

Patient and Public Involvement at the Primary Care Unit

Report of 2020 Audit

21/12/2020

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1. Executive summary

The audit aimed to explore and report on the extent and effectiveness of Patient and Public Involvement (PPI) carried out at the Primary Care Unit in 2019/20 and to make recommendations to the Strategy Group to strengthen PPI at the Unit.

Methods: Staff survey (n=17) and interviews with PPI representatives (n=2) covering the time period July 2019 – June 2020.

Extent of PPI across the research cycle: PPI was most commonly incorporated into the early and mid-stages of research (design, planning and undertaking). There was less PPI involvement in the later stages of research such as dissemination.

NIHR National Standards for Public Involvement in Research: Researchers and PPI representatives were asked to assess PPI at the Unit, with reference to the National Standards:

1. Inclusive opportunities

- ✓ Researchers took steps to ensure inclusive and accessible PPI opportunities, but this varied considerably between groups.
- ✗ Many PPI activities take place with a small group of experienced PPI representatives, and diversity is limited.

2. Working together

- ✓ PPI representatives and researchers described productive relationships based on mutual respect and regular communication, sometimes over long periods of time.
- ✗ Roles and responsibilities of the PPI representatives were not always clearly defined, which can make it difficult for them to contribute.

3. Training and support

- ✓ Relationship building over time, allowing time for active listening and the tailored provision of information were all described as important.
- ✗ Lack of resources for development opportunities for PPI representatives was reported.

4. Governance

- ✓ The stance of those in research leadership roles was important in setting the tone for meaningful PPI involvement in governance. Clear 'asks' to PPI representatives are required.
- ✗ Some researchers suggested that such involvement in governance might not always generate meaningful contributions.

5. Communications

- ✓ Thoughtful timely feedback, frequently offered to PPI representatives, was described as essential.
- ✗ Ambiguous requests could cause confusion and remote work requires careful support.

6. Impact

- ✓ Many large and small changes to research in response to PPI input were described and this was a major motivation for continuing involvement for our PPI representatives.
- ✗ Researchers did not always formally record this impact or gather data relating to impact on the PPI representatives themselves.

Support wanted by researchers: a dedicated point of contact to share experience and knowledge, Unit-wide guidelines and templates, improved finance procedures standardised across the Unit, case studies of PPI conducted within the unit, formal training opportunities, informal peer group support. Endorsement of senior staff was important.

Recommendations to strengthen PPI at the Unit:

PPI practice at the Unit, while often strong and innovative, emerged as inconsistent and patchy, with significant gaps in involvement in governance, and a clear lack of resources to support researchers, leading to the reinvention of many wheels by researchers.

Quick wins

- Publish tips for researchers based on this project
- Develop standardised finance system for PPI fees and expenses
- Peer support for researchers working on PPI

Develop PPI capacity at the unit

- Attract funds for a PPI coordinator to work with researchers and PPI representatives

Key steps for medium term

- Build PPI into annual cycle for the Unit's Strategy Group.
- Appoint and support small Unit PPI panel to provide rapid responses and strategic input.
- Dedicated capacity to coordinate PPI, and to share knowledge and resources.
- Develop Unit resources for researchers and PPI representatives
- Develop funding pot to enable cross-Unit PPI activities, innovation and outreach.

2. Introduction – aims and scope of the audit and this report

This project set out to explore the extent and effectiveness of Patient and Public Involvement (PPI) carried out at the Primary Care Unit (the Unit). Currently, without a Unit-wide PPI strategy, we found that the quality, extent and amount of PPI conducted varies considerably between research groups. It appears to depend on the researchers and PIs leading individual research projects and on external sources of help. We aimed to learn about experiences of PPI challenges and successes, as well as find out what might help Unit researchers and PPI representatives to conduct PPI effectively and efficiently in the future.

PPI in this report means research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.

The report reviews our findings and proposes recommendations to the Strategy Group to strengthen PPI at the Unit.

3. Methodology

We conducted an online staff survey at the Unit in September 2020, asking for responses from staff who had themselves conducted PPI between July 2019 and June 2020. The 17 respondents to the online survey provided data about PPI in 39 Unit research programmes or projects, with a good spread across Unit research groups. Because of the different infrastructure for PPI in place at THIS Institute, we excluded THIS Institute researchers from the survey.

