

# Our approach to Patient and Public Involvement & Engagement (PPIE) in our funded work



What does good public involvement look like?

People, teams and organisations in health research will often ask this question - of themselves as much as others. They know that high quality public involvement can make a real difference to research and to its beneficiaries. They want to evolve and improve their public involvement so it is the very best it can be.<sup>1</sup>

## **Contents**

<b>Introduction</b>	<b>4</b>
<b>Terminology</b>	<b>5</b>
<b>Patient and Public Involvement and Engagement –What it is (and what it isn’t)</b>	<b>5</b>
<b>The importance of PPIE</b>	<b>6</b>
<b>What does PPIE look like?</b>	<b>6</b>
i. <b>Advisory/consultative</b>	<b>6</b>
ii. <b>Collaboration</b>	<b>8</b>
iii. <b>Co-production</b>	<b>10</b>
<b>What should PPIE in ARC East Midlands look like?</b>	<b>11</b>
<b>When should I involve PPIE Partners?</b>	<b>12</b>
<b>What support can I expect from ARC EM?</b>	<b>12</b>
<b>Support for PPIE partners</b>	<b>13</b>
<b>Identifying PPIE Partners</b>	<b>14</b>
<b>Practical advice when planning meetings and events</b>	<b>15</b>
<b>Travel expenses</b>	<b>18</b>
<b>Evaluating involvement</b>	<b>20</b>
<b>Final stages of involvement</b>	<b>20</b>
<b>Appendix</b>	<b>21</b>
<b>References</b>	<b>22</b>

## Introduction

An internal evaluation of NIHR CLAHRC East Midlands' Patient and Public Involvement and Engagement (PPIE) practice (conducted between 2016-19) found a discrepancy between policy and practice regarding how PPIE was carried out in CLAHRC EM funded research projects. A wealth of resources, including **INVOLVE guidelines**, the **Public Involvement Impact Assessment Framework (PiiAF)** and an internal strategic document composed by the then PPIE Lead, were available, but many researchers were either unaware of these documents or felt that the ideas and principles they presented were inappropriate and/or unrealistic for their project.

There was a perception that for all health and social care research, the 'gold standard' of PPIE was co-production with PPIE partners throughout the duration of the project cycle (from application to implementation). The breadth of projects across NIHR CLAHRC EM meant that for many projects, this was an unattainable, inappropriate model of PPIE. As such, a tailored, flexible approach was requested to identify good practice that could be applied to NIHR ARC EM projects. This document outlines this approach.

Three separate reviews were conducted to produce this document. These were:

1. An umbrella review (a summary of systematic reviews) of stakeholder involvement within the health sector and from other selected sectors.
2. A review of existing INVOLVE guidelines.
3. A review of Association of Medical Research Charities (AMRC) and Medical Research Council (MRC) public involvement and engagement strategies.

**This document was produced by Chris Craig, Graham Martin and Oli Williams. The copyright © belongs to NIHR ARC East Midlands. It was last updated in November 2019 by Emma Rowley.**

## Terminology

- Patient and Public Involvement and Engagement will hereafter be referred to as **PPIE**.
- Patient and public representatives will be referred to as **PPIE partners** to affirm ARC EM's commitment to a collaborative approach to applied health and social care research.
- **CLAHRC** stands for 'Collaboration for Leadership in Applied Health Research and Care' – applied healthcare research organisations funded by the National Institute for Health Research from 2008-13, and 2014-19.
- **ARC** stands for 'Applied Research Collaboration', the successor bodies to CLAHRCs, funded from 2019 onward.
- **INVOLVE** is the National Institute for Health Research's national advisory group on PPIE in health and healthcare research.

## Patient and Public Involvement and Engagement – What it is (and what it isn't)

INVOLVE defines PPIE as research which is “carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”<sup>2</sup>.

PPIE can occur at any point in the research process, from identifying a research question right through to influencing policy makers when disseminating the results.

'Involvement' is often used interchangeably with 'participation' or 'engagement'. Here, we define the terms slightly differently. Participation is when patients or health volunteers take part in research projects as a subject. This is when research is done to them, not with them. Engagement is when information on research is shared with the public, for example by hosting public talks, writing publicly available blogs or holding outreach events to publicise research.

