

NIHR Patient Engagement in Clinical Development Service Are you interested in research? Then this opportunity to shape the design of a cancer clinical trial is for you!

The National Institute for Health Research Clinical Research Network is pleased to share an opportunity to participate in a review of patient facing study documents and a remote insight session for a treatment for patients with head and neck cancer. By sharing your experience we hope to ensure that this and future trials are designed with patients and for patients. We want to make trials as accessible as possible for everyone.

Am I eligible to participate?

The NIHR is looking for 6 adult individuals (over 18) to participate in this opportunity.

We're looking for individuals who have head and neck cancer and are undergoing chemotherapy or radiotherapy and would be willing to review a patient information sheet and for a study sent to them via email as well as participate in a remote insight session.

Please note that due to the COVID-19 pandemic you will need access to an internet connection and laptop to complete the review.

Due to regulatory reasons, you will be unable to participate if you are currently a prescribing clinician – if you're unsure, please get in touch (details below).

What do I have to do?

Our intention is to host an electronic document review, where we will send the Patient Information Sheet (PIS), for the clinical trial to you to review and provide comments.

Once the review of the PIS is completed we will ask you to join a one hour insight session to discuss how individuals manage their condition, how we may be able to address potential issues to improve the quality of life for this condition and how we can ensure this trial is designed to be as accessible as possible.

You will be asked to dial into an online video conference platform such as Zoom or WebEx at a time agreed with all participants. Timings can be flexible, such as evening or late afternoon hours to allow for working hours.

These meetings will be chaired and led by an NIHR facilitator and everyone will be given an opportunity to speak on a range of topics and share their insights.

How long will it take?

We are proposing to provide a week for the documents to be reviewed, but are sensitive to availability and therefore flexible with this. We will then arrange the one hour insight session.

Will I get paid?

The NIHR, on behalf of the life science company, will reimburse you £100 for your participation.

Information about payment and tax and national insurance can be found here.

What's the NIHR Patient Engagement in Clinical Development Service?

The NIHR Patient Engagement in Clinical Development Service is designed to enable the Life Science Industry to engage with individuals such as yourself, to ensure that trials can be co-designed with individuals most likely to be impacted by them, to ensure that the objectives of the trial align with those of the patient community and that these are as easy to join and complete as they can possibly be.

You can find out more about this service at the following:

<u>Information Sheet for Patients</u>

NIHR Patient Engagement in Clinical Development Service – Home Page

Are these commercial trials? What does this mean? Will they be able to access my information?

These are clinical trials created by and funded by a commercial sponsor (the company). They will be hoping to deliver these clinical trials with the NHS.

As the information at this stage is sensitive we can't share with you the company name but if you agree to participate we will be able to share this with you.

As the service is being facilitated by the NIHR we will not be sharing your details with the company, this will be managed by the NIHR.

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

What Information will the NIHR need about me?

To ensure we're engaging with as diverse a demographic of people as possible we'd ask you to share with us your name, age, experiences of your condition (either as a patient or a carer), if you've participated in clinical trials previously or similar initiatives.

What happens afterward?

Once the review has been completed the NIHR will arrange to reimburse you for your time and efforts.

After your feedback has been digested and potential changes made, a report will be shared with you highlighting the impact that your shared insights have had.

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 or simply if you have any questions in relation to this please email

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