



Patient and public involvement in research on the Cambridge Biomedical Campus



Key information to help you build
PPI into your research

The contents of this Researcher Support Pack have been put together by the Patient and Public Involvement (PPI) Team at the NIHR Cambridge Biomedical Research Centre (BRC), with input from the Cambridge University Hospitals (CUH) PPI Panel and will therefore have the most relevance to researchers associated with the NIHR Cambridge BRC, although general information and advice may be of wider interest.

The specific services described in this pack, including the advice and support of the NIHR Cambridge BRC PPI Team, are available free of charge for publicly funded researchers based in Cambridge and the surrounding areas. For researchers further afield, we will try and connect you with support in your local area.

If you wish to share any information from this pack, please acknowledge the NIHR Cambridge BRC PPI Team and inform us by emailing cuh.ppi@nhs.net.

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Foreword

Hopefully, since you're picking up this support pack toolkit, it means you have decided to involve patients and the public in your project and we're happy to help you as much as we can. The NIHR Cambridge BRC PPI team support researchers that are sponsored by CUH or the University of Cambridge and conducting research that is publicly funded (or applying for public funding), free of charge. Workload permitting, we are happy to support commercial or for-profit organisations on a cost recovery basis. Please ask for a meeting with the PPI team if you are working on commercially funded research.

The NIHR Cambridge BRC Patient and Public Involvement (PPI) team have put together this series of fact sheets, with the help of some of our lay panel members, to provide you with some local guidance and to help get you started.

'Involvement' is a term that is often confused or conflated with other ways that the public are invited to interact with our research, such as 'engagement' or 'participation'. Although it is important not to get too caught up in semantics, these are equally important, but distinct ways of including the public in our research. What sets involvement apart from these activities is that involvement is really about listening. Listening to what patients and the public want from our research and making appropriate changes and accommodations where we can. Asking patients and the public about their needs and priorities helps to make research more relevant, more accessible and more likely to succeed in the real world.

We recognise that it can be a bit daunting to open up your research to an 'outsider' view and that good PPI is a significant investment of time and resources – but I have yet to meet a researcher who was not pleasantly surprised and impressed by the insight of their public contributors and the useful suggestions they made.

Please get in touch by emailing cuh.ppi@nhs.net if you would like to speak with us about your PPI needs or if you have comments about this Support Pack.

Dr Amanda Stranks

Patient and Public Involvement and Engagement Lead, NIHR Cambridge BRC

The Cambridge University Hospitals (CUH) Patient and Public Involvement (PPI) Panel

Identifying, recruiting, and retaining patient and public contributors can be a challenging first step in good PPI. We are here to help – we can help you identify relevant stakeholders, suggest ways to recruit members of the communities that you identify, share involvement opportunities via our communications channels and review your proposed recruitment materials.

However, one of the most practical resources we can offer is the assistance of members of the public who have already expressed an interest in getting involved in research – the CUH PPI Panel.

About the CUH PPI Panel

The 'panel' currently consists of around 60 members of the public, with and without health conditions, who are interested in getting involved in research projects. They cover a range of ages, ethnicities, occupations, experiences with illness and the NHS, and research experience. Some of them have been on the panel for over 5 years (and therefore have considerable experience in PPI) and others are new joiners (and therefore have excellent insight into what research looks like to those who have rarely or never encountered it before).

Many panel members also come from backgrounds such as law, marketing, education, or business that can add insightful value to your research; others have first- or second-hand experiences of health conditions or caring responsibilities. All are members of the public and can also give a 'public interest and understanding' viewpoint to your work. The panel is open to anyone who is not currently employed in research or the media. Members only respond to projects that they find interesting and there is no obligation to respond to any project.

Involving the panel is free of charge for researchers affiliated with the Cambridge BRC (e.g., through CUH, the University of Cambridge or another research institute) who are applying for, or in receipt of, public (e.g., from the Department of Health or NIHR) or charity funds to conduct their research project.

If you hold an academic or clinical position but also work for, are personally funded by, or have project funding from a private company, please speak with the PPI Team to determine the best way to proceed.

Document reviews

Members of the panel are happy to review your research related documents (e.g., funding proposals, lay summaries, PPI plans, consent forms, patient information leaflets, public engagement plans, recruitment strategies etc). This is done via email.

What happens?

After consultation, researchers must complete the “Document Review Request” [form](#) and send a maximum of three documents to the PPI Coordinator for review. The panel is then sent an invitation to get involved with some details on the project along with the documents. Interested panel members have 14 calendar days to respond with their comments. One working day later, these are compiled into an anonymous report and returned to you.

How do I get the most out of this experience?

Completing the form with as much information as possible helps provide the panel with context on your (proposed) research. You may also wish to share information with us on the following:

- A brief outline of your own background and career stage
- Why and how you came to be working on this project
- A brief ‘sales pitch’ about why your work is important

It is also useful to **think about what you would like to get from the experience**, and whether you have questions you would like the panel to answer. If you do, there is space at the end of the form to clarify this. It also helps to be clear in the form about anything that cannot be changed in the documents.

Feedback

As you will see at the start of the Document Review Request form, working with the CUH PPI Panel comes with an expectation that you will provide feedback on their comments and share updated versions of the documents changed as a result of their suggestions. We may refuse to send further documents to the panel on your behalf if you have not sent feedback for an earlier project. You are also expected to share important updates about your project (e.g., whether you obtain funding, when the project starts, whether there have been any publications etc.).

Discussion groups

Discussion groups are ideal if you would like real-time discussion of your ideas or project, if you would like to get some consensus views, if you have a project that is difficult to describe on paper or when 'retrospective PPI' is required (e.g., for a project already funded and underway that has met with public difficulties).

Discussion groups can also be particularly useful to follow up on issues raised during document review.

What happens?

After consultation, researchers complete the 'Discussion Group Preparation Form' and return it to the PPI Coordinator. Researchers then liaise with the PPI Team to arrange a suitable time and date. Discussion groups are conducted through the PPI team Zoom account. Once the details have been agreed, the PPI Coordinator will send an invitation out to the panel on behalf of the researcher, with a brief introduction/outline of the proposed research to be discussed. Attendees then participate in group discussion of the research idea/proposal/project, usually for around 90 minutes.

How do I get the most out of this experience?

There is no fixed format, but we suggest that researchers give a short presentation about their background and research question. Possible points for inclusion could be:

- A brief outline of your own background and career stage.
- A little bit about your funding or the funding programme you are applying for.
- Why and how you came to be working on this project.
- A brief 'sales pitch' about *why* your work is important.
- An outline of the topics that you would like to discuss in the discussion group.

Slides are welcomed for the presentation and can be useful to act as prompts for some discussion points later in the meeting. It is best practice to share your slides with the PPI Team ahead of time so that they can be reviewed from an accessibility perspective. It also helps to be clear about what can and cannot be changed in the

project. The PPI Team can help to facilitate focus groups and can take notes on topics covered.

Ongoing involvement

If you have an opportunity for ongoing involvement as part of your research project (e.g., on a trial steering committee or patient advisory group), we can share this with our group and more broadly amongst the PPI community as part of our 'Weekly Roundup' email. The weekly roundup contains a list of opportunities for researchers, patients, and members of the public living in and around Cambridge including PPI training events, involvement opportunities and participation opportunities. Please complete the form here <https://forms.office.com/e/3Xqn2jVvmg>.

