A CONSULTATION WITH STAKEHOLDERS ABOUT RESEARCH PRIORITIES FOR THE MARTIN HOUSE RESEARCH CENTRE: 11 SEPTEMBER 2017

A REPORT ON THE DAY AND OUTCOMES TO DATE

Bryony Beresford, Alison Booth and Lorna Fraser
February 2017

Martin House Research Centre, Department of Health Sciences, Seebohm Rowntree Building,
University of York, Heslington, YORK, YO10 5DD
www.york.ac.uk/healthsciences/research/public-health/projects/martinhouse/
Contact us: mhrc@york.ac.uk

Introduction

In September 2017 a consultation event was organised and hosted by Martin House Research Centre at the University of York. The objective of the event was to consult with stakeholders about the sorts of work this newly established centre for research concerning children and young people with life-limiting conditions should be doing.

Prior to this event we had conducted a systematic scoping review of existing research prioritisation exercises which were relevant to children and young people with life-limiting conditions, their families and the staff that care for and support them. The findings from this review were used as a starting point for our consultation event.

Findings from our scoping review of existing research prioritisation exercises

We found 24 existing research prioritisation exercises which are relevant to children and young people with life-limiting conditions. These exercises had generated a total of 279 issues or research questions. We organised these under 15 topic areas:

- Epidemiology/population
- Measurement and assessment
- Service delivery and models of care
- Health interventions: pharmacology and/or invasive
- Symptom management and control
- Other interventions: physical health and functioning
- Intervention adherence
- Emotional and psychological issues
- Participation and inclusion
- Communication and decision-making
- Other family needs and support
- Practices related to palliative and end-of-life care
- Bereavement
- Ethics
- Workforce

An additional cross-cutting topic emerging from existing prioritisation exercises concerned priorities regarding allocation of ‘research funding’. Most topic areas had a number of sub-topics, and sometimes quite specific ‘sub-sub topics’.

Prior to our consultation event, we sent a short report of the review and its findings to the individuals who would be attending. A full report of the review and its findings has been submitted for journal publication.

About the event

Participants

A range of stakeholders from across the UK were invited to the consultation event with the great majority (n=43) accepting the invitation and 37 attending. Issues with children's/young people's health meant that, on the day, two young people and three parents were unable to attend. Two professionals also sent apologies. The stakeholder groups represented at the event are set out in Table 1.

Table 1: Stakeholder representation at the consultation event

Stakeholder group	Number attended
Young people/young adults	3
Parents	8
Strategic leads of charity / third sector organisations, including children's hospices	5
Children's hospice medical / care leads	4
Members of children's hospice care teams – community & in-house	4
Members of children's hospice bereavement team	1
Paediatric palliative care consultants	2
Other paediatric consultants: oncology, community paediatrics, neonatology,	3
Chaplains (NHS and hospice)	2
Clinical psychologists	1
Researchers (applied social science, health economics)	4

What happened

A copy of the programme for the event can be found in Appendix 1. The event was chaired and facilitated by members of the Martin House Centre Research Team. We briefly presented the findings from our review of existing research prioritisation exercises relevant to children and young people with life-limiting conditions, their families and the staff who support and care for them. The remainder of the day was spent engaged with a series of activities designed to explore and elicit views on research priorities for the Martin House Research Centre and associated research questions. For the small group work, each group was supported by a member of the Martin House Research Centre research team whose role was to keep the group 'on-task' and to act as note-taker.

'Burning questions' exercise

In the first activity people were invited to write down their 'burning question' for research. A copy of the pro-forma used is presented in Appendix 2. The responses were displayed over the lunch break. Each participant was given three stickers (marked with a code identifying the different stakeholder groups) which they used to vote for the burning question(s) they believed were most important.

Identifying research priorities

For the two main sessions of the event, delegates worked in groups of similar people (e.g. parents, clinicians who work with children with complex needs, professionals who provide 'non-clinical/medical' care and support) to consider the topics and sub-topics which existing research prioritisation exercises had identified as research priorities. There were seven groups as follows:

- young people
- parents (2 groups)
- charity/third sector strategic leads
- professionals who provide non-clinical/medical care and support
- medical and nursing professionals specialising in delivery of palliative care
- medical and nursing professionals working with children with complex needs

