

PPI checklist for researchers

This resource is for researchers to plan or evaluate their PPI activities in the context of the NIHR's [UK Standards for Involvement](#). It can be used at any stage of the research project, i.e. before, during and after PPI activities.

The recommendations are based on findings from the PPI audit conducted at the University of Cambridge [Primary Care Unit](#) in 2020 (researcher survey and interviews with PPI representatives), and therefore is not intended to be a comprehensive guide. This checklist is a thinking tool to prompt reflection on your PPI activities at any stage, guided by the six Standards for Involvement. It may also be useful when putting together progress reports for funders!

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The checklist was put together by Miranda Van Emmenis and Lucy Lloyd (Primary Care Unit), Roberta Lovick and Phil Alsop (PPI representatives). The 2020 PPI audit on which this checklist is based was funded by the NIHR SPCR (grant G107172).

If you have any suggestions or resources to add to this document, please contact Miranda at mv404@cam.ac.uk

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1. INCLUSIVE OPPORTUNITIES

This is about offering public involvement opportunities that are accessible and inclusive for all

Recommendation	Actions
Accurately cost PPI to include accessibility requirements	<ul style="list-style-type: none">• E.g. childcare, carers, specialist support, translation, travel, accommodation.• See the NIHR payment guide
Ensure your PPI activities and events are accessible	<ul style="list-style-type: none">• Make involvement as easy and convenient as possible for members of the public, e.g. consider evenings/weekends and meeting online.• Make sure events are fully accessible for your PPI group. Ask PPI representatives what they need in order to carry out their duties.• Here is a handy checklist of questions to help you assess face-to-face accessibility requirements. It includes questions such as: <i>Can you pay for taxi transport? Is your catering clearly labelled?</i>• Gov.uk have produced a blog with advice for making events and presentations accessible, with considerations such as the readability of PowerPoint slides.
Widen recruitment methods to find people from underrepresented population groups	<ul style="list-style-type: none">• Consider reaching out to groups who are typically underrepresented in healthcare decision-making, also known as the 'seldom heard' or under-served.• This could include people who don't use the Internet, people from black and ethnic minority backgrounds, asylum seekers and refugees, people with mental health issues or learning disabilities.• Consider reaching these groups through existing community and/or faith groups.• The NIHR 'INCLUDE' project provides guidance for improving the inclusion of under-served groups in research. They host a free 1-hour online training course for researchers, on the NIHR learn website (requires NIHR identity gateway account).• For Black, Asian and Minority Ethnic (BAME) communities in particular, see this checklist to help when designing and recruiting your research/PPI.
Buddy system	<ul style="list-style-type: none">• If some of your PPI representatives are new to research involvement, consider pairing them with an existing, more experienced PPI representative for extra support.• Research can sometimes appear daunting or intimidating. A buddy system could help encourage a new member of public from an existing network to sign up who may previously have felt less empowered to get involved in research.

<p>Process payment and expenses as quickly as possible</p>	<ul style="list-style-type: none"> • Make it as easy as possible for PPI representatives to apply for expenses e.g. pre-fill expense forms, use prepaid envelopes. • Process expense forms promptly and if possible, update the PPI representative once the form has been submitted, so they get a rough idea of when to expect payment. • Be sensitive in discussions around payments. Some PPI representatives may want discussions to be kept private (e.g. some people may decline to accept payment). • See the PCU intranet quick guide for paying fees to patients and the public. It includes advice on whether fees are appropriate, how much to pay, and which Finance forms to use.
<p>Allow for fluctuating levels of input from PPI representatives</p>	<ul style="list-style-type: none"> • Health conditions of PPI representatives may need to be taken into account. Plan for fluctuating levels of input over time and make sure they know that they can dip in and out of the project as needed.

