

# PenARC Public Engagement Strategy 2019-24

**Vision, principles and priorities for researchers and public collaborators working together**



PenARC = Applied Research Collaboration South West Peninsula

PenARC is funded by the UK National Institute for Health Research (NIHR)

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## Who is this strategy for and what is its purpose?

Thank you for your interest in our work. This strategy outlines PenARC's vision and priorities for working with public collaborators. The strategy is written for and by:

- **PenARC's Public Involvement and Engagement Team (PPIE team):** This team brings researchers and public collaborators together so that we can design, plan, carry out and share findings on research *together*. This strategy will guide the work of this team until 2024.
- **Researchers in PenARC or working with PenARC:** PenARC's research team spans the South West Peninsula region (see map below), including the universities of Plymouth and Exeter. This strategy outlines to all researchers what PenARC's expectations are for working with public collaborators.
- **PenPEG:** The Peninsula Public Engagement Group, formerly known as PenPIG, is funded by PenARC. This is a group of people who have a joint interest in making research relevant to the people and communities being studied. This strategy complements the PenPEG Membership Pack and outlines what PenPEG can expect of PenARC. This strategy also guides PenPEG in terms of their contributions to PenARC.
- **Public collaborators:** In addition to PenPEG, PenARC researchers work other public involvement groups and individual public collaborators who are involved in research for many different reasons. This strategy outlines what they can expect of PenARC in terms of engagement and involvement. More information about the involvement activities of PenARC, and some of the groups we work with, is available on our website: <https://arc-swp.nihr.ac.uk/>.



The geographical region of PenARC

### What is PenARC?

The Applied Research Collaboration South West Peninsula (PenARC) is one of 15 ARCs across England. These are funded by the National Institute for Health Research (NIHR) until 2024. ARCs do research that is relevant to health and social care services. This means that their research is *applied*: it looks at what works in

practice. For example, this can mean testing out whether a treatment can be delivered safely in a GP surgery instead of at the hospital. PenARC works with health and social care services and public collaborators in Cornwall, Devon and Somerset. More information can be found on the PenARC website: <https://arc-swp.nihr.ac.uk/>.

## Vision and Aims for involvement and engagement

The PenARC PPIE team staff and PenPEG members aspire to support involvement and engagement in research that is inspirational, adds enjoyment to research processes, and results in research findings that are directly useful to service planning and use. PenARC's leadership group and researchers are committed to supporting PenPEG and the PPIE team, and aspire to work with public collaborators in ways that are experienced as inclusive. Together we value different kinds of knowledge and want to create a research space where we work together.

The PPIE team and PenPEG members work to embed meaningful involvement and engagement within PenARC, involving the public as both users and producers of knowledge. We are committed to enabling public collaborators and researchers to *work together*. Public collaborators are active in suggesting, improving and choosing research questions, as co-applicants on funding grants and by sharing information and putting research into practice. These activities enable PenARC to undertake the right research and to do so in a way which has the best chance of producing the information people need to manage their health and wellbeing.

Our commitment to involvement and engagement is driven by both ethical and pragmatic concerns. First, spending of public resources should involve members of the public in decision-making. This includes building bridges between health and social care, academic establishments, and the communities we aim to serve with our work. Second, public involvement in the design of research projects can improve the quality and applicability of research findings. Perhaps most important of all is the recognition that the public and service users are uniquely qualified to identify what impacts most on their lives, and that this should influence what and how research is undertaken.

In this crocheted blanket by PenPEG member Lynn Tatnell all the colours come together with equal importance to produce the overall impact.

We have chosen this as a symbol of PenARC's vision for involvement and engagement in research. In this vision public collaborators and researchers work together, with other partners, to create research outputs that are relevant and important to patients, service users, carers and communities.



