

Participant Information Sheet

Sleep in adults with ADHD: Your Strategies for Navigating Difficulty Sleeping – Questionnaire

Version 2.3

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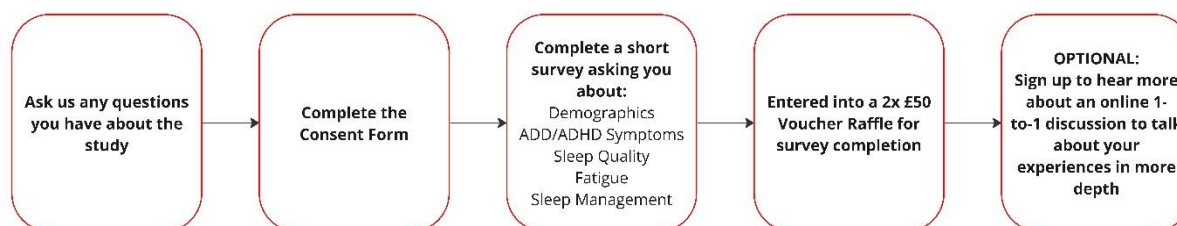
Invitation to Participate in our Project:

We would like to invite you to take part in our research project. The project explores sleep disturbances in adults with lived experience of ADD/ADHD.

Before you decide whether you would like to take part in the survey, **please read the following information carefully**. We would like you to understand why the research is being done, what it will involve, and what will happen to your data.

Discuss it with others if you wish. If anything is unclear, please get in touch using the contact email at the top of the page.

Study Overview



Attention Deficit Hyperactivity Disorder (often called ADD or ADHD) is a condition that can affect people's behaviour. People with ADD/ADHD can seem restless, may have trouble concentrating, and may act on impulse. It has also been reported that many people with ADD/ADHD have difficulty sleeping. We want to hear about your experiences of sleep disturbances as an adult with lived experience of ADD/ADHD. We would do this by asking you to **complete a survey**. This survey will ask you about:

- Your background (Age, Gender, Ethnic Origin, Employment status)
- Your sleep quality
- Your ADD/ADHD symptoms
- Your levels of fatigue
- Your experiences with various sleep management strategies.

The survey will take around 15 minutes to complete. Once completed, you can sign up to enter a raffle for 2x £50 online vouchers.

There will also be an opportunity to sign up for a follow-up online one-to-one discussion. This will be an opportunity to talk about your experiences in more depth with the researchers. This can be done at a time of your choosing.

Signing up for an extra discussion is entirely **optional**. You do not have to sign up for the online discussion if you don't want to, and it won't affect your rights in any way. If you do choose to sign up for an online discussion, we will contact you with further information.

What is the purpose of the project?

- Attention Deficit Hyperactivity Disorder (often called ADD or ADHD) is a condition that can affect people's behaviour. People with ADD/ADHD can seem restless, may have trouble concentrating, and may act on impulse.
- Many adults with ADD/ADHD also have trouble sleeping. For example, having difficulty falling asleep, daytime sleepiness, restless legs, or waking in the night.
- We want to understand what these experiences of sleep difficulties are like. We are interested in how they relate to your experience of ADD/ADHD.
- We are also interested in understanding your experiences with different strategies for improving your sleep.
- This might include sleep hygiene techniques, changes to your sleep area you have made, or anything else you've done to try and improve your sleep.
- The research here will form part of a PhD thesis and MSc dissertation at the University of Bristol.

Why have I been invited to participate?

You are reading this page as you may meet our criteria for taking part in the study, which are:

- Being over the age of 18
- Having internet access to take part in an online survey
- Have been given a diagnosis of ADD/ADHD by a medical professional, or consider yourself to have ADD/ADHD
- Currently experience difficulty sleeping, or have done so in the past

Do I have to take part?

No. **Taking part is voluntary**. You can discuss anything about the study with us before you make a decision. Please contact us using the email address at the top. We would be happy to talk through any questions you may have.

Please feel free to discuss the details of the study with others if you wish.

If you decide you would like to take part, we will ask you to sign a **consent form before completing the survey**.

You are free to withdraw from the study at any time, without giving a reason. If you decide not to take part or if you withdraw, this will not affect your rights in any way. You can withdraw your already collected data up until the point where we begin analysing it. You can notify us of your withdrawal by contacting us at the listed email address.

What will happen to me if I take part and what will I have to do?

If you are happy to take part, we will ask you to fill out an online survey. The survey will assess your eligibility and ask for your consent to take part in the study. We will then ask you to complete the questions. At the end, you can sign up to hear more about one-to-one online discussions with the researchers.

What questions will we ask?

The survey is made up of several parts. The survey will ask you about several topics. These topics include questions that ask about sensitive information, including:

- Your background (Age, Gender, Ethnic Origin, Employment status)
- Your sleep quality
- Your ADD/ADHD symptoms
- Your levels of fatigue
- Your experiences with various sleep management strategies.