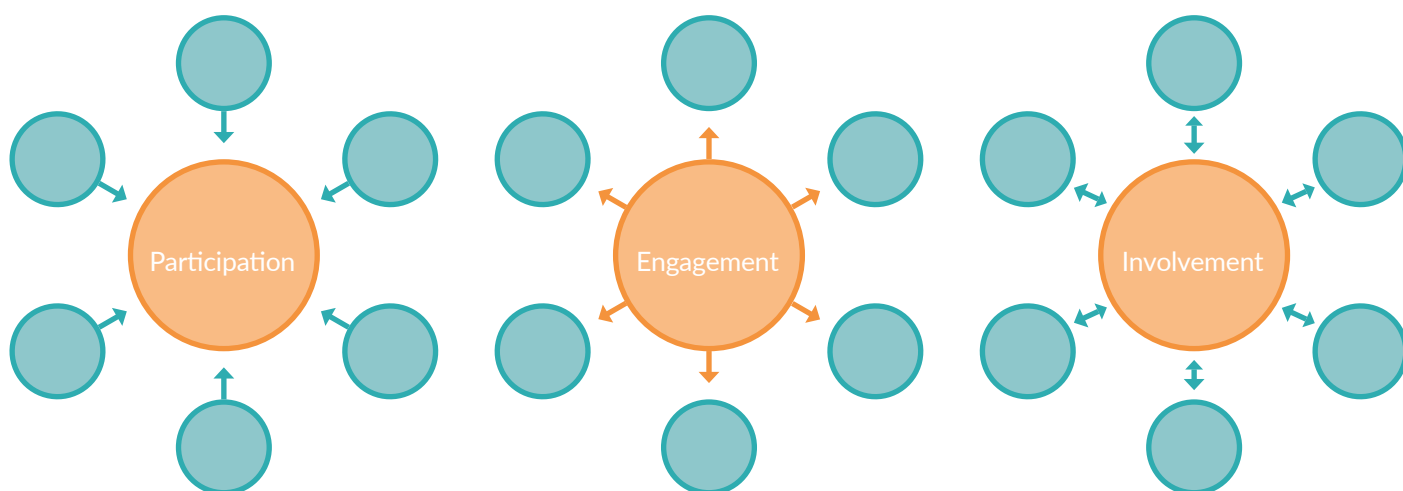


Figure 1: Taken from 'Patient and Public Involvement – A researcher's guide' by Arthritis Research UK<sup>3</sup>

## **The importance of PPIE**

PPIE is a necessary requirement for research funded by the NIHR and many other funding bodies. A clear description of how PPIE partners will be meaningfully involved needs to be demonstrated in a funding application.

PPIE partners bring a unique perspective arising from their experience of living with, or caring for someone with, a healthcare condition. Learning from and incorporating these experiences promotes better quality research which prioritises the care of patients in its design, not just the 'causes' or 'cures'.

## **What does PPIE look like?**

Three particular methods for involving PPIE partners—'advisory/consultative', 'collaboration', and 'co-production'—are discussed in this section. They are illustrated with examples from health and social care research, and from other fields such as environmental planning and the built environment, to encourage NIHR ARC EM researchers to take a tailored approach when planning and implementing PPIE on a strategic or operational level in their work.

### **i. Advisory/consultative**

Advisory/consultative involvement is characterised by involving PPIE partners in one-off exercises, or a series of exercises which can take place at any point of a project where a lay perspective on a specific issue or issues is required. There are a variety of ways PPIE partners can be involved using advisory/consultative methods: online/postal surveys, one-on-one interviews; focus groups and so on<sup>4, 5, 6, 7</sup>. These are outlined below, along with some advantages and disadvantages (adapted from the Cancer Research UK PPIE toolkit for researchers)<sup>8</sup>.

Table 1: Characteristics of commonly used PPIE advisory methods

Surveys	Interviews	Focus Groups
<p>A set of questions designed to gather opinions and perspectives from many people to inform and shape your research project. A time efficient way of gathering views.</p>	<p>An in-depth conversation that allows you to gather richer information. Interviews can be conducted face to face or over the phone and can be structured, semi-structured or informal. Expenses (if face-to-face) should be offered to participants if they travel to meet with you.</p>	<p>An event where you bring a group of people together to take part in well planned and facilitated discussions on a topic. You can use different activities and facilitation techniques to gather insights. Focus groups generally run over a half or full day. Expenses should be reimbursed, and refreshments, including food if appropriate, should be provided.</p>
<p>£££ £££ £££  </p>	<p>£££ £££ £££  </p>	<p>£££ £££ £££  </p>
<p>Advantages:</p> <ul style="list-style-type: none"> <li>- Potentially large samples</li> <li>- Time efficient</li> <li>- Responses can be analysed with quantitative methods</li> </ul>	<p>Advantages:</p> <ul style="list-style-type: none"> <li>- Good for complex issues</li> <li>- Can clarify questions or answers</li> <li>- Rich qualitative information</li> </ul>	<p>Advantages:</p> <ul style="list-style-type: none"> <li>- Good for complex issues</li> <li>- In-depth discussion</li> <li>- Group can bounce ideas off each other</li> </ul>
<p>Disadvantages:</p> <ul style="list-style-type: none"> <li>- Can't clarify questions or answers</li> <li>- Can't gather in-depth insights</li> <li>- Limited on the type and number of questions</li> </ul>	<p>Disadvantages:</p> <ul style="list-style-type: none"> <li>- Small sample size</li> <li>- Time consuming</li> </ul>	<p>Disadvantages:</p> <ul style="list-style-type: none"> <li>- People can be influenced by others' opinions</li> <li>- Time consuming</li> <li>- Potentially more expensive</li> <li>- Not always accessible to some groups</li> </ul>

£ Cost /  Reach /  Time

The most obvious benefit of using advisory methods for PPIE is that a large number of views can be collected even though it is not as time consuming, costly or labour intensive as some other forms of involvement. This can result in instant feedback on aspects of your project, e.g. simplifying patient recruitment information, which can have a significant positive effect on the outcome of your project.