The following aims will guide all involvement and engagement activities of PenARC and PenPEG. Jointly, these aims respond to the vision outlined above:

- AIM 1:** To build on and develop the involvement and engagement legacy of PenCLAHRC
- AIM 2:** To run a programme of involvement that is experienced as engaging and creative, which facilitates the excellent research that can be achieved with meaningful public collaboration
- AIM 3:** To reach a diverse group of public collaborators through proactive, varied and creative involvement and engagement activities, formed through working together
- AIM 4:** To integrate public involvement at the heart of PenARC to support early and ongoing involvement in all research ideas
- AIM 5:** To research and evaluate involvement so that we can improve practices and capture involvement impact
- AIM 6:** To enable and support researchers, health and social care service providers and members of the public to build their capacity for collaborative work

These aims are defined in more detail below:

**AIM 1: To build on and develop the involvement and engagement legacy of PenCLAHRC**

**Definition and rationale:** PenARC used to be called PenCLAHRC (2008-2019). PPIE was central to most aspects of PenCLAHRC as a whole, as well as in specific projects: involvement was seen as a key methodological component along with other methods support. In PenCLAHRC there was substantial development of PPIE, through research, practice and evaluation. The PenCLAHRC legacy includes an established PPIE infrastructure in the form of policies and practices regarding the running of meetings, supporting researchers, reimbursing public members for their time and expenses, and involving members of the public in research governance, planning and practice. We will build on this in the next four years.



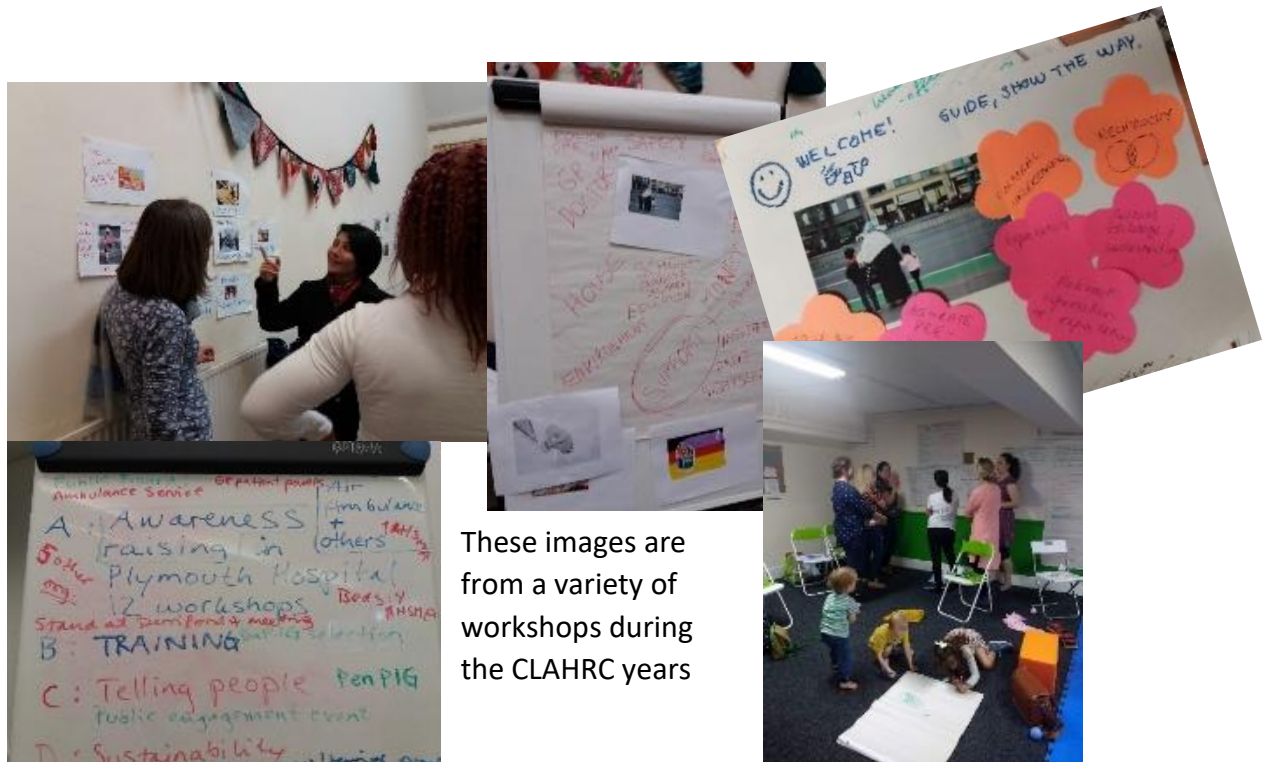
This photo was taken in January 2020, at an event celebrating PenCLAHRC and moving on as PenARC

