

Supplementary Terms of Reference

Patient and Public Involvement & Engagement (PPI&E) Task and Finish Group

Remit

To identify what infrastructure exists to support PPI&E within different trials units and the pros and cons of different approaches. To do this the group will plan and deliver a brief survey followed by a face to face workshop. We will also explore current links with PPI&E organisations and initiatives (Eg. INVOLVE and the Trials Change Lives Initiative) and identify existing resources to support PPI&E both within registered CTUs and in the wider PPI&E community.

Aims

- To identify successful approaches for delivering PPI&E within registered trials unit
- To map existing PPI&E resources along the timeline of a clinical trial.
- To develop more effective collaborative working across registered CTUs in relation to PPI&E

Members

Member	CTU
Heather Bagley (Chair)	Liverpool Clinical Trials Research Centre
Public research partner	Vacancy
Adwoa Hughes-Morley	York Trials Unit
Caroline Rick	Birmingham CTU
John Cleland	Glasgow CTU
Kym Thorne	Swansea Trials Unit
Laura Mader	Cambridge CTU
Lisa McDaid	Norwich CTU
Steven Blackburn	Keele CTU
Daniel Beaver	Sheffield CTRU
Claire Vale	MRC Clinical Trials Unit at UCL

Activity of the Working Group

The group will meet twice during the year by teleconference and communicate in between via e-mail. The intended activities of the group are to:

1. Develop a survey to be administered to trials units within the UKCRC Reg CTUs Network
2. Further develop a list of PPI&E contacts at each of the CTUs and invite them to participate in a brief survey
3. Administer the survey
4. Use responses from the survey to inform the development of a scoping workshop and identify potential participants.
5. Arrange the PPI&E scoping workshop, including patient representative attendance and support for their involvement.
6. Host the scoping workshop
7. Review the resources and models used at each CTU
8. Develop an action plan for better collaborative working, sharing of best practice and avoiding duplication of effort.