

Understanding the pastoral, spiritual and religious care and support needs of children and young people with life-threatening or life-shortening conditions, and their families

About the study

- The purpose of this study is to generate evidence which the NHS and children's hospices can use to inform provision and practices related to the pastoral, spiritual and religious care of children and young people, particularly those facing (the possibility of) end of life.
- It is the first study of chaplaincy funded by the Department of Health's National Institute for Health Research (NIHR).
- Its focus on children and young people with life-limiting conditions is because young people identified their spiritual care as a research priority.
- Researchers at the University of York are leading the work. The study team also includes NHS and hospice chaplains, clinicians, psychologists and leads of key third sector organisations.
- The study team and the study's Steering Committee include people who will help ensure study findings are shared effectively and with maximum impact.

What the study involves

- First of all, we need to find out about NHS chaplaincy services for all patient groups, and then look at whether there are differences between patient groups. **During the autumn we will be surveying chaplaincy service leads across all NHS Acute Trusts.**

If you are a service lead/head of service, please look out for an email inviting you to take part in this survey.

If you work in a chaplaincy team, please share news about this study with your colleagues and encourage your head of service to complete the survey.

- **Next year** we will be:
 - running focus groups with chaplaincy teams and clinical/care teams,
 - interviewing children, young people and parents.

Further information

Study website: <https://www.york.ac.uk/spru/projects/children-young-people-life-threatening-conditions/>

Study registration: <https://doi.org/10.1186/ISRCTN41288313>

Study dates: 1 August 2020 – 30 September 2022

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