefi\$ or hinder\$ or hindran\$ or barrier? or facilitat\$)).ti,ab.
44	(information\$ adj3 (program\$ or need\$ or requirement\$ or seek\$ or access\$ or dissem\$ or shar\$ or provision)).ti,ab,kw.



#	Searches
45	(information\$ adj3 (type? or content? or method? or practical\$)).ti,ab.
46	((additional or extra) adj3 information).ti,ab.
47	or/34-46
48	9 and 33 and 47

### E.1.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx,kw.
12	dying.tw,tx,kw.
13	(end adj3 life).tw,tx.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
18	(last year of life or LYOL or life\$ end).tw,tx.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw,tx,kw.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.tw,tx,kw.
25	LIVING WILLS.kw.
26	living will?.tw,tx,kw.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).tw,tx,kw.
29	PALLIATIVE CARE.kw.
30	palliat\$.tw,tx,kw.
31	HOSPICE CARE.kw.
32	hospice?.tw,tx,kw.
33	or/10-32
34	INFORMATION SEEKING BEHAVIOR.kw.
35	CONSUMER HEALTH INFORMATION.kw.

#	Searches
36	PATIENT EDUCATION AS TOPIC.kw.
37	PUBLICATIONS.kw.
38	PAMPHLETS.kw.
39	INTERNET.kw.
40	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (information\$ or educat\$)).ti,ab,kw.
41	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 (information\$ or educat\$)).ti,ab,kw.
42	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab,kw.
43	(information\$ adj3 (help\$ or support\$ or benefi\$ or hinder\$ or hindran\$ or barrier? or facilitat\$)).ti,ab,kw.
44	(information\$ adj3 (program\$ or need\$ or requirement\$ or seek\$ or access\$ or dissem\$ or shar\$ or provision)).ti,ab,kw.
45	(information\$ adj3 (type? or content? or method? or practical\$)).ti,ab,kw.
46	((additional or extra) adj3 information).ti,ab,kw.
47	or/34-46
48	9 and 33 and 47

1

### E.1.52 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.

#	Searches
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.1.61 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	TERMINALLY ILL PATIENT/
11	TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
24	advance? directive?.ab,ti.
25	LIVING WILL/
26	living will?.ab,ti.

#	Searches
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE THERAPY/
30	CANCER PALLIATIVE THERAPY/
31	palliat\$.ti,ab.
32	HOSPICE CARE/
33	HOSPICE PATIENT/
34	hospice?.ab,ti.
35	or/10-34
36	INFORMATION/
37	CONSUMER HEALTH INFORMATION/
38	INFORMATION DISSEMINATION/
39	INFORMATION SEEKING/
40	*PATIENT EDUCATION/
41	*MEDICAL INFORMATION/
42	*PUBLICATION/
43	*INTERNET/
44	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (information\$ or educat\$)).ti,ab.
45	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 (information\$ or educat\$)).ti,ab.
46	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
47	(information\$ adj3 (help\$ or support\$ or benefi\$ or hinder\$ or hindran\$ or barrier? or facilitat\$)).ti,ab.
48	(information\$ adj3 (program\$ or need\$ or requirement\$ or seek\$ or access\$ or dissem\$ or shar\$ or provision)).ti,ab.
49	(information\$ adj3 (type? or content? or method? or practical\$)).ti,ab.
50	((additional or extra) adj3 information).ti,ab.
51	or/36-50
52	9 and 35 and 51
53	limit 52 to english language
54	letter.pt. or LETTER/
55	note.pt.
56	editorial.pt.
57	CASE REPORT/ or CASE STUDY/
58	(letter or comment*).ti.
59	or/54-58
60	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
61	59 not 60
62	ANIMAL/ not HUMAN/
63	NONHUMAN/
64	exp ANIMAL EXPERIMENT/
65	exp EXPERIMENTAL ANIMAL/

#	Searches
66	ANIMAL MODEL/
67	exp RODENT/
68	(rat or rats or mouse or mice).ti.
69	or/61-68
70	53 not 69

### E.1.71 Database: PsycInfo

#	Searches
1	adolescenc\$.ag.
2	(adolescenc\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,id,jw.
3	(child\$ or school\$ or preschool\$).ag.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,id,jw.
5	(infan\$ or neonat\$).ag.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies or p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,id,jw.
7	or/1-6
8	TERMINALLY ILL PATIENTS/
9	TERMINAL CANCER/
10	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
11	"DEATH AND DYING"/
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
22	ADVANCE DIRECTIVES/
23	advance? directive?.ab,ti.
24	living will?.ab,ti.
25	(terminal\$ adj3 (care\$ or caring)).ti,ab.
26	PALLIATIVE CARE/
27	palliat\$.ti,ab.
28	HOSPICE/
29	hospice?.ab,ti.
30	or/8-29
31	INFORMATION/
32	INFORMATION DISSEMINATION/
33	INFORMATION SEEKING/
34	CLIENT EDUCATION/

#	Searches
35	INTERNET/
36	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (information\$ or educat\$)).ti,ab.
37	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 (information\$ or educat\$)).ti,ab.
38	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
39	(information\$ adj3 (help\$ or support\$ or benefi\$ or hinder\$ or hindran\$ or barrier? or facilitat\$)).ti,ab.
40	(information\$ adj3 (program\$ or need\$ or requirement\$ or seek\$ or access\$ or dissem\$ or shar\$ or provision)).ti,ab.
41	(information\$ adj3 (type? or content? or method? or practical\$)).ti,ab.
42	((additional or extra) adj3 information).ti,ab.
43	or/31-42
44	7 and 30 and 43
45	limit 44 to english language
46	limit 45 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal" or "0130 peer-reviewed status unknown" or "0500 electronic collection")

### E.1.81 Database: CINAHL (Cumulative Index to Nursing and Allied Health Literature)

#	Searches
1	ADOLESCENCE/
2	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*).ti,ab,jw,nw.
3	CHILD/
4	CHILD, PRESCHOOL/
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*).ti,ab,jw,nw.
6	INFANT/
7	exp INFANT, NEWBORN/
8	(infan* or neonat* or newborn* or baby or babies).ti,ab,jw,nw.
9	PEDIATRICS/
10	PUBERTY/
11	(p*ediatric* or pubert* or prepubert* or pubescen* or prepubescen*).ti,ab,jw,nw.
12	or/1-11
13	TERMINALLY ILL PATIENTS/
14	((terminal* or final or advance* or incurable or life limit*) adj3 (ill* or disease* or condition*)).ti,ab.
15	dying.ti,ab.
16	(end adj3 life).ti,ab.
17	((approach* or close* or near* or imminent* or impending) adj3 death).ti,ab.
18	(Body adj2 (shut* down or shutting down or deteriorat*)).ti,ab.
19	(deathbed* or death bed* or passing away or passing on or expiring or expiration).ti,ab.
20	((last or final) adj1 (hour* or days* or minute*)).ti,ab.
21	(last year of life or LYOL or life* end).ti,ab.

#	Searches
22	(advance* stage* or final stage* or end stage* or last stage* or late stage* or terminal stage*).ti,ab.
23	((advanced or late or last or end or final or terminal) adj phase*).ti,ab.
24	RESUSCITATION ORDERS/
25	(resuscitat* adj3 (policies or policy or order* or decision* or withhold*).ti,ab.
26	ADVANCE DIRECTIVES/
27	advance* directive*.ti,ab.
28	LIVING WILLS/
29	living will*.ti,ab.
30	TERMINAL CARE/
31	(terminal* adj3 (care* or caring)).ti,ab.
32	PALLIATIVE CARE/
33	palliat*.ti,ab.
34	HOSPICE CARE/
35	hospice*.ti,ab.
36	or/13-35
37	CONSUMER HEALTH INFORMATION/
38	HEALTH INFORMATION/
39	INFORMATION SEEKING BEHAVIOR/
40	*PATIENT EDUCATION/
41	*INFORMATION RESOURCES/
42	PAMPHLETS/
43	INTERNET/
44	((client* or patient* or user* or carer* or consumer* or customer* or famil* or parent* or father* or mother* or caregiver*) adj3 (information* or educat*).ti,ab.
45	((pamphlet* or leaflet* or booklet* or manual* or brochure* or publication* or handout* or website* or web site* or web page* or webpage* or video* or dvd*) adj3 (information* or educat*).ti,ab.
46	((client* or patient* or user* or carer* or consumer* or customer* or famil* or parent* or father* or mother* or caregiver*) adj3 (pamphlet* or leaflet* or booklet* or manual* or brochure* or publication* or handout* or website* or web site* or web page* or webpage* or video* or dvd*).ti,ab.
47	(information* adj3 (help* or support* or benefi* or hinder* or hindran* or barrier* or facilitat*).ti,ab.
48	(information* adj3 (program* or need* or requirement* or seek* or access* or dissem* or shar* or provision)).ti,ab.
49	(information* adj3 (type* or content* or method* or practical*).ti,ab.
50	((additional or extra) adj3 information).ti,ab.
51	or/37-50
52	12 and 36 and 51 [Limit to: (Language English)]

## E.2.1 Communication

### E.2.1.2 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.

#	Searches
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	COMMUNICATION BARRIERS/
35	(communicat\$ adj3 (barrier? or facilitat\$)).ti,ab.
36	(communicat\$ adj3 (help\$ or unhelp\$ or un-help\$ or encourag\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or in-effect\$ or poor\$ or difficult\$)).ti,ab.
37	(communicat\$ adj3 (time? or timing? or initiat\$)).ti,ab.
38	or/34-37
39	9 and 33 and 38
40	COMMUNICATION/
41	HEALTH COMMUNICATION/
42	exp LANGUAGE/
43	exp NONVERBAL COMMUNICATION/
44	PERSUASIVE COMMUNICATION/



#	Searches
45	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab.
46	or/40-45
47	PHYSICIAN-PATIENT RELATIONS/
48	PROFESSIONAL-FAMILY RELATIONS/
49	PROFESSIONAL-PATIENT RELATIONS/
50	NURSE-PATIENT RELATIONS/
51	PHYSICIAN-PATIENT RELATIONS/
52	INTERPERSONAL RELATIONS/
53	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$) adj3 (relation\$ or skill? or rapport\$ or experience?)).ti,ab.
54	exp EDUCATION, PROFESSIONAL/
55	((medic\$ or profession\$) adj3 (educat\$ or train\$)).ti,ab.
56	(special\$ adj3 train\$).ti,ab.
57	SOCIAL SKILLS/
58	((social\$ or interpersonal\$) adj3 (skill? or abilit\$ or competen\$)).ti,ab.
59	DISCLOSURE/
60	TRUTH DISCLOSURE/
61	(disclos\$ or bad news).ti,ab.
62	TRUST/
63	trust\$.ti,ab.
64	NEGOTIATING/
65	(negot\$ or arbitrat\$ or mediat\$).ti,ab.
66	"DISSENT AND DISPUTES"/
67	(dissent\$ or disput\$ or disagre\$).ti,ab.
68	HEALTH KNOWLEDGE, ATTITUDES, PRACTICE/
69	exp "PATIENT ACCEPTANCE of HEALTH CARE"/
70	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 accept\$).ti,ab.
71	ATTITUDE OF HEALTH PERSONNEL/
72	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj3 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab.
73	"ATTITUDE TO DEATH"/
74	"ATTITUDE TO HEALTH"/
75	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (opinion\$ or attitude? or feel\$)).ti,ab.
76	CONSUMER PARTICIPATION/
77	RELIGION/
78	SOCIOECONOMIC FACTORS/
79	exp ETHNIC GROUPS/
80	exp CONTINENTAL POPULATION GROUPS/
81	CULTURAL CHARACTERISTICS/
82	CULTURAL DIVERSITY/
83	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ab,ti.
84	TRANSLATIONS/

#	Searches
85	TRANSLATING/
86	(translat\$ and english).ti,ab.
87	(translat\$ adj3 (language? or service?)).ti,ab.
88	(translation? or translator?).ti,ab.
89	exp COMMUNICATION DISORDERS/
90	((communicat\$ or language? or learn\$) adj3 (disabilit\$ or disorder? or dysfunction\$)).ti,ab.
91	or/47-90
92	9 and 33 and 46 and 91
93	39 or 92
94	limit 93 to english language
95	LETTER/
96	EDITORIAL/
97	NEWS/
98	exp HISTORICAL ARTICLE/
99	ANECDOTES AS TOPIC/
100	COMMENT/
101	CASE REPORT/
102	(letter or comment*).ti.
103	or/95-102
104	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
105	103 not 104
106	ANIMALS/ not HUMANS/
107	exp ANIMALS, LABORATORY/
108	exp ANIMAL EXPERIMENTATION/
109	exp MODELS, ANIMAL/
110	exp RODENTIA/
111	(rat or rats or mouse or mice).ti.
112	or/105-111
113	94 not 112

### E.2.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescenc\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescenc\$ or prepubescenc\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.

#	Searches
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(communicat\$ adj3 (barrier? or facilitat\$)).ti,ab.
24	(communicat\$ adj3 (help\$ or unhelp\$ or un-help\$ or encourag\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or in-effect\$ or poor\$ or difficult\$)).ti,ab.
25	(communicat\$ adj3 (time? or timing? or initiat\$)).ti,ab.
26	or/23-25
27	5 and 22 and 26
28	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab.
29	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$) adj3 (relation\$ or skill? or rapport\$ or experience?)).ti,ab.
30	((medic\$ or profession\$) adj3 (educat\$ or train\$)).ti,ab.
31	(special\$ adj3 train\$).ti,ab.
32	((social\$ or interpersonal\$) adj3 (skill? or abilit\$ or competen\$)).ti,ab.
33	(disclos\$ or bad news).ti,ab.
34	trust\$.ti,ab.
35	(negot\$ or arbitrat\$ or mediat\$).ti,ab.
36	(dissent\$ or disput\$ or disagre\$).ti,ab.
37	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 accept\$).ti,ab.
38	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj3 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab.
39	(attitude adj3 (death? or health\$)).ab,ti.
40	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (opinion\$ or attitude? or feel\$)).ti,ab.
41	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ab,ti.
42	(translat\$ and english).ti,ab.
43	(translat\$ adj3 (language? or service?)).ti,ab.
44	(translation? or translator?).ti,ab.
45	((communicat\$ or language? or learn\$) adj3 (disabilit\$ or disorder? or dysfunction\$)).ti,ab.
46	or/29-45
47	5 and 22 and 28 and 46
48	27 or 47

### E.2.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti,kw.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	COMMUNICATION BARRIERS/
35	(communicat\$ adj3 (barrier? or facilitat\$)).ti,ab,kw.
36	(communicat\$ adj3 (help\$ or unhelp\$ or un-help\$ or encourag\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or in-effect\$ or poor\$ or difficult\$)).ti,ab.
37	(communicat\$ adj3 (time? or timing? or initiat\$)).ti,ab.
38	or/34-37
39	9 and 33 and 38
40	COMMUNICATION/
41	HEALTH COMMUNICATION/

#	Searches
42	exp LANGUAGE/
43	exp NONVERBAL COMMUNICATION/
44	PERSUASIVE COMMUNICATION/
45	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab,kw.
46	or/40-45
47	PHYSICIAN-PATIENT RELATIONS/
48	PROFESSIONAL-FAMILY RELATIONS/
49	PROFESSIONAL-PATIENT RELATIONS/
50	NURSE-PATIENT RELATIONS/
51	PHYSICIAN-PATIENT RELATIONS/
52	INTERPERSONAL RELATIONS/
53	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$) adj3 (relation\$ or skill? or rapport\$ or experience?)).ti,ab,kw.
54	exp EDUCATION, PROFESSIONAL/
55	((medic\$ or profession\$) adj3 (educat\$ or train\$)).ti,ab,kw.
56	(special\$ adj3 train\$).ti,ab.
57	SOCIAL SKILLS/
58	((social\$ or interpersonal\$) adj3 (skill? or abilit\$ or competen\$)).ti,ab,kw.
59	DISCLOSURE/
60	TRUTH DISCLOSURE/
61	(disclos\$ or bad news).ti,ab,kw.
62	TRUST/
63	trust\$.ti,ab,kw.
64	NEGOTIATING/
65	(negot\$ or arbitrat\$ or mediat\$).ti,ab,kw.
66	"DISSENT AND DISPUTES"/
67	(dissent\$ or disput\$ or disagre\$).ti,ab,kw.
68	HEALTH KNOWLEDGE, ATTITUDES, PRACTICE/
69	exp "PATIENT ACCEPTANCE of HEALTH CARE"/
70	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 accept\$).ti,ab,kw.
71	ATTITUDE OF HEALTH PERSONNEL/
72	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj3 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab,kw.
73	"ATTITUDE TO DEATH"/
74	"ATTITUDE TO HEALTH"/
75	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (opinion\$ or attitude? or feel\$)).ti,ab.
76	CONSUMER PARTICIPATION/
77	RELIGION/
78	SOCIOECONOMIC FACTORS/
79	exp ETHNIC GROUPS/
80	exp CONTINENTAL POPULATION GROUPS/
81	CULTURAL CHARACTERISTICS/
82	CULTURAL DIVERSITY/

#	Searches
83	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ab,ti,kw.
84	TRANSLATIONS/
85	TRANSLATING/
86	(translat\$ and english).ti,ab.
87	(translat\$ adj3 (language? or service?)).ti,ab.
88	(translation? or translator?).ti,ab,kw.
89	exp COMMUNICATION DISORDERS/
90	((communicat\$ or language? or learn\$) adj3 (disabilit\$ or disorder? or dysfunction\$)).ti,ab,kw.
91	or/47-90
92	9 and 33 and 46 and 91
93	39 or 92

#### E.2.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx,kw.
12	dying.tw,tx.
13	(end adj3 life).tw,tx.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
18	(last year of life or LYOL or life\$ end).tw,tx.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw,tx,kw.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.tw,tx,kw.
25	LIVING WILLS.kw.
26	living will?.tw,tx,kw.
27	TERMINAL CARE.kw.

#	Searches
28	(terminal\$ adj3 (care\$ or caring)).tw,tx,kw.
29	PALLIATIVE CARE.kw.
30	palliat\$.tw,tx,kw.
31	HOSPICE CARE.kw.
32	hospice?.tw,tx,kw.
33	or/10-32
34	COMMUNICATION BARRIERS.kw.
35	(communicat\$ adj3 (barrier? or facilitat\$)).ti,ab,kw.
36	(communicat\$ adj3 (help\$ or unhelp\$ or un-help\$ or encourag\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or in-effect\$ or poor\$ or difficult\$)).ti,ab,kw.
37	(communicat\$ adj3 (time? or timing? or initiat\$)).ti,ab,kw.
38	or/34-37
39	9 and 33 and 38
40	COMMUNICATION.kw.
41	HEALTH COMMUNICATION.kw.
42	LANGUAGE.kw.
43	NONVERBAL COMMUNICATION.kw.
44	PERSUASIVE COMMUNICATION.kw.
45	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab,kw.
46	or/40-45
47	PHYSICIAN-PATIENT RELATIONS.kw.
48	PROFESSIONAL-FAMILY RELATIONS.kw.
49	PROFESSIONAL-PATIENT RELATIONS.kw.
50	NURSE-PATIENT RELATIONS.kw.
51	PHYSICIAN-PATIENT RELATIONS.kw.
52	INTERPERSONAL RELATIONS.kw.
53	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$) adj3 (relation\$ or skill? or rapport\$ or experience?)).ti,ab,kw.
54	EDUCATION, PROFESSIONAL.kw.
55	((medic\$ or profession\$) adj3 (educat\$ or train\$)).ti,ab,kw.
56	(special\$ adj3 train\$).ti,ab,kw.
57	SOCIAL SKILLS.kw.
58	((social\$ or interpersonal\$) adj3 (skill? or abilit\$ or competen\$)).ti,ab,kw.
59	DISCLOSURE.kw.
60	TRUTH DISCLOSURE.kw.
61	(disclos\$ or bad news).ti,ab,kw.
62	TRUST.kw.
63	trust\$.ti,ab,kw.
64	NEGOTIATING.kw.
65	(negot\$ or arbitrat\$ or mediat\$).ti,ab,kw.
66	"DISSENT AND DISPUTES".kw.
67	(dissent\$ or disput\$ or disagree\$).ti,ab,kw.
68	HEALTH KNOWLEDGE, ATTITUDES, PRACTICE.kw.
69	"PATIENT ACCEPTANCE of HEALTH CARE".kw.

#	Searches
70	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 accept\$).ti,ab,kw.
71	ATTITUDE OF HEALTH PERSONNEL.kw.
72	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj3 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab,kw.
73	"ATTITUDE TO DEATH".kw.
74	"ATTITUDE TO HEALTH".kw.
75	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (opinion\$ or attitude? or feel\$)).ti,ab,kw.
76	CONSUMER PARTICIPATION.kw.
77	RELIGION.kw.
78	SOCIOECONOMIC FACTORS.kw.
79	ETHNIC GROUPS.kw.
80	CONTINENTAL POPULATION GROUPS.kw.
81	CULTURAL CHARACTERISTICS.kw.
82	CULTURAL DIVERSITY.kw.
83	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ti,ab,kw.
84	TRANSLATIONS.kw.
85	TRANSLATING.kw.
86	(translat\$ and english).ti,ab,kw.
87	(translat\$ adj3 (language? or service?)).ti,ab,kw.
88	(translation? or translator?).ti,ab,kw.
89	COMMUNICATION DISORDERS.kw.
90	((communicat\$ or language? or learn\$) adj3 (disabilit\$ or disorder? or dysfunction\$)).ti,ab,kw.
91	or/47-90
92	9 and 33 and 46 and 91
93	39 or 92

### E.2.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.



#	Searches
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.2.61 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	TERMINALLY ILL PATIENT/
11	TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.

#	Searches
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
24	advance? directive?.ab,ti.
25	LIVING WILL/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE THERAPY/
30	CANCER PALLIATIVE THERAPY/
31	palliat\$.ti,ab.
32	HOSPICE CARE/
33	HOSPICE PATIENT/
34	hospice?.ab,ti.
35	or/10-34
36	COMMUNICATION DISORDER/
37	(communicat\$ adj3 (barrier? or facilitat\$)).ti,ab.
38	(communicat\$ adj3 (help\$ or unhelp\$ or un-help\$ or encourag\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or in-effect\$ or poor\$ or difficult\$)).ti,ab.
39	(communicat\$ adj3 (time? or timing? or initiat\$)).ti,ab.
40	or/36-39
41	9 and 35 and 40
42	INTERPERSONAL COMMUNICATION/
43	exp LANGUAGE ABILITY/
44	exp VERBAL COMMUNICATION/
45	exp NONVERBAL COMMUNICATION/
46	PERSUASIVE COMMUNICATION/
47	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab.
48	or/42-47
49	HUMAN RELATION/
50	DOCTOR PATIENT RELATION/
51	NURSE PATIENT RELATIONSHIP/
52	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$) adj3 (relation\$ or skill? or rapport\$ or experience?)).ti,ab.
53	exp MEDICAL EDUCATION/
54	((medic\$ or profession\$) adj3 (educat\$ or train\$)).ti,ab.
55	(special\$ adj3 train\$).ti,ab.
56	SOCIAL ADAPTATION/
57	((social\$ or interpersonal\$) adj3 (skill? or abilit\$ or competen\$)).ti,ab.
58	(disclos\$ or bad news).ti,ab.
59	TRUST/
60	trust\$.ti,ab.
61	(negot\$ or arbitrat\$ or mediat\$).ti,ab.
62	CONFLICT/

#	Searches
63	(dissent\$ or disput\$ or disagre\$).ti,ab.
64	exp PATIENT ATTITUDE/
65	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 accept\$).ti,ab.
66	exp HEALTH PERSONNEL ATTITUDE/
67	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj3 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab.
68	ATTITUDE TO DEATH/
69	ATTITUDE TO HEALTH/
70	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (opinion\$ or attitude? or feel\$)).ti,ab.
71	RELIGION/
72	SOCIOECONOMICS/
73	exp "ETHNIC OR RACIAL ASPECTS"/
74	ETHNIC GROUP/
75	CULTURAL COMPETENCE/
76	CULTURAL SENSITIVITY/
77	CULTURAL BIAS/
78	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ab,ti.
79	"TRANSLATING (LANGUAGE)"/
80	(translat\$ and english).ti,ab.
81	(translat\$ adj3 (language? or service?)).ti,ab.
82	(translation? or translator?).ti,ab.
83	exp COMMUNICATION DISORDERS/
84	((communicat\$ or language? or learn\$) adj3 (disabilit\$ or disorder? or dysfunction\$)).ti,ab.
85	or/49-84
86	9 and 35 and 48 and 85
87	41 or 86
88	limit 87 to english language
89	letter.pt. or LETTER/
90	note.pt.
91	editorial.pt.
92	CASE REPORT/ or CASE STUDY/
93	(letter or comment*).ti.
94	or/89-93
95	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
96	94 not 95
97	ANIMAL/ not HUMAN/
98	NONHUMAN/
99	exp ANIMAL EXPERIMENT/
100	exp EXPERIMENTAL ANIMAL/
101	ANIMAL MODEL/
102	exp RODENT/
103	(rat or rats or mouse or mice).ti.
104	or/96-103

#	Searches
105	88 not 104

### E.2.71 Database: PsycInfo

#	Searches
1	adolescen\$.ag.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,id,jw.
3	(child\$ or school\$ or preschool\$).ag.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,id,jw.
5	(infan\$ or neonat\$).ag.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies or p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,id,jw.
7	or/1-6
8	TERMINALLY ILL PATIENTS/
9	TERMINAL CANCER/
10	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
11	"DEATH AND DYING"/
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
22	ADVANCE DIRECTIVES/
23	advance? directive?.ab,ti.
24	living will?.ab,ti.
25	(terminal\$ adj3 (care\$ or caring)).ti,ab.
26	PALLIATIVE CARE/
27	palliat\$.ti,ab.
28	HOSPICE/
29	hospice?.ab,ti.
30	or/8-29
31	COMMUNICATION BARRIERS/
32	(communicat\$ adj3 (barrier? or facilitat\$)).ti,ab.
33	(communicat\$ adj3 (help\$ or unhelp\$ or un-help\$ or encourag\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or in-effect\$ or poor\$ or difficult\$)).ti,ab.
34	(communicat\$ adj3 (time? or timing? or initiat\$)).ti,ab.
35	or/31-34
36	7 and 30 and 35
37	COMMUNICATION/
38	exp LANGUAGE/

#	Searches
39	exp VERBAL COMMUNICATION/
40	exp NONVERBAL COMMUNICATION/
41	PERSUASIVE COMMUNICATION/
42	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab.
43	or/37-42
44	INTERPERSONAL RELATIONSHIPS/
45	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$) adj3 (relation\$ or skill? or rapport\$ or experience?)).ti,ab.
46	exp MEDICAL EDUCATION/
47	((medic\$ or profession\$) adj3 (educat\$ or train\$)).ti,ab.
48	(special\$ adj3 train\$).ti,ab.
49	SOCIAL SKILLS/
50	((social\$ or interpersonal\$) adj3 (skill? or abilit\$ or competen\$)).ti,ab.
51	(disclos\$ or bad news).ti,ab.
52	trust\$.ti,ab.
53	NEGOTIATION/
54	(negot\$ or arbitrat\$ or mediat\$).ti,ab.
55	(dissent\$ or disput\$ or disagree\$).ti,ab.
56	HEALTH KNOWLEDGE/
57	CLIENT ATTITUDES/
58	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 accept\$).ti,ab.
59	HEALTH PERSONNEL ATTITUDE/
60	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj3 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab.
61	DEATH ATTITUDES/
62	HEALTH ATTITUDES/
63	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (opinion\$ or attitude? or feel\$)).ti,ab.
64	CLIENT PARTICIPATION/
65	RELIGION/
66	SOCIOECONOMIC STATUS/
67	exp SOCIOCULTURAL FACTORS/
68	"RACIAL AND ETHNIC DIFFERENCES"/
69	"RACIAL AND ETHNIC ATTITUDES"/
70	"RACIAL AND ETHNIC GROUPS"/
71	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ab,ti.
72	FOREIGN LANGUAGE TRANSLATION/
73	INTERPRETERS/
74	(translat\$ and english).ti,ab.
75	(translat\$ adj3 (language? or service?)).ti,ab.
76	(translation? or translator?).ti,ab.
77	interpreter?.ti,ab.
78	exp COMMUNICATION DISORDERS/

#	Searches
79	((communicat\$ or language? or learn\$) adj3 (disabilit\$ or disorder? or dysfunction\$)).ti,ab.
80	or/44-79
81	7 and 30 and 43 and 80
82	36 or 81
83	limit 82 to english language
84	limit 83 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal" or "0130 peer-reviewed status unknown" or "0500 electronic collection")

### E.2.81 Database: CINAHL (Cumulative Index to Nursing and Allied Health Literature)

#	Searches
1	ADOLESCENCE/
2	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*).ti,ab.
3	CHILD/
4	CHILD, PRESCHOOL/
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*).ti,ab.
6	INFANT/
7	exp INFANT, NEWBORN/
8	(infan* or neonat* or newborn* or baby or babies).ti,ab.
9	PEDIATRICS/
10	PUBERTY/
11	(pediatric* or paediatric* or pubert* or prepubert* or pubescen* or prepubescen*).ti,ab.
12	or/1-11
13	TERMINALLY ILL PATIENTS/
14	((terminal* or final or advance* or incurable or "life limit*") adj3 (ill* or disease* or condition*)).ti,ab.
15	dying.ti,ab.
16	(end adj3 life).ti,ab.
17	((approach* or close* or near* or imminent* or impending) adj3 death).ti,ab.
18	(Body adj2 ("shut* down" or "shutting down" or deteriorat*)).ti,ab.
19	(deathbed* or "death bed*" or "passing away" or "passing on" or expiring or expiration).ti,ab.
20	((last or final) adj1 (hour* or days* or minute*)).ti,ab.
21	(last year of life or LYOL or life* end).ab,ti.
22	(advance* stage* or final stage* or end stage* or last stage* or late stage* or terminal stage*).ti,ab.
23	((advanced or late or last or end or final or terminal) adj phase*).ab,ti.
24	RESUSCITATION ORDERS/
25	(resuscitat* adj3 (policies or policy or order* or decision* or withhold*)).ab,ti.
26	ADVANCE DIRECTIVES/
27	advance* directive*.ab,ti.
28	LIVING WILLS/
29	living will*.ab,ti.
30	TERMINAL CARE/
31	(terminal* adj3 (care* or caring)).ti,ab.
32	PALLIATIVE CARE/
33	palliat*.ti,ab.

#	Searches
34	HOSPICE CARE/
35	hospice*.ab,ti.
36	or/13-35
37	COMMUNICATION BARRIERS/
38	(communicat* adj3 (barrier* or facilitat*)).ti,ab.
39	(communicat* adj3 (help* or unhelp* or un-help* or encourag* or prevent* or good or bad* or effect* or ineffect* or in-effect* or poor* or difficult*)).ti,ab.
40	(communicat* adj3 (time* or timing* or initiat*)).ti,ab.
41	or/37-40
42	12 and 36 and 41
43	COMMUNICATION/
44	exp LANGUAGE/
45	exp NONVERBAL COMMUNICATION/
46	PERSUASIVE COMMUNICATION/
47	(communicat* or talk* or converse* or conversation* or language* or read* or reading or speech* or speak* or translat* or write or writing or written or terminolog* or semantic* or vocab* or verbal* or nonverbal* or non-verbal* or online or web-based).ti,ab.
48	or/43-47
49	PHYSICIAN-PATIENT RELATIONS/
50	PROFESSIONAL-FAMILY RELATIONS/
51	PROFESSIONAL-PATIENT RELATIONS/
52	NURSE-PATIENT RELATIONS/
53	INTERPERSONAL RELATIONS/
54	((physician* or doctor* or patient* or profession* or personnel or famil* or nurs*) adj3 (relation* or skill* or rapport* or experience*)).ti,ab.
55	exp *EDUCATION/
56	((medic* or profession*) adj3 (educat* or train*)).ti,ab.
57	(special* adj3 train*).ti,ab.
58	SOCIAL SKILLS/
59	((social* or interpersonal*) adj3 (skill* or abilit* or competen*)).ti,ab.
60	TRUTH DISCLOSURE/
61	(disclos* or "bad news").ti,ab.
62	TRUST/
63	trust*.ti,ab.
64	NEGOTIATION/
65	(negot* or arbitrat* or mediat*).ti,ab.
66	DISSENT AND DISPUTES/
67	(dissent* or disput* or disagre*).ti,ab.
68	PATIENT ATTITUDES/
69	((client* or patient* or user* or carer* or consumer* or customer* or famil* or parent* or father* or mother* or caregiver*) adj3 accept*).ti,ab.
70	ATTITUDE OF HEALTH PERSONNEL/
71	((physician* or doctor* or profession* or personnel or nurs* or patient*) adj3 (opinion* or attitude* or feel* or empath*)).ti,ab.
72	ATTITUDE TO DEATH/
73	ATTITUDE TO HEALTH/

#	Searches
74	((client* or patient* or user* or carer* or consumer* or customer* or famil* or parent* or father* or mother* or caregiver*) adj3 (opinion* or attitude* or feel*)).ti,ab.
75	CONSUMER PARTICIPATION/
76	RELIGION AND RELIGIONS/
77	SOCIOECONOMIC FACTORS/
78	exp ETHNIC GROUPS/
79	CULTURAL VALUES/
80	CULTURAL DIVERSITY/
81	CULTURAL BIAS/
82	CULTURAL COMPETENCE/
83	CULTURAL SENSITIVITY/
84	((demog* or social* or socio-economic* or socioeconomic* or race or racial* or ethnic* or cultur* or linguist* or religi*) adj5 (factor* or reason* or determin*)).ab,ti.
85	TRANSLATIONS/
86	INTERPRETER SERVICES/
87	(translat* and english).ti,ab.
88	(translat* adj3 (language* or service*)).ti,ab.
89	(translation* or translator*).ti,ab.
90	exp COMMUNICATIVE DISORDERS/
91	((communicat* or language* or learn*) adj3 (disabilit* or disorder* or dysfunction*)).ti,ab.
92	or/49-91
93	12 AND 36 AND 48 AND 92
94	42 or 93 [Limit to: (Language English)]

## E.3.1 Advance Care Plan

### E.3.1.2 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.



#	Searches
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	TERMINAL CARE/
22	(terminal\$ adj3 (care\$ or caring)).ti,ab.
23	PALLIATIVE CARE/
24	palliat\$.ti,ab.
25	HOSPICE CARE/
26	hospice?.ab,ti.
27	or/10-26
28	PATIENT CARE PLANNING/
29	(care plan\$ adj2 patient?).ab,ti.
30	(plan\$ adj2 patient? care).ab,ti.
31	ADVANCE CARE PLANNING/
32	((advance or advanced) adj2 care plan\$).ab,ti.
33	ADVANCE DIRECTIVES/
34	advance? directive?.ab,ti.
35	LIVING WILLS/
36	living will?.ab,ti.
37	CASE MANAGEMENT/
38	case management.ab,ti.
39	CRITICAL PATHWAYS/
40	(critical adj2 (path? or pathway?)).ab,ti.
41	(parallel adj2 plan\$).ab,ti.
42	RESUSCITATION ORDERS/
43	(resuscitat\$ adj2 (policies or policy or order? or decision? or attempt\$)).ab,ti.
44	WITHHOLDING TREATMENT/
45	EUTHANASIA, PASSIVE/
46	((Withhold\$ or withdraw\$) adj2 treatment?).ab,ti.
47	or/28-46
48	DECISION MAKING/
49	((make? or making or made) adj3 (decision? or decid\$)).ab,ti.
50	48 or 49
51	exp INTERPERSONAL RELATIONS/
52	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$ or interpersonal\$ or inter personal\$ or intergenerational\$ or inter generational\$ or interprofessional\$ or inter professional\$) adj2 (relation\$ or skill? or rapport\$)).ti,ab.
53	((social\$ or interpersonal\$ or inter personal\$) adj2 (skill? or abilit\$ or competen\$)).ti,ab.
54	trust\$.ti,ab.
55	(negot\$ or arbitrat\$ or mediat\$ or dissent\$ or disput\$ or disagre\$).ti,ab.
56	(famil\$ adj2 (involv\$ or conflict\$ or factor?)).ti,ab.
57	exp EDUCATION, PROFESSIONAL/
58	((medic\$ or profession\$) adj2 (educat\$ or train\$)).ti,ab.
59	"PATIENT ACCEPTANCE OF HEALTH CARE"/

#	Searches
60	PATIENT PARTICIPATION/
61	PATIENT SATISFACTION/
62	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (accept\$ or participat\$ or satisf\$)).ti,ab.
63	ATTITUDE OF HEALTH PERSONNEL/
64	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj2 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab.
65	"ATTITUDE TO DEATH"/
66	"ATTITUDE TO HEALTH"/
67	HEALTH KNOWLEDGE, ATTITUDES, PRACTICE/
68	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (opinion\$ or attitude? or feel\$)).ti,ab.
69	REFUSAL TO TREAT/
70	TREATMENT REFUSAL/
71	(refus\$ adj2 treat\$).ab,ti.
72	RELIGION/
73	SOCIOECONOMIC FACTORS/
74	exp ETHNIC GROUPS/
75	exp CONTINENTAL POPULATION GROUPS/
76	CULTURAL CHARACTERISTICS/
77	CULTURAL DIVERSITY/
78	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj2 (factor? or reason? or determin\$ or barrier? or facilitat\$)).ab,ti.
79	COMMUNICATION BARRIERS/
80	(communicat\$ adj2 (barrier? or facilitat\$)).ti,ab.
81	((communicat\$ or informat\$) adj2 (help\$ or unhelp\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or poor\$ or difficult\$)).ti,ab.
82	TRANSLATIONS/
83	TRANSLATING/
84	(translat\$ or interpret\$).ti,ab.
85	exp COMMUNICATION DISORDERS/
86	((communicat\$ or language? or learn\$) adj2 (disabilit\$ or disorder? or dysfunction\$)).ti,ab.
87	MENTAL COMPETENCY/
88	(mental\$ adj2 (competen\$ or incompeten\$)).ti,ab.
89	INFORMED CONSENT/
90	INFORMED CONSENT BY MINORS/
91	(informed adj2 consent\$).ti,ab.
92	((involv\$ or includ\$ or inclusive\$) adj2 (child\$ or minor\$ or young person? or young people or teenage\$)).ti,ab.
93	TIME FACTORS/
94	timing.ti,ab.
95	UNCERTAINTY/
96	(uncertain\$ or un-certain\$).ti,ab.
97	or/51-96
98	9 and 27 and 47 and 50
99	9 and 27 and 47 and 97

#	Searches
100	98 or 99
101	ADVANCE DIRECTIVE ADHERENCE/
102	(directive? adj2 (adhere\$ or compl\$)).ab,ti.
103	101 or 102
104	9 and 27 and 103
105	100 or 104
106	limit 105 to english language
107	LETTER/
108	EDITORIAL/
109	NEWS/
110	exp HISTORICAL ARTICLE/
111	ANECDOTES AS TOPIC/
112	COMMENT/
113	CASE REPORT/
114	(letter or comment*).ti.
115	or/107-114
116	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
117	115 not 116
118	ANIMALS/ not HUMANS/
119	exp ANIMALS, LABORATORY/
120	exp ANIMAL EXPERIMENTATION/
121	exp MODELS, ANIMAL/
122	exp RODENTIA/
123	(rat or rats or mouse or mice).ti.
124	or/117-123
125	106 not 124

### E.3.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.

#	Searches
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(terminal\$ adj3 (care\$ or caring)).ti,ab.
17	palliat\$.ti,ab.
18	hospice?.ab,ti.
19	or/6-18
20	(care plan\$ adj2 patient?).ab,ti.
21	(plan\$ adj2 patient? care).ab,ti.
22	((advance or advanced) adj2 care plan\$).ab,ti.
23	advance? directive?.ab,ti.
24	living will?.ab,ti.
25	case management.ab,ti.
26	(critical adj2 (path? or pathway?)).ab,ti.
27	(parallel adj2 plan\$).ab,ti.
28	(resuscitat\$ adj2 (policies or policy or order? or decision? or attempt\$)).ab,ti.
29	((Withhold\$ or withdraw\$) adj2 treatment?).ab,ti.
30	or/20-29
31	((make? or making or made) adj3 (decision? or decid\$)).ab,ti.
32	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$ or interpersonal\$ or inter personal\$ or intergenerational\$ or inter generational\$ or interprofessional\$ or inter professional\$) adj2 (relation\$ or skill? or rapport\$)).ti,ab.
33	((social\$ or interpersonal\$ or inter personal\$) adj2 (skill? or abilit\$ or competen\$)).ti,ab.
34	trust\$.ti,ab.
35	(negot\$ or arbitrat\$ or mediat\$ or dissent\$ or disput\$ or disagree\$).ti,ab.
36	(famil\$ adj2 (involv\$ or conflict\$ or factor?)).ti,ab.
37	((medic\$ or profession\$) adj2 (educat\$ or train\$)).ti,ab.
38	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (accept\$ or participat\$ or satisf\$)).ti,ab.
39	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj2 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab.
40	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (opinion\$ or attitude? or feel\$)).ti,ab.
41	(refus\$ adj2 treat\$).ab,ti.
42	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj2 (factor? or reason? or determin\$ or barrier? or facilitat\$)).ab,ti.
43	(communicat\$ adj2 (barrier? or facilitat\$)).ti,ab.
44	((communicat\$ or informat\$) adj2 (help\$ or unhelp\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or poor\$ or difficult\$)).ti,ab.
45	(translat\$ or interpret\$).ti,ab.
46	((communicat\$ or language? or learn\$) adj2 (disabilit\$ or disorder? or dysfunction\$)).ti,ab.
47	(mental\$ adj2 (competen\$ or incompeten\$)).ti,ab.
48	(informed adj2 consent\$).ti,ab.
49	((involv\$ or includ\$ or inclusive\$) adj2 (child\$ or minor\$ or young person? or young people or teenage\$)).ti,ab.
50	timing.ti,ab.
51	(uncertain\$ or un-certain\$).ti,ab.
52	or/32-51
53	5 and 19 and 30 and 31

#	Searches
54	5 and 19 and 30 and 52
55	53 or 54
56	(directive? adj2 (adhere\$ or compl\$)).ab,ti.
57	5 and 19 and 56
58	55 or 57

### E.3.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	TERMINAL CARE/
22	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
23	PALLIATIVE CARE/
24	palliat\$.ti,ab,kw.
25	HOSPICE CARE/
26	hospice?.ab,ti,kw.
27	or/10-26
28	PATIENT CARE PLANNING/
29	(care plan\$ adj2 patient?).ab,ti.
30	(plan\$ adj2 patient? care).ab,ti,kw.
31	ADVANCE CARE PLANNING/
32	((advance or advanced) adj2 care plan\$).ab,ti,kw.
33	ADVANCE DIRECTIVES/
34	advance? directive?.ab,ti,kw.
35	LIVING WILLS/

#	Searches
36	living will?.ab,ti,kw.
37	CASE MANAGEMENT/
38	case management.ab,ti,kw.
39	CRITICAL PATHWAYS/
40	(critical adj2 (path? or pathway?)).ab,ti,kw.
41	(parallel adj2 plan\$).ab,ti.
42	RESUSCITATION ORDERS/
43	(resuscitat\$ adj2 (policies or policy or order? or decision? or attempt\$)).ab,ti,kw.
44	WITHHOLDING TREATMENT/
45	EUTHANASIA, PASSIVE/
46	((Withhold\$ or withdraw\$) adj2 treatment?).ab,ti,kw.
47	or/28-46
48	DECISION MAKING/
49	((make? or making or made) adj3 (decision? or decid\$)).ab,ti,kw.
50	48 or 49
51	exp INTERPERSONAL RELATIONS/
52	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$ or interpersonal\$ or inter personal\$ or intergenerational\$ or inter generational\$ or interprofessional\$ or inter professional\$) adj2 (relation\$ or skill? or rapport\$)).ti,ab,kw.
53	((social\$ or interpersonal\$ or inter personal\$) adj2 (skill? or abilit\$ or competen\$)).ti,ab,kw.
54	trust\$.ti,ab,kw.
55	(negot\$ or arbitrat\$ or mediat\$ or dissent\$ or disput\$ or disagre\$).ti,ab,kw.
56	(famil\$ adj2 (involv\$ or conflict\$ or factor?)).ti,ab,kw.
57	exp EDUCATION, PROFESSIONAL/
58	((medic\$ or profession\$) adj2 (educat\$ or train\$)).ti,ab,kw.
59	"PATIENT ACCEPTANCE OF HEALTH CARE"/
60	PATIENT PARTICIPATION/
61	PATIENT SATISFACTION/
62	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (accept\$ or participat\$ or satisf\$)).ti,ab,kw.
63	ATTITUDE OF HEALTH PERSONNEL/
64	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj2 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab,kw.
65	"ATTITUDE TO DEATH"/
66	"ATTITUDE TO HEALTH"/
67	HEALTH KNOWLEDGE, ATTITUDES, PRACTICE/
68	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (opinion\$ or attitude? or feel\$)).ti,ab.
69	REFUSAL TO TREAT/
70	TREATMENT REFUSAL/
71	(refus\$ adj2 treat\$).ab,ti,kw.
72	RELIGION/
73	SOCIOECONOMIC FACTORS/
74	exp ETHNIC GROUPS/
75	exp CONTINENTAL POPULATION GROUPS/
76	CULTURAL CHARACTERISTICS/
77	CULTURAL DIVERSITY/

#	Searches
78	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj2 (factor? or reason? or determin\$ or barrier? or facilitat\$)).ab,ti,kw.
79	COMMUNICATION BARRIERS/
80	(communicat\$ adj2 (barrier? or facilitat\$)).ti,ab,kw.
81	((communicat\$ or informat\$) adj2 (help\$ or unhelp\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or poor\$ or difficult\$)).ti,ab.
82	TRANSLATIONS/
83	TRANSLATING/
84	(translat\$ or interpret\$).ti,ab,kw.
85	exp COMMUNICATION DISORDERS/
86	((communicat\$ or language? or learn\$) adj2 (disabilit\$ or disorder? or dysfunction\$)).ti,ab,kw.
87	MENTAL COMPETENCY/
88	(mental\$ adj2 (competen\$ or incompeten\$)).ti,ab,kw.
89	INFORMED CONSENT/
90	INFORMED CONSENT BY MINORS/
91	(informed adj2 consent\$).ti,ab,kw.
92	((involv\$ or includ\$ or inclusive\$) adj2 (child\$ or minor\$ or young person? or young people or teenage\$)).ti,ab.
93	TIME FACTORS/
94	timing.ti,ab.
95	UNCERTAINTY/
96	(uncertain\$ or un-certain\$).ti,ab,kw.
97	or/51-96
98	9 and 27 and 47 and 50
99	9 and 27 and 47 and 97
100	98 or 99
101	ADVANCE DIRECTIVE ADHERENCE/
102	(directive? adj2 (adhere\$ or compl\$)).ab,ti,kw.
103	101 or 102
104	9 and 27 and 103
105	100 or 104

### E.3.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescenc\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.

#	Searches
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx.
12	dying.tw,tx.
13	(end adj3 life).tw,tx.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
18	(last year of life or LYOL or life\$ end).tw,tx.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
21	TERMINAL CARE.kw.
22	(terminal\$ adj3 (care\$ or caring)).tw,tx.
23	PALLIATIVE CARE.kw.
24	palliat\$.tw,tx.
25	HOSPICE CARE.kw.
26	hospice?.tw,tx.
27	or/10-26
28	PATIENT CARE PLANNING.kw.
29	(care plan\$ adj2 patient?).tw,tx.
30	(plan\$ adj2 patient? care).tw,tx.
31	ADVANCE CARE PLANNING.kw.
32	((advance or advanced) adj2 care plan\$).tw,tx.
33	ADVANCE DIRECTIVES.kw.
34	advance? directive?.tw,tx.
35	LIVING WILLS.kw.
36	living will?.tw,tx.
37	CASE MANAGEMENT.kw.
38	case management.tw,tx.
39	CRITICAL PATHWAYS.kw.
40	(critical adj2 (path? or pathway?)).tw,tx.
41	(parallel adj2 plan\$).tw,tx.
42	RESUSCITATION ORDERS.kw.
43	(resuscitat\$ adj2 (policies or policy or order? or decision? or attempt\$)).tw,tx.
44	WITHHOLDING TREATMENT.kw.
45	EUTHANASIA, PASSIVE.kw.
46	((Withhold\$ or withdraw\$) adj2 treatment?).tw,tx.
47	or/28-46
48	DECISION MAKING.kw.
49	((make? or making or made) adj3 (decision? or decid\$)).tw,tx.
50	48 or 49
51	INTERPERSONAL RELATIONS.kw.
52	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$ or interpersonal\$ or inter personal\$ or intergenerational\$ or inter generational\$ or interprofessional\$ or inter professional\$) adj2 (relation\$ or skill? or rapport\$)).tw,tx.



#	Searches
53	((social\$ or interpersonal\$ or inter personal\$) adj2 (skill? or abilit\$ or competen\$)).tw,tx.
54	trust\$.tw,tx.
55	(negot\$ or arbitrat\$ or mediat\$ or dissent\$ or disput\$ or disagre\$).tw,tx.
56	(famil\$ adj2 (involv\$ or conflict\$ or factor?)).tw,tx.
57	EDUCATION, PROFESSIONAL.kw.
58	((medic\$ or profession\$) adj2 (educat\$ or train\$)).tw,tx.
59	PATIENT ACCEPTANCE OF HEALTH CARE.kw.
60	PATIENT PARTICIPATION.kw.
61	PATIENT SATISFACTION.kw.
62	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (accept\$ or participat\$ or satisf\$)).tw,tx.
63	ATTITUDE OF HEALTH PERSONNEL.kw.
64	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj2 (opinion\$ or attitude? or feel\$ or empath\$)).tw,tx.
65	ATTITUDE TO DEATH.kw.
66	ATTITUDE TO HEALTH.kw.
67	HEALTH KNOWLEDGE, ATTITUDES, PRACTICE.kw.
68	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (opinion\$ or attitude? or feel\$)).tw,tx.
69	REFUSAL TO TREAT.kw.
70	TREATMENT REFUSAL.kw.
71	(refus\$ adj2 treat\$).tw,tx.
72	RELIGION.kw.
73	SOCIOECONOMIC FACTORS.kw.
74	ETHNIC GROUPS.kw.
75	CONTINENTAL POPULATION GROUPS.kw.
76	CULTURAL CHARACTERISTICS.kw.
77	CULTURAL DIVERSITY.kw.
78	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj2 (factor? or reason? or determin\$ or barrier? or facilitat\$)).tw,tx.
79	COMMUNICATION BARRIERS.kw.
80	(communicat\$ adj2 (barrier? or facilitat\$)).tw,tx.
81	((communicat\$ or informat\$) adj2 (help\$ or unhelp\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or poor\$ or difficult\$)).tw,tx.
82	TRANSLATIONS.kw.
83	TRANSLATING.kw.
84	(translat\$ or interpret\$).tw,tx.
85	COMMUNICATION DISORDERS.kw.
86	((communicat\$ or language? or learn\$) adj2 (disabilit\$ or disorder? or dysfunction\$)).tw,tx.
87	MENTAL COMPETENCY.kw.
88	(mental\$ adj2 (competen\$ or incompeten\$)).tw,tx.
89	INFORMED CONSENT.kw.
90	INFORMED CONSENT BY MINORS.kw.
91	(informed adj2 consent\$).tw,tx.
92	((involv\$ or includ\$ or inclusive\$) adj2 (child\$ or minor\$ or young person? or young people or teenage\$)).tw,tx.

#	Searches
93	TIME FACTORS.kw.
94	timing.tw,tx.
95	UNCERTAINTY.kw.
96	(uncertain\$ or un-certain\$).tw,tx.
97	or/51-96
98	9 and 27 and 47 and 50
99	9 and 27 and 47 and 97
100	98 or 99
101	ADVANCE DIRECTIVE ADHERENCE.kw.
102	(directive? adj2 (adhere\$ or compl\$)).tw,tx.
103	101 or 102
104	9 and 27 and 103
105	100 or 104

### E.3.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/

#	Searches
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.3.61 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	TERMINALLY ILL PATIENT/
11	TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	TERMINAL CARE/
24	(terminal\$ adj3 (care\$ or caring)).ti,ab.
25	PALLIATIVE THERAPY/
26	CANCER PALLIATIVE THERAPY/
27	palliat\$.ti,ab.
28	HOSPICE CARE/
29	HOSPICE PATIENT/
30	hospice?.ab,ti.
31	or/10-30
32	PATIENT CARE PLANNING/
33	(care plan\$ adj2 patient?).ab,ti.

#	Searches
34	(plan\$ adj2 patient? care).ab,ti.
35	*PATIENT CARE/
36	((advance or advanced) adj2 care plan\$).ab,ti.
37	advance? directive?.ab,ti.
38	LIVING WILLS/
39	living will?.ab,ti.
40	CASE MANAGEMENT/
41	case management.ab,ti.
42	CLINICAL PATHWAYS/
43	(critical adj2 (path? or pathway?)).ab,ti.
44	(parallel adj2 plan\$).ab,ti.
45	(resuscitat\$ adj2 (policies or policy or order? or decision? or attempt\$)).ab,ti.
46	TREATMENT WITHDRAWAL/
47	EUTHANASIA, PASSIVE/
48	((Withhold\$ or withdraw\$) adj2 treatment?).ab,ti.
49	or/32-48
50	DECISION MAKING/
51	((make? or making or made) adj3 (decision? or decid\$)).ab,ti.
52	50 or 51
53	HUMAN RELATION/
54	DOCTOR PATIENT RELATION/
55	NURSE PATIENT RELATIONSHIP/
56	((physician? or doctor? or patient? or profession\$ or personnel or famil\$ or nurs\$ or interpersonal\$ or inter personal\$ or intergenerational\$ or inter generational\$ or interprofessional\$ or inter professional\$) adj2 (relation\$ or skill? or rapport\$)).ti,ab.
57	SOCIAL ADAPTATION/
58	((social\$ or interpersonal\$ or inter personal\$) adj2 (skill? or abilit\$ or competen\$)).ti,ab.
59	TRUST/
60	trust\$.ti,ab.
61	CONFLICT/
62	(negot\$ or arbitrat\$ or mediat\$ or dissent\$ or disput\$ or disagre\$).ti,ab.
63	(famil\$ adj2 (involv\$ or conflict\$ or factor?)).ti,ab.
64	exp MEDICAL EDUCATION/
65	((medic\$ or profession\$) adj2 (educat\$ or train\$)).ti,ab.
66	exp PATIENT ATTITUDE/
67	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (accept\$ or participat\$ or satisf\$)).ti,ab.
68	exp HEALTH PERSONNEL ATTITUDE/
69	((physician? or doctor? or profession\$ or personnel or nurs\$ or patient?) adj2 (opinion\$ or attitude? or feel\$ or empath\$)).ti,ab.
70	ATTITUDE TO DEATH/
71	ATTITUDE TO HEALTH/
72	HEALTH KNOWLEDGE, ATTITUDES, PRACTICE/
73	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj2 (opinion\$ or attitude? or feel\$)).ti,ab.
74	PATIENT ABANDONMENT/
75	(refus\$ adj2 treat\$).ab,ti.

#	Searches
76	RELIGION/
77	SOCIOECONOMIC S/
78	exp "ETHNIC OR RACIAL ASPECTS"/
79	ETHNIC GROUPS/
80	CULTURAL COMPETENCE/
81	CULTURAL SENSITIVITY/
82	CULTURAL BIAS/
83	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj2 (factor? or reason? or determin\$ or barrier? or facilitat\$)).ab,ti.
84	(communicat\$ adj2 (barrier? or facilitat\$)).ti,ab.
85	((communicat\$ or informat\$) adj2 (help\$ or unhelp\$ or prevent\$ or good or bad\$ or effect\$ or ineffect\$ or poor\$ or difficult\$)).ti,ab.
86	"TRANSLATING (LANGUAGE)"/
87	(translat\$ or interpret\$).ti,ab.
88	exp COMMUNICATION DISORDERS/
89	((communicat\$ or language? or learn\$) adj2 (disabilit\$ or disorder? or dysfunction\$)).ti,ab.
90	MENTAL CAPACITY/
91	(mental\$ adj2 (competen\$ or incompeten\$)).ti,ab.
92	INFORMED CONSENT/
93	(informed adj2 consent\$).ti,ab.
94	((involv\$ or includ\$ or inclusive\$) adj2 (child\$ or minor\$ or young person? or young people or teenage\$)).ti,ab.
95	TIME/
96	timing.ti,ab.
97	UNCERTAINTY/
98	(uncertain\$ or un-certain\$).ti,ab.
99	or/53-98
100	9 and 31 and 49 and 52
101	9 and 31 and 49 and 99
102	(directive? adj2 (adhere\$ or compl\$)).ab,ti.
103	9 and 31 and 102
104	100 or 101 or 103
105	limit 104 to english language
106	letter.pt. or LETTER/
107	note.pt.
108	editorial.pt.
109	CASE REPORT/ or CASE STUDY/
110	(letter or comment*).ti.
111	or/106-110
112	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
113	111 not 112
114	ANIMAL/ not HUMAN/
115	NONHUMAN/
116	exp ANIMAL EXPERIMENT/
117	exp EXPERIMENTAL ANIMAL/

#	Searches
118	ANIMAL MODEL/
119	exp RODENT/
120	(rat or rats or mouse or mice).ti.
121	or/113-120
122	105 not 121

## E.4.1 Place of care and place of death

### E.4.1.2 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	or/10-30
32	((place? or location? or site?) adj3 care).ab,ti.
33	((place? or location? or site?) adj3 (death? or dying)).ab,ti.

#	Searches
34	HOME CARE SERVICE/
35	(Home? adj3 (care or caring)).ab,ti.
36	homecar\$.ab,ti.
37	HOME NURSING/
38	(patient? adj3 (home? or house?)).ab,ti.
39	(outside adj3 hospital?).ab,ti.
40	((death? or die? or dying) adj3 (home? or house?)).ab,ti.
41	INTENSIVE CARE/
42	INTENSIVE CARE, NEONATAL/
43	INTENSIVE CARE UNITS/
44	INTENSIVE CARE UNITS, PEDIATRIC/
45	INTENSIVE CARE UNITS, NEONATAL/
46	intensive care.ab,ti.
47	PICU.ab,ti.
48	NICU.ab,ti.
49	CANCER CARE FACILITIES/
50	HOSPICE CARE/
51	HOSPITALS/
52	HOSPITALS, COMMUNITY/
53	HOSPITALS, GENERAL/
54	HOSPITALS, PRIVATE/
55	HOSPITALS, RELIGIOUS/
56	HOSPITALS, PEDIATRIC/
57	51 or 52 or 53 or 54 or 55 or 56
58	(care or caring).ab,ti.
59	(die or death? or dying).ab,ti.
60	58 or 59
61	57 and 60
62	((hospital? or hospice?) adj3 (care or caring)).ab,ti.
63	HOSPITAL MORTALITY/
64	((hospital? or hospice?) adj3 (die or death? or dying)).ab,ti.
65	32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 61 or 62 or 63 or 64
66	DECISION MAKING/
67	((make? or making) adj2 decision?).ab,ti.
68	((determine\$ or influenc\$ or affect\$ or effect\$ or factor?) adj3 decision?).ab,ti.
69	"PATIENT ACCEPTANCE OF HEALTH CARE"/
70	(preference? or preferred).ab,ti.
71	(choice? or choose or choosing).ab,ti.
72	PATIENT SATISFACTION/
73	CONSUMER BEHAVIOR/
74	(satisfied or satisfaction).ab,ti.
75	"HEALTH SERVICES NEEDS AND DEMAND"/
76	option?.ab,ti.
77	priorit\$.ab,ti.
78	"ATTITUDE TO DEATH"/

#	Searches
79	"ATTITUDE TO HEALTH"/
80	RELIGION/
81	SOCIOECONOMIC FACTORS/
82	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ab,ti.
83	HEALTH SERVICES ACCESSIBILITY/
84	(access\$ adj3 (care or service?)).ab,ti.
85	ADVANCE CARE PLANNING/
86	advance care plan\$.ab,ti.
87	parallel plan\$.ab,ti.
88	66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87
89	9 and 31 and 65 and 88
90	limit 89 to english language
91	LETTER/
92	EDITORIAL/
93	NEWS/
94	exp HISTORICAL ARTICLE/
95	ANECDOTES AS TOPIC/
96	COMMENT/
97	CASE REPORT/
98	(letter or comment*).ti.
99	or/91-98
100	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
101	99 not 100
102	ANIMALS/ not HUMANS/
103	exp ANIMALS, LABORATORY/
104	exp ANIMAL EXPERIMENTATION/
105	exp MODELS, ANIMAL/
106	exp RODENTIA/
107	(rat or rats or mouse or mice).ti.
108	or/101-107
109	90 not 108

#### E.4.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.



#	Searches
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	or/6-20
22	((place? or location? or site?) adj3 care).ab,ti.
23	((place? or location? or site?) adj3 (death? or dying)).ab,ti.
24	(Home? adj3 (care or caring)).ab,ti.
25	homecar\$.ab,ti.
26	(patient? adj3 (home? or house?)).ab,ti.
27	(outside adj3 hospital?).ab,ti.
28	((death? or die? or dying) adj3 (home? or house?)).ab,ti.
29	intensive care.ab,ti.
30	PICU.ab,ti.
31	NICU.ab,ti.
32	((hospital? or hospice?) adj3 (care or caring)).ab,ti.
33	((hospital? or hospice?) adj3 (die or death? or dying)).ab,ti.
34	or/22-33
35	((make? or making) adj2 decision?).ab,ti.
36	((determine\$ or influenc\$ or affect\$ or effect\$ or factor?) adj3 decision?).ab,ti.
37	(preference? or preferred).ab,ti.
38	(choice? or choose or choosing).ab,ti.
39	(satisfied or satisfaction).ab,ti.
40	option?.ab,ti.
41	priorit\$.ab,ti.
42	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ab,ti.
43	(access\$ adj3 (care or service?)).ab,ti.
44	advance care plan\$.ab,ti.
45	parallel plan\$.ab,ti.
46	or/35-45
47	5 and 21 and 34 and 46

#### E.4.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescens\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.

#	Searches
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	or/10-30
32	((place? or location? or site?) adj3 care).ti,ab,hw.
33	((place? or location? or site?) adj3 (death? or dying)).ti,ab,hw.
34	HOME CARE SERVICE/
35	(Home? adj3 (care or caring)).ti,ab,hw.
36	homecar\$.ti,ab,hw.
37	HOME NURSING/
38	(patient? adj3 (home? or house?)).ti,ab,hw.
39	(outside adj3 hospital?).ti,ab,hw.
40	((death? or die? or dying) adj3 (home? or house?)).ti,ab,hw.
41	INTENSIVE CARE/
42	INTENSIVE CARE, NEONATAL/
43	INTENSIVE CARE UNITS/
44	INTENSIVE CARE UNITS, PEDIATRIC/
45	INTENSIVE CARE UNITS, NEONATAL/

#	Searches
46	intensive care.ti,ab,hw.
47	PICU.ti,ab,hw.
48	NICU.ti,ab,hw.
49	CANCER CARE FACILITIES/
50	HOSPICE CARE/
51	HOSPITALS/
52	HOSPITALS, COMMUNITY/
53	HOSPITALS, GENERAL/
54	HOSPITALS, PRIVATE/
55	HOSPITALS, RELIGIOUS/
56	HOSPITALS, PEDIATRIC/
57	51 or 52 or 53 or 54 or 55 or 56
58	(care or caring).ti,ab,hw.
59	(die or death? or dying).ti,ab,hw.
60	58 or 59
61	57 and 60
62	((hospital? or hospice?) adj3 (care or caring)).ti,ab,hw.
63	HOSPITAL MORTALITY/
64	((hospital? or hospice?) adj3 (die or death? or dying)).ti,ab,hw.
65	32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 61 or 62 or 63 or 64
66	DECISION MAKING/
67	((make? or making) adj2 decision?).ti,ab,hw.
68	((determine\$ or influence\$ or affect\$ or effect\$ or factor?) adj3 decision?).ti,ab,hw.
69	"PATIENT ACCEPTANCE OF HEALTH CARE"/
70	(preference? or preferred).ti,ab,hw.
71	(choice? or choose or choosing).ti,ab,hw.
72	PATIENT SATISFACTION/
73	CONSUMER BEHAVIOR/
74	(satisfied or satisfaction).ti,ab,hw.
75	"HEALTH SERVICES NEEDS AND DEMAND"/
76	option?.ti,ab,hw.
77	priority\$.ti,ab,hw.
78	"ATTITUDE TO DEATH"/
79	"ATTITUDE TO HEALTH"/
80	RELIGION/
81	SOCIOECONOMIC FACTORS/
82	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ti,ab,hw.
83	HEALTH SERVICES ACCESSIBILITY/
84	(access\$ adj3 (care or service?)).ti,ab,hw.
85	ADVANCE CARE PLANNING/
86	advance care plan\$.ti,ab,hw.
87	parallel plan\$.ti,ab,hw.
88	66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87

#	Searches
89	9 and 31 and 65 and 88

#### E.4.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx,kw.
12	dying.tw,tx,kw.
13	(end adj3 life).tw,tx.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
18	(last year of life or LYOL or life\$ end).tw,tx.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw,tx.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.tw,tx.
25	LIVING WILLS.kw.
26	living will?.tw,tx,kw.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).tw,tx.
29	PALLIATIVE CARE.kw.
30	palliat\$.tw,tx,kw.
31	or/10-30
32	((place? or location? or site?) adj3 care).tw,tx.
33	((place? or location? or site?) adj3 (death? or dying)).tw,tx.
34	HOME CARE.kw.
35	(Home? adj3 (care or caring)).tw,tx.
36	homecar\$.tw,tx.
37	HOME NURSING.kw.
38	(patient? adj3 (home? or house?)).tw,tx.

#	Searches
39	(outside adj3 hospital?).tw,tx.
40	((death? or die? or dying) adj3 (home? or house?)).tw,tx.
41	INTENSIVE CARE.kw.
42	intensive care.tw,tx.
43	PICU.tw,tx.
44	NICU.tw,tx.
45	CANCER CARE FACILITIES.kw.
46	HOSPICE CARE.kw.
47	HOSPITAL?.kw.
48	(care or caring).tw,tx.
49	(die or death? or dying).tw,tx.
50	48 or 49
51	47 and 50
52	((hospital? or hospice?) adj3 (care or caring)).tw,tx.
53	HOSPITAL MORTALITY.kw.
54	((hospital? or hospice?) adj3 (die or death? or dying)).tw,tx.
55	32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 51 or 52 or 53 or 54
56	DECISION MAKING.kw.
57	((make? or making) adj2 decision?).tw,tx.
58	((determine\$ or influence\$ or affect\$ or effect\$ or factor?) adj3 decision?).tw,tx.
59	"PATIENT ACCEPTANCE OF HEALTH CARE".kw.
60	(preference? or preferred).ti,to,ab.
61	(choice? or choose or choosing).ti,to,ab.
62	PATIENT SATISFACTION.kw.
63	CONSUMER BEHAVIOR.kw.
64	(satisfied or satisfaction).ti,to,ab.
65	"HEALTH SERVICES NEEDS AND DEMAND".kw.
66	option?.ti,to,ab.
67	priority\$.ti,to,ab.
68	"ATTITUDE TO DEATH".kw.
69	"ATTITUDE TO HEALTH".kw.
70	RELIGION.kw.
71	SOCIOECONOMIC FACTORS.kw.
72	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).tw,tx.
73	HEALTH SERVICES ACCESSIBILITY.kw.
74	(access\$ adj3 (care or service?)).tw,tx.
75	ADVANCE CARE PLANNING.kw.
76	advance care plan\$.tw,tx.
77	parallel plan\$.tw,tx.
78	56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77
79	9 and 31 and 55 and 78

#### E.4.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

#### E.4.62 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.

#	Searches
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	*TERMINALLY ILL PATIENT/
11	*TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	*DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
24	advance? directive?.ab,ti.
25	*LIVING WILL/
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE THERAPY/
30	*CANCER PALLIATIVE THERAPY/
31	palliat\$.ti,ab.
32	or/10-31
33	((place? or location? or site?) adj3 care).ab,ti.
34	((place? or location? or site?) adj3 (death? or dying)).ab,ti.
35	HOME CARE/
36	(Home? adj3 (care or caring)).ab,ti.
37	homecar\$.ab,ti.
38	(patient? adj3 (home? or house?)).ab,ti.
39	(outside adj3 hospital?).ab,ti.
40	((death? or die? or dying) adj3 (home? or house?)).ab,ti.
41	INTENSIVE CARE/
42	NEWBORN INTENSIVE CARE/
43	INTENSIVE CARE UNIT/
44	intensive care.ab,ti.
45	PICU.ab,ti.
46	NICU.ab,ti.
47	CANCER CENTRE/
48	HOSPICE CARE/

#	Searches
49	HOSPITAL CARE/
50	((hospital? or hospice?) adj3 (care or caring)).ab,ti.
51	((hospital? or hospice?) adj3 (die or death? or dying)).ab,ti.
52	33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51
53	DECISION MAKING/
54	PATIENT DECISION MAKING/
55	FAMILY DECISION MAKING/
56	((make? or making) adj2 decision?).ab,ti.
57	((determine\$ or influence\$ or affect\$ or effect\$ or factor?) adj3 decision?).ab,ti.
58	PATIENT PARTICIPATION/
59	PATIENT ATTITUDE/
60	PATIENT PREFERENCE/
61	PLACE PREFERENCE/
62	(preference? or preferred).ab,ti.
63	(choice? or choose or choosing).ab,ti.
64	PATIENT SATISFACTION/
65	(satisfied or satisfaction).ab,ti.
66	HEALTH CARE NEED/
67	option?.ab,ti.
68	priorit\$.ab,ti.
69	ATTITUDE TO DEATH/
70	ATTITUDE TO HEALTH/
71	RELIGION/
72	SOCIOECONOMICS/
73	CULTURAL FACTOR/
74	RACE DIFFERENCE/
75	ETHNIC DIFFERENCE/
76	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ab,ti.
77	(access\$ adj3 (care or service?)).ab,ti.
78	advance care plan\$.ab,ti.
79	parallel plan\$.ab,ti.
80	or/53-79
81	9 and 32 and 52 and 80
82	limit 81 to english language
83	letter.pt. or LETTER/
84	note.pt.
85	editorial.pt.
86	CASE REPORT/ or CASE STUDY/
87	(letter or comment*).ti.
88	or/83-87
89	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
90	88 not 89
91	ANIMAL/ not HUMAN/
92	NONHUMAN/



#	Searches
93	exp ANIMAL EXPERIMENT/
94	exp EXPERIMENTAL ANIMAL/
95	ANIMAL MODEL/
96	exp RODENT/
97	(rat or rats or mouse or mice).ti.
98	or/90-97
99	82 not 98

#### E.4.71 Database: PsycInfo

#	Searches
1	adolescenc\$.ag.
2	(adolescenc\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,id,jw.
3	(child\$ or school\$ or preschool\$).ag.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,id,jw.
5	(infan\$ or neonat\$).ag.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies or p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,id,jw.
7	or/1-6
8	TERMINALLY ILL PATIENTS/
9	TERMINAL CANCER/
10	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
11	"DEATH AND DYING"/
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
22	ADVANCE DIRECTIVES/
23	advance? directive?.ab,ti.
24	living will?.ab,ti.
25	(terminal\$ adj3 (care\$ or caring)).ti,ab.
26	PALLIATIVE CARE/
27	palliat\$.ti,ab.
28	or/8-27
29	((place? or location? or site?) adj3 care).ab,ti.
30	((place? or location? or site?) adj3 (death? or dying)).ab,ti.
31	HOME CARE/
32	(Home? adj3 (care or caring)).ab,ti.

#	Searches
33	homecar\$.ab,ti.
34	(patient? adj3 (home? or house?)).ab,ti.
35	(outside adj3 hospital?).ab,ti.
36	((death? or die? or dying) adj3 (home? or house?)).ab,ti.
37	INTENSIVE CARE/
38	NEONATAL INTENSIVE CARE/
39	intensive care.ab,ti.
40	PICU.ab,ti.
41	NICU.ab,ti.
42	HOSPITALS/
43	HOSPICE/
44	((hospital? or hospice?) adj3 (care or caring)).ab,ti.
45	((hospital? or hospice?) adj3 (die or death? or dying)).ab,ti.
46	or/29-45
47	DECISION MAKING/
48	((make? or making) adj2 decision?).ab,ti.
49	((determine\$ or influence\$ or affect\$ or effect\$ or factor?) adj3 decision?).ab,ti.
50	CLIENT ATTITUDES/
51	(preference? or preferred).ab,ti.
52	CHOICE BEHAVIOR/
53	(choice? or choose or choosing).ab,ti.
54	CLIENT SATISFACTION/
55	CONSUMER BEHAVIOR/
56	(satisfied or satisfaction).ab,ti.
57	HEALTH CARE UTILIZATION/
58	option?.ab,ti.
59	priorit\$.ab,ti.
60	DEATH ATTITUDES/
61	HEALTH ATTITUDES/
62	RELIGION/
63	RELIGIOUS BELIEFS/
64	PSYCHOSOCIAL FACTORS/
65	exp SOCIOCULTURAL FACTORS/
66	((demog\$ or social\$ or socio-economic\$ or socioeconomic\$ or race or racial\$ or ethnic\$ or cultur\$ or linguist\$ or religi\$) adj5 (factor? or reason? or determin\$)).ab,ti.
67	(access\$ adj3 (care or service?)).ab,ti.
68	advance care plan\$.ab,ti.
69	parallel plan\$.ab,ti.
70	or/47-69
71	7 and 28 and 46 and 70
72	limit 71 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal" or "0130 peer-reviewed status unknown" or "0500 electronic collection")

#### E.4.81 Database: CINAHL (Cumulative Index to Nursing and Allied Health Literature)

#	Searches
1	ADOLESCENCE/

#	Searches
2	(adolescen* OR teen* OR youth* OR young OR juvenile* OR minors OR highschool*).ti,ab
3	CHILD/
4	CHILD, PRESCHOOL/
5	(child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid* OR kindergar* OR boy* OR girl*).ti,ab
6	INFANT/
7	exp INFANT, NEWBORN/
8	(infan* OR neonat* OR newborn* OR baby OR babies).ti,ab
9	PEDIATRICS/
10	PUBERTY/
11	(pediatric* OR paediatric* OR pubert* OR prepubert* OR pubescen* OR prepubescen*).ti,ab
12	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11
13	TERMINALLY ILL PATIENTS/
14	((terminal* OR final OR advance* OR incurable OR "life limit*") adj3 (ill* OR disease* OR condition*)).ti,ab
15	dying.ti,ab
16	(end adj3 life).ti,ab
17	((approach* OR close* OR near* OR imminent* OR impending) adj3 death).ti,ab
18	(Body adj2 ("shut* down" OR "shutting down" OR deteriorat*)).ti,ab
19	(deathbed* OR "death bed*" OR "passing away" OR "passing on" OR expiring OR expiration).ti,ab
20	((last OR final) adj1 (hour* OR days* OR minute*)).ti,ab
21	("last year of life" OR LYOL OR "life* end").ti,ab
22	("advance* stage*" OR "final stage*" OR "end stage*" OR "last stage*" OR "late stage*" OR "terminal stage*").ti,ab
23	((advanced OR late OR last OR end OR final OR terminal) adj1 phase*).ti,ab
24	TERMINAL CARE/
25	(terminal* adj3 (care* OR caring)).ti,ab
26	PALLIATIVE CARE/
27	palliat*.ti,ab
28	13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27
29	((place* OR location* OR site*) adj3 care).ti,ab
30	((place* OR location* OR site*) adj3 (death* OR dying)).ti,ab
31	HOME HEALTH CARE/
32	(Home* adj3 (care OR caring)).ti,ab
33	homecar*.ti,ab
34	HOME NURSING/
35	(patient* adj3 (home* OR house*)).ti,ab
36	(outside adj3 hospital*).ti,ab
37	((death* OR die* OR dying) adj3 (home* OR house*)).ti,ab
38	INTENSIVE CARE UNITS/
39	INTENSIVE CARE UNITS, PEDIATRIC/
40	INTENSIVE CARE UNITS, NEONATAL/
41	INTENSIVE CARE, NEONATAL/
42	"intensive care".ti,ab
43	PICU.ti,ab

#	Searches
44	NICU.ti,ab
45	CANCER CARE FACILITIES/
46	HOSPICE CARE/
47	exp HOSPITALS/
48	(care OR caring).ti,ab
49	(die OR death* OR dying).ti,ab
50	48 OR 49
51	47 AND 50
52	((hospital* OR hospice*) adj3 (care OR caring)).ti,ab
53	HOSPITAL MORTALITY/
54	((hospital* OR hospice*) adj3 (die OR death* OR dying)).ti,ab
55	29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 51 OR 52 OR 53 OR 54
56	DECISION MAKING/
57	DECISION MAKING, FAMILY/
58	DECISION MAKING, PATIENT/
59	((make* OR making) adj2 decision*).ti,ab
60	((determine* OR influenc* OR affect* OR effect* OR factor*) adj3 decision*).ti,ab
61	(preference* OR preferred).ti,ab
62	(choice* OR choose OR choosing).ti,ab
63	PATIENT SATISFACTION/
64	CONSUMER SATISFACTION/
65	(satisfied OR satisfaction).ti,ab
66	HEALTH SERVICES NEEDS AND DEMAND/
67	option*.ti,ab
68	priorit*.ti,ab
69	ATTITUDE TO DEATH/
70	ATTITUDE TO HEALTH/
71	RELIGION AND RELIGIONS/
72	GEOGRAPHIC FACTORS/
73	SOCIOECONOMIC FACTORS/
74	RACE FACTORS/
75	CULTURAL VALUES/
76	((demog* OR social* OR socio-economic* OR socioeconomic* OR race OR racial* OR ethnic* OR cultur* OR linguist* OR religi*) adj5 (factor* OR reason* OR determin*)).ti,ab
77	HEALTH SERVICES ACCESSIBILITY/
78	(access* adj3 (care OR service*)).ti,ab
79	ADVANCE CARE PLANNING/
80	"advance care plan*".ti,ab
81	"parallel plan*".ti,ab
82	56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65 OR 66 OR 67 OR 68 OR 69 OR 70 OR 71 OR 72 OR 73 OR 74 OR 75 OR 76 OR 77 OR 78 OR 79 OR 80 OR 81
83	12 AND 28 AND 55 AND 82 [Limit to: (Language English)]

## E.5.1 Organ and tissue donation

### E.5.1.2 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	exp "TISSUE AND ORGAN PROCUREMENT"/
35	((tissue? or organ?) adj3 (donat\$ or procur\$)).ab,ti.
36	exp TISSUE DONORS/
37	((tissue? or organ? or transplant\$) adj3 donor?).ab,ti.
38	exp ORGAN TRANSPLANTATION/
39	(organ? adj3 (transplant\$ or graft\$)).ab,ti.
40	34 or 35 or 36 or 37 or 38 or 39

#	Searches
41	exp COMMUNICATION/
42	COMMUNICATION BARRIERS/
43	HEALTH COMMUNICATION/
44	PERSUASIVE COMMUNICATION/
45	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab.
46	or/41-45
47	exp CONSUMER HEALTH INFORMATION/
48	PATIENT EDUCATION AS TOPIC/
49	PARENTS/ed
50	PUBLICATIONS/
51	PAMPHLETS/
52	INTERNET/
53	(information\$ or knowledge).ti,ab.
54	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 educat\$).ti,ab.
55	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 educat\$).ti,ab.
56	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
57	or/47-56
58	9 and 33 and 40 and 46
59	9 and 33 and 40 and 57
60	(discuss\$ adj5 (organ? or tissue? or donat\$ or donor? or transplant\$)).ti,ab.
61	9 and 33 and 60
62	58 or 59 or 61
63	limit 62 to english language
64	LETTER/
65	EDITORIAL/
66	NEWS/
67	exp HISTORICAL ARTICLE/
68	ANECDOTES AS TOPIC/
69	COMMENT/
70	CASE REPORT/
71	(letter or comment*).ti.
72	or/64-71
73	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
74	72 not 73
75	ANIMALS/ not HUMANS/
76	exp ANIMALS, LABORATORY/
77	exp ANIMAL EXPERIMENTATION/
78	exp MODELS, ANIMAL/
79	exp RODENTIA/
80	(rat or rats or mouse or mice).ti.