**AIM 2: To run a programme of involvement that is experienced as engaging and creative, which facilitates the excellent research that can be achieved with meaningful public collaboration**

**Definition and rationale:** Research and evaluation on PenCLAHRC PPIE showed that fun and enjoyment were important aspects of PPIE for public contributors. This was reiterated in the workshops informing this strategy. Fun and enjoyment are highly subjective experiences, and we have therefore re-worded this to “engaging” and “creative”. All PenARC PPIE work



will be relevant and focused on improving research, and we believe this is more likely to be achieved if the PPIE is experienced as a creative and engaging process.



These images are from a variety of workshops during the CLAHRC years

**AIM 3:** To reach a diverse group of public collaborators through proactive, varied and creative involvement and engagement activities, formed through working together

**Definition and rationale:** There is a desire by all stakeholders to broaden the diversity of public involvement and engagement in PenARC in terms of age, ethnicity, service use experience, and cross-region representation. This includes community engagement, working with geographical or identity communities that are bound by experiences related to their location or social experiences. This aim includes actions to ensure involvement activities are inclusive. This aim also addresses the need to work with people who are experiencing health and social care inequalities, so they are involved in agenda setting and design of research to reduce inequalities.



**AIM 4:** To integrate public involvement at the heart of PenARC to support early and ongoing involvement in all research ideas

**Definition and rationale:** Involvement is more meaningful and impactful if it is initiated early on in research development, or before the research idea has been formed. Early involvement gives public collaborators more chance to influence the research. As such, this aim

addresses the risk of researchers formulating questions that are not aligned to the needs and priorities of patients, carers and communities. Early involvement can also enable more

**AIM 5:** To research and evaluate involvement so that we can improve practices and capture involvement impact

[illegible]

The above is a collage of photographs chosen by young people with experience of receiving mindfulness treatment for depression and anxiety. They used these photos to help the researchers choose what to focus on when evaluating mindfulness.

## Values and Principles for involvement and engagement

- **Inclusive opportunities:** offer public involvement opportunities that are accessible and that reach people and groups according to research needs
- **Working together:** work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
- **Support and learning:** offer and promote support and learning opportunities that build confidence and skills for public involvement in research
- **Governance:** involve the public in research management, regulation, leadership and decision making
- **Communications:** use plain language for well-timed and relevant communications, as part of involvement plans and activities
- **Impact:** seek improvement by identifying and sharing the difference that public involvement makes to research

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

At our involvement activities researchers and public collaborators will be reminded to respect the different kinds of expertise people bring, including knowledge gained through lived experiences. The PenARC PPIE team will facilitate conditions for open and polite communication, and evaluate this facilitation so that we improve our practices. We value relationships with public collaborators and invest time to establish relationships that are experienced as meaningful by all involved.

The PenARC PPIE team will co-ordinate and support involvement activities, but it is the responsibility of everyone involved to make relevant contributions in a spirit of generosity, curiosity and a willingness to learn from others.

This strategy supports the long-term aims of PenARC:



<b>PenARC's long term aims</b>	<b>Contributions by patient and public involvement and engagement activities</b>
To produce a step change in the generation of patient-focused research.	Involving patients in all research ideas and development of research studies.
To improve health outcomes through effective use of evidence.	Engaging patients, service users, carers and members of the public in the production, evaluation and use of evidence.
To increase the capacity of health and social care staff to use and generate research evidence.	Developing and delivering training and information about patient and public involvement in research. Enabling connections between research-active health and social care staff and research-involved patients and public.
To generate wealth by increasing service effectiveness thus saving resources, working with the third and private sectors to identify solutions to health problems, and by increasing productivity through preventing or ameliorating disease.	Innovating services in collaboration with patients and the public.



