

YourTube Study Newsletter

Study update

The Your Tube study started in February 2019 and involves two linked studies. The first is 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.

Earlier in the year we finished the first phase of the study. You can read more about the findings and how we have used these below.

In the cohort study we are currently working with around 30 NHS Trusts and 3 children's hospices to recruit 300 children and young people with a gastrostomy. As of today, 150 families have expressed an interest in taking part and 100 of these have now signed up. This is an important milestone and we celebrated with an online team quiz!

For now, we have paused recruitment and data collection for the cohort study because of Covid-19. Please read the Covid-19 update for more information.

Findings from our interviews with families and staff

When we were designing the Your Tube study we had some ideas about the aspects of children's health and well-being we should assess in the cohort study. However, we needed to be sure this included things most important to families.

We interviewed families (20 parents, 2 young people), and more than 40 health professionals (dietitians, doctors and nurses) took part in a group interview.

Importantly, families identified outcomes that we had not considered. We also learned other information that we have used to improve the cohort study. Below are the key changes we have made:

- ◆ we are now asking about problems with retching and gagging which were not included in the original list of symptoms we had planned to ask about
- ◆ we are now asking about problems with children's sleep
- ◆ we are including questions about children's physical comfort
- ◆ we have changed the way we are measuring children's quality of life because parents did not think the measure we were using was appropriate.

Get to know the team

Mark O'Neill - Study Coordinator

Mark has previously worked in research in the NHS and holds an MSc in Clinical and Public Health Nutrition from UCL.



"I'd just like to thank Mark for all his hard work in helping to recruit the first 100 families to the study"

Jo Taylor, Study Manager

Covid-19 update

On 23rd March 2020, we paused the study to make sure it does not impact on the capacity of our NHS partners to deal with the virus.

Some of our NHS partners are now ready to help with the study and we hope to start recruiting again soon. The timing of this may vary between services and we will contact participating families directly about this. You can also check our website for the status of each participating organisation.

The study team would like to take this opportunity to thank our participating families and NHS and children's hospice partners for supporting the study.

Covid-19 parent survey

Are you a parent of a child (age 0-25) who has a life-threatening or life-limiting condition?

We would like to know how the virus is impacting on you and your child. Please complete this survey.

<https://www.isurvey.soton.ac.uk/37377>

We will use the information to identify the needs of children and families, and share the findings with our NHS and charity partners.



Contact the study team

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Study website

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