#	Searches
81	or/74-80
82	63 not 81

### E.5.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatic\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	((tissue? or organ?) adj3 (donat\$ or procur\$)).ab,ti.
24	((tissue? or organ? or transplant\$) adj3 donor?).ab,ti.
25	(organ? adj3 (transplant\$ or graft\$)).ab,ti.
26	or/23-25
27	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab.
28	(information\$ or knowledge).ti,ab.
29	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 educat\$).ti,ab.
30	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 educat\$).ti,ab.
31	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
32	or/28-31
33	5 and 22 and 26 and 27

#	Searches
34	5 and 22 and 26 and 32
35	(discuss\$ adj5 (organ? or tissue? or donat\$ or donor? or transplant\$)).ti,ab.
36	5 and 22 and 35
37	33 or 34 or 36

### E.5.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti,kw.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	exp "TISSUE AND ORGAN PROCUREMENT"/
35	((tissue? or organ?) adj3 (donat\$ or procur\$)).ab,ti,kw.
36	exp TISSUE DONORS/



#	Searches
37	((tissue? or organ? or transplant\$) adj3 donor?).ab,ti,kw.
38	exp ORGAN TRANSPLANTATION/
39	(organ? adj3 (transplant\$ or graft\$)).ab,ti,kw.
40	34 or 35 or 36 or 37 or 38 or 39
41	exp COMMUNICATION/
42	COMMUNICATION BARRIERS/
43	HEALTH COMMUNICATION/
44	PERSUASIVE COMMUNICATION/
45	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab.
46	or/41-45
47	exp CONSUMER HEALTH INFORMATION/
48	PATIENT EDUCATION AS TOPIC/
49	PARENTS/ed
50	PUBLICATIONS/
51	PAMPHLETS/
52	INTERNET/
53	(information\$ or knowledge).ti,ab.
54	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 educat\$).ti,ab.
55	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 educat\$).ti,ab.
56	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
57	or/47-56
58	9 and 33 and 40 and 46
59	9 and 33 and 40 and 57
60	(discuss\$ adj5 (organ? or tissue? or donat\$ or donor? or transplant\$)).ti,ab.
61	9 and 33 and 60
62	58 or 59 or 61

#### E.5.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8

#	Searches
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx.
12	dying.tw,tx.
13	(end adj3 life).tw,tx.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
18	(last year of life or LYOL or life\$ end).tw,tx.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw,tx.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.tw,tx.
25	LIVING WILLS.kw.
26	living will?.tw,tx.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).tw,tx.
29	PALLIATIVE CARE.kw.
30	palliat\$.tw,tx.
31	HOSPICE CARE.kw.
32	hospice?.tw,tx.
33	or/10-32
34	"TISSUE AND ORGAN PROCUREMENT".kw.
35	((tissue? or organ?) adj3 (donat\$ or procur\$)).tw,tx.
36	TISSUE DONORS.kw.
37	((tissue? or organ? or transplant\$) adj3 donor?).tw,tx.
38	ORGAN TRANSPLANTATION.kw.
39	(organ? adj3 (transplant\$ or graft\$)).tw,tx.
40	or/34-39
41	COMMUNICATION.kw.
42	COMMUNICATION BARRIERS.kw.
43	HEALTH COMMUNICATION.kw.
44	PERSUASIVE COMMUNICATION.kw.
45	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti.
46	or/41-45
47	CONSUMER HEALTH INFORMATION.kw.
48	PATIENT EDUCATION AS TOPIC.kw.
49	PUBLICATIONS.kw.
50	PAMPHLETS.kw.
51	INTERNET.kw.

#	Searches
52	(information\$ or knowledge).ti,kw.
53	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 educat\$).tw,tx.
54	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 educat\$).tw,tx.
55	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).tw,tx.
56	or/47-55
57	9 and 33 and 40 and 46
58	9 and 33 and 40 and 56
59	(discuss\$ adj5 (organ? or tissue? or donat\$ or donor? or transplant\$)).tw,tx.
60	9 and 33 and 59
61	or/57-60

### E.5.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.

#	Searches
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.5.61 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	TERMINALLY ILL PATIENT/
11	TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
24	advance? directive?.ab,ti.
25	LIVING WILL/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE THERAPY/
30	CANCER PALLIATIVE THERAPY/
31	palliat\$.ti,ab.
32	HOSPICE CARE/

#	Searches
33	HOSPICE PATIENT/
34	hospice?.ab,ti.
35	or/10-34
36	*TRANSPLANTATION/
37	((tissue? or organ?) adj3 procur\$).ab,ti.
38	*ORGAN DONOR/
39	((tissue? or organ? or transplant\$) adj3 donor?).ab,ti.
40	((tissue? or organ?) adj3 donat\$).ab,ti.
41	exp *ORGAN TRANSPLANTATION/
42	(organ? adj3 (transplant\$ or graft\$)).ab,ti.
43	or/36-42
44	*INTERPERSONAL COMMUNICATION/
45	exp *LANGUAGE ABILITY/
46	exp *VERBAL COMMUNICATION/
47	exp *NONVERBAL COMMUNICATION/
48	*PERSUASIVE COMMUNICATION/
49	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab.
50	or/44-49
51	*INFORMATION/
52	*CONSUMER HEALTH INFORMATION/
53	*INFORMATION DISSEMINATION/
54	*INFORMATION SEEKING/
55	*PATIENT EDUCATION/
56	*MEDICAL INFORMATION/
57	*PUBLICATION/
58	*INTERNET/
59	(information\$ or knowledge).ti,ab.
60	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 educat\$).ti,ab.
61	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 educat\$).ti,ab.
62	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
63	or/51-62
64	9 and 35 and 43 and 50
65	9 and 35 and 43 and 63
66	(discuss\$ adj5 (organ? or tissue? or donat\$ or donor? or transplant\$)).ti,ab.
67	9 and 35 and 66
68	64 or 65 or 67
69	limit 68 to english language
70	letter.pt. or LETTER/
71	note.pt.
72	editorial.pt.

#	Searches
73	CASE REPORT/ or CASE STUDY/
74	(letter or comment*).ti.
75	or/70-74
76	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
77	75 not 76
78	ANIMAL/ not HUMAN/
79	NONHUMAN/
80	exp ANIMAL EXPERIMENT/
81	exp EXPERIMENTAL ANIMAL/
82	ANIMAL MODEL/
83	exp RODENT/
84	(rat or rats or mouse or mice).ti.
85	or/77-84
86	69 not 85

### E.5.71 Database: PsycInfo

#	Searches
1	adolescen\$.ag.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,id,jw.
3	(child\$ or school\$ or preschool\$).ag.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,id,jw.
5	(infan\$ or neonat\$).ag.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies or p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,id,jw.
7	or/1-6
8	TERMINALLY ILL PATIENTS/
9	TERMINAL CANCER/
10	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
11	"DEATH AND DYING"/
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
22	ADVANCE DIRECTIVES/
23	advance? directive?.ab,ti.
24	living will?.ab,ti.
25	(terminal\$ adj3 (care\$ or caring)).ti,ab.

#	Searches
26	PALLIATIVE CARE/
27	palliat\$.ti,ab.
28	HOSPICE/
29	hospice?.ab,ti.
30	or/8-29
31	TISSUE DONATION/
32	((tissue? or organ?) adj3 (donat\$ or procur\$)).ab,ti.
33	((tissue? or organ? or transplant\$) adj3 donor?).ab,ti.
34	ORGAN TRANSPLANTATION/
35	(organ? adj3 (transplant\$ or graft\$)).ab,ti.
36	or/31-35
37	COMMUNICATION/
38	exp LANGUAGE/
39	exp VERBAL COMMUNICATION/
40	exp NONVERBAL COMMUNICATION/
41	PERSUASIVE COMMUNICATION/
42	(communicat\$ or talk\$ or converse? or conversation? or language? or read? or reading or speech\$ or speak\$ or translat\$ or write or writing or written or terminolog\$ or semantic\$ or vocab\$ or verbal\$ or nonverbal\$ or non-verbal\$ or online or web-based).ti,ab.
43	or/37-42
44	INFORMATION/
45	INFORMATION DISSEMINATION/
46	INFORMATION SEEKING/
47	CLIENT EDUCATION/
48	INTERNET/
49	(information\$ or knowledge).ti,ab.
50	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 educat\$).ti,ab.
51	((pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$) adj3 educat\$).ti,ab.
52	((client\$ or patient\$ or user\$ or carer\$ or consumer\$ or customer\$ or famil\$ or parent\$ or father\$ or mother\$ or caregiver\$) adj3 (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or website\$ or web site\$ or web page\$ or webpage\$ or video\$ or dvd\$)).ti,ab.
53	or/44-52
54	7 and 30 and 36 and 43
55	7 and 30 and 36 and 53
56	(discuss\$ adj5 (organ? or tissue? or donat\$ or donor? or transplant\$)).ti,ab.
57	7 and 30 and 56
58	54 or 55 or 57
59	limit 58 to english language
60	limit 59 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal" or "0130 peer-reviewed status unknown" or "0500 electronic collection")

#### E.5.81 Database: CINAHL (Cumulative Index to Nursing and Allied Health Literature)

#	Searches
1	ADOLESCENCE/

#	Searches
2	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*).ti,ab.
3	CHILD/
4	CHILD, PRESCHOOL/
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*).ti,ab.
6	INFANT/
7	exp INFANT, NEWBORN/
8	(infan* or neonat* or newborn* or baby or babies).ti,ab.
9	PEDIATRICS/
10	PUBERTY/
11	(pediatric* or paediatric* or pubert* or prepubert* or pubescen* or prepubescen*).ti,ab.
12	or/1-11
13	TERMINALLY ILL PATIENTS/
14	((terminal* or final or advance* or incurable or "life limit*") adj3 (ill* or disease* or condition*)).ti,ab.
15	dying.ti,ab.
16	(end adj3 life).ti,ab.
17	((approach* or close* or near* or imminent* or impending) adj3 death).ti,ab.
18	(Body adj2 ("shut* down" or "shutting down" or deteriorat*)).ti,ab.
19	(deathbed* or "death bed*" or passing away or passing on or expiring or expiration).ti,ab.
20	((last or final) adj1 (hour* or days* or minute*)).ti,ab.
21	("last year of life" or LYOL or "life* end").ab,ti.
22	("advance* stage*" or "final stage*" or "end stage*" or "last stage*" or "late stage*" or "terminal stage*").ti,ab.
23	((advanced or late or last or end or final or terminal) adj phase*).ab,ti.
24	RESUSCITATION ORDERS/
25	(resuscitat* adj3 (policies or policy or order* or decision* or withhold*)).ab,ti.
26	ADVANCE DIRECTIVES/
27	"advance* directive*".ab,ti.
28	LIVING WILLS/
29	"living will*".ab,ti.
30	TERMINAL CARE/
31	(terminal* adj3 (care* or caring)).ti,ab.
32	PALLIATIVE CARE/
33	palliat*.ti,ab.
34	HOSPICE CARE/
35	hospice*.ab,ti.
36	or/13-35
37	ORGAN PROCUREMENT/
38	TISSUE AND ORGAN HARVESTING/
39	((tissue* or organ*) adj3 (donat* or procur*)).ab,ti.
40	exp TRANSPLANT DONORS/
41	((tissue* or organ* or transplant*) adj3 donor*).ab,ti.
42	exp ORGAN TRANSPLANTATION/
43	exp TISSUE TRANSPLANTATION/
44	(organ* adj3 (transplant* or graft*)).ab,ti.



#	Searches
45	or/ 37-44
46	COMMUNICATION/
47	COMMUNICATION BARRIERS/
48	exp LANGUAGE/
49	exp NONVERBAL COMMUNICATION/
50	PERSUASIVE COMMUNICATION/
51	(communicat* or talk* or converse* or conversation* or language* or read* or reading or speech* or speak* or translat* or write or writing or written or terminolog* or semantic* or vocab* or verbal* or nonverbal* or non-verbal* or online or web-based).ti,ab.
52	or/46-51
53	CONSUMER HEALTH INFORMATION/
54	HEALTH INFORMATION/
55	INFORMATION SEEKING BEHAVIOR/
56	*PATIENT EDUCATION/
57	*INFORMATION RESOURCES/
58	PAMPHLETS/
59	INTERNET/
60	(information* or knowledge).ti,ab.
61	((client* or patient* or user* or carer* or consumer* or customer* or famil* or parent* or father* or mother* or caregiver*) adj3 educat*).ti,ab.
62	((pamphlet* or leaflet* or booklet* or manual* or brochure* or publication* or handout* or website* or "web site*" or "web page*" or webpage* or video* or dvd*) adj3 educat*).ti,ab.
63	((client* or patient* or user* or carer* or consumer* or customer* or famil* or parent* or father* or mother* or caregiver*) adj3 (pamphlet* or leaflet* or booklet* or manual* or brochure* or publication* or handout* or website* or "web site*" or "web page*" or webpage* or video* or dvd*)).ti,ab.
64	or/53-63
65	12 and 36 and 45 and 52
66	12 and 36 and 45 and 64
67	(discuss* adj5 (organ* or tissue* or donat* or donor* or transplant*)).ti,ab.
68	12 and 36 and 67
69	65 or 66 or 68 [Limit to: (Language English)]

## E.6.1 Multidisciplinary team

### E.6.12 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8

#	Searches
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	PATIENT CARE TEAM/
35	((patient? or medical or health) adj1 care team).ab,ti.
36	healthcare team?.ab,ti.
37	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$ or integrated or network\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
38	mdt?.ab,ti.
39	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
40	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
41	(palliative care adj2 team?).ab,ti.
42	pcct?.ab,ti.
43	network meeting?.ti,ab.
44	INTERDISCIPLINARY COMMUNICATION/
45	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
46	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.

#	Searches
47	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (communicat\$ or collaborat\$ or relation\$)).ab,ti.
48	((co-ordinat\$ or coordinat\$ or network\$) adj3 (care or service? or practice?)).ab,ti.
49	or/34-48
50	9 and 33 and 49
51	*PALLIATIVE CARE/og, st [Organization and Administration, Standards]
52	*TERMINAL CARE/og, st [Organization and Administration, Standards]
53	or/51-52
54	and/9,53
55	or/50,54
56	limit 55 to english language
57	LETTER/
58	EDITORIAL/
59	NEWS/
60	exp HISTORICAL ARTICLE/
61	ANECDOTES AS TOPIC/
62	COMMENT/
63	CASE REPORT/
64	(letter or comment*).ti.
65	or/57-64
66	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
67	65 not 66
68	ANIMALS/ not HUMANS/
69	exp ANIMALS, LABORATORY/
70	exp ANIMAL EXPERIMENTATION/
71	exp MODELS, ANIMAL/
72	exp RODENTIA/
73	(rat or rats or mouse or mice).ti.
74	or/67-73
75	56 not 74
76	limit 75 to yr="1995 -Current"

### E.6.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.

#	Searches
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	((patient? or medical or health) adj1 care team).ab,ti.
24	healthcare team?.ab,ti.
25	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$ or integrated or network\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
26	mdt?.ab,ti.
27	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
28	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
29	(palliative care adj2 team?).ab,ti.
30	pcct?.ab,ti.
31	network meeting?.ti,ab.
32	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
33	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
34	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
35	((co-ordinat\$ or coordinat\$ or network\$) adj3 (care or service? or practice?)).ab,ti.
36	or/23-35
37	and/5,22,36
38	limit 37 to yr="1995 -Current"

### E.6.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.

#	Searches
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	PATIENT CARE TEAM/
35	((patient? or medical or health) adj1 care team).ab,ti.
36	healthcare team?.ab,ti.
37	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$ or integrated or network\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti,kw.
38	mdt?.ab,ti.
39	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
40	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
41	(palliative care adj2 team?).ab,ti.
42	pcct?.ab,ti.
43	network meeting?.ti,ab.
44	INTERDISCIPLINARY COMMUNICATION/
45	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti,kw.

#	Searches
46	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
47	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
48	((co-ordinat\$ or coordinat\$ or network\$) adj3 (care or service? or practice?)).ab,ti.
49	or/34-48
50	9 and 33 and 49
51	*PALLIATIVE CARE/og, st [Organization and Administration, Standards]
52	*TERMINAL CARE/og, st [Organization and Administration, Standards]
53	or/51-52
54	and/9,53
55	or/50,54
56	limit 55 to yr="1995 -Current"

#### E.6.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx,kw.
12	dying.tw,tx,kw.
13	(end adj3 life).tw,tx.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
18	(last year of life or LYOL or life\$ end).tw,tx.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw,tx.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.tw,tx.
25	LIVING WILLS.kw.
26	living will?.tw,tx,kw.
27	TERMINAL CARE.kw.

#	Searches
28	(terminal\$ adj3 (care\$ or caring)).tw,tx.
29	PALLIATIVE CARE.kw.
30	palliat\$.tw,tx,kw.
31	HOSPICE CARE.kw.
32	hospice?.tw,tx,kw.
33	or/10-32
34	PATIENT CARE TEAM.kw.
35	((patient? or medical or health) adj1 care team).tw,tx.
36	healthcare team?.tw,tx.
37	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$ or integrated or network\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).tw,tx,kw.
38	mdt?.tw,tx.
39	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).tw,tx.
40	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).tw,tx.
41	(palliative care adj2 team?).tw,tx.
42	pcct?.tw,tx.
43	network meeting?.tw,tx.
44	INTERDISCIPLINARY COMMUNICATION.kw.
45	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).tw,tx.
46	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).tw,tx.
47	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).tw,tx.
48	((co-ordinat\$ or coordinat\$ or network\$) adj3 (care or service? or practice?)).tw,tx.
49	or/34-48
50	9 and 33 and 49

### E.6.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.

#	Searches
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

#### E.6.61 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	*TERMINALLY ILL PATIENT/
11	*TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	*DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.



#	Searches
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
24	advance? directive?.ab,ti.
25	*LIVING WILL/
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE THERAPY/
30	*CANCER PALLIATIVE THERAPY/
31	palliat\$.ti,ab.
32	*HOSPICE CARE/
33	*HOSPICE PATIENT/
34	hospice?.ab,ti.
35	or/10-34
36	MULTIDISCIPLINARY TEAM CARE/
37	((patient? or medical or health) adj1 care team).ab,ti.
38	healthcare team?.ab,ti.
39	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$ or integrated or network\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
40	mdt?.ab,ti.
41	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
42	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
43	(palliative care adj2 team?).ab,ti.
44	pcct?.ab,ti.
45	network meeting?.ti,ab.
46	*INTERDISCIPLINARY COMMUNICATION/
47	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
48	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
49	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
50	((co-ordinat\$ or coordinat\$ or network\$) adj3 (care or service? or practice?)).ab,ti.
51	or/36-50
52	and/9,35,51
53	limit 52 to english language
54	letter.pt. or LETTER/
55	note.pt.

#	Searches
56	editorial.pt.
57	CASE REPORT/ or CASE STUDY/
58	(letter or comment*).ti.
59	or/54-58
60	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
61	59 not 60
62	ANIMAL/ not HUMAN/
63	NONHUMAN/
64	exp ANIMAL EXPERIMENT/
65	exp EXPERIMENTAL ANIMAL/
66	ANIMAL MODEL/
67	exp RODENT/
68	(rat or rats or mouse or mice).ti.
69	or/61-68
70	53 not 69
71	limit 70 to yr="1995 -Current"

#### E.6.71 Database: PsycInfo

#	Searches
1	adolescen\$.ag.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,id,jw.
3	(child\$ or school\$ or preschool\$).ag.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,id,jw.
5	(infan\$ or neonat\$).ag.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies or p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,id,jw.
7	or/1-6
8	TERMINALLY ILL PATIENTS/
9	TERMINAL CANCER/
10	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
11	"DEATH AND DYING"/
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
22	ADVANCE DIRECTIVES/
23	advance? directive?.ab,ti.

#	Searches
24	living will?.ab,ti.
25	(terminal\$ adj3 (care\$ or caring)).ti,ab.
26	PALLIATIVE CARE/
27	palliat\$.ti,ab.
28	HOSPICE/
29	hospice?.ab,ti.
30	or/8-29
31	INTERDISCIPLINARY TREATMENT APPROACH/
32	((patient? or medical or health) adj1 care team).ab,ti.
33	healthcare team?.ab,ti.
34	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$ or integrated or network\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
35	mdt?.ab,ti.
36	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
37	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (team? or staff\$ or task force? or approach\$ or program\$ or system? or panel? or forum? or care or manag\$ or service?)).ab,ti.
38	(palliative care adj2 team?).ab,ti.
39	pcct?.ab,ti.
40	network meeting?.ti,ab.
41	((interdisciplinary or inter-disciplinary or interprofession\$ or inter-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
42	((multidisciplinary or multi-disciplinary or multiprofession\$ or multi-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
43	((transdisciplinary or trans-disciplinary or transprofession\$ or trans-profession\$) adj3 (communic\$ or collaborat\$ or relation\$)).ab,ti.
44	((co-ordinat\$ or coordinat\$ or network\$) adj3 (care or service? or practice?)).ab,ti.
45	or/31-44
46	7 and 30 and 45
47	limit 46 to english language
48	limit 47 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal" or "0130 peer-reviewed status unknown" or "0500 electronic collection")
49	limit 48 to yr="1995 -Current"

### E.6.81 Database: CINAHL (Cumulative Index to Nursing and Allied Health Literature)

#	Searches
1	MH ADOLESCENCE
2	TI (adolescen* OR teen* OR youth* OR young OR juvenile* OR minors OR highschool*) OR AB (adolescen* OR teen* OR youth* OR young OR juvenile* OR minors OR highschool*)
3	MH (CHILD) OR MH (CHILD, PRESCHOOL)
4	TI (child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid* OR kindergar* OR boy* OR girl*) OR AB (child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid* OR kindergar* OR boy* OR girl*)
5	MH (INFANT) OR MH (INFANT, NEWBORN+)
6	TI (infan* OR neonat* OR newborn* OR baby OR babies) OR AB (infan* OR neonat* OR newborn* OR baby OR babies)

#	Searches
7	MH (PEDIATRICS) OR MH (PUBERTY)
8	TI (pediatric* OR paediatric* OR pubert* OR prepubert* OR pubescen* OR prepubescen*) OR AB (pediatric* OR paediatric* OR pubert* OR prepubert* OR pubescen* OR prepubescen*)
9	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8
10	MH TERMINALLY ILL PATIENTS
11	TI ((terminal* OR final OR advance* OR incurable OR "life limit*") N3 (ill* OR disease* OR condition*))
12	AB ((terminal* OR final OR advance* OR incurable OR "life limit*") N3 (ill* OR disease* OR condition*))
13	TI (dying) OR AB (dying)
14	TI (end N3 life) OR AB (end N3 life)
15	TI ((approach* OR close* OR near* OR imminent* OR impending) N3 death)
16	AB ((approach* OR close* OR near* OR imminent* OR impending) N3 death)
17	TI (Body N2 ("shut* down" OR "shutting down" OR deteriorat*))
18	AB (Body N2 ("shut* down" OR "shutting down" OR deteriorat*))
19	TI (deathbed* OR "death bed*" OR "passing away" OR "passing on" OR expiring OR expiration) OR AB (deathbed* OR "death bed*" OR "passing away" OR "passing on" OR expiring OR expiration)
20	TI ((last OR final) N1 (hour* OR days* OR minute*))
21	AB ((last OR final) N1 (hour* OR days* OR minute*))
22	TI ("last year of life" OR LYOL OR "life* end") OR AB ("last year of life" OR LYOL OR "life* end")
23	TI ("advance* stage*" OR "final stage*" OR "end stage*" OR "last stage*" OR "late stage*" OR "terminal stage*") OR AB ("advance* stage*" OR "final stage*" OR "end stage*" OR "last stage*" OR "late stage*" OR "terminal stage*")
24	TI ((advanced OR late OR last OR end OR final OR terminal) N1 phase*)
25	AB ((advanced OR late OR last OR end OR final OR terminal) N1 phase*)
26	MH RESUSCITATION ORDERS
27	TI (resuscitat* N3 (policies or policy or order* or decision* or withhold*))
28	AB (resuscitat* N3 (policies or policy or order* or decision* or withhold*))
29	MH ADVANCE DIRECTIVES
30	TI (advance* directive*) OR AB (advance* directive*)
31	MH LIVING WILLS
32	TI (living will*) OR AB (living will*)
33	MH TERMINAL CARE
34	TI (terminal* N3 (care* OR caring))
35	AB (terminal* N3 (care* OR caring))
36	MH PALLIATIVE CARE
37	TI (palliat*) OR AB (palliat*)
38	MH HOSPICE CARE
39	TI (hospice*) OR AB (hospice*)
40	10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39
41	MH (MULTIDISCIPLINARY CARE TEAM+)
42	TI ((patient* or medical or health) N1 care team)
43	AB ((patient* or medical or health) N1 care team)

#	Searches
44	TI (healthcare team*) OR AB (healthcare team*)
45	TI ((multidisciplinary or multi-disciplinary or multiprofession* or multi-profession* or integrated or network*) N3 (team* or staff* or task force* or approach* or program* or system* or panel* or forum* or care or manag* or service*))
46	AB ((multidisciplinary or multi-disciplinary or multiprofession* or multi-profession* or integrated or network*) N3 (team* or staff* or task force* or approach* or program* or system* or panel* or forum* or care or manag* or service*))
47	TI (mdt*) OR AB (mdt*)
48	TI ((interdisciplinary or inter-disciplinary or interprofession* or inter-profession*) N3 (team* or staff* or task force* or approach* or program* or system* or panel* or forum* or care or manag* or service*))
49	AB ((interdisciplinary or inter-disciplinary or interprofession* or inter-profession*) N3 (team* or staff* or task force* or approach* or program* or system* or panel* or forum* or care or manag* or service*))
50	TI ((transdisciplinary or trans-disciplinary or transprofession* or trans-profession*) N3 (team* or staff* or task force* or approach* or program* or system* or panel* or forum* or care or manag* or service*))
51	AB ((transdisciplinary or trans-disciplinary or transprofession* or trans-profession*) N3 (team* or staff* or task force* or approach* or program* or system* or panel* or forum* or care or manag* or service*))
52	TI (palliative care N2 team*)
53	AB (palliative care N2 team*)
54	TI (pcct*) OR AB (pcct*)
55	TI (network meeting*) OR AB (network meeting*)
56	TI ((interdisciplinary or inter-disciplinary or interprofession* or inter-profession*) N3 (communic* or collaborat* or relation*))
57	AB ((interdisciplinary or inter-disciplinary or interprofession* or inter-profession*) N3 (communic* or collaborat* or relation*))
58	TI ((multidisciplinary or multi-disciplinary or multiprofession* or multi-profession*) N3 (communic* or collaborat* or relation*))
59	AB ((multidisciplinary or multi-disciplinary or multiprofession* or multi-profession*) N3 (communic* or collaborat* or relation*))
60	TI ((transdisciplinary or trans-disciplinary or transprofession* or trans-profession*) N3 (communic* or collaborat* or relation*))
61	AB ((transdisciplinary or trans-disciplinary or transprofession* or trans-profession*) N3 (communic* or collaborat* or relation*))
62	TI ((co-ordinat* or coordinat* or network*) N3 (care or service* or practice*))
63	AB ((co-ordinat* or coordinat* or network*) N3 (care or service* or practice*))
64	41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63
65	9 AND 40 AND 64

## E.7.1 End of life care around the clock

### E.7.1.2 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/

#	Searches
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	exp TELEMEDICINE/
35	(telehealth\$ or tele health\$ or telemedicine\$ or tele medicine\$ or teleconsult\$ or tele consult\$ or mobile health or mhealth or ehealth).ab,ti.
36	(region\$ adj5 tele\$).ab,ti.
37	ANSWERING SERVICES/
38	HOTLINES/
39	(answer\$ adj3 service?).ab,ti.
40	(hotline? or switchboard? or switch board? or call centre? or call service? or backup service?).ab,ti.
41	((email\$ or e-mail\$ or telephon\$ or phone? or videoconferenc\$ or video conferenc\$) adj10 (advice or advis\$ or opinion\$ or consult\$ or support\$)).ab,ti.
42	AFTER-HOURS CARE/
43	(after hours or out of hours).ab,ti.

#	Searches
44	((("24/7" or "24 hour" or "twenty four hour") and (advice or advis\$ or opinion\$ or consult\$ or support\$ or service?)).ab,ti.
45	((speciali\$ or consultant? or doctor? or senior nurse? or registrar nurse? or expert? or professional?) adj3 (advice or advis\$ or support\$)).ab,ti.
46	MODELS, NURSING/
47	COMMUNITY HEALTH NURSING/
48	"HOSPICE AND PALLIATIVE CARE NURSING"/
49	(nurs\$ adj3 (communit\$ or hospice? or palliative)).ab,ti.
50	(nurs\$ adj3 speciali\$).ab,ti.
51	((("24/7" or "24 hour" or "twenty four hour") adj10 nurs\$).ab,ti.
52	(nurs\$ adj3 support\$).ab,ti.
53	or/34-52
54	9 and 33 and 53
55	limit 54 to english language
56	LETTER/
57	EDITORIAL/
58	NEWS/
59	exp HISTORICAL ARTICLE/
60	ANECDOTES AS TOPIC/
61	COMMENT/
62	CASE REPORT/
63	(letter or comment*).ti.
64	or/56-63
65	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
66	64 not 65
67	ANIMALS/ not HUMANS/
68	exp ANIMALS, LABORATORY/
69	exp ANIMAL EXPERIMENTATION/
70	exp MODELS, ANIMAL/
71	exp RODENTIA/
72	(rat or rats or mouse or mice).ti.
73	or/66-72
74	55 not 73

### E.7.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.

#	Searches
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(telehealth\$ or tele health\$ or telemedicine\$ or tele medicine\$ or teleconsult\$ or tele consult\$ or mobile health or mhealth or ehealth).ab,ti.
24	(region\$ adj5 tele\$).ab,ti.
25	(answer\$ adj3 service?).ab,ti.
26	(hotline? or switchboard? or switch board? or call centre? or call service? or backup service?).ab,ti.
27	((email\$ or e-mail\$ or telephon\$ or phone? or videoconferenc\$ or video conferenc\$) adj10 (advice or advis\$ or opinion\$ or consult\$ or support\$)).ab,ti.
28	(after hours or out of hours).ab,ti.
29	((("24/7" or "24 hour" or "twenty four hour") and (advice or advis\$ or opinion\$ or consult\$ or support\$ or service?)).ab,ti.
30	((speciali\$ or consultant? or doctor? or senior nurse? or registrar nurse? or expert? or professional?) adj3 (advice or advis\$ or support\$)).ab,ti.
31	(nurs\$ adj3 (communit\$ or hospice? or palliative)).ab,ti.
32	(nurs\$ adj3 speciali\$).ab,ti.
33	((("24/7" or "24 hour" or "twenty four hour") adj10 nurs\$).ab,ti.
34	(nurs\$ adj3 support\$).ab,ti.
35	or/23-34
36	5 and 22 and 35

### E.7.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8



#	Searches
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab,kw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab,kw.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab,kw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab,kw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab,kw.
18	(last year of life or LYOL or life\$ end).ti,ab,kw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab,kw.
20	((advanced or late or last or end or final or terminal) adj phase\$).ti,ab,kw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ti,ab,kw.
25	LIVING WILLS/
26	living will?.ti,ab,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ti,ab,kw.
33	or/10-32
34	exp TELEMEDICINE/
35	(telehealth\$ or tele health\$ or telemedicine\$ or tele medicine\$ or teleconsult\$ or tele consult\$ or mobile health or mhealth or ehealth).ab,ti,kw.
36	(region\$ adj5 tele\$).ab,ti,kw.
37	ANSWERING SERVICES/
38	HOTLINES/
39	(answer\$ adj3 service?).ab,ti,kw.
40	(hotline? or switchboard? or switch board? or call centre? or call service? or backup service?).ab,ti,kw.
41	((email\$ or e-mail\$ or telephon\$ or phone? or videoconferenc\$ or video conferenc\$) adj10 (advice or advis\$ or opinion\$ or consult\$ or support\$)).ab,ti,kw.
42	AFTER-HOURS CARE/
43	(after hours or out of hours).ti,kw.
44	((("24/7" or "24 hour" or "twenty four hour") and (advice or advis\$ or opinion\$ or consult\$ or support\$ or service?)).ab,ti,kw.
45	((speciali\$ or consultant? or doctor? or senior nurse? or registrar nurse? or expert? or professional?) adj3 (advice or advis\$ or support\$)).ab,ti,kw.
46	MODELS, NURSING/
47	COMMUNITY HEALTH NURSING/
48	"HOSPICE AND PALLIATIVE CARE NURSING"/
49	(nurs\$ adj3 (communit\$ or hospice? or palliative)).ab,ti,kw.

#	Searches
50	(nurs\$ adj3 speciali\$).ab,ti,kw.
51	((("24/7" or "24 hour" or "twenty four hour") adj10 nurs\$).ab,ti,kw.
52	(nurs\$ adj3 support\$).ab,ti,kw.
53	or/34-52
54	9 and 33 and 53

#### E.7.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ti,ab.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ti,ab.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.ti,ab.
25	LIVING WILLS.kw.
26	living will?.ti,ab.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE.kw.
30	palliat\$.ti,ab.
31	HOSPICE CARE.kw.
32	hospice?.ti,ab.
33	or/10-32
34	TELEMEDICINE.kw.

#	Searches
35	(telehealth\$ or tele health\$ or telemedicine\$ or tele medicine\$ or teleconsult\$ or tele consult\$ or mobile health or mhealth or ehealth).tw,tx.
36	(region\$ adj5 tele\$).tw,tx.
37	ANSWERING SERVICES.kw.
38	HOTLINES.kw.
39	(answer\$ adj3 service?).tw,tx.
40	(hotline? or switchboard? or switch board? or call centre? or call service? or backup service?).tw,tx.
41	((email\$ or e-mail\$ or telephon\$ or phone? or videoconferenc\$ or video conferenc\$) adj10 (advice or advis\$ or opinion\$ or consult\$ or support\$)).tw,tx.
42	AFTER-HOURS CARE.kw.
43	(after hours or out of hours).ab,ti.
44	("24.kw.7" or "24 hour" or "twenty four hour") and (advice or advis\$ or opinion\$ or consult\$ or support\$ or service?).tw,tx.
45	((speciali\$ or consultant? or doctor? or senior nurse? or registrar nurse? or expert? or professional?) adj3 (advice or advis\$ or support\$)).tw,tx.
46	MODELS, NURSING.kw.
47	COMMUNITY HEALTH NURSING.kw.
48	"HOSPICE AND PALLIATIVE CARE NURSING".kw.
49	(nurs\$ adj3 (communit\$ or hospice? or palliative)).tw,tx.
50	(nurs\$ adj3 speciali\$).tw,tx.
51	("24.kw.7" or "24 hour" or "twenty four hour") adj10 nurs\$).tw,tx.
52	(nurs\$ adj3 support\$).tw,tx.
53	or/34-52
54	9 and 33 and 53

### E.7.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.

#	Searches
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

#### E.7.61 Database: Embase

#	Searches
1	*ADOLESCENT/ or *MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp *CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp *INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp *PEDIATRICS/ or exp *PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx.
9	or/1-8
10	*TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	*RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.

#	Searches
23	*ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	*LIVING WILLS/
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	*HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	exp *TELEHEALTH/
35	(telehealth\$ or tele health\$ or telemedicine\$ or tele medicine\$ or teleconsult\$ or tele consult\$ or mobile health or mhealth or ehealth).ab,ti.
36	(region\$ adj5 tele\$).ab,ti.
37	*TELEPHONE/
38	(answer\$ adj3 service?).ab,ti.
39	(hotline? or switchboard? or switch board? or call centre? or call service? or backup service?).ab,ti.
40	((email\$ or e-mail\$ or telephon\$ or phone? or videoconferenc\$ or video conferenc\$) adj10 (advice or advis\$ or opinion\$ or consult\$ or support\$)).ab,ti.
41	(after hours or out of hours).ab,ti.
42	((("24/7" or "24 hour" or "twenty four hour") and (advice or advis\$ or opinion\$ or consult\$ or support\$ or service?)).ab,ti.
43	((speciali\$ or consultant? or doctor? or senior nurse? or registrar nurse? or expert? or professional?) adj3 (advice or advis\$ or support\$)).ab,ti.
44	*COMMUNITY HEALTH NURSING/
45	HOSPICE NURSING/
46	PALLIATIVE NURSING/
47	(nurs\$ adj3 (communit\$ or hospice? or palliative)).ab,ti.
48	(nurs\$ adj3 speciali\$).ab,ti.
49	((("24/7" or "24 hour" or "twenty four hour") adj10 nurs\$).ab,ti.
50	(nurs\$ adj3 support\$).ab,ti.
51	or/34-50
52	9 and 33 and 51
53	limit 52 to english language
54	letter.pt. or LETTER/
55	note.pt.
56	editorial.pt.
57	CASE REPORT/ or CASE STUDY/
58	(letter or comment*).ti.
59	or/54-58
60	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
61	59 not 60
62	ANIMAL/ not HUMAN/
63	NONHUMAN/
64	exp ANIMAL EXPERIMENT/

#	Searches
65	exp EXPERIMENTAL ANIMAL/
66	ANIMAL MODEL/
67	exp RODENT/
68	(rat or rats or mouse or mice).ti.
69	or/61-68
70	53 not 69

## E.8.1 Rapid transfer

### E.8.1.2 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.

#	Searches
33	or/10-32
34	PATIENT TRANSFER/
35	(rapid\$ adj5 transfer\$).ab,ti.
36	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 transfer\$).ab,ti.
37	((program\$ or Care plan\$ or parallel plan\$ or Ambulance? or transport\$ or vehicle? or Staff\$ or speciali\$ nurse? or p?ediatrician? or Medication? or medicine? or symptom? management plan? or sedat\$ or Equipment or suppl\$ or Regulat\$ or legal oblig\$ or coroner? or consent form? or service? or facilitat\$) adj7 transfer\$).ab,ti.
38	(compassion\$ adj5 extubat\$).ab,ti.
39	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 extubat\$).ab,ti.
40	((program\$ or Care plan\$ or parallel plan\$ or staff\$ or health care professional? or HCP or nursing or nurse? or support\$ or speciali\$ or chaplain? or communicat\$ or discuss\$ or service? or facilitat\$) adj5 extubat\$).ab,ti.
41	((life sustain\$ or life support\$) and (treatment? or care) and (transfer\$ or extuba\$)).ab,ti.
42	((availab\$ or option\$ or potential\$ or possib\$ or support\$) adj5 (extubat\$ or transfer\$)).ab,ti.
43	or/34-42
44	9 and 33 and 43
45	limit 44 to english language
46	LETTER/
47	EDITORIAL/
48	NEWS/
49	exp HISTORICAL ARTICLE/
50	ANECDOTES AS TOPIC/
51	COMMENT/
52	CASE REPORT/
53	(letter or comment*).ti.
54	or/46-53
55	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
56	54 not 55
57	ANIMALS/ not HUMANS/
58	exp ANIMALS, LABORATORY/
59	exp ANIMAL EXPERIMENTATION/
60	exp MODELS, ANIMAL/
61	exp RODENTIA/
62	(rat or rats or mouse or mice).ti.
63	or/56-62
64	45 not 63

### E.8.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.

#	Searches
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(rapid\$ adj5 transfer\$).ab,ti.
24	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 transfer\$).ab,ti.
25	((program\$ or Care plan\$ or parallel plan\$ or Ambulance? or transport\$ or vehicle? or Staff\$ or speciali\$ nurse? or p?ediatrician? or Medication? or medicine? or symptom? management plan? or sedat\$ or Equipment or suppl\$ or Regulat\$ or legal oblig\$ or coroner? or consent form? or service? or facilitat\$) adj7 transfer\$).ab,ti.
26	(compassion\$ adj5 extubat\$).ab,ti.
27	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 extubat\$).ab,ti.
28	((program\$ or Care plan\$ or parallel plan\$ or staff\$ or health care professional? or HCP or nursing or nurse? or support\$ or speciali\$ or chaplain? or communicat\$ or discuss\$ or service? or facilitat\$) adj5 extubat\$).ab,ti.
29	((life sustain\$ or life support\$) and (treatment? or care) and (transfer\$ or extuba\$)).ab,ti.
30	((availab\$ or option\$ or potential\$ or possib\$ or support\$) adj5 (extubat\$ or transfer\$)).ab,ti.
31	or/23-30
32	5 and 22 and 31

### E.8.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/



#	Searches
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ab,ti,kw.
12	dying.ab,ti,kw.
13	(end adj3 life).ab,ti,kw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ab,ti,kw.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ab,ti,kw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ab,ti,kw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ab,ti,kw.
18	(last year of life or LYOL or life\$ end).ab,ti,kw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ab,ti,kw.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti,kw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti,kw.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ab,ti,kw.
29	PALLIATIVE CARE/
30	palliat\$.ab,ti,kw.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	PATIENT TRANSFER/
35	(rapid\$ adj5 transfer\$).ab,ti,kw.
36	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 transfer\$).ab,ti,kw.
37	((program\$ or Care plan\$ or parallel plan\$ or Ambulance? or transport\$ or vehicle? or Staff\$ or speciali\$ nurse? or p?ediatrician? or Medication? or medicine? or symptom? management plan? or sedat\$ or Equipment or suppl\$ or Regulat\$ or legal oblig\$ or coroner? or consent form? or service? or facilitat\$) adj7 transfer\$).ab,ti,kw.
38	(compassion\$ adj5 extubat\$).ab,ti,kw.
39	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 extubat\$).ab,ti,kw.
40	((program\$ or Care plan\$ or parallel plan\$ or staff\$ or health care professional? or HCP or nursing or nurse? or support\$ or speciali\$ or chaplain? or communicat\$ or discuss\$ or service? or facilitat\$) adj5 extubat\$).ab,ti,kw.
41	((life sustain\$ or life support\$) and (treatment? or care) and (transfer\$ or extuba\$)).ab,ti,kw.
42	((availab\$ or option\$ or potential\$ or possib\$ or support\$) adj5 (extubat\$ or transfer\$)).ab,ti,kw.
43	or/34-42
44	9 and 33 and 43

### E.8.41 Database: Cochrane Database of Systematic Reviews

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ab,ti.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ab,ti.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ab,ti.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ab,ti.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ab,ti.
12	dying.ab,ti.
13	(end adj3 life).ab,ti.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ab,ti.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ab,ti.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ab,ti.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ab,ti.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ab,ti.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.ab,ti.
25	LIVING WILLS.kw.
26	living will?.ab,ti.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).ab,ti.
29	PALLIATIVE CARE.kw.
30	palliat\$.ab,ti.
31	HOSPICE CARE.kw.
32	hospice?.ab,ti.
33	or/10-32
34	PATIENT TRANSFER.kw.
35	(rapid\$ adj5 transfer\$).ab,ti.
36	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 transfer\$).ab,ti.
37	((program\$ or Care plan\$ or parallel plan\$ or Ambulance? or transport\$ or vehicle? or Staff\$ or speciali\$ nurse? or p?ediatrician? or Medication? or medicine? or symptom? management plan? or sedat\$ or Equipment or suppl\$ or Regulat\$ or legal oblig\$ or coroner? or consent form? or service? or facilitat\$) adj7 transfer\$).ab,ti.
38	(compassion\$ adj5 extubat\$).ab,ti.

#	Searches
39	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 extubat\$).ab,ti.
40	((program\$ or Care plan\$ or parallel plan\$ or staff\$ or health care professional? or HCP or nursing or nurse? or support\$ or speciali\$ or chaplain? or communicat\$ or discuss\$ or service? or facilitat\$) adj5 extubat\$).ab,ti.
41	((life sustain\$ or life support\$) and (treatment? or care) and (transfer\$ or extuba\$)).ab,ti.
42	((availab\$ or option\$ or potential\$ or possib\$ or support\$) adj5 (extubat\$ or transfer\$)).ab,ti.
43	or/34-42
44	9 and 33 and 43

### E.8.51 Database: Database of Abstracts of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx.
12	dying.tw,tx.
13	(end adj3 life).tw,tx.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
18	(last year of life or LYOL or life\$ end).tw,tx.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw,tx.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.tw,tx.
25	LIVING WILLS.kw.
26	living will?.tw,tx.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).tw,tx.
29	PALLIATIVE CARE.kw.
30	palliat\$.tw,tx.
31	HOSPICE CARE.kw.
32	hospice?.tw,tx.

#	Searches
33	or/10-32
34	PATIENT TRANSFER.kw.
35	(rapid\$ adj5 transfer\$).tw,tx.
36	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 transfer\$).tw,tx.
37	((program\$ or Care plan\$ or parallel plan\$ or Ambulance? or transport\$ or vehicle? or Staff\$ or speciali\$ nurse? or p?ediatrician? or Medication? or medicine? or symptom? management plan? or sedat\$ or Equipment or suppl\$ or Regulat\$ or legal oblig\$ or coroner? or consent form? or service? or facilitat\$) adj7 transfer\$).tw,tx.
38	(compassion\$ adj5 extubat\$).tw,tx.
39	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 extubat\$).tw,tx.
40	((program\$ or Care plan\$ or parallel plan\$ or staff\$ or health care professional? or HCP or nursing or nurse? or support\$ or speciali\$ or chaplain? or communicat\$ or discuss\$ or service? or facilitat\$) adj5 extubat\$).tw,tx.
41	((life sustain\$ or life support\$) and (treatment? or care) and (transfer\$ or extuba\$)).tw,tx.
42	((availab\$ or option\$ or potential\$ or possib\$ or support\$) adj5 (extubat\$ or transfer\$)).tw,tx.
43	or/34-42
44	9 and 33 and 43

#### E.8.61 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/

#	Searches
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.8.71 Database: Embase

#	Searches
1	*ADOLESCENT/ or *MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp *CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp *INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp *PEDIATRICS/ or exp *PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx.
9	or/1-8
10	*TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	*RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	*ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	*LIVING WILLS/
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE CARE/

#	Searches
30	palliat\$.ti,ab.
31	*HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	*PATIENT TRANSPORT/
35	(rapid\$ adj5 transfer\$).ab,ti.
36	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 transfer\$).ab,ti.
37	((program\$ or Care plan\$ or parallel plan\$ or Ambulance? or transport\$ or vehicle? or Staff\$ or speciali\$ nurse? or p?ediatrician? or Medication? or medicine? or symptom? management plan? or sedat\$ or Equipment or suppl\$ or Regulat\$ or legal oblig\$ or coroner? or consent form? or service? or facilitat\$) adj7 transfer\$).ab,ti.
38	(compassion\$ adj5 extubat\$).ab,ti.
39	((home? or house? or hospital? or hospice? or intensive care unit? or ICU or PICU or NICU or intensive therapy unit? or ITU or high dependency unit? or HDU) adj5 extubat\$).ab,ti.
40	((program\$ or Care plan\$ or parallel plan\$ or staff\$ or health care professional? or HCP or nursing or nurse? or support\$ or speciali\$ or chaplain? or communicat\$ or discuss\$ or service? or facilitat\$) adj5 extubat\$).ab,ti.
41	((life sustain\$ or life support\$) and (treatment? or care) and (transfer\$ or extuba\$)).ab,ti.
42	((availab\$ or option\$ or potential\$ or possib\$ or support\$) adj5 (extubat\$ or transfer\$)).ab,ti.
43	or/34-42
44	9 and 33 and 43
45	limit 44 to english language
46	letter.pt. or LETTER/
47	note.pt.
48	editorial.pt.
49	CASE REPORT/ or CASE STUDY/
50	(letter or comment*).ti.
51	or/46-50
52	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
53	51 not 52
54	ANIMAL/ not HUMAN/
55	NONHUMAN/
56	exp ANIMAL EXPERIMENT/
57	exp EXPERIMENTAL ANIMAL/
58	ANIMAL MODEL/
59	exp RODENT/
60	(rat or rats or mouse or mice).ti.
61	or/53-60
62	45 not 61

## E.9.1 Care based in the child or young person's home

### E.9.1.2 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.

#	Searches
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	HOME CARE SERVICES/
35	HOME CARE SERVICES, HOSPITAL-BASED/
36	COMMUNITY HEALTH NURSING/
37	HOME HEALTH NURSING/
38	FAMILY NURSING/
39	HOME CARE AGENCIES/
40	HOME NURSING/
41	(homecar\$ or home-car\$ or homebased or home-based).ab,ti.
42	((home or in-home or domicil\$) adj3 (base\$ or care or caring)).ab,ti.
43	((hospital\$ or hospice?) adj3 home).ab,ti.
44	((nurse? or nursing) adj3 home).ab,ti.
45	(patient? adj3 home).ab,ti.

#	Searches
46	HEMODIALYSIS, HOME/
47	((hemodialysis or renal dialysis) adj3 home).ab,ti.
48	HOME INFUSION THERAPY/
49	(infusion therap\$ adj3 (home or outpatient?)).ab,ti.
50	PARENTERAL NUTRITION, HOME/
51	PARENTERAL NUTRITION, HOME TOTAL/
52	(parenteral\$ adj3 home).ab,ti.
53	HOMEMAKER SERVICES/
54	homemaker service?.ab,ti.
55	or/34-54
56	9 and 33 and 55
57	limit 56 to english language
58	LETTER/
59	EDITORIAL/
60	NEWS/
61	exp HISTORICAL ARTICLE/
62	ANECDOTES AS TOPIC/
63	COMMENT/
64	CASE REPORT/
65	(letter or comment*).ti.
66	or/58-65
67	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
68	66 not 67
69	ANIMALS/ not HUMANS/
70	exp ANIMALS, LABORATORY/
71	exp ANIMAL EXPERIMENTATION/
72	exp MODELS, ANIMAL/
73	exp RODENTIA/
74	(rat or rats or mouse or mice).ti.
75	or/68-74
76	57 not 75

### E.9.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.



#	Searches
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(homecar\$ or home-car\$ or homebased or home-based).ab,ti.
24	((home or in-home or domicil\$) adj3 (base\$ or care or caring)).ab,ti.
25	((hospital\$ or hospice?) adj3 home).ab,ti.
26	((nurse? or nursing) adj3 home).ab,ti.
27	(patient? adj3 home).ab,ti.
28	((hemodialysis or renal dialysis) adj3 home).ab,ti.
29	(infusion therap\$ adj3 (home or outpatient?)).ab,ti.
30	(parenteral\$ adj3 home).ab,ti.
31	homemaker service?.ab,ti.
32	or/23-31
33	5 and 22 and 32
34	limit 33 to english language

### E.9.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab,kw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.

#	Searches
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti,kw.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	HOME CARE SERVICES/
35	HOME CARE SERVICES, HOSPITAL-BASED/
36	COMMUNITY HEALTH NURSING/
37	HOME HEALTH NURSING/
38	FAMILY NURSING/
39	HOME CARE AGENCIES/
40	HOME NURSING/
41	(homecar\$ or home-car\$ or homebased or home-based).ab,ti,kw.
42	((home or in-home or domicil\$) adj3 (base\$ or care or caring)).ab,ti,kw.
43	((hospital\$ or hospice?) adj3 home).ab,ti.
44	((nurse? or nursing) adj3 home).ab,ti.
45	(patient? adj3 home).ab,ti.
46	HEMODIALYSIS, HOME/
47	((hemodialysis or renal dialysis) adj3 home).ab,ti,kw.
48	HOME INFUSION THERAPY/
49	(infusion therap\$ adj3 (home or outpatient?)).ab,ti,kw.
50	PARENTERAL NUTRITION, HOME/
51	PARENTERAL NUTRITION, HOME TOTAL/
52	(parenteral\$ adj3 home).ab,ti,kw.
53	HOMEMAKER SERVICES/
54	homemaker service?.ab,ti,kw.
55	or/34-54
56	9 and 33 and 55
57	limit 56 to english language

## E.9.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx,kw.
12	dying.tw,tx,kw.
13	(end adj3 life).tw,tx.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
18	(last year of life or LYOL or life\$ end).tw,tx.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw,tx.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.tw,tx.
25	LIVING WILLS.kw.
26	living will?.tw,tx,kw.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).tw,tx.
29	PALLIATIVE CARE.kw.
30	palliat\$.tw,tx,kw.
31	HOSPICE CARE.kw.
32	hospice?.tw,tx,kw.
33	or/10-32
34	HOME CARE SERVICES.kw.
35	HOME CARE SERVICES, HOSPITAL-BASED.kw.
36	COMMUNITY HEALTH NURSING.kw.
37	HOME HEALTH NURSING.kw.
38	FAMILY NURSING.kw.
39	HOME CARE AGENCIES.kw.
40	HOME NURSING.kw.
41	(homecar\$ or home-car\$ or homebased or home-based).tw,tx,kw.

#	Searches
42	((home or in-home or domicil\$) adj3 (base\$ or care or caring)).tw,tx,kw.
43	((hospital\$ or hospice?) adj3 home).tw,tx.
44	((nurse? or nursing) adj3 home).tw,tx.
45	(patient? adj3 home).tw,tx.
46	HEMODIALYSIS, HOME.kw.
47	((hemodialysis or renal dialysis) adj3 home).tw,tx,kw.
48	HOME INFUSION THERAPY.kw.
49	(infusion therap\$ adj3 (home or outpatient?)).tw,tx,kw.
50	PARENTERAL NUTRITION, HOME.kw.
51	PARENTERAL NUTRITION, HOME TOTAL.kw.
52	(parenteral\$ adj3 home).tw,tx,kw.
53	HOMEMAKER SERVICES.kw.
54	homemaker service?.tw,tx,kw.
55	or/34-54
56	9 and 33 and 55

### E.9.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/

#	Searches
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.9.61 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	TERMINALLY ILL PATIENT/
11	TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
24	advance? directive?.ab,ti.
25	LIVING WILL/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE THERAPY/
30	CANCER PALLIATIVE THERAPY/
31	palliat\$.ti,ab.

#	Searches
32	HOSPICE CARE/
33	HOSPICE PATIENT/
34	hospice?.ab,ti.
35	or/10-34
36	HOME CARE/
37	(homecar\$ or home-car\$ or homebased or home-based).ab,ti.
38	((home or in-home or domicil\$) adj3 (base\$ or care or caring)).ab,ti.
39	((hospital\$ or hospice?) adj3 home).ab,ti.
40	((nurse? or nursing) adj3 home).ab,ti.
41	(patient? adj3 home).ab,ti.
42	homemaker service?.ab,ti.
43	HOME DIALYSIS/
44	((hemodialysis or renal dialysis) adj3 home).ab,ti.
45	HOME HEALTH AGENCY/
46	HOME INTRAVENOUS THERAPY/
47	((intravenous or IV) adj3 home).ab,ti.
48	HOME OXYGEN THERAPY/
49	(oxygen adj3 home).ab,ti.
50	COMMUNITY HEALTH NURSING/
51	FAMILY NURSING/
52	(infusion therap\$ adj3 (home or outpatient?)).ab,ti.
53	(parenteral\$ adj3 home).ab,ti.
54	or/36-53
55	9 and 35 and 54
56	limit 55 to english language
57	letter.pt. or LETTER/
58	note.pt.
59	editorial.pt.
60	CASE REPORT/ or CASE STUDY/
61	(letter or comment*).ti.
62	or/57-61
63	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
64	62 not 63
65	ANIMAL/ not HUMAN/
66	NONHUMAN/
67	exp ANIMAL EXPERIMENT/
68	exp EXPERIMENTAL ANIMAL/
69	ANIMAL MODEL/
70	exp RODENT/
71	(rat or rats or mouse or mice).ti.
72	or/64-71
73	56 not 72

### E.9.71 Database: PsycInfo

#	Searches
1	adolescen\$.ag.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,id,jw.
3	(child\$ or school\$ or preschool\$).ag.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,id,jw.
5	(infan\$ or neonat\$).ag.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies or p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,id,jw.
7	or/1-6
8	TERMINALLY ILL PATIENTS/
9	TERMINAL CANCER/
10	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
11	"DEATH AND DYING"/
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
22	ADVANCE DIRECTIVES/
23	advance? directive?.ab,ti.
24	living will?.ab,ti.
25	(terminal\$ adj3 (care\$ or caring)).ti,ab.
26	PALLIATIVE CARE/
27	palliat\$.ti,ab.
28	HOSPICE/
29	hospice?.ab,ti.
30	or/8-29
31	HOME CARE/
32	HOME CARE PERSONNEL/
33	HOME VISITING PROGRAMS/
34	(homecar\$ or home-car\$ or homebased or home-based).ab,ti.
35	((home or in-home or domicil\$) adj3 (base\$ or care or caring)).ab,ti.
36	((hospital\$ or hospice?) adj3 home).ab,ti.
37	((nurse? or nursing) adj3 home).ab,ti.
38	(patient? adj3 home).ab,ti.
39	((hemodialysis or renal dialysis) adj3 home).ab,ti.
40	(infusion therap\$ adj3 (home or outpatient?)).ab,ti.
41	(parenteral\$ adj3 home).ab,ti.

#	Searches
42	homemaker service?.ab,ti.
43	or/31-42
44	7 and 30 and 43
45	limit 44 to english language
46	limit 45 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal" or "0130 peer-reviewed status unknown" or "0500 electronic collection")

### E.9.81 Database: CINAHL (Cumulative Index to Nursing and Allied Health Literature)

#	Searches
1	ADOLESCENT/
2	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*).ti,ab.
3	CHILD/
4	CHILD,PRESCHOOL/
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*).ti,ab.
6	INFANT/
7	exp INFANT, NEWBORN/
8	(infan* or neonat* or newborn* or baby or babies).ti,ab.
9	exp PEDIATRICS/
10	exp PUBERTY/
11	(pediatric* or paediatric* or pubert* or prepubert* or pubescen* or prepubescen*).ti,ab.
12	or/1-11
13	TERMINALLY ILL PATIENTS/
14	((terminal* or final or advance* or incurable or "life limit*") adj3 (ill* or disease* or condition*)).ti,ab.
15	dying.ti,ab.
16	(end adj3 life).ti,ab.
17	((approach* or close* or near* or imminent* or impending) adj3 death).ti,ab.
18	(Body adj2 ("shut* down" or "shutting down" or deteriorat*)).ti,ab.
19	(deathbed* or "death bed*" or "passing away" or "passing on" or expiring or expiration).ti,ab.
20	((last or final) adj1 (hour* or days* or minute*)).ti,ab.
21	("last year of life" or LYOL or "life* end").ab,ti.
22	("advance* stage*" or "final stage*" or "end stage*" or "last stage*" or "late stage*" or "terminal stage*").ti,ab.
23	((advanced or late or last or end or final or terminal) adj phase*).ab,ti.
24	RESUSCITATION ORDERS/
25	(resuscitat* adj3 (policies or policy or order* or decision* or withhold*)).ab,ti.
26	ADVANCE DIRECTIVES/
27	"advance* directive*".ab,ti.
28	LIVING WILLS/
29	"living will*".ab,ti.
30	TERMINAL CARE/
31	(terminal* adj3 (care* or caring)).ti,ab.
32	PALLIATIVE CARE/
33	palliat*.ti,ab.
34	HOSPICE CARE/



#	Searches
35	hospice*.ab,ti.
36	or/13-35
37	HOME HEALTH CARE/
38	COMMUNITY HEALTH NURSING/
39	FAMILY NURSING/
40	HOME NURSING,PROFESSIONAL/
41	HOME HEALTH AIDES/
42	HOME VISITS/
43	HOME NURSING/
44	(homecar* or home-car* or homebased or home-based).ab,ti.
45	((home or in-home or domicil*) adj3 (base* or care or caring)).ab,ti.
46	((hospital* or hospice*) adj3 home).ab,ti.
47	((nurse* or nursing) adj3 home).ab,ti.
48	(patient* adj3 home).ab,ti.
49	HOME DIALYSIS/
50	((hemodialysis or "renal dialysis") adj3 home).ab,ti.
51	HOME INTRAVENOUS THERAPY/
52	((intravenous OR IV) adj3 home).ti,ab
53	HOME NUTRITIONAL SUPPORT/
54	(parenteral* adj3 home).ab,ti.
55	HOME HEALTH AGENCIES/
56	HOMEMAKER SERVICES/
57	"homemaker service*".ab,ti.
58	HOME CARE EQUIPMENT AND SUPPLIES/
59	("infusion therap*" adj3 (home OR outpatient)).ti,ab
60	or/37-59
61	12 and 36 and 60 [Limit to: (Language English)]

## E.101 Emotional and psychological support and interventions

### E.10.12 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	CAREGIVERS/
11	FAMILY/
12	exp PARENTS/

#	Searches
13	SIBLINGS/
14	(carer\$ or caregiver\$ or care-giver\$ or famil\$ or parent\$ or father\$ or mother\$ or brother\$ or sister\$ or sibling?).ti,ab,jw,nw.
15	or/10-14
16	TERMINALLY ILL/
17	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
18	dying.ti,ab.
19	(end adj3 life).ti,ab.
20	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
21	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
22	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
23	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
24	(last year of life or LYOL or life\$ end).ab,ti.
25	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
26	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
27	RESUSCITATION ORDERS/
28	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
29	ADVANCE DIRECTIVES/
30	advance? directive?.ab,ti.
31	LIVING WILLS/
32	living will?.ab,ti.
33	TERMINAL CARE/
34	(terminal\$ adj3 (care\$ or caring)).ti,ab.
35	PALLIATIVE CARE/
36	palliat\$.ti,ab.
37	HOSPICE CARE/
38	hospice?.ab,ti.
39	or/16-38
40	exp *PSYCHOTHERAPY/
41	*PROBLEM SOLVING/
42	((cogniti\$ or family or behavio?r\$ or psycholog\$) adj3 (intervention\$ or treatment\$ or therap\$)).ti,ab.
43	((colo?r or music or play or Animal Assisted or Equine-Assisted or Art or Relaxation or Dance or Gestalt or Horticultural or narrative or Nondirective or Psychoanalytic or Reality or Socioenvironmental or Milieu or Couple? or Family or Marital or Collaborative or Exposure or Group or Inte?grative or Reminisce or Attachment Focus?ed or Brief Solution Focus?ed or compassion focus?ed or Dynamic or Interpersonal or inter personal or Life Review or Mentali#zation based or Person Centred or Personal Construct or Rational emotive or acceptance or commitment or multi system\$ or multisystem\$ or systemic or parent? operant) adj (therapy or therapies)).ti,ab.
44	(Psychotherap\$ or bibliotherap\$ or hypnotherap\$).ti,ab.
45	(hypnosis or relaxation or Autogenic Training or Meditation or Crisis Intervention or Catharsis or Therapeutic Community or Psychodrama or Guided Imagery or Mindfulness or Psychoeducation or Compassionate Mind or Eye Movement Desensiti?ation or EMDR or Intensive Interaction? or Mellow Babies Program? or Parenting Program? or Positive psychology or Rogerian counsel?ing or Triple P or Positive Parenting Program? or Webster Stratton).ti,ab.

#	Searches
46	((Multifamil\$ or Family or families or Sibling?) adj3 support group?).ti,ab.
47	problem solving.ti,ab.
48	((cope? or coping) adj (therap\$ or skill?)).ti,ab.
49	or/40-48
50	9 and 39 and 49
51	15 and 39 and 49
52	*ADAPTATION, PSYCHOLOGICAL/
53	THERAPY.fs.
54	9 or 15
55	39 and 52 and 53 and 54
56	exp *BEREAVEMENT/
57	THERAPY.fs.
58	15 and 39 and 56 and 57
59	50 or 51 or 55 or 58
60	limit 59 to english language
61	LETTER/
62	EDITORIAL/
63	NEWS/
64	exp HISTORICAL ARTICLE/
65	ANECDOTES AS TOPIC/
66	COMMENT/
67	CASE REPORT/
68	(letter or comment*).ti.
69	or/61-68
70	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
71	69 not 70
72	ANIMALS/ not HUMANS/
73	exp ANIMALS, LABORATORY/
74	exp ANIMAL EXPERIMENTATION/
75	exp MODELS, ANIMAL/
76	exp RODENTIA/
77	(rat or rats or mouse or mice).ti.
78	or/71-77
79	60 not 78

### E.10.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescenc\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	(carer\$ or caregiver\$ or care-giver\$ or famil\$ or parent\$ or father\$ or mother\$ or brother\$ or sister\$ or sibling?).ti,ab,jw,nw.

#	Searches
7	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
8	dying.ti,ab.
9	(end adj3 life).ti,ab.
10	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
11	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
12	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
13	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
14	(last year of life or LYOL or life\$ end).ab,ti.
15	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
16	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
17	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
18	advance? directive?.ab,ti.
19	living will?.ab,ti.
20	(terminal\$ adj3 (care\$ or caring)).ti,ab.
21	palliat\$.ti,ab.
22	hospice?.ab,ti.
23	or/7-22
24	((cogniti\$ or family or behavio?r\$ or psycholog\$) adj3 (intervention\$ or treatment\$ or therap\$)).ti,ab.
25	((colo?r or music or play or Animal Assisted or Equine-Assisted or Art or Relaxation or Dance or Gestalt or Horticultural or narrative or Nondirective or Psychoanalytic or Reality or Socioenvironmental or Milieu or Couple? or Family or Marital or Collaborative or Exposure or Group or Inte?grative or Reminisce or Attachment Focus?ed or Brief Solution Focus?ed or compassion focus?ed or Dynamic or Interpersonal or inter personal or Life Review or Mentali#zation based or Person Centred or Personal Construct or Rational emotive or acceptance or commitment or multi system\$ or multisystem\$ or systemic or parent? operant) adj (therapy or therapies)).ti,ab.
26	(Psychotherap\$ or bibliotherap\$ or hypnotherap\$).ti,ab.
27	(hypnosis or relaxation or Autogenic Training or Meditation or Crisis Intervention or Catharsis or Therapeutic Community or Psychodrama or Guided Imagery or Mindfulness or Psychoeducation or Compassionate Mind or Eye Movement Desensiti?ation or EMDR or Intensive Interaction? or Mellow Babies Program? or Parenting Program? or Positive psychology or Rogerian counsel?ing or Triple P or Positive Parenting Program? or Webster Stratton).ti,ab.
28	((Multifamil\$ or Family or families or Sibling?) adj3 support group?).ti,ab.
29	problem solving.ti,ab.
30	((cope? or coping) adj (therap\$ or skill?)).ti,ab.
31	or/24-30
32	5 and 23 and 31
33	6 and 23 and 31
34	32 or 33

### E.10.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/

#	Searches
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	CAREGIVERS/
11	FAMILY/
12	exp PARENTS/
13	SIBLINGS/
14	(carer\$ or caregiver\$ or care-giver\$ or famil\$ or parent\$ or father\$ or mother\$ or brother\$ or sister\$ or sibling?).ti,ab,jw.
15	or/10-14
16	TERMINALLY ILL/
17	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
18	dying.ti,ab.
19	(end adj3 life).ti,ab.
20	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
21	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
22	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
23	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
24	(last year of life or LYOL or life\$ end).ab,ti.
25	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
26	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
27	RESUSCITATION ORDERS/
28	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti,kw.
29	ADVANCE DIRECTIVES/
30	advance? directive?.ab,ti,kw.
31	LIVING WILLS/
32	living will?.ab,ti,kw.
33	TERMINAL CARE/
34	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
35	PALLIATIVE CARE/
36	palliat\$.ti,ab.
37	HOSPICE CARE/
38	hospice?.ab,ti,kw.
39	or/16-38
40	exp PSYCHOTHERAPY/
41	PROBLEM SOLVING/
42	((cogniti\$ or family or behavior\$ or psycholog\$) adj3 (intervention\$ or treatment\$ or therap\$)).ti,ab.
43	((colo?r or music or play or Animal Assisted or Equine-Assisted or Art or Relaxation or Dance or Gestalt or Horticultural or narrative or Nondirective or Psychoanalytic or Reality or Socioenvironmental or Milieu or Couple? or Family or Marital or Collaborative or Exposure or

#	Searches
	Group or Inte?grative or Reminisce or Attachment Focus?ed or Brief Solution Focus?ed or compassion focus?ed or Dynamic or Interpersonal or inter personal or Life Review or Mentali#zation based or Person Centred or Personal Construct or Rational emotive or acceptance or commitment or multi system\$ or multisystem\$ or systemic or parent? operant) adj (therapy or therapies)).ti,ab.
44	(Psychotherap\$ or bibliotherap\$ or hypnotherap\$).ti,ab,kw.
45	(hypnosis or relaxation or Autogenic Training or Meditation or Crisis Intervention or Catharsis or Therapeutic Community or Psychodrama or Guided Imagery or Mindfulness or Psychoeducation or Compassionate Mind or Eye Movement Desensiti?ation or EMDR or Intensive Interaction? or Mellow Babies Program? or Parenting Program? or Positive psychology or Rogerian counsel?ing or Triple P or Positive Parenting Program? or Webster Stratton).ti,ab.
46	((Multifamil\$ or Family or families or Sibling?) adj3 support group?).ti,ab.
47	problem solving.ti,ab,kw.
48	((cope? or coping) adj (therap\$ or skill?)).ti,ab.
49	or/40-48
50	9 and 39 and 49
51	15 and 39 and 49
52	ADAPTATION, PSYCHOLOGICAL/
53	th.fs.
54	9 or 15
55	39 and 52 and 53 and 54
56	exp BEREAVEMENT/
57	th.fs.
58	15 and 39 and 56 and 57
59	50 or 51 or 55 or 58

#### E.10.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	CAREGIVERS.kw.
11	FAMILY.kw.
12	PARENTS.kw.
13	SIBLINGS.kw.
14	(carer\$ or caregiver\$ or care-giver\$ or famil\$ or parent\$ or father\$ or mother\$ or brother\$ or sister\$ or sibling?).tw,tx,jw,rw.
15	or/10-14
16	TERMINALLY ILL.kw.

#	Searches
17	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
18	dying.ti,ab.
19	(end adj3 life).ti,ab.
20	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
21	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
22	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
23	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
24	(last year of life or LYOL or life\$ end).ab,ti.
25	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
26	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
27	RESUSCITATION ORDERS.kw.
28	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
29	ADVANCE DIRECTIVES.kw.
30	advance? directive?.ab,ti.
31	LIVING WILLS.kw.
32	living will?.ab,ti.
33	TERMINAL CARE.kw.
34	(terminal\$ adj3 (care\$ or caring)).ti,ab.
35	PALLIATIVE CARE.kw.
36	palliat\$.ti,ab.
37	HOSPICE CARE.kw.
38	hospice?.ab,ti.
39	or/16-38
40	PSYCHOTHERAPY.kw.
41	PROBLEM SOLVING.kw.
42	((cogniti\$ or family or behavio?r\$ or psycholog\$) adj3 (intervention\$ or treatment\$ or therap\$)).ti,ab.
43	((colo?r or music or play or Animal Assisted or Equine-Assisted or Art or Relaxation or Dance or Gestalt or Horticultural or narrative or Nondirective or Psychoanalytic or Reality or Socioenvironmental or Milieu or Couple? or Family or Marital or Collaborative or Exposure or Group or Inte?grative or Reminisce or Attachment Focus?ed or Brief Solution Focus?ed or compassion focus?ed or Dynamic or Interpersonal or inter personal or Life Review or Mentali#zation based or Person Centred or Personal Construct or Rational emotive or acceptance or commitment or multi system\$ or multisystem\$ or systemic or parent? operant) adj (therapy or therapies)).ti,ab.
44	(Psychotherap\$ or bibliotherap\$ or hypnotherap\$).ti,ab.
45	(hypnosis or relaxation or Autogenic Training or Meditation or Crisis Intervention or Catharsis or Therapeutic Community or Psychodrama or Guided Imagery or Mindfulness or Psychoeducation or Compassionate Mind or Eye Movement Desensiti?ation or EMDR or Intensive Interaction? or Mellow Babies Program? or Parenting Program? or Positive psychology or Rogerian counsel?ing or Triple P or Positive Parenting Program? or Webster Stratton).ti,ab.
46	((Multifamil\$ or Family or families or Sibling?) adj3 support group?).ti,ab.
47	problem solving.ti,ab.
48	((cope? or coping) adj (therap\$ or skill?)).ti,ab.
49	or/40-48
50	9 and 39 and 49

#	Searches
51	15 and 39 and 49
52	ADAPTATION, PSYCHOLOGICAL.kw.
53	9 or 15
54	52 and 53
55	39 and 52 and 53
56	BEREAVEMENT.kw.
57	49 and 56
58	50 or 51 or 55 or 57

### E.10.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.



#	Searches
33	or/10-32
34	9 and 33

### E.10.61 Database: Embase

#	Searches
1	*ADOLESCENT/ or *MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp *CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp *INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp *PEDIATRICS/ or exp *PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx.
9	or/1-8
10	*CAREGIVER/
11	*FAMILY/
12	exp *PARENT/
13	*SIBLING/
14	(carer\$ or caregiver\$ or care-giver\$ or famil\$ member? or parent\$ or father\$ or mother\$ or brother\$ or sister\$ or sibling?).ti,ab,jx.
15	famil\$.ti.
16	or/10-15
17	*TERMINALLY ILL/
18	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
19	dying.ti,ab.
20	(end adj3 life).ti,ab.
21	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
22	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
23	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
24	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
25	(last year of life or LYOL or life\$ end).ab,ti.
26	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
27	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
28	*RESUSCITATION ORDERS/
29	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
30	*ADVANCE DIRECTIVES/
31	advance? directive?.ab,ti.
32	*LIVING WILLS/
33	living will?.ab,ti.
34	*TERMINAL CARE/
35	(terminal\$ adj3 (care\$ or caring)).ti,ab.
36	*PALLIATIVE CARE/
37	palliat\$.ti,ab.

#	Searches
38	*HOSPICE CARE/
39	hospice?.ab,ti.
40	or/17-39
41	exp *PSYCHOTHERAPY/
42	*PROBLEM SOLVING/
43	((cogniti\$ or family or behavio?r\$ or psycholog\$) adj3 (intervention\$ or treatment\$ or therap\$)).ti,ab.
44	((colo?r or music or play or Animal Assisted or Equine-Assisted or Art or Relaxation or Dance or Gestalt or Horticultural or narrative or Nondirective or Psychoanalytic or Reality or Socioenvironmental or Milieu or Couple? or Family or Marital or Collaborative or Exposure or Group or Inte?grative or Reminisce or Attachment Focus?ed or Brief Solution Focus?ed or compassion focus?ed or Dynamic or Interpersonal or inter personal or Life Review or Mentali#zation based or Person Centred or Personal Construct or Rational emotive or acceptance or commitment or multi system\$ or multisystem\$ or systemic or parent? operant) adj (therapy or therapies)).ti,ab.
45	(Psychotherap\$ or bibliotherap\$ or hypnotherap\$).ti,ab.
46	(hypnosis or relaxation or Autogenic Training or Meditation or Crisis Intervention or Catharsis or Therapeutic Community or Psychodrama or Guided Imagery or Mindfulness or Psychoeducation or Compassionate Mind or Eye Movement Desensiti?ation or EMDR or Intensive Interaction? or Mellow Babies Program? or Parenting Program? or Positive psychology or Rogerian counsel?ing or Triple P or Positive Parenting Program? or Webster Stratton).ti,ab.
47	((Multifamil\$ or Family or families or Sibling?) adj3 support group?).ti,ab.
48	problem solving.ti,ab.
49	((cope? or coping) adj (therap\$ or skill?)).ti,ab.
50	or/41-49
51	9 and 40 and 50
52	16 and 40 and 50
53	*ADAPTIVE BEHAVIOR/
54	th.fs.
55	9 or 16
56	40 and 53 and 54 and 55
57	*BEREAVEMENT/
58	th.fs.
59	16 and 40 and 57 and 58
60	*BEREAVEMENT COUNSELING/
61	16 and 40 and 60
62	51 or 52 or 56 or 59 or 61
63	limit 62 to english language
64	letter.pt. or LETTER/
65	note.pt.
66	editorial.pt.
67	CASE REPORT/ or CASE STUDY/
68	(letter or comment*).ti.
69	or/64-68
70	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
71	69 not 70
72	ANIMAL/ not HUMAN/

#	Searches
73	NONHUMAN/
74	exp ANIMAL EXPERIMENT/
75	exp EXPERIMENTAL ANIMAL/
76	ANIMAL MODEL/
77	exp RODENT/
78	(rat or rats or mouse or mice).ti.
79	or/71-78
80	63 not 79

### E.10.71 Database: PsycInfo

#	Searches
1	adolescenc\$.ag.
2	(adolescenc\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,id,jw.
3	(child\$ or school\$ or preschool\$).ag.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,id,jw.
5	(infan\$ or neonat\$).ag.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies or p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,id,jw.
7	or/1-6
8	CAREGIVERS/
9	FAMILY/
10	PARENTS/
11	SIBLINGS/
12	(carer\$ or caregiver\$ or care-giver\$ or famil\$ or parent\$ or father\$ or mother\$ or brother\$ or sister\$ or sibling?).ti,ab,id,jw.
13	or/8-12
14	TERMINALLY ILL PATIENTS/
15	TERMINAL CANCER/
16	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
17	"DEATH AND DYING"/
18	dying.ti,ab.
19	(end adj3 life).ti,ab.
20	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
21	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
22	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
23	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
24	(last year of life or LYOL or life\$ end).ab,ti.
25	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
26	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
27	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
28	ADVANCE DIRECTIVES/
29	advance? directive?.ab,ti.
30	living will?.ab,ti.
31	(terminal\$ adj3 (care\$ or caring)).ti,ab.

