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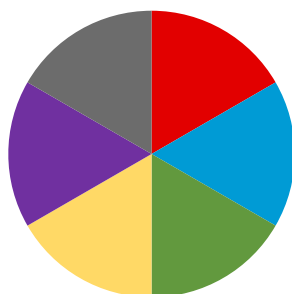
Supplementary File 2: Table of research priorities categorised by topic

The included studies were undertaken by variety of health professionals and researchers based in a range of settings. We have used pie charts to give you an indication of the contexts from which the topics have emerged. The key to the colours is given here:

Question numbers = ranking in publication

[] = category/domain in publication

£ = value based method used



- Service: Palliative, hospice and end-of-life care
- Service: Tertiary referral centres
- Service: Oncology
- Service: PICU and NICU
- Condition: Life limiting condition
- Condition: Cancer

1. EPIDEMIOLOGY / POPULATION (INCLUDING ACCESS TO SERVICES)

a. Incidence and prevalence



5. Identify the symptoms experienced by children with very rare LLCs to develop management and control strategies. (*Malcolm et al*)
7. Development of an accurate database on children and families with a LLC in order to support service development. ((*Quinn et al*) et al)
10. Chronic pain in children – prevalence and its impact on child and family [Childhood pain] (*Brenner et al*)

b. Access to services






1. Find out what services and supports are available for adolescents with palliative care needs and what, if any, gaps exist. [Staff/ volunteers: Bereavement and support for young people]. (*de Vries et al*)
4. Develop a public campaign with volunteers and staff that reflects an image of what hospice actually is, the patient groups cared for (e.g., not just cancer), and the focus of the Hospice work within the community. [Staff/ volunteers: Community]. (*de Vries et al*)
6. Access to services for children with life limiting conditions [End of life care] (*Brenner et al*)
8. Work together with local services to review and develop outreach respite teams across Scotland, which would allow more families to access hospice services within their own homes and/or communities. Malcolm





c. Needs



1. What matters most for patients and parents receiving paediatric palliative services/ (86% consensus). (*Steele et al*)
1. Find out the needs of young people (16 +) with LLCs from the viewpoint of young people themselves, their parents and professionals. (*Malcolm et al*)
2. Explore the support needs of family member/caregivers of people who are dying. [Staff/ volunteers: Patient/family]. (*de Vries et al*)
2. Sports participation/activity restrictions [Issue]. (*Zeigler et al*)
2. Play (*Williams et al*)
4. Exercise/ physical activity [theme] (*Bradley et al*)
5. Peer support/ social activities [Psychosocial research domain] (*Clinton-McHarg et al*)£
5. Education [theme] (*Bradley et al*)
6. What are the needs of families caring for a child with a LLC in Ireland? (*Quinn et al*)

<p>6. Identify things that patients look forward to, and the goals or things they want to achieve. [patients /family: Recognition of need and response of service] (<i>de Vries et al</i>)</p> <p>7. Find out the specific care needs of young people (16 +) with limited cognitive abilities (learning, understanding, communicating), e.g. how will their care needs change during the transition to adult services. (<i>Malcolm et al</i>)</p> <p>10. Find out what families across Scotland, including rural and remote areas, want with regard to home care services provided by the hospice. (<i>Malcolm et al</i>)</p>	
<p>d. Prevention</p> <p>3. Explore new health promotion strategies within PMH, e.g. the impact of having a child health nurse on site on parenting education, health promotion; in-house TV station dedicated to health information (<i>Wilson et al</i>)</p> <p>5. Develop programmes (e.g. school health, antenatal) with emphasis on long-term changes and educating the next generation of parents (reducing alcohol abuse, preventing accidents, child abuse, etc.) (<i>Wilson et al</i>)</p>	
<p>e. Populations</p> <p>1. Newly-diagnosed [Population research] (<i>Clinton-McHarg et al</i>)£</p> <p>2. Relapsed [Population research] (<i>Clinton-McHarg et al</i>)£</p> <p>3. Finished treatment [Population research] (<i>Clinton-McHarg et al</i>)£</p> <p>4. Receiving treatment [Population research] (<i>Clinton-McHarg et al</i>)£</p> <p>5. Receiving palliative care [Population research] (<i>Clinton-McHarg et al</i>)£</p> <p>6. Parents/ carers [Population research] (<i>Clinton-McHarg et al</i>)£</p> <p>7. Siblings [Population research] (<i>Clinton-McHarg et al</i>)£</p> <p>8. Partners/ close friends [Population research] (<i>Clinton-McHarg et al</i>)£</p>	
<p>f. Stages of care</p> <p>1. Prevention, screening and early detection (18 funding units) (<i>Medlow et al</i>)£</p> <p>2. Receiving treatment (17 funding units) (<i>Medlow et al</i>)£</p> <p>3. Finished treatment (17 funding units) (<i>Medlow et al</i>)£</p> <p>4. Relapsed (15 funding units) (<i>Medlow et al</i>)£</p> <p>5. Receiving palliative care (12 funding units) (<i>Medlow et al</i>)£</p> <p>6. Newly-diagnosed (12 funding units) (<i>Medlow et al</i>)£</p> <p>6. Well/very young/new born screening [theme] (<i>Bradley et al</i>)</p> <p>7. Significant others (8 funding units) (<i>Medlow et al</i>)£</p>	

