How to guide

How to write the PPI part of your research bid

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Introduction

Research funding bids are sometimes written in great haste in response to precise calls and tight deadlines. Principal Investigators, who lead the bid writing process, often have considerable experience of the research topic and can draw on previous applications that they have made. However, they sometimes are less familiar with the literature and best practice relating to public involvement.

This 'How To' paper compiles the best words that have been used in some successful bids to create a pick list that you can draw upon as you write.

Almost everything here is drawn from publicly available submissions, and the text below attempts to blend the ideas and phrases into a coherent whole. It would be impractical to individually reference the source of each phrase, bullet point or word, so we fully acknowledge here our debt to the authors of the bids listed in footnote 2 and elsewhere in this document and ask you to avoid plagiarism as you use this resource.

This document contains all the ideas we have found, so if you just cut and paste it, you will have made a very large promise!

It was drafted by Peter Bates on behalf of the [East Midlands Academic Health Science Network](#) as part of its work on Public Leadership. Additional material has been provided via email[1] and from relevant literature[2].

As readers provide feedback, further insights will be used to update the paper. Please contact shahnaz.aziz@nottingham.ac.uk to suggest improvements or tell us how you have made use of this paper.

A note on language and the reach of this paper

In this paper, the term *public* means patients, service users, carers and members of the general public.

General principles

1. **Avoid tokenism.** If you are new to patient and public involvement in research, or there are few local examples of good practice, please take the time to learn what is entailed in doing this well.

2. **Answer the question.** The most common mistake occurs when the form asks how public contributors will be engaged as project advisors and the answer explains how research participants will be recruited.

3. **Seek advice.** Ask your local lay assessors[3], or patient advisory group[4]. Alternatively, ask a staff colleague with responsibility for promoting public

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[1] With thanks to Neil Chadborn for his comments on an earlier draft.

[2] An archive of research protocols can be found at http://www.nets.nihr.ac.uk/projects?collection=netscc&meta_P_sand=Project. Protocols from this archive that are referenced in this document appear as hyperlinked footnotes. The following protocols were also checked but did not have a PPI section. 0916024, 130325, 131301, 131805, 131906, 134355, and 1415104. The following studies do not have a protocol on their webpage: 1111707, 121019, 1215004, 1217314, 1217817, 1220630, 1220652, 1311613,

[3] Some local research organisations have recruited and trained public contributors to provide pre-submission assessment of draft funding applications. The funding bodies will send the applications that they receive to their own lay assessors for comment for deciding on whether to make a funding award. The East Midlands AHSN has funded a training programme for lay assessors (contact adele.horobin@nottingham.ac.uk).

[4] Each GP practice, Clinical Commissioning Group and NHS Trust should have a patient participation group and there are a number of other groups too. You can find some of these groups listed at http://www.emahsn.org.uk/public-involvement/east-midlands-public-involvement-map/

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involvement[5] or the NIHR Research Design Service may be aware of possible groups. Reach out beyond the 'usual suspects' whenever possible.

4. **Be specific.** In reporting what you have done already, name particular groups[6], indicate how often they met and be precise about how many people attend.

5. **Aim for diversity.** Some researchers find it difficult to engage with seldom heard groups[7], so underscore your efforts on this. Show how you have taken your conversation to them.

6. **Show impact.** Explain how consultation with public contributors has already had an impact on the shape of the proposal.

7. **Refer to the evidence.** The other sections of a funding application routinely quote the available literature[8], but this is remarkably rare in the PPI section[9].

8. **Embed PPI throughout.** As well as writing a robust section on Patient and Public Involvement, ensure it appears in other places in your application to avoid any impression that it forms an add-on rather than an embedded practice. Walk the talk!

9. **Expect change.** Building effective working relationships with public contributors can have a lasting impact on the way that academic researchers view and conduct their work[10], so getting together to construct a funding application can be the start of a transformative journey.

What follows is a series of adapted and merged quotations from successful applications for you to use as a springboard for your own thinking and writing.