#	Searches
32	PALLIATIVE CARE/
33	palliat\$.ti,ab.
34	HOSPICE/
35	hospice?.ab,ti.
36	or/14-35
37	exp *PSYCHOTHERAPY/
38	*PROBLEM SOLVING/
39	((cogniti\$ or family or behavior?r\$ or psycholog\$) adj3 (intervention\$ or treatment\$ or therap\$)).ti,id.
40	((colo?r or music or play or Animal Assisted or Equine-Assisted or Art or Relaxation or Dance or Gestalt or Horticultural or narrative or Nondirective or Psychoanalytic or Reality or Socioenvironmental or Milieu or Couple? or Family or Marital or Collaborative or Exposure or Group or Inte?grative or Reminisce or Attachment Focus?ed or Brief Solution Focus?ed or compassion focus?ed or Dynamic or Interpersonal or inter personal or Life Review or Mentali#zation based or Person Centred or Personal Construct or Rational emotive or acceptance or commitment or multi system\$ or multisystem\$ or systemic or parent? operant) adj (therapy or therapies)).ti,id.
41	(Psychotherap\$ or bibliotherap\$ or hypnotherap\$).ti,id.
42	(hypnosis or relaxation or Autogenic Training or Meditation or Crisis Intervention or Catharsis or Therapeutic Community or Psychodrama or Guided Imagery or Mindfulness or Psychoeducation or Compassionate Mind or Eye Movement Desensiti?ation or EMDR or Intensive Interaction? or Mellow Babies Program? or Parenting Program? or Positive psychology or Rogerian counsel?ing or Triple P or Positive Parenting Program? or Webster Stratton).ti,id.
43	((Multifamil\$ or Family or families or Sibling?) adj3 support group?).ti,id.
44	problem solving.ti,id.
45	((cope? or coping) adj (therap\$ or skill?)).ti,id.
46	or/37-45
47	7 and 36 and 46
48	13 and 36 and 46
49	exp *BEREAVEMENT/
50	(therap\$ or intervention?).id.
51	13 and 36 and 49 and 50
52	47 or 48 or 51
53	limit 52 to english language
54	limit 53 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal" or "0130 peer-reviewed status unknown" or "0500 electronic collection")

## E.11.1 Social and practical support

### E.11.12 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.

#	Searches
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	SELF-HELP GROUPS/
35	SOCIAL SUPPORT/
36	COMMUNITY NETWORKS/
37	PEER GROUP/
38	(peer support or budd\$).ti,ab.
39	(self-help group? or self help group?).ti,ab.
40	(social support or social network? or cultural support).ti,ab.
41	(community adj3 (support or network?)).ti,ab.
42	support group?.ti,ab.
43	(cargiver? support or carer? support or parent\$ support).ti,ab.
44	((mother or father or sibling\$ or brother\$ or sister\$) adj3 support).ti,ab.
45	or/34-44
46	RESPIRE CARE/
47	respire.ti,ab.
48	DAY CARE, MEDICAL/
49	day care.ti,ab.
50	HOMEMAKER SERVICES/

#	Searches
51	HOME NURSING/
52	or/46-51
53	(homecar\$ or home-car\$ or homebased or home-based).ab,ti.
54	((nurse? or nursing) adj3 home).ab,ti.
55	((home or in-home or domicil\$) adj3 (base\$ or care or caring or service?)).ab,ti.
56	(non-medical? or non-professional? or family or friend? or relative? or carer? or caregiver? or volunte\$ or charit\$ or communit\$ or self-help or self help or support group?).ti,ab.
57	(or/53-55) and 56
58	exp HOME CARE SERVICES/ and (advic\$ or info\$ or support or group? or network?).ti,ab.
59	((domestic adj (service? or help or aid or assist\$)) or (home-help or home help)).ti,ab.
60	((house or home) adj3 arrange\$).ti,ab.
61	*OCCUPATIONAL THERAPY/
62	occupational therapy.ti,ab.
63	(house adaptat\$ or home adaptat\$).ti,ab.
64	((ambulance? or transport\$ or vehicle?) adj5 (body or bodies or mortuar\$ or autopsy or coroner? or post?mortem or post mortem)).ti,ab.
65	"Equipment and Supplies"/
66	(equipment adj3 home).ti,ab.
67	(assistive device? or medical device\$).ti,ab.
68	((financial or economic or monetary) adj3 (support or help or benefit? or grant? or advic\$ or info\$)).ti,ab.
69	(medical cost\$ adj3 (support or help or benefit? or grant?)).ti,ab.
70	((legal\$ or regulatory or law) adj3 (require\$ or advic\$ or info\$)).ti,ab.
71	*LEGISLATION, MEDICAL/
72	or/59-71
73	MORTUARY PRACTICE/
74	(Mortuar\$ or undertaker?).ab,ti.
75	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
76	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti.
77	exp FUNERAL RITES/
78	(Funeral? or Burial? or Cemeter\$ or Cremat\$ or Embalm\$).ab,ti.
79	((spread\$ or dispos\$) adj3 ash\$).ab,ti.
80	or/73-79
81	(practical adj3 (advic\$ or info\$)).ti,ab.
82	(education\$ adj3 arrangement?).ti,ab.
83	45 or 52 or 57 or 58 or 72 or 80 or 81 or 82
84	9 and 33 and 83
85	limit 84 to english language
86	LETTER/
87	EDITORIAL/
88	NEWS/
89	exp HISTORICAL ARTICLE/
90	ANECDOTES AS TOPIC/
91	COMMENT/
92	CASE REPORT/
93	(letter or comment*).ti.

#	Searches
94	or/86-93
95	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
96	94 not 95
97	ANIMALS/ not HUMANS/
98	exp ANIMALS, LABORATORY/
99	exp ANIMAL EXPERIMENTATION/
100	exp MODELS, ANIMAL/
101	exp RODENTIA/
102	(rat or rats or mouse or mice).ti.
103	or/96-102
104	85 not 103

### E.11.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatic\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(peer support or budd\$).ti,ab.
24	(self-help group? or self help group?).ti,ab.
25	(social support or social network? or cultural support).ti,ab.
26	(community adj3 (support or network?)).ti,ab.
27	support group?.ti,ab.
28	(cargiver? support or carer? support or parent\$ support).ti,ab.
29	((mother or father or sibling\$ or brother\$ or sister\$) adj3 support).ti,ab.

#	Searches
30	respite.ti,ab.
31	day care.ti,ab.
32	or/23-31
33	(homecar\$ or home-car\$ or homebased or home-based).ab,ti.
34	((nurse? or nursing) adj3 home).ab,ti.
35	((home or in-home or domicil\$) adj3 (base\$ or care or caring or service?)).ab,ti.
36	(non-medical? or non-professional? or family or friend? or relative? or carer? or caregiver? or volunte\$ or charit\$ or communit\$ or self-help or self help or support group?).ti,ab.
37	(or/33-35) and 36
38	((domestic adj (service? or help or aid or assist\$)) or (home-help or home help)).ti,ab.
39	((house or home) adj3 arrange\$).ti,ab.
40	occupational therapy.ti,ab.
41	(house adaptat\$ or home adaptat\$).ti,ab.
42	((ambulance? or transport\$ or vehicle?) adj5 (body or bodies or mortuar\$ or autopsy or coroner? or post?mortem or post mortem)).ti,ab.
43	(equipment adj3 home).ti,ab.
44	(assistive device? or medical device\$).ti,ab.
45	((financial or economic or monetary) adj3 (support or help or benefit? or grant? or advi\$ or info\$)).ti,ab.
46	(medical cost\$ adj3 (support or help or benefit? or grant?)).ti,ab.
47	((legal\$ or regulatory or law) adj3 (require\$ or advi\$ or info\$)).ti,ab.
48	(Mortuar\$ or undertaker?).ab,ti.
49	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
50	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti.
51	(Funeral? or Burial? or Cemetery\$ or Cremat\$ or Embalm\$).ab,ti.
52	((spread\$ or dispos\$) adj3 ash\$).ab,ti.
53	(practical adj3 (advi\$ or info\$)).ti,ab.
54	(education\$ adj3 arrangement?).ti,ab.
55	or/38-54
56	5 and 22 and 55

### E.11.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.



#	Searches
13	(end adj3 life).ti,ab,kw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab,kw.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab,kw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab,kw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab,kw.
18	(last year of life or LYOL or life\$ end).ti,ab,kw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab,kw.
20	((advanced or late or last or end or final or terminal) adj phase\$).ti,ab,kw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti,kw.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	SELF-HELP GROUPS/
35	SOCIAL SUPPORT/
36	COMMUNITY NETWORKS/
37	PEER GROUP/
38	(peer support or budd\$).ti,ab,kw.
39	(self-help group? or self help group?).ti,ab,kw.
40	(social support or social network? or cultural support).ti,ab,kw.
41	(community adj3 (support or network?)).ti,ab,kw.
42	support group?.ti,ab,kw.
43	(cargiver? support or carer? support or parent\$ support).ti,ab,kw.
44	((mother or father or sibling\$ or brother\$ or sister\$) adj3 support).ti,ab,kw.
45	or/34-44
46	RESPITE CARE/
47	respite.ti,ab,kw.
48	DAY CARE/
49	day care.ti,ab,kw.
50	HOMEMAKER SERVICES/
51	HOME NURSING/
52	or/46-51
53	(homecar\$ or home-car\$ or homebased or home-based).ab,ti,kw.
54	((nurse? or nursing) adj3 home).ab,ti,kw.
55	((home or in-home or domicil\$) adj3 (base\$ or care or caring or service?)).ab,ti,kw.
56	(non-medical? or non-professional? or family or friend? or relative? or carer? or caregiver? or volunte\$ or charit\$ or communit\$ or self-help or self help or support group?).ti,ab,kw.

#	Searches
57	(or/53-55) and 56
58	HOME CARE SERVICES/ and (advi\$ or info\$ or support or group? or network?).ti,ab.
59	home care services.kw. and (advi\$ or info\$ or support or group? or network?).ti,ab.
60	((domestic adj (service? or help or aid or assistance)) or (home-help or home help)).ti,ab,kw.
61	((house or home) adj3 arrange\$).ti,ab,kw.
62	OCCUPATIONAL THERAPY/
63	occupational therapy.ti,ab,kw.
64	(house adaptat\$ or home adaptat\$).ti,ab,kw.
65	((ambulance? or transport\$ or vehicle?) adj5 (body or bodies or mortuar\$ or autopsy or coroner? or post?mortem or post mortem)).ti,ab,kw.
66	"EQUIPMENT AND SUPPLIES"/
67	(equipment adj3 home).ti,ab,kw.
68	(assistive device? or medical device\$).ti,ab,kw.
69	((financial or economic or monetary) adj (support or help or benefit? or grant?)).ti,ab,kw.
70	(medical cost\$ adj3 (support or help or benefit? or grant?)).ti,ab,kw.
71	((legal\$ or regulatory or law) adj3 require\$) or advic\$).ti,ab,kw.
72	LEGISLATION, MEDICAL/
73	or/58-72
74	MORTUARY PRACTICE/
75	(Mortuar\$ or undertaker?).ab,ti,kw.
76	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
77	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti,kw.
78	exp FUNERAL RITES/
79	(Funeral? or Burial? or Cemeter\$ or Cremat\$ or Embalm\$).ab,ti,kw.
80	((spread\$ or dispos\$) adj3 ash\$).ab,ti,kw.
81	or/74-80
82	(education\$ adj3 arrangement?).ti,ab.
83	(practical adj3 (advi\$ or info\$)).ti,ab.
84	45 or 52 or 57 or 73 or 81 or 82 or 83
85	9 and 33 and 84

#### E.11.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.

#	Searches
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.ab,ti.
25	LIVING WILLS.kw.
26	living will?.ab,ti.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE.kw.
30	palliat\$.ti,ab.
31	HOSPICE CARE.kw.
32	hospice?.ab,ti.
33	or/10-32
34	(SELF-HELP GROUPS or SELF HELP GROUP?).kw.
35	SOCIAL SUPPORT.kw.
36	COMMUNITY NETWORK?.kw.
37	PEER GROUP.kw.
38	(peer support or budd\$).ti,ab.
39	(self-help group? or self help group?).ti,ab.
40	(social support or social network? or cultural support).ti,ab.
41	(community adj3 (support or network?)).ti,ab.
42	support group?.ti,ab.
43	(cargiver? support or carer? support or parent\$ support).ti,ab.
44	((mother or father or sibling\$ or brother\$ or sister\$) adj3 support).ti,ab.
45	or/34-44
46	RESPIRE CARE.kw.
47	respire.ti,ab.
48	DAY CARE.kw.
49	day care.ti,ab.
50	HOMEMAKER SERVICE?.ti,ab,kw.
51	HOME NURSING.kw.
52	or/46-51
53	(homecar\$ or home-car\$ or homebased or home-based).ab,ti.
54	((nurse? or nursing) adj3 home).ab,ti.

#	Searches
55	((home or in-home or domicil\$) adj3 (base\$ or care or caring or service?)).ab,ti.
56	(non-medical? or non-professional? or family or friend? or relative? or carer? or caregiver? or volunte\$ or charit\$ or communit\$ or self-help or self help or support group?).ti,ab.
57	(or/53-55) and 56
58	HOME CARE SERVICE?.kw. and (advi\$ or info\$ or support or group? or network?).ti,ab.
59	((domestic adj (service? or help or aid or assistance)) or (home-help or home help)).ti,ab.
60	((house or home) adj3 arrange\$).ti,ab.
61	OCCUPATIONAL THERAPY.kw.
62	occupational therapy.ti,ab.
63	(house adaptat\$ or home adaptat\$).ti,ab.
64	((ambulance? or transport\$ or vehicle?) adj5 (body or bodies or mortuar\$ or autopsy or coroner? or post?mortem or post mortem)).ti,ab.
65	(EQUIPMENT or SUPPLIES).kw.
66	(equipment adj3 home).ti,ab.
67	(assistive device? or medical device\$).ti,ab.
68	((financial or economic or monetary) adj (support or help or benefit? or grant?)).ti,ab.
69	(medical cost\$ adj3 (support or help or benefit? or grant?)).ti,ab.
70	((legal\$ or regulatory or law) adj3 require\$) or advic\$).ti,ab.
71	LEGISLATION.kw.
72	or/58-71
73	MORTUARY PRACTICE.kw.
74	(Mortuar\$ or undertaker?).ab,ti.
75	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
76	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti.
77	FUNERAL RITES.kw.
78	(Funeral? or Burial? or Cemeter\$ or Cremat\$ or Embalm\$).ab,ti.
79	((spread\$ or dispos\$) adj3 ash\$).ab,ti.
80	or/73-79
81	(practical adj3 (advi\$ or info\$)).ti,ab.
82	(education\$ adj3 arrangement?).ti,ab.
83	45 or 52 or 57 or 72 or 80 or 81 or 82
84	9 and 33 and 83

### E.11.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/

#	Searches
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.11.61 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	TERMINALLY ILL PATIENT/
11	TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.

#	Searches
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
24	advance? directive?.ab,ti.
25	LIVING WILL/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE THERAPY/
30	CANCER PALLIATIVE THERAPY/
31	palliat\$.ti,ab.
32	HOSPICE CARE/
33	HOSPICE PATIENT/
34	hospice?.ab,ti.
35	or/10-34
36	*self help/
37	*social support/
38	*caregiver support/
39	*community care/
40	*peer group/
41	(peer support or budd\$).ti,ab.
42	(self-help group? or self help group?).ti,ab.
43	(social support or social network? or cultural support).ti,ab.
44	(community adj3 (support or network?)).ti,ab.
45	support group?.ti,ab.
46	(cargiver? support or carer? support or parent\$ support).ti,ab.
47	((mother or father or sibling\$ or brother\$ or sister\$) adj3 support).ti,ab.
48	or/36-47
49	exp respite care/
50	respite.ti,ab.
51	*day care/
52	day care.ti,ab.
53	*home care/
54	*home health agency/
55	*visiting nursing service/
56	homemaker service?.ti,ab.
57	or/49-56
58	(homecar\$ or home-car\$ or homebased or home-based).ab,ti.
59	((nurse? or nursing) adj3 home).ab,ti.
60	((home or in-home or domicil\$) adj3 (base\$ or care or caring or service?)).ab,ti.

#	Searches
61	(non-medical? or non-professional? or family or friend? or relative? or carer? or caregiver? or volunte\$ or charit\$ or communit\$ or self-help or self help or support group?).ti,ab.
62	(or/58-60) and 61
63	*community health nursing/
64	*family nursing/
65	home care service?.ti,ab.
66	(advic\$ or info\$ or support or group? or network?).ti,ab.
67	(or/63-65) and 66
68	((domestic adj (service? or help or aid or assist\$) or (home-help or home help)).ti,ab.
69	((house or home) adj3 arrange\$).ti,ab.
70	*occupational therapy/
71	occupational therapy.ti,ab.
72	(house adaptat\$ or home adaptat\$).ti,ab.
73	((ambulance? or transport\$ or vehicle?) adj5 (body or bodies or mortuar\$ or autopsy or coroner? or post?mortem or post mortem)).ti,ab.
74	medical device/
75	((equipment or supplies) adj3 home).ti,ab.
76	(assistive device? or medical device\$).ti,ab.
77	((financial or economic or monetary) adj3 (support or help or benefit? or grant? or advic\$ or info\$)).ti,ab.
78	(medical cost\$ adj3 (support or help or benefit? or grant?)).ti,ab.
79	*law/
80	((legal\$ or regulatory or law) adj3 (require\$ or advic\$ or info\$)).ti,ab.
81	or/68-80
82	*POSTHUMOUS CARE/
83	(Mortuar\$ or undertaker?).ab,ti.
84	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
85	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti.
86	(Funeral? or Burial? or Cemeter\$ or Cremat\$ or Embalm\$).ab,ti.
87	((spread\$ or dispos\$) adj3 ash\$).ab,ti.
88	or/82-87
89	(practical adj3 (advic\$ or info\$)).ti,ab.
90	(education\$ adj3 arrangement?).ti,ab.
91	48 or 57 or 62 or 67 or 81 or 88 or 89 or 90
92	9 and 35 and 91
93	limit 92 to english language
94	letter.pt. or LETTER/
95	note.pt.
96	editorial.pt.
97	CASE REPORT/ or CASE STUDY/
98	(letter or comment*).ti.
99	or/94-98
100	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
101	99 not 100
102	ANIMAL/ not HUMAN/
103	NONHUMAN/

#	Searches
104	exp ANIMAL EXPERIMENT/
105	exp EXPERIMENTAL ANIMAL/
106	ANIMAL MODEL/
107	exp RODENT/
108	(rat or rats or mouse or mice).ti.
109	or/101-108
110	93 not 109

## E.12<sub>1</sub> Spiritual and religious support

### E.12.12 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/



#	Searches
32	hospice?.ab,ti.
33	or/10-32
34	exp SPIRITUAL THERAPIES/
35	exp *RELIGION/
36	HUMANISM/
37	(religio\$ or spiritual\$ or soul or faith? or sacred).ab,ti.
38	((belief? or believe?) adj3 system\$).ab,ti.
39	Meditat\$.ab,ti.
40	pray\$.ab,ti.
41	(pastoral adj3 (care or caring)).ab,ti.
42	(Anoint\$ or blessing).ab,ti.
43	laying on of hands.ab,ti.
44	(Deity or divinity or divine or God or supreme being or higher being).ab,ti.
45	(psychic healing or inner peace).ab,ti.
46	yoga.ab,ti.
47	(church? or cleric? or chaplain\$ or clergy? or priest? or preacher? or vicar? or rabbi? or synagogue? or mosque? or imam? or druid\$).ab,ti.
48	(shaman\$ or mystic\$ or transcend\$ or esoteric).ab,ti.
49	(Tradition\$ adj3 heal\$).ab,ti.
50	(existential\$ or salutogenesis).ab,ti.
51	(Buddhis\$ or Christian\$ or catholic\$ or eastern orthodox? or Jehovah? Witness\$ or protestant? or Hindu? or muslim? or Islam? or Judaism or Tao\$ or Sikh? or Rastafari\$ or agnostic\$ or atheis\$ or humanis\$ or secular\$).ab,ti.
52	(confucianis? or eastern philosophy).ab,ti.
53	Last rite?.ab,ti.
54	MORTUARY PRACTICE/
55	(Mortuar\$ or undertaker?).ab,ti.
56	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
57	((ritual\$ or rite?) adj3 death?).ab,ti.
58	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti.
59	exp FUNERAL RITES/
60	(Funeral? or Burial? or Cemeter\$ or Cremat\$ or Embalm\$).ab,ti.
61	((spread\$ or dispos\$) adj3 ash\$).ab,ti.
62	memorial service?.ab,ti.
63	or/34-62
64	9 and 33 and 63
65	limit 64 to english language
66	LETTER/
67	EDITORIAL/
68	NEWS/
69	exp HISTORICAL ARTICLE/
70	ANECDOTES AS TOPIC/
71	COMMENT/
72	CASE REPORT/
73	(letter or comment*).ti.
74	or/66-73

#	Searches
75	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
76	74 not 75
77	ANIMALS/ not HUMANS/
78	exp ANIMALS, LABORATORY/
79	exp ANIMAL EXPERIMENTATION/
80	exp MODELS, ANIMAL/
81	exp RODENTIA/
82	(rat or rats or mouse or mice).ti.
83	or/76-82
84	65 not 83

### E.12.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatic\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(religio\$ or spiritual\$ or soul or faith? or sacred).ab,ti.
24	((belief? or believe?) adj3 system\$).ab,ti.
25	Meditat\$.ab,ti.
26	pray\$.ab,ti.
27	(pastoral adj3 (care or caring)).ab,ti.
28	(Anoint\$ or blessing).ab,ti.
29	laying on of hands.ab,ti.
30	(Deity or divinity or divine or God or supreme being or higher being).ab,ti.

#	Searches
31	(psychic healing or inner peace).ab,ti.
32	yoga.ab,ti.
33	(church? or cleric? or chaplain\$ or clergy? or priest? or preacher? or vicar? or rabbi? or synagogue? or mosque? or imam? or druid\$).ab,ti.
34	(shaman\$ or mystic\$ or transcend\$ or esoteric).ab,ti.
35	(Tradition\$ adj3 heal\$).ab,ti.
36	(existential\$ or salutogenesis).ab,ti.
37	(Buddhis\$ or Christian\$ or catholic\$ or eastern orthodox? or Jehovah? Witness\$ or protestant? or Hindu? or muslim? or Islam? or Judaism or Tao\$ or Sikh? or Rastafari\$ or agnostic\$ or atheis\$ or humanis\$ or secular\$).ab,ti.
38	(confucianis? or eastern philosophy).ab,ti.
39	Last rite?.ab,ti.
40	(Mortuar\$ or undertaker?).ab,ti.
41	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
42	((ritual\$ or rite?) adj3 death?).ab,ti.
43	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti.
44	(Funeral? or Burial? or Cemetery\$ or Cremat\$ or Embalm\$).ab,ti.
45	((spread\$ or dispos\$) adj3 ash\$).ab,ti.
46	memorial service?.ab,ti.
47	or/23-46
48	5 and 22 and 47

### E.12.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab,kw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab,kw.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab,kw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab,kw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab,kw.
18	(last year of life or LYOL or life\$ end).ti,ab,kw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab,kw.
20	((advanced or late or last or end or final or terminal) adj phase\$).ti,ab,kw.

#	Searches
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ti,ab,kw.
25	LIVING WILLS/
26	living will?.ti,ab,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ti,ab,kw.
33	or/10-32
34	exp SPIRITUAL THERAPIES/
35	exp *RELIGION/
36	HUMANISM/
37	(religio\$ or spiritual\$ or soul or faith? or sacred).ab,ti,kw.
38	((belief? or believe?) adj3 system\$).ab,ti.
39	Meditat\$.ab,ti,kw.
40	pray\$.ab,ti,kw.
41	(pastoral adj3 (care or caring)).ab,ti.
42	(Anoint\$ or blessing).ab,ti,kw.
43	laying on of hands.ab,ti,kw.
44	(Deity or divinity or divine or God or supreme being).ab,ti,kw.
45	(psychic healing or inner peace).ab,ti,kw.
46	yoga.ab,ti,kw.
47	(church? or cleric? or chaplain\$ or clergy? or priest? or preacher? or vicar? or rabbi? or synagogue? or mosque? or imam? or druid\$).ab,ti,kw.
48	(shaman\$ or mystic\$ or transcend\$ or esoteric).ab,ti,kw.
49	(Tradition\$ adj3 heal\$).ab,ti.
50	(existential\$ or salutogenesis).ab,ti,kw.
51	(Buddhis\$ or Christian\$ or catholic\$ or eastern orthodox? or Jehovah? Witness\$ or protestant? or Hindu? or muslim? or Islam? or Judaism or Tao\$ or Sikh? or Rastafari\$ or agnostic\$ or atheis\$ or humanis\$ or secular\$).ab,ti,kw.
52	(confucianis? or eastern philosophy).ab,ti,kw.
53	Last rite?.ab,ti,kw.
54	MORTUARY PRACTICE/
55	(Mortuar\$ or undertaker?).ab,ti,kw.
56	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
57	((ritual\$ or rite?) adj3 death?).ab,ti.
58	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti.
59	exp FUNERAL RITES/
60	(Funeral? or Burial? or Cemetery\$ or Cremat\$ or Embalm\$).ab,ti,kw.
61	((spread\$ or dispos\$) adj3 ash\$).ab,ti.
62	memorial service?.ab,ti,kw.
63	or/34-62

#	Searches
64	9 and 33 and 63

### E.12.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ti,ab.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ti,ab.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.ti,ab.
25	LIVING WILLS.kw.
26	living will?.ti,ab.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE.kw.
30	palliat\$.ti,ab.
31	HOSPICE CARE.kw.
32	hospice?.ti,ab.
33	or/10-32
34	SPIRITUAL THERAPIES.kw.
35	RELIGION.kw.
36	HUMANISM.kw.
37	(religio\$ or spiritual\$ or soul or faith? or sacred).tw,tx.
38	((belief? or believe?) adj3 system\$).tw,tx.

#	Searches
39	Meditat\$.tw,tx.
40	pray\$.tw,tx.
41	(pastoral adj3 (care or caring)).tw,tx.
42	(Anoint\$ or blessing).tw,tx.
43	laying on of hands.tw,tx.
44	(Deity or divinity or divine or God or supreme being).tw,tx.
45	(psychic healing or inner peace).tw,tx.
46	yoga.tw,tx.
47	(church? or cleric? or chaplain\$ or clergy? or priest? or preacher? or vicar? or rabbi? or synagogue? or mosque? or imam? or druid\$).tw,tx.
48	(shaman\$ or mystic\$ or transcend\$ or esoteric).tw,tx.
49	(Tradition\$ adj3 heal\$).tw,tx.
50	(existential\$ or salutogenesis).tw,tx.
51	(Buddhis\$ or Christian\$ or catholic\$ or eastern orthodox? or Jehovah? Witness\$ or protestant? or Hindu? or muslim? or Islam? or Judaism or Tao\$ or Sikh? or Rastafari\$ or agnostic\$ or atheis\$ or humanis\$ or secular\$).tw,tx.
52	(confucianis? or eastern philosophy).tw,tx.
53	Last rite?.tw,tx.
54	MORTUARY PRACTICE.kw.
55	(Mortuar\$ or undertaker?).tw,tx.
56	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).tw,tx.
57	((ritual\$ or rite?) adj3 death?).tw,tx.
58	((Cold or cool\$) adj3 (room? or bedroom?)).tw,tx.
59	FUNERAL RITES.kw.
60	(Funeral? or Burial? or Cemetery\$ or Cremat\$ or Embalm\$).tw,tx.
61	((spread\$ or dispos\$) adj3 ash\$).tw,tx.
62	memorial service?.tw,tx.
63	or/34-62
64	9 and 33 and 63

### E.12.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatic\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.

#	Searches
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.12.61 Database: Embase

#	Searches
1	*ADOLESCENT/ or *MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp *CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp *INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp *PEDIATRICS/ or exp *PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx.
9	or/1-8
10	*TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.

#	Searches
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	*RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	*ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	*LIVING WILLS/
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	*HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	exp *ALTERNATIVE MEDICINE/
35	exp *RELIGION/
36	*HUMANISM/
37	(religio\$ or spiritual\$ or soul or faith? or sacred).ab,ti.
38	((belief? or believe?) adj3 system\$).ab,ti.
39	Meditat\$.ab,ti.
40	pray\$.ab,ti.
41	(pastoral adj3 (care or caring)).ab,ti.
42	(Anoint\$ or blessing).ab,ti.
43	laying on of hands.ab,ti.
44	(Deity or divinity or divine or God or supreme being or higher being).ab,ti.
45	(psychic healing or inner peace).ab,ti.
46	yoga.ab,ti.
47	(church? or cleric? or chaplain\$ or clergy? or priest? or preacher? or vicar? or rabbi? or synagogue? or mosque? or imam? or druid\$).ab,ti.
48	(shaman\$ or mystic\$ or transcend\$ or esoteric).ab,ti.
49	(Tradition\$ adj3 heal\$).ab,ti.
50	(existential\$ or salutogenesis).ab,ti.
51	(Buddhis\$ or Christian\$ or catholic\$ or eastern orthodox? or Jehovah? Witness\$ or protestant? or Hindu? or muslim? or Islam? or Judaism or Tao\$ or Sikh? or Rastafari\$ or agnostic\$ or atheis\$ or humanis\$ or secular\$).ab,ti.
52	(confucianis? or eastern philosophy).ab,ti.
53	Last rite?.ab,ti.
54	*POSTHUMOUS CARE/
55	(Mortuar\$ or undertaker?).ab,ti.
56	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
57	((ritual\$ or rite?) adj3 death?).ab,ti.
58	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti.
59	(Funeral? or Burial? or Cemetery\$ or Cremat\$ or Embalm\$).ab,ti.
60	((spread\$ or dispos\$) adj3 ash\$).ab,ti.



#	Searches
61	memorial service?.ab,ti.
62	or/34-61
63	9 and 33 and 62
64	limit 63 to english language
65	letter.pt. or LETTER/
66	note.pt.
67	editorial.pt.
68	CASE REPORT/ or CASE STUDY/
69	(letter or comment*).ti.
70	or/65-69
71	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
72	70 not 71
73	ANIMAL/ not HUMAN/
74	NONHUMAN/
75	exp ANIMAL EXPERIMENT/
76	exp EXPERIMENTAL ANIMAL/
77	ANIMAL MODEL/
78	exp RODENT/
79	(rat or rats or mouse or mice).ti.
80	or/72-79
81	64 not 80

#### E.12.71 Database: CINAHL (Cumulative Index to Nursing and Allied Health Literature)

#	Searches
1	ADOLESCENCE/
2	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*).ti,ab.
3	CHILD/ or CHILD, PRESCHOOL/
4	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*).ti,ab.
5	INFANT/ or exp INFANT, NEWBORN/
6	(infan* or neonat* or newborn* or baby or babies).ti,ab.
7	PEDIATRICS/ or PUBERTY/
8	(p*ediatric* or pubert* or prepubert* or pubescen* or prepubescen*).ti,ab.
9	or/1-8
10	TERMINALLY ILL PATIENTS/
11	((terminal* or final or advance* or incurable or "life limit*") adj3 (ill* or disease* or condition*).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach* or close* or near* or imminent* or impending) adj3 death).ti,ab.
15	(Body adj2 (shut* down or shutting down or deteriorat*).ti,ab.
16	(deathbed* or "death bed*" or "passing away" or "passing on" or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour* or days* or minute*).ti,ab.
18	("last year of life" or LYOL or "life* end").ab,ti.
19	("advance* stage*" or "final stage*" or "end stage*" or "last stage*" or "late stage*" or "terminal stage*").ti,ab.

#	Searches
20	((advanced or late or last or end or final or terminal) adj phase*).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat* adj3 (policies or policy or order* or decision* or withhold*)).ab,ti.
23	ADVANCE DIRECTIVES/
24	“advance* directive*”.ab,ti.
25	LIVING WILLS/
26	“living will*”.ab,ti.
27	TERMINAL CARE/
28	(terminal* adj3 (care* or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat*.ti,ab.
31	HOSPICE CARE/
32	hospice*.ab,ti.
33	or/10-32
34	exp *SPIRITUALITY/ and *SPIRITUAL CARE/
35	exp *RELIGION AND RELIGIONS/
36	*HUMANISM/
37	(religio* or spiritual* or soul or faith* or sacred).ab,ti.
38	((belief* or believe*) adj3 system*).ab,ti.
39	Meditat*.ab,ti.
40	pray*.ab,ti.
41	(pastoral adj3 (care or caring)).ab,ti.
42	(Anoint* or blessing).ab,ti.
43	“laying on of hands”.ab,ti.
44	(Deity or divinity or divine or God or “supreme being” or “higher being”).ab,ti.
45	(“psychic healing” or “inner peace”).ab,ti.
46	yoga.ab,ti.
47	(church* or cleric* or chaplain* or clergy* or priest* or preacher* or vicar* or rabbi* or synagogue* or mosque* or imam* or druid*).ab,ti.
48	(shaman* or mystic* or transcend* or esoteric).ab,ti.
49	(Tradition* adj3 heal*).ab,ti.
50	(existential* or salutogenesis).ab,ti.
51	(Buddhis* or Christian* or catholic* or “eastern orthodox*” or “Jehovah* Witness*” or protestant* or Hindu* or muslim* or Islam* or Judaism or Tao* or Sikh* or Rastafari* or agnostic* or atheis* or humanis* or secular*).ab,ti.
52	(confucianis* or “eastern philosophy”).ab,ti.
53	“Last rite*”.ab,ti.
54	*POSTMORTEM CARE/
55	(Mortuar* or undertaker*).ab,ti.
56	((care or caring or wash*) adj7 (body or bodies) adj7 death*).ab,ti.
57	((ritual* or rite*) adj3 death*).ab,ti.
58	((Cold or cool*) adj3 (room* or bedroom*)).ab,ti.
59	*BURIAL PRACTICES/
60	(Funeral* or Burial* or Cemetery* or Cremat* or Embalm*).ab,ti.
61	((spread* or dispos*) adj3 ash*).ab,ti.
62	“memorial service*”.ab,ti.

#	Searches
63	or/34-62
64	9 and 33 and 63 [Limit to: (Language English)]

### E.12.81 Database: AMED (Allied and Contemporary Medicine)

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	CHILD/ or CHILD, PRESCHOOL/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	PEDIATRICS/ or PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx.
9	or/1-8
10	TERMINAL ILLNESS/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	living will?.ab,ti.
26	TERMINAL CARE/
27	(terminal\$ adj3 (care\$ or caring)).ti,ab.
28	PALLIATIVE CARE/
29	palliat\$.ti,ab.
30	HOSPICE CARE/
31	hospice?.ab,ti.
32	or/10-31
33	exp SPIRITUAL THERAPIES/
34	SPIRITUALITY/
35	exp RELIGION/
36	(religio\$ or spiritual\$ or soul or faith? or sacred).ab,ti.
37	((belief? or believe?) adj3 system\$).ab,ti.
38	Meditat\$.ab,ti.

#	Searches
39	pray\$.ab,ti.
40	(pastoral adj3 (care or caring)).ab,ti.
41	(Anoint\$ or blessing).ab,ti.
42	laying on of hands.ab,ti.
43	(Deity or divinity or divine or God or supreme being).ab,ti.
44	(psychic healing or inner peace).ab,ti.
45	yoga.ab,ti.
46	(church? or cleric? or chaplain\$ or clergy? or priest? or preacher? or vicar? or rabbi? or synagogue? or mosque? or imam? or druid\$).ab,ti.
47	(shaman\$ or mystic\$ or transcend\$ or esoteric).ab,ti.
48	(Tradition\$ adj3 heal\$).ab,ti.
49	(existential\$ or salutogenesis).ab,ti.
50	(Buddhis\$ or Christian\$ or catholic\$ or eastern orthodox? or Jehovah? Witness\$ or protestant? or Hindu? or muslim? or Islam? or Judaism or Tao\$ or Sikh? or Rastafari\$ or agnostic\$ or atheis\$ or humanis\$ or secular\$).ab,ti.
51	(confucianis? or eastern philosophy).ab,ti.
52	Last rite?.ab,ti.
53	(Mortuar\$ or undertaker?).ab,ti.
54	((care or caring or wash\$) adj7 (body or bodies) adj7 death?).ab,ti.
55	((ritual\$ or rite?) adj3 death?).ab,ti.
56	((Cold or cool\$) adj3 (room? or bedroom?)).ab,ti.
57	FUNERAL RITES/
58	(Funeral? or Burial? or Cemeter\$ or Cremat\$ or Embalm\$).ab,ti.
59	((spread\$ or dispos\$) adj3 ash\$).ab,ti.
60	memorial service?.ab,ti.
61	or/33-60
62	9 and 32 and 61

## E.13<sub>1</sub> Managing Pain

### E.13.12 Database: Medline

1	<b>ADOLESCENT/ or MINORS/</b>
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	<b>TERMINALLY ILL/</b>
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.

1	ADOLESCENT/ or MINORS/
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	exp PAIN/
35	(pain\$ or headache? or migraine? or neuralgia or myalgia or metatarsalgia or sciatica).ab,ti.
36	34 or 35
37	exp ANALGESICS/
38	exp ANESTHETICS, LOCAL/
39	exp ANTICONVULSANTS/
40	exp ANTIDEPRESSIVE AGENTS/
41	exp ANTI-INFLAMMATORY AGENTS, NON-STEROIDAL/
42	exp MUSCLE RELAXANTS, CENTRAL/
43	exp PARASYMPATHOLYTICS/
44	exp SEROTONIN UPTAKE INHIBITORS/
45	exp STEROIDS/
46	(acetaminophen or acetylsalicylic acid or alendronic acid or alfentanil or amitriptyline or aspirin or baclofen or baclophen or benzocaine or bupivacaine or buprenorphine).mp.
47	(butorphanol or carbamazepine or chlorprocaine or choline magnesium trisalicylate or clonazepam or clonidine or codeine or dexamethasone or dexmetetomidine or dextroamphetamine or tinzanidine).mp.
48	(dextropropoxyphene or diamorphine or diazepam or diclofenac or dihydrocodeine or domperidone or fentanyl or fluoxetine or gabapentin or hydrocodone).mp.
49	(hydromorphone or hyoscine hydrobromide or ibuprofen or ketamine or ketoprofen or ketorolac or levo bupivacaine or lidocaine or loperamide or lorazepam or EMLA).mp.
50	(mefenamic acid or meperidine or methadone or methylphenidate or midazolam or morphine or naproxen or nitrous oxide or nortriptyline or oxycodone).mp.
51	(pamidronate or paracetamol or paroxetine or pentazocine or pethidine or phenobarbital or phenytoin or piroxicam or pregabalin? or propoxyphene).mp.
52	(risedronate sodium or sodium clodronate or tetracaine or tramadol or valproic acid or ametop).mp.

1	<b>ADOLESCENT/ or MINORS/</b>
53	((local or conduction blocking or topical) adj3 an?esthetic?).ti,ab.
54	exp BENZODIAZEPINES/
55	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
56	exp DOPAMINE ANTAGONISTS/
57	(dopamine adj3 antagonist?).ab,ti.
58	(dopamine receptor? adj3 block\$).ab,ti.
59	(Acepromazine or Amoxapine or Azaperone or Benperidol or Butaclamol or Chlorpromazine or Chlorprothixene or Clopenthixol or Domperidone or Flupenthixol or Fluphenazine or Fluspirilene or Haloperidol or Loxapine or Mesoridazine or Methotrimeprazine or Penfluridol or Perazine or Perphenazine or Pimozide or Prochlorperazine or Promazine or Raclopride or Remoxipride or Risperidone or Spiperone or Sulpiride or Thiethylperazine or Thioridazine or Thiothixene or Tiapride Hydrochloride or Trifluoperazine or Trifluperidol or Triflupromazine).mp.
60	exp MUSCARINIC ANTAGONISTS/ or CHOLINERGIC ANTAGONISTS/
61	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent?)).ab,ti.
62	((cholinergic or muscarinic) adj2 antagonist?).ab,ti.
63	(glycopyrronium or hyoscine).mp.
64	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dexetimide or Dicyclomine or Emepronium or Glycopyrrolate or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzylcholine Mustard or Quinidine or Quinuclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide or oxybutynin).mp.
65	exp SOMATOSTATIN/
66	(somatostatin adj3 analogue?).mp.
67	OCTREOTIDE/
68	(Octreotide or Sandostatin).mp.
69	(Lanreotide or Somatuline).mp.
70	(Pasireotide or Signifor).mp.
71	exp ADRENAL CORTEX HORMONES/
72	(Adrenal Cortex Hormone? or corticosteroid? or 17-Ketosteroid? or Androstenedione or Androsterone or Dehydroepiandrosterone or Estrone or Etiocholanolone or Glucocorticoid? or Beclomethasone or Betamethasone or Budesonide or Clobetasol or Desoximetasone or Dexamethasone or Diflucortolone or Flumethasone or Fluocinolone Acetonide or Fluocinonide or Fluocortolone or Fluorometholone or Fluprednisolone or Flurandrenolone or Melengestrol Acetate or Methylprednisolone or Paramethasone or Prednisolone or Prednisone or Triamcinolone or Hydroxycorticosteroid? or 11-Hydroxycorticosteroid? or Aldosterone or Corticosterone or Hydrocortisone or 18-Hydroxycorticosterone or Tetrahydrocortisol or 17-Hydroxycorticosteroid? or Cortisone or Cortodoxone or Hydrocortisone or Tetrahydrocortisol or Tetrahydrocortisone or Desoxycorticosterone or 18-Hydroxydesoxycorticosterone or Pregnenolone or 17-alpha-Hydroxypregnenolone).mp.
73	DIPHOSPHONATES/
74	(diphosphonate? or bisphosponate?).mp.
75	CALCITONIN/
76	calcitonin.mp.
77	BOTULINUM TOXINS, TYPE A/
78	botulinum toxin? type a.mp.

1	ADOLESCENT/ or MINORS/
79	DANTROLENE/
80	Dantrolene.mp.
81	SUCROSE/
82	DIETARY SUCROSE/
83	(saccharose or sucrose or sugar?).mp.
84	CANNABIS/ or CANNABINOIDS/
85	(cannabi\$ or Nabiximol? or Sativex).mp.
86	(palliat\$ adj2 (chemotherap\$ or radiotherap\$)).ti,ab.
87	ETOPOSIDE/
88	Etoposide.mp.
89	(Temozolomide or Temodar or Temodal).mp.
90	or/37-89
91	exp ACUPUNCTURE THERAPY/
92	(acupunture or electroacupuncture).ti,ab.
93	exp THERAPY, SOFT TISSUE/
94	(massag\$ or reflexology or acupressure or Shiat?u or chih ya or zhi ya).ti,ab.
95	PHYSICAL THERAPY MODALITIES/
96	exp EXERCISE THERAPY/
97	(physiotherap\$ or physical therap\$).ab,ti.
98	((heat or hot or cold) adj3 therap\$).ti,ab.
99	ELECTRIC STIMULATION THERAPY/
100	TRANSCUTANEOUS ELECTRIC NERVE STIMULATION/
101	(transcutaneous adj3 (electr\$ or nerve? or stimulat\$)).ti,ab.
102	(tens or electroanalgesia).ti,ab.
103	MUSIC THERAPY/
104	(music\$ adj3 therap\$).ti,ab.
105	or/91-104
106	9 and 33 and 36 and 90
107	9 and 33 and 36 and 105
108	PAIN MANAGEMENT/mt [METHODS]
109	9 and 33 and 108
110	106 or 107 or 109
111	limit 110 to english language
112	LETTER/
113	EDITORIAL/
114	NEWS/
115	exp HISTORICAL ARTICLE/
116	ANECDOTES AS TOPIC/
117	COMMENT/
118	CASE REPORT/
119	(letter or comment*).ti.
120	or/112-119
121	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
122	120 not 121
123	ANIMALS/ not HUMANS/

1	ADOLESCENT/ or MINORS/
124	exp ANIMALS, LABORATORY/
125	exp ANIMAL EXPERIMENTATION/
126	exp MODELS, ANIMAL/
127	exp RODENTIA/
128	(rat or rats or mouse or mice).ti.
129	or/122-128
130	111 not 129

### E.13.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(pain\$ or headache? or migraine? or neuralgia or myalgia or metatarsalgia or sciatica).ab,ti.
24	(acetaminophen or acetylsalicylic acid or alendronic acid or alfentanil or amitriptyline or aspirin or baclofen or baclophen or benzocaine or bupivacaine or buprenorphine).mp.
25	(butorphanol or carbamazepine or chlorprocaine or choline magnesium trisalicylate or clonazepam or clonidine or codeine or dexamethasone or dexmetetomidine or dextroamphetamine or tinzanidine).mp.
26	(dextropropoxyphene or diamorphine or diazepam or diclofenac or dihydrocodeine or domperidone or fentanyl or fluoxetine or gabapentin or hydrocodone).mp.
27	(hydromorphone or hyoscine hydrobromide or ibuprofen or ketamine or ketoprofen or ketorolac or levo bupivacaine or lidocaine or loperamide or lorazepam or EMLA).mp.
28	(mefenamic acid or meperidine or methadone or methylphenidate or midazolam or morphine or naproxen or nitrous oxide or nortriptyline or oxycodone).mp.



#	Searches
29	(pamidronate or paracetamol or paroxetine or pentazocine or pethidine or phenobarbital or phenytoin or piroxicam or pregabalin? or propoxyphene).mp.
30	(risedronate sodium or sodium clodronate or tetracaine or tramadol or valproic acid or ametop).mp.
31	((local or conduction blocking or topical) adj3 an?esthetic?).ti,ab.
32	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
33	(dopamine adj3 antagonist?).ab,ti.
34	(dopamine receptor? adj3 block\$).ab,ti.
35	(Acepromazine or Amoxapine or Azaperone or Benperidol or Butaclamol or Chlorpromazine or Chlorprothixene or Clopenthixol or Domperidone or Flupenthixol or Fluphenazine or Fluspirilene or Haloperidol or Loxapine or Mesoridazine or Methotrimeprazine or Penfluridol or Perazine or Perphenazine or Pimozide or Prochlorperazine or Promazine or Raclopride or Remoxipride or Risperidone or Spiperone or Sulpiride or Thiethylperazine or Thioridazine or Thiothixene or Tiapride Hydrochloride or Trifluoperazine or Trifluperidol or Triflupromazine).mp.
36	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent?)).ab,ti.
37	((cholinergic or muscarinic) adj2 antagonist?).ab,ti.
38	(glycopyrronium or hyoscine).mp.
39	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dextimide or Dicyclomine or Emepronium or Glycopyrrolate or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzilylcholine Mustard or Quinidine or Quinuclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide or oxybutynin).mp.
40	(somatostatin adj3 analogue?).mp.
41	(Octreotide or Sandostatin).mp.
42	(Lanreotide or Somatuline).mp.
43	(Pasireotide or Signifor).mp.
44	(Adrenal Cortex Hormone? or corticosteroid? or 17-Ketosteroid? or Androstenedione or Androsterone or Dehydroepiandrosterone or Estrone or Etiocholanolone or Glucocorticoid? or Beclomethasone or Betamethasone or Budesonide or Clobetasol or Desoximetasone or Dexamethasone or Diflucortolone or Flumethasone or Fluocinolone Acetonide or Fluocinonide or Flucortolone or Fluorometholone or Fluprednisolone or Flurandrenolone or Melengestrol Acetate or Methylprednisolone or Paramethasone or Prednisolone or Prednisone or Triamcinolone or Hydroxycorticosteroid? or 11-Hydroxycorticosteroid? or Aldosterone or Corticosterone or Hydrocortisone or 18-Hydroxycorticosterone or Tetrahydrocortisol or 17-Hydroxycorticosteroid? or Cortisone or Cortodoxone or Hydrocortisone or Tetrahydrocortisol or Tetrahydrocortisone or Desoxycorticosterone or 18-Hydroxydesoxycorticosterone or Pregnenolone or 17-alpha-Hydroxypregnenolone).mp.
45	(diphosphonate? or bisphosphonate?).mp.
46	calcitonin.mp.
47	botulinum toxin? type a.mp.
48	Dantrolene.mp.
49	(saccharose or sucrose or sugar?).mp.
50	(cannabi\$ or Nabiximol? or Sativex).mp.
51	(palliat\$ adj2 (chemotherap\$ or radiotherap\$)).ti,ab.
52	Etoposide.mp.
53	(Temozolomide or Temodar or Temodal).mp.

#	Searches
54	or/24-53
55	(acupuncture or electroacupuncture).ti,ab.
56	(massag\$ or reflexology or acupressure or Shiat?u or chih ya or zhi ya).ti,ab.
57	(physiotherap\$ or physical therap\$).ab,ti.
58	((heat or hot or cold) adj3 therap\$).ti,ab.
59	(transcutaneous adj3 (electr\$ or nerve? or stimulat\$)).ti,ab.
60	(tens or electroanalgesia).ti,ab.
61	(music\$ adj3 therap\$).ti,ab.
62	or/55-61
63	5 and 22 and 23 and 54
64	5 and 22 and 23 and 62
65	63 or 64

### E.13.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescent\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab,kw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab,kw.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab,kw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab,kw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab,kw.
18	(last year of life or LYOL or life\$ end).ti,ab,kw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab,kw.
20	((advanced or late or last or end or final or terminal) adj phase\$).ti,ab,kw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ti,ab,kw.
25	LIVING WILLS/
26	living will?.ti,ab,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.

#	Searches
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ti,ab,kw.
33	or/10-32
34	exp PAIN/
35	(pain\$ or headache? or migraine? or neuralgia or myalgia or metatarsalgia or sciatica).ti,ab,kw.
36	34 or 35
37	exp ANALGESICS/
38	exp ANESTHETICS, LOCAL/
39	exp ANTICONVULSANTS/
40	exp ANTIDEPRESSIVE AGENTS/
41	exp ANTI-INFLAMMATORY AGENTS, NON-STEROIDAL/
42	exp MUSCLE RELAXANTS, CENTRAL/
43	exp PARASYMPATHOLYTICS/
44	exp SEROTONIN UPTAKE INHIBITORS/
45	exp STEROIDS/
46	(acetaminophen or acetylsalicylic acid or alendronic acid or alfentanil or amitriptyline or aspirin or baclofen or baclophen or benzocaine or bupivacaine or buprenorphine).mp.
47	(butorphanol or carbamazepine or chlorprocaine or choline magnesium trisalicylate or clonazepam or clonidine or codeine or dexamethasone or dexmetetomidine or dextroamphetamine or tinzanidine).mp.
48	(dextropropoxyphene or diamorphine or diazepam or diclofenac or dihydrocodeine or domperidone or fentanyl or fluoxetine or gabapentin or hydrocodone).mp.
49	(hydromorphone or hyoscine hydrobromide or ibuprofen or ketamine or ketoprofen or ketorolac or levo bupivacaine or lidocaine or loperamide or lorazepam or EMLA).mp.
50	(mefenamic acid or meperidine or methadone or methylphenidate or midazolam or morphine or naproxen or nitrous oxide or nortriptyline or oxycodone).mp.
51	(pamidronate or paracetamol or paroxetine or pentazocine or pethidine or phenobarbital or phenytoin or piroxicam or pregabalin? or propoxyphene).mp.
52	(risedronate sodium or sodium clodronate or tetracaine or tramadol or valproic acid or ametop).mp.
53	((local or conduction blocking or topical) adj3 an?esthetic?).ti,ab,kw.
54	exp BENZODIAZEPINES/
55	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
56	exp DOPAMINE ANTAGONISTS/
57	(dopamine adj3 antagonist?).ti,ab,kw.
58	(dopamine receptor? adj3 block\$).ti,ab,kw.
59	(Acepromazine or Amoxapine or Azaperone or Benperidol or Butaclamol or Chlorpromazine or Chlorprothixene or Clopenthixol or Domperidone or Flupenthixol or Fluphenazine or Fluspirilene or Haloperidol or Loxapine or Mesoridazine or Methotrimeprazine or Penfluridol or Perazine or Perphenazine or Pimozide or Prochlorperazine or Promazine or Raclopride or Remoxipride or Risperidone or Spiperone or Sulpiride or Thiethylperazine or Thioridazine or Thiothixene or Tiapride Hydrochloride or Trifluoperazine or Trifluoperidol or Triflupromazine).mp.

#	Searches
60	exp MUSCARINIC ANTAGONISTS/ or CHOLINERGIC ANTAGONISTS/
61	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent?)).ti,ab,kw.
62	((cholinergic or muscarinic) adj2 antagonist?).ti,ab,kw.
63	(glycopyrronium or hyoscine).mp.
64	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dextemide or Dicyclomine or Emepronium or Glycopyrrolate or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzylcholine Mustard or Quinidine or Quinuclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide or oxybutynin).mp.
65	exp SOMATOSTATIN/
66	(somatostatin adj3 analogue?).mp.
67	OCTREOTIDE/
68	(Octreotide or Sandostatin).mp.
69	(Lanreotide or Somatuline).mp.
70	(Pasireotide or Signifor).mp.
71	exp ADRENAL CORTEX HORMONES/
72	(Adrenal Cortex Hormone? or corticosteroid? or 17-Ketosteroid? or Androstenedione or Androsterone or Dehydroepiandrosterone or Estrone or Etiocholanolone or Glucocorticoid? or Beclomethasone or Betamethasone or Budesonide or Clobetasol or Desoximetasone or Dexamethasone or Diflucortolone or Flumethasone or Fluocinolone Acetonide or Fluocinonide or Fluocortolone or Fluorometholone or Fluprednisolone or Flurandrenolone or Melengestrol Acetate or Methylprednisolone or Paramethasone or Prednisolone or Prednisone or Triamcinolone or Hydroxycorticosteroid? or 11-Hydroxycorticosteroid? or Aldosterone or Corticosterone or Hydrocortisone or 18-Hydroxycorticosterone or Tetrahydrocortisol or 17-Hydroxycorticosteroid? or Cortisone or Cortodoxone or Hydrocortisone or Tetrahydrocortisol or Tetrahydrocortisone or Desoxycorticosterone or 18-Hydroxydesoxycorticosterone or Pregnenolone or 17-alpha-Hydroxypregnenolone).mp.
73	DIPHOSPHONATES/
74	(diphosphonate? or bisphosphonate?).mp.
75	CALCITONIN/
76	calcitonin.mp.
77	BOTULINUM TOXINS, TYPE A/
78	botulinum toxin? type a.mp.
79	DANTROLENE/
80	Dantrolene.mp.
81	SUCROSE/
82	DIETARY SUCROSE/
83	(saccharose or sucrose or sugar?).mp.
84	CANNABIS/ or CANNABINOIDS/
85	(cannabi\$ or Nabiximol? or Sativex).mp.
86	(palliat\$ adj2 (chemotherap\$ or radiotherap\$)).ti,ab,kw.
87	ETOPOSIDE/
88	Etoposide.mp.
89	(Temozolomide or Temodar or Temodal).mp.
90	or/37-89
91	exp ACUPUNCTURE THERAPY/
92	(acupunture or electroacupuncture).ti,ab,kw.
93	exp THERAPY, SOFT TISSUE/

#	Searches
94	(massag\$ or reflexology or acupressure or Shiat?u or chih ya or zhi ya).ti,ab,kw.
95	PHYSICAL THERAPY MODALITIES/
96	exp EXERCISE THERAPY/
97	(physiotherap\$ or physical therap\$).ti,ab,kw.
98	((heat or hot or cold) adj3 therap\$).ti,ab,kw.
99	ELECTRIC STIMULATION THERAPY/
100	TRANSCUTANEOUS ELECTRIC NERVE STIMULATION/
101	(transcutaneous adj3 (electr\$ or nerve? or stimulat\$)).ti,ab,kw.
102	(tens or electroanalgesia).ti,ab,kw.
103	MUSIC THERAPY/
104	(music\$ adj3 therap\$).ti,ab,kw.
105	or/91-104
106	9 and 33 and 36 and 90
107	9 and 33 and 36 and 105
108	PAIN MANAGEMENT/mt [METHODS]
109	9 and 33 and 108
110	106 or 107 or 109

#### E.13.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ti,ab.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ti,ab.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.

#	Searches
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.ti,ab.
25	LIVING WILLS.kw.
26	living will?.ti,ab.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE.kw.
30	palliat\$.ti,ab.
31	HOSPICE CARE.kw.
32	hospice?.ti,ab.
33	or/10-32
34	PAIN.kw.
35	(pain\$ or headache? or migraine? or neuralgia or myalgia or metatarsalgia or sciatica).tw,tx.
36	34 or 35
37	ANALGESICS.kw.
38	ANESTHETICS, LOCAL.kw.
39	ANTICONSULTANTS.kw.
40	ANTIDEPRESSIVE AGENTS.kw.
41	ANTI-INFLAMMATORY AGENTS, NON-STEROIDAL.kw.
42	MUSCLE RELAXANTS, CENTRAL.kw.
43	PARASYMPATHOLYTICS.kw.
44	SEROTONIN UPTAKE INHIBITORS.kw.
45	STEROIDS.kw.
46	(acetaminophen or acetylsalicylic acid or alendronic acid or alfentanil or amitriptyline or aspirin or baclofen or baclophen or benzocaine or bupivacaine or buprenorphine).mp.
47	(butorphanol or carbamazepine or chloroprocaine or choline magnesium trisalicylate or clonazepam or clonidine or codeine or dexamethasone or dexmetetomidine or dextroamphetamine or tinzanidine).mp.
48	(dextropropoxyphene or diamorphine or diazepam or diclofenac or dihydrocodeine or domperidone or fentanyl or fluoxetine or gabapentin or hydrocodone).mp.
49	(hydromorphone or hyoscine hydrobromide or ibuprofen or ketamine or ketoprofen or ketorolac or levo bupivacaine or lidocaine or loperamide or lorazepam or EMLA).mp.
50	(mefenamic acid or meperidine or methadone or methylphenidate or midazolam or morphine or naproxen or nitrous oxide or nortriptyline or oxycodone).mp.
51	(pamidronate or paracetamol or paroxetine or pentazocine or pethidine or phenobarbital or phenytoin or piroxicam or pregabalin? or propoxyphene).mp.
52	(risedronate sodium or sodium clodronate or tetracaine or tramadol or valproic acid or ametop).mp.
53	((local or conduction blocking or topical) adj3 an?esthetic?).tw,tx.
54	BENZODIAZEPINES.kw.
55	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
56	DOPAMINE ANTAGONISTS.kw.
57	(dopamine adj3 antagonist?).tw,tx.
58	(dopamine receptor? adj3 block\$).tw,tx.

#	Searches
59	(Acepromazine or Amoxapine or Azaperone or Benperidol or Butaclamol or Chlorpromazine or Chlorprothixene or Clopenthixol or Domperidone or Flupenthixol or Fluphenazine or Fluspirilene or Haloperidol or Loxapine or Mesoridazine or Methotrimeprazine or Penfluridol or Perazine or Perphenazine or Pimozide or Prochlorperazine or Promazine or Raclopride or Remoxipride or Risperidone or Spiperone or Sulpiride or Thiethylperazine or Thioridazine or Thiothixene or Tiapride Hydrochloride or Trifluoperazine or Trifluoperidol or Triflupromazine).mp.
60	(MUSCARINIC ANTAGONISTS or CHOLINERGIC ANTAGONISTS).kw.
61	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent?)).tw,tx.
62	((cholinergic or muscarinic) adj2 antagonist?).tw,tx.
63	(glycopyrronium or hyoscine).mp.
64	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dexetimide or Dicyclomine or Emepronium or Glycopyrrolate or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzylcholine Mustard or Quinidine or Quinuclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide or oxybutynin).mp.
65	SOMATOSTATIN.kw.
66	(somatostatin adj3 analogue?).mp.
67	OCTREOTIDE.kw.
68	(Octreotide or Sandostatin).mp.
69	(Lanreotide or Somatuline).mp.
70	(Pasireotide or Signifor).mp.
71	ADRENAL CORTEX HORMONES.kw.
72	(Adrenal Cortex Hormone? or corticosteroid? or 17-Ketosteroid? or Androstenedione or Androsterone or Dehydroepiandrosterone or Estrone or Etiocholanolone or Glucocorticoid? or Beclomethasone or Betamethasone or Budesonide or Clobetasol or Desoximetasone or Dexamethasone or Diflucortolone or Flumethasone or Fluocinolone Acetonide or Fluocinonide or Fluocortolone or Fluorometholone or Fluprednisolone or Flurandrenolone or Melengestrol Acetate or Methylprednisolone or Paramethasone or Prednisolone or Prednisone or Triamcinolone or Hydroxycorticosteroid? or 11-Hydroxycorticosteroid? or Aldosterone or Corticosterone or Hydrocortisone or 18-Hydroxycorticosterone or Tetrahydrocortisol or 17-Hydroxycorticosteroid? or Cortisone or Cortodoxone or Hydrocortisone or Tetrahydrocortisol or Tetrahydrocortisone or Desoxycorticosterone or 18-Hydroxydesoxycorticosterone or Pregnenolone or 17-alpha-Hydroxypregnenolone).mp.
73	DIPHOSPHONATES.kw.
74	(diphosphonate? or bisphosphonate?).mp.
75	CALCITONIN.kw.
76	calcitonin.mp.
77	BOTULINUM TOXINS, TYPE A.kw.
78	botulinum toxin? type a.mp.
79	DANTROLENE.kw.
80	Dantrolene.mp.
81	SUCROSE.kw.
82	DIETARY SUCROSE.kw.
83	(saccharose or sucrose or sugar?).mp.
84	(CANNABIS or CANNABINOIDS).kw.
85	(cannabi\$ or Nabiximol? or Sativex).mp.
86	(palliat\$ adj2 (chemotherap\$ or radiotherap\$)).tw,tx.
87	ETOPOSIDE.kw.

#	Searches
88	Etoposide.mp.
89	(Temozolomide or Temodar or Temodal).mp.
90	or/37-89
91	ACUPUNCTURE THERAPY.kw.
92	(acupuncture or electroacupuncture).tw,tx.
93	THERAPY, SOFT TISSUE.kw.
94	(massag\$ or reflexology or acupressure or Shiat?u or chih ya or zhi ya).tw,tx.
95	PHYSICAL THERAPY MODALITIES.kw.
96	EXERCISE THERAPY.kw.
97	(physiotherap\$ or physical therap\$).tw,tx.
98	((heat or hot or cold) adj3 therap\$).tw,tx.
99	ELECTRIC STIMULATION THERAPY.kw.
100	TRANSCUTANEOUS ELECTRIC NERVE STIMULATION.kw.
101	(transcutaneous adj3 (electr\$ or nerve? or stimulat\$)).tw,tx.
102	(tens or electroanalgesia).tw,tx.
103	MUSIC THERAPY.kw.
104	(music\$ adj3 therap\$).tw,tx.
105	or/91-104
106	9 and 33 and 36 and 90
107	9 and 33 and 36 and 105
108	106 or 107

### E.13.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.



#	Searches
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.13.61 Database: Embase

#	Searches
1	*ADOLESCENT/ or *MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp *CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp *INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp *PEDIATRICS/ or exp *PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx.
9	or/1-8
10	*TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	*RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	*ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	*LIVING WILLS/

#	Searches
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	*HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	exp *PAIN/
35	(pain\$ or headache? or migraine? or neuralgia or myalgia or metatarsalgia or sciatica).ab,ti.
36	34 or 35
37	exp *ANALGESIC AGENT/
38	exp *LOCAL ANESTHETIC AGENT/
39	exp *ANTICONVULSIVE AGENT/
40	exp *ANTIDEPRESSIVE AGENT/
41	exp *NONSTEROID ANTIINFLAMMATORY AGENT/
42	exp *CENTRAL MUSCLE RELAXANT/
43	exp *SEROTONIN UPTAKE INHIBITOR/
44	exp *STEROID/
45	(acetaminophen or acetylsalicylic acid or alendronic acid or alfentanil or amitriptyline or aspirin or baclofen or baclophen or benzocaine or bupivacaine or buprenorphine).mp.
46	(butorphanol or carbamazepine or chlorprocaine or choline magnesium trisalicylate or clonazepam or clonidine or codeine or dexamethasone or dexmetetomidine or dextroamphetamine or tinzanidine).mp.
47	(dextropropoxyphene or diamorphine or diazepam or diclofenac or dihydrocodeine or domperidone or fentanyl or fluoxetine or gabapentin or hydrocodone).mp.
48	(hydromorphone or hyoscine hydrobromide or ibuprofen or ketamine or ketoprofen or ketorolac or levo bupivacaine or lidocaine or loperamide or lorazepam or EMLA).mp.
49	(mefenamic acid or meperidine or methadone or methylphenidate or midazolam or morphine or naproxen or nitrous oxide or nortriptyline or oxycodone).mp.
50	(pamidronate or paracetamol or paroxetine or pentazocine or pethidine or phenobarbital or phenytoin or piroxicam or pregabalin? or propoxyphene).mp.
51	(risedronate sodium or sodium clodronate or tetracaine or tramadol or valproic acid or ametop).mp.
52	((local or conduction blocking or topical) adj3 an?esthetic?).ti,ab.
53	exp *BENZODIAZEPINE DERIVATIVE/
54	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
55	exp *DOPAMINE RECEPTOR BLOCKING AGENT/
56	(dopamine adj3 antagonist?).ab,ti.
57	(dopamine receptor? adj3 block\$).ab,ti.
58	(Acepromazine or Amoxapine or Azaperone or Benperidol or Butaclamol or Chlorpromazine or Chlorprothixene or Clopenthixol or Domperidone or Flupenthixol or Fluphenazine or Fluspirilene or Haloperidol or Loxapine or Mesoridazine or Methotrimeprazine or Penfluridol or Perazine or Perphenazine or Pimozide or Prochlorperazine or Promazine or Raclopride or Remoxipride or Risperidone or Spiperone or Sulpiride or Thiethylperazine or Thioridazine or

#	Searches
	Thiothixene or Tiapride Hydrochloride or Trifluoperazine or Trifluoperidol or Triflupromazine).mp.
59	exp *MUSCARINIC RECEPTOR BLOCKING AGENT/ or *CHOLINERGIC RECEPTOR BLOCKING AGENT/
60	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent?)).ab,ti.
61	((cholinergic or muscarinic) adj2 antagonist?).ab,ti.
62	(glycopyrronium or hyoscine).mp.
63	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dexetimide or Dicyclomine or Emepronium or Glycopyrrolate or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzylcholine Mustard or Quinidine or Quinclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide or oxybutynin).mp.
64	*SOMATOSTATIN/
65	(somatostatin adj3 analogue?).mp.
66	*OCTREOTIDE/
67	(Octreotide or Sandostatin).mp.
68	(Lanreotide or Somatuline).mp.
69	(Pasireotide or Signifor).mp.
70	exp *CORTICOSTEROID/
71	(Adrenal Cortex Hormone? or corticosteroid? or 17-Ketosteroid? or Androstenedione or Androsterone or Dehydroepiandrosterone or Estrone or Etiocholanolone or Glucocorticoid? or Beclomethasone or Betamethasone or Budesonide or Clobetasol or Desoximetasone or Dexamethasone or Diflucortolone or Flumethasone or Fluocinolone Acetonide or Fluocinonide or Fluocortolone or Fluorometholone or Fluprednisolone or Flurandrenolone or Melengestrol Acetate or Methylprednisolone or Paramethasone or Prednisolone or Prednisone or Triamcinolone or Hydroxycorticosteroid? or 11-Hydroxycorticosteroid? or Aldosterone or Corticosterone or Hydrocortisone or 18-Hydroxycorticosterone or Tetrahydrocortisol or 17-Hydroxycorticosteroid? or Cortisone or Cortodoxone or Hydrocortisone or Tetrahydrocortisol or Tetrahydrocortisone or Desoxycorticosterone or 18-Hydroxydesoxycorticosterone or Pregnenolone or 17-alpha-Hydroxypregnenolone).mp.
72	*BISPHOSPHONIC ACID DERIVATIVE/
73	(diphosphonate? or bisphosponate?).mp.
74	*CALCITONIN/
75	calcitonin.mp.
76	*BOTULINUM TOXIN A/
77	botulinum toxin? type a.mp.
78	*DANTROLENE/
79	Dantrolene.mp.
80	*SUCROSE/
81	*SUGAR INTAKE/
82	(saccharose or sucrose or sugar?).mp.
83	*CANNABIS/ or exp *CANNABINOIDS/
84	(cannabi\$ or Nabiximol? or Sativex).mp.
85	(palliat\$ adj2 (chemotherap\$ or radiotherap\$)).ti,ab.
86	*ETOPOSIDE/
87	Etoposide.mp.
88	*TEMOZOLOMIDE/
89	(Temozolomide or Temodar or Temodal).mp.
90	or/37-89

#	Searches
91	exp *ACUPUNCTURE/
92	(acupunture or electroacupuncture).ti,ab.
93	*THERAPY, SOFT TISSUE/ or *MASSAGE/ or *REFELEXOLOGY/
94	(massag\$ or reflexology or acupressure or Shiat?u or chih ya or zhi ya).ti,ab.
95	*PHYSIOTHERAPY/
96	exp *KINESIOTHERAPY/
97	(physiotherap\$ or physical therap\$).ab,ti.
98	((heat or hot or cold) adj3 therap\$).ti,ab.
99	*ELECTROSTIMULATION THERAPY/
100	*TRANSCUTANEOUS NERVE STIMULATION/
101	(transcutaneous adj3 (electr\$ or nerve? or stimulat\$)).ti,ab.
102	(tens or electroanalgesia).ti,ab.
103	*MUSIC THERAPY/
104	(music\$ adj3 therap\$).ti,ab.
105	or/91-104
106	9 and 33 and 36 and 90
107	9 and 33 and 36 and 105
108	*ANALGESIA/
109	9 and 33 and 108
110	106 or 107 or 109
111	limit 110 to english language
112	letter.pt. or LETTER/
113	note.pt.
114	editorial.pt.
115	CASE REPORT/ or CASE STUDY/
116	(letter or comment*).ti.
117	or/112-116
118	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
119	117 not 118
120	ANIMAL/ not HUMAN/
121	NONHUMAN/
122	exp ANIMAL EXPERIMENT/
123	exp EXPERIMENTAL ANIMAL/
124	ANIMAL MODEL/
125	exp RODENT/
126	(rat or rats or mouse or mice).ti.
127	or/119-126
128	111 not 127

## E.14.1 Managing Agitation

### E.14.1.2 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.

#	Searches
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	PSYCHOMOTOR AGITATION/
35	(agitat\$ or akathisia or restless\$).ab,ti.
36	DELIRIUM/
37	deliri\$.ab,ti.
38	or/34-37
39	9 and 33 and 38
40	limit 39 to english language
41	LETTER/
42	EDITORIAL/
43	NEWS/
44	exp HISTORICAL ARTICLE/
45	ANECDOTES AS TOPIC/

#	Searches
46	COMMENT/
47	CASE REPORT/
48	(letter or comment*).ti.
49	or/41-48
50	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
51	49 not 50
52	ANIMALS/ not HUMANS/
53	exp ANIMALS, LABORATORY/
54	exp ANIMAL EXPERIMENTATION/
55	exp MODELS, ANIMAL/
56	exp RODENTIA/
57	(rat or rats or mouse or mice).ti.
58	or/51-57
59	40 not 58

#### E.14.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(agitat\$ or akathisia or restless\$).ab,ti.
24	deliri\$.ab,ti.
25	or/23-24
26	5 and 22 and 25

### E.14.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti,kw.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	PSYCHOMOTOR AGITATION/
35	(agitat\$ or akathisia or restless\$).ab,ti,kw.
36	DELIRIUM/
37	deliri\$.ab,ti,kw.
38	or/34-37
39	9 and 33 and 38

### E.14.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.ab,ti.
25	LIVING WILLS.kw.
26	living will?.ab,ti.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE.kw.
30	palliat\$.ti,ab.
31	HOSPICE CARE.kw.
32	hospice?.ab,ti.
33	or/10-32
34	AGITATION.kw.
35	PSYCHOMOTOR AGITATION.kw.
36	(agitat\$ or akathisia or restless\$).tw,tx.
37	DELIRIUM.kw.
38	deliri\$.tw,tx.
39	or/34-38
40	9 and 33 and 39



### E.14.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.14.62 Database: Embase

#	Searches
1	*ADOLESCENT/ or *MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp *CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.

#	Searches
5	exp *INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp *PEDIATRICS/ or exp *PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx.
9	or/1-8
10	*TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	*RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	*ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	*LIVING WILLS/
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	*HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	*AGITATION/
35	*RESTLESSNESS/
36	(agitat\$ or akathisia or restless\$).ab,ti.
37	*DELIRIUM/
38	deliri\$.ab,ti.
39	or/34-38
40	9 and 33 and 39
41	limit 40 to english language
42	letter.pt. or LETTER/
43	note.pt.
44	editorial.pt.
45	CASE REPORT/ or CASE STUDY/
46	(letter or comment*).ti.
47	or/42-46
48	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.

#	Searches
49	47 not 48
50	ANIMAL/ not HUMAN/
51	NONHUMAN/
52	exp ANIMAL EXPERIMENT/
53	exp EXPERIMENTAL ANIMAL/
54	ANIMAL MODEL/
55	exp RODENT/
56	(rat or rats or mouse or mice).ti.
57	or/49-56
58	41 not 57

## E.15<sub>1</sub> Managing Respiratory distress

### E.15.12 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.

#	Searches
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	DYSPNEA/
35	dyspnea?.ab,ti.
36	breathless\$.ab,ti.
37	((Difficult\$ or labo?red or problem\$ or short\$ or distress\$) adj3 (breath\$ or respirat\$)).ab,ti.
38	RESPIRATORY SOUNDS/
39	BRONCHI/se [Secretions]
40	LUNG/se [Secretions]
41	(respirat\$ adj3 (sound\$ or secret\$)).ab,ti.
42	((bronchial or retained or pulmonary or airway or non-expectorated) adj3 secret\$).ab,ti.
43	((respirat\$ or breath\$) adj3 nois\$).ab,ti.
44	((death or breath\$) adj3 rattl\$).ab,ti.
45	or/34-44
46	exp DIURETICS/
47	(Acetazolamide or Amiloride or Bendroflumethiazide or Bumetanide or Chlorothiazide or Chlorthalidone or Clopamide or Cyclopenthiiazide or Ethacrynic Acid or Ethoxzolamide or Furosemide or Hydrochlorothiazide or Hydroflumethiazide or Indapamide or Mefruside or Methazolamide or Methyclothiazide or Metolazone or Muzolimine or Polythiazide or Potassium Citrate or Spironolactone or Ticrynafen or Triamterene or Trichlormethiazide or Xipamide).mp.
48	exp MUSCARINIC ANTAGONISTS/ or CHOLINERGIC ANTAGONISTS/
49	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dexetimide or Dicyclomine or Emepronium or Glycopyrrolate or Glycopyrtronium or Hyoscine butylbromide or Hyoscine hydrobromide or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzilylcholine Mustard or Quinidine or Quinuclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide).mp.
50	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent\$)).ab,ti.
51	((cholinergic or muscarinic) adj2 antagonist\$).ab,ti.
52	exp BRONCHODILATOR AGENTS/
53	(Adrenomedullin or Albuterol or Aminophylline or Atropine or Budesonide or Clenbuterol or Colforsin or Cromakalim or Dyphylline or Epinephrine or Fenoterol or Hexoprenaline or Hyoscyamine or Ipratropium or Isoetharine or Isoproterenol or Khellin or Metaproterenol or Nitric Oxide or Procaterol or Pseudoephedrine or Racepinephrine or S-Nitrosoglutathione or S-Nitrosothiol? or Terbutaline or Theobromine or Theophylline or Tretoquinol).mp.
54	(bronchodilator\$ or broncholytic\$).ab,ti.
55	exp STEROIDS/ and ADMINISTRATION, INHALATION/
56	(Beclomethasone or Vanceril or Beclovent or Qvar or Flunisolide or Aerobid or Mometasone furoate or Asmanex or Triamcinolone or Azmacort or Fluticasone propionate or Flovent or Budesonide or Pulmicort or Advair or Symbicort or Dulera).mp.
57	(SODIUM CHLORIDE/ or SALINE SOLUTION, HYPERTONIC/) and exp "NEBULIZERS AND VAPORIZERS"/
58	(Nebuli?ed adj2 saline).ab,ti.
59	exp "HYPNOTICS AND SEDATIVES"/
60	(sedat\$ or antianxiet\$ or anti anxiet\$ or anxiolytic\$).ti,ab.

#	Searches
61	(Alprazolam or Amobarbital or Azaperone or Barbitol or Bromisovalum or Chloral Hydrate or Chloralose or Chlordiazepoxide or Chlormethiazole or Dexmedetomidine or Diazepam or Diphenhydramine or Ethchlorvynol or Etomidate or Etorphine or Flurazepam or Glutethimide or Hexobarbital or Lorazepam or Medazepam or Medetomidine or Mephobarbital or Meprobamate or Methapyrilene or Methaqualone or Midazolam or Nitrazepam or Oxazepam or Paraldehyde or Pentobarbital or Phenobarbital or Propofol or Secobarbital or Temazepam or Thiamylal or Thiopental or Xylazine).mp.
62	exp ANTI-ANXIETY AGENTS/
63	(Alprazolam or Bromazepam or Buspirone or Chlordiazepoxide or Chlormezanone or Clorazepate Dipotassium or Diazepam or Estazolam or Flunitrazepam or Flurazepam or Fluvoxamine or Lorazepam or Medazepam or Meprobamate or Midazolam or Nitrazepam or Nordazepam or Ondansetron or Oxazepam or Oxprenolol or Prazepam or Ritanserin or Temazepam or Tranlycypromine or Trazodone or Triazolam or Zolazepam).mp.
64	exp ANALGESICS, OPIOID/
65	(Alfentanil or Alphaprodine or Buprenorphine or Butorphanol or Codeine or Dextromoramide or Dextropropoxyphene or Dihydromorphine or Diphenoxylate or Enkephalin or Ethylketocyclazocine or Ethylmorphine or Etorphine or fentanyl or Heroin or Hydrocodone or Hydromorphone or Levorphanol or Meperidine or Meptazinol or Methadone or Methadyl Acetate or Morphine or Nalbuphine or Opiate Alkaloids or Opium or Oxycodone or Oxymorphone or Pentazocine or Phenazocine or Phenoperidine or Pirinitramide or Promedol or Sufentanil or Tilidine or Tramadol).mp.
66	exp BENZODIAZEPINES/
67	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
68	OXYGEN/
69	oxygen.mp.
70	or/46-69
71	RESPIRATORY THERAPY/
72	DRAINAGE, POSTURAL/
73	(postur\$ adj2 drain\$).ab,ti.
74	(fan? or fanned or fanning).ab,ti.
75	(open\$ adj3 window?).ab,ti.
76	BREATHING EXERCISES/
77	((breath\$ or respirat\$ or inhalat\$) adj3 (exercise? or therap\$ or technique?)).ab,ti.
78	(active cycle adj2 breath\$).ab,ti.
79	(square adj2 breath\$).ab,ti.
80	((breathing or expiratory flow) adj2 control\$).ab,ti.
81	(thoracic expansion exercise? or tidal breath\$ or inspiratory muscle training or forced expiration technique? or ELTGOL or positive expiratory pressure or PEP or oscillatory or oscillating device? or High frequency chest or vest? or flutter or percussion or clapping or autogenic drainage).ab,ti.
82	expiration with the glottis open in the lateral posture.ti,ab.
83	CHEST WALL OSCILLATION/
84	chest wall oscillation?.ab,ti.
85	exp RESPIRATION ARTIFICIAL/
86	(Respirat\$ adj2 Artificial\$).ti,ab.
87	((High Frequen\$ or Liquid or Noninvasiv\$ or non-invasiv\$ or One-Lung) adj2 Ventilat\$).ti,ab.
88	(Positive Pressure adj2 (Respirat\$ or Breath\$ or Ventilat\$)).ti,ab.

