

The Paediatric Narcolepsy Project: Intervention Study

A report of a public involvement event with children with narcolepsy and their parents

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The Paediatric Narcolepsy Project: Intervention Study

A public involvement event to inform the development of a NIHR Post-Doctoral Fellowship Application

“A feasibility study evaluating the efficacy of a behavioural sleep intervention for improving sleep, well-being and quality of life in children with narcolepsy”

Introduction

Narcolepsy is a lifelong neurological sleep disorder characterised by excessive daytime sleepiness and attacks of muscle weakness triggered by emotions (cataplexy). The condition has recently been brought to the attention of the media following an increase in the number of children diagnosed with narcolepsy after receiving the swine-flu vaccination in 2010.

Narcolepsy has a devastating impact on a child's life. Children experience disturbed night time sleep, hallucinations, sleep paralysis and weight gain. These symptoms have a detrimental effect on mental health, quality of life, relationships and school performance.

To date, there has been no research investigating the efficacy of behavioural interventions for improving the sleep, quality of life and well-being of children with narcolepsy. It is important that this research is conducted because not all children tolerate the current medication available for this condition.

The Sleep Service at Sheffield Children's Hospital has experienced an increase in the number of children with narcolepsy being seen in the clinic from across the region. As part of a new collaboration between the clinical sleep team at Sheffield Children's Hospital and the scientific team based at The University of Leeds, I would like to conduct the first ever feasibility study evaluating the efficacy of a behavioural sleep intervention for improving sleep, well-being and quality of life in children with narcolepsy.

The proposed intervention is a behavioural sleep intervention designed by The Children's Sleep Charity (<https://www.thechildrenssleepcharity.org.uk/>) which aims to improve children's sleep. Sleep practitioners (trained by the charity) provide parents with tailored advice about how to manage their child's behavioural sleep problem. Advice includes: how to set up a good bedtime routine, information about the child's developmental stage and sleep needs, ideas for the bedroom and information about self-settling.

The behavioural sleep intervention has been chosen because the objective and subjective data from my PhD research (The Paediatric Narcolepsy Project) and the current literature suggests that children with narcolepsy have disturbed night time sleep. A recent meta-

analysis of studies evaluating the efficacy of behavioural interventions for sleep problems in children with neuro-developmental disorders found that they can be effective in reducing sleep problems. I would like to investigate whether this behavioural sleep intervention has a beneficial effect on the nocturnal sleep of the children with narcolepsy and whether this leads to improvements in their well-being and quality of life.

There are currently two behavioural sleep clinics running each week at Sheffield Children's Hospital. During these clinics, the sleep practitioner assesses the sleep problem and provides a tailored programme for the parents to follow at home which aims to improve their child's sleep.

In the planned feasibility study, I aim to recruit 30 children with narcolepsy and their parents through Sheffield Children's Hospital. The families will be randomised to receive either the intervention or treatment as usual (waiting-list control). In order to evaluate the efficacy of this intervention, I plan to conduct an initial assessment of the child's sleep problems, well-being and quality of life using standardised questionnaires and a detailed interview with the parents and child before the families attend the behavioural sleep clinic at the hospital and two months afterwards. This will allow us to assess whether the child's sleep problem, well-being and quality of life has changed before and after the intervention. I will conduct the same assessments with the waiting list control group but they will not receive the intervention. The waiting-list control group will be treated as usual and then they will receive the intervention after the two month follow up assessments are completed.

The results of this study will benefit both the children treated at Sheffield Children's Hospital and the wider population of children with narcolepsy as we will better understand the efficacy of behavioural sleep interventions for improving sleep, well-being and quality of life in this population. The feasibility study will inform the design of a larger randomised controlled trial evaluating the efficacy of the behavioural sleep intervention at multiple sites across the UK.

Aim

To assist with the development of my post doctoral fellowship application which is due for submission to the NIHR in December 2017, I arranged a public involvement event which took place on Saturday 8th July 2017. This event enabled the research team to discuss the proposed research with children with narcolepsy and their parents. We gathered feedback on the acceptability of the intervention, the study methodology and the proposed follow-up period. We also asked for their views on the importance and relevance of the research.

