Involvement (PPI), this project aimed to understand parents’ opinions and experiences around their child’s sleep and sleep interventions in order to tailor a BSI for use in the CASTLE (Changing Agendas on Sleep, Treatment and Learning in Epilepsy) study clinical trial with CWE.

**Method**

Semi-structured interviews were conducted with 10 mothers of CWE and 3 CWE recruited via online adverts on epilepsy relevant websites. A thematic analysis was conducted on the interview data.

**Results**

Several strong themes were apparent including that i) families felt in need of information, support and help with sleep, ii) parents valued other parents’ experience/understanding (over professionals’ advice), iii) any intervention needed to be personalised and non-prescriptive, and iv) parents’ concerns needed to be included. Two theory-driven BSIs, used in evidence-based level 1 studies, were adapted to incorporate parents’ requirements, developed into an online intervention (CASTLE Online Sleep Intervention or COSI) for parents of CWE and refined following parental evaluation (via online questionnaire built into COSI) until 100% approval from parents was reached.

**Discussion**

Adaptations and additions to content and delivery format were necessary to ensure that COSI best met parents’ needs; the final version will be used in the CASTLE study clinical trial (http://castlestudy.org.uk/). It is hoped that the use of evidence-based techniques delivered with consideration of factors identified through PPI, can increase parent-engagement and optimise effectiveness.

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**P012**

A FEASIBILITY STUDY OF THE USE OF AN EXERCISE INTERVENTION TO IMPROVE WELL BEING USING A MOBILE APP FOR MONITORING PATIENT RELATED OUTCOMES IN CHILDREN WITH NARCOLEPSY

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**Introduction**

Narcolepsy is a chronic neurological condition in which the brain’s ability to regulate the sleep-wake cycle is disturbed and can result in reduced quality of life (QOL). A positive association between exercise and QOL has been found in children. The aim of this study was to assess the feasibility of implementation of an exercise intervention with a mobile app to monitor outcomes in children with narcolepsy.

**Methods**

This feasibility study received service evaluation (SE1308), and University of Sheffield ethical approval (project number: 022995). A patient and parent engagement exercise to inform study design was carried out during the ‘Sheffield Children’s Hospital Annual Narcolepsy Family Day’. An exercise intervention was designed based upon NHS recommendations and tailored to the child’s activity levels. Weekly goals were set and progress was reviewed weekly, using an app specifically developed by Aparito Ltd (Wrexham, UK). QOL was monitored using the Pediatric Quality of Life Inventory (PedsQL). Patients were asked for feedback at the end of the intervention, to assess its feasibility and acceptability.

**Results**

117 children and parents took part in the engagement exercise. 12 patients took part in the feasibility study (mean age 12.9 years). The focus group highlighted the importance of motivation, timing and tailoring exercise interventions to the individual. Children said exercise should be fun to help motivation.

Average physical activity increased from 229 minutes to 254 minutes. Of those who had successfully increased their exercise, baseline average PedsQL score increased from 70.6 to 77.6 (figure 1). Feedback on the app and exercise intervention were both positive.

**Conclusion**

This feasibility study has shown that a targeted exercise intervention can improve QOL in children with narcolepsy. The Aparito app, it is being developed further for children with narcolepsy.

**REFERENCE**

1. Health Survey for England 2015: Physical Activity for Children

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**P013**

A NURSE-LED BEHAVIOURAL SLEEP PROGRAMME CAN REDUCE MELATONIN PRESCRIBING

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**Introduction**

Many children with sleep difficulties are prescribed melatonin. However, melatonin is costly and evidence for its efficacy is limited. The aim of this study was to...
evaluate a nurse-led sleep clinic to look at outcomes in terms of melatonin prescribing.

**Methods** All new referrals attending a nurse-led sleep clinic were examined from June 2016 to March 2017. Patients/parents attending the clinic were given an individualised sleep programme to implement with their child at home, with ongoing follow-up support. Families received an average of 3 face-to-face clinic visits and 3 follow-up telephone calls from first visit to discharge. Retrospective data was gathered from clinic records [Clinical Audit approval number CA1309].

**Results** 69 patients aged 1–17 years (31 males) were analysed. The primary complaint was ‘problem with sleep initiation and maintenance’ (81%), ‘problem with sleep initiation’ (13%) and ‘problem with sleep maintenance’ (6%). 84% of patients had medical co-morbidities; 54% of which were neuro-disability, the commonest being ASD and/or ADHD. 40/69 patients were successfully discharged from the clinic during the evaluation period. 65% were discharged without melatonin (23% with neurodisability; 42% without neurodisability), of which 35% were weaned off melatonin and 30% avoided melatonin prescriptions. 12% felt that the sleep intervention had been successful but still required melatonin, 15% were referred to medical/psychology clinics, and 8% were non-compliant with the behavioural sleep programme and were discharged still taking melatonin.

**Discussion** In this cohort of paediatric insomnia patients, a brief but intensive behavioural programme with support from a specialist sleep nurse was effective in resolving sleep difficulties and reducing melatonin usage.

We recommend that standardised sleep support from trained practitioners should be available prior to prescribing melatonin for children with sleep difficulties. This approach is not only beneficial in effectively resolving sleep problems but is cost-effective when compared with melatonin prescribing.

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**Abstract P014 Table 1  A summary of stakeholder findings**

<table>
<thead>
<tr>
<th>Opinions on:</th>
<th>Families (n=20)</th>
<th>Health Professionals (n=27)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sleep Diaries</strong></td>
<td>Confusing to complete</td>
<td>Missing data</td>
</tr>
<tr>
<td></td>
<td>Complicated start times of each day</td>
<td>Mismatch with actigraphy</td>
</tr>
<tr>
<td></td>
<td>Hard to estimate sleep times</td>
<td>Incorrectly completed</td>
</tr>
<tr>
<td></td>
<td>Is all the information collected necessary?</td>
<td>Useful for sleep perception mismatch</td>
</tr>
<tr>
<td></td>
<td>Would prefer electronic version</td>
<td>Useful for behavioural sleep strategies</td>
</tr>
<tr>
<td></td>
<td>Useful to see sleep/wake patterns</td>
<td></td>
</tr>
<tr>
<td><strong>Actigraphy</strong></td>
<td>Embarrassing especially at school</td>
<td>Time consuming resource-wise</td>
</tr>
<tr>
<td></td>
<td>Uncomfortable</td>
<td>Variability in actigraphy used and outcomes recorded</td>
</tr>
<tr>
<td></td>
<td>Refusal to wear at school</td>
<td>Useful for daytime napping</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Useful for circadian rhythm shifts</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some centres autoscoring actigraphy, some manual</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Would like to do actigraphy but no current resources</td>
</tr>
</tbody>
</table>

**P014** PAEDIATRIC SLEEP DIARIES AND ACTIGRAPHY–OPINIONS OF THE STAKEHOLDERS

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**Introduction** Paper sleep diaries and actigraphy are useful tools in Sleep Medicine to evaluate sleep wake patterns in the home environment over the course of 7–14 days. In our service, the demand for actigraphy far outweighs the...