



On being a public panel member

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PRP core panel member.

So...

Who Am I and why did I choose to be a panel member and why did they choose me?

- Carer all my life of family members with numerous conditions. So experience of the coal face realities of life.
- Aspergers syndrome makes me hard working and passionate about doing what is right. I am also hard of hearing and diabetic so service user myself.
- Not afraid to speak out and tell it how it is. Known for the quote “The plain English Summary is Crap” A real good critical friend.
- Experience of PPI involvement for too many years to remember now. It just comes naturally to me.

And...

- I tried to leave but was told I was Invaluable. In reality I came back after my husband past away.
- Know about a lot of the good practice guidance as during my time on the INVOLVE advisory group I helped write some of it. The co applicants guidance grew out of my own frustration with being included on an application to box tick. I hadn't even been given the chance to read the application.
- What I am not – An academic dropped out at Masters Arts level. A scientist a statistician or a clinician or government official I am an independent voice.



” A critical friend can be defined as: “a person who asks the obvious or sometimes difficult questions” that nobody else has asked. Many researchers have never been a patient, carer or cared for by somebody else, and so they may miss things from their research plans that seem obvious to you. As an independent member of the public, you have the freedom to ask the awkward question (sometimes known as ‘pointing out the elephant in the room’) in a friendly and supportive way”.

Some things I look for in an application.

- Clear roles.
- Diversity
- Reflects the National Institute Health Research (NIHR) Patient Public Involvement (PPI) standards
- Worthwhile question with sensible measures
- Patient benefit
- Plain English summary is plain English and easy to understand.

Some things I look for in an application.

- Burden on participants
- Evidenced involvement so far.
- Learning and development opportunities to allow real involvement.
- Budget – if it is not in the budget it won't happen. Too low budget.
- A gut feeling? Sometimes it just doesn't seem right.
- **Clarity** - well defined **roles** are healthier for all.



- Have you got a lead in your team responsible for PPI?
- Have roles been negotiated with PPI representatives.
- If you have a public co-applicant please be clear about how much involvement they will have.

See HRA (health research authority), RDF (research design forum) and Involve co produced guidance - *I think I am co author on that one.*

Public reviewers will be looking for this sort of information to see the PPI plan is well thought out.

Diversity

- Have you gone to the usual suspects for your PPI?
- This is often evidenced by a *Crap* plain English summary. You need those who are not research savvy to review it. Make it clear campaign helps with this. Reading age should not exceed 8 year old for most patient information. Not just words used but also is it easy to understand. WHO? WHAT? WHY? WHERE?
- I firmly believe that PPI should reflect our diverse population and all should be done that is possible to be inclusive.
- Often those with PPI experience can mentor others

Diversity

- Thinking outside the box in terms of support and sorts of inclusive activities that would lead to greater diversity. Not everyone can or wants to sit on a steering committee or advisory group with professionals.
- I always question diversity when there are only a couple of previously involved PPI people are included or where charity representatives are used to reflect others views.
- To include the real diverse public will mean that the research reflects the needs of those who will benefit from it.

The PPI Standards

INCLUSIVE OPPORTUNITIES

Offer public involvement opportunities that
are accessible and that reach people and
groups according to research needs

COMMUNICATIONS

Use plain language for well timed and
relevant communications, as part of
involvement plans and activities

SUPPORT AND LEARNING

Offer and promote support and learning
opportunities that build confidence and
skills for public involvement in research

The PPI Standards

WORKING TOGETHER

Work together in a way that values all

contributions, and that builds and sustains

mutually respectful and productive

relationships

GOVERNANCE

Involve the public in research management,

regulation, leadership and decision making

IMPACT

Seek improvement, by identifying and sharing

the difference that public involvement makes to

research

Worthwhile question with sensible measures

- Is the question important to service users and carers and will how they are measuring it work and get worthwhile answers?
- Sometimes this seems obvious and so I raise it. I am not a scientist but sometimes I can be a critical friend here just to open the debate with those who may know more.

Patient benefit

This one still confuses me a bit as it is for the benefit of Policy decisions but ultimately those policies affect the public.

So again I will raise it for further discussion if I cannot really see any worthwhile results with this particular application. The scientists, clinicians, academics, and representatives from the government in the room can explain it to me.

Burden on participants

Often as a patient rep I can see where recruitment will be low because the research places too much burden on the participants or does not reflect the needs and support required of the study participants.

Evidenced involvement so far.

Word count depending, it would be good to see concise active language description of previous involvement in study not just we consulted with 2 people? Use the words well to show us what decisions have been influenced by your PPI.

Learning and development!

- You may need to provide training to help your PPI representatives e.g. basic meeting skills or statistics or interview techniques or anything else they may require to perform their roles well. Need to know what training is being given and who is providing that training.
- Learning for involvement link in resources could help with this.
- An easy induction document and audio version can be found <https://www.invo.org.uk/posttypepublication/starting-out/>
- It is also good practice to acknowledge skills gained whilst doing PPI roles. So aiding personal development.

PPI Budget

- **Involve cost calculator** – In full applications I would like to see fully broken down expenditure. See links. This has ideas of what should be costed in. Part of team that created it.
- In short applications I can usually tell if the budget seems low or just made up in a quick application. It costs quite a lot to do PPI well and provide support and necessary conditions to allow a diverse selection of people to feel like part of the research team.

So what is it like being a PRP panel member?

- Valued member of the team
- Well supported and encouraged to speak out.
- Over worked at times a lot of reading and often complicated concise critical appraisal needed. Following everyone's viewpoint and learning through the meeting to change/adapt my ideas. Have to be understanding and flexible.
- It fires me up knowing I can make a difference to getting only good quality research funded.
- As someone with Aspergers it may take me several days to recover.
- I must enjoy it or I wouldn't come back for more.

Useful links

- <https://drive.google.com/file/d/1nMJiQVBf0g-Yrx2s0f5szCZ9bffnXBeV/view>
- <http://www.donorhealth-btru.nihr.ac.uk/wp-content/uploads/2019/02/NIHR-Guidance-on-Public-Co-applicants-2019.pdf>
- <https://www.invo.org.uk/mahttps://www.invo.org.uk/resource-centre/learning-and-development/public-reviewing-with-the-national-institute-for-health-research-nihr/keitclear/>
- <https://learningforinvolvement.org.uk/>
- <https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/>

Note:

some of the INVOLVE links may not be fully updated so check latest rulings or seek advice from the **new department**

<https://www.nihr.ac.uk/news/a-new-nihr-centre-for-patient-and-public-involvement-engagement-and-participation-and-research-dissemination-arrangements-from-april-2020/20251>