What happens?

CUH PPI Panel members interested in learning more about further involvement opportunities are given a first look at the list, which is circulated on Thursday afternoons. For other interested parties, this information can be accessed on our [PPI Opportunities web page](#), which is updated each Friday.

If you have an opportunity that you would like us to share in our weekly roundup, please complete with full details, included who should be contacted by interested people. The CUH PPI Team will not act as a point of contact for ongoing involvement activities. Items must be shared before Wednesday noon to be published on Friday.

How do I get the most out of this experience?

Have a clear outline of what you would like public involvement in your project to achieve, and what information and feedback about your project you would be willing to act upon. Once you have found interested people, ask your contributors what their expectations of involvement are, what training they need and how they would like to be supported. Outline your own expectations and reach a shared understanding of the relationship. Nominate a person within the research team who will act as point of contact.

Pre-document review advice

Before you create your research documents, consider these common pieces of feedback from our lay members:

1. What can be changed?

“They asked us what we thought of it and then told us nothing could be changed!”

The number one piece of feedback that we get from our panel members is frustration over being asked to comment on documents where nothing can be changed. If you are submitting protocols that have already been to ethical review, validated surveys or other documents that are ‘fixed’ for whatever reason, please be clear about this and explain what you would like people to comment on and how you will use any feedback that is given. If your documents can’t be changed, but you would still like public feedback on your project, please speak to the PPI Team.

2. What feedback are you looking for?

“Is this document for researchers or for patients?” “Why am I being asked for feedback on a statistical analysis plan when I know nothing about statistics!”

Most research documents can benefit from public review, but clear information needs to be given so that the panel understand what feedback you would like for each document. Give context; explain where each document is headed, who the intended audience is, how it will be used and what your intended aims are. This is particularly important if you have submitted several documents with different intended audiences e.g. you might explain that your research proposal will be read by a funding body and reviewed by research specialists, a Patient Information Sheet will be read by participants and family members to explain the research process, and a lay summary may need to be read by the funding body, study participants and members of the general public visiting a website.

3. Is there avoidable jargon?

“Overwhelming use of jargon!”

Panel members understand well that medical research is a technical field, yet unnecessarily technical language frequently finds its way into lay summaries and patient documents. Describe medical, technical, and business terms in plain language and explain (not just expand) acronyms. For example, “This study will investigate

whether endoscopy (where a tiny camera is inserted into the body to examine internal organs or take samples) is effective at..." You may also wish to consider the inclusion of a glossary.

Also try to use the simplest word or phrase that you can wherever possible - instead of 'requested', try 'asked'; rather than asking people to 'make a decision', ask them to 'decide'. Avoid Latin terms like "per" and symbols that people may be less familiar with such as "<" (less than) or "n=" (number of).

4. Are there unexplained words hidden in plain sight?

"Please explain [ambiguous generic medical/research word]" "I would have thought a positive test is a good thing?"

Panel members often comment that common words in the English language have specific meanings in science that members of the public may not be aware of. In some ways, these kinds of words can be jargon in disguise, because they are like everyday speech but different in the research context. Examples we often see are intervention, randomised, significant, anonymised, bias, pathway, protein, theory, model, positive/negative, novel etc.

5. Are descriptions clear?

"There was no clear description... information was implied rather than stated."

The lay readers have no background context for your work except for what you have given them, nor do they have an in-depth understanding of research protocols or processes. Provide context up front to be clear in your objectives and introduction section. Describe clearly what will happen to data that is collected, how it will be used and analysed, what is involved in the research plan. Also, use simple and explicit instructions where you are expecting the end user to do something (e.g., tick the box, sign the form, give/send it to etc). Try to keep sentences short wherever possible, as these are easier to understand.

6. Is key information consistent throughout?

"There is a contradiction about [process/procedure/length of time etc.] between part A and part B. Which is correct?"

It is vital that all your documents are internally consistent and relate to each other, otherwise readers have no way of knowing what is correct and what is an error! Will

other, otherwise readers have no way of knowing what is correct and what is an error! Will there be three visits to the hospital or four? Will the data be stored for five years or ten? Will you have to wear a device, or two devices? In particular, make sure that you are consistent between a PIS and a consent form, to make sure you don't ask people to sign consent for something that you have not actually outlined to them in the PIS.

It is also important to be consistent in the terms that you use in the document. For example, if you have initially stated that data will be 'de-identified', continue to use this term, rather than referring to data as 'anonymised' or 'pseudonymised'.

7. Would a simple diagram help?

“A simple diagram would have helped!” “The photos helped remove uncertainty about what was meant.”

There is a tendency to over-rely on (lots of) descriptive text when images/diagrams would be more accessible and equally appropriate. Diagrams, images, are particularly helpful when the procedure/device/intervention is difficult to envision for people who have never seen it before. Similarly, flowcharts, diagrams, tables and timelines are a good way to visualise complex protocols or research programmes. Make sure you give plenty of thought to design to make sure it can be understood by people who may not typically see diagrams, and make appropriate use of titles, figure legends and labels.

8. Could the document be shorter?

“This document was so long, I struggled to get to the end of it”

There is a tendency for researchers to put everything they can think of into a document to ensure that any consent obtained is 'informed'. However, it is important that documents contain what needs to be said as opposed to things you might like to include or trying to include absolutely every possibility. This ensures that panel members (and the future readers of your documents) give your research or research documents the attention it needs for them to understand it, and, importantly, to consent (if relevant). Over-long documents with multiple repeats of information or wordy paragraphs may mean people will not read them, decline to participate or not fully understand what they are consenting to.

9. Did anybody proof-read this?

“There were several typos throughout the document” “Some sentences were too long to be understandable” “Was this checked for readability?”

CUH PPI Panel members give their time to provide thoughts and opinions on research projects and should not be seen as a proof-reading service. Before you send your documents to the panel we strongly recommend:

- **Proof-read your document:** Check for any typos or sentences that don't make sense. It's also important to think about whether all the information in your document is located in the most sensible place. Has an explanation come at the first use of a term, or is it half way through the document?
- **A readability check is run on the text:** This will highlight any over-long or complex sentences and grammatical issues. Examples of free readability checks can be found here ([Hemmingway](#)) and here ([Readability Formulas](#)) or via search engine. These scores will give you an overall impression of readability, but are not a substitute for having it read by a human.
- **Ask somebody with a fresh pair of eyes to look through your document:** This could be another member of your research team or department for example. They will almost certainly be able to see something new in a document you have already read six times yourself!

10. Related, but different:

“We've seen this before” “...a re-hash of topics already studied by health research”

Our panel is frequently exposed to studies that appear to the lay person as very similar, and this echoes a wider sentiment (and misconception) about research being unnecessarily repeated, time and money wasted, and results not acted upon. Sometimes this is as simple as two (or more!) researchers from the same research group approaching the panel with their (understandably) related projects.

Researchers can help lay readers (and proposal reviewers!) better appreciate the uniqueness and importance of their research by clearly indicating how, where and why the research is related to other similar projects, and highlighting what aspect of their work is unique and ground-breaking. For example, explaining that it is approaching an existing problem in a novel way, or trying an existing protocol on a different population/disease etc. When in doubt, spell it out!

