

Participant Information Sheet

Research title: Understanding Allied Health Approaches to Behavioural Sleep Disorders in Children with Neurodisability

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Ethics approval number: 2025/HE002274

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Thank you for your interest in participating in this research project. Please read the following information about the project so that you can decide whether you would like to take part in this research. Please feel free to ask any questions you might have about your involvement in the project. You can also talk to someone you trust, like a family member or friend, before deciding if you want to participate.

Participation in this research is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to stop at any time, and you would not need to give any explanation for your decision to stop participating.

If you decide to take part, you will be asked to sign a Consent Form and will be given a copy of that signed form and this Participant Information Sheet to keep. Your decision whether you take part, or not to take part, or to take part and then withdraw, will not affect your relationship with The University of Queensland.

What is the purpose of this research?

This study is looking at (1) the perspectives of allied health specialist clinicians on the management of sleep problems in children with neurodisability (ND), and (2) the challenges and potential barriers faced by allied health clinicians when managing sleep problems in children with neurodisability.

We know that sleep problems in children with neurodisability are very common, and the way this is managed is important and healthcare professionals' experiences and perspectives on these areas are under-researched. This study will address this gap.

Who can participate?

Allied health clinicians working within community or hospital settings who work with children with neurodisability under the age of 18.

What does participation involve?

If you consent to participate, you will be invited to complete an online survey that consists of questions with a combination of free text and drop-down response options. This is a one-off survey that will take 15-20 minutes to complete.

What are the possible benefits of taking part?

This study may not have any direct benefits for you, but the information obtained about your experiences in the delivery of care to children with ND experiencing sleep problems whilst providing care for other health problems will be used to inform the development of a national guideline and possibly additional resources. Improved resources will benefit you, your fellow allied health workers, and the patients that interact with allied health professionals who have access to improved resources

What are the possible risks and disadvantages of taking part?

There are no significant risks associated with this study. The information collected will be deidentified. There is a minor risk of psychological discomfort associated with answering questions about your experiences in delivering care to children with ND. However, should you become uncomfortable or distressed, you can stop the survey at any time without any adverse consequences.

What will happen to the information about me?

By signing the Consent Form you consent to UQ collecting, using and (where applicable) disclosing your information as set out in this Participant Information Statement and the Consent Form. Information obtained in connection with this project will be retained and disposed of in accordance with relevant University of Queensland policies and State and National regulations. For further information regarding the management of research data and information, you may refer to UQ's [Research Data Management Policy](#).

Any information obtained in connection with this research project that can identify you will remain confidential. Confidentiality will be maintained by having all the data obtained from this study will be stored in an online secure database called UQRDM (an electronic file with password protection available only to the research team) with no reference to your name (we will use the number and date of the survey completion).

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. Results will be published in open access outlets that will be directed at allied health clinicians.

Any information obtained during the research project is subject to inspection (for the purpose of verifying the procedures and the data) by the relevant authorities and authorised representatives of The University of Queensland, or as required by law. Designated University individuals (data stewards or custodians) may also have access to the information for the purposes of ensuring long term retention and disposal. By signing the Consent Form, you authorise release of, or access to, this confidential information to the relevant research personnel and authorities as noted above.

Personal Information

The personal information collected for this research project includes: Name and email address

Collection – Your personal information is collected for the purpose to express your interest in participating in future research relevant to this project.

Use – Your personal information will be used for future research relevant to this project and any other purpose described in this Participant Information Sheet and the Consent Form.

Storage and security – Your personal information will be maintained confidentially by ensuring appropriate access and security is applied to the research project data. Your personal information will be accessed by authorised research staff, authorised staff of UQ (for the purposes of managing data holdings) and third parties as described in this Participant Information Sheet and the Consent Form.

Disclosure – Your personal information will only be disclosed in a manner consistent with this Participant Information Sheet and the Consent Form. Your personal information will remain confidential and will not be disclosed to a third party without your agreement, or as required by law.

You have the right to request access to the personal information about you that is collected and stored by the research team. If you are seeking to update or correct any information, it is recommended that you liaise with the research team in the first instance (see contact details at the top of this information sheet).

You are also able to request amendment via a University of Queensland Right to Information and Privacy officer (rti@uq.edu.au). For further information regarding the management of your personal information, please refer to UQ's [Research Data Management Policy](#), [Privacy Management Policy](#) and [Privacy Management Procedure](#).

What will happen if I decide to withdraw?

Your participation in this research is voluntary, and you are free to withdraw without needing to provide an explanation. If you decide to withdraw, we will not collect additional data or information from you. Any data, samples and information already collected may be retained as described in this Participant Information Sheet and the Consent Form to ensure that the results of the research project can be measured properly and to comply with relevant regulations. Withdrawal after the survey has been completed is not possible, however you will not be contacted for any additional research opportunities.

Can I hear about the results of this research?

The results from the study will be written up for publication in peer reviewed journal(s) and prepared for presentations at scientific meetings. The results will be shared amongst the societies/networks

where the participants were approached to participate. The results will not be sent directly to the participants.

Who can I contact if I have any concerns about the project?

Questions about the nature of this project and participation in it should be directed to the research team (see top of information sheet for details).

This study adheres to the principles of the National Statement on Ethical Conduct in Human Research. The study has received ethics approval in accordance with the review processes of The University of Queensland. You are free to discuss concerns regarding this study or your participation in it with the research team, but if you would like to speak to an officer of the University not involved in the study, you may contact the Human Research Ethics Team via email humanethics@research.uq.edu.au or phone (see contact details at: <https://research-support.uq.edu.au/research-support/ethics-integrity-compliance/contacts>).