While you may appreciate the instant feedback from PPIE partners on information you present to them, this overlooks an inherent weakness of advisory approaches – that PPIE partners have only a short period of time to consider the information presented to them to make informed comments<sup>9</sup>. Many researchers use an advisory PPIE approach and while this can be a helpful way of involving PPIE partners, there are warnings that should be heeded when using this approach. Because advisory/consultative methods are not as onerous or costly as other methods, there is a temptation to use this approach even in a one-off, superficial way. Projects adopting this approach are vulnerable to accusations of being tokenistic and seeking legitimacy, especially if PPIE partners are involved midway through your project so that any comments made will have little impact on the design or results of the study<sup>10, 11</sup>. This may prevent more meaningful PPIE, which has real consequences for the way the study is done, and the potential for it to be a genuinely useful exercise in developing and strengthening a research project.

Inviting feedback on specific aspects of your project might be done using Facebook, Twitter or other online forums, though it is important to be sensitive to people's preferences in the way they use these media. While online methods can potentially help to broaden the pool of stakeholders providing input into your research, there are disadvantages to relying on an online approach. Patients who have had negative experiences may wish to seize such opportunities to vent their frustrations of their experiences, and it may not be straightforward to make use of these insights in developing research studies. Likewise, there may be an over-representation of 'digital natives' which may mean that some perspectives are more prevalent than others<sup>12</sup>. You may wish to use this approach as an adjunct to other methods to get the most from it<sup>13</sup>.

## **ii. Collaboration**

Collaborating with PPIE partners is characterised as a process whereby decisions are shared between all stakeholders, including PPIE partners, who have influence throughout a project (as opposed to the ad hoc input at particular points in time that usually comes with advisory/consultative approaches). Researchers will need to develop a strategy for collaborating with PPIE partners, with a clear rationale for who will be invited to be involved, in relation to what aspects of the study, and when.

Different approaches are permissible at any stage but there should be a reasoned justification for why a particular approach will lead to meaningful PPIE. It might be useful, for example, for research teams to invite a PPIE partner to sit on the interview panel when recruiting prospective members of the research team<sup>14</sup>. Training PPIE partners to conduct data collection (quantitative or qualitative) is another potentially fruitful approach, particularly if there are reasons to believe they might be better able to do this than professional researchers. For example, training PPIE partners to recruit participants from



so-called 'seldom-heard' groups has proved effective at reaching groups whom researchers may struggle to access and engage with<sup>15, 16, 17</sup>. They will need to receive training on research methods and Good Clinical Practice, and may be subject other organisational clearances (e.g. Disclosure and Barring Service check) and policies (e.g. Lone Working).

Having individuals on the research team with lived experience of a condition that the research relates to will help refine the study design, including the strategy for recruiting participants. Flurey highlights **the benefit of co-designing a study looking at the effect of rheumatoid arthritis (RA) in men**: "Involving people with RA has enabled me to design studies in the way most acceptable to patients, to encourage engagement and participation".

Reviewing written material provided to prospective participants to ensure it is sensitive to their situation and is easily understood is essential – something which might be overlooked by other members of the research team. Research funding bodies are increasingly expecting Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) as outcome measures which are most important to patients but still maintain scientific excellence. Even then, it is important to ensure that the choice of PROMs and PREMs is seen as appropriate by the people who will be involved as research participants, who will be the ones completing the questionnaires, as well as to practitioners, to ensure that the measures are commensurate with those that would be used normally in standard health/social care situations.

PPIE partners can also support the analysis of collected data. For example, reading research interview transcripts through the lens of a patient/public/practitioner perspective can help to identify themes which directly align with their experiences.

Once data have been analysed, PPIE partners can also prove invaluable when planning and implementing dissemination and implementation strategies. For example, Cancer Research UK's 'Ambassador Programme' encourages PPIE partners to actively persuade policy makers to invest in cancer services. This includes corresponding with their MP, engaging with the local community, lobbying Parliament and engaging with local press to highlight research funded by Cancer Research UK<sup>18</sup>. One of the conditions for researchers applying for an Alzheimer's Society's Implementation Grant is that "at least one person affected by dementia must be listed as a co-application on the project"<sup>19</sup>.

The level of expectation placed on PPIE partners increases when collaborating, so we encourage researchers to develop a 'role, responsibilities and expectations' document for researchers and PPIE partners alike (akin to a job description and person specification – a template can be found in the appendix of this document). This will also outline the support PPIE partner/s can expect from the research team.

One area of support PPIE partners may require is training in research methods – especially if they are going to be involved in recruiting participants, or in data collection. This is a particularly good example of collaborating with PPIE partners as many participants may feel more comfortable being approached about research, or recruited to a project, by a peer rather than a researcher<sup>(16)</sup>.

### iii. Co-production

Co-production of research with PPIE partners is very similar to collaborative approaches with two key distinguishing features.

First, PPIE partners will help to define the research topic/question in addition to collaborating with the research team using methods explained in the previous section. For example, the AMRC funded research charity Bloodwise consulted over 2000 patients, families, carers, healthcare professionals and researchers to establish a comprehensive core of research priority questions. The 'Patient Need' survey identified six priority areas which were priorities for patients, such as the greater provision for signposting to resources for patients affected by blood cancer. This is similar to the James Lind Alliance's 'Priority Setting Partnerships' (PSPs) which bring together patients, carers and clinicians to identify and prioritise research questions on specific topics.

