



Participant Information Sheet

Study title

How is Sleep related to Sensitivity to Noises, Touch and Lights in Adults with Learning Disabilities?

Version number and date

Version Carer-3: 10/12/2024

Researcher's name

Dr Valdas Noreika

Queen Mary Ethics of Research Committee reference number:

QME24.0084

Invitation paragraph

You are being invited to participate in a research study. Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us questions if there is anything that is not clear or if you would like more information.

What is the purpose of the study and what would taking part involve?

In this online study, we aim to investigate a possible link between sleep quality and daytime functioning among adults with learning disabilities and typically developed adults as a comparison group. The study involves answering questions from standard psychological scales focusing on sleep quality, sensory sensitivity and general daytime functioning. All questions will be about the individual with learning disabilities for whom you have caring responsibilities, i.e. the questions are not about you. You are encouraged to answer all questions with the individual with learning disabilities, enabling them to provide their opinion and help you with the survey. For instance, you could read survey questions, explain them in your own words, and ask for their opinion on responding. Once you hear their opinion, please

respond to the best of your knowledge. In some cases, they may not be aware of a problem they have, but you may know about it.

If the person with learning disabilities becomes too tired or lose interest in the survey, you can make a note in the survey and complete it by yourself. Alternatively, you can save it, take a break and return to the study later once the person with learning disabilities is ready to help you. In both cases, the responses are valid, and both of you will receive payment for participating in the study. Ideally, the person with learning disabilities would contribute to filling out the survey, but we accept that it is not always possible.

You will be asked to answer all questions online, and it may take about 60 minutes to complete the survey. If you answer alone, it might take only 30 min. However, if you manage to engage the person with learning disabilities to help you, and you need to read and explain every question, it may take longer than 60 min. You can answer all questions in one go; however, you can take a break or several breaks and return to the study after some time. Also, you might be invited to participate in the follow-up study (if you wish).

Why am I being invited?

You are invited to participate in this research study as a carer and/or parent of an adult with learning disabilities. You are expected to have good vision or vision corrected to good, using glasses or contact lenses, as you will need to read the survey questions on the screen. You should not participate in this study if the adult with learning disabilities you are taking care of is younger than 18 years or older than 45. Your age does not matter for the study.

Do I have to take part?

This participant information sheet has been written to help you decide if you want to participate. It is up to you whether you wish to take part. If you choose to participate, you will be free to withdraw at any time without providing a reason and with no penalties or detrimental effects.

What are the possible benefits of taking part?

The study's results may help develop interventions to improve the sleep and daytime functioning of individuals with learning disabilities. As such, this study may also benefit the community in which individuals with learning disabilities reside, including their families and carers. Also, you will receive an individualised report summarising responses you provided and where do they stand compared to other participants of the study.

What are the possible disadvantages and risks of taking part?

We will not collect your name or address; however, seeking to compensate for your time with an e-voucher, we will collect your email address, which will not be linked to your survey responses. However, if you and the individual you care for are interested in participating in a follow-up study, we must keep your email linked to your responses. In such a case, your email address and a code linking it with your data will be held offline in an encrypted hard disk in a locked office of Dr Valdas Noreika at the Queen Mary University of London. This will mitigate the risk of confidentiality breaches if there is an online attack on university servers.

Expenses and payments

You will be compensated £15 for taking part in the study. The payments will be delivered electronically via email as a digital gift voucher to Love2shop that can be spent in more than 50 popular retail shops, or alternatively, a £15 Amazon voucher. Individual with a learning disability may also receive a £15 voucher from us (if they helped you to answer the survey). We encourage both of you to decide together how their voucher should be spent.

What information about me will you be collecting?

We will collect Sociodemographic and Health Information (17 questions) about the age, level of education, ethnicity, medical conditions (such as epilepsy, Down's syndrome, ADHD, ASD, etc.) and general health (such as smoking, BMI, etc.) of the individual with learning disabilities you care for. The main survey about their sleep and daytime functioning will consist of the following psychological questionnaires:

- Pittsburgh Sleep Quality Index (Buysse et al., 1989), 19-items
- Epworth Sleepiness Scale (Johns, 1991), 7-items
- Morningness-Eveningness Questionnaire (Horne & Östberg, 1976), 19-items
- Sensory Perception Quotient (Tavassoli et al., 2014), 92 items
- Sensory Gating Inventory (Hetrick et al., 2012), 36 items
- Aberrant Behaviour Checklist (Aman et al., 1985), 58 items

We will collect your own name, confirmation of caring responsibilities and email address.

How will my data be stored and who will have access to it?

The data you will provide will be stored in a de-identified format on password-protected university servers. To reduce the risk of disclosure, personal email addresses will be stored separately from the research data in the password-protected encrypted hard disk in the locked QMUL office room. They will only be accessible to the research team. If you are interested in participating in the follow-up study, the stored email list will contain a key linking your email address and data.

The research team (lead researcher Dr Valdas Noreika, collaborators Dr Giorgia Michelini and Dr Margherita Malanchini, postdoctoral researcher Dr Maria Niedernhuber, Research Assistant, and MSc students) will have access to the research data. The data will be stored in an anonymous format (except for a separate offline key file linking the data to email addresses) on password-protected university servers.

When and how will my data be destroyed?

The main data will be stored at QMUL computers for at least 5 years, and we do not plan to destroy them. The key file linking the data with email addresses will be held for 2 years, allowing us to invite participants to a follow-up study. Afterwards, it will be deleted from the encrypted disk, and the disk itself will be overwritten by other files.

How will my data be used and shared?

Fully anonymized data will be made available through Open Access on the project's OSF page, <https://osf.io/>. It will be provided as an Excel sheet and an additional text file explaining the meaning of columns and rows. However, no email addresses will be shared. The study

results will be reported anonymously in scientific conferences, journals, and dissertation reports.

Under what legal basis are you collecting this information?

Queen Mary University of London processes personal data for research purposes in accordance with the lawful basis of 'public task'.

Please read [Queen Mary's privacy notice for research participants](#) containing important information about your personal data and your rights in this respect. If you have any questions relating to data protection, please contact Queen Mary's Data Protection Officer, Queens' Building, Mile End Road, London, E1 4NS or data-protection@qmul.ac.uk or 020 7882 7596.

What will happen if I want to withdraw from this study?

You can withdraw your participation in the study at any time without providing a reason. If you decide to withdraw, please do not feel bad about it; it is understandable if you find the survey too long or too difficult, and decide it is not for you. In such a case, all data collected from you will be deleted. After you submit all responses, you will be able to ask for access to the information you provide. You will be able to request the destruction of that information at any time before 1 week. Afterwards, you will not be able to request access to or withdraw the information you provided. Just so you know, access to the information and its destruction will be possible only if you express your interest in participating in the follow-up study, and your email address will be linked to your data.

What should I do if I have any concerns about this study?

If you have any concerns about the manner in which the study was conducted, in the first instance, please contact the researcher responsible for the study, Dr Valdas Noreika, by email: v.noreika@qmul.ac.uk. If you have a complaint which you feel you cannot discuss with the researchers then you should contact the Research Ethics Facilitators by e-mail: research-ethics@qmul.ac.uk. When contacting the Research Ethics Facilitators, please provide details of the study title, description of the study and QMERC reference number (where possible), the researcher(s) involved, and details of the complaint you wish to make.

Who can I contact if I have any questions about this study?

Lead researcher Dr Valdas Noreika
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