# NHR National Institute for Health and Care Research

NIHR Patient Engagement in Clinical Development Service: Are you interested in shaping health research? Then this is your opportunity to help shape the design of a future clinical trial in menstrual migraines!

<u>The National Institute for Health and Care Research</u> is pleased to share an opportunity for members of the public who have lived or caring experience of menstrual migraines to be involved in the design of a commercial clinical trial.

We are working with a company to help them improve their proposed research. Our partner is looking for people who are willing to share their experiences and insights, to help them design a study that is focused on the needs of the patient, their families, and their communities. This will help to make their research as inclusive as possible for everyone.

## Who are we looking for?

- Approximately 8 female adults
- Age 18-45
- Living in the UK
- Regularly has migraines just before, or at the start of, your menstrual period
- Comfortable with using, and able to access, an online video calling platform, such as Zoom
- Happy to discuss your lived experience of a health condition in a group

Reimbursement rate - £55 Deadline for applications –  $7^{th}$  July 2024 Please note: we may need to close the form early if we receive a high number of applications

## What do I have to do?

If you are interested in taking part, please complete the application form linked below. If you are successfully selected for the session, we will invite you and the other public contributors to take part in an online group meeting, hosted by the NIHR PECD team together with the company we are supporting. The session will be held on **12<sup>th</sup> July 2024.** 

The session will involve an explanation of the planned research and a discussion with the company about research issues such as whether the study considers the needs of potential participants, how patients might be recruited, and

whether the study visits might pose any challenges to participants. You might also be asked to discuss more generally the management of your health condition, and how this impacts on your quality of life.

The NIHR PECD team will support you throughout the session and will ensure that you have access to any information or guidance you need to allow you to participate fully.

Timings of the session can be flexible, such as evening or late afternoon to allow for working hours, but will be agreed in advance by participants and the company representatives. The meeting will usually last for 2 hours and will have a short break.

## Will I get paid?

As a thank you for your time and participation, the NIHR PECD team will reimburse you £55, on behalf of the company, after taking part in the session. This is usually paid 4-6 weeks following the activity by bank transfer. Please review further information about payment, tax and national insurance considerations <u>here</u>.

# **Frequently asked questions**

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

The NIHR Patient Engagement in Clinical Development Service enables commercial health and care companies (sometimes referred to as the life sciences industry) to engage with members of the public, to ensure 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 here:

#### **Information Sheet for Patients**

NIHR Patient Engagement in Clinical Development Service – Home Page

#### Are these commercial trials? What does this mean?

Commercial research is clinical trials or studies created by and funded by a commercial sponsor (the company). They will be hoping to deliver their research within the NHS.

As the information at this stage is confidential, we cannot share the company name or details of the study, but if you are selected and agree to participate, we will tell you who the company is, the name of the trial and any additional information you will need.

## Will you share my personal information with the company?

We will not share any of your personal details with the company, and any personal information you share will managed by the NIHR. We will only share anonymised information about the participants we have selected such as age, diagnosis and selected demographic information, to ensure we select a varied group of participants.

You can find additional information about this in the <u>Information Sheet for</u> <u>Patients</u> and in our <u>privacy notice</u>.

## What Information will the NIHR need about me?

We will ask you to share with us your name, age, diagnosis (if you have one), any key experiences of your condition (either as a patient or a carer), if you have participated in clinical research previously and some demographic information such as ethnicity, sex or gender identity, and religion.

# What happens after the session?

You will be reimbursed for your time following the session and we will ask you to complete a feedback form about your experience that will be anonymised and shared with the NIHR PECD team and the company.

The NIHR PECD team will write an anonymised report for the company, summarising the session's discussions. The PECD team will send an update from the company to all contributors to let you know how your insights were used to improve their study.

## How do I find out more?

If you would like to participate in this opportunity please complete this application form: <u>https://forms.office.com/e/mV8nbApZ9Z</u>

If you have any questions about the service or the session, please contact: NIHR PECD Service Coordinator pecd@leeds.ac.uk