



CASTLE Advisory Panel (CAP) Handbook



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Hello and welcome to the CASTLE Advisory Panel (CAP) Handbook.

We want this handbook to help explain;

- Who the CASTLE team are.
- What the CASTLE research is doing.
- What the CASTLE Advisory Panel will be doing.
- How the CASTLE Advisory Panel members will work together.

Who are the CASTLE team?

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

The two people you will see or speak to most are Rachael and Sam who are the Family Engagement Officers for the CASTLE study and their job is to facilitate the panels.



Rachael Martin is based at Edge Hill University and runs the family consultation work in the North of England.



Samantha Lyle is based at Kings College London and runs the family consultation work in the South of England.

Other members of the research team you are likely to see:



**Professor
Lucy Bray**



**Professor
Bernie Carter**



**Professor
Paul Gringas**



**Professor
Deb Pal**



**Dr Chris
Morris**

There is information about all of the CASTLE research team on the website.

<http://castlestudy.org.uk/>

What is CASTLE?

CASTLE stands for - **C**hanging **A**gendas on **S**leep, **T**reatment and **L**earning in **E**pilepsy

Why does the research matter?

Epilepsy is a common long-term condition of the brain. Children with epilepsy experience seizures (some people say 'fits'). The CASTLE study is focused on rolandic epilepsy which is the most common type of epilepsy – affecting about one-sixth of all children with epilepsy in the UK – that means over 10,000 people!

Children with rolandic epilepsy often find that their learning, sleep, behaviour, self-esteem and mood are also affected, and the condition can cause stress in the family.

What is the research focused on?

Treating epilepsy with drugs to reduce seizures has been the traditional treatment. However, just reducing seizures doesn't necessarily make much difference to the way children and parents feel. The drugs used to treat epilepsy often slow down a patient's thinking and learning. It can be difficult to weigh up whether it is best for a child to take medicine or not.

The researchers will work with children, parents, doctors and nurses to choose the best ways to measure health and quality of life for children with epilepsy. Then the researchers will compare three groups of children: those on the standard drug treatment, those taking a newer drug that doesn't impact on thinking and learning as much, and those on no drug treatment. The researchers will examine which is best to improve children's health and quality of life.

The researchers will also include talking to parents and children about their experiences in relation to sleep, taking medication, learning and how taking part in the study has impacted on them.

If you want to find out more about the study please ask us or have a look at the CASTLE website

<http://castlestudy.org.uk/>

CASTLE Advisory Panel (CAP)

What is an Advisory Panel?

An advisory panel is a group of people including mums, dads, young people and carers who are contributing to the research project. An advisory panel is made up of people who are interested in a specific topic and the panel helps to guide a study, check progress and work out the best way to share the results.

You do not need any specific skills to be a member of one of our advisory panels and we welcome people with all sorts of experiences.



What will the CASTLE Advisory Panel do?

The CASTLE Advisory Panel members will let us know their opinions and views by attending meetings with others and/or through phone conversations, post or email. Members of the advisory panels can choose which activities to get involved with, and step in and out as it suits them.

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

- Sharing your ideas and opinions on the research.
- Reading the study related documents and telling us what you think about them.
- Helping us work out the best way to share the findings of the study.

What you can expect from attending a CASTLE Advisory Panel meeting?

Our CASTLE Advisory Panel meetings are friendly and informal and can be fun!

Each meeting will usually take no longer than a morning or afternoon. The meetings will involve working with the other advisory panel members and the Family Engagement Officers. One or more researchers may also be present. We will try and write down the important things the panel talk about and decide. You will be treated as an equal and an expert.



You will be reimbursed for travel expenses and receive financial compensation as thanks for your time. Lots of lovely refreshments will be provided too!

You can expect to have a say on when and where meetings will take place and you will be given good notice to allow you to make any necessary care or work arrangements to allow you to attend.

Other ways to tell us what you think



We understand that some people can't attend meetings due to other commitments. If a person is unable to attend a meeting but would still like to contribute, let us know. We can send information to you through the post or by email for you to look at or we can talk things through on the phone.

