

IMPROVING PPI IN THE CENTRE FOR PRIMARY CARE: ADDRESSING SUPPORT AND DIVERSITY

The Patient Hack Day was run on April 30th 2014, and included an afternoon session for participants to talk about problems in PPI and suggest solutions. The combined audience of 20 researchers and 25 PPI partners were involved in the discussions.

The two main areas we talked about were inspired by pitches from:

- *Angela Ruddock - Barriers to diversity in PPI.*
- *Deborah Bhatti - Support needs in PPI.*

We also held a follow up meeting in July 2014, attended by Angela and Deborah, Sarah Knowles and Rebecca Morris on behalf of the Centre for Primary Care, and Ailsa Donnelly, PPI chair of PRIMER and the GMPSTRC RUG. The aim of the meeting was to put together all the suggestions from the discussion on the day and create a list of recommendations for improving PPI practice.

NB. PPI partners refers to members of the public who are involved in PPI work through one of the Faculty PPI groups, attended the NIHR funded EQUIP PPI research methods training course, are involved in PPI work within the North West or have a professional PPI role (e.g. service user researchers) .

Support

Support for Researchers

- The groups all pointed out that PPI can be just as challenging for researchers as PPI partners! This was especially as it tended be younger/less experienced researchers who worked on PPI.
- Getting more senior staff involved could help support less experienced researchers, especially in the early stages of a project.
- Within the Centre, we need to signpost researchers to sources of support (for example the regular PPI clinics that we run) and also give them opportunities to “debrief” after PPI meetings.
- A lot of the skills needed for researchers to do PPI were around communication and management. We are going to look into the possibility of developing a skills & communication course for researchers in PPI here at the University.

Support for PPI partners:

Two kinds of support were seen as important for PPI partners. Firstly, they need support to develop their own skills and knowledge. Secondly, they need more emotional or social support.

Skills development

- We need to give more recognition of the skills development that happens when PPI partners work with us. PPI partners could then build up a record of the different work they have done that could be used not just in research but possibly outside the university as well. We will recommend that projects provide certificates of participation to PPI partners. We'll also encourage people to use the R&D Involvement Portfolio.

<http://www.rdforum.nhs.uk/content/working-groups/service-user-carer-working-group/involvement-portfolio/>

Personal Support

- Introducing a buddy system for new PPI partners to link with experienced PPI partners could be helpful, so that partners have someone to speak to who has been through the same things. This model has been tested through PRIMER and feedback suggests it has worked well.
- If the PPI partner isn't comfortable raising an issue with the researchers they're working with, it would be helpful for them to have someone external within the faculty who could mediate problems. We will talk to the Faculty Co-ordinating Centre about the possibility of setting this up.
- PPI partners talked about a lack of 'closure', particularly on one-off projects, which was difficult as projects would end and PPI partners wouldn't know what happened next. We will encourage researchers to provide summaries to PPI partners at the end of the project about what happened. On longer projects, where the results might not be available for months or years, PPI partners should be told what the timescale will be.
- PPI partners very rarely, if ever, got to reflect after a project with the researchers on how the PPI itself went. This misses opportunities to learn and improve PPI and also means PPI partners don't get to give

their views. We will recommend projects in the Centre cost for an additional ‘reflection’ meeting at the end of the projects when the team can talk about this.

- PPI partners involved on specific projects who weren’t part of specific PPI groups (such as PRIMER) weren’t always sure who to contact about issues such as finance, training, arranging meetings. We will ask that each project has a named contact with whom the PPI partner can get in touch.

Diversity

It was felt that diversity was harder to tackle immediately, but there were ideas for how to begin making PPI groups more “diverse”

- Universities lack ‘role models’ for certain groups which could encourage them to get involved, for example men. Having more diverse academics visibly involved in PPI work may help with this and we will raise this issue with the Centre management.
- People without academic backgrounds might feel worried or uncertain about getting involved in research. It was suggested that we should do more public engagement and outreach events to help people understand what involvement means and how everyone has something to contribute.
- The websites for PPI groups in the University (including PRIMER and the Faculty Co-ordinating Centre) were considered very academic and not very easy to read. We are limited in how much we can change this (as the sites have to be consistent across the University and include certain information). It was suggested that we could have a more accessible website which gives a very simple introduction to PPI and signposts visitors to people they can contact for more information, rather than just providing blocks of text.
- The lack of support for PPI partners joining new projects can also contribute to the lack of diversity. Making clear what support and financial arrangements are available could help reassure people who are nervous about getting to involved. We will recommend that researchers make very clear what support and costs will be provided when they advertise for PPI partners to get involved.

- Delays around finance were also seen as contributing to exclusion for people who will be put at a disadvantage by having to wait for expenses to be repaid. The Centre now recommends cash-on-the-day expenses for all PPI activities. However we haven't had any progress in getting our Finance department to provide a better tracking system for expenses that go through the University system. We will recommend that researchers make very clear to PPI partners what the timescale might be for them to get reimbursed through the system, and to provide cash on the day as a first choice.
- Holding meetings during working hours and at the University was seen to exclude people who are working or caring for others, and those who might not be able to travel to the University itself. We will encourage researchers to think about holding meetings away from the University and to try to make different hours available.