Second, there is "joint ownership of key decisions"<sup>20</sup>, with a view to securing a relationship of equals across the research team. An easier way to differentiate between collaborative and co-produced approaches is that all co-produced research is collaborative, but not all collaborative research is co-produced (since it may not attempt to involve PPIE partners as equals, involved at every stage in the process including the definition of the research topic/question—or it may not succeed in doing so).

PPIE partners who co-produce projects in NIHR ARC EM may also be involved in the formation of a research topic/question, study design, conducting parts of the study (e.g. recruitment, study site visits, data analysis) and dissemination of the results. Therefore, there are greater expectations and accountability for PPIE partner/s, as well as a stronger influence on the study. As with collaborative approaches, the first step researchers should take is to develop a 'role, responsibilities and expectations' document. This may extend to providing a formal contract of employment to the PPIE partner for the duration of the study, if the activity is agreed by all to be 'work', and should be recompensed with an appropriate level payment and employment rights.

There are examples of co-produced randomised controlled trials (RCTs)<sup>21</sup>. RCTs can be conducted to evaluate a wealth of interventions, so if you need to identify the needs of the local population, consider working with PPIE partners to design an RCT. Recruiting PPIE partners to a Trial Management Group (TMG) or a Trial Steering Committee (TSC) is one way of achieving this<sup>22</sup>. The role of PPIE partners in TMGs and TSCs ranges from contributing to the research proposal, designing or refining participant materials, visiting study sites to ensure the participants are being recruited according to the protocol, making suggestions to improving the recruitment/follow-up rates, checking the quality of data being returned, disseminating the results of a project and contributing to academic outputs. A co-produced approach would encompass all of these contributions. It can be particularly beneficial to co-present the results of your project with a PPIE partner with whom you have worked, as this may help in communicating findings clearly, promoting public trust in your research, and showing how your research is grounded in patients' needs.

## **What should PPIE in ARC East Midlands look like?**

The Meaningful PPIE Spectrum (Figure 2) has been developed to help researchers plan a tailored, flexible PPIE strategy which involves PPIE partners in a meaningful way in their work (i.e. which has consequences for the design and realisation of the study) and to show that there is no singular 'right' or 'wrong' way of involving PPIE partners. As a starting point, we encourage researchers to consider the question "what do we know about the needs of the local population or groups?"

If the needs of local populations are already well defined (e.g. a higher than average rate of HIV in specific local demographic groups) then researchers should focus on collaborating with the relevant populations to strengthen the research design, delivery and dissemination of results of project/s which address this need/needs. Seeking advice or consulting PPIE partners is a valid approach – but this should be complemented with other collaborative methods which meaningfully involve PPIE partners.

If there is little evidence on what the needs of the local population are, then a more co-productive approach will be required to listen to groups of patients and the public in order to establish what their needs are. This might involve, for example, developing a project with local communities to establish what their health priorities and unmet care needs are that could be addressed through applied health research. Once the needs of local populations have been identified, then researchers should continue to collaborate with PPIE partners to design and deliver the project. Such an approach can help NIHR ARC EM ensure that our research portfolio addresses local needs rather than merely reflecting the research interests of researchers working locally.

Whatever approach you develop, it is important to ensure that all those involved (professional researchers, PPIE partners and other stakeholders) are clear about how their inputs will be valued and drawn upon. In a truly co-produced study, these norms and expectations should be developed with PPIE partners (not imposed on them by professional researchers). For other forms of involvement, be clear from the start with all those contributing to the study—including prospective PPIE partners—about the scope of their involvement, and about where accountability and decision-making authority lies. State that while you value their input, just like any other member of the research team, not all their suggestions and recommendations will be incorporated in to the project. Tempering expectations is essential in avoiding conflict later on in the project, as is ensuring that when reporting PPIE activities you can demonstrate how PPIE partners have influenced the project.

Additionally, it is important to note that all involvement takes place within an organisational structure and so decisions made at the application phase regarding which projects to fund, what are deemed the most appropriate methods to conduct this research (e.g., an RCT for a new approach to diabetes prevention), and what is considered legitimate costing for PPIE activities will in part determine the type and quality of PPIE that occurs at project level. Therefore, the responsibility to deliver meaningful PPIE is a shared one between NIHR ARC EM's decision-making structures and the researchers we fund.

## ARC project selection



### Practicalities of conducting different types of research

## When should I involve PPIE Partners?

NIHR ARC EM encourages our funded research teams to involve PPIE partners as early as possible in the study development phase. Even before you have received funding, attend meetings of local patient groups to listen to their concerns about their care and what their health needs are. Having contact by phone, post or e-mail to get input from potential PPIE partners before the research question is defined and a funding application is submitted does not cost a lot, but will help to ensure your project is grounded in the needs of the relevant population.

A beneficial by-product of early involvement is that it engenders a sense of collective ownership of the project. Establishing what is expected of all members of the research team, and the scope of what the project is expected to achieve, is an important approach to ensure there is not a fundamental and potentially detrimental difference of opinions later on in the project.