Hour-long interviews were conducted with PPI representatives Roberta Lovick and Phil Alsop in September 2020.

The survey and the interviews were guided by the NIHR National Standards for Public Involvement in Research. For more information on the standards see [here](#).

The data from the survey and the interviews were analysed manually by Lucy Lloyd and Miranda Van Emmenis and provided material for this report, to which Roberta Lovick and Phil Alsop contributed. Stephen Barclay acted as academic lead for the project.

The PPI roles were advertised to PPI representatives with recent involvement at PCU. Roberta and Phil were selected for their contrasting experiences with the Unit and evident commitment to improving PPI. Roberta and Phil have contributed to this report, helped select the PPI case studies that will be published as part of the project and will co-present the recommendations to the Strategy Group.

We acknowledge that responses from researchers and PPI representatives may be biased. Those with positive experiences of conducting PPI may have been more likely to respond to the survey (researchers) or recruitment advert (PPI representatives) than those with negative experiences.

4. PPI at the Unit

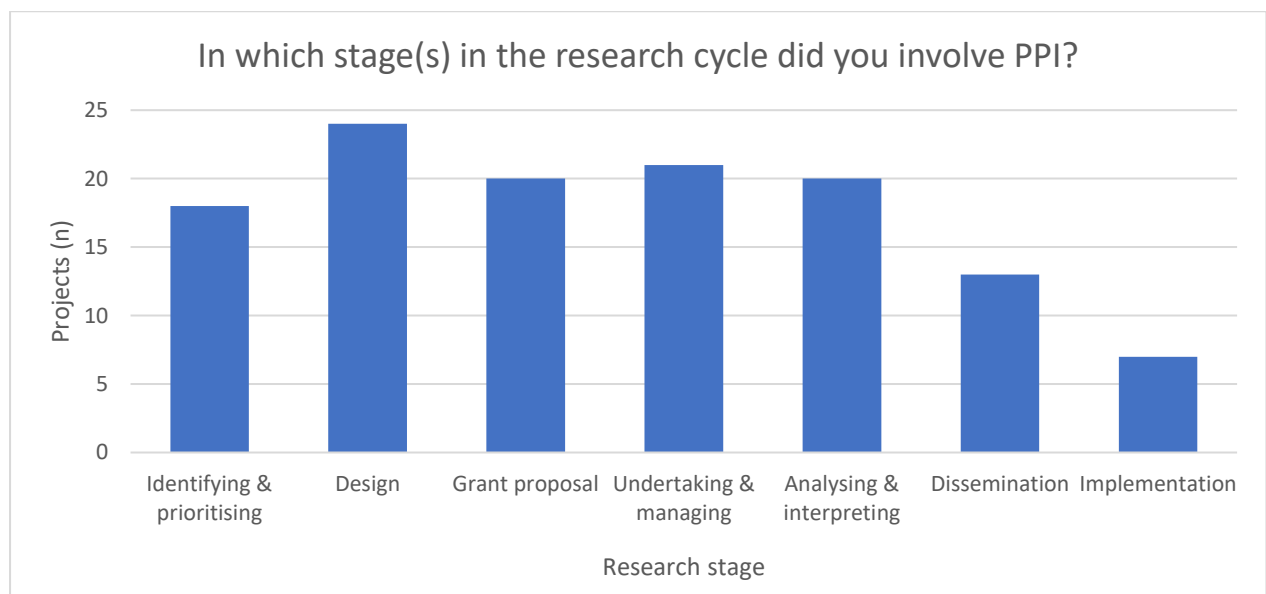
In this section we describe PPI at the Unit, drawing on the survey and interview data we collected.

4.1 Research types which feature PPI activity

39 projects involving PPI were reported, of which 28% were mixed methods studies and 26% were qualitative studies. Less common were RCTs (15%), surveys (13%) and literature reviews (10%). A small number involved PPI with programme grant funding (5%) and health economic modelling (3%).

