



Participant Information Sheet

Target Group: 18–25-year-old with a Diagnosis of Tourette Syndrome Living in Great Britain who have used both medicine and creative art forms such as music, art, or drama to help their tics.

Title of Project: Primary Lived Experience of Tourette Syndrome and the Effectiveness of arts-based intervention vs Pharmacological Intervention.

Researcher name: Meg Hatfield

Researcher Description: The researcher is a neurodivergent & disability activist and advocate with 3 years' experience working in EDI and accessibility at institutions such as The University of Exeter, The National Children's Choir of Great Britain, and The Northcott Theatre. They are 22 years old and have been diagnosed with Tourette Syndrome, ADHD, Dyslexia and Dyspraxia. This study forms the completion of their Msc Psychology conversion at The University of Exeter. In 2022 they worked with Ione Georgiakakis from Tourette's Action, and the University of Exeter EDI team to run workshops to improve accessibility and inclusion for students with Tourette's.

1) Invitation and brief summary:

This study focuses on the complexity of lived experiences of 18–25-year-olds with Tourette Syndrome to capture the disorders idiosyncrasy and assess the effectiveness of arts-based interventions vs pharmacological interventions. Tourette Syndrome differs markedly between individuals in terms of tic presentation and rate of tics which requires different interventions to be recommended for individual profiles and particular situations. It will also discuss the social pressure to suppress tics, and its detrimental effect on tic attacks. With no current cure for the disorder and primarily pharmacological interventions available; this study provides an analysis of attitudes of people with TS to both the disorder and the interventions they use to highlight the pressing need for funding into Tourette's Research and intervention creation.

This study involves two methods of research:

- 1) A 2-week completion of a tic diary designed to assess the success of interventions and the effect of tics on daily routine.
- 2) A 40 minute in person interview in an accessible room in a library or university room in your area to capture your lived experience of Tourette's and attitudes toward interventions that you have used.

Thank you very much for your interest in this research study. Please read this information sheet carefully and take your time to discuss it with family and friends. Accessibility and inclusivity are very big priority for this study so if you have any questions or require accessibility provisions, please get in touch at mph220@exeter.ac.uk.

2) Purpose of the research:

This study focuses on the lived experiences of 18–25-year-old adults with Tourette Syndrome including their self-identity and approaches to self-care. It will investigate the economic and social pressures that individuals face due to their tics, including greater unemployment rates, more strain on social and familial relationships and avoidance of large public spaces. Participants will be asked to question on the pressure to suppress tics, tic sensations, attitude to tics- whether humour is used as a coping strategy and intervention attitudes. Social and resultant economic pressures can reduce access

to interventions, as well as people's perceptions of and ability to engage with such interventions. Discussing the lived experience of those with TS is important because therefore important to identify and recommend successful interventions.

Secondly, this paper explores people's perceptions of interventions, both pharmacological and arts-based, and the effectiveness they've experienced. Much of the current research on TS either refers to participants with TS as a collective or separates them based on preconceived notions of severity, without consideration of the idiosyncrasy of the disorder. Instead of defining 'severity', this study recognises the unpredictability of individuals' tic presentation, including rate and profile. The diversity of tic presentation will influence the choice(s) of intervention, be they pharmacological or arts-based, that will benefit the person in different situations. This research project uses participants' commentary on their experiences of interventions to highlight the impact of the broadness of TS presentation on the necessity of a diverse range of interventions to ensure comfortability and Quality of Life.

3) Why have I been approached?

This study is looking for 6 participants between the ages of 18-25 who have been diagnosed by a Neurologist with Tourette Syndrome. You must live in Great Britain and have proficiency in English language to take part. The study is particularly interested in areas near Cardiff, Bristol, London, Edinburgh, Manchester, and Nottingham to also take into account the distance from the participants location and the headquarters of Tourette's Action in London.

4) What would taking part involve?