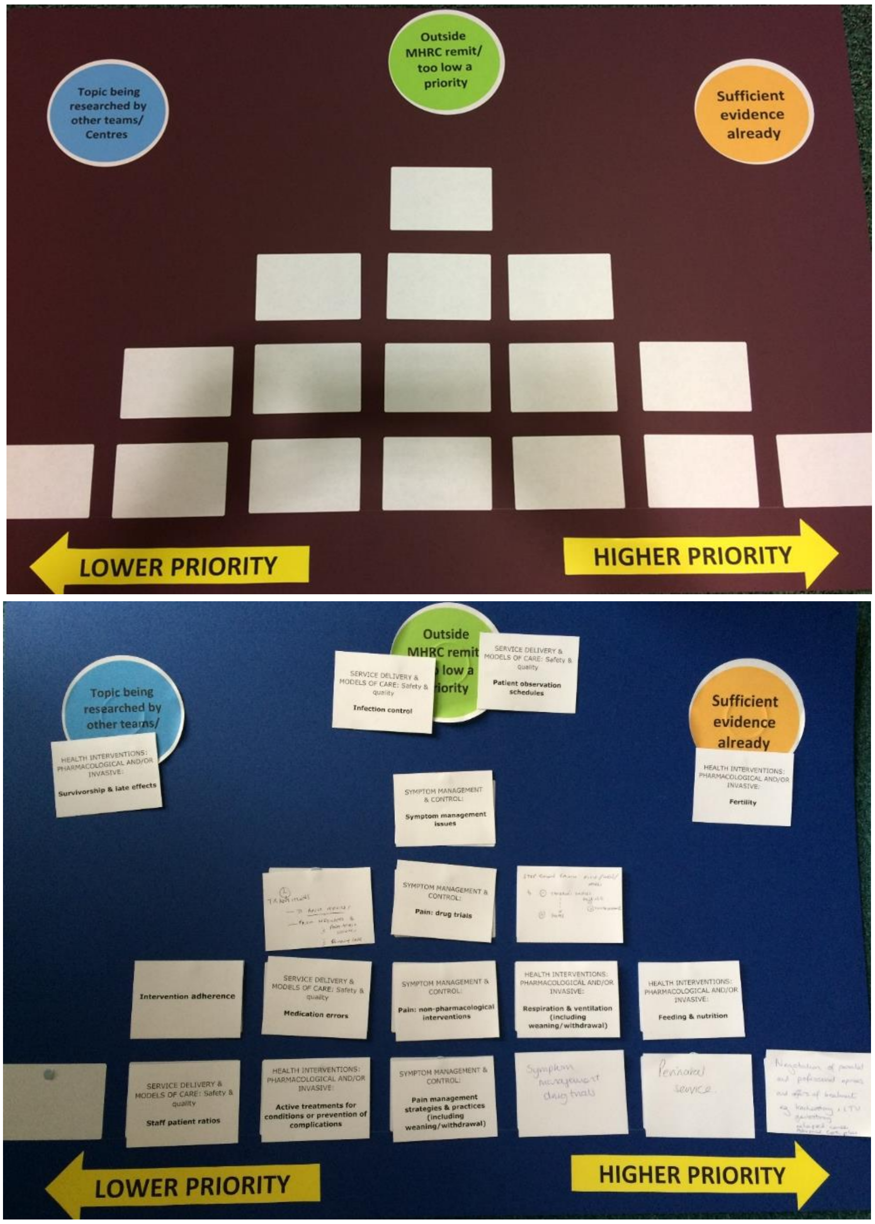
Researchers attending the event were allocated to the group most aligned to their area of expertise (excluding the young people's and parents' groups).

In order to make the task more manageable within the time available, and in recognition of the different types of interest and expertise represented, the research topics were split into three themes (see Appendix 3):

- Theme A: Medical treatments, condition & symptom management
- Theme B: Non-medical aspects of care and support
- Theme C: Topics of shared interest & expertise

In the morning, medical and nursing professional groups reviewed and prioritised Theme A topics and the remainder worked on Theme B topics. In the afternoon, all groups considered Theme C topics. Topics within each theme were presented on a set of cards and a research prioritisation grid was used to display the outcomes of each group's deliberations, see Figure 1.