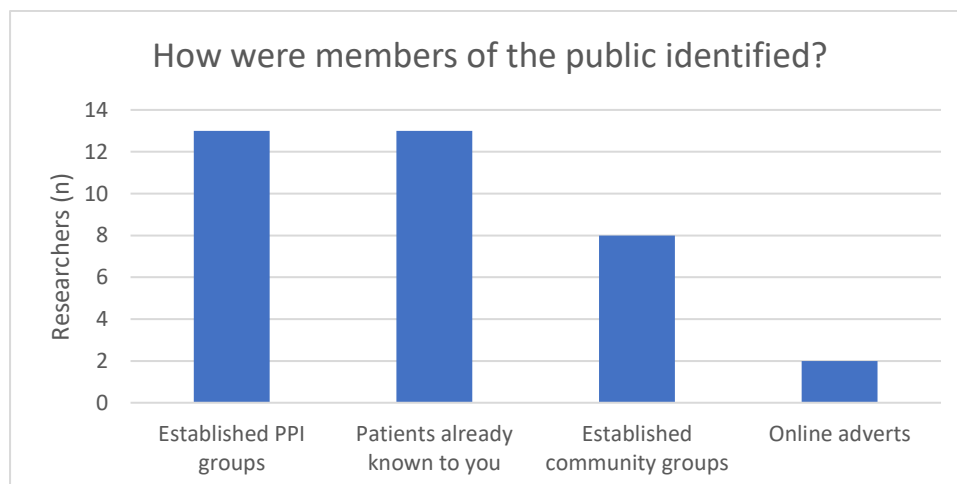
4.2 Where PPI tends to be located in the research cycle at PCU

PPI was most commonly involved in the early and mid- stages of research, i.e. planning, design, managing, analysing. PPI involvement was less common in the final stages of research such as dissemination and implementation of findings.



4.3 How PCU researchers recruit PPI members

The two most common methods to recruit PPI were to approach established PPI groups (notably the NIHR Cambridge BRC PPI panel) or to approach members of the public known to researchers already.



5. The six Standards

The NIHR National Standards for Public Involvement in Research, published in 2019, were designed to improve the quality and consistency of public involvement in research. We used the Standards to help us to identify successes, challenges and explore how improvements might be made in PPI at the Unit.

Our data enabled us to describe Unit actions that supported each Standard, as well as some of the specific challenges experienced by researchers and PPI representatives at the Unit. We suggest steps that our respondents thought would help to mitigate the challenges.

5.1 Inclusive opportunities

This Standard is focused on how public involvement can be made inclusive and accessible.

The majority of survey respondents agreed that the PPI they organised was somewhat (63%) or completely (25%) inclusive. 6% were neutral and 6% disagreed somewhat. Researchers described actions they took to ensure inclusive PPI opportunities, which varied between projects from minor actions, such as proactive expense forms, to larger scale actions, such as funding for support workers. PPI interviewees provided examples of actions to tackle inclusivity at the Unit, but also pointed out that much involvement takes place with a small group of experienced PPI representatives and only specific population groups seemed to be represented.

Actions that encouraged inclusivity at the Unit

Designing carefully costed support and researcher time for PPI into project proposals emerged as critical – no PPI is cost-free. Some population groups may need considerable support if they are to contribute. One research group, for example, has been awarded funding for support workers/assistants so that people with severe impairments can be involved.

Enabling confident input: even the most experienced PPI representatives can get nervous before meetings, especially if they are new to the group. Pre-meetings with PPI representatives allow for explanations of scientific content or getting to know people in the project group to build confidence. Health conditions may need to be taken into account and fluctuating levels of input planned for.

“Each member has different skills and abilities and I was concerned at times that it can be challenging for those with less knowledge or research experience. This group all have health issues so there also needs to be awareness that energy, capacity and cognition fluctuates considerably.” [Researcher]

Guided access to information about clinical conditions is valued by those who may not have direct experience of a condition. Signposting to condition-specific or membership websites was recommended.

Access to PPI meetings, when physical access is possible, was widened by small actions such as: welcoming partners who drive PPI representative to meetings, care with menus to accommodate requirements, accommodation and door-to-door taxi transport if required. Out-of-hours meetings meant those who work full-time can attend.