After agreeing to take part in this study the participant will be asked to sign a consent form which ensures you have made an informed decision to involve yourself in the study. Then you will be sent an invitation to a 5-10minute zoom call to meet the researcher where they can explain what the study will look like practically, answer your questions and explain the tic diary. In this zoom meeting you will also agree a pseudonym with the researcher that will be used to anonymise your data within the study. Depending on your comfortability you are given the choice to choose a name, or the researcher will use a name from one of the characters of a popular British franchise such as the chronicles of Narnia. The age and approximate location of the participant will be documented in the study because this has a bearing on the results, however any names of people or neighbourhood places will be anonymised.

During the Microsoft teams call the participant will be sent the two-week self-monitoring tic diary which will contain daily questions on the intensity of their tics and the intervention strategies they have used to moderate symptoms. During Diagnosis assessments for TS patients are often asked to record every time they tic in a diary to bring to their neurology appointment as evidence of their disorder. Not only can this method increase tics because individuals will be hyper-focusing on ticcing, but for people who experience large bouts of heavy ticcing it is impractical. Instead, this study's tic diary is designed so that when participants experience a bout of tics, they record the sensation that they experienced and what intervention strategy they used to calm the tics and continue their daily routine. This technique provides access to data concerning the sensation of the premonitory urge that would otherwise be inaccessible. Moreover, it trains the participant to consider the circumstances of tic occurrence and the resultant relief after interventions which can help them with their own tic management strategies. The participants monitor their tics and intervention usage per day. The success of interventions will be marked on a scale of measuring *intervention effectiveness (0-100)* with degrees of control marked as perfect 81-100, good 61-80, moderate 41-60, weak 21-40, poor 1-20, none 0. These questions will take approximately 10 minutes to answer and can be completed at the end of each day.

After completing the tic diary, you will be invited to an in-person interview in an accessible room in either a library or university building near where you live so that you don't encounter any travel cost.

The interview will last for 40 minutes and will begin with a 5 minute reflection on the research process so far and how beneficial they found the tic diary. Their thoughts on the diary and its contents will be used as data to develop a critique of the methods in the research report. After these reflections there will be two categories of questions the first on their lived experience of TS and the 2nd on what pharmacological or arts-based interventions they have used and what they believe was the most successful. Arts-based interventions for this study include, listening to music, playing music, singing, acting, dancing or writing, as often individuals with Tourette's have reported a lessening of their tics while participating in these activities without suppressing them. There will then be 5 minutes at the end of the interview to reflect on the questions, summarise any points and a space for further questions.

The room will be booked for 2 hours so that if the participant needs to take a break they can at any moment. This will particularly be used if the participant gets stuck on a particular tic that keeps re-occurring. If this happens, they can leave the room get some fresh air and come back. While the interview room will be set up with desk and chairs, the fidget toys will also encourage free movement and if the participant is more comfortable in an alternative position such as standing, walking around, or sitting on the floor the room will be adapted to accommodate this. Tics are very unpredictable so this process will ensure accessibility adaptations can be made – for instance if the participant uses a wheelchair due to their leg dropping tics the room for the interview will be on the ground floor and near a wheelchair accessible or changing places bathroom.

Summary:

- Sign consent forms.
- 5-10 minute team call explaining study.
- Complete tic diary for two weeks
- 40 minute in person interview in participants area
 - 5-minute reflections on the tic diary and research process so far
 - 15 minutes questions on Lived experience of TS
 - 15 minutes of questions on interventions
 - 5 minute reflection on questions and space for further questions

5) What are the possible benefits of taking part?

Through completing the intervention tic diary participants will gain a greater awareness of their Tic presentation and learn what interventions support their daily routine. This can help inform a tic attack plan or suggest beneficial accessibility aids. This study will be working with Tourette's Action, national charity dedicated to Tourette's research, they will be able to use the completely anonymised results of the study to inform further intervention research.

6) What are the accessibility provisions for this study?