Figure 1: Grid used by groups to sort topic areas in terms of their priority: images of an un-used and completed grid



Using these materials, the groups were asked to do the following tasks:

i. identify gaps in research topics within the theme and create new topic cards to represent these;
ii. decide which topics should not be considered as priorities for the Martin House Research Centre, and designate the reason for this decision as either:
    - sufficient evidence already,
    - outside of the remit of MHRC,

    - topic already being researched by other teams.

iii. for their top priority topic, to identify the two primary reasons (from a list of six) why the topic/research was a priority for research. The six reasons were:
    - It is an issue which is relevant to many children and young people with LLC (or their families or staff) [Relevant to many]
    - There is potential that improvements in evidence could have a great impact on children / families / staff's lives. [Great impact]
    - The lack of evidence means there is currently a potential for harm or significant negative consequences. [Potential for harm]
    - This issue will continue to be a high priority for at least three to five years. [Priority into future]
    - Investing in research on this issue or uncertainty represents good value for money. [Value for money]There is a good chance the evidence will be used by 'decision-makers' (this could be service commissioners, professionals/practitioners or families) [Used by decision-makers]

iv. generate at least one research question related to the topic the group had agreed was highest priority (copy of pro-forma presented in Appendix 4).

The exception to this way of working was the young people's group. They worked on the total set of set topic areas in the morning. We slightly modified the way topic areas were described to ease comprehension (see Appendix 5). In the afternoon the young people joined another group of their choice to observe and contribute to discussions.

Outcomes of the event

Topic areas which were not prioritised by stakeholders
Four of the fifteen topic areas which existing studies reported to be research priorities were not regarded by stakeholders attending our consultation event as priorities for the Martin House Research Centre. These were: interventions targeting functioning and general physical health; intervention adherence; participation and inclusion; and ethics.

Priority topics and research questions
Almost all of the new issues, or sub-topics, identified by participants could be subsumed under one of the existing topics. However, one new substantive topic area was identified: spiritual needs and care.

Table 2 sets out the research topics which were prioritised by those attending our consultation event, the research questions they generated and the most popular ‘burning questions’. It also details why stakeholders believed research on the topic should be prioritised and the stakeholder group which made it a priority. Appendix 6 provides a complete report of the priorities assigned to topic areas.

Table 2: Research topics prioritised by stakeholders, research questions generated, and the most popular 'burning questions' 🔥 [1]

Research questions generated	**Why?**[2]	**Who?**[3]
Topic: **EPIDEMIOLOGY / POPULATION RESEARCH: numbers, needs and access to services**		
How many children and young people could benefit from palliative care and **what are their needs**?	• Potential for harm • Used by decision-makers	Non-clinical care & support professionals
What are the challenges and barriers to accurately **identifying the multi-faceted needs** of infants, children and young adults with LLC, and their families	• Potential for impact • Used by decision-makers	Medical & nursing professionals: complex needs
What are **the barriers** (geographical, socio-cultural and economic) to **accessing** high quality palliative care services?	• Potential for impact • Used by decision-makers	Medical & nursing professionals: complex needs
Topic: **MEASUREMENT AND ASSESSMENT OF OUTCOMES**		
How do we **measure the quality of care outcomes** for children with life-limiting conditions?	• Potential for impact • Used by decision-makers	Paediatric palliative care medical & nursing professionals
The **development of (global) outcome measures** of practical use in busy clinical practice.	• Relevant to many • Priority into future	Medical & nursing professionals: complex needs
Topic: **SERVICE DELIVERY AND MODELS OF CARE: access to, and evaluation of models of care**		
What **models of care best meet the needs** (holistic) of children and young people?	• Relevant to many • Used by decision-makers	Charity /3rd sector strategic leads / service providers
How are **professionals not specialist in paediatric palliative care** dealing with children with LLC? How, what, why & when do they have conversations about palliative care? What is the content of those conversations?	• Relevant to many • Used by decision-makers	Paediatric palliative care medical & nursing professionals

What are the **patterns of uptake of specialist paediatric palliative care services**, and how do **outcomes** compare between those who access and those who do not access these services?	• Value for money • Used by decision-makers	Paediatric palliative care medical & nursing professionals
Topic: **HEALTH INTERVENTIONS: pharmacological (medicines) and/ or invasive treatments**		
Research into **medicines and technologies** which **treat** health conditions or **keep children and young people as well as possible**.		Young people
Topic: **SYMPTOM MANAGEMENT: recognition and management of pain**		
How **can parents assess** the impacts and needs of children and young people when receiving treatment and care when they are unable to communicate?	• Relevant to many • Potential for harm	Parents
Are **pain assessment/recognition tools effective** in improving pain control in pre-term infants/small babies/non-verbal children (being cared for at home)?	• Potential for impact • Potential for harm	Medic & nursing professionals: complex needs
Can the system for **pain control prescribing** between GP/hospital and chemist be improved?	• Relevant to many	Medic & nursing professionals: complex needs
Topic: **EMOTIONAL & PSYCHOLOGICAL ISSUES: measurement & identification; role of palliative care; how to provide support; spiritual & cultural needs**		
How do we **identify and measure** psychological needs and difficulties?		Non-clinical care & support professionals
What are the **goals of palliative care with respect to emotional and psychological well-being** from the perspectives of children and their families?		Non-clinical care & support professionals
🔥 What are the **most effective psychological interventions** (i.e. therapeutic modalities) for children, young people and families who have been given a life-limiting/ terminal/ palliative prognosis?	• Potential for impact • Value for money	🔥 Professionals' vote (3rd)

