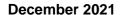




How to write the Patient Public Involvement (PPI) part of your research bid



A longer version of this document is available here



Introduction

Research funding bids are sometimes written in great haste in response to precise calls and tight deadlines. Bid writers often have considerable experience of the research topic and can draw on their previous applications. They may be less familiar with best practice relating to Patient and Public Involvement (PPI). This Guide blends the best words that were found in a selection of successful bids to create a long list from which the reader can choose a manageable subset.

General principles

- 1. **Co-author the application.** Write the application with Public Contributors, not for them.
- 2. Avoid tokenism. If you are new to patient and public involvement in research, or there are few local examples of good practice, take the time to learn what is entailed in doing it well.
- 3. Answer the question. The PPI section of the application form asks how Public Contributors will co-design and co-deliver the research, not how you will recruit research participants.
- 4. **Seek advice.** Ask a staff lead for PPI to put you in contact with Public Contributors and reach out to people from diverse groups who are often seldom heard and underserved.
- **5. Be specific.** In reporting what you have done already, name the PPI Group, how often they meet and be precise about how many people attend.
- **6. Aim for diversity.** Say how you have taken your conversation out to seldom heard groups.
- 7. Show impact. Explain how Public Contributors have already shaped the proposal.
- **8. Refer to the evidence.** Other sections in the funding application routinely quote available literature, but this is remarkably rare in the PPI section¹.
- **9. Embed PPI throughout.** As well as writing a robust PPI section, ensure it appears throughout the application to avoid any impression that it is merely an add-on.
- **10. Expect change.** Building effective working relationships with Public Contributors can have a lasting impact on the way that academic researchers view and conduct their work², so getting together to construct a funding application can be the start of a transformative journey.

What follows is a taster of quotations from successful applications to stimulate the reader's thinking and writing. The <u>companion paper</u> to this summary contains more examples of statements made under each of the following headings.



Taster quotations

Values, theoretical approach, and evidence base. "We will a use a model of PPI that emphasises the key dimensions of good quality PPI as demonstrated in research³, i.e., engagement with user concerns, strength of the PPI voice, responding to that voice and appropriate and flexible modes of engagement throughout different elements of the research process. There is evidence to show that involving service users improves services and empowers patients⁴."

Choice of research topic. "This trial has been developed in response to a James Lind Alliance Priority Setting Partnership that identified this as an important topic for further research for patients and clinicians. We note that local initiatives are more likely to generate shared ownership than a top-down framework for involvement⁵."

Preparing the application. PPI feedback led to the following changes to the application:

Topic	Feedback from Public Contributors
Our proposed work and who should be invited to join the research team	Additional members representing the voluntary sector to be invited to join the Advisory Group
The experience of service use from the PPI perspective	We increased the number of qualitative interviews
The relevance of our proposed outcomes ⁶	We asked more questions about the acceptability of the proposed treatment
Acceptability of the research methods, including development of Standard Operating Procedures ⁷ .	We shortened the interviews
The role of PPI input in developing and guiding the research programme.	We strengthened the links between the Patient Advisory Group and the Project Steering Group
This application form (including the plain English summary ⁸), reviewers' comments and the suggested revisions.	The plain English summary and five other sections of this application form were made much clearer
Application for Research Ethics Committee approval, including attendance and presentations.	The Public Co-applicant will join the team presenting the proposal to the Ethics Committee

Public Co-applicant. "In line with local <u>guidance</u> on co-applicants, Ms XXX has agreed to be the PPI lead representative. She has experience as an NIHR lay reviewer, has served for many years on a Research Ethics Committee and has lived experience relevant to the research topic."



Project Advisory Group. "A PPI Project Advisory Group comprising six Public Contributors will be formed under the guidance of the PPI lead and will meet quarterly. Membership will be diverse, recruited through a process of open advert and include both experienced and new voices. Members of the Advisory Group will be invited to participate in staff recruitment panels, contribute to workstream meetings, participate in the literature reviews⁹, collect, and analyse data, collaborate in analysis, and present findings.

Focus Groups. "In addition to the ongoing involvement of the PPI Advisory Group, we will arrange several focus groups at key decision points in the research and utilise a variety of engagement approaches in order to obtain the richest possible range of views."

