

## **NIHR Patient Engagement in Clinical Development Service: Are you interested in improving health and care research? Then this opportunity to shape the design of a study into thalassaemia is for you!**

The [National Institute for Health and Care Research](https://www.nihr.ac.uk) is pleased to share an opportunity to be involved in shaping a commercial research study in thalassaemia by participating in an online document review. We want to hear your experiences of living with, or supporting others with, this condition to ensure that this and future research is as accessible as possible for everyone, by designing it for patients, with patients.

### **Am I eligible to participate?**

For this opportunity, we are looking for up to 6 adult individuals (aged 18 or over), living in the UK, who meet the following criteria:

- Lived experience of beta thalassaemia, as a patient or carer
- Not reliant on regular blood transfusions

This activity will be most relevant to people who fall into all of the above categories, but we would still be happy to hear from you even if you do not match them all, or if you have lived experience of other forms of thalassaemia or red blood cell disorders.

You will need to be comfortable with reviewing the documentation and sending back comments online and be willing to discuss your experiences and management of this condition.

Prescribing clinicians are not permitted to participate for regulatory reasons. If you are a prescribing clinician and are unsure about your eligibility, please get in touch to discuss this.

### **What do I have to do?**

This activity involves carrying out an online document review where you will be asked to comment upon the design of a research study and feed back on how the information introducing the research is presented to patients. We want to ensure that the documents are informative, accessible, engaging and fit for purpose, and that the language used is appropriate for potential participants and carers.

### **How long will it take?**

We anticipate that it would take you up to 2 hours to read the documents and fill in the feedback form. We are proposing a 10-day time limit to complete the review but are sensitive to availability.

### **Will I get paid?**

The NIHR, on behalf of the life sciences company, will reimburse you £50 for your participation. Please review information about payment, tax and national insurance [here](https://www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372#the-implications-of-being-paid-for-involvement) on our website ([www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372#the-implications-of-being-paid-for-involvement](https://www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372#the-implications-of-being-paid-for-involvement))

## **What is the NIHR Patient Engagement in Clinical Development Service?**

The NIHR Patient Engagement in Clinical Development Service is designed to enable the life sciences industry to engage with members of the public, so that research can be co-designed with the individuals most likely to be impacted by it. Through this collaboration, we help to ensure that the objectives of the research align with those of the patient community, and that the studies are as easy to join and complete as they can possibly be.

You can find out more about this service on the following webpages:

[NIHR Patient Engagement in Clinical Development Service](http://www.nihr.ac.uk/explore-nihr/industry/pecd.htm) ([www.nihr.ac.uk/explore-nihr/industry/pecd.htm](http://www.nihr.ac.uk/explore-nihr/industry/pecd.htm))

[Information Sheet for Patients](http://www.nihr.ac.uk/documents/patient-engagement-in-clinical-development-service-information-sheet-for-patients/11701) ([www.nihr.ac.uk/documents/patient-engagement-in-clinical-development-service-information-sheet-for-patients/11701](http://www.nihr.ac.uk/documents/patient-engagement-in-clinical-development-service-information-sheet-for-patients/11701))

## **Are these commercial research studies? What does this mean? Will the company be able to access my personal information?**

These are research studies created by and funded by a commercial sponsor (the company). The company might produce pharmaceuticals, biotechnology or medical devices, and will be hoping to deliver their research within the NHS. As information about the proposed research is sensitive at this stage, we can't share with you the company name at the moment. But if you agree to participate, we will be able to provide you with this information.

The service is being facilitated by the NIHR, and we will not be sharing your details with the company. Your reimbursement and any personal details provided will be managed by the NIHR. You can find additional information about this in the Information Sheet for Patients and in the [NIHR Privacy Policy](http://www.nihr.ac.uk/documents/nihr-privacy-policy/12242) ([www.nihr.ac.uk/documents/nihr-privacy-policy/12242](http://www.nihr.ac.uk/documents/nihr-privacy-policy/12242)).

## **What information will the NIHR need about me?**

To ensure we're engaging with as diverse a demographic of people as possible, we ask you to share with us your name, sex, age, experiences of the condition being researched (either as a patient or a carer), and if you've participated in research studies or similar research involvement initiatives previously. Sometimes we may need to ask additional information to help ensure you're an appropriate match with the opportunity.

## **What happens afterward?**

You will be reimbursed following the document review. We will also ask the company to tell us how they used and responded to the feedback they received and will pass this information back to you.

## **I'd like to be involved; how do I find out more?**

If you'd like to register your interest in participating in this opportunity, please complete the application form [available here](https://forms.office.com/e/AnqxV2D8Mz) (<https://forms.office.com/e/AnqxV2D8Mz>).

If you have any questions, or if you have any problems completing the application form, please contact Isabella Darbyshire, Service Coordinator, by emailing [pecd@leeds.ac.uk](mailto:pecd@leeds.ac.uk)

**Deadline for Expressions of Interest: Wednesday 22<sup>nd</sup> May 2024**