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2. WORKING TOGETHER

This is about valuing all contributions, building mutually respectful relationships with members of the public, with clearly defined roles and responsibilities

Recommendation	Actions
Have a clear job specification for recruiting PPI representatives	<ul style="list-style-type: none">• Create a 'job specification' listing both the planned tasks and the required attributes of the person (e.g. do you need someone with a specific health condition, or knowledge of ethics?)• The NIHR Involve website have put together a list of example PPI role descriptions and templates here, including working agreements for long-term projects.
Foster mutual respect	<ul style="list-style-type: none">• At the beginning of a project, set aside some time to listen to what PPI representatives have to say and reassure them that their input is valid and there are no wrong answers.
Provide specific instructions	<ul style="list-style-type: none">• When asking for comments on a document or piece of work, provide a list of <i>specific questions</i> to prompt the PPI representative.• Be clear about how detailed the feedback should be and which parts are amenable to PPI input and which cannot be changed (e.g. GDPR statements).• Consider sharing a guidance sheet for members of the public who are new to research/PPI. This one-page 'thinking tools' sheet provides tips and reassurance that there are no wrong answers in PPI.
Ensure meetings are managed effectively (in person or Zoom)	<ul style="list-style-type: none">• <i>Before the meeting:</i> set the rules for the meeting etiquette – how do people ask questions? How will you prevent people talking over each other?• <i>During the meeting:</i> make sure the Chair regularly checks in with the PPI representatives. A maximum group size of 6 to 7 will ensure everyone has a fair chance to contribute.• <i>After the meeting:</i> follow-up with PPI representatives to check if they have additional thoughts.
Virtual meetings – tips and advice	<ul style="list-style-type: none">• For tips on how to run virtual meetings, see the NIHR SPCR's comprehensive guide for researchers "How do I hold a PPI meeting using virtual tools?" This has helpful tips such as the importance of preparation and an inclusive meeting Chair.

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3. SUPPORT AND LEARNING

This is about offering support and development opportunities to build the confidence and skills of members of the public

Recommendation	Actions
Provide a point of contact for PPI members to receive support	<ul style="list-style-type: none">• Make sure PPI representatives know who to contact for questions and support, within the research team.• Check-in with PPI representatives regularly to see if they have any outstanding queries or needs in relation to the project. This small gesture goes a long way.
Provide induction materials for PPI representatives	<ul style="list-style-type: none">• Offer an introductory meeting or induction pack for PPI representatives at the beginning of the project.• This could include three types of information:<ol style="list-style-type: none">1) Background information on the research topic being studied – is there any scientific jargon that needs explaining?2) How the PPI work fits into the wider research project3) Signpost to guidance on how to approach PPI activities, such as the NIHR BRC ‘thinking tools’ sheet. This is particularly important for people who are new to PPI who might worry about saying the ‘wrong’ thing.• For example induction materials, see the induction pack from Cancer Research UK and a shorter two page induction document from the PCU’s CanTest project.• Note that even the most experienced PPI representatives can get nervous before meetings, especially if they are new to the group. Short pre-meetings with PPI representatives allow them to get to know everyone and build confidence.
Signpost to external training opportunities	<ul style="list-style-type: none">• Share a list of upcoming training opportunities or information sessions with members of the public. This could be online training or in person. (NB not all PPI representatives want to receive ‘training’ as it can take away from the unique perspective of a lay representative.)• The NIHR Cambridge BRC PPI coordinators based at Addenbrooke’s provide high quality information sessions for members of the public interested in PPI. They list information sessions and events on their website• Make use of free online training sessions provided by people across the UK. Keep an eye out for upcoming virtual training advertised on the @NIHRInvolvement and @CambridgeBRC Twitter accounts.

	<ul style="list-style-type: none">• The NIHR has a free, self-paced online course for members of the public who are new to PPI, called What Is Health Research?
Secure funding for internal training and events	<ul style="list-style-type: none">• For example, one research group in the PCU invited professional speakers to talk with the PPI panel about the research subject area and demonstrate some of the technical aspects/equipment related to the research.

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4. GOVERNANCE

This is about involving the public in research management, regulation, leadership and decision-making.

