NIHR | Applied Research Collaboration East of England

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Public and Community Involvement, Engagement and Participation (PCIEP) Strategy

Author:	Dr Bryony Porter PCIEP Lead ARC East of England
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Consultation & Approval Committee/Groups which signed off the policy)	MEG, PCIEP Coordinating Group
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Public and Community Involvement, Engagement and Participation (PCIEP) Strategy

List of Acronyms

ACRONYM	DEFINITION	INFORMATION
ARC EoE	Applied Research Collaboration East of England	ARC EoE is funded by the NIHR. It is a five-year collaboration between Cambridgeshire and Peterborough NHS Foundation Trust, and the Universities of Cambridge, East Anglia, Hertfordshire and Essex along with other NHS Trusts, Local Authorities, Regional Sustainability and Transformation Partnerships (STPs), patient-led organisations, charities, and industry partners across the region.
BRC	Cambridge Biomedical Research Centre	The BRC is based on the Cambridge Biomedical Campus, and combines scientific research in world-class institutes, patient care in NHS hospitals, and drug discovery in pharmaceutical companies.
CPFT	Cambridgeshire & Peterborough NHS Foundation Trust	The Trust delivers many of the NHS services that are provided outside of hospital and in the community such as physical, mental health and specialist services. ARC EoE is hosted by CPFT.
CRN	Clinical Research Network	Funded by the NIHR, the CRN provides an infrastructure which allows high-quality clinical research to take place in the NHS, so that patients can benefit from new and better treatments. It supports research across 30 different health themes. There are 15 CRNs across England.
EAHSN	Eastern Academic Health Science Network	The EAHSN is funded by the NHS and the Office for Life Sciences to bring together academia, citizens, health services and industry to realise the value of innovations more quickly.
IIRP theme	Inclusive Involvement in Research for Practice Led Health and Social Care theme	The IIRP theme is one of seven ARC EoE research themes. It aims to find the best ways of involving patients, service users, carers and members of the public with different experiences, in research on health and social care.
INVOLVE		INVOLVE was part of, and funded by, the NIHR to support active public involvement in NHS, public health and social care research. Replaced by NIHR CED, a new NIHR centre for patient and public involvement, engagement & participation and research dissemination
NIHR	National Institute of Health and Care Research	The NIHR is the nation's largest funder of health and care research. It works in partnership with the NHS, universities, local government, other research funders,

patients and the public to deliver and enable world-class research that transforms people's lives, promotes economic growth and advances science. It is largely funded through the Department of Health and Social Care.

NIHR EoE PI Collaborative	[NIHR East of England Public Involvement Collaborative](#)	Membership includes public involvement leads and patient representatives from NIHR and AHSN organisations in the east of England region. The remit of the group is to align regional public involvement strategies, plans and resources to deliver NIHR priorities in the region.
NIHR CED	Centre for Engagement and Dissemination	The Centre brings together activities in patient and public involvement, engagement and participation with research dissemination. The aim is to further enhance the strong collaborative culture already established in involvement, engagement across the NIHR.
PCIEP	Public and Community Involvement, Engagement and Participation	PCIEP is where members of the public are actively involved in research projects and in research organisations.
PiFs	Populations in Focus	ARC EoE aims to understand community health research needs locally by working in partnership with communities and organisations who live and work in the Populations in Focus areas; Stevenage, Peterborough, Fenland, Thurrock, Great Yarmouth and Waveney,
RDS	Research Design Service	The RDS provides design and methodological support to health and social care researchers across England to develop grant applications to the NIHR and other national peer-reviewed funding programmes. RDS advisers in bases across England offer a unique breadth of experience and a proven track record in improving research applications. Advice is confidential and free of charge.
Shaping Our Lives		A national organisation and network of user-led groups, service users and disabled people. It is a user-led organisation committed to inclusive involvement and specialises in the research and practice of involving diverse communities in policy, planning and delivery of services.

Introduction

A collaborative approach, which values active co-production with our four populations-in-focus (PiFs) (Great Yarmouth; Peterborough and Fenland; Stevenage; and Thurrock), is at the heart of the Applied Research Collaboration East of England (ARC EoE) Public and Community Involvement, Engagement and Participation (PCIEP) strategy. Our host Trust, Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) has a leading, national role in PCIEP and champions our work in this area, and our close working with the Eastern Academic Health Science Network (EAHSN) supports this. However, we recognise that more is needed to achieve our goal of establishing a model of PCIEP that increases meaningful and effective engagement and involvement of diverse groups and enables truly collaborative and co-produced research design and implementation.