#	Searches
89	positive airway pressure.ab,ti.
90	BIPAP.ab,ti.
91	CPAP.ab,ti.
92	(airway clear\$ adj2 technique?).ab,ti.
93	suction\$.ab,ti.
94	OXYGEN INHALATION THERAPY/
95	or/71-94
96	9 and 33 and 45 and 70
97	9 and 33 and 45 and 95
98	DYSPNEA/dt, th [Drug Therapy, Therapy]
99	RESPIRATORY SOUNDS/de, dt, th [Drug Effects, Drug Therapy, Therapy]
100	98 or 99
101	9 and 33 and 100
102	96 or 97 or 101
103	limit 102 to english language
104	LETTER/
105	EDITORIAL/
106	NEWS/
107	exp HISTORICAL ARTICLE/
108	ANECDOTES AS TOPIC/
109	COMMENT/
110	CASE REPORT/
111	(letter or comment*).ti.
112	or/104-111
113	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
114	112 not 113
115	ANIMALS/ not HUMANS/
116	exp ANIMALS, LABORATORY/
117	exp ANIMAL EXPERIMENTATION/
118	exp MODELS, ANIMAL/
119	exp RODENTIA/
120	(rat or rats or mouse or mice).ti.
121	or/114-120
122	103 not 121

### E.15.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescens\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescens\$ or prepubescens\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.

#	Searches
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	dyspnea?.ab,ti.
24	breathless\$.ab,ti.
25	((Difficult\$ or labo?red or problem\$ or short\$ or distress\$) adj3 (breath\$ or respirat\$)).ab,ti.
26	(respirat\$ adj3 (sound\$ or secret\$)).ab,ti.
27	((bronchial or retained or pulmonary or airway or non-expectorated) adj3 secret\$).ab,ti.
28	((respirat\$ or breath\$) adj3 nois\$).ab,ti.
29	((death or breath\$) adj3 rattl\$).ab,ti.
30	or/23-29
31	(Acetazolamide or Amiloride or Bendroflumethiazide or Bumetanide or Chlorothiazide or Chlorthalidone or Clopamide or Cyclopenthiiazide or Ethacrynic Acid or Ethoxzolamide or Furosemide or Hydrochlorothiazide or Hydroflumethiazide or Indapamide or Mefruside or Methazolamide or Methyclothiazide or Metolazone or Muzolimine or Polythiazide or Potassium Citrate or Spironolactone or Ticrynafen or Triamterene or Trichlormethiazide or Xipamide).mp.
32	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dexetimide or Dicyclomine or Emepronium or Glycopyrrolate or Glycopyrronium or Hyoscine butylbromide or Hyoscine hydrobromide or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzylcholine Mustard or Quinidine or Quinuclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide).mp.
33	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent?)).ab,ti.
34	((cholinergic or muscarinic) adj2 antagonist?).ab,ti.
35	(Adrenomedullin or Albuterol or Aminophylline or Atropine or Budesonide or Clenbuterol or Colforsin or Cromakalim or Dyphylline or Epinephrine or Fenoterol or Hexoprenaline or Hyoscyamine or Ipratropium or Isoetharine or Isoproterenol or Khellin or Metaproterenol or Nitric Oxide or Procatamol or Pseudoephedrine or Racementerol or S-Nitrosoglutathione or S-Nitrosothiol? or Terbutaline or Theobromine or Theophylline or Tretoquinol).mp.
36	(bronchodilator\$ or broncholytic\$).ab,ti.
37	(Beclomethasone or Vanceril or Beclovent or Qvar or Flunisolide or Aerobid or Mometasone furoate or Asmanex or Triamcinolone or Azmacort or Fluticasone propionate or Flovent or Budesonide or Pulmicort or Advair or Symbicort or Dulera).mp.
38	(Nebuli?ed adj2 saline).ab,ti.
39	(sedat\$ or antianxiet\$ or anti anxiet\$ or anxiolytic?).ti,ab.

#	Searches
40	(Alprazolam or Amobarbital or Azaperone or Barbitol or Bromisovalum or Chloral Hydrate or Chloralose or Chlordiazepoxide or Chlormethiazole or Dexmedetomidine or Diazepam or Diphenhydramine or Ethchlorvynol or Etomidate or Etorphine or Flurazepam or Glutethimide or Hexobarbital or Lorazepam or Medazepam or Medetomidine or Mephobarbital or Meprobamate or Methapyrilene or Methaqualone or Midazolam or Nitrazepam or Oxazepam or Paraldehyde or Pentobarbital or Phenobarbital or Propofol or Secobarbital or Temazepam or Thiamylal or Thiopental or Xylazine).mp.
41	(Alprazolam or Bromazepam or Buspirone or Chlordiazepoxide or Chlormezanone or Clorazepate Dipotassium or Diazepam or Estazolam or Flunitrazepam or Flurazepam or Fluvoxamine or Lorazepam or Medazepam or Meprobamate or Midazolam or Nitrazepam or Nordazepam or Ondansetron or Oxazepam or Oxprenolol or Prazepam or Ritanserin or Temazepam or Tranlycypromine or Trazodone or Triazolam or Zolazepam).mp.
42	(Alfentanil or Alphaprodine or Buprenorphine or Butorphanol or Codeine or Dextromoramide or Dextropropoxyphene or Dihydromorphine or Diphenoxylate or Enkephalin or Ethylketocyclazocine or Ethylmorphine or Etorphine or fentanyl or Heroin or Hydrocodone or Hydromorphone or Levorphanol or Meperidine or Meptazinol or Methadone or Methadyl Acetate or Morphine or Nalbuphine or Opiate Alkaloids or Opium or Oxycodone or Oxymorphone or Pentazocine or Phenazocine or Phenoperidine or Pirinitramide or Promedol or Sufentanil or Tilidine or Tramadol).mp.
43	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
44	oxygen.mp.
45	or/31-44
46	(postur\$ adj2 drain\$).ab,ti.
47	(fan? or fanned or fanning).ab,ti.
48	(open\$ adj3 window?).ab,ti.
49	((breath\$ or respirat\$ or inhalat\$) adj3 (exercise? or therap\$ or technique?)).ab,ti.
50	(active cycle adj2 breath\$).ab,ti.
51	(square adj2 breath\$).ab,ti.
52	((breathing or expiratory flow) adj2 control\$).ab,ti.
53	(thoracic expansion exercise? or tidal breath\$ or inspiratory muscle training or forced expiration technique? or ELTGOL or positive expiratory pressure or PEP or oscillatory or oscillating device? or High frequency chest or vest? or flutter or percussion or clapping or autogenic drainage).ab,ti.
54	expiration with the glottis open in the lateral posture.ti,ab.
55	chest wall oscillation?.ab,ti.
56	(Respirat\$ adj2 Artificial\$).ti,ab.
57	((High Frequen\$ or Liquid or Noninvasiv\$ or non-invasiv\$ or One-Lung) adj2 Ventilat\$).ti,ab.
58	(Positive Pressure adj2 (Respirat\$ or Breath\$ or Ventilat\$)).ti,ab.
59	positive airway pressure.ab,ti.
60	BIPAP.ab,ti.
61	CPAP.ab,ti.
62	(airway clear\$ adj2 technique?).ab,ti.
63	suction\$.ab,ti.
64	or/46-63
65	5 and 22 and 30 and 45
66	5 and 22 and 30 and 64
67	65 or 66



### E.15.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab,kw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab,kw.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab,kw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab,kw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab,kw.
18	(last year of life or LYOL or life\$ end).ti,ab,kw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab,kw.
20	((advanced or late or last or end or final or terminal) adj phase\$).ti,ab,kw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ti,ab,kw.
25	LIVING WILLS/
26	living will?.ti,ab,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ti,ab,kw.
33	or/10-32
34	DYSPNEA/
35	dyspnea?.ti,ab,kw.
36	breathless\$.ti,ab,kw.
37	((Difficult\$ or labo?red or problem\$ or short\$ or distress\$) adj3 (breath\$ or respirat\$)).ti,ab,kw.
38	RESPIRATORY SOUNDS/
39	BRONCHI/se [Secretions]
40	LUNG/se [Secretions]
41	(respirat\$ adj3 (sound\$ or secret\$)).ti,ab,kw.

#	Searches
42	((bronchial or retained or pulmonary or airway or non-expectorated) adj3 secret\$).ti,ab,kw.
43	((respirat\$ or breath\$) adj3 nois\$).ti,ab,kw.
44	((death or breath\$) adj3 rattl\$).ti,ab,kw.
45	or/34-44
46	exp DIURETICS/
47	(Acetazolamide or Amiloride or Bendroflumethiazide or Bumetanide or Chlorothiazide or Chlorthalidone or Clopamide or Cyclopenthiiazide or Ethacrynic Acid or Ethoxzolamide or Furosemide or Hydrochlorothiazide or Hydroflumethiazide or Indapamide or Mefruside or Methazolamide or Methyclothiazide or Metolazone or Muzolimine or Polythiazide or Potassium Citrate or Spironolactone or Ticrynafen or Triamterene or Trichlormethiazide or Xipamide).mp.
48	exp MUSCARINIC ANTAGONISTS/ or CHOLINERGIC ANTAGONISTS/
49	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dexetimide or Dicyclomine or Emepronium or Glycopyrrolate or Glycopyrtronium or Hyoscine butylbromide or Hyoscine hydrobromide or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzilylcholine Mustard or Quinidine or Quinuclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide).mp.
50	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent?)).ti,ab,kw.
51	((cholinergic or muscarinic) adj2 antagonist?).ti,ab,kw.
52	exp BRONCHODILATOR AGENTS/
53	(Adrenomedullin or Albuterol or Aminophylline or Atropine or Budesonide or Clenbuterol or Colforsin or Cromakalim or Dyphylline or Epinephrine or Fenoterol or Hexoprenaline or Hyoscyamine or Ipratropium or Isoetharine or Isoproterenol or Khellin or Metaproterenol or Nitric Oxide or Procaterol or Pseudoephedrine or Racepinephrine or S-Nitrosoglutathione or S-Nitrosothiol? or Terbutaline or Theobromine or Theophylline or Tretoquinol).mp.
54	(bronchodilator\$ or broncholytic\$).ti,ab,kw.
55	exp STEROIDS/ and ADMINISTRATION, INHALATION/
56	(Beclomethasone or Vanceril or Beclovent or Qvar or Flunisolide or Aerobid or Mometasone furoate or Asmanex or Triamcinolone or Azmacort or Fluticasone propionate or Flovent or Budesonide or Pulmicort or Advair or Symbicort or Dulera).mp.
57	(SODIUM CHLORIDE/ or SALINE SOLUTION, HYPERTONIC/) and exp "NEBULIZERS AND VAPORIZERS"/
58	(Nebuliz?ed adj2 saline).ti,ab,kw.
59	exp "HYPNOTICS AND SEDATIVES"/
60	(sedat\$ or antianxiet\$ or anti anxiet\$ or anxiolytic?).ti,ab,kw.
61	(Alprazolam or Amobarbital or Azaperone or Barbitol or Bromisovalum or Chloral Hydrate or Chloralose or Chlordiazepoxide or Chlormethiazole or Dexmedetomidine or Diazepam or Diphenhydramine or Ethchlorvynol or Etomidate or Etorphine or Flurazepam or Glutethimide or Hexobarbital or Lorazepam or Medazepam or Medetomidine or Mephobarbital or Meprobamate or Methapyrilene or Methaqualone or Midazolam or Nitrazepam or Oxazepam or Paraldehyde or Pentobarbital or Phenobarbital or Propofol or Secobarbital or Temazepam or Thiamylal or Thiopental or Xylazine).mp.
62	exp ANTI-ANXIETY AGENTS/
63	(Alprazolam or Bromazepam or Buspirone or Chlordiazepoxide or Chlormezanone or Clorazepate Dipotassium or Diazepam or Estazolam or Flunitrazepam or Flurazepam or Fluvoxamine or Lorazepam or Medazepam or Meprobamate or Midazolam or Nitrazepam or Nordazepam or Ondansetron or Oxazepam or Oxprenolol or Prazepam or Ritanserin or Temazepam or Tranlycypromine or Trazodone or Triazolam or Zolazepam).mp.
64	exp ANALGESICS, OPIOID/

#	Searches
65	(Alfentanil or Alphaprodine or Buprenorphine or Butorphanol or Codeine or Dextromoramide or Dextropropoxyphene or Dihydromorphine or Diphenoxylate or Enkephalin or Ethylketocyclazocine or Ethylmorphine or Etorphine or fentanyl or Heroin or Hydrocodone or Hydromorphone or Levorphanol or Meperidine or Meptazinol or Methadone or Methadyl Acetate or Morphine or Nalbuphine or Opiate Alkaloids or Opium or Oxycodone or Oxymorphone or Pentazocine or Phenazocine or Phenoperidine or Pirinitramide or Promedol or Sufentanil or Tilidine or Tramadol).mp.
66	exp BENZODIAZEPINES/
67	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
68	OXYGEN/
69	oxygen.mp.
70	or/46-69
71	RESPIRATORY THERAPY/
72	DRAINAGE, POSTURAL/
73	(postur\$ adj2 drain\$).ti,ab,kw.
74	(fan? or fanned or fanning).ti,ab,kw.
75	(open\$ adj3 window?).ti,ab,kw.
76	BREATHING EXERCISES/
77	((breath\$ or respirat\$ or inhalat\$) adj3 (exercise? or therap\$ or technique?)).ti,ab,kw.
78	(active cycle adj2 breath\$).ti,ab,kw.
79	(square adj2 breath\$).ti,ab,kw.
80	((breathing or expiratory flow) adj2 control\$).ti,ab,kw.
81	(thoracic expansion exercise? or tidal breath\$ or inspiratory muscle training or forced expiration technique? or ELTGOL or positive expiratory pressure or PEP or oscillatory or oscillating device? or High frequency chest or vest? or flutter or percussion or clapping or autogenic drainage).ti,ab,kw.
82	expiration with the glottis open in the lateral posture.ti,ab,kw.
83	CHEST WALL OSCILLATION/
84	chest wall oscillation?.ti,ab,kw.
85	exp RESPIRATION ARTIFICIAL/
86	(Respirat\$ adj2 Artificial\$).ti,ab,kw.
87	((High Frequen\$ or Liquid or Noninvasiv\$ or non-invasiv\$ or One-Lung) adj2 Ventilat\$).ti,ab,kw.
88	(Positive Pressure adj2 (Respirat\$ or Breath\$ or Ventilat\$)).ti,ab,kw.
89	positive airway pressure.ti,ab,kw.
90	BIPAP.ti,ab,kw.
91	CPAP.ti,ab,kw.
92	(airway clear\$ adj2 technique?).ti,ab,kw.
93	suction\$.ti,ab,kw.
94	OXYGEN INHALATION THERAPY/
95	or/71-94
96	9 and 33 and 45 and 70
97	9 and 33 and 45 and 95
98	DYSPNEA/dt, th [Drug Therapy, Therapy]
99	RESPIRATORY SOUNDS/de, dt, th [Drug Effects, Drug Therapy, Therapy]

#	Searches
100	98 or 99
101	9 and 33 and 100
102	96 or 97 or 101

### E.15.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ti,ab.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ti,ab.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.ti,ab.
25	LIVING WILLS.kw.
26	living will?.ti,ab.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE.kw.
30	palliat\$.ti,ab.
31	HOSPICE CARE.kw.
32	hospice?.ti,ab.
33	or/10-32
34	DYSPNEA.kw.
35	dyspnea?.tw,tx.
36	breathless\$.tw,tx.

#	Searches
37	((Difficult\$ or labo?red or problem\$ or short\$ or distress\$) adj3 (breath\$ or respirat\$)).tw,tx.
38	RESPIRATORY SOUNDS.kw.
39	(respirat\$ adj3 (sound\$ or secret\$)).tw,tx.
40	((bronchial or retained or pulmonary or airway or non-expectorated) adj3 secret\$).tw,tx.
41	((respirat\$ or breath\$) adj3 nois\$).tw,tx.
42	((death or breath\$) adj3 rattl\$).tw,tx.
43	or/34-42
44	DIURETICS.kw.
45	(Acetazolamide or Amiloride or Bendroflumethiazide or Bumetanide or Chlorothiazide or Chlorthalidone or Clopamide or Cyclopenthiiazide or Ethacrynic Acid or Ethoxzolamide or Furosemide or Hydrochlorothiazide or Hydroflumethiazide or Indapamide or Mefruside or Methazolamide or Methyclothiazide or Metolazone or Muzolimine or Polythiazide or Potassium Citrate or Spironolactone or Ticrynafen or Triamterene or Trichlormethiazide or Xipamide).mp.
46	(MUSCARINIC ANTAGONISTS or CHOLINERGIC ANTAGONISTS).kw.
47	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dextimide or Dicyclomine or Emepronium or Glycopyrrolate or Glycopyrronium or Hyoscine butylbromide or Hyoscine hydrobromide or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzylcholine Mustard or Quinidine or Quinuclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide).mp.
48	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent?)).tw,tx.
49	((cholinergic or muscarinic) adj2 antagonist?).tw,tx.
50	BRONCHODILATOR AGENTS.kw.
51	(Adrenomedullin or Albuterol or Aminophylline or Atropine or Budesonide or Clenbuterol or Colforsin or Cromakalim or Dyphylline or Epinephrine or Fenoterol or Hexoprenaline or Hyoscyamine or Ipratropium or Isoetharine or Isoproterenol or Khellin or Metaproterenol or Nitric Oxide or Procateterol or Pseudoephedrine or Racementephrine or S-Nitrosoglutathione or S-Nitrosothiol? or Terbutaline or Theobromine or Theophylline or Tretoquinol).mp.
52	(bronchodilator\$ or broncholytic\$).tw,tx.
53	(STEROIDS and INHALATION).kw.
54	(Beclomethasone or Vancertil or Beclovent or Qvar or Flunisolide or Aerobid or Mometasone furoate or Asmanex or Triamcinolone or Azmacort or Fluticasone propionate or Flovent or Budesonide or Pulmicort or Advair or Symbicort or Dulera).mp.
55	((SODIUM CHLORIDE or SALINE SOLUTION) and (NEBULIZERS or VAPORIZERS)).kw.
56	(Nebuli?ed adj2 saline).tw,tx.
57	(HYPNOTICS or SEDATIVES).kw.
58	(sedat\$ or antianxiet\$ or anti anxiet\$ or anxiolytic?).tw,tx.
59	(Alprazolam or Amobarbital or Azaperone or Barbitol or Bromisovalum or Chloral Hydrate or Chloralose or Chlordiazepoxide or Chlormethiazole or Dexmedetomidine or Diazepam or Diphenhydramine or Ethchlorvynol or Etomidate or Etorphine or Flurazepam or Glutethimide or Hexobarbital or Lorazepam or Medazepam or Medetomidine or Mephobarbital or Meprobamate or Methapyrilene or Methaqualone or Midazolam or Nitrazepam or Oxazepam or Paraldehyde or Pentobarbital or Phenobarbital or Propofol or Secobarbital or Temazepam or Thiamylal or Thiopental or Xylazine).mp.
60	ANTI-ANXIETY AGENTS.kw.
61	(Alprazolam or Bromazepam or Buspirone or Chlordiazepoxide or Chlormezanone or Clorazepate Dipotassium or Diazepam or Estazolam or Flunitrazepam or Flurazepam or Fluvoxamine or Lorazepam or Medazepam or Meprobamate or Midazolam or Nitrazepam or Nordazepam or Ondansetron or Oxazepam or Oxprenolol or Prazepam or Ritanserin or Temazepam or Tranlycypromine or Trazodone or Triazolam or Zolazepam).mp.
62	ANALGESICS, OPIOID.kw.

#	Searches
63	(Alfentanil or Alphaprodine or Buprenorphine or Butorphanol or Codeine or Dextromoramide or Dextropropoxyphene or Dihydromorphine or Diphenoxylate or Enkephalin or Ethylketocyclazocine or Ethylmorphine or Etorphine or fentanyl or Heroin or Hydrocodone or Hydromorphone or Levorphanol or Meperidine or Meptazinol or Methadone or Methadyl Acetate or Morphine or Nalbuphine or Opiate Alkaloids or Opium or Oxycodone or Oxymorphone or Pentazocine or Phenazocine or Phenoperidine or Pirinitramide or Promedol or Sufentanil or Tilidine or Tramadol).mp.
64	BENZODIAZEPINES.kw.
65	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
66	OXYGEN.kw.
67	oxygen.mp.
68	or/44-67
69	RESPIRATORY THERAPY.kw.
70	DRAINAGE, POSTURAL.kw.
71	(postur\$ adj2 drain\$).tw,tx.
72	(fan? or fanned or fanning).tw,tx.
73	(open\$ adj3 window?).tw,tx.
74	BREATHING EXERCISES.kw.
75	((breath\$ or respirat\$ or inhalat\$) adj3 (exercise? or therap\$ or technique?)).tw,tx.
76	(active cycle adj2 breath\$).tw,tx.
77	(square adj2 breath\$).tw,tx.
78	((breathing or expiratory flow) adj2 control\$).tw,tx.
79	(thoracic expansion exercise? or tidal breath\$ or inspiratory muscle training or forced expiration technique? or ELTGOL or positive expiratory pressure or PEP or oscillatory or oscillating device? or High frequency chest or vest? or flutter or percussion or clapping or autogenic drainage).tw,tx.
80	expiration with the glottis open in the lateral posture.tw,tx.
81	CHEST WALL OSCILLATION.kw.
82	chest wall oscillation?.tw,tx.
83	RESPIRATION ARTIFICIAL.kw.
84	(Respirat\$ adj2 Artificial\$).tw,tx.
85	((High Frequen\$ or Liquid or Noninvasiv\$ or non-invasiv\$ or One-Lung) adj2 Ventilat\$).tw,tx.
86	(Positive Pressure adj2 (Respirat\$ or Breath\$ or Ventilat\$)).tw,tx.
87	positive airway pressure.tw,tx.
88	BIPAP.tw,tx.
89	CPAP.tw,tx.
90	(airway clear\$ adj2 technique?).tw,tx.
91	suction\$.tw,tx.
92	OXYGEN INHALATION THERAPY.kw.
93	or/69-92
94	9 and 33 and 43 and 68
95	9 and 33 and 43 and 93
96	94 or 95

### E.15.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.15.62 Database: Embase

#	Searches
1	*ADOLESCENT/ or *MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp *CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.

#	Searches
5	exp *INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp *PEDIATRICS/ or exp *PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescent\$).ti,ab,jx.
9	or/1-8
10	*TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	*RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	*ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	*LIVING WILLS/
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	*HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	*DYSPNEA/
35	dyspnea?.ab,ti.
36	breathless\$.ab,ti.
37	((Difficult\$ or labo?red or problem\$ or short\$ or distress\$) adj3 (breath\$ or respirat\$)).ab,ti.
38	*ABNORMAL RESPIRATORY SOUND/
39	(respirat\$ adj3 (sound\$ or secret\$)).ab,ti.
40	((bronchial or retained or pulmonary or airway or non-expectorated) adj3 secret\$).ab,ti.
41	((respirat\$ or breath\$) adj3 nois\$).ab,ti.
42	((death or breath\$) adj3 rattl\$).ab,ti.
43	or/34-42
44	exp *DIURETIC AGENT/
45	(Acetazolamide or Amiloride or Bendroflumethiazide or Bumetanide or Chlorothiazide or Chlorthalidone or Clopamide or Cyclopenthiiazide or Ethacrynic Acid or Ethoxzolamide or Furosemide or Hydrochlorothiazide or Hydroflumethiazide or Indapamide or Mefruside or Methazolamide or Methyclothiazide or Metolazone or Muzolimine or Polythiazide or



#	Searches
	Potassium Citrate or Spironolactone or Ticrynafen or Triamterene or Trichlormethiazide or Xipamide).mp.
46	exp *MUSCARINIC RECEPTOR BLOCKING AGENT/ or exp *CHOLINERGIC RECEPTOR BLOCKING AGENT/
47	(Atropine or Benactyzine or Benztropine or Biperiden or Butylscopolammonium Bromide or Cyclopentolate or Dexetimide or Dicyclomine or Emepronium or Glycopyrrolate or Glycopyrtronium or Hyoscine butylbromide or Hyoscine hydrobromide or Hyoscyamine or Orphenadrine or Oxyphenonium or Pirenzepine or Procyclidine or Propantheline or Propylbenzilylcholine Mustard or Quinidine or Quinuclidinyl Benzilate or Scopolamine Hydrobromide or Trihexyphenidyl or Tropicamide).mp.
48	((anticholinergic\$ or anti-cholinergic\$ or antimuscarinic\$ or anti-muscarinic\$) adj3 (drug\$ or agent?)).ab,ti.
49	((cholinergic or muscarinic) adj2 antagonist?).ab,ti.
50	exp *BRONCHODILATING AGENT/
51	(Adrenomedullin or Albuterol or Aminophylline or Atropine or Budesonide or Clenbuterol or Colforsin or Cromakalim or Dyphylline or Epinephrine or Fenoterol or Hexoprenaline or Hyoscyamine or Ipratropium or Isoetharine or Isoproterenol or Khellin or Metaproterenol or Nitric Oxide or Procaterol or Pseudoephedrine or Racepinephrine or S-Nitrosoglutathione or S-Nitrosothiol? or Terbutaline or Theobromine or Theophylline or Tretoquinol).mp.
52	(bronchodilator\$ or broncholytic\$).ab,ti.
53	exp *STEROID/ and *INHALATIONAL DRUG ADMINISTRATION/
54	(Beclomethasone or Vanceril or Beclovent or Qvar or Flunisolide or Aerobid or Mometasone furoate or Asmanex or Triamcinolone or Azmacort or Fluticasone propionate or Flovent or Budesonide or Pulmicort or Advair or Symbicort or Dulera).mp.
55	*SODIUM CHLORIDE/ and exp *NEBULIZER/
56	(Nebulizer?ed adj2 saline).ab,ti.
57	exp *HYPNOTIC SEDATIVE AGENT/
58	(sedative\$ or anti-anxiety\$ or anti-anxiety\$ or anxiolytic?).ti,ab.
59	(Alprazolam or Amobarbital or Azaperone or Barbitol or Bromisovalum or Chloral Hydrate or Chloralose or Chlordiazepoxide or Chlormethiazole or Dexmedetomidine or Diazepam or Diphenhydramine or Ethchlorvynol or Etomidate or Etorphine or Flurazepam or Glutethimide or Hexobarbital or Lorazepam or Medazepam or Medetomidine or Mephobarbital or Meprobamate or Methapyrilene or Methaqualone or Midazolam or Nitrazepam or Oxazepam or Paraldehyde or Pentobarbital or Phenobarbital or Propofol or Secobarbital or Temazepam or Thiamylal or Thiopental or Xylazine).mp.
60	exp *ANXIOLYTIC AGENT/
61	(Alprazolam or Bromazepam or Buspirone or Chlordiazepoxide or Chlormezanone or Clorazepate Dipotassium or Diazepam or Estazolam or Flunitrazepam or Flurazepam or Fluvoxamine or Lorazepam or Medazepam or Meprobamate or Midazolam or Nitrazepam or Nordazepam or Ondansetron or Oxazepam or Oxprenolol or Prazepam or Ritanserin or Temazepam or Tranlycypromine or Trazodone or Triazolam or Zolazepam).mp.
62	exp *NARCOTIC ANALGESIC AGENT/
63	(Alfentanil or Alphaprodine or Buprenorphine or Butorphanol or Codeine or Dextromoramide or Dextropropoxyphene or Dihydromorphine or Diphenoxylate or Enkephalin or Ethylketocyclazocine or Ethylmorphine or Etorphine or fentanyl or Heroin or Hydrocodone or Hydromorphone or Levorphanol or Meperidine or Meptazinol or Methadone or Methadyl Acetate or Morphine or Nalbuphine or Opiate Alkaloids or Opium or Oxycodone or Oxymorphone or Pentazocine or Phenazocine or Phenoperidine or Pirinitramide or Promedol or Sufentanil or Tilidine or Tramadol).mp.
64	exp *BENZODIAZEPINE DERIVATIVE/
65	(Benzodiazepine? or Alprazolam or Benzodiazepinone? or Anthramycin or Bromazepam or Clonazepam or Devazepide? or Diazepam or Nordazepam or Flumazenil or Flunitrazepam or Flurazepam or Lorazepam or Nitrazepam or Oxazepam or Pirenzepine? or Prazepam or

#	Searches
	Temazepam or Chlordiazepoxide? or Clorazepate Dipotassium or Estazolam or Medazepam or Midazolam or Triazolam).mp.
66	*OXYGEN/
67	oxygen.mp.
68	or/44-67
69	*POSTURAL DRAINAGE/
70	(postur\$ adj2 drain\$).ab,ti.
71	(fan? or fanned or fanning).ab,ti.
72	(open\$ adj3 window?).ab,ti.
73	BREATHING EXERCISE/
74	((breath\$ or respirat\$ or inhalat\$) adj3 (exercise? or therap\$ or technique?)).ab,ti.
75	(active cycle adj2 breath\$).ab,ti.
76	(square adj2 breath\$).ab,ti.
77	((breathing or expiratory flow) adj2 control\$).ab,ti.
78	(thoracic expansion exercise? or tidal breath\$ or inspiratory muscle training or forced expiration technique? or ELTGOL or positive expiratory pressure or PEP or oscillatory or oscillating device? or High frequency chest or vest? or flutter or percussion or clapping or autogenic drainage).ab,ti.
79	expiration with the glottis open in the lateral posture.ti,ab.
80	*CHEST WALL OSCILLATION/
81	chest wall oscillation?.ab,ti.
82	exp *ARTIFICIAL VENTILATION/
83	(Respirat\$ adj2 Artificial\$).ti,ab.
84	((High Frequen\$ or Liquid or Noninvasiv\$ or non-invasiv\$ or One-Lung) adj2 Ventilat\$).ti,ab.
85	(Positive Pressure adj2 (Respirat\$ or Breath\$ or Ventilat\$)).ti,ab.
86	positive airway pressure.ab,ti.
87	BIPAP.ab,ti.
88	CPAP.ab,ti.
89	(airway clear\$ adj2 technique?).ab,ti.
90	suction\$.ab,ti.
91	*OXYGEN THERAPY/
92	or/69-91
93	9 and 33 and 43 and 68
94	9 and 33 and 43 and 92
95	*DYSPNEA/dt, th [Drug Therapy, Therapy]
96	*ABNORMAL RESPIRATORY SOUND/dt, th [Drug Therapy, Therapy]
97	95 or 96
98	9 and 33 and 97
99	93 or 94 or 98
100	limit 99 to english language
101	letter.pt. or LETTER/
102	note.pt.
103	editorial.pt.
104	CASE REPORT/ or CASE STUDY/
105	(letter or comment*).ti.
106	or/101-105

#	Searches
107	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
108	106 not 107
109	ANIMAL/ not HUMAN/
110	NONHUMAN/
111	exp ANIMAL EXPERIMENT/
112	exp EXPERIMENTAL ANIMAL/
113	ANIMAL MODEL/
114	exp RODENT/
115	(rat or rats or mouse or mice).ti.
116	or/108-115
117	100 not 116

## E.16<sub>1</sub> Managing Seizures

### E.16.12 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/

#	Searches
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	SEIZURES/
35	(seiz\$ or convuls\$).ab,ti.
36	34 or 35
37	9 and 33 and 36
38	limit 37 to english language
39	LETTER/
40	EDITORIAL/
41	NEWS/
42	exp HISTORICAL ARTICLE/
43	ANECDOTES AS TOPIC/
44	COMMENT/
45	CASE REPORT/
46	(letter or comment*).ti.
47	or/39-46
48	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
49	47 not 48
50	ANIMALS/ not HUMANS/
51	exp ANIMALS, LABORATORY/
52	exp ANIMAL EXPERIMENTATION/
53	exp MODELS, ANIMAL/
54	exp RODENTIA/
55	(rat or rats or mouse or mice).ti.
56	or/49-55
57	38 not 56

### E.16.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.

#	Searches
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(seiz\$ or convuls\$).ab,ti.
24	5 and 22 and 23

### E.16.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti,kw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti,kw.
25	LIVING WILLS/
26	living will?.ab,ti,kw.

#	Searches
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	SEIZURES/
35	(seiz\$ or convuls\$).ab,ti,kw.
36	34 or 35
37	9 and 33 and 36

#### E.16.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.ab,ti.
25	LIVING WILLS.kw.
26	living will?.ab,ti.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.

#	Searches
29	PALLIATIVE CARE.kw.
30	palliat\$.ti,ab.
31	HOSPICE CARE.kw.
32	hospice?.ab,ti.
33	or/10-32
34	SEIZURES.kw.
35	(seiz\$ or convuls\$.tw,tx.
36	34 or 35
37	9 and 33 and 36

### E.16.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$.tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$.tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$.tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/

#	Searches
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.16.61 Database: Embase

#	Searches
1	*ADOLESCENT/ or *MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp *CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp *INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp *PEDIATRICS/ or exp *PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx.
9	or/1-8
10	*TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	*RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	*ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	*LIVING WILLS/
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	*HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	*SEIZURE/
35	(seiz\$ or convuls\$).ab,ti.
36	or/34-35
37	9 and 33 and 36



#	Searches
38	limit 37 to english language
39	letter.pt. or LETTER/
40	note.pt.
41	editorial.pt.
42	CASE REPORT/ or CASE STUDY/
43	(letter or comment*).ti.
44	or/39-43
45	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
46	44 not 45
47	ANIMAL/ not HUMAN/
48	NONHUMAN/
49	exp ANIMAL EXPERIMENT/
50	exp EXPERIMENTAL ANIMAL/
51	ANIMAL MODEL/
52	exp RODENT/
53	(rat or rats or mouse or mice).ti.
54	or/46-53
55	38 not 54

## E.17<sub>1</sub> Hydration

### E.17.12 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.

#	Searches
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	FLUID THERAPY/
35	(fluid\$ adj3 (therap\$ or balance\$ or manag\$)).ab,ti.
36	(rehydrat\$ or re-hydrat\$).ab,ti.
37	hydrat\$.ab,ti.
38	DEHYDRATION/
39	(dehydrat\$ or de-hydrat\$).ab,ti.
40	REHYDRATION SOLUTIONS/
41	HYPODERMOCLYSIS/
42	hypodermoclysis.ab,ti.
43	((intravenous\$ or IV or enteral tube? or subcutaneous\$ or oral\$ or infusion?) adj5 (fluid? or water or electrolyte solution?)).ab,ti.
44	((mouth\$ or lip?) adj3 (care or caring)).ab,ti.
45	34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44
46	9 and 33 and 45
47	limit 46 to english language
48	LETTER/
49	EDITORIAL/
50	NEWS/
51	exp HISTORICAL ARTICLE/
52	ANECDOTES AS TOPIC/
53	COMMENT/
54	CASE REPORT/
55	(letter or comment*).ti.
56	or/48-55
57	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
58	56 not 57
59	ANIMALS/ not HUMANS/
60	exp ANIMALS, LABORATORY/
61	exp ANIMAL EXPERIMENTATION/
62	exp MODELS, ANIMAL/
63	exp RODENTIA/
64	(rat or rats or mouse or mice).ti.
65	or/58-64

#	Searches
66	47 not 65

### E.17.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.
21	hospice?.ab,ti.
22	or/6-21
23	(fluid\$ adj3 (therap\$ or balance\$ or manag\$)).ab,ti.
24	(rehydrat\$ or re-hydrat\$).ab,ti.
25	hydrat\$.ab,ti.
26	(dehydrat\$ or de-hydrat\$).ab,ti.
27	hypodermoclysis.ab,ti.
28	((intravenous\$ or IV or enteral tube? or subcutaneous\$ or oral\$ or infusion?) adj5 (fluid? or water or electrolyte solution?)).ab,ti.
29	((mouth\$ or lip?) adj3 (care or caring)).ab,ti.
30	23 or 24 or 25 or 26 or 27 or 28 or 29
31	5 and 22 and 30

### E.17.32 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.

#	Searches
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.
33	or/10-32
34	FLUID THERAPY/
35	(fluid\$ adj3 (therap\$ or balance\$ or manag\$)).ti,ab,hw.
36	(rehydrat\$ or re-hydrat\$).ti,ab,hw.
37	hydrat\$.ti,ab,hw.
38	DEHYDRATION/
39	(dehydrat\$ or de-hydrat\$).ti,ab,hw.
40	REHYDRATION SOLUTIONS/
41	HYPODERMOCLYSIS/
42	hypodermoclysis.ti,ab,hw.
43	((intravenous\$ or IV or enteral tube? or subcutaneous\$ or oral\$ or infusion?) adj5 (fluid? or water or electrolyte solution?)).ti,ab,hw.
44	((mouth\$ or lip?) adj3 (care or caring)).ti,ab,hw.
45	34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44
46	9 and 33 and 45

## E.17.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	TERMINALLY ILL.kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx,kw.
12	dying.tw,tx,kw.
13	(end adj3 life).tw,tx.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
18	(last year of life or LYOL or life\$ end).tw,tx.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
21	RESUSCITATION ORDERS.kw.
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw,tx.
23	ADVANCE DIRECTIVES.kw.
24	advance? directive?.tw,tx.
25	LIVING WILLS.kw.
26	living will?.tw,tx,kw.
27	TERMINAL CARE.kw.
28	(terminal\$ adj3 (care\$ or caring)).tw,tx.
29	PALLIATIVE CARE.kw.
30	palliat\$.tw,tx,kw.
31	HOSPICE CARE.kw.
32	hospice?.tw,tx,kw.
33	or/10-32
34	FLUID THERAPY.kw.
35	(fluid\$ adj3 (therap\$ or balance\$ or manag\$)).tw,tx.
36	REHYDRATION.kw.
37	(rehydrat\$ or re-hydrat\$).tw,tx.
38	HYDRATION.kw.
39	hydrat\$.tw,tx.
40	DEHYDRATION.kw.
41	(dehydrat\$ or de-hydrat\$).tw,tx.

#	Searches
42	REHYDRATION SOLUTIONS.kw.
43	HYPODERMOCLYSIS.kw.
44	hypodermoclysis.tw,tx.
45	((intravenous\$ or IV or enteral tube? or subcutaneous\$ or oral\$ or infusion?) adj5 (fluid? or water or electrolyte solution?)).tw,tx.
46	((mouth\$ or lip?) adj3 (care or caring)).tw,tx.
47	or/34-46
48	9 and 33 and 47

### E.17.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.

#	Searches
33	or/10-32
34	9 and 33

### E.17.61 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	*TERMINALLY ILL PATIENT/
11	*TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	*DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
24	advance? directive?.ab,ti.
25	*LIVING WILL/
26	living will?.ab,ti.
27	*TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	*PALLIATIVE THERAPY/
30	*CANCER PALLIATIVE THERAPY/
31	palliat\$.ti,ab.
32	*HOSPICE CARE/
33	*HOSPICE PATIENT/
34	hospice?.ab,ti.
35	or/10-34
36	FLUID THERAPY/
37	FLUID RESUSCITATION/
38	(fluid\$ adj3 (therap\$ or balance\$ or manag\$)).ab,ti.

#	Searches
39	REHYDRATION/
40	ORAL REHYDRATION THERAPY/
41	(rehydrat\$ or re-hydrat\$).ab,ti.
42	HYDRATION/
43	hydrat\$.ab,ti.
44	DEHYDRATION/
45	(dehydrat\$ or de-hydrat\$).ab,ti.
46	ORAL REHYDRATION SOLUTION/
47	HYPODERMOCLYSIS/
48	hypodermoclysis.ab,ti.
49	((intravenous\$ or IV or enteral tube? or subcutaneous\$ or oral\$ or infusion?) adj5 (fluid? or water or electrolyte solution?)).ab,ti.
50	((mouth\$ or lip?) adj3 (care or caring)).ab,ti.
51	or/36-50
52	9 and 35 and 51
53	limit 52 to english language
54	letter.pt. or LETTER/
55	note.pt.
56	editorial.pt.
57	CASE REPORT/ or CASE STUDY/
58	(letter or comment*).ti.
59	or/54-58
60	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
61	59 not 60
62	ANIMAL/ not HUMAN/
63	NONHUMAN/
64	exp ANIMAL EXPERIMENT/
65	exp EXPERIMENTAL ANIMAL/
66	ANIMAL MODEL/
67	exp RODENT/
68	(rat or rats or mouse or mice).ti.
69	or/61-68
70	53 not 69

#### E.17.71 Database: CINAHL (Cumulative Index to Nursing and Allied Health Literature)

#	Searches
1	ADOLESCENCE/
2	(adolescen* OR teen* OR youth* OR young OR juvenile* OR minors OR highschool*).ti,ab
3	CHILD/
4	CHILD, PRESCHOOL/
5	(child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid* OR kindergar* OR boy* OR girl*).ti,ab
6	INFANT/
7	exp INFANT, NEWBORN/
8	(infan* OR neonat* OR newborn* OR baby OR babies).ti,ab
9	PEDIATRICS/



#	Searches
10	PUBERTY/
11	(pediatric* OR paediatric* OR pubert* OR prepubert* OR pubescen* OR prepubescen*).ti,ab
12	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11
13	TERMINALLY ILL PATIENTS/
14	((terminal* OR final OR advance* OR incurable OR "life limit*") adj3 (ill* OR disease* OR condition*)).ti,ab
15	dying.ti,ab
16	(end adj3 life).ti,ab
17	((approach* OR close* OR near* OR imminent* OR impending) adj3 death).ti,ab
18	(Body adj2 ("shut* down" OR "shutting down" OR deteriorat*)).ti,ab
19	(deathbed* OR "death bed*" OR "passing away" OR "passing on" OR expiring OR expiration).ti,ab
20	((last OR final) adj1 (hour* OR days* OR minute*)).ti,ab
21	("last year of life" OR LYOL OR "life* end").ti,ab
22	("advance* stage*" OR "final stage*" OR "end stage*" OR "last stage*" OR "late stage*" OR "terminal stage*").ti,ab
23	((advanced OR late OR last OR end OR final OR terminal) adj1 phase*).ti,ab
24	TERMINAL CARE/
25	(terminal* adj3 (care* OR caring)).ti,ab
26	PALLIATIVE CARE/
27	palliat*.ti,ab
28	13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27
29	FLUID THERAPY/
30	FLUID RESUSCITATION/
31	(fluid* adj3 (therap* OR balance* OR manag*)).ti,ab
32	ORAL REHYDRATION THERAPY/
33	(rehydrate* OR re-hydrat\$).ti,ab
34	hydrat*.ti,ab
35	DEHYDRATION/
36	(dehydrat* OR de-hydrat*).ti,ab
37	REHYDRATION SOLUTIONS/
38	HYPODERMOCLYSIS/
39	hypodermoclysis.ti,ab
40	((intravenous* OR IV OR "enteral tube*" OR subcutaneous* OR oral* OR infusion*) adj5 (fluid* OR water OR "electrolyte solution*")).ti,ab
41	((mouth* OR lip OR lips) adj3 (care OR caring)).ti,ab
42	29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41
43	12 AND 28 AND 42 [Limit to: (Language English)]

## E.18<sub>1</sub> Nutrition

### E.18.12 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.

#	Searches
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
12	dying.ti,ab.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab.
31	HOSPICE CARE/
32	hospice?.ab,ti.
33	or/10-32
34	NUTRITION ASSESSMENT/
35	exp NUTRITION THERAPY/
36	exp FEEDING METHODS/
37	GASTROSTOMY/
38	JEJUNOSTOMY/
39	INTUBATION, GASTROINTESTINAL/
40	((nutrition\$ or fed or feed\$) adj3 (therap\$ or support\$ or artificial\$)).ti,ab.
41	((enteral\$ or enteric\$ or parenter\$ or intravenous\$ or IV or subcutaneous or intragastric\$ or intra gastric\$ or nasogastric\$ or naso gastric\$ or intrainstestinal\$ or intra intestinal\$ or tube) adj3 (feed\$ or fed or nutrition\$ or nutrient?)).ti,ab.
42	(gastrostom\$ or jejunostom\$ or gastrojejunostom\$ or gastro jejunostom\$).ti,ab.
43	or/34-42
44	and/9,33,43

#	Searches
45	limit 44 to english language
46	LETTER/
47	EDITORIAL/
48	NEWS/
49	exp HISTORICAL ARTICLE/
50	ANECDOTES AS TOPIC/
51	COMMENT/
52	CASE REPORT/
53	(letter or comment*).ti.
54	or/46-53
55	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
56	54 not 55
57	ANIMALS/ not HUMANS/
58	exp ANIMALS, LABORATORY/
59	exp ANIMAL EXPERIMENTATION/
60	exp MODELS, ANIMAL/
61	exp RODENTIA/
62	(rat or rats or mouse or mice).ti.
63	or/56-62
64	45 not 63

#### E.18.21 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
7	dying.ti,ab.
8	(end adj3 life).ti,ab.
9	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
10	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
11	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
12	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
13	(last year of life or LYOL or life\$ end).ab,ti.
14	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
15	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
16	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
17	advance? directive?.ab,ti.
18	living will?.ab,ti.
19	(terminal\$ adj3 (care\$ or caring)).ti,ab.
20	palliat\$.ti,ab.

#	Searches
21	hospice?.ab,ti.
22	or/6-21
23	((nutrition\$ or fed or feed\$) adj3 (therap\$ or support\$ or artificial\$)).ti,ab.
24	((enteral\$ or enteric\$ or parenter\$ or intravenous\$ or IV or subcutaneous or intragastric\$ or intra gastric\$ or nasogastric\$ or naso gastric\$ or intrainestinal\$ or intra intestinal\$ or tube) adj3 (feed\$ or fed or nutrition\$ or nutrient?)).ti,ab.
25	(gastrostom\$ or jejunostom\$ or gastrojejunostom\$ or gastro jejunostom\$).ti,ab.
26	or/23-25
27	and/5,22,26

### E.18.31 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
9	or/1-8
10	TERMINALLY ILL.sh,kw.
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
12	dying.ti,ab,kw.
13	(end adj3 life).ti,ab.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
18	(last year of life or LYOL or life\$ end).ab,ti.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
20	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
23	ADVANCE DIRECTIVES/
24	advance? directive?.ab,ti.
25	LIVING WILLS/
26	living will?.ab,ti,kw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
29	PALLIATIVE CARE/
30	palliat\$.ti,ab,kw.
31	HOSPICE CARE/
32	hospice?.ab,ti,kw.

#	Searches
33	or/10-32
34	NUTRITION\$ ASSESSMENT.sh,kw.
35	DIET THERAPY.kw.
36	exp NUTRITION THERAPY/
37	exp FEEDING METHODS/
38	GASTROSTOMY/
39	JEJUNOSTOMY/
40	INTUBATION, GASTROINTESTINAL/
41	((nutrition\$ or fed or feed\$) adj3 (therap\$ or support\$ or artificial\$)).ti,ab,kw.
42	((enteral\$ or enteric\$ or parenter\$ or intravenous\$ or IV or subcutaneous or intragastric\$ or intra gastric\$ or nasogastric\$ or naso gastric\$ or intrainstestinal\$ or intra intestinal\$ or tube) adj3 (feed\$ or fed or nutrition\$ or nutrient?)).ti,ab,kw.
43	(gastrostom\$ or jejunostom\$ or gastrojejunostom\$ or gastro jejunostom\$).ti,ab,kw.
44	or/34-43
45	and/9,33,44

#### E.18.41 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx,kw.
11	dying.tw,tx,kw.
12	(end adj3 life).tw,tx.
13	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
14	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
15	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
16	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
17	(last year of life or LYOL or life\$ end).tw,tx.
18	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw,tx.
19	((advanced or late or last or end or final or terminal) adj phase\$).tw,tx.
20	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw,tx,kw.
21	advance? directive?.tw,tx,kw.
22	living will?.tw,tx,kw.
23	(terminal\$ adj3 (care\$ or caring)).tw,tx,kw.
24	palliat\$.tw,tx,kw.
25	hospice?.tw,tx,kw.

#	Searches
26	or/10-25
27	NUTRITION\$ ASSESSMENT.kw.
28	DIET THERAPY.kw.
29	FEEDING METHODS.kw.
30	INTUBATION, GASTROINTESTINAL.kw.
31	((nutrition\$ or fed or feed\$) adj3 (therap\$ or support\$ or artificial\$)).tw,tx,kw.
32	((enteral\$ or enteric\$ or parenter\$ or intravenous\$ or IV or subcutaneous or intragastric\$ or intra gastric\$ or nasogastric\$ or naso gastric\$ or intrainestinal\$ or intra intestinal\$ or tube) adj3 (feed\$ or fed or nutrition\$ or nutrient?)).tw,tx,kw.
33	(gastrostom\$ or jejunostom\$ or gastrojejunostom\$ or gastro jejunostom\$).tw,tx,kw.
34	or/27-33
35	and/9,26,34

### E.18.51 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/

#	Searches
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.18.61 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	TERMINALLY ILL PATIENT/
11	TERMINAL DISEASE/
12	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
13	DYING/
14	dying.ti,ab.
15	(end adj3 life).ti,ab.
16	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
17	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
18	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
19	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
20	(last year of life or LYOL or life\$ end).ab,ti.
21	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
22	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
23	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
24	advance? directive?.ab,ti.
25	LIVING WILL/
26	living will?.ab,ti.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).ti,ab.
29	PALLIATIVE THERAPY/
30	CANCER PALLIATIVE THERAPY/
31	palliat\$.ti,ab.
32	HOSPICE CARE/
33	HOSPICE PATIENT/
34	hospice?.ab,ti.
35	or/10-34

#	Searches
36	NUTRITIONAL ASSESSMENT/
37	NUTRITIONAL SUPPORT/
38	exp ARTIFICIAL FEEDING/
39	GASTROSTOMY/
40	JEJUNOSTOMY/
41	GASTROJEJUNOSTOMY/
42	((nutrition\$ or fed or feed\$) adj3 (therap\$ or support\$ or artificial\$)).ti,ab.
43	((enteral\$ or enteric\$ or parenter\$ or intravenous\$ or IV or subcutaneous or intragastric\$ or intra gastric\$ or nasogastric\$ or naso gastric\$ or intrainestinal\$ or intra intestinal\$ or tube) adj3 (feed\$ or fed or nutrition\$ or nutrient?)).ti,ab.
44	(gastrostom\$ or jejunostom\$ or gastrojejunostom\$ or gastro jejunostom\$).ti,ab.
45	or/36-44
46	and/9,35,45
47	limit 46 to english language
48	letter.pt. or LETTER/
49	note.pt.
50	editorial.pt.
51	CASE REPORT/ or CASE STUDY/
52	(letter or comment*).ti.
53	or/48-52
54	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
55	53 not 54
56	ANIMAL/ not HUMAN/
57	NONHUMAN/
58	exp ANIMAL EXPERIMENT/
59	exp EXPERIMENTAL ANIMAL/
60	ANIMAL MODEL/
61	exp RODENT/
62	(rat or rats or mouse or mice).ti.
63	or/55-62
64	47 not 63

## E.18.71 Recognising that a child or young person is likely to die 2 within hours or days

### E.18.83 Database: Medline

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.



#	Searches
9	or/1-8
10	SYMPTOM ASSESSMENT/
11	DIAGNOSIS/ or PROGNOSIS/
12	((diagnos\$ or prognos\$ or assess\$ or criteria\$ or predict\$).ti.
13	(sign or signs or symptom\$ or recogni\$ or identif\$).ti,ab.
14	or/10-13
15	exp UNCONSCIOUSNESS/
16	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 conscious\$).ti,ab.
17	COGNITION/
18	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 cogniti\$).ti,ab.
19	exp SKIN PHYSIOLOGICAL PHENOMENA/
20	((chang\$ or temperature? or colo?r\$) adj3 skin?).ti,ab.
21	exp EATING/
22	exp FEEDING METHODS/
23	((will\$ or tolerat\$ or able or abilit\$) adj3 (fluid\$ or feed\$ or food\$ or eat\$)).ti,ab.
24	ILLNESS BEHAVIOR/
25	((alter\$ or chang\$) adj3 (behav\$ or state?)).ti,ab.
26	STRESS, PSYCHOLOGICAL/
27	ANXIETY/
28	PSYCHOMOTOR AGITATION/
29	(agitat\$ or anxiet\$ or anxious\$).ti,ab.
30	((social\$ or patient?) adj3 withdraw\$).ti,ab.
31	((cessat\$ or cease\$ or stop\$) adj3 talk\$).ti,ab.
32	exp URINATION DISORDERS/
33	URINATION/
34	(urine or urinat\$ or urinary).ti,ab.
35	exp VITAL SIGNS/
36	vital sign?.ti,ab.
37	((blood or diastolic or systolic) adj3 pressure?).ti,ab.
38	((body or bodies or organ?) adj3 temperature?).ti,ab.
39	((heart? or pulse?) adj3 (rate? or pattern?)).ti,ab.
40	(respirat\$ adj3 (rate? or pattern?)).ti,ab.
41	(normal\$ adj3 baseline?).ti,ab.
42	DYSPNEA/
43	dyspnea?.ab,ti.
44	breathlessness\$.ab,ti.
45	((Difficult\$ or labo?red or problem\$ or short\$) adj3 breath\$).ab,ti.
46	RESPIRATORY SOUNDS/
47	((respirat\$ or breath\$) adj3 (sound\$ or nois\$ or secret\$)).ab,ti.
48	((death or breath\$) adj3 rattl\$).ab,ti.
49	FATIGUE/
50	(fatigue? or weary or weariness or lassitude).ti,ab.
51	or/15-50
52	DEATH/
53	(dying or die\$ or death).ti.

#	Searches
54	TERMINALLY ILL/
55	((terminal\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
56	TERMINAL CARE/
57	(terminal\$ adj3 (care\$ or caring)).ti,ab.
58	PALLIATIVE CARE/
59	(palliat\$ adj3 (care\$ or caring or stage\$)).ti,ab.
60	HOSPICE CARE/
61	hospice?.ab,ti.
62	or/52-61
63	(end adj2 life).ti,ab.
64	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
65	((advanced or late or last or end or final or terminal or dying) adj1 phase\$).ab,ti.
66	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage? or dying stage?).ti,ab.
67	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
68	(dying adj2 (actively or begin\$ or begun)).ti,ab.
69	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
70	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
71	or/63-70
72	9 and 14 and 62 and 71
73	9 and 51 and 62 and 71
74	72 or 73
75	limit 74 to english language
76	LETTER/
77	EDITORIAL/
78	NEWS/
79	exp HISTORICAL ARTICLE/
80	ANECDOTES AS TOPIC/
81	COMMENT/
82	CASE REPORT/
83	(letter or comment*).ti.
84	or/76-83
85	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
86	84 not 85
87	ANIMALS/ not HUMANS/
88	exp ANIMALS, LABORATORY/
89	exp ANIMAL EXPERIMENTATION/
90	exp MODELS, ANIMAL/
91	exp RODENTIA/
92	(rat or rats or mouse or mice).ti.
93	or/86-92
94	75 not 93

### E.18.91 Database: Medline In-Process & Other Non-Indexed Citations

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.

#	Searches
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
4	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
5	or/1-4
6	(diagnos\$ or prognos\$ or assess\$ or criteria\$ or predict\$).ti.
7	(sign or signs or symptom\$ or recogni\$ or identif\$).ti,ab.
8	or/6-7
9	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 conscious\$).ti,ab.
10	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 cogniti\$).ti,ab.
11	((chang\$ or temperature? or colo?r\$) adj3 skin?).ti,ab.
12	((will\$ or tolerat\$ or able or abilit\$) adj3 (fluid\$ or feed\$ or food\$ or eat\$)).ti,ab.
13	((alter\$ or chang\$) adj3 (behav\$ or state?)).ti,ab.
14	(agitat\$ or anxiet\$ or anxious\$).ti,ab.
15	((social\$ or patient?) adj3 withdraw\$).ti,ab.
16	((cessat\$ or cease\$ or stop\$) adj3 talk\$).ti,ab.
17	(urine or urinat\$ or urinary).ti,ab.
18	vital sign?.ti,ab.
19	((blood or diastolic or systolic) adj3 pressure?).ti,ab.
20	((body or bodies or organ?) adj3 temperature?).ti,ab.
21	((heart? or pulse?) adj3 (rate? or pattern?)).ti,ab.
22	(respirat\$ adj3 (rate? or pattern?)).ti,ab.
23	(normal\$ adj3 baseline?).ti,ab.
24	dyspnea?.ab,ti.
25	breathlessness\$.ab,ti.
26	((Difficult\$ or labo?red or problem\$ or short\$) adj3 breath\$).ab,ti.
27	((respirat\$ or breath\$) adj3 (sound\$ or nois\$ or secret\$)).ab,ti.
28	((death or breath\$) adj3 rattl\$).ab,ti.
29	(fatigue? or weary or weariness or lassitude).ti,ab.
30	or/9-29
31	(dying or die\$ or death).ti.
32	((terminal\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
33	(terminal\$ adj3 (care\$ or caring)).ti,ab.
34	(palliat\$ adj3 (care\$ or caring or stage\$)).ti,ab.
35	hospice?.ab,ti.
36	or/31-35
37	(end adj2 life).ti,ab.
38	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
39	((advanced or late or last or end or final or terminal or dying) adj1 phase\$).ab,ti.
40	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage? or dying stage?).ti,ab.
41	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
42	(dying adj2 (actively or begin\$ or begun)).ti,ab.
43	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
44	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
45	or/37-44

#	Searches
46	5 and 8 and 36 and 45
47	5 and 30 and 36 and 45
48	46 or 47

### E.18.101 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatic\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
9	or/1-8
10	SYMPTOM ASSESSMENT/
11	DIAGNOSIS/ or PROGNOSIS/
12	(diagnos\$ or prognos\$ or assess\$ or criteria\$ or predict\$).ti.
13	(sign or signs or symptom\$ or recogni\$ or identif\$).ti,ab.
14	or/10-13
15	exp UNCONSCIOUSNESS/
16	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 conscious\$).ti,ab,kw.
17	COGNITION/
18	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 cogniti\$).ti,ab,kw.
19	exp SKIN PHYSIOLOGICAL PHENOMENA/
20	((chang\$ or temperature? or colo?r\$) adj3 skin?).ti,ab,kw.
21	exp EATING/
22	exp FEEDING METHODS/
23	((will\$ or tolerat\$ or able or abilit\$) adj3 (fluid\$ or feed\$ or food\$ or eat\$)).ti,ab,kw.
24	ILLNESS BEHAVIOR/
25	((alter\$ or chang\$) adj3 (behav\$ or state?)).ti,ab.
26	STRESS, PSYCHOLOGICAL/
27	ANXIETY/
28	PSYCHOMOTOR AGITATION/
29	(agitat\$ or anxiet\$ or anxious\$).ti,ab,kw.
30	((social\$ or patient?) adj3 withdraw\$).ti,ab.
31	((cessat\$ or cease\$ or stop\$) adj3 talk\$).ti,ab.
32	exp URINATION DISORDERS/
33	URINATION/
34	(urine or urinat\$ or urinary).ti,ab,kw.
35	exp VITAL SIGNS/
36	vital sign?.ti,ab,kw.
37	((blood or diastolic or systolic) adj3 pressure?).ti,ab,kw.
38	((body or bodies or organ?) adj3 temperature?).ti,ab,kw.
39	((heart? or pulse?) adj3 (rate? or pattern?)).ti,ab,kw.

#	Searches
40	(respirat\$ adj3 (rate? or pattern?)).ti,ab,kw.
41	(normal\$ adj3 baseline?).ti,ab.
42	DYSPNEA/
43	dyspnea?.ab,ti,kw.
44	breathlessness\$.ab,ti.
45	((Difficult\$ or labo?red or problem\$ or short\$) adj3 breath\$).ab,ti.
46	RESPIRATORY SOUNDS/
47	((respirat\$ or breath\$) adj3 (sound\$ or nois\$ or secret\$)).ab,ti,kw.
48	((death or breath\$) adj3 rattl\$).ab,ti.
49	FATIGUE/
50	(fatigue? or weary or weariness or lassitude).ti,ab,kw.
51	or/15-50
52	DEATH/
53	(dying or die\$ or death).ti.
54	TERMINALLY ILL/
55	((terminal\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
56	TERMINAL CARE/
57	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
58	PALLIATIVE CARE/
59	(palliat\$ adj3 (care\$ or caring or stage\$)).ti,ab,kw.
60	HOSPICE CARE/
61	hospice?.ab,ti,kw.
62	or/52-61
63	(end adj2 life).ti,ab.
64	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
65	((advanced or late or last or end or final or terminal or dying) adj1 phase\$).ab,ti.
66	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage? or dying stage?).ti,ab.
67	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
68	(dying adj2 (actively or begin\$ or begun)).ti,ab.
69	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
70	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
71	or/63-70
72	9 and 14 and 62 and 71
73	9 and 51 and 62 and 71
74	72 or 73

### E.18.111 Database: Cochrane Database of Systematic Reviews; Database of Abstracts 2 of Reviews of Effects

#	Searches
1	(ADOLESCENT or MINORS).kw.
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw,tx,jw,rw.
3	CHILD.kw.
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw,tx,jw,rw.
5	INFANT.kw.

#	Searches
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw,tx,jw,rw.
7	(PEDIATRICS or PUBERTY).kw.
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw,tx,jw,rw.
9	or/1-8
10	SYMPTOM ASSESSMENT.kw.
11	(DIAGNOSIS or PROGNOSIS).kw.
12	(diagnos\$ or prognos\$ or assess\$ or criteria\$ or predict\$).ti.
13	(sign or signs or symptom\$ or recogni\$ or identif\$).tw,tx.
14	or/10-13
15	UNCONSCIOUSNESS.kw.
16	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 conscious\$).tw,tx.
17	COGNITION.kw.
18	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 cogniti\$).tw,tx.
19	SKIN PHYSIOLOGICAL PHENOMENA.kw.
20	((chang\$ or temperature? or colo?r\$) adj3 skin?).tw,tx.
21	EATING.kw.
22	FEEDING METHODS.kw.
23	((will\$ or tolerat\$ or able or abilit\$) adj3 (fluid\$ or feed\$ or food\$ or eat\$)).tw,tx.
24	ILLNESS BEHAVIOR.kw.
25	((alter\$ or chang\$) adj3 (behav\$ or state?)).tw,tx.
26	STRESS, PSYCHOLOGICAL.kw.
27	ANXIETY.kw.
28	PSYCHOMOTOR AGITATION.kw.
29	(agitat\$ or anxiet\$ or anxious\$).tw,tx.
30	((social\$ or patient?) adj3 withdraw\$).tw,tx.
31	((cessat\$ or cease\$ or stop\$) adj3 talk\$).tw,tx.
32	URINATION DISORDERS.kw.
33	URINATION.kw.
34	(urine or urinat\$ or urinary).tw,tx.
35	VITAL SIGNS.kw.
36	vital sign?.tw,tx.
37	((blood or diastolic or systolic) adj3 pressure?).tw,tx.
38	((body or bodies or organ?) adj3 temperature?).tw,tx.
39	((heart? or pulse?) adj3 (rate? or pattern?)).tw,tx.
40	(respirat\$ adj3 (rate? or pattern?)).tw,tx.
41	(normal\$ adj3 baseline?).tw,tx.
42	DYSPNEA.kw.
43	dyspnea?.tw,tx.
44	breathlessness\$.tw,tx.
45	((Difficult\$ or labo?red or problem\$ or short\$) adj3 breath\$).tw,tx.
46	RESPIRATORY SOUNDS.kw.
47	((respirat\$ or breath\$) adj3 (sound\$ or nois\$ or secret\$)).tw,tx.
48	((death or breath\$) adj3 rattl\$).tw,tx.
49	FATIGUE.kw.
50	(fatigue? or weary or weariness or lassitude).tw,tx.

#	Searches
51	or/15-50
52	DEATH.kw.
53	(dying or die\$ or death).ti.
54	TERMINALLY ILL.kw.
55	((terminal\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw,tx.
56	TERMINAL CARE.kw.
57	(terminal\$ adj3 (care\$ or caring)).tw,tx.
58	PALLIATIVE CARE.kw.
59	(palliat\$ adj3 (care\$ or caring or stage\$)).tw,tx.
60	HOSPICE CARE.kw.
61	hospice?.tw,tx.
62	or/52-61
63	(end adj2 life).tw,tx.
64	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw,tx.
65	((advanced or late or last or end or final or terminal or dying) adj1 phase\$).tw,tx.
66	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage? or dying stage?).tw,tx.
67	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw,tx.
68	(dying adj2 (actively or begin\$ or begun)).tw,tx.
69	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw,tx.
70	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw,tx.
71	or/63-70
72	9 and 14 and 62 and 71
73	9 and 51 and 62 and 71
74	72 or 73

### E.18.121 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.

#	Searches
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

#### E.18.131 Database: Embase

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
9	or/1-8
10	*SYMPTOM ASSESSMENT/
11	*DIAGNOSIS/ or *PROGNOSIS/
12	(diagnos\$ or prognos\$ or assess\$ or criteria\$ or predict\$).ti.
13	(sign or signs or symptom\$ or recogni\$ or identif\$).ti,ab.
14	or/10-13
15	exp *UNCONSCIOUSNESS/
16	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 conscious\$).ti,ab.
17	*COGNITION/
18	((deteriorat\$ or reduc\$ or loss or lost or losing) adj3 cogniti\$).ti,ab.
19	"FUNCTIONS OF THE SKIN AND ITS APPENDAGES"/
20	*SKIN TEMPERATURE/
21	((chang\$ or temperature? or colo?r\$) adj3 skin?).ti,ab.
22	*EATING/
23	*FOOD INTAKE/



#	Searches
24	((will\$ or tolerat\$ or able or abilit\$) adj3 (fluid\$ or feed\$ or food\$ or eat\$)).ti,ab.
25	*ILLNESS BEHAVIOR/
26	((alter\$ or chang\$) adj3 (behav\$ or state?)).ti,ab.
27	*MENTAL STRESS/
28	*ANXIETY/
29	*RESTLESSNESS/
30	(agitat\$ or anxiet\$ or anxious\$).ti,ab.
31	((social\$ or patient?) adj3 withdraw\$).ti,ab.
32	((cessat\$ or cease\$ or stop\$) adj3 talk\$).ti,ab.
33	exp *URINARY DYSFUNCTION/
34	*MICTURITION/
35	(urine or urinat\$ or urinary).ti,ab.
36	*VITAL SIGN/
37	vital sign?.ti,ab.
38	((blood or diastolic or systolic) adj3 pressure?).ti,ab.
39	((body or bodies or organ?) adj3 temperature?).ti,ab.
40	((heart? or pulse?) adj3 (rate? or pattern?)).ti,ab.
41	(respirat\$ adj3 (rate? or pattern?)).ti,ab.
42	(normal\$ adj3 baseline?).ti,ab.
43	*DYSPNEA/
44	dyspnea?.ab,ti.
45	breathlessness\$.ab,ti.
46	((Difficult\$ or labo?red or problem\$ or short\$) adj3 breath\$).ab,ti.
47	*ABNORMAL RESPIRATORY SOUND/
48	((respirat\$ or breath\$) adj3 (sound\$ or nois\$ or secret\$)).ab,ti.
49	((death or breath\$) adj3 rattl\$).ab,ti.
50	*FATIGUE/
51	(fatigue? or weary or weariness or lassitude).ti,ab.
52	or/15-51
53	*DEATH/
54	(dying or die\$ or death).ti.
55	*TERMINALLY ILL PATIENT/
56	*TERMINAL DISEASE/
57	((terminal\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
58	*TERMINAL CARE/
59	(terminal\$ adj3 (care\$ or caring)).ti,ab.
60	*PALLIATIVE THERAPY/
61	(palliat\$ adj3 (care\$ or caring or stage\$)).ti,ab.
62	*HOSPICE CARE/
63	hospice?.ab,ti.
64	or/53-63
65	(end adj2 life).ti,ab.
66	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
67	((advanced or late or last or end or final or terminal or dying) adj1 phase\$).ti,ab.
68	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage? or dying stage?).ti,ab.

#	Searches
69	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
70	(dying adj2 (actively or begin\$ or begun)).ti,ab.
71	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
72	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
73	or/65-72
74	9 and 14 and 64 and 73
75	9 and 52 and 64 and 73
76	74 or 75
77	limit 76 to english language
78	letter.pt. or LETTER/
79	note.pt.
80	editorial.pt.
81	CASE REPORT/ or CASE STUDY/
82	(letter or comment*).ti.
83	or/78-82
84	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
85	83 not 84
86	ANIMAL/ not HUMAN/
87	NONHUMAN/
88	exp ANIMAL EXPERIMENT/
89	exp EXPERIMENTAL ANIMAL/
90	ANIMAL MODEL/
91	exp RODENT/
92	(rat or rats or mouse or mice).ti.
93	or/85-92
94	77 not 93

## E.19<sub>1</sub> Health economics (Global Search)

### E.19.12 Database: Medline

#	Searches
1	ECONOMICS/
2	VALUE OF LIFE/
3	exp "COSTS AND COST ANALYSIS"/
4	exp ECONOMICS, HOSPITAL/
5	exp ECONOMICS, MEDICAL/
6	exp RESOURCE ALLOCATION/
7	ECONOMICS, NURSING/
8	ECONOMICS, PHARMACEUTICAL/
9	exp "FEES AND CHARGES"/
10	exp BUDGETS/
11	budget*.ti,ab.
12	cost*.ti,ab.
13	(economic* or pharmaco?economic*).ti,ab.
14	(price* or pricing*).ti,ab.

#	Searches
15	(financ* or fee or fees or expenditure* or saving*).ti,ab.
16	(value adj2 (money or monetary)).ti,ab.
17	resourc* allocat*.ti,ab.
18	(fund or funds or funding* or funded).ti,ab.
19	(ration or rations or rationing* or rationed).ti,ab.
20	ec.fs.
21	or/1-20
22	ADOLESCENT/ or MINORS/
23	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
24	exp CHILD/
25	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
26	exp INFANT/
27	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
28	exp PEDIATRICS/ or exp PUBERTY/
29	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw,nw.
30	or/22-29
31	TERMINALLY ILL/
32	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
33	dying.ti,ab.
34	(end adj3 life).ti,ab.
35	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
36	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
37	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
38	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
39	(last year of life or LYOL or life\$ end).ab,ti.
40	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
41	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
42	RESUSCITATION ORDERS/
43	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
44	ADVANCE DIRECTIVES/
45	advance? directive?.ab,ti.
46	LIVING WILLS/
47	living will?.ab,ti.
48	TERMINAL CARE/
49	(terminal\$ adj3 (care\$ or caring)).ti,ab.
50	PALLIATIVE CARE/
51	palliat\$.ti,ab.
52	HOSPICE CARE/
53	hospice?.ab,ti.
54	or/31-53
55	30 and 54
56	21 and 55
57	limit 56 to english language

#	Searches
58	LETTER/
59	EDITORIAL/
60	NEWS/
61	exp HISTORICAL ARTICLE/
62	ANECDOTES AS TOPIC/
63	COMMENT/
64	CASE REPORT/
65	(letter or comment*).ti.
66	or/58-65
67	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
68	66 not 67
69	ANIMALS/ not HUMANS/
70	exp ANIMALS, LABORATORY/
71	exp ANIMAL EXPERIMENTATION/
72	exp MODELS, ANIMAL/
73	exp RODENTIA/
74	(rat or rats or mouse or mice).ti.
75	or/68-74
76	57 not 75

#### E.19.21 Database: Cochrane Central Register of Controlled Trials

#	Searches
1	ECONOMICS/
2	VALUE OF LIFE/
3	exp "COSTS AND COST ANALYSIS"/
4	exp ECONOMICS, HOSPITAL/
5	exp ECONOMICS, MEDICAL/
6	exp RESOURCE ALLOCATION/
7	ECONOMICS, NURSING/
8	ECONOMICS, PHARMACEUTICAL/
9	exp "FEES AND CHARGES"/
10	exp BUDGETS/
11	budget*.ti,ab.
12	cost*.ti,ab.
13	(economic* or pharmaco?economic*).ti,ab.
14	(price* or pricing*).ti,ab.
15	(financ* or fee or fees or expenditure* or saving*).ti,ab.
16	(value adj2 (money or monetary)).ti,ab.
17	resourc* allocat*.ti,ab.
18	(fund or funds or funding* or funded).ti,ab.
19	(ration or rations or rationing* or rationed).ti,ab.
20	ec.fs.
21	or/1-20
22	ADOLESCENT/ or MINORS/
23	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw.

#	Searches
24	exp CHILD/
25	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw.
26	exp INFANT/
27	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw.
28	exp PEDIATRICS/ or exp PUBERTY/
29	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jw.
30	or/22-29
31	TERMINALLY ILL/
32	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab,kw.
33	dying.ti,ab,kw.
34	(end adj3 life).ti,ab.
35	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
36	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
37	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
38	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
39	(last year of life or LYOL or life\$ end).ab,ti.
40	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
41	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
42	RESUSCITATION ORDERS/
43	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
44	ADVANCE DIRECTIVES/
45	advance? directive?.ab,ti.
46	LIVING WILLS/
47	living will?.ab,ti,kw.
48	TERMINAL CARE/
49	(terminal\$ adj3 (care\$ or caring)).ti,ab,kw.
50	PALLIATIVE CARE/
51	palliat\$.ti,ab,kw.
52	HOSPICE CARE/
53	hospice?.ab,ti,kw.
54	or/31-53
55	30 and 54
56	21 and 55
57	limit 56 to english language

### E.19.31 Database: NHS Economic Evaluation Database

#	Searches
1	ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/

#	Searches
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat\$)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

#### E.19.41 Database: Health Technology Assessment

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).tw.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).tw.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).tw.
7	exp PEDIATRICS/ or exp PUBERTY/
8	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).tw.
9	or/1-8
10	TERMINALLY ILL/

#	Searches
11	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).tw.
12	dying.tw.
13	(end adj3 life).tw.
14	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).tw.
15	(Body adj2 (shut? down or shutting down or deteriorat*)).tw.
16	(deathbed? or death bed? or passing away or passing on or expiring or expiration).tw.
17	((last or final) adj1 (hour\$ or days\$ or minute\$)).tw.
18	(last year of life or LYOL or life\$ end).tw.
19	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).tw.
20	((advanced or late or last or end or final or terminal) adj phase\$).tw.
21	RESUSCITATION ORDERS/
22	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).tw.
23	ADVANCE DIRECTIVES/
24	advance? directive?.tw.
25	LIVING WILLS/
26	living will?.tw.
27	TERMINAL CARE/
28	(terminal\$ adj3 (care\$ or caring)).tw.
29	PALLIATIVE CARE/
30	palliat\$.tw.
31	HOSPICE CARE/
32	hospice?.tw.
33	or/10-32
34	9 and 33

### E.19.51 Database: Embase

#	Searches
1	HEALTH ECONOMICS/
2	exp ECONOMIC EVALUATION/
3	exp HEALTH CARE COST/
4	exp FEE/
5	BUDGET/
6	FUNDING/
7	RESOURCE ALLOCATION/
8	budget*.ti,ab.
9	cost*.ti,ab.
10	(economic* or pharmaco?economic*).ti,ab.
11	(price* or pricing*).ti,ab.
12	(financ* or fee or fees or expenditure* or saving*).ti,ab.
13	(value adj2 (money or monetary)).ti,ab.
14	resourc* allocat*.ti,ab.
15	(fund or funds or funding* or funded).ti,ab.
16	(ration or rations or rationing* or rationed).ti,ab.
17	or/1-16

#	Searches
18	exp ADOLESCENT/
19	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jx.
20	exp CHILD/
21	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jx.
22	exp INFANT/
23	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jx.
24	exp PEDIATRICS/ or exp PUBERTY/
25	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
26	or/18-25
27	TERMINALLY ILL PATIENT/
28	TERMINAL DISEASE/
29	((terminal\$ or final or advance\$ or incurable or life limit\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
30	DYING/
31	dying.ti,ab.
32	(end adj3 life).ti,ab.
33	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
34	(Body adj2 (shut? down or shutting down or deteriorat\$)).ti,ab.
35	(deathbed? or death bed? or passing away or passing on or expiring or expiration).ti,ab.
36	((last or final) adj1 (hour\$ or days\$ or minute\$)).ti,ab.
37	(last year of life or LYOL or life\$ end).ab,ti.
38	(advance\$ stage? or final stage? or end stage? or last stage? or late stage? or terminal stage?).ti,ab.
39	((advanced or late or last or end or final or terminal) adj phase\$).ab,ti.
40	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ab,ti.
41	advance? directive?.ab,ti.
42	LIVING WILL/
43	living will?.ab,ti.
44	TERMINAL CARE/
45	(terminal\$ adj3 (care\$ or caring)).ti,ab.
46	PALLIATIVE THERAPY/
47	CANCER PALLIATIVE THERAPY/
48	palliat\$.ti,ab.
49	HOSPICE CARE/
50	HOSPICE PATIENT/
51	hospice?.ab,ti.
52	or/27-51
53	26 and 52
54	17 and 53
55	limit 54 to english language
56	letter.pt. or LETTER/
57	note.pt.
58	editorial.pt.
59	CASE REPORT/ or CASE STUDY/
60	(letter or comment*).ti.