Key challenges to inclusivity

Unrepresentative socio-economic mix: Both PPI interviewees and some researchers pointed out that their experiences of PPI have given them the impression that PPI representatives at PCU are overwhelmingly relatively wealthy, middle-class, well-educated, retired and white.

"[We] often struggle to find people who are not retired." [Researcher]

"I think the nature of current PPI attracts certain people and puts off others – sometimes this inhibits the voices heard." [Researcher]

A small number of researchers stated that they did not make any particular effort to increase the inclusivity or accessibility of their PPI activities.

Managing expenses, fees and invoices emerged repeatedly as a problem issue for researchers, who find the system difficult to navigate and for PPI representatives, who would like expense forms provided pro-actively, together with prompt payment. They would like to keep discussion on expenses private.

Recommended actions to build inclusivity in PPI at the Unit

- Support researchers to recruit PPI representatives from outside existing connections, including reaching wider sections of the population and community/faith/minority groups.
- Support researchers to accurately cost their PPI workstreams, both in terms of researcher time for PPI work and in terms of external costs such as childcare, carers, specialist support, translation.
- Encourage established PPI representatives to bring in new representatives from their existing networks. A buddy system, where existing representatives are paired with newcomers would encourage recruitment of people who might previously have felt less empowered to get involved in research.
- Ensure consistent and efficient expenses/payment system, working with the Department's finance team.

5.2. Working Together

This standard is focused on building mutually respectful relationships with roles and responsibilities clearly defined.

56% of researchers completely agreed, and 38% somewhat agreed, that they built mutually respectful relationships with PPI representatives. We found examples of cohesive, long-lasting and productive relationships between PPI representatives and researchers. However within these successful partnerships there were some instances of vague requests and a call from PPI representatives for clear expectations and precise instructions.

Actions that encouraged working together

Successful relationships based on regular communication and mutual respect were described between researcher and PPI colleagues. Relationships developed over time, as people got to know each other. This provided rewarding contact in itself and it allowed PPI representatives to ask

questions when they needed to, without fear of feeling foolish. A sense of value and achievement was described, sometimes in the face of extremely challenging experiences or health conditions.

“I’ve always felt like one of the team.” [PPI representative]

“The main thing is to listen to what the PPI Advisory Group say, and also to be seen to be listening and taking account of what is said, so people feel their contribution is valued (which it is).” [Researcher]

Key challenges

Vague instructions: researchers sometimes found it difficult to define roles and responsibilities, which can be confusing for the PPI representatives and make it harder to contribute.

“At first I didn’t know whether I was expected to evaluate the whole methodology, simply say if the procedure was acceptable to patients, comment on the grammar and spelling, or how easy it was to read.” [PPI representative]

Unproductive meetings: PPI representatives may feel inhibited from contributing if the meeting group size is too large or if the chairing is not effective. PPI representatives may feel uncomfortable participating in some of the ‘higher level’ or more scientific activities unless careful preparation has been done. An optimal group size of 6 to 7 people was mentioned for both in-person and virtual meetings, because it was felt that size allows everyone to input equally.

Confidence to ask questions: PPI representatives sometimes feel reluctant to ask for help because they don’t want to ‘bother’ people.

Recommended actions to encourage successful PPI relationships

- Foster mutual respect. Plan time to listen to what PPI representatives have to say and make sure they know that everyone’s point of view is important and valid.
- Provide specific instructions for PPI representatives. Be clear about how detailed the feedback should be and which parts are amenable to PPI input and which cannot be changed.
- When recruiting PPI representatives, create a “role description” so PPI representatives understand what will be asked of them. This could include the planned tasks and the required attributes of the person (e.g. someone with a specific health condition). PPI representatives can then make an informed decision about the suitability of the opportunity.
- Ensure meetings are managed effectively: offer clear rules for meeting etiquette, such as how to ask questions. Ensure everyone has a fair chance to contribute (small group sizes and an inclusive Chair were key). Follow-up after each meeting to check in with PPI representatives if they have additional thoughts.

5.3 Support and Learning

This standard is about offering support and development opportunities to build the confidence and skills of PPI representatives.