Sensory toys and weighted blankets will be provided in the interview to help relieve stress and prevent damage from self-injurious tics. Free movement is also encouraged in the room as sitting down for long periods of time can often increase tics. The participant is also able to have rest breaks when they like so that they can go and get some fresh air or stretch their legs if they become uncomfortable in the room.

7) What are the possible disadvantages and risks of taking part?

The researcher who will be conducting the study has Tourette Syndrome. While this primary lived experience should improve participant comfortability and connection, it could increase the frequency of the participants tics because tics tend to interact with each other in close proximity. This may incur mild discomfort during the interview which will be moderated through rest breaks and accessibility aids. Moreover, to ensure participants are prepared for the tics on the day, the researcher will email in the morning of the interview what the tics are like that day so that they can prepare themselves.

Topics of tic suppression and quality of life may also be upsetting. This study has resources prepared through Tourette's action and connection to support groups across Great Britain that can help support the participant. Participants will be directed towards these support networks and communities.

8) What will happen if I don't want to carry on with the study?

Participants can withdraw from this study at any time through emailing mph220@exeter.ac.uk. You do not have to provide a reason, although if you had feedback that would be very beneficial. If you pull out towards the end of the process a certain amount of data will have been collected prior to your departure which will still be used within the study. For instance, if the participant has completed the tic diary but not the interview the tic diary may still be used. This data will have already been completely anonymised so there is no connection to the original participant. In the interview participants can also refuse to answer a question or come back to it if they want more processing time.

9) How will my information be kept confidential?

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection

Data will be stored in a folder marked 'TS Research Project' on the researchers Exeter University One Drive which is password protected. The semi-structured interviews will be audio-recorded using a Digital voice recorder to then be transcribed by the interviewer. Direct transcription through audio software while more time effective may not work regarding vocal tics which can be noises and it will then be coded with the participants tics also included in the transcription. The audio from the interview will be deleted by October 2024 after the completion of the dissertation. Moreover, one of the questions will be to draw what Tourette's feels like to you, if the participant decides to draw the sensation, this drawing will be photocopied and placed within the dissertation with the date and pseudonym of the owner.

Tourette's Action will be supporting this research, and in return for their provision of nonfinancial aid they are able to see the results of the study to inform later research on interventions. This will all be stipulated in a further data consent form once Tourette's action have signed their support of the project.

10) Will I receive any payment for taking part?

There is insufficient funding available to offer payment or vouchers for time in the study, however the university of Exeter is expense claiming the researcher to ensure that they can travel to the participants to make sure the venue for interviews is as accessible as possible. The researcher has also sourced accessibility aids such as weighted blankets and sensory toys to ensure the room is comfortable and to aid with tic moderation in the interview.

11) What will happen to the results of this study?

The results of the study will be produced into a research report to fulfil course requirements. This will not be shared. This report may be used as the basis for a later academic publication which if submitted will be available through open-access journals. The course also requires a poster summarising the research and a 1000-word lay summary which will be available on completion of the course (October

2024) to all participants and supporting agencies. Distribution of the lay summary will be through email.

12) Who has reviewed this study?

This project has been reviewed by the Research Ethics Committee at the University of Exeter. It has also been supported by Tourette's Action, national charity dedicated to Tourette's research.

13) Further information and contact details

Participants can contact the researcher through their university email address mph220@exeter.ac.uk. They will reply between the hours of 9-5 each day including the weekends. If you have any questions about the study or wish to take part please use this email.

If you are unhappy with any aspect of the project please contact the researchers project supervisor Liz Winter at E.A.Winter@exeter.ac.uk or the research ethics and governance manager Gail Seymour at g.m.seymour@exeter.ac.uk, 01392 726621.

14) Data Protection Notice

The information you provide will be used for research purposes and your personal data will be processed in accordance with current data protection legislation and the University's notification lodged at the Information Commissioner's Office. Your personal data will be treated in the strictest confidence and will not be disclosed to any unauthorised third parties. The results of the research will be published in anonymised form through pseudonyms.

Thank you very much for your interest in this project, have a lovely rest of your week.