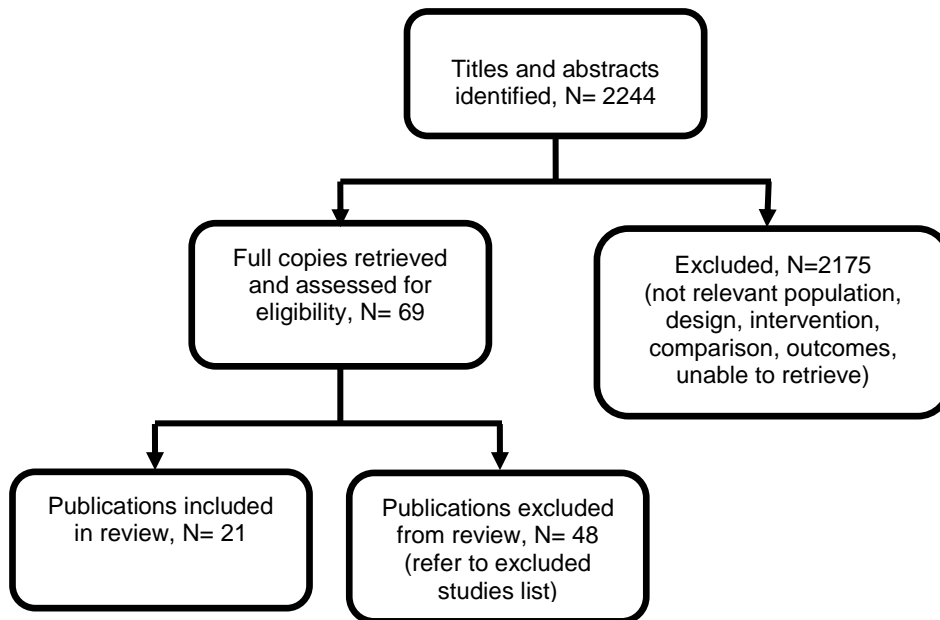
#	Searches
61	or/56-60
62	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
63	61 not 62
64	ANIMAL/ not HUMAN/
65	NONHUMAN/
66	exp ANIMAL EXPERIMENT/
67	exp EXPERIMENTAL ANIMAL/
68	ANIMAL MODEL/
69	exp RODENT/
70	(rat or rats or mouse or mice).ti.
71	or/63-70
72	55 not 71

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## Appendix F: Summary of identified studies

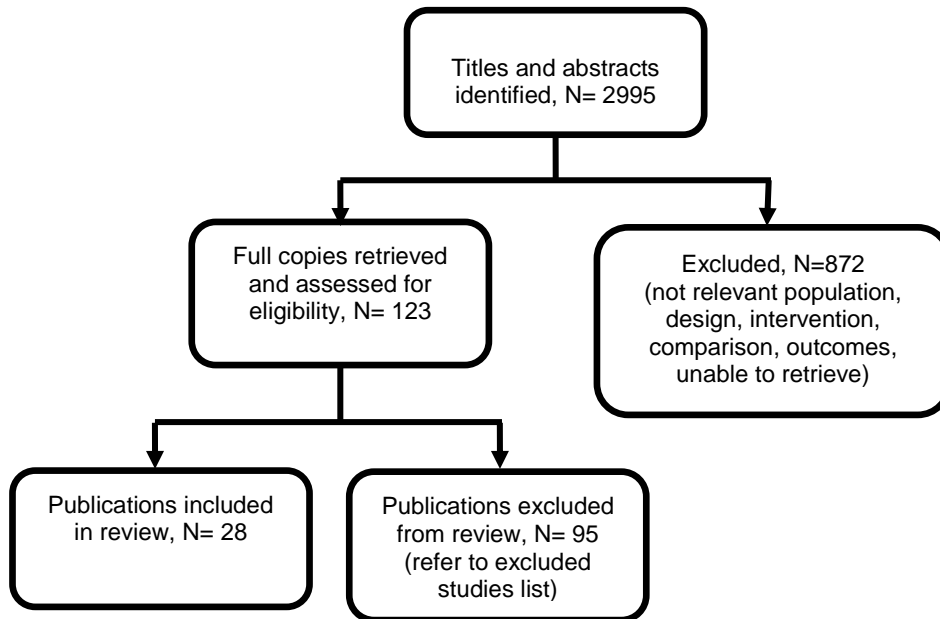
Figure 1: Flow diagram of clinical article selection for information provision review



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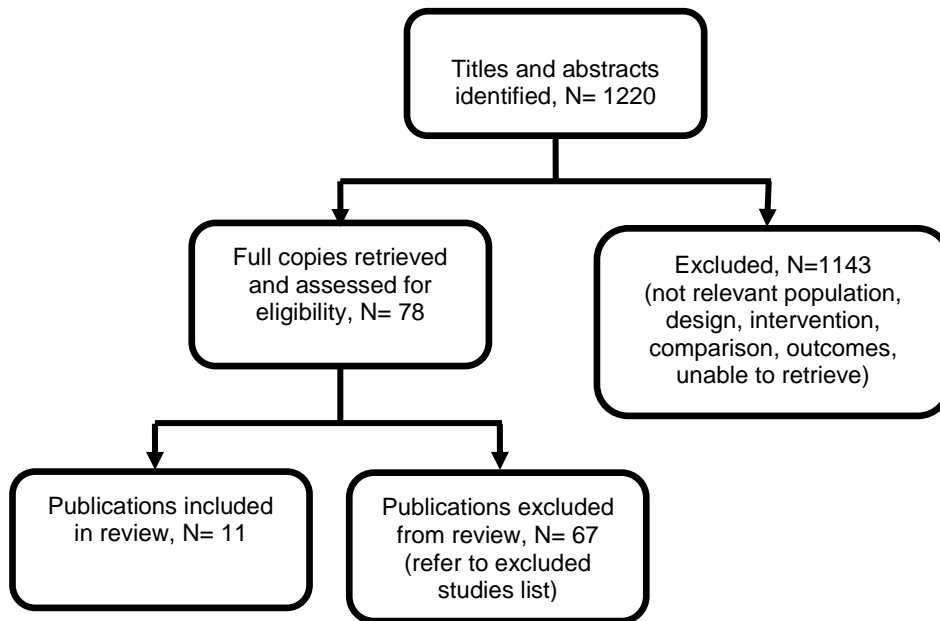
**Figure 2: Flow diagram of clinical article selection for communication review**



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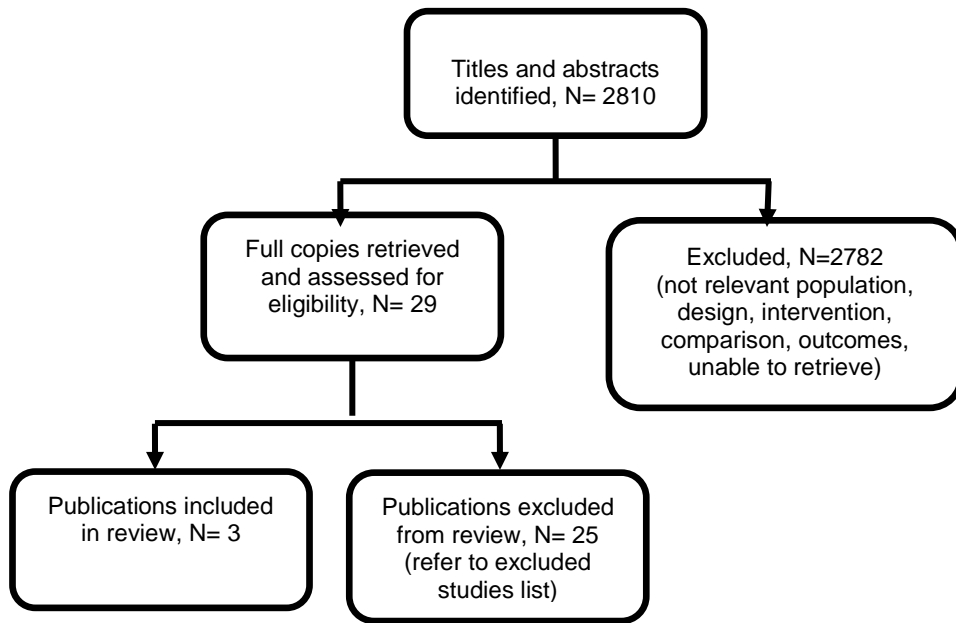
**Figure 3: Flow diagram of clinical article selection for personalised, parallel and advanced care planning review**



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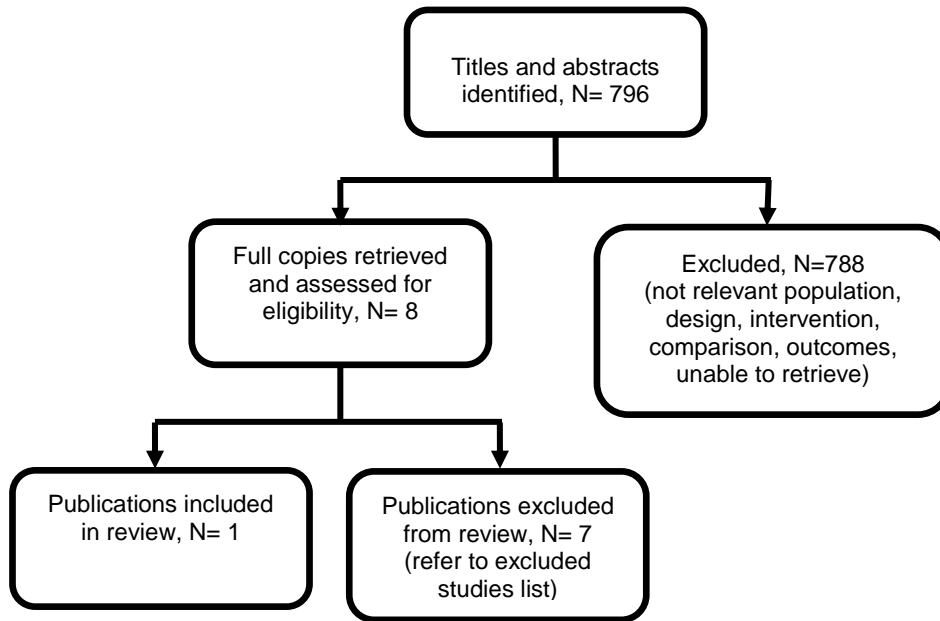
**Figure 4: Flow diagram of clinical article selection for preferred place of death review**



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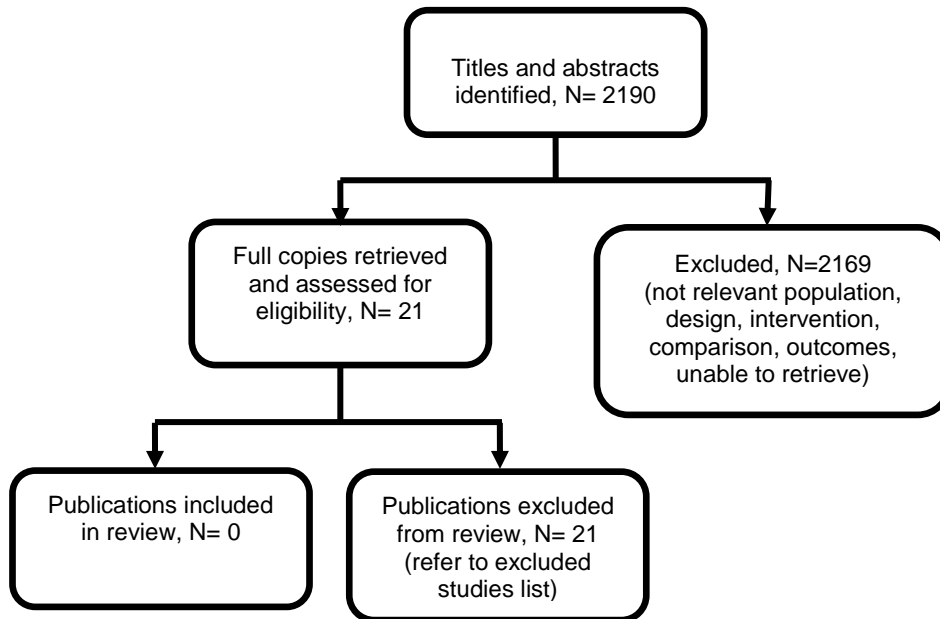
**Figure 5: Flow diagram of clinical article selection for organ and tissue donation review**



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1 **Figure 6: Flow diagram of clinical article selection for MDT review**

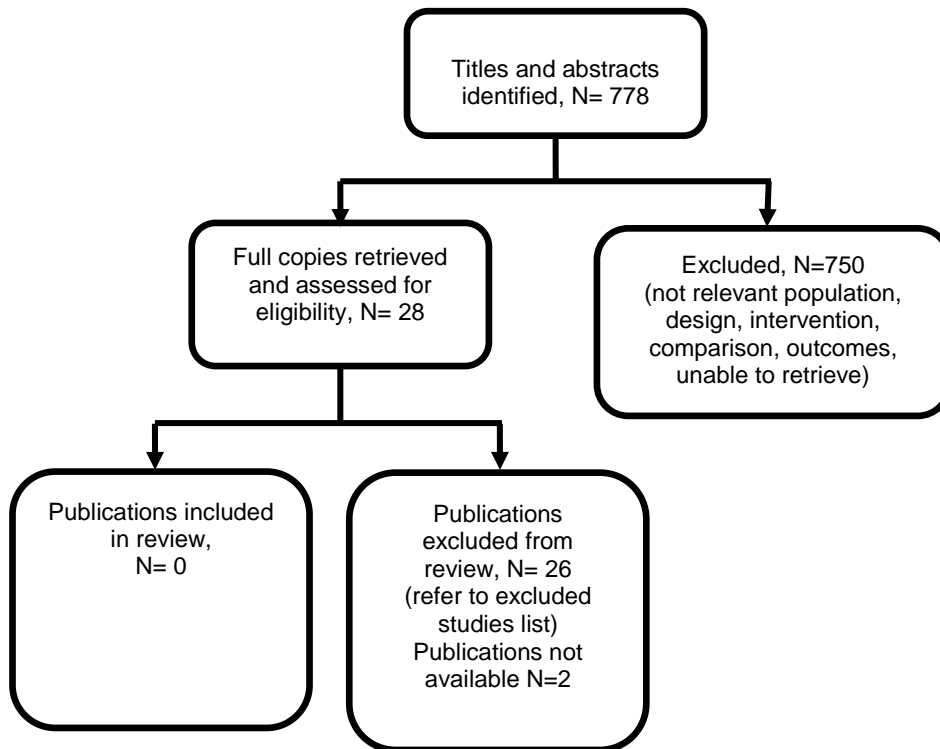
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**Figure 7: Flow diagram of clinical article selection for end of life care around the clock**

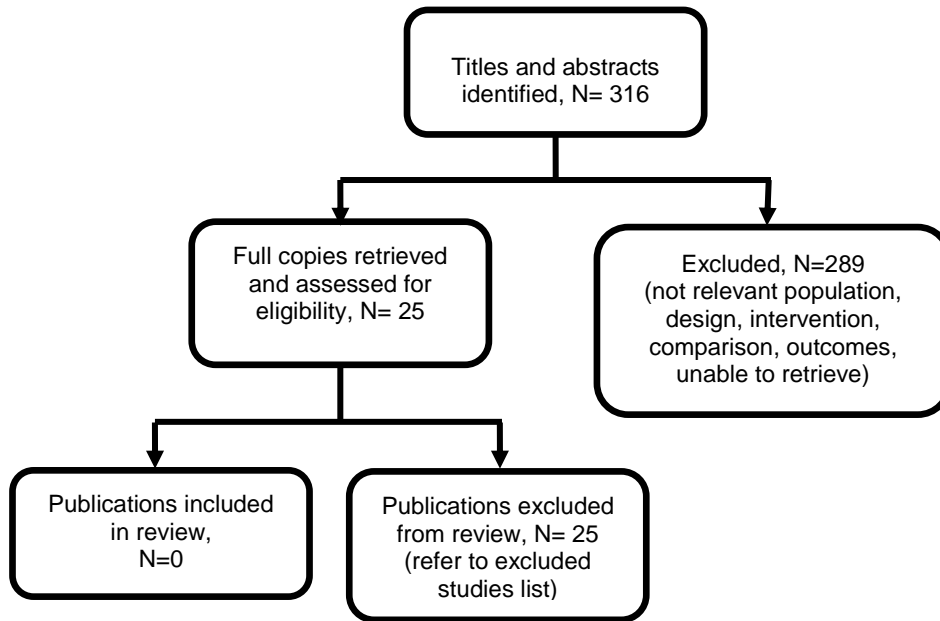


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1 **Figure 8: Flow diagram of clinical article selection for rapid transfer service**  
2 **delivery review**

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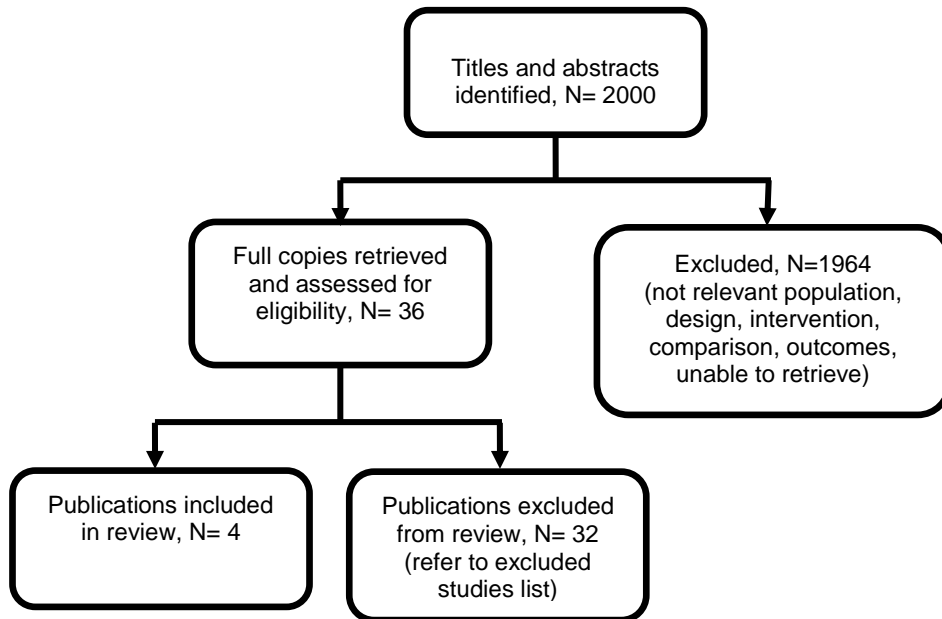
4

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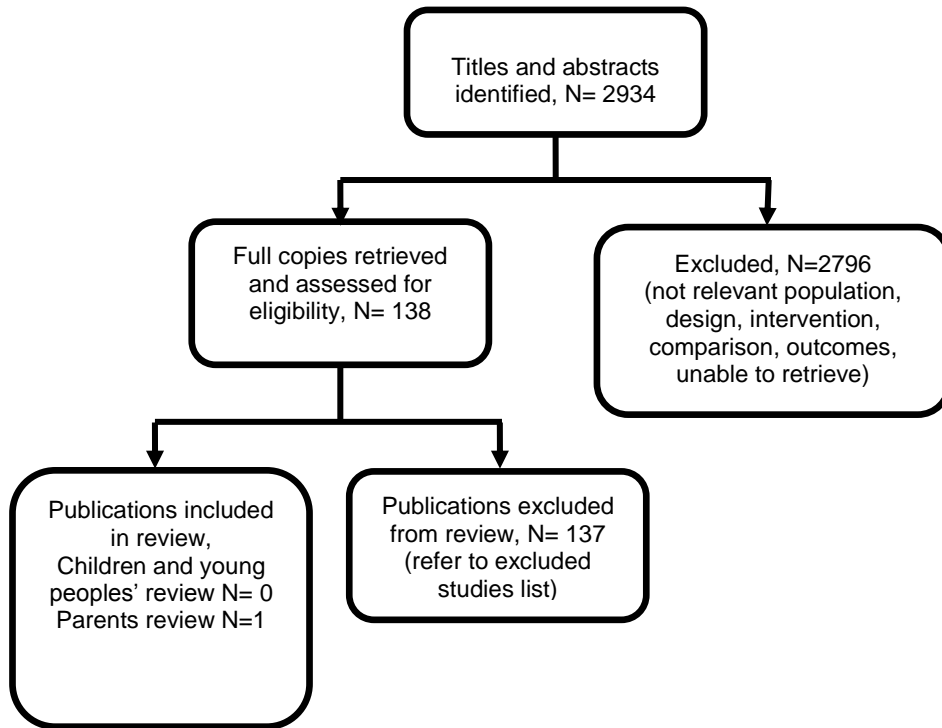
**Figure 9: Flow diagram of clinical article selection for home-based care review**



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1 **Figure 10: Flow diagram of clinical article selection for emotional and psychological**  
2 **intervention review**

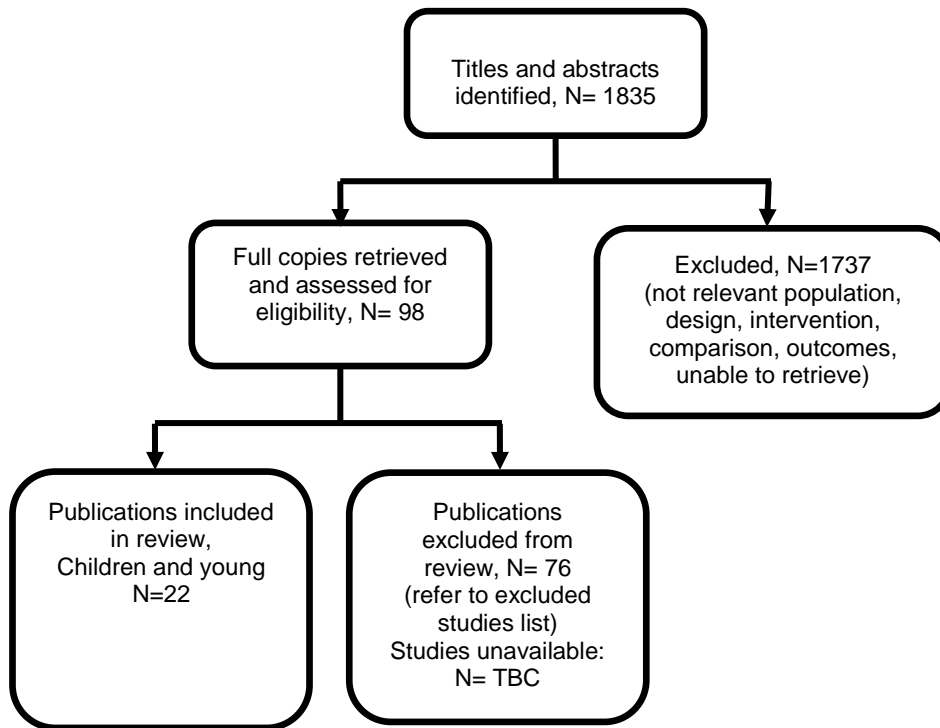
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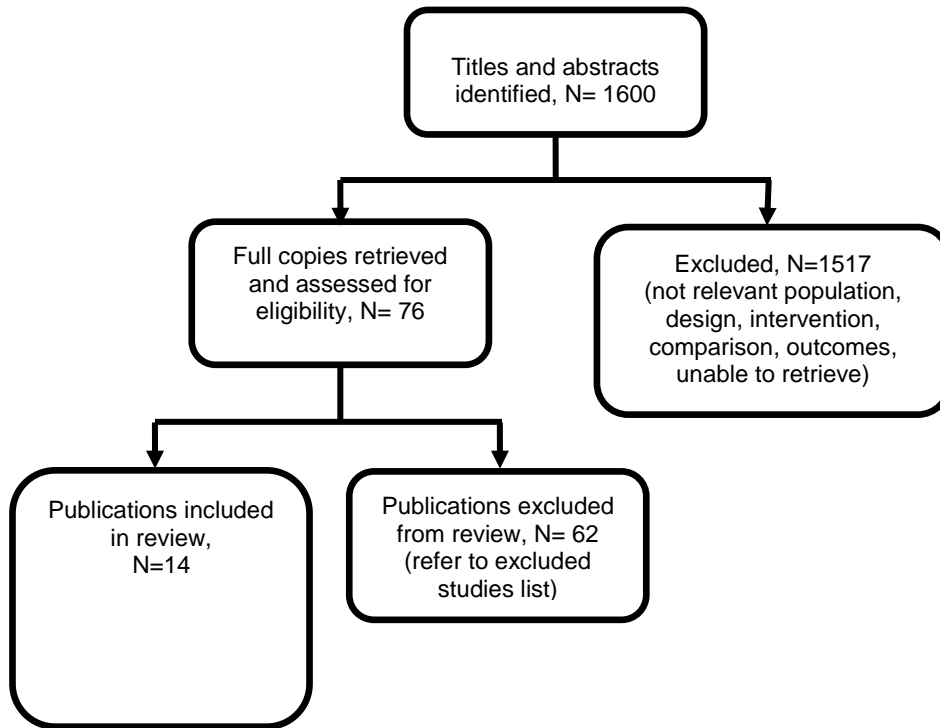
**Figure 11: Flow diagram of clinical article selection for social and practical support review**



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1 **Figure 12: Flow diagram of clinical article selection for spiritual and religious support**  
2 **review**

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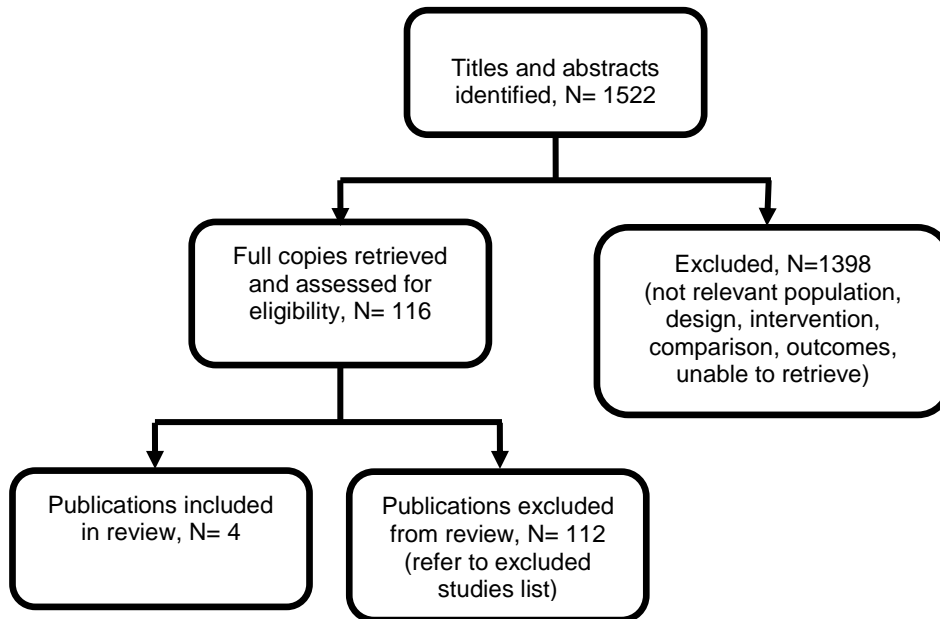
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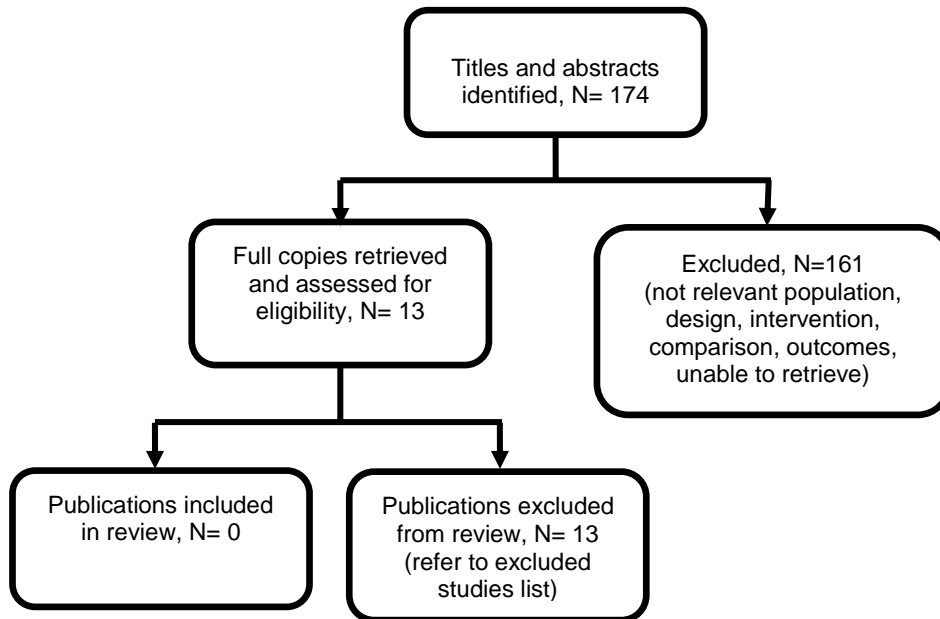
**Figure 13: Flow diagram of clinical article selection for managing pain review**



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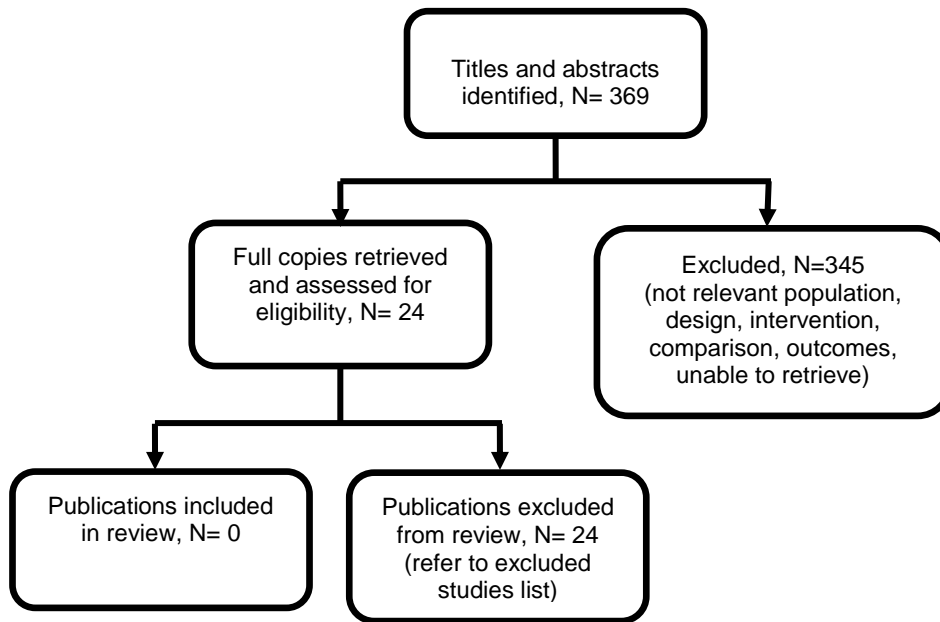
**Figure 14: Flow diagram of clinical article selection for managing agitation review**



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**Figure 15: Flow diagram of clinical article selection for managing respiratory distress review**

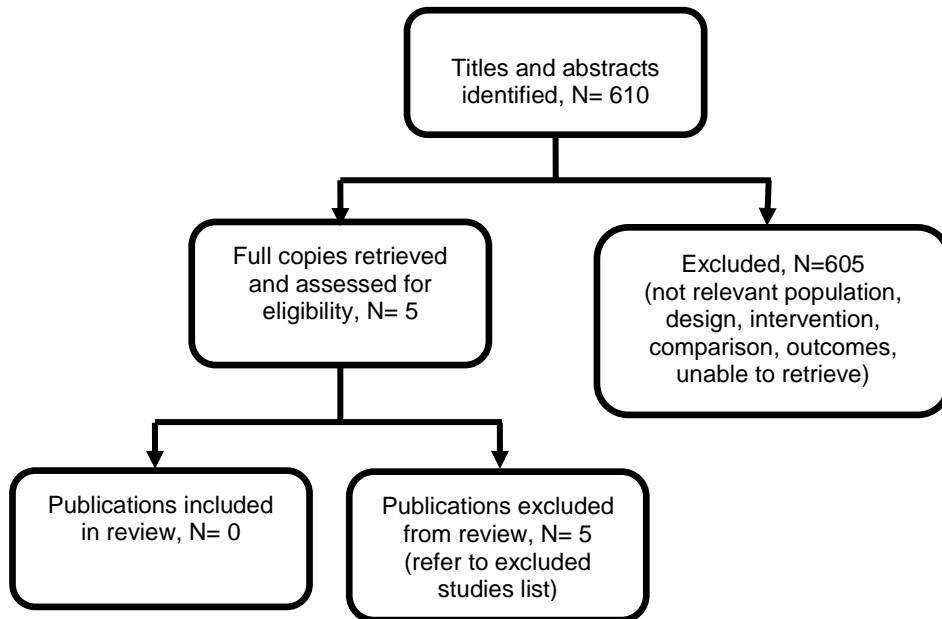


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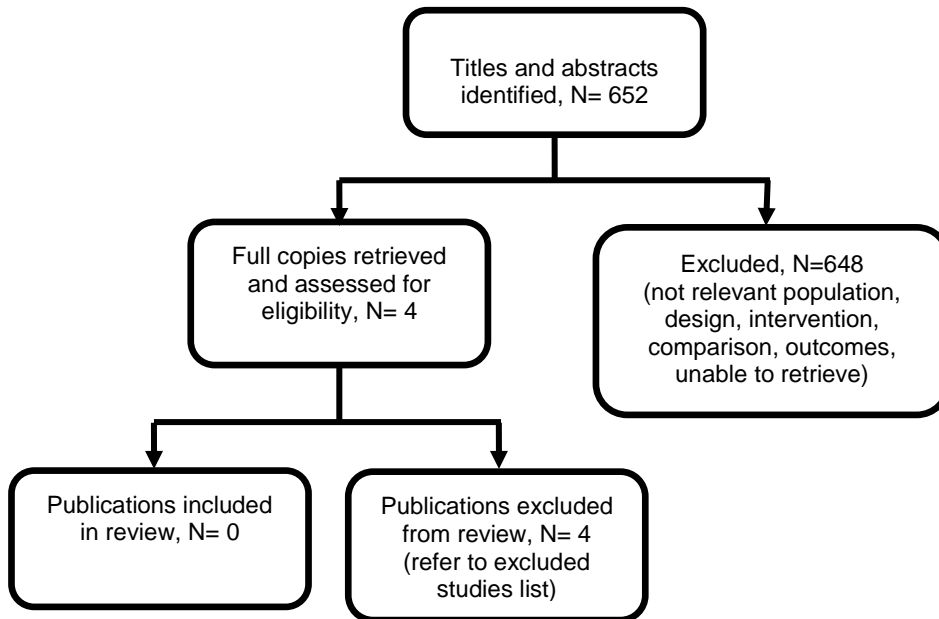
**Figure 16: Flow diagram of clinical article selection for managing seizures review**



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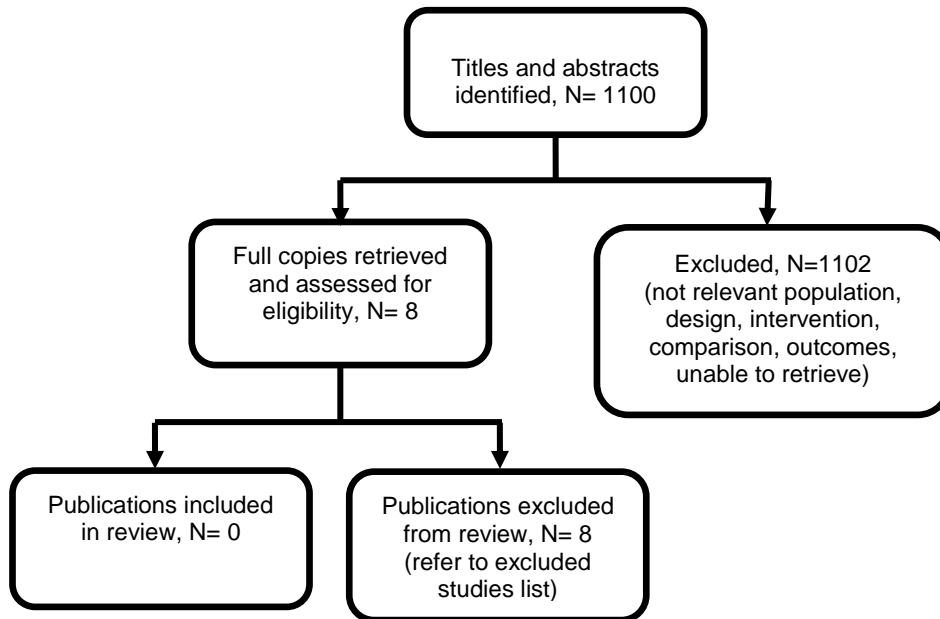
**Figure 17: Flow diagram of clinical article selection for managing hydration review**



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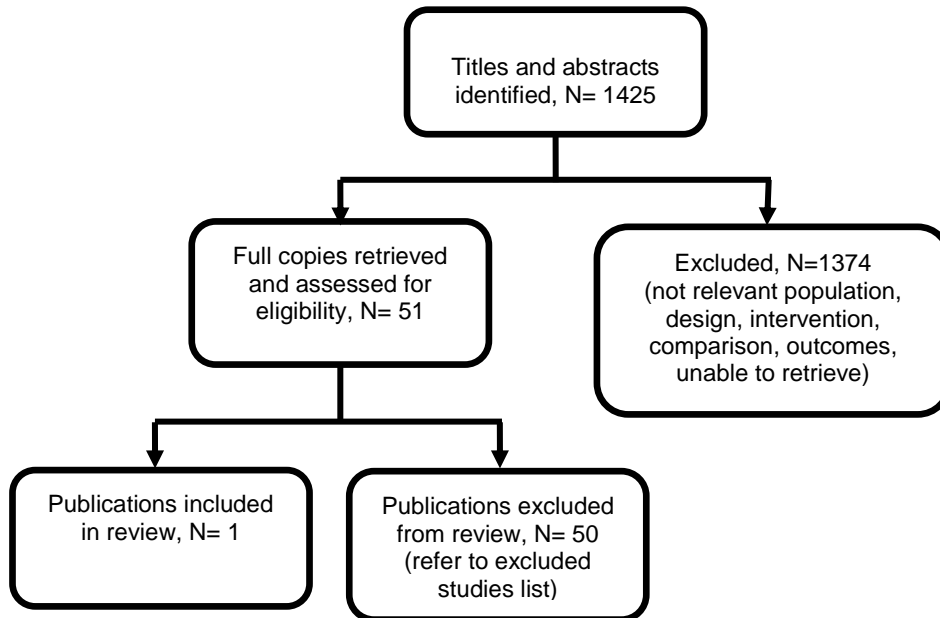
**Figure 18: Flow diagram of clinical article selection for managing nutrition review**



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1 **Figure 19: Flow diagram of clinical article selection for recognising that a child or**  
2 **young person is likely to die within hours or days**

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## **Appendix G: Evidence tables**

2

Please find these in separate Appendix document

3

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# 1 Appendix H: Excluded studies

## 2 H.1 Review question: Information provision

Reference	Reason for Exclusion
Decisions relating to Cardiopulmonary Resuscitation: A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, <i>Journal of Medical Ethics</i> , 27, 310-316, 2001	Background reading paper
Adams, M., Information and education across the phases of cancer care, <i>Seminars in Oncology Nursing</i> , 7, 105-112, 1991	Discussion paper about adults with cancer
Alifrangis, C., Koizia, L., Rozario, A., Rodney, S., Harrington, M., Somerville, C., Peplow, T., Waxman, J., The experiences of cancer patients, <i>Qjm</i> , 104, 1075-81, 2011	All participants aged above 20 years.
Ashby, M. A., Kosky, R. J., Laver, H. T., Sims, E. B., An enquiry into death and dying at the Adelaide Children's Hospital: a useful model?, <i>Medical Journal of Australia</i> , 154, 165-70, 1991	Repetitive themes have been reported by other included studies; less relevant setting.
Barbarin, Oscar A., Chesler, Mark A., The medical context of parental coping with childhood cancer, <i>American Journal of Community Psychology</i> , 14, 221-235, 1986	Information seeking was conceptualized and assessed as part of the coping strategy of parents when their child was diagnosed with cancer. The focus was not on the information type or content that was deemed helpful or unhelpful.
Barrera, M., D'Agostino, N., Gammon, J., Spencer, L., Baruchel, S., Health-related quality of life and enrollment in phase 1 trials in children with incurable cancer, <i>Palliative &amp; Supportive Care</i> , 3, 191-6, 2005	The focus of the study was what constituted HRQOL in families with child living with incurable cancer, no relevant information
Benko, M., National strategy for developing Rehabilitation Centers for Cancer Kids in Croatia, <i>Neuro-Oncology</i> , 12 (6), ii111, 2010	Experience sharing paper based on one social worker's work experience, no sample, no data analysis.
Boss, R., Larson, S., Roter, D., Donohue, P., Characterizing parent-clinician discussions about critically ill infants: Empirical observation of real-time conversations, <i>Journal of Pain and Symptom Management</i> , 49 (2), 413-414, 2015	Abstract only.
Collier, J., Pattison, H., Watson, A., Sheard, C., Parental information needs in chronic renal failure and diabetes mellitus, <i>European Journal of Pediatrics</i> , 160, 31-6, 2001	Survey data on parents' information needs, not what they experienced or perceived as helpful/unhelpful.
Conley, V. M., Burman, M. E., Informational needs of caregivers of terminal patients in a rural state, <i>Home Healthcare Nurse</i> , 15, 808-17, 1997	Study on adults
Curtis, J. R., Engelberg, R. A., Wenrich, M. D., Nielsen, E. L., Shannon, S. E., Treece, P. D., Tonelli, M. R., Patrick, D. L., Robins, L. S., McGrath, B. B., Rubinfeld, G. D., Studying communication about end-of-life care during the ICU family conference: development of a	The purpose of the study was to understand the way of communication occurred between family-clinician communication about withholding/withdrawing life support equipment on the specific occasion of family conferences. The study did not report what aspects of the

Reference	Reason for Exclusion
framework, <i>Journal of Critical Care</i> , 17, 147-60, 2002	communication with regard to information provision was deemed helpful or unhelpful in the process.
Dalberg, T., Jacob-Files, E., Carney, P. A., Meyrowitz, J., Fromme, E. K., Thomas, G., Pediatric oncology providers' perceptions of barriers and facilitators to early integration of pediatric palliative care, <i>Pediatric Blood &amp; Cancer</i> , 60, 1875-81, 2013	No relevant information of interest reported.
de Gonzalez Victorica, M. I., Bertolino, L., Pavlovsky, S., Argentina. Telling the truth to cancer patients in a multicultural society, <i>Annals of the New York Academy of Sciences</i> , 809, 152-62, 1997	Discussion paper
de Groot-Bollujt, W., Mourik, M., Bereavement: role of the nurse in the care of terminally ill and dying children in the pediatric intensive care unit, <i>Critical Care Medicine</i> , 21, S391-2, 1993	Discussion paper
deCinque, N., Monterosso, L., Dadd, G., Sidhu, R., Macpherson, R., Aoun, S., Bereavement support for families following the death of a child from cancer: experience of bereaved parents, <i>Journal of Psychosocial Oncology</i> , 24, 65-83, 2006	Findings of the study not relevant to the review.
Diez, B., Lascar, E., Alizade, A., Talking to a child with cancer. A valuable experience, <i>Annals of the New York Academy of Sciences</i> , 809, 142-51, 1997	Narrative experience sharing paper, no sample selection, no data analysis performed.
Dunsmore, J., Quine, S., Information, support, and decision-making needs and preferences of adolescents with cancer: Implications for health professionals, <i>Journal of Psychosocial Oncology</i> , 13, 39-56, 1995	Participants' age ranged between 15 to 24 years (mean 18 years) and less than half of them aged under 18 years.
Eden, L. M., Callister, L. C., Parent Involvement in End-of-Life Care and Decision Making in the Newborn Intensive Care Unit: An Integrative Review, <i>Journal of Perinatal Education</i> , 19, 29-39, 2010	Background reading paper for reference checking
Goggin, M., Parents perceptions of withdrawal of life support treatment to newborn infants, <i>Early Human Development</i> , 88, 79-82, 2012	Discussion paper for background paper
Gordon, C., Barton, E., Meert, K. L., Eggly, S., Pollacks, M., Zimmerman, J., Anand, K. J., Carcillo, J., Newth, C. J., Dean, J. M., Willson, D. F., Nicholson, C., Accounting for medical communication: parents' perceptions of communicative roles and responsibilities in the pediatric intensive care unit, <i>Communication &amp; Medicine</i> , 6, 177-188, 2009	The same theme on timely and correct information provision identified in the study has been reported by other studies and included; less relevant setting.
Hendricks-Ferguson, V. L., Parental perspectives of initial end-of-life care communication, <i>International Journal of Palliative Nursing</i> , 13, 522-31, 2007	Paper explaining parents' perspective on when end-of-life care of their child should be initiated and communicated, not of interest to the review.
Hinds, P. S., Kelly, K. P., Helping parents make and survive end of life decisions for	Discussion paper

Reference	Reason for Exclusion
their seriously ill child, Nursing Clinics of North America, 45, 465-74, 2010	
Horrocks, S., Somerset, M., Salisbury, C., Do children with non-malignant life-threatening conditions receive effective palliative care? A pragmatic evaluation of a local service, Palliative Medicine, 16, 410-416, 2002	Before-and-after evaluation of a service, no information on information provision.
Kaunonen, Marja, Tarkka, M., Hautamaki, K., Paunonen, M., The staff's experience of the death of a child and of supporting the family, International Nursing Review, 47, 46-52, 2000	Narrative summary of the nature of the support given by nursery staff who experienced new-born death, no relevant indication of what has been deemed unhelpful or unhelpful.
Kelly, K. P., Porock, D., A survey of pediatric oncology nurses' perceptions of parent educational needs, Journal of Pediatric Oncology Nursing, 22, 58-66, 2005	The purpose of the study was to identify educational topics from paediatric oncology nurse's perspectives, not information provision deemed helpful or unhelpful.
Knapp, C. A., Contro, N., Family support services in pediatric palliative care, American Journal of Hospice & Palliative Medicine, 26, 476-82, 2009	Discussion paper, no qualitative data analysis was performed.
Knapp, C., Madden, V., Marcu, M., Wang, H., Curtis, C., Sloyer, P., Shenkman, E., Information seeking behaviors of parents whose children have life-threatening illnesses, Pediatric Blood & Cancer, 56, 805-11, 2011	Survey with only quantitative descriptive data.
Kutner, J. S., Steiner, J. F., Corbett, K. K., Jahnigen, D. W., Barton, P. L., Information needs in terminal illness, Social Science & Medicine, 48, 1341-52, 1999	Participants living with terminal illness were all above 18 years.
Lamiani, G., Meyer, E. C., Browning, D. M., Brodsky, D., Todres, I. D., Analysis of enacted difficult conversations in neonatal intensive care, Journal of Perinatology, 29, 310-316, 2009	The analysed conversation in the paper was enacted between real practitioners and family members portrayed by professional actors, not based on real family members' perspective of view.
Markward, J., Benner, Kalea, Freese, Rebekah, Perspectives of parents on making decisions about the care and treatment of a child with cancer: A review of literature, Families, Systems & Health: The Journal of Collaborative Family HealthCare, 31, 406-414, 2013	background reading paper for reference checking
Meert, K. L., Eggly, S., Pollack, M., Anand, K. J., Zimmerman, J., Carcillo, J., Newth, C. J., Dean, J. M., Willson, D. F., Nicholson, C., National Institute of Child, Health, Human Development Collaborative Pediatric Critical Care Research, Network, Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit, Pediatric Critical Care Medicine, 9, 2-7, 2008	Relevant themes (honest and complete information, consistent information) identified in the study have been reported in another study conducted by the same researcher, which has been included.
Meert, K. L., Thurston, C. S., Sarnaik, A. P., End-of-life decision-making and satisfaction with care: parental perspectives, Pediatric Critical Care Medicine, 1, 179-85, 2000	Just quantitative descriptive data reported without qualitative analysis.
Meyer, E. C., Ritholz, M. D., Burns, J. P., Truog, R. D., Improving the quality of end-of-life care in the pediatric intensive care unit:	The same "themes" on honest and complete information provision and ready access to staff for information identified in the study have been



Reference	Reason for Exclusion
parents' priorities and recommendations, <i>Pediatrics</i> , 117, 649-57, 2006	reported by other studies and included; less relevant setting.
Miller, V. A., Baker, J. N., Leek, A. C., Drotar, D., Kodish, E., Patient involvement in informed consent for pediatric phase I cancer research, <i>Journal of Pediatric Hematology/Oncology</i> , 36, 635-40, 2014	Non-qualitative study with descriptive data only
Mitchell, W., 'I know how I feel': listening to young people with life-limiting conditions who have learning and communication impairments, <i>Qualitative Social Work</i> , 9, 185-204, 2010	Review and discussion paper about how to conduct research among children learning and communication impairments, no qualitative data analysis.
Monterosso, L., Kristjanson, L., Phillips, M., The supportive and palliative care needs of Australian families of children who die from cancer, <i>Palliative Medicine</i> , 23, 526-536, 2009	survey with only quantitative descriptive data reported.
Moro, T. T., Kavanaugh, K., Savage, T. A., Reyes, M. R., Kimura, R. E., Bhat, R., Parent decision making for life support for extremely premature infants: from the prenatal through end-of-life period, <i>Journal of Perinatal &amp; Neonatal Nursing</i> , 25, 52-60, 2011	The focus of the paper of life-support decision making for extremely premature infants. It didn't mention what information or information type perceived as helpful or unhelpful.
Payot, A., Gendron, S., Lefebvre, F., Doucet, H., Deciding to resuscitate extremely premature babies: how do parents and neonatologists engage in the decision?, <i>Social Science and Medicine</i> , 64, 1487-1500, 2007	The focus of the study was to explore empirically how physicians and parents came to different understandings/conclusions regarding the communication they had about resuscitation decision making, not about information experienced as helpful or unhelpful.
Schonfeld, D. J., Talking with children about death, <i>Journal of Pediatric Health Care</i> , 7, 269-74, 1993	Discussion paper for background reading
Singh, R. K., Raj, A., Paschal, S., Hussain, S., Role of communication for pediatric cancer patients and their family, <i>Indian Journal of Palliative Care</i> , 21, 338-40, 2015	Only quantitative survey findings were reported.
Spinetta, John J., Swarner, Joyce A., Sheposh, John P., Effective parental coping following the death of a child from cancer, <i>Journal of Pediatric Psychology</i> , 6, 251-263, 1981	Parents' support and information giving to child before the child's death was assessed together with life meaning and support collectively to predict post-death adjustment using regression analysis. No qualitative analysis was undertaken.
Steele, R., Strategies used by families to navigate uncharted territory when a child is dying, <i>Journal of Palliative Care</i> , 21, 103-10, 2005	The focus of the paper was strategies families used to navigate through the process when their child was dying, not what information was experienced or perceived as helpful.
Stevenson, M., Achille, M., Lugasi, T., Pediatric palliative care in Canada and the United States: a qualitative metasummary of the needs of patients and families, <i>Journal of Palliative Medicine</i> , 16, 566-77, 2013	review paper for background reading
Valdez-Martinez, E., Noyes, J., Bedolla, M., When to stop? Decision-making when children's cancer treatment is no longer curative: a mixed-method systematic review, <i>BMC Pediatrics</i> , 14, 124, 2014	paper for background reading

Reference	Reason for Exclusion
Xafis, V., Gillam, L., Hynson, J., Sullivan, J., Cossich, M., Wilkinson, D., Caring decisions: The development of a written resource for parents facing end-of-life decisions, <i>Journal of Palliative Medicine</i> , 18, 945-955, 2015	The study was about the parents' and HCP's views on a handbook about decision making, no relevant theme to this review.
Xafis, V., Wilkinson, D., Sullivan, J., What information do parents need when facing end-of-life decisions for their child? A meta-synthesis of parental feedback, <i>BMC Palliative Care</i> , 14, 19, 2015	Relevant findings/themes on honesty, hope and false hope, sensitivity, timely information, involvement in decision making, medical jargons, complete information, written and oral information have all been identified and reported by the guideline's reviews on information provision and communication.
Xafis, Vicki, Wilkinson, Dominic, Gillam, Lynn, Sullivan, Jane, Balancing obligations: Should written information about life-sustaining treatment be neutral?, <i>Journal of Medical Ethics: Journal of the Institute of Medical Ethics</i> , 41, 234-239, 2015	discussion paper
Yun, Y. H., Kwon, Y. C., Lee, M. K., Lee, W. J., Jung, K. H., Do, Y. R., Kim, S., Heo, D. S., Choi, J. S., Park, S. Y., Experiences and attitudes of patients with terminal cancer and their family caregivers toward the disclosure of terminal illness, <i>Journal of Clinical Oncology</i> , 28, 1950-7, 2010	Study on adults

## 1 H.2 Review question: Communication

Reference	Reason for Exclusion
Abib El Halal, G. M., Piva, J. P., Lago, P. M., El Halal, M. G., Cabral, F. C., Nilson, C., Garcia, P. C., Parents' perspectives on the deaths of their children in two Brazilian paediatric intensive care units, <i>International Journal of Palliative Nursing</i> , 19, 495-502, 2013	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported. Less relevant setting as well.
Adams-Greenly, Margaret, Helping children communicate about serious illness and death, <i>Journal of Psychosocial Oncology</i> , 2, 61-72, 1984	Case study, not a qualitative research. No reporting of how data were collected, analysed or themes derived.
Alifrangis, C., Koizia, L., Rozario, A., Rodney, S., Harrington, M., Somerville, C., Peplow, T., Waxman, J., The experiences of cancer patients, <i>Qjm</i> , 104, 1075-81, 2011	Study on adults.
Armentrout, D., Cates, L. A., Informing parents about the actual or impending death of their infant in a newborn intensive care unit, <i>Journal of Perinatal &amp; Neonatal Nursing</i> , 25, 261-7, 2011	Review paper for background reading.
Aschenbrenner, A. P., Winters, J. M., Belknap, R. A., Integrative review: parent perspectives on care of their child at the end of life, <i>Journal of Pediatric Nursing</i> , 27, 514-22, 2012	Review paper for background reading.
Barakat, L. P., Sills, R., LaBagnara, S., Management of fatal illness and death in children or their parents, <i>Pediatrics in Review</i> , 16, 419-23; quiz 424, 1995	Narrative about children's understanding of death, not qualitative research.

Reference	Reason for Exclusion
Beale, E. A., Baile, W. F., Aaron, J., Silence is not golden: communicating with children dying from cancer, <i>Journal of Clinical Oncology</i> , 23, 3629-31, 2005	Case study and discussion paper, not qualitative study.
Beckstrand, R. L., Rawle, N. L., Callister, L., Mandleco, B. L., Pediatric nurses' perceptions of obstacles and supportive behaviors in end-of-life care, <i>American Journal of Critical Care</i> , 19, 543-52, 2010	Descriptive data was only analysed quantitatively in the paper.
Bloomer, M. J., O'Connor, M., Copnell, B., Endacott, R., Nursing care for the families of the dying child/infant in paediatric and neonatal ICU: nurses' emotional talk and sources of discomfort. A mixed methods study, <i>Australian Critical Care</i> , 28, 87-92, 2015	The study explored nurses' perspectives on communication when caring for a child living with LLC and when it's around the child's death. Similar themes on "taking the child as an individual," "emotions" have been identified and reported. No new themes and saturation in data analysis on these themes has been achieved.
Bloomer, M., Endacott, R., Copnell, B., O'Connor, M., Nurses caring for dying patients and their families in paediatric and neonatal ICU: A linguistic inquiry approach, <i>Australian Critical Care</i> , 28, 51-52, 2015	Conference abstract
Bradford, Natalie, Irving, Helen, Murray, Judith, Pedersen, Lee-Anne, Roylance, Julie, Crowe, Liz, Herbert, Anthony, Paediatric palliative care services in Queensland: an exploration of the barriers, gaps and plans for service development, <i>Neonatal, Paediatric &amp; Child Health Nursing</i> , 15, 2-8, 2012	Information on communication was only descriptive quantitative data.
Bray, Y. M., Goodyear-Smith, F. A., A migrant family's experience of palliative care, <i>Journal of Hospice &amp; Palliative Nursing</i> , 9, 92-100, 2007	Paper on adults approaching the end of life.
Brooten, Dorothy, Youngblut, JoAnne M., Seagrave, Lynn, Caicedo, Carmen, Hawthorne, Dawn, Hidalgo, Ivette, Roche, Rosa, Parent's perceptions of health care providers actions around child ICU death: What helped, what did not, <i>American Journal of Hospice &amp; Palliative Medicine</i> , 30, 40-49, 2013	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported
Brosig, C. L., Pierucci, R. L., Kupst, M. J., Leuthner, S. R., Infant end-of-life care: the parents' perspective, <i>Journal of Perinatology</i> , 27, 510-6, 2007	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported
Brown, Erica, Patel, Reena, Kaur, Jasveer, Coad, Jane, The interface between South Asian culture and palliative care for children, young people, and families-A discussion paper, <i>Issues in Comprehensive Pediatric Nursing</i> , 36, 120-143, 2013	Background reading.
Browning, D., To show our humanness--relational and communicative competence in pediatric palliative care, <i>Bioethics Forum</i> , 18, 23-8, 2002	Discussion paper for background reading.
Butler, A., Hall, H., Willetts, G., Copnell, B., Parents' experiences of healthcare provider actions when their child dies: an integrative review of the literature, <i>Journal for Specialists in Pediatric Nursing: JSPN</i> , 20, 5-20, 2015	Systematic review on parents' experience around the death of their child living with LLCs. Relevant themes on communication, staff affect, care to the parents and continuity of care have been identified and reported by relevant review

Reference	Reason for Exclusion
	questions of the guideline. Saturation in data analysis on these themes has been achieved.
Butler, Ashleigh, Hall, Helen, Willetts, Georgina, Copnell, Beverley, Parents' experiences of healthcare provider actions when their child dies: An integrative review of the literature, <i>Journal for Specialists in Pediatric Nursing</i> , 20, 5-21, 2015	Review paper for background reading.
Catlin, A., Transition from curative efforts to purely palliative care for neonates: does physiology matter?.[Erratum appears in <i>Adv Neonatal Care</i> . 2011 Aug;11(4):297], <i>Advances in Neonatal Care</i> , 11, 216-22, 2011	Descriptive data was only analysed quantitatively in the paper.
Chen, C. H., Huang, L. C., Liu, H. L., Lee, H. Y., Wu, S. Y., Chang, Y. C., Peng, N. H., To explore the neonatal nurses' beliefs and attitudes towards caring for dying neonates in Taiwan, <i>Maternal &amp; Child Health Journal</i> , 17, 1793-801, 2013	Descriptive data was only analysed quantitatively in the paper.
Chesterfield, P., Communicating with dying children, <i>Nursing Standard</i> , 6, 30-2, 1992	Discussion paper for background reading.
Chin, L. E., Loong, L. C., Ngen, C. C., Beng, T. S., Shireen, C., Kuan, W. S., Shaw, R., Pediatric palliative care: using miniature chairs to facilitate communication, <i>American Journal of Hospice &amp; Palliative Medicine</i> , 31, 833-5, 2014	Case study of how miniature chairs could help the communication between child and parents/physicians, not qualitative study.
Christenson, K., Lybrand, S. A., Hubbard, C. R., Hubble, R. A., Ahsens, L., Black, P., Including the Perspective of the Adolescent in Palliative Care Preferences, <i>Journal of Pediatric Healthcare</i> , 24, 286-292, 2010	Case study, not qualitative study.
Coad, J., Patel, R., Murray, S., Disclosing terminal diagnosis to children and their families: palliative professionals' communication barriers, <i>Death Studies</i> , 38, 302-7, 2014	The review focused on communication skills, relevant papers have been checked for inclusion.
Curtis, J. R., Engelberg, R. A., Wenrich, M. D., Nielsen, E. L., Shannon, S. E., Treece, P. D., Tonelli, M. R., Patrick, D. L., Robins, L. S., McGrath, B. B., Rubenfeld, G. D., Studying communication about end-of-life care during the ICU family conference: development of a framework, <i>Journal of Critical Care</i> , 17, 147-60, 2002	The paper focused on observing the interaction between family and HCPs in family conferences, not on barriers and facilitators of communication.
Davies, B., Larson, J., Contro, N., Cabrera, A. P., Perceptions of discrimination among Mexican American families of seriously ill children, <i>Journal of Palliative Medicine</i> , 14, 71-6, 2011	The focus of the study was discrimination experienced, not aspects of communication on end of life issues.
Davies, Betty, Sehring, Sally A., Partridge, J., Cooper, Bruce A., Hughes, Anne, Philp, Julie C., Amidi-Nouri, Aara, Kramer, Robin F., Barriers to palliative care for children: Perceptions of pediatric health care providers, <i>Pediatrics</i> , 121, 282-288, 2008	The study focused on general palliative care, not particularly related to aspects of communication.
Davies, D. E., Tanvetyanon, T., Kreicbergs, U., Valdimarsdóttir, U., Steineck, G., Talking about death with dying children... Kreicbergs U,	Commentary.

Reference	Reason for Exclusion
Valdimarsdóttir U, Onelöv E et al. Talking about death with children who have severe malignant disease. <i>N Engl J Med</i> 2004;351:1175-86, <i>New England Journal of Medicine</i> , 352, 91-93, 2005	
de Rooy, L., Aladangady, N., Aidoo, E., Palliative care for the newborn in the United Kingdom, <i>Early Human Development</i> , 88, 73-7, 2012	Background reading.
de Vos, M. A., Bos, A. P., Plotz, F. B., van Heerde, M., de Graaff, B. M., Tates, K., Truog, R. D., Willems, D. L., Talking with parents about end-of-life decisions for their children, <i>Pediatrics</i> , 135, e465-76, 2015	The paper is not related to barriers or facilitators of communication, rather, it focused on the processes of how conversations were conducted in real life.
De, S., Aranda, S., When a child cannot be cured -- reflections of health professionals, <i>European Journal of Cancer Care</i> , 14, 132-141, 2005	The paper did not focus on barriers or facilitators of communication, rather, it focused on HCPs' reflection of experiences.
Diez, B., Lascar, E., Alizade, A., Talking to a child with cancer. A valuable experience, <i>Annals of the New York Academy of Sciences</i> , 809, 142-51, 1997	Narrative paper on experience sharing, not a qualitative study.
Dunlop, S., The dying child: should we tell the truth?, <i>Paediatric Nursing</i> , 20, 28-31, 2008	Discussion paper for background reading.
Dunsmore, J., Quine, S., Information, support, and decision-making needs and preferences of adolescents with cancer: Implications for health professionals, <i>Journal of Psychosocial Oncology</i> , 13, 39-56, 1995	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported
Engler, A. J., Cusson, R. M., Brockett, R. T., Cannon-Heinrich, C., Goldberg, M. A., West, M. G., Petow, W., Neonatal staff and advanced practice nurses' perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants, <i>American Journal of Critical Care</i> , 13, 489-98, 2004	Descriptive data was only analysed quantitatively in the paper, not related to communication.
Epelman, C. L., End-of-life management in pediatric cancer, <i>Current Oncology Reports</i> , 14, 191-6, 2012	Paper for background reading.
Epstein, E. G., End-of-life experiences of nurses and physicians in the newborn intensive care unit, <i>Journal of Perinatology</i> , 28, 771-779, 2008	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported
Epstein, E. G., Moral obligations of nurses and physicians in neonatal end-of-life care, <i>Nursing Ethics</i> , 17, 577-589, 2010	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported
Epstein, E. G., End-of-life experiences of parents, nurses and physicians in the newborn intensive care unit, -297, 2007	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported
Fergus, C. J., Chinn, D. J., Murray, S. A., Assessing and improving out-of-hours palliative care in a deprived community: a rapid appraisal study, <i>Palliative Medicine</i> , 24, 493-500, 2010	Study on adults.
Feudtner, C., Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making, <i>Pediatric Clinics of North America</i> , 54, 583-607, ix, 2007	Background reading.

Reference	Reason for Exclusion
Fine, E., Reid, M. C., Shengelia, R., Adelman, R. D., Directly observed patient-physician discussions in palliative and end-of-life care: a systematic review of the literature, <i>Journal of Palliative Medicine</i> , 13, 595-603, 2010	Paper for background reading.
Gaab, M., Owens, R., MacLeod, D., Siblings Caring for and about Pediatric Palliative Care Patients, <i>Journal of Palliative Medicine</i> , 17, 62-68, 2014	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported
Gilmer, Mary Jo, Foster, L., Bell, J., Mulder, John, Carter, S., Parental Perceptions of Care of Children at End of Life, <i>American Journal of Hospice &amp; Palliative Medicine</i> , 30, 53-59, 2013	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported
Goggin, M., Parents perceptions of withdrawal of life support treatment to newborn infants, <i>Early Human Development</i> , 88, 79-82, 2012	Discussion paper for background reading.
Grossman, L., Understanding anger in parents of dying children, <i>American Family Physician</i> , 58, 1211-2, 1998	Paper for background reading.
Haddad, A., Ethics in action. The parents of a terminally ill child do not want anyone to let on how sick he actually is, <i>RN</i> , 63, 21-3, 2000	Discussion paper.
Hatton, Chris, Akram, Yasmeen, Robertson, Janet, Shah, Robina, Emerson, Eric, The Disclosure Process and its Impact on South Asian Families with a Child with Severe Intellectual Disabilities, <i>Journal of Applied Research in Intellectual Disabilities</i> , 16, 177-188, 2003	Participants interviewed were parents of children with severe intellectual difficulties, not necessarily children living with LLCs.
Havermans, T., Tack, J., Vertommen, A., Proesmans, M., de Boeck, K., Breaking bad news, the diagnosis of cystic fibrosis in childhood, <i>Journal of Cystic Fibrosis</i> , 14, 540-546, 2015	No relevant qualitative findings on relevant themes of interest to the protocol was reported by the study.
Heath, J. A., Clarke, N. E., McCarthy, M., Donath, S. M., Anderson, V. A., Wolfe, J., Quality of care at the end of life in children with cancer, <i>Journal of Paediatrics &amp; Child Health</i> , 45, 656-9, 2009	Descriptive data was only analysed quantitatively in the paper.
Heinze, K. E., Nolan, M. T., Parental decision making for children with cancer at the end of life: a meta-ethnography, <i>Journal of Pediatric Oncology Nursing</i> , 29, 337-45, 2012	Review paper for background reading.
Hendricks-Ferguson, V. L., Sawin, K. J., Montgomery, K., Dupree, C., Phillips-Salimi, C. R., Carr, B., Haase, J. E., Novice Nurses' Experiences With Palliative and End-of-Life Communication, <i>Journal of Pediatric Oncology Nursing</i> , 32, 240-52, 2015	Study among nurses. Themes identified such as "uncertainty" around communication, emotions involved on both sides, on-going communications, "hope" have been identified and reported in the guideline's relevant reviews and saturation in data analysis has achieved.
Hilden, J. M., Watterson, J., Chrastek, J., Tell the children, <i>Journal of Clinical Oncology</i> , 21, 37s-39s, 2003	Case study, not qualitative research paper.
Hinds, P. S., Schum, L., Baker, J. N., Wolfe, J., Key factors affecting dying children and their families, <i>Journal of Palliative Medicine</i> , 8 Suppl 1, S70-8, 2005	Discussion paper for reference check.

Reference	Reason for Exclusion
Hockley, J., Psychosocial aspects in palliative care--communicating with the patient and family, <i>Acta Oncologica</i> , 39, 905-10, 2000	Discussion paper with case studies.
Holston, Jane Treadwell, Supporting Families in NEONATAL LOSS: Relationships and Faith Key to Comfort, <i>Journal of Christian Nursing</i> , 32, 18-26, 2015	Discussion paper.
Inglin, S., Hornung, R., Bergstraesser, E., Palliative care for children and adolescents in Switzerland: a needs analysis across three diagnostic groups, <i>European Journal of Pediatrics</i> , 170, 1031-8, 2011	Paper excluded due to data saturation. The relevant theme reported in the paper has been reported.
Jalmsell, L., Kontio, T., Stein, M., Henter, J. I., Kricbergs, U., On the Child's Own Initiative: Parents Communicate with Their Dying Child About Death, <i>Death Studies</i> , 39, 111-7, 2015	The study focused on the communication between parents and dying children, not between the family and HCPs.
Janvier,A., Barrington,K., Farlow,B., Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology, <i>Seminars in Perinatology</i> , 38, 38-46, 2014	Discussion paper of a communication model.
Kamihara, J., Nyborn, J. A., Olcese, M. E., Nickerson, T., Mack, J. W., Parental hope for children with advanced cancer, <i>Pediatrics</i> , 135, 868-74, 2015	The theme on "hope" and parents realising there could be no cure for their child has been identified and reported. Saturation in analysis has been achieved.
Khaneja, S., Milrod, B., Educational needs among pediatricians regarding caring for terminally ill children, <i>Archives of Pediatrics &amp; Adolescent Medicine</i> , 152, 909-14, 1998	Descriptive data were only analysed quantitatively in the study.
Kuttner, L., Talking with families when their children are dying, <i>Medical Principles and Practice</i> , 16, 16-20, 2007	Review paper for background reading.
Lee, K. J., Dupree, C. Y., Staff experiences with end-of-life care in the pediatric intensive care unit, <i>Journal of Palliative Medicine</i> , 11, 986-90, 2008	The paper did not focus on the aspects of communication.
Levetown, M., Communicating with children and families: From everyday interactions to skill in conveying distressing information, <i>Pediatrics</i> , 121, e1441-e1460, 2008	Review paper for background reading.
Lindsay, Gail, Cross, Nadine, Ives-Baine, Lori, NARRATIVES OF NEONATAL INTENSIVE CARE UNIT NURSES: EXPERIENCE WITH END-OF-LIFE CARE, <i>Illness, Crisis &amp; Loss</i> , 20, 239-254, 2012	The paper focused on paediatric nurses' experiences in EOL care, not particularly related to aspects of communication.
Linebarger, J. S., Sahler, O. J., Egan, K. A., Coping with death, <i>Pediatrics in Review</i> , 30, 350-5; quiz 356, 2009	Narrative review, not qualitative research.
Long, C. O., Ten best practices to enhance culturally competent communication in palliative care, <i>Journal of Pediatric Hematology/Oncology</i> , 33 Suppl 2, S136-9, 2011	Discussion paper for background reading.
Mack, J. W., Joffe, S., Communicating about prognosis: ethical responsibilities of	Background reading.

Reference	Reason for Exclusion
pediatricians and parents, <i>Pediatrics</i> , 133 Suppl 1, S24-30, 2014	
Markward, M. J., Benner, K., Freese, R., Perspectives of parents on making decisions about the care and treatment of a child with cancer: a review of literature, <i>Families, Systems, &amp; Health</i> , 31, 406-13, 2013	General review paper for background reading
Marten, G. W., Mauer, A. M., Interaction of health-care professionals with critically ill children and their parents, <i>Clinical Pediatrics</i> , 21, 540-544, 1982	Narrative review, not a qualitative study.
Mazanec, P., Tyler, M. K., Cultural considerations in end-of-life care: how ethnicity, age, and spirituality affect decisions when death is imminent, <i>American Journal of Nursing</i> , 103, 50-60, 2003	Discussion paper for background reading.
Melin-Johansson, C., Axelsson, I., Jonsson Grundberg, M., Hallqvist, F., When a child dies: parents' experiences of palliative care-an integrative literature review, <i>Journal of Pediatric Nursing</i> , 29, 660-9, 2014	Review paper for background reading.
Mitchell, Wendy, 'I know how I feel': Listening to young people with life-limiting conditions who have learning and communication impairments, <i>Qualitative Social Work: Research and Practice</i> , 9, 185-203, 2010	The focus of the study was to explore how a range of tools were developed for the communication with children living with cognitive impairment, not barriers or facilitators of communication.
Nielson, D., Discussing death with pediatric patients: implications for nurses, <i>Journal of Pediatric Nursing</i> , 27, e59-64, 2012	Discussion paper for background reading.
Noble, H., Price, J. E., Porter, S., The challenge to health professionals when carers resist truth telling at the end of life: a qualitative secondary analysis, <i>Journal of Clinical Nursing</i> , 24, 927-36, 2015	Relevant theme reported in this study was the "truth-telling" among HCPs and the parents/carers' wishes to protect their child with cancer or cared for in children's hospice. Similar themes have been identified and reported, saturation in data analysis has been achieved for this particular theme.
Nuss, S. L., Redefining parenthood: surviving the death of a child, <i>Cancer Nursing</i> , 37, E51-60, 2014	The paper focused on parents' experience surviving their child's death, not related to aspects of communication.
O'Brien, Rowena, Expressions of hope in paediatric intensive care: a reflection on their meaning, <i>Nursing in Critical Care</i> , 19, 316-322, 2014	Paper for background reading.
Papadatou, D., Martinson, I. M., Chung, P. M., Caring for dying children: A comparative study of nurses' experiences in Greece and Hong Kong, <i>Cancer Nursing</i> , 24, 402-412, 2001	The paper focused on nurses' experiences caring for children, not related to aspects of communication.
Parker-Raley, J., Jones, B. L., Maxson, R. T., Communicating the death of a child in the emergency department: managing dialectical tensions, <i>Journal for Healthcare Quality</i> , 30, 20-31, 2008	HCPs caring for children died in ED were interviewed, not specified whether children they cared for were living with LLCs or not.
Price, J., McNeilly, P., Surgenor, M., Breaking bad news to parents: the children's nurse's role, <i>International Journal of Palliative Nursing</i> , 12, 115-20, 2006	Discussion paper for background reading.



Reference	Reason for Exclusion
Reder, E. A., Serwint, J. R., Until the last breath: exploring the concept of hope for parents and health care professionals during a child's serious illness, Archives of Pediatrics & Adolescent Medicine, 163, 653-7, 2009	Not related to barriers and facilitators of communication.
Rider, E. A., Volkan, K., Hafler, J. P., Pediatric residents' perceptions of communication competencies: Implications for teaching, Medical Teacher, 30, e208-17, 2008	Descriptive data was only analysed quantitatively in the paper.
Sanches, M. V., Nascimento, L. C., de Lima, R. A., [Children and adolescents with cancer under palliative care: experience of family members], Revista Brasileira de Enfermagem, 67, 28-35, 2014	Paper on Spanish.
Slatyer, Susan, Pienaar, Catherine, Williams, M., Proctor, Karen, Hewitt, Laura, Finding privacy from a public death: a qualitative exploration of how a dedicated space for end-of-life care in an acute hospital impacts on dying patients and their families, Journal of Clinical Nursing, 24, 2164-2175, 2015	Study carried out among HCPs, the study did not report clearly whether they cared for adults or children and young people under 18 years of age.
Slort, W., Blankenstein, A. H., Deliens, L., van der Horst, H. E., Facilitators and barriers for GP-patient communication in palliative care: a qualitative study among GPs, patients, and end-of-life consultants, British Journal of General Practice, 61, 167-72, 2011	Study on adults.
Snaman, J. M., Torres, C., Duffy, B., Levine, D. R., Gibson, D. V., Baker, J. N., Parental Perspectives of Communication at the End of Life at a Pediatric Oncology Institution, Journal of Palliative Medicine, 19, 326-32, 2016	Themes reported in this study on "relationship between family and staff members," "empathetic explanation and reassurance of medical care/plan," and "individualised interaction" have been identified and reported in relevant reviews of the guideline. No new theme identified and saturation of data analysis has achieved.
Spratling, Regena, The experiences of medically fragile adolescents who require respiratory assistance, Journal of Advanced Nursing, 68, 2740-2750, 2012	Participants were medically fragile young people who required respiratory assistance, not necessarily those approaching the end of life.
Thienprayoon, R., Marks, E., Funes, M., Martinez-Puente, L. M., Winick, N., Lee, S. C., Perceptions of the pediatric hospice experience among english- and Spanish-speaking families, Journal of Palliative Medicine, 19, 30-41, 2016	Themes on honest, truthful, and timely information; and emotional factors such as anxiety and panic on the side of parents/carers during the communication have been identified and reported. Saturation in data analysis has been achieved.
Tubbs-Cooley, H. L., Santucci, G., Kang, T. I., Feinstein, J. A., Hexem, K. R., Feudtner, C., Pediatric nurses' individual and group assessments of palliative, end-of-life, and bereavement care, Journal of Palliative Medicine, 14, 631-7, 2011	Descriptive data was only analysed quantitatively in the paper.
van der Geest, I. M., van den Heuvel-Eibrink, M. M., van Vliet, L. M., Pluijm, S. M., Streng, I. C., Michiels, E. M., Pieters, R., Darlington, A. S., Talking about Death with Children with Incurable Cancer: Perspectives from Parents, Journal of Pediatrics, 167, 1320-6, 2015	The study was about communication between parents and their child living LLCs, not with HCPs.

Reference	Reason for Exclusion
van, C., Using play therapy in paediatric palliative care: listening to the story and caring for the body, <i>International Journal of Palliative Nursing</i> , 15, 510-515, 2009	Discussion paper.
Whitty-Rogers, J., Alex, M., MacDonald, C., Gallant, D. P., Austin, W., Working with children in end-of-life decision making, <i>Nursing Ethics</i> , 16, 743-759, 2009	Discussion paper for background reading.
Williams, C., Munson, D., Zupancic, J., Kirpalani, H., Supporting bereaved parents: practical steps in providing compassionate perinatal and neonatal end-of-life care. A North American perspective, <i>Seminars In Fetal &amp; Neonatal Medicine</i> , 13, 335-40, 2008	Discussion paper for background reading.
Zelcer, S., Cataudella, D., Cairney, A. E., Bannister, S. L., Palliative care of children with brain tumors: a parental perspective, <i>Archives of Pediatrics &amp; Adolescent Medicine</i> , 164, 225-30, 2010	EOL experience of children with brain tumour, not focused on communication barriers or facilitators.

