

# YourTube Newsletter

Study

## Study update

The Your Tube study started in February 2019 and involves two linked studies. The first was a qualitative study involving interviews with families and healthcare professionals to understand more about the impacts (which we call outcomes) of gastrostomy feeding. The second is what we call a cohort study. This will assess the safety, benefits and risks of gastrostomy feeding, comparing children who have formula feeds with children who have blended food in their diet. We hope to include 300 children in this part of the study.

Throughout 2020 our work has focused on recruiting families to take part in the study and starting to collect information from them. We paused this work for a little while because of Covid-19, but from July we have been working with our NHS and children's hospice partners to get the study restarted.

Amazingly, 152 families have now signed-up to take part in the study and another 50 have expressed an interest and will hopefully sign up soon. Many of the families who are taking part have been recruited since the study re-started in July.

We would like to thank families for taking the time to participate in this research during what has been a difficult year for many. We would also like to thank our fantastic NHS and children's hospice partners for continuing to support the study.

To mark another milestone, we have now started to collect participant data in the form of parent questionnaires and information from clinicians. Many of the families who were the first to complete the study questionnaires have kindly provided useful feedback, making it easier for subsequent families to provide us with information. Some of our families are still waiting patiently to complete these questionnaires and this is a priority for us in the New Year.

Due to the pandemic, much of the study is being conducted online, using electronic consent forms and online questionnaires for collecting data. However, families are still able to complete a paper questionnaire that they can return by post if they prefer.

## Get to know the team

### Jo Taylor—Study Manager

Jo is a researcher in the Martin House Research Centre. Jo's research is mainly about children and young people with complex health care needs. Jo's PhD explored how parents and young people make decisions about a gastrostomy.



"It's great to be working on this important study. Evidence that can improve the advice and support that families of children with a gastrostomy receive is still really needed."

## Our parent advisors

As part of the study we have a Project Advisory Panel, which includes parents of children with a gastrostomy. These parents have provided ongoing advice throughout the study, and have been involved in the following:

- Choosing the study name - in fact, one of our parents came up with the name Your Tube
- Making sure that our website and the documents we provide to families contain the right information
- Encouraging us to recruit families via social media
- Deciding which outcomes we should measure in the cohort study.

The Project Advisory Panel will continue to support the study by helping us to understand what the findings mean and sharing these with others.

## Measuring mid-upper arm circumference

The Your Tube Study team has produced a short video to help parents and clinicians measure children's mid-upper arm circumference.

This video is available at:

<https://youtu.be/cGWtRRNveLc>



## Contact the study team

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### Study website

<https://www.york.ac.uk/healthsciences/research/public-health/projects/yourtube/>