Patient / community member of the Patient and Public Involvement (PPI) Group

We are inviting you to join the PPI Group

- Please take time to read the following information carefully. Take time to decide whether or not you wish to get involved.
- You can resign from the PPI Group at any time, though we would like you to tell us you are leaving, and if possible, why.
- Ask us if there is anything that is not clear or if you would like more information.
- Thank you for reading this information.

Important things that you need to know

- We are committed to PPI as we believe that it improves the quality of our research.
- The PPI Group of the Medical Research Council Clinical Trials Unit at UCL (MRC CTU at UCL) is responsible for providing leadership, advice and support about all aspects of PPI to staff at the MRC CTU at UCL.
- Patient/community members have a specific role to bring a patient/community perspective to the work of the PPI Group.
- The PPI Group meets every three months at the offices of the MRC CTU at UCL in central London. Meetings usually last 2-3 hours. This appointment is for two years in the first instance.
- Training and support will be given as needed
- A small fee is given for participating, and reasonable expenses will be covered.

Contents

1 What is patient and public involvement (PPI) in research?
2 What is the Medical Research Council Clinical Trials Unit at UCL (MRC CTU at UCL)?
3 What do I need to know about PPI at the MRC CTU?
4 What will I need to do if I join the group?
5 What sort of experience or background should I have?
6 Can I resign after I’ve joined the PPI Group?
7 Contacts for further information

How to contact us

If you have any questions about being a member of the MRC CTU at UCL PPI Group, please contact Claire Vale, PPI Group chair. Email: claire.vale@ucl.ac.uk
1 What is patient and public involvement (PPI) in research?

What is PPI in research?
PPI in research is research that is carried out ‘with’ or ‘by’ patients and/or members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example:

- Working with research funders to prioritise research
- Offering advice as members of a project steering group
- Commenting on and developing research materials
- Undertaking interviews with research participants

What is the Medical Research Council Clinical Trials Unit at UCL (MRC CTU at UCL)?

The MRC CTU at UCL is one of the UK’s leading not-for-profit centres for clinical trials. Our research helps to improve health care in the UK and around the world. We specialise in research in cancer, HIV/AIDS and TB, but we also do research in other areas.

We plan and run clinical trials, and we bring together the results of a number of trials that look at the same illness or condition (this is called systematic review or meta-analysis). We undertake observational studies. We also carry out methodological research to improve the design, conduct and analysis of clinical trials, systematic reviews and meta-analyses.

The Unit employs around 150 staff and is currently coordinating about 30 trials and other research studies. For more information, see http://www.ctu.mrc.ac.uk/

2

3 What do I need to know about PPI at the MRC CTU?

What is PPI at the MRC CTU?
At the MRC CTU at UCL we use the term ‘patients and public’ to include current, former and potential patients, carers, people who use health and social care services, and people from organisations that represent people who use these services. We also consider the active involvement of trial participants, as partners in research, as a key component of PPI. We understand that the perspectives of patients and members of the public are distinct from those who have a professional role in these services.

We are committed to PPI as we believe that it improves the quality of our research.

We actively involve patients and the public in almost all of our studies and we have policies and procedures in place to support this. We also actively involve patients and the public at an organisational level.

What is the PPI Group responsible for?
The PPI Group is responsible for providing leadership, advice and support about all aspects of PPI to staff at the MRC CTU and in the wider research community. Full terms of reference for the Group are available. In summary these state that the role of the Group is to:

- Promote and support PPI within the MRC CTU at UCL
• Ensure that the Unit’s PPI Strategy, and annual PPI Implementation Plans are developed and delivered
• Promote the development of PPI at study, strategic and organisational levels within MRC CTU at UCL
• Promote research around issues related to PPI within MRC CTU at UCL studies

And that PPI Group members:
• Attend PPI Group meetings and carry out activities as necessary between meetings
• Participate in working groups to take forward particular pieces of work
• Offer advice and support to staff about how best to involve patients and the public in MRC CTU-supported studies
• Act as ambassadors for PPI at MRC CTU at UCL in the wider research and patient communities.

What will I need to do if I get involved?

What is the role of PPI Contributors?
Patient/community members share the general roles of all PPI Group members outlined in section 3 above. They also have a specific role to bring a patient/community perspective to the work of the Group. This might include:

• Providing a link to patients’ organisations and groups
• Talking with other patients/community members about the work of the PPI Group and seeking their views or input where appropriate
• Offering advice to staff who are planning or reviewing PPI in a study
• Representing the PPI Group at meetings and events both within and outside the CTU

How often does the group meet?
The Group meets every three months at the offices of the MRC CTU at UCL in central London. Meetings usually last 2-3 hours.

How long would I be a member of the Group?
This appointment is ideally for two years in the first instance.

What training or support will I be offered?
The PPI Group chair, or another experienced member of the PPI Group, will talk with you before you first attend a PPI Group meeting to give you a background to the work of the PPI Group and to address any questions you may have. They will also be available to discuss any concerns or questions at any time during your involvement.

You may also be able to access any appropriate training you identify, or that is identified by other PPI Group members.

Is there any payment for being on the Group?
Patient/community members of the Group will be able to claim a fee for taking part in meetings and related activities. This is based on National Institute for Health Research (NIHR) guidance (currently £150 per day). Meetings last a maximum of half a day, so typically, a payment of £75 is offered.
It is your responsibility to ask your tax/benefits office about the effects of any such claims on your personal financial circumstances such as sickness and unemployment benefits etc.

**Will I get back any travel costs?**
Patient/community members are entitled to claim travel and related expenses for attending meetings. Wherever possible and appropriate, travel bookings should be made by the MRC CTU at UCL to ensure individuals are not out of pocket whilst expense claims are being processed by UCL. Further information about what can be claimed and how to claim it will be given if you join the PPI Group.

**6 Can I resign after I’ve joined the PPI Group?**

We hope that you will remain an active member of the PPI Group for the duration of your term of office. However, if your circumstances change, or you have concerns about your involvement, you can resign from the PPI Group. We ask that you talk to the PPI Group Chair (or any other member of the PPI Group if you feel that is not appropriate) first. They might be able to advise you about any concerns you may have.

If you still decide to resign from the PPI Group, we ask that you speak with the Chair, so that a replacement can be recruited.

**5 What sort of experience or background should I have?**

You should have:

a) Experience of active involvement in clinical trials – for example through membership of a trial management group and/or trial steering committee - from the perspective of being a patient, trial participant, carer or lay member.

b) An ability to offer a patient/community perspective, whilst at the same time valuing other perspectives.

c) An ability to work effectively within a committee setting – this includes listening skills as well as an ability to make points clearly and succinctly.

d) A commitment to attend PPI Group meetings for the duration of the term of office.

Ideally you should also have experience of offering a patient/community perspective at a strategic or organisational level.

**7 More information**

If you want further information about the PPI Group, please contact the Chair – contact details are on page 1.

More information is also available on our website [www.ctu.mrc.ac.uk](http://www.ctu.mrc.ac.uk)

Thank you for taking the time to consider taking part in the PPI Group.