🔥 Offering **emotional support** in a practical and sensitive way when the child is **palliative but not dying**.	• Relevant to many • Potential for impact	🔥 Parents' vote (=1st)
Topic: **COMMUNICATION AND DECISION-MAKING: involving children and young people and parents, impact on outcomes**		
How do we facilitate **children and young adults to have a voice in decision-making** related to their own care and lives?	• Relevant to many • Potential for harm	Medic & nursing professionals: children complex needs
What impact does **effective communication have on positive outcome**s for families/children receiving palliative or end of life care? What does effective communication look like in this context?	• Relevant to many • Potential for harm	Parents
Parental involvement in decision-making once their child is **18+yrs**	• Priority into future • Value for money	Parents
🔥 **How involved** are children & young people in decisions around their care?	• Relevant to many • Great impact	🔥 Professionals' vote (1st)
Topic: **CARE AND SUPPORT NEEDS (NON-MEDICAL): families' needs, impact of unmet need, effective provision to address these needs**		
What is **the impact of a lack of support** on families: particularly on parents and young adults' lives?	• Relevant to many • Potential for harm	Parents
What **roles do parents play** in the lives, treatment and care of young adults (18-30 years)? And what impact does their role have on outcomes?	• Relevant to many • Potential for impact	Parents
What are the **service and support needs of young adults** (incl over 25 yrs), are they getting them and who/how should they be funded?		Young people
Of **existing services, which have the greatest impact**? What are the **unmet needs**?	• Relevant to many • Potential for impact	Charity /3rd sector strategic leads / service providers
🔥 The support to families and children where the **path of conditions is unclear**, or conditions **undiagnosed**.	• Relevant to many • Potential for impact	🔥 Parents' vote (=1st)

Topic: **PRACTICES RELATED TO PALLIATIVE & END-OF-LIFE CARE: what should it look like?; perinatal palliative care**		
Research into **the sorts of care & support children, young people, young adults, & their families, need** when nearing **the end of their lives** and **planning for this**.		Young people.
🔥 **What support** do families, children and young people with LLC want from children's palliative care services, **and where** do they want it to be given?	• Priority into future • Used by decision-makers	🔥 Professionals' vote (2nd)
What is the impact/effect of **advance care planning/engagement with perinatal palliative care team** on emotional & physical well-being of families (parents, siblings) & pregnancy outcomes?	• Potential for harm • Used by decision-makers	Medical & nursing professionals: babies & children - complex needs
Topic: **BEREAVEMENT: evaluation of interventions**		
What are timely and effective **interventions** for bereavement care?		Non-clinical care & support professionals
See also: **Spiritual needs and care below**		
Topic: **WORKFORCE: well-being and support**		
How do organisations support professionals following difficult end-of-life care experiences?	• Potential for harm • Value for money	Medic & nursing professionals: children with complex needs
How to support staff who care for and work with children and young people with LLC.		Young people
NEW Topic: **SPRITUAL NEEDS AND CARE**		
What are children & young people's **cultural, spiritual and religious needs**, & how **are they met**?		Non-clinical care & support professionals.
🔥 **Bereavement support** (post- and pre-) with the real emphasis on providing **spiritual and religious** support.	• Potential for impact Potential for harm impact	🔥 Young people's vote

Reflections and conclusions

The objective of this consultant exercise was to create a forum in which to hear and explore stakeholders' views regarding the sorts of research the Martin House Research Centre should seek to engage with. We observed a high level of engagement with the event's activities by those who attended and believe our objective was achieved. The event also generated, or renewed, connections with individuals interested in collaborating further with the Centre – either as research partners and/or through involvement in further consultation work. We were gratified with the range of stakeholder groups represented – indeed, it was a more diverse gathering than any of the research prioritisation exercises we identified in our scoping review. The representation of chaplains at the event certainly led to spiritual needs and care being identified as a new topic area not previously identified; and was also independently identified as a high research priority for young people in terms of pre- and post-bereavement support.