## How will we meet our aims?

We will work flexibly to meet our stated aims. This means responding to the interests and priorities of our public collaborators and PenARC researchers. For this reason we have outlined some core activities below that are essential in helping PenARC to meet the aims. Additional and responsive activities will be added every year.

### AIM 1: To build on and develop the involvement and engagement legacy of PenCLAHRC

The legacy from PenCLAHRC includes: a team to support patient and public involvement in research (the PPIE team); support *of* and collaborative work *with* PenPEG (previously known as PenPIG); PenARC leadership team commitment to involvement and engagement; and substantial resourcing at approximately 8% of the core funding.

#### About the PPIE team:

The team currently has four PPIE researchers/facilitators and one administrator. In March 2021 these members are Kristin Liabo, Kate Boddy, Emma Cockcroft, Naomi Morley and Tanya Hynd. If you wish to learn more about the background of the PPIE team, please visit the PenARC site (<https://arc-swp.nihr.ac.uk/>). The team works closely with PenPEG and other public collaborators, and PenARC researchers. With researchers, we help them build relationships with public collaborators and show them how involvement and engagement can improve their research. With public collaborators, we introduce them to researchers who work in areas of mutual interest and introduce them to the research environment. The community and engagement administrator is central to ensuring that PPIE activities are accessible, and that public collaborators are reimbursed and paid in a timely manner.

The team is part of an informal PPIE network of many different individuals and groups based across the South West Peninsula region. This includes parents of children with neurodisabilities, people representing underserved communities, people living with dementia or caring for someone with dementia, people with specific conditions or service experiences, and people engaged in research on the connection between human health and the environment. Some are long-term 'standing groups', others come together for specific research projects. All are part of a fluid group of people who work with PenARC, bringing their very different perspectives and backgrounds.

#### About PenPEG:

This is a group of people who have an interest in health and social care research. In March 2021 PenPEG has twenty-one members. Each member brings their own lived experience and expertise to the group: some are living with long-term conditions, some have used social services, some are younger, and some are older. Members of PenPEG have different educational backgrounds and live in Devon, Cornwall and Somerset (although most current members live in Devon). PenPEG members' involvement in PenARC includes but is not limited to: being co-applicants on funding applications; working with researchers from start to finish on a study; reviewing written research outputs; presenting at conferences; and attending PenARC Management Board meetings. Two members of PenPEG hold administrative roles within the group: the business secretary and the membership secretary.

## Clarification on how this set-up addresses aims

Having a **dedicated PPIE administrator** means:

- One point of contact for public collaborators' practical questions, including travel booking, payment queries and access concerns.
- The administrator organises a monthly newsletter, called Connect, which helps bring public collaborators and the PPIE team together.
- The administrator books rooms and refreshments for meetings. This enables the PPIE researchers/facilitators to focus on the content of meetings, supporting public collaborators in advance of, during and after meetings. The support will depend on what the public collaborator would like but can include a pre-meeting to explain the meeting agenda and who will be at the meeting, and a de-brief after the meeting to check if anything was unclear.

Having a **well-resourced team** means:

- A framework for PPIE and support in line with the NIHR Public Involvement Standards.
- In particular, this means time to build relationships with public collaborators and organising meetings in a variety of venues not just at the university.
- Time to support inclusive involvement and engagement. For example, if a public collaborator is unfamiliar with an online calling programme such as Zoom, a PPIE team member will arrange to introduce them to it and test it out in advance of a meeting. Or, if a public collaborator has an access need the team can organise interpreters or reimburse costs for enablers. The PPIE team will cater to these requests to ensure there are no burdens to involvement for public collaborators and that individuals are able to engage meaningfully.

