

NIHR Patient Engagement in Clinical Development Service: Are you interested in helping to improve health and care research? Then this is your opportunity to help shape the design of a clinical trial for Haemophilia!

The [National Institute for Health and Care Research](#) is pleased to share an opportunity for members of the public who have lived or caring experience of Haemophilia to be involved in the shaping of a commercial 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 patient, their family, and their community.

Who is the NIHR looking for?

This opportunity is for 4-8 adults (aged 18 or over) who:

- Live in the UK
- Have lived experience, as a patient or carer, of Haemophilia A or B.
- 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, and that the language used 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.

How long will it take?

We expect it to take a few hours of your time to read the documents and complete the feedback form(s). You will be given 10 days to complete your review(s) and send back your comments.

Will I get paid?

The NIHR, on behalf of the company we are working with, will reimburse you between £50 to £125 for your participation – the amount is dependent on the number of pages to be reviewed. This will be paid by bank transfer, usually 6 weeks after the activity has taken place (although it can occasionally take a little longer). You can find information about payment for research involvement activities, and the impact this may have on your tax and national insurance [here](#).

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 do I apply or find out more information?

If you would like to take part in this opportunity, please complete this application form: [PECD Application Form - Haemophilia \(064\) – Fill out form](#)

If you have any questions about the PECD Service or the planned activity, or have any difficulties completing the application form, please contact the NIHR PECD Service Coordinator by emailing pecd@leeds.ac.uk

Deadline for applications: Sunday 30th November

Frequently Asked Questions

What's 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 in our [Information Sheet for Patients](#) or on the [PECD Service webpage](#).

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.

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 document review, 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.

What information will the NIHR need about me? Will you share my personal information with the company?

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.

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.

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.

You can read more about how we manage your data in our [privacy notice](#).