We deliberately chose not to seek to generate a ranked list of research topics in terms of priorities. This is the objective of a traditional research prioritisation exercise but there were a number of reasons why we took an alternative approach. These include: the multi-disciplinary nature of the Centre, the range of expertise represented within the team, the lack of a reasonable evidence base across much of children's palliative care, and the range of potential (but not necessarily predictable) funding opportunities. Our intention therefore was to use the outputs of this event – and our experiences of participating in it - to inform both the short- and longer-term focus of the Centre and the decisions made regarding the Centre's portfolio of work.

An early piece of work conducted after the event was to map current and planned activities for the MHRC against the research topics and 'burning questions' which those attending this consultation event felt the Centre should prioritise. It proved a very useful device by which to assess the extent to which the Centre's work aligned with stakeholders' priorities, as well as identifying gaps which the Centre should consider addressing. The findings from this process were shared with the committee which oversees and scrutinises the on-going funding partnership between Martin House Children's Hospice and the University of York, and the Centre's Advisory Board. We shall repeat this evaluation of our work on an occasional, but regular, basis.

Acknowledgements

Our sincere thanks to all those who attended this event and for their enthusiastic and thoughtful work and contributions throughout. In particular, we are acknowledge the involvement of the parents and young people for whom attendance may well have involved additional work and effort.

We also acknowledge the contribution of colleagues who assisted with facilitating small groups during the event (Jan Aldridge, Stuart Jarvis, Jane Maddison, Roger Parslow and Bob Philips) and Jenny Parry who provided administrative support throughout

Appendix 1: Consultation event programme

Martin House Research Centre: research priorities consultation event

11 September 2017
The Lakehouse, Ron Cooke Hub, East Campus, University of York

Programme

10:30:	**REGISTRATION AND REFRESHMENTS**
11:00	**Welcome** **An introduction to the Martin House Research Centre** **Purpose and overview of the day** *(Lorna Fraser and Bryony Beresford, Director and Assistant Director, MHRC)*
11:10	**Exercise 1: What is your burning question or uncertainty?**
11:20	**Findings from a review of existing research prioritisation exercises relevant to children and young people with life-limiting conditions** *(Alison Booth, Research Fellow, Martin House Research Centre)*
11:35	**Exercise 2: identifying the gaps and key research priorities: Topic cluster 1 or 2**
12:30	**Review of morning session** *(Bryony Beresford)*
12:35	**LUNCH**
13:15	**Exercise 3: identifying the gaps and key research priorities: Topic cluster 3**
14:20	**Review of work achieved, next steps**. *(Bryony Beresford)*
14:25	**Closing comments** *(Lorna Fraser)*
14:30	**Refreshments and networking**.
15:00	**Depart**

Appendix 2: 'Burning question' pro-forma

In terms of the management, care and support of children and young people with life-limiting conditions, their families, or the workforce ………. what do you think is the most pressing issue or uncertainty that needs to be researched?

What issue or uncertainty needs an answer, or more evidence? *(Please write clearly and be as specific as possible. <u>If relevant</u>, please specific condition/ diagnoses, age, stage of disease process etc.)*

Why is this is your most pressing issue or uncertainty where evidence is needed? (Please tick the <u>two</u> most appropriate statements)

☐ It is an issue which is <u>relevant to many</u> children and young people with LLC (or their families or staff)

☐ There is potential that improvements in evidence could have a <u>great impact</u> on children / families / staff's lives.

☐ The lack of evidence means there is <u>currently a potential for harm</u> or significant negative consequences.

☐ This issue will <u>continue to be a high priority</u> for at least three to five years.

☐ Investing in research on this issue or uncertainty represents <u>good value</u> for money.

☐ There is a good chance the evidence <u>will be used by 'decision-makers'</u> (this could be service commissioners, professionals/practitioners or families)

☐ Other ____

I am……..