2. MEASUREMENT AND ASSESSMENT

<p>a. Global outcomes (e.g. quality of life)</p> <p>1. Quality of life from the children's perspective [Psychosocial care needs] (<i>Soanes et al</i>)</p> <p>6. Measuring outcomes of care [Interventions and models of care] (<i>Downing et al</i>)</p>	
<p>b. Pain and breathlessness</p> <p>5. Assessment of the WHO two-step analgesic ladder for pain management in children [Clinical care] (<i>Downing et al</i>)</p> <p>6. Identifying best practices for pain assessment [Domain 1: Pain and stress] (<i>Wielenga et al</i>)</p> <p>7. What is the best way to judge whether a premature infant is feeling pain, eg by their face, behaviours or brain activities? (<i>Uhm et al</i>)</p> <p>1. Develop a tool that measures anxiety associated with breathlessness including all causes of breathlessness in advanced illness. [Staff/volunteers: Symptom Management] (<i>de Vries et al</i>)</p>	
<p>c. Sedation</p> <p>10. Identifying best practices in sedation assessment [Domain 2: Pain and sedation] (<i>Tume et al</i>)</p>	
<p>d. Antibiotics</p> <p>4. The most appropriate way to assess antibiotic levels [Nursing procedures] (<i>Soanes et al</i>)</p>	

7. Antibiotics [theme] (*Bradley et al*)

e. Psychosocial issues

- 2. Develop psychosocial measures [Psychosocial research domain] (*Clinton-McHarg et al*)£
- 7. Developing measures to identify psychosocial concerns (8 funding units) (*Medlow et al*)£



3. SERVICE DELIVERY AND MODELS OF CARE

Service delivery and models of care

- 3. Organisation, structure and delivery of healthcare (16 funding units) (*Medlow et al*)£
- 4. Treatment centre/ care delivery [Psychosocial research domain] (*Clinton-McHarg et al*)£
- 6. Utilisation, expenditure, economics and financing systems (80 funding units) (*Medlow et al*)£
- 7. Health policy, reform, governance and law (7 funding units) (*Medlow et al*)£
- 10. Explore models of ambulatory care /hospital in the home/community services to assist in care of children with chronic/complex needs (*Wilson et al*)



a. Settings of care: service delivery and outcomes

i. Inpatient vs outpatient

- 2. Compare outcome variables of cost, quality of life, and disease response when therapy is given on an outpatient vs. inpatient basis. (*Fochtman et al*)
- 3. Measure caregiver burdens for families receiving outpatient therapy vs. those families receiving primarily inpatient therapy. (*Fochtman et al*)
- 8. Compare the quality of life among patients who receive care primarily as outpatients vs. inpatients. (*Fochtman et al*).

ii. Home-based care

- 1. Determine the most common treatment related problems that patients and families experience at home. (*Fochtman et al*)
- 1. Explore how family member/caregivers manage side effects of medication when caring for palliative patients at home. [patients /family: Symptom management] (*de Vries et al*)
- 1. What is good clinical governance when care is provided in the home? How can good clinical governance be maintained without increasing levels of bureaucracy for families? (*Quinn et al*)
- 3. Evaluate the impact and cost effectiveness of increasing home care in paediatric oncology. (*Monterosso et al*)
- 4. Identify aspects of both nursing and medical care that could be provided in the home environment, and evaluate the impact this would have on the family. (*Monterosso et al*)
- 5. Find out what it is like for family member/caregivers to have responsibility for monitoring patient changes and adjusting medications in the home. [Staff/ volunteers: Patient/family]. (*de Vries et al*)
- 6. Explore how family member/caregivers manage side effects of medication when caring for palliative patients at home. [staff and volunteers: Patient/family] (*de Vries et al*)
- 8. Care planning: what are the challenges in developing, maintaining and communicating care plans when care is provided in the home? (*Quinn et al*)

iii. Virtual / tele-care

- 7. On-line interventions and technology [Psychosocial research domain] (*Clinton-McHarg et al*)£
- 7. Evaluate telephone-based interventions used by nurses in response to calls from patients and families. (*Fochtman et al*)







b. Joint working

i. Shared care

- 1. Find out what general practices and primary health nurses expect from a specialist palliative care program. [Staff/ volunteers: Community]. (*de Vries et al*)
- 4. What support/information do shared care hospitals want from the Regional Centre? [Professional issues] (*Soanes et al*)



