

Working together to develop public involvement training

By Rosamund Yu

At the National Institute for Health Research (NIHR) Biomedical Research Centre (BRC) at University College London Hospitals (UCLH) NHS Foundation Trust and University College London (UCL) we have just finished running a month's programme of training workshops for researchers on actively involving patients and the public in research. This article explains how we went about it and some of the – very practical – lessons we learnt.

Why we needed this training

Our aim is to make sure that when patients and the public take an active part in biomedical research, their input has a real impact. We want to make sure that patient and public involvement (PPI) in research is a positive experience for everyone – patients, public and researchers.

Many of the researchers who consult our PPI team lack confidence to carry out PPI and many don't even know where to start. So training is a key part of our work and we have for some time been running workshops on topics like setting up a patient group.

In February – thanks to our academic health services centre UCLPartners – we received funds from Health Education North Central and East London to develop this training into a more intensive programme of workshops for academic clinical researchers right across UCLPartners organisations. The programme had to be delivered by the end of March.

Working together to design training

Even though it was a rush, we met up with patients and members of the public who had helped us in the past and asked them what kind of training researchers needed. We also surveyed one of our PPI panels. People told us they wanted training that broadened researchers' horizons and brought home just how valuable PPI is to research.

We worked with expert PPI trainers, as well as patients, charities, lay people who review funding and ethics applications, UCLPartners and PPI leads, and used results from a training needs assessment of over 100 researchers, to design a programme of nine workshops (see www.uclhospitals.brc.nihr.ac.uk/sites/default/files/Programme_Involving_patient%2C_carers_and_the_public_in_research_workshops.pdf).

Workshops tended to be for a half day and subjects ranged from setting up a patient group and filling in a grant application form to PPI in laboratory research and communications. Some sessions were delivered by expert trainers and others by patients and members of the public. We also made sure that at least one lay person came to each workshop to help us bring home the 'other perspective' to researchers.

In-built evaluation

We set up a system of evaluation, with participants asked to fill in surveys before each workshop and immediately after. We will also be surveying researchers six months down the line. Our aim is to find out exactly how helpful workshops were. It's all very well researchers saying that the workshop was good, but a few months later have they been able to use the skills they acquired?

We advertised the workshops as best we could and the response from the research community was overwhelming. In the end we

delivered nine oversubscribed workshops across a range of locations including UCLH, UCL, Moorfields BRC, the Royal London Hospital, London Cancer and City University. Over 120 researchers took part in workshops and 119 of them filled in before and after surveys.

Early analysis of the surveys is promising: the training impacted on researchers' confidence and enthusiasm for research. Before the workshops 50% of researchers were PPI enthusiasts and most of the rest were interested in PPI but hadn't done it. After the workshops the proportions had changed and 60% were PPI enthusiasts. Surveys also showed steep improvements in confidence and understanding of PPI.

Lessons Learned

This programme had to be designed and executed within the space of six weeks, so we had lots of scary moments when we thought things would go hideously wrong.

These are the things we could have done better:

- Make sure everyone – participants, trainers and administrators – knows who the workshop is for and what it will be giving them. You need to be crystal clear what kind of experience and interest workshop participants need to have. This avoids disappointments and frustration when workshops don't deliver what people expect.
- Workshop attendees like to have an agenda and to know exactly what they will get out of the training – again this avoids frustration and disappointments.
- Unless you are going to line people up in a formal lecture style, allow for plenty of space when identifying and booking rooms. We were often told by facilities management that a room had a certain capacity only to find on the day that it was overcrowded and hot. Check the capacity, go and see for yourself.

- Find a way of discouraging 'do not attends'. We had oversubscribed workshops that were half full because people didn't bother to cancel. A charge for not attending is the best answer in our experience.
- Make sure you have a good system for logging bookings and replying to people. Although no one got missed, we had some close shaves.

But we also learned how much this training was needed and wanted. Indeed we were inundated with people signing up.

We could not have done it without the enthusiasm, commitment and patience of the expert trainers, patients and members of the public, who put up with rushed timetables, squashed rooms and confusion. Without a spirit of 'mucking in' none of us could have pulled such a project off. Special thanks to Bec, Carol, Derek and Jamie, as well as Madeleine, Kavita and Kellie.

Contact: **Rosamund Yu, PPI and Communications Manager, Joint Research Office**

Email: rosamund.yu@ucl.ac.uk

Tel: **020 7679 6166**