Further, the PenARC set-up means:

- Public collaborators are invited to research meetings early on in the research planning. Sometimes this means working with public collaborators to develop studies informed by their priorities.
- Public collaborators are invited to be co-applicants on funding applications to generate external research income.
- Researching public involvement and engagement in research and sharing findings from this widely.
- Delivering training for public collaborators and researchers, co-developed with both groups.
- Public collaborators have roles within PenARC's governance structures, such as the Management Board.
- Involving public collaborators in any health and social care-related research study, including technical and methodological studies.

- PPIE team members at times co-ordinating and supporting co-produced or co-designed research funding applications, or leading funding applications.

AIM 2: To run a programme of involvement that is experienced as engaging and creative, which facilitates the excellent research outcomes that can be achieved with meaningful public collaboration

Some public collaborators like to work on formal committees, others prefer to attend workshops facilitated specifically for them. No matter what forum public collaborators are invited to, they should be provided with the tools they need to participate in conversations and decision-making. For meetings run by the PPIE team, we will continue to develop and test varied and diverse ways of working together.

#### **Examples of how we will work to meet this aim:**

2021-23:

- The PPIE team will write meeting notes when using new involvement tools in meetings, and ask people's views on the tools.
- The PPIE team and PenPEG will use the meeting notes and what people tell us to co-design approaches to involvement that are creative and inspiring for public collaborators and researchers.
- Public collaborators and researchers who have creative ideas for involvement tools, techniques and approaches will be supported by the PPIE team to develop these.
- The PPIE team will continue to meet weekly and practice reflexively, sharing tools and approaches. The team will participate in national networks, attend conferences and training events and bring these insights into work.

2022-23:

- The PPIE team will organise two networking events for public collaborators to meet people involved in other ARCs and other programmes of research, to foster sharing of experiences and connection.

2024:

- Organise at least 6 events with public collaborators and researchers where they revisit what has worked and what has been a challenge in PenARC PPIE since 2019. Compare what they say with what was said in the workshops informing this strategy. This will help the PPIE team, PenARC leadership and PenPEG to consider how this strategy has met its aims.

AIM 3: To work with a diverse group of public collaborators through pro-active, varied and creative involvement and engagement activities, formed through working together

Overall, this aim can only be met if the PPIE team and PenPEG members are proactive in sharing information about PenARC with interested people. This happens informally, when we attend meetings or in social situations. It also happens through planned events held in communities who are experiencing inequality of service and health inequalities.

To achieve diversity in our engagement we need to consider who PenARC is currently working with, and whether we are missing any important perspectives. We then need to consider ways of engaging with people who are not currently involved. The engagement we initiate needs to be reciprocal. This means considering why working with us would be of

interest and benefit to the people we meet. Once we meet with people, we need to initiate open and ongoing conversations to build relationships.

#### **Examples of how we will work to meet this aim:**

2021:

- The PPIE staff and PenPEG members will jointly attend diversity training so that we learn more about working in inclusive ways. We will particularly seek training that emphasises racial equality.
- After the training the PPIE team will assess which perspectives are missing in PenARC. The consideration will be broad and with researchers, to capture community collaborations within PenARC that do not include the PPIE team or PenPEG.
- The PPIE team and PenPEG will revisit and change existing membership policies for PenPEG so that we are prepared to welcome new people who might want to become involved as a result of our increased efforts to diversify.
- The PPIE team will connect with community leaders: for conversations to identify mutual interests and aims. We will approach community leaders based on our assessment of diversity earlier in the year.
- The PenARC communications team will invite external review of our website and other information about PenARC, the PPIE team and PenPEG to identify barriers to reaching us. Only people who are not currently involved in PenARC will be able to assess blind spots we might have on how to reach us.

2022-23:

- The PPIE team and PenPEG members will visit community groups, based on conversations with community leaders in 2021. If social distancing prevails, we might have to connect online, and we are aware of some online community initiatives which we can approach.
- The PPIE team will approach PPIE groups and individuals involved in NHS and social care services to organise learning exchange meetings and explore cross-fertilisation opportunities.

