



Children & Young Person's Advisory Panel (CYPAP) Handbook

I have
childhood
epilepsy

I want to help
make the
CASTLE Sleep-E
epilepsy research
better

I am happy to
share what I
think about
things



Hello and welcome to the CASTLE Sleep-E (CYPAP) Handbook.

This handbook will explain:

- Who the CASTLE Sleep-E team are?
- What the CASTLE Sleep-E research study is doing?
- What the CASTLE Sleep-E Advisory Panel will do?
- How the CASTLE Sleep-E Advisory Panel members will work together?

For more information about CASTLE Sleep-E, the team and what we are doing check out the website <http://castlestudy.org.uk/>

Who are the CASTLE Sleep-E team?

The CASTLE Sleep-E research team is quite large, there are 17 of us altogether.

The two people you will see or speak to most are Rachael and Lucy. Rachael is the Family Engagement Officer for the CASTLE Sleep-E study and Lucy leads PPI and is involved in qualitative elements of the CASTLE Programme. Their job is to help organise and run the panel.



Rachael Martin



Prof Lucy Bray

You may also meet some of these people.....

			
Prof Bernie Carter	Prof Paul Gringas	Dr Chris Morris	Prof Deb Pal

What is the CASTLE Sleep-E research study doing?

CASTLE Sleep-E stands for:-

C.....Changing
A.....Agendas on
S.....Sleep
TTreatment and
L.....Learning in
E.....Epilepsy

Sleep-E Refers to the sleep element of the trial and E as most of it will be conducted electronically

Epilepsy is a common condition which can cause people to have seizures (also known as 'fits'). The CASTLE Sleep-E study is focused on rolandic epilepsy which is the most common type of childhood epilepsy.

Normally, epilepsy is treated with medicines to reduce the seizures. However, the medicines used to treat epilepsy can slow down a person's thinking and learning and it can be difficult to weigh up whether it is best to take medicine or not. This is what we are trying to work out.

The researchers will compare two groups of children and young people:

1. Those on a controlled trial comparing sleep intervention with standard care.
2. Those receiving standard care but with no sleep behaviour intervention.

Due to the nature of the intervention the trial is not blinded. Participants will be randomised with a 1:1 allocation ratio.

The researchers will look at which is best for young people's health and quality of life.



What will the CASTLE Sleep-E Advisory Panel do?

The CASTLE Sleep-E children and young person's advisory panel members will let us know what they think about different parts of our research and what we are doing.

If you are part of the advisory panel, you may be involved in some of the following activities:

- Sharing your ideas and opinions on the research.
- Reading some of the things we write and telling us what you think about them.
- Helping us work out the best way to share information about the study.
- **You do not need to have done anything like this before.**

There are lots of ways you can let us know what you think.

We will try and meet up as a panel about twice a year (you will not have to miss school or college).

We understand that you might not be able to make it to a meeting so you can let us know what you think via e-mail, the phone or WhatsApp.



You will get shopping vouchers as a thank you for your time and we will pay your travel costs.

Lots of lovely refreshments will be provided too!

How will the CASTLE SLEEP-E Advisory Panel members work together?



It is important that everyone feels welcome and valued as part of the panel, so we ask children and young people who join in to:

- Treat other members with respect.
- Try not to share information about the other members outside of the group.
- Allow each other to speak in turn.
- Ask us if something is not clear or does not make sense.
- If you're not happy or feel upset about something that happens during the meetings, let us know and we can help.

Funders and collaborators