## What support can I expect from ARC EM?

NIHR ARC EM will provide training for all researchers to understand the principles and practicalities of stakeholder engagement (including involving PPIE partners). Additionally, there is a wealth of interactive learning material available to train researchers available from [INVOLVE](#) and the [Patient Centered Outcome Research Institute](#).

Our study teams may also wish to draw on the guidance offered by our local NHS partners in their involvement strategies:

- [University Hospitals of Leicester](#)
- [Nottinghamshire Healthcare NHS Foundation Trust](#)

## Support for PPIE partners

Being a PPIE partner can be a challenging experience for some people, for instance, if they are unfamiliar with a research environment or re-living negative experiences. Pairing the PPIE partner with another PPIE partner who has greater experience of being involved in research as a mentor is recommended. Name a member of the research team with whom PPIE partner/s can discuss any concerns they have, or discuss any project-related issues.

Depending on the nature of their involvement, some PPIE partners will need additional training. If they are going to be involved by recruiting participants, Good Clinical Practice (GCP) training will need to be provided and adhered to. Additional training in research methods and research ethics may also be required to educate PPIE partners about the processes which researchers have to adhere when conducting research.

Within the East Midlands, PPIE partners are also able to access support and training from the [Sharebank](#) team.

## Identifying PPIE Partners

If your project relates to a specific health/social care issue, NIHR ARC EM require that at least one PPIE partner with lived experience of that issue should be involved on your project (see funding application form). It can be difficult to identify PPIE partners you can meaningfully involve, but there are a number of avenues to explore to help broaden your network. The first place to start is to discuss your project with the NIHR ARC EM Programme Managers and the Community Voices Panel who may have contacts within their networks, and who are willing to discuss involvement in your project with you.

Contact established charities and voluntary groups working in the area you are interested in researching to develop links with them, with a view to identifying well-suited and willing PPIE partners who may be invited to join your team. Likewise, contacting service providers directly and developing links with them can be helpful. Health and social care professionals working in these environments are crucial gatekeepers, so contact these people and ask them to make patients aware of the opportunity to become involved in research. The Patient Advice and Liaison Service (PALS) at your local NHS Trust may also be able to circulate information about your research to interested parties.

The '[People in Research](#)' website advertises opportunities for PPIE in the NHS, public health and social care research. This online forum allows you to add your opportunity for PPIE to identify members of the public to get involved in your research. Prospective PPIE partners can then browse opportunities for involvement. This approach can be particularly useful if there is no specific patient group in the East Midlands, meaning you have to extend your search to other regions. Opportunities advertised on this website cover all aspects of research:

- Identifying and prioritising
- Commissioning
- Designing and managing
- Undertaking
- Disseminating
- Implementing
- Evaluating impact
- Reviewing

There are many special interest patient groups (local and national) in primary and secondary care who have an interest in research on topics which directly affect them. If you use this approach, it is important to listen to the group's interest rather than imposing your research proposal on them to build relationships with prospective PPIE partners. If you are unable to attend, send some information by post or e-mail to them with your contact details should anyone in the group be interested in discussing further.

Social media such as Twitter, Facebook and YouTube have all been used to identify PPIE partners. The EcLiPSE (Emergency use of Levetiracetam vs Phenytoin in Status Epilepticus) trial used Facebook to identify parents of children who had been admitted to emergency care who then co-designed patient information sheets and the study design<sup>23</sup>.

Using social media to identify prospective PPIE partners is a novel method, and arguably should not be the main method for identifying PPIE partners. Some people may view their social media as private, and may not wish to be involved in this way. For further information on the pros and cons of identifying PPIE partners through social media, INVOLVE have produced an [in-depth guideline](#). You may also like to read the recent [guidance](#) from the Health Research Authority, and the recently published [standards for PPIE](#).

## **Practical advice when planning meetings and events**

It is easy to overlook some of the practical measures which need to be considered when planning meetings or events. Some things are relatively intuitive i.e. asking about dietary or access requirements, though, should not be overlooked. Other practicalities may not be immediately obvious to the research team, yet these, if not acted upon, can prevent PPIE partners from attending and providing input.

A prime example is location; meetings should be arranged to take place at venues appropriate, convenient and comfortable for all those involved. This may be a university building, NHS/social care premises, a faith centre, or the offices of a charity. The decision of where to hold meetings should be a collective one that takes into account the comfort and convenience of all participating members. This may mean alternating meetings between two locations (e.g., a university building and charity office) so as to ease the travel burden.

The timing of meetings also needs to be agreed upon. Meetings/events held in office hours may exclude those of a working age, though meetings held in the evening may be more challenging for those with family commitments. The perfect time and venue are unlikely to be found, therefore, careful consideration of the relative pros and cons of different options should be made.

Depending on any impairments which PPIE partners may have, it might be necessary to conduct an 'access audit' prior to deciding on a meeting venue. This can normally be done fairly quickly, but you will need to ensure:

- Disabled parking spaces adjacent to the venue.
- The venue is easily accessed using public transport routes (for those who don't drive).
- The venue is not a significant distance from their home and is easy to find (make sure to include a picture of the venue on any pre-meeting correspondence).
- The venue and meeting room are fully accessible (this may include being wheelchair accessible, stairs that have a rail to hold on to and the room is fitted with a hearing loop for those with hearing difficulties).
- Signs which make it clear where the meeting room is and where the emergency exits are, and easily accessible toilets close to the meeting room.