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[5] Many of the staff in the English East Midlands who lead on public involvement are listed at http://www.emahsn.org.uk/public-involvement/east-midlands-public-involvement-map/

[6] See protocol 135908

[7] See http://www.shapingourlives.org.uk/documents/BTUSReport.pdf See, for example, this paper on engaging people with communication impairments in research - http://rcnpublishing.com/doi/abs/10.7748/nr2013.01.20.3.12.c9491

[8] See for example, Brett et al Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect.* 2014 Oct;17(5):637-50. Abstract http://www.ncbi.nlm.nih.gov/pubmed/22809132

[9] A brief scan of 37 protocols found only two that had made any reference to the PPI literature.

[10] See http://www.invo.org.uk/resource-centre/examples/exploring-public-involvement-in-nihr-research-funding-applications/

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Values, theoretical approach and evidence base

We are involving patient and public representatives in developing this proposal and undertaking the research with the aim of ensuring that study procedures are acceptable to participants, that outputs are comprehensible to patients and the public, and that patient and public perspectives are central to informing our understanding of the benefits, risks and costs of healthcare interventions[11].

To make PPI effective necessitates a whole organisation perspective and supportive infrastructure[12], with serious commitment from the programme, all workstream leads and appointed research staff[13]. Our principal investigator was the co-founder of a local patient support group that now has 5,000 members worldwide.

Such an approach requires power sharing between academic researchers and public contributors, and so we have learnt from studies of user-controlled research[14].

We will a use a model of PPI that emphasises the key dimensions of good quality PPI as demonstrated in research[15], 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[16]. There is evidence to show that involving service users improves services and empowers patients[17].

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[11] See protocol 132101

[12] See protocol 1220109

[13] See protocol 12500302

[14] See http://sscr.nihr.ac.uk/PDF/ScopingReviews/SSCR-Scoping-Review_5_web.pdf

[15] Staley K. (2009) *Exploring Impact: Public involvement in NHS, public health and social care research.* INVOLVE, Eastleigh. Available at http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf. See also http://www.rds.nihr.ac.uk/wp-content/uploads/RDS-PPI-Handbook-2014-v8-FINAL.pdf.

[16] See protocol 135908. Gibson A, Britten N, Lynch J. Theoretical directions for an emancipatory concept of patient and public involvement. *Health* (London, England: 1997) 2012; 16(5):531-47. See also Evans, B.A., Bedson, E., Bell, P., et al. (2013). Involving service users in trials: developing a standard operating procedure. *Trials*, 14, 219. Also Evans D, Coad J, Cottrell K, Dalrymple J, Davies R, Donald C, et al.Public involvement in research: assessing impact through a realist evaluation. *Health Serv Deliv Res* 2014;2(36).

[17] Service user involvement: impact and participation: a survey of service user and staff perspectives, Omeni, E., et al., *BMC health services research*, 2014. **14**: p. 491. See http://www.biomedcentral.com/1472-6963/14/491.

The choice of research topic

This trial[18] 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.

Furthermore, a recent on-line survey of patients in our locality demonstrated the relevance and importance of this approach and highlighted the most important outcomes to be measured in future studies. We note that local initiatives are more likely to generate shared ownership than a top-down framework for involvement[19].

Preparing the application

PPI feedback was invited in the December bulletin of *Public Face[20]* - a publication by EMAHSN that promotes PPI involvement in health research and is circulated to interested members of the public.

This proposal has benefitted from feedback received at a local PPI Group meeting - attended by a researcher, 4 local PPI leads and 11 patients, carers or members of the public.

Part of the pre-submission PPI work has been supported by the RDS East Midlands Patient and Public Involvement in Research Development Award. The award was used to reimburse the lay reviewers for their time in reviewing an earlier draft of this application. As a result, we were able to offer participation payments to the four lay reviewers who advised on an earlier draft of this submission.

The reviewers had a wide range of experience and made specific suggestions[21] regarding:

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[18] See protocol [122402](#)

[19] Patient and Public Participation in the English NHS: an assessment of experimental implementation processes, Veronesi, G., *Public Management Review*, 2015. **17**(3): p. 543-564. See http://econpapers.repec.org/article/tafpubmgr/v_3a17_3ay_3a2015_3ai_3a4_3ap_3a543-564.htm

[20] http://emahsn.org.uk/public-involvement/public-face-newsletter/

[21] See protocols [130433](#) and [132601](#).

