

## INFORMATION SHEET FOR PARTICIPANTS

*Ethical Clearance Reference Number: HR/DP-24/25-46556*



### YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

#### **Title of project**

Experiences of educational professionals engaging with students with tuberous sclerosis complex (TSC)

We would like to invite you to participate in this research project which forms part of my qualitative research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

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#### **What is the purpose of the project?**

This study aims to understand experiences of educational professionals supporting students with tuberous sclerosis complex (TSC) including their difficulties and successes of educational experiences, educational outcomes and what emotions professionals experience. Educational professionals, such as teachers, support staff, counsellors, clinicians, head teachers and pastoral staff, may experience similar difficulties as families caring for a young person who has a diagnosis of TSC.

#### **Why have I been invited to take part?**

You are being invited to participate in this project because you are actively supporting students with TSC and have been teaching or involved in education programs for a minimum of one school term (~13 weeks). This study will be conducted virtually; therefore, there is no requirement to travel.

#### **What will happen if I take part?**

If you choose to take part in the project you will be asked to engage in one semi-structured interview which may take up to one hour via Microsoft Teams or Zoom. You will be

provided with a study advert and participant information sheet. You will be asked to provide written consent, using an online form, to participate in the semi-structure interview which will be audio and video recorded for data collection and analysis. Verbal consent will be confirmed upon meeting virtually with the interviewer. The interviewer will explore pre-determined questions about educational experiences, module training and follow-up questions relevant to information provided during the interview.

Pre-determined questions:

- How many pupils with TSC do you support?
- How many pupils with TSC have an EHCP? If they do not have an EHCP, do they receive other bespoke support? Do these students have additional co-occurring conditions?
- How would you characterize the impact of TSC on the pupils? What subject areas are the most challenging for them? How are those outcomes measured? Are these measures different compared to other pupils?
- What are the successes and difficulties implementing specific support or strategies for pupils with TSC?
- Discussions of emotional experiences supporting pupils with TSC.

As part of participation, you will be asked to provide basic demographic information such as level of education obtained, type of school setting (e.g. special education, mainstream) and job title/role. This information will be used to understand future implications and support for educational professionals. Following the interview, you will be contacted to provide feedback via an online survey. You will be informed of the results if consent is provided.

### **Do I have to take part?**

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you decide about taking part. If you decide to take part, we will ask you to sign a consent form, and you will be given a copy of this consent form to keep. As previously stated, consent will be re-confirmed upon meeting with the researcher online.

### **Incentives**

Participants will be compensated with a £20 voucher.

### **What are the possible risks of taking part?**

We do not envisage there being any risks, but you should know that it is not always possible to predict if and how a semi-structured interview may affect an individual. Although semi-structured interviews are directed by specific questions, this allows for topics to remain somewhat spontaneous. Therefore, discussing historical and current events may serve as distressing. The participant will be informed of the scheduled

questions. During the interview, the participant will be offered breaks, prompted to resume the interview at a later date, or the interview will be discontinued, if necessary.

Support will be signposted if this is the case and if further support is required, seen below. The contacts are also listed in the Signposting and Support Information Sheet. The TSA support line sustains their own safeguarding protocols which will be explained, when necessary. Considering the confidentiality of the interviews between one educational professional and one interviewer, King's College London safeguarding protocols and policies will be followed confirming the individual's information remains confidential. If necessary, specific information shared with appropriate professionals (e.g. TSA support line) will be confirmed with the educational professional prior to sharing information.

