

NIHR Patient Engagement in Clinical Development (PECD) Service

DOCUMENT REVIEW OPPORTUNITY (REF: 017)

Are you interested in helping to improve health and care research for children with inflammatory neuropathies?

This is your opportunity to give your feedback on patient-facing documents for a study on childhood inflammatory neuropathies

About this Opportunity

The National Institute for Health and Care Research (NIHR) is pleased to share an opportunity for members of the public who have experience of inflammatory neuropathies to be involved in the shaping of a commercial clinical trial.

We are working with a company to help them improve their planned research. Our partner is looking for people who are willing to read through draft documents that have been prepared for people interested in taking part in the study and giving feedback on how clearly the information has been written and presented. This will help them to design a study that is focused on the needs of the participant, their family, and their community.

Who is the NIHR looking for?

This opportunity is for **8 adults** (aged 18 or over) who:

- Live in the **UK**.
- Have lived experience as a parent or carer of a child with **CIDP or other inflammatory neuropathies (such as Guillain-Barré syndrome, or multifocal motor neuropathy)** .
- Can access and use a **word processing programme** such as Microsoft Word to read the documents and fill out a feedback form.

What do I have to do?

If you are interested in taking part, please complete the application form linked below. If you are selected for the activity, you will be asked to read the draft documents and share your thoughts on how clearly the information is presented.

We want to make sure that the materials are:

- Informative
- Accessible
- Engaging and fit for purpose
- Using language that is appropriate for potential participants and carers

The NIHR PECD Team will support you throughout this process and provide any information or guidance you may need.

Project Details

TIME, PAYMENT & PROCESS

How long will it take?

We expect it to take three to four hours of your time to read the documents and complete the feedback forms. You will be given 10 days to complete your reviews and send back your comments.

£ Payment

The NIHR, on behalf of the company we are working with, will reimburse you **£137.50** for your participation.

This will be paid by bank transfer, usually 6 weeks after the activity has taken place (although it can occasionally take a little longer).

Important Information on Tax & Benefits:

You can find detailed information about payment for research involvement activities, and the impact this may have on your tax and national insurance here:

<https://www.nihr.ac.uk/payment-guidance-members-public-considering-involvement-research>

What happens after the review?

The NIHR PECD team will write an anonymised report for the company, summarising the feedback from all the reviewers. The company will use this report to make changes to their study information sheets based on the group's feedback.

A few months after the activity, the PECD team will send an update from the company to all contributors detailing how the insights were used to improve the study information.

How to Apply

If you would like to take part in this opportunity, please complete the application form:

[CLICK HERE TO APPLY](https://forms.office.com/e/2hM7Um6AtJ)

(<https://forms.office.com/e/2hM7Um6AtJ>)

Deadline to apply: Sunday, 17th May (5 pm)

We may close applications before this date if we receive a lot of interest in this opportunity

Frequently Asked Questions

INFORMATION & PRIVACY

Q. What is the NIHR Patient Engagement in Clinical Development (PECD) Service?

The PECD Service brings together commercial health and care companies (sometimes referred to as the “life sciences industry”) with members of the public. The activities that we facilitate mean that future health and care research that comes to the UK can be designed and shaped by patients and is in the best interests of the people affected by particular health conditions. You can find out more about this service on the PECD Service webpage: www.nihr.ac.uk/get-involved/join-patient-engagement-activities-commercial-clinical-research

Q. What are commercial trials?

Commercial research refers to clinical trials or studies created and funded by a company or business. Research that is created or funded by universities or charities is often known as academic or non-commercial research. The companies that use the PECD Service will be hoping to deliver their research in the UK through the NHS.

Q. Why is the company name confidential?

Information about the planned research is confidential, so we cannot share the company name or details of the study at this stage. But if you are invited to take part in the activity, we will tell you who the company is, the name of the study and any additional information you might need to be able to contribute to the activity. You can withdraw from the activity at any point if you no longer want to take part.

Your Personal Information

What we need from you:

To make sure that we involve the most appropriate people in each activity, we will ask you to provide us with some information about your diagnosis, healthcare history, and previous experiences of research when you apply to take part. To monitor the equality, diversity and inclusion of our activities, we will also ask for some demographic details such as your year of birth, ethnicity, sex and gender identity.

Payment details:

So that we can contact you, we will also ask you to share with us your name and email address. And if you complete the engagement activity, we will need your bank details, date of birth, address and National Insurance number so that we can pay you.

Will you share my data?

Any personal information you share will be stored and managed by the NIHR: we will not share anything that could identify you with the company we are working with.

Privacy Notice:

You can read more about how we manage your data in our full privacy notice here:

<https://www.nihr.ac.uk/patient-engagement-clinical-development-pecd-privacy-notice>