

Information Sheet (V2.0; 01/11/2020)

Study Short Title: Sleep in adults with Intellectual Disabilities

Invitation Paragraph

Before you agree to take part in the current study, I would like you to understand why we are completing this research. This research will form part of a PhD project by Paul Shanahan.

Has this study obtained ethical approval?

The current project has received approval from the Health Research Authority (HRA) ethics committee through the Integrated Research Application System (IRAS). Following receipt of ethical approval through the HRA, it has also been granted approval through the University of Surrey Ethics Committee prior to starting.

Please read the information sheet below and feel free to contact Paul Shanahan (p.j.shanahan@surrey.ac.uk) with any queries.

What is the purpose of the study?

The purpose of the study is to understand the relationship between sleep and behaviours that challenge in adults with a learning (or intellectual) disability. First, we want to confirm the relationship between sleep and behaviours that challenge. Then we aim to understand that relationship better. We will do this by looking at the relationship between each sleep factor such as time in bed, how long it takes to fall asleep and how often someone wakes at night and if it impacts on behaviours that challenge. Once we have a clearer idea of these, we will then invite some participants to talk to us further about this to get an idea of potential causes for these issues.

Do I have to take part and what are the possible benefits?

You do not have to take part in this research. If at any time you chose to no longer take part, you can decide to withdraw without consequence or providing a reason. The possible benefits are that it will help to contribute to the understanding of the causes of behaviours that challenge in adults with a learning disability.

What will happen if I take part?

If you agree to take part, you will be sent a number of forms and questionnaires. One will aim to record daily, the number of times behaviours that challenge occur over two weeks. We will also post an activity watch for the person you support. Towards the end, we will ask you to complete several other questionnaires about behaviours that challenge and your quality of life. In the event that you are selected and have agreed to take part in the second stage of the study, we will contact you to arrange a 30-minute phone or video call. This will be focused on better understanding the sleep of the person

you support. At any stage in the current study, if you incur any costs such as travel or postage, you will be reimbursed.

What are the possible risks or disadvantages of taking part?

The main disadvantage and risk associated with this study is that the additional checklist that you are requested to complete and questionnaires may increase the caring burden that you have. Considering this, we have made the forms as brief as possible to record and those which may take longer have a wider time to complete and can be completed at your leisure.

Who should I contact for further information?

If you have any questions or require further information about this study, please contact Paul Shanahan on the following details;
p.j.shanahan@surrey.ac.uk

Information about your data:

In this research study we will use information from you and the person you support. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it and for future research.

We will make sure no-one can work out who you are from the reports we write.

The information pack tells you more about this.

How will we use information about you?

We will need to use information from you and the person you support for this research project. This information will include your initials, name, and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details.

Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

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 information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- <http://www.yourhealthcare.org/en-gb/contact-us-/customer-care-complaints/>
- by asking one of the research team
- by sending an email to feedback@yourhealthcare.org or
- by ringing us on 0208 339 8092.

Thank you for taking your time to read this information sheet.