Method

The public involvement event was held on Saturday 8th July 2017 at The Holiday Inn in Rotherham as part of the Sheffield Children's Hospital annual "Narcolepsy Family Day". Families were invited to attend the Narcolepsy Family Day via a letter sent to their home. This letter provided an outline of the programme for the day, including information about the public involvement event.

The public involvement event began at 11.30am and lasted approximately 1 hour. At the start of the session, I presented an overview of the proposed research to the families. The format of the presentation was based on the popular TV show "Dragon's Den" where an idea or invention is pitched to a panel of experts. The audience were told they are the "narcolepsy experts" and that we (the research team) really needed their feedback on a research idea. The presentation was designed to be appropriate for the lay audience and any complicated terms were explained for the younger children. After this 15 minute presentation, the audience were split into the following age- appropriate groups and each table was led by a staff member:

- **Table 1.** Children with narcolepsy under the age of 12 (Discussion led by Jane Blackwell-PhD Student/Sleep Practitioner)
- **Table 2.** Adolescents with narcolepsy age 13-16 years old (Discussion led by Mrs Janine Reynolds-Specialist Narcolepsy Nurse/Sleep Practitioner)
- **Table 3.** Parents/Carers/Grandparents (Discussion led by Professor Heather Elphick-Sleep Consultant)
- **Table 4.** Parents/Carers/Grandparents (Discussion led by Dr Ruth Kingshott-Sleep Physiologist/Researcher)
- **Table 5.** Parents/Carers/Grandparents (Discussion led by Dr Kelechi Ugonna-Sleep Consultant).

The participants were split into these groups so that we could gather the views of the parents/carers and children separately.

Before any discussion began, the group leaders asked the participants whether they were happy to take part (verbal consent). Parents were also asked to give their verbal consent for their children to take part. The children and adolescents were asked by the group leaders (Jane Blackwell and Janine Reynolds) whether they were happy to take part and they all gave their assent.

Each table was provided with large pieces of flip pad paper and colourful marker pens so that all participants could record their views during the discussion.

Each group was asked to answer six questions about the research which helped to guide the discussion and keep the participants focussed on the task. The children and adolescents were asked slightly different questions than the adults. This was because the questions for the children were designed to be easier to understand and more focussed on issues important to them.

Participants

Table 1. Children with narcolepsy under the age of 12

- Participant 1 (Female, age 12)
- Participant 2 (Female, age 10)
- Participant 3 (Male, age 10)
- Participant 4 (Male, age 9)
- Participant 5 (Male, age 10)

Table 2. Adolescents with narcolepsy age 13-16 years old

- Participant 1 (Female, age 15)
- Participant 2 (Female, age 15)
- Participant 3 (Female, age 14)
- Participant 4 (Female, age 15)
- Participant 5 (Female, age 14)
- Participant 6 (Male, age 12)
- Participant 7 (Male, age 13)
- Participant 8 (Male, age 12)
- Participant 9 (Male, age 14)

- Two siblings (age 13-16 years old) also took part in this session

Table 3. /Table 4. /Table 5. - Parents/Carers

- 25 Parents/Carers took part in this session and were separated into three tables of approximately 8 people per group.

Each participant wore a name badge and introduced themselves before the discussion began. This created a more relaxed environment as people knew each other by name.

Funding

An RDSYH Public Involvement Grant was awarded to facilitate the involvement of 'expert patients' in the development of my post doctoral fellowship grant application. The £432 of funding was divided into:

- **£112**-used to provide Tea/Coffee/Juice for the participants
- **£320**-was used to purchase 32 £10 Love2Shop vouchers. These vouchers were given out after the session. As more families wanted to take part than we had originally anticipated in our grant application, the vouchers were split equally across the families. Each child who took part received a voucher (16 children) as did one of the adults (16 adults) that accompanied them.

Results

All of the questions that the participants were asked are listed below. The responses are also listed below each question. These responses were written on the large sheets of paper by the participants.

Responses from Children with narcolepsy aged between 9-12 years old

Discussion led by Jane Blackwell

1. Do you have any problems with your sleep that you would like some help with? What sort of problems do you have with your sleep?