Recommendation	Actions
Create a PPI strategy	<ul style="list-style-type: none">• Have a strategy in place for involving members of the public in research. What do you want to achieve? What resources do you have (money, staff, time)? Review this plan regularly with the help of PPI representatives.
Endorse PPI at the highest level	<ul style="list-style-type: none">• Endorse PPI consistently and proactively at the highest levels of the research project. The stance of people in research leadership roles is important for setting the tone for meaningful involvement in governance.<ul style="list-style-type: none">- Ensure there is buy-in from the PI- Ensure PPI is allocated proper resources and time
Invite PPI representatives to collaborate at high level	<p>Some examples of involving members of the public at more 'senior' levels of a research project:</p> <ul style="list-style-type: none">• Name PPI representatives as grant co-applicants and co-investigators of project workstreams.• Bring a PPI representative to the ethics committee meeting to demonstrate the importance or relevance of the application to patients. Alternatively, as one PCU research group has done, pre-record a video message from the PPI representatives to play during the ethics committee meeting.• Similarly, bring a PPI representative to funding meetings if you need to request funding or time extensions - they can help argue the case.• Invite PPI representatives to co-author research publications and other outputs.• Invite PPI representatives to present at conferences on behalf of the research project.
Include 'PPI' as a stand-alone item on meeting agendas	<ul style="list-style-type: none">• Include a recurring 'PPI' slot on the agenda at team/project meetings. This will ensure that PPI is never an afterthought.• Invite PPI representatives to join team meetings, or share the minutes with the PPI representatives who are interested.
Ensure meaningful/genuine involvement for public and patients.	<ul style="list-style-type: none">• Above all, PPI should never be tokenistic or feel part of a 'box ticking' exercise. <i>"PPI members have at times been instrumental in steering many aspects of the research programme. Our time is precious, we deserve to be taken seriously, and not merely used to fulfil a criteria for involvement."</i> [Roberta Lovick, PPI representative at the PCU]

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5. COMMUNICATION

This refers to regular communication with PPI representatives in a timely manner and using plain language.

Recommendation	Actions
Provide a point of contact	<ul style="list-style-type: none">• Provide a clear point of contact for the PPI representatives to communicate with the research team.• It helps if you can offer both an email address and phone number- for some people, a brief phone call one-to-one is a more convenient way to provide comments than email.
Share regular updates on the project	<ul style="list-style-type: none">• Update PPI representatives regularly- even if the project didn't get funded, or if it's been a long time since the initial PPI activity.• Questions that PPI representatives will want to know:<ol style="list-style-type: none">1) What happens next for the project?2) When will you expect funding/ethical approval/results?3) Will you require PPI input down the line, and if so, when?4) What were the results of the study?
Share outputs and publications with the PPI representatives	<ul style="list-style-type: none">• Send all outputs and publications to PPI representatives – even if it's been years since their initial involvement. It helps them to feel part of the research process and motivated for future projects.• Include a lay summary for each publication.
Provide guidance on using teleconference software	<ul style="list-style-type: none">• Provide guidance on using teleconference software and offer alternative methods of communication for those unfamiliar with technology, such as telephone calls, letters or face-to-face meetings, which can be more accessible for some people.• If your PPI representatives aren't familiar with using video conference technology you can point them towards the NIHR's "how to" guides for Zoom and Microsoft teams, designed specifically for patients and members of the public.

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6. IMPACT

This is about identifying and sharing the impact that public involvement has on research and members of the public

Recommendation	Actions
Keep an up-to-date record of PPI activities and subsequent impact	<ul style="list-style-type: none">• Keep a centralised spreadsheet of all PPI activities conducted for your research project. Record details such as: <i>date, duration, people involved, what tasks did PPI representatives do? What changed as a result of PPI input?</i>• This record will come in handy when writing funder reports.• See template spreadsheets here (Excel) and here (Word doc).
Demonstrate recognition of PPI in research outputs	<ul style="list-style-type: none">• Name PPI representatives in outputs such as publications, or ask them to present at conferences.• This has two benefits i) it makes the PPI member feel valued <i>“it was a nice touch to be asked”</i> [Phil, PPI representative for the PCU] ii) promotes the profile of PPI to others.
Provide specific and meaningful feedback to PPI representatives on their impact	<ul style="list-style-type: none">• Show PPI representatives how they have made a difference to the research project. Be specific – did it alter your perspective? What did you change as a result of their input? Meaningful feedback is really valued by PPI representatives and makes them feel appreciated.• See this evidence-based guidance for researchers on how to provide feedback to patients and the public, including a template feedback sheet.
Evaluate the patient involvement activities	<ul style="list-style-type: none">• Encourage reflection from PPI representatives on their experience(s) working on the project, in order to improve PPI for future projects. This could be both during and after project completion.• E.g. ask PPI representatives <i>“What do you feel went well? Did you experience any challenges? How could your experience be improved in the future?”</i>

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