

Article title: The Burden of Caring for Individuals with Tuberous Sclerosis Complex (TSC) Who Experience Epileptic Seizures: A Descriptive UK Survey

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Recruitment text

Do you care for someone with Tuberous Sclerosis Complex?

Who are we looking for?

We are looking for parents, guardians or other people who are the main, unpaid caregivers of people with Tuberous Sclerosis Complex (TSC) to take part in an online survey. This research is designed to help understand the impact of TSC on caregivers of people living with the condition and other family members.

What would we ask you to do?

The survey will take approximately 20 to 30 minutes to complete. As a token of appreciation for your time, a charity donation of £20 will be made on your behalf to the Tuberous Sclerosis Association (TSA).

Who is conducting the study?

This study is being conducted by an independent research consultancy, Acaster Lloyd Consulting Ltd, based in London, the United Kingdom. The pharmaceutical company sponsoring the study will be revealed on the last page of the survey to avoid survey responses being influenced by the study sponsor's identity.

What would we do with your data?

Data from all study participants will be combined and analysed together. Your participation is anonymous; we will not ask you for identifying personal information in the survey.

The aggregate study results will be used to help healthcare decision-makers (such as NICE in the UK) understand the impact of TSC on people's lives. We anticipate that the aggregated study results will be presented at academic conferences and published in peer-reviewed medical journals. We also plan to share these results with patient organizations supporting the TSC community, such as the TSA.

Are you interested in taking part in the study?

We would be very grateful for your help with this important research by completing the online survey via the link below: *[LINK]*