Ethical considerations in PPI

One of the most common questions we are asked about PPI is whether activities such as focus groups and posters to recruit public participants require approval from a research ethics board. Health Research Authority (HRA) guidance confirms that you do not require ethical approval for PPI activities:

“Do I need HRA ethical approval before I work with patients and the public?”

No. You do not need to submit an application to a Research Ethics Committee in order to involve the public in the planning or the design stage of research, even if the people involved are NHS patients.

Please note: *Public Involvement does not refer to research participants taking part in a study. To find out which reviews your project needs, please use our [tool](#).*

You should describe how you plan to involve people in the management, conduct, analysis, or dissemination of your study in your application for Research Ethics Committee review, because doing so is likely to address ethical considerations which are of interest to the Research Ethics Committee. See best practice in public involvement principle 4.”

HRA. Public Involvement: What do I need to do? Last updated: December 2020.

However, there are a number of ethical considerations that you should be mindful of as you involve the public in your research.

Be clear about what involvement is

Make sure your contributors understand that they are assisting you with making your research better and providing feedback or contributing to the design and execution of a research project, and NOT participating in the research as a research participant.

Raw emotions and Trauma

We involve patients and the public in research in order to learn from their lived experience of their health condition and their interaction with the research process. However, this naturally means asking and reminding people of potentially difficult or traumatic experiences in their lives. For many such contributors, involvement can be a way of dealing with these experiences, to improve research and disease outcomes for future participants and patients, but it can bring to the surface emotions and frustrations related to things you have no control over. Be prepared to listen and to moderate/facilitate interactions between contributors and research staff if things get emotional or heated. It is also useful to acknowledge potentially emotive or triggering topics in advance of activities, and give contributors options about how they participate.

Inclusive and Accessible Opportunities

Good PPI aims to include the voices of a range of people that may be affected by your research, and this may include people who need special consideration when planning your PPI activities. Be mindful of the timing, location and required facilities of your contributors when planning your PPI strategy, and include a range of different roles, activities and ways of involvement in your plans if you can. When applying for funding, make sure that you include the resources you need to be able to support accessible, inclusive PPI – such as funding for translation, large print or carer/childcare cover.

Financial considerations

As a rule of thumb, no one should be out of pocket as a result of getting involved in research, so it is important to ensure that you have appropriate finance and processes in place to reimburse contributors for pre-agreed, reasonable expenses related to their involvement.

Offering honoraria payments can make involvement opportunities available to a wider audience, and if you are applying for research funding you should include budget for involvement payments. As payments can affect taxation requirements and benefits payments, it is important to signpost contributors to up to date advice.

If you do offer honoraria payments, it is important to be clear about the payments process and options and to set clear expectations of what contributors need to do to qualify for a payment.

Avoid involvement and participation crossover

Patient contributors should not generally be involved in a research project that they are also currently a participant in as it can become difficult for them to understand the difference between the roles and can introduce issues with blinding, access to patient data etc. Former participants make great contributors to future projects however, as do carers. If a condition is particularly rare, dual involvement / participation roles may be appropriate with careful planning and discussion.

Researcher/clinician relationships

Existing relationships with patients can bring benefits to involvement as you have already established a rapport. However, such relationships can also blur the lines between treatment and research and make patient contributors more reluctant to give you candid feedback about your research. Be aware of such relationships and clearly separate research activities from clinical treatments (consider alternate locations, different attire etc). Ideally, also seek the views of other contributors who are independent of your clinical duties.

Research/medical words vs experience words

Be mindful of the words you use when interacting with contributors. For example, a commonplace research word like 'foetus' could be 'baby' and 'cancer patients' could be 'people with cancer' to everyday people.

Payment guidance for public contributors involved in NIHR Cambridge BRC research

Patients and the public bring invaluable expertise and experience to the world-class research delivered on campus, and we believe that they should receive appropriate recognition for their contributions.

Payments and reimbursements are essential to ensuring that involvement in research activities is as equitable and accessible as possible. We encourage all researchers to ensure that financial concerns are not a barrier to public involvement in their work.

Definitions

Public contributors: patients, service users, carers and/or members of the public who are engaged by research teams for the purpose of shaping and improving their research project.

Payment/honoraria: The offer of money to recompense a public contributor for their time and expertise.

Reimbursement: The offer of money to compensate for expenses incurred in the course of involvement activities (e.g. travel, food or accommodation costs).

Payment or reimbursement? To pay or not to pay...

Reimbursement for expenses incurred in the course of involvement activities should **always** be offered to public contributors to ensure that financial constraints are not a barrier to involvement and to ensure that opportunities are accessible to as wide an audience as possible. Reimbursements do not affect benefit entitlements and should be offered whether or not further recompense is available.

The decision about whether to offer payment for public contributions is ultimately up to the Principal Investigator of the research project. What is appropriate will be different for each project, depending on what is required of the public contributors, the resources available and the individual circumstances of the contributors.

Increasingly, there is an expectation that honoraria are offered for public involvement – particularly at the post funding stage. Honoraria are particularly expected for activities/roles where involvement is on-going, comes with specifi

Legally, it is the responsibility of the individual to clarify the potential impact of involvement activities with their Benefits Advisor and make their own judgements about what level of payment they are prepared to receive and declare.

However, it is important that research teams are prepared to strongly encourage their contributors to obtain specialist information and equipped to signpost to appropriate resources, such as those provided by the [NIHR](#) and the [Benefits Advice Service](#).

As of August 2024, the NIHR has asked Bedford Citizens Advice Bureau to deliver a Benefits Advice Service for public contributors. Researchers and staff within NIHR organisations or NIHR-funded research projects who are supporting members of the public to get involved are invited to contact the service for tailored, specialist advice. To access the Benefits Advice Service, please contact the NIHR Centre for Engagement and Dissemination by emailing ced@nihr.ac.uk or calling 020 8843 7117. You will then be referred to the Benefits Advice Service. Depending on the circumstances, you may be given a reference number to be quoted, which shows that a conversation was had with the NIHR and may aid your conversation with the Benefits Advice Service.

Importantly, public contributors have the option of refusing payment or requesting a lower amount for their involvement activities, without it affecting their welfare benefits.

Expenses for Public Contributors

You should consider including funds to cover the following types of expense, where relevant:

- Travel/parking
- Accommodation
- Food
- Stationary or equipment necessary to carry out involvement activity
- Facilitator fees (e.g. carer, translator)
- Conference or event booking fees

It is expected that public contributors will use the most economical and practicable form of transport available, while meeting their individual needs. Travel by private

car should be via the most direct route available and is set at 45p/mile by CUH – this is a minimum amount and individual travel circumstances may warrant higher reimbursement (e.g. travelling long distances). Other organisations may use a different schedule of payments. All travel claims should be supported by appropriate receipts.

Claims for reimbursement need to be made promptly following each involvement activity by submitting the appropriate expenses form to finance, which must be signed by both the claimant and the budget holder. Copies of all receipts should be attached.

Records of expense reimbursement are kept by CUH in cases of enquiries regarding benefits or tax. Similarly, Inland Revenue and/or the Benefits Agency may request details of payments made to individuals, and we can accept no responsibility if public contributors are penalised for failure to declare income.

Suggested rates for payments and reimbursements

The Principal Investigator or nominee will have responsibility for the final approval, monitoring and timely processing of payments. The following table outlines suggested payment levels for common involvement activities (taken from [NIHR Payment Guidance for Researchers and Professionals](#), updated August 2024). The NIHR is clear that these are not mandated minimum rates, and understands that funding and other circumstances will vary. You are free to set alternative rates for your activities.