Researchers agree somewhat (53%) or completely (20%) that they offered support or learning to their PPI colleagues. 20% of researchers were neutral and 7% disagreed somewhat. Formal training

and information sessions were often provided by external organisations. A small number of researchers organised bespoke sessions to brief PPI representatives and to listen and respond to questions as projects progressed.

How support is provided at the Unit

Both researchers and PPI representatives agreed that relationships built over time with space for emotional support was key for building the confidence and self-esteem of PPI individuals. It was clear that time for active listening is often needed, so PPI colleagues know their contribution is heard and valued.

“The main area has been confidence building, making them feel valued, articulating what it is they are all doing so well. So confidence building was the initial aim, but then over time have been building skills too. Many of them have great pre-existing skills (design, English, mental health clinician experience, law etc.)” [Researcher]

‘Information’ sessions tend to be welcomed, for example, on scientific concepts, the condition that will be researched, or on specific skills relating to the research process. Formal training in how to ‘do PPI’ can be perceived by some PPI representatives as overriding the individual perspective that members of the public bring to research projects.

Key challenges

Resources: researchers reported that it is difficult to attract funding for development opportunities for PPI representatives. Only a small number of Unit projects costed in specific training and education sessions for PPI representatives.

“Professional” PPI: Some PPI representatives are from professional/scientific backgrounds and very experienced. While their input can be highly valued, their expert perspective can be intimidating to other PPI representatives, as well as shifting the viewpoint away from that of the “person on the street”.

Recommended actions to improve support and training opportunities for PPI representatives

- Develop signposting to external training opportunities for PPI representatives, such as the NIHR Cambridge BRC PPI panel ‘information sessions’ for members of the public and resources from other Universities.
- Provide induction materials, learning space and/or meetings for PPI representatives at the beginning of the project. This could include three types of information i) how the PPI work fits into the wider research project and the Unit; ii) background information on the research topic being studied iii) signpost to guidance on how to approach PPI activities. This is particularly important for people who are new to PPI.
- Provide a point of contact for support. Check in with PPI representatives regularly to see if they have any outstanding queries or needs in relation to the project. Appreciate that the most productive relationships are often formed over long periods of time.

5.4 Governance

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

Researchers agreed somewhat (56%) or completely (19%) that they involved members of the public in governing their research projects. 13% were neutral and 14% disagreed. The stance of those in research leadership roles appeared important in setting the tone for meaningful involvement in governance. Some researchers explained that such involvement might not always generate meaningful contributions. One of our PPI interviewees explained that getting involved in governance would feel uncomfortable unless the required input was very clearly defined.

Examples of successful involvement in governance at the Unit

We found notable examples of high-level influence at a senior level in some research groups at the Unit. Some PPI representatives were members of steering committees, named collaborators or co-investigators on grants, co-authors on publications, and some join regular project team meetings. One leads the PPI workstream on a large project. PPI input to a Research Ethics Committee meeting was described as critical to approval for a research project.

“Membership of programme steering committee is an important forum for this. The chair is very inclusive and respectful (luckily), making a particular effort to engage PPI members in the discussion and listen to their viewpoint.” [Researcher]

Key challenges

Cross-Unit planning: the Unit does not currently ask for PPI input into cross-Unit governance. Such input would need to be carefully structured to offer decisions or processes that are genuinely amenable to influence by PPI. This type of involvement will be attractive to some PPI representatives but could be far removed from the issues (eg research into a specific condition) which initially interested others. It would require clarity of purpose, careful recruitment and ongoing briefing and support to the PPI representative(s).

Making PPI input into governance genuine and useful: Some researchers explained that it was difficult to know what ‘governance’ meant and how to put this into practice within their research projects.

“All PPI members are invited to steering group meetings. Whether they really are involved in senior level decision-making at those meetings I think is questionable.” [Researcher]

A few researchers expressed doubt that the PPI they had seen taking place was truly taken on board in the research project.

“I don't believe that PPI voices were valued at the senior level of the research project. PPI activities can sometimes feel tokenistic and box ticking for funding reports.” [Researcher]

PPI representatives emphasised the crucial importance of making sure that the involvement of members of the public in research is genuine and that their work is meaningful. PPI representatives should never feel part of a ‘box ticking’ exercise.