2024:

- The PPIE team will keep a log of our activities and efforts to connect with people. In 2024 we will trace back through our log to identify whether these activities resulted in us broadening out.
- The PPIE team will invite people we met through our concerted efforts to diversify. If they are willing to meet with us, we will discuss with them their experiences, thoughts on moving forward and whether they have seen any changes in our involvement and engagement practices since they first met us. If people are unwilling to meet with us we will take this as a sign that we failed this aim.

#### **AIM 4: To integrate public involvement at the heart of PenARC to support early and ongoing involvement in all research ideas**

Much of PenARC's research activities are focused on applying for external funding. Many topics are chosen by the research funding organisations. Other applications are informed by ideas from researchers, public collaborators or staff in local services. It is the job of the PPIE team to keep reminding their researcher colleagues to involve public collaborators early on. It is also their job to look out for involvement opportunities within PenARC. To reinforce the importance of early involvement, the PPIE team and PenPEG members will sometimes



refuse involvement: when the invitation to public collaborators comes so close to the application deadline that the time point for influential involvement has passed.

**Examples of how we will work to meet this aim:**

2021:

- The PPIE team will regularly remind researchers that they need to invite public collaborators at the start of their research development journey. We will develop a guide for researchers on this, put this up on our website and share it widely.
- The PPIE team will seek to convey practical examples of how researchers can connect with public collaborators to jointly develop research ideas. These will be showcased in a researcher seminar, on the PenARC website and in PPIE advice clinics held for researchers.

2021-24:

- Researchers who want to grow research ideas and build long-term relationships with public collaborators will be prioritised for support from the PPIE team and PenPEG.
- The PPIE team will be sensitive to research ideas emerging from conversations with public collaborators and seek opportunities for growing these further.
- For each Annual Report the PPIE team will track data on involvement; from our finance spreadsheet, paperwork on submitted applications and meeting paperwork. We will also speak to public collaborators. Combined, this information will tell us how many studies involved public collaborators:
  - o In the development of the research idea
  - o Early on in the funding application, by which we mean public collaborators were present at the first team meeting or attended a workshop to inform the application before the researchers had started to write the application
  - o Mid-way in the funding application, by which we mean there was time for public collaborators to influence some aspects of the application
  - o Late in the funding application, by which we mean public collaborators were brought in less than one month before the submission deadline
- If the above annual review finds an increase in late or mid-way involvement, we will action more pressure and incentives for researchers.

**AIM 5: To research and evaluate involvement so that we can improve practices and capture involvement impact**

The PPIE team has in the past conducted research on their own practices. In 2020 we published an article, co-developed with three involvement groups including PenPEG, on good quality PPIE. We have also researched the kinds of knowledge that is shared in PPIE meetings, identifying the value of group involvement. Through this research the PPIE team and PenPEG members have learnt about our own practices and made adjustments to how we work.

**Examples of how we will work to meet this aim:**

2021-2022:

- With public collaborators, the PPIE team will publish at least three articles reporting on PPIE research data which the team has collected in the past three years.
- With co-authors (researchers and public collaborators) the PPIE team will produce an accessible poster, using images, sometimes called an infographic. This will be based on our 2020 publication on good quality PPIE, expanding the reach and audience of this article.

- The PPIE team will review feedback forms filled in by researchers in the past three years to consider needs for improvement in the way PPIE is facilitated and enabled (or not). Team members will discuss this with public collaborators to consider needs for further evaluation, and how best to do this.

2022-24:

- The PPIE team and PenARC researchers will action any evaluation needs identified in conversations with public collaborators.
- The PPIE team and PenARC researchers will support interested public collaborators to co-research or lead a study on PPIE, informed by interests in PenPEG.