<p>4. Explore the aspect of trust with health professionals and the hospice when there has been a misdiagnosis. [Staff/ volunteers: Patient/family]. (<i>de Vries et al</i>)</p> <p>6. Explore ways to provide additional medical cover so children whose condition is fragile or medically unstable can be cared for in the hospice instead of a hospital. (<i>Malcolm et al</i>)</p> <p>ii. Care coordination and intra/multi-agency working</p> <p>1. Explore ways to increase the level of “continuity in the care” of patients and decrease the number of contacts with multiple staff. [Staff/ volunteers: Patient/family]. (<i>de Vries et al</i>)</p> <p>2. Development of a national strategy for intra-agency service provision in children's palliative care (<i>Quinn et al</i>)</p> <p>3. Examine what makes effective partnering with other providers and specialists in the care of palliative patients. [Staff/ volunteers: Community]. (<i>de Vries et al</i>)</p> <p>3. Explore ways to increase the level of “continuity in the care” of patients and decrease the number of contacts with multiple staff. [Staff/ volunteers: Recognition of need and response of service] (<i>de Vries et al</i>)</p> <p>4. Team work – linking to a more efficient service (<i>Williams et al</i>)</p> <p>5. Creating linkages between maternity services and children’s palliative care services to better support new families. (<i>Quinn et al</i>)</p>	
<p>c. Transitions between service or care settings</p> <p>2. Safe transfer of critically ill children in hospital and between hospitals [Clinical care concerns] (<i>Brenner et al</i>)</p> <p>2. How do we measure a successful transition or evaluate a transition programme? (<i>Fletcher-Johnston et al</i>)</p> <p>3. What are the factors that influence healthcare transitions (not just adherence) and also how do these various factors influence each other? (<i>Fletcher-Johnston et al</i>)</p> <p>4. Does a ‘successful transition’ lead to improved health outcomes in adulthood? (<i>Fletcher-Johnston et al</i>)</p> <p>5. What are the potential successes or risk factors for successful transitions (i.e. type of illness, age of child, family involvement, level of support systems, progression of illness)? (<i>Fletcher-Johnston et al</i>)</p>	
<p>d. Palliative and end-of-life care: service models</p> <p>2. Compare outcomes for patients and families who have early access to PPC programs with outcomes for patients and families referred late in the illness trajectory. [care coordination to include mechanisms of support] (<i>Baker et al</i>)</p> <p>3. Funding for and the cost of Centre for Palliative Care [Policies and Procedures] (<i>Downing et al</i>)</p> <p>5. Study strategies for integrating quality palliative care practices into the ongoing care of seriously ill children in a variety of care settings, and evaluate the impact of these strategies on relevant care processes and outcomes.[care coordination to include mechanisms of support] (<i>Baker et al</i>)</p> <p>6. Interventions and models of care for Centre for Palliative Care [Interventions and models of care] (<i>Downing et al</i>)</p> <p>7. Study the benefits (e.g., costs, satisfaction with care, quality of life, burden of care) of palliative care programs and services for patients, siblings, and parents in diverse clinical contexts.[care coordination to include mechanisms of support] (<i>Baker et al</i>)</p>	
<p>e. Patient experience</p> <p>1. Understanding and improving all aspects of the patient journey through the hospital system? (e.g. appointments, transfers, waiting times, admissions, discharge, communication with community services) (<i>Williams et al</i>)</p> <p>7. Identify strategies to reduce waiting times for same day care patients. (<i>Monterosso et al</i>)</p> <p>9. Investigate the effect on hospitalised adolescents of lack of privacy and gender issues arising from the ward environment. (<i>Monterosso et al</i>)</p>	
<p>f. Safety and quality</p> <p>4. Disparities in care (14) (<i>Medlow et al</i>)£</p> <p>5. Quality performance, safety and outcomes (11) (<i>Medlow et al</i>)£</p>	

7. Evaluate effect of critical incidents feedback on subsequent occurrence of critical incidents (*Wilson et al*)

i. Infection control

2. How can infection in preterm infants be better prevented? (*Uhm et al*)

5. Ward-based isolation procedures using a multidisciplinary approach involving infection control, nurses, play specialists [Nursing procedures] (*Soanes et al*)

5. Interventions to reduce healthcare-associated infections [Domain 3: Quality and safety] (*Tume et al*)

8. The evidence on chlorhexidine/alcohol-based hand washing products – are they more effective than ‘ordinary dispensed soap’? [Nursing procedures] (*Soanes et al*)

9. Infection control [theme] (*Bradley et al*)

ii. Medication errors

1. Identify strategies to reduce medication errors (*Wilson et al*)

2. Identifying and evaluating strategies to reduce medication errors [Domain 4: Quality and safety] (*Wielenga et al*)

7. Identifying safe medication administration practices [Domain 4: Quality and safety] (*Wielenga et al*)

iii. Patient observation schedules

7. The necessity of 4-hourly observations on all patients and their significance [Nursing procedures] (*Soanes et al*)

iv. Staff patient ratios

1. To investigate safe nurse: patient ratios levels for PICU. (*Aylott et al*)

4. To explore the effect of increased technology on the nurses’ ability to keep pace with workload. (*Aylott et al*)

6. Identifying appropriate nurse staffing levels and recruitment strategies [Domain 7: Professional issues in nursing] (*Tume et al*)