☐ a young person	☐ a health care professional
☐ parent	☐ a non-health care professional

Appendix 3: Allocation of topics to themes

Theme 1: Medical treatments, condition & symptom management

Service delivery and models of care

- safety and quality
    - infection control
    - medication errors
    - patient observation schedules
    - staff patient ratios

Health interventions: pharmacological and/or invasive

- active treatments for conditions or prevention of complications
- minimising impacts of treatments: preparation and pre-medication
- respiration and ventilation (including weaning/withdrawal)
- feeding and nutrition
- survivorship and late effects
- fertility

Symptom management and control

- symptom management
- pain management strategies and practices (including withdrawal/weaning)
- pain: non-pharmacological interventions
- pain: drug trials

Intervention adherence

Theme 2: 'Non-medical' aspects of care and support

Emotional and psychological issues

- coping and resilience
- impacts, needs and experiences
    - children and young people
    - parents and carers
    - siblings
- support systems and structures
- interventions

Participation and inclusion

- preventing discrimination and exclusion
- independence and young adulthood
- mobility

Other family needs and support

- service organisation and provision

- parents as carers
- supporting self-management

Bereavement
- needs and support for children and young people
- needs and support for parents and other family members

Theme 3: Topics of shared interest & expertise

Epidemiology / population
- incidence and prevalence
- access to services
- needs
- prevention

Measurement and assessment
- global outcomes (eg quality of life)
- pain and breathlessness
- sedation
- antibiotics
- psychosocial issues

Service delivery and models of care
- evaluating service delivery and models of care
- settings of care: service delivery and outcomes
- joint working
- transitions between service or care settings
- palliative and end-of-life care: service models
- patient experience

Other interventions: physical health and functioning
- management of musculo-skeletal function
- continence
- communication
- sleep
- general physical health

Communication and decision-making
- documenting care
- communication between staff / within team
- communication between staff and children/parents/families
- treatment and care decision-making

Practices related to palliative and end-of-life care
- advance care planning and preparing for death
- identification of best practice

Ethics

Workforce

- retention and well-being
- training and education

Appendix 4: Prioritisation decision and research question form

'TOPIC DECISION AND RESEARCH QUESTION' FORM

Group: ________ Session: Morning / Afternoon

Our highest priority topic: ____________________________

Why has the group identified this topic as its top research priority? (Please tick the two most appropriate statements)

☐ It is an issue which is relevant to many children and young people with LLC (or their families or staff)

☐ There is potential that improvements in evidence could have a great impact on children / families / staff's lives.

☐ The lack of evidence means there is currently a potential for harm or significant negative consequences.

☐ This issue will continue to be a high priority for at least three to five years.

☐ Investing in research on this issue or uncertainty represents good value for money.

☐ There is a good chance the evidence will be used by 'decision-makers' (this could be service commissioners, professionals/practitioners or families)

☐ Other: ____

Within this topic, what specific question(s) should be prioritised?

Your question: (Try to start your question…. *Is, What, How, Which, When, Where*?)

Further details:

Population (eg. condition, age, stage of disease):

Setting (eg. home, hospital, hospice):

Appendix 5: Topic areas as presented to the young people

Epidemiology/population
Research into … things so we know more about the numbers of children and young people with life-limiting conditions and whether there are enough services for everyone

Measurement and assessment
Research into … how we can measure children and young people's quality of life, and other things such as their experiences of pain and their emotional well-being

Service delivery and models of care
Research into…..the way health and care services are organised, transferring between services and types of care, and where to best deliver care and support.

Health interventions: pharmacological and/or invasive
Research into…. medicines and technologies which treat health conditions or which keep children and young people as well as possible (eg feeding, ventilation).

Symptom management and control
Research into… how best to control pain, and care for children and young people in pain or experiencing other distressing symptoms

Other interventions: physical health functioning
Research into … the best ways to support children and young people to be as physically strong and mobile as possible, to sleep well, to be able to communicate independently, and to be toilet-trained.

Intervention adherence
Research into….. how to help children, young people and families manage and stick to their treatment and therapy plans.

Emotional and psychological issues
Research into ….. the emotional and psychological needs and experiences of children and young people, and their families; and how to best care for and support their emotional needs.

Participation and inclusion
Research into …. how children and young people can be as independent as possible, can make the most of school, have friends and take part in things outside of school

Communication and decision-making
Research into ….. the best ways for professionals to talk to, share information with, and make decisions with children and young people and their families. And how to make sure professionals are good at sharing information with each other.

Other family needs and support
Research into …the sorts of support parents may need, and how to provide that support.

Practices related to palliative and end-of-life care
Research into …. the sorts of care and support children and young people nearing the end of lives, and their families, and how they want to plan for that time

Bereavement
Research into … supporting children and young people, and parents, who have been bereaved.

