

INFORMATION SHEET



Who is conducting this study?

Researchers from the School of Psychology at University College Dublin (UCD) are conducting this research study: Ms Lisa Keenan, MSc, Dr Michelle Downes, PhD, and Prof Jessica Bramham, PhD.

What is this research about?

This research is about sleep, learning, and everyday behaviour in children with Tourette syndrome (TS).

Why are we doing this research?

We are doing this research to better understand sleep in children with TS. We are also interested in how tics might impact sleep, and how sleep might affect children's learning and everyday behaviour.

Why have you been invited to take part?

We are inviting parents of children with TS to complete this questionnaire. You are eligible to take part if your child has a diagnosis of TS and is aged between 7 and 17. If you have more than one child with TS aged between 7 and 17, please answer questions based on just one child. You are, however, free to take the questionnaire more than once if you wish to provide responses for each child.

What will happen if you decide to take part?

This study involves an online questionnaire with a series of short questions. It should take around 20 minutes to complete, but it is not timed and you can take breaks at any point. There will be a progress bar at the bottom of the screen, showing how much of the questionnaire you have completed. You will be asked some questions about you and your child (e.g. age, gender, country of residence), your child's TS symptoms, sleep, and behaviour. You will also have the option to share more details at the end of the questionnaire, where some questions will be open-ended. We are really interested in gaining any insights, thoughts, or experiences that you would be happy to share with us.

Optional: If your child wears a Fitbit watch, you will have the opportunity to share sleep data from the device at the end of the questionnaire. Step-by-step instructions will be given. See the Child Information Sheet attached below if taking part in this aspect of the study.

We recommend completing the study using a computer / laptop if possible.

How will your data be used?

Your anonymous responses to the questionnaire will be saved in a password-protected document. This document will contain responses from everyone who completed the questionnaire. No identifiable information will be stored. Data will be analysed, then written up as a research paper. Data will be stored for future use by the current research team at UCD and other researchers or students who may join the team in the future. Data will be open access, meaning that other verified researchers can use the data upon request. This is to maximise impact of the information we gather from this study. Any use of the data

will be in line with ethical requirements and data protection regulations.

What will happen to the results of the study?

The results of this study will form part of a PhD thesis for Lisa Keenan, one of the researchers involved in this study. Results will also be submitted for publication in an academic journal and presented at conferences. Finally, we will share findings on our lab website through blogs and posters designed for parents and children, which we hope will be of interest to the you and the wider TS community.

How will your privacy be protected?

Your responses will be stored in a password-protected document. You will not be asked to disclose any personal information (e.g. name, address) in this questionnaire. However, if you accidentally provide identifiable details (e.g. in open-ended questions), they will be deleted to protect your privacy. At the end of the questionnaire, you have the option to provide an email address to be entered into a prize draw, with a chance to win a €50 voucher (or local equivalent). Your email will not be shared with anyone outside of the research team and will be stored separately to your responses, so will not be linked in any way to the answers you provide.

What are the benefits of taking part?

If you complete the questionnaire, you can choose to be placed in a prize draw for a voucher worth €50. While there are no other direct benefits of taking part, your participation will help researchers gain insight into sleep in children with TS. This information will inform future research aimed at improving quality of life in children with TS. Your participation will also allow us to develop free online resources based on the results of this study, which we hope will be of interest to parents and children affected by TS.

What are the risks of taking part?

There are no major risks of taking part and the study has been ethically approved by the UCD School of Psychology. While it is possible that you may find some of the questions upsetting or difficult to answer, the risks involved are no more than what you might experience in day-to-day life. You are free to take breaks throughout the questionnaire as it is not timed. This information sheet, along with a list of TS organisations worldwide, can be downloaded using the link below.

Can you change my mind at any stage and withdraw from the study?

Your participation is voluntary and you can end the questionnaire at any time by closing your current tab. However, any anonymous information you provide before exiting will be saved for the study. You will not be able to remove your answers as there will be no way to separate your personal responses from those of all other respondents. If you would like to complete the questionnaire but do not want to answer a certain question, you are free to skip these questions.

How will you find out what happens with this research?

We will update our lab website and social media pages when this research is complete. We also encourage you to download this information sheet below so you have our contact details to easily get in touch with us with queries or for updates.

Contact details for further information:

If you have any questions or feedback, you can contact Lisa Keenan at lisa.keenan1@ucdconnect.ie. See the UCD information for participants page [here](#) for further details.

We would like to thank the members of the TS community who kindly reviewed a draft of this questionnaire and provided much-appreciated feedback.

For a list of TS support organisations around the world, go to <https://www.essts.org/directory>