This strategy sets out the aims and objectives of PCIEP and how we are achieving these. We use the INVOLVE definition of involvement which defines public involvement in research as research being carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them, and uses the following terms to distinguish between the different activities:

- **Involvement** – where members of the public are actively involved in research projects and in research organisations
- **Participation** – where people take part in a research study
- **Engagement** – where information and knowledge about research is provided and disseminated

We aim to:
1. Extend research into PCIEP
The Collaboration for Leadership in Applied Health Research and Care East of England (CLAHRC EoE); ARC EoE's predecessor, delivered significant change through its Patient and Public Involvement in Research theme, which investigated and developed new and optimal ways to achieve PCIEP in applied health research and its implementation. The theme continues to nationally lead in terms of recommendations for feeding-back the results of research to participants. Building on these achievements, the ARC EoE 'Inclusive Involvement in Research for Practice-Led Health and Social Care (IIRP)' theme continues to develop methods for best-practice in PCIEP, including developing resources for inclusive involvement through online methods, as a result of the rapid increase in online and virtual methods during the Covid-19 pandemic.

2. Extend PCIEP of diverse groups
We strive to be an exemplar of diverse and thriving community engagement, involvement and participation in health and social care research and implementation. To ensure the involvement of diverse groups, ARC EoE makes use of already established links, and has sought new connections with local communities and regional organisations that represent communities. An example of this is a project led by University of Essex to create a community of practice to explore the strengths, barriers and prioritise solutions to healthcare access for Travelling Communities.

3. Extend PCIEP of under-represented communities

We have increased engagement, involvement and participation of under-represented communities as a priority for our ARC, our university partners, and for the [NIHR East of England Public Involvement Collaborative](#) (NIHR EoE PI Collaborative). We continue to reach out to under-represented communities in our ARC's four populations-in-focus, which were selected as areas in the East of England with socioeconomic and health inequalities that could benefit from research. We involve community representatives (such as community workers, patients, service users and carers) from each area, in shaping our work through wide-ranging and regular engagement activities. This [included walks in Essex (Grays), Peterborough, Stevenage and Waveney](#) over the Summer of 2022 to find out more about local experiences and healthcare needs.

Resources

Dr Bryony Porter was employed as the PCIEP Lead in June 2022 as part of the ARC EoE Core Team. Training and support for researchers and public contributors is supported by the Universities and the ARC Core Team, through the PCIEP Lead. Each research theme is allocated a specific PCIEP budget to support involvement of public contributors across the various stages of research and responsive to the needs of the theme. We also hold a central PCIEP budget for PCIEP activity supporting governance arrangements (see below), covering fees and expenses for involvement and centrally (ARC) led events such as conferences and training related to PCIEP. In Autumn 2022, the central PCIEP budget paid for cultural competence in research training for the PCIEP Coordinating Group members, for example. PCIEP is given a high priority for any underspend. In 2022 we undertook a review of public contributor reimbursement approaches and we developed a guidance document for our approach, [available in the ARC Core Public Contributor Reimbursement Guidance (2022)](#).

Management and Governance

PCIEP is embedded throughout governance structures in the ARC EoE. The NIHR ARC EoE Board meets biannually and includes two representatives from the PCIEP Coordinating Group. PCIEP Representation contributes to the NIHR ARC EoE Expert Advisory Group and the Capacity Building Committee. The PCIEP Lead and PCIEP Representative attend regional PPI Collaborative meetings. The chair role of the PCIEP Coordinating Group is shared by a PCIEP representative and the PCIEP Lead.

UK National Standards of Public Involvement

We use the [UK Standards for Public Involvement](#) as a framework in our strategy. These are based on initial work in values and principles of public involvement undertaken by NIHR INVOLVE and Health and Care Research Wales. They provide clear, concise statements of effective public involvement against which improvement can be assessed; details of the standards can be found in Appendix 1. Research theme representatives collate PCIEP reports ahead of each PCIEP Coordinating Group Meeting, using these standards to reflect and identify areas for future improvement.