- I eat food through the night when my mum dad and sister are asleep (Female, age 10)
- I have nightmares (Female, age 10)
- I have some nightmares (Female, age 12)
- I twitch in my sleep when I am in bed (Female, age 10)
- My sisters wake me up at night (Female, age 12)
- I go on my phone to help me go to sleep (Female, age 12)
- I have a phone in my bedroom (Female, age 12)
- I share a room with my two sisters and they watch things on their phone and it wakes me up (Female, age 12)
- My sister wakes me up when she plays the piano (Female, age 10)
- Waking up in the night (Male, age 10)
- I watch movies or TV shows to get to sleep (Male, age 10)

- I switch bed in the night (to parents) (Male, age 10)
- Waking up in the night (Male, age 10)
- Nightmares (Male, age 10)
- Waking up in the night (Male, age 9)
- I switch bed in the middle of the night (Male, age 9)
- Wake up early in the morning (Male, age 9)

2. Do you think it is a good idea to find out if changing some of your habits and routines could improve your sleep? (If yes-why? / If no-why?)

- We would like to try changing our habits (Female, age 10) (Female, age 12)
- I think it's good to change habits (Female, age 12)
- I think it is a good idea to change habits because it makes you more calm and relaxed (Female, age 10)
- Personally I think that it would be a good idea to change my sleeping habits because I wake up in the middle of the night all the time. (Male, age 10)
- Yes so I don't wake up in the night (Male, age 10)
- I think it is a good idea to change my routine so I can sleep easier (Male, age 9)

3. Would you be happy to try changing some of your habits and behaviours to see if it could improve your sleep? (If yes-why? / If no-why?)

- I love watching Love Island at 9pm at night but if I am too tired to watch love Ireland I could watch it the next morning on catch up (Female, age 12)
- I would be happy to change my habits (Female, age 12)
- I would be happy only to try (Male, age 10) I think that my parents would be happy for me to change my sleep habits (Male, age 10)
- Happy only to try (Male, age 10)
- Happy to try a new routine (males, age 9)
- Advice: Turn off devices by the wall during the night (so standby light doesn't wake you up) (Male, age 9)

4. Would you be happy to have another appointment with a sleep practitioner (like Janine) during your usual visit to Sheffield Children's Hospital?

- We would be happy to go and see Janine and Heather but we would like to see Janine after Heather (Female, age 10) (Female, age 12)
- I am happy to have an appointment with Jane (Female, age 12)
- I would be happy to have another appointment (Male, age 10)

- Happy to have appointment (Male, age 10)
- Happy to have an appointment (Male, age 9)

5. Do you think families would need a reward for taking part? (yes or no. If yes- what type of reward)

- A reward is necessary for parents (about £20 would be nice) (Female, age 12)
- A reward for children is necessary (£15-£25) (Female, age 10)
- A reward is most certainly necessary (Male, age 10)
- I think that children should have a £17 voucher (Male, age 10)
- Happy to have a reward and it is necessary (male, age 10)
- Happy to have £10-£15 reward but part of the reward is actual help with sleep (Male, age 9)

6. Does anyone have any other thoughts about the research idea?

Responses from Adolescents with narcolepsy aged between 13-16 years old

Discussion led by Janine Reynolds

1. Do you have any problems with your sleep that you would like some help with?

What sort of problems do you have with your sleep?

- Nightmares
- Hallucinations
- Sleep walking
- Disturbed sleep
- Sleep paralysis
- Someone watching you stood at the bottom of the bed
- Feels like someone is breathing on you

2. Do you think it is a good idea to find out if changing some of your habits and routines could improve your sleep? (If yes-why? / If no-why?)

- Yes can try and prevent sleep occurring through the day when you do not want it to happen-would appreciate any help with this. (Boys)
- No, don't want to quit rugby, cannot see how changing routine would help (boy)
- Ensure that nothing monumental is on (make sure it is the right time) E.g. "Love Island" (Girls)
- Stop watching TV before bed -it would ruin our social life. The girls talk about it next day at school (you haven't seen it) would ruin day chat and therefore social life.
- Addicted to sugary stuff before bed and feel it helps-would be resistant to giving this up.
- Yes happy to have time limits put in place, so that day can be organized and you know where you are – willing to do anything, if I have more energy to do homework (boy)
- No - a couple of girls completely adamant that routine would be fatal. Narcolepsy takes enough time and fun, why should they waste more time on routine and appointments.
- With the boys help and discussion, the girls said they would be happy to carry out the intervention if it followed on from Love Island, and they were able to do it after their programme finished.