4. HEALTH INTERVENTIONS: PHARMACOLOGICAL AND/OR INVASIVE

a. Active treatments for conditions or prevention of complications

1. Determine evidence based practices for neuroprotection post hypoxic arrest (*Ramelet et al*)

3. Which interventions are most effective to prevent necrotising enterocolitis in premature infants? (*Uhm et al*)

4. Determine best practice for the management of post-cardiac arrest patients (*Ramelet et al*)

4. What is the best treatment for lung damage in premature infants? (*Uhm et al*)



b. Minimising impacts of treatments: preparation and pre-medication

2. How well nausea and vomiting is controlled for patients having chemotherapy, following discharge [Nursing procedures] (*Soanes et al*)

2. Preparation for procedures (is there adequate use of play specialists) [Psychosocial care needs] (*Soanes et al*)

6. Methods available to pre-medicate children [Nursing procedures] (*Soanes et al*)

8. Psychological preparation of children prior to procedures [Clinical care concerns] (*Brenner et al*)

10. Determine the most effective schedule of administration for differing antiemetics. (*Fochtman et al*)



c. Respiration and ventilation (including weaning/withdrawal)

2. Airway clearance [theme] (*Bradley et al*)

7. To examine staff & family perceptions of withdrawal of treatment on ECMO (Extracorporeal Membrane Oxygenation). (*Aylott et al*)

8. Inhaled therapies [theme] (*Bradley et al*)



9. Determine best practice for nurse-led ventilation weaning (*Ramelet et al*)

10. Identifying best practices in the care of non-invasive ventilation in infants [Domain 6: Respiratory & ventilation] (*Wielenga et al*)





d. Feeding and nutrition



<p>3. If we are appropriately assessing and treating children's nutritional needs [Nursing procedures] (<i>Soanes et al</i>)</p> <p>6. What is the optimum milk feeding strategy and guidance (including quantity and speed of feeding and use of donor and formula milk) for the best long-term outcomes of premature infants? (<i>Uhm et al</i>)</p> <p>10. Nutritional support [theme] (<i>Bradley et al</i>)</p>	
<p>e. Survivorship and late effects</p> <p>1. Survivorship (22) (<i>Medlow et al</i>)</p> <p>4. Identify the impact of late treatment effects on the patient's subsequent educational efforts. (<i>Fochtman et al</i>)</p> <p>9. Determine the impact of early screening and intervention on cognitive functioning of patients treated with cranial irradiation or intrathecal medications. (<i>Fochtman et al</i>)</p>	
<p>f. Fertility</p> <p>4. What are the options for children regarding their future fertility? Are children/teenagers offered opportunities to bank sperm/ovaries and are these opportunities equal? [Psychosocial care needs] (<i>Soanes et al</i>)</p>	

5. SYMPTOM MANAGEMENT AND CONTROL

<p>a. Symptom management</p> <p>1. Identifying effective interventions to prevent or reduce pain or stress [Domain 1: Pain and stress] (<i>Wielenga et al</i>)</p> <p>2. Identify services, techniques and provisions available to relieve pain and other symptoms in children with LLCs and assess how effective they are. (<i>Malcolm et al</i>)</p> <p>2. Conduct systematic reviews on interventions, care and best practice for each of the main symptom issues in palliative care and update the Hospice palliative care guidelines. [Staff/ volunteers: Symptom Management] (<i>de Vries et al</i>)</p> <p>3. What are effective strategies to alleviate suffering at the end of life? (57% consensus) (<i>Steele et al</i>)</p> <p>5. Symptom management in end of life care – healthcare professional's knowledge [End of life care] (<i>Brenner et al</i>)</p> <p>9. Test symptom interventions (eg, pain, dyspnea, fatigue, nausea, constipation, disturbed sleep, anxiety, depression) for infants, children, and adolescents.[symptom management] (<i>Baker et al</i>)</p>	
<p>b. Pain management strategies and practices (including weaning/withdrawal)</p> <p>2. To investigate the problem of opioid & sedation withdrawal syndrome in post ECMO (Extracorporeal Membrane Oxygenation) patients. (<i>Aylott et al</i>)</p> <p>2. Determine how pain assessment impacts on pain management (including nurses' perceptions of pain assessment, effectiveness of different analgesic groups, postoperative pain management) (<i>Wilson et al</i>)</p> <p>3. What is the best method to assess benzodiazepine and opioid withdrawal? (<i>Ramelet et al</i>)</p> <p>3. Effective interventions to reduce and prevent pain [Domain 2: Pain and sedation] (<i>Tume et al</i>)</p> <p>3. What are the best practice standards in pain and symptom management? (57% consensus) (<i>Steele et al</i>)</p> <p>4. Pain assessment and management in children's nursing [Childhood pain] (<i>Brenner et al</i>)</p> <p>5. To explore pain management with the cardiac & ECMO (Extracorporeal Membrane Oxygenation) patient. (<i>Aylott et al</i>)</p> <p>5. Identify most effective pain management strategies for use with terminally ill patients. (<i>Fochtman et al</i>)</p> <p>5. Pain management for non-cancer children with chronic life-threatening illness [Clinical care] (<i>Downing et al</i>)</p> <p>7. Investigate opioids and benzodiazepines weaning strategies. (<i>Ramelet et al</i>)</p> <p>8. Investigate the impact of pain and sedation assessment on patient's comfort (<i>Ramelet et al</i>)</p> <p>8. Use of opioids in children [Clinical care] (<i>Downing et al</i>)</p> <p>9. Identifying best practices for preventing analgesia and sedation withdrawal [Domain 2: Pain & sedation] (<i>Tume et al</i>)</p>	

