



# EDiTS STUDY

## Winter Newsletter 2025



Hello and happy holidays from  
the EDiTS team!  
**Welcome to our EDiTS Study Winter  
Newsletter 2025** 🧑‍🎄❄️

We are excited to announce that we will  
soon be starting the **primary school  
phase** of the EDiTS study.

Our research would not be possible  
without our amazing EDiTS families, so we  
want to say a HUGE thank you to all of  
you for your contributions! Your support  
makes a real difference to our study.

The EDiTS team sends their best wishes  
for the holiday season, and we hope you  
have had a fantastic 2025!





# What is EDiTS?

The EDiTS study aims to identify differences in development between children with tuberous sclerosis complex (TSC) and children without TSC, in order to find out whether these differences predict outcomes later on in life. We use a range of measures and assessments that are suitable for detecting these changes over time.

The findings from this study will improve our understanding of the association between TSC and different behavioural outcomes, such as autism and ADHD. The findings may also inform the development of early interventions to improve quality of life for individuals living with TSC.




## Where are we now?

The EDiTS Study has been ongoing for **9 years!**

The infant phase began in 2016, and followed infants from 3 months to 24 months during their first two years of life.

The preschool phase launched in 2022, and examined development in children aged 3 to 5 years.

We are excited to share that the **primary school phase** is expected to begin soon!





# Primary School Phase!

The **EDiTS Primary School Phase** will be led by our PhD student, Cheyenne.

The upcoming primary school phase will look at how early life factors might help predict educational achievement in primary school.

The study will focus on children of primary school age (6-11 years) with or without a diagnosis of TSC.

**Recruitment and data collection is estimated to begin in the near future!**



We plan to continue using a range of tools designed to track changes over time, which can be completed remotely, at home, or in school settings.

The proposed assessments and measures are similar to those used in the infant and preschool phases of the study.



These measures will evaluate areas such as cognitive function, intelligence, social cognition, executive function, sleep, and academic abilities.

Participation is expected to involve a combination of parent-report questionnaires and interviews, child observational assessments, and teacher-report questionnaires.



# Ongoing Studies

## Study 1: Experiences of educational professionals engaging with students with tuberous sclerosis complex

Purpose: To understand experiences of educational professionals supporting pupils with TSC in the UK.

Participation involves discussing your experiences of educational successes, challenges and emotions when working with pupils with TSC via short questionnaires and an online interview.



HR/DP-24/25-46556

Please scan the QR code for more information.

## Study 2: Impact of education on children with tuberous sclerosis complex: voices of primary school aged children and families

Purpose: To understand experiences and perspectives of primary school aged children with TSC in education.



HR-24/25-48980

Looking for children aged 6-11 years, enrolled in primary school (mainstream, specialist education, or home school), with a confirmed diagnosis of TSC.

Please scan the QR code for more information.

# New Advisory Group

Cheyenne works with an **advisory group** that supports her studies as a form of Patient and Public Involvement and Engagement (**PPIE**).



## What is PPIE?

- Members of the public and people with lived experiences are actively involved in the research process
- Involves sharing information and findings with the public and raising awareness of the research in the wider community
- PPIE makes research more accessible and meaningful for participants



## Advisory Group Roles

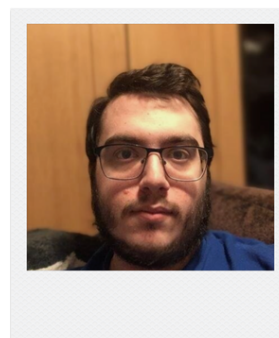
- Involves data training, data analysis, dissemination
- Members review and provide feedback on studies
- Share insights from lived experience to strengthen research
- Their input improves accessibility, clarity and relevance of content



# Advisory Group Members

## **Tom (Young adult with TSC):**

I am a recent graduate from Bournemouth University with a BSc in Psychology. I joined the EDiTS Advisory Group because I saw it as a great opportunity to be able to help with something that I've had a bit of experience in. I hope to be able to gain experience in communication skills and learn a bit more about the research in TSC.



## **Debs (Parent of child with TSC):**

My son has tuberous sclerosis, and he is now a young adult. We participated in the TS2000 Study at King's. I saw this opportunity and thought, 'I wanted to help and share my experiences'. I look back to when my son was born, in those years the help had just elevated. My motivation was to give advice and help.

The advisory group includes a third member who is a **parent and an educational professional**, they have chosen not to have their identity published.

A **volunteer panel** also provides support and feedback through virtual, behind-the-scenes work.



# Team Updates



Charlotte

Hello EDiTS families, as we head into the winter break, I wanted to take a moment to thank you all for your continued involvement in the EDiTS Study. This year marks an important transition point, as we prepare to move into the primary school phase and follow children into the next stage of their development. Thanks to your long-term commitment, EDiTS is now able to explore how early life experiences and development relate to learning, wellbeing and everyday life at school age. Your contributions over many years are what make this work possible, and we are incredibly grateful to you all for contributing your time and experiences! We look forward to sharing our findings with you in the new year. I hope you have a restful and enjoyable festive period, and we look forward to keeping in touch as the study continues into 2026.



Cheyenne

I am a PhD student that will be leading the EDiTS Studies. I have been busy developing several studies this year and collaborating with the Tuberous Sclerosis Association. I have two live studies: 1) understanding experiences of educational professionals supporting pupils with TSC in the UK, and 2) understanding perspectives of primary school aged children with TSC in education. I am also preparing the third phase of EDiTS, which focuses on how early life factors may help predict educational achievement in primary school. This work is supported by a community advisory group as a form of PPIE to improve accessibility and engagement with our participants.



Kate

I am a trainee Clinical Psychologist at King's College London, working across the South London and Maudsley Trust. Prior to training, I completed a PhD at Cardiff University, examining self-regulation processes in young children with emotional, behavioural and cognitive difficulties at school. My research interests are in autism, ADHD and emotion regulation in children with neurogenetic syndromes and epilepsy.

# Team Updates



Georgena

Hi EDiTS families! My name is Georgena and I am a third year BSc Psychology student from King's College London. I am joining the NEST lab team as an undergraduate research assistant for my placement year, and I will mainly be working on the EDiTS study. My interests include developmental psychology and clinical psychology. I look forward to gaining research experience in neurodevelopmental and neurogenetic conditions in children.



Malwina

I am a third-year BSc Psychology student currently on my placement year at King's College London. I am particularly interested in developmental psychology and how early identification and understanding of Autism and ADHD can support children in their development and promote positive future outcomes. I look forward to working closely with families and the study team to contribute towards meaningful research in neurogenetic conditions and epilepsy, helping to better understand these experiences and inform earlier, more tailored interventions.



Katie

Hi EDiTS families, I hope you are having a lovely festive period! I have had the privilege of supporting the EDiTS study for over 2 years as a research assistant and I am now beginning my own research journey as a pre-doctoral fellow, working at masters level. This will then be followed by a PhD which was inspired by my work in EDiTS and previous experience in social care. My research will be looking at how communication influences behaviour, particularly in pre-verbal children who may use sounds to communicate instead of typical speech at a later age. I will be using information from EDiTS to help frame my research ideas and I can't wait to take this research further!

# Thank You!

We would like to extend a huge thank you to all the EDiTS families, all the support you have given us over the years is greatly appreciated!  
Happy holidays and see you in 2026 🌟🔔



Best wishes,  
Dr Charlotte Tye and the EDiTS Study Team

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