### 1 H.3 Review question: Advance Care Planning

Study	Reason for Exclusion
Appel, J., When any answer is a good answer: a mandated-choice model for advance directives, <i>Cambridge Quarterly of Healthcare Ethics</i> , 19, 417-21, 2010	The study design does not meet the inclusion criteria
Boerner, K., Carr, D., Moorman, S., Family relationships and advance care planning: do supportive and critical relations encourage or hinder planning?, <i>Journals of Gerontology Series B-Psychological Sciences &amp; Social Sciences</i> , 68, 246-56, 2013	Adult population
Boss, R. D., Hutton, N., Griffin, P. L., Wieczorek, B. H., Donohue, P. K., Novel legislation for pediatric advance directives: surveys and focus groups capture parent and clinician perspectives, <i>Palliative Medicine</i> , 29, 346-53, 2015	Context. Refers to the implementation of novel legislation for paediatric advanced directives in Baltimore, USA
Burchardi, N., Rauprich, O., Hecht, M., Beck, M., Vollmann, J., Discussing living wills. A qualitative study of a German sample of neurologists and ALS patients, <i>Journal of the Neurological Sciences</i> , 237, 67-74, 2005	Adult population only.
Catlin, A., Carter, B., Creation of a neonatal end-of-life palliative care protocol, <i>Journal of Perinatology</i> , 22, 184-195, 2002	Consensus document
Chong, C. H., Muthiah, M. D., Fan, H. R. K., Lei, H., Chan, N., Tam, Y. C., Low, H. C., Shi, J., Aye, T. M., Leng, K. L. B., Taking charge of my life: Advance care planning in patient with end stage liver disease, <i>Hepatology International</i> , 1), S447, 2016	Conference abstract. No additional themes reported.
Dallas, R. H., Wilkins, M. L., Wang, J., Garcia, A., Lyon, M. E., Longitudinal Pediatric Palliative Care: Quality of Life & Spiritual Struggle (FACE):	Protocol

Study	Reason for Exclusion
design and methods, Contemporary Clinical Trials, 33, 1033-43, 2012	
Devictor, D. J., Latour, J. M., Eurydice li study group, Forgoing life support: how the decision is made in European pediatric intensive care units, Intensive Care Medicine, 37, 1881-7, 2011	Survey with quantitative data only
Docherty, S. L., Miles, M. S., Brandon, D., Searching for "the dying point:" providers' experiences with palliative care in pediatric acute care, Pediatric Nursing, 33, 335-41, 2007	Does not discuss planning aspects of care
Durall, A., Barriers to conducting advanced care discussions for children with life-threatening conditions (720), Journal of Pain and Symptom Management, 41 (1), 284, 2011	Survey with quantitative data only. Conference abstract.
Durall, A., Zurakowski, D., Wolfe, J., Barriers to conducting advance care discussions for children with life-threatening conditions, Pediatrics, 129, e975-82, 2012	survey with quantitative data only
Edwards, J. D., Kun, S. S., Graham, R. J., Keens, T. G., End-of-life discussions and advance care planning for children on long-term assisted ventilation with life-limiting conditions, Journal of Palliative Care, 28, 21-7, 2012	Retrospective chart review
Egg, J., Hurly-Browning, L., Lynch, M. P., Insuring interdisciplinary spiritual care for young adults living with advanced cancer, Psycho-Oncology, 24, 302-303, 2015	Conference abstract. No relevant data provided.
Emanuel, L. I., Barry, M. J., Stoeckle, J. D., Ettelson, L. M., Emanuel, E. J., Advance directives for medical care - a case for greater use, New England Journal of Medicine, 324, 1991	Adult population
Emanuel, L. L., Barry, M. J., Stoeckle, J. D., Ettelson, L. M., Emanuel, E. J., Advance directives for medical care--a case for greater use, New England Journal of Medicine, 324, 889-95, 1991	Adult population
Felt, D. H., Early, J. L., Welk, T. A., Attitudes, values, beliefs, and practices surrounding end-of-life care in selected Kansas communities, American Journal of Hospice & Palliative Medicine, 17, 401-6, 2000	Adults only.
Ferguson, V. L., Haase, J. E., Pradhan, K. R., Kane, J. R., Hinds, P. S., Interdisciplinary development of a communication intervention for parents of children with brain tumors, Neuro-Oncology, 12 (6), ii80, 2010	Protocol only
Finlay, F., Lewis, M., Lenton, S., Poon, M., Planning for the end of children's lives--the lifetime framework, Child: Care, Health & Development, 34, 542-4, 2008	Study design does not meet the inclusion criteria of the review
Fraser, J., Harris, N., Berringer, A. J., Prescott, H., Finlay, F., Advanced care planning in children with life-limiting conditions - The Wishes Document, Archives of Disease in Childhood, 95, 79-82, 2010	Study design does not meet the inclusion criteria

Study	Reason for Exclusion
Garvie, P. A., He, J., Wang, J., D'Angelo, L. J., Lyon, M. E., An exploratory survey of end-of-life attitudes, beliefs, and experiences of adolescents with HIV/AIDS and their families, <i>Journal of Pain &amp; Symptom Management</i> , 44, 373-85.e29, 2012	Study design. Survey with quantitative data only.
Gillam, L., Sullivan, J., Ethics at the end of life: who should make decisions about treatment limitation for young children with life-threatening or life-limiting conditions?, <i>Journal of Paediatrics &amp; Child Health</i> , 47, 594-8, 2011	Review
Glass, A. P., Nahapetyan, L., Discussions by elders and adult children about end-of-life preparation and preferences, <i>Preventing Chronic Disease</i> , 5, A08, 2008	adult population
Go, R. S., Hammes, B. A., Lee, J. A., Mathiason, M. A., Advance directives among health care professionals at a community-based cancer center, <i>Mayo Clinic Proceedings</i> , 82, 1487-90, 2007	Adult population
Goggin, J., Obstacles to palliative or end-of-life care in cystic fibrosis, <i>Pediatric Pulmonology</i> , 47, 431, 2012	Survey with quantitative data only. Conference abstract.
Heckford, E., Beringer, A. J., Advance care planning: challenges and approaches for pediatricians, <i>Journal of Palliative Medicine</i> , 17, 1049-53, 2014	Study design. Retrospective case note review.
Hickey, D., Quinn, S., 'I don't want to talk about it.' Raising public awareness of end-of-life care planning in your locality, <i>International Journal of Palliative Nursing</i> , 18, 241-7, 2012	Mixed adult and child population
Hinds, P. S., Oakes, L., Furman, W., Foppiano, P., Olson, M. S., Quargnenti, A., Gattuso, J., Powell, B., Srivastava, D. K., Jayawardene, D., Sandlund, J. T., Strong, C., Decision making by parents and healthcare professionals when considering continued care for pediatric patients with cancer, <i>Oncology Nursing Forum</i> , 24, 1523-8, 1997	No descriptive data of interest reported
Hines, S. C., Glover, J. J., Babrow, A. S., Holley, J. L., Badzek, L. A., Moss, A. H., Improving advance care planning by accommodating family preferences, <i>Journal of Palliative Medicine</i> , 4, 481-9, 2001	Adult population
Holt, S., Lim, J., Jones, C., Bricker, L., Turner, M., Agarwal, U., Subhedar, N., Brook, L., Antenatal advance care planning: 3 years experience from a single centre, <i>Archives of Disease in Childhood</i> , 99, A189, 2014	Retrospective review. Conference abstract only.
Hoover-Regan, M., Neumann, M., Advanced directives and advanced care planning in pediatrics: Where are we now?, <i>Journal of Pain and Symptom Management</i> , 43 (2), 382, 2012	Describes the use of AD in pediatric care practice. Conference abstract only.
Isaacs, D., Controversial End-of-Life Issues in the Neonatal Intensive Care Unit, <i>American Journal of Bioethics</i> , 11, 43-44, 2011	Study design does not meet the inclusion criteria

Study	Reason for Exclusion
Ivo, K., Younsuck, K., Ho, Y. Y., Sang-Yeon, S., Seog, H. D., Hyunah, B., Kenji, H., Xiaomei, Z., A survey of the perspectives of patients who are seriously ill regarding end-of-life decisions in some medical institutions of Korea, China and Japan, <i>Journal of Medical Ethics</i> , 38, 310-6, 2012	Adult population
Jacobs, S., Perez, J., Cheng, Y. I., Sill, A., Wang, J., Lyon, M. E., Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer, <i>Pediatric Blood and Cancer</i> , 62, 710-714, 2015	Qualitative survey results only
Janvier, A., Barrington, K., Farlow, B., Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology, <i>Seminars in Perinatology</i> , 38, 38-46, 2014	Discussion paper.
Jefferson, L. S., White, B. C., Louis, P. T., Brody, B. A., King, D. D., Roberts, C. E., Use of the Natural Death Act in pediatric patients, <i>Critical Care Medicine</i> , 19, 901-5, 1991	Study design does not meet the inclusion criteria
Justin, R. G., Record health care directives before terminal illness!, <i>Canadian Family Physician</i> , 36, 891-5, 1990	Majority adult population
Leuthner, S. R., Pierucci, R., Experience with neonatal palliative care consultation at the Medical College of Wisconsin-Children's Hospital of Wisconsin, <i>Journal of Palliative Medicine</i> , 4, 39-47, 2001	Not all participants had a life-limiting condition
Lieberman, D. B., Pham, P. K., Nager, A. L., Pediatric advance directives: parents' knowledge, experience, and preferences, <i>Pediatrics</i> , 134, e436-43, 2014	Survey with quantitative data only.
Lotz, J. D., Jox, R. J., Borasio, G. D., Fuhrer, M., Pediatric advance care planning: a systematic review, <i>Pediatrics</i> , 131, e873-80, 2013	Study design does not meet the inclusion criteria
Lyon, M. E., Family centered advance care planning for teens, <i>Journal of Palliative Medicine</i> , 16 (4), A7-A8, 2013	RCT. Conference abstract. No relevant information provided for the review.
Lyon, M. E., Jacobs, S., Briggs, L., Cheng, Y. I., Wang, J., Family-centered advance care planning for teens with cancer, <i>JAMA Pediatrics</i> , 167, 460-7, 2013	Design. RCT with no qualitative data. Also includes participants from 14 to 21 years (indirect population)
Lyon, M. E., Jacobs, S., Briggs, L., Cheng, Y. I., Wang, J., A longitudinal, randomized, controlled trial of advance care planning for teens with cancer: anxiety, depression, quality of life, advance directives, spirituality, <i>Journal of Adolescent Health</i> , 54, 710-7, 2014	Design. RCT
Lyon, M. E., McCabe, M. A., Patel, K. M., D'Angelo, L. J., What do adolescents want? An exploratory study regarding end-of-life decision-making, <i>Journal of Adolescent Health</i> , 35, 529.e1-6, 2004	Explores differences between healthy and chronically ill adolescents.

Study	Reason for Exclusion
McAliley, L. G., Hudson-Barr, D. C., Gunning, R. S., Rowbottom, L. A., The use of advance directives with adolescents, <i>Pediatric Nursing</i> , 26, 471-80, 2000	Population: healthy adolescents.
McBride, D., Advanced care planning discussions with adolescents and young adults with cancer, <i>Journal of Pediatric Nursing</i> , 28, 406-7, 2013	Editorial
Meyer, E. C., Burns, J. P., Griffith, J. L., Truog, R. D., Parental perspectives on end-of-life care in the pediatric intensive care unit, <i>Critical Care Medicine</i> , 30, 226-31, 2002	Included death from all causes
Mitchell, S., Plunkett, A., Dale, J., Use of formal advance care planning documents: a national survey of UK Paediatric Intensive Care Units, <i>Archives of Disease in Childhood</i> , 99, 327-30, 2014	Survey with quantitative data only
Pezeshki, B. B., Kuo, A., Stevens, C., Increasing advance directive completion among end-of-life patients, <i>Journal of Investigative Medicine</i> , 62 (1), 228, 2014	Conference abstract. Age unclear. Methods unclear.
Raijmakers, N. J., Rietjens, J. A., Kouwenhoven, P. S., Vezzoni, C., van Thiel, G. J., van Delden, J. J., van der Heide, A., Involvement of the Dutch general population in advance care planning: a cross-sectional survey, <i>Journal of Palliative Medicine</i> , 16, 1055-61, 2013	Includes general population.
Ramsey, C. P., Young Adult African American family members' perceptions, knowledge, attitudes, and utilization toward advance directives, <i>ABNF Journal</i> , 24, 51-9, 2013	Adult population
Rhodes, A. M., Treatment decisions, <i>MCN, American Journal of Maternal Child Nursing</i> , 16, 225-6, 1991	Study design does not meet the inclusion criteria of the review
Rosato, J. L., The ultimate test of autonomy: should minors have a right to make decisions regarding life-sustaining treatment?, <i>Rutgers Law Review</i> , 49, 1-103, 1996	Study design did not meet the inclusion criteria
Ruff, H., Jacobs, R. J., Fernandez, M. I., Bowen, G. S., Gerber, H., Factors associated with favorable attitudes toward end-of-life planning, <i>American Journal of Hospice &amp; Palliative Medicine</i> , 28, 176-82, 2011	Adult population
Silberberg, A. A., Gallo, J. E., Managing end-of-life decisions in critical infants: a survey of neonatologists in Cordoba, Argentina, <i>Acta Paediatrica</i> , 102, e475-7, 2013	Not all participants have a life-limiting condition
Sloan, J. P., Advance directives: patient preferences in family practice, <i>Canadian Family Physician</i> , 36, 876-8, 1990	Adult population
Sneiderman, B., McQuoid-Mason, D., Decision-making at the end of life: the termination of life-prolonging treatment, euthanasia (mercy-killing) and assisted suicide in Canada in South Africa, <i>Comparative &amp; International Law Journal of Southern Africa</i> , 33, 193-209, 2000	Does not meet the study design inclusion criteria

Study	Reason for Exclusion
van der Heide, A., van der Maas, P. J., van der Wal, G., Kollee, L. A., de Leeuw, R., Holl, R. A., The role of parents in end-of-life decisions in neonatology: physicians' views and practices, <i>Pediatrics</i> , 101, 413-8, 1998	Quantitative statistics only
van Thiel, G. J., van Delden, J. J., de Haan, K., Huibers, A. K., Retrospective study of doctors' "end of life decisions" in caring for mentally handicapped people in institutions in The Netherlands, <i>BMJ</i> , 315, 88-91, 1997	Adult population
Walsh-Kelly, C. M., Lang, K. R., Chevako, J., Blank, E. L., Korom, N., Kirk, K., Gray, A., Advance directives in a pediatric emergency department, <i>Pediatrics</i> , 103, 826-30, 1999	Does not meet the study design specified in the inclusion criteria
Weir, R. F., Peters, C., Affirming the decisions adolescents make about life and death, <i>Hastings Center Report</i> , 27, 29-40, 1997	Study design did not meet the inclusion criteria of the review
Wharton, R, Levine, K, Buka, S, Emanuel, L, Advanced Care Planning for Children With Special Health Care Needs: A Survey of Parental Attitudes, <i>Pediatrics</i> , 97, 682-687, 1996	Reported quantitative data and unclear if all children had life-limiting conditions
Wiener, L., Ballard, E., Brennan, T., Battles, H., Martinez, P., Pao, M., How I wish to be remembered: the use of an advance care planning document in adolescent and young adult populations, <i>Journal of Palliative Medicine</i> , 11, 1309-13, 2008	Survey type study with little qualitative data. Also mixed population. Just 45% of participants are between 16-19 years old, and results are not presented separately for them. No further themes identified.
Wiener, L., Battles, H., Zadeh, S., Pao, M., Osherow, J., Development and clinical use of an advance planning document for adolescents and young adults, <i>Pediatric Blood and Cancer</i> , 56 (7), 1163, 2011	Abstract that only reports quantitative data
Wiener, L., Zadeh, S., Wexler, L. H., Pao, M., When silence is not golden: Engaging adolescents and young adults in discussions around end-of-life care choices, <i>Pediatric Blood &amp; Cancer</i> , 60, 715-8, 2013	Study design does not meet the inclusion criteria
Zadeh, S., Pao, M., Wiener, L., Opening end-of-life discussions: how to introduce Voicing My CHOiCESTM, an advance care planning guide for adolescents and young adults, <i>Palliative &amp; Supportive Care</i> , 13, 591-9, 2015	Discussion paper
Zadeh, S., Wiener, L., Pao, M., Helping providers to help adolescents and young adults be involved in end-of-life care: The conversation no one wants to have, <i>Psycho-Oncology</i> , 22, 97-98, 2013	Conference abstract. Abstract does not provide enough information for inclusion in the review
Zhukovsky, D., Robert, R., Levetown, M., Advance care planning with children and adolescents: It's a choice to make! (SA522), <i>Journal of Pain and Symptom Management</i> , 45 (2), 407-408, 2013	Protocol

1 **H.4 Review question: Preferred place of care and place of**  
2 **death**

Reference	Reason for Exclusion
Abarshi, E., Echteld, M., Van den Block, L., Donker, G., Deliens, L., Onwuteaka-Philipsen, B., Transitions between care settings at the end of life in the Netherlands: results from a nationwide study, <i>Palliative Medicine</i> , 24, 166-74, 2010	Cannot determine estimates for participants < 18 years old
Alonso-Babarro, A., Bruera, E., Varela-Cerdeira, M., Boya-Cristia, M. J., Madero, R., Torres-Vigil, I., De Castro, J., Gonzalez-Baron, M., Can this patient be discharged home? Factors associated with at-home death among patients with cancer, <i>Journal of Clinical Oncology</i> , 29, 1159-67, 2011	Only 4 participants < 16 years. Cannot derive estimates from manuscript
Anteneh, A., Araya, T., Misganaw, A., Factors associated with place of death in Addis Ababa, Ethiopia, <i>BMC Palliative Care</i> , 12, 2013	Setting not in high income country and difficult to discern estimates for < 18 years as age group broad
Bell, C. J., Skiles, J., Pradhan, K., Champion, V. L., End-of-life experiences in adolescents dying with cancer, <i>Supportive Care in Cancer</i> , 18, 827-35, 2010	Place of death reported but not preference of place of death
Bluebond-Langner, M., Beecham, E., Candy, B., Langner, R., Jones, L., Preferred place of death for children and young people with life-limiting and life-threatening conditions: a systematic review of the literature and recommendations for future inquiry and policy, <i>Palliative Medicine</i> , 27, 705-13, 2013	Children but also young people up to the age of 25 years were included for this systematic review. Individual studies were cross-checked.
Braun, K. L., Onaka, A. T., Horiuchi, B. Y., End-of-life preferences in Hawaii, <i>Hawaii Medical Journal</i> , 59, 440-6, 2000	Study not in high-income country setting (OECD)
Broad, Joanna B., Gott, Meryn, Kim, Hongsoo, Boyd, Michal, Chen, He, Connolly, Martin J., "Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics": Erratum, <i>International Journal of Public Health</i> , 58, 327, 2013	Participants not < 18 years old
Cavaliere, T., Should neonatal palliative care take place at home, rather than the hospital? Pro, <i>MCN, American Journal of Maternal Child Nursing</i> , 32, 270, 2007	Not relevant
Cawkwell, P. B., Gardner, S. L., Weitzman, M., Persistent racial and ethnic differences in location of death for children with cancer, <i>Pediatric Blood &amp; Cancer</i> , 62, 1403-8, 2015	Preference was not assessed. Not relevant.
Chen, C. H., Lin, Y. C., Liu, L. N., Tang, S. T., Determinants of preference for home death among terminally ill patients with cancer in Taiwan: a cross-sectional survey study, <i>Journal of Nursing Research</i> , 22, 37-44, 2014	Participants not < 18 years
Chvetzoff, G., Garnier, M., Perol, D., Devaux, Y., Lancry, L., Chvetzoff, R., Chalencon, J., Philip, T., Factors predicting home death for terminally ill cancer patients receiving hospital-based home	Participants not < 18 yrs old



Reference	Reason for Exclusion
care: the Lyon comprehensive cancer center experience, <i>Journal of Pain &amp; Symptom Management</i> , 30, 528-35, 2005	
de, Broca Alain, Lutun, Anne, Gourmel, Antoine, Debon, Sophie, Tinot, Thérèse, Peret, Virginie, Devoldère, Catherine, Advance care planning and place of death in a paediatric palliative care unit in France, <i>European Journal of Palliative Care</i> , 23, 16-19, 2016	The study assessed the impact of advance care planning. However no relevant finding on place of care or death was reported.
Dussel, V., Kreicbergs, U., Hilden, J. M., Watterson, J., Moore, C., Turner, B. G., Weeks, J. C., Wolfe, J., Looking beyond where children die: determinants and effects of planning a child's location of death, <i>Journal of Pain &amp; Symptom Management</i> , 37, 33-43, 2009	Study focused on reasons of planning rather than preferences.
Dussel, V., Kreicbergs, U., Hilden, J. M., Watterson, J., Moore, C., Turner, B. G., Weeks, J. C., Wolfe, J., Dussel, Veronica, Kreicbergs, Ulrika, Hilden, M., Watterson, Jan, Moore, Caron, Turner, G., Weeks, C., Wolfe, Joanne, Looking beyond where children die: determinants and effects of planning a child's location of death, <i>Journal of Pain &amp; Symptom Management</i> , 37, 33-44, 2009	The study focused on what determines planning a child's location of death rather than preference.
Escobar Pinzon, L. C., Weber, M., Claus, M., Fischbeck, S., Unrath, M., Martini, T., Munster, E., Factors influencing place of death in Germany, <i>Journal of Pain &amp; Symptom Management</i> , 41, 893-903, 2011	Participants > 18 years old
Escobar, L. C. Lc, Weber, M., Claus, M., Fischbeck, S., Unrath, M., Martini, T., Münster, E., Factors influencing place of death in Germany, <i>Journal of Pain &amp; Symptom Management</i> , 41, 893-904, 2011	Cannot derive estimates for < 18 year olds
Foreman, L. M., Hunt, R. W., Luke, C. G., Roder, D. M., Factors predictive of preferred place of death in the general population of South Australia, <i>Palliative Medicine</i> , 20, 447-53, 2006	Cannot derive estimates for < 18 year olds as age group categories are too broad
Gomes, B., Higginson, I. J., Calanzani, N., Cohen, J., Deliens, L., Daveson, B. A., Bechinger-English, D., Bausewein, C., Ferreira, P. L., Toscani, F., Menaca, A., Gysels, M., Ceulemans, L., Simon, S. T., Pasman, H. R., Albers, G., Hall, S., Murtagh, F. E., Haugen, D. F., Downing, J., Koffman, J., Pettenati, F., Finetti, S., Antunes, B., Harding, R., Prisma,, Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain, <i>Annals of Oncology</i> , 23, 2006-15, 2012	Unable to derive estimates for children due to broad age group
Grande, G., Ewing, G., Informal carer bereavement outcome: Relation to quality of end of life support and achievement of preferred place of death, <i>Palliative Medicine</i> , 23, 248-256, 2009	Participants not < 18 years

Reference	Reason for Exclusion
Heath, J. A., Clarke, N. E., Donath, S. M., McCarthy, M., Anderson, V. A., Wolfe, J., Symptoms and suffering at the end of life in children with cancer: an Australian perspective, <i>Medical Journal of Australia</i> , 192, 71-5, 2010	Not relevant
Hinson, P., Rosoff, M., Where Children Die, <i>Clinical Pediatrics</i> , 55, 101-107, 2016	General discussion paper.
Hunt, J., Shlomo, Natalie, Addington-Hall, Julia, End-of-life care and achieving preferences for place of death in England: Results of a population-based survey using the VOICES-SF questionnaire, <i>Palliative Medicine</i> , 28, 412-422, 2014	Participants not < 18 years
Ko, W., Miccinesi, G., Beccaro, M., Moreels, S., Donker, G. A., Onwuteaka-Philipsen, B., Alonso, T. V., Deliens, L., Van den Block, L., Euro, Impact, Factors associated with fulfilling the preference for dying at home among cancer patients: the role of general practitioners, <i>Journal of Palliative Care</i> , 30, 141-50, 2014	Participants > 18 years old
Ko, Winne, Miccinesi, Guido, Beccaro, Monica, Moreels, Sarah, Donker, A., Onwuteaka-Philipsen, Bregje, Alonso, V., Deliens, Luc, Van, den Lieve, Factors associated with fulfilling the preference for dying at home among cancer patients: the role of general practitioners, <i>Journal of Palliative Care</i> , 30, 141-151, 2014	Participants not < 18 years
Kurashima, A. Y., Latorre, M. R., Teixeira, S. A., De Camargo, B., Factors associated with location of death of children with cancer in palliative care, <i>Palliative &amp; Supportive Care</i> , 3, 115-119, 2005	The study focused on factors associated with location of death, preference was not considered.
Siden, H., Miller, M., Straatman, L., Omesi, L., Tucker, T., Collins, J. J., A report on location of death in paediatric palliative care between home, hospice and hospital, <i>Palliative Medicine</i> , 22, 831-4, 2008	Measured place of death not preference of place of death
von Lutzau, P., Otto, M., Hechler, T., Metzger, S., Wolfe, J., Zernikow, B., Children dying from cancer: parents' perspectives on symptoms, quality of life, characteristics of death, and end-of-life decisions, <i>Journal of Palliative Care</i> , 28, 274-81, 2012	Not relevant
Wilson, D. M., Cohen, J., Deliens, L., Hewitt, J. A., Houttekier, D., The preferred place of last days: results of a representative population-based public survey, <i>Journal of Palliative Medicine</i> , 16, 502-8, 2013	Cannot determine estimates for < 18 years old
Wolff, J., Robert, R., Sommerer, A., Volz-Fleckenstein, M., Impact of a pediatric palliative care program, <i>Pediatric Blood &amp; Cancer</i> , 54, 279-83, 2010	Investigators did not explicitly ask caregivers/parents questions on preference of end of life care or place of death

## 1 H.5 Review question: Organ and tissue donation

Study	Reason for Exclusion
Bailey, N. A., Lay, P., New horizons: infant cardiac transplantation, <i>Heart &amp; Lung</i> , 18, 172-8, 1989	Narrative paper on infant cardiac transplantation, not a qualitative study.
Charles, E., Scales, A., Brierley, J., The potential for neonatal organ donation in a children's hospital, <i>Archives of Disease in Childhood Fetal &amp; Neonatal Edition</i> , 99, F225-9, 2014	Only quantitative descriptive data reported.
Hidalgo, G., Tejani, C., Clayton, R., Clements, P., Distant, D., Vyas, S., Baqi, N., Singh, A., Factors limiting the rate of living-related kidney donation to children in an inner city setting, <i>Pediatric Transplantation</i> , 5, 419-24, 2001	Study carried out among children who received renal donation and transplantation. Only quantitatively descriptive data reported.
Lopez Martinez, J. S., Martin Lopez, M. J., Scandroglio, B., Martinez Garcia, J. M., Family perception of the process of organ donation. Qualitative psychosocial analysis of the subjective interpretation of donor and nondonor families, <i>Spanish Journal of Psychology</i> , 11, 125-36, 2008	Study on adults living with LLCs.
Naim, M. Y., Hoehn, K. S., Hasz, R. D., White, L. S., Helfaer, M. A., Nelson, R. M., The Children's Hospital of Philadelphia's experience with donation after cardiac death, <i>Critical Care Medicine</i> , 36, 1729-33, 2008	Only quantitative data on organ donation completed in a hospital.
Siminoff, L. A., Traino, H. M., Gordon, N. H., An exploratory study of relational, persuasive, and nonverbal communication in requests for tissue donation, <i>Journal of Health Communication</i> , 16, 955-75, 2011	The study quantitatively assessed how relational, persuasive, and non-verbal communication affected consent to tissue donation from decision makers. Deceased patients were children or adults not specified.
Wood, D., Finlay, F., Doctors' knowledge of tissue donation in children, <i>Archives of Disease in Childhood</i> , 95, 926-7, 2010	Only quantitative descriptive data reported.

## 2 H.6 Review question: MDT

Reference	Reason for Exclusion
Baker, J. N., Singhal, S., Yang, J., Wang, C., Kane, J. R., The impact of a consult-based palliative care team on pediatric neuro-oncology patients who died, <i>Neuro-Oncology</i> , 12 (6), ii17, 2010	Conference abstract, unable to locate full article.
Belasco, J. B., Danz, P., Drill, A., Schmid, W., Burkey, E., Supportive care: palliative care in children, adolescents, and young adults--model of care, interventions, and cost of care: a retrospective review, <i>Journal of Palliative Care</i> , 16, 39-46, 2000	Evaluation of a supportive care program to pediatric palliative care, no comparison was made.
Bess, H. N., Richey, M. T., Pickle, E. O., Smith, A. A., End of life for pediatric brain tumor patients: Standardizing communication across disciplines to provide proper care, <i>Neuro-Oncology</i> , 12 (6), ii80, 2010	Conference abstract, unable to locate full article.
Christiansen, N., Pharmacist impact on medicine management and patient safety in paediatric	Conference abstract, unable to locate full article.

Reference	Reason for Exclusion
palliative care, Archives of Disease in Childhood, 99 (8), e3, 2014	
Gorin, S. S., Haggstrom, D., Fairfield, K., Han, P., Krebs, P., Clauser, S. B., Cancer care coordination systematic review and meta-analysis: Twenty-two years of empirical studies, Journal of Clinical Oncology, 1), 2013	Conference abstract, unable to locate full article.
Houttekier, D., Cohen, J., Van den Block, L., Bossuyt, N., Deliens, L., Involvement of palliative care services strongly predicts place of death in Belgium, Journal of Palliative Medicine, 13, 1461-8, 2010	Participants aged between 1 and 85 years were included. No separate results for children were reported.
Hughes, R. E., Thompson, K., Integration of specialist palliative care services into a multidisciplinary adolescent and young adult (AYA) oncology team, Journal of Clinical Oncology, 1), 2014	Conference abstract, unable to locate full article.
Johnson, L. M., Snaman, J. M., Cupit, M. C., Baker, J. N., End-of-life care for hospitalized children, Pediatric Clinics of North America, 61, 835-54, 2014	Discussion paper
Keele, L., Keenan, H. T., Bratton, S. L., The Effect of Palliative Care Team Design on Referrals to Pediatric Palliative Care, Journal of Palliative Medicine, 19, 286-91, 2016	Survey study, the correlation between individual HCP in the team and referral rate was reported, not the composition of the MDT in comparison with another or no MDT as specified in the protocol.
Keele, L., Keenan, H., Bratton, S., The effect of pediatric palliative care team design on referrals to pediatric palliative care, Critical Care Medicine, 1), A177, 2013	Conference abstract, unable to locate full article.
Khan Ghazi, E., Development and implementation of the psycho-oncology department in children cancer hospital using integrative medicine: A multidisciplinary approach, Pediatric Blood and Cancer, 61, S361, 2014	Conference abstract, unable to locate full article.
Knapp, C., Madden, V., Marston, J., Midson, R., Murphy, A., Shenkman, E., Innovative pediatric palliative care programs in four countries, Journal of Palliative Care, 25, 132-6, 2009	Narrative review, no data analysis was carried out.
Knapp, C., Madden, V., Wang, H., Curtis, C., Sloyer, P., Shenkman, E., Music therapy in an integrated pediatric palliative care program, American Journal of Hospice & Palliative Medicine, 26, 449-55, 2009	PICO not met: the study compared the effect of music therapy on children near the end of life against those who were in early stage of pediatric palliative care, wrong comparator.
Mauricio, R. V., Okhuysen-Cawley, R., The caring continuum: role of the pediatric critical care advanced practice nurse in palliative care program development, Critical Care Nursing Quarterly, 33, 292-7, 2010	Discussion paper
Maynard, L., Lynn, D., Innovative approach to providing 24/7 palliative care for children, Nursing Children and Young People, 26, 27-34, 2014	Evaluation of a 24/7 palliative care service, which was not embedded in an MDT program, no comparison, and no time frame.
Remke, S. S., Schermer, M. M., Team collaboration in pediatric palliative care, Journal	Discussion paper

Reference	Reason for Exclusion
Of Social Work In End-Of-Life & Palliative Care, 8, 286-96, 2012	
Schiff, D. E., Kline, C., Auger, J., Willert, J., Roberts, W. D., Reineke, A., Effects of a unique hematology-oncology pediatric palliative care program on medical decision-making and communication between health care providers and families, Journal of Clinical Oncology, 1), 2011	Conference abstract, unable to locate full article.
Strasser, F., Sweeney, C., Willey, J., Benisch-Tolley, S., Palmer, J. L., Bruera, E., Impact of a half-day multidisciplinary symptom control and palliative care outpatient clinic in a comprehensive cancer center on recommendations, symptom intensity, and patient satisfaction: A retrospective descriptive study, Journal of Pain and Symptom Management, 27, 481-491, 2004	The study included participants aged between 17 and 91 years (mean 54 years), no separate results for children and young people were reported.
Vern-Gross, T., Establishing communication within the field of pediatric oncology: a palliative care approach, Current Problems in Cancer, 35, 337-50, 2011	Discussion paper
Vissers, K. C., van den Brand, M. W., Jacobs, J., Groot, M., Veldhoven, C., Verhagen, C., Hasselaar, J., Engels, Y., Palliative medicine update: a multidisciplinary approach, Pain Practice, 13, 576-88, 2013	Discussion paper
Willert, J., Auger, J., Bower, K., Reineke, A., Faircloth, S., Diener, K., Bringier, S., Early integration of a pediatric supportive care program in pediatric oncology, Journal of Pain and Symptom Management, 39 (2), 449, 2010	Conference abstract, unable to locate full article.

## 1 H.7 Review question: End of life care around the clock

Reference	Reason for Exclusion
Bensink, M. E., Armfield, N. R., Pinkerton, R., Irving, H., Hallahan, A. R., Theodoros, D. G., Russell, T., Barnett, A. G., Scuffham, P. A., Wootton, R., Using videotelephony to support paediatric oncology-related palliative care in the home: from abandoned RCT to acceptability study, Palliative Medicine, 23, 228-37, 2009	Acceptability study on the use of videotelephone after 2 abandoned RCTs on the effectiveness of it.
Bensink, M., Armfield, N., Russell, T. G., Irving, H., Wootton, R., Paediatric palliative home care with Internet-based video-phones: lessons learnt, Journal of Telemedicine & Telecare, 10 Suppl 1, 10-3, 2004	Discussion paper
Bradford, N. K., Armfield, N. R., Young, J., Herbert, A., Mott, C., Smith, A. C., Principles of a paediatric palliative care consultation can be achieved with home telemedicine, Journal of Telemedicine & Telecare, 20, 360-4, 2014	Case series studies based on a convenience sample, not 24/7 telemedicine either.
Bradford, N. K., Armfield, N. R., Young, J., Smith, A. C., Paediatric palliative care by video consultation at home: a cost minimisation	Paper on health economics

Reference	Reason for Exclusion
analysis, BMC Health Services Research, 14, 328, 2014	
Bradford, N. K., Young, J., Armfield, N. R., Herbert, A., Smith, A. C., Home telehealth and paediatric palliative care: clinician perceptions of what is stopping us?, BMC Palliative Care, 13, 29, 2014	Qualitative study for background reading
Bradford, N., Armfield, N. R., Young, J., Smith, A. C., The case for home based telehealth in pediatric palliative care: A systematic review, BMC Palliative Care, 12, 2013	Systematic review on home based telehealth to support palliative care families, not 24/7. Included studies checked.
Bradford, N., Irving, H., Smith, A. C., Pedersen, L. A., Herbert, A., Palliative care afterhours: a review of a phone support service, Journal of Pediatric Oncology Nursing, 29, 141-50, 2012	The purpose of the study was to evaluate who used the services and for what reasons.
Bradford, N., Pedersen, L. A., Herbert, A., Irving, H., Palliative care afterhours phone support, who calls and why: A retrospective review of an afterhours phone service, Pediatric Blood and Cancer, 57 (5), 842, 2011	Conference abstract
Bradford, N., Young, J., Armfield, N. R., Bensink, M. E., Pedersen, L., Herbert, A., Smith, A. C., A pilot study of the effectiveness of home teleconsultations in paediatric palliative care, Journal of Telemedicine and Telecare, 18, 438-442, 2012	Descriptive analysis on quality of life for those who received home teleconsultations compared with usual care, not 24/7.
Caruso Brown, A. E., Howard, S. C., Baker, J. N., Ribeiro, R. C., Lam, C. G., Evaluating home-based pediatric palliative care globally: A systematic review, Pediatric Blood and Cancer, 60, 171, 2013	Conference abstract
Centre for Reviews and Dissemination, Impact of home care on hospital days: a meta analysis (Structured abstract), Database of Abstracts of Reviews of Effects, 2015	Studies on paediatric home care were excluded from this review, not relevant.
Chambers, E. J., Oakhill, A., Models of care for children dying of malignant disease, Palliative Medicine, 9, 181-5, 1995	Descriptive paper on care models.
Chi, N. C., Demiris, G., A systematic review of telehealth tools and interventions to support family caregivers, Journal of Telemedicine & Telecare, 21, 37-44, 2015	Systematic review on tele-health tools, individual studies checked.
Deakin, C. D., Evans, S., King, P., Evaluation of telephone-cardiopulmonary resuscitation advice for paediatric cardiac arrest, Resuscitation, 81, 853-856, 2010	The intervention assessed was not 24/7 telephone access, unclear whether children were living with life limiting conditions, no outcome of interest was assessed.
Demiris, G, Oliver, D, Courtney, K, Day, M, Telehospice tools for caregivers: A pilot study, Clinical Gerontologist, 31, 43-57, 2007	Study among adults receiving care in hospices.
Dunn, V., Edwards, C., Boulton, M., The context of respite care, Palliative Medicine, 1), S170, 2010	Conference abstract
Irving, H., Bensink, M., Herbert, A., Bradford, N., Videotelephony: An innovative mode of palliative care service delivery in regional and remote	Conference abstract

Reference	Reason for Exclusion
areas, <i>Pediatric Blood and Cancer</i> , 55 (5), 948, 2010	
Levy, S., Diffusion of innovation: Telehealth for care at home, <i>Studies in Health Technology &amp; Informatics</i> , 216, 963, 2015	Conference poster, discussion on telehealth.
Maynard, L., Lynn, D., Innovative approach to providing 24/7 palliative care for children, <i>Nursing Children and Young People</i> , 26, 27-34, 2014	Qualitative study, evaluation on the 24/7 palliative care (consultant-nurse led service, on-call system available at night and weekends) in the UK.
Schrijnemaekers, V., Courtens, A., Kuin, A., van der Linden, B., Vernooij-Dassen, M., van Zuylen, L., van den Beuken, M., A comparison between telephone and bedside consultations given by palliative care consultation teams in the Netherlands: results from a two-year nationwide registration, <i>Journal of Pain &amp; Symptom Management</i> , 29, 552-8, 2005	Patients who received palliative care were adults.
Spencer, L., Battye, L., Palliative care in the community for children with cancer in South East England, <i>European Journal of Oncology Nursing</i> , 5, 190-198, 2001	Qualitative study for background reading
Steinhorn, D., Dabbs, D., Casavant, D., Chrastek, J., Warren, T., Dimand, R., Enhancing home palliative care for children through telehealth, <i>Journal of Pain and Symptom Management</i> , 47 (2), 397-398, 2014	Conference abstract
Tsimicalis, A., De Courcy, M. J., Di Monte, B., Armstrong, C., Bambury, P., Constantin, J., Dageleman, B., Eves, M., Jansen, P., Honeyford, L., Stregger, D., Tele-practice guidelines for the symptom management of children undergoing cancer treatment, <i>Pediatric Blood and Cancer</i> , 57, 541-548, 2011	Background reading paper for reference checking. Individual studies either included children newly diagnosed with cancer or an overall assessment was made to all (children and adults).
Tuffrey, C., Finlay, F., Lewis, M., The needs of children and their families at end of life: an analysis of community nursing practice, <i>International Journal of Palliative Nursing</i> , 13, 64-71, 2007	The study just described the community nurses' workload 2 months before the child's death, no relevant analysis.
While, A. E., Dyson, L., Characteristics of paediatric home care provision: the two dominant models in England, <i>Child: Care, Health &amp; Development</i> , 26, 263-76, 2000	Discussion paper for background reading
Young, N. L., Bennie, J., Barden, W., Dick, P. T., Tele-Homecare, Team, An examination of quality of life of children and parents during their Tele-Homecare experience, <i>Telemedicine Journal &amp; E-Health</i> , 12, 663-71, 2006	More than 77% of participants were living a chronic condition, not specifically on 24/7 specialist telephone advice either.

## 1 H.8 Review question: Rapid Transfer service delivery

Study	Reason for Exclusion
Brook, L. A., Tewani, K., End of life care in hospital. Scope for paediatric palliative care involvement?, <i>Archives of Disease in Childhood</i> , 100, A153, 2015	Conference abstract

Study	Reason for Exclusion
Crabtree, L., Harrison, C., Hands, S., Wolfendens, A., National survey of transport team involvement in palliative care in the UK, <i>Intensive Care Medicine</i> , 37, S426, 2011	Conference abstract
Doorenbos, A., Lindhorst, T., Starks, H., Aisenberg, E., Curtis, J. R., Hays, R., Palliative care in the pediatric ICU: challenges and opportunities for family-centered practice, <i>Journal Of Social Work In End-Of-Life &amp; Palliative Care</i> , 8, 297-315, 2012	Discussion paper
Dulkerian, S. J., Douglas, W. P., Taylor, R. M., Redirecting treatment during neonatal transport, <i>Journal of Perinatal &amp; Neonatal Nursing</i> , 25, 111-4, 2011	Background reading
Eason, E. B., Castriotta, R. J., Gremillion, V., Sparks, J. W., Withdrawal of life sustaining treatment in children in the first year of life, <i>Journal of Perinatology</i> , 28, 641-5, 2008	Case report on withdrawal of life sustaining treatment
Fraser, L. K., Fleming, T., Miller, M., Draper, E. S., McKinney, P. A., Parslow, R. C., Paediatric Intensive Care Audit, Network, Palliative care discharge from paediatric intensive care units in Great Britain, <i>Palliative Medicine</i> , 24, 608-15, 2010	The paper examined what clinical variables were associated with referral of palliative care, not effect of interventions
<b>Gupta, N., Harrop, E., Lapwood, S., Shefler, A., Journey from pediatric intensive care to palliative care, <i>Journal of Palliative Medicine</i>, 16, 397-401, 2013</b>	Retrospective review
<b>Harrison, C., Hands, S., Crabtree, L., Wolfendens, A., The role of embrace transport service in palliative care transfers, <i>Intensive Care Medicine</i>, 37, S427, 2011</b>	Conference abstract
Howes, C., Caring until the end: a systematic literature review exploring Paediatric Intensive Care Unit end-of-life care, <i>Nursing in Critical Care</i> , 20, 41-51, 2015	Review of qualitative studies, background reading
Jones, J., Job, S., Pal, S., Maynard, L., Curley, A., Clarke, P., The babies who unexpectedly survive long-term after withdrawal of neonatal intensive care, <i>Archives of Disease in Childhood</i> , 99, A196, 2014	Conference abstract
Laddie, J. R. L., Craig, F., Brierley, J., Withdrawal of ventilatory support outside the intensive care unit, <i>Archives of Disease in Childhood</i> , 97, A166-A167, 2012	Background reading
Laddie, J., Craig, F., Brierley, J., Kelly, P., Bluebond-Langner, M., Withdrawal of ventilatory support outside the intensive care unit: guidance for practice, <i>Archives of Disease in Childhood</i> , 99, 812-6, 2014	Background reading
Linebarger, J. S., Ajayi, T. A., Jones, B. L., Adolescents and young adults with life-threatening illness: Special considerations, transitions in care, and the role of pediatric palliative care, <i>Pediatric Clinics of North America</i> , 61, 785-796, 2014	Background reading
McPherson, M. L., Jefferson, L. S., Smith, E. O., Sitler, G. C., Graf, J. M., Reverse transport of children from a tertiary pediatric hospital, <i>Air Medical Journal</i> , 26, 183-7, 2007	Background reading, health economics information
Menon, A. P., Lee, J. H., Loh, L. E., Mok, Y. H., Paediatric palliative transport: A single Centre's experience, <i>Pediatric Critical Care Medicine</i> , 1), 181, 2014	Conference abstract
Nelson, H., Mott, S., Kleinman, M. E., Goldstein, R. D., Parents' Experiences of Pediatric Palliative Transports: A Qualitative Case Series, <i>Journal of Pain &amp; Symptom Management</i> , 50, 375-80, 2015	Background reading
Noyes, J., Edwards, R. T., Hastings, R. P., Hain, R., Totsika, V., Bennett, V., Hobson, L., Davies, G. R., Humphreys, C., Devins, M., Spencer, L. H., Lewis, M., Evidence-based planning and	Paper with health economics information, no information on clinical effectiveness



Study	Reason for Exclusion
costing palliative care services for children: novel multi-method epidemiological and economic exemplar, <i>BMC Palliative Care</i> , 12, 18, 2013	
Pike, A. M., Manual handling the deceased child in a children's hospice, <i>Journal of child health care: for professionals working with children in the hospital and community</i> , 8, 198-209, 2004	Background reading paper.
Pritchard, L. E., Supporting families with end of life decisions in paediatric intensive care, <i>Archives of Disease in Childhood</i> , 97, A155, 2012	Conference abstract
Simpson, E. C., Penrose, C. V., Compassionate extubation in children at hospice and home, <i>International Journal of Palliative Nursing</i> , 17, 164-169, 2011	Qualitative study for background reading
Skaar, A, Juvet, L, Smedslund, G, Bahus, MK, Pedersen, R, Fure, B, End-of-life care - how to find the appropriate level and intensity of medical treatment of seriously ill and dying patients (Structured abstract), <i>Health Technology Assessment Database</i> , 2015	Abstract only
Stenekes, S., Press, C., Plouffe, J., Brown, D., Burge, S., Lambert, D., Veroukis, S., Harlos, M., Transitioning from the pediatric intensive care unit: Withdrawal of life-sustaining treatment in the home (760), <i>Journal of Pain and Symptom Management</i> , 41 (1), 309, 2011	Conference abstract
Straatman, L., Keats, K., Boyer, K., Withdrawal of ventilation in a non-icu setting: More than a procedure, it's a philosophy of care, <i>Paediatrics and Child Health</i> , 15, 62A, 2010	Conference abstract
Tan, H. J., Hughes, M. I., Characteristics of deaths in children with neuromuscular disease, <i>Developmental Medicine and Child Neurology</i> , 51, 52-53, 2009	Conference abstract

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## 3 H.9 Review question: Care based in the child or young 4 person's home

Reference	Reason for Exclusion
Caruso Brown, A. E., Howard, S. C., Baker, J. N., Ribeiro, R. C., Lam, C. G., Evaluating home-based pediatric palliative care globally: A systematic review, <i>Pediatric Blood and Cancer</i> , 60, 171, 2013	Conference abstract. Full paper retrieved but nature is mainly descriptive (asses core elements with respect to availability, gaps, and under-reported aspects of different palliative care services). Also the setting is not relevant (low and middle income countries).
Centre for Reviews and Dissemination, Systematic review of international evidence on the effectiveness and costs of paediatric home care for children and young people who are ill (Structured abstract), <i>Database of Abstracts of Reviews of Effects</i> , 2015	Abstract only. Full paper requested.
Centre for Reviews and Dissemination, Impact of home care on hospital days: a meta analysis (Structured abstract), <i>Database of Abstracts of Reviews of Effects</i> , 2015	Duplicate: abstract only. Same reference as Hughes 1997 (ID. 351174). Original study excluded as it does not include paediatric population.
Chambers, E. J., Oakhill, A., Cornish, J. M., Curnick, S., Terminal care at home for children with cancer, <i>BMJ</i> , 298, 937-40, 1989	Descriptive study. No comparison made.

Reference	Reason for Exclusion
Chong, L. A., Khalid, F., Paediatric palliative care at home: a single centre's experience, Singapore Medical Journal, 57, 77-80, 2016	Descriptive study: case review
Davis, C., Caring for children at home, Nursing Standard, 21, 20-1, 2007	Discussion paper.
Duffy, C. M., Pollock, P., Levy, M., Budd, E., Caulfield, L., Koren, G., Home-based palliative care for children--Part 2: The benefits of an established program, Journal of Palliative Care, 6, 8-14, 1990	Compares with a pilot home-based care project, not home versus hospital care.
Eskola, K., Bergstraesser, E., Zimmermann, K., Cignacco, E., Paediatric end-of-life care in the home care setting (PELICAN HOME)--a mixed methods study protocol, Journal of Advanced Nursing, 71, 204-13, 2015	Qualitative study. Protocol only.
Friedrichsdorf, S. J., Postier, A., Dreyfus, J., Osenga, K., Sencer, S., Wolfe, J., Improved quality of life at end of life related to home-based palliative care in children with cancer, Journal of Palliative Medicine, 18, 143-50, 2015	Duplicate
Gans, D., Kominski, G. F., Roby, D. H., Diamant, A. L., Chen, X., Lin, W., Hohe, N., Better outcomes, lower costs: palliative care program reduces stress, costs of care for children with life-threatening conditions, Policy Brief (Ucla Center for Health Policy Research), 1-8, 2012	Policy brief using descriptive data.
Goldman, A., Beardsmore, S., Hunt, J., Palliative care for children with cancer - Home, hospital, or hospice?, Archives of Disease in Childhood, 65, 641-643, 1990	Descriptive paper. Non-comparative data.
Grande, G. E., Todd, C. J., Barclay, S. I. G., Farquhar, M. C., Does hospital at home for palliative care facilitate death at home? Randomised controlled trial, British Medical Journal, 319, 1472-1475, 1999	Population: adults only
Hansson, H., Schmiegelow, K., Hallstrom, I., Hospital-based home care program for children with cancer: Developing palliative care at home, Pediatric Blood and Cancer, 61, S215, 2014	Conference abstract. Provides descriptive data only.
Hughes, S. L., Ulasevich, A., Weaver, F. M., Henderson, W., Manheim, L., Kubal, J. D., Bonarigo, F., Impact of home care on hospital days: a meta analysis, Health Services Research, 32, 415-32, 1997	This review excludes articles on paediatric home care
Kanaris, C., Yates, R., Morgan, D., Taking a child home to die: The challenges of discharging a patient home for palliative care from the paediatric intensive care unit, Archives of Disease in Childhood, 100, A156, 2015	Conference abstract. No relevant data reported.
Kaye, E. C., Rubenstein, J., Levine, D., Baker, J. N., Dabbs, D., Friebert, S. E., Pediatric palliative care in the community, CA: a Cancer Journal for Clinicians, 65, 316-33, 2015	Discussion paper
Kerr, C. W., Donohue, K. A., Tangeman, J. C., Serehali, A. M., Knodel, S. M., Grant, P. C.,	Mostly adults, data for people under 18 years not reported separately

Reference	Reason for Exclusion
Luczkiewicz, D. L., Mylotte, K., Marien, M. J., Cost savings and enhanced hospice enrollment with a home-based palliative care program implemented as a hospice-private payer partnership, <i>Journal of Palliative Medicine</i> , 17, 1328-35, 2014	
Kerr, W., Donohue, A., Tangeman, C., Serehali, M., Knodel, M., Grant, C., Luczkiewicz, L., Mylotte, Kathleen, Marien, J., Cost Savings and Enhanced Hospice Enrollment with a Home-Based Palliative Care Program Implemented as a Hospice-Private Payer Partnership, <i>Journal of Palliative Medicine</i> , 17, 1328-1336, 2014	Participants were mostly adults. Just 13 out of 686 were between 0 and 50 years old. No separate data for children.
<b>Kuhlen, M., Holl, J. I., Sabir, H., Borkhardt, A., Jansen, G., Experiences in palliative home care of infants with life-limiting conditions, <i>European Journal of Pediatrics</i>, 175, 321-7, 2016</b>	Case series
<b>Levy, M., Duffy, C. M., Pollock, P., Budd, E., Caulfield, L., Koren, G., Home-based palliative care for children--Part 1: The institution of a program, <i>Journal of Palliative Care</i>, 6, 11-5, 1990</b>	Implementation study, non-comparative
Martinson, I. M., Armstrong, G. D., Geis, D. P., Home care for children dying of cancer, <i>Pediatrics</i> , 62, 106-113, 1978	Descriptive study.
Martinson, I. M., Geis, D., Anglim, M. A., Peterson, E., Nesbit, M., Kersey, J., When the patient is dying: home care for the child, <i>American Journal of Nursing</i> , 77, 1815-7, 1977	Case report.
Martinson, I. M., Henry, W. F., Home care for dying children, <i>Hastings Center Report</i> , 10, 5-7, 1980	Analysis of case records.
Mastro, K. A., Johnson, J. E., McElvery, N., Preuster, C., The Benefits of a Nurse-Driven, Patient- and Family-Centered Pediatric Palliative Care Program, <i>The Journal of nursing administration</i> , 45, 423-428, 2015	Descriptive study
Moldow, D. G., Martinson, I. M., From research to reality--home care for the dying child, <i>MCN, American Journal of Maternal Child Nursing</i> , 5, 159-66, 1980	Does not report on outcomes of interest.
Parker, G., Spiers, G., Gridley, K., Atkin, K., Birks, Y., Lowson, K., Light, K., Systematic review of international evidence on the effectiveness and costs of paediatric home care for children and young people who are ill, <i>Child: Care, Health &amp; Development/Child Care Health Dev</i> , 39, 1-19, 2013	SR, but no studies (RCTs) on end-of-life were included.
Postier, A., Chrastek, J., Nugent, S., Osenga, K., Friedrichsdorf, S. J., Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution, <i>Journal of Palliative Medicine</i> , 17, 183-8, 2014	Duplicate (at re-runs). Already included in the review.
<b>Price, J., McNeilly, P., McFarlane, M., Paediatric palliative care in the UK: past,</b>	Discussion paper

Reference	Reason for Exclusion
present and future, <i>International Journal of Palliative Nursing</i> , 11, 124-6, 2005	
Seow, H., Barbera, L., Howell, D., Dy, S. M., Using more end-of-life homecare services is associated with using fewer acute care services: a population-based cohort study, <i>Medical Care</i> , 48, 118-24, 2010	Adults only
Shepperd, Sasha, Doll, Helen, Angus, Robert M., Clarke, Mike J., Iliffe, Steve, Kalra, Lalit, Ricauda, Aimonino Nicoletta, Wilson, Andrew D., Hospital at home admission avoidance, <i>Cochrane Database of Systematic Reviews</i> , 2011	Adult patients only. Not end of life care.
Trigoso, E., Palliative care in paediatric oncology. ADINO programme, <i>Bone Marrow Transplantation</i> , 48, S477-S478, 2013	Abstract only. Descriptive non-comparative study.
Tripathi, S. S., Cantwell, G. P., Ofir, A., Serrecchia, D., Peck, S., Pediatric palliative care in the medical home, <i>Pediatric Annals</i> , 41, 112-116, 2012	Discussion paper

## 1 H.10 Review question: Emotional and psychological support and interventions

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Reference	Reason for Exclusion
Adams, M. A., A hospital play program: helping children with serious illness, <i>American Journal of Orthopsychiatry</i> , 46, 416-24, 1976	Study type and intervention: play therapy programme, without a clear psycho-therapeutic content. Only cases are reported.
Aho, Anna Liisa, Tarkka, Marja-Terttu, Astedt-Kurki, Paivi, Sorvari, Leena, Kaunonen, Marja, Evaluating a bereavement follow-up intervention for grieving fathers and their experiences of support after the death of a child-a pilot study, <i>Death Studies</i> , 35, 879-904, 2011	Interventions in this study were provided by peers and HCPs, not registered or regulated professionals. Causes of child's death were not LLCs (66% still birth. Regarding fathers' experience, only quantitative descriptive data were reported.
Akechi, T., Psychotherapy for depression among patients with advanced cancer, <i>Japanese Journal of Clinical Oncology</i> , 42, 1113-9, 2012	Study design: review, non-systematic
Akechi, Tatsuo, Okuyama, Toru, Onishi, Joji, Morita, Tatsuya, Furukawa, Toshi A., Psychotherapy for depression among incurable cancer patients, <i>Cochrane Database of Systematic Reviews</i> , 2013	Population: adult patients only
Allen, R. S., Harris, G. M., Burgio, L. D., Azuero, C. B., Miller, L. A., Shin, H. J., Eichorst, M. K., Csikai, E. L., DeCoster, J., Dunn, L. L., Kvale, E., Parmelee, P., Can senior volunteers deliver reminiscence and creative activity interventions? Results of the legacy intervention family enactment randomized controlled trial, <i>Journal of Pain &amp; Symptom Management</i> , 48, 590-601, 2014	Population: adult patients 55
Alvarado-Aguilar, S., Guerra-Cruz, H. G., Cupil-Rodriguez, A. L., Calderillo-Ruiz, G., Onate-Ocana, L. F., [Psychosocial adjustment in colorectal cancer patients undergoing	Paper in Spanish.

Reference	Reason for Exclusion
chemotherapy or chemoradiotherapy], Cirugia y Cirujanos, 79, 439-46, 2011	
Andersen, B. L., Psychological interventions for cancer patients to enhance the quality of life, Journal of Consulting & Clinical Psychology, 60, 552-68, 1992	Study design: review, non-systematic.
Anonymous,, How do you talk to a dying child?, Resident & Staff Physician, 24, 143, 147, 1978	Discussion paper
Askins, M. A., Sahler, O. J., Sherman, S. A., Fairclough, D. L., Butler, R. W., Katz, E. R., Dolgin, M. J., Varni, J. W., Noll, R. B., Phipps, S., Report from a multi-institutional randomized clinical trial examining computer-assisted problem-solving skills training for English- and Spanish-speaking mothers of children with newly diagnosed cancer, Journal of Pediatric Psychology, 34, 551-63, 2009	Population: children newly diagnosed with cancer (Cochrane RS).
Barling, J. A., Stevens, J., Davis, K. M., Family members' retrospective stories of the treatment stage of an adolescent or young adult who subsequently died of cancer, Cancer Nursing, 36, E39-48, 2013	Aim of the study not related to the protocol. This article aimed to uncover from the stories of family members the experience after the treatment of an adolescent or young adult family member (aged 13-23 years) who subsequently died. It does not specifically address psychological interventions. Includes mixed population.
Barlow, J. H., Ellard, D. R., Psycho-educational interventions for children with chronic disease, parents and siblings: an overview of the research evidence base, Child: Care, Health & Development, 30, 637-45, 2004	Population: SR of interventions for children with chronic diseases, not palliative or end of life care.
Bartell, A. S., Kissane, D. W., Issues in pediatric palliative care: understanding families, Journal of Palliative Care, 21, 165-72, 2005	Study design: review, discussion paper. Individual references were checked for relevance.
Beccaro, M., Di Leo, S., Morasso, G., Costantini, M., Psychological distress during the last three months of life of Italian cancer patients. Results from the Italian Survey of the Dying of Cancer (ISDOC), Minerva Psichiatrica, 49, 1-8, 2008	Populations: adults only
Belletti, M., Mallia, L., Lucidi, F., Reichmann, S., Mastroianni, C., De Marinis, M. G., Casale, G., Complementary therapy and support services for formal and informal caregivers in Italian palliative care hospices: an exploratory and descriptive study, Supportive Care in Cancer, 19, 1939-47, 2011	Population: this study includes formal and informal caregivers in palliative care hospitals, but the age of the patients is undefined. Family or cares of ICYP are not discussed or addressed separately. Also the study reports purely qualitative descriptive data.
Bentley, B., O'Connor, M., Breen, L. J., Kane, R., Feasibility, acceptability and potential effectiveness of dignity therapy for family carers of people with motor neurone disease, BMC Palliative Care, 13, 12, 2014	Population: family carers of adults with MND.
Bentley, B., O'Connor, M., Kane, R., Breen, L. J., Feasibility, acceptability, and potential effectiveness of dignity therapy for people with motor neurone disease, PLoS ONE, 9, 2014	Population: participants over 18 years old
Bernstein, Paula P., Duncan, S., Gavin, Leslie A., Lindahl, Kristin M., Ozonoff, Sally, Resistance to psychotherapy after a child dies:	Study design: review, non-systematic cases

Reference	Reason for Exclusion
The effects of the death on parents and siblings, <i>Psychotherapy: Theory, Research, Practice, Training</i> , 26, 227-232, 1989	
Berti, Gustavo, Berti, Alicia Schneider, When an offspring dies: Logotherapy in bereavement groups, <i>International Forum for Logotherapy</i> , 17, 65-69, 1994	Study design: discussion paper
Best, Elizabeth K., VanDevere, Chris, The hidden family grief: An overview of grief in the family following perinatal death, <i>International Journal of Family Psychiatry</i> , 7, 419-437, 1986	Study design: review, non-systematic
Beynon, T., Radcliffe, E., Child, F., Orlowska, D., Whittaker, S., Lawson, S., Selman, L., Harding, R., What are the supportive and palliative care needs of patients with cutaneous T-cell lymphoma and their caregivers? A systematic review of the evidence, <i>British Journal of Dermatology</i> , 170, 599-608, 2014	Population: adults defined as age > 18 years old
Binger, Charles M., Psychosocial intervention with the child cancer patient and family, <i>Psychosomatics: Journal of Consultation and Liaison Psychiatry</i> , 25, 899-902, 1984	Discussion paper
Black, Dora, Urbanowicz, M., Family intervention with bereaved children, <i>Child Psychology &amp; Psychiatry &amp; Allied Disciplines</i> , 28, 467-476, 1987	Aim and population of the study not relevant to the protocol. This paper describes and intervention study carried out with 45 families (83 children) where one of the parents died.
Brem, A. S., Brem, F. S., McGrath, M., Spirito, A., Psychosocial characteristics and coping skills in children maintained on chronic dialysis, <i>Pediatric Nephrology</i> , 2, 460-5, 1988	Aim and intervention of this study is not related to the protocol. This paper is not about psychological interventions or needs.
Brown, M. R., Sourkes, B., Psychotherapy in pediatric palliative care, <i>Child &amp; Adolescent Psychiatric Clinics of North America</i> , 15, 585-96, viii, 2006	Not a qualitative study (no study objective, data collection or analysis involved).
Callahan, Alexandria B., The parent should go first: A dance/movement therapy exploration in child loss, <i>American Journal of Dance Therapy</i> , 33, 182-195, 2011	Study design: review, non-systematic. Individual references were checked for relevance.
Capitulo, Kathleen Leask, Evidence for healing interventions with perinatal bereavement, <i>MCN: The American Journal of Maternal/Child Nursing</i> , 30, 389-396, 2005	Aim of the study not related to the protocol. The purpose of this article is to explore the concept of perinatal grief and evidence-based healing interventions for it. The paper does not specifically address psychological interventions.
Carlson, Kenneth M., Brumback, Roger A., Psychological processes associated with premature death in Duchenne muscular dystrophy, <i>Psychological Reports</i> , 52, 165-166, 1983	Discussion paper
Carr, D., Goudas, L., Lawrence, D., Pirl, W., Lau, J., DeVine, D., Kupelnick, B., Miller, K., Management of cancer symptoms: pain, depression, and fatigue, <i>Evidence Report: Technology Assessment (Summary)</i> , 1-5, 2002	This is a full HTA report. It does not include evidence on psychological interventions carried out with ICYP with LLC and/or their families or carers.
Carr, T., Keeping-Burke, L., Hansen, L., Lang, A., Duhamel, F., Fleischer, A., Aston, M., Primary bereavement care across health care settings	Systematic review protocol

Reference	Reason for Exclusion
and contexts: A systematic review protocol of qualitative evidence, JBI Database of Systematic Reviews and Implementation Reports, 11, 88-99, 2013	
Cates, Jim A., Grief therapy in residential treatment: A model for intervention, Child Care Quarterly, 15, 147-158, 1986	Study design: review, non-systematic, and case studies
Choi, Yoon Kyung, The effect of music and muscle relaxation on anxiety, fatigue, and quality of life in family caregivers of hospice patients, Journal of Music Therapy, 47, 53-69, 2010	Population: This study includes family caregivers of hospice patients. The relationship with the patient was spouse (62%) or adult child (38%). Definition of adult child is not provided. Data for family caregivers of adult children is not provided separately.
Currier, J.M., Holland, J.M., Neimeyer, R.A., Do CBT-based interventions alleviate distress following bereavement? A review of the current evidence, International Journal of Cognitive Therapy, 3, 77-93, 2010	Population: This is a review (systematic??) to evaluate the degree to which CBT-based interventions improved psychological adjustment to bereavement compared to other commonly practiced therapies and no-treatment. Age of the death person is not specified as inclusion or exclusion criteria, but results for family carers of children are not provided separately.
Curtis, J. R., Ciechanowski, P. S., Downey, L., Gold, J., Nielsen, E. L., Shannon, S. E., Treece, P. D., Young, J. P., Engelberg, R. A., Development and evaluation of an interprofessional communication intervention to improve family outcomes in the ICU, Contemporary Clinical Trials, 33, 1245-54, 2012	Aim of the study not related to the protocol. This paper describes the development and evaluation of an intervention designed to improve the quality of care in the ICU by improving communication among the ICU team and with family members of critically ill patients.
D'Agostino, N. M., Edelstein, K., Psychosocial challenges and resource needs of young adult cancer survivors: implications for program development, Journal of Psychosocial Oncology, 31, 585-600, 2013	Population: young adults over 18 years old
Davies, B., Collins, J., Steele, R., Cook, K., Distler, V., Brenner, A., Parents' and children's perspectives of a children's hospice bereavement program, Journal of Palliative Care, 23, 14-23, 2007	Intervention and results: the intervention is run by nurses of family support volunteers, and it not specified that it has a psychological content. Results are mostly descriptive.
de Vries, Marco J., Schilder, Johannes N., Mulder, Cornelis L., Vrancken, Adriana M., Remie, Margot E., Garszen, Bert, Phase II study of psychotherapeutic intervention in advanced cancer, Psycho-Oncology, 6, 129-137, 1997	Population: mixed population, mostly adults (mean age 52 years, range 16 to 76 years). Results for under 18 year old are not provided separately.
Duncan, Janet, Joselow, Marsha, Hilden, Joanne M., Program Interventions for Children at the End of Life and Their Siblings, Child and Adolescent Psychiatric Clinics of North America, 15, 739-758, 2006	Review, non-systematic
Eccleston, Christopher, Fisher, Emma, Law, Emily, Bartlett, Jess, Palermo, Tonya M., Psychological interventions for parents of children and adolescents with chronic illness, Cochrane Database of Systematic Reviews, 2015	Population: this Cochrane SR includes parents of children with a chronic illness, not end of life care. Individual studies have been retrieved for assessment.
Elda, C., The use of multiple group therapy in support groups for grieving families: a model of bereavement support for a hospice program,	Protocol for a study.

Reference	Reason for Exclusion
American Journal of Hospice Care, 3, 27-31, 1986	
Freeman, K., O'Dell, C., Meola, C., Childhood brain tumors: children's and siblings' concerns regarding the diagnosis and phase of illness, Journal of Pediatric Oncology Nursing, 20, 133-40, 2003	Aim of the study not related to the protocol. The objective of this study was to identify commonly reported problems and helpful resources important to children with brain or spinal cord tumors and siblings during phases of illness. There is no specific information in relation to psychological needs.
Galway, Karen, Black, Amanda, Cantwell, Marie, Cardwell, Chris R., Mills, Moyra, Donnelly, Michael, Psychosocial interventions to improve quality of life and emotional wellbeing for recently diagnosed cancer patients, Cochrane Database of Systematic Reviews, 2015	Population: adults, 18 years old
Garlan, R., Butler, L., Rosenbaum, E., Siegel, A., Spiegel, D., Perceived benefits and psychosocial outcomes of a brief existential family intervention for cancer patients/survivors, Omega: Journal of Death and Dying, 62, 243-268, 2010	Population: adults 18
Gerber, Marcelle, The physician, the child and death: Fear of death during the course of psychotherapy of children, Revue de Medecine Psychosomatique et de Psychologie Medicale, 10, 419-423, 1968	Paper in French
Gerhardt, C. A., Fairclough, D. L., Grossenbacher, J. C., Barrera, M., Gilmer, M. J., Foster, T. L., Compas, B. E., Davies, B., Hogan, N. S., Vannatta, K., Peer relationships of bereaved siblings and comparison classmates after a child's death from cancer, Journal of Pediatric Psychology, 37, 209-19, 2012	Aim of the study: this study compares bereaved siblings with controls. No psychological intervention is given to any of the groups.
Goldstein, J., Alter, C. L., Axelrod, R., A psychoeducational bereavement-support group for families provided in an outpatient cancer center, Journal of Cancer Education, 11, 233-7, 1996	Population. This study includes bereaved adults. The age of the loss patients is not specified as such, but the description of the sample implies that mostly, if not only, relatives of adult patients were included. "The bereavement group consisted of 7 adults. The relationship to the deceased varied, 3 spouses, 2 siblings, and 1 couple whose adult daughter died."
Green, Eric J., Connolly, Marianne E., Jungian family sandplay with bereaved children: Implications for play therapists, International Journal of Play Therapy, 18, 84-98, 2009	Study design: review, non-systematic
Greer, S., Moorey, S., Baruch, J., Evaluation of adjuvant psychological therapy for clinically referred cancer patients, British Journal of Cancer, 63, 257-60, 1991	Population: adults only (mean 47.9, range 17 to 77)
Griffith, Toni, Assisting with the "big hurts, little tears" of the youngest grievors: Working with three-, four-, and five-year-olds who have experienced loss and grief because of death, Illness, Crisis, & Loss, 11, 217-225, 2003	Discussion paper
Harding, R., Higginson, I. J., Leam, C., Donaldson, N., Pearce, A., George, R., Robinson, V., Taylor, L., Evaluation of a short-	Population: This study includes informal carers of patients attending a home palliative care



Reference	Reason for Exclusion
term group intervention for informal carers of patients attending a home palliative care service, <i>Journal of Pain and Symptom Management</i> , 27, 396-408, 2004	service. The age of the patients is not specified, but just 11% were parents.
Harper, Gary W., A developmentally sensitive approach to clinical hypnosis for chronically and terminally ill adolescents, <i>American Journal of Clinical Hypnosis</i> , 42, 50-60, 1999	Study design: review and case samples
Heffron, W. A., Bommelaere, K., Masters, R., Group discussions with the parents of leukemic children, <i>Pediatrics</i> , 52, 831-840, 1973	Intervention: group discussion without a specific psychological content
Henriksson, A., Arestedt, K., Benzein, E., Ternestedt, B. M., Andershed, B., Effects of a support group programme for patients with life-threatening illness during ongoing palliative care, <i>Palliative Medicine</i> , 27, 257-64, 2013	Population: family members of patients with a LLC. Only 6.4% of participants in the intervention group were parents. Age of patients unknown.
Henriksson, A., Benzein, E., Ternestedt, B. M., Andershed, B., Meeting needs of family members of persons with life-threatening illness: a support group program during ongoing palliative care, <i>Palliative &amp; Supportive Care</i> , 9, 263-71, 2011	Population: this study includes family members of people leaving with a LLC. It is a mixed population, and data is not provided separately for parents.
Herschbach, P., [Psychotherapeutic and psychosocial interventions in cancer], <i>Nervenarzt</i> , 86, 274, 276-8, 280-1, 2015	Paper is published in German language.
Hill, F., Palliative care in the young, <i>Practitioner</i> , 234, 292-6, 1990	Discussion paper.
Hoekstra-Weebers, J. E., Heuvel, F., Jaspers, J. P., Kamps, W. A., Klip, E. C., Brief report: an intervention program for parents of pediatric cancer patients: a randomized controlled trial, <i>Journal of Pediatric Psychology</i> , 23, 207-14, 1998	Population: the parents of children with short-life expectancy were excluded from the study.
Hoffman, I., Futterman, E. H., Coping with waiting: psychiatric intervention and study in the waiting room of a pediatric oncology clinic, <i>Comprehensive Psychiatry</i> , 12, 67-81, 1971	Descriptive paper
Holm, M., Carlander, I., Furst, C. J., Wengstrom, Y., Arestedt, K., Ohlen, J., Henriksson, A., Delivering and participating in a psycho-educational intervention for family caregivers during palliative home care: a qualitative study from the perspectives of health professionals and family caregivers, <i>BMC Palliative Care</i> , 14, 16, 2015	Population: this study includes family caregivers during palliative home care, but the age of the patients is undefined. Family or carers of ICYP are not discussed or addressed separately.
Hopmeyer, Estelle, Werk, Annette, A comparative study of family bereavement groups, <i>Death Studies</i> , 18, 243-256, 1994	Population: this study includes three groups: widows, family survivors of suicide, and family survivors (other than parents) of the death of a family member by cancer. The third group does not indicate if it includes siblings of ICYP with a LLC.
Hudson, P. L., Aranda, S., Hayman-White, K., A psycho-educational intervention for family caregivers of patients receiving palliative care: a randomized controlled trial, <i>Journal of Pain and Symptom Management</i> , 30, 329-41, 2005	Population: this study includes family caregivers, but no patients were under 31 years of age

Reference	Reason for Exclusion
Hudson, P. L., Remedios, C., Thomas, K., A systematic review of psychosocial interventions for family carers of palliative care patients, <i>BMC Palliative Care</i> , 9, 17, 2010	Population: this is a systematic review of psychosocial interventions for family carers of palliative care patients, but the age of the patients is undefined. Family or carers of ICYP are not discussed or addressed separately.
Hudson, P., Aranda, S., The Melbourne Family Support Program: evidence-based strategies that prepare family caregivers for supporting palliative care patients, <i>BMJ supportive &amp; palliative care</i> , 4, 231-7, 2014	Population: this study includes family caregivers of palliative care patients, but the age of the patients is undefined. Family or carers of ICYP are not discussed or addressed separately.
Hudson, P., Trauer, T., Kelly, B., O'Connor, M., Thomas, K., Summers, M., Zordan, R., White, V., Reducing the psychological distress of family caregivers of home-based palliative care patients: Short-term effects from a randomised controlled trial, <i>Psycho-Oncology</i> , 22, 1987-93, 2013	Population: This study includes family caregivers of home-based palliative care patients. The relationship with the patient is not indicated. Data for family caregivers of ICYP patients is not reported separately (if any).
Hudson, P., Trauer, T., Kelly, B., O'Connor, M., Thomas, K., Zordan, R., Summers, M., Reducing the psychological distress of family caregivers of home based palliative care patients: longer term effects from a randomised controlled trial, <i>Psycho-Oncology</i> , 24, 19-24, 2015	Population: this study includes family caregivers of home based palliative care patients, but the age of the patients is undefined. Family or carers of ICYP are not discussed or addressed separately.
Jones, G., Complementary and psychological therapies in a rural hospital setting, <i>International Journal of Palliative Nursing</i> , 13, 184-9, 2007	Review, non-systematic
Kars, M. C., Grypdonck, M. H., van Delden, J. J., Being a parent of a child with cancer throughout the end-of-life course, <i>Oncology Nursing Forum</i> , 38, E260-71, 2011	Aim of the paper not related to the protocol. This study aims to elucidate parents' experiences when caring at home for their child with incurable cancer and to show how parents give meaning to their experiences throughout the end-of-life phase. Psychological needs and interventions are not specifically addressed.
Kato, P.M., Mann, T., A synthesis of psychological interventions for the bereaved, <i>Clinical Psychology Review</i> , 19, 275-296, 1999	Population: This is a qualitative and quantitative review (systematic?), but age of patients is not specified. Results for ICYP and/ or their carers are not provided separately. Individual references were checked for relevance.
Keall, R. M., Clayton, J. M., Butow, P. N., Therapeutic life review in palliative care: a systematic review of quantitative evaluations, <i>Journal of Pain &amp; Symptom Management</i> , 49, 747-61, 2015	Population: adults
Kim, Y., Lucette, A., Loscalzo, M., Bereavement needs of adults, children, and families after cancer, <i>Cancer Journal (United States)</i> , 19, 444-457, 2013	Study type and population: this is a non-systematic review and includes mixed populations. Individual studies were checked for inclusion.
Koch, U., Muthny, F. A., Quality of life in patients with end-stage renal disease in relation to the method of treatment, <i>Psychotherapy &amp; Psychosomatics</i> , 54, 161-71, 1990	Population: mixed population, mostly adults.
Kogler, M., Brandstatter, M., Borasio, G. D., Fensterer, V., Kuchenhoff, H., Fegg, M. J., Mindfulness in informal caregivers of palliative patients, <i>Palliative &amp; Supportive Care</i> , 13, 11-8, 2015	Population: this study includes informal caregivers of palliative care patients. Just 3.1% of the total sample (n=130) were parents of children.

Reference	Reason for Exclusion
Kopel, K., Mock, L. A., The use of group sessions for the emotional support of families of terminal patients, <i>Death Education</i> , 1, 409-22, 1978	Discussion paper.
Kornfeld, Marcia S., Siegel, Irwin M., Parental group therapy in the management of a fatal childhood disease, <i>Health &amp; Social Work</i> , 4, 99-118, 1979	Intervention: this study describes a parental group therapy, but not a specifically a psychological therapy. It does not focus on psychological needs either.
Krieger, G., Bascue, L., Terminal illness: Counseling with a family perspective, <i>The Family Coordinator</i> , 24, 351-355, 1975	Discussion paper.
LaGrand, Louis E., The nature and therapeutic implications of the extraordinary experiences of the bereaved, <i>Journal of Near-Death Studies</i> , 24, 3-20, 2005	Discussion paper.
Lane, C., Mason, J., Meeting the needs of siblings of children with life-limiting illnesses, <i>Nursing Children and Young People</i> , 26, 16-20, 2014	Discussion paper
Lascari, Andre, The dying child and the family, <i>The Journal of Family Practice</i> , 6, 1279-1286, 1978	Discussion paper.
Law, D, Demonstrating clinical outcomes and psychological well-being in children, young people and families, <i>Child and family clinical psychology review</i> , 1, 1-3, 2013	Editorial
Leighton, Sharon, Bereavement therapy with adolescents: Facilitating a process of spiritual growth, <i>Journal of Child and Adolescent Psychiatric Nursing</i> , 21, 24-34, 2008	Study design: case reports
Levac, Anne Marie C., McLean, Sue, Wright, Lorraine M., Bell, Janice M., A "reader's theater" intervention to managing grief: Posttherapy reflections by a family and clinical team, <i>Journal of Marital and Family Therapy</i> , 24, 81-93, 1998	Study design: case study
Llewelyn, S., Murray, A., Johnston, M., Johnston, D., Preece, P., Dewar, J., Group therapy for metastatic cancer patients: Report of an intervention, <i>Psychology, Health &amp; Medicine</i> , 4, 229-240, 1999	Population: women with breast cancer
Lovrin, Mellen, Interpersonal support among 8-year-old girls who have lost their parents or siblings to AIDS, <i>Archives of Psychiatric Nursing</i> , 9, 92-98, 1995	Population and intervention: this study includes girls that have lost their parents or siblings to AIDS. Data is not provided separately. The intervention evaluated is bibliotherapy and it is not clear that it has a psycho-therapeutic content in it, nor who runs the intervention.
Macleod, A. D., Psychotherapy at the end of life: Psychodynamic contributions, <i>Progress in Palliative Care</i> , 17, 3-12, 2009	Discussion paper.
Marsland, A. L., Long, K. A., Howe, C., Thompson, A. L., Tersak, J., Ewing, L. J., A pilot trial of a stress management intervention for primary caregivers of children newly diagnosed with cancer: preliminary evidence that perceived social support moderates the psychosocial	Population: children newly diagnosed with cancer (Cochrane RS).