“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.” [PPI representative]

It is also important to acknowledge that while some PPI representatives would like to be invited to continue with the project and engage in governance or strategic decisions, some might choose to opt out at that stage. For successful PPI engagement at the strategic or governance level,

researchers must be clear about the purpose of the activity, the work involved and the knowledge and/or experience required.

Recommended actions for the Unit

- Develop opportunities for structured PPI input into the business of the Unit's leadership group, the PCU Strategy Group. Relevant business might include research priorities and cross-Unit research questions, bid development, cross-Unit plans, recruitment and promotion recommendations, public engagement and communications, PPI itself.
- Develop a Unit PPI strategy to clarify the purpose of involvement and the Unit's approach to PPI, with shared values and principles as the foundation for strategic action.
- Develop resources to support specific PPI plans for individual research projects, which could define how public involvement will take place, including in higher level decision-making and project governance.
- Endorse PPI consistently and pro-actively at the highest levels.
- Develop capacity to support researchers to conduct meaningful PPI across the Unit.

5.5 Communication

This standard refers to regular communication with PPI representatives using plain language.

Researchers agreed somewhat (53%) or completely (41%) that they communicated with members of the public clearly. 6% were neutral. There were lots of instances of thoughtful, timely feedback from Unit researchers, which PPI representatives found essential.

Unit practices that help

Regular feedback and updates on the project, even if nothing had happened or if the project didn't get funded, were very highly valued by PPI representatives. Regular updates help PPI representatives to feel part of the research process and motivated for future projects.

"It's something we deserve. [Otherwise] you're just sending it off into the ether, you don't know your impact and you don't learn" [PPI representative]

A brief phone call one-to-one can help put the PPI representative at ease, or is sometimes a more convenient way to provide feedback compared to email.

For remote communications, researchers tended to offer guidance on using teleconference software, and alternative methods of communication such as letters or telephone calls for those unfamiliar with technology.

Key challenges

Ambiguous language: make sure requests are clear and check understanding to avoid unnecessary stress for PPI representatives. 'Interview,' for example, could be part of a selection process or it could be a data gathering conversation.

Communicating remotely requires clear guidance for participating in the meeting, how to make sure people don't talk over each other, and handling technical issues.

Recommended actions to improve PPI communications

- Provide regular updates on questions like: what changes were made after the PPI input? What happens next for the study? When will you expect funding/ethical approval/results? Will you require further PPI input down the line, and if so when?
- Share the results of the research with PPI representatives, even if some time has passed. This could include lay summaries and published papers.
- Provide a clear point of contact for communicating with the research team.
- Provide guidance on using teleconference software and offer alternative methods of communication such as telephone calls, letters or face-to-face meetings for those unfamiliar with technology, which can be more accessible for some people.

5.6 Impact

This standard is about identifying and sharing the impact that public involvement makes to research.

Researchers agreed somewhat (58%) or completely (24%) that they identified and shared the difference that public involvement made to their research. 18% of researchers were neutral – neither agreed nor disagreed. We found many examples of changes that had been made after PPI input and of recognition of this impact on the research process. This kind of impact was described as the biggest motivation for continuing involvement by our PPI representatives. However, researchers did not always formally record this impact or gather data relating to impact on the PPI representatives themselves.

Positive impact on the research

Researchers reported positive impacts of PPI on their research: shaping grant proposals, problem-solving study recruitment, improving readability of patient documents, adding richness to data analysis. At the Unit, sharing this impact with PPI representatives is done mostly informally, via email and newsletters.

“PPI are an invaluable source of experience and information who can add a significant value to every stage of the research project one” [Researcher]

“PPI helped to generate novel ideas and solutions by thinking outside the box.” [Researcher]

Positive impact on PPI representatives

“PPI involvement has not only given me the confidence to engage in other roles, it has enabled me to highlight important issues which affect patients, carers and family members. It proves that we are taken seriously and that our voices are powerful in reshaping the future for such people.” [Roberta Lovick, PPI representative]

“It’s been a real confidence builder for me knowing that simply by being myself, I have a useful part to play. I’d recommend it to anybody.” [Phil Alsop, PPI representative]

Key challenges

Formal recording of impact: The impact of PPI input was not always formally or officially recorded by researchers, e.g. through progress reports or internal logs. This means it may be missing from evaluation reports and other measurements.

