

Yourtube Newsletter

Study

Study update

As a reminder, the Your Tube study aims to assess the safety, benefits and risks of gastrostomy feeding, comparing children who have formula feeds, with children who have blended food in their diet.

The number of families who provided information at baseline (the first time point in the study) was **180**. 104 of these families feed their child on blended food, whether that's in addition to some prescribed formula feeds or on a blended-only diet. 76 of these families feed their child on prescribed formula feeds only.

The study is now in the 'follow-up' stage where we continue to collection information from parents and clinicians. As a reminder, we will ask families to provide information about their child three times over an 18 month period. We call these three time points, 'baseline', '12 month follow-up' and '18 month follow-up'. Many of the parents reading this will have already been asked to provide '12 month follow-up' information; so far we've had a great response to this. The 12 month-follows will be on-going until December so don't worry if you've not been contacted yet.

A small number of families have now completed the third and final study questionnaire, the '18 month follow-up'. A huge thank you to these families, who have now completed their participation in the study. We aim to keep these families engaged in the research by continuing to share important updates, culminating in sharing the findings from the final report, which we hope to publish towards the end of summer 2023.

We would like to once again take this opportunity to thank all of the healthcare professionals and research personnel, for their continuing support with providing important study data.

It's not too late to complete your study questionnaire!

If we have sent you a 12 month follow-up questionnaire some time ago, and you have stopped receiving reminders from us, it's not too late to complete the questionnaire and send it back to us.

If you are keen to complete the questionnaire but are struggling to find the time, do please get in touch and we can suggest some options that might make things a bit easier, like completing the questionnaire together over the phone.



Get to know the team

Alison McCarter - Community dietitian

Alison has over 15 years experience in home enteral tube feeding of both children and adults. Alison has worked in Somerset for the last 20 years.

Alison is committed to working collaboratively to improve evidence to help with the choices open to children, who are tube fed, to enable them to grow, thrive and take part in family life.



It is exciting to be working on this research that involves patients and their families, alongside healthcare professionals and experts, to help understand what works best for tube-fed children; to improve their quality of life along with their families'.

Participant and Public Involvement Award

Award for The Martin House Research Centre

The Your Tube Study is just one of many research projects being carried about by the Martin House Research Centre. The Martin House Research Centre is a multi-disciplinary centre for research on the care and support of children and young people with life limiting conditions or medical complexity, their families and the workforce that care for them.

Researchers at the University's Martin House Research Centre (MHRC) in Health Sciences have won an award recognising their commitment to involving children and their families in the design and delivery of research projects. The team, led by Professor Lorna Fraser, received the PIER (Paediatric Involvement and Engagement in Research) Award from the National Institute for Health Research (NIHR) and the Royal College of Paediatrics and Child Health (RCPCH). Find out more about the award for the MHRC by [clicking here](https://www.york.ac.uk/healthsciences/news-and-events/news/events-2022/awardformartinhousereseearchteam/).

<https://www.york.ac.uk/healthsciences/news-and-events/news/events-2022/awardformartinhousereseearchteam/>

Contact the study team

Study Manager - Julia Hackett
Study Coordinator - Mark O'Neill
✉ yourtube@york.ac.uk
☎ 01904 321347 / 07919 293229

Study website

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