

The changing landscape of a clinical trials unit: working to make patient and public involvement part of the culture of our organisation

Patient and Public Involvement Group, MRC Clinical Trials Unit at UCL

Background

The MRC Clinical Trials Unit (MRC CTU) at UCL develops, runs and reports clinical trials and studies in cancer, HIV and other diseases. A survey of patient and public involvement (PPI) at the Unit in 2012⁽¹⁾ showed that most researchers saw potential benefits of involving consumers. But although there was a good deal of involvement in newer studies, we felt there was room for improvement. Therefore, the Unit's PPI Group has been working towards:

- increasing the profile of PPI across the Unit
- making PPI an integral part of our research culture

This poster highlights some of the ways we have tried to do this. We also identify and outline our plans for the future. To find out more about our work see our webpages:

ctu.mrc.ac.uk/resources/patient_involvement/



Who we are

The PPI group at the MRC CTU at UCL is a small group of staff members and patient representatives who look at issues around PPI across the broad range of work of the MRC CTU at UCL. Our aims are to encourage, support and evaluate PPI activities within the Unit. Our current membership is:

Annabelle South
 Bec Hanley
 Ben Cromarty
 Claire Murphy
 Claire Vale
 Denise Ward
 Karen Scott
 Mitzzy Gafos
 Richard Stephens

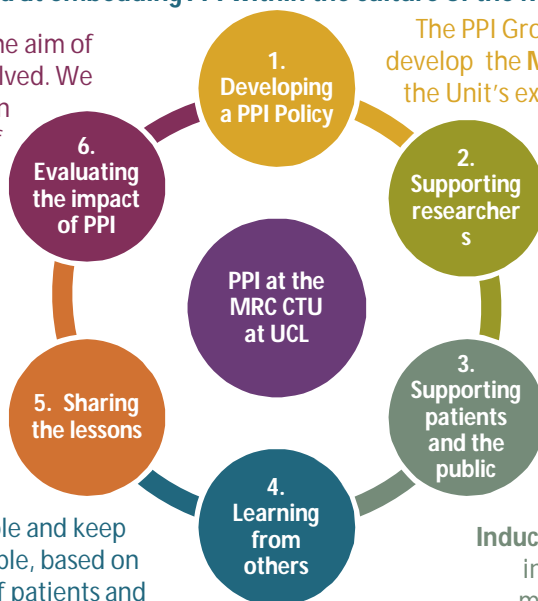


Strategies aimed at embedding PPI within the culture of the MRC CTU at UCL

We evaluate our PPI activities, with the aim of improving the experience for all involved. We also aim to assess the impact of PPI on research, by publishing evaluations of patient involvement. We are also collecting **case studies** of examples of PPI in our research, which we will publish.

We share information with our colleagues and inform them of any new initiatives. We also share our resources through the **MRC CTU website** (ctu.mrc.ac.uk)

We speak to broad networks of people and keep up to date with new ideas. For example, based on work by Knapp et al⁽²⁾, partnerships of patients and researchers have redeveloped our **patient information sheet template**.



The PPI Group worked with the Unit's Director to develop the **MRC CTU PPI policy**. It clearly sets out the Unit's expectations for PPI in all new research

Working with colleagues, we devised **guidance for researchers**, helping them with practical aspects of PPI in their research, such as redeveloping a patient information sheet template.

We listened to feedback from patients and patient representatives involved in our trials. This led to the development of a **Trial Management Group (TMG) Induction Pack**, for people becoming newly involved in our work. We have recently made a **series of short films about PPI**.

Conclusions

- Reviewing our practices and assessing the needs of researchers and involved patients has led towards embedding PPI in our clinical research.
- Having a dedicated PPI Group to oversee this has helped this process.
- Continued partnerships between researchers and patient representatives should help to ensure that we continue to develop and strengthen PPI in all of our future research.

Come and see us at INVOLVE 2014!!

- Involving patients and the public from hard-to-reach groups in clinical trials.
 Wednesday 26th November, Session 1.6 (14.50 - 15.50)
- Writing patient information sheets (a workshop)
 Thursday 27th November, Session 3.7 (1.00-12.00)

Watch our films!!

- What is patient and public involvement?
- Why do patients get involved in our research?
- How do patients make a difference to our research?
- The practicalities of patient and public involvement in clinical research

References:

1. Vale C, Thompson LC, Murphy C, Forcat S and Hanley B. Involvement of consumers in studies run by the Medical Research Council Clinical Trials Unit: Results of a survey. *Trials* (2012) 13:9
2. Knapp P, Raynor DK, Silcock J, Parkinson B. Can user testing of a clinical trial patient information sheet make it fit-for-purpose?--a randomized controlled trial. *BMC Medicine* (2011) 9:89