

Parent and professional experiences of 24/7 paediatric end-of-life care: a mixed methods process evaluation

Study information

What is the study about?

This study is being carried out to increase understanding about the end of life care children and young people in the UK receive and how this can be improved. We will do this by identifying the different approaches (which we call models of care) to providing end of life care to children across the country and examining what these differences mean for children and their families. This study is mainly concerned with the availability of 24/7 end of life care services and how this might relate to healthcare use and place of death, as well as looking at differences in these between areas and different sociodemographic groups. You can find out more about our research here

[\(https://www.york.ac.uk/healthsciences/research/public-health/public-health-research/phs-ltc/\)](https://www.york.ac.uk/healthsciences/research/public-health/public-health-research/phs-ltc/)

Why is this research important?

Around 4500 children and teenagers in England will require end of life care each year. Currently, 24/7 children's palliative care is not provided in the same way across the UK. We do not have a good understanding of how this is provided, what professionals think of current provision, what would help them deliver better care; or of children's or young people's and families' experiences of accessing care out of hours, and what they need.

We will use data already collected within the NHS to find out about A&E and emergency hospital admissions, the costs of these admissions to the NHS, and where children die, both within the Yorkshire and Humber region and comparing across England to areas with and without 24/7 end of life care services. We will speak to families to find out about their experiences of OOH care, before and after its introduction. We will speak to professionals to find out what they think about current provision, expectations and needs of the proposed service; and experiences of delivering care after its introduction.

For example, some children can access care from palliative care professionals or children's hospices whereas others cannot. The end of life care that children receive from their cancer team may also vary, with some children continuing to receive high intensity treatments such as chemotherapy or ventilation and others who do not. However, there is little evidence to tell us how the current approaches to providing end of life care should change to ensure that all children who die with cancer have access to the care they need.

What is the aim of the study?

This study aims to describe the differences in healthcare use near the end of life and in place of death across the Yorkshire and Humber region. It also aims to identify any

differences in these outcomes between other areas with and without a 24/7 end of life care service.

What will the study involve?

We will examine the information available to researchers from children's and young people's medical records and death records. This will tell us about the use of healthcare and variations in place of death.

Because children's records are held in different places, we will need to link different sources of data together (e.g. the records from the Office for National Statistics death registration data and hospital records). NHS England look the medical records and will link the data for us so that we don't see children's identifiable information. This information will be removed before the linked data is provided to us so the researchers would not see any identifiable information on your child.

Privacy Notice

Where do we obtain data from?

This study uses data from Hospital Episode Statistics (HES) data which is provided by NHS England. It is data about admissions at NHS hospitals in England. This data is collected during patients' time at hospital and is collated centrally to allow hospitals to be paid for the care they deliver. HES data is designed to enable other non-clinical uses, such as research into aspects of NHS care. More information is available on the NHS England website (<https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics>).

For those children who have died we also have data about their death from the Office for National Statistics national registration data. These data are also supplied by NHS England.

What data do we hold?

The data does not contain patients' names, addresses, phone numbers, NHS numbers, or records from primary care. It contains the month and year of patients' births, although not the date. The death record data contains the date of death, the cause(s) of death and the address at which death took place.

These data do include a unique identifier, which if combined with data held by NHS England would allow identification of an individual therefore these data are classed as 'personal data' under the General Data Protection Regulation (GDPR).

Who will process my personal information?

Only researchers at the University of York will process your data. We do not share the personal data for this study with anyone else. All publications and presentations will be undertaken using aggregate level data.

What is the purpose and legal basis of the processing?

Under the General Data Protection Regulation (GDPR), the University has to identify a legal basis for processing personal data and, where appropriate, an additional legal basis for processing special category data.

In line with our charter which states that we advance learning and knowledge by teaching and research, the University processes personal data for research purposes under Article 6 (1) (e) of the GDPR:

Processing is necessary for the performance of a task carried out in the public interest

Special category data is processed under Article 9 (2) (j):

Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes

Research will only be undertaken where ethical approval has been obtained, where there is a clear public interest and where appropriate safeguards have been put in place to protect data.

How will you keep my data secure?

The data controllers for this study are the University of York.

The University will put in place appropriate technical and organisational measures to protect your personal data and/or special category data.

Information will be treated confidentially and shared on a need-to-know basis only. The University is committed to the principle of data protection by design and default and will collect the minimum amount of data necessary for the project.

How can I access my personal information or opt out?

Various rights under data protection legislation, including the right to access personal information that is held about you, are qualified or do not apply when personal information is processed solely in a research or archival context. This is because fulfilling them might adversely affect the integrity of, and the public benefits arising from, the research study or project.

The full list of (qualified or inapplicable) rights is: the right to access the personal information that is held about you by the University (further details are published [here](#)), the right to ask us to correct any inaccurate personal information we hold about you, to delete personal information, or otherwise restrict our processing, or to object to processing (including the receipt of direct marketing) or to receive an electronic copy of the personal information you provided to us.

If you have any questions regarding your rights in this context, please use the contact details below.

Please note as we do not hold names or addresses for this study we cannot remove participants from this study. However, families can choose that their child's information is not used for this study (before data are provided to us) and for other studies by contacting NHS England: <https://www.nhs.uk/your-nhs-data-matters/>

How long is my information kept?

Although the analyses conducted by the Research Team cannot identify any individual from the HES data provided to it by NHS England, it takes great care in protecting the HES data. The team is subject to strict contractual standards imposed by NHS England, as the data provider.

As contractually required, HES data is not kept for longer than the length of the research study and is then securely destroyed.

Who can I contact?

If you have any questions about this research study, please contact the principal investigator Dr Julia Hackett on julia.hackett@york.ac.uk.

If you have any general questions about how your personal information is used by the University, or wish to exercise any of your rights, please consult the University's [data protection webpages](#). If you need further assistance, please contact the University's Data Protection Officer at dataprotection@york.ac.uk.

How can I complain?

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer can be contacted at dataprotection@york.ac.uk

For information on reporting a concern to the Information Commissioner's Office, please follow this [link](#).