



Participant Information Sheet

Title of Research Study:

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

Version number and date

Version ID 3.0: 10.12.2024

Lead Researcher's name

Dr Valdas Noreika

Queen Mary Ethics of Research Committee reference number:

QME24.0084

Welcome

- You are **invited to take part** in a study about sleep and how adults with learning disabilities feel during the day.
- Please **read this text carefully**. You can **talk about it with your carer or parent** if you want.
- If you have any **questions, please ask us**.

What will I need to do?

- You will need to **answer questions** about your **sleep** and how **you feel things like sounds and smells during daytime**.
- We want to see if sleep affects how you feel during the day.
- You will answer the questions with the assistance of your carer. This is to keep the experiment the same for everyone.
- Answering the questions will take about **1 hour**. You can **take breaks** if you want.
- If you get **tired or lose interest**, you can have a break or ask your carer to assist you.

Why am I being invited?

- You are invited you **because you have a learning disability**. This study aims to find new ways to help people like you.
- This study is only for people aged 18-45

Do I have to join?

- You do not have to join if you do not want to join.
- You can **stop anytime you want**. You **do not have to tell us why**.

What are the benefits?

- The study can help find **new ways to improve sleep** and daily life for people with a learning disability (IQ < 70)
- You will also **get a report** about your answers.

What are the risks?

- You might **get tired** of answering questions. You can stop when you want.

Will I get anything?

- You will get a **£15 voucher** if you take part in the study.
- If your carer answers themselves, only they will get £15. If you answer the questionnaires together with your carer, both receive £15.
- Each voucher will be sent to the email address (or email addresses) you indicate on the form. It can be your own email address, or the address of a trusted person or carer.

What information will you collect about me?

- We will collect data about your **health, sleep and what you feel and do during the day.**
- We will not collect your name or your address.

How will my information be kept safe?

- We will store your data using a special code that will not connect it back to your name.
- There will be a **key document** which will link your code to the email of your parent or carer.
- We will keep all your data at the university.

How long will you keep my information?

- Your data will be kept for **at least 5 years** at the Queen Mary University of London

How will my information be used?

- We will use it to write **scientific reports**.
- Your information **will be shared with other scientists**.

What if I change my mind?

- You can stop taking part in this study anytime.

Who Can Answer My Questions?

- If you have any questions, please get in touch with Dr Valdas Noreika, v.noreika@qmul.ac.uk.