Reference	Reason for Exclusion
benefit of intervention, <i>Journal of Pediatric Psychology</i> , 38, 449-61, 2013	
Mathyssek, C. M., Olino, T. M., Hartman, C. A., Ormel, J., Verhulst, F. C., Van Oort, F. V., Does the Revised Child Anxiety and Depression Scale (RCADS) measure anxiety symptoms consistently across adolescence? The TRAILS study, <i>International Journal of Methods in Psychiatric Research</i> , 22, 27-35, 2013	Aim not related to the protocol: this study aims to assess the usefulness of the Revised Child Anxiety and Depression scale, and does not include a psychological intervention.
McMillan, S. C., Small, B. J., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L., Haley, W. E., Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial, <i>Cancer</i> , 106, 214-22, 2006	Populations: this study includes caregivers of adult patients with cancer.
Milberg, A., Olsson, E. C., Jakobsson, M., Olsson, M., Friedrichsen, M., Family Members' Perceived Needs for Bereavement Follow-Up, <i>Journal of Pain and Symptom Management</i> , 35, 58-69, 2008	Population: This study includes bereaved family members. Only 37 out of 248 participants had a parent-child relationship. Child age was not specify either.
Miller, D. K., Chibnall, J. T., Videen, S. D., Duckro, P. N., Supportive-affective group experience for persons with life-threatening illness: Reducing spiritual, psychological, and death-related distress in dying patients, <i>Journal of Palliative Medicine</i> , 8, 333-343, 2005	Population: this study includes adult persons with LLC.
Mirosevic, J. K., Giljevic, J. S., Miholic, D., Complementary supportive therapy for a child in rehabilitation and palliative care, <i>Libri Oncologici</i> , 39, 31-35, 2011	The aim, methods and results of this study are described very vaguely. The study describes the use of a complementary supportive therapy (TEMAS, tell me a story) for children in rehabilitation and palliative care. It is not clear who delivered the therapy. Results are describe narratively only and are very vague. None of the outcomes of interests are included in the study.
Moules, Nancy J., Simonson, Kari, Fleiszer, Andrea R., Prins, Mark, Glasgow, Bob, The Soul of Sorrow Work: Grief and Therapeutic Interventions with Families, <i>Journal of Family Nursing</i> , 13, 117-141, 2007	Population: This is a review (non-systematic) and qualitative study. It includes 6 family members who had lost a relative, including a child (n not indicated). Quotes do not specify age of the loss patient. Individual references were checked for relevance.
Mulhern, R. K., Lauer, M. E., Hoffmann, R. G., Death of a child at home or in the hospital: subsequent psychological adjustment of the family, <i>Pediatrics</i> , 71, 743-7, 1983	Aim of the study not related to the protocol. This study evaluates the difference in psychological adjustment following patient's death at home or hospital
Mullins, L. L., Fedele, D. A., Chaffin, M., Hullmann, S. E., Kenner, C., Eddington, A. R., Phipps, S., McNall-Knapp, R. Y., A clinic-based interdisciplinary intervention for mothers of children newly diagnosed with cancer: a pilot study, <i>Journal of Pediatric Psychology</i> , 37, 1104-15, 2012	Population: children newly diagnosed with cancer (Cochrane RS).
Murray, Judith A., Terry, Deborah J., Vance, John C., Battistutta, D., Connolly, Y., Effects of a program of intervention on parental distress following infant death, <i>Death Studies</i> , 24, 275-305, 2000	Causes of child's death are still birth, neonatal death including SIDs. Proportions of babies died of LLCs were not reported nor could be ascertained.

Reference	Reason for Exclusion
Nicholas, D. B., Picone, G., Selkirk, E. K., The lived experiences of children and adolescents with end-stage renal disease, <i>Qualitative Health Research</i> , 21, 162-73, 2011	Aim of the study not related to the protocol. The study aims to describe the experiences and perceptions of children with End Stage Renal Disease. There is no focus on psychological needs and/ or interventions.
Nuss, S. L., Redefining parenthood: surviving the death of a child, <i>Cancer Nursing</i> , 37, E51-60, 2014	Aim of this study not related to the protocol. This study aims to evaluate how parents of children in the advanced stage of a LLC trajectory communicated about death. It does not address psychological needs and/ or interventions.
Ogrodniczuk, John S., Joyce, Anthony S., Piper, William E., Changes In Perceived Social Support After Group Therapy for Complicated Grief, <i>Journal of Nervous and Mental Disease</i> , 191, 524-530, 2003	Population: this study includes adults with a diagnosed psychiatric disorder due to complicated grief. Also only 7% had lost a child and data is not reported separately.
Ogrodniczuk, John S., Piper, William E., Joyce, Anthony S., McCallum, Mary, Rosie, John S., Social support as a predictor of response to group therapy for complicated grief, <i>Psychiatry: Interpersonal and Biological Processes</i> , 65, 346-357, 2002	Population: this study includes adults with a diagnosed psychiatric disorder due to complicated grief. Also only 8% had lost a child and data is not reported separately.
Poznanski, E. O., Miller, E., Salguero, C., Kelsh, R. C., Quality of life for long-term survivors of end-stage renal disease, <i>JAMA</i> , 239, 2343-7, 1978	Aim of the study not related to the protocol. This paper describes the psychological adaptation of children and adolescents who survive end-stage renal failure. No psychological interventions are evaluated.
Raitio, Katja, Kaunonen, Marja, Aho, Anna Liisa, Evaluating a bereavement follow-up intervention for grieving mothers after the death of a child, <i>Scandinavian Journal of Caring Sciences</i> , 29, 510-520, 2015	This was a before-after comparison study assessing the effect of a grief intervention among parents who just lost their child. Intervention was delivered by trained hospital practitioners (not registered or regulated professional). The study didn't report the cause of death of deceased child either.
Ramirez Johnson, M., Mental health interventions with medically ill children: A review of the literature 1970-1977, <i>Journal of Pediatric Psychology</i> , 4, 147-164, 1979	Study type: review, non-systematic. Individual references were checked for inclusion.
Renz, M., Mao, M. S., Bueche, D., Cerny, T., Strasser, F., Dying is a transition, <i>American Journal of Hospice &amp; Palliative Medicine</i> , 30, 283-90, 2013	Population: adults only, age range: 21 to 86
Romanoff, Bronna D., When a child dies: Special considerations for providing mental health counseling for bereaved parents, <i>Journal of Mental Health Counseling</i> , 15, 384-393, 1993	Review, non-systematic. Discussion paper
Rosen, Elliott J., Family therapy in cases of interminable grief for the loss of a child, <i>Omega: Journal of Death and Dying</i> , 19, 187-202, 1988	Study type and intervention. This paper reports on cases of parents where grieving for the death of the child extends beyond normal parameters.
Rosner, R., Kruse, J., Hagl, M., A meta-analysis of interventions for bereaved children and adolescents, <i>Death Studies</i> , 34, 99-136, 2010	Individual studies were checked. Only one Ph.D dissertation (Webb-Ferebee, 2003) include children whose siblings deceased. However causes of siblings' death not reported.
Rueda, JoseRamon, Sola, Ivan, Pascual, Antonio, Subirana Casacuberta, Mireia, Non-invasive interventions for improving well-being and quality of life in patients with lung cancer,	Population: this is a Cochrane SR aimed at assessing the effectiveness on non-invasive interventions delivered by healthcare professionals in improving symptoms,

Reference	Reason for Exclusion
Cochrane Database of Systematic Reviews, 2015	psychological functioning and quality of life in patients with lung cancer. It includes patients of any age, but results are not reported separately for children. References were checked for relevance.
Sahler, O. J., Dolgin, M. J., Phipps, S., Fairclough, D. L., Askins, M. A., Katz, E. R., Noll, R. B., Butler, R. W., Specificity of problem-solving skills training in mothers of children newly diagnosed with cancer: results of a multisite randomized clinical trial, <i>Journal of Clinical Oncology</i> , 31, 1329-35, 2013	Population: children newly diagnosed with cancer.
Sahler, O. J., Fairclough, D. L., Phipps, S., Mulhern, R. K., Dolgin, M. J., Noll, R. B., Katz, E. R., Varni, J. W., Copeland, D. R., Butler, R. W., Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: report of a multisite randomized trial, <i>Journal of Consulting &amp; Clinical Psychology</i> , 73, 272-83, 2005	Population: children newly diagnosed with cancer (Cochrane RS).
Sahler, O. J., Varni, J. W., Fairclough, D. L., Butler, R. W., Noll, R. B., Dolgin, M. J., Phipps, S., Copeland, D. R., Katz, E. R., Mulhern, R. K., Problem-solving skills training for mothers of children with newly diagnosed cancer: a randomized trial, <i>Journal of Developmental &amp; Behavioral Pediatrics</i> , 23, 77-86, 2002	Population: children newly diagnosed with cancer (Cochrane RS).
Schut, H., Stroebe, M. S., Interventions to enhance adaptation to bereavement, <i>Journal of Palliative Medicine</i> , 8 Suppl 1, S140-7, 2005	Study type and population: review, non-systematic. The review does not focus on bereaved family caregivers of children with a LLC.
Schut, Henk, Stroebe, Margaret, Effects of support, counselling and therapy before and after the loss: Can we really help bereaved people?, <i>Psychologica Belgica</i> , 50, 89-102, 2010	Review, non-systematic, discussion paper
Schwartz-Borden, Gwen, Grief work: Prevention and intervention, <i>Social Casework</i> , 67, 499-505, 1986	Discussion paper
Semple, Cherith, Parahoo, Kader, Norman, Alyson, McCaughan, Eilis, Humphris, Gerry, Mills, Moyra, Psychosocial interventions for patients with head and neck cancer, <i>Cochrane Database of Systematic Reviews</i> , -, 2013	Population: Cochrane SR, adults only
Shekarabi-Ahari, G., Younesi, J., Borjali, A., Ansari-Damavandi, S., The effectiveness of group hope therapy on hope and depression of mothers with children suffering from cancer in tehran, <i>Iranian Journal of Cancer Prevention</i> , 5, 183-8, 2012	Intervention: group hope therapy, the study was carried out in Iran.
Sood, A. B., Razdan, A., Weller, E. B., Weller, R. A., Children's reactions to parental and sibling death, <i>Current Psychiatry Reports</i> , 8, 115-120, 2006	Discussion paper

Reference	Reason for Exclusion
Soricelli, Barbara A., Utech, Carolyn L., Mourning the death of a child: The family and group process, <i>Social Work</i> , 30, 429-434, 1985	Discussion paper.
Sourkes, Barbara M., The broken heart: Antipatory grief in the child facing death, <i>Journal of Palliative Care</i> , 12, 56-59, 1996	Study deign: case study
Steele, A. C., Kaal, J., Thompson, A. L., Barrera, M., Compas, B. E., Davies, B., Fairclough, D. L., Foster, T. L., Jo Gilmer, M., Hogan, N., Vannatta, K., Gerhardt, C. A., Bereaved parents and siblings offer advice to health care providers and researchers, <i>Journal of Pediatric Hematology/Oncology</i> , 35, 253-9, 2013	Intervention: this papers does not specifically address psychological needs and/ or interventions.
Stehl, M. L., Kazak, A. E., Alderfer, M. A., Rodriguez, A., Hwang, W. T., Pai, A. L., Boeving, A., Reilly, A., Conducting a randomized clinical trial of an psychological intervention for parents/caregivers of children with cancer shortly after diagnosis, <i>Journal of Pediatric Psychology</i> , 34, 803-16, 2009	Population: children newly diagnosed with cancer (Cochrane RS).
Strada, E., Sourkes, Barbara M., Psychotherapy in the palliative care setting, <i>Primary Psychiatry</i> , 16, 34-40, 2009	Discussion paper
Stuber, M. L., Shemesh, E., Post-traumatic stress response to life-threatening illnesses in children and their parents, <i>Child &amp; Adolescent Psychiatric Clinics of North America</i> , 15, 597-609, 2006	Discussion paper.
Syrjala, K. L., Donaldson, G. W., Davis, M. W., Kippes, M. E., Carr, J. E., Relaxation and imagery and cognitive-behavioral training reduce pain during cancer treatment: a controlled clinical trial, <i>Pain</i> , 63, 189-98, 1995	Population: adult patients 18 years old
Tadmor, Ciporah S., A crisis intervention model for a population of mothers who encounter neonatal death, <i>The Journal of Primary Prevention</i> , 7, 17-26, 1986	Discussion paper.
Taylor, Janeen McCracken, Gortler, Ellen, Psychosocial issues for practitioners in early intervention, <i>Infant-Toddler Intervention</i> , 6, 283-294, 1996	Study design: review, non-systematic
Tew, Krisit, Landreth, Garry L., Joiner, Kimberly D., Solt, Misty D., Filial therapy with parents of chronically ill children, <i>International Journal of Play Therapy</i> , 11, 79-100, 2002	Can't be ascertained whether participants were parents of child living with LLCs.
Thirlwall, K., Cooper, P. J., Karalus, J., Voysey, M., Willetts, L., Creswell, C., Treatment of child anxiety disorders via guided parent-delivered cognitive-behavioural therapy: randomised controlled trial, <i>British Journal of Psychiatry</i> , 203, 436-44, 2013	Population: not end of life care
Thomas, K., Hudson, P., Trauer, T., Remedios, C., Clarke, D., Risk factors for developing prolonged grief during bereavement in family carers of cancer patients in palliative care: a	Aim of the study not related to the protocol. This study aims to ascertain whether family carers who have high levels of prolonged grief (PG) symptoms and those who develop PG disorder

Reference	Reason for Exclusion
longitudinal study, <i>Journal of Pain &amp; Symptom Management</i> , 47, 531-41, 2014	at 6 and 13 months postdeath can be predicted from predeath information.
Tonkins, Sue Anne Morrison, Lambert, Michael J., A treatment outcome study of bereavement groups for children, <i>Child &amp; Adolescent Social Work Journal</i> , 13, 3-21, 1996	Population: mixed population. This study includes children who had lost a family member. 85.7% of the cases had experienced the death of a parent and 12.5% of the cases had experienced the death of a sibling. Data for children who had lost a sibling is not reported separately.
Truog, R. D., Meyer, E. C., Burns, J. P., Toward interventions to improve end-of-life care in the pediatric intensive care unit, <i>Critical Care Medicine</i> , 34, S373-9, 2006	Discussion paper.
Ungureanu, Ileana, Sandberg, Jonathan G., Caring for dying children and their families: MFTs working at the gates of the Elysian fields, <i>Contemporary Family Therapy: An International Journal</i> , 30, 75-91, 2008	Population: professionals working with children with a LLC
Ungureanu, Ileana, Sandberg, Jonathan G., "Broken together": Spirituality and religion as coping strategies for couples dealing with the death of a child: A literature review with clinical implications, <i>Contemporary Family Therapy: An International Journal</i> , 32, 302-319, 2010	Intervention: spirituality and religion as coping strategies.
Vollmer, T. C., Wittmann, M., Schweiger, C., Hiddemann, W., Preoccupation with death as predictor of psychological distress in patients with haematologic malignancies, <i>European Journal of Cancer Care</i> , 20, 403-11, 2011	Population: adult patients 18
Whitehead, B., O'Brien, M. R., Jack, B. A., Mitchell, D., Experiences of dying, death and bereavement in motor neurone disease: A qualitative study, <i>Palliative Medicine</i> , 26, 368-378, 2012	Intervention: the study does not focus on psychological interventions
Whittam, E. H., Terminal care of the dying child. Psychosocial implications of care, <i>Cancer</i> , 71, 3450-62, 1993	Discussion paper
Wiener, L., Battles, H., Mamalian, C., Zadeh, S., ShopTalk: a pilot study of the feasibility and utility of a therapeutic board game for youth living with cancer, <i>Supportive Care in Cancer</i> , 19, 1049-54, 2011	Pilot study. Aim, intervention and results are very vague. This study evaluates Shop Talk, a therapeutic game in youth living with cancer. It is not clear who carried out the therapeutic game (social work professionals?). Also it is mainly used as a diagnostic tool to identify coping skills and adjustment, rather than as intervention as such. It is concluded in the abstract that it may have some therapeutic value, but no results are reported in relation to this.
Wilkinson, S., Croy, P., King, M., Barnes, J., Are we getting it right? Parent's perceptions of hospice child bereavement support services, <i>Palliative Medicine</i> , 21, 401-407, 2007	Participants were parents of bereaved child, who may have lost a parent, a sibling, or family member. Bereavement support were provided by workers without specific training. Causes of family members' death not specified.
Woolley, H., Stein, A., Forrest, G.C., Baum, J.D., Cornerstone care for families of children with life-threatening illness, <i>Developmental Medicine and Child Neurology</i> , 33, 216-224, 1991	Aim of the study not related to the protocol.



Reference	Reason for Exclusion
Yancey, D., Greger, H. A., Coburn, P., Determinants of grief resolution in cancer death, <i>Journal of Palliative Care</i> , 6, 24-31, 1990	Population: this study includes family members and friends of deceased cancer patients. It is a mixed population, and data is not provided separately for parents.

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• **Review question: Rapid transfer service delivery**

Study	Reason for Exclusion
Brook, L. A., Tewani, K., End of life care in hospital. Scope for paediatric palliative care involvement?, <i>Archives of Disease in Childhood</i> , 100, A153, 2015	Conference abstract
Crabtree, L., Harrison, C., Hands, S., Wolfendens, A., National survey of transport team involvement in palliative care in the UK, <i>Intensive Care Medicine</i> , 37, S426, 2011	Conference abstract
Doorenbos, A., Lindhorst, T., Starks, H., Aisenberg, E., Curtis, J. R., Hays, R., Palliative care in the pediatric ICU: challenges and opportunities for family-centered practice, <i>Journal Of Social Work In End-Of-Life &amp; Palliative Care</i> , 8, 297-315, 2012	Discussion paper
Dulkerian, S. J., Douglas, W. P., Taylor, R. M., Redirecting treatment during neonatal transport, <i>Journal of Perinatal &amp; Neonatal Nursing</i> , 25, 111-4, 2011	Background reading
Eason, E. B., Castriotta, R. J., Gremillion, V., Sparks, J. W., Withdrawal of life sustaining treatment in children in the first year of life, <i>Journal of Perinatology</i> , 28, 641-5, 2008	Case report on withdrawal of life sustaining treatment
Fraser, L. K., Fleming, T., Miller, M., Draper, E. S., McKinney, P. A., Parslow, R. C., Paediatric Intensive Care Audit, Network, Palliative care discharge from paediatric intensive care units in Great Britain, <i>Palliative Medicine</i> , 24, 608-15, 2010	The paper examined what clinical variables were associated with referral of palliative care, not effect of interventions
Gupta, N., Harrop, E., Lapwood, S., Shefler, A., Journey from pediatric intensive care to palliative care, <i>Journal of Palliative Medicine</i> , 16, 397-401, 2013	Retrospective review
Harrison, C., Hands, S., Crabtree, L., Wolfendens, A., The role of embrace transport service in palliative care transfers, <i>Intensive Care Medicine</i> , 37, S427, 2011	Conference abstract
Howes, C., Caring until the end: a systematic literature review exploring Paediatric Intensive Care Unit end-of-life care, <i>Nursing in Critical Care</i> , 20, 41-51, 2015	Review of qualitative studies, background reading
Jones, J., Job, S., Pal, S., Maynard, L., Curley, A., Clarke, P., The babies who unexpectedly survive long-term after withdrawal of neonatal intensive care, <i>Archives of Disease in Childhood</i> , 99, A196, 2014	Conference abstract
Laddie, J. R. L., Craig, F., Brierley, J., Withdrawal of ventilatory support outside the intensive care unit, <i>Archives of Disease in Childhood</i> , 97, A166-A167, 2012	Background reading

Study	Reason for Exclusion
Laddie, J., Craig, F., Brierley, J., Kelly, P., Bluebond-Langner, M., Withdrawal of ventilatory support outside the intensive care unit: guidance for practice, <i>Archives of Disease in Childhood</i> , 99, 812-6, 2014	Background reading
Linebarger, J. S., Ajayi, T. A., Jones, B. L., Adolescents and young adults with life-threatening illness: Special considerations, transitions in care, and the role of pediatric palliative care, <i>Pediatric Clinics of North America</i> , 61, 785-796, 2014	Background reading
McPherson, M. L., Jefferson, L. S., Smith, E. O., Sitler, G. C., Graf, J. M., Reverse transport of children from a tertiary pediatric hospital, <i>Air Medical Journal</i> , 26, 183-7, 2007	Background reading, health economics information
Menon, A. P., Lee, J. H., Loh, L. E., Mok, Y. H., Paediatric palliative transport: A single Centre's experience, <i>Pediatric Critical Care Medicine</i> , 1), 181, 2014	Conference abstract
Nelson, H., Mott, S., Kleinman, M. E., Goldstein, R. D., Parents' Experiences of Pediatric Palliative Transports: A Qualitative Case Series, <i>Journal of Pain &amp; Symptom Management</i> , 50, 375-80, 2015	Background reading
Noyes, J., Edwards, R. T., Hastings, R. P., Hain, R., Totsika, V., Bennett, V., Hobson, L., Davies, G. R., Humphreys, C., Devins, M., Spencer, L. H., Lewis, M., Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar, <i>BMC Palliative Care</i> , 12, 18, 2013	Paper with health economics information, no information on clinical effectiveness
Pike, A. M., Manual handling the deceased child in a children's hospice, <i>Journal of child health care: for professionals working with children in the hospital and community</i> , 8, 198-209, 2004	Background reading paper.
Pritchard, L. E., Supporting families with end of life decisions in paediatric intensive care, <i>Archives of Disease in Childhood</i> , 97, A155, 2012	Conference abstract
Simpson, E. C., Penrose, C. V., Compassionate extubation in children at hospice and home, <i>International Journal of Palliative Nursing</i> , 17, 164-169, 2011	Qualitative study for background reading
Skaar, A, Juvet, L, Smedslund, G, Bahus, MK, Pedersen, R, Fure, B, End-of-life care - how to find the appropriate level and intensity of medical treatment of seriously ill and dying patients (Structured abstract), <i>Health Technology Assessment Database</i> , 2015	Abstract only
Steneke, S., Press, C., Plouffe, J., Brown, D., Burge, S., Lambert, D., Veroukis, S., Harlos, M., Transitioning from the pediatric intensive care unit: Withdrawal of life-sustaining treatment in the home (760), <i>Journal of Pain and Symptom Management</i> , 41 (1), 309, 2011	Conference abstract

Study	Reason for Exclusion
Straatman, L., Keats, K., Boyer, K., Withdrawal of ventilation in a non-icu setting: More than a procedure, it's a philosophy of care, Paediatrics and Child Health, 15, 62A, 2010	Conference abstract
Tan, H. J., Hughes, M. I., Characteristics of deaths in children with neuromuscular disease, Developmental Medicine and Child Neurology, 51, 52-53, 2009	Conference abstract

## 1 H.11 Review question: Social and practical support

Reference	Reason for Exclusion
Adams, D. W., Helping the dying child. Practical approaches for nonphysicians, Issues in Comprehensive Pediatric Nursing, 8, 95-112, 1985	No study design: discussion paper
Adkins, L., Hospice care for terminally ill children, Child Welfare, 63, 559-62, 1984	No study design: discussion paper
Aldrich, L. M., Helping children with the death of someone close, Caring, 15, 64-6, 1996	No study design: discussion paper
Almaawiy, U., Pond, G. R., Sussman, J., Brazil, K., Seow, H., Are family physician visits and continuity of care associated with acute care use at end-of-life? A population-based cohort study of homecare cancer patients, Palliative Medicine, 28, 176-183, 2014	No relevant population: participant aged between 0-8 years, no subgroup analysis of interest
Ando, M., Morita, T., O'Connor, S. J., Primary concerns of advanced cancer patients identified through the structured life review process: a qualitative study using a text mining technique, Palliative & Supportive Care, 5, 265-71, 2007	No relevant population: study among adults
Arland, L. C., Hendricks-Ferguson, V. L., Pearson, J., Foreman, N. K., Madden, J. R., Development of an in-home standardized end-of-life treatment program for pediatric patients dying of brain tumors, Journal for Specialists in Pediatric Nursing: JSPN, 18, 144-57, 2013	No study design: only quantitative data reported - no relevant data reported
Armentrout, D., Cates, L. A., Informing parents about the actual or impending death of their infant in a newborn intensive care unit, Journal of Perinatal & Neonatal Nursing, 25, 261-7, 2011	No study design: discussion paper
Brewer, H. M., Smith, J. A., Eatough, V., Stanley, C. A., Glendinning, N. W., Quarrell, O. W., Caring for a child with Juvenile Huntington's Disease: helpful and unhelpful support, Journal of Child Health Care, 11, 40-52, 2007	"Support" in this study was interpreted by parents from the perspective of being listened to and understood by HCPs. Those have been reported in relevant reviews of the guideline.
Brinkman-Stoppelenburg, A., Onwuteaka-Philipsen, B. D., van der Heide, A., Involvement of supportive care professionals in patient care in the last month of life, Supportive Care in Cancer, 23, 2899-2906, 2015	No relevant population: participant aged between 0-8 years, no subgroup analysis of ?
Candy, Bridget, Jones, Louise, Drake, Robyn, Leurent, Baptiste, King, Michael, Interventions for supporting informal caregivers of patients in	No relevant population: study among adults

Reference	Reason for Exclusion
the terminal phase of a disease, Cochrane Database of Systematic Reviews, 2011	
Chibnall, J. T., Bennett, M. L., Videen, S. D., Duckro, P. N., Miller, D. K., Identifying barriers to psychosocial spiritual care at the end of life: A physician group study, American Journal of Hospice and Palliative Medicine, 21, 419-426, 2004	No relevant population: study about physicians perspectives – no relevant data about parents/children
Coleman, F. W., Coleman, W. S., Helping siblings and other peers cope with dying, Issues in Comprehensive Pediatric Nursing, 8, 129-50, 1985	No study design: review paper and case report
Collins, J. J., Stevens, M. M., Cousens, P., Home care for the dying child. A parent's perception, Australian Family Physician, 27, 610-4, 1998	No study design: descriptive study with no thematic qualitative analysis performed
Corkin, D. A., Price, J., Gillespie, E., Respite care for children, young people and families--are their needs addressed?, International Journal of Palliative Nursing, 12, 422-7, 2006	No study design: review paper with no qualitative analysis
Cote-Arsenault, D., Denney-Koelsch, E., "My baby is a person": parents' experiences with life-threatening fetal diagnosis, Journal of Palliative Medicine, 14, 1302-8, 2011	no relevant findings
Dangel, T., Fowler-Kerry, S., Karwacki, M., Bereda, J., An evaluation of a home palliative care programme for children, Ambulatory Child Health, 6, 101-114, 2000	No study design: only quantitative survey data reported
Danvers, L., Freshwater, D., Cheater, F., Wilson, A., Providing a seamless service for children with life-limiting illness: experiences and recommendations of professional staff at the Diana Princess of Wales Children's Community Service, Journal of Clinical Nursing, 12, 351-9, 2003	No relevant populations: study among HCPs – no relevant data
Davies, B., Assessment of need for a children's hospice program, Death Studies, 20, 247-268, 1996	No study design: needs assessment study with no qualitative analysis
Davies, B., Eng, B., Arcand, R., Collins, J., Bhanji, N., Canuck place: a hospice for dying children, Canadian Nurse, 92, 22-5, 1996	No study design: discussion paper
Davies, B., Gudmundsdottir, M., Worden, B., Orloff, S., Sumner, L., Brenner, P., "Living in the dragon's shadow" fathers' experiences of a child's life-limiting illness, Death Studies, 28, 111-35, 2004	No relevant objectives: SUPPORT NO SPECIFIED - no relevant findings
de Rooy, L., Aladangady, N., Aidoo, E., Palliative care for the newborn in the United Kingdom, Early Human Development, 88, 73-7, 2012	No study design: review paper with no qualitative analysis
deJong-Berg, M. A., deVlaming, D., Bereavement care for families part 1: a review of a paediatric follow-up programme, International Journal of Palliative Nursing, 11, 533-9, 2005	No relevant objectives: evaluation of a paediatric follow-up programme - no relevant findings
Donovan, L. A., Wakefield, C. E., Russell, V., Cohn, R. J., Hospital-based bereavement	No study design: review paper for background

Reference	Reason for Exclusion
services following the death of a child: a mixed study review, <i>Palliative Medicine</i> , 29, 193-210, 2015	
Donovan, L., Wakefield, C., Cohn, R., Russell, V., Recreating life after death-the place of professional and social support in the lives of parents following the death of a child from cancer, <i>Psycho-Oncology</i> , 24, 13-14, 2015	No study design: conference abstract
Donovan, L., Wakefield, C., Russell, V., Cohn, R., Transitional social support: A developing framework for hospital-based bereavement care following the death of a child from cancer, <i>Psycho-Oncology</i> , 24, 23-24, 2015	No study design: conference abstract
Floriani, C. A., Home-based palliative care: challenges in the care of technology-dependent children, <i>Jornal de Pediatria</i> , 86, 15-20, 2010	No study design: discussion paper
Foliart, D. E., Clausen, M., Siljestrom, C., Bereavement practices among California hospices: results of a statewide survey, <i>Death Studies</i> , 25, 461-7, 2001	No study design: only quantitative survey data reported
Freeman, K., O'Dell, C., Meola, C., Childhood brain tumors: children's and siblings' concerns regarding the diagnosis and phase of illness, <i>Journal of Pediatric Oncology Nursing</i> , 20, 133-40, 2003	No study design: only quantitative survey data reported with no qualitative analysis performed
Fujii, Y., Watanabe, C., Okada, S., Inoue, N., Endoh, A., Yajima, S., Hongo, T., Ohzeki, T., Suzuki, E., Analysis of the circumstances at the end of life in children with cancer: a single institution's experience in Japan, <i>Pediatrics International</i> , 45, 54-9, 2003	No study design: only quantitative survey data reported
Gaveras, E. M., Kristiansen, M., Worth, A., Irshad, T., Sheikh, A., Social support for South Asian Muslim parents with life-limiting illness living in Scotland: A multiperspective qualitative study, <i>BMJ Open</i> , 4, 2014	No relevant population: participant parents of children with LLCs and having children under the age of 18
Gillance, H., Tucker, A., Aldridge, J., Wright, J. B., Bereavement: providing support for siblings, <i>Paediatric Nursing</i> , 9, 22-4, 1997	No study design: descriptive study with no qualitative analysis performed
Hechler, T., Blankenburg, M., Friedrichsdorf, S. J., Garske, D., Hubner, B., Menke, A., Wamsler, C., Wolfe, J., Zernikow, B., Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer, <i>Klinische Padiatrie</i> , 220, 166-74, 2008	No study design: only quantitative survey data reported with no qualitative analysis performed
Heiney, S. P., Wells, L., Ruffin, J., A memorial service for families of children who died from cancer and blood disorders, <i>Journal of Pediatric Oncology Nursing</i> , 13, 72-9; discussion 80, 1996	No study design: discussion paper
Hinds, P. S., Kelly, K. P., Helping parents make and survive end of life decisions for their seriously ill child, <i>Nursing Clinics of North America</i> , 45, 465-74, 2010	No study design: discussion paper
Hoekstra-Weebers, J. E. H. M., Wijnberg-Williams, B. J., Jaspers, J. P. C., Kamps, W. A.,	No relevant population: no parents of children approaching the end of life

Reference	Reason for Exclusion
Van De Wiel, H. B. M., Coping and its effect on psychological distress of parents of pediatric cancer patients: A longitudinal prospective study, <i>Psycho-Oncology</i> , 21, 903-911, 2012	
Ito, Y., Okuyama, T., Ito, Y., Kamei, M., Nakaguchi, T., Sugano, K., Kubota, Y., Sakamoto, N., Saitoh, S., Akechi, T., Good death for children with cancer: a qualitative study, <i>Japanese Journal of Clinical Oncology</i> , 45, 349-55, 2015	No relevant population: participant were young people survived cancer and parents whose child dead of cancer “ no relevant findings
Junger, S., Pastrana, T., Pestinger, M., Kern, M., Zernikow, B., Radbruch, L., Barriers and needs in paediatric palliative home care in Germany: a qualitative interview study with professional experts, <i>BMC Palliative Care</i> , 9, 10, 2010	No relevant population: study among HCPs “ no relevant data
Kassam, A., Skiadaresis, J., Habib, S., Alexander, S., Wolfe, J., Moving toward quality palliative cancer care: parent and clinician perspectives on gaps between what matters and what is accessible, <i>Journal of Clinical Oncology</i> , 31, 910-5, 2013	No study design: only quantitative survey data reported with no qualitative analysis performed
Kavanaugh, K., Moro, T.T., Savage, T.A., How nurses assist parents regarding life support decisions for extremely premature infants, <i>JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing</i> , 39, 147-158, 2010	No relevant population: study among HCPs “ no relevant data
Lane, C., Mason, J., Meeting the needs of siblings of children with life-limiting illnesses, <i>Nursing Children and Young People</i> , 26, 16-20, 2014	No study design: discussion paper
Ling, J., Respite support for children with a life-limiting condition and their parents: a literature review, <i>International Journal of Palliative Nursing</i> , 18, 129-34, 2012	No study design: review paper with no qualitative analysis
Lydon, A., Hennings, J., Woolley, B. R., Evaluation of a British child bereavement service: the user's perspective, <i>Palliative &amp; Supportive Care</i> , 8, 297-303, 2010	Evaluation of a child bereavement program which focused on children bereaved of death of family members, irrelevant population.
Mangurten, H. H., Home death and hospital follow-up of the dying infant, <i>American Journal of Perinatology</i> , 7, 302-306, 1990	No study design: case report
Marlow, S., Martin, M., 'A voyage of grief and beauty': supporting a dying family member with an intellectual disability, <i>International Journal of Palliative Nursing</i> , 14, 342-9, 2008	No relevant objectives: the primary goal is not about social/ practical care, only on carers of children with LLCs approach end of life - relevant references checked
Martinson, I. M., Nesbit, M. E., Kersey, J. H., Physician's role in home care for children with cancer, <i>Death Studies</i> , 9, 283-93, 1985	No relevant populations: study among HCPs “ no relevant data
Meyer, E. C., Burns, J. P., Griffith, J. L., Truog, R. D., Parental perspectives on end-of-life care in the pediatric intensive care unit, <i>Critical Care Medicine</i> , 30, 226-31, 2002	No study design: only descriptive quantitative data reported
Monerosso, L., Kristjanson, L. J., Supportive and palliative care needs of families of children who	Theme of communication has been reviewed previously

Reference	Reason for Exclusion
die from cancer: An Australian study, Palliative Medicine, 22, 59-69, 2008	
Monterosso, L., Kristjanson, L. J., Phillips, M. B., The supportive and palliative care needs of Australian families of children who die from cancer, Palliative Medicine, 23, 526-36, 2009	No study design: only quantitative survey data reported with no qualitative analysis performed
Nicholas, D. B., Picone, G., Selkirk, E. K., The lived experiences of children and adolescents with end-stage renal disease, Qualitative Health Research, 21, 162-73, 2011	No relevant population - no children with LLCs
Nugent, L. S., The social support requirements of family caregivers of terminal cancer patients, Canadian Journal of Nursing Research, 20, 45-58, 1988	Only 1 cancer patient cared for was < 18 years of age, no separate analysis was performed either.
Parker, D., Maddocks, I., Stern, L. M., The role of palliative care in advanced muscular dystrophy and spinal muscular atrophy, Journal of Paediatrics & Child Health, 35, 245-50, 1999	No relevant population: participant included parents whose child with LLCs dyed between 17-21 years, among those died between 8 to 31 years “ no relevant findings
Pearson, H., Managing the emotional aspects of end of life care for children and young people, Paediatric Nursing, 22, 31-5, 2010	No study design: discussion paper
Potts, S., Farrell, M., O'Toole, J., Treasure Weekend: supporting bereaved siblings, Palliative Medicine, 13, 51-6, 1999	No qualitative analysis performed
Pritchard, S., Cuvelier, G., Harlos, M., Barr, R., Palliative care in adolescents and young adults with cancer, Cancer, 117, 2323-8, 2011	No study design: discussion paper
Quinn, C., Bailey, M. E., Caring for children and families in the community: experiences of Irish palliative care clinical nurse specialists, International Journal of Palliative Nursing, 17, 561-7, 2011	No relevant population: study among HCPs “ no relevant data
Rafty, J. P., Addington-Hall, J. M., MacDonald, L. D., Anderson, H. R., Bland, J. M., Chamberlain, J., Freeling, P., A randomized controlled trial of the cost-effectiveness of a district co-ordinating service for terminally ill cancer patients, Palliative Medicine, 10, 151-61, 1996	The patients in the trial aged between 16 and 64, no subgroup analysis was conducted.
Reid, F., Grief and the experiences of nurses providing palliative care to children and young people at home, Nursing Children and Young People, 25, 31-6, 2013	No relevant population: study among nurses “ no relevant data
Rodriguez, A., King, N., The lived experience of parenting a child with a life-limiting condition: a focus on the mental health realm, Palliative & Supportive Care, 7, 7-12, 2009	No relevant findings
Rosenberg, A. R., Baker, K. S., Syrjala, K. L., Back, A. L., Wolfe, J., Promoting resilience among parents and caregivers of children with cancer, Journal of Palliative Medicine, 16, 645-52, 2013	no relevant findings
Sirkia, K., Saarinen, U. M., Ahlgren, B., Hovi, L., Terminal care of the child with cancer at home, Acta Paediatrica, 86, 1125-30, 1997	No study design: only quantitative survey data reported with no qualitative analysis performed

Reference	Reason for Exclusion
Stein, A., Forrest, G. C., Woolley, H., Baum, J. D., Life threatening illness and hospice care, Archives of Disease in Childhood, 64, 697-702, 1989	Only descriptive quantitative survey results were reported. NO qualitative analysis was performed.
Swallow, V., Forrester, T., Macfadyen, A., Teenagers' and parents' views on a short-break service for children with life-limiting conditions: a qualitative study, Palliative Medicine, 26, 257-67, 2012	The paper described how short-break service could be better provided to parents and their child. However, it was not clear whether the children were in advanced illness or were approaching the end of the life..
Swinney, R., Lu, Y., Lee, A., Rubin, D., Anderson, C., The role of support staff in pediatric palliative care: Their perceptions, training, and available resources, Journal of Palliative Care, 23, 44-50, 2007	No study design: only quantitative survey data reported
Thielemann, P., Educational needs of home caregivers of terminally ill patients: literature review, American Journal of Hospice & Palliative Medicine, 17, 253-7, 2000	No study design: review paper focusing on adults
Thompson, R. J., Jr., Gil, K. M., Burbach, D. J., Keith, B. R., Kinney, T. R., Psychological adjustment of mothers of children and adolescents with sickle cell disease: the role of stress, coping methods, and family functioning, Journal of Pediatric Psychology, 18, 549-59, 1993	No study design: only descriptive quantitative data reported
Vickers, J. L., Carlisle, C., Choices and control: parental experiences in pediatric terminal home care, Journal of Pediatric Oncology Nursing, 17, 12-21, 2000	No relevant findings
Wang, J., Kearney, J. A., The experience of Chinese American parents of children with life-limiting illness: a comprehensive review, International Journal of Palliative Nursing, 19, 347-54, 2013	No study objectives: the primary goal is not about social/ practical care when child with LLCs approach end of life - relevant references checked
Ware, J., Raval, H., A qualitative investigation of fathers' experiences of looking after a child with a life-limiting illness, in process and in retrospect, Clinical Child Psychology & Psychiatry, 12, 549-65, 2007	The theme reported in this review on "hope" has been covered in communication review.
Whiting, M., Children with disability and complex health needs: the impact on family life, Nursing Children and Young People, 26, 26-30, 2014	No relevant findings
Whittam, E. H., Terminal care of the dying child. Psychosocial implications of care, Cancer, 71, 3450-62, 1993	No study design: discussion paper
Whitton, C., Williams, C., Wright, B., Jardine, J., Hunt, A., The role of evaluation in the development of a service for children with life-limiting conditions in the community, Child: Care, Health & Development, 34, 576-83, 2008	Theme of communication has been reviewed previously
Wilkinson, S., Croy, P., King, M., Barnes, J., Are we getting it right? Parents' perceptions of hospice child bereavement support services, Palliative Medicine, 21, 401-7, 2007	Participants were parents whose children had a parent, grandparent or sibling who had died.
Williams, C., Munson, D., Zupancic, J., Kirpalani, H., Supporting bereaved parents:	No study design: discussion paper



Reference	Reason for Exclusion
practical steps in providing compassionate perinatal and neonatal end-of-life care. A North American perspective, <i>Seminars In Fetal &amp; Neonatal Medicine</i> , 13, 335-40, 2008	
Woolley,H., Stein,A., Forrest,G.C., Baum,J.D., Cornerstone care for families of children with life-threatening illness, <i>Developmental Medicine and Child Neurology</i> , 33, 216-224, 1991	No relevant theme was reported.
Wright, B., Aldridge, J., Wurr, K., Sloper, T., Tomlinson, H., Miller, M., Clinical dilemmas in children with life-limiting illnesses: decision making and the law, <i>Palliative Medicine</i> , 23, 238-47, 2009	Discussion paper for background reading
Yam, B. M., Rossiter, J. C., Cheung, K. Y., Caring for dying infants: experiences of neonatal intensive care nurses in Hong Kong, <i>Journal of Clinical Nursing</i> , 10, 651-9, 2001	No relevant population: study among nurses “no relevant data

## 1 H.12 Review question: Spiritual and religious support

Reference	Reason for Exclusion
Belief in divine intervention affects palliative care quality, <i>Nursing Standard</i> , 26, 9-10, 2012	Journal news
Akard, T. F., Dietrich, M., Baudino, M., Stone, A., A comparison of continuing bonds over time in bereaved parents and siblings after the death of a child, <i>Journal of Pain and Symptom Management</i> , 51 (2), 451, 2016	Conference abstract.
Arzuaga, B., Adam, H., Ahmad, M., Padela, A., Attitudes towards the resuscitation of periviable infants: A national survey of American Muslim physicians, <i>Acta Paediatrica, International Journal of Paediatrics</i> , 105, 260-267, 2016	Study design: survey with descriptive data only
Attig, T., Beyond pain: the existential suffering of children, <i>Journal of Palliative Care</i> , 12, 20-3, 1996	Narrative review.
Berde, C., Wolfe, J., Pain, anxiety, distress, and suffering: interrelated, but not interchangeable, <i>Journal of Pediatrics</i> , 142, 361-3, 2003	Discussion paper
Black, J., Broaden your mind about death and bereavement in certain ethnic groups in Britain, <i>British Medical Journal Clinical Research Ed.</i> , 295, 536-9, 1987	Background reading.
Broadhurst, K., Harrington, A., A mixed method thematic review: the importance of hope to the dying patient, <i>Journal of Advanced Nursing</i> , 72, 18-32, 2016	Population: adults only
Centre for Reviews and Dissemination, Pediatric palliative care in Canada and the United States: a qualitative metasummary of the needs of patients and families (Structured abstract), <i>Database of Abstracts of Reviews of Effects</i> , 2015	Abstract only (DARE). Full paper requested.
Champagne, E, Living and dying: a window on Christian children's spirituality, <i>International</i>	Children participating in the study are recruited from the general population.

journal of Children's Spirituality, 13, 253-263, 2008	
Chibnall, J. T., Bennett, M. L., Videen, S. D., Duckro, P. N., Miller, D. K., Identifying barriers to psychosocial spiritual care at the end of life: A physician group study, American Journal of Hospice and Palliative Medicine, 21, 419-426, 2004	Physicians working with different populations. Data for paediatricians not reported separately.
Crisp, C. L., Faith, Hope, and Spirituality: SUPPORTING PARENTS WHEN THEIR CHILD HAS A LIFE-LIMITING ILLNESS, Journal of Christian nursing: a quarterly publication of Nurses Christian Fellowship, 33, 14-21, 2016	Narrative review
Davison, S. N., Jhangri, G. S., Existential and supportive care needs among patients with chronic kidney disease, Journal of Pain & Symptom Management, 40, 838-844, 2010	Adults only
Drutchas, A., Anandarajah, G., Spirituality and coping with chronic disease in pediatrics, Rhode Island Medicine, 97, 26-30, 2014	Narrative review/ discussion paper
ElGindy, G., Cultural competence Q & A. Death and dying across cultures: at this most difficult time in the lives of patients and their families, end-of-life care that is sensitive to diverse religious and cultural needs becomes supremely important, Minority Nurse, 54-57, 2004	Discussion paper
Elkins, M., Cavendish, R., Developing a plan for pediatric spiritual care, Holistic Nursing Practice, 18, 179-84; quiz 185-6, 2004	Narrative review
Feudtner, C., Haney, J., Dimmers, M. A., Spiritual care needs of hospitalized children and their families: a national survey of pastoral care providers' perceptions, Pediatrics, 111, e67-72, 2003	Survey with descriptive data only.
Fitchett, G., Lyndes, K. A., Cadge, W., Berlinger, N., Flanagan, E., Misasi, J., The role of professional chaplains on pediatric palliative care teams: perspectives from physicians and chaplains, Journal of Palliative Medicine, 14, 704-7, 2011	This paper explores the role of chaplains from the perspective of both physicians and chaplains. No relevant data reported.
Forster, E., Hafiz, A., Paediatric death and dying: exploring coping strategies of health professionals and perceptions of support provision, International Journal of Palliative Nursing, 21, 294-301, 2015	Aim out of the remit of this review. This paper describes healthcare professionals coping strategies in relation to death.
Friedrichsdorf, S., Lund, P., Pediatric pain and symptom management in the context of diverse spiritual belief systems in palliative care, Journal of Palliative Care, 22, 193-194, 2006	Conference abstract. No relevant data reported.
Hart, D., Schneider, D., Spiritual care for children with cancer, Seminars in Oncology Nursing, 13, 263-70, 1997	Narrative review.
Holston, Jane Treadwell, Supporting Families in NEONATAL LOSS: Relationships and Faith Key to Comfort, Journal of Christian Nursing, 32, 18-26, 2015	Case report

Jones, B, Weisenfluh, S, Pediatric palliative care and end of life care: developmental and spiritual issues of dying children, <i>Smith College Studies in Social Work</i> , 73, 423-443, 2003	Narrative review and case reports.
Kamper, R., Van Cleve, L., Savedra, M., Children with advanced cancer: responses to a spiritual quality of life interview, <i>Journal for Specialists in Pediatric Nursing: JSPN</i> , 15, 301-6, 2010	Descriptive data
Kilby, D., Pretlove, J., Russell, R. Bedford, Multidisciplinary palliative care in unborn and newborn babies: Coordinated clinical care and psychological spiritual, and social support must be provided throughout the process, <i>BMJ: British Medical Journal (Overseas &amp; Retired Doctors Edition)</i> , 342, 836-838, 2011	Editorial
Knapp, C., Madden, V., Wang, H., Curtis, C., Sloyer, P., Shenkman, E., Spirituality of parents of children in palliative care, <i>Journal of Palliative Medicine</i> , 14, 437-43, 2011	Telephone survey. No relevant data reported
Kobler, K., Barnes, M., Bereaved parents experience of a hospital memorial service, <i>Journal of Pain and Symptom Management</i> , 51 (2), 421, 2016	Conference abstract. Only preliminary results reported.
LeFavi, R. G., Wessels, M. H., Life review in pastoral counseling: background and efficacy for use with the terminally ill, <i>The Journal of Pastoral Care &amp; Counseling: JPCC</i> , 57, 281-92, 2003	Discussion paper
Long, C. O., Cultural and spiritual considerations in palliative care, <i>Journal of Pediatric Hematology/Oncology</i> , 33 Suppl 2, S96-101, 2011	Narrative review.
Lyon, E., Garvie, A., Kao, Ellin, Briggs, Linda, He, Jianping, Malow, Robert, D'Angelo, J., McCarter, Robert, Spirituality in HIV-infected Adolescents and Their Families: Family CEntered (FACE) Advance Care Planning and Medication Adherence, <i>Journal of Adolescent Health</i> , 48, 633-637, 2011	No outcomes of interest reported
Lyon, E., Wang, Jichuan, Longitudinal Randomized Controlled Trial of Advance Care Planning for Teens: Religiousness and End of Life Treatment Preferences, <i>Journal of Adolescent Health</i> , 58, S84-NaN, 2016	Aim of the study: not relevant
Lyon, M. E., Jacobs, S., Briggs, L., Cheng, Y. I., Wang, J., A longitudinal, randomized, controlled trial of advance care planning for teens with cancer: anxiety, depression, quality of life, advance directives, spirituality, <i>Journal of Adolescent Health</i> , 54, 710-7, 2014	RCT. No interventions of interest.
Lyon, M. E., Townsend-Akpan, C., Thompson, A., Spirituality and end-of-life care for an adolescent with AIDS, <i>AIDS Patient Care and STDs</i> , 15, 555-560, 2001	This is an RCT that aims to test the feasibility, acceptability and safety of a paediatric ACP intervention. Spirituality is an outcome, not part of the intervention.
Mazanec, P., Tyler, M. K., Cultural considerations in end-of-life care: how ethnicity, age, and spirituality affect decisions when death	Discussion paper

is imminent, American Journal of Nursing, 103, 50-60, 2003	
McGraw, S. A., Dobihal, E., Baggish, R., Bradley, E. H., How can we improve care at the end of life in Connecticut? Recommendations from focus groups, Connecticut Medicine, 66, 655-64, 2002	Focus groups conducted with people from various age groups (median 47.4; range 14 to 88). Data not reported separately.
Meyers, H. I., Spiritual care in pediatric hospice, American Journal of Hospice Care, 6, 12, 1989	Discussion paper
Miller, D. K., Chibnall, J. T., Videen, S. D., Duckro, P. N., Supportive-affective group experience for persons with life-threatening illness: Reducing spiritual, psychological, and death-related distress in dying patients, Journal of Palliative Medicine, 8, 333-343, 2005	Population: adults only
Misko, M. D., dos Santos, M. R., Ichikawa, C. R., de Lima, R. A., Bousso, R. S., The family's experience of the child and/or teenager in palliative care: fluctuating between hope and hopelessness in a world changed by losses, Revista Latino-Americana de Enfermagem, 23, 560-7, 2015	The aim of this paper is to understand the family's experience of the CYP in palliative care, but does not specifically address religious or spiritual aspects.
Monterosso, L., Kristjanson, L. J., Supportive and palliative care needs of families of children who die from cancer: an Australian study, Palliative Medicine, 22, 59-69, 2008	No themes related to spiritual or religious needs or support reported.
Mueller, C. R., Spirituality in children: understanding and developing interventions, Pediatric Nursing, 36, 197-203, 2010	Discussion paper.
Pendleton, S. M., Cavalli, K. S., Pargament, K. I., Nasr, S. Z., Religious/spiritual coping in childhood cystic fibrosis: a qualitative study, Pediatrics, 109, E8, 2002	Children with CF. Not end of life care.
Petersen, L., Spiritual care of the child with cancer at the end of life: a concept analysis, Journal of Advanced Nursing, 70, 1243-1254, 2014	Literature review. Studies relevant to spiritual care have been identified for assessment.
Purow, B., Alisanski, S., Putnam, G., Ruderman, M., Spirituality and pediatric cancer, Southern Medical Journal, 104, 299-302, 2011	Discussion paper
Reverend Alister, Bull, Gillies, M., Spiritual needs of children with complex healthcare needs in hospital, Paediatric Nursing, 19, 34-8, 2007	Narrative review. Relevant references identified for assessment.
Robertson, M. J., Aldridge, A., Curley, A. E., Provision of bereavement care in neonatal units in the United Kingdom, Pediatric Critical Care Medicine, 12, e111-5, 2011	No study design: only quantitative survey data reported
Roy, Dj, Prayer in palliative care?, J Palliat Care, 15, 3-4., 1999	Editorial. No relevant data reported.
Seecharan, G. A., Andresen, E. M., Norris, K., Toce, S. S., Parents' assessment of quality of care and grief following a child's death, Archives of Pediatrics and Adolescent Medicine, 158, 515-520, 2004	Aim not related to the review question

Smith-Stoner, M., End-of-life preferences for atheists, <i>Journal of Palliative Medicine</i> , 10, 923-8, 2007	Adults only
Snethen, J. A., Broome, M. E., Kelber, S., Warady, B. A., Coping strategies utilized by adolescents with end stage renal disease, <i>Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association</i> , 31, 41-9, 2004	Descriptive data only
Sommer, D. R., The spiritual needs of dying children, <i>Issues in Comprehensive Pediatric Nursing</i> , 12, 225-33, 1989	Discussion paper
Stevenson, M., Achille, M., Lugasi, T., Pediatric palliative care in Canada and the United States: a qualitative metasummary of the needs of patients and families, <i>Journal of Palliative Medicine</i> , 16, 566-77, 2013	Qualitative meta-summary of the needs of patients and families. References related to spiritual needs identified for potential inclusion.
Thienprayoon, Rachel, Campbell, Ryan, Winick, Naomi, Attitudes and Practices in the Bereavement Care Offered by Children's Hospitals: A Survey of the Pediatric Chaplains Network, <i>Omega: Journal of Death &amp; Dying</i> , 71, 48-60, 2015	Survey to chaplains regarding bereavement care offered by hospitals. No relevant data reported.
Torres, K., Einav, S., Villarreal, R., Varon, J., Religion and life support withdrawal in children: What do healthcare providers wish?, <i>Resuscitation</i> , 96, 130-131, 2015	Conference abstract. No relevant data reported.
<b>Ufema, J., Insights on death &amp; dying. Mourning rituals: youngest pallbearer, <i>Nursing</i>, 33, 18-19, 2003</b>	Comment
<b>van der Geest, I. M., van den Heuvel-Eibrink, M. M., Falkenburg, N., Michiels, E. M., van Vliet, L., Pieters, R., Darlington, A. S., Parents' Faith and Hope during the Pediatric Palliative Phase and the Association with Long-Term Parental Adjustment, <i>Journal of Palliative Medicine</i>, 18, 402-7, 2015</b>	Survey with only quantitative descriptive data reported.
van der Geest, I. M., van den Heuvel-Eibrink, M. M., van Vliet, L. M., Pluijm, S. M., Streng, I. C., Michiels, E. M., Pieters, R., Darlington, A. S., Talking about Death with Children with Incurable Cancer: Perspectives from Parents, <i>Journal of Pediatrics</i> , 167, 1320-6, 2015	This qualitative study aims to investigate parents decisions to discuss death with a child. No spiritual or religious themes were reported.
Vilalta, Aleix, Valls, Joan, Porta, Josep, Viñas, Juan, Evaluation of Spiritual Needs of Patients with Advanced Cancer in a Palliative Care Unit, <i>Journal of Palliative Medicine</i> , 17, 592-601, 2014	Population: adults only
Waldman, E., Handzo, G., Exploring spiritual needs of children facing life-threatening illness, <i>Journal of Pain and Symptom Management</i> , 51 (2), 350-351, 2016	Conference abstract. No relevant data reported.
Walter, T., Hospices and rituals after death: a survey of British hospice chaplains, <i>International Journal of Palliative Nursing</i> , 9, 80-5, 2003	This study describes the views of chaplains regarding hospice rituals after death. It does not explore children's and/ or the families' needs.
Weidner, N. J., Cameron, M., Lee, R. C., McBride, J., Mathias, E. J., Byczkowski, T. L.,	The aim of this study is to understand the family's needs during end of life care, but does

End-of-life care for the dying child: what matters most to parents, <i>Journal of Palliative Care</i> , 27, 279-86, 2011	not specifically address religious or spiritual aspects.
Whittle, M., Cutts, S., Time to go home: assisting families to take their child home following a planned hospital or hospice death, <i>Paediatric Nursing</i> , 14, 24-8, 2002	Aim not relevant to the review question
Wiener, L., McConnell, D. G., Latella, L., Ludi, E., Cultural and religious considerations in pediatric palliative care, <i>Palliative &amp; Supportive Care</i> , 11, 47-67, 2013	Narrative review. Good for background reading and reference checking.
Woodgate, R. L., Degner, L. F., Yanofsky, R., A different perspective to approaching cancer symptoms in children, <i>Journal of Pain &amp; Symptom Management</i> , 26, 800-17, 2003	Qualitative paper on the experience of pain and other symptoms.

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### 3 H.13 Review question: Managing pain

Study	Reason for Exclusion
Anghelescu, D. L., Snaman, J. M., Trujillo, L., Sykes, A. D., Yuan, Y., Baker, J. N., Patient-controlled analgesia at the end of life at a pediatric oncology institution, <i>Pediatric Blood &amp; Cancer</i> , 62, 1237-44, 2015	This study describes the use of patient-controlled analgesia, with no comparison
Anghelescu, D. L., Zhang, K., Faughnan, L. G., Pei, D., The Safety and Effectiveness of Patient-controlled Analgesia in Outpatient Children and Young Adults With Cancer: A Retrospective Study, <i>Journal of Pediatric Hematology/Oncology</i> , 37, 378-82, 2015	This study describes the use of patient-controlled analgesia, with no comparison
Bauer, Kathrin, Skoetz, Nicole, Monsef, Ina, Engert, Andreas, Brillant, Corinne, Comparison of chemotherapy including escalated BEACOPP versus chemotherapy including ABVD for patients with early unfavourable or advanced stage Hodgkin lymphoma, <i>Cochrane Database of Systematic Reviews</i> , -, 2011	The authors of this review did not identify any trial conducted with children that met the inclusion criteria
Beecham, E., Candy, B., Howard, R., McCulloch, R., Laddie, J., Rees, H., Vickerstaff, V., Bluebond-Langner, M., Jones, L., Pharmacological interventions for pain in children and adolescents with life-limiting conditions, <i>Cochrane Database of Systematic Reviews</i> , 3, CD010750, 2015	This Cochrane review includes children with LLC, but only identifies studies with children with CP and osteogenesis imperfecta. Not EOLC pain management.
Bell, S. G., The pharmacology of palliative care, <i>Neonatal Network - Journal of Neonatal Nursing</i> , 23, 61-4, 2004	Discussion paper
Ben-Arush, M. W., Barak, A. B., Bar-Deroma, R., Ash, S., Goldstein, G., Golan, H., Houri, H., Waldman, D., Nevo, N., Shalom, R. B., Berniger, A., Nevelsky, A., Toren, A., Yaniv, I., Kuten, A., Targeted therapy with low doses of <sup>131</sup> I-MIBG is effective for disease palliation in highly refractory neuroblastoma, <i>Israel Medical Association Journal</i> , 15, 31-34, 2013	Retrospective chart review

Study	Reason for Exclusion
Berde, C. B., Walco, G. A., Krane, E. J., Anand, K. J. S., Aranda, J. V., Craig, K. D., Dampier, C. D., Finkel, J. C., Grabois, M., Johnston, C., Lantos, J., Lebel, A., Maxwell, L. G., McGrath, P., Oberlander, T. F., Schanberg, L. E., Stevens, B., Taddio, A., Von Baeyer, C. L., Yaster, M., Zempsky, W. T., Pediatric analgesic clinical trial designs, measures, and extrapolation: Report of an FDA Scientific Workshop, <i>Pediatrics</i> , 129, 354-364, 2012	Discussion paper
Bhasker, S., Bajpai, V., Turaka, A., Palliative radiotherapy in paediatric malignancies, <i>Singapore Medical Journal</i> , 49, 998-1001, 2008	Descriptive analysis of cases
Bosnjak, S., Jelic, S., Susnjar, S., Luki, V., Gabapentin for relief of neuropathic pain related to anticancer treatment: a preliminary study, <i>Journal of Chemotherapy</i> , 14, 214-9, 2002	Adults only (mean age 55.04)
Bradt, J., Dileo, C., Music therapy for end-of-life care, <i>Cochrane Database of Systematic Reviews</i> , CD007169, 2010	No studies with children were identified for inclusion in this review. Note: this Cochrane review is no longer available at The Cochrane Library, as it is not updated).
Breen, M., An evaluation of two subcutaneous infusion devices in children receiving palliative care, <i>Paediatric Nursing</i> , 18, 38-40, 2006	Aim of the study not relevant to the protocol. This study evaluates two infusion devices.
Cai, W. S., Wu, R., Zhao, H. Y., Wang, W. L., Wen, D. L., Zhang, J. H., Wang, Y., Tan, Y. G., Zou, H. W., Institutional experience of five-day courses of irinotecan as palliative chemotherapy in Chinese patients with refractory neuroblastoma, <i>Hong Kong Journal of Paediatrics</i> , 17, 223-229, 2012	Case series
Candrilli, S.D., Davis, K.L., Iyer, S., Impact of constipation on opioid use patterns, health care resource utilization, and costs in cancer patients on opioid therapy, <i>Journal of Pain and Palliative Care Pharmacotherapy</i> , 23, 231-241, 2009	This study includes mixed population (people < 18 represent 1.05% of the population)
Cassileth, B., Complementary therapies, herbs, and other OTC Agents, <i>Oncology</i> , 23, 647, 2009	Abstract only. No details are given about the population.
Causa, L., Hijal, T., Michon, J., Helfre, S., Role of palliative radiotherapy in the management of metastatic pediatric neuroblastoma: a retrospective single-institution study, <i>International Journal of Radiation Oncology, Biology, Physics</i> , 79, 214-9, 2011	A retrospective single-institution study
Chari, P., Venkataraman, R. K., Trikha, A., Singh, H., Management of pain in pain clinic (review of 1348 cases), <i>Indian Journal of Medical Sciences</i> , 43, 151-6, 1989	This study includes mixed population (age range 15 to 77). Data is not reported separately for children.
Collins, J. J., Intractable pain in children with terminal cancer, <i>Journal of Palliative Care</i> , 12, 29-34, 1996	Discussion paper and cases
Collins, J. J., Grier, H. E., Kinney, H. C., Berde, C. B., Control of severe pain in children with terminal malignancy, <i>Journal of Pediatrics</i> , 126, 653-7, 1995	Descriptive study

Study	Reason for Exclusion
Collins, J. J., Grier, H. E., Sethna, N. F., Wilder, R. T., Berde, C. B., Regional anesthesia for pain associated with terminal pediatric malignancy, <i>Pain</i> , 65, 63-9, 1996	Discussion paper
Conway, M., White, N., Jean, C. S., Zempsky, W. T., Steven, K., Use of continuous intravenous ketamine for end-stage cancer pain in children, <i>Journal of Pediatric Oncology Nursing</i> , 26, 100-6, 2009	Case reports
Dougherty, M., DeBaun, M. R., Rapid increase of morphine and benzodiazepine usage in the last three days of life in children with cancer is related to neuropathic pain, <i>Journal of Pediatrics</i> , 142, 373-6, 2003	Study design: case series
Fellowes, D., Barnes, K., Wilkinson, S., Aromatherapy and massage for symptom relief in patients with cancer, <i>Cochrane Database of Systematic Reviews</i> , CD002287, 2004	No studies with children were identified for inclusion in this review. (Note: this Cochrane review is no longer available at The Cochrane Library, as it is not updated).
Finkel, J. C., Pestieau, S. R., Quezado, Z. M. N., Ketamine as an Adjuvant for Treatment of Cancer Pain in Children and Adolescents, <i>Journal of Pain</i> , 8, 515-521, 2007	Descriptive study
Fosburg, M. T., Crone, R. K., Nitrous oxide analgesia for refractory pain in the terminally ill, <i>Journal of the American Medical Association</i> , 250, 511-513, 1983	Case reports
Friedrichsdorf, S. J., Collins, J. J., Principles of pediatric pain management during the end-of-life period, <i>Medical Principles and Practice</i> , 16, 10-15, 2007	Discussion paper
Friedrichsdorf, S. J., Kang, T. I., The management of pain in children with life-limiting illnesses, <i>Pediatric Clinics of North America</i> , 54, 645-72, x, 2007	Discussion paper
Galloway, K. S., Yaster, M., Pain and symptom control in terminally ill children, <i>Pediatric Clinics of North America</i> , 47, 711-46, 2000	Discussion paper
Garten, L., Daehmlow, S., Reindl, T., Wendt, A., Munch, A., Buhner, C., End-of-life opioid administration on neonatal and pediatric intensive care units: nurses' attitudes and practice, <i>European Journal of Pain</i> , 15, 958-65, 2011	Aim not related to the protocol
Gitto, E., Aversa, S., Salpietro, C. D., Barberi, I., Arrigo, T., Trimarchi, G., Reiter, R. J., Pellegrino, S., Pain in neonatal intensive care: Role of melatonin as an analgesic antioxidant, <i>Journal of Pineal Research</i> , 52, 291-295, 2012	Treatment: melatonin is not included in the protocol
Grond, S., Zech, D., Schug, S. A., Lynch, J., Lehmann, K. A., Validation of World Health Organization guidelines for cancer pain relief during the last days and hours of life, <i>Journal of Pain &amp; Symptom Management</i> , 6, 411-22, 1991	This study includes adults (mean age 58)
Guest, J. F., Ruiz, F. J., Russ, J., Gupta, R. D., Mihai, A., Greener, M., A comparison of the resources used in advanced cancer care	This study includes mixed population. Results are not provided separately for children.



Study	Reason for Exclusion
between two different strong opioids: an analysis of naturalistic practice in the UK, Current Medical Research & Opinion, 21, 271-80, 2005	
Hall, W., Christie, M., Currow, D., Cannabinoids and cancer: causation, remediation, and palliation, Lancet Oncology, 6, 35-42, 2005	Discussion paper
Hanks, G. W., Hanna, M., Finlay, I., Radstone, D. J., Keeble, T., Efficacy and pharmacokinetics of a new controlled-release morphine sulfate 200-mg tablet, Journal of Pain & Symptom Management, 10, 6-12, 1995	This study includes adults (18 )
Harlos, M. S., Stenekes, S., Lambert, D., Hohl, C., Chochinov, H. M., Intranasal fentanyl in the palliative care of newborns and infants, Journal of Pain & Symptom Management, 46, 265-74, 2013	Retrospective chart review
Harmer, M., Slattery, P. J., Rosen, M., Vickers, M. D., Intramuscular on demand analgesia: double blind controlled trial of pethidine, buprenorphine, morphine, and meptazinol, British Medical Journal Clinical Research Ed., 286, 680-2, 1983	This study includes adults only
Harris, J. T., Suresh Kumar, K., Rajagopal, M. R., Intravenous morphine for rapid control of severe cancer pain, Palliative Medicine, 17, 248-56, 2003	This study includes mixed population, mostly adults. Results are not reported separately for children
Hohl, C.M., Stenekes, S., Harlos, M.S., Shepherd, E., McClement, S., Chochinov, H.M., Methotrimeprazine for the management of end-of-life symptoms in infants and children, Journal of Palliative Care, 29, 178-185, 2013	Retrospective chart review
Hooke, M. C., Grund, E., Quammen, H., Miller, B., McCormick, P., Bostrom, B., Propofol use in pediatric patients with severe cancer pain at the end of life, Journal of Pediatric Oncology Nursing, 24, 29-34, 2007	Retrospective chart review
Houck, C. S., Wilder, R. T., McDermott, J. S., Sethna, N. F., Berde, C. B., Safety of intravenous ketorolac therapy in children and cost savings with a unit dosing system, Journal of Pediatrics, 129, 292-6, 1996	Descriptive study
Houlahan, K. E., Branowicki, P. A., Mack, J. W., Dinning, C., McCabe, M., Can end of life care for the pediatric patient suffering with escalating and intractable symptoms be improved?, Journal of Pediatric Oncology Nursing, 23, 45-51, 2006	Discussion paper
Jenkin, R. D. T., Berry, M. P., Sequential half-body irradiation in childhood, International Journal of Radiation Oncology Biology Physics, 9, 1969-1971, 1983	Discussion paper
Johnson, J. R., Miller, A. J., The efficacy of choline magnesium trisalicylate (CMT) in the management of metastatic bone pain: a pilot study, Palliative Medicine, 8, 129-35, 1994	This study includes adults only (18 )
Jordan-Marsh, M., Hubbard, J., Watson, R., Deon Hall, R., Miller, P., Mohan, O., The social	Social ecological approach

Study	Reason for Exclusion
ecology of changing pain management: do I have to cry?, <i>Journal of Pediatric Nursing</i> , 19, 193-203, 2004	
Kanbayashi, Y., Hosokawa, T., Okamoto, K., Fujimoto, S., Konishi, H., Otsuji, E., Yoshikawa, T., Takagi, T., Miki, T., Taniwaki, M., Factors predicting requirement of high-dose transdermal fentanyl in opioid switching from oral morphine or oxycodone in patients with cancer pain, <i>Clinical Journal of Pain</i> , 27, 664-7, 2011	This study includes mixed population, mostly adults. Results are not provided separately for children
Komatz, K., Carter, B., Pain and symptom management in pediatric palliative care, <i>Pediatrics in Review</i> , 36, 527-533, 2015	Narrative review, discussion paper
Koontz, B. F., Clough, R. W., Halperin, E. C., Palliative radiation therapy for metastatic Ewing sarcoma, <i>Cancer</i> , 106, 1790-3, 2006	Chart review
Kumar, K. S., Rajagopal, M. R., Naseema, A. M., Intravenous morphine for emergency treatment of cancer pain, <i>Palliative Medicine</i> , 14, 183-8, 2000	This study includes adults
Leavens, M. E., Hill, C. S., Jr., Cech, D. A., Weyland, J. B., Weston, J. S., Intrathecal and intraventricular morphine for pain in cancer patients: initial study, <i>Journal of Neurosurgery</i> , 56, 241-5, 1982	Descriptive study
Lebel, A., Cancer pain and palliative care in children, <i>Techniques in Regional Anesthesia and Pain Management</i> , 9, 145-151, 2005	Discussion paper
Madadi, P., Enato, E.F.O., Fulga, S., Umeoduagu, C.C., MacLeod, S.M., Koren, G., Einarson, T.R., Patterns of paediatric analgesic use in Africa: A systematic review, <i>Archives of Disease in Childhood</i> , 97, 1086-1091, 2012	This systematic review aims to evaluate the patterns of paediatric analgesic use. No outcomes of interest are reported
Maickel, R. P., Current chemotherapeutic trends and the need for additional research (for the dying patient and the bereaved), <i>J. Thanatology</i> , 2, 854-857, 1972	Discussion paper
Marinangeli, F., Ciccozzi, A., Leonardis, M., Aloisio, L., Mazzei, A., Paladini, A., Porzio, G., Marchetti, P., Varrassi, G., Use of strong opioids in advanced cancer pain: a randomized trial, <i>Journal of Pain &amp; Symptom Management</i> , 27, 409-16, 2004	This study includes a mixed population (15 to 81). Results for children are not provided separately.
Mavrogenis, A. F., Rossi, G., Altimari, G., Calabro, T., Angelini, A., Palmerini, E., Rimondi, E., Ruggieri, P., Palliative embolisation for advanced bone sarcomas, <i>Radiologia Medica</i> , 118, 1344-59, 2013	Descriptive study
Mavrogenis, A. F., Rossi, G., Rimondi, E., Calabro, T., Papagelopoulos, P. J., Ruggieri, P., Palliative embolization for osteosarcoma, <i>European journal of orthopaedic surgery &amp; traumatologie</i> , 24, 1351-6, 2014	This study includes adults (mean age 35)
McCulloch, R., Collins, J. J., Pain in children who have life-limiting conditions, <i>Child &amp;</i>	Discussion paper

Study	Reason for Exclusion
Adolescent Psychiatric Clinics of North America, 15, 657-82, 2006	
McDonald, A. J., Cooper, M. G., Patient-controlled analgesia: an appropriate method of pain control in children, Paediatric Drugs, 3, 273-84, 2001	Discussion paper
McGrath, P. A., Development of the World Health Organization Guidelines on Cancer Pain Relief and Palliative Care in Children, Journal of Pain & Symptom Management, 12, 87-92, 1996	Discussion paper
McQuay, Henry J., Collins, Sally L., Carroll, Dawn, Moore, Andrew R., Derry, Sheena, Radiotherapy for the palliation of painful bone metastases, Cochrane Database of Systematic Reviews, 2013	No studies with children were identified for inclusion in this review. Note: this Cochrane review is not longer available at The Cochrane Library, as it is not updated).
McWilliams, K., Keeley, P. W., Waterhouse, E. T., Propofol for terminal sedation in palliative care: a systematic review, Journal of Palliative Medicine, 13, 73-6, 2010	Systematic review of case series and case reports. It is unclear whether it includes children.
Meiring, M. A., Managing pain in children at the end of life: what the GP should know, South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde, 104, 512, 2014	Summary article
Mercadante, S., Pain treatment and outcomes for patients with advanced cancer who receive follow-up care at home, Cancer, 85, 1849-58, 1999	Population: adults only
Mettner, J., Pain reliever, Minnesota Medicine, 92, 12-3, 2009	Discussion paper
Meyler, W. J., de Jongste, M. J., Rolf, C. A., Clinical evaluation of pain treatment with electrostimulation: a study on TENS in patients with different pain syndromes, Clinical Journal of Pain, 10, 22-7, 1994	This study includes adults(mean age 52.7)
Mherekumombe, M. F., Collins, J. J., Patient-controlled analgesia for children at home, Journal of Pain & Symptom Management, 49, 923-7, 2015	Retrospective chart review
Miser, A. W., Davis, D. M., Hughes, C. S., Mulne, A. F., Miser, J. S., Continuous subcutaneous infusion of morphine in children with cancer, American Journal of Diseases of Children, 137, 383-5, 1983	Descriptive study
Miser, A. W., Miser, J. S., Clark, B. S., Continuous intravenous infusion of morphine sulfate for control of severe pain in children with terminal malignancy, Journal of Pediatrics, 96, 930-2, 1980	Descriptive study
Monteiro Caran, E. M., Dias, C. G., Seber, A., Petrilli, A. S., Clinical aspects and treatment of pain in children and adolescents with cancer, Pediatric Blood & Cancer, 45, 925-32, 2005	Descriptive study, institutional prospective study
Namrata, R., Ramamani, P., Saroja, G., Pain management in pediatric age group, Indian Journal of Palliative Care, 15, 84-5, 2009	Descriptive study, good for background reading

Study	Reason for Exclusion
Nguyen, T. T. A., Zacharin, M. R., Pamidronate treatment of steroid associated osteonecrosis in young patients treated for acute lymphoblastic leukaemia - Two-year outcomes, <i>Journal of Pediatric Endocrinology and Metabolism</i> , 19, 161-167, 2006	Osteonecrosis is not a condition of interest in the protocol
Noyes, M., Irving, H., The use of transdermal fentanyl in pediatric oncology palliative care, <i>American Journal of Hospice &amp; Palliative Medicine</i> , 18, 411-6, 2001	Descriptive study
Orsey, A. D., Belasco, J. B., Ellenberg, J. H., Schmitz, K. H., Feudtner, C., Variation in receipt of opioids by pediatric oncology patients who died in children's hospitals, <i>Pediatric Blood &amp; Cancer</i> , 52, 761-6, 2009	Descriptive study (hospital records)
Otis, J., Rothman, M., A Phase III study to assess the clinical utility of low-dose fentanyl transdermal system in patients with chronic nonmalignant pain, <i>Current Medical Research &amp; Opinion</i> , 22, 1493-501, 2006	This study includes adults
Partridge, J.C., Wall, S.N., Analgesia for dying infants whose life support is withdrawn or withheld, <i>Pediatrics</i> , 99, 76-79, 1997	Descriptive study (hospital records)
Paulino, A. C., Palliative radiotherapy in children with neuroblastoma, <i>Pediatric Hematology &amp; Oncology</i> , 20, 111-7, 2003	Descriptive study
Petzke, F., Radbruch, L., Zech, D., Loick, G., Grond, S., Temporal presentation of chronic cancer pain: transitory pains on admission to a multidisciplinary pain clinic, <i>Journal of Pain &amp; Symptom Management</i> , 17, 391-401, 1999	Mixed population, mostly adults (16 to 97). Results for children are not provided separately.
Portenoy, R. K., Moulin, D. E., Rogers, A., Inturrisi, C. E., Foley, K. M., I.v. infusion of opioids for cancer pain: clinical review and guidelines for use, <i>Cancer Treatment Reports</i> , 70, 575-81, 1986	Mixed population (mean age 42, range 1.5 to 67). Results for children are not reported separately
Quigley, C., Wiffen, P., A systematic review of hydromorphone in acute and chronic pain, <i>Journal of Pain &amp; Symptom Management</i> , 25, 169-78, 2003	This systematic review includes both children and adults, however the 3 studies that involve children are not relevant to our protocol due to the nature of their condition
Radha Krishna, L. K., Poulose, J. V., Tan, B. S., Goh, C., Opioid use amongst cancer patients at the end of life, <i>Annals of the Academy of Medicine, Singapore</i> , 39, 790-7, 2010	Mixed population (mean 62, range 15 to 96). Results for children are not provided separately
Raphael, J., Hester, J., Ahmedzai, S., Barrie, J., Farquhar-Smith, P., Williams, J., Urch, C., Bennett, M. I., Robb, K., Simpson, B., Pittler, M., Wider, B., Ewer-Smith, C., DeCourcy, J., Young, A., Lioffi, C., McCullough, R., Rajapakse, D., Johnson, M., Duarte, R., Sparkes, E., Cancer pain: part 2: physical, interventional and complimentary therapies; management in the community; acute, treatment-related and complex cancer pain: a perspective from the British Pain Society endorsed by the UK Association of Palliative Medicine and the Royal	Discussion paper

Study	Reason for Exclusion
College of General Practitioners, Pain Medicine, 11, 872-96, 2010	
Rasmussen, L. A., Gregoire, M. C., Challenging neurological symptoms in paediatric palliative care: An approach to symptom evaluation and management in children with neurological impairment, Paediatrics & Child Health, 20, 159-65, 2015	Discussion paper and case report
Remke, S. S., Chrastek, R., Improving care in the home for children with palliative care needs, Home Healthcare Nurse, 25, 45-51; quiz 52-3, 2007	Discussion paper
Rief, H., Jensen, A. D., Bruckner, T., Herfarth, K., Debus, J., Isometric muscle training of the spine musculature in patients with spinal bony metastases under radiation therapy, BMC Cancer, 11, 482, 2011	This study includes adults
Rork, J. F., Berde, C. B., Goldstein, R. D., Regional anesthesia approaches to pain management in pediatric palliative care: a review of current knowledge, Journal of Pain & Symptom Management, 46, 859-73, 2013	Review of case reports and case series
Schechter, N. L., Allen, D. A., Hanson, K., Status of pediatric pain control: a comparison of hospital analgesic usage in children and adults, Pediatrics, 77, 11-5, 1986	Aim of the study not related to the protocol (analgesic usage)
Schmidt-Hansen, M., Bromham, N., Taubert, M., Arnold, S., Hilgart, J. S., Buprenorphine for treating cancer pain, Cochrane Database of Systematic Reviews, 3, CD009596, 2015	No studies with children were identified for inclusion in this review.
Sharma, D. N., Gairola, M., Mohanti, B. K., Rath, G. K., Radiation therapy in skeletal metastases, Medical Journal of Malaysia, 54, 210-5, 1999	Population: mixed population (mean age 52, range 14 to 80). Results for children are not reported separately
Shaw, T. M., Pediatric palliative pain and symptom management, Pediatric Annals, 41, 329-334, 2012	Discussion paper
Siever, B. A., Pain management and potentially life-shortening analgesia in the terminally ill child: the ethical implications for pediatric nurses, Journal of Pediatric Nursing, 9, 307-12, 1994	Discussion paper (ethics)
Singh, M., Cugati, G., Singh, P., Singh, A. K., Programmable morphine pump (an intrathecal drug delivery system) - A promising option for pain relief and palliation in cancer patients, Indian journal of medical and paediatric oncology: official journal of Indian Society of Medical & Paediatric Oncology, 33, 58-9, 2012	Discussion paper
Sirkia, K., Hovi, L., Pouttu, J., Saarinen-Pihkala, U. M., Pain medication during terminal care of children with cancer, Journal of Pain & Symptom Management, 15, 220-6, 1998	Descriptive study (patients records)
Sjogren, P., Banning, A. M., Henriksen, H., [High-dose epidural opioid treatment of malignant pain], Ugeskrift for laeger, 151, 25-8, 1989	Paper in German