c. Pain: Non-pharmacological interventions

4. Patient: Children (6–18 years) with chronic pain. Intervention: Psychoeducation Cognitive behavioural therapy Parenting interventions. Comparator: Care as usual. Outcome: Symptom severity (pain, fatigue, sleep disturbance), quality of life, disability and functioning (school attendance, ability to perform activities of daily living). (*Lioffi et al*)
5. Examine medicalization/pharmacology versus therapeutic interventions in management of symptoms in hospice practice. [Staff/ volunteers: Symptom Management] (*de Vries et al*)
9. Patient: Children (6-18 years) with cancer. Intervention: Massage using the 'M' technique. Intervention: Placebo or care as usual. Outcome: Symptom severity (pain, fatigue, anxiety). (*Lioffi et al*)

d. Pain: drug trials




1. Patient: Children (6-18 years) with chronic pain with neuropathic characteristics. Intervention: Gabapentin. Intervention: Placebo or active comparator. Outcome: Symptom severity (pain, fatigue, sleep disturbance), quality of life, disability and functioning (school attendance, ability to perform activities of daily living) (*Lioffi et al*)
2. Patient: Pre-school children (0-5 years) after surgery. Intervention: IV NSAIDS. Comparator: No comparator, placebo or active comparator for efficacy studies. Outcome: Pharmacokinetics, pain score, rescue analgesic requirements, cardio-respiratory stability, renal function and hepatic function. (*Lioffi et al*)
3. Patient: Children (0-18 years) with acute pain at home (including pre-hospital). Intervention: Opioids. Comparator: No comparator, placebo or active for efficacy studies. Outcome: Pharmacokinetics, pain score, rescue analgesic requirements, cardio-respiratory stability, tolerability, renal function and hepatic function (*Lioffi et al*)
5. Patient: Children (6-18 years) with chronic pain with neuropathic characteristics. Intervention: Amitriptyline. Comparator: Placebo or active comparator. Outcome: Symptom severity (pain, fatigue, sleep disturbance), quality of life, disability and functioning (school attendance, ability to perform activities of daily living). (*Lioffi et al*)
6. Patient: Children (0-18 years) receiving palliative care on long-acting opiate stable dose with poorly controlled pain. Intervention: Ketamine. Comparator: Patient own comparison. Outcome: Pain severity, quality of life and side effects. (*Lioffi et al*)
7. Patient: Children (0-18 years) receiving palliative care, experiencing breakthrough pain. Intervention: Fentanyl buccal. Comparator: Morphine IR or oxycodone IR. Outcome: Time to obtain clinically significant pain reduction, time and length of clinical effect, pharmacokinetics, side effects. (*Lioffi et al*)
8. Patient: Pre-term (<37 weeks gestational age) and low birthweight infants. Intervention: IV paracetamol. Comparator: No comparator, placebo or active for efficacy studies. Outcome: Pharmacokinetics, pain score, rescue analgesic requirements, cardio-respiratory stability, renal function and hepatic function. (*Lioffi et al*)
10. Patient: Children (0-18 years) receiving palliative care, on opiates and other adjuvants with poorly controlled pain. Intervention: Methadone (as adjuvant). Comparator: Patient own comparison. Outcome: Pain severity, opiate requirements, quality of life and side effects (*Lioffi et al*)

6. OTHER INTERVENTIONS: PHYSICAL HEALTH AND FUNCTIONING


a. Management of musculo-skeletal function

1. Does the timing and intensity of therapies (e.g. physical, occupational and speech and language therapy, 'early intervention', providing information, etc) alter the effectiveness of therapies for infants and young children with neurodisability, including those without specific diagnosis? What is the appropriate age of onset/strategies/dosage/direction of therapy interventions? (*Morris et al*)
6. What is the (long-term) comparative safety and effectiveness of medical and surgical spasticity management techniques (botulinum neurotoxin A, selective dorsal rhizotomy, intrathecal baclofen, orally administered medicines) in children and young people with neurodisability? (*Morris et al*)



b. Continence

7. Does a structured training programme, medicines and/or surgery speed up the achievement of continence (either/or faecal or urinary) for children and young people with neurodisability? (<i>Morris et al</i>)	
c. Communication	
2. To improve communication for children and young people with neurodisability: (A) what is the best way to select the most appropriate communication strategies? And (B) how to encourage staff/carers to use these strategies to enable communication? (<i>Morris et al</i>)	
d. Sleep	
10. What is the long-term safety, effectiveness and sustainability of behavioural strategies and/or drugs (eg, melatonin) to manage sleep disturbance in children and young people with neurodisability (outcomes include time to onset, duration, and reducing impact on family)? (<i>Morris et al</i>)	
e. General physical health	
8. What strategies are effective to improve engagement in physical activity (to improve fitness, reduce obesity, etc) for children and young people with neurodisability? (<i>Morris et al</i>)	