Where contributors are involved in part of a session, payment can be made pro rata.

Activity	Details	Suggested rate	Notes
Attending events where asked to give individual views only	N/A	Expenses and provision of refreshments	E.g. Using the CUH PPI Panel for document review or single focus group
Task such as reading and commenting on a document	Less than an hour	£12.50 per activity	N/A
Involvement in working groups, focus groups,	In-person or online	£25/hour during activity, plus	Refreshments should be provided if activity is in

committees or recruitment panels		expenses	person
Involvement in all-day meetings (without substantial prior preparation)	In-person or online	£150	E.g. attending a committee or panel meeting as an observer or NIHR training course
Involvement in all-day meetings (with substantial preparation)	In-person or online	£300	E.g. Chairing/co-chairing a meeting

The below table outlines further allowances that you may wish to consider costing when applying for PPI funding.

Allowance type	Details	Amount	Notes
Remote/home working costs	N/A	£5 per meeting	E.g. Cost of telephone calls, WiFi, printing etc.
Overnight accommodation (bed and breakfast)	To allow attendance at conference or meeting	£130 for inner cities and £100 elsewhere	This is CUH guidance
Meal allowance	Per 24-hour period	£20	This is CUH guidance
Lunch allowance	When more than 5 hours from home	£5	This is CUH guidance
Evening meal allowance	When more than 10 hours away from base and return home after 7pm	£15	This is CUH guidance
Childcare costs	To support involvement	Varies depending on personal arrangements	View: Guidance for childcare costs
Carer costs	To support involvement	Varies depending on personal arrangements	View: Guidance for carer costs

Personal assistants / support workers	To support involvement of some disabled people	Usually National Living Wage, £8.91 per hour for adults over 23 years of age.	If the personal assistant is staying overnight, there may be a reduced hourly rate for that time.
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Payment of young people (<18 years) involved in research

Participation in involvement activities for young people is allowed provided it does not significantly impact on their health, education or physical development and that consent has been obtained from parents/carers. It is the responsibility of the researchers to ensure that consent has been received for each young person involved.

Consent must also be obtained in order to be able to offer payments to young people. Involvement activities are not counted as 'employment' for people aged under 14 (since the young person is unlikely to be earning enough to pay tax), and thus researchers have some discretion over how cash payments are used.

However, young people who are no longer subject to compulsory schooling may be in receipt of benefits, which could be affected by payments. Such young people should be strongly encouraged to seek personalised benefits advice, and researchers should be prepared to assist with signposting them toward useful resources.

It is also possible that parent benefits could be influenced by a young person's involvement activities, and thus parents should be encouraged to seek advice.

Support and advice

Research teams should support their public contributors to be properly involved in their research projects in order to reach the desired aims of the involvement activities. This includes provision of stationery and materials that are essential to a given activity as well as copies (either hard copies or electronic) of relevant documents.

Other areas of suggested support are the provision of appropriate training for public contributors (e.g. research methods, clinical trials) and assistance for completing forms and reimbursement claims.

We recommend that research groups have a named team member who public contributors can contact with queries, and that this person is equipped to sign-post to resources, organise appropriate training and assist with reimbursements and payments.

[Please note that the full NIHR guidance on payment and reimbursement for researchers and professionals \(updated July 2024\) can be found online.](#)

[We also recommend reading this NIHR guide on determining the most appropriate payment approach \(published April 2023\).](#)

Recognition and feedback

Public contributors that we work with consistently tell us that knowing whether and how they have made a difference is important for making them feel like their time spent on involvement is worthwhile. Providing regular, detailed feedback and updates on project outcomes and milestones are essential to appropriately recognising the impact public involvement has had on your research. In our experience, this form of recognition is even more important to contributors than financial compensation, and lack of feedback/not feeling like they're making a difference is much more commonly cited as a reason for leaving PPI than not being paid.

The simplest way to find out what form of feedback your contributors expect and prefer is to ask them! Being consistent over time – particularly if your project is ongoing – is also very important.

1. Feedback about the impact of PPI contributions

Please inform your PPI members what input prompted changes and what those changes were. This may include alterations to documents, study design, recruitment strategy, ethics section or even your overall approach to your work. There may be reasons why certain comments cannot be incorporated – for example, if the comments were outside the scope of your work, infringe word limit, would cause ethical implications etc. Similarly, the views of your PPI members may be divergent or contradictory, such that it would not be possible to incorporate all (or any) of the opinions. Acknowledgement that there were differing views and a simple explanation of what was included and why is appreciated.

An explanation of PPI impact is required by many funding bodies (e.g. NIHR) as part of the application process. The impacts that you feed back to your contributors should provide you with the material that you need for this section of the application.

2. Outcomes and updates

PPI contributors volunteer their services out of a genuine interest in research, the research process and a desire to improve outcomes. The vast majority of lay contributions happen at early stages of research, often prior to grant application or funding commencement (which is a good thing!). However, people are also very

interested in the wider impact of their contributions and want to know what happens to the research after they see it – were the ethics approved? Grant funded? Study initiated? Recruitment finalised? Or, eventually... study concluded? Please update your PPI contributors even when the news isn't good. You'll help ensure that people continue to get involved with research.

3. Acknowledgement

When PPI has contributed to research that is subsequently presented or published, please acknowledge the PPI panel in the appropriate section.

Giving feedback to the CUH PPI Panel

Researchers engaging with the CUH PPI Panel agree to share details on the changes made to their documents as a result of panel feedback, and to provide updates on project status.

We request that researchers provide responses to individual comments in a 'You Said, We Did' log. A template for this is provided with your anonymised feedback report. Some researchers choose to reply to all comments left by panel members, whilst others select the most pertinent comments and only give responses to these. If you have not implemented a suggestion, it is important to note this and explain why. Panel members are good at accepting that their changes haven't been made if they are given a justifiable rationale!

Dr Jordan Moxey, a medical doctor and researcher at the THIS Institute has kindly agreed to share her response log as an example for other researchers. There are good examples below of declining to implement panel suggestions for practical reasons (e.g. the survey platform does not allow titles beyond a certain length, even though a suggested title is clearer than the original) or due to professional judgement (e.g. keeping a scale the same because the panel members concern has not been observed in a pilot study).

Please see the next page for an abridged version of Jordan's full comment log.

Researchers must provide updated versions of their documents for the PPI Coordinator to share with the CUH PPI Panel as a minimum requirement. Sharing both a 'You Said, We Did' log and updated copies of documents is best practice.

Failure to provide any feedback may result in the PPI Team refusing to send further documents to the panel on your behalf.