Feedback not collected on the impact on PPI representatives of getting involved: Of the 17 researchers, none routinely asked for feedback from PPI representatives on the process of being involved in research. One PPI representative proactively provides feedback to researchers in real time as the project is going on. This is important, as feedback at the end can be too late to act upon.

Recommended actions to improve the identification of impact on research and on PPI representatives

- Keep a record of PPI activities and the impact these had on the research. Publish examples of the impact that PPI has had on research e.g. within case studies.
- Provide specific and meaningful feedback to PPI representatives on the impact that their input had on the research; ensure responsibility for this is located in the research team or with a central support person.
- Describe and demonstrate recognition of PPI methodology and input by naming representatives in outputs such as publications, or asking them to present at conferences. This has two benefits i) making the PPI member feel valued *“it was a nice touch to be asked”* ii) promoting the profile of PPI.
- Assess and record the impact of involvement on PPI representatives both during and after the project. Encourage feedback from PPI representatives on their experiences in order to improve PPI in future projects. Researchers could make use of a template feedback sheet with guide questions such as *“What you feel went well? How could your experience be improved in the future?”*

6. Support, training and development for researchers

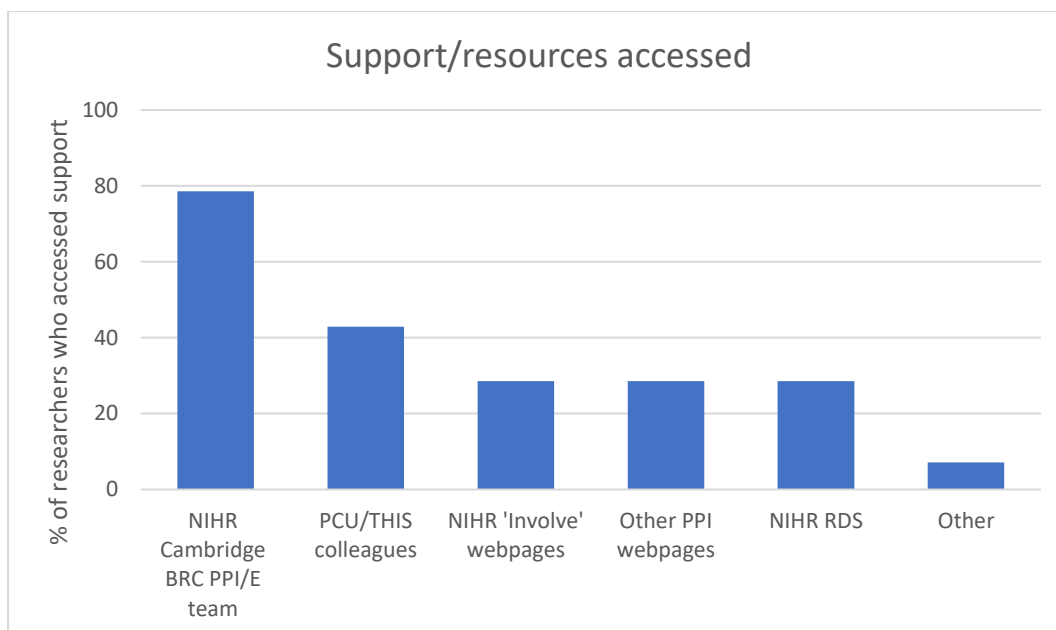
6.1. Summary of researchers’ usage and stated requirements

Training: 29% of researchers undertook formal training related to PPI, either provided by an external agency, as part of a previous job, or by the NIHR Cambridge BRC PPI team.

Support accessed: 82% of researchers accessed support to help them conduct PPI activities. Of these, the most commonly accessed were the NIHR Cambridge BRC PPI/E team (79%), which helped set up PPI and gave advice as well as directly recruiting PPI representatives for studies.

43% received advice and direction, as well as template payment policies, from colleagues in the PCU or THIS Institute.

Lastly, 28% accessed each of the following: NIHR Involve webpages e.g. to develop PPI budget and for general information; other PPI webpages, e.g. to approach patients via a charity website; NIHR research design service, although one researcher noted that input was not always useful or focused enough for their needs.