7. INTERVENTION ADHERENCE


1. Adherence [theme] (<i>Bradley et al</i>)	
6. Identify reasons for parental non-compliance of treatment and explore strategies to increase compliance (e.g. asthma prevention and management, children with psychiatric disorders) (<i>Wilson et al</i>)	
7. Medication noncompliance [Issue] (<i>Zeigler et al</i>)	

8. EMOTIONAL AND PSYCHOLOGICAL ISSUES


a. Coping and resilience	
1. Identify risk and resilience [Psychosocial research domain] (<i>Clinton-McHarg et al</i>)£	
2. Identify and assess the coping mechanisms that adolescents develop when coping with diagnosis and subsequent treatment. (<i>Monterosso et al</i>)	
5. Identifying risk or resilience for poor psychological health (11 funding units) (<i>Medlow et al</i>)£	
b. Impacts, needs and experiences	
3. Examine anxiety, breathlessness and sleeplessness (as a symptom cluster) and their impact on patients and family member/caregivers during palliative care and bereavement. [Staff/ volunteers: Symptom Management] (<i>de Vries et al</i>)	
6. Behaviour (10 funding units) (<i>Medlow et al</i>) £	
<i>i. Children and young people</i>	
1. Fear of being shocked [Issue] (<i>Zeigler et al</i>)	
1. Children's understanding of death and dying [Psychological issues] (<i>Downing et al</i>)	
1. Find out about the sense of loss for patients in not being able to participate in activities and hobbies they have previously enjoyed, e.g., tramping; dancing. [patients /family: Bereavement and Loss] (<i>de Vries et al</i>)	
3. Feeling different from peers/peer acceptance [Issue] (<i>Zeigler et al</i>)	
4. Children's rights perspective: including the voice of the child in children's palliative care. (<i>Quinn et al</i>)	
4. Depression [Issue] (<i>Zeigler et al</i>)	
5. Adjustment problems [Issue] (<i>Zeigler et al</i>)	
6. Fear of death [Issue] (<i>Zeigler et al</i>)	
8. Acting out [Issue] (<i>Zeigler et al</i>)	
9. Body change/ weight gain [Issue] (<i>Zeigler et al</i>)	
10. Assess the long-term psychological effects, particularly related to body image, on adolescent female patients of the clinical focus on their diet, weight etc. (<i>Monterosso et al</i>)	
<i>ii. Parents and carers</i>	


<p>3. To explore family care needs on PICU during ECMO (Extracorporeal Membrane Oxygenation). (<i>Aylott et al</i>)</p> <p>4. Identifying strategies to support the needs of parents and family members [Domain 2: Clinical nursing care practices] (<i>Wielenga et al</i>)</p> <p>10. Compare outcomes for families who pursue aggressive treatment with curative intent in the care of children with advancing illness with outcomes for families who pursue supportive, non-cure-directed care. [decision making] (<i>Baker et al</i>)</p> <p><i>iii. Siblings</i></p> <p>5. If sibling donors are getting adequate support and preparation before, during and after bone marrow transplant [Psychosocial care needs] (<i>Soanes et al</i>)</p>	
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<p>c. Support systems and structures</p> <p>4. Review the psychological support the hospice provides to young people (16 +) who know they have a LLC and make recommendations for staff training and development. (<i>Malcolm et al</i>)</p> <p>5. Evaluate the psychological support systems available to adolescents in the unit. (<i>Monterosso et al</i>)</p> <p>8. Assess the need for psychological support and intervention for all patients. (<i>Monterosso et al</i>)</p>	
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<p>d. Interventions</p> <p>2. Testing benefits of physical or psychological therapies (20 funding units) (<i>Medlow et al</i>)£</p> <p>5. Are counselling/psychological strategies (eg, talking therapies) effective to promote the mental health of children and young people with neurodisability? (<i>Morris et al</i>)</p> <p>6. Identify effective interventions that promote optimal adjustment in survivors of childhood cancer. (<i>Fochtman et al</i>)</p> <p>6. Physical/ psychological therapies [Psychosocial research domain] (<i>Clinton-McHarg et al</i>)£</p>	
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9. PARTICIPATION AND INCLUSION


<p>a. Preventing discrimination and exclusion</p> <p>3. Are child-centred strategies to improve children’s (ie, peers) attitudes towards disability (eg, buddy or circle of friends, etc) effective to improve inclusion and participation within educational, social and community settings? (<i>Morris et al</i>)</p> <p>9. Which school characteristics (eg, policies, attitudes of staff, etc) are most effective to promote inclusion of children and young people with neurodisability in education and afterschool clubs? (<i>Morris et al</i>)</p>	
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<p>b. Independence and young adulthood</p> <p>10. Issues related to planning for adulthood [Issue] (<i>Zeigler et al</i>)</p>	
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<p>c. Mobility</p> <p>4. Does appropriate provision of wheelchairs to enable independent mobility for very young children improve their self-efficacy? (<i>Morris et al</i>)</p>	
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10. COMMUNICATION AND DECISION-MAKING