We strive to meet each standard as a whole programme, using them to reflect upon and improve practices. The six standards and how we continue to meet them are as follows:

1. Inclusive Opportunities

ARC EoE provides inclusive and accessible opportunities for patients, carers, service users and public members at all levels of our governance and stages of research. We do this by:

- Adopting a 'community-led' approach whereby we support communities to define what is important to them about their health and wellbeing and the factors that impact on these, to inform the research we undertake. This has included [community research partnerships to develop support for end-of-life care in the local communities](#).
- Co-designing, co-developing and co-producing our research and PCIEP with members of the public to ensure it is relevant, informative, and accessible
- Advertising any public member roles widely across the region via a range of communication platforms and networks to maximise the chance of reaching a range of people
- Recognising that people should be renumerated for their time and expertise by following guidance from our host Trust, the [NIHR CED (Centre for Engagement and Dissemination](#)) and university partners
- Undertaking inclusion and diversity workshops delivered by the IIRP theme and Shaping Our Lives (a user-led organisation), such as a workshop about [Inclusive Research Post-Covid-19: Making it Different](#), facilitated by Shaping Our Lives.
- Investing in training for ARC colleagues designed to increase knowledge, awareness, and confidence in addressing issues related to community engagement, widening participation, diversity and inclusion. In Autumn 2022, the PCIEP Coordinating Group attended training on Effective Community Engagement and Cultural Competence, led by the Centre for Ethnic Health Research, funded by ARC EoE.

2. Working together

We are working with and value public members in our research, implementation and core business activities. We do this by:
- Fostering close working relationships between public members and researchers via the PCIEP Coordinating Group. This group is co-chaired by a public member and provides mutual support, and opportunities to work together and learn
- Working with individuals and community groups from our PiFs and advisory groups within our university partners at every stage of the research process, and using emerging findings from the IIRP theme to foster community-led approaches
- Including members of the communities from all our PiFs in our implementation workshops
- Working with people in ways that suit them including attending community groups rather than expecting them to come to us, inviting members to participate and 'present' their work at ARC meetings and events

- [Creating an interactive map](#) of engagement activities across the PiFs to ensure a coordinated approach to working with communities
- Working with the NIHR EoE PI Collaborative on common goals of community engagement
- Following the good practice guidance in the [INVOLVE and NIHR Research Design Service's 'Reaching Out' initiative](#), to ensure regional NIHR PCIEP strategic objectives support community approaches

3. Supporting and Learning

We are offering and promoting opportunities for support and learning that build confidence and skills to enhance public involvement. We do this by:

- Developing and delivering PCIEP training for researchers new to PCIEP in partnership with the [NIHR Cambridge Biomedical Research Centre (BRC)](#)
- Working with the NIHR EoE PI Collaborative and other organisations to deliver events and workshops to promote PCIEP within ARC EoE and the wider NIHR
- Working with our public members to review their roles, identify learning and networking opportunities to ensure they can meaningfully contribute and participate
- Ensuring PCIEP members participate in various workstreams, research themes and groups to empower them to make informed contributions
- Signposting PCIEP members to learning in the region and across the national ARC network
- Sharing the [CLAHRC EoE PCIEP Handbook for Researchers](#) to new members of the ARC EoE
- Funding training for ARC researchers to enable them to increase their knowledge, awareness and confidence in addressing issues related to equality and diversity (see Inclusivity above)
- Learning from the COVID-19 pandemic to make sure that public members are supported in using online platforms and technologies to ensure that they can continue to participate when face to face meetings are not possible
- Acknowledging that online platforms suit some members of the public well, while ensuring we work with those communities who are digitally disadvantaged to support them to be involved. We have published blogs about this to share lessons from the ARC, [written by a Penny Vicary (Public Contributor) and Elspeth Mathie (University of Hertfordshire, ARC East of England).](#)

4. Communications

We communicate effectively with all our partners, collaborators, and the public to develop shared understanding. We do this by:

- Exploring various communication channels and tailoring these to suit individual needs to be as accessible and flexible as possible
- Disseminating ARC EoE PCIEP activity via national platforms by sharing updates at national ARC PCIEP meetings, the NIHR EoE PI Collaborative, in the Annual Report, through social media channels, the ARC EoE website, newsletter, BITEs and at events and conferences

- Developing the [PCIEP page of the ARC EoE website](#) with public members and including content that is relevant to the researchers and communities we work with
- Working closely with the Eastern AHSN to support our communication within and beyond the region
- Sharing [CLAHRC EoE's PCIEP Feedback Guidance](#) with researchers which highlights how to communicate clearly and effectively with a range of audiences, including PCIEP representatives. We have shared the [Researcher Feedback Form,](#) available for to download and reuse for free on the PCIEP Resources webpages.