Comment	Response
<p>Reviewer 1: Interesting. I get what the research is trying to do but if I was asked to do this survey as a patient I would think it's missing the main issue for me. I don't mind my GP leaving the room to get a blood pressure gauge but I do mind having to wait to see my GP when I really need them.</p>	<p>This research is not aiming to address wider issues of access to GP care, but to focus on where we can intervene to improve the efficiency of day-to-day working for GPs. One possible outcome of this may, of course, be to free up GP time to address some of the difficulties in access which primary care is struggling with. There will be a free text box at the end where patients can provide comments on areas where the survey does not fit their experience. These comments will be analysed qualitatively, will inform the future direction of our research within this area and reported in our outputs.</p>
<p>Reviewer 1: I think setting the survey up to be clear it's about removing some of the frustrations and inefficiencies the Drs have to face is key. So I would recommend stronger wording to position the document: 'Doctors practices are an essential part of the NHS. Successful Dr consultations are key to ensuring the best medical care for the patients and this survey looks at things that may impact the Drs performing their work as efficiently as they can'.</p>	<p>Thank you for providing suggestions on how we could provide greater clarity about the purpose of the survey. We have incorporated some of your suggestions into the survey introductory text.</p>

<p>Reviewer 1: The term operational failure might confuse as it could be misunderstood for medical operations that have gone wrong.</p>	<p>Thank you, we agree - without context this term could absolutely be misinterpreted in that way! This term is used in the scientific literature to distinguish everyday problems from "medical errors" and to differentiate purely from "interruptions" which can often be positive and improve patient care. At present, there is no patient-friendly alternative to "operational failures", however we will make sure that the definitions appear very clearly within the survey in appropriate language.</p>
<p>Reviewer 2: I do not see the need for/relevance of the questions around the participant's ethnicity and preferred sexual orientation; this kind of "box ticking" is clearly not considered significant to the study (as answers are voluntary) so why include it?</p>	<p>Thank you for raising this. We collect this important information to inform and assess our recruitment strategies to ensure that our research is reaching and collecting a diversity of experiences and range of voices. It will not be used to analyse the dataset and remains optional, so that participants can opt out if they wish.</p>
<p>Reviewer 2: P3. 1.3 Impact. Last line - replace "have" with "provide"</p>	<p>Thank you, we have amended this.</p>
<p>Reviewer 2: P4. 1.5 should be Problems contacting other healthcare professionals about patients, not "others"</p>	<p>Thank you for noticing the typo, we have corrected this.</p>
<p>Reviewer 2: P4. 1.7 Impact. Second sentence should start "These problems can also increase..."</p>	<p>Thank you we agree with this as a suggested change. (Now found in section 1.5 in the final survey template)</p>

<p>Reviewer 2: The scientist in me revolts at the idea of inviting participants to change their responses (presumably to improve consistency with the majority view). Surely, lack of a clear consensus is itself a valid result and any attempt to manipulate responses --- however subtly and for whatever reason --- negates the credibility of the whole exercise....</p>	<p>Thanks for this feedback, which raises an important point about our communication of our study methods. This research study is an online consensus building exercise that employs a "modified Delphi technique". In a traditional Delphi study, participants would be invited to face-to-face workshops where we would present them with an initial survey, analyse the answers, show everyone the group's feedback then invite discussion about the ratings in order to form consensus about which issues should be prioritised. Following the discussion, participants would go back individually and re-rate their answers. This process helps to achieve consensus and prioritisation when there are a large number of issues that on the surface may all appear to be quite important. Disagreement or non-consensus is a valid, essential finding of this method that helps us to narrow down the issues into a prioritised shortlist. In COVID times, we were unable to do previously planned face-to-face workshops, and instead have adapted the study method to an online technique. The benefits of bringing the discussion online is that we are able to include far more voices in the discussion than we would have if we had done this process face-to-face.</p>
<p>Reviewer 3: I think all the draft text is perfectly patient-friendly – all completely clear and understandable.</p>	<p>Thank you for your feedback!</p>

<p>Reviewer 3: Final point on page 2. Unless you were to tell me that there are specific constraints on the rating system, I would want to put a score on 9 on all.</p>	<p>Thank you for this. A score of 9 for all of them would be perfectly valid if you were participating in this survey! The likelihood of all participants scoring 9 for every issue in both rounds of the survey is incredibly low, and has not been seen in the GP version of this survey.</p>
<p>Reviewer 4: The definitions of Operational Systems, Operational failures, Interruption and use of the word Task may be confusing to members of the public as don't directly relate to words that may associated with a GPs job.</p>	<p>Thank you for this feedback, we completely agree. To help ensure patient understanding of the terms used in this project (beyond including the definition and impact statements), we are collaborating with 7 local Healthwatch across the country who are assisting with recruitment. All Healthwatch reps have been fully briefed about the project (through 1:1s and a launch meeting). They are very comfortable with the terminology used and the kinds of issues we will be asking patients to rate, so will be able to field any questions. We have also provided Healthwatch with recruitment materials that gives examples of what operational failures are and guidance on what to say, or who to direct queries to, if potential participants have further questions that they cannot answer.</p>
<p>Reviewer 4 comment on 1.9 impact statement: Not sure this will be well understood</p>	<p>Thanks for this feedback, we simplified the wording from "problems in the culture of teamwork" to "problems in teamworking", however since receiving data analysis from external collaborators at RAND Europe about previous survey rounds, this section is no longer included in the final template.</p>

<p>Reviewer 5: I have no issues with definition and impact statements themselves but think the heading should be simpler something along the lines of commonly identified issues that have been identified and how they may affect a GPs ability to provide good patient care .</p>	<p>Thank you for this - I agree that this may read better on paper. Unfortunately, on our online survey platform we are very limited in terms of space and what will read well on a mobile device. Our user experience designer, software developer and citizen science colleagues recommend that the titles for pop-up boxes (which is how we will show the text you've just reviewed) should be kept as short as possible i.e. one word like "definition" or "impact".</p>
<p>Reviewer 5: May be helpful to state that problems in the Operational systems can be divided into two categories: the supply of necessary materials or information needed for your GP to complete their everyday work/job(task) and Interruptions which are anything that distracts them from doing their work/job (task) May be helpful to include some real life examples.</p>	<p>Thank you for highlighting this. We are mindful about the length of the information we include on the online survey platform, particularly in the introduction pages, and want it to remain as readable and accessible as possible on a range of devices including computer, mobile and tablet. Through our collaboration with Healthwatch, who are helping with recruitment, we hope to answer queries that arise.</p>
<p>Reviewer 6 comment: Surely this is under the control by the GP as they can set it to 'do not interrupt'.</p>	<p>Unfortunately, these are often not under the GP's control. Pop up alerts include instant messages, automated medication alerts, alerts about e-prescriptions and others that cannot be switched off and must be interacted with before the GP can continue with their work (e.g. by having to click "x" or "close" in the top right corner).</p>

PPI activity and impact record form

Project title:

Principal researcher/named PPI lead:

Date	Activity	Involved	Feedback (outcomes)	Actions taken (impact)
Research design phase				
20/04/2024	Discussion group with PI and research team	5 patients from clinic	Current description of project not clear and difficult to follow	Write lay summary and share with both CUH PPI Panel and interested patients for review
			Concerns about number of study visits	Reviewed protocol to assess feasibility of changes. Study visits kept at 4, but will discuss with patients other ways to reduce burden
14/05/2024	Lay summary distributed for comment	15 members of CUH PPI Panel and 3 patients from previous discussion group	Layout was felt to be confusing and some aspects of wording were felt to be insensitive. Excessive use of jargon. Suggested diagram may be beneficial.	Adopted recommendations about wording and layout. Improve lay understanding and removed jargon. Produced diagrams for treatment flow.
Data production phase				
Post project/dissemination phase				

The PPI activity and impact form can be used to record specific key learnings from PPI discussions and the actions taken as a result of these. Recording feedback and actions in this way can help when writing up your grant application, research materials, papers

and press releases. It can also be shared with your PPI contributors to demonstrate the impact they have had on the research process.