Best practice – which we encourage all our NIHR ARC EM funded teams to follow, is to ask people when inviting them to a meeting or event, what would enable them to attend and participate, and to always provide contact details of someone they can get in touch with to discuss needs and concerns, if they wish to.

During meetings, ensure that all PPIE partners know that they are free to leave meetings or have a break from involvement at any time. In some cases, PPIE partners may have particular health and wellbeing needs that should be accounted for in planning meetings. Careful consideration should be given to the content included in meetings, and its potential to cause anxiety or upset to those attending. If appropriate, those attending the meeting should be given warning at the start of meetings about any potentially 'triggers', and informed about spaces nearby to which they can retreat. Have contingency plans in place in case a PPIE partner becomes upset due to the nature of the topic being discussed and if necessary, know where to signpost them for any support.

Develop an agenda and send this to PPIE partners, along with any pre-meeting material, at least two weeks ahead of any meetings to allow ample time to read and digest the information. If necessary, post this information rather than just providing it in an e-mail – not everyone has printing facilities. Ensure at least one named contact is available before the meeting to discuss or clarify any points so all stakeholders are on the same page.

Once meetings are underway, it is necessary to reaffirm the footing of all stakeholders, and ensure that all contributions are listened to and given due consideration. Appoint a chair who will ensure that clear language (avoiding specialist / academic jargon) is used throughout, that all stakeholders understand what is being discussed, and that everyone is given a chance to contribute. Appoint someone else to take minutes. Ensure that sufficient breaks are factored into the agenda so there is no information overload. Having someone attend, such as a mentor or advocate, may be useful in supporting PPIE partners during the meeting if they do not have the confidence to voice their opinion. Ask all those attending in the meeting if they have any recommendations to enhance future meetings. Once the meeting has concluded, circulate the minutes and a summary of the meeting.

## **Payment**

NIHR ARC EM recognises that it is good practice to offer compensation for time and effort incurred, and expertise shared through PPIE activity. There is, however, no obligation for PPIE partners to accept this payment. If they do, the onus is on the PPIE partner to report this to the HMRC, and to manage any tax or benefit related issues that may arise from receiving the payment. PPIE partners choosing to accept payment for their time/expertise will be required to sign up as a casual member of staff at the organisation that employs the research team, as this is the only payment mechanism available to us. For details on how to do this, please contact your ARC Programme Manager.



Suggested rates of payment to be offered according to particular types of PPIE activity are outlined in the table below. This is not an exhaustive list; for agreed PPIE activities falling outside of these suggestions, we recommend that you use the information below to inform the offer you make to your PPIE partner. As with the suggestions below, the guidance marked \* must still be followed.

PPIE type	Description and role / activity examples	Suggested rate*
Category A	“Open access opportunities” – such as attending drop-in sessions, seminars, training, conferences by choice (i.e. not requested by ARC research team).	No payment offered; no travel expenses reimbursed.
Category B	Expert Adviser Role, to include lay reviewer of research applications.	£20 per activity; no travel expenses reimbursed.
Category C	Attendance at one-off events, such as a focus group to inform part of a research study (involvement / engagement NOT study participant i.e. research consent should not be taken)	£10 per hour (up to 2 hours maximum). Travel expenses reimbursed.
Category D	Expert Adviser Role, to include preparation (i.e. reading papers, making notes) and attendance at ARC panels (interviews, Scientific Committee, funding and peer review panels), and responding to any actions / post meeting requirements.	£10 per hour, to include travel time (up to a maximum of 7 hours per session). Travel expenses reimbursed.
Category E	Expert Adviser Role, to include regular attendance at ARC working groups (such as the Community Voices Panel, research study meetings), demonstrating strategic and accountable PPIE leadership and decision-making.	£10 per hour (up to 3 hours long). Travel expenses reimbursed.

\*Payments and activities must be agreed in advance, between the ARC research teams and the PPIE partners, and should be approved by an ARC Programme Manager. There is no expectation that payment must be taken – but it must be offered (and so research teams must ensure that they have an appropriate budget set aside).

If payment is taken, the PPIE partner must sign a disclaimer acknowledging that they are responsible for disclosing the funds to HMRC and any benefits office, as appropriate.

If payment is not taken, a disclaimer form must be signed by the PPIE partner, and kept by the research team in the study files. Payment rates offered must equate to more than the national living wage, which in October 2019, was £8.21 per hour.

A useful document providing an overview of payment considerations and HMRC implications can be [found here](#).

## Travel expenses

Rates of reimbursement must be made clear to PPIE partners and should be offered in every case. PPIE partners have a right to refuse the reimbursement of expenses for any reason (or no reason), but NIHR ARC EM teams must ensure that reimbursement of expenses is always offered.