#### General Information and Support

- NHS: <https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/>

#### Mental Health Organisations

- MIND: [www.mind.org.uk](http://www.mind.org.uk) or <https://www.mind.org.uk/about-us/local-minds/local-minds/> Phone: 0300 123 3393
- Samaritans: [www.samaritans.org.uk](http://www.samaritans.org.uk) Phone: 08457 90 90 90
- Mental Health Foundation: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)
- Sane: [www.sane.org.uk](http://www.sane.org.uk), email [sanemail@org.uk](mailto:sanemail@org.uk) Phone: 0845 767 8000
- YoungMinds: [www.youngminds.org.uk](http://www.youngminds.org.uk) Phone: 0808 802 5544 (parents' helpline)
- Rethink Mental Illness: [www.rethink.org](http://www.rethink.org) Phone: 0300 5000 927
- Mencap: [www.mencap.org.uk](http://www.mencap.org.uk) Phone: 0808 808 1111
- TSA Support Line <https://tuberous-sclerosis.org/> Phone: 0808 801 0700

#### **What are the possible benefits of taking part?**

Your participation in this study will help us understand educational professional's experiences supporting students with TSC and understanding their experiences and educational outcomes. The TSA will be informed of the anonymized results; therefore, they can support and facilitate additional funding for educational needs and research.

#### **Data handling and confidentiality**

Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018). These state that we must have a legal basis (specific reason) for collecting your data.

To safeguard your rights, we will use the minimum personally identifiable information possible such as an alias or number to represent your name. Any personal, identifying information we have about you, such as your name, date of birth, email address, will be stored separately from the pseudonymized data. Only the study team will be able to link participant ID numbers to the personal, identifying information and only the study team will have access to this data. We will use this data to describe who took part in our study such as describing the job titles or education programs e.g., educational professionals who worked in SEN and mainstream schools took part in our study.

While we remain in contact during the study, we will keep personal details (e.g. name, email address, contact number) in an encrypted and password protected document. If you withdraw from the study, your contact details will be deleted from our database. If you wish to be contacted for future studies, with your consent, we will keep your information confidential.

After the interview, the video/audio recording will be encrypted and stored in a King's College London password protected folder. This recording will be typed into a transcript – the researcher will not type any additional information which may identify an individual. Once the transcript is checked, the recording will be erased to maintain the participants anonymity. Our study team will have access to the recording and transcripts during the study, and it will remain in a password protected folder for up to 3 years following conclusion of the research project.

Anonymized transcriptions will be shared with the TSA for future research purposes. The TSA will not hold corresponding data, and they will not contact you to reference any shared information with the interviewer.

Data will not be shared outside of the EU. King's College London has a responsibility to keep information collected about you safe and secure, and to ensure the integrity of research data. Specialist teams within King's College London continually assess and ensure that data is held in the most appropriate and secure way. This may include storage of anonymised or pseudonymised data with a contracted GDPR compliant third-party storage provider within the UK, where they are assessed as the best data storage option. In such cases the third-party storage provider will not have access to any data that could directly identify you.

### **Data Protection Statement**

If you would like more information about how your data will be processed under the terms of UK data protection laws, please visit the link below:

<https://www.kcl.ac.uk/research/research-environment/rgei/research-ethics/use-of-personal-data-in-research>

### **What if I change my mind about taking part?**

You are free to withdraw at any point of the study without having to give a reason. Withdrawing from the project will not affect you or opportunities to participate in possible future research studies in any way. If you choose to withdraw from the study prior to the interview, we will not retain the information you have given thus far. Participants who take part in interview have the right to withdraw up to 30 days after the interview. The research team aim to anonymize and transcribe data to be shared with the TSA for reflection and development purposes. Consent will be gained prior to sharing your anonymized data.

**How is the project being funded?**

This project is being funded by London Interdisciplinary School Science Doctoral Training Program (LISS DTP).

**What will happen to the results of the project?**

The results of the project will be summarized in a layperson's format to submit into the TSA magazine. Findings will contribute towards a PhD thesis and a publication of a scientific journal. Data will remain anonymized; therefore, any publication of data will not directly identify an individual.

**What if I have further questions, or if something goes wrong?**

If you have concerns or complaints about any aspect of this study, you should request to speak with the researchers who will aim to answer your questions: Cheyenne Contreras, email: [Cheyenne.contreras@kcl.ac.uk](mailto:Cheyenne.contreras@kcl.ac.uk), Dr. Charlotte Tye, email: [charlotte.tye@kcl.ac.uk](mailto:charlotte.tye@kcl.ac.uk).

**Thank you for reading this information sheet and for considering taking part in this research.**