Example learning log

Date	Collector	Perspective	Context	Learning
21/05/2024	Dr Jones	Researcher	Discussion with patient in clinic	Hadn't responded to invitation as thought previous experience excluded her.
12/06/2024	M Smith	PPI coordinator	Focus group discussion	Several participants late, directions in guide wrong and arrangements for parking not well described.
24/06/2024	P Green	Contributor	PPI meeting	Meeting chair didn't realise who I was or why I was there. Felt a bit awkward.
17/08/2024	M Smith	PPI coordinator	Public review of Patient Information Leaflet	Lots of confusion around the term 'usual care' - need to avoid or explain in future docs.
02/09/2024	F Cox	Contributor	Discussion with patient support group	Several members at meeting had never heard of this study - general patient awareness is still very low.

The learning log can be used to capture learnings by all team members, including PPI contributors. These findings may be general and not result in obvious change. The learning log can comprise observations and reflections that may directly or indirectly impact your current research project and future research projects. Developing an ongoing repository of PPI learnings can help to collect the evidence needed for wider change in your team and for other teams in your department/institution. Learning logs should be openly shared and regularly reviewed.

Selecting a PPI Lead for your project

NIHR Guidance states that:

‘There should be a named person with appropriate skills and experience who is responsible for leading the PPI element within the project. This role should be an adequately costed and resourced research team member who is able to manage the PPI plans and related activities.’

Here we provide further guidance on the role of ‘PPI Lead’.

Named person

This can be a person already listed in the application e.g. The lead applicant, a fellow/associate, public co-applicant or research coordinator, or a standalone role. They do not need to have already been appointed – the funds to cover the post can be included in the funding application for later recruitment. It goes without saying that the appointed person should be aware of the fact they are named as the PPI lead!

Appropriate skills and experience

There is an acknowledged scarcity of experienced PPI practitioners, but skills and experience that are appropriate for PPI are widely transferable from related fields – for example, working with patients, charities or community groups could be relevant experience. The most important skills required are interpersonal – the ability to identify, build and support relationships between researchers and relevant communities and patient groups.

We have [specialised training](#) and support available on campus to support new PPI leads and increase PPI capacity. The NIHR Cambridge BRC PPI strategic lead is available to support recruitment, the development of role descriptions and to provide support and guidance to new (and existing) PPI leads. The PPI team run both introductory and specialised PPI training throughout the year with content relevant to all PPI practitioners.

Adequately costed and resourced

Good PPI takes time and has a large volume of administrative work that comes with it (organising events/activities, keeping in touch with contributors, arranging

reimbursements, keeping records, assessing and reporting, among other things) and the PPI lead needs to be (FTE) resourced appropriately. As with much of research set up, PPI-related time is usually higher at the beginning of a research project. PPI activities themselves also require resourcing, and planned activities should be carefully costed within the funding application.

Leading and managing PPI plans

The PPI lead needs a solid understanding of the research project and a good rapport with the rest of the research team to be able to develop and lead an appropriate PPI strategy. Most importantly, they either need to have sufficient agency and trust within the research team to be able to implement the PPI findings/feedback, or have a project lead and research team that is willing to work closely with them.

Ideally, the PPI Lead should be involved in the development of the PPI strategy and plans for the research project. If they are recruited after a project has begun, they should be given detailed information about the PPI plans submitted with the application and the rationale for them, along with the findings/learning from earlier PPI activities and events.

The PPI lead should attend research meetings along with other research team members to be able to update the research team with relevant findings/learning from PPI activities, and to support identification of issues and questions that are relevant to further PPI activities or discussion with project PPI groups and committees.

The PPI lead should also be equipped to inform project PPI members what input prompted changes and what those changes were.

What if someone would make a good public co-applicant, but they aren't sure if they want to take on the role?

Nobody should ever feel pressured into taking on a co-applicant role, so if they don't wish to contribute in this way, that's absolutely fine. What can be useful is looking to understand why people might not wish to be listed as a co-applicant and identify whether there is another way that they can be involved.

Many people approached to be co-applicants live with health conditions and have busy personal and professional lives. It's therefore quite commonplace for people to care about your project but simply not have the time or resource to commit to being a public co-applicant. If they would still like to be involved, consider how else they could be involved. Do you have an advisory group or steering committee you would like someone to sit on?

Are you planning a discussion group that they could attend? Will there be an opportunity to review any patient/participant facing documents? You can always leave the door open for people to move between different levels of commitment or activity as the project goes on - some people might only be able to look over a lay summary because they have exams approaching but be interested in joining an advisory group in a year's time!

Sometimes, somebody is really interested in the co-applicant role and has time to dedicate to many of the tasks required but doesn't feel comfortable taking on the role officially. This might be because they don't wish to commit for the whole duration of the research project. Perhaps they have a condition that causes flare-ups that are difficult to manage. Or perhaps they might wish to move in a year and wouldn't be able to continue attending in-person meetings. Perhaps research remains an unknown quantity and they simply don't want to be equally responsible for a research project. In this case, you could discuss whether they would prefer to take on a similar-but-less-formal role such as 'patient partner' instead. In practice, the influence and contributions of a patient partner can be the same as a co-applicant, without the need to jump through the bureaucratic hoops of being formally added to the 'system

Working with public co-applicants

'I've heard I should have a public co-applicant on my application, can you find me one?'

is a common question from researchers writing up their funding applications.

There is a misconception (occasionally bolstered by feedback from rejected applications) that public co-applicants are essential if a researcher wants to be successfully funded – and what researcher doesn't want to be funded?

We are fortunate to work with a number of members of the public who are experienced co-applicants, as well as with many researchers who have chosen to work with a co-applicant on their research. We have worked with these contributors and researchers to put this guidance together, to complement the [guidance released by the NIHR and HRA in 2021](#).

We strongly recommend that you read the NIHR guidance in full to understand all your responsibilities in relation to recruiting and working with a public co-applicant.

NIHR guidance

NIHR guidance for researchers is clear that public co-applicants are NOT mandatory for successful applications:

'There is no formal requirement to include a public co-applicant in NIHR funded research.'

Working with a public co-applicant is one of many ways that researchers can involve members of the public (including, of course, patients) in their research. **NIHR guidance is also clear that a co-applicant should not be the only way you involve members of the public in your research.**

What exactly is a public co-applicant?

A public co-applicant is a formal member of the research team who is named on the funding / regulatory application(s). **They have the same obligations and responsibilities as other co-applicants and are considered to be an equal member of the research team.** This is a greater level of responsibility than is expected of your other public contributors.

Overall legal responsibility for the study lies with the lead investigator and study sponsor. However, as full team members, all co-applicants are responsible for proper management of confidential information and study data. You should discuss with your host institution's legal team whether a non-disclosure agreement will be necessary and whether the co-applicant will be covered within the hosts indemnity insurance arrangements or what other appropriate solutions are available if this is not possible for any reason.

As with other forms of PPI, ethical approval is not required to include a public co-applicant in your research. The exception to this is if the co-applicant is likely to come into direct contact with any study participants. If this is the case, the public co-applicant may also need to follow other policies applicable to research staff, such as risk assessments, research governance training, DBS checks etc.

So, should I consider a public co-applicant for my research?