3. Would you be happy to try changing some of your habits and behaviours to see if it could improve your sleep? (If yes-why? / If no-why?)

- No one put their hands up
- You need your sleep-would not manage through the day (boys)
- Depends on what routine
- Got mocks, exams-no time for routine
- Give us a year for exams

4. Would you be happy to have another appointment with a sleep practitioner (like Janine) during your usual visit to Sheffield Children's Hospital?

- Miss too much school already, another hour means two lessons lost
 - Sometimes pretends to go to sleep so would be happy to miss more school to attend an appointment (boy)
 - Embarrassing going to sleep in the day, so anything that would help improve this I would come to get help.
- 5. Do you think families would need a reward for taking part? (yes or no. If yes-what type of reward)**
- Theme park
 - Vouchers
 - Chocolate
 - Arcades
 - Aqua Park

6. Does anyone have any other thoughts about the research idea?

- Not holiday time (all agree with this)
- Two months will always hit a holiday so needs doing in term time
- Term time
- Length too long
- Reduce length

Responses from Parents/Carers

Feedback from Table 3, Table 4 and Table 5 .Discussions led by Professor Heather Elphick, Dr Ruth Kingshott and Dr Kelechi Ugonna.

1. Do you think the research question is important and relevant to you and your child? (If yes-why? / If no-why?)

- Table 3-consensus positive
- To reduce bad habits and gain control
- Encourage routine
- Change drinks
- Gadgets
- Formalise it and know there is a benefit at the end of 2 months
- Research is vital to helping us understand the illness and causes
- It is worth trying any ways of managing sleep

- Children taking ownership of the results
- Ruth's table-tailor to the needs of narcolepsy-adapt for narcolepsy "not punishment"
- Ruth's table-33 years of experience with narcolepsy
- Ruth's table- really like the non-medicated approach.

2. Would you be willing to try the intervention? (If yes-why? / If no-why?)

- Table 3-all parents willing to try the intervention
- People cope with means of helping children relax-i.e. via phone, TV, videos etc. How to stop these devices being used-concerns about withdrawal from gadgets.
- Parents will be more willing initially than the children. It will be the children making the changes but because it is a limited period of time it may be easier.
- Sibling buy in maybe needed.
- Children don't want to be treated differently.
- Children may feel it won't make a difference.
- Routine is important
- Ruth's table-children more willing to listen to sleep practitioner "expert" rather than mum and telling them what to do.
- Young person takes ownership/responsibility-email/texts (daytime prompts)

3. What do you think about the time commitment involved in taking part in this study?

- Table 3-time commitment involved is ok
- The time scale is small compared to lifetime with narcolepsy
- The 2 month period would need to suit the person. I.e. school holidays/exams etc.
- The extra hour is valuable to us expenses wise-i.e. travelling twice
- Ruth's table-time commitment is fine

4. Do you think that 2 months is the right amount of time to trial the intervention in your home before having a follow up appointment with a sleep practitioner?

- Table 3- all think the length of the trial is ok (difference seen in two-three weeks?)

- 2 months is fine. It's long enough-maybe too long for the children.
- Ruth's table-start in September time-if you can get straight on top of it September time.

5. Is an incentive needed for families to take part in this study? If yes, what do you think would be an appropriate incentive?

- Table 3-Just to help child and family is enough reward
- The incentive is to help parents help their child
- The children may need an incentive to see how they can help others with narcolepsy
- Ruth's table-vouchers for children are needed but travel expenses are not. Keep any other funding for more research.

6. Does anyone have any other comments or feedback on the research proposal?

- Consider split parent families-how the routine would work in two homes.
- Easier to do this in cooler months.
- Individual plan per child.
- Children can participate in planning.
- Sharing with other children.
- Ruth's table-different sleep routines for week/weekend/holidays/school.
- School-better time to try intervention when more routine in place.
- Narcolepsy vs "naughtiness" "teenage" "attitude"
- Ask young person what is narcolepsy/what is you.
- How would the routine work in grandparents' home and different parent's homes.
- Understand the routine has to be strict to work but want maybe an extra hours leeway at weekends and in holidays
- Ruth's table-all willing to take part and wanted it to be a whole family thing rather than the child with narcolepsy being singled out as having yet another negative thing attached to their condition.