<p>a. Documenting care</p> <p>3. If parent-held records assist in communication between the Regional Centre and District General Hospital [Psychosocial care needs] (<i>Soanes et al</i>)</p> <p>3. The most effective form of documenting care [Professional issues] (<i>Soanes et al</i>)</p>	
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<p>b. Communication between staff / within team</p> <p>1. Identify effective methods of communication in a multi-disciplinary team. (<i>Monterosso et al</i>)</p> <p>8. Improving healthcare team communication [Domain 3: Quality and safety] (<i>Tume et al</i>)</p>	
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c. Communication between staff and children/parents/families



1. Whether effective and appropriate negotiation takes place between nursing staff and families [Psychosocial care needs] (*Soanes et al*)
2. Information giving to families at diagnosis – who tells the child about their cancer? [Psychosocial care needs] (*Soanes et al*)
3. Whether families are being given adequate information to give informed consent [Psychosocial care needs] (*Soanes et al*)
5. Whether parents who have English as their second language really understand their child's illness and protocols [Professional issues] (*Soanes et al*)
6. Assess the effectiveness of current advice given to families at discharge following their child's initial cancer diagnosis. (*Monterosso et al*)
9. Effective communication with children in hospital [Family-centred care] (*Brenner et al*)

d. Treatment and care decision-making



1. Develop and evaluate strategies to help families make difficult EOL care decisions [decision making] (*Baker et al*)
1. Examine informed consent and decision-making processes prior to carrying out care in the Hospice (e.g., pre-catheterization; terminal sedation).[patients /family: Decision-making] (*de Vries et al*)
2. Examine how patients are supported to make decisions about how they want to be cared for and planning for the future.[patients /family: Decision-making] (*de Vries et al*)
2. Communicating and decision making around forgoing and sustaining treatment [Domain 6: Ethics] (*Tume et al*)
8. Study the role of the child in making treatment decisions about his or her palliative and EOL care.[decision making] (*Baker et al*)
8. Explore parents' perception of aspects of family-centred care (particularly family involvement in care and/or decision-making) (*Wilson et al*)
9. Explore the impact of parental involvement in hospital care including decision-making (impact on child, parent and staff) (*Wilson et al*)

11. OTHER FAMILY NEEDS AND SUPPORT

a. Service organisation and provision



1. Identify how responsive the service is to patients and family member/caregivers. [patients /family: Recognition of need and response of service] (*de Vries et al*)
4. Explore the impact on a family of a child requiring long-term care (complex care, disability, burns, cystic fibrosis, scars, allergies, etc.) and identify supportive measures for families (e.g. Case managers, respite care) (*Wilson et al*)
5. Supporting parents/parent pathway. (*Williams et al*)

b. Parents as carers



4. Examine how well family member/ caregivers are recognized and supported in their care for patients. [patients /family: Recognition of need and response of service] (*de Vries et al*)
5. What should be included in packages of care to support parents and families or carers when a premature infant is discharged from hospital? (*Uhm et al*)
7. Parental participation in the care of children at home with a chronic condition – their perceptions [Chronic illness] (*Brenner et al*)
- 8- Should parents be present at resuscitation? (*Aylott et al*)
9. What emotional and practical support improves attachment and bonding, and does the provision of such support improve outcomes for premature infants and their families? (*Uhm et al*)

c. Supporting self-management

1. What skills and knowledge do adolescents need to learn in order to better manage their chronic illness and enable successful transition to adult health care and adulthood? How would they best like to learn these skills and knowledge? (*Fletcher-Johnston et al*)
3. Examine the balance between when nursing visits are needed by patients and when patients would like to be independent, with support when they want it. [Staff/ volunteers: Patient/family]. (*de Vries et al*)
4. Find out from patients what level of information they receive about symptoms and ways to manage them. [Staff/ volunteers: Symptom Management] (*de Vries et al*)
5. Explore the importance of maintaining independence and self-management from a patient's view. [patients /family: Recognition of need and response of service] (*de Vries et al*)



12. PRACTICES RELATED TO PALLIATIVE AND END-OF-LIFE CARE

4. End of life care (12 funding units) (*Medlow et al*)£

a. Advance care planning and preparing for death

6. Study strategies designed to help parents understand what to expect and to prepare them for the possibility of death. [decision making] (*Baker et al*)

b. Identification of best practice

1. Improving end-of-life and palliative care for children and their families [Domain 6: Ethics] (*Tume et al*)
1. Timely recognition, communication and intervention of the deteriorating child [Resuscitation concerns] (*Brenner et al*)
2. Look at what "dying well" means from the family member/caregivers and professional perspective. [patients /family: Recognition of need and response of service] (*de Vries et al*)
2. What is best practice for end of life care? (*Ramelet et al*)
3. Improving end-of-life care for neonates and their families [Domain 5: Ethics] (*Wielenga et al*)
4. Develop and validate evidence-based practice guidelines in PPC.[quality improvement] (*Baker et al*)
3. Parent's/Family's perceptions of care at end of life [End of life care] (*Brenner et al*)
5. Identifying interventions to implement evidence into NICU nursing practice [Domain 8: Professional issues in NICU nursing] (*Wielenga et al*)