Ethics
Research into … what people in society think about some of the very difficult decisions doctors sometimes have to make.

Workforce
Research into …. how to support staff who care for and work with children and young people with life-limiting conditions.

Appendix 6: Results of the small group exercises on research priorities

THEME 1: MEDICAL TREATMENTS, CONDITION & SYMPTOM MANAGEMENT	**Group E**	**Group F**
Health interventions: pharmacological and/or invasive		
Active treatments for conditions or prevention of complications	5	1
Feeding and nutrition	2	3
Fertility	S	OL
Minimising impacts of treatments: preparation and pre-medication	7	7
Respiration and ventilation (including weaning/withdrawal)	3	3
Survivorship and late effects	RE	3
Intervention adherance	6	2
Service delivery and modes of care		
Safety and quality: Infection control	OL	SE
Safety and quality: Medication errors	5	4
Safety and quality: Patient observation schedules	OL	OL
Safety and quality: Staff patient ratios	6	5
Symptom management and control		
Pain management strategies and practices (including withdrawal/weaning)	4	4
Pain: drug trials	4	4
Pain: non-pharmacological interventions	4	6
Symptom management issues	4	2
New issue/topic area identified by group		
Negotiation of parental and professional opinions and offers of treatment eg tracheostomy & LTV, gastronomy, relapsed cancer, advance care plan	1	
Perinatal service	2	
Step down from PICU/DHU/NNUs - Children's hospices for EOLC, convalescence, Home	3	
Symptom management drug trials	3	
Transitions - to adult services - from neonatal & paediatric services, primary care	5	
Advance care planning in antenatal palliative care?		1
Service models for perinatal palliative care? Involvement of PPC in decision making regarding pregnancies.		4

Key

OL: outside of remit of MHRC or too low priority
RE: already being researched by other centres/teams
SE: sufficient evidence already
-- : not rated by group

Groups

A: Parents
B: Parents
C: 3rd sector strategic leads/providers
D: Non-clinical care & support professionals
E: Paediatric palliative care medical & nursing professionals
F: Medical & nursing professionals: children with complex needs
G: Young people & young adults

THEME 2: 'NON-MEDICAL' ASPECTS OF CARE AND SUPPORT	Group A	Group B	Group C	Group D
Bereavement				
Needs and support for children and young people	5	4	2	3
Needs and support for parents and other family members	4	4	4	4
Emotional and psychological issues				
Coping and resilience	2	5	RE	SE
Impacts, needs and experiences of children and young people	3	1	2	1
Impacts, needs and experiences of Parents and carers	2	4	7	2
Impacts, needs and experiences o Siblings	2	3	6	3
Interventions	6	4	4	4
Support systems and structures	5	3	3	5
Other family needs and support				
Parents as carers	2	5	3	3
Service organisation and provision	-	7	1	RE
Supporting self-management	5	RE	4	OL
Participation and inclusion				
Mobility	4	SE	OL	SE
Independence and young adulthood	4	6	3	OL
Preventing discrimination and exclusion	3	OL	5	OL
New issue/topic area identified by group *(reported as written)*				
UN Report on 'grave' disability rights violations under UK reforms: impact on c& yp & families quality of life	1			
Recognition of impact on parents of having to constantly fight for things (emotional, financial, time costs).	1			
18+ provision: Recognising ongoing importance of parents and family	3			
Children and Young People - Communication re: needs for non-verbal children (give children means to communicate)		2		
Emotional/ psychological support systems and structures - separated into eol and palliative care		2		
Bereavement need and support: Extended bereavement support well before EOL		3		
Parents and carers - Financial support		5		
Family's practical support needs - transport, housing, medical supplies			4	
Rights based approach including UN convention on the rights of the child				2
Participation and inclusion: Cultural, spiritual and religious issues				4
Bereavement: Effective interventions in supporting bereaved parents/carers				4
Social care and housing - to ensure support is broader than health support.				5

