

Tips and tricks for researchers.

Here's a few thoughts from a fairly experienced PPI-er who has enjoyed 15 years of work in the field.

Are you applying for funding? Submitting to Ethics? Think your research stands on its own merit and you don't need help? It may well be Nobel material but why not give it that extra special edge with *good* public and patient involvement? Here's how.

What is PPI?

Just to clarify - This is research with Patient and Public Involvement, where the patients and public are part of your research team. It is not research *on* patients, but *with* patients.

Why do PPI?

Here's why. There are several dimensions to PPI

- the ethical dimension - the experimentees ie the public should agree difficult issues before you start. Also, patients can be more adventurous than you might think. Sort out those tricky issues before Ethics gets their hands on your work.
- the moral dimension - most research is carried out using public money from tax-payers and charities. Science must be open and honest about its activities. Patients can, and do, support difficult and important activities eg tissue and data donation, post mortem tissue donation, difficult topics in interviews and questionnaires.
- the trust dimension - involving the lay public will increase their trust in what you do. Mention in your PIL that you have lay people on your team.
- the patient dimension - lay summaries and patient-facing documents benefit from the lay team simplifying and improving the language. Does this improve recruitment? Quite possibly.
- the economic dimension - better research with a patient focus means people back to work, and functioning in society much more quickly. This means more taxes are collected, some of which goes back into your research...
- the researcher dimension - your work will be strengthened and improved. Your work will be more relevant, be of greater benefit to the lives of the public and perhaps even yourself in due course. Your work will be more fulfilling. What's not to like?

"Involving people who have personal knowledge and experience of a research topic as a patient, service user or carer will strengthen and improve the quality of research and make it more relevant." Jim Elliott - Public Involvement Lead, Health Research Authority

Even bench scientists benefit by knowing why their work is important and how patients are impacted!

How to approach PPI.

Embed it in your work right from the start. Your PPI team will gain more understanding of your work and the scientific process if they know how you are thinking and why. Explain all. They may not understand the first time and may ask a lot of questions. This is good. You will gain experience in talking about your work to lay people, and they will be able to use their newfound knowledge in the next piece of work. It's a win-win for everybody.

When reviewing applications for NIHR Doctoral Funding Panels, and for Ethics, I and my colleagues look for PPI embedded throughout the project. Mention it in the lay summary, scientific summary, dissemination, etc throughout, where-ever it has been used. This shows that the patient is your focus.

Breeze through Ethics. Mention that any 'elephant-in-the-room' questions and/or tricky ethical issues have been, or will be, sorted out with the help of PPI.

Don't forget taking a lay PPI person to Ethics committee meetings to show importance/support/relevance for the application. The majority of researchers think it's a pros only event and they cannot do this. They can, and it impresses committees no end. They might not ask questions, but will still be impressed. Lay members will take you to their hearts.

If your PPI team have designed something you will be using eg a poster, flyer, etc, and are happy with the wording and images, then tell your readers who made them for you.

The PPI section needs to be quite detailed. Follow GRIPP2 standards, the short form (see below) and mention these somewhere in the text. Show what you have changed as a response to PPI input.

Put together a decent budget for PPI. Follow INVOLVE guidelines, and mention this in the PPI budget section. Put the detail in this section and show how the amount has been arrived at. Be generous rather than stingy to encourage people to do more, which builds experience - and you get a better PPI team as time goes on.

Reward is important and takes many forms. Some people may refuse monetary reward. You may see this as admirable. It isn't particularly. Always offer travel expenses and a nice lunch at the very least. If a member of the PPI team is on benefits and they are eligible for monetary reward, show you are aware of it and offer something else instead, eg vouchers.

Reward can include end of project party, payment, conferences, vouchers, trips round departments of interest, demonstrations - boys toys are good for this. A look at surgical robots, MRI machines, pathology labs, plasticated anatomy models, are very well received by many.

We look for at least two people on the steering committee - to support each other, enable discussion of contentious topics in an HCP-free zone, and contingency for the research team should one fall ill. The latter is a common problem if involving patients with a chronic or life threatening condition in your work, so be prepared.

A letter of support to Panels and Committees from the PPI team goes down well, too. Don't fall for the oft repeated (researcher) line that you 'can't put that many documents in the application'. As far as I'm aware, you can. If they offer - jump at the opportunity.

I also look for evidence of looking after the patient as well as the PPI contingent. Patient comfort is important, patients will be under stress. Researchers should be aware of this, and demonstrate it. Eg if interviewing patients about topics which may cause distress or upset, show concern by having a plan to deal with it, eg referral to counselling services, GP, etc. Of course, your PPI team will have been heavily involved in that questionnaire. Yes?

Language is extremely important. Please don't call your trial participants 'Clinical samples', or 'Clinical material' - as in 'walk the clinical samples to the interview room'. It is demeaning, and denies our humanity. It sets my teeth on edge and won't win you any brownie points - on the contrary. Psychology departments seem to like this term for some reason.

Similarly, use the words 'burden' and 'failure' with great care. Examples: The treatment fails the patient, not the other way round. And treatment of an illness or condition is a cost to the

NHS, not a burden. The patient bears the burden of illness, the NHS exists to pick up the cost, as you know.

GRIPP2 reporting (see below) is likely to become standard eventually, according to my NIHR contacts, so researchers may as well get to grips with it now and gain kudos therefore. There is a longer form for research into PPI itself. At least be aware of it, and state your reasons for using something else if you do.

Say where you get your lay people from, and if building a PPI team for a department, include this in the budget and PPI section. Gaining expertise, experience, training, valuable bridges to the lay public etc etc. Perhaps even friendship. Say what you are doing, and why.

If your PPI costs are paid by your institution so no budget is necessary, state this in your application so we don't come to the wrong conclusion and think you are being mean.

Is publication a jealously guarded goal only for researchers? Why not spread the word about good practice and thank your study participants in all your publications? Credit your PPI team with their efforts on your behalf. Include them in the list of authors if they have contributed in any way to your paper. Remember - no patients, no profits, no research. And no academic reputation either.

Remember that being a co-applicant gives kudos to lay people as well as fellow academics.

Researchers should also mention whether they have accessed INVOLVE and RDS for advice re PPI, and whether *they* are getting training in PPI. This gives us lay public confidence in you.

Getting to grips with GRIPP2

This is GRIPP2 reporting. There are two forms. This is the short form for any research in which PPI is not the topic.

Table 2 GRIPP2 short form

Section and topic	Item	Reported on page No
1: Aim	Report the aim of PPI in the study	
2: Methods	Provide a clear description of the methods used for PPI in the study	
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	
4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	
5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	

PPI=patient and public involvement

PPI Resources

INVOLVE invo.org.uk

Local RDS
Local academic institution
Local hospital trust.

And finally...

We want our researchers to succeed. If your work is published, that is success for us as well as you. If you win your doctorate, your funding, your professorship, then that is a success for us too. Please give us feedback. Tell us what helped you, and what did not. Tell us when your work is published and when you win your degrees and honours. Make science our joint effort.

Good luck.