Conclusions

The participants found the proposal acceptable but were also able to suggest useful enhancements to the design of The Paediatric Narcolepsy Project: Intervention Study.

Summary of the key messages from the public involvement event:

- Sleep issues are common in children and teenagers with narcolepsy
- Parents/carers are willing to try the intervention
- Under 12's are willing to try the intervention
- Teenagers are not keen but would like the intervention to happen in term time (September) when they already have a structured routine and not in holiday time. They would like the length of trying the intervention to be reduced.
- Children should take ownership of the research and taking part-communication should be directed to them
- Families would like us to consider how the intervention would work in split-parent families and at Grandparents houses
- Parents/carers do not think a reward for themselves is necessary-help alone is enough
- Children would like a reward for taking part (~£20 voucher or trip out voucher)

As a results of this public involvement meeting, the following changes to my post-doctoral fellowship application will be made:

- In the Gantt chart, we will plan for the intervention to begin in September 2019 which will suit the teenagers with narcolepsy and the families that said it would be easier to trial the intervention in the cooler months.
- We will reduce the length of the follow up from 2 months to 3 weeks. This is in response to the teenagers who said that 2 months was too long to trial the intervention.
- Communication about the study will be directed to the children and adolescents with narcolepsy as well as their parents so that they can take ownership of the research.
- We will cost into the grant an appropriate reward for children and adolescents with narcolepsy.

We were also able to recruit four lay people (two teenagers and two parents) to be “advisors” throughout the application process and during the research (if we are successful).

The information gathered during this public involvement event has resulted in enhancements to the design of The Paediatric Narcolepsy Project: Intervention Study and has enabled us to establish a means of maintaining public involvement throughout the application process and beyond.