13. BEREAVEMENT

a. Needs and support for children and young people

2 Explore what bereavement is for a young person, what coping strategies they use and where they find support. [Staff/ volunteers: Bereavement and support for young people]. (*de Vries et al*)

b. Needs and support for parents and other family members

2. What are the bereavement needs of families in paediatric palliative care? (57% consensus) (*Steele et al*)
9. Bereavement. (*Quinn et al*)
9. Find out what families want from the hospice with regard to end-of-life and bereavement care. (*Malcolm et al*)



14. ETHICS

8. Exploring the role of parents in ethical decision making [Domain 5: Ethics] (*Wielenga et al*)
9. To explore the effect of ethical dilemmas of staff. (*Aylott et al*)



15. WORKFORCE



a. Retention and well-being

1. Retaining staff what incentives do staff need e.g. study time, time owing? [Professional issues] (*Soanes et al*)
2. Explore factors for retaining and building the volunteer workforce for the future in hospice. [Staff/ volunteers: Education]. (*de Vries et al*)
2. Investigate the support and education needs of general practices for provision of palliative care in primary health. [Staff/ volunteers: Community]. (*de Vries et al*)
2. The incidence of stress/burnout on the unit and support available [Professional issues] (*Soanes et al*)
3. Staff well-being, patient care and productivity (*Williams et al*)
6. How can we improve recruitment & retention of PICU staff? (*Aylott et al*)
6. Identify the best strategies to recognise and manage nursing stress/burnout (*Ramelet et al*)
9. Identifying strategies to reduce stress and improve performance in NICU nursing [Domain 8: Professional issues in NICU nursing] (*Wielenga et al*)
10. To investigate the relationship between shift patterns & absence of work in the PICU area. (*Aylott et al*)



b. Training and education

1. Investigate the experiences of staff providing family member/caregiver counselling who are not formally trained as Counsellors and examine what the education needs of these staff members are [Staff/ volunteers: Education]. (*de Vries et al*)
1. If nurses have knowledge to implement effective symptom management to their patients on a day-to-day bases [Nursing procedures] (*Soanes et al*)
1. Youth healthcare needs and professional development (25 funding units) (*Medlow et al*)£
3. Development of specific training programmes for nurses in children's palliative care (*Quinn et al*)
3. Develop strategies to teach clinicians how to help parents make difficult EOL decisions and evaluate the impact of this education on relevant clinical outcomes. [decision making] (*Baker et al*)
3. Explore the needs of hospice staff regarding bereavement and how to communicate with children and their families on end-of-life issues. (*Malcolm et al*)
3. Translate research into practice [Psychosocial research domain] (*Clinton-McHarg et al*)£
3. Education and communication (16 funding units) (*Medlow et al*)£
4. The effect of continuous education and training methods on nursing competence and knowledge [Domain 7: Professional issues in nursing] (*Tume et al*)
4. Training needs for Centre for Palliative Care [Education] (*Downing et al*)
5. How to best meet education needs for nurses at different stages of development (*Ramelet et al*)
7. Identifying and implementing strategies to improve evidence-based nursing practice [D1: Clinical nursing care practices] (*Tume et al*)
7. Integration of Centre for Palliative Care into core health curriculum [Education] (*Downing et al*)
8. Information/ education [Psychosocial research domain] (*Clinton-McHarg et al*)£

16. FUNDING RESEARCH



a. Setting Research Questions

1. Strategic (*Clinton-McHarg et al*)£
2. Investigator-driven (*Clinton-McHarg et al*)£
3. Outcomes [theme] (*Bradley et al*)



b. Areas

1. Clinical medicine and science (*Clinton-McHarg et al*)£
1. Cancer control and outcomes (20 funding units) (*Medlow et al*)£
2. Psychosocial (*Clinton-McHarg et al*)£
2. Anti-cancer treatment (18 funding units) (*Medlow et al*)£
2. Clinical research and implementation (19 funding units) (*Medlow et al*)£
3. Basic science (*Clinton-McHarg et al*)£
3. Early detection, diagnosis and prognosis (18 funding units) (*Medlow et al*)£

4. Health services (*Clinton-McHarg et al*)£
4. Prevention (15 funding units) (*Medlow et al*)£
5. Public Health (*Clinton-McHarg et al*)£
5. Aetiology (12 funding units) (*Medlow et al*)£
6. Biology (11 funding units) (*Medlow et al*)£
7. Scientific Model Systems (5 funding units) (*Medlow et al*)£