Travel expenses should be offered at the non-staff expenses rate of your employing organisation, using the relevant non-staff expenses form. Reimbursement will usually be made via BACS payment direct into the PPIE partner's bank account. For example:

Organisation	Car (driver only)	Car (with passenger attending the same meeting / purpose)	Motorcycle	Bicycle
University of Nottingham	45p per mile	N/A	24p per mile	20p per mile
University of Leicester	45p per mile for the first 80 miles of a round trip, and then 31p per mile	45p per mile for whole journey (passenger must be named in the claim)	15p per mile	12p per mile
Nottinghamshire Healthcare NHS Foundation Trust	45p per mile	+2p per mile in addition to the 45p per mile	24p per mile	20p per mile
University Hospitals Leicester NHS Trust (as per NHS Employers, Agenda for Change rates of reimbursement)	56p per mile (up to 3,500 miles p/a)	+5p per mile in addition to the 56p per mile	28p per mile	20p per mile

Car parking charges or public transport fares (including taxis where required) incurred as part of PPIE activities should be reimbursed using the relevant non-staff expenses form. Please advise PPIE partners that receipts / parking tickets will need to be submitted as evidence.

Make it clear to PPIE partners that they are responsible for making sure their car is legally parked and any blue badges are correctly displayed – any parking fines incurred are their responsibility and cannot be claimed for. PPIE partners also need to ensure their car is taxed, insured, and any breakdown policy is valid.

Rail travel should be booked in advance where appropriate by a member of the ARC administrative team, unless flexibility is required in time of travel; any railcards or other discounts available to the PPIE partner should be used. If possible, ensure ARC pays directly for train tickets, removing the need for this expense to be reclaimed at a later date (leaving the PPIE partner temporarily out of pocket). Please note that ARC will only cover standard class travel and **not** first class travel. Ensure the PPIE partner informs you of any practical assistance they may need when alighting the train. Where a taxi is required, for example for PPIE partners with accessibility needs, this must be agreed in advance with ARC. A fixed price can usually be negotiated.

In the evaluation of CLAHRC EM, it was found that it was common for PPIE partners not to reclaim their expenses due to the administrative burden involved. The administrative burden for claiming expenses should fall on the research team, not the PPIE partner. A member of the research team should take responsibility for completing the relevant non-staff expenses form with each PPIE partner after every meeting /claim, and ensure that this is sent off for processing and payment.

All short meetings should be catered with refreshments. Some meetings will need to provide a lunch or dinner (depending on the time of the meeting). Alternatively, a meal allowance per PPIE partner may be set, and should be included in the expenses reimbursed. The rate of meal reimbursement will be dictated by your employing organisation's expenses policy.

## Evaluating involvement

Evaluating PPIE is a requirement for all projects in the ARC EM portfolio. It is important to understand what went well and what needs to be improved in the future. To help guide evaluation, two documents which have been designed specifically for evaluating PPIE are:

- [Public Involvement Impact Assessment Framework \(PiiAF\)](#)
- [Guidance for Reporting the Involvement of Patients and the Public \(GRIPP\)](#)

Evaluating PPIE is often an afterthought. Partly in consequence, there is only a small evidence base to highlight the effectiveness of PPIE in health and social care research. INVOLVE are always keen to hear of the impact PPIE has had on projects and have developed an [evidence library](#) for researchers to contribute to.

## Final stages of involvement

It is important to start preparing PPIE partners involved on your project when things are nearing an end. Consider having an exit interview with all PPIE partners involved on your project to discuss how their suggestions have made an impact on the project (or if they have not, why their suggestions have not been implemented). This shows PPIE partners you genuinely value their input and how things have changed thanks to their involvement. This can be structured in the following way:

1. Summarise what the original aims and objectives of the project were
2. How PPIE partners were involved
3. What the contributions of PPIE partners were
4. How these suggestions have been implemented
5. Anything else you'd like to add

PPIE partners may also be instrumental in helping to get your study implementation ready, and working with the ARC's Implementation Hub (in collaboration with you) to develop potential pathways to impact.

## Appendix

**Role Title:** NIHR ARC East Midlands PPIE partner for the [ ] study.

**Study Start/End Dates:**

**Summary of role:**

The ARC PPIE reimbursement policy suggests 5 role types / payment levels. These should be agreed prior to activity is undertaken.

Outline what the PPIE partner will be expected to do on the project. This can be as little or as much as possible, depending on the role. The following can be considered for inclusion in this section:

- Meetings to attend in person – if possible include dates, location and frequency of meetings.
- Expectations of preparation to be done ahead of meetings i.e. reading the circulated material.
- The perspective they can provide – i.e. lived experience of living with a condition, being a carer for someone.
- Activities associated with the role – i.e. providing comments on participant information material, recruiting participants, analysing data.

**Payment and expenses:**

- ARC teams must offer reimbursement for time/skills/expertise. There is no obligation for PPIE partners to accept this. If however payment is taken up, then the PPIE partner must register as a casual member of staff in the research teams' employing organisation.
- All claims for reimbursement of expenses should be made on the relevant non-staff expenses form of the research team's employing organisation.
- Remember to tell PPIE partners that reimbursement of expenses will most likely be made via a BACS payment directly into their bank account.

**Support:**

Give a named individual or individuals who the PPIE partner can contact to discuss project related material i.e. to clarify any misunderstanding ahead of meetings, to signpost to any additional training/ resources required for the PPIE partner to execute their role or if they have any concerns.

