

CHILDREN'S HEALTH QUEENSLAND**LETTER ATTACHED WITHIN SURVEY TO PARENT/CARER REGARDING STUDY INFORMATION****Project Title****Understanding Parental Perceptions and Current Community Management Strategies for Sleep Problems in Children with Neurodevelopmental Disorders**

HREC Number HREC/21/QCHQ/79027
Investigator Dr Jasneek Chawla
Version Number: 1.0
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“It is ok to say NO”

The information is to help you decide whether or not you would like to take part in the research. Please read this Information Statement carefully. Thank you for taking the time to read and consider completing the survey.

If you choose to take part in this study, you will be asked to complete some questionnaires via the survey link. There is no face to face appointments. All data that is entered into the survey is converted to de-identifiable data meaning there are no names, addresses or email shared with us.

Neurodevelopmental disorders are a group of conditions with onset in early life that impair motor, social and intellectual function.

We aim to increase knowledge and understanding of sleep problems in children with ND – Estimate the prevalence of sleep problems in children with ND in the community. Identify sleep priorities of families and children with ND, Understand the current management received by children with ND for sleep problems.

The questions we will be gathering answers for relate around –

What is the prevalence of sleep problems in a community-based sample of children with ND?

What are the sleep health priorities for families of children with ND?

What are the current management strategies used to treat sleep problems in children with ND?

There is no funding involved with this research study with participation being voluntary. If you do not wish to complete the survey or wish to withdraw from the study, please close the browser no information will be stored.

A total of 4 questionnaires are linked within the survey.

- Demographics and a short medical history form
- Sleep health priorities questionnaire
- Modified Simonds and Parraga Questionnaire
- Paediatric Sleep Questionnaire.

All data from the survey will be stored on a database named RedCap. This database is located on Queensland Children's Hospital computers which are password protected. Only the study team will have access to RedCap again with individual passwords to protect your privacy. Your data will be stored without your name, using a unique ID number that you will be allocated for the study.

If you would like further information of the research and its outcomes please email me on SleepService@health.qld.gov.au

The Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC) has approved this study. If you have any concerns and/or complaints about the project, the way it is being conducted or your child's rights as a research participant, and would like to speak to someone independent of the project, please contact the below:

HREC Information:

Name: HREC Coordinator
Contact telephone: 07 3069 7002
Email: CHQETHICS@health.qld.gov.au

Local Governance Contact Information:

Name: Children's Health Queensland Research Governance Officer
Contact telephone: (07) 3069 7008
Email: CHQ_RGO@health.qld.gov.au

Thank you for your time
Dr Jasneek Chawla