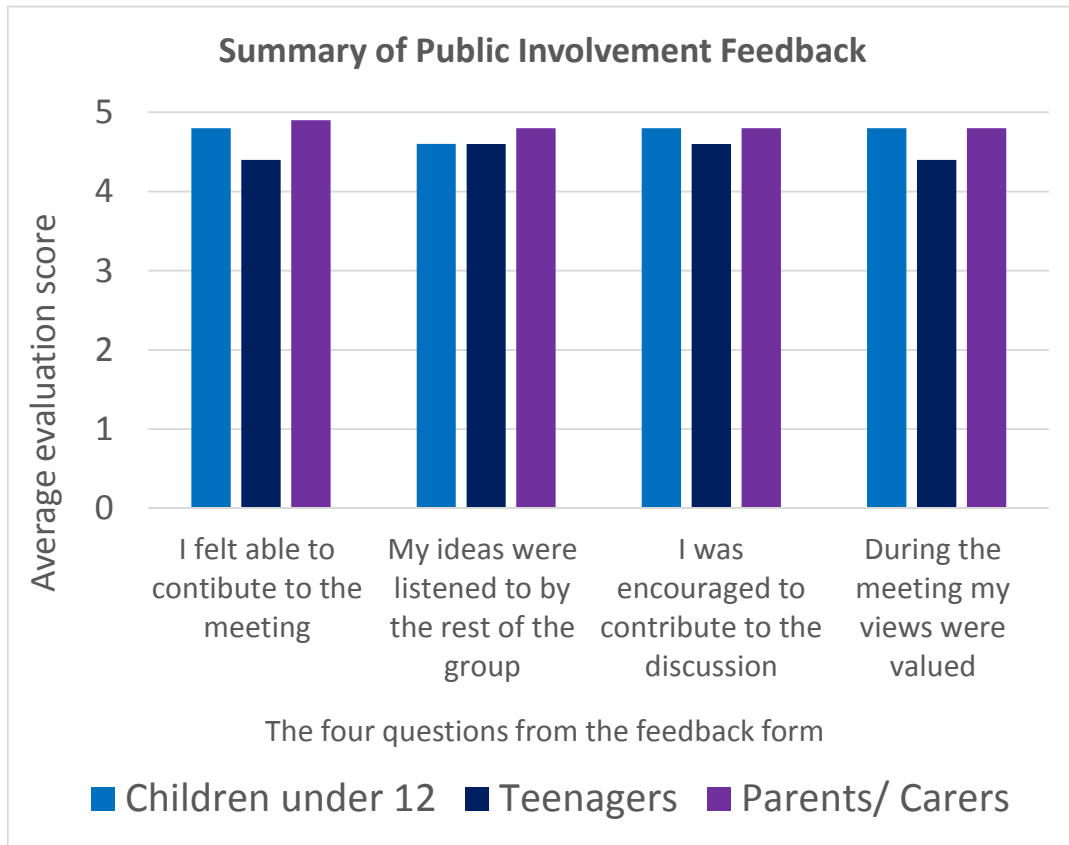
Evaluation

After the event all attendees were invited to complete an evaluation form (please see Appendix 1). Attendees agreed that during the meetings: they were able to contribute to the meeting; their ideas were listened to by the rest of the group; they were encouraged to contribute to discussion, and during the meeting their views were valued (please see Figure 1.)

The evaluation form also asked attendees to note: the most useful part of the meeting; the least useful part of the meeting; and, improvements that could be made for future meetings. In addition, a space was provided for any other comments. The feedback is summarised below.

Summary of the feedback from participants

Figure 1.



Feedback scores: 1= Strongly Disagree 2=Disagree 3=Neutral 4=Agree 5=Strongly agree

The comments from the evaluation forms are below. The comments have been divided into three groups: feedback from children under the age of 12, feedback from adolescents and feedback from parents/carers.

Table 1. Feedback from the evaluation form-Children under 12 years old

<p>Q5. The most useful part of the meeting was:</p>	<p>Getting advice from other people (Female, age 12)</p> <p>Getting advice from other people (Female, age 10)</p> <p>Deciding on the voucher money (Male, age 10)</p> <p>Being able to give and get advice (Male, age 10)</p> <p>Deciding on the voucher money and what we are going to be like in the future (Male, age 10)</p>
<p>Q6. The least useful part of the meeting was:</p>	<p>Nothing (Female, age 12)</p> <p>Nothing (Female, age 10)</p> <p>Nothing (Male, age 10)</p> <p>Nothing (Male, age 10)</p>
<p>Q7. Future meetings could be improved by:</p>	<p>Don't know (Female, age 12)</p> <p>Don't know (Female, age 10)</p> <p>Nothing, perfect (Male, age 10)</p> <p>Nothing (Male, age 10)</p>

<p>Q8. Any additional comments:</p>	<p>I think this was a helpful conversation (Female, age 12).</p> <p>Don't know (Female, age 10)</p> <p>Interesting (Male, age 10)</p> <p>Fun and interesting (Male, age 10)</p> <p>It was interesting (Male, age 10)</p>

Table 2. Feedback from the evaluation form-Adolescents aged between 13-16 years

<p>Q5. The most useful part of the meeting was:</p>	<ul style="list-style-type: none"> • Discussing peoples options • Discussing our views on the intervention • Listening to everyone views • Discussing everyone's views and ideas • Listening to other people's views on narcolepsy • To answer lots of questions and have a discussion with other people with narcolepsy • Introducing myself to others and what they could improve • Changing your routine in a beneficial way, not doing what you like
<p>Q6. The least useful part of the meeting was:</p>	<ul style="list-style-type: none"> • The end • Some ideas have not been useful • Talking about the TV series "Love Island"

	<ul style="list-style-type: none"> • Nothing I thought everything was good • None of it was least useful • The timing of the routine
Q7. Future meetings could be improved by:	<ul style="list-style-type: none"> • More ideas to be discussed • Coming prepared-with ideas • It could be improved by some more people talking and answering questions. I think I should answer more questions as well. • It could be improved by telling us what we can do and can't do when we are older • Talking about what schools can do with homework/revision
Q8. Any additional comments:	

