



**The NIHR Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology seeks ways to support the involvement of patients and the public in influencing the vision research that is conducted on our site. Examples are given here for 2014.**

**We need the views, experiences and insights of patients, family members and friends to ensure that research meets the needs of people affected by eye conditions.**

**So why not get involved?**

# About the NIHR Moorfields Biomedical Research Centre:

The NIHR Moorfields Biomedical Research Centre (BRC) is a partnership between Moorfields Eye Hospital NHS Foundation Trust and the UCL Institute of Ophthalmology.

Our centre is one of 11 national Biomedical Research Centres and is the only one dedicated to eye conditions. Our aim is to provide rapid-track delivery of new diagnostic methods and therapies, developed both internally and in partnership with other organisations.

If you want to know how you can be involved in influencing the design and focus of eye research, please contact us by email at [BRC@moorfields.nhs.uk](mailto:BRC@moorfields.nhs.uk) or by telephone on 020 7253 3411 ext.4658.

Involvement in influencing eye research is different to participating in a clinical research study. If you are keen to participate in a study, please speak to a member of the clinical team you meet when you visit Moorfields.



# WHO WE ARE



## **Professor Sir Peng Tee Khaw**

- Director of the NIHR Moorfields Biomedical Research Centre and of Research and Development
  - Lead of the research theme of Regenerative Medicine and Pharmaceuticals
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## **Professor Philip J Luthert**

- Director of the UCL Institute of Ophthalmology (partner to Moorfields Eye Hospital in the NIHR Biomedical Research Centre)
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## **Mr Frank Larkin**

- Deputy Director of the NIHR Moorfields BRC
  - Director of the NIHR Moorfields Clinical Research Facility
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## **Professor Robin Ali**

- Lead of the research theme of Gene Therapy
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## **Professor John Marshall**

- Lead of the research theme of New Technologies and Devices



### **Professor Andrew Dick**

- Lead of the research theme of Inflammation and Immunotherapy
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### **Professor David Garway-Heath**

- Lead of the research theme of Visual Assessment and Imaging
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### **Professor Andrew Webster**

- Lead of the research theme of Genotyping, Phenotyping and Informatics

### **Core members of the NIHR Moorfields BRC Patient and Public Involvement Team:**

- **Karen Bonstein:** Manager of the NIHR Moorfields BRC
- **Debbie Bryant:** Personal Assistant to Professor Sir Peng Tee Khaw
- **Catey Bunce:** Principal Statistician
- **Richard Cable:** PPE & PPI Research Assistant
- **Jocelyn Cammack:** NIHR Moorfields BRC Research Fellow
- **Jane Clipston:** NIHR Moorfields BRC Administrator
- **Andi Skilton:** Ocular Gene and Cell Therapy Communications Manager
- **Maaret Virtanen:** Undergraduate Education Coordinator
- **Meike Walcha-Lu:** Research Technician for Multimedia Innovations

There are many ways that patients and the public can get involved in influencing research. Here are some examples of how the patients and the public were involved in 2014:

## **FOCUS GROUPS**

By inviting patients to share experiences of what it is like to live with a particular condition, researchers are able to: gain insight into the impact of a condition on people's lives so that they can design surveys of large numbers of people and then plan research projects of true relevance to needs; discuss the priority of questions that need to be answered through a research project; seek opinion on the acceptability of the procedures that could form part of a project. A focus group can range between 3 and 30 patients (although there is no set limit of attendees).



### **Examples of topics discussed in 2014:**

- **Acanthamoeba Keratitis:** this is a condition caused by an amoeba that can

be transferred to the eye if contact lenses come into contact with water (e.g. by cleaning them with tap water, by wearing them in the shower or while swimming in a pool, etc.). The cornea can become irritated and it sometimes leads to blurred or double vision, pain and even loss of vision.



A group of patients with the condition formed a focus group with researchers. Arising from these discussions: a patient-friendly information leaflet was produced about the rare condition; a patient designed a “no water” sticker for use on boxes in which contact lenses are packaged; patients and researchers produced a series of information films about cleaning contact lenses that were distributed to new university students in the autumn of 2014.

- Cataract patients and researchers discussed the design of a trial to evaluate different ways of removing cataracts. The research group was subsequently successful in gaining funding for the trial and will be recruiting patients later this year.
- A focus group discussion was held for corneal limbal stem cell deficiency, which is a condition that sometimes arises in patients with Aniridia or Stevens-Johnson Syndrome. The group helped to design a questionnaire which will be used to support the diagnosis of this deficiency.
- Patients who had surgery to repair macular holes advised on the information needed by patients who are asked to ‘posture’ or ‘position’ themselves face down or face forward after surgery for several days. The advice we acquired from our discussion group will be given to participants on a trial about “positioning” after surgery.

## **RESEARCH DAYS**

We hold research days for patients, relatives, friends and researchers to: learn about people’s experiences of different eye conditions; hear about ongoing and future research for

those conditions; and to consider the priorities and challenges of developing new diagnostics and treatments. Our research days include between 100 and 300 attendees.

### **Examples of research days in 2014:**

- We held a Low Vision Day to discuss ongoing and future low vision research. The points raised from the different group discussions on the day will be available to view on our website in 2015.

During the event, a study was discussed that had tested the effect of different contrast levels for low vision patients. The study provided evidence that using high contrast for surfaces in the built environment would be helpful for people with low vision, e.g. distinguishing a pavement edge from the road or a doorway to a shop.

The comments and support given by participants to the results of the study were used to illustrate the study's



findings at a presentation given at The Royal Institute of British Architects.

- An Age-related Macular Degeneration (AMD) Day, partly funded and supported by the NIHR Moorfields BRC, gave us an opportunity to gather patients' opinions on a proposed study to design a self-operated device for monitoring changes at the back of the eye – which received a large amount of support! We are pleased to report that the study and principal researcher have received funding from the National Institute for Health Research and the study will start in March 2015.
- We also held a Glaucoma Day to discuss ongoing and future glaucoma research. The points raised from the different group discussions on the day will be available to view on our website in 2015.



# QUESTIONNAIRES AND SURVEYS

We invited members of our Research Community to participate in surveys. For example, patients with Central Retinal Vein Occlusion (CRVO) were asked to review the information that was being given to patients on a trial looking at the effectiveness of drug treatments for macular oedema in CRVO.

## Where now?

Capitalising on what we have learnt over the past few years from discussing research opportunities with patients, our research centre is keen to widen the involvement of patients in influencing research as well as to continue to meet with groups of patients and researchers to discuss specific topics in detail.

Here are a few examples of upcoming patient involvement activities in 2015:

- Seeking the views, via a survey, of glaucoma patients about different treatments, e.g. eye drops, surgery, laser surgery.

The results of this survey will help to inform whether there is a need for a trial focussing on one or more of these treatments.

- Convening research days for the public and healthcare professionals for discussion about blepharospasm; macular holes and retinal trauma; pemphigoid.

If you want to know how you can be involved in influencing research, please contact us on email at [BRC@ Moorfields.nhs.uk](mailto:BRC@ Moorfields.nhs.uk) or by telephone on 020 7253 3411 ext.4658.

Please check our website regularly for news and upcoming research days: [www.brcophthalmology.org](http://www.brcophthalmology.org).