5. Impact

We are measuring and evaluating the effectiveness and impact of PCIEP across ARC EoE. We are doing this by:

- Developing a logic model to represent a proposed understanding of how PCIEP across ARC EoE has an impact (Appendix 2).
- Evaluating the effectiveness and impact of PCIEP across ARC EoE, through the creating of impact case studies of examples of PCIEP across ARC EoE.
- Supporting ARC EoE themes to evaluate the impact of PCIEP on their research
- Producing a well contextualised and innovative body of PCIEP evidence that will aim to inform NHS and Social Care PCIEP policy and practice. Examples of completed and ongoing projects can be found on the [Inclusive Involvement in Research for Practice Led Health and Social Care webpages.](#)
- Engaging PCIEP members in our reviews of success

6. Governance

We are providing opportunities for the public to influence and be actively involved in the governance and leadership of the ARC at all stages of our research and projects so that our decisions promote and protect the public interest. We are doing this by:

- Involving PCIEP representatives in the development of our PCIEP strategy and its yearly review
- Involving PCIEP representatives in recruitment and appointment panels, particularly for key ARC EoE positions
- Involving PCIEP representatives on our Board, Expert Advisory Group, Capacity Building Committee and PCIEP Coordinating group, which is co-chaired by a public member
- Making PCIEP a standing agenda item at theme and implementation meetings, and inviting PCIEP representatives to contribute to research and implementation meetings and events
- Holding 'community engagement events' across our four PiFs (here are examples from [Thurrock](#), [Peterborough and Fenland community engagement events)](#) where members from those communities will participate and inform our research.
- Ensuring PCIEP representatives sit on all steering groups and advisory groups in our studies and have the necessary support and training to be a critical friend in these meetings

Appendices

Appendix 1 - UK Standards for Public Involvement

INCLUSIVE OPPORTUNITIES: We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

WORKING TOGETHER: We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

SUPPORT & LEARNING: We offer and promote support and learning that builds confidence and skills for public involvement in research.

COMMUNICATIONS: We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

IMPACT: To drive improvement, we capture and share the difference that public involvement makes to research.

GOVERNANCE: We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

https://sites.google.com/nihr.ac.uk/pi-standards/home

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Appendix 2 ARC EoE PCIEP Logic Model

Inputs	Mechanisms for change	Outputs	Outputs 2022/23	Outputs 2023/24	Outputs 2024/25	Outcomes
Vision increase meaningful and effective engagement and involvement of diverse groups and enables truly collaborative and co-produced research design and implementation **People and resources** ARC Core – PCIEP Lead PCIEP Coordinating Group members Public Contributors ARC research themes, representatives and collaborators University Core support for ARC funded staff and projects Funds for PCIEP in ARC Core and Research themes Research funding – multiple sources **Partnerships** Academic, service and community partners e.g., • Populations in Focus • Regional NIHR infrastructure • National ARC groups • University partners • Local authorities, NHS, Integrated Care Systems	Adopting and implementing best practice for public engagement Cross-ARC researcher / public engagement and ARC Core leadership ARC Engagement with regional infrastructure National ARC Engagement	Logic model for PCIEP planning in place Regional and national collaborations developed PCIEP Strategy collaboratively developed and reviewed PCIEP involvement in research projects and funding applications PCIEP Payment policy reviewed	PCIEP payment policy review Review approach to evaluating PCIEP impact Review PCIEP Coordinating Group Terms of Reference Review PCIEP Coordinating Group membership and review new public contributors Equality, Diversity and Inclusion training for PCIEP Coordinating Group PCIEP Coordinating Group meetings x 4 Regional Collaborative meetings National PCIEP meetings	Evaluate impact of PCIEP in ARC PCIEP Coordinating Group meetings x 4 PPI Training for ARC researchers Update PCIEP webpages Regional Collaborative meetings National PCIEP meetings	Impact of PCIEP evaluation and future planning for PCIEP impact evaluation PCIEP Coordinating group meetings x 2 PPI training for ARC researchers Regional Collaborative meetings National PCEIP meetings	Increased public engagement in ARC infrastructure and governance Increased researcher understanding and engagement with PCIEP in projects and funding applications ARC researchers can access resources on PCIEP Clear involvement and engagement across research themes and with populations in focus (impact case study report) Contribution to the development of PCIEP research evidence Identification of opportunities to increase diversity of public contributor engagement in ARC infrastructure and research ARC Researchers and Public Contributors improved understanding equality, diversity and inclusion in research