Ways of working together

It is important that everyone feels valued, so we ask advisory panel members to agree to:

- Treat other advisory panel members with respect and courtesy.
- Respect the confidentiality of information shared at the panels.
- Try and stay on topic during meetings.
- Allow each other to speak in turn.
- Stay in touch, we know that plans can change at the last minute.
- If there is a disagreement with another panel member, let us know and we can work with you to resolve the issue.



Our policies around payment, travel and childcare for parents, carers and young people who are involved.

The CASTLE project is funded by the National Institute for Health Research (NIHR) and through this budget we can reimburse families for their attendance, travel expenses and childcare costs when attending CASTLE Advisory Panel meetings.

How to claim:

We are part of Edge Hill University and reimbursement for attendance and expenses is paid through their finance system. At the first meeting we will help you to:

- Complete a new starter form, the university will keep a copy whilst you are helping with the project.
- When you attend a meeting for CASTLE or help us with some work, we will ask you to fill out a short claim form.
- Please remind us if you are not given one. The form needs to be completed and signed by you and returned to for signing and processing.
- If you need to post the form to us, we will provide you with a freepost envelope. The address for all correspondence is: Rachael Martin, Family Engagement Officer, CASTLE Programme, Faculty of Health and Social Care, Edge Hill University, St Helens Road, Ormskirk, L39 4QP

- You will receive the money direct into your bank account (please note that depending on when the form is received by our finance department, payment can take 4 - 6 weeks).

Please see information below regarding receiving reimbursement for expenses and attendance payments.

Current amounts for expenses:

Travel:

Car journeys: 45p per mile

Local Bus/train/taxi: an original ticket or receipt for that journey will be required.

Please note: we are happy to organise and pay for your rail ticket in advance, please let us know in advance what you would prefer

Childcare costs:

We can cover cost of childcare expenses for parents to attend meetings; you will need to provide a receipt from a registered childcare provider.

CASTLE attendance rates:

For all work associated with CASTLE advisory panel meetings

£20 an hour for meetings, reviewing documents, talking to us about your feedback

E.g. For a half day meeting:

£20 pre meeting preparation + £60 attendance + £20 post meeting liaison = £100

Children and young people involved with CASTLE:

We can offer financial reward to any children who are involved in the separate children and young people advisory panels; we are able to do this in the form of a shopping voucher up to the value of £50.



Things you might need to consider before receiving payment (the following information is just a guide)

You are advised that any payment for your participation **might affect your entitlement to benefits**. We would suggest that people who are considering paid or unpaid involvement should speak with their personal adviser at Jobcentre Plus **before starting**. Further guidance can be found at: <http://www.invo.org.uk/resource-centre/benefits-advice-service/>

The rules differ depending on which benefits you receive, and we would advise you to consult your local Jobcentre Plus office or local advice agency (e.g. Citizens Advice Bureau (CAB) if you are in any doubt about the effects any payments may have on your benefits, or wish to seek advice in relation to your income tax arrangements.

It is each **individual claimant's responsibility** to inform the relevant authorities of any payment received. It is also the individual claimant's responsibility to declare any payments received if they are self-employed or in full-time employment.

Note: Statutory organisations are required to give accurate details of any payments made to you if requested to do so, and Edge Hill University will have to comply with this.

Some key terms and meanings you will come across in this handbook and through your activities with the CAP.

Advisory Panel

Many research projects have an advisory panel which helps to develop, support, advise and monitor the project. The panel often includes people who use services, carers, researchers and other health and social care professionals, who can provide relevant advice.

Engagement

Where information and knowledge about research is provided and shared, for example, education forums, open days, media coverage.

Patient and Public Involvement

An active partnership between patients and the public and researchers in the research process, rather than the use of people as 'subjects' of research.

Patient and public involvement in research is often defined as doing research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them. This would include, for example, involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.

Protocol

A protocol is the plan for a piece of research and includes:

- What question the research is asking and its importance/relevance
- Background of the research, including what other research has been done before
- How many people will be involved
- Who can take part
- The research method
- What will happen to the results and how they will be publicised

Research

The term research means different things to different people but is essentially about finding out new knowledge that could lead to changes to treatments, policies or care.

The INVOLVE website below includes the meanings of additional terms and words which you may see or hear whilst part of the advisory panel.

<http://www.invo.org.uk/resource-centre/jargon-buster/>



Funders and collaborators