6.2 Support wanted by researchers.

Researchers asked for support in the following areas, listed in order of preference: a dedicated point of contact to share experience and knowledge, Unit-wide guidelines and templates, improved finance procedures standardised across the Unit, case studies of PPI conducted within the unit, formal training opportunities, informal peer group support. Endorsement of senior staff was important.

“PPI can be time-consuming and is usually added to an already busy coordinator role. We need dedicated time allocated and finance.” [Researcher]

“Everyone just keeps reinventing the wheel each time, such a waste. A Unit level PPI policy and payment guides would ensure consistency and fairness across unit studies.” [Researcher]

“PPI is an essential part of delivering research and developing grant applications. More information on the availability of such resources and how they can be accessed, would be helpful.” [Researcher]

7. What’s needed?

We found that PPI input into research at the Unit was common, especially in the early stages of the research cycle, and was varied in scale and type, with lots of evidence of innovation, meaningful collaboration and genuine insights within research groups. Some long term collaborations were especially valued by researchers and by PPI representatives. Researchers sometimes found peer support and often accessed resources and capacity from external providers, notably the NIHR BRC Cambridge team.

But we also found that PPI practice was inconsistent and patchy, with significant gaps in involvement in governance, and a clear lack of resources and capacity to support researchers, leading to the reinvention of many wheels by researchers and a heavy reliance on external providers. There is no openly shared theoretical framework or strategy for conducting PPI, and we do not make our

commitment to PPI explicit beyond the required adherence to the principles and values that our various funders require. We found indications that participation is narrowed by limited recruitment pools/methods and that the lack of shared funds, resources and capacity to curate contact with community groups perpetuate this.

The next section suggests how the Strategy Group might strengthen PPI consistently at the Unit, drawing on report data and findings.

Quick wins

- Publish tips for researchers based on this project (possible within capacity for the audit project)
- Develop standardised finance system for PPI fees and expenses (in development already)
- Peer support for researchers working on PPI, perhaps connected with existing Unit peer support groups, to share tips and best practice
- Explicit and ongoing recognition from PIs and the Strategy Group of the value PPI can bring to research

Develop PPI capacity at the Unit

- Develop the case to attract funds for a PPI coordinator to work with researchers and PPI representatives; develop online resources and a Unit PPI knowledge bank; plan, deliver monitor and evaluate PPI activities; innovate; coordinate PPI input into Unit governance and planning

Key steps for the medium term

- Develop funding pot to enable cross-Unit PPI activities, innovation and outreach, for example to recruit from target population groups
- Build PPI into annual cycle for the Unit's Strategy Group, to deliver PPI influence on Unit planning and strategic decisions
- Appoint and support Unit PPI panel to provide rapid responses and strategic input. This could be a small scale group combining long term contributors with some newly recruited individuals.
- Dedicate capacity to curate contact with communities and individuals, and to work with researchers on PPI to innovate, share up-to-date knowledge, external resources and experience
- Develop Unit-specific resources for researchers and PPI representatives as needed, drawing on external expertise and resources (Unit-specific resources might include case studies, templates and guidance on PPI, internal training sessions on popular topics, signposts to external sources of training and other resources, advice on remote methods of communication, guidance/contacts to assist researchers reaching out to minority groups, buddying tips, evaluation and monitoring tools)

Concluding statement

The recommendations in this report are based on findings from the researcher survey and interviews with two PPI representatives, who also co-authored the report.

The proposal for new PPI capacity at the Unit with a budget attached would, we believe, go a long way towards enabling researchers at the Unit to build on the successful PPI and address the challenges outlined in this report.

We suggest that Strategy Group leadership will be equally as important if we are to achieve a shift in Unit culture so that PPI is visibly intrinsic to all our research, across our varying research groups and funding regimes.

Finally, we suggest that the costs associated with increasing PPI capacity will be outweighed by the benefits that a consistent, thorough, well thought out PPI approach can bring to individual research projects and the Unit's business as a whole.

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Reference

1. NIHR UK standards <https://sites.google.com/nih.ac.uk/pi-standards/home>