**Treatment at the end of life in children with cancer**

## What is the study about?

This study is one of several studies we are carrying 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 focusing on children with cancer and will assess the treatments that children who die with cancer receive towards the end of their life.

You can find out more about our research here ([www.york.ac.uk/mhrc](http://www.york.ac.uk/mhrc))

**Why is this research important?**  
Around 500 children and teenagers in England with cancer will require end of life care each year. Currently, the provision of this care varies across the country and little is known about how this variation impacts on children and their families. 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 use of high intensity treatments in children who have died with cancer and assess whether the variations in these treatments are related to the model of care that is delivered in the child’s hospital team.

**What will the study involve?**

We will examine the information available to researchers from children’s medical records. This will tell us about the treatments provided to around 4000 children and young people treated in cancer services in England who died from 2012-2020.

Because children’s records are held in different places, we will need to link different sources of data together (e.g. the records from intensive care units and the records from cancer services). This will enable us to build a full picture of the journey of a child’s care before they die. NHS England look after children’s cancer records and will link the data for us so that we don’t see children’s identifiable information. However, the organisations which hold other data sources will need to share the identifiable information of each child with NHS England so that they can match up all the information we need. This will include the child’s name, date of birth, NHS number and postcode. 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.

**Do families have to take part in the study?**

This study has approval from the Confidentiality Advisory Group to use these data without asking the individual children and their families for permission. However, families can request that their child’s information is not used for this study by NHS England here <https://www.ndrs.nhs.uk/patients/opting-out/>

**More information about the organisations that collect data**

Cancer registration - NHS England <https://www.ndrs.nhs.uk/about-us/>

Children’s Intensive Care – PICANet <https://www.picanet.org.uk>

Adult intensive care – ICNARC <https://www.icnarc.org>