Consider? Yes!

Public co-applicants can bring unique experiences, expertise and perspectives that strengthen research. As a formal member of the research team, they can help to ensure that patient and/or public perspectives are integral to the design of the research, the development of the application and the 'delivery' of the research itself.

When does working with (or being) a public co-applicant work best?

The experience tends to work best when it develops naturally from an existing relationship with someone who has relevant experience. This might be someone involved in your previous research, a patient from your clinic, or somebody you have met through a patient charity or support group. Importantly, they must be interested and invested in the research and known to all (or at least all senior) members of the research team. That way, when your team feels that they're ready to write up their research application, the relationship with your public contributor is already developed and it is natural to simply include them as part of the application.

How can I find a public co-applicant?

If you don't already have a 'natural' public relationship, it may still be possible to successfully identify and involve someone as a co-applicant. You could consider advertising through the following or similar forums:

- **Use [People in Research](#).** After creating an account, you can post an opportunity on this site.
- **Collaborate with charities working within your area of interest.** Ask if you can advertise the opportunity to their networks. A list of Patient Support and Community Groups already associated with CUH R&D can be viewed [here](#).
- **Advertise through the CUH PPI Team network.** We advertise external PPI opportunities to the CUH PPI Panel and selected PPI contacts in the East of England every Thursday. This is also published on [our PPI Opportunities webpage](#). You can submit opportunities to the weekly round up using this form: <https://forms.office.com/e/3Xqn2jVvmg>

What makes for a successful co-applicant/research team relationship?

Successful involvement of a co-applicant needs a **prepared and committed research team** and, of course, a **willing co-applicant with suitable experience, commitment and motivation** who is involved with the project from the **earliest stages**.

It also places the needs of the contributor first – agreeing the position with the right person, and then refining the role, tasks and practicalities around their preferences.

Commitment from the research team

Working successfully with a co-applicant must start with all initial research team members agreeing that they want to commit to successfully involving a public co-applicant – and it really is important that the whole team is involved in this process. A co-applicant is a member of the research team, and all other members of the team must recognise, respect and include them as such for the duration of the project.

'Suitable' and willing co-applicant

A 'suitable' co-applicant will be someone who has relevant experience or perspective on your research, and who is happy and able to take on the commitment that being a co-applicant brings. Some public contributors can feel pressured to take on the role of co-applicant when they would prefer to be involved in your research in a different capacity or they might agree but then have concerns or

confusion about what the role actually entails.

Although the exact tasks can (and should) be agreed with the co-applicant once they agree to the role, it is important that your candidate has a clear idea of what the role will entail from your initial discussions. It is useful to be able to give an idea of the likely time commitment involved – both in terms of weekly/monthly time outlay, and the full duration of the funding. Whenever the rest of the research team are meeting and/or decisions are being made, the public co-applicant should be invited to attend. You'll also need to factor in time for them to read and review the research application itself.

Deciding on co-applicant status should be a mutual decision between contributor and research team and it is important to be clear that interested contributors can be valuably involved in a variety of ways, even if they don't choose to become a co-applicant.

Earliest stages

For a co-applicant to be able to meaningfully influence the research project, they must be involved early enough that change is still possible. All too often co-applicants are only recruited or involved at such a late stage as to 'sign off' or endorse a pre-existing application (that they may or may not have had time to read, let alone discuss). Co-applicants need time to get to know the research team, become familiar with the rationale/background to the research and to read, digest and discuss the application itself.

What not to do: public co-applicants as 'tick box' PPI

Possibly more than any other format of public involvement, 'adding' a co-applicant runs a particular risk of being nothing more than tick box PPI if not entered into in good faith and with commitment by the research team. 'Tick box' PPI fails to involve people in a way that benefits the research project and leaves public contributors feeling alienated.

I have sat on a number of meetings where you can see that the researcher is ticking the box and honestly I wish they wouldn't bother. For me, if I feel that I'm truly part of the team then I will happily take part and be committed but if I'm there as lip service then I have better things to do with my time!

CUH PPI Panel Member

I have myself sometimes felt moral pressure to be a co-applicant and/or co-author and not realised fully what it entailed. One thing that really makes me feel bad is when a researcher writes in away that makes it seem my involvement was much more than it actually was to present the thing in a better light. I feel more used and sad than if they simply ignored me.

CUH PPI Panel Member

What makes co-applicants feel like they are being used to tick a box?

- Not being given time to meaningfully contribute to the application/project
- Not being adequately supported or provided with information they feel would help them to undertake their role to the best of their ability (e.g. not being briefed before meetings etc.)
- Only being asked to comment on parts of an application or not being given full information
- Being involved only in 'PPI' decisions and not 'research' or team-focussed decisions
- Not being included in important email discussions or provided with relevant documentation
- Not being listened to or being made to feel that their comments aren't taken into consideration
- Not being contacted/updated once the funding has been secured or the application rejected
- Having other team members not know/understand who they are or questioning the co-applicants role or remit
- Only working/interacting with one team member
- Not being recognised for their work – financially and/or through other lack of acknowledgement (co-authorship, for example)
- Feeling as though their contributions have not been accurately reported or reflected, either because they are not credited appropriately for their ideas, or because their role is falsely overstated in an attempt to "look good to the funder"

Supporting public co-applicants

Public co-applicants need to be adequately supported for everyone to get the best out of their role – with the ‘right’ support depending on the needs and experience of each individual. If they don’t have previous experience of the research (and particularly funding) process, they may also not be able to anticipate what support they need. Researchers can also struggle to anticipate what support might be necessary, so don’t be afraid to ask your public contributor questions!

Support to define the role

You should make every effort to create a genuinely two-way relationship that allows open discussion and honest feedback from the very earliest stages. Developing a clear, mutually agreed role description can be beneficial for both the public co-applicant and the research team. Setting expectations and getting them down on paper helps everyone know what their responsibilities are from the beginning and provides a useful resource to refer back to, if required. You might find that reviewing and revising this over time is helpful to account for changes as the project progresses.

Support to register as a co-applicant

The research funding application system itself can be quite alien and exclusive for public co-applicants who haven’t experienced it before (and even some who have!). It can be useful to show your contributors what the application portal looks like and discuss what you know about the steps in the research review and selection process. Some contributors (and researchers!) find the process of being ‘added onto the system’ confusing and frustrating and can worry that their skills and experience are lacking. It can be helpful to offer to run through the application together (or at least over the phone) and reassure them that no formal research knowledge or experience is expected or required.

Support to read and digest the application and the research project

This is mostly about providing adequate time – time to read, reflect and ask as many questions about the rationale, background research, alternatives, and options as necessary for them to feel comfortable questioning and suggesting. Depending on the needs of individual co-applicants, it may also be necessary to provide support with printing, internet, IT, or library access.

Support throughout project meetings

Keeping an ongoing, open dialogue before and after meetings and activities can help to identify how the team can make the experience positive for public contributors. For example, asking *'Can you think of anything that would be useful for you to know or have before we meet next week?'* followed up with *'thanks for joining us at the meeting. Do you have any follow up questions? In retrospect, was there anything that would have been useful to have or know that we didn't think of before the meeting?'* can be a good pattern to get into across the whole team.

