



UNIVERSITY  
*of York*

**RESEARCH**



The  
**Martin House**  
RESEARCH CENTRE

**WHAT ARE THE  
RESEARCH  
PRIORITIES FOR  
CHILDREN AND  
YOUNG PEOPLE  
WITH LIFE-LIMITING  
CONDITIONS?**

# MARTIN HOUSE RESEARCH CENTRE

## The issue

Sometimes research is carried out without first understanding what matters to patients, their families and professionals. From the outset, the Martin House Research Centre wanted to make sure it did research on the issues most important to families and professionals, and which would make the most difference. One of the centre's first pieces of work was to identify which topics or research questions the centre should prioritise.

## The project

First, we looked for existing work on identifying research priorities related to the care and support of children and young people with life-limiting conditions. Next, we held a consultation event with young adults, parents, professionals (eg medical, nursing and other care staff, clinical psychologists, chaplains) and national charities. 37 people took part, including three young adults and eight parents.

## What we found

We found 24 existing projects on research priorities. Most only involved medical and nursing professionals. Altogether these studies identified 15 different priority areas for research (eg bereavement support, symptom-management). Those attending the consultation event agreed all the topics were important and, for each topic, specific research questions were generated. A new topic was also identified: spiritual care.

Groups differed on the topics that, for them, were the most important. For example, for parents it was typically psychological care, young people prioritised spiritual care and professionals were most likely to say children/young people's involvement in decision-making was a top priority. This highlights the importance of making sure any work on research priorities involves all stakeholders.

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## Published paper

[https://spcare.bmj.com/  
content/early/2021/06/28/  
bmjspcare-2021-003019](https://spcare.bmj.com/content/early/2021/06/28/bmjspcare-2021-003019)

## Our research themes:

CREATIVITY | CULTURE AND COMMUNICATION | ENVIRONMENT SUSTAINABILITY AND RESILIENCE | JUSTICE AND EQUALITY  
HEALTH AND WELLBEING | RISK, EVIDENCE AND DECISION MAKING | TECHNOLOGIES FOR THE FUTURE