A series of five examples of public involvement in research developed by the NIHR Evaluation, Trials and Studies Coordinating Centre.

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# Example four: Health-Related Quality of Life in two treatment pathways for primary open angle glaucoma and ocular hypertension: a randomised controlled trial of initial selective laser trabeculoplasty versus conventional medical therapy

## About the research

**Lead researcher:** Mr Gus Gazzard, Consultant, Moorfields Eye Hospital NHS Foundation Trust, London and Senior Lecturer, Institute of Ophthalmology, University College London (UCL).

**Funder:** National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Programme.

**Project aim:** To compare the quality of life for patients receiving one of the following two treatments for early glaucoma: (1) eye drops which have to be used for the rest of the patient's life, and (2) a one-off laser treatment, which may prevent or at least delay the need for subsequent treatment with eye drops.

**Type of research:** Clinical trial.

**Duration:** Five years, October 2012 - October 2017.

## Who we spoke to

We interviewed Amanda Davis, the Research Manager at the National Institute for Health Research (NIHR) Moorfields Clinical Research Facility.

## About the involvement

### Patient / carer involvement prior to applying for funding

The research team consulted an existing group of patients who read the protocol at the outline application stage and an early version of the consent form. The group suggested making some changes to the consent form, but none to the protocol, other than to express their support.

> "We asked our colleagues how they did patient involvement. Someone told us about a patient and public involvement (PPI) group that our organisation runs, and we approached those people. "
>
> **Amanda**

**Involvement in the project**

When the project began, two members of the PPI group were invited to one of the early team management group meetings. They were asked to comment on the written material for trial participants: the patient information sheet, consent form and the questionnaires that were to be used to assess patients' quality of life.

> "It was good to have patients look over the information sheet and consent forms because as researchers, we just tend to think of what's needed in terms of the regulations. We don't look at it from a patient perspective.
>
> It was also helpful to have the patient perspective on the questionnaires, for example whether they were too long. They made the suggestion to put the forms online, so people can complete them on a computer. " **Amanda**

The two patient representatives then joined the Trial Steering Committee and they attend meetings annually. The research team plans to involve them at later stages to help develop ways to motivate participants to stay engaged.

> "Now we're at the end of recruitment, we need to make sure we get the quality of life questionnaires back. It is a worry with long trials and it can be hard to keep people interested. The questionnaire is 12 pages long as well – so we're planning to work with the PPI reps to think about how to encourage patients to fill them out and send them back." **Amanda**

**Lessons learnt**

> "I would recommend that everyone involves patients, as you need the patients' views on how a study should be run and how to make it easy and accessible to take part. As researchers, we don't have that perspective." **Amanda**

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