Topic	Feedback from public contributors
Our proposed programmes of work including 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 were persuaded to increase the number of qualitative interviews
The relevance of our proposed outcomes[22]	We asked more questions about the acceptability of the proposed treatment
Acceptability of the research methods, including development of Standard Operating Procedures[23].	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[24]), 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

Co-applicant

In line with local [guidance](#) on co-applicants, Ms XXX has agreed to be the PPI lead representative[25]. She has experience as an NIHR lay reviewer, has

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[22] See Juan Pablo Domecq et al (2014) Patient engagement in research: a systematic review *BMC Health Services Research* 2014, 14:89. Available at http://www.biomedcentral.com/1472-6963/14/89

[23] See http://www.trialsjournal.com/content/14/1/219

[24] Advice from 2013 at http://www.invo.org.uk/wp-content/uploads/2013/03/Improving-quality-of-plain-English-summaries-report-final.pdf and from 2017 at https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-017-0066-y

[25] See protocol 133414

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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[26] comprising six public contributors will be formed under the guidance of the PPI lead and will meet quarterly throughout the duration of the programme, starting in month two of the first year. The Project Advisory Group will be chaired in line with best practice[27].

Membership will be diverse, representing carers, patients, industry, voluntary sector, seldom heard groups and independent members. Members will have identified roles in a range of NHS and community organisations. There will be clearly identified links from the PPI Project Advisory Group to wider networks of patients.

Members will be recruited through a process of open advert on *Public Face* bulletin, the [People in Research](#) website, the RDS and other bulletins, and relevant clinical services. We are in touch with a number of public contributors who have actively supported previous research projects and this experience will be balanced with new voices. In addition, we have commitments from named voluntary sector organisations and managers of local services to assist us with identifying potential public contributors to join the group. The general approach will be driven by insights from community development research[28].

This Group will act as a 'critical friend' to the academic research team.

Members of the PPI Project Advisory Group and other public representatives may be invited to:

- participate in interview panels to select research assistants in line with local [guidance](#)
- contribute to workstream meetings
- participate in the literature review[29]

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[26] See protocols [130117](#), [130422](#) and [130430](#)

[27] See https://sites.google.com/a/nihr.ac.uk/crn-chairing-skills/

[28] See http://www.journalslibrary.nihr.ac.uk/__data/assets/pdf_file/0006/94281/FullReport-phr01040.pdf

[29] See http://www.futuremedicine.com/doi/abs/10.2217/cer.12.46

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- Advise on project publicity, research briefs and reports to ensure that jargon is avoided and the research process and consent is clear for potential participants[30]

- Shape the intervention based on their suggestions and experience

- Help with the design of our scoping study

- advise on how we sample and recruit research participants

- contribute to the design of survey items, interview schedules and search terms

- Comment on the development of our evidence synthesis by helping to identify emerging themes and interpret findings[31].

- Help with the development of models and implementation toolkits

- Assist with the dissemination of outcomes to both academic and community audiences, including the production of non-academic reports to reach diverse communities, based on evidence that there is public demand for this kind of information[32].

- Provide verbal and or written feedback on their experiences of being involved in the project

- Attend peer support meetings and conferences.

During the study, regular e-mail correspondence will occur with public contributors.

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[33] in order to obtain the richest possible range of views.

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[30] See http://www.hra.nhs.uk/resources/before-you-apply/consent-and-participation/consent-and-participant-information/. See also protocol 1311701

[31] See http://www.ncbi.nlm.nih.gov/pubmed/22958162

[32] See http://ec.europa.eu/public_opinion/archives/ebs/ebs_401_en.pdf

[33] http://www.emahsn.org.uk/images/Section%208%20-%20Resource%20hub/Useful_Documents_and_Links/PPI_Guide_to_engagement_techniques_-_Leicester_City_NHS.pdf

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Coordination of PPI activity

Named person. The PPI element of this project will be supported by a named person who has suitable expertise and experience. She is an experienced PPI support manager who has coordinated the PPI aspect of various studies, including work in relation to this health condition.