**Glossary of frequently used terms:**

Provide clear definitions to frequently used terms and acronyms for PPIE partners to refer to.

## References

- 1 [https://www.invo.org.uk/wp-content/uploads/2019/02/71110\\_A4\\_Public\\_Involvement\\_Standards\\_v4\\_WEB.pdf](https://www.invo.org.uk/wp-content/uploads/2019/02/71110_A4_Public_Involvement_Standards_v4_WEB.pdf)
- 2 INVOLVE (2012) Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh.
- 3 Arthritis Research UK. Patient and Public Involvement: A Researcher's guide.
- 4 Forsythe LP, Szydowski V, Murad MH, Ip S, Wang Z, Elraiyah TA, et al. A systematic review of approaches for engaging patients for research on rare diseases. *J Gen Intern Med.* 2014;29(SUPPL. 3):S788-S800.
- 5 Price A, Albarqouni L, Kirkpatrick J, Clarke M, Liew SM, Roberts N, et al. Patient and public involvement in the design of clinical trials: An overview of systematic reviews. *Journal of evaluation in clinical practice.* 2018;24(1):240-53.
- 6 Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: a systematic review. *BMC health services research.* 2014;14:89.
- 7 Dawson S, Campbell SM, Giles SJ, Morris RL, Cheraghi-Sohi S. Black and minority ethnic group involvement in health and social care research: A systematic review. *Health Expect.* 2018;21(1):3-22.
- 8 [www.cancerresearchuk.org/funding-for-researchers/patient-involvement-toolkit-for-researchers](http://www.cancerresearchuk.org/funding-for-researchers/patient-involvement-toolkit-for-researchers) - last accessed 29/04/19.
- 9 Farmakas A, Theodorou M, Galanis P. Public participation in healthcare priority setting: A systematic review. *Nursing Care and Research.* 2015;41:15-26.
- 10 Fung A. Putting the Public Back into Governance: The Challenges of Citizen Participation and Its Future. *Public Administration Review.* 2015;75(4):513-22.
- 11 May AD. Encouraging good practice in the development of Sustainable Urban Mobility Plans. *Case Studies on Transport Policy.* 2015;3(1):3-11.
- 12 Haklay M, Jankowski P, Zwolinski Z. Selected modern methods and tool for public participation in urban planning - A review. *Quaest Geogr.* 2018;37(3):127-49.
- 13 Leyden KM, Slevin A, Grey T, Hynes M, Frisbaek F, Silke R. Public and Stakeholder Engagement and the Built Environment: a Review. *Current environmental health reports.* 2017;4(3):267-77.
- 14 Baxter S, Clowes M, Muir D, Baird W, Broadway - Parkinson A, Bennett C. Supporting public involvement in interview and other panels: a systematic review. *Health Expect.* 2017;20(5):807-17.
- 15 Conklin A, Morris Z, Nolte E. What is the evidence base for public involvement in health-care policy?: results of a systematic scoping review. *Health expectations : an international journal of*

public participation in health care and health policy. 2015;18(2):153-65.

- 16 Schilling I, Gerhardus A. Methods for Involving Older People in Health Research-A Review of the Literature. *International journal of environmental research and public health*. 2017;14(12).
- 17 Crocker JC, Ricci-Cabello I, Parker A, Hirst JA, Chant A, Petit-Zeman S, et al. Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis. *BMJ-British Medical Journal*. 2018;363:17.
- 18 [www.cancerresearchuk.org/get-involved/volunteer/become-a-campaigns-ambassador](http://www.cancerresearchuk.org/get-involved/volunteer/become-a-campaigns-ambassador) -last accessed 29/04/19
- 19 [www.alzheimers.org.uk/research/researchers/our-funding-schemes/implementation-grants](http://www.alzheimers.org.uk/research/researchers/our-funding-schemes/implementation-grants) - last accessed 29/04/19.
- 20 Guidance on co-producing a research project; Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszewska, S., Tembo, D., Turner, K. (2018). Southampton: INVOLVE.
- 21 Goldsmith LP, Morshead R, McWilliam C, Forbes G, Ussher M, Simpson A, et al. Co-producing Randomized Controlled Trials: How Do We Work Together? *Frontiers in Sociology*. 2019;4(21).
- 22 Vale CL, Thompson LC, Murphy C, Forcat S, Hanley B. Involvement of consumers in studies run by the Medical Research Council Clinical Trials Unit: results of a survey. *Trials*. 2012;13:9-.
- 23 Woolfall K, Young B, Frith L, Appleton R, Iyer A, Messahel S, et al. Doing challenging research studies in a patient-centred way: a qualitative study to inform a randomised controlled trial in the paediatric emergency care setting. *BMJ open*. 2014;4(5).



The National Institute for Health Research (NIHR) Applied Research Collaboration East Midlands (ARC EM) is a partnership between Nottinghamshire Healthcare NHS Foundation Trust and the Universities of Leicester and Nottingham.

[www.arc-em.nihr.ac.uk](http://www.arc-em.nihr.ac.uk) [@arc\\_em](https://twitter.com/arc_em) [arc-em@le.ac.uk](mailto:arc-em@le.ac.uk)