Making every effort to avoid jargon and acronyms, and regularly checking with public contributors whether there is any terminology that they do not understand, is particularly important. It can also be beneficial to check that public co-applicants feel comfortable with language and terminology used, particularly if there are specific sensitivities around the health condition you are researching. Although commonly used in healthcare, many medical terms can feel cold or alienating to patients and using more appropriate alternatives, where available, can aid conversations.

It is often useful for co-applicants to have a named/main contact in the research team – though, be aware that only approaching the co-applicant via this individual can make co-applicants feel isolated.

Many researchers choose to keep a learning log to track what different team members learn throughout the project. If you choose to do this, encourage the public co-applicant to contribute and use the log as a basis for discussions.

Sign posting to support with benefits and taxation

If you choose to pay your public co-applicant honoraria for certain tasks or activities, make sure that they are fully informed about how to claim payment. You will also need to explain how accepting honoraria for PPI activities might affect their benefit entitlements or tax obligations. [The NIHR provides comprehensive guidance on considerations when paying public contributors](#), including definitions, budgeting and important documents you may need to provide.

In some cases, your institution may require the co-applicant to become an employee, with a contract for the duration of the project. You should consult with your Human Resources department at an early stage to clarify whether you will need to take this route and be transparent with the public co-applicant about how

becoming an employee could affect them. Your role description and an estimation of the total time and frequency of meetings will support this discussion.

Non-financial Acknowledgement

It is also important to remember that there are also many non-monetary ways to say 'thank you' to public contributors, such as crediting them in publications, inviting them to events such as conferences and offering to provide useful services e.g. talks to the charity they are associated with. These actions should still be taken, even if payment has been offered and accepted!

Support with specific needs and requirements

Acting as a public co-applicant should be an opportunity that is available to any interested person, regardless of their gender, ethnicity, health condition, educational background or any other characteristic. Activities you wish your public co-applicant to be involved in must be built around their specific needs and requirements. You must make any reasonable adjustments that will help them to perform their role. Speak to your public contributor about their needs. You may wish to consider:

- Are there times or dates that they are regularly unavailable for due to existing commitments e.g. due to other work, caring responsibilities, regular hospital appointments etc.?
- Is your meeting location accessible e.g. is there access for people with limited mobility? Could your public contributor dial in or must they attend in-person? Will they be able to easily find the space and feel welcome?
- Do you need to adapt any materials e.g. using large print, braille or translating into another language?
- Do you need to provide an interpreter (e.g. a translator or British Sign Language interpreter) or enable closed captioning for online meetings?

What if someone would make a good public co-applicant, but they aren't sure if they want to take on the role?

Nobody should ever feel pressured into taking on a co-applicant role, so if they don't wish to contribute in this way, that's absolutely fine. What can be useful is looking to understand why people might not wish to be listed as a co-applicant and identify

whether there is another way that they can be involved.

Many people approached to be co-applicants live with health conditions and have busy personal and professional lives. It's therefore quite commonplace for people to care about your project but simply not have the time or resource to commit to being a public co-applicant. If they would still like to be involved, consider how else they could be involved. Do you have an advisory group or steering committee you would like someone to sit on? Are you planning a discussion group that they could attend? Will there be an opportunity to review any patient/participant facing documents? You can always leave the door open for people to move between different levels of commitment or activity as the project goes on - some people might only be able to look over a lay summary because they have exams approaching but be interested in joining an advisory group in a year's time!

Sometimes, somebody is really interested in the co-applicant role and has time to dedicate to many of the tasks required but doesn't feel comfortable taking on the role officially. This might be because they don't wish to commit for the whole duration of the research project. Perhaps they have a condition that causes flare-ups that are difficult to manage. Or perhaps they might wish to move in a year and wouldn't be able to continue attending in-person meetings. Perhaps research remains an unknown quantity and they simply don't want to be equally responsible for a research project. In this case, you could discuss whether they would prefer to take on a similar-but-less-formal role such as 'patient partner' instead. In practice, the influence and contributions of a patient partner can be the same as a co-applicant, without the need to jump through the bureaucratic hoops of being formally added to the 'system'.

Further Useful Resources

Guidance developed by the BTRU in Organ Donation and Transplantation and NHS Blood and Transplant (NHSBT): *Great Expectations – inclusion of public co-applicants*
<https://www.rdsresources.org.uk/great-expectations-inclusion-of-public-co-applicants>

Guidance on completing PPI sections for NIHR grants

Read the application questions and any supporting information carefully to make sure you fully answer any PPI related questions.

Most NIHR applications ask 2 main questions about your PPI:

- 1) What PPI have you already done to inform this application?
- 2) What PPI do you plan to do during the remainder of this research?

Detail is important – aim for information about the 5 W's:

- Who was (and/or will be) involved?
- What have you (and/or will you) involved them in?
- When have (and/or will you) you involved them?
- Where in the research pathway have you (and/or will you) involve them?
- What activities have (and/or will you) involve them in? Why did you decide to do it that way?

Most importantly, you need to describe what you have done in response to the feedback gained through involvement. Specifics, specifics, specifics!

Instead of writing “we involved a number of patients throughout this project. They have provided excellent feedback”, try something like:

“Before we started writing this application, we met (via Zoom) with 5 patients that we recruited through our clinic and through a local patient support group. Their feedback has been incorporated throughout the application (details in the research plan) and they assisted in drafting and reviewing the lay summary. We also found considerable variation in their experiences, and they suggested we reach out to x patient support group with a short survey to gain a wider variety of experiences. We chose this approach because our planned intervention will be used in our clinic, and we wanted feedback both from patients who attend our clinic and from those with different experiences” etc etc.

Include details about the PPI you have already done

Outline how PPI has informed the development of the project so far. For example, involvement in shaping the research project outlined in the application, the study protocol, recruitment plans, data collection tools, information materials, outcome measures, follow-up, intervention design and delivery. Your public contributors can also support you in the development of your PPI strategy.

Include details about how you will continue to involve people throughout your project

Describe your plans for involving patients, carers and the public at each appropriate stage of the research project lifecycle. This might include being involved in recruitment, data collection, analysis, producing study materials, sitting on steering or oversight committees and sharing findings.

Demonstrate your PPI throughout the application

You can (and should) refer to your PPI throughout the application where relevant – for example when detailing the need for this project (your PPI contributors agreed it was important/patients brought it up in clinic), the project endpoints (determined in conjunction with your public contributors) etc etc.

Plan ahead for Stage 2

In the Stage 2 application you will be asked how the PPI will be managed, reported and evaluated. It is not necessary to provide the details for these in Stage 1, but these details are important to have in mind as you consider the role of PPI lead and design your PPI strategy.

Costing PPI plans

Each PPI activity and role mentioned in the PPI section or elsewhere in the application needs to be carefully and accurately costed. Take care to consistently describe the roles and activities you are planning, and use the same terms in the costing section – eg. if you say you will develop a 'PPI group' in your PPI plans, don't refer to them as your 'public representatives' in the funding section. Similarly, avoid confusing or conflating the PPI lead with public co-applicants etc.

Support for PPI Strategy Development

The NIHR Cambridge BRC PPI team is here to support you in the development and delivery of your PPI strategy. We are happy to meet with researchers at any stage of their applications or research projects to provide advice, support or signposting. We also have an extensive network across local and national NIHR infrastructure, research organisations and patient groups to help you find the information you need.

The PPI lead can also review PPI sections of research proposals and arrange for public feedback through the CUH PPI Panel.