Track record. We have successfully established PPI reference groups for two NIHR funded projects that break new ground in public involvement. This proposal will benefit from this experience.

Support for academics. He will also help researchers identify appropriate issues where a PPI perspective will add value and seek advice at the right time.

Impact on public contributors. We will monitor and evaluate the experiences and reflections of public contributors.

Administration. Our organisation has established processes in place to enable us to manage marketing and recruitment to the PPI Project Advisory Group, to manage confidentiality[34] and safeguarding issues and to administer payments.

Ongoing support for public contributors

Training. This will include:

- A day of training will be provided to cover various aspects of the study including our intervention, study design and study implementation.
- We will support public contributors to attend relevant conferences (e.g. INVOLVE conference).
- Other training needs will be addressed on an individual basis.
- We will hold a generic workshop about PPI that researchers and public contributors will attend together, as we anticipate that this will contribute to enhanced research skills and increased capacity through enabling further community engagement in research, and PPI in the implementation of service innovations.

Links with clinical teams. Where members of the PPI Reference Group or others who are consulted by the project are currently in receipt of health or

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[34] See http://www.nihr.ac.uk/CCF/Confidentiality-guidance.pdf

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social care services, the PPI coordinator will liaise with clinical teams when necessary to ensure that people are well supported and confidentiality is appropriately maintained. This may be particularly appropriate where people have fluctuating long term conditions.

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[35], in line with recognised good practice[36]. This group will meet quarterly starting in month 2 of the first year and include a PPI report as a standing item with time ring-fenced to ensure that public contributors can play an active role.

Including Public Contributors on the Research Management Group will provide another important safeguard for the study as a whole.

We would like the funding body to appoint a Public Contributor to the Independent Steering Committee.

We will ensure the inclusion of PPI within the main duties and responsibilities of a dedicated individual in every workstream of the study.

Specific activities

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.

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[35] See protocols 113102, 119201 and 1217045

[36] Steel, R. (2003). *Brief Summary and Checklist for Researchers, Research Commissioners and Research Groups for Involving Vulnerable and Marginalised People.* Eastleigh: INVOLVE.

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We will collaborate with public contributors when writing the funders' report, subsequent publications and developing a strategy for dissemination to users[37]. We will take note of [guidance](#) on engaging public contributors as co-authors.

Our PPI team hold regular support sessions and have helped patients to speak at national and international conferences and co-author peer reviewed papers.

Both positive and negative findings from the study will be shared with community groups[38] and presented at a PPI event in the final year of the programme and at relevant national conferences.

Our contacts in patient-led charities will be asked for guidance on how best to disseminate the research to the wider patient community.

The PPI aspect of the study will be monitored in line with best practice[39], and a final report on PPI experiences and impact will be produced in line with internationally agreed reporting guidelines[40].

A project website with dedicated public and professional domains will be developed to disseminate information[41], using a range of methods such as podcasts and blogs. We will also utilise social media (e.g. Twitter, Facebook, Flicker, YouTube) to promote public engagement and update the most frequently used online sources of information, such as Wikipedia and Map of Medicine.

Budget

We will use local best practice guidance[42] to ensure that all relevant aspects of PPI are included in the overall budget.

The total PPI costs, including the staff cost for the PPI lead, comprise 5% of the total project costs.

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[37] See protocols [12167102](#), [130749](#)

[38] See protocol [1216726](#)

[39] See http://www.piiaf.org.uk/

[40] Staniszewska S, Brett J, Mockford C & Barber R (2011) The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research *International Journal of Technology Assessment in Health Care*, 27:4 (2011), 391–399.

[41] See protocol [131040](#)

[42] See *How to estimate the costs of public involvement in research* at http://emahsn.org.uk/public-involvement/how-to-guidance/

Public contributors will be informed of the rates being offered for the particular type of involvement work they would like to undertake before they agree to undertake it. Payment levels[43] will align with the funder's published recommendations[44] and local policies.

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[43] See protocol 130739

[44] See http://www.invo.org.uk/resource-centre/library-resource/?id=342&section=involve

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