Study	Reason for Exclusion
Smeets, P. M., Beusmans, G. H., Weber, W. E., Prospective study of home morphine infusion in 62 terminally ill patients, <i>Journal of Pain &amp; Symptom Management</i> , 18, 390-400, 1999	This study includes adults(mean age 62)
Southall, D. P., Burr, S., Smith, R. D., Bull, D. N., Radford, A., Williams, A., Nicholson, S., The Child-Friendly Healthcare Initiative (CFHI): Healthcare provision in accordance with the UN Convention on the Rights of the Child. Child Advocacy International. Department of Child and Adolescent Health and Development of the World Health Organization (WHO). Royal College of Nursing (UK). Royal College of Paediatrics and Child Health (UK). United Nations Children's Fund (UNICEF), <i>Pediatrics</i> , 106, 1054-64, 2000	Discussion paper
Stanton, T. R., Wand, B. M., Carr, D. B., Birklein, F., Wasner, G. L., O'Connell, N. E., Local anaesthetic sympathetic blockade for complex regional pain syndrome, <i>Cochrane Database of Systematic Reviews</i> , 8, CD004598, 2013	This Cochrane review includes people with complex regional pain syndrome. Not EOLC pain management.
Stevens, B., Pain assessment and management in infants with cancer, <i>Pediatric Blood &amp; Cancer</i> , 49, 1097-101, 2007	Discussion paper
Stevens, M. M., Dalla Pozza, L., Cavalletto, B., Cooper, M. G., Kilham, H. A., Pain and symptom control in paediatric palliative care, <i>Cancer Surveys</i> , 21, 211-31, 1994	Discussion paper and case report
Stevens, Rosemary, Macbeth, Fergus, Toy, Elizabeth, Coles, Bernadette, Lester, Jason F., Palliative radiotherapy regimens for patients with thoracic symptoms from non-small cell lung cancer, <i>Cochrane Database of Systematic Reviews</i> , 2015	No studies with children were identified for inclusion in this review.
Sutters, K. A., Miaskowski, C., The problem of pain in children with cancer: a research review, <i>Oncology Nursing Forum</i> , 19, 465-71, 1992	Narrative review
Takeda, F., Japanese field-testing of WHO guidelines, <i>PRN Forum</i> , 4, 4-5, 1985	Discussion paper
Tobias, J. D., Applications of intrathecal catheters in children, <i>Paediatric Anaesthesia</i> , 10, 367-375, 2000	Case reports
Torda, T. A., Pybus, D. A., Clinical experience with epidural morphine, <i>Anaesthesia &amp; Intensive Care</i> , 9, 129-34, 1981	Mixed population (range 17 to 82). Results for children are not reported separately for under 18.
Toscani, F., Piva, L., Corli, O., Gallucci, M., Speranza, R., Tamburini, M., De Conno, F., Ventafridda, V., Ketorolac versus diclofenac sodium in cancer pain, <i>Arzneimittel-Forschung</i> , 44, 550-4, 1994	This study includes adults (18 )
Twycross, R. G., The use of narcotic analgesics in terminal illness, <i>Journal of Medical Ethics</i> , 1, 10-7, 1975	Population: adults (mean age 63)
Uthaya, S., Mancini, A., Beardsley, C., Wood, D., Ranmal, R., Modi, N., Managing palliation in	Discussion paper

Study	Reason for Exclusion
the neonatal unit, Archives of Disease in Childhood: Fetal and Neonatal Edition, 99, F349-F352, 2014	
Vallero, S. G., Lijoi, S., Bertin, D., Pittana, L. S., Bellini, S., Rossi, F., Peretta, P., Basso, M. E., Fagioli, F., End-of-life care in pediatric neuro-oncology, Pediatric Blood & Cancer, 61, 2004-11, 2014	Descriptive study
van der Heide, A., van der Maas, P. J., van der Wal, G., Kollee, L. A., de Leeuw, R., Using potentially life-shortening drugs in neonates and infants, Critical Care Medicine, 28, 2595-9, 2000	Aim of the study not related not the protocol, no outcomes of interest reported.
Weisman, S. J., Cancer pain in children: Etiology, guidelines, and symptom control, Problems in Anesthesia, 10, 498-506, 1998	Discussion paper
Wiffen, Philip J., Wee, Bee, Moore, Andrew R., Oral morphine for cancer pain, Cochrane Database of Systematic Reviews, -, 2014	The authors did not identify any children trial that met the inclusion criteria
Wilkinson, D., Three myths in end-of-life care, Journal of Medical Ethics, 39, 389-90, 2013	Discussion paper
Yennurajalingam, S., Kang, J. H., Hui, D., Kang, D. H., Kim, S. H., Bruera, E., Clinical response to an outpatient palliative care consultation in patients with advanced cancer and cancer pain, Journal of Pain & Symptom Management, 44, 340-50, 2012	Mixed population, mostly adults (16 to 89). Results are not reported separately for children.
Zech, D. F., Grond, S., Lynch, J., Hertel, D., Lehmann, K. A., Validation of World Health Organization Guidelines for cancer pain relief: a 10-year prospective study, Pain, 63, 65-76, 1995	Aim not relevant to the protocol (validation of the WHO guidelines)
Zeltzer, L. K., Bush, J. P., Chen, E., Rivala, A., A psychobiologic approach to pediatric pain: Part II. Prevention and treatment, Current Problems in Pediatrics, 27, 264-84, 1997	Discussion paper
Zeltzer, L. K., Tsao, J. C., Stelling, C., Powers, M., Levy, S., Waterhouse, M., A phase I study on the feasibility and acceptability of an acupuncture/hypnosis intervention for chronic pediatric pain, Journal of Pain & Symptom Management, 24, 437-46, 2002	Children with chronic conditions, not LLC/ EOLC

## 1 H.14 Review question: Managing agitation

Reference	Reason for Exclusion
Beecham, Emma, Candy, Bridget, Howard, Richard, McCulloch, Renee, Laddie, Jo, Rees, Henrietta, Vickerstaff, Victoria, BluebondLangner, Myra, Jones, Louise, Pharmacological interventions for pain in children and adolescents with life-limiting conditions, Cochrane Database of Systematic Reviews, 2015	The cochrane review on pain management, no outcome on agitation.
Bower, K., Hirst, J., Pirrello, R., A whirlwind tour: Psychopharmacologic management of depression, anxiety, delirium, and insomnia in children - A palliative care perspective (308)	Conference abstract

Reference	Reason for Exclusion
(advanced) pediatric, Journal of Pain and Symptom Management, 41 (1), 184, 2011	
Chiu, T. Y., Hu, W. Y., Lue, B. H., Cheng, S. Y., Chen, C. Y., Sedation for refractory symptoms of terminal cancer patients in Taiwan, Journal of Pain & Symptom Management, 21, 467-72, 2001	Only 2.1% of included patients were under age 8, no outcomes on agitation either.
Fosburg, M. T., Crone, R. K., Nitrous oxide analgesia for refractory pain in the terminally ill, Journal of the American Medical Association, 250, 511-513, 1983	Case reports
Harlos, M. S., Stenekes, S., Lambert, D., Hohl, C., Chochinov, H. M., Intranasal fentanyl in the palliative care of newborns and infants, Journal of Pain & Symptom Management, 46, 265-74, 2013	Description of intranasal fentanyl's use in 11 dying neonates. No results reported.
Hohl, C.M., Stenekes, S., Harlos, M.S., Shepherd, E., McClement, S., Chochinov, H.M., Methotrimeprazine for the management of end-of-life symptoms in infants and children, Journal of Palliative Care, 29, 178-185, 2013	Case report, no comparison was made.
Holden, P., The critically ill child or adolescent, Problems in Critical Care, 2, 86-100, 1988	Discussion paper.
Hooke, M. C., Grund, E., Quammen, H., Miller, B., McCormick, P., Bostrom, B., Propofol use in pediatric patients with severe cancer pain at the end of life, Journal of Pediatric Oncology Nursing, 24, 29-34, 2007	No outcomes on agitation reported.
Houlahan, K. E., Branowicki, P. A., Mack, J. W., Dinning, C., McCabe, M., Can end of life care for the pediatric patient suffering with escalating and intractable symptoms be improved?, Journal of Pediatric Oncology Nursing, 23, 45-51, 2006	Discussion paper
Radha Krishna, L. K., Poulouse, V. J., Goh, C., The use of midazolam and haloperidol in cancer patients at the end of life, Singapore Medical Journal, 53, 62-6, 2012	Age of participants ranged from 15 to 96 years (median 62), no subgroup analysis by age was conducted.
Santra, S., Simmons, L., Wassmer, E., Levomepromazine as a treatment for non-epileptic movement disorder in advanced neurodegenerative lysosomal disorders, Molecular Genetics and Metabolism, 114 (2), S101-S102, 2015	Conference abstract
Selvaggi, K., Fitzgerald, K., Moment, A., Rickerson, E., Bernacki, R., If it's not one thing, it's another: The pain is gone but the suffering continues (SA521), Journal of Pain and Symptom Management, 45 (2), 407, 2013	Conference proceedings
Stoddard, F.J., Usher, C.T., Abrams, A.N., Psychopharmacology in Pediatric Critical Care, Child and Adolescent Psychiatric Clinics of North America, 15, 611-655, 2006	Narrative review



## 1 H.15 Review question: Managing respiratory distress

Reference	Reason for Exclusion
Birnkrant,D.J., Pope,J.F., Eiben,R.M., Management of the respiratory complications of neuromuscular diseases in the pediatric intensive care unit, <i>Journal of Child Neurology</i> , 14, 139-143, 1999	Narrative review about the management of respiratory complications of neuromuscular diseases in the paediatric intensive care unit
Bosch-Alcaraz, A., [Non-invasive ventilation improves comfort in pediatric palliative care patients], <i>Enfermeria Intensiva</i> , 25, 91-9, 2014	Not in English
Dy, SM, Aslakson, R, Wilson, RF, Fawole, OA, Lau, BD, Martinez, KA, Vollenweider, D, Apostol, C, Bass, EB, Closing the quality gap: revisiting the state of the science series - Improving health care and palliative care for advanced and serious illness (Structured abstract), <i>Health Technology Assessment Database</i> , 2015	AHRQ abstract. Aim not relevant.
Friedrichsdorf, S., From coke to pepsi to mountain dew? Rotating opioids in advanced pediatric palliative care, <i>Journal of Pain and Symptom Management</i> , 47 (2), 434, 2014	This study evaluates the role of rotating opioids, but it is not focused on respiratory distress. Conference abstract.
Friedrichsdorf, S. J., Collins, J. J., Management of non-pain symptoms in pediatric palliative care, <i>Medical Principles and Practice</i> , 16, 3-9, 2007	Discussion paper
Gonzalez, S., Thompson, D., Hayward, R., Lane, R., Treatment of obstructive sleep apnoea using nasal CPAP in children with craniofacial dysostoses, <i>Childs Nervous System</i> , 12, 713-9, 1996	Not relevant population: obstructive sleep apnoea
Harlos, M. S., Stenekes, S., Lambert, D., Hohl, C., Chochinov, H. M., Intranasal fentanyl in the palliative care of newborns and infants, <i>Journal of Pain &amp; Symptom Management</i> , 46, 265-74, 2013	This study does not focus on respiratory distress. Case series.
Hilton, T., Orr, R. D., Perkin, R. M., Ashwal, S., End of life care in Duchenne muscular dystrophy, <i>Pediatric Neurology</i> , 9, 165-77, 1993	Discussion paper
Hohl,C.M., Stenekes,S., Harlos,M.S., Shepherd,E., McClement,S., Chochinov,H.M., Methotrimeprazine for the management of end-of-life symptoms in infants and children, <i>Journal of Palliative Care</i> , 29, 178-185, 2013	Retrospective chart review. Does not address respiratory distress.
Houlahan, K. E., Branowicki, P. A., Mack, J. W., Dinning, C., McCabe, M., Can end of life care for the pediatric patient suffering with escalating and intractable symptoms be improved?, <i>Journal of Pediatric Oncology Nursing</i> , 23, 45-51, 2006	Discussion paper
Hu, W. Y., Chiu, T. Y., Cheng, S. Y., Chen, C. Y., Morphine for dyspnea control in terminal cancer patients: is it appropriate in Taiwan?, <i>Journal of Pain &amp; Symptom Management</i> , 28, 356-63, 2004	Mostly adults. Only 2.2% were <18 years. Results are not provided separately.
Korzeniewska-Eksterowicz, A., Przynslo, L., Fendler, W., Stolarska, M., Mlynarski, W., Palliative sedation at home for terminally ill	Retrospective analysis of medical records.

Reference	Reason for Exclusion
children with cancer, <i>Journal of Pain and Symptom Management</i> , 48, 968-974, 2014	
Lorenz, K, Lynn, K, Dy, S, Cancer care quality measures: symptoms and end-of-life care (Structured abstract), <i>Health Technology Assessment Database</i> , 2015	HTA abstract. Focused on cancer quality measures.
Meade, M. O., Herridge, M. S., An evidence-based approach to acute respiratory distress syndrome, <i>Respiratory Care</i> , 46, 1368-76; discussion 1376-9, 2001	Review on acute respiratory distress syndrome.
Pfenninger, J., Gerber, A., Tschappeler, H., Zimmermann, A., Adult respiratory distress syndrome in children, <i>Journal of Pediatrics</i> , 101, 352-7, 1982	Population not relevant: Adult respiratory distress syndrome in children
Polosa, Riccardo, Simidchiev, Alexander, Walters, Haydn E., Nebulised morphine for severe interstitial lung disease, <i>Cochrane Database of Systematic Reviews</i> , 2011	Adults only
Prodhan, P., Noviski, N., Pediatric acute hypoxemic respiratory failure: management of oxygenation, <i>Journal of Intensive Care Medicine</i> , 19, 140-53, 2004	This paper reviews the management of paediatric acute hypoxemic respiratory failure.
Robinson, W. M., Palliation of dyspnea in pediatrics, <i>Chronic Respiratory Disease</i> , 9, 251-6, 2012	Narrative review.
Schiller, O., Schonfeld, T., Yaniv, I., Stein, J., Kadmon, G., Nahum, E., Bi-level positive airway pressure ventilation in pediatric oncology patients with acute respiratory failure, <i>Journal of Intensive Care Medicine</i> , 24, 383-8, 2009	This paper includes children with acute respiratory failure.
Sinha, S., Moya, F., Donn, S. M., Surfactant for respiratory distress syndrome: are there important clinical differences among preparations?, <i>Current Opinion in Pediatrics</i> , 19, 150-4, 2007	This paper reviews the role of exogenous surfactant replacement for respiratory distress syndrome.
Ullrich, C. K., Mayer, O. H., Assessment and management of fatigue and dyspnea in pediatric palliative care, <i>Pediatric Clinics of North America</i> , 54, 735-56, xi, 2007	This paper reviews the management of fatigue and dyspnoea. Review and cases.
Wee, Bee, Hillier, Richard, Interventions for noisy breathing in patients near to death, <i>Cochrane Database of Systematic Reviews</i> , -, 2012	This Cochrane review only includes studies with adults. None of the excluded studies were carried out with children.
Wolfe, J., Grier, H. E., Klar, N., Levin, S. B., Ellenbogen, J. M., Salem-Schatz, S., Emanuel, E. J., Weeks, J. C., Symptoms and suffering at the end of life in children with cancer, <i>New England Journal of Medicine</i> , 342, 326-33, 2000	This paper describes the prevalence of symptoms and suffering at the end of life in children with cancer.
Yu, W. L., Lu, Z. J., Wang, Y., Shi, L. P., Kuang, F. W., Qian, S. Y., Zeng, Q. Y., Xie, M. H., Zhang, G. Y., Zhuang, D. Y., Fan, X. M., Sun, B., Collaborative Study Group of Pediatric Respiratory Failure, The epidemiology of acute respiratory distress syndrome in pediatric intensive care units in China, <i>Intensive Care Medicine</i> , 35, 136-43, 2009	This study only includes children with acute respiratory distress.

## 1 H.16 Review question: Managing seizure

Reference	Reason for Exclusion
Coppola, G., Toro, A., Operto, F. F., Ferrarioli, G., Pisano, S., Viggiano, A., Verrotti, A., Mozart's music in children with drug-refractory epileptic encephalopathies, <i>Epilepsy &amp; Behavior</i> , 50, 18-22, 2015	Descriptive study
Friedrichsdorf, S. J., Collins, J. J., Management of non-pain symptoms in pediatric palliative care, <i>Medical Principles and Practice</i> , 16, 3-9, 2007	Discussion paper for reference.
Krouwer, H. G., Pallagi, J. L., Graves, N. M., Management of seizures in brain tumor patients at the end of life, <i>Journal of Palliative Medicine</i> , 3, 465-75, 2000	Discussion paper on 'DO's' and 'DON'Ts' when managing people with seizures. Age of patients mentioned unclear either.
Postovsky, S., Moaed, B., Krivoy, E., Ofir, R., Arush, M. W. B., Practice of palliative sedation in children with brain tumors and sarcomas at the end of life, <i>Pediatric Hematology and Oncology</i> , 24, 409-415, 2007	The article only reported that palliative sedation was used without further information on specific medications.
Wusthoff, C. J., Shellhaas, R. A., Licht, D. J., Management of common neurologic symptoms in pediatric palliative care: seizures, agitation, and spasticity, <i>Pediatric Clinics of North America</i> , 54, 709-33, xi, 2007	Discussion paper

## 2 H.17 Review question: Managing hydration

Reference	Reason for exclusion
End of life neonatal care: withdrawal of artificial nutrition and hydration, <i>Journal of Paediatrics &amp; Child Health</i> , 49, 787-788, 2013	Editorial, not relevant
Chiu, T. Y., Hu, W. Y., Chuang, R. B., Chen, C. Y., Nutrition and hydration for terminal cancer patients in Taiwan, <i>Supportive Care in Cancer</i> , 10, 630-6, 2002	No participants were < 18 years old. Only 5 participants were 18. Unable to extract estimates for children. Study not relevant
Morin, K. H., Infant nutrition during palliative care, <i>MCN, American Journal of Maternal Child Nursing</i> , 32, 320, 2007	Not relevant
Moreno Villares, J. M., [Nutrition and Hydration in Newborns: Limiting Treatment Decisions], <i>Cuadernos de Bioetica</i> , 26, 241-9, 2015	Paper in foreign language

## 3 H.18 Review question: Managing nutrition

Reference	Reason for Exclusion
Chiu, T. Y., Hu, W. Y., Chuang, R. B., Chen, C. Y., Nutrition and hydration for terminal cancer patients in Taiwan, <i>Supportive Care in Cancer</i> , 10, 630-6, 2002	Adult population only.
Kruzel, A., Jakubczyk, M., Kusza, K., Szopinski, J., Dabrowiecki, S., Wandowska, M., Home enteral nutrition in children and adult cancer patients, <i>Pediatrica Wspolczesna</i> , 13, 161-165, 2011	Indications for home enteral nutrition. Not last days of life. Out of the scope of the review.
Lorenz, K., Lynn, K., Dy, S, Cancer care quality measures: symptoms and end-of-life care (Structured	HTA report. Does not cover nutrition.

Reference	Reason for Exclusion
abstract), Health Technology Assessment Database, 2015	
MacFie, J., Ethical and legal considerations in the provision of nutritional support to the perioperative patient, <i>Current Opinion in Clinical Nutrition and Metabolic Care</i> , 3, 23-29, 2000	Emphasis is on adult patients rather than children and not on the issues that surround the terminally ill patient.
Pousset, G., Bilsen, J., Cohen, J., Mortier, F., Deliens, L., Continuous deep sedation at the end of life of children in Flanders, Belgium, <i>Journal of Pain &amp; Symptom Management</i> , 41, 449-55, 2011	Deep sedation at the end of life. Not relevant.
Rapoport, A., Shaheed, J., Newman, C., Rugg, M., Steele, R., Parental perceptions of forgoing artificial nutrition and hydration during end-of-life care, <i>Pediatrics</i> , 131, 861-9, 2013	Qualitative study.
Siden, H., Tucker, T., Derman, S., Cox, K., Soon, G. S., Hartnett, C., Straatman, L., Pediatric enteral feeding intolerance: a new prognosticator for children with life-limiting illness?, <i>Journal of Palliative Care</i> , 25, 213-7, 2009	Case series.
Tsai, E., Withholding and withdrawing artificial nutrition and hydration, <i>Paediatrics &amp; Child Health</i> , 16, 241-4, 2011	Canadian Paediatric Society. Practice point.

## 1 H.19 Review question: Recognising that a child or young person is likely to die within hours or days

2

Study	Reason for Exclusion
Abarshi, E. A., Echteld, M. A., Van den Block, L., Donker, G. A., Deliens, L., Onwuteaka-Philipsen, B. D., Recognising patients who will die in the near future: a nationwide study via the Dutch Sentinel Network of GPs, <i>British Journal of General Practice</i> , 61, e371-8, 2011	This study mostly includes adults. Age group 1-64: 20%
Anonymous,, Cancer care during the last phase of life, <i>Journal of Clinical Oncology</i> , 16, 1986-96, 1998	Discussion paper/ society statement
Apple, F. S., Murakami, M. M., Pearce, L. A., Herzog, C. A., Predictive value of cardiac troponin I and T for subsequent death in end-stage renal disease, <i>Circulation</i> , 106, 2941-5, 2002	This study includes adults only
Banupriya, C., Ratnakar,, Doureradjou, P., Mondal, N., Vishnu, B., Koner, B. C., Can urinary excretion rate of malondialdehyde, uric acid and protein predict the severity and impending death in perinatal asphyxia?, <i>Clinical Biochemistry</i> , 41, 968-73, 2008	This study evaluates the impact of perinatal asphyxia
Beretta, S., Polastri, D., Clerici, C. A., Casanova, M., Cefalo, G., Ferrari, A., Luksch, R., Massimino, M., Meazza, C., Podda, M. G., Spreafico, F., Terenziani, M., Bellani, F. F., End of life in children with cancer: experience at the pediatric oncology department of the istituto nazionale tumori in Milan, <i>Pediatric Blood &amp; Cancer</i> , 54, 88-91, 2010	This study describes experiences of children with cancer receiving palliative care.

Study	Reason for Exclusion
Blume, E. D., Balkin, E. M., Aiyagari, R., Ziniel, S., Beke, D. M., Thiagarajan, R., Taylor, L., Kulik, T., Pituch, K., Wolfe, J., Parental perspectives on suffering and quality of life at end-of-life in children with advanced heart disease: an exploratory study, <i>Pediatric Critical Care Medicine</i> , 15, 336-42, 2014	The study aims to look at parents' perception of quality of life in the last month.
Bozcuk, H., Bilge, U., Koyuncu, E., Gulkesen, H., An application of a genetic algorithm in conjunction with other data mining methods for estimating outcome after hospitalization in cancer patients, <i>Medical Science Monitor</i> , 10, CR246-51, 2004	This study includes adults only
Bruera, S., Chisholm, G., Dos Santos, R., Crovador, C., Bruera, E., Hui, D., Variations in vital signs in the last days of life in patients with advanced cancer, <i>Journal of Pain &amp; Symptom Management</i> , 48, 510-7, 2014	This study includes adults only
Carter, B. S., Howenstein, M., Gilmer, M. J., Throop, P., France, D., Whitlock, J. A., Circumstances surrounding the deaths of hospitalized children: opportunities for pediatric palliative care, <i>Pediatrics</i> , 114, e361-6, 2004	This study includes children who did not have a recognized life-limiting condition
Catlin, A., Transition from curative efforts to purely palliative care for neonates: Does physiology matter?, <i>Advances in Neonatal Care</i> , 11, 216-222, 2011	No outcomes of interest reported
Catlin, A., Carter, B., Creation of a neonatal end-of-life palliative care protocol, <i>Journal of Perinatology</i> , 22, 184-195, 2002	This study describes the development of a neonatal EOLC protocol.
Chan, Raymond J., Webster, Joan, End-of-life care pathways for improving outcomes in caring for the dying, <i>Cochrane Database of Systematic Reviews</i> , 2013	This Cochrane review evaluates the use of care pathways for improving end of life care.
Chiplen, F., Lawton, S., Linklater, G., Salunke, S., Cogdell, L., Fraser, A., Vijayan, B., End of life care in liver disease, <i>Gut</i> , 63, A224, 2014	Conference abstract. Little information available. Undefined age group.
Chong, P. H., Chan, M. Y., Yusri, L. I., Do children die? A retrospective review of deaths in a children's hospital, <i>Singapore Medical Journal</i> , 53, 192-5, 2012	This study included children who died without a life-limiting condition
Cohen, R. I., Goggin, J., Dellon, E. P., Sabadosa, K., Homa, K., Marshall, B. C., Care processes for adults dying from complications of cystic fibrosis: Results of a nationwide survey, <i>Pediatric Pulmonology</i> , 48, 395-396, 2013	This study includes adults only
Cohen-Gogo, S., Marioni, G., Laurent, S., Gaspar, N., Semeraro, M., Gabolde, M., Dufour, C., Valteau-Couanet, D., Brugieres, L., End of life care in adolescents and young adults with cancer: experience of the adolescent unit of the Institut Gustave Roussy, <i>European Journal of Cancer</i> , 47, 2735-41, 2011	Retrospective chart review.
Cui, N., Bao, X. L., Yang, Z. D., Lu, Q. B., Hu, C. Y., Wang, L. Y., Wang, B. J., Wang, H. Y., Liu, K., Yuan, C., Fan, X. J., Wang, Z., Zhang, L.,	This study included children without a life-limiting condition

Study	Reason for Exclusion
Zhang, X. A., Hu, L. P., Liu, W., Cao, W. C., Clinical progression and predictors of death in patients with severe fever with thrombocytopenia syndrome in China, <i>Journal of Clinical Virology</i> , 59, 12-17, 2014	
Dvorak, A., Neumann, M., Diamond, C., Outcomes after admission to the pediatric intensive care unit following pediatric hematopoietic stem cell transplant, <i>Pediatric Research</i> , 70 (4), 434, 2011	Conference abstract, data provided not relevant.
Engle, W. A., Peters, E. A., Gunn, S. K., West, K. W., Langefeld, C., Hui, S. L., Mortality prediction and interval until death in near-term and term neonates with respiratory failure, <i>Journal of perinatology: official journal of the California Perinatal Association</i> , 13, 368-375, 1993	This study included children without a life-limiting condition
Escobar Pinzon, L. C., Claus, M., Zepf, K. I., Fischbeck, S., Weber, M., Symptom Prevalence in the Last days of Life in Germany: The Role of Place of Death, <i>American Journal of Hospice and Palliative Medicine</i> , 29, 431-437, 2012	This study mostly includes adults. Age group 1-59: 8.7% -
Feudtner, C., Hexem, K. R., Shabbout, M., Feinstein, J. A., Sochalski, J., Silber, J. H., Prediction of pediatric death in the year after hospitalization: a population-level retrospective cohort study, <i>Journal of Palliative Medicine</i> , 12, 160-9, 2009	This study aims to develop a predictive tool of paediatric death, but includes hospitalized children, and not children receiving EOLC
Gamba, G., Mejia, J. L., Saldivar, S., Pena, J. C., Correa-Rotter, R., Death risk in CAPD patients. The predictive value of the initial clinical and laboratory variables, <i>Nephron</i> , 65, 23-7, 1993	This study includes adults only
Guertin, M. H., Cote-Brisson, L., Major, D., Brisson, J., Factors associated with death in the emergency department among children dying of complex chronic conditions: population-based study, <i>Journal of Palliative Medicine</i> , 12, 819-25, 2009	This study aims to determine the risk of death according to health condition, but does not look at the prognostic value of the different signs and symptoms
Hechler, T., Blankenburg, M., Friedrichsdorf, S. J., Garske, D., Hubner, B., Menke, A., Wamsler, C., Wolfe, J., Zernikow, B., Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer, <i>Klinische Padiatrie</i> , 220, 166-74, 2008	The study aims to look at parents' perception of quality of life in the last month.
<b>Heckford, E., Beringer, A. J., Advance care planning: challenges and approaches for pediatricians, <i>Journal of Palliative Medicine</i>, 17, 1049-53, 2014</b>	Retrospective case note review
Hinds, P. S., Oakes, L., Quargnenti, A., Furman, W., Bowman, L., Gilger, E., Gattuso, J., Martinson, I., Yi, K. H., Drew, D., An international feasibility study of parental decision making in pediatric oncology, <i>Oncology Nursing Forum</i> , 27, 1233-43, 2000	This study aims to describe parental decision making in relation to treatment

Study	Reason for Exclusion
Holt, S., Lim, J., Jones, C., Bricker, L., Turner, M., Agarwal, U., Subhedar, N., Brook, L., Antenatal advance care planning: 3 years experience from a single centre, <i>Archives of Disease in Childhood</i> , 99, A189, 2014	Retrospective review of antenatal palliative care referrals
Hongo, T., Watanabe, C., Okada, S., Inoue, N., Yajima, S., Fujii, Y., Ohzeki, T., Analysis of the circumstances at the end of life in children with cancer: symptoms, suffering and acceptance, <i>Pediatrics International</i> , 45, 60-4, 2003	Retrospective review of medical records. descriptive data only. Signs and symptoms >2 weeks before death
Howes, C., Caring until the end: a systematic literature review exploring Paediatric Intensive Care Unit end-of-life care, <i>Nursing in Critical Care</i> , 20, 41-51, 2015	This systematic review aims to look at the provision of end of life care. No outcomes of interest reported
Hui, D., Dos Santos, R., Chisholm, G., Bansal, S., Souza Crovador, C., Bruera, E., Bedside clinical signs associated with impending death in patients with advanced cancer: preliminary findings of a prospective, longitudinal cohort study, <i>Cancer</i> , 121, 960-7, 2015	This study includes adults only
Hui, D., Hess, K., dos Santos, R., Chisholm, G., Bruera, E., A diagnostic model for impending death in cancer patients: Preliminary report, <i>Cancer</i> , 121, 3914-21, 2015	This study includes adults only
Hui, D., Kilgore, K., Fellman, B., Urbauer, D., Hall, S., Fajardo, J., Rhondali, W., Kang, J. H., Del Fabbro, E., Zhukovsky, D., Bruera, E., Development and cross-validation of the in-hospital mortality prediction in advanced cancer patients score: a preliminary study, <i>Journal of Palliative Medicine</i> , 15, 902-9, 2012	This study includes adults only
Jalmsell, L., Kreicbergs, U., Onelov, E., Steineck, G., Henter, J. I., Symptoms affecting children with malignancies during the last month of life: a nationwide follow-up, <i>Pediatrics</i> , 117, 1314-20, 2006	Survey to parents to study symptoms in the last month of life.
Karvellas, C. J., Bagshaw, S. M., Advances in management and prognostication in critically ill cirrhotic patients, <i>Current Opinion in Critical Care</i> , 20, 210-7, 2014	This study includes adults only
Kawarai, H., Kajimoto, K., Minami, Y., Hagiwara, N., Kasanuki, H., Risk of sudden death in end-stage hypertrophic cardiomyopathy, <i>Journal of Cardiac Failure</i> , 17, 459-464, 2011	This study includes adults only
Lee, G. Y., Gin-Mesta, K., Lin, K., Schreiber, M. D., Meadow, W. L., Prognostic equipoise: HFOV neither obscures nor clarifies intuitions of impending death in neonates, <i>Pediatric Research</i> , 51, 43A, 2002	Conference abstract. No relevant information included in the abstract.
Marroni, C. P., de Mello Brandao, A. B., Hennigen, A. W., Marroni, C., Zanotelli, M. L., Cantisani, G., Fuchs, S. C., Liver Transplantation, Group, MELD scores with incorporation of serum sodium and death prediction in cirrhotic patients on the waiting list for liver transplantation: a single center	This study includes adults only (people aged 17 or older)

Study	Reason for Exclusion
experience in southern Brazil, <i>Clinical Transplantation</i> , 26, E395-401, 2012	
Pritchard, M., Srivastava, D. K., Okuma, J. O., Powell, B., Burghen, E., West, N. K., Gattuso, J. S., Spunt, S. L., Baker, J. N., Kane, J., Furman, W. L., Hinds, P. S., Bereaved parents' perceptions about when their child's cancer-related death would occur, <i>Journal of Pain &amp; Symptom Management</i> , 38, 561-7, 2009	This study describes parent's perceptions regarding their child's death, but does not explore signs or symptoms of imminent death.
Shore, P. M., Huang, R., Roy, L., Darnell, C., Grein, H., Robertson, T., Thompson, L., Development of a bedside tool to predict time to death after withdrawal of life-sustaining therapies in infants and children, <i>Pediatric Critical Care Medicine</i> , 13, 415-22, 2012	This study focuses on laboratory parameters, which is out of the scope of the review.
Sizoo, E. M., Braam, L., Postma, T. J., Pasman, H. R., Heimans, J. J., Klein, M., Reijneveld, J. C., Taphoorn, M. J., Symptoms and problems in the end-of-life phase of high-grade glioma patients, <i>Neuro-Oncology</i> , 12, 1162-6, 2010	This study includes adults only
Skaug, K., Eide, G. E., Gulsvik, A., Prevalence and predictors of symptoms in the terminal stage of lung cancer: A community study, <i>Chest</i> , 131, 389-94, 2007	This study includes adults only
Skiles, J. L., Bell, C., Pradhan, K. R., Champion, V., Patterns of death and dying in pediatric oncology patients: A retrospective review, <i>Pediatric Blood and Cancer</i> , 52 (6), 717, 2009	Retrospective chart review on the patterns of death.
Strout, T. D., Haydar, S. A., Han, P. J. K., Bond, A. G., Utility of the modified "surprise question" for predicting inpatient mortality in emergency department patients, <i>Annals of Emergency Medicine</i> , 1), S81, 2015	Conference abstract. Mixed population, mean age 63 years. Data not reported separately for children
Sturman, J., Cassidy, J. V., End of life care in a paediatric critical care setting, <i>Current Anaesthesia and Critical Care</i> , 17, 271-275, 2006	Discussion paper
Sutradhar, R., Atzema, C., Seow, H., Earle, C., Porter, J., Barbera, L., Repeated assessments of symptom severity improve predictions for risk of death among patients with cancer, <i>Journal of Pain &amp; Symptom Management</i> , 48, 1041-9, 2014	This study includes adults only
Ullrich, C. K., Dussel, V., Hilden, J. M., Sheaffer, J. W., Moore, C. L., Berde, C. B., Wolfe, J., Fatigue in children with cancer at the end of life, <i>Journal of Pain &amp; Symptom Management</i> , 40, 483-94, 2010	This is a retrospective cross-sectional study that describes the management and understanding fatigue in the last month.
Vigano, A., Donaldson, N., Higginson, I. J., Bruera, E., Mahmud, S., Suarez-Almazor, M., Quality of life and survival prediction in terminal cancer patients: a multicenter study, <i>Cancer</i> , 101, 1090-8, 2004	This study includes adults only
von Lutzau, P., Otto, M., Hechler, T., Metzger, S., Wolfe, J., Zernikow, B., Children dying from cancer: parents' perspectives on symptoms, quality of life, characteristics of death, and end-	The study aims to look at parents' perception of quality of life



Study	Reason for Exclusion
of-life decisions, Journal of Palliative Care, 28, 274-81, 2012	
Wolfe, J., Grier, H. E., Klar, N., Levin, S. B., Ellenbogen, J. M., Salem-Schatz, S., Emanuel, E. J., Weeks, J. C., Symptoms and suffering at the end of life in children with cancer, New England Journal of Medicine, 342, 326-33, 2000	This is a survey-based study where parents report on common symptoms and related suffering in the last month of life.
Wusthoff, C. J., Shellhaas, R. A., Licht, D. J., Management of common neurologic symptoms in pediatric palliative care: seizures, agitation, and spasticity, Pediatric Clinics of North America, 54, 709-33, xi, 2007	Discussion paper about symptom management

## 1 H.20 HE Excluded studies

2

Study	Reason for Exclusion
Ananth, P., Melvin, P., Berry, J. G., Wolfe, J., Health care utilization and costs in the last year of life for children with malignancies, Pediatric Blood and Cancer, 61, S238, 2014	Conference abstract. US setting makes it of questionable relevance and generalisability to current UK context.
Ananth, P., Melvin, P., Wolfe, J., Berry, J. G., Trends in hospital utilization among children receiving inpatient palliative care, Journal of Pain and Symptom Management, 47 (2), 467, 2014	Conference abstract only reporting preliminary analyses. Concluded that palliative care consultation could reduce hospitalisation in US setting but this did not directly relate to review questions
Belasco, J. B., Danz, P., Drill, A., Schmid, W., Burkey, E., Supportive care: palliative care in children, adolescents, and young adults--model of care, interventions, and cost of care: a retrospective review, Journal of Palliative Care, 16, 39-46, 2000	The cost analysis is not comprehensive, is slightly dated and is based on a US setting where charges are unlikely to be generalizable to UK context, especially the restrictions imposed by managed care.
Beringer, A. J., Eaton, N. M., Jones, G. L., Providing a children's palliative care service in the community through fixed-term grants: the staff perspective, Child: Care, Health and Development, 33, 619-624, 2007	Qualitative review based on semi-structured telephone interviews. Does discuss issues relating to funding/resources but not quantified.
Bogetz, J. F., Ullrich, C. K., Berry, J. G., Pediatric hospital care for children with life-threatening illness and the role of palliative care, Pediatric Clinics of North America, 61, 719-733, 2014	Focus is life threatening illness rather than end of life per se. It is a discussion paper which cites other sources to support a case for paediatric palliative care but is not economic data and doesn't report in any detail on resource use and/or costs
Bona, K., Bates, J., Wolfe, J., Successful implementation of a novel state-funded pediatric palliative care program (413-B), Journal of Pain and Symptom Management, 41 (1), 230-231, 2011	Conference abstract discussing barriers to the provision of palliative care and a Massachusetts model for the provision of paediatric palliative care. Describes the funding for this model but otherwise no resource use or cost data
Boyte, W. R., Newell, J., Paine, C. C., Pediatric palliative care program development, Journal of Palliative Medicine, 17 (3), A3-A4, 2014	This is a Conference abstract and is a description of a newly developed paediatric palliative care programme. It is a very top level description and doesn't include cost or resource use data
Bradford, N. K., Armfield, N. R., Young, J., Smith, A. C., Paediatric palliative care by video consultation at home: a cost minimisation	Context is not generalizable to UK setting and the study is motivated by the practical difficulties of arranging face-to-face consultations in the

Study	Reason for Exclusion
analysis, BMC Health Services Research, 14, 328, 2014	state of Queensland because of the distances involved. Air travel costs had a significant bearing on the results
Bradford, N., Armfield, N. R., Young, J., Smith, A. C., The case for home based telehealth in pediatric palliative care: A systematic review, BMC Palliative Care, 12, 2013	Systematic review with very limited focus on resource issues
Bradford, N., Pedersen, L. A., Herbert, A., Irving, H., Palliative care afterhours phone support, who calls and why: A retrospective review of an afterhours phone service, Pediatric Blood and Cancer, 57 (5), 842, 2011	Context is not generalizable to UK setting and the study is motivated by the practical difficulties of arranging face-to-face consultations in the state of Queensland because of the distances involved. Air travel costs had a significant bearing on the results
Byock, I., Twohig, J. S., Merriman, M., Collins, K., Promoting excellence in end-of-life care: a report on innovative models of palliative care, Journal of Palliative Medicine, 9, 137-51, 2006	The US context and projects are in the main not generalizable to a UK setting and there is limited financial/resource use data. Most of the evaluated projects are in adult populations
Creek, L. V., A homecare hospice profile: description, evaluation, and cost analysis, Journal of Family Practice, 14, 53-8, 1982	Adult population. Additionally, it is very dated and from a US setting and is unlikely to be generalizable to the current UK context.
Fraser, L. K., van Laar, M., Miller, M., Aldridge, J., McKinney, P. A., Parslow, R. C., Feltbower, R. G., Does referral to specialist paediatric palliative care services reduce hospital admissions in oncology patients at the end of life?, British Journal of Cancer, 108, 1273-9, 2013	Specialist paediatric palliative care services not part of guideline remit, some limited resource use data but no formal costing
Gans, D., Kominski, G. F., Roby, D. H., Diamant, A. L., Chen, X., Lin, W., Hohe, N., Better outcomes, lower costs: palliative care program reduces stress, costs of care for children with life-threatening conditions, Policy Brief (Ucla Center for Health Policy Research), 1-8, 2012	A specific US palliative care programme which includes some costs but which doesn't map onto a particular guideline review question
Guerriere, D. N., Zagorski, B., Fassbender, K., Masucci, L., Librach, L., Coyte, P. C., Cost variations in ambulatory and home-based palliative care, Palliative Medicine, 24, 523-32, 2010	Adult population
Knapp, C., e-Health in pediatric palliative care, American Journal of Hospice & Palliative Medicine, 27, 66-73, 2010	US context which is unlikely to be generalizable to UK. Discussion article highlighting areas of palliative care that could benefit from e-health with no costing
Knapp, C. A., Shenkman, E. A., Marcu, M. I., Madden, V. L., Terza, J. V., Pediatric palliative care: Describing hospice users and identifying factors that affect hospice expenditures, Journal of Palliative Medicine, 12, 223-229, 2009	Article seeks to identify factors which determine hospice expenditures but not a comparison of competing alternatives.
Knapp, C. A., Thompson, L. A., Vogel, W. B., Madden, V. L., Shenkman, E. A., Developing a pediatric palliative care program: addressing the lack of baseline expenditure information, American Journal of Hospice & Palliative Medicine, 26, 40-6, 2009	Study aims to identify factors that predict health care expenditures at the end of life but no comparison of competing alternatives.

Study	Reason for Exclusion
Laco, M. F., Friebert, S., Time: Why does it take so many people to take care of these patients?, <i>Journal of Palliative Medicine</i> , 15 (3), A2, 2012	This is a conference abstract with no resource use or cost data
Lindley, L. C., Lyon, M. E., A profile of children with complex chronic conditions at end of life among Medicaid beneficiaries: implications for health care reform, <i>Journal of Palliative Medicine</i> , 16, 1388-93, 2013	This is a cost of illness study but does not relate to EoLC review questions. It is also based on the US health care system and costs are unlikely to be generalizable to NHS.
Maltoni, M., Travaglini, C., Santi, M., Nanni, O., Scarpi, E., Benvenuti, S., Albertazzi, L., Amaducci, L., Derni, S., Fabbri, L., Masi, A., Montanari, L., Pasini, G., Polselli, A., Tonelli, U., Turci, P., Amadori, D., Evaluation of the cost of home care for terminally ill cancer patients, <i>Supportive Care in Cancer</i> , 5, 396-401, 1997	The focus is primarily adults as median age of 574 patients is aged 70 years (range 5-97 years). Set in Italy it is also quite dated and is unlikely to be generalizable to the context of EoLC
Maynard, L., Lynn, D., Innovative approach to providing 24/7 palliative care for children, <i>Nursing Children and Young People</i> , 26, 27-34, 2014	Descriptive report of 24/7 service provided by hospice but little by way of costing or economic evaluation
McPherson, M. L., Jefferson, L. S., Smith, E. O., Sittler, G. C., Graf, J. M., Reverse transport of children from a tertiary pediatric hospital, <i>Air Medical Journal</i> , 26, 183-7, 2007	The focus is not for the rapid transfer in the final days of life, although a subset of the small number of patients may fit that category. Also the context is not appropriate to the UK with very large travel distances often by fixed wing
Morch, M. M., Timpka, T., Granerus, A. K., Thirty years' experience with cancer and non-cancer patients in palliative home care, <i>Journal of Palliative Care</i> , 15, 43-8, 1999	The average age of the study population is between 65.5 and 71.7 years and focus is not children, although occasionally a child has been admitted to the programme. The study period is 1962-1993 making it quite dated and the Swedish setting makes it less applicable to UK context. It is fairly limited in terms of its resource and cost content.
Nelson, K., Mahant, S., Sander, B., Muir, J., The role of anti-reflux surgery in tube-feeding for children with severe neurologic impairment: A cost-effectiveness analysis, <i>Journal of pain and symptom management</i> , 47 (2), 494, 2014	Anti-reflux surgery was outside of the scope of the guideline
Ogelby, M., Goldstein, R. D., Interdisciplinary care: using your team, <i>Pediatric Clinics of North America</i> , 61, 823-34, 2014	Whilst it discusses membership of the team there is little on actual resource use or costs
Pady, C., Subramanian, G., Audit of the cost of futile invasive care in paediatric intensive care, <i>Archives of Disease in Childhood</i> , 97, A169, 2012	Not directly related to a review question
Pascuet, E., Cowin, L., Vaillancourt, R., Splinter, W., Vadeboncoeur, C., Dumond, L. G., Ni, A., Rattray, M., A comparative cost-minimization analysis of providing paediatric palliative respite care before and after the opening of services at a paediatric hospice, <i>Healthcare Management Forum</i> , 23, 63-6, 2010	A study which evaluated the costs of managing respite care before and after a paediatric hospice was made available. The Canadian setting is unlikely to be generalizable to the NHS and the provision of paediatric hospices is not part of the EoLC scope
Postier, A., Chrastek, J., Nugent, S., Osenga, K., Friedrichsdorf, S. J., Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care	Focus is on the provision of children's palliative care/hospice services. This is largely outside the remit of the scope of the EoLC guideline

Study	Reason for Exclusion
charges at a single institution, Journal of Palliative Medicine, 17, 183-8, 2014	
Rolls, L., Payne, S., Childhood bereavement services: a survey of UK provision, Palliative Medicine, 17, 423-32, 2003	Survey about the provision of childhood bereavement services. No costing or economic analysis
Rowse, V., Home-based palliative care for children: the case for funding, Paediatric Nursing, 18, 20-25, 2006	This is an opinion piece which is useful background on the wider context but does not contain cost or resource use data
Schweitzer, S. O., Mitchell, B., Landsverk, J., Laparan, L., The costs of a pediatric hospice program, Public Health Reports, 108, 37-44, 1993	A costing of a home-based paediatric hospice service but very dated and from a US health care financing perspective
Smith, A., Andrews, S., Maloney, C., Bratton, S. L., Pediatric palliative care in high cost patients, Pediatric Critical Care Medicine, 14 (9), 922-923, 2013	Abstract only. Population isn't restricted to those at end of life and is not directly relevant to service delivery questions being addressed in scope.
Steinhorn, D., Dabbs, D., Casavant, D., Chrastek, J., Warren, T., Dimand, R., Enhancing home palliative care for children through telehealth, Journal of Pain and Symptom Management, 47 (2), 397-398, 2014	This is a conference abstract with no resource use or cost data
Verlooy, J., Mattheeuws, K., De Clercq, M. J., De Porre, J., Benoit, Y., Nearly twenty years experience of palliative and curative home-care for pediatric hematology/oncology patients, Pediatric Blood and Cancer, 55 (5), 957, 2010	Conference abstract only. Describes the 20-year experience of a special team providing palliative care, including support at home. However, little economic/resource component other than highlighting a reduction in hospitalisation
Ward-Smith, P., Korphage, R. M., Hutto, C. J., Where health care dollars are spent when pediatric palliative care is provided.[Erratum appears in Nurs Econ. 2008 Jul-Aug;26(4):224], Nursing Economics, 26, 175-8, 2008	US study comparing the costs in children receiving palliative care and those who did not receive palliative care. Not directly relevant to any review question

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# Appendix I: Forest plots

## I.1 Information provision

Not applicable to this review

## I.2 Communication

Not applicable to this review

## I.3 Advance Care Planning

Not applicable to this review

## I.4 Preferred place of care and place of death

Not applicable to this review

## I.5 Organ donation

Not applicable to this review

## I.6 Multidisciplinary Teams

Not applicable to this review

## I.7 End of life care around the clock

Not applicable to this review

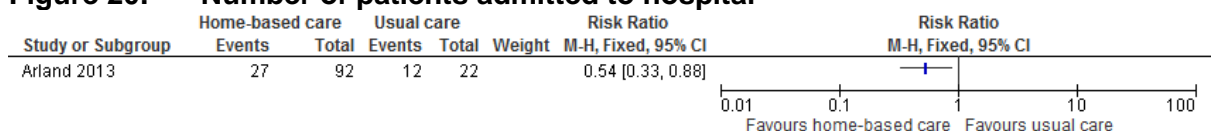
## I.8 Rapid transfer

Not applicable to this review

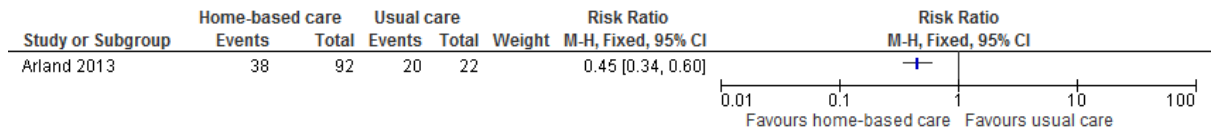
## I.9 Care based in the child or young person's home

### I.9.1 What is the clinical and cost-effectiveness of a home-based programme of care compared with care in other settings?

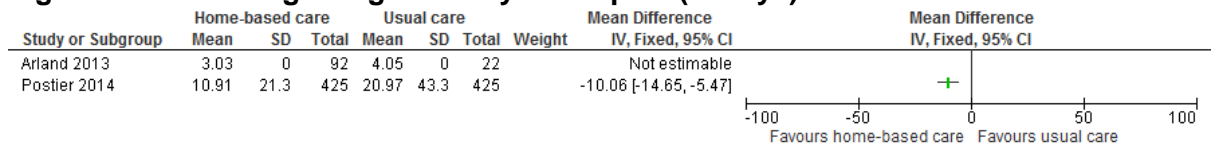
**Figure 20: Number of patients admitted to hospital**



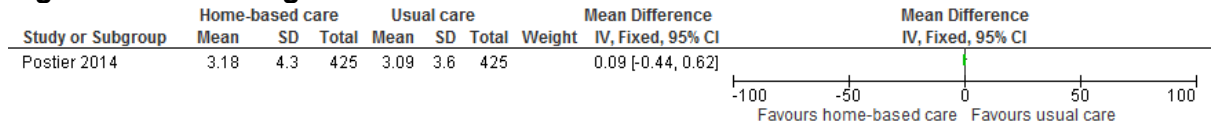
**Figure 21: Total number of admissions**



**Figure 22: Average length of stay in hospital (in days)**

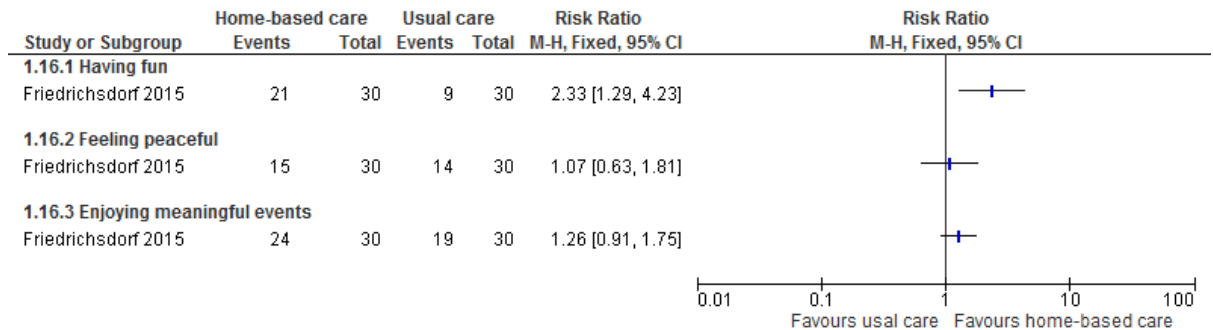


**Figure 23: Average number of admissions**



1

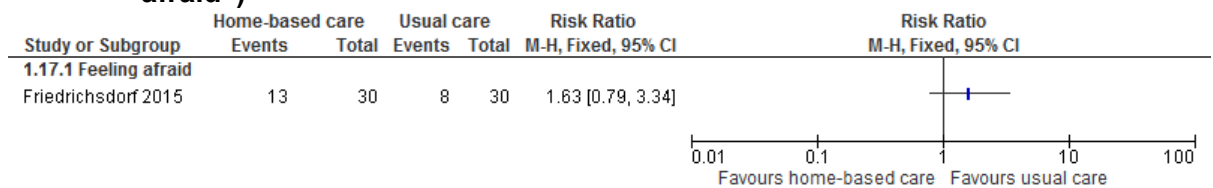
**Figure 24: Children or young person's quality of life (proxy outcome: "having fun, feeling peaceful and enjoying meaningful events")**



Follow-up: not reported; Measured with: own scale; nominal scale great deal/ a lot/ some vs little/ none

2

**Figure 25: Children or young person's quality of life (proxy outcome: "feeling afraid")**



Follow-up: not reported; Measured with: own scale; nominal scale great deal/ a lot/ some vs little/ none

3

1 **I.10 Emotional and psychological support and interventions**

2 Not applicable to this review

3 **I.11 Social and practical support**

4 Not applicable to this review

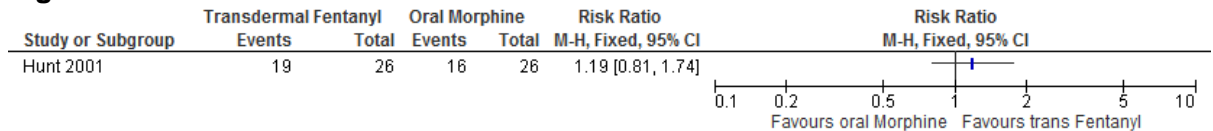
5 **I.12 Spiritual and religious support**

6 Not applicable to this review

7 **I.13 Managing pain**

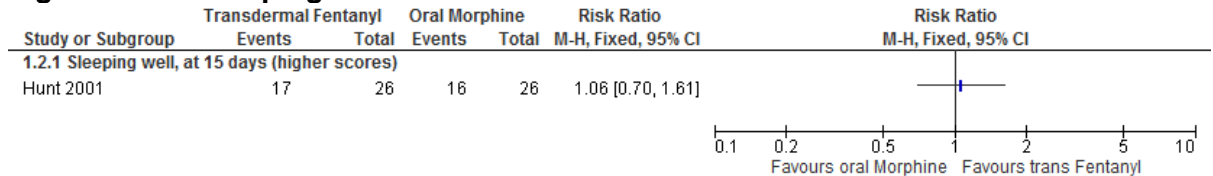
8 **I.13.1 Opioids: transdermal fentanyl versus oral morphine in children with pain due**  
9 **to cancer and other life-limiting conditions**

10 **Figure 26: Pain well controlled at**



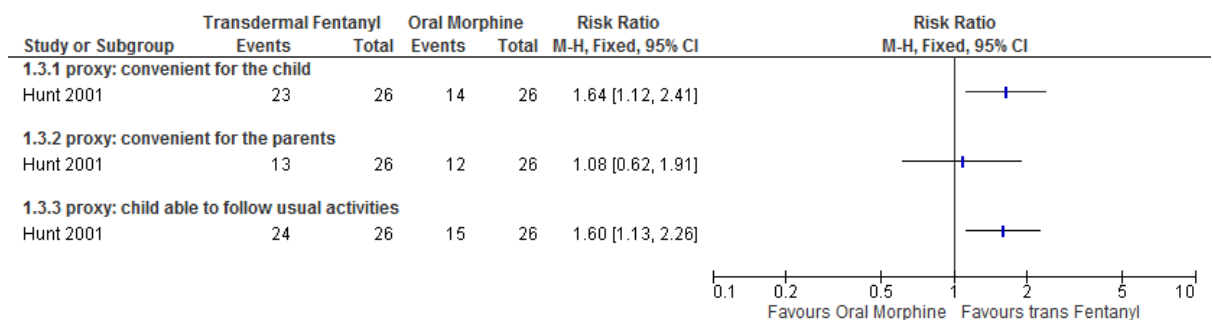
11 *Follow-up: 15 days; Measured with own scale, nominal scale categories not reported*

12 **Figure 27: Sleeping well**



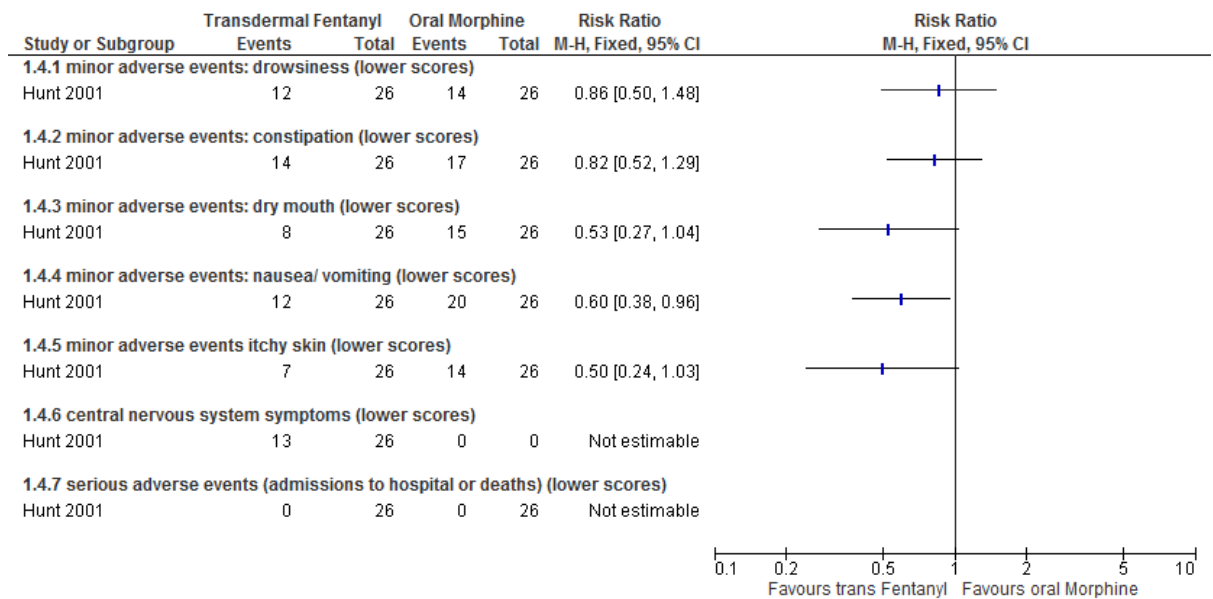
13 *Follow-up: 15 days; Measured with own scale, nominal scale categories not reported*

14 **Figure 28: Quality of life**



15 *Follow-up: 15 days; Measured with own scale, nominal scale categories not reported*

**Figure 29: Adverse events**



1 *Follow-up: 15 days*

2 **I.13.2 Opioids (morphine): patient-controlled analgesia (PCA) versus usual care in**  
3 **children with pain due to cancer**

4 No forest plots available for this comparison.

5

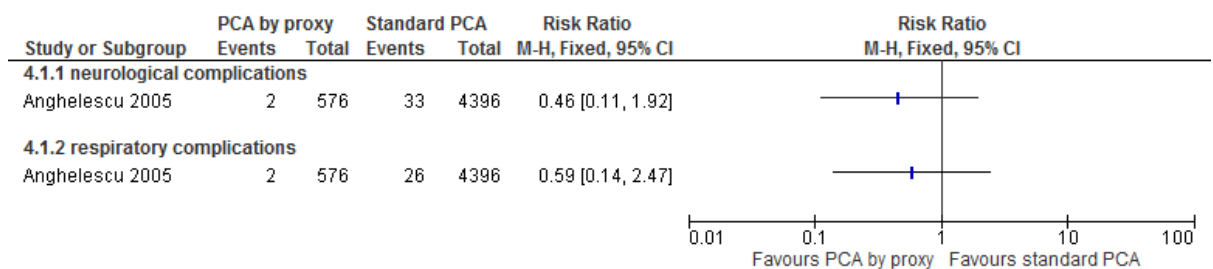
6 **I.13.3 Opioids (fentanyl): patient-controlled analgesia (PCA) versus usual care in**  
7 **children with pain due to cancer**

8 No forest plots available for this comparison.

9

10 **I.13.4 Opioids: patient-controlled analgesia (PCA) by proxy versus standard patient-**  
11 **controlled analgesia (PCA) in children and young people with pain due to**  
12 **cancer**

**Figure 30: adverse events**



13 *Follow-up: 24 hours*

14



1 **I.14 Managing agitation**

2 Not applicable to this review

3 **I.15 Managing respiratory distress**

4 Not applicable to this review

5 **I.16 Managing seizures**

6 Not applicable to this review

7 **I.17 Managing hydration**

8 *Not applicable to this review*

9 **I.18 Managing nutrition**

10 *Not applicable to this review*

11 **I.19 Recognising that a child or young person is likely to die**  
12 **within hours or days**

13 Not applicable to this review

14

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16

## 1 **Appendix J: GRADE tables**

### **J.1.2 Information provision**

3 Not applicable to this review

### **J.2.4 Communication**

5 Not applicable to this review

### **J.3.6 Advance Care Planning**

7 Not applicable to this review

### **J.4.8 Preferred place of care and place of death**

9 Not applicable to this review

### **J.5.0 Organ donation**

11 Not applicable to this review

### **J.6.2 Multidisciplinary team**

13 Not applicable to this review

### **J.7.4 End of life care around the clock**

15 Not applicable to this review

## J.8<sub>1</sub> Rapid transfer service delivery

2 Not applicable to this review

## J.9<sub>3</sub> Care based in the child or young person's home

4 Table 2: Clinical evidence profile: Palliative home-based care versus usual care

Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Home-based palliative care	Usual care	Relative (95% confidence interval [CI])	Absolute		
<b>Number of patients admitted to hospital (follow-up 5 years; assessed with: Hospital records)</b>												
1 (Arland 2013)	observational studies (retrospective cohort study)	very serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	serious <sup>3</sup>	none	27/92 (29.3%)	12/22 (54.5%)	Relative risk (RR) 0.54 (0.33 to 0.88)	251 fewer per 1000 (from 65 fewer to 365 fewer)	VERY LOW	IMPORTANT
<b>Total number of admissions (follow-up 5 years; assessed with: Hospital records)</b>												
1 (Arland 2013)	observational studies (retrospective cohort study)	very serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	no serious imprecision	none	38/92 (41.3%)	20/22 (90.9%)	RR 0.45 (0.34 to 0.6)	500 fewer per 1000 (from 364 fewer to 600 fewer)	VERY LOW	IMPORTANT
<b>Average number of admissions (follow-up 24 months; measured with: Hospital records)</b>												
1 (Postier 2014)	observational studies (uncontrolled study)	very serious <sup>4</sup>	no serious inconsistency	serious <sup>5</sup>	serious <sup>3</sup>	none	425	425	-	Mean difference (MD) 0.09 higher (0.44 lower to 0.62 higher)	VERY LOW	IMPORTANT
<b>Average length of stay (days) (follow-up 5 years ; measured with: Hospital records)</b>												
1 (Arland 2013)	observational studies (retrospective cohort study)	very serious <sup>1</sup>	no serious inconsistency	Serious <sup>2</sup>	Not calculable	none	92	22	-	MD 1.01 higher (0 to higher)	VERY LOW	IMPORTANT
<b>Average length of stay (days) (follow-up 24 months; measured with: Hospital records)</b>												

Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Home-based palliative care	Usual care	Relative (95% confidence interval [CI])	Absolute		
1 (Postier 2014)	observational studies (uncontrolled study)	very serious <sup>4</sup>	no serious inconsistency	serious <sup>5</sup>	no serious imprecision	none	425	425	-	MD 10.06 lower (14.65 to 5.47 lower)	VERY LOW	IMPORTANT
<b>Burden relief for caregivers (follow-up 7.5 months; measured with: own scale, range of scores 0 to 10); better indicated by higher values)</b>												
1 (Groh 2013)	observational studies (uncontrolled study)	very serious <sup>6</sup>	no serious inconsistency	serious <sup>7</sup>	Not calculable	none	40 Median: 19.0 (6)	40 Median : 28.0 (8.5)	-	Not calculable	VERY LOW	IMPORTANT
<b>Caregiver stress and burden (follow-up 7.5 months; measured with: HADS(Hospital Anxiety and Depression Scale), range of scores 0 to 21 Better indicated by lower values)</b>												
1 (Groh 2013)	observational studies (uncontrolled study)	very serious <sup>6</sup>	no serious inconsistency	serious <sup>7</sup>	Not calculable	none	40 Median: 7.0 (3)	40 Median : 10.0 (2)	P<0.001	Not calculable	VERY LOW	IMPORTANT
<b>Control of symptoms (follow-up 7.5 months; measured with: own scale range of scores 0 to 10; better indicated by higher values)</b>												
1 (Groh 2013)	observational studies (uncontrolled study)	very serious <sup>6</sup>	no serious inconsistency	serious <sup>7</sup>	Not calculable	none	40 Median: 9.0 (2)	40 Median : 5.0 (3)	P<0.001	Not calculable	VERY LOW	IMPORTANT
<b>(Children or young person's) health-related quality of life (follow-up 7.5 months; measured with: own scale , range of scores 0 to 10; better indicated by higher values)</b>												
1 (Groh 2013)	observational studies (uncontrolled study)	very serious <sup>6</sup>	no serious inconsistency	serious <sup>3</sup>	Not calculable	none	40 Median (range): 4.0 (4)	40 Median (range): 2.5 (2)	P<0.001	Not calculable	VERY LOW	CRITICAL
<b>Children or young person's health-related quality of life: having fun (follow-up not reported; measured with own scale, nominal scale great deal/ a lot/ some vs little/ none)</b>												
1 (Friedrichsdorf 2015)	observational studies (retrospective cohort study)	Very serious <sup>8</sup>	no serious inconsistency	no serious indirectness	Serious <sup>3</sup>	none	21/30 (70%)	9/30 (30%)	RR 2.33 (1.29 to 4.23)	300 fewer per 1000 (from 300 fewer to 300 fewer)	VERY LOW	CRITICAL
<b>Children or young person's health-related quality of life: feeling peaceful (follow-up not reported; measured with own scale, nominal scale great deal/ a lot/ some vs little/ none)</b>												
1 (Friedrichsdorf 2015)	observational studies (retrospective cohort study)	Very serious <sup>8</sup>	no serious inconsistency	no serious indirectness	Serious <sup>3</sup>	none	15/30 (50%)	14/30 (46.7%)	RR 1.07 (0.63 to 1.81)	467 fewer per 1000 (from 467 fewer to 467 fewer)	VERY LOW	CRITICAL
<b>Children or young person's health-related quality of life: feeling afraid follow-up not reported; measured with own scale, nominal scale great deal/ a lot/ some vs little/ none)</b>												

Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Home-based palliative care	Usual care	Relative (95% confidence interval [CI])	Absolute		
1 (Friedrichsdorf 2015)	observational studies (retrospective cohort study)	Very serious <sup>8</sup>	no serious inconsistency	no serious indirectness	Very serious <sup>9</sup>	none	13/30 (43.3%)	8/30 (26.7%)	RR 1.63 (0.79 to 3.34)	267 fewer per 1000 (from 267 fewer to 267 fewer)	VERY LOW	CRITICAL
<b>Children or young person's health-related quality of life: enjoying meaningful events (follow-up not reported; measured with own scale, nominal scale great deal/ a lot/ some vs little/ none)</b>												
1 (Friedrichsdorf 2015)	observational studies (retrospective cohort study)	Very serious <sup>8</sup>	no serious inconsistency	no serious indirectness	Serious <sup>3</sup>	none	24/30 (80%)	19/30 (63.3%)	RR 1.26 (0.91 to 1.75)	633 fewer per 1000 (from 633 fewer to 633 fewer)	VERY LOW	CRITICAL
<b>Parents or caregivers quality of life (follow-up 7.5 months; measured with: QOLTI-F; better indicated by higher values)</b>												
1 (Grogh 2013)	observational studies (uncontrolled study)	Very serious <sup>6</sup>	no serious inconsistency	serious <sup>7</sup>	Not calculable	none	40 Median (range): 7.1 (1.3)	40 Median (range): 5.8 (1)	P<0.001	Not calculable	VERY LOW	CRITICAL

- 1 1 This is an observational study and the quality of the evidence was further downgraded by 2 due to high risk of selection and performance bias and unclear risk of attrition and detection bias
- 2 2 The quality of the evidence was downgraded by 1 because the sample is limited to children with brain tumours. Also sample includes home and hospice care.
- 3 3 The quality of the evidence was downgraded by 1 because the CI crosses 1 default MID
- 4 4 This is an observational study and the the quality of the evidence was further downgraded by 2 due to high-risk of selection bias and performance bias
- 5 5 The quality of the evidence was downgraded by 1 because the ICYP participants in this sample have a life expectancy >2 months (24 at least) (indirect population)
- 6 6 This is an observational study and the the quality of the evidence was further downgraded by 2 due to high risk of selection, performance and detection bias
- 7 7 The quality of the evidence was downgraded by 1 because the life expectancy in this sample is beyond 2 months (indirect population)
- 8 8 This is an observational study and the the quality of the evidence was further downgraded by 2 due to high risk of performance and detection bias
- 9 9 The quality of the evidence was downgraded by 2 because the CI crosses 2 default MIDs

## J.10<sup>1</sup> Emotional and psychological support and interventions

12 Not applicable to this review

## J.11<sub>1</sub> Social and practical support

2 Not applicable to this review

## J.12<sub>3</sub> Spiritual and religious support

4 Not applicable to this review

## J.13<sub>5</sub> Managing pain

6 Table 3: Clinical evidence profile: Transdermal fentanyl versus oral morphine

Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Opioids: transdermal fentanyl	Oral morphine	Relative (95% CI)	Absolute		
<b>Pain well controlled (follow-up mean 15 days; measured with: own scale, nominal scale, categories not reported; better indicated by higher values)</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	19/26 (73.1%)	16/26 (61.5%)	RR 1.19 (0.81 to 1.74)	117 more per 1000 (from 117 fewer to 455 more)	VERY LOW	CRITICAL
<b>Other distressing symptoms: sleeping well (follow-up mean 15 days; measured with: own scale, nominal scale, categories not reported; better indicated by higher values)</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	17/26 (65.4%)	16/26 (61.5%)	RR 1.06 (0.7 to 1.61)	37 more per 1000 (from 185 fewer to 375 more)	VERY LOW	IMPORTANT
<b>Quality of life - proxy: convenient for the child (follow-up mean 15 days; measured with: own scale, nominal scale, categories not reported; better indicated by higher values)</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	29/26 (111.5%)	14/26 (53.8%)	RR 1.64 (1.12 to 2.41)	345 more per 1000 (from 65 more to 759 more)	VERY LOW	CRITICAL
<b>Quality of life - proxy: convenient for the parents follow-up mean 15 days; measured with: own scale, nominal scale, categories not reported; better indicated by higher values</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	13/26 (50%)	12/26 (46.2%)	RR 1.08 (0.62 to 1.91)	37 more per 1000 (from 175 fewer to 420 more)	VERY LOW	CRITICAL
<b>Quality of life - proxy: child able to follow usual activities (follow-up mean 15 days; measured with: own scale; better indicated by higher values)</b>												

Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Opioids: transdermal fentanyl	Oral morphine	Relative (95% CI)	Absolute		
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	24/26 (92.3%)	15/26 (57.7%)	RR 1.6 (1.13 to 2.26)	346 more per 1000 (from 75 more to 727 more)	VERY LOW	CRITICAL
<b>Minor adverse events: drowsiness (follow-up mean 15 days; better indicated by lower values)</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	12/26 (46.2%)	14/26 (53.8%)	RR 0.86 (0.5 to 1.48)	75 fewer per 1000 (from 269 fewer to 258 more)	VERY LOW	CRITICAL
<b>Minor adverse events: constipation (follow-up mean 15 days; better indicated by lower values)</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	very serious <sup>3</sup>	none	14/26 (53.8%)	17/26 (65.4%)	RR 0.82 (0.52 to 1.29)	118 fewer per 1000 (from 314 fewer to 190 more)	VERY LOW	CRITICAL
<b>Minor adverse events: dry mouth (follow-up mean 15 days; better indicated by lower values)</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	8/26 (30.8%)	15/26 (57.7%)	RR 0.53 (0.27 to 1.04)	271 fewer per 1000 (from 421 fewer to 23 more)	VERY LOW	CRITICAL
<b>Minor adverse events: nausea/ vomiting (follow-up mean 15 days; better indicated by lower values)</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	12/26 (46.2%)	20/26 (76.9%)	RR 0.6 (0.38 to 0.96)	308 fewer per 1000 (from 31 fewer to 477 fewer)	VERY LOW	CRITICAL
<b>Minor adverse events itchy skin (follow-up mean 15 days ; measured with: own scale; better indicated by lower values)</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	serious <sup>2</sup>	none	7/26 (26.9%)	14/26 (53.8%)	RR 0.5 (0.24 to 1.03)	269 fewer per 1000 (from 409 fewer to 16 more)	VERY LOW	CRITICAL
<b>Adverse events: central nervous system symptoms (follow-up mean 15 days; better indicated by lower values)</b>												
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	Not calculable	none	13/26 (50%)	not reported			VERY LOW	CRITICAL
<b>Serious adverse events (admissions to hospital or deaths) (follow-up mean 15 days; better indicated by lower values)</b>												

Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Opioids: transdermal fentanyl	Oral morphine	Relative (95% CI)	Absolute		
1 (Hunt 2001)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	Not calculable	none	0/26 (0%)	0/26 (0%)			VERY LOW	CRITICAL

- 1 <sup>1</sup> This is an observational study and the quality of the evidence was further downgraded by 2 due to high risk of selection, performance bias and detection bias  
 2 <sup>2</sup> The quality of the evidence was downgraded by 1, as the CI crosses 1 default MID  
 3 <sup>3</sup> The quality of the evidence was downgraded by 2, as the CI crosses 2 default MIDs

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6 **Table 4: Clinical evidence profile: Opioids (morphine) – Patient-controlled analgesia (PCA) by patient or proxy versus usual care**

Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Opioids, morphine: PCA (by patient or proxy)	Usual care	Relative (95% CI)	Absolute		
<b>Pain (follow-up: median 9 days; own scale 0 to 10; better indicated by lower values)</b>												
1 (Schiesl 2008)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	Not calculable	none	8 Median range: 0 to 3	8 Median (range): 3.7 (0 to 6)			VERY LOW	CRITICAL

- 7 <sup>1</sup> This is an observational study and the quality of the evidence was further downgraded by 2 due to high risk of selection, performance bias, reporting bias and detection bias

8 **Table 5: Clinical evidence profile Opioids (fentanyl) – patient-controlled analgesia (PCA) versus usual care**

Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Opioids, fentanyl: PCA	Usual care	Relative (95% CI)	Absolute		
<b>Pain, (follow-up mean 48 hours measured with Affective Facial Score (AFS), range of scores 0 to 9;; better indicated by lower values)</b>												



Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Opioids, fentanyl: PCA	Usual care	Relative (95% CI)	Absolute		
1 (Ruggiero 2007)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	Not calculable	none	18 Mean: 4.18	18 Mean: 6.5	-	p<0.01	VERY LOW	CRITICAL
<b>Pain, (follow-up mean 48 hours; measured with Visual Analogue Scale (VAS), range of scores 0 to 90; better indicated by lower values)</b>												
1 (Ruggiero 2007)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	Not calculable	none	18 Mean: 40	18 Mean: 68.5	-	p<0.01	VERY LOW	CRITICAL
<b>Minor adverse events (itchiness, vomiting, rashes, constipation) (follow-up mean 48 hours)</b>												
1 (Ruggiero 2007)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	no serious indirectness	Not calculable	none	7/18 (38.9%)	Not reported			VERY LOW	CRITICAL

1 <sup>1</sup> This is an observational study and the quality of the evidence was further downgraded by 2 due to high risk of selection, performance bias, reporting bias and detection

2 **Table 6: Clinical evidence profile: Opioids – patient-controlled analgesia by proxy (PCA by proxy) versus patient-controlled analgesia (PCA)**

Quality assessment							No. of patients		Effect		Quality	Importance
No. of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Opioids: PCA by proxy	Standard PCA	Relative (95% CI)	Absolute		
<b>Adverse events (follow-up mean 24 hours)</b>												
1 (Angheliescu 2005)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	very serious <sup>3</sup>	none	4/1152 (0.35%)	59/8792 (0.67%)	RR 0.52 (0.19 to 1.42)	3 fewer per 1000 (from 5 fewer to 3 more)	VERY LOW	CRITICAL
<b>Adverse events - neurological complications (follow-up mean 24 hours)</b>												
1 (Angheliescu 2005)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	very serious <sup>3</sup>	none	2/576 (0.35%)	33/4396 (0.75%)	RR 0.46 (0.11 to 1.92)	4 fewer per 1000 (from 7 fewer to 7 more)	VERY LOW	CRITICAL
<b>Adverse events - respiratory complications (follow-up mean 24 hours)</b>												
1 (Angheliescu 2005)	observational studies (Uncontrolled study)	very serious <sup>1</sup>	no serious inconsistency	serious <sup>2</sup>	very serious <sup>3</sup>	none	2/576 (0.35%)	26/4396 (0.59%)	RR 0.59 (0.14 to 2.47)	2 fewer per 1000 (from 5 fewer to 9 more)	VERY LOW	CRITICAL

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2 <sup>1</sup> This is an observational study and the quality of the evidence was further downgraded by 2 due to high risk of selection, performance bias and detection bias <sup>2</sup> The quality of

3 the evidence was downgraded by 1 as part of the population included in the study was over 18 years (indirect population)

4 <sup>3</sup> The quality of the evidence was downgraded by 2 as the CI crosses 2 default MIDs

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- 1 **J.14 Managing agitation**  
2 Not applicable to this review
- 3 **J.15 Managing respiratory distress**  
4 Not applicable to this review
- 5 **J.16 Managing seizures**  
6 Not applicable to this review
- 7 **J.17 Managing hydration**  
8 Not applicable to this review
- 9 **J.18 Managing nutrition**  
10 Not applicable to this review
- 11 **J.19 Recognising that a child or young person is likely to die  
12 within hours or days**  
13 Not applicable to this review  
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## **Appendix K: Health economics chapter**

Please find these in separate Appendix document

## **Appendix L: Together for Short Lives Report**

Please find this in separate Appendix document