



Does your doctor know how sleepy your child really is?

What do you think about a new Sleepiness Scale?

- Sleepiness scales (e.g. the Epworth) help to plan narcolepsy treatment
- It is important that these scales give a clear picture of everyday sleepiness and that children can fill them in too
- Families tell us that the scales we use don't give an accurate picture of the problem and some children struggle to fill them in
- The Southampton Children's sleep clinic has created a new scale using words and pictures – the 'Situational Sleepiness Scale'
- We would love to hear what you think about this to make the scale better!

Who can take part?

- A parent/guardian of a child with narcolepsy of any age up to their 16th birthday
- A child aged 11-15 years with narcolepsy

If you are interested you must have a computer with access to the internet, camera and microphone.

Thank you for reading. We hope to hear from you!

What will I have to do?

You will be invited to a 30-minute video interview over Microsoft Teams with me, Osasere, the medical student running the project. Dr Cathy Hill (paediatrician) may join the call too.

You will be shown different scales and asked to give your comments

Children aged 11-15 will also be invited to an interview with myself. Either Dr Hill or Joanne McCubbin, our nurse, will join too. We want to know what children think about the new scale and we want to see if they understand the pictures and words we have chosen for the scale.

If you are interested to take part or have any questions, please get in touch:

- Osasere Osayimwen (Student researcher)
- Osasere.Osayimwen@uhs.nhs.uk
- Please use the subject 'Expression of Interest'

We will send you some more information so you can decide if you want to take part.

The deadline to express interest is October 4th 2020