The survey should take around 15 minutes to complete. You can take a break during the survey at any point and return to it later for completion.

What are the possible disadvantages and risks involved in taking part in the project?

Some people may find it difficult to review their experiences of living with ADD/ADHD and sleep difficulties.

If you find a question difficult, or you do not want to give a response, you do not have to complete it. You can leave your response as a blank. You can take a break during the survey or stop at any time.

What are the possible benefits of taking part?

For completing the survey you can choose to sign up to enter a raffle. This is for the chance to win one of 2x £50 shopping vouchers.

We also hope you find the study to be an interesting experience.

We want to use the research as an opportunity for as many people to share their experiences of managing sleep with ADD/ADHD.

Will my participation in this project be kept confidential?

Yes. All information collected about you will be kept strictly confidential in line with data protection legislation and university information security guidelines.

What will happen with my data?

We will only have access to the data that you give us. There will be two types of data. There is administrative data (not used in research) and research data. Both types may include personal data about you, but they are used for different purposes.

Administrative data: For us to run this research, we may need to collect some personal data about you. This will include a unique identifier which may contain your initials and, should you agree to provide it, your email address.

Research data: We will also collect personal data about you as part of the research itself. This is known as the research data. This will be collected from you using the responses provided to the survey. It will include personal data collected from you about:

- Your ethnic origin
- Your occupation
- Your gender
- Your age
- Data relating to your health (ADHD symptoms, mental health diagnoses, sleep quality, fatigue symptoms)

The research data and the administrative data from this survey will be separated. The data will be stored apart in password-protected files. These files will be kept on encrypted University of Bristol servers.

The study staff will closely protect your personal data. During the study, both types of data will only be accessible to the research members. We will process the data so that no one is able to connect your research data with information that identifies you.

As part of the survey, we will ask you to come up with a unique identifier. Your research data is attached to this unique identifier. If you wish to withdraw your data, we will use this unique identifier to identify your data and destroy it.

Once data collection is complete, we will pseudo-anonymise your research data. This means any information that could be used to identify you is removed from the research data.

Once your data has been pseudo-anonymised, nothing will link the research data back to you. If you withdraw consent after we have pseudo-anonymised your data, we may not be able to remove the research data from the analysis. Therefore, there is a window of **two weeks** after data collection to withdraw your consent and have all your data destroyed. You can still withdraw consent after this window, but we cannot guarantee that your research data can be removed. But we will destroy all other administrative data held about you.

Once the study is complete, we will destroy all administrative data.

We will analyse the research data and publish our findings. This will be in an academic journal or at academic conferences. The published data will include an analysis of the responses provided to the survey. You will not be identified in any publication from this study.

At the end of the study, your pseudo-anonymised research data will be retained securely for up to 10 years in a controlled online database. This would allow for other researchers to apply for access to the research data. Any research data that is held in the database will not have any information attached to it that would identify you.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason. But, we will keep pseudo-anonymised research data if you withdraw after the two-week cut-off from data collection.
- If you agree to take part in this study, your pseudo-anonymised research data saved from this study may be used for future research. This data will be stored in the University of Bristol Research Data Repository.

What will happen to the results of the research project?

The results of this project will be used as a submission for an MSc Thesis and a PhD Thesis. Results will also be written up for publication in a peer-reviewed academic journal. No identifiable information about you will be included in the write-ups.

If you agree to be contacted, a copy of the thesis write-ups and any publication will be sent to you after completion.

Who is organising and funding the research?

This research is funded through the UK's Engineering and Physical Sciences Research Council (EPSRC) as part of a doctoral training grant for PhD research in Digital Health.

It is being organised by Fin Schofield & Dr Hanna Isotalus in the Centre for Digital Health, School of Engineering Maths and Technology, Faculty of Engineering, University of Bristol, UK. Other members of the research team include Megan Golding and Sam Palmer, Applied Neuropsychology MSc students in the School of Psychology, Faculty of Life Sciences, University of Bristol.

Who has reviewed the study?

This study has been reviewed and approved by the University of Bristol, Faculty of Engineering Research Ethics committee (Reference no. 17961).

Further information and contact details

The Research Team

- *Fin Schofield*
- *Megan Golding*
- *Sam Palmer*
- *Dr Hanna Isotalus*

If you would like more information about the research project, please feel free to contact us at: sleep-in-adhd-study@bristol.ac.uk

Digital Health & Care, University of Bristol, 1 Cathedral Square, Trinity Street, Bristol, BS1 5TS

<https://www.bristol.ac.uk/engineering/research/digital-health/>

Independent Contact

If you have any concerns related to your participation in this study please direct them to the Faculty of Engineering Human Research Ethics Committee, via Liam McKervey, Research Governance and Ethics Officer (Tel: 0117 331 7472 email: Liam.McKervey@bristol.ac.uk).

Thank you for taking the time to read this information sheet