

## FAQ for Staff and Patients

# Participation in a trial at Moorfields


---

### What is research?

**In general terms**, research seeks to advance knowledge through carrying out an ordered plan of tests and analysis. At Moorfields, we aim through research to find **treatments and diagnostic tools** that are **better than the best currently available** for people who have eye conditions. Research starts with a question or theory which the researcher attempts to answer through a series of rigorously planned approaches which can include simply capturing novel information so that evidence is available where previously there was none. Researchers publish the results of their work so that anyone in the world seeking answers to related questions can benefit from the results obtained.

**For research involving patients:** once we have sufficient experimental proof of a theory, we need to conduct a series of studies (“clinical research projects” or “clinical trials”) to find out firstly whether the approach is *safe* for use in patients, then whether there *may* be some beneficial use for patients in continuing to explore the approach, and then whether the approach has promising outcomes in a wider number of patients before introducing it on a large scale and monitoring its value. The *average* amount of time such testing takes before a new treatment might be adopted widely by the NHS is 17 years.

**Participating in research:** to assess all of these phases (safety, potential efficacy in small numbers, efficacy in large numbers of people), we may invite some of our patients to consider joining a clinical research project or trial as a “research participant”. The criteria for such projects are very specific and are determined by such factors as an eye disease affecting a particular area in the eye or by a family history of a genetic change. Sometimes, participation in a study may not require an ongoing commitment: for example, we may ask patients to provide a blood sample for research purposes or to answer a questionnaire. Sometimes, participation does require many visits to the hospital over a period of time. All of the anticipated implications for a particular study are



discussed with patients and adequate time is given for consideration about taking part in a study. If a patient decides to take part, they are asked to provide their written consent to become a participant.

**1. As a patient of Moorfields, how can I join a research study?**

If you are visiting Moorfields Eye Hospital for an appointment you can ask your doctor about taking part in research or alternatively you can contact one of the numbers listed at the end of this document.

**2. As a patient elsewhere in England, Wales or Scotland or even overseas, how can I join a research study at Moorfields?**

You will need to discuss with your current Ophthalmic Consultant or GP, your wish to take part in research at Moorfields. You may find that research is already happening in your current hospital and that you may be eligible to take part there. If you want to take part in research at Moorfields, it may mean that all of your eye care has to be transferred to Moorfields even though, until you have transferred, we shall not be able to assess whether you meet the criteria for any of our research studies. You are advised to consider with your current Ophthalmic Consultant or GP whether this might be a helpful course of action for you and the implications for travel for routine care, etc. If you decide you want to transfer care for your eyes to Moorfields, your current Ophthalmic Consultant or GP will need to write to Moorfields indicating that you are interested in taking part in research. We shall then be able to screen you for eligibility to join a research study.

**3. Can I be put on a waiting list/database to be recruited to a clinical trial in the future?**

No, we have a team of researchers who screen notes of patients to identify people who may be eligible to be recruited into research studies and clinical trials. Should you be eligible, your clinical care team will approach you to discuss the details and the process. You may be approached about the possibility of participating in research while you are a patient at Moorfields unless you opt out of participating.

**General information about studies and trials:**

**4. How can I find out what clinical trials and research studies are being carried out at Moorfields?**

Please contact [res-admin@moorfields.nhs.uk](mailto:res-admin@moorfields.nhs.uk) with your request and they will be able to update you on the current research portfolio.

## 5. How can I find out all the clinical trials being carried out for eye conditions in England?

You can visit the following websites which will provide you with details of research projects being undertaken in the United Kingdom:

<http://public.ukcrn.org.uk/search/>

<http://www.ukctg.nihr.ac.uk/default.aspx>

## 6. How can I find out all the clinical trials being carried out for eye conditions in England when I don't have internet access?

You can contact the National Institute for Health Research (NIHR) National Patient, Carer and Public Involvement and Engagement Office for Ophthalmology on 0113 343 0441.

## 7. Can children take part in research?

Yes. However, "informed consent" from the participant and/or their guardian must be obtained first. Research with children up to the age of 16 can only be carried out with the informed consent of the parent/guardian and/or child depending on the competence of the child. This process will be fully explained if a patient appears to be eligible to take part in a study.

## Following up on a publication or research in a particular area:

### 8. I've seen a reference to an interesting research published by researchers at Moorfields/UCL Institute of Ophthalmology, how can I find out more information about the research?

You can email [res-admin@moorfields.nhs.uk](mailto:res-admin@moorfields.nhs.uk) and your question will be passed to the most appropriate person.

### 9. What are the latest developments for treating a particular condition, e.g. glaucoma, age-related macular degeneration, etc?

You can visit the following websites for Moorfields (<http://moorfields.nhs.uk>) and the NIHR Biomedical Research Centre at Moorfields Eye Hospital and UCL Institute of Ophthalmology (<http://www.brcophthalmology.org>) for news about important discoveries, and about patient/researcher events where you can talk with researchers about latest developments.



## List of Contacts

Staff Member	Contact Number	Email Address
<b>Karen Bonstein</b>	0207 253 3411 Ext 4657	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>
<b>Richard Cable</b>	0207 253 3411 Ext 4658	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>
<b>Ed White</b>	0207 566 2059	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>
<b>Amanda Davis</b>	0207 566 2059	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>
<b>Sabeena Johal</b>	0207 253 3411 x2937	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>
<b>Geeta Ghadiali</b>	0207 253 3411 x2036	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>
<b>Tania West</b>	0207 253 3411 x2036	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>
<b>Jaki Parkin</b>	0207 566 2818	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>
<b>Julie Dolan</b>	0207 566 2108	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>
<b>Supeetha David</b>	0207 566 2108	<a href="mailto:res-admin@moorfields.nhs.uk">res-admin@moorfields.nhs.uk</a>