This is an author produced version of *Conducting unattended home sleep studies in children with narcolepsy and healthy matched controls: a feasibility study*.

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**Conference or Workshop Item:**
CONCLUSIONS

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• This research has shown that conducting unattended home sleep studies to measure sleep architecture in children with narcolepsy and healthy controls for research purposes is feasible and is tolerated by the majority of children.

• The advantages of home sleep studies include the convenience for families, children can sleep in their own home environment and they can be cost-effective.

• However, our data show that unattended home sleep studies carry a risk of data loss, even when set up in the home by a trained researcher. This is due to lack of monitoring during the night, meaning that technical failures cannot be rectified.

INTRODUCTION

The paediatric narcolepsy project is a case-control study, with 23 children with narcolepsy and 23 age-and-gender matched controls.

This study examined the relationship between sleep, activity, school performance and well-being in children with narcolepsy.

The gold standard for measuring sleep is full polysomnography (PSG). Routinely polysomnography is conducted in a sleep laboratory, however it is possible to record sleep in the home environment using portable equipment. To date, there have been very few studies evaluating portable monitoring in children and we are not aware of any studies that have evaluated portable monitoring in children with narcolepsy.

AIM

The aim of the current study was to investigate the technical feasibility and acceptability of conducting unattended home sleep studies for research purposes in children with and without narcolepsy.

As part of the larger descriptive study (The Paediatric Narcolepsy Project), we aimed to investigate the differences in sleep architecture between children with and without narcolepsy.

METHODS

• 23 children with narcolepsy (age: 8-15 years) and 23 healthy gender and age-matched controls were recruited from England and the Republic of Ireland (Figure 1). The children with narcolepsy were recruited through the charities Narcolepsy UK and Sufferers of Unique Narcolepsy Disorder (S.O.U.N.D) in the Republic of Ireland. There were 15 males and 8 females in both groups.

• The researcher (JB) visited the children in their own homes to set up the polysomnography equipment. The children underwent home polysomnography (PSG) using a portable PSG system (Embla® Systems-Embletta MPR PG & ST+ Proxy was used with 41 children, Micromed-Morpheus was used with 3 children). The Embla® equipment is displayed in figures 2 and 4. Figure 3 shows the additional equipment needed to set up the recording in the home.

• A standard montage was used to measure sleep architecture with nine EEG channels (F3, F4, C3, Cz, C4, O1, O2, M1, M2), two electro-oculography (EOG) and two electromyography (EMG) channels.

• Study failure was defined as a sleep recording with less than four hours of interpretable sleep data. Failed home studies were classified into three main areas of sensor removal (n=4), equipment failure (n=1) or battery failure (n=1).

RESULTS

• 22/23 children with narcolepsy underwent home PSG.

• One child declined due to a previous negative PSG experience in hospital.

• Similarly, 22/23 matched controls underwent the PSG sleep recording.

• One child became unwell during the set up, so did not proceed.

• 16/22 (73%) of the children with narcolepsy were successfully studied and all 22 of the control children were successfully studied.

CONCLUSIONS

• The advantages of home sleep studies include the convenience for families, children can sleep in their own home environment and they can be cost-effective.

• However, our data show that unattended home sleep studies carry a risk of data loss, even when set up in the home by a trained researcher. This is due to lack of monitoring during the night, meaning that technical failures cannot be rectified.