2021-2024:

- At the end of every calendar year the PPIE team will survey all public collaborators who have been part of PenARC research that year. The survey will be co-produced and address aspects such as communication, experiences of research involvement, and values. Findings from the survey will be shared with all public collaborators, who will be invited to an event the following January. At this event, we will discuss findings from the survey and how to improve PPIE in PenARC. The first survey will be at the end of 2021, and the first event will be in January 2022. Events will be online if social distancing requirements remain in place.<sup>2</sup>

#### AIM 6: To enable and support researchers, health and social care service providers and members of the public to build their capacity for collaborative work

Public collaborators and the PPIE team have co-designed two training workshops. One of these was developed with Kristina Staley, for public collaborators new to research. The second workshop was developed with public collaborator Jane Ring, and is designed for researchers and public collaborators who are about to start working together. In addition to training, the PPIE team offers PPIE advice clinics for researchers, and PenPEG members offer PPIE cafes for researchers (organised by the PPIE team). The PenARC website contains PPIE information for researchers and public collaborators. The PPIE team also engages in national training opportunities and PPIE seminars to enhance their learning. The PPIE team's approach is to provide flexible support for training and mutual learning in a variety of ways, based on the needs of individual people and groups. This will continue.

#### Examples of how we will work to meet this aim:

2021-22:

- One member of the PPIE team, with Kristina Staley and PenPEG members, will design a training workshop for researchers, based on the existing workshop for public collaborators new to research.
- The PPIE team, with PenPEG members and PenARC researchers, will organise two community engagement events. The focus of the events will be informed by discussions with community leaders and visits outlined under Aim 2.

2023-24:

- The co-producers of the new training will deliver at least three workshops to researchers, including PhD students.
- The PPIE team, with PenPEG members and PenARC researchers, will organise at least three community engagement events. The focus of the events will be informed by discussions with community leaders and visits outlined under Aim 2.

2021-24:

- The following activities, also listed under Aim 1, build PPIE capacity:

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<sup>2</sup> We got this idea from an article written by Sarah Barger and colleagues, published in BMC Medical Research Methodology in 2019: <https://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/s12874-019-0764-2>

- PPIE advice clinics for researchers
- PPIE cafes for relationship building and connecting PenPEG members and researchers
- PPIE team and PenPEG teaching undergraduate and post-graduate students
- Buddying system for new members of PenPEG
- Delivering existing training (Staley and Ring)
- As before, the PPIE team will organise capacity building for researchers and public collaborators flexibly and in response to their expressed wishes for this. We commit to organising at least one responsive training event per year and capture whether these are well attended and received.

## Who will monitor how the aims are met?



The PenARC Senior Management Team will have oversight of the PPIE team's progress to achieving the aims outlined in this strategy. In March 2021 this group consists of: Director Prof Stuart Logan, Operations Director Jo Shuttleworth, Deputy Director Prof Richard Byng, Implementation Lead Dr Nick Axford, Communications Manager David Walker, and Operations Manager Jo Smith.

The PPIE team will meet with this group twice per year to report on progress and activities to support each aim.

Every year PenARC delivers a report on its activities to the NIHR.

This is a good opportunity for the PPIE team to take stock on our progress, with some help from the PenARC communications team, PenPEG and the PenARC Leadership team. We will use the strategy to inform our activities for each year, and these will be reported on in the Annual Report. Due to the word limit of the Annual Report we will write a section for our own purpose and edit this down for the NIHR report.

The PPIE team will be responsible for monitoring the majority of the activities reported under each aim. Communication and relationship building are central to the Team's work and underpins their reflexive practice. To further support this they will undertake an annual review to evaluate their work, as outlined in Aim 4.

To increase transparency and accountability, additional monitoring will be provided by PenARC's Leadership team, Communications team and by PenPEG members.

The PenARC Leadership team will monitor:

- Adequate budgeting for PPIE within PenARC and in external grant applications.
- The organisation of annual reviews with public collaborators, and that learning from these is implemented in the PPIE team and more generally in PenARC.

The PenARC Communications team will monitor:

- An engaging website with creative and appropriate material that is experienced as helpful, interesting and current by researchers and members of the public. Site visits and content views will be analysed.
- Publications on PPIE co-authored with public collaborators.