Table 3. Feedback from the evaluation form-Parents/Carers

Q5. The most useful part of the meeting was:	<ul style="list-style-type: none"> • Talking to other parents (Male adult) • To see how others felt about the research (Female adult) • Splitting the children from their parents so that they got involved (Female adult) • Being with people in the same situation (Female adult)
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	<ul style="list-style-type: none">• Meeting other parents. Having something creative for the children to do (Female adult)• Listening to other parents/carers discussing the same about their children (Female adult)• Focussing on the needs of children with narcolepsy (Female adult)• Shared opinions and views with other parents/carers and specialists within the sleep group (male adult)• Listening to other parents ideas (female adult)• Meeting other people with the same challenges (female adult)• Talking to other parents (Female adult)• Meeting other parents and hearing their experiences with their children (Male adult)• Thinking that many ideas are better than one (Grandparents)• Looking at further help (Female adult)• Hearing you are not on your own (Female adult)
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	<ul style="list-style-type: none"> • Listening to what other parents had to say (Female adult) • Sharing ideas/thoughts with other people in a similar situation (Male adult) • Being able to talk with other parents (Female adult) • Talking to parents with children with narcolepsy (Female adult) • Speaking and listening to other parents (Male adult). • Meeting other people-discussing ideas. Learning from others experiences. (Male adult) • Helping with ideas (Male adult) • Talking to others and comparing experiences (Female adult) • Providing better sleep practice (Female adult)
<p>Q6. The least useful part of the meeting was:</p>	<ul style="list-style-type: none"> • Was all useful (Female adult) • Nothing (female adult) • None (Female adult) • Noisy (Female adult)
<p>Q7. Future meetings could be improved by:</p>	<ul style="list-style-type: none"> • Stricter time limits per question (female adult)

	<ul style="list-style-type: none"> • The tables being further apart so that we could hear more clearly (Grandparents) • Moving tables out and reduce spread of noise (Female adult)
<p>Q8. Any additional comments:</p>	<ul style="list-style-type: none"> • Excellent (Male adult) • Can't wait to see the results (Female adult) • Thank you for being such a wonderful team (Female adult) • Fantastic (Female adult) • All help gratefully received (Female adult) • Great to get together with parents and kids (Female adult)

Future public involvement

At the end of the group discussions, a short summary was provided about what will happen next with the feedback the participants have provided. The participants were told that their feedback would be discussed by the research team and any changes to the application would be made. The audience were then asked if anyone would like to be a research "advisor" going forward. The role of a research advisor was explained and one family of four signed up to be advisors. They will now be involved via email throughout the application process and beyond if we are successful.

We will ask for them to comment on:

- Whether the lay summary for the NHS ethics application is clear and easy to understand
- Whether the study information sheets and consent/assent forms are age appropriate (for children of different ages)
- Whether the methods of recruitment are appropriate (Letters from their consultant)
- If any problems arise during data collection, such as issues with families completing certain questionnaires, they will be consulted to give comments and suggestions.
- We will ask for their advice when analysing and interpreting the research findings so that we can understand which findings are most relevant and important to them.

- The adults will be asked to read over final drafts of articles before submission to journals.
- The family can be involved in the dissemination of the research results through the many narcolepsy social media networks and face to face events (e.g. Narcolepsy UK local meet ups, narcolepsy social media groups, the Sheffield Children's Hospital Narcolepsy Facebook group, The Paediatric Narcolepsy Project Facebook and Twitter Page).
- The family may be able to share their experiences of advising the research team and share the results of the research by writing an article for the 'cat nap' newsletter circulated by Narcolepsy UK. <http://www.narcolepsy.org.uk/catnap-newsletter>
- The lead applicant has presented at the national Narcolepsy UK conference for the past 3 years. The family could be involved in helping to present the study results and they could add their experiences of advising the research team and what the results mean to them.

NIHR Post Doctoral Fellowship Application

I plan to submit my NIHR Post Doctoral Fellowship application in December 2017 and we expect to know the outcome by mid-2018.

Appendices

Appendix 1. The evaluation form designed by the research team for use at the public involvement event on Saturday 8th July 2017.

Your name: _____

I am a: Young person with narcolepsy Parent/Carer

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
I felt able to contribute to the meeting					
My ideas were listened to by the rest of the group					
I was encouraged to contribute to the discussion					
During the meeting my views were valued					

1. The most useful part of the meeting was:
2. The least useful part of the meetings was:
3. Future meetings could be improved by:
4. Any additional comments:

Thank you!