Coordination of PPI activity. "Mr XXX has coordinated the PPI aspect of various studies, including work in relation to this health condition. He will also help researchers identify appropriate issues where a PPI perspective will add value and seek advice at the right time. He will monitor and evaluate the experiences and reflections of Public Contributors. Our organisation has established processes in place to enable us to manage marketing and recruitment to the Advisory Group, manage confidentiality and safeguarding issues, and to administer payments."

Training. "We will arrange training to cover various aspects of the study including our intervention, study design and study implementation as well as supporting Public Contributors to attend relevant conferences. Other training needs will be addressed on an individual basis."

Links with clinical teams. "Where Public Contributors are currently in receipt of health or social care services and give consent, the PPI coordinator will liaise with clinical teams when necessary to ensure that people are well supported, and confidentiality is appropriately maintained."

Overall Governance. "The Research Management Group will be chaired by the Principal Investigator and include co-applicants and two members of the PPI Project Advisory Group. The agenda will be managed to ensure that Public Contributors can play an active role. We would like the funding body to appoint a Public Contributor to the Independent Steering Committee."

Information for patients. "Our experience has shown the value of early PPI input into the design of patient-facing materials to ensure they employ user-friendly language which is clear and easy to understand and address issues of relevance to our patients. This will help to ensure that patients are not put off from taking part in the research."

Burden. "We will seek input on study procedures to ensure that burdens placed on participants are justifiable and well explained, also to identify potential recruitment barriers."

Reporting and dissemination. "We will collaborate with Public Contributors when writing the funders' report, subsequent publications and our strategy for dissemination to the wider public. Public Contributors will speak at national and international conferences and coauthor peer reviewed papers. Both positive and negative findings from the study will be shared with community groups. A project website with dedicated public and professional domains will be developed to disseminate information, using a range of methods such as podcasts and blogs. We will also utilise social media to promote public engagement."



Budget. "Total PPI costs, including the staff cost for the PPI lead, comprise x% of the total budget. Public Contributors will be informed of the rates being offered prior to taking on a particular task. Payment levels will align with the funder's published recommendations and local policies."

Conclusion

Public Contributors have the potential to add value to many aspects of research into health and social care, so their contribution needs to be built into many parts of a research funding proposal. This guide has suggested a range of ways in which this might be done. It is, of course, only the start since most of the real work of co-production begins once funding has been approved.

References

- ¹ A brief scan of 37 protocols found few referenced the PPI literature The 37 Test Peter Bates.
- ² See Manafo, E., Petermann, L., Mason-Lai, P. *et al.* (2018) Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research. *Health Res Policy Sys* **16,** 5.
- ³ Biddle MS, Gibson A, Evans D. Attitudes and approaches to patient and public involvement across Europe: a systematic review. *Health & social care in the community*. 2021 Jan;29(1):18-27.
- ⁴ Modigh A, Sampaio F, Moberg L, Fredriksson M (2021) The impact of patient and public involvement in health research versus healthcare: a scoping review of reviews. *Health Policy*. Sep 1;125(9):1208-21.
- ⁵ Veronesi, G (2015) Patient and Public Participation in the English NHS: an assessment of experimental implementation processes *Public Management Review*, **17**(3): p. 543-564.
- ⁶ McCarron TL, Clement F, Rasiah J, Moran C, Moffat K, Gonzalez A, Wasylak T, Santana M. Patients as partners in health research: A scoping review. *Health Expectations*. 2021 Aug;24(4):1378-90.
- ⁷ Evans, B.A., Bedson, E., Bell, P. et al. Involving service users in trials: developing a standard operating procedure. *Trials* 14, 219 (2013). https://doi.org/10.1186/1745-6215-14-219
- ⁸ Stoll M, Kerwer M, Lieb K, Chasiotis A. Plain Language Summaries: A Systematic Review of Theory, Guidelines, and Empirical Research. Download from https://cutt.ly/NU4D4U1.
- ⁹ Pollock A, Campbell P, Struthers C, Synnot A, Nunn J, Hill S, Goodare H, Morris J, Watts C, Morley R. (2018) Stakeholder involvement in systematic reviews: a scoping review. *Systematic reviews*. Dec;7(1):1-26.