PenPEG and other public collaborators will monitor:

- Progress on all actions outlined underneath each aim in this strategy, which will be reported by the PPIE team to PenPEG members annually. This will happen in November or December each year and in addition to the annual review (survey and event) with all public collaborators each December and January.

## Words used in this document

Public collaborator: who does this term include?

PenARC works with many different people who contribute to and are partners in research due to their personal experiences.

Many terms have been used to describe these people, for example: patients, members of the public, public advisers, community members, service users.

PenARC will collaborate with people who identify as all these things and more. To help us write with clarity in this strategy a

joint decision was made in February 2020, through a voting poll of PenPEG members, to use the term **public collaborator**.



## Involvement or engagement?

Similarly, many terms have been used to describe public collaborators' relationships and work with researchers: community participation, consumer involvement, public engagement. In the NIHR the following definitions are used:

**Participation:** Where people take part in a research study

**Engagement:** Where information and knowledge about research is provided and disseminated

**Involvement:** Where members of the public are actively involved in research projects and research organisations

In PenARC we consider these activities to be interlinked. If participating in research is a positive and reciprocal experience, it might make more people interested in research and wanting to collaborate. If researchers engage with the public in a positive way, people might want to be more involved, either as participant or public collaborator.



In this strategy we have chosen to use the term PPIE as shorthand for public, community, patient and carer involvement and engagement. This is partly because PPI has become a well-known acronym for involvement.

### Acronyms

We have tried to avoid using acronyms in this strategy, apart from well-known ones incorporated into the English language (such as NHS and GP). However, some less common acronyms have been used to ensure flow in the text:

PenARC: Applied Research Collaboration South West Peninsula

NIHR: National Institute for Health Research

PenPEG: Peninsula Public Engagement Group

PPIE: Patient and Public Involvement and Engagement

### How this strategy was developed

This strategy was developed during 2020, beginning with an event in January 2020 to celebrate the public involvement achieved by PenCLAHRC and looking forward with PenARC. At this event all attendees (public collaborators and researchers) were asked to write down their hopes for PenARC. These suggestions were a starting point for the development of the strategy aims.



*These photos are from the celebration event starting off the strategy in January 2020*

In the autumn of 2020, a series of meetings were held with public collaborators, researchers, and the PenARC senior management team to interpret ideas raised at the celebration event and draft strategy aims. Researchers expressed enthusiasm after their meetings and told us they found it inspirational to discuss views, experiences and ideas for improving public involvement and engagement.

The first draft of the strategy was reviewed by researchers and public collaborators who provided written feedback. In the first draft we had used a table format that outlined activities to meet the stated aims, what success would look like, and how we would evidence outcomes. Many public collaborators objected to the measure-focus in the tables. Some found the table format too academic as it was using terms like 'measured by' and 'monitored by'. Others felt that the emphasis on evidencing engagement and involvement

on paper obscured the importance of building relationships and having conversations. Public collaborators stressed the importance of being treated in the same way as other partners in research, and many rejected the first draft's emphasis on providing demographic details or filling in evaluation forms about meetings.

The reviews were first considered by members of the PPIE team who grouped the feedback so that key messages could be discussed in two workshops with PenPEG members. People at these workshops helped decide how to change the strategy in line with the reviews. This resulted in a complete redraft: sections were moved around and a planned table format outlining how the aims will be met was scrapped. The resulting strategy has aimed to address these and other important criticisms, while bringing in ideas brought forward on activities to help meet the aims.

During the reviews some public collaborators brought forward ideas for activities to meet our aims. We are reluctant to include all of these in the strategy since we do not have capacity to carry them all out. We also want to be flexible in our approach and adapt it to changing circumstances (national priorities, COVID-19 developments, local needs identified by other organisations, team capacity). We have kept a list of suggested activities as a resource for involvement and engagement ideas.

### Acknowledgements and authorship

This strategy was written by Kristin Liabo and Kate Boddy, both members of the PenARC PPIE team, with extensive review by public collaborators (including many who are PenPEG members), PenARC staff and research colleagues. Due to the COVID-19 pandemic, the strategy was signed off in March 2021.

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