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Patient and public involvement in research on the Cambridge Biomedical Campus

Key information to help you build PPI into your research

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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 ppi@addenbrookes.nhs.uk.

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Contents

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 'outsiders' 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 ppi@addenbrookes.nhs.uk 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

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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 significant 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 a "Document Review Request" form, provided by the PPI Team and return a completed version to the PPI Coordinator, along with a maximum of three documents 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 particular 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 or not 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 very 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, date and location. For in-person groups, the PPI Team have a meeting room that can be used when available. For virtual groups, the PPI Team Zoom can be used. 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 can't 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 various opportunities for researchers, patients and members of the public living in and around Cambridge including PPI training events, involvement opportunities and participation opportunities.

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 you would like us to share in our weekly roundup, please email ppi@addenbrookes.nhs.uk 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 Thursday noon in order 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.

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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 about how you might be able to incorporate PPI.

2. What will these documents be used for?

"Is this document for researchers or for patients?"

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 PIS 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. Where appropriate, the intended audience should also be clear within documents (e.g. patient information leaflets).

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 clear 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 medical and research 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 general public may not be aware of. In some ways, these kinds of words can be jargon in disguise, because they are similar to every day 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've 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 the document/between documents?

"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 also relate to each

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 too.

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.

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.

Equality of access

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 events.

Financial considerations

As when recruiting participants for research studies, payment rates need to strike the balance between maximising inclusion of as many voices as possible and creating coercive incentives. Please also direct contributors to seek personalised guidance before they accept any payments.

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.

Raw emotions

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 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.

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.

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Payment guidance for public contributors involved in 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.

There is no 'one size fits all' rule but offering payment may be more appropriate where involvement is on-going, comes with specific expectations, has a significant time burden, requires particular skills, experiences or expertise or where suitable contributors were selected via an application/acceptance model (akin to a job

interview). Conversely, involvement opportunities that are flexible, require little time or preparation, do not require specific skill sets and are open to anyone may be suitable for voluntary contributors.

Aims and expectations

Public involvement has the greatest impact when research teams have a good understanding of what they expect to gain from it. Everyone gets more out of the experience when expectations are made clear so that they can be adequately met by all parties. An awareness of what you hope they will achieve will help you determine who you need, what you want them to do and how long for.

Once this has been determined, it should be formalised for public contributors in a Role Description or Letter of Engagement that outlines the expectations (terms) of involvement, the level of support provided and details (amount and when, how and to whom they will be paid) of payments offered so that the public can make an informed decision about whether they would like to be involved.

Contributors in receipt of benefits

NIHR guidance from April 2021 states that payment (including non-cash payments such as gift vouchers) for involvement activities can be considered as income by HMRC and can therefore affect benefit entitlements. Benefits that have weekly earnings limits are affected by 'permitted work' rules, and people who are in receipt of such benefits are required to obtain prior permission to start paid involvement. Those in receipt of Universal Credit will need to notify the Jobcentre Plus of any earnings before their next payment is due. You may wish to look at the NIHR example letter outlining an involvement opportunity for provision to the Jobcentre Plus.

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 2021, 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.

Funding for payments and reimbursements

Funds for public involvement can (and should) be included as part of securing funding. Once public involvement opportunities and needs have been evaluated during the research design phase, expected costs for involvement should be included as part of the funding bid.

Claiming expenses

The following expenses may be claimed with the prior agreement of the Principal Investigator:

- 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). 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, published April 2021). 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, committees or recruitment panels	In-person or online	£25/hour during activity, plus expenses	Refreshments should be provided if activity is in 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.

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.

Question checklist for reimbursement planning

** This checklist is intended to inform **planning** for public contributor payments, not as a prescriptive or exhaustive list of items to cover before you begin activities!*

- Will I have the same contributors over time, or a mix of different activities (and thus payment rates)?
- What expectations (time/expertise etc.) do I have of them?
- What expenses will likely be incurred by contributors?
- What potential barriers to participation might they face?
- What PPI activities might be most suitable for contributors and my research?
- Am I aware of the resources available to public contributors in receipt of benefits and am I prepared to signpost them in the right direction?
- Have I prepared a 'role description' that can be given to potential participants outlining what involvement in my research would entail?
- Have I confirmed the correct procedure for reimbursement for my research team and can I find the forms etc that would be required for contributors to complete?

Please note that the full guidance on payment and reimbursement for researchers and professionals (published April 2021) can be found online.

Recognition and feedback

The simplest way to find out what form of feedback your contributors expect and prefer is to ask them! 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 and acknowledging the efforts of your contributors and they will expect to hear from you!

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. 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
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.	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.
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'.	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.

Reviewer 1: The term operational failure might confuse as it could be misunderstood for medical operations that have gone wrong.	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.
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?	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.
Reviewer 2: P3. 1.3 Impact. Last line - replace "have" with "provide"	Thank you, we have amended this.
Reviewer 2: P4. 1.5 should be Problems contacting other healthcare professionals about patients, not "others"	Thank you for noticing the typo, we have corrected this.
Reviewer 2: P4. 1.7 Impact. Second sentence should start "These problems can also increase…"	Thank you we agree with this as a suggested change. (Now found in section 1.5 in the final survey template)

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....	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.
Reviewer 3: I think all the draft text is perfectly patient-friendly – all completely clear and understandable.	Thank you for your feedback!

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.	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.
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.	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.
Reviewer 4 comment on 1.9 impact statement: Not sure this will be well understood	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 collborators at RAND Europe about previous survey rounds, this section is no longer included in the final template.

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 .	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".
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.	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.
Reviewer 6 comment: Surely this is under the control by the GP as they can set it to 'do not interrupt'.	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).

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PPI activity and impact record form

Project title:

Principal researcher/named PPI lead:

Date	Activity	Involved	Feedback (outcomes)	Actions taken (impact)
Research design phase				
20/04/2021	*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*
14/05/2021	*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.

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Example learning Log

Date	Collector	Perspective	Context	Learning
21/05/2021	*Dr Jones*	*Researcher*	*Discussion with patient in clinic*	*Hadn't responded to invitation as thought previous experience excluded her.*
12/06/2021	*M Smith*	*PPI coordinator*	*Focus group discussion*	*Several participants late, directions in guide wrong and arrangements for parking not well described.*
24/06/2021	*P Green*	*Contributor*	*PPI meeting*	*Meeting chair didn't realise who I was or why I was there. Felt a bit awkward.*
17/08/2021	*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.*
02/09/2021	*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.

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Selecting a PPI Lead for your project

NIHR Stage 1 Guidance Notes (updated April 2021) state 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 and have a project lead and research team that is willing to work closely with them. 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. 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.

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Guidance on completing PPI sections for NIHR grants

Please read the NIHR guidance 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) involve them in?
- When have (and/or will you) you involve 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.

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.