THEME 3: TOPICS OF SHARED INTEREST & EXPERTISE	Group A	Group B	Group C	Group D	Group E	Group F
Communication and decision-making						
Communication between staff / within team	-	1	5	4	5	4
Communication between staff and children/parents/families	2	1	6	3	5	4
Documenting care	6	-	OL	OL	SE	RE
Treatment and care decision-making	-	4	3	4	4	3
Epidemiology / population						
Access to services	-	4	2	7	OL	2
Incidence and prevalence	-	S	4	1	2	1
Needs	5	-	3	1	2	1
Prevention	-	-	OL	SE	SE	OL
Ethics	4	-	4	S	4	OL
Measurement and assessment						
Developing quality/core set of outcome measures - including family & clinical	-	-	-	3	-	-
Antibiotics	-	-	OL	OL	-	RE
Global outcomes (eg quality of life)	7	-	4	SE	1	2
Pain and breathlessness	-	-	R	5	SE	RE
Psychosocial issues	-	4	5	R	3	3
Sedation	-	-	OL	OL	-	RE
Other interventions: physical health and functioning						
Communication	-	3	5	SE	7	4
Continence	-	-	SE	5	RE	RE
General physical health	3	-	SE	SE	RE	RE
Management of musculo-skeletal function	-	-	SE	SE	RE	RE
Sleep	4	2	SE	5	6	RE
Practices related to palliative and end-of-life care						
Advance care planning and preparing for death	S	3	RE	6	4	3
Identification of best practice	S	6	7	4	OL	5

…..continued

Service delivery and models of care						
Evaluating service delivery and models of care	5	7	1	6	4	OL
Joint working	3	4	2	S	3	5
Palliative and end-of-life care: service models	5	5	6	2	OL	6
Patient experience	2	3	1	3	SE	RE
Settings of care: service delivery and outcomes	6	-	3	RE	OL	6
Transitions between service or care settings	3	6	4	6	6	RE
Workforce						
Retention and well-being	4	5	RE	4	5	4
Training and education	4	2	RE	4	RE	4
New issue/topic area identified by group (reported as written)						
The hidden cost of caring (finanicial, health, broken relationship and other human costs)	1					
Communication: The ongoing importance of the role of family (parents/carers/siblings etc) in the life, treatment, care etc of young adults 18+	1					
Communication and decision-making: Need for mediator/advocate		1				
Money					3	
Influence of environmental factors on variation in outcome opportunities for children and young specifically. Attitudes of professionals and communities towards disabled children and young people.						5

GROUP G REVIEWED THE COMPLETE SET OF TOPIC AREAS AT THE SAME TIME (Topic areas as presented to group)	**Group G**
HEALTH INTERVENTIONS: PHARMACOLOGICAL AND/OR INVASIVE • …. medicines and technologies which treat health conditions or which keep children and young people as well as possible (eg feeding, ventilation).	1
SERVICE DELIVERY AND MODELS OF CARE • …..the way health and care services are organised, transferring between services and types of care, and where to best deliver care and support.	1
SYMPTOM MANAGEMENT AND CONTROL • …. how best to control pain, and care for children in pain or experiencing other distressing symptoms.	OL
INTERVENTION ADHERENCE: ….. how to help children, young people and families manage and stick to their treatment and therapy plans.	7
BEREAVEMENT • …. supporting children and young people, and parents, who have been bereaved.	3
EMOTIONAL AND PSYCHOLOGICAL ISSUES • ….. the emotional and psychological needs and experiences of children and young people, and their families; and how to best care for and support their emotional needs.	2
OTHER FAMILY NEEDS AND SUPPORT • ….the sorts of support parents may need, and how to provide that support.	5
PARTICIPATION AND INCLUSION • …. how children and young people can be as independent as possible, can make the most of school, have friends and take part in things outside of school.	2
COMMUNICATION AND DECISION-MAKING • ….. the best ways for professionals to talk to, share information with, and make decisions with children and young people and their families. And how to make sure professionals are good at sharing information with each other.	3
EPIDEMIOLOGY / POPULATION • ….. things so we know more about the numbers of children and young people with life-limiting conditions and whether there are enough services for everyone.	4
ETHICS ….. what people in society think about some of the very difficult decisions doctors sometimes have to make.	6
MEASUREMENT AND ASSESSMENT • ….. how we can measure children and young people's quality of life, and other things such as their experiences of pain and their emotional well-being	3
OTHER INTERVENTIONS: PHYSICAL HEALTH AND FUNCTIONING • ….. the best ways to support children and young people to be as physically strong and mobile as possible, to sleep well, to be able to communicate independently, and to be toilet-trained.	5
PRACTICES RELATED TO PALLIATIVE AND END-OF-LIFE CARE • …. the sorts of care and support children and young people nearing the end of lives, and their families, and how they want to plan for that time.	1
WORKFORCE • …. how to support staff working with children and young people with life-limiting conditions.	2