

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 Long COVID!

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 conditions that might put them more at risk of developing Long COVID 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 share their experiences and insights in an online group discussion. This will help them to design a study that is focused on the needs of the patient, their family, and their community.

Who are you looking for?

This opportunity is for 6 adults (aged 18 or over) who:

- Live in the UK
- Have lived experience, as a patient or carer, of being severely immunocompromised due to disease or treatment
 - As examples, this could be due to undergoing chemotherapy, undergoing radical radiotherapy, solid organ transplant, bone marrow or stem cell transplant, multiple myeloma or genetic disorders affecting the immune system, a history of blood cancer, including leukaemia, lymphoma, and myeloma
- Can access and use an online video calling platform such as Zoom
- Are happy to discuss their lived experience in a group.

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 which will last for 2 ½ hours.

The meeting will be hosted by the NIHR PECD Team, together with the company we are supporting. The session will involve:

- Hearing about the impact your health condition has on your life
- The company talking to you about their planned research
- Sharing your thoughts and feedback on the planned research

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

When will the meeting take place?

We would like to hold the meeting on 9th or 10th September in the afternoon or early evening, however this will depend on when public contributors are available so may change. The activity will last for 2 ½ hours, including a short break.

Will I get paid?

The NIHR, on behalf of the company we are working with, will reimburse you £67.50 for your participation. This will be paid by bank transfer roughly 4 weeks after the activity has taken place. 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 session?

The NIHR PECD team will write an anonymised report for the company, summarising the session's discussions. The company will use this report to review their plans and make changes to their study 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's design.

How do I apply or find out more information?

If you would like to take part in this opportunity, please complete this application form: <https://forms.office.com/e/TiYiUrcmGK>